A GUIDE ON

Advanced Care Planning Resources

FOR PEOPLE LIVING WITH DEMENTIA AND THEIR CARE PARTNERS

BOLD PUBLIC HEALTH CENTER OF EXCELLENCE ON DEMENTIA CAREGIVING

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Table of Contents

Overview 3

About advanced care planning 4

About this guide 5

Advanced Care Planning Resources 6

Considerations and Resources to Support Decision-Making Throughout the Dementia Journey 10

Appendix A 13

Appendix B 15

Overview

This resource guide contains a range of tools, materials and information related to advanced care planning, including financial, housing, medical, legal, and palliative/hospice care assistance. It is the result of a comprehensive, environmental scan of available dementia-specific advanced care planning resources.

This guide is intended to be used primarily by **people living with dementia and their care partners**. It should be used as a tool to help navigate and provide recommendations for effective care, services, and considerations at various stages of cognitive impairment and dementia.

How to use the tools and resources included in this guide:

1. After reviewing the below resources, please share what you found helpful with other care partners/caregivers, and the person living with dementia (if applicable).
2. Follow up with the healthcare provider(s), and any legal or financial consultants about chosen care plans.
3. Share the advanced care planning choices with family members and friends who should be aware of these decisions and/or who might help provide care and support to the person living with dementia.

Public health agencies may also use this guide to raise awareness about the importance of advanced care planning, and promote the use of best practices and tools in dementia care planning. They can distribute this guide to local community organizations, healthcare systems and aging services providers, and encourage them to further share it with community members living with dementia and the family caregivers they serve. In addition, public health departments can also make this toolkit available on their website and any online, public databases of ADRD-related resources and materials.

Note: the terms care partner and caregiver are used interchangeably throughout this guide to refer to non-professional caregivers, that is, relatives and friends who provide care and support to a person living with dementia.

About advanced care planning

What is advanced care planning and why is it so important for those living with dementia?

Advanced care planning is the process of learning of and taking action to prepare for future decisions about one's care. This includes informing one's family and healthcare providers about their preferences. An important part in this process is an advance directive, which is a legal document that states one's preferences that will be followed if one is incapacitated or unable to speak for themselves.

Advanced care planning is important because it allows individuals to plan and take control of their care and affairs before they are no longer able to voice their wishes. It is important for people living with dementia to be involved in these decisions while they are able to do so.

Palliative and Hospice Care: What's the difference?

Two important terms related to advance care planning are palliative care and hospice care. They are key components of medical care planning for people with dementia, and it is important to under-stand their definition and note differences.

PALLIATIVE CARE

Palliative care is specialized medical care for people living with a serious illness. Its goal is to improve quality of life for the individual and their family, as well as relief from the symptoms and stress of the illness. A palliative care team can onsist of physicians, nurses, physical therapists, and other specialists to provide optimal support to an individual.

A palliative care plan is based on an individual's specific needs and not on the expected course of the illness. Therefore, palliative care can be provided at any stage of illness and can be paired with other treatments, if desired.

Palliative care is important for those living with dementia because it can provide needed support and relief from early-stage symptoms and continue through end-of-life care.

HOSPICE CARE

Hospice care focuses on providing comfort and sustaining quality of life for individuals who have a serious illness and are approaching the end of life. It is commonly used when attempts to medically treat the disease have been stopped. It is standard for hospice care to start when an individual has a terminal illness and a life expectancy of 6 months or less.

A hospice care team can include nurses, physicians, social workers, spiritual advisors, and other specialists that work together to provide medical, emotional, and spiritual support as needed. They support the individual with the illness, their care partner(s)/caregiver(s), and family members.

It's important for those living with dementia and their family caregivers to talk about hospice care with their care provider and start it early enough so that it can provide months of meaningful care and quality time with loved ones.

About this guide

The section titled *"Advanced Care Planning Resources"* is a comprehensive list of various dementia-specific advanced care planning resources intended to be utilized by people living with dementia, their care partners, and the care team.

The section titled "*Considerations and Resources to Support Decision-Making Throughout the Dementia Journey"* showcases information about the different stages of cognitive impairment and dementia, options for planning ahead and choosing the right level of care, as well as caregiver role and self-care. It also provides context for many of the resources listed in the *"Advanced Care Planning Resources*" section.

To assist navigation and use, resources and materials are organized according to several criteria.

Type of resource

Refers to the format in which the resource is accessible.

Presentation | Website | Document | Video | Podcast

Type of information

For each resource we indicate whether it contains information related to financial, housing, medical, legal, and/or palliative and hospice care planning.

Legal | Healthcare | Financial | Housing | Palliative/ Hospice Care

Intended users

Most of the resources listed here were originally created with the intent to be utilized by either people living with dementia, their caregivers, or both. However, we believe that all resources may be used by the person living with dementia and anyone else on their care team throughout the planning process. To more easily identify the intended users, each resource has been color-coded as follows:

- For both people living with dementia and their care partners/caregivers
- For people living with dementia
- For care partners/caregivers

Geographic relevance

Some of the resources included here are general and can be used anywhere, while others are state-specific. Area Agencies on Aging (AAA) can be found using the Eldercare Locator linked in the state-specific section below, and they can help identify local aging- and dementia-related resources and services. Also included here is a link to advance care directive and living will documents for each state, and two exemplar state-related resources.

Advanced Care Planning Resources

NATIONAL RESOURCES

For people living with dementia and their care partners

RESOURCE & DESCRIPTION	TYPE OF RESOURCE	TYPE OF INFORMATION
National Academy of Elder Law Attorneys This site from the *National Academy of Elder Law Attorneys* provides information and consumer resources about legal planning. It includes a tool that allows individuals to find and contact Elder Law Attorneys within their community.		
Dementia and End of Life Care This video from the *Alzheimer's Society of Manitoba* describes care planning for those with dementia, including discussion of palliative care, decision-making, and healthcare interventions.		
Safety Assessment and Guide and Checklist This toolkit from the *Alzheimer's Association* provides checklists and guides relating to the safety of an individual with dementia. This includes driving, managing medications, and home safety.		
For Caregivers of People with Alzheimer's or Other Forms of Dementia This toolkit from the *Conversation Project* and the *Institute for Healthcare Improvement* provides a guide for care partners to help approach the conversation about care planning with those living with dementia. It includes templates and scales to facilitate conversation.		
Get Palliative Care: Dementia and Palliative Care This website from *Get Palliative Care* provides information about palliative care and dementia, including when one can start palliative care and how it can benefit that individual. In addition, it includes a Palliative Care Provider Directory for people to search for a provider in their area.		
Dementia Conversations: Driving, Doctor Visits, Legal & Financial Planning This video from the *Alzheimer's Association* provides an overview on how to address some of the common issues that are difficult to discuss: going to the doctor for a diagnosis or medical treatment, deciding when to stop driving, and making legal and financial plans for future care.		
How Palliative Care Helps Families with Dementia Focus on Quality of Life This podcast from *Get Palliative Care*, features a story of an individual living with dementia and her family member's experience with their palliative care team.		
In-Home Care This website from the *Alzheimer's Association* provides information about the various types of in-home care options for those who live with dementia. In addition, there are links to finding local care and how to choose a care provider.		

For people living with dementia and their care partners *(continued)*

RESOURCE & DESCRIPTION	TYPE OF RESOURCE	TYPE OF INFORMATION
Planning for the Future After a Dementia Diagnosis This toolkit from *Alzheimers.gov* provides comprehensive information and guidance on housing, healthcare, financial, and legal decisions for those living with dementia. Included are the varying decisions about care and the differences between each one can choose.		

For people living with dementia

RESOURCE & DESCRIPTION	TYPE OF RESOURCE	TYPE OF INFORMATION
Living with Dementia: Planning for Your Health Care This resource from the *National Alzheimer's and Dementia Resource Center and the Administration for Community Living* provides healthcare decision-making resources to plan for future care.		
Dementia Directive This directive from *Dementia Directive* describes the need and importance of documenting one's wishes and provides a directive form for individuals with dementia to complete.		
Living with Dementia: Financial Planning This resource from the *National Alzheimer's and Dementia Resource Center and the Administration for Community Living* provides financial decision-making resourcesto plan for future care.		
Advance Care Planning: Decisions Matter for Memory Loss Patients and Families This presentation from the *Hawai'i Alzheimer's Disease Initiative and the Administration for Community Living* describes the importance of advanced care planning. It also provides guidance on how to start a conversation about end of life care and describes Advance Health Care Directives and Provider Order for Life-Sustaining Treatment (POLST) forms.		
Living with Dementia: Planning for Your Care This resource from the *National Alzheimer's and Dementia Resource Center and the Administration for Community Living* provides information about various types of housing and care options for people with dementia to plan for their future.		
The LEAD Guide: Life-Planning in Early Alzheimer's & Other Dementias This resource from the *University of Utah* and *the Utah Commission on Aging* provides those living with dementia a place to document their end-of-life wishes, values, and preferences concerning healthcare, financial, and housing considerations.		

For care partners

RESOURCE & DESCRIPTION	TYPE OF RESOURCE	TYPE OF INFORMATION
What Does Good Dementia Care Look Like? This podcast from *Get Palliative Care*, features dementia experts and clinical professionals discussing how to provide optimal care for those living with the disease and support their family.		
Care Plans Help Both Older Adults and Caregivers This toolkit from the *Centers for Disease Control* provides information about maintaining a care plan for those with dementia, including complete care plan and daily care plan forms available free for download. It also includes resources on caregiver health.		
Legal and Financial Planning for People with Dementia This toolkit provided by the *National Institute on Aging* includes information on legal, financial, and healthcare planning for those with dementia. Information and details about planning documents is described, as well as additional resources.		
Dementia Care Planning This toolkit from the *Alzheimer's Association* offers resources on cognitive assessment and care planning. It provides information on Current Procedural Terminology (CPT) codes and service elements of CPT code 99483.		
End-of-Life Decisions This toolkit from the *Alzheimer's Association* provides guidance for end-of-life care including treatment options, resolving family conflicts, and related terminology definitions.		
Caregiver Profile Checklist This document from the *Alzheimer's Association* provides multiple resources for caregivers based on common questions asked.		
End of Life Checklist This document from the *Alzheimer's Association* provides multiple resources for end-of-life affairs including, financial, l egal, and healthcare decisions.		
Cognitive Assessment and Care Planning Services This toolkit from the *Alzheimer's Association* provides detailed information on the CPT code 99483, including provider and healthcare procedures. In addition, it includes specific suggested measures to support the care planning process, commonly used ICD-10 codes for dementia, and CPT codes that can be reported with code 99483.		
24/7 Wandering Support for a Safe Return This site from the Alzheimer's Association provides information about a nationwide response service for returning someone living with Alzheimer's Disease to their residence.		

Advanced Care Planning Resources

For care partners *(continued)*

RESOURCE & DESCRIPTION	TYPE OF RESOURCE	TYPE OF INFORMATION
Financial & Legal Planning for Caregivers This website from the *Alzheimer's Association* provides a comprehensive overview of financial and legal topics relating to caring for someone living with dementia such as planning for care costs, paying for care, insurance, Medicare, legal planning, and more.		
Signs Your Parent May Need Assisted Living This website from the Elder Care Alliance provides guidance on what signs to look for in your loved one that may indicate they are ready to move into assisted living or memory care.		
Supporting Someone Living with Dementia in Making Decisions This guide from the *National Alzheimer's and Dementia Resource Center and the Administration for Community Living* provides recommendations for those helping care for a person with dementia including providing support for healthcare, financial, legal, and other types of decision making.		

STATE-SPECIFIC RESOURCES

RESOURCE & DESCRIPTION	TYPE OF RESOURCE	TYPE OF INFORMATION
Area Agencies on Aging This page from *Eldercare Locator* describes the Area Agencies on Aging and provides Searchable Database as a way to find an individual's local chapter. Additionally, it provides information on the Aging Network and Long Term Care Planning.		
Your State's Advance Care Directive and Living Will Information This site from *Compassus* provides every state's living will or advance care directive form. It also provides information for care partners/caregivers about palliative and hospice care.		
DELAWARE **Advance Planning for People with Dementia: Legal Services Voucher Program in Delaware and New Consumer Planning Guides** This video from the *National Alzheimer's and Dementia Resource Center and the Administration for Community Living* includes advanced care planning information and legal services offered in Delaware, including a legal vouchers program, continuing legal education, and guides on financial and healthcare planning.		
WASHINGTON **Advanced Care Planning for Dementia** This video from *PeaceHealth* includes general information on advanced care planning for those with dementia, and discusses advanced directives, the Dementia Road Map, the Living with Dementia Mental Health Advance Directive, and other resources.		

Considerations and Resources to Support Decision-Making Throughout the Dementia Journey

This section expands on the *"Advanced Care Planning Resources"* by providing context for many of the resources presented there. The links embedded throughout this section, along with many others, are also listed in Appendix A.

Dementia affects each person differently and their need for support may fluctuate over time as the disease progresses. Because there is not a single, "linear" experience of dementia, decisions about care and levels of support tend to follow a "windy path". While the considerations for care, planning and support included below are presented chronologically for the different stages of dementia, we should note that a person living with the disease and their care partner(s) may move back and forth between stages and may make decisions at different points in time. Therefore, if you are viewing this resource in a later stage of caregiving or dementia, please be sure to review the information included in the previous stages.

Whatever stage of dementia a person may be in, it's important to remember that **the earlier you start planning, the better, but it is never too late.**

	STAGES OF COGNITIVE IMPAIRMENT AND DEMENTIA			
	Mild Cognitive Impairment	**Early Stage (Mild)**	**Middle Stage (Moderate)**	**Late Stage (Severe)**
Changes you might notice in a person living with MCI or dementia	MCI normally involves problems with memory or mental function that are noticeable to the person affected but are not serious enough to interfere with everyday life. People living with MCI might forget important information that they would have previously recalled easily, have decreased ability to follow the sequence of steps needed to complete a complex task, or might frequently lose the train of thought, among others. *A person living with MCI is still living independently in their home, in the community.*	The person living with mild dementia is largely independent with self-care activities (bathing, dressing and walking). However, they might start to have difficulty with keeping appointments, coming up with the right word, recalling familiar places and people, planning and organizing and might misplace things and lose the ability to retrace steps, among others. Organizational tasks, such as managing a daily schedule or handling the household budget tend to become very challenging. *A person living with mild dementia likely still resides at home/in the community, with or in close proximity to their family and/or care partners, or they might reside in a specialized "memory care" facility. They may still drive, work and /or actively volunteer.*	The person living with moderate dementia is becoming more dependent on others to perform familiar tasks and might need assistance with an increasing number of personal care activities such as eating, dressing and grooming. They might jumble words and lose their ability to express thoughts and follow conversations. They might also become easily angry or frustrated and exhibit challenging behaviors (eg. compulsiveness, repetitive movements, delusions, verbal outbursts, etc.), among others. *A person living with moderate dementia might reside at home with significant assistance from others, an Assisted Living Facility (ALF), or a specialized "memory care" facility.*	The needs of the person living with severe dementia become more deep and complex. They usually have difficulty eating, swallowing and walking, and need around-the-clock assistance with daily personal care. They become more vulnerable to infections. *A person living with severe dementia might live at home with around-the-clock assistance or in a skilled nursing facility (SNF).*

	STAGES OF COGNITIVE IMPAIRMENT AND DEMENTIA			
	Mild Cognitive Impairment	**Early Stage (Mild)**	**Middle Stage (Moderate)**	**Late Stage (Severe)**
Role of the care partner(s)	Help identify strategies to assist with memory, organize tasks, information or materials, and provide cues or reminders when needed. Be on the lookout for continued changes to the cognitive or mental status that might interfere with daily life.	Assist with organizational tasks (eg. budget, scheduling, etc.), provide cues and develop strategies to maximize the person's independence (eg. cues and reminders to assist with memory.)	As the functioning and abilities of the person with dementia become more diminished, care partners/ caregivers tend to take on increasing responsibilities. Your role will focus on **adapting daily routines and providing structure.**	The role of care partners/ caregivers focuses on **preserving quality of life and dignity** for the person with dementia. If the person lives in a long-term care facility, it is important for the care partner/caregivers to stay connected and communicate with the care team to make decisions about care.
Planning ahead	Financial and legal: • Consider consulting with an elder law attorney (find one near you at naela.org) • Prepare your financial advance directive documents (a will, a durable power of attorney for finances and/or living trust) • Assist/supervise with any financial matters Health care: • Establish primary care provider (PCP) to discuss memory loss and get referrals to recommended testing or specialty care • If comfortable, begin discussions about what constitutes quality of life with the PCP, person living with MCI, and the care partner/caregiver. • Prepare healthcare advance directive documents (durable power of attorney for health care), and the type of care they want, including: DNI, DNR, POLST, MOLST, organ and tissue donation, brain donation • Prepare a care plan with the person living with MCI	Financial and legal: • Review, remind, and have conversations with the person living with dementia about financial and legal plans • Work with a social worker to understand care costs and your payment options • If you haven't yet, and while the person with dementia still has legal capacity to make decisions, prepare your financial advance directive documents (a will, a durable power of attorney for finances and/or living trust) Health care: • Establish a PCP, Geriatric Care and any other recommended specialty care (Neurology, Imaging, Psychiatry, etc.) • Understand the type of dementia and what to expect as the disease progresses • If you haven't yet, work with the PCP to prepare healthcare advance directive documents (living will, durable power of attorney for health care, and the type of care they want, including: DNI, DNR, POLST, MOLST, organ and tissue donation, brain donation • Work with a social worker to understand the care available under Medicare and Medicaid services, if eligible.	Health care: • Use specialty care as recommended by PCP (Neurology, Therapy, etc.) • Periodically, review the care plan and type of care the person living with dementia wishes.	Health care: • Actively communicate and engage with the care team to understand the plan of care and any decisions that need to be made.

	STAGES OF COGNITIVE IMPAIRMENT AND DEMENTIA			
	Mild Cognitive Impairment	Early Stage (Mild)	Middle Stage (Moderate)	Late Stage (Severe)
Choosing the right level of care	Some people living with dementia remain at home with help from family and friends, but for some, their needs exceed what their family and friends are able to support. It is important to continuously assess the need to transition to a congregate care setting, by balancing the risks (safety, etc.) and benefits (independence, etc.) of the person living with dementia remaining in their current residence or moving to a different environment. **If remaining at home,** make adaptations that can help compensate for assistance need with ADLs (Activities of Daily Living): • Make adjustments and repairs to the home to create a safe environment • Monitor and supervise potentially dangerous activities such as cooking, using power tools, etc. • Declutter, organize, and label important documents • Be prepared for emergencies (have contact information on hand and somewhere easily visible) • Continue to assess home for safety hazards and identify opportunities for adaptations **Connect with services in the community:** • Transportation • Adult Day Service Centers • Respite Care • Handyman services to make repairs and safety adaptations at home • Home meal and grocery delivery • Sign up for a wandering response service • In-Home Care **If the person living with dementia is currently living independently,** assess their need to move to a higher level of care, such as an assisted living facility **or with a family member. To decide, consider some of the following:** • Weigh the risks (eg. safety) and benefits (eg. quality of life and sense of autonomy) of remaining at home or living inthe community. • Are they neglecting household maintenance? • Are they becoming increasingly isolated, withdrawn and/or depressed? • Do they need assistance with up to 3 ADLs? • Do they become disoriented, get lost easily or wander away? • Do they have a dementia diagnosis or cognitive decline that requires significant supervision? • Is it becoming increasingly difficult for you to support them at home without significantly impacting other important aspects of your life? • Are you experiencing significant stress and need help? **If the person living with dementia is currently living in an assisted living facility, assess their need to move to a higher level of care, such as a skilled nursing home or a memory care unit. To decide, consider some of the following:** • Weigh the risks (eg. safety) and benefits (eg. quality of life and sense of autonomy) of remaining at home or living in the community • Is it recommended by facility staff if they are currently living in assisted living? • Are they exhibiting aggressive or other behaviors that are difficult to manage at home or at the assisted living facility? • Do they need assistance with more than 3 ADLs? • Is their overall health declining? • Are they suffering from loss of balance/coordination, incontinence, stiff muscles, fatigue, etc.? • Are they requiring 24-hour supervision, and are you not able to provide that support while balancing other priorities and work? **Start planning for long-term care needs:** • Get informed about the different long-term care options, including location, availability, eligibility, application process, and options for financing			
Considerations for care partner selfcare	• Professional help/counseling • Connect with others in your support network and your “family of choice” to share insights, get support or make plans to meet the person with dementia in their own environment • Consider enrolling in caregiver training programs to gain skills in managing dementia-related behaviors and symptoms			

Appendix A

NATIONAL RESOURCES

Abbreviated list of dementia-specific advanced care planning resources.

For people living with dementia and their care partners					
National Academy of Elder Law Attorneys	•				
Dementia and End of Life Care		•			•
Safety Assessment and Guide and Checklist		•		•	
For Caregivers of People with Alzheimer's or Other Forms of Dementia		•			
Get Palliative Care: Dementia and Palliative Care					•
Dementia Conversations: Driving, Doctor Visits, Legal & Financial Planning	•	•	•		
How Palliative Care Helps Families with Dementia Focus on Quality of Life					•
In-Home Care		•		•	
Planning for the Future After a Dementia Diagnosis	•	•	•	•	

For people living with dementia					
Living with Dementia: Planning for Your Health Care	•	•			
Dementia Directive		•			•
Living with Dementia: Financial Planning			•		
Advance Care Planning: Decisions Matter for Memory Loss Patients and Families	•	•			
Living with Dementia: Planning for Your Care		•	•	•	•

For care partners					
What Does Good Dementia Care Look Like?		•			•
Care Plans to Help Both Older Adults and Caregivers		•			
Legal and Financial Planning for People with Dementia	•	•	•		
Dementia Care Planning		•			
End-of-Life Decisions	•	•			•
Caregiver Profile Checklist				•	
End of Life Checklist	•	•	•		•
Cognitive Assessment and Care Planning Services		•			•
24/7 Wandering Support for a Safe Return		•			
Financial & Legal Planning for Caregivers	•		•		
Signs Your Parent May Need Assisted Living				•	
Supporting Someone Living with Dementia in Making Decisions	•	•	•	•	

Appendix A *(continued)*

STATE-SPECIFIC RESOURCES

Abbreviated list of dementia-specific advanced care planning resources.

Area Agencies on Aging	•	•		•	
Your State's Advance Care Directive and Living Will Information	•	•			•
DELAWARE Advance Planning for People with Dementia: Legal Services Voucher Program in Delaware and New Consumer Planning Guides	•	•	•		
WASHINGTON Advanced Care Planning for Dementia	•	•	•		•

Appendix B

An inventory of non dementia-specific resources on advanced care planning. Even though these resources aren't tailored specifically for people living with dementia and their caregivers, they may still be applicable and useful to them.

Resource Title	Organization
Family Caregiver Guide	AARP
Advance Care Planning — Conversation Guide	Coalition for Compassionate Care of California
Advance Care Planning — Making your wishes known	NSW Health
Advance Care Planning – Minnesota	Minnesota Department of Health
Advance Care Planning Guide	ACP Decisions
Advance Care Planning Information Booklet	Family Caregiver Alliance
Advance Care Planning: Health Care Directives	National Institute on Aging
Advance Directives	CaringInfo
Advanced Care Directives	Medline Plus
Advanced Care Planning	Coalition for Compassionate Care of California
Care Plans Help Both Older Adults and Caregivers	CDC
CaringInfo	CaringInfo
Cognitive Assessment and Care Planning Services	Alzheimer's Association
Community Resources	Mayo Clinic
Complete Care Plan	CDC
Download and Complete Your State or Territories Advance Care Directive	CaringInfo
EMS and MOLST: 5 Things You Can Do Ahead of an Emergency	Honoring Choices Massachuesetts
End-of-Life Decisions	Alzheimer's Association
Geriatrics Education Series: Advance Care Planning	Project ECHO Nevada
Getting Started Tool Kit	Honoring Choices Massachuesetts
Let's Talk ACP Guide	Goals of Care Coalition of New Jersey

Appendix B *(continued)*

Making Decisions: Advance Care Planning	Veterans Affairs
Minnesota Health Care Directive Planning Toolkit	University of Minnesota
National Agency Location Service	National Association for Home Care and Hospice
Respecting Choices	Respecting Choices
Palliative Care	Honoring Choices Massachuesetts
Palliative Care Resources	Get Palliative Care
Prepare for Your Care	PREPARE for Your Care
Serious Illness-Implementation	U.S. Department of Veterans Affairs
Thinking Ahead	ONE Caregiver Resource Center
Thinking Ahead: My Way, My Choice, My Life and the End	Coalition for Compassionate Care of California
U.S. Advance Care Plan Registry	U.S. Advance Care Plan Registry
Your Conversation Starter Guide	Institute for Healthcare Improvement
Your Guide for Talking with a Health Care Team	Institute for Healthcare Improvement
Your Guide to Choosing a Health Care Proxy	Institute for Healthcare Improvement

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