
Planning Together

For Living
with Dementia



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Professional Support Version



Norma Rhoads and family

My Inspiration



May your choices reflect your hopes,
not your fears.

-Nelson Mandela

Agenda

- Dementia-What to Expect
- Care Options & Preferences
- Advance Care Planning Tools
- Questions & Answers

Dementia

- Decline in cognitive function that interferes with daily activities
- Typically 4-8 year progression, but can last up to 20 years
- Timing & type of symptoms vary

[What is Dementia? | alz.org](https://www.alz.org)



Stages

- Three Stages: Early, Middle, & Late
- Length of each stage varies
- Symptoms occur in different order for different people, especially in early stage
- Difficult to predict when decision making ability will be lost
- Dementia is a terminal illness

Early Stage:
Learn & Plan
Together

Middle Stage:
Ensure Safety &
Seek Support

Late Stage:
Implement Plan &
Interact Positively

Stages & Behaviors | Alzheimer's Association

Cognitive

- Memory
- Word Recall
- Processing Speed
- Decision Making
- Spatial Perception

Psychological

- Depression
- Anxiety
- Anger
- Apathy
- Hallucinations/Delusions

Physical

- Mobility
- Incontinence/Personal Hygiene
- Eating/Swallowing
- Sleep Disturbances
- Tremors

Social

- Language & Speech
- Withdrawal
- Impulsivity/Loss of Inhibition
- Mood Changes
- Loss of Independence

Different Journeys

Alzheimer's Disease

- Memory
- Word Recall
- Depression
- Decision Making

Lewy Body Dementia

- Spatial Perception
- Hallucinations
- Tremor or slow movement
- Sleep disorder
- Symptoms fluctuate more

...for each person

Person-Centered Care

- Flexibility
- Autonomy
- Community Connection
- Meaningful Purpose
- Honors Personal Preferences
- Focuses on Abilities

Pioneer Network | Changing Care

Teepa Snow's Positive Approach to Care – YouTube

Home - Positive Approach to Care (teepasnow.com)

Jewish Family Service - For Seniors (jfsutah.org)

Personal Preferences

- Access to Nature
- Music
- Physical Movement
- Social Activity & Privacy
- Meals, Snacks, Personal Care
- Environment & Décor
- End of Life Care

What Questions Should I Ask? | Pioneer Network

Advance Care Planning

- Financial [Know What to Expect | Alzheimer's Association](#)
- Legal [Plan For Your Future | Alzheimer's Association](#)
- Late Stage Care [Leaving Well: Utah Guide to End-of-Life](#)
- End of Life Care
- Care Team

Medical Planning

- Utah Advance Directive
- POLST-Life with Dignity Directive
- End of Life Planning Toolkit

[Utah Advance Health Care Directive Forms and Instructions](#) | [Utah Commission on Aging](#)

Utah Advance Health Care Directive
Pursuant to Utah Code Sections 75-2a-100 et seq.

Part I: Allows you to name another person to make health care decisions for you when you cannot make decisions or speak for yourself.
Part II: Allows you to record your wishes about health care in writing.
Part III: Tells you how to revoke or change this directive.
Part IV: Makes your directive legal.

My Personal Information

Name: _____
Address: _____
Address: _____
Telephone: (____) _____ Call Phone: (____) _____
Birth Date: _____

Part I: My Agent (Health Care Power of Attorney)

A: No Agent
If you do not want to name an agent, initial the box below, then go to Part II. Do not name an agent in B, or C, below. You are not required to name an agent, and no one can force you to name an agent.

I do not want to choose an agent.

B: My Agent

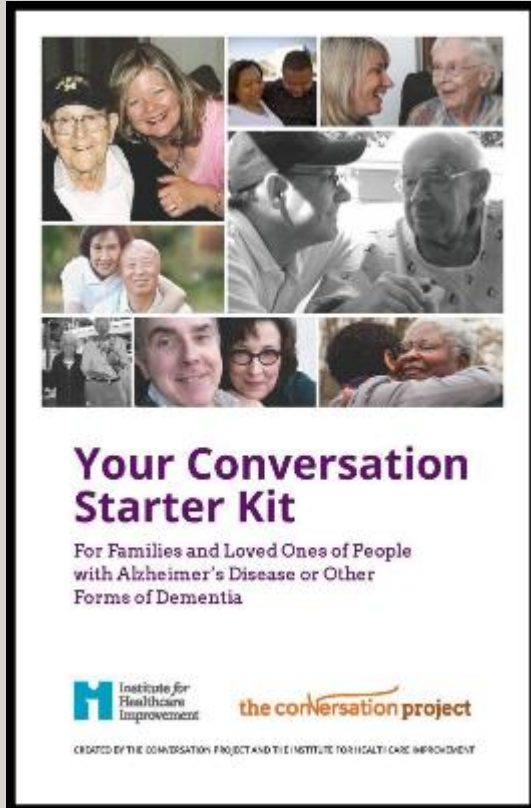
Agent's Name: _____
Street Address: _____
City, State, Zip: _____
Home Phone: (____) _____ Call Phone: (____) _____ Work Phone: (____) _____

C: My Alternate Agent
This person will serve as your agent if your agent is unable or unwilling to serve.

Agent's Name: _____
Street Address: _____
City, State, Zip: _____
Home Phone: (____) _____ Call Phone: (____) _____ Work Phone: (____) _____

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Dementia Specific Planning

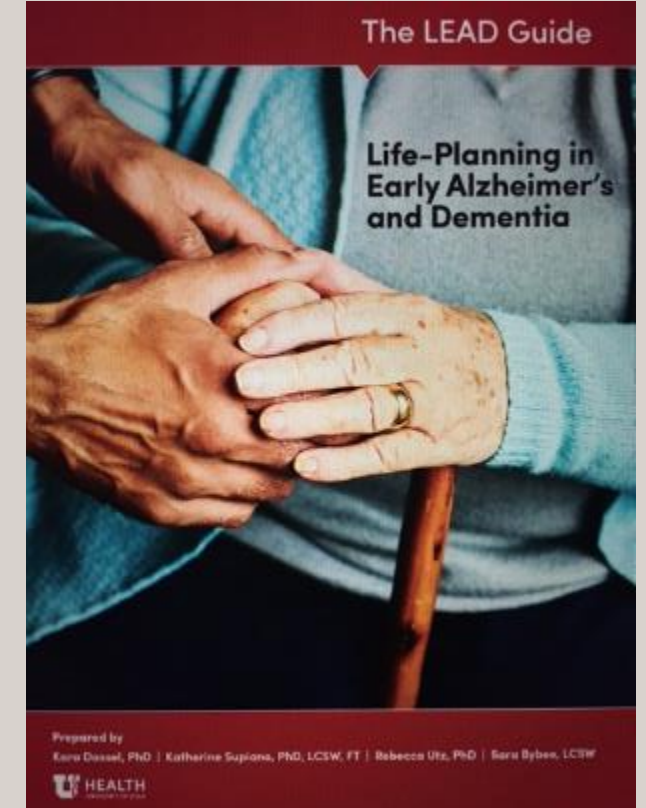


[Alzheimer's Starter Kit](#)



**What If I Had
Dementia?
Planning for the future**

[Advance Directive for Dementia](#)



[LEAD Guide | utahgwep.org](#)

Step 1 Get Ready

“Should I have the conversation with my loved one?”

Step 2 Get Set

“Okay, I’ve decided that I want to have the conversation with my loved one. But how do I begin?”

“What if the illness is so advanced that my loved one is not able to express his or her wishes?”

Step 3 Go

“Now that you’ve had the conversation with your loved one — or you’ve gathered family members and done your best to fill out the Starter Kit as if your loved one were filling it out — you have a good idea of what matters most to him or her when it comes to end-of-life care.”

<https://theconversationproject.org/>

If I have mild dementia then I would want the main goal for my care to be:

- To live for as long as I can...
- To receive treatments to prolong my life, but if my heart stops beating or I can't breathe on my own, I would not want my heart shocked to restart it (DNR) and I would not want to be put on a breathing machine...
- To only receive care in the place where I am living. I would not want to go to the hospital even if I were very ill, and I would not want to be resuscitated (DNR)...
- To receive comfort-oriented care only, focused on relieving my suffering such as pain, anxiety, or breathlessness...

<https://dementia-directive.org/>

The LEAD Guide

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

“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.”

https://www.utahgwep.org/files/LEAD_Guide_print.pdf

Advance Planning Tips

- ❖ Sooner is better
- ❖ Not easy, but worth it
- ❖ Write and discuss
- ❖ Keep it accessible

References

Alzheimer's Association (2020). *Dementia vs. Alzheimer's Disease: What is the difference?* <https://www.alz.org/alzheimers-dementia/difference-between-dementia-and-alzheimer-s>

Alzheimer's Association (2020). *Plan for your future.* <https://www.alz.org/help-support/i-have-alz/plan-for-your-future>

Alzheimer's Association (2020). *Stages of Alzheimer's.* <https://www.alz.org/alzheimers-dementia/stages>

Alzheimer's Association (2020). *Treatments for behavior.* <https://www.alz.org/alzheimers-dementia/treatments/treatments-for-behavior>

References

Alzheimer's Association (2020). *What is dementia?*

<https://www.alz.org/alzheimers-dementia/what-is-dementia>

Dassel, K., Utz, R., Supiano, K., Bybee, S., & Iacob, E. (2019). Development of a dementia-focused end-of-life planning tool: The LEAD guide (Life-Planning in Early Alzheimer's and Dementia). *Innovation in Aging*, 3(3), 1-12. <https://doi.org/10.1093/geroni/igz024>

DLB Consortium. (2017). Diagnosis and management of dementia with Lewy bodies: Fourth consensus report of the DLB Consortium. *Neurology*, 89(1), 88-100. (2017).

<https://doi-org/10.1212/WNL.0000000000004058>

References

Gaster, B. (2017). *What if I had dementia? Planning for the future*. Health directive for dementia.

<https://static1.squarespace.com/static/5a0128cf8fd4d22ca11a405d/t/5cd9efd571c10b87cbaf4676/1557786582104/dementia-directive.pdf>

Goodreads. (2020). *Nelson Mandela quotes*. <https://www.goodreads.com/quotes/956662-may-your-choices-reflect-your-hopes-not-your-fears>

Institute for Healthcare Improvement. (2021). *The conversation project*. <https://theconversationproject.org/>

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Philadelphia, PA: Open University Press.

References

Utah Commission on Aging. (2021). Advance care planning.
<https://ucoa.utah.edu/directives/>

Utah Hospital Association. (2019). *Leaving Well Utah*.
<https://leaving-well.org/make-wishes-clear/making-plans>

Yochim, B. P. (2018). Neurocognitive disorders in late life. In B. P. Yochim, & E. L. Woodhead (Eds.), *Psychology of aging: a biopsychosocial perspective* (pp. 201-222). Springer Publishing Company, LLC.