

The LEAD Guide: Life-Planning in Early Alzheimer's and Dementia

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WHY IS ADVANCE CARE PLANNING IMPORTANT?

- People cannot read minds!
- Ensures that your care aligns with your values and preferences
- Avoid unnecessary interventions
- It relieves feelings of guilt or burden on those making decision on your behalf



BACKGROUND

Current EOL assessment tools:

- Vague
- Assess care preferences based on hypothetical “untreatable disease”
- Disease specific tools are associated with cancer
- Do not address decline of cognition associated w/ neurodegenerative diseases

Need for new tool:

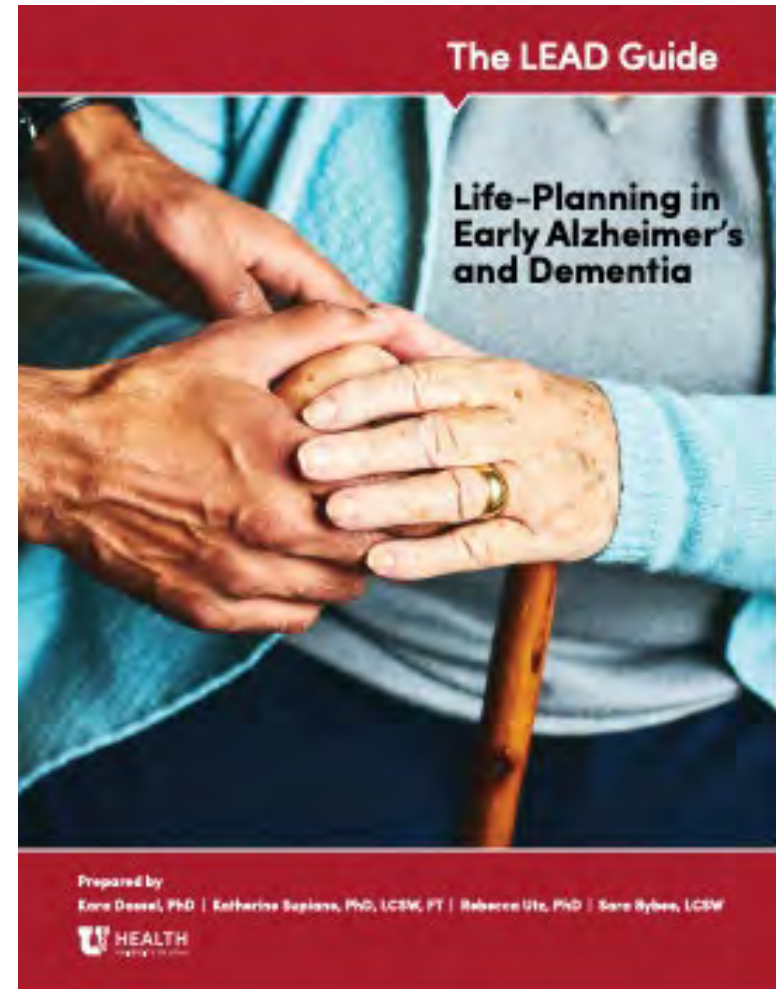
- Values
- Preferences
- Dementia-specific



THE LEAD GUIDE – LIFE-PLANNING IN EARLY ALZHEIMER’S AND DEMENTIA

LEAD Guide Format:

- Ways to use the LEAD Guide
- How the LEAD Guide helps with EOL planning
- Part 1 – EOL Documentation
- Part 2 – Values
- Part 3 – Preferences
- Blank pages at end to add additional information
- Glossary



Available at: www.utahgwep.org under the "Resources" tab.

HOW DO I USE THE LEAD GUIDE?

Four Ways to Use the LEAD Guide:

1. Use it by yourself
2. Use it with the person you have named your medical power of attorney
3. Use it to guide general conversations about your care if you developed cognitive impairment
4. Use it to help your doctor understand your EOL wishes



HOW DO I USE THE LEAD GUIDE?

There are many ways to use the LEAD Guide:

1. You can use it by yourself. Using the LEAD Guide will take you through a series of common 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, and/or health care provider.*

2. You should use it with the person you have named or wish to name as your medical power of attorney. Using the LEAD Guide will help you and your medical power of attorney have a clearer understanding of what you would want done and what you would not want done if you develop a cognitive impairment and will need that person to make decisions for you.

3. You may also use it to have a more general conversation with any of your family and friends so that the people you trust the most understand what you would want done and what you would not want done if you developed a cognitive impairment. Using the LEAD Guide will help your family and friends have a shared understanding of your wishes, and may prevent conflict in the future.

4. You may use it to help your doctor understand your wishes for the end of your life. Completing the LEAD Guide and sharing it with your health care providers will help them understand and honor your wishes if you develop a cognitive impairment and cannot make your own health care decisions.

Is the LEAD Guide the same as an advance directive?

No. An advance directive is a legal document that broadly states what you want at end-of-life and who you want to make decisions for you, if you are unable to do so for any reason. While important, advance directive documents do not cover all the end-of-life decisions that can develop in dementia. We advise everyone to complete advance directive documents in their home state. The advance directive documents are available on your State website. We recommend that everyone complete the LEAD Guide to prepare for the special issues that may come with a cognitive impairment.

HOW DOES THE LEAD GUIDE HELP WITH EOL PLANNING?

3 Ways the LEAD Guide Facilitates EOL Planning:

1. Review what steps you've taken regarding preparing for your future EOL care
2. Share your values about how you envision your end of life
3. Share your preferences for your care at the end of life



The LEAD Guide
Life-Planning in **E**arly **A**lzheimer's and **D**ementia
Please note, all items in **red** are defined in the glossary.

The LEAD Guide (Life-Planning in Early Alzheimer's and Dementia) was created to help persons with **dementia** (or at risk for dementia) think about, document, and then share their wishes for their **end-of-life care**. The LEAD Guide also helps you specify how and with whom you want to make your decisions about your care. The LEAD Guide asks you specifically whether your **preferences** and **values** may change if you have a **cognitive impairment** that prevents you from making your own decisions.

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

- 1**
Review what you have done so far about end-of-life care; things like 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 would you desire 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.

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PART 1: EOL DOCUMENTATION

Review EOL Documentation:

1. Advance Directive
2. No Not Resuscitate Order
3. Medical Power of Attorney
 - Name the person

*Sign and Date



END-OF-LIFE DOCUMENTS

END-OF-LIFE DOCUMENTATION

A **living will** or **advance directive** is a legal written 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

A **do not resuscitate order (DNR)** indicates that if your heart stopped, you would not want to be resuscitated.

Have you completed this documentation?

Yes

No

A **medical power of attorney** is a person who you designate, by law, to make health care decisions for you if you cannot make your own decisions.

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

Yes

No

Who is your medical power of attorney?

Completed by:

Name _____

Date ____ / ____ / ____



PART 2: END-OF-LIFE VALUES

Questions about Burden:

1. Financial
2. Emotional
3. Physical

Likert-scale 1-5 with 1= strongly disagree
to 5= strongly agree

END-OF-LIFE VALUES

Below are a series of statements regarding your attitudes towards to end-of-life care. These values are unique to you and do not typically change very much and, therefore, can serve as guideposts for a caregiver (i.e., family member or close friend) to make decisions on your behalf.

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

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 <input type="checkbox"/> Strongly Disagree	2 <input type="checkbox"/> Disagree	3 <input type="checkbox"/> Neither Agree or Disagree	4 <input type="checkbox"/> Agree	5 <input type="checkbox"/> Strongly Agree
--	---	--	--	---

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 <input type="checkbox"/> Strongly Disagree	2 <input type="checkbox"/> Disagree	3 <input type="checkbox"/> Neither Agree or Disagree	4 <input type="checkbox"/> Agree	5 <input type="checkbox"/> Strongly Agree
--	---	--	--	---

I am concerned about being a physical burden to my family or close friends.
Physical burden includes assistance bathing, toileting, transferring from the bed to a chair, or the time spent providing care.
Please rate your level of agreement on a scale of 1 to 5 (Check one box)

1 <input type="checkbox"/> Strongly Disagree	2 <input type="checkbox"/> Disagree	3 <input type="checkbox"/> Neither Agree or Disagree	4 <input type="checkbox"/> Agree	5 <input type="checkbox"/> Strongly Agree
--	---	--	--	---



PART 2: END-OF-LIFE VALUES

Questions about Quality versus

Length of Life:

1. Importance of each
2. Conditional responses

Likert-scale 1-5 with 1= strongly

disagree to 5= strongly agree

QUALITY VERSUS LENGTH OF LIFE

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

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 <input type="checkbox"/> Strongly Disagree	2 <input type="checkbox"/> Disagree	3 <input type="checkbox"/> Neither Agree or Disagree	4 <input type="checkbox"/> Agree	5 <input type="checkbox"/> Strongly Agree
--	---	--	--	---

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 <input type="checkbox"/> Strongly Disagree	2 <input type="checkbox"/> Disagree	3 <input type="checkbox"/> Neither Agree or Disagree	4 <input type="checkbox"/> Agree	5 <input type="checkbox"/> Strongly Agree
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Given the choice, I would 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 <input type="checkbox"/> Strongly Disagree	2 <input type="checkbox"/> Disagree	3 <input type="checkbox"/> Neither Agree or Disagree	4 <input type="checkbox"/> Agree	5 <input type="checkbox"/> Strongly Agree
--	---	--	--	---

I would prefer to live as long as I can even if that longer life is not of the highest quality.
Please rate your level of agreement on a scale of 1 to 5 (Check one box)

1 <input type="checkbox"/> Strongly Disagree	2 <input type="checkbox"/> Disagree	3 <input type="checkbox"/> Neither Agree or Disagree	4 <input type="checkbox"/> Agree	5 <input type="checkbox"/> Strongly Agree
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PART 2: END-OF-LIFE VALUES

Decision Making – Autonomy versus

Collaborative

1. Self

2. Family

3. Doctor

Room for Supplemental Information

about Values (next slide)



DECISION MAKING

DECISION MAKING

In general, I prefer that **end-of-life** decisions be made by:

- me only
- me with the assistance and advice of my family
- me with the assistance and advice of my doctor
- me with the assistance and advice of my family and doctor
- my family alone (without my input)
- my doctor alone (without my input)
- my family and doctor together (without my input)
- uncertain at this time

NOW think about specific types of decisions that need to be made during the end of life:

I prefer that decisions related to the **location of ongoing care** be made by:

- me only
- me with the assistance and advice of my family
- me with the assistance and advice of my doctor
- me with the assistance and advice of my family and doctor
- my family alone (without my input)
- my doctor alone (without my input)
- my family and doctor together (without my input)
- uncertain at this time

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PART 2: END-OF-LIFE VALUES

I prefer that decisions related to **location of death** be made by:

- me only
- me with the assistance and advice of my family
- me with the assistance and advice of my doctor
- me with the assistance and advice of my family and doctor
- my family alone (without my input)
- my doctor alone (without my input)
- my family and doctor together (without my input)
- uncertain at this time

I prefer that decisions related to **life-prolonging measures** be made by:

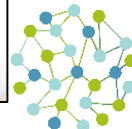
- me only
- me with the assistance and advice of my family
- me with the assistance and advice of my doctor
- me with the assistance and advice of my family and doctor
- my family alone (without my input)
- my doctor alone (without my input)
- my family and doctor together (without my input)
- uncertain at this time

I prefer that decisions related to **controlling when I die** be made by:

- me only
- me with the assistance and advice of my family
- me with the assistance and advice of my doctor
- me with the assistance and advice of my family and doctor
- my family alone (without my input)
- my doctor alone (without my input)
- my family and doctor together (without my input)
- uncertain at this time

Additional Information

Is there anything about these values discussed above that you would like your family or health care providers to know about your values?



PART 2: END-OF-LIFE VALUES

Preference for Location of Care:

1. Own home
2. Someone else's home
3. Residential hospice
4. Nursing home
5. Hospital
6. Uncertain

Answer Questions for 2 Conditions:

1. When you are able to make decisions...
2. When you are unable to make decisions...



END-OF-LIFE CARE

END-OF-LIFE PREFERENCES

Below is a series of statements regarding your preferences towards end-of-life care. These preferences may change based on your circumstances. You will be asked to complete the statements based on two situations:

1. When you DO have the ability to make decisions for yourself and
2. When you DO NOT have the ability to make decisions for yourself as a result of memory loss associated with Alzheimer's disease or a related dementia.

LOCATION OF ONGOING CARE

If you were to require 24-hour care and supervision for medical needs TODAY, where is your preferred location to receive this care? (please select only one option)

In my home

In someone else's home (please specify): _____

In a residential hospice center if available

In a nursing home

In a hospital

Uncertain at this time

Would your preference for the location of your care change IF YOU CAN NO LONGER MAKE YOUR OWN DECISIONS?

Yes No (If NO, skip to the next section: Life Prolonging Measures)

If YES, where would you want to receive your care and supervision if you can no longer make your own decisions? (please select only one option)

In my home

In someone else's home (please specify): _____

In a residential hospice center if available

In a nursing home

In a hospital

Uncertain at this time

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PART 3: END-OF-LIFE PREFERENCES

Life-Prolonging Measures:

1. Ventilator
2. Feeding tube
3. Severe pain
4. Brain-dead

Answer Questions for 2 Conditions:

1. When you are able to make decisions...
2. When you are unable to make decisions...



LIFE PROLONGING MEASURES

Below are a series of statements regarding your preferences for end-of-life care. These preferences may change based on your circumstances. You will be asked to complete the statements based on two situations:

1. When you DO have the ability to make decisions for yourself and
2. When you DO NOT have the ability to make decisions for yourself as a result of memory loss associated with Alzheimer's disease or a related dementia.

In regards to life prolonging measures, please respond to the following statements:

AS IF YOU HAD TO CHOOSE TODAY: I would want to live as long as possible, even if I had to be on a life support or breathing machine.

Yes No Uncertain at this time

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

Yes No Uncertain at this time

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

Yes No Uncertain at this time

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

Yes No Uncertain at this time

Does your preference for life prolonging measures change IF YOU CAN NO LONGER MAKE YOUR OWN DECISIONS?

Yes No (If NO, skip to section: Controlling when you die)

If YES, please respond to the following statements for the life prolonging measures you would wish to receive IF YOU CAN NO LONGER MAKE YOUR OWN DECISIONS.

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

Yes No Uncertain at this time

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PART 3: END-OF-LIFE PREFERENCES

Controlling the Timing of One's Death:

1. Stop eating and drinking
2. Self-directed means
3. Medication from doctor

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

Yes No Uncertain at this time

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

Yes No Uncertain at this time

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

Yes No Uncertain at this time

CONTROLLING WHEN YOU DIE

In regards to controlling when you die, please respond to the statements AS IF YOU HAD TO CHOOSE TODAY.

I would consider ending my own life through 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



PART 3: END-OF-LIFE PREFERENCES

Room for Supplemental
Information about Preferences

Additional Information

Is there anything about these items discussed above that you would like your family or health care providers to know about your preferences?

Please provide a summary of your end-of-life values and preferences.

Your personal values and preferences may change over time, so this document should be revisited regularly or as health conditions and/or cognitive functions change. Information can be added or changed so that this document reflects your current end-of-life wishes.

Please consider sharing this information with your family members or primary care physician.



GLOSSARY

Why is a Glossary Needed?

1. Reading level 11th grade
(Lower than Utah State
Advance Directive reading
level)
2. Glossary of terms to provide
definitions for technical
words such as DNR, life-
prolonging measures, etc.

GLOSSARY

Advance directive – A legal document allowing you to spell out your decisions about end-of-life care ahead of time in the case that you become unable to make your own medical decisions

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

Cognitive impairment – when a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life.

Controlling when I die – either voluntarily stopping eating and drinking to hasten death or assistance provided by a physician to patients who are otherwise going to die, who seek help in controlling the timing and circumstances of their death through medical intervention.

Dementia – usually a progressive condition (such as Alzheimer's disease) marked by the development of multiple cognitive deficits, such as memory impairment, aphasia, and the inability to plan and initiate complex behavior.

Do not resuscitate order (DNR) – an order placed in a person's medical record by a doctor that informs the medical staff that cardiopulmonary resuscitation (CPR) should not be attempted. Because CPR is not attempted, other resuscitative measures that follow (such as electric shocks to the heart and artificial respirations by insertion of a breathing tube) will also be avoided. This order has been useful in preventing unnecessary and unwanted invasive treatment at the end of life.

Emotional burden – is a situation where a person is emotionally stressed due to a variety of reasons such as feelings of guilt, obligation, or difficulty making decisions.

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

Financial burden – in the context of healthcare, this term describes monetary problems a patient has related to the cost of medical care. Not having health insurance or having a lot of costs for medical care not covered by health insurance can cause financial problems and may lead to debt or bankruptcy.

Length of life – how long a person lives.

Life-prolonging measures or treatments – medical care provided that prolongs life when organs have stopped working. Treatments can include a machine to help with breathing (ventilator), a machine to help with your kidneys (dialysis), a tube put into your stomach to provide food (nasogastric or gastrostomy tube), a tube put into your vein to provide fluids and medicines (intravenous, IV tube), and/or a tube or mask to supply oxygen.

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

Location of ongoing care – the place where you will be provided care when you are unable to care for yourself (home, nursing home, hospital, etc.).

Living will – a written statement describing a person's desires regarding their medical care in situations where they are no longer able to express their wishes

Medical or health care power of attorney – The person you legally appoint to make health care decisions in the event you become unable to do so. Sometimes referred to as a Health Care Proxy or Proxy Decision maker.

Nursing home – a public or private residential facility providing a high level of long-term personal or nursing care for persons (such as the aged or the chronically ill) who are unable to care for themselves properly.

Preferences – something that you give priority, 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 (provision of supportive comfort care) care.

Values – something (such as a principle or quality) intrinsically valuable or desirable.

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



SUPPLEMENTAL INFORMATION

4 Blank Pages for Additional Information:

1. How do I define “quality of life”
2. What do I want done when I no longer recognize my family
3. Under XYZ circumstances, I want XYZ
4. If I were to develop pneumonia, I would/not want antibiotics
5. I only want to receive care at home, if
.....

After completing this guide, some people think of more details they want to document regarding their end-of-life care (e.g. “How do you define quality of life?”). Feel free to use the following blank pages or add additional pages to record those thoughts.



SUMMARY & IMPLICATIONS



The LEAD Guide:

- Assesses general EOL **values** that we believe to be static and representative of the individual's wishes
- Specific EOL **care preferences** which may be malleable as caregiving situation ADRD progression.
- Comprehensive, but concise.
- Has tests psychometric validity and reliability
 - ✓ Utility in research & practice
- Applicable for healthy adults, those concerned or at-risk for ADRD, and persons in the preclinical or early-stages of ADRD



Thank You!

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