1 million friends and neighbors: Increasing Awareness of End-of-Life Options

End of Life Washington is embarking on an ambitious campaign to ensure that more of our friends and neighbors—up to one million more Washingtonians over the next three years—learn about their end-of-life options.

Continuing: Community and health care provider presentations on Death with Dignity (DWD), Voluntary Stopping Eating and Drinking (VSED), End of Life Planning and Advance Directives.

New this year: End of Life Ready presentation with Q&A—an introductory online workshop offered monthly through EOLWA and by request for groups.

And more... Coast to Coast conversations with End of Life Choices New York and educational programs on emerging options such as Psilocybin therapy and advocacy in public policy to improve end-of-life choices for those with Dementia.

Your help is needed! Do you know a community group or organization that would welcome an End of Life Washington presentation? Are you skilled in public speaking and interested in sharing end-of-life information with community groups? Please contact Community Outreach Manager, Rachel Haxtema rhaxtema@endoflifewa.org to share your ideas and find out about volunteering with this effort.

Her Legacy is my Learning
By Bob Free/Board of Directors, President

My older, smart, vibrant sister Janice was always a role model for me. She was the first in our family to attend college, and I followed her to UC Berkeley for my degree. She was a confirmed liberal, and she paved the way for me to follow in her footsteps. In 2016, Janice was formally diagnosed with Alzheimer’s disease—the diagnosis was heartbreaking.

Through my sister’s journey, my family and I had a close-up view into the unyielding anguish of the disease. Watching her become a different person and slowly relinquishing her quality of life, we felt helpless. She would not have wanted to live this way. The Death with Dignity law which we knew provided relief for hundreds—victims of cancer, heart attacks, and other terminal illnesses—could not help Janice. A victim of dementia or Alzheimer’s is not considered terminal, and in the late stage of the disease, the person no longer has the cognitive ability required to take advantage of the law. Therefore, most are forced to live out a difficult and lengthy decline.

This reality prompted much reflection as to what I could do to help Janice die with dignity and later myself if this was my own affliction. I began exploring and considering legal choices to pursue a dignified death if I or other loved ones were confronted with serious dementia—choices that would enable us to control how and when our life would end and avoid unnecessary suffering.

If diagnosed in the early stages of the disease, Janice could have chosen to Voluntarily Stop Eating and Drinking (VSED). This option is available to individuals who still have sufficient cognitive ability to choose between life and death, and enough fortitude to see the VSED process through. (continues on p. 6)
Letter from Executive Director Judy Kinney

I step into 2021 feeling very hopeful. My sense of hope isn’t naïve; I expect challenges as much as celebrations. I am fully aware that change and unknowns will continue to keep us nimble and humble.

My hope is based on evidence. My experience these past nine months have consistently shown me that you want End of Life Washington to be bold in our pursuit of quality end of life choices and that you are committed to helping things go well. You generously finance our efforts and speak up to improve our neighbors’ choices that lead to more peaceful last days.

I am hopeful because I see what we accomplish together. The community we’re building, from Richland to Bellingham, from Vancouver to Spokane, is thirty+ years strong and experienced. In 2020, we spoke with over 1,500 people by phone regarding their end-of-life choices, served over 530 clients, and stabilized our organization for future growth.

While we are national leaders in many regards, improving access is essential to fulfilling our mission to work with communities of color. Additionally, while we have the right to Death with Dignity, access is not guaranteed. Over 50% of the health systems in Washington restrict aid-in-dying services. I am hopeful that recent seed funding will support Virginia Mason health providers to become EOLWA volunteers, enabling them to provide continuous care for their patients seeking Death with Dignity medication.

I am hopeful that more Washingtonians will become aware of their end-of-life choices, including Voluntary Stopping Eating and Drinking (VSED) through expanded outreach, thanks to designated donations. This effort will include training and supporting a group of End of Life Washington Ambassadors to share resources more broadly.

You are key to our success. Let me know if you want to be a part of any of these initiatives or projects as a volunteer, a donor, or to connect us to people who can help advance these priorities. Like you, our goals this year are inspiring and bold.

In the spirit of community,

End of Life Washington

Your gifts protect choice: Thank you!

Your financial donations in 2020 helped us support:

- 1,500 people seeking phone support and referrals.
- 530 clients and their families accessing Death with Dignity services.
- Clients’ family members with Grief Support Groups.
- More people seeking Voluntary Stopping Eating and Drinking (VSED) support.
- Thousands of people seeking information about their end-of-life options.

Please include End of Life Washington in your will, trust, or other estate plans. Appreciated Stock, Qualified Charitable Distribution, Employer Matching and Employee Giving Programs are additional ways you can provide important support for our services, education, and advocacy.

Contact Judy at jkinney@endoflifewa.org or 206-274-9975 to explore giving options.

Filling an Unmet Need: Aftercare for Loved Ones

By Sally Thomas/Clinic Services Coordinator

With many excellent grief support groups offered by hospices and other agencies across the state, some may wonder why it is necessary to offer an aftercare group specifically for those grieving the loss of a loved one who used Washington State’s Death with Dignity law.

One of our first group members shared: “I attended a group through hospice and, while I did get something out of it, I didn’t mention death with dignity once during any of the sessions. I didn’t feel comforted because I didn’t know how others would react. It felt incomplete.”

Our groups bring together people who are exploring their grief and their “new normal,” but are also looking at it all through the unique lens of knowing that a choice was made to hasten death. Some people are 100% onboard with their loved one’s decision, others may have some lingering doubts. Perhaps giving the details about death with dignity led to some unkind judgement from someone, or maybe uncertainty about a feared reaction has meant withholding an important part of sharing the story.

It is essential to be able to talk about feelings of grief and loss, and the experience of a loved one’s passing without having to censor details due to fears of being unfairly judged. And it feels good to be in the company of others who have walked a similar walk with their loved one.

EOLWA is proud to offer a safe, inclusive space for people to come together and explore their feelings, not only about death and loss, but about choice. Groups are kept small (maximum 10) and open to grieving friends and family members whose loved ones chose to use Death with Dignity or VSED at least four months ago. Groups are held remotely via Zoom, thus reaching people across the state and those family members who live out of state. Contact facilitator, Sally Thomae, MSW, sthomas@endoflifewa.org for more information about upcoming grief support groups.

A Place to Die: Community Supported Dying

By Lashanna Williams/Volunteer Executive Director, A Sacred Passing

Not everyone has a safe and supportive space to exercise their choice to use Medical Aid in Dying (MAID) and Voluntary Stopping of Eating and Drinking (VSED). Some hospitals, hospice facilities, care homes, and living centers have rules that do not support a person exercising their legal right to choose. Some people do not have a home. Some people choose not to exercise these rights in their home, a home of a friend or family member, for a variety of reasons, none of which we question. We are creating a network of places to die; not medical facilities, but rooms in the homes of community members. All are welcome.

Do you have a room in your home that you would like to offer to a person to live out their dying through VSED and or MAID? We are looking to grow this network, across Washington. Please know that if you have space to share, it’s needed. The more houses we have, the easier it will be for individuals to access spaces without driving too far. Please Offer a Place, Seek a Place, or Volunteer to Support a Place at A Place to Die: www.asacredpassing.org/a-place-to-die or contact: aplaceatdie@asacredpassing.org 206-494-0023
There is no requirement for a prognosis of six months or less to live, and with hospice and palliative support, it can be a natural and peaceful way to die without suffering. The stories that have been shared by families of dementia patients who have made this choice are inspiring.

Unfortunately, Janice was not given the Alzheimer’s diagnosis until fairly late in her illness. Her neurologist said after my sister’s death that it was likely that she had Alzheimer’s when he first examined her in 2014, and he gave her medication to treat Alzheimer’s, but he told the family the diagnosis was “mild cognitive impairment,” probably to protect us. It is important to get a truthful diagnosis early on, even if the truth is painful, so that important decisions can be made with full knowledge.

With VSED not an option for late-stage Alzheimer’s, I explored what other choices people would have with advanced dementia. I learned that almost all patients living with dementia eventually reach an unresponsive stage when nourishment becomes unwanted and unimportant to them. However, many caretakers believe they have an absolute duty to provide nourishment, frequently cajoling people to eat and drink beyond the time a person is interested in doing so. People in a virtually comatose state can be kept alive this way for years, but this does not have to happen. Forced-feeding is tantamount to an assault on the body, and people living with dementia have the right to decline food and liquids. Learning this, I encouraged my niece, Janelle, who lived close by to her mother, to have a serious talk with the administrators at Janice’s memory facility.

Through her outreach to the administrators of Janice’s care, Janelle discovered unwanted nourishment was indeed the case. Janice’s appetite had diminished. Instead of allowing her to naturally reduce her food and water intake, the staff was repeatedly offering her food and patiently attempting to spoon-feed her when she could no longer feed herself. Following Janice’s Advance Directives, Health Care Power of Attorney, and POLST forms giving her decision-making power, Janelle instructed them not to spoon-feed her unless it was clear she wanted to eat. Janelle also instructed them to not treat certain illnesses if they did not cause pain, as was documented in her advance directive. With the help of hospice, she lived another five months; many months shorter than she might have lived in a vegetative state had unwanted nourishment continued.

We were fortunate that the memory facility and the hospice caretakers listened to Janelle and respected what she told them her mother wanted. However, I learned that many facilities are not always as cooperative, and instructions needed to be carefully formalized in writing. To allow for this, EOLWA Board members, Robb Miller, Terry Barnett, and I drafted in October 2017 a document which expresses a person’s decision about when to be offered food and fluids during late-stage dementia. It is called “Instructions for Oral Feeding and Drinking.” It is similar to an Advance Directive. Our document is the first of its kind in the nation, leading other organizations throughout the U.S. to follow and create similar dementia directives. These documents allow for a surrogate health care decision maker to ensure caregivers honor a person’s wishes-allowing them to naturally follow the body’s desire to reduce nourishment.

VSED and The Instructions for Oral Feeding and Drinking are legal and certainly morally acceptable ways of helping people die with dignity, if Alzheimer’s or other serious dementia strikes. Both can provide solace to people who contract these terrible diseases. My sister’s legacy is now my learning; learning which End of Life Washington shares broadly to let people know that death with dignity is possible even in these tragic circumstances.

Resources from End of Life Washington:
Dementia Directives and Instructions for Oral Feeding and Drinking: www.endoflifewa.org/dementia
More information about Voluntary Stopping Eating and Drinking: www.endoflifewa.org/vsed

The Washington State legislative session began on January 11, 2021. We are proud to be collaborating with Compassion and Choices to advance these priority bills that will impact end-of-life choices.

HB 1141: Increasing access to the Death with Dignity act.
Sponsors: Representatives Rude, Macri
This bill maintains the core safeguards of the original Death with Dignity Act approved by voters in 2008. HB 1141 would remove barriers that make it difficult for our terminally ill neighbors and family members to access the law in the final days and weeks of their life. EOLWA believes that these barriers should be removed to reduce unnecessary suffering.

HB1141 will remove barriers that are difficult for our terminally ill neighbors and loved ones to overcome in their final days and weeks of their life as they seek Death with Dignity.

• Reduce the waiting period from 15 days to 72 hours.
• Expand the definitions of attending and consulting providers to include Advanced Practice Registered Nurses and Physician Assistants.
• Expand the types of mental health providers eligible to assess patients for mental capability.
• Permit the prescription to be electronically sent to the pharmacy.
• Allow the medication to be delivered by mail.
• Protect providers working in restricted medical systems to be able to provide access to Death with Dignity outside the scope of the provider’s capacity as an employee.

Keep Our Care Act
With the increasing number of health care consolidations occurring in our state, the Keep Our Care Act, introduced by Senator Emily Randall, would hold health systems accountable when they consolidate and ensure all our communities have access to vital health care. This bill contains a number of provisions that will increase accountability and transparency, provide opportunities for public input, and ensure that there is continued access to end-of-life, reproductive and gender-affirming care, after a consolidation. The Keep Our Care Act will ensure that these health care systems listen to community voices and that these consolidations do not come at the expense of the affordability and availability of existing services.

SB 5185: Concerning health care decisions made by a designated person.
Sponsors: Senators Pedersen, Holy, and Wilson, C.
This bill expands the list of persons who may provide informed consent for health care decisions for an adult who is incapacitated or incompetent to include a person designated by the patient. The patient must make the designation while still retaining decision-making capacity and must communicate the designation by orally or personally informing a physician, nurse practitioner, or physician assistant. The provider must sign and enter the information into the patient’s health care record.

End of Life Washington Legislative Priorities 2021

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Comfortable being Uncomfortable
By Dawn Warnaca/Volunteer Client Adviser

Choice at the end of life and in dying was a comfortable topic of conversation in the house where I grew up.

Now I am embarking on a new avocation, helping people on their own end-of-life journeys and trying hard to find that same level of comfort.

My mother was an early Hemlock Society member and felt strongly that the kindness we offer to animals—in ending their suffering—ought to extend to our friends and family.

We lived in liberal, cutting-edge Eugene, OR (which helps explain to some of my Republican friends how I think). Mom collected signatures for the Death with Dignity initiative and as she aged, used the ensuing law as a reason to stay put even when moving closer to me might be easier on both of us.

Mom felt well prepared for her end of life as lung cancer, kidney disease, and congestive heart failure assailed her body. She had spoken to her doctors about her Death with Dignity wishes, and none resisted. In the end, she was able to get her life-ending medication, but her plans were derailed by a virulent bladder infection.

Over the next year I meandered along with my life and loss, often thinking about the gratitude I felt for the Oregon volunteer who helped Mom through her trial. And I wondered how someone could become “someone like that.”

Not long thereafter I wondered if perhaps I could become “someone like that.” In an effort to try, I Googled Death with Dignity in Washington and was transported to the End of Life Washington site. After a short contemplation, I filled out an application to be a short contemplation, I filled out an application to be a volunteer client advisor.

While I gained a good bit of knowledge from my education and learned much when I shadowed fellow volunteers as they met with clients and helped families with deaths, I remained humbled and uncomfortable.

Now, after months of online training, Zoom meetings, and educational opportunities, I have a couple of my own clients. That is not the end of the short-and-happily-ever-after story.

As an “apprentice,” I felt I had too little to share, and certainly no experience in how to talk about Death with Dignity to a complete stranger. I also felt an awkwardness in rooms redesigned to accommodate a hospital bed or being led down the hallway into the bowels of the home reconfigured to deal with a terminal disease.

What was it I was uncomfortable with? It took me a while to realize it was the evidence, not of life, but of the dying process I recognized. The triggers of my own experiences with my mother’s death included the carpet stains, the overwhelming amass of items without a dedicated space–pill bottles, the walker, the wheelchair, the hospital bed, the wounds on walls and furniture, the pile of used tissues–these were like foghorns sending warning blasts into my mind.

Chris Fruitaich, my mentor, did not seem to be affected in the same way I was. He shared the facts around DWD, the steps to take, and his experiences with kindness, sincerity, and gentle reality. He took clients and family through the process from first oral request to day-of-death focused on the person that mattered: The client.

Today I am more comfortable with the information, sharing it, and I feel as though I have learned that the external scars and markings of the death journey are similar and yet unique in each case.

I have appreciated having a mentor to talk to, as well as others within the EOLWA community. They have been there as I learned to navigate the EOLWA client database, and talk to physicians, families, and clients.

Now I can say that I am getting comfortable with discomfort and that has helped me to grow in confidence. I do not talk quite so fast as I did that first time. I do not worry about getting everything in perfect order. I use the End-of-Life checklist as a guide and reminder of the important points. As the COVID-19 virus has largely shut down the in-home visits, I feel the comfort and discomfort now comes with less color to my cheeks, and I am able to focus more on the needs of the client.

I have more to learn about my role with End of Life Washington, and sometimes worry I am not “someone like that.” My lesson thus far, is that getting comfortable being uncomfortable will give me the time to experience being a VCA in full.

We are actively seeking volunteers in Mason County and all parts of Eastern Washington, particularly Tri-Cities, Yakima, Wenatchee, and Spokane. If you or someone you know might be a good fit as a Volunteer Client Advisor with End of Life Washington, please visit: www.endolifewa.org/volunteer

“The most powerful thing we can give each other in the face of death is companionship and witness.”
Greta Christina, Comforting Thoughts About Death That Have Nothing to Do with God

Our Mission:
End of Life Washington upholds your right to the full range of end-of-life choices, including Death with Dignity, through advocacy, education, and support.

EQUITY & INCLUSION working group

Since the summer of 2020, the Equity and Inclusion Working Group has been helping EOLWA to ensure that our organization is genuinely inclusive, welcoming, and competent to serve all Washingtonians who are considering their end-of-life options.

Accomplishments:
• The vast majority of board members, staff, and volunteers participated in a three-day Racial Equity Training facilitated by Majors Leadership Group and Reverb DEI.

Next Steps:
• Further explore, as staff, Board of Directors, and volunteers, how our own racism contributes to organizational issues impacting Black, Indigenous, People of Color (BIPOC) folks’ end-of-life choices.

From there, we hope to begin to:
• Outline how we can integrate our learning into our work.
• Develop relationships with people and organizations serving Black, Indigenous, People of Color throughout Washington State.
• Increase representation and retention of Black, Indigenous, People of Color volunteers, board members, and staff.

If you would like to join or partner with us, please e-mail Judy at jkinney@endolifewa.org. We would love to work with you!