



# Dementia Legal Planning Toolkit

# Welcome to the Dementia Legal Planning Toolkit!

We are glad you're here and interested in planning for the future. We created the Dementia Legal Planning Toolkit to help you think about the kinds of financial and health care decisions you will need to make if you are living with mild cognitive impairment or dementia. We have also included some do-it-yourself legal forms to get you started.

## Who should use this toolkit?

If you live in Washington State and you have recently been diagnosed with mild cognitive impairment (MCI) or dementia or you want to plan for this possibility, this toolkit is for you.

Care partners, friends and family members of people living with dementia may also find this toolkit useful in helping their loved ones plan ahead.

## Why is early planning important for people with dementia?

If you start planning as soon as possible, you are more likely to be able to sign important legal documents, choose who will help you, and write down your health care preferences, which can guide your care partners, friends, family and medical providers in the future.

## What if you don't plan ahead?

Without early planning, other people in your life—family members, medical providers, or even a judge—may need to make decisions for you. In some cases, these decisions may not be the choices you would have made for yourself.

Although this toolkit covers a wide range of health care and legal planning needs, no toolkit can cover every possibility. Try to talk with a trusted health care provider, lawyer or financial planner about your unique situation.

Planning ahead will help you retain a sense of who you are and how you want to receive help and care.

It will also help your care partners, friends and family know how best to support you. **It is a gift to yourself and to them.**

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# DEMENTIA PLANNING: The Basics

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When you are diagnosed with mild cognitive impairment or dementia, it is important to prepare and sign legal forms as soon as possible because dementia will affect your ability to sign legal forms in the future. Planning means deciding **who** should make decisions on your behalf and **what** kinds of care you want in the future.

## Dementia and Capacity

### Alzheimer's and dementia: are they the same thing?

Dementia is not a specific disease, but an overall term describing a wide range of symptoms, including loss of your ability to remember, think or reason that is severe enough to interfere with your everyday life. It is not normal aging. Dementia is caused by damage to the brain from disease or trauma. Alzheimer's disease is the most common cause of dementia, but there are also types of dementia that can be different than Alzheimer's: including vascular dementia, dementia with Lewy bodies, and frontotemporal dementia.

### What does "capacity" mean in dementia legal planning?

Lawyers use the term "legal capacity" to refer to your ability to understand and sign a legal form to make it legally enforceable. For example, someone probably has legal capacity to sign a legal form, like a power of attorney or health care directive form, if they understand the consequences of their actions and can make rational decisions.

If you have any doubts about your capacity to sign legal planning forms, you should talk to your medical provider. It may be helpful to have a capacity evaluation or assessment just before you sign legal planning forms.

## Legal Planning Forms: An Introduction

Here are four common dementia planning forms you should consider completing now:



**Power of Attorney  
for Finances**



**Power of Attorney  
for Health Care**



**Health Care  
Directive**



**Dementia  
Directive**

### What is a **Power of Attorney** form?

A power of attorney form lets you choose a trusted friend or relative to help you with your finances or health care decisions. You get to choose who can speak for you if you no longer can speak for yourself.

### What is a **Health Care Directive** form?

A health care directive form lets you choose what kind of medical treatments you do or do not want to have if you are terminally ill or permanently unconscious. It also allows you to express your general values, hopes, and concerns about **all** health care needs.

### What is a **Dementia Directive** form?

A dementia directive is a health care directive form that lets you make choices about dementia care and other issues that are likely to arise as you live with dementia. We have included the *Living with Dementia Mental Health Care Advance Directive* form in this toolkit which lets you choose how you want to receive care and how you want others to help you as you live with dementia over time, including how you want to manage personal relationships and safety. You can also find a link on the Resource List to the *Advance Directive for Dementia* which lets you say how much medical care you want during different stages of dementia.

You can hire a lawyer or attend a free legal clinic to have these documents prepared for you or you can do them yourself. Do-it-yourself forms are included in this toolkit.

## Action Steps

We recommend the following first steps for planning ahead:

- ☐ **Complete a Durable Power of Attorney for Finances.**
- ☐ **Complete a Durable Power of Attorney for Health Care.**
- ☐ **Complete both Health Care Directives:** one for general health care and a second one that is dementia-specific, like the *Living with Dementia Mental Health Advance Directive*.
- ☐ **Complete an estate plan.** Your estate plan may include legal documents such as a Will and maybe a trust. It may also include a plan for your remains (burial, cremation, or some other option).
- ☐ If you have doubts about your capacity to sign legal documents, **get a medical assessment** to find out whether your capacity to sign legal documents is an issue.
- ☐ **Have conversations with your family members, friends and care partners** about what's most important to you when it comes to dementia planning. Let them know about your plan and any necessary next steps.







# Financial Decisions

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A dementia diagnosis makes financial planning more complex and more important. With proper planning, you can choose a trusted friend or relative to help you pay your bills and manage your property. You can also decide how to pay for the care you will need for day-to-day activities and how you want your affairs to be managed after death. Much of this planning can be accomplished using legal forms while parts will require advice or assistance from professionals.

### Durable Power of Attorney for Finances

A durable power of attorney for finances form lets you choose a trusted friend or family member to help you with your finances, such as paying your bills, rent or mortgage payments; withdrawing and depositing money in a bank account; making sure you are eligible for public benefits programs; and renting or selling property. You can still make your own financial decisions while you are capable. The power of attorney form is a backup plan in case you can't manage your money and property independently in the future. You can change or cancel your power of attorney form at any time. We have included a do-it-yourself power of attorney for finances form in this toolkit with more information and instructions.

### Representative Payee

A representative payee is someone who manages your government benefits (like Social Security or Veterans benefits). Often, the payee is a family member or close friend, but the payee can also be a non-profit organization or professional fiduciary. The payee will generally set up a separate account to receive your government benefits and use the account to pay your bills.

## Paying for Care

### What is long-term care?

Long-term care can mean a variety of services to help people with a chronic illness or disability who cannot care for themselves. Long-term care can include help with grocery shopping, meal preparation, eating, bathing, dressing, grooming, and using the toilet. You may need long-term care in your home with a personal caregiver or in an assisted living facility, adult family home or nursing home.

### Does Medicare or my health insurance pay for long-term care?

Medicare and most standard health insurance plans do not cover long-term care costs. You might be able to borrow cash or receive a loan from your life insurance policy. Talk to a lawyer or your insurance providers to find out what options you have for long-term care.

### What does Medicaid cover?

Medicaid is the single largest payer of long-term care expenses for people with dementia in the United States. Medicaid covers many long-term care expenses for people living with dementia that other insurance plans will not cover. But Medicaid usually requires income and property limits that can be complicated. You should talk to someone at your local aging and disability resource center or a lawyer about Medicaid to determine whether you meet the income and property requirements. You should never give away money or property to try to qualify for Medicaid without the advice of an expert.

## Estate Planning

This toolkit is focused on legal planning for living with dementia. You should also consider planning for settling your estate matters after your death while you have the capacity to do so. It is best if you can talk with an estate planning lawyer about making an estate plan.

### What is a Will?

A Will is a document that says who you want to manage your estate (such as money, property or belongings) and to whom you want your money, property or belongings to go after you die. A Will is usually prepared by a lawyer.

### What is a Trust?

A trust holds money and property for a “beneficiary” and is managed by a “trustee.” You might need a trust if you have money and property and want to let someone else manage it for you. Additionally, you might need a trust if you receive government benefits, like Medicaid, and you receive an inheritance or legal settlement. Trusts are complicated, so talk to a lawyer about whether a trust is right for you.



## What is a Disposition of Remains form?

A disposition of remains form lets you say how you want your body to be handled after you die, including whether you want to be buried, cremated or composted and also your preferences for your funeral or other ceremony honoring your life. It also says who will handle your funeral arrangements.

## What is a Death Certificate?

The Washington State Department of Health issues an official Death Certificate for each death that takes place in the State. It tells the date, time, place, and official cause of death.

### Am I eligible for other benefits? You might be eligible for other kinds of income or insurance, including:

- **Social Security Disability Insurance (SSDI).** The federal SSDI program offers monthly payments to people with disabilities under age 65 who have earned enough work credits. Under the Compassionate Allowances program, those with younger-onset dementia and some specific dementia diagnoses may also be eligible for SSDI.
- **Supplemental Security Income (SSI).** The federal SSI program offers monthly payments to people who have not earned enough work credits and have limited income and assets.
- **Veterans benefits.** If you or your spouse served in the military, even for a short period, you may be eligible for health insurance or long-term care benefits from the Department of Veterans Affairs. Benefits may include coverage of adult day care, respite care, caregiver support, nursing home expenses, and long-term care services such as assistance eating, bathing, and dressing.
- **Unemployment benefits.** If you lose your job as a result of your dementia diagnosis, you may be eligible to get Washington state unemployment benefits.
- **COBRA.** COBRA may allow for insurance coverage for those under age 65 and may be less expensive than purchasing an individual health insurance plan. If you have private insurance, ask if similar coverage is available under a disability extension of benefits covering dementia-related disabilities.

Links to more information and resources to help with long-term care and financial decisions are on pages 11 – 12.





# Health Care Decisions

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It is important to make decisions now about the kind of health care you want in the future and who will make sure you get that care if you can't speak for yourself. You should also talk with your friends, family members and care partners about your health care preferences and values, especially end-of-life treatments and decisions.

Your health care values may include your religious, cultural, or ethical beliefs, your preferences around pain tolerance and pain management, and your preferences for preserving quality of life.

### Durable Power of Attorney for Health Care

A durable power of attorney for health care form lets you choose a trusted friend or relative to help you make health care decisions. You can still make your own health care decisions while you are capable. You can change or cancel your power of attorney form at any time. We have included a do-it-yourself durable power of attorney for health care form in this toolkit with more information and instructions.

### Health Care Directive

A health care directive lets you say what kind of medical treatments you want or do not want in an end-of-life situation if you can't speak for yourself. It is sometimes called a "Living Will". It also gives you the opportunity to express additional instructions about your values, hopes, and concerns for all health care decisions, not just care at the end-of-life. You can change or cancel your directive at any time. We have included a do-it-yourself health care directive form in this toolkit with more information and instructions.

## Dementia Health Care Directive

A dementia directive is a health care directive form that lets you make choices about dementia care and other issues that are likely to arise as you live with dementia. We have included the *Living with Dementia Mental Health Care Advance Directive* form in this toolkit. It lets you choose how you want to receive care and how you want others to help you as you live with dementia over time, including how you want to manage personal relationships, driving and safety. Dementia is not a “mental health” disability, but a cognitive impairment. The use of the term “mental health” in the *Living with Dementia Mental Health Advance Directive* refers to special treatments and/or care settings you might need while you are living with dementia.

You might also consider completing the *Advance Directive for Dementia* form which lets you say how much medical care you want during different stages of dementia. It can be found at [www.dementia-directive.org](http://www.dementia-directive.org).

## Mental Health Advance Directive

A mental health advance directive form lets you choose what kinds of mental health treatments you want if you cannot make these decisions for yourself due to a mental illness. We have not included this form in this toolkit, but you can find a link to the form included in the Resource List below.

## Portable Orders for Life-Sustaining Treatment (POLST)

A POLST form is a bright green medical form. It is an important way to tell all medical providers what kind of treatment you want or do not want. It can also tell first responders what kind of treatment you want or do not want in a medical emergency. You can ask your medical provider for a POLST form and discuss your options with them. After your medical provider signs your POLST form, you should keep it in an easily accessible location at home (for example, on your refrigerator) and bring it along with you anytime you go to an emergency room or see a new provider.

## Choices about End-of-Life Care

People can live well with dementia or mild cognitive impairment. Each person’s experience, including if, or how, the condition changes over time can be very different. Planning ahead includes thinking about how you want to live and the type of care you eventually want near the end of life. You can write down your wishes for end-of-life care in a health care directive and discuss your wishes with your friends, relatives and medical providers.

Your plans might include palliative care. Palliative care is available for people living with a serious illness, including dementia. Palliative care focuses on providing relief from the symptoms and stress of illness with a goal to improve quality of life for both the patient and the family. A palliative care team can be helpful as you consider end-of-life choices.

You can also reach out for more information from the Alzheimer’s Association and/or End of Life Washington, included in the Resource List.

No matter what you choose, talk to your medical providers, family and caregivers and write out your values and wishes in a health care directive so others will know how best to care for you.

Links to more information and resources to help with health care decisions are on page 12.



# Resources for You

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## General Information

### **Community Living Connections – Find Care & Support Options**

[www.memorylossinfowa.org](http://www.memorylossinfowa.org)

### **Dementia Action Collaborative (DAC)**

[www.dshs.wa.gov/altsa/dementia-action-collaborative](http://www.dshs.wa.gov/altsa/dementia-action-collaborative)

### **Dementia Friendly America**

[www.dfamerica.org](http://www.dfamerica.org)

### **Dementia Road Map: A Guide for Family and Care Partners**

[www.memorylossinfowa.org](http://www.memorylossinfowa.org)

### **End of Life Washington**

[www.endoflifewa.org](http://www.endoflifewa.org)

### **Northwest Justice Project**

[www.washingtonlawhelp.org](http://www.washingtonlawhelp.org) and  
[www.nwjustice.org](http://www.nwjustice.org)

### **Alzheimer's Association, Washington State Chapter**

[www.alz.org/alzwa](http://www.alz.org/alzwa)

1-800-272-3900

## Financial Information

### **Power of Attorney for Finances Form**

[www.washingtonlawhelp.org](http://www.washingtonlawhelp.org)

### **Representative Payee Program**

[www.ssa.gov/payee](http://www.ssa.gov/payee)

### **Statewide Health Insurance Benefits Advisors**

[www.insurance.wa.gov/statewide-health-insurance-benefits-advisors-shiba](http://www.insurance.wa.gov/statewide-health-insurance-benefits-advisors-shiba)

1-800-562-6900

### **Long-Term Care Insurance**

[www.insurance.wa.gov](http://www.insurance.wa.gov)

### **Washington Long-Term Care Ombudsman Program**

[www.waombudsman.org](http://www.waombudsman.org)

### **Washington DSHS Aging and Long-Term Support Administration**

[www.dshs.wa.gov/altsa](http://www.dshs.wa.gov/altsa)

### **Medicare**

[www.mymedicare.gov](http://www.mymedicare.gov)

### **Medicaid and other benefits**

[www.washingtonconnection.org](http://www.washingtonconnection.org)

1-855-567-0252

*(continued from previous page...)*

**Social Security Benefits**

[www.ssa.gov/onlineservices](http://www.ssa.gov/onlineservices)

1-800-772-1213

**Veterans Benefits**

[www.va.gov](http://www.va.gov) and [www.dva.wa.gov](http://www.dva.wa.gov)

1-800-562-2308

**COBRA**

[www.dol.gov/general/topic/health-plans/cobra](http://www.dol.gov/general/topic/health-plans/cobra)

**Estate Planning Lawyers**

[www.naela.org/findlawyer](http://www.naela.org/findlawyer)

**Disposition Authorization and**

**Designated Agent forms**

[www.peoplesmemorial.org](http://www.peoplesmemorial.org)

## Health Care Information

**Power of Attorney for Health Care form**

[www.washingtonlawhelp.org](http://www.washingtonlawhelp.org)

**Living with Dementia Mental Health**

**Advance Directive form**

[www.endoflifewa.org](http://www.endoflifewa.org)

**Advance Directive for Dementia**

[www.dementia-directive.org](http://www.dementia-directive.org)

**Mental Health Advance Directive form**

[www.hca.wa.gov/health-care-services-supports/behavioral-health-recovery/mental-health-advance-directives](http://www.hca.wa.gov/health-care-services-supports/behavioral-health-recovery/mental-health-advance-directives)

**End of Life Choices**

[www.endoflifewa.org/end-life-choices](http://www.endoflifewa.org/end-life-choices)

**Portable Order for Life-Sustaining Treatment (POLST)**

[www.wsma.org/POLST](http://www.wsma.org/POLST)

**Health Care Values and the Letter Project**

[www.med.stanford.edu/letter.html](http://www.med.stanford.edu/letter.html)

**Conversations about End-of-Life Care**

[www.honoringchoicespnw.org](http://www.honoringchoicespnw.org)

**Driving Contract**

[www.alz.org/help-support/caregiving/safety/dementia-driving](http://www.alz.org/help-support/caregiving/safety/dementia-driving)

**Driver License Restrictions**

[www.dmv.com/wa/washington/senior-drivers](http://www.dmv.com/wa/washington/senior-drivers)

## Translated Information

**Washington Law Help (24 languages)**

[www.washingtonlawhelp.org/languages](http://www.washingtonlawhelp.org/languages)

**The Conversation Project (13 languages)**

Includes a starter kit for caregivers of people with dementia

[www.theconversationproject.org](http://www.theconversationproject.org)

**The Stanford Letter Project (8 languages)**

[www.med.stanford.edu/letter.html](http://www.med.stanford.edu/letter.html)

**National Hospice and Palliative Care Organization (3 languages)**

[www.caringinfo.org](http://www.caringinfo.org)

You can find the Dementia Legal Planning Toolkit online, along with additional dementia planning resources on the Community Living Connections website – [www.memorylossinfowa.org](http://www.memorylossinfowa.org).



## APPENDIX A

# Dementia Legal Planning Checklist

You should complete or update the following legal planning forms as soon as possible after a diagnosis of dementia or suspected dementia:

- ☐ Durable Power of Attorney for Finances
- ☐ Durable Power of Attorney for Health Care
- ☐ Health Care Directive
- ☐ Dementia Health Care Directive

Some other letters and forms you should consider completing now include:

- ☐ A form or letter to care partners about your health care values if they are not covered in your health care directive form.
- ☐ A list of your closest family and friends, agents, doctors, lawyers, accountants, financial planners, and others who may have important medical, legal, or financial information about you.
- ☐ A list of important papers, including legal planning forms, and where they are located
- ☐ Portable Orders for Life-Sustaining Treatment (POLST) Form
- ☐ Authorization and Disposition of Remains Forms
- ☐ Last Will and Testament

## APPENDIX B

# Meeting with a Lawyer Checklist

If you decide to meet with a lawyer for legal planning, you should consider bringing the following papers:

- ☐ Any previously signed will, trust, power of attorney, or health care directive
- ☐ A list of your family members, including parents, siblings, children, and grandchildren
- ☐ Any divorce agreement, premarital agreement, community property agreement or other agreement with a spouse or ex-spouse
- ☐ A list of possible personal representatives and agents: You should think about who you want to make financial decisions and health care decisions for you if you need help. You should also think about who will manage your money and property after you die.\*
- ☐ Financial statements for checking, savings, money market, brokerage, pension, IRA, etc. (The first page of your most recent statement may do.)
- ☐ Any deed(s) for your house and/or land
- ☐ Any life insurance policy information
- ☐ Any business agreements for any business you own
- ☐ Any trademark, patent and copyright registration certificates
- ☐ Any stock certificates
- ☐ Completed questionnaire given to you by the lawyer, if they gave you one

\* If you don't have any agents in mind, there are professional agents who can help you. The lawyer can tell you about professional agents.



## About the Dementia Action Collaborative (DAC)

The Washington State Plan to Address Alzheimer's Disease and Other Dementias was published in January 2016. The Plan identifies goals, strategies and recommendations to prepare for the future. The Plan also called for the formation of a next generation workgroup to implement the recommendations. This group is known as the Dementia Action Collaborative (DAC), a statewide collaboration of public and private partners committed to implementing recommendations in the Plan. The DAC includes a range of appointed members, including people with dementia, family caregivers, advocates, representatives of the aging network, Alzheimer's organizations, long-term care providers, health care professionals, legislators and governmental agencies. Find out more about the DAC and their activities at [www.dshs.wa.gov/altsa/stakeholders/alzheimers-state-plan](http://www.dshs.wa.gov/altsa/stakeholders/alzheimers-state-plan).