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White Paper: Building a Continuum of End of Life Care in Whatcom County: Inspire Culture Change

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Building a Continuum of End of Life Care in Whatcom County: Inspire Culture Change

October 2014

Prepared by Marie Eaton, PhD

Overview

This Task Force was charged with identifying best practices related to cultural change regarding end of life issues. However, we believe that there is no single best practice at the community level. Our community and cultural responses related to living with serious illness and facing our own mortality or experiencing the death of loved ones continue to evolve. Our generation is the first that has cared for parents or other loved ones in a health care system that has the potential for keeping people alive too long – and these experiences are changing our feelings about what choices we want at the end of life. Additionally our community is becoming more diverse and that change also will be reflected in attitudes, emotions, and customs related to death and dying. There are many critical questions that still need to be asked and countless answers and solutions. We provide recommendations in four major domains: Collaboration, Conversations, Education/Access, and Activation.

“There is so much we do as a community that is part of being in this journey we call life together. We take care of each other; we learn from one another, we take action together. We are on this collection of roads together and we often do it really well, regardless of the lack of instructions we have been given. My friend, Sydney once wrote, ‘life is a journey where the roadmap is handed out at the end. We figure it out, and often elegantly. There is no cure for life, it is terminal for us all, but we often find grace along the way.’” ~Geof Morgan, director of the Whatcom Family and Community Network



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Goal

To produce a vision of what Whatcom's End-of-Life services and culture would be like if we were a Community of Excellence, and to make recommendations for activities to support the development of that community.

Note: We acknowledge that it is beyond WAHA's scope to take on all of the initiatives and activities recommended in this document, but since we were invited to think broadly about cultural change, we did not limit our ideas to those which can be provided within typical healthcare systems. Part of WAHA's task in accepting this report is to determine which activities

- are within WAHA's scope and mission
- are opportunities for WAHA to partner with other agencies and community groups
- are seeds which WAHA could nurture in other parts of the community
- WAHA should know about and rejoice that others will provide the leadership

Work Group

Marie Eaton, PhD, Chair
Professor, Western Washington University

Lois Batesman
Community member

Ashley Benem
Death Midwife/Massage Practitioner/Artist

Janet Ott
Community member

Mary Ann Percy
Advanced Care Specialist, WAHA

Richard Scholtz
Community member

Sandy Stork
Death Café Founder, Community member

Bobbi Virta
Pastor, United Church of Ferndale

Josselyn Winslow
Alzheimer's advocate, Community member

This White Paper is one of five working papers, each of which covers a different content area and was developed by a separate Work Group. These papers were used to inform the development of the Blueprint for Community Excellence at End of Life. As such, this White Paper is not to be viewed as a formal or standalone document, but rather as supplemental and expanded material for those who may be interested in additional information and content in a specific area. If there are any discrepancies between this paper and the Blueprint, the Blueprint represents the final decision of the Steering Committee.

WHITE PAPER

Executive Summary

Objective

To produce a vision of what Whatcom's End-of-Life services and culture would be like if we were a Community of Excellence, and to make recommendations for activities to support the development of that community.

Vision

A supportive community where those with serious long term or terminal illness do more than just survive; they thrive.

Gaps and Challenges

- End-of-life/dying has become increasingly medicalized.
- Access to information about services and supports (both formal and informal) that already exist in our community is fragmented and scattered.
- The PeaceHealth brand has a challenge with reputation in the community, particularly related to end-of-life.

Recommendations

Our recommendations are in four major domains: Collaboration, Conversations, Education/Access, and Activation. Details about proposed implementation of these recommendations can be found in the body of this report.

Collaboration: We recognize that building a truly palliative community and fostering community cultural change around palliative care and end-of-life practices requires honest collaboration among providers, community agencies and leadership, including both formal and informal networks. True community is created when everyone has a chance to contribute and all stakeholders can bring their wisdom to the table.

Recommendation #1: Develop a *Standing Committee on Community Cultural Change* to continue partnerships that have begun in the Palliative Care Initiative and this Task Force and to support other continued collaborative work on culture change.

Recommendation #2: Work with the Palliative Care Initiative or another appropriate group to convene this standing committee and provide fiscal agency, support, and direction for some of the culture changing activities recommended by our Task Force.

Recommendation #3: Disseminate this report to other agencies and community groups that could be collaborators in developing some of these projects.

Conversations: Culture change begins with and is fostered by robust conversations in many domains that challenge our 'death denying' cultural norm and allow us to explore and express our understanding of end-of-life and the emotions that accompany this exploration.

Recommendation #4: Cultivate multiple venues to tell stories about death and long term illness, to challenge the illusion that we walk around perfect and immortal, and to explore the role of language, education, and cultural competency in addressing these questions.

Education/Access: Many in the community need more understanding of end-of-life processes and practices, in either their professional roles or personal lives. Others need more information about how to access the services that are already available to them.

Recommendation #5: Support formal informational and educational activities related to process and practices that are supported through multiple collaborative networks.

Activation: Providing carepartners with more information and choices about end-of-life will result in a more activated community – one that demands a reciprocal and respectful relationship between carepartners and health professionals and provides choices for supporting those with serious illness or facing the end-of-life.

Recommendation #6: Promote activities that will support the development of a more activated community.

Metrics

Provides some suggested metrics for assessing the impact of culture changing activities.

Appendices

Lists varied assets already present in the community.

Objectives

The objectives of the Community Culture Task Force are as follows:

- To produce a vision of what Whatcom's End-of-Life services and culture would be like if we were a Community of Excellence.
 - To explore ideas about Whatcom County becoming "A good place to live and a good place to die."
 - To think about ways we can improve the experiences of those with long-term or terminal illness as they navigate the systems related to palliative care and to "find grace along the way."
 - To foster conversations that will result in better and more frequent advance care planning, and enact the kinds of cultural changes that will drive changes

in both in-patient and outpatient palliative care and end-of-life care delivery outlined in the other End-of-life Steering Committee Task Force reports.

- To survey and describe the culture around serious and/or terminal chronic conditions and end-of-life as it currently exists in Whatcom County as well as review two or three other communities of “emerging practice.”
 - To identify assets and strengths of our community in order to make visible and capitalize on the network of supports and practices (both formal and informal) that already exist in our community.
 - To identify weaknesses, gaps, and challenges in culture and services.
- To develop and prioritize activities that will normalize conversations about serious illness and death and dying, develop “activated consumers,” and link patients and carepartners to resources.

Vision

Our Vision for Whatcom's End-of-Life services and culture as a Community of Excellence:

- A supportive community where those with serious long term or terminal illness do more than just survive; they thrive.
- A community that is able to talk about death as a natural part of the cycle of life. When we talk about death, we have to talk about the whole cycle of birth to death – not just dying as an “island” at the end.
 - Conversations that include all members of the community – children to elders.
 - Conversations that help us create space for both understanding and emotion.
 - Conversations that help us distinguish between giving up and letting go – that help us understand that death is not a failure – that part of living well is also dying well.
 - Conversations that include discussions about “medically assisted dying.”
 - Conversations that go beyond how to fill out the forms.
- A community rich in ritual and language that supports engaged conversations and shared experiences related to dying and grief, where we are given permission to create meaning from and celebrate the process of dying, including support of not only the medical/physical aspects of serious illness or death, but also the spiritual, emotional and psychological aspects.

- A community where we believe we can ask for help and get it, where we care for each other and watch out for each other – where we strengthen our understanding of palliative care as our shared responsibility as neighbors, friends and family.
- A community that collaborates, coordinates and builds upon a continuum of clinical, social, spiritual, and complementary care to support palliative care, where these end-of-life services are available to all carepartners, including the indigent and homeless, because we believe that no one should have to face a life-threatening illness alone.
- A community that honors elders (teacher/crone/sage).
- A community where we honor the reciprocity of knowledge and roles shared by the community as well as healthcare providers.
- A community where we actively make choices about our living/dying processes – choices about our health care, advance directives/living wills, and POLST orders, and have prepared ahead for legal concerns, including powers of attorney, wills, and choices about the disposition of our bodies, and support for those who wish to die at home.
- A community where doctors and other health professionals have the skills to foster honest conversations about these choices, provide needed services/care and honor a patient’s or advocate’s decision to say ‘no more.’

Gaps and Challenges in Culture and Services

As we see it, the following are the key challenges facing our community:

- We recognize that PeaceHealth has a challenge with reputation. We recognize that if all the elements of end-of-life planning and palliative care are linked to the PeaceHealth brand, many in the community may choose not to participate.
- End-of-life/dying has become increasingly medicalized, but death resists being siloed. Much of healthcare occurs inside structures that are guided by forms and rules and regulations, but caring for those with serious or terminal illnesses occurs within a larger community. Although we want to engage the community to help change healthcare institutions, that focus alone will not build a ‘palliative community.’
- While many services and supports (both formal and informal) already exist in our community, access to information about them is fragmented and scattered.

Recommendation: Collaboration

We recognize that building a truly palliative community and fostering community cultural change around palliative care and end-of-life practices requires honest collaboration among providers, community agencies, and leadership, including both formal and informal networks. Community change is not the same as consumer provider change. Healthcare systems and providers are a part of a wider community that also has resources and wisdom. True community is created when everyone has a chance to contribute and all stakeholders can bring their own wisdom to the table. If we find the places where trusting communities already exist, we can build on those relationships through additional educational and social resources.

Recommendation #1

Develop a *Standing Committee on Community Cultural Change* to continue partnerships that have begun in the Palliative Care Initiative and this Task Force and to support continued collaborative work on culture change. Cultural change is already happening – building a plan and having centralized leadership is not a pre-requisite, but finding ways for healthcare professionals and community members to partner with and support each other's functions and expertise will strengthen these cultural shifts.

The next stage of the “Changing the Culture” initiative might best be designed by convening a group of those who are already involved in overlapping initiatives through their community and professional roles, including those businesses or initiatives outside of healthcare, and taking into consideration how the changes we envision might help or hurt their businesses (See Asset List in Appendix A for list of possible collaborators).

Recommendation #2

Work with the Palliative Care Initiative or another appropriate group to convene the *Standing Committee on Community Cultural Change* recommended above, to help find appropriate collaborators, to serve as the fiscal agency, and to provide other support and direction for some of the culture changing activities recommended by our task force (listed with more detail below). As noted above, we acknowledge that many of these activities are outside of WAHA's scope of practice, but the WAHA Board and staff can help determine the appropriate players for the activities recommended in this document. Through these collaborations funding could be sought for various projects through the newly developed Whatcom Center for Philanthropy and other funding groups.

Recommendation #3

Disseminate this report to other agencies and community groups that could be collaborators in developing some of these projects (See Appendix A).

Recommendation: Conversations

"I think that biggest impact this course had on me was that it taught me the value of conversation. As a society, we need to talk about death and dying because it is the only thing in life that is truly inevitable and universal. I realized that we must address issues of death and dying in the public discourse. We need to talk about end-of-life costs; we need to talk about advanced directives; we need to talk about our fears and beliefs regarding the afterlife. The more we talk about death, the less scary it becomes. If anything, this course taught me that talking about death and dying in our everyday lives is a must."

~Student in Spring term 2014 Death & Dying class, Fairhaven College, Western Washington University

Recommendation #4

We strongly recommend cultivating multiple venues to tell stories about death and long term illness, to challenge the illusion that we walk around perfect and immortal, and to explore the role of language, education, and cultural competency in addressing these questions. Opening many different avenues into these conversations may provide more opportunities to reach out to local populations whose approaches to death and dying differ, engage with them in culturally appropriate and sensitive ways, and engage our community across the life span. Some of these opportunities include:

Develop an on-going Whatcom County Conversation Series: Under the auspices of the Palliative Care Initiative, develop a cadre of facilitators to offer topic-based discussion groups on a regular basis. These discussions should be complementary to Death Café and be facilitated. Some of the topics might include: "When to initiate palliative care?" Carepartner support, grief support, rituals and ceremony, burial/funeral options, creating your own death plan, alternative end of life options. It could use WECU Health Education Center in Bellingham, the WECU space in Ferndale, or County Libraries as venues. The *Standing Committee on Community Cultural Change* (see above) proposes to launch this project under the auspices of the Palliative Care Initiative.

Inter-Generational Conversations: One of the "action" initiatives at the Palliative Care Institute in July suggested the development of a better curriculum to foster conversations about end-of-life across generations, including the suggestion to include material about dying and end-of-life in the standard curriculum, and to host a Death Café in local high schools. It could be offered as an elective for credit in the schools.

The Arts: The arts (theatre, music, poetry, dance) can invite community members to explore ideas and emotions about serious illness or end-of-life. The language of healthcare is inadequate to capture the range and depth of emotions that arise as we contemplate our own mortality or the death of those we love. The arts are essential for sharing, experiencing and processing these emotions. The Art of Death (TheArtofDeathBellingham.Wordpress.com) and the Kuntz & Company dance piece commissioned by the Palliative Care Initiative (Ellis Won't Be Dancing Today) are good examples, and more of these events should be nurtured. Collaboration with the Bellingham Storytellers Guild (Doug Banner - <http://bellinghamstorytellersguild.org>) might also be fruitful.

Conversations about Rituals and Ceremony: Different cultural groups and faith traditions in our community have robust rituals and practices that support patients and families through end-of-life and grief cycles. Learning more about these rituals and making them more visible to others in the community may spark the exploration of such options in their own lives, and help medical professionals provide culturally appropriate service to our various communities. These discussions might also be appropriate in connection with the annual Art of Death events in Whatcom County.

Book for Whatcom Reads (Whatcom Dies/Whatcom Plans): Organize a book reading for the county around the issues of planning for death or living with serious illness. We have no suggested titles at this time. Chuck & Dee at Village Books are going to provide a section/display on End-of-life in October in conjunction with the Art of Death project.

Information Booths: Many organizations have booths at community events like the Public Market, Pride Festival, Senior Fair, and Sea to Ski. WAHA volunteers have staffed information booths about Advanced Care Planning and other services for palliative and end-of-life care. This could be expanded to include other EOL information and services.

811 Number: We recommend a community initiative to develop an '811' number to call when a companion is needed to help with the dying and letting go, rather than heroics to prolong the dying process.

Recommendation: Education and Access

During our discussions we identified many resources in our community, both formal and informal, that already provide palliative care and end-of-life services. However, we noted that gaining access to information about these resources is often daunting and frustrating. We also noted that many in the community need more understanding of end-of-life processes and practices in both their professional roles and in their personal lives. Some important culture changing activities will include formal education about these process and practices.

Recommendation #5

We recommend that formal informational and educational activities related to process and practices be supported through multiple collaborative networks. Some opportunities include:

Web Presence/Network: An integrated website (perhaps titled Whatcom End of Life Choices & Resources) could help provide access. We recommend using web technologies to develop a robust on-line presence to link traditional inpatient and outpatient palliative and end-of-life care to complementary and alternative care, spiritual care, and other ancillary services or supports, both formal and informal. This web site could also link to a YouTube library of informational videos related to serious illness and end-of-life.

This web presence should be independent of any current health-related institution and should have a community feel. For example, although WAHA has already been funded by RiverStyx to research a Whatcom Healthcare Website and to develop operational and business plans, we see this website as having a broader focus. Links to the WAHA website and PeaceHealth's Palliative Care services should be on this website, but it should be managed by a community based group. See Appendix A for other agencies already serving both end-of-life and palliative care needs that might also be networked.

Other social media outlets, such as Facebook, should also be used to help network the multiple agencies and community members who are already providing support for those facing long-term illness and end-of-life.

The *Standing Committee on Community Cultural Change* (see above) proposes to launch this project under the auspices of the Palliative Care Initiative using a Kickstarter Campaign for initial funding and using the current Death Café website as the platform to begin this development. If a community center is developed (see below), this website could be eventually be connected with that site/services.

Healthcare Navigator/Concierge: The need for more help in accessing and navigating the healthcare and palliative care systems (a kind of "concierge function") when facing long-term serious illness or death surfaced in multiple conversations. We recommend that initiatives related to developing and funding the functions of a "healthcare advocate" or "navigator" role be nurtured. In addition, navigators could also help provide:

- More information about what could happen to the body after death. There are more options than cremation or burial.
 - MedCure (through Moles). Contribute your body to science after you die
 - Organ donation
 - Green burial
 - Death Midwifery –Vigils
- Help for the carepartner and/or family in navigating the rest of the "after death" maze is also needed. There is significant work (and confusion) about probate, closing up houses, shutting down phones, getting off mailing lists, off of Facebook, etc. Becoming the best place to die also means better help and services for those who are still alive and grieving.

Although no one agency or initiative is currently providing a single point of entry for this kind of coordination, there are several existing agencies that could/can help. Groups like the Alzheimer's Society are good models, and there are supporting services, such as the Northwest Regional Council (NWRC), Senior Information and Assistance service, faith communities, the health navigator class at Whatcom Community College, and multiple local businesses that provide some of these needed services. Life Passages in Eugene is a model for some elements of this idea.

How to pay for these services continues to be a question, and solving that gap will be part of the puzzle. The traditional payers have been reluctant to pay for this kind of “case management” function. Perhaps a grant might be available through the NWRC to develop some type of program. A presentation on long term planning which included EOL issues might “sell.”

Community Resource Center/Coffeehouse: As noted previously, we strongly support a community hub that could help link the multiple resources and services that currently exist in our community and could launch other collaborative initiatives.

This Resource Center should be welcoming to all, no matter what age or health status, and be an access point for clinical and complementary care and other community resources and services. This Center might sponsor a kind of “Farewell Wagon” service (like the “Welcome Wagon”). If the right space were developed, this physical site and its staff could oversee the web presence and sponsor some of the artistic and informational events which would foster robust community discussions and educational events about thriving during serious illness and end-of-life.

Annual Educational Series: We suggest establishing an ongoing series of events that consistently bring the topics of Palliative Care and End-of-life to the attention of the community – perhaps October as “Death/Dying Awareness” month in conjunction with the Day of the Dead and the Art of Death and/or April in conjunction with National Healthcare Decision Day. The seminars offered by the Southern Oregon End-of-Life Coalition in the Rogue River Valley might be a model. This kind of series would be a good opportunity for multiple community and healthcare organizations to collaborate in around end-of-life issues. This recommendation should be forwarded to the Palliative Care Initiative.

“Other Portals” Training: We recognize that there are many service providers in the community who have significant contact with those with serious illness or who are terminally ill. They may be the first to notice that a patient is entering a phase where they need more support. Providing community based training for them on how to access palliative care resources or how to initiate conversations about end-of-life choice would be effective: for example, beauticians and barbers, cab drivers, postal workers, home cleaners, library staff, meter readers, bank tellers, financial officers, and pharmacists. Spokane’s Gatekeeper program might provide a model (<http://www.ncbi.nlm.nih.gov/pubmed/9257625>). We also recommend that some of these trainings be mounted in connection with the annual Art of Death event in Whatcom County.

Be in the Presence of Death: In order to restore and regain the traditional knowledge of how to be in the presence of death, we recommend encouraging the community to take advantage of the opportunities in our lives to be in the presence of those who are dying. Viewing dying as a shared experience for families and friend networks helps reduce the fear of talking about death. More formal mentoring programs and classes such as Death Doula, Hospice training, or classes are also available.

Recommendation: Activation

Providing carepartners with more information and choices about end-of-life will result in a more activated community – one that demands a reciprocal and respectful relationship between carepartners and health professionals and provides choices for supporting those with serious illness or facing the end-of-life.

Recommendation #6

Promote activities that will support the development of a more activated community. Some opportunities include:

“Plan Ahead” Seminars: Developing end-of-life plans just like most new parents develop birth plans. We see these seminars linked to, but broader than, the WAHA Advanced Care Planning initiative.

Similar “Plan Ahead” seminars in San Diego which might be a model can be found at the Community Classes & Events Tab (<http://www.csupalliativecare.org/palliativecommunity/index.html>). *“The CSU Institute for Palliative Care is dedicated to raising public awareness of palliative care in San Diego, California and beyond. Our goal is to help seriously or chronically ill individuals, their families and friends recognize palliative care as a means to alleviate suffering and maximize their quality of life.”*

- A cadre of trained community volunteers could lead these seminars/discussions (See Appendix B for a list of proposed sites). There would need to be ongoing training and support for these volunteers.
- Janie Pemble’s Friendly Visitor’s program to decrease social isolation, directed through a NW Regional Council grant, might be one model. See “In the Company of their Peers.”
- Shanti, a community volunteer organization in San Francisco, provides a model (<http://www.shanti.org>).
- The Whatcom Volunteer Center could also be a resource.
- We could incentivize the volunteer model by setting up a volunteer network as part of a cooperative to bank hours against one’s own care needs at end-of-life.

The new "services" do not necessarily need to be done by volunteers. Volunteers are the best for some things, but some of these services are the kind of work that could support a business.

Corporate Education: Palliative Care and “Plan Ahead” Seminars could be developed in collaboration with local businesses as an employment “perq.” One model for Corporate Education can be seen at <http://www.csupalliativecare.org/CorporateEducation.html> which

describes customized programs in palliative care for profit-making and nonprofit organizations.

Clinic Challenge/Community Palliative Care “Seal of Commendation”: Mount a “Clinic Challenge” among the different clinics, nursing homes, and other care facilities for those working with the seriously ill or those facing end-of-life. This challenge could document the number of ACP documents filed and the level of staff training related to palliative care (as identified by the Clinical Training DTF). Either the Palliative Care Initiative or WAHA could issue a “Seal of Commendation.”

For the ACP document part of the challenges, WAHA volunteers could staff each clinic to provide individual planning support for a three week period, rotating among clinics. This initiative could start with naturopathic clinics and or massage therapists who might already be more inclined. Staff should complete their own ACP documents first. This could encourage the community to ask their practitioners about engagement in ACP or other end-of-life training activities.

Marketing: In order to create an activated community that seeks to engage in any of these activities, we acknowledge that marketing will be required to promote these initiatives. We recommend that this report and/or selections from these recommendations be used to mount a series of public service announcements in the local media to promote these initiatives. For example, a special issue of the Bellingham Herald’s PrimeTime Magazine (Editor: Dean Kahn) or Cascadia Weekly (Editor: Tim Johnson), a radio segment on KMRE, selecting specific topics for table topics at the Death Café, or hosting conversations at local Senior Centers.

We want to help the average person, before they are even patients, to become more literate about their health and engaged in self-advocacy and agency in order to change the “I’m not responsible for my own health...” attitude. It takes money, but when ideas are conveyed in succinct, pithy, crisp words, we believe the money will come. Some suggestions include:

- A Back of the Bus Billboard campaign: This initiative was suggested at the recent Palliative Care conference. Placards for buses would have some pithy comment and a resource number to call to get more information. Perhaps a community contest could be held to choose the campaign slogans. For example:

Death Rate 100%,
Talk about it and plan now!
800-#

Being Human is Fatal
What is your plan?
800-#

Have you had the
conversation?
Who have you talked to?

Death- “Have it Your Way”
Do you have a plan?
Talk About it?

800-#/Scan code

Some other language that might resonate:

- “If you don’t talk with your kids, it will be much harder”
 - “Legacy you want to leave your children”
 - Framed as “this is the loving thing to do” or “Responsibility for family”
 - “Birth plans...death plan...”
-
- Local Museum Exhibit: Encourage an exhibit and a social event.
 - Bookstore Display: Host author events for books regarding end-of-life care.
 - Engage the Chamber of Commerce: Bellingham has become a popular place for retirees. All systems of support are in place to spread the word that Bellingham and Whatcom County is a community that will support the best palliative care for those with chronic or serious illness or facing the end-of-life. We could play on the “City of Subdued Excitement” theme. One measurable might be to track if the Chamber of Commerce, Sustainable Connections and realtors start talking up this resource in our community. Does the fact that Whatcom County is "the best place to die" become part of the "pitch" for Bellingham and the county along with Greenways, mountains, parks and no local income tax?
 - Get Bellingham Wholly Healthy Initiative: Holistic Health care means care for the whole life, which includes death, and slightly beyond. We envision a model that supports the whole life cycle: Pregnancy-childbirth-early childhood education-high school-higher education-career-volunteer ops-family living-infirm-death-pregnancy (Use circle as image).
 - Other Places to Market: Hang posters on relevant community initiatives in Co-op food stores, WECU and other places where people relax and have fun such as bookstores, eateries and pubs. We need a catch phrase (something like “Transforming Health Care” or “Have you had the conversation?”) plastered all over the County.
 - Run/Walk: We could sponsor a run or kayak trip to increase awareness.
 - Memorial Tributes: Park Benches and other memorials could be developed as a funding source.

Measuring Culture Change

We developed multiple ideas about ways to measure culture change, both locally and nationally. Some ideas include:

Local

- Library trends in EOL material. Books checked out of the city and county libraries related to death/dying/advance care planning
- Book sales in EOL material (data from bookstores)
- Number of ACP directives scanned at PHSJMC, our county's designated repository for Advance Directives
- Number of EOL events in last two years. Attendance at these events:
 - Death Café
 - Green Burial
 - Palliative Care Initiative community conversations & conferences
 - Number of ACP workshops and attendees
 - Moving the Bones: Lively songs about Death concert
 - Classes offered at WWU, Compassion and Choices, and other sites
- Threshold Choir, Women with Wings – number of patients and volunteers
- Groups who respond to the invitation to join the committees
- "The creation of new businesses" that work in this area- not new departments in already existing businesses like FCN and PeaceHealth, but others in community settings
- Number of EOLC Facilitators at WAHA
- Hospice Stats
 - Volunteers at Hospice
 - Patients through hospice system
- Numbers of community members engaging Death Midwifery
- Internet browser search statistics
- Law offices – End-of-life planning
- Death is a growth industry – measuring the new businesses is a metric

National

- Films released and numbers
- Books released
- Senior assistance programs
- Purchases of long term disability insurance
- NHFA enrollment numbers
- FCA enrollment numbers
- People's choice memorial
- YouTube videos
- Art exhibitions
- Green Burial council
- Yale recognizing Death Midwifery and training
- Number of copies of END-OF-LIFE – Helping with Comfort and Care (National Institute on Aging & National Institute of Health) that are distributed in the community

APPENDICES

Appendix A: Community Assets

GRASSROOTS AND COMMUNITY ASSETS AND STRENGTHS

There are many grassroots initiatives and assets in our community that support our goals. While there are likely more that are not mentioned, the following is a list of the ones we know about.

Death Café: Has fostered robust conversations outside of the medical settings about death and end-of-life. They are adding a companion site in Ferndale this summer. The Death Café webpage (deathandcoffee.com) provides links to resources/calendar of events, conferences, books, movies, and articles.

Art of Death: Art and End-of-life Choices Exhibition: October 5-11, 2014 (and annually) *“The goal of The Art of Death Exhibit is to bring a broader awareness to the choices surrounding and supporting death.”*

A Sacred Passing: Death Midwifery Service.

Walking the Path of the Elder Discussion and Reflection Group: Contact Heidi Ruth (heidiruthr@gmail.com) (See Appendix B).

Bellingham Threshold Singers & Women With Wings: These two groups bring women’s song circles to those who are ill, isolated or suffering and to individuals who are struggling to live or struggling to die; to bring ease and peace at life’s thresholds.

Silver Winds: Therapeutic Music Service. Randi Sulkin, Flutist. www.silver-winds.com

INSTITUTIONAL ASSETS AND STRENGTHS

See also “Senior Resources” in July 2014 Herald – Prime Time for a more robust list.

Palliative and End-of-life Care: General

Palliative Care Initiative: Collaboration among Western Washington University, WAHA, Palliative Care at Peace Health, and Whatcom Hospice. Sponsoring professional development and community conversations. <http://www.wvu.edu/ee/bsn/palliative.shtml>

Western Washington University: Offers classes related to aging, death, and dying in the BSN program, Sociology, Political Science, Anthropology, Human Services, and Fairhaven College.

Palliative Care/PeaceHealth: Bree Johnston, MD, Meg Jacobson, MD and others are working on improving clinician skills and programs. <http://www.peacehealth.org/st-joseph/services/palliative-care/Pages/default.aspx>

Whatcom Hospice: Provides services both in home and in the Hospice House for people who have a prognosis of six months or less to live. <http://www.hospicehelp.org>

Whatcom Alliance for Healthcare Advancement: Whatcom End-of-Life Community Collaboration and the End-of-life Choices: Advanced Care Planning Initiative.
<http://whatcomalliance.org>

Faith Community Nurses: Jeanne Brotherton, RN, BSN, Med is the FCN Education Coordinator and Lead Faculty.
http://www.healthministriesnetwork.net/Providers/Nurses/FCN_Basic_Course.htm

Skilled Nursing Facility (SNF) Council: A collaboration of the Whatcom County SNFs. For more information contact Tonja Myers (tmyers@avamere.com).

Evergreen Wellness Advocates: EWA provides community outreach, education, prevention outreach, counseling and testing, mental health counseling, clinical support groups, emergency financial assistance, food assistance, housing assistance, peer advocacy, volunteer services, and psychosocial support for persons with chronic illness and their families.

Compassion and Choices: *“Compassion & Choices helps people plan for and achieve a good death. We work to change attitudes, practices and policies so that everyone can access the information and options they need to have more control and comfort at the end of life”* (<https://www.compassionandchoices.org>). Their “Good to Go Resource Guide” (<https://www.compassionandchoices.org/userfiles/Good-To-Go-Resource-Guide.pdf>) and their “Good to Go Toolkit” (<https://www.compassionandchoices.org/userfiles/Good-to-Go-Toolkit.pdf>) are useful advance care planning tools that include advice for dementia patients. Compassion and Choices of Washington *“assists people with all aspects of end-of-life decision making as they face incurable and terminal illness.”*
<http://compassionwa.org>

Transportation

Northwest Regional Council: Non-ambulance transportation for people eligible for Medicaid with no other means of transportation to medical services. 360-676-6749, nwrwa.org

Whatcom Transportation Authority: Specialized transportation program and safety net service. 360-733-1144, ridewta.com

In Home Services

Apria Healthcare: Home infusion, respiratory therapy, and medical equipment sales, service and supplies. 360-738-8300, apria.com

Caregiver Network: Housekeeping, meal prep, and full care. 360-724-4456, caregiver-network.com

Catholic Community Services: Housekeeping, personal care, transfers, supervision, live-in care, transportation to medical appointments, and respite. 360-738-6163, ccsww.org

Circle of Life Caregiver Cooperative: Worker-owned business provides home and personal care for elders, disabled persons. Cooking, cleaning, transportation, medication

reminders, bathing, laundry, respite, and companionship. 360-647-1537, circleoflifecoop.com

Department of Social and Health Services: Variety of services for aging and people with disabilities. 360-756-5750, dshs.wa.gov

Home Attendant Care: Personal hygiene, transfers, transportation, housekeeping, dementia care, and safety supervision. 360-734-3849, homeattendantcare.com

Infusion Solutions: Locally-owned home infusion pharmacy offers personalized infusion care in Whatcom, Island, Skagit, Snohomish counties. 360-933-4892, infusionsolutionsinc.com

Meals on Wheels: Delivers frozen meals weekly. 360-733-4030, wcco.org/mow.htm

Right at Home: Light housekeeping, meals, laundry, errands, and non-medical personal hygiene care. 360-392-3934, rahnwwa.com

Signature Home Health: Disease management and nutrition, wound management, physical therapy, occupational therapy, and speech therapy. 360-671-5872, 4signatureservice.com

Visiting Angels Living Assistance Services: Meal preparation, light household chores, personal care, dementia care, post-operative and respite care. 360-671-8388, visitingangelswa.com

Eden Home Health: Skilled nursing, wound care, nutrition support, home infusion, perinatal/postpartum, respiratory services, oxygen, and physical, occupational, and speech therapy. 360-733-7799.

Inslee, Maxwell & Associates: Provide limited and full guardianship for estate or elder care management and/or case management for individuals with disabilities.

COMMUNITY ASSETS NOT YET FULLY UTILIZED

These agencies and community members could be included in plans to foster normalized conversations about serious illness, end-of-life care and death, or provide support outside of medical interventions.

Interfaith Coalition: This coalition of 44 member congregations has a mission of working for healthcare and homes for all. End-of-life care could be part of this mission.

Walking the Path of the Elder: Discussion and Reflection Group. Contact: Dr. Heidi Ruth (Riggenbach) heidiruthrigg@gmail.com

“This group inquires and reflects on our aging experiences, to sort out the truth from the myths regarding aging, and to explore more deeply the unexamined issues surrounding aging and dying. They propose over the longer term a series of community panel discussions, seminars, and in-home ‘circles’ and conversation groups. It is our hope that we can incorporate ritual and ceremony that honors the transition into elder-hood.”

Elder Service Providers (ESP): About 85 representatives from a broad array of programs and supportive services for elders who meet monthly and present an annual caregiver conference. Debbie Gann from Home Attendant Care would have more information.

Adult Day Health program: ADH program is a major supportive service for families who are trying to maintain a loved one at home. Any strong palliative program that serves people with long-term chronic illnesses (or disabilities) needs to have both in-home and supportive community services. Having an ADH program can be a lifesaver for some carepartners. ADH and respite care can make a difference in allowing people to remain in their homes.

Community Organizing Group for Health (COGH): This group could be invited to focus on some questions about end-of-life/serious illness.

Home Health Care Providers: Both professional and family carepartners.

Neighborhood and Community Development Organizations

Whatcom Village: This movement could be a possible partner in developing neighborhood conversations, replicating Boston's movement.
http://www.thenorthernlight.com/news/article.exm/2014-02-12_it_takes_a_village_to_stay_connected_as_we_age

Bellingham Co-Housing

Neighborhood Associations

Transition Whatcom: "A community networking site for those interested in helping us achieve our vision of resilient and more self-reliant communities throughout Whatcom County." Contact: Cindy Landreth. <http://transitionwhatcom.ning.com>

Cascadia: "Cascadia is a lens to reframe and break down larger and intangible issues onto a local level where change is happening on a daily basis - and a scale where connections make sense. We want to transform our society so that each person can be their own agent of change around what they feel is important."
<http://cascadianow.org>

Funeral homes: Funeral homes already have some services and should be included in end-of-life planning.

Lawyers: Specifically those in our community who work with end-of-life planning

Support Groups for chronic illness.

Tribal communities

Complementary Care Associations: Including American Massage Therapy Association (Whole care).

Faith Communities: Some named by our committee in particular:

Congregation Beth Israel: Rabbi Josh Samuels

Christ the King: Lay Minister- Wendy Powell (wendyp@ctkbellingham.com) Christ Lutheran Ferndale Pastor--Jana Schofield

Center for Spiritual Living: Dr. Andrea Asebedo

Group of Progressive Clergy

Jewish Renewal Shabbat Service: Marti Leviel

Interfaith Minister and Spiritual Guidance: Jillian Froebe

United Church of Ferndale: Pastor Bobbi Virta

Stephen Ministry: Lay Care Giving program, including Friendly Visitors and Peer Counselors

School counselors: To help support intergenerational conversations about serious illness and end-of-life.

Rites of Passage Groups: These include Rooted Emerging. *“Our mission is to create the elements of a healthy culture by joyfully coming together to support one another during times of transition.”* <http://www.rootedemerging.org/mission/> Or Earthways Nature School. Contact Cody Beebe <https://www.facebook.com/pages/Earthways-Nature-School/247694278607309>

Bellingham Birth Center: Dealing with the issues of abortion, miscarriage or stillbirth, but also connecting with the whole continuum of care from birth to death. <http://bellingshambirthcenter.com>

Whatcom Dispute Resolution Center: To help negotiate when family members can't agree on end-of-life issues.

Appendix B: Possible Sites for Plan Ahead Seminars

- Support groups (Diabetes, Alzheimer's, Adult Day Care, PeaceHealth long term care)
- Interfaith
- Libraries
- YWCA and other Athletic Clubs as part of good health
- Helmet campaign
- "Can You Talk About It?"
- Neighborhood groups
- Places where people relax and have fun, e.g. bookstores, eateries and pubs
- Hospice/Hospital/Grief groups: Two years post hospice (four months) - Bereavement groups. Create your death plan. Involve the funeral industry
 - We want to make sure that your death is planned the way you want it to go
 - Expand the dealing with grief to a planning for your own death
 - PeaceHealth's list of those who are dis-satisfied with the care their own loved one. Talk with Melissa Morrison, Director of Patient Experience
- Faith communities
- In nursing homes for both residents and families

Appendix C: Additional Resources

- End-of-life: Helping with Comfort and Care: These booklets are available from the National Institute on Aging/NIH & UDHHS and provide a good summary. They could be included as handouts to groups and maybe available at doctor's offices. We might be able to use them as a statistical item - count the number distributed in the community.
- Hard Choices for Loving People:
http://www.hnehealth.nsw.gov.au/___data/assets/pdf_file/0016/54250/HardChoices.pdf
- "Ag-ing to Sage-ing": Carol Scott Kassner out of Seattle University. Gifting the world as we age. Exercise of dying and being the director of one's own death. Playful and non-threatening. Sage-ing.org
- My Gift of Grace: Conversation game online about living and dying well.
<http://mygiftofgrace.com>
- Prepare for your Care: Template for a discussion.
<https://www.prepareforyourcare.org>
- Health Leads: *"Health Leads believes that a different kind of healthcare system is possible for America – one that addresses all patients' basic resource needs as a standard part of quality care. We believe that one day, all healthcare providers will be able to prescribe solutions that improve health, not just manage disease."*
<https://healthleadsusa.org/>
- Our TreeHouse: Provides a safe environment where children and their families grieving a death can share their experiences and help them heal. <http://www.our-treehouse.org/cgi-bin/htmllos/content.html?pgname=home>

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.

If you have questions or comments regarding this report, please contact Mary Ann Percy at mpercy@hinet.org or 360-788-6526.



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