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

1. DISEASE MANAGEMENT
   - Primary diagnosis
   - Prognosis
   - Comorbidities

2. PHYSICAL
   - Pain and other symptoms
   - Function
   - Safety
   - Wounds

3. PSYCHOLOGICAL
   - Depression, anxiety
   - Emotions
   - Fears
   - Control, dignity, independence
   - Conflict, guilt, stress, coping responses

4. SOCIAL
   - Cultural values, beliefs, practices
   - Relationships, roles
   - Financial resources
   - Legal (e.g., powers of attorney)
   - Family caregiver protection

5. SPIRITUAL
   - Meaning, value
   - Existential, transcendental
   - Values, beliefs
   - Rites, rituals

6. PRACTICAL
   - Activities of daily living
   - Caregiving

7. END OF LIFE CARE/DEATH MANAGEMENT
   - Life closure
   - Legacy creation
   - Anticipation and management of physiological changes in the last hours of life

8. LOSS, GRIEF
   - Loss, grief
   - Bereavement
   - Mourning

PATIENT AND FAMILY CHARACTERISTICS
- Demographics
- Culture
- Personal values, beliefs, practices
Trajectories of Dying

Cancer
Organ failure *
Physical frailty and dementia

(*end-stage cardiac or respiratory disease)

Source: J Am Geriatr Soc © 2011 Blackwell Publishing
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?”

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
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

Old

Life Prolonging Care  Medicare Hospice Benefit

New

Life Prolonging Care  Hospice Care  Bereavement

Dx  Palliative Care  Death
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.

Kelton Global. The Conversation Project National Survey. 2013
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 (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.
How An Advance Directive and POLST Form Work Together

All Adults

- Complete an Advance Directive

  - Update Advance Directive Periodically

    - Diagnosed with Advanced Illness or Frailty (*at any age*)

      - Complete a POLST Form

        - Update POLST as Health Status Changes

          - Treatment Wishes Honored

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 Gunderson 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

I, ____________________________

hereby appoint ____________________________

John Doe
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.

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

<table>
<thead>
<tr>
<th>Resource</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>End of Life Choices</strong></td>
<td>Downloadable forms and steps. Help scheduling time with trained facilitators in our community.</td>
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<tr>
<td>Whatcom Alliance for Health Advancement</td>
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<tr>
<td><strong>Make Your Wishes Known</strong></td>
<td>Quarterly seminars on the realities of advance care interventions. Calendar at link.</td>
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<tr>
<td><a href="http://makeyourwishesknown.blogspot.com">http://makeyourwishesknown.blogspot.com</a></td>
<td></td>
</tr>
<tr>
<td><strong>Honoring Choices</strong></td>
<td>Information on terminology and medical interventions. Other resources for planning.</td>
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<tr>
<td><a href="http://honoringchoicespnw.org">honoringchoicespnw.org</a></td>
<td></td>
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<tr>
<td><strong>Palliative Care Institute</strong></td>
<td>Information about the Palliative Care Institute and links to upcoming events</td>
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<tr>
<td><a href="https://pci.wwu.edu">https://pci.wwu.edu</a></td>
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### Resources

#### Other Resources

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<tr>
<th>The Conversation Project</th>
<th>A starter kit and “How to Talk to Your Doctor” Guide</th>
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<tr>
<th>5 Wishes – Aging with Dignity</th>
<th>Resources for developing a living will and planning care at the end-of-life</th>
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<th>Vital Talk</th>
<th>A non-profit with the mission of building healthier connections and communication between patients and clinicians.</th>
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<tr>
<th>Hard Choices for Loving People</th>
<th>Hank Dunn, a nursing home and hospice chaplain, provides guidance for patients and families with end-of-life decisions.</th>
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<tr>
<td>hankdunn.com</td>
<td>Exploring the varied roles of palliative care and hospice care.</td>
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<tr>
<td><strong>National Hospice and Palliative Care Organization</strong></td>
<td>Educational materials about palliative and end-of-life care.</td>
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<tr>
<td><a href="http://www.nhpco.org/advance-care-planning">www.nhpco.org/advance-care-planning</a></td>
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<td><strong>Stanford Palliative Care Training Portal</strong></td>
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<td>palliative.stanford.edu</td>
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