

The LEAD Guide

Life-Planning in Early Alzheimer's & Other Dementias





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INSTRUCTIONS

Please note that all words in red are in the glossary.

What is dementia?

Dementia is a general term for loss of memory, language, problem-solving, and other thinking abilities that are severe enough to interfere with daily life. There are many types of dementia, such as Alzheimer's disease, vascular dementia, and Lewy body dementia. Alzheimer's disease is the most common type of dementia. This document uses the term "dementia" to include all types of dementia.

What is the LEAD Guide?

The LEAD Guide (Life-Planning in Early Alzheimer's and Other Dementias) was created to help persons with **dementia** (or at risk for dementia) think about, document, and share their preferences for their **end-of-life care**. The LEAD Guide also lets you specify how and with whom you want to make your decisions about your care. The LEAD Guide asks whether your **preferences** and **values** may change if you develop dementia or your dementia worsens.

The LEAD Guide is a set of questions to help you prepare for future healthcare needs. It helps you:

- 1. Review** what you have done about planning for end-of-life care, such as naming a decision-maker or filling out **advance directive** documents.
- 2. Share your values** about how you foresee the end of your life. For example, if you develop **dementia**, do you prefer to live longer or desire a shorter time with a better **quality of life**?
- 3. Share your preferences** for your care; for example, where you wish to live and who will care for you.

HOW DO I USE THE LEAD GUIDE?

There are many ways to use the LEAD Guide:

- 1. You can use it by yourself.** The LEAD Guide will take you through a series of questions about values and preferences associated with what types of care you want or do not want at the **end of life**. *Note: Even if you complete the LEAD Guide by yourself, it is a good idea to share it with your family, friends, or healthcare provider (doctor, nurse practitioner, physician assistant, etc.).*
- 2. Use the LEAD Guide with the person you have named or wish to name as your medical power of attorney.** Using the guide will help your medical power of attorney understand what care you want to receive if you develop dementia.
- 3. You may also use it for a more general conversation with your family and friends.** This way, the people you trust will understand what care you want to receive if you develop dementia. Using the LEAD Guide will help your family and friends have a shared understanding of your preferences and may prevent conflict in the future.
- 4. You may use it to help your healthcare providers understand your preferences for your end-of-life care.** This information will help them honor your preferences for end-of-life care if you develop dementia.

5. Regularly revisit the LEAD Guide as your circumstances and preferences may change.

Is the LEAD Guide the same as an advance directive?

No. An advance directive is a legal document that broadly states what care you want to receive at the end of your life. It also says whom you want to make decisions for you if you cannot do so for any reason. While important, advance directive documents do not cover all the end-of-life decisions that can arise with dementia. We advise everyone to complete advance directive documents in their home state. The advance directive documents are available on your state government's website.

Is the LEAD Guide a legally binding document?

No. The LEAD Guide is an end-of-life planning tool that supplements legal documents such as an advance directive, do-not-resuscitate order, or medical power of attorney. The LEAD Guide does not replace those documents. We recommend completing both legal documents and the LEAD Guide.

END-OF-LIFE DOCUMENTS

The LEAD Guide

Life-Planning in **E**arly **A**lzheimer's and Other **D**ementias

Name: _____

Date of Completion: _____ / _____ / _____

END-OF-LIFE DOCUMENTATION

1. A living will or advance directive is a legal document that states the kind of medical care you would want if you could not speak for yourself.

Have you completed this documentation?

☐ Yes

☐ No

2. A do not resuscitate order (DNR) indicates that you do not want to be revived if your heart stops.

Have you completed this documentation?

☐ Yes

☐ No

3. A medical power of attorney is a legal document that allows you to designate a person to make health care decisions for you if you cannot make your own decisions.

Have you completed the documentation to appoint a medical power of attorney?

☐ Yes

☐ No

If applicable, who is your medical power of attorney?
(Name and relationship)

END-OF-LIFE VALUES

END-OF-LIFE VALUES

*Below are a series of statements regarding your **attitudes** towards end-of-life care. These **values** are unique to you and mostly stay the same. Therefore, they can help guide a caregiver (i.e., a family member or close friend) to make decisions for you.*

QUALITY VERSUS LENGTH OF LIFE

Thinking about your end-of-life care, please respond to the following statements:

4. Quality of life is more important than length of life.

Please rate your level of agreement on a scale of 1 to 5 (check one box)

1 ☐ Strongly Disagree	2 ☐ Disagree	3 ☐ Neither Agree nor Disagree	4 ☐ Agree	5 ☐ Strongly Agree
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5. Length of life is more important than quality of life.

Please rate your level of agreement on a scale of 1 to 5 (check one box)

1 ☐ Strongly Disagree	2 ☐ Disagree	3 ☐ Neither Agree nor Disagree	4 ☐ Agree	5 ☐ Strongly Agree
--	---	---	--	---

6. Given a choice, I prefer to live a shorter but more satisfying life.

Please rate your level of agreement on a scale of 1 to 5 (check one box)

1 ☐ Strongly Disagree	2 ☐ Disagree	3 ☐ Neither Agree nor Disagree	4 ☐ Agree	5 ☐ Strongly Agree
--	---	---	--	---

7. I prefer to live as long as possible, even if that longer life is lower quality.

Please rate your level of agreement on a scale of 1 to 5 (check one box)

1 ☐ Strongly Disagree	2 ☐ Disagree	3 ☐ Neither Agree nor Disagree	4 ☐ Agree	5 ☐ Strongly Agree
--	---	---	--	---

What does “quality of life” mean to you?

For example, you can list activities and abilities that contribute most to a good quality of life.

[illegible]

BURDEN

Thinking about your end-of-life care, please respond to the following statements:

8. I am concerned about being a **financial burden to family or close friends.**

Please rate your level of agreement on a scale of 1 to 5 (check one box)

1	2	3	4	5
☐	☐	☐	☐	☐
Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree

9. I am concerned about being an **emotional burden to my family or close friends.**

Please rate your level of agreement on a scale of 1 to 5 (check one box)

1	2	3	4	5
☐	☐	☐	☐	☐
Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree

10. I am concerned about being a **physical burden to my family or close friends (such as needing assistance with bathing, toileting, and eating).**

Please rate your level of agreement on a scale of 1 to 5 (check one box)

1	2	3	4	5
☐	☐	☐	☐	☐
Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree

DECISION MAKING

DECISION MAKING

Thinking about your end-of-life care, please respond to the following statements:

11. I want to have conversations about my **end-of-life care options with** *(check all that apply)*

☐ my spouse/partner

☐ my child(ren)

☐ my healthcare provider

☐ other: _____

☐ uncertain at this time

List the name(s) of persons you'd like involved in these conversations:
(name and relationship)

12. When I cannot express my care preferences, I want the primary decision-maker regarding my end-of-life care to be
(check one)

☐ my spouse/partner

☐ my child(ren)

☐ other: _____

☐ uncertain at this time

List the name(s) of persons you'd like involved in these conversations:
(name and relationship)

Now, think about specific types of decisions made during the end of life and respond to the following statements:

13. I want decisions related to the **location of my ongoing care to be made by:**

(check all that apply)

- ☐ myself, if able
- ☐ spouse/partner
- ☐ child(ren)
- ☐ other: _____
- ☐ uncertain at this time

14. I want decisions related to the **location of my death to be made by:**

(check all that apply)

- ☐ myself, if able
- ☐ spouse/partner
- ☐ child(ren)
- ☐ other: _____
- ☐ uncertain at this time

15. I want decisions related to my **life-prolonging measures to be made by:**

(check all that apply)

- ☐ myself, if able
- ☐ spouse/partner
- ☐ child(ren)
- ☐ other: _____
- ☐ uncertain at this time

16. I want decisions related to **controlling when I die to be made by:**

(check all that apply)

- ☐ myself, if able
- ☐ spouse/partner
- ☐ child(ren)
- ☐ other: _____
- ☐ uncertain at this time

Additional Information

Is there anything else you want your family or healthcare providers to know about your end-of-life values?

[illegible]

END-OF-LIFE PREFERENCES

END-OF-LIFE PREFERENCES

*Below is a series of statements regarding your **preferences** toward end-of-life care. These preferences may change based on your circumstances. You are to complete the following information based on two situations.*

SITUATION 1:

What are your end-of-life care preferences today, when you can communicate your choices and make decisions?

LOCATION OF ONGOING CARE

17. If you were to require 24-hour care and supervision for medical needs today, where is your preferred location to receive care? (check one)

- ☐ In my home
- ☐ In someone else's home (specify): _____
- ☐ In a residential hospice center, if available
- ☐ In a nursing home
- ☐ In a hospital
- ☐ Uncertain at this time

LIFE PROLONGING MEASURES

18. What are your preferences if you were to require life-prolonging measures today?

I would want to live as long as possible, even if I had to be on life support or a breathing machine.

- ☐ Yes ☐ No ☐ Uncertain at this time

I would want to live as long as possible, even if my brain stops working.

- ☐ Yes ☐ No ☐ Uncertain at this time

I would want to live as long as possible, even if fed through a tube.

☐ Yes ☐ No ☐ Uncertain at this time

I would want to live as long as possible, even in severe pain.

☐ Yes ☐ No ☐ Uncertain at this time

CONTROLLING WHEN YOU DIE

19. What are your preferences today regarding controlling when you die?

I would consider ending my own life by not eating or drinking.

☐ Yes ☐ No ☐ Uncertain at this time

I would consider independently ending my own life through self-directed means.

☐ Yes ☐ No ☐ Uncertain at this time

I would consider taking a prescription medication to end my life under the supervision of a physician (if legal in my state and if I were deemed competent).

☐ Yes ☐ No ☐ Uncertain at this time

SITUATION 2:

In the later stages of dementia, the ability to understand, make decisions, and communicate is impaired. You will need someone else to make decisions for you in this situation.

What end-of-life care decisions would you like someone else to make for you when you are in the later stages of dementia and cannot express your care preferences?

LOCATION OF ONGOING CARE

20. In the later stages of dementia, where is your preferred location to receive care if you require 24-hour care and supervision for medical needs? *(check one)*

- ☐ In my home
- ☐ In someone else's home (specify): _____
- ☐ In a residential hospice center, if available
- ☐ In a nursing home
- ☐ In a hospital
- ☐ Uncertain at this time

LIFE PROLONGING MEASURES

21. In the later stages of dementia, what are your preferences regarding life-prolonging measures?

I would want to live as long as possible, even if I had to be on life support or a breathing machine.

☐ Yes ☐ No ☐ Uncertain at this time

I would want to live as long as possible, even if my brain stops working.

☐ Yes ☐ No ☐ Uncertain at this time

I would want to live as long as possible, even if fed through a tube.

☐ Yes ☐ No ☐ Uncertain at this time

I would want to live as long as possible, even in severe pain.

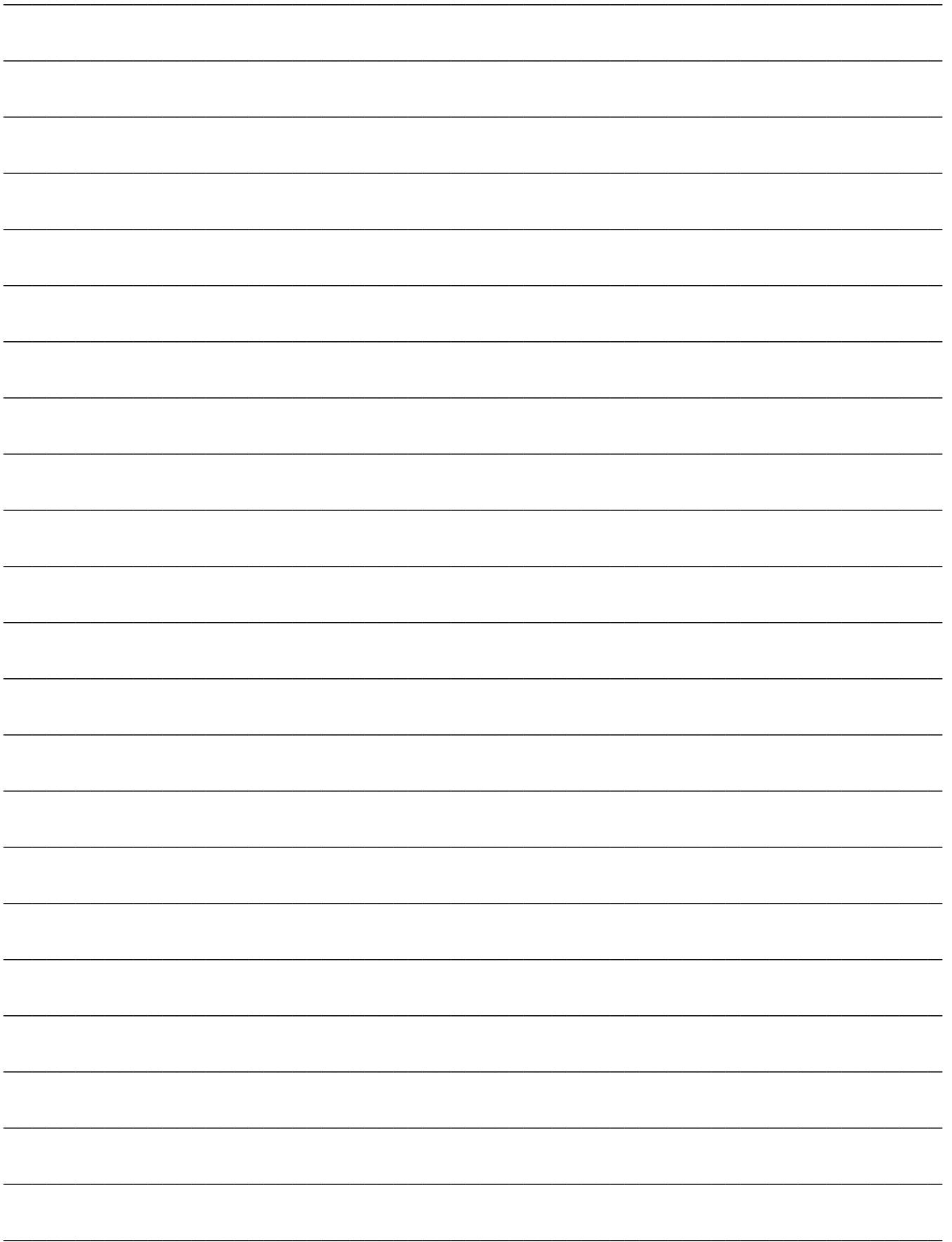
☐ Yes ☐ No ☐ Uncertain at this time

Additional Information

Is there anything else you would like your family or healthcare providers to know about your end-of-life preferences?

Please add any additional instructions you have for your end-of-life care. This can include, for example, grooming instructions for your hair or preferred clothing style, religious observances, music preferences, or people you would like included or excluded from visiting or being involved in your end-of-life care.

Please summarize your wishes for after your death, such as funeral and burial plans.



NEXT STEPS: SHARING YOUR LEAD GUIDE

It is critical that this guide, and any legal documents for your end-of-life care, be shared with the person(s) who will make decisions for you if you cannot express your end-of-life care preferences.

This section will help you make a plan to share this document and any legal documentation you have.

Place a checkmark next to all the steps you will take to share your LEAD Guide.

- | | |
|--|---|
| ☐ Send to my healthcare provider(s) | ☐ Send to my spouse/partner |
| ☐ Send to my care manager | ☐ Send to a close friend |
| ☐ Send to my children | ☐ Add to my legal paperwork, such as my will or my advance directive |
| ☐ Discuss at a family meeting | |

Fill in below any additional steps you will take to share your LEAD Guide and any additional legal documents.

UPDATING YOUR LEAD GUIDE

Changes in your thinking skills or health may alter your preferences for end-of-life care.

We recommend revisiting the LEAD Guide at least yearly during your physical exam with your healthcare provider or when you or your care partner see a change in your medical condition.

Below, write the date of your next physical exam or another date that will be convenient to review your LEAD Guide.

Date _____/_____/_____

GLOSSARY

Advance Directive/Living Will – a legal document describing a person's desires regarding their medical care in situations where they can no longer express their preferences.

Attitudes – a settled way of thinking or feeling about someone or something, typically reflected in a person's behavior.

Cardiopulmonary Resuscitation (CPR) – is an emergency life-saving procedure performed when the heart stops beating. Common CPR methods are chest compressions and mouth-to-mouth breathing. Sometimes an electric shock to the heart is used.



Controlling when I die – voluntarily stopping eating and drinking to hasten death or assistance provided by a healthcare provider. This care is for patients who are going to die and seek help in controlling the timing of their death through medical intervention.

Dementia – usually a progressive condition (such as Alzheimer's disease) that is associated with multiple impairments in thinking skills, such as memory, language skills, and the inability to plan and initiate complex behavior.

Do Not Resuscitate Order (DNR) – is an order that informs medical staff that they should not attempt to restart your heart if it stops beating (CPR). This order helps prevent unnecessary and unwanted invasive treatment at the end of life. This order may be a part of your state's POLST form (Provider Order for Life-Sustaining Treatment).

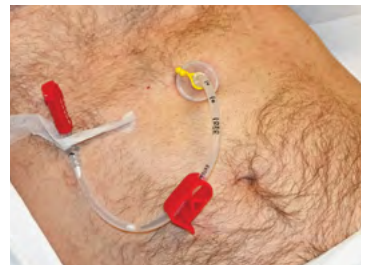


Emotional burden – a situation where a person experiences emotional stress due to a variety of reasons such as guilt, obligation, or difficulty making decisions.

End of life – refers to the final period of hours, days, weeks, and months in a person's life in which it is medically apparent that death is forthcoming.

End-of-life care – is the term used to describe the support and medical care given during the time surrounding death.

Feeding tube – a flexible tube is inserted through the nose or stomach area to provide nutrients by delivering liquid nutrition directly into the stomach or small intestine. This is used when a person does not eat or is not getting enough nutrition through eating.



Financial burden – in the context of healthcare, this term describes a patient's monetary problems related to the cost of medical care that may lead to debt or bankruptcy.

Length of life – how long a person lives.

Life-prolonging measures or treatments – medical care that prolongs life when organs stop working. Life-prolonging treatments can include a ventilator, a device to help your kidneys function (dialysis), a feeding tube, or a tube put into your vein to give fluids and medicines (intravenous, IV tube).

Location of death – where you die, such as your home, the hospital, a long-term care center (nursing home, assisted living), or a residential hospice center.

Location of ongoing care – where you receive care when you cannot care for yourself (home, nursing home, hospital, etc.).

Medical or health care power of attorney – The person you legally appoint to make health care decisions when you cannot do so. Sometimes referred to as a health care proxy or proxy decision maker.

Nursing home – is a public or private residential facility that provides a high level of long-term personal or nursing care for persons (such as the aged or the chronically ill) who cannot care for themselves properly.

Physical burden - caregiver stress related to assisting with feeding, bathing, toileting, transferring from the bed to a chair, or other daily tasks.

Preferences – things that you give priority to, or like better or best.

Quality of life – the way each person describes how good or bad their life situation is.

Residential hospice center – is a peaceful home-like residence where terminally ill people receive short-term hospice comfort care care.

Values – what you find important or valuable in life, such as your ideals, your principles, and morals

Ventilator – is a type of therapy that helps you breathe or breathes for you when you can't breathe on your own. You might be on a ventilator during surgery or if your lungs aren't working properly. Mechanical ventilation keeps your airways open, delivers oxygen, and removes carbon dioxide.

Definitions provided or adapted from Merriam-Webster, Merck Manual, Centers for Disease Control, Medline Plus, & National Institutes of Health.





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