

THE



Dignity Report

A publication of the Death with Dignity National Center

SPRING 2020



Dispatch From a World Transformed
Grants for Grassroots Advocates | The Latest on Legislation
Life File: A Checklist for End-of-Life Planning

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On the cover:
William "Sunni" and K.C. Ash, in 2016.

GIVE DIGNITY

Death with dignity laws provide peace of mind to qualified terminally ill residents in *California, Colorado, District of Columbia, Hawai'i, Maine, New Jersey, Oregon, Vermont, and Washington.*

You can help expand the option to all Americans with a generous contribution:

- a one-time or recurring gift;
- a gift in honor or in memory of a loved one;
- a gift of stock or mutual funds;
- a legacy gift.



Please visit DeathwithDignity.org/Support to learn more and contribute.

THANK YOU!

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Dispatch from a World Transformed



Back in January, I wrote my editorial while in the thick of the 2020 legislative session. Today, I am reimagining work and life as a pandemic sweeps the globe.

OUR REALITY, UPENDED

Our world has been upended by COVID-19. Like many organizations, our office is closed; by order of Oregon's governor, my staff members and I are working remotely while staying at home. Nearly every state legislature has suspended activity. Our advocates and lobbyists have put in-person work on pause. It is a new reality for us all. And yet, in many ways, our work remains the same.

THE WORK CONTINUES

We continue to collaborate with advocates across the country, giving them the tools they need to succeed. And we are working to lay the foundation for future legislative campaigns.

People still call us with questions about how to access death with dignity and other options. Most questions now focus on end-of-life planning in light of COVID-19. We're

providing the same level of factual information and emotional support. Online, we're answering your most pressing COVID-19 questions with help from a panel of medical ethicists and care providers. Visit our website to read more and submit your own questions.

PHYSICAL DISTANCE, EMOTIONAL CONNECTION

As we all adjust to physical distancing, I am connecting with longtime supporters and advocates more frequently. They have checked in on me, and I've checked in on them. I feel immense gratitude for these kind and resilient individuals and am proud of the network we've created together.

YOU GIVE US STRENGTH

You are part of our community, too. Thanks to you, we can advance our mission to bring control and peace of mind to Americans with terminal illness, even in uncertain times. We are honored to have you by our side as we weather this storm together.

With gratitude,

Peg Sandeen, Executive Director

Legislative Updates: Pre-Pandemic Edition

Nearly every state legislature adjourned or suspended their 2020 legislative sessions due to the coronavirus (COVID-19) pandemic. Here is an update on what we accomplished before legislatures began to close.



MARYLAND

Death with Dignity Executive Director Peg Sandeen testified at a February hearing on Maryland's End-of-Life Option Act. We worked extensively with lawmakers, our lobbying team, and grassroots advocates to advance the bill.



MASSACHUSETTS

The End of Life Options Act is still under consideration by lawmakers, who must take action on the legislation by May 30. We continue to support our partners at Western Massachusetts Death with Dignity, who are working to educate the public about the bill.




NEW HAMPSHIRE

New Hampshire Death with Dignity advocates met regularly with advocates and legislators in early 2020. Steering Committee members and Death with Dignity staff testified at a hearing on an assisted dying bill in February.



NEW YORK

We and our coalition partners continue our work to broaden support for the Medical Aid in Dying Act. Our friends at End of Life Choices New York recently helped secure an endorsement of the bill by The Arc New York, a prominent disability-rights organization.

Legislators introduced bills for the first time in Florida, Georgia, and Kentucky. And we are laying the groundwork for 2021 campaigns in Arizona, Nevada, and New Mexico. 

Creating Your Life File: A Checklist for End-of-Life Planning

For many years, we've provided information and advice to individuals about death with dignity and end-of-life care.

Now, more than ever, we're receiving inquiries about end-of-life planning: what it involves and where to start.

There are many resources that explore this topic in depth, and it can be hard to know how to tackle what feels like a monumental task.

In order to get you started, we've developed a checklist (see centerfold) to help you create your life file.

WHAT IS A LIFE FILE?

A Life File is a central place to keep "how and what" documents that ensure your wishes are honored at the end

of your life and your loved ones have the information they need to take care of your affairs when you die.

If you choose, it also can include guidelines for how to honor your life and your legacy.

A LIFE FILE OFFERS PEACE OF MIND

We know that creating a Life File is an easy task to put off, but once you're done, you'll have peace of mind. And you don't have to do it all at once!

After you've compiled your Life File, make sure to revisit and update it if you experience a major life change like a marriage, illness, divorce, or the birth or adoption of a child.

(Continued on p. 6 and 7)

Discover more resources to help you create a Life File at
DeathwithDignity.org/Life-File.

LIFE FILE: AN ACTION CHECKLIST

YOUR DATA AND DOCUMENTS

- Create a password list.** Include phone, tablet, computer, email, social media accounts, etc. Consider using password software like LastPass or 1Password, which allows you to pass on your passwords to your heirs.
- Review your social media accounts and decide what you'd like to happen with them when you die.** Every social media platform has different options.
- Document your bank account information,** including safe-deposit box locations.
- Document any life insurance policies and beneficiaries,** including information on funeral insurance or pre-paid burial plot, if applicable.
- Include your will.** Consider updating it if things have changed in your life since you last did it.
- Make a list of bills with due dates and amounts.** Note how statements are received and payments made. Identify which bills are ongoing and which have an end date.

YOUR CARE

- Create an advance directive,** a document that articulates your wishes concerning medical treatments at the end of your life and designates an individual—your healthcare agent—to ensure those wishes are honored should you no longer be able to speak for yourself.
 - Make your advance directive specific.** Address a variety of different scenarios, e.g. in what situation you would want to receive morphine, when would you not want to be intubated, etc.
 - Consult tools and resources** like The Mayo Clinic's detailed guide to completing an advance directive or a comprehensive tool for creating an end-of-life care plan at MyDirectives.com.
 - Make copies of your advance directive** to provide to your healthcare agent or trusted family/friends.
- Talk to your physician about your advance directive.** Explore whether or not your wishes can be turned into a POLST/MOLST (Physician/Medical Orders for Life-Sustaining Treatment) form in your state.

Have multiple conversations with your healthcare agent about your wishes. Take them out to tea, have them over for dinner, go to a bar or library. Talk about what you want. This can be a serious conversation, or it can be full of laughs. You get to decide how this conversation plays out.

YOUR POSSESSIONS

- Designate meaningful items to be given away to specific people.* Consider doing so now, rather than spelling it out in your will. Consider reading *The Gentle Art of Swedish Death Cleaning*, by Margareta Magnusson, to give yourself some guidance on how to slowly distribute important things to your loved ones.
- Dispose of any items you own that you wouldn't want your heirs to find,* or include instructions about disposing of sensitive items, e.g. your high-school diaries, for a trusted friend or family member.
- Identify the location of any cash you have stored for emergencies,* and provide instructions on how to use it.
- Draft a "Where to Find..." document* identifying the location of important things your heirs might need after your death: the deed to your house, the title and keys to your car, your social security and Medicare cards.

YOUR LEGACY

- Write your own obituary.* Doing so will give you control over how you are publicly remembered.
- Write down instructions for your final disposition.* What do you want to happen to your body when you die?
- Plan for your funeral/remembrance ceremony.* Who are your chosen speakers? What music would you like to include? Write down and share your vision.
- Create a message for loved ones.* Write a letter, make a video, whatever you think will be most meaningful for the people who matter most.

SECURE YOUR LIFE FILE

- Purchase a fireproof home safe and a USB thumb drive* to store your Life File.
- Make copies of the Life File's contents* and leave them with a trusted friend or family member.

Give Joe the Choice

By Lindsay Goldstein, New Hampshire

My husband, Joe, and I met in graduate school. I was instantly attracted to his wit, his energy, his devotion to love, and his passion for life. I also came to admire his deep belief in personal liberty, as well as his abiding respect for the sacrifices so many have made to safeguard the precious ability to choose one's own path.

We have had countless joyful moments together, but recently Joe's rare and incurable neurodegenerative disease has come to dominate our lives.

"EVERYTHING HURTS"

Even as his disease robs him of

his mobility, Joe rarely utters a word of complaint. But since his terminal illness has advanced, he has told me that everything hurts all the time.

LOSS OF CONTROL


What makes his disease particularly bad, beyond the excruciating physical suffering, is the complete loss of control. That is a form of psychological torture. Things will never improve. And things will get worse.

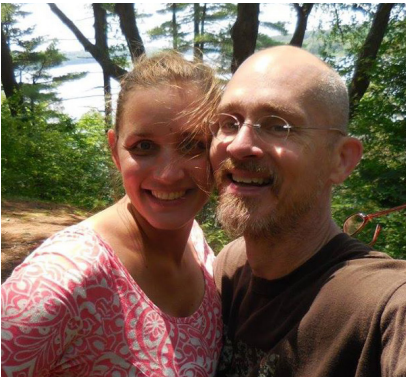
LIBERTY AND DIGNITY

Like so many, Joe can't control this disease. Why can't we let him choose to control the time, place, and manner of his own death if he chooses? Choice is the foundation of our intrinsic liberty and dignity.

Medical prolonging of life is a miracle of our time. It should not be confused with the medical prolonging of suffering.

A MORE HUMANE LAW

Drugs aren't going to save Joe. There is no healing his body. But we can heal our current law to make it more humane. 



Lindsay and Joe Goldstein, in 2003.

Her Song Lives On

Donor Spotlight: William “Sunni” Ash

William “Sunni” Ash first glimpsed his future wife, K.C., singing at a Seattle club in 2005. He was immediately drawn to her ability to connect with the audience.

“She would sing at every table,” he recalled, “she would even interrupt her own song to sing someone ‘Happy Birthday.’”

“HER OWN SONG”

In the years that followed, K.C. and Sunni led a joyful life. But in late 2019, a terminal diagnosis turned their world upside down.

K.C. was diagnosed with aggressive cancer in her head

and neck. Her prognosis was poor, and she endured terrible pain.

She qualified for and chose to access Washington’s Death with Dignity Act.

NAVIGATING CHALLENGES

Sunni and K.C. faced challenges finding doctors and pharmacists in their small coastal town. Death with Dignity’s website helped them find local support and navigate the end-of-life process.

FINDING RELIEF

“It was the relief that Death with Dignity was there and gave me tools to add to my toolkit that inspired me to donate,” Sunni said. “Using death with dignity gave K.C. the strength to fight as much as she could, knowing that when it got to be too much, she would be able to [decide] what she needed to do.”

The day K.C. died, Sunni sang to her at her bedside. They shared a smile before she took the medication. She died peacefully, and their time together ended as it began: with a song. 🎵



K.C. performing at the Westport Blues Festival, in 2015. Photo by Michael Bruce.

Grants Bolster Grassroots Advocacy Across the Nation

Death with Dignity recently awarded grants to six grassroots organizations through our Dignity50 Grant Fund to help them grow their capacity and strengthen the death with dignity movement.

The recipients include just-formed groups and long-standing coalitions:

- Arizona End-of-Life Options;
- Dying Right North Carolina;
- Marylanders for End-of-Life Options;
- New Hampshire Death with Dignity;
- New Mexico End-of-Life Options Coalition; and
- Ohio End of Life Options.

FROM MAINE CAMPAIGN TO MENTOR

Valerie Lovelace, who manages our Dignity50 State Leadership Incubator program, works with grassroots groups to provide them with mentoring and tools to help their state efforts.

"It's such an honor to work with these groups," Lovelace said. "The determination and

compassion of grassroots supporters to achieve passage in their state is really what fuels this movement."

FORMALIZING AND ORGANIZING

Bob McCown, the co-founder of **New Hampshire** Death with Dignity, established in fall 2019, is looking forward to kickstarting the grassroots movement in the Granite State with the new funds.

"We're planning to formalize our organization, and start the outreach and education needed to get the law passed," McCown said.

EDUCATING AND ADVOCATING

Dying Right **North Carolina** co-founder Ed Tiryakian has been working for years to recruit death with dignity supporters from across the state and to meet with legislators on both sides of the aisle.

The grant will help Tiryakian and other advocates "educate legislators of the need for medical aid in dying legislation [and] to the positive good it provides people."



New Hampshire Death with Dignity co-founders (from left) Bob McCown, Cheri Bach, and Rebecca Brown with Death with Dignity National Center's Valerie Lovelace (center) and Peter Korchnak (second from right) before the February 12 legislative hearing in Concord.

BOLSTERING RURAL OUTREACH

Barak Wolff, a member of the **New Mexico Coalition's** steering committee, will use their grant to "communicate more routinely and robustly with our supporters statewide. It will also help our rural outreach efforts to engage smaller communities about end-of-life issues and identify local champions to help us improve our advocacy efforts."

PROVIDING MENTORSHIP AS WELL AS DOLLARS

"Working under Val's experienced guidance and meeting others

in states working toward this goal has been both inspiring and helpful," **Ohio End of Life Options Executive Director Lisa Vigil Schattinger** said.

Lovelace expressed gratitude to donors across the country whose contributions to our movement help grassroots groups make lasting change.

"Without the generosity and goodwill of contributors large and small, providing support like this would just not be possible," Lovelace said. ☺

Read more about all the grant recipients and projects at DeathwithDignity.org/Dignity50-Grants.



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—LINDSAY GOLDSTEIN, NEW HAMPSHIRE

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