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Serious Illness Conversations

Project ECHO Palliative Care
Kay Miller Temple MD
October 8, 2019

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Disclosures/Disclaimers

- Opinions are not to be considered endorsed by RHIhub, FORHP, HRSA, CRH, or UNDSMHS.
- I have no financial disclosures.
- No industry ties.
- No medication use will be discussed.

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Objectives:

1. Review the disease trajectory of 5 serious illness categories
2. Review the basic constructs of serious illness conversations with patients/families
3. Understand differences between POLST and Advance Directives

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Dying Trajectories

- *The path an illness/disease takes as it progresses through its natural (or treated) course until death occurs.*
- Assists planning purposes
  - Providers
  - Patients/families

Original 3 from 1968 Glaser/Strauss:

1. Abrupt, surprise deaths
2. Expected deaths, short-term and lingering
3. **Entry-reentry deaths:** slow decline but return home between hospitalizations

Original Contribution JAMA May 14, 2003
"Patterns of Functional Decline at the End of Life"
https://www.ncbi.nlm.nih.gov/pubmed/12746362

1. Sudden death
2. Terminal illness
3. Organ Failure
4. **Frailty**

Original four categories:

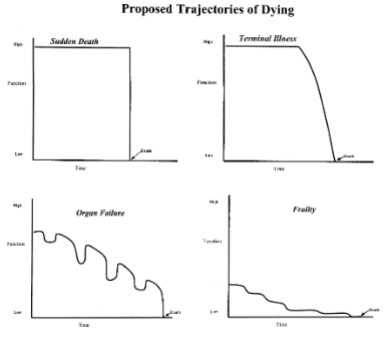

Figure 1. Trajectories of dying.

Image source: Profiles of older medicare decedents.
Lunney JR1, Lynn J, Hogan C.
J Am Geriatr Soc. 2002 Jun;50(6):1108-12.
https://www.ncbi.nlm.nih.gov/pubmed/12110073

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Dying Trajectories

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4. **Frailty**

Ballentine's 5th: ***Catastrophic event***

"The Five Trajectories: Supporting Patients During Serious Illness" CSU IPC
https://csupalliativecare.org/wp-content/uploads/Five-Trajectories-eBook-02.21.2018.pdf

New Directions in Aging
The Gerontological Society of America Journal July 2018
"Trajectories of End of Life: A Systematic Review"
https://academic.oup.com/psychsocgerontology/article/73/4/564/3938843
~Meta-analysis trajectories and End of Life expenditures
Search terms: TD = "**terminal decline**" or "**terminal drop**"

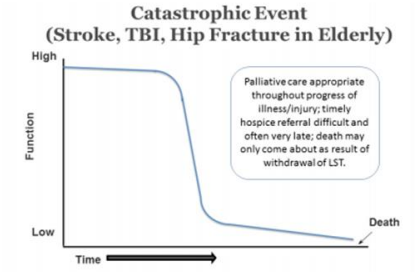


Figure 5: Catastrophic Event Trajectory (reprinted with permission of the author from Ballentine, 2013).

"The Five Trajectories: Supporting Patients During Serious Illness"
Jennifer Moore Ballentine
The California State University Institute for Palliative Care

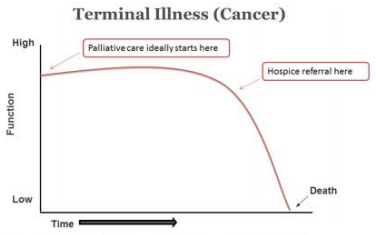


Figure 2: Terminal Disease Trajectory. Adapted with permission from Lynn, 2004.

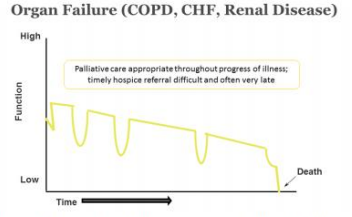


Figure 3. Major Organ Failure Trajectory. Adapted with permission from Lynn, 2004.

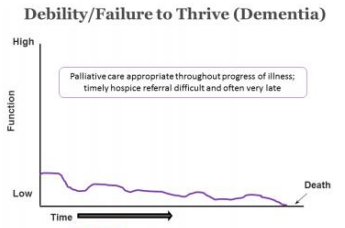
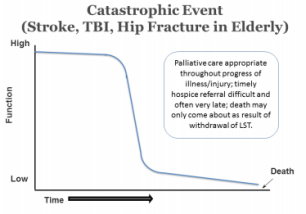


Figure 4. Frailty Trajectory. Adapted with permission from Lynn, 2004.



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https://csupalliativecare.org/wp-content/uploads/Five-Trajectories-eBook-02.21.2018.pdf

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The Talk:
Having conversations about serious illness

Who leads the conversation?

Patients/Surrogates

Medical team:

- Providers,
- Chaplains,
- Social Workers

****Trained lay community members**

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The Talk:
Having conversations about serious illness

Who (target audience):

- One-on-one and heart-to-heart
- Patient first
- Depending on permission/cognitive status: family

Where

- **Clinic/"Home"**
- **Hospital**
- **Emergency Room**

When

- Theoretically: As far in advance of hospice eligibility as possible
- *In reality…*

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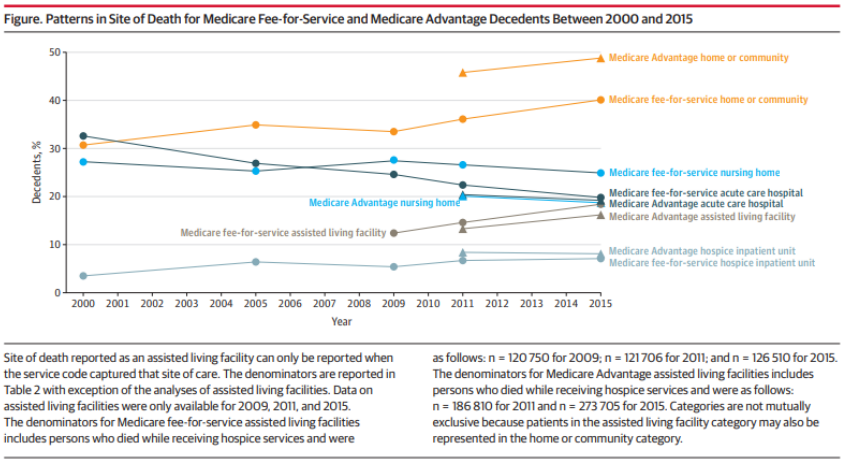
Why do we have conversations around serious illness?



Site of Death, Place of Care, and Health Care Transitions Among US Medicare Beneficiaries, 2000-2015.
JAMA. 2018 Jul 17;320(3):264-271. doi: 10.1001/jama.2018.8981.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6076888/ (Free Full Text)

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Why do we have conversations around serious illness?

1. Because "we not only save lives, we prolong lives"

2. To make sure we understand who we are treating:
   ?Patient
   ?Family
   ?Ourselves

3. Because we are ***good*** providers:
   Obligation to discuss ***all*** treatments including ***less*** treatment along with C/D treatment (comfort/dignity)

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The Talk:

Having conversations about serious illness

How:

Meier's Ten Steps for What to Say and Do	**Serious Illness Conversation Guide**
Understand the problem(s) and the pros/cons of options/treatment(s)	Set up the conversation
Gather the patient/decision makers/ family/caregivers	Assess understanding and preferences
Introduce rules: no interruptions/everyone speaks	Share prognosis
Ask what they know	**Explore key topics:** **Goals, Fears/Worries/Strength sources/Critical Abilities/Tradeoffs/Family**
A-T-A:	Close Conversation
Ask	Document Conversation/EHR parking lot
Tell	Community with other key clinicians
Ask	
Answering questions	
Pros and Cons of Options	
Write	

capc

ARIADNE LABS

BRIGHAM HEALTH BRIGHAM AND WOMEN'S HOSPITAL

HARVARD T.H. CHAN SCHOOL OF PUBLIC HEALTH

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Diane E. Meier, MD, FACP, FAAHPM

Director, Center to Advance Palliative Care
Co-director, Patty and Jay Baker National Palliative Care Center
Professor, Department of Geriatrics and Palliative Medicine
Catherine Gaisman Professor of Medical Ethics, Icahn School of Medicine of Mount Sinai

https://www.capc.org

Meier's Ten Steps for What to Say and Do
1. Understand the problem(s) and the pros/cons of options/treatment(s)
2. Gather the patient/decision makers/ family/caregivers
3. Introduce rules: no interruptions/everyone speaks
4. Ask what they know
A-T-A:
5. Ask
6. Tell
7. Ask
8. Answering questions
9. Pros and Cons of Options
10. Write

https://www.youtube.com/watch?time_continue=2&v=7kQ3PUyhmPQ

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Serious Illness Conversation Guide	
Set up the conversation	SET UP: "I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — **is this okay?**"
Assess understanding and preferences	ASSESS: "What is **your understanding** now of where you are with your illness?" "How much **information** about what is likely to be ahead with your illness would you like from me?"
Share prognosis	SHARE: "I want to share with you **my understanding** of where things are with your illness…" *Uncertain:* "It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I'm **worried** that you could get sick quickly, and I think it is important to prepare for that possibility." OR *Time:* "I **wish** we were not in this situation, but I am **worried** that time may be as short as ___ *(express as a range, e.g. days to weeks, weeks to months, months to a year).*" OR *Function:* "I **hope** that this is not the case, but I'm **worried** that this may be as strong as you will feel, and things are likely to get more difficult."
Explore key topics: Goals, Fears/Worries/Strength sources/Critical Abilities/Tradeoffs/Family	EXPLORE: "What are your most important **goals** if your health situation worsens?" "What are your biggest **fears and worries** about the future with your health?" "What gives you **strength** as you think about the future with your illness?" "What **abilities** are so critical to your life that you can't imagine living without them?" "If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?" "How much does your **family** know about your priorities and wishes?"
Close Conversation	CLOSE: "I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we ___. This will help us make sure that your treatment plans reflect what's important to you." "How does this plan seem to you?" "I will do everything I can to help you through this."
Document Conversation/EHR parking lot	
Communicate with other key clinicians	

http://www.instituteforhumancaring.org/documents/Providers/PSJH-Serious-Illness-Conversation-Guide.pdf

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The Talk:

Having conversations about serious illness

How:

U.S. Department of Veterans Affairs

National Center for Ethics in Health Care

Goals of Care Conversations Training for Physicians, Advance Practice Nurses, & Physician Assistants

https://www.ethics.va.gov/goalsofcaretraining/Practitioner.asp

Goals of Care Conversations Training for Nurses, Social Workers, Psychologists, and Chaplains

https://www.ethics.va.gov/goalsofcaretraining/team.asp

SPIKES	Delivering Serious News
SETTING	Find a quiet location; private if possible. Invite the important people to be present. Have tissues and enough chairs. Turn off the ringer on your phone/pager.
PERCEPTION Determine what the patient knows already	"Tell me what you understand about your illness." "What have the other doctors told you about your illness?" Look for knowledge and emotional information as the patient responds
INVITATION Clarify information preferences	"Would it be okay for me to discuss the results of your tests with you now?" "How do you prefer to discuss medical information in your family?" "Some people prefer a global picture of what is happening and others like all the details, what do you prefer?"
KNOWLEDGE Give the information	Give a warning…"I have something serious we need to discuss" Avoid medical jargon. Say it simply and stop. (e.g."Your cancer has spread to your liver. It is getting worse despite our treatments.")
EMPATHY Respond to emotion	Wait quietly for the patient. "I know this is not what you expected to hear today.""This is very difficult news."
SUMMARY Next steps and followup plan	"We've talked about a lot of things today, can you please tell me what you understand." "Let's set up a follow-up appointment."

Goals of Care Conversations training was developed by VA National Center for Ethics in Health Care through contracts with VitalTalk. Updated 01/2018.
www.ethics.va.gov/goalsofcaretraining/practitioner.asp

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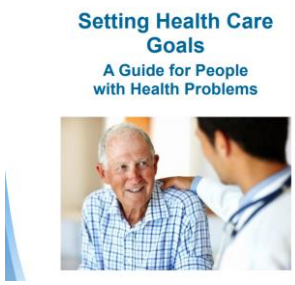
The Talk:

Having conversations about serious illness

How: VA | U.S. Department of Veterans Affairs, Veterans Health Administration, National Center for Ethics in Health Care



https://www.ethics.va.gov/LST/SettingHealthCareGoals.pdf

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KMT process: ~30 minutes
Understand the problems/options
Gather the family
White board for provider; paper and pencils patient & family (Alternative: sit with family gathered around)
Ask what is known (Don't interrupt or try to clarify—make notes to yourself if needed)
Update information: I write/They take notes
Give time to process/Field Questions
Give treatment options including care provided when treatment options are declined
Ask what is feared/biggest worry
Decide on next steps
General review
Billing… End-of-Life Care Conversations: Medicare Reimbursement FAQs

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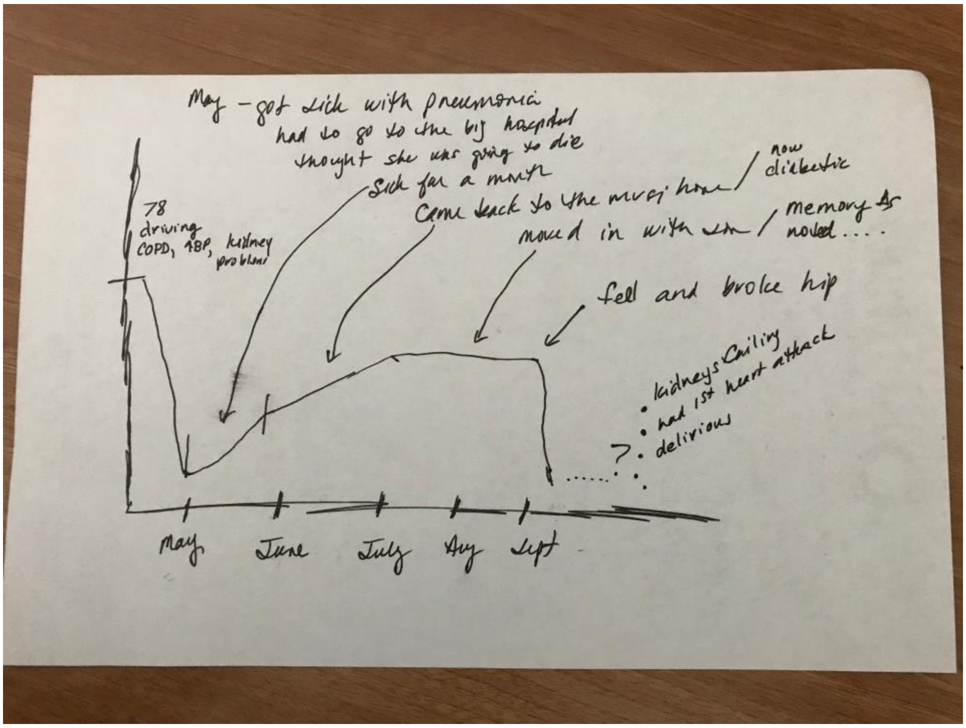
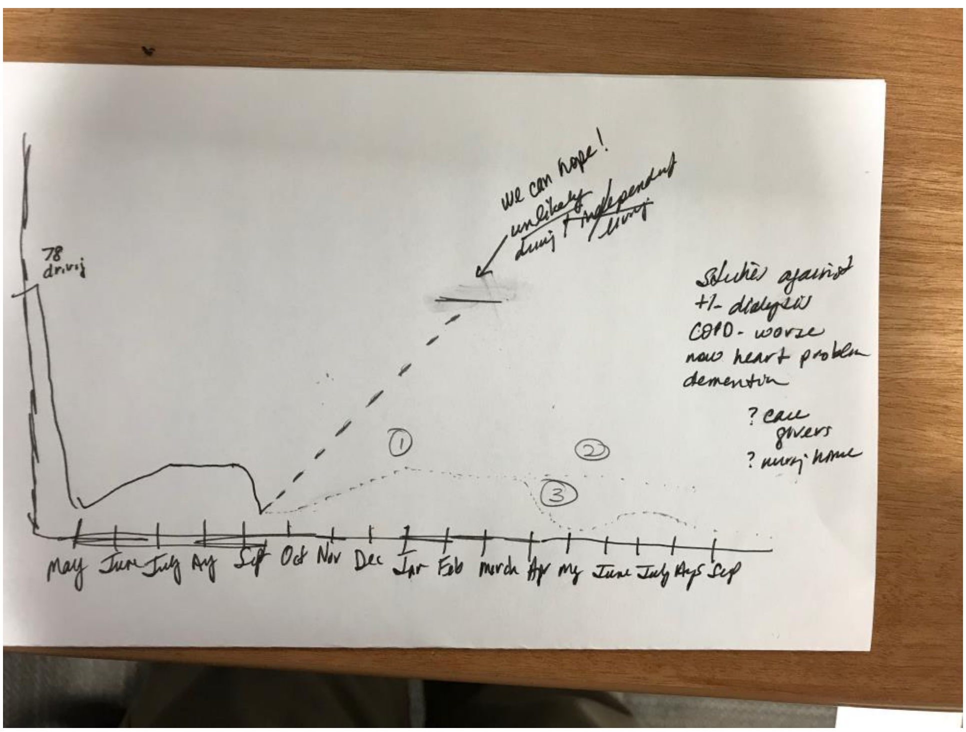
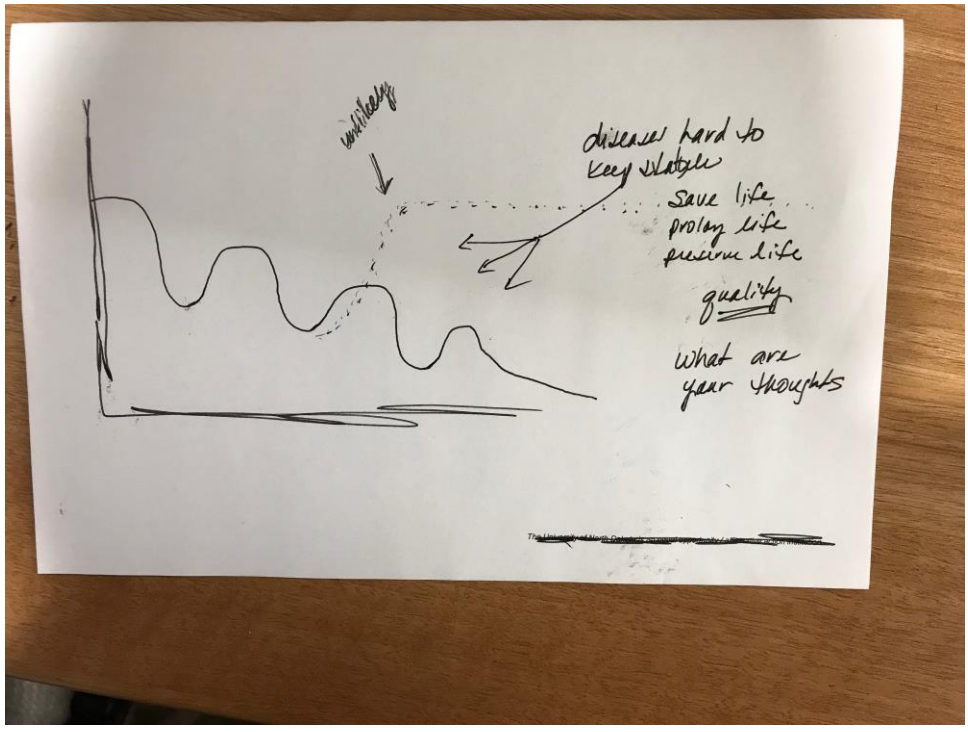

May – got sick with pneumonia
had to go to the big hospital
thought she was going to die
Sick for a month
Came back to the nursing home
now diabetic
moved in with son
78
driving
COPD, ↑BP, kidney problem
fell and broke hip
• kidneys failing
• had 1st heart attack
• delirious
May
June
July
Aug
Sept


78
driving
we can hope!
COPD - worse
now heart problem
dementia
? care givers
? nursing home
May Jun July Aug Sept Oct Nov Dec Jan Feb March Apr May June July Aug Sep



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KMT process quick —When things are critical and time is short 10 minutes
Gather/Call the family
Ask what is known (Make notes to yourself if needed)
Update information
Give treatment options including care provided when treatment options are declined 1. Aggressively intervene and hope 2. Intervene with limits and still there is equal hope 3. Focus on comfort
Ask what is feared/biggest worry
Decide on next steps
General review after nurses updated

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Advance **D**irectives, **H**ealthcare **D**irectives, and **P**hysician **O**rder for **L**ife **S**ustaining **T**reatment/POLST

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	Healthcare Directive/Advance Directive	POLST medical order form
Document type	Legal document that provides guidance.	Standardized form providing a **medical order.**
Population	All adults >18 years	Any age, serious illness, advanced frailty or life-limiting condition
Time Frame	Future care/future conditions	Current care/current condition
Setting for completion	Any setting, medical and non-medical	Medical setting
Document content	Patient or appointed healthcare surrogate provides general care preferences	Specific medical orders based on shared decision making
Healthcare Agent Role	Cannot complete	Can consent if patient lacks capacity
EMS	No impact on care	Provides a useable medical order regarding care
Portability	Patient/family responsibility	Healthcare professionals' responsibility
Periodic review/ "Expiration Date"	Patient/family responsibility	Healthcare professionals' responsibility to review when: transfer from one facility to another, change in medical status, or patient-driven preferences
Agents	Patient/surrogate/witness	Medical Provider

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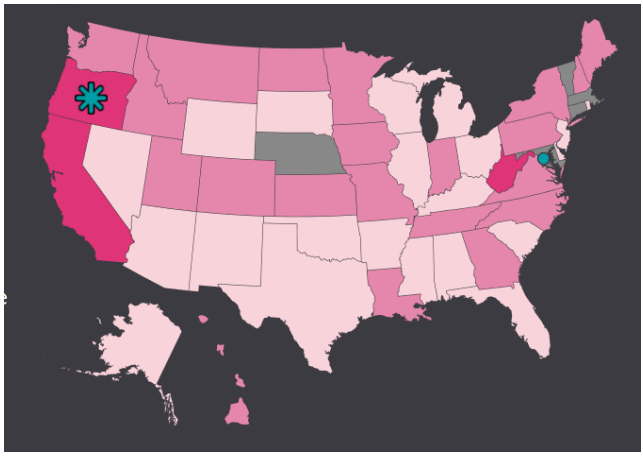

- 3 mature
- 24 endorsed
- 22 developing
- 5 non-conforming
- Oregon separated from the National POLST Paradigm in 2017

Totals include WASHINGTON DC. MATURE Programs are also Endorsed and are counted in both the Mature and Endorsed Program totals.

https://polst.org/programs-in-your-state/

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RHIhub Rural Health Information Hub | *The* Rural Monitor

FEATURES | RURAL SPOTLIGHT INTERVIEWS | AROUND THE COUNTRY

Advance Care Planning: Strategic for All Adults, Even the Healthy

Age and health status shouldn't be barriers to advance care planning. Advocates share that proactive discussions now can impact the ease of future decision-making about personal healthcare needs.

November 14, 2018

Advance Care Planning Tools

Five Wishes, Aging with Dignity

Health Care Decision-Making, American Bar Association

Respecting Choices®, Coalition to Transform Advanced Care

The Conversation Project, Institute for Healthcare Improvement

Advance Care Planning, National Institute on Aging

Starting the Conversation about Health, Legal, Financial and End-of-Life Issues, National Association of Area Agencies on Aging (n4a)

https://www.ruralhealthinfo.org/rural-monitor/advance-care-planning/

Additional Resources

General Resources

Chartbook on Healthy Living: Supportive and Palliative Care, Agency for Healthcare Research and Quality

Palliative Care, National Institute on Aging

Rural Palliative Care Resource Center, Stratis Health

National Organizations

American Academy of Hospice and Palliative Care

Center to Advance Palliative Care

- For Patients: Get Palliative Care
- Palliative Care Provider Directory
- Mapping Community Palliative Care

Hospice and Palliative Nurses Association

National Coalition for Hospice and Palliative Care

National Hospice and Palliative Care Organization

Community-based Palliative Care: Scaling Access for Rural Populations

The benefits of palliative care are described as "the heart of healthcare." Experts and advocates share the importance of scaling this care to rural outpatients with serious illness and chronic medical conditions.

October 31, 2018

https://www.ruralhealthinfo.org/rural-monitor/palliative-care/

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Thank You!

Kay Miller Temple
Web Writer | Rural Health Information Hub
University of North Dakota Center for Rural Health
Suite E231 | 1301 N Columbia Road, Stop 9037
Grand Forks, ND 58202-9037
Direct: 701-777-6146 | Toll-free: 1-800-270-1898
kay@ruralhealthinfo.org
ruralhealthinfo.org

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