



INSTRUCTIONS FOR THE LIVING WITH DEMENTIA MENTAL HEALTH ADVANCE DIRECTIVE

The instructions contained in this document will enable you to complete and implement the Living With Dementia Mental Health Advance Directive (referred to from now on as “Directive”). **Because this document offers you the option of permanently giving away your rights to make certain decisions, it is very important that you read and fully understand these instructions and the entire Directive before you complete and sign the Directive.**

ABOUT THIS DIRECTIVE

This Directive is the result of a collaborative effort between Seattle University School of Law Professor Lisa Brodoff and Robb Miller, former Executive Director of End of Life Washington. It was created to allow mentally competent people dealing with Alzheimer’s and dementia to document their wishes related to where to live, how to finance their care, when to stop driving, and many other issues. You can also use it to give someone the power to make your decisions for you. **This document is not a Living Will or Durable Power of Attorney for Health Care and does not document your wishes for medical or end-of-life care.**

In 2002 Washington State passed a law about mental health advance directives primarily for people with mental health illnesses like schizophrenia and bipolar disorder to make decisions about their mental health care, to state their treatment preferences, and to appoint a substitute decision-maker. This Directive is a mental health advance directive that has been customized for people with Alzheimer’s/dementia. **Because this Directive is based on Washington State law, it may not be legal or honored outside of Washington.**

Although other states have enacted mental health advance directives, legal requirements differ from state to state. **If you do not reside in Washington and you live in a state that has a mental health advance directive law similar to Washington’s, you may be able to modify this Directive to make it legal in your state.** If you want this option, check with a local Alzheimer’s Association (<http://www.alz.org>, 800.272.3900), senior service organization, elder law attorney, geriatric care manager, or other professional who specializes in advance planning for people with Alzheimer’s/dementia. **Even if this Directive is not legal where you live, you can still use it to document your wishes and provide a guide for your family, health care providers, long-term care providers, and others.**

In order to make this document, you must be an adult with capacity to understand the possible risks and benefits of your choices. “Incapacitated” means that you have been found by a court or group of professionals to be unable to understand your choices and make informed decisions. You may not make this Directive if you are incapacitated or a guardian has been appointed to make your health care decisions.

Although Washington State law states that your Directive should be followed to the “fullest extent possible,” it does not guarantee that all your choices will be honored by your family or health care providers. For example, you cannot force a family member to take care of you or a long-term care facility to accept you. However, making this Directive will help ensure your wishes are considered and increase the likelihood they will be honored. Documenting your actual desires and care goals when you are well enough to make decisions can result in much less stress on your family and other loved ones and allows you to exert more control about decisions made on your behalf in the future.

Many very personal and difficult issues are addressed and documented in this Directive, and reading about some of them can paint a skewed or scary picture of life with Alzheimer's/dementia. Addressing your concerns or fears with a mental health professional that specializes in working with people who have been diagnosed with Alzheimer's/dementia may be very helpful. It is also advisable to seek legal advice from an experienced elder law attorney. See the Guide section below for resources for finding these professionals.

Even with good care, people who experience Alzheimer's/dementia may have very different outcomes. Some may appear as a pleasantly confused person with humor intact living in relative peace with the disease. Others may experience symptoms or behaviors that are more difficult to manage. Most people's experiences and behaviors will change over time. **With the goal of being prepared, this Directive is intended to help plan for the worst-case scenarios.** Although this planning may be difficult, it can be a huge relief to you and your family to deal with these important issues upfront.

GUIDE TO MAKING YOUR DIRECTIVE

- This is a long, complex document, and you or your partner/spouse and/or family may not understand what you will be facing with an Alzheimer's/dementia disease diagnosis. Therefore, the help of professionals, such as a mental health professional, geriatric care manager, and/or an elder law attorney, is highly recommended. In Washington, End of Life Washington may be able to assist with referrals to these professionals. Elsewhere, your local Alzheimer's Association (www.alz.org, 800.272.3900), your state's psychological association, and senior service organizations may be able to help you find qualified, experienced professionals. You may also want to check the National Association of Elder Law Attorneys at alturl.com/ixo85 and the National Association of Geriatric Care Managers at memberfinder.caremanager.org.
- Once again, read the instructions and the Directive in their entirety before completing your Directive. It may take much time, thought, and many conversations, along with consultation with professionals to complete your Directive.
- Make a few photocopies of the Directive before you start, in case you need to start over. You will probably want to use one of the copies as a "working document."
- If you are a person in the early stages of Alzheimer's/dementia or you have a family history of Alzheimer's, it is advisable to do this planning early. Doing this planning while you are still clearly capable of making these decisions helps prevent questions later about whether you had the capacity to make the Directive. You cannot make this Directive if you become incapacitated.
- Talk with your family, friends, physicians, and/or attorney about your decision to complete this Directive.
- This is your document. When completed, it should express your wishes. Cross out sections, sentences, or words with which you don't agree.
- In the spaces provided, initial every statement that you agree with. If you do not agree with the statement, put a line through the spaces provided. Do not leave any blank spaces.
- Follow the short directions provided within the form between the brackets, "{ }." For example: {Initial only one, and draw a line through the others.}
- If you have questions or need guidance in preparing the Alzheimer's Disease/Dementia Mental Health Advance Directive, please contact End of Life Washington (206.256.1636, 877.222.2816 toll-free, info@EndofLifeWA.org, www.EndofLifeWA.org) and a staff member will be glad to assist you.

THE NUMBERS AND LETTERS IN THE GUIDE BELOW CORRESPOND TO THE SAME SECTIONS IN YOUR DIRECTIVE

1. WHEN AND HOW LONG I WANT THIS DOCUMENT TO BE EFFECTIVE

The first section of this document is also one of the most important. There are three choices, and you must pick only one.

Choice	Advantage	Disadvantage
a. Effective immediately.	No doubts about when Directive is effective. Immediate benefit of advocacy from your agent.	Professionals may not understand that you must still be consulted about decisions.
b. Effective if you lose capacity.	Professionals don't have to consult with your agent until you are incapacitated. There can be a definitive finding that you are incapacitated.	You may become incapacitated before a formal finding that you are incapacitated. Your agent cannot advocate for you until you are deemed incapacitated.
c. Effective when certain symptoms or behaviors occur.	You can tailor your Directive to fit a particular symptom or symptoms, such as when you no longer recognize your spouse/partner.	It may not always be clear to others when the circumstances, symptoms, or behaviors you choose occur.

2. WHEN I MAY REVOKE THIS DIRECTIVE

You must choose one or the other, or your Directive will not be valid.

Choice	Advantage	Disadvantage
Only when I have capacity.	Can protect you from making bad decisions when you are incapacitated.	When you are incapacitated, you cannot change your mind about your treatment choices made in this Directive.
Even if I am incapacitated.	You can revoke this Directive at any time, even when you are incapacitated.	If you become incapacitated, you could make decisions that are not in your own best interests or are contrary to your Directive.

Important: Choosing “Even if I am incapacitated” may result in your entire Directive being revoked by you, effectively ending all the advance planning you did while you had capacity. You could also make a decision while incapacitated that terminated your mental health care agent’s authority to act on your behalf and result in someone else becoming your legal surrogate decision-maker for your mental health care decisions. Your new legal surrogate decision-maker could then become someone you do not want to have this authority (see “If you do not designate a mental health care agent...” below).

3. MY MENTAL HEALTH CARE AGENT

Designating a mental health care agent is highly recommended. If you do not designate a mental health care agent, Washington State law authorizes the following people, in order of priority, to make mental health care decisions for you.

- A court-appointed guardian with decision-making authority.
- Your spouse or registered domestic partner.
- Your adult children.
- Your parents.
- Your adult siblings.

When there is more than one person in a category, such as your adult children, then all must agree.

If you choose not to name a mental health care agent in section 3, cross out sections 3 and 4, and go on to section 5.

Important: The person you name as your mental health care agent should be the same person you name as your Health Care Agent in your Durable Power of Attorney for Health Care, a document that allows you to name someone to make medical (not mental health care) decisions for you when you cannot speak for yourself. If the agents named in these two documents are not the same person, conflict about certain issues could occur. While this conflict is being resolved, the choices you make in this Directive could be delayed or prevented.

Be sure the people you appoint as your health care agents understand your wishes and agree to honor them. Do not name someone to be your health care agent without his or her knowledge and permission.

You should also name an alternate mental health care agent, if possible. This allows someone else to advocate for you if your primary mental health care agent is unavailable or you outlive him or her.

If you are married or partnered to the person you name as your primary mental health care agent, be sure to indicate whether you would want your spouse/partner to continue to be your agent if you were separated or divorced from him or her. Sometimes partners/spouses divorce for reasons that may have no bearing on their trust of the current partner/spouse to carry out their wishes (for example, divorce for the purpose of qualifying for public assistance such as Medicaid).

The person you name to be your mental health care agent:

- Must be at least 18 years old and mentally competent.
- May be a family member or close friend whom you trust to make serious decisions.
- Should clearly understand your wishes and be willing to accept the responsibility of making mental health care and other decisions for you.
- Should be someone who can be assertive in the event that caregivers, family members, or health care providers challenge your wishes.
- Does not have to be your spouse, partner, or a member of your biological family.
- Need not live in Washington but should be readily available in the event of a mental health emergency.

The person you appoint as your mental health care agent cannot be:

- Your doctor or an employee of your doctor.
- An owner, operator, administrator, or employee of a health care facility in which you are a patient at the time you sign your advance directive.

However, if one of the individuals listed above (your doctor, an employee of your doctor, etc.) is also your spouse, adult child, or sibling, you may appoint that individual to be your mental health care agent.

Note to same-sex spouses and registered domestic partners: If you do not designate your spouse or registered domestic partner as your primary mental health care agent, your spouse or domestic partner may not have the right to make your mental health care decisions or even have access to you in an emergency mental health situation outside of Washington.

4. THE AUTHORITY I GIVE MY MENTAL HEALTH CARE AGENT

This section gives your mental health care agent broad authority to make decisions about your mental health care. If you do not want your agent to have the authority to do something described here, cross out those words or sentences.

5. HOW TO MAKE MENTAL HEALTH CARE DECISIONS AND IMPLEMENT THIS DIRECTIVE

No document can foresee and express your choices about every situation that may occur. This section provides guidance to your mental health care agent and others if issues not addressed by this Directive arise.

6. PERSONAL HISTORY AND CARE VALUES STATEMENT

One of the most important steps you can take to ensure your wishes will be honored and you get the care you want is to write a statement about your values, faith, history, beliefs, work history, important past and present relationships, interests, or anything else you believe is important for your caregivers to know. By knowing and understanding the person before them, caregivers can more easily connect with you on a more personal level. When the general values about care are stated, people who make decisions for you will have a better idea of what to do in situations that cannot be anticipated. Although writing a statement is optional, it is highly recommended. The more your providers, your agent, and others interested in your welfare know about you and your wishes, the better they are able to react to, and deal with, situations as they arise.

7. PREFERENCES AND INSTRUCTIONS ABOUT MY CARE AND TREATMENT

a. Preferences regarding care in my home.

- (1) One of the first decisions that people with Alzheimer's/dementia will need to make concerns the type of care they would want to receive while still in their own homes. At the beginning stages of the illness most people with Alzheimer's/dementia are able to remain at home, either alone or with a spouse, partner, family, or others. As the disease progresses, you will eventually need assistance with personal care, reminders to take medication, housekeeping, cooking, grocery shopping, and driving to appointments.

This personal care can be delivered in a number of ways – by family members (for pay or as volunteers), individuals hired for this service, and agencies. Some people may prefer that personal care be done only by family members, while others would never want their family members to do those tasks.

Giving advance permission for individuals who are not family members to provide your care could take the pressure and guilt off your family or mental health care agent for bringing in nonfamily care providers.

- (2) If you have any cultural, religious, and/or gender preferences about your personal care and assistance, write them here. Discuss your preferences and choices with your family, mental health care agent, and/or geriatric care manager to be sure they are feasible.

b. Preferences and instructions involving out-of-home placements.

One of the most predictable decisions that a person with Alzheimer's/dementia will have to face concerns a future placement outside the family home. When, where, and how that out-of-home placement will occur are decisions that can be anticipated and dealt with by people with Alzheimer's/dementia in consultation with their family, their medical providers, and other geriatric care professionals.

There are now a variety of out-of-home placements that can be discussed and decided upon in advance, including assisted-living facilities and adult family homes that specialize in Alzheimer's/dementia care. These placement decisions can best be made in consultation with a professional geriatric care or case manager who is familiar with the various placement options in your community. Without prior planning, families and mental health care agents can find themselves in an emergency situation, faced with their relative or loved one with Alzheimer's/dementia being evicted with no place to go and no alternative plan of action.

- (1) Identifies the location where you would like to live. Before you name a family member or other loved one as a person you want to live with, be sure this person (and his or her family) is willing to let you move in.
- (2) Identifies the setting where you would prefer to live, such as an assisted-living facility or adult family home and provides the option to name the home or facility. Each of these less-than-nursing-home institutional options may become unsustainable at some point in the course of the disease, because the care needed in the final stages of Alzheimer's (and some people with dementia) is beyond that provided in most assisted-living and adult family home facilities. Because nursing home placement is currently the likely end option, making your wishes known here regarding that ultimate decision can go a long way toward relieving the family's stress and guilt over making that difficult decision on their own.
- (3) Identifies a person, such as a geriatric care manager, or agency to assess your ability to remain in your home.

c. Preferences and instructions about dealing with combative, assaultive, or aggressive behaviors, with authority to consent to inpatient treatment.

Probably the most difficult effect of Alzheimer's and some forms of dementia on some people with these illnesses is the appearance of new and unexpected behaviors. Between thirty and fifty percent of people with Alzheimer's will become combative, assaultive, or sexually aggressive during the course of their illness. These behaviors can come as a surprise to family and caregivers who have never before seen their loved ones behave in this way. It can also be dangerous for both people with the disease and their caregivers.

Unfortunately, these situations can also result in an emergency situation involving law enforcement and emergency medical care. Sometimes people with Alzheimer's/dementia who are resistant or combative are committed to psychiatric hospitals on an emergency basis. These situations are extremely upsetting and distressing for the person with Alzheimer's/dementia and for the family.

This Directive provides you with the ability to plan in advance to avoid sudden and involuntary commitment by allowing you to voluntarily consent to hospitalization, as well as stating a preference for a facility specializing in providing Alzheimer's/dementia care or that you believe will provide the quality of care desired. Providing your consent in this Directive increases the likelihood that you will receive specialized quality treatment. Once stabilized, you have a greater chance of returning home (whether to your family home, adult family home, or other setting).

- (1) Allows you to bind yourself to hospitalization and treatment and express your preference for treatment at a facility specializing in Alzheimer's/dementia care, even if you are objecting to it at the time. It is important to understand that no matter which option you select, involuntary commitment could still occur.
- (2) Indicates you want treatment from trained caregivers who know you and your history.
- (3) Expresses a preference to be admitted to a particular specialized geriatric or dementia care unit, or a similar facility, if available.
- (4) Expresses a preference not to be admitted to a particular facility or facilities.

d. Preferences regarding the financing of my care.

The financial burden imposed upon people with Alzheimer's/dementia and their families can be overwhelming. Moreover, those costs are exponentially greater when nursing home care is required. As a result, even relatively well-off people may find it impossible to meet their care needs in the later stages of Alzheimer's/dementia without depleting their assets and savings, putting the remaining family members and dependents (if there are any) at risk of impoverishment. People who hope to leave their home and savings to their children, family, or friends after they die may not be able to do so. This financial burden adds significant stress and worry to an already difficult diagnosis.

Given that a substantial percentage of people with Alzheimer's/dementia will ultimately need this expensive care in either their home or nursing facility, it is critical that advance planning on how to finance care be considered, discussed, and ultimately executed. Paying privately, using long-term care Insurance, public assistance through the Medicaid program, or a combination of all three are the typical ways that this high cost of care is covered. Some people with Alzheimer's/dementia may opt to use Medicaid planning methods to become eligible for coverage, to preserve assets for a spouse/partner, or to pass on their property after death. Others may choose to use all savings and income on purchasing the highest quality of private care and only apply for Medicaid if and when all available money has been spent.

While this section of the document allows you to indicate your preferences regarding the financing of your care, you will almost certainly need significant legal and financial advice in order to make well-informed decisions on these issues and to understand the impacts on your spouse/partner, family, or heirs. **Consulting with an experienced elder law attorney about financing your care is very highly recommended before making any decisions about these important issues.**

Your local Alzheimer's Association, senior service organizations, and the local bar association may be able to help you find a qualified elder law attorney. You may also want to check the National Association of Elder Law Attorneys at alturl.com/ixo85. In Washington State, End of Life Washington (206.256.1636, 877.222.2816 toll-free, info@EndofLifeWA.org, www.EndofLifeWA.org) may also be able to assist with referrals.

e. Preferences regarding future intimate relationships.

Unfortunately, people with Alzheimer's/dementia experience changes that generally result in both partners in the relationship losing the personal and sexual intimacy that can be such a crucial part of their lives together. Discussing your hopes and values with your partner/spouse with regard to intimacy, as well as feelings about entering into other intimate relationships, may help sort out any tricky situations that arise later on when you may not be able to express your wishes. Working with therapists trained in sexuality and Alzheimer's/dementia may be necessary to reach agreements about these charged topics.

This part of the Directive allows you to plan for three possibilities involving intimate relationships.

(1) Expresses your preference regarding maintaining intimate relationships with your spouse/partner.

Many people with Alzheimer's/dementia and their spouses/partners want to continue their intimate relationship for as long as possible. For people with Alzheimer's/dementia, remaining sexually active can provide an important way of maintaining their role in the relationship and giving back to their partners. For partners/spouses, sexual intimacy can be an important way to maintain connection and give support. Maintaining sexual relationships can benefit both partners by easing depression by providing emotional and physical support.

Despite the significant benefits to committed couples who keep the sexual relationship intact, there can be barriers to doing so, including cognitive changes due to Alzheimer's/dementia; well partners/spouses being upset by the sexual advances of a partner/spouse when he or she can no longer remember or recognize them; and dealing with spouses/partners who become sexually aggressive. Your spouse or partner may also worry that you may have reached a point where you cannot consent to a sexual relationship, creating concerns about forcing herself or himself upon you.

While expressing your preferences may not resolve all the problems, documenting them can help ease some of the conflicts, guilt, and obstacles that may arise.

(2) Expresses your preferences regarding your partner/spouse having relationships outside the bounds of your partnership/marriage or other commitment.

Because of the emotional stresses, loss of sexual intimacy, and depression experienced by well partners/spouses of people with Alzheimer's/dementia, it is not uncommon for the well partner to have, or want to have, intimate relationships with others. But the guilt suffered by the well partner, who believes he or she has violated their partnership/marriage vows or their ill partner's/spouse's wishes, can be enormous.

It may or may not be the case that you would consent to your partner/spouse having an intimate relationship when you are no longer able to be there emotionally or sexually for your partner/spouse. Some people might give their well partner their blessing to seek out other relationships at a point when there is no longer any recognition of him or her by the ill partner/spouse. Others may believe that their religious and moral code holds that the couple should be together and faithful through sickness, as well as health.

In either case, discussing this charged topic in advance may allow you and your partner/spouse a sense of respect for each other's dilemmas and lead to agreements and consents about future behavior.

(3) Expresses your preferences for future intimate relationships for yourself.

People with advanced Alzheimer's/dementia still can, and do, have sexual desires. It is not unusual for a person with Alzheimer's/dementia who is in a long-term care facility to want to have a romantic or sexual relationship with another person at the facility. Long-term care staff are required to consider whether or not the relationship should be allowed at all, whether to let family know about it and seek their approval, and whether the resident has the capacity to consent to a sexual relationship.

Well partners/spouses may understand and tolerate their ill partner/spouse having another relationship because they see their partner/spouse as happy again. Often the people who do take issue with a developing romantic relationship are the adult children of a parent with Alzheimer's/dementia.

Documenting whether or not you would be agreeable to a relationship with someone else could spare your family, facility staff, and the resident of a long-term care facility the grief and upheaval that can result when trying to guess what you would want if a romantic relationship develops.

f. Preferences regarding my pet(s).

If you have a pet or pets, give consideration regarding whom you would want to care for them when you can no longer provide care. This is especially important if you live alone. If you want a family member or friend to adopt your pet(s), make sure he or she agrees to do so.

8. CONSENT TO PARTICIPATION IN EXPERIMENTAL ALZHEIMER'S/DEMENTIA DRUG TRIALS

Although there is no cure for Alzheimer's and many forms of dementia, there are currently clinical trials being conducted on many new drugs that have the potential to improve symptoms or prevent the full onset of the illness. Many people with Alzheimer's/dementia want to participate in research studies, not only for the possibility of improving their own health, but also in the hopes of contributing to the research for a cure.

This section allows you to describe if and when you would consent to participate in a drug trial or trials, along with a description of your values and preferences around participating. For example, you can list what side effects of tested drugs would be intolerable (such as nausea or headache) or what procedures you would reject or accept (injections or blood draws).

In order to participate in a drug trial, people with Alzheimer's/dementia must be able to give informed consent after learning of the possible side effects and benefits of the treatment. Or they must have a mental health care agent or other legal surrogate decision-maker give consent on their behalf. Although the ability to give your consent in advance is controversial and not certain, stating your preference to participate in your Directive may make it possible.

Follow the directions in the brackets “[]” very carefully.

9. CONSENT REGARDING SUSPENSION OF MY DRIVING PRIVILEGES

Eventually, everyone with Alzheimer's/dementia will need to stop driving; in the later stages of the illness impairments in judgment, reaction time, and focus will make driving dangerous. However, people with mild Alzheimer's/dementia often are still able to drive safely, sometimes years after diagnosis.

A decision about when driving is no longer safe is a difficult one for you and your family, because it signifies disease progression and results in the loss of independence and autonomy. For you, it could result in feeling demeaned by the loss of control and dependence on others to get from place to place. For the person or people who have to stop you from driving, it can result in guilt.

This Directive allows you to indicate that you want a medical professional or your mental health care agent to make the decision that the time to stop driving has come. It also provides you with the option to name the medical professional(s) you trust to make this important decision. Please note that choosing not to initial either option or crossing out this entire section does not mean that you may continue driving.

10. REGARDING A HEALTH CARE INSTITUTION REFUSING TO HONOR MY WISHES

Some health care facilities and long-term care providers adhere to certain religious directives, moral teachings, and/or organizational policies and may not be willing to honor your Directive if it conflicts with their institutional policies. In Washington State, many hospitals, hospices, and long-term care providers are being acquired by, or falling under control of, religious-affiliated organizations.

The first statement in this section affirms that your admission to such a facility does not mean you consent to procedures, policies, or courses of treatment that conflict with your Directive. Indicating that you want your wishes to take precedence over a facility's policies affirms your lack of consent and provides guidance to your mental health care agent or other legal surrogate decision-makers.

The second statement documents that if the health care or long-term care facility where you are a patient or resident declines to follow your wishes as set out in this Directive, you want your mental health care agent or other legal surrogate decision-maker to have you transferred to another facility, if possible, that will agree to honor your wishes as spelled out in this Directive.

In some parts of Washington or the state where you live, a facility that may not honor all your wishes may be the only one available or close enough to your partner/spouse, mental health care agent, family, or other loved ones, or it may be the best facility for your particular needs. In any of these cases, requesting that your agent transfer you may not always be feasible, possible, or advisable.

11. IF A COURT APPOINTS A GUARDIAN FOR ME

Unlike many states, Washington law does not direct that a health care agent (named in a Durable Power of Attorney for Health Care) or a mental health care agent (named in this Directive) should be the court's first choice for guardian.

You can use this section to say who you want your guardian to be, if a court appoints one for you. A judge is required to appoint the person you request, except for good cause or disqualification. Filling out this section does not mean you agree to have a guardian.

It makes sense to request that your mental health care agent serve as your guardian, because that is the person you trust to make your mental health care decisions. However, if a guardian is named for you, he or she will also take control of your medical decisions. This is another reason why your health care agent named in a Durable Power of Attorney for Health Care and your mental health care agent named in this Directive should be the same person.

Make sure the person you nominate to be your guardian is willing to do it, and get his or her consent before writing in his or her name.

12. OTHER DOCUMENTS

Making this Directive is just one part of the comprehensive advance and estate planning recommended for a person with Alzheimer's/dementia. This document is designed to be used along with other advance planning documents such as a Living Will (also known as a Health Care Directive or Directive to Physicians), Durable Power of Attorney for Health Care, Durable Power of Attorney for Finances, and a Will. You may also want to make a Physician Orders for Life-Sustaining Treatment (POLST), a nonhospital medical order concerning life-sustaining treatment for people with serious illnesses.

If you live in Washington, End of Life Washington offers a good, free Living Will and Durable Power of Attorney for Health Care for people dealing with Alzheimer's/dementia. It includes several Alzheimer's and dementia provisions and combines these two documents into one. To obtain a free copy, download the document from www.EndofLifeWA.org, or call 206.256.1636 or 877.222.2816 toll-free.

Making all the necessary advance planning documents and providing the information requested here could prove invaluable when these documents are needed.

13. SUMMARY AND SIGNATURE

Do not sign and date your form until you are in the presence of valid witnesses and a notary if you are having your document notarized.

14. STATEMENT OF WITNESSES

In order to make your advance directive legally binding, you must sign the document in the presence of two adult witnesses (and a notary, if you elect to have your document notarized). Make sure your witnesses meet the criteria for being a witness. The two witnesses cannot be:

- a. A person designated to make medical decisions on the principal's behalf.
- b. A health care provider or professional person directly involved with the provision of care to the principal at the time the directive is executed.
- c. An owner, operator, employee, or relative of an owner or operator of a health care facility or long-term care facility in which the principal is a patient or resident.
- d. A person who is related by blood, marriage, legal domestic partnership, or adoption to the person, or with whom the person making this document has a dating relationship as defined in RCW 26.50.010 in the State of Washington or applicable law in other states.
- e. An incapacitated person.
- f. A person who would benefit financially if the principal undergoes mental health treatment.
- g. A minor.

About Notarization: Notaries do not normally affirm anything beyond the identity of the person signing the document before them. While Washington State does not require notarization of this Directive to make it legal, this form includes a notary statement because notarizing may help ensure that the document is treated as validly executed. Additionally, some states do require directives like this one to be notarized.

Notaries can be found at your bank, insurance office, or some office supply stores (call ahead to make sure they will be present). End of Life Washington provides complimentary notarization of this and other advance directives at its Seattle office.

15. RECORD OF DIRECTIVE

Making a list of everyone you have given your Directive to is a good way to keep track of who has and hasn't received a copy. If you revoke or replace your directive, you can use this list to retrieve copies of your Directive or request that the person or institution that has a copy destroy it.

16. REVOCATION OF MY LIVING WITH DEMENTIA MENTAL HEALTH ADVANCE DIRECTIVE

If you revoke your advance directive as per section 16, make sure you notify your mental health care agent(s), partner/spouse, family, medical and long-term care providers. If possible, retrieve and destroy copies of your revoked Directive, or instruct those who have revoked copies to destroy them. Keep one copy of your revoked Directive in your records with the word "REVOKED" written across the front.

AFTER COMPLETING YOUR LIVING WITH DEMENTIA MENTAL HEALTH ADVANCE DIRECTIVE

- 1. Where to keep your Directive:** Your Directive is an important legal document, but unlike a Will and some other legal documents, copies are just as valid as the original. Keep the original signed documents in a secure but accessible place. Do not give the original document to your attorney or put it in a safe deposit box or any other security box that would keep others from having access to it in the event of an emergency. Your mental health care agent(s), partner/spouse, or other close family and friends should know exactly where to look for your document. **Tip:** To ensure documents are on hand, put copies of this Directive and other advance directives in the glove box of your vehicle(s) or in a compartment in your suitcases. Also, ask your mental health care agent to keep a copy in his or her glove box and suitcase.
- 2. Who should have a copy?** Give copies of the signed originals to your mental health care agent(s), partner/spouse, doctors, lawyer, family, close friends, clergy, and anyone else who might become involved in your mental health care. If you enter a hospital, nursing home, or other institution, make sure that a copy of your Directive is placed in your medical records.
- 3. Tell important people about your wishes:** The importance of discussing your document with the important people involved cannot be overemphasized. Discuss your wishes concerning your mental health care with your mental health care agent(s), doctor(s), clergy, family, and friends, and do this well before you lose capacity. Make clear to other family members that your mental health care agent(s) has or will have final authority to act on your behalf. **Tip:** One of the best ways to communicate your wishes to family members is with a family meeting. Having all key people present at one meeting may reduce the likelihood of disagreements between family members and your spouse/partner, and/or your mental health care agent, especially if your mental health care agent is not your spouse/partner or a member of your family.
- 4. Will your mental health care providers and current or future long-term care facility honor your wishes?** When you, your partner/spouse, or mental health care agent present your Directive, ask if it will be honored. If not, you or the person acting on your behalf may wish to find different health care providers, choose another facility, or move to a different one.
- 5. Making changes:** If you want to make changes to this Directive after it has been signed and witnessed, you should complete a new document while you still have capacity. However, updating addresses or phone numbers of your mental health care agent(s) is permissible. Updates should be initialed and dated.
- 6. Review and update your Directive, if necessary:** As long as you have capacity, review your Directive every year to be sure it reflects your current preferences and values, especially if it becomes apparent that you are losing capacity. **Tip:** Use the calendar program on your computer or phone to create an annual reminder to review your Directive.
- 7. Travel to other states:** If you travel, you may want to take copies of your Directive with you, as other states may honor it. Same-sex married couples and registered domestic partners, should be diligent about carrying this Directive (and other advance directives) when traveling outside of states where same-sex marriage or domestic partnership is legal. Unmarried or non-registered domestic partners should make sure this Directive (and other advance directives) is available at all times (see “**Tip**” in number 1. above, “**Where to keep your directive.**”)



LIVING WITH DEMENTIA MENTAL HEALTH ADVANCE DIRECTIVE OF:

(Print your name here.)

As a person with capacity, I willfully and voluntarily execute this mental health advance directive, so that my choices regarding my mental health care and Alzheimer’s/dementia care will be carried out in circumstances when I am unable to express my instructions and preferences regarding my future care. If I live in a state that has not adopted laws that provide me with the legal right to make this advance directive, then I want this document to be used as a guide for those who make decisions on my behalf when I am no longer capable of making them for myself.

The fact that I may have left blanks in this directive does not affect its validity in any way. I intend that all completed sections be followed.

I understand that nothing in this directive, including any refusal of treatment that I consent to, authorizes any health care provider, professional person, health care facility, or agent appointed in this directive to use or threaten to use abuse, neglect, financial exploitation, or abandonment to carry out my directive.

I intend this Living With Dementia Mental Health Advance Directive to take precedence over any other mental health directives I have previously executed, to the extent that they are inconsistent with this Living With Dementia Mental Health Advance Directive.

I understand that there are some circumstances where my provider may not have to follow my directive, specifically if compliance would be in violation of the law or accepted standards of care.

1. WHEN AND HOW LONG I WANT THIS DOCUMENT TO APPLY

(Initial only one – a., b., or c. – and draw a line through the others)

- a. I intend that this directive become effective immediately upon signing and that it remains valid and in effect until revoked according to the terms specified in section 16 or until my death.
b. I intend that this directive become effective if I become incapacitated to the extent that I am unable to make informed consent decisions or provide informed consent for my care, as determined by my treating physician, and that it remain valid and in effect until revoked according to the terms specified in section 16 or until my death.
c. I intend that this directive become effective when any of the following circumstances, symptoms, or behaviors occur, and that it remain valid and in effect until revoked according to the terms specified in section 16 or until my death: (Initial all that apply, and draw a line through the rest.)
(1) I am no longer able to communicate verbally.
(2) I can no longer feed myself.
(3) I can no longer recognize my partner/spouse.
(4) I put myself or my family or others in danger because of my actions or behaviors.
(5) Other (describe):

2. WHEN I MAY REVOKE THIS DIRECTIVE

I intend that I be able to revoke this directive: *(Initial one, and draw a line through the other.)*

_____ Only when I have capacity: I understand that choosing this option means I may only revoke this directive if I have capacity. I further understand that if I choose this option and become incapacitated while this directive is in effect, I may receive treatment that I specify in this directive, even if I object at the time.

_____ Even if I am incapacitated: I understand that choosing this option means that I may revoke this directive even if I am incapacitated. I further understand that if I choose this option and revoke this directive while I am incapacitated I may not receive treatment that I specify in this directive, even if I want the treatment.

3. MY MENTAL HEALTH CARE AGENT

I appoint the following person as my primary mental health care agent to make mental health care treatment decisions for me as authorized in this document and request that this person be notified immediately when this directive becomes effective: *(Optional, but highly recommended.)*

Name _____
Address _____
Telephone _____
(day) (evening) (mobile)

If the person named above is my partner or spouse at the time I make this document: {Initial one and put a line through the other. If your primary mental health care agent is not your spouse or partner, cross this section out.}

_____ His or her authority to act is hereby revoked if I am separated or divorced from her or him.

_____ His or her authority to act shall be unaffected if I am separated or divorced from her or him. In the event that my primary mental health care agent is unable, unavailable, or unwilling to serve, or I revoke his or her authority to serve, then I name this alternate mental health care agent and request that this person be notified immediately when this directive becomes effective or when the primary mental health care agent is no longer my agent: *(Optional, but highly recommended.)*

Name _____
Address _____
Telephone _____
(day) (evening) (mobile)

If my alternate mental health care agent acts for me because my first agent is unavailable, I intend that the alternate act only while my first agent is unavailable.

4. THE AUTHORITY I GIVE MY MENTAL HEALTH CARE AGENT

I grant my mental health care agent complete authority to make all decisions about mental health care on my behalf. This includes, but is not limited to (a) consenting, refusing consent, and withdrawing consent for mental health treatment recommended by my physicians and other medical providers; (b) requesting particular mental health treatments consistent with any instructions and/or limitations I have set forth in this directive; (c) accessing my medical records and information pertaining to my mental health care; (d) employing and dismissing mental health care providers; and (e) removing me from any mental health care facility to another facility, a private home, or other place. I authorize and request that all "covered entities" under the Health Insurance Portability and Accounting Act of 1996, as hereafter amended, release and disclose full and complete protected medical

information to my health care agent named herein. Such information should include, but not be limited to, medical records, office notes, laboratory results, radiology and other visualization records, prescription records, medical opinions, and all other materials that might assist in medical decision-making or a determination of my capacity. I understand that this information may include information about sexually transmitted diseases, AIDS, HIV, and the use/abuse of alcohol and drugs. This consent is subject to revocation at any time except to the extent that the entity which is to make the disclosure has already taken action in reliance on it. If not previously revoked, this authorization will terminate upon my death.

The authority conferred herein shall be exercisable notwithstanding my disability or incapacity.

5. HOW TO MAKE MENTAL HEALTH CARE DECISIONS AND IMPLEMENT THIS DIRECTIVE

I want whoever makes mental health care decisions for me to do as I would want in the circumstances, based on the choices I express in this document. If what I would want is not known, then I want decisions to be made in my best interest, based on my values, the contents of this document, and information provided by my health care providers.

I do not want my mental health care agent or others to substitute their choices for mine because they disagree with my choices or because they think their choices are in my best interests. I do not want my intentions to be rejected because someone thinks that if I had more information when I completed this document, or if I had known certain medical facts that developed later, I would change my mind.

6. PERSONAL HISTORY AND CARE VALUES STATEMENT

(Optional. If you attach a statement, initial this. If not, draw a line through it.)

_____ I have completed and attached an additional statement describing why I am making this mental health advance directive and/or to provide information about the important people in my life, some personal history, general values around care, or anything else that is not addressed by this document.

7. PREFERENCES AND INSTRUCTIONS ABOUT MY CARE AND TREATMENT

a. Preferences regarding care in my home.

- (1) **I prefer that my personal care and assistance be provided by:** *(Number the choices below, using the number 1 for your first choice, 2 for your second choice, etc. Draw a line through those that do not apply.)*

_____ Family members who would do so voluntarily.

_____ Individuals who are not family members who would do so voluntarily.

_____ Family members who are hired to provide my care.

_____ Individuals who are not family members who are hired to provide my care.

_____ Other *(describe)*:

- (2) **I have the following cultural, religious, and/or gender preferences about my care and assistance:**
(Optional. If you do not have any preferences, draw a line through this space.)

b. Preferences and instructions involving out-of-home placements.

I recognize that I may need to receive care outside of my home – even in my least desirable setting (a nursing home or other placement) – when my care at home becomes too burdensome or difficult to manage. This may be necessary if I become combative, aggressive, incontinent, resistant to care, or too difficult to transfer. If my mental health care agent decides that I need to live in a setting outside of my home, then the following are my preferred locations and settings, in order of preference:

- (1) **The location where I would prefer to live:** (Number the choices below, using the number 1 for your first choice, 2 for your second choice, etc. Draw a line through those that do not apply.)

_____ With/near the following family member or other loved one near my current home:

_____ With/near the following family member or other loved one far away from my current home:

_____ Near my current home.

_____ Other (describe):

- (2) **The setting where I would prefer to live:** (Number the choices below, using the number 1 for your first choice, 2 for your second choice, etc. Draw a line through those that do not apply.)

_____ Adult family home. Name: (optional) _____

_____ Assisted living facility. Name: (optional) _____

_____ Nursing home. Name: (optional) _____

_____ Specialized memory care unit. Name: (optional) _____

_____ Moving in with family. Name: (optional) _____

_____ Other (describe):

- (3) **If an assessment and/or recommendations about my ability to remain in my home become necessary, the following person/people or agency/agencies is preferred:** *(Optional. If you do not have a preference, draw a line through this space.)*

c. Preferences and instructions about dealing with combative, assaultive, or aggressive behaviors, with authority to consent to inpatient treatment. *(Initial all that apply, and draw a line through those that do not.)*

- (1) I recognize that sometimes people with Alzheimer's/dementia become aggressive, assaultive, or combative, despite good care. If this happens, and emergency or other treatment is necessary: *(Initial one or the other directly below; i.e., give your consent or do not consent. If neither is initialed, or you do not consent to voluntary admission to inpatient treatment, commitment could still occur without consideration of the provisions in the "I consent..." statement.)*

_____ I consent and authorize my mental health care agent to consent to voluntary admission to inpatient treatment for up to 14 days, if deemed appropriate by my agent and treating physician. I prefer to receive treatment in a facility specializing in Alzheimer's/dementia care to work on the reduction of my behavioral symptoms and stabilization of my condition.

_____ I do not consent to voluntary admission to inpatient treatment.

- (2) _____ I want treatment from trained caregivers who know me and my history, and who know how to handle the situation.

- (3) _____ My preference is to be admitted to the specialized geriatric or dementia care unit at

_____ or a similar facility, if available.

- (4) _____ My preference is **not** to be admitted to the following facility or facilities:
(Optional. If you do not have a preference, draw a line through this space.)

d. Preferences regarding the financing of my care.

I know that the cost of my care could become high over the course of my illness. I have the following preferences regarding the financing of my care: *(Initial all that apply. Draw a line through those that do not.)*

_____ My hope is that my care costs will not consume the lifetime of savings I have reserved for retirement and for my children or other heirs at my death.

_____ I want my partner/spouse to maintain the standard of living we now have as much as possible.

_____ I want to preserve as much as possible of my income, assets, and savings for my partner/spouse, children, and heirs. Please use all available planning options to meet this goal, including, but not limited to: *(Cross out any that you do not agree with or that are not applicable.)*

- (1) Medicaid planning.
- (2) Gifting.
- (3) Divorce or legal separation.
- (4) Changing estate planning documents.
- (5) Tax planning.

_____ Please use my income, assets, and savings to buy the highest quality private care for me.

_____ If my savings run out, I want my home to be sold to finance any further care I need.

_____ I prefer public assistance only if no other option exists for paying for my care.

e. Preferences regarding future intimate relationships.

(1) Continuation of my intimate relationships with my partner/spouse: *(Initial all that apply. Draw a line through those that do not. Cross out this entire section if it is not applicable.)*

_____ My intimate relationship with my partner/spouse,
(name here) _____, is important to both of us.

_____ I consent to maintaining our sexual relationship even in the event that we dissolve our partnership or legal domestic partnership or divorce.

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

_____ I know that I may forget my partner/spouse as my Alzheimer's/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.

_____ I completely trust my partner/spouse to make any judgments about the continuation of our intimate relationship, including when to stop if s/he is no longer comfortable.

_____ Other preference(s):

(2) Preferences regarding my partner/spouse having relationships outside the bounds of our partnership/marriage or other commitment, legally recognized or otherwise: *(Initial all that apply. Draw a line through those that do not. Cross out this entire section if it is not applicable.)*

_____ I understand that my illness may last a long time, and that I likely will no longer recognize or be able to function emotionally or sexually for my partner/spouse. I also care deeply that my partner/spouse not continue to be a victim of this disease and that s/he live her/his life to the fullest. This could include becoming involved in other relationships. I would not consider this a violation of our vows to each other. Rather, I hope that s/he does seek out companionship and intimacy when I can no longer provide that in the relationship.

_____ Our moral, religious, and/or ethical values dictate that we remain faithful to one another through sickness and in health. We have both discussed this, and believe that a relationship outside our partnership/marriage or other committed relationship is not permissible and should not be pursued.

_____ I completely trust my partner/spouse to make any judgments about having relationships outside the bounds of our partnership/marriage, or other committed relationship.

_____ Other preference(s):

(3) Preference regarding future intimate relationships for myself: *(Initial all that apply. Draw a line through those that do not.)*

_____ I know that residents at long-term care facilities sometimes develop relationships with each other that can result in a less depressing and/or happier time for both. I am not completely opposed to my having such a relationship if, in my mental health care agent's judgment, I seem happier and am not coerced in any way.

_____ My moral, religious, and/or ethical beliefs preclude my engagement in any other relationship besides my partnership/marriage, or other committed relationship, whether legal or otherwise. I do not consent to any other intimate relationships, even if I appear to be happier at the time.

_____ Other preference(s):

f. Preferences regarding my pet(s). *(If you have a pet or pets, write your preferences here. If not, draw a line through this space.)*

8. CONSENT TO PARTICIPATION IN EXPERIMENTAL ALZHEIMER'S/DEMENTIA DRUG TRIALS

(If you initial a, b, or c, or any combination of a, b, or c, you must draw a line through d. If you initial d, you must draw a line through a, b, and c. Draw a line through any that you do not initial.)

- a. _____ I consent to participation in any clinical drug trials for drugs that have the potential to ameliorate the symptoms of Alzheimer's/dementia or prevent the full onset of the disease. I not only hope to improve my own health, but also to contribute to research to find a cure for the disease. I give my mental health care agent full power to consent on my behalf to my participation in any such study, considering my preferences regarding side effects.
- b. _____ I do not want to take medications that have the following side effects or have the following treatments:
{optional}
- c. _____ If my memory loss can be slowed down by the experimental drug(s), 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.
- d. _____ I do not consent to participation in any drug trials.

9. CONSENT REGARDING SUSPENSION OF MY DRIVING PRIVILEGES

(Initial only one, and draw a line through the other.)

_____ My ability to drive is a very important part of my maintenance of independence. I enjoy driving and want to continue to do so as long as I am safe. On the other hand, I know that the time will come when I no longer have the ability to drive safely. I trust my physician(s) or other skilled health care professional(s) who are providing my treatment. *(Name of health care professional(s) here; optional. If you do not want to name someone, put lines through these spaces.)*

_____ If s/he is not available, I want any other skilled health care professional to test my visual and mental acuity to determine if I am no longer safe to drive.

_____ I trust my mental health care agent's judgment on this issue. If my mental health care agent determines that I am unfit to drive, I consent to my driving privileges being suspended. If I continue to drive or attempt to drive after this, I agree to my keys being hidden or taken away from me and/or access to my car being eliminated.

10. REGARDING A HEALTH CARE INSTITUTION REFUSING TO HONOR MY WISHES

(Initial all that reflect your views. Draw a line through any that do not.)

_____ I understand that circumstances beyond my control may cause me to be admitted to a health care or long-term care facility whose policy is to decline to follow advance directives that conflict with certain religious or other beliefs or organizational policies. If I am a patient in such a health care institution or long-term care facility when this Alzheimer's/Dementia Mental Health Advance Directive takes effect, I direct that my consent to admission shall not constitute implied consent to procedures, policies, or courses of treatment mandated by religious or other policies of the institution or facility, if those procedures, policies, or courses of treatment conflict with this mental health advance directive.

_____ If the health care or long-term care facility in which I am a patient declines to follow my wishes as set out in this mental health advance directive, I direct that I be transferred, if possible, in a timely manner to another institution or facility which will agree to honor the instructions set forth in this mental health advance directive.

11. IF A COURT APPOINTS A GUARDIAN FOR ME

If a guardian is appointed by a court to make mental health decisions for me, I intend this document to take precedence over all other means of ascertaining my intent and preferences. The appointment of a guardian of my estate or my person or any other decision-maker shall not give that guardian or decision-maker the power to revoke, suspend, or terminate this Directive or the powers of my mental health care agent, except as authorized by law.

In the event the court appoints a guardian who will make decisions regarding my mental health treatment, I nominate the following person as my guardian:

Name _____

Address _____

Telephone _____

(day)

(evening)

(mobile)

12. OTHER DOCUMENTS

In planning for my health care, estate, and potential incapacity, I have executed the following documents: *(Initial and provide information for all that apply. Draw a line through those that do not.)*

_____ **General Power of Attorney:** *(Name and contact info of primary agent.)*

Name

Address

Telephone

_____ **Durable Power of Attorney for Finances:** *(Name and contact info of primary agent.)*

Name

Address

Telephone

_____ **Durable Power of Attorney for Health Care:** *(Name and contact info of primary health care agent.)*

Name

Address

Telephone

_____ **Living Will/Health Care Directive/Directive to Physicians:** *(Name and contact info of person who has a copy.)*

Name

Address

Telephone

_____ **Physician Orders for Life-Sustaining Treatment (POLST):**

(Optional; name and contact information of person who has access to your POLST.)

Name

Address

Telephone

_____ **Other Document:** *(Optional; name here: _____.)*

Name

Address

Telephone

13. SUMMARY AND SIGNATURE

I understand what this document means. I make this document of my free will, and I believe I have the mental and emotional capacity to do so.

By signing here, I indicate that I understand the purpose and effect of this document, and that I am giving my informed consent to the treatments and/or admission that I have consented to, or that I have authorized my agent to consent to, in this directive. I intend that my consent in this directive be construed as being consistent with the elements of informed consent under RCW chapter 7.70 in the State of Washington or applicable law in other states.

Signature of person making this document.

Date

(Sign only in the presence of two witnesses and a notary, if notarizing.)

14. STATEMENT OF WITNESSES

This directive was signed and declared by

(Print your name – not the names of your witnesses – on the following line.)

_____ to be her/his directive. It was signed in our presence at her/his request. We declare that at the time of the creation of this directive

(Print your name – not the names of your witnesses – on the following line.)

_____ is personally known to us and, according to our best knowledge and belief, has capacity at this time and does not appear to be acting under duress, undue influence, or fraud. We further declare that none of us is:

- a. A person designated to make medical decisions on the principal's behalf.
- b. A health care provider or professional person directly involved with the provision of care to the principal at the time the directive is executed.
- c. An owner, operator, employee, or relative of an owner or operator of a health care facility or long-term care facility in which the principal is a patient or resident.
- d. A person who is related by blood, marriage, legal domestic partnership, or adoption to the person, or with whom the person making this document has a dating relationship as defined in RCW 26.50.010 in the State of Washington or applicable law in other states.
- e. An incapacitated person.
- f. A person who would benefit financially if the principal undergoes mental health treatment.
- g. A minor.

WITNESS 1

WITNESS 2

Signature

Date

Signature

Date

Printed Name

Phone

Printed Name

Phone

Address

Address

NOTARIZATION *(optional)*

STATE OF _____ COUNTY OF _____

I certify that I know or have satisfactory evidence that _____
signed this document and acknowledged it to be his/her free and voluntary act for the uses and purposes mentioned in
this document.

NOTARY PUBLIC in and for the State of _____
Residing at _____
My commission expires _____

15. RECORD OF DIRECTIVE

I have given a copy of this directive to the following persons:

