

Blueprint for Creating a Community of Care and Support for People with Serious Illness

December 2014, Revised November 2016, January 2017

OVERVIEW

A movement has taken hold in America that is supported by mounting evidence and propelled by personal conviction. The central idea of this movement is quite simple: serious illness and death are best understood as a natural part of life, and we are better off as a culture if we act as if this were true.

In April 2014, the Whatcom Alliance for Health Advancement (WAHA) convened a Task Force composed of experts and community leaders who were asked what it would take to transform Whatcom County into a center of excellence for all those with and impacted by serious, life-threatening illness.

Focusing on advance care planning, palliative care, provider training, and community culture, the Task Force developed a blueprint for community excellence that includes short and long-term strategies for sustainability.¹ The End-of-Life (EoL) Coalition, now called Northwest Life Passages Coalition (NWLPCoalition), is the vehicle for realizing the plan and facilitating and coordinating the implementation of the recommendations outlined in this paper. The group includes healthcare and social service providers, educators, and community leaders from a variety of fields.

Two years into implementation, the NWLPCoalition has affirmed the original vision while revising the Blueprint to reflect projects completed, lessons learned, new goals, and desired outcomes.

¹ The Task Force who developed the original Blueprint in December, 2014 included: **Marie Eaton, PhD Chair** Professor, Western Washington University; **Ashley Benem**, Death Midwife/Massage Practitioner/Artist; **Margaret Jacobson, MD**, PeaceHealth Medical Group/Whatcom Hospice; **Bree Johnston, MD, MPH**, PeaceHealth Medical Group/Palliative Care; **Serge Lindner, MD**, Center for Senior Health, PeaceHealth Medical Group; **Dan Murphy**, Executive Director, Northwest Regional Council; **Tonja Myers**, Administrator, St. Francis of Bellingham; **Chris Phillips**, Director of Community Affairs, PeaceHealth St. Joseph Medical Center; **Berdi Safford, MD**, Medical Director, VP of Quality, Family Care Network; **Casey Shillam, PhD, RN-BC**, Nursing Academic Program Director, Western Washington University; **Sandy Stork**, Death Café Founder, Community member; **Larry Thompson**, Executive Director, Whatcom Alliance for Health Advancement; Rev. **Bobbi Virta**, Pastor, United Church of Ferndale; **Josselyn Winslow**, Alzheimer's advocate, Community member; **Mary Ann Percy, MS**, Advanced Care Specialist, Whatcom Alliance for Health Advancement; **Liz Jones, MPH**, Health Policy Specialist, Whatcom Alliance for Health Advancement.

WAHA would like to thank these volunteers who shared their experience, knowledge, and wisdom. In addition to meeting regularly over a six month period, these individuals spent countless hours reviewing articles, meeting in subgroups, and writing, reviewing, and approving White Papers. The work of the Task Force was supported by generous grants from the RiverStyx Foundation, Whatcom Community Foundation, and Chuckanut Health Foundation.

VISION

Whatcom County is a community where death is recognized as a natural part of life, where no one lives with untreated pain as they live with serious illness or approach life's end, where the entire spectrum of residents' chosen wishes for their care are known, respected, and honored.

People with chronic or serious illness, regardless of age, live their last months to their fullest, with pain and suffering alleviated, their fears and questions heard and addressed, and their relational, spiritual, and cultural needs met with loved ones around them.

Our community is one where family, friends and caregivers feel supported up to and following the death of a loved one.

A complete range of professional and volunteer services to support this vision is organized, easily accessible to all, and financially sustainable.

NWLP Coalition

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INTRODUCTION

There is growing awareness nationwide about the importance of care during serious illness and at end-of-life.² The Institute of Medicine (IOM) Report, *Dying in America*, released in 2014, recommends a person-centered, family-oriented approach that honors individual preferences and promotes quality of life. The IOM Report emphasizes that implementing this vision is a matter of national priority and urgency.

In Whatcom County, there is a rising tide of initiatives, interest, and excitement about the idea of creating a community excellence for people with serious illness. Whatcom County has supported a successful Hospice and inpatient palliative care service for a number of years, and we enjoy a community-wide culture of collaboration that has spawned a university-based institute for palliative care.

The NWLP Coalition Task Force was established in 2014 and developed a blueprint that articulates a coherent vision and a plan for collaborative community action toward achieving community excellence for end-of-life care. The original Task Force produced five White Papers that helped inform the original Blueprint. Posted on the WAHA website, the papers cover the following topics: Advance Care Planning; Palliative Care; Community Culture; Provider Training; and Financing the Future. The 2014 Blueprint provided brief background statements for each of these topics, along with *keys to excellence*, *community assets*, and *recommended steps* toward realizing the Blueprint vision.

Two years into implementation, the NWLP Coalition is issuing this revised blueprint. Under an expanded title that invites community excellence in “serious illness care” as well as end of life care, the Coalition is re-affirming the original vision, and revising the Blueprint with new recommendations that reflect projects completed and lessons learned as well as a set of aspirational community measures.

²Locally we have multiple community-based educational and cultural events about serious illness and end of life. At the state level, the Washington State Hospital Association has recently adopted the Honoring Choices Advance Care Planning Initiative, and Death with Dignity is an available option. The State of Washington is also considering the expansion of caregiver support services in its upcoming Healthcare Transformation Waiver with the Center for Medicare and Medicaid Services (CMS). Nationally, Palliative Care Services are now offered in 61% of U.S. hospitals with more than 50 beds, and CMS is offering to fund numerous pilot projects related to end-of-life care.

BLUEPRINT

I. ADVANCE CARE PLANNING

BACKGROUND: Advance Care Planning (ACP) is an organized process of communication to help individuals understand, reflect upon, and discuss goals for future healthcare decisions in accordance with their values and beliefs. When this process is done well, it can result in a written plan – an Advance Directive – that accurately represents the individual’s goals, values, and preferences, and helps prepare others to make healthcare decisions consistent with these preferences. In the absence of such a plan caregivers and family members are left guessing about the patient’s wishes, often resulting in unnecessary stress and strife.

KEYS TO EXCELLENCE

- Clear processes that make it easy for people to prepare Advance Directives and for healthcare providers, caregivers, and families to access the directives and carry them out.
- A set of outreach strategies with a focus on primary healthcare practices, while also including complementary providers, financial planners, elder attorneys, faith community leaders, Native American, Hispanic and other cultural and ethnic communities.

COMMUNITY ASSETS

- The WAHA End of Life Choices program has valuable and extensive experience and has implemented best practices for training volunteers, engaging with health professionals and conducting community outreach.
- The PeaceHealth system is serving as a ‘pilot’ for Honoring Choices Pacific Northwest a state-wide initiative of the Washington State Medical Association and the Washington State Hospital Association.
- There are over 20 WAHA-trained community facilitators currently active, helping people complete their Advance Directives.

RECOMMENDATIONS

- Under the auspices of the NWLP Coalition, WAHA and PeaceHealth *Honoring Choices* should collaborate to increase the numbers of people who complete their Advance Directives.
- WAHA should lead the development of an ongoing outreach and marketing effort that targets people from a wide range of population groups within Whatcom County.
- A reliable document filing process should be developed in coordination with the community repository at PeaceHealth St Joseph Medical Center that ensures cross-organizational electronic access.

DESIRED OUTCOMES

- By 2020, all Whatcom County residents that die in the hospital will have an Advance Directive and/or POLST on file.
- Increase the number of Advance Care Planning conversations held each day with the help of trained facilitators throughout the county.

II. COMMUNITY-BASED PALLIATIVE CARE SERVICES

BACKGROUND: Palliative care is specialized care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain, and stresses of a serious illness. The goal is to improve quality of life for both the patient and family. Palliative care is provided by a team of doctors, nurses, social workers, chaplains, and other specialists who work together to support people with serious illness and their loved ones. It is appropriate at any age and at any stage in a serious illness, and can be provided along with curative treatment. It is widely recognized that palliative care improves quality of life for patients with advanced illness and their families while reducing costs. Inpatient palliative care is provided in the hospital setting, and outpatient palliative care is provided in any other setting in line with patient preference.

KEYS TO EXCELLENCE

- Strong clinical leadership well versed in symptom management and the importance of emotional, psychosocial, and spiritual support.
- Programming that is well-coordinated with existing services, and available across the continuum of care, including homes, assisted living, and skilled nursing facilities, and when appropriate, alongside other specialty services or clinics.
- Close collaboration with community partners and availability to all residents, regardless of their primary source of health care services.

COMMUNITY ASSETS

- Whatcom County has established a significant array of palliative care services, including a strong Hospice Program, an inpatient palliative care consultation service, and a low volume outpatient palliative care clinic for patients with advanced cancer (based in the PeaceHealth Cancer Center). Family Care Network maintains a low volume home-care program for vulnerable patients.
- A robust community of complementary practitioners providing support and palliation for seriously ill people.
- Passionate, active community advocates interested in supporting the work.

RECOMMENDATION

- Leading clinical entities, in collaboration with the NWLP Coalition, should develop community-based palliative care services that are built on cross-organizational cooperation with support from grants and philanthropy as needed.

DESIRED OUTCOMES

- Everyone that dies at home has access to pain and symptom management.
- Early referrals for hospice program admissions and hospice lengths of stay increase.
- Referrals to a community-based palliative care service steadily increase.

III. TRAINING

BACKGROUND: It is widely recognized that palliative care improves quality of life for people with advanced illness and their families, reduces costs. The need for palliative care is growing, due to increases in chronic and serious conditions and the aging population's desire for quality of life as well as quality of care. A workforce of traditional and complementary providers in all disciplines, specialties, and practice settings, trained in basic palliative care competencies, is essential to meeting this need.

KEYS TO EXCELLENCE

- Organizational commitment and leadership from PeaceHealth, Family Care Network, community clinics, area nursing homes, home health agencies, and other community partners.
- Training curriculum and opportunities that are inclusive of the multiple disciplines are a hallmark of palliative care, including allopathic physicians and nurses, certified nursing assistants, social workers, chaplains, and complementary providers.

COMMUNITY ASSETS

- PeaceHealth is in the process of establishing basic palliative care training recommendations for physicians treating patients with serious, life-threatening illness; all staff at Family Care Network is receiving training in Advance Care Planning conversations; the RN-to-BSN Program at Western Washington University (WWU) is training nurses in palliative care competencies.
- The Palliative Care Institute associated with the WWU Nursing program is well positioned to design and serve as the hub for a cross-organizational, multi-disciplinary training program.

RECOMMENDATIONS

- Under the auspices of the NWLP Coalition, the Palliative Care Institute and PeaceHealth should provide training opportunities that support the establishment of basic palliative care competencies for traditional and complementary providers in all disciplines, specialties, and practice settings.
- Training opportunities should be a mix of interdisciplinary community workshops; ongoing Continuing Education events within and across disciplines, and on-line training modules oriented toward specific community-based and clinical issues.

DESIRED OUTCOMES

- Quality training for traditional and complementary providers is offered in the community in various forms that addresses:
 - Pain and symptom management
 - Communication
 - Cultural competence
 - Optimal resource utilization
 - Care coordination.
- Number of practitioners who receive Serious Illness Training ([Ariadne Labs](#)) or other in-depth palliative care training increases annually.

IV. COMMUNITY CULTURE AND ACTIVATION

BACKGROUND: Our generation is the first that has cared for parents or other loved ones in a health care system that has the potential for providing treatments that may prolong the length of life while reducing the quality of life. We are faced with new challenges as we care for those with chronic conditions and serious illnesses – and we are changing our feelings about choices we want at the end-of-life. Additionally, our community is becoming more diverse, and that change is reflected in the attitudes, emotions, and customs related to death and dying. There are many critical questions that need to be asked and countless answers and solutions that have yet to emerge. Helping individuals and families grapple with end of life issues is part of what it means to live in a caring community.

KEYS TO EXCELLENCE

- Community engagement in realizing the Blueprint Vision through ongoing and evolving educational events, small group conversations, and artistic expressions of issues related to serious illness, death and dying.
- Institutional support from major educational, legal, faith and healthcare organizations aimed at understanding and amplifying positive cultural trends such as community-based palliative care and the “de-medicalization” of serious illness, death and dying.
- Engaged and activated patients and families who understand their long-term care options and end-of-life choices.

COMMUNITY ASSETS

- The Palliative Care Initiative at WWU, Health Ministry Network, the Hospice Volunteer Recruitment and Training Program, and other community groups focusing on chronic and serious illness, grief support and end of life.
- Numerous grassroots initiatives exist in our community, including Death Café, Death Midwifery Service, “Realities of Advanced Medical Interventions,” Bellingham Threshold Choir, and Women with Wings.
- Whatcom County enjoys constructive relationships at the State level with End of Life Washington, a leading proponent of the WA State Death with Dignity Act; Honoring Choices Pacific Northwest; and the Washington End-of-Life Coalition.

RECOMMENDATIONS

- Under the auspices of the NWLP Coalition, the Palliative Care Institute (PCI) at WWU should lead in the development of an integrated website and advocate for a community resource center.
- PCI should continue to advocate for and support community organizations and individuals who are convening conferences, conducting community conversations, and arranging artistic events that address such topics as successful aging, living with chronic conditions, serious illness care, and end of life choices.
- PCI should develop mutual learning opportunities with other communities, with particular focus on inclusive and culturally competent practices.

DESIRED OUTCOMES

- Community events are well attended by new and returning attendees representative of all populations within Whatcom county.
- Community events are planned in varied formats and venues to support community education and activation about serious illness and end of life care.

V. *FINANCIAL SUSTAINABILITY*

BACKGROUND: While most medical services, including serious illness and end-of-life care, are reimbursed on a fee-for-service basis, other payment models such as pay for coordination, bundled payments, pay for performance, shared savings, and capitation may provide more innovative and patient-centered models for providing end-of-life services. A number of existing clinical programs have shown promise in utilizing these innovative models to provide end-of-life services, including Medicare Special Needs Plans, Partners in Palliative Care, and Life Passages.

KEYS TO EXCELLENCE

- Recognition by all concerned that healthcare and cultural norms regarding serious illness, death and dying are changing; fee for service is shifting to population-based payment methods, and quality of life concerns are driving change in the type of care that people want for themselves and their loved ones.
- The ability to implement pilot projects and make iterative changes to those pilots that lead to improvements in patient care increases in patient satisfaction, reduced cost, and increases in clinician satisfaction.

COMMUNITY ASSETS

- Philanthropic organizations and individual supporters in our community are interested in serious illness and end-of-life issues. Foundation support includes RiverStyx, Hospice Foundation, Chuckanut Health Foundation, Whatcom Community Foundation, WWU Foundation, and PeaceHealth Foundation.
- WAHA, NWLP Coalition, and other partners have significant development and healthcare financing expertise.
- The PeaceHealth System is committed to serious illness and end-of-life excellence and has market-share to potentially move the rest of our local health care delivery system in a particular direction.

RECOMMENDATIONS

- NWLP Coalition should develop a sustainability plan that will ensure the fulfillment of the Blueprint.
- Community providers and payers should be encouraged to develop pilot projects that invest in the transformation of our care delivery system to better support people with serious illness and those in need of end of life care.
- NWLP Coalition and the Whatcom community should advocate for policy changes at the state and federal level that will support and sustain appropriate care for people with serious illness and those at the end of life.

SUMMARY OF RECOMMENDATIONS

While it is certainly possible for the lead organizations involved in each of the initiatives outlined above to develop programs and funding opportunities independently, the NWLP Coalition is convinced that our vision can only be fully realized through community collaboration and advocacy. Whatcom County is poised and ready to enact significant change. Using this Blueprint and working together, we will become a center of excellence in serious illness and end-of-life care and a “best place” to live and die in America.

The NWLP Coalition will continue to facilitate the coordinate the initiatives outlined in this update, including:

- Developing an updated Advance Care Planning campaign that relies on collaboration between WAHA and PeaceHealth/Honoring Choices.
- Developing a community-based, cross-organizational outpatient palliative care program.
- Enhancing the community-wide effort aimed at ensuring the establishment of basic palliative care competencies for traditional and complementary providers in all disciplines, specialties, and practice settings.
- Accelerating cultural change through education and activation activities planned collaboratively between the Palliative Care Institute at Western Washington University and other community resources. Further implementation of a central resource in our community that includes information of the full spectrum of available options regarding serious illness, death and dying.
- Collaborative advocacy efforts and sustainability planning by NWLP Coalition and community partners that will facilitate investment in the transformation of the community’s care delivery system.

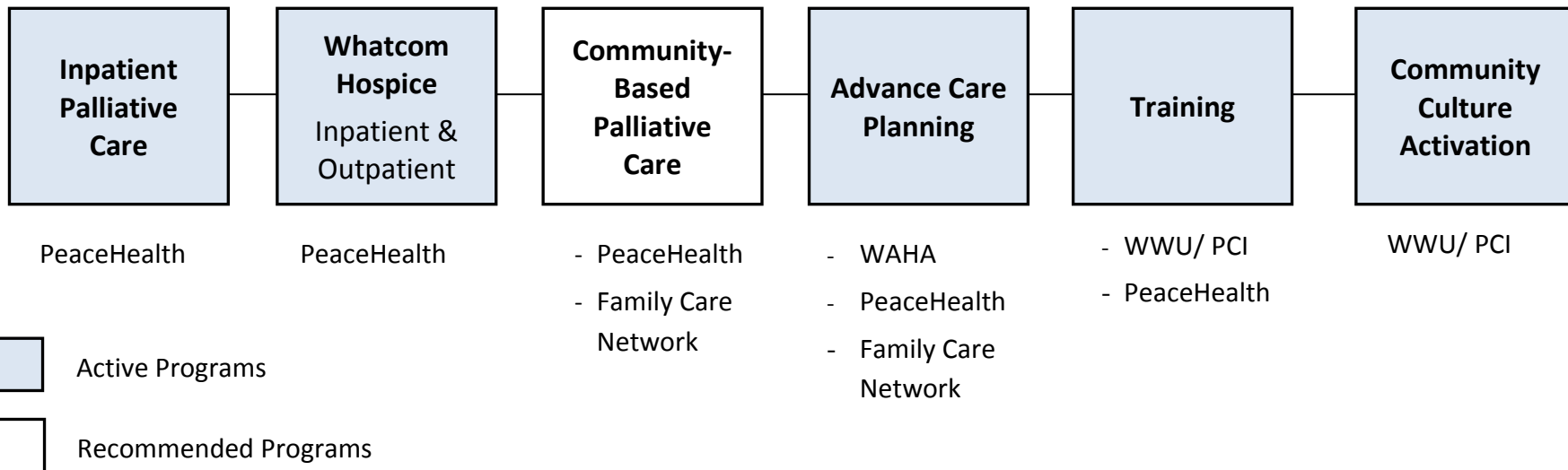
The NWLP Coalition also recommends that WAHA continue to serve as its backbone organization.

Toward an Integrated Continuum of Serious Illness and End-of-Life Services

Northwest Life Passages Coalition

Coalition Steering Committee

- Mary Carlson (Whatcom Council on Aging)
- Marie Eaton, PhD (Western Washington Univ.)
- Heather Flaherty (RiverStyx Foundation)
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- Rev. Bobbi Virta (Community Advocate)



The Whatcom Alliance for Health Advancement (WAHA) is a 501(c)(3) nonprofit organization with a mission *to connect people to health care and to facilitate transformation of the current system into one that improves health, reduces costs, and improves the experience of care*. The WAHA Leadership Board includes consumers and community leaders from the nonprofit, business, and governmental sectors, as well as many local healthcare organizations.

Please contact WAHA at www.whatcomalliance.org if you have questions or comments.