



2024
FSHD
CONNECT

Care to Enhance Quality of Life

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Community Resources

Home Health

- Skilled level services – RN, CNA, PT, OT, SLP, SW
- Short-term, rehabilitative
- Usually covered by insurance

Home Care/Caregivers

- Non-skilled services
- Usually paid out-of-pocket

Palliative Care

- Goal and value-based care
- Congruent with other services

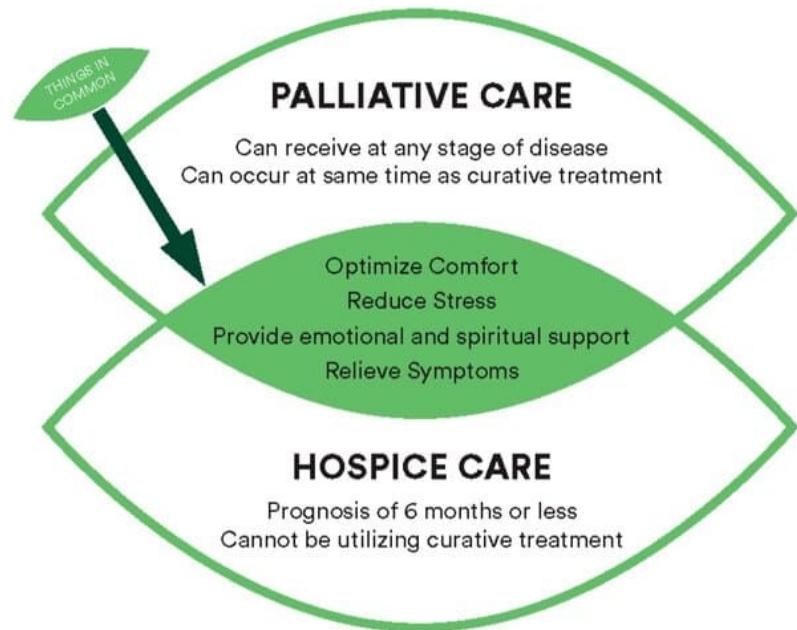
Hospice Care

- Support for those with estimated 6 month or less prognosis

Area Agency on Aging (AAA)



Palliative Care



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What is it?

- Support for people living with a serious illness, focusing on quality of life
- Consultative medical provider & SW

What can they do for me?

- Offer guidance on how to manage symptoms
- Help you understand your treatment options
- Emotional support for you and your caregivers

When would palliative care be appropriate?

- Difficulty breathing (dyspnea)
- Difficulty swallowing (dysphagia)
- Challenges with mobility and motility ²

Palliative Care

Symptom Management

- Pain
 - Different guidelines per agency for management vs consultation
 - Non-pharmacologic measures
 - Marijuana
 - Battlefield Acupuncture
 - Topical agents
- Constipation
 - Dietary modifications
 - Bowel regimen

- Dyspnea (shortness of breath)
 - Body positioning
 - Considerations for CPAP
 - Severe cases – use of opioids
- Dysphagia (difficulty swallowing)
 - Dietary modifications
 - Medication review
 - Family support

Social Work

- Determinants of Health
- Serious Illness Counseling
- Community Resources

Care Environments

Assisted Living Facility (ALF) vs Skilled Nursing Facility (SNF)

- Paid out-of-pocket
 - Medicaid
 - PACE
 - Income-based
 - Age 55+
 - Tiered levels of care
 - ADL assistance
 - Medication management
- Rehab
 - “Qualifying event” – 3 nights in a hospital
 - Up to 100 days/year under Medicare
 - Long Term Care
 - Paid out-of-pocket
 - Medicaid Long-Term Care
 - Long Term Care Insurance

Advance Directives

Give the gift of guidance to your loved ones

What is it?

- medical directives for treatment, MDPOA

Facts

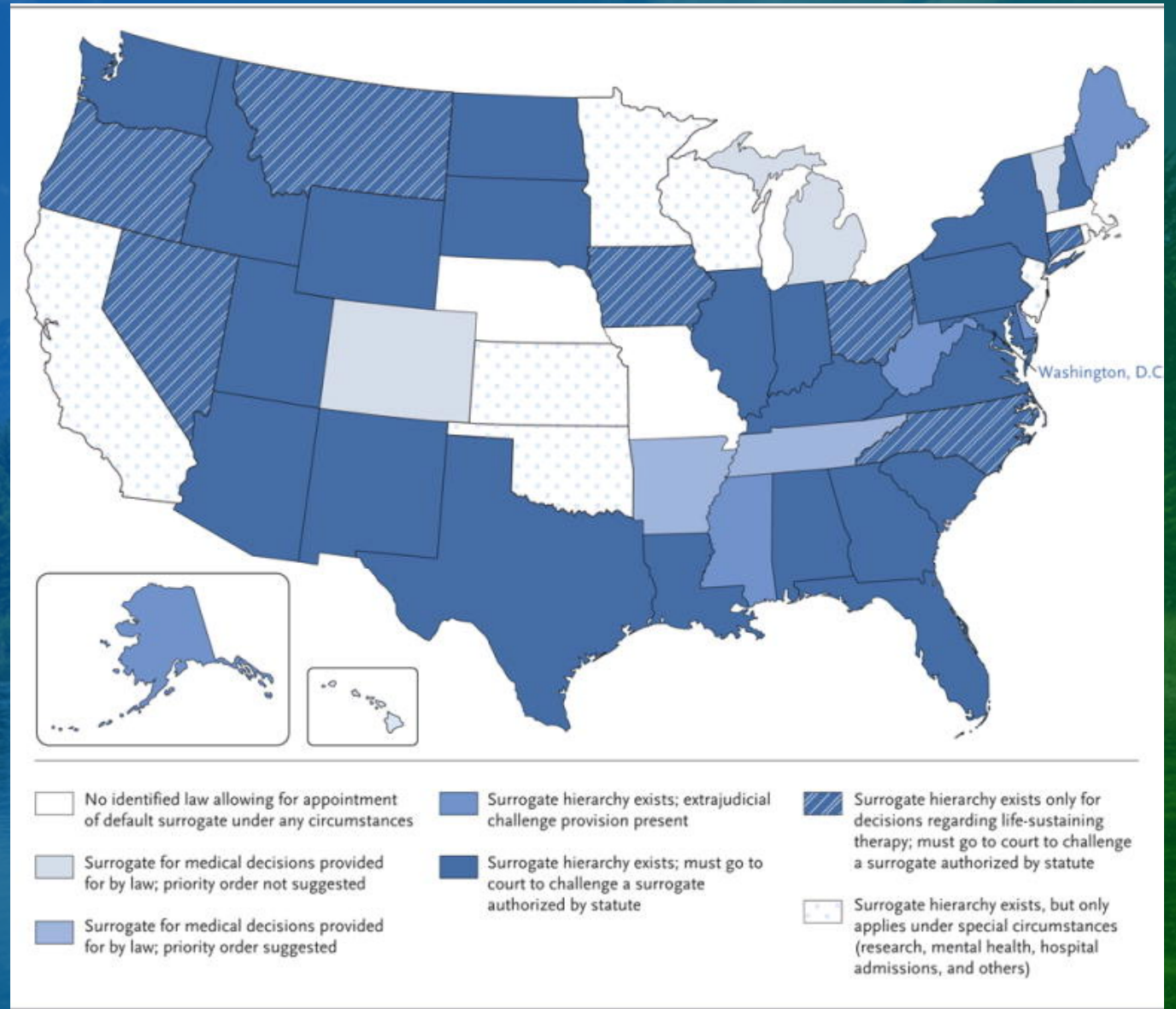
- 80% of patients endorse it; < 35% have completed advance directives³
- Out-of-hospital CPR: 11% chance of survivability, 9% chance neurological recovery⁴

Medical Durable Power of Attorney (MDPOA)

- Activated when you are unable to make decisions for yourself
- Role: advocate for YOUR healthcare wishes
- Does not require a lawyer!
- List of agents
- Can be revised at any time
- Expires upon death

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<https://cdphe.colorado.gov/palliative-care/advance-care-planning-for-patients-and-families>



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Medical Directives

Forms

- MOST/POLST/MOLST forms
- DNR directive
- Five Wishes
- Living Will

Medical Aid in Dying

- Compassionandchoices.org
- California, Colorado, DC, Hawaii, Maine, Montana, New Jersey, New Mexico, Oregon, Vermont, Washington

Legal Implications

- Protected under Patient Self-Determination Act⁶

THANK YOU!



References

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