

**COMPLETING THE PALLIATIVE
CARE PUZZLE:
INVOLVING COMMUNITY PARTNERS
IN THE DEVELOPMENT OF
PALLIATIVE CARE INITIATIVES**

**DR. DEVYANI CHANDRAN
DR. MARIE EATON**



THE PALLIATIVE CARE INSTITUTE

-A partnership with others in our region to transform palliative care in our community and support the human responses to living and dying.



PURPOSE



PCI seeks to make a significant contribution to improved care for all those with serious or terminal illness through...

- Mounting collaborative research and demonstration projects
- Facilitating community conversations about serious illness, death and dying
- Developing educational programs to improve knowledge in palliative and end of life care
- Hosting conferences, providing caregivers and medical staff a common venue to learn each other's concerns

COMMUNITY ENGAGEMENT & ACTIVATION: MISSING PIECE OF THE PUZZLE




SOME EXAMPLE PROJECTS

1. *A Blueprint for Creating a Community of Care and Support for People with Serious Illness* which guides the Institute's community work
2. The *Touch of Grace* project – developing educational modules on end-of-life care for staff of nursing homes.
3. *Covid-19 Focus groups* to gather data on the challenges of community-based service providers in the COVID 19 pandemic.

NORTHWEST LIFE PASSAGES COALITION

*A Blueprint for Creating a Community of Care and Support for Patients
with Serious Illness*

**Whatcom Alliance for Health Advancement ≈ Family
Care Network ≈ Palliative Care Institute at Western
Washington University ≈ PeaceHealth St. Joseph
Medical Center ≈ Northwest Regional Council ≈
Whatcom Hospice ≈ Health Ministries ≈ Circle of Life
Cooperative ≈ Whatcom Council on Aging ≈ Chuckanut
Health Foundation ≈ Lummi Tribal Health Center ≈
AHEC of WW ≈ RN-BSN Nursing Program WWU ≈ Skilled
Nursing Facilities ≈ NW WA Medical Society ≈
Community Representatives**



NORTHWEST LIFE PASSAGES COALITION & BLUEPRINT HISTORY

Task Force convened in 2014

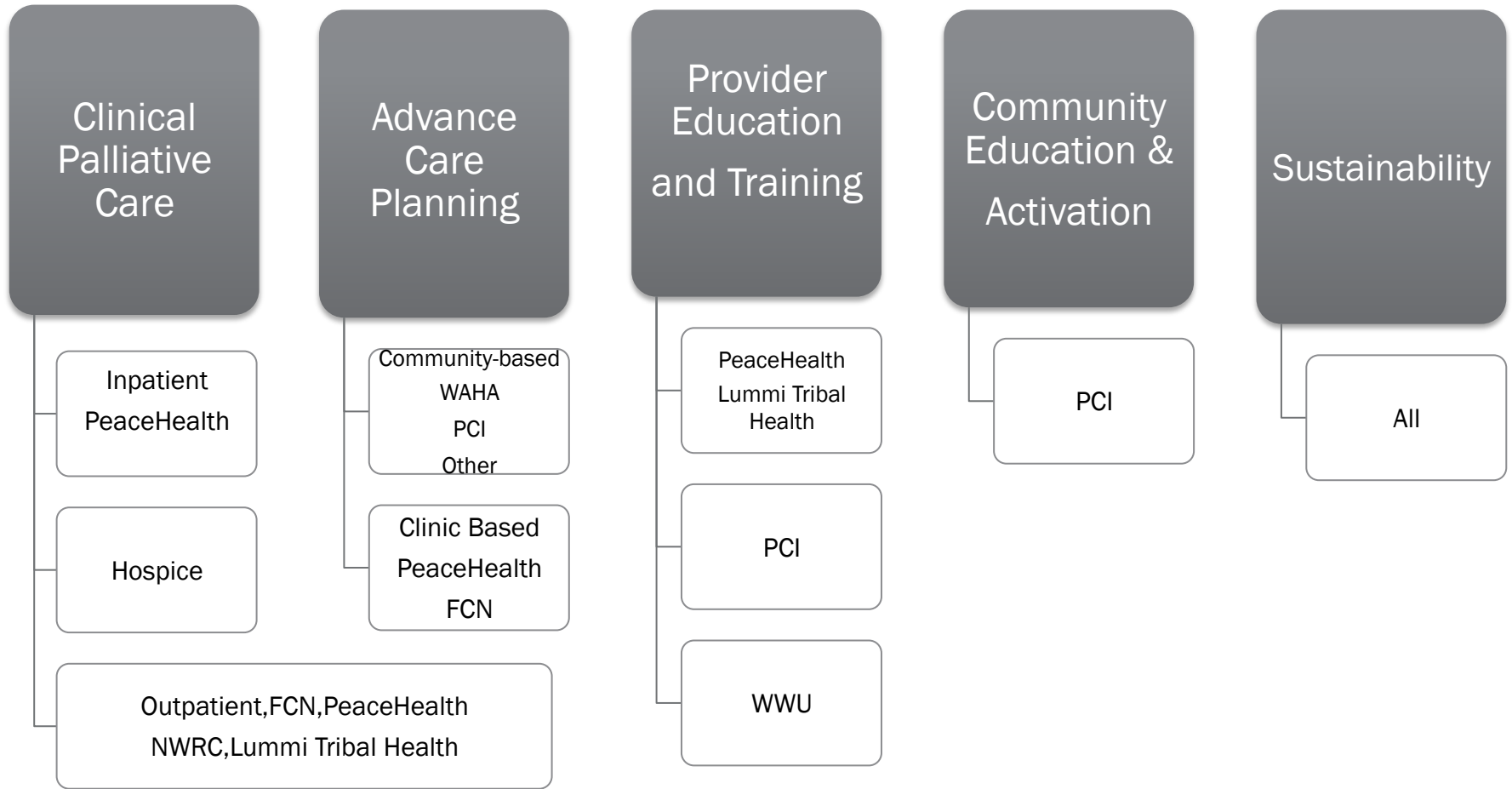
Question: ‘What will it take to transform Whatcom County into a center of end-of-life excellence?’

Explored existing resources for those with serious illness, advance care planning, palliative care services, and the community understanding about death as a natural part of the cycle of life.

Identified gaps and areas of need

Wrote Blueprint to guide improvement (revised in 2017)

NORTHWEST LIFE PASSAGES BLUEPRINT PILLARS



THE TOUCH OF GRACE PROJECT

Inspired by the death and dying experience of a woman named Grace who lived in a long-term-care community.

Grace had Alzheimer's and later developed sepsis.

THE INSPIRATION



Grace M. Tannenbaum

June 1, 1931 - June 10, 2016

TOUCH OF GRACE PROJECT EOL TRAINING FOR SUPPORT STAFF



THE TOUCH OF GRACE PROJECT

Funding from Centers for Medicare and Medicaid Services (CMMS)

Development of training videos

Pilot program at skilled nursing home with staff of 400

Replication in two other skilled nursing facilities

Revisions to the training videos based on the feedback pilot partners and from experts in end-of-life-care.

THE TRAINING MODULES

1. The role of support staff in the death and dying process
2. Verbal and non-verbal communication skills
3. The role of support staff in symptom and pain management
4. Creating a comfortable environment in final days and hours
5. Supporting grieving families and co-workers

FINDINGS: TWO STEPS AND A BREATH

The pause

- A method to refine compassion and care toward a dying patient: “A pause, before stepping into the room, to remind ourselves that someone is actively dying in the room.”

FINDINGS: CREATING A SACRED SPACE

“A really beautiful gesture to honor those [in the room], as well as remind you that this person is still alive and deserves dignity and kindness.”

“The pause” ritual of two steps and a breath gave her:
“time to gather and compose yourself to be prepared to create a space for the patient and their loved ones that will be comforting and respectful.”

FINDINGS: COMMUNICATION

- “When something tragic happens, instead of speaking, offering a smile and shaking your head can go a long way.”
- “It is not always necessary to speak at all. Sometimes it can be more valuable to just listen, to understand, to truly put yourself there with the patients and their families.”

FINDINGS: CULTURE AND THE EXPERIENCE OF PAIN

”I hadn’t ever really thought about how one culture can affect the way they experienced pain. Of course, I was aware that some people show it more than others, and to some cultures the act of crying alone is considered a weakness. But the Touch of Grace module about pain put it into perspective for me that the way we experience pain is largely shaped by our culture (our environment, our families, etc.)”

FINDINGS: THE PRACTICE OF GRIEF

“In my own practice, I have noticed that I become very uncomfortable and unsure what to do when there is a large gathering of family members in the room of a patient nearing their end, and doubly so when the family is visibly emotional. I feel that I do not know what to do or say in such situations, and as a result spend less and less time in the room.”

FINDINGS: DEATH ANXIETY

“Everyone fears death to some extent. How can we not?
There are so many questions, so many uncertainties.”

“Self-care after [a death] is so important and not talked about very much. I remember one time I hid in the breakroom and cried. There was no formal support for caregivers or acknowledgment of the trauma that we all go through.”

STRATEGIES FOR COMMUNITY ENGAGEMENT: PRE-COVID

- Deep engagement through community based conversations.
- Face to face meetings
- Organization of large conferences to present the latest knowledge on palliative initiatives in the community, as well as offering continued education credits to health care professionals in the community

STRATEGIES FOR COMMUNITY ENGAGEMENT: PRE-COVID

Providing space for community and family caregivers to engage with providers and each other in informal and formal settings.

Using an engaged community research framework to document and disseminate our work in state, local and national venues.

Infusing curricula with content on aging, death and dying and end-of life decision making.

STRATEGIES FOR COMMUNITY ENGAGEMENT: DURING THE PANDEMIC

Fostering partnerships has moved online.

Webinars

Online research projects

Support groups via Zoom

Online meetings with community-based providers

EXPLORING CAREGIVER CHALLENGES AND COPING MECHANISMS DURING COVID 19

Palliative Care Institute researchers conducted six online focus groups using the Zoom platform.



EXPLORING CAREGIVER CHALLENGES AND COPING MECHANISMS DURING COVID 19

Gathered important information on the experiences of caregivers

Provided a virtual space for support

Explored technological innovations to support workforce retention.

Fostered communication between community, care providers and clients in various care settings

Explored strategies for safe reentry post COVID.

FOR MORE INFORMATION ABOUT OUR WORK VISIT:

PALLIATIVE CARE INSTITUTE WEBSITE

<https://pci.wwu.edu/>

PALLIATIVE CARE INSTITUTE *CEDAR* SITE

CEDAR = *Contributing to Education through Digital Access to Research*: A digital repository of past conferences, events, academic papers

<http://cedar.wwu.edu/pci>