Understanding Palliative Care

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Disclosures

Today's speaker has no financial relationships with an ineligible company relevant to this presentation to disclose.

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UW Medicine

UW SCHOOL OF MEDICINE

Objectives

- Define palliative care.
- Review the role of palliative care in patients and families facing serious illness.
- Contrast the differences between palliative care and hospice.
- Review the importance of advance care planning, for everyone!
- Identify palliative care resources in the community.

What is palliative care?

- Have you heard of Palliative care before?
  - Yes, but I don't know much about it.
  - 🦗 ...
  - Isn't that for people at the end of their life?

Public Opinion Survey of Palliative Care: Consumer Awareness

How knowledgeable, if at all, are you about palliative care?

Source: *Data from a Public Opinion Strategies national survey of 800 adults age 18+ conducted June 5-8, 2011.

https://media.capc.org/filer_public/18/ab/18ab708c-f835-4380-921d-fbf729702e36/2011-public-opinion-research-on-palliative-care.pdf

What is Palliative Care?

Center to Advance Palliative Care™ capc

- **Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis.**
- **The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.**

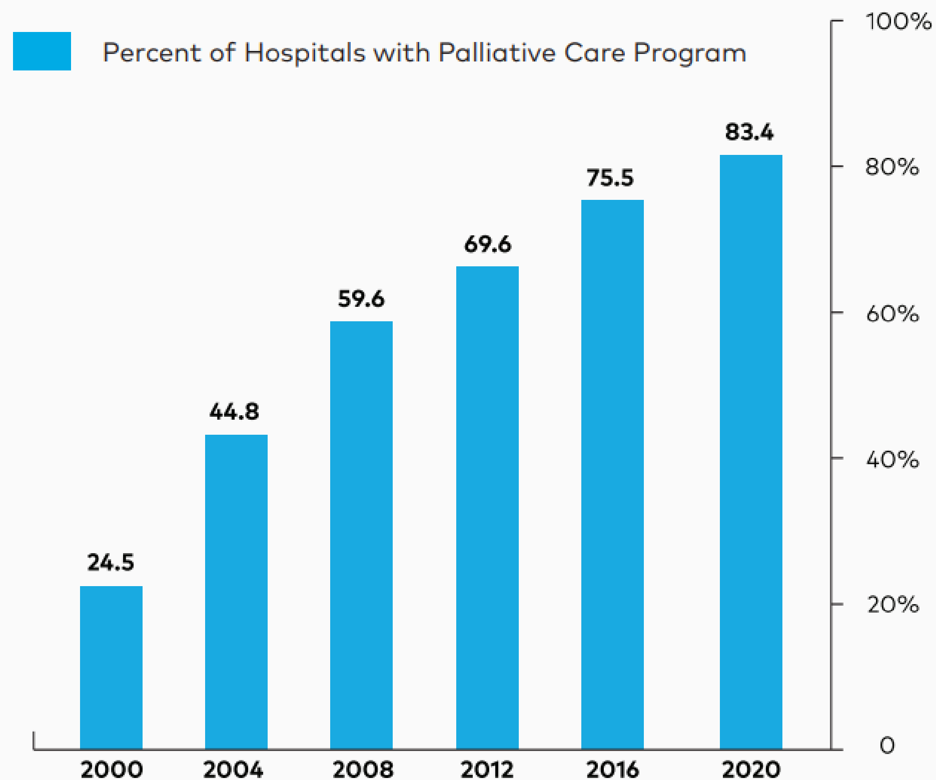
Simple Definition of Palliative Care

Palliative care: It's an extra layer of support for patient's with serious illness.

GET PALLIATIVE
CARE

https://getpalliativecare.org/

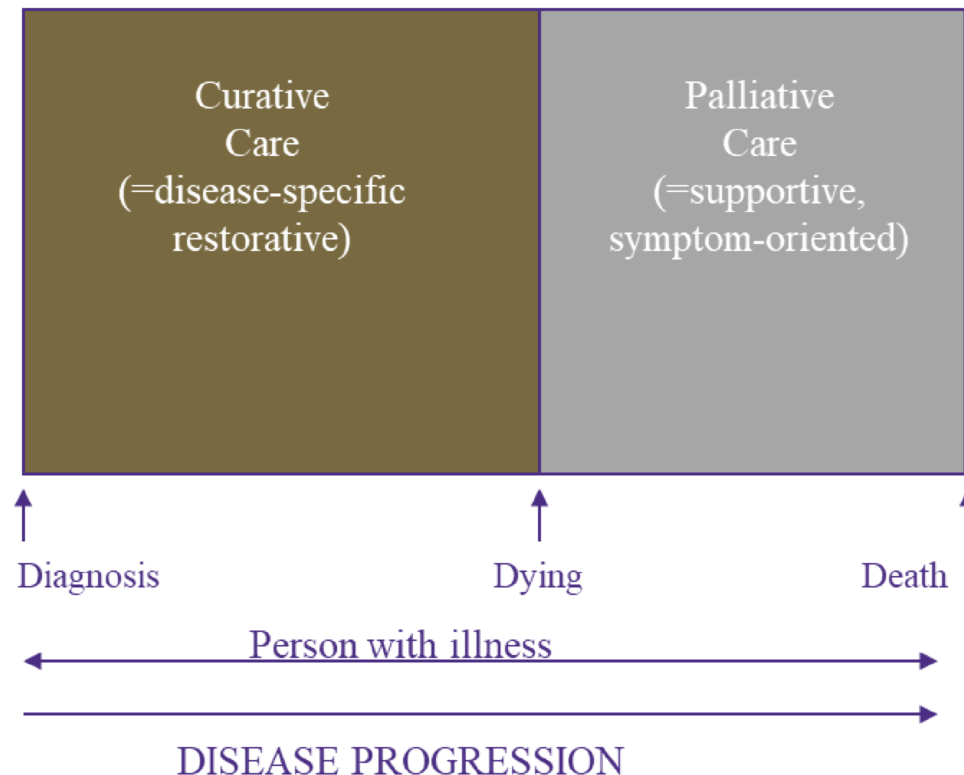
Growth of Palliative Care



https://www.capc.org/documents/download/1031/

Old Definition of Palliative Care

Out-Dated Model of Curative Care Followed by Palliative Care for Chronic Progressive Illness



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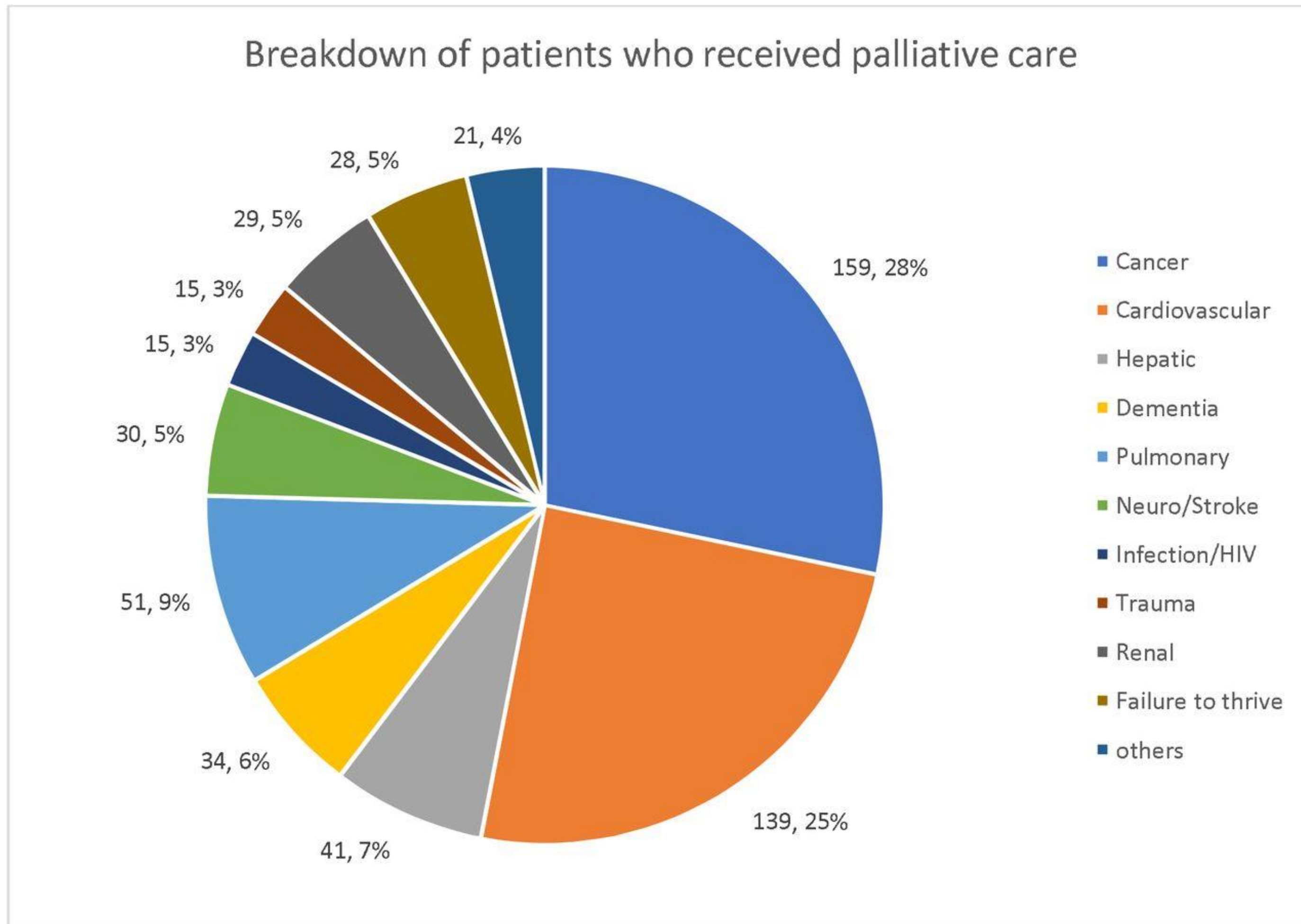
Improved Definition of Palliative Care

Conceptual Shift for Palliative Care

Hospice Could be Here

Who receives palliative care?



https://doi.org/10.1101/2020.08.05.20169235

Evidence for Early Palliative Care

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

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

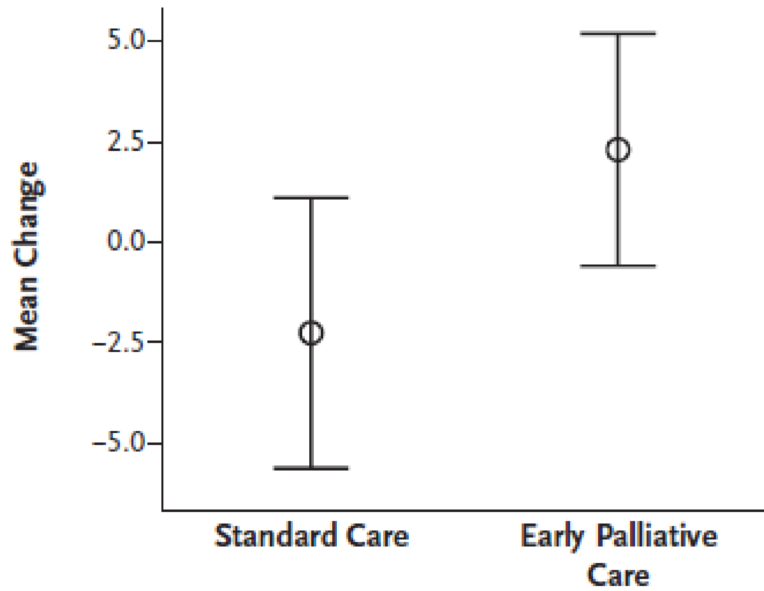
Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A.,
Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H.,
Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N.,
Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H.,
J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.

CONCLUSIONS

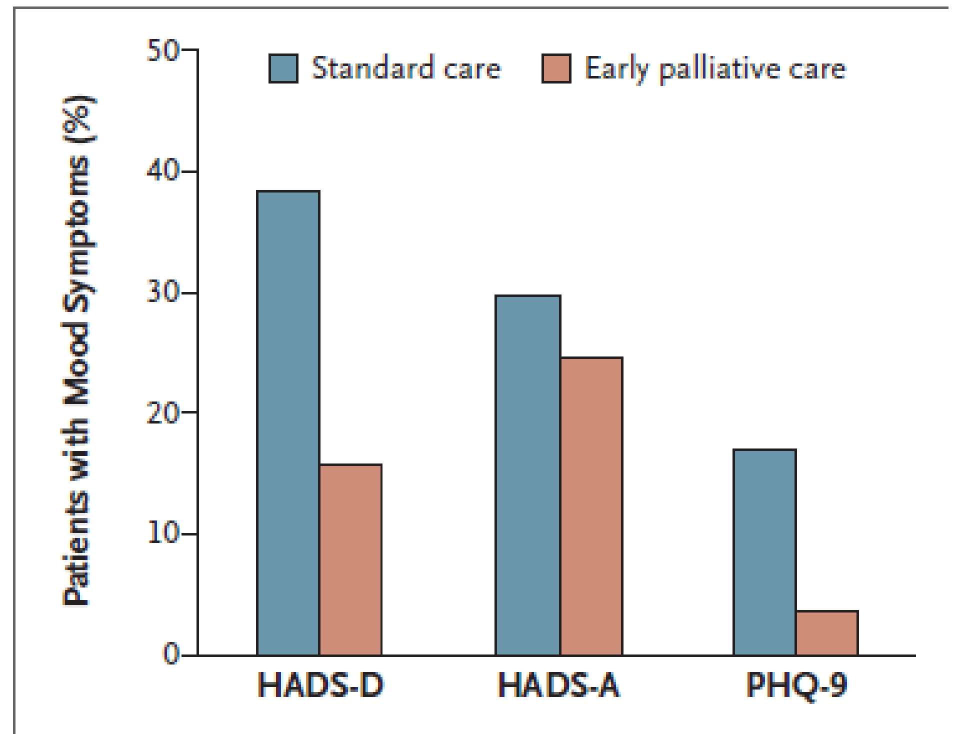
Among patients with metastatic non–small-cell lung cancer, early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival. (Funded by an American Society of Clinical Oncology Career Development Award and philanthropic gifts; ClinicalTrials.gov number, NCT01038271.)

N ENGL J MED 363;8 NEJM.ORG AUGUST 19, 2010

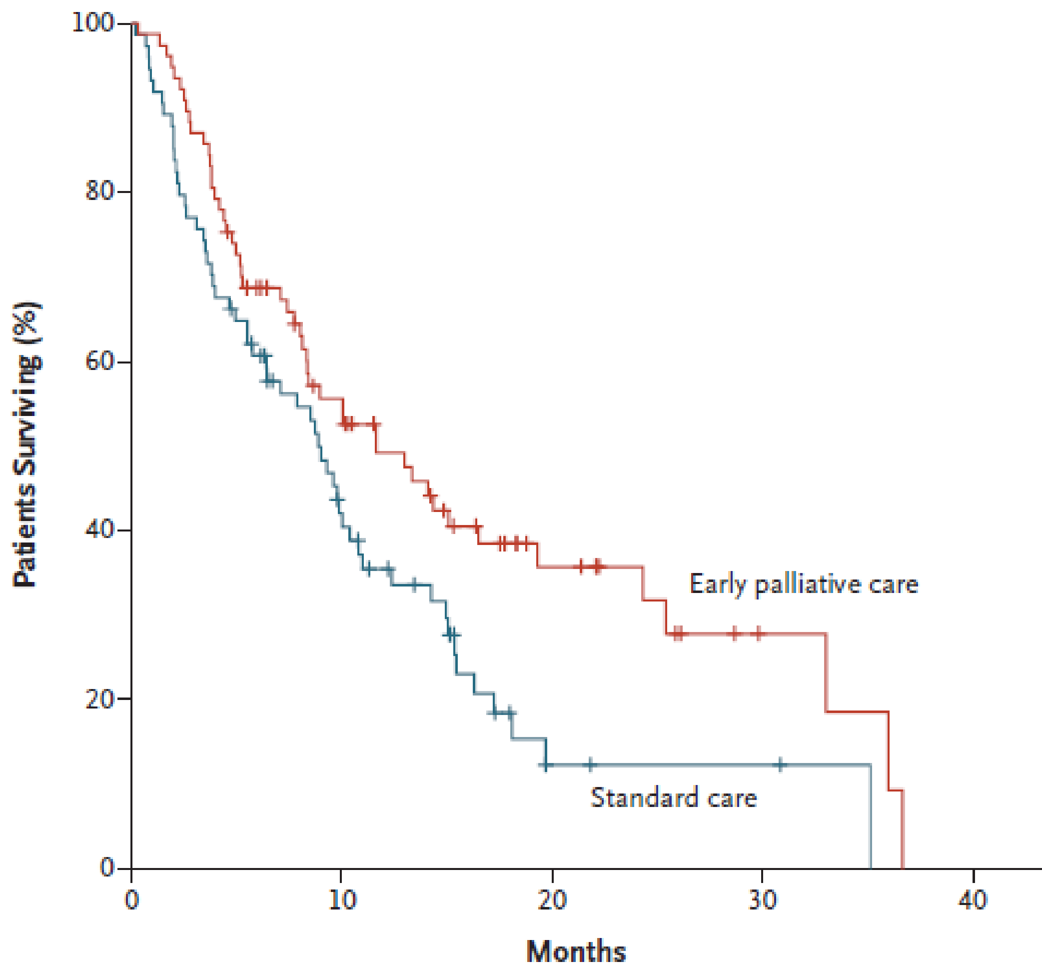
Lower depression scores for palliative care



Higher quality of life scores for palliative care



Temel, *et al.* NEJM 2010



Median survival was ***longer*** among patients receiving early palliative care (~12 months vs. 9 months, P=0.02)

Temel, *et al.* NEJM 2010

Timing is Everything…

https://www.onlygfx.com/umbrella-clipart-png-transparent/

Late palliative care referral...

JAMA Oncol. 2022;8(5):681-682. doi:10.1001/jamaoncol.2021.8210

Early palliative care referral..

JAMA Oncol. 2022;8(5):681-682. doi:10.1001/jamaoncol.2021.8210

What Palliative Care is NOT

HOSPICE

https://www.123rf.com/clipart-vector/hospice_care.html

Hospice is:

- Medical care for people with an anticipated life expectancy of 6 months or less, when a cure isn't an option, and the focus shifts to symptom management and quality of life.
- 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.
- Provided primarily where a person lives.
- Includes bereavement care, which is available during the illness and for more than a year after the death for the family/intimate network.
- A Medicare benefit, to which all Medicare enrollees have a right. Covered by most private insurance plans.

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

Hospice is not:

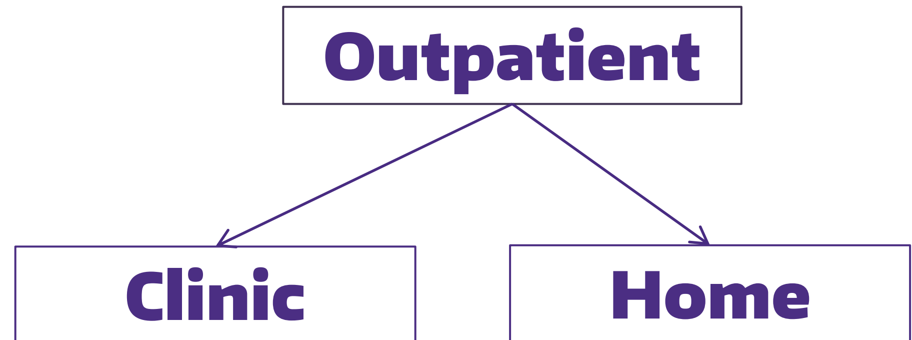
- Focused on curative therapies or medical intervention designed to prolong life.
- A replacement for nursing home care or other residential care.
- 24/7 care, in the majority of cases.
- Care that hastens death.

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

Palliative Care Consultation

Location of Services

Inpatient (in the hospital)



What We Actually Do...

Guided Narrative Technique

Guided Narrative for Difficult Discussions in a Palliative Care Setting (Farber, 2011)

- What do you already know?
  - What is your understanding of your situation?
  - How do you see things?
- What is important to you right now?
  - What is important to discuss today?
  - What do you see as your future?
- What are your experiences?
  - Have you ever cared for someone who is seriously ill?
  - What are your experiences with loss?
- Goals of care
  - What are you hoping for?
  - What are you concerned (worried, afraid) about?
- What else do you want me to know about who you are or what you believe to help me take better care of you?

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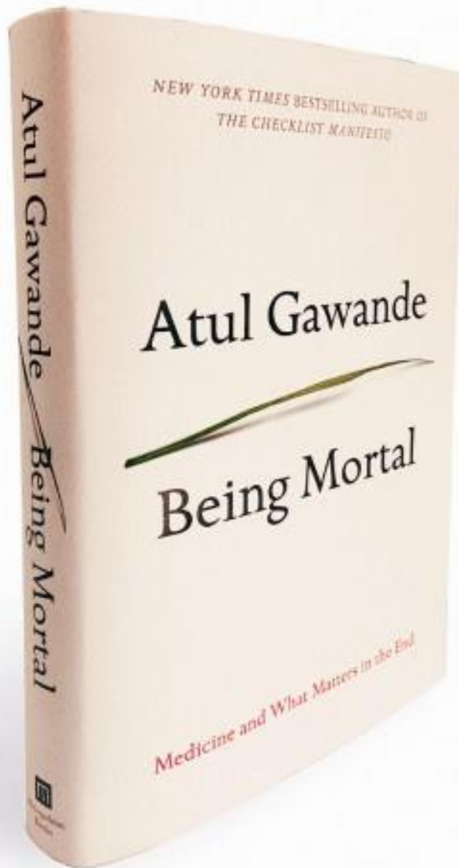
Being Mortal – Atul Guwande



Guided Narrative Meets Popular Press in 2014

We need to know:

1. What is your understanding of where you are and of your illness?

2. Your fears or worries for the future?

3. Your goals and priorities?

4. What outcomes are unacceptable to you? What are you willing to sacrifice and not?

5. What would a good day look like?

Guided Narrative as an Equation

Patient/Family is the expert of their story/life	+	Health care providers are the experts in the medical care	=	The two combined help elicit and drive the best plan of care

Communication and Coordination

Focus care on your priorities
Coordinate care
Translate medical information
Weigh treatment options
Prognosis

Symptoms

Pain
Nausea
Shortness of breath
Constipation
Diarrhea
Fatigue

Advanced Care Planning

Advance Directives
Durable Power of Attorney
Future plans

Psychosocial/Spiritual Support

Support to family
Support to caregivers
Community Resources
Spiritual support
Grief and bereavement
Anxiety/Depression

Advance Care Planning

Advance Directives vs. Advance Care Planning

Advance Care Planning	Advance Directive
Conversation between the patient, the family or health care surrogate and ones medical providers about values and preferences regarding medical care	Legal forms completed by patients assigning a health care agent and/or stating specific wishes regarding medical care

Advance Care Planning in the U. S.

- Patient Self-Determination Act (PDSA)

→ Federal law passed 1991

→ Goal:

  – guarantee individuals the right to make health care decisions and indicate preferences regarding life-sustaining treatments

Advance Directives

> Some Examples

- Durable Power of Attorney for Healthcare
- Living Will (Health Care Directive)
- POLST

Durable Power of Attorney for Health Care

1. Creation of Durable Power of Attorney for Health Care

I intend to create a power of attorney (Health Care Agent) by appointing the person or persons designated herein to make health care decisions for me to the same extent that I could make such decisions for myself if I was capable of doing so, as recognized by RCW 11.94.010. This designation becomes effective when I cannot make health care decisions for myself as determined by my attending physician or designee, such as if I am unconscious, or if I am otherwise temporarily or permanently incapable of making health care decisions. The Health Care Agent's power shall cease if and when I regain my capacity to make health care decisions.

2. Designation of Health Care Agent and Alternate Agents

If my attending physician or his or her designee determines that I am not capable of giving informed consent to health care, I ____, designate and appoint:

Name ____ Address ____________________________________

City__________________________________ State ____________ Zip ___________ Phone_________________________

as my attorney-in-fact (Health Care Agent) by granting him or her the Durable Power of Attorney for Health Care recognized in RCW 11.94.010 and authorize her or him to consult with my physicians about the possibility of my regaining the capacity to make treatment decisions and to accept, plan, stop, and refuse treatment on my behalf with the treating physicians and health personnel.

http://depts.washington.edu/hdcoe/wp-content/uploads/2020/04/WSMA-Advance-Directives-July-2019.pdf

Living Will

HEALTH CARE DIRECTIVE

Directive made this ______________________________ day of _________, ______________.
(Year)

I, ____being of sound mind, willfully, and voluntarily make known my desire that my dying shall not be artificially prolonged under the circumstances set forth below, and do hereby declare that:

(A) If at any time I should have an incurable and irreversible condition certified to be a terminal condition by my attending physician, and where the application of life-sustaining treatment would serve only to artificially prolong the process of my dying, I direct that such treatment be withheld or withdrawn, and that I be permitted to die naturally. I understand "terminal condition" means an incurable and irreversible condition caused by injury, disease or illness that would, within reasonable medical judgment, cause death within a reasonable period of time in accordance with accepted medical standards.

(B) If I should be in an irreversible coma or persistent vegetative state, or other permanent unconscious condition as certified by two physicians, and from which those physicians believe that I have no reasonable probability of recovery, I direct that life-sustaining treatment be withheld or withdrawn.

(C) If I am diagnosed to be in a terminal or permanent unconscious condition, [*Choose one*]

I want __________ do not want __________

artificially administered nutrition and hydration to be withdrawn or withheld the same as other forms of life-sustaining treatment. I understand artificially administered nutrition and hydration is a form of life-sustaining treatment in certain circumstances. I request all health care providers who care for me to honor this directive.

http://depts.washington.edu/hdcoe/wp-content/uploads/2020/04/WSMA-Advance-Directives-July-2019.pdf

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AN INITIATIVE OF

Washington State
Hospital Association

Foundation
for Health Care Improvement

Talk about it

Write it down

Share it around

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Talk About It

- Goals of care need to be addressed before discussing advance directives.
- Questions to facilitate a conversation about healthcare attitudes:
  - What does quality of life mean to you?
  - Who are the people who are most important?
  - Can you talk about what hopes and dreams you have for your family for the future?
  - Can you think about where you would like to be or what you would like to see if you were to become very ill or near death?
  - If you are very ill or near death, would you want to be kept alive as long as possible no matter what?
  - Can you imagine a state of living that would be worse than death?

Your Conversation Starter Guide

How to talk about what matters to you and have a say in your health care.

the conversation project

©2021 The Conversation Project, an initiative of the Institute for Healthcare Improvement (IHI)

The Conversation Project

Talk about it

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Document Your Wishes

Write it down

Advance Care Planning

OVERVIEW

Honoring Choices®
PACIFIC NORTHWEST

Foundation

This form meets the requirements of Washington state law.

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NAME

DATE OF BIRTH / /
(mm/dd/yyyy)

Tell the important people

Share it around

- Share your values and preferences with those you love.
  - Especially your surrogate decision maker!
- Share your DPOA-HC and Living Will with your medical provider(s).

ATTENTION HEALTH CARE PROVIDERS	**PLEASE HONOR** MY WISHES
MY NAME:	**MY HEALTH CARE AGENT** (named on DPOA-HC):
MY DATE OF BIRTH: / /	BEST PHONE: ( )
MY HEALTH CARE PROVIDER:	MY ☐ ADVANCE DIRECTIVE ☐ POLST CAN BE FOUND AT:
PROVIDER OFFICE PHONE: ( )	

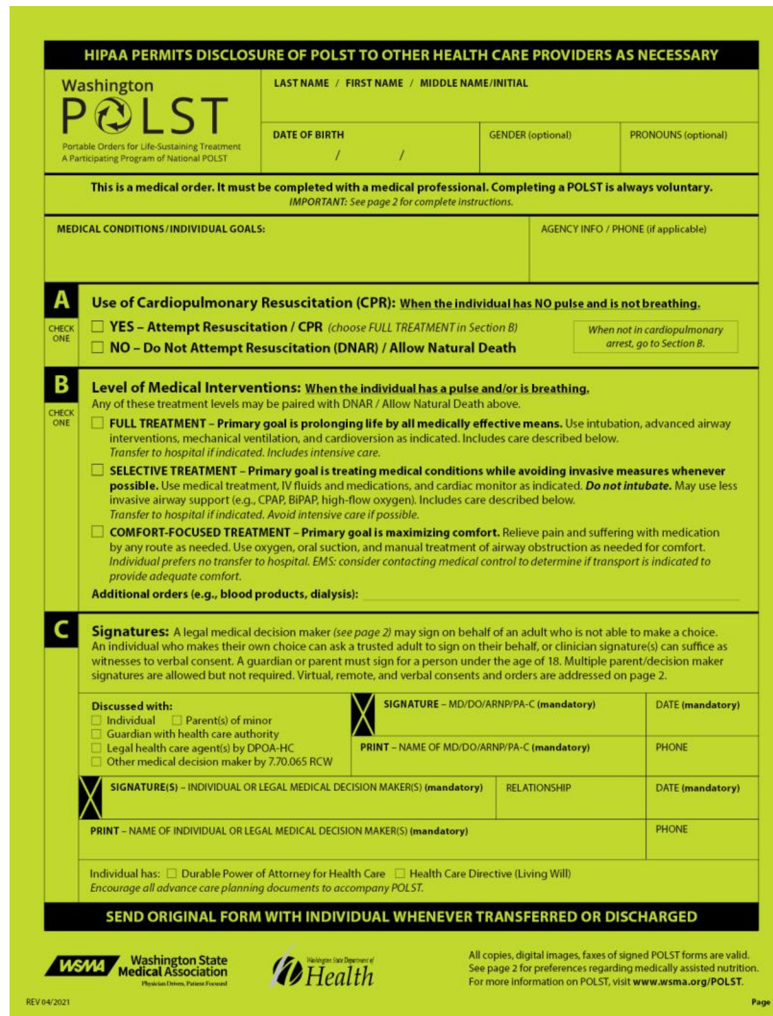
Clip and carry this wallet card with you to let others know you have a health care agent.

https://www.honoringchoicespnw.org/wp-content/uploads/2021/04/Wallet-Card-Instructions.pdf

Pros and Cons of Living Wills

PROS	CONS
Gets people thinking	Preferences are made about future, often hard to imagine decisions, underestimates adaptation
Gets patients, families and providers talking	Often only applies to irreversible and terminal conditions
Gets something down on paper	Not available in emergent situations
Helps guide surrogates, and relieve surrogate distress	Only applies when the patient looses capacity, relies on interpretation by surrogates
Is a legal document	Has to be witnessed, cannot be followed by emergency personnel

Then what is a POLST?



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

Washington POLST
Portable Orders for Life-Sustaining Treatment
A Participating Program of National POLST

LAST NAME / FIRST NAME / MIDDLE NAME/INITIAL		
DATE OF BIRTH / /	GENDER (optional)	PRONOUNS (optional)

This is a medical order. It must be completed with a medical professional. Completing a POLST is always voluntary.
IMPORTANT: See page 2 for complete instructions.

MEDICAL CONDITIONS / INDIVIDUAL GOALS:	AGENCY INFO / PHONE (if applicable)

A CHECK ONE

Use of Cardiopulmonary Resuscitation (CPR): When the individual has NO pulse and is not breathing.

- ☐ **YES – Attempt Resuscitation / CPR** *(choose FULL TREATMENT in Section B)*
- ☐ **NO – Do Not Attempt Resuscitation (DNAR) / Allow Natural Death**

When not in cardiopulmonary arrest, go to Section B.

B CHECK ONE

Level of Medical Interventions: When the individual has a pulse and/or is breathing.
Any of these treatment levels may be paired with DNAR / Allow Natural Death above.

- ☐ **FULL TREATMENT – Primary goal is prolonging life by all medically effective means.** Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. Includes care described below. *Transfer to hospital if indicated. Includes intensive care.*
- ☐ **SELECTIVE TREATMENT – Primary goal is treating medical conditions while avoiding invasive measures whenever possible.** Use medical treatment, IV fluids and medications, and cardiac monitor as indicated. ***Do not intubate.*** May use less invasive airway support (e.g., CPAP, BiPAP, high-flow oxygen). Includes care described below. *Transfer to hospital if indicated. Avoid intensive care if possible.*
- ☐ **COMFORT-FOCUSED TREATMENT – Primary goal is maximizing comfort.** Relieve pain and suffering with medication by any route as needed. Use oxygen, oral suction, and manual treatment of airway obstruction as needed for comfort. *Individual prefers no transfer to hospital. EMS: consider contacting medical control to determine if transport is indicated to provide adequate comfort.*

Additional orders (e.g., blood products, dialysis): ____________

C

Signatures: A legal medical decision maker *(see page 2)* may sign on behalf of an adult who is not able to make a choice. An individual who makes their own choice can ask a trusted adult to sign on their behalf, or clinician signature(s) can suffice as witnesses to verbal consent. A guardian or parent must sign for a person under the age of 18. Multiple parent/decision maker signatures are allowed but not required. Virtual, remote, and verbal consents and orders are addressed on page 2.

Discussed with:
- ☐ Individual ☐ Parent(s) of minor
- ☐ Guardian with health care authority
- ☐ Legal health care agent(s) by DPOA-HC
- ☐ Other medical decision maker by 7.70.065 RCW

X SIGNATURE – MD/DO/ARNP/PA-C (mandatory)	DATE (mandatory)
PRINT – NAME OF MD/DO/ARNP/PA-C (mandatory)	PHONE

X SIGNATURE(S) – INDIVIDUAL OR LEGAL MEDICAL DECISION MAKER(S) (mandatory)	RELATIONSHIP	DATE (mandatory)
PRINT – NAME OF INDIVIDUAL OR LEGAL MEDICAL DECISION MAKER(S) (mandatory)		PHONE

Individual has: ☐ Durable Power of Attorney for Health Care ☐ Health Care Directive (Living Will)
Encourage all advance care planning documents to accompany POLST.

SEND ORIGINAL FORM WITH INDIVIDUAL WHENEVER TRANSFERRED OR DISCHARGED

WSMA Washington State Medical Association
Physician Driven, Patient Focused

Washington State Department of Health

All copies, digital images, faxes of signed POLST forms are valid.
See page 2 for preferences regarding medically assisted nutrition.
For more information on POLST, visit **www.wsma.org/POLST**.

REV 04/2021

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Comparison…

Characteristics	Living Will	POLST
Population	All Adults	Seriously ill
Time Frame	Future Care	Current Care
Who completes	Patient	Patient + Health care provider
Surrogates	Cannot complete	Can complete, or override prior POLST if patient lacks capacity
Witnessed	Yes	No
Followed by Emergency Responders?	No	Yes

How do I access Palliative Care?

Palliative Care Access at UW Medicine

- Inpatient Palliative Care
  - UWMC (Montlake and Northwest Campuses)
  - Harborview Medical Center
  - Valley Medical Center

Palliative Care Access at UW Medicine

- Outpatient Palliative Care
  - Harborview
    - Outpatient Clinic (including telehealth)
    - Embedded in UW Medicine Oncology Clinic
    - Homeless Outreach
  - Valley Medical Center
    - Palliative and Supportive Care Clinic
  - Other Embedded Specialty Clinics
    - The Heart Institute
    - Multidisciplinary ALS Clinic
    - Memory, Brain, and Wellness
    - Northwest Kidney Center

Palliative Care Access at UW Medicine

- Outpatient Palliative Care
  - Fred Hutch Cancer Center
    - South Lake Union (including telehealth)
    - Oncology at UWMC-Northwest
      - Medical Oncology
    - Oncology at UWMC-Montlake
      - Gynecologic Oncology
      - Urology
      - Alvord Brain Tumor Center

Additional Palliative Care Access

- Evergreen Health
- Virginia Mason Franciscan Health
- Providence Transitions Program

How is it paid for?

- Medicare (copay)
- Medicaid
- Private Insurance
- Charity Care (some)

Thank You!

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