Advance Care Planning - End of Life Decisions – Life after Caregiving

Last updated August 2025

Advance Directive for Dementia

A Simple Way to Document the Medical Care You Would Want If You Had Dementia

How much medical care would you want if you had Alzheimer's disease or another type of dementia? This form is free to download and use as an Alzheimer's-specific living will.

Click here for more information and to download the Advance Directive for Dementia

Fill it out now, share it with your loved ones, then give a copy of it to your doctor. Provide guidance now. Feel better that you'll get the medical care that you would want. Help your loved ones if they are faced with making difficult decisions on your behalf.

This directive was developed by Barak Gaster, MD with help from experts in the fields of geriatrics, neurology, and palliative care. Dr. Gaster can be reached at barakg@uw.edu.

To learn more: read this JAMA essay about the rationale behind this project, and listen to this feature about it on NPR.

Guide on Advanced Care Planning Resource

The BOLD Public Health Center of Excellence on Dementia Caregiving has released a guide on advanced care planning resources, which contains tools, materials and information about an array of advance care planning elements like financial, housing, medical, legal and palliative care/hospice assistance for people living with dementia and their care partners.

Click here to download the guide – Updated Dec 2023.

The BOLD Public Health Center of Excellence on Dementia Caregiving

Ready, Set, Plan: A Step-by-Step Guide to Advance Care Planning

National Institute of Aging Email Series

Have you ever wondered what may happen in the event of an emergency or at the end of life regarding your medical treatment? Do you have a plan in place, so your loved ones know your preferences? If you don't, now is the time to start thinking about your advance care plan.

Advance care planning (ACP) involves discussing and preparing for future decisions about your medical care if you become seriously ill or unable to communicate your wishes. Having meaningful conversations with your loved ones is one of the most important parts of planning for your future care.

Get started with your own advance care plan by signing up for NIA's new email series, "Ready, Set, Plan! A Step-by-Step Guide to Advance Care Planning." Over seven weeks, you will receive weekly emails to help you learn about advance care planning and create a plan that works for you.

Click here for more information and to subscribe to the email series.

National Institute of Aging

Honoring Choices Minnesota – Light the Legacy

Honoring Choices Minnesota is focused on helping every adult Minnesotan understand what Advance Care Planning is, and working with health care providers to make sure they offer assistance to all patients, and will honor your choices.

As of September 2022, Light the Legacy is now taking on this role from the Twin Cities Medical Society (TCMS).

Light the Legacy
The Conversation Blog
Health Care Directive downloads – in multiple languages

Advance Planning Guides for People Living with Dementia

Advance planning empowers people to make their own decisions about important topics like finances, health care, and living arrangements before the need arises. Despite this, most people living with dementia have not created advance directives.

The National Alzheimer's and Dementia Resource Center (NADRC) created a series of consumer guides to help people living with dementia and their family members or other care partners know what to plan for and how to get started.

The guides cover 4 topics:

1. Health care planning
2. Financial planning
3. Care planning
4. Supporting someone living with dementia in making decisions

Click here to download the Advance Planning Guides for People Living with Dementia.

There are four different files; please use the Standard versions unless you are co-branding.

Grantees, their partners, and other providers serving older adults are encouraged to distribute these guides to their local communities and professional networks. The NADRC also created a version of these guides for organizations to co-brand with their logo. Interested organizations can consult the instructions and guidelines available on the NADRC website.

National Alzheimer's and Dementia Resource Center

Compassion & Choices

Dementia Tools

Compassion & Choices is working to transform how people die with dementia to ensure people are aware, empowered and supported in getting the care they want – or do not want – should dementia take hold.

The newly updated Dementia Values & Priorities Tool will guide you through a series of questions to consider the care you want if diagnosed with dementia. Once complete, you will receive a document outlining those wishes, which you can save or print to keep with your advance directive and share with others.

Tip: Look out for key terms in blue text as you go through the tool. Clicking on those terms opens a brief video that explains the concept in more detail.

A Compassion & Choices exclusive, the Dementia Provision adds language to an advance directive advising physicians and family of your wishes should you be unable to direct your care due to Alzheimer's disease or other forms of dementia.
Download and print your own Dementia Provision.

The website contains information about Advance Care Planning, the Dementia Decoder (an aid to clinical appointments) and the VERSD program (voluntarily stopping eating and drinking), plus links to helpful webinars and information about many other topics such as hospice and palliative care.

My End-of-Life Decisions Guide

This advance planning guide and toolkit was designed to help you capture your thoughts and make decisions about the care you receive and other important considerations unique to your situation.
End-of-life planning is a way to live more fully, connect more deeply and approach life with fewer regrets.

Click here to read the guide. You can download this guide and personalize it for your own use.

What is a POLST and Who Needs One?

June 4, 2024 – Link to the Recording

Compassion & Choices Medical Director Dr. Susan Wilhoit, a palliative care physician, will explain how the Minnesota POLST fits into end-of-life planning. She'll discuss who needs a POLST and how a POLST differs from an Advance Care Directive. The Provider Orders for Life Sustaining Treatment (POLST) is a portable medical order that can give patients with serious illness increased control over the treatment they do and do not want to receive at the end of life. The POLST helps ensure the patient's wishes are conveyed to emergency services and other medical providers. There will be plenty of time to ask questions.

As the End Nears: Dying with Dementia

August 8, 2023 Link to the recording

This webinar, the fifth of an ongoing series, follows the final stages of living with dementia, including treatments, symptoms and the physical experience. We aim to offer you a better understanding of what to expect with advanced dementia. With this information, we hope you feel more empowered to plan, prepare and make the

decisions necessary to guide your care. We will discuss disease progression and options for the end of life. There will be a Q & A session following the presentation.

Dr. Natalie Young, a geriatrician and palliative care physician at the University of California San Francisco, will join Compassion & Choices Medical Director Dr. Susan Wilhoit for the discussion.

Compassion & Choices

Palliative Care Through a Dementia Lens

Care Connection Webinar
December 14, 2023 Link to the Recording

In this webinar session, Ann Wyatt, MSW will address the ways a palliative approach can bring comfort to people with advanced dementia, and to their caregivers, by focusing on the activities of everyday life, such as eating, sleeping, environmental factors, meaningful engagement, and addressing pain.

PDF of webinar presentation material

Alzheimer's Foundation of America

Finding Comfort - Living with Advanced Dementia in Residential Care

This booklet is for family members, friends and caregivers of a person who has dementia. The purpose is to provide information about the best ways to offer comfort and the best possible quality of life for someone whose dementia is progressing.

Click here for more information and to download the free booklet or view it online in English or Spanish.

CaringKind

Palliative Care for People with Dementia Guidelines

In the absence of a medical cure or effective treatment, families and professional caregivers often feel helpless and hopeless. The principles behind our palliative care project offer help and the promise that we can make a residents' life better. This guide is for palliative care professionals.

Click here for more information and to download the free booklet.

CaringKind

Ellen Goodman Talks about End of Life and Dementia

Ellen Goodman and her mother spoke about everything except one thing: how her mother wanted to live at the end of her life. Watch this moving video where Ellen shares her personal experience of caring for her mom who had dementia.

"I didn't know how important it was to have these conversations early…"

Conversation Project

Conversation Starter Kits for Healthcare Directives

Conversation Starter Kit for Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia
Dementia Family Starter Kit

Your Conversation Starter Kit
Conversation Starter Kit

Who Will Speak for You? How to choose and be a Health Care Proxy
Health Care Proxy

Go Wish cards

Go Wish cards is a simple tool to help anyone articulate their end-of-life wishes enabling easy, trusting, "what do I want" discussions at any stage of life. These cards can help you with this tough, but most necessary conversation enabling your families, professionals and caregivers to honor your wishes.

Play the Go Wish On-line Interactive Version for free.

POLST (Physician/Provider Orders for Life-Sustaining Treatment)

Minnesota POLST and COVID 19
Basic discussion about the value of a POLST during the pandemic.
MN POLST and COVID-19

POLST Basics - An Overview of Important Treatment Decisions
This video is an overview of the Indiana POLST form, which is very similar in content to the Minnesota POLST form. Patients and families are encouraged to watch this video to understand the basics of the POLST form. The video is designed for people with advanced illness or frailty and their family members. It provides an overview of important treatment decisions in order to prepare a patient for a for POST (Physician Orders for Scope of Treatment) discussion with his or her medical provider.
POLST Basics

POLST (Provider Orders for Life-Sustaining Treatment)
Link to Minnesota POLST form
MN POLST Form

POLST Minnesota: Information for Patients and Family Members
MN POLST Info for Patients and Families

POLST Fundamentals
Overview and links to information about the POLST and its use.
National POLST program overview and links

POLST Minnesota: Frequently Asked Questions
MN POLST Frequently Asked Questions

What is an End-of-Life Doula?

Also known as a death doula or death midwife, end-of-life doulas provide care and support to those transitioning through the dying process. For the dying patient, they may provide emotional, physical, and spiritual support and help address the patient's wants and needs during the final days of life. They may also assist with logistical tasks, not limited to creating a death plan, planning a memorial service, and organizing a legacy project for future generations. An end-of-life doula may also offer support for family members during their loved one's dying process and offer grief support afterwards.

End with Care

Minnesota Death Collaborative

The Minnesota Death Collaborative is your resource for bridging the gap from life to death, for navigating the journey, and for reconnecting to the natural aspects of death. They also have useful resources to help cope with end-of-life decisions during the pandemic.

Minnesota Death Collaborative
MN Death Collaborative COVID-19 Resources

Brain Support Network – Brain Donation

Arrange to donate your brain or a loved one's brain in order to obtain a confirmed diagnosis (from an autopsy report), and to support research into the causes, treatments, and cures for neurodegenerative disorders.

The Brain Support Network helps you arrange for a brain donation even if you are not enrolled in a current research study. Today, brain banks focused on neurodegenerative diseases are interested in brain donation from persons with diagnoses such as Lewy Body Dementia, Progressive Supranuclear Palsy, Multiple System Atrophy, Corticobasal Degeneration, Parkinson's Disease, Frontotemporal Dementia, etc.

See the Brain Support Network FAQ for more about eligibility.

Whether you are planning in advance or thinking about this when the end of life may be days away, thank you for considering brain donation!

Brain Support Network

Brain Autopsy Program

HealthPartners Center for Memory and Aging

Having a loved one with memory loss or dementia can be devastating. There are unanswered questions about what caused the illness and whether it will affect other family members. A brain autopsy is often the only way to determine what disease caused the dementia symptoms.

A brain autopsy is important to:

- Get a clear diagnosis of the disease and provide a sense of closure
- Provide an accurate medical history for family members.
- Improve future research and treatments.

Fees start at $875, but costs vary depending upon the location of death. When prearranged, there should be no delay for typical funeral arrangements. The procedure will be performed within 24 hours of death. There are no obvious marks from a brain autopsy, which allows for an open casket funeral. No one will know unless you tell them. A confidential report is sent to authorized family members 4-5 months after the procedure.

For more information, please call 651-495-6565

Death, Dying, and End of Life Resources

You are invited to explore and contribute to a new digital library: Death, Dying, and End of Life Resources

Explore: A new online digital library of death, dying, and end of life resources, including burial and disposition.

Curated by: An interprofessional team of faculty, librarians, and community experts

Designed for: Health Sciences students, learners, instructors, and professionals as well as patients, families, and caregivers.

Cost: Freely available online

Engage: Contributions are welcomed and will be reviewed for quality and relevance.

Browse

Contribute Resource

National Center for Interprofessional Practice and Education
University of Minnesota

FamilyMeans – The Center for Grief & Loss

The Center for Grief & Loss offers specialized therapy for complicated grief, trauma and life transitions. All of our staff are clinically trained mental health therapists, which allows us to competently work with a variety of concerns for which individuals and families seek mental health care.

Our staff is particularly passionate about and experienced in helping individuals and families experiencing healing and growth from grief and trauma.

The Center for Grief & Loss provides services specific to loss and trauma

- Individual, couple, and family therapy for all ages.
- Support groups
- Consultation and critical incident response to businesses, schools and organizations in the aftermath of a sudden death or traumatic experience.
- Clinical supervision, professional workshops and training.

Contact FamilyMeans Center for Grief & Loss at 651-641-0177.

Community Grief Ritual

Explore and Express the Pain of Grief in Community
Fourth Saturdays | 2:00 - 4:00 PM CDT - in person
Showtime Coffee Community Room - 2700 Lexington Avenue N, Roseville MN 55113

This is a hard time to be a human with feelings, when trying to hold both our personal losses and the sufferings of the world is truly overwhelming. Don't sorrow alone. Find your community here - all varieties of grief and all ways of grieving are welcome.

The Grief Ritual is a free community offering. Donations help us continue this work. Please bring a photo or an object that represents something that you are grieving. Dress for comfort. Beverages are available to purchase. This is a safe place - all are welcome here.

Twin Cities Grief Collective - Creating a sacred space for loss and longing to be tended in the community

Caregiving & Beyond – Support Group

Sessions held quarterly – March, June, September and December. Sessions include resources, facilitated discussion, reflection, and support about life after caregiving.
Register by contacting Sarah Gavin at 651-789-4004
or email sgavin@familymeans.org.

Center for Grief & Loss

Support for Later Caregiving/After Caregiving

The group serves both former caregivers and those in later stages of caregiving.

It meets in person from 1:00-2:00 p.m. on the fourth Wednesday of each month at Prince of Peace Lutheran Church, 13801 Fairview Dr., Burnsville. Fewer meetings are scheduled for August and September.

For more information contact: Vicki Patterson, 651-373-6786
or email victoria.patterson@darts1.org.

Sponsored by DARTS in Dakota County

Former Dementia Caregiver Re-Entry Group

Find the "New" you after caregiving. In an informal setting, share with others who have had a similar journey. This is an opportunity to move past the grief and loss to reclaim "you", and create a meaningful life beyond your caregiver role. Experienced facilitators will coordinate and offer referrals and resources as needed.

Sessions held online via Zoom 1:00-2:30 p.m. on the second and fourth Tuesdays of each month. Topics and organization are determined by participants.

Contact Warren Wolfe at 612-791-5316 or email warren.wolfe11@gmail.com.

Sponsored by Roseville Alzheimer's & Dementia Community Action Team

Moving Forward – Life After Dementia Caregiving

Meets online 9:30-11 a.m. on the second and fourth Tuesdays monthly.

Online group sponsored by the Alzheimer's Association, Minnesota-North Dakota chapter. Designed for spouses who have recently lost their partner due to Alzheimer's or other types of dementia. Although grief and loss are discussed, this is not a typical grief group. The group focuses on building connections with others who understand the unique challenges of losing a spouse due to dementia and moving forward, life after dementia caregiving.

Register by contacting Jenna Pogorels at 218-722-4335 or jpogorels@alz.org.
Alzheimer's Association of Minnesota/North Dakota

Transitioning From Caregiving to Living

Being a family caregiver can be severely taxing financially, emotionally, and physically. But when caregiving responsibilities end, family caregivers may find it difficult to transition back to their former life. Next Avenue's Myrna Marofsky draws on the expertise of medical professionals and former caregivers to give guidance on how to readjust to a life without caregiving.

Click here to read the article from the December 12, 2024 issue of NextAvenue