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# We Persevere on Behalf of Our Clients

By Dr. Terry Law EOLWA Board Member and Volunteer Medical Adviser

Many of you undoubtedly read the March 5 *Seattle Times* article "Northwest doctors rethink aid-in-dying drugs to avoid prolonged deaths," written by Kaiser Health News correspondent JoNel Aleccia.

As Ms. Aleccia's article indicates, these are interesting times for the aid-in-dying movement as we consider efficacious medications for Death with Dignity. We all want to believe that birth and death are sacred times, unaffected by the vagaries of politics, science, or state budgets. The article points out some difficult truths:

- Protests over capital punishment have led to poor availability of medications known to result in a fast and peaceful death.
- In today's business climate, drug companies such as Valeant, the manufacturer of Seconal, are free to triple the price of the medication frequently used in aid in dying, leading to costs of over \$3000.
- The medical community's focus on cure over comfort has led to a lack of good science in studying, tracking, or developing medication combinations for patients choosing Death with Dignity.
- In the state of Washington, aid-in-dying medications are rarely covered by Medicaid, which makes it difficult for people who do not have financial resources to consider using the law.

Despite all of this, we at End of Life Washington continue to persevere. Every year usage of the Death with Dignity law increases. We are committed to keeping this option available in Washington for qualifying adults of all financial means. Our resourceful team of Volunteer Medical Advisers has scoured the options as well as existing literature and continues to provide doctors with prescription recommendations so they can assist their patients who desire to explore this choice. We have heard the "slippery slope to euthanasia" argument since the law came into effect eight years ago. Yet the fact remains that the Death with Dignity law continues to be used appropriately by terminally ill, competent adults who self-administer by ingestion. Death is as much mystery as science, and, whether the vigil is long or short, we at End of Life Washington are there to provide support, reassurance, and as much information as we can. That is an important commodity in these interesting times.

#### Your support continues the critical work described across these pages

Please consider one of the many ways you can give:

- Go online directly at <a href="www.endoflifewa.org">www.endoflifewa.org</a> and click "Donate" to make your one-time or recurring gift
- Call our office, 206-256-1636, to make a credit card donation
- Send a check to End of Life Washington, POB 61369, Seattle, WA 98141 (Please use the remittance envelope in your Spring newsletter)
- Make an appreciated stock gift by calling Kathy Sparkman, Development Director, 206-274-9974, for easy delivery instructions
- Give through Seattle Foundation's GiveBIG from April 27 through May 10 online gifts only (www.givebigseattle.org)

Each year, End of Life Washington helps hundreds of Washington residents navigate the intricacies of the Death with Dignity Law. Our skilled, caring Volunteer Client Advisers are involved with 95% of those who chose to use the Law. EOLWA also makes numerous presentations around the state to individuals, organizations, hospices and healthcare groups to ensure that everyone knows their rights.



Your life.
Your death.
Your choice.



Message from Executive Director Sally McLaughlin

### Positive Energy Keeps Driving EOLWA Forward

Much has transpired on the End of Life Washington (EOLWA) front since our Fall 2016 newsletter, most of it positive and energizing, and some of it concerning. Our goal is to keep you aware of it all.

The tireless efforts of our 44 Volunteer Client Advisers (VCAs) definitely top the "positive and energizing" list. As they continue to serve all the residents of Washington State, under the astute leadership of Client Support Coordinator, Beth Glennon, and her assistant, Becky Errera, our VCAs make a significant difference in the lives and deaths of our EOLWA clients. In 2015, 166 residents of Washington State availed themselves of the Death with Dignity Act. Of those, 161 were clients of End of Life Washington.

We have re-envisioned our Volunteer Medical Adviser (VMA) program in order to better serve Washington State physicians seeking information about Death with Dignity protocols. We continue to encourage more physicians, hospices, and medical and residential facilities to support their patients who have terminal prognoses as they explore their options under the law.

To that end, Dr. Dwight Moore, PhD, a Whatcom County VCA and an EOLWA speaker, has developed his "Nurturing Doctors" program, which you can read about in his separate article. We also welcome Dr. Raleigh Bowden of the Methow Valley as our VMA for Eastern Washington, who, with her colleague and friend, Dr. Betsy Weiss, serves our clients "east of the mountains." Access for eastern Washington residents remains an important priority for EOLWA, one that we will seek to improve in 2017.

Our financial status constitutes yet another highlight in the "positive and energizing" category! Under the expert guidance of Kathy Sparkman, our Development Director, as well as the board's Development Committee, we are steadily approaching this year's fiscal goal of clearing \$525,000 to support our important programs and initiatives – Community Education and Outreach, Client Support, and Public Policy, to name a few.

With regards to Community Education and Outreach, our sturdy bank of volunteer speakers continue to travel Washington State to deliver presentations and seminars on Advance Directives for Health Care,



"The tireless efforts of our 44 Volunteer Client Advisers definitely top the 'positive and energizing' list."

End of Life Choices, and other end-of-life related topics. I had the opportunity to craft a new presentation entitled *Cultural Aspects of Death and Dying* for the March 8-9 "With A Little Help, Inc."

Caregivers Conference. I was honored as well to share insights on Washington's Death with Dignity Law with over 200 oncology nurses at their annual "Puget Sound Oncological Nursing Symposium" on March 4. Speaker Arline Hinckley will be featured on a panel discussing suicide on Spokane Public Radio on March 22, during which I have no doubt that she will masterfully explain how using Death with Dignity is *not* considered suicide, nor is the term "physician-assisted suicide" proper or correct. Watch for the link we will post on our website to what promises to be a most interesting discussion.

The issues that concern us are both local and national. This month EOLWA board members and volunteers, Dr. Terry Law, MD, and Arline Hinckley, MSW, traveled with me to Olympia to testify against Senate Bill 5433, which seeks to reopen the Death with Dignity Act (RCW 70.245) in order to add language that we deem deleterious (for more on this, see our article dedicated to this consideration). EOLWA's lobbyist in Olympia, Nancy Sapiro, JD, works long hours on our behalf, seeking to safeguard our legal access to Death with Dignity in a rather challenging political climate.

#### Message from Board President Bob Free



## A Call to Question Trump's Nominee

End of Life Washington's Board President, Bod Free, wrote the following letter addressing our concerns about Judge Neil Gorsuch's possible appointment to the U.S. Supreme Court. It was published in the Seattle Times on February 6, 2017.

#### GORSUCH APPOINTMENT OF PARTICULAR IMPORTANCE TO WASHINGTON STATE

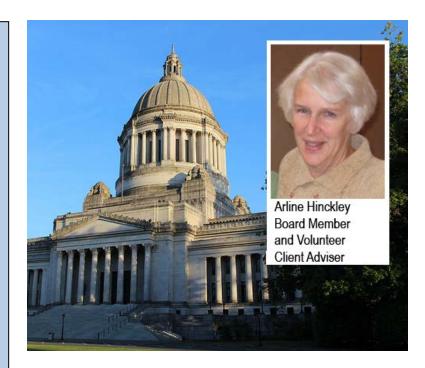
Washington state residents should be particularly concerned about the prospect of Judge Neil Gorsuch becoming a Supreme Court justice.

There are many reasons both to support or oppose his confirmation by the Senate, but one area of Judge Gorsuch's history and judicial philosophy must be thoroughly examined. Judge Gorsuch has stated his opposition to laws which permit terminal patients to hasten their death with physician assistance — laws including Washington's own Death with Dignity Act, passed by initiative in 2008, with almost 60 percent of the vote. Judge Gorsuch authored a book in 2006, "The Future of Assisted Suicide and Euthanasia," in which he argued that terminally ill patients do not have a right and should not be permitted the choice to hasten their own death with their doctor's assistance, regardless of their suffering. To permit this, he argues, is immoral.

End of Life Washington (formerly Compassion & Choices of Washington), which drafted the 2008 initiative and monitored and oversaw its implementation, can attest that our law has helped many Washingtonians choose a peaceful, dignified death and that the imagined abuses foreseen by opponents of the law have not come to pass.

It is possible that death with dignity cases may come before the Supreme Court again, as one did in 2006 when President Bush and Attorney General John Ashcroft challenged Oregon's law. In Gonzalez v. Oregon, the Court's majority ruled in favor of Oregon, but that outcome is not guaranteed in the future if Judge Gorsuch advocates and votes for a different result.

The Senate must press the nominee to affirm that he will not interfere with states' laws which give freedom of choice to their citizens. This issue affects not only Washington and the five other states — California, Oregon, Colorado, Vermont, and Montana — which have legalized aid in dying, but the many other states which are considering passing similar freedom of choice laws for their citizens.



# Death with Dignity: EOLWA Opposes Proposed Change

On March 7 Senate Bill 5433 was debated on the Senate floor. The final vote was 26 to 23 in favor of amending the bill to include the requirement that prescribing physicians suggest that their patients might hold out for a cure and acknowledge that their lives could be extended. This is a marked improvement over last year when the vote was 34 to 14. We have every hope that this bill, which further complicates an already arduous procedure, will not make it out of committee once it reaches the House Health Care Committee. (If you'd like to view the debate, go to <a href="http://www.tvw.org/watch/?eventID=2017031045">http://www.tvw.org/watch/?eventID=2017031045</a>, and scan until minute 51:53.)

What follows is the inspired testimony from Arline Hinckley, who testified against the proposed legislation.

"Good morning chairman Padden and committee members. Thank you for this opportunity to speak to you about Senate Bill 5433. My name is Arline Hinckley. I am a Board member and Volunteer Client Adviser with End of Life Washington, formerly Compassion and Choices of Washington. I am also a social worker and have spent my career working with terminally ill adults. End of Life Washington provides information, referral, and support for dying clients and their families. This includes discussing all options for approaching the end of life, from continuing care to the option of Death with Dignity. We support the clients in whatever option they choose. If their choice includes Death with Dignity, we are most often with them when they take the final medication. We have no vested interest in people using the Death with Dignity Act (DWDA). What we do have is an interest in helping people have the kind of death they want.

"Since 2008 when nearly 60% of Washington citizens agreed that choice at the end of life should be the right of every competent adult, I have supported over 150 people as they have gone through the process in deciding whether to obtain medications under the DWDA, through to the point of death, whether or not they took the medication. I have never encountered a client who did not know their medical prognosis in great detail, or who had failed to fully discuss their options for life-extending treatment.

"People seeking to use the Death with Dignity Act have already had extensive conversations about appropriate and relevant treatment options. They have either exhausted all possible treatments or have decided to forgo further treatment, as is their right. They have already been told their conditions are terminal, which, by definition, means there is no cure.

"To mandate a further conversation about life extension and cure for a person seeking qualification for Death with Dignity is unnecessary – physicians who qualify people for Death with Dignity are already mandated to discuss all feasible alternatives. Cure is not a feasible alternative! It makes no sense to require a physician who is confirming a terminal diagnosis to suggest the patient can be cured. It makes no sense to require that physician to discuss further treatment when the patient has exhausted all options or has made the very difficult decision to stop treatment. To do so would undermine the patient's trust in the physician.

Let me tell you about a client of mine – a delightful, bright, and successful businessman. At age 68, he was diagnosed with pancreatic cancer. He chose to undergo a Whipple procedure, a complex surgery involving removal of parts of the pancreas, the duodenum, part of the common bile duct, the gallbladder, and part of the stomach. After a grueling recovery, he did well for over two years. When the cancer recurred, he underwent three rounds of difficult chemotherapy which gave him another year of relatively good health. Another recurrence was then treated with radiation therapy. This was effective in temporarily shrinking the tumors, by now throughout his body, reducing his pain. Still he persisted, but the time came when the tumors were too big, the pain was too intense. A bad fall on the way to the bathroom was the last straw, and he asked his physician to help him qualify for Death with

Dignity. What possible reason would there be to force a conversation with this man about life-extending treatment or cure?

"Another client was a 48-year-old man with ALS. His diagnosis was made four years before I met him. During that time, he took what little treatment there was for ALS, but the disease continued its relentless course. His ability to walk was the first to go. After two years, he was in a wheelchair. He spent much of his time writing long letters to his then six-year-old daughter, to be opened on the special occasions in her life. Despite it being very difficult for him, he continued to be as active as possible in her life. Gradually, he lost the ability to talk clearly. He continued visits to his MD and was involved with the local ALS group. He used all available equipment - a fancy wheelchair, language assists, a lift to transfer him from bed to chair to bathroom, etc. His life was precious to him and to his family. When he began to have breathing problems, he chose not to prolong his life with a respirator and sought Death with Dignity. What possible reason would there be to force a conversation with this man about life extending treatment or cure?

"Those who support Senate Bill 5433 speak about the importance of hope as a justification for the bill. Terminally ill people DO have hope. It might not be the hope of a cure or a longer life but it is there – the hope to see a new grandchild, to reach another wedding anniversary, or to see another Christmas. Their primary hope is often for choice at the end of life, for a good death, for the kind of death they choose."

Washington's Death with Dignity Act has been in effect for almost eight years. It has operated as written flawlessly without misuse or coercion. I urge you to respect the will of the voters, to reject Senate Bill 5433, and leave the initiative unchanged.



## Nurturing Our Doctors

By Dr. Dwight Moore, PhD EOLWA Speaker and Volunteer Client Adviser

die with dignity. The paperwork can seem tedious, and there may be last minute rushes for prescriptions to be written or requests to be charted. Our volunteers in Whatcom and Skagit counties of northern Washington decided to set a goal to nurture their physicians in the region, with an eye to increase the visibility of End of Life Washington, as well as to reach out to support the doctors' efforts. We identified 55 doctors who had expressed an interest in the past and telephoned each of them. As you can imagine, getting through the network of administrators, nurses, and Physician Assistants was laborious, but it started important conversations about End of

As volunteers, we greatly appreciate the

work our doctors do to allow our clients to

Life Washington. Letters were then sent to the doctors who did not call back which described the law briefly, expressed support, and included the card of a volunteer in the county.

"It started important conversations about End of Life Washington."

Additionally, the volunteers discovered that some of the practice managers of the clinics were interested in hosting a brief presentation for their doctors. As a result, two presentations ensued. Informational in nature, the presentations afforded volunteers the opportunity to answer the doctors' questions and discuss the finer points of the law. Best of all, these sessions generated nine new interested doctors!

In the coming months we plan to hold a lunch for the six "Best Friends Forever" doctors who have shown our organization consistent support. We will then contact the directors of the 40 long term care centers to discuss Washington State's Death with Dignity Law and explain how End of Life Washington can support them.

#### In memoriam: Joanne Brekke

By Midge Levy, End of Life Board Member

Joanne, who died earlier this year, served in the Washington State House of Representatives from 1978 – 1993 and during her tenure introduced three Right-to-Die bills. Joanne served on Washington's Hemlock Society board beginning in 1996.

The Hemlock Newsletter quoted Joanne: "During my tenure, I had the honor of working on legislation on end-of-life issues. I had the privilege of supporting both my mother and my step-father at the end of their lives in 1994, and am now even more convinced of the need to control one's destiny."

Joanne chaired our Legislative Action Committee and served as a volunteer lobbyist. Former End of Life Washington Executive Director, Robb Miller, remembers her invaluable assistance to him in keeping him informed of state political developments.