Living Fully, Living Well: Palliative Care Approaches in ALS

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The ALS Association 2024 Webinar

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MEDICINE

Disclosures

- I receive speaking honoraria from the Muscular Dystrophy Association

Questions We'll Explore

- What is palliative care and how does it help people living with ALS?
- What is hospice and how does it help people living with ALS?
- What does palliative care do to improve care for care partners?

The ALS Journey

Mr. R is 59-year-old man who loves to run. One day, he had a near fall while running and then he developed low back pain that persisted. Because he was a long-distance runner, he didn't think much of it, but he began to have progressive gait instability. He was even able to complete a marathon 2 months later, but because of his instability he had to stop running after this.

He had a spine evaluation 6 months later and was treated with an inflammation injection into his low back in , but by December, he had continued weakness now in his core.

He was referred to see Neurology 1 year after his first fall and was diagnosed with ALS. He slowly lost weight, developed significant anxiety, had insomnia, and worsening breathing.

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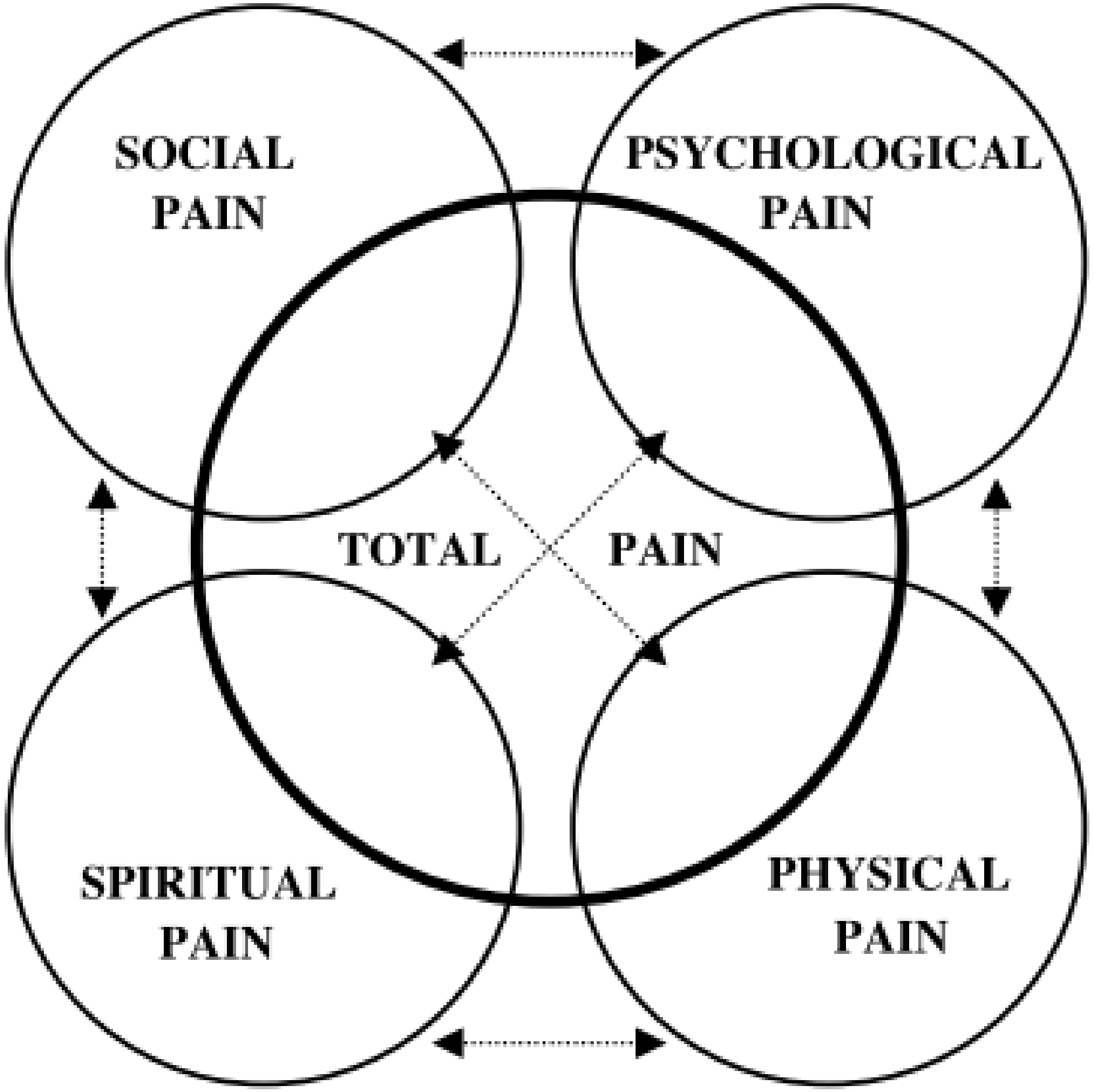
What is Palliative Care?

"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."

- Dame Cecily Saunders



1. The total pain experience: an interactive model.

Mehta, A. and L. Chan, Journal of Hospice & Palliative Nursing, 2008.

Myth or Truth:
Patients must stop seeing their ALS team if they are seeing palliative care

✓ Truth

⊖ Myth

🙄 Unsure

The role of a palliative care specialist for people with ALS

TRAINED TO BE COMFORTABLE WITH UNCERTAINTY

DIFFERENT APPROACH TO MANAGING COMPLEX SYMPTOMS

MULTIDISCIPLINARY TEAM APPROACH

ADDITIONAL TIME FOR SUPPORT

CONTINUITY OF CARE IN SPECIFIC SETTINGS

TRANSITIONS TO END-OF-LIFE CARE

What are the Goals of Palliative for ALS?

Alleviating	• Alleviating symptoms and improving comfort
Enhancing	• Enhancing emotional and psychological well-being
Facilitating	• Facilitating communication and decision-making
Supporting	• Supporting patients and families throughout the journey

Unique palliative needs for people with neurological diseases

- High symptom burden
- Communication limitations
- Understanding/capacity limitations
- Prolonged decline
- High care partner needs
- Prognostic uncertainty
- Complex decision-making throughout disease course

Myth or Truth: Patients cannot continue ALS treatments with palliative care

- ✓ Truth
- ⊖ Myth
- 🙄 Unsure

The ALS Journey Continued

Mr. R continued to struggle with breathing and anxiety. He started BiPAP that helped his energy and breathing significantly. Antidepressants and anxiety medications were started that helped somewhat.

By 1.5 years after his fall, he was losing weight and his ALS team recommended a feeding tube, which he had done.

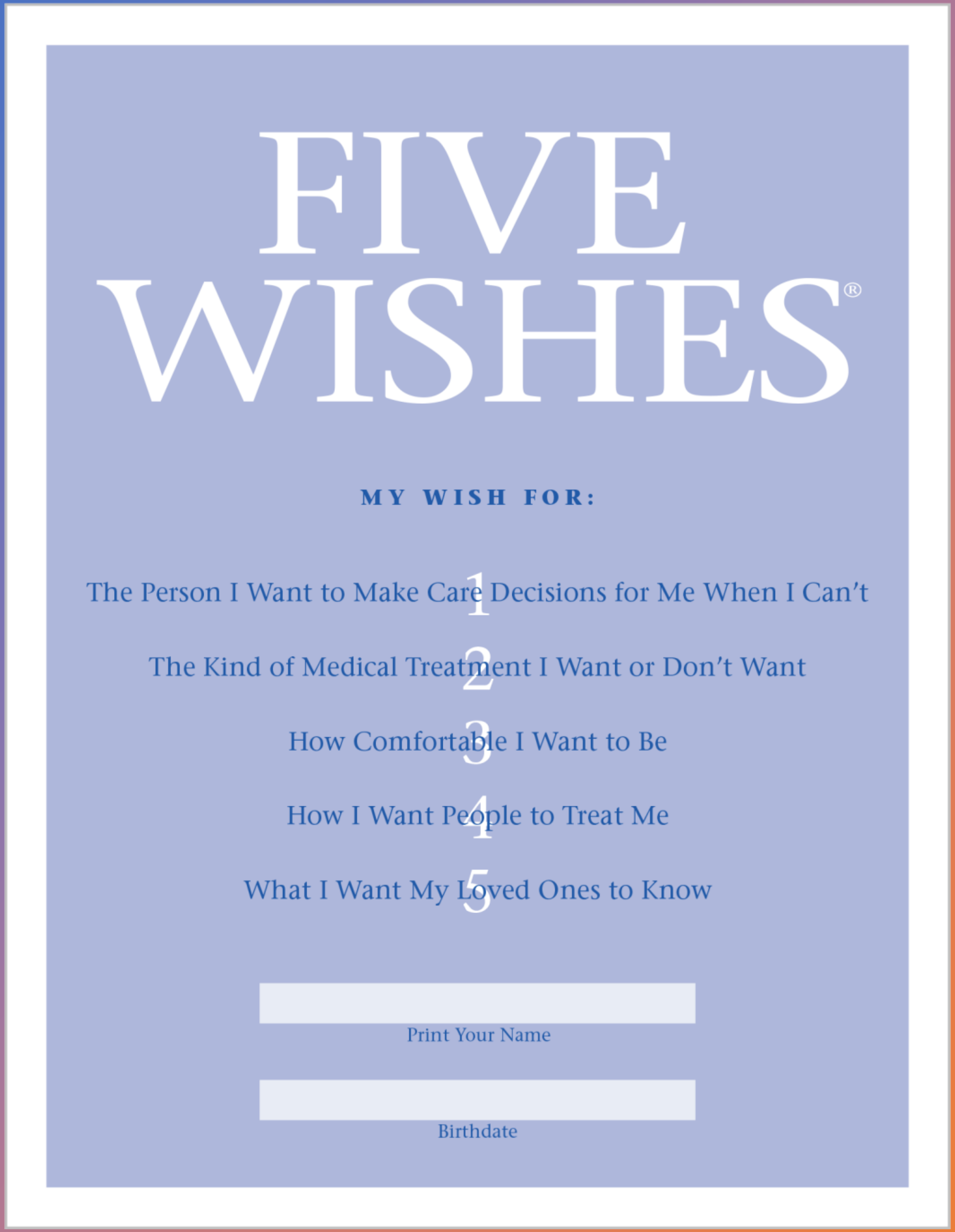
I saw him around this time for uncontrolled anxiety. He was having panic attacks constantly.

Complex Decisions in ALS

- Feeding limitations
- Breathing challenges
- Speech and communication decline
- Resuscitation

Healthcare Agent / Power of Attorney

- Who can speak on your behalf if you cannot?
- "What would XXX say if they were able to?"
- Solely medical (not financial)
- If no one is selected, decisions are deferred to a surrogate (determined state to state)



FIVE WISHES®

MY WISH FOR:

1. The Person I Want to Make Care Decisions for Me When I Can't
2. The Kind of Medical Treatment I Want or Don't Want
3. How Comfortable I Want to Be
4. How I Want People to Treat Me
5. What I Want My Loved Ones to Know

Print Your Name

Birthdate

Advance Directives / Living Wills

- Legal documents
- Do not need an attorney to complete
- Update regularly
- Includes healthcare agent designation
- Different from POLST forms

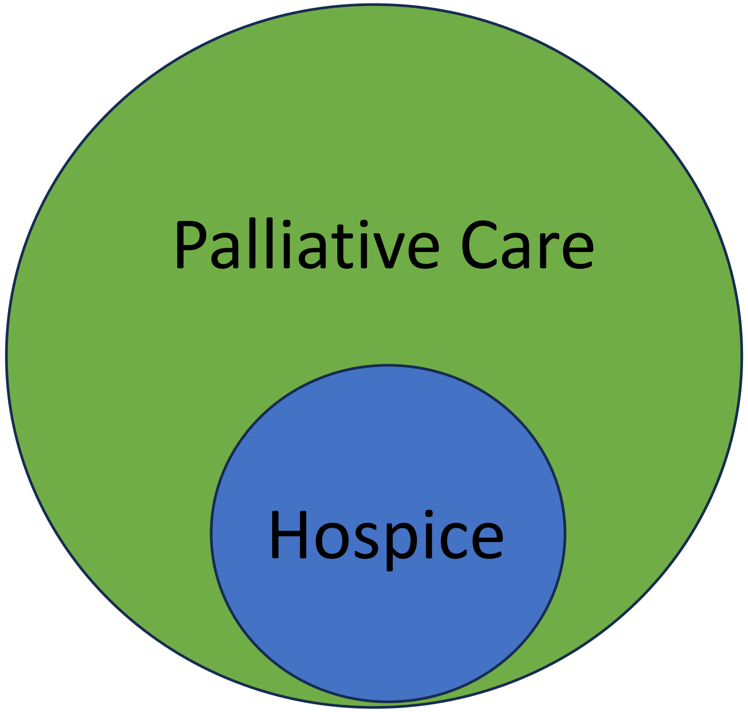
https://www.fivewishes.org/

What is Hospice?

"Specialty care that is person-centered, stressing coordination of care, clarification of goals of care, and communication.

An interdisciplinary team of professionals trained to address physical, psychosocial, and spiritual needs of the person; the team also supports family members and other intimate unpaid caregivers.

Medical care for people with an anticipated life expectancy of 6 months or less, when cure isn’t an option, and the focus shifts to symptom management and quality of life."



https://hospicefoundation.org/Hospice-Care/Hospice-Services

Hospice Care in ALS

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- Focus on and treats the person (not the disease)
- When is it time for hospice?
  - Changes in breathing numbers (FVC)
  - Weight loss
  - Mental status decline
  - Unable to perform activities of daily living
  - Cannot tolerate eating or tube feeds
  - Decision not to pursue a tracheostomy or mechanical ventilation
  - A person wants to focus solely on comfort as the priority

Myth or Truth: Patients cannot continue ALS medications in hospice

Truth

Myth

Unsure

Myth or Truth:
Patients must change their code status to DNR to enroll in hospice

- Truth
- Myth
- Unsure

Myth or Truth: All patients are moved into a hospice when they enroll

✓ Truth

⊖ Myth

🙄 Unsure

Where Do You Go for Hospice?

- Wherever you call home!
- Other options, if needed, include in a nursing home or in special circumstances, in an inpatient hospice facility
- Insurance will not cover visits to the ALS team, pulmonologist, etc

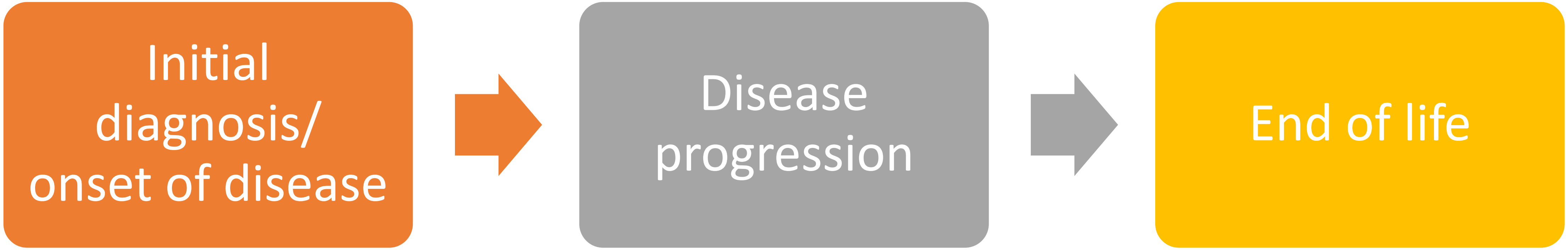
What To Expect	What Not to Expect
Symptoms management	Does not provide 24-hour care at the bedside
Provision of medications, medical supplies, and equipment	Medications for ALS aimed at prolonging life will stop (Riluzole, Radicava, Relyvrio)
Care partner support with more touchpoints at home	Nutrition through a feeding tube ALREADY in place can continue until they are causing problems
Grief support	Trilogy machines, BiPAP machines - discuss with hospice beforehand to prevent auto-discontinuation
"On call" team 24/7 to prevent ER visits/hospitalizations	Rehabilitation services, surgeries, or ALS specific machines will not be started (will be continued)
	Experimental treatments, clinical trials, medical treatments solely to prolong life

Care Partner Support

The Importance of Care Partner Support

- Empowers self care
- Improves their quality of life
- Improves the quality of life of the person with ALS

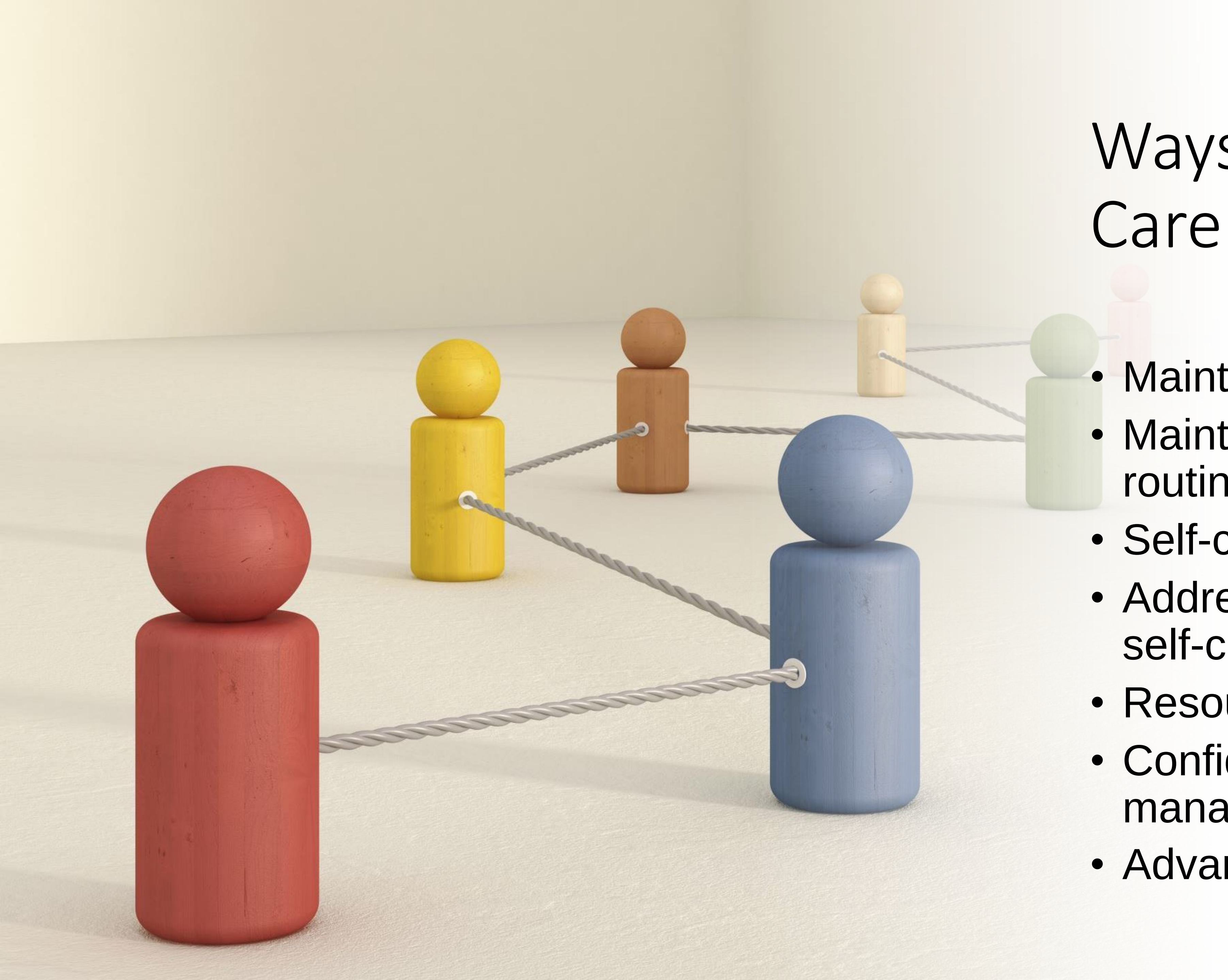
Evolving Needs Over Disease Progression



Initial diagnosis/ onset of disease

Disease progression

End of life



Ways to Support Care Partners

- Maintaining connections
- Maintaining daily routines
- Self-care
- Addressing barriers to self-care
- Resource utilization
- Confidence in disease management
- Advance care planning

Always Have a Backup Plan

If something were to happen to you today…who will take care of your loved one tonight?[1]

Other necessary logistics to plan for?

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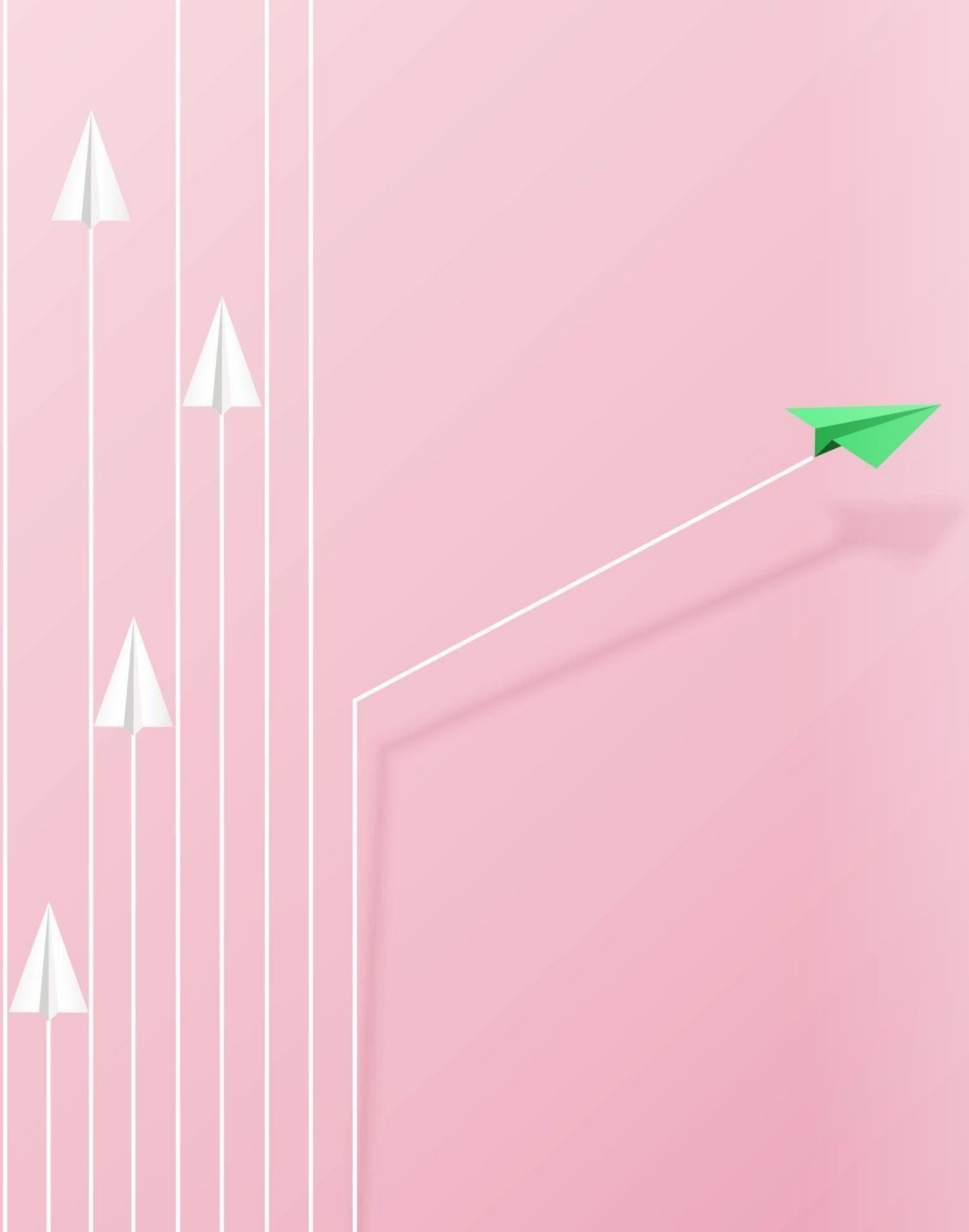
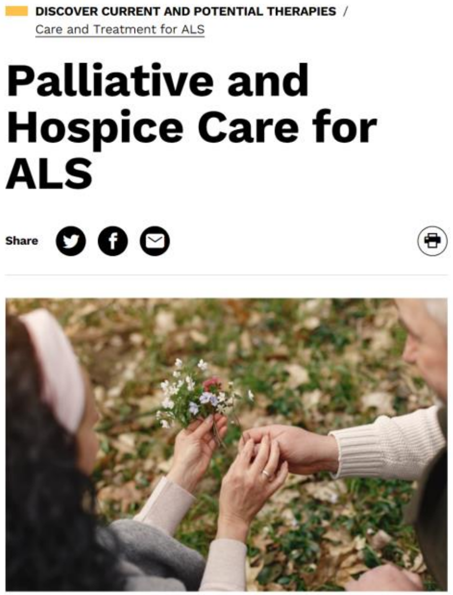
1. Tan Z. [Audio podcast] 2020



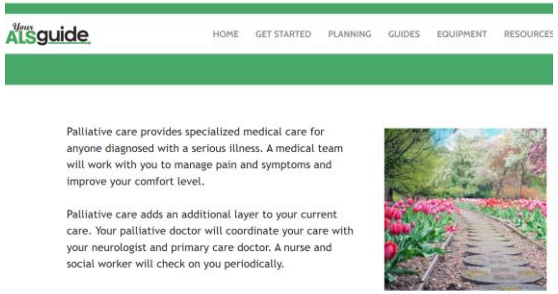
Resources

Education

- The ALS Association
- www.roon.com/als/home
- https://iamals.org/
- https://www.youralsguide.com/
- www.inpcs.org

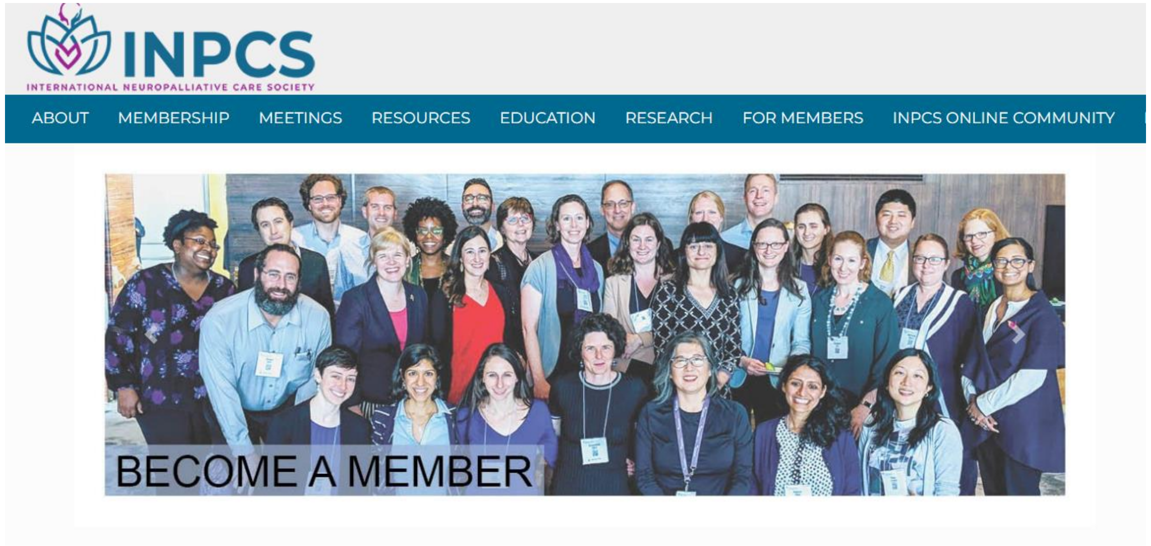


Palliative and Hospice Care for ALS



Palliative care provides specialized medical care for anyone diagnosed with a serious illness. A medical team will work with you to manage pain and symptoms and improve your comfort level.

Palliative care adds an additional layer to your current care. Your palliative doctor will coordinate your care with your neurologist and primary care doctor. A nurse and social worker will check on you periodically.



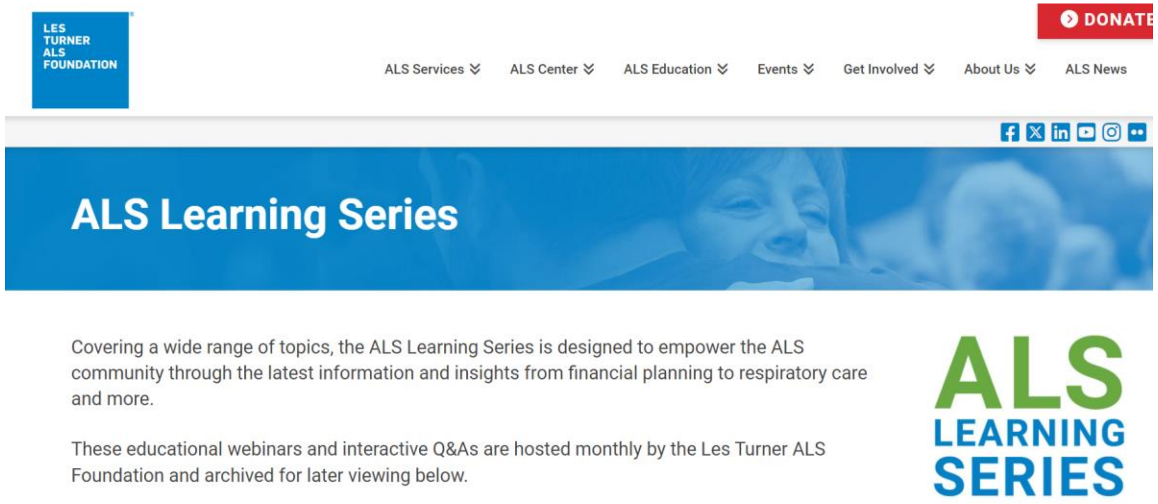
For Care Partners

- [ALS Learning Series • Les Turner ALS Foundation]()
- [Support for ALS Caregivers | The ALS Association]()

Support for Caregivers

Being the primary caregiver for a loved one living with ALS can be stressful. In addition to being on call 24/7, you may have additional responsibilities, like working a full- or part-time job and taking care of children.

Caregivers are often so busy supporting their loved ones that their own physical or mental health takes second priority. It's important that you get the support and assistance you need so you can care for your loved one to the best of your abilities.



ALS Learning Series

Covering a wide range of topics, the ALS Learning Series is designed to empower the ALS community through the latest information and insights from financial planning to respiratory care and more.

These educational webinars and interactive Q&As are hosted monthly by the Les Turner ALS Foundation and archived for later viewing below.

The ALS Journey Closing

Mr. R had expressed his wishes not to be resuscitated, not to have invasive ventilation, and to prioritize comfort over all else. His partner knew his wishes, and when he was close to the end of life, they chose hospice care and comfort-focused medicines.

He died peacefully with his wife by his side.

Thank you!
Questions?