

WELCOME !

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The ALS Association

National Office-Care Services

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The Value of Incorporating Palliative or Hospice Services into a Strategic Healthcare Plan

Guest Speaker:

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Evaluating the Value of Palliative or Hospice Services in the setting of ALS

Laura Foster, MD

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Disclosures

- Laura Foster has no relevant financial disclosures
- I am an employee of the University of Colorado School of Medicine
- I collaborate with the ALS Association in the care of patients

Goal & Homework Assignment



Goal: spark discussion about your own care or a loved one's



Homework Assignment: tell one person one thing from today's discussion

Outline

- I. Palliative care & hospice explained
- II. Choosing a path: approach to decision-making

Palliative care: is it
a person, place, or
idea?

A palliative philosophy is to maximize quality of life *at any stage* of a serious illness

- Aggressively manage symptoms, including pain, shortness of breath, cramps, excess saliva, and others
- Serious illness conversations to prioritize what's most important to people living with serious illness, given what's possible

People who provide palliative care

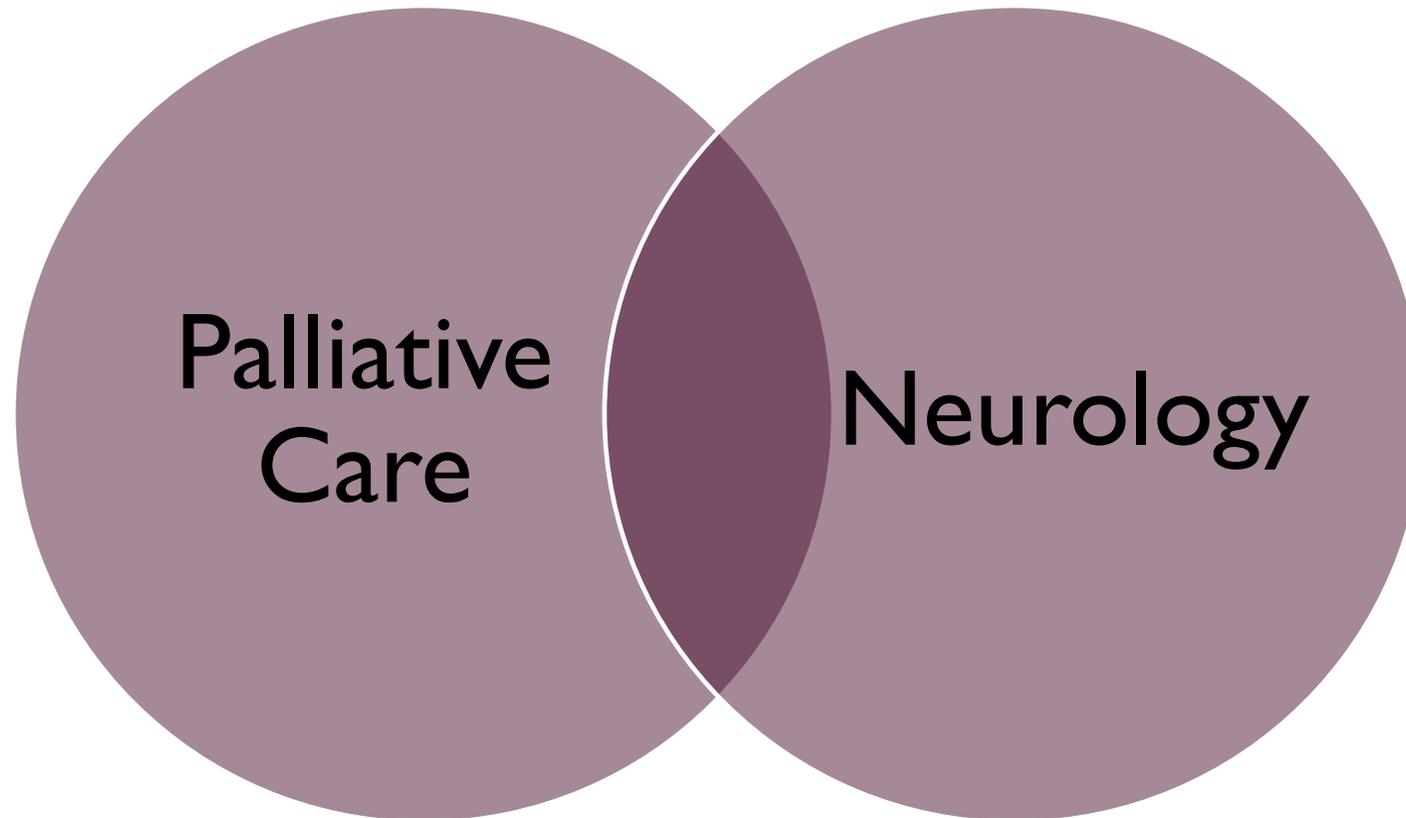
Primary palliative care

- Neurologists
- Psychiatrists
- Primary care clinicians
- People with disease-specific knowledge
- Social workers
- Others...

Specialty palliative care

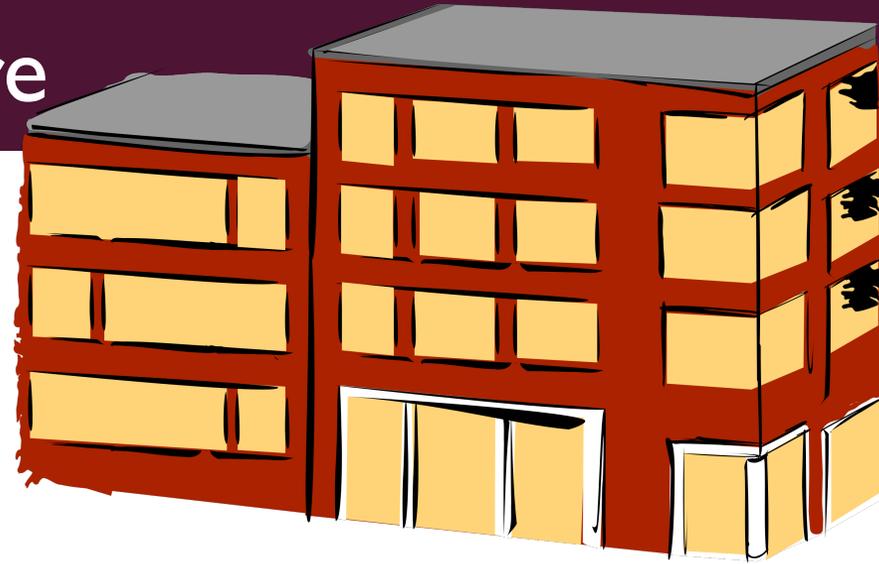
- Doctors, nurses, advanced practice providers, social workers, chaplains and therapists with extra training in
 - Pain & symptom management
 - Communication
 - End-of-life care

Palliative care has its roots in cancer care, so specialists may have limited experience with ALS

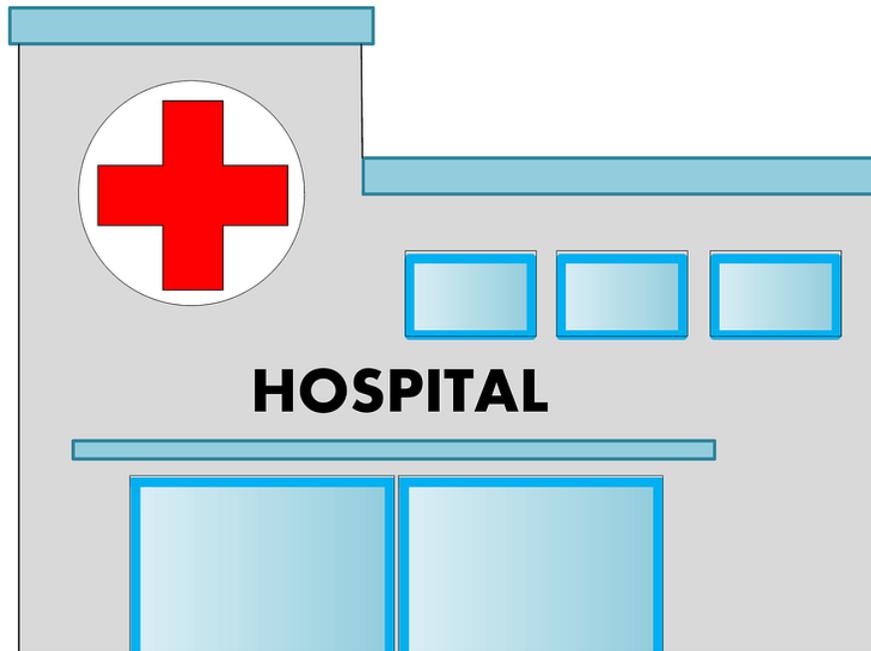


In March 2013, 53 people in the US were board-certified in palliative medicine and neurology

Places to get palliative care



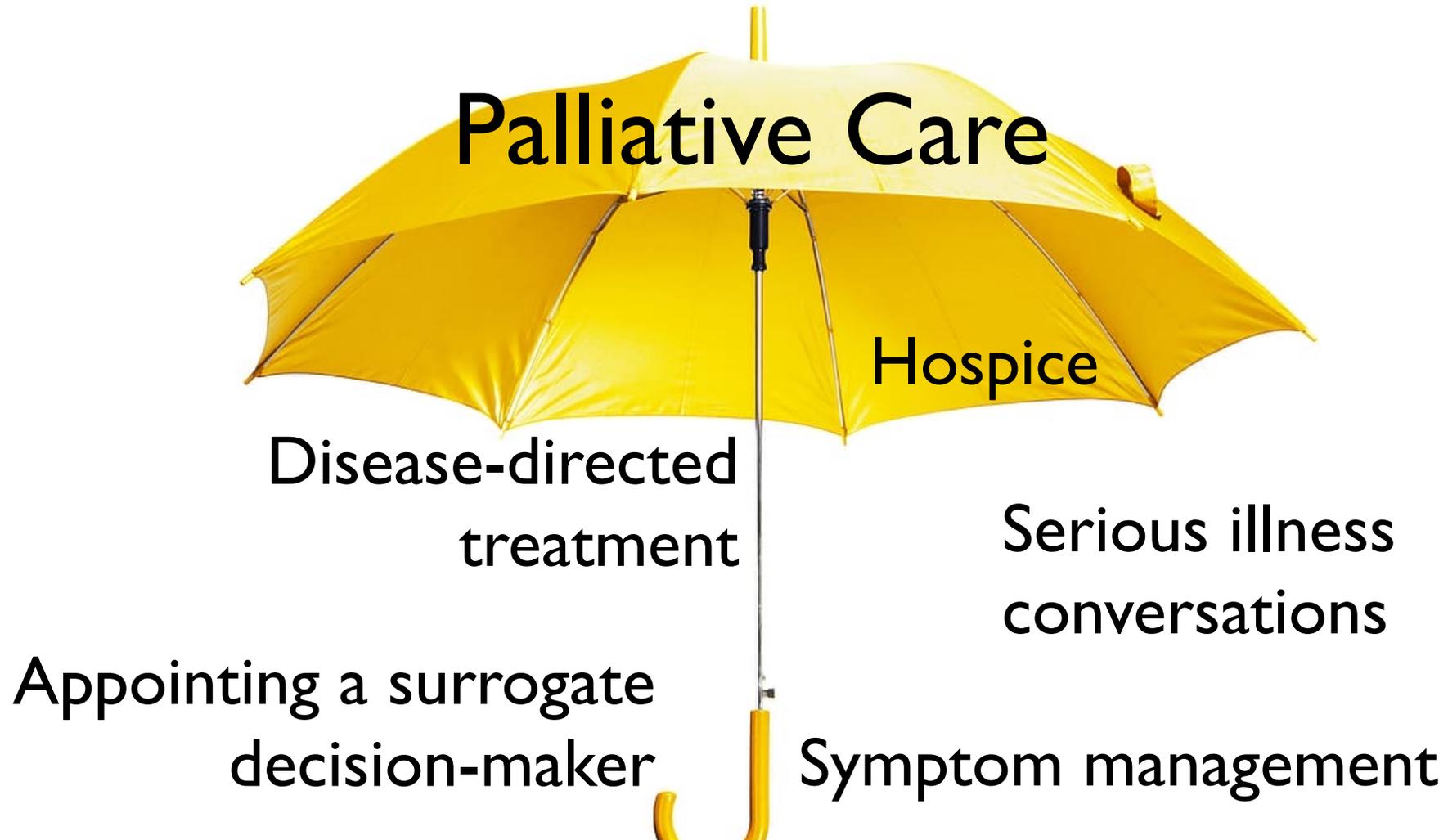
Clinic



Home

Hospice: is it a
person, place, or
idea?

Hospice is one of many aspects of palliative care



Hospice
philosophy:
maximize quality
of life for
whatever time a
person has left,
forgoing additional
disease-directed
treatments



People who deliver hospice care

- Hospice organizations: doctors, nurses, advanced practice providers, certified nurse assistants, chaplains, social workers, therapists

Hospices are well equipped to help people with serious illness at the end of life

Hospice DOES provide

- Symptom management expertise
- Medications for symptom management
- Some in-home equipment (bed, commode)
- Caregiver support
- 24/7 telephone support, in-person support if needed

Hospice DOES NOT provide

- Medications for prolonging life/maintaining function (riluzole, edaravone)
- Work-up for why a person's body changes (labs)
- Hospitalization (unless indicated for symptom management)
- Power wheelchairs
- Feeding tube placement
- Initiation of ventilation (non-invasive or invasive)

Hospice is fully covered by most insurances

- Usually no out-of-pocket cost.

People can request an informational session with a hospice organization without making a commitment.

When do people living with ALS become eligible for hospice services?

- Less than 6 months prognosis if the disease takes its natural course
- How do we tell when that is?
 - How quickly a person is losing function
 - Respiratory compromise: lung function (FVC/SVC), shortness of breath, shallow breathing, weak cough, insomnia due to trouble breathing
 - Nutritional compromise: significant weight loss, aspiration, choking, trouble swallowing with excessive oral secretions

Places to get hospice care



Home



Skilled
nursing
facility



Inpatient
hospice



Choosing a path: approach to decision-making

PART II



Basic steps to navigating decisions in the setting of serious illness

1. Gauge how much information you want
2. Seek out that information from a trusted source
3. Identify what's most important
4. Decide on a next step

Step 1: Gauge how much information you want



Less information
• Big picture



More information
• Details
• Numbers



Step 1: Gauge how much information you want



Less information

- Recommendation



More information

- All the options

Step 2: Seek out information from a trusted source



Speech/Swallowing



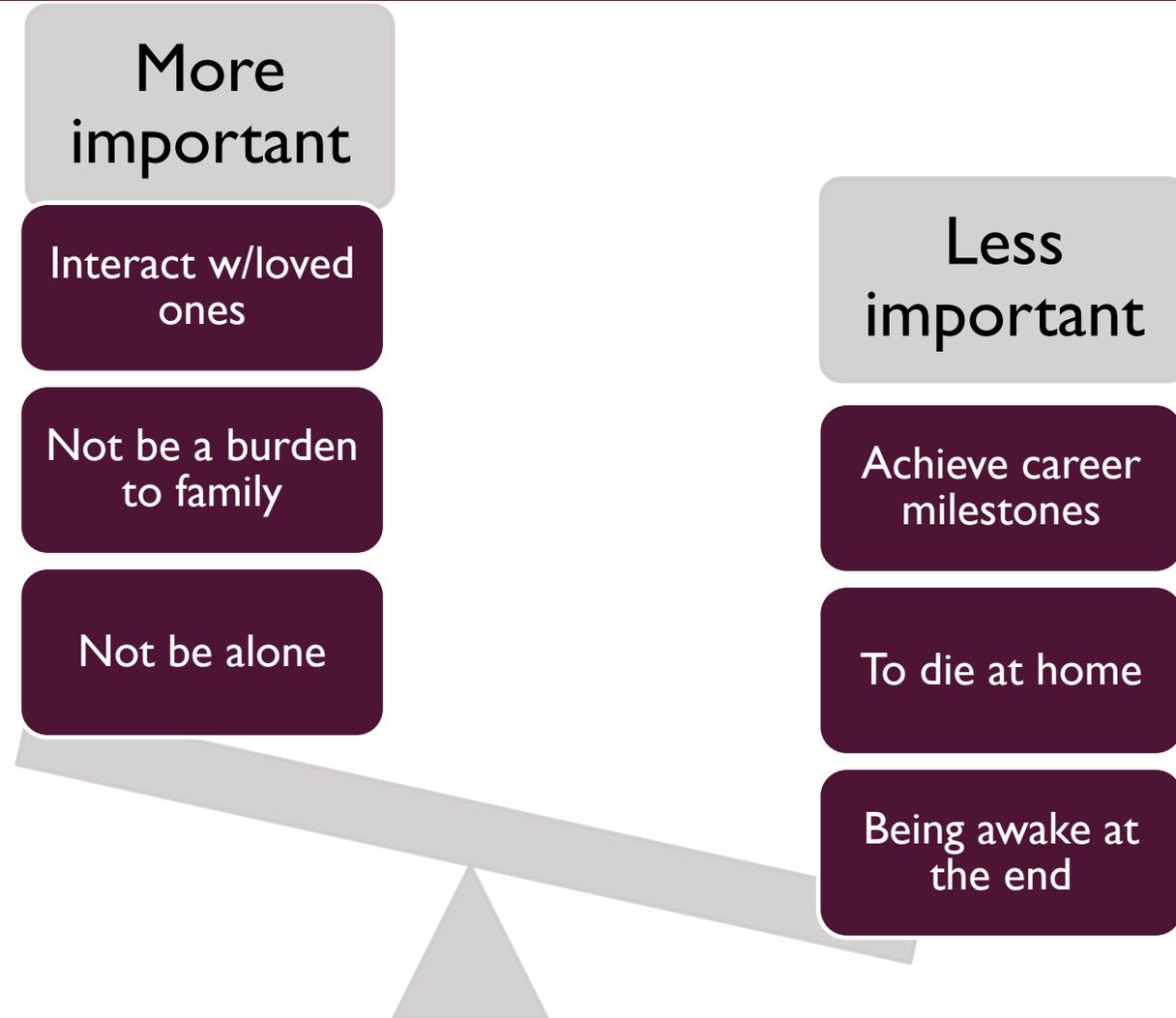
- [Suggestions and Information about Speech Changes & Augmentative Alternative Communication \(AAC\)](#)
- [Managing Excessive Saliva](#)
- [Information About Feeding Tubes](#)
- [High Calorie and Easy to Chew Recipes](#)
- [Safe Swallowing: What I Need to Know and Why it Matters](#)^{en}
- [PEGS and Nutrition in People with ALS](#)^{en}

Step 3: given the circumstances, identify what's important



- Contemplation, self-examination
- Grief

If I (LF) had an illness that would likely end in death within a year, here's what's most important to me



Sample question for identifying what's most important

As walking gets harder, what's most important?

- Getting to my grandkids' soccer games
- Maintaining independence (not inconvenience others)

Sample question for identifying what's most important

As respiratory function gets worse, what's most important?

- Living longer
- Not feeling short of breath

Take a minute to identify 1-2 things that are most important to you

Interact w/loved ones

Achieve career milestones

GoWish.org

Not be alone

To die at home

Not be a burden to family

Being awake at the end

Step 4: Decide on a next step

Common medical decisions in ALS

- Wheelchair & other adaptive equipment
- Feeding tube
- Non-invasive ventilation
- Invasive ventilation (tracheostomy)
- Research
- Hospice

Other decisions

- Moving
- Arrange a caregiver

EXAMPLE: FEEDING TUBE PLACEMENT



A woman with bulbar-onset ALS for a couple years had more trouble swallowing. She drinks several cans of a nutritional beverage each day. She isn't sure whether she wants a feeding tube and visits her nurse practitioner.

- Step 1: how much information? More than she has. Would a feeding tube help preserve function?
- Step 2: get information. Getting a feeding tube wouldn't make you stronger or maintain function longer.
- Step 3: identify what's most important. Independence = playing golf. When she can no longer play golf, then she'll be too dependent on other people for getting dressed, etc.
- Step 4: decide on next step. Not get a feeding tube.

EXAMPLE: CLINICAL TRIAL VERSUS HOSPICE

A gentleman with ALS was exhausted by trips to the clinic for participation in a clinical trial. His son is in town for a few months, and he'd like to spend more time with family. He meets with his doctor for advice on what to prioritize.

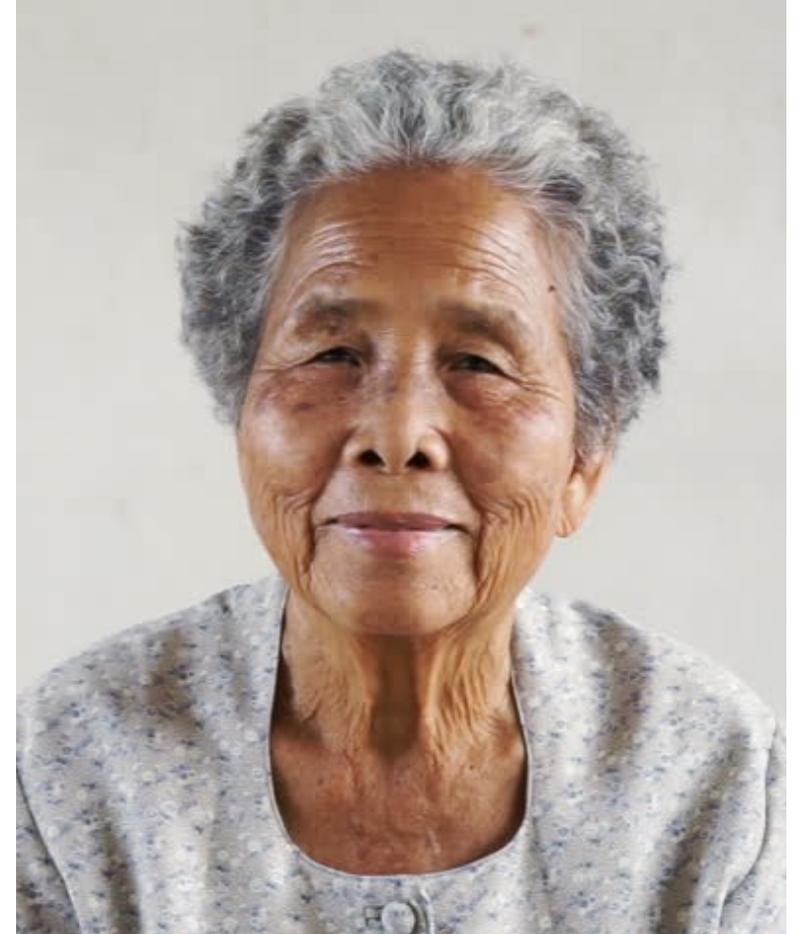
- Step 1: how much information? Just enough to decide.
- Step 2: get information. Based on trouble breathing, it was likely that time was not years but months.
- Step 3: identify what's most important. Being with family.
- Step 4: decide on next step. Stop the clinical trial & enroll in hospice.



EXAMPLE: WHERE TO LIVE

A woman with bulbar-onset ALS comes to clinic for the first follow-up appointment after diagnosis.

- Step 1: how much information? Concrete details, keep talking if she cries. Husband takes notes.
- Step 2: get information. Over the past few months, she's gone from walking normally to benefiting from an AFO, so it's likely she'll need more help with mobility in the coming months and perhaps a wheelchair within a year.
- Step 3: identify what's most important. Sharing caregiving load among family members so no one person is over-burdened.
- Step 4: decide on next step. Move to be closer to family.



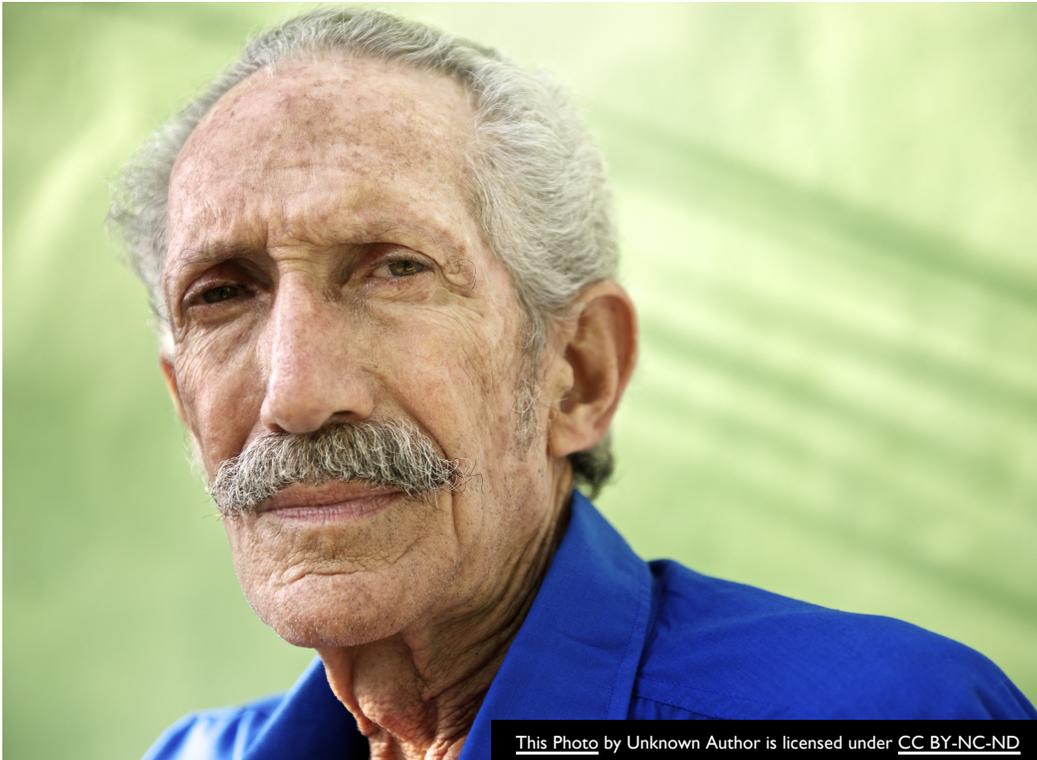
EXAMPLE: WHERE TO LIVE, VERSION 2

A woman with bulbar-onset ALS comes to clinic for the first follow-up appointment after diagnosis.

- *Step 1: how much information? Concrete details, keep talking if she cries. Husband takes notes.*
- *Step 2: get information. Over the past few months, she's gone from walking normally to benefiting from an AFO, so it's likely she'll need more help with mobility in the coming months and perhaps a wheelchair within a year.*
- **Step 3: identify what's most important.** The live on farmland that has been in the family for 5 generations. It's really important to be in her home throughout her life, including in her final years.
- **Step 4: decide on next step.** Set up a phone tree with neighbors to be a back-up for her husband.



EXAMPLE: LET STRANGERS FROM HOSPICE INTO THE HOUSE



A gentleman with ALS was recently hospitalized for pneumonia. He has more trouble getting out of the house because of weakness. He has a telehealth appointment with his doctor and his daughter.

- Step 1: how much information? None. Daughter wanted to understand how other families manage.
- Step 2: get information. His daughter went into a different room and learned about hired caregivers, home health, and hospice.
- Step 3: identify what's most important. Privacy.
- Step 4: decide on next step. Continue with family only as caregivers.

EXAMPLE: ASK FOR HELP OR NOT



A gentleman with ALS sat awkwardly after a mis-hap in his wheelchair until family got home from work rather than calling his neighbor for help--who had offered to come over anytime.

- Step 1: how much information? Wants to know whys.
- Step 2: get information. Can get pressure sores or other wounds from being in awkward positions.
- Step 3: identify what's most important. Service (giver or receiver).
- Step 4: decide on next step. Call the neighbor next time he fell.