Advance Directive for Living with Dementia

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An Advance Directive for Living with Dementia can help you, loved ones, and caregivers understand your wishes and preferences for care during the long course of illness and when you can't speak for yourself. It covers who you'd like to provide your personal care, where you'd want to live if you can't stay safely at home, how to pay for care, what to do if you become combative, future relationships for you and your spouse/partner, and when to stop driving. (Form and instructions)

Form attached:
Advance Directive for Living with Dementia (NJP Planning 512)

What's included in this Advance Directive?

You can include anything that might help others know how to give you the care you need and make decisions for you when you can't make them for yourself. This could be:

- Who you want to provide care for you in your home.

- Where you want to live if you can't live at home anymore.
- Your cultural, religious, and gender preferences about your care.
- What to do if you become combative or abusive because of dementia.
- Preferences for financing your care.
- Preferences about future intimate relationships for yourself and/or your spouse or partner.
- When you should stop driving.

What's not included?

This Advance Directive **doesn't address your preferences for end-of-life care**. For that, you need to make a Health Care Directive (living will) to document your wishes and a Power of Attorney that names someone to make decisions for you when you can't make them for yourself.

Is it legal?

It is a legal advance directive under Washington state law. Medical, long-term and other providers are usually legally required to follow your advance directives. There are exceptions.

Even if you live outside Washington state, this advance directive provides valuable guidance to your loved ones and caregivers.

Does it need to be notarized?

It's best to sign your directive in front of a notary.

If you can't find a notary, you can sign in front of 2 qualified witnesses. The form says who qualifies.

What should I do after I sign?

Give copies to any medical providers, loved ones, and people involved in providing your care or making decisions for you. If you have any Powers of Attorney, give copies to them.

The best way to make sure your wishes will be honored is to talk with your medical team, your care facility, your caregivers, and your loved ones about this Advance Directive. Ask them to honor your choices and decisions.

What else can I do to plan ahead?

This Advance Directive is about living with dementia, but we have other directives you can use to plan for your end of life care. (See Related links below.)

The Dementia Action Collaborative's Dementia Legal Planning Toolkit (https://www.dshs.wa.gov/altsa/dac/individualsandfamilies) can help you make important financial and health care decisions and give you a place to write them down.

Who can help me plan how to pay for long-term care?

Long-term care is expensive. You can pay for it with your own savings, long-term care insurance, and/or public assistance from Medicaid. We **strongly recommend** you seek help from an experienced elder law attorney to plan how to finance your care. The Washington Academy of Elder Law Attorneys (https://waela.org/) has a directory.

Advance Directive for Living with Dementia

My name is _____. My date of birth is _____.

I am a person with decision-making capacity. I voluntarily sign this mental health directive under RCW 71.32.260. If I cannot make decisions for myself, my relatives, friends, agents, and medical providers should fully honor every part of this directive. If any part of this directive is invalid, the rest should be honored. I revoke any Advance Directive for Living with Dementia that I have signed in the past.

This directive instructs my health care agent or other legal decision-maker ("decision-maker") and all caregivers how to act on my behalf.

1. **Start date.** This directive is effective (*check one*):
   - ☐ Now.
   - ☐ Only if I can't make decisions for myself (if I'm incapacitated).
   - ☐ When my decision-maker determines that any of these circumstances, symptoms, or behaviors have occurred (*check all that apply*):
     - ☐ I am no longer able to communicate verbally.
     - ☐ I can no longer feed myself.
     - ☐ I can no longer recognize people who are important to me.
     - ☐ I put myself or others in danger because of my actions or behaviors.
     - ☐ Other (*describe*): _____
2. **End date.** I want this directive to remain in effect until revoked.
3. **Revocation.** I can cancel (revoke) this directive (*check one*):
   - ☐ **Only when I can make decisions for myself (when I have capacity).** I understand this means I can't cancel this directive unless I have capacity. It means I may receive the medical care and medication listed in this directive even if I object at the time.
   - ☐ **Even if I cannot make decisions for myself (if I'm incapacitated).** I understand this means I can cancel this directive at any time. This means I may not get the medical care and medication listed in this directive when I am incapacitated.
4. **Health care decisions**

   I want whoever makes dementia care decisions for me to do as I would want in the circumstances, based on the choices I express in this directive. If my wishes are not known, then I want decisions to be made in my best interest, based on my values, this directive, and information provided by my health care providers.
5. **Personal history and care values statement**
   - ☐ None.
   - ☐ Attached.

➢ Preferences and instructions about my care and treatment

6. Care in my home

I prefer that my personal care and assistance be provided by these people in the order I've numbered them (*put "1" for your first choice, "2" for second choice, and so on*):

___ Volunteer caregivers who are family members.

___ Volunteer caregivers who are not family members.

___ Paid caregivers who are family members.

___ Paid caregivers who are not family members.

___ Other (*describe*): _____

7. Cultural, religious, and/or gender preferences about my care and assistance

☐ None.

☐ (*Describe*) _____

_____

_____

_____

_____

_____

8. Out-of-home placements

If I cannot receive care in my home, I would like to receive care in the following place/s, if possible (*put "1" for your first choice, "2" for second choice, and so on*):

__ A friend or family member's home.

Name (*optional*): _____

__ Adult family home.

Name and/or location (*optional*): _____

__ Assisted living facility.

Name and/or location (*optional*): _____

__ Nursing home.

Name and/or location (*optional*): _____

__ Other (*describe*): _____

9. Assessment. If someone needs to do an assessment or make recommendations about my ability to remain in my home, I prefer this be done by the following person/s or agencies:

☐ No preference.

☐ (*Name/s*) _____

10. Psychiatric Hospitalization

Sometimes people with Alzheimer's or dementia become aggressive, assaultive, or combative, despite good care. If this happens, emergency or other treatment may be necessary. You can consent to psychiatric hospitalization in advance. If you don't consent, someone would have to get a court order for your involuntary commitment to a psychiatric hospital.

Important! By consenting to inpatient mental health treatment now, while you are well, you may get treatment sooner if you decompensate.

Check one (sign if consenting):

☐ **I consent** to voluntary admission to inpatient mental health treatment for (*up to 14*) _____ days if my mental health care agent and treating medical providers decide it is appropriate. I prefer to receive treatment in a facility specializing in Alzheimer's/dementia care to reduce my behavioral symptoms and stabilize my condition.

▶ _____

My signature (*in front of a notary or witnesses*)

☐ **I do not consent** to inpatient mental health treatment.

11. Psychiatric hospital or other facility preferences

☐ If I need hospitalization, I prefer to go to a specialized dementia care unit at:

_____

☐ If I need hospitalization, I **do not** consent to these hospitals or facilities:

_____

☐ I want treatment from trained caregivers who know me and my history, and who know how to handle the situation.

☐ No preference.

12. Financing my care

I know that the cost of my care could become high over the course of my illness. I have the following preferences about financing my care (*check one*):

☐ Please use my income, assets, and savings to buy the highest quality private care for me, even if this requires selling my home and other property.

☐ I want to preserve my income, assets, and savings for my partner/spouse, children, and heirs, if possible. Please use all available planning options to meet this goal, including, but not limited to (*check all that apply*):

- ☐ Medicaid planning
- ☐ Gifting
- ☐ Divorce or legal separation
- ☐ Changing estate planning documents
- ☐ Tax planning

13. Future intimate relationships – partner or spouse

☐ Skip this section.

☐ My partner or spouse is (*name*):_____.

a. Preferences about continuing our intimate relationship (c*heck all that apply*):

☐ My intimate relationship with my partner/spouse is important to both of us.

☐ We want to maintain our sexual relationship for as long as possible.

☐ I completely trust my partner/spouse to make any judgments about continuing our intimate relationship, including when to stop if they're no longer comfortable.

☐ I want to maintain our sexual relationship even if we divorce or end our legal domestic partnership for financial reasons.

☐ I know that I may forget my partner/spouse as my Alzheimer's or dementia progresses. Even if this happens, I want to continue to be intimate for as long as my partner/spouse wants to and feels comfortable doing so.

☐ If I need nursing home care, I request the privacy needed for us to continue our relationship, as required by law.

☐ Other preference/s: _____

_____

b. Preferences about my partner/spouse having relationships with someone else (c*heck one*):

☐ I want my partner/spouse to seek companionship and intimacy when I can no longer provide that in our relationship if they wish to do so. I would not consider this a violation of our vows or commitment to each other. I understand that my illness may last a long time, and that I may no longer recognize or be able to function emotionally or sexually with my partner/spouse.

☐ I believe that a relationship outside our partnership/marriage or other committed relationship is **not** permissible and should **not** be pursued by either of us.

Other preference/s, if any: _____

_____

14. My future intimate relationships

☐ Skip this section.

☐ Whether or not I have a current partner or spouse (c*heck one*):

☐ I know that residents at long-term care facilities sometimes develop intimate or romantic relationships with each other. I am not opposed to having such a relationship if my caregivers or medical providers believe the relationship improves my mental health and I am not coerced in any way.

☐ I do **not** consent to any intimate relationships, even if the relationship improves my mental health, except as stated in section 13 if I have a spouse or partner.

Other preference/s, if any: _____

_____

15. Driving

If it's unsafe for me to drive, I agree that people can take steps to stop me from driving including hiding my keys, disabling my car, and denying me access to my car.

The decision about whether I'm safe to drive can be made by (*check all that apply*):

☐ My legal decision-maker/s.

☐ A qualified professional who can test my visual and mental acuity.

16. Pets

☐ I don't have any pets.

☐ When I can no longer care for my pets, I prefer (*describe who you want to care for them or if someone has agreed to adopt them*):

_____

_____

_____

17. Participation in experimental Alzheimer's or dementia drug trials (*check one*):

☐ **I consent** to participation in any clinical drug trials for drugs that might improve the symptoms of Alzheimer's/dementia or prevent the full onset of the disease. I am willing to participate in the trial even if it could lead to my earlier death. I would rather die sooner but with my memory more intact.

☐ **I do not consent** to participation in any drug trials.

18. Durable Power of Attorney for Mental Health Care

Important! *A general power of attorney for health care can't authorize mental health hospitalization. If you want your power of attorney to be able to consent to this (in section 10, above), you must complete the power of attorney for mental health care section below. You should appoint the same person as your agent for mental health care as for general health care to avoid confusion.*

☐ I am **not** appointing a power of attorney **for mental health care**.

☐ I am appointing a power of attorney for mental health care as follows. I revoke (cancel) any other power of attorney **for mental health care** documents I signed in the past.

a. Agent. I choose (*name*): _____ as my agent with full authority to manage my mental health care.

☐ **Alternate.** If the agent named above is unable or unwilling to act, I choose (*name*): _____ as my agent with full authority to manage my mental health care.

☐ **2nd Alternate.** If both the agent and alternate named above are unable or unwilling to act, I choose (*name*): _____ as my agent with full authority to manage my mental health care.

b. Spouse or partner.

☐ Does not apply. I didn't name my spouse or partner as an agent or alternate.

☐ One of the agents or alternates named above is my spouse or domestic partner. If we divorce or legally separate (*check one*):

☐ Their authority to act as my agent is revoked.

☐ They will continue to have authority to act as my agent.

c. My Rights. I keep the right to make mental health care decisions for myself if I am capable.

d. Durable. My agent can use this power of attorney to manage my affairs even if I become sick or injured and cannot make decisions for myself. My disability will not affect this power of attorney.

e. Revocation. I understand that I may revoke this power of attorney at any time by giving written notice of revocation to my agent.

f. Powers. My agent shall have full power and authority to make mental health treatment decisions on my behalf, consistent with any instructions and/or limitations in this directive. If my agent does not know my wishes, I authorize my agent to make the decision that my agent determines is in my best interest.

g. Nomination of Guardian. I nominate my agent as my guardian for consideration by the court if guardianship proceedings become necessary.

h. HIPAA Release. I authorize my healthcare providers to release all information governed by the Health Insurance Portability and Accountability Act of 1996 (HIPAA) to my agent.

19. Other documents

In planning for my health care, estate, and potential incapacity, I have signed the following documents (*check all that apply and attach copies, if possible*):

☐ Durable Power of Attorney for Health Care (**not** mental health)

☐ Durable Power of Attorney for Finances

☐ Health Care Directive ("Living Will")

☐ Other (*Examples: POLST, Advance Directive for Voluntary Stopping of Eating and Drinking (VSED)*):

_____

_____

I understand the purpose and effect of this Advance Directive for Living with Dementia. I understand consent to treatment or admission in this directive constitutes my informed consent. I am signing of my own free will for the purposes stated in this document.

▶ _____ _____

My signature (*in front of a notary or witnesses*) Date

Notarization (preferred)

State of Washington
County of _____

This document was acknowledged before me on (date) _____

by (name) _____.

▶ _____

Signature of Notary

Notary Public for the State of Washington.

My commission expires _____.

Statement of Witnesses (only if you cannot find a notary)

On (*date*): _____, (*name*): _____ signed this Advance Directive for Living with Dementia in my presence. This person is personally known to me or provided proof of identity. I believe they are able to make health care decisions, to understand this document, and to have signed it voluntarily. They do not appear to be acting under duress, undue influence, or fraud.

I am **not**:

- A person designated to make medical decisions for them
- A health care provider or professional directly involved in their care at the time the directive is made
- An owner, operator, employee, or relative of an owner or operator of a health care facility or long-term care facility where they are a patient or resident
- A person related by blood, marriage, or adoption to them
- In a dating relationship with them (see RCW 7.105.010)
- A minor or incapacitated person
- A person who would benefit financially if they undergo mental health treatment

Witness 1

▶ _____
Signature

Print Name: _____

Address: _____

_____

Phone: _____

Witness 2

▶ _____
Signature

Print Name: _____

Address: _____

_____

Phone: _____

Advance Directive for Living with Dementia
Attachment: Contact info

My information

My name _____

My date of birth _____

My phone number _____

My email address _____

My mailing address _____

_____

My primary care medical provider

_____

Power of attorney

☐ I have a **Durable Power of Attorney for Health Care** that let someone else (an "agent") make health care decisions for me if I'm not able.

My health care agent (if any)

Name _____

Relationship to me (*Examples: friend, partner, spouse, sister, etc.*)

_____

Phone _____

Email _____

My alternate health care agent (if any)

Name _____

Relationship to me (*Examples: friend, partner, spouse, sister, etc.*)

_____

Phone _____

Email _____

My 2nd alternate health care agent (if any)

Name _____

Relationship to me (*Examples: friend, partner, spouse, sister, etc.*)

_____

Phone _____

Email _____

Record of Directive

I've given a copy of this directive to the following people:

Advance Directive for Living with Dementia
Optional Attachment:
Personal History and Care Values

I have written this advance directive because:

- ☐ I have a current diagnosis of dementia and want to plan ahead.
- ☐ I have no current diagnosis, but have seen family and/or friends with dementia and know what I would want.
- ☐ Other: _____

I want my caregivers, family, and friends to know and remember who I am and what is important to me for when I may not be able to remember or fully express this.

Important people in my life:

My education, work history, skills, accomplishments:

Things I love to do or to experience:

Important events in my life:

How I would like caregivers, family, and friends to treat and care for me if I can no longer say (*Examples: Treat me as an adult, not a child; allow me privacy when dressing, bathing, and toileting; help me maintain my personal hygiene and appearance.*):