UCSF Weill Institute for Neurosciences

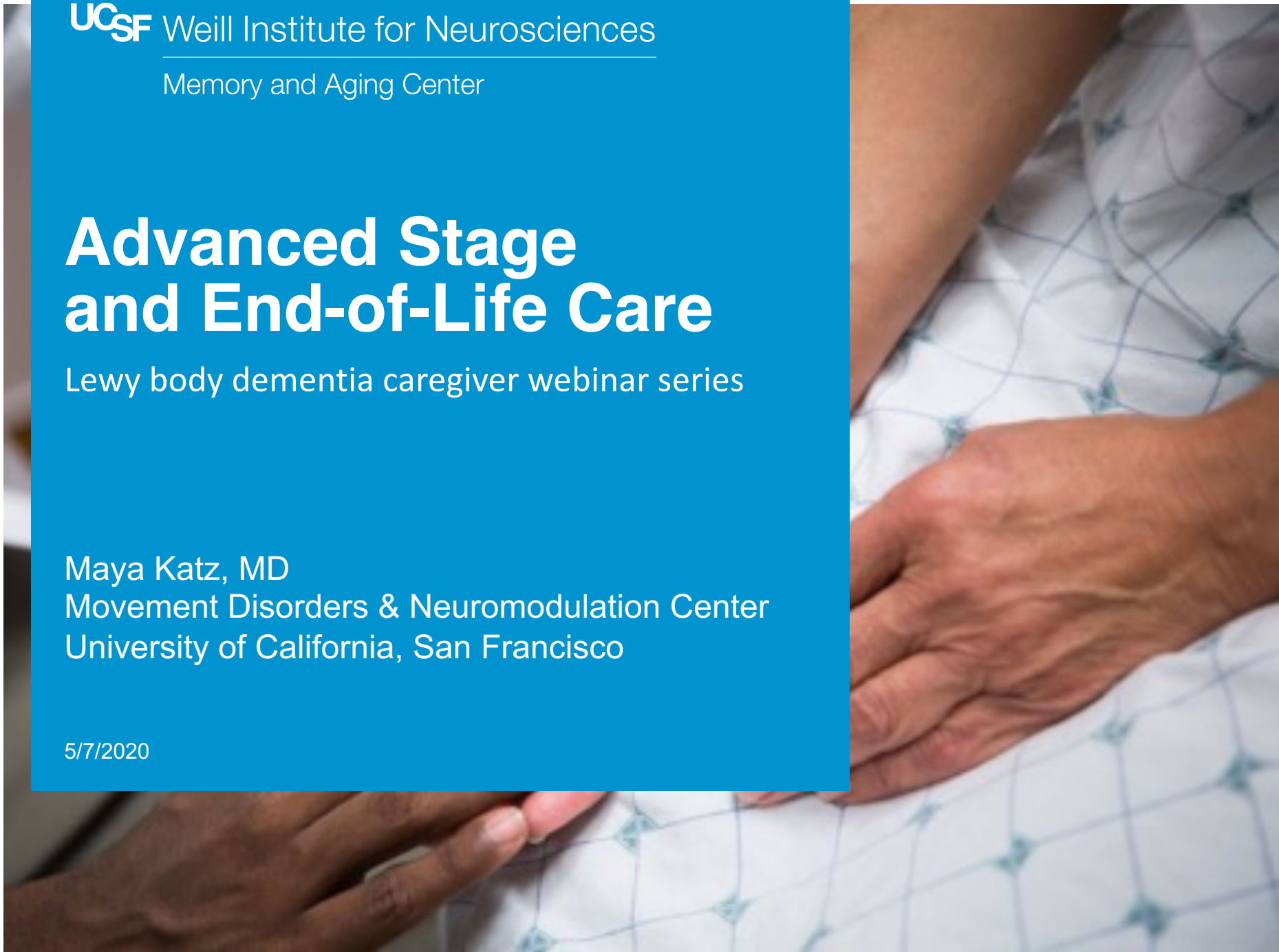
Memory and Aging Center

Advanced Stage and End-of-Life Care

Lewy body dementia caregiver webinar series

Maya Katz, MD
Movement Disorders & Neuromodulation Center
University of California, San Francisco

5/7/2020



My background

Neurologist

Specialized in treating neurological movement disorders

- Associate Professor
- UCSF Movement Disorders and Neuromodulation Center
- Clinical work and research focuses on bringing palliative care to patients and caregivers affected by LBD

Discussion Topics

- Caregiving in Advanced LBD
- End-of-Life Care
- Prognostic indicators
- Advance care planning

Care for the Caregiver

Total Pain of LBD

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Caregiving in Advanced LBD

- Difficult emotions:
  - Grief
  - Guilt
  - Existential distress

What is resilience?

Resilience Is About How You Recharge, Not How You Endure

by Shawn Achor and Michelle Gielan

JUNE 24, 2016

Harvard Business Review

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Burnout as a healthy, adaptive response!

Burnout can serve as an alarm clock that wakes us up, so we can keep ourselves safe.

→ *But **first we need to notice** that the alarm is ringing!*

Noticing is sometimes referred to as 'mindfulness'

Mindfulness

What does self-care look like?

- **Monitoring** for signs of burnout (noticing)
- **Promoting well-being**, and finding balance
- **Building resilience**
  - Strengthening **meaning / pro-social purpose**
  - **Connecting** with self and others
  - Broadening understanding of **choices** (self-efficacy)

End-of-Life Care in Lewy Body Dementia

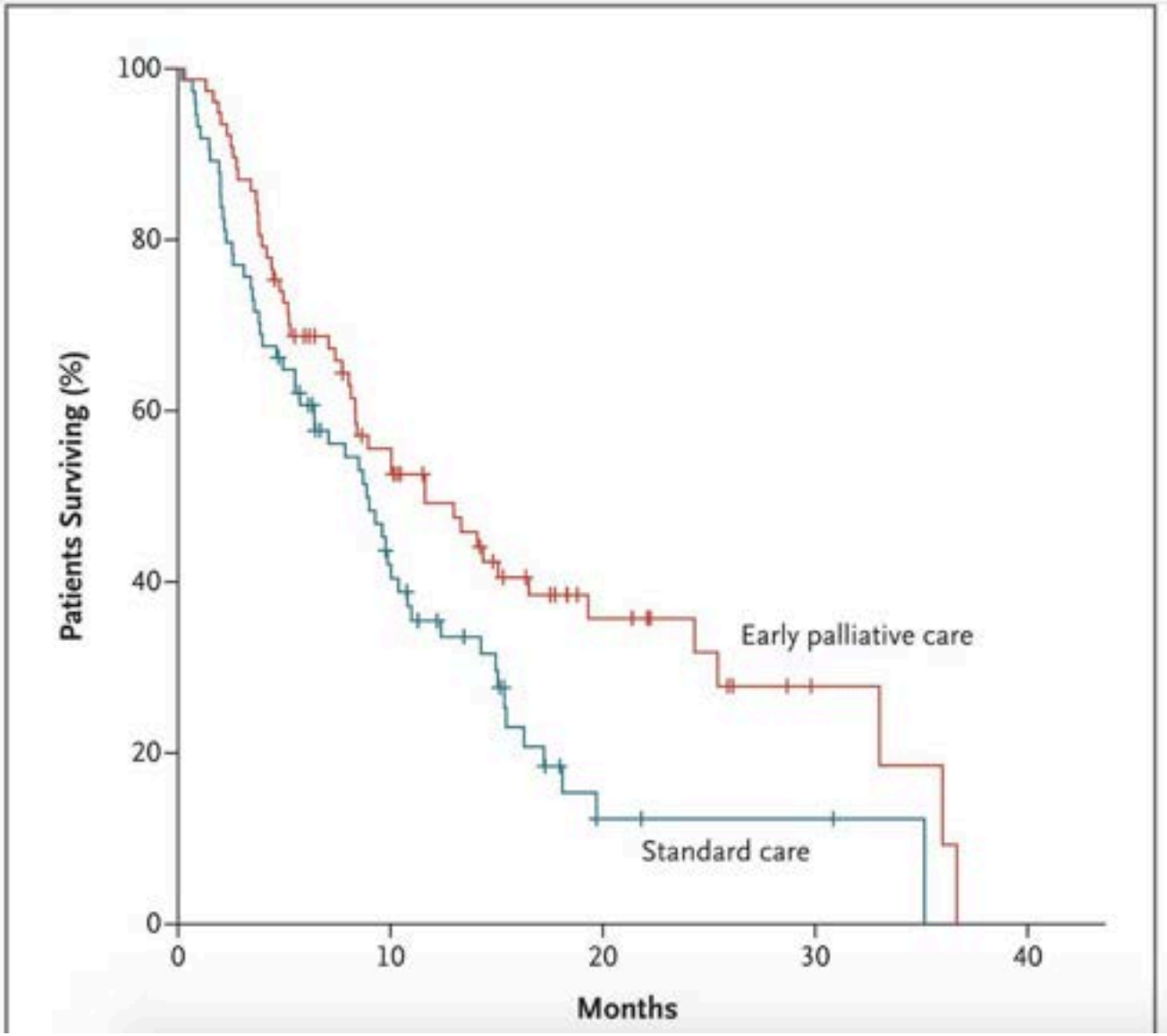
Definition of Palliative Care

- **approach that improves the quality of life** of patients and their families facing the problems associated with life-threatening illness
- provides **relief from pain or other distressing symptoms**
- **affirms life and regards dying as a normal process**
- integrates the **psychological and spiritual aspects** of patient care
- offers a support system to **help the family cope** during the patient‘s illness and in their own **bereavement**
- is applicable **early in the course of illness**, in conjunction with other therapies that are intended to prolong life.

WHO. National Cancer Control Programs: Policies and Managerial Guidelines, 2nd ed. Geneva: WHO, 2002

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

The NEW ENGLAND JOURNAL of MEDICINE Temel et al., 2010



Caregiver Preparedness

Cause of Death and End-of-Life Experiences in Individuals with Dementia with Lewy Bodies

Melissa J. Armstrong, MD, MSc,[*†] *Slande Alliance, MPH, MCHES,*[*] *Pamela Corsentino, MS,*[‡] *Steven T. DeKosky, MD,*[*†] *and Angela Taylor, BA*[‡]

- **Physicians rarely bring up EOL issues (22%)**
- **Fewer than half of caregivers felt prepared for EOL care**

Motor Symptoms in Advanced LBD

Increased stiffness and slowness:
- Can cause discomfort and pain
- Can lead to contractures

Increased falls:
- Loss of balance
- Impulsivity
- Requiring 24-7 supervision

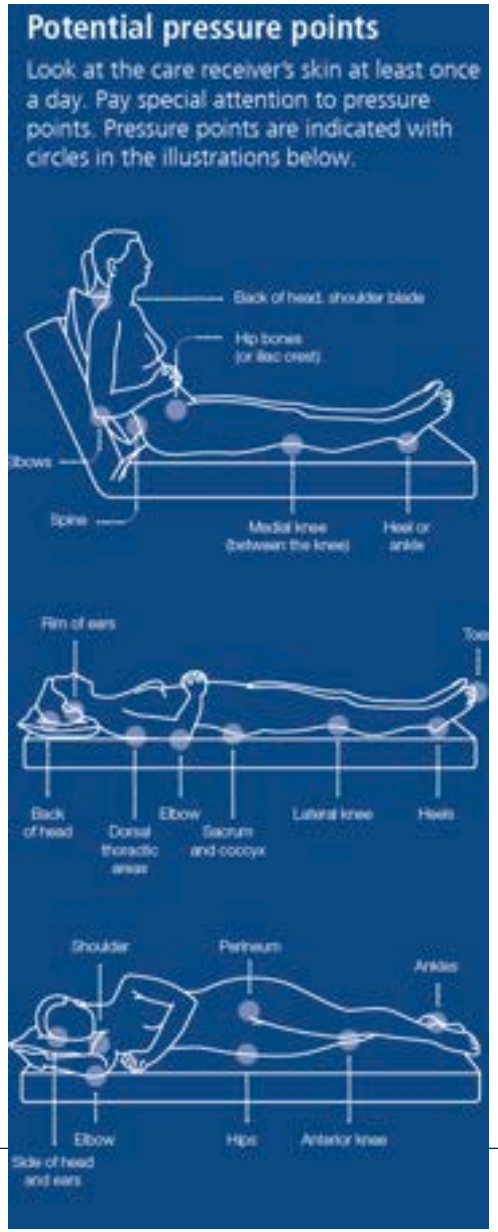
Wheelchair-dependent

Bedridden

Motor Symptoms in Advanced LBD

Treatments

- range of motion exercises
- massage
- skin care (dry, clear)
- change positioning every 2 hours
- gait belt
- mechanical lifts may be needed
- use specialized cushions
- Broda chair



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The NEW ENGLAND JOURNAL of MEDICINE

January 31, 2019
N Engl J Med 2019; 380:408-409
DOI: 10.1056/NEJMp1809354

Perspective

Rehabbed to Death

Lynn A. Flint, M.D., Daniel J. David, R.N., Ph.D., and Alexander K. Smith, M.D., M.P.H.

For a substantial minority of older adults, a stay in a post-acute care facility is the gateway into a cycle between the hospital and the nursing home that spans the final months of life. Certain Medicare and Medicaid policies perpetuate this cycle.

Communication in Advanced LBD

- Voice changes
- Poor attention
- Confusion
- Word finding problems
- Can lead to anxiety and agitation

Communication in Advanced LBD

Say "yes, and..." - Do not argue 	Find a place and time to talk without distractions 	Speak clearly in a calm voice  -Tone is often more important than content -Be aware of your tone and facial expressions
Maintain eye contact 	Refer to people by their names - Avoid "he," "she," and "they"	Have patience 
Offer a reassuring response to frequently asked questions	Recognize what you're up against 	When giving instructions, use simple sentences 
Ask "yes" or "no" rather than open-ended questions 	Talk about one thing at a time 	Understand there will be good days and bad days 

Psychiatric Symptoms in Advanced LBD

- Hallucinations can be severe and frightening
- Tell your loved one's neurologist and psychiatrist about these symptoms.

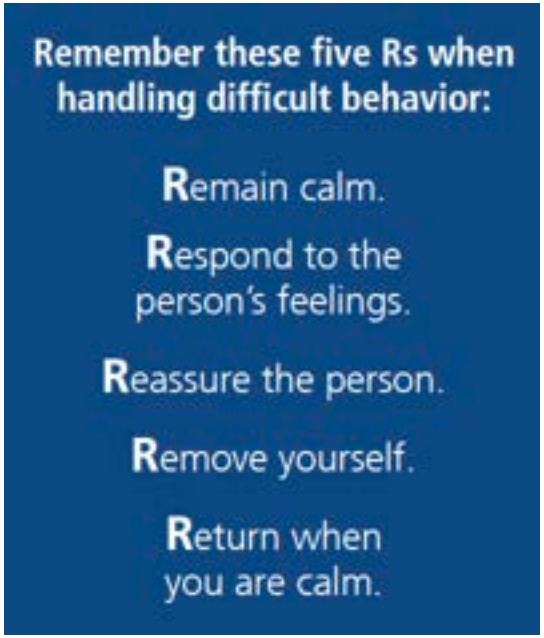
Behavioral treatments

- Cover reflective surfaces
- Use a calm tone of voice
- Avoid confrontation

Medication treatments

- At end-of-life, the symptoms are severe and medications are typically needed to control psychosis

Difficult Behavior in Advanced LBD



Family Caregiver Handbook

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Challenges with Eating and Taking Medications in Advanced LBD

Family Caregiver Handbook

Help with eating

When helping adults eat, show respect and help them be as independent as possible by doing these things:

- Always treat them as adults.
- Encourage the care receivers to help you plan meals.
- Let them choose what they want to eat and when to eat.
- Help them only when they ask for it.
- Offer finger foods if it is difficult for them to use a fork and spoon. For instance, scrambled eggs and toast can be made into an egg sandwich.
- Have them in a sitting position whenever possible and keep their head slightly tilted forward.
- Make sure they can see the food on the plate. The color of the plate should contrast with the food.
- Tell them what you're doing: "I'm giving you peas now."
- They should remain upright for at least 20 to 30 minutes after finishing a meal.
- Have a doctor check if there are sudden changes in eating or swallowing.

Challenges with Eating and Taking Medications in Advanced LBD

- **Refusing to eat**
- **Swallowing Trouble**:
  - Aspiration
  - Choking
  - Pocketing (swallowing apraxia)

Recommendations:

- Do not use thickeners
- Try Carbonated beverages
- Smoothie consistency drinks
- Give medications with apple sauce
- Alternate between a bite of food and a sip of liquid
- Chin tuck when swallowing
- Benevolent trickery

Weight loss in Advanced LBD

Anorexia and Cachexia
Failure to Thrive
Marker of end-stage disease
Not responsive to supplements

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An initiative of the ABIM Foundation

American Geriatrics Society

Released February 27, 2014; revised April 23, 2015

Avoid using prescription appetite stimulants or high-calorie supplements for treatment of anorexia or cachexia in older adults; instead, optimize social supports, discontinue medications that may interfere with eating, provide appealing food and feeding assistance, and clarify patient goals and expectations.

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CHOOSING WISELY: THINGS WE DO FOR NO REASON

Things We Do for No Reason: The Use of Thickened Liquids in Treating Hospitalized Adult Patients with Dysphagia

J. Hosp. Med. 2019 May;14(5):315-317. Published online first February 20, 2019.

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AMDA – The Society for Post-Acute and Long-Term Care Medicine

Released September 4, 2013

Don't insert percutaneous feeding tubes in individuals with advanced dementia. Instead, offer oral assisted feedings.

Strong evidence exists that artificial nutrition does not prolong life or improve quality of life in patients with advanced dementia. Substantial functional decline and recurrent or progressive medical illnesses may indicate that a patient who is not eating is unlikely to obtain any significant or long-term benefit from artificial nutrition.

Incontinence and Toileting in Advanced LBD

- Timed voiding
- A pad inside the briefs provides extra protection
- Liberty Catheter
- Urinal or commode at the bedside

Giving privacy

- Look the other way for a few moments.
- Leave the room (if it is safe to do so).
- Allow the care receiver extra time.
- Be patient when the person asks for your time when you are busy with other things.

Toileting is a very private matter. Your reassurance can help lessen feelings of embarrassment and discomfort.

Family Caregiver Handbook

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Dental Care in Advanced LBD

- Brush teeth twice a day
- Lemon juice can aid in swallowing

Fluctuations in alertness

- Natural part of the disease course
- Cause is unclear
- No known treatment
- Not a medical emergency

End-of-Life Care: Days to Weeks

Create Comfortable Surroundings

- Include meaningful pictures and mementos
- Bring nature indoors
- Choose favorite music
- Soothing massage

End-of-Life Care: Days to Weeks

- Continue sinemet for as long as possible
- Reduce medications to only what is critical
- Use liquid formulations if available
- Use suppositories if unable to swallow
- Most patients need sedating medications

Prognostic Indicators in Lewy Body Dementia

Medicare hospice eligibility for Adult Failure to Thrive

BMI < 22, **and**

PPS ≤ 40%

Mainly in bed

Assistance with ADLs

Palliative Performance Scale (PPS)

%	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Level of Conscious
100	Full	Normal activity, no evidence of disease	Full	Normal	Full
90	Full	Normal activity, some evidence of disease	Full	Normal	Full
80	Full	Normal activity with effort, some evidence of disease	Full	Normal or reduced	Full
70	Reduced	Unable to do normal work, some evidence of disease	Full	Normal or reduced	Full
60	Reduced	Unable to do hobby or some housework, significant disease	Occasional assist necessary	Normal or reduced	Full or confusion
50	Mainly sit/lie	Unable to do any work, extensive disease	Considerable assistance required	Normal or reduced	Full or confusion
40	Mainly in bed	Unable to do any work, extensive disease	Mainly assistance	Normal or reduced	Full, drowsy, or confusion
30	Totally bed bound	Unable to do any work, extensive disease	Total care	Reduced	Full, drowsy, or confusion
20	Totally bed bound	Unable to do any work, extensive disease	Total care	Minimal sips	Full, drowsy, or confusion
10	Totally bed bound	Unable to do any work, extensive disease	Total care	Mouth care only	Drowsy or coma
0	Death	—	—	—	—

Medicare hospice eligibility for:

Dementia

At least one of the following in the past 12 months:

- aspiration pneumonia
- pyelonephritis
- septicemia
- stage 3-4 pressure ulcers
- recurrent fever
- 10% weight loss
- albumin < 2.5 mg/dL

and

≥ **7C** on the **FAST** Scale

Functional Assessment Scale (FAST)	
1	No difficulty either subjectively or objectively.
2	Complains of forgetting location of objects. Subjective work difficulties.
3	Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity.
4	Decreased ability to perform complex tasks (e.g. personal finances).
5	Requires assistance in choosing proper clothing to wear.
6	a) Needs help putting on clothes b) Needs help bathing c) Needs help toileting **d) Urinary incontinence** **e) Fecal incontinence**
7	a) Speaks 5-6 words per day **b) Speaks only 1 word clearly per day** **c) Cannot walk without personal assistance** d) Can not sit up without personal assistance e) Can no longer smiler f) Can no longer hold up head independently

Terminal events in LBD

- Aspiration pneumonia (30%)
- Sepsis (8%)
- Reduced mobility, falls or fractures (13%)
- Failure to thrive (20%)

Hospice Care: Role of Neurologist

- Haloperidol
- Metoclopramide
- Phenergan

Hospice Care: Role of Neurologist

- ~~Haloperidol~~
- ~~Metoclopramide~~
- ~~Phenothiazine~~

- **Quetiapine**
- **Ondansetron**

Predictors of mortality in LBD

Major predictors of mortality within 6-12 months:

- BMI <18.5 (medically malnourished)
- Significant reduction in dopaminergic medications due to psychiatric side effects

Advance Care Planning

California Advance Health Care Directive

This form lets you have a say about how you want to be treated if you get very sick.

This form has 3 parts. It lets you:

Part 1: Choose a medical decision maker.

A medical decision maker is a person who can make health care decisions for you if you are too sick to make them yourself.

Part 2: Make your own health care choices.

This form lets you choose the kind of health care you want.

This way, those who care for you will not have to guess what you want if you are too sick to tell them yourself.

Part 3: Sign the form.

It must be signed before it can be used.

Healthcare Directive for Dementia

If I had mild dementia then I would want the goal for my care to be:

- ☐ **To live for as long as I could**. I would want full efforts to prolong my life, including efforts to restart my heart if it stops beating.

- ☐ **To receive treatments to prolong my life, but if my heart stops beating or I can't breathe on my own then do not shock my heart to restart it (DNR) and do not place me on a breathing machine**. Instead, if either of these happens, allow me to die peacefully. Reason why: if I took such a sudden turn for the worse then my dementia would likely be worse if I survived, and this would not be an acceptable quality of life for me.

- ☐ **To only receive care in the place where I am living. I would not want to go to the hospital even if I were very ill,** and I would not want to be resuscitated (DNR). If a treatment, such as antibiotics, might keep me alive longer and could be given in the place where I was living, then I would want such care. But if I continued to get worse, I would not want to go to an emergency room or a hospital. Instead, I would want to be allowed to die peacefully. Reason why: I would not want the possible risks and trauma which can come from being in the hospital.

- ☐ **To receive comfort-oriented care only, focused on relieving my suffering such as pain, anxiety, or breathlessness**. I would not want any care that would keep me alive longer.

Healthcare Proxy

Part 1: Choose your medical decision maker — California Advance Health Care Directive

By signing this form, you allow your medical decision maker to:

- agree to, refuse, or withdraw any life support or medical treatment if you are not able to speak for yourself
- decide what happens to your body after you die, such as funeral plans and organ donation

If there are decisions you do not want them to make, write them here:

When can my medical decision maker make decisions for me?

- ○ ONLY after I am not able to make my own decisions
- ○ NOW, right after I sign this form

Write the name of your medical decision maker.

I want this person to make my medical decisions if I am not able to make my own:

first name | last name

phone #1 | phone #2 | relationship

address | city | state | zip code

If the first person cannot do it, then I want this person to make my medical decisions:

first name | last name

phone #1 | phone #2 | relationship

address | city | state | zip code

Witnesses or Notary

Before this form can be used, you must have 2 witnesses sign the form or a notary. The job of a notary is to make sure it is you signing the form.

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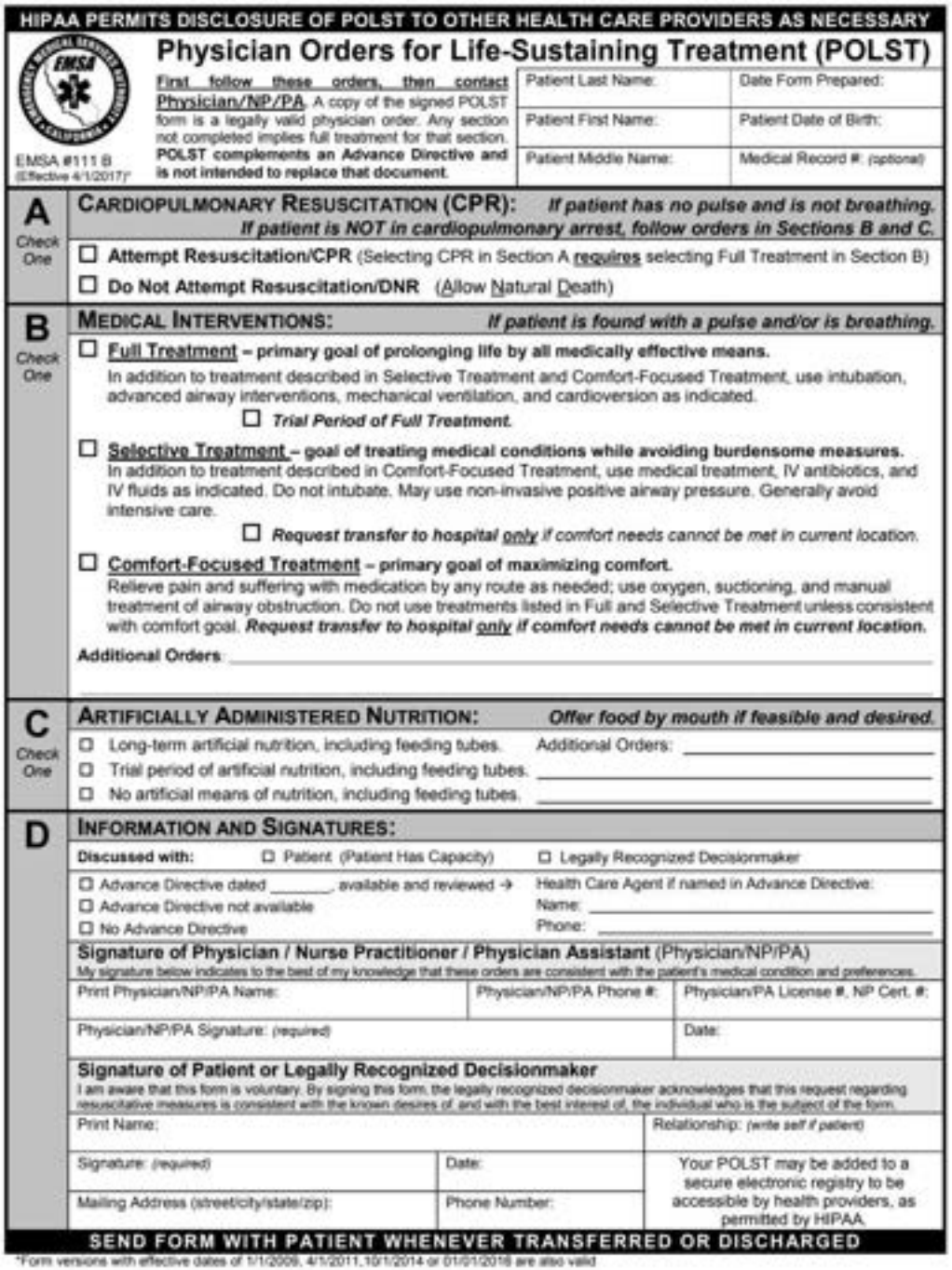
POLST

Physician Order for Life Sustaining Therapy



HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

EMSA #111 B (Effective 4/1/2017)*

First follow these orders, then contact Physician/NP/PA. A copy of the signed POLST form is a legally valid physician order. Any section not completed implies full treatment for that section. **POLST complements an Advance Directive and is not intended to replace that document.**

Patient Last Name:	Date Form Prepared:
Patient First Name:	Patient Date of Birth:
Patient Middle Name:	Medical Record #: (optional)

A Check One — **CARDIOPULMONARY RESUSCITATION (CPR):** *If patient has no pulse and is not breathing. If patient is NOT in cardiopulmonary arrest, follow orders in Sections B and C.*

- ☐ **Attempt Resuscitation/CPR** (Selecting CPR in Section A requires selecting Full Treatment in Section B)
- ☐ **Do Not Attempt Resuscitation/DNR** (Allow Natural Death)

B Check One — **MEDICAL INTERVENTIONS:** *If patient is found with a pulse and/or is breathing.*

- ☐ **Full Treatment – primary goal of prolonging life by all medically effective means.** In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated.
  - ☐ *Trial Period of Full Treatment.*
- ☐ **Selective Treatment – goal of treating medical conditions while avoiding burdensome measures.** In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.
  - ☐ *Request transfer to hospital only if comfort needs cannot be met in current location.*
- ☐ **Comfort-Focused Treatment – primary goal of maximizing comfort.** Relieve pain and suffering with medication by any route as needed; use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. ***Request transfer to hospital only if comfort needs cannot be met in current location.***

Additional Orders: _____

C Check One — **ARTIFICIALLY ADMINISTERED NUTRITION:** *Offer food by mouth if feasible and desired.*

- ☐ Long-term artificial nutrition, including feeding tubes.
- ☐ Trial period of artificial nutrition, including feeding tubes.
- ☐ No artificial means of nutrition, including feeding tubes.

Additional Orders: _____

D — **INFORMATION AND SIGNATURES:**

Discussed with: ☐ Patient (Patient Has Capacity) ☐ Legally Recognized Decisionmaker

- ☐ Advance Directive dated _____, available and reviewed →
- ☐ Advance Directive not available
- ☐ No Advance Directive

Health Care Agent if named in Advance Directive:
Name: _____
Phone: _____

Signature of Physician / Nurse Practitioner / Physician Assistant (Physician/NP/PA)
My signature below indicates to the best of my knowledge that these orders are consistent with the patient's medical condition and preferences.

Print Physician/NP/PA Name:	Physician/NP/PA Phone #:	Physician/PA License #, NP Cert. #:
Physician/NP/PA Signature: (required)		Date:

Signature of Patient or Legally Recognized Decisionmaker
I am aware that this form is voluntary. By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.

Print Name:		Relationship: (write self if patient)
Signature: (required)	Date:	Your POLST may be added to a secure electronic registry to be accessible by health providers, as permitted by HIPAA.
Mailing Address (street/city/state/zip):	Phone Number:	

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

*Form versions with effective dates of 1/1/2009, 4/1/2011, 10/1/2014 or 01/01/2016 are also valid

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Advance Care Planning

…our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer.

Being Mortal: Medicine and What Matters in the End
Atul Gawande, M.D.

Advance Care Planning:
Two Questions to Ask

If you look ahead, what worries you the most?

When you look to the future, what are you hoping for?

Our ultimate goal, after all, is not a good death, but a good life to the very end.

Atul Gawande, M.D.

Being Mortal:

Illness, Medicine and What Matters in the End

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