End of Life Care

City of Lake Oswego
Adult Community Center Presentation

January 8, 2025

What are the Facts about End-of Life Care ?

- Most of us are **unprepared** for our End-of-Life care
- The US health care system is **fragmented**
- **Moral injuries and distress** among Health Care professionals concern End-of-Life care
- **Death is not the end** for the surviving loved ones

People Die as they Lived

Eriko Onishi

Growing up in Japan, I often heard these words, yet never fully understood them — until I began caring for the dying and their families and friends.

At the end of life, some are infused with love and caring, while others struggle with anger, fear and frustration. These feelings, I learned, do not form overnight, but rather reflect lives lived.

And so, as a physician, I shared with my patients and those close to them that preparing to die well consists of living well now.

During the final stages of life, prepared or not, patients experience the full range of caring. As physicians, we meet those who need handholding at each step, as well as those who are dying, who guide us as we accompany them on their journey.

Whenever someone nears death, the best way is still forward. While we know our what our final destination is, we make these last precious steps meaningful, tender and unique.

There is always something we can do.

It is such a privilege to accompany so many on these final steps; they are among the most dignifying of their lives — and ours.

This is why I am so passionate about my work. And I want as many as possible to have the best experience they deserve ...

What is End-of-Life Care?


Core Principles for End-of-Life Care
Clinician Perspectives
1. Respect the dignity of both patient and caregivers
2. Encompass alleviation of pain and other physical symptoms
3. Assess and manage psychological, social, and spiritual / religious problems
4. Offer continuity
5. Provide access to palliative and hospice care
6. Respect the right to refuse treatment
7. Respect the physician's professional responsibility to discontinue treatments when appropriate
8. Promote clinical and evidence-based research on providing care at end-of-life

Domains of Quality End-of-Life Care from *Patients'* Perspectives

- Receiving adequate pain and symptom management
- Avoiding inappropriate prolongation of dying
- Achieving a sense of control
- Relieving burden
- Achieving peace with their God
- Having finances in order
- Strengthening relationships with their loved ones
- Feeling that their lives were meaningful

Who Should Initiate Your End-of-Life Care?

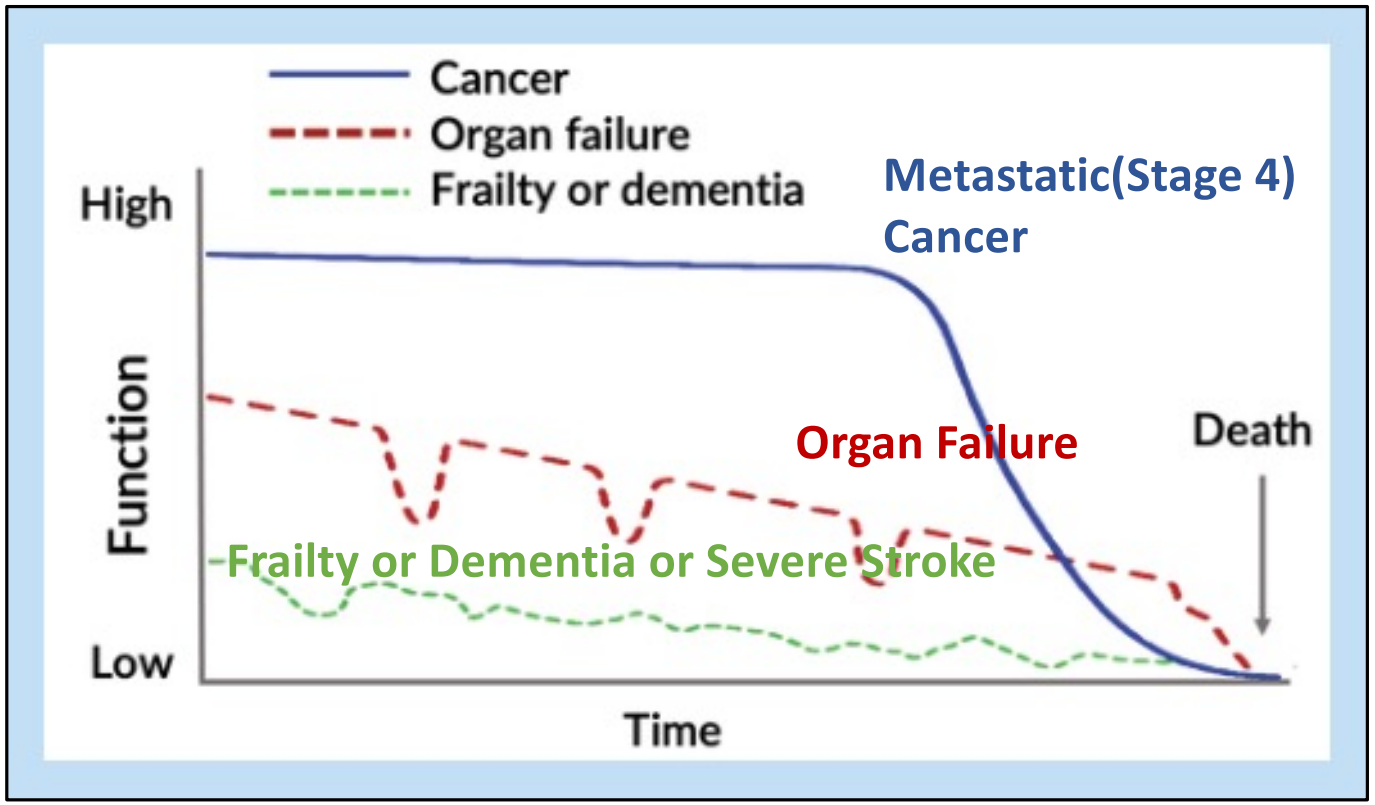
- Ideally **YOU** and Your Family/Loved ones, accompanied by discussion with your medical team as you **approach end of life**
- The Timing depends on individual preferences … !?

Definitions

- **Withholding treatment**: Choosing not to start a life-sustaining intervention.
- **Withdrawing treatment**: Stopping a treatment that is already in place.
- **Withholding and withdrawing treatments are ethically and legally identical**.
- **Life sustaining treatments:** Medical interventions used to extend a person's life when their body is unable to sustain essential functions on its own.
  - Ventilators - breathing machines that support oxygenation
  - Dialysis - clean blood when kidneys are not working well
  - Artificial Nutrition and Hydration - via feeding tube, IV hydration

How do I know that I am approaching End of Life?

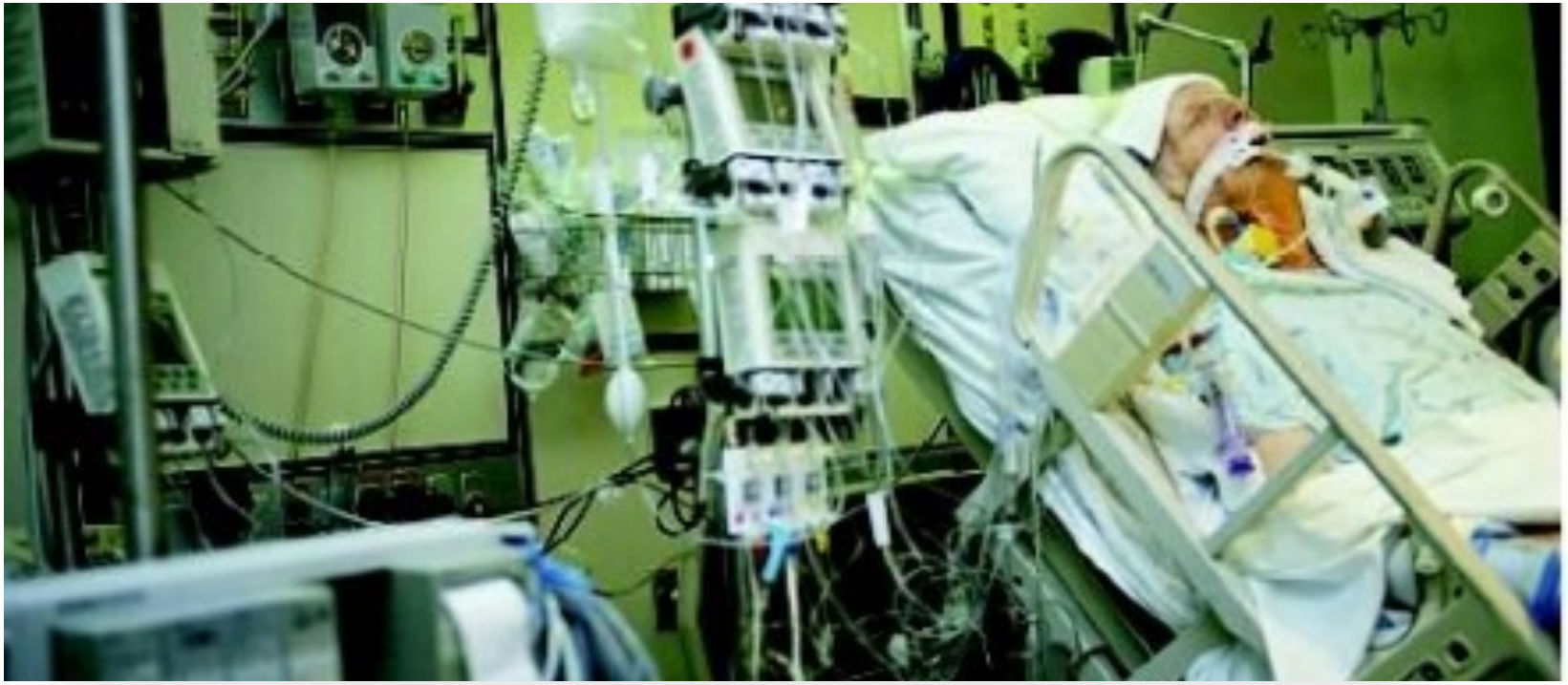
Three Most Common Illness Trajectories



Organ Failure:
Heart Failure
Severe Lung disease
Kidney Failure
Liver Failure

Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age, J. Lynn and D. Adamson

THE TRUTH



Withholding or withdrawing treatment is eventually part of every Care Plan … because Death is Inevitable.

If a patient doesn't Withdraw or Withhold before imminent death, they may choose …

CPR

Cardiopulmonary Resuscitation

ECMO

Extracorporeal Membrane Oxygenation

Intubation

A "breathing machine"

Dialysis

Surgery

Medications

… and find themselves a ‘box’ on an endless conveyor-belt, sometimes feeling like a ‘pin cushion’ ...

… and eventually, the medical team will rush in like a marching army, intent on saving a life ...

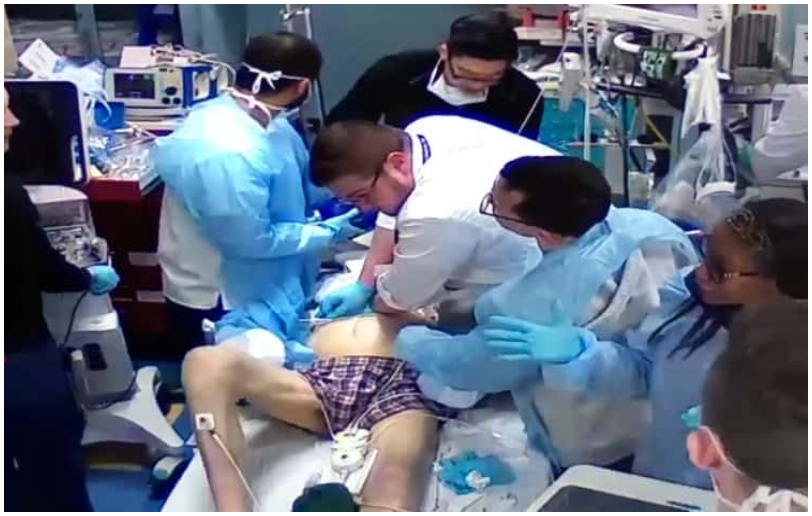
…and will initiate CPR.

Cardiopulmonary Resuscitation

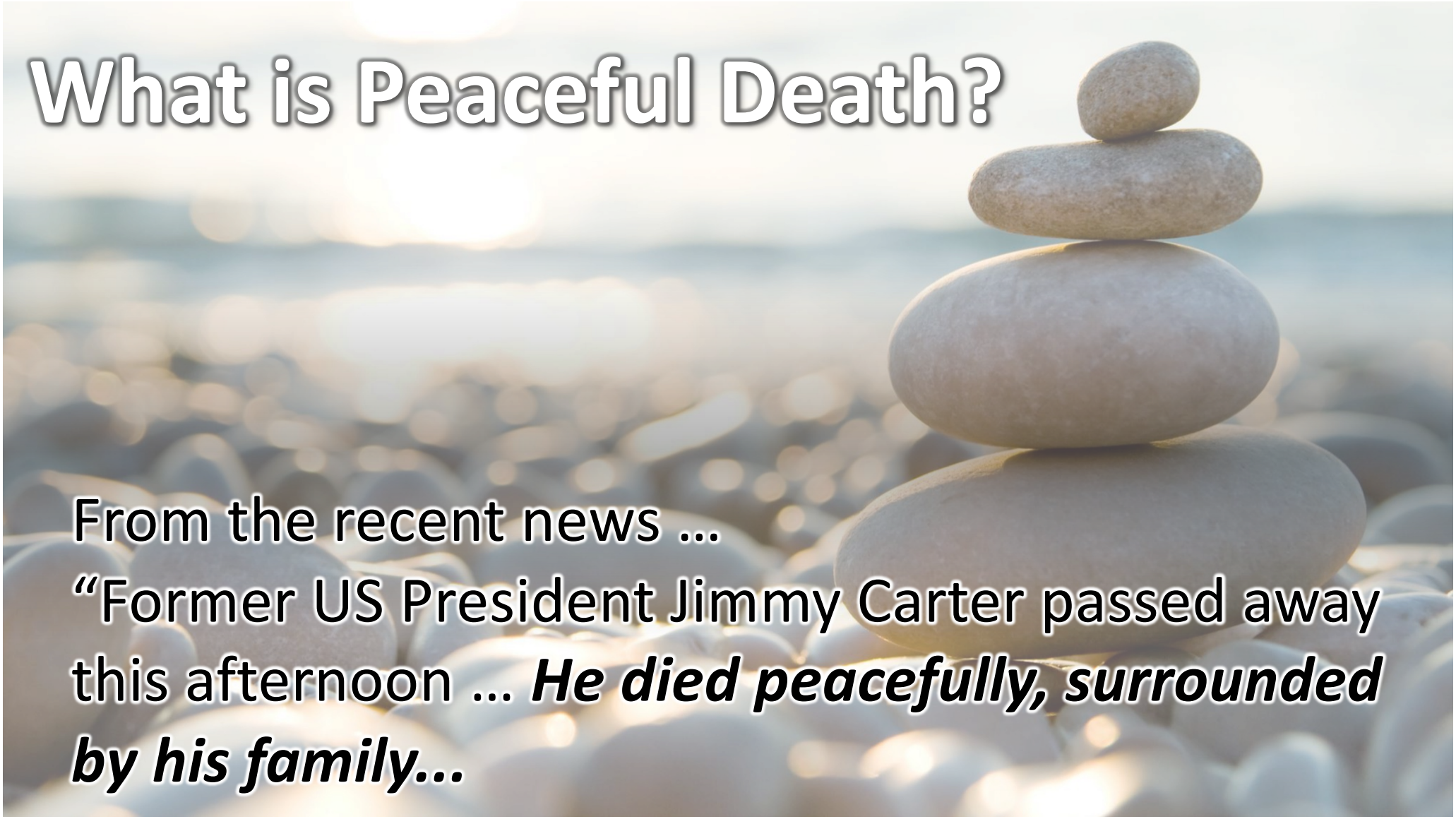
An emergency procedure performed when the heart has stopped beating and there is no breathing (DEATH)

At the Time of Patient Death

With CPR:
Surrounded by a Medical Team



Without CPR:
Surrounded by Loved Ones


What is Peaceful Death?
From the recent news …
“Former US President Jimmy Carter passed away this afternoon … He died peacefully, surrounded by his family…


How Do We Prepare?

Preparing for Serious Illness and End of Life

1. Always be kind to and show love to your family and friends.
2. Establish and cultivate a primary care provider that you can trust.
3. Establish and cultivate a medical team that you can trust.
4. Prepare for your priorities and share them with those who will advocate for you.

When you are sick or dying …

… you need someone who will advocate and care for you.

People die as they lived.

How Can You Best Work with Your Primary Care Provider?

- **<u>Let your primary care provider/team follow you!</u>**
  - →Make a routine appointment every 1-3 months to update them on your situation and allow them to catch up with you.
- Discuss your concerns about **everything**, including any physical or mental symptoms you have and your care in general. Let your team **<u>brainstorm with you</u>**!
- When needed, ask for extended visit time (e.g. schedule 40 minutes instead of the usual 15-20min)
- **Always, always, make follow up plans.**

"When should I follow up with you, Doc?"

How Can You Best Work with Your Primary Care Provider?

- Bring your family and other loved ones with you to the appointment
- Initiate your Advance Care Planning: discuss future medical care with your provider and your loved ones
  - → Appoint your Health Care Representative/Surrogate decision maker
  - → Complete your Advance Directive and/or update it as needed
  - → → You may benefit from completing POLST (Portable Order for Life Sustaining Treatment)


My Advance Care Planning Journey
Time to Get My Ducks in a Row!
Name Surrogate Decision Maker
Complete Advance Directive
Complete POLST
EOL Care Decisions
Healthy
Less Healthy
and/or Older
Ongoing Conversations and Dialogues with
Your Loved Ones and/or Medical Team

Priorities

What is my line in the sand?

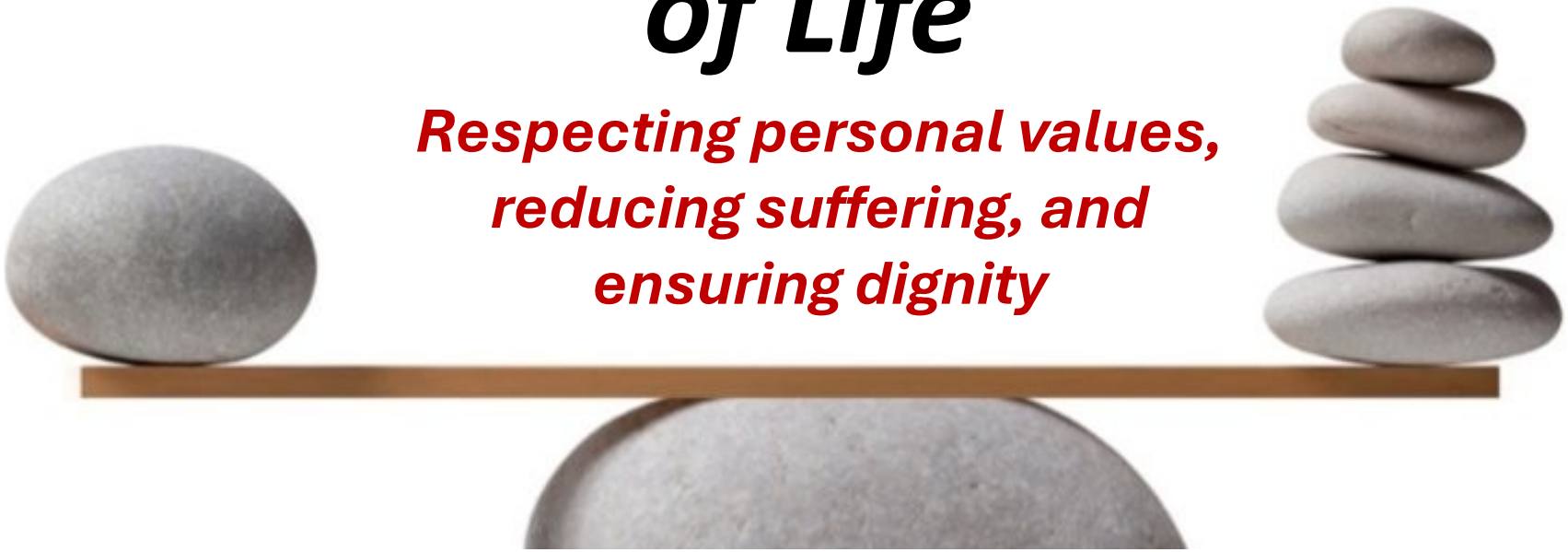
1. *Which functional and mental compromises are acceptable to me, which could I live with long-term, and which are unacceptable to me?*
2. *What trade-offs am I willing to make, and for how long, in order to have my desired Quality of Life?*

The Ultimate Question

Quality vs. Quantity

of Life

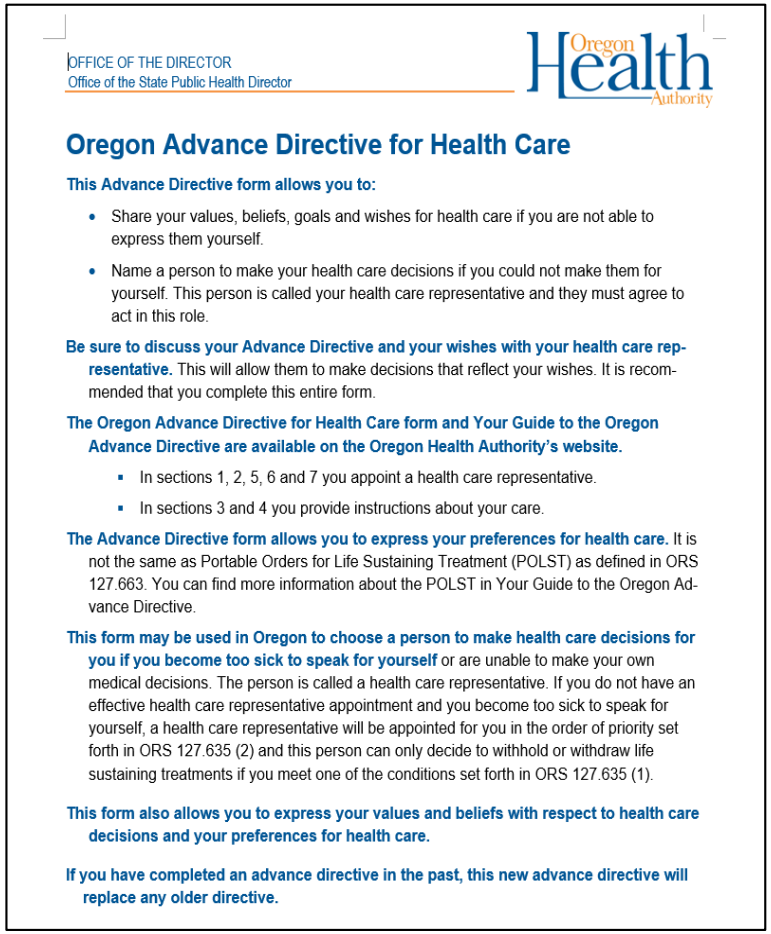
Respecting personal values, reducing suffering, and ensuring dignity



Your Oregon Advance Directive

1. **Formally appoints your Health Care Representative**

2. **Provides written medical instructions, based on your personal preferences**



OFFICE OF THE DIRECTOR
Office of the State Public Health Director

Oregon Health Authority

Oregon Advance Directive for Health Care

This Advance Directive form allows you to:

- Share your values, beliefs, goals and wishes for health care if you are not able to express them yourself.
- Name a person to make your health care decisions if you could not make them for yourself. This person is called your health care representative and they must agree to act in this role.

Be sure to discuss your Advance Directive and your wishes with your health care representative. This will allow them to make decisions that reflect your wishes. It is recommended that you complete this entire form.

The Oregon Advance Directive for Health Care form and Your Guide to the Oregon Advance Directive are available on the Oregon Health Authority's website.

- In sections 1, 2, 5, 6 and 7 you appoint a health care representative.
- In sections 3 and 4 you provide instructions about your care.

The Advance Directive form allows you to express your preferences for health care. It is not the same as Portable Orders for Life Sustaining Treatment (POLST) as defined in ORS 127.663. You can find more information about the POLST in Your Guide to the Oregon Advance Directive.

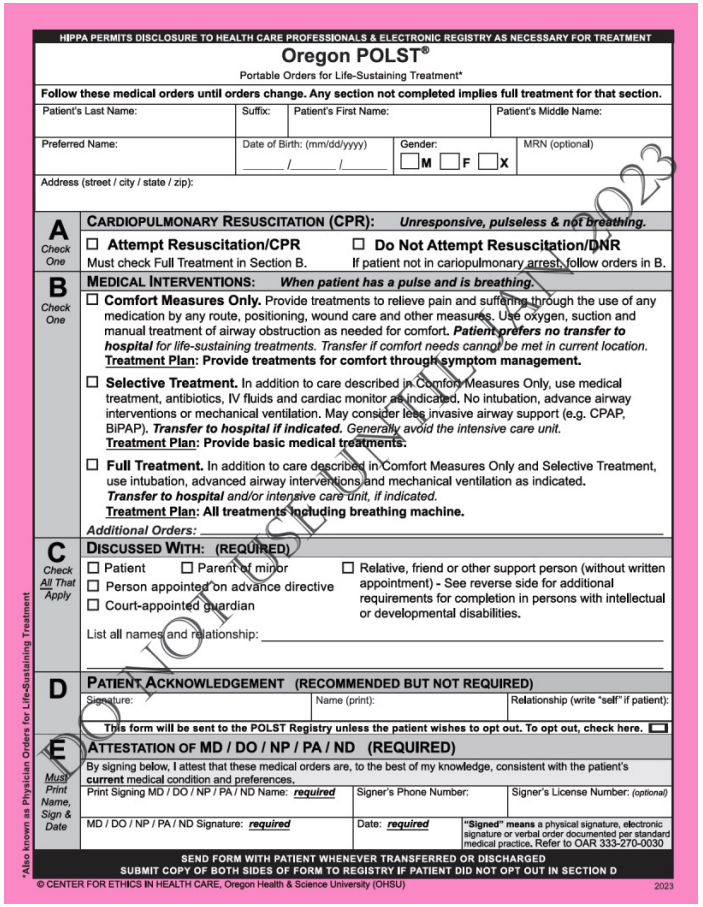
This form may be used in Oregon to choose a person to make health care decisions for you if you become too sick to speak for yourself or are unable to make your own medical decisions. The person is called a health care representative. If you do not have an effective health care representative appointment and you become too sick to speak for yourself, a health care representative will be appointed for you in the order of priority set forth in ORS 127.635 (2) and this person can only decide to withhold or withdraw life sustaining treatments if you meet one of the conditions set forth in ORS 127.635 (1).

This form also allows you to express your values and beliefs with respect to health care decisions and your preferences for health care.

If you have completed an advance directive in the past, this new advance directive will replace any older directive.

Portable Orders for Life-Sustaining Treatment

- A medical order written by health care providers (eg. Physicians, Nurse Practitioners, Physicians Assistants, Naturopathic physician)
- For people with serious progressive illness: (eg. Advanced Organ Failure or Advanced Cancer, Advanced Dementia, Advanced Frailty, Advanced age) **AND** who want to set limits on their medical treatment
- Intended to be followed by EMS, or other emergency medical personnel, as an out-of-hospital medical order set.



HIPPA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS & ELECTRONIC REGISTRY AS NECESSARY FOR TREATMENT

Oregon POLST®

Portable Orders for Life-Sustaining Treatment*

Follow these medical orders until orders change. Any section not completed implies full treatment for that section.

Patient's Last Name:	Suffix:	Patient's First Name:	Patient's Middle Name:
Preferred Name:	Date of Birth: (mm/dd/yyyy) ____/____/____	Gender: ☐M ☐F ☐X	MRN (optional)

Address (street / city / state / zip):

A *Check One* — **CARDIOPULMONARY RESUSCITATION (CPR):** ***Unresponsive, pulseless & not breathing.***

☐ **Attempt Resuscitation/CPR** — Must check Full Treatment in Section B.

☐ **Do Not Attempt Resuscitation/DNR** — If patient not in cariopulmonary arrest, follow orders in B.

B *Check One* — **MEDICAL INTERVENTIONS:** ***When patient has a pulse and is breathing.***

☐ **Comfort Measures Only.** Provide treatments to relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. ***Patient prefers no transfer to hospital*** *for life-sustaining treatments. Transfer if comfort needs cannot be met in current location.*
Treatment Plan: Provide treatments for comfort through symptom management.

☐ **Selective Treatment.** In addition to care described in Comfort Measures Only, use medical treatment, antibiotics, IV fluids and cardiac monitor as indicated. No intubation, advance airway interventions or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). ***Transfer to hospital if indicated.*** *Generally avoid the intensive care unit.*
Treatment Plan: Provide basic medical treatments.

☐ **Full Treatment.** In addition to care described in Comfort Measures Only and Selective Treatment, use intubation, advanced airway interventions and mechanical ventilation as indicated. ***Transfer to hospital*** *and/or intensive care unit, if indicated.*
Treatment Plan: All treatments including breathing machine.

Additional Orders: _____

C *Check All That Apply* — **DISCUSSED WITH: (REQUIRED)**

☐ Patient ☐ Parent of minor
☐ Person appointed on advance directive
☐ Court-appointed guardian
☐ Relative, friend or other support person (without written appointment) - See reverse side for additional requirements for completion in persons with intellectual or developmental disabilities.

List all names and relationship: _____

D — **PATIENT ACKNOWLEDGEMENT (RECOMMENDED BUT NOT REQUIRED)**

Signature:	Name (print):	Relationship (write "self" if patient):

This form will be sent to the POLST Registry unless the patient wishes to opt out. To opt out, check here. ☐

E *Must Print Name, Sign & Date* — **ATTESTATION OF MD / DO / NP / PA / ND (REQUIRED)**

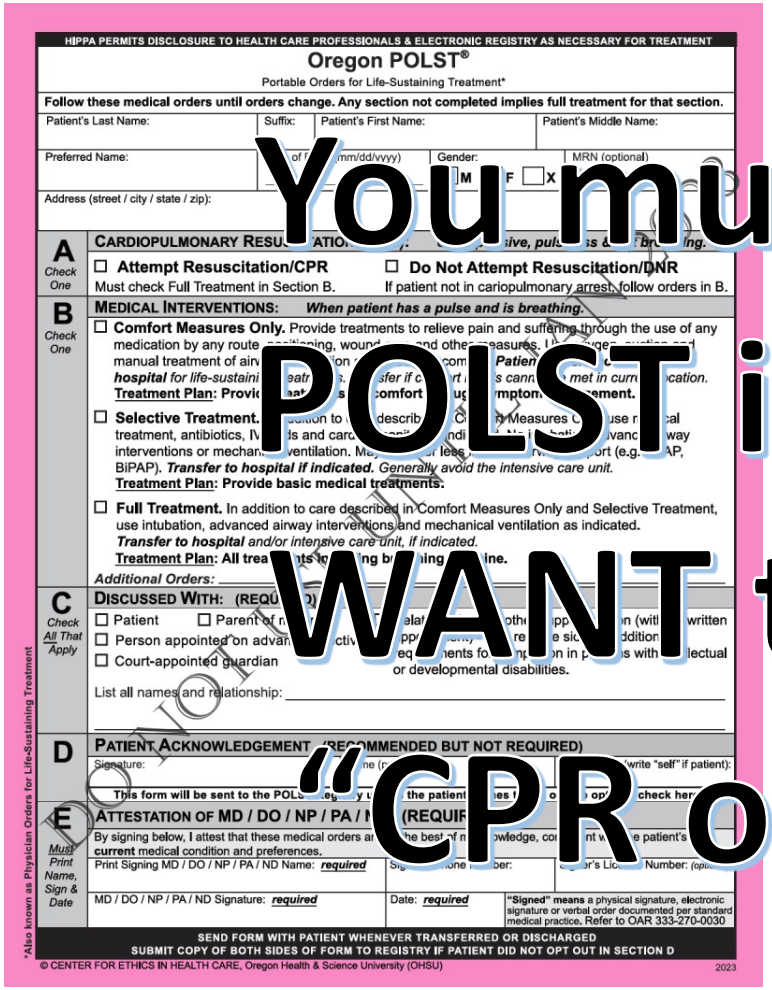
By signing below, I attest that these medical orders are, to the best of my knowledge, consistent with the patient's **current** medical condition and preferences.

Print Signing MD / DO / NP / PA / ND Name: ***required***	Signer's Phone Number:	Signer's License Number: *(optional)*
MD / DO / NP / PA / ND Signature: ***required***	Date: ***required***	**"Signed" means** a physical signature, electronic signature or verbal order documented per standard medical practice. Refer to OAR 333-270-0030

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED
SUBMIT COPY OF BOTH SIDES OF FORM TO REGISTRY IF PATIENT DID NOT OPT OUT IN SECTION D

*Also known as Physician Orders for Life-Sustaining Treatment

A Preemptive Medical Order Outlining Specific Choices



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Portable Orders for Life-Sustaining Treatment*

Follow these medical orders until orders change. Any section not completed implies full treatment for that section.

Patient's Last Name: | Suffix: | Patient's First Name: | Patient's Middle Name:

Preferred Name: | (mm/dd/yyyy) | Gender: ☐M ☐F ☐X | MRN (optional)

Address (street / city / state / zip):

A Check One — **CARDIOPULMONARY RESUSCITATION** (...sive, pulseless & not breathing.)

☐ **Attempt Resuscitation/CPR** — Must check Full Treatment in Section B.

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B Check One — **MEDICAL INTERVENTIONS:** ***When patient has a pulse and is breathing.***

☐ **Comfort Measures Only.** Provide treatments to relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. ***Patient may be transferred to hospital*** *for life-sustaining treatment if comfort needs cannot be met in current location.* **Treatment Plan: Provide medication by any route necessary to maintain comfort. Position, suction and manually clear airway as needed. Use oxygen, bag mask ventilation as needed.**

☐ **Selective Treatment.** In addition to those described in Comfort Measures Only, use medical treatment, antibiotics, IV fluids and cardiac monitoring as indicated. Use advanced airway interventions or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). ***Transfer to hospital if indicated.*** *Generally avoid the intensive care unit.* **Treatment Plan: Provide basic medical treatments.**

☐ **Full Treatment.** In addition to care described in Comfort Measures Only and Selective Treatment, use intubation, advanced airway interventions and mechanical ventilation as indicated. ***Transfer to hospital*** *and/or intensive care unit, if indicated.* **Treatment Plan: All treatments including cardiac resuscitation, if indicated. Use intensive care medicine.**

Additional Orders:

C Check All That Apply — **DISCUSSED WITH:** (REQUIRED)

☐ Patient ☐ Parent of minor ☐ Healthcare agent ☐ Other appropriate person (with written documentation)

☐ Person appointed on advance directive ☐ Representative with decision-making authority

☐ Court-appointed guardian

List all names and relationship:

D — **PATIENT ACKNOWLEDGEMENT** (RECOMMENDED BUT NOT REQUIRED)

Signature: | Name (print): | If not patient, write "self" if patient:

This form will be sent to the POLST registry unless the patient opts out. Check here to opt out.

E Must Print Name, Sign & Date — **ATTESTATION OF MD / DO / NP / PA / ND** (REQUIRED)

By signing below, I attest that these medical orders are consistent with the best of my knowledge, consistent with the patient's current medical condition and preferences.

Print Signing MD / DO / NP / PA / ND Name: ***required*** | Signature Number: | Signer's License Number: (optional)

MD / DO / NP / PA / ND Signature: ***required*** | Date: ***required*** | **"Signed" means** a physical signature, electronic signature or verbal order documented per standard medical practice. Refer to OAR 333-270-0030

*Also known as Physician Orders for Life-Sustaining Treatment

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED
SUBMIT COPY OF BOTH SIDES OF FORM TO REGISTRY IF PATIENT DID NOT OPT OUT IN SECTION D

 2023

You must complete a POLST if You DO NOT WANT to be tried on “CPR or Intubation”

A. Cardiopulmonary Resuscitation (CPR)

☐ Attempt Resuscitation/CPR → Do it

X Do Not Attempt Resuscitation/DNR → Do not do it

B. Medical Interventions

X Comfort Measures Only

Symptom management for comfort, usually in hospital care

☐ Selective Treatment

Basic medical treatments, including hospital care

☐ Full Treatment

All treatments available


Palliative Care vs Hospice Care

Palliative Care

- Patient- and family-centered care
- Optimizes quality of life by anticipating, preventing, and treating suffering
- Involves addressing physical, intellectual, emotional, social, and spiritual needs throughout the continuum of illness
- Facilitates patient autonomy, access to information, and choice

Definitions from the Clinical Practice Guidelines for Quality Palliative Care

Developed as part of the National Consensus Project


Palliative Care
...a team to provide an extra layer of support.
...appropriate at any age and at any stage in a serious illness ... provided together with curative treatment.
By Center to Advance Palliative Care

Palliative Care and Hospice Care

Clinical Practice Guidelines for Quality Palliative Care

Hospice

- The model for quality, compassionate care for people facing **a life-limiting illness or injury.**
- A team-oriented approach to expert medical care, symptom management, and emotional and spiritual support - expressly tailored to the person's needs and wishes.
- Support is provided to the person's loved ones as well.

Hospice

- Focuses on caring, NOT curing
- In most cases, provided in the person's "home" residence (AFC, ALF, ICF, RCF).
- Can be provided in a free-standing hospice center or hospital, if medically indicated
- For patients of **any terminal illness** and **age**
- Hospice staff is on-call 24/7
- Benefits are provided for an **unlimited period of time as long as they are appropriate**
- Covered by Medicare, Medicaid, and most private insurance plans.

Hospice

Interdisciplinary Team Approach to Care:

- Nurses
- Physicians
- Social Workers
- Chaplains
- Home Health Aides
- Bereavement Counselors
- Volunteers
- Pharmacists
- Certain Therapists
  (e.g. PT/OT, Dietary Counselors)

What Services are Covered by Hospice Care?

Hospice will cover services to manage the terminal illness and related conditions to treat symptoms

- Hospice Physician, Nurse Practitioner (NP), or Physician Associate (PA)
- Your own doctor
- Nursing care
- Medical equipment
- Medical supplies
- Medications to manage pain and symptoms
- Hospice aide and homemaker services
- Physical therapy
- Occupational Therapy
- Speech/Language Pathology Services
- Medical Social Services
- Dietary Counseling
- Spiritual Counseling
- Individual and/or family grief and loss counseling before and after the patient's death
- Short-term inpatient pain control, symptom management, and respite care

Hospice is NOT…

… a care giving service.

… paying for room and board at a facility setting.

Medicare Part A Benefits

- **Inpatient hospital care**
- **Skilled nursing facility care**
- **Hospice care**
- **Some home health care**
- **Medical equipment** Covers 20% of the Medicare-approved amount for certain medical equipment, such as wheelchairs and walkers

Medicare DOES NOT Cover Long-term care

Hospice Levels of Care

Level of Care	What
Routine Home Care	Provided in the patient's place of residence
Continuous Home Care	Requires prolonged nurse(s) visits/days (8-24 hours) at home
General Inpatient Care	Require bringing patients to the inpatient unit (hospital), with RN available for 24 hours, for acute symptom management
Respite care	For caregiver relief (5 days)

NHPCO
National Hospice and Palliative Care Organization

National Alliance for Care at Home

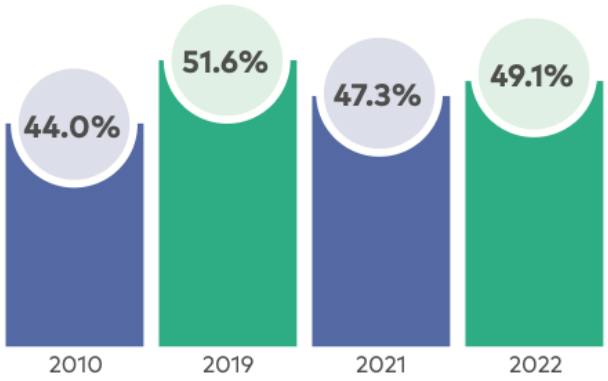
NHPCO Facts and Figures

2024 EDITION

Published September 2024

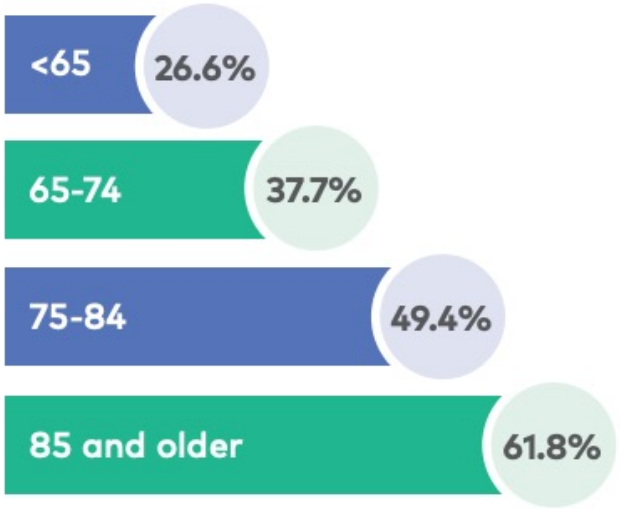
Who Receives Hospice Care?

Medicare Decedents who Received Hospice Care by Year



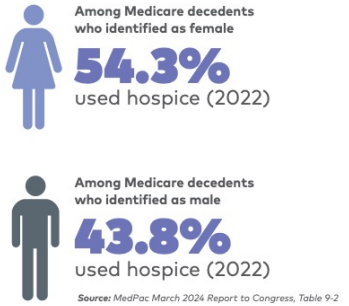
Source: MedPac March 2024 Report to Congress, Table 9-2

Medicare Decedents who used Hospice by Age (2022)



Source: MedPAC March 2024 Report to Congress, Table 9-2

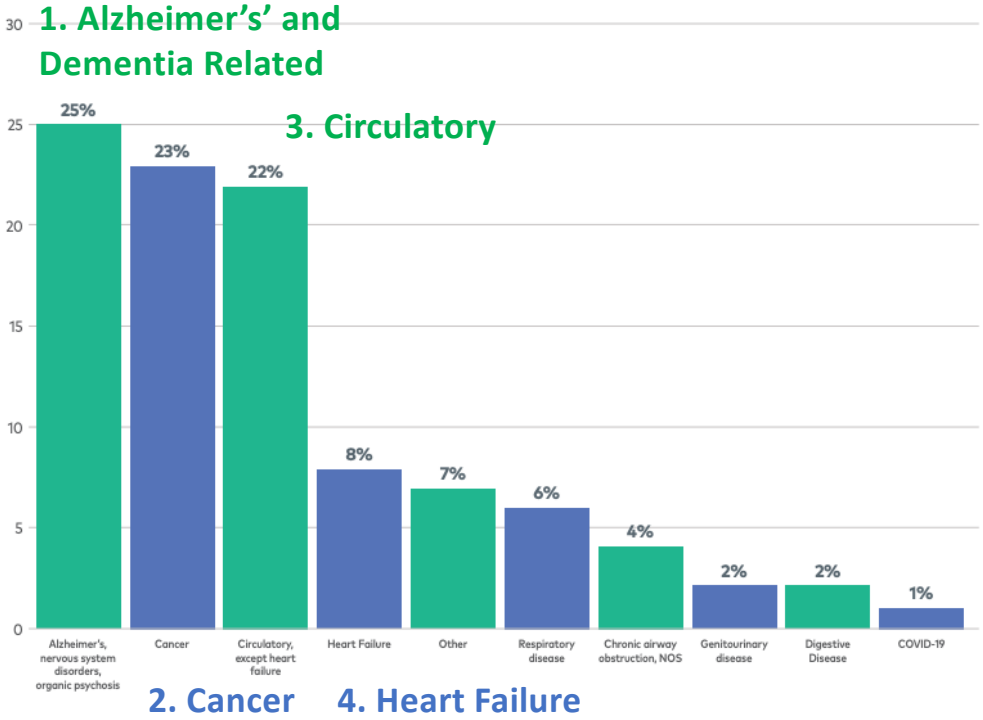
Patient Gender in 2022



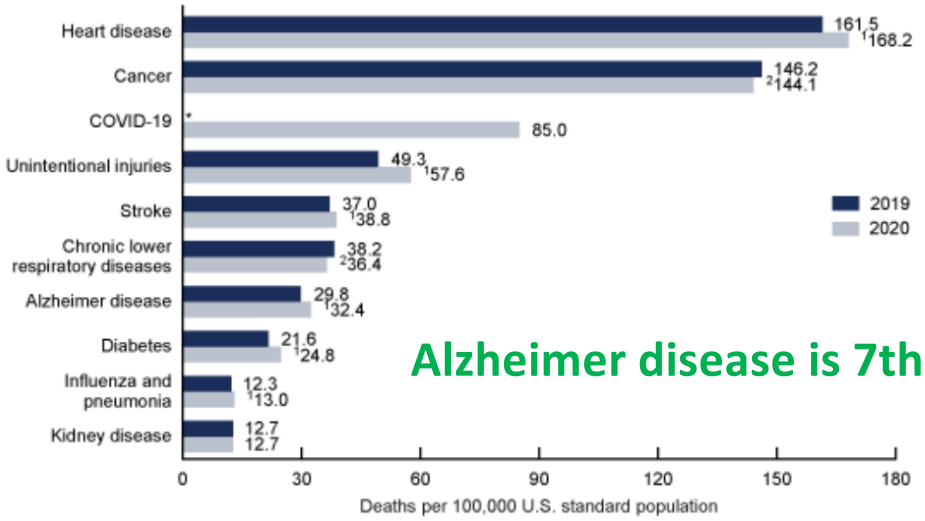
Total US Deaths 2024: 3.27 Million

Who Receives Hospice Care?

Medicare Decedents Using Hospice by Top 10 Principal Diagnoses (2021)



Age-Adjusted Death Rates for the 10 Leading Causes of Death 2019, 2020



Alzheimer disease is 7th

How Much Care is Received?

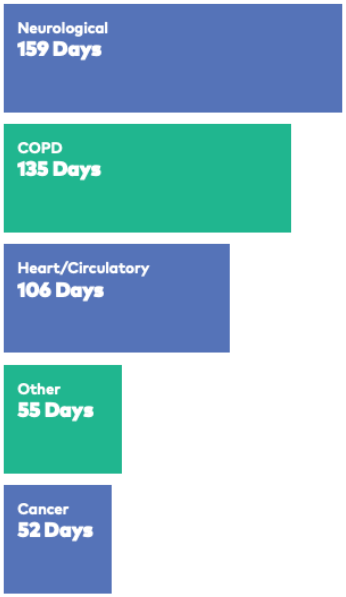
Average Lifetime Length of Stay

Year	Average lifetime length of stay among decedents (in days)	Median lifetime length of stay among decedents (in days)	Number of Medicare decedents who used hospice (in millions)
2010	87.0	18	0.87
2019	92.5	18	1.20
2021	92.1	17	1.29
2022	95.3	18	1.30

Note: *"Lifetime length of stay" is calculated for decedents who were using hospice at the time of death or before death and reflects the total number of days the decedent was enrolled in the Medicare hospice benefit during their lifetime.*

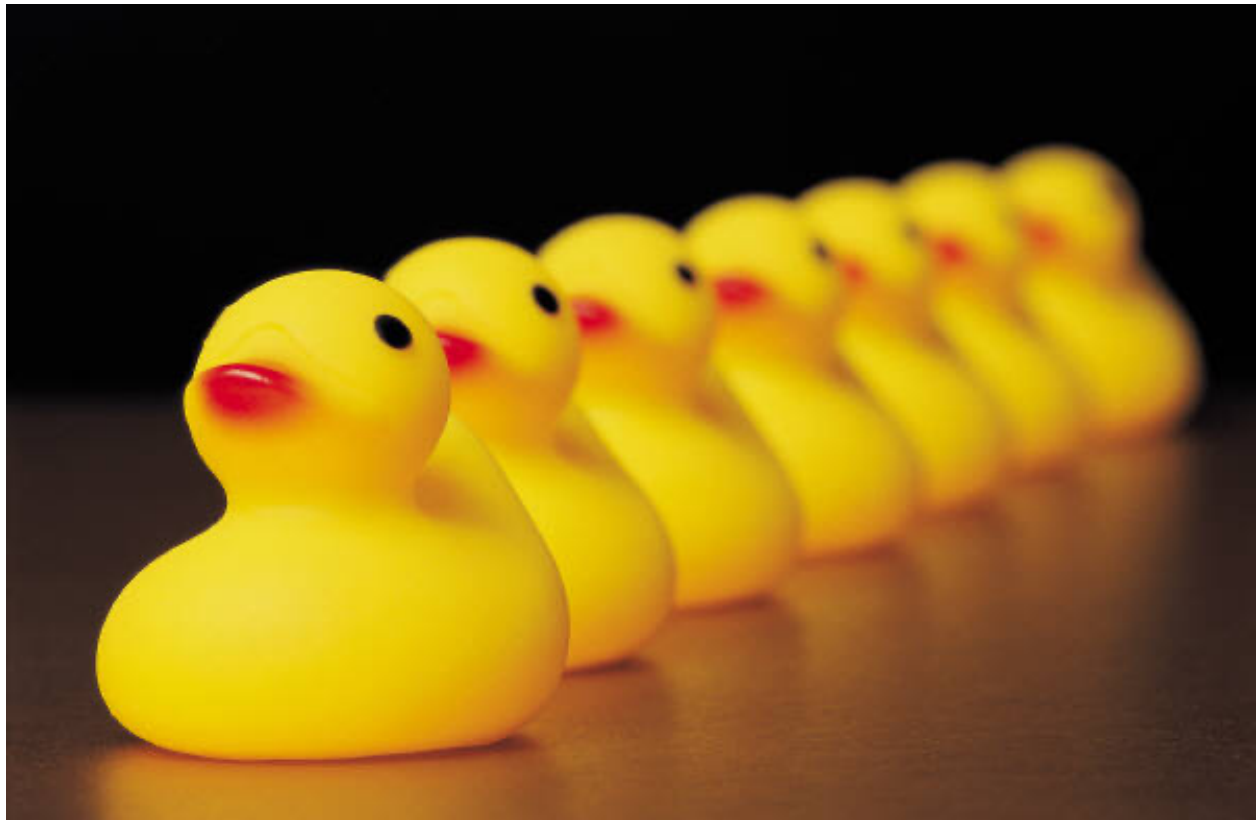
Source: *MedPAC March 2024 Report to Congress, Table 9-3*

Figure 14: CY 2021-2022 Average length of stay, in days, by diagnosis



Source: *MedPAC July 2024 Data Book, Chart 11-15; MedPAC July 2023 Data Book, Chart 11-14*

Hospice Eligibility



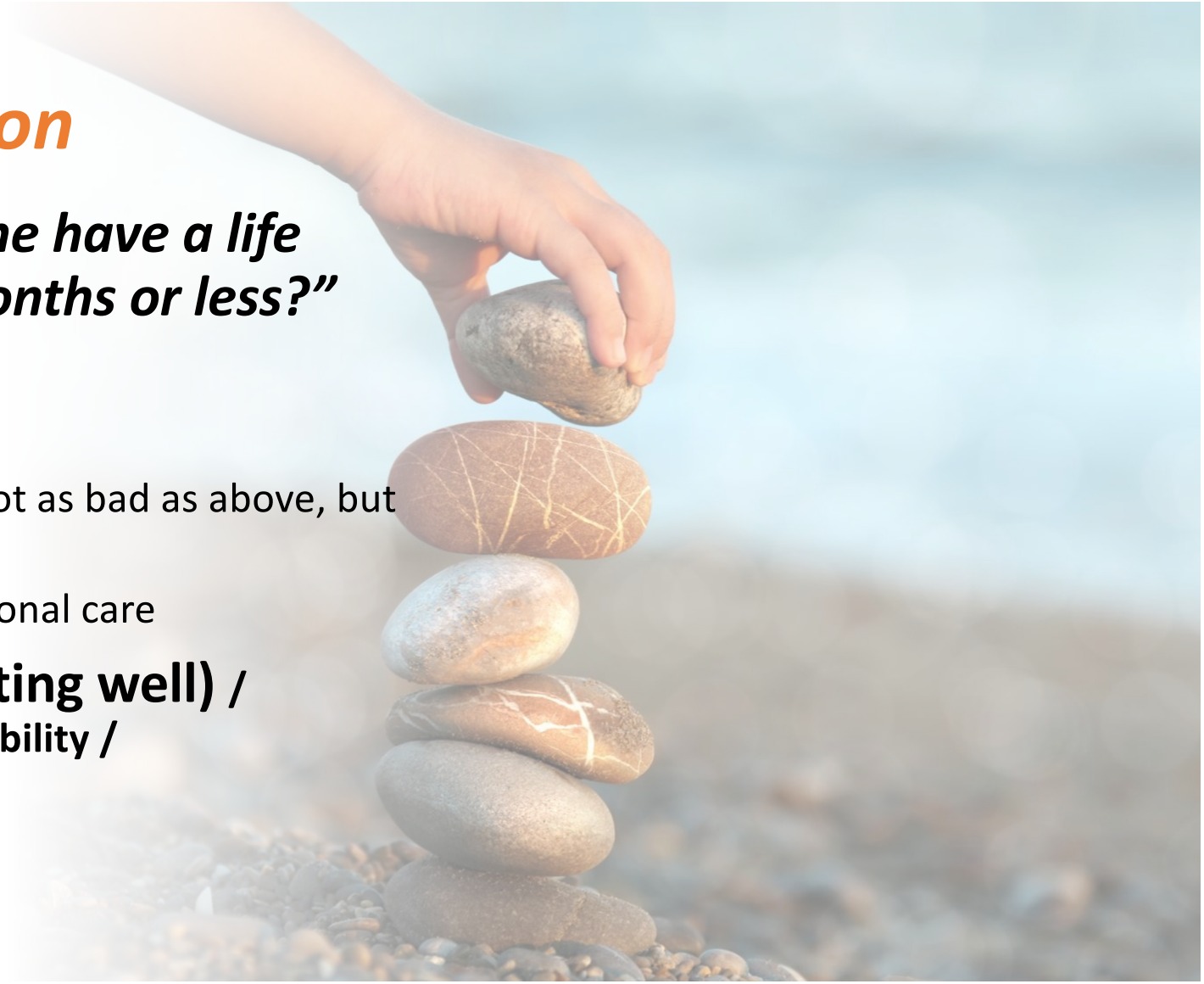
Hospice Eligibility

1. **A Serious Illness**: Must have a condition like advanced cancer, heart failure, or another illness that **cannot be cured**
2. **Life Expectancy of 6 Months or Less**: Doctors believes that the person may not live longer than six months, if the illness follows its normal course
3. **Focus on Comfort, Not Cures**: The person (or their family) has decided to stop treatments (**Withdrawal/Withhold**) aimed at curing the illness and instead focus on comfort and quality of life

The Big Question

"When does someone have a life expectancy of six months or less?"

- Main medical issue
- Other medical issues, not as bad as above, but has several
- More difficult with personal care
- **Nutrition (Not Eating well) /**
  Decreased Functional ability /
  Cognition /Age
- **Rapid Decline**



Function and Prognosis

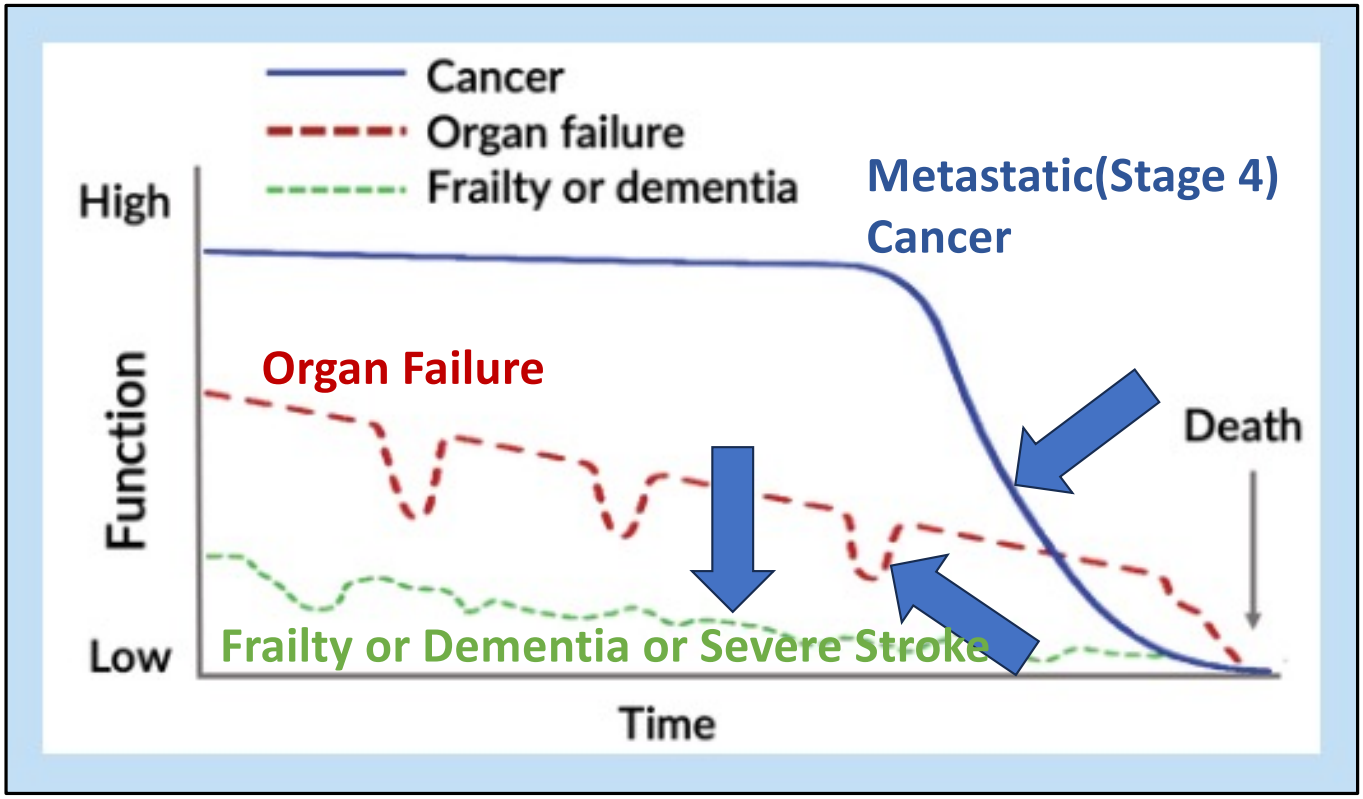
- Lack of **Activities of Daily Living (ADL)** are the most important predictor of 6-month mortality:

  Ambulation, Bathing, Dressing,

  Toileting, Transfer, Feeding

- Stronger than Diagnosis, Mental Status, or ICU admission, especially when happening <u>rapidly.</u>

At Which Point Would YOU be Ready for Hospice Care IF you had the option?



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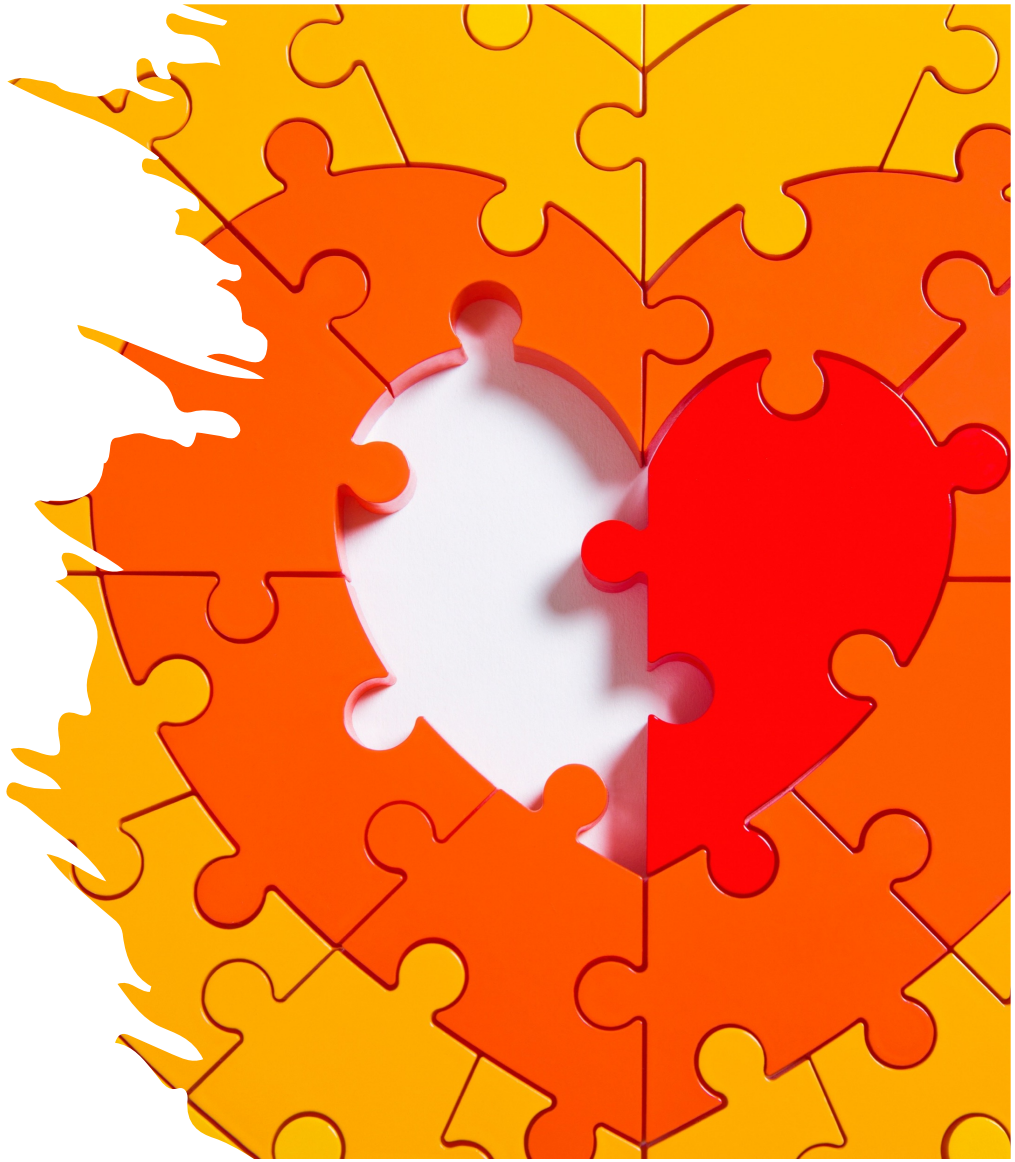
Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age, J. Lynn and D. Adamson

Hospice Care FAQ

- I do not have a terminal diagnosis, but I am getting weaker. Can I still be eligible for hospice care?
- What happens if I don’t pass away within six months? Will I be removed from hospice care?
- If I change my mind, can I leave hospice care?
- Is there any penalty for leaving my hospice service?
- Can I return to hospice care later?
- Does hospice cover all of my medications?

Hospice and End-of-Life Care Myths

- *"Oh, No!! I do not want hospice!! They just give up and kill patients!"*
  → **Hospice hastens death?!**
- *"I do not want Morphine…..Morphine killed my mother!"*
  → **Does morphine hasten death?**
- *"Dad starved to death!"*
  → **Do people starve at end of life?**
- I need a referral from my doctor to a hospice agency to get their evaluation.



Place of Care and Level of Care

Care Facility Comparison

Facility Type	Level of Care	Services Provided	Typical Residents	Cost	Duration	Regulation
Skilled Nursing Facility	High	24/7 nursing care, rehabilitation, medical supervision	Individuals with serious health issues or recovery needs	High (often covered by insurance)	Short-term to long-term	State and federal regulations, often Medicare certified
Long Term Care Facility	Moderate to High	Personal care, daily living assistance, medical support	Seniors with chronic illnesses or disabilities	Moderate to high	Long-term	State regulations, licensing varies by state
Assisted Living Facility	Moderate	Personal care, medication management, social activities	Seniors who need assistance but are relatively independent	Moderate	Long-term	State licensing and regulations vary; may be less stringent than nursing homes
Adult Foster Care Facility	Moderate	Personal care, meals, companionship in a home-like setting	Seniors or individuals with disabilities needing supervision	Variable (often lower than larger facilities)	Long-term	Varies by state; often requires licensing and regular inspections
Memory Care Facility	High	Specialized care for dementia and Alzheimer's, safety features	Individuals with memory-related issues	High	Long-term	Strict regulations due to specialized care requirements, state licensed

Hopewell House is the only 12-bed residential care facility dedicated to end-of-life located in Southwest Portland. It operates using an innovative collaborative model that keeps costs down unlike a hospital.

Residents at Hopewell House have private rooms with outdoor views and include our expert clinical staff who work with hospice teams to provide around-the-clock care for each resident, allowing loved ones and visitors to relax and focus on time together in a peaceful setting.

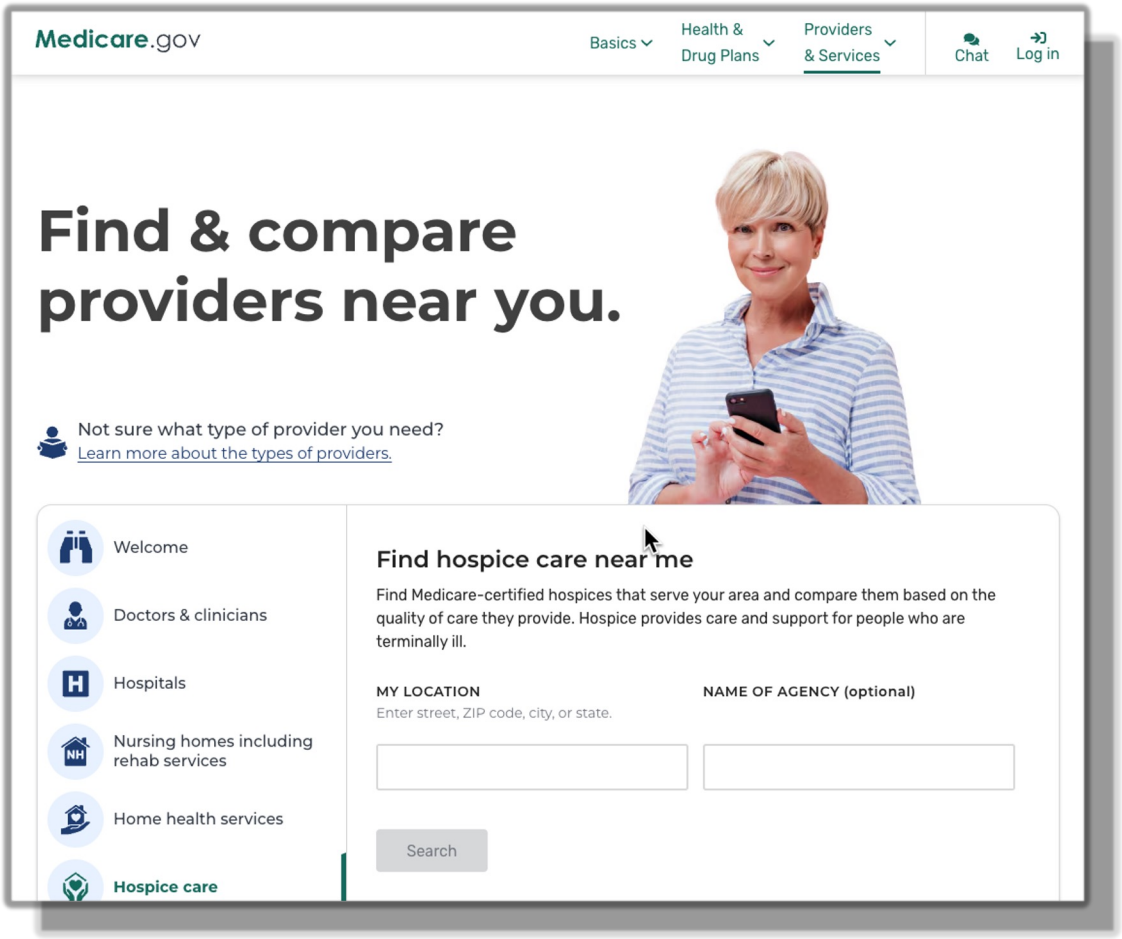
https://hopewellhousepdx.org/

Which Hospice Care Should I Choose?

Ask your family and friends about their experiences.
Be prepared!

Often, it is a case of whoever is available when the patient is dying …

We should have a better way to be prepared…



https://www.cms.gov/newsroom/fact-sheets/hospice-compare-website?utm_source=chatgpt.com

- We die as we lived … good life = good death, so live your life well NOW!!
- At some point, luckily, most of us will have some control over our End-of-Life care.
- It's **better** to have someone who can advocate and support you through End-of-Life.
- Love your family and friends and be kind to each other!