

hear/say

global stories of aging and connection




GLOBAL
BRAIN HEALTH
INSTITUTE

hear/say
global stories of aging and connection

A collaboration between the
Global Brain Health Institute and Voice of Witness

hear/say Team
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This volume of *hear/say* is dedicated
to aging storytellers everywhere

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I've Always Had an Interest in Older People

I've always had an interest in older people, even as a child. When I entered medicine, my interest in caring for older people continued.

I've also always been interested in different settings and people. Perhaps this is why, after four years of medical school in rural Vermont, where many assumed I would stay, I packed my bags and hit the road—first to Colorado for internal medicine training, then to South Africa to work in rural medicine, followed by Hawaii for training in geriatric medicine.

In Hawaii, my program happened to be linked to a study of dementia in Japanese Americans. I'm grateful for this good fortune, for this is where my interest in dementia was cemented. Caring for older people with cognitive problems requires a clear understanding of the context of their care at home. To do this, I've had to delve into their personal narratives—their stories. Learning about the lives of elders I've cared for is one of the most satisfying parts of my job.

As Executive Director of the Global Brain Health Institute (GBHI) and the Atlantic Fellows for Equity in Brain Health program, I am fortunate to be surrounded by a community of innovative, passionate, and skilled individuals who devote their lives to protecting brain health.

Our community is built on the idea that achieving fairer, healthier, more inclusive societies requires leaders with diverse perspectives to collaborate and to learn from one another. We aim, in part, to improve brain health worldwide by training a new generation of leaders to meet community needs with local resources.

FOREWORD

GBHI is the product of decades of work at UCSF's Memory and Aging Center led by my boss, Bruce Miller, MD, and his efforts to train people from around the world; and The Atlantic Philanthropies, whose grand ambitions for social change and humbling generosity help to push societies to address social justice.

As the world's population increases, so does the burden of dementia. However, the global burden of dementia is hard to estimate, largely because it's hidden. Thus, we must continue to share and to uncover the stories of dementia and all affected—the patients, caregivers, family members, and providers. Each has a unique, powerful and important story to tell.

I'm humbled by the stories presented in this second volume of *hear/say*, which continues to raise the voices of elders and their role in society. As you will read, these stories of aging, dementia, art and life may look and sound different—in many cultures, dementia is associated with “crazy,” resulting in stigma and social isolation, while other cultures adore their elders, as reflected in focused care and supportive environments—but often the themes are the same, and they unite us as humans.

As I grow older, my interest in older people continues. I am grateful to explore, to connect, and to learn from diverse perspectives. I hope this collection of stories will have a similar effect on you.

Victor Valcour, MD, PhD
Executive Director
Global Brain Health Institute

Your Voice is Just as Important as My Voice

The *hear/say* project began as a collaboration between the Memory and Aging Center (MAC) at the University of California, San Francisco (UCSF) and Voice of Witness in 2016. Our goal was to forge space for patients, caregivers, doctors, family members, researchers, nurses, artists, and more to share “stories of aging, dementia, art, work, and life.” We wanted to shed light on the personal and rarely heard day-to-day experiences of aging and dementia, and through the oral history process, reduce the stigma and othering that occurs by perpetuating a “single story.”

Caroline Prioleau, *hear/say* team member and MAC staffer, sums up the energy that drove the project: “My passion for collecting and sharing stories of elders is the chance to increase empathy through curiosity and wonder (versus reaction and judgment). If we can be curious about what someone is experiencing, we can connect and understand better. The more we can connect, the less isolation and stigma there is.”

Adding to that curiosity and wonder, Jennifer Merrilees, MAC staffer and *hear/say* team member, includes enlightenment as a driving force. She recounts an observation from a family caregiver: “Everything I do for my mother is largely invisible to the world. The majority of what I do as her caregiver is within the walls of our home.” By wanting to counter the reactions and judgments, and make room for empathy and enlightenment, we were motivated to turn the single story of aging, dementia, and caregiving into many stories that contained multiple perspectives and realities.

So, we kicked into full storytelling mode: oral history trainings, interviews, editing sessions, book publication, and a culminating

public reading of some of our collected narratives. Immediately after the reading, it became clear that *hear/say* would be a game changer for MAC and Voice of Witness. The emotional experience reminded us that storytelling was uniquely adept at normalizing (and even celebrating) issues we struggle to talk about and that our project heartily embraced the intersections of aging, art, healthcare, and social justice. The project also had an impact on the culture of both organizations as we experienced the most creative aspects of healthcare and the many caregiving aspects of storytelling. It took us about a week to regroup and ask ourselves, “What’s next?”

“What’s next?” turned out to be an expansion of the *hear/say* project to include the Global Brain Health Institute (GBHI) and work directly with the Atlantic Fellows for Equity in Brain Health, an international cohort dedicated to protecting the world’s aging populations from threats to brain health. The expansion also included the making of a short documentary film (more on that later). The new iteration of the *hear/say* oral history training was conducted with the fellows, faculty, and staff at both GBHI founding sites, UCSF and Trinity College Dublin, in the late fall/early winter of 2018.

Our main areas of focus were to “go global” with our commitment to sharing multifaceted stories of aging and dementia from myriad voices, and through oral history training, to provide each fellow additional tools for leadership, and to enhance their practices and individual community projects. The *hear/say* team wanted to give fellows and other participants an opportunity to embody empathy through storytelling, and to further their interview and listening skills—specifically in considering the impact of stories told without rigid prompts or directed outcomes. In short, stories that made space for the poetry of everyday experience—stories that don’t always stay within the lanes of our ascribed identities as

patients, doctors, artists, caregivers, elders, neurologists, researchers, and more.

By collaborating with a talented group like the Atlantic Fellows, we hoped to inspire them to use the *hear/say* process in their home countries and communities during and after their fellowships. We hoped to inspire them to use storytelling to amplify the needs, desires, and inequities that surround aging and dementia, and by doing so, articulate a key principle of social justice that demands individuals be given the right to express the fullness of their humanity.

Most of the stories that appear in this volume are provided by the Atlantic Fellows, as well as the faculty and staff of GBHI and the MAC. Still more global stories of aging are forthcoming through a documentary short film by award-winning filmmaker, Cynthia Stone, which will make the stories even more accessible through the universal language of film.

Cynthia shares how interviews for the film impacted her and reflect the *hear/say* project as a whole: “While making this film I was just beginning to go through something similar to what many of the caregivers I was interviewing had been going through for decades. It helped me glimpse their immense courage, compassion, and strength. I am eternally grateful to each one for sharing their stories. Their wisdom helped me find equanimity, meaning, and beauty in caring for my mom.”

The *hear/say* project aspires to help others see the meaning and beauty that Cynthia experienced. For stories like hers, and the feelings that drive them, to ripple outwards to a global community that recognizes the need for action and empathy in caring for our aging population. Both of these approaches need to work in tandem. For example, in 2019, Alzheimer’s Disease International issued a call for three-quarters of countries worldwide to provide support and training programs for carers and families of people

with dementia by 2025. We hope urgent steps like this, combined with narratives that reinforce what we all have in common, will contribute to a much-needed sea change in healthcare for our elders. The *hear/say* contribution is offered through the power of oral history.

Voice of Witness Education Associate and *hear/say* team member, Erin Vong, eloquently captures the connectivity this kind of storytelling nurtures: “In every country, every city, every village, these stories exist. Similar themes of loss, love, joy, and compassion flow through all of these narratives, and truly bind the human experience.”

The stories in this volume contain all of these themes and more. They also highlight the importance of sharing your experience and speaking your truth. The words of *hear/say: global stories of aging and connection* narrator, and Alzheimer’s and dementia advocate, Helen Rochford-Brennan perfectly express the rationale for what you’re about to read, “So many times people have come up and said, ‘You’re telling my story. That is how my life is, but I’ve always been afraid to say it.’ And I say to them, ‘You know, you go and become an advocate just like me because you are going to help somebody else. Your voice is just as important as my voice.’”

Enjoy *hear/say: global stories of aging and connection*, and please share it with a friend, family member or loved one. The resources at the end are to help you develop your empathy-driven oral history skills and add to the global community of shared stories.

With respect,

Cliff Mayotte and the *hear/say* team: Jennifer Merrilees, Lorina Naci, Caroline Prioleau, Cynthia Stone, Dominic Trépel, Erin Vong



Photograph by Ronan Fox, Cinematographer

Misery is Optional

NARRATED BY

HELEN ROCHFORD-BRENNAN

INTERVIEWED BY CYNTHIA STONE,

DOCUMENTARY FILMMAKER

Helen Rochford-Brennan is a woman from Tubbercurry, Ireland who was diagnosed with early-onset Alzheimer's disease at the age of 62. She is a powerful activist for the rights of those with Alzheimer's disease and Alzheimer's disease-related dementias. She appears very composed but is also witty and vulnerable. She employs various strategies to manage the disease, and her husband, Sean, and her son, Martin, have been vital supports. By her sheer will and determination, Helen works tirelessly to advocate for her rights and the rights of others with dementia and Alzheimer's, encouraging others to use their voices to advocate for themselves. One of her biggest goals is to create more inclusive and integrated communities for all people with hidden disabilities. Helen has good days and bad days, but she refuses to let her Alzheimer's define her.

The Darkest Hole

My name is Helen Rochford-Brennan, and I come from this beautiful place called Tubbercurry in County Sligo, Ireland. It was once a very industrious town—it's not so much anymore. But we have a community of great spirit, and we have beautiful tourist attractions, and we try to promote them as best we can. And it's a lovely place to live because we're in rural Ireland, and the rural areas really are a lovely place to be. Oh, my life was so busy. Too busy in fact. I was working full time. I was very involved in my community. I've always been involved with the Chamber of Commerce since I've been here, and I was involved with lots of disability organizations because I worked in the

disability sector. I was involved with and was the chair of a state agency. In Ireland, they don't put too many women as Chairs, so it was just a great honor for me to have this appointment. I'm a Peace Commissioner, which means that if somebody wants to get a passport or to sign legal documents, then I verify signatures. I was always busy with my job, and I'm a wife and a mother. So I thought I was too busy and that I had too much going on, and so did Sean and Martin. Life was a bit hectic, but I loved it. That was my life. I loved going to the theater. I loved to travel, and I really had a very joyful life.

I was 62 when I was diagnosed with early-onset Alzheimer's, but I was struggling from 57.

I was beginning to forget things. Martin would call me, and I would forget what he had talked to me about. Sean would say to me, "Helen, we need to get something," or maybe "renew the contacts online," or "do something in the house," and I would forget it. It could be as simple as, "Can you buy milk on the way home?" and that was forgotten about. It seemed that the more that I was forgetting things, the more I realized that there was something wrong. I used to go to work in the morning hours and think, "What is wrong with me? These tasks are so simple." I found myself at meetings, and the words just didn't come. Then there was that burning silence of, "What is going on here?" I knew that there was something wrong. I had previously had a head injury, and there was a possibility there could be cognitive impairment. So Sean was getting more frustrated, and Martin was getting more frustrated. I started to slow down and started to not go to as many meetings.

Oh gosh, when I was first diagnosed, I just saw nothing but the end of the world. And I got a diagnosis of early-onset Alzheimer's disease, and I spent ten months in this area just absolutely completely in the darkest hole of depression you could ever

believe. I just couldn't believe that it was happening to me. Nights were endless. Sleep deprivation. Pain for a life you will never have. I found myself at home sitting here doing absolutely nothing because I just couldn't function. There was no job. There was nothing to get up for in the morning, really. I just thought we were planning our retirement in a few years; we've got our lovely new home, Martin had just finished college, and it was a time to be enjoying our lives instead of being faced with a chronic illness. But I think that when you're diagnosed, you just have to accept it just like any other chronic illness and hope that you find the strength, like I did in time, to come and accept that this is not going to change. So I have to accept it.

It was very difficult. I found my way home after my diagnosis and talked to Sean, and it was very devastating. Then Martin came home, and I talked to him. We sat at the kitchen table, and I don't remember the conversation, but I certainly remember the pain of it. How does any mother tell their only child that they have Alzheimer's disease? He was just finishing law school and embarking on a career. So it was difficult for us. But I think that somehow, as a family, we were very strong. We communicated a lot. And so that really helped. Really helped.

I think in the early days it was worse because Sean didn't understand it. But now he knows that I can travel by myself. Sean is very supportive and has always been very supportive of whatever I want to do. It's not easy when he's been ill. I canceled quite a lot of events so I could be home with him, and I continue to. It's important. We have to have that balance. We don't get any support from our health services, and that's why it's very disappointing. But I couldn't do what I'm doing without Sean's support. There is no question about it. I love him to bits.

I talked to the doctor, and the doctor suggested that I go to the Alzheimer's Society. So I did go to an Alzheimer's group, but the

Alzheimer's group was just as I expected. All very old people. Which is what I, myself, identified Alzheimer's with. I had no idea how your life would pan out when you get Alzheimer's, and I certainly never heard of early-onset. And so I went to the Alzheimer's group, and it was just awful. I came out, and I sat in the car, and I cried and cried and cried, and I thought this is how my life is going to be.

It's Not a Death Sentence

I got so angry that there were no services and there were no supports. And why should the age of sixty-five matter? Why should it matter? Why should it matter that I'm under sixty-five or over sixty-five? And I thought I was going to get all these magical services when I was over sixty-five. Why should it matter? Just a number and that's what really drove me. I thought, "Hang on a second here. This is a violation of my human rights. This is a violation of everybody's human rights under the age of sixty-five." And so that's what drove me to really get involved and say, "These are the rights of people with a disability. We have a chronic illness. There is no cure for it." There are very few services for people under sixty-five that want to remain active. For many of the elderly, it's care homes. And in this country, we give lots of money for people to go into a care home. We call it a Fair Deal in Ireland. It's where the government takes a portion of the value of your house to support you in your nursing home, but they will not give that portion for you to stay in your own home.

I wish people were more aware and had better training. Training and education — there's a huge lack of training — quality training! There is lots of training, but I mean there is not enough specific dementia training, and there's certainly not enough training in airports. "Why would I have somebody come traveling with me?"

My volunteer assistant Carmel Geoghegan is my travel companion. She travels with me to make sure that I get to my destination, supports me in my meetings, and allows me not to get anxious whilst traveling...it's bizarre, to say the least, that I can't be guaranteed airport assistance. Airports vary.

When I first got the diagnosis, there was so much stigma. I do remember a story about when I was walking down the street. I was going downtown, and I saw this lady that I would speak to very regularly, and she walked across the street. And then I noticed some other people just didn't speak to me.

They'd just say hello, and I thought I could have spoken for 10 or 15 minutes, as you do in rural Ireland. I mean, a conversation. And then the conversations stop. So that was hard to digest. That was very hard. I think it's very hard, especially that I had made it very public because once I spoke about it, first, all the local radio stations and newspapers—and powerful national ones—they all interviewed me. So it wasn't that people weren't aware that I had it and that I could get out and get on with my life. I just found it hard. But I think that is just education and awareness. And back then I didn't understand that. But today I understand that that's what it is. It's about education. It's about people understanding what early-onset Alzheimer's disease is, or early-onset whatever dementia you have. There was a lot of stigma then. Oh, the stigma. In some rural areas, we still have stigma, and stigma is something that—honestly, we have to tackle on a daily basis.

Sometimes I wake up in the middle of the night and put my hand up to see if Sean is alive beside me in the bed. When I wake up at night, it's not anything good I wake up about. It's like waking up with this gray fog that is never going to lift. It's very hard to describe because it's very difficult. For me, it's like, "What happened yesterday?" My biggest problem is short term memory. It's like a heavy gray fog that you can't remember when you're trying to remember,

and it's there forever. I wish it would lift for just five minutes so that I could just remember. You want to remember all the joyous moments. It can be quite painful, and that's why I try to keep active because the more I keep active and keep my brain active, every researcher tells us the better quality of life we can have. There's nothing else I can have more than quality of life.

It's unfortunate, but I have to try and turn it around by being in the garden or going for a walk by the lake or in a lovely location on a sunny day or giving an interview. If I have a dark moment, I can at least apply strategies again to whatever the moment is. Maybe that strategy is to put on my coat when it's freezing cold outside and walk around the garden or walk around the house to just get rid of that. Sean and I were advised by my doctor to contact an Alzheimer's group, which I did. I visited Western Alzheimer's, and it was what I expected, a group of much older people than me. The nurse, all she could offer was to advise me to get involved in research. I went to my car and cried for thirty minutes before I could drive home, as I had never been involved with research in my life. I felt there was no HOPE.

I was at our local hospital talking to a nurse, and she heard Professor Ian Robertson on the radio. The nurse came here, and knocked on the front door, and handed me a piece of paper. She said that he was talking about research and dementia. Martin was home with us for the weekend, and he absolutely insisted that we send Ian an email. So, at eleven o'clock on Saturday night, we sent the email. And at nine o'clock on Monday morning, we got a response from Ian, and the rest is history. Ian referred me to lecturer Michelle Durham who was carrying out research with the Alzheimer's Society on Cognitive Rehabilitative Therapy. She introduced me to a group that was being newly formed, the Irish Dementia Working Group, who are people like myself with dementia. I had just lost any hope of ever being involved in anything at

that time. And Michelle came to the house, and she worked with me to get my diary up and running, to write everything down, no matter how small, to label cupboards to put all these things in place. Just strategies, simple strategies.

Cognitive Behavioral Therapy is about giving you strategies about how you can just make your life a lot easier. And so I think it gave me some sense of empowerment that I can actually do something again. She said to me, “Is there something in this house that you really want to do that you haven’t done?” And so I suggested photographs. And she told me, “Scan all of those photographs onto the computer, and you will have a book of memories for your son.” And I said, “God, I had somebody else scan things for me all my life.” I didn’t do much scanning myself, so I had to learn. The husband of one of my nieces came to my house and showed me how to scan. And it was then I realized that I actually could do something.

Oh God, I honestly don’t think I would function without cognitive rehab therapy, I really don’t. But I think back on the dark days that I had no sense of purpose and no sense of doing anything, and I think that’s what it has helped me with. And I talk about it a lot because it’s important to me — because it has given me a quality of life and a sense of purpose.

All I have is hope. There’s no cure. Only the week before last, one more chemical trial failed. And now it’s over. I’m just extremely sad about it. I’m where any of us with the illness is — waiting and wondering. We’re hopeful that someday there will be a cure. So then you question yourself for maybe twenty-four hours or so, “Are they looking in the right place? Is it all about amyloid¹ in our brains?”

¹ Amyloid is a protein that is found deposited in large quantity in the brain of people with Alzheimer’s disease.

Life is hard work if you want it to be, really. There's a great saying: "Misery is optional." I don't want to be miserable. I want to work hard at trying to live as good as I can. And so I have to work with the strategies to do whatever it takes to give me a quality of life, and to give those around me a quality of life.

I want to give people who have just gotten a diagnosis hope. Hope that you can have a quality of life, that it isn't the end. It's not a death sentence. Yes, it's difficult. Yes, it's extremely difficult to not remember what happened yesterday. Then maybe it wasn't that important. But it's just to give people hope to see that we can get up, we can get out, we can move, we can do most of the things we did before — with strategies. We have to have strategies. And that is one of the things that I want to get out to people, that we can get on with our lives. That it's as simple as a diary. It's as simple as baking. It's as simple as doing your driving assessment, or going for a walk, or getting into your garden, or doing whatever you did. If you played golf, we must encourage people to continue to play golf. If you played tennis, if you played bridge — whatever you did in your life beforehand, try to get your neighborhood, try to get your friends to help you to continue doing those things. And once you do that then, yes, as progression happens, life becomes a little more difficult, and you have to have some support from your health service. But in the meantime, when you're diagnosed, just do what you've been doing. I joined a ladies' group, and we were all very busy knitting and sewing, and I'm afraid I'm not a knitter or a sewer, but that was good fun. Good conversations. I think it's about...getting out of there, getting out of the darkness, the awfulness of the pain that it brings.

You can be very independent and can live with it. Absolutely I live with it. Every day is not easy but I actually enjoy my life. I enjoy it. It's my Alzheimer's life. It's not the end of the world. It's to

be lived. I try and enjoy every moment of it. I think that's really important.

Meitheal

Because I'm so passionate about rights and really being fully integrated into the community, I do not believe that we should have special aisles for me. Or that I should be treated specially. There's nothing special about me. I'm just the same as everybody else. And so, I am not a lover of dementia-friendly communities because I don't see a diabetic-friendly community. I don't see a Parkinson's-friendly community. I don't see a multiple sclerosis-friendly community. I see an inclusive community. And I want to be included in my community. No label. I want to be fully integrated into the communities that I live in, and I think that we must stop treating ourselves as special. Yes, we have a hidden disability, but then there are loads of other hidden disabilities, and there's nothing special for them. And whilst I appreciate people having a very strong view on a friendly community, it's not for me. It's about total integration, and it's really about my community adjusting to me, not me adjusting to my community.

Because we have a huge farming area, we need to get our farmers to understand that when somebody is diagnosed in their community, that there's support all around them. We have an old Irish saying called *meitheal* and *meitheal* means that everybody—all the farmers—came to help the farmer when he was saving his hay or whatever. And so I often say today we need *meitheal* to take care of that person when they're diagnosed with dementia in their community. And if we have the support of our community, then if I'm stuck, I can ring my neighbors. Once you talk about it, then all that badness that was there is just gone because people

are more aware. But it's about awareness. There's nothing greater than awareness and education. And where do we start? We start with our children at school.

Gosh, having young people around brings so much joy to my life because we need to be intergenerational. Intergenerationality is so important. I speak at schools because I think our children need to know that across the world, we're trying to get diagnoses younger. And so when you are diagnosed in your 30s or 40s and you have young children, as I've witnessed many times, those children need to understand that when mom or dad repeat the same thing, I tell them they don't remember, but that they understand it—and you bring that language to their level. And we have a hidden disability, and there are children in their schools that have hidden disabilities. So it's about me going to the schools and speaking, and the child with autism speaking with me.

And so I want children not to see the difference, but to see that that child that has whatever disability they have, and my disability, that they work hand-in-hand. And this really is fantastic. It's important that the next generations—teenagers, little children, know this...that they understand the illness, and that they understand that we say things that we shouldn't say, that we repeat things. We constantly repeat. So I have my nieces come with the children. It just brings a lot of joy in my life because they're funny, they're witty, they ask funny questions, and they also tell you all about what's happening in their lives, and they can go on and tell their friends at school, "Well, Auntie Helen has got this thing called Alzheimer's disease, and she doesn't remember, and she doesn't remember my name sometimes, and she mixes me up." This relationship is to be built and nurtured, so they have the joy of remembering their grandparents, which is really important today.

Nothing About Us Without Us

I want to remember my email to Professor Ian Robertson. That was the turning point in my life, that's when I suppose I could see that there may be some hope. That's when I decided not to stay silent anymore, when I was very much supported by the Alzheimer's Society of Ireland too. I then realized that going to my meetings, the working group—that was helping others as well. I think that's what gave me the strength, and also to know that I was fighting back, and that my rights would not be violated any longer. I think that rights-based approach for me was absolutely, fundamentally the most important thing. It really was. It was just...this is a total injustice of how people in Ireland are treated—just because of a number? A couple of numbers? And I think that changed my life. It just gave me that fight to carry on. But it also gave me a sense of, "I'm doing something good."

It may not be the great, overwhelming sense of happiness I would have experienced in the past, but certainly, it gave me a feeling of, "This is good. We are making some headway. We now have brochures that we have in doctors' surgeries. We can go on YouTube, and you can hear and look at our videos on stigma and our videos on living well." Being able to participate in them was really important. We need to have strategies. We need to have plans. And you could see some good coming out of it, which is what I really wanted. I didn't want to be lonely, and I definitely didn't want anybody else to be in the same boat as myself in those early days when there was nobody to talk to. If there was just somebody there that could have said to me, "This is how you tell your children. This is how you tell your husband. We are here to support you." There was no signpost, no pathway of care then, and that's what I strive to change.

After I started to advocate with the Alzheimer's Society, we went to our Dáil Éireann (House of Representatives), and we presented about the difficulties that we have, and why we need more money. I spoke, and I remember looking down and there were three or four handsome young men at the back. Martin and his friends had come from work, and it was just amazing to see these young people here with all these politicians supporting me. It was in many ways just difficult because there were lots of people really crying because they thought of my life as being over. But I didn't want them to cry for my life. I wanted them to understand that I finally spoke up for the people of Ireland, and to not be afraid. After that, I became the first Irish person to go on National Television to really talk about it, and then to get up and not be afraid to speak and not have our carers speak for us. We can speak for ourselves. In republics, advocacy doesn't have to be about public speaking. It can just be about creating awareness in your neighborhood or workplace and, "Please be an inclusive neighborhood and include all disabilities." That was a good breaking point because that was when we started the Irish Dementia Working Group. Our working group did loads of media work, and we made videos. We did pamphlets, and we did all kinds of things to just try and raise awareness. I realized that I wasn't alone meeting others in the Irish Dementia Working Group. I realized that our voices were really important and that our voices should be heard.

It was quite extraordinary when I started to do advocacy work because one of the first pieces was on one of our main television shows here and on Primetime — Primetime television on a Saturday. Nerve-racking as it was, it was a good opportunity for me to understand that my voice, the voice of the person with dementia, is really important and that we have lots of people that talk about us. So I suppose it goes back to, "Nothing about us without us."

I started to do more and more talking to whoever wanted to hear my story, whoever wanted to write about my story because I feel more passionate now than I felt back then about getting the story out. Because at that stage, I'd gone through all the difficulties myself and had said, "Gosh, somebody's going to be diagnosed tomorrow. This young person." And there's nothing there, so the more I can speak and advocate, and the more I travel, and the more I can talk about this, the easier it is for other families.

So many times people have come up and said, "You're telling my story. That is how my life is but I've always been afraid to say it." And I say to them, "You know, you go and become an advocate just like me because you are going to help somebody else. Your voice is just as important as my voice."

I often talk to the pharmaceutical companies. They're making medicine for me. They never had anybody with the illness talk to their staff. Scientists don't always necessarily agree with us. But they also need to listen to us when we tell them about the difficulties we experience every day. And certainly, even in diagnosis, post-diagnostic supports, pathways of care. Hopefully finding the drug that's going to help us—whilst we wait, pharma can support us with non-pharmacological interventions. I mean at the end of the day, we have to try and help ourselves. And so that's when you advocate. That's what you advocate for. There's great joy in it, and you meet so many wonderful people in advocacy.

Advocacy is great for education. At the end of the day, it's about education. We need to talk to our medical schools; we need to talk to our nursing schools; we need to talk to business; and we need to talk to children of all ages. You know, address all kinds of conferences, whether it's physiotherapists or social workers. It's about them getting into our shoes, about them hearing about the difficulties that we're challenged with every single day. The

endless lists, the endless emails, the endless conversations on the telephone — because that's how we survive.

I hope the work that I continue to do has an impact on how we change things in Ireland. I certainly have challenged every politician I can find. I certainly challenge. I sit on the monitoring committee of our first national dementia strategy. I'm sure there are times that I have a very strong voice. They don't agree with me, but that's okay. I have a job to do: to make life better for people with dementia and to make sure that we get the funding. It was very disheartening this past year that the budget came, and we got no money in the budget for dementia in Ireland. When you think of all the hours, the endless hours you've given to advocacy, and there's no return. But I can't stop. I must go on to make sure that no one ends up in a black hole.

There's just something about it that really tells me, "Be grateful." You know it's just about being grateful for that opportunity to hear the birds, not being isolated, and not being afraid to talk about it. I have Alzheimer's, so I have Alzheimer's. We have to break down stigma. Back then it was really, really difficult because we didn't have a lot of stigma campaigns. Today it's different. And I hope in some way that I've contributed to breaking that down.

A Note from Helen

I feel so blessed to participate in research around the world, for the opportunity to be first Chair of the Irish Dementia Working Group, to be the current Chair of the European Working Group of People with Dementia, and the opportunity to be on the Board of Alzheimer Europe. I'm also grateful to be on the Monitoring Committee of Ireland's first National Dementia Strategy and to

have been invited by the World Health Organization to participate in events.

I have been supported by my most amazing family, by my selfless travel companion and volunteer Carmel Geoghegan, and by the marvelous teams at Alzheimer Society of Ireland and Alzheimer Europe.

To have received an Honorary Doctor of Laws from the National University of Ireland, Galway for my advocacy on the Rights of People with Dementia was a glorious unforgettable day for my family and me.

MISERY IS OPTIONAL



Photograph by Alex Kornhuber, Atlantic Fellow

Eternalistic Geriatrics

**NARRATED BY
CHRISTOPHER COURT**

**INTERVIEWED BY
ALEX KORNHUBER,
ATLANTIC FELLOW**

Christopher Court is a co-facilitator for the Bay Area Radical Mental Health Collective Support Group at the Berkeley Free Clinic, a place for people to express themselves. Christopher is very active and expressive himself, and he likes to listen to other people's stories. He believes that listening carefully and trying to understand and share back all the information that he's heard is excellent for his mental health. He has a passion for languages and foreign cultures. He's really curious about humanity; a cross between an anthropologist, a linguist, a sociologist, and an advocate.

What we do in radical mental health is to explore being sane, while having ideas which conventional mental health theory would consider pathological. So to think that you are the entire cosmos or that you're eternal is a delusion of grandeur according to ordinary mental health theory. But what if it's just a glimpse into another level of reality? That's what we're doing in radical mental health—a radical reinterpreting or re-visioning of conventional ideas.

So, we're just talking about aging, and I thought of a spin-off from radical mental health; we could have radical geriatrics or radical gerontology, a radical theory of aging. Part of this idea that I have is that although by the calendar I'm getting older every day, in other ways I'm getting younger every day. So, that if you can succeed in doing that, if you can succeed in growing younger as you get older, when you finally die it's also going to be a birth. In fact, death and birth are just incidents in a continuing cell force, a continuum that is not really contained in space and time. So I tried to represent that once; if you go back 100 years, I wasn't yet in this world in this form, and in 100 years I won't be here. But

this drawing is the part of me that's always here. So that's a little... That's a sort of primitive, primitivistic artistic expression of radical geriatrics. The eternalistic geriatrics, you might call it. Thank you very much.



Photograph by Alex Kornhuber, Atlantic Fellow

城鄉醫療不應該有差異，這是社會正義！

由曹汶龍醫師敘述

鄭文立醫師採訪



This is Social Justice!

NARRATED BY CAO WENLONG

**INTERVIEWED BY TEE BOON LEAD,
ATLANTIC FELLOW**

曹汶龍醫師算是台灣神經科界很資深的一位前輩。他曾擔任台灣神經學學會及台灣癲癇醫學會的理事長，並協助建立了台灣神經科的雛形。面對如此德高望重的前輩，首次見面時，心裡是有些忐忑與期待的。不過當見到曹醫師“廬山真面目”時，瞬間覺得很溫暖，並理解為何大家總暱稱曹醫師“曹爸”。曹醫師總是笑咪咪地，有著彎月般的笑眼搭配時不時的爽朗笑聲，雖有七旬的歷練卻帶有年輕人的活力，讓人覺得和藹可親。熟悉曹醫師的人或許曉得“曹爸”也是一名網紅。曹醫師的令堂也深受失智症的困擾，然而曹醫師總能以輕鬆有趣的方式來照顧曹媽媽，並把趣事分享到社交媒體上，降低失智症患者與家屬的孤立感與不安。

身為後進，最為好奇的就是曹醫師在退休後決定到偏鄉服務的緣由。在台北三總擔任過神經科主任、台灣神經學學會及台灣癲癇醫學會的理事長後，少有前輩會決定在退休年紀遷居到偏鄉去重新打拼“第二春”的事業。然而曹醫師離開三總後，毅然決定舉家遷移至花蓮與大林，協助慈濟醫院發展神經科，並跨足至失智症科，發展頗具規模的社區型的失智症照護。在談到這個議題時，曹醫師分享了訪談中讓我印象最為深刻的一段話：“如果台北人與花蓮人繳的健保費並沒有不一樣，那為什麼醫療服務要不一樣呢？城鄉醫療不應該有差異，這是社會正義！”的確，在忙碌的生活中，嘴上掛著“社會正義”口號的人不少，然而能如此以身作則地落實“社會正義”的人為數不多。看著七旬的曹醫師述說這番話的熱誠，我彷彿看到了他那堅持留給年輕一代更美好的未來的浪漫情懷。

曹醫師即是一位德高望重的醫師，也身兼了一位失智症患者的家屬的身分。與一般家屬不同的是，他總帶著輕鬆自在的態度面對母親的疾病。“因為我越來越體會到失智症不是一個病，它是一個過程。就像孕育孩子成長一般，失智症亦是一個心智變化的過程。我們能

Dr. Cao Wenlong once served as the Chairman of the Taiwan Neurology Society and the Taiwan Epilepsy Medical Association and helped pioneer the establishment of neurology specialty in Taiwan. Among his colleagues, he has a nickname called “Daddy Cao.” Instantly when I met him, I understood why. Dr. Cao always carries a benevolent smile that curves his eye into a crescent moon shape, combined with his bursts of laughter, it is not hard to see why people warm up to him easily. At the age of 70, he possesses the vibes of a young person with unlimited enthusiasm and positive energy.

Some may be aware that Dr. Cao is also an internet celebrity. For the past decade, his mother has also been a victim of dementia. Maybe because of his experiences in the medical field, Dr. Cao has many fun and interesting ways to care for Mama Cao, and regularly shares them on social media, indirectly reducing the isolation and anxiety of dementia patients and their families.

If one is familiar with Dr. Cao’s biography, one would likely be intrigued by his unconventional retirement plan. After stepping down as Chief of Neurology in Taiwan’s Tri-Service General Hospital and the director of the Taiwan Neurology Society and the Taiwan Epilepsy Medical Association, most retirees of his caliber would choose to enjoy life in a leisure manner. Dr. Cao, however, chose to move to a rural part of Taiwan, Hualien, and Dalin with his family. He then helped establish the neurology department at Hualien and Dalin Buddhist Tzu Chi Hospital and developed local community care for the dementia population. When probed on this topic, Dr. Cao said, “If the health insurance premiums paid by Taipei people (capital) and Hualien people are not different, then

享受陪伴小孩成長過程的變化，一樣也能珍惜失智症賦予人生最終旅程的色彩。”嘗試透過患有失智症媽媽的角度去探索世界，成為曹醫師的日常樂趣之一。高齡九十歲的曹媽媽總認為自己如今依然五旬，因為在她年輕時的記憶，很少九旬的人依然能活動自如，如她一般到處走動。有趣的是曹媽媽卻依然判斷得出曹醫師已七十歲，因此爭論曹醫師為何七十卻是她的兒子，變成他們鬥嘴的話題之一。順著疾病走、尊重生老病死的永恆循環似乎是曹醫師面對失智症族群的核心原則。“人家失智的智能會越來越沒了，就好像黃昏，慢慢地要黑掉。當你接受這個事實時，老人家也絕對會接受的。其實我們就是給他畫了一個美好的人生結局，而不一定硬要去強拉他。”因此每天曹醫師總是玩遊戲般的哄樂曹媽媽，淡然地接受她逐漸的心智退化，以陪伴撫平疾病所帶來的孤獨與徬徨。有時學會放手比拼命爭取來得更為困難。或許多年站在生死的戰場上，成就了他豁達面對人生的態度。對媽媽的未來，曹醫師說：“一直到最後我都想辦法讓她喜悅，這個過程就這樣走就好。”一個看似最簡單的心願，也是一個充滿愛意與智慧的相守。

why should medical services differ? If we don't charge differently, there should not be disparities in medical services. This is social justice!" Many have talked about "social justice," but to embody social justice and lead by example is not commonly seen in people in power. Looking at how passionately the 70-year-old Dr. Cao articulated these words, it is clear that he is an idealistic elder with a strong sense of patriotism who thrives to leave a legacy by building a better future for younger generations.

Being both a dementia expert and caregiver of dementia, Dr. Cao adopts a very unique approach in the face of his mother's illness. "I am more and more aware that dementia is not only a disease but also a journey. Just like child development, dementia is also a journey in which one experiences gradual mental changes. If we can enjoy the growth journey of children, we can definitely find a way to appreciate what dementia bequeaths to the final voyage of life." Exploring the world from the perspective of a mother with dementia becomes the daily entertainment Dr. Cao shares with his mother. Mama Cao, a 90-year-old elder, often believes that she is in her fifties because based on the memories when she was young, few 90-year-old people in that era were able to remain ambulatory. Interestingly, Mama Cao can perceive that Dr. Cao is seventy years old, so they often engage in daily fun squabbles about Dr. Cao being her son but yet is older than her.

Respecting the circle of life appears to be the core principle of Dr. Cao's when in the face with dementia. "Demented elderly will gradually lose wisdom and identity, just like the dusk, slowly darken vanishing into the night. When you as family accept this fact, our loved one will also gradually find peace in it. In fact, instead of working against nature and trying to pull them forcefully out of the down spiraling circle, we should focus on painting a beautiful life ending with them." Therefore, every day Dr. Cao plays fun games with Mama Cao, gracefully accepts her

HEAR/SAY

gradual mental deterioration, and attempts to drive out loneliness and despair through companionship. Perhaps it is from the many years of experiences of battling in the field of life and death, that Dr. Cao attained such an open-minded attitude towards life. For Mama Cao's future, he expressed: "I will always try to make her happy until the very end, that is all I wish for." A seemingly simple wish yet so full of love and wisdom.



To Harbor Any Ill Will or Misplaced Hope is Stupid

NARRATED BY MARC CALDERON

**INTERVIEWED BY JACK TAYLOR,
UC SAN FRANCISCO**

Marc Calderon lives in the California Bay Area and cares for his mother, who has a slowly progressing form of dementia well into its middle stages. His willingness to provide advice to others through open discussion about his experiences as a caregiver, coupled with his continuously bright and sunny demeanor, is greatly appreciated by many caregivers in the Bay Area's community. Here, Marc graciously shares some of the more arduous and poignant sides of caregiving, with the intent of reminding others that they are not alone in difficult times.

My mother and I have had an extremely close relationship since I can remember. She basically made me the most special child in her life, although with three other children, perhaps that wasn't fair. Part of that dynamic, however, was that she expected absolute allegiance to everything she said or did. She's a very kind woman, but very strong and entitled too. She was on the pedestal—in everything that I did, she was in the back of my mind. Even moving back from Europe when I didn't want to because I was afraid that something might happen to her. She might need me, and of course, she did.

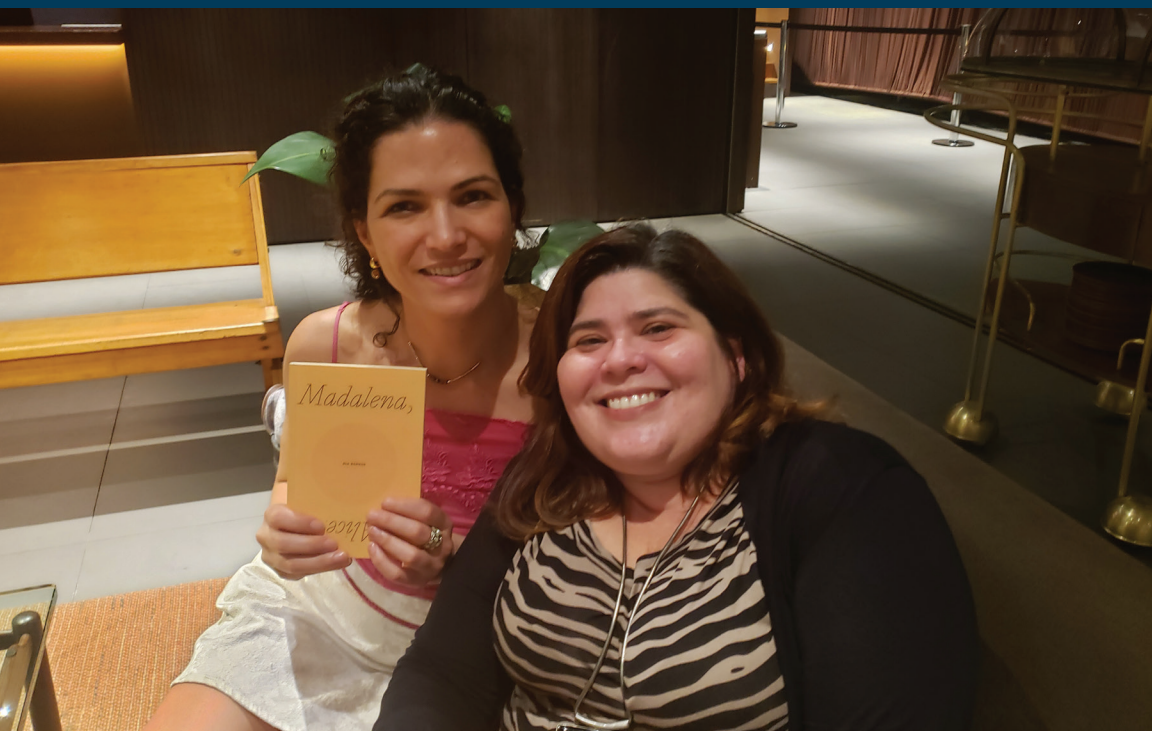
With her illness, Alzheimer's-related dementia, there are trigger points of anger to her when I don't act like the child I used to be, the child she always believed I was. But the roles have changed. My mother does live with me now, and I provide 24/7 care. We used to be somewhat of a team, at first. I could bounce things off of her. That's no longer possible. I've become the parent, the strong one, the decision-maker. I'm in charge emotionally, financially, spiritually, and in this, there is a loss. I have lost a part of myself because this is not a role I ever wanted.

The hardest thing, I think, is trying to balance my sanity by finding the time to carve out a small part of my life when I have this tremendous, tremendous responsibility. And getting over my anger—that I should have my own life or feeling that I have already given enough to her, or that my other three siblings have not stepped up to the plate, unwilling to give up their entitlement issues and be a part of this journey. One of the lessons I have learned is to let the anger go because this journey is extremely difficult, and to harbor any ill will or misplaced hope is stupid. It can only tear you down. To let go of things...to let go of what could have been...might have been. Still, I miss the fact that we could travel with each other, I miss the fact that she was capable of doing the simplest things, and now I always have to be right behind her. I had to let go of what I expected from her when she was my mother because if I did act as if that were still true, I would be throwing myself under the bus rather than taking the reins of my job now. She's my mother. But that relationship is not as it was before.

Ela é Minha Mãe

HISTÓRIA DE BIA BARROS

**ENTREVISTADA POR
LAÍS FAJERSZTAJN,
ATLANTIC FELLOW**



She is My Mother

NARRATED BY BIA BARROS

**INTERVIEWED BY
LAÍS FAJERSZTAJN,
ATLANTIC FELLOW**

Nascida e criada em Fortaleza, uma cidade do nordeste Brasileiro, Bia Barros mudou-se para São Paulo na juventude para estudar jornalismo e ciências sociais. Voltava para Fortaleza vez ou outra apenas para visitar a família. Em 2005 voltou para Fortaleza por um período mais longo para cuidar do pai doente. Pouco tempo antes ela tinha feito uma matéria sobre a doença de Alzheimer para o Jornal da Band, onde trabalhava produzindo as reportagens. Ao chegar em casa, notou mudanças no comportamento da mãe que mais tarde se confirmaram ser Alzheimer. Começou aí uma longa e intensa jornada de convívio com a doença, como filha e cuidadora que culminou na publicação do livro Madalena, Alice, um romance que retrata a pesada rotina com a doença. Foi através deste livro que conheci a Bia, ao ouvir uma de suas entrevistas para o rádio. O livro foi um suporte para ela durante o processo da doença e está transformando a experiência dela com a mãe, com ela mesma e com o mundo.

O Início: Diagnóstico e Primeiros Sintomas

O meu pai estava doente e em 2005 fui para casa para cuidar dele. Foi aí que percebi que minha mãe não estava bem. Ela parecia meio fora do ar, mas no começo achei que fosse uma depressão. Às vezes eu achava que poderia ser Alzheimer porque eu tinha feito uma matéria para o jornal sobre a doença pouco tempo antes de viajar, mas também pensava: “será que eu não estou induzindo isso porque eu fiz a matéria?” Quando eu conversei com a minha irmã, e disse: “olha eu estou preocupada por isso, por isso, e por isso”, a minha irmã — que é médica em Campinas — já me mandou ir para o neurologista. Ela indicou um

Born and raised in Fortaleza, a city located northeast of Brazil, Bia Barros moved to São Paulo at an early age to study journalism and social sciences. She only went back to Fortaleza to visit the family. In 2005 she returned to Fortaleza for a longer period to take care of her sick father. This occurred shortly after she wrote a report about Alzheimer's disease for the television journal she used to work for. While she took care of her father, she noticed changes in her mother's behavior that were later confirmed as symptoms of Alzheimer's disease. It started a long, intense journey in the Alzheimer's world as a caregiver and a daughter that finally resulted in the book Madalena, Alice, a romance about the daily routine of caring for a loved one with the disease. I met Bia through her book and her interviews on the radio. The book supported her through the Alzheimer's process and has transformed her relationship with the disease, her mother, herself, and the world.

The Start: Diagnosis and First Symptoms

My father was sick. In 2005 I went back home to Fortaleza¹ to take care of him, but I realized that my mother was not well. She seemed a bit apathetic, but in the beginning, I thought it was a depression. Sometimes I would think that it could be Alzheimer's disease because I wrote a report about the disease just

¹ Fortaleza is a city in Northeast Brazil, the capital of a state named Ceará.

médico em Fortaleza que confirmou o diagnóstico. Foi um choque. Mas minha mãe começou a ser tratada muito cedo e ficou oito anos com um quadro bem estável.

Antes de eu fazer a matéria sobre a doença de Alzheimer, eu tinha aquele olhar de senso comum, de chegar a achar engraçado, de dizer em algumas circunstâncias: “ah ele está gagá”. Mas no momento que eu fiz a matéria, eu entendi a gravidade da doença. Entendi que não era normal, que não era uma coisa que acontecia com todo mundo e nem da mesma forma. No Brasil o diagnóstico é muito difícil. As pessoas não têm acesso aqueles exames detalhados para definir qual o tipo de demência. Aqui os médicos fazem uma ressonância e uma tomografia. Se não for AVC e se não for um tumor na cabeça eles já falam que é Alzheimer. Por isso, eu não tenho certeza se o caso da minha mãe é mesmo o Alzheimer ou alguma outra síndrome demencial.

A minha mãe devia estar com uns 70 anos quando eu notei que ela não estava bem. Ela sempre foi meio distraída, mas esse traço começou a ficar muito mais grave. Ela repetia um milhões de vezes a mesma coisa e começou a perder tudo. Depois você encontrava as coisas nos lugares mais inusitados. E ela começou também com uma coisa de perseguição, ela achava que todo mundo estava roubando-a porque ela não conseguia encontrar nada. Ela também não sabia exatamente o ano que estávamos, se confundia.

A minha mãe sempre foi meio atrapalhadinha. Então a gente achava tudo meio engraçado. Só que depois a gente começou a perceber que ela estava sofrendo. Muitas vezes as pessoas não tinham paciência com ela. Por exemplo, meu irmão dizia: “mãe você já repetiu isso 20 milhões de vezes” e você via que ela ficava constrangida. Eu percebia que ela estava sofrendo por causa da agonia que ela sentia por achar que todo mundo estava roubando-a. Pra ela aquilo era real. Na época, eu não compreendi que isso era um sintoma.

before traveling. But at the same time, I would think, “Am I leading this diagnosis because I wrote the paper?” I talked to my sister and said, “Look, I am worried because of this, this, and this.” My sister lives in Campinas² and is a physician. She recommended a neurologist in Fortaleza, and he confirmed the diagnosis. It was a shock. But my mother started the treatment very early and stayed stable for eight years.

Before writing the article about Alzheimer’s disease, I had a general idea of the disease. I would sometimes find it funny and joke, “That person is *gaga*.” But after I wrote the article, I understood the disease’s severity. I understood it was not normal, that it was not something that happened to everybody, and in the same way. In Brazil, diagnosis is very hard. People do not have access to the very detailed exams that define the type of dementia. Physicians order brain scans using magnetic resonance and computerized tomography. If it is not a stroke or a brain tumor, they say it is Alzheimer’s disease. I was not sure if my mother’s case was really Alzheimer’s or another dementia syndrome.

My mother was around seventy years old when I noticed that she was not okay. She was always a distracted person, but this characteristic started to become more prominent. She would repeat the same thing a thousand times and started to lose everything. Afterward, you would find objects in the most unusual places. She also developed an accusatory behavior: she would think that everybody was stealing from her because she could never find her things. She started to not know which year we were in...she got confused.

My mother was always a bit “disturbed,” so we used to think that her behaviors were kind of funny. After a while, we started to realize that she was suffering. Most of the time, people had no

² Campinas is a city in Southeast Brazil, a city of one million people located in the state of São Paulo.

Quem vai Cuidar da Mãe?

Quando o meu pai morreu morreu, os três filhos se encontraram para decidir o que fazer com a mamãe. Foi complicado porque eu era a única solteira. O meu irmão é do Ministério Público e estava cuidando de todas as coisas dela e do meu pai, do inventário, de tudo. A minha irmã médica estava com quatro filhos e um deles com paralisia cerebral. Naturalmente era visto que eu deveria ficar com a mamãe. A gente começou a discutir os detalhes: quem administra as contas? Como já estava tudo com o meu irmão, ele levou a minha mãe para casa dele. No processo de mudança para a casa do meu irmão, eu senti que a minha mãe piorou. Foi difícil para ela essa mudança de casa.

Meu irmão morava em Fortaleza, mas foi transferido por conta do trabalho. Ele então me disse: “olha agora é a sua vez porque agora não dá mais.” Eu não tinha como voltar para Fortaleza porque minha vida profissional estava toda em São Paulo. Então eu trouxe a mamãe para morar comigo em São Paulo. Eu não tinha ideia de como era realmente a rotina de alguém com Alzheimer.

Eu acho que cuidar das pessoas com demência é uma obrigação de todos os filhos. Aqui no Brasil esse papel é muito deixado para a filha mulher. Mas hoje a gente precisa criar outras formas de solidariedade, porque a gente já não tem mais aquelas famílias grandes, em que todos dividem as tarefas. Temos um exército de pessoas que estão envelhecendo sozinhas. Quando a minha mãe chegou aqui, como eu ainda estava trabalhando, eu coloquei ela numa espécie de centro dia para idosos. Ela fazia várias atividades durante o dia e depois eles traziam ela para casa à noite. Era ótimo porque a minha mãe chegava com banho tomado e ela fazia várias atividades durante o dia. Eu convivía com ela apenas no período da noite, não era tão pesado. O problema foi quando eu fiquei sem emprego, porque eu não tinha recurso, não tinha como pagar. Ouvi dizer que este lugar que a minha mãe frequentou

patience with her. For example, my brother would say, “Mother, you already repeated this twenty million times,” and you could see that she was embarrassed. I could notice she was suffering because of the agony she felt by thinking that everyone was stealing from her. For her, that was real. For a long time, I did not realize that this was a symptom.

Who will Take Care of Mom?

When my father passed away, my siblings and I sat together to decide what to do with mom. It was complicated because I was the only single one. My brother works for the Public Prosecutor Office and was taking care of mom and dad’s stuff—the inventory, etc. My physician sister has four kids, one with cerebral palsy. Naturally, it was believed that I should stay with mom. We became deadlocked: who will manage this? And that? Given that my brother was managing everything, he took my mother to his place. When she moved, I noticed that she declined. It was confusing for her because she was not at her home.

My brother was living in Fortaleza but got transferred from his job. When he had to move, he told me, “Now it is your time because I can’t do it anymore.” I could not return to Fortaleza because my professional life was set up in São Paulo. So, I brought mom to live with me. I had no idea what the daily life of someone with Alzheimer’s was like.

In my opinion, caring for people with dementia is the responsibility of all children, female and male. In Brazil, this role is reserved only for the daughter. These days, we have to create other ways of supporting them because we don’t have big families anymore, where everyone can share the duties. We have an army of people aging alone. When my mom arrived home, I was

fechou e não conheço outros lugares como este em São Paulo, mas era uma ótima iniciativa.

Minha Mãe na Minha Casa

A questão de gênero virou a questão da minha vida. Eu entrei no mestrado em sociologia, mas tive que trancar em função do desemprego. Eu não tinha mais como pagar a PUC.

No Nordeste era muito comum que as filhas mais novas ficassem cuidando dos pais. Isso aconteceu na minha família, tanto com as minhas tias maternas quanto com a irmã caçula do meu pai. Eu tinha muito medo de acabar como as minhas tias porque eu nunca entendi o sentido da vida delas, que abdicaram de tudo, dos seus amores, do sexo, de toda a própria vida para ficar cuidando dos outros. Todas elas acabaram de uma forma muito triste. A tia paterna, que cuidava da minha avó, teve um cancer no útero e morreu sozinha. As pessoas falavam: “Ai ela era uma santinha”, mas que vida foi essa? A minha tia por parte de mãe teve um Alzheimer precoce porque quando a minha avó morreu, ela perdeu o sentido de viver. Ela é um caso estudado pela medicina porque está durando muitos anos. Uma outra tia solteira cuida dela agora. Eu tinha muito medo de assumir esse papel. Eu não queria abrir mão da minha vida, mas foi ficando cada vez mais difícil eu ter controle sobre a minha própria vida.

Minha mãe não me reconhecia mais. Ela achava que ela estava num cativeiro e que eu era uma bandida. Meu pai era muito mais velho do que ela e sempre foi muito controlador, muito ciumento. Então ela reconhecia que não estava na casa dela e ela ficava desesperada para voltar logo para casa, senão o meu pai ia brigar. Ela vivia nessa expectativa da briga o tempo todo.

Minha mãe tinha uma agitação descontrolada. Ela ficava 24 horas por dia chorando sem parar, da hora que ela acordava até a hora que

still working, so I enrolled her in a daycare facility for older adults. She did many activities during the day, and then they brought her home. It was great because she would arrive a bit tired from the activities, and she took a shower at the daycare. I would just spend the night with her, and it was not that hard. The problem was that after I stopped working, I could no longer pay for it. I heard that the place my mother went to closed, and I am not aware of other places like this in São Paulo.

Mom's at My Place

Gender roles became my life question. I enrolled in a master's program to study gender issues but had to quit because I lost my job and could no longer pay for my studies. In the Northeast, the younger daughters usually stayed to take care of the parents. It happened with my maternal aunties and with my father's younger sister. I was scared to end up like my aunts because I felt so sorry for them. I never understood the meaning of life for people like my aunts who renounce their lives—love, sex, everything to take care of others. All of their lives ended sadly. My paternal aunt, the one who took care of my grandma, had cervical cancer—and died alone. People said, “Oh she was a saint,” but what kind of life was that? My maternal aunt had early-onset Alzheimer's disease. When my grandma died, she lost the meaning of life. She is a case study for medicine because she has lived for many years. Another single aunt takes care of her now. I was so scared to assume this role. I did not want to give up my own life, but it became increasingly hard for me to control it.

My mom did not recognize me anymore. She thought that she was being held captive, that I was a thief, and that she had to go back home. My father was a lot older than her and was a controlling

ela dormia. Para mim foi desesperador. Porque quando a gente fala que ela não parava de chorar um minuto, as pessoas acham que é retórica. Mas não é. A minha mãe teve que tomar litros de soro pra repor a quantidade de água que ela perdia chorando, ela estava desidratando. Como a lágrima é ácida, começou a fazer uma assadura no rosto dela que exigia todo um cuidado. E o som do choro o tempo todo, sem parar, sem parar, sem parar, ia irritando as pessoas também. Era desesperador, ninguém aguentava mais.

Eu acho que a minha mãe tinha alguma outra doença de base que nunca foi tratada, uma síndrome do pânico ou algo assim, algo que a doença de Alzheimer só piorou. Ela estava sempre com medo, porque ela sempre via perigo em alguma coisa. Uma época eu era uma sequestradora, outra época tinha um homem que ia fazer mal para ela. O que eu achei mais doido disso tudo é que eu comecei a absorver essas coisas. Cheguei um momento que ela falava tanto desse homem, que eu comecei a ter medo dele, de verdade.

Despesas com o Cuidado e Burocracia

Trazer minha mãe para casa foi concomitante ao processo de sair do meu trabalho na prefeitura. No Brasil não tem uma política pública que pense em ajudar pessoas com demência, a responsabilidade recai toda sobre a família. Com o agravante de que as condições de vida são muito precárias. As despesas são muito altas. Por exemplo, só de medicamento eu gastava cerca de três mil reais. Ai tem fralda, 5, 6 trocas por dia. Comida enteral. Quando ela saiu do coma ela estava recebendo comida por sonda. O potinho é do tamanho de um pote de leite Ninho. Não dá nem um mês porque são umas quatro ou cinco refeições por dia e é cinquenta e oito reais. São gastos muito grandes. Quando você procura no SUS tem todo um processo extremamente burocrático, óbvio, né? Você tem que passar por uma perícia. A pessoa

person, easily jealous. She would recognize she was not at her house and would start to feel desperate to return to her house quickly. Otherwise, my father would start a fight. She was always anticipating a fight.

My mom had uncontrollable agitation. She spent twenty-four hours a day crying without pause, from the time she woke up until she went back to bed. For me, it was despairing. When we said that she would cry all day, people thought we were joking. It was not a joke. My mother had to ingest liters of serum to replace the water she was losing—she was dehydrated. Because tears are acidic, she developed a skin rash that needed special care. And the crying sound, all the time, non-stop, non-stop, non-stop, annoyed people, too. It was despairing...you could not handle it.

I think my mother had another condition that was never treated before, like panic attacks or something, but the Alzheimer's made it worse. She was always in fear because she always saw danger in things. Once I was a kidnapper, another time there was this man wanting to injure her. It is interesting because by the end you absorb all of these things. She would talk so much about this man, this man, this man, that I also started to fear him. It's true.

Care Expenses and Bureaucracy

At the same time, I brought my mother home, I left my job with the municipal government. In Brazil, there is no public policy that helps people with dementia. Families have to deal with all the responsibilities. In Brazil, living standards are low, and expenses are very high. For example, just the medicine is three thousand *reais*. Then there are the diapers—five, six changes per day. And enteral food. When she woke up from the coma she was being fed by tubes. The food package lasts for less than a month because you

fica horas na fila para ser atendida. Minha mãe passou mais de seis horas na fila da perícia. Ela é uma pessoa agitada. Chegou uma hora que eu pensei: “eu vou deixar ela gritar aí o quanto ela quiser para ver se eles me atendem.” Funcionou porque ninguém aguentava mais ela gritar. Ela ficou seis horas sem comer, sem tomar remédio.

A burocracia é desesperadora. Quando a pessoa tem demência, o processo correto é interditá-la. Para proteger essa pessoa com demência de pessoas mal intencionadas, o Judiciário bloqueia tudo, como as contas bancárias e os cartões de crédito da pessoa. Então eu estava sem emprego, com um gasto altíssimo e sem recurso. Neste momento aconteceram cenas tão bizarras! Por exemplo, roubaram o cartão da minha mãe e começaram a comprar coisas na internet com ele. Compraram vários celulares nas Lojas Americanas, no Extra e em outras redes de supermercado e eu não conseguia bloquear o cartão dela. Eu ligava no banco e dizia: “Olha, estão comprando no cartão dela”. E o atendente respondia: “Senhora só o titular da conta pode bloquear”. Eu replicava: “Minha mãe tem demência. Tem aí no documento que ela está interdita, entende?”. E o atendente insistia: “Senhora só a sua mãe pode bloquear”. O banco não tem preparo para lidar com esse tipo de situação. O gerente do banco me disse que o juiz precisaria especificar tudo o que eu podia fazer na conta dela. O juiz me disse que escreveu que eu represento minha mãe em todas as atividades civis, que todas são todas, e ele não tem que especificar o que é todas. Nessa briga, você vai ficando completamente sem recursos. Parecia aquele filme inglês “Eu Daniel Blake”. O filme é sobre um homem que quer se aposentar na Inglaterra e é impedido pela burocracia. Ele morre sem conseguir se aposentar. Eu encaro a situação que eu passei como um sufocamento a distância.

have to make four or five meals a day. It costs fifty-eight *reais*. The expenses are huge. When you go to look for it through the public system, there is, of course, a long, bureaucratic process. You have to go through a qualification process. The person must wait for hours to receive assistance. Once, my mother waited for more than six hours in line, and she was agitated. After a while, I let her yell to see if we could receive assistance. It worked because no one could stand it anymore. She stayed six hours without food and without her medicine.

The bureaucracy is despairing. When someone has dementia, the right thing to do is an interdiction. However, to protect this person's identity from being stolen and abused, the judiciary system blocks everything—like bank and credit card accounts. Thus, I was without a job, with very high expenses and without resources. And very weird things happened. My mom's card was stolen by someone for online purchases. They bought many cell phones, and I was unable to block her card. I would call the bank and report that they were buying with her card, and the attendant would repeat, "Madam, only the owner of the account is allowed to block the card." I would reply, "Look at her account documents, it is saying that she is under interdiction," but she kept repeating, "Madam, only the owner of the account is allowed to block the card." The bank is not prepared to deal with this type of situation. When I called the bank, the manager said that the judge has to specify what my mother cannot do in the account. But when I reported the situation to the judge, he answered that the document he signed says that I represent my mother in all civil activities. All means all. During this fight, the problem grew, and I felt incapable of solving anything. It's similar to that English film about a man who tries to retire but is stopped by the bureaucracy. He dies without being able to solve things. I summarize this situation as a "remote suffocation."

Apoio

Quando eu ainda estava trabalhando, eu colocava cuidadoras para ficar com ela. Mas durava pouquíssimo porque ela era muito agitada. Ninguém conseguia ficar com ela. Uma vez, uma cuidadora me disse: “Bia, eu adoro você, mas eu não posso mais ficar porque este trabalho está afetando o meu relacionamento com o meu marido. Eu chego em casa tão nervosa que começo a brigar com ele”. O que eu ia dizer? Se eu que era a filha também não aguentava. Eu tentei fazer de tudo. Comprei caderno de desenho, colocava a televisão em programas de missa, tudo o que você puder imaginar eu fiz. A minha irmã vinha no final de semana para eu descansar. Quando a minha mãe estava hospitalizada, minha irmã vinha fazer rodízio comigo no hospital. Só que o dia a dia era muito difícil mesmo.

Quando eu ia ao médico, eles me diziam: “Você tem que se cuidar, né? Senão você vai ficar doente”. Só que não me apresentavam nada concreto, o que é que eu realmente poderia fazer?

Quando eu procurei o grupo de apoio para cuidadores uma mulher me chamou de chata. Eu queria soluções para coisas específicas, por exemplo, ela esta chorando o dia inteiro, o que eu faço? Não adianta você vir com um discurso: “Você tem que ter paciência, você tem que amar.... Ok, mas o que eu faço na hora que ela acha que eu sou uma bandida, que ela está num cativeiro e que ela tenta fugir? O que é que eu tenho que fazer? As pessoas falavam para eu tentar mudar de assunto, tentar chamar a atenção para outra coisa. Não funcionava com a minha mãe. Eu fiz tudo. Até mãe de Santo eu levei em casa para tentar acalmá-la.

Estresse do Cuidador

O processo foi se tornando cada vez mais difícil. A minha mãe ficava muito agitada e a pressão dela ia lá pra cima. Um das vezes eu tive

Support

While I was still working, I would find caregivers to stay with her. But because my mother was so agitated, they wouldn't last long. No one could stay with her. No one. Once, a caregiver told me, "Bia, I adore you, but I no longer can stay because this job is impacting my relationship with my husband. I am so nervous when I get home that I start to fight." What could I say? I am the daughter, and I couldn't handle it.

I tried everything. I bought books for drawing, I turned on the TV, I did everything you can ever imagine. My sister would come for the weekends, so I could relax. When my mother was in the hospital, my sister came to take turns with me, but the everyday life was still very hard.

When I visited a doctor, he would tell me, "You have to take care of yourself. Otherwise you will get sick." But they never presented me with feasible strategies—what could I really do?

When I looked for caregiver support groups, I was looking for solutions for specific situations. For example, she is crying all day long—what should I do? According to them, "Love and be patient." Fine, but what should I do in the exact moment when she thinks I am a thief, she thinks she is being confined, and she tries to run? What should I do? People told me to change the conversation topic, to draw attention to something else. It won't work with mom. I did everything. I even brought a *Mãe de Santo*³ to try to calm her down.

³ Mãe de Santo is a female priest of Umbanda, Candomblé and Quimbanda, the Afro-Brazilian religions. The Portuguese words translate as "mother of [the] saint[s]."

que a levar para o hospital. Ela estava tão agitada, que eles foram dando um monte de coisa e ela não respondia. Ai eles deram aquela anestesia usada em endoscopia. Ela entrou em coma hepático e não acordou mais. Ela estava tomando uma quantidade de remédio tão alta que os médicos não podiam fazer mais nada, tínhamos que ver se ela conseguiria se recuperar por conta própria. Ela ficou 40 dias internada.

Depois eles liberaram a minha mãe para casa sem medicamento nenhum. Disseram: “a gente não pode dar nada porque ela está com o fígado comprometido”. Eu achei muita, muita, muita irresponsabilidade dos médicos. Foi desesperador porque ela começou a ciclar. Ela ficava três dias acordada direto surtando e depois dormia um dia inteiro. Só que nesse dia inteiro que ela dormia, era o dia que eu tinha para fazer compra, para ir no mercado, para ir para banco. Foi um período que fiquei só mesmo. A cuidadora não tinha mais condições de ficar e eu já não tinha mais dinheiro para contratar outra pessoa. Eu tive que colocar o meu apartamento à venda. A minha irmã vinha no final de semana. Nesse período meu sobrinho morreu. Em julho de 2016 ele morreu. Eu não queria colocar a responsabilidade de cuidar da minha mãe nas costas da minha irmã. Ela passou sete anos cuidando de um filho com paralisia cerebral e eu não achava justo. Então eu fui absorvendo tudo, tudo, tudo, tudo, até que me deu um piripaque.

Eu tive um surto. Eu apaguei, nem lembro o que aconteceu. Quando eu acordei já estava no hospital. Não sei quem me levou para o hospital. Um médico vira para mim e diz: “ai, a famosa síndrome do cuidador”. Eu juro que eu quis matá-lo. Era quase um menosprezo, como se fosse frescura. Mas até hoje eu não consigo dormir.

Depois também fui diagnosticada com depressão e estou tomando remédio até hoje. Desde então eu não consigo mais dormir e eu estou fazendo tratamento até agora. Eu tive muita dificuldade até de assumir para mim mesmo que eu não tinha mais condições de cuidar da minha mãe. Eu achava que era um fracasso. Era um sentimento contraditório, porque eu não queria reperir a história das minhas tias, mas eu tinha

Caregiver Stress/Burnout

Things were getting harder to manage. My mom would get very agitated, and her blood pressure would get super high. Once, I had to take her to the hospital. She was so agitated! They were giving her a lot of medicine, but she would not calm down. So they gave her the anesthetic that they give to people who go through endoscopy exams, and the next thing that happened was that my mom fell into a coma, a hepatic coma. She was taking so many drugs that the doctors couldn't do anything else for her...she had to recover by herself. She was in the hospital for forty days.

After they discharged my mom without any medication, they told me, "We cannot prescribe her anything because her liver is impaired." The doctors were very, very, irresponsible in my opinion. It was despairing because she had started a new cycle. She would stay awake for three days in a row while having a mental breakdown, and then she would sleep for a full day. The day that she slept was the only day I could go shopping, go to the grocery store, go to the bank. It was a period when I was completely alone. The caregiver I hired said she could not stay. I didn't have money to hire someone else. I had to put my apartment up for sale. My sister would come over for the weekend. During this period, her son died. He died in July 2016. I didn't want to put the responsibility on my sister's back. She spent seven years taking care of a son with cerebral palsy, and I thought it was not fair. So I was absorbing everything, everything, everything up to the point that I had a burnout.

I had an outburst. I completely faded—I don't remember what happened. When I woke up, I was already in the hospital. I don't know who took me. I was seen by a psychiatric team. A doctor looked at me and said, "Oh, the famous caregiver

uma culpa muito grande, muito grande. E ainda tenho. Não está resolvido. Já faz uns dois anos.

Quando eu estava no hospital minha irmã pegou a minha mãe. Quando eu ia visitar a minha mãe, e ela começava a ficar agitada, eu já começava a tremer, o meu coração disparava, dava vontade de sair correndo. Eu não conseguia ficar com ela mais de cinco minutos. Então vinha a culpa em dobro. A culpa por estar sobrecarregando a minha irmã, a culpa por mais uma vez a minha mãe ter que mudar de casa.

Hoje em dia está mais tranquilo. Eu não tenho mais vontade de sair correndo, mas foi um longo processo. Eu tive que aumentar aos poucos o tempo que eu ficava com ela. Primeiro eu ficava quinze minutos e tinha vontade de chorar e sair correndo. Agora está tudo bem. No entanto, visitar a minha mãe ainda traz uma memória muito pesada, da exaustão que eu senti naquele período. Também é muito difícil ver a minha mãe tão debilitada.

O Livro

Eu escrevi as histórias num momento de desespero, quando a minha mãe morava comigo. Eu fiquei muito sozinha. Quando eu vi eu tinha um volume muito grande de histórias. Um conteúdo que me parecia um romance. Eu perguntei para uma amiga que trabalhava numa editora, se as pessoas teriam algum interesse pelo que escrevi. Perguntei se ela achava que era literatura. Ela respondeu: “Bia, eu vou te publicar”. Me deu muita força! Foi incrível. No começo foi difícil para eu entender que aquilo podia ser um livro porque eu só conseguia ver tudo como negativo.

Logo depois que a Aninha falou que me publicaria veio a crise do Brasil. O projeto que ela tinha de publicar novos autores contemporâneos acabou indo para o ralo e demitiram ela. Ela me disse para que eu não desistisse do meu livro, me passou uma lista de concursos literários

syndrome.” I swear I wanted to kill the doctor. Yet, the syndrome was disregarded. But to this day, I still can’t sleep.

Afterward, I was also diagnosed with depression, and I am still under medication. I no longer sleep, and I am still under treatment. It was very hard to admit to myself that I could not take care of mom anymore. I saw it as a failure. It was a contradictory feeling. I didn’t want to repeat the history of my aunts, but I felt huge guilt. I still feel guilty. It’s not solved. It’s been two years already.

When I was at the hospital, my sister took my mom. When I went to visit, she started to become agitated, and I started to shake. My heart would beat faster, and I felt like running away. I couldn’t stay with her for more than five minutes. And the guilt would return twice as heavy. The guilt of overtaxing my sister, the guilt of making my mother change homes again.

Today, I’m more relaxed. I don’t feel like running away anymore, but it’s been a slow process. I had to slowly increase the time I would spend with her. In the beginning, I would stay fifteen minutes, and then I felt like crying and running. Now it’s fine. But visiting my mom still brings difficult memories of the exhaustion I felt during that period. It is also very difficult to see how frail my mom is now.

The Book

I wrote these stories in a despairing moment when my mom was living with me. I was alone. I suddenly realized I had a large volume of stories. The content looked like a romance to me. I asked my friend Aninha, who worked at an editorial company, if people would be interested in what I wrote. I asked her if she thought it was literature. She answered, “Bia, I will publish your work.” It gave me so much strength! It was amazing. In the beginning it

e me disse: “escreve o seu livro que ele ganha”. Eu inscrevi. Fiz meio no automático. Eu me inscrevi nos concursos porque eu precisava me agarrar a alguma coisa. Eu queria me sentir viva de novo. Eu tenho impressão que morreu um lado meu durante todo esse processo. E o livro me mostrava que eu ainda estou aqui de alguma forma.

Para minha surpresa o livro acabou ganhando um prêmio em Portugal chamado “União das Cidades e Capitais de Língua Portuguesa”. Foram mais de 865 obras e mais de 722 autores. A editora NÓS acabou publicando o meu livro e eu o lancei na Flip, a feira literária de Paraty.

O livro na verdade, dá um misto de medo e de admiração. No fundo ele é uma enorme declaração de amor. Mas ele é um livro muito pesado, porque ele conta muito desse dia a dia sufocante.

O livro é dividido em duas partes. A primeira quem narra é a pessoa com Alzheimer. A segunda é a perspectiva da filha, da cuidadora. O que achei mais engraçado é que, de uma certa forma, escrever esse livro me aproximou da minha mãe e das minhas raízes. Eu vim pra São Paulo muito cedo, eu tenho mais tempo de vida em São Paulo do que tempo de vida na cidade que eu nasci, que é Fortaleza. E foi engraçado porque no processo da escrita vieram expressões, questões do Nordeste que eu nem imaginava que estavam tão dentro de mim. Eu me lembrei de regionalismos, coisas que a minha mãe fazia, músicas que ela cantava.

Tem uma parte do livro que eu acho muito bonita. A filha e a mãe não conseguem se comunicar porque a mãe não reconhece mais ela como a figura da filha. A filha cria uma mediadora entre as duas, uma Santa. A mãe é muito religiosa. A filha se passa por uma santa para conseguir conversar com a mãe, para conseguir ser ouvida pela mãe. Eu sinto que isso era a minha tentativa de falar com a minha mãe.

Eu começo a entender esse livro agora, dois anos depois. Dei entrevistas para a rádio e para a TV. Descobri um monte de gente que passava pela mesma situação. Escrever esse livro foi um momento muito solitário. Por isso, eu nunca iria imaginar que ele fosse ter eco na vida de outras pessoas.

was hard for me to understand that the stories could be a book because I was only able to see the dark side.

An economic crisis started right after I talked to Aninha. Her project on publishing new authors was canceled, and she was fired. She told me to not give up on my book. She gave me a list of literature competitions and said to enter my book, and she told me that it would win. I did enter the competitions because I needed to stick to something. I wanted to feel alive again. I had the impression that a part of me died during the process. And the book showed me I was still here.

To my surprise, the book won an award in Portugal named *União das Cidades e Capitais de Língua Portuguesa*.⁴ Over 865 works and 722 authors entered the competition, and the editor Nós published me. I launched my book at the FLIP literary festival.⁵

The book gives me mixed feelings of fear and admiration. At its heart, it is a huge declaration of love. But it's a difficult book because it reports much of this everyday suffocating.

The book is divided into two parts. In the first part, the narrator is the person with Alzheimer's disease. The second part is the daughter's perspective, the caregiver. The interesting thing is that somehow this book makes me closer to my mom and my roots. I came to São Paulo very early—I lived in São Paulo for longer than in Fortaleza, the city where I was born. It is interesting because while I was writing, I remembered expressions and questions from the Northeast that I was not aware were inside me. I remembered the words and things that my mother did, and songs that she used to sing.

4 União das Cidades e Capitais de Língua Portuguesa (UCCLA) is an international organization of cities that speak Portuguese Language

5 FLIP stands for Festa Literária Internacional de Paraty, or International Literary Festival of Paraty in English. It is a literary festival held yearly since 2003 in the Brazilian city of Paraty, in the state of Rio de Janeiro.

Hoje, quando eu vejo as pessoas me procurarem para contar sobre o que elas passaram, sobre o que elas estão passando e como o livro está ajudando...isso para mim é muito forte. Eu nunca imaginei que o livro teria esse efeito. As pessoas começaram a me chamar para contar sobre esse outro lado do cuidado, que é essa solidão, essa situação cruel no Brasil de deixar tudo só no âmbito da família, na maioria das vezes sob o cuidado de uma mulher. Essa mulher vai aos poucos perdendo a sua vida e seus recursos financeiros. Há um processo de pauperização muito grande. Agora com o livro pronto, eu vejo uma rede de pessoas querendo se apoiar. Agora eu consigo ver que escrever foi o meu suporte. Era o meu único momento.

Meu relacionamento com a minha mãe está muito diferente agora. A doença teve um avanço, ela já está num estágio mais debilitado, então ela não está mais naquela agitação, ela não fala mais, não anda, então é uma outra relação. Quando eu estava com ela nesses momentos que eram muito agitados eu não tinha condições de pensar assim com carinho. Agora eu consigo voltar a ter o carinho, voltar a ter o amor, voltar a dizer: “Ela é minha mãe”.

O livro é bem pesado. Todo mundo fala para mim que ele é um soco no estômago. Quando eu estava escrevendo eu não tinha a dimensão de que ele era tão pesado. Eu achava até que era bobinho porque ele não traduzia tudo o que eu estava sentindo naquele momento. Mas agora, quando sou obrigada a ler de novo durante os eventos que eu estou participando, eu vejo que no fundo o livro é uma declaração de amor para ela. O meu jeito de dizer: “mãe, eu fiz tudo que eu pude fazer por você”.

Redes de apoio

As pessoas me procuram na internet, amiga da amiga, no facebook. Eu sinto que eu tenho um papel. Que é o papel de ajudar outras

There is a part in the book that I find so beautiful. The mother and daughter are having a bad time communicating with each other because the mother cannot recognize the daughter anymore. The daughter ends up creating a mediator between the two of them: a saint. The mother is very religious. The daughter pretends she is a saint to talk to her mother. I feel that this was my personal effort to try to talk to my mom.

I've started to understand the book now, two years later. I gave interviews for the radio and TV. I discovered that a lot of people go through this situation. Writing this book was lonely. I felt so lonely that I could never have imagined that it could resonate with other people.

Today when people tell me what they went through, what they are going through, and how the book is helping them...it is very powerful for me because it was written in a moment of deep loneliness. I never imagined that it could have this effect. People started to invite me to talk about this other side of caregiving, this loneliness, this cruel reality in Brazil of letting the responsibility fall on the family's back, mostly on women. She slowly starts to lose her life, but also her financial resources. It is a big impoverishment process. Now, after the book, I see a network of people willing to support each other. Now I can see that writing was my support. It was my moment, my unique moment.

My relationship with my mother is very different now. The disease is progressing—she is in a more severe stage. She is frailer, so she is not as agitated anymore. She doesn't speak, doesn't walk... When I was with her during her very agitated moments, I didn't have the capacity to think with love. Now I am able to have and feel the love, to say she is my mother.

The book is very heavy. People tell me it is a punch in the stomach. However, when I was writing, I did not realize how heavy it was. I thought it was simple, a bit foolish because it did not translate

peças a não se sentirem tão sozinhas como eu me senti. E isso me fortalece.

Eu acabei virando a conselheira de todo mundo. Eu comecei a dar informações para as pessoas. Como é que você lida com a justiça, com essa burocracia.... Porque o sistema acaba te empurrando pra fazer errado. Por exemplo, nessa situação de bloquear o cartão da minha mãe. Chega uma hora que você tenta tanto fazer as coisas do jeito certo e não consegue, que dá vontade de ligar para o banco, se passando por ela e bloquear o cartão. Só que eu tive a orientação de um bom advogado. Ele me disse: “Bia não faça isso, porque o banco ainda pode te processar por fraude, por você estar usando identidade falsa.” Eu divido essa orientação com outras pessoas. As pessoas me perguntam sobre como devem agir e eu já sei a resposta.

Dois amigas que eu não via há muito tempo me procuraram depois de uma entrevista que dei sobre o livro. As duas são cuidadoras e estavam indo para o caminho da depressão. Eu as aconselhei com coisas que eu queria ter ouvido naquela época, que eu não tinha culpa do que estava acontecendo, que eu fiz o que eu podia fazer dentro das circunstâncias, que outras pessoas também passam por situações como essa, que não é um problema só meu. Que você não está sendo impaciente ou irritada porque você quer. A circunstância é muito perversa. É muito difícil ter que provê e cuidar ao mesmo tempo. Eu acho que eu estou dando apoio para muita gente que está no mesmo sentimento de solidão que eu estive.

everything I was feeling at the moment. Now, when I have to read it again at events, I realize that at its core, it's my declaration of love to my mom. It was my way to say, "Mom, I did everything I could for you."

Supporting Networks

People search for me on the internet, friends of friends, on Facebook.⁶ I feel like I have a role of helping other people, so they don't feel as alone as I did. This makes me stronger.

I ended up being an advisor for everyone. I started to give information to people. How to deal with the law, with bureaucracy—because the system pushes you to do the wrong thing. For example, I needed to block the credit card purchases. I tried so hard to do the right thing and didn't succeed. I felt like calling the bank and pretending that I was my mom canceling the credit card. Luckily, I had the guidance of a good lawyer. He told me, "Bia don't do this because if you call the bank pretending you are your mother, the bank can sue you for fraud, for using a false identity." I shared this advice with other people. People ask me what they should do in different situations, and I already know the answer.

Two friends that I haven't seen for a long while reached out to me after one of my interviews about the book. They're both caregivers and were going through the same depression that I was going through for a long time. I advised them with words that I would have liked to have heard during that time. That I was not guilty of what was going on, that I did what was possible in those circumstances, that I was not the only person in the world with this problem. You are not being impatient or irritated just because you

⁶ Bia was invited to be interviewed via Facebook.

HEAR/SAY

want to be. The circumstances were harsh. It was very hard to be the sole provider and caregiver at the same time. I am supporting many people that are experiencing the same feelings of solitude that I felt.



Behavior is Communication

NARRATED BY PAM ROBERTS

**INTERVIEWED BY
JENNIFER MERRILEES,
UCSF MEMORY AND AGING
CENTER & GBHI**

Dave and Pam Roberts met in the Los Angeles area in 1973 and were married two years later. In their time together, Dave and Pam have had many adventures, spending time hiking, camping, and sailing. Dave also became an avid rock climber and pursued this sport for about 10 years with two friends—Roy and Burleigh—and periodically he remembers their names. In 1976, Dave and Pam, along with two friends, hiked across the Sierra Mountains, taking ten days to hike about eighty miles and to climb Mt. Whitney. In the early 1990s, Dave and Pam rented out their house and lived on their sailboat for fifteen months and sailed from San Francisco to Cape Cod in Massachusetts. Dave's diagnosis of Alzheimer's disease brought with it some incredible challenges, along with the experience of enduring love, connection, and resilience.

Questions Dave Asks Frequently

Why can't I drive?

My answer: “Unfortunately Dave, you have a condition called Alzheimer's, but you are not alone. There are 6 million people with Alzheimer's, and no one with Alzheimer's is allowed to drive.” Dave listens. He may ask me to repeat...then kind of nods his acceptance.

Where is my Dad?

My answer: “Your Dad is in heaven with my Dad.”

What happened?

“They got older and then they went to heaven.”

Dave listens. He may say “OK” as acceptance.

Sometimes he cries thinking of his Dad, who loved to play with the kids and tickle and chase them...and sometimes Dave smiles when remembering his Dad.

Where is my Mother?

My answer: “Your Mother is in heaven with my Mother.”

No’s and Not’s

I worked to never say “No” or “Not” and to think of how to change the situation or re-direct.

I learned to not correct his stories, and when they were quite unreal, I tried to engage saying, “tell me more” and then gradually re-direct trying to change the subject.

If he was persistent about doing something, I would say, “Yes, I agree, and I will work on that this afternoon...or tomorrow.”

I had to learn to tolerate compulsions and not to say, “No, don’t do that!” such as on our hikes and walks when Dave would stop to pick up feathers...every feather...and then it was pine cones...and then it was rocks. I learned to carry a plastic bag to hold everything that he was picking up.

We had to give up window shopping and browsing in stores since he wanted to buy things we did not need and could not afford, like cameras and paintings and bikes.

Social Intelligence

Social intelligence lasted a long time even in the moderate to later stages. When seeing someone he knew like a doctor, dentist, vet, hair cutter, he would light up and banter a bit.

Maybe about once a month, someone we knew really well might come for dinner, and we would sit in the dining room. At the table, Dave would light up and follow the conversation and engage now and then, even laughing and making a pun now and then... until after about 40 minutes. He would just hit a wall, and then he would get up and, without saying anything, go back to his room to lie down. The next day he would be totally exhausted from the effort the evening before and sleep and nap much more than usual, which was normally fairly a lot.

Dave loved his high school experience in the small town where he grew up (Webster, NY— farm country on Lake Ontario) and even with aphasia I could tell when he wanted to talk about his high school friends, and I would bring out his yearbook, and he would light up and be all smiles looking at pictures and I could help him find words to retell his stories.

Temper Tantrums, Kicking, Hitting, Swearing...

Dave did all of these things at some point. When I couldn't figure out what was happening and change things for him, I learned to back off...to stay out of his reach...to go outside and walk around the house a few times and to stay out of his sight for a while.

After an episode, he would frequently just stay in his room for a short time, *or* for a long time, and I would try to stay out of his sight until he asked for help with something...and sometimes

he would look at me and say he was sorry. Almost every day at one point, even with aphasia, he would say “thank you” or “I love you.”

In Closing

Behavior is communication. I was not always good at deciphering what was going on, but in my experience when things did calm down, even in aphasia, eye contact remained—the avenue for communication and connection, along with silence and just being there.

Nada le Complace

**NARRADA POR
LUISA ESCUDERO-CORIA**

**ENTREVISTADA POR
STEFANIE PIÑA ESCUDERO,
ATLANTIC FELLOW**



Nothing Pleased Him

**NARRATED BY
LUISA ESCUDERO-CORIA**

**INTERVIEWED BY
STEFANIE PIÑA ESCUDERO,
ATLANTIC FELLOW**

Luisa era la mayor de seis hermanos. Trabajó la mayor parte de su vida en la Ciudad de México en México. Cuando se retiró, se mudó al pequeño rancho donde nació que se llama Caballerías con sus padres y las familias de su hermano y su hermana menores. Ella fue la única entre sus hermanos que no se casó ni tuvo hijos por lo que se esperaba que dedicara sus años de jubilación al cuidado de sus padres. Ella compartió la historia de su papá quien falleció el 18 de enero de 2013.

Mi nombre es Luisa y vivo en Villa Morelos, Michoacán en México. Es un pueblo muy pequeño donde el acceso a servicios de salud, transporte y apoyo para los adultos mayores es extremadamente limitado. No hay muchos médicos y a decir verdad, la mayoría son estudiantes de medicina que están haciendo su servicio social. Los que ya se graduaron son médicos generales y no tienen mucha paciencia con adultos mayores.

Mi padre, Alfonso, tenía demencia mixta. El proceso de su enfermedad fue muy difícil para él y para nosotros en este escenario. Cuando mi padre estaba sano, aunque no fuera ya tan joven, siempre estaba pensando en trabajar, en hacer cosas y no quería simplemente pasar el tiempo sin hacer nada. Siempre fue una persona muy cariñosa y espontánea. Le agradaban todas las personas, sin importar quienes fueran. Él siempre le abría las puertas de la casa a todos, incluso a extraños. Los invitaba a comer, a tomar refresco, un vaso de agua o cualquier cosa. Los hacía sentirse bien actuando de esta forma y él se sentía feliz también. Él disfrutaba la vida siempre. Cuando se enfermó, empezó a perder la memoria y la capacidad de moverse. Comenzó a estar deprimido porque se volvió dependiente de otras personas y eso es algo que él nunca quiso que le pasara. Nosotros sufrimos también porque no podíamos hacer nada que evitara que

Luisa is the oldest of six siblings. She worked most of her life in Mexico City, Mexico. When she retired, she went back to the very small ranch where she was born that is called Caballerías with her parents and the families of her younger brother and sister. Since she was the only one among the siblings that did not get married or had kids, she was expected to devote her retirement life to take care of her parents. She shared the story of her father who died January 18, 2013.

My name is Luisa. I live in Villa Morelos, Michoacán, in Mexico. It is a very small town where access to health services, transportation, and support for older adults is extremely limited. There are not a lot of doctors and, to tell the truth, most of them are medical students doing their year of social service. Those who already graduated are general practitioners, and they do not have a lot of patience with older adults.

My dad, Alfonso, had mixed dementia. The process of his disease was very difficult for him, and for us, in this setting. When my dad was healthy, even though he was not very young anymore, he was always thinking about work, about doing things; he did not want to just do nothing. He had always been a very spontaneous and very affectionate person. He liked all people, whoever they were. He always opened the doors of the house to anyone, even if they were strangers. He invited them to the house to eat, to have a soda, a glass of water, or anything. He made them feel happy and he was happy acting this way. He enjoyed life always. When he got sick, he started losing his memory and his ability to move. He started to feel depressed because he became dependent on others, and that's something he never wanted to happen to him.

empeorara. Nos sentíamos impotentes. Tratábamos de ayudarlo tanto como podíamos, pero seguramente necesitábamos más información de como ayudarlo de forma apropiada para que no sufriera tanto.

Recuerdo que cuando comenzó a ser incapaz de caminar bien, mi mamá y yo acordamos que debíamos remodelar la casa para que las cosas fueran más fáciles para él porque pensábamos que llegaría a requerir una silla de ruedas en algún momento. Entonces, quitamos las puertas, las hicimos más anchas y construimos espacios más grandes para que él se pudiera mover. Él sufrió un poco el proceso, pero sabía que iba a tener un cuarto nuevo con mucha luz y lo esperaba con mucha emoción. Su cuarto fue lo primero que estuvo terminado y cuando lo supo exclamó —¡Me voy a mudar inmediatamente a mi nuevo cuarto! — y estaba muy muy feliz. Después, cuando vio la casa terminada, estaba aún más feliz y comentó mientras miraba todo — Nunca pensé que ni casa se vería de esta manera. La casa en la que vivíamos la había construido él más de 50 años antes cuando se casó con mi madre. Estaba hecha de adobes en una forma muy rústica. Después de la remodelación, había partes más modernas hechas de ladrillo y el cambio fue muy notorio. Se veía muy linda y la vista desde su cuarto era preciosa. Le había gustado tanto lo que habíamos hecho para él que quería que hiciéramos una fiesta. No hicimos una fiesta muy grande, pero si tuvimos una rica comida familiar que disfrutó mucho. Gracias a Dios que logró disfrutar su casa por algunos años.

Considero que todo el esfuerzo que hicimos para él en ese tiempo lo motivó mucho pero conforme la enfermedad fue progresando, aunque tuviera más espacio para moverse dentro y alrededor de la casa, él quería ir más lejos y eso ya no era tan sencillo. Tratamos de hacer todo lo que pudimos, lo distraíamos y tratábamos de sacarlo a pasear en el coche. Él era una persona muy alta y muy fuerte que para nosotros era muy difícil de mover, aún con la silla de ruedas. Después comenzaron los momentos más duros y en ocasiones era muy complicado sobreponerse. Los doctores de aquí no entienden lo que un adulto

We suffered too because we could not do anything to stop him from getting worse. We felt impotent. We tried to help him as much as we could, but surely, we needed more information about how to help him properly so that he would not suffer so much.

I remember that when he started to be unable to walk very well, my mom and I agreed that we should remodel the house to make things a little easier for him because we thought that he was going to need a wheelchair at some point. Maybe for us it was not going to be so comfortable, but we were thinking about him at that moment. So, we removed the doors, made them wider, and built larger spaces so that he could move. He suffered a little bit throughout this process, but he knew he was going to have a room with a lot of sunlight, and he looked forward to it with lots of excitement. His room was the first part that was finished, and when it was ready, he exclaimed, "I will immediately go to my new room!" and he was very, very happy. And then, when he saw the house finished, he was even happier and said, "I never thought I would see my house looking like this." The house we live in was built by him more than 50 years before, when he married my mother. It was built of adobes in a very rustic way. After the remodeling, there were more modern things built out of brick; the change was very noticeable. It looked very nice and the view from his room was very beautiful. He liked what was done for him so much that he wanted us to throw a party. We did not do a big party, but we had a nice family meal, which delighted him. Thank God he had time to enjoy his house for some years.

All of the effort we made at the time helped him feel happier and more active, but as the disease progressed, even when he had more room to move inside and around the house, he wanted to be able to go further away from the house, and that was not easy. We tried to do everything we could: we distracted him, tried to take him on strolls. We drove him around, but for us, he was a very tall

mayor requiere, sólo dan recetas como si fueran “personas normales” o nos decían —Trate de ayudarlo — pero muchas veces no sabíamos que hacer y hacíamos lo que creíamos que era el mejor cuidado posible pero carecíamos del conocimiento para en verdad hacer lo que debíamos haber hecho.

Comenzó a tener muchas alucinaciones. Algunas reflejaban cosas que le habían pasado y otras no. Una vez que estuvo hospitalizado, no recuerdo porque motivo, su cuarto estaba junto al área de maternidad. Yo creo que un bebé acababa de nacer cuando llegamos porque podíamos escucharlo llorando mucho. Mi padre estaba preguntando — ¿Por qué nadie le dice a la mamá de ese bebé que lo cuide, que lo proteja, que le ayude? Está llore y llore. Creo que este recuerdo se quedó muy grabado en la mente de mi padre porque algunas veces cuando alucinaba decía que podía ver un bebé, que era una niña y que estaba llorando. Él deseaba que cuando se muriera pusiéramos a la bebé en su ataúd. Otro de sus delirios fue que mi madre lo estaba traicionando con un hombre más joven y que por eso ella ya no le prestaba atención y quería que él se muriera. También comentaba que él ya no era importante para nadie y que mis hermanas y yo solamente solapábamos a mi madre. Todas estas cosas sólo el podía percibir las porque nadie más podía hacerlo. Algunas veces cuando teníamos invitados en la casa les decía —¡Mira! ¡Ahí está! Por favor pídele que se vaya de esta casa. Esto afectaba mucho a mi madre y no podíamos hacer nada para ayudarla. Ella estaba devastada.

Otra cosa que empezó a pasarle fue que si cambiábamos la más mínima cosa en su cuarto decía que lo estaban secuestrando o que le hablaríamos a la policía porque alguien lo había secuestrado y lo tenían de rehén en una casa que no era la suya. Por este motivo, no podíamos mover absolutamente nada de su cuarto. Tenía que estar exactamente de la misma forma todos los días porque si no estaba así se confundía. Tampoco podía ver mucha gente en su cuarto porque pensaba que podían asesinarlo. No podía ya identificar que éramos

and strong person who was complicated to move, even with the wheelchair. Then the hard times started, and sometimes they were very difficult to overcome. Doctors here don't understand what an old person needs. They only give prescriptions as if they were "normal people" and tell us to "try to help him," but many times we did not know what to do, and we did what we thought was the best care, but we lacked the knowledge to actually do the right thing.

He started to have lots of hallucinations. Some of them reflected things that had happened to him, some of them did not. One time, he was admitted to the hospital. I cannot remember why, but what I remember is that his room was next to the maternity area. I think a baby had been born the moment we arrived because we could hear a baby crying a lot. My dad was asking, "Why does nobody tell the baby's mom to take care of him, to protect him, to help him? He is crying and crying." I think this memory became ingrained in my dad's mind because sometimes when he hallucinated, he said that he could see a baby. She was a girl and she was crying. He said that when he died, he wanted us to put the baby in his coffin. Another of his delusions was that my mom was betraying him with a younger man. That was the reason my mom stopped paying attention to him and wanted him to die. He said that he was no longer important to anybody and that my sisters and I just covered my mom up. These were things that only he could see because nobody else could see this situation going on. Sometimes when we had guests at home he said, "Look! There he is. Please make him leave this house!" This affected my mom very much, and I could not help her. She was devastated.

Another thing that started to happen to him was that if we changed a minimal thing in his room, he said we were kidnapping him, or that we should call the police because someone had kidnapped him and was keeping him hostage in another home. So, we could not move absolutely anything in his room. It

parte de su familia. Hubo un momento en que él sintió que no valía nada y que ya nadie lo apoyaba y se quería aventar por la ventana. Mi padre también repetía mucho que no entendía porque si él había sido un buen hermano y un buen amigo nadie lo visitaba más. Sí lo visitaban, pero se le olvidaba y esta imposibilidad de recordarlo siempre lo hacía sufrir.

Como mencione anteriormente, era muy difícil encontrar un médico que fuera confiable para manejar estas situaciones. Llevarlo y traerlo de la Ciudad de México también era extremadamente problemático porque es una distancia muy larga, era muy difícil moverlo y él se cansaba mucho. Pese a todo, lo llevamos muchas veces hasta que él comenzó a gritar —¡Ya no quiero que me muevan!, ¡No quiero que me lleven a ningún lado! ¡Déjenme aquí morir en paz! —Era muy triste. No me puedo imaginar lo que podría haber estado pensando. En verdad yo necesitaba más información sobre como ayudarlo. No sabía en donde buscar o a quien preguntarle. No tenemos internet ni teléfono. No tenemos ninguna forma de comunicarnos con nadie.

Conforme su enfermedad fue avanzando, y ahora que miro hacia atrás, pienso que tal vez tenía una deshidratación severa y anemia que no atendimos a tiempo porque ningún médico las detectó a tiempo. Tal vez si hubiéramos sabido, hubiéramos podido hacer algo que lo hubiera mantenido con vida por más tiempo. No queríamos que se molestara, entonces, si decía que no quería comer o tomar agua no lo forzábamos a hacerlo. Siempre pensé que si no quería comida o agua era porque su cuerpo no los necesitaba. Ahora pienso que eso empeoró la situación, que debí haber intentado otras maneras de convencerlo. Pero era complicado porque, por un lado, cuando decía que no quería algo ni siquiera abría la boca y no sabía cuanto le iba a afectar el insistirle. Por otro lado, el no insistirle lo llevó a una situación muy seria que era difícil de manejar, al menos para nosotros. Un día, fui a la Ciudad de México y aparentemente él estaba bien, pero al día siguiente, mi hermana se comunicó conmigo y me dijo que mi padre había tenido

had to be exactly the same way every day because if not, he got confused. Also, there could not be a lot of people in his room because he thought he could get murdered. He could not identify we were a part of his family anymore. There was a time when he felt that he was worthless, that nobody supported him anymore, and he wanted to throw himself from the window. He was saying that he could not understand why, if he had been a good brother and a good friend, none of his brothers or friends visited him anymore. They did, but my father forgot they had been there and the impossibility to remember always made him suffer.

As I said, it was very hard to find a reliable doctor to help us manage these situations. Taking him to Mexico City and bringing him back was also extremely problematic because it is a long distance, and he was very hard to move, and he got extremely tired. Regardless, we took him many times until he started saying, "I don't want you to move me! I don't want you to take me anywhere! Leave me here to die in peace!" It was very sad. I am not able to imagine what he might have been thinking. I really needed more information on how to help him. I did not know where to look or whom to ask. We don't have internet. We don't have a telephone. We don't have any way of communicating with anyone.

And his disease progressed, and now that I look back, I think he might have had severe dehydration and anemia that we did not treat on time because no doctor detected it on time. Maybe if we would have known, we could have done something to help him live longer. We did not want to upset him, so if he said he did not want to eat or to drink water, we did not force him. I always thought that if he did not want food or water it was because maybe his body did not need it. Now I think that might have made the situation worse, that I should have tried different ways to convince him. But it is complicated because, on the one hand, when he said he did not want something, he did not even open his mouth and I did not

un infarto y que había fallecido. Eso fue muy duro para mi porque no estuve ahí con él. Aunque hubiera estado, no hubiera podido hacer nada. Mi hermana me dijo que ella no sabía que estaba teniendo un infarto porque nunca había visto uno, pero yo tampoco he visto uno. Mi hermana y mi hermano trataron de ayudarlo y fueron por el médico, pero la distancia para llegar por él y llevarlo hasta la casa es muy larga y para el momento en que llegaron ya no había nada más que se pudiera hacer. Cuando regresé, hicimos un gran velorio en la casa con muchos familiares y amigos. Lo sepultamos en el panteón del pueblo junto a su familia.

Como cuidadora, creo que la parte más difícil fue tener calma y paciencia. Necesitaba entender que mi padre era una persona mayor y que tenía muchos problemas. Él podía ser muy grosero si no lo trataba con mucho cariño y cuidado. La situación fue muy dolorosa para ambas partes. Algunas veces existe mucho conflicto porque uno tiene que hacer otras cosas y no se puede estar al lado del enfermo todo el tiempo. Necesitaba imaginarme que estaba cuidando un bebé porque así era como mi padre se comportaba. Algunas veces era muy terco y lloraba por todo o empezaba a arrojarme cosas. Nada lo complacía. Algunas veces cantaba, otras reía, otras no comía nada en todo el día — su ánimo cambiaba mucho. Por lo tanto, tenía que tratarlo como a un niño pequeño y tratar de entender que no se comportaba de esa forma porque quisiera hacerme enojar. Creo que él tenía muchas emociones al mismo tiempo y como su cuidadora yo no era capaz de comprenderlo. Por encima de todo, lo que siempre traté de mostrarle a mi padre fue lo mucho que lo quería.

know how much it would affect him if I insisted. On the other hand, not insisting lead to a serious state that was very hard to manage, at least for us. One day, I went to Mexico City, and he was apparently okay, but the next day he had a heart attack, and my sister called me to tell me he had died. That was very hard for me because I was not there with him. But even if I had been there, I would not have been able to do anything. My sister told me that she did not know he was having a heart attack because she had never seen one, and neither had I. She and my brother tried to help him, and they went to get the doctor, but the distance to get to the doctor is very long and by the time the doctor got home, there was nothing that could be done. When I got there, we held a big service at home with lots of family and friends. My father was buried in the local cemetery where his family was.

As a caregiver, I think the hardest part was having calmness and patience. I needed to understand that my dad was an older adult that had a lot of problems. He could turn to be very rude if I did not treat him nicely and carefully. The situation is painful both ways, and sometimes one faces a conflict because you also need to do other things. You cannot be there by the side of the sick person all the time. I needed to imagine I was taking care of a baby because that is how my father behaved, like a baby. Sometimes he was stubborn and cried about everything or started to throw things at me. Nothing pleased him. Sometimes he sang, sometimes he laughed, sometimes he did not eat anything in the entire day—his mood changed a lot. So, I had to treat him like a little child and tried to understand that he was not behaving that way because he was trying to upset me. I think that he had too many emotions at the same time that sometimes, as his caregiver, I was not able to understand. I think that overall what I always tried to show to my father was that I loved him.



Oh, It's a Koi, watercolor by William Yokoyama

You Kind of Have to Enjoy the Process

**NARRATED BY
JENNIFER YOKOYAMA**

**INTERVIEWED BY ROWENA RICHIE,
ATLANTIC FELLOW**

*Jennifer Yokoyama holds a doctorate in genetics and is on faculty at the University of California, San Francisco Memory and Aging Center and the Global Brain Health Institute. I was nervous interviewing her. She is so sharp, so curious and clever, but she is also warm and bubbly. Jen talked with her hands. Her voice was raspy, and she has an infectious laugh. Her father was an artist and teacher, her mom a pharmacist. Jen's a genetic byproduct of her parents: a scientist, professor, and trained musician. There's a musicality to her body language. Her face danced through a series of expressions while she mulled over my questions. She carefully considered my invitation to be interviewed for **hear/say** before she agreed. She was thorough and thoughtful. And so down to earth it took me a moment before I got the gravity of some of the things she shared with me.*

I was Very Intrigued about How Things Work!

I have always enjoyed knowing how things work. My parents used to tell me stories of when I was little. I would take apart ballpoint pens so I could see what was inside, and my parents were always afraid I was going to swallow the little springs or parts, but I just wanted to see how it worked. Then I would put it all back together in the right order, and then I'd make sure it worked again. I think those are some of the early signs that I was very intrigued about how things work!

In high school, I took a biology class and I was one of two or three freshmen in the class, and we had this awesome teacher, Mr. Pruitt. I think he had either gotten a special grant or spent his own money to get equipment to do a special unit on genetics. He got all this special equipment to do lab projects, and everyone's experiments failed. I ended up doing really well on the test. Mr. Pruitt used to call the people that got the best scores on tests the queen of the prom or the king of the prom. The only time I would ever be the queen of any homecoming prom or dance was in this genetics course in biology. I was drawn into this field of genetics and that was my first exposure early in school.

I had This Fantasy of Being a Scientist by Day and a Musician by Night

I've done a lot of music throughout my life, and I guess I learned piano and was also learning how to read. I had this fantasy of being a scientist by day and a musician by night. My father was an artist and teacher and my mother is a pharmacist. I really like science and art, and, as a teenager, you're like, "Two things I will never be is a teacher or a pharmacist." Then I found myself in graduate school entering the program in pharmaceutical sciences of pharmacogenomics and being very interested in teaching opportunities. We try to deny our roots so often, but even now as an instructor or a teacher I remember things that my dad would tell me. These little aspects I've picked up on. Both my parents were interested in music, my mother played piano throughout her childhood. So there was definitely music throughout my growing up.

I think there's a mathematical aspect of music, and some might even say that aesthetics in art have a kind of a mathematical or

biological component. For me, I think research is fun because you can be creative. I may not have as much time for music, but I like lots of arts and crafts and have since I was a kid. So even if it's creating jewelry or knitting things or sewing things or creating my own patterns for stuff that doesn't always turn out right, it's very similar research, right? Because you have these tools or these skills and you're applying them in new ways or different ways and trying to see if you can reach your goal. So now my research is much more anchored in trying to translate some of our biological understandings into things that will really help patients and help us find cures for diseases. And so you know, it's kind of a new way to apply the same types of tools that you've developed over time.

I Never Had That Type of Interaction with a Patient Before

I was doing my postdoctoral training and I would observe patients. I was totally new as a non-clinician to this entire area. I was trying to stay silently against the wall as much as possible and not bother anybody. I'm just observing, and at the end of it, the research participant—actually a person in a wheelchair because of a movement disorder—was thanking everybody in the room for doing the work that we do, and she gave me a hug. It was so touching, and I was like, “Oh this is why I do this work.” I never had that type of interaction with a patient before. It's a story I'm still telling my trainees. Sometimes when they're feeling, “Oh what's the purpose of this work, it's never going to reach people.” Actually, there are many people out there who know that what we are finding may not help them, but they're still very grateful for that. That was definitely something that stuck with me.

I Have Dog DNA in My Refrigerator in My Lab, Not at Home

For all of my postdoc, I worked in the lab of Steve Hamilton, who's an MD, PhD researcher and psychiatrist. We were very interested in leveraging the domestic dog and pure breeds of dog as genetic models for studying anxiety. A lot of that work involved literally going out into the field—sheep herding fields—to recruit dogs and their owners for research. Technically, the owners were giving consent, but the dogs had to be willing also. We would get DNA from their blood or saliva or buccal samples (cheek swabs) and do genetic studies of the different dogs that had different kinds of behavioral profiles. We would ascertain through questionnaires that had been developed by our veterinary collaborator—they're very much quantitative or semi-quantitative ways of ascertaining the behavior of dogs in the context of different stimuli. It's akin to research done with children and parents where you're saying, "Okay, in the context of a thunderstorm, how does your dog respond? X, Y, Z all the time? Sometimes? Never?" It turns out that the anxiety responses of dogs are very similar to that of humans. We can treat dogs with the same types of medication we use to treat human anxiety. We thought this was a really potentially powerful genetic paradigm for understanding more about the biology of anxiety.

I Think I Know Something That Nobody Else in the World Knows Yet!

A lot of our work in genetics research is on a computer, although we are starting to work more in the lab, where we are basically

collecting immune cells from the blood of patients that come in and are purifying those. We store them all in our freezer and then we use those for genetic studies to try to understand both what biologically is happening in the patients — particularly in individuals with genetic forms of disease that are in the process of maybe converting from being pre-symptomatic to symptomatic. So, learning about the biology of that and also trying to develop that as a biomarker for tracking disease progression. So, at the end of the day, the bulk of the work is still on a computer because of analytics, but we are starting to kind of dabble more in the cell biology space, and our research is continuing.

I get to do varying degrees of teaching and interacting with trainees brainstorming about research projects. What results mean. What's next. Planning. Those are always fun. Every once in a while, I have brainstorming sessions where we're like, "What is this story going to look like?" This research story is just like any other storytelling process. It's figuring out what do we know, what do we not know? How are we going to tell the story in a way that's realistic, but compelling for readers or others in the field?

My colleague, Virginia Sturm, who I share an office with, talks about these moments — every once in a while in research, and this is...this is like the secret sauce that draws all of us into research, where there's 99 percent failure, and every once in a while something that actually works is that moment where you're like, "Oh my gosh! I think I know something that nobody else in the world knows yet!" Those occasional moments are I think what keeps people in the field — people like us.... I think the people who tend to work with me share that kind of excitement, of like "Oo, oo, oo! I think I discovered something new! Or I think there's a connection between this thing over here and this thing over there that people didn't think were connected." Maybe we can figure out how

they're connected or what that means in terms of the biology of disease or biology in general.

Make Those Nice Big Discoveries

We're very technologically advanced, and in a very short amount of time we can generate these really amazing advances, and we still don't know some fundamental things about the field. Even in neurodegeneration, we identify all these genes or proteins that are fundamental causes of disease, but we often have very little understanding of what those proteins or genes do in their normal function. I think if we don't understand on a fundamental level what they're doing in their normal lives and their normal functioning, then it might be harder for us to find ways to fix them.

Geneticists often are very siloed, very protective of their information. If your academic currency is genetic discovery for a grant or a paper, then all of your eggs are in this basket of the cohort you're studying, and the genetic data that you've generated. You don't want to share that. You want to save it and protect it until you've published it in *Nature*. So the field now is very much realizing we actually need to share and learn from each other to make those nice big discoveries. In that way, I think genetics and the genomics field is really kind of on the leading edge of being very open about data sharing and repurposing existing data for secondary or new analysis that can ask either the same or different questions from different perspectives. I'm much prouder to be a geneticist in the context of this kind of openness of science and data. It's nice now that I have these colleagues from abroad who are willing to share or join forces.

I'm Going to Celebrate the Circle of Life

My father was diagnosed with terminal lung cancer, and he was towards the end of his disease trajectory when I found out I was pregnant with my first and only son. My dad was dying, and I was carrying this new, very tiny little body and it was very interesting thinking about how my father's genetic material would still live on in my son. For lack of a better word, I guess it was good timing in some way for him to have died while I was pregnant. For better or worse, I know the biology of grief and stress, and how a mother's physiology can have impacts on a developing fetus or ball of cells.

So, I purposefully did not overly wallow in grief. I mean, I mourned my father's death, but also celebrated his life, and tried to make sure I didn't get too down in the dumps. I know that my physiological milieu could impact the gene expression patterns of my developing son. It's almost too much, but it's kind of for the best. I was like, "Okay I'm going to celebrate the circle of life." And I would just sing that song, "Circle of Life" from *The Lion King* movie in my head to give myself a funny cheering up. And then just enjoying the delights of being nauseous and feeling somebody punching you from the inside. This whole experience of carrying a human is just pretty wild.

I see a lot of my personality in my son, and from my dad and mom as well. Certainly the stubbornness. My son loves drawing and coloring and he's super creative. He loves art. He also loves watching action movies and then creating his own action movies. Talking about them and narrating them and singing these funny theme songs or little beats as he's doing his action scenes. I see that kind of love of action movies and horror films, and all these funny things that my dad liked. I don't think there's a gene for

liking horror films. It's like these funny interests that are shared between them.

What every parent hopes for is that their child will be successful. I think as long as he's happy, I'm fine.

Genetic Material Being Passed Down Through Generations

The best legacy for most academics is training a cadre of people that go out and do even better work. It's kind of like parenting. The legacy of your children going out into the world and doing things, it's the same concept. This theme of the genetic material kind of being passed down through generations. That's what scientists and instructors give. I hear myself channeling Steve Hamilton. I hear myself channeling MAC faculty members Howie Rosen or Bruce Miller. I hear myself channeling these nuggets of wisdom, and it's funny when you hear one of your trainees doing the same thing.

If one thing I've taught to my trainees, who are much brighter than me, leads to them discovering something really neat and important for the field, that's good enough. Even if they don't discover anything but feel like they live better lives and are happier because of what I've been able to do, that's okay, too.

I mean often, with researchers, there's so much failure that you kind of have to enjoy the process. It's not very fun because if you're only really driven by being right or successful, that doesn't happen that often. That's probably not enough to sustain you, but if you just revel in that process, then I think it's a bit more sustaining.



The Gift of Today

NARRATED BY MARY NARDULLI

**INTERVIEWED BY CYNTHIA STONE,
DOCUMENTARY FILMMAKER**

Mary Nardulli has a very close, warm relationship with her son, Nick, who has juvenile-onset Huntington's disease. Before caring for Nick, Mary spent 20 years caring for Nick's father, Kevin, who also had Huntington's. Mary reflects on her decision to have Nick, the progression of his disease, and the positivity and humor that allows her and her son to enjoy their time together.

The Power to Decide

You hear people talk about an old soul, and Nick's always been one of those people. When he was four years old, he told me one day that God and Santa Claus are a lot alike. And I said, "Well, why do you think that?" And he said, "Because God does magical things and so does Santa. And some people believe in Santa and some people don't. And some people believe in God and some people don't." I said, "Were you talking to somebody about this?" He goes, "No, just thinking about it."

Nick was a very smart child. He loved to read. My grandsons asked me once if I paid Nick to read because everywhere we went, he would always have a book in his hand and he just would read because he enjoyed it. And he was athletic. Nick played basketball starting in second grade. That was great for him because otherwise, he could just stay in his head, and I wasn't going to let that happen. So I always insisted that he have another activity outside of school. And he ran for fun. Nick ran several marathons until it became too difficult for him to do that.

Nick's always been very nurturing. When he was a child I got him a baby doll that he would take care of and he'd love doing

that. And so I always knew he would be a great dad. He was very good with my grandsons. Always loved to play with children. He'd be out there playing basketball with them or sitting down on the carpet playing with them. He's open-minded. Not really judgmental. I think he's accepting of other people — certainly accepting of limitations. And he also loved older people. When he was in high school, he needed to do volunteer work for the program he was in. We got active in the church that we were going to and he would take things to the elders in the church. For example, we made some cookies and then took them to the elders that couldn't come to church on Sunday. And Nick said he really enjoyed talking to them because of their stories. They had so much that was interesting for them to share that Nick enjoyed hearing from them.

Nick's dad Kevin had the Huntington's disease gene. But he had it more at a normal age; typically somebody starts showing symptoms about the mid-thirties and the disease lasts for about 15 to 20 years until death. I saw Kevin's early symptoms when I was still pregnant with Nick. I was very open with Nick when his father was getting sick and declining. His dad was a very anxious person but also was very angry. I didn't want Nick to be afraid of his dad. I wanted him to say, "OK, it's the disease, it's not my dad," because he really was a loving, kind person. We had always talked about his dad having Huntington's. At one point, when Nick was about ten or eleven, he said, "Well, Mom, my dad's been sick my whole life."

Nick had to make some difficult decisions as a young child because of his dad being sick. And I would always try to give Nick the power to decide. For example, we moved to Sacramento when he was in sixth or seventh grade. He was going to have a birthday party. Now, these weren't people that he had known for a long time and so I asked him, "Do you want to have your dad come to the party?" And he thought about it and he said, "You know, I do,

Mom. If they don't understand that my dad's sick, then I don't want to be friends with them." Nick's dad may act not normal to other people, but he was his dad and Nick was happy that he was there.

Worth the Risk

Before Nick was born, we knew that Kevin was at risk for Huntington's. We did not know whether he had it. In the brain, everybody has the Huntington's gene; it's on the fourth chromosome. People that have Huntington's have too many repeats of the gene. Those extra repeats cause a protein to then basically eat holes in the brain. Huntington's is a form of dementia, along with physical symptoms. One way that Huntington's has been described is that it's a combination of Alzheimer's, Parkinson's, and ALS; they have the worst of all of those symptoms in one disease.

And at the time, they still had not discovered where the gene was. They could do a test where they would do genetic markers and determine whether Kevin was going to have it or not. But, at that moment, he did not want to find out. So we talked for two years about whether we wanted to have a child. We wanted to have a child. However, considering it's a 50 percent chance that Kevin would have it, and if Kevin had it, then our child would have a 50 percent chance. Now, if Kevin didn't have it, then our child would have zero percent chance. So it's not something that will skip generations.

Our rationale for having a child with Huntington's was it's not something that affects your quality of life from day one. Kevin's father was a doctor and had been practicing for years before he had to retire because of Huntington's. So you can still go to college, you can be educated. There are so many things that you can do, we decided that it was worth the risk.

There is a risk of the gene expanding and then there's something called juvenile-onset Huntington's disease, which is where they show symptoms before the age of 20. And obviously, that robs them of the normal progression. That was my fear. We went to genetic counseling because of my age when I was pregnant with Nick and because they could do a genetic marker test on the fetus. But if we found out that the baby had it, then that would mean that Kevin would find out that he had it and he was not ready to do that. Also, we had decided because it was not going to affect him from day one that we wouldn't abort the pregnancy. So they recommended that we not find out.

I used to always tell myself, "Oh, by the time, you know, our child has it, there'll be a treatment." Because, of course, that's what they've been working on and they keep saying, it's coming, it's coming, and I firmly believe that there is a treatment coming—whether it's going to be in a year, 10 years, 20 years, you just don't know. Unfortunately, I now know that it will not be here in time to help Nick.

Calm Myself and Then Forget

Some of the early signs can be very, very strange. One of the things I noticed with Nick's father early on when he was showing the disease was that I would come home from work and there would be multiple cupboard doors open. And that had never happened before. So it was a new behavior. And he just was not aware. So I did notice that with Nick one summer when he came home from college. I mentioned it to my daughter and then, of course, I forgot about it. I just would calm myself and then forget about it. The next summer, I saw exactly the same thing. And I told my daughter and she said, "Well, you know, Mom, you told me the

same thing last year,” and I had blanked it out. Because you don’t really want to know that.

But sometimes, you really know. Right around his 20th birthday, Nick got in an automobile accident. He had pulled out in front of a car. He was very lucky that he and his girlfriend were not hurt seriously because basically the front of his car was wiped out. He went to college in San Diego. So I went down there and told him that if he was going to get another car, we had to do some driving lessons, and so I actually arranged for him to be evaluated by a driving instructor and go through some lessons. And that was when I watched him walk. One night we just we went out for dinner and I watched him walk and that’s when I noticed him hitting the wall. Within 10 feet, he kept hitting the wall—he couldn’t walk without hitting the wall. And so I looked it up and it’s very glaring in the literature, it talks about the unsteady gait and not being able to walk straight.

I actually didn’t face it head-on. I’m like, “Okay, well, it sounds like it probably is Huntington’s. But I need to look at other things.” I got back to Northern California and started looking up more things and that’s when I figured out, “Oh my gosh, this really is Huntington’s. He’s displaying the symptoms.” And at that point, I could not deny it to myself. I’m a tax accountant and it was February by this time. And once I realized that Nick had Huntington’s, every night I would wake up at some point in the middle of the night thinking that it was a nightmare, and then I would realize, “It’s not, it’s really true,” and so then I would cry myself back to sleep until I woke up again. And I really didn’t fully deal with it until the day after tax season. I woke up and all of those emotions that I had been putting at bay just came flooding in and it didn’t just come at night. It was around the clock.

Nick was 20, so it was the juvenile-onset, which typically means it goes faster. So while someone with a typical onset lives for 15 to 20

years from the show of symptoms, somebody with juvenile-onset typically has about 10 years from the onset of symptoms. It was my worst fear, you know. First, it was awful that Kevin had it and I dealt with that for 20 years. And then the fact that Nick had it and he had the juvenile-onset, it was truly the worst of the worst. So, of course, it's now been seven, eight years later, so I can talk without crying. That took a couple of years to be able to actually do that.

I thought I knew. But I really didn't know the depths of the pain that you can feel when it's your child and I mean, of course, nobody wants that to happen to anybody. But to happen to your child, and a child that had such a bright future, and was such an incredible, kind, loving, person. It's just not fair.

A Benefit and a Curse

The biggest struggle is that Nick's life has changed so much from what it was, even two and a half years ago. He was living in San Francisco, on his own, with his best friend. They were sharing an apartment. Right out of college, he got a full-time job as a hedge fund accountant. He could walk to work. He was working for a great company and a profession that he enjoyed. And we would go out to lunch every week. He was able to be involved in different things. He actually had a long-term girlfriend.

For Nick now, because he's not out in the world, he tends to get more isolated. He can't call up a friend and say, "Hey, let's go to the movies." He could but he hasn't been able to drive, he gave up driving years ago. And, of course, when we lived in San Francisco, he could call an Uber or a Lyft and go somewhere—which he can't do now. We actually relocated to be closer to family and to have a little bit more room than we had in the city, and people don't necessarily come more often. Some people that live relatively

close, we still see the same or maybe even less than when we lived 100 miles away.

A year ago, Nick was able to walk. He was still unsteady but didn't need a wheelchair. Now, he is in a wheelchair most of the time. 98 percent of the time, he is in a wheelchair. He needs that level of support. Communication was much clearer. His ability to analyze things. We've always enjoyed going to the movies and we love to go to art movies and documentaries. So his ability to even understand a year ago was so much different than today. Today sometimes I'll have to maybe explain basic plot things because he may not understand it. He has not been able to read for years. We've tried other things, but it's too difficult for him to concentrate.

Nick is aware that it's different, and I guess it's a benefit, but it's also a curse, as the disease progresses. To be aware of everything going on around you, but maybe not being able to express it or not to be able to confront it because of your limited ability. And now, Nick definitely doesn't understand subtleties that may happen. If there's a group of people, it's pretty difficult for him to participate. It almost has to be one-on-one or two-on-one who are, of course, very sensitive and give him enough time to respond to questions or statements.

No Time to Waste

What's going on in Nick's brain has been described to me as a city. Think of a city, and your thoughts are the buildings in that city. With Huntington's, all of the roads and the sidewalks get wiped out. You're in a building, you're thinking about whatever the thought is, and then people move on and they switch a topic or if they ask him something different. He has a difficult time getting to the next

building because there is no clear path to go there. Even to express what is in the building and what's going on is also difficult for him.

But in the core, he's still Nick. I think he's accepted it, and once you have a level of acceptance, whatever challenges you have, you make the best of it. He's always been a very positive person. You know, "What can I do today that I enjoy?" So, of course, as he has become more disabled, his world is more limited. But he still loves to go to San Francisco. As a matter of fact, if I don't have it on the calendar, he says, "What day are we going to the city, Mom?" He will be relentless until I schedule it.

At one point, after he couldn't work anymore because of the Huntington's, he had some money that he had inherited when his father passed. I told him, "I'm going to be fine. You need to spend that money on doing what you want to do." And so I worked with him to come up with his bucket list of what it was. He had traveled and studied another summer in Europe. He had seen quite a bit but he had always wanted to go to Norway to see the fjords and he had always wanted to go to India. And so we planned a trip. He and I went to Norway for a month and then we went to India for a month.

He's always loved sports, basically basketball and football. He was talking about how he didn't want to take our big trip until after the football season was over. I said, "Why don't you go to the Super Bowl?" And so he did. He was able to take his best friend, Jesus, to the Super Bowl. I just felt like he had to have as many experiences and he just didn't have any time to waste. And so we talked extensively about that. He has a very positive attitude because he says, "My life is short. You know, I just don't have time to sit around and be negative or feel sorry for myself."

Here with Him

It's been a long road for me. I've been dealing with Huntington's for over 30 years because Nick's dad was sick for 20 and Nick has been sick for a number of years. It was almost 20 years from the time Kevin started showing symptoms until he died. So that was 20 years of grieving, 20 years of needing to help him as his ability declined. And then, of course, there are financial implications as they can't work and make as much money. And you don't go through the final grieving process really until they die.

I have become very accepting. And not in a complacent manner, but I have to accept where Nick is. Because otherwise, it's just more painful and I can't appreciate the moments. So I truly try to practice mindfulness. I'm here with him. I do have moments where I get very emotional and it's typically when I see a decline. I almost feel like I get smacked in the head and I'm almost disoriented trying to reconcile myself: "Okay, this is the way it's going to be." Because Huntington's is a constant grieving process. You're always grieving what you're losing. But I can't focus on it. I mean, I do go through that grieving process, but I have to focus on the positive things. Otherwise, what's the point of getting up? And I'm missing moments with him. I do spend time with him every day, even now that he's not living at home, to capture as many moments as I can. It's very comforting that I can be there with Nick, to help him in the world. And just to enjoy being with him. Because at some point, he won't be here and my goal, of course, is to make sure that I'm here to help him until he's not here.

I like Nick. Just who he is as a person. Sometimes you can love people and maybe not like them. It's the way he sees the world. Maybe it's a little bit selfish on my part because we tend to see the world pretty much the same. Not exactly the same, but we tend to be on the same side of the fence typically when we look at things.

Look Him in the Eye

People, certainly, should not rush to judgment when you see somebody that's struggling. There's probably a reason why that's going on. You just don't know. You just don't know what the details are. Something's happened probably, something out of their control and with Huntington's, that's the case. So I would say treat Nick as you would anybody else, look him in the eye, try to ask him a question, as opposed to always looking to the caretaker. Because Nick's the one that has the thoughts inside and it truly is still him. But people don't see that, particularly people that don't know him.

It would be nice if friends and family are as involved as they could be. And I believe some people, they're as involved as they think they could be. But time is short. Five years from now Nick won't be here. Probably even three years from now. So, they're missing opportunities to spend time with him and they're also missing opportunities to help support me to deal with all of the things that come up. I know Nick appreciates me being there for him and that's why I need to do whatever I can to take care of myself, which is always the hardest thing, I believe, of being a caretaker. Making yourself a priority. Because the person that you're taking care of means so much, that's what you tend to put all your energy into.

I can't explain the real depths of what a caregiver goes through because you have to feel it. I thought I knew but I really didn't. When I would see my mother-in-law walking with her daughter who had the juvenile-onset, I used to say, "Oh, someday that could be me." But I didn't know what that meant.

An Entire Dimension

Nick and I have always had a good relationship. And I'm very fortunate that we have that because I'm able to provide some comfort for him and to be there and to help him through this process. Humor is so important for us. We love to laugh and I probably don't practice dark humor as much with him, but we do find things funny. The owner of the home where he lives now says she loves to pull up because she will hear Nick in his room just laughing hysterically because something is funny on television. And typically it's irreverent humor, you know, making fun of things going on in the world. I love irreverent humor and he does, too.

I think it's just a relief, and it allows you to be positive. Because you get out the pent-up frustration or sadness that you could just dwell in. I mean, I could curl up in a ball and just cry all day. But the realities are, I would miss the gift of today.

If I could go back and say, knowing what I know now, *would I make a different decision to have a child and to have Nick?* I wouldn't change my decision. He's truly brought so much joy and love and added an entire dimension to my life and other people's lives. So I wouldn't change it.

THE GIFT OF TODAY



I'm Still the Same Person

NARRATED BY NICK NARDULLI

**INTERVIEWED BY CYNTHIA STONE,
DOCUMENTARY FILMMAKER**

Nick Nardulli was diagnosed with juvenile onset Huntington's disease just two years after his father passed away from Huntington's. Now 28, Nick reflected on keeping a positive attitude; his connection with his mother, Mary Nardulli; and the message he wants to share with the world. The questions have been edited and included in this interview for clarity.

Can you tell me why you wanted to participate in this interview?

I wanted to make sure that I got the message out because not enough people know about Huntington's and the effect that it has. I just—I want people to know about the disease and also the effects that it could have on your life. It makes you have—Well, my life has changed dramatically with having the disease.

Tell me about some of the dramatic changes.

Mostly, the biggest thing is with my balance and coordination. It's very hard for me to stand up and that has progressively gotten worse. So probably like six years ago I ran a marathon, but I don't—but obviously, I'm not planning any work now.

Do you still have the spirit of a marathoner?

Yeah, of course.

And when you were a kid you were quite athletic, right?

Yep. I have always played sports and I love to just run everywhere. But obviously not now.

And what about your ability to be able to communicate?

That has definitely diminished. It's harder for me to communicate and tell people what I'm thinking. Also, it's hard for...it's difficult for me to comprehend questions and answer them.

What did you do for a living?

I used to be a [hedge] fund accountant. So, I liked working with numbers, big companies.

Can you tell me about the company?

I was very lucky to work with such an understanding company that was very helpful in letting me come to work an hour later, and also, they gave me easier funds to work on.

And when you had to make the decision to leave? How was that?

Difficult, but I had to make it at some point. I felt stressed out from work 'cause it was just too intense.

Mary added, “He’s also trained as an accountant, and his job as a hedge fund accountant was extremely difficult because it was not preparing financial statements. Other people did it, and his job was to make sure they had done it right. You have to check their work, and then get them to correct it, and then check it again. Complex, very detail-oriented.”

How did the company react when you shared your diagnosis with them?

They were very understanding with—well, essentially we got together and had a group meeting with the people who worked there, the other people that I worked with. They were very understanding.

Mary said, “I did an onsite job training for them. Basically, they let everybody take an hour out of their time so that I could come in and train them about what is Huntington’s, and also how to make it easier for Nick to be productive. And they actually changed some of their work habits there.”

You seem to have a real acceptance of this disease, was it always like that?

Yep. I always have a very positive personality. But not very many people are like that. Even my dad, and he was—he had a very bad mood and temper.

How does the positive personality help you cope?

It dramatically helps me because there's a lot of other people who look at this negatively, but I look at it positively so I can live my life in enjoyment.

Can you talk a little bit about your dad?

He died, I think, when I was...so eight years ago. And after he died, like about two years later, I was diagnosed with the disease. So he never knew that I had it.

And do you remember living with your dad with Huntington's Disease?

Yeah, it was very hard because I really didn't get to know my dad.

Can you tell me a little bit about your mom?

She is amazing. I would hate life if she wasn't in it. Because we're attached at the hip.

You've had some great adventures together, right?

We've traveled quite a few different times. I think our biggest and our best trip though was when we went to Norway and did a cruise around Norway which was amazing. It's amazing because it's so different from anything else. It's very unique because they call it *ffjords*. But it's basically you know, giant mountains coming out of the water.

What kind of feeling did that give you?

That made me really happy.

What kind of support have you gotten from the rest of your family?

Well, I like—I feel like I've been cut off. It makes me sad to think about it and to think about...well like, people used to come visit a lot more often.

How does that feel?

Bad. I feel like people are ignoring me.

What would you like to tell people?

To stop ignoring me.

What could people do to help you not feel like that?

Keep more open and understanding about the effects of the disease. Inside I have—I have never changed. But on the outside, I have changed a lot lately.

Can you tell me about the walk that you do?

Every year we go. Me and my family we walk along the pier for like a mile or two. And to raise awareness for Huntington's.

What does your shirt say?

Team HOPE. That's the name of the walk that I went on. Because they're hopeful for a cure.

How do you feel about that?

I've kind of lost hope because it's not gonna happen while I'm alive.

So what do you focus on instead?

Having fun.

How has it helped you to stay positive?

It's very helpful because it lets me enjoy life. I want to give the message out—because there are still a lot of people who don't understand or know what the disease is. I'm always the same,

even though a lot of people don't understand that and just see the disease.

What do you wish they saw?

That I'm still the same person. My mom is amazing. Because we have a very close relationship, and she sees past the disease.

What do you think, Mary?

I think that people that aren't getting to see him and spend time with him are missing out. Really.

Nick added, "Yeah."

Are you proud of him, Mary?

Oh yeah. We've had a lot of good times.

"Yep," agreed Nick.

"Few sad times but...we try to minimize those," said Mary.

"Yep."

"Make the best of it."

"Yeah."

I'M STILL THE SAME PERSON





It is a Crazy Good Thing

NARRATED BY NENE

**INTERVIEWED BY
LENISA BRANDAO,
ATLANTIC FELLOW**

Nene is 72 years old and has moderate-severe disfluency due to expressive aphasia. He was an electrical technician, and he retired due to disability after his first stroke. Nene had three strokes (the first was eight years ago). He arrived with two-year chronic aphasia. He lives in the back of his sister's house and does not often see other relatives. When he first arrived in our support group, he was often frustrated and less communicative. We recommended dancing classes for a start. After three months of dancing, he started clowning in our clown group. He developed friendships and leadership skills. He always arrives early to prepare material for everybody. In the last five years, he has been one of the most successful clowns in our group.

Nene in His Own Words and Gestures

When I used to work...everything I did had to be right. Everything had to be done in time.... I couldn't just not be angry when things would go wrong. So then I had...a stroke. This made me start doing other things. I started speech therapy. I went for...*(makes a dancing gesture and sings while doing so)* I decided to be a clown. That's when I started being able to play with everybody. It became like a good thing in my life. It gets better every time. My clown name is Nene. Today Nene is what I have, and I will be now Nene. He is a playful guy. He has speech problems, and he plays. He knows that becoming angry doesn't help with anything. Life is like that. When he presents in the theater...ahhh it is so good *(laughs)*... It is a crazy good thing *(smiles showing contentedness)*.



Blaze of Glory

NARRATED BY DEIDRA COUCH

**INTERVIEWED BY
CAROLINE PRIOLEAU,
UCSF MEMORY AND AGING
CENTER & GBHI**

Deidra Couch is a Medical Science Liaison for Lundbeck Pharmaceuticals and holds a doctorate in pharmacology. She is also a wife of 18 years, mother of two (13 and 11), and was the primary caregiver of her mother who passed away from complications due to dementia. She reflects on her experience as a caregiver and scientist, and how that impacts her priorities for her life.

I Just Say “Dementia”

My mother suffered from Alzheimer’s disease for, I would say, seven years, give or take. It all kind of came to a head in 2010. My father passed away in June of 2011, and she was already diagnosed with what we’ll call Alzheimer’s because the neurology treatment team ruled out all other types of dementia. I just say *dementia*. After doing a little of my own research I think some of the symptoms that she displayed aren’t very characteristic of legitimate Alzheimer’s disease. Usually people with Alzheimer’s are not physically aggressive, and she had a physical aggression that occurred with a very, very strong paranoia. The team did rule out dementia due to a vascular nature or frontotemporal degeneration, so, we’ll just say *ipso facto* Alzheimer’s.

I do have to preface my story of being a caregiver for my mother until she passed from complications due to dementia with the fact that my grandmother also passed away from complications due to the same disorder. So, when I saw the signs, the diagnosis was already in my mind. I already recognized the clues. That’s why I say she probably had been suffering since the end of 2009 or 2010 but the signs became more prominent in 2010.

My Mom Was a Stronger Version of Me

At that time, my kids were really young, four and six, and my parents would come up to DC three times a year, and the kids would go down to North Carolina in the summertime where my family lived. It was very convenient because my mother lived in Raleigh and my mother-in-law lived in Durham about 25 minutes away. So, the kids would go down for about a week, maybe two weeks, and they'd split up their time with their grandparents, first my parents and then my in-laws. And there was a time when my mother-in-law called me, and she was very upset. They would always "politely" argue about the amount of time they could see the kids—the time had to be split down to the hour sometimes. This particular time, however, my mom had gotten verbally angry with my mother-in-law and said, "You've come too early," and my mother-in-law was confused. They always got along really well. And so she called me, and I was like, "Okay, that's kind of weird."

When I mentioned it to my mom, she had a really strong reaction, and I didn't understand where that was coming from. So I was like, "Okay. Something's going on." During this time frame, I would have conversations with Mom, and she'd repeat herself, a lot. And I would say, "Mom, have you gone to the neurologist? We know what this is like because Grandma suffered from it." And my mom took care of my grandmother. My mom was one of nine siblings. The sisters tried to split up their time, but my mom and my aunt were the closest in distance to my grandmother. My grandmother ended up having to go to a nursing home maybe 15 minutes from my mom's house. I personally witnessed my mom caring for my grandmother. And so, when she was repeating herself and I would say, "Mom, we know Grandma went through this," she would always put it off. "I'm gonna see the neurologist. I'm gonna see the neurologist." Nothing ever happened. I think she was afraid,

and I think she really wasn't coming to terms with the things that were going on. She just didn't have the insight.

In October 2010, I started a new job and had to go to China. I needed my parents to come up and care for the kids. Literally the day before they were supposed to come, my mom canceled. I was extremely upset because I was going out of town and didn't have backup childcare. "I don't understand, Mom. I really needed you." And the apathy that she had was just startling. I mean just, "Well, I'm sorry I can't come. I'll talk to you later, Sweetheart. I love you." As if she said, "I can't send you that care package." And here I am waiting for her, my husband was relying on his in-laws, and her response was just so apathetic.

When she didn't show much empathy towards the stress she could clearly hear in my voice, I knew something was wrong. I knew that the connection that I had with her was gone because truly she was my best friend, and I talked to her probably three or four times a week. She has never been like that. If I ever in the past displayed any type of stress or negative emotion, her response would be, "What can I do?" This time she was just like, "Well, I'm sorry I can't help you. I'll talk to you later." That's really when I knew.

So, I started going down to North Carolina every three to four weeks. My dad was still in the house, and he did not want to admit anything was wrong. Now, mind you, my dad was a chronic alcoholic. It was literally the blind caring for the blind.

Mom and I had an appointment with a neurologist. He said, "Yes, something is going on. I'm not going to give her a full diagnosis of dementia. Let's see where it goes."

I try to be as intellectual as I possibly can. I try to make sure I've done my due diligence on things. In my profession, I'm a medical resource for my territory, so I have to know certain things, but I also try to instill a certain work ethic in my kids. All of these

attributes came from my parents. The work ethic, I got from both parents. But I got the caring from my mom. So, to see her change over time was really difficult. My mom was a stronger version of me.

All-Points Bulletin!

Fast forward to April 2011 and getting a phone call from a friend of my mom, a former co-worker, to tell me Mom had to go to the hospital because she was so weak, she couldn't stand up. Now mind you, I have been going back and forth to care for them, but they were doing kind of okay. She said, "You need to come."

I went to the hospital. They were giving her intravenous fluids for serious gastrointestinal issues. And that was why she was so weak. She couldn't hold food down. When I went into the house, that's when I knew something was really, really wrong. I knew they were going to make an official diagnosis of dementia because of the condition of the house. My mother was a neat freak; you could smell the bleach before you got into the house. This time, however, the dishes were piled up, and there were those little fruit flies all around. I opened the oven, and there was all this leftover food that people had brought to the house. They knew that my parents were getting older so they were bringing them food. I found all of this food in the fridge and in the oven completely uneaten. I knew something was wrong.

She was in the hospital for probably about four or five days. The internist said, "It's either delirium, or it's dementia. Something is going on."

So, come to find out, she was not remembering to eat. She's a diabetic—remembering to eat also prompts her memory to take her insulin. She's not eating. She's not taking her insulin.

It's just this cyclic downward spiral. And one of the risk factors for exacerbated episodes in dementia is not having a controlled glucose level. Once they got her glucose in control, she was more coherent.

The day she was discharged from the hospital, I brought her home then went to the drug store to get her medicine. When I returned, the car was gone. I said, "Dad, where's Mom?" "Oh, she went to the store." Well, she was retired from the police department, so I called one of the cops that I knew, and I said "Okay. She's really sick, and I don't exactly know where she is." And while I was talking to him, I was thinking, "All-points bulletin! Find my mom!" And as I'm on the phone with him, the hospital called. "Your mom's back!" She went back to the hospital, in the car. They knew something was wrong because she drove on a section of road at the hospital that was a walkway. How she was able to get her car, this huge Cadillac, past the barriers was beyond them and me. That's when I knew I had to do something. So, I kicked it up. Probably every two weeks (sometimes every week) I was driving back from DC to Raleigh with two kids—a 4-year-old and a 6-year-old.

It wasn't until I was coming down more frequently that I saw their bills weren't being paid. The house almost went through foreclosure. I went to the mortgage company, and when I walked into the office, the woman said, "Who are you?" And I said, "I'm Fannie Montague's daughter." She said, "Thank God you're here." Because they almost had a foreclosure. But my parents had the money in the account.

Kicking It into Full Gear

When she was discharged, the doctor said, "You need to take her to a neuropsychologist and actually get her tested and see what's

going on.” I came back at the end of April, maybe early May, to get the testing done, and they fully diagnosed her.

So, then I was kicking it into full gear trying to make sure she was okay. We got the doctors’ appointments in line. I had a neurologist that specialized in the geriatric population and her primary care physician in constant contact. So, we’re getting all that done. And I remember the internist at the hospital said, “You really need to get your parents to do a power of attorney and a will.” Because I couldn’t find their existing will, I got a lawyer to draft a new one. He actually drove to the house to establish the draft. Somehow, she was still well enough because she was in her familiar surroundings, to agree to let me be the power of attorney, both health care and durable. The lawyer also agreed to drive back to the house to sign the final draft. Thank goodness I did not have to take them to the lawyer’s office because it would not have worked. Getting them out the door was just in itself chaotic and stressful. So, he came back to do the final will at the home, and that was in May. Five weeks later Dad died.

I was really lucky. I have a very strong spiritual connection. I was like, “This is God’s will.” Because after Dad died, there’s no way she would have done the power of attorney.

I Don’t Have Dementia. I’m Fine.

I knew the dementia was bad before my dad died. My parents lived in one of those old-school neighborhoods where nobody moves. So, the neighbor next door had been my neighbor since I was eight. She was a caregiver for her mother who also suffered from dementia. After her mother passed away, she opened up a small facility in her honor and cared for other dementia patients. She had a lot of experience with getting caregivers and told me, “Don’t go through

an agency because that's usually 20 dollars an hour. I know several people who will do it for you for half the price. And I trust them." And so, probably for about a three-month time frame before dad passed away, I had a caregiver coming in to check on Mom, but Mom would kick her out every day. Because Mom's perspective was, "I don't have dementia. I'm fine." I would get a phone call, "Your mom's not letting me in," and I'd have to call to say, "Mom, somebody's at the door. Let 'em in."

So, one day the caregiver came in to make breakfast. And my mom was in a really, really bad mood, and she'd even called me that day. "Your dad's driving me crazy." And I said, "Oh my gosh, Mom, whatever. Y'all just go watch Matlock. Y'all will be fine. Everything'll be fine." He was already dead when she called me.

Usually when the caregiver would get to the house, Dad would come from the bedroom and sit in the recliner while she was preparing food for them. When he didn't come from the bedroom that morning, she said, "Ms. Montague, where is Mr. Q?" They used to call him Mr. Q. My mom said "Oh, he's sleeping, and you respect his privacy. Leave him alone." She was getting really agitated, and the caregiver just kind of forced her way back there and saw him lying on the floor. It looked as if he had tried to get out of bed and fallen on the floor. There was a blanket over him.

So, the caregiver called my neighbor. My neighbor called me. "You should come home." I said, "Is it Mom?" She said, "No, it's your dad." To this day, we don't know exactly when he passed away, that night or early that morning. In her mind, he was sleeping. This event was when I knew the dementia was really bad because she didn't have a level of insight to understand that her husband had passed away, let alone call 911.

Now, the scary thing about this event is, I was supposed to come down with the kids the next day. And usually when I pull up in the driveway, the kids would jump out of the car, run into the

house. I can't imagine the trauma on my kids if I had been the one to actually find him instead of the caregiver.

So, all these things were happening. Long story short, when he passed away, I had her come up and live with us. I said, "Mom, this is a perfect time. Spend time with your grandkids. They would love it." But I just didn't let her go back home, and she resented me ever since.

I Want to Go Back

She lived with us for two and a half years. I would try to get caregivers to come in and care for her. It always resulted in them quitting or her kicking them out. And finally, I was expressing my frustration with one of my clients, who is a healthcare professional specializing in the elderly. She said, "You know what? If your mom is mobile and can care for herself, just get a babysitter. Do you have a babysitter for the kids? If your mom likes that babysitter, she'll view the babysitter as a friend. Just let her hang out with the babysitter." So that's exactly what I did. My last caregiver for my mom, in my house, was the babysitter for our kids. And she loved her. She was just thinking, "Oh, she comes over during the day. She's preparing things for the kids and...." So that's how it worked out.

I was the exact example of a sandwich generation because I was a mom to very young children, a wife, and a daughter caring for her elderly parent. And to add to that level of stress, a caregiver for a mother who literally resented me even when she was bedridden. She was like, "I want to go back to Raleigh, North Carolina. And you're the reason why I'm up here in the DC area." So that was really hard.

When she passed, people were expecting me to fall apart, to mourn the death of my mother. But I mourned those first two and a half years she lived with me because she was no longer my best friend. I mourned the death of our relationship. That was the hardest. She was legitimately my patient, and I was her caregiver. And I no longer could go and sit on the edge of her bed and ask her for advice or just discuss my day or discuss her day. It really was, *I'm caring for her*. And I'm trying to navigate her paranoia, her hostility.

Those Babies

There would be times where there were such great stories, and she would talk about the kids, and every once in a while, we would connect on music. She loved music. But to just sit down and have an actual conversation, not really.

I was there when she took her last breath. By the time she passed, I was very close with the staff at the facility, especially the lead CNA (certified nurse aide), and I had constant communication with her. I told her, "I don't want her to be alone when she passes away. And if I am physically able to be there, I want to be." So, I was there when she took her last breath, but I had mourned our relationship five years before.

I think the dementia taught me to live in the moment. To not be so overcome and overwhelmed by work. Weekends were always when we needed to run errands. And my mom would say to me, "Well, just let the kids have fun" or "Why don't we go out to eat?" Before Mom lived with us, it would never dawn on me to have 'impromptu fun'. To think, "Oh, while we're running errands, let's stop and have lunch." I would always be like, "No, that's not healthy. Let's go home, and we're gonna make sandwiches or have salad."

And she'd be like, "Well no, let's just stop at Golden Corral." My family's very blue collar, so buffet restaurants were always a fast, economical solution for eating out. And the kids would be like, "Oh! The chocolate fountain, yeah!" And my reaction would be "Oh my God, all of that sugar..."

There were definitely some lessons learned.

In the two and a half years that she lived with us, she improved a little bit because the kids were around. And there's something about those babies that just.... They were like, "Ooh, we're with Grandma." They spent so much time in her room just hanging out watching TV or listening to music. And they loved it! They grew close to her. It helped her and it helped them. Now my son was aware, even at seven. He was aware of things that were going on, and he knew something was different. But even up until my mother passed away, my daughter did not understand why she couldn't move back with us. She was four when it happened, and she was ten when Mom passed away. She was like, "Now explain to me why Grandma can't live with us? She's in the bed. Why can't we just get a bed and have it here at the house?"

A Blaze of Glory

After everything I've experienced with this disease in both my mother and grandmother, I'm going out in a blaze of glory. And it doesn't mean that I'm going to be drinkin' like a fool or smoking weed and doing reckless things. None of that, but blaze of glory in the fact that I'm gonna be happy. And you know, if my husband's like, "I don't want to go to this concert." Fine, I'll go with a friend. Or if I want to take the kids on a hike, and we have time, we're going to go for a hike, you know. I need to be happy. I'm 48. My grandmother and my mother were diagnosed in their late 60s,

early 70s. So, just in case, I'm going to enjoy my life. Her disease changed my perspective. Living in the moment. Let's try these different foods. I'm no longer like, "Oh my gosh, I have this project. I can't take the kids to downtown DC." No. We're gonna do it.

I'm Adamant

Being a PhD in neuroscience, the biggest thing for me now, experiencing what my mom endured, what my grandmother endured, is that I am going to, in some form or fashion, be a subject for a trial because I may be a high-risk individual. I'm a black female, with two previous relatives who had dementia. You should study me because if I'm not a carrier, then I must at least be a high-risk subject. There's got to be a risk factor.

The biggest obstacle is the fact that I won't be able to be part of a study until I'm 55. I've reached out to research groups as a fellow PhD who previously specialized in basic research. But every trial in which I've tried to be a participant says I'm limited by my age. Like, are you kidding me? At the Society for Neuroscience meeting, I went up to the Alzheimer's Association booth, and they said "Yeah, there's nothing we can do." I'm like, "Shouldn't we take a picture of this? I'm telling you I want to be a subject, and I'm at the Society for Neuroscience, and you're telling me you can't do anything?"

I am part of the Alzheimer's research registry. I've also contacted the Harvard Brain Bank because when I was a postdoc at NIH, I worked in a lab that was doing postmortem brain research. So, I already knew then that I was going to donate my brain, but now with everything that's happened with my grandmother and my mother, I'm adamant.

This Dementia is a Beast

The most difficult part of being a caregiver was not internalizing her anger. Because it all was against me. That is when I knew, okay, this dementia is a beast. I would tell myself, “That’s not her. That’s not my mother. That’s the disease talking.”

She would get so angry with me and get in my face. Because she would pace all night long at times, she would actually come into our room, and she would stand over me. I would wake up to her standing over me. She would just look at me and then walk away. She was so angry. My husband and I would make a joke out of it. The next morning, he would say, “Did you see the bogeyman last night?” That’s what we called it. And I was like, “I think I did.”

To this day we have the funniest stories about the things she said. Oh my gosh. My husband had a second family in the basement. I got fired from my job for illegal activities. You know, just the whole thing, and she’d tell her sisters all this stuff and the babysitter, and then they would tell me. I was cheating on my husband with one of her former co-workers. Literally, I could see the disconnection. She said to me, “I don’t know how you do your marriage, but in my day, you were faithful to your husband.” And I’m looking at her, and I could literally see, physically see, that she was not connected to the real world around her.

I did on some level feel good about what I was doing as her caregiver. I knew that my mother had sacrificed so much to care for me, and the fact that I could be there to the best of my ability just made me feel so good. That was probably the most rewarding. And to see the relationship that she developed with the kids because their rooms were just down the hall. So that was great to see. I take that with me all the time. The kids have a special relationship with her. My son came to see my mother up until the week before she passed away. And my daughter came to see her

up until two weeks before she passed away. They were dedicated. The staff at the facility were amazed by how much the kids just cared for my mom.

We'll Take Her

If I could have, I would have kept her in my house, until she passed away. But I couldn't because she became physically aggressive and paranoid, and she had to be hospitalized in the psych ward. The hardest time was having her committed because I had to prove to them that she was not competent, and that required the staff calling the sheriff into her hospital room in the ER and questioning her, and witnessing her combative behavior.

Now she didn't put her hands on the officer, but she got so angry with me that she got in my face in the ER. Then they said, "Okay, we'll take her." They would not let me escort her to the unit. The officer had to do it. And so, watching the door close and her getting into the wheelchair—this frail 5'4" spitfire being escorted to the unit—I did cry. I cried because I couldn't go with her. And her last job for 15 years was working with the police department, so the fact that a cop committed her was heartbreaking. She didn't fight him, but the fact that that was what it took to get her admitted was painful. It broke my heart. That was traumatic.

Nowhere to Go

I was so incredibly fortunate that she had a pension and that she had Social Security because we paid out of pocket for the facility. I used her money and a little bit of my money to do that because the facility did not accept Medicaid. But my mother wouldn't have

qualified for Medicaid. I would have had to have sold everything down, and I was too stressed out to do that. So I just paid.

But once Medicare-funded hospice came in that last year, she had a nurse, she had a volunteer that came and sat with her every day. She had a social worker. She had a chaplain that came. She had musical therapy. All of these services were provided by Medicare. So, the biggest takeaway to me was: If you are independently wealthy, you can have all these services because you can pay people to guide you. If you are below the poverty level, you can qualify for Medicaid, and you have all these services provided. But if you're in the middle, there's nowhere to go.

If I had had someone advising me in the beginning when she was diagnosed and telling me what to do with her money, things would have been completely different. Instead, I paid for an elder law attorney to guide me on how to spend her money so she could qualify for Medicaid. I wasn't blaming her, but I was thinking to myself, "I just wasted eight thousand dollars with you when really what I needed was a social worker." If social workers can be hired hourly/weekly/monthly instead of being contracted, it would change the dementia care landscape. I needed a case manager, and I never had that. What it taught me was, "Gosh, if we could change the system. Where people in the middle could get guidance. It would make such a large impact." That's all I needed. I didn't need an elder law attorney. And the funny thing is I could have gotten a case manager if she had qualified for Medicaid.

The biggest assistance from the elder law attorney was her paralegal, a former social worker. One particular day was really rough. The facility was raising mom's rent and there was a lot of personal stress at home. I basically called her office and cried. She said, "You know what, I'm going to have my paralegal check in with you weekly."

The paralegal contacted the care facility where my mom was, and they talked. She talked them into decreasing mom's rent to a cost I could handle. She spoke on behalf of me. It was those first three months of me talking to her paralegal every week that got me through it. That was what I needed. I needed someone who knew the system and who could speak on my behalf. I needed practical advice and resources. So, I think if there's anything I would share, it would be advice on changing the system where people like myself with parents in the middle of the socioeconomic ladder can get help.

BLAZE OF GLORY

Sábado Santo

**NARRADA POR
LUZ EDITH VALENTINA**

**ENTREVISTADA POR
STEFANIE PIÑA ESCUDERO,
ATLANTIC FELLOW**



Holy Saturday

**NARRATED BY
LUZ EDITH VALENTINA**

**INTERVIEWED BY
STEFANIE PIÑA ESCUDERO,
ATLANTIC FELLOW**

Luz es una mujer de 22 años. Nació y creció en Michoacán, México. Es hija única y creció entre adultos quienes esperaban que ella se comportara como uno de ellos desde que era muy joven. Ella ha cuidado a su abuelo que tiene Alzheimer desde que tenía 16 años y compartió la siguiente historia.

Yo describiría la experiencia de ser cuidadora como algo bastante triste. Una de las partes más difíciles ha sido tratar de entender que ninguno de los comportamientos de mi abuelo son intencionales. Es complicado tratar con alguien que no sabe quien es, donde está o que es lo que quiere. Encontrar la paciencia para convencer a alguien de hacer algo que no quiere hacer porque no sabe para que lo tiene que hacer no es algo sencillo. Por ejemplo, en una ocasión estuvo en el hospital porque se lastimó un pie y no lograba convencerlo de tomar los medicamentos. No sabía que eran o para que eran y me repetía que quien debía tomar esos medicamentos era yo. Creo que cuando eres tan joven no siempre tienes la paciencia para cuidar a alguien más. Hay momentos en los que me gustaría hacer cosas o ir a lugares con toda mi familia, pero como él no puede o no quiere pues no lo hacemos. Esto me afecta mucho y por eso trato de hacer cosas divertidas con él. En las tardes, vemos Disney Channel. Él siempre me dice que quiere ver las noticias, pero cada vez que las pongo en la televisión se queda dormido. Cuando pongo Disney Channel siempre está muy atento.

Mi momento divertido favorito con él fue un Sábado de Gloria. En México, es una tradición arrojar agua a las otras personas como símbolo de purificación ya que en la antigüedad no tenías que bañarte durante la Semana Santa por lo que todos esperaban el sábado para ser purificados. Ahora es más como un juego en el que el objetivo es mojar a otras personas mientras tratas de mantenerte seco. Ese sábado

Luz is a 22-year-old woman. She was born and raised in Michoacán, México. She is an only child who was raised among adults that expected her to behave as an adult since she was very young. She has been taking care take of her grandfather with Alzheimer's disease since she was 16. She shared the following story.

I would describe my experience of being a caregiver as something that is somewhat sad. One of the hardest parts has been trying to understand that none of his behaviors are on purpose. It is complicated to deal with a person who does not know who he is, where he is, or what he wants. Trying to find the patience to convince someone to do something that he does not want to do because he does not know what to do it for, is tough. For example, there was this one time when he was at the hospital because he hurt his foot, and I could not convince him to take the medication. He did not know what it was or what it was for and he kept telling me that I was the one who should have taken it. I think that when you are so young you don't always have the patience to take care of someone else. There are moments when I would like to do stuff or go to places with all my family, but since he cannot go, we don't do those things. This affects me a lot, and that's why I try to do fun stuff with him. In the afternoons we watch Disney Channel. He always says he wants to watch the news, but every time I put it on, he falls asleep. When we watch Disney Channel, he is very attentive.

My favorite fun moment with him was a Holy Saturday. In Mexico it is a tradition to throw water at other people as a sign of purification because in the old days you were not supposed to take a shower during Holy Week, so everybody waited until

estábamos como 10 primos jugando en el gran jardín de la casa y mi abuelo, que ya no se podía mover, estaba justo sentado en ese jardín viéndonos y riendo cada vez que mojábamos a alguien. Usualmente jugamos entre primos y siempre respetamos a nuestros mayores, pero ese día ya llevábamos mucho tiempo jugando y ya todos estábamos mojados. Vi a mi abuelo sentado ahí y pensé que sería divertido involucrarlo en el juego y le eché una cubeta con agua encima. Estaba muy sorprendido porque no esperaba que lo mojáramos. Su expresión fue tan chistosa que todos reímos mucho. A partir de ese momento, como él ya estaba mojado, mis tíos, mis tías y hasta mi abuela participaron el juego. Me divertí mucho y mi familia tuvo un respiro de los días difíciles. Todos se veían contentos.

Saturday to be purified. But now it is more like a game where your objective is getting the other people wet while you try to stay dry. We usually play among cousins and respect the older generations. We had about ten cousins at home that day, and we were playing in the big garden outside of the house. My grandfather was sitting in the garden, and he was unable to walk by himself already, so he was watching us, and he laughed every time someone new got wet. We had been playing for a while, and all of us were very wet already. I saw my grandfather sitting there, and I thought it would be fun to get him involved in the game, so I threw water all over him. He was very surprised—he was not expecting to get wet. His expression was so funny that everybody laughed and, since he was already wet, my aunts, uncles and even my grandmother participated in the game. I had a lot of fun that day, and my family got a break from the hard days. Everybody looked happy.



Tom and Susan— Since About 1989

NARRATED BY TOM

**INTERVIEWED BY
JENNIFER MERRILEES,
UCSF MEMORY AND AGING
CENTER & GBHI**

Tom and Susan share an exuberance and joy about their life together. Susan's diagnosis, at a young age, of Alzheimer's disease has created numerous challenges to that joy yet their love and Tom's dedication to her, shine through.

Susan says, “we grew up together” and even though we met in our mid/late twenties, it's true. Our letterhead says, “Tom and Susan-since about 1989.” We joke that we both just skipped that whole “first marriage thing”. After becoming constant companions, we lived in our own sitcom except that the laughter was real. We worked and played and made our mistakes and laughed like mad though most of it. We eventually got serious about the working world, shook off the salad days for the most part anyhow. We bought a tiny house that we love, got a dog and everything else. We were able to travel. Susan and I were on a trajectory that we ourselves could hardly believe. Our careers were variously booming and busting but mostly booming. We have a robust array of friends that serve to keep it all going.

Susan is the social center of every job she ever had. She is masterful at making a fun situation out of nothing. She is linguistically and humorously gifted and has left a trail of smiling happy people in her wake.

Favorite saying: “The sooner you accept life's essential unfairness, the better off you'll be.” Irony isn't so funny sometimes.

What's It Like for Caregivers?

Here is Tom's answer to the question: “**What's it like for caregivers?**”
It's terrifying.

But only financially, logistically, practically, emotionally and existentially.

That leaves...eventually, not very much.

She loves the disposal. Thinks it has to run a for a long time each time the tiniest morsel is sent to its whirling, violent and loud fate. It happens when I'm trying to get the gist of the news or play a song or have a conversation. I haven't had a complete thought in over three years.

I do nothing once. I do it, it gets undone. I do it again.

Every household job is now mine. Planning meals, shopping, putting the groceries away, prepping, cooking and cleaning up. The dishwasher, the laundry, the garbage the yard, the bills, applying makeup, everything in the bathroom, the daily picking up of the 100 things that get brought out but never put back. I marshal the meds, make the beds and maintain any and all systems: cable, internet, email, sump pumps, light bulbs, cleaning products, appointments, insurance.

There are no roadmaps. I can't work. She can't work. There are no tax breaks for our triple whammy situation. Two incomes gone, and neither can work. I have always been a person who maps out the various paths ahead, but I'm no longer able to see beyond my headlights, and that's disturbing.

The danger; cleaning knives, cleaning out germey trash from the bathroom trash can. The meds. Now when I leave, she forgets where I went. She cannot use her phone well enough to call for help. She now needs constant supervision because without it she will miss the chair when she wants to sit. I have found coffee cups and wine glasses in the bed. Steps are a danger. Being out in public when there is no family bathroom is particularly vexing.

Asking friends to look after her is now far more difficult when it involves the bathroom. Our choices have narrowed considerably.

Can't really watch a movie for her restlessness. Can't listen quietly to the news, play my guitar, compose a post without interruption. Interruption to ask for the 40th time what time the appt is, or what day is this or that, or will you put on my makeup, put on my shoes, find my tweezers....

I no longer tell her that friends are coming over this weekend or that we have a hair appointment in two weeks. She will think it's today.

She's up several times a night to pee, and if she's up, I'm up. Only I never really go back to sleep. I am in a constant state of sleep deprivation. I cannot nap unless she naps as well.

It all adds up to a thousand kinds of constant frustration and there is no off switch. At no time am I not responsible. It's fine mostly, but more and more it grinds me down to a vapor thin temperament that I am not always proud of.

I have repeated almost everything I've said for more than two years.

If you're wondering what it's like, it's all this stuff. All this stuff that used to just be small stuff, but now it's the only stuff as the world gets smaller and smaller.

The words I heard were "In sickness and in health."

I'm not going anywhere.

TOM AND SUSAN—SINCE ABOUT 1989



Mi Mamá Manuelita

NARRADA POR LOURDES MAQUERA

**ENTREVISTADA POR
MARITZA PINTADO-CAIPA, ATLANTIC FELLOW**



My Mom Manuelita

NARRATED BY LOURDES MAQUERA

**INTERVIEWED BY
MARITZA PINTADO-CAIPA,
ATLANTIC FELLOW**

Lourdes, o Lula como le dicen por cariño, tiene 54 años, siempre ha vivido con sus padres y al momento es quien se ha hecho cargo del cuidado de su madre, Manuela, a quien le diagnosticaron Enfermedad de Alzheimer hace más de 2 años.

Manuelita

Manuela es mi madre, todos los que la quieren le dicen Manuelita, ella tiene 94 años y hace más de 2 años le diagnosticaron demencia, enfermedad de Alzheimer nos dijo el doctor.

Ella nació en un pequeño y hermoso pueblo llamado Tarata, en la zona interandina de Tacna, en el sur del Perú. Fue la única hija mujer de 3 hermanos, por esa razón fue muy querida y protegida por su padre y sus hermanos. Se casó con mi padre, Paulino, a los 33 años y vinieron a vivir a Tacna. Tuvo cinco hijos, dos mujeres y tres varones. Siempre fue una persona muy tranquila, amorosa y buena, una mujer muy activa y trabajadora, colaboraba mucho con mi padre, viajando juntos a Tarata para dedicarse a actividades de la agricultura, en forma paralela a sus actividades como ama de casa en Tacna.

No estoy segura de cuándo empezaron sus síntomas, pero desde hace varios años atrás olvidaba algunas cosas, como dónde colocaba las cosas, aunque en realidad nunca le prestamos atención a esos síntomas, eran muy sutiles y pensábamos que era normal. Todo empeoró cuando tuvo una caída en donde se lesionó su columna, eso ocasionó que estuviera postrada por más de un mes en cama. Durante ese tiempo, notamos que su conducta ya no era normal, a veces reaccionaba mal, no dormía en las noches, lloraba todo el día, llamaba a sus padres, gritaba, se desesperaba, se angustiaba, la vimos trastornada

Lourdes, or Lula, which is a lovely name, is 54 years old, has always lived with her parents and now takes care of her mother, Manuela, who was diagnosed with Alzheimer's disease more than two years ago.

Manuelita

Manuela is my mother. Everyone who loves her calls her “Manuelita.” She is 94 years old, and she was diagnosed with dementia more than two years ago. “Alzheimer’s disease,” said the doctor.

She was born in a small and beautiful town named Tarata, in the middle of the mountains of Tacna in the south of Peru. She was the only woman of three siblings, and for this reason, was very dear and sheltered by her father and her brothers. She married my father, Paulino, at 33 years old and came to live in Tacna. She and Dad had five children, two girls and three boys. She always was a very quiet, lovely and good person. She always was so active and a working woman—she collaborated with my father, traveling together to Tarata for agricultural activities in addition to her role as a housewife in Tacna.

I’m not sure when her symptoms started, but several years ago she started forgetting things, like where she put things, although actually, we didn’t pay attention to these symptoms. It was very subtle. We thought it was all normal. Everything got worse when she had a fall, where she injured her spine and had to be in bed for more than a month. During this time, we noticed that her behavior was not normal—she sometimes had bad reactions and didn’t

y no sabíamos cómo ayudarla. Para mi padre y para mí fueron meses terribles, no podíamos descansar ni de día ni de noche ya que teníamos que cuidarla las 24 horas, no sabíamos qué hacer, fue muy raro para nosotros y no entendíamos lo que sucedía.

Los Ancianos se Olvidan

Con el tiempo, los síntomas fueron empeorando, busqué a mis hermanos para pedirles ayuda pero no me creyeron, pensaban que hablaba por gusto. Entonces me comuniqué con mi única hermana que vive en Valparaíso, Chile, al sentir mi desesperación ella vino a visitarnos y vio lo que estaba sucediendo. Cuando ella llegó a casa se dio cuenta de la preocupante situación y fue quien llamó nuevamente a mis hermanos para conversar. Entre todos decidimos que debíamos hacer algo, fue así que inicialmente llevamos a mi madre al Seguro Social, ahí los médicos nos dijeron: “eso es normal — los ancianos se olvidan” y le dieron medicinas para dormir que en realidad no le hacían efecto, sus síntomas no mejoraban.

Recordé en ese momento a una prima, médico neuróloga que vivía en Lima, Capital. La llamé y le conté lo que sucedía, y ella me dijo que quizá estábamos frente a un caso de demencia y me recomendó que acudiéramos a un Neurólogo de mi localidad, Tacna. Cuando llegamos al doctor, Dr. Cornejo, él le hizo muchas preguntas a mi madre, hizo algunos exámenes y finalmente nos dijo que mi madre tenía demencia, “Principios de Enfermedad de Alzheimer”. Él indicó algunos medicamentos a mi madre para mejorar sus síntomas, nos reunió a todos los hermanos y nos explicó sobre la enfermedad y el pronóstico, nos dijo que deberíamos cuidarla, darle calidad de vida y colaborar en su cuidado, pues la carga podría ser mucha para una sola persona, nos dijo que quizá necesitaríamos en algún momento ayuda de un cuidador profesional; lamentablemente nosotros no tenemos dinero para cubrir

sleep at night, cried all day, called out for her parents, shouted, despaired, and was distressed. We saw her upset, and we didn't know how to help her. These were terrible months for my father and me. We couldn't sleep or rest, day or night because we had to care for her 24 hours. We didn't know what to do—it was very strange, and we couldn't understand what was going on.

The Elderly Forget

With time, these symptoms increased. I asked my brothers for help, but they didn't believe me. They thought that I was speaking to speak. Then, I called my sister who lives in Valparaiso, Chile. She felt my despair, and she came to visit us and saw what was happening. When she arrived at the house, she realized the worrying situation and asked one more time for my brothers to talk. Together, we decided that we should do something, so we initially took my mom to her Health Social Security. There the physicians said: "This is normal—the elderly forget," and they gave her medicines to sleep, which didn't have any effect—her symptoms did not improve.

Then, I remembered a cousin, a neurologist who lived in Lima, the capital. I called her, and I told her what was going on, and she said that maybe we were facing a case of dementia and recommended that I look for a neurologist in my city, Tacna. When we were with the doctor, Dr. Cornejo, he asked my mom a lot of questions and did some exams. Finally, he told us that my mom had dementia, "She has Alzheimer's disease." He gave my mom some medicines to improve her symptoms, and he brought us all together and explained to us about the disease and the prognosis. He said that we should take care her, provide quality of life and collaborate in her care because the burden of taking care of her

los gastos de un cuidador profesional. Desde entonces dividimos entre todos los gastos económicos que requerimos para sus medicamentos, pues los medicamentos aquí en Perú son muy caros y su seguro social no los cubre. Su cuidado nocturno lo dividimos de forma rotativa también entre todos. Mis hermanos han tenido que aprender a cuidarla y tratarla, a veces les ha resultado muy complicado tener paciencia y poder sobrellevarla, pero hacen su esfuerzo.

Pongamos los Cubiertos

Por el hecho de que vivo en la casa de mis padres, también tengo que cuidarla durante todo el día, todos los días. En realidad soy su única cuidadora diurna. A veces me canso, me estreso y me saturó, reniego pues a veces no sé qué hacer. A veces siento que no tengo paciencia, y termino llorando, cuando veo su rostro triste por algo que creo que no hice bien. A veces mi papá también reniega pues también es mayor de edad y no le tiene mucha paciencia. Por otro lado, quisiera y debiera pasar más tiempo con mi propia familia, con Roberto, mi esposo, y mis hijos; pero en realidad paso más tiempo con mis padres. Mi familia me apoya mucho, pero siento que los he descuidado. No puedo atenderlos antes o ahora, como yo quisiera, no puedo salir con mi esposo los fines de semana, incluso no tengo tiempo para atender mis propios asuntos o tiempo para mí misma, tengo que esperar que alguno de mis hijos se quede con mi mamá para yo poder salir. Mi esposo entiende mi situación y me anima a seguir cuidando de mi madre; él la quiere mucho y ella también lo quiere a él, estamos juntos más de 30 años. Cuando vamos a comer, mi madre siempre quiere que pongamos los cubiertos para todos, pregunta por mis hijos y mi esposo, los espera y quiere que estemos siempre a su lado. Este es un detalle muy bonito de su parte.

would be too much for just one person. He said that maybe, in time, we will need help from a professional caregiver, but regrettably, we don't have money for a professional caregiver. Since then, we have divided between us the economical expenses required for medicines because the medicines here in Peru are so expensive, and her social health insurance doesn't cover that. We rotate night care among us. My brothers have had to learn to care for her. Sometimes it has been hard to be patient and endure, but they make the effort.

Setting the Cutlery

Because I live in my parents' house, I have to care for my mom during the day, all day, every day. Actually, I am the only caregiver during the daytime. Sometimes I'm tired, I'm stressed, and I feel saturated. I get upset because I don't know what to do. Sometimes I feel that I don't have patience, and I end up crying when I see her sad face for something that I think I didn't do well. Sometimes my father also is angry. He gets upset because he is also older and doesn't have much patience. I would like to and should spend more time with my own family: Roberto, my husband, and my children. But actually, I spend more time with my parents. My family supports me so much, but I feel that I have neglected them a lot. I can't attend to them as I would like. I can't go out with my husband on the weekends. I don't even have time for my personal issues or time to myself—I have to wait for one of my children to stay with mom so I can leave. My husband understands my situation and encourages me to continue caring my mom; he loves her so much, and she loves him too. We have been together almost 30 years. When we go to eat, my mother always wants us to set the cutlery for everyone. Then she asks for my children and

Haciendo y Deshaciendo

Ahora está mucho mejor, duerme mejor, come tranquila sus alimentos, pero a veces es muy inquieta, pues ella siempre fue una mujer activa, a veces quiere encender la cocina y cocinar, por eso debo tener mucho cuidado e ingeniarle mil maneras para mantenerla ocupada. Por ejemplo, hago que cuente cartas de 5 en 5 o que las separe por colores, las agrupa, si siente que se equivoca se corrige y vuelve a pensar, puede pasar toda la mañana en eso hasta que se aburre. Hemos destejido chompas de lana para que luego enrolle y desenrolle la lana, los combina por colores, la tenemos como Penélope,¹ haciendo y deshaciendo. Dobla muchas servilletas, siempre siguiendo un modelo que yo le hago. Usualmente me ayuda a cocinar, pela las verduras (papas, zanahorias, arvejas, etc.). Hacemos humitas (un postre típico a base de maíz), desgrana los choclos, cuenta las humitas, las selecciona para cada uno de sus hijos, nunca olvida que tiene 5 hijos y para cada uno separa una porción.

Gracias Mami, Gracias Mamá

Cuido de ella, la baño, la visto, la peino, le digo que está muy bonita, “estas guapa” le digo y eso le gusta, es muy vanidosa, quiere elegir el peinado que le hago. Es una persona muy agradecida, te dice gracias desde que despierta hasta que se duerme, por cada cosa que hagas con ella te agradece mucho y me dice mamá “gracias mami, gracias mamá” son las palabras más bonitas que puedo escuchar y son las que me animan a seguir y saber que no lo estoy haciendo tan mal.

¹ Penélope es la esposa de Odiseo en la mitología griega. Ella pasa el día tejiendo una mortaja de entierro para su suegro y luego la desteje por la noche para mantener a raya a sus pretendientes, diciéndoles que no volverá a casarse hasta que termine la mortaja.

my husband, waits for them, and wants us to be always by her side. This is a nice detail on her part.

Doing and Undoing

Now, she is much better, sleeps better, and eats her food very well, but sometimes she is very impatient because she was always a very active woman. She wants to go in the kitchen and cook, so I need to be very careful, and I have to be very ingenious to create many ways to maintain her busy. For example, I make her count cards, 5×5, she divides them by colors and groups them. If she feels that she made a mistake, she corrects herself and starts again. She can spend all morning doing that until she gets bored. We knit woolen wool sweaters, and she rolls and unrolls the wool, combines it by colors, and is almost like Penelope,¹ doing and undoing. She folds a lot of napkins always following a model that I do. Usually, she helps me to cook, peel the vegetables (potatoes, carrots, peas, etc.). When we make *humitas*—a typical corn dessert—she shells the corn, counts the *humitas*, and selects some of them for each of her children. She never forgets that she has five children, and each of gets one portion.

Thank You, Mom; Thank You, Mom

I take care of her, I shower her, I dress up her, I comb her hair, I tell her that she is beautiful, “*Estas guapa*” I say to her. She likes that; she is very vain. She wants to choose the hairstyle that I do. She is a very grateful person; she thanks me from waking up until

¹ Penelope is Odysseus' wife in Greek mythology. She spends her day weaving a burial shroud for her father-in-law and then unweaves it at night to keep her suitors at bay, telling them she won't remarry until the shroud is finished.

A Quien en su Momento te Dio Todo

Hay muchas cosas que he aprendido sola, aquí no contamos con ningún apoyo, no existen instituciones gubernamentales ni privadas que nos orienten en cómo hacer esta labor de cuidar un paciente con demencia, no hay lugares ni grupos con quien compartir nuestras dudas, quejas y preocupaciones. Uno no está preparado para afrontar esta situación, muchas veces no sabemos qué hacer con ellos, a veces no sé si lo que estoy haciendo es correcto o no, sólo hago lo mejor que puedo.

Ella es mi mamá, yo la voy apoyar siempre, hasta el último momento de su vida, hasta donde yo pueda, hasta cuando Dios me dé salud voy a estar con ella y con mi papá. Hemos pasado muchas cosas juntos, hemos llorado, hemos reído. Como hijos, tenemos que tener fuerza de voluntad, paciencia, darnos tiempo para ellos. Cuesta mucho trabajo pero no hay mejor regalo que ver a tus padres y tener la satisfacción de que haces lo mejor por ellos, finalmente son nuestros padres, siempre estuvieron con nosotros desde niños. A veces ellos están en silencio, no dicen nada pero me pregunto, ¿Qué sienten?, ¿Qué piensan?, ¿Me pregunto si no se sienten solos o abandonados?, ¿Quizá en un momento de soledad, lloran?, quizá sufren y se preguntan ¿Dónde están mis hijos? ¿Por qué no están a mi lado ahora que los necesito? ¿Por qué cuando estaba sano venían y estaban a mi lado y ahora que los necesito, ya no están aquí? Quizá no lo dicen pero creo que lo piensan y lo sienten. Yo estoy muy agradecida, por estar con ellos. Pienso que me voy a quedar tranquila conmigo misma porque estoy haciendo lo que puedo, aunque me gustaría hacer más. Hay que seguir para adelante, hay que tener la satisfacción de que diste todo de ti a quien en su momento te dio todo de ella.

going bed. She says thank you for everything that you do for her, and sometimes she says to me, “Thank you, Mom; thank you, Mom” (“Gracias mami, gracias mamá”). Those are the most beautiful words that I can hear, and they encourage me to continue and know that I am not doing so badly.

To the One Who Gave You Everything

There are many things that I had learned alone. Here we don't have any support. There aren't governmental or private institutions to guide us on how to care for patients suffering from dementia. There are no places or groups to share our doubts, complaints, and concerns. We are not prepared to face this situation, and many times we don't know what we have to do with the people we care for. Sometimes I don't know if what I'm doing is right or not, I just do what I can do.

She is my mother, and I will support her always, until the last moment of her life, as far as I can, until when God heals me, I will be with her and my father. We have lived many things together, we have cried, we have laughed. As children, we have to have willpower, patience, and take our time with them. It is a lot of work, but there is no better gift than caring for your parents and having the satisfaction that you are doing the best for them. They are our parents, since birth they were always with us. Sometimes they are silent, they say nothing, but I ask myself, “What do they think? What do they feel? Do they feel alone or abandoned? Maybe in a lonely moment do they cry? Maybe they are suffering and asking themselves, ‘Where are my children? Why aren't they around me now when I need them? When I was healthy, they were coming and were with me, and now I need them, why aren't they here?’” Maybe they don't say anything, but they feel that. I'm

HEAR/SAY

very grateful because I'm with them. I think that I am at peace with myself because I'm doing all that I can do, even though I would like to do more. You have to keep going, you have to have the satisfaction that you gave everything from yourself to the one who gave you everything from her.



We Just Kind of Went With It

NARRATED BY ROBIN KETELLE

**INTERVIEWED BY
CAROLINE PRIOLEAU,
UCSF MEMORY AND AGING
CENTER & GBHI**

Robin Ketelle is a nurse at the University of California, San Francisco Memory and Aging Center. She has spent her career in geriatrics, psychiatry and neurology and brings a wealth of knowledge and experience to her practice. She is retiring this year and shares her thoughts on what drew her to work in the field of aging.

Being a dementia care nurse is, I think, a little bit of an accident of my upbringing. My mother was a nurse. I watched her polish her white shoes and iron her starched cap. So, it was a part of my life without much consciousness. And I didn't really, to be honest, know what it was that she did. But on her days off (I don't think she ever really had a day off—I think this was her nature), one of her "jobs" was to visit the elderly who couldn't come to church. They were called "the sick and shut in." So, on Sundays after church, we would collect the altar flowers, and—I was the youngest in my family, so I had little say in what I was going to do—I was taken along on these trips to the sick and shut in.

Even as a young kid, it didn't bother me. I wasn't scared. I actually enjoyed it. My mother did a lot to smooth the interactions over with her social graces. She had a mission to deliver those flowers and visit the sick and shut in. And so that's what we did! And she taught me. I was very young, but I would sit on the couch, and she'd visit with people. They'd visit with her, and they'd talk to me. It took some of the scariness away from illness for me.

And then she would also take flowers to people who were living in long-term care. They lived in the "rest home," as we would call it or the "nursing home." And so, you know, I was indoctrinated

into being my mom's sidekick on these visits. It was never scary. It was fascinating.

I loved being in other people's houses, and around the same time as that, I was captivated with animal behavior. I was drawn to Africa and African animals. So, I did a lot of reading about these places and animals: the *Born Free* books, and then Jane Goodall when I was a little older, and Dian Fossey. It interested me that there were people who were observing behaviors. And as a family, we were all complete people-watchers. So, if we would go anywhere, being kind of introverted, we'd finish talking to each other, and then we'd watch people. That was a recreational activity we had.

When I was in nursing school, I had a rotation through the psychiatric service, and I developed a great affection for the professor. I thought she was fantastic. Something about her really registered. She was brilliant. She was young and glamorous. She knew a lot about psychology, which I was interested in, and human behavior. All those things combined, and here I was on a geriatric psychiatry unit. And I thought, "This is everything I could ever want!" I felt comfortable in the environment. I could literally sit on a couch and talk to someone and learn their life story or understand what their suffering was about that particular day. It all came together for me in that unit. And I received a lot of positive feedback on how I was doing. It combined much that was fascinating to me: science, the brain, human and animal behavior, old people, psychiatrically ill people. I've talked to other nurses who would say, "I don't know how you could do that. I could never do that. I hated my psych rotation". And then I'd say, "I don't know how you can be an operating room nurse." The OR freaked me out. It was frightening and foreign to me.

Listening for Something Else

Being a nurse wasn't so much about what I did in terms of tasks. It was about who I was, what I could bring to it, the structure and the theory of nursing, the history of nursing, and the parts of nursing that have to do with being somebody who can change things. That's what it meant to me. Part of it was the notion that I had a place at this table. I was an equal member of the team. I could pull up and say what I know about that patient or situation, and I don't have to apologize for it. I belong.

People call nursing the "caring" profession. The longer I have worked, I find this more and more curious. Every single person who works at the UCSF Memory and Aging Center (MAC), and almost every person I've ever worked with, whether they were a nurse or not—cares about the patients. It's not like nurses have exclusive real estate with caring; it's not care versus cure. That you do one or the other. People will say: "Nurses are the care experts." I don't run across very many people in this business who don't care for the patients. What nurses bring is a unique perspective of a lived experience of illness. We're thinking about what happened before. What's happening now. What's going to happen next. Probably in a different way than a physician is. We're thinking about it from the standpoint of day-to-day life. Nurses traditionally spend a lot of time with patients because the care they have to render is personal and intimate much of the time. Just the time they spend doing that, it might be teaching, listening or performing a task like changing an IV bag. Nurses are spending all this time with those patients, and so they have a unique opportunity to gather a completely different set of observations—a nursing assessment.

I think people find it a lot easier to talk to the nurses. Partly because we aren't as much in a power position and partly because our job is to listen for things. We're listening for something else:

for tone and mood, descriptions of what they are going through and how it's really affecting them. How it's affecting their family. What suggestions do we have for comfort or quality of life, and ideas for managing life with an illness? Here at the Memory and Aging Center, we focus a lot on behavior and practical approaches to what's going on in real life. Every day. How is it to live with this? That's my practice now. A hospital nurse does something very different from what I'm doing. But there are a lot of similarities too. There is always going to be that interface, that extremely close interface with patients, and with others on the health care team. In order to care we have to understand physiology, anatomy, chemistry and lab values and try to put all the pieces together. And then talk to patients and families about that in a way that makes sense. At the Memory and Aging Center, we've had the great luxury to be free to do a form of nursing that directly benefits our patients and families in practical ways.

There's Always Hope for Something

I've been able to see difficult or challenging patients as the reason I'm here. At the Memory and Aging Center and all my other jobs, people aren't coming to you for help because things are going great. I am sure there are other jobs where that's true, but it's never been built into the deal for me. The suffering is visible and palpable and that doesn't turn me away. I don't have to go fix it, but I say, "Well, that's why they're here. That's why I'm here. That's why I decided to do this." I do think that it takes a toll. As we practice and get better at it, and you're around people who are good at it, we learn how to handle the pain of these situations. Another truth for me is that I know I am not doing this alone. There are times as a nurse when you've got to figure it out quickly and

make a decision and it's important to do that. But I've always felt that I had people. I had a team. I had people backing me up. I had people I could talk to about it. I feel really fortunate that I've been able to have that in my career. I also seek that out. I've been lucky, and also intentional, in seeking out jobs where collegiality is valued, and teams are integrated. I try not to end up too isolated – either at home or at work. I'm not a hugely extroverted person, but I also know I need my people. And so, I find my people wherever I work. That's been crucial to me.

Whether or not you take it all on, people bring their problems to us. How do I meet that challenge with integrity and honesty and maintain balance and teach others to do that? Some patients have trouble with boundaries, especially if frontotemporal dementia (FTD) is the diagnosis. So, then it's back to my fundamental interest: "Wow! This is interesting." And I know it's easy for me to say, and it's not "interesting" if you have to live with the disease 24/7. If it was me and the tables were turned, and I was coming to somebody for help, I would rather have somebody be curious about my loved one or family member. I would not want a provider to be shut off or have a rigid idea about behaviors, or, especially, to be judging of my family or me.

So that's the approach I try to take. Sometimes the inclination is to try to control difficult behavior. Family members have to do this – and safety is paramount, but a lot of the time that isn't the issue. It's that the behavior is embarrassing or uncomfortable. We don't want to encourage behaviors, but we do want to observe. Even if some of the behaviors are disgusting, off-putting or scary. We want to keep an open mind about what people are doing and examine the behaviors with curiosity. I can be helpful because of my distance from the situation. This can be therapeutic. I didn't know them before they had this illness in their lives. I want to acknowledge the importance of that. I realize that people have

changed so much, and there's no way that I can know how that feels and how much people have lost. I still try to bring dignity to their experience. This element of nursing care is vital—that you can be with people in some of the worst situations in their lives. Where you think that all is lost, and there still can be some hope. There can still be dignity. We put a lot on the disease, “it's the disease” doing these awful things. The disease doesn't have much dignity. Much has been lost. But what can we do now? Maintain a level of quality of life. Good care. Honest care. Dignified care. It can be a lofty goal at times. There's always hope for something. Always something we can do.

People with dementia can be difficult, and that's why they're here. That's why they come to us, right? That's why I'm doing this work. Patients and families are hurting. I wish these things weren't happening. But since they are, I'm glad they come here.

Curious People

I love science. I respect the science of nursing. I'm attracted to the research environment. I enjoy being around people who are curious and who are comfortable talking about science. I feel at home in that environment. I'm comfortable asking questions. I mean, we all want to have answers, and I think we have answers for some things, but so many things we do not. I am attracted to people who are trying to figure it out.

I'm frustrated that we haven't gotten further. When I started as a nurse on the psychiatry unit, we were doing a clinical trial of trazodone, which is a drug that has been used as an antidepressant. It turned out not to be great as an antidepressant, but it's been around for almost 40 years now for treating sleep problems. I worked on the clinical trials of Aricept 27 years ago. We

only have one or at most two drugs for Alzheimer's disease on the market, and it's been 27 years. So, I feel a little disappointed in the field. That we haven't come up with more. However, this job has inspired me. The people I work with. The patients. The families. If I'm going to believe anybody, I will believe the people who work here at the MAC. Absolutely. Because I know how much they want it. It's not for lack of wanting it to happen or working hard or going after it. It's just such a tough problem, and nobody can solve it with a simple answer. Maybe we can find a treatment that pushes the disease down the road a little bit. Buys some time until a better medication comes along.

Not in Isolation

Getting that first job at UCLA on the geriatric psych unit was, at the time, so exciting. Different things have happened with geriatrics over the years, but at that time it felt like a new frontier, and geriatrics was a specialty that excited people. In the unit where I worked, there was a different way of looking at psychiatric illness. It was a very hopeful place. It was a place where, rather than control or keep people away from other people, we were trying to help them with their social situation and their everyday life skills, and we were trying to change the course of their disease. I caught a bug there. I really did. Helping people reframe illness. Take the shame out of it. Psychiatric illness is hugely stigmatized, even more than dementia. We had several people on that unit who were concentration camp survivors. They had numbers tattooed on their arms. They lost multiple family members, and that was a profound experience to be that close to a historical event. Yes, I knew about it, but to actually see that, the consequence of that, that was very, I don't know if I should

say, political. But it was a way that I realized that what I was doing wasn't just in isolation, and it wasn't a job. That everything that we do either as an individual or a society is going to have repercussions down the road. So that job put me on a track to study and find jobs where I could be directly involved with a patient, face to face preferably, one patient at a time. Exploring their story. Trying to understand the changes that happen in people's brains and in their behavior.

Looking back, we probably had people on the psych unit who had frontotemporal dementia, and they were being treated for some sort of psychiatric illness. There were some very behaviorally impaired people. When I started, Alzheimer's disease was called "senile dementia of the Alzheimer's type" or a few years before that it was "organic brain syndrome." Every dementia was thought to be related to Alzheimer's in some way. On the psych unit, patients with dementia had more behavioral symptoms than was thought to be typical. We needed names for what these syndromes were. We had names for bipolar disorder, schizophrenia, depression, mixed forms. But dementia was dementia. Neurologists never came over to see the dementia patients in that unit. At the MAC, Bruce Miller has blended psychiatry and neurology. My training and my experience had been psychiatry and geriatrics. It makes sense I would end up here. After all, it's the brain and behavior.

Curiosity and Attraction

Another curiosity I have is dementia-friendly communities. I live in a community where it would be possible to work on that notion. It would be a very manageable project. Start by teaching school kids about the brain, and then focus on how to build community that's sensitive to differences in behavior and instill a curious

approach. Draw kids in middle school or high school towards brain and behavior, neuroscience and neurology to figure this stuff out. Encourage lifelong attraction and curiosity. I'm not advocating walking up to strangers and trying to figure out why they're doing what they're doing, but no matter where you go, you're going to see behavior. So, observe it. Rather than react to it. Ultimately, it makes us better people. It makes our society a better place to live. Probably makes us a little more helpful to each other. I hope. Working here, having heard all these stories and seeing a lot of people struggle, has made me infinitely more sensitive to that. And that's why I'm grateful that I've been able to work in a place where curiosity and attraction is not just our prerogative, it's our imperative. The MAC couldn't function without an attitude of openness and inclusivity.

It's funny because when I first started working at UCSF back in the late 1980s, I did a ton of home visits. Doing the visits was part of the program I worked for at the time: the goal was to assess people with dementia at home. I went all over San Francisco, and different parts of the Bay Area, and I went into people's homes, and I remember thinking, "This is so cool! It's just like visiting the sick and the shut in!" My mother was my career counselor. She got me started at the age of 7, and we just kind of went with it.

WE JUST KIND OF WENT WITH IT



Photograph by Alex Kornhuber, Atlantic Fellow

The Gelatin Silver is Locked in Space and Time

**NARRATED BY
STEPHEN SOMERSTEIN**

**INTERVIEWED BY
ALEX KORNHUBER,
ATLANTIC FELLOW**

*Stephen Somerstein is a documentary photographer who has captured many iconic moments in contemporary American history. Among his work is the photographic book, *Marching to Freedom: Selma 1965*. Stephen is very curious, moving, searching for the best frame to make the strongest image. He's persistent. Stephen has a lot of energy, always looking and learning.*

It's hard to really say whether photography is getting easier. It's that I'm a better photographer, a sharper photographer, and a more aware photographer. But...As I've approached my 70s, I find that I'm not as agile a photographer. Quite often I cannot complete a photograph that I want to complete, simply because I can't either get there as quickly or, there are hurdles which in my younger days, I might have found a lot easier and more casual about doing. So...there are these two competing forces in my life. I can look at my photographs with a sharper or more clear eye, and I can compose them better. But do I have the energy and the will to accomplish all that? That's always the question I'm asking myself.

I look at the work that I did 50 years ago, and some of it's very, very good, and sometimes I would like to relive it and do it over again, from a slightly different angle, or whatever. Especially my days in Greenwich Village when I used to go into the clubs, meet in the cafés and photograph at night. I could do a better job now than I could have done then. But unfortunately, 50, 60 years have gone by, and I have to live with the work that I did then. It's not bad. But I guess we all criticize ourselves and try to improve ourselves all the time. I think it's a continuing process.

I never think I'm static, that I've achieved a level of competence and that's good enough. I'm never good enough. There's only some

step that I haven't taken yet. I could make that shot a little bit better or light it differently, compose it differently. I'm always criticizing myself. I have to figure out how to be fresh, and the only way to be fresh is to be critical of yourself. No matter what people may say about your work. You have to look to your inner voice and see what it's saying. I hope for me it's saying, "Not good enough. You can do better." I hope that my work that I'm doing now is better than it was 10 years or 20 years ago, but the opportunities are different all the time. I can never walk in the same footsteps that I walked in. I'll never walk behind Dr. King again and photograph him from a different angle. Whatever work I did is what it is. The gelatin silver is locked in space and time, so I have to find new subjects, new challenges and new opportunities.



You Never Know What's Going to Happen Next

NARRATED BY CAROL KAMENY

**INTERVIEWED BY JACK TAYLOR,
UC SAN FRANCISCO**

Carol Kameny is a resident of San Francisco, living with her husband, Paul Kameny. Twelve years ago, she received a diagnosis of Alzheimer's disease, but in spite of this, she continues to live life as a social and active individual. Carol is currently a daily participant in the Irene Swindell's Social Day Group for adults with dementia and related cognitive impairments. She was happy to partake in our interview and reflect on her life in both the past and present. The following excerpts reveal a few of the cognitive obstacles against which she contends. However, they also demonstrate her remarkable ability to adapt to those challenges and maintain her comforting and warm personality.

JACK: Well look at that. Here we are, and it's recording.

CAROL: Oh! *[raising her eyebrows]*

So, would you like to say your name?

I'm Carol Kameny.

And what's cool about you?

I'm a teacher. Taught elementary school most of the time.

That's very cool. My mom was a teacher for high school students.

Was she? Oh.

Yeah, she was actually my biology teacher.

Oh really? That's — *[starts chuckling]*

It was kind of fun —

—That's how you came to be!

Yes ex — [wheezing] — exactly.

[Alison, day center director, chimes in from the background, "HAHA! Biology baby!"]

Yes, somebody understands biology here.

Don't worry about it. I won't say anything. *[more laughter]*

Okay! So, you taught elementary school. In San Francisco?

Mmm. The district. Very nice.

And that was your whole career?

Yeah. Changed a few grades but yes, it was.

Do you have any fun stories from that time?

Mmm.... No, *[with bright eyes]* I can't remember. *[chuckles with a shrug]*

Yeah, that's okay. Well how about nowadays? What do you like to do on the day-to-day?

[pausing] Umm, let's see. I like being with children.

Oh, yeah. Why do you like being with children?

Because I was with them all my life. *[giggles]*

Yeah, that makes sense.

I mean not only my own children, but others before I had my own.

How many did you —

Two!

Two of them? That's a lot of fun. Do they still come visit?

Yes. Or well...

Here and there?

Sort of.

Yeah. That's typical family. People get busy.

Yes *[in a tone of agreement]*. Yeah *[chuckling]*. Right.

Carol, may I ask you some questions about your memory?

Sure!

Do you know if you have a specific diagnosis or anything like that?

If I have a specific what?

A diagnosis. Like have you seen a doctor and they said, you know, "You have this [insert-answer-here hands]."

No? Let's see. It's been a long time. What are you asking for?

I guess I would like to know something about your experience having memory issues. Sometimes it's hard for someone like me to imagine because I don't go through that on my day-to-day. So, what's your experience like?

Well, I always worked with children. And so I learned a lot from the kids, and that was fun. I like learning from kids. Hmm trying to think what else. Well, when I stayed home, I liked that too.

Yeah, that's awesome. So you're very much enjoying your days still?

Oh yeah!

Yeah, and Paul *[Carol's husband]* told me that you two still get along very well together.

Yes. We do. He tells me what he does, and I tell him what I do *[smiling with laughter]*.

Do you have a favorite thing that you like to do here at the center?

I haven't been here very long. Have I?

Umm...[knowing the answer is several years] Not that long?

Not that long? *[nodding in agreement]*

Yeah, not that long. Long enough for people to know your face though because, you know, people like hanging out with you, from what I hear.

Well, I like people. I like knowing what they do, and if they want to know what I do, they can ask, and I tell 'em!

As our conversation continued, Carol told me about her upbringing in Milwaukee, Wisconsin, where she met her husband Paul. She talked to me about her move out to California, which was inspired by her love of travel. I began telling her about my trip to Taiwan.

Have you heard of the Chinese Lantern Festival, where they let go of the lanterns, and they all float up? You ever heard of something like that?

Sounds like it'd be interesting. No, I never have.

It's at the end of their New Year's festival. They all make these big paper lanterns, and then they put a candle at the bottom. That heats the air inside the lantern, and then they float.

Oh, what fun!

Like a hot air balloon. And so there's, like, hundreds of people, and they all have their lanterns, and everyone lets them go at the same time, and you see a big cloud of lanterns flying out.

[smiling] I bet that's wonderful. That's great. I'm going to remember that.

Yeah.

I may call you first and say uh...*[laughing]*.

***[impersonating Carol]* “Hey Jack, tell me again about that lantern festival!”**

Yes! *[laughing]* Something like that. Yes.

Well, let’s see, what else can I ask you?

Well, I was a teacher, so I used to teach people.

Oh, okay. You taught—

Elementary.

Elementary? Which grades did you teach?

The lower ones.

Lower. Like one, two, and three?

Yeah, and they’re fun!

So much energy! Kids at that stage.

Yes, you never know what’s going to happen next. *[smiling]*

Carol, it’s been a wonderful interview.

Well thank you for asking me questions. I’m glad to answer them for you.

YOU NEVER KNOW WHAT'S GOING TO HAPPEN NEXT



The Last One to Figure It Out

NARRATED BY PAUL KAMENY

**INTERVIEWED BY JACK TAYLOR,
UC SAN FRANCISCO**

Paul Kameny lives in San Francisco with his wife Carol. In this interview, Paul describes his experience as the primary caregiver for Carol, who copes with a slowly progressing form of dementia. Paul also discusses some of the ways in which his life with Carol has continued to bring them fulfillment and happiness.

I was the last one to figure it out. We [Paul, Carol, and friends] would be in Panama, and Carol would get lost occasionally. I was with some close friends, and they'd say, "We think she's got Alzheimer's disease," and I'd say, "Naaw, she's just getting old, that's all." I didn't think about it much. Yeah, I was the last one to figure it out. The husband's always the last person—I think that's an overgeneralization, but you know.... So they finally convinced me I should take her to a doctor and have her tested. We did, and she had Alzheimer's disease.

I was so depressed about everything, you know, and so sad for Carol. When I first really realized that she had Alzheimer's disease, I broke down and started crying. It had finally hit me. But that's the big cry. I believe that there's always that big cry. You just let it out—all the stress, everything—and after that, you don't cry. Although from then on, every time I went to a sentimental movie, I cried a little. Little tears would drop out. *[Paul laughing, then acting as if had just told a big secret.]* But don't tell 'em! I'm a macho man. *[More smiles and laughter.]*

She's had it for about twelve years now, and my sage advice is: hang in there and don't spend a lot of money on people. I mean, it could be sometimes seven thousand per month. I was already taking care of her and things like that, but then I started hiring students from the local college. They loved it because they learned

how to take care of Carol. Students are so reasonable, and they're so loving...they hate their parents, but they love old people [*chuckling*]. Eventually, I graduated to a woman who was still in her twenties but had a lot of experience working in caregiving. She made it professional, kept records, giving five hours per day, and in exchange, we were fortunate to be able to provide her with room and board. In total we spent \$20,000 per year, which is really cheap. The students and caregivers won't say it, but I know they do so much more. So every so often I give a little extra money. After all, I think if they go all day with Carol, they'd deserve something more, maybe an extra...dollar fifty [*laughing*]. No no...I give more.

Carol and I have had a really nice relationship. We still go to symphonies, operas, and especially plays—I used to produce shows. Some of them she'd really understand, and others she wouldn't. The point is that we still spend the day together doing something we both can enjoy. She's not always very responsive anymore, but oddly enough, her attitude is, "So I don't remember, so what?" She lives for the day and stays attentive in the moment. She'll sometimes pop in with something spot on, even when you think she wasn't listening. One time at the Institute on Aging, a bunch of people were interrupting the main speaker, and she got up like an old school teacher and said, "You be quiet! We're trying to hear!" [*laughing in reverie*]. In some senses, she's doing very well.

On the other hand, her empathy is mostly gone. For example, she's not sympathetic if I say I've got a headache. "Big deal," I imagine her saying, "I've got a memory problem." Then, I think of all the things that she's been empathizing with me over, putting up with me for all these thirty-seven years. I shouldn't worry because if she doesn't worry about not remembering, then I won't remember her not having been as empathetic as she could be. I do think about what lies ahead though, and I must sound pretty cruel, but if

she doesn't know who I am anymore, I'm going to institutionalize her..., but I probably won't. I owe her so much. I love her so much. She still likes to hold my hand as she sleeps. How do you like that, huh? That hasn't changed.

THE LAST ONE TO FIGURE IT OUT



Instant Joy

**NARRATED BY JOYCE CALVERT,
JANE DAHLGREN, CAILIN LECHNER,
AND MADHU MANIVANNAN**

**INTERVIEWED BY PHAEDRA BELL,
ATLANTIC FELLOW**

The following represents a conversation with Jane, a woman living with mid-stage Alzheimer's disease, her wife and care partner, Joyce, and two younger people, Madhu and Cailin. Jane, Joyce, Madhu, and Cailin were participating in a prototype for an adaptation of the Multimodal Intergenerational Social Contact Intervention for Creative Engagement (MISCI-CE). This adaptation involves matching two younger people with a person living with dementia and his/her/their care partner to meet two times per month over three months to enjoy creative activities at the home of the older couple.

JOYCE: Franky and Grace. Franky is bigger, and softer, and furrier, and has blue eyes. And we got them through the SPCA because they were—there was that fire. Remember that fire? And they burned their feet, right? Yeah.

CAILIN: *[smiling]* You adopted us too. You don't remember, Jane?

JOYCE: *[joking]* You signed the papers and everything. Wait, what did we do? No, no. We met with Cailin and Madhu like twice a month for three months. And we did stuff. Mostly at the kitchen table, really. Except for hanging out on the patio one time. And then we had a meal another time. We didn't do a whole lot but eat.

CAILIN: Yeah, so I brought a bunch of my old *New Yorker* magazines that were collecting dust, frankly. But then Jane, you had a bunch of supplies from your career as an art teacher—and also as an artist.

JOYCE: And I would tear up pieces of news, yeah. I have it still on my desk. Made a collage.

CAILIN: So, I guess some of the materials were like formal art supplies. Like we had clay and paints. But a lot of the materials were also just found objects that Jane collected for I don't know how long.

JOYCE: She collects found objects. Often.

JANE: Yeah, all the time.

JOYCE: We try to keep a Zip-lock bag with us.

JANE: Oh, that's right. You still have it?

JOYCE: I haven't had one with me for a while. She was picking up cigarette butts. So, I always had a Zip-lock bag with me for that. And you made like a poster and you glued all the cigarette butts in the shape of lungs.

JANE: I remember that. Because when I'd walk down the street, there's butts everywhere. And they're in the street. And I saw mostly men in the street, and they were homeless. And they were just smoking cigarettes and lying in the gutters. And especially, it really hurt me that he—they were just in the gutter, drinking. I mean, well they were drinking, too. But mostly smoking. And, you know, and I just thought, they have no life doing that. And what can you do to help?

JOYCE: So, you made a protest piece, maybe, or a kind of a statement piece about how dangerous it is to smoke for your lungs.

A Very Natural Friendship

I asked Cailin and Madhu how they got involved in this prototype.

CAILIN: I work at the Memory and Aging Center. However, I'm sort of the black sheep of our lab because I don't really work with patients who have neurodegenerative diseases, I work with movement and mood disorders. But up until recently, I didn't get much interaction one-on-one with patients. And I felt like I was sort of missing that component. And so, that's how I initially became involved with MISCI. I had such a great experience in the first round of the program that when they reached out and asked for some volunteers to do this pilot with care partners, I thought it would be a great opportunity. And I really enjoyed the experience.

MADHU: I also work in the Memory and Aging Center. I did the MISCI program last session, and I loved that and enjoyed it so much. And I actually wasn't initially thinking of signing up for MISCI for the spring. I just felt like I might be too busy, and I wasn't exactly sure what my schedule was going to be like. Cailin had already told me about Jane and Joyce and how great they were from the first meeting though, so it just seemed natural. I just definitely wanted to be a part of it. And it's just been really rewarding getting to form relationships with people and having a structure where it's safe to meet people and that kind of encourages these kinds of friendships and relationships. So I'm very, very grateful to be part of this.

I really like just being able to come here, and we always kind of start with coffee or tea. And we just start with how our weeks went. The conversation has been really easy and flows really easily. Usually, we would get all our arts and crafts out

on the table and just each be working on different things. And it was just like this really fun ritual that we had on Sunday afternoons. The cats would come around, and I would freak out because they're so cute. And we'd just eat some stuff and talk about literally everything. Anything and everything and just also get to work on creative projects together, too. It's just a really fun time getting to know both of you, Jane and Joyce, and you, Cailin, more.

CAILIN: I think the conversations were the most rewarding aspect of just our six meetings that we had. I really liked that we had this premise of coming to the kitchen table and working on art. But the thing that really mattered more was just us getting to know each other. And the art project just seemed more of a method to facilitate that conversation. But it really has felt like a very natural friendship. Nothing really all that forced. Nothing really like a homework assignment, or something like that.

JOYCE: But of course, I wanted it to be a homework assignment at the beginning. "Okay, you guys are in charge, tell me what to do."

CAILIN: Structure is nice, I mean I like that we came and like you said, Joyce, like having a reason to complete the slate project that you've been thinking about doing for a long time. And this was sort of a designated time to actually work on that. So, I enjoy making collages. But I feel like often, I pressure myself to have some sort of reason behind what I'm making. And so, it's kind of nice to just come with no expectations. And no criteria that you're trying to meet. We just sat around here and made for the sake of making things.

That was the best part. I'm proud of the fact that I made some sort of strange sculpture that you've got sitting back there. I'm proud—I feel like a kid who's got their homework assignment like on the fridge or something. But the things that I enjoyed the most were just getting to talk to you all.

JOYCE: It was neat too for me, like when you talked about that club. And some other stuff like, your friends are coming into town, you're doing this, you're doing that. And so, it was kind of this other perspective of another life that's different than ours. And that was nice to just be here and hear about it. Learn about it. Listen. You know? Because I did a lot of talking. So, I had to stop and listen. And the times that I did really mattered. So, I felt connected.

JANE: I was just going to say that the two things that I like to get together to do are some art and—I like people. And I like to ask things about you. You know, I can know somebody better because I just like people.

CAILIN: I think towards the end, we sort of finally figured out that what works for us is coming here, having tea, and congregating at the table, and then just working on some projects and having a conversation. I think in the beginning, we were kind of trying to figure out like, oh, should we like have a more formal ritual to open? Should we have a closing ritual? Should we plan on what medium we should use for the next time? We were just getting to know each other. So, just figuring out what structure worked best for the meetings, and it ended up being a very loose format that worked best.

JOYCE: That freaked me out. *[Group laughs]* That's just me, though. That's just me. That's my—not really OCD but that, you know, structure makes me feel safe. Finally, after like the second

meeting or so, I went, well, throw it, you know, to the wind. It's okay. Whatever we do is going to be great with me. That's when I got my rocks out, and I got some other stuff. Like okay, I'm doing my thing rather than trying to expect some structure or whatever. So, I was comfortable towards the end without any structure, or plan. But then like I discussed with you, I looked over the suggestion sheet after our last meeting. It had some really good ideas that we kind of almost did naturally. You know, not really a ritual thing. But, yeah, the art and getting together, communing. You know, I benefited greatly.

One thing, too, Jane—just to try to be honest with yourself. Can you remember making art by yourself or with others? Can you remember some of those times when you've done art. How long did you take, and did you just do it by yourself? I don't think anybody worked with you on it?

JANE: I think that I did by my—I just got into it.

JOYCE: I like to tell the story of sometimes I would find Jane out in her studio cradling one of these sculptures when it's half done and with like a rasp¹ in her hand, and maybe a chisel. She's kind of fallen asleep with this creature that she's developing. So, it's a lot of solo stuff, a lot of jewelry. Firing, and pounding, and drilling and.... So, yeah, she's solo. I think she kept a lot of her process to herself. You may have shared more of that with your other artist friends that you've had. But my observation is that Jane is a technician. She's a true technician. And she could draw a straight line just out of the middle of nowhere. And it would be perfect—take a straightedge to it after she'd draw it. So, I know her technical art—and then the

¹ A rasp is a tool used in wood work, a type of file used to shape the wood by hand.

creativity, I think, flowed from it. Not the other way around as some snooty artists like to believe. “It was my creativity; it just came out of me.” And to be perfectly frank, there’s been critique of Jane’s art that I haven’t agreed with because it came from that place of—“there’s no creativity, it’s just all technical.” But the technician in you always had this creative place that came out. Like how could you not say that that doesn’t have a creative—the sculpture right there of the Asian woman? I mean, even the look in her eye tells you that there was a lot more behind that than just the technical.... Yeah, see stuff like that? The carvings, you know, and the crucifixes.

JANE: The woman.

JOYCE: But if you take the little one on the left and turn him over, he has a full, detailed spinal column all the way down. Really detailed.

JANE: Yeah, that one was hard for me, to...

JOYCE: Is it out of cottonwood? Both of them.

JANE: Not that. In the head...feeling bad about someone.

JOYCE: The emotion? So, some of your pieces I would say a lot of your process is about...it’s either a political statement or an emotional statement. So, this series is about children that are trafficked. There were three more. And it was a series of *New York Times* articles that she grabbed a hold of and decided to do a series. And that one won best of show in Corrales the first couple years we were there in 2004, or 2006, or 2008, or something. It’s called *Waiting for Redemption*.

JANE: Yeah, that was kind of hard to do that. Emotional.

JOYCE: I know, and the last one you did was, I don't know, the last one she did was of Polly Class.

JANE: What?

JOYCE: Polly Klaas.² And yeah, she couldn't finish it. She didn't finish it. It was too hard. Yeah, so that's her process. If that helps explain it.

JANE: Even today it's hard to look at these because of what happened.

JOYCE: Wow, you want me to take them down?

JANE: What?

JOYCE: Do you want me to take them out of the living room? I'm serious.

JANE: Where are we going to put it? In the garage?

JOYCE: Well, it's about whether you want to look at them.

JANE: Sometimes it reminds me about what happened. And then sometimes I like to just look out there [*indicating the window*] and forget it.

She's not a Drunk Chick, She's a Teacher

I asked Jane and Joyce to share the story of how they met at the Gay Pride event in San Francisco almost twenty years ago.

² Polly Klaas was an American 12-year old murder victim whose case gained national attention in 1993.

JANE: Every once in a while I remember that again. Because we wouldn't have met. Yeah, if it hadn't been for that...what was that, a Women's...? It was the motorcycle contingent. So, the Women's Motorcycle Contingent. And I looked at that motorcycle and I thought, oh, I always wanted to get on a motorcycle.

JOYCE: I got lucky.

JANE: So did I. But then I took lessons and I went down a few thousand times.

JOYCE: You went down one time during the test. You locked up your front brake on the panic stop.

JANE: And I was panicked.

JOYCE: Tossed you right off that bike. And so, she flunked the test because you can pass it and they'll give you your license if you take the California Highway Patrol (CHP) classes. So, Jane took the CHP classes. And so, this was her test. She flunked it. And then she goes, "That's okay. All right, I'm okay." So, she had bought a little motorcycle. Little 650 Shadow. And so, we would take it down to AT&T Park, and she would ride around. I'd give the dog a walk, and she'd ride the motorcycle.

JANE: And down I go.

JOYCE: No, you never went down again. That was the only time.

JANE: You think so?

JOYCE: Yeah, I know so.

JANE: But I didn't run again. I mean I didn't...

JOYCE: Yeah, you didn't take the test again. But you rode your motorcycle. You rode it around.

JANE: A little bit.

JOYCE: Off road.

JANE: You know what...I decided...I had fun, but I don't really need to do this. So...

JOYCE: We sold it before we moved to New Mexico.

JANE: So, you know, I said it was fun, but I don't think this is my thing.

JOYCE: So, the story of how we met? Jane had a friend named Carrie. And Carrie was a road captain that year and so was I. But I didn't know Carrie. And when I arrived, Carrie walked up to me very excited, very passionate. "I have a friend, it's her birthday. She really wants to ride in the parade, but I can't take her on mine because I've already promised a ride to someone else. So, will you take her?"

And I said, "No. I won't take—" Because oftentimes people, you know, are tearing their shirts off, and they're drunk, and they're on the back of your motorcycle that way. So, I said, "No, I do not want a drunk chick on the back of my bike."

"No, no, no, no, no, she's not a drunk chick, she's a teacher, she's a schoolteacher." I went well, okay. And so, it was Jane. And we went out for coffee afterwards with Carrie. And then I gave her a ride home on my motorcycle, and she left the following day for New Mexico for the summer. So, we wrote letters and talked on the phone. And our first date was me flying out to Albuquerque for three days in 2001. Jane was living here in this house but spending summers there.

So, you knew you wanted to buy a little house out there when you retired from teaching. And I knew I was going to have to make a decision because I had a house in Rohnert Park and my daughter lives here. And she wasn't having children then. So, as soon as we moved, she got pregnant. Like...now I have to come back and forth. So, I don't think we let six months go by where we didn't fly back here. Or Portland, or them fly to us for the grandkids. And now they have three boys.

JANE: Boys, a hundred of them.

JOYCE: Feels like it sometimes, doesn't it? We were just there yesterday.

JANE: Six? I know, but are there six of them?

JOYCE: Three.

JANE: Three? Well it seemed like six.

The Positive Emotions Afterwards Just Became Stronger and Stronger

I asked all four of them if they felt any different after they held one of their creative engagement meetings.

JANE: I don't think that there was any difference because I'm who I am. And the thing of it is, is I like people. And I like doing art. And I like helping people. That's it. That's who I am.

JOYCE: Okay. So, it was all that, and it's at two o'clock. Are we going to make it? One time I texted Cailin, like, "You can come later if you want."

CAILIN: It ended up working out for us because I think we were at the Kamala Harris rally, so.... It was great.

JOYCE: Yeah, it just worked. So, and then after—like I said, once I let go of any structure, I’m always in a much better place. Really, very enjoyable. The girls came. We got a couple hours with the girls. I really felt great after you guys left.

CAILIN: I definitely did. I think in every single meeting, the positive emotions afterwards just became stronger and stronger. The last meeting especially because I was having a particularly bad weekend to the point where I was actually crying before. I was like, “I’ve got to like get it together because I’m going to hang out with Jane, and Joyce, and Madhu.” And I told her that I’m going to go, and we’re going to have a great time, and I’m just going to like forget all this dumb stuff that happened in the last couple days. And it absolutely like changed my entire day. I mean that was the day that we just hung out on the patio. We wore hats, took pictures.

MADHU: Wore all of Jane’s hats.

CAILIN: It was exactly what I needed.

JOYCE: All of your hats on the wall, yeah, all of them in different hats.

JANE: You can change them, you know?

CAILIN: Personalize, add some stickers. Some badges for impeaching Trump.

JOYCE: Yeah, “Impeach Trump” badges.

MADHU: Yeah, for me I felt the same way. I was always really looking forward to our meetings. And I guess...like, I live at

home right now with my mom and my stepdad. I go home to them, and they're like, "What did you do today?" And I just like telling them about you guys. They want to meet you both at some point. And yeah, just getting to talk to my friends about what we've been doing, and this relationship that we're building. So, I'm always just really happy and excited for the next meeting. And just getting to come to a place, and it's not performative. It's not contrived. It's very natural. That's really lucky to have that kind of interaction. Because it's hard—I think it can be hard for four people to like get along with personalities and everything. You know, we're all different. But it's still very easy and fun.

JANE: We didn't talk a whole lot like about culture and stuff like that. We just didn't. It's not that I wasn't curious. I just felt like it was fine without it. I know you live in San Mateo, and I know you're from San Diego.

JOYCE: San Mateo.... Yep. We were trying to make that trip to San Mateo and the high school where you taught, Jane. I did hear back from them. And it's not going to work. I was really kind of surprised by her response.

JANE: I just, I like to do just about anything. I like people, even this person. [*Indicating Joyce.*] Well, you know, when you live in a person's house, you don't always...

JOYCE: No one's had a mother they deserve. That's my mantra, being a mother myself—and knowing it. Yeah, no one's got the mother they deserve. We all deserve wonderful, loving mothers. Well, maybe some people have the mother they deserve. I don't know very many people who do.

JANE: My mother wasn't all that nice.

JOYCE: We're just hard judgers of mothers I think, as a society.

MADHU: I think I have a good mom. And you guys need to meet her.

CAILIN: Yeah, I've met her. She is a good mom.

JANE: So, my mother was a little what would we—oh, excuse me.
[looking out the window]

CAILIN: Bird, birds. Yeah.

JOYCE: Yeah, you keep track of the things that fly.

JANE: Yeah. I always wanted to fly.

MADHU: Yeah, same. I feel it. Sometimes I just want to jump
off a cliff and just soar.

JANE: Yeah.

MADHU: But I won't do that.

JANE: No, no. You know, you know you can't do that.

MADHU: I know I can't.

JANE: Well, you could. But you'd probably die.

JOYCE: There was a national park show on last night on KQED.
One of the gentlemen that was talking about...they were in
Arches, up in the four corners in Colorado, Arizona, what-
ever. He was sitting on the precipice on the edge of this
cliff and looking out over part of the Grand Canyon, Mesa
Verde, or something. And he said, "This makes me want to
fly. Like I wish I could fly." That's exactly what I thought about
when he said that. Jane's right there with him.

JANE: Mm-hmm.

JOYCE: Like those guys that wear the suits?

CAILIN: Yeah, that's exactly what I was going to say. We were there, and she said, "Would you ever wear one of those like flying squirrel suits?" And you said, "Absolutely."

JOYCE: Absolutely.

CAILIN: I'm afraid to do anything that's not tandem. I'd want an expert there.

MADHU: You get certified, you would feel confident, then you could do it.

JANE: Well, you know, even experts can go down.

JOYCE: That's a lot of training.

CAILIN: Yeah. But I'm sure their success rate is better than mine.

MADHU: Accidents...

JANE: But I've always had that feeling of—in fact, while we were talking about this, I saw the birds coming. And I thought, "Oh, I wish I could do that."

MADHU: It's like they're mocking us. "You can't do this."

JANE: Yes, yes.

JOYCE: I just thought I heard somebody meow, did you?

MADHU: Yeah.

MADHU: They are so cute.

JANE: And what would we do without them?

JOYCE: Oh, man. They're like instant joy. You know, you open the door and there's joy.

JOYCE: Yeah, they're really sweet. They trashed the house today catching a fly. A horse fly got in somehow.

MADHU: They caught it?

JOYCE: Yes. Franky did, actually. I'm surprised because she's kind of not the brightest bulb in the box. She'll hit a wall if she's sliding, she doesn't really know how to, and she crashes right into it. She does some really funky things. But yeah, they just ripped the house apart. Jane's art table was all over the floor and all of her colored pencils. And they went upstairs and just obliterated the bathroom up there. Ripped everything up by chasing it.

JANE: Well, they wanted to do some art.

MADHU: Yeah, we didn't let them do any art with us, so.

CAILIN: They were the subjects of our photography and affection.





Clowning Does Me Good

NARRATED BY YAYA

**INTERVIEWED BY
LENISA BRANDAO,
ATLANTIC FELLOW**

Yaya is 67 years old and lives with expressive aphasia and depression. For all her life, she has worked as a cook and in the last years, she has worked as a caregiver for a person living with dementia. She does not often see relatives. She lost her mother some years ago. Her story with us began after she survived two strokes. She immediately started individual speech therapy with our team in the university hospital. She came to our aphasia group in the university six months after that, presenting mild disfluency. A few months after starting in the group, while arriving for one of our meetings, she had a frightening episode. She thought she was having another stroke. I (Lenisa) accompanied her in the ambulance and stayed with her for four hours in the community health center. As it turned out, it was a false alarm and, fortunately, nothing had happened. In the next week, Yaya asked to start clowning. A few months after, she chose to be exclusively in the clowning group and has been clowning ever since.

Yaya's Words about Clowning

I like when we are clowning, that is when I like to talk and see all people talking.... Before clowning, I did not go anywhere; I just left home and went to work. Since I lost my mother, I've never been doing anything else.... Clowning does me good. When our clowning day of the week comes, at six o'clock in the morning I am already up. Because I know I will come clown, I am already thinking about the time I have to leave my work to come. Now at work I have fun and play with my boss [*a person with dementia that she takes care of*]. Every once in a while I play with him and say, "How about Yaya today?" He likes it, that does me good. Clowning changes me a lot. It makes me forget many things...many things.... I feel something else when I am a clown...as if I am someone else.... I made that number with the tarot reading, playing that I can guess things...it seems that we are actually living that, I feel that...it is...especially when we are in the theater. When I rehearse, I put on my clothes and make-up. I like that I feel something else. I do not know how to explain, but I feel more at ease...calmer, more comfortable, I feel at ease. When I was a kid, I acted in a theater presentation in school, and I never forgot that. Clowning brings me back to childhood.



Wait a Minute!

NARRATED BY LAURA MITIC

**INTERVIEWED BY
CAROLINE PRIOLEAU,
UCSF MEMORY AND AGING
CENTER & GBHI**

Laura Mitic is Chief Science Officer for The Bluefield Project to Cure Frontotemporal Dementia (FTD) and holds a doctorate in cell biology. The foundation is focused on finding therapeutics for FTD caused by mutations in the progranulin gene (GRN) that result in decreased production of the protein progranulin. In the narrative below, she shares what drew her to the field of aging and the role foundations can play in the search for a cure.

A Huge Eye Opener

I was always interested in biology. In part because I grew up next to a farm and spent a lot of time outside, and during high school, I did an independent research project at Johns Hopkins University, which was about a 40-minute drive from my suburban public school. In retrospect, the science was less than stellar, but at the time I didn't know that. I was really into it. I tested treatments on young versus old mice to get the old mice to run the maze as fast as the young mice. There was never any difference because I didn't design the experiment correctly. And the poor scientist who was my assigned mentor at Hopkins—he was very kind and gentle with me, but I was clearly not a high priority of his. I would still go there every now and then and discuss data with him. The end result was that it exposed me to a whole new world of research out there, to which I had no exposure or idea about otherwise. That was a huge eye opener to go to Hopkins and see research labs. I knew nothing about it. No one in my family was in science, and so it was completely foreign.

That Wasn't What was Supposed to Happen!

The reason I became interested in aging is my great-grandmother, who was 90. She was completely cognitively normal when she died and in great physical shape right up to the end. Her mother had lived to 99, and it was the same deal. We had some long-lived relatives. And so, it was a super shock when my grandmother developed Alzheimer's disease in her 70s because her mother and her grandmother had been so long-lived and so cognitively healthy. When she developed Alzheimer's, I kind of felt like, "Wait a minute! That wasn't what was supposed to happen! What happened?" Of course, nobody thought about the male line. And it could have been sporadic too, but we'll never know because my grandmother's father was injured in World War I, and that shortened his life dramatically. He died in his 50s. So, if it were genetic, it would have come through the male line, but that never occurred to me as a kid. I was like, "We have all these long-lived women. I'm a woman. I'm going to live long too." So, when she developed Alzheimer's disease, that just seemed unfair and not right.

That's how it started. That was what drew me in. I knew I wanted to study aging. I went to university, eventually majored in biology, although it was molecular biology and had no direct correlation to aging at all. I joined a lab, and the principal investigator was a very, very good teacher. He really mentored everyone in the lab. He advised me to get the best training I could and then focus on what I wanted to study for the long term: aging. He advised that your graduate school work should not be in the area that you ultimately want to focus on because it's important to move around in science. I don't think that's necessarily the case anymore. I think you do find people who say they want to study sugar biology. They

start studying sugar biology in graduate school and then continue in their postdoc. But at the time, the advice I was given was to move around substantially because that gives you a broader understanding of science.

Projectile Vomiting

So, I did my graduate work on tight junctions, which are basic cell biological structures. They're very important. They keep all your cells joined together and keep the urine in your bladder from diffusing throughout the rest of your body. The lab was in a digestive diseases department, and we had seminars on things like "Projectile Vomiting." My favorite was a scientist from the Minnesota Health Department who gave a series on unsolved public health crises involving the digestive system. There was this outbreak called Brainerd diarrhea in Minnesota where people basically had near continuous diarrhea for years. It ruined their lives, right? Of course, this was like 20 years ago. Maybe they've solved it by now. But they weren't sure what the infectious agent was, and there were many things like that that were fascinating about that whole world. But, I never intended to stay in digestive diseases.

A Heyday of Insane Aging Research

I came to UCSF to do a postdoc in a lab that studied the genetics of aging using a small worm. It was a long route, right? But I ultimately did what I had set out to do.

I thought it would be great to work on worms, in part because you can freeze them for storage. I was attracted to the idea of a career in small college teaching, where it's important to use a model system

in which undergrads can go away for summers and vacations every year, as opposed to really labor intensive and expensive things like cell lines and, God forbid, mice or other actual vertebrates. So, worms were very attractive, and that was kind of a heyday of insane interest in aging research. *The New York Times* was regularly in the lab. But it was also discouraging to see the feeding frenzy in the media around anti-aging research. That was the era of red wine and resveratrol possibilities, and this idea that you could hugely extend lifespan by caloric restriction and other things. By the time I got there, that heyday was coming to an end. Ultimately, by the end of my postdoc, I was ready to leave the basic aging research field, and I was excited to start a new career in industry.

What Harm Would It Do?

I didn't have any experience with industry, but I was attracted to the idea of working directly on products to help people. While I was on maternity leave, a friend at the UCSF Memory and Aging Center contacted me and said, "You should come in and look at this new effort at UCSF. I think you'd find it interesting." I said, "Absolutely not. I'm going to industry. And I'm on maternity leave anyway, so I'm not even going to think about this." But she reached out again six weeks later and said, "I really think you should take a look at this." So I said, "Ok. Fine." Kind of like, "What harm would it do?" But when I learned more about it, I was quickly hooked. That was 10 years ago!

The Biggest Asset

In addition to directly funding research, I think where foundations can really add value is by 1), catalyzing interest in a developing

space, where there hasn't previously been a lot of work. That's really important. And 2), by providing a neutral third party to facilitate efforts. That's also a main benefit. We increasingly help lay the groundwork or sometimes fund collaborative efforts between parties that otherwise couldn't collaborate as easily. An example would be a biomarker effort that UCSF has with a large pharmaceutical company. If the two parties had to contract directly, it would have created additional challenges. Instead, Bluefield said to UCSF, "We will fund this work" via a research grant, and the effort could proceed more quickly. Being a neutral third party, I think, can be very helpful.

And then there are things like a precompetitive consortium we're trying to get up and running. It's similar. We have a number of pharma companies—some of whom are directly competing, some are not. Academic investigators and other foundations are also participating, and everyone is coming together under a shared goal, but they need somebody in the middle to facilitate the effort. It's also important that we are a trusted organization that maintains confidentiality. Funding comes into Bluefield, and we distribute it to the project's vendors. I think that Bluefield being that nexus allows other important groups, people, and organizations to do things collaboratively that they wouldn't otherwise easily be able to do—that, in many ways, is a significant benefit we offer to the FTD community.

We support the development of new therapeutics in a number of ways. Sometimes it's just by reassuring teams that are new to our indication that there is a helpful group they can call upon. They may feel like, "Okay, we have people we can talk to. We kind of have a head start because Bluefield has already assembled key leaders and thought deeply about the path forward. We can get reagents and technical advice from them." These things really lower the entry barrier. That's turned out to be very important.

The Luxury to Just Focus

It's from a distance, but I do feel like I have an understanding of how awful this disease is. I read the stories from caregivers about how frustrated they are, about how inexplicable so much of their loved one's behavior is, and about how there are no drugs that work. There's a lot of online discussion about practical details, like door locks and keeping a loved one safe, or about which adult diapers work the best. It's a reminder that, "This is the day-to-day life of these families and this disease is devastating. We've got to do something." I take it to heart.

I was just at a meeting with a biotech company that proposed a timeline to the clinic in 2020 that would be the first trial in humans. I felt like, "That is just too long. Shorten it up!" And they can't because everything has to be sequential, right? The drug development process takes a long time. And that's necessary, but tough. Let's hope that this drug is the drug that's going to be the cure, but it's hard watching how long it takes.

It's Nice to Just Be an Optimist

I'm very hopeful that this disease will be cured in the next five years, before we sunset in six years. Maybe "cure" is not the right word, but at least we'll have a number of investigational drugs in the clinic hopefully very soon. Hopefully.

I have high hopes for gene therapy. It's an unknown territory, but at the end of the day, replacing the gene is what we want to do and, ultimately, we'll get to gene editing someday. Not in the short term, but eventually. I do have worries about issues around reimbursement and our larger health care infrastructure that will not be able to support gene therapy for hundreds of rare diseases.

The price tag is going to be millions of dollars per treatment, right? The cost has to come down eventually. But I think for now it's nice to just be an optimist.

We're going to have some challenges, like we may have more therapies to test than we have patients available to participate in trials. But I think really that's a good problem to have. That you have to actually choose between potential trials.

Great Ideas and Big Gaps

I think we could've been more aggressive in developing drugs from the start, in retrospect. In the early days I remember meeting with pharma, and they asked, "Why don't you just replace it? Why don't you just add back recombinant protein (a protein made from DNA that has been combined by laboratory methods)? Or why don't you just use gene therapy?" We chose instead to try to really understand the biology of progranulin. Little was known about progranulin, and we thought we needed to really understand it in order to be able to develop effective therapies. And that resulted in many incredible scientific discoveries. But at the end of the day, the therapies advancing towards the clinic now, with some exceptions, didn't require a comprehensive understanding of progranulin biology to get where they are, given the straightforward mechanism of this disease. If we just wanted to find a cure, we probably could have approached it differently.

Our mission now is to enable clinical trials' success. It's not to directly develop a cure anymore because that is now happening elsewhere, with our pharma and biotech collaborators. There is a whole pipeline of promising therapeutic approaches, including antibodies, antisense oligonucleotides ("ASOs" or small pieces of DNA or RNA used to treat genetic disorders), gene therapy, small

WAIT A MINUTE

molecules, and maybe protein replacement. Approaches are moving into the clinic, but we don't yet have consensus on trial design or end points. Fortunately, this is an area where UCSF leads the way, and where Bluebird bio is able to make a big impact. Our efforts now are directed towards supporting work that will enable clinical success, so that we can cure this disease!

¡Eres Tan Joven Para Estar Aquí!

**NARRADA POR
NATALIA SÁNCHEZ-GARRIDO**

**ENTREVISTADA POR
STEFANIE PIÑA ESCUDERO,
ATLANTIC FELLOW**



You Are So Young to Be Here!

**NARRATED BY
NATALIA SÁNCHEZ-GARRIDO**

**INTERVIEWED BY
STEFANIE PIÑA ESCUDERO,
ATLANTIC FELLOW**

Natalia es una medico joven quien se encuentra completando su residencia en geriatría en la Ciudad de México. Ella se convirtió en cuidadora antes de adquirir mucho conocimiento médico. La manera en la que trata a los pacientes a sus familiares ahora tiene una fuerte influencia de la experiencia que adquirió como cuidadora de su padre. Ella intenta que el cuidado que le otorga a sus pacientes sea cada vez mejor. Ella raramente cuenta su historia, sin embargo, accedió a compartir la forma en la que se sentía aprendiendo a cuidar de alguien siendo estudiante de medicina e hija a la vez con lágrimas en los ojos y la voz entrecortada.

Mi padre era biólogo y venía de una familia de pescadores en Mazatlán, Sinaloa en México. Tenían poco dinero, su padre lo golpeaba y en general su historia familiar era complicada. Él no estaba destinado a asistir a la escuela, pero de alguna forma logró graduarse de la primaria local. Después de la secundaria, se ganó una beca muy prestigiosa para convertirse en técnico pesquero. En otras palabras, un pescador formal. En ese momento las cosas empezaron a cambiar para él. Se fue a estudiar al estado de Veracruz. Desconozco de dónde sacó los libros o cómo financió su estancia ahí, pero completó el curso y regresó a Mazatlán para empezar a trabajar en laboratorios de pesca en donde se centró más en realizar en investigación que en pescar como tal. Durante esos años, se volvió comunista y decidió venir a la Ciudad de México a estudiar biología en la universidad. Se enfocó en biología marina porque desde que nació su trabajo siempre giró en torno al mar. Él era un hombre muy sano, corría maratones, sólo fumaba un cigarro al día y tenía una dieta muy saludable. Hasta ahora, no he logrado identificar ningún factor de riesgo significativo que pudiera

Natalia is a 29-year-old young physician completing her residency in geriatrics in Mexico City. She became a caregiver before knowing much about medicine. The way she treats patients and their families now has a strong influence from the experience she had taking care of her father. She tries to improve the care she gives each time she sees a patient. She rarely tells her story, and she agreed to share how she felt navigating through learning how to provide care, both as a medical student and as a daughter, with tears in her eyes and a broken voice.

My dad was a biologist, and he came from a family of fishermen in Mazatlán, Sinaloa, México. They had almost no money, and his dad hit him. Overall, he had a complicated family story. He was not destined to go to school, but somehow, he graduated from the local elementary school. After junior high, he won a very prestigious scholarship to become a fishing technician. In other words, a formal fisherman. Here is where things started to change for him.

He went to the state of Veracruz to study. I don't know where he got the books from or how he managed his expenses there, but he finished school and returned to Mazatlán and started to work in fishing laboratories, where he focused more on fishing research than actual fishing. During these years, he became a communist. He decided to come to Mexico City to study biology in the University and focused on marine biology because, since he was born, his work had always been around the sea. He was a very healthy man. He ran marathons, only smoked one cigarette a day, and had a very healthy diet. Even now, I cannot think of any significant lifestyle factors that could have contributed to his illness. He

haber contribuido a su enfermedad. Siempre fue olvidadizo, pero más que eso era triste. Mi mamá dice que es porque tuvo una vida difícil.

Él conoció a mi mamá en la ciudad de México, se casó con ella y se separaron cuando yo tenía alrededor de 13 años. Era muy difícil para mí notar que algo no estaba bien en aquel momento, pero ahora, en retrospectiva, puedo entender que algunas cosas no lo estaban. Mis memorias más claras son de cuando tenía alrededor de 16 años y yo empezaba a hacerme cargo de las cuentas en los restaurantes porque mi papá no podía hacerlo. No era capaz de hacer dos cosas a la vez y yo era la que lo llevaba manejando en el coche en lugar de que fuera al contrario. Recuerdo que no le decía a mi mamá nada de esto para evitar que discutieran. En ese momento en el tiempo, él era profesor de una universidad. En contraste a lo que leí en sus diarios de los ochentas—que estaban llenos de poemas hermosos en los que quedaba claro su dominio de las letras—comenzaba a escribir que no podía recordar la fecha y escribía absolutamente todo incluyendo las clases que había impartido durante años porque ya no podía recordarlas. En la universidad comentaron que tenía dificultad para expresarse, lo que era curioso tomando en cuenta su previo dominio del lenguaje. Conforme pasaron los años, la situación fue empeorando y esto se veía reflejado en sus diarios, pero nadie nos comentaba nada. Tenía problemas en la universidad, pero sus amigos lo encubrían hasta que un día en una de sus clases simplemente se quedó en blanco. Lo llevaron a la enfermería y las autoridades de la universidad decidieron cambiarlo a un puesto administrativo para que no perdiera su trabajo. Para el momento que esto ocurrió yo tendría alrededor de 18 o 19 años y estaba empezando la carrera de medicina. Él se percató de que algo no estaba bien y acudió al Instituto Nacional de Psiquiatría donde lo diagnosticaron con depresión y trastorno por déficit de atención e hiperactividad. Le comentaron que estos eran los motivos de su pérdida de memoria. Ahora, logro percatarme que estos no eran sus problemas principales, pero en ese momento fue para lo que recibió tratamiento.

had always been forgetful, but more than that, he was a sad man. My mom always said it was because he had a tough life.

He met my mother in Mexico City, married her, and then split up with her when I was around 13 years old. It was very hard for me to notice something was not completely right back then, but in retrospect, I can tell that some things were not okay. My clearest memories are from when I was around 16 years old, when I started taking care of the check at restaurants because my dad could not do the math. He could not do two things at the same time. I had to drive him around instead of the other way around, and I remember not telling any of the things I was doing for him to my mom so that they would not fight. By this time, he was a teacher at a university. In contrast to what I found in his diaries in the eighties—full of wonderful poems in which you could tell he was a master of language—he started to write that he was not able to remember the date, and he started writing absolutely everything down, including lectures he had been giving for years because he was not able to remember them anymore.

At the university they said that he started having trouble expressing himself, which was curious, and as the years went by, the situation got worse, as his diaries reflected. But nobody told us anything. There were problems at the university, but his friends covered for him until one day, he went blank in one of his lectures. He was taken to the infirmary, and people at his work decided to change him to an administrative position so that he wouldn't lose his job. By the time this happened, I was around 18 or 19 years old, and I was just starting medical school. He realized he was not okay and went to the National Institute of Psychiatry, where he was diagnosed with depression and attention deficit and hyperactivity disorder. They told him that these were the main reasons for his memory loss. Now I realize that these were not the main problems, but those are what he got treatment for. He continued to be

Continuó su seguimiento en este Instituto y desconozco exactamente las cosas que comentó con mi mamá respecto a su condición médica, sin embargo, recuerdo que el amigo que lo acompañaba a sus consultas desarrolló un tumor cerebral y falleció antes que mi papá. Sé que no sólo lo atendió un psiquiatra de mucho renombre, también lo vio una psicoanalista y ambos sólo escuchaban como sus síntomas empeoraban. Comenzó a perderse y a caerse, pero para ellos estos no eran síntomas alarmantes. Recuerdo que durante estos años yo simplemente seguí encubriéndolo.

Después comenzó a decir que su casero le había robado y que no tenía dinero para pagar la colegiatura de mi hermana. Ese fue el momento en el que mi mamá se dio cuenta que algo muy grave estaba ocurriendo. Mi mamá se sentó con él y le preguntó que le había dicho el doctor. Ella le exigió saber lo que estaba pasando y todo lo que mi papá pudo decir fue — Sólo quiero morirme. Inmediatamente mi mamá hizo una cita con un neurólogo. Recuerdo que le hicieron una resonancia magnética, pero yo nunca la vi y hasta el día de hoy no sé cual fue el reporte. Recuerdo que se mencionó algo vascular como algunas hiperintensidades pero nada muy claro. Todo lo que obtuvimos de esa consulta fue que ya no era capaz de manejar y que no podía continuar viviendo solo. Se había caído dos veces y había habido otros accidentes. No sé porque nadie nos dijo que tenía demencia si era muy claro que la tenía. Me pregunto por qué nadie habrá pensado que era importante hacer un diagnóstico — si no por él, al menos por mi y por mi hermana.

En aquel momento vimos el que se mudara con nosotras (con mi mamá, mi hermana y conmigo) como algo casi imposible. Ahora, en retrospectiva creo que lo que hicimos estuvo muy mal y que algo así no se le debe hacer a nadie, pero no sabíamos lo que estábamos haciendo y nadie nunca nos explicó nada. Nadie nos dijo con que nos enfrentaríamos ni que era lo que podíamos esperar. Nadie nos habló de las cosas que debíamos o no hacer. Entonces, el punto era que no podía estar sólo y que mi casa era muy pequeña. Yo estaba en la universidad y mi

treated in this institution, and I don't know exactly all the things that he might have told my mom about his medical condition, but I remember that the friend who used to go with him to the doctor developed a brain tumor and died before my dad. I know that not only a very well-renowned psychiatrist saw him, but also a psychoanalyst, and they were just there listening constantly to how his symptoms worsened. He started falling and getting lost, but to them these were not alarming symptoms. I remember that all I continued to do over these years was to keep covering for him.

He started saying that his landlord had stolen money from him and that there was no money to pay my sister's tuition. That is when my mom realized something was very wrong. My mom sat with him and asked him what the doctor had told him. She demanded to know what was going on and all he could say was, "I just want to die." In that moment my mom scheduled an appointment for him with a neurologist. I remember that an MRI was done, but I never saw it, and to this day, I have no idea what the report was. I remember there was something vascular, like some hyperintensities, but nothing was really clear. All we obtained from that appointment was that he was not able to drive anymore and that he could no longer live alone. He had fallen twice, and there had been other accidents. I don't know why nobody told us he had dementia; it was very clear he did. I wonder why nobody thought it was important to make the diagnosis—if not for my dad, at least for me and for my sister.

In that moment, we saw him moving in with my mom, my sister, and me as something almost impossible. Now, in retrospect, I think that what we did was very wrong, and things like that should not be done to anyone. But we did not know what we were doing, and nobody ever explained anything to us. Nobody told us what we would be facing or what we could expect. No one spoke to us about what should or should not be done. So, the point

hermana en la preparatoria y como mi papá no podía trabajar, mi mamá no podía dejar de hacerlo, de otra forma hubiera sido imposible que lo lográramos. Lo primero que teníamos que hacer por él era pensarlo. Si se retiraba por discapacidad, la universidad tenía que pagarle su salario completo. Tenía un seguro especial en el que podía acceder a unos meses extra de su sueldo también. Necesitábamos probar que no era capaz de trabajar y fue hasta ese momento que contar con un diagnóstico se volvió necesario. En México, si trabajas para el estado, como era el caso de mi padre, la pensión por discapacidad la otorga una institución que se llama Instituto de Seguridad y Servicios Sociales de los Trabajadores del Estado (ISSSTE) y el reporte de discapacidad tiene que elaborarlo uno de sus médicos. Entonces, llevamos la resonancia magnética y dijeron que tenía demencia. El segundo paso, era conseguir un poder legal que nos permitiera administrar la pensión que recibiría por él. Este paso fue bastante simple porque mis padres jamás se divorciaron de forma oficial por lo que todo lo legal recaía simplemente sobre mi madre. Decidimos enviar a mi padre a un asilo, pero como mi mamá tenía que trabajar y mi hermana era muy joven, yo me volví responsable de su cuidado. Yo era la encargada de llevarlo al médico porque como yo era que estaba estudiando medicina “sabía de que se trataban las cosas”. La verdad es que no tenía idea de nada. No era algo como diabetes sobre lo que podía leer e intentar entender. Las demencias nunca se mencionan en la carrera de medicina y por lo tanto no tenía idea con lo que me estaba enfrentando.

El asilo era más bien un lugar improvisado y terrible. Al principio visitábamos a mi papá una o dos veces al mes cuando podíamos. Los días que tenía que llevarlo al doctor, eran días que tenía que faltar a la escuela. En las consultas de neurología sólo le daban medicina para el colesterol y aspirina. No hacían nada más. Durante el primer año que estuvo en el asilo, perdió mucha funcionalidad. Antes de estar ahí él iba a su trabajo, aunque en realidad no lo hiciera. En el asilo, pasó de poder caminar a estar sentado todo el tiempo y perder mucho peso.

was that he could not be alone, and my house was small. I was in college, and my sister was in high school, and since my dad could not work anymore, my mom was the one that had to work. Otherwise it would have been impossible for us to make it.

The first thing we needed was for him to retire. If he retired because he was disabled, the university had to keep paying him his whole salary. He also had a special insurance where he would have access to some extra months of his salary. We needed proof that he was disabled, and it was at this moment the diagnosis became necessary. In México, if you work for the state, as my father did, your disability pension came from an institution called Instituto de Seguridad y Servicios Sociales de los Trabajadores del Estado (ISSSTE), and the disability report needs to come from the doctors in their medical institutions. So, we took the MRI to them, and they said he had dementia. The second step was to get a power of attorney to administrate the money for him. This was rather easy, since my parents never got officially divorced, and everything could just lay on my mother. We decided to put him in a nursing home, but since my mother had to work and my sister was too young, I became the one responsible for his care. I took him to the doctor because since I was studying medicine—I was the “one who knew how things were.” The truth is that I had no idea about anything. It was not like diabetes where I could go and read and try to understand. Dementias are never mentioned in medical school, and I had no idea of what I was dealing with.

The nursing home was more of an improvised, terrible place. In the beginning, we visited him once or twice a month when we could. The days I took him to the doctor were days I had to miss school. In the neurology consultation, all they gave him was cholesterol medicine and aspirin. They did not tell me anything else. During the first year living in this nursing home, he lost a lot of function. Before being there, at least he went to his job, even

Lo único que hacía era pretender leer las noticias. La única cosa que parecía conservar era su pasión por defender a los otros adultos mayores que vivían con él. Si alguno de los cuidadores trataba mal a alguna de las residentes, mi papá siempre se interponía y empezaba a gritarle al cuidador. Empezó a estar más rígido y cada vez me costaba más trabajo moverlo. Me sentía muy enojada porque en realidad no quería estar ahí tratando de moverlo y llevándolo al médico, pero al mismo tiempo pensaba —¿Por qué no quiero? —Si lo quería. Esta situación me hacía sentir muy culpable. Después empezó a caerse por lo que el personal del asilo me llamaba y tenía que llevarlo a urgencias y estar en la sala de espera durante ocho horas donde pese a que tenía el rostro muy lastimado jamás le hicieron una tomografía. Esto ocurrió tres o cuatro veces y en el asilo lo amarraron a la silla para evitar que se cayera. Yo sabía que estaba mal, pero no quería terminar en urgencias con él nuevamente. Por encima de todo, cuando eres joven, es muy difícil entender porque tienes que estar ahí. Sientes que no es tu papel, especialmente porque cuidar es algo que no tiene ninguna relación contigo. Los abuelos con los que tengo más contacto ahora tienen alrededor de 80 años y son perfectamente funcionales. No tenía ninguna idea de lo que se trataba la discapacidad. El único concepto que tenía de cuidar a alguien era el de cuidar bebés. Estuve enojada con mi mamá y con mi hermana por mucho tiempo porque dejaban que la responsabilidad de todo recayera sobre mí. Ellas no venían conmigo cuando mi papá necesitaba algo. En retrospectiva, mi hermana era menor de edad por lo que no podía acompañarme y mi mamá estaba trabajando para sacar todo adelante. En verdad no había otra opción. Me sentía ultra sola. Era algo que tampoco podía comentar con mis amigos. Tenía un novio en aquel momento, pero no sabía nada. Yo sólo le comentaba que tenía que llevar a mi papá al médico, pero nunca le dije nada más. Me sentía avergonzada en dos formas: La primera era la relacionada a sentir vergüenza y la segunda era estar avergonzada porque no quería que la situación fuera real. Tenía la sensación de que,

if he did not quite work. In the nursing home, I saw him going from being able to walk to sitting all the time and losing a lot of weight. All he did by that time was pretend to read the news. The only thing he did not seem to lose was that he always defended the elders that lived in the nursing home with him. If a caregiver was being rude with one of the lady residents, my dad always got in the way and started yelling at the caregiver. He started to be very rigid and weak, and taking him to the doctor was more complicated every time. I had a very hard time trying to move him. I felt angry because I really did not want to be there trying to move him and taking him to the doctor but at the same time I thought, "Why didn't I?" if I loved him. That made me feel guilty.

Then he started falling, so the people from the nursing home called me. I had to take him to the emergency room where we had to wait for around eight hours and, even though he had a lot of injuries in his head and face, a CAT scan was never performed. This happened three or four times, and in the nursing home, they tied him to his chair to prevent him from falling. I knew it was wrong, but I did not want to end up in the emergency room with him again. Above all, when you are young, it is hard to understand why you have to be there. You feel that is not your role. Especially because you feel that giving this type of care is something that does not relate to you. The grandparents that I have the most contact with are now in their 80s, and they are perfectly functional. I had no idea what disability was about. The only concept of caring for someone that was in my mind was caring for babies.

I was angry at my mom and my sister for a very long time because they let everything rely on me. They did not come with me when my father needed something. But in retrospect, my sister was a minor, so she could not. My mom was working for things to work out. There was indeed no other option. I felt ultra-alone. It was something I could not tell my friends either. I had a boyfriend

si ocultaba lo que estaba pasando, era como si todo lo que sentía que estaba mal no estuviera ocurriendo en realidad. Entonces, sólo decidí esconderlo, quejarme y enojarme por todo y con todos. Estaba enojada porque a mi papá le había tomado 60 años salir de la pobreza y en un año y medio ese hombre al que habíamos conocido toda nuestra vida se había ido.

Cuando estaba en el cuarto año de la carrera, empecé una materia que se llamaba “Salud en el Anciano” y fue entonces que empecé a darme cuenta de lo que en verdad estaba pasando. Me tomó muchos años de medicina llegar a ese punto. Tal vez mi mamá y mi hermana jamás entendieron lo que pasó. Desafortunadamente, ese fue el año en el que ocurrió la primera neumonía. Recuerdo esa primera neumonía como una de las peores experiencias de mi vida en general. Él tenía fiebre, muchísimas secreciones y lo llevé al hospital. Primero, fuimos al hospital que nos quedaba cerque que se llamaba Darío Fernández, pero estaba en remodelación por lo que no tenían suficiente espacio y lo refirieron a otro hospital que se llamaba López Mateos. En los hospitales en México, sólo el paciente puede estar en el área donde recibe la atención. Los familiares tienen que estar en la sala de espera. Me encontraba durmiendo en una banca (gracias a Dios hacía calor y no frío) cuando alrededor de las tres de la mañana me solicitaron entrar con él porque estaba demasiado inquieto y no podían lidiar con él. Él estaba ahí, en un reposet porque no había camas ni camillas disponibles y yo estaba a su lado aún en mi uniforme blanco de la facultad de medicina. Estábamos rodeados de otros cuidadores que tenían alrededor de 50 años cuidando a sus familiares quienes tenían alrededor de 80 años. Todos estábamos haciendo lo mismo, pero todos me decían — ¡Oh! ¡Eres muy joven para estar aquí! Y ¡Él es tan joven también! ¿Qué paso? Tu no encajas con nosotros. Yo recuerdo que tenía un importante examen de cardiología al día siguiente. Llamé a mi mamá y le dije — Tengo que ir a hacer el examen, no puedo faltar al examen. No había dormido nada y lo único que hice durante todo el

back then, and he did not know anything. I just said, “I’m taking my dad to the doctor,” but I never shared more than that. I felt embarrassed in two ways: the embarrassment that is related to shame and the embarrassment of not wanting the situation to be real. It was a feeling that if I hid what was going on, it was somehow as if all those things I felt were wrong were not happening. So, I just decided to hide it and complain and get angry about everything with everyone. I was angry because it took him 60 years to get out of poverty, and in one and a half years, the man that we had known our whole lives was gone.

When I was in my fourth year of med school, we started a subject called “Elder Health,” and it was then that I started realizing what was going on. It took me years of medical education to get to that point. Maybe my mother and my sister never understood. Unfortunately, that was the year he got pneumonia for the first time. I remember that first pneumonia as one of the worst experiences of my life in general. He had a fever and lots and lots of secretions. I took him to the hospital. First, we went to the one that was close to us, that was a hospital named Darío Fernandez, but they were remodeling it and did not have enough space, so they referred us to another hospital called Lopez Mateos. In hospitals in Mexico, only the patient can be inside of the area where medical attention is been given. The family needs to stay in the waiting room. I was sleeping on a bench in the waiting area—thank God the weather was warm and not cold—when around 3am they asked me to go inside with him. He was extremely restless, and they could not deal with him. He was there, on a recliner because there were no beds or gurneys available, and I was at his side still in my white med school uniform.

We were surrounded by other caregivers who were around 50 watching after their patients, who were around 80. We were all doing the same, but everybody was telling me “Oh! You are so

examen fue llorar. No recuerdo si lo contesté o que contesté. Todos me estaban mirando y preguntándome lo que me pasaba. Respondí que mi papá estaba en el hospital y que tenía neumonía o al menos eso era lo que los doctores me habían dicho. Después de tres o cuatro días en el servicio de urgencias pudo regresar al asilo. Después de esa hospitalización se movía aún menos que antes. Platicué con mi profesor de Salud en el Anciano después de la clase y le expliqué la situación y o que dijo fue — Bueno, pero ¿entiendes lo que significa lo que le esta ocurriendo a tu papá en términos de pronóstico? ¿Entiendes que puede morir en los siguientes seis meses? —Y yo sólo pensaba — ¿De qué está hablando? —Era algo obvio que mi papá se iba a morir, pero al mismo tiempo muchas preguntas venían a mi cabeza como — ¿Por qué tiene neumonía en septiembre? ¿Por qué se está moviendo aún menos? —No me consideraba particularmente torpe y de alguna forma era parte del mundo de la medicina, pero este tipo de cosas si nadie te las dice, si nadie te explica que pueden ocurrir, simplemente no vienen a tu mente.

Hubo otros dos o tres episodios de neumonía en los que pasó tres o cuatro días en el hospital. Después llegó diciembre, año nuevo y su cumpleaños número 64. Era un cumpleaños importante porque le gustaban mucho los Beatles y esta era una edad peculiar. Recuerdo haber ido al asilo con mi hermana y comer pastel con mi papá. A penas lograba hablar, pero sí dijo que estaba muy feliz y que éramos sus flores, sus estrellas. Él seguía comiendo muy bien, especialmente dulces. Estuvimos con el por un rato y ahora noto que todo el tiempo que estuvimos ahí él estuvo en la misma posición, que nadie en el asilo lo movilizó, a nadie le importaba cuidar las cosas que ahora sé lo hubieran ayudado a vivir más y mejor. Sólo lo dejaron ahí sentado. En abril tuvo otra neumonía severa. Dormí durante cuatro o cinco días en la sala de espera del hospital López Mateos. Me hice amiga de la mujer que estaba sentada junto a mi y nos ayudábamos entre nosotras. Ella reservaba mi lugar cuando me pedían que entrara a darle de comer a mi papá. Esta vez estaba en una camilla. Estaba sujeto y

young to be here! And he is so young too! What happened? You do not fit with us.” I remember that I had an important cardiology test the next day. I called my mom and told her “I need to go take the test; I cannot miss the test.” She managed to stay with him while I went to do the test. I had not slept, and the only thing I did during the whole time during the test was cry. I don’t remember if I answered any questions, or what I answered. Everybody was staring at me, asking me what was wrong, what had happened. I said that my dad was in the hospital and that he had pneumonia, or at least that’s what the doctors had told me. After three or four days in the emergency room, he was able to go home.

After this hospitalization, he moved even less than before. I talked to my Elder Health teacher after class and explained the situation to him, and he said “Well, but do you understand the meaning of what is happening to your dad in terms of prognosis? Do you understand that he might die in the following six months?” And I was like “But why, what are you talking about?” It was sort of obvious that my dad was going to die, but at the same time lots of questions started popping into my head like “Why does he have pneumonia in September?” or “Why is he moving even less now?” I did not consider myself particularly dumb and, in a way, I was part of the medical world, but those were things that if nobody tells you about, that if nobody explains to you that they can happen, they simply do not come to your mind.

There were two or three other pneumonia episodes where he spent two or three days in the hospital. And then came December, the New Year, and his 64th birthday. It was an important birthday to him because he loved The Beatles, so this was a peculiar age. I remember going to the nursing home with my sister, and we ate cake. He barely talked, but he did say he was very happy and that we were his flowers, his stars. He was still eating a lot, especially candy. We were there for a while, and now I realize

ahora sé que en ese momento tenía un problema con la deglución, pero en ese momento no lo sabía. Hice exactamente lo que no debí haber hecho. Le di de comer completamente acostado. Hice algunas otras cosas muy mal debido a mi falta de conocimiento. Estos momentos eran difíciles para mi porque algunos de mis compañeros estaban haciendo rotaciones clínicas en el hospital y yo estaba avergonzada. No sabía como explicar lo que estaba pasando. Durante la hospitalización los médicos me dijeron — ¿Ya te diste cuenta de que la posibilidad de que tu padre requiera ser intubado es alta? —Y para ser honesta, no... no lo había notado. No había cruzado por mi mente. Había platicado previamente con mi mamá sobre lo que me habían dicho en la escuela sobre estar preparadas con una respuesta en caso de que su salud se deteriorara y requiriera intubación u otras maniobras avanzadas. Mi mamá ya había dicho que no. Sin embargo, de lo que yo no estaba consciente era que tomar estas decisiones fuera algo tan inminente. Le dije a mi mamá lo que los médicos me habían dicho en el hospital y en esa ocasión pensamos en probablemente permitir el apoyo porque ocurrió alrededor del cumpleaños de mi hermana y no queríamos que mi papá falleciera en su cumpleaños. Afortunadamente se recuperó y regresó al asilo.

No estoy segura si desarrolló una úlcera por presión en el sacro como una consecuencia de la hospitalización o si fue ocurrió en el asilo. Nadie nos dijo que existía hasta que ya era muy profunda (grado 3). En el hospital me dijeron que había que realizarle una curación todos los días. No lo iban a hacer en el asilo, no sabían como hacerlo. Entonces, yo iba cada tercer día cuando podía. No sabía nada de como curar una herida, no tenía idea de lo que estaba haciendo. Cuando le limpiaba la úlcera tenía tanto dolor, gritaba tanto...La única cosa que tenía era xilocaína en spray que usaba para mis pies en el ballet y eso era lo que usaba para ayudarlo, pero no era suficiente, gritaba y gritaba de dolor. No podía evitar pensar — ¿Qué estoy haciendo? ¡Lo estoy torturando! —Sobra decir que esa úlcera por presión jamás cerró.

that he was in the same position all the time, that nobody in the nursing home moved him. Nobody cared about those things that we know would help him to live better longer. They left him just sitting there.

In April he had terrible pneumonia again. I slept like four or five days in the waiting room at the Lopez Mateos Hospital. I became friends with the lady sitting next to me, and we helped each other. She reserved my place when I needed to go help my dad eat. This time he was on a gurney, and he was tied up. I now know in that moment, he had a swallowing disorder, but I did not know it back then. I did exactly what you are not supposed to do. I fed him while he was completely lying down. I did other things very wrong because of my lack of understanding. This time it was hard for me because some of my classmates from med school were doing their clinical rotations at that hospital, and I was embarrassed. I did not know how to explain what was going on. During that hospitalization the doctors asked me, “Have you realized that the possibility that your father requires intubation is high?” And to be honest... no, I had not noticed that. It had not crossed my mind. I had previously talked to my mother about what they had told me in school, that we needed to be prepared with an answer in case his health deteriorated, and he required intubation or advanced maneuvers. My mother had said no. But what I was not aware of is that making these decisions was so imminent. I told my mom what they had told me at the hospital, and this time we were thinking about probably letting them because it was around my sister’s birthday, and we did not want my dad to die on her birthday. Luckily, he made it, and he returned to the nursing home.

I am not sure if he developed a pressure sore as a consequence of being in the hospital, or if it appeared in the nursing home. But nobody told us until it was very deep—grade three—in his sacrum. At the hospital, they told me that we needed to clean and treat

Lo que sí tenía era un colchón de descarga porque me habían dicho en la escuela que le consiguiera uno, entonces lo hice.

Él seguía comiendo bien y creo que no porque tuviera hambre sino porque tenía muy grabado desde pequeño que no podía rechazar la comida porque no siempre tendría en casa, pero con su trastorno de deglución, volvió a presentar neumonía en mayo. Tenía fiebres muy altas y no había tenido respuesta a los antibióticos que le habían dado en el asilo. Entonces estábamos en urgencias nuevamente con una historia similar: Él amarrado a una camilla y yo durmiendo en la sala de espera. Esta ocasión estaba peor y el tiempo que había pasado en la sala de urgencias no había sido suficiente por lo que tenían que internarlo en el piso de geriatría para una hospitalización más prolongada. Yo ya tenía muchos problemas en la escuela. No podía faltar más. Recuerdo que le tenía que decir a la doctora que nos daba la clase que me tenía que ir para no perder el informe médico que sólo daban a cierta hora. Cuando trabajas en el hospital esas cosas sólo se vuelven parte de tu rutina, pero no te imaginas como es que las personas deben adaptar sus vidas para escuchar los informes. Todo tiene que adaptarse en torno a las necesidades del hospital. Recuerdo que en aquella época tenía que presentar un examen de francés para competir por un lugar para un programa de intercambio. Esa es la cosa, necesitas continuar con tu vida encima de todo. Entonces, cuando mi papá estaba en el piso, mi mamá contrató a una cuidadora. Ella se quedaba con mi papá durante la noche y algunas horas del día para que yo pudiera dormir e ir a la escuela.

Mi mamá y yo tuvimos una conversación en la que le dije —Todo esto puede ser bastante fútil, va a estar hospitalizado, va a estar mejor, lo van a hidratar, a cuidar, etc. Pero en el momento en el que salga de aquí todo va a estar terrible de nuevo y vamos a estar en la misma situación el siguiente mes. Va a estar con dolor y con dificultad para respirar. —Creo que se nos hizo fácil en ese momento y decidimos llevarlo a casa. Creo que es lo más cruel que pudimos haberle hecho.

the wound every day. They were not going to do it in the nursing home; they did not know how. So, I went every other day whenever I could. I knew nothing about wound care, and I did not have any idea of what I was doing. When I cleaned his wound, he was in so much pain, he screamed so much. The only thing I had was xylocaine spray that I used for my feet in ballet, and that is what I used to help him, but it was not enough: he screamed and screamed in pain. I could not avoid thinking “What am I doing? I am torturing him!” Needless to say, that pressure ulcer never healed. He did have his alternating pressure mattress because they had told me to get one at school. So, I did.

He still ate very well—I believe this was not because he was hungry, but because it was ingrained in him that he could not reject food because there might not always be food at home. But with his swallowing disorder, he had pneumonia again in May. He had very high fevers, and he did not respond to the antibiotics they had already given him in the nursing home. So, we were at the emergency room again with a very similar story: him being tied up to a gurney, me sleeping in the waiting room. But this time the pneumonia was worse, and the time he spent in the emergency room was not enough. This time they were going to move him to the geriatrics ward for a longer hospitalization. I already had a lot of trouble at school. I could not miss any more time. I remember telling the teacher that I had to leave the class to not miss the medical report that they only gave at a certain time. When you work at the hospital, those things become just part of the routine for you, but you don’t imagine how people need to adapt their lives to listen to your report. Everything needs to be adapted around the hospital’s needs. I remember that I had a French test and that I was fighting for a place to go on an exchange program. And that is the thing, you need to continue with your life on top of everything. So, when he was in the ward, my mom hired a caregiver. She

Yo no tenía la más remota idea de lo que significaba tener un paciente terminal en casa y no manejarlo en la muerte. Cuando recuerdo ese momento sólo me pregunto a mí misma en qué estaba pensando. Digo, no sé si hubiera cambiado la decisión de detener el manejo que potencialmente podría haberlo curado pero la forma en la que hicimos las cosas simplemente no fue la correcta. No debimos haberlo hecho de esa forma. Tuvo una muerte terrible. Lo llevamos con nosotras a casa en el auto de mi mamá y cuando llegamos, su pie se atoró con la puerta y estaba gritando de dolor mientras intentábamos sacarlo del auto. Sólo podía estar acostado, entonces pusimos la cubierta de mi cama en la sala que estaba en la planta baja y lo acostamos ahí. Todo era muy improvisado. No nos dieron ninguna instrucción en el hospital, al menos pudieron habernos explicado el riesgo de llevarlo a casa. Se estaba ahogando en sus propias secreciones y tenía mucho dolor. Lo único que podía hacer por él era darle gotas de tradol y traguitos de Ensure porque no sabía que más hacer. Me habían dado algunos “tips” como darle butiliosina pero no tenía ningún sentido ya que no se la podía tragar. Llevaba ahí dos días y era un viernes, yo ya estaba cansada de todo y quería que alguien más se hiciera cargo. Lo único que mi papá podía hacer era quejarse de su dolor y mi mamá sólo me decía — ¡Muévelo! ¡Ayúdalo! ¡Haz algo! —y yo no quería hacer ya nada más. Ese día la abuela de uno de mis amigos falleció y como yo estaba anticipando que tendría que ir a un funeral pronto le dije que iría al día siguiente y me fui de fiesta con una de mis amigas. Me puse muy borracha esa noche y no quería regresar a mi casa. Me quedé en casa de mi amiga y me costó mucho trabajo levantarme al día siguiente, pero me acordé que tenía que ir al funeral. Entonces, me fui a casa con una cruda terrible. Me bañé y vi a mi papá por un par de minutos. Su cara realmente se iluminó cuando me vio. En aquel momento pensé que estaba mejor en casa porque estaba con nosotras y nadie lo quería tanto como mi mamá, mi hermana o yo. Pero honestamente, fue una mala idea. Esa es mi conclusión. Fui al funeral y mi hermana se fue a la

stayed with my dad during the night and some hours of the day so that I could sleep and go to school.

My mom and I had a conversation. I told her “All of this might be very futile.” He is going to be in the hospital, he will be fine, they will hydrate him, take care of him, etc. But the moment we take him home, everything will be terrible again, and we will be in this same situation next month. He will be in pain, unable to breathe. I guess we found it easy in that moment to decide to take him home. I think that was the cruelest thing we could have possibly done to him. I did not have the remotest idea of what it meant to take a terminal patient home and not give him any management. When I remember that moment, I just say to myself, “What was I thinking?” I mean, I don’t know if I would have changed the decision of stopping the medication to potentially cure him, but the way we did things was simply not the right way. We should not have done things that way.

He had a terrible death. We took him home in my mom’s car, and when we got home, his foot got caught in the door, and he was screaming in pain when we tried to carry him out of the car. He could only lay down, so we put the cover of my bed in the living room downstairs and laid him there. Everything was so improvised. They did not give us any further instructions at the hospital—they could have at least explained to us the risk of taking him home. He was choking on his own secretions, and he was in so much pain. The only thing I could do for him was to give him drops of Tradol and sips of Ensure because I did not know what else to do. I had received some “tips” like to give him some hyoscine, but it was meaningless since he could not swallow it.

He had been there for around two days. It was a Friday. I was tired of the whole thing. I wanted someone else to take over. The only thing my dad could do was complain about his pain, and my mom just told me, “Move him, help him, do something.” I did

fiesta de cumpleaños de mi prima en Hidalgo, que es otro estado del país. Estaba en el funeral cuando mi mamá me llamó y me dijo:

—Por favor regresa, creo que no está respirando.

—¿Cómo que crees que no está respirando? ¿Está o no está respirando?

—No está respirando y no sé hacer

Yo no sabía que hacer tampoco — ¿Qué tiene que hacer uno cuando alguien no está respirando? —Mis amigas escucharon lo que estaba pasando y me dijeron que manejara despacio de vuelta a casa. No querían que me pasara nada malo. Recuerdo la canción que estaba en el radio cuando estaba manejando de vuelta. Cada vez que la escucho, recuerdo ese día.

Llegué a la casa y en efecto, mi papá no estaba respirando. Mi mamá me dijo que estaba tosiendo mucho y estaba con dolor por lo que lo volteó y fue a la cocina. Le estaba platicando cuando de pronto dejó de escucharlo y fue de regreso al cuarto y se percató de que ya no estaba respirando. No creo que haya sido cualquier cosa que ella hubiera hecho. Digo, tenía pus saliéndole del pulmón durante días. Entonces, empezó el siguiente drama. Era domingo en la noche. —¿Dónde íbamos a conseguir un certificado de defunción en domingo en la noche? —Por su puesto las funerarias privadas te proveen de uno pero el servicio costaba más de 100 000 pesos y no podíamos pagarlos. El ISSSTE le daba los servicios funerarios y todo lo que se requiriera, pero necesitábamos el certificado. Llamamos a un doctor del ISSSTE para que fuera a la casa. Cuando llegó dijo — Bueno, efectivamente está muerto, pero yo no puedo darles el certificado — y nos explicó toda la burocracia hospitalaria que necesitábamos hacer.

Le llamé a mi abuela en Hidalgo para preguntarle sobre mi hermana y me dijo que ya estaba en el camino de vuelta a la casa. Tenía que interceptarla. No podía permitir que regresara de una fiesta y encontrara a su papá muerto en la sala- Cuando la vi a través de la ventana, salí y cerré la puerta detrás de mí. Le dije — Mi papa se murió. Tu papa se murió. Ella parecía bastante confundida y no recuerdo si lloró o no

not want to know anything else. That day, the grandmother of one of my friends died, and since I anticipated that I would have to go to a funeral soon, I said that I would go the next day and went to a party with one of my friends that night. I got so drunk that night, and I refused to go back home. I stayed at my friend's house, and I had a lot of trouble waking up the next day, but I remembered I had to go to the funeral. So, I went back home with a terrible hangover. I took a shower, and I saw my dad for a couple of minutes. His face really lit up when he saw me. Then I thought that he was better at home because he was with us, and nobody loved him the way my mom, my sister and I loved him. But honestly, it was a bad idea. That is my conclusion.

I went to the funeral, and my sister went to my cousin's birthday party in another state, Hidalgo. I was at the funeral, and my mom called me and told me, "Please, come back, I think he is not breathing." I asked her "What do you mean you think he is not breathing? Is he or is he not breathing?" And she answered, "He is not breathing, and I don't know what to do." I did not know what to do either. What should one do when someone is not breathing? My friends overheard what was going on and told me to drive slowly back home. They did not want anything to happen to me. I remember the song that was on the radio while I was driving back home. Every time I hear it, I remember that day.

I got home, and he was in fact not breathing. My mom told me that he was coughing a lot and in pain, and my mom turned him over and went to the kitchen. She was talking to him, when suddenly she didn't hear him and got back to the room and found he was not breathing anymore. I don't think there was anything my mom could have possibly done. I mean, pus had been coming out of his lungs for days. Then the next drama started. It was a Sunday night. Where are you going to get a death certificate on a Sunday night? Of course, private funerary services provided you with it,

cuando la dejé entrar a la casa. Mis amigos empezaron a llamar para saber si había llegado bien a casa y les dije que mi papá había fallecido. Más amigos empezaron a llamar y uno de ellos me preguntó si necesitaba que fuera, yo le dije que no, que estaba bien pero mi mamá me dijo —¡No! ¡Dile que venga! Voy a ir con tu hermana por el certificado de defunción y no quiero dejarte aquí sola con el cuerpo. Eso fue un poco surreal. Los servicios funerarios terminaron llevándose el cuerpo como a las cuatro de la mañana. El día siguiente fue un día largo. Yo nunca había sido anfitriona de un funeral antes. Es como esta sensación de que eres el anfitrión y el afectado al mismo tiempo. Digo, no eres el más afectado, que en este caso era mi papá que estaba muerto, pero, se entiende lo que quiero decir.

Cremamos a mi papa y decidimos que tenía que regresar al mar. Él pertenecía al mar, el mar era su vida. Mi hermana y yo esparcimos las cenizas en el mar en Mazatlán en una pequeña, pero muy significativa ceremonia con su familia.

Creo que esta historia es terrible, pero creo que no es la más terrible de todas las historias. Lo que si creo es que ilustra lo que pasa en las familias como la mía. No estábamos en la situación económica más terrible, no estábamos en la peor situación social y creo que si alguien nos hubiera explicado antes las cosas, hubiéramos estado mejor preparadas y mi papá hubiera tenido un mejor cuidado. Es sólo que nadie creía que tuviera demencia a los 50. Nosotros como médicos tenemos una preparación muy pobre para atender a estos pacientes y explicarles las cosas a la familia. He visto que ni siquiera quienes tienen un lugar para atender a este tipo de pacientes saben lo que están haciendo. En la televisión y en las películas la historia no está adecuadamente narrada y en las que se acercan más a la realidad, se acercan más a la realidad de Estados Unidos, donde existen más recursos. En países como el nuestro, con muy pocos recursos, estas enfermedades nos brindan la oportunidad de volver a hacer comunidad en el mundo,

but they were over 100,000 pesos, and we could not afford that. The ISSSTE provided him with the funerary services and everything required, but we needed the death certificate. We called a doctor from the ISSSTE to come to our home. When he arrived he said, “Well, he is indeed dead, but I cannot give you the certificate,” and he explained all the bureaucracy we needed to go through at the hospital.

I called my grandmother in Hidalgo to ask her about my sister, but she told me she was on her way back home already. I needed to intercept her—I could not let her just come back from a party and find her dad dead in the living room. When I saw her through the window, I went outside and closed the door behind me. I told her, “My dad died. Your dad died.” She seemed very confused, and I don’t remember if she cried after I let her into the house or not. My friends called to see if I had gotten home all right, and I told them my dad was dead. Other friends started to call me, and one of them asked me if I needed him to come over. I said, “No, I am fine, thanks,” but then my mother told me “No! No! Tell him to come! I am going to take your sister with me to get the death certificate, and I don’t want you to stay home alone with a corpse.” That was a little surreal. The funerary services ended up taking the corpse at around 4 a.m. The next day was a long day. I had never hosted a funeral before. It is this weird feeling of you being the host and the affected person at the same time. I mean, not the most affected person, which in this case was my dead father, but you know what I mean.

We cremated my dad and decided he had to return to the sea: he belonged to the sea, the sea was his life. My sister and I spread his ashes in the sea in Mazatlán in a small but very meaningful ceremony with his family.

I think this story was terrible, but I don’t think it was the most terrible of all stories. But I do believe it illustrates everything

de aprender juntos y apoyarnos los unos a los otros en el cuidado. De realmente cambiar la narrativa que existe hoy en día.

that happens to families like mine. We were not in the most terrible economic situation; we were not in the worst social situation. I believe that if someone would have explained things earlier or better, we could have been more prepared, and my dad would have had better care. It's just nobody believed he could have dementia in his fifties. We as doctors are very poorly prepared to see these patients, to explain things to the family. I observed that not even people who own places to take care of this type of patient know what they are doing. In TV and movies, the story is not adequately portrayed, and the ones that are closer to reality are closer to the US reality, where more resources exist. In countries like ours, with very low resources, these diseases are giving us a new opportunity to be a community in the world, to learn together and to support each other in the care. To really change the existing narrative.



On the Brain's Beauty, Surfing, and Mortality

NARRATED BY SERGGIO LANATA

**INTERVIEWED BY
CAMELLIA RODRÍGUEZ-
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Serggio Lanata, MD, MS, is an Assistant Professor of Clinical Neurology at UCSF and is on the faculty of the Global Brain Health Institute (GBHI). In 2019, he was recognized as an inaugural recipient of the UCSF School of Medicine Population Health and Health Equity Scholar award. Sergio was raised in Peru, spent most of his childhood summers in a remote coastal town that had three public phones, no TV, and no electricity after 9 p.m. — there he learned to surf. He has surfed the entire northern coast of Peru. Sergio shares his journey to becoming a physician, his drive to address inequities in health care, and feeling “stoked.”

Career Path & the Beauty of the Brain

My interest in medicine arrived relatively late. I wasn't one of those kids who knew very early what to do in life, how to make a living in society. Surfing was a big part of my life back then. My dad was fine with this as long as I kept myself busy in school, but after I graduated high school and he saw me doing nothing other than surf, he wasn't as supportive, to say the least. One day he gave me an ultimatum: “Enroll in a university or else...” So, I enrolled in a university that was nearby my house and conveniently located near the highway I drove on to get to the beach.

I wasn't sure at all about what I wanted to study or do with my life. This all changed rather suddenly during a human anatomy course that included dissections of human cadavers. I still vividly remember my professors performing incredibly detailed dissections of the brain and being blown away by how detailed and eloquent their knowledge of neuroanatomy was, especially

functional neuroanatomy. I specifically remember one professor who would guide us through this meticulously layered narrative of the brainstem that produced in me an intense sense of awe and admiration of this small, yet incredibly complex and important part of the brain. It felt to me that I had discovered something beautiful, frankly. This experience committed me to the field of medicine. It was an intense fascination for the human body, especially the brain, that pulled me in. Today, I can still connect with this sense of awe of the brain, like when we discuss a case in our clinicopathological case conferences, for example, and I'm struck by the fact that a specific microscopic disease process has such a profound impact on a person's "humanness."

Behavioral Neurology as Meeting Point

At some point, usually early on, every medical student begins to see themselves as a surgeon or a clinician. I never felt attracted to surgery. I didn't dislike it, but it didn't fire me up either. Within the world of clinical medicine, psychiatry was intellectually interesting to me, but my psychiatry rotations were so disappointing mainly because discussions of the brain were practically absent while my attendings evaluated and treated people with psychiatric disease. How could it be, I asked myself, that they weren't critically thinking of the brain while examining patients with suspected schizophrenia or bipolar disease? These experiences stood in stark contrast with my rotations in neurology, when discussions of the brain and the nervous system were at the center of the diagnostic and therapeutic approach for every patient. It seemed to me the neurological sciences validated the entire model of modern medicine in my mind more than any other specialty.

Looking back, I think this is why I ended up going into neurology. Later, I found that behavioral neurology brought together the fields of psychiatry and neurology in a very appealing way, and that's how I came to be where I am now.

From Peru to San Francisco — Seeing Social Inequity

I think growing up in a country like Peru, where social inequities across different domains are so blatant, had an impact on me. Then after living in the U.S. for years and going back home, the social reality of my country felt even more desperate. Inevitably, you start telling yourself, “This is wrong.” And at first your response is something like, “Somebody has to do something about this.” But if the discomfort sticks in your mind long enough, you start thinking that somebody could be you, and that no effort is too small. I think I'm leaning towards trying to be a part of the solution now, and I'm so grateful for my colleagues at the UCSF Memory and Aging Center and the Global Brain Health Institute for inspiring me and enabling me to do this work. I also recently received an awesome endowment that supports my work in this area, and that's also incredibly inspiring too.

Observing People, Having Wonder

I feel like studying the brain has profoundly changed the way I see myself and my fellow humans. This view evolves as I advance in my career too. The way I observed humans, including myself, as a resident in neurology is very different than the way I see them now. I feel like I have a fuller perspective on humanity now, more

than ever before, as a result of my studies in behavioral neurology. This happens at home as well—the way I observe my kids, for example, and start to wonder about their brains, their cognitive and emotional strengths and weaknesses, and what I can do to facilitate an environment that helps them flourish. I can imagine that for some people this sounds rather “cold,” too rational, but to me it’s the opposite. Seeing humans through the lens of neurology and neuroscience engenders in me a unique sense of empathy and shared camaraderie, a special connection to my loved ones and other people. We’re all in this together, literally through our shared human brain. I feel that this profession makes me infinitely curious about people. It’s almost like I’m looking at them and wondering, “What’s unique about you?”, meaning, “What’s unique about your brain?” Because every brain is unique. It’s not like this is constantly happening in my mind! But I imagine that every neurologist, especially behavioral neurologists, at times can’t help from seeing something in a stranger or a loved one that makes them wonder about their brains.

Patient Care & Narrative: Intersection of Science and Culture

To me, one of the most meaningful experiences in the clinic is when the neurological evaluation becomes enlightening to the patient and family in ways that go beyond the issues that motivated the clinical encounter to begin with. I remember caring for a patient and family that had immigrated from a vulnerable region of Latin America. The patient clearly had a neurodegenerative disease, and the family history strongly suggested an autosomal

dominant mutation¹ as a cause. This was later confirmed through testing. Upon sharing this information with them, I learned that for generations the family had passed along a narrative of sorcery and witchcraft to explain this disease. This narrative had crept up through numerous generations of this family. The process of freeing this family from this narrative of illness using neuroscience was profoundly gratifying to me because this knowledge in a way liberated them from a stigmatizing belief. I've been in similar situations with other families several times, and it's always so moving.

Surfing— Getting in “the Zone”

Surfing has been a part of my life for many years, since I was around 10 years old. It's been a passion of mine ever since. Now I don't surf as frequently as I used to, but I live near the ocean and enjoy every surfing moment as much as ever. It's difficult to describe what surfing does to me, to my brain. Surfers describe feeling “stoked” after a good surfing session. It's a cleansing feeling, as if the ocean somehow pushed a primitive “reset button” deep inside. I wonder if this experience is not unique to surfing, perhaps people can feel “stoked” through other means. I remember talking to Heidi Clare, a musician and Atlantic Fellow at GBHI, about this. After I tried to describe how surfing made me feel, she said, “Well I think surfing is your music!” And I said, “No! I think music is your surfing!” I don't know, maybe there is something unique about being in the ocean though.

¹ A pattern of inheritance caused by a genetic mutation in just one copy of the gene. Each child of a parent with an autosomal dominant condition has a 50% chance of inheriting the mutation and also developing the condition.

I believe it's so important for people to find an activity that puts them in what I hear people call "the zone." To me, what's happening through these activities is that people are so into them that thoughts seem to quiet down, and this can be liberating in a way. You are throwing yourself fully into an activity, a movement, whatever it may be, and this shuts off other brain networks. For some people it's martial arts, music, writing, dancing — it can be anything really. For me, it's surfing, and I'm deeply grateful for it. I've met people who don't feel they have such an activity. I tell them I don't think it's ever too late to try to find it, seriously. I sometimes talk to my patients about this too, about finding moments when you lose yourself into the act of doing something. It's important, I think.

Looking at Social Determinants to Understand Brain Health

Clearly, there are several environmental factors that shape brain health, all the way from our early development to late adulthood. So far, the bulk of evidence available in this field strongly supports the hypotheses that these factors drive brain health disparities across racial groups in the U.S. Researchers have reported on differences in the prevalence of Alzheimer's disease between Latinos, Blacks, Asians, and Whites, for example. Yet fewer researchers investigate the social factors that may be driving these differences, instead focusing on biological factors, like genetics, as the cause of these differences. But there's just no way that brain health differences between socially defined racial groups correlate with genetic differences between these groups, that's just not possible based on what we know about genetics and human variation. This is why my research focuses on capturing various social determinants of health and studying how these factors influence brain health,

including epigenetics and dementia risk. I want to ask our research participants questions about educational attainment, quality of education, exposure to childhood violence, food insecurity throughout life, and other important factors, and correlate these findings with various brain health markers. If we don't gather this type of data, then when we find group differences between Latinos and Caucasians, for example, we'll have nothing other than race to ascribe these differences to, and this is problematic for many reasons.

Mortality

I may be deceiving myself, but I am very comfortable with the idea that I have no idea what happens after death. My knowledge of the brain perhaps shapes this position. I mean, what's left of me after my brain is gone? You see, it's pretty clear that I am my brain, or at least I—meaning everything that I am—depends on this brain inside my skull. Some people argue that there's no way of proving that consciousness is created by the brain. Fine, but no one can deny that the brain is necessary for human consciousness and experience. Some philosophers use the analogy of the radio transmitter: the idea that radios transmit information that is originating outside said radio, they don't create information. Fine, but without radios there is no transmission, and that's what we care about. I'm okay with this uncertainty. Not knowing whether my brain is a radio transmitter or a primary source of signals doesn't bother me because in both scenarios the brain is crucially important to me and everyone's human experience. Maybe when I die, I'll suddenly know that my brain was just a radio, but will I be able to transmit this knowledge to anyone?

On Children, Curiosity, and Valuing Difference

My children know I'm a brain doctor, and they ask me questions about the brain, so I'm hoping I pass on that sense of awe and curiosity to them. The research work I'm developing also aligns with what I try to teach them at home too. My oldest is very aware that she is in a school district where many Latino immigrant families send their kids. Many of these kids don't speak English. She sees that English and Spanish speakers start to separate into groups—they don't hang out. I think this is the beginning of the tribal mentalities that are so strong in the San Francisco Bay Area, the segregation. It happens around language, socially defined racial or ethnic groups, income, etc. This is how people start thinking along the lines of "we're different people because we speak different languages, look different, eat different food..." I talk to my oldest daughter about this. This mode of thinking carries over to health outcomes too. People start believing that certain diseases are more prevalent in certain racial groups just because "that's how things are," or because there must be something biological about a certain group that puts them at increased risk. Like people thinking that there's something genetic about Latinos, for example, that increases their risk of diabetes, not considering the shared environmental circumstances of many Latino communities in the U.S. which may be increasing their risk of diabetes. I hope that my work, which will shed light on the influence of various social determinants of health on brain health, will change ideas that people have about dementia in different socially-defined groups of people.



True Happiness is Helping Others

NARRATED BY RB HACKENBERG

**INTERVIEWED BY
JENNIFER MERRILEES,
UCSF MEMORY AND AGING
CENTER & GBHI**

Mr. Hackenberg cared for his wife who had Huntington's disease (HD). While the diagnosis brought relief and an explanation for Mary's symptoms, they both struggled with the how the disease disrupted what was supposed to be an adventurous retirement of travel and exploration. Mr. Hackenberg is an active supporter of the Huntington's Disease Society of America (HDSA) and former HDSA NorCal Chapter President. The following is the story that Mr. Hackenberg shared with our Atlantic Fellows for Equity in Brain Health at the Global Brain Health Institute in 2017.

After her diagnosis in March 2010, Mary, my wife of 54 years, died from Huntington's disease (HD) complications on August 20, 2015. It was a difficult five years beginning with a terrible shock as we did not know HD was in her father's family. He was never symptomatic. We learned more later from distant relatives.

HD often appears with involuntary movement known as chorea and/or tentative gait. Executive decision-making can become difficult. Mary had begun to walk very slowly, pulling me back if I had her arm. As home manager, she was having difficulty planning, paying bills, handling checks, even compulsively collecting newspaper travel articles to be filed.

In her last year she became more emotional—sudden crying, anger, angst—treated successfully with Mirtazapine. Gradually, she lost her ability to communicate and her mobility, and either lost her appetite or decided not to eat in spite of my efforts. When she died, she weighed 65 pounds. I carried her up and down stairs. Toilet had become an issue, so we used Depends, excellent; and sometimes had to manage her bowels, not so excellent.

We met with the UCSF Memory and Aging Team annually at first, then twice annually in the last two years. We had three neurologists in three years, all intelligent, caring female MD/PhDs. The physical therapist showed us exercises, how to get up from a fall and suggested we get a dog. We did, and the effect was joyful for Mary and the entire family.

One of the most rewarding dog values is “dog-owner sociability.” During early morning and late afternoon walks we met new neighbors down the street and around the block because the dogs reacted to each other and the dog owners talked, got acquainted and sometimes became close friends. These daily encounters were mini respites, and I met a woman, who has become a dog-walking best friend.

Another dog walker became a part-time caregiver. She and her dog came four days a week for two-hour periods allowing me to work around the house, run errands, and attend my Tai Chi class. The dogs would play to everyone’s delight. We had part time caregivers everyday but Sunday. Since care giving is more art than science, a loving, four-legged friend can make a big difference.

UCSF Neurologist Alexandra Nelson, MD, PhD, authorized hospice care in March 2014, and Social Worker Natasha Boissier, LCSW, provided referrals. We engaged Pathways Healthcare Hospice services, a godsend as the RN/Case Manager came weekly, a social worker and spiritual guide once or twice a month. After six months we were on a rolling 60-day review by a different case manager or medical director. We got a wheelchair and later a hospital bed where Mary spent her last days.

The most important hospice team member was a volunteer whose day job was department administrator at Ohlone Community College, but came every Saturday for four hours, for more than a year. On August 15, she said she would be coming the following Thursday, the day Mary left us. She was like our angel.

More than a year before Mary died, our two daughters, both university professors, steered me to a grief counselor as we all were grieving for the Mary we knew. I saw the counselor for two years, before and after Mary died. After her passing, I joined a Pathways bereavement group completing four six-week sessions.

As caregivers, we need to take care of ourselves so we can be effective in helping our loved ones. Even with our hospice team, part time caregivers, support groups, workshops and professional guidance, I had difficulty staying patient and managing anger. When someone's brain begins to fail and becomes erratic, it's hard to reconcile the behavior. You have to keep reminding yourself that it's the disease. But, most of us get frustrated, fatigued, and angry.

By their example and service, the Pathways Team taught me how to really be a caregiver, and I began to realize that helping others, especially those who cannot care for themselves is joyful. During my business career I believed in and practiced mentoring, and I learned early on from my parents and grandparents that it's more blessed to give than to receive. So, the last year of Mary's life, while difficult, was enlightening and, all things considered, rewarding.

Having lost relatives and my parents in my fifties, I knew something about love, loss, and grief. I know much more now. I turned 80 last year and have become more mindful—relaxing in the present, trying not to rehash the past or rehearse the future. I've learned the importance of counting my blessings and to fully appreciate the dualities in life—if there was no sorrow, how could we know joy? If grief is the price of love, life with Mary was a deal!

But, the most important life lesson of all—true happiness is helping others—and for the past six months I've been having weekly caregiving visits with an 84-year-old HD-positive man and his wife whose five children, 18 grandchildren, and 12 great grandchildren

are at risk for HD; both are generous donors to HD research. In fact, that's where I'm headed after this meeting.

Hear the words of Indian Guru-Poet-Composer Rabindranath Tagore—

I slept and dreamt that life was Joy.

I awoke and saw that life was Service.

I acted, and behold, Service was Joy!



He Was Still a Person

**NARRATED BY
RODRIGO URIBE-MANZANO**

**INTERVIEWED BY
STEFANIE PIÑA ESCUDERO,
ATLANTIC FELLOW**

Rodrigo is 33 years old and originally from Mexico City, but he currently lives in Colombia. He is the youngest of two sons from his father's second marriage, and the youngest of all six siblings. His dad had Lewy Body Syndrome and passed away on April 30, 2018. Rodrigo kindly shared his father's story, and his own experience as a caregiver.

My father before his illness was a very, very difficult man when dealing with other people. It's not that he wasn't a loving person, or that he didn't have emotional relationships; it was more that he wanted the people in his life to explore their full potential. He was very demanding and strict with me and had high expectations for my professional and personal future. He always said that if we put in little effort in life, we would get little back. He taught us that if we wanted big rewards, we needed to put in big effort. When he began to get sick, it was because of this personality that he refused to ask for help from his family, and we refused to believe he needed it. At first, we just thought he was stressed because of his lifestyle and owning a business, but we realized afterwards that he was not capable of doing the same things he used to be able to do.

One Sunday, my father disappeared from the house. We didn't know where he was, and he was not answering his phone. We had no way to find him. Eventually, he called my mother and told her that he was on his way to my grandmother's house to go to Mass. Because on Sundays we always went to my grandmother's house to take her to Mass. The building's security guard told us later that my father had left the apartment, gone downstairs, greeted him, asked him to call a taxi, gotten into the taxi, said goodbye

and told the taxi driver where he wanted to go. While he was on his way, he suddenly forgot where he was going. He panicked. He did not recognize the taxi driver because he was not part of his everyday life. The taxi driver realized that my father was scared and confused, so he helped him make a phone call. They ended up very close to my grandmother's house.

Luckily, my brother was there that day, so he coordinated with the taxi driver to pick up my dad at a mall. When my brother got there, my father did not recognize him at first. He also couldn't remember how he had gotten there. So, my brother took him to a restaurant to eat something and calm down. While they were eating, we called a geriatrician that my godfather had recommended. When she arrived, she asked him questions and conducted a few tests. She also did a physical exam. When she finished, she asked us all to sit around the table and told us that my father had some kind of Parkinson's variant. She asked for a lot of follow-up studies to confirm the diagnosis. By the end of the week, she confirmed her diagnosis and forbade my dad from driving. My dad was very sad when my mom took his keys from him.

He Never Knew How to Deal with Loneliness

From then on, my mother was my father's main caregiver for many years. I always set up some recreational activities for her so that she wouldn't burn out. Eventually, I moved out of the house. During the last eight months that my mother was alive, I supported her less and less, but I coordinated my five siblings to take care of my father on the weekends. It was about five years between my dad's diagnosis and my mom's death. During this period, he deteriorated in many ways. First, his body became stiffer. Then,

he began to lose cognitive processes associated with short-term memory, and personality and mood swings. Sometimes he had episodes in which he became aggressive, and episodes in which he turned into a child. He would want us to be with him, play with him, and chat with him. On top of it all, his personality turned into one of a very dependent person. He never knew how to deal with loneliness. He loved having someone next to him. Even though you were not doing anything at all, the fact that he could feel you by his side gave him security and comfort.

My mother died in a car accident, and I was in charge of telling my father. I had to tell him four times. Every time I gave him the news, he went through a very difficult emotional crisis where he cried and shouted, and then he would suddenly stop and ask for his wife again. It wasn't until the fourth time that he managed to retain the information. He became very depressed after losing his partner of over 32 years. It was this moment when I became my father's main caregiver.

He wanted everything his way. Getting him in the shower was a problem. He did not want to shower in the morning because it was very cold, and he complained if we did not buy him a certain type of shampoo that did not irritate his eyes. He got mad at us when we dried him because he thought we were too rough. Food was one of the biggest struggles during my father's illness. Before the cognitive disorder, he had tuberculosis and the diagnosis took a very long time to be made, so he already had impaired health and he was underweight. He did not want to eat anything except what he wanted, how he wanted it. It was difficult. One day, my brother took his things and left the house because we argued about what was the best care for our father. Eventually he returned, and little by little he started to understand what was happening to my father and that it was nobody's fault. He

made a conscious decision to help, and between both of us we started generating a budget for my father's care.

I Know You're My Son

I remember that my father used to tell me that I was his dad. The first few times he called me "Dad," I was angry and said, "I'm not your dad, I'm your son." I thought he was going through a setback where he thought he was a child and because of our genetics, he associated me with his father. But one day, my father talked to me and said, "No, don't get mad. I know you're not my dad, I know you're Rodrigo, I know you're my son. I see you as a father because nobody cares for me like you because nobody is as patient as you are with me and because no one knows me as well as you do. In one way or the other, you're becoming my dad because I am sick and I am very sorry to cause you trouble. I never wanted to reach the age where my son had to clean my butt, bathe me, shave me, brush my teeth or feed me because my hands do not work right even when I want to do things." I stopped getting mad after he told me that. These kinds of talks were small victories or small blessings within the process of his illness. Other days were simply him arguing or shouting because he did not want to do something because he did not want to eat something because we did not take him to the park, the movies, etc.

Give Yourself A Break

Even though he was sick, he was still a person, and he enjoyed doing things that made him happy. Sometimes when we care for someone, we provide what they need but leave out what makes them happy. What made my father happy were things as silly

as a chocolate ice cream with sprinkles. There were also the little things that my father told me, tidbits that made life worthwhile. There's one particular moment that I share sometimes when I give talks at universities. It happened while I was going through a profound emotional loss three years ago. I felt horrible, and it was worse because I felt that as a caregiver, I did not even have the right to feel bad. I needed to focus on taking care of my father. But one day, I exploded. My father was sitting in the living room and I felt like he did not understand what I was saying. I was actually screaming my emotions towards the living room, not to my dad, just to the room. I shouted that nobody cared about my feelings, or the things that were hurting me, and I did not know what to do. My father spoke to me. In a soft voice, he said, "Rodrigo, Rodrigo."

I said, "I can't hear you," and moved closer to him.

He gathered inner strength and tried to shout, "Mmmm... Rodrigo, can you hear me?"

I replied, "Yes, I hear you, don't be upset."

He asked, "You don't know what to do?"

I said, "No, I do not know what to do."

My father grabbed my head with his frail hands and put his forehead against mine. He said, "Give yourself a break, but do not give up. I think this is the best advice I can give you because if you surrender in life, nobody will pull you out. Just as I fight my illness, you have to fight what life puts in front of you. Give yourself a break, but do not give up."

This is something that I always carry in my heart and mind. My dad used to know several poems to recite them by heart at work meetings and impress his clients and co-workers, one of them was "when things go wrong." He used something that made him happy to make me happy. Days like these were rare toward the end.

An Act of Love

The most difficult part of taking care of my father was the economic burden, the lack of sleep, and the bad days. It was also difficult to watch the person you once knew disappear in front of your eyes. Not because the body wasn't there, but because he had turned into a shell that did not contain what I thought it should. I clung too tightly to a memory and a concept of who my father was that it was hard to understand that he was still my father. He was still my loved one, but he was never going to be that person I experienced new things with. And even though it sounds horrible, this new individual requires a lot more from you than you from him. I lost the idea of him as the strong, unbreakable man, and replaced it with a frail and scared person who felt defenseless towards his own disease, and a burden to his children. The absolute worst thing was the inability to fix it for him. No medication would improve his condition. All the doctors told us the same thing: there is no cure, and the only thing the medications could do was to help him have some better days than others.

I think very few people, and I am not amongst them, are trained to be caregivers for patients with dementia. I can say I was a very unexpected caregiver, but I always had the best intentions. There is a lack of awareness not only around brain health but around the aging process in general in Latin America. Nowadays, looking things up on the internet is very easy, but the truth is that worse than not having information is having the wrong information. We do not have the ability to differentiate useful information from harmful information and I was always lucky to have health professionals that clarified all my doubts. Becoming a caregiver is, even though it might sound cheesy, an act of love. If you do not feel emotionally prepared to make this sacrifice, you should not do it. It's true that the person did not choose to be sick, but

we as caregivers have the power to choose whether we want to be responsible for a person, and that comes with a high physical, economical, and emotional burden that you will never be fully prepared to bear. But I believe anyone who makes this choice will never regret it.

HE WAS STILL A PERSON

「己所不欲勿施 於人」的更高境界

鄭嘉欣敘述

鄭文立醫師採訪



Conquering Misfortune with Kindness

NARRATED BY DORIS CHENG

**INTERVIEWED BY TEE BOON LEAD,
ATLANTIC FELLOW**

鄭嘉欣律師除了是台灣國內知名律師外，她也為法扶協會與台灣阿茲海默症協會服務，提供失智症患者與家屬法律諮詢服務。輾轉機緣，我們有幸採訪鄭律師，透過她的故事，我們見證到了何謂【己所不欲勿施於人】的更高境界。鄭律師的令堂也身受失智症的困擾。疾病初期不幸遭受金融詐騙。深受其害的鄭律師開始探索如何為失智症患者與家屬創造一個安全的環境。透過法律諮詢服務，她減輕了不少失智症病患與家屬的痛苦與煩惱。

當詢問鄭律師為何她堅持提供為失智症族群提供法律諮詢服務時，她說道：“沒什麼特別…因為我自己是家屬啊！…因為我一路看到這個疾病對於一個人的改變，我自己母親也被詐騙過。如果可以的話，我希望同樣的事情，別人不需要再這樣碰到，不需要經歷過像我們這麼多的摸索、這麼多的懷疑…我知道有很多的家屬或許完全不知道要做一些預防，所以他們之後可能會面不同訴訟、不同的紛爭。如果可以的話，可能就是不要有其他的人有這樣的等於是一個不利益的狀況。”

淡然地，鄭律師透露了驅使她投入了這公益行為的動力，彷彿這是一個再平常不過的舉動。縱觀周遭，不幸事件發生時，有些人會選擇【以牙還牙】，將不幸繼續漫延甚至擴大，也有人會選擇不作為，持著【己所不欲勿施於人】的態度，但總有少數的人會選擇如鄭律師般積極避免不幸再度發生，【以德報怨】，終止悲劇再度重演。

以失智症患者的視角面對世界

“為了(避免)忘記結帳而被認為是偷東西這件事情…我們也很擔心她會不會去了商店沒有結帳，所以當時我的作法是我去附近的派出所，我去拜託派出所的人，從所長開始告訴他們說我母親有這樣的

In addition to being a well-established lawyer in Taiwan, Ms. Doris Cheng also provides legal counseling services for people with dementia and their families through the Taiwan Legal Aid Foundation and the Taiwan Alzheimer's Dementia Association. Her story epitomizes an example of conquering misfortune with kindness. Ms. Cheng's mother suffers from dementia and was a victim of financial fraud at the early stage of the disease. Since the incident, Ms. Cheng has been exploring ways to create a safe environment for dementia patients and their families. By providing legal counseling services, she has alleviated the pain and sorrows of many people with dementia and their families.

When asked why Ms. Cheng dedicated her limited free time in providing legal counseling services for the dementia community, she said: “Nothing special...because I am a family member! Because I saw how the disease changes a person, and I saw my own mother defrauded. If it is within my capability, I hope that no one else would experience the same thing...not to be lost and suspicious like we were.... I know that many families do not know how to prevent fraud from happening, so they may likely face different litigations and disputes in the disease course. If possible, I hope no other person has to go through such misfortunes.”

In her modest manner, Ms. Cheng revealed the driving force behind her charity act, as if this was the social norm. Often when misfortune occurs, people choose to retaliate, “an eye for an eye, a tooth for a tooth,” and they spread misery. Some decide to abstain from action and stop the wheel of misfortune from spinning. Occasionally, there are a few that rise above the situation,

情況，我母親有可能會忘了結帳，她可能會有走失的狀況。我希望他們遇到這樣的狀況的話，第一時間通知我，我可以去付錢或把她帶回來，（我會）做一些這樣的預防或防堵這樣的措施。那我甚至拿了一筆錢，放在離我家最近的便利商店，那我告訴他們說，如果我母親來，買了東西忘了結帳，就把這個錢扣掉，扣到最後沒有錢的時候再通知我，我會來結帳。當他們（店員）知道有這樣的狀況時，他們就會友善的對待他。那我也告訴我們附近路邊的小吃攤，說我母親可能會走失或不知道吃東西要結帳，那通知我，我就回來結帳。”在為母親創造失智症友善社區的同時，鄭律師也不自不覺地邀請了周遭的人以失智症患者的視角生活，帮助大家更深刻地體會失智症對個體所帶來的影響，也點出任何人其實都可以為提升失智症族群的生活品質做出貢獻。

自主與安全的權衡

然而為失智症族群打造安全的環境並不容易，如何在尊重自主權與安全考量做出權衡就是一大議題。“我們在講【身心障礙者權利公約】的時候，它主張賦予這些有身心障礙的人有完全自主的權利，包括財務自覺。例如在我們談到友善金融的時候，就是不能夠有任何的歧視，包括徵收性、借款貸款不能有歧視，你要給予他們一個財務發展的空間。可是失智症這個疾病，他是一個長時期不停地在變化的，甚至可能每天的狀況會有所不同的，因此友善金融的範圍可能要再更擴大。那要擴大到什麼樣的程度或者賦予這些金融業者到多高的注意義務，這我一直都在思考這個問題…因為大部分的身體障礙都是一望即知，而且很多是先天性的，所以從小父母就做好財務規劃或成人的監護宣告。偏偏失智症是本來具有的能力漸漸失去，（他們）甚至會掩飾，只有透過長時間的觀察，你才會看到有些狀況，可是這時候會不會發現的太晚，或者財務的剝奪可能已經發生了，這個（時段）是（財務的安全保障）跟【身心障礙者權利公約】最有矛盾的地方。所以我們一直在思考這個友善金融的範圍，它應該是要擴大到什麼程度。其實銀行在標示財務風險等級時，就應該要就其失智症

like Ms. Cheng, and choose to confront misfortune with kindness and a mission to prevent such incidents from occurring to others.

Seeing the World from the “Eye” of Dementia

“We were worried that she would go to the store, take things and forget to pay. So to [avoid] her being mistaken as a thief, I visited the nearby police station and spoke to the police officers, from the director to the patrolling officers, explaining to them that my mother has a condition and that she could forget to pay and she gets lost easily. I hope if they encounter such a situation, they will contact me, and I will come and pay or pick her up. I took preventative measures. I left a sum of money at the nearest convenience store and explained to them that if my mother came in and forgot to pay, to please deduct from the money I left behind, and then notify me when the money runs out. When they understood her condition, they treated her kindly. I also did the same to the hawkers near our place.” Through her own effort, Ms. Cheng created a dementia friendly community for her mother. Unknowingly she was also inviting people to build their lives around an individual with dementia, seeing the world through the perspective of one suffering from dementia, helping them understanding the impact of the disease on an individual. She is an ambassador of dementia. She showed to her neighbors that everyone can play a part in improving the quality of life for people with dementia.

的輕、中、重度做個註記，連帶其財務風險等級也要做出不同程度的提高，針對疾病的嚴重程度做不同程度的審查…金融機構缺乏辨識失智症的能力。我們曾發函給金融機構，告知個案經醫師診斷，患有失智症，爾後如果他一個人來提款或匯款，請通知他的家屬做進一步的查證…可是金融機構會回函說【我們沒有這樣的義務】。因為我們如今沒有一個指引闡明各方的義務與責任…。我一直要力推的是在【身心障礙者權利公約】的精神上，面對失智症患者擴大友善金融的範圍，不只是考量平等原則。如果過度強調【身心障礙者權利公約】的平等、自主、自覺的時候，其實他反而變成是金融機關在處理失智症個案的護身符，所以我們反而是要針對不同身心障礙的疾病提供不同的模式保護模式…（另外）家屬（有時）發現時都已經財務失去了，那這個要追回來在現在的司法制度上面其實是有一定的困難性。因為財務一定要存在司法才能進行扣押，而申請扣押的流程是需要時間的，但這段時間會不會財務就已經不見了，所以在法律層面上的處理都有時程或動作上面沒有辦法那麼迅速或即時的困難點。”

失智症不只是醫界的責任

不單是金融剝削，同樣的問題也出現在刑法責任上。“台灣刑法19條的第一及第二項，他有規定說如果你可以認知這件事情是違法的，那你就要被處罰。反之如果你在犯罪的當下，是不知道這是促法會被處罰的，那這在法律上被稱之為辨識能力不足。這件事情長久以來司法界與精神醫學界是一直嘗試要對話，但還是沒有辦法接的很無縫，原因是因為法律的用語或認知跟醫學的鑑定是有落差的…失智症的表現隨著時間與環境的不同是會時好時壞的，所以要還原到他行為當時的情況是有困難的。因此判斷個案犯罪當下是否有受到失智症的影響而違法，在醫學上面的鑑定是很困難的。那在法律上面對於這個鑑定的接受程度可能也不是百分百。另一個困難的地方是失智症患者會掩飾，他可能一被警察逮到的當下就認罪…他一認罪可能就進入簡易判決的流程。簡易判決處理就是法官不需面見被告就可以直接做出裁決，因此個案或家屬辯解的機會都沒有，個案

Autonomy versus Safety

However, creating a safe haven for the dementia community is not easy. Balancing autonomy and safety is a delicate issue. “The Convention on the Rights of Persons with Disabilities (CRPD) advocates providing people with physical and mental disabilities with full autonomy, including financial autonomy. For example, we cannot discriminate on financial matters, including loan and investment applications. However, a person with dementia’s cognitive performance fluctuates within a day. Therefore, the scope of barrier-free financial friendliness policy may have to be refined. I have been thinking about this problem because most of the disabilities are evident visually, and many are congenital, so parents often complete financial planning or financial guardianship arrangements before adulthood. Dementia, however, is a process where one gradually loses cognitive function, and people often try to mask it, so you can only discover it through long-term observation. So by the time one is noted to be demented, it might be too late and financial exploitation may have already occurred. This period of time is when balancing between autonomy and financial security become most contradictory. So we should rethink our barrier-free financial friendliness policy. It should be refined to an extent that protects individuals with dementia. Financial risk assessment should take into account the client’s dementia level and vary the financial autonomy policy accordingly.... Financial institutions lack the ability and obligation to identify dementia. There was a case in which we sent a letter, signed by the doctor stating that the person had been diagnosed with dementia, to the financial institution in hope that they would alert the family if the person withdrew or remitted money. However, the financial institutions simply replied that they have no such obligation because there is not a guideline to clarify

就已經被判決了。實質上，類似的法律流程是沒有辦法充分考慮到醫學上失智症的影響……以我在實際處理案件的經驗，刑法19條運用在失智症的案件並不很高。”可見為失智症創造安全的環境，單靠醫界的力量是有限的。鄭律師這段話帶出了促進醫界、司法界與金融界針對這些議題對話與達成共識的重要性。

失智症的【家家有本難念的經】

“這個疾病其實不只對個案本身，對整個家庭都造成很大的影響。例如會產生扶養個案責任分配的爭議、或者當資產被剝削時，個案也說不清楚不見的時間或原因時，容易造成家屬間的誤解，造成手足撕裂。也有個案是老人家想要結婚，那子女想要阻止他，這也是一種。那有的是個案要去收養外人，或個案收養了好幾個子女，而衍生出終止收養關係或收養正當性的問題……那我們本來就不是很善於在家庭當中去溝通聊天、促進情感聯繫的民族。現實上來說，很多時候法律只能提供解決最基本的安全醫療照護保障，但老人家即使有失智的情況，在看不到自己的子女家人，其實對他心理上的傷害是很大的。對老人家來說，對遺棄罪的家屬進行法律層面的處罰並不是他要的，在這件事情上法律是很無力，法律是無法帶來家庭和諧的。”如果【法律是道德的最低標準】，那我們是否應該只以法律規範的標準來照護我們失智年老的族群呢？

擴展退休計畫的面向

“議定監護人與財務剝削的預防是可以提早做預告或註記的，包括友善金融、友善的戶政或友善的地政，目前是推到輕度認知障礙的階段在做宣導的。”鄭律師帶出了提早規劃的重要性，將財務與醫療決策的規劃納入退休計畫的一部分，或許是邁入樂齡階段贈與家人最

the obligations and responsibilities of all parties. I am advocating that in addition to the spirit of the Convention on the Rights of Persons with Disabilities, barrier-free financial friendliness policy for people with dementia should not be solely about the principle of equality. If we overemphasize the equality, autonomy and mindfulness of the Convention on the Rights of Persons with Disabilities, it becomes an excuse for financial institutions to hide under when dealing with dementia cases, so we should provide different protection mechanisms for diseases with different physical and mental disorders.... Also under the current judicial system, by the time family members discover the financial exploitation, it is difficult to recover the assets. Because the assets must be within possession in order to detain, and the application process of assets seizure takes time, but more often than not, by the time the legal process is completed, the assets are long gone and untraceable.”

Dementia: Everyone’s Responsibility

Not only financial exploitation, but the same problem arises in criminal law responsibility. “The first and second items of Article 19 of the Taiwan Criminal Law stipulate that if one has the ability to recognize an action is illegal, then one will be punished by law. If at the moment when crime is committed, one cannot comprehend that the action is illegal, then the action will not be punishable by law, this is the legal definition for “lack of identification capacity.” This issue has long lacked consensus between the judiciary and the psychiatric community. There exists a gap in the terminology and understanding of such conditions.... The cognitive performance of dementia varies and fluctuates with time and environment, so it is difficult to restore the situation completely to when the incident occurred. It is medically challenging enough to decide

好的禮物。

近九十分鐘的訪談，鄭律師以柔和的聲音及堅定的眼神，跟我們分享了很多大家還有待努力的方向。然而近一萬字的訪談中，她不曾使用“愛”這個字。她似乎以行動表明了她對母親的愛與照護，或許唯有如此深度的親情才能成就她對失智症這般深刻的了解及驅使她對其他失智症個案偉大的無私付出。

whether a person committed an illegal act due to dementia. Furthermore, such medical opinions are not widely accepted in the judicial system. Another challenge is that dementia individuals may try to conceal their condition and plead guilty when arrested by the police.... The legal process would then enter the “expedited ruling” process in which the judge can directly hand out a ruling without meeting the defendant. Such a ruling process, therefore, deprives the individuals with dementia and their family members the chance to defend their actions due to medical reasons. In short, the legal processes do not take into account of the impacts and characteristics of dementia. My experience is that the application of Article 19 of the Taiwan Criminal Law in individuals with dementia is not very high.” Thus, creating a safe environment for people with dementia cannot rely solely on the medical community, but has to expand and include other professionals as well. This statement by Ms. Cheng highlighted the importance of communication and establishing consensus among the medical, judicial and financial communities in building a dementia-friendly society.

Dementia and Law: Domestic Solutions?

“Dementia does not only impact the diseased individuals, but also impacts the family members deeply. For example, disputes over the caring obligations for the individuals with dementia, or when the assets are being exploited and the individual with dementia is not able to provide clear information on when or where it went missing, misunderstandings arise between family members that can tear them apart. There are also cases where an elderly couple wants to get married, and the children want to stop them. Some

HEAR/SAY

cases have conflicts on the legitimate adoption of an outsider, or other siblings.... Our ethnicity is not very good at communicating with people or strengthening emotional bonds. In reality, the law can only provide the most basic security for care, but even for an elderly person with dementia, estrangement from family could cause huge psychological damage. For the elders, penalizing their family members with abandonment law is not what they yearned for. The law is very weak on this matter, and law cannot bring family harmony.” If the law is the lowest standard of morality, then should we only conform to judicial standards when caring for our elders?

Expanding the Scope of Retirement Plans

“Directives for financial matters and financial preferences can be documented in advance, including financial investment, assets, or lands, which (the government) is currently promoting for the population with mild cognitive impairment.” The importance of early planning and the inclusion of financial and medical decision-making as part of retirement planning may well be the best gift elders can bequeath to their loved ones.

In this 90-minute interview, with a soft gentle tone, Ms. Cheng shared with us her insights on how we can build a better future for individuals with dementia. She expressed nearly ten thousand words in the interview, but none of them was the word “love.” Yet it is apparent that her actions portray love. Perhaps it is the profound love that she has for her mother that granted her the gift to empathize with people who have dementia and dedicated her into her selfless services for the dementia community.



She Was Going to Be Independent

**NARRATED BY JENNY ZITZER,
ATLANTIC FELLOW**

**INTERVIEWED BY
JENNIFER MERRILEES,
UCSF MEMORY AND AGING
CENTER & GBHI**

Jenny Zitzer's grandmother, Katherine, was full of character and integrity. Her strength, honesty, and sense of humor never faded with age. While living in Hungary during World War II, Katherine was the only one of Jenny's grandparents' family who avoided being put in a concentration camp. She was able to do this by obtaining, with the help of her husband, fake identification papers (that he couldn't get for himself). Katherine influenced Jenny in countless ways. Katherine's tenacity and generosity left an indelible mark, not only on Jenny, but on her grandchildren and great-grandchildren's lives. Katherine's story is a profound reminder of the powerful nature of the relationship between a grandparent and a grandchild.

She Was Going to Be Independent in Spite of Whatever He Said

It's nice to talk about my grandma. I really, really do miss her. She was born in 1920, in Budapest. She was there after the Second World War, and then she moved to Venezuela in 1946 when she was 26.

She got married in April 1944, during the war. It was very funny because the Nazis got to Hungary in 1944. Hungary was one of the last countries that they actually got to. When my grandma's parents got the letter that they needed to put the star on their clothes and go to the concentration camps, she said that she's not doing that. Her brother was already taken; he was in Germany. He was one of the first to be taken by the Nazis. But she was living with her

parents and her grandma. And she's like, "I'm not going to do that. I'm gonna get some fake papers, and I'm not going anywhere." Her grandma started crying, saying to her, "How can you do that? How can you leave me alone? You just can't." She said to her — she was 23 or 24 at the time, "You're a grandma. You have already lived. I have not. So, yes, I cannot be thinking of you at the moment. I need to think about myself." She actually did get fake papers. She was the only one of my four grandparents that was never in a concentration camp. The other three were in concentration camps. She had fake papers, and she even used them to work in a police station. She would carry a Christian Bible with her, and she would know all the prayers, and she had her fake name. It was all part of her disguise.

When my uncle was born in 1947, she didn't realize she was pregnant because of the fact that she didn't eat so much and wasn't getting her period regularly. It took her seven years between my mom and my uncle. They're seven years apart. She endured a lot during that time. She worked as a helper in a prostitution house. You couldn't talk about prostitutes in front of her. She would always, always defend them. Oddly enough, she ended up getting kicked out of there because one time she was cooking for them, and she couldn't help it — she ate the food that she was cooking. They only kicked her out, instead of sending her to the police.

When she moved to Venezuela, she took my grandpa's name, which is not a Jewish name. My brother and I don't have Jewish names either. She was her own person, always. She always had friends. She always, always worked. She started when she got to Venezuela. My grandpa didn't let her work in the beginning. You know: "You're a woman. You're a married woman. You're not supposed to work." She didn't agree, so she started taking driving lessons because she was going to be independent in spite of whatever he said. But she was doing it in secrecy. He didn't know that

she was taking driving lessons until one day someone told him, "I saw your wife driving by the other day," and he was like, "What?" So, he hired someone on a motorcycle. They would clear the way for her because he was like, "You cannot drive. You just don't have the capabilities." Obviously, she ended up driving. His job was importing cars from abroad to Venezuela, so at some point he gave in, and she started being the one to drive the new cars from the port to Caracas, and then they continued working together until he retired. At some point, they started making cars in Venezuela, so they stopped importing. Then they opened a T-shirt factory, and she started working in the T-shirt factory when he retired. She worked there 'til the factory had to shut down in 1999. After that, she did community work. She basically worked until she moved to Israel. She didn't want to move to Israel, but the situation in Venezuela got too bad.

Three Levels

I feel that my relationship with my grandma has three levels. As a kid, I don't remember her ever playing with me. It was more like I was there, and she was there, and we each did our own thing, but it was comfortable. I think I actually started talking to her when I grew older, and I started seeing how difficult her life was and what she made out of it, and how she managed to stay happy. It's not like she was a happy person. She was a very bitter and sarcastic person. But I loved it. She had this dark humor that would be super funny for me. I remember one anniversary of my parents', and they were talking about their thirty years together, and she was like, "Oh, it's starting to get serious," and my parents were like, "Up until now we were playing around." I used to go to her house every Saturday, and I used to spend spring break or

Christmas break at her beach apartment. I don't remember having conversations with her back then. But she was always there.

The second level was actually when we started *fighting* a lot. I had a horrible relationship with my oldest cousin, and my grandma tried to fix it a couple of times, but she never could. I would get so mad at her for even trying. And she used to make fun of me. It would drive me crazy. I know I have a difficult character a lot of times. I know that I can be a difficult person, but she would point it out. I was ten, and I'm like, "Why are you pointing that out? Like why?" So, we had a really tough couple of years. There was a time that I told my mom, "I don't want to go to sleep at her place anymore. I don't. I'm old enough to stay home alone when you're on date night." I was around 10 at that time that I was having trouble with her.

And then I think there's a third level, when I grew older and started understanding how, even though she's not the most amazing grandma, how much of an amazing *person* she is, and how much I could learn from her. So that's why I started admiring her more...everything she needed to do, she did. I hated how she drove. We say that when she would give you a kiss or when she tried to caress you it was also very...like there was a hardness or something. As if it wasn't something completely natural. But that doesn't mean that her love wasn't natural. She had something that I cannot quite explain, that for me was very contradictory in her character, like she was very giving and very egoist at the same time.

It just still amazes me today, that while she wasn't the warmest person, she managed to keep a strong family base. Like while she wasn't the warmest person, she was a social person. Which is this contradiction that she had surrounding her all the time - it's something that really amazes me, I guess, that she just felt so comfortable being who she was. Maybe she wasn't the sweetest grandmother, but as a person, I think there was a lot to learn

from her. From always wanting to learn, and always wanting to be useful.

She was always like, “My money is here to be yours.” A lot of people want to hold their money and she’s like, “No, my money is to share with the family.” My brother is the oldest grandkid, and he was 16 when my grandfather passed. My grandma gave my brother my grandpa’s car. She was so giving with her money. Like I remember when I wanted to buy a house, she gave me part of the start-up money. I think her values came from her life experience, where the things that you need, the things you should have...she could provide that. When she turned 80, she did a trip for the whole family in Europe that started, obviously, in Hungary. And she took my parents and my uncle and his wife and my cousins and my brother to Europe for three weeks. She loved to travel. She would travel twice a year. She wanted to see all the continents, and so she did. And she read a lot. She read until the end of her life. I think she liked drama books a lot. Maybe some novels.

I remember my parents used to have a date night every Saturday, so that is why I used to sleep at her place every Saturday. I remember watching telenovelas with her because my parents wouldn’t let me, and she would watch it with me. And I remember that she would also let me drink coffee in the morning, so I had the most amazing coffee at her house, but it wasn’t made by her. She had a maid who was there since my mom was nine. And, she was also kind of like a grandma to us. And she would make the most amazing coffee ever, and they would make *palacsinta*, which are like Hungarian crepes. I would eat one every Sunday morning with the coffee. My grandma would let me eat the weirdest stuff. In Venezuela, they sell powdered milk. She would let me eat the powder that my parents wouldn’t let me eat. I remember there was a wide plate with a flower on the side, and she would let me fill it into the flower. And I would eat powdered milk at her place.

Safta Safta

She was 94 when she moved to Israel, and she worked up until that time in Venezuela. And that's actually when she started to decline—when she stopped working. My grandma moved to Israel the day my middle child was born in March 2015. The oldest one still calls her “Safta Safta.” *Safta* means grandma in Hebrew. And they all still call her that. It was actually very funny because with each kid she was completely convinced that they were going to be boys. And every time I was pregnant, she was like, “It's going to be a boy!” And it never was a boy.

She has a funny relationship with each of my three daughters. My oldest daughter has her name, sort of. Her name is Katherine, and we call her Kate. Now, Ashkenazi Jewish people don't pass on names until the person dies. But I really, really, really wanted my daughter to have her name. Like I said before, the day my grandma moved to Israel is the day I delivered my second daughter. I delivered in the morning, and in the afternoon she got to Israel. Then, my grandma passed away two weeks before my youngest was born, and according to Jewish religion, your soul passes on to the next person in your family that is born. So, I always say that my youngest daughter has her soul. And the youngest one, hopefully she carries her.

She stopped working when she moved to Israel. Also, she moved into my parent's house, and she lived with my parents for around eight months. She hated it. She always felt that she was in the way of my parents. I remember that when she moved to Israel, she used to tell me, “I hate being here. But I understand that what I miss is not in Venezuela anymore.” I think that's actually why at some point she just gave up. She was like, “This is not a life worth living,” because she couldn't take care of herself. And then

she ended up moving to an elderly house, and things continued going downhill from there.

She didn't want to put anything in her room because she was like, "This is not my place." And in Venezuela, you always have a maid at home—I grew up with a maid. That's how old South American countries are. She had someone, like a caregiver, at the elderly home, but the person wasn't helping her. Yes, they cooked, they cleaned. And the fact that there was someone there specifically to help her just drove her crazy. But she needed the help. She wasn't capable of cooking anymore. And her balance wasn't so great. She needed someone to be there in case she fell. She still showered by herself, but she needed someone to be there in case she fell. She hated it because she was always very independent.

I think that the hardest part for her was when we took the car away. She had a really bad car accident, and we were like, "Okay, that's it. You're not driving anymore." We took her independence away. She was already eighty or ninety or something.

My Grandma Always Needed to be Learning Something

My grandma was very impressive—she always wanted to learn, and when she was still in the elderly house, she was taking Hebrew lessons. She was ninety-four. She was taking lessons because she was like, "If I'm going to be in Israel, I need to know how to talk!" She never gave up on anything regarding learning. My grandma always conceded that you needed to keep learning, and she always said to me, "Don't ever stop working. Whatever you do, don't ever stop working." She didn't have a purpose anymore. She knew that she wasn't accomplishing very much with her Hebrew lessons, and I think that bothered her.

Like I said, my grandma always needed to be learning something. I remember when they opened this program for elderly people in the Venezuelan Jewish community. They used to come and pick her up from her house and take her there. It was very comfortable, but after two weeks, she came back and said, "I'm not going there anymore." I asked why, and she was like, "Because they play with Play-Doh! I went through kindergarten ninety years ago! I don't need to go through this again!" She wasn't very mad, but...we were like, "Okay, grandma. Yeah, point taken."

At some point we wanted to get my grandma with this really nice guy in the community. We wanted to get them together. And she was like, "Are you crazy? He's like ninety years old!" And I'm like, "Yeah, so are you!" And she said, "Yeah, I grew old, but my taste didn't!"

My grandma did change at some point. She started taking less care of herself, and it seemed that it didn't matter if she didn't look good. So, there was a change toward the end.

The last time I saw my grandma was in the hospital. Her death was very hard on all of us because even though she was 96, she was fine. She just started complaining about being dizzy, and my mom decided to take her to the emergency room. And I told her, "Please don't do that. You don't want a 96-year-old person hospitalized. There's no worse idea than that." But my mom just felt that she didn't have any more options because they had been sending her from one doctor to another. And you know, it's a universal health system, which could be great, but then each appointment takes two months to get. So, she ended up hospitalizing her.

My grandma called me, and she said, "Jenny I have a cough. You think you can bring me some medication for the cough?" And I was like, "Grandma, you're in a hospital, ask the nurse, ask the doctor." And she said to me, "They don't really care." I feel really bad in retrospect that I didn't make more of an issue with that.

I went to the hospital the next day, and I told them that we're gonna take her home against advice. And then on Friday, the doctor who was on call, who was actually *not* a resident from the service, called me and he was like, "Look I don't know your grandma—I don't know the patient, I don't know the case. But she has a very bad cough." And I was like, "Oh yeah she's been complaining about it for three days." And he's like, "And I'm seeing that they haven't taken blood samples since she was hospitalized on Sunday. So, before I release her, at least I want to make her do an X-ray and take some blood samples." And then we realized she had very bad pneumonia.

She ended up dying from that. But she really didn't want me to remember it. She said, "The last image stays with you forever. And I don't want your last image of your grandma to be like that." So sometimes I wonder if it was a mistake to see her like that because...like I said she was always a strong person, *even* when she was shrinking in the moment.

Her death got me mad at the system, which is something that I didn't have before because she was complaining of a cough since Tuesday, and no one even took a blood sample. And when I tell this story, people are like, "Well, but she's 96," and I'm like, "Who cares, she's alive!" And you know that hospitalizing people at 96 is not a good idea, but it's like that complete lack of respect for a person just because of their age.

My grandma was a curious person for sure. She wasn't content sitting back; she was always wanting to learn. She was *very* practical. She didn't love sharing about what it was like being in Hungary during the war and visiting my grandpa. I think that if I had tried harder, she might have shared more because she did start talking more about her past life. Something that I came to realize only a month before she died is that she actually worked as a nurse helper in a hospital, in the geriatric service. She said,

“Well, I wanted to be a doctor, so I needed some experience.” And I never knew that! She always wanted to be a doctor. And I’m surprised that she never pursued it after she got to Venezuela.

Some Final Thoughts

This epilogue was written in 2017, when Jenny was pregnant with her third daughter.

My grandma passed. Yes, I know, she was 96; she lived a full and happy life. She had a nice family, a nice house and couldn’t ask for more. I know all the things we tell ourselves to make this separation less painful, but as much as they’re truth, they don’t really take the pain away. Yes, she was 96, but she was still a human being, she was still a mom, she was still a grandma, *my* grandma, and somehow, she managed to convince me that she’ll be here forever.

To those who met her at the end of her life, she was such a sweet person. Boy, were they wrong! She didn’t even know how to properly caress someone. As I look back, I remember that I spent most of my childhood fighting with her. My mom used to say that we were too much alike, according to her that was the problem, and I truly hope my mom is right. No doubt we had a connection, her birthday is a day before mine; she always dreamed about becoming a doctor, but World War II didn’t let her, so I got to realize her dream. When I moved to Israel, she use to say that her dad, the eternal Zionist, brought me here for her to follow. My eldest daughter has her name, my youngest was born on the day she made Aliyah, and the one that’s in my belly, according to Judaism, will get her soul.

So, as I was saying, *sweet* is not the word to describe her. She was way more than that, she was a fighter. Every story she ever told me was filled with love for life. She told me that when the Nazis came to Budapest and asked all the Jews to wear a star and pack their stuff in order to move to concentration camps, she said “NO!” She got a fake Christian ID and took off; her grandma cried and begged her not to leave, but she said: “You’re old, you had your life, so stop crying and let me go get mine.” That was her, never mincing words.

But it wasn’t only during the war that she was tough, she was always tough. I remember I took her back from the cemetery after Magda, her best friend, died. During that car ride she complained to me that all her friends were dying. I tried to cheer her up and gave her examples of other friends who were still alive, but her answer was: Are you crazy, she’s not my friend! I don’t even fight with her; ’cause you only fight and try to change the opinion of those whose opinions are important to you. Magda, that same friend, asked her back in 2002 to go watch *The Pianist* with her, but in the middle of the movie she couldn’t take it and wanted to get out of the theater. What did my sweet grandma answer? “Are you crazy? You were there, you knew what we were coming to see, so if you made me pay for the ticket we’re staying till the end!” Super sweet!

Still, last week when I visited her, she was studying Hebrew because if she was to be here, she wanted to learn the language. She asked almost every day: “What’s the plan today?” Couldn’t stay still. So, if my mom is right, and we used to fight ’cause we are too much alike, then I’m a lucky woman, ’cause she’s the person that I admire the most in this planet. She was strong, outspoken, assiduous, decisive, hardworking, smart, stubborn, and still toward the end of her days, she left an impression in everyone she met.

“Grandma, I don’t even know if I ever told you how much I love you and admire you; and yes, 96 years is a lot, but when you get to the end of it, it’s probably not so much. However, it got to be too much even for you. You hated seeing yourself forgetting stuff or depending on other people, so I will try to remember you dancing till 4:00 a.m. like you did at my wedding, and I’ll tell myself what everyone says: It was better this way, it was what she wanted and she lived a full and happy life. I hope you’re resting wherever you are, and that you know how much of an inspiration you will always be for me.”





He Just Does It

NARRATED BY RANDI SWINDEL

**INTERVIEWED BY JACK TAYLOR,
UC SAN FRANCISCO**

In this interview, Randi Swindel shared a handful of stories, including several important moments, people, and lessons from her life. Randi was also able to articulate the connections between these stories and her current experience as a caregiver to her husband, Jim Swindel. Randi is an active participant in one of the Alzheimer's Association's caregiver support groups hosted at the San Francisco Institute on Aging. Her experience and compassion continue to provide great support to the other group members, both new and seasoned.

There Was Just—A Spark

The end of the 70s, early 80s—that was really the peak of the record business. Saturday Night Fever was a record and a movie, and that one flew—literally flew—off the shelves. I mean we had stacks of them to the ceiling. Then, not long after that came Michael Jackson's Thriller. The money was flowing fast and furious—it was crazy. It was three-martini lunches and more.

I was managing a record store in Fresno, and Jim was the regional marketing director. He walked in the store, and...we developed a business relationship. We became friendly—business-relationship-friendly, and being in the business, we obviously had a lot of common interests in music and friends...but we both had a rule that we didn't date people in the business. Well, we had a lot of fun once we met. You know, he worked for Quincy Jones, he worked for Clive Davis, and we met a lot of celebrities, worked with a lot of people. Some of them were wonderful, and some of them were awful. So, cut up to a couple of years later, we

were backstage at a show. We had our rules that we didn't date people in the business, but I always got the sense that he was kind of interested in me, romantically.

That night, when we went to the show, something happened. We were backstage, looking at each other from across the room, and there was just—A SPARK.

I'd come with somebody, he'd come with somebody else, but we ended up going home together. Sure, there were some logistical things that we needed to take care of, but really from that point on, we've been together. Our relationship had a foundation of great friendship and professional, mutual respect, so when the romance came, it was great. We were able to party and make a living at it, and all our social needs were met, as well as our financial needs. It was a lot of fun, and there was sex, drugs, and rock and roll—there was definitely that. That was thirty—oh my God—that was thirty-seven years ago. Yes, thirty-seven, and we've been married for almost thirty-five.

There Was No Big Bang

Our relationship has grown in ways. We have children, we've got a granddaughter, we've got extended family. What was great was that he fit really well into my nuclear family. I fit really well into his. I loved his family. He loved mine. And even our parents had a lot in common, and they would see each other socially from time to time, apart from us. His sister is my best friend. Our family has given our relationship a really strong foundation, but clearly, now that I'm his full-time caregiver, it's gone through a big change.

Jim's diagnosis is Lewy body dementia (LBD), but the classic symptoms that often bring people to get a diagnosis of LBD—hallucinations and REM sleep disturbances—he had none of

that. I realized—I don't know what happened—but I started sort of looking back, and thinking about the things I had noticed over the preceding year...

Jim, for an old guy, was always very technologically savvy, and he'd switched from a Blackberry to an iPhone. He was having a hell of a time figuring out his iPhone. Now, I got an iPhone around the same time. I'm a technological moron. I had no trouble with it, going from a flip phone. So that was one thing. Adding up a restaurant bill. All of a sudden, he could not add up a restaurant bill, let alone figure out the tip, but he was using an expense account and was out to dinner all the time; it was second nature for him. He'd become super dependent upon me, stopped reading his Kindle, and he was a little more stooped. I noticed that when he got out of bed at night, I could hear his feet shuffling on the floor, which I'd never heard before. Pretty subtle, right? So there was no big bang—it wasn't all of the sudden. This was over time.

I said to Jim, I said to him, "I think there's a cognitive problem here, and we need to get you tested." And instead of like most people saying, "Oh no, not me, I'm fine." He was like, "Really? Sure." Well, his memory was still quite good, but his executive functioning was going. It's been about five and a half years since I noticed something.

I Feel Like the Cobwebs are Clearing

[Jim's] mom had Alzheimer's disease, and we think his dad had Lewy body. My mom had Alzheimer's. So, we've had some experience. We have a context for what's happening now, and that's been helpful to us—to Jim. He knows what he has, he knows what he's going through, he's got a context for it. But we saw a doctor. I guess I said, "Well what about Aricept?" And maybe

three months later, they were like, “Yeah, let’s try it!” We did, and it made a huge difference. For about a year, I mean it was night and day, and Jim would say, “I feel like the cobwebs are clearing,” and it felt like we reset. And then it sort of stopped working. However, he’s still on it. He’s still not having hallucinations. So we’re sort of positing that perhaps it has kept the hallucinations or maybe even the REM sleep disorder at bay. He sees...well you know when we look at clouds, and we can see a horse or a pig or dragon—he would look at this [*Randi pointed to the wooden tabletop*], and he would see many patterns that turn into things. But he doesn’t have the classical hallucinations—of people in the corner.

He Would Be There for Me

What’s changed is that his executive functioning has continued to diminish. The Parkinson’s now has really started to take hold, and as a matter of fact, we’re about to start with some medication for it. We didn’t want to add another drug, but I think it’s time. He has lots of slowness, trouble balancing or transferring from chairs, visual-spatial issues...trying to get dressed, you know, two legs in one pant leg, arm through the head hole. He needs a lot of help and assistance with daily living. It’s hard.

At times when I get frustrated, I remember he was there for me. I’ve had a couple of bouts of cancer, and I’m in my second nine-year remission. When I was sick, both times, Jim was a great caregiver. I know if the situation was reversed, absolutely, he would be there for me. He wants me to take care of myself, too, which is why I think he feels good that he can be home alone, and that he doesn’t need somebody to come babysit him. He is very cautious, has a life alert, has this little dog, and he wants to remain as independent, within the parameters, as he can. He’s

being mindful of the stress that it puts on me, and he does his best to be a good caregiver.

As I said, Jim was not in denial about his diagnosis, and I didn't have to hide it or go on the DL to cover it up and pretend it wasn't happening. When he got his diagnosis, he literally got on the phone with his closest family and friends and said, "Look, I don't want you to hear from somebody else, I want you to hear it from me." So as a caregiver, that right there took off a huge burden because I know so many caregivers who not only have to keep it a secret but also (half the time) their loved ones don't even recognize that they have dementia. It's also been really important for me to ask for help and look for help. I had a really good friend one time say, "You know what?" [*Randi smiled, laughing*] She was really pissed at me. She said, "Why are you denying me, and other people that love you, the ability to support you?" It was a real eye-opener. So I am open, and I ask for help if I need something.

So that's sort of how it is, about four years in. My hope is for him to be able to stay home for the whole thing. But, then again, he's 6'5", he weighs 200 pounds. I don't know how feasible that's going to be. I don't have a crystal ball. If I had dementia, I'd want to climb under the covers and not get out of bed, but Jim does it. He puts one foot in front of the other, and he just does it.

Coda

The interview concluded with Randi receiving a phone call from Jim. The little dog had escaped from the house, and Jim felt quite anxious. Randi spoke to him with a calm, reassuring love and excused herself gracefully. The dog was found shortly after.

Since this interview, Jim passed peacefully, surrounded by family. “We are grateful for the wonderful care and support he received at UCSF; especially from his neurologist, Dr. Aimee Kao, who has become a treasured friend over the past five years. Jim’s brain was donated to UCSF Neurodegenerative Disease Brain Bank in the hopes that this can promote research that may help others affected by dementia.

Jim always said, “You are welcome to my brain—I’d just like to hang onto it a little longer.”

Resources

The stories in this book are derived from interviews with a narrator that are recorded, transcribed and then edited into the final form. We encourage you to collect stories from the people in your life—especially those that may not have had a chance to voice their lived experience.

Intrinsic to the *hear/say* process is the understanding that stories belong to their narrator. The narrators choose the experiences they want to share, and they decide how broadly to distribute the final story. If you do interview someone, be sure to explain your intent and process and give them every opportunity to ask questions and reconsider participating (or not). When you work closely with the narrator to honor their story in their own words, the ultimate connection between interviewer and narrator is tangible and profound. Go find out for yourself!

The following resources have been collected as a starting point for oral history projects. They include books on methodology, oral history organizations and archives, resources on trauma and self-care, and devices and services used during the interview process.

ORAL HISTORY METHODOLOGY BOOKS

Mayotte, Cliff, and Claire Kiefer. *Say It Forward: A Guide to Social Justice Storytelling*. Haymarket Books, 2019.

Ritchie, Donald. *Doing Oral History*. 2nd ed. Oxford University Press, 2003.

ORGANIZATIONS AND ARCHIVES

Studs Terkel Radio Archive: studsterkel.wfmt.com

Columbia University Center for Oral History:

library.columbia.edu/locations/ccoh.html

Oral History Association: www.oralhistory.org

StoryCorps: storycorps.org

TRAUMA AND SELF-CARE RESOURCES

Stamm, B. Hudnall, ed. *Secondary Traumatic Stress: Self-Care Issues for Clinicians, Researchers, and Educators*. Sidran Press, 1995.

Lipsky, Laura van Dernoot, and Connie Burk. *Trauma Stewardship: An Everyday Guide to Caring for Self While Caring for Others*. Berrett-Koehler, 2009.

Compassion Fatigue Awareness Project:

www.compassionfatigue.org

Emergency Kits by Capacitar:

www.capacitar.org/capacitar-emergency-kit

INTERVIEWING SOMEONE WITH A COGNITIVE IMPAIRMENT

Everyone has stories, and a cognitive impairment does not have to be a barrier for someone to share a story. The person with a memory impairment, trouble finding the right word, or other issues affecting speech can and should be able to engage

in an interview. As an interviewer, being mindful of supportive strategies can help make the interview a success.

If your narrator speaks slowly, be patient and give them the time they need to complete what they want to say. If the narrator has trouble coming up with the right word, you can gently and respectfully suggest a word, yet make sure the narrator appreciates your assistance. If they would rather finish speaking on their own, let them.

For a narrator with memory deficits, avoid asking long and complicated questions as the person may lose track of what you are asking. Instead, ask concise questions that perhaps have less to do with facts but focus more on emotions and feelings. For example, rather than asking, “How many years did you live in the town you were born?” you might ask, “Can you tell me something about your childhood?” If your narrator mixes up facts, it’s not important to correct them: they are telling you the story in the way they remember it.

If the person becomes restless or anxious, this can be a sign that the interview process is becoming stressful or overwhelming. Consider ending the interview—you can try again at another time.

PRODUCTION RESOURCE LIST

The following is a list of recording devices, transcription services, website hosts, and print publishers that you might consider for creating and sharing your oral history project. The technology involved can be as simple or as complex as the project requires.

Recording Devices

Your smartphone's pre-installed applications:

Voice Memo for iPhone and Voice Recorder for Samsung

Rev: a free app for iOS and Android

Voice Record Pro: free and paid versions available for iOS

Transcription

Trint (free trial): www.trint.com

InqScribe (free trial): www.inqscribe.com

Wreally (free trial): www.transcribe.wreally.com

Websites

Wordpress: www.wordpress.com

Wix: www.wix.com

Google Sites: www.sites.google.com

Print Publishing

Lulu: www.lulu.com

CreateSpace: www.createspace.com

Lightning Source: www.lightningsource.com

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About GBHI

In 2015, The Atlantic Philanthropies offered significant funding to the University of California, San Francisco (UCSF) and Trinity College Dublin (TCD) to establish the Global Brain Health Institute (GBHI) to tackle the looming dementia epidemic and improve brain health worldwide. GBHI works to reduce the scale and impact of dementia in three ways: by training and connecting the next generation of leaders in brain health through the Atlantic Fellows for Equity in Brain Health program; by collaborating in expanding preventions and interventions; and by sharing knowledge and engaging in advocacy.

GBHI brings together a powerful mix of disciplines, professions, backgrounds, skill sets, perspectives, and approaches to develop new solutions. We strive to improve brain health for populations across the world, reaching into local communities and across our global network. We focus on working compassionately with people in vulnerable and underserved populations to improve outcomes and promote dignity for all.

UC San Francisco
675 Nelson Rising Lane, Suite 190
San Francisco, California 94143
USA
GBHI.org

Trinity College Dublin
Room 0.60, Lloyd Institute
Dublin 2
Ireland



About Voice of Witness

Voice of Witness (VOW) is an award-winning nonprofit that advances human rights by amplifying the voices of people impacted by injustice. Cofounded by Dave Eggers, Mimi Lok, and Dr. Lola Vollen, we explore issues of criminal justice, migration, and displacement, and forge space for marginalized voices to be heard. Our book series depicts these issues through the edited oral histories of people most closely affected by them. Our education program connects educators, students, and members of justice movements with oral history tools for storytelling and social change.

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