

VSED: Expanding Choice

By **Cassandra Sutherland**/Client Services Manager

First, it was small things, he would forget that I had called, he stopped being able to cook a meal and unable to follow a recipe. He lost his ability to read because he would forget what had just happened a few pages back. They were minor things, evidence of his mild dementia, but they escalated as his disease progressed. Our family had watched my Grandma's journey with dementia. After more than eight years she died in a facility knowing no one and feeling alone and confused. My father was adamant about not wanting his disease to progress to the end stages of dementia, and he wanted a choice. Many things can prevent you from accessing Washington State's Death with Dignity (DWD) legislation. Dementia diseases are an automatic disqualifier. In July 2017 my dad started preparing for VSED: goodbyes, last meals, and even getting his first, and last, pedicure because he didn't want to have "ugly feet for VSED." His death was an act of courage, and he died twelve days later, releasing himself from a devastating disease and having achieved his own death with dignity.

Voluntary Stopping Eating and Drinking (VSED) is a legal, ethical, and effective way to achieve a peaceful death. In a study of hospice nurses, they rated the quality of VSED deaths on a ten-point scale. VSED was given an 8/10 scoring equal, or better, than DWD in terms of suffering, pain, and peacefulness (Ganzini, 2003). VSED gives you time to say goodbye, to live fully, and to celebrate life.



I don't advocate for VSED lightly. My father's experience was imperfect and came with lots of learnings. We fumbled through the preparation and process and lacked proper support to manage his pain and symptoms. It wasn't easy, it wasn't always comfortable, but it was better than the alternatives. He got his wish: a peaceful death, at home, surrounded by family that he still remembered. We celebrated for two years prior to his death. (continues p. 6)

End of Life Washington Board of Directors

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End of Life

Washington Staff

Judy Kinney
Executive Director

Alex Gramps
Operations Manager

Cassandra Sutherland
Client Services Manager

Kathleen D'Amelio
Office Manager

Rachel Haxtema
Community Outreach Manager

Sally Thomae
Client Services Coordinator



2020 ANNUAL MEETING

OCTOBER 3, 2020
SATURDAY, 1-2:30 PM

OUR WAY FORWARD

ADVANCING THE VISION:
EXECUTIVE DIRECTOR JUDY KINNEY



MEETING TOGETHER ONLINE THIS YEAR
WWW.ENDOFLIFEWA.ORG/ANNUALMEETING

INTERACTIVE Q&A AND
CONVERSATION FOR CONNECTIONS

STATE AND NATIONAL NEXT STEPS WITH GUEST SPEAKERS:
STATE REPRESENTATIVE SKYLER RUDE,
16TH DISTRICT
GEORGE EIGHMEY JD, DEATH WITH DIGNITY
NATIONAL CENTER, BOARD PRESIDENT

MORE INFO ON SPEAKERS INSIDE P. 2

Letter from Executive Director Judy Kinney

As we step into Autumn, End of Life Washington (EOLWA) is a dynamic blend of ideas, experiences, and talents that our founders, and longtime and new staff, board members, Volunteer Client Advisors (VCAs), and supporters bring to our cause. There is so much happening. Our varying perspectives are our strength, guiding our responses to the opportunities and challenges that you'll read about below and throughout this newsletter.

I hope to see you at our Annual Meeting on October 3. While we won't be able to see each other in person, this year's meeting will be more accessible to folks around the state. More information is available in other parts of the newsletter and through email updates.



I want to make sure that you know about the HB 1608: Protecting Patient Care Act. This law enables providers to share needed death with dignity information, resources, and services with their patients without fear of repercussion from their employer. Please share this news widely and contact us if you need our brochures to share with the people you work with.

Information alone isn't enough. Currently, 30% of our clients lack the support of their physician and need help finding a physician to access the law. As more terminally ill people become aware of Death with Dignity, we will need to expand our pool of physicians. With the pending Virginia Mason-CHI Franciscan merger, 50% of all Washington state hospitals and clinics will be religiously affiliated. Death with Dignity may be the law, but the fight for access continues! Stay up to date through e-news, <https://bit.ly/EOLWAnews>

Let me close by saying thank you. Our services are free and we're responding to our changing world because individuals like you support us with personal donations. Your financial support is the fuel that keeps us running. Thank you for making a personally meaningful, tax-deductible gift to us today.

In the spirit of community,

COVID-19 continues to change how we work, train, and provide services. VCAs, clients, and families are either connecting through tele-support or are following Governor Inslee's safety guidelines for in-person gatherings. Until we can safely meet in large groups again, all training will be provided online through platforms like Zoom. Look for online continuing education opportunities to begin later this fall. If you or a loved one become infected, our COVID-19 Guidance is updated and easy to find on our website.

2020 ANNUAL MEETING OUR WAY FORWARD

OCTOBER 3, 2020
SATURDAY, 1-2:30PM

JOIN US ONLINE FOR AN INFORMATIVE
AND EXCITING GATHERING.

HOW TO JOIN, ASSISTANCE WITH ZOOM
AND UPDATED INFORMATION AVAILABLE:
WWW.ENDOFLIFEWA.ORG/ANNUALMEETING

GUEST SPEAKERS:



State Representative Skyler Rude, 16th District
Born, raised, and educated in Walla Walla, Skyler has spent his adulthood finding ways to serve his community. He has been a champion of the Death with Dignity Act and making sure it is accessible to all, including new legislation that will be reintroduced in 2021 to study barriers to access.



George Eighmey, JD. Death with Dignity Board President
George practiced law for nearly 30 years before serving as Oregon state representative from 1993 to 1999. He was a staunch advocate for the groundbreaking Death with Dignity Act. He became E.D. of Compassion in Dying Oregon and after 12 years helping more than 1,600 terminally ill Oregonians navigate Oregon's Death with Dignity Act, he retired and later joined the board of Death with Dignity National Center.

VOLUNTEER DIARY

How June unfolded in service to EOLWA clients

By Chris Fruitrich/Volunteer Client Adviser

What follows is a much-abbreviated summary of this volunteer's work with clients seeking information on the Death with Dignity law. While there is no "average" month (June in this case) in a volunteer's life, this would be typical for many. To maintain confidentiality, names and sometimes genders have been changed, and all locations or other identifying elements expunged.

June 2: June, who has been with me since April, called to see where she stood. I explained that the medication would be ready within four days. We would talk eight more times in June as her comprehension faded. At month's end she signed off by asking when we were meeting for dinner. She lost her opportunity to use the law due to diminished mental capacity.

June 4: Mark had decided against Death with Dignity in May because his organs could not be donated. After I told him his corneas and tissue **could** be donated, he promised to update me on his status. Our last conversation was difficult as his comprehension was greatly diminished. He remains undecided, despite worsening neurological symptoms.

June 7: I've been working with Mary since March and she selected today to die. At her home I found an emaciated soul barely able to communicate and utterly defeated by cancer. She wept as she gave voice to her struggle. In the end, she ingested her medication and died just 23 minutes later.

June 10: Clint already had his medication and wanted our help on the day of his death. This was someone who fought for the betterment of the human condition his entire-but-too-short life. He was resigned to the loss of the cancer fight but refused to go easily. He took his medication like a trooper (with help from only two spoons of sorbet against the horrible-tasting brew) then nodded off and spent five hours deciding to die. "He won't go easily," said his wife. "He's fought hard all his life."

June 22: I met with new Wanda and spouse via Facetime. She wants to use Death with Dignity as soon as possible, but her physicians will not help. Dr. Bob Wood arranges for doctors who must either visit or contact them via tele-medicine because of the pain involved in traveling to a medical office. Both expressed their appreciation over and over. "You have lifted such a heavy weight off me," she said. She plans to take her medications in August.

One volunteer's month in numbers

- 9 - Active clients
- 5 - New clients (9 active clients total)
- 18 - Client encounters (Contacts by phone, text, email, or in-person)
- 11.8 hours - Time spent on client encounters
- 12.4 hours - Other time (doctor contacts, research, EOLWA projects, etc.)
- 2 - Death with Dignity deaths
- 3 - Natural deaths

June 22: New client Dorothy calls for help, has no doctor, and cannot use any technology for meetings. The next day Dr. Wood arranges for a doctor who will see Dorothy, and I recommend they ask for referral to a hospice that can provide a consulting physician. After multiple phone calls, she has decided on an early-August death.

June 24: Daughter of Catherine – with whom I worked in 2015 but who didn't use the law – calls to say her mother wants to take her medication now. This was a complicated case with siblings at odds, including one who called Adult Protective Services to stop the Death with Dignity process.

June 26: I accept new Fred and call his son. We walk through the Death with Dignity process, and the son says his parent's doctor will not participate by writing the prescription for Death with Dignity.

June 28: Fred's son calls to say his dad's doctor reversed course and will help. All went smoothly and his prescription was sent to the pharmacy three weeks later. On the day the prescription was delivered, I called to check with the son and was told his father had "been comatose for three days" and would not use the law.

June 29: Catherine's daughter calls to say death is imminent, and her mother is unable to avail herself of the Death with Dignity law.

(We plan to continue publishing stories about the work done in the field by End of Life Washington's volunteer client advisers. Watch our newsletter, website, and emails for more.)

VSED (Continued from p. 1) ... Filling up on happy memories, we watched sunsets, bantered over delicious meals, and sipped martinis while listening to Bob Seger. It was some of the best time we spent together. I have the privilege of remembering my father's last years with a smile.

End of Life Washington (EOLWA), wants to provide a wider range of end-of-life choices to reduce terminally ill Washingtonians' suffering. Moving forward, and through the efforts of the VSED Working Group, Dementia Taskforce, the Public Policy and Law Committee, and staff, EOLWA will:

- Reactivate our commitment to providing information and client support for the option of VSED.
- Expand our client support program to meet the needs of the rapidly growing number of people and families dealing with dementia.
- Pursue legislative, regulatory, and legal advocacy to improve end-of-life choices and make more peaceful deaths available to people with dementia.

Works Cited: Ganzini L, Goy ER, Miller LL, Harvath TA, Jackson A, Delorit MA. *Nurses' experiences with hospice patients who refuse food and fluids to hasten death.* N Engl J Med. 2003;349(4):359-365. <https://bit.ly/2C5Gtv4>

Dementia Facts:

- **One in 10 people aged 65 and older (10%) has Alzheimer's dementia.**
- Currently 6 million Americans are living with Alzheimer's in the United States. This number is expected to more than double to 14 million by 2050.
- Older African Americans are about twice as likely to have Alzheimer's or other dementias as older whites.
- Hispanics are about 1.5 times as likely to have Alzheimer's or other dementias as older whites.

Alzheimer's Association, 2020 Facts and Figures: <https://bit.ly/3kuMGSX>



Cassandra Sutherland



Rachel Haxtema



Alex Gramps

Three new staffers advance our mission

**Cassandra Sutherland
Client Services Manager**

Cassandra (a.k.a. Cassa) Sutherland is from Bellingham, WA. She earned her undergraduate degree in San Francisco before moving to Bolivia to work in sustainable development. Her work has taken her across the globe, and she values fairness, curiosity, education, and adventure.

Cassa learned about EOLWA when she moved back to Washington in 2015 to support her father in his end of life. She then applied her experience of her father's dementia and death while earning her Master's in Global Public Health from the University of Washington. Cassa is committed to supporting the EOLWA community and showing up authentically, and hopes that one day soon every Washingtonian will have their end-of-life choices honored.

**Rachel Haxtema
Community Outreach Manager**

Rachel is thrilled to participate in the important work of End of Life Washington through education, communications, and outreach. She will support our ongoing work to increase awareness about end-of-life options across Washington and also facilitate educational opportunities for our whole EOLWA community.

Rachel has deep experience in community engagement and education. She has worked in higher education, environmental, and faith-based nonprofits following graduate studies in theology and social theory. Rachel is committed to social, economic, and environmental justice and building community wherever she lives and works. She loves living in Tacoma with her family and volunteers with Tacoma Community House, serves as a board member with Earth Ministry, and loves to garden.

**Alex Gramps
Operations Manager**

Alex is excited to contribute to End of Life Washington her systems-thinking skills, and a deep passion for doing what's right and doing it well.

Alex has a Master's in Public Administration with a certificate in Nonprofit Management. After finishing graduate school, she spent a few months working with Maher, an organization in India that nurtures and empowers people finding their way out of terrible life situations. Alex believes deeply that people deserve choices and dignity in all aspects of life and is proud to join End of Life Washington in doing this work.

PUBLIC POLICY AND LAW

Watching over Washington's Death with Dignity Law

By Bob Free / President, Board of Directors



Our work with clients seeking a hastened and dignified death takes center stage at End of Life Washington. However, we also devote substantial time and resources to advancing and improving public policies and laws dealing with end-of-life issues. To guide our efforts, we have an active Public Policy and Law Committee with four attorney members and two others, including our esteemed lobbyist, Nancy Sapiro.

In the coming fiscal year 2020/2021, we will:

- ✓ Ensure that the Protecting Patient Care Act—which we helped pass last session—protects medical providers who choose to offer their patients Death with Dignity (DWD) information and referrals to EOLWA. Those protections are particularly important as some hospitals and medical groups try to block physicians from providing such services.
- ✓ Continue helping our State Attorney General in his lawsuit – successful so far – to combat President Trump's efforts to prioritize religious beliefs over providing DWD information.
- ✓ Begin consideration of ways to improve our DWD law, such as removal of the 15-day waiting period.
- ✓ Sponsor legislation to help people with dementia utilize Voluntary Stopping Eating and Drinking (VSED) to hasten their death.

We are always open to new ideas on improving and expanding end-of-life choices. Contact us at info@endoflifewa.org.

Equity and Access Working Group

This summer a small group of VCAs, staff, and board members began meeting (online) to discuss how End of Life Washington can evolve into a more inclusive, equitable organization.

The goals of the working group include:

- Developing a greater understanding of the reasons why EOLWA's volunteer and client bases historically have been overwhelmingly white.
- Partnering with the Board of Directors, staff, volunteers, and organizations throughout the state to ensure that our organization is genuinely inclusive, welcoming, and competent to serve all Washingtonians who are considering their end-of-life options.

The working group currently includes board member/VCA Arline Hinckley, VCAs Hank Balson and Lashanna Williams, and staff members Judy Kinney and Cassandra Sutherland.

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

EOLWA hosts bereavement support groups

A safe, nonjudgmental, welcoming space to share your grieving experience.

End of Life Washington will begin offering Bereavement Support Groups in October. We invite you to meet via Zoom and share with others whose loved ones exercised their right to use Washington's Death with Dignity Law.

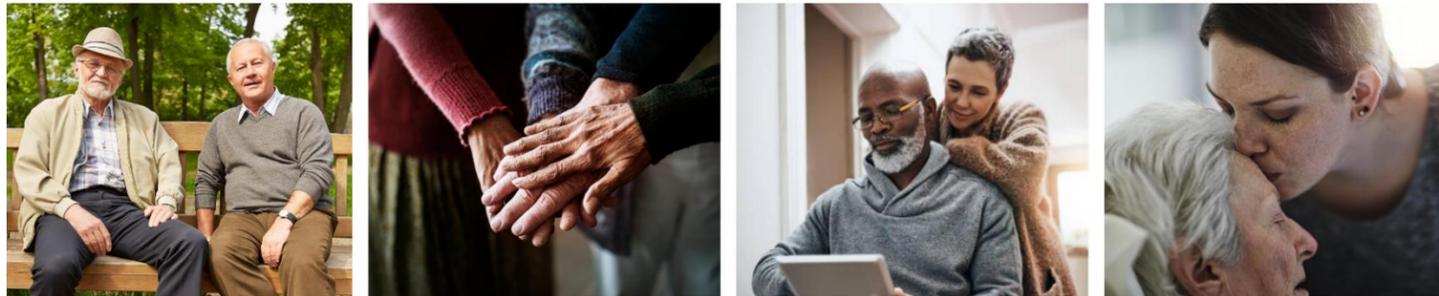
Accessible from the comfort of your own home, you will learn that you are not alone. Whether you are struggling with deep sorrow, want to share a little bit of your loved one's story, or just be in the company of those who understand that you may not be ready (or may be past due!) to smile and laugh again, we are here to support you.

If you are mourning the loss of a loved one who chose Death with Dignity, contact facilitator Sally Thomae, MSW, at 425-270-8745 to ask about our groups.





2019-2020 ANNUAL REPORT



We envision a world where people understand their end-of-life choices and can die on their own terms, without barriers.

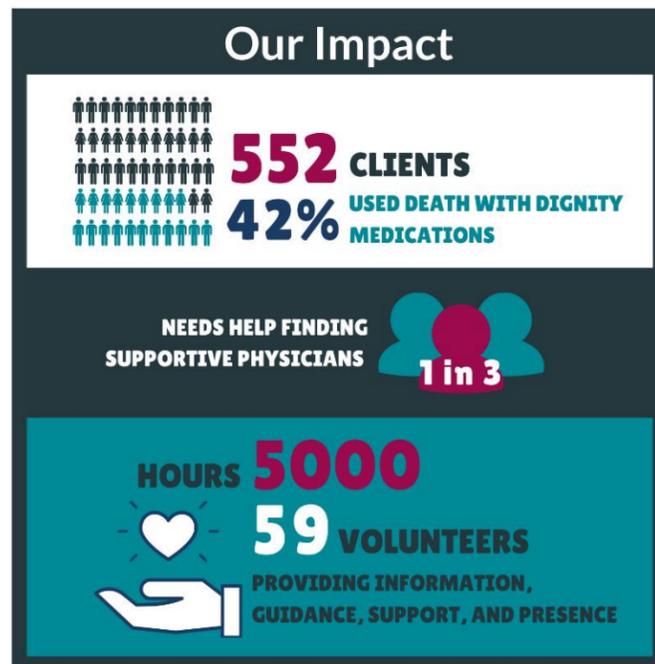
In a world filled with changes and challenges, we continue to uphold your right to the full range of end of life choices, including Death with Dignity, through our support, advocacy, and education.

Support

Volunteers are the heart and soul of End of Life Washington.

For more than 30 years, End of Life Washington has been a national model for demonstrating how neighbors can support their terminally ill neighbors to access their end-of-life options.

Volunteer Client Advisors (VCAs) work in eight regional teams from Bellingham to Vancouver and Sequim to Spokane. VCAs provide excellent support, even as COVID-19 has introduced new challenges to our work. We have added tele-health support and continue to provide personalized support, even with technology to attend to our clients' needs.



"I can't begin to tell you how thankful we are. You have been so spectacular in so many ways: responsive, caring, thoughtful... Gives me faith that there are such good people and organizations out there like you."
-EOLWA Client

Advocacy

EOLWA continues to pursue legislation to increase access to information and end-of-life choices, including Death with Dignity.

The Protecting Patient Care Act (PPCA) HB 1608 increases awareness of Death with Dignity by ensuring that health care professionals can provide information and resources that are in the best interests of their patients without restriction.

Win: HB 1608

Thank you to State Rep. Nicole Macri & State Rep. Skyler Rude our legislative champions!

"HB1608 is necessary because a sharply increasing number of health systems in Washington prohibit or limit the information, resources, and services a health provider may offer to a patient. Such prohibitions hurt patients and they disproportionately harm women, the LGBT community, and people who need end-of-life care."
ACLU Washington

Education

COVID-19 meant shifting from in-person educational sessions to online learning, allowing for statewide reach.

Priorities for 2020-2021:

- Create and facilitate engaging online educational opportunities and increase access across the state to ensure all have access to end-of-life choices.
- Provide Continuing Educational Unit educational programs to the community increasing outreach and awareness.

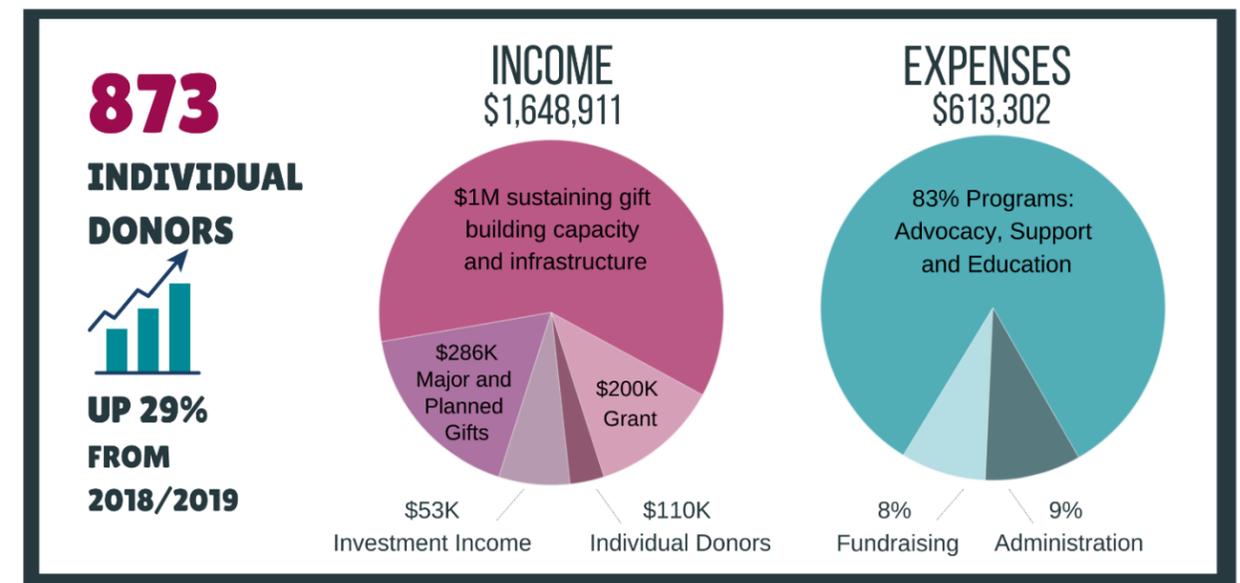


Finances

Donations from EOLWA's dedicated community ensure that our services are free and allow us to fight for greater end-of-life choices for all Washingtonians.

A \$1 Million anonymous gift in the 2019-2020 fiscal year provides critical stability to help support End of Life Washington's work for years to come. EOLWA also received a \$200,000 grant for a public awareness campaign.

We are honored to be excellent stewards of your support, you fund more than 40% of our operating budget.



Deep gratitude for our donors, Board of Directors, volunteer client advisors, staff, physicians, and service providers.