

VOLUNTEER TOOLKIT

CONTENTS OF THIS TOOLKIT

- Host a Meetup
- Talk about Dying
- Mission and Vision
- Language is Power

Volunteers have been the foundation of Death with Dignity for decades. In 1994, Oregon was the first state to pass a Death with Dignity law. It was passed through a ballot initiative, which means dedicated volunteers, like you, worked tirelessly to gather signatures, share their stories, and build awareness about this vital healthcare option. Since then, volunteers and advocates have been on the frontlines, helping to pass medical aid-in-dying laws in nine states, and the District of Columbia.

Over the years, volunteers and advocates continue to shape history by sharing their stories with friends, family, and legislators. This toolkit will help you share your own story, encourage others to share theirs, and be a part of a long-standing movement that believes everyone should be able to die with dignity.

HOST A MEETUP

Volunteers come to the Death with Dignity movement for a variety of reasons. Hosting a meetup is one way you can share your reasons and connect with others. Meetups create a space for people to share their stories and can be a powerful way to bring those close to you together to discuss how we can improve the dying experience in this country.

I VOLUNTEER BECAUSE...

"I started volunteering with Death with Dignity because I have always been passionate about ethics, human rights, and social justice. I strongly believe that individuals should have the right to choose how they want to live and want to die." —EMILY

"I volunteer for my grandmother and my own desire to make sure more people can die good deaths and live full and joyous lives." —BEN

"I volunteer because I believe everyone should have freedom and autonomy in how they die. I want to be a part of a movement that helps others and changes how we talk about death." —EMMA

"Volunteering with Death with Dignity gave me the opportunity to talk with people about an issue I care about." —LANE

Here are some tips for preparing and hosting your Death with Dignity meetup:

BEFORE

Choose the location and date of your meetup. Many will choose to host at their own residence, but others prefer a public setting or an online gathering. The location and date you choose should be comfortable and accessible for your guests.

Send your invites. Choosing a date a few weeks in advance will help give you and your guests time to prepare. You can provide guests a "RSVP by" date so you can plan for space, food, and beverages accordingly.

Review resources on our website. Take some time to explore the variety of resources we have on our website to share with your guests. You can also find information on our website about each state's Death with Dignity law.

Prepare to share your story. Why is Death with Dignity important to you? Everyone comes to the movement for different reasons. Many have experienced the loss of a loved one who suffered greatly at the end of their life. Others may know someone in their life who used the Death with Dignity law. What we all have in common is that we want better end-of-life choices, and for people to be able to have control and autonomy over their deaths.

DURING

Below is a suggested agenda for your party:

Welcome. Give your guests time to settle in and talk with one another.

Thank everyone for coming, introductions to one another if applicable. After all guests have arrived, gather everyone together and thank them for attending. If there are members of the group that don't know each other, you can ask everyone to introduce themselves.

Talk about the purpose. After introductions, share a little bit about Death with Dignity for those that are unfamiliar. You may want to share how you learned about the movement.

Share your story. Share the story you prepared and talk about why you care about Death with Dignity. Sharing your story may empower some of your guests to share their own stories.

Open discussion. Invite others to share their story or the impact the death of a loved one had on them. Let the conversations flow naturally, or use a prompt if needed.

Call to action. As the discussion wraps up, make your call to action. Thank everyone for engaging in a vulnerable and informative conversation. You'll want to remind them that they can be part of a movement that will help all Americans have the right to die with dignity. Ask them to:

1. Share their story or reshare one of our social media posts.
2. Identify their legislators and talk to them about passing Death with Dignity.
3. Host their own meetup.



Discussion Prompts

When you think of Death with Dignity or aid-in-dying, what comes to mind?

How comfortable do you feel about talking about death? Why do you think it's difficult for many people?

Have you lost a loved one who suffered at the end of their life?

What impact would the Death with Dignity law have on your life?

AFTER

Send a thank you message.

Make sure to send any additional information requested during your time together.

Share with us! Please share successes, photos, and any questions that may have come up during or after your meetup. You can send this information to info@deathwithdignity.org.

Stay in touch with your guests.

Continue the conversation about Death with Dignity after your meetup. Keep folks accountable by checking in periodically to see what type of action they have taken, or if they would like help hosting their own meetup.

TALK ABOUT DYING

Talking about death and end-of-life options is the first step to breaking the stigma. In addition to a meetup, there are many ways to connect with others through conversation and action. Our website's "resources" section provides helpful starting points and additional information for these conversations.

Here are five ways to start the conversation about end-of-life options and connect with others:



- 1.** Organize a movie night or a film screening. Films like *The Last Campaign of Governor Booth Gardner* and *How to Die in Oregon* are relevant to the Death with Dignity movement and can be used to engage family, friends, and the public in lively discussion.
- 2.** Inspired by *Death over Dinner*, set up a monthly or quarterly meet up with friends, family, or loved ones to talk about end-of-life issues.
- 3.** Complete your advance directive or Life File Checklist (see our website for details) and help a friend with theirs.
- 4.** Write an Op-Ed or a Letter to the Editor in your local newspaper, and encourage a friend or a family member in another state to write one as well.
- 5.** Gather a group of people together who are passionate about Death with Dignity and meet with your state legislators.

MISSION AND VISION

Death with Dignity is a national leader in end-of-life advocacy and policy reform. The mission of the Death with Dignity movement is to improve end-of-life care by expanding options for those who are dying and confronting injustices in the healthcare system.

Join us in imagining a world where people experience a balance of health care, spiritual, family, and community support at the end of their lives—where dying well is deemed essential to living well.



LANGUAGE IS POWER

The language we use matters. There are many terms you may have heard in reference to Death with Dignity. Some are purposefully used by opposition in order to misrepresent the law. Other terms have been misused by the media, painting an inaccurate picture of the law and work we do.

Death with Dignity is a term originating from the title of the first medical-aid-in-dying law passed in the country. Because our founders authored this law in Oregon, it's our preferred term for the practice.

Here are some additional terms for Death with Dignity, and some terms that are incorrect, inaccurate, and are often used by the opposition.

Other terms for Death with Dignity:

- Physician-assisted death/dying
- Medical aid-in-dying
- Aid-in-dying
- Physician aid-in-dying

Incorrect and inaccurate terms:

- Assisted suicide
- Doctor-assisted suicide
- Physician-assisted suicide
- Active euthanasia

TERMINOLOGY

To avoid any confusion about appropriate terminology, here is a list of key terms related to the Death with Dignity movement and end-of-life care:

Advance Directive: This is a general term describing two kinds of legal documents: a Living Will and Durable Powers of Attorney. Such documents allow a person to give instructions about future medical care in case they are unable to participate in medical decisions due to serious illness or incapacity. Each state has its own regulations concerning the use of advance directives.

Assisted Death: A legal option in states with Death with Dignity laws, which permits mentally competent adult patients with terminal illness to request a prescription for life-ending medications from their physician. The patient must self-administer and ingest the medication without assistance, and can forgo the process at any point.

Life-Sustaining Treatment: This is any treatment, the discontinuation of which would result in death. Such treatments include technological interventions like dialysis and ventilators. They also include simpler treatments, such as feeding tubes and antibiotics.

Living Will/Advance Directive: Documents that allow a patient to document their wishes concerning medical treatments at end of life.

Palliative Care: This medical speciality is often associated with hospice; however, it can also be used independently and alongside curative treatments. Palliative care (sometimes called comfort care) is available in every state, appropriate for anyone at any stage of life suffering with a debilitating illness—terminal or not—and focuses on pain management and providing comfort.

Terminal (or Palliative) Sedation: Generally practiced during the final days or hours of a dying patient's life, this coma-like state is medically induced through medication when symptoms such as pain, nausea, breathlessness, or delirium cannot be controlled while the patient is conscious. Patients generally die from the sedation's secondary effects of dehydration or other intervening complications. This option is rarely used and requires a health care provider to have speciality knowledge.

Stopping or Not Starting Medical Treatment: For some people with terminal illness, aggressive medical treatment may not be helpful and may prolong the dying process without improving quality of life. Under certain circumstances, treatments can increase suffering, ruin the remaining quality of life, or even shorten life. Stopping treatment can be combined with hospice and palliative care or voluntarily stopping eating and drinking to shorten the dying process and reduce suffering.

Voluntarily Stopping Eating and Drinking (VSED): Declining food, liquids, and artificial feeding as a means of shortening the dying process.