



hear/say

Stories about aging, dementia, art, and life

UCSF Weill Institute for
Neurosciences

Memory and
Aging Center

hear/say

Stories about aging, dementia, art, and life

A collaboration between
UCSF Memory and Aging Center
and Voice of Witness

Cover image courtesy of Salvatore Spina, MD, PhD, and the UCSF Neurodegenerative Disease Brain Bank. The long, spindle-shaped cells in cyan are von Economo neurons. Found only in select mammalian species, including humans, they are proposed to play a role in complex social behavior. They are also among the first cells to degenerate in patients with frontotemporal dementia.

The typeface is Mrs. Eaves XL, designed by Zuzana Licko in 1996. Mrs. Eaves is a transitional serif typeface derived from the Baskerville typeface, designed by John Baskerville in 1757. Mrs. Eaves, the typeface, was named for Sarah Eaves, the live-in housekeeper and later wife of John Baskerville. The XL series has a larger x-height and tighter spacing to facilitate reading lengthy text.

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This volume of hear/say stories is dedicated to the patients, caregivers, providers, and artists who shared their stories – and to storytellers everywhere.

Further gratitude is extended to the Hellman family, and Warren Hellman in particular, for their generosity and foresight in fostering an artist in residence program that binds science and art together in a shared human endeavor, to the betterment of everyone involved.

Take a Walk

Foreword by Bruce L. Miller, MD

When I started my career as a behavioral neurologist, dementia was universally classified as caused by Alzheimer's disease with no hope of ever distinguishing it from other thought-to-be-rare diseases that could cause dementia. But listening to patients and caregivers tell their stories and then combining those stories with the stories told by imaging, neurological, neuropsychological, and laboratory tests, suggested to me that stories could tell a fuller picture of the roots of the disease. I began to work with patients who had frontotemporal dementia and learned that their stories were remarkably different from people who had Alzheimer's disease, Lewy body dementia, or vascular dementia. Forty years later, we have become much better at predicting the molecular pathology leading to a person's symptoms based on the story that is told by the patient and their loved ones. Listening to stories also helped me see that some patients develop new creativity in the face of declining cognitive skills. This intrigued me and led to me to understand the push and pull of the brain where dominant skills can mask latent skills. The demise of the dominant allows the latent skill to grow, and now we recognize the growth of expressive art that reflects the changing perceptions and experiences of the patient.

No longer was I focused exclusively on a patient's weaknesses, but their strengths became an important part of the "clinical narrative." Not only were strengths important for helping to determine a diagnosis, but they steer caregivers and the patient towards therapeutic measures around these strengths. The entire process of assessment was humanized. I realized that if I was going to be truly effective as a physician, I needed to listen more and listen better. Each patient had a unique story and trajectory, and defining the expected trajectory was required for realizing how and why that trajectory had trained. If a patient with a degenerative disease became more artistic, what did it mean to those of us who lacked art in our own lives?

A love of art and a deep appreciation of the creative brain has led to a long time interest in artists and patient-artists. Warren Hellman,

the San Francisco financier and philanthropist, was also a passionate aficionado of bluegrass music. His love and passion for this music led him to become a musician and songwriter. When we met years ago to discuss how to support young researchers in the field of memory and aging, we also agreed that an artist should be part of the mix. That is how the Hellman Visiting Artist program was created. Each year an accomplished artist from the visual, literary, or performing arts spends a year in residence at the UCSF Memory and Aging Center. In this year, the artist learns about neurodegenerative disease, and we learn about the artist's art form and creativity. Events and activities include faculty, staff, patients, caregivers and the San Francisco community. We are a fortunate center to have these wonderful exchanges of ideas and experiences that cut across the often separated worlds of science, medicine, and art.

The chance to pair up with Cliff Mayotte and the Voice of Witness team was a special chance to create story art. Voice of Witness specializes in stories of social justice, and people with dementia are our society's underdogs. There is still too much misunderstanding and stigma around brain change. Science and medicine help us to understand and explain what is going on, but art helps us express that and share it with the world in an accessible way that unites and connects people.

The stories in this book were collected by members of the Memory and Aging Center team who interviewed patients, caregivers, faculty, staff, and artists about their stories. We hope this collection helps to convey some of the breadth of experience around aging and dementia. There is no single story, and there are threads in each story that resonate with each of us. Enjoy the walk in someone else's shoes.

Offer No Assumptions

Foreword by Cliff Mayotte

“As a nurse, I have this value, which is, ‘Offer no assumptions.’ That’s how I’m most comfortable working with people. I’m here to listen and offer guidance and help. I may feel that I understand and can relate to what they are going through, but I don’t assume I really know what this experience is for them.”

—Jennifer Merrilees, Clinical Nurse Specialist,
UCSF Memory and Aging Center

When Voice of Witness was approached by staff members of the Memory and Aging Center at the University of California, San Francisco in the summer of 2015, I held many assumptions about creativity, science, health care, and what it means to be a clinician. During our initial meeting, a handful of my assumptions were immediately challenged as we talked about amplifying the unheard stories of patients, caregivers, and family members that were living with the realities of Alzheimer’s and dementia. By the time the meeting was over, I had shed some of my assumptions, and became excited by the possibilities of our collaboration.

The project (later to be called *hear/say*), was built around the creation of an oral history collection that would help debunk the “single story” related to dementia and Alzheimer’s. Our goal was to utilize personal narrative to lessen a societal tendency to treat people living with these diseases as “others,” and the people who care for them as super human. Even though I was several assumptions lighter, I still had a few reservations about how our distinct methodologies would complement each other. While I knew that the Memory and Aging Center practiced active listening and nurtured empathy, I was concerned that our approach would end up being too clinical, and answer-driven. Within this construct, how could we possibly embrace the nuances, ambiguities, and general messiness of personal narrative?

We began our Hellman Artist in Residency at MAC with a two-day oral history training with a cohort of participants that included

nurses, doctors, students, psychologists, and more. At Voice of Witness, we like to call these encounters “mutual sightings.” It was during these first sessions that I began to get the full measure of the creativity on display by our MAC partners. I was impressed by their finely tuned levels of empathy, artistry, and curiosity. More of my assumptions vanished as I learned about the many ways of listening they had developed. For example, Nurse Specialist Jennifer Merrilees talked about the particular brand of patience required in listening to a patient who lacked the “social inhibitors” that drive most “normal” daily interactions. Dr. Elissaios Karageorgiou spoke of his detailed approach for interviewing patients with different levels of dementia. His strategies not only demonstrated a complex understanding of the human brain, they were also deeply intuitive, and creative. In short, the MAC team’s level of preparation, and deep desire to understand the experiences of others, was extraordinary.

When the details of the collaboration were being hammered out, it was understood that Voice of Witness would be offering MAC a professional development opportunity that would enhance their already prodigious communication skills. Without selling ourselves short, I was not totally prepared for the professional development that Voice of Witness would receive in return. This reminded me of something Nurse Specialist and *hear/say* participant Sarah Dulaney shared from her interview experience with MAC professor and psychologist, Dr. Virginia Sturm: “Oh, that was weird, it kind of felt like therapy,” and I remember thinking, “Do you think it felt like therapy for you or for me?” At this point, any remaining assumptions I had about the dichotomy between creativity, science, and health care had officially vanished.

The melding of storytelling and science continued during a clinic I attended with Dr. Bruce Miller and a team that consisted of a psychologist, a nurse, a pathologist, and a doctor that specialized in reading brain scans. The clinic was devoted to discussing a single patient and looking at her care from all angles to determine an effective course for treatment. Through the lens of each team member’s particular discipline, they took turns describing their recent interactions with the patient, and shared their findings and recommendations for future care. In between each report, Dr. Miller would ask clarifying questions, and gently interrogate their conclusions.

He then led the group in what I can only describe as a “journey of interpretation” of the stories that were shared. Each clinician had constructed a narrative about the patient based on their observations, test results, brain scans, patient history, interviews, etc. In essence, each of them was saying, “here’s what I think this story means.” By putting all of these stories together, they created a detailed and highly nuanced portrait of the patient. I was stunned. I no longer felt that I was in a room with skilled medical professionals, but was sharing the space with artists and storytellers. I began seeing artists as clinicians, and clinicians and caregivers as artists.

The stories in this collection reflect this realization at the same time they expand our understanding of the day-to-day realities of living with dementia and Alzheimer’s. There’s Louise Tilston’s description of her almost unnoticeable transformation to full-time caregiver for her husband, Jim: “It was so gradual and it was like a fog rolling in, and rolling in, and rolling in, and you don’t notice it. It just gets thicker, and thicker, and thicker, and then it’s so thick, and it’s been there for so long that you can’t remember what it was like when the sun was out.” Or the education Dr. Mary De May receives from her patients: “Your ultimate task is to be present in the moment, and I think this work has really pushed me to be present. Think about the patient with Alzheimer’s disease who’s got short-term memory deficit, right? I mean, all that matters is ‘did you see the Giants’ game yesterday?’ I’ve learned so much from those patients, because you realize that’s the only way to be.” These are just two small samples of the many surprising and heartfelt stories that follow.

Ultimately, the *hear/say* project represents a successful “mutual sighting” between MAC and Voice of Witness. By participating in this process, I discovered that MAC is really an arts organization masquerading as a medical clinic, and that Voice of Witness, a non profit devoted to amplifying unheard voices, is lovingly staffed with clinicians. Both organizations place a high value on the capacity for personal narrative to challenge assumptions, and its power to illuminate human experience. What binds these ideas (and organizations) together is an empathic impulse for curiosity and courage. I hope you experience both as you read the stories in *hear/say*.

hear/say

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Welcome to the Family

Narrator: Sarah

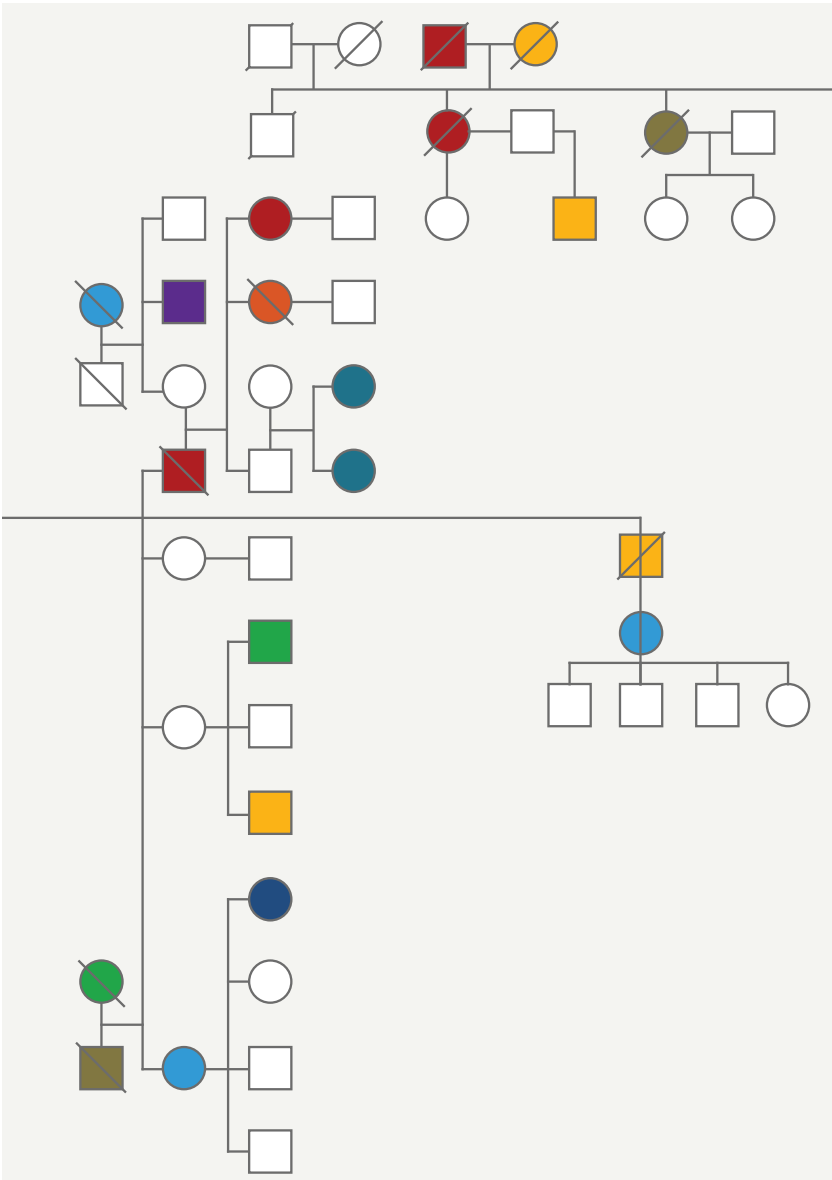
Interviewer: Jennifer Merrilees, clinical nurse specialist

Sarah cares for her husband Mark who has Alzheimer's disease. She and Mark are advocates for the Alzheimer's Association and are dedicated to raising public awareness and relegating its stigma to a thing of the past. When Sarah took a theatrical improvisation class 10 years ago on a lark, she never imagined the "yes, and" technique would prove so helpful in interacting with Mark as the disease affects his thinking. "When the unexpected arises I fall back on the games we played in those 10 improv classes. I recommend improv to all caregivers. It's a great way to get out of your own head and see things from your loved one's perspective and go with it for awhile. As Alzheimer's robs our loved ones of empathy, I find being playful with an issue can reach a meeting of the minds that rationality cannot touch."

I heard there was an early onset caregivers' support group in Berkeley on Wednesday nights. It met only once a month. Mark wasn't diagnosed yet. I was under the impression this disqualified me to go...but I just had to. After a few months I got the nerve to show up.

It was amazing.

They'd introduce themselves like, "My wife was diagnosed eight years ago." I was the only one there whose loved one didn't have a diagnosis. So I said, "I don't know if I'm supposed to be here, but I need to be here. Because even if the doctor is not willing to call it Alzheimer's, that doesn't mean I'm not living with Alzheimer's. I really need advice and understanding. I don't know where else to turn." They were so wonderful and welcoming. At the end of the meeting one man turned to me and said, "Welcome to the family," which really warmed my heart.



Genetic counselors and researchers use family pedigrees to help understand patterns of inheritance. This image is an abstraction of several patient pedigrees. Original pedigrees courtesy of Joanne Taylor, LCGC.

We're in Love and We Just Stay That Way

Narrators: Ione & Steve Kuhner

Interviewer: Kristie Wood, former research coordinator and current artist

I had never met Ione and Steven Kuhner before I interviewed them. Arriving at their home in San Bruno, Steve, Ione's husband and care partner, was warm and showed me to their dining room. On the way, the walls were painted with bold colors and decorated with framed photographs of their family. As I learned about their story, one thing was very clear: these two people are in love – with life, their children, and each other. Steve is protective and thoughtful, with a sadness about Ione's condition that you can only respect. Ione is observant, positive, and expresses a kind of regretful acceptance of her diagnosis. Together, they exude hope and friendship. On my way out, I asked about a picture hanging by the door. Ione re-lived the day it was taken as she told me the story behind her children's poses. I could see she was fighting tears, but when I got into my car after the interview, I couldn't hold back my own. I thought about the memories she'd shared with me and how she and her family must live with the worry that she doesn't have much time left to make new ones or enjoy her old ones. The Kuhners embody an inspiring, caring way of relating to people and the world. It is my pleasure to share a small piece of their story.

I'm Ione Kuhner, 60 years old, and I was diagnosed with Alzheimer's disease on January 19, 2014 at the age of 57.

I Thought it Was Stress

I started to notice my symptoms when both our children got married in 2012, and I'd say a bit with my son – he got married first, and I kinda felt left out of the whole thing, but that was also something to do with

family dynamics. But then when my daughter got married and the girls were staying and getting ready in a little house, I bought food, and I had 2 friends helping me, and they went off on a walk and I was getting a little nervous. I had directions on how to do my daughter's train. It had all these buttons and I kept making sure it was with me. I kept going back and making sure, making sure, making sure, and there was this other woman who was gonna help me with it, and she had disappeared. I was freaking because I was having trouble and didn't have the instruction sheet with me. I knew there was *something*, but never did it ever dawn on me that it could be Alzheimer's; I thought it was stress.

Having Alzheimer's Stinks

Having Alzheimer's stinks: not being able to work, knowing what's going to happen; it stinks. That's all I can say, but you just have to do what you have to do to make your life while you're here as good as you can and don't dwell.

When He Found out I had Alzheimer's, He Cried

I was a dental assistant, but I quit that. I loved what I was doing; it's hard not being able to work. In a dental office, cabinets are full of stuff they've had for 20 years, they don't throw things away, and sometimes they need it, and the dentist would ask me to go get something and I'd go right in there and [snap] get it. But then, all the sudden, it wasn't like that. I had trouble setting up trays. If it was, a standard tray, it was fine but if you had to add more for other procedures, it was taking me longer. And, my anxiety started there and I quit before I was diagnosed because my boss wasn't handling it well. He was snippy with me, which was shocking because he's usually really good at reading people and really gets into people's lives and what's going on with them. He's very personable, and I was just shocked that he didn't pick up – after so many years I worked for him – that something's going on with Ione. We still keep in touch and when he found out I had Alzheimer's, he cried. We went to his house and we sat down and talked to him, and his wife and he cried.

I am Afraid of Dying With My Disease

I am afraid of dying with my disease because I know what it's like; I've watched my father with Alzheimer's die. But, we kinda lost contact with him before he died; he got ornery. Now, when I look back at the situation when he got worse, I realized that he had the disease at the time, and unfortunately, no one picked up on it at all. That's scary, but I'm not worried something like that's gonna happen to me because Steve watches over me very well.

My relationships haven't really changed since I was diagnosed, I would say it's a little different with my kids, not so much my daughter, but more my son and his wife. They're more cautious. For instance, I'm still driving and recently they asked if we could come and watch the kids. We'd have to pick them up at their school and the daycare, and my husband couldn't do it, and I said, "I'll do it," and they said, "No." They didn't want me having the kids in the car driving anywhere, which I don't quite understand because I was driving them before, and I don't think I'm any worse than at that time. I understand. But, that kinda stuff bothers me.

Then there's a situation recently – I didn't say anything to my daughter, but we were going down south, a couple cities down and I was driving in traffic, and all the sudden, I had to put my brakes on, quickly. Well, then my daughter, she drove home. [laughs] So, I'm like "hmm."

But I Just Keep Going

Some people think that we forget everything, and they don't understand it's short-term memory that's impaired; it's not your long-term memory. Sometimes people try to be a little bit helpful, where it's like, "Give me a minute and it will come to me." I know my short-term memory is memory is, ya know – mediocre, but sometimes I surprise people. My long-term memory is great, which sometimes my husband wishes it wasn't. [laughs] That's really the only difference I see in myself. But I just keep going. I keep myself active.

A good day is when I have a lot to do when I'm with my family or friends, and I'd say a bad day would be if somebody hurts me by not

being honest with me. Sometimes people will tell my husband instead of telling me things to my face. I find out.

I love to travel. My favorite vacation was going to Fiji. The most important thing in my life is my family: husband, children, grandchildren. I want them to remember me as loving, compassionate, sometimes funny [laughs], helpful, and always there. My favorite color is purple, and my favorite quote is, “Do unto others as you would have them do unto you,” because you should always be kind to people and you don’t want people to be unkind to others or to you.



I’m Steven Kuhner, age 65, Ione’s care partner. We don’t use the term “caretaker” because we’re partners. The caregiver is someone who you’re paying; a care partner is your partner.

It Gets Better

We were both little kids when we met. We’ve known each other our whole lives. Our relationship has evolved over the years; it gets better. Life, life in general, gets better over the years. We’re in love, and we just stay that way and it gets better as you go. It’s just aging and part of it is being good friends. We enjoy each other’s company. We laugh a lot, we can laugh about the Alzheimer’s and different things that happen. She’ll do something and go, “Oh, my brain!” and go off and we just laugh about it.

I Love Doing Everything Together

I love doing everything together. I enjoy our morning walks with the dog or going out to the beach. Just spending time. Traveling. We both like to travel. She’s the most happy when it’s just the two of us, doing something. When you get more than two people together it gets confusing.

Some days you can’t say anything, she can be real sensitive, which– I don’t blame her, I would be, too. Lately, sensitive discussions have been about driving or doing things– simple, simple things. She gets

after me when she cooks because she's afraid I'm gonna say something, or roll my eyes or something, but we've gotten better.

Sometimes she can be a little more, how do you say... I'll give you an example: last night she walked in the door and she went into her purse. Someone had given her a check for the Alzheimer's Association and she couldn't find it. She started losing it right away, bouncing off the walls. I said, "Calm down, it's here someplace." And she was getting herself really upset, and a minute later she found it and she was back down to being normal. I was FaceTiming my daughter with the grandchildren, and everything went back to being normal real quick. In the past, she'd get upset but it wouldn't set her off like it did.

She Left her Luggage There and Walked Away

I pay more attention to what she's doing now. We were in an airport, and she just turned around and left her luggage there, and walked away. I just grabbed it. I didn't say anything until now. It's little things like that. I'm more protective now, paying more attention.

I'm Mad About It

The way this disease progresses, you start to lose the person. That's one of the most challenging, hardest things to deal with, the fact that I'm gonna lose her. I'm pissed off. It's not fair. It's just cutting everything short. *I'm mad about it.* And there's absolutely nothing that can be done. You can't prepare for this. I think...I think this is just something that's a natural progression. Since her first diagnosis, I, myself, have pretty much kept my head in the sand, trying not to look at the future – I want to live day-to-day and not worry about tomorrow. And, that's been one of the hardest things. I want us to travel, enjoy each other's company, enjoy the grandchildren, our kids, and life.

I deal with things quietly. I don't talk a lot. So, I'll go sit, not pout, but just ponder. I cry a lot. Not as much as I did at the beginning. [laughs] I get emotional. I go off by myself when I'm upset. She doesn't need to know. And it wouldn't be fair to her for me to come in and be down and then drag her down; that's not fair. When we're together, I try

to be happy. There are occasions when we get upset with each other, but we don't dwell.

We're Flying By The Seat of our Pants

As a care partner, I don't know if I'm doing a good job. We're flying by the seat of our pants. [laughs] I mean, I feel that everything is fine. She's happy; I guess that would be the barometer. As long as she's happy I must be doing a good job.

Find Somebody to Talk to

If someone is struggling as a care partner, find somebody to talk to. It's really important. We go to an Alzheimer's group in San Francisco every other week. Our group of care partners all vent or discuss things, and if I have a question I can ask. So, get involved in a group, someplace. It's been very helpful. I'm pretty quiet, but since the diagnosis I've talked more about feelings and how I feel with different people than I have in my whole life. [laughs]

The Most Helpful Thing From Others is to Just Understand

Understand that she's gonna have good days, bad days. She isn't gonna remember your name a half hour from now. Or, if she asks you a question, "when are you leaving today?" Well, if she asks five minutes later, don't say, "You already asked that question." Just say, "We're leaving at noon." I do it all the time, I mean, she doesn't know. And sometimes she asks if she already asked, and I say no, I lie. Because she doesn't need to know. Just answer the question.

Just ask. It's simple.

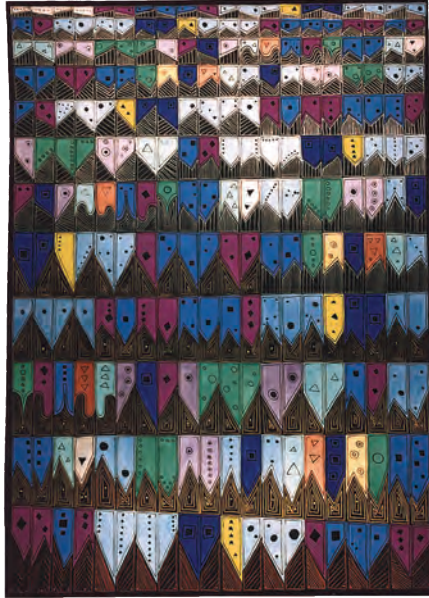
I wish people would just ask questions. Just ask. It's so simple. And, I know for Ione, she wouldn't be upset about anyone asking any question.

But, there are people who don't want to talk about the disease, but they should open up and let people know. You can ask me any question or her any question about what it's like, and we should be able to answer that. People should be able to open up and talk.

Having Fun and Enjoying Each Other's Company

Reflecting, if I would have known this was going to happen, I still would have gotten married, I wouldn't have run, but I might have looked at life a little differently and not let the little things affect me as much. And I think Ione also – we both would have overlooked the smaller things in life and maybe worked a little harder at having fun and enjoying each other's company. But, the natural progression of marriage and living together, there are so many ups and downs. I would have tried to eliminate some of them. As Ione's care partner, I just want everything to be the best it can be for her, throughout the process, and do what's right and do what she wishes to be done, and take care of her the way she wishes to be taken care of. I want to make sure it's all done to her standards.

I wish and hope that science continues working and working hard on a cure, or if they don't get a cure, something that slows the progression of the disease.



***Unravelling Boléro* by Anne Adams, 1994. In this painting, she illustrates Ravel's Boléro. Anne Adams had primary progressive aphasia and became more visually creative as she lost her language. Unbeknownst to Anne, it is likely Ravel suffered from primary progressive aphasia as well.**

Everyone Counts as One

Narrator: *Dr. Bruce L. Miller, Director of the Memory and Aging Center*

Interviewer: *Erica T. Johnson, former research coordinator and current software engineer*

International and interdisciplinary collaboration percolates in the air at Dr. Bruce Miller's workspace. Upon arriving at Dr. Miller's office, I stepped into a United Nations of neuroscience: today, the hubbub of hellos and introductions were from three visiting behavioral neurologists from South America. As they made their way out, professional bluegrass violin player Heidi Clare tag-teamed in. A revolving door of visitors in and out of Dr. Miller's office is not too out of the ordinary, but as I soon learned, I happened to meet with Dr. Miller on the opening reception day of the Global Brain Health Institute for which he serves as co-director. Heidi Clare, along with the aforementioned physicians, are all part of the Atlantic Fellows at GBHI, a cohort of unique leaders selected to develop the critical skills and brain health knowledge through the integration of music, art, and science to make transformative change in their own countries and communities. Through translating research evidence into effective policy and practice, GBHI hopes to reduce the scale and impact of dementia around the world with a new generation of leaders. Before I sat down to speak with Dr. Miller, he eagerly waved Heidi and me over to his desk to take a look at what he had pulled up on his computer screen: the just-released schedule for the upcoming Hardly Strictly Bluegrass Festival. We were curious to take peek at the musical lineup.

Leadership

On Tuesday, I'm giving the first GBHI lecture and it's on leadership. It's sort of my ideas on what makes a leader. You know, I never really thought of myself as a leader, almost ever. I was a little introverted and locked into shyness, I think, and I didn't bloom until later. I think that is in some ways an advantage.

I think there are wonderful leaders who are profoundly extroverted and I don't know what our current president, Barack Obama is, but I get the sense that he is a little introverted at heart. I think when you're introverted, if you're open to looking at others and looking at them carefully, you learn some much more than when you're in the act of extroversion and aren't observing as well; you're just *doing*. I'm an introvert. Quiet. It's how I recharge. Days go by when I might not say a word. It's so important to be both though, isn't it? I've sort of learned extraversion and feeling comfortable through my work, but if I didn't have confidence in the quality of what I'm doing, it would make it harder for an essentially introverted person to be extroverted. I think if you think of yourself as important and needing lots of space and lots of gifts from the environment surrounding you, I think sometimes you miss out on the great things about other people. So that's one thing.

I think the other thing is my parents really believed in humility. One of my father's favorite expressions was, "Everyone counts as one," and I think in a nice doctoring way he really enforced those values around us.

One of my favorite experiences with my dad was watching him with a patient, a very young and very disturbed young boy, very violent, spitting... and he had fallen onto the floor and hurt himself. The first thing my dad did was take off his very fancy jacket and gave it to this kid who was cold. When you have a parent like that, it really impresses on you the greatness of people all around you, and I think no system works unless everybody is appreciated and everybody is fantastic.

One of the biggest failures in medicine, in general, are physician-centric programs where everything is about the doctor, and they don't realize that even *more* important than the doctor is the person who answers the phone and talks to the patients for the first time and makes that connection. I think a lot of the time if *that* doesn't work right, the whole system breaks down and you never get to caring properly. I think some of it is just biological, and I think a lot of it taught – and we can be taught.

The third thing for me is just my sense of awe and gratitude for being in San Francisco. It was really always the place I sort of wanted to be. Coming to San Francisco, it was considered a risk by just about everyone. Everyone I asked, they said to line up on one side the

negatives and the positives. Of course, there were lots of negatives and only two people said, “You should go,” and that was my dad and Dan Geschwind, but that was my gut though. I started to run against a more conventional list of why I shouldn’t go: it would ruin my frontotemporal dementia cohort, I would never establish another one, UCSF was a mean place and I would get pushed down, and it’s been *all* the opposites. UCSF is not mean at all, and it’s wide open, and it’s given me much *more* opportunity.

You got to train your gut. I think what I do with my gut is I try to get a sense of what I’ll feel like with making a decision or not making a decision, and it’s not just the decision and the pros and cons, *it’s what would it feel like?* What would it feel like a year from now when you’re sitting in San Francisco or when you’re sitting in Irvine? For me, one just felt thrilling and challenging and tough, and every morning if I didn’t feel good, I’d be going down the route that didn’t threaten me. But I think the gut there really helped me.

The people I met here were just so incredible – the drive and ambition and social-mindedness of people around me just continuously amazes me, so I’ll never lose gratitude for that. And now, people are studying gratitude and awe. Virginia Sturm in our group is thinking about how we can evoke gratitude and awe, and it most certainly is related to good brain health. Long-winded, sorry.

Wagging Your Tail

The greatest compliment I ever got was from my two-and-a-half-year-old grandson when he found out that I was coming to visit him. He had just arrived in San Francisco along with my daughter and her husband, and I was driving up and he was saying with great joy to my daughter, “My oppa...” – that’s my name – “My oppa is coming! My oppa is coming!” He was really proud and excited that I was going to be there for him. That, I think, was the ultimate compliment. It doesn’t get any better than that.

So, let me talk about “wagging your tail” and give a little anecdote. I was brought up in a different world in neurology: it was harsh, critical. When someone had told me that my teacher had written a consult to them, he said, “that’s not a consult, that’s a smear,” and so it was like

an area where we knew, we described and perforated and criticized, but didn't necessarily think about healing. My teachers were like that, and so, I think it rubbed off on me in a negative way. I approached new situations and people with a sense of suspicion. It created problems. At the same, I had a new dog, a Labrador. Max was really an incredible dog. He was male and he didn't like other males, and so every time Max and I would run into a male on a trail, he would have a fight. Sometimes, it would be very embarrassing and he would go after any male dog. One day, Max and I were running and he started wagging his tail, you could see how really joyous and happy he was, and there was a big Siberian female husky that he saw, and he was so excited. I said, "Max! That's your *friend!*" and he'd wag even harder and harder. Every time we would run into another dog, I would say, "Max! That's your *friend!*" and his tail would start to wag, and *I* started to wag much better, too. I think, rather than approaching things with suspicion, everything was great. I think this philosophy is so much better: that the world is filled with friends to learn from and there are no threatening people and there are no threatening ideas – it's infectious and though it wasn't a natural one, I think that's a philosophy I've really adapted here.

Miller Traits

My dad was intensely extroverted, really brilliant. He was the chair of psychiatry for almost forty years and very driven. He wasn't an immigrant but really had an immigrant-sort-of-drive, a sense of having to succeed and pushed it hard on us. I think some people would say he was kind of tough. I found him tough when I was younger, but as I got older I really appreciated it because I think if your folks aren't tough, the world is tough. My mom was much more of an artist, she was very warm, she accepted us flaws and all. I think having that combination of a dad who pushed you pretty hard and a mom who accepted you for everything wasn't at all a bad combination for me.

We used to have Sunday night dinner where we would prepare a report of some kind on some topic. My dad was really a philosopher and would have people like Alan Watts come through and talk with us. I was overprivileged, and I really was very lucky in that I did not have to

worry where my next meal was coming from. My dad also exposed us to great people and great thoughts, so I call this *overprivilege*.

The Millers are social. I think my wife and my children are quite different socially, easy-to-like. I think we're probably more verbally talented than visually. My wife was the oldest of eight, and none of her nieces or nephews were visual. My brother's five kids weren't. My sister's too, but maybe a little more. My grandson, Mason, is a Legomaster, but he was really the first *really* visual and mechanical little kid in this cohort of twenty.

So, I think quick-to-talk, facilitation with words, a philia for words, a love for words is a Miller quirk – I think this is what I was like as a kid, just *loved* books, loved to read, couldn't wait to read, obsessive about one topic and had to read about baseball for a whole year. My parents hated it because I would check out all the sports books and they wanted me to read historical novels, so Bruce Miller was banned from reading baseball books for about six months, and I didn't check a book out the whole time. Love of words, thoughts, and ideas could be counted as a trait.

I find a joy in certain things, in an obsessive way – like movies – I watch them constantly and it influences the way I think about patients and how I think about research and books. The kind of inspiration I get everyday from listening to songs, reading books, or movies – I'm constantly reshaping my ideas. Just recently I saw the "Before" series, I can't believe I had never watched them before. That I just adored. I loved the serendipity and the connection. A couple moments in that movie was almost better than going back to an old friend. Julie Delpy's character and Ethan Hawke's character finally realize that they are going to make love in the park, although it's ambiguous whether or not they really do until you find out in the second movie, but there's this song that was playing and I just thought it was so haunting and it's "Come Here" – and so, I had to download "Come Here." I think that one little moment just really captures between the song and the non-verbal communication between them a really intense love, it's just amazing. In the second movie, "Before Sunset," at the end of it they're in an apartment, and again, it's really uncertain whether or not they're going to be together, and all of a sudden, she starts listening to Nina Simone and sort of channels Nina Simone, she's very erotic. I think the last sentence in the movie is, "You're going to miss your plane," and he

says, “I know.” I think that moment *so* captures what intense love is like. It’s just gorgeous and beautiful. Movies are very important to me, and music – they shape me every day.

Circuits and Understanding

I learned a lot about it from my friend, Bob Levenson, at Berkeley who has talked about the disease that we’re both interested in: frontotemporal dementia, the rock opera of emotion. Evoking The Who song from “Tommy,” he talks about “*feel me, see me, touch me, heal me,*” and the sort of breakdown in the whole system that goes on in frontotemporal dementia. I think our great scientists here like Kate Rankin, Kate Possin, and Howie Rosen, are really delineating the anatomy of these systems: where are they in the brain, what are the things that activate them, what goes wrong when subtle parts of that system aren’t working, and I think this has grand implications for psychiatry and just normal behavior and education, understanding those circuits. Without them, most people fail.

I think a lot of us are at circuits that facilitate creativity, and I think we all want to be creative. I think some of us are locked out of certain rooms of creativity, and we can’t all be comedians, we can’t all be writers, some writers can only be poets. I think I’m most creative in the writing mode, and sometimes it’s simply changing a word or two in one of our students’ documents, reading a document and realizing it won’t evoke a “wow” experience in the reader, so figuring out how to shift those words around to make the reader experience it. I think good writing is a lot of thinking about communication with others and getting a feeling and mind state of who is supposed to be reading this. At my leadership course, I will share a little piece of writing I did around two different parts of my life, though I’m not sure how good it is. I think the theme is leadership, appearance and reality, altruism, empathy, understanding what people experience, and why they do things they shouldn’t do. I think that’s a lot about a neurology leader: it’s being able to understand behavior on a very microcircuit level, but at the same time understanding *why* behavior might go awry, at the same time activating those microcircuits in your *own* brain to make you

a better person and more likely to have an impact on others and more likely to help other people.

It's such an interesting time because we, in some ways, in academia and in society are getting a little bit censored. We've had a dean at Berkeley who hugged people get in trouble – I don't know the intent, but I presume, people have said it was not good. I think we are increasingly more restrained in the way that we can mentor and help people, and in the way that we can express our feelings for them. With those constraints, I think it's really important that we compliment and recognize the strengths in people. One of the things I always do with my caregivers and my patients is say, "You have done an incredible job with this *very* difficult problem." A lot of times, I think that if you just say that, the loved one starts to cry because they have never been complimented, only criticized, only been under this constant siege. I think this is one of the things that is very much a part of *me*: feeling comfortable recognizing the exception in people that I'm around and being able to tell them that they're exceptional. I think that that is one of the ways in which I express my love and appreciation of people, it's telling them how great they are.

I feel like I'm the most over-appreciated man in the world! I just feel like I have been so lucky in San Francisco, and I get so much appreciation every day. Just the sense of being able to work with a young person who is just beginning to think about where they want to go in life is a really wonderful experience. I can't believe how lucky I am to work with all the research assistants and the young professors. *This* is the way I feel appreciated, because we work with some of the best people here.

Pinballing Into the Future

It's funny, I live in a world of serendipity, like a pinball. I get more "bounced" into situations than creating them. I don't necessarily go backwards and think about people I *must* talk to or *must* meet. Life rushes so fast for me and I've never had much of a vacation, the time I associate with when you think about the past and who you want to see. In some ways, you reshape it and you re-experience it in your mind, but I don't have to be back there with people in the past necessarily.

My schedule is booked out a year in advance. I haven't had a vacation in a while, but if I did take one, it'd really be doing nothing other than swimming in Tahiti, Hawai'i, or Fiji. I really love islands, and I love swimming and the tropical feeling you get. There I can relax. But right now, I'm just thrilled with opportunities I have in the next six months, and every day is fun.

We're going to Oxford in November, and we're going to think with the Rhodes people how to train our next leaders. That's an adventure, and I'm an Anglophile, so even better! We are going to be working because of this wonderful Global Brain Health Institute effort with leaders not only in medicine, but Atlantic has also funded leadership programs around racial equity, social equality, and most of those young leaders are going to meeting with our leaders and with us at the Rhodes House in Oxford. The Rhodes program is going to work with us around uniting these leaderships, working with the Rhodes scholars as well. Rhodes has been incredible in teaching about leadership, and I think we are going to have a chance to teach about the kind of leadership we ultimately believe in, which is working with the underserved, thinking about the brain, using the brain to help to create successes in areas where failures have only occurred. So, *that's* opportunity.

I think medicine's experience, every year and every new patient you see, especially if you're pushed by people brighter than yourself – which is what's great about being here is that there are so many people who are brighter than me – you learn new things and you kind of apply them back to patients. I've learned about loved ones through our nurses, genetics I've learned from Jen Yokoyama, and all these new things I learn about helps to turn around better diagnosis and treatment.

I think more and more we are going to start making a more tangible impact. I think the first stage with all of these processes is understanding, understanding mechanism and what happens to people, what happens to their loved ones, and I think we understand that pretty well now, and we can track it biologically. I think we're going to get a deeper understanding with genetics and other “-omics” with predictors of what is going to happen next, but I think we really are on our way there. The brain is the hardest of all organs to develop therapies for, but we want therapies. These things are common in the next five years. It's going to be much more exciting than it is today, it will attract a different kind of person: people who want to “do” and

make an impact. I think it's a very exciting time for dementia, and we seem to have the money to study it for the first time.

I think we all worry about humanity. Are we smart enough or selfless enough to see the steps we need to do to protect the next generations? Sometimes you wonder. In that area, I'm almost fanatical. I think it's *critically important* we worry about climate change and our oceans. The U.S. should be helping poor countries with forests to protect them. Rather than thinking about selfish things, I think, unfortunately, for all that we have here, we're not enough focused on protecting the world. We can see a lot of this discussion in our current presidential race.

I like birthdays. My daughter has one for a whole month, that's her tradition. Some of them affect me a lot, others not so much, but my 65th was a big one, that one affected me a lot. I really had to think about the next stage of my life. It really had a big effect on my sense of time and the limited time I have. 50? Hardly. I was still skiing around Vancouver, one of my favorite places, but 65th? Don't know why, but I just knew it was a different time. It was less about "me" and much more about the next generations, that's what was really important, and I think every year after 40, you realize it more and more. It's so much about who is to follow you.

hear/say



The house where Alison and Peter grew up, now for sale

At the Bottom of All of It is Love

Narrator: *Alison*

Interviewer: *Kasia Gawlas, research coordinator*

Alison and Peter are half-siblings from Washington, DC. They are the biological children of Deborah, who was diagnosed with early-onset Alzheimer's disease around the age of 60. Deborah's husband, Peter's father, passed away suddenly of a heart attack in 2015, which is when Alison and Peter came together to be Deborah's main caregivers. In the following chapter, they each share their unique perspective about their caregiving journey.

My name's Alison, I am 33. My God, I forget sometimes how old I am. I live in Washington, DC, which is where I grew up, and right now I'm living in the home where I grew up. I moved back here about a year and a half ago or so, to live with my mom who has Alzheimer's. My mom is pretty young; she is 64, born in 1951. She has early-onset Alzheimer's. I'd been living in Los Angeles when my stepfather, her husband, passed away really suddenly, had an unexpected heart attack. So not only did my mom lose her husband, her partner, but she also lost her care partner. At that point it was still pretty early into her Alzheimer's diagnosis, and it was very clear that someone was gonna have to be with her; she couldn't live alone for sure. So I left LA really abruptly. My stepfather passed away on a Saturday morning, and I was in DC Sunday afternoon and moved back into the bedroom that I last moved into when I was 12 years old.

When I came back here there were so many feelings, and a lot of different things were seeming to take priority. There was no question that I had to come, that I was going to come back home, but that didn't mean that it was easy. I had pretty recently moved to LA and had been there for about four months. I had just put my stuff in storage and was about to head to Nicaragua and then to Costa Rica where the school that I study yoga is. And I knew I was going to return to Los Angeles. My stuff

was there and someone was renting my car... so in this interesting way I had created a lot of space in my life before I started planning for those trips. I wanted to be really clear about not having anything that was tying me, physically, to a place, so I could leave easily.

So, that is the long lead up to say that I had created all of this space for something, for some big experience, some big event. And it turned out that that big experience, that big event, was me moving back to Washington. I was ready to leave LA, my bags were literally packed, and I had to quickly unpack and repack and throw in a black dress to wear to a funeral and a couple of sweaters. When I arrived in DC, I still had my little travel backpack that had my bikinis and my yoga gear and my grubby work clothes, and a small duffel bag that had the sweaters and the dress and a pair of tights. So I think, if you look at the way that I had packed for my arrival here, I wasn't fully ready to admit to myself that this was going to be as permanent as it turned out to be. I'm here, physically, very present, very much engaged in it, but I'm not letting go of that dream, you know, that part of my life.

When I got here it was really, really hard, really hard... it was such an abrupt transition. It was hard because I was grieving, it was hard because I had no idea what I was doing at all, I had really no idea what my mom needed, none of us really did. Charlie, her husband, had done a hundred percent of the caregiving up to that point, and I think if I had reached out more to him I could have learned more and been more involved in this process. But he wasn't really opening up the experience to other people, and I wasn't asking, which meant that in the beginning there were all kinds of very basic questions: Can she be left alone? Has she been left alone? What does she need? Where are we, where is she, in all this?

And that first week was just so awful. We're planning for a funeral, we're going through all of the paperwork and the legal concerns.... My stepfather passed away so unexpectedly that there were a lot of loose ends. There was one really practical piece that was going on, and then there was this very emotional piece of going through the loss of someone, and then there was this other practical piece of, what's going to happen with Deborah, with my mom? And for many reasons — I'm her oldest biological child, and I'm a freelance writer and a yoga teacher, and I'm unmarried. So societally I have this life that kind of looks like, "Oh that's perfect, you can just go, you can just be there, you don't have

anything that's tying you down or holding you back." And I started to resent people saying things like, "It's so great that you can just pick up and be there." And I'm thinking: that doesn't mean that my life and the choices I've made up to this point are any less valid or important than the choices that someone with a full-time 9-5 job or someone married and with kids has made. So that was something that I was really sensitive to, this sense of, "Oh well it'll be kind of *easy* for her to uproot her life in that way, cause she doesn't really have anything going on, what does she do anyway? She's a freelance writer? Oh, she can do that anywhere." But that is one of the reasons I'm a freelance writer, because it enables me to be light on my feet, and to move and travel, for sure. The choices that I have made to get to that point in my life are just as valid as choices that other people have made that have fixed them in places that are more rigid. So that was another piece that was going through my mind of, "Well, yes, it does 'make sense' on paper for me to step into this role," but for me to say that I walked into this house being like Florence Nightingale and saying, "Here I am, ready to move home and be the caregiver!" Absolutely not. I was terrified, I was angry, I was confused, I was sad, I was scared. All of those things. All of them.

So that first week the house was full with family and food was coming in all the time, and there was lots of community support. Then we had the funeral, and then everyone left. And it was me and my mom in this big house, just the two of us. And it felt like, every morning I would wake up with that feeling of when you have a dream that you are underwater and you wake up gasping for air. Just getting through every day felt like I was underwater in a totally unknown terrain and just trying to hold it together for both of us, and feeling on some level really equipped to do it, and then on some other level feeling like I had no idea what to do. I'm also a person who thinks a lot, and I am very aware of my processes, and I'm very attuned to emotional processes. I write and I meditate and I think, so I had the blessing and the curse of being able to witness myself experiencing everything that I was experiencing, which almost made it feel like it was happening twice.

That was the month of February when I first got here, and I had had plans to go to Costa Rica in March, and I was going to do some additional advanced trainings at this yoga school there, and my family totally stepped up and wanted to make that happen for me. So my mom ended up spending the month of March with her sisters on the East

Coast. It was amazing that I was able to have that time, and what that month allowed me to do was that it gave me the space to choose this role, because initially I felt like I didn't have a choice. And I thought: Well, if I didn't come back, someone else would step up. Someone else would step up and take on this role, and could I live with that? How would that make me feel? What I came down to ultimately was, no, I can't do that. I don't want to do that. And the basis of all of that, underneath the sense of obligation or guilt, or others' expectations of me, and all these other factors that kind of influence decisions that I make, that at the bottom of all of that was love. And that my love for my mom was just way bigger than any of those things. And, you know it took me about fifteen minutes of this very serious kind of soul-searching to say, "No, that's not going to happen." That then gave me this moment that I would be able to look back on in the future and realize, "No, you chose this, take responsibility for this. This did not just 'happen.' You are actively a participant in this whole process." So that was a really important step for me to take. And just to have that literal space away from home and from my mom, all of that, so that I could make my own decision was so incredible.... And I was then and am now so grateful, to my mom's sisters, my stepsisters, to make that happen. I think it set up a nice precedent for me and for everyone else who's been a part of this process that I have to take care of myself, I absolutely have to. And that for me it means a lot of times to physically leave this home. Physically get out of it, for a week, a weekend, a month, two months, whatever. And I chose early on to not feel guilty about that at all.

Then in April, May, and June it was definitely challenging, because it was still just the two of us in the house. But I think the major shift for me happened that summer. Two things happened: one, my brother, Peter, moved back into the house and that changed our life in so many ways. Because there was another person around I could go to the grocery store and not be like, "Shoot, should I be away from her?" I could go for a bike ride, I could do things and not be worried. And then on a greater level, it's Peter, we all love him, he is the best. And he brings so much vitality and energy to this house. We also have really different styles of dealing with this whole thing, different ways that we approach it. He's kind of playful and easy, and just really naturally kind in general, but especially with our mom. I'm a lot more concerned with things like, "has she eaten, has she slept, is she feeling ok, you know

she's doing this so it must mean this." I'm just in general a lot more uptight, because I feel responsible for her continued overall wellbeing. Then Peter can come in and just kind of be goofy and fun and playful with her, which is not to say that he's not concerned with her overall wellbeing, we just approach it differently. So there was another person in the house who was messy and loud and had friends over, and it just brought some life back in so that was a huge shift.

At the same time my mom started going to an adult day program; it's called Iona House. That has been such a blessing- it's an incredible organization with really beautiful people who run it. She started going two days a week, so all of a sudden I had these chunks of time where I was off, where at first I didn't even know what to do with myself - it was incredible. And then slowly over time she was really clear that she was really enjoying it, and so she started going three days, and now she's going four days a week. It kind of felt like the transition in parenting, when your kid starts going to preschool a few days a week, and you think, "Ahh ok, I can be in the house and just get stuff done, and not be aware of the presence of this other person that I'm kind of in charge of." Whether it's the banal things that we have to do like the bill-paying and cleaning, or the fun extracurricular stuff, I was able to start scheduling those things, which then made the time when I was home with my mom so much different. And of course, I missed her, you know? I'd pretty much take her there and drop her off, and then pick her up most days because I like doing that; I want to be a part of that process. I think that surprised me a little bit, that I was really sad that first day when we dropped her off. She was sad and upset and nervous and didn't want to go, and so Peter and I had to kind of pep talk her and get her in the car and get her there. But once she was safely in there, then *I* broke down, you know. First of all, "What are we doing? Is this the right thing?" and then this sense of loss.

My mom is really self-sufficient at this point - she bathes herself and brushes her teeth and can go to the bathroom, all of the things that I think of as being pretty major. The way that I see my role is in creating an environment that is safe and loving and that's fully functional, so that's basically running any household: making sure that we all have toilet paper, that there's enough food around, and that it's accessible and prepared. To also try to have a home environment that feels warm and happy and good. A lot of what I'm doing is trying to constantly

anticipate my mom's needs or what it is that she wants, because her speech is definitely going. It seems like it's getting more difficult for her to find the words she's looking for. And you know, I joke, "Oh mom, it's a really good thing I can read your mind," because she'll start a sentence and not be able to finish it. But I know her well enough, and I know the situation well enough that usually on the second or third try, I get it.

We're definitely at a place of transition as far as her abilities go. Getting dressed and taking a shower and going to the bathroom – she's still able to do all of those things, but I can see all of that slipping, and getting dressed is definitely harder for her and more of a process. Anything involving sequential decisions is very challenging, and I think Peter and I, without even really talking about it, are in line in our thinking of wanting her to do as much for herself as she can. So for me that means putting the cereal and the milk and the blueberries and a bowl with a spoon out on the counter and then asking her to do the rest. To put the dish in the dishwasher or at least in the sink when she's done. So I know that getting dressed is a struggle for her now, so sometimes I'll go and check on her and she's in one outfit, and I'll go down to the kitchen and go back and she's in a totally different outfit, and I'm like, "Okay, obviously something happened in between then and now." Or when she explicitly asks for help, which she will do sometimes, she'll be like, "What do I do now?" then I'm with her step by step. Witnessing the cracks, watching something that was so automatic become really unfamiliar is definitely challenging for everyone. Fear is really an emotion that I'm careful around; I don't ever really want to be motivated by fear or live from that place, so something that I'm aware of or just watchful for with my mom is her moments of deep frustration when she's unable to perform or do something that she really wants to. On the mornings when she comes downstairs in her bathrobe, hair dripping wet, and she doesn't know what she's supposed to do next, and I see this desperation and this look of "help me" but also she's angry – "what am I supposed to do next?" I don't know if she's ever said those words, but it's kind of this look. Shoulders shrugged, you know, and I'm like, "Okay, let's blow dry your hair and find some clothes," and I'm thinking "okay, okay, okay, back on track." Finding these familiar benchmarks of where to go. For me, witnessing what must be so terrifying and just so alienating and unfamiliar, to witness her feel that, and to really have no idea what that feels like, that's really hard. The

only way I can approach it is to clap my hands and say, "Let's go blow dry your hair and pick out an outfit!" I have to temper my emotional response and come in like a cheerleader just so we can keep moving, get dressed, get out the door, get on with the day, rather than being stuck in this morass.

I see her get really frustrated, she misplaces things a lot, and you know we pretty much always find them, but she gets so anxious about it, and I sense that's where the anger starts to seep out. Anger at the disease and at herself and at everything. Then it's this hard place of being like, "Oh you're looking for your glasses? Did you try x, y and z places?" and kind of empowering her to problem-solve and have a sense of ownership over her own life, allowing her the space to do that on her own. But then I'm in the kitchen knowing that she's upstairs looking for her glasses and I'm like, "Okay I'm going to give myself x number of minutes before I go and help her," because the longer she can't find them, the more distraught she's going to be. So I might saunter off to go do something, and I might say, "Oh just go look in your bathrobe pocket" knowing that I'm counting the minutes, while at the same time frantically thinking to myself, "Okay where could they be," because if we can't find them I know she's gonna flip out, you know? Another part of the caregiving is the creation of the environment where I have to always be in control, I have to always have all the answers, because that's where the safety comes in. If she feels no one is driving the bus, then: panic. I think that's the difference between me and Peter and our approaches, because I have designated myself the bus driver. I'm not in shotgun, I'm not the DJ. That's the fun role. I have my eyes on the road, which means that I'm sometimes not as nice or as playful or as fun with her as I'd like to be! I'm driving. Here are your glasses.

I think for me, a good day is when I can be loose with her and forget that I am driving the bus, and we can just laugh and not take everything so seriously, and just connect on a human level. I'm also really happy with a day where we all ate good food and everyone was healthy and got good sleep. A day of appropriate emotional responses to what was going on. I actually think a great day of caregiving is when my mom feels comfortable with me enough to cry about something she's sad about or to be able to express her anxiety about something that's happening, and not feel like she can't share those concerns with me. When we can just be real with each other and talk about the hard stuff.

She misses her husband, it wasn't that long ago that she lost him and it was really sudden, so I can hold space for her to talk about that. That's a good day of caregiving.

I think that the power of language is really important. I try to be really conscious of how I talk about this experience and how I talk about my mom's experience. I think we place things on this continuum of good to bad, and then this idea of normal – not normal, and I've tried to be really conscious of not talking about what my mom is experiencing as a decline, or a lack... or this move from good and normal to bad and not normal. My mom is moving into a different iteration of herself. She's transforming. And just because it's not familiar to me, just because we don't speak the same language as much anymore, it doesn't make her language any less valid or valuable.... So I think if instead of trying to bring her back, bring her back, bring her back, I can just meet her where she is and not get angry at myself for not being able to speak her language either. It's an understanding from both of us that we're coming from different places and one isn't better than the other. People ask, "How is she, how is she?" And I think they kind of want to hear about the decline you know, what she can't do. And that's a part of it, but really it's like, "Well, what is she doing?" She gets up every day, she gets up, and she's here, and she gets dressed and she goes out into the world and she smiles and engages, and it's so brave and strong. She is navigating this whole totally new unfamiliar world, constantly being reminded, constantly being infringed upon by this other way of being that is not her way anymore. I think that is pretty remarkable that she's able to continue just *being*, and being grateful and funny and kind and real with herself, you know?



Narrator: *Peter*

Interviewer: *Kasia Gawlas, research coordinator*

I'm Peter... I'm 23, and I'm from DC, and am living back home in DC, working in DC, and living with my mom and my sister. I'm helping care for my mom, she is 64 and has early-onset Alzheimer's... she's wonderful, and pretty funny honestly... but has definitely started to not be able to take care of herself, for the last few years. Really smart, really smart woman, who had a really great career and life, and now we're all figuring out how she can stay stimulated. When she was working, she worked as a counsel for the Senate Energy Committee, most recently. She did a few other things before that, but most of her work has been in the Senate, working on energy issues. She did things like write legislation to transition towards fluorescent light bulbs. Little things that make a big difference to offset weatherization programs for homes.

When she stopped working, it wasn't apparent that it was Alzheimer's, but it was a function of the symptoms that she was experiencing that she decided to stop working. I think that... she wouldn't have retired when she did if it hadn't been for the onset. Of Alzheimer's. So, right now she's pretty high functioning so it's really meal time, and just entertainment and activities more than anything. And getting her places and doing things with her, and helping her keep her life in order to a certain extent, like my sister, me, and Nana, a caregiver, who comes a few days a week... sort of all work together to do various aspects of that.

I think a lot of this year, honestly I felt stretched thin because I work in a school during the day. So I would come home and then also feel like I was still sort of supporting – I wasn't off. So there were a lot of moments of frustration. Frustrating because it's also very confusing to be caring for *her*. I think... there was never any time where I was independent without her being dependent. There was no coequal period. And so I think that has made this abrupt, and startling, and very weird because she's my mom, she's the woman who cared for me and raised me and now, she can't do a lot of the things that she used to be able to do. Even if I wasn't necessarily her caregiver at the start, because my dad was, it was still hard to conceptualize. That she now needed me. My mom needed me. My dad really took on a lot of the

burden and didn't really seek out our help. So I think in large part, my life continued on as it would have. I did a lot of the same things I would have done otherwise until my dad passed.

After he passed I definitely felt like it had changed. I had to be a much more active part, and Alison really had to be a much more active part. He was so much the rock of the family and her rock especially, that the wider family was well aware of my mom's condition before my dad passed, and so it was kind of the first thought on our minds once we were able to process things. My mom took it pretty hard, I mean, she was totally able to comprehend it, you know she's not at that point, but she knew that... Dad was... gone. She was the one who found him and I think that was really shocking for her, and there are a lot of things in this house that remind her of him, inevitably, so I think that's made it very hard for her. It's just a loss of stability for her.

On Sharing Caregiving

During the school year when I'm working, Alison has a much more flexible schedule, so she takes the lion's share of the work. But since we've started working with Nana it's become a lot more balanced which is really good, and allows Alison to really live her life, thankfully. What we try to do is just be as flexible as possible for the other, to make sure that if one of us is thinking about doing something they're able to do that, and make sure that someone is with Mom and doing something with her. We try to make sure that one of us is always here, we coordinate those weekends where we're going away so that they're not the same. Or if there happens to be a weekend where we're both out of town, my mom sometimes stays with her sisters in New Jersey. It's been nice to have that constellation of support, wider network, but Alison and I just try to be really proactive in our communication and let each other know what our idea is on a week-to-week basis and a month-to-month basis. And definitely, Alison moved back to DC to be here, and so talking about what our longer term plans are, where she sees herself, and where I see myself, and how those can best be aligned to support Mom.

When things get hard, a lot of the time I just try to keep going... but, I think the person I've had the most meaningful conversations with about this is Alison. She's here, she knows more than anyone. I'm

really thankful to have had her here. I think that the rest of my family has been here certainly to the extent that we could ask them to be, you know? My mom's stepdaughters – my half-sisters, Catherine and Christine, have been really supportive throughout the whole process. And especially with the process of selling the house, they've been very involved in that from early on. I mean, Catherine has her own family so, you know it's very hard for her to commit a lot of time, Christine, I mean Catherine still finds time to come over, and we do a good job of getting together as a family.... Christine comes over on some nights when we need someone to be here... she's spent weekends here. It's been a really wonderful family aspect. I mean it's been bittersweet because it's a wonderful silver lining of my dad passing, but it's probably exactly the kind of thing that could have saved him.

On Selling Their Home

More than anything the thing that we've had to do together is clean this house out and sell things, package things, donate things, store them. That's been an interesting process to come together, and go through a lot of family things. And my mom—I mean it's been pretty tricky because a lot of the house has been rearranged, and so it's been at times fairly disorienting for her. I ran out the other day to grill some meat, and then realized that we had sold our grill at the estate sale— so if that happens to me, for my mom that's even more startling. She gets somewhat sad about it but she is sort of able to grasp the bigger picture of why it's happening, I think she's just inevitably sad about it, as we all are. I think we all feel the same way, that it logically makes sense to sell the house, but also emotionally feels pretty bad, even if there may be some positive feelings from a fresh start, it's still weird. It doesn't eliminate the negative.

I think we knew financially it made sense to sell the house and it also made sense just as a practical matter, it's a big house, there's no need for the size, and as a fresh start it made sense and so when we decided to sell, we thought about what the next steps could be and assisted living made the most sense. We felt that it fit. At this point, Mom can still form a community, she's still quite active and engaged; and she can adapt to a space like that rather than having to sort of be

brought there at some point, she's happy to go. I mean, *happy* is a huge oversimplification, but she is ready to go and knows that it makes sense. She's been there with some friends and they like it, things like that, so it makes sense for her. And it greatly simplifies things for everyone. Having Mom in a location where we know she's consistently cared for, provided for, will actually allow Alison and me to live how we would like to live, and see Mom regularly and consistently but not be the ones that are caring for her on a daily basis.

There's definitely an element of guilt, I think with any parent moving to assisted living, there's an element of guilt and feeling like you could — you could stay with them or they could stay with you, you know whatever, however you want to look at it. And there's a certain worry or sense of guilt or sense of potential future guilt that I won't — I just won't see her as much as I should, as much as she needs, as much as I need just because we won't live in the same place. But the hope is that, just by doing it regularly and building in quality time will make a difference.

I'm gonna move in with two of my friends from work, maybe a couple other people. Slowly become an adult. It's gonna be really great, I'm looking forward to it. For the next year at least I'm still here in DC, and I'll probably be in DC for the foreseeable future. I don't have any concrete plan past next year, probably grad school, or continuing work in DC, but I'm just not certain. I want to stay in DC, at least at this point. It feels important to be here while Mom transitions to assisted living. And I'm really happy that I've spent this year doing this, even if it's been frustrating at times. It was good for me and good for my mom and good for Alison.

On Social Support

Sometimes it's frustrating knowing that I couldn't do something if I wanted to. That I don't have a certain freedom of movement, there are just certain constraints... but I mean honestly it hasn't been a significant issue, thankfully I live at home and I have a wonderful group of friends who are here from many different backgrounds, like Tufts, friends from high school, friends from just former jobs, people I know from different ways. And that broad variety of friends has

enabled me to find a lot of other ways to be social. And also I just, I don't know I have people over more, and that's – that's fine and it's really nice when I have a potluck and Mom just hangs out and talks with people, it's really nice. So I mean in some ways it's been really good for me, honestly to be rooted at home.

[My girlfriend] Anni has just been there for me through a lot of this, she's been someone that I could lean on when I needed to, especially in the time right after my dad passed. Even though we weren't in the same place, it was still reassuring or comforting to be able to talk to her and with her about these things, and I mean it's been... it's a bit of a strain cause I can't... we just had to carefully coordinate when we saw each other, but we got through that, she's here now she lives in DC now and that's wonderful. We're past the long distance phase and that's really nice. We made it through that. It's sort of an interesting turn – I don't know if I would have come home right after graduation if my dad hadn't passed away. If I... and if my mom was independent. I might be somewhere totally different, and definitely, it grounded me and made me want to come back home more clearly than I had before. And in an interesting way, living at home has allowed me the financial flexibility to actually travel to see Anni where with the job I'm doing right now I wouldn't have had that. So it's kind of funny how that worked. And Anni loves my mom, and my mom loves Anni.

My friends have been amazing interacting with my mom. They just sort of keep going, I mean, it is sometimes hard to notice in initial conversations, it seems like maybe she's pausing or is just kind of silly. And so, they just talk with her like they would have before. It's really nice. I've never been upset or sad about the way my mom interacted with a friend. Sometimes she gets a little overwhelmed, but overall it's been pretty great how my friends have been with my mom. I don't know that they, I mean certain friends really get it, certain friends really don't. But that's largely just a function of how much I've talked about it, you know, or whether they have a personal experience with it. My friends have been really great through a lot of this.

On Stress

Hmm. Um, it's stressful having the same conversation over and over again, repeating the same bullet points and not knowing whether it's going to be received this time, knowing that a part of it will be lodged in there. Often with my mom, she really wasn't like this before, but she's grown a bit more anxious, she worries more, she has less control over the situation. She knows that. So it's a bit stressful when she starts to get anxious or stressed, because we'll have this conversation that's reassuring her, multiple times over. You know and it's not like the conversations are building off of one another, really, they're sort of being re-hashed. Because she'll grab parts of them, not consistently. Or maybe not hold on to any of it.

The day-to-day thing that honestly gives me the most stress is... my reaction to a situation a lot of the times. My mom will just try to do something and not do it correctly. She'll do laundry with one pair of underwear, and I'm like, "Wait, wait, let me put some other stuff in there," but it comes out much more sharply, to her probably sounds like a reprimand. Sometimes I'm just kind of incredulous. Mornings are very tough for her... so she'll pour her coffee in her cereal, or what she does a lot is she puts maple syrup in her coffee sometimes, or sometimes instead of putting the milk in the cereal, she'll put the coffee or the maple syrup in the cereal, just little things where I'm like "No! You're not going to enjoy that now, we have to redo this... alright."

And I don't like the moments where I react and do something for her. Especially early on in this process, she used to be able to do a lot of things, but we all kind of assumed that she couldn't and then I think that made her feel like she couldn't and so she stopped being able to do those things. My dad really struggled with that, because he really didn't know what she could and couldn't do, what she could and couldn't remember... that was one of the things that weighed really heavily on him. At first I think it seemed like she was just being forgetful, or honestly to him, initially kind of lazy. She'd leave dishes in the sink or something. And he would be like, "Deborah, come on, what's going on here?" And it took us a while to recognize how... widespread I guess it was, and how it wasn't just localized in any kind of thing. So I get really frustrated when I do something that takes away her agency further, but

I also just – I don't know what else to do. I'm trying not to overestimate her but not underestimate either.

She's a Little More Free

It is really nice to be at home with Mom and be living with Alison, because even though — even though my mom is very different from the person that she was, in some ways, she's a little more free. She never used to let herself – she used to be pretty serious and pretty composed all the time. I feel like there was a long period of my life where she was like that. And it's been really nice being able to laugh with her a lot more. She wasn't harsh or anything like that, she just carried herself with a lot of composure. I remember at my sister Catherine's wedding seeing my mom tipsy was NUTS. It was like, *what is going on??* My mom was laughing and talking up a storm. She was a different person. And now, that was seven years ago? Eight years ago I guess? Maybe three years or so before symptoms started to show. And that was a really rare moment. And now I feel like maybe she's more anxious and more worried or she shows that more often, she also laughs a lot more. And finds things, like she's been able to laugh at ridiculous things that I've done, that she has done, that we have done together, which is great.

At this point I feel like we do have a pretty good handle on things. In terms of my interactions with Mom, the best interactions are like this: when we're going for a walk, this happened the other week, and there are a couple houses in my neighborhood with basketball hoops and balls that they just keep out front, and at two of them Mom and I just started playing HORSE... it was great, and definitely something we would not have been doing and we were both really terrible, but it was really fun. And she was trying something that she – I had never seen her touch a basketball that I can remember, so it was just kind of funny, moments like that make me feel like I'm doing something good, I'm a good presence for Mom.

Just a Starkly Different Chapter

This experience has made family a lot more important for me. Losing my dad and caring for my mom, a combination of those things. I mean that's been fairly big. It's not been fairly big, it's been really big. It's been really huge. It's been a big shift. Part of that's just, a different point in my life, you know. Being back home, being closer to family, and that really brings them closer to me, emotionally.

It's been a little bit of a sense of insecurity, my mom's diagnosis has brought a bit of a sense of insecurity, in that I wonder, and Alison has also expressed this fear to me that – that we will have the same early-onset of Alzheimer's. That we will experience the same thing that my mom is experiencing currently. And that sucks. The thought of that, because it's a stupid thought and there's no point thinking about it, really... other than taking like, ginkgo pills or something, I don't know, or whatever it is I should be taking. Yeah, that thought sucks because I know the effect that it has on a family and... it's just, I would hate to lose that agency, I would hate to lose that ability to *do*. I've been having a tough time with that, I think. And on the other hand, it's shown me that my mom can still have a good life, she can still have a lot of friends that are really close and supportive, she's made new friends, I mean it's not the end of anything, it's just a starkly different chapter. So periodically I think about it. Yeah. Yeah. It doesn't happen a lot, well I don't know.

I think it's important to note that I've been able to draw a lot of silver linings from this experience, but my situation is one of comfort. And there are so many resources that we've been able to draw on that most people cannot draw on. Financially and also just a really supportive extended family. And that has made my situation fairly easy. I'm incredibly thankful for that, but my life would look a lot different if I came from a different background, and this had all happened.

The Instant Bond

Narrator: *Charlie Maguire*

Charlie Maguire was a caregiver for his wife JoEllen, and he is a member of the Memory and Aging Center's Family Advisory Council. He graciously agreed to give a talk for the launch of the Global Brain Health Institute. The launch took place at UCSF with a simulcast with Trinity College Dublin on November 17, 2015. We felt that Charlie's articulate and heartfelt message had a place in the hear/say collection.

Thank you, Dr. Miller, for the introduction. It is so fitting that I have the opportunity to share our story in this venue. JoEllen so loved Ireland, and our visits to Dublin were never complete without a walk through the beautiful Trinity College campus and a visit to the library to see *The Book of Kells*. Writing and everything associated with writing was JoEllen's passion, and it is so ironic that one of the first things the disease took away was her gift of writing.

JoEllen and I were married for 51 years. We began our years together as high school sweethearts at the tender age of 16. Our marriage was truly incredible, and we often wondered why our lives were so blessed with family, friends, and good health. JoEllen was such a joy-filled woman, full of life, and the best friend, best mother, and grandmother anyone could have.

When JoEllen was 63, I began to notice subtle changes to her personality and speech. Soon after we embarked on a frustrating two-and-a-half year journey of doctor appointments, CT scans, MRIs, and speech therapy sessions, until a doctor mentioned the possibility of a neurologic disease called *primary progressive aphasia*. He wasn't 100 percent sure, so we were dismissed with a sheet of paper about the disease and an appointment a year later. In a few minutes, our lives changed forever with nowhere to turn for support or guidance and left to determine our future alone. By chance I read an article in a local newspaper about the UCSF Memory and Aging Center clinic, and I began a six-month process to change medical insurance and wait for

an opening at the clinic. I will never forget the first visit in May 2008, and the instant bonding between JoEllen and Dr. Mary De May. Later, JoEllen told me in her halting speech, “I love that doctor.” For the first time in three years I realized what lay ahead of us. More importantly, I knew we were finally with people who really cared. I was JoEllen’s caregiver at home for the next three years. By then the disease had so changed her, and the stress of 24-hour caregiving was taking a physical and mental toll on me. With the urgings of family, doctors and friends that I needed to care for myself, I made the devastating decision to place JoEllen in a memory care facility. For another three years she continued to decline to the ravages of the disease leaving her speechless, crippled and ultimately bed bound until her death in July 2014, ending nine years of turmoil. She was 72.

As I reflect back on back on our journey I realize how fortunate we were to have had care and guidance from UCSF. Sessions with nurses, social workers, clinicians, legal, and pharmacy staff all helped shaped my care plan. The frontotemporal dementia support group became my crutch and led to lasting friendships with others on the same journey. I am so grateful for UCSF helping us and others fight the horror of dementia.

Thank you.

Investigating Memory Through Art

Narrator: *Deborah Aschheim*

Interviewer: *Caroline Prioleau, Writer & Designer*

Deborah Aschheim was the inaugural Hellman Visiting Artist at the Memory and Aging Center from 2009–2011. She is a visual artist who lives in Pasadena, California and has a studio in Los Angeles.

Entering the MAC Orbit

When I first came into the gravitational field of the Memory and Aging Center (MAC), I was on an artist residency at Headlands Center for the Arts, which is this great artist colony in the Marin headlands. And so I had just finished a series of installations that was called *Neural Architecture*. It was a series of nervous systems for buildings based on the question of if buildings were becoming smart buildings and developing their own nervous systems, what would they look like? And so I had been creating these giant room-sized installations for galleries and museums across California and across the country that were cobbled together out of translucent PVC tubing and hand sewn out of plastic bath mats. To animate them and give them their sensing structures, they had baby monitors and motion sensors and little spy cameras, and they were basically, the electronic equivalent of *our* nervous systems that was this imaginary idea if buildings were growing their own.

I wasn't sure what I wanted to do next, but I was really curious to understand more about memory. And I was mapping my own memories, and I was doing some autobiographical work out of a family archive. My grandfather, my great grandfather, great aunt, and my great uncle had all suffered from various kinds of dementia at the end of their quite long lives. But it was still disturbing enough to me that it

made me wonder what memory was and how it could it be that when your memory started to fail, the self was sort of erased.

Some friends of mine from New York, who are mutual friends of Rosalie [Gearhart]'s, invited me to a party for my friend's dad. It was like his 70th birthday party, and they asked, "What are you working on out there in the Marin Headlands?" And I said, "I'm working on a project about memory." And they said, "Well, you need to meet Rosalie — she works at the Memory and Aging Clinic." They just knew she worked with memory, and Rosalie said, "If you're interested in memory, you should start coming to Friday clinic. You could learn a lot about memory and forgetting from meeting some of our patients." And so, I started coming to Friday clinic. I just was hooked.

And at a certain point, I was like, "You know, you guys should have an artist in residence." And Rosalie said, "We don't know what that is, but we're intrigued."

I told her it would be really neat to have somebody observing all this stuff and trying to make art out of it. And so, we decided that I would come for a week, just to see if it was feasible and do a little pilot week. So I came and had this crushing schedule of trying to meet with everyone that might want to meet with me. I met with people from language, and I met with psychologists, and I met with people studying genetics, and social workers and the nurses, just to see what might be a project. And to try to figure out how people would work with an artist. Because everybody was into art, which was a really cool thing about the MAC, but no one had really thought about how they would work with an artist, and I don't think anyone thought that what they were doing would be interesting to me, until I started looking at what they were doing. Then we were on.

Eye Tracking

So I had a really specific goal that I wanted to do when I was here. There were all these different projects going on all over the MAC, and the MAC was all spread out across San Francisco. And so, what I proposed was that I would do things over the two years that help make a connection between the various locales and working groups at the MAC and also between the clinic and research. But also try to transform the culture

of the patient areas to bring some of the clinical program that I found real exciting into their space. So I made a lot of temporary installations, and if you were paying attention, you might see and realize, “Oh, I saw something like that in Bruce Miller’s office,” but probably the most prominent one was in the Ambulatory Care Center. I was working with Indre Viskontas who was a post doc and also a classically trained opera singer and had a lot of interest in art, and she’d been working in Adam Boxer’s lab on some eye tracking studies. And so she was like, “Oh, I wish people could see our data. It’s so cool looking. It’s these beautiful photographs, and then we have this animated line showing where this patient’s eye tracking is going, and it’s really accessible. And you can actually really see the difference between the normal controls and the patients with frontotemporal dementia (FTD) because surprisingly enough, the people with FTD aren’t just remembering things differently, they’re paying attention differently.” I was like, “Wow, that seems really cool.” So, she showed me, and I was like, “Let’s do something with these films.”

And so I made this installation that was like this sort of neural network made of blue plastic LED-lit nodes that represented like synaptic connections in the brain. And then we had two little monitors, and one of them had the actual data from the eye tracking and the other one was people from all around the MAC performing the patients’ eye tracking – they tried to move their eyes where the patients had moved theirs. And it was the opposite of a black band over their eyes – it was a little band that just showed their eyes moving. And that was in the lobby where patients waited to see the neurologist. And when they were in the neurology exam, the physician would say, “Okay, can you follow my finger with your eyes?” And they could refer to the artwork in the lobby. So, that was really neat. And it was really accessible you know, and it wasn’t, anything that they would find too much of the body, because it was the eyes, but it would help them to understand what was going on in the in the exam. And also to get a sense of some of the research that was going in to try to understand memory and forgetting. You know, that was pretty cutting edge research that they were doing at the time. And I was just really happy, because I’d watched people waiting for hours until it was time to be seen. And literally, my artwork, in terms of what they could be distracted by while they were waiting, was replacing – I’m not kidding, there was a *National Geographic* from 1989.

And so I was like, “This is a little more appropriate.” But you know, I felt like the culture of waiting at the doctor’s, it’s an anxious space and you’re also bored but a lot of times the art is like flowers or something that is supposed to be soothing. Something that takes you *out* of your experience, instead of helping connect you with it. So, I wanted to make things that might be more of a conversation starter or let the people get educated about, what *is* the difference between a teaching hospital and just a regular patient care hospital? What are these studies that we’re getting asked to be in?

Embracing the Complexity

I’ve always been interested in the idea of art as a research practice. But I think that I got a much more rigorous and higher level definition of that during my time at MAC. I think anything I would want to do now is based on wanting to actually ask questions that I don’t know the answers to and make the artwork as a way of getting the answer to that.

But I’d say the other really important thing that changed my work was – it’s not necessarily particularly about aging or memory, but getting to know the patients. So [musical collaborator Lisa Mezzacappa] and I went and visited patients in their homes a few times. And we were so moved by that experience. It was amazing to get to know them as whole people and also just getting to know the caregivers, because everybody that we got to meet had such a devoted and really loving caregiver that was basically devoting their life to trying to preserve the quality of life left to someone that had an incurable degenerative disease and that was sometimes so moving. But the patients being willing to share their experience with us was really moving too, because, you know, often we would ask them, like, “Here you are, and you’re very lucid now, and you’re functional. And you know you have this limited time, and you could be spending it with friends and family – you could be doing everything on your bucket list, and yet, you’re letting us have one of your days.” And they would say the most important thing to them was to try to move the research forward so that other people wouldn’t get these diagnoses. And that was heroic to us.

So, after being artist-in-residence here, I wound up doing a lot of community projects where I interviewed people. It made me really

want to understand more about people's lives, and it changed my work in terms of wanting to have direct engagement with other people and the content of experiences inside of their head. And I think that when I was doing *Neural Architecture*, I had a sort of mechanistic view of the brain, or to me, it was one way of escaping from the personal worry about what might happen to me, because maybe there's this disease in my family, or even if there isn't – I'm going to forget everything I know eventually and cease to be. And I think I wanted to escape into this impersonal part – way that science can like let you feel like, "Well, I'm the scientist. I'm looking at the mechanistic body. I'm not thinking of myself as a person with a body." And the patients made me stop doing that. And so, I think in this profound way, it made me have to embrace the humanity and the complexity and even the painful parts of being a person and having a body. All bodies are eventually going to break. As opposed to thinking that science was a way to distance yourself from that and not have to deal with that. So it probably flipped everything over to the opposite.

Tangents

The definition of a good scientific experiment is that it's reproducible. And that it doesn't matter who does it. It should be objective. And it should be the same results, no matter what. It should generalize across a large population of patients. But as artists, we're allowed to be subjective. And so I think sometimes, scientists and doctors don't feel comfortable bringing themselves in and talking about themselves. Like in the beginning I kind of had that – I didn't want to say that there was Alzheimer's in my family because I felt like that made my interest in it seem personal, which was less rigorous or less intellectual. Or I might be seen as somebody that just had an agenda. So, I think that getting over that and being able to say, "Well, I'm an artist, and I'm comfortable with my subjectivity. And you can be too." That was probably really helpful for the doctors and for the scientists to be around somebody that said, "Actually, that adds value. That's a vehicle for empathy. That a way to connect with patients." So that was pretty interesting. But when you get to know them well, a lot of doctors and scientists have back-stories and motivations like that. So hopefully, we maybe opened up a

dialogue about that being okay – to talk about why you’re interested in what you’re interested in or your own story. The idea that subjectivity could be a strength, not only a contamination.

The most important impact on me, I think, was ambiguity. A lot of times we were doing things just cause we were curious. We didn’t have a reason why we were doing it, or something would start happening that we didn’t expect, or we or we would get a bad result, we would think, “Well, that wasn’t really that interesting, or I don’t know what to do with that.” Like when we, for example, I had Lisa Mezzacappa come into Adam Gazzaley’s EEG lab, and we hooked her up to the 64-electrode EEG, and we scanned her brain while she played the stand-up bass. And I wanted to see what would happen if she played from memory, from sheet music, improvised, and just played warm up tones. First we thought the thing that was useful about it was that you could actually get some usable data from that. Because that should have been way too uncontrolled and violated a lot of the rules of EEG. So that was exciting at first, but then it was sort of ambiguous. I mean, you couldn’t write a paper about it, and it wasn’t art. And so for like two years, I didn’t know what to do with this stuff. And we tried all these things, and we had all these meetings, and we met with somebody that did data visualization for MAC data. We were spinning our wheels for a really long time. And then it finally turned into this video that we were really happy with. And Lisa took the sound recordings from the original session in the lab, and then she brought other musicians in, and Indre sang on it. It just took a really long time to resolve.

And I think for me, it took a while for me to remember that like you don’t always have to know why you’re doing something when you’re doing it. And I think that’s probably a good research thing too. Sometimes a negative result or something that disproves what you hoped was going to happen could be more promising, could raise questions that are bigger or ultimately lead to, or more fertile for new research than just proving the thing that you set out to prove. But it took a long time. It was really uncomfortable to have there be two years where we didn’t know why we had done something that took a lot of resources and a lot of people had to help us, and some people were waiting to see what we came up with. And so, that seemed good – the idea that something could take you off on a tangent that’s more interesting than the things that you thought you were originally trying

to do. Or that something that you don't know why you did might still wind up having had value.

Time Traveling

There's a lot of dementia on my mother's side but I think there was a lot of denial as well. My grandfather was a reticent, taciturn, New Englander with a hearing aide, and that parallels the symptoms of Alzheimer's. It's like a reserved man who might have his hearing aide turned off who doesn't talk very much. So, he was definitely mid-stage by the time he was diagnosed. And that's kind of the way it was with everybody in our family. And so, I think that by the time we had made the connection that there was something neurological going on with people's behavior, it was so far into the disease that we felt like, "Oh my God, that should have been obvious."

I think from a lot of my work with other people's family members, there's part where I was like, "I wish I had been more present and more understanding about what was going on with my family members." When I met with other people, I mostly met them through my work, so it wasn't like I knew them before and saw them decline. But I was able to just be really present with the person and try to enjoy the person that they are and not compare them to the person that they were. Or not be continually rehearsing things and trying to get them to remember things that happened that they can't remember. I've been able to do that in a way that I couldn't have ever done in my family. It would have been too painful.

I did a residency at the McColl Center in North Carolina right after I was here. There were about six or seven memory patients at this place called Huntersville Oaks that I made memory portraits of. The project was called *The Time Travelers* because some of the people that I worked with, they couldn't remember me from day to day, and they didn't know where they were and they were sort of anxious and disoriented. But if I would show these people pictures of themselves in their twenties and thirties – and I learned this from observing Dr. Miller in clinic where he would ask people stories from the 40s and Pearl Harbor, they'd tell these amazing memories when they maybe couldn't remember September 11 or who was president now. And so, it was

really fun and sort of lovely, like time traveling with these people. And having them tell me stories without knowing what came later. So they had this access to maybe a brother or a husband who had died without the sadness of knowing that they maybe didn't live very long or that they left them alone. And they would just be telling me all of these great things. One woman told me, "Well, I'm dating the bus driver. It's really easy for him cause I'm on his route. He wants me to marry him, but I'm not sure if I want to get married." And she had married him, and they had two grown children, you know. It was just really fun and neat.

And I don't think I could have done that with somebody I knew. I think that it would have been too painful and hard. I went back for a celebration of the project, and a lot of the families that I had gotten to know were like, "You might be the last person that made friends with my parent. And you're the only person who's only known them this way." And so that was sort of special in a funny way. I think I was able to accept them just as different and not needing them to be who they were, but I don't think I could do that with someone that I loved. To me, they were kind of delightful. But to their family members, they were like someone else.

Getting Older

Well, no one likes getting older. For me, the origin of a lot of my art is something I'm anxious about. And I love research. What I like to do is immerse myself in the subject to the point where it just becomes mine. In a way, I fall in love with it, or I just feel such ownership of it that I can't go back to the way that I used to feel. So for me now, like the brain and how it works and memory and aging, they're like something I've spent so much time thinking about that, it's not exactly therapeutic, and I'm not like over it, but it's just like – it's my subject now. It's something I'm really fascinated with. I think I look at this whole continuum of how the brain works at different times in your life and that there are things that you're better at when you're young. And there're things that are parts of healthy aging. And just thinking about like it's much harder to have distraction as you get older and memory doesn't work as well, you're not as good at multitasking, you know. And you can set up situations where your memory's going to work better but

also just seeing some of these people who are like in their 90s and are so incredibly sharp. I guess that's what you do with everything about aging. You realize how to get the most out of your body and your abilities and understanding that you're born with, and then you grow and these changes happen to your body throughout your life, and one day you won't exist. I don't know if any of us are great at coming to terms with all that, but definitely looking at the whole landscape is helpful. I talk to people that are anxious, and they're worried about themselves or like a lot of my friends are getting to the age where they start to say, "I don't feel like I remember things as well as I used to." And I tell them about Joel Kramer's research and things that they can do like, if something's really important to you, turn off the television and don't answer the phone in the middle of it. So like I think some of that research is very reassuring or soothing or useful to people who don't necessarily – they're not necessarily worried about having a disease diagnosis, but they're just worried about things changing and what to do about that.

I was talking once to Susan Amara, she was the head of Neurology at the University of Pittsburgh. And she was saying that forgetting is great. That's why the brain is better than a computer. She was like, "You can't just look at forgetting as being bad." Like we don't have to keep like getting more and more cortical mass in order to have the same amount of function. The computer is actually bad because you keep having to get more and more hard drives because you can't forget things. And so, sometimes I try to think about that too. It's not necessarily as much about you get older and you're forgetting. You always are forgetting all the time. And feeling like that's actually a strength, you know, as opposed to being freaked when someone tells you something, and you're like, "I don't remember us doing that!" And you feel terrible. Or "Who was that actor?" "What's that word I'm looking for?" And starting to panic.

Blazing Through

So I made these kind of like word-map drawings that one of them was this sort of narrative drawing of everybody that I met in clinic. Some things that were just like symptoms that they had, but some things that were more autobiographical about them (but they were all anonymous).

I had an exhibit in a gallery, and a man came up to me said, “I think I know what this drawing is about. It’s about an episode of *House*, right?” And I was like, “You’re close, but no.”

But also I made these word drawing portraits of three of the patients that we visited at their homes. And one of them was this woman who had corticobasal degeneration. She had 20/20 vision, but her brain couldn’t make sense of the images, and she said when she tried to read, it was like the words were in a foreign script. And so her husband said, when we were there, he said, “You know what I wish you could do? I wish you could make an artwork that showed me how she sees. I so desperately want to know how she sees.” And so, I didn’t exactly do that, but I tried to make some drawings from the inside of the patient’s point of view. Like one of the patients that we met with had frontotemporal dementia, the semantic variant, and she had a very, very limited vocabulary. It seemed like she only used like 26 words or something. But, she was so expressive with those words. And she was very creative. She still wanted to express so much. She did all this photography, and she wrote these poems. And the poems got a lot across, even with this incredibly limited vocabulary. And so, I tried to make these portraits of the people from their symptoms, but not just as a collection of symptoms, but as trying to get across the way that this individual person still blazed through in this kind of limited or different way of seeing the world. They had a disease that was going to kill them, so it wasn’t just like whimsical and like with autism or something where you could just say, “Oh, that’s neat. They’re different.” Like it was tragic. And painful. But on the other hand, there was something remarkable and enlightening about how they saw the world. That if nothing else, made you aware of all these background processes that you didn’t notice that you were doing – that allowed you to decode everything and make sense of everything or find all the words that you needed all the time and be frustrated when you can’t find one. So, I felt like that was a way of talking about what was happening to them that was also really about me or the person that was the viewer and not so much, like, objectifying them and making it a sentimental story. Or depersonalizing them like a subject.

And then I didn’t know how to do that in the beginning. In the beginning, I saw people as subjects and I saw them as interesting symptoms and that was really profound. Going to their houses and

seeing how they and their families were living with this and trying to be present. And trying to cope with the tragedy of things having changed but also get as much connection with the person out of the time that they had left and valued that. I don't know another word. It seemed heroic, people trying to do that. I mean they didn't have a choice, but they could have fallen into despair.

The Changing Face of Alzheimer's

I met Bruce Miller the first time I came to Friday clinic. I followed some young attending around in the morning, and then I went to the meeting where everybody got together and weighed in on diagnoses. And we looked at the MRIs, and that was really fascinating. I'd never seen anything like that. And it was also really fascinating because I was just the outsider and they even asked me what I thought, the very first day. You know, and later on, it was kind of shocking to me, because Bruce would actually ask my diagnosis and I'd be like, "You know of the people in the room, I didn't go to med school, and I'm not a neurologist." And he'd be like, "But what do you think he got on the Mini [Mental Status Exam]? And what do you think it is, based on the lesions and results?"

The first day – I always remembered this. We went back to meet with this man who had come in complaining of memory problems, and because I was the new person, Bruce was explaining a lot of stuff to me. So he said, "You know, this is the changing face of Alzheimer's. This is a disease that used to be diagnosed by the caregiver, and the person was very resistant – the patient. But now the stigma is going away, and we're starting to see people self-diagnosing a lot earlier, and the other people don't want to hear it." And that was exactly the case. It was this man in his 80s, a very nice man, very well dressed in a green suit. And he had this girlfriend, and she had a lot of turquoise on, and she was dressed very arty. And she was like, "There's nothing wrong with him. He's just getting older. He doesn't remember stuff." He actually had had a really scary experience because he was driving, and he was disoriented, and he didn't know where he was. And he knew that if he told that story, he wasn't going to be allowed to drive anymore. I was impressed – he overcame all these consequences to come in.

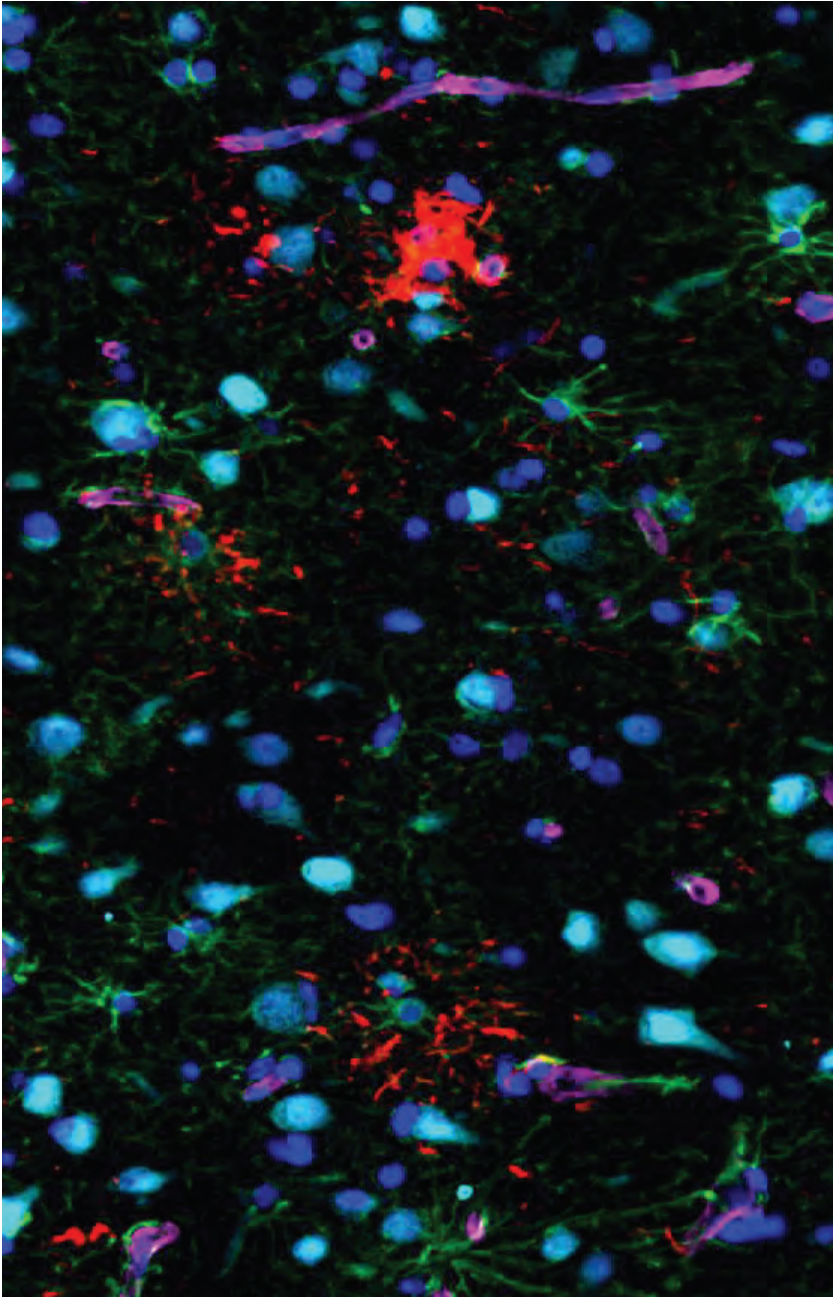
The main thing I remember that was when I first was like, “Who is Bruce Miller? This guy is kind of amazing.” Because he was so gentle with them, and he was so understanding. He was asking them some things. He did some of the standard things. He said a lot of words to him. And they were words that a man that age would know. Then he had a conversation with them, and then he asked him if he remembered any of the words, and the man didn’t. He said some of the words to him, and the man didn’t recognize any of them. Then he turned to me, and he said, “Well, this is classic hippocampal disease where he really can’t make new long-term memories and remember them for ten minutes.” And then he was asking him to tell him the names of presidents. He did the first name, and he got up to like Carter, I think he said “Jimmy” and the guy said “Carter.” Then he said “Ronald,” and he couldn’t do “Reagen.” He said “George,” and he couldn’t do “Bush,” but then he said “Monica,” and he did produce “Lewinsky.” So all the young doctors laughed, which was kind of funny. And he asked him if he remembered where he was on September 11, and he didn’t. And he asked him if he remembered where he was when Kennedy was assassinated, which was the classic one that they always talk about in the literature. And he didn’t, but he said, “I can tell you where I was on Pearl Harbor.” And he told this absolutely beautiful crystalline story that was like a poem. He was driving on a dusty road in California. He was in the service with another military officer, and he was talking about the light coming in. It was this yellow light that was full of dust and so the car. And this broadcast came over the radio about Pearl Harbor and how shocked they were. And I just remember noticing – that was really fascinating to me that he could remember something with such clarity when he couldn’t remember anything later.

But the thing that was so impressive about Bruce is that he listened to all of this, and it was all kind of textbook, I learned later, and he said, “The thing I really want to ask you is, you seem like you have very early stage memory loss but you seem very sad. I’m more concerned with your emotional state.” And it was true. The man seemed very sad. And then everything changed when he asked him that. And he said, “You know, my whole life I was looking forward to retiring because I love to read. I love to read novels. And I was going to enjoy reading. And I can’t read because I don’t remember the characters and what they did in the last chapter. And so I’m really bored. And I lost my

great love of reading.” And that was the first time I really understood what it would be like to have one of these memory diseases. And I thought that was incredible that Bruce, who’d seen so many patients, cut right to it. And he got to the thing that the person was experiencing – that was taking the meaning away from his life. And it wasn’t driving. It wasn’t the volunteer work that he did. It wasn’t that he was afraid. He was fairly old, but he wasn’t afraid of anything that was going to happen to him. It was that he couldn’t enjoy narrative art form anymore. That always stuck with me. That’s when I realized that a lot of people orbit around Bruce Miller because he has that capacity to really get to the heart of the person and see each person as who they are. That always really impressed me, despite his not inconsiderable occasional goofiness. [laughing]



***Clinic & Research* by Deborah Aschheim, rotocast resin, vacuum formed plastic, LEDs, fiber optic, video, paint, digital printing on Duralar**



**Image courtesy of Salvatore Spina, MD, PhD,
and the UCSF Neurodegenerative Disease Brain Bank**

Valuing Underappreciated Assets

Narrator: *Christine Ritchie, MD*

Interviewer: *Caroline Prioleau, Writer & Designer*

Dr. Christine Ritchie is a palliative care physician and a geriatrician at the University of California, San Francisco where she is also Professor of Medicine in the Division of Geriatrics in the School of Medicine.

An Opportunity to Care

I'm a health services researcher, and I'm particularly interested in implementation science – how we can actually bring all the good clinical innovation that we're learning about to practices and communities around the country and around the world. A lot of things – things as simple as like, taking aspirin after you've had a heart attack, take many, many years to actually be adapted and routinely incorporated into practice. And so, our opportunity, especially with respect to dementia care, is to figure out how the data and the scientific information that we have is actually translated into good practice by healthcare practitioners across all settings, in rural areas, in urban areas, regardless of someone's socioeconomic status, so that really, people get the best care when we're talking about dementia care. And so, what implementation science does, is it offers new conceptual models, including approaches to behavior change, in this case health provider behavior change, to really encourage adaption of best practices.

I've been involved in geriatrics and the care of individuals with dementia for my entire professional life. I got into geriatrics because of a recognition that there was a real need to provide better care for older adults, especially vulnerable older adults who have multiple chronic conditions, functional limitations, and other sort of challenges because

of other vulnerabilities, including, their socioeconomic status. Many vulnerable older individuals have dementia. So, dementia care is a natural part of that journey and of that mission. However, it became all very personal to me when my own father developed dementia, and he came to live with me. And I got to learn firsthand what it was like to be a caregiver. And even though I had been a geriatrician and a palliative care physician, actually being a first-hand caregiver really made this very personal and very important to me.

Making Changes and Having Impact

Dementia is a real unfortunate and important disease that we really need to be doing a much better job both combating, and then supporting and managing when people develop dementia. It's really one of the most important conditions that we're facing now as we age. A recent study showed that of all of our chronic conditions, dementia is one of the most costly, if not the most costly. It certainly is more costly than both cardiovascular disease and cancer combined, when you think about the toll it takes on people – to both the person who's experiencing it and to their loved ones, over time.

There are a lot of things that we can do to delay and prevent dementia, and some of the big ones relate to health behavior and making changes around physical activity, engagement with communities, and reduction of risk factors for heart disease and other vascular diseases, seem to be really important in dementia prevention as well. And then I think for those individuals who do have dementia, there's a lot of secondary and tertiary prevention that needs to occur there as well. How do we help people manage their finances, how do we help keep them and their loved ones safe, how do we make sure that folks don't fall or experience undue injury or harm? So all of those are really important issues, and, from the standpoint of prevention, there are opportunities for prevention before the disease actually starts to all along the illness continuum.

The Global Brain Health Institute (GBHI) is an amazing partnership between Trinity College Dublin and the University of California, San Francisco with the goal of having a global impact on dementia, both in terms of prevention of dementia, and then for

those individuals who experience dementia, mitigating against the toll that it takes both for that person who's experiencing it and their loved ones. And its focus is not just on the research itself, but around empowering individuals who are interested in making an impact in dementia to have that impact in the most effective way possible. So, it's about arming people with the skills and the knowledge and the expertise to both do the research and then to translate that research into practice. The goal is to inculcate leadership capabilities to have a sustainable impact that's scalable over time. We have an amazing array of individuals that are involved, from psychologists, neuroscientists, social workers, nurses, physicians, people from different disciplines in medicine, all sort of coming together, economists, and epidemiologists, all coming together to say, "How can we actually have an impact on this very, very, important condition and do something to mitigate against the tremendous toll that it's taking?"

The Atlantic Fellows at GBHI program is for anyone who has the mission and passion and drive to take the time to learn the skills to engage in effective change. The world needs more leaders to engage in this work. Leadership is really hard. It means persevering through difficulty, overcoming obstacles. You will encounter problems. Managing those problems, solving those problems, working effectively with others, learning what is the most appropriate strategy for addressing a particular issue – it is not something that many of us learn in our traditional professional training programs. Leaders often benefit from having other leaders that they can work with and have a network to learn from. My hope is that GBHI will serve as a place where leaders can be born, go back to their communities, and have a network of other leaders that they can come to for both guidance, peer mentoring, and support.

There are so many opportunities to make a difference in the care of those individuals with dementia. With Care Ecosystem, we're trying to develop an effective and sustainable clinical care delivery model that will have meaningful impact on caregivers and individuals experiencing dementia. We will also learn a lot about how to interface in a very effective way with healthcare systems and with healthcare providers, and hopefully, to use technology effectively so that we can leverage that and provide, again, deeper, more meaningful support to individuals with dementia and their caregivers.

Thousands of Losses

Caregivers are really one of our most underappreciated assets in most of our communities. They contribute so much to the wellbeing of those individuals who otherwise actually might be in settings that could be much more costly and that also would be honestly potentially less promoting of quality-of-life and dignity. So, caregivers have an extremely important role in the care of individuals with dementia, and their job is really hard. And their job is hard because they experience thousands of losses as their person, as their loved one who has dementia, you know, loses parts of their cognitive function that they had in the past. And they also experience often significant financial hardship. They experience hardship around just the physical burden of caregiving, along with, of course, the emotional toll that it can take. So caregivers are an important, very important asset, and we need to do everything possible to actually help them do well, to actually find meaning in the services that they're providing, and give them the tools to actually do that care with the least amount of harm and the most amount of gratification and gain.

Caregiving can be profoundly meaningful. It provides a sense of purpose, it can be very gratifying, and for many, it's a way of giving back. It's certainly not all negative by any stretch of the word. But there can be real – some significant bumps along the road, and if one doesn't actually have the skills to actually manage those challenges, then it can be just overwhelming. And, so, we have the opportunity to help people know what strategies are best for caring for their loved one in the most effective way... and how can they manage some of the potential frustrations that they encounter.

So much of caregiver support is around anticipatory guidance, education, providing caregiving pearls or tricks-of-the-trade in terms of figuring out how to best support somebody when they're having trouble navigating their environment, and, when folks have those tools, caregiving becomes a more an enjoyable experience.

One of the things about Care Ecosystem that really makes it remarkable is it is actually trying to serve as a this extra layer of support for people who are experiencing dementia and their caregivers. And then, in addition to that, serving as a link and a bridge between those

individuals who are experiencing dementia, and their healthcare providers. By doing that, it creates connections instead of what's usually a very fragmented set of individuals who are not adequately connected to each other. Care Ecosystem is trying to leverage technology effectively, so that it can be both sustainable and translatable in a lot of different settings – translatable in a rural setting, in an urban setting, in multiple languages. If we have something that has technology as part of its driver, then we can more easily translate the work that we're doing into other languages. If we have technology supporting people in their homes, then we can potentially know when people are running into trouble before it gets too far out of hand. So we see Care Ecosystem as an important foundation for clinical innovation for individuals with dementia, and because it starts at the person who's experiencing dementia first, along with their caregivers and then spreads out to other relevant members, it is a person-centered strategy, as opposed to many strategies actually that are utilized in dementia care that are more health system-focused or provider-focused and not necessarily focused on the person who's actually walking through this.

There are a lot of things that we're going to learn from this journey. And I think that through our work in GBHI and Care Ecosystem, there will be a lot of things that we're going to learn from our patients, caregivers, and partners from around the world that can have local and global impact.



Greg Was Still Greg

Narrator: Norene

Interviewer: Suzee E. Lee, MD, Assistant Professor of Neurology

This snapshot reveals the journey of Greg and Norene, who endured a disease that took away so much, yet remarkably left other abilities unaffected.

“As life on land becomes increasingly complex and frustrating, some take pleasure in knowing that the ocean is still an exciting, wild place where they can escape the crowds. It only adds to the sense of adventure knowing that a person can step into the ocean, drop the burden of being the world’s most dangerous animal and feel the exquisite alertness that comes from possibly being stalked by a fierce predator with home-field advantage.” – Greg Ambrose, Shark Bites¹

Greg and Norene first visited me during my neurology fellowship in San Francisco. That day, the three of us sat gathered around the desk in the stark clinic room as we talked about his worries.

San Francisco weather often feels like cold office air-conditioning, but Greg wore a short-sleeved Hawaiian shirt printed with large flowers. He had soft, intelligent eyes and a thick but neat, gray moustache. One by one, we mulled over Greg’s symptoms that had curiously surfaced all at the same time. Low platelets. Stomach pains. And mild changes in short-term memory. We explored the usual questions: When did these symptoms start? Are they getting progressively worse or are they stable? Was he misplacing objects or forgetting appointments?

Details of his recent memory had faded slightly, but he also had developed unusual visual phenomena. To his surprise, Greg once saw a row of letters on a written page of text fall vertically, trailing downwards on the page. When driving at night, he saw flashes of light, like mini lightening bolts peppering his field of view. But the first truly concerning event that Norene noticed was when he parked his car across two parking spaces and could not easily fit it between the painted lines. Yet, his speech seemed as smooth and eloquent as ever

when he recounted vividly how he grew smitten with Norene on Waikiki beach years ago. These days, one rarely encounters someone who can spin a tale without “likes” “you knows” or “ums” punctuating casual conversation, but as Norene puts it, “Greg always had the gift of gab.”

Norene was a vivacious woman with gumption. Everything seemed like it was going wrong all at once, and she wanted to get to the bottom of it. So did I. Did these different symptoms piece together? In medical school, we learn about the duality and tension between “lumping” and “splitting” a patient’s symptoms into a single diagnosis versus several diagnoses. A clinician’s foremost challenge is to determine whether clusters of symptoms may be related or unrelated and to choose the most likely scenario based on imperfect information. My gut told me that an illness was brewing, but that this constellation of symptoms resembled no known pattern consistent with a specific diagnosis. Over subsequent months, we pursued appointments with different specialists, and probed and searched for an underlying thread that might unite these seemingly unrelated occurrences.

After all the tests were done, I knew we had reached the limits of what medical technology could tell us. Even though it remained unclear why he suffered from these memory lapses, they were mild and manageable for the time being.

“If this is as bad as it is, we can deal with this,” they thought. “It’s not a big deal. We can handle it.”



Greg’s passions were surfing and storytelling. He worked as a journalist with the *San Francisco Chronicle*. Norene described how everyone loved Greg to edit their copy, because he could correct it and improve it, without making it his. He also wrote books about life in Hawaii, including a surfer’s guide and an anthology of vignettes about people who survived shark bites when surfing. A couple of years after we first met, Greg mentioned that he was writing a new book about a well-known Hawaiian woman who was beloved in her community. Because it was growing harder for Greg to organize transcripts and synthesize them into an overarching storyline, Norene helped him with this latest magnum opus.

Things grew worse, very slowly. “We adjust, things change a bit more, and we adjust again.” Greg loved music, but started to have trouble operating the stereo, because he could not visually distinguish its identical-appearing black buttons. Norene put colored numbered stickers on the buttons, with notes describing which button to press for each function: “play,” “pause,” “rewind.” These strategies thoughtfully and creatively tried to solve the simple problems of daily life, to levy his remaining strengths and abilities against his waning memory and visuospatial function.

But things weren’t always easy. One evening, Norene was rushing to get them ready to meet some friends and handed Greg his socks to wear. When she emerged from the shower, he was sitting in his chair, looking puzzled. “There’s something wrong,” he said, “I only have one sock.” “What do you mean, Greg? I handed you both socks. It has to be here somewhere!” she exclaimed in frustration. They searched the room frantically, but the second sock had vanished. They were running an hour late. Finally, Norene noticed in exasperation that he had placed both socks on one foot. Greg was starting to quickly forget where things were too.

Life became increasingly challenging as Greg grew more blind. Normal vision generates the illusion that our perception of color, motion, object recognition and position are united and indivisible. In reality, different visual systems integrate in the brain to construct a seamless representation of our world. The dorsal visual stream, which tells us an object’s position, was slowly disintegrating in Greg’s brain, even though his ventral visual stream, responsible for identifying the object, remained intact. His blindness arose from brain degeneration, not his eyes. Thus, the strategies that people with eye blindness employ were lost on Greg, because his ability to create a mental map of objects’ locations was progressively disintegrating. I sometimes try to envision how people living with this disease, called posterior cortical atrophy, perceive the world. Salient properties of objects such as bright color and shape may be recognized, but perhaps appear to phase in and out of view, floating like an ever-shifting collage with no fixed position or distance between them.

At first, Greg’s visual impairments were mild, but over time it grew harder for him to recognize objects. Eventually, he could only see part of an object instead of seeing its whole. Yet, remarkably, his

storytelling eloquence persisted undeterred, and he continued to vividly recount situations better than most people unaffected by dementia. Although details escaped his memory, he never repeated himself and the schism between his fading vision and memory and his verbal gifts deepened further.

As the illness marched on, Greg became more trapped, yet fully aware of what was happening to him. One day, when Norene arrived home from work, she found him lying on the bed glaring at the ceiling. He was silent and furious. The cable had disconnected and Greg couldn't figure out how to reboot it, so he was alone with nothing to do for the entire day. He couldn't call Norene because he couldn't operate the buttons on the phone, yet at the same time, Greg did not want anyone to assist him at home. Norene begged him to accept help from others, but he refused. For Norene, this too showed that Greg was still Greg. Proud, independent, and fully aware of his growing dependence on her.



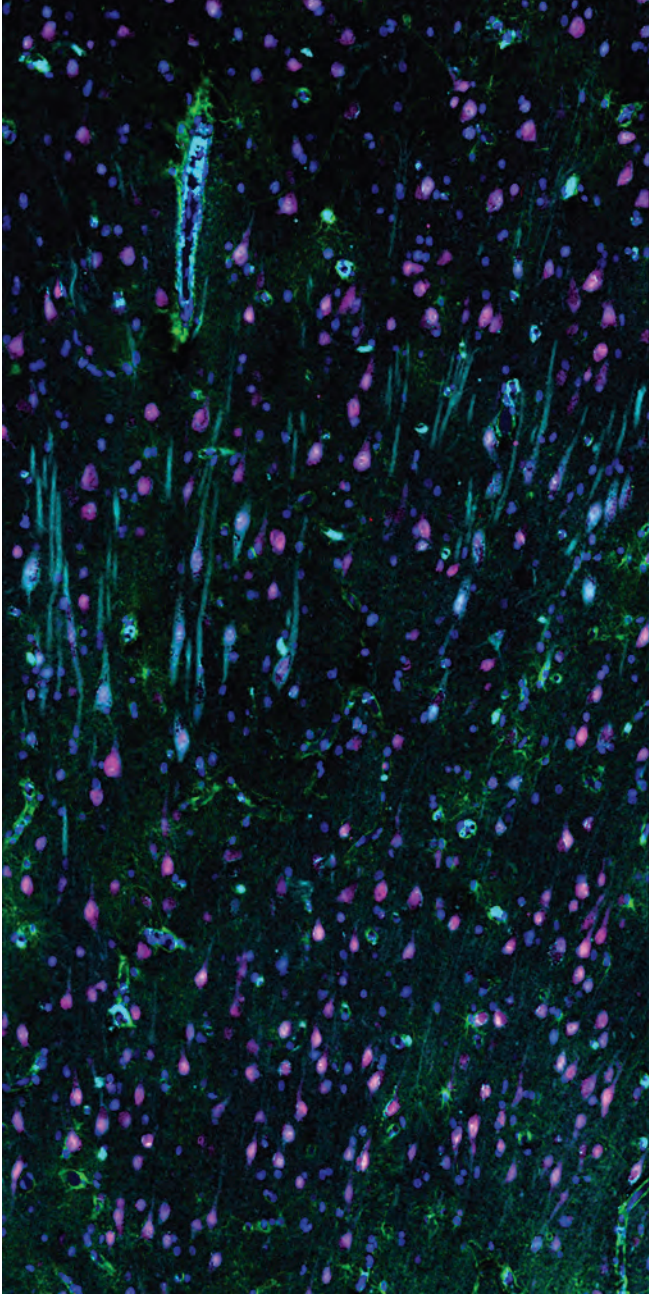
When I arrived at Norene and Greg's home a couple of months ago, I gasped, "It feels like Hawaii here!" Outside the house, a little shed sheltered about eight surfboards of various lengths and breadths, no doubt for harnessing waves with variable immensity and speed. Colorful stickers boasting the names of the best surf spots in the world lined the shed's walls. In the living room, soft armchairs wore a happy green and black Hawaiian palm frond print. A motley of wooden and ceramic shark figurines with beady little glass eyes peered down menacingly from a high shelf.

Reading the spines of the books on the shelves, I noted numerous volumes about surfing and Hawaii. I instantly remembered the day that I had told Greg and Norene that I was worried about his surfing—that he might not be able to see gigantic looming waves, some the size of small buildings, crashing on his head. His usually friendly expression fell in despondence and frustration. It was a dreadful thing for him to hear. I knew that surfing was not just a hobby for Greg, but only in his home did I recognize that surfing represented his spiritual communion with the ocean and a way of life. Greg was ever present in these books, figurines, and the people who loved him, even though he was now gone. Norene mused, "What do I do with these surfboards? I'm not going to

use them, but I can't get rid of them." I nodded. It would be impossible to get rid of them.

Reference

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**Image courtesy of Salvatore Spina, MD, PhD,
and the UCSF Neurodegenerative Disease Brain Bank**

Lowering a Child

Narrator: *Carol Lei*

Interviewer: *Julia Heunis, former research coordinator and current medical student at the UCSF School of Medicine*

Carol Lei was a caregiver to her husband, Ray, who had early-onset Alzheimer's disease. She has two daughters, currently in the tenth and eleventh grades. She works full time for the City and County of San Francisco as a program manager, and she is a member of the UCSF Memory and Aging Center Family Advisory Council. I got to know Carol at Family Advisory Council meetings, where I was touched by her authenticity, sincerity, and tenacity, and the time and effort she was willing to give back to help others in positions similar to her own. I was so grateful to have had the opportunity to hear her story, and to be able to share it – and Carol's "spark – with you.

My name is Carol Lei, and my husband Ray was diagnosed with Alzheimer's. He passed away two years ago. It'll be two years in two months, and life's a little different now that he's not here...

I Was Wife Number Three; He Was Husband Number Two

We met through work. I was an instructor for a required IBM management training, and he was a manager. He was living in southern California and came up to San Francisco for the course. That's how we met. Nothing big. Friends. There were a couple of work-related kinds of things that we kept in contact about. Then my husband and I separated. Ray was at the tail end of his marriage and got ready to leave his wife. We started comparing notes.

Work-wise, he wound up transferring to San Francisco, which is where he wanted to be. He really liked it and he wanted to be with me. It worked out. Since I was going through a divorce and he was going through a divorce, I was in a moment of, "No, I don't need men, forget this." Having friends who said, "You need a rebound guy. Why don't

you be his rebound girl and he could be your rebound guy?” I just said, “Fine, he would be my rebound guy.”

We joked about the fact that we’d never dated because we always said that dating meant that someone asked someone else out. No one asked anyone out. We were just hanging out as friends. Not only do you date, you ask someone out with the idea of moving the relationship forward. We were supposed to be each other’s rebound person so there was just never, ever any dating. We used to just have fun with this whole thing. We took a dancing class together at one point. People asked, “Are you married?” “Yeah, we’re married but not to each other,” we would joke. That was our relationship.

At some point we decided “Alright, let’s get married” but really it was more about having kids. I said, “I can go adopt the kids.” He said, “No, I want my name on the paperwork. I want the kids to know I wanted them right from the beginning, too.” We just kind of jointly decided to go to city hall. We picked a date, looked at each other’s calendars. “All right, does Thursday work for you?” “Yeah, OK.” We just settled in then, and we got married. After we got married, we turned in the paperwork for the kids. It was a little too practical.

Would I have married him if I knew that this was coming? I might not have, because there’s no shame in living independently, keeping separate finances, being partners in life. It’s not like we were young. It wasn’t our first marriage. But would we have adopted the kids if I knew he was going to go through all this? I think we would have, because that’s an “us” thing. You don’t just shut down life just because you’ve got the diagnosis. You don’t know how many years of life you’ve got.

Early Onset

We have two kids and that was the biggest issue. When someone gets sick you try to deal with it and you focus on the patient. My first focus was really, “Oh my gosh. There’s him, but there’s also the kids, too.”

Beginning 2005 – the kids were four and five – something just didn’t seem right to me. Initially, the only way I could put it is that I noticed things were different. I would consider, “Is it me? Menopause? What’s going on here?” We weren’t really connecting, to the point where I was thinking, “Is this time for a divorce? This is not working.” We had the

kids, and stuff, yet it would just pop in my head every so often: divorce. Then he had a heart attack, and I thought, “I can’t divorce him now.”

Until the following year, 2006, when I said, “You’ve got to go to a neurologist.” I can’t tell you what it was or what caused me to say, “See a neurologist.” Again, we just weren’t connecting. But he came back from the neurologist and said, “I’m fine. Nothing is wrong” and I thought it must be in my mind.” Two years later, in 2008, I’m really going, “Something is wrong, but I can’t figure out what. He’s already seen a neurologist. Everything is fine. What do I do?”

In reality, by 2008, I really knew something was wrong: I’m home cooking dinner. He picks up the mail on the way home. He comes in through the door, and he’s got the mail in his hand. He knows, any mail for me, put it on my side of the bed, which means I have to go through the mail before I can get to bed. I went to bed, and the mail was missing. I said to him, “I know I saw you bring the mail in, so where did you put it?” He goes, “I don’t know.” I’m looking all over the place for the mail. Couldn’t find it. Looking through the garbage. It happened to be garbage night. I literally went through the garbage can, and found the mail in the garbage can. He had thrown it away. He had no recollection he had thrown away the mail. OK. That was one, weird, ‘off’ thing. He was busy, whatever. You just bypass that.

Another incident came about when I was cooking dinner. He came in and said, “Can I help?” I said, “Yeah. Grab a salad dressing. You’re going to toss salad there on the counter. There’s a fruit salad and a tossed salad. Pick a dressing, and toss the salad.” I continued cooking, didn’t think anything about it. I turned around, and he’s poured salad dressing all over the fruit salad, and tossing the fruit salad. I said, “you didn’t realize...? I have melons in there – even the weight when you’re tossing it – it’s not lettuce, that’s light.” This was heavy melons. He did not realize he had poured salad dressing all over the fruit until I pointed it out. Then it became an, “Oh my gosh,” to him. Like, how did that happen? He realized when I pointed it out. It was a little embarrassing. OK, these were not, I forgot where my keys are, kinds of stuff. Those things surprised me a little bit. Like, you don’t recognize these things are going on? That’s when I told my doctor, “I don’t know if something’s wrong. It just seems something’s off.”

The following year, I knew something was really wrong. He saw a doctor and was tested for mild cognitive impairment. That’s how fast

the progression was. At that point, he wasn't even diagnosed with the Alzheimer's yet. Literally, the day he decided to tell the people at work about the mild cognitive impairment, he walked into his manager's office and HR was already there. He was going to tell them, but they beat him to it and said that he was fired. He had the job for two years. He had been fired from his previous job. I was still trying to figure out – was he already showing signs at his previous job before he was fired?

We Knew Early on That It was Alzheimer's

Some things make me really glad that we knew early on that it was Alzheimer's...like having the ability to really talk about it while it was still mild cognitive impairment instead of full-blown Alzheimer's. I'm really glad that we had this conversation: "OK, what about the kids?" His wishes, crying about all of it while the kids were at school, and them not being there hearing about it. That made it easier going down the path later on in making decisions – making decisions about the kids, about him...He had this big thing, even before we adopted the kids, he had always been, "The kids come first." ...And I'm like, "Not me?"

No, the kids came first. You hear the stories about Alzheimer's patients who can go a mean route, angry mean route, or it could be the nice route. I was very lucky he went, for the most part, the nice route. But we had that talk that if at any point the kids are ever scared of him, they feel threatened by him, they don't like him being around, he's out of the house. We had that agreement and I knew that, decision-wise... the kids came first. I said, "OK, do we get to the point where we have someone come in and help when we need help?" He said, "No, I don't want a stranger in the house with the kids. I don't want a stranger in the house." Those kinds of things that we talked about early on made it a lot easier. It made it a lot easier with the kids.

The kids had to learn, too... You know, you keep telling kids, "don't lie." But I would always talk about telling white lies, to "go along with Dad." It was really hard in that sense, teaching them two things at one time. Those were hard lessons.

But having the kids also made taking care of Ray easier. In some ways, I thought I had it easier as a caregiver than others because you've got caregiving with kids, and now you just got a third kid.

The biggest trick, the biggest thing, is that I would place an age on him. Put on age on them and you don't get as frustrated. It's like...a kid has a tantrum on the floor, and you go, "Well, the child's two. This is the terrible two's." You don't like it, but you're not expecting that kid to be walking and driving a car, being a responsible adult. This is a two-year-old.

I'd go, "He's a teenager. I can expect certain things out of him." He can feed himself, dress himself; we can have a conversation. But do I trust that he's always going to make the best decision as a teenager? No! Double-check some of those decisions. You're advising, but he's still capable. There are times where I'm like, "Oh my gosh, he's an eight-year-old. I have to watch him a little bit." He can still brush his teeth, get dressed. Now I'm making those decisions. Then when he's a four-year-old, you really have to watch out and tell him what to do. He can follow one – or two-step instructions. You can't give him big instructions thinking he's going to figure it out.

It worked out really well. Thinking of my "three kids," I kept trying to figure out at what point would the kids grow up and he would grow down to be the same age. It's really sort of weird, and really sort of funny how that worked out. Because the kids were still young enough that he was still the adult. He could still cook. The kids joked, "Mom, this whole time you were out, we always had spaghetti with meat sauce and broccoli. Because that's all dad can make." He used to cook a lot of good things, but as time went on, it was that or macaroni and cheese and hot dogs. He was still the adult, and the kids would still listen to him. Then as time went on you start to realize, "Oh my gosh, the kids are now taking care of him, too."

In November of 2013, I realized, "It's no longer fair. The kids shouldn't be taking care of someone. They're still kids." That is a hard decision to say, "OK, he's got to move out." He was starting to lose it a little bit. I couldn't leave him alone by himself. I couldn't leave him alone with the kids because it was no longer safe. I was worried about the kids' safety, and I was worried about his safety. Really, both. Even though he went to adult daycare, there were about one to two hours in the afternoon when they all came home about the same time. Within a 30-minute window, he would be home when the kids would be home. Two incidents occurred, until I finally said, "It's time for him to go."

One was, I came home and the dishwasher was on. I thought, “OK, the dishwasher’s on. That’s no big deal.” He came out and said, “Oh, the kids and I had a snack and we had dirty dishes.” Then I realized, “OK, but wait a minute, I emptied that dishwasher this morning. So that dishwasher’s totally empty.”

I opened it and there were two plates in there, so I still thought, “You ran the dishwasher for two plates?” But it wasn’t that. He said, “Well, I put the plates in there, and I don’t know what happened but I pushed some buttons and something went on.” I realized, he just pushed buttons. And he didn’t know. I said, “Where are the girls?” “They’re in their room doing their homework.” I started to think, “Well, the kids are in the bedroom so they’re not watching him, and there’s a stove right there. What if he’d turned on the stove, instead of the dishwasher?” So what if I lose a cycle of dish-washing water, but what if it was the stove? That one scared me...

Second one was, I had to work late, so I came home about eight o’clock, knowing the girls could cook at this point and take care of themselves. I said, “Where is Dad?” The older one said, “He’s gone to bed.” I said, “What? Is he in bed?” She said, “Well, he said he had to go to work.” I said, “What?” “He said he’d go to work. My daughter told him he didn’t work anymore. He kept saying he had to go to work. She finally said, ‘It’s night time, dad. You don’t go to work at night.’” She convinced him he didn’t have to go to work, and he said to her, “Then I better get ready for bed, I’m going to work tomorrow.”

It dawned on me that she was smart enough to figure how to talk him out of it, but what if she couldn’t have talked him out of it, and he walked out of the house? She’s tiny enough that she couldn’t stop him. Not only would he be lost and unsafe, but if something did happen to him, for the rest of her life, it would be on her that she let Dad go, and Dad got hurt. That’s not fair to put on a child. That’s a lot. It’s one thing to have a 13-year old who can babysit a child because she could physically pick up a child, and confine the child. But she can’t physically stop Dad from walking out of the house or doing something. I had to think about the safety for him, and the safety for the girls – emotional safety, physical safety.

For the kids, growing up, and knowing since the third, fourth grades that dad’s got a disease, they were OK. They were pretty open about it, and they’re open about being adopted. We never hid anything

from them, and they were OK. Until you hit about middle school, and then you don't disclose so many things. It's the teenage years. You're going to be embarrassed by your parents, no matter what. Even if the parents have no disease, they're just going to be embarrassed by their parents. By that time, he sort of withdrew. It was harder socializing with people, so they didn't bring friends to come over anymore. They wound up either going out, or to their friends' houses. I think, still today, socializing and having friends around is hard for them. Even though now I'm a cool mom, according to them.

He's Got to Go Somewhere

We also had a big thing with the girls and where, "If he ever gets to the point where you're scared of Dad, he goes. He threatens you, he goes." The girls said, "We don't want to change his diapers." If it gets to the point where he's wearing Depends, OK. We had a little agreement on that. It was getting to the end of that time frame when I realized, "He's not safe. The girls aren't safe. I need to find boarding care." I also timed it to do it during Winter Break. I have him hold out a little bit. Literally, the week before Winter Break he started acting weird with the pants. He started having accidents. I thought, "OK. Great timing."

We would get through Christmas as a family, but the weekend after Christmas we would move him, which would give us still one week of winter break for the kids to get adjusted. For me to adjust. For him to adjust in case we had to do anything special.... Part of the reason was the older one was in eighth grade. Her grades counted toward getting into a specific high school. I did not want to disrupt her studies for her getting into the high school she wanted. That was the end of 2013.

He was in a board and care. Just a general board and care place. It worked out great. By April, he fell and needed stitches to the head. He stayed in hospital for a week, and then went back to the board and care. You could start seeing the slide by about the beginning of May. He was still OK, but he was going fast.

I got my job and started working full-time, early June. He's got board and care, so I can get the full-time job now. The kids are old enough. We made it through the school year. It's summer; I could do this now. Second week on the job, I get the phone call. They're kicking

him out of the board and care. He escaped twice. He is now threatening and hitting the staff. He's gone mean. He's scaring the other residents. He wakes up in the middle of the night and goes into the other residents' rooms and won't leave, scaring the other residents. This is my second week on the job. I had no vacation or extra time. Luckily, that night I found an assisted living facility that was able to take him temporarily for two weeks. I could look for a permanent place.

It took three weeks for me to place him in a specialized dementia care in Daly City. The previous one was not specialized. I figured he was going to live another 5 to 10 years. He was doing good. That was early July, and five weeks later, he went pretty quick. He just quit eating. He just kept sleeping. They decided to call and get an ambulance to take him to the emergency room. It just so happened, I saw him the Sunday before. He was sleeping a lot. He's not eating. Something must be wrong, but we don't know what. We said, "OK. Give him 24 hours. Let's see if he comes back, if he's just tired or something." The next day, this one doctor said, "His blood work looked OK. He's probably dehydrated. His kidney, liver looks a little off, but he's probably dehydrated. We'll hydrate him and keep him here for a couple of days. Hydrate and probably release him." It wasn't until the next night that they said, "We're hydrating him. It's not working." They discovered that it's the kidneys.

When Dad Passes Away

"Do you want me to pull you out of school? Do you want me to call you at school? Do you want to take some time off?" Who should we notify immediately? Both kids were very adamant. No, nothing changes. Do not pull me out of school. Do not tell anyone. All my appointments, all my things, we are going to keep our regular schedule. They were like, "No; dad's passing is not going to change my schedule."

The doctors said he was going to pass away soon, because of his kidneys, so they were going to release him back to the assisted living facility. My initial thought was, no, he cannot go to the assisted living because it's in Daly City which means his death certificate would be San Mateo County. He lived in San Mateo County for five weeks. He loved San Francisco. He moved to San Francisco. The family's in San Francisco. This is his life. He loved the kids and the family. This was the first time

in his life that he really felt family, was with us. I couldn't let him die in San Mateo. I had to find a hospital. I had to find a way to move him to San Francisco. That's literally what happened. I moved him to hospice. He was discharged, settled in at four o'clock. He passed away that night before midnight, in San Francisco. The death certificate says "San Francisco." Life would have been easier for me if I had said, "Yeah, OK. San Mateo, not bad" but it would not have been what he wanted.

I'm really glad I dragged the kids to say goodbye to him. It was their first week of school. The older one, literally, first day of high school. The second one, first day of eighth grade, last year of middle school, and the semester that counts trying to apply to high school. I dropped them off, ready to head to work, and I get a phone call. He's been taken to the emergency room, from the assisted living facility. That was Monday. I had to go and tell the kids, "Dad's at the emergency room." They went to school the next day and at the end of day two, I get a phone call that says, his kidney is going, so I have to make a decision, put him on dialysis, or let him go. This is day two of school. I have to go home and talk to the kids. Easy decision, we're letting him go. Day three, Wednesday, I take the kids to say goodbye to him at the hospital. They didn't want to go, but I forced them, "You guys say goodbye to dad." That was Wednesday night. Thursday, I moved him to a hospice.

He passed away late that night. The kids were 13 and 14. The hospice knew if he passed away in the middle of the night, not to call me. Because what am I going to do in the middle of the night? It'll probably scare the kids, they'll wake up in the middle of the night. So I didn't find out until Friday morning. They called me, but by then the kids had already gone to school, and I honored their wish not to pull them out of school.

As a caregiver, I am very, very logical, very practical. Not quite robotic, but I separate the emotions from what I need to get done. If you grow up with a no-use-crying-for-spilled-milk kind of attitude, the emotions don't buy a whole lot. I've got to admit, though, with Ray having Alzheimer's, what also helped was realizing I was saying goodbye to him. By the time he passed away, I'd already said my goodbyes. I had said my goodbyes and done my crying while we were still together. When he still had the mild cognitive impairment I was literally, like, "This is goodbye. You're not going to be my husband anymore. You're my husband on paper but you're not the person I

married.” I had to say goodbye to the adult, the teenager, the kid, the toddler, the baby. I said goodbye in stages. Each time I gave him a new age, I gave myself two weeks to grieve the loss. I always had that inside joke for myself – I always gave myself two weeks, and then started doing something to get myself out of that, to go on with my life, to build my life again.

Some advice I would give to others who are going through this, is learning to say goodbye to the person, and give them the age so you don't get as frustrated, what to expect and be better prepared for some things. Those two things, I think, carried me through a lot of things.

There were a lot of things, techniques and things, that I learned along the way, like going to support groups. I tried several support groups and they were hard. When you're a caregiver and it's still early on, you go there and you hear all the horror stories of people talking about, “Oh, my loved one is at a later stage.” You're just like, “I can't relate.” What I got out of it was listening to everyone else's stories and thinking, “So, this might happen,” and to hear about techniques and to think about how people got through it. Whether he was going to go down that path or not, there was a lot that made me realize, “OK, that might happen? Oh my gosh!” I had time to prepare, at least mentally prepare, that that might happen. Listen to techniques that people used so I was ready for those techniques. Hear the horror stories to feel, “All right, I'm not that bad.” I thought, “This is good. All right, I got lucky here.” I think if I didn't go to the support groups, I wouldn't have known how I was faring. Am I doing well? Am I way out of whack? Am I crazy? It gave me that little bit of perspective.

Another way I made it work for me, was that I didn't get all emotional. I'm too practical for my own good. I'm also pretty self-reliant – I'm capable on my own, never fully depended on him. That part made it easier for me than, I think, someone who is dependent on the Alzheimer's patient because now they've lost a lot more. I lost a partner. For him going and for me, I knew I could take care of myself. With that, I felt like I could take care of my kids, too, no matter what. No different than people who get divorced. You've got to deal with these kinds of things. Not fun to go through, but you can make it. I looked at it as caregiving for the kids, caregiving for a third kid. Single parent, doing this, no different than someone who's divorced. There are lots of divorced people out there. I didn't get that feel-sorry-for-myself kind

of thing. The story is a little different but the practical, day-to-day stuff is the same. The differences are going to be the financial, the legal, the paperwork, kinds of stuff. That part is difficult. Realizing how much it cost us as a family because as much as I thought he was a teenager and could handle things, yeah, he was a teenager but he didn't make great decisions about money.

Keeping It All Straight in Your Head

You're not living just your life. You're living their lives, too, as far as keeping schedules. You're now keeping four schedules. Who's seeing the doctor, who's supposed to be where, when? That's no different than someone who's got a bunch of kids and keeping track of their schedules. You're also keeping track of their safety and what you think they want their lives to be.

There are times that, if I wanted to protect the kids from certain things, I had to remember not to share certain stories. I could always go to my husband and say, "Guess what the kids did today" but if Dad did something embarrassing, or whatever, did I need to go, "Oh, guess what Dad did today"? No. You don't do that. You can get lost very easily – whose stories, what's real, what's not real, and juggling all that in your head. You can get sucked into that too easily.

That's what I think my advice for other caregivers would be – you can get lost very easily. To family and friends, I'd say, "take care of the caregiver. Don't worry about the patient, they're taken care of. Take care of the caregiver. Don't ask, just do it." I realize, looking back, how many times people offered. People want to help, but don't know how. "Let me know." "Call me if you need help." "What can I do to help you," kinds of stuff. I never called the people. I never did anything. It's thinking of things that's harder, even if they said, "You want me to take the kids one night? Just let me know what night." I never did think about what night.

Take care of the caregiver. Just do it and let the person say no. Don't ask, "When do you want to go out for lunch?" or say "Let's go out for lunch one day. Let me know when you're available." Never going to happen. Instead, "I'm coming to pick you up for lunch on such and such a day." "Hey, I'm going to Costco. Let me pick up something for

you while I'm there" or "Hey, my kids are going to soccer practice can I pick up your daughter from soccer practice?" "Whoa! Yes."

I also had my stepsister and my friends. I would write, "Today was a bad day." Almost like a diary, but I would email it to them, knowing that there was someone there, other than a diary that no one's ever going to read or hear. I think in some ways that's the little call for help. Putting that out there is like double-checking, "Am I crazy? Out of whack?" I knew that these people would either say, "Okay, she's fine." or come back at me and go, "Whoa. That was huge. That was big. Do you need help? I'm coming over." That was one of the things I did to keep my sanity. There were a lot of emails that went out. Lots of them were complaining about stuff, about how horrible things were. "Guess what he did today?" kinds of stuff. I think that helped. Having people that were taking care of the caregiver helped. If you want to take the whole mantra of "it takes a village to raise a child," well, we're doing the opposite of raising. We're lowering a child here. Be part of that village.

I'm not sure I really got to the point where I was, like, I'm getting ready to give up. I had people around me to check my sanity, like if I was going to blow a fuse. "OK, I'm not going to blow. I'll manage this."

But, other times, you just go, "Die already." Yes. There were the times of, "Could he get pneumonia and we just get this over with?" That's because I heard someone else who had Alzheimer's got pneumonia. I was like, "Really, they didn't have to go back to the board and care?" There were times where it would make life so much easier. So when he passed away, it was like pneumonia, it just took a little longer.

Five months earlier, I forced the neurologist to tell me how long he had. I said, "I need to know, budget-wise, if he's going to live in a board and care or assisted living. I just need to know how do I pay for this – my retirement and the kids' college, or him?" She says, "Well, you're not going to get 10 years, but he'll probably make 5." I said, "Okay, 5 to 10." Five months later, he's gone. So I was, like, "Okay, we have college money." It was a big relief. It's sad that I don't have a husband, but financially, he's given us a gift. He really gave us a gift. College money.

The other one that he gave me as a gift – this is our inside story that I will share... he had been married twice; I'd been married once before. We debated, should we really get married? The previous marriages didn't go well. How do we know this one is going to work? I used to joke about filling out forms – there's always those forms that

say you have to check “single,” “married,” divorced.” I said, “I’ve never checked off ‘widowed’.” He came to me and said, “You know what? You can never check off widowed if you never marry me.” I said, “All right.” That was our inside joke. We’re getting married because I’ll never be able to check it off if I don’t marry him.

When he passed away, I had to laugh about it. The sense of, “You’re right. That’s your last gift to me. You gave me the checked off “widow” box.” It’s sort of a weird way to convince me to marry him, but now there’s a box I’ve checked!

But the thing is, I wonder... Go through the Alzheimer’s and all these years of slow goodbyes, or a car accident and it’s like, “What? I didn’t get the chance to say goodbye!” Which one is easier, harder?

I always wonder about that. He had a heart attack in 2005. UCSF luckily saved him without any damage to his heart. I love the fact it even made *The New York Times*. UCSF was written up about the procedures and what they do with heart patients, and they needed a patient story. March 7, 2007, you can Google that under my name or Ray’s name. UCSF saved him one time and I wondered, “Well, if UCSF hadn’t saved him on that one, he would have been gone sooner.” Would that have been easier? Harder? The kids were four and five. It would have been harder with the kids being four and five.

I still look at it as very lucky that he held on long enough to the point where the kids were able to be self-sufficient. If he had gone when they were four and five, it would have been so much harder taking care of the kids. The kids are old enough that they are able to feed themselves, get to school, manage... But I know he had a goal of wanting to be around to make it through high school. It didn’t happen. It didn’t even happen through middle school for the second one. He made it through middle school for the first one but she didn’t want him at her graduation. At that point, she didn’t want to see him. She didn’t want anything to do with him. She was already saying her goodbyes. That was hard.

It was a journey. It’s a story. As horrible as it may seem, it’s still sort of funny that it gives you something to talk about. It makes you interesting. You learn a lot. You learn about the kids, their resilience. They’ve done things like the Walk to End Alzheimer’s. They’re team captains, and they’ve each raised like \$2,000 each. They’re going

to have their stories on things, and I'll have my stories. It makes conversations a lot more interesting.

Life Has Changed a Lot

When I was taking care of him, I had two or three part-time jobs that were my socialization, seeing different people all the time and talking to them. That was my escape, my sanity moment. That was the time where I could talk to adults. It wasn't talking to the kids or the third kid. I didn't watch over them. I could have intelligent conversations with adults or feel accomplished in a certain way, and they were a great support. They all knew what was going on. The jobs were all flexible hours so I could work after the kids were in bed. It worked out great.

Now, I start to realize that there was always lots to talk about. When people knew what was going on, they would ask, "How's he doing? What's going on now?" I don't have that now. It's more about me. I realize, for so many years, scheduling life was around him. I just got back from vacation, and I realize I haven't figured out me. I haven't figured out my life, my schedule, my doing. I have got to go back to figuring out who my friends are, but it's hard to get yourself back out there. I'm trying to rediscover that now, who I am. It's really hard. What is it I enjoy? The theater, things I used to enjoy, and stuff like that. He's not there to go to the theater with, so do I go back to the theater? I'm trying to find some friends now to go to the theater with. But what else do I like? I don't know anymore. That's where it's hard. It is rediscovering me to stop being the caregiver. I still have the caregiver part for the kids, but I sometimes wonder, "Am I doing too much?" I was caregiving so much – Ray and the two kids – that that becomes habit and not necessarily what I should be doing or want to do.

There were a lot of things that I'd go, "It's for him." He'd always had a dog, but I said, "No, we don't really need a dog." He goes, "One day we're going to get a dog." "Yup, one day." We got the kids, and the younger one, every year for Christmas, every birthday, would say, "I want a dog, I want a dog, I want a dog." He kept saying, "We'll get a dog, someday." In 2010, he was diagnosed with the Alzheimer's and within a month of that, we thought, "someday" better be now, so we went to the SPCA and got a dog – his dog. Stupid me kept thinking, "Well, this

will be good. The dog will bark or alarm us if he leaves the stove on. He walks away, or maybe he gets lost, the dog will know how to get home.” But we got a stupid dog. Strangers or anything, the dog doesn’t do anything. Cute dog, but other than cuteness, didn’t really do a lot. It was great because it forced him to walk to the dog to get him out of the house, not be in the house. He and the dog got along great, and gave him a purpose in life. But that’s only for a couple years until he couldn’t do it anymore.

Even now it’s like, “OK.” As much as the kids say, “I’ll feed the dog, I’ll walk the dog,” you know the kids don’t do it. I’m walking the dog. I’m feeding the dog. Small dog, so it’s going to live a long time. The kids are going to go to college one day, and I’m going to be left with that damn dog he wanted.



UCSF Memory and Aging Center, 2002



UCSF Memory and Aging Center, 2016

Growing a Center

Narrator: *Rosalie Gearhart*

Interviewer: *Erin Vong, Education Associate with Voice of Witness*

Rosalie Gearhart, RN, MS, was one of the first people hired by Dr. Bruce Miller when he arrived at UCSF. They began their working partnership seeing patients in clinic and running a clinical trial together. The MAC has grown significantly under her leadership and synergistic program development with Dr. Miller and other leaders at the center. As the administrative nurse, she has a perceptive history of the program and its development and is passionate about future goals and directions.

Go After Everything We Possibly Can in Hopes of Doing Good

My name's Rosalie Gearhart, and I'm from Maryland. I was born on the eastern shore of the Chesapeake Bay in a very small town. I was raised in Baltimore and attended school there, and I did my undergraduate college work and nursing in Philadelphia at the University of Pennsylvania. I returned to Baltimore and started my nursing career at Johns Hopkins Hospital. I had always thought I would go to California, just because I love the beach and the ocean. I'd check it out for a year or two, but you get here and it's hard to leave.

I came to UCSF in 1988, and I started at the Memory and Aging Center in 1998. I'd spent 10 years in the hospital and then had just moved to the Department of Psychiatry and worked in a memory clinic in the outpatient arena on a state grant. That grant lost its funding, and I was about to go back into the hospital when Bruce Miller arrived, so I call myself "Employee Number 2" at the Memory and Aging Center. We were in an old inpatient unit over at Mount Zion. Dr. Miller had an inpatient room with a television on the wall and a bathroom, and I was in the inpatient room next door, so we had our own little unit and we would have patients come in. I'd be like, "Oh, we're gonna remodel this space

next time you come!” And then they’d come back for their annual visit, and it’d be like a little memory test for them: “Still in your patient room?”

Every Year There’s a New Challenge

We have evolved over time. We’re always tackling something new or taking a new direction. Every year there’s a new challenge. We’ve gotten so many different types of research programs started, and we’ve expanded our interprofessional group to involve geneticists and neuroethicists, beyond the typical clinicians involved in dementia care. I think it’s an incredible interprofessional group of people here.

Right now we’re challenged by our size. And that’s really what we need to pay attention to. I always think of us as a modern science group. We’re very collaborative, and most of the work is dependent on others within the center. There’s a lot of interdependency, which in the setting of constrained resources is just the way you have to operate, but that’s not traditional academic medicine. Other people have their own labs, and they’re very competitive with each other, but we don’t have that here. I think it’s unique. To maintain that, given our size, is my biggest challenge. People feel a little less connected, and they don’t always know who’s who around here. They aren’t aware of everybody else’s work that could be beneficial to their research or to their patients. Just trying to keep us working tightly together for the good of all is important. I think that’s how we grew together. Our goal is to be open source and open sharing and accelerate through research as quickly as we can, by being generous and sharing, as well as supporting others.

I Knew Right Away Who It Was

I was always attracted to the older patient because I got a lot from them, just hearing their stories and meeting their families. Back in the day they had a lot of strange terms for dementia, like “change in mental status” or “failure to thrive,” so it was always hard. I felt like an advocate for older patients in the hospital who really couldn’t represent themselves well. The patients are always what keep me grounded and coming back every day. The population that we serve is so important to me, and it’s growing.

We still have so much work to do to provide the care that's required, and the drive to get treatment for these neurodegenerative diseases. I'm called here for the patient care. I, myself, don't do that much patient care anymore, but it's still very important to me, and everyone here understands and respects the involvement of the patients and their families. The professionals, the staff and faculty here have that same kind of commitment to the patients.

When I was doing intakes, a principal of an elementary school kept calling and wanting to come in. She was fully functional, and really bright, and really nice, and I was trying to reassure her, "Well, I don't really know if we're even the right spot for you, because you're obviously not dementing to me," but she convinced me. And I just, I knew. It's one of those nurse intuitions: worried people are usually worried for a reason. We used to call them the "worried well," and I learned early on that they're not well if they're that worried. So she came in, and she indeed had a neurodegenerative disease, it was just super super super super super super early, so we followed her through the course of her illness.

We have these clinical-pathological correlation presentations. That's when the pathology team presents a case and then we're supposed to guess the pathology of it. They present the clinical history, and then they show the slides of the brain after autopsy and such. When they presented her clinical history, I knew right away who it was. Even though I'd sat in on brain cuttings... it was so emotional to realize that that was my patient's brain there, up on the slide. That was really hard for me. We've learned so much from our patients and families.

There's so Much More We Need to Do to Help

There's so much involved in neurology and neurobehavioral nursing, because there's so many different types of dementia, and it impacts the whole family unit. There are very few cures at this point in time. It's really challenging as a specialty, but really rewarding because the needs are so high. There's so much more we need to do to help.

hear/say



Musician Heidi Clare

Talking Without Words

Narrator: *Heidi Clare*

Interviewer: *Caroline Prioleau, Writer & Designer*

Heidi Clare was the second Hellman Visiting Artist at the Memory and Aging Center from 2011–2012. She is a Grammy-nominated performing old-time fiddler and a teacher. She has returned to the Memory and Aging Center as an Atlantic Fellow at the Global Brain Health Institute, a program that works to reduce the scale and impact of dementia around the world by training and supporting a new generation of leaders to translate research evidence into effective policy and practice.

Music as a Power Tool

I had a band called The Reeltime Travelers. That was my successful band for my career that sold many, many CDs, and we had a national presence. Warren Hellman and Dawn Holliday hired my band to play at Sugarbowl, which was a short-lived festival at Sugarbowl Ski Resort. And whenever I tour, I always run because it keeps me sane. I love playing ski resorts, because I get to run up the ski hill. Apparently, Warren saw me running up the ski hill and later found out that I rode horses. When I moved back to California, back home, he found out that I was there, and he knew that I rode horses so he introduced me to the sport of ride-and-tie, a team sport with two humans and a horse. And that was the beginning of our friendship. On weekends, we would ride horses in the morning and play music in the afternoon. We became friends through ride-and-tie and music.

I found out about the Hellman Visiting Artist program because I received a letter in the mail, and I opened it, read it, and I thought, “Oh, they sent this to the wrong person.” So I threw it away. I figured that it would go to the right person the next time. And then it came again! So, I thought, “Oh! I better read this a little more closely.”

One of the great things about the Hellman Visiting Artist residency is that you are allowed to build your own program, which was just magical for me. I couldn't believe it! I had a vision of having a monthly gathering throughout the year. And each month, I chose a topic whether it be movement, composition, improvisation, absolute pitch, etc. – all of course music and the brain. A different topic every month that might give some insight into these strange musical brains. I still remember everyone dancing and singing – making a ruckus in the atrium of the MAC.

Having taught for so many years and having performed for so many years, which are really two of the same thing to me – opening the brain to receive, I was excited to show how powerful music is as a tool in our lives. Not just as entertainment, but as a good, strong tool for brain health... if it is actively used.

On top of that, I was really hoping to work with older patients as well. I worked in Novato at an adult day care center. I have many fond memories from that time. I intrinsically knew that it would be good – that it would be powerful, but I didn't know how it was going to unfold. I have so many memories from those experiences. When I came out and did the workshop here at UCSF, I went to Novato and worked with the group of elders.

The Tango

The group at the adult day care center in Novato affected me in a powerful way. They were 20–30 depending on who was there when I was there. I always worked with them for an hour. On the first day it took most of the full hour to engage them. I didn't engage all of them. I left and said, "Okay, now what do I do? How do I get the rest? How do I get through to them?"

So the next time, I took them a little bit further. By the fourth time – this just shocked me – by the fourth time, the moment that I walked into the group, they were already with me. I didn't have to engage them because they already knew what was going to happen. They knew what to expect, so they created it. Instead of me creating it. We did it together. That was a powerful moment for me.

There was a fellow who told me the very first day that he was a tango dancer. And of course, I'm a dancer, a traditional dancer. I, of course, danced for them. But I don't know how to tango, so I told him I don't tango. On my next visit I brought somebody with me who plays guitar. I asked him to play a waltz, and then I asked this fragile man if he would waltz with me. I thought, "The caregivers are going to kill me!" He gently stood up, and then once I was in his arms, it was as if he became inflated – with energy. He was inflated with energy. He danced me around that room like I've never been danced with by anybody before or since. I'm a musician, so rhythm is important to me, and I've had a lot of wonderful dance experiences in my life but never anything as beautiful. As women often we want to lead because, I don't know, we just do. I wasn't even tempted. I was completely in his hands, and it was perfect. It was the most perfect dance experience. The next time I returned to Novato, the woman who directs the center said, "I have a story to tell you." He was found in the middle of the night, by the police. They stopped and asked him, "What are you doing out here in the street?" He said, "I'm looking for Heidi." Of course, we don't want people wandering around out on the streets, but what the story told me – I suspected this, but this just rang so clearly to me – is that the ripple effect for music through dance or singing for just a simple hour, if the brain is properly engaged in the music, and the humans are engaged with each other... is very powerful.

Quantum Entanglement

My job as the teacher, or as a performer, is to give openly. To prepare for sure but the preparation is only successful if I'm fully engaged with the brains that I'm working with when I'm doing it. I think that has to do with trust. Once they see that I am willing to give openly and consistently they engage. When we begin as musicians our successes and failures, as we see them, are *huge*. The swings are huge. However, the more we engage our brains musically, the more quickly those swings become quite small. Our lows really aren't very noticeable. They are to us. We feel them. We are disappointed, but we also understand that we've gotten so close to our equilibrium which makes the swings subtle. I have the same experience in teaching. When I teach, I know

I'm not always perfectly engaged the way I want to be, but the highs and the lows are so close that it's not so noticeable.

Music is a language. When I come in to a group of people who have dementia, I use almost no language. No spoken language. I use the language of music. I avoid the language that probably is the most problematic to them, and I bring in one that has very little negative baggage around it.

In meditation, there's so much talk around nothingness or emptiness or letting go and all those are so useful, but not in music. In music, it's the opposite, in my experience. You engage. You harness. And by doing that, all that other stuff happens. There is a harnessing of the mind that is necessary.

It is very similar to sports. When the harnessing has occurred, my awareness is heightened. And once my awareness is heightened, then the adaptability of my brain is very, very quick. Therefore, I can respond to many things – the band, the changes, the subtleties that need to happen in the band. It's a dance. The bass player is slightly ahead, slightly behind. There's a push-pull that you always want. You want tension and resolution in music. That engagement is actually sought. If the feel of a groove gets too comfortable, then I think, "Oh, I've got to push. Or I've got to pull. We've to get this song back to something that is better, we need to re-engage." And then there's the audience. I'm bringing them in along for the ride, or sometimes, they beat me to it. They're like, "Woohoo!" I'm like, "Okay, okay! I'm with you! Let me catch up!"

It's not completely definable. It's like quantum entanglement. Each acting force cannot be described independently of the others. There're so many moving parts, and I guess the crux of it is engaging the brain musically. That's always the first thing I do for myself. Once I engage my brain musically, I gain a focus that is both pointed and broad.

I think it's an active part of engaging in music, whether you're singing or playing or dancing. Listening is good, but it's not as valuable as participating. If you're listening to live music with a performer who is really engaging – Prince was such a giving performer – then you are engaging fairly high level but if it's somebody who is sort of just going through the motions and not really trying to draw in their audience, then I don't think the value is so high. It's just not as good for the brain. And ironically, humans know this, even if they don't think they are

musically talented or know whether it's good or bad, they all do. I've seen it so many times. They get bored and sometimes they think it's their fault because they're not "getting it" but it's not the case. They know there is more and they want it.

Precious and Mysterious

The work with the group of elders in Novato really blew my mind because I didn't realize how fast the engagement could happen – how quickly I could change the way that their brains, their minds engaged with music. That experience fired me up. I did a lot of reading. I had a lot of discussions on the subject. I think the other thing that it did for me is to widen my perspective. As a teacher, I've always been so interested in how people learn and always trying to figure out, "How do I get to that student today?" And even through a lesson, "How do I do it?" Or an audience, you may ask, "What am I doing wrong? I'm not getting through to them." Or you think you're not, but you are. And so, I spend a whole lot of time thinking about how to engage brains. Thinking about it more from that aspect, caused me to dive in and get a bit more focused on the neurology. I started reading Dr. Oliver Sacks, Dr. Bruce Miller, Dr. Ian Roberston and started to get into some much more deep, intellectual parts. When Dr. Bruce Miller asked me if I would be willing to come help at GBHI and see what I could do with music and the brain, I thought, "Wow! This is really big!" How do I look at it? The biggest challenge may be taking two separate disciplines and trying to break the boundary down to allow them to interact. In a way it's very simple, but because it involves humans, it's *very* complex. We have an understanding of music being, I think in a way, precious and mysterious. In a way I want to leave it be and not confuse it with the science of today, because the two have become divergent in today's world but my goal is to get them to truly interact. Not to bring music into science and measure it all, or to bring science over to here and break down the measurable borders, but to actually prompt the collaboration while retaining the integrity of both science and music.

Opening the Conversation

Music doesn't play a big enough role in aging, education and health care, in my opinion. I think the arts in general don't have enough of an impact on our daily lives. Music is one of the easiest art choices because it's so accessible, and it's very inexpensive. We all have it right in our heads. It is easy to share. I realize that our culture doesn't feel this way in general. We're often afraid to sing, afraid to dance, but if that boundary is broken down, which is very easy to do if one knows how to do it, then, suddenly, you've got this incredible communication. All the arts can make the lives of our elders much better. What I notice when I engage elders with music, is that they become empowered, and that is really beautiful. Whether that's important enough for us as a culture, I don't know because when people become empowered, they're not necessarily easier. Elders have been a very important part of my life ever since I can remember. Their wisdom has been important in the way I have matured. I was truly raised by a village in a tiny little town. I'm so rich as a human because of the things I was given from all of those elders. I think that there's an exchange that can happen. Not so much that we're going to take care of them and make their lives better, but if we open this door, they will give us their wisdom and their art, but we have to be the catalyst because we as a culture have shoved them aside. I believe that it is our responsibility to engage them and re-open the conversation. And if we do this, I think we'll be very pleasantly surprised at the gifts that we gain as a society.

“If there's no wisdom in getting old, it's just falling apart”

I would argue that the seed of my new record is entirely linked to my year as Hellman Artist. It was a huge departure on the outside from what I've done with my musical life – I am a trained classical musician but been a folk artist for much of my career, and this collection of songs came from different place. The content of the lyrics, the idea behind the lyrics, the musical choices, the melodic choices have a uniqueness in contrast to my past recordings. The seed of it, especially one particular song, was set around that time.

When people get old, they lose their beauty, or at least that's what our culture says to us. There's a wonderful quote by singer, Carla Bruni, "If there's no wisdom in getting old, it's just falling apart." The wisdom is what allows the beauty. I am working on a song that engages in this idea. What is beauty in a human? And if a person has dementia – if they don't have the mind that they have understood to have until that point, and they start to lose their way of using their brain as they were accustomed (or those around them were accustomed), do we see that as a loss of beauty? Do *they* see that loss of beauty? It's an intense question, because as a culture, we often say, "Oh, they are old now, so they're not beautiful. They're not useful, they're not beautiful." My argument is that we have to look. We have to pay attention because we are missing out. They're not going to share their beauty with us unless we pay attention. We don't deserve it unless we pay attention and bring openness to the conversation!

I know a man who has Parkinson's who has had a meaningful and successful career in civil rights and being a civil rights lawyer, a father, and a husband. He feels like he's trying to be graceful as he ages but his Parkinson's makes it hard. He's still very much in the dance of life with dementia. He has not given up but he knows that he's seen as a person who is not well so those who see him don't look for beauty. They see the weakness and they don't look beyond. When I first saw him, I could tell something was not quite right but I didn't ask him anything. I didn't know him, so I was just minding my own business. We ended up in a conversation that allowed him to bring it up in his own way. In later conversations, he was surprised that I didn't say, "Is something wrong?" I felt like such a comment had no point. He obviously was doing fine. He didn't need any help from me. That's the way music works. That's why art works. It is more powerful to be subtle in teaching and performing. Indirect communication always seems to give much more in the long run.

When Space is Made

It is so hard to see someone that you know and love change toward dementia because you don't want them to change. I think that's the hardest part – allowing them to change. That's our job. That is our

responsibility – to allow them to change. By allowing them to change and coming to them with the best version of ourselves, we not only allow them to change, but we actually bring out the best version of them at any given moment. That's what I learned from the people in Novato. I was trying to bring the best version of myself to them, and it seemed to bring out their best with great consistency. I think that's the value of art, especially of music. It is beautiful communication.



I'm Not a Vegetable Yet

Narrator: *Mark*

Interviewer: *Julie Feuer, social worker*

“You live a certain amount of time, and then you plotz. So you do what you can do.” Mark has done a lot. In his 64 years so far, he has been a father, husband, son, friend, community orchestra violist, Stanford alum, business owner, Certified Public Accountant, long-serving board director for several arts organizations, Toastmaster, and in his retirement: an avid cable TV news watcher. In 2013, Mark added person-with-early-onset-Alzheimer’s-disease to that list. Since then, he’s become a teacher and public policy advocate for treatment advances.

A Picture is Worth a Thousand Words

At a certain point, one of the doctors at UCSF, Dr. Rosen, showed me a picture that clearly said that I had Alzheimer’s, early onset. I was in denial for a while before that obviously. But that was what really put me over the edge. And once I saw the picture, I said I have to close my accounting practice. I would check myself and recheck my work as much as I could, but you wonder if you might get sued if you screw up or something. So it was kind of a relief to close it. It was hard to do, but once I did it... It’s a relief, really, not having that responsibility.

So let’s see, what else... What can I say...?

I’ve been very lucky to have Sarah in my life. She’s very tease-able and that’s a wonderful asset for me, at least. [smiles and laughs]

The day that I was diagnosed, when I saw the picture, Sarah was with me. By then I hadn’t been driving for quite a long time, so she would drive me pretty much everywhere. In general, I kind of forget now. So I certainly have to... I rely a lot on Sarah, my wife. I sometimes have to ask for Sarah to just confirm what we’re going to be doing. She’s very good at remembering these things. And I sometimes just forget, or

I'm just not sure, and so I ask her and she knows. And then I tease her, so that's good. [laughs warmly again]

But yes, in many ways, closing my practice was a relief. A picture is worth a thousand words, that's the thing. And the picture clearly showed me that I had cognitive problems. I think I've always had a bad memory, probably for most of my life, but it got worse obviously. Particularly when I got diagnosed, it became obvious. [laughs] But I wouldn't say I had a great memory even when I was young, not that I can remember really what it was like to be young...

I was born two months premature... in 1952... I always kind of wondered, I still don't know, if maybe that would've been a factor. If I was born to full weight and stuff, whether I would be a different person, I don't know. But you just do what you can do, and just enjoy life as much as you can. My mom had had several miscarriages earlier, and I was the only one that survived and that was in Hawaii... I'm a native Hawaiian. I think I told, did I tell you that? I'm a native Hawaiian just like Barack Obama. I love to tell everybody that.

Oh, By the Way, I Have Alzheimer's

It took me a while to start letting people know that I had the diagnosis. And basically everybody I've told, they've been totally understanding and great. But initially, it was hard for me to tell. It was hard for me to say, "Oh, by the way, I have Alzheimer's."

One of my clients, she started crying when I told her. She was a longtime client... But I think now, because so much more is known about the existence of Alzheimer's, it's starting to make a big difference.

We're Not Vegetables Yet

So we're going to be doing advocacy in Sacramento this month. Last year we went to Washington, D.C., too. This year, we're going to go to Sacramento only, instead of going to both.

We're trying to spread the word. It's important, I think, for all of us with the condition to tell people that we're not vegetables yet, to show that we still can do things. And ya know, we're not perfect. But at

least it keeps us busy when we do these things, like advocacy and going to our group. We have a group that we do twice a month, with those who also, like me, have early-onset Alzheimer's. So we get together and we get to share, and we get to learn something. We're very lucky to have the resources that UCSF has. We're lucky. Lots of people in other parts of the country do have the problem, but they're stuck in the middle of god knows where, but there's a lot of resources here in San Francisco.

Doing What I Can While I Can

I guess I've learned that Alzheimer's is something that you can live through. It took me a little while to absorb it, and then close my practice. But I guess I'd have to say that I'm not a vegetable yet, so I'm going to do whatever I can while I'm still able to do what I can. I don't really think about it really, it'll be what it will be.

And so, life is whatever it is. I've been this way my whole life. I like to be around people. But because I've lost my... I've closed my practice, I kind of feel like, with my diagnosis, I'm kind of a stick in the mud a little bit in the house. When we do things, usually Sarah thinks of something we should do, or could do, and we go out and do something. But she instigates it. And ya know, it's good to get out sometimes. But other times I want to watch and see what's going on with Trump and all those people, so it varies.

I like to be around my wife, and I'm happy that my daughter decided to come back and be closer, once I was clearly diagnosed. And I have a fair amount of friends, partly because I used to play music with them, and we're lucky to live here. And it's nice to get around, get about, and it's also nice to see what's going on in the world. I have the opportunity to do something that I probably never could've done before, is watch so much TV, and then sometimes we go out and do things, and you know...

Everybody Plotzes Eventually

Everybody plotzes eventually. I don't know when I'm going to plotz. But at this moment, I feel like I can still make a difference.

UCSF has this [Patient as Teacher] program, where I'm assigned a different person each year, and we teach these young people – people who are going into the medical field – about Alzheimer's. Basically, they're seeing us in action so they understand it, so they see who we are. And so we go and we talk, we go to museums and we go out to eat. And it's nice to do that, I feel like I'm making a difference. And it's given me more things to do. So we're lucky, and I hope I'll be assigned someone else this year.

It's hard sometimes with the Alzheimer's and with getting older. I don't necessarily trust what I'm thinking about – you heard me, sometimes I can't come up with a word – so it helps if someone like Sarah, or sometimes my daughter can sometimes help me finish whatever it is. So I guess I could say I'm in decrepit mode, but I'm doing the best I can. [laughs] I do have some pains, but you just kinda cope. I'm still going, you do what you can do.

And I think I already said this, but we're going to Sacramento in the next week or two. We're trying to get more resources to make things better going forward. We're making a difference by going there and even just showing them how we are, who we are. There's advocacy in all kinds of situations, not just Alzheimer's, and we're trying to make a difference. And that's what makes me feel good, is when we might be making a difference.

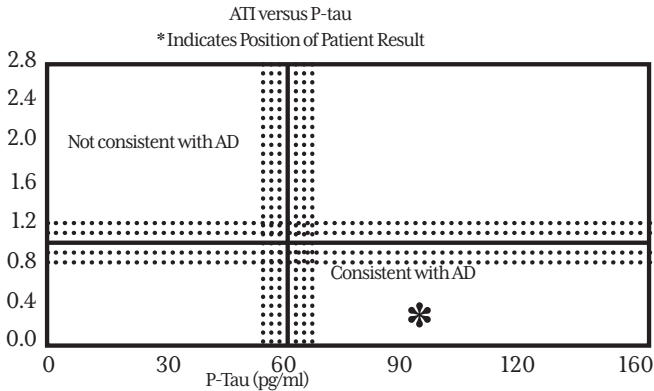
Just going there so they see that we can actually communicate still. But unlike some of the other diseases like... what is it, the big one...? [cancer].... They started so much earlier than we have with Alzheimer's, so we're trying to catch up with that, you might say. Because there's a lot more resources going into that arena than with us. We're getting there; it just takes a long time.

It's Not the End of the World

The best thing would be something that would solve the disease, ultimately, that's what we're talking about. Seeing if there's other drugs that may be useful in the context. But this is relatively new... well it's been around for a long time, but it wasn't acknowledged until recently. So you just hope that something will be solved, probably won't be in my lifetime, I would guess, but you never know, it'd be nice.

Short of a solving the disease, the best way to help is by teaching people we aren't vegetables yet. Just spreading the word. Because for many people, they think, "Oh my God, it's the end of the world." And it's not the end of the world. It's not great, but it's not the end of the world. And that's important to let people know. That's why having our group is good, being able to teach people who are in the medical profession, and I think advocacy is great... people with the disease talking, telling our story. Sharing our story is so powerful, with any disease. If research needs to be done, we can tell them why by showing our story.

And people should also know that you can still have a sense of humor when you have a disease. You live a certain amount of time, and then you plotz. And you do what you can do. I like being a teacher. So I hope it stays in your head, because I'll probably forget it!



The picture that Dr. Howard Rosen presented to Mark



***Shaman* by Kristie Wood, acrylic and wood**

The Gray Zone

Narrator: *Dr. Anna Chodos*

Interviewer: *Alissa Bernstein, PhD, MPH, Postdoctoral Fellow, Institute for Health Policy Studies & Atlantic Fellow, Global Brain Health Institute*

Dr. Anna Chodos is an Assistant Professor of Medicine in the Division of General Internal Medicine at Zuckerberg San Francisco General and the Division of Geriatrics, both within the Department of Medicine at UCSF. Her clinical work is in both general primary care and in outpatient specialty care in geriatrics, and her academic work is focused on understanding the unmet needs of older adults who are seen in primary care in the safety net and improving clinical programs.

Finding My Place in Medicine

I get asked the question of how I got into the field of geriatrics a lot because most people don't go into geriatrics. I think to some degree retrospectively I could try to think of an *aha* moment but for the most part I think it really was just cumulative experiences. If I had to say where it started, I think I was interested in areas of medicine that had some social justice bent or involved work with the underserved because of family influences. My mom worked in OBGYN and with women, particularly at a time when it was harder for a woman to make an impact in medicine or be taken seriously. I think she really emphasized that medicine was a social good. She felt that the inequality her female colleagues were experiencing was an issue that personally she wanted to address, so she was, of course, an important role model for me.

I often say I have four parents, because I have my biological parents but I have two parents, John and Lilly, who raised me because they were my nannies and they lived with us growing up. Lilly was a nurse when I was growing up, and she has done a lot of things with her nursing career. One thing she did was work with older adults for a long time, and she did that in the home. Lilly among other things was just an

incredibly warm and loving person, kind of across the board. The way she talked about her older patients was so loving. I think it primed me to really look at older adults in a warm and loving way. I just kind of loved the stories she told and I think she was very open about how difficult it was for people, particularly at the end of life, to navigate that time.

In college I was living in San Francisco and volunteered with a hospice agency, really as a social visitor. When I went into medicine I wanted to be that person who could answer anyone's questions, a generalist. Then as a medical student I wanted to learn more about people who take care of older people and people at the end of life. I wasn't really sure what I was more interested in, but what I enjoyed most was working with older people, just because of the accumulated life experience and perspectives. It has always been joyful for me. Well, I decided that I like general medicine and I like geriatrics and older adults, so I figured out how to do both. That is what I do. I of course had a lot of wonderful role models. Fortunately, because it's a small field, I still know and work with some of them. I think it's just one of those things when we're training, we just explore lots of different areas and then you keep revisiting things that you like and realize and reinforce that this is the right place for you to be. That was my experience working in geriatrics.

Human Dignity

My grandfather had dementia. He had vascular dementia, and I didn't understand it at the time – I was probably nine or ten or around that age – but he had declined pretty significantly and abruptly, not surprisingly, and needed to be in a long-term care facility near where they were already living. Of course, my grandmother would visit him every day, and I would go see him at the rare couple times a year when we would visit. One time we went with her to visit him. I think because of those long periods in between it was quite jarring as someone who knew him well to see him without a lot of his ability to do the things I remember him being able to do. He wasn't very verbal anymore so it was a big difference.

But two things that happened that I still think about are, despite the fact that he couldn't really talk, you could tell a couple things about

him were still the same. He really lit up with a hug; he was a very huggy, warm grandfather, a bear hug kind of guy. The other thing I remember is that he was very fastidious about his appearance and his hygiene, as many people are. His caregiver, who was a complete unknown to me, but someone who knew my grandfather very well at this point, had, because he knew we were visiting, really dolled him up and made him look really nice; he almost presented him to us. My grandfather just looked so great, the best he could look, and this guy, the caregiver, was really proud. He knew we were all there to see him, and I think he was proud of the fact that he in some ways presented my grandfather with dignity. And that's actually a moment I think a lot about because I think we really do unnecessarily rob people with dementia of dignity. I think we're confused about what dignity is as human beings. The way we treat older adults, and very generally the way we treat older adults with dementia, unnecessarily robs them of dignity in other people's eyes. I think that is something I see a lot: people who are not enabled to be as capable as they are and are not allowed to possess the dignity that we are all born with. We have very ageist and kind of disparaging views that just immediately discount people.

This is amplified here at Zuckerberg San Francisco General Hospital. People are already coming from a place of poverty or inequity, which is already a loss of dignity. I work in a kind of public health system that serves the underserved, either uninsured or low-income people, pretty much exclusively. Most of my colleagues have an interest and life-long commitment to working with the underserved. I would say most of my colleagues are dedicated generalists and are extremely dedicated to "underserved" as a principle. They are very sympathetic to the notion that older adults with dementia are particularly vulnerable and maybe need extra attention and protection. I think the hardest thing is you see a lot of people who have been robbed of their dignity in the sense that they are really made unnecessarily vulnerable.

I can't speak about people with more means, but I can speak about my own patients who are already very vulnerable. They are the natural prey to the webs of complicated and tough systems, like all the systems people have to go through when they are low income and reliant for certain benefits. All of those things really get amplified in complexity when you have cognitive impairment. There's just more of a chance that something is going to go wrong. It happens all the time. And then

you layer on that English isn't their first language, and you layer on no formal education, and you layer on poverty, and people are just very exposed. Certainly, poverty and social hardships don't necessarily preclude good family ties and good family support. Obviously it's a community where a lot of people have families of choice. But a lot of people have left their families, biological families, and they just seem to be more vulnerable to being alone. Then when dementia sets in people just become really, really, really vulnerable. I think on a larger global scale my work has made me feel lucky for the family I have. I want my family around and I want to be present with them now.

A Substitute Community

There is one woman in her late 70s that I think I refer back to a lot when I talk about my work with people with dementia because her experience is somewhat emblematic. Another primary care provider was working with her and just having a hard time, mostly around medications. She had uncontrolled blood pressure, but she was on all of these medications; something just wouldn't add up. It was clear that she was forgetful, but she was just very sweet, very socially engaged; I just mean she was really personable. She had little excuses about why she wouldn't take her medications sometimes, and her primary was just sort of pulling her hair out because she thought, *Something doesn't seem right, I think she might have dementia, or early memory problems*. In terms of family, she didn't have any children and her husband had passed away. She did have good church friends, and she talked about her church friends, but there was nobody bringing her to appointments. Increasingly, her primary was getting phone calls from the friends saying *Is it possible for us to talk to you? How does this work?* We figured out that it would be possible to do a home visit with her and her friends, that I could do a more general geriatrics assessment at her house.

So, right away, first of all, a lot of things were obvious that it wasn't possible to detect when someone's taken out of their environment and put into a clinic setting and then put back into their environment. I mean you can't always ascertain everything that's going on. One of the first things was she had photos everywhere. It turned out she had been a nanny and a caregiver for a lot of people, and she had a lot of their

photos around. It was part of what was meaningful to her, but at this point in her life she was living alone. She had these friends who checked in on her, but a cognitive assessment detected mild dementia for sure. It detected the fact that she had no clue what was going on with her meds, which were kind of everywhere, and she was definitely making things up as she went along. She tried to show us how she used the kitchen. She was trying to use ice cream lids as pots and pans, so it actually set a couple fires and was getting the building manager really worked up. This is why her friends wanted more help, because she was posing a safety hazard, and they were worried she was going to get kicked out. When we looked in her fridge there was nothing there, and her friends didn't understand why because they were dropping food off all the time. We figured out that people were constantly stealing her food.

But all the while when we were there, it was like I was the most important guest in the world in her house. She was incredibly put together in this sort of hostess way. I talk about her a lot when I try to remind people that as social beings, this is one of the things that can remain intact even as other parts fade away. I think about her in her home, really vulnerable to accidents and dangerous consequences, yet still doing a lot for herself. She is someone who I think is typical of people you see, people where no one is really responsible. The natural connections like a husband sort of faded away, as people passed away. We have a lot of people who are in that space, and you know, I think we're a substitute community, a care circle.

We tried to figure out the best way to get involved and help. We tried to talk to her friends about taking a more formal role, which they thought about really hard, but they couldn't. I think they knew what they were getting into and couldn't say yes right away, and that's real. At least she had people that were concerned enough to say something is wrong. These people were worried about her building situation, which is a very relevant health-related problem if you're going to get evicted, and something she would not have been able to fight off on her own. So, we helped her friends stabilize the housing situation. We got nonprofit legal services involved to protect her rights to be there. Not surprisingly, the building was making threats that were not legal about getting rid of her for public safety reasons. There were other ways to handle it that wouldn't involve evicting a woman with dementia. We made way more realistic goals given what she could manage. We got her a caregiver, and

that caregiver has stayed with her for a really long time. Once we got a caregiver, and once we sort of simplified things and reframed them in the context of what she could and could not realistically manage, everything medically stabilized immediately, and most of the social stuff got to a less crisis level.

Clearly dementia affects older adults disproportionately to younger age groups, and so it's always in my mind, and it's always part of what I'm evaluating people for when I'm seeing them, if they are older. But now, as I'm sort of bridging primary care, just general primary care and geriatrics, I realize that dementia is a shockingly complex and difficult entity in the way primary care is set up now, and it's really challenging for so many providers in ways that other conditions just aren't. I'm finding that it's incredibly important for me to be able to discuss and help other primaries guide their diagnoses, assessments, and care planning. In a lot of ways I'm still not really sure why it's quite that much more difficult than a lot of other complex chronic diseases, but I will say that it's one of the things that general primary care providers still have a lot of challenges with managing. Part of that is the system and part of that is probably still inherited from all of the training we do and don't have in that area.

I do know that I really don't mind the gray zone. Maybe I actually prefer it when we don't really know, when there's not a clear guideline or some sort of algorithm you are supposed to follow with people. I really enjoy navigating the nooks and crannies with people, like, This is a really funky situation, what solution can we come up with? I like the fact that there is sort of an à la carte choice of issues you have to put together in different ways with older adults, and especially people with dementia; there's no such thing as a blanket care plan because it has such individual manifestations. You know there's a standard that you would like to get to for most things, but it doesn't mean that everything is going to apply. I enjoy figuring out that process with the person. And, for whatever reason, I enjoy some of the more outlandish situations, and we have a lot of them, the colorful situations, I guess you could say. In some areas of medicine there's a pill for everything, or a survey for everything, or an intervention for everything. I am just so the opposite where I think we kind of over-medicalize a lot of what is going on, and in fact, do harm when we do that. But with older adults, with people with dementia, it's an imperative to make sure you don't harm them

unnecessarily. That is something that feels right to me, that I feel really comfortable with. That's the paradigm we should be following anyway, and that's one that I tend to prefer. I think probably, hopefully, people would say that I am dedicated and caring, and that's probably all I care that they say.

***When I'm With My Patients, I Always
Feel Like I Get More Than I Give***

A lot of times people remind you to do the gut check, because we are all very busy, and you always have more work than you can do in a day. When I think about my work, I think about the core of my work as my clinical work, and that is what is incredibly sustaining. I'm a listener, and the way I know that is that my appointments always go long. It's not because I'm inefficient, but because with my patients I do tend to listen. I feel listening is part of the intervention, as well; it helps me get to know them. I think the reason it is always worth it is that when I'm with my patients I always feel like I get more than I give, even if I feel like I'm giving all that I can, and I'm completely exhausted. I think I just meet really remarkable amazing people that I can't say I would have the pleasure to meet as frequently as I do if I didn't get to care for them. At this point I feel that what I'm doing is so, not symbiotic – that's a biology word – but so synchronous with my identity that it's just very comfortable, I guess, and that's a really fortunate place to be. I feel very fortunate. I really feel I'm doing what I'm supposed to be doing, especially when working with patients. I just feel so at home, so comfortable. So, how I really feel about my work is that I am insanely lucky, and I feel energized most of the time. I'm just lucky to love the work I do. I really love it.

hear/say



It's in God's Hands

Narrator: *John*

Interviewers: *Kasia Gawlas and Julia Heunis, current
and former research coordinators*

John is devoted husband and caregiver to his wife, Sarah, who is now in the late stages of Alzheimer's disease and lives in a care home in San Jose, California. They have four children together: Susan, Wendy, Joe, and Chuck, who are all involved in helping John care for their mom. We felt lucky to hear about John's journey and his hopeful and inspiring message for other caregivers.

The Beginning

I'm caring for my wife Sarah of 53 years. She's been in a care facility now for six years. It probably started maybe two and a half years earlier. And it began with Sarah had what she believed to be an eye problem. She said, "Look in my left eye, there's a flickering."

She said almost like a *brrrrrrrrrr*, like a super eight film, the old films, *brrrr*, and I looked and I couldn't see anything and she'd say, *it's right now it's right now*, so we went to my ophthalmologist here in San Jose, our doctor here in San Jose, and also in Carmel, and they couldn't see anything, but they referred us to someone else and 30 seconds after he looked at Sarah he said, "You don't have an eye problem, you have a brain problem."

Well that, that completely changed everything, it was like...*wha!* And so he scheduled an MRI and from that, we then got a neurologist, and our personal family physician of some 15 years, we pretty much identified it as Alzheimer's through various tests she was going through. We started the medication, Namenda, Aricept at that time, and the neurologist was really very very good.

Then we were aware of UCSF's program with Dr. Bruce Miller, and so we were accepted at our first meeting, and it was great. Answered

all the questions, it really was the one bright spot in this whole battle, there was hope...the medication and the care, I honestly felt that they cared. The rest of the doctors, I would say were supportive, but it was really UCSF in my opinion that was our safety line and nice to hold on to. And that's so important because you're really in uncharted waters, I mean it's an irreversible, degenerative disease, and the outcome is what it's going to be.

But then, as it began to deteriorate, it became very apparent, I could not take care of Sarah myself. I had a caretaker, Christine, about a year and a half at home, and she would come in on the weekdays and if I ever had to travel – I was retired at that time, but I did a lot of work with the Heart Association. And so she would stay with Sarah. My problem at that time was really sleep, because I never get much sleep anyway, but I could get by the first night with no problem, three hours no big deal. The next day if I had to repeat that, then I'd get pretty groggy, and the third day I'm a zombie. So that was a point where I knew we had to get more 24/7 help, not just eight hours during the weekdays.

Seeing the Signs

My brother may have said it best to my kids when he said, "You've basically lost your mom, don't lose your dad." So, I think they've been very attentive to me, in terms of, *Dad let's get together for dinner, let's play golf, let's do this, work in my backyard*, whatever it may be, but just involvement, and they've done a real good job on that. Susan was probably the most in, I'd say the stage of denial. My two boys, they had seen an incident where early in the morning I had to call over, and it was a bad morning, hallucinations and everything. My daughter Wendy came up from Newport one day said, "Dad you've got to get some sleep, let me be with Mom." And so that night we, hah, it's funny now, wasn't at the time, but about one o'clock or midnight, Sarah gets up and starts walking around. Wendy said, "I'm here Dad." So they go downstairs, and then I'd say six o'clock or so I went down there, they were on the sofa and Mom was sleeping against Wendy's shoulder. So Wendy and I are talking softly, and Sarah wakes up, looks around...

"Are you still here?" to my daughter. Sarah had been the kindest, sweetest, person in the world.

“Yes, Mom, I am, Mom, I’m here.”

“Want to go home.”

“Okay well, let’s just sit down a little bit.” And they were standing at the time, and Sarah punched her in the belly — Once again, she wouldn’t hit a fly, let alone.... Wendy says, “Mom, that hurt.” And it was a light blow, but Mom says, “Too bad.” Right now we laugh about it, but it wasn’t so funny! But that was maybe the first time Wendy said, *Houston control, we got a problem.*

That was a few years ago. When we first diagnosed it, I felt things were going pretty doggone good, they say it can’t improve, all you can do is try to keep it level. I knew things were going a little bit downhill when Sarah, on our Christmas cards for example, Sarah used to write every single card. I’d say *Merry Christmas, Love John and Sarah*, but Sarah would write, *Oh, the kids are doing well, Chuck is doing this...* like an essay. So I would always address the Christmas cards, and Sarah would write, but then I’d look at the handwriting, and I’d say, “Honey, what?! What is this?!”

“Aw — is that not too clear?”

“No!” And so the handwriting was one of the things that was really extremely obvious. The others – signing your name to checks. Driving. That was a tough thing, but I tried to be a good chauffeur and take her wherever she wanted to go *whenever* she wanted to go. But that still was kind of a tough thing; you realize that she can’t drive.

I purposely avoided certain things that I knew would be uncomfortable for Sarah. For example, going to a restaurant where there was loud noise. If I could, I’d get a private room or a corner table where the noise level was not way up. Going to where there was a band, it was a joke, I mean because Sarah loved talking and she loved conversation. When she couldn’t hear, then she was lost. A big party, the same way, where the noise level is up to here. Those were uncomfortable for her and I knew they were uncomfortable, so I’d say, “Thanks, but no thank you.” And my friends, I would just say, “There’s going to be too much movement, too much noise, it’s going to be uncomfortable for her, so thanks, I hope you understand.” But if they don’t, too bad. Most people understood. Now in terms of couples’ events, I purposely avoid most couples’ events, because it’s just, “How’s Sarah?” Well, things haven’t changed in six years, non-ambulatory, can’t speak, and so on, so I don’t really do too much in terms of social

affairs like that. I have things I'm involved in now on my own, golfing and so on.

The Last Trip We'd Ever Take

The real coup de grâce came – I knew it'd probably be the last trip we'd ever be taking, so I took Sarah back to Des Moines, Iowa, which is where her home was and her brothers and sisters were still back there. The flight there was difficult. Coming back was near impossible. I never speak badly about TSA anymore, I had two people who were absolute angels. Sarah was lying down on the floor and going up to people at counters, "Take me home, take me home." I mean, it was maybe one of the lower points we had. And when we got to Southwest Airlines, we got to be the first ones on, and my brother was with us in Omaha, he said, "There's no way you're going to be able to go on." I thought the same thing, but I thought once on the plane maybe she could quiet down.

We got on, the captain comes in and talks to me, he says something to the effect,

"Is your wife afraid of flying?"

I said, "No, no, she's not afraid of flying, flown all over the world. She's an Alzheimer patient, and I think once we're airborne she'll fall asleep, it'll be fine."

"Well I understand that we had some problems in the waiting area."

I said, "Correct."

He says, "Can you manage her?"

We'd been married at that time it was like 48 years or whatever, I said, "Yeah, I can manage her."

He said, "Well I've let the passengers on the plane..."

Well, about this time I was ready to say, "Captain, get your damn bus off the tarmac."

I thought if we could reach the halfway point, if we could land in Las Vegas I could drive the rest of the way to San Jose. The stewardesses who were coming around trying to be very polite, "Can we do anything?" I said, "no, nothing." My brother waited for an hour and a half in the Omaha airport; he said he was convinced we'd be returning. So we made Las Vegas, then San Jose, and that was pretty much definitive that we had to do something. And that's when we were blessed finding

a wonderful place, Cedar Creek in Los Gatos, about six blocks from the hospital, and we were there for just under two years. Then Sarah became non-ambulatory, and we had to move over to Lincoln Glen, which has been another wonderful facility. So, it's been... six and a half years in total at the care facility.

Small Moments

I'll come see her either during lunch when they'll feed her and then when they put her to bed. First we go from the lunchroom to her room, and then they put her on the toilet, and then they put her to bed for about a two-hour nap. I'll usually be there during that period, and I'll sit and talk to her because her conversation is, "Dah dah dah dah" now. And her universe is the bed, the wheelchair, and the toilet... and that's it. Does she understand what you're saying? Well, I don't think she understands at all, but they say, "Does she *know* you?" I'd like to think yes. In reality probably no, but it's my *voice* that I *know* there's a connect because many times, she's in this position, eyes closed sleeping, it's not like she's watching anything per se, and I come up behind her and I say, "Sarah, Sarah honey I love you." And she'll be like... "DAH DAH DAH DAH DAH DAH," almost acknowledging that she's heard. That's not an everyday thing, but it happens often. So I'm convinced she knows my voice. If she's eating with her eyes closed, I'll say, "Sarah honey, that *sure* looks good, I have lemon meringue for you." And I get, "AH, GAH DAH GAH GAH GAH." So my voice, I am convinced, there's recognition there — small things.

And the facility staff here is wonderful. I love them. I tell them if I see anything wrong, which I rarely do because they're so on top of it. I look at it very much as a team, they're taking care of someone I care the dearest about, so I'm there to help them. Don't want to be counterproductive, but if I see some things, this isn't her pillow because I got special ones for her, and it might be being cleaned at the time et cetera, but then they track it down. The nurses and the executive staff are great. I met the director the first day I came in here, and he took us through, showed us everything, got to the easy lift, and I said,

"Show me how that works."

"Oh yeah, you just press this button and it goes up."

I said, “Nah, show me, let me sit in it, take me to the toilet.”

“What do you mean? Lift you up?”

“Yeah.”

So anyway, they lifted me up, took me to the toilet, and they said, “Do you want me to let you down?”

“Yeah, let me down on the toilet and take me to the bed.”

Which I knew they would have to do if she were living there.

Sarah was dead weight. And so over at Cedar Creek you’re having two young nurses who’re probably maybe 120 pounds trying to lift 135 pounds of dead weight. And so it could be harmful to Sarah, could be very harmful to the staff, so they had no choice but to — I hate to say *fire* me, fire Sarah, but they had to get her to somewhere that had the facilities to lift her. So that’s why we’re over here at Lincoln Glen. It was a wonderful decision. Worked out well.

Convert the “Have-to” into “Want-to”

We had a wonderful life. Sarah was a wonderful best friend, mother, wife, a real giver. She did a wonderful job with the kids, basically took care of all the things at home while I was doing my business. When it started, before I really understood as much as I should have about the disease itself, when the hallucinations would occur where you’re not sure what the heck to do, you’re trying your best, those are exasperating times I’m sure for both of us. Once we understood and particularly when she’s completely dependent upon you (and my kids could probably tell you better than I because it’s always difficult to self-analyze), but I’ve never been a really patient person per se, and I think my patience with not just Sarah (I’d do anything for her) but with others has gone up. I see a white-haired driver going slowly, I used to pass them honking. And now it’s just, *God bless them*, he or she is on the road trying to get from point A to point B. I’m sure not going to add to any grief. It’s probably difficult enough just trying to navigate. I’d like to think my patience factor has gone up. I think I’m really a lot more appreciative of many things that maybe you take for granted. Caring for someone who really is totally dependent and there’s no way she can express anything, then it will be up to me if I see something. Now once again, the staff is so on top of everything, but there’s other things that

come up that do need to be tended to, and that's where my role as an advocate I think comes in. And I'm not very bashful in asking for the orders, so if I think something should be done, I try to get it done.

In a way, hand-in-hand with my responsibility, I try to recognize limitations. There's a lot of things that I don't know that they do, and I'll 'consider the source.' Dr. Miller, whatever he would say, I would do. My respect for many of the people here is such that if they say we should be doing this, we basically go along with it, we listen to them. You try to surround yourself with people who know what the heck they're doing, because you don't have all the answers by any means.

I think everyone goes through feeling lost, not knowing what they're doing...to a certain degree. But did I ever feel like quitting? Well, the answer to that is no. In terms of wondering how to get through this, I really felt comfortable with the medical people I had around me; I think that in itself was pretty comforting. I think those who take care of the caretakers are extremely important. My daughter Susan uses the expression, "Dad's the first team, and we're all the second team." I think of it all on a pretty level footing, because I use the analogy, in an airplane when the oxygen masks come down, what're you supposed to do? You put it on yourself first, not your child, because if you're unable to function, the child is going to die. In many cases I look upon a caretaker's role as the same way. In terms of feeling guilty, would I feel guilty if I had dinner with my son tonight and not with Sarah? The answer to that is definitely not, because I *know* she's being extremely well taken care of. If I'm not there one night to put a smile on her face, hopefully tomorrow we'll do that. But, if I come to the point where, *I have to go, I have a temperature, I'm feeling sick, but I have to go*, try to convert those "*have to*" situations into "*want to*." You really have to want to be there. Don't feel guilty, I mean there are enough negative rocks piled upon people as it is, you don't need more. You're doing your best to get there as often as you can, that's all one can ask of you — more importantly, that's all you can ask of yourself. Forget about what others, may think. Be true to thy own self.

And it doesn't help to think about how things were, but as they are. Here's the hand you're dealt right now, it's not what we *were* doing, going to restaurants or places that we used to love to go together, but we're in this place now. I think one of the big things I find is the inability to share. If you do something, it's fun to share it with someone.

Whatever it may be. And I've got my buddies, my family, but in terms of Sarah, a lot of things we shared, and that – that's not going to be the case now.

I still have most all of Sarah's clothes in the closets, and that's something I really do have to take care of. I got rid of a lot of stuff but a number of things, which people could use, I mean these are some beautiful things, but I find it difficult to part with everything. I've cleaned out a lot of stuff but in terms of certain things — our home in Carmel, and it's been six years. Is it right or wrong? I have no idea. I think it was right for me, and I'm really not too concerned what others may or may not think about it. Try not to judge anyone, because what may work for them would never work for you and vice versa. Accepting those things is sometimes the harder part. You can sometimes diagnose what you think the problem is but then accepting the solution or consequences is the more difficult part.

I'd say the hardest part being the front line, recognizing that you're very responsible for the individual, because that individual isn't going to be able to act on his or her behalf, so it's up to you to try to do the right thing in all areas. So, that would probably be... that'd probably be the hardest thing. You want to do the right thing, and in many cases you don't know what the right thing is. You just have to hope and pray that (and Sarah's a very religious person), you just have to have faith in God. That was Sarah's foundation. And I think, I certainly am nowhere near as strong as Sarah because no one is, quite frankly, but you try to get to that point. So, you have to have faith in God, in my opinion, and faith in yourself that you're given the wisdom to do the right thing. And you pray a lot.

Looking Forward

Those are some deeper questions... two of the guys in our group, Bob and Charlie, they've been having this support group. They've asked me, "John if you ever want to join up in San Francisco..." And I told them at the time, "Guys, I don't think I really need any support at the moment, but if Sarah passes, you guys have all gone through this," I said, "when I really do need a little help." We almost lost Sarah about a year and a half ago; I had her in the hospital she started aspirating, temperature

went up, they thought she had pneumonia. It was bronchitis, and after four days in the hospital things weren't getting any better. She had lost I think about, I don't know, eight pounds or so in four days, and I had hospice involved and I really thought, this was probably it. And they had a great speech therapist over there, she was supposed to have a test about 7:30 in the morning; I got there about 8:30 or 9 o'clock.

"How'd it go?"

"She was too weak." And the gal said to me, she said, "This test isn't going to tell us anything we don't already know. It's painful." And she said, "I wouldn't do it at all." So I said, "fine." Went to the head doctor and told him, and he said, "well there's nothing we can really do for her here, so we might as well take her back." And I thought this will probably be — I went out and I had... the church ready, I had the mortuary ready, the caterers ready... I was ready to go. Anyway, we brought her back and we put her in bed, got her regular jammies on instead of those hospital gowns, and she just looked so much more comfortable. The first day, I must have met twenty people from hospice. I had so many business cards, I could have had a playing deck. About the third day it occurred to me, I don't want to be told something after the fact that I should have done. So I was never clear in my own mind who was the quarterback. I called my personal physician, I called hospice, and I said, "I want a meeting, I'd like to get together with both of you guys."

My doctor came first. And I said, "It seems to me we've got a real conflict of interest here, your job as doctor is to keep her alive, your job as hospice is to make her comfortable, I'm afraid that could be a conflict, and who basically makes the decisions?"

And my doctor said, "Well, under these circumstances, since hospice is involved, they're trying to comfort your wife." I asked him what he would do. He said, "Well she had a UTI (urinary tract infection) when she went in, I'd take a catheter and make sure that we're okay there, and I'd get a blood panel." I decided that sounds reasonable to me. "Do it."

About a half hour later hospice comes in, I tell her the same thing, and I said, "By the way, my doctor was here a half hour earlier and he recommended this."

She said, “Well, that’s invasive, we wouldn’t recommend that, and as far as the blood panel is concerned, I’m not sure what that would tell us.” She said, “You want me to run this by the hospice doctor?”

I felt like I’m not sure what it could hurt, and I told him to go ahead and do this. Each day it got a little better, Sarah picked up a pound here, and then a little more color in the face, and a smile here and there. After another week hospice said, “I don’t think there’s much more we can do, I’ll recommend we take her off hospice.”

That was January of 2015. So it’s been about a year and a half. And that’s a tough thing; I’m a big believer in hospice, I love what they do, but I went through this with my mom, and it’s countdown time. Tick tick tick tick and then dead. So for Sarah that turned out well for us.

Do I think about her dying? Without question. I think it’s going to be difficult, once again, that’s the way it is. I went to a funeral service recently; my sales assistant’s son was killed in an accident, 16, 17, 18 years old, just a young kid. At the service, all the friends, the whole high school was there, and they were in tears and everything, and we were all feeling very badly, and I remember the pastor said, “We’re all hurting right now, but God has been good enough to give this young man to us for 17 years. Think of the memories we’re going to have years and years and years out, what a blessing. What a blessing.” And I think with Sarah – what am I, 77? She’ll be 76 in September – what a blessing! She’ll be in God’s hands, and so it’s easy to be non-emotional about it. Now, I’m sure I’ll be a basket case when it happens. Nonetheless, in terms of what I would do, probably not a whole lot different from what I’m doing now.

It’s important when you talk to people to take that circle of friends or acquaintances you have and think what they could do. People want to help. But if you don’t ask for help, they’ll never know what to do. So if you can think of something, no matter how small it may be, get them involved. It’s like that pebble in the water, it just expands outward, so, but I think if you as a caretaker fail to reach out, you’re really limiting your abilities. It requires a little bit of thought. I think once a person begins asking for some assistance it’ll become easier because people do want to help, they just don’t know what to do, and in the absence of not knowing what to do, they’ll do nothing. Bottom line is then you’re doing the whole thing yourself. And that’s difficult.

If the caretaker isn't taken care of, the patient will suffer. So whatever you can do for these individuals, everyone benefits. Because if that caretaker is not looked after, he or she will probably be in a pretty dire situation, not Alzheimer's per se, but whatever disease he may be susceptible to, in a weakened condition. So, mentally and physically, it is very important to look after the caretaker. I certainly have a much deeper appreciation for the caretakers now having gone through it, much deeper appreciation for the nurses who have to do what they do. It's a tough business. You're around death all day. Have faith in God, have faith in those around you, have faith in yourself. That's it.



Vivien Lou Chen performing on drums

It Was Important for Me to Step Up

Narrator: *Vivien Lou Chen*

Interviewer: *Jennifer Merrilees, clinical nurse specialist*

Vivien Lou Chen is a reporter who also cares for her mother with Alzheimer's disease. Six years ago, when it became impossible for her mother to live safely on her own, Vivien moved her into her home. I had heard about Vivien from our staff that worked with her through one of our projects at the MAC, and I was so struck by her dedication and motivation to care for her mother. We are so grateful that Vivien consented to share her story.

Cosmic Retribution

My name is Vivien Lou Chen, and I'm originally from Los Angeles. I was born in Hollywood, and I'm a reporter. I've been a reporter since I was 14. I haven't really done anything else. Before this all happened, I was covering the financial crisis, and traveling with the treasury secretary and Janet Yellen and people at the Federal Reserve. In the years leading up to all this, I was basically on the road, all the time. Traveling with pretty important people.

And then my mom got robbed. I was in Wisconsin in January and I couldn't get a flight home for two days because of the weather. The Oakland police had called me to say, "Your mother's been robbed." She went missing for about ten hours, and they found her at a church. And I thought, *Okay, maybe I should not leave her alone.* So I got a caregiver for her. A caregiver was with her two hours a day. While the caregiver and my mom were on a walk outdoors, she was robbed again from behind. So I said, *Okay the problem is that she's in Oakland.* That was when I was like, *Okay I'm done, she'll be living with me.* I've been doing it for five or six years. When this all started she would just walk right out the

door in the middle of the night. I remember being kind of depressed because I was like, *Man, no matter how much I do, she is still a high-risk wanderer.* I could literally have her in my home, and she'll get up and walk out in the middle of the night. I put her in a day center because everyone was pressuring me, "You gotta put her in a day center and let her socialize with people." Well, the day center let her out. By accident, let her go. She went missing for fourteen hours. The police found her at 4:30 in the morning on California Street. For the first year or so, I literally never left my home, because I never knew when she was gonna disappear on me. There were months when I had no help. I would pay people to go buy my groceries for me and never left my home.

I have gone from that extreme to another extreme which is, now she can't walk at all, she can barely move, and she needs help in everything. She has to be spoon-fed, she has to be taken to the bathroom, and she has to be turned. There was one point when I was turning her in bed every two hours around the clock. So, every stage there is always a risk of something. I couldn't let my guard down. That's been going on for five or six years. She's tough. I also think I'm pretty tough, but no. My mom is ridiculously tough.

I have moments where I think this is cosmic retribution, you know, I had all this freedom, and now I have no freedom. And then other times I think, *Well, I don't have that longing, I don't have wanderlust anymore.* So maybe there's a weird logic to it. Maybe that's the reason I was allowed to do so much so early, because now I'm in this situation where I literally can't go anywhere. I am still a reporter; I just work from home now.

I Feel Like I Owe It to Her

I think my mom is a really unusual person, in the sense that she came to the United States as a housemaid. She was very ambitious, had no education. She wanted to get away from Taiwan. She wanted to make a lot of money. She's like, *I'm going to the U.S.* She was just very charming, she knew how to speak English, and she got a military family to sponsor her. Which was really unheard of. She got married in the U.S., and then she and my dad divorced when I was six months old, so now she's a single mom. But she didn't have any family or friends. She did

the whole thing on her own. There were a lot of missing parts of my childhood. I didn't really understand why she left my dad. There was a period when she first got sick that I went to go look for all these answers. I looked for my dad. Found my dad. I found all the people who knew my dad. I found everybody who knew the story of what happened to me during that period when she decided to leave. And so I was able to fill in the whole thing, the whole puzzle. We were on welfare for the first seven years of my life. Once I was old enough to be alone, she would get jobs, but they were often graveyard shifts. She just kept doing it and doing it until I could get to college.

It Was Important for Me to Step Up

I know what she did and what was going through her head the whole time. That's what motivates me to do what I'm doing. I feel like I owe it to her in some ways. She did so much for me, I can't let her be in this condition and not do something. Sometimes I get mad that other people don't quite understand why I'm doing what I'm doing. *Why would you do it? What's in it for you?* I think people have this notion that you should push people away when they're ill. At the same time, I don't think they have the benefit of my experience with my mom. So clearly they don't understand why I would do this. I try not to think about other people anymore. Because it's not their problem, and it's not my problem that they have a problem with what I'm doing. On this one particular point, it was important for me to step up. This person needs you. Suddenly needs you. So one of the greatest things that you could do during your lifetime is to be the person to step up. And I don't regret it.

These Things are Not Within My Control

My mom is in the late stage of Alzheimer's disease, and nobody told me how long this is going to go on. I'm told it could go on for quite a long time [laughs]. Which I think is really funny. It's funny, and it's kind of scary to me because I actually thought at the time she was diagnosed in 2006, that 2016 would be it. Because most people say, "Within ten years." Well, we're just entering the last stage, and I don't know how long this

is going to go on [laughs]. I don't actually want to spend my entire 40s doing nothing else but caregiving. But that's fine, if I have to, I have to. It wouldn't be my first choice but these things are not within my control.

I Was Not Ready

She has almost passed away twice. This last time, in March, people said, "It's time to say goodbye. We don't mean to push you but you should probably do it now, because we don't know if it's gonna be the next five minutes or the next hour, but she's not gonna make it through the night." I was not ready. And of course she makes it through the night. They took her to the intensive care unit, and her eyes were glowing and she looked great, and I just thought, *How does she do this? How did she make it?* I don't know. Then they transferred her from the ICU where she was lovingly cared for to a normal room. They said, "Let's see if she can eat on her own." She wasn't eating on her own. And that particular ward said, "See, she's not gonna make it." I was like, wait a minute, she has to be spoon-fed. So, I put one of my workers there, had them sit by her bed for five hours, spoon-feeding her. She was eating everything in sight. Then they said to me "Yeah, but still." I was like, "Ok, clearly you don't get where I'm coming from with this." And, yet it's funny. I went from thinking, *Oh my God, she's not going to make it to, Oh my God, how long am I going to keep doing this for?* There's a possibility that I'll be doing this for my entire 40s. I'm gonna be 46.

I'm the One You're Supposed to be Asking About

We brought her home, and she's passed the six-month hospice care mark where everybody thought this was it. She's 4'10", 60 pounds. Everyone thinks she's so fragile. And yet she's tough. She's a lot tougher than I am. But we're "how-to-get-something-done"-kinda people. Most of the time she looks pretty good. She's a pretty happy person right now. If somebody was taking care of me all day, I'd be pretty happy, too. So, everyone asks, "How is your mom doing?" And I say, "I'm the one you're supposed to be asking about. She's doing great."

By the way, the reason she's so happy right now is she loves being cared for. She loves having people wait on her. I can tell. She lights up. She finally gets to be waited on after all these years of doing all the work. I have a lot of people wanting to work with me, it's because of her. It makes people happy to see her. She's happy and people love it. They love being around her.

Take Me to New Places

As far as taking care of myself, well, I don't exercise as much as I should. I can't get out of my home. So, the one thing I told myself was if I couldn't actually physically go anywhere, then mentally, I would try to go as far away as I could. So, I started studying music full-time about a year or two ago. And that seems to do the trick. Drumming, in particular. Which sounds like a very strange thing for somebody to do in my position, but it's not any different than painting or something. It takes my mind off everything, and it's good for me. But I didn't realize I would end up practicing four to six hours a day. And, it's taking off, to my surprise. I just never thought it would go anywhere. But I'm hopeful that once this is over with, I'll actually have something that I'm doing on a semi full-time basis. And hopefully that will take me to new places when I can actually travel. I'm proud that taking care of myself hasn't been that important. 'Cause life is not all about me.

I'm Just Doing Whatever I Have to Do

There is a famous saying that, "If you want something done, you have to ask a busy person." I had never heard that saying before. I've been doing this full time, taking care of my mom for five or six years. I am still a reporter; I work from home mostly. I have a property in Oakland that's falling apart. It's a condominium. There are ten owners, and nobody has done anything. I risk losing everything if I don't fix this. So I'm like fine, I'll do this. I'm just doing whatever I have to do. I collect money, make repairs, hire handymen, all of it, and I think it's so funny because I often hear people say how busy they are. I'm just thinking,

You don't even know. And, just when you think that you can't handle it anymore, you actually can. So bring it on.

Resourcefulness to Me is the Number One Best Quality

I'm ridiculously resourceful. When she first moved in with me, I didn't have anybody. There was this videogame from the 1990s called "Myst" where you're on a desert island, and you have to figure out how you're gonna get off the island. You have to look around and, "Okay, I see a coconut tree, I see a leaf, I see a ladder. How am I gonna use those to get off the island?" I was looking around in my neighborhood, and I was like, "Okay, what do I see?" There's a high school right across the street. I can afford high school students. So, I put a job listing there. And the people at the high school say there's actually a citywide job listing you can use, and it goes to all the kids in the city. So, that's how I started getting help. At the beginning it was, *Just make sure she doesn't leave the house.* She did try to leave the house, and this one boy goes, "I stopped her. I held my hands out, and I blocked her from leaving." He wanted me to be really proud, and I was like, "Okay, I'm really proud of you." They'd buy my groceries when I couldn't leave. One of them stayed with me for five years. She started with me as a freshman and now she's trying to go to medical school. There was one boy, and everybody he knows wanted a job. So he keeps bringing people to me. He brought his mom, his cousin, his cousin's mom is now working for me. I haven't had to look for anybody. And the finances were all out of order in the property in Oakland. There were \$12,000 of fraudulent expenses that were included in our financial statements, and it's just a mess. I got one of the girls who took care of my mom to work for the Homeowners Association (HOA) because she spoke Chinese and English. I didn't realize she was also a math and computer genius. This 19-year-old, freshman in college at Berkeley has completely straightened out our HOA. Singlehandedly, she has straightened out the HOA.

No one really talks about being resourceful. But resourcefulness to me is the number one best quality you could ever have. Because I don't have to be the smartest person in the room. I just need to go find the smartest person in the room.

Another thing is that I'm hugely adaptable. If something doesn't work, I drop it. I don't stay with it very long. I have this theory about physics, because they say every action produces a reaction, right? If you get a bad reaction, then your action should be the complete 180-degree opposite of what you just did. I use that a lot. And it usually works. When she was in her wandering phase, I thought initially the best way was just to physically block her. Stand in front of her and stop her. And clearly that doesn't work because that just infuriated her. So, I let her go. I'd follow her. To me that was a better option than enraging her. If I wasn't enraging her, then I was winning.

I'm very, very good with managing time. Which kind of scares me a little bit. Because if you're resourceful, and you know how to manage your time really well, then suddenly you're doing like all sorts of things you didn't know you could do.

My Mom is Quite Aware of What's Going on Around Her

Our society believes that we should write off people with dementia. That there is no hope, and we should write them off. I believe we are giving up too soon on people with Alzheimer's and dementia. I can see every single day how she's reacting and what's going on with her. Let's say you have a thousand light bulbs in your head that keep you operating every day, and 50 of the light bulbs go out. And as it gets worse, 100, and once it gets to the late stages it gets down to maybe a few hundred that are working. That's the way I look at dementia now. Which means they're still operating. There's still stuff going on there. My mom is quite aware of what's going on around her. She knows when she's being treated well, and she knows when she's not being treated well. She has an instinct about people. And I end up finding out her instincts were right. My personal view is, and I feel very strongly about this, that it is a mistake to write people off with dementia. In some ways they are even more aware of what is going on than before when they were not sick. I bought a burial niche because everyone told me, "She's not gonna make it, be prepared," and I showed her the picture. I said, "See, this is for you." And she said, "It's too small." I just remember thinking, *Oh, my God, she's aware.*

If You are Doing Things Well, Why Would Anybody Want to Help?

I don't get mad as easily as I did before. Because I'm around an old person all the time, I just can't lose my temper. So it takes a lot for me to get mad. Strangely enough, I have never been mad at her. I think because she went missing two or three times, and you don't know if they're gonna get hit by a car, you don't know what is gonna happen to them. Those were agonizing hours for me. I was just glad that she was alive. So everything else that she does, I can put up with. I was often told, "Just go home and relax." Really? You want me to go home and relax? There's that saying about the guy upstairs doesn't give you anything that you can't handle. So I feel like I did really well.

When I look back, even while I was having nervous breakdowns, everything was working out pretty well. I probably shouldn't have had a nervous breakdown, because what I was doing was all working out. There was no reason for me to be upset. My nervous breakdowns really centered around the fact that no one was helping. I always thought my friends and family would step up. And I was thinking, *What is it about me that nobody wants to help?* However, if you are doing things well, why would anybody want to help? [Laughs] I think that was a really valuable lesson for me.

It's About the People

Narrator: *Jennifer Merrilees*

Interviewer: *Daniela Kortan, research coordinator*

Jennifer Merrilees RN, PhD, is a clinical nurse specialist at the UCSF Memory and Aging Center where she has worked since 2001. She is part of a multidisciplinary team focused on the evaluation and management of people with cognitive and behavioral symptoms. Her work focuses on family caregivers and strategies for managing problematic behavioral symptoms.

Becoming a Nurse

I was a big reader when I was a kid, and I really fell in love with the Nancy Drew books. I was influenced by these young women who could solve problems and help people. And I remember thinking at an early age that nursing would probably fit those qualifications as a career. When I went to college at UC Irvine I enjoyed this somewhat fringe program *Social Ecology*. What I loved was that it wasn't so theoretically based, as a lot of programs are, but really allowed us to be out in the field and work directly with people. The experience that stands out the most for me was tutoring kids that were at risk in the juvenile justice system. And then probably one of the most significant events in my life happened, my father passed away suddenly. I was halfway through college, and I moved back home with my mother and got several part-time jobs in order to finish school. And then I graduated with a degree in Social Ecology, but found I couldn't really do much with it, so that's when the idea of becoming a nurse resurfaced.

To make sure nursing was a good fit for me, I got a job at a nursing home and became a nursing assistant. And I got to meet these seventy and eighty-year olds. I was just fascinated by them, because they often had a lot of physical frailties, but they could certainly tell their story. I remember meeting an eighty-year-old who had danced for the Bolshoi

Ballet, and someone else who had traveled through Europe as a gypsy. How did they all end up in California and in this lousy nursing home? And, that's when I decided that I really liked the field of nursing, and really liked working with older adults especially.

I went to nursing school and did what a lot of people do when they are fresh out of nursing school – I got a job in a hospital. I worked at Alta Bates in Berkeley. I worked on adult units in intensive care step-down, post-op, orthopedics, and oncology. I worked with some of the most amazing nurses on the night shift, and I learned *a lot*. One in particular who is still one of my best friends today. I loved paying attention to people's comfort, pain management, and helping them to cope with their illness or their surgeries and how these medical issues were life-altering. After several years working at Alta Bates, which is a community hospital, I started working in the float pool at UCSF. It was a very different experience working in a large academic teaching hospital. One of my friends who was also in the float pool used to tease the young medical students, "Does your mother know you are out past 10 p.m.?" And then I decided to get my masters degree in nursing, in the field of gerontology at UCSF School of Nursing. And I met Helen Ripple who was the Director of Nursing at UCSF, and she offered me a job as their Geriatric CNS. So I started here in the hospital on Parnassus, and carved out sub-specialties from there because the hospital is so specialized. I developed more of an expertise in wound care, pressure ulcers, and I also worked with patients with delirium and dementia. We did a lot of work around fall prevention, how to keep people out of restraints, things like that. So my love, or my passion, for working with the geriatric population and the cognitively impaired really just kept growing.

And then I left work for two to three years and went home to be a full-time mom with our two daughters. When I was getting ready to go back to work, I called Rosalie Gearhart, who was working here at the Memory and Aging Center with Dr. Bruce Miller. And they said to come on in and talk to them. And Dr. Miller offered me a job and said, "Come here and work for us – find out what it is you like to do." And it was the best job offer I'd ever gotten.

The Ability to Advocate for People

And all these years later it still is the best job ever. You can find the path of what you like to do and what you are good at. One of the things that originally attracted me to nursing was to the ability to advocate for people. That was a really important characteristic for me to pursue. And to advocate for them in relieving their suffering and misery. To help them feel “normal” despite illness, disability, and loss. To look for solutions to problems. And every day I have the opportunity to advocate for people’s best interest on all sorts of levels: one-on-one, but also at a program level, and even a policy level. I feel very privileged to work with the family caregivers. I’m just so struck by how courageous and kind and patient they are. And although they will often say that they’re not always courageous, kind, or patient, I really think that they are, given all the challenges they face.

“Well That Explains a Lot!”

One of my favorite things (I have a lot of favorite things I do here at the MAC) is the Nurse Consult Clinic. Cindy Barton, Robin Kettle, and I have been holding this clinic for six years now, maybe even seven. We started off calling it a Behavior Management Clinic, with the purpose of helping with the patients that were having hard-to-manage behaviors. And then a few years ago, we changed the title to the Nurse Consult Clinic because we realized that there were other reasons to refer to us and issues we felt we could help with. So if caregivers are really overwhelmed, or if people’s expectations about the future or the diagnosis were not quite right, or if what was going on was difficult... this clinic is one way to offer more support.

We take into account the resources that they have and what they want to work on. So it tends to be very personalized. And we’ve had some good successes. There’s one example I can think of that was a really nice moment. A family came in, the husband, the dad, had Alzheimer’s disease. They had a family business that they were all involved in that I think the dad had actually started. So there was a lot of pride around the business, and it was more of an artistic business – it

required a lot of visual skills. They came in because they were really frustrated that the dad, who they still wanted involved in the business and in the work place, was messing up some of the work, and it was costing money. And they felt he just wasn't trying hard enough. And, it was very simple, really. We showed them how he drew the intersecting pentagons [cognitive test] and how they were very distorted; he just didn't have good visual spatial skills anymore. And I remember the daughter leaned over, and she looked at the drawing, and she said, "Well, that explains a lot!" And they immediately shifted from, "Why is he trying to create problems for us?" and "Why can't he try harder?" to "He really *can't* do it any better than what he's doing." And they shifted their expectations. They still brought him to the business, but they shifted what he had access to and what his participation was going to be. And they did in a really nice, gentle way. And everybody left happy. And this was also good for the patient. Because instead of being argued with and getting all this frustration from his family, they were much more understanding about what he was able to do and of how to fit him into the business.

Countless Little Wonderful Moments of Connection

When I reflect on being a nurse, I can't imagine doing anything different. Nursing allows you to interact with people when they are most vulnerable, and I've always felt it a privilege to be part of people's lives during such intimate and personal times. A lot of my satisfaction comes from working in the field of dementia and with the family caregivers... and a lot of it is the Memory and Aging Center. It's just the most remarkable place to work, and Bruce is the most visionary leader. So a lot of the attraction is the place and the people I get to work with. I love the fact that I get to work with a bunch of people that have chosen to work in a field that is as challenging as it is. Because it's not simple and it's not easy. The problems we work on are pervasive and relentless, and you typically don't feel you've done enough for the families. And, it's such an honor to work with the caliber of people who are here. I guess the final thing I would say is that when I think of all my caregivers, and patients, and colleagues, that there are countless wonderful moments of connection that I have had with them and for that I am truly grateful.

You Don't Go to a Funeral Home to Meet People

Narrators: *Matt and Laura*

Interviewer: *Sarah Dulaney, clinical nurse specialist*

This is the incredible love story about how Matt met Laura (and her mom Muoi). Muoi is a patient at the UCSF Memory and Aging Center.

Matt: So yeah, the year was 2013. Laura's father had passed away, and so did my mom a few months after that. And it just so happens that we were both looking to buy grave plots for the family, which is a very unusual thing to do, especially at our age. At least that's what the funeral director tells us [laughing]. Usually you only see 50–60 year olds, they're the ones that buy grave plots [laughing]. But I was just buying it for the family because that's something that my parents always taught me; to kind of always be prepared for the future, because those grave plots – man they are so expensive! They definitely astronomically get so much more expensive over time. Like my dad purchased the grave plots back in the 1980s, and they were like about \$2,000 each spot. Now, they're like \$20,000! Yes. No kidding. And that's just the space, the hole, and the vault. That doesn't include the coffin, and it doesn't include the gravestone. So, like, when you look at just the increase in cost, it's insane. Yeah, 'cause then on top of that the actual funeral service, with the hearse, the cleaning of the body, make-up, renting the space, feeding the family afterwards. That just by itself is about \$10,000. So all in all it's about \$30,000 to be buried in the ground. I mean, even if you're just doing cremation, it's at least \$10,000, yeah — it's expensive to die! So, that's why my brother and I were like, *hey you know, let's follow in our parents' footsteps and buy a couple of plots* [laughing] and this is before I met

[Laura] of course! So then Laura, she was looking for a grave plot as well for her mom and...

Laura: It was actually for my mom, but she didn't want a grave plot, she was superstitious. She says that she needs a monk to come and look at the grave plot – it's the feng shui she thinks. I have no idea what she was talking about, but I said to her, "Don't be superstitious, you have to see where you want to be buried. I don't mind getting the plot for you, just tell me where. Because I don't want, at the very end – when you're not here, you won't know where you're going to be buried, and I don't know if you will like your plot if I choose one for you." So, that's the reason I went to get a plot for her and also because my dad passed away, and I was in charge of his funeral, and I didn't know what to do with his body. Thank God for his best friend – he's the one that advised me and told me what to do. And also thank God that next to my grandma was an empty plot that all my uncles contributed to and bought, and since my dad passed away, and since he's the first to go, then that plot was his. They gave that plot to him. So to prevent all these headaches I told myself, *I have to get a plot for my mom for the future*, and since she was so superstitious, I told her, "You know what? How about if I get one next to you?" And she feels more safe, and she said okay. And that's when I went with her to get the plot. So I bought one for myself too, because of her. I am 39, but back then I was 37.

Matt: Yeah, so then I was with my family looking for grave plots, and Laura was with her Dad's best friend looking for grave plots, and uh this was sometime in September of 2013. And then the lady there, the funeral director – her name is Rita, she's seen me before because unfortunately I've been there a few times already, and she's met my mom before. So I went there by myself, and she mentioned, "Oh there was a girl here just a couple hours before you and you know she's Chinese, and she's Christian – you're Catholic right? That's about the same thing, right? And I know you're both family oriented because I've seen you in here with your mom... so, I usually don't do this but uh, would you mind if I exchange your numbers?" And then I was just like, *huh?* [laughing]. So here I am, just a few months after my mom's funeral, and I'm starting to kind of – I'm forcing myself to come

back to reality; just starting to move forward – building for the future again. And usually, you know a lot of times parents, relatives or whatever, they're like, "Oh, I want to advise you or introduce you to this daughter of my friend," or whatever, and so many times – all the time – I would say, "No, it's okay, Mom. It's okay." The same thing for you too, right [Laura]?

Laura: Yep, same thing for me, my friend would try to introduce me to this guy, and I was like, "No, it's okay."

Matt: But then for me, it was just such an unusual request, and I uh fortunately, I just progressed enough I guess to be open to perhaps meeting someone. And [Rita] even mentioned, "Oh, hey you know, if it doesn't work out, you can always be friends." [laughing]

Laura: She said the same thing to me! [laughing]

Matt: Yeah so it's just such an off-the-wall request! And here I am about to spend tens of thousands of dollars to buy a plot, and here you are asking me about exchanging numbers with a girl I don't even know? And then I'm like, *Yeah sure, why not? What's the harm?* And then I thought about it a little more and I'm like, "Okay well, I should call her first right? Because that's the gentlemanly thing to do" [laughing]. And [Rita] says, "Yeah, yeah, okay. I'll contact her later and I'll let you know." So I'm like, I probably won't hear from her again, or maybe in a week, I'll hear from her in a week and an hour later! [laughing]. I get a call from [Rita], and she says, "Oh, she said yes!" [laughing]. I'm like, okay. So I remember that was a Saturday, and I'm thinking, okay well I'll go ahead and text her the next day on Sunday. You know, I don't want to scare her off by calling, so maybe just text just to kind of see where she's at. Because I have no idea who this person is, so I should try to get to know her...

Laura: Yeah, and you mentioned about an hour earlier, I actually called her! I called Rita because the uncle that brought me to the funeral home to look for plots, he said, "Make sure that that lady gave you a discount." [laughing]. And I was like, "No she did she did, it's on my contract she did." And he said, "No, no, no, call her! Call her just to make sure, just to confirm." So I called Rita, and that's when she took the opportunity to ask me, "Oh there's this guy, and I want to introduce you to this gentleman. He's really nice and yeah, when you meet him, if it doesn't work out, you guys could

be friends!” I thought, *oh I don't know you*. I was a little hesitant. But then um, she was really good, she was very convincing [laughing]. And so I said, “Okay, okay, yeah, I'll give him my number.” So, that was the one hour after.

Matt: Yeah, there's something about Rita's personality – she instills trust [laughing]. So we were both like, okay we'll give it a shot!

Laura: Yeah and plus you know I was like, *Wow, this is kind of strange!* Funeral homes are where you go to buy a plot and do funeral business – you don't go there to meet people.

Matt: Yeah, so at the very least it will make for a great story! [laughing] And a great story just became the best story! So we started texting each other, and then I wanted to set up a date so I'm like, “Oh hey, I don't even know what you look like, so, why don't you send me a picture so when I come to meet you I don't talk to the wrong person?” [laughing]. And then you thought...

Laura: I said, this guy is quite sneaky! [laughing]

Matt: So then we exchanged pictures. When I received her picture, I was at a Giant's game with a couple of my friends, and they were like, “Oh yeah, good job, good job!” And I'm like, *Wow, she's so pretty!* And then when you got my picture...

Laura: Yeah, when I got his picture I was like no way – I know this guy [laughing], I know him from 15 years ago! A long time ago...

Matt: Yeah it was funny, the friend I was with at the Giant's game she's like, “I think I know this girl.” I'm like, “No you don't.” So then the following day we talk, and Laura says, “I think I know you, were you a part of this organization at SF State?” And I'm like, *No way!* [laughing]. And then I just started to think (because that was 15 years ago), and I'm like, *Oh, I hope I didn't do anything to give a bad impression or do anything bad!* [laughing]. So yeah, just from the very get-go, from our first text, there was chemistry there. But at that point it was even more so, you know, it was just like wow... It was almost fated; the way that we met. And I am spiritual, but Laura is much more spiritual than I am, and why don't you (Laura) talk about that?

Laura: I was praying; I was praying to God to let me meet someone that's right for me. And He let me meet him (Matt). When I got his text I was like, *Okay God, okay next step. Can you confirm if it's this guy or not?* [laughing] And then when he sent me his picture I was like,

Oh, no way! This is a joke! And that's when I was like, *okay, okay, God wants me to be with this guy.* Yeah.

Matt: Yeah. So one thing led to another, we went on our first date, and we just hit it off from the very get-go. And I was like *wow, you know, maybe she is the one.* And I was talking to my friends about it, I was thinking about it, praying on it, and then it just got to the point where I'm like you know, we not only have great chemistry, but we also have the same life goals, the same principles, and then we also have varied interests so it's always interesting, we're just always having fun, and she's very open-minded and interested in trying different things, and I'm always quite adventurous too, so I'm always seeing what she wants to do. So then basically, I decided to take her on a trip to Hawaii, um, she already knew that I wanted to ask her to marry me. It was not a surprise, like, I'm not going to plop down a lot of money to go to Hawaii, buy a ring, and then leave it up to fate to decide whether or not she's going to say yes or no! I'm not one of those people on YouTube where they propose to some girl at Oracle Arena in front of everybody and then the girl walks out. I'm not going to do that. So we had already talked about it; we already talked about kids even and what we see our role as husband and wife. So I already knew she would say yes. But you know, there's always that little doubt until they say yes, and you put that ring on her finger; so there's always that anticipation. So I knew she was also taking care of the Mom, and I knew that the Mom needed a lot of help from her, and I didn't quite understand dementia that much. I was trying my best to be as supportive as I can, and I knew that I would need to bring her mom along to Hawaii because otherwise, even though she would be physically with me in Hawaii, her mind would be constantly worrying about the Mom the whole time. So I'm like, let's just all three of us go fly to Hawaii, enjoy it like one family, and we'll figure out the details but that way we know the Mom's safe, she's taken care of, and then Laura's happy and comfortable, and then also it's my way of showing her that once we get married, I'm not going to have you just abandon your mom.

So at that time, we didn't quite realize the extent of Muoi's (Laura's mother's) limitations. We knew at that point, we weren't just going to leave her alone the entire trip – literally, we had

her with us the entire time except for like three hours towards the second to the last day of the trip. I just really wanted to have some time out just for us, this was our engagement trip. So we decided to go up to the North Shore of Oahu and pick up some garlic shrimp scampi and Matsumoto's shaved ice, and the plan was to enjoy the sunset. So that was our plan and the Mom was taken care of; we actually took her out in the morning just to kind of get that out of her system so that she doesn't feel cooped up, and we took her out to lunch so she had a full meal. We brought back snacks and refreshments, we had her book, had her TV on, and reminded her not to go out on her own, and she said "Okay, yeah." So then fast forward, and we get a phone call from the hotel security saying, "Hey, are you so and so? Um, I believe we found your mom wandering the hallways." And I'm like, *Oh my God, what is going on?* [laughing] At that point maybe two hours had passed, and the security guard explained that a hotel guest found her and now she is sitting down in the lobby so then we're like, "Oh my God we're coming back as soon as possible! We're going back right now! So yeah, thank you so much for finding her!" [laughing] Yeah, that was the first time she did that. So we got back, and the security guard had brought her back to her room, and then Laura was talking to her to find out what she was doing.

Laura: Yeah like, "What happened? Why did you go outside?" And she said she wanted to throw out the garbage, because she thought that that was her apartment, and she does that all the time at her own apartment; she would dump garbage (down the garbage shoot) by herself.

Matt: Yeah so she basically locked herself out, she forgot what room she was at, and she wasn't able to communicate. I have major respect for the security guard because they were able to deduce which room she came out from [laughing], I guess we were the only Asian family on that floor. So then we're like wow okay, what do we do now? We definitely need to keep a closer eye on her and check-up on her more. That's why when we got back the following morning, Laura made a point to go check on her right when she wakes up at like seven in the morning. But she already woke up; she woke up at six something – who knows, but apparently she was fixated with a night-light on her wall, a night-light that's

been there for years that never bothered her before. I get a call from Laura, "Oh my mom fell! I'm taking her to the ER right now." Apparently the Mom was trying to pull that night-light out from the wall for some reason, and she fell backwards and hit her spine against her bedpost.

Laura: Yeah it fractured her back. And then the doctor said it would take about five months to heal because she also has osteoporosis. And I thought, *Oh my gosh, five months!* That's a long time, and she was in pain, real pain, she couldn't get up, she couldn't walk, she just had to be in bed all the time. At that time, I was still going to work, and it happens that I asked the janitor if she knew any acupuncture doctors who were good. She recommended this doctor, and I told Matt about him, and so that's when I first brought her to acupuncture.

Matt: So we took her to the doctor's office and just maybe after one or two sessions her back was completely healed. Literally. She could walk. [laughing] Before that Laura would have to constantly literally stay with her you know to take care of her, to feed her, take her to the bathroom,

Laura: She can't even sit up because her back was hurting that much.

Matt: Yeah, she couldn't even get in and out of bed, so the doctor was able to heal that fracture, and we were still focused on that, but then the doctor said, "You know what, I'm not even worried about that, I'm worried about something else, I'm worried about this (pointing to his head)." He basically told us that yeah, she has dementia. And I think that was probably maybe the first time we actually began to realize that there is a name for it. [laughing] So we really didn't know the name for it before.

Laura: I think he (the Chinese Doctor) mentioned it was the look of her eyes; I'm not sure how he examined her eyes, but he told me that it was the look of her eyes (that showed signs of dementia).

Matt: That's one of the things that makes this doctor so great; because we come in with an ailment, but he observes your entire body, and he actually points out all the things that are wrong with you! [laughing] He's doing a body scan, and like, *Oh there's something wrong with your liver and kidney.* I joke around with him, I'm like, "You have strong kung fu."

Laura: The neurologist did warn me that we should start removing the knobs on the stove otherwise she might burn food or burn down the house [laughing], and I took her advice. I noticed that when she cooks she would burn food, and she would put strange things in the pot; she would put potato, beans, and just everything in the pot, and I was like, *Oh, what's this?* So, I removed all the knobs, and now whenever I need to cook for her, I have to put the knobs back on the stove. But I've noticed that I also use a microwave a lot. Before, I always used the stove, but now I have to do things really quickly, because I have work too. So, I have to come during lunch – thank goodness I work close by her place, half an hour lunch run to her place, put things in the microwave, then give her food and make sure she's okay and everything's alright, and then run back to work. So that was my schedule almost every day.

Oh and one time, she was very hungry, and she was going to eat jewelry cleanser, but good thing the jewelry cleanser was new so it was all sealed up (she couldn't open it). But yeah, I came home just in time, and I asked her, "Oh, what are you doing?" In one hand, she was holding the jewelry cleanser, and in the other she had chopsticks, and she said, "Oh, I want to eat this, I'm hungry."

Matt: Yeah, so then at that point we removed all poisonous chemicals out of the home. [laughing]

Laura: And knives, because she was hiding knives in the bookshelf!

Matt: Yeah, she was really good at hiding things, so we tried our best to find everything we could, but then we just came to the realization that she needed 24-hour supervision. That's just the bottom line, she needs 24/7 supervision, she can't be left alone. We literally visited her all the time when she was still living at the apartment. We would visit her at least three times a day, we would call throughout the day, we would watch the baby cam, between the two of us it was insane.

Laura: Very stressful.

Matt: Very stressful [laughing], and at that point, we were still able to call her over the phone if we saw her doing something dangerous or trying to wander out. She would still follow instructions, you know. We'd tell her, it's really cold outside – and it would be cold outside, or raining, or just wait for us after work, and we'll take you out – and we would, we would take her out. And it got to the

point where she wouldn't cooperate, and she would just hang up (when we called). Or she would just let the phone ring, ring, ring, ring, because she started to forget how to pick up the phone! Or she remembered how to pick up the phone, but she would forget how to hang up the phone, she definitely can't dial. So yeah, every little thing just progressed.

Endeavors of Discovery

Narrator: *Jane Hirshfield*

Interviewer: *Caroline Prioleau, Writer & Designer*

Jane Hirshfield was the third Hellman Visiting Artist at the Memory and Aging Center from 2012–2013. She is a prize-winning poet, translator and essayist who has authored eight collections of poetry and edited and co-translated four books containing the work of poets from the past. Her honors include fellowships from the Guggenheim and Rockefeller foundations, the National Endowment for the Arts, and the Academy of American Poets, and she has been a visiting professor at Stanford, UC Berkeley, University of Virginia, and elsewhere. Hirshfield's poetry speaks to the central issues of human existence – desire and loss, impermanence and beauty, the many dimensions of our connection with others and the wider community of creatures and objects with which we share our lives. Her work appears in The New Yorker, The Atlantic, The New York Times, Harper's, and eight editions of The Best American Poems. In 2012 she was elected a Chancellor of the Academy of American Poets.

Affirming the Difficult

I first heard about the Hellman Visiting Artist program when Bruce Miller asked if I would be interested in taking the position. I had known him already in other ways as a person interested, as I am, in the intersection of art and science. Bruce had heard me read some poems about an older poet I'd known for a long time and seen during his progression into Alzheimer's, and so Bruce knew I was already at least a little engaged in this area. I jumped at the invitation.

I think many poets, possibly all poets, are voracious about experience. A poet has to be open to the full range of what it is to be a human being, what it is to exist in a world of aging, diminishment, change. And for me, it was especially poignant when my elder poet friend, whose work I had admired for so long, phoned and said, "I've

been diagnosed with Alzheimer's. I'm letting my close friends know, just in case you ever see anything off, anything strange." Watching the great continuing eloquence of his work for quite a long time after that, for me, was reassuring and informative and opening.

As an artist, I don't plan ahead what I'm going to write about. I didn't know I was going to write about my friend or about our last visit together. But I do know that, as a poet, it is my desire to capture the things that are hard to capture and to capture the things by which I am moved. Looking at what's difficult, finding words to face that with, I find myself encouraged. This subject of affirming the difficult has long been a part of my work and my life. It's difficult for me to say which comes first. Does the interest in navigating a life well create the artist, or does the interest in art-making pull the person toward creating a life capable of making art? I think both are equally so.

The Practices of Poetry and Science

Science seems to me a very particular vocabulary of understanding. One of the things I've long found similar between the practice of poetry and the practice of science is that both are endeavors of discovery. They aren't about expressing what you already know. Some people might think that poetry is that, but it never is, not the good poems, anyhow. Good poems always tell you something you didn't quite understand before, something you couldn't quite articulate before. You write to further the boundaries of what you know and what you can say of what you know. And the vocabulary and knowledge science is so fundamentally grounded in the particular, in specifics and the real. I am interested only in the real, even though it is the job of art-making to bring imagination and feeling and resonance, the full response of the human heart, mind, ear, eye, and tongue, to the expression of our factual existence. The real is the real, but facts are never only factual. They reside in our lives, and have meaning only within our lives, our hopes, our feelings.

And that, for me, was one of the most moving things about being in this program. To witness how absolutely dedicated the MAC researchers are not to understanding only neurons and tau proteins and, and what might go wrong at a physiological level, but always,

always feeling how that physiology unfolds within actual lives, actual patients, about whom – it was so clear to me – everyone at the Memory and Aging Center profoundly cares.

I do think that recognizing the marriage of universal truths about our lives and the minute specific, particular expression of them within individual lives is perhaps the only truly ethical way to approach any kind of investigation, whether it is science or painting or poetry or dance or music. A life only unfolds in this moment and in the exact expression of this moment, this body, this person, this life, this history. Moment by moment life is what is recorded in every cell of our being. It is the task of science and the task of poetry to serve our broader and deeper and wider experience of that and our understanding of that. One of the fundamental questions in approaching both science and art is: *Are we trying to understand or are we trying to change?* The answer in both fields, I think, is both. There's no change of heart or of medicine without first finding some understanding. And there is no understanding that doesn't affect how we then act and choose and go forward into whatever it is we do in and with our lives.

A Fracture in My Own Life and Heart

I very often begin a poem with a question, or because of some tear or fracture in my own life and heart. Art, for me, begins not in knowing, but in not-knowing. I write when I must find something outside my own grasp. If I already knew my question's answer, if I felt sufficient whatever emotion I was already feeling, why should I write a poem? There'd be no need for one. For me art is not embroidery, it is the fabric of my life made again whole.

Also, poems are not ever uni-dimensional, even the ones that seem simple. They always include, somewhere under the surface, more than one direction of understanding. In poems of joy, there will be grief under the surface. In poems of grief, there will be the counterweight recognition of beauty. And any good work of art includes uncertainty. And uncertainty, of course, is fundamental to the progress of science. Progress is about expanding perimeter past the known. Including uncertainty is perhaps not fundamental to the *answers* of science. It is, though, fundamental to the answers of poetry. If a poem is too

pat, it will be forgettable. But if its words and music leave something rough and unfinished in your heart, you will keep returning to it, to re-experience the provisional answer that a good poem gives to our questions. I mean that a good poem answers the question for a moment, but the questions we bring to art are so volatile that they can't be answered permanently. The answers can't be held. The need for art is like the need for eating. A good meal will answer hunger for a moment, for a few hours. Then it's gone. But then, if you're lucky, you can go back to the restaurant.

A Cricket Singing

Art works always are new, even when they seem to be the same set of molecules distributed on a canvas or in the ink of a page. They change a little every time we return to them, because we change a little every time we return to them.

And so there are poems I love deeply that change their meaning for me radically, depending on the circumstances and mood in which I reenter them. The same poem can be one day a poem of grief, another a poem of gallantry, like this haiku by the Japanese 19th-century poet Kobayashi Issa:

On a branch
floating downriver
a cricket, singing

Now, that is a portrait of, first, simply what is. There probably was a river, a branch, a cricket, which Issa probably saw. But this is also, in its few small words, a portrait of our human existential dilemma: we live in time, we will vanish, and we sing. But how do I experience this image of a branch floating downriver, and its cricket, singing? Sometimes, it seems to me a bitter truth, and sometimes it brings enormous consolation.

The Richness of Being

Over my life, my relationship to writing has formed a gradually altering arc. When I was young, I was wildly prolific. I might write three poems in a day, in college. I wrote with music in the background. I wrote with distractions. The flow of language felt natural and unstoppable.

Now, I am much less prolific. Of course, I have changed. But also, by now I've written about many things already. I'm not interested in repeating myself, and so new subjects are a little more elusive, new perspectives more rare to come to. I write more infrequently now, but I hope with more complexity and subtlety and depth.

My subject matters have changed as my life has. Aging couldn't help but come into my work, because one notices it and because the focus of much of my poetry is the inhabitation and the feeling of this one, individual life. No matter what a poet's subject matter is, you see from inside your own eyes and body. One of the most powerful experiences a human being has is the experience of time and of our altered and altering relationship to it. Aging arrived as a theme in my work just as I was turning 40, in a poem or two. Since then, there've been increasingly more in the books.

I have come to treasure the increasing body of work written by older poets. As health care has improved, more poets are living longer. The Polish Nobel poet who I loved greatly, Czesław Miłosz, wrote superb poems into his 90s. And part of what he was witnessing in them was his own relationship to time and to aging. That was far from his only subject – he was a poet of immense range and moral depth, who took the state of all humanity as his subject, our largest suffering, our smallest pleasures. Another Polish poet is Julia Hartwig, who, at 94, is still publishing. Stanley Kunitz was an American poet who lived to 100 and was writing almost until the end. These are lantern poets, who show me the way.

Or I should say, very specifically, that the work of these older poets has shown me the richness of being that is possible even when the body grows frail, the richness of mind and heart and spirit, and of an awake and continually changing understanding. These poets didn't write the same poem over and over. And so it is evidence for us all, that if we are lucky, there is a life that can go on until the end, surprising us.

Contrary to Keatsian Joy

One of the things most moving to me in my friendship with my older poet friend, as he went more and more deeply into Alzheimer's, was discovering that although there were gaps in his ability to speak in a linear, connected fashion, he did not lose his eloquence. He lost something else, but not his core relationship to a life of language, his own and others'.

The best way I can offer this experience to you is with the two poems I wrote following our last visit. The first is more about my response to what I discovered, that far down the path. I hadn't understood, you see. I hadn't known someone intimately with Alzheimer's before. When I went for that visit, I phoned the director of the care residence where he then lived, and asked what to expect. She said, "He might not know who he is. He might not know who you are. He might not know he was ever poet. You might find him on the floor of his room."

I suppose I was lucky in the timing of my visit, because that is not what I found. What I found was what this poem describes.

Alzheimer's

When a fine, old carpet
is eaten by mice,
the colors and patterns
of what's left behind
do not change.
As bedrock, tilted,
stays bedrock,
its purple and red striations unbroken.
Unstrippable birthright grandeur.
"How are you," I asked,
not knowing what to expect.
"Contrary to Keatsian joy," he replied.

That is a far better answer than I have ever given to the question, “How are you?”

Later, I wrote a second poem from that visit. It begins looking out the window of my house the next morning.

The Pear

November. One pear
sways on the tree past leaves, past reason.
In the nursing home, my friend has fallen.
Chased, he said, from the freckled woods
by angry Thoreau, Coleridge, and Beaumarchais.
Delusion too, it seems, can be well read.
He is courteous, well-spoken even in dread.
The old fineness in him hangs on
for dear life. “My mind now?
A small ship under the wake of a large.
They force you to walk on your heels here,
the angles matter. Four or five degrees,
and you’re lost.” Life is dear to him yet,
though he believes it his own fault he grieves,
his own fault his old friends have turned against him
like crows against an injured of their kind.
There is no kindness here, no flint of mercy.
Descend, descend,
some voice must urge, inside the pear stem.
The argument goes on, he cannot outrun it.
Dawnlight to dawnlight, I look; it is still there.

What I had not known or understood before, is how uneven the losses in Alzheimer’s can be. And that’s also what I saw here, in the patients I met during my time as Hellman Artist – how much joy can remain, how much talent can remain, and how much that will vary, depending on the geography of the losses.

In one session during my residency, we invited Memory and Aging Center patients and caretakers to make poem-cards, doing both painting and writing. One woman had lost words almost entirely, but

loved to paint. By the end of the session, she had done a beautiful painting, setting a very few perfect words on it. Her whole being lit up with incredible joy, at having done this and at having been able to see it received. That, for me, was an unforgettable moment and an education – to see that no matter how much she had lost, what she had, who she was, brought more than enough of joy for any life. And her caretaker's poem-card was also a revelation, in a different way.

What I learned from these experiences is not unlike what I've found with friends who are dying. People are not a condition, are not reducible to any single description. I remember the first time I went into a room for what I'd been warned would be our final visit. I thought I was going in to see a person who was dying. But who I saw was a person who was fully alive. My friend.

We have categories and labels in our mind, and reality never fits into category or label. The reality is that your friend is alive, completely himself, as he is in that particular moment. And I have never failed to feel this reminder of the full aliveness of the living as a great privilege.

In this Hellman residency, I think one thing we visiting artists can do in presenting our witness and responses to our experience is to help other people feel less afraid, to help them remember that difference is not something to fear, that a diagnosis is not an erasure of a life. To be with the patients and to be with the research community here at UCSF each felt to me a great gift and a privilege.

The 360-degree Roundness of Existence

Stereotypes and general ideas and categories are always punctured and undone by works of art. I suppose there are caricatures and cartoons that can be thought of as art. Daumier comes to mind. But a good poem is never a caricature. Art's task is to see the very person in front of our eyes – sometimes ourselves, sometimes others – in the 360-degree roundness of existence.

In good poetry, empathy will always be present. There's always some recognition of the profound connection between us and everyone else, everything else. You can't describe another person or thing or landscape or weather without taking it into yourself. You can't even meet someone without taking them into yourself, at least a little.

Empathy is what understanding is based on. And the understanding of art is always, I think, an attempt to take things in with the most permeability and breadth we have in us. Art shakes off stereotype the way you would shake the rain off and then shut an umbrella when you come into a house. A house is a realm of intimacy, of safety, a place where you don't any longer need protection from rain. Stereotypes and generalities are what we turn to when we're frightened and overwhelmed. They are ways to force separation, to blunt. Art is where we turn to be intimate and permeable.

The life that we have in common with others will speak for itself, in art. If we name exact experience, the commonality will come forward without being explicitly summoned. It's there in the viewer or reader or listener's recognition: "Ah, that is my experience, also." We don't have to worry about universality as artists. The realm of the shared life is self-sustaining and inevitable. The true commonality of our lives can only be found in the particular, the specific. It has nowhere else to live.

With Gratitude

It's difficult to name any one part of my residency that stands out – the entire year was full of pleasures and surprises. I loved everything we did together, right from the first event, in which I first gave an introductory reading of my own poems, choosing ones that had to do with memory and aging, and then members of the MAC research community came to the microphone to read their own favorite poems. The delight and joy and range of what they brought was a great introduction for me, showing their own delight and joy and range. I think they surprised and delighted one another as well.

My next-started project was to offer a poem each month, centered on time, aging, or memory, along with short introductions. Those are still available on the MAC website, I'm pretty sure. One month was a classical Chinese poem by Tu Fu, another a poem by Shirley Kaufman, an American poet whose daughter is in the gerontology research community, describing how she felt when turning 90, another was the last poem written by the 20th-century Russian poet Osip Mandelstam. I wanted to use poems by living poets, long-dead poets, American poets,

poets from other cultures and languages. These were sent out by email and also set out as printed sheets. I loved choosing the poems and finding things to say about them and their authors' lives, and I loved knowing that they were being received with gratitude.

Once I sat in on a diagnostic testing session, and then with the group conference afterward. That was fascinating and instructive. I ran into the man being tested and his wife in the coffee shop on campus just after. And so again, I found that my experience was of the full, specific, entire human being, as well as of brain imagery, and of the working discussion about what might be going on with him.

The conversations in which I learned about frontotemporal dementia, especially, gave me some new insights into phenomena I'd seen out in the world and hadn't understood so clearly, and again, gave me also a deeper appreciation for the full range, even of what we consider normal in human beings, and of how vast that range is, and how some strengths step forward when others recede. It gave me a sense of the brain's resilience, and of people's resilience.

The two final events of my residency were larger, public ones. The first was an evening on "Poetry and Science," in which four MAC research scientists spoke about areas of brain research relevant to language and the arts, and then four poets (former U.S. Poet Laureate Kay Ryan, geology-trained Forrest Gander, UCSF physician David Watts, and I) each read poems of our own that in some way had science in them. The event was made part of Litquake, San Francisco's citywide October literary festival, and it was standing room only. The UCSF fire department came and insisted that some people leave. They listened in an outside hall by remote feed. That event was a lifetime highlight.

The final, December event was also a big-attendance public program, this time on "Poetry and the End of Life." The program was amazingly varied and rich, a conversation held at the intersection of practicing physicians, hospice directors, and researchers who have found poetry of use in their work, and poetry speaking for itself. Sandra Gilbert read from her own elegies, and she and I read a suite of Emily Dickinson's death poems in collaboration with an improvising musician, Shira Kammen. The many stories the physicians and hospice people brought into the auditorium were harrowing and humbling. Art truly matters, truly changes. Art's presence in our lives and at our lives' ends is not decorative background, it is a life raft.

And then, after my year had officially ended, we did one more event for the research community, in which Kay Ryan, who has a deep love of Emily Dickinson, talked about Dickinson's poems of brain and mind and thought, and the way thought sometimes slides away from us. There may be no larger or precise body of literature describing the specifics of wrestling with one's own cognition and feeling than can be found in the roughly 2,000 poems that Dickinson left us. Kay was marvelously eloquent in her readings of the poems (both saying them and her thoughts about them), and was herself completely excited to have the chance to talk with the science community about poems she so loves. Not least because we who are poets tend to talk mostly to people in our own field and in only the context of literature. To speak with people who have as specific a vocabulary, but in an entirely different way, is one of the most thrilling things for any artist. E.M. Forster said, famously, "Only connect." The joy of a broader connection was at the center of my time as the Hellman Visiting Artist.

Two Poems

I'm going to finish by offering you two poems that touch on aging in very different ways. One is a poem I wrote when I was fifty-nine, and so it is a poem of my own relationship with aging during that signal year in a person's life. It's got a different music than most of my work, and is the closest thing I'll likely ever written to an Irish ballad, though the rhymes are not quite so neat and clean as all that. But the spirit of an Irish ballad is under it.

I Ran Out Naked In The Sun

I ran out naked
in the sun
and who could blame me
who could blame

The day was warm

I ran out naked
in the rain
and who could blame me
who could blame

the storm

I leaned toward sixty
that day almost done
it thundered
then

I wanted more I
shouted *More*
and who could blame me
who could blame

had been before

could blame me
that I wanted more

One of the things awareness of aging, and also awareness of the too-early deaths of some friends, has brought me to is a sharpened desire for experience. What I felt when I wrote that poem, and feel still, is not a diminished hunger for life, but an increase of it. I'm sixty-three now, and have just taken up backpacking again. I want to be out in the wild while I can be, I want to plunge into the beauty of this fragile earth while it and I are both still here.

The second poem I'm going to offer was written more recently, after my Hellman Residency ended. My ninety-three year old mother almost died two years ago. She was in hospital, and there was absolutely no way to know which way it was going to go.

The hospital doctors were sure she was dying and wanted to move her from ICU to an out of hospital hospice. Her personal physician was not so sure — she said to me, “Your mother’s a fighter, let’s give it more time.” And so it is thanks to that personal physician’s knowing the person, not just the illness, that my mother is still alive now and doing

rather well. It made me think about these kinds of opinions, and how much they are part of medicine, along with antibiotics and nursing care and medical knowledge. I am quite sure that even my mother's own body, or spirit perhaps, didn't know which way it wanted to go, until it decided. And so after, a few months later, I wrote this poem.

They Have Decided

Comes a time they have decided who you are.
But you have not decided who you are.

Your wrists have decided.
Your knees have decided.
The hair that will leave its braidings behind has decided.

Your ears, your rebelling ears,
have decided: enough.
They surrender cities, pianos, sentences, whistlings, cries.

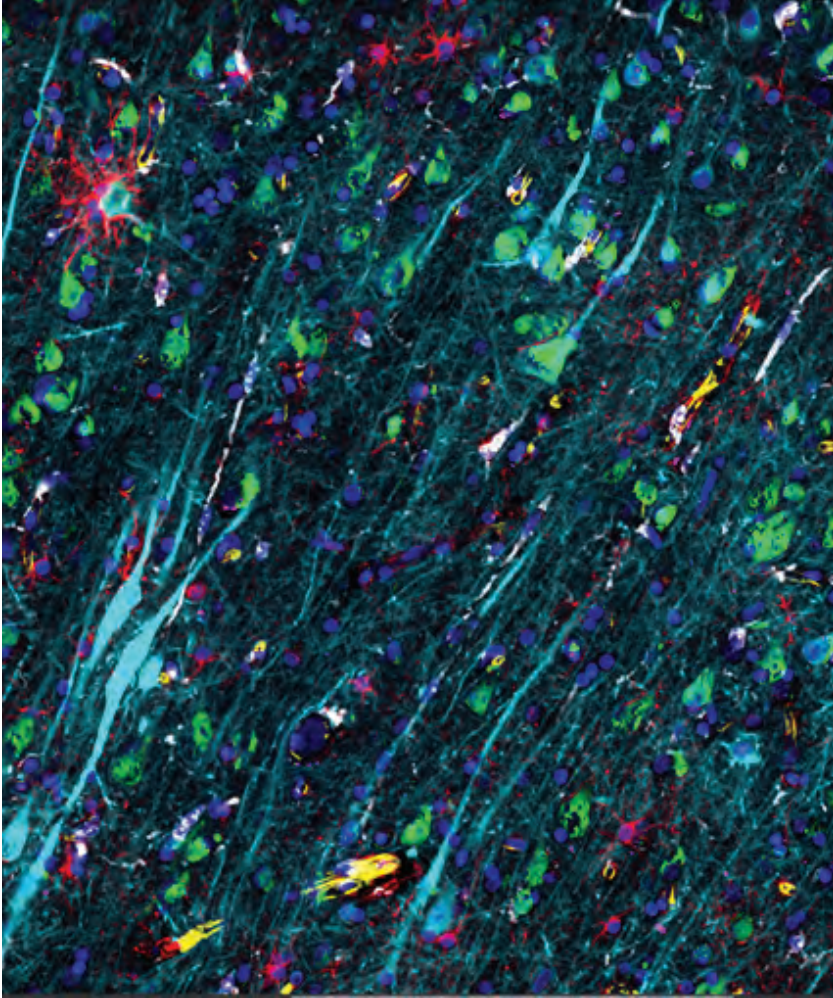
Your thoughts, it seemed once, had decided.

But you, past naming, past weighing, had not yet decided.

Like a foal still trying to find which leg goes where for standing,
you have not decided.

It was only when my mother started taking the spoonfuls of yogurt I offered that her body's decision was made to live. This old, old woman, so very sick in her hospital bed, became in those moments just like a newborn foal. So many different parts of the world are in us at any moment, so many parts of our lives are in us.

My mother herself was sure she wanted to die, but something in her decided to live.



**Image courtesy of Salvatore Spina, MD, PhD,
and the UCSF Neurodegenerative Disease Brain Bank**

It Works for Us

Narrator: 68-year-old caregiver in the Care Ecosystem Project

Interviewer: Alissa Bernstein, PhD, MPH, Postdoctoral Fellow, Institute for Health Policy Studies and Atlantic Fellow, Global Brain Health Institute

The Care Ecosystem is a telephone-based supportive care and care navigation intervention for people with dementia and their caregivers. Participants are assigned a Care Team Navigator, an unlicensed dementia care specialist, who works in coordination with a clinical support team. Care Ecosystem is being evaluated as part of a three-year randomized control clinical trial funded through a Centers for Medicare and Medicaid Studies Innovation Healthcare Innovations Award and carried out in California, Nebraska, and Iowa.

Good Days and Difficult Days

We've been through the full range of experiences. On a good day basically, he's like this, he's happy. He'll watch TV and sleep and get over here and paint. I see him in his chair, and he's in his own little world. I'll come back here to visit with him. On a difficult day he gets edgy, and he's growling at me and hateful. I've gotten used to it. There are so many things that I can do, and there's a lot that I can't, so I just kind of walk away and say there's nothing I can do, and I go and talk to the cat. When everything's fine, then I come back. So, you have to learn how to balance.

It Works for Us

Part of this is love, part of it is finances, and part of it is I just couldn't walk away from forty years. If he did go into a home, it would be state care, and I don't want him to do that. So here we are, he's stuck with me and I'm stuck with him, and oh well. It works for us.

Solitude and Escape

The hardest thing dealing with this is the solitude. I get out about twice a week, I feel like I escape. But it's hard for me to get out. I don't like to leave him alone, so I can't just pick up and go when I want. I'm afraid that he would try to get out or something would happen, he would get up and he would fall, or he would be hurt while I was gone. And, the guilt would not be happy.

But then, like I said, I got kind of used to it just being the two of us. I am pretty much used to it. It's always just been him and me, and I've always been the one that took care of him. I run up ahead of him and clear off the path, he goes through, and I come behind him and clear up the path that he's made, so that's kind of been what we do, and that works for both of us

I am a stubborn girl. Dad always wanted a boy, and what he got was me, so I was raised as a tomboy – very independent, do for yourself, don't rely on anybody. So it has helped, it has really helped.

Putting it on Paper

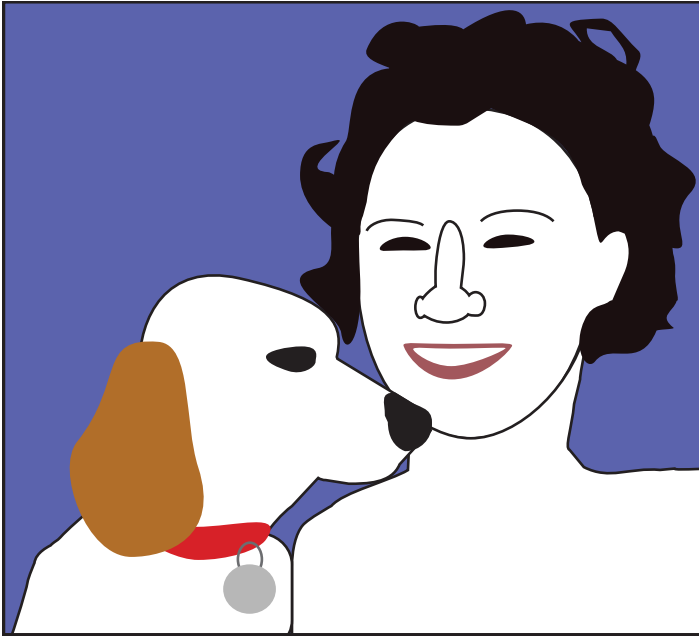
A doctor recommended us to Care Ecosystem, so I figured any type of support or information I could get was for my benefit. The more you learn the better you are, I learned that from my mother. Education is the key. My Care Team Navigator helped me get my actual power of attorney, on the paper, official. That was part of it, not knowing how to do it, and mostly it was being pushed to do it because that was acceptance that there was something wrong. That was hard. I'm sorry. That was just, that was hard. But she got me through that, too.

I would consider her a friend, someone I can talk to, a confidante, and yes, I know I can tell her whatever I want to. She has done a lot, she's done a lot for me and she's made me do things that needed to be done, she's given me that little friendly kick in the butt, go do it, yeah. It was so hard, the acceptance that this wasn't just a bad dream. Putting it on paper. I don't really want to accept it, but you have to. Reality is just a pain in the ass, it always has been, because what is going on in your head is much better than reality.

Every Once in a While He'll Come Back

We've always been very adventurous. I never knew what he was going to say, never knew what he was going to do. His personality now is gone, except for the artwork. He doesn't have his interest in reading anymore; he used to be just fluent in everything. He knew everything that was going on, read the news and everything, he was just on top of it. He had an opinion and he was going to tell you whether you wanted to hear it or not.

Every once in a while he'll come back, he'll be, I can tell by his eyes. Every once in a while he will recognize me. He comes in and then leaves again, or he'll say something that I know that he's back, and then he disappears again.



Self Portrait by Caroline Prioleau

All Friends and Dogs Welcome

Narrator: *Caroline Prioleau*

Interviewer: *Julie Feuer, social worker*

Caroline Prioleau is the Memory and Aging Center's expert on all things design and communications. Taking a varied and wandering path to her official title as Information & Multimedia Producer, Caroline has helped bring together the many people and stories that make up the hear/say project. Although she won't acknowledge the value of her own story, she was strong armed into sitting (and laughing) with one of our social workers for an interview in October 2016.

Amorphous Roles

I'm Caroline Prioleau. I'm... I don't really know how to describe what I do at the MAC. I'm always amused to hear how people introduce me. I guess I could start with where I started. I joined the technology group, and my title was an information data analyst or something along that line, but I was working more on information sharing and collaboration — websites, wikis, things like that, and it's expanded. Now I mostly do a lot of writing, editing, graphic design, video, intranet, information architecture, websites, social media. I guess what I do all sort of falls broadly under communications, so sometimes I just say *Writer/Designer* and figure that kind of covers most of it. [hearty laugh]

I Fell in Love With Research, But Design is the Key Thread

I would say that design is the key thread that's followed my path all the way through. The first official design class I took was in high school. There was a design project, and I remember thinking, *I love this, I want*

to do this. But then I got to college, and all the artists were really good, and there wasn't a graphic design program. They were all painters and drawers and sculptors and amazing artists and I thought, *Yeah, I'm not one of them.* [laughs] So I think I was scared off by art for a while, so I kinda went in a different direction.

I just assumed I'd be a history or poli-sci major and would probably end up teaching or something like that. Then I took a psychology course, fell in love with Psych 101 – I think most everybody does – and was convinced I was gonna be a clinical psychologist. And so they said, "Okay, you need research experience." So then I worked at Carolina's Medical Center doing temporal lobe lobectomy and brain mapping work with a group of neurologists and a neurosurgeon who helped people with epilepsy, and I totally fell in love with research. [laughs]

And I really loved the anatomy. It was just amazing – we would turn on the electricity and things would happen.... People would have fully formed visual hallucinations, speech patterns would start or stop. It was amazing to see, and, hopefully, the end result of this is that we were curing their epilepsy, or at least stopping their seizures, and not damaging healthy brain areas. And we did a lot of pre- and post-neuropsych testing, following patients for two years post-op, to see if stopping the seizures helped their cognition. So this was really fun stuff. And wonderful to see how people's lives changed for the better once the seizures stopped.

Part of the research that I really loved – and I didn't expect this at all 'cause I always grew up saying, *Oh, I hate math and science...* – was the statistics. Because, to me, statistics was the first time that you got numbers that actually meant something. It wasn't just some abstract, arbitrary problem you were working. It was like, "This means you have an effect... It means something!" And I thought that was really cool, and that got me really excited. So that's when I started on my track of *Oh, I'm going to do an MD/PhD, and I'm going to go into either neurology or neurosurgery, and I'm going to do neuroscience, and dahdahdah...*

And then I was on full-steam ahead – don't think, don't move, just do. 'Cause I had it mapped out – I think I was gonna be 45 before I had my first job, so I was like, *Oh my God, I gotta get going! I'm in a hurry!* [laughs]

Looking back, I think the real problem was I chose the wrong school. I didn't know how to choose a graduate school. So I went where they promised I could do a case-based learning program. Then I got

there, and they said, “No, no, no, MD/PhDs can’t do it because you’re different...” So I didn’t get the learning style that I wanted, and every time I tried to propose a thesis, no one could support what I wanted to do.

Every now and then I fantasize about finishing my MD/PhD, but I ended up leaving about half way through. In hindsight, I realize you need to choose a mentor and go work in that lab. When I got here to UCSF later on, I got so excited. There were like ten different labs I could work in, and I would love it.

Bad Design Bugged Me

But I left med school thinking I wanted to go to architecture school [laughs] and back to the design thing. Because I’d been doing some basic science research with rats – which, unfortunately, I’m not too happy about now as a vegetarian – and I kept thinking about what we could do to make the animals more comfortable... their IVs, how could the lab be designed better?

Bad design bugged me. And not just when it got in the way of getting the work done. I looked at hospitals and was like, “Ugh, they’re set up for nurses and doctors. They’re not set up for patients. They could be so much better.” And that’s how I got back to the design direction. But I got scared off by the drawing again! [laughs]

So I came out to California ‘cause I figured if I went back East I would just keep doing the same thing I had been doing with the same people I’d been doing it with, and I wouldn’t figure out what to do when I grew up...I had some family out here, I had a couple of friends. Other than that, I didn’t have a job, I just showed up with a duffle bag and found a job doing electrophysiology research. It was a nonprofit research foundation combined with a for-profit hardware/software company. I was always kind of a techie anyways, and that got me more interested in developing and testing software and developing the hardware that goes with it – that was during the first dot.com days – and so then I went off in the tech direction, then worked at public policy for a little while, then did freelance writing for a long time. Then finally decided I wanted a job where I showed up every day again. [laughs]

I Took a Funny Path to Get Here, But I Like That

I think it's 'cause I've done so many different things, and I'm interested in a lot of different things – that's why I have the weird position I do. I don't particularly like being pigeonholed into one slot. [laughs] It's funny, I will always laugh about applying for the job here. It was Joe Hesse who originally hired me. And he was like, "The job you applied for, you're not qualified for." I think he saw I'd be useful; I just wasn't useful in this specific job I applied for. It was like, "Okay, we don't need you there, but we do need you here" and then it was kind of like, "Well, what else can you do, since you're here?" And I appreciate him for humoring me. [laughs] It's been a really good fit. I've been really happy to be here. I feel like I've been able to do something, and it's been tremendous for me. I've met all kinds of wonderful people.

And I think I took a funny path to get here, but I like that I did that. Because that fact means that I have a lot of skills that other people don't have, because they took a more direct path. So I think there's some benefit to the wandering in the wilderness for a while. For some reason, neurologists, to me, generally seem to be people who have also wandered a little bit, done other things before coming into this path. I don't know why... I don't know if it's just an interest in the brain, and therefore you're interested in other things. But I feel like in neurology, people are more like, "Oh, well I was always interested in that and that and that, and then finally..."

Art is Highly Connected to What We Do

One thing that's close to my heart that I've been very involved with is, of course, the Hellman Artist Program. And I'm not sure if when I arrived here I would've said I wanted to do it; I sort of inherited it. But it has been such a pleasure. All the artists we've had here have been just amazing. It's been so fun. Through each artist, I've learned something.

I think art is highly connected to what we do. And yet, it's also tangential to what we do, and I kind of like that. I like the unexpected; I like being one of the only neurology units I've ever heard of that has an artist in residence program. I think that's really cool.

There's so much artists can do to help with stigma, and I know people with dementia have a lot of problems – even healthy aging people have problems with stigma. And with societal issues, where you're told, "Okay, back off, make room for the young people..." I just feel like we're missing out. People in other countries and cultures seem to revere their elders much more than we do here, and I think it's something this culture misses. There's a lot we could learn from each other. There is a great quote I heard – "*Magic happens when the young seek to understand the wisdom of their elders, and elders hold on to the explorer spirit of their youth.*" It just feels like we're missing out on what we have to give to each other. And both would benefit. I think artists have a tremendous ability to bridge that gap in a more accessible way.

There's also a film project we've been working on with the Tideswell program at UCSF. It's just been such an honor to be at these people's houses and hear them talk. I walk out of each one, going like... One was a husband/wife partner, and I'm like, "I want a spouse like that." And one was children and their mother/mother-in-law; "I want a husband and a daughter like that." [laughs] And the other ones are sisters, and I'm like, "I want a sibling like that!" I'm just amazed at how much they have to give, and how committed they are. They come from different places and different traditions, and they express it differently. They're all dedicated, but they bring a different spirit to it. With each interview, you just think that this person is so lucky, they have this other person who cares so much. And it's just neat to hear them say that yes, in some ways – I don't want to say it's putting your life on hold – but in some ways, it's not what you expected. It's not what you had planned for yourself, you expected to be off and doing this and that, and yeah, it's a big change, but it's also a chance for growth and development.

You Plan for Healthy, but You Have to Have a Plan B in Case "Healthy" Doesn't Happen

Being in this field of work, I definitely worry about the future, getting dementia. Especially with how little I sleep I get – one of the other problems of doing too many things... [laughs] But particularly, being a single person with no children, I worry about it. How do we take care of elders? Where does the onus fall? I guess traditionally you'd look

to your children or your spouse to take care of you... If you don't have children or a spouse, is the onus on you to find something? Or do you just get packed off to a nursing home whether you want to or not? Do you get to have any say in which one you go to?

My dream is to have a compound of little mini houses somewhere with a bunch of friends, where we all have our separate residences, but we're all right there so someone notices if you don't get up for a day or two [laughs], didn't make it to a meal or two, or something like that. The kinda deal where you have a community that may not be in your face, but just be aware of you. I feel like everyone wants to be as independent as they can for as long as they can, and with the highest quality of life. And so I have a deal with a friend of mine – one of my dear friends and a second cousin. We're like, "Okay, if we get to our 70s or so, we're going to move somewhere together and have adjoining houses [laughs], a little space for each other..." Come join us! All friends and dogs welcome!

When you think about the future, there's what you hope your trajectory will be, and you plan for healthy. But I think you have to have a plan B in case "healthy" doesn't happen... And especially if you don't have someone else who can then jump in and make decisions for you. But even if you do have someone that can make decisions for you, that's putting a lot of the onus on them, when your children or your spouse may not know exactly what you want. So the more you can spell that out and be clear about it, I think, the more helpful it is to everybody.

Translating Science into English

The drive towards clarity is at the root of what I do at the MAC. I have a passion for translating science into English. I don't mind if I don't know something, because I trust I can jump in and figure it out. So, whether it's Jakob-Creutzfeldt disease (CJD), frontotemporal dementia (FTD), or something else, it's okay. You start reading papers and a lot of those are very academic and very formal, and so I like that process of figuring out, "Okay, how do I re-say that in a way that's in English for people?" And I don't want to dumb it down. It's clarifying it by changing the style. Because the academic style is appropriate for the audience it's geared towards, but it's not appropriate for the general audience – it's

in a foreign language. And I always like supplying that original source, so if you're reading my interpretation of it, you can go back to the original and see if I did it right! [laughs] But if you don't wanna have to muck through that and think about it too long, you have, hopefully, the simpler-to-read version. That feels personal to me.

It's probably the same for me with design, too. Being in the print shop, standing there, making art – those are times that work feels very personal to me. When I did the portrait of Mr. Clausen downstairs, I hand drew that, and then split it into separate screens for each color, and was mixing the colors to make it... There's something about it. One, nobody else is around me, and two, nobody else can make these decisions. And there's a kind of a fun in that. "Does it look like him? Are the colors right?" It's my meditation, it's my work.

I'm big on the idea that every decision has a meaning behind it. I don't like things when things are just, "Eh, because I like blue..." Well, why do you like blue? Why is blue the right color for this? Or why is this font the right one for this, why this size, and why that margin? I guess they're questions that a lot of other people don't even think about, but to me, it matters. Is it readable? Is it the right size for this audience? What age is the audience that's gonna be reading it? Maybe you don't want to go smaller if they're likely to have vision problems. Maybe they're stressed out, so you want more white space around it so it's a calmer setting, you want a gentler font, rather than a purely modern or scientific font. There are choices you make that give a warmth to the words. And when someone likes what you've done, that means it resonates with them. It was useful.

I had a great dance teacher who said that a lead can be too strong and it can be too weak, but it can never be too clear. And I feel the same way with design and with writing – you can overstate something, you can understate something, but really what you're aiming for is clarity. People often don't understand that design isn't just pushing pixels around. Great illustrations can really clarify the content. You have visual people, you have verbal people, and sometimes it's a mixture of the two. Like, "Oh, I see these words, and I see that the pictures are great. And okay, I get it. I see that they're connected." So I think there's a lot of choice you can make. Some of it maybe is creating a brand, looking like it comes from UCSF, this comes from an authoritative place, I can believe it, it's not Doctor Google, you know....

And some of it's also that it's the right line length to read and there's the right amount of space so I'm not losing my place on the line... Particularly for people with posterior cortical atrophy (PCA). If they're having trouble following a long line, or if the lines are too tight together, they can't tell which line they're on... Ya know, taking things like that into consideration, designing specifically for people with neurodegenerative disease. Like if you have these sorts of visual problems, how can we create a book that you can actually read and enjoy? Or for our website, maybe the answer is more multimedia, more video instead of more text. Maybe that's the problem.

I got really interested in this when I first moved out here, and in projects that were helping people with disabilities to use computers and technology as a way to live independently despite... And I think that's a cool thing, whether it's a neurodegenerative disease, whether it's a lost limb, whether it's a lost sense. If we can design cool things so that people aren't limited, aren't left out of society because they can't do one thing... Who cares? Let's just find another way for them to do it! And maybe do it better than the "abled" way! [laughs excitedly]

I Just Never Want to Stop Learning

I would definitely describe myself as very curious. I'm taking another class now – I thought I just had to pay for it, but apparently I had to interview to get into it. I was describing all of the courses I had done recently, and I was like, "Yeah, I'm kind of a professional student." I think that kind of sums me up. I just never want to stop learning. Whenever I'm tired or worn out, that's what gets me going again, it's that, "Oh, wait, I can learn something new, and then I can use it here, here, here, and here." And it's fairly broad based, it doesn't really matter. I play a lot of tennis, and when I learn new things on the court, that can be really exciting. Oh yeah, that was a job before coming here [laughs] – playing tournaments. It's a very wandering path. [laughs]. And so I guess I would say curious and, hopefully, kindness. [laughs] And hopefully some generosity. Those are things at least that I aspire to. I'm sure I fall short a thousand times, but that's at least what I aspire to.

People Always Say I Laugh a Lot, Which I Love

People always say I laugh a lot, which I love. I have all these pockets of friends on my walk to and from work that I see everyday, and we all say hello to each other, and we don't know each other's names, and we don't even all speak the same languages. But we still all say hello, and we laugh, and we speak enough of each other's languages to share a moment. [laughs]

And I think that's nice. Life's short. Smile and be friendly, and you'll get through a lot just by that.

hear/say



It's a Very Important Role to Me

Narrator: *Helen Medsger*

Interviewer: *Jennifer Merrilees, clinical nurse specialist*

Helen Medsger cares for her sister Maureen Shaw who has dementia with Lewy bodies. Helen was also the primary caregiver for her parents who had brain disease. Helen is a passionate voice in raising awareness about dementia. Among her many activities, she serves as a member of the UCSF Memory and Aging Family Advisory Council. Maureen has had an impressive career as a medical social worker informing policy to improve the lives of others. Maureen served as program director for senior services prior to becoming the executive director of Catholic Charities of the Diocese of Santa Rosa. During her 27-year tenure, one of the many programs she founded was its Alzheimer's Respite Program, designed to provide day respite and relief to family caregivers. The respite program was renamed the Shaw Center for Memory Care in her honor. Helen and Maureen have a dynamic and intelligent presence. They are clearly devoted to one another. They have given a lot of their time and expertise to the Memory and Aging Center, including sharing their story with hear/say.

My name is Helen Medsger, and I am the younger sister of Maureen Shaw. I've been designated, for the last twenty-five years, as the family caregiver. I was living in Sonoma County when first my sister and her family, then my parents, moved here. In 1988, my father starting exhibiting symptoms of parkinsonism and, shortly thereafter, he was diagnosed with a related dementia. Fast forward to 2002, and we started noticing symptoms in my sister. These were at first dispelled. You know, she was in her early fifties, menopause, depression – maybe. But we discovered in a few months that it was probably Parkinson's disease and, soon, we knew it went beyond that. She had a very high level executive position and she was having difficulty in her role. She asked for my help, "Sis, I need help. I'm having difficulty kind of sifting through what the physicians are saying." And it's been over ten years

that I've been, not only her sister, but her medical power of attorney and health care advocate. It's a very important role to me.

Maureen and I have always been close, but this takes it to a whole new level. There's a level of intimacy that goes along with it. In the early stages it was her fears. Fear that, "I'm losing myself, who I am, my essence. I don't want people to remember me as a demented person." So we have really strived to keep her involved and engaged. She sat on corporate boards, and she is still allowed to go and listen. While she can no longer vote, she can enjoy that type of competitive arena. And she still shines in it.

We make sure she stays very engaged socially. We have family friends that come and take her to church. She sings in the choir, when she can, although her role has changed. She is no longer a lead, no longer a cantor, but she can certainly be one of the chorus. And those days mean everything to her. So, part of my role is to be certain that those things continue for her as long as possible. I know many people want to shut their loved ones away once they have a diagnosis, and I'm really opposed to that. It not only destroys who they are, but it will cause their disease to really take over because they lose their sense of self. The other thing we do is humor. It's significantly important.

I'll never forget, we were signing her POLST (Physician's Order for Life Sustaining Treatment), and because of her slow processing speed, it took three 2-hour sessions. There was family input, there was social worker input, and I, being her sister and not the immediate legal family, sat and was the fly on the wall. The social worker asked her, "Maureen, what is most important to you? What does this journey mean to you?" And she said, "Well, this is about my end-of-life decisions. What is important now is my time with them [family]." And so the social worker went around the room and asked each of us what was important. And when they got to me, I said, "All I want each day for her is the opportunity for her to smile. If I get a smile and, better yet, if I get a laugh, then that's the best gift I can give her." And I've strived to make it as much about the individual as possible. Surround them with those that love them. Make it a village, whether it be family or friends or someone on the street.

I don't have the final say on how others are going to impact her. I've learned to let go. In the beginning, that was a very difficult thing to do, knowing that she was in a situation that might bring her

distress and possibly ruin her day and that we might have to deal with ramifications, physically or emotionally, over the next few days. I still have to allow it to happen because those are her choices.

I'll give you a very good example of a very stressful situation for her. This was approximately seven years ago. It was right after our first very successful trip down to UCSF. We had met with Dr. Geschwind and his team. And for Maureen, it was a very long day. There was a twenty-page report, and Dr. Geschwind's team had forwarded it to her physician, her neurologist in Santa Rosa. So we scheduled a follow up with the neurologist. We arrive at the appointment, and I know he's had the report for several weeks. He looks at me and says, "Why are you here? You aren't due for an appointment." And I said, "Well, there's a report from UCSF that needs follow-up. Have you read it?" "No, it's in my inbox." "Well, I have the report here if you want to look at my copy?" And he said, "No, I'll get mine." So he went and he came back. He started looking at it but he was getting unhappy with the fact that it was a twenty-page report, and he was being put on the spot. So, I looked at him and said, "Turn to page 17, that's where it gets really good." The physician proceeded to comment, "Oh my goodness, this is awful. Oh my." And you could see Maureen's eyes, terror welling up in her. I just grabbed her hand, and he said, "Well, I don't know how to respond." And just cast the report aside. I said, "You know what? When you've had more time to review it, we'll come back." So we walked out, and I looked at Maureen and said, "Well, what did you think of that appointment?" Her response, "I don't like it, Sis." I said, "Would you like to find another physician here?" Her response, "Yes, I would." So, I said, "Okay."

And that was our first step forward in trying to mitigate some of the negative energy that sometimes health care systems can present. We've had different kinds of interesting appointments. I try to advance plan, whatever it is. I plan a week in advance. I talk with her. "How are you feeling? These are the items. We need to boil it down to a couple of issues, so what do you think?" I try to give her as much choice and leeway as I think she's capable of. I make a list. I review it with her, and then I also review her meds in advance; that's absolutely critical. So when we go in, I have a laundry list for the physician: "Here are her current meds, our current complaints we'd like addressed today." And, previously, I had done this for my mother and my father. In my mother's case, who had a cerebral damage from an aneurysm, she

wanted it to be social time. “Let’s just talk with the doctor! How are your children and this and that.” When we had a huge variety of things to cover, I would fax a list in advance, so the doctor knew these are the things we need to discuss. It helps to keep the appointment on track which is mutually beneficial for the family and the physician.

Sometimes, Maureen and I disagree. We’ve had those kinds of discussions. We try to argue them out before we get there. And, if the doctor already has the list, he can redirect. Normally, we don’t argue too much. Now that she’s under 24-hour care, she will say, “Well, you’re on their side.” [laughs] That’s the one time she’ll kind of get me. And I’ll try to explain to her that the bottom line is her health and safety. But she knows that as long as she can, she’s a part of the decision-making process.

Words are Full of Air, But They're So Much More Meaningful

Narrator: *Isabel Hubbard*
Interviewer: *Anna Milter, Writer*

Isabel Hubbard, PhD, is a speech language pathologist at the UCSF Memory and Aging Center (MAC). She has been conducting research and evaluating patients at the MAC for two and a half years.

Yesterday

I recruit participants who come in for their evaluations through the Memory and Aging Center, and I work particularly with those who have trouble with language: they have primary progressive aphasia.

So yesterday, I had a consult with one of our upcoming participants for his consent to participate in our treatment study for naming. He's going to be receiving treatment via distance, so we practiced downloading the software that he'll use to videoconference with the speech pathologist. We met with the speech pathologist he'll be working with because he's bilingual, and she will provide treatment in both languages. Though I'm not that person, it helps because we got to meet in person and walk through the steps, to be sure he could execute them when he moves back to Dubai so that he's able to receive treatment.

That actually took surprisingly a long time, but I think he'll step up just fine. Maybe a little counseling 'cause he's still having trouble with understanding his diagnosis and understanding that... it's rare. His particular problem – semantic variant primary progressive aphasia – is rare, but not so rare that I've never seen it before.

And so there was a little bit of talking about different treatments approaches. You know, most people are looking for a medical intervention, and during the consent we had to talk a lot about how speech and language therapy is therapeutic, but that it doesn't actually intervene against the disease process. So I sort of explained this one way, and then had to explain it again, because he'll ask a question that's very similar, and we just kinda come right back to, *this is the best thing that you can do*. When you're taking good care of your body physically, you're engaged in your community, and you eat right, this is the only thing that's kinda left for us to do.

A lot of people ask about what the cause is. They're looking for a causal relationship, so if they fell down once and bumped their head, is that what it was? I just told him that we don't know why it happens and that it's actually something very small that misfires, that begins sort of a cascade. It's been a long time since he's first noticed his symptoms, but you know, he still has a very long time.

Optimism

I had a phone conversation with a caregiver, one who's starting a treatment study with me this month, and he is really unsatisfied with research and with the amount of time that it takes to initiate it. I explained it to him and he seems to understand, but he's frustrated 'cause he's seeing his wife change. He's a businessman, so he's a very proactive kind of person, and he just says, *When are the drugs gonna be available? When is the next thing gonna be available?*

I told him that we're optimistic and that we're moving forward, and that our biggest concern is to keep people safe. But he said to me, and it sort of stuck with me, he said, *How do you do this everyday? You seem like a really optimistic person and a happy, cheerful person. How do you do this? Well... I don't know, but the only thing I can be for him is optimistic, I imagine. We have to keep looking forward and strive together. Not everybody's gonna be satisfied with the process, but it's the best we can do.*

Action

I think that people really like the idea that there's something they can do. As the person who is coming in with a protocol, with a plan and a way to initiate it, I really think that just having something to implement and something to strive for provides relief to the caregivers and to the participants. Even if they know there's a limit to what speech and language therapy can do, we hope to maintain intact qualities for as long as possible. We're not able to stop the progression of the disease, but it's something to do. It's a plan and it's written down, and people have looked at it and they say, *Okay, that's good*. It's a way that people can be successful.

We build treatment very much based off of moving into a direction where we see what's wrong, and we support the function that's impaired. So for participants who are having trouble naming, we provide support by teaching them to access spared functions. For people who have logopenic progressive aphasia, they have intact semantic processing, so we say, *Well, tell me about it*. And they can use that description – that intact ability to describe objects and to put it into context – to help make the word retrieval a little more robust. It's just providing a little more richness. Does it take a little more time? Yes, but are they still able to retrieve words often? Yes. And so, the treatment provides some success.

People

Not long ago, one of our participants who's been here many years, his oldest daughter had just gotten engaged, and they set the wedding so far in advance that I really worried about his ability to participate as the father of the bride. And not just me, the entire team. In our family conference we talked about the amount of time and where things were, and although it was still a year away at that point, they moved the wedding up maybe six or seven months.

I spoke to the wife of this gentleman two weeks ago, and she said, *This is the weekend our daughter was to be married before we moved the wedding*. She said if they had kept the original date he probably wouldn't

have been able to participate like he did. He gave a really nice toast that we worked on very hard for months, and it's different than the toast he might have given if he wasn't having trouble speaking. But he still got up there and said some lovely sentences about his daughter and her new husband and their new family. And he worked on it for months, which I think says so much more than just those 11 sentences. He probably practiced for five months, and she just said, *I don't think he would've been able to give the toast*. I don't know how true that is, but just hearing her say that... it's not a happy story, but she *has* a happy story.

Meaning

My sister was working for Frito Lay, and she's logistics, so she was talking about how to get this truck there and this truck there in the most efficient manner. She's not at this job anymore, but she said, *At the end of the day, I ship mostly air... in bags of chips*. And I guess I go home feeling really good about what I do. Words are full of air, but they're so much more meaningful!

Dementia sucks. It sucks! Nothing good about it. But I've also seen really beautiful things come from it. It takes struggle sometimes to bring people together. I've also seen not so positive things, but you know, hopefully the good outweigh the bad. [singing] You take the good, you take the bad, you take them both and then you have the facts of life!
Do you know that song?

Thou Nature Art My Goddess

Narrator: *Geoff Hoyle*

Interviewer: *Caroline Prioleau, Writer & Designer*

Geoff Hoyle was the fourth Hellman Visiting Artist at the Memory and Aging Center from 2013–2014. He is an actor, comedian, mime, and writer. He moved to the Bay area from his native England and worked with the Pickle Family Circus as Mr. Sniff, the Clown. He has been performing his own material and working in various productions of plays at various theaters throughout the country and occasionally appearing in film and TV.

Stripping Down

The best part of performing for me is people clapping and laughing. Making people laugh, making them feel part of a group, as opposed to a series of individuals of, “Am I gonna like this? What is it? Is it over? I don’t know.” At the end, you know if the show’s gone well and the material has had some bite to it, it’s almost, not quite religious, but there is a transformational effect, a shamanistic effect when it works.

Every night is different, and every night is a challenge, and every night is a seduction, a conspiracy. Bringing the audience to see things the way I’m seeing them and having them understand if it’s accurate, “Ah yes, that’s true, and thank you for making us feel that we all have the same feelings about or perceptions about certain things.”

I think comedy is a stripping down. It’s a leveler. And it makes the audience feel that we have a shared, common humanity and a shared dilemma, which is that we’re animals, mostly. Regardless of whether we’d like to think of ourselves as highly developed and civilized and intellectual, intelligent beings. It’s hard to corral the id, the nature of the seven deadly sins, and to expose the fact that that is the case and

admit it and say, “Okay, share that. We agree. We work. We’re beasts, and we’re all gonna die.”

What do we do about that? How do we make that not war, poverty, various forms of discrimination, privilege, lack of opportunity? How do we mitigate those? Because no one has any greater right. We should all have the same opportunity. And comedy, I think, sort of points that up. And when people laugh, it’s the laughter, hopefully, of recognition.

So, I see my work as having social import. Not that I’m going to change the world massively, but it’s an illustrator, in the same way that a good cartoonist can do that and a commentator. And now that we, we’re losing the press and the public comments, it’s good to have people point this out. And great comedians can do that.

Absurdity

The mask of comedy and the mask of tragedy are always next to each other. They’re two sides of the same coin. And without the tragic mask, the comedy doesn’t work. And without the comedy, the tragedy is too overwhelming. I sit somewhere in the middle, which is perhaps absurdity. So that some things are hilariously funny, but at the same time contain tragedy. And tragedy is awful and depressing and, at the same time, it’s comedic, because it’s so ridiculous. So there’s something kind of absurdly funny about Hamlet’s death, you know? And there’s something absurdly funny – not laugh out loud – about King Lear’s death. Why does he have to die? And we know that for 200 years, the ending of King Lear was rewritten to make it into a happy ending, and people bought this for 200 years. And then people said, “No, it’s not true. It doesn’t have the truth to it. It doesn’t tell us anything.”

The Acceptance of Uncertainty

One of the things I used to do at the Memory and Aging Center (MAC) was come in and be a fly on the wall, allowed to take notes at people’s, discretion and the attending physician’s discretion. I used to look at patients and study them very carefully, and I would draw them while I was there. I’m not a brilliant drawer, but I actually captured some

of the feelings on the faces that I was observing. Then I'd run into the bathroom, and I'd look at myself and try and reproduce their facial expressions.

I remember there was one man who had frontotemporal dementia, and his face was a map of his feelings in contradiction to what he was saying. And when he thought of his past work life, he was fine and open and jolly. But then when he talked about what was happening now, his face became confusion, pain, depression, loss. And I just found that was riveting.

Similarly there was a man who had...I forget what it was. But he had this smile where he bared his teeth. And it was frightening, and I said, "That's the face of Edmund in King Lear. That's the villain."

I mean these are broad generalizations, but I could see how what was on his face was not mirrored by what he was feeling. "Thou nature art my goddess. To thy laws my services are bound." I was entranced by the ability to imitate, not my ability necessarily, but my attempts to imitate these faces, these postures, these vocal tones, which were not "normal." They were often in direct opposition, peculiarly – not really comically – but, surreal. What you're getting is not what they're giving, and things are offkilter. It's fascinating and it's disturbing. One of the main things I felt was just an enormous sense of gratitude that people would allow me to be part of their situation. This is not only the patients, some of whom had no clue that I was even there, but also the caregivers, who were so gracious and so hungry for any kind of support, conclusion, conclusiveness.

Another time, the daughter says, "There is something going on here." The patient says, "I'm very happy," but finally starts a massive crying phase, great distress, which can almost immediately clear to zero. This is the pseudobulbar affect. Lear says, "You think I'll weep. No, I'll not weep. I have full cause of weeping, but this heart shall break into a thousand flaws, or 'ere I'll weep." Shakespeare may be talking about the pseudobulbar affect there, or maybe he's just observing, the way I did. So, I don't know whether I was of any use to the folks who were carers. [sighs]

One of the most disturbing patients was examined by Joel Kramer. The patient's wife was there. She had just been diagnosed with cancer. I mean, it's like, "Pile it on," you know. "Thank you, God. That's another one of your jokes. Are you having a laugh? Is God having a laugh?"

The man had stopped responding completely, and they ran a series of tests. Nothing worked, even the most basic thing. And I said to Joel, “What’s going on? What is that?” And he said, “I suspect prions.” So it was the very end of Creutzfeldt-Jakob, and it was affecting his brain.

I came back later that month, and Joel was there. I said, “Joel, what happened with this patient?” He said, “He died in two weeks.” I just was stunned by that. It was frightening, and I just felt such an outpouring for his wife. She had no clue. She said, “I can’t get him to respond. I don’t know what’s going on. This has happened in the last few weeks.” And it was so heartbreaking.

There were times when I’d come out, and I’d just want to cry, because these people were in the thick of it, and thank God for the Memory and Aging Center, because that was one of their main resources.

At a conference that I went to, which I understood about one-eighth of what was being said, Ira Lesser, a speaker, said, “There is wisdom in the acceptance of uncertainty,” and I thought, “Whoa, I can use that in my own life.”

The Greatest Unused Social Scientist

A very carefully honed observational sense is one of the prime tools an actor uses to create a character, coupled with an actor’s training to reinvent the feelings of someone they’re trying to perform as a character, based on observation. And not only reinvent the feelings, but also reinvent the physical life and the mechanism they use to speak, so that you begin to reproduce the placing of the vocal mechanism, which is lips, tongue, teeth.

Clive Barker, my mentor, would say things like, “I’ll go to my grave believing that the artist, the actor, is the greatest unused social scientist we could ever have, because the actor is able to embody various states and recreate them.”

Acting for me, with his influence, was always about, “How do you reproduce the processes which are going on in the body? The mind, the feelings that engender this expression, whether it’s silent or through speech, or through heightened speech, as in Shakespeare – carefully crafted iambic pentameter or prose?” And how do you enliven that and make people feel, “That’s right. That’s accurate. Yes, I get that,” and

put it in a context where you're not just swallowed up by the emotion, which is what Bertolt Brecht always wanted *not* to happen – that you actually observe the decisions that people are making, and the cause and effect, and their personal interests, so that history is changing.

As Brecht said, “Philosophers have always tried to explain the world. The point, however, is not to explain it, but to change it,” and acting can show why things need to be changed, why things have not changed, why things might change. And so in a selfish way, watching these patients and families at the Memory and Aging Center served me as material. But at the same time shocked me, because they're not playing by the regular rules, so my interest in plays about madness or so-called madness happened to intersect with my becoming a visiting artist here at the Memory and Aging Center.

I was working on King Lear, who supposedly is mad, or goes mad, but maybe all that madness is explicable both in terms of social pressure and the fact that he's 80 years old. “I'm a very foolish fond old man, fourscore and upward.” He doesn't even know how old he is, but he thinks he's over 80. Maybe some mild cognitive impairment? Maybe prions? Maybe frontotemporal dementia? Certainly some plaque. He doesn't remember things. “I think this lady to be my child, Cordelia.”

Jubilado

Things change. You need security. Life changes. And even though I am The Boy Wonder, I don't go up Twin Peaks as fast on my bike, and I'm not necessarily wanting to act that much, except if I really want to. And it's been hard making that transition into... I don't want to call it retirement, because I'm not retired. It's a bad word. The Spanish is *jubilado*. It means *jubilated*. A friend calls it “the harvest years,” as opposed to *retirement*. To pull away from, in French: *la retraite, retreat, retirement*. It's a different kind of engagement. It is definitely a pulling back that I'm experiencing, but I'm going deeper into other things, you know. Grandchildren, children, a lot of more reading.

I miss the artist program. It was a whole new world, in terms of not only all the research and the nomenclature, and the science of it, which is completely fascinating and totally overwhelming, but the idea that there's this interface and overlap between the arts and science, and

this is an interesting idea that there would be visiting artists who would come in and talk to patients and create something specific, and also just have it be something which influences in a general sense.

I want us to get back together, and say, "Is there more?" I don't know how useful I was to these folks. I was there, and I observed and I felt huge outpourings. I'd tear up at the end of sessions sometimes, just because it's such unknown territory and hopefully will become much more familiar to everybody.



Siempre Nació en Mí Cuidar de Personas que Me Necesitan, Y Siempre lo Hice de Corazón

Narrator: *Eugenia Garcia*

Entrevistador: *Yessenia De la Vega, coordinadora de investigación*

Traductor cultural: *Thalia Leon, coordinadora de investigación*

(Story follows in English)

Eugenia Garcia es paciente del Hospital General de San Francisco y la conocí por medio de su doctora de cabecera Anna Chodos, quien también es doctora de su suegra. Eugenia es muy persona muy simpática y alegre; cualquiera puede fácilmente pasar horas hablando de la vida con ella. Ella me contó que recién le diagnosticaron cáncer por segunda vez, pero ella se muestra positiva y con muchas ganas de luchar. Eugenia y su suegra fueron la primera familia a la cual inscribí al estudio clínico Care Ecosystem del Centro de Memoria y Envejecimiento, UCSF. Eugenia piensa que Medi-Cal es una bendición para las familias de bajos recursos como la de ella, y como en agradecimiento como pago, ella siempre está dispuesta a colaborar con la ciencia y más proyectos. Ella dice que gracias a los beneficios que su suegra recibe, ella puede recibir un cuidado digno que toda persona merece en los últimos días de vida. Eugenia lleva trabajando como cuidadora de ancianos y personas enfermas ya por muchos años; ella refiere a lo que hace como una carrera con vocación.

“Nunca creí que mi historia fuese algo interesante”

Mi nombre es Eugenia Garcia y cuido de mi suegra que está diagnosticada con Alzheimer's por más de cuatro años ya. Yo nací en El Salvador, pero mi familia viene de Guatemala y vine a este país cuando

tenía 19 años, en 1986. Mi niñez nunca fue fácil. Mientras crecía, mi país pasaba por una guerra civil y había mucha muerte alrededor. Como soy hermana mayor de siete, tuve que empezar a trabajar desde muy temprana edad para ayudar a mantener a mi familia. Mientras crecía, me acuerdo que siempre quise estudiar enfermería, pero la escuela no era una opción para mí. Mi madre no tenía dinero para educarme, y al contrario, ella me apuró en conseguir un trabajo y poder ayudar al resto de la familia. Mi sueño desde niña siempre fue ser enfermera, pero para ser honesta en esa época las enfermeras sólo lidiaban con pacientes muriendo por la guerra civil y creo que yo nunca hubiera podido hacer eso. Ahora veo la muerte de diferente manera.

Cuando llegué a Estados Unidos lo único que hacía era trabajar para poder mandar dinero a mi familia en El Salvador. Logré pagar la carrera de un hermano que ahora es cirujano y de otra que es enfermera. Nunca creí que mi historia fuese algo interesante. Siempre nació en mí cuidar de personas que me necesitan, y siempre lo hice de corazón.

En ese entonces también aprendí que este es el país de las oportunidades, que los sueños se pueden alcanzar. Me acuerdo que yo todavía no tenía la residencia legal, mis papeles migratorios seguían en transición, pero encontré una escuela que te entrenaba para ser asistente en enfermería. Yo tomé todas las clases, aprendí mucho, pero no pude graduarme. Todavía me acuerdo aquel día cuando perdí mi examen de licenciatura en Sacramento, mi estatus migratorio todavía no me permitía graduarme formalmente.... y la verdad nunca lo pude hacer.

“Todos somos libre de expresarnos libremente con tal que no ofendamos a nadie”

En esa época cuando recién me acostumbraba al ritmo de este país y sólo trabajaba para mandar dinero a mi familia, conocí a un ángel. Una señora que me enseñó muchas cosas positivas de la vida. Ella ya vivía en este país por muchos años y tenía mucha experiencia con el sistema y el ritmo de la gente acá. Me acuerdo que ella me llevó a una iglesia, a la cual sigo yendo hasta ahora, y en donde conocí a mi esposo. Tengo muchas buenas memorias de esta señora. Recuerdo que un día ella me dio unos consejos para “poder sobrevivir en este país”: que nunca discuta por política, amor o religión (sonrisas...) ¡Hasta ahora practico los consejos que me dio mi ángel! También aprendí que en este país todos somos libres de expresarnos de la manera que queramos con tal que no ofendemos a nadie. Eso no es muy común

en mi país, o por lo menos no lo era cuando todavía vivía allá... ¡Me acostumbré muy fácil a eso!

“Como en muchos hogares Latinos...”

Nosotros somos una familia humilde. Mi esposo y yo trabajamos en dos trabajos para poder sobrevivir y pagar nuestros gastos. Mi esposo trabaja en las noches y yo durante el día, hay días que no lo veo. Él es muy bueno conmigo, siempre lo fue, aunque hay veces que él no ayuda mucho en casa, pero es porque trabaja mucho y también está enfermo. Mi día a día es muy ocupado. Nosotros tenemos tres hijos, pero sólo uno vive en casa. Yo tengo que despertar muy temprano y preparar el desayuno para él y mi suegra. Mi suegra necesita mucha ayuda, ella está alcanzando la etapa final de su enfermedad, y es como otra bebe para mí. Después me voy a trabajar, y en la tarde corro de vuelta a casa para preparar la cena y limpiar. Yo trato de tener un día libre solo para mí, o por lo menos unas horas libres para desconectarme de todo, muchas veces son los martes. Después que mi hijo se va a la escuela, mi suegra al centro de adultos mayores, y mi esposo a dormir después de trabajar toda la noche, a mí me encanta salir y manejar por el Distrito de la Misión, el barrio de los Latinos en San Francisco. Ahí mismo voy de compras, hago mi lavandería. Mientras lavo mi ropa, me gusta ir a un café para conectarme con mi familia, ponerme al día con mi Facebook y las nuevas fotos que todos comparten (sonrisas...).

Viviendo con mi suegra

Desde hace ya casi diez años que mi suegra mostró síntomas de la pérdida de su memoria. Yo siempre adopté a la mamá de mi esposo como la mía, y siempre estuvimos encargados de su cuidado. En ese entonces ella vivía en El Salvador y nosotros solíamos mandar dinero para su cuidado, medicinas y más. Hace ya unos cuatro años cuando visitamos El Salvador es que nos dimos cuenta que ella necesitaba mucho más cuidado y decidimos traerla a casa y asumir la responsabilidad de cuidarla en mi hogar. Mi casa no es grande ni mucho menos tiene las facilidades que ella pueda necesitar, pero mi

esposo y yo sabíamos que ella estaría mejor con nosotros acá en casa y con personas que la aman, que en El Salvador con extraños. Ahora vivo con mi suegra, velo por ella y hago todo lo posible por que tenga una vida digna. Yo trabajo como su cuidadora de IHSS, pero yo no lo hago por dinero, lo hago porque sé que no hay nadie más que lo pueda hacer como yo. Es más, el dinero que recibo por cuidar de ella lo guardo para pagar el nicho en donde ella será enterrada. Nosotros queremos que sus restos estén cerca de la familia, y los gastos funerarios en este país son muy caros... También mi religión no permite que la crememos, la tenemos que llevar a un cementerio y rendir homenaje por siempre.

No mucha gente puede hacer lo que yo hago

Yo sé que no es mi obligación cuidar de mi suegra, pero lo hago por que ella es madre de mi esposo, y yo amo a mi esposo. Yo estoy muy agradecida hacia ella por haberlo traído al mundo. Ella es como una madre para mí, y nosotros la cuidamos por que es correcto hacerlo. Todos los días yo la limpio, le doy de comer y la baño. Yo no hago esto por dinero, lo hago porque yo escogí hacer esto por ella. No mucha gente puede hacer lo que hago por una suegra. Por ejemplo, para que ella tome sus medicinas todos los días es casi una aventura diferente. Algunas veces yo misma me sorprendo cuan creativa puedo llegar a ser. Para que ella se bañe es otra historia. Hay algunos días cuando yo tengo que bañarme con ella. Recuerdo que una noche ella tuvo un accidente durante la media noche, yo no podía dejarla así toda la noche, entonces decidí que las dos nos bañaríamos juntas. La única manera en la que ella puede bañarse sin hacer problemas es con música, a ella le encanta escuchar música mientras se asea. La música ha sido y es una gran ayuda. Cuando estamos solas en casa, me encanta poner música ¡a ella le fascina! Las dos bailamos y cantamos ¡especialmente los domingos! Cuidar de ella no es muy fácil, hay días que se muestra con diferentes estados de ánimo, hay veces que ella me grita, y otras que no quiere comer; pero yo descubrí que la música es la cura en ella para todo. Yo siempre tengo que tener la aplicación de YouTube lista en mi teléfono para calmarla y poder terminar nuestras tareas.

Siempre Nació en Mí Cuidar de Personas que Me Necesitan, Y Siempre lo Hice de Corazón

I Have Always Considered Myself a Caregiver at Heart

Alcanzando un Sueño

Yo sé que hoy en día no soy una enfermera de profesión pero la vida me dio la oportunidad de alcanzar mis sueños y poder cuidar de gente que me necesita.



I Have Always Considered Myself a Caregiver at Heart

Narrator: *Eugenia Garcia*

Interviewer: *Yessenia De La Vega, research coordinator*

Cultural Translator: *Thalia Leon, research coordinator*

(La siguiente historia es presentada arriba en
su transcripción original en español)

Eugenia Garcia is a patient at Zuckerberg San Francisco General Hospital. I met her through her primary care physician, Dr. Anna Chodos, who is also Eugenia's mother-in-law's primary care physician. Eugenia is a very friendly, happy and approachable person. She told me that she was recently diagnosed with cancer for the second time, but she is very positive. Eugenia and her mother-in-law were the first people I enrolled in the Care Ecosystem Study at UCSF Memory and Aging Center. Eugenia thinks that Medi-Cal is a blessing for low income families like hers, and since Medi-Cal pays for her care, she is more than willing to participate and contribute to science. She feels grateful for the benefits that her mother-in-law is receiving, because it allows her to receive the care she deserves approaching her final days. Eugenia has been working as a caregiver for many years and refers to her work as a career with a purpose.

I Never Thought my Story Would be of Interest to Anyone

My name is Eugenia Garcia and I've been caring for my mother-in-law for more than four years. I was born in El Salvador, but my family originates from Guatemala. I came to this country in 1986 when I was 19 years old. My childhood wasn't easy; El Salvador was facing a civil war at the time. People were killed daily. Being the eldest of seven I had to work at an early age to provide for my family. Growing up I always

wanted to be a nurse, but school wasn't an option for me. My mom couldn't afford to pay for my education; she encouraged me to get a job and support my family. To be honest I don't think I would have been able to deal with all the death nurses had to face at the time. I see death differently now.

When I came to the United States I worked really hard to send money to my family in El Salvador. I was able to put my brother and sister through school. My brother is now a surgeon and my sister is a nurse. I never thought my story would be of interest to anyone. I have always considered myself a caregiver at heart.

I learned that this country is a place filled with opportunities and that dreams do come true. I remember when I first got here and I wasn't a legal resident, my papers were still being processed, but I found a school for nursing assistants. I took all of my classes, I learned a lot, but I never graduated. I still remember the day that I missed my final exam in Sacramento; because of my immigration status, I wasn't going to be able to graduate.

We Are All Free to Express Ourselves as Long as We Don't Hurt Others

I met an angel. She was a woman on the street who taught me to have a positive outlook on life. She had been living in this country for many years and had a lot of experience with the system and way of life here. This woman introduced me to the church; it's the church where I met my husband and that I still attend today. I have very fond memories of this woman. She gave me a piece of advice in order "to survive in this country": never argue over politics, love or religion [smiles]. I still follow my angel's piece of advice. I also learned that we are all free to express ourselves as long as we don't hurt others. This freedom of self-expression isn't very common in my country, or at least it wasn't when I was living there. I adjusted to this idea very quickly!

Like in Many Latino Homes

We are a hardworking family. My husband and I both work two jobs to survive and pay our bills. My husband works nights, and there are days where I don't see him. My husband is very nice to me, he always has been. There are days where he doesn't help me much around the house, but that is because he is sick and works so much. My day-to-day life is so busy. We have three kids, but only one of them lives at home. I have to wake up early every morning to prepare breakfast for my son and mother-in-law. My mother-in-law needs a lot of help; she is approaching her final stage in the disease, and it feels like I am taking care of another child. After I prepare breakfast for them I head over to work and come back in the afternoon to prepare dinner and clean the house. I try to have a day for myself, or at least a few hours to myself, so that I could disconnect myself from everything. It's usually on Tuesdays. I love to go out and drive around San Francisco's Mission district, also known as the Latino cultural district. I can only do this once my son is in school, my mother-in-law is at her adult day program and my husband is fast asleep after a long night of work. I love to do my laundry and go shopping there. While my clothes are in the wash I like to go to a café and connect with my family, get up to date with my Facebook notifications and see all of the pictures my friends share [smiles].

Living with my Mother-In-Law

My mother-in-law has been showing signs of memory loss for over ten years. I always viewed my husband's mom as my own, and we have always been in charge of her care. At the time she was living in El Salvador, and we would send money over for her care and medicine. About four years ago we went to El Salvador to visit her. It wasn't until we saw her in person that we realized she wasn't getting adequate care, so we decided to bring her back home with us and take full responsibility for her care. My house isn't big, but my husband and I know that she is better off here at the house with us, surrounded by people who love and support her, not like in El Salvador living with a bunch of strangers. I live with my mother in law now and do everything

that I can so that she could have a comfortable life. I work as an In-Home Supportive Services (IHSS) worker, but I don't do it for the money, I do it because I know that there is no one who will care for her like I do. To be honest, the money that I receive from caring for her I save for her funeral expenses. We want her remains to be close to the family, and funeral expenses are very pricey. Also my religion doesn't allow us to cremate her; we have to take her to the cemetery to have a proper burial.

Not Many People Can Do What I Do

I know that I don't have to care for my mother-in-law, but I do it because she is my husband's mother, and I love my husband. I am grateful that she brought him into this world. She is like a mother to me, and I take care of her because it's the right thing to do. I clean her, feed her and bathe her every day. I don't do this for the money; I do it because it's my calling. Not many people can do what I do. Having her take her medications is quite the adventure; I surprise myself at how creative I get. Now bathing her is another story. There are days where I have to shower with her. I remember her having an accident during the middle of the night; I couldn't leave her like that so I had to get in the shower with her. The only way I could get her to take a shower is with music; she loves listening to music while in the shower. Music has been a great outlet for us. When we are alone, I like to put on music, and she loves it. We both dance and sing, especially on Sundays! Taking care of her isn't easy, she often has mood swings, there are times where she yells at me and doesn't want to eat, but I have found that music is the cure for it all. I always have YouTube readily available on my phone to calm her down and help her complete our tasks.

Pursing my Dream

I know that I may not be a registered nurse, but life has given me the opportunity to pursue my dream in caring for people in need.



Blessed to Do What I Do

Narrator: *Cindy Barton*

Interviewer: *Daniela Kortan, research coordinator*

Cindy Barton, RN, NP, is a geriatric nurse practitioner at the UCSF Memory and Aging Center and holds an Associate Clinical Professor position in the UCSF School of Nursing. She is involved in assessing patients and helping patients and families manage behavioral symptoms associated with dementia.

I Was Fascinated by Their Reality

No one in my family had ever worked in health care. I have no idea why from the time I was little I wanted to be a nurse. But my very first job, when I turned sixteen, was in a nursing home taking care of people. That was many years ago at a time when there wasn't a lot of regulation or training requirements. So, basically, I got the job, someone showed me how to give a bed bath, and they put me to work. And it was with very little supervision.

I usually worked on the ambulatory unit, and the majority of the patients on that unit had dementia or some type of cognitive impairment. I didn't understand it at all, but I was fascinated by their reality and the way they each saw their world. It wasn't until much later when I went back to graduate school that I really decided that I wanted to do geriatrics and that I really wanted to focus on dementia. So, it took me a while to get there, but it really was that first job and my exposure to those patients that made me want to pursue a career in this field.

Even if We Can't Help

I truly feel blessed to do what I do. I think it's really a privilege to be let into people's lives the way that we are. For them to share the things

with us that they do and for us to be able to, even if we can't help – at least accompany them on their journey. To be there for them to talk to, or to cry to, to be angry at. All of those things happen. And although at sixteen I really felt like this was an amazing disease and an amazing group of people that I wanted to work with, I could never foresee it being this rich and this rewarding.

A Huge Wave

I think it's wonderful that we're really focusing now on early identification, early diagnosis, and early intervention. The focus of intervention trials are increasingly targeted toward early in the neurodegenerative disease process. But we also know from the research that the course is very long, and I worry that there's a whole group of people that are being left behind, who are still going to require care. These are people who still need to be the focus of different types of interventions and research. These are patients who are already beyond the early stage or will be, once a treatment for early stage patients becomes available. So it's a huge wave of people that I'm worried about being left behind without good options.

I'm Inspired Every Day by Families

I'm inspired every day by families. By people who are coping with incredible changes in their relationship, incredible changes in their loved one, financial difficulties, occupational stresses, and are finding ways to manage all this. I'm inspired every day that they get up, and they're devoted and they advocate for their family. It is truly inspiring to see what people can handle. It's pretty amazing.

A family that stands out is one of my very first patients with frontotemporal dementia. He was in his 60s, and came in accompanied by a very devoted wife. He had the behavioral variant form of the disease. He lived in a really small town in Northern California, and he had some really disruptive behaviors. You know, he did things in public that were not acceptable. He would steal from stores. He would rummage through garbage. He would bring home all sorts of

inappropriate things from the trash. His wife was devoted. She made sure that the community knew and was supportive of him, and because it was a small town, she was able to do that. She never, ever lost her sense of humor. She would send emails or send pictures of the latest thing that he brought home. She was amazing. And she advocated for him until the very end. She was really very inspirational.

Taking Care of Patients

That's a great example of how a community can come together to help someone. And we have an incredible community here at the MAC as well. It's amazing to me that I can work with so many people who are so smart. But to a person, they are really dedicated to providing good clinical care. They are definitely brilliant scientists, but I've seen them interact with patients and with families... and I'm talking about the neurologists, the neuropsychologists, the other nurses... it's an incredible cadre of people who seem to be able to be both incredibly smart and scientific but also incredibly caring. To have so many people in one setting who have both of those qualities is really pretty impressive. It's a high bar to measure up to. For me, the gratification and the enjoyment and the power in what we do is really in that one-to-one interaction with the patient or with the family. Taking care of patients is still where my joy comes from.

Insight

I think we could be better at listening to patients, and especially for those with an earlier stage diagnosis it's really important to include patients. People with early stage dementia often have insights and know what's going on, or can still make decisions. We tend to defer a lot to the caregivers, but I think we have to be careful to still include the patient. If interviewed alone, patients will often share things that a caregiver or provider hasn't heard before. They may have been too slow to speak or too embarrassed to speak up, or the questions may have been specifically directed at the caregiver. I learned this through experience. I once had an elderly patient who was conserved, and was

very impaired, but had recently gotten married. And over the course of appointments with just him, he repeatedly told me how unhappy he was. He described how his wife was not taking good care of him. And it actually turned out to be true. Through a lot of work with other professionals and his conservator, we actually ended up helping him get a divorce. Of course sometimes people share things that are not true, and that's why it's important to work with other professionals and evaluate things closely. But this was a really good lesson for me, reaffirming that even some of the most impaired people have insight or have something to share.

Maybe I Can Keep Them From Getting Worse

I wish caregivers didn't feel they had so much power over the disease, which I think would help them with guilt. Very few family members feel guilty if someone gets worse with cancer. You sort of visualize a tumor growing and you say, "there's nothing I can do about it." But for whatever reason, whether it's because what we're dealing with isn't so visual, or there's this stigma with the brain, or overlap with mental health... whatever it is, I think caregivers feel like, "If I do everything right, maybe I can keep them from getting worse." Versus what we'd like them to understand which is, this is a disease that gets worse no matter what you do, no matter how well you take care of them, or no matter how devoted you are. So I wish I could convince them to enjoy the good times and not be so guilty about the progression, which is out of their control.

A True Continuum of Care

I think another thing that could really help is if we could improve the continuum where care is provided. My dream would be to see a true continuum of care that had skilled, well-paid providers at every level. I think the outpatient side is pretty good. But assisted living has become an industry where enormous numbers of people are going, and yet I'm not sure that the staff or the structure is really there to support patients in the way they need to be.

I think one of the biggest issues is with nursing homes. Everybody will say, “I don’t want to go to a nursing home.” But I’ve always thought, people should not, not want to go. We should make them a place where people would want to go. So if you can make the facility attractive, more home-like, that might help. But I think the biggest part is having staff there that are trained, that are acknowledged for their expertise and the hard work that they do, and that are well-paid. I think that too often working in nursing homes is seen as a low skill career, but I don’t think that’s true. The patients are incredibly challenging to take care of; they often can’t tell you what’s wrong with them, and you have to figure it out on your own. I think it takes an incredible level of skill.

I don’t think nursing homes currently have the nursing infrastructure that they really need to be able to care for those patients. I would love to see the nursing profession take on nursing homes and make them the example of good care that they could be. There will always be people for whom a nursing home is the best or only option. So I would love to see us reach a place where, rather than saying, “You could only get a job at a nursing home”, we would say, “Oh wow! You got a job at the nursing home!” This would be a complete pivot in our approach, but I think it could revolutionize that setting.

Is This Annoying or is This Dangerous?

One thing that people struggle with is how to deal with behavior changes in the person that they love. I think it can be helpful to think about behaviors on a continuum. Is this annoying or is this dangerous? If something is just annoying, maybe I don’t have to do anything. You know, I can put ear plugs in or try to ignore it. But I do have to do something if it’s dangerous. So it’s helpful to think about how quickly you have to do something, or if you have to do anything at all. I will have to do something if he’s going to harm himself; but if he’s just messing up my sock drawer, then maybe I don’t need to do anything.

What is Meaningful Changes Over Time

There is also the struggle people go through about trying to keep patients engaged in meaningful activities. But I think meaning is not stagnant; what is meaningful changes over time. I think most people do want to be engaged. But I think there are also parts of the brain that get affected where people can't be engaged. And I think we have to acknowledge that that's a brain disease, and that no amount of cajoling is going to make them interested.

I think that also, because of the cognitive problems, patients often require somebody to help them engage and to engage with them. This is often hard for caregivers. They want an activity that will engage the patient in a way that resembles their previous ability, when the patient could start and finish things on their own, versus doing two pieces of a puzzle and then needing to move onto another activity. It is really hard for caregivers to understand that the patient's attention span is so short that they may only fold one pair of underwear before they have to move on to the next activity. And if somebody has been a very intellectual person, it can be hard for their family to realize that it might be okay for folding the laundry to be a meaningful activity. The idea of trying to match activities to ability is really difficult, especially because a patient's ability will keep changing over time.

It's Not Loss in the Traditional Sense

This is a long, slow loss. And it's not loss in the traditional sense that's acknowledged by a lot of social norms. So if your husband dies, or your wife dies, there's a funeral, there's a burial, there's an obituary. People bring food and they try and support you through. But I think in this case, a person disappears slowly over time. There's still a stigma so people become pretty isolated. And I think that caregivers start grieving that loss while the person is still alive. So it goes on for a really long time. And it's not very publicly acknowledged or supported.

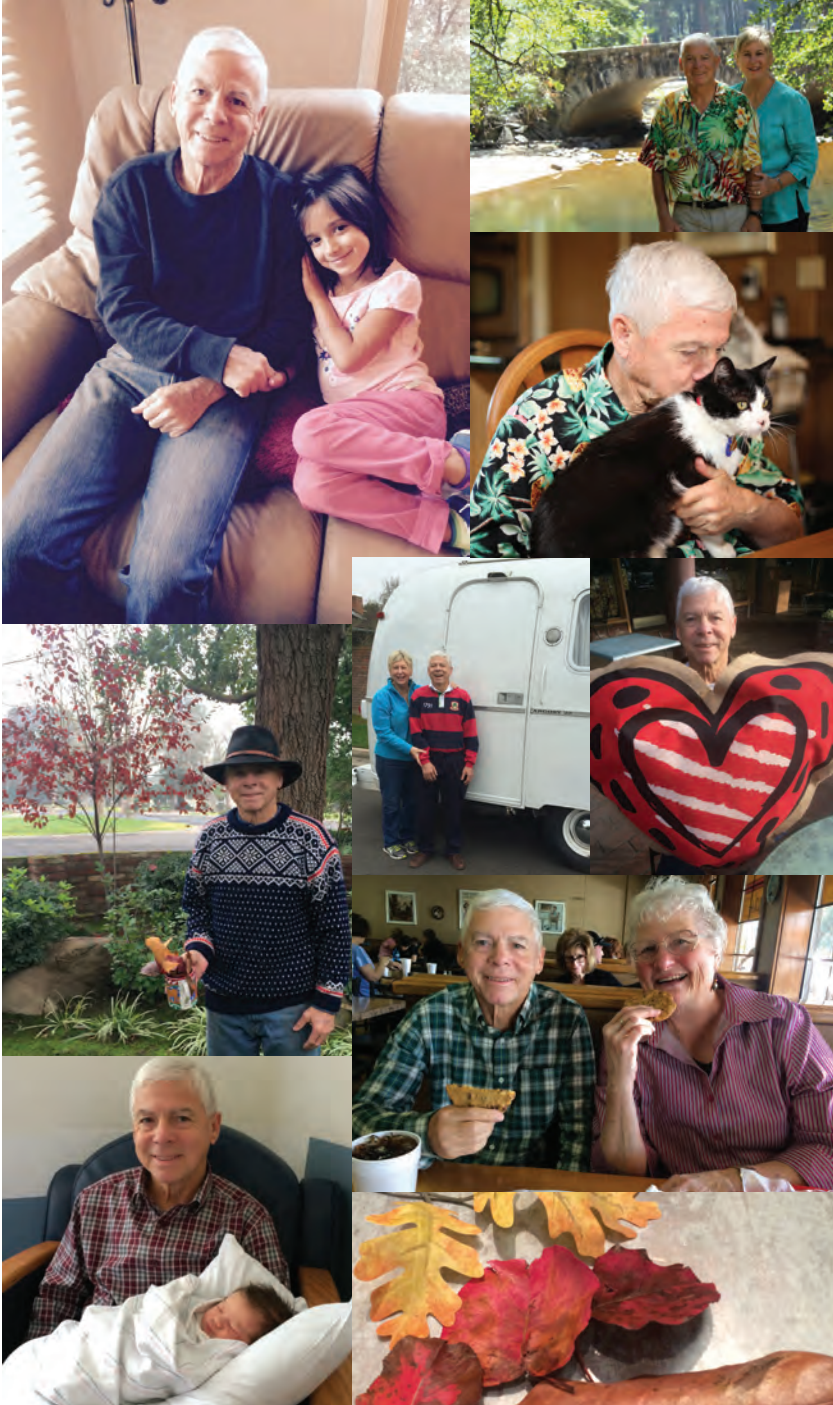
There's a wonderful book called *A Curious Kind of Widow* that has some excerpts in it where the patient's wife is trying to program the answering machine for the first time. And she is just really upset that

she is having to do this. She never had to do these kinds of technical things before. And you realize, it's like being widowed. You now have to learn how to program the garage door and pay all the bills, and do all these things that maybe you never wanted to know, and you often have to do it without much support. So I think there's the loss of that practical side.

There's certainly a huge loss in your partner. So especially for couples, they are losing a person that they have shared decisions with all along. It's a huge burden to have to decide on important things for other people. And not to have that person there to discuss important issues like, "should I sell the house" or "should we move to assisted living?" It's just not the same to have that conversation with your children or with a friend. So I think that's a huge loss, to be missing that person that you shared all those conversations with. And again, it goes on so long and so gradually that I think it's particularly painful for people.

There is No Right Time

People always ask, "When should I place my loved one?" You know, or "How do I know when it's time?" I always tell people, there is no right time. It's very individual. Some people go into an assisted living or nursing home way before I would have expected, and some people are cared for until death at home. It's so personal. And I try to encourage people to think about what they can handle at home. And even to have that conversation with each other. I know one of my patients early on, he said, "When I'm incontinent or when I don't know who you are, put me in a nursing home." And when that time came it was so much easier for her because they had that conversation.



Don the Mon

Narrators: *Jill and Don Harmon*

Interviewer: *Julia Heunis, former research coordinator and current medical student at the UCSF School of Medicine*

Jill Harmon is married to, and lovingly takes care of, her husband Don Harmon, who was diagnosed with frontotemporal dementia (FTD) a few years ago. I met Jill when I had the privilege of being her and Don's "Care Team Navigator" as a part of the Care Ecosystem project at the UCSF Memory and Aging Center. Jill, who was a teacher/counselor for 40 years, taught me more about devotion, resilience, and love in the two years I worked with her than many people are taught through a lifetime of experience.

Jill: Hello. I'm Jill Harmon. I've been married to Don since February 14, 1981, Valentine's Day.

Don: I'm the Mon.

Jill: What's your name? Don...

Don: Don the Mon.

Jill: Don the Mon Harmon.

Don: That's what they say.

Jill: Or Sweet Chickie. People call you Sweet Chickie, Sugar Puddings...

Don: Oh, yeah, we have stuff.

Jill: He's a babe magnet, this cutie. Oh, yeah. He is. I know it. Everybody thinks he's flirting or just smitten by him, and I'm OK with that. I am. Even my counselor says I dress him well, but he's always been dapper and so it's good. I just keep it up. I don't want him defined because of the memory loss. I want to keep him clean and fresh. I've even learned that if I put a little mascara on his eyebrows, it just makes him pop.

How We Met

One evening, I said to my girlfriend, "We've been with high school students all week. Let's just go be with some adults." We went to this

nice dinner house and it transitioned into dancing and all of that later, but she and I just sat there. We weren't big drinkers at all, so we didn't even have a drink. Then a friend of mine called me to his table and asks me to meet his two friends. Don was one of them and almost immediately said to me, "Do you like to dance?" I said, "Sure." He says, "Oh, you're too tall!" I said, "Oh no." I took my shoes off. We danced. That's how I met him! I was 33 and he was 31.

Then they asked me to go have dinner with them. I said, "You guys don't want to take me with you. You guys are on the prowl and I've been teaching all day. I'm just going to go home." He goes, "No, no. Come on, Jill. It's too early." So I go to TGI Friday's with these three guys. He's so cute and flirting with the waitresses. I ordered quiche, which he shared with me, and we laughed about that book "Real Mean Eat Quiche."

After we had dinner, he says, "How about if we go to my house, and I'll get these materials for my EST training?" (a popular self-awareness program he was so excited about that he was driving people crazy). I said, "Well, I would do that because I would like to check out your BMW." He had an old BMW, and I was thinking about buying one. We went over to his house, got the literature, and I said, "Let's go back to my place." I was living alone, so he came over, he talked to me about EST until I was bored, and then we played Ping-Pong until I beat him after having an Elephant beer. It was really late and he was going to an EST training in San Jose at five in the morning, but it was two o'clock and he lived way on the other side of town, so I said, "You could stay here on the couch. I'm OK with that. Goodnight." I locked my door and went to bed.

About a month later, I had a business card on my door and it said, "Harmons' Almonds, please call on the back. I called my friend I had been teaching with and said, "Who's this Harmon guy? I don't give people my phone number or my address. Who is this guy? It sounds familiar." I called him and I said, "Hi. Did you leave your card at my house?" He started laughing.

He says, "Yeah, do you know who I am?" "I was with Bob and Steve." I replied. "Oh, yeah, yeah the EST guy." He says, "You want to go out?" I said, "Well, maybe sometime." He says, "You want to go out tonight?" I go, "Tonight? No, no. I can't." The next day, "No." "How about the next?" "No," I said, "Is this how you date? You just keep

badgering a girl till she goes out?" He said, "OK, how about Friday night?" I said, "OK."

He says, "I'll call you and we'll make arrangements." He calls me up and he says, "Why don't you go get Chinese food and we'll go to the movies because I'm running late?" I said, "This is our first date. I'm not getting Chinese food for us." I was being really kind of indignant. I'm not really like that so I don't know why, except I had three earlier dates that week that included Chinese food. It is not my favorite anymore.

Our first date, we went to see this silly "Cheech and Chong" movie and afterwards he says, "Well, did you like that?" I said, "Not really. It was a good time but I kind of see you with a dingy blond or something, but thank you very much." I became the blond sooner than I thought.

He calls me up the next week and says, "Hey, you want to go with me to my cabin? We can go out sailing." I said, "Where is it?" He said, "Huntington Lake." I said, "OK, I'll go."

The following week he comes to get me with his dad. I looked out and here was the cutest guy popping out of this big pickup truck in these little short shorts. Tan as a berry. I was laughing because I had never gone out with a guy in short cutoffs before. I'm just thinking this is the cutest thing I've ever seen; this is a new adventure for me. I'd only been to Huntington Lake when I was 15 and he was 13. We realized that's when we first met at the dance up there and he walked me home to the cabin we were renting. He used to spend all his summers up there. Don of course was the local cutie, so he had a new girlfriend every two weeks as the campers were rolling in.

Anyways, we get to the cabin and had a nice day. His mother said I thought you were bringing Judy who he invited the weekend before. I said to him is this your pattern? His mother made sure I knew where my room was as if I had any doubts about that. The next day we went sailing and had a really fun time. It was good. We went to have a beer and, when he went to order it, I turned to look at him and that's when I felt it. It didn't make sense. I'm going, "This is him? This is my true love?" I thought, "Oh, my gosh. I've met my soul mate. I can't believe it! It's the second date. How can this be?" I had this visceral experience. Honestly, it was this tremendous sensation and boy it never left. From that point on it grew deeper. I truly fell in love with him, like I'd never felt before.

We are making soup on evening and he says, "Let's get married before Christmas." I changed the subject to our dinner. I'm thinking, "I don't know if I want to get married again. I've been single eight years, almost nine. I marry him in eight months, in the mountains on Valentine's Day. A sunny day after snow fell that week.

People who met us as a couple from our area remarked on how much we had in common. His dad was a principal and my dad was a principal in the same district. His mother and sister were teachers and my mother and siblings taught. They would say, said, "Why didn't we ever introduce you guys? How did we not ever see you two together?"

But I was married to a corporate man and I left after five years, no children. At that time, he was single in his life, and then I'm single and then he's married, and so we had to wait until we were both single in our 30s to find each other again as true love.

Don: I was looking for something.

He'd only been married for two years. His former wife had addiction problems. Don was devoted to his four-year-old son, David, who was in our wedding. It was a young marriage for her, a rebound thing for Don. So, in eight months I married this guy and became a mother. I never made it an issue about having a child. I'm the oldest of five, and I've helped raise my brothers and sisters, so it was natural.

We weren't able to adopt David, though, and it was very contentious for so many years. David's our only child. Now, we looked into having children, but when we got married then, I was 35. We went through genetic counseling, and with the diabetes in my family, which is heavy with my dad's side of the family, and then Don had been diabetic since 14. The doctor said that our chances were in the 80 percent that we could have a child with diabetic complications. We thought we would be irresponsible in having a child with that predisposition. . "We have one great son, though. Don't we, Don? "We raised him together happily.

Things are good and healthy with our son, although he's pretty reserved about Don. He said that it is hard to see his hero failing. He doesn't come around much. I do understand his work is demanding and he is busy with a young family. The kids are just...They just love their Papa. Olivia's so cute, "C'mon Papa," she says, "Let me help you across the street." And she certainly doesn't cheat at cards anymore with him.

One time I went in there, I heard the biggest commotion. Olivia, who was five, and Don were playing Fish with those little tiny magnetic fish – the little fish with little magnetic poles. She’s cheating on him. The next thing I hear is Don shouting, “Wait a minute that was my orange fish. You are cheating, you are cheating.” He was damn serious. It was like two five-year-olds in a squabble. I had to run in there and I’m cracking up. I said, “Olivia, did you cheat on Papa?” She goes, “Yeah, but I didn’t think he’d know.” He says, “I’m never playing with you again.” He says, “You cheat.” Then she cried and then he felt bad. It was a mess. I said, “You need to apologize.” I said, “You are crying because you are embarrassed that you cheated on Papa, and so you need to say ‘I’m sorry’ and we’ll start all over again.” So she apologized. She wasn’t playing fair. It was the biggest fiasco. This little fish game with the little tiny fish, oh my God, the little tiny poles [laughs].

My New Reality

Somebody was talking in this play, about a man and says, “He’s losing his reality.” It’s taken me experiencing dementia but I’ve grown into this, and the way I see it now is that people with memory loss aren’t losing their reality, their reality is changing. The hard part for caregivers and supporters is that, although we don’t see how they might hold their reality, it’s important for us to become them and try to see it their way, and certainly, not blame them or get angry.

I know what’s important and what’s not, and like spilling stuff, that’s nothing. We get upset about the tiniest things in life. I have learned to be current, to be focused, to be compassionate, to be grateful. I can touch him and I can feel him. He is present not physically gone. I do notice how much I have my hands on him all the time. Because I know from losing my mom four years ago, that when they are gone, they are gone. That was my first death, but I’ve got him. I’ve still got him. I know the finality of losing my mom, so it makes me appreciate what I have here with him.

I Don't Mean It's Always Roses

The days seem to go so fast, and sometimes I think, what did I really accomplish today? What did I do of importance? It's because I worked for 40 years and now I'm doing these daily mundane things, but then I remind myself, *Remember when you wanted to date him, and you were in love with him, and what you wanted to do more than anything else? Spend time with him; be with him. It didn't matter what we did, you just wanted to be with him.*

This is where I am, and I wouldn't want to be in any other place – how lucky I am that I can and want to spend every moment with him. I left work four years ago because of his dementia. I had a pretty dynamic career as a college counselor. It's a more mellow life for me now, but everybody says we stay pretty active. It's getting a little more difficult because of the need to find the bathroom quickly, accidents, more child-like behavior, and that kind of thing.

But we go to concerts, we go the mountains, we go to the coast, and he loves the house, and he loves his bed, and he loves his new shower, and he loves to make faces. Do you know how to yodel Don?

Don: Yodel-ay-yodel-ay-yodel-ay-ee-oooo!

Jill: There was a concert benefit for this horse therapy program. He wasn't sure where I was taking him, but I got him all dressed up – he likes to wear his boots and his jeans and he has a couple of Western shirts – and I said, “You'll like it when we get there.”

It was at a church, and we were listening to all of the beautiful singing and they said, “We must apologize because our yodeler didn't show up.” In the audience, there goes Don yodeling.

They were all, “Wait a minute, where is he?” There are several hundred people and here he is yodeling in the audience. Jack, the main singer says, “Oh, there's my friend Don. He knows how to yodel.”

Don: I've been doing it all my life – especially in the mountains.

Jill: Even when you were singing, you did it a lot, didn't you?

Don: [laughs] I don't remember. I liked it. Yeah, I had gone ahead and did some stuff on these things that we were going to do, well, they already did it. You get over there and get somebody else to go and say, “Hey, I need somebody over here.” That's all.

Jill: One of our biggest challenges is giving him enough exercise. Some periods he sleeps quite a bit, and it always concerns me that he is not

getting enough exercise, but we take each day, and I try to do the best I can, and so does our caregiver, Beth. I hired a trainer for him for a while, but he didn't like those machines and didn't want to do it. That was a disaster. Then I asked the doctor to give him physical therapy, because I wanted to help him get strong and not weak. We went a couple of times and on the third time that we went, he heard this music and started to dance around like crazy, doing all this stuff. Thee therapist says, "I don't think he needs physical therapy. I can't justify this. Look at him."

So we made up a game, Spa Paddle, so we could laugh and play together. We hit a large ball with a large child paddle over the top of the spa-like Ping-Pong. Dancing – we have music on all the time. He just loves music; it really brings him happiness. He'd be whistling to the birds if they were in here.

We go with his moods, but he's definitely safe, and he's secure and knows he's loved. I must tell him 100 times a day how much I love him. "Until the Twelfth of Never." How do you know I love you, Don?

Don: [gesturing to Jill's hand on his lap] Because that thing is right over there.

Jill: "How am I going to know you love me?" and he says, "Look at my eyes." That's what he says. Sometimes he just comes up with the most incredible things. He was over there advising our caregiver, Beth, about going to school, that she just needs to try and get out there and do something.

Don: Do something.

Jill: That's what you told her, didn't you? You said, "Do something." Yes.

Don: That's it.

Jill: Do you and Beth get along pretty well, Don?

Don: Oh yeah. You betcha.

Jill: I call her Angel, don't I, Don? She's our angel. We also have a cat, Belle Rose, a black and white kitty that Don likes, don't you?

Don: Mm-hmm.

Jill: She's ten now. She loves you, doesn't she? She sleeps on you.

Don: Yeah, she does.

Jill: She does, it's funny, I think she senses a difference. She brings great joy to us. He'll say, "What is that little something over there?" Or he'll know something's missing.

That could include Beth, as well. There's loss of words but an understanding he's missing something.

I Call His Pull-Ups "Power Pants"

I'm known for nicknames, and I thought it was probably easier for Depends, whatever or me to accept that he had to wear something like that. One of the cute stories about him, when we first started using them, was I was given some from a friend whose partner died, and the first time we put them on, they had ruffles. My little bud here, he had the pull-ups on with the ruffles. It didn't seem to bother him but he said, "These are like girls'," and so we got through those.

We have some lavender ones that were given to us from the same person, so we got through that, but now we have to wear small, extra-small women's, because his tush so small! It doesn't bother me and it doesn't him. We call them "The Powers." He has to have one on at night particularly, because when I wake up it's heavy. When he's lying down, I've just got to say, "Okay, we're going to take the powers off, here we go. Whoop whoop whoop! Shoop!" Make it a game – pull them off and put new ones on.

To put them on, I'll say, "Okay, raise this foot." I tap this foot and then I tap the other foot, because just giving someone directions or commands, he doesn't get it cognitively. The physical touch seems to work better. I always touch the foot and say, "Okay, this foot, this foot, lift it up." Or, I have to lift it up myself.

We also brush our teeth together. I race him to see who pushes the electric button on his brush before the other. But sometimes he doesn't want to take care of the physical cleanliness and hygiene, and it gets to be a challenge so I'll just go on to something else rather than argue about it or spend a great deal of time on something that's going to irritate him or upset him. You just have to say, how important is this?

I often hear caregivers say, "Oh, I'm glad he's not difficult." I don't know, but sometimes I think that it's the way you respond. I think if you have an agenda and you are rigid about things, they can pick up on your emotion more than they understand the words or anything. He knows when people care about him. He may not know their names, but he knows who likes him. He knows love and compassion.

We've been grinding his pills and putting them in yogurt or sugar-free pudding. That was better than Jell-O; we tried Jell-O for a while. Otherwise, when I give him his pills he spits it out in the water, so we've wasted a lot of pills.

He doesn't know how to swallow them, so I'll have to tell him, "Throw them in, on your tongue, put them on your tongue. Put them on your tongue like this." Sometimes I'm successful, and sometimes I'm not. We grind them almost exclusively now.

Another thing we've tried are those plastic bottle urinals in the car, but it's too difficult if you're wearing power pants. We only tried it once – we were driving and he had to use it because we were tied up in this Bay Area traffic going to Tahoe. The power pants have to go down, and he'll say, "My somebody can't get out!" Then, he dumped it all over the floor, so we're not using that anymore. We're not going to use that silly thing because how do you use it if you have pull-ups?

Another thing is that we don't leave garbage cans out because when he has the urge and he sees a garbage can, he's going to go in it. I've heard some people put tape around their toilet. I just make sure that, in his bathroom, the lights are always on, and both seats are up. Otherwise, neither goes up and he's gone in the cat dish. He's gone in the garbage cans. He's gone outside. He's made a mess on the top of the rim of the toilet, so I just make sure it's up.

I usually go with him, and I take him into women's restrooms now. If people look at me funny I just explain, and they all say, "Oh, that's okay." Women are very understanding, but it puts a lot of pressure on me to find bathrooms when all of a sudden he has to go in the middle of Target. You're flying through the towels section and the baby section to get to the bathroom, and then you turn around and he's undone his belt and everything. You have to watch constantly.

We went to this concert recently and were in line to go into the female bathroom, and then I just turned my head and boom! He went into the men's room just like that, so fast. I'm standing there and this other guy comes out and goes, "Jesus Christ! There's some asshole in there urinating in the garbage can." Everyone is laughing and stunned.

I said, "Hey, excuse me! But I think that's my husband, and he has dementia. Will you make sure he washes his hands?" He said, "Oh, I'm so sorry." I wanted him to understand, and boy he did. Another great teaching moment.

I Would Probably be Lying if I Said I Didn't Get Stressed

But I'm so busy I don't even think about it. I'm sure that it does something, but it doesn't keep me awake at night at all, or anything. I am certainly never mad. I just go with it, whereas before I could never say to people that he had dementia. I just could never get the word "Alzheimer's" out. Of course, it's his frontal lobe, so it's a little different with similarities.

I'm at ease now telling people, and people are very gracious and understanding. I didn't say it five years ago, because I felt it diminished him, and I didn't want people see him differently. But then when he was different, it wasn't fair. I felt it was only fair to explain to people. Because with this, with frontal lobe, you never know what he's going to do.

He loves children, when they're jumping up and down. You don't want him to put his hands on people or make fun of them and then not know what's going on. There is a concern that he'll see somebody that's overweight and say, "Oh, that guy needs to stop eating." I stand in front of him so the guy doesn't see that he was pointing to him or something. But he was so cute the other day; he said, "Pointing is rude. You don't point. It's rude." It just came to him. I had never said it to him, but he got it.

Testing his blood sugar all the time, and making sure that he's eating healthy and all the stuff that you're supposed to do, it all just piles up and then, when he goes to bed at nine, I find myself alone, watching TV, when I really want that connection with him and a conversation that's not just funny or cute. But I'm lucky I still have him, and I am very grateful.

People Don't Come Around

I know that's very common, because in the short time that I was in a support group, I heard that over and over. We haven't seen his sister in months, and she lives three blocks away; we've seen his brother twice in a year. None of the men friends say, "Hey, let me take you to dinner," or "Let's go to the show." Part of it, I'm sure, is their comfortableness, or

vulnerability, or their fears. I try to assure them it's fine, but nobody ever really asks. But now they have reason not to come around, without any discussion, because of the concern with the bathroom and the diabetes.

I just don't want to make people do things. That comes out of the generosity of their souls. Our son has gone to San Francisco for a doctor appointment with me. That was good. He certainly loves and cares for his dad. He told my sisters in November how difficult this is because Don has always been his champion, his hero. That's the first time he really expressed his feelings.

He's Part of My Body, This Man

It's my need to support him, be connected to him, to know he's safe.

Don: What do you want to know?

Jill: Are you loved?

Don: Yeah, of course.

Jill: I am the one who loves you.

Today was one of our big moments. Today was one of the biggest moments; we were in the shower together. The water was warm. It was sensual. We were by each other. It's our new shower that we changed from a Roman bath, so that it's safer and we can walk right in. Of course, Don says it's the best idea he ever had. The whole bathroom is wet after a while, but it's not slippery, it's safe.

It was romantic and sweet. It was a sense of intimacy I haven't had for years with him, at an adult level. It was just nice, hugging each other in the water. I thought, "Wow, no wonder people have sex in the shower. Why didn't I ever try that?"

To be very honest, actually, he got a little excited. He goes, "Wow. This is feeling good." I was just rubbing his back and showering him with the hand shower. I don't think I'll ever forget it. You need to have your intimacy and closeness, and this shower was as close to that as we could get. Of course, I got all soaking wet. I didn't plan to get my hair wet.

But he loves it; he says, "This is great play!" He loves to eat, too; he really enjoys his food. People ask because he's down from size 34, the biggest he's ever been. He's usually 33, but now he is a 30. He is much smaller, and he doesn't have the muscle mass he used to have. He

makes Beth, our caregiver, feel good as she makes his food healthy and attractive for him.

Sometimes he piles things up and makes designs on the plate. Being an art major, he sees things like that.

A special thing about Don that I have to share is how he likes to help and give to people.

Jill: Do you like people, Don?

Don: I do.

Jill: Do you like to help?

Don: Uh-huh.

Jill: What do you like to do to help them?

Don: Make sure we got what we need. When you want to play, or whatever, you need certain... or something.

Jill: You want to be there for them, huh?

Don: ... do stuff; I want to make it go.

Jill: I'll go along with conversations that are going nowhere and mean nothing. I try to praise him as much as I possibly can, so that what's left of something like this kind of silly conversation is that he might feel better about himself and feel like he has contributed.

It's really so important for me to know that he feels good about himself, because there is so much he can't do. It's like he doesn't remember all that he could do.

What's interesting is how we have helped people with this situation that we have. We were at the Bier rock place, having a meal. I put him in a booth and I said, "OK, I'll go up and order some food." I'm not even up there three minutes, and I turn around, and he's in another booth, eating a cookie with this woman.

I said, "Oh my gosh. Do you have a new friend?" She says, "Yes, he found me or my cookie." I say, "It sounds like he found both of you. Can I buy you a new cookie?" She says, "No." I said, "Well, are you by yourself?" She said, "Yes." I said, "Do you mind if we join you?" She says, "Oh, I would really like that." We sat down and we met this woman.

It was her 46th wedding anniversary while her husband had Alzheimer's and was in a unit in Oregon. She had given away the health directive to the daughter. The stepdaughter removed him and put him in a home. She couldn't get him out, and she was in tears. We were able to sit and visit with her. Don made a difference for her, because she was so alone.

He Loves Leaves

Of course, in the fall, he collects leaves and they're sitting everywhere. They're in the screen door. They're in the mailbox. They're in the cabinets. They're in his shoes and his pockets. He presents them to people. He just lights up when he's with people and he can pick up the energy that they like him.

We were walking down the street in San Luis Obispo this fall, and there was a homeless man sitting on a step. He said, "Wait," and he went back with his leaves and he says to the man, "Here, these are for you. Aren't they beautiful?" The man at first looked a little stunned because he didn't know if Don was making fun of him or being sincere, and I said, "He sincerely loves leaves." The man just says, "Well, look, Mister, Mister, look!" and he put the leaves in his hat.

Then we've been in stores, and he's given people leaves, and they put them in their pocket or they put them on a necklace or something.

I also bought him a little child's grocery cart because I had a dream about it and then found one in an antique store. It's so adorable. It's a little yellow one and it's for his balance and he puts his leaves in it. We go down the street, and he'll walk so slow collecting leaves.

It's a richer life, it is. It really makes you see life through their eyes. With him, he sees such beauty in things. I remember my kindergarten students bringing rocks for Show and Tell. You're like, "Oh, great. A rock. OK." But then you start seeing it the way they see it, the way he sees it, and pretty soon you're standing looking at crystals.

I Take His Picture All The Time

I have all these shots of him because I just never know... I turn around and he's got sunglasses and Ugg boots on and he's in bed. He finds the bedroom and he's just so excited. He says, "This is the best thing ever. I knew I'd find this place. I knew it." Beth and I have to keep the door closed because you turn around and boom! There he is on the bed, happy as a clam. There are just so many cute pictures of him doing different things that are just enjoyable to him, and I love capturing it.

He loves to whistle. He loves to yodel. I just see him and he's so happy. When he is watching something and he's really enjoying it, like at a concert, he will bring his hands together like a church steeple.

There Was a Lot More Frustration

When he hadn't progressed so far, he remembered that he wasn't remembering. The awareness was there. It was painful because I could see his confusion – in some sense, it was harder then. He would get frustrated when he didn't know something, and would say, "If I went to the mountains, it'll be all right. I just want to go to the mountains." He had lived up there every summer from the time he was six weeks old, and for seven years when he was single. But now, if he's cold, he wants to come home. He appreciates the pinecones and kicking stuff around out in the yard, but it's not the same.

We were there last weekend. He's cold, so I got him a blanket and he wrapped himself around. I brought breakfast over, and he said, "Well, I can't eat. I don't have hands." I never know what he's going to do – he's just a riot.

The Progression of Things

I see it, like when he's hurt or his eyes are just flat, or he just wants to sleep. That's hard, really hard. There are times that it doesn't make sense to him and he doesn't want to take his shots, he doesn't want to take his pills, and it just reminds me that it's there. Other than that, I'm just trying to make it a new normal.

You look beyond what the affliction is and look at the relationship, but life is complicated. There are so many situations we're in where he can't follow the sequence of things, or understand why it's a safety issue to do this or not do this. It's tough to keep him in the world and be doing things as normally as possible.

I can see why some people retreat, but I take him and we do things, and if we have to come home we do, because I need it as much as he does. You've got to replenish yourself by retreating and resting,

or doing something that's good for you, because it can take you down. I can see that.

A few years ago, I was pretty spent out, and I went to the Unitarian church. Don wasn't with me. There was a beautiful song, and all of a sudden, I started crying. It just broke me down, because it was all about change. I'm not a negative or a sad person – I stay in the present – but it helped me get rid of a lot of tension.

I Really Cherish Him

I can't go forward and think of the loss I'm going to have, because when I go there, I'm deeply saddened. I just pull myself back and stay in the present. I don't want to think it's always fun and games, it isn't. But the majority of it is.

I get myself overextended because I have high energy and I'm driven to get things done because I'm not a negative person; I like to be moving forward, completing things.

I have learned that when I go see my personal counselor maybe twice a month, we just talk, nothing heavy, but it gives me a place to talk, and she's good. Sometimes I say, "I even don't know why I'm here. I'm just chatting." But there's value in that. I certainly know that, I'm a trained counselor so I should know that. When I'm with my girlfriends and we're having lunch or something, I don't want it to be the dominant topic. I just want to have fun and get away from it a bit. So my counselor gives me a separate, safe place to talk about it so I can feel what's really... what I'm really thinking about.

The Change of Our Reality

When I stop and think, "Wait a minute. This is our reality." I think how it used to be, because he could do everything. He was a paramedic. He was a safety engineer flying around in helicopters and lit fuses off – avalanches – so the miners could go in at the Helms Project electrical plant, or at China Peak where he was in charge of ski patrol for 30 years. He taught for 25 years. He could do it all. You can see he's not the average Joe; you can tell when you look at his whole workshop. I think his man

friends feel the same way – they don't know what to say because they all look up to him. He was their hero really. He's my hero, too. He really is.

Early on, I stopped going to the counselor for a while. I had gone for about six months, and I said, "I'm not going to come anymore." She said, "Why?" I said, "Because you can't make it go away. You can't take it away from me and make it right. Just want it right and it can't be. I have got to figure it out. I have to do it. Nobody else can."

I was always hoping that I was going to find something that was going to correct this, because I'm a doer. I'm used to jumping in, being an academic counselor, and solving problems, but my friend, Doris, says, "You're so arrogant you think you can fix everything." That was real tough... to know I couldn't fix this. I couldn't change it. I couldn't make it go away. The other day, at one point when I was really overtired and maybe a bit bored, I just thought, "God, this life I'm living... I would never have known that this would be my life." But then I thought, "Well, aren't you lucky, it could be so many other people's lives that are worse," so I let go of that. It was a fleeting moment. I moved on quickly in gratitude.

All the time, people say they don't know how I do it, that I'm a saint, that I'm a this, and I'm a that. I said to my counselor, "I don't know why people say that because everyone should do the same when you love somebody. It's not being a saint. It's just loving that person and treating them like you'd want to be treated." Lessons I learned from my parents.

He's irreplaceable. One could say that about someone they love. I know that but I also know, having worked with so many people over the years and being an educator for 40 years, that he's extraordinary. Warm, loving, talented, and darling.

He's Extraordinary

It brings me peace because sometimes I look around and go, "Oh, look at these couples," but I don't see myself out there doing that again and I don't have to. I don't have to.

Dear Care Ecosystem Team

Narrator: *Julia Heunis, former research coordinator and
current medical student at UCSF School of Medicine*

Julia Heunis was the first Care Team Navigator hired to work on the Care Ecosystem study. She delivered a speech during her goodbye party as she was leaving the MAC for medical school at UCSF. We thought she captured a lot of why people love working here, so we've included portions of what she said.

As most of you probably know by now, I will be starting medical school at UCSF this fall, so this letter is not so much a “goodbye” as it is a “see you later.” Yeah, as it turns out you can’t get rid of me that easily... After over a year of applying and interviewing, I finally made one of the most difficult decisions I have made yet, but one that seemed so straightforward to me (and *everyone* else) as soon as I made it.

I’m sure this letter couldn’t begin to do my sentiments justice, since I can’t even begin to tell you how much you all and the patients and caregivers with whom we work have taught and inspired me in the time I’ve been a part of this incredible team. Over the past two years, I have learned *so* much. I’ve learned about what building a research project from the ground up entails, and all the kinks that pop up along the way. I have learned what “agile design” really means: “nothing is ever good enough, so we’ll just keep changing and redoing everything.” (I think Sarah’s favorite interview question is “So... how would you say you cope with change?”) I have learned about interprofessional collaboration and what it means to be a part of team made up of passionate, intelligent, and high-achieving individuals like yourselves. I have learned about what it’s like to be afflicted with dementia, and what it’s like to be a caregiver. I have learned about the impact these diseases have on the families that lie in their wake. I have learned about the inordinate amount of challenges families face, from medications to behavioral symptoms to family dynamics to legal/financial concerns

to caregiver burden, and have also learned how unprepared we are, as a society, to deal with any/all of these challenges and help the families that are forced to live with them. Beyond these more ‘tangible’ educational points, I have learned about (and witnessed firsthand) commitment, sacrifice, suffering, loss of independence, selflessness, loyalty, dedication, burden, empathy, guilt, struggle, and resilience (both physical and emotional). Lastly, I have learned about myself – about my own strengths, and also about my shortcomings; about what I can do to help, what I have no control over, and the gap between the two – the existing gap that I hope to continue to address. This project, you all, have helped me learn *all* of this.

Words can’t express how grateful I am to have had the opportunity to learn from a team of incredibly talented, brilliant, and passionate individuals like yourselves, as well as the dedicated families we are so privileged to serve. While I have always considered myself a driven, passionate, knowledge-seeking individual, never did I think that I would find a job for which I would happily spend hours of free time attending work-related events, staying late at work to talk to caregivers, and poring over dementia-related scientific literature. Never did I think I could feel so comfortable and so at home as I do at the MAC and on this team.

One of my favorite quotes has always been from A. A. Milne’s Winnie the Pooh, who so wisely said, “How lucky I am to have something that makes saying goodbye so hard.” I couldn’t agree more. As difficult as it is to say “goodbye,” I wouldn’t have traded this experience for any other, even if it meant an easier goodbye. Thank you. Each and every one of you has left unique footprints on my heart, and I am eternally grateful.

Amazing Gifts

Interview with Keith Moreau

Interviewer: *Caroline Prioleau, Writer & Designer*

Keith Moreau was the fifth Hellman Visiting Artist at the Memory and Aging Center from 2014–2015. He is a filmmaker, cinematographer, and videographer. He is also a caregiver for his mother, who may have Alzheimer's disease.

The Tennis Match

I've known you, Caroline [Prioleau], for a really long time, and you had mentioned there were opportunities for filming at the Memory and Aging Center (MAC), and you said that the director, Bruce Miller, was very interested in film. Honestly, I didn't know that much about the MAC, and I didn't have much personal interest in the subject myself. No people close to me had brain issues.

Then a few years ago when someone flaked on a gig, you called me the day before an event and said, "Hey, can you show up tomorrow, Saturday, at 7 a.m. and film something for me?" And I said, "Yeah, okay." "And, we can't pay you very much." It was almost a freebie, but I thought, I'll cancel what I was going to do and come down and film it. It'll be interesting. It'll be nice to see where Caroline works and also get introduced to the subject matter. It was a multicamera shoot, and a little challenging to get the sound right, but we got it. The shoot lasted a few hours, but editing it later was challenging. It was a lot of work.

But it was a good experience. Then there was an opening for the Hellman Artist, and it was an exciting opportunity for me, although I still honestly did not have that much appreciation for the subject matter. My subject matter is very visceral. It's a lot of action, like a music video or filming an artist at work or filming outdoor nature things. It was hard for me to even think about how to approach it. But I said I'll show up for the meeting and show my stuff. So I had this

meeting with several people at MAC, where I played several of my films for them.

I think they liked the style. I think they thought I could bring something to it. Although I knew I could bring something technically good to it, I wasn't sure about the story. Pretty soon after that, they said, "Let's do it," and that was really exciting for me, and so, that's how I got involved. All thanks to playing tennis with Caroline 15 years ago.

Filming as Research

I felt like I was just going to be filming a bunch of stuff. Essentially my filming was research, and it maybe it could be usable and maybe not. I filmed a bunch of the personnel, filmed a lot of caregivers, and a lot of patients, and I still didn't really know what it was going to be. But I had an idea that caregivers were going to be a good focal point, because filming a patient was problematic technically, unless you spend 24/7 with them. The good moments would be few and far between. And sometimes, when you do films, you have to consider the efficiency of it as well. You can't just keep filming and filming and filming and hope something's going to happen. And I definitely did not want to use actors, no matter how great the actors are. If I was doing a narrative production and had a huge crew and a gigantic budget, yeah, why not. But even then, it might not capture the authenticity, unless it was really written well and executed well.

In the meantime, there were some other gigs that happened because of my presence here at UCSF, which was inevitable, in a way, because I was around these people, and a lot of people here need to have videos made. That also became part of the filmmaking process, doing these little projects. For example, we did one on Dr. Katherine Possin's paper on a human version of the Morris water maze for mice, which was really neat. We got to go into this laboratory and had mice do a navigation test that was similar to one humans would do. The mice were swimming around in a tub of water, and we would mimic what the mouse would see while traveling through the water, which was pretty fun. A little GoPro with a little waterproof case, from the mouse's POV (point of view). And that's an example of one project.

Bubbling Up

I thought initially the full-length documentary would be about the Global Brain Health Institute, GBHI. Because when GBHI came, I thought, “This is actually a focusable thing.” But it didn’t happen for various reasons. It probably could have, but it wasn’t coming together that quickly, and also a lot of people involved, some here and some in Ireland. So, that was problematic, because to really tell that story you have to travel there, and then I’d have to get money to do all the traveling, which wasn’t part of the artist budget. Eventually, we may incorporate that into whatever film comes out. I think it’s an important part of the story.

I was waiting to see what bubbled up, and it’s still bubbling. However, one thing that happened this year is that my dad passed away. He had a terminal cancer, so we knew for several months that he was going to pass away at some point. Also during that time, we realized that my mom had some form of dementia. My sister and I didn’t realize this before, because they were totally independent until this thing happened.

That actually happened right at the end of my Hellman Artist residency. So I thought, “I can make this story a lot more personal if the UCSF Memory and Aging Center is involved with my mom’s situation. There was really not enough time to do this, realistically, because I planned to do this a few weeks before I had to present my Hellman Artist work. It was really pushing it.

But I managed to get my mom into the program through all the great people at UCSF, and I was able to film her going through her diagnostic testing and evaluation, at least the initial one. And that actually became the main film that I produced during my Hellman Artist residency.

The Accidental Gift

I think my year here changed me and the film direction pretty profoundly. I was looking from the outside in and trying to figure out what kind of story to tell, and then it became more of a personal story. I

could still tell other people's stories, but because now I have a personal relationship with the subject matter, I think it's even more powerful.

And I think when people saw that film they sensed that it was special because of that. And I wouldn't say that it's good luck, because I hoped my mom didn't have this issue, but if it was going to happen anyway to my mom, the fact that it happened during my residency, and it was just so appropriate for the subject matter, was amazing. In a way my mom accidentally gave me a gift. And my dad, by dying when he did, gave me a gift by exposing this issue.

The timing was my dad actually passed away on March 19, 2016, but the actual filming of my mom's part of this film did not happen until after my dad died. And then my presentation was in May. So, I had a little over a month to actually produce something usable. And of course, all the complications of my dad passing away and everything else. I mean all this was sad, and still is sad for me, but in such sadness there's also a lot of fortunate and amazing luck as well.

Is It or Isn't It

I've been kind of ignoring it, because I've been so busy, but I'm going to have my mom go through more testing. There's a test that she can get to see if she actually does have Alzheimer's or not, because I'm not sure if we're positive she has Alzheimer's. It's not definitive. I'm not an expert, obviously, but she has some of the signs of Alzheimer's. But at the same time, she's very, very able. It's just her memory's really bad, so maybe there's something else going on. She's really functional, and, for the most part, she makes a lot of sense.

I'm not enough of an expert to know if that's normal or not, but my feeling is maybe it's something else. There's a test that they can inject a radioactive protein, or something, that attaches to the Alzheimer plaques, if they exist. And then they can put it through a scan and actually see if it's there or not. An amyloid PET scan. That's what Dr. Rosen actually suggested. So, I just have to connect with the various people here again to make that happen. So they can say, "This is probably Alzheimer's, most likely is Alzheimer's."

I was talking to my sister about it, and she said, “Yeah, I’m not even sure if she even has Alzheimer’s, because she’s really able and really conscious, and able to function.”

My sister’s husband, Don, his dad actually died of Alzheimer’s. He had it really bad though. He was at the point where he was wandering and didn’t recognize his son. He was really belligerent and really angry, and he actually died of it. And it wasn’t that long. It was like a few years. It seemed like it progressed really quickly. She had firsthand knowledge of that, so that touched her. And I guess, thinking back, that was probably my closest contact with Alzheimer’s, but I wasn’t that close to them, the parents of my brotherinlaw. But that was a little connection.

But getting back to this, I was talking to my sister, and she said, “They can’t test for it. We can’t know if she has Alzheimer’s unless you do an autopsy, right?” I said, “Well, there is a test that they recommended during this session that we did.” So, we’ll probably have Mom do that, which they inject it into the spinal fluid, which I guess is a little risky, an invasive thing, but I think it’s probably worth it by now.

He Was Kind of Off

Five or six years ago, I did a film of my family. My mom’s Chinese and on her side, I have a cousin named Richard Lui. He was a CNN anchor, and now he’s an MSNBC anchor. And he’s the only Asian anchorman ever or something. Mom had 11 or 12 siblings. There’s a lot of them. So I guess the chances of one of them being a famous anchor is pretty high. But anyway, Richard Lui is my cousin, and he’s the son of Steven Lui who has Alzheimer’s. I filmed Steven Lui and Rose Lui, his parents, along with Richard, because Richard had suggested that we get a record of the whole family for posterity and maybe make a film, because it’s a pretty interesting history they have growing up in the early to mid 1900s in San Francisco. And, so I filmed them. And then when I was filming Rose and Steven, his parents, I realized how bad Steven was getting. You know, he didn’t really know who I was, even though a year or two before, he knew who I was. And he was recounting stories that he was just making stuff up. And his wife was, was, saying, “No, that didn’t happen.” “It’s not like that, no.” So even five years ago, he was kind of off.

The Medical, Physiological, and Social Problem

I've learned a lot about aging and dementia. One thing is that it seems like there's a lot of research being done, and our understanding of causes and other things is getting better. But we still need to try to solve the problems. Maybe this is depressing, or maybe not, but it seems like it's still kind of far off to me. Maybe I'm totally wrong, but a 30year timeline? By the time I get it, it'll be solved?

It's a vast issue, and there're a lot of different angles being taken. And my perspective is, it doesn't seem as close as I thought it was to being solved, but it still also seems like there's a lot of brainpower being devoted to it. And I think probably, with all this brainpower and devotion, it will eventually get solved. So that part's great.

In the meantime, how do we deal with the issue? Because the issues are very present and very real. And as our population ages, it seems like these issues are more and more common. People used to die before they got dementia. Now, now they're living for many years with dementia, and it's a big burden to society. It's a big burden to their families, and so how are we going to deal with that?

I think especially with a problem that's so prevalent, that touches everybody, a documentary can make people feel like they're not alone. That there are other people that are experiencing similar things, and that even though it's a difficult issue, there are resources and they can possibly get help or at least a different way of approaching things. Some of the projects that I'm working on, like the Tidesswell collaboration, are in that same area. It's directed to caregivers and giving them approaches to dealing with difficult problem.

Not only is the research trying to solve the problem, the medical problem, physiological problem, but it's also trying to solve the social problem, which I think is great. We have to deal with the present and, hopefully, in the future, we'll resolve it, but for now we have to deal with it.

Adding to the Arsenal

There're two aspects to filmmaking – an artistic aspect and a financial, making-a-living aspect. I try to help people. The thing about documentaries in general is that you don't really make much money at them. But you do it to try to expose a situation or help a cause. And I think now my talents will be directed to helping this cause. Whereas before this residency and personal experience happened, I probably wouldn't have gone there. So yeah, add me to your arsenal of tools against memory and aging problems.

88 Days of Shooting

There're some documentarians that put out a lot of stuff. They're prolific, and their ratio of usable stuff to notusable stuff is probably pretty high. But I have the cameras rolling all the time. I don't start and stop the camera. That's how I approach it. It's hundreds and hundreds of hours of stuff.

And then the filtering process – the fact that I'm here for all the filming allows me to remember things that stick out in my mind. If I'm reviewing footage later, I'll even say, "Oh yeah, there was a really great part here. I definitely want to try to put that in."

The fact that I'm editing the stuff that I shot is very useful and makes it more efficient. Sometimes an editor won't be involved in the filming process. They'll just be a separate person that the director, or whoever, works with and sends the footage to. And they're probably talented people that can make a great story out of something. But it's really timeconsuming, because they haven't experienced it before, so they have to view all the footage, and then they have to log the parts that they like, and then they have to go back and edit it. I can skip some of that.

Sometimes a whole day will be totally lost, like it just won't be worth it. And then sometimes you might get a few seconds or a couple minutes. Sometimes more. It just depends on the situation. But there's so much footage, and it gets pulled down to something usable.

When I did my Hellman presentation, I thought it would be fun to have a little film of all the different shoots that we did, just like five seconds for each day. And I can't remember now how many days it was, but it was like 88 days of shooting. It was a lot of days. It was crazy.

Authenticity

In documentary, you deal with what you have or what's available. And the interest is to be authentic and to reflect what's really there, not to create an artificial moment. I don't consciously plan on being authentic or not, but you kind of know it when it's happening. You know when something is fake. I don't really like staged stuff unless it's very, very quick. If it goes on and on and on and it's staged, then people sense that. So, as far as worrying about being authentic or not, I don't worry about it. I'm not just going in there and saying, "Got to make this real." But it is a consideration.

For example, when we were considering the Tideswell project, we decided to go into real people's homes and real situations. And the people and stories are amazing. A lot of the stuff we'd seen was really staged and really fake, and people turn off immediately when they see that, because they're not connecting with the subject. They know it's staged, so they immediately start turning off and saying, "This is staged. This is not real. It's fake, and I'm not going to listen to it too much." The same way people react to politicians or other things in society.

Some people are fooled. Some people are really good at fooling other people. They're really good actors and they're really good at lining things up so that people believe. But for the most part, people are pretty good. They can sense enough authenticity. And I think they go away from fake and inauthentic things towards more real things. In a way like reality TV, even though it's staged and fake, is kind of an example of that. People are really captivated by seeing something that's pseudo real. But if it gets too fake and too outlandish, then they won't watch it anymore.

And then there's a new style of filmmaking, which is kind of like documentary making. A lot of documentary makers have crossed over to narrative films because that style of filmmaking is perceived as being more impactful. An example, maybe more in a technical way, is the

shaky cam – the handheld camera, which you can tell that somebody's holding it. It seems like documentaries are done that way too or news gathering, they're holding the camera so it's not perfectly still.

Avoiding stereotypes is also a stereotype. I think you just need to go in. That's why a lot of times people will say, "Oh, did you see this documentary on...?" when you're making a film about similar subject matter. And it's just like, "No, I don't even want to watch it, because I don't want to be influenced by somebody else's vision of something." If it turns out that I make exactly the same film, so be it. Because it'll be mine. It won't be avoiding doing something else people have done before. It's inauthentic to not be true to yourself, and you can't be true to yourself if you're always avoiding stuff that's been done before.

Take songwriting, for example. I used to be a songwriter and still am. Songwriting is like three chords, most of it. Almost all the Beatles songs are three chords, and all the famous songs in history are three chords, maybe five chords. But, there's not that many chords and rhythms. There's not that many different ways of doing things theoretically. But if you do it with authenticity and from your heart, then it's totally unique and can be appreciated. So being authentic is not avoiding stereotypes. Being authentic is being true to yourself.

To me, being a good artist is finding something that resonates in you that you like, and not worrying so much about being liked but actually creating something that you like, because if you're always searching for things that other people like, you'll be searching forever, and you produce a bunch of lousy stuff. You might eventually resonate with somebody if you're so skilled at producing things that other people like, and maybe you'll have a hit or something here and there. But I feel like if you really, really like it, and it resonates with you, and it feels really real, then at least you and a few other people will like it. And that's all you can hope for.

Good Vibes

The thing that I actually enjoy is that it seems like everybody is very devoted to working here. It doesn't seem like people hate their jobs here. You go to other places, and everybody's complaining and the

morale's really low, and they're always overworked and underpaid, and they complain about stuff, and there's not a good vibe.

Here, there's a good vibe. I know that people work really hard. But I think overall that's what I have sensed and appreciate the most about this organization. It seems like a fairly healthy organization in that regard. I really think Bruce Miller is a fascinating guy. He's so busy, but he's a unique person.

An Amazing Gift

I'm hoping that with a young spirit you can stay mentally young forever. I know that age is inevitable, but I think you can forestall it with the right attitude. Try to keep mentally young, and I think you will you'll remain physically young for longer. And never stop learning, never stop exercising your brain. And don't ever check out. Not that you should be stressed out and overworked, but life is a really amazing gift. To try to escape from wherever you are is not the way to live. You want to be in the moment, and be where you are.



They Actually Made Another One

Narrators: *Laura Gould & Severo Ornstein*

Interviewers: *Kasia Gawlas, research coordinator & Jennifer Merrilees, clinical nurse specialist*

Laura and Severo have been married for 45 years. They have children from previous marriages. Both are accomplished in their fields: Severo was an early pioneer in the field of computer science and an author. Laura, a linguist and author, won the Distinguished Teaching Award from the University of California, Berkeley for her work using computers in the humanities. They both helped found Computer Professionals for Social Responsibility. Now in their 80s, Laura has been recently diagnosed with early stage Alzheimer's disease. Severo and Laura share a life of travel, hiking, music, and intellectual pursuits. Their closeness, devotion to one another, and mutual interests are obvious in the cadence of their shared dialogue. We were grateful and honored to be invited into their beautiful home and hear their story.

He's Hardware and I'm Software

Laura: *We met at a professional workshop about computers–*

Severo: *And education–*

Laura: *And specialists in education–*

Severo: *We were both teachers at that time. Laura was teaching at Berkeley and I was teaching at Harvard–*

Laura: *And I had done something that was thought to be impossible, and therefore, I got Berkeley's teaching award. I taught humanities students how to program a computer. That was thought to be completely impossible. Engineering? Maybe. Chemistry? Maybe. Humanities? Don't be silly. I decided "Why not?" They want it. And so I told them on the first day of class that a lot of their grade would depend on an independent project of their invention. That would be due the last week of the semester. And this was too early today to think about*

what it was, but a week from now when they had more foundation they should start thinking about what their special project would be. Which was three months or more away. We're talking about punch cards being shoved down the throats of things that are bigger than this room. And I was blown away at the end of the semester. It was just astonishing the things they thought up. So I went running into the office and said, "LOOK!" and I gave all the credit to the students 'cause they were the ones that had the great ideas. So I was nominated for the Berkeley teaching award as a result, and it's on the wall of my office, something that's unusual for me, and only because it says: "To Laura Gould for HIS distinguished teaching and HIS outstanding contribution to the Berkeley campus." Shows you that mostly men had gotten it before.

Severo: And it was about that point that we met at this workshop. Laura had just received the award, and I had been off in a meeting in Honolulu...It was clear that we fit together very well. And I think we knew pretty much immediately that we belonged together. We just looked at one another and thought, "God, they actually made another one?!" We're strange birds. We're quite different from most other people we know. But we're just very much alike in many ways.

Laura: *And we both had very, very unusual upbringings-*

Severo: We weren't kids at that point - we had an image of what life was supposed to be like. And we see the world in the same way. Our interests are very aligned. How many women are delighted and thrilled to go backpacking? Laura just loved it as much as I did. We went all through the Sierras and all over the world. And you know, there aren't too many women who are up for that. It was a pretty rough life sometimes. And we both loved it. And we both are music lovers. We're both readers and writers-

Laura: *We're not just music lovers. I've studied the piano very hard, and I've also studied the violin, the viola, and the cello.*

Severo: And slightly red-diaper kids from politically leftist backgrounds. So we had very little to argue about-

Laura: *And we haven't found anything either. But he's hardware, and I'm software.*

We Got Married Over the Lunch Hour

We didn't care if we got married. The only reason we got married was so that I could have health insurance. Otherwise, we were happy not to be married, we don't care-

In those days, it was a little more radical. Today, most people have been together for a long time before getting married. It was just practical,

and, yes, we got married on our lunch hour and then went back to work. And a couple of weeks later I put up a sign, because I was giving a lecture in Buffalo, and I put up a sign that said: *Just married, Gone to Niagara Falls.* [Laughs] You and I were married by a judge in his home in Belmont, Massachusetts...

Very austere-

I bought you a flower on the way back to work after getting married. I just suddenly remembered that flower and that was sort of the extent of our celebration. But marriage, the legal marriage, didn't mean anything to us. We thought of getting a divorce even if it benefited-

It was all about taxes...

Yeah, neither of us-

It didn't matter to us. And neither of us were religious-

It didn't matter but what finally settled it was that, having left Berkeley, Laura didn't have didn't have any health insurance. So if she married me, she'd get health insurance-

Yeah that was the main thing-

We later thought about getting divorced because it was costing us a bundle tax-wise to stay married-

So we thought if it's too much, we'll just get divorced.

We actually consulted a lawyer and said, "Tell us why we should stay married?"

And we don't care now whether we're married.

He said, "I'll have to look into it." And after he looked into it and he said the only benefit legally is that if one of us dies, the other inherits tax free. I thought well okay, we travel everywhere together, we always have. So if the plane goes down or we have a serious car accident, it's likely we'll both die. So it won't make any difference. And if one of us gets sick or has a prolonged illness, we can have a deathbed reconciliation. And the lawyer said, well you don't need me. [Laughs]

So we ran circles around the lawyer-

So I went and got the do-it-yourself divorce papers, and when I looked at them, there on page two it said "Irreconcilable Differences," and Laura said, "I can't sign that, it's not true." And after considering it for a second I said, "I can! So we *do* have an irreconcilable difference!" But in the end we didn't do that because it turned out that someone came along, what was her name? Millicent Fenwick. She was the representative from New Jersey and was hell bent on correcting the

inequities in the tax structure (i.e., marriage tax) and managed to do so to the point that it wasn't worth bothering about. But it had been costing us a quite a few thousand dollars a year to stay married and if we didn't care about being married—

It was ridiculous! What a marriage penalty.

We Used to Just Get in the Car and Go

We did a lot of traveling, I mean, over the 30+ years we've lived here. Well, in the last few years we've done relatively little, but we have been on every continent. We've been to Antarctica; we've been to Nepal a couple of times. We went to New Zealand a couple of times and Australia and all over Africa, I mean you name it. We had friends in all these places, and we found it was more fun to travel and see friends that travel isolated. We had friends in Norway, so we went there a few times. So we pretty much got that out of our system although I thought this last year, (well we've done a lot of traveling, we've done that) and I started feeling restless a month or two ago so we've arranged to meet some friends, some old friends down in Baja later in January. We've been high up in altitude—

We've been up to 18 thousand five something or other...

We quit working early so that we could do the kind of adventurous travel that we liked before we got too old. I didn't wait to "retire," and we didn't inherit any significant money. We just saved our pennies and lived very inexpensively and when we traveled it was with a backpack and a tent and we were very fit—

We had to buy the airplane tickets, of course—

We used to just get in the car and go. But these days, we plan a little more than we used to. We almost ended up spending the night — where was it? Florence? There was no place open: we practically had to sleep on a bench, but I don't think we ever actually didn't find some place to stay.

I Don't Like to Plan: I Like Things to Happen

We were both working at a research center in Palo Alto, Xerox Research PARC. Well, Xerox called me in one day and said, "We forgot to tell

you but you're actually eligible for early retirement: would you like to retire?" Laura was sitting in the car waiting for me. We were going to go mountain climbing up in British Columbia and I said, "I can't answer a question like that, just off the cuff." And I went out to the car and said "Laura, guess what?!" And so we drove off and halfway up to Canada we stopped, called a real estate agent, and we figured we could sell our house in Portola Valley. We had been planning on retiring within a few years anyway. And so, we went off into the mountains and forgot about it. And when we got back, the real estate agent said there are people interested in our house, so I called the personnel people at the PARC, and there was a long silence on the phone and then they said, "Severo we hate to tell you, but we made a mistake and you were not eligible for early retirement." And I said, "Well, my brain retired while we were away, and my body didn't come to work." But, I renegotiated, and we stayed another year, because I had the last of my daughters finishing school, and it helped with the finances. So we stayed another year, and then we quit. And we intended to go and live in Europe, but also in the meantime started a thing called Computer Professionals for Social Responsibility (CPSR). It was a group of anti-nuclear types, and we were computer people, and we thought we had a voice of wisdom, and soon we were running it-

And it was growing like mad-

And we couldn't just walk off and leave it. We had sold our place in Portola Valley by then, and one day Laura said-

We own a lot of paper. But no roof.

We had moved temporarily up onto the Skyline, and we liked it, so we started looking around for a place to buy. And no place we found had a living room the size that was necessary to house [our grand piano] and us, so we finally saw this piece of land and decided to build and did-

We are also really devoted to this place-

Absolutely, and having carved this out of the wilderness we are much more attached than other people, "A house is a house, big deal," but for us, we *are* this place, this place is in our blood. We've made every inch of it ourselves. We actually worked on the house, and I built a lot of the structures so this place really is us. So leaving it will be particularly difficult. Other than that, I don't think we're planners. We just live day-to-day-

It's true. I don't like to plan: I like things to happen-

Well, I'm a planner but only locally, and in a limited time, because who knows?

I might plan what's for dinner.

This Spoon is in the Wrong Drawer

So about six years ago, I think, I don't really know, is when I first noticed something peculiar. We were out in the hot tub and talking about, I don't remember who, but suddenly Laura said something that didn't quite make sense; she had crossed wires and had mixed up the person we were talking about with someone else. Just momentarily and I went, "Huh?" and didn't think anything more about it at the time. But then later I thought it was really strange. And it was after that sometime, I don't know, maybe six months, that suddenly things in the kitchen started to appear in the wrong place—

This spoon is in the wrong drawer...

And so then eventually we went to see a neurologist. I said, "Something is going wrong here," and we told him about Laura's mother and her genetic inheritance, but he said, "Just normal aging." I said to myself, he's not got it. So we didn't go back to him for that reason. He's probably okay, but he did a very superficial test whereas by then someone of his ilk should have been able to perceive that something was wrong. And so it became increasingly clear to me that things were going wrong. So then we went up to see Dr. Boxer at UCSF. He was noncommittal at first and suggested we do an MRI, but Laura was reluctant. She said "What's the action item? What's it going to show that we can do something about?" Perfectly reasonable: who could argue with her? We both concluded that such a test was mostly a matter of investigation for their purposes, for statistics. What good was it going to do us if nothing could be fixed?

And it was very expensive, too. We could afford it but—

But then another couple of years went by, and I finally persuaded Laura that maybe we should do the MRI after all, to try to understand as much as possible because there were other things that could be ruled out by an MRI. But the MRI showed clear evidence that the hippocampus is considerably shrunken, and he said that's pretty definitive, and I asked about the other investigative things, what will they show? And he said it's just not worth it; he felt the evidence from the MRI was pretty clear,

and we were trying to find some way to avoid the Alzheimer's diagnosis, But that was not going to happen.

Well, It's a Vivid Memory

So here we are... all these years later and still putting along. And you know, life is gradually getting more difficult, but not terribly. And yeah, our conversations now don't range as widely as they used to. It doesn't seem to affect our devotion of one another. I get annoyed with Laura, and she gets annoyed with me in ways we didn't used to—

I get annoyed with him, because he gets annoyed with me—

Exactly. But on the other hand, we don't let it get out of hand and you know, things matter less as you get older. At least we look back and say we've done it all. We've had it all. We're coasting at this point and as long as we can manage to stretch it out, we want to do that because we really love each other. We snuggle up close together: we sleep outside, we have an outdoor bed so most of the time we—

We sleep out on the deck—

We sleep on the deck. We just curl up together every night—

Occasionally we have of course, coyotes, and foxes—

We haven't had any in bed with us yet, but they're around—

And I saw a mother mountain lion with her two cubs—

Yes, you already told them already—

Well, it's a vivid memory.

So Laura has some things she believes, some memories that are false memories, because I don't remember them, and I would know because I'm with her 24 hours a day. We've been together 24 hours a day practically forever now. So, I know pretty much anything that happens to her, and she does have a few, very specific false memories—

Name one.

No, we're not going to do that because you are going to argue that—

No, I just want..

No, no—

Alright.

And I've learned that they don't matter, that it doesn't make any difference. At first I'd say, "Wait a minute! Nonsense!" But it turns out, they are very real to Laura, they're absolutely real. Some of them may be

right, but it doesn't matter. Ordinarily, if she weren't suffering from this memory problem, I'd fight with her about it, and we'd *work* it out. But, it's not worth it: these things don't matter. The things that do matter, we have to resolve, and there are practical things that I have taken over.

Keep Going

You know mountain climbing teaches you a few things. One is to suck it up — keep going. And so I wonder to what extent I'm doing that now, and I do sometimes wonder if I'm going to collapse at some point because I'm trying so hard and because we are pushing it here, by staying on here. But on the other hand, I'm physically strong for somebody my age—

And so am I—

Yeah, we're both physically in pretty good shape so far, well except for some creaky joints, the usual thing. But at 86, who can complain? And I'm getting a little more help taking care of the place, but mostly I can do it myself. When we're gone, we're gone. But we're hanging around as long as we can.



Trusting Your Intuition

Narrator: *Robert Levenson, PhD*

Interviewer: *Peter Pressman, MD, neurologist formerly with the UCSF Memory and Aging Center and now on faculty at University of Colorado*

Robert (Bob) Levenson, PhD, is a Professor in the Department of Psychology and the Director of the Institute of Personality and Social Research at University of California, Berkeley. His work focuses on human psychophysiology and the nature of human emotion.

PP: Just to set the stage, I'm sitting with Robert Levenson and maybe just for people who will be reading this, if you could describe your day yesterday, for part of what you do as a researcher.

RL: Yesterday I was just doing paperwork. Today was a more typical day. We're in the middle of the summer, and today I spent the day at Berkeley, and I had a programming meeting in the morning with one of my lab techs. We're working on a computer program together which we'll use in the lab, and also using that as a way to sort of teach him how to use this programming language that we use to write the software for our laboratory. We've been putting in some time together on this programming project for the last month or so.

And I met one of my colleagues in Public Health, Ron Dahl. He studies adolescence as a gateway for some of the adjustment challenges and health challenges that occur later in life. He's started a center for the study of adolescence here in Berkeley and was telling me how they've become one of the go to places for a lot of foundations that are looking for big projects that are going to make a difference in the public health space. Then I came back to IPSR (the Institute of Personality and Social Research), the institute that I direct, and had a meeting with my lab staff, and staff meeting with my IPSR staff and today a book was published called *The Creative Architect* that was written by Pierluigi Serreno, it was based on a study done in 1958 at the institute here where they brought in a lot of famous architects (some famous

and some not so famous) and many who became more famous, for a three-day study in personality and performance. Pierluigi went to our archives and found the materials and wrote a book about the study and what was done and what it said about the lives of these architects.

PP: Now I really do feel like I'm on an NPR interview, we've got a book plug in there and everything.

RL: Well we don't get any money from the book, unfortunately, but it was nice. One of the first decisions I had to make when I became director of the institute was whether to throw all the stuff away from those old studies or to preserve some of it, and I decided to save the data from 16 of the original studies and this one of them.

PP: You've described a wide array of duties and tasks. What would you say is your favorite part of being a researcher?

RL: Well, the rest of the day after the staff meetings has been a series of meetings mostly with students and postdocs and the fellows who are in my lab and checking in with the projects their working on, the manuscripts they're thinking about, and giving them feedback about papers I've read or that have come back from journal editors... I pretty much enjoy all of these activities. Summer is a good time. I like the planning for the lab and the institute, and really enjoy the process of staying close to the research data. We're in a period now where there's a number of interesting discoveries coming out of our work, particularly the new work we're doing with caregivers... it's a long and very interesting day.

PP: This may be a bit of a tough question with such a career such as yours, but can you identify some of the discoveries that you're most proud of or that you love the most?

RL: I think that thinking back over the work that we've done over the years probably the work that has been the most lasting in its effect... It's interesting, since you do this work and you sometimes don't know how it's going to sort out at the time. Looking back I'd say as a rule of thumb the work that has lasted the longest and is most respected in the field is

the work that we had the most trouble publishing and were given the most disparaging feedback on when we did it. There is an element of being your own critic and trusting your intuitions about science and not worrying a great deal about what critics say... not ignoring it, but not letting it define your research agenda. So I think the things that I've done that have been probably the most influential going back to when I first started doing emotion research, the work that Paul Ekman and Wally Friesen and I did documenting and kind of reviving this idea that different emotions have different autonomic nervous system signatures. We did that using a task that was kind of unusual, where we had people move their facial muscles in ways that produced different emotional facial expressions, and so the work had two interesting outcomes. One, we provided pretty good evidence that you can initiate emotion through peripheral motor activity, and then also that the autonomic patterns that were activated were different for different emotions. Work that was controversial when we did it, remains controversial today, but we went at it very carefully, doing the studies we felt were necessary to disconfirm the ideas. One of the things we had to do, we decided we'd test the relationship in a different culture and Paul Ekman and I went to West Sumatra for two months one summer and repeated these studies in a group of people who had really no prior experience with Western research. It was serious work that we took seriously, and work I remain very proud of.

PP: When did you decide then that you wanted to branch into dementia?

RL: Well we'd been doing this basic research on emotion for decades, and we'd also been interested in how emotions function in close relationships, and John Gottman and I had worked together on a number of years developing a methodology which enables you to study emotion during dyadic interaction. And a lot of people were sort of getting into MRI work and functional MRI work and using it to study emotion, but I didn't find that very satisfying because I was used to studying real emotion, going to Sumatra to study how the Minangkabau expressed anger, and looking at couples who were in the throws of horrible marriages and looking at the argue... and it just, to me, putting someone in a magnet on their back and having them read a paragraph and say how would you feel in that situation or is that person angry, it

just seemed like a pale imitation of the real phenomenon. I'd always thought it would be great to study brain and emotion, but I just didn't like the methodology that everyone was using. Then I went to a talk that this guy Bruce Miller gave, he had just moved up to the Bay area from Los Angeles and was studying a understudied group of patients who had frontotemporal dementia or frontotemporal lobar degeneration it was called at that point, and these were people who were cognitively pretty intact but there were all these changes in their emotion and their social behavior and we talked after his talk and I said, "It sounds like this is a disease that really affects emotion and social functioning. Have these patients ever been studied by somebody who specializes in studying emotion and social behavior?" He said no and I said, "Would you have any interest in that some time?" and he said "Yeah, how about I'll put you in touch with one of my fellows and we can start bringing some people over later in the week." And so we started studying these patients and of course they were a perfect way to study the relationship between brain and emotion and they were also extremely interesting in and of themselves. I spent a sabbatical with Bruce's group learning about the patients and about the diagnosis of dementia and pretty soon we were writing grants together and twenty years later we have this body of collaborative work.

PP: And you know that I share this fascination intellectual with connecting brain and behavior and emotion and social interaction. One of the things that people are frequently curious about, as an MD, is how what I know changes my perspective of things such as getting older, sickness, death, dying. How has what you have learned changed your own perspective, going about your own life, about getting older?

RL: I think one of the most dramatic things about studying dementia is you realize that brains age and deteriorate in very, very different ways, and this means the aging brain is not a monolith, and it is interesting to think about the way your own brain ages, and the things I can do today that I could also do when I was 17, and the things that I can't do as well, and of course, you know it's an interesting story that's different for different people. I think part of the wisdom of aging that is informed by this is to maximize what you can do and use it in creative and constructive ways and not to fight the battle to do things that you

can't do as well. You hope that one of the things as you age is that you'll maintain the insight to take inventory of your own abilities and your own capacities so that you can kind of optimize what you have and continue to use it effectively and not try to overuse what you don't do well and have it take you down paths that are not as productive.

PP: You lead a very rich life outside of science as well. What are some of the most enriching things for you outside of science?

RL: Well, for most of my life I've been very involved with music in addition to whatever else I was doing to pay the bills. For a short period of my life I was actually paying the bills by playing music, and I found that that was not very satisfying. I found that for me music was best to be sort of an added pleasure in life and not a way of paying the bills. So when I came out to Berkeley I went for about a decade where I didn't play at all. It was an interesting experience because I would find myself dreaming about it almost every night. And then by happenstance I started playing a little bit a gain and then that led to really a pretty rich musical part of my life. At this point I play in a number of bands, both some jazz bands and some more contemporary music bands, and I conduct a 30-piece community jazz band which I've been doing I think for about 8 or 9 years now and I also really enjoy music recording and using the digital recording technologies and I have a recording studio in my home and I do 2-3 projects for bands, mostly jazz bands in the community where I enjoy that work as well. It's a pretty big part of my life.

PP: Music is often, what tainted, inspired, by these reflections of aging or mortality. Do you feel like that, or maybe it's the opposite, because of your work you're inspired to tackle your work with more of a joie de vivre?

RL: Yeah, I think it's... music's interesting... it's one of those things that tends to stay with you. You hear these anecdotes of people with really severe Alzheimer's who still respond to music from their youth and remember even may be lyrics to songs and things like that. It really amazes me that so many of your motor skills decline so markedly as you age, you don't walk as well you don't run very quickly you can't play basketball anymore your tennis game sucks, you're just sort of shuffling around, but you see these jazz musicians who get up on stage and they

can still play the horn, and sometimes play it in a more emotionally rich way than in any other time of their lives. It seems like it's part of our lives that's built for the long term, so it's something you can enjoy, even if you can't play your scales quite as fast as you used to be able to or learn new songs as quickly, it still is something that relative to other things in most people lives is kind of there for the long term.

You see some people retire from their jobs and they take the piano lessons they've always wanted to take. You can't get as good when you start at 70 as when you were 7, but there's great pleasure to be had and it's still something that for most people can be an important part of their lives.

PP: What sort of things do you look forward to when you get older?

RL: Well, I don't live my life that way, I don't look very far ahead. For me the secret of being happy is to be sure I'm making good use of what I'm doing now. That's sort of my focus. I look forward to the next day, and the next hour. Tonight I'm going to a rehearsal with a really interesting band that I play with every once in a while. It's these guys who are a bit younger than me, most of them are in the tech world, and we play this very abstract unstructured jazz, it's very different from most of the things that I do.

PP: This is a question then that I stole from your playbook, actually, thinking about the future: If heaven exists, what would you like to hear God say when you arrive at the pearly gates, and if heaven doesn't exist what would you like others, your family, friends, colleagues to say after you're gone?

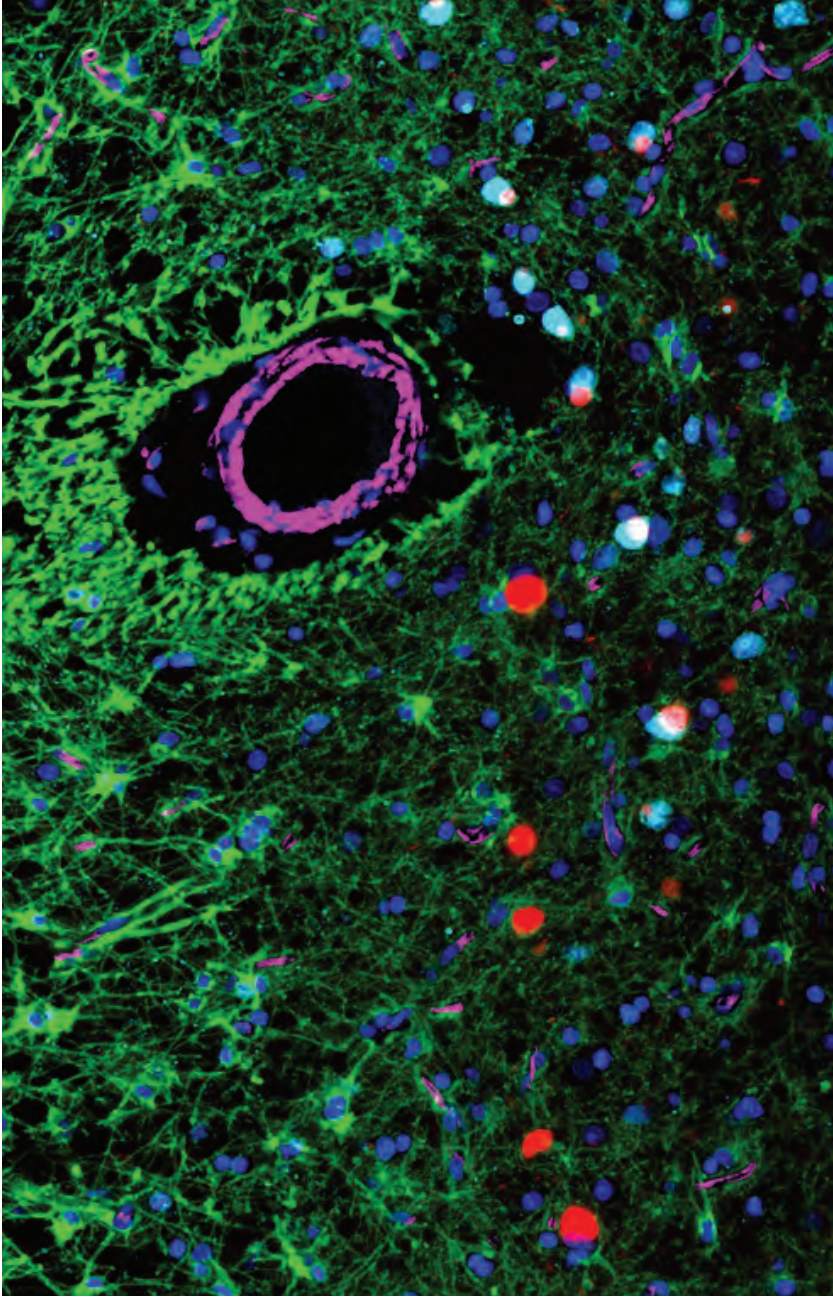
RL: This is a James Lipman question that he asks on Inside the Actors Studio, which he stole from someone else.

PP: It's a good question.

RL: It would be nice if people said he did good things, he did them carefully and seriously, he was kind to other people, and he made the world a more enjoyable place.

PP: And a question that I always end my own patient interviews with, are there questions that I haven't asked you that you wish I had?

RL: I thought you were going to ask if I needed you to refill my meds. I suppose the one thing that you didn't ask about that has been really important in my life, my professional life, is that I've had some really productive collaborations with Paul Ekman and Wally Friesen, with John Gottman, Laura Carstensen, and now Bruce Miller on this work with caregivers, I think I've been really blessed to work with extremely gifted people who in varying ways I've developed kind of a closeness. With Paul and John we're really close friends, and with Bruce there's kind of a camaraderie and a mutual respect and enjoyment. Science can often be very lonely and a big part of it is slaving away by yourself on your data. I think that good collaborators kind of cut through that loneliness, and part of the social part of science, not only does it add to the enjoyment, but you can do things together that you'll never be able to do by yourself. You know I almost always say no to collaborations, but the ones that I've said yes to have been tremendous experiences.



**Image courtesy of Salvatore Spina, MD, PhD,
and the UCSF Neurodegenerative Disease Brain Bank**

The Science of Feelings

Narrator: *Virginia Sturm*

Interviewer: *Sarah Dulaney, clinical nurse specialist*

Virginia Sturm, PhD, is an Assistant Professor at the UCSF Memory and Aging Center. Her research focuses on laboratory measurement of emotion and social behavior in patients with neurodegenerative disease.

My Calling

I think I was always interested in understanding people, probably from birth. When I first took biology in high school I thought, this is it – this is what I’m interested in! I was really fascinated by biology and also psychology, and really, where those fields met – I think I’m still really interested in that. I would say my interest in this probably goes back to at least when I was 14 or 15. In college I was a biology major, but I was never interested in going to medical school, I’m probably too squeamish for that. So I was only one of two biology majors who were not pre-med in my class and that was really hard because I had to take a lot of pre-med classes, and I couldn’t take some other courses that I wanted to take, so I ended up switching to a psychology major and a biology minor, and a Spanish minor because I went to Spain for a year.

So yeah, I think I was always really interested in connecting the mind with biology, and when I found out about the field of neuropsychology I was convinced that was my calling. I did a little bit of volunteering with a neuropsychologist, and after college I ended up getting a job here at the MAC with Joel Kramer. He kindly hired me as a research assistant despite my very little experience! [laughing] So I learned a lot about neuropsychology and discovered this world of degenerative disease and FTD (frontotemporal dementia). Bruce Miller was very inspiring and creative, and it really was this connection between mind, brain, experience, and behavior that I really thought

was fascinating. Then I was lucky enough to get into graduate school to continue studying with Bob Levenson at Berkeley. There I learned basic emotion research methods – laboratory-based approaches, where we study autonomic physiology and facial expression primarily. It was a really innovative approach to understanding diseases and brain-behavior relationships, and emotional symptoms. I spent six years learning those methods as well as learning neuropsychology, and then I was fortunate enough to come back to UCSF to do an internship in psychiatry. I did a year of post-doc in psychiatry and then I came back to the MAC to do two more years of post-doc, and then I got to stay on as an assistant professor doing my own independent research. That's my whole path, so it's definitely a pretty straight path, I didn't veer off the course that much, but I do feel like my passion about my work and my dedication to my own cause has increased over time.

Understand Emotions

The goal of my work in general, is to understand the biological basis of emotion, the neurological basis of emotion, and how disruption in emotion systems relates to affective symptoms in people with neurological or psychiatric disorders. So my driving question is how can we dissect the biological systems that support facial expression and the autonomic changes in the body that occur during an emotion, and relate those systems to symptoms that people have that are common across many disorders? Things like anxiety, or low mood, or feelings of mania, or euphoria – things like that. What's the circuitry underlying those symptoms? I don't think we understand that very well in general across any patient population. I think there's one system in the brain that supports emotion, and if we understood that system, and how it generates emotions, and how emotions are regulated, then we would really make a lot of progress in understanding many, many disorders, and advance treatments, and relieve symptoms, and long-term goals like that. I think emotional symptoms are the most devastating symptoms of any illness. Mental illness is so poorly understood and causes such incredible suffering for not only the patient, but their family and friends. We really don't understand the biology, we don't have good treatments, there's a lot of stigma, and these problems are

incredibly debilitating. I think if we could eradicate that suffering that accompanies these problems for the person and their loved ones, then that would be the ultimate goal.

Measure Emotions

Emotions are hard to study. People don't think you can study them, and every time that I talk to people, I try to first convince them that you can. Even if we can't study them perfectly, we can study a lot of important components. The subjective component of them is very difficult to assess, so I don't try to assess subjective feelings. I try to stick to the parts that I can measure without asking anyone to tell me anything. So I measure the body and I measure the face. You can control the face to some extent, but you can't really control your heart rate and your breathing in response to an emotional cue. Feeling states really influence all behavior. And those feeling states are very close to what emotions are, if not emotions themselves. These (emotions) are just circuitry that connects the brain to the body, and that's a key thing: the brain is constantly communicating with the body. There's no point to have a brain on its own, isolated, it has to be telling the body what to do. The body also has to be informing the brain on what it's doing, and all that information has to be relayed from the brain to the body, from the body to the brain, in order to guide good decision-making and relationships and all these complex things we need to do.

Help People Understand Why It Matters

What I do is really interdisciplinary, and I love that about it – that's why I do it. I'm trying to bridge basic emotion theory, affective science methods, degenerative diseases, and brain imaging into one set of studies. I think anytime you try to be integrative across fields it's challenging, because often there isn't another person who knows all the fields as well as you know them. So you're trying to convince the dementia researcher that emotions are relevant to dementia, and you're trying to convince the emotion researcher that dementia is relevant to emotion, and that can be challenging. The farther I go, the

deeper I get into the literature, my questions get more nuanced. When you're asking a more complex question, you have to bring people along with you a little farther to get to why that question is relevant. You have to lay the groundwork with all the other stuff. So it's hard, but I think that I have learned how to teach and explain things in a way that helps people. That didn't come naturally to me, I had to learn that you should do that, but it does help. You want to be innovative and push the field, but you can't go too far so no one understands why it matters, I think there's a balance there.

Discovery

To me, the most rewarding thing about my work is discovering things that no one knows in the world. I really think that is what science is all about. A lot of science is really slow, and tedious, and painstaking, and hard, and boring, and frustrating; however, the small percentage of time you spend discovering something makes it completely worth it! You know something that no one else knows, and that's amazing! [laughing] I can't get past that being totally amazing, and it makes it worth it to me. But for other people it's not worth it, you know it's a lot of sacrifice to get to that point, but if it's worth it for you then science is all worth it. I think you really have to want the discovery; you have to be driven – not able to sleep until you know the answer to this question, or reading until you figure it out, and going past the point where normal people would stop. [laughing] I think it's really about the moment of like, “Oh my gosh: we were right!” or “We were wrong.” We are going to change how people think (about emotions), and that's cool!

The Unknown

I'm surprised at how invested I am in my own questions. For me I think it was only when I got to the point of knowing a lot in a lot of areas, and I could ask the questions that no one else was thinking about, that I became even more committed. When you learn enough that the people that you go to ask questions don't know the answers – and then you feel good! [laughing] Like you've gone to the point where if you don't

know, probably no one knows – it’s just not something we know, and that’s a good question to pursue. I think the key for everyone is to find something you’re passionate about, because you invest so, so much time in the work, that if you’re not 100 percent obsessed with the question and committed to finding the answer, then it’s not that worth it. It’s just not as pleasurable to do. I think every person needs to find that question if they think they want to pursue research.

No Rules

It is scary. I try to balance what our lab is doing with reasonable things that are pretty safe, good questions, and things that haven’t been studied, but are not that conceptually risky, with other things that are pretty risky, and unknown, and come from my sheer curiosity. Now I have the ability to test those ideas, because I have my own data, and I have some help, and we can work on these questions. So that’s how I try to mitigate the scariness factor, but yeah, I mean there are no guarantees, and I am fine with having bad ideas, or ideas that are wrong, but you can’t have all bad ideas! [laughing] Like you have to have something that works out, so you want to balance the safer bets and the riskier bets – that’s at least how I manage that stress. I think one thing about research that some people love, and some people hate, is that there’s no wrong way to go. You can have a problem and attack it in an infinite number of ways, and I love that, but it can also be scary. There are no rules, and even if you try to base what you do on what other people do, still, you can do that, or you can say why you didn’t do that.

Physiology versus Psychology

I find inspiration everywhere, mostly from patients – or people who have mental illness. I’ve known a lot of people with mental illness or emotional symptoms, and I see them daily in my clinical work, and anytime I interact with a patient who has an interesting behavior, or change in personality, or emotion, I really try to understand it physiologically. If I can’t understand it – it is on my mind until I can figure it out. That leads me to ask questions, and do studies about

different aspects of these behaviors. I think we often make up reasons why people have (emotional) symptoms, which are totally possible, but I think that a lot of these (emotional symptoms) are manifestations of disease that are not necessarily psychological. Whenever I see anyone, I try to assume that if I didn't know anything about their internal state, or their mind, and their experience, and their language-based interpretation of all that, how could I understand a very small part of their behavior? Like, how is their face moving, or why is their heart rate so high? Then I really dig deep; I read literature across many different species and levels of thinking, and try to get at questions in a new way without being constrained by the norms or the discipline's boundary.

Think Differently

I have always put myself in a situation where I am never asked questions about psychology; I'm never asked questions about things I really studied [laughing]. I'm always asked questions about things that are slightly outside, that make me think about things in a new way. I put myself in a place where I'm never completely comfortable [laughing]. My friends who work in psychology departments, they have the opposite problem. I was talking to someone who is in a psychology department, and I was explaining how I'm constantly trying to convince people that what I do is meaningful, and it matters, and they should fund it, and he was like, 'Wow I never have to convince anyone of that because we're all psychologists and we all just realize what we're doing is so important.' And at the same time, he never has any contact with any other department, neurology or anything else, so there was very clear the difference; like he's very comfortable but doesn't get the rich diversity of thought, and I'm not uncomfortable, but I'm pushed to integrate and communicate my ideas to a broader audience. I get the benefit of lots of different ideas and to me that's always been worth it. So I don't think it's random that I ended up in this position, but I do it because it makes the work better, so that's why I do it.

Women in Science

As a woman, there aren't that many role models in science. The higher I go, I feel like it is more, and more, male dominated. You have to find your own way of being equal and being an expert, and it might not be the way that your male mentor did it. I might not be able to use that same approach in order to get through challenges. I think I struggle with that. I am really lucky to have had a few extremely supportive champions of my work, who were really supportive even when other people might not have understood why I was doing what I was doing, or why it was important. Having a few key players who are on your side makes a big, big difference in this whole field. So I feel super lucky to have had unwavering support from those people, and they do offer me critical feedback also — but only in a way to push me to move forward.

Turn off the Fear Experience

I think to have confidence you do have to at least temporarily shut off the fear experience; 'maybe I'm wrong, or maybe people aren't going to like this, or maybe I shouldn't be doing this,' or all those negative self-doubts that we all have. You either have to temporarily shut that off and push forward; convincing yourself that what you have to say is meaningful and important, or, you truly believe, and you have no self-doubts. Some people experience very little self-doubt and those people are graced with being able to be very confident and have no worry of negative consequences. So I guess another way of saying that would be, if you think about reward systems and punishing systems in the brain, in order to have confidence you have to be tapped into that reward system and quiet down that punishment system that is looking for the criticism [laughing]. Like, "This is going to be great! I have important things to say!" And that helps you to present your work, or do whatever it is that you need to do to not withdraw from an opportunity. You are never good enough in science. You're always striving to do something better, more important, or more innovative than what you've already done. I think people who enjoy that process (of constantly trying to get better) are drawn to the challenge. The more you follow one line of work

and it's successful, the more you can create new questions, and it is like a snowball; you can just keep building on what you've already done.

Don't Give Up

I guess I've learned to stay the course, take in feedback and skepticism, and things like that, but also follow your gut. Sometimes people mean well and are being cautious, or they don't understand what you're doing for various reasons, and they discourage you. It's important to listen to that sometimes, but other times it's important to follow what you believe to be true, because you have a lot of reasons to think it, and you have a lot of other pieces of evidence to support it that maybe you haven't articulated. I have learned to follow my gut feeling and pursue the questions that I really believe are important. A lot of the time people will believe you later, once you have either proven it, or proven it several times, and then told them about it several times and then they're like, "Oh this is a really interesting idea!" I think finding that balance of following your gut feeling versus taking in helpful feedback has been key for me in order to not just drop things when I get some negative input. I used to listen to that [negative input] more and just give up on things, and now I'm less likely to give up. [laughing]

Glad I Didn't Know

Narrator: *Callie Floor*

Interviewer: *Sarah Dulaney, clinical nurse specialist*

Callie Floor is a costume designer and caregiver for her husband John Chapot, who is a patient at the UCSF Memory and Aging Center.

It's Like Diving into a Big Empty Pit

What does it feel like (to be a caregiver)? In the big scope it's overwhelming, because Alzheimer's doesn't have a clear trajectory, so it's like diving into a big empty pit. That's what you feel like you're doing, because that person that you're caring for is slowly going away.

He Was Never a Master of the Universe

One of the things I say about John is that I'm really glad he was never a master of the universe because I think it's really helpful now. He's a really sweet guy, he's not somebody who has to make all of the decisions. In my observation it seems harder for people who are with guys who were used to being in control because they cannot give up that control. John is not like that, he's very grateful for help and very gracious. I think he's handling this for the most part with an incredible amount of grace and humor. I'm very grateful for that, but um, he needs more and more help all the time.

I Am Aware of How Lucky I Am

What goes through my mind is that I am really lucky in a lot of ways. I have a friend, an old friend of mine who was my long-term boyfriend

who became friends with John. He's on disability, so he comes, and I can pay him to help me with John. He's someone who's really caring, and he's a very methodical person. He used to be a teacher so he's very like, "*How do I get to this person,*" "*How can I help this person.*" He's really a great person for me. I can ask him how he feels about things, or how he thinks about things, and he'll report back to me what kind of day they had when he comes in and makes lunch for John. I mean you can imagine what that's like for me to have somebody who I can call. And he's not a family member so he doesn't have any of his own emotional baggage with John, I am so grateful for that you don't know. John really likes him, John will call him before he calls me for a lot of things, so I am aware of how lucky I am. How lucky I am to have a facility like UCSF in my backyard. We're not wealthy by any means, but we have enough money to deal with this. So, I'm not so freaked out like, what's going to happen down the road. We have long-term care insurance, and all that stuff really helps me relax, right?

Keep Doing What You Like To Do

We are not at a point where we have really bad days and really good days. I'm still able to work, and no one has told me that I should quit my job. In fact, people tell me the opposite — keep your job, keep doing what you like to do, so I'm really grateful for that. But since I have a day job, I get up at seven in the morning, and by eight o'clock I like to make sure John's up and dressed, and then he has some pills he has to take and some eye drops. I make sure he has a cup of coffee, I make sure he has food for the morning, make sure the TV is on, make sure he brushes his teeth, and that he has all his bits and pieces. It's getting harder and harder for him to dress. He can't really dress himself anymore, so he worries that if he doesn't get up with me so that he can get dressed, then he's kind of stuck, and he's aware of that, so that's that. And then I go to work, and then a couple hours later Don will show up and make sure he has lunch and make sure he's kind of set up for the afternoon. I do some extra projects so if I'm not going to come home at night, very often somebody else in the family will come over. Sometimes he's stuck by himself, that's getting harder now. I know that John's son looked at me like, "*You're still doing theater projects — I thought you were going to [stop],*"

and I'm like, "*No, I'm not stopping.*" You know, cause even when this is over, or he's in assisted living, if you're just doing that (caregiving), then what are you going to do with yourself? Right? I'm not, at my age, going to stop and then get to be able to start up again. It's just too hard. Even John's doctor said to me, I said, "*Yeah, I think at some point I need to give up doing my work*" and his internist, who's an older guy who's known John for years and years said, "*I would do everything to dissuade you from that, you don't have to do that.*" So that's what feels right to me is to live my life, because I think if I didn't then I don't think I'd be very nice to him. But there is some balance there; I'm trying to gauge things a little bit better so I'm not gone all the time.

He Gets Untethered Now

It does worry him; I think he gets untethered now. It used to be that he'd go to the store a couple of times a day. We have a supermarket a block away, and he can go there, but he's losing initiative, so he won't think to go to the grocery store just to kind of occupy himself. He doesn't think to do that. He can't think of what he'd want to eat. So it seems like he's untethered, and he doesn't have anywhere to land, because he doesn't have a sense of initiative.

I Know How to Deal with Where We Are at Now

I think he's kind of holding on. We have a dog that I leave home with him, and that helps him. He takes her for walks still, it's a little scary but he does self-limit. He knows that he can get lost so he'll mostly just take her around the block now instead of going to the Panhandle. Don will take them for a walk in the Panhandle, which is right by our house.

So I would say, the most difficult thing is just not knowing what the future is. I know how to deal with where we're at now, if it just continued on like this we would be fine, but what's the next cliff that we face? And also, what if something terrible happens, you know, like what if the dog gets run over when he's in his care, or he does get really lost, or gets really injured? That's the stuff that's really scary. Is some really awful thing going to happen — and then we're going to have to

cope with it. I'm not willing to lock him in the house before he's ready to be locked into the house.

When You Land on Something Like That, It's Incredibly Rewarding

I would say the most rewarding thing is that he is really sweet, he notices stuff in the moment. He's always telling me how nice I look, you know, *"Your outfit is really great."* I think it definitely just gives him something to talk about. He's always like this (looking up), looking. You know he's always been interested in astronomy, so he's always looking at the clouds and that kind of thing. So he lives a little more in the moment. If he can find something that makes him really happy — like going to music, I think a lot of people like music, he's really appreciative. So that's — when you land on something like that, it's incredibly rewarding. And I think the fact that he has such a nice personality is really helpful. It could change, like he could get more frustrated and start getting violent. I hope it doesn't go that way. I also worry about things that I don't think I will be able to deal with. Like I don't know if I'm going to be able to change a diaper, that just might be the limit for me. You know, I don't know how other people deal with that.

He Knows, but He Doesn't Want to Face It

I think it's embarrassing for him, I mean he's aware that he's losing it. I think he's hit a cliff; he needs more and more help, and so I said, *"Well you know, what would you think about having more activity during the day?"* because I would like to get him into a day program, and he's like, *"No."* Well you know, he goes to tai chi once a week — which really helps him, Dr. De May said it really, she could see where it's really helpful to him. He loves it, he did it in college and he remembers it. It's something he feels like he can do, so I said, *"Well like you know when you do tai chi,"* and he said, *"Well yeah, it's a bummer that that tai chi is only once a week."* *"But what if we found something..."* and he knows that what I'm saying: you need to go somewhere where you're being watched. And I said, *"I just think that you know, I feel like sometimes you're lonely here by yourself, or you could use more*

activity,” and he’s like, “*No.*” We had this conversation where he’s like, “*Why can’t you find a volunteer position for me?*” You know, he’ll say, “*Give me something to do,*” and I’ll say, “*Well here’s a broom, go sweep the steps,*” and he’ll come back and say, “*Where, where am I supposed to go?*” or I can tell he doesn’t know where he’s going in the house. You know, so I can’t really get him a volunteer job. I mean, he knows, but he doesn’t want to face it. So, it’s just trying to figure out a way to get him into a care program that is palatable to him. He’s aware, but it’s still too creepy to him to admit fully.

Kind of Childlike, and It’s a Little Selfish

He wants to be of use, he always wanted to be of use, he always wanted to be helpful, he’s always really grateful — and then he said to me yesterday, because I was running late trying to get out for work, and he’s like, “*Oh, well we have to figure out a way where you’re not stressed out in the morning.*” And I’m like, “*Well, I just need to get up earlier.*” You know, so I think there’s a part of him that’s kind of childlike, and it’s a little selfish. Like when he talks about Don, I said, “*Well you know Don can’t come over all the time,*” and he said, “*Yeah, he kind of like gets tired and stuff,*” and I said, “*Yeah, he’s on disability you know, he does get tired.*” But what he doesn’t understand is that it’s a job for Don. He just thinks he’s a friend who just comes and hangs out; he does not understand that Don has to really watch out for him and know when to hold back and when to push him a little bit, you know, it’s a job. It’s not relaxing just hanging out. So John’s not aware, I can tell it’s a selfish response, it’s not like he’s concerned about Don’s welfare. It’s more like, “*What does it mean for me?*” And I think that’s the childlike part of this.

He Really Misses That Part of Our Relationship

It definitely has affected our relationship. One of the nice things about having somebody like Don around is that it means that I can have more of a marriage with John. When he gets lost, he’ll call Don because it’s embarrassing for him to call me, so I feel that has preserved part of our marriage — but it isn’t a marriage. You know, I really don’t feel very

sexual with him and I think he is really sad about that. The mechanics of it don't work so well so it's not so much fun, and it's also like, you're telling somebody he has to brush his teeth, and you're trying to put his underwear on correctly, and it's not — it doesn't feel the same. I know he really misses that part of our relationship, and I don't know how to fix that. I don't want to. And you know, it's kind of shitty of me that I don't and I feel bad, I mean I wish I could, and yeah, I feel bad. That's just the way it is. I can't make his body work and I can't make mine respond.

I Think It's Something I Just Need to Admit

I'd say the least comfortable part about it is that our relationship has changed so much, and I don't know if I'm capable of going — I mean, I know I can go the distance emotionally, and I know I'm not gonna leave him or anything. But in terms of being a physical caregiver — I don't know that I can do it. Or be the 24-hour person — I know there are people who can do that for their spouses — I don't think that's me. I mean, I think it's just something I just need to admit, and um, there's a little bit of guilt about that. I know people burn themselves out, and you know die before their partner dies, because they burn themselves out. So I'm thinking, "*Okay, well I don't need to do that, right?*" I don't need to do that. At this point I feel like I can handle what's being asked of me, so I don't feel like I have to like throw in the towel. I feel very grateful for my resources, and I don't feel like anything that I've had to do has been beyond what I should be able to do. I don't know, talk to me in six months.

Times That by a Million for Him

I try to be prepared, I think it helps, and I feel like there are resources out there so why shouldn't I take advantage of them? I mean, I don't know what not confronting this would give me — I always feel like knowledge is power. I started going to that support group that Robin runs as soon as we got a diagnosis. I called UCSF and talked to a social worker there, and they said there's this support group, and I hightailed it. Then also, there's a couple of Facebook groups for people who are caregivers, and they are incredibly useful. Yeah, yeah because there are

people who have been dealing with it longer — like last January, John got a chest cold, and I swear to God, in one day I felt like I was dealing with somebody who had late stage, um he couldn't, he could not absorb any verbal anything. Oh my God, and I couldn't get a hold of Dr. De May, so I wrote on the Facebook page, and I asked anybody, “*Is this something?*” And everyone was like “*Yeah, yeah — when somebody is feeling sick, it's like all the resources that they use to cope (because he's dealing with just a little bit of his intellect to do everything), and when you feel foggy when you have a cold — I mean, times that by a million for him.*” It was a few days, and they said, “*Yeah he most likely will get back to where he was.*” [laughs]

His Verbal Skills Were Above Average for People his Age

John was the oldest of six with two step siblings, and you know they're not perfect, but they're not terrible people. There's some weird family dynamics that are not unusual for a family of any size. There's definitely some historical stuff that's rearing its head, but I think that they really do care about him. And I think it's harder for siblings than anybody really? He was the oldest, and his verbal skills were above average for people his age. So that's been the hardest thing because he's starting to lose his verbal skills, and his siblings have said that's been the hardest thing for them. He was always really quick on his feet and very funny, and he can barely I mean, he can still talk, but you know it's like thank God I know what you're saying, because I don't think I would [understand what he is saying] if I didn't know him.

I Can't Deal With Your Dad and Process This For You

His son was difficult the first couple years that he was dealing with this. He had a lot of judgment about it, a lot of like, “*He should be doing this, he should be...*” you know, which made me want to just punch him in the face. He was living with us, and he blew up in a really ugly way. Thank God he had a girlfriend, and he just like moved in with her, and they're gonna get married now, and I am forever grateful. I said to him, I said, “*You know Joey, I can't deal with your dad and process this for you. You're gonna have to go to a therapist or talk to your mom. I can't process this for you.*” John's

kids' mom has been wonderful. She comes over about once a week and is pretty much there emotionally, which has been great. His daughter, who is usually more mature about stuff has had a really hard time, and she's admitted that she's had a hard time, and she's kind of recused herself a lot. But, I think she's just, she's trying to figure it out. Joey is way better now; he's involved in a more productive way. He comes over once a week and spends an afternoon and is inclusive and usually pretty nice in front of me. You know it's hard though, you can't always — I mean, I've lost it a couple of times, and it's embarrassing and you know, it's hard sometimes.

You Still get to Process your Feelings

Um, I think my strengths are that I can just get things done, and I think I'm developing the ability to listen to him more. I mean, he's still an autonomous human being and when he has an opinion about, like going to a day program, he said, *"Well you know we must be at an impasse."* I said, *"No we're not at an impasse, you said no, I'm going to honor that. It's your choice, this is for you."* And then a couple of times he said, *"I need to talk about this,"* and it's like, *"Oh, right! You still get to process your feelings."* I'm getting better at that and I think it's because he's been very clear, like *"I still need to have a say."*

Try Not To Lose It

I just try to be able to be patient with myself and realize that part of the childlike kind of thing is that before anything, he picks up on emotions. And then he feels bad, and he shouldn't feel bad. You know he ends up apologizing and I'm like, *"You don't really have anything to apologize for, you're working really hard!"* Um, the other day he said, *"Oh you're just having a great time with this — you're just laughing — it's just funny to you,"* or something, and I'm like, *"Not really."* You know I mean, that's the kind of thing that would make me lose it — really make me angry. Because it's like, we're all trying really hard here to make your life better and make it easy for you to go out of the house — you know buy tracking devices and all this — so he gets to leave, and if he gets lost we can find him. So,

um that's the kind of thing that will make me lose it. Ha ha! Um, but I think I'm getting better, that was my New Year's resolution was try not to lose it. But I can understand why people become abusive, and I think if I was full-time it would be really, really hard to not get... you know, and he's pretty nice! Like for people who are with people who are not nice, what do you — how do they cope? I don't know! So, I'm just really grateful that I'm where I am, and I can still work.

I Just Wanta Always Honor Him as a Person

I like being prepared. I just think that's kind of who I am, you know, like when you go on a trip, part of the fun of going on a trip is planning it. I am kind of a planner and like to know what's going to go on, I like being prepared. And then I can get used to it, I mean just like my fear of dementia has changed, I'm not as afraid of the whole thing because I feel like I'm reading a lot more stuff and reading stuff by people who have the disease as well as people who have taken care of people, and how treatment has changed — like how they don't drug people up anymore, and they give you advice like, *“Try to live in their world instead of trying to bring them to your world”* and all that stuff is really — it is actually very helpful. So um, I feel like knowledge is power, and I'm not as afraid of it — even though I do worry about what I can't handle.

I think one of the things that came out early in the support group is that it's okay to tell people that you're with somebody who's got dementia. The first woman, her name was Heather Gray, she works at the Alzheimer's Association, and she said, *“You can tell people.”* And I'm like, *“Even if you're not telling HIM that you're telling other people?”* And she said, *“No, you can tell people.”* And that was actually a relief, because when you go into a restaurant and he's having difficulties, or you're at the Apple store, and he's staring at his phone like this, and it's like (whispering to the clerk), *“He has dementia,”* and they're like, *“Ahh! Thank you, okay, now we know.”* So I've told other people that, too.

I know that, like the social workers at UCSF, they're like, *“Oh, are you sure you don't want to restrict him?”* and I'm like, *“Yeah, actually I am.”* You know, I don't want to — I mean, that would drive him crazy — and I think it's not fair to him. You know he's not a danger, he's not leaving the stove on and stuff like that. He's a very careful person — he's not like

handing the credit card over to people or doing anything that's a danger to anybody. And I feel like he has a right to be out and about. I mean, don't you think? Yeah, so what it means is like, this is what you're handed, you know. I mean, you don't ever know in your life what road you're really walking down, right? And you just don't wanta, I mean, I just wanta always honor him as a person, and I know that if I was in the same position, he would do whatever he could to take care of me. I mean, one time I had food poisoning when we were just dating, and my roommate at the time was kind of worthless. It was in the middle of the night, and I just called him. He came and took me to the hospital and sat with me at the hospital 'cause I was getting dehydrated and kind of delirious and until it was time to go and take his kids to school — he was just there. And I know that if I was in this position he would do whatever he could — in a very calm way — to make it right.

It Would be Hard to Have Your Compassion Well Run Dry

I mean you do feel cheated because you are. There's no way to not feel cheated when this is — and this will be what my marriage is about, because he's been diagnosed for four years, and we've been married for 13. So I mean, we were married for nine years, and when I look back he probably always had it. I think he had it longer than maybe I've even known him — so you just never know what kind of road you're walking down. But I also think that because we haven't been together that long, we don't have 30 years of resentment you know, 'cause a lot of people when they're married a long time, there's a lot of water under the bridge. I mean I know that there are people, like women who when they get diagnosed with a major illness, will divorce their husbands 'cause they'll say, *"I don't want this to be what the rest of my life is about. I don't want to have to die of cancer being married to this guy."* I've read that more than once, so I think in some ways I feel like it's easier for me 'cause I don't have all that water under the bridge with him. I mean, just listening to women in the [support] group — you know it's all women in our group, and listening to the ones that have had more difficult marriages — it would be really hard to be in this position and have your compassion well run dry. I don't feel like I'm at that point at all with him. We had a really great time — we traveled quite a bit when we were first together, I loved

having his kids in my life. Marrying him helped me with my design career, because he was always there for me. If I needed somebody to help me lug costumes around he was always there. I feel badly that I can't include him more that way 'cause he used to love to help me, and now he's a hindrance. So no, I don't regret marrying him at all. I know that if I knew at the time that [early-onset Alzheimer's disease] was going to happen — I wouldn't have married him. It's just such a schlogg, but I'm like, glad I didn't know, I think.

I'm Not Ready for This

My mom just turned 93, and she's having difficulties, but she lives in another state, and my brothers are really bearing the brunt of that. I talk to her a lot, and they call me when she's being a jerk, because I can talk her into stuff that they can't [laughing]. My brothers are really great, they're really attentive of her, and they're really communicative, and we talk all the time. We were raised Greek Orthodox, and one of my brothers is pretty religious, but my mom wants to be cremated — which is against the rules in Greek Orthodoxy, like majorly. My mom's always said she wants to be cremated cause the whole dead body thing really grosses her out [laughing]. And my religious brother is like making sure that everything's in place for when that happens. She's getting ready to go into assisted living because her balance isn't good, and she's falling, so we're all talking about how to make that happen, and I'm really lucky that that's not falling on me. I'm the only daughter, and usually it would fall on me, wouldn't it? I'm the only daughter, and I don't have my own kids, so that would be like a natural. So I haven't had to do that, and it's kind of interesting that it's happening now, and John's happening now. I just put down a deposit for assisted living for him 'cause his internist said it's time to make sure that he has a place to go when it's time. And you know, when we signed up for the assisted living, and I wrote the check, I just felt really sad. 'Cause I think, I mean, I'm not ready for this. I'm not ready for my marriage to be over, and once he goes there, it's like he won't be at my house anymore. You know, I won't have a husband at home anymore. I won't have anyone to sleep in my bed with anymore. So there's that.

Just One More Thing

Nobody says anything good about this, you know, this is just terrible, and it pretty much is. And it's like if anybody thought this was a good idea, to watch a person just be erased in front of your eyes, it really, really sucks. But every now and again, like a woman I know said that when her dad had dementia, she said he just got so sweet, and he noticed stuff that he never noticed before, and I do say that about John. He lives in the moment, his natural sweetness is still there, his sense of humor is still there, and you just really learn to appreciate the qualities that somebody has. Maybe we pay more attention to them because that's what's kind of left of him.

I just think you have to be really matter-of-fact about the help he needs and not you know, it's like, it doesn't mean anything beyond the fact that he needs more help. That's what it is. So I just, like today — Don said, *"If you can make sure before you leave the house, that his cell phone is actually in his pocket,"* I'm like *"Oh right, okay, add that to the list."* You know, it's like I have to make sure that he's brushed his teeth, that he's eaten something, that he's dressed, and that he has his cell phone — I'm making sure that everything's charged up, and now I've got to make sure it's in his pocket. You know, it's just one more thing.

Knowing What to Do is Not Enough

Narrator: *Dr. Victor Valcour*

Interviewer: *Daniela Kortan, research coordinator*

Dr. Valcour is a Professor of Geriatric Medicine within the Memory and Aging Center at UCSF. He holds dual appointments in Geriatric Medicine and Neurology. He is an advocate for underserved populations and a voice of change for how we perceive elders and their role in society. His work and research takes him to Thailand, Cambodia, Uganda, Kenya, Tanzania, and Nigeria. He serves as Co-Deputy Director of the Global Brain Health Institute, a training ground for the next generation of leaders in brain health.

You Have to Dig In and Do It

On the bottom of my email signature, I have a quote: “*Knowing what to do is not enough. Be creative and think big to tackle the world’s real problems.*” That comes from my mentor and PhD adviser, who unfortunately died in a plane crash shortly after I received my PhD. He was a special man who founded a group to address poverty and medication access in Africa at the University of Amsterdam. He believed in what this quote says. He was a well-read man and every time you would meet him, he would give you a book – that was his gift to you. He was a voracious reader, which I admire, but I don’t do it myself. He had this passion that we should give the same kind of care to everybody regardless of where they lived; and that everybody should have access to care. A lot of his work revolved around access to HIV medications, but it got a lot larger than that. He established an organization for diseases that are forgotten, that are not cared for. At one point, during a protest, I heard that somebody threw a red paint on him – meant to indicate blood. But he knew what he believed in, and he knew how to move it forward. I heard he once

helped build a hospital in Kenya in a rural area. Apparently, he went for two weeks – he just walked out of his office for his vacation, flew to Kenya, and started building the hospital because he was working with a doctor, and that doctor didn't have a hospital. He was an inspiring person. And he was really driven by tackling real, big problems and was not afraid of trying. As the quote says, just knowing the answer, just being smart – it's not enough. You have to *do it*. You have to really dig your hands in it and tackle the big problems.

How You Can Alleviate Suffering

We're trained to cure through medical schools. At least, when I was in training, that was the focus, on how to cure diseases. Something that's hard for providers is that we need to have a level of comfort that it's not always possible to cure. And dementia is a classic area that confronts this, because we're dealing with diseases that don't have cures right now. That's probably the key thing that I wish people had a better grasp of – understanding how you can alleviate suffering, without curing, in a real way, it is perhaps one of the most important things – as important as curing.

A patient I saw recently got angry with me when I mentioned the word “palliative care.” And it wasn't in the context of doing anything in particular. It came out of our conversation about someone he knew who had suffered. I was just trying to make the connection to palliative care because, in some ways, I thought he needed to hear a little bit of that. I worried that some of his ideas for a cure were unrealistic. But he got really angry about it, and that's unfortunate.

If you mention palliative care, we often think about “death squads” – choosing who survives and who does not. This is the way we're being exposed to the concept in society. The truth is, my patients get palliative care, whether they know it or not, because it is excellent care. In my clinic, 100 percent of my patients have a limited life expectancy. As doctors, we need to keep that in mind as we make decisions. Sending people for a number of tests that could benefit them only in ten years, when their life expectancy is four years, is probably not alleviating suffering. It's probably burdening the family, burdening the caregiver, burdening the patient, and burdening the system, all

to no good end. Palliative care can be about preventing situations that are going to cause suffering. Then there's just the very honest question of, are people having pain? Are they stressed? Are they having bad relationships with their families? Is there a way we can alleviate depression, and suffering from depression? Those are more proactive ways.... That's the way I perceive things.

The Way You Treat Your Elders will be the Way Your Country is Going to be Perceived

I was speaking to the Minister of Health for a small African nation, recently. I found myself saying that the way you treat your elders will be the way your country is going to be perceived. I think there's a lot of truth to that. If you do not treat your old people in your society well, it will definitely change the perception of your society, overall. You see that a little bit in some of the Asian countries where elders are revered and in countries where they used to stay in multi-generational homes with their families. There's a sense that there's a need to care for elders.

Yet, in other societies, elders are perceived of as more of a burden. I would put the US a little bit more on that side. Not as a whole, but many times, we perceive elders as being more of a burden than a benefit. I think that whole framework needs to be flipped. I don't think the current perception is necessarily what we want; but in the very stressful lives that we live, we tend to go to the lowest common denominator for a lot of things. There's a lot of value to be gained from our elders that is now is being overlooked because of other competing challenges we all face. We have a lot of work to do in our society now to try to change the language, maybe one word at a time, starting with "elder."

I Don't Like the Word "Elderly"

It's uncommon for people to use the word, "elder." It's not in our vocabulary. We use the word "elderly," but I don't like that word. It suggests somebody who's frail. Although a lot of our elders are frail, it misidentifies the strengths that they have, for example wisdom, history

and stories, depth in narration, and depth in what has happened – how we got to where we are now. There’s a lot that can be shared by elders.

The label of elderly gives a sense that there is nothing but need. It can feel uncomfortable for people to say *elder*. Some people think that it’s a very distinct term. In a society, in a group, they are the convener, the most important person. But it also connotes wisdom and the fact that you have done things – you have lived 80 years of life! I think everyone who lives to 80 years is an elder in so many ways. They have the knowledge that I don’t have. They have 30 years more knowledge than I do.

I tend to use the term *elder* as often as I can.

I’ve Always Been an Old Soul

I’ve always been an old soul. I don’t know why. I even took a class on death and dying when I was in college. That seems odd for somebody at 20 years of age to say, “Yeah, I’d like to learn about death and dying.” But that’s who I was. Geriatrics was a natural place to go. It was particularly natural for me, because I’m not that fast. I can’t run a clinic and see 40 patients and make these split decisions. I have to get to know somebody a little bit before I start making decisions with them about which medicines and treatments they need. Geriatrics really affords you the possibility to do that. My appointments are usually three quarters of an hour long. When I was doing primary geriatric medicine, the first half hour was often spent just trying to get the patient into the room, in a gown, and on the examining table. You can do a lot of talking during that time. Then, you can really get to know people from the perspective that they’re approaching their care, why they’re coming to see you. You get a sense of what they really would want to do. You can offer more customized care.

Often Dementia is Not Diagnosed in a Primary Care Setting

The program in Honolulu where I studied geriatric medicine had a robust program on dementia. They had taken a cohort of people followed for cardiac disease – about 6,000 men. Men, because in

the 1960s you didn't enroll women in studies. Over 6,000 men were enrolled in this study for heart disease in the '60s, and in around the 1990s they were all getting into their 80s and 90s, and the investigators were able to convert the study into a dementia study. They had a robust way to look at what people looked like in mid-life and what they developed in late-life. This was a niche for them in terms of identifying cardiovascular risks in mid-life and dementia in late-life, and even constipation in mid-life and onset of Parkinson's disease in late-life. If you wanted to do research, and you wanted to be successful, you would kind of align yourself with that research infrastructure. So that's how I got engaged in dementia.

As a fellow, I wrote a project to look at how often dementia is not diagnosed in a primary care setting. We went into a group practice and told the doctors that we were going to ask them, after a visit, if their patient had dementia. We did this for 300 people, and regardless, the doctors had no clear idea who was demented and who was not. We later showed that the people who were impaired were more likely to get into car accidents and yet, the doctors didn't know.

So you know, you take on a project like that as a young person, and it really kind of changes your life. That's how I got into dementia, and I've just been building on that ever since.

A Public Health Approach to Preventing Dementia

The baby boomer generation is kind of a different generation. They're going to push for advocacy around care for these things. It's a different generation of people, and that may push the envelope some and a big impact is going to occur through technology. But the thing that will change all this, that will make the biggest change, is when we can convince people that there's treatment. Right now, there's a sense that there's no treatment.

I think there's a lot that we can do now around a public health approach to preventing dementia. If people understand and value their brain health, they may push to monitor it, and at the same time try to address factors that could reduce their risk for deterioration. For example, exercise, maintain a good weight, stay cognitively active, and don't smoke – all the things that would prevent a person from getting

a stroke. Make sure they know that if they have an irregular heart rate, their doctors should know about it and see that it's treated. If we can get that signal out to people, that there are things they can do, it may change things a little bit.

We Don't Have the Luxury of Waiting for the Magic Pill

I give a talk for the Global Brain Health Institute called "Preventing Dementia in our Lifetime." It's about the narrative that we have the ability to prevent dementia. I quote a paper from Kristine Yaffe, one of our faculty, where she's modeled what would happen if we really aggressively treated hypertension, smoking, obesity, and sedentary lifestyles.

If you look at the frequency to which these diseases exist around the world, and you look at their correlation to developing dementia, you can start to get effect sizes for how much they have an effect on dementia. You can then begin to model what would happen if you decrease those risk factors by 10 or 20 percent around the world. In those models, it appears that you can have a fairly substantial impact on decreasing the prevalence of dementia. So there is a public health approach to trying to decrease our risk for this disease. It is not something where we need to wait to find a drug.

People have been reticent to step up to the plate for two reasons, I think. One is that people in general don't like to alter behaviors; they'd rather take a pill. It's true for me. I take a pill to make sure my cholesterol is in a normal range, where I could just lose 15 or 20 pounds, but it would probably take me another 20 years, and I'm not sure I would get there. So this is how we often approach medicine. I think that's a big barrier to a public health approach to preventing dementia. The other big barrier is that the data are not completely solid. The data are primarily epidemiologic showing associations without causality. There are scattered data that show if you change these risk factors, you do get better outcomes; but there are very few randomized trials to inform that we could really accomplish this.

We are going out on a limb a little bit, but we have pretty good data that a lot of these things will help your heart, your joints, and probably help your mood. And we have a crisis. The burden of caring

for people with dementia is more expensive than heart disease, cancer, and stroke combined. The costs are astronomical – caring for someone with dementia approaches one percent of the global GDP. There is no disease in the world that even comes close to that. If we have the increases in dementia that we are expecting in the next 30 years, countries will become crippled if they care for them properly. So that's what my talk is on. That we have evidence that we can do a lot. It's not perfect evidence, but there are a lot of secondary gains – and we really don't have a choice. If we don't do something soon, we are going to be in a huge pickle. We don't have the luxury of waiting for the magic pill.

*“Knowing what to
do is not enough. Be
creative and think big
to tackle the world’s
real problems.”*

hear/say

hear/say

hear/say storytelling project

Storytelling is DNA

Narrator: *Cliff Mayotte*

Interviewer: *Caroline Prioleau, Writer & Designer*

Cliff Mayotte was the sixth Hellman Visiting Artist at the Memory and Aging Center from 2015–2016. Cliff serves as Education Program Director for Voice of Witness, and his professional education career has included years as a full-time classroom teacher, theater director, curriculum designer, program director, and arts instructor. His belief in the power of storytelling feeds his daily practice.

The Megaphone

Voice of Witness is a nonprofit that focuses on storytelling and nurturing empathy through our oral history book series that focuses on contemporary social justice issues and human rights crises in the United States and around the world. We're trying to amplify stories that might not otherwise be heard, have been under-represented and under-reported. I think what makes our work unique, and by extension our education program, is that we're not editorializing about issues. We're doing things that a lot of journalistic sources and historical reporting don't do. We're spending time speaking to and hearing directly from and listening to the stories of the individuals who are most directly affected by these issues and sharing their own stories through oral history. Through our education program we are facilitating and encouraging, and hopefully inspiring, other classrooms and communities around the country to tell their own stories.

The Larger Balance of Stories

I think in the world that we live in today, we create access, or in some ways we limit access, to the number of stories that actually need and

deserve to be heard. Whether it's mainstream media or just lack of access, there are so many stories in the world, and we're only hearing an incredibly small portion of them. Everybody is a part of a historical narrative and not just the people that have a microphone or not just the people who are at the top of some sort of social or economic or cultural food chain. That they are the ones whose stories become history. And everyone else's stories, well you can talk about them at family gatherings but they're not actually part of a larger context in a larger balance of stories. I think that for all of us, the world, and our perspectives, get a lot bigger from having an opportunity to engage with and hear stories from a variety of places around the world. Multiple perspectives and experiences nurture empathy. I think it becomes a place for us to acknowledge what connects us as human beings.

Seeing Where It Goes

There's a certain amount of "seeing where it goes," because that's where the wonderful, unexpected stories come from. And so often that when somebody who shared that story is reading it or listening to an audio file of the interview, they say, "I can't believe I said that!" or "I haven't thought about that for a long time!" They begin to interpret their own experience in a really, really different way. There are the experiences that we allow ourselves to share on a daily basis. We all have our scripts – "this is what I am comfortable talking about." I wouldn't say that there is an agenda. There is an intense curiosity about that person's experience, and I think there's an understanding that while we want to get a sense of this narrator as a full and complete human being, and not just focus on one story, there is an understanding that this aspect of their experience is going to be discussed as well. And part of that story is those stories being underrepresented. "We really think it's important for the world to hear this aspect of a story, because I don't think people know. And I think they'd be really excited and encouraged or outraged or inspired by hearing you share this part of your experience." Without pigeonholing them and saying, "This is how we identify you." That's a piece of who they are, but that doesn't begin to tell the whole story of who they are.

Who's in Control?

We connect with people who are sharing stories about their growing up and their families and what they think about and what they care about and what frightens them and the kind of bikes they like to ride and so many things. Not just that one part of that story. I think it's something about power for somebody to say, "Look, I only want to hear about this part of your story. Because I'm going to take that story and share it in a way that maybe you'll appreciate and maybe you won't, but I'm dictating the terms." I think in oral history, the narrator's in control of the interview. As opposed to the other way around in journalism, like there is this authority figure that you're trying to answer the questions properly or "I want to give them what they want" or want to make them happy. I think oral history is a little bit different and a bit more democratic.

The Unheard Stories around Dementia

The origin of our collaboration began with Jennifer Merrilees becoming inspired by a Voice of Witness (VOW) book she had borrowed from Diana Cohn. The two of them discussed the potential fits between the dementia world and the VOW methodology for amplifying unheard voices. Diana connected us with Jennifer and we started a series of conversations with the UCSF Memory and Aging Center (MAC) about VOW participating in their Hellman Artist in Residence program. "Maybe what you do at Voice of Witness, and the kind of storytelling projects you sponsor, maybe there is potential between Voice of Witness and MAC in telling the unheard stories around dementia and Alzheimer's." And that was really intriguing to me, thinking about how this oral history methodology, and the idea of nurturing empathy and listening through storytelling, could apply in a clinical setting. How to combine the clinical methodology that MAC practices with the storytelling methodology of Voice of Witness. And so that was a really inspiring idea. You were on board from the very beginning. In fact, I think you were the one who had first suggested the artist in residence idea! It just seemed like a very good match, and

I think it was an opportunity for both organizations to broaden and expand and experiment.

A Mosaic of Stories

This residency is very different from other artists that have participated before in that one of the goals that I see as this collaboration is that the stories of MAC are the subject. As opposed to me as an artist selecting what aspects of what goes on here at MAC to focus on for a story or for an artwork or for a play. We are literally taking the daily-lived experiences of caregivers, patients, providers, nurses, neurologists, pathologists, brain scanners and saying, “What are the stories around dementia and Alzheimer’s that you think people need to know about?” It’s really fascinating because we have very stereotypical or incomplete ideas about what dementia and Alzheimer’s is. And I think the only way we can really experience what it’s like or to share in an empathic way what it’s like for someone to have Alzheimer’s or to care for somebody with Alzheimer’s or dementia is to hear their stories, and to hear them as a first-person narrative. Relatively unfiltered. So I think for me, the vision of the project is to create a mosaic of stories around what happens at MAC and to share it with the general audience.

They are Both Called History

There is a big connection between medical history taking and oral history taking. Medical history is looking at so many aspects of somebody’s experience: medical history, diet, age, location, geography, residence, heredity. Things that impact their health and who they are. The same thing goes for an oral history, because somebody is sharing aspects of their personal experience that have to do with time and place and experience and family. So I see them as a very similar path. They are both called history. They’re both narrative, and they’re both storytelling. A medical history will have a much more clinical approach, but an oral historian is very clinical as well in mining aspects of personal experiences to come to a lot of the same conclusions.

Mind Blown

My experience as a Hellman artist working with the MAC has been completely mind-blowing and completely life altering. I think for some of the reasons we've been talking about in terms of the similarities between oral history and storytelling and medical history and narrative.

I was thinking about one of the case conferences that I was able to attend, and I was sitting with a group of people talking about somebody's history. And we heard the update from a neurologist and a registered nurse, and then Dr. Bruce Miller was able to comment on some of the findings and experiences. Then the patient and a caregiver came in, and an interview took place with Dr. Miller. I was watching Dr. Miller interview the patient and the caregiver, and there were a lot of the same questions that I would ask in an oral history interview. The strands of the stories were quite different, but there was an interesting perspective that each person brought to it.

I think one of the things that was really incredible to me was watching how somebody's professional and personal experience shaped the story that they told or how they interpreted the tea leaves or the brain scan of that person's experience. That was incredible to be in the room with that. Because I felt very connected to the other people in the room and not just, "Wow, I feel connected to a neurologist." But I felt like we were all dealing with various kinds of narrative, and it was just a question of how we interpret that narrative, and how we share it. That was incredible to me, and I really enjoyed learning about the links in a chain in a person's medical history and how that's shaped who they are at this moment and potentially where they might go in the future. I'm always thinking about what's going to happen after the story's over. Because our stories end at some point, I think what's amazing and mind-blowing about MAC is that you're interpreting what that story might be 10, 15, 20 years from now. And making some really informed ideas about what might support that family or that patient or that caregiver as that story evolves 20 years from now. So, I'm really blown away by how far ahead MAC thinks in their storytelling.

The Culture Fortress

My wife is in the medical field, and so she is always encouraging me to advocate for myself and to really not be afraid to ask questions. Just like a narrator and an interviewer, it's like as a patient, "I'm in charge! It's my story. It's my life. It's my health that we're talking about right now." And quite often I get sort of overwhelmed in the clinical environment. I can feel very shut down and just sort of accept everything like, "This is okay. Whatever is said, I don't need to ask any questions. I feel a little uncomfortable doing that." And I think what's been inspiring to be around MAC is that this is an incredibly impressive institution and yet, and the work here that goes on is extraordinary and deep and philosophical and comprehensive, and I feel very comfortable here. I feel very comfortable talking to anyone. I'm in this incredibly huge, immense culture fortress – this teaching university – and everybody I talk to is inclusive and accommodating and kind and great listeners. So this is a very empathic building with lots of great storytellers and lots of great listeners. And I don't always experience that. And so that has given me a lot of courage going forward. So that has been a huge influence going forward for me. Advocating for myself.

Gravity Works

I am really starting to see the difference between aging and growing old. And I've been thinking about that a lot during my time here at MAC. Aging is something we all do. And there's a process. We don't invite ourselves into that process, we are part of that process whether we want to be or not. And I think it's how we decide to engage in that process. I think a lot of people think, "Well, I'm growing old. And I stop doing this, and I stop doing that. And this is not important anymore. I don't have the strength for this, or I don't have the willpower to do this." And yes, there are setbacks and challenges, and there are difficulties, but I think the aging process is a lot more holistic, and it's looking at the fact that gravity works. This is happening to everybody. But if you think about the quality of your life and the quality of the moment-to-moment of how you experience the world, how you experience your friends

and your family, your culture, your passions. I think that's aging. As opposed to growing old.

Cultural Memory Transfer

I think the best of our books and education projects we've supported have been multi-generational and inter-generational. There's something incredibly powerful about an elder sharing a story with a younger person. And so I think that's been a constant aspect of our work. It's about cultural memory transfer.

I think, for example, of a lot of high school students that we work with. They might have an assignment that is connected to an oral history project that they are doing through Voice of Witness that might be, "Okay, you're going to interview a grandparent. Or an elder in your family. Or a caring elder in your community or your family." And at first, there's the eye-rolling and, "Oh this, oh no, I don't want to do that." And then when the interview takes place, that student comes back to class, and they report to their teacher, "*That was amazing!* I had no idea that my grandmother did that!" Or, "She never talked about that aspect of her story before. And now I see them in a totally different way. In a beautiful way. My grandmother occurs to me in a different way now, and I'm in awe of her."

Curiosity and Empathy

I think we're very socially conditioned to *not* share, even though that's something that's a human impulse. We want to share. Empathy is a way to belong to each other and to connect with each other. So I think that's a natural drive that we have. But so much social conditioning goes against that. Don't talk to strangers. Don't do this. Don't do that. Don't stare at somebody. Don't make eye contact. And I think as kids, it doesn't honor our curiosity about other people. Curiosity and empathy are connected. How can we be curious about somebody in a respectful way? In a way that they still feel seen and acknowledged and respected and not judged and not feel like their privacy and their sense of personal space is being violated in any way. I think as a society, if we

allowed ourselves to be more openly curious about each other, I think the stories would start to flow a lot more. One of the things about social conditioning that impacts how we tell stories, we feel like we're not allowed to share our story unless somebody else gives us permission. As opposed to being, "Well, I'm really curious about sharing my story," or "I'm really curious about hearing yours. And I don't need permission from somebody to do that. I'm just going to put myself in that space, and I'm going to see what happens."

There's something very elemental about sitting down with somebody one-on-one and having, in oral history what we call, a "mutual sighting" between one person and another person – seeing and being seen. What we've experienced in our work at Voice of Witness and through oral history is how that makes people feel in their own bodies as a result of having that experience of listening and being listened to. We almost get high off of it. We laugh a lot more, and we smile a lot more, and we feel a lot more connected and a lot more a part of things than we normally would.

Flipping a Coin

I think art and health care and health care and art are two sides of the same coin. The ability to express, the ability to feel creative and imaginative is very connected to health and education and wellbeing. I think the way we see and experience each other through art is very healing, and it creates a sense of community and connection. People who are dealing with various health care issues feel very isolated. Art is a really powerful way to lessen that isolation. To feel, "I'm not alone in the world. Other people feel what I feel. Other people think what I think. Other people are frightened of what I'm frightened of. And I can read a story, or I can look at a photograph, or I can listen to some music, or I can write a poem that lessens my sense of isolation." And I think *that* in relation to health care and art, that connective tissue, is very powerful.

One of the connections between art and health care is the capacity for listening. The capacity for listening to somebody else but also listening to ourselves. Listening to our own impulses and our own desires and how to communicate that.

Artistic Commitment

One of the surprises for me has been the incredible commitment that I have experienced from everybody who has participated in this project. Not just commitment to their practice, like, “Well, I’m a very good neurologist,” but their intense commitment to the wellbeing of everyone that they come in contact with: patients, caregivers, everybody. And how connected they are to that, and how artistic everybody is in approaching their work here. The clinical work is very evident and that people are incredibly competent in a very clinical way, but I’m really surprised and impressed at the humanities aspect. I feel like, “I know I’m at the Memory and Aging Center, but I feel like I’m at a small, liberal arts college.” So, that’s been a real surprise.

Make No Assumptions

I think at MAC, the world’s gotten a lot bigger for me. And for an artist, I think that’s crucial. If the world gets too small, you start assuming things to be true. One of the things that has really influenced me about MAC, and will impact my work going forward, is that I will continue to check my own assumptions about what I think to be true and what I assume about somebody else. Especially as I question and check my assumptions around ableness. And I think incorporating that into my work in a more mindful way is very important to me. And that’s something I’ve definitely learned in my time here at MAC.

Wait for the Opening

The way that I experience now somebody with dementia, or even a caregiver or somebody who is supporting somebody with dementia, is very different. Like many people, I felt an otherness – somebody with Alzheimer’s was an “other.” Because I had a lot of assumptions, I had a lot of surface stereotypical ideas about what that was like or what kind of a person you must be. For instance, there’s absolutely no way for me to communicate with you. Better for me and better for you if I

just ignore you. There's going to be no common ground. There's going to be no point of entry for a relationship. In the past, I have found that frightening, and I have shied away from that. And not that I feel like I am a clinician now all of a sudden, but I think there's a sense of ease and my natural impulses for connection are much stronger now.

I think I have a greater capacity to listen and to take people as they are and take them as they come. To look for an opportunity or for an opening for a relationship or communication but not feel like I have to lead that. Or that I am in charge of that in some way because I have a sense of my own ableness that has me think I don't have to see you in the same way – that you're incredibly able and you're incredibly profound and curious. I'm going to wait for an opening to listen and communicate and create relationship.

And That's Where it Started

My path to oral history as a storyteller was primarily through performing art and primarily through theater. I was doing a lot of teaching of theater and teaching of humanities and English and storytelling and journalism. An aspect of the storytelling involved oral history. At one point I had been hired to direct a play that was based on an oral history, Studs Terkel's book *Hard Times* about The Depression. And in preparing for this adaptation of Studs Terkel's book, I was reading Studs Terkel for the very first time. And I was completely blown away. I went back to the producers, and I said, "You know, all due respect to the person who did this adaptation, I would much rather stage Studs Terkel's book than do the adaptation of it." And that's where it started. And my teaching and learning has combined aspects of social justice and civic engagement and art and storytelling and journalism. And I think where they have all sort of come together has been around first person narrative and oral history. But I think I have always had an attachment by inclination and training to being a storyteller.

The Chatty Curator

I think the difference between biography and oral history is that oral history is a lot more surprising. Oral history sneaks up on you a little bit more. And oral history is inconclusive. Whereas biographies are a little too carefully curated, a little too manicured. And I think it's very selective. I think oral history has the capacity to include more of the narrator's personality. I find oral history more surprising and more open-ended and a little more relatable. Because a biographer is telling me about somebody, and in an oral history, they're telling me about themselves.

I think most people, if they're writing an autobiography, work with a ghostwriter. There's an oral history element to it certainly. But I think that those experiences are so tailored, there's nothing left to surprise. I can't imagine somebody writing an autobiography and completely surprising themselves.

In autobiography and in oral history, there's a freshness. In an oral history, there's a sense of that person's voice and vernacular and a way of communicating that kind of jumps off the page at you, even if you're reading it (as opposed to listening to it) that I don't personally experience in an autobiography. I can find an autobiography very thoughtful, but there's a feeling of somebody carefully presenting a curated museum. And a difference between an autobiography and an oral history is I can be walking through that same museum but the person whose story is the museum is actually standing right next to me talking to me all the way through the museum and interpreting their own experiences. As opposed to me just staring at something and reading the sign. Oral history – the chatty curator!

Ethics and Practicalities

The process of one of our oral history trainings is looking at the ethics and practicalities of conducting oral history. And I think it's looking at how those two speak to each other. You explore power dynamics and representation and creating brave and inclusive spaces for people to share stories. How do you take those ethical considerations

and translate them into technical choices? Like, how do those ethics translate into an editing choice? And how can I honor my ethical considerations in honoring a narrator and representing them in the way they want to be represented by practicing a particular editing technique? Or looking at this audio recording and how can I incorporate that into the process so that my ethics and the technical choices that I make are speaking to one another? That they fit together. And not just, “I’m providing a safe space for a story, and then I’m going to edit this in a way that’s going to be really brutal and very non-inclusive and not think about the ownership and the agency of the person that told me the story.”

Some of the ways that the ethical and the practical speak to each other is in what we leave in and what we take out. How much of somebody’s “voice” am I really going to try to maintain, and what does it mean to “correct” grammar, and how do I do that in a way that’s going to honor the narrator but also be compelling and clear for somebody that’s reading it? Or somebody that’s listening to it. In part of our training and part of our workshops, we help participants find a balance between creating a compelling narrative that an audience is going to want to read because that’s part of the intention of our work, and at the same time, honoring a narrator and a storyteller’s sense of agency and power. We also think about delivery systems for oral histories and what’s going to be the best delivery system for the community those stories are coming out of? You know, you might decide for your oral history project, “We’re going to create this incredible website” but the community around these stories – maybe 70 percent of that community has unreliable internet access. And so, that’s an example of a practical and an ethical consideration at the same time. Part of the ethical and the practical becomes a question of access. Who has access to the stories, and how are they going to be accessed? I think multiple points of entry and delivery systems are very inclusive. Because if one system isn’t quite perfect, hopefully, between several, you’ll make an impact, and people will have access to their own stories.

Connecting our DNA

On the first day in Genentech Hall I was completely overwhelmed and a little frightened, because it's a very imposing building. It took me a little time to feel comfortable, and it was a sort of labyrinth of conference rooms and offices and places where really amazing, important things were being done. And I just sort of had to just get over that. Until I connected literally with the DNA in that building (there is a large DNA sculpture in the lobby), and thought, "Okay, this makes sense. This is the visual metaphor for me. Storytelling is DNA. We're connecting our DNA through storytelling." As soon as I felt like I was a part of what was going on there, I was fine. And everybody at MAC was very accommodating and made it easy for me to get over myself.



**The painting that Diana “loved” by David Wetzl.
S.C.I.P. (Still Content and Image Provider), 2000. Acrylic, graphite and collage
on panel, 42 × 48 inches. Crocker Art Museum, Collectors’ Guild Purchase,
2001.50.**

Stories from “Dementia Land”

Narrator: *Diana Daniels*

Interviewer: *Sarah Dulaney, clinical nurse specialist*

Diana Daniels is an art curator and caregiver for her husband, artist David Wetzl. David was diagnosed with semantic variant frontotemporal dementia at UCSF in 2012. They live in Sacramento and participate in research at the UCSF Memory and Aging Center.

Falling In Love

David and I met in December 2001, at the Crocker Art Museum, where I was recently hired as a curator. During the hiring process, I spent several minutes examining a painting in a little space outside the director’s office. The museum had just acquired a painting by David that I found fascinating. A few months after coming on board, I was doing a reinstallation of the contemporary gallery, and of course, I put this painting on view. The chief curator, my boss and a longtime friend Scott, asked if I would like to meet the artist who created the painting that I “loved.” We were introduced to each other at the museum’s annual fundraising ball. David and I quickly found we had a lot in common. I had only recently moved to Sacramento from Oakland and David occupied a live/work space in Oakland. We both loved Oakland’s Parkway Theater, walking at Lake Merritt, and several of the same restaurants. At the end of the conversation, I gave him my actual phone number! When Scott and I left the building that evening, he told me, “*I think you may have met your first husband.*”

Signs of Change

By 2005, David and I had been living together for three years. I pinpoint 2005 as the year David's art began to change. Nothing drastic, but some of the ideas that now engaged him appeared rather oddball. When I would question him about his choices he was often defensive. He had a strong ego, an intensely stubborn streak, and a love of debate, especially about art and art theory. With me, his coup de grâce was, *"Art historians only care about words, not the art."* No counter argument I offered persuaded him to rethink some of what seemed like missed musical notes in the new paintings or how off-putting the overly elaborate titles he bestowed the final work were.

The other thing that stood out that year was a decline in his spelling abilities. David taught at California State University, Sacramento, and at Sierra College in Rocklin. For his courses, he did a tremendous amount of prep work. He was incredibly dedicated and prided himself on his commitment to transmitting fundamental skills to students. When we were at home, he was often prepping for school in our "office" while I read or watched television in the adjacent bedroom. He began to occasionally yell out to me to spell a word for him. When it seemed clear this behavior was to be a habit, I thought to myself, *"You're being lazy. Look it up yourself! You've got a dictionary right there on the desk."* Surprisingly, I mostly calmly offered him the spellings, only having an outburst every so often. But I was puzzled, David was an excellent writer and had published art criticism before teaching became all-consuming. His taste in television also began to change. The programs that he followed were increasingly feel-good, family-oriented shows, especially those featuring teenagers. I thought okay, well he grew up in a noisy household, so maybe there was something comforting to him in more idyllic visions of family life, and maybe a bit of mid-life nostalgia, but part of me was like, *"This is weird, what's going on?"* What pushed us towards getting a medical diagnosis happened in June 2012. We were packing for a camping trip when David came to me with a pair of shoelaces in his hand and asked, *"What are these called?"* This was a trigger. Certainly, some behaviors had begun to make him appear like a cautious old man. Some even reminded me of the behaviors or symptoms my father displayed during his battle with

progressive supranuclear palsy. We lost my dad in 2009. But with the shoelaces, it all suddenly added up.

It turns out that friends were becoming increasingly frustrated with him also, but they were all too polite to say anything to me. There were hints, David would sometimes tell me how his relentless teasing had made someone sore. However, it was only when I brought up the topic with his friends, giving them permission I guess, that the sharing happened. For example, he needled one of his best friends by asking questions of a highly personal nature, and no matter how often he was asked to drop a topic, he just would not. He would repeatedly ask things like, "*When are you getting divorced?*" "*When are you getting divorced?*" "*When are you getting divorced? Are you going to marry so-and-so?*" After others began sharing, what became apparent to me was how much effort and ingenuity he had been putting into concealing and masking the personality and behavioral changes confronting him. There was some relief in knowing that my growing frustrations were not just about us as a couple. Frankly, it had begun to appear to me that I had married a great talker turned jerk. [laughing] When his judgment began to slip in tiny ways, it was all sort of at this intuitive level for me, I was never acknowledging it. I think maybe that's the case for a lot of people. But just because you are not immediately cognizant doesn't mean there is not a running loop somewhere in your brain noting and processing things. So if he was going out with his friends, I'd say things like "*Now remember, no one else is going to wipe your butt when you're old.*" But now I feel like I threw bad thoughts into the universe and bad things happened. But at the time, I was doing it in this sarcastic, meant-to-be-funny way.

The Balance Between Safety and Autonomy Weighs on my Soul

Being a caregiver for him, it's like being a parent. I try to balance making sure he has dignity and autonomy, but then also, especially in public, putting up this very protective mommy-like feel. You know, touching him a lot, saying *honey*, anything I can to give indicators to other people that something's not business-as-usual here. That way if he doesn't give someone enough body space, cuts somebody off, barks or whistles in strangers' ears, or displays other repetitive behaviors

like asking friends and strangers over and over, “*How many gods do you think there are?*” or “*Do you know who I am? Do you know what my name is?*” To which he answers that he is *Payaso*, which is Spanish for *clown*. I just want people to have cues that it’s not being done to them because he’s a rude jerk. To know he needs a bit of accommodation. The nice thing about an urban area is people seem more used to unusual behaviors. When I provide the explanation for the behavior, almost every time you will see a change in their face. They become a little bit more understanding, or at least less irritated or frustrated. He does get more excitable or agitated in public and I have to monitor him nonstop. But he’s such a social being, he wants to engage with others and he has this energy to do so. At restaurants he just has to get up and walk around, like he’s driven by a motor. If the restaurant has a television, he will go up to the bar and ask that they change the program to golf, and he really expects the world to just do everything because he’s more like a four-year-old. It’s his universe. That said, he looks so healthy — ten years younger than his age — which makes such interactions very confusing for others to process. He doesn’t believe he is entitled, he just no longer understands that other people’s needs ought to be considered, too. So I feel this need to make sure nothing bad happens to him. Yet, I don’t want to cut him off completely from the world. Not while he still has the motivation to do things. It’s brave of him to venture out into the world and be active. But letting him go, and not being there to monitor him, I know I cannot keep him safe. He cannot self-monitor. He is disconnected from understanding how his behaviors might endanger him. And he has always been strong-willed. I am afraid that he will get beaten up, physically harmed, even perhaps fatally.

What is Lost and What Remains

David has always been the most motivated person, I have known. when he made the decision to be an artist, he worked hard to make it happen. For decades he worked as a carpet subcontractor, laying carpet and linoleum. He paid his way through graduate school. He earned his MFA from the San Francisco Art Institute and before that earned his MA in studio art at California State University of Sacramento. When his first marriage failed, he lived in his art studio without hot water, and

he was fine with that. He was willing to do whatever it took to succeed as an artist, even if it meant living lean. And it paid off. When he began teaching, his finances stabilized. He did have to commute from Oakland to Sacramento for those jobs. I used to feel guilty that he made the decision to leave his live/work space in Oakland because of me, because frankly his prospects for gaining greater attention and having a fuller career were better in the Bay Area. I made him too bourgeois. David always was an early riser, he only ever needed six hours of sleep. He could get things done — at home, at school, in the studio. That drive is still with him, just altered. He still gets up every day to do his art on the computer and at his studio. And he does go frequently to the Target, close by, right in our neighborhood. Although he picks up fewer and fewer things on the household shopping list. Instead, he gets an ever-narrowing range of items he wants like pretzels. Although, he does remember to buy me milk and coffee.

He's just now starting to get frustrated. In early April, we lost his father. A sudden health situation arose that appeared at first to be serious, but not critical. And, then a stroke occurred. The family wanted to be together with him when the end came, but David was too agitated. He kept repeating, "*I gotta go. I gotta to. I gotta go.*" And he pulled and yanked on me when I resisted leaving. It was upsetting for his mom that he would not stay and during the ride home, I pulled the car over and yelled at him about his behavior as loudly as I could. I have a theory that when necessary — and only when absolutely critical — if I yell at him boldly enough, I can make a connection with him somewhere deep inside his brain. Of course it makes me feel terrible morally, physically, and emotionally. But it worked, by getting so worked up I found that connection, and he could articulate for me that being in the hospital was just too upsetting for him. It was too hard for him to see his Dad that way. I explained to him that it meant a lot to his mom for us to be there, but he said it was, "*Really, really hard.*" And I understood and didn't force the issue anymore.

The difference between before the disease and now is stunning. David had these amazing social skills, he could start a conversation with anyone and put people at ease. Now he has only a few topics of conversation he can follow. I, on the other hand, must steel myself up to meet new people. I will talk too much to fill silence. David had the gift for chit chat. I loved knowing that with him, no matter where we

went, we were going to fit in just fine because he was going to make that happen for us. Now his conversational topics are so limited and offbeat that it is off-putting to others. And, his conversation is one-sided, because he can no longer process or comprehend what others say in return. He's just lost so many words. But that need to be socially engaged remains.

Finding Little Islands of Time

I think one of the hardest things of being a caregiver is time management. My time management skills were maybe questionable to begin with, and now they really get taxed! I always feel like I'm trying to find little moments, little extra moments of stillness or times where I can veg, so I'll have more patience as we go forward. Before we had the diagnosis, back in 2009, the year my dad died, he started calling me at work several times a day. More than he ever had in years previous. It was sweet, but he would say silly stuff and sometimes humorous but inappropriate stuff. Nothing scandalous, but my office space at that time consisted of a cubicle in a very tight environment. So I was highly aware that even when I'm saying "*Okay hon, I gotta go. I gotta go now,*" and this routine would repeat, and repeat before the call ended, that I was annoying my colleagues. Of course now [laughing], it only occurs to him sporadically to call me at work. Almost never. We can go an entire 8-hour day without conversing. Even if I call him to check on him he will not answer the phone, generally because he is hyper-focused on what he is doing in the moment. He chooses to ignore the call. Or, he has the music up too loud. Or maybe it doesn't even register at all that the ringing is something he ought to attend to. This is one of those little things of unease that as a caregiver you are constantly managing. We're almost ready for services to assist, but not quite yet. I've cut my hours at work, but it still doesn't seem enough. We're in an uncomfortable holding pattern. It's becoming more nerve-racking to leave him for so long. It's more about my sense of, is it moral for me to leave him when he's impaired? Or will other people think it's immoral that I leave him alone? He is impaired; he doesn't understand what 911 is anymore, and things happen. Last September, we were victims of a home invasion, someone kicked in the front door. David was not at home, but when he

did arrive he didn't know how to cope. All he could explain to me when he called me at work was, "*It's so bad what they did. It's so bad. It's so bad.*" Of course, I do not know what he means by this. The saving grace in the situation was that my commute from office to home was five minutes.

Try to Enjoy it When it's Enjoyable

When we're in restaurants, and I am monitoring his behavior — for example, he is up and roaming around or repeats his order over and over to the wait-staff — I will offer, "*Apologies, he has early onset dementia.*" To which, David will look surprised and ask, "*Dementia? I'm suffering from dementia?*" And, then laughs a laugh that I've come to realize expresses either his embarrassment or discomfort. Those emotions are still there somewhere, just not readily available. This particular laugh may be the only way he can express these feelings. I know it bothers him that I am forthright with people, but at the same time, it's easier to be forthright than to let pass all the awkward thoughts that play across people's faces. Sometimes, if the restaurant experience gets too awkward, I end up tipping nearly 40 percent, because it's not easy when you're wait staff to keep a smile on your face while some strange man repeats things, especially when other tables are gesturing for your attention. If he were an actual six-year-old or four-year-old getting up and running around tables, it would all be a bit more acceptable. But with David looking like a perfectly healthy middle-aged adult, people expect him to behave appropriately. I know that at the support groups the professionals underscore that it is the disease and not the person behind the behavior. Understood. But, they also take the position that you should still treat them like adults. I've found that more and more, child-rearing techniques are better. They make a huge difference in soothing him. And, they help me keep my patience. What I am noticing more and more is that if his mind is not preoccupied, at a dining table, for example, then he wants to be done faster and wants to leave sooner. When he's eating, he's in the moment. Once he finished, he's ready to move on. No patience for us to eat leisurely and enjoy adult conversation. For him, because he can't participate in conversation, there is a vacuum. He has to fill the vacuum. Golf on TV is terrific. Now I try to remember to bring professional sketchbooks and colored pencils

for him, if there will be a long wait in public to keep him occupied. I just try to remember what it was like to be younger and have a different sense of time and feel that everything was taking forever, I try to remember how horrible that feeling of waiting was. And if that is what he is feeling, or if that is the closest I can get to understanding what he is feeling, then I want to help him fill that void.

It took me so long to find David. When I think about these things I get very sad. So most of the time I just push it down, rather than probe the loss. I overshare details about his behaviors with family and friends, I couch them as funny stories from “Dementia Land.” Sometimes the stories are rather sweet. I recently taped David rediscovering his shadow. It was early evening with the sun getting low in the west. I was still out of the car, but David was calling and gesturing to me, “*What is this? What is this? I’m so tall! This has never happened to me before!*” [laughing]. Right away I just knew what he meant, so I managed to get my cell phone out just in time to record the remainder of the encounter. David discovering his shadow! I went over and stood next to him while filming and he says, “*Look at you. You’re so tall!*” and again, “*This has never happened before!*” It was this charming moment. I did share it with his family who were at his father’s bedside in the hospital. I know it was sad for them, but I think they appreciated the sweetness and joy of the moment. There’s this certain point where you have to accept it for what it is. Do not be mistaken that I feel these are redeeming things in being a caregiver. I think it’s a shitty deal. None of the stuff about life and lessons learned, building or improving character sugar coats this for me. But on the other hand, if you recognize that this person’s experience is kind of precious... well, for me, if this is the journey he is on, then I am going to try to enjoy it when it is enjoyable. Again, I don’t think there’s anything rewarding about having my husband reduced to a moment like that. I don’t see it as a personal reward. I just see it as this is an interesting and darling and precious and poignant signpost on the journey. For me, you manage to cope and to adapt because as humans we are supposed to adapt. If you don’t adapt, then you utterly fail yourself, and you fail the person you love. It’s a shitty deal, but sometimes the stories are funny. I don’t mean to embarrass him, but sometimes the stories are just too cute not to retell.

Telling the Full Story

I'm trying to recall a recent story that would fall into this category. Oh, this is a good one! [laughing] So I was having trouble with a sinus infection and not really moving out of bed. I was lying in bed — failing as a caregiver to make lunch — with my aching head, imploring David to make me a sandwich when he made his tuna. So getting him to understand that I wanted peanut butter and jam — *jam* being a new addition to his missing words — was a challenge. Eventually, I directed him to “*use the red stuff in the refrigerator.*” Which he did. I could see the red peeking out of the bread. Only when I bit into it, I discovered not a strawberry/peanut combo but ketchup and peanut butter! Not good in any way.

I try to squeeze every little bit of effort out of him that I can get. Whether that's because I know it's “use-it-or-lose-it,” it's good for him, or because I'm damn lazy [laughing], I do know that everyday things are going to get tougher and tougher. So if I can keep some lazy in there while I can... people in the support group, when I tell stories like the sandwich or about keeping some lazy in my routine, they always say they wish they had that back for themselves; the little moments of interaction. I guess where their loved ones are is beyond where I am with David right now. So their words remind me to be patient and somehow find the humor in the journey. Because this too will change and disappear. I'll reminisce about how great it was when he could make me a peanut butter and ketchup sandwich, or interrupt me in the bathroom when I'm getting ready for bed in order to shake his penis at me, to remind me it's there. [laughing] And I'm like, “*Yes Honey, put that thing away, yes I see it.*” You know, it's like his way of letting me know that he's all man! [laughing]

On Mother's Day, we were gathered at our house, and I come downstairs to see him standing next to his 84-year-old mother with his pants open! Her response was very dramatic, “*No! Don't, don't do that to me!*” as she covers her eyes. The best part is David says, “*But, it's Mother's Day. You're my mommy. You used to see this all the time.*” His brother and I were looking at each other, and then we both lose it. I composed myself enough to say, “*Honey, that's only for me remember? That's only for me — not for anybody else, only for me.*” [laughing] Telling this story I realize could

embarrass him still, but then again I'm like, well the humor, the stories, are what I am getting out of this deal. [laughing]

On that particular day he didn't really remember or understand why we were having his mother over. Even before his family arrived, he ate his meal instead of dining with all of us. His mother, has such a hard time with such things; the disease has been very hard for the family. Accepting the progression and decline are particularly hard, they are often caught off guard. I live with him every day, so I know when to pick battles over his behavior and when to let things go. Because you're not going to recreate that lost pathway in his brain. Even if there is another pathway, the disease is still progressive, and that pathway too will be lost. A battle I've given up on is his need to overfill the cat food bowl. We constantly have kibble all over the kitchen floor. Another battle conceded is with his cookies. He eats a lot of carbohydrates, and he must keep the packages arranged on the countertop. Some of this may bear similarity to encounters in childrearing, but without the reward of knowing that the child will outgrow the nuisance behavior.

Unless people are there with you to see, I don't think you can adequately convey the situation with words. I often feel that I'm doing my best to articulate, yet I'm still not telling the fullness of the story – or the frustration of it. That's where the challenge lies – in conveying the experience to other people. Some friends have been very, very supportive; others have drifted. Some of that is not due to the disease, but to their life stage, with kids and full schedules. I'm lucky that my friend Leanne and her husband Billy are always open to including David. But I am afraid of becoming socially isolated as the disease progresses. My first deep sense of loss, other than losing him, was knowing that this disease was going to take away my career. I'm a curator of contemporary art, not an in-demand profession, yet one with many who aspire to it. I've often seen that once you step out of the role, there is no return. I've been most fortunate that so many associated with the museum – board members, donors, docents – are playing an active part in being my support group. David and I are more financially vulnerable than others in our age range. We do not have the resources for care that others in our age group might have attained. So the career remains in jeopardy. This disease is utterly destructive. It takes a terrible toll on the survivors as well as the afflicted.

My Emotional Bucket Gets Full so Fast

Last fall, I knew he was in a place where he needed more time with me. And, that our time together was becoming ever more precious. And my projects began to suffer, I felt surrounded by cascading failures. Mentally, I was overtaxed by trying to please everyone and seemingly pleasing no one. I was prepared to resign, but I was convinced to cut my hours instead. All I can do is see how the current accommodation goes. I've accomplished a lot. I wish I could accomplish more. But, I have no choice but to adapt. I hope there won't be regrets. But I'll cross that bridge when it comes. I'm still not sure it was the right decision to stay on part-time. My emotional bucket gets full so fast. And people who are not dealing with a caregiving situation just cannot picture what it is that you are facing. Caregiving for an otherwise physically healthy adult is *not the same* as rearing children. There is no improvement or recovery from dementia. It's an illness that unless they've directly confronted it in their own families, others do not understand. And I'm reaching the point where I can no longer sublimate the burden, the loss of sleep, and the fear, to a veneer of professionalism in the workplace.

Every single day you have a new loss to grieve. Every day you cope with the fact that you do not have what "normals" have. That you will not grow old with this person, you cannot even be certain if your spouse will be able to say any words to you in six months. Every day you grapple with the uncertainty about your financial future in the short term, while your spouse is alive, and in the long term, when you are all alone, twenty some years from retirement with your career ruined, your retirement accounts robbed, and your savings gone. When you no longer have youth and physical attractiveness as assets. Coping with uncertainty about where you'll be in two weeks. And perhaps this is all much harder for me than someone else? Perhaps I am too sensitive for this challenge? Too fragile? All I know is that when there is crap happening at the job – petty posturing over authority and decision-making, new policy over coffee mugs in the office, or an updated version of Microsoft Windows or Office – my emotional bucket overflows in a hurry. These little things threaten to upend whatever systems I've put in place in order to survive and appear normal against the challenges the disease poses on a daily basis.

And then there's simply the fact that I have no control over any aspect of my life. A sense of control is a big part of human composure. And when I am losing with David – over the cat bowl, over where the thermostat is set, over not eating food that has fallen on the floor – and then over a decision at work that ought to be under my purview – the frustration cascades. Often I am aware that when the bucket starts to overflow at work it's because I have just gone through rounds of *“Don't do that,” “You'll hurt yourself,” “Don't break that,” “That's not food,” “Don't open that email link,” “Yes, you have to take your medicine,”* and *“Yes, you have to see the doctor”* at home. The issue for all caregivers is that employers need only see you as someone they pay to do the job they tell you to do. Caregiver and employee are incompatible missions. And emotionally, because of this disease, I am not able to compartmentalize as well as I could before. I will say that it's much easier now than it was when we first got the diagnosis. Before, I could be at work and just burst into tears over nothing. Sometimes it was something, like the sense of being cheated, or a lack of hope, or the extreme fear over how will we live. How will we pay for David's care when he can neither stand nor swallow? California is so expensive, and I'm in my mid-40s. These may be my last good years. Will I be employable after I've stepped out of employment at this age? I'm working at the moment, but no longer contributing to retirement. What happens if the rent is raised? How do we maintain a quality – not an ostentatious and perhaps not even comfortable – standard of living? In a safe place that functions? What do we do when David can no longer do self-care, toilet himself? I've never been such an emotional person in my life. It all stems from this lack of control; this constant uncertainty. Some days are good, and some days I really fear I will collapse.

Often the triggers just come entirely out of the blue. I'm in one room working, and then I hear David's Pandora stream play *“Dust in the Wind,”* and I'm sobbing. He is completely oblivious. He just doing his computer art, completely engaged by the colors and the structures he creates. He does respond to my emotions when I'm coming down with an illness.

Sometimes You Just Have to Laugh

I recently worked late hours to speak at a new member orientation. Something that in the past I would have been pleased to do — to have the public see me in my role. The orientation lasted longer than I anticipated, so I arrived home much later than my usual. David's routines are highly rigid. For example, when he has his meals is a matter of he has to eat when he has to eat. There is no waiting. So that night, when I returned from work, the house smelled really odd. Something like cat urine. Various mental calculations began. Our cats have never made mistakes outside the litter box, so what could possibly be going on? When I went into the kitchen, I see on the stovetop, directly on a burner, an undercooked frozen pizza. My one reaction was, "Well, I'm not eating that." Since I could not find a cause for the smell, I decided screw it, I'm just going to go upstairs and lay down after a long, long day. The next morning, on my way out the door to work, I notice a big plastic shard on the kitchen countertop. Immediately, I know what has happened. David had mistaken my plastic cutting board for the cookie sheet he normally used for frozen pizzas. So when I came home the night before, the house was full of toxic fumes from melted plastic. That's what smelled! But here's the thing: David had realized his error. The plastic had melted around the grill inside the oven, but he took the grill out, found a hammer in the garage, and then chipped off the cooled plastic. He put all the chipped pieces in a bag, he twisted the bag closed, and then he didn't just throw the bag in the garbage — he buried it down in the can so I wouldn't find it! Yep. The little nonslip feet on the cutting board were a different type of plastic. A softer type that completely melted and dropped yellow, sticky goo on the bottom of the oven leaving me with the problem of how to remove that! So I'm scraping this nastiness out of the oven you know [laughing] ... it was just one of those things where you had to laugh.

So I had to stay home from work so we could have a big conversation about how when he makes his frozen pizza — which he loves — he can only use the cookie sheet. Now that sheet is always out of the cabinet, visible to him on the counter. There's still IQ there, and there's will, and he will figure out how to do what he really wants to do. That said, I know we are getting closer to more apathy. Knowing that is

coming is not an easy thing to live with. But neither is knowing that the gaps in his judgment could affect other people's safety.

Shedding Ambition and Selfishness

I have a good friend who calls and checks on me. She's highly perceptive. She can tell from my voice or the look on my face and say, "Okay, tell me what happened." What I appreciate more is that she tells me the stories about what's going on with her own life. Little bits of success for her children, little bits of drama. It's the fact that she shares with me that makes such a difference. I'd rather not be in this situation where my cord is so tightly connected to myself. I'd like to be less preoccupied with our situation. I'd like to be less overwhelmed. The best thing is to have friends that tell me what is going on with them so it's not always "The Diana Show." It is such a hard thing not to succumb to self-pity, to not become bitter. I think it is even harder not to become completely self-absorbed because that loop of worry is constantly running, you're constantly hyper-vigilant to all these little things. I was probably born too interested in myself already. [laughing] I already knew I was ambitious and that I was selfish. But with this disease, you have to shed the ambition and as much of the selfish as you are capable.

Children

David and I didn't have children because of this intuition thing. I was too scared to take the leap to get pregnant. I couldn't truly explain it at the time. But I'm so glad that I listened to my intuition. No matter how hard this is for us, I do not know how I would manage David's needs and those of a child, nor do I know how I could bear to watch a young child watch their father deteriorate. I realize I am very lucky, because I know a lot of families that are affected by this disease, including those with younger children and teens. If we had our kids when we were going to — which was always our intention — the ages would be six or seven years-old now. And if David has only got two or three years left... How do you? Intuition, magical thinking. It wasn't truly selfishness about my career. It was this sense of something not being right, but

not knowing where that sense was coming from, or what it was about. You know, we were coming back around to the idea of trying (to get pregnant) the year he got the diagnosis, and then the shoelace incident happened. After that, it was out of the question. It's a disappointment not to have children, for us, for the family. But we all agree is a hundred percent better not to have done so. This journey has surprised me by the emotion it has brought out in me. The "after" is another big unknown. Everyone likes to think, to plan for situations, to have a grip. But I've completely surprised myself with the things I remain calm about, and those over which I completely fall apart.

Six Months Later

Last time we spoke I was pretty near a breakdown. But anger can be a useful tool. Something at work made me very angry and just gave me the courage to finally stop waffling and feeling sorry for myself – and so I gave my very sudden resignation. Since that time my brain has been better. It's taken a while, but I realize now how severely sleep deprived I was at our last meeting and how much adrenaline alone was keeping me going. My thoughts were definitely fractured and scattered. [laughing] I was trying valiantly to be the person who didn't give in too easy, who didn't take the easy way out, I was the warrior. I had some accommodation, my job became part-time, though the challenge was, it didn't really become part-time. But with that accommodation, I thought I was going to come through this on the other side intact. And, reading the transcripts to do the editing, was so humbling. But what I take away from it is just a little bit of wonder that I lasted as long as I did. That I even got that far. The world's not going to end if you are suddenly no longer curator of contemporary art. A week after I quit, I got the opportunity to teach modern art history at Sacramento State. So I feel extremely blessed. It's not a huge amount of income, but it is supplemental income. More importantly, it keeps me in the workforce in some sense and ultimately I hope will keep me from going feral [laughing]. Keeping me out among other people, so I don't forget to do things like chew my food with my mouth closed. [laughing] I do joke when I see friends that take me to lunch. I'm like, "I'm so thankful for the adult conversation time, and I apologize for speaking so much and

so fast.” [laughing] The good thing with caregiving is David’s just been so much happier. I knew he was scared and every once in a while, he had some clarity in his ability to communicate with me, and he would tell me that he was scared. I empathize with what it would be like if I were going through these changes; how terrified I would be. But within two weeks (after I quit my job) he was just better. And it doesn’t mean his words were better, doesn’t mean his overall behaviors were better, he was just better. He just seemed more content, and if that alone is all I gain out of all of these changes, I think I feel good about that. I think I feel good about making him feel secure. I think he was lonely. I think he was really lonely.

One nice thing this year, after the change in the medication, was that he remembered my birthday! He didn’t have to be prompted. Last year on my birthday there was nothing. No card, no gift. There was a little bit of recognition of my birthday, but nothing much more to it. This year he had a card and had signed it, and he got me a gift. That morning when he brought me my coffee, he said “It’s your birthday!” He gave me the card and a gift. It was *very* sweet and also very exciting.

It’s a funny thing. I think a lot of people have a stronger sense of their self than I do. I mean, I know what I want, and I know how to go after it. But, I can be affected too much by other people’s thoughts. Besides the economics of our situation, because David and I are so young, we didn’t have massive retirements, massive IRAs, all of that kind of stuff to lean on for a transition like this. Plus, I have only now turned 47, which means when this is over, I am going to have to go back into the workforce. And do so knowing full well that 50-year-olds are not attractive as new hires. That’s my personal predicament. I spend less money now that I don’t work, but it’s also easier to manage money now that my brain’s not so fried. Easier to muster the diligence to monitor expenses. Although I’m terrified about the upcoming challenges, like the expense of adult diapers. David and I were not well-established – no home ownership, still struggling with student debt – but many are worse off than us. I worry for people who have not had our advantages.

But speaking to what I think other people think... I have in my circle a lot of individuals that are extraordinary, but they do tend to see support programs as being handouts to lazy people. Right now, I feel happy, because I can better manage David’s care, and better manage

him because of the resources we have – which does include social security. But I am sensitive to the political outlooks of those in my circle of friends and contacts. Maybe that's just me over thinking it, but I start to see them thinking, "Oh, she's having a nice vacation on my taxpayer dime." And that's really, really challenging to process. The other thing is that until you become a caregiver, there seems to be no way for you to make others understand. I think for certain people whose lives have not thrown a lot of those challenges at them, they really think you're whining. And it can be really hard for them to sustain compassion. My attitude is, well, we've got quality of life. We are not lavish. We have dignity, and we just want to preserve. I have to hope that my friends do not judge, because without added financial support, we could not make it here. We'd have to relocate, which is the other reason why I'm really grateful that I have the teaching job. At least I'm still doing public service. They understand that I'm not really making an income, but I'm doing public service.

Now I have created a space for myself, so I don't have to fight off depression every waking moment. I'm better armed to deal with the blues, and a lot of that probably is due to having adequate, restful sleep. Social connection, having moments with my friends and contacts does bring me happiness. It doesn't erase my sorrow, it doesn't erase my fear, it doesn't still the constant wheel of fear turning inside of me. But it does give me social connection and the emotional resources to continue on.





***Metamorphosis* by Kristie Wood, acrylic and wood**

Being Present

Narrator: *Dr. Mary De May*

Interviewer: *Kasia Gawlas, research coordinator
at the UCSF Memory and Aging Center*

Dr. Mary De May trained in geriatric psychiatry at the University of Pittsburgh. She has been a professor of neurology and clinician at the UCSF Memory and Aging Center for seventeen years. She has been named a distinguished professor and the center's Hellman Master Clinician. Dr. De May strives to always be present in the moment with her patients and shared her unique views on the end-of-life experience.

My Favorite Thing is the People

I met Dr. Miller, Bruce Miller, who directs the Memory and Aging Center (MAC), in 1999. I was in private practice in Marin County, and I sent him a very complicated patient who I felt I couldn't assess any further. She was a forty-some year old woman physician who was losing her cognition, and I sent her to Dr. Miller. He called me up very shortly thereafter, and he told me that he didn't know what was wrong with her either (although I'm guessing that really wasn't true), and then he invited me to lunch. I went to lunch with him, and three months later I had closed my practice in Marin and came to work with him at UCSF.

My favorite thing about being at the MAC is the people. I always say the people, and then after that, what I'm most grateful for and appreciate every day is the environment that Dr. Miller has created — I almost want to say specifically for me, in the sense that what I need to be the best doctor I can be is available to me here; if I need three hours to do an assessment, that's what I get. So I have the most ideal environment that I could think of to be the best doctor. And that clearly comes from Dr. Miller, who communicates his support and respect for my work so that I can just do my work. I don't think too many doctors

anywhere can say that. The people here are extraordinary, and I think everybody who works here would agree; there are 30 or 40 young people who give me hope for the future, give me hope for who's going to take care of people my age when we need care. There's a huge sense of respect and appreciation, and in many ways love for each other, that I appreciate every day.

I know that I learn something from every family that I see. I do think about and remember patients and families who had a particularly terrible time of things. Since this is a neurodegenerative clinic — not everybody dies, but I'd say the vast majority will die, and part of the beauty for me of working here is that I can take care of them until death. And so, it's allowed me to be able to be present for end-of-life care and to help advise people about end-of-life care. It's been a very, very, very rewarding part of my career here. Maybe in some ways the families that most shape me are the families that I've seen all the way through. It's a really interesting topic for me, because there's so much being written now, more for the lay press, about you know, being mortal, and I guess it's becoming something that people are showing more interest in, but are also so terribly dissatisfied with what physicians do.

Let's Talk About Where This Could Go

I think of end of life as an enormous topic, because I think that someone who gets a diagnosis of pancreatic cancer and dies in three months is in a very different situation from someone who has Lewy body disease that goes on for over a decade, and they're completely delirious by the end of their life, and it's worn out everybody around them and themselves, and it's unremitting and unrelenting. I think they're two very different types of problems, and I think that when one is dealing with neurodegenerative disease, it's good to have a conversation well before it's needed in a way to talk about what the goals are of that phase of life. And so I often bring it up in that manner with family. We don't know when your loved one is going to have a change in condition, but right now, let's think about what we want for this person. Every single bit of care here is a team, and so I work so closely with our incredible nurses and our social workers, and our fellows and other attending level doctors. And I think that the team

approach to the care here prevents a lot of the really terrible things that happen to people at end of life. And so my colleagues who work in private practice — they're kind of on their own... those people's patients end up with feeding tubes and gastrostomy tubes and pacemakers and all sorts of things that “prolong life” in people with end-stage illness. I've been very grateful that our approach to the end-of-life care has been articulated enough to families that they understand where things are going, and they don't look for some magic, you know, “If we can only keep them eating they'll live longer” when that's not really true. It's been very interesting to compare my experience, which I really attribute to this place being so unique, versus my many colleagues around the country who I talk to and who have a very different experience with end-of-life care with their patients. This is a whole different world here.

I also see almost all of the patients with chromosomal abnormalities like Down's syndrome, trisomy 8, and a lot of the hereditary genetic problems like spastic paraplegias and those kinds of illnesses that have a cognitive component to them that we didn't even understand not that long ago. This morning I had a conversation over the telephone with the parents of one of my patients with Down's syndrome who is starting to have episodes of loss of consciousness. But he's been a very highly functioning man, and as a result I think his parents never worried too much about what happens to him down the road, when Alzheimer's disease actually manifests, as it absolutely will. So now he's having these episodes of loss of consciousness, and he lives in a kind of remote part of the state, and has pretty conservative medical care, and my patient doesn't want to have anything done to him. Doesn't want to have a blood draw, doesn't want to have an MRI, nothing. He doesn't like anything, which I understand. But now he's having loss of consciousness, and one of these is going to result in a bad injury, and so I talked to the parents this morning about who's the decision maker for their son, and it hadn't been determined, so they're going to work on that, and they're going to see their attorney, which has to be done. It would fall to them anyway in an emergency, but these things are best done not in an emergency. We talked about goals for his care and what happens in a couple years when things are a little different. And what happens when he has one of these episodes. You know, this could be seizure, this could be cardiac rhythm abnormality,

it could be any number of things; what if he has one out on the street and what if someone calls 911, and they take him to the hospital, and we go down this whole path.

So, I'm a little bit the person who pushes, "Let's talk about where this could go," so that people aren't making really challenging decisions under terrible duress. So I do tend to bring it up; I can't tell you what makes me decide today's the day. And I've never had people say, "Can't go there, don't want to talk about it." Never. It's remarkable. I've been doing what I do a long time, so I'm probably a little better at it than I was 20 years ago, maybe I've hit 10,000 times or something? But I think I'm temperamentally very well suited to my work, and so I'm not uncomfortable talking about these things, and I actually think I'm doing something very important to talk about it, as part of the care of my patients and families, so I think it all comes together in that context. I don't think anybody ever looks at me and thinks, "Why the hell is she bringing that up? What's wrong with her?" It's always perceived, or received, as coming from good care, I think.

Recycling Empathy to Energy

I don't do this without getting worn out. Last night driving home I thought, "Have I ever been this tired?" So I don't do it without wear and tear on me, but what tires me is probably not what necessarily would seem to tire me. People often say, "I don't know how you do what you do. You know, you just watch people's brains deteriorate, and they're no longer the person that they were." And you know, true and true, but somehow I have energy for that. In general, my approach is that if I just let my natural personal empathy just do its thing, if I just leave it alone, and just be me, I get so much back; I think the empathy recycles somehow, and the energy comes back. It goes out as empathy it comes back as a little bit of energy. I think when we try to keep some sort of a barrier or a distance from our patients, that takes a lot of work. That's a lot of work to say, "Well this person's got the worst illness on the planet, he's going to have a horrible death, and I need to make sure that I don't get too caught up in that" ... I just see that as actually antithetical to what would be most helpful, which is to say, "Yeah, life really deals terrible things to people, but how can I be most present for

that person?” And I think that my instincts, and in some ways I think my Jewish tradition, which I take very seriously, gives me a lot of fuel for the work that I do. So I do get tired, I mean I’m not a spring chicken anymore, but it’s not from the nature of the work. And every now and then I hear people talking about how you can’t let it get to you, and you can’t take it home with you, and it’s so interesting — I should say for me, that if you’re just there, it doesn’t wear you out the way that it does if you’re trying to keep it at bay. I don’t think you can do this work and not have it with you all the time. I guess I feel that by being present — I mean it’s all sad, but helping people through that isn’t sad, and so I guess that’s part of that recycling of empathy to energy.

It’s really interesting, because in the Jewish tradition, one of the most important things we do is keep alive the memory of a person. And so I think about that a lot, keeping alive the memory of the person. But, what we also do is pass it down, generation to generation. And so I actually feel that we can be fully present with someone who doesn’t have any memory, and that person can be fully human, because ultimately what matters is this right now. You and I are talking right now. Your ultimate task is to be present in the moment, and I think this work has really pushed me to be present in the moment because just think about the patient with Alzheimer’s disease who’s really got short-term memory deficit, right? I mean, all that matters is “Did you see the Giants’ game yesterday?” “Yeah” “Did you see the Giants’ game yesterday?” I mean you have to be there as if it’s the first and only time, over and over and over and over and over. I’ve learned so much from those patients, because you realize that the only way to be is as if that was the first time that person asked that question. And so, that shapes one’s ability to be present.

The Influence of Judaism

As for my Judaism, I came to it later in life. All the people who would know are long dead, but the best any of us can figure out my mother’s family was Jewish and from the Strasbourg area of Alsace, which was alternately German, French, German, French depending sort of on who had the power at the time. And when they moved to the US, my great-grandfather was a very successful livestock dealer, and they had

a home in an area outside of Boston, and it was incredibly anti-Semitic. So when my mother's family arrived in the Boston area, there were all these signs — no Jews hired, et cetera. So, when they came over in the 1850s, I don't know who was the instigator of "We're not Jewish," but that was the next move. So here's this family that was relatively well off, and I think really just did everything it could to hide their Jewish roots, but like all secrets of that nature, everybody "knows," right, so everybody knew!

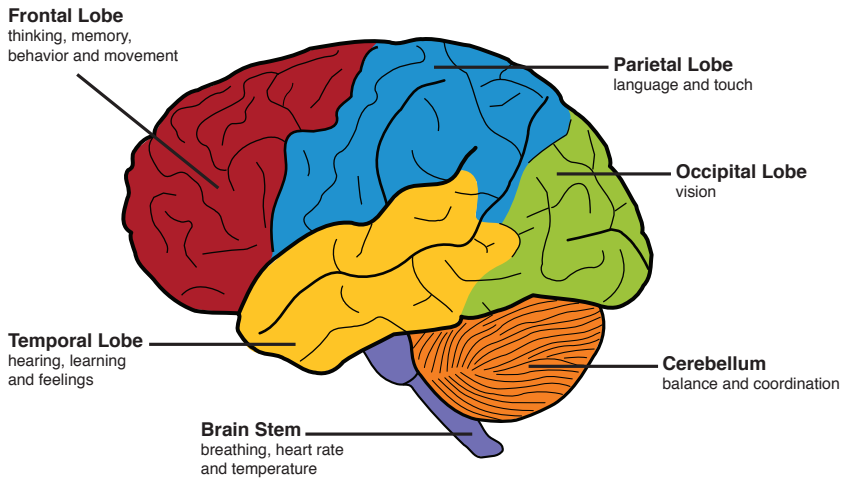
And so even though they wouldn't say that they were Jews, everybody knew, and so even to my generation, one of my cousins was beaten up in a schoolyard for being a Jew. Boston was kind of a rough place anyway, so I wasn't raised Jewish. Anyway, by the time I had a couple of kids, I decided it was like the bones of my ancestors rising to the surface for me — I decided "Okay, that's it, I can't raise my own children outside of this tradition, because I know that it's the right thing." So it was very easy thing for me to complete that process, and my husband was amazingly helpful in it all, a non-Jew, but very helpful. So that's how I ended up coming to my Judaism, and then I got involved in an organization some 20 years ago called the Bay Area Jewish Healing Center, which is four rabbis and a beleaguered administrative assistant who provide Jewish care to people who are ill, grieving, or at end of life. I've been working with them for over 20 years, and I'm their board chair right now, so we did a lot of things, we started a Jewish hospice, started end of life care, we've done a lot. So it's always part of everything I do, to be honest with you, my Jewish belief system and my Jewish roots. And it's made it easier, I think, to do my work, because part of what we're supposed to do is visit the sick, I'm able to visit the sick when I do my home visits. There's a lot that a doctor does that is very consistent with the Jewish obligation to care for others.

We Are Born to Die

I guess what I have been thinking about a lot lately is there's a huge risk right now to dissociate life and death. We have as a culture, as a society, become increasingly distanced from the absolute, one-hundred-percent guarantee that we are born to die, and that what we do with that time, and how we die, I think it's difficult for people... I

think it's a mistake that we've grown into, just culturally maybe with more technology, more interacting, you know, I mean it's a miracle when two people can sit face to face, as opposed to texting one another or something less personal. Our culture requires that we do everything instantaneously, and instantaneous doesn't really work with end of life, and we need something... it sounds kind of funky, but sort of a conversation about death. We need to understand that medicine and science and doctors and nurses are not going to stop you from dying. They're not supposed to. Dying is the way we make room for the next iteration of humanity. If I could change anything, I would try to help create a more broad conversation about death and what our expectations are. I think it really impacts on how we live.

hear/say



Behaviors are rooted in anatomy. The symptoms seen in a person who has dementia, whether it be memory, personality or movement, derive from specific changes in the brain.

Fight for the Joy

Narrator: *Patricia*

Interviewer: *Jennifer Merrilees, clinical nurse specialist*

Patricia and Joe have been married for 43 years. They have a son and a grandson. Their daughter passed away several years ago. Joe has been recently diagnosed with frontotemporal dementia. It is an honor to include Patricia's story. She has dealt with events that most of us will never experience. Patricia works daily at creating a life that reflects her core values of strength, family and finding joy.

It's Not a Date

My husband Joe grew up in the Deep South, one of 12 children with nothing, sharecroppers. When we met, I was teaching. I was 27. I was single, and it was kind of a rough time. I had lost my father at 16, so I was living on my own. My brother took me to see *Butch Cassidy and the Sundance Kid*. In the movie, Butch and the Sundance Kid invite Emma to go to Mexico, and she looked at them and said, "I'm single, I'm a school teacher. I'm 27." She said it as if the world was over. I remember my brother laughing and elbowing me and saying, "It's you!" [laughs] I met Joe right after that, and I just didn't want to be involved. I didn't want to get hurt. He invited me to go play volleyball at a recreation center, and I said, "I won't go with you, but I'll meet you there. It's not a date." And after that he asked, "Want to go get pizza?" And I thought he was a nice person, and I could use a friend. So I said, "I'll meet you there because it's not a date." [laughs] So we went to the pizza parlor, and he got the pizza, and he put it on the table. He said, "Well, you can forget about any other guys, because you're going to marry me." I was so upset, and I thought, *How dare you say that to me! I'm not going to marry you and now we're done, we're done.* But he kept calling and our conversations would get longer and longer, and after three weeks I finally said, "Okay, I'll go out to dinner with you." This was the late 60s, and we went to a really

nice restaurant, and there was a couple across the room (my husband is African American, and I'm Caucasian). They kept looking at us and kind of shaking their heads. It was really uncomfortable. I was about to say, "We have our food, let's just go somewhere else." He looked at me, and he said, "I'll be right back," and I thought he was going to the restroom. Well, no, he was headed over to their table. He reached out his hand to the man and said, "My date Patricia and I, we know you." And he shook his hand. "But we can't figure it out. You keep looking at us trying to figure out how we know each other." And he mentioned places like the school district and where Joe worked. They kind of got red, and Joe said, "Well, it's good to see you again and have a good dinner." They never looked at us again. But it impressed me so much, coming from the South where he had horrible, horrible experiences to be able handle that situation with humor and grace and still get his message across. I mean, I was just in awe of that, and it didn't take long for him to win me over.

Through our marriage he's been the rock. He's had this incredible sense of humor. For the first five years of our marriage, he would leave me a note everyday. It might be on a paper towel. Just something like, "I love you" and "You're beautiful." Something everyday. Cards whenever he could afford them. He was a janitor and I was a teacher, but he wanted to finish college. He started college when our daughter had just started high school and our son was in sixth grade. He graduated from college. He coached both our children in sports. He did Cub Scouts. It was like he was reliving the things he never did. Family has been everything to him.

Our beautiful daughter passed away suddenly in 2011. I got a hold of my husband and said, "You need to come home." When he came home, we held each other really close. She was his baby girl. He just looked at me with this blank look, and he said, "I don't understand." I said, "Honey, we don't know exactly what happened but she's passed away." When my son came, my husband held him, and they cried. In the living room, fifteen minutes later, all these people had come over, and my son came and said, "Mom, what's wrong with Dad?" I said, "Honey what do you mean?" He said, "Well, look out on the porch." Joe was out there playing dominoes with some friends, laughing. My son said, "Mom, I don't understand." I didn't either. I thought, *He must just be in shock: he's not accepting this.*

It's Been a Fight to Get Someone to Listen to Me

His behavior was really changing, and he was diagnosed with depression, which made sense in the beginning, because of course he would be depressed. But he was also doing things that were so out of character for him, for the man that I know. He became obsessed with porn. Suddenly. He was heavily into purchasing porn. Using any money that he could get, and that was totally unlike him. He became so distant. He lost all interest in anything he ever really wanted to do. I was teaching, and Joe would come with me everyday. I didn't make him come, but he came everyday, and he would sit and have kids read to him or run things off or just sit and stare into space. It was very bizarre. He was very sweet, and people that worked there loved him. He would ask, "What can I do to help you?" He would stay with me and go home with me. I thought my old Joe would have so many things to do; this would not be what he'd choose to do.

It's been a fight to get someone to listen to me. In the beginning, when we met with a doctor, I knew it was something more than depression. I had documented the behaviors. The doctor looked at me, never having seen me before, and said, "You're overreacting, he's just got depression." I could feel being dismissed as a woman and I said, "You don't understand, we've been married 41 years. I know what I'm talking about." And he just stood up and gave him a prescription for depression. I remember going on the internet, trying to find out what was going on. I saw some things about dementia and about behavior. I asked for a referral to neurology, and he was diagnosed with mild cognitive impairment, but that didn't help us, that didn't explain it.

And so, we separated. Forty-one years of marriage. I adored him. But I didn't know him anymore. I thought, at that time, that he was having a midlife crisis and just had been so hurt by the loss of our daughter that he didn't want to be around people, he didn't want to love anymore, he didn't want to invest in that, he didn't want to be hurt. Certainly he was gone emotionally and... I can't believe I was in that place.

How Do I Say Goodbye to You When You're Still Here?

As it got worse, and the behavior got worse, I went to a divorce attorney. My world was falling apart. We had even cashed in a life insurance policy so we could pay \$20,000 for Joe to go to Los Angeles to a sexual recovery institute. Because we didn't know what was going on. But I was willing to do anything to help him to save our marriage. I remember thinking, *It doesn't fit, this doesn't fit*. I pushed for another referral, and he was diagnosed with frontotemporal dementia (FTD). It wasn't until we came here to UCSF, and they confirmed it and showed us the MRI, that I accepted it. Yet, I was still in a place where this is all a game. He's just playing a game with me. It's not a funny game. I actually thought I would rather have Joe be playing a game with me, and we separate, than have this happen to him. Either way I'm going to lose him. But if I lose him, and I know he's okay on his own, I can deal with that. But this way, I'm going to lose him, and I'm going to watch him go. How do I say goodbye to him when he's still here?

On the way home from that appointment, the only thing Joe had heard from our family conference is that he has mild FTD. He was like, "YES! Not a problem! Mild we can deal with." When we got home, he said he wanted to leave me. He didn't like all the controls. He wanted to get his own apartment. I said, "Well, we'll lose the house." And he asked why? And I said, "Well, honey we can't afford both an apartment and a house if we're going to get a divorce." He said, "Why would we get a divorce?" [laughs] I could no longer have conversations with him. In a good relationship you come to a middle ground. We couldn't have those conversations, there was no reflection, no feelings about it, and he couldn't understand my feelings.

A Reversal of Roles

Now it's this total reversal of roles. When we met, we were still kind of old school. I stayed home with the kids, and we didn't have much but that's what I wanted to do. Joe was working, and we had a little apartment, and we made it work. He was the protector. He took care of everything. When we wanted to buy a house, he made sure that it

happened, and when I wanted to go back to teaching, he supported that totally. Now I've taken over finances, I do everything. I do anything that needs to be done and mainly it's that he's just not interested. Some things he's lost the ability to do.

I Don't Know Where We're Going

It's day by day. I went home after the appointment at UCSF and had a very good cry. It helped. It helped me a lot to say, *Okay, put on your big girl boots. This is your path. You wanted to go this way, but you're going that way.* I don't know where we're going. I told Joe that I really, really want us to have the best life we can have on this new journey. After our daughter passed, you realize the only choices you have are how you react to things. I realized I was in a fight. I was in a fight to bring joy back into my family's life. To not give up holidays. Not be afraid to laugh. To see hope again. And it is a tremendous fight. It is not easy when you lose a child. And, I realize with Joe, it's the same thing. I am fighting for us to do this with grace and with humor. And patience.

It's My Now

Another thing you fight is fear. Fear of losing someone else that you love. I want my son to just come home and never leave the house. I don't want my husband to leave. What if something happens to me? It's debilitating. And yet, I don't want to constantly think about that, because it robs me of my now. It's my now. I've got him, right now, and he's laughing, and he's compliant, and he seems to be okay being with me. I've got to focus on that. I know that it is my honor and my good fortune to be able to physically, mentally, be there for him now. It's not my job; it's not my duty. It's my gift, my journey. This disease will not destroy my family. And it is absolutely a choice, because IT IS WORK. It is not easy. It's not like you just wake up and say, *Well, I'm going to be okay with this.* Every moment is a conscious choice. But the work is worth it! What other work is there? To make somebody's life better? I mean I've taught for almost 40 years, raised two wonderful, beautiful children, fought against prejudice, racism, but the most important thing right

now is trying to make the world a better place for my family in spite of all this stuff.

That's a Worthy Fight

One thing that worries me is how close we came to separating and divorcing because it was so hard to get this identified. It makes me very sad to know there are other families going through this. It's really important that somehow doctors, primary care physicians, certainly neurologists, psychiatrists, know about this. Even now, Joe's primary care physician and his psychiatrist do not know about FTD. They don't know! We just went to a different doctor, and I mentioned he has FTD and she asked, "What is that?" I thought, *this is the problem*. Even the people that know us, our friends, don't understand this disease. They don't understand why we're together 24/7. We'll have dinner, and afterwards they'll say, "Joe seems fine. He's fine." They don't understand how that devalues what I'm saying.

So, fight for answers, and fight, and fight, and don't be dismissed. When you have that feeling of a fight in you, that's a worthy fight. It's not a negative thing. It's an empowering thing. I would say fight for the joy. It's a different person but in their essence, they're still that person. Hold on to those memories and talk to them, and show them pictures. Fight for their joy. Even though Joe doesn't have many of the same emotions, I still want to believe he needs to be respected and he needs to be treated like my partner, when I can. I have to be very careful about that because I don't want to steal that from him while he's still with me, where he's still aware. He needs those moments where he feels he can do things for me.

It's These Constant Surprises

We watch our grandson one day every week. He calls Joe, "Baba." As Joe's changed, one of the things I noticed is that instead of interacting with our almost three-year-old grandson as an adult, he's interacting with him almost as peer. For example, I was driving on the freeway and hearing hysterical laughter from the backseat of the car because Joe

was trying to take our grandson's truck saying, "Mine!" Our grandson was laughing, saying, "No, Baba, no," but Joe doesn't know when to stop. [laughs] Joe reads stories to him, children's books, and he gets the words mixed up. So now he ad-libs, you know, "The duck robbed the bank" or something. I don't know what language my grandson is going to end up with, but it is funny! My grandson said something (I didn't hear it), and I heard Joe say, "Don't mock me," and my grandson said, "Don't mock ME!" [laughs] But I don't leave them alone together. I noticed six months ago our grandson was starting to do things that he could get hurt, like climb up on the sofa, and Joe would just sit there. He can't see the risk, but he plays with him and adores him. They adore each other. But I have two "kids." The younger one is the easier one.

It's like carrying a basket and in the basket are all these different kinds of fruits and some are nuts in there, too. Sometimes you pull out this beautiful apple that when you bite into it, it's a surprise. You have moments like that. Sometimes you reach down, and you pick out this mushy banana. *Well, okay, I didn't want that right now.* It's these constant surprises. I think as a caregiver you just never know what's going to happen next. *So, this is okay, I got this. I can do this.*

hear/say

失智症

The Chinese characters for dementia

It's Good to Have Someone to Talk to

Narrator: *Jeff Choi*

Interviewer: *Alissa Bernstein, PhD, MPH, Postdoctoral Fellow, Institute for Health Policy Studies and Atlantic Fellow, Global Brain Health Institute*

Jeff Choi is a research coordinator and Care Team Navigator who works primarily with Cantonese-speaking patients and caregivers enrolled in Care Ecosystem.

Language and Trust

A Care Team Navigator is a person who the patient and caregiver can identify with and trust. I think that's especially true for the Cantonese-speaking population, because if you speak their language they are more likely to trust you in health care. They may not feel comfortable talking about all these things with strangers on the phone; it's much better if you can speak Cantonese because they can feel more close to you and they might be more open about everything.

There's a patient who had a stroke in 2012. The caregiver has been taking the patient to Chinatown to see a neurologist but she was really struggling because it was quite far for her and she had to wheel the patient up and down, because it is hilly. That's been pretty stressful for her. So, I helped her to switch neurologists, but even switching neurologists was quite hard for them because the caregiver didn't know where to go. They needed help because they had to go through all this insurance stuff that they had no idea about and they didn't know what it covers or where they could go or what was the process. We made a lot of phone calls to coordinate that. First, talking to the insurance company; then I had to work with her primary care physician to send the referral letter and find out what she needs to bring to the clinic, like the medical history and the images of her husband. It's really

complicated and she is happy that someone can help her with it. She feels more comfortable talking to me in Cantonese about these kinds of things. I think it's pretty important, the language part of it.

Putting a Label on It

There's only one term in Chinese really – you just say, *it's dementia*. They don't talk about different types. I guess it's also a stigma, it's kind of shameful if you have a person with dementia for the Chinese population; it is just not something that they want to tell everyone. It is more likely to think that losing memory is part of aging, that people at this age are supposed to lose some memories. I guess a lot of people don't realize it's a disease – they think it is a normal process. I guess sometimes people don't go to doctors because of that. They don't want anyone to put a label on them that *he has dementia* or something like that.

“Then We'll go Take My Mom to See a Doctor”

Compared to the English-speaking population, there are definitely less resources out there in Cantonese. A lot of things are in English and people feel intimidated to go for them; talking on the phone and registering in English is hard for them. It's not really something they could just handle for themselves, especially the older generations. It is hard to find things that are suitable for them – they often feel like, *Where do I even start?* I guess that's why we are here. We have been working on finding resources that are tailored to the Chinese population, like a Cantonese-speaking support group or home care that have people who speak Cantonese.

One time we were on TV, on Channel 26, which is a channel that a lot of the Chinese population watches. And we had a little segment on a news program to talk about the Care Ecosystem. This one dyad (patient and caregiver), after they saw the news, they emailed us and said, *Oh, my mom is showing these symptoms but we have never seen a doctor about it but I want to join Care Ecosystem*. Then we told them, *actually, you can't join without a diagnosis*, so they said, *Oh, then we'll go take my mom to see a doctor*. So, without this awareness-raising and publicity they would

never have seen a doctor for it, which is stunning. It's actually the most expensive disease to treat right now in the US, but it's not as commonly heard of as cancer or heart disease. If we really build awareness about the disease, and more education, then the disease might become less stigmatized; they might feel like, *Yeah, I should see a doctor for this symptom.*

Hard Questions

There are some questions that can be hard to discuss. For example, *What kind of health care goals do you want to prioritize? Do you want to prioritize comfort care or treatments that help you live as long as possible?* But I'm pretty grateful about how open people are with me. I guess in this country it's hard to find someone who can spend that much time to listen to you and who can speak your language and connect with you. I listen and try to understand what they might need or how to best help them or even just simply listen, and that helps them feel better. Some caregivers say, *Oh yeah, it's good to talk to you, it's good to have someone to talk to and work through the issues that I am dealing with.* So that's what we do. We try to help people through.

hear/say



The Canadian flag

Who Has More Fun Than People?

Narrator: *Louise Tilston*

Interviewer: *Jennifer Merrilees, clinical nurse specialist*

Louise Tilston and her husband Jim (both proud Canadians) have four children. At the age of 48, Jim was diagnosed with dementia (first thought to be frontotemporal dementia with the diagnosis later changed to Alzheimer's disease). His course was characterized by multiple changes in his personality and behavior. At the onset of his illness, their daughter Carey was out of state raising a family, their son Chancey was away at school, and daughters Jaime and Shannon were in their early teens living at home. Louise juggled full-time work as a public health nurse and raising their children, and has been caring for Jim for the past twenty-one years. Jim lives in a long-term care facility where he has resided for the last eight years.

I wanted to interview Louise for hear/say, because I have always had so much respect and admiration for how she's handled all the challenges with Jim's behaviors, raising their children, and working. I knew she had a compelling, unique, and at times, humorous story to tell and yet, I found there was a lot that I didn't know about how shared family values shape Jim's care.

He Was Pretty Functional in an Annoying Way

It was a very slow onset and slow progression for him in the beginning, actually years before he was diagnosed, but for the first several years he was still pretty functional in an annoying way. [Laughs]. I think he was always more fun and I was the more responsible one and certainly as his behavior got more and more eccentric (and our kids being teenagers) he was fitting in with their norms. He was a great guy, and he was very, very kind but he was also more apt to be on their level of "What do you think would be a fun thing to do?" Like, for example, he hit something with my car. Two of our kids were with him and he told

them not to tell. “Don’t tell your mom.” *Perfect! We wouldn’t tell either.* So, I went to get my car parked in front of the house and there’s a big dent in the side. So I come into the house, and I said, “Jim, somebody hit my car.” And he doesn’t say anything and one of the girls says, “Oh, Dad told us not to tell.” And I was like [Laughs], “Are you kidding me?!” He just thought, “If we don’t tell her, she won’t notice.” So that fit perfectly with how teenagers think.

Fit Into an Environment That Accepts Everybody

When he was in his roaming days with Molly (our dog) and I was working, his favorite place to go was Wal-Mart, which is clear on the other end of town, down a pretty busy street. And they would walk, Molly at his side, never on a leash. And, they’d hang out at Wal-Mart, you know strolling the aisles, probably stealing the odd ice cream bar because “That’s what they’re there for. Help yourself.” And then he’d often get lost on the way home. And now he would be in the bad part of town with the drug dealers and those people who are, you know, kind of living on the edge. And they were so good. I would get home so many times and there would be a message on my phone. (I still have my home phone; I was always afraid to give it up because Jim had that number memorized). “I’ve got your husband here. He says you’re at work, so come and get him when you can.”

And I would go and he would be in these sketchy apartments where they were drinking and doing drugs half the day and yet they would just welcome him in and his dog and just keep him. Somehow know that he needed to be protected. Whereas, in a neighborhood like mine...well, there was one lady that used to bring him cookies and bring him home from the park but for the most part, people were pretty standoffish around here and he did a lot for these neighbors when he was able to. But Chancey would say he burned his bridges, he probably borrowed tools and didn’t return them. Or that the men he knew were having a hard time dealing with mortality – seeing one of their own, a young man, losing his mind. And that was perhaps hard for them. And I also noticed that the dog people would engage with him. They knew him and they knew his dog and were more apt to say, “Oh, did you need help finding your house?” And we noticed the same thing in San

Francisco. He used to spend a lot of time in the Panhandle, and we used to say, “The people that live in the park were so good to him.” And he was good to them, you know, he knew them and they knew him, and he just fit in. Fit into an environment that accepts kind of everybody. There was something very non-threatening about him. And, I think because of my work in public health (I work so much with people that others would have been afraid of and I never was) that I always felt comfortable in those kinds of environments, too. So, I guess we both have the same, you know, perspective on people and it might be more of the Canadian thing too, less likely to be suspicious and more like to assume the best.

People will always live up to your expectations. I mean we ran into a group one time and Jim had lost his bike in the park and it was after dark and I was looking for the bike with him and we came up on a group of guys standing around trying to find trouble. And by then Jim was refusing to walk home because he was tired and we hadn't found the bike. So I thought, *I have to go get my car*. So I said to these guys, “Okay, my husband is staying here. I need you to keep an eye on him, and we're looking for his bike and it's black and it's somewhere around here, so if you want to look for the bike, I'll be back when I get the car.” And they're like, “Well, okay.” So, I went home. I got the car. I got back. They're looking for the bike. They've got Jim with them. They're fine. They were all stepping up to the plate. You ask somebody to do something and be responsible and they will.

When I Realized This Was Way Bigger Than What I Thought

Before he was diagnosed I had taken him to a neurologist who determined he was fine, despite all of the examples I was giving him of behaviors that indicated that he was not fine, and was not acting as a responsible parent or person. And the doctor said to me, “Well, then I guess you just have to be more attentive and more watchful.” And I remember thinking, *why should I be? I'm not the parent here. He's an adult. I have to be responsible for myself; he should be, too*. But obviously he wasn't. And so I had to be sure that responsible parenting was happening. And I started taking over to make sure that things got done. He was perfectly capable of taking care of everything for himself that he wanted to, but

I had to make sure that what he was doing was okay, so I think that's where caregiving started for me.

I did try to divorce him [laughs] because his behavior was so bizarre and it was just not, he wasn't living life the way I had imagined we would be living our life, and he was pretty unrealistic and unreasonable. So, I brought it up several times, and he could never understand the concept [laughs]. He kept saying, "Well, no, why would we? We always have been married, always will be." It was not a conversation to be had, and then I realized he doesn't even know what I'm talking about, like you can't divorce somebody who doesn't even know what you're talking about, or why you are having this conversation, and that's when I realized this was way bigger than what I thought. This was just huge, and I still didn't know where this was going. I mean I clearly knew that even if I divorced him the state of California, being a community property state, maybe we'd each get half. We'd have to sell the house. I'd have to give him half. He probably give that money away or lose it and I'd still have to take care of him because what are you going to do? Let him be homeless on the street?

Like Fog Rolling In

You don't really even notice becoming a caregiver, because it's just one more thing. And, as a mother there's always a gazillion things you are doing anyway, and you're working, and you're just trying to keep everything together. And so, if Jim can't do the dishes now, well then, I guess I'll do that too. It was so gradual, and it was like a fog rolling in and rolling in and rolling in, and you don't notice it. It just gets thicker and thicker and thicker, and then it's so thick, and it's been there for so long that you can't remember what it was like when the sun was out. And you can't remember what your life was like when you didn't have to do everything, 'cause you just gradually take it on. Like a sponge I guess. You gradually absorb all the water. And yet, there was never a time that I thought, "I can't do this." I mean I was always such a competitive person. And stubborn, so it wasn't an option to not do it.

You Wanted Some Attention by Becoming a Caregiver?

Jim loved to go to the all-day buffet [laughs], and he'd stay there all day like the seniors. And I would tell him, "I have to go back to work, but you can stay if you want." And he'd say "Oh really, you think they'll notice if you're not there or not? You know, you're really not that important." [laughs]. And he really believed that I was only going to work because I chose to. I remember when I broke my wrist, and I had a drain and a cast. He would say to me, "Oh anything for attention. Now you've put a cast on your arm." That empathy was gone. He'd say to me, "So you didn't see being a caregiver coming, 'eh?" [Laughs]. "So you think you wanted some attention by becoming a caregiver?"

He also became quite argumentative and stubborn and irrational and determined and manipulative and self centered and selfish. Unable to see anyone else's point of view. And Dr. Seeley said, "It's not that he doesn't care: he doesn't have the ability to care." I think it was an important thing for me to hear, because it makes you realize they're not really doing this on purpose. It is just like arguing with a drunk, you are never going to win, the person is never going to get what you are saying. So, you might as well just stop. Save your energy for something else. Maybe it had been so long for me by the time I heard it, that I was ready to kind of get it.

There Are Two of Us Here

So what does it feel like being a caregiver? I've been so many. I've been the, "I'm not really a caregiver," "I'm the reluctant caregiver," "I'm a caregiver but nobody knows I am," "I am a caregiver for a person who doesn't want a caregiver," and "I have to be a caregiver." And now, "I'm a caregiver from a distance," and that's changed into "I need to be an advocate, and I have to ensure good care from somebody else." So the words I came up with cross all of those. *Lonely* and *overwhelming*. And it's also pretty thankless. Nobody wants to be cared for. No adult wants to be cared for. Nobody wants anybody telling him or her what to do or that you really shouldn't go out dressed like that, nobody wants that. My kids didn't want me taking care of their dad. They're okay with it now,

but back when I was having to make decisions for him, nobody wanted that. They wanted their parents to be functioning independent people. We used to be partners, and now I am telling him how he should be and I'm watching over him in a different way. And I think *misunderstood* is also a word I would use because you're doing it because you are trying to be protective, but it can be seen as being almost punitive in that you're taking somebody's liberty and freedoms away. And also I think *gratifying* and *necessary*. You get some satisfaction from it. And it's *guilt*, always guilt because as you see the person is no longer able to do things that you can do, there's a part of you that thinks you shouldn't be doing them anymore, too. Like if Jim can't go to the gym because he can't operate the equipment or he might go into the ladies change room, then I shouldn't be going either. Because if I go to the gym, what is he going to do? And he would always say, "Oh, going off without me again?" So you know, to make you feel even guiltier. Plus, I was working, so in his mind I was already gone all day, and I was having fun all day.

I remember watching my kids: they'd put on his music, turn his chair towards the TV so that he didn't have to move his head, you know, run his bubble bath, play his music, paint his nails, and I remember saying to them once, "You know, it's not all about your Dad. It's not all about your Dad." Because I felt like all the attention was going to him, and it was. But it needed to. But there are two of us here. That was probably ten years ago. I think as they've accepted his illness, there's been a degree of separation or something. For one, we didn't know how much time we had. And two, I think there was a feeling that maybe you could prevent something from happening by coddling or hyper vigilance or whatever it might be. It took a really long time for them to get to that place.

Jim's Got Cheated of a Lot of Things in His Life

He was very kind, very funny, charismatic, and outlandish. Devil may care, a great Dad, an exceptional teacher, always irresponsible. Huge animal lover: he was known in circles as the dog whisperer. Talked to anybody and always complimentary. He was a proud Canadian. He was a speed freak: he liked to drive fast. He learned to race his car on the ice, you know, we grew up in Canadian winters. Hockey player, motorcycle

driver, super confident. And he was a great public speaker. He could stand up in front of a room in front of as many people as you could pack in, and you could just hand him a topic and he could talk about that topic forever. And always an advocate for the underdog and the disadvantaged.

I very much feel that Jim's got cheated of a lot of things in his life. He probably wouldn't see it that way. He always used to say, "If I die tomorrow, I lived a great life." And he had that philosophy of "I don't need to be really good at everything, but I'm going to try everything once." So, once I've skied downhill, I don't need to go skiing for ten years. I'm going to try rock climbing or skydiving. And he had his pilots' license, and he would scuba dive. I mean all the things that he could think of to do, he did. That's good, but I just feel like he was deprived of his retirement, deprived of seeing his kids grow up and be responsible adults. Deprived of knowing his grandchildren, all the things that people work their life for, and he's not enjoying any of it. So I feel that I have to have twice as much fun for both of us. Because I think, it's bad enough that the disease has taken so much from him, but I refuse to let it take so much from me. It's already taken its toll; it's shaped our family in ways that we probably don't even know. I think mostly for the good. It's made our kids really empathetic and strong and caring, but I don't know that we'll ever know how much we lost. But for sure he would have been a great example for his grandkids.

We Also See Who He Was

If I take Jim to a coffee shop now in his very advanced disease of course, he looks probably frightening and unusual. Doesn't fit in with, you know, anybody's perception of who's going to be at the coffee shop. He's become a person who you might look at and say, "He is a shell of his former person." He's very small. He's lost a lot of weight. He's very aged. He's limited in what he can and can't do, but for us that's just Jim now. So when we see Jim, know we see who he is now, but we also see who he was.

My Last Teenager

I eventually put him in a care facility, that was eight years ago (we had already been living with this for about 12 years), and he could take care of himself, but he was becoming a safety concern for me, and I realized he wasn't safe to be at home anymore. I had him in an adult day care program. I had hired a person that hung out until I got home from work, so he really was not on his own, but in the middle of the night he could get up and he could escape, and so I came to the point where we had to put him a facility, and I had to do it pretty quickly.

It was kind of like a relief because he was, at that point, my last teenager. And I'm going to make sure I say this: raising somebody or having somebody with dementia is kind of the opposite of raising your kids. You raise them from infancy, and they become more and more capable, and you pour all your attention into them because you know they're going to benefit from it. You know they'll become more and more responsible and capable, and you teach them to do things and they learn, and it's very gratifying and it's very rewarding. Having to take care of someone with dementia is like starting with the teenager and going back to infancy. You start with the rebellious teenager and who would take that child? They're used to doing whatever they want, they're used to being the masters of their universe, and they can't be. And so you're kind of hoping every day that nothing bad happens, hoping every day they don't get into an accident, hoping every day they don't get steal something, hoping every day they don't do something that will land them in jail. And you can't rationalize with them. Jim was cagey, manipulative, very self-centered, very selfish in wanting to have what he wanted and do what he wanted and from there it goes down to infancy. They gradually lose abilities and each time they lose something, it seems like a good thing. Oh good, now he's forgotten how to drive the car, that's a good thing because now I don't have to worry about him stealing my car, getting into an accident, and he doesn't have insurance. However, now there's something else he can't do. Now he can't go anywhere by himself, and so I have to take him everywhere and they become this person who is totally dependent like the cute infant that you get, but they're no longer cute. So is it a blessing or is it not?

I would always rather something happen to him when he's trying to have fun than he sit in a chair for the rest of his life. That was Jim. He was a risk taker he would have been the guy jumping out of the airplane, and if the parachute didn't go off, then he would be good with that. I think they (the staff at the facility) do not get that. They see the tasks. Feed the person, bathe them. Feed and bathe. And put them to bed. So, if I walked in, and they were dancing around with him in his wheelchair, I'd be pretty happy. I would be thrilled. And there are little moments. Like he just went to the symphony. They took a bunch of them to the symphony. And he was in the front row. It was great. I mean it shocks me when people will ask me, "What kind of music does he like?" I mean he's been there for years! You should know this. Or, "What does he like to eat?" Pretty much anything. Put it in front of him, and he'll eat it. I told them don't take me literally when I say I'd rather he choke on a hamburger than eat one more week of pureed food, but in reality, that's what I'm saying. [laughs] Sounds a little callous.

Our Expectations Really Shift

All I know it's been a really long haul. For all of us. And yet, a year and a half ago now when he was in the hospital, I really didn't think he was going to pull through, and our daughter was out of the country, and I was really freaking out about it. And I remembered thinking that I should have been feeling relieved, that this is kind of the end of a really long haul for him, and for all of us. But I was not feeling relieved. I wasn't ready for him to go. Which wasn't how I expected to feel. And there he was, he's 69 years old and just a cocoon lying in the bed unable to do even sit up or swallow or anything and yet, it was okay. It was good enough. This is who he is now, and it's good enough, and I don't have any other expectations. I don't expect him to say anything to me. I don't expect him to, you know, bring me flowers. You know, people have so many expectations for your spouse, and I've let them all go. I just expect him to still be here, and so, here he is, a year and a half later [laughs].

And you might look at him, and say, "Who would want that?" And I might look at him and say, he had his music today and he had a beer. And so I guess our expectations really shift. I mean, I have so many things I want in a given day; heaven forbid I not have my coffee in the

morning, and you know, Jim probably hasn't had coffee in three years because they don't think of giving him coffee. So, his world is so small but also simple. And he's really happy to have that music once a day, or have our daughter visit and put him on her phone so you can see him with his goofy grin. And someone else might look at him and be horrified by how he looks, very vacant and very absent, and yet that's not what we see. But who knows if we'd been caring for him, and he went from A to Z in a year we'd probably be struggling trying to keep up. So, you know, I guess, maybe it's been a gift in the way it's been so gradual, and we've all just gotten used to the role. In fact, if I wasn't a caregiver, I don't know what I'd be now, because it's all I know.

My son asked me a year or so ago if I'd ever thought about dating, and I was like "No, I'm actually married." And of course that's just a title, I mean I consider myself married, but I'm not really married. I'm not really in a relationship, but I still feel definitely committed to, you know, seeing this through in whatever time it takes.

Jim Passed Away a Few Weeks After This Interview Following a 21-Year Struggle with Alzheimer's Disease

A final message from his children: One of the difficult challenges many caregivers face is struggling to make end of life decisions on behalf of their loved one. Our family was fortunate to be able to support each other in making a unanimous decision that given the quality of his life, our loved one would want to pass away with limited medical interventions. Jim was placed on hospice, and when he was no longer able to take in any water or food without aspirating, our family gathered around to support him through his final remaining days. Jim passed peacefully in the early morning hours of December 16, a few days before celebrating his 43rd year of marriage to his devoted wife, Louise. His two youngest daughters were by his side engulfing him in hugs and whispering, "I love you" so many times it would be impossible to forget. His favorite folk singers played in the background for hours on end, and it was during Bob Dylan's song, *Lay Down Your Weary Tune*, that Jim took his final breath. He touched the lives of many, and for all of those who knew him, he will be forever remembered for his sweet spirit, wild sense of humor, and immense zest for life.

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These stories could not have been shared without the dedicated team of interviewers and narrators we had. Thank you all for your contributions.

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hear/say

Neurodegenerative diseases like Alzheimer's disease, frontotemporal dementia or Huntington's disease can cause dementia symptoms. The term "dementia" describes a progressive, degenerative decline in cognitive function that gradually destroys memory and the ability to learn, reason, make judgments, communicate and carry out daily activities. While it often includes memory loss, memory loss by itself does not mean that a person has dementia, and memory loss is not a symptom that every patient experiences. The diseases that cause dementia are defined by a progressive loss of brain structure or function leading to a range of symptoms such as changes in thinking, personality change, difficulty walking and using the body, or problems with language. In many of these diseases, the underlying cause of this progressive destruction is the buildup of abnormal and misfolded proteins in the brain.

Dementia is fast becoming a public health crisis with the number of people affected to grow to 13.8 million people in the U.S. by 2050.¹ The personal toll is staggering. People with dementia may survive for years while experiencing progressive decline in their abilities to function and deal with the everyday experience that most of us take for granted. And, families assume the highest burden for the care of loved ones with dementia, at great risk to their own health and wellbeing. Families face emotional, financial and personal costs for this work.

For almost 20 years, the UCSF Memory and Aging Center has been providing the highest quality of care for individuals with cognitive problems, conducting research on the causes and cures for degenerative brain diseases, and educating health professionals, patients and their families. The multidisciplinary team is made up of neurologists, neuropsychologists, neuroscientists, speech pathologists, genetic counselors, nurses, pharmacologists, social workers, research coordinators, technologists, communicators and administrators.

A vision of financier, philanthropist and musician Warren Hellman, the unique Hellman Visiting Artist Program was created at the Memory and Aging Center to foster dialogue between scientists, caregivers, patients, clinicians and the public regarding creativity and

the brain. Each year, an accomplished artist (visual artist, musician, writer or other creative individual) is invited to be “in residence” at the Memory and Aging Center to learn about neurodegenerative disorders like Alzheimer’s disease and frontotemporal dementia. We encourage a creative exchange between the artist and the researchers, as well as interactions with patients and families who agree to participate. The Visiting Artist also shares their creativity with the larger community through a public performance.

Visit *memory.ucsf.edu* to learn more.

¹Alzheimer’s Association (www.alz.org/facts)



Voice of Witness (VOW) is an award-winning non-profit that transforms the way people report, consume, and engage with contemporary human rights and social justice issues. Our work is driven by the transformative power of the story, and by a strong belief that an understanding of crucial issues is incomplete without deep listening and learning from people whose lives are most directly impacted by injustice.

We further our mission of promoting human rights and dignity through our core programs: (1) Our oral history book series, which amplifies the voices of individuals most directly impacted by injustice using a humanizing, literary approach, and (2) Our education program, which provides training and curricular support to educators and invested communities to foster empathy, critical thinking, and a participatory vision of history.

Visit voiceofwitness.org to learn more.

