Dementia Care Planning Toolkit

A Resource for Individuals and Their Care Partners, Families, and Care Providers

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Dementia Care Planning Team of the
Massachusetts Advisory Council on
Alzheimer's Disease and All Other Dementias
February 2025

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Introduction

This toolkit was developed by the Care Planning Team of the Massachusetts Advisory Council on Alzheimer's Disease and All other Dementias (Council) [1]. Its goal is to facilitate the development of person-centered dementia care plans that support living well with dementia. Its target audience is the wide range of individuals involved in effective dementia care planning. These individuals include people living with dementia, dementia care partners [2], families, community-based service providers, and health care providers. It was developed to help readers understand:

- the importance and benefits of person-centered dementia care planning;
- the unique characteristics of dementia that necessitate person-centered care plans; and
- what dementia care planning involves and includes.

In addition to guidance on dementia care planning, this toolkit provides examples of dementia care plans, and a section called "Dementia Care Planning Resources," featuring links to helpful materials and tools, including those developed by the Council's teams.

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[1] See Appendix A for a list of the team's members. View the Council's website here: https://www.mass.gov/massachusetts-advisory-council-on-alzheimers-disease-and-all-other-dementias

[2] "Care partner" and "caregiver" are terms used throughout this document to refer to the primary unpaid person supporting an individual with Alzheimer's disease or any type of dementia.

Person-Centered Dementia Care Planning

Importance of Person-Centered Dementia Care Planning

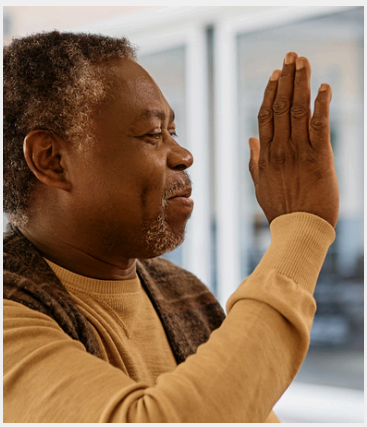
Why develop a person-centered dementia care plan? The simple answer is that care without a person-centered plan is often fragmented and disconnected from the very factors that affect a person's response to dementia, thus impacting their health and wellbeing. Such factors include more than the person's medical conditions. Effective dementia care planning:

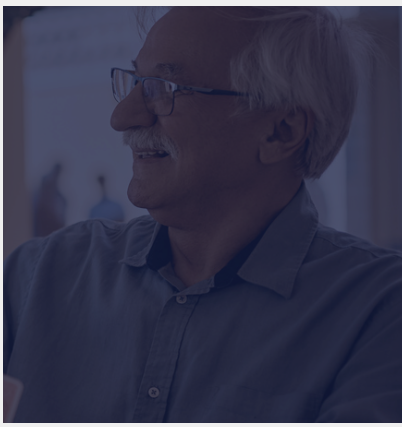
- **Aligns care with individual goals and values:** Person-centered dementia care plans focus on aligning care and support with the goals, values, preferences, and unique personality and life experiences of each individual.
- **Prioritizes what matters most to people living with dementia and their care partners:** These plans empower individuals to navigate the complexities of dementia, reduce uncertainty, minimize crises, and reduce care partner stress.
- **Reflects collaborative care:** Effective dementia care planning requires integrated systems that promote clear communication and collaboration among care recipients, care partners, families, and care providers.
- **Supports responsive care:** Regardless of the stage of dementia, care plans can remain person centered, responsive, and as person directed as possible, offering individuals and their care partners with control over decisions as their needs evolve.

Benefits of a Person-Centered Dementia Care Plan

While there are exceptions, anecdotal evidence suggests that despite their importance, dementia care planning is inconsistent; may omit key elements like patient values and care partner roles; and may fail to adapt to disease progression. Even if treatment is unavailable, ongoing care and support for care recipients and care partners are not only available for Massachusetts residents but essential to living well with dementia [3]. A person-centered care plan:

- **Enhances engagement in and adherence to effective care and support.** When the dementia care recipient and care partner participate in personalized goal-setting designed to meet their specific needs and wishes, it can lead both of them to improved health and wellbeing.
- **Supports personal strengths and builds in supports where there are challenges.** There is much that can be done to support people living with dementia, and a care plan can be a tool to build in those supports in an individualized way.
- **Can be brief, built gradually, and serve as a communication tool throughout care.** Person-centered care plans in any form can help providers, care recipients, and care partners manage care, navigate support through all stages, make adjustments, and minimize crises.



[3] See Community-Based Services and Supports for Massachusetts Residents Living with Dementia and Their Care Partners at https://www.mass.gov/doc/community-based-services-and-supports-for-massachusetts-residents-living-with-dementia-and-their-care-partners-february-2025/download

Unique Aspects of Dementia Care Planning

Person-centered dementia care planning considers the unique challenges and needs of individuals living with dementia, their families, and care partners, reflecting the care recipient's needs beyond their diagnosis or symptoms. Below are some particularly unique aspects of dementia care planning as compared with care planning for people affected by other diseases.

- **Person-centeredness is particularly important given that dementia affects a person's cognition and often their behavior, communication skills, and sense of personhood and self-determination.** Person-centered dementia care plans result in practices that focus on the person, which not only improves health, but promotes overall wellbeing by enabling a sense of identity and agency.
- **Similarly, while care planning for other conditions often focuses primarily on treating the disease, effective dementia care planning prioritizes maintaining quality of life**, which often includes emotional well-being, social engagement, meaningful relationships, spirituality, and maintaining dignity. Given the nature of dementia, care planning and care must remain person-centered and responsive as the condition progresses.

- **Family members and dementia care partners often play a primary role in caregiving, especially in the later stages of the condition.** Furthermore, their insights into the care recipient's experiences and preferences often necessitate their inclusion in the planning process. Care partners often benefit from dementia education and support, which can improve care and enhance communication, thus ensuring care recipients feel understood and respected.
- **With dementia being a progressive condition, needs and preferences will change over time so the care plan must adjust to reflect those changes**. Effective dementia care planning includes discussions that help care partners and families understand the progression of the disease as they work with providers in setting goals. Additionally, recent and upcoming advances in pharmacological and non-pharmacological treatments necessitate updates to dementia care plans as well as advocacy on the part of care partners for ongoing quality of care.
- **People with dementia may sometimes experience agitation, behavioral challenges, or situations that affect their safety**. Effective care plans explore possible causes, address contributing factors, and include supports to reduce these behaviors and address safety risks. For example, dementia care plans should include educational resources for care partners on managing distress and its common triggers. The plans must also address safety concerns, such as wandering, getting lost, or falling. Care planning should include discussions with persons living with dementia and their care partners on options that can reduce risks while supporting quality of life.

Understanding Person-Centered Dementia Care Planning

Person-centered dementia care planning is the process of creating a structured and personalized approach to identify and address the health and social needs of both the person living with dementia and their care partner. It involves assessing unique circumstances and developing a plan that outlines the goals, services, treatment, and support necessary to live well with dementia. Effective dementia care planning:

- **Begins early, preferably upon a dementia diagnosis**. Cyclical in nature, it is repeated as the condition progresses; as things change medically or functionally; as support systems change; and as new issues arise. The care plan should always be based around what matters most to the person living with dementia, and this too will change as the disease progresses.
- **Includes thorough assessments and personalized care planning that put the person living with dementia and their care partner at the center.** High quality dementia care requires understanding, respecting, and addressing individual needs and preferences. It integrates personally meaningful goals with clinical goals; reflects wishes for the future; and helps the care recipients and care partners move forward with confidence.
- **Requires that everyone involved in the person's care develop the plan together.** It includes input from the person living with dementia, their care partner, family members, health care providers, and community-based service providers.

Crafting Dementia Care Plans: Key Elements and Examples

Creating a comprehensive care plan for someone living with dementia involves a wide range of key elements. Those elements are listed in the table on the next page. While it's important to understand them, it's not realistic or necessary to address every single one in one care plan. Instead, care planning is most effective when it focuses on what matters most at a particular time, recognizing that priorities will evolve with each stage of the disease. To help illustrate this, select the link below to view sample care plans for a fictional individual, "Mr. Jones."

Click this button to view Sample Dementia Care Plans, or visit mass.gov/doc/sample-dementia-care-plans-february-2025/download

Key Elements of Person-Centered Dementia Care Planning

DISCUSS AND GATHER INFORMATION

Discuss and gather relevant person-centered information, and agree on a plan of action

- ☑ Convene discussions among all involved including health care providers, community-based providers, the person living with dementia, their care partners, and family members.
- ☑ Gather all relevant information including the person's concerns, values, beliefs, interests, abilities, preferences, and wishes for the future.
- ☑ Identify gaps in care and support.
- ☑ Explore options on how to fill gaps in care and support for the care recipient and care partner.
- ☑ Consider ways to address care partner needs, including options like support groups, respite services, and educational programs.
- ☑ Assess the risks and benefits of each intervention.
- ☑ Agree on approaches that consider potential risks and benefits of care, support, and treatment options.
- ☑ Agree on what care and support will be provided to the care recipient and care partner, and how.
- ☑ Conduct ongoing discussions among all involved while monitoring health, quality of life, and wellbeing to ensure the plan meets changing needs.

Key Elements of Person-Centered Dementia Care Planning

DOCUMENT AND UPDATE INFORMATION

Document and update goals, strategies, and other pertinent information

- ☑ Goals of care with a focus on what matters most to the person.
- ☑ Assessment of cognitive and functional status
- ☑ An action plan to address medical needs, physical safety concerns; and emotional, spiritual, and social needs and preferences.
- ☑ Strategies on how to address or mitigate risks to health, safety, wellbeing, and quality of life.
- ☑ Approach for managing medication.
- ☑ Identification of care partners and the care recipient's circle of support.
- ☑ Care partner needs assessment and strategies for meeting their needs.
- ☑ Referrals to health care specialists and community-based services and supports.
- ☑ A plan for when/if person living with dementia or their care partner becomes ill or hospitalized.
- ☑ A plan for how to address potential health-related changes, crises, and end-of-life care.
- ☑ Sharing of the plan with everyone involved in providing care and support.
- ☑ Updates to the care plan in response to changing needs and preferences.

Dementia Care Planning Resources [4]

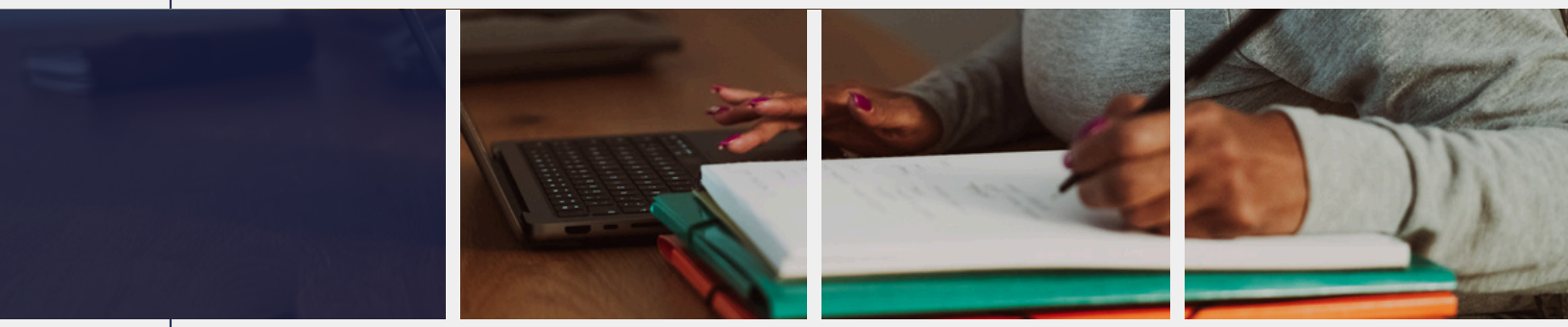
1. Brief Guides Specifically Developed for This Toolkit

Provided below are links to three brief guides designed by teams of the Massachusetts Advisory Council on Alzheimer's Disease and All Other Dementias. They intend to help:

- connect Massachusetts residents to local resources for dementia care and support;
- encourage meaningful dementia care planning discussions; and
- promote equity and inclusion in dementia care planning.

1.1 Community-Based Services and Supports for Massachusetts Residents Living with Dementia and Their Care Partners, Dementia Care Planning Team of the Massachusetts Advisory Council on Alzheimer's Disease and All Other Dementias.
https://bit.ly/CommunityBasedServices

- A one-page description of where to turn to learn about and access the wide range of community-based services available in Massachusetts for people affected by dementia. It is intended for residents living with dementia and their care partners, health care providers, and community service providers.



[4] This list, which appears in no specific order, should not be considered exhaustive.

1.2 Discussing What's Important: A Guide for You and Your Dementia Care Team, Dementia Care Planning Team of the Massachusetts Advisory Council on Alzheimer's Disease and All Other Dementias.
https://bit.ly/DiscussingWhatsImportant

- A worksheet designed to help people living with dementia and their care partners create a list of important topics to discuss with both service providers and health care providers. It is intended for people living with dementia and their care partners, health care providers, and community service providers.

1.3 Equity and Inclusion Considerations for Dementia Care Planning, Equity and Inclusion Team of the Massachusetts Advisory Council on Alzheimer's Disease and All Other Dementias
https://bit.ly/EquityandInclusionConsiderations

- A guide to help people ensure that dementia care planning is equitable and inclusive. It lists considerations intended for health care and community providers as well as people affected by dementia.

2. Living Well with Dementia Toolkit, Ariadne Labs

2.1 Living Well with Dementia Toolkit, Ariadne Labs [5]

www.ariadnelabs.org/dementia-solutions/

The Dementia Care Planning Team of the Massachusetts Advisory Council on Alzheimer's Disease and All Other Dementias advised Ariadne Labs in the development of its Living Well with Dementia Toolkit. It is a resource for person-centered assessment and care planning for people living with dementia and their care partners.

The *Living Well with Dementia Toolkit* can be used by clinicians, community-based service providers, and people living with dementia and their care partners. It is designed to facilitate person-centered conversations that lead to action plans that help support living well with dementia. It includes interactive tools to help people living with dementia and their care partners navigate, plan for, and build person-centered care and support.

[5] Ariadne Labs is a joint center for health systems innovation at Brigham and Women's Hospital and the Harvard T.H. Chan School of Public Health.

3. Care Planning Resources for People Living with Dementia, Care Partners, and Community Service Providers

3.1 ***Pathways to Well-Being with Dementia***, Dementia Action Alliance
https://daanow.org/pathways/mc_cid=6e1e48b3e7&mc_eid=a88de28390

- A comprehensive resource about living with dementia written as a collaborative effort with dementia care professionals and people living with dementia.

3.2 ***Dementia Self-Management Guidebook,*** Dementia Engagement, Education, and Research (DEER) Program, School of Public Health, University of Nevada, Reno.
https://deerprogram.org/dementia-self-management/

- A guidebook developed collaboratively with people living well with dementia. It contains information designed to help individuals develop personalized strategies to live their best lives.

3.3 ***By Us for Us Guides,*** Research Institute for Aging, Canada
https://the-ria.ca/resources/by-us-for-us-guides/

- A series of guides created by people living with dementia and care partners. The guides provide strategies for managing the daily challenges of living with dementia.

3.4 ***Centering Our Values™ Toolkit,*** University of Chicago
https://centeringourvalues.org/

- A hands-on guide to dementia care and decision making.

3.5 ***I Have Alzheimer's***, Alzheimer's Association
https://www.alz.org/help-support/i-have-alz

- Information and online tools to help individuals affected by dementia build confidence to face challenges and have a voice in how to live their best lives.

3.6 ***ALZNavigator™*** Alzheimer's Association
https://www.alz.org/help-support/resources/alznavigator

- An online tool to help people living with dementia find the support they need after answering just a few questions about their situation.

3.7 ***The Dementia Guide: Living Well After Your Diagnosis***, Alzheimer's Society
https://www.alzheimers.org.uk/get-support/publications-factsheets/the-dementia-guide

- A guide with tips and advice to help individuals diagnosed with dementia continue to do the activities they enjoy, live as well as possible, and plan for the future.

3.8 ***Dementia Caregiving Resources***, Alzheimer's Association
https://www.alz.org/help-support/caregiving

- Resources and information about support for dementia caregivers.

3.9 ***10-Step Planning Process,*** The University of California San Francisco Memory and Aging Center
https://memory.ucsf.edu/caregiving-support/planning-care

- A guide on how to plan for dementia care in 10 steps.

3.4 ***If You Have Younger-Onset Alzheimer's Disease,*** Alzheimer's Association
https://www.alz.org/help-support/i-have-alz/younger-onset

- Resources for those under age 65.

4. Dementia Care Planning Resources for Clinicians

4.1 ***Dementia Care Plan and Clinical Tool: Beyond Diagnosis***, Dementia Action Collaborative, Washington State, September 2022.
https://www.dshs.wa.gov/sites/default/files/ALTSA/stakeholders/documents/AD/Dementia%20Care%20Plan%20and%20Clinical%20Tool%20Beyond%20Diagnosis.pdf

- Guidance for clinical care after a dementia diagnosis including topics of interest with links to professional resources and resources to share with people affected by dementia.

4.2 ***Care Planning Visit and Cognitive Assessment and Care Plan Services,*** *Alzheimer's Association*
https://www.alz.org/professionals/health-systems-medical-professionals/management/care-planning

- A review of cognitive assessment and care planning services covered by Medicare.

4.3 ***Information and Support for Professional Dementia Care Providers,*** Alzheimer's Association
https://www.alz.org/professionals

- Recommended best practices and educational opportunities for professional care providers.

4.4 ***Care Ecosystem Protocols: Care Planning,*** University of California, San Francisco
https://ucsf.app.box.com/v/CareProtocols2022/folder/170279084467

- Care planning protocols within the Care Ecosystem model of dementia care.

4.5 ***Dementia: Good Care Planning***, NHS England
https://www.england.nhs.uk/wp-content/uploads/2020/02/FINAL-_Update_Dementia-Good-Care-Planning-.pdf

- A guide designed to help improve care planning in dementia by supporting a standardized approach.

5. Resources for End-of-Life Planning

End-of-Life Planning Resources for People Living with Dementia and Their Care Partners

5.1 ***Your Conversation Starter Guide for Caregivers of People with Alzheimer's or Other Forms of Dementia,*** Institute for health care Improvement, Conversation Project
https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-StarterKit-Alzheimers-English.pdf

- A tool designed to help people living with dementia discuss their wishes for care through the end of life so those wishes can be understood and respected.

5.2 ***Advanced Directive for Dementia***, Dementia-Directive.org
https://dementia-directive.org/

- A form that helps people identify and document their medical care wishes during the mild, moderate and severe stages of dementia.

5.3 ***Advance Planning for People Living with Dementia,*** National Alzheimer's and Dementia Resource Center, Administration for Community Living
https://nadrc.acl.gov/details?search1=137

- Guides that help people affected by dementia know what to plan for and how to get started.

Other End-of-Life Planning Resources

5.4 ***Honoring Choices Massachusetts***
https://www.honoringchoicesmass.com

- Step-by-step guidance on choosing a Health Care Agent, appointing an Agent in a Health Care Proxy; discussing health care wishes; and creating a Personal Directive.

5.5 ***My End-of-Life Decisions: An Advance Planning Guide and Toolkit,*** Compassion & Choices
https://compassionandchoices.org/wp-content/uploads/2018/10/my-end-of-life-decisions-guide-online-interactive-version-final-7-1-20-pdf.pdf

- A guide that helps people prioritize end-of-life care, complete an advance directive, select a representative, and understand medical interventions. It includes planning aids and forms to refine decisions.

5.6 ***Caring Conversations® Materials,*** Center for Practical Bioethics
https://www.practicalbioethics.org/resources/caring-conversations

- Guidance through the advanced care planning process with a highly individualized focus.

5.7 ***Five Wishes®***
https://www.fivewishes.org/for-myself/

- An advance directive document that helps adults consider and document how they want to be cared for at end of life, including medical, personal, emotional, and spiritual needs.

Appendix A

Care Planning Team of the Massachusetts Advisory Council on Alzheimer's Disease and All Other Dementias

Team Co-Leads	
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Former Family Caregiver, Retired Nurse

Appendix B

References

Person-Centered Assessment and Care Planning, The Gerontologist, Volume 58, Issue suppl_1, February 2018, Pages S32–S47, The Gerontologist, Volume 58, Issue suppl_1, Pages S32–S47, February 2018 https://doi.org/10.1093/geront/gnx173

- Guidelines for dementia assessment and care planning derived from a review of research literature and applying to all care settings and stages of dementia.

Personalized Goal Attainment in Dementia Care: Measuring What Persons with Dementia and Their Caregivers Want, Journal of the American Geriatrics Society, October 9, 2018 https://doi.org/10.1111/jgs.15541

- A study that emphasizes the importance of directly involving people with dementia and their caregivers in setting goals that align with their specific needs and priorities.