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White Paper: Building a Continuum of End of Life Care in Whatcom County: Expand Advance Care Planning Efforts

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Overview

Advance care planning is the process of discussing and recording patient preferences concerning goals of care for patients who may lose capacity or communication ability in the future. In 2012, after consideration of several options, WAHA adopted the Respecting Choices® model of Advance Care planning, and began the WAHA End of Life Choices Initiative (EOLC). Key strengths of the current EOLC practice include community engagement, quality resource materials, trained and certified facilitators, increased community and clinical awareness of advance care planning and of our program. Key gaps in current EOLC practice include lack of integration with clinical community and other professionals, data retrieval system, sustainable financing, or outreach to diverse population subsets.

The WAHA End of Life Community Collaboration Steering Committee seeks to have advance directives on file at PeaceHealth St. Joseph Medical Center for 60% of Whatcom residents ages 65 and older by 2019, the “60 x 65 Campaign.” In order to achieve this we will focus on Caregivers (Clinicians), Community, and Infrastructure. In other words, we will secure backing and commitment from clinical leadership, gain support and adoption through culture-changing activities, and establish institutional procedures and protocols to achieve the “60 x 65 Campaign” vision.

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Goal

The goal for the WAHA End of Life Choices initiative is that 60% of Whatcom residents ages 65 and over will have Advance Directives completed and on file at PeaceHealth St. Joseph Medical Center (PHSJMC) by the end of 2019.

Work Group

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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

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 the context of their values and beliefs (Respecting Choices®, 2011). When this process is done well, it has the power to produce a written plan—an Advance Directive (AD)—that accurately represents the individual's preferences and thoroughly prepares others to make healthcare decisions consistent with these preferences. When this process is not done well, it produces written plans that are ambiguous, which leaves loved ones unprepared to make decisions on behalf of the patient. When it is not done at all, medical personnel and family members are left guessing about the patient's wishes, often resulting in unnecessary stress and strife.

Historically advance directives were often completed by attorneys and put away in filing cabinets in legal offices or at home. Little time or thought was given for reflection on one's goals, values, and beliefs for future healthcare decisions, and rarely was there a conversation with loved ones or medical providers about one's preferences and the values that informed them. Not surprisingly, this resulted in advance directives being inaccessible, ambiguous, and/or not honored.

In recent years, a number of approaches have been developed to encourage advance care planning conversations and/or to produce an actionable document to record one's wishes for care.

The Conversation Project, begun in 2010, is dedicated to helping people talk about their wishes for end-of-life care. Its focus is not specifically on completing an advance directive, but rather on sharing the way we want to live at the end of our lives, and communicating about the kind of care we do and do not want for ourselves. While it is helpful in some respects, The Conversation Project lacks an organizational implementation plan and a process for completing and accessibly storing advance directives.

Five Wishes, introduced in 1997, is an advance directive document written in everyday language and meeting legal requirements in 42 states; it helps start and structure important conversations about care in times of serious illness. Its strength is in the area of values clarification for those completing it. However, it is a stand-alone document and like The Conversation Project, lacks an organizational implementation plan.

The Respecting Choices® Advance Care Planning model grew out of the federal Patient Self-Determination Act of 1991, which guarantees patients the right to accept or refuse treatment and to complete advance medical directives. It was developed by leaders of the two major health organizations in LaCrosse, Wisconsin, whose goal was to create a comprehensive approach to ACP that included community engagement, ACP facilitator skills training, systems that honor patient preferences, and quality improvement. Numerous studies over the years have documented the success of this program in increasing the raw numbers of AD's on file, increasing adherence to patients' treatment preferences while making end of life decisions, increasing patient and family satisfaction with end of life care, and decreasing costs of care (Hammes & Rooney, 1998; Hammes, Rooney & Gundrum, 2010). Moreover, these outcomes are consistent across racial and

ethnic lines (Pecanac et al., 2014). Respecting Choices® is a person-centered and staged approach, addressing ACP needs based on an individual's health status, readiness to learn, and venue of care. It is recognized as best practice and has been replicated across the U.S. and abroad.

In 2012, after reviewing available data about ACP models, Dr. Meg Jacobson and Chris Phillips approached WAHA about sponsoring Respecting Choices® in Whatcom County. The WAHA Board agreed with this suggestion and secured seed funding from the RiverStyx Foundation to launch the WAHA End of Life Choices initiative.

Strengths of WAHA End of Life Choices Initiative

In the past two years, our focus has been community engagement and education using the Respecting Choices® advance care planning process and model. In that time:

- Local culture has moved toward a greater understanding of Advance Care Planning and Advance Directives
- Approximately 900 people have participated in WAHA workshops and have engaged in other meaningful discussions about end of life care
- Over 25 volunteer ACP facilitators have been trained; 22 are currently active
- WAHA has produced quality resource materials, including an advance directive and supportive communication tools
- There has been rising demand from individuals for WAHA ACP materials, information, and facilitated sessions
- Throughout our community, there has been a groundswell of programs, activities and interest in the end of life field including:
    - Whatcom Hospice
    - The Palliative Care Initiative at Western Washington University
    - Death Café
    - Inpatient Palliative Care at PHSJMC
    - Outpatient palliative care in the cancer clinics
    - WAHA End of Life Community Collaboration and its Community Culture Task Force
- The clinical community, including primary care clinics, Skilled Nursing Facilities (SNFs), the Chief Medical Officer, and others at PeaceHealth St. Joseph Medical Center, are increasingly recognizing the value of ACP and WAHA End of Life Choices, as well as the importance of participating in a shared process
- The process of incorporating ACP at PHSJMC has begun, and all Case Managers are now required to receive POLST training

- Processes have already been implemented to increase availability of AD's at time of need:
    - There is community-wide agreement to use PHSJMC as the central repository for Advance Directives (or Health Care Directives as they are known at PHSJMC)
    - They are easily accessible on the electronic medical record at PHSJMC and in the Family Care Network system
    - There is an established scanning-in procedure, an awareness of how to access the AD, and clear instructions on what to do with an AD at PHSJMC

- Throughout Washington, several communities are now planning implementation of the Respecting Choices® model for Advance Care Planning. Additionally, two state-wide initiatives, Honoring Choices Pacific Northwest and The Bree Collaborative are working toward statewide programs involving advance care planning to improve end of life care. These include a statewide ACP program, a statewide registry to provide access to ADs, and engaging the state legislature to incentivize providers to conduct ACP conversations. Momentum in this area is clearly building.

Gaps of WAHA End of Life Choices Initiative

Though significant progress has been made in Whatcom County in the past two years toward building awareness of the need for advance care planning and in the numbers of individuals participating in that process, much more remains to be accomplished:

- Need for awareness and integration of WAHA End of Life Choices and advance care planning process with local clinical community

- Need for wider awareness and integration of WAHA End of Life Choices and advance care planning process throughout community

- Need to be able to track the number of people with Advance Directives filed at PHSJMC, the central repository for AD's in our county

- Need for on-going and dedicated financing to ensure long-term sustainability and integration within entire community

- Need to ensure long-term practical sustainability of this program, and availability of sufficient numbers of Facilitators to meet growing community needs for advance care planning sessions

- Need to ensure that Advance Directives are accessible when they are needed, and all physicians incorporate ADs into their treatment orders

Recommendation: The 60 x 65 Campaign

The WAHA End of Life Choices Executive Committee has named this vision "The 60 x 65 Campaign," and recommends directing resources toward three large areas of focus: Caregivers (i.e. Clinicians), the larger Community, and Infrastructure. Within each area of focus, strategies will be adopted, and activities to support these strategies will be implemented.

Caregivers
Clinical leaders in each setting (i.e. Family Care Network, PHMG, Interfaith Community Health Center, PHSJMC, Nursing Homes and Assisted Living Facilities, etc.) will support and make a commitment to the End of Life Choices initiative and our 60 x 65 Campaign as evidenced by:

- Adoption of the WAHA advance directive throughout their systems
- Training of health professionals to initiate ACP discussions in order to complete the ACP process with their patients themselves, or to refer their patients for sessions with WAHA trained facilitators
- Performing case finding by determining who does and who does not have a current advance directive, and making certain that each patient admitted to PHSJMC has an advance directive on file
- Informing and training all staff (e.g., physicians, nurses, medical assistants, social workers, and chaplains) about their ACP responsibilities during orientation
- Engagement with Case Managers, Care Transitions, and other social service programs so that they may refer their clients for advance care planning sessions and AD completion.

Community
We will continue and expand the existing community emphasis on advance care planning, increasing awareness in both the general community and in key groups or constituencies.

This will involve linking the work of the EOL Steering Committee with the outreach and marketing activities of WAHA's End of Life Choices. The reports from several of the Steering Committee Task Forces will include recommendations and opportunities to promote advance care planning and the EOLC initiative:

- Community Culture Task Force: ideas for engaging community members with and education about advance care planning
- Palliative Care Task Force: including ACP conversations with community-based palliative care patients

- Clinician Training Task Force: training clinicians in both how to have advance care planning conversations with their patients as well as familiarity with indicators for referral to our program

We need to engage our community in culture-changing activities to support advance care planning and adoption of the 60 x 65 Campaign. Activities toward this end include:

- Making our End of Life Choices materials more universally accessible, with translations into Spanish and Russian

- Increasing community awareness of the necessity of properly filing advance directives at PHSJMC so they will be accessible in times of need

- Increase both the number and the reach of EOLC community workshops and trained facilitators, as well as provide additional resources and support for facilitators such as in-services

We need to identify and target key lever groups, such as elder attorneys and financial planners, faith, tribal, Hispanic and other cultural and ethnic communities to adopt the 60 x 65 Campaign, and to:

- Establish referral mechanisms for ACP sessions with these groups

- Create a plan to distribute all of our EOLC written materials to them

- Encourage relevant groups to establish links on their website to our EOLC website, as well as the Prepare For Your Care advance care planning website, which accessible to individuals with lower literacy levels

Additional outreach strategies include:

- Utilizing social media and other avenues to reach younger adults to encourage them to complete their AD and engage them in the conversation needed with older loved ones

- Translating our AD document and supporting materials into Spanish and Russian and perhaps other locally spoken languages

- Developing a speaker series

- Continuing to work with community partners to expose individuals to consistent, understandable, and repetitive messages about the importance of ACP for all adults

- Incorporating ACP into employee wellness programs with local employers

In order to ensure the long-term sustainability of this program and availability of a sufficient number of Facilitators to meet growing community needs for advance care planning sessions, it is essential to train and certify a local Respecting Choices® Instructor who could offer additional Facilitator trainings.

Infrastructure
To achieve the above goals, certain shared infrastructure will need to be in place.

Existing infrastructure needs to be fortified and new infrastructure created to support the 60 x 65 campaign, ensuring a set of protocols and procedures exist at the PHSJMC and in the community such that:

- Each patient admitted to PHSJMC either has a healthcare directive, or follows an established process for discussion and completion of advance directive
- Procedures and protocols, "an improved trigger for action," need to be in place at PHSJMC to make Health Care Directives available to treatment staff
- All physicians incorporate ADs into their treatment orders
- Data retrieval mechanism exists to track the number of ADs on file at PHSJMC (in process). Establishment of baseline, and process for ongoing measurements and tracking needed
- Storage, retrieval, and transfer processes for ADs exist within and between healthcare settings
- Create links to the WAHA End of Life Choices website on all healthcare providers' websites to provide visibility and easy access to ACP materials
- Establish relationships with and implement use of Clarity Health and other existing referral tools to simplify and add credibility and tracking ability to the referral process for ACP client sessions
- Establish common language about advance care planning to increase understanding about the process and the document, and to reduce confusion

Sustainable funding must be in place to realize the expanded vision of the EOLC initiative:

- Secure ongoing and dedicated financing to ensure long-term sustainability of the EOLC program and integration within entire community
- Develop and promote co-branding opportunities with local corporations who may use our written materials and ACP service as an employee benefit
- Explore offering (for a fee) our professionally produced print resource materials for use in emerging advance care planning programs in other communities

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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