

***It Always Seems Too Early,
Until It's Too Late.***

Palliative Care & Advance Care Planning



Marie Eaton

Director, Palliative Care Institute, Western Washington University

Chair, Northwest Life Passages Coalition

March 13, 2017 - Rotary Club of Bellingham

What is the Palliative Care Institute?



A partnership with other members of the NorthWest Life Passages Coalition Blueprint Group to transform palliative care in Whatcom community and support the human responses to living and dying.

Northwest Life Passages Coalition



- ▶ Creating a Community of Care and Support for Patients with Serious Illness

Whatcom Alliance for Health Advancement ≈ Palliative Care Institute at Western Washington University ≈ PeaceHealth St. Joseph Medical Center ≈ Family Care Network ≈ Northwest Regional Council ≈ Whatcom Hospice ≈ Health Ministries ≈ Whatcom Council on Aging ≈ Chuckanut Health Foundation ≈ Community Representatives



What is Palliative Care?

Specialized care for people living with chronic and serious illness.

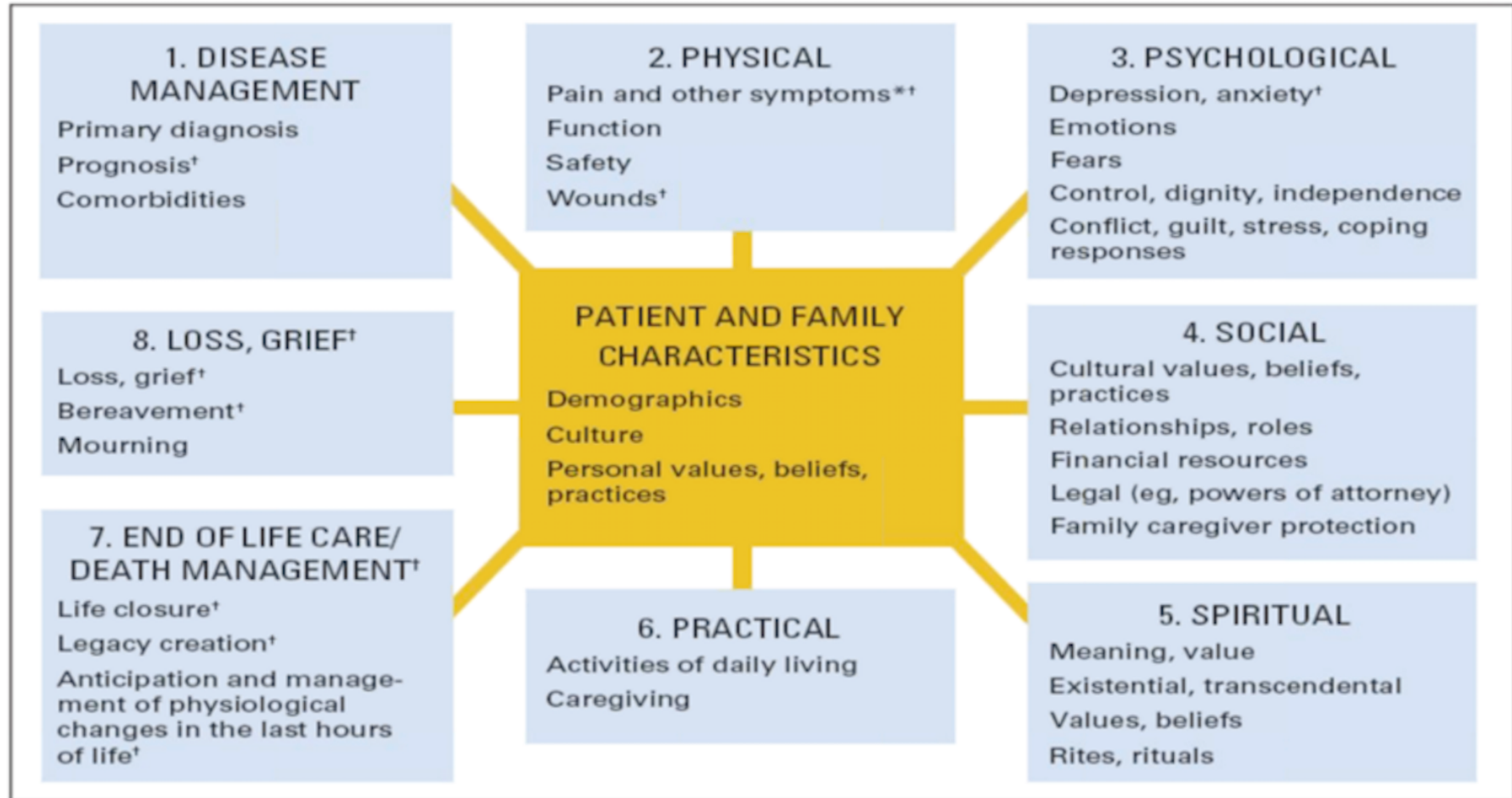
Goal is to improve quality of life for both the patient and the family when cure is not possible.

Focuses on providing relief from the symptoms and stress of a serious illness

Provided by an interdisciplinary team of palliative care doctors, nurses, social workers, chaplains, family members and others who work together to provide an extra layer of support.

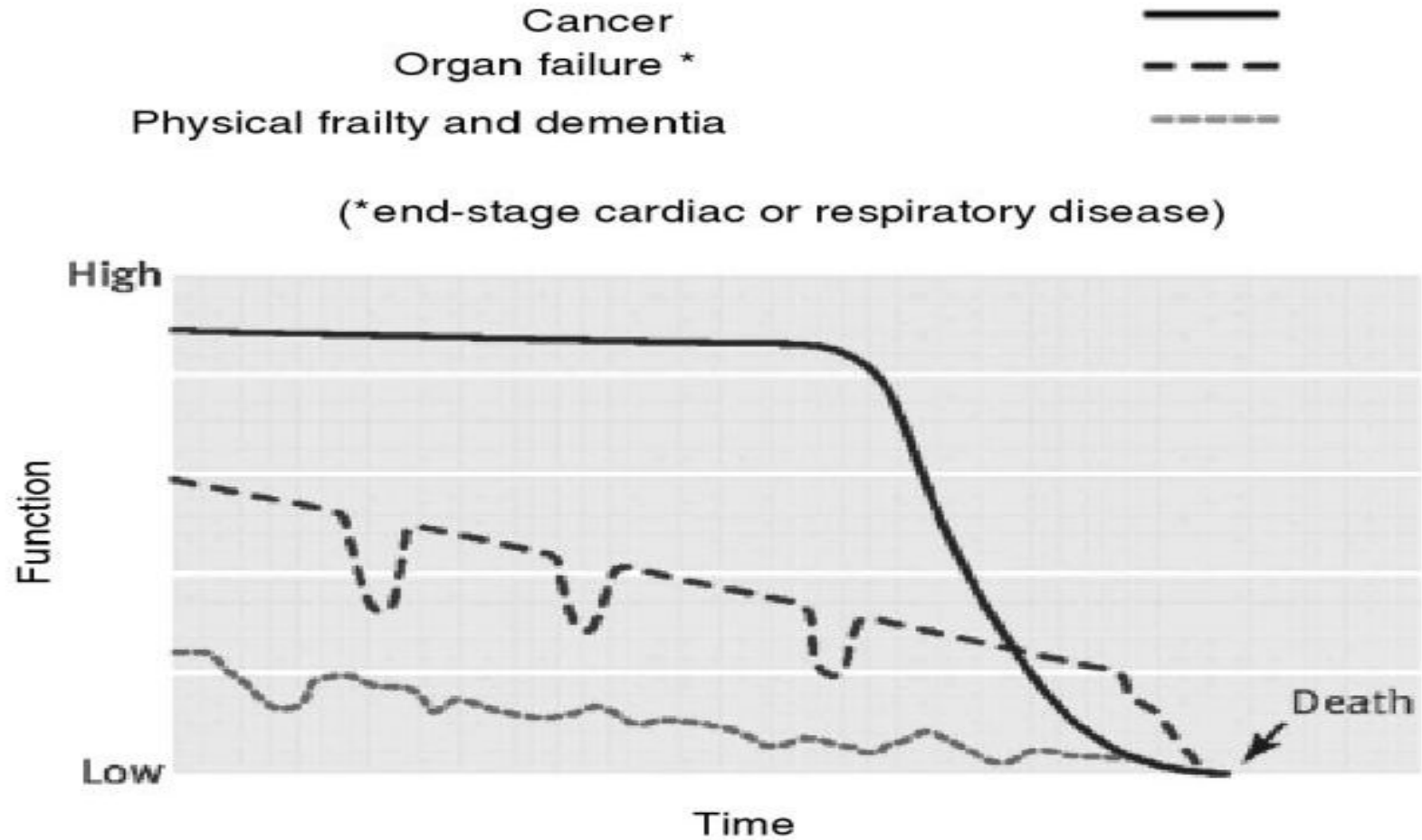
Appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment

ASCO Model of PC



Trajectories of Dying

Medscape





When is intervention a Medical error?

“Many doctors used to feel that the greatest of our professional hazards was the mistake that kills.

Has it now been usurped by the mistake which keeps the patient alive?”

M Emery-Roberts, Death and Resuscitation. BMJ, 1969(4). 364-5.

Study on the priorities of Older Patients with Advanced Serious Illness

Given the current situation, what is most
important to you?

1. Live Independently
2. Not being a burden
3. Have my symptoms managed
4. Live longer



Institute of Medicine 2014



Palliative Care and Hospice

Both focus on symptom management and quality of life



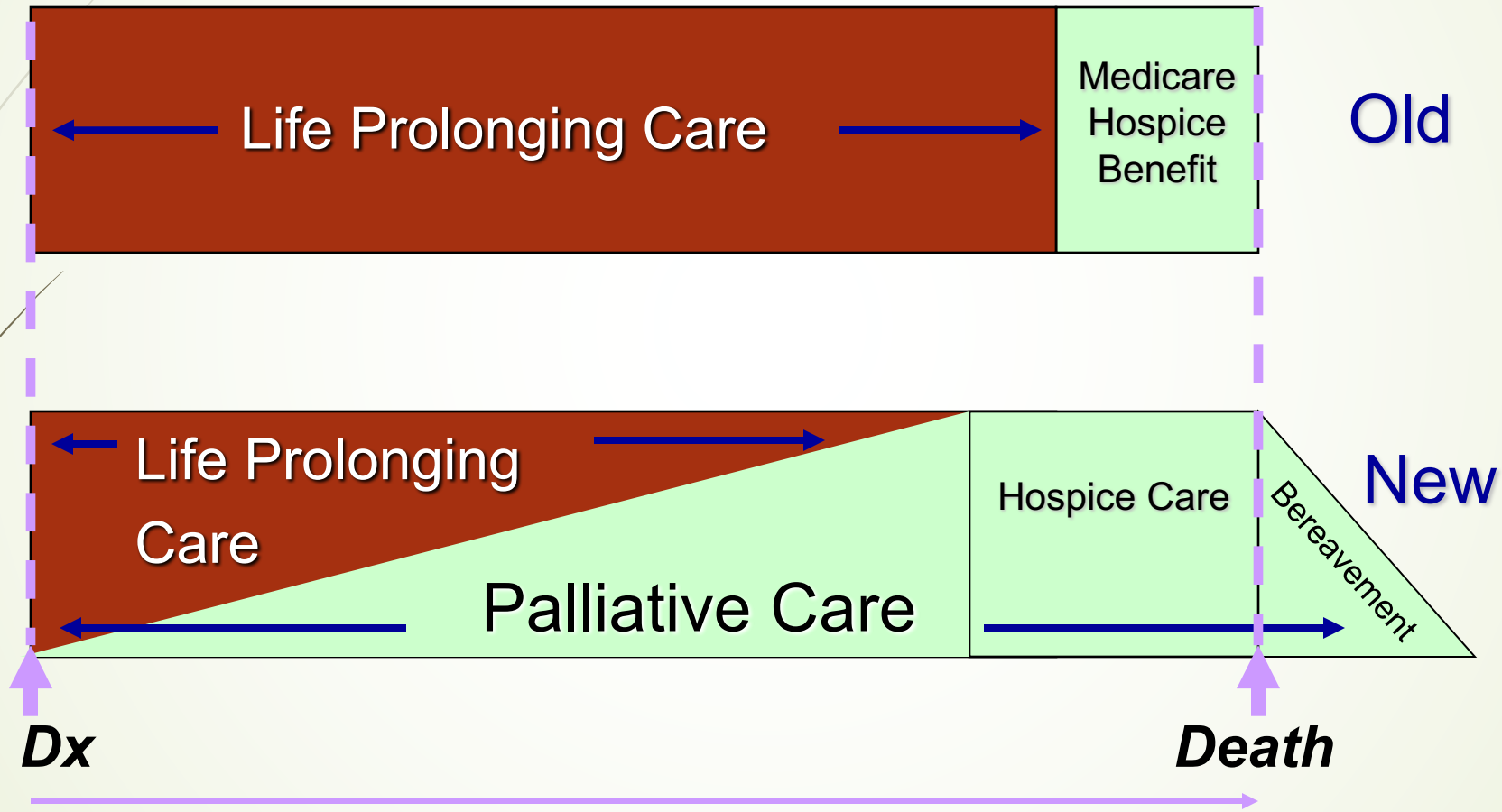
Palliative Care

Symptom management of a life-limiting illness.

Hospice Care

Symptom management and comfort care at the end of life.

Conceptual Shift in Palliative Care Goals



Who will speak for you when you cannot speak for yourself?

- These conversations are best had before a health crisis, sitting at the kitchen table rather than around a hospital bed.





Public Support for Advance Care Planning

Over 80% of Americans believe that it is important to talk about what kind of treatment one should receive at the end-of-life.

Only 30% have actually had that conversation with their loved ones.

Only 7% have discussed their preferences with their doctors.

Only 35% of general practitioners have initiated these conversations with their patients.

Difference between Living Will, Advance Directive and a POLST?





Living Will

- A living will is a limited type of advance directive.
- A written statement detailing a desires about life - sustaining procedures in the event that your death from a terminal condition is imminent despite the application of life-sustaining procedures or you are in a persistent vegetative state (permanent unconsciousness).
 - ✓ Often a check list of procedures
 - ✓ Often without any consideration of context



Advance Care Directive

- Advance Care Directive includes the naming of a health care agent. You make decisions about life sustaining procedures you desire in the event of terminal condition, persistent vegetative state AND end stage condition.
 - ✓ The best ACDs are based on conversations about your values regarding quality of life.
 - ✓ Your health care proxy is guided not only by the document, but also those conversations and all the context in the moment.

POLST

- ➔ **POLST** (Physician Orders for Life-Sustaining Treatment) is a form that documents specific medical orders to be honored by health care workers during a medical crisis.
- ➔ Must be signed by both a physician and the patient.

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

Physician Orders for Life-Sustaining Treatment

Last Name - First Name - Middle Initial _____

Date of Birth _____ Last 4 #SSN _____ Gender M F

FIRST follow these orders, **THEN** contact physician, nurse practitioner or PA-C. The POLST is a set of medical orders intended to guide emergency medical treatment for persons with advanced life limiting illness based on their current medical condition and goals. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.

Medical Conditions/Patient Goals: _____ **Agency Info/Sticker:** _____

A **CARDIOPULMONARY RESUSCITATION (CPR):** Person has no pulse and is not breathing.
 Check One CPR/Attempt Resuscitation DNAR/Do Not Attempt Resuscitation (Allow Natural Death)
Choosing DNAR will include appropriate comfort measures and may still include the range of treatments below. When not in cardiopulmonary arrest, go to part B.

B **MEDICAL INTERVENTIONS:** Person has pulse and/or is breathing.
 Check One **COMFORT MEASURES ONLY** Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, oral suction and manual treatment of airway obstruction as needed for comfort. **Patient prefers no hospital transfer: EMS contact medical control to determine if transport indicated to provide adequate comfort.**
 LIMITED ADDITIONAL INTERVENTIONS Includes care described above. Use medical treatment, IV fluids and cardiac monitor as indicated. Do not use intubation or mechanical ventilation. May use less invasive airway support (e.g. CPAP, BiPAP). **Transfer to hospital if indicated. Avoid intensive care if possible.**
 FULL TREATMENT Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. **Transfer to hospital if indicated. Includes intensive care.**
 Additional Orders: (e.g. dialysis, etc.) _____

C **SIGNATURES:** The signatures below verify that these orders are consistent with the patient's medical condition, known preferences and best known information. If signed by a surrogate, the patient must be decisionally incapacitated and the person signing is the legal surrogate.

Discussed with: <input type="checkbox"/> Patient <input type="checkbox"/> Parent of Minor <input type="checkbox"/> Legal Guardian <input type="checkbox"/> Health Care Agent (DPOAHC) <input type="checkbox"/> Spouse/Other:	PRINT — Physician/ARNP/PA-C Name	Phone Number
	<input checked="" type="checkbox"/> Physician/ARNP/PA-C Signature (mandatory)	Date
	PRINT — Patient or Legal Surrogate Name	Phone Number
	<input checked="" type="checkbox"/> Patient or Legal Surrogate Signature (mandatory)	Date

Person has: Health Care Directive (living will) Living Will Registry Durable Power of Attorney for Health Care

Encourage all advance care planning documents to accompany POLST

SEND ORIGINAL FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

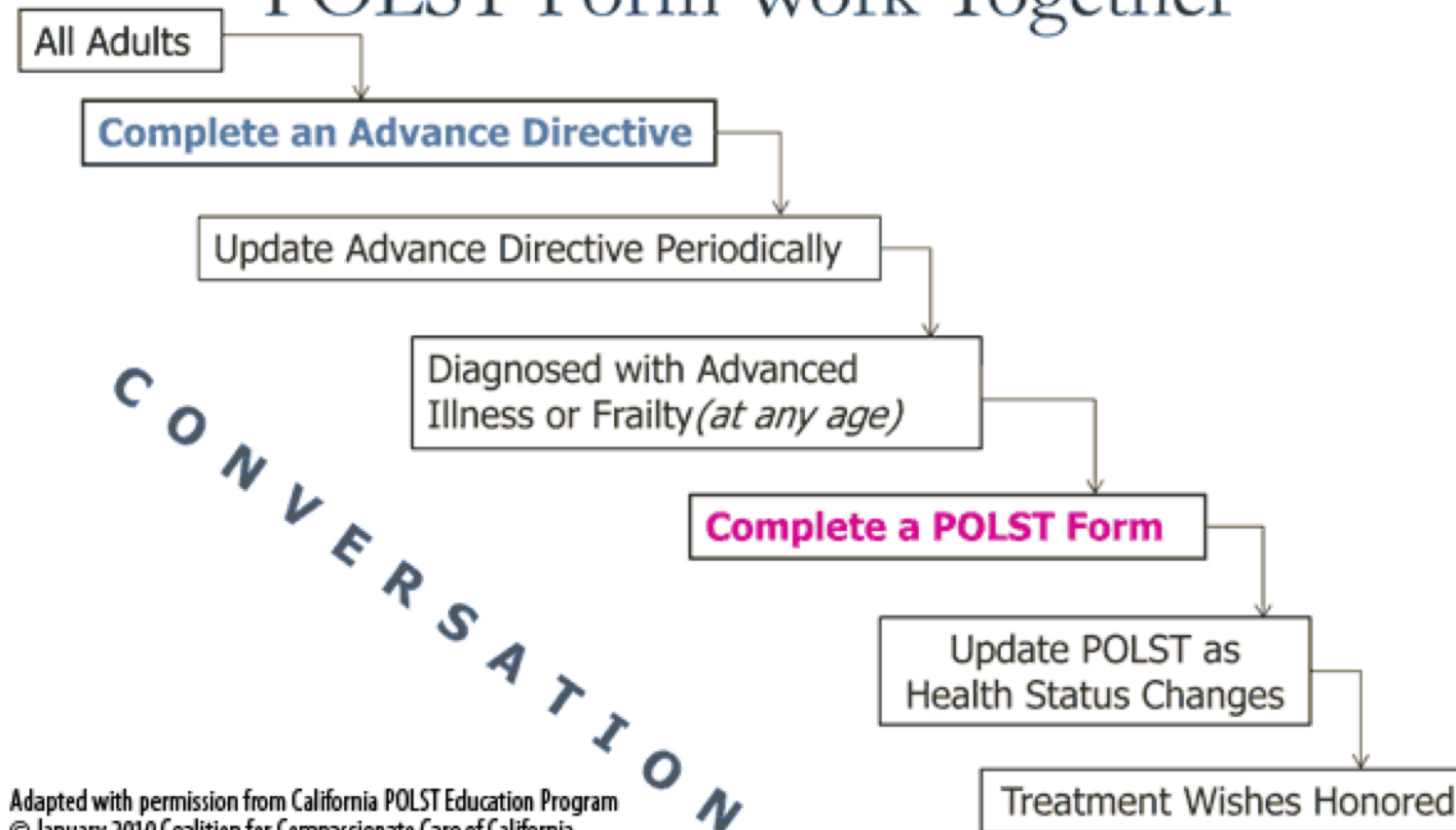
Revised 2/2011 Photocopies and FAXes of signed POLST forms are legal and valid. May make copies for records

Washington State Medical Association
WSMA
Physician Driven Patient Focused


Washington State Department of Health

OVER ▶

How An Advance Directive and POLST Form Work Together



Adapted with permission from California POLST Education Program
© January 2010 Coalition for Compassionate Care of California



Benefits to you, your family and your community

- Reassurance that if you cannot speak for yourself, your loved ones will know your wishes.
- Improved quality of care at the end of life.
- Less trauma and easier bereavement for those who know their loved ones' wishes
- Potential cost savings for families and the community.



Case Study: La Crosse, Wisconsin

The Town Where Everyone Talks About Death

- ▶ Initiative in the Gundersen Medical System over 10 years with goal to improve the quality of care at the end-of-life
- ▶ 96% of people who die in La Crosse have an Advance Directive filed.
- ▶ Side benefit - La Crosse spends less on health care for patients at the end of life than any other place in the country

Steps in Advance Care Planning

- Reflect
- Learn
- Decide
- Talk
- Record and File
- Revisit





Reflect: Explore questions like: “Is my life meaningful if I....?”

- No longer can recognize or interact with family or friends.
- No longer can think or talk clearly. No longer can respond to commands or requests.
- Am in severe untreatable pain most of the time.
- No longer can walk but can get around in a wheel chair.
- No longer can get outside and must spend all day at home. ‘

Learn: Familiarize yourself with terminology.



**YOUR VOICE - YOUR CHOICE :
LET'S TALK ABOUT IT**

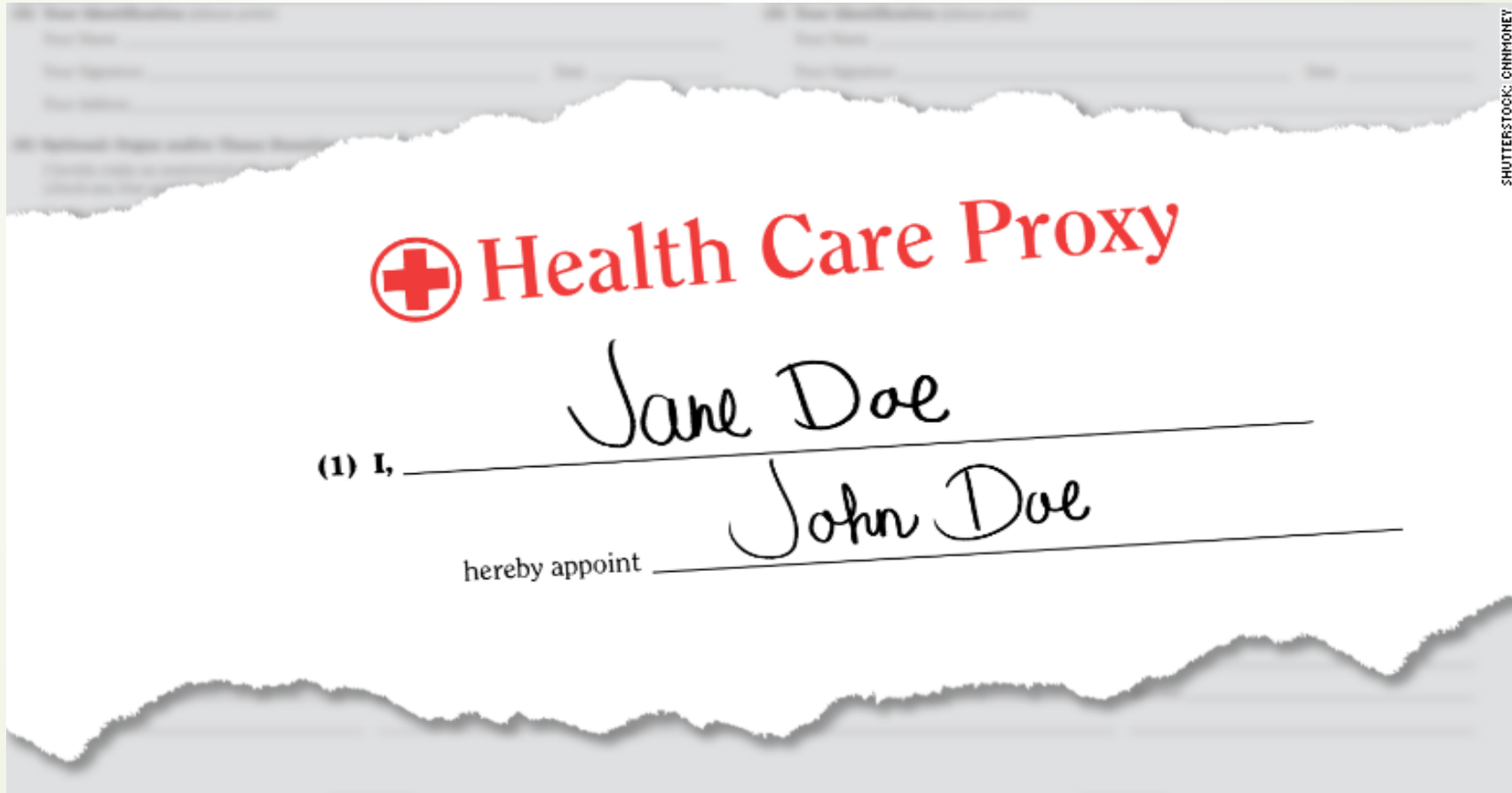
Advance Directives honor YOUR choices

SAVE THE DATE

March 22, 2017 6:00 pm

St. Luke's Health Education Center, 3333 Squalicum Pkwy

Decide: Who will speak for you on your behalf?



+ Health Care Proxy

(1) I, Jane Doe

hereby appoint John Doe

SHUTTERSTOCK: CHINMONEY

Talk: *Start the conversation.*





Record: Communicate your wishes.

- ✓ Your designated spokesperson (proxy)
- ✓ Your loved ones (parents, spouse/partner, siblings, children)
- ✓ Your doctor
- ✓ Your hospital
- ✓ Wallet card



Revisit Periodically

- ▶ Your ideas about what treatments you might want or accept may change.
- ▶ On the average, as their disease processes progress, there is a trend toward wanting less aggressive treatment.
- ▶ Study of over 2000 elderly patients (Chapel Hill and Seattle) over two year period.

Danis M, Garrett J, Harris R, Patrick DL *Stability of choices about life-sustaining treatments*. *Annals of Internal Medicine*, 1994. 120(7), 567-73



ACP as an Employee Benefit?

- End-of life issues affect workers' productivity and absentee and "presenteeism" rates, and often undermines employees' effectiveness at work.
- May also impact employers' cost of benefits,
- ACP prepares employees and their families for the progression of a serious illness or a sudden health crisis.
- Satisfaction with healthcare services offered by an employer often carry over to how employees feel about where they work.



Informal Employer Support

- *Promote the value of ACP* through internal resources (company newsletters, intranet, team meetings, etc.) to all employees, regardless of age or health status.
- Post information in HR network about local ACP seminars and ACP planning support and resources
- Include ACP in your Healthy Employee Programming - seminars and links
 - Tesoro Health Fair
 - WWU Wise and Well U



Formal Employer Support

- Include ACP in your Employee Assistance Programs
- Provide incentives for completing ACP
 - PEBB *SmartHealth* programs
 - Providence Health
 - Mission Hospital
 - Pitney Bowes



Resources

Local Resources

End of Life Choices

Whatcom Alliance for Health Advancement

<http://whatcomalliance.org/end-of-life-care/>

Downloadable forms and steps.
Help scheduling time with trained facilitators in our community.

Make Your Wishes Known

<http://makeyourwishesknown.blogspot.com>

Quarterly seminars on the realities of advance care interventions. Calendar at link.

Honoring Choices

honoringchoicespnw.org

Information on terminology and medical interventions. Other resources for planning.

Palliative Care Institute

<https://pci.wvu.edu>

Information about the Palliative Care Institute and links to upcoming events



Resources

Other Resources

The Conversation Project

<http://theconversationproject.org>

A starter kit and “How to Talk to Your Doctor” Guide

5 Wishes – Aging with Dignity

agingwithdignity.org

Resources for developing a living will and planning care at the end-of-life

Vital Talk

vitaltalk.org

A non-profit with the mission of building healthier connections and communication between patients and clinicians.



Resources

Other Resources

Hard Choices for Loving People
hankdunn.com

Hank Dunn, a nursing home and hospice chaplain, provides guidance for patients and families with end-of-life decisions.

National Hospice and Palliative Care Organization
www.nhpco.org/advance-care-planning

Exploring the varied roles of palliative care and hospice care.

Stanford Palliative Care Training Portal
palliative.stanford.edu

Educational materials about palliative and end-of-life care.