2nd Edition

Dementia
Self-Management
GUIDEBOOK

Discover Your Journey

This resource is provided by:

DEER
The Dementia Engagement, Education, and Research Program
School of Public Health

The DEER Program builds capacity within individuals, organizations, and communities to support living well with dementia.

To make a **charitable gift** to the DEER Program using the QR code below:

1. Open your phone's camera.
2. Hold your phone so the QR code appears in view.
3. Tap the link to open our giving page.

DEERprogram.org

2nd Edition

Dementia
Self-Management
GUIDEBOOK

Discover Your Journey

DEER
The Dementia Engagement, Education, and Research Program
School of Public Health

The printing and dissemination of this free resource in San Diego County was funded by the County of San Diego Health and Human Services Agency, Aging & Independence Services.

LIVE WELL
SAN DIEGO

CC BY-NC-ND: This license allows reusers to copy and distribute the material in any medium or format in unadapted form only, for noncommercial purposes only, and only so long as attribution is given to the creator.

CC BY-NC-ND includes the following elements:
BY – Credit must be given to the creator
NC – Only noncommercial uses of the work are permitted
ND – No derivatives or adaptations of the work are permitted

Second edition. © 2025, 2023 by Jennifer Carson, Casey Venturini, Amber Walsh, Brennan Pott, Bradlyn Wissert, Marc Lemon, and Jennifer Williams-Woods. *Contact:* deerprogram@unr.edu. This book is an open access publication.

Open Access This book is licensed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International (CC BY-NC-ND 4.0), which permits *Sharing:* Copy and redistribute the material in any medium or format, as long as you give appropriate credit to the original authors and the source, provide a link to the license, and indicate if changes were made. You may do so in any reasonable manner, but not in any way that suggests the licensor endorses you or your use and under the following terms: *Attribution:* You must give appropriate credit, provide a link to the license, and indicate if changes were made. You may do so in any reasonable manner, but not in any way that suggests the licensor endorses you or your use. *Non-Commercial:* You may not use the material for commercial purposes. *No Derivatives:* If you remix, transform, or build upon the material, you may not distribute the modified material. *No additional restrictions:* You may not apply legal terms or technological measures that legally restrict others from doing anything the license permits.

The images or other third-party material in this book are included in the book's Creative Commons license, unless indicated otherwise in a credit line to the material. All photographs in this book are iStock images, unless indicated otherwise in credit line. If material is not included in the book's Creative Commons license and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder.

The use of general descriptive names, registered names, trademarks, service marks, etc. in this publication does not imply, even in the absence of a specific statement, that such names are exempt from the relevant protective laws and regulations and therefore free for general use.

The authors are safe to assume that the advice and information in this book are believed to be true and accurate at the date of publication. The authors do not give a warranty, expressed or implied, with respect to the material contained herein or for any errors or omissions that may have been made.

ACKNOWLEDGMENTS

The *Dementia Self-Management Guidebook* is a publication of the **Dementia Engagement, Education, and Research (DEER) Program** in the School of Public Health at the University of Nevada, Reno (UNR). The DEER Program is the administrative home of **Dementia Friendly Nevada.** The DEER Program would like to acknowledge and thank members of Dementia Friendly Nevada, and especially members of its Dementia Conversations program, for the inspiration and many of the ideas shared within this Guidebook. The DEER Program would also to like acknowledge and thank the **Nevada Division of Public and Behavioral Health's Chronic Disease Prevention and Health Promotion Program** for providing the grant funding to support the development and dissemination of the *Dementia Self-Management Guidebook* (specific funding sources are listed on the last page). Dementia Friendly Nevada is also supported with funding from the Nevada Aging and Disability Services Division.

N DEER
The Dementia Engagement, Education, and Research Program
School of Public Health

Dementia Friendly America™
NEVADA

NEVADA DIVISION of PUBLIC and BEHAVIORAL HEALTH

ADVISORY TEAM

Thank you to the following members of Dementia Friendly Nevada—experts of lived experience—for their individual and collective contributions to this Guidebook.

Jim Loane
Chuck McClatchey
Nancy Nelson
Sam Simon
Barbara Stockton
Yvonne Sweeten

GUIDEBOOK DEVELOPMENT TEAM

Thank you to the following members of the Dementia Engagement, Education, and Research (DEER) Program, based in the School of Public Health at the University of Nevada, Reno (UNR):

Jennifer Carson, PhD; Director, DEER Program; and Clinical Associate Professor, School of Public Health, UNR
Casey Venturini, MA; Assistant Director, DEER Program; and Director, Dementia Friendly Nevada
Amber Walsh, MFA; Designer, DEER Program; and Teaching Associate Professor, Reynolds School of Journalism, UNR
Bradlyn Wissert, MPH; Community Programs and Education Coordinator, DEER Program
Marc Lemon, MPH; Letter of Appointment Faculty, DEER Program

ACKNOWLEDGEMENTS

First edition authors: Jennifer Carson, PhD; Casey Venturini, MA; Amber Walsh, MFA; Brennan Pott; and Jennifer Williams-Woods, MPH

First edition external review provided by: Sara Dombrowski; Hannah Linden, MPH; Peter Reed, PhD; and Bob Felten

PREFACE

Welcome to the *Dementia Self-Management Guidebook*, inspired by members of Dementia Conversations, a program of Dementia Friendly Nevada. Dementia Conversations is a twice-weekly, Zoom-based public discussion forum for people living with dementia and support partners to explore ideas and strategies for living well. Each Dementia Conversation is co-hosted by a person living with dementia and a support partner. Each week, participants share their experiences and insights regarding dozens of topics. Over the years, these exchanges have generated many helpful ideas. The co-hosts and participants wondered what it would be like to capture some of that content on the page, to serve as a resource for people living with dementia. This thinking led to the submission of a successful grant proposal and subsequent formation of a small workgroup of advisors living with dementia who helped develop this Guidebook.

On the following page is a letter from Dementia Conversations participants, welcoming you to the Guidebook and to the supportive community we've created together.

PHOTO *Dementia Friendly Washoe County at "Walk With Me" in June 2019*

Hello Friend,

We are a group of individuals living with dementia who, together with our support partners, choose to live well and find comfort and joy in one another. We would like to share our experiences with you and your family.

We know firsthand that receiving a dementia-related diagnosis is dramatic and difficult. Please give yourself time to process what this means. It is not unusual to feel anger, fear, frustration, shame, denial, or anxiety. But know: **you are not your disease.** You are the same person who walked into your healthcare provider’s office before receiving a diagnosis. There is much to learn and **it is possible to live well with dementia for many years.**

Dementia may progress very slowly. Some of us have been living well with dementia for 5, 6, 7, or more years, and hope for many more to come. We hope to share our insights, experiences, and resources with you and your family. **You are not alone—we are in this together.** We invite you to join us when you are ready.

Please visit our website for more information (see below). As members of Dementia Friendly Nevada, we are here to support anyone affected by dementia, in Nevada or elsewhere.

In unity,
Your Friends from Dementia Conversations
A program of Dementia Friendly Nevada

Dementia Friendly Nevada
DFNV.org

PART ONE
Learning and Planning

PART TWO
Pathways to Living Well

I

Introduction

INTRODUCTION

Introduction to Dementia Self-Management

Maximizing independence and supporting well-being while living with dementia is essential. The goal of this *Dementia Self-Management Guidebook* is to help you develop personalized strategies for living well with dementia and provide you with essential self-management tips to achieve this goal. This Guidebook, developed in partnership with a team of advisors who are living well with dementia, walks you through content aimed at helping you: understand and cope with dementia, plan your lifestyle and medical care, advocate for yourself, explore different pathways to living well, and connect with a variety of helpful resources. Although this is a “self-management” guidebook, we encourage you not to take this journey alone, but to engage family, friends, and a range of healthcare professionals as “support partners,” and to remain active within your community.

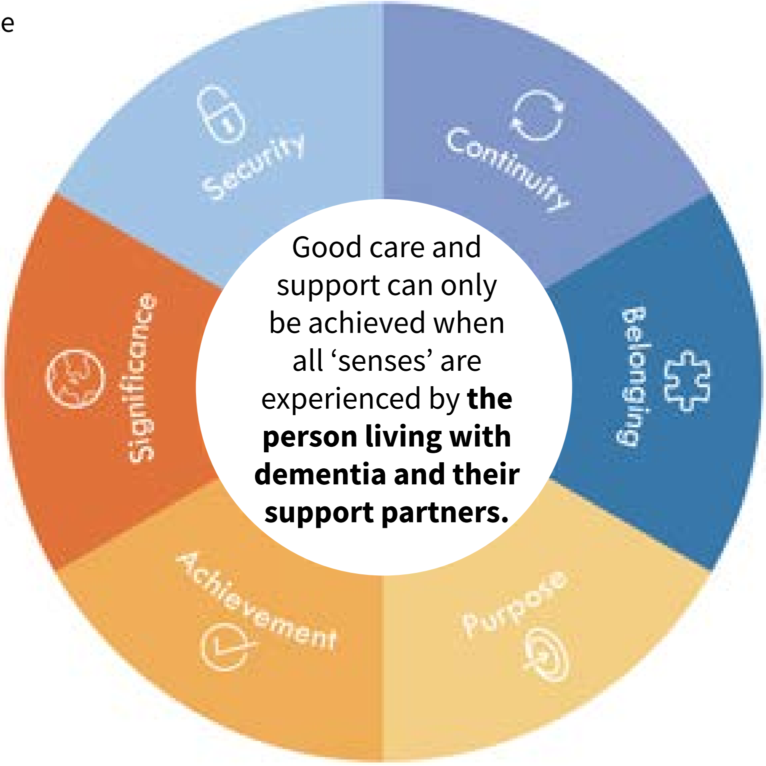
Individuals live with dementia differently, so *personalized* strategies are needed to promote self-management. Dementia self-management differs from other chronic disease self-management programs as dementia can impact cognition and independence, making it more difficult to plan or take action. This Guidebook aims to give you the information, encouragement, and resources to manage your own health and adjust to living with dementia.

Understanding dementia and setting realistic goals with yourself and others can help you live well with dementia. Effective care and support can only be achieved when everyone involved in the context of care experience the following senses:

KEEPING RELATIONSHIPS AT THE CENTER OF DEMENTIA

This includes the following senses:
1. Security
2. Continuity
3. Belonging
4. Purpose
5. Achievement
6. Significance

The Senses Framework[1]



Good care and support can only be achieved when all ‘senses’ are experienced by **the person living with dementia and their support partners.**

The above six senses are prerequisites for good care and support.

Introduction to Brain Health

Our brain affects most aspects of daily life, including learning, memory, communication, emotion and sleep. As we age, our brains change. Every person has different lifestyles and genetics, so no two people's brains are the same. Regardless of these differences, brain health is important for everyone to consider, even after a dementia-related diagnosis.

This Guidebook explores Six Pillars of Brain Health[2] , as outlined by the Cleveland Clinic: get moving, eat smart, control risks, rest well, keep sharp, and stay connected. Focusing on these pillars can reduce the risk and impact of dementia, stroke, and cardiovascular disease, as well as provide many other benefits to your mental and physical health. This Guidebook addresses each of these pillars through actionable goals and tools aimed at helping you live well with dementia.

GET MOVING.

EAT SMART.

CONTROL RISKS.

REST WELL.

KEEP SHARP.

STAY CONNECTED.

*See **"Six Pillars of Brain Health"** in Module Three, Planning Your Lifestyle, on **pages 91–112.***

Here’s a brief overview: When you **get moving** and exercise regularly, your body benefits greatly. Exercise helps more than just your strength and physical health. It can improve your mood, sleep, and memory. **Eating smart** by choosing healthy foods can also help you think and function better. While risk factors vary from person to person, everyone can benefit from a healthy lifestyle that aims to **control risks**, including following medical advice and avoiding unhealthy habits. **Resting well** keeps your brain and body rested, which can help you stay active, reduce stress, avoid or fight illness, and more. Efforts to **keep sharp** by using your brain can help you adapt to changes and build a stronger, more resilient brain. **Staying connected** with family, friends, and your community is a great way to foster purpose, reduce stress, and have fun. Focusing on these Six Pillars of Brain Health can help you live well regardless of your diagnosis.

For more information and to receive your personalized Brain Check-Up Health Report, visit ***wi.healthybrains.org/log-in/***

Six Pillars of Brain Health[3]

GET MOVING.
Get into strength training.
Work on flexibility and balance.

REST WELL.
Get at least six hours of sleep.
Stay positive. Relax.

EAT SMART.
Enjoy a Mediterranean diet.
Cook fresh. Savor the taste.

KEEP SHARP.
Build your brain reserve. Use it or lose it. Play, learn and study.

CONTROL RISKS.
Keep medical conditions in check.
Quit smoking.

STAY CONNECTED.
Treasure your loved ones.
Be social. Have purpose in life.

VISUALIZATION AND GRAPHICS Cleveland Clinic. All rights reserved.

Meet the 2022 Advisory Team

Jim Loane

Recommended resource: Cleveland Clinic Lou Ruvo Center for Brain Health

Jim worked for the banking industry for fifty years. He started working in a local bank as a teller and retired in 2013, having served as a Senior Vice President for two banks. Jim is married to his wonderful wife, Linda, and has four children. He is also "Pop-Pop" to four grandchildren and nine great-grandchildren. Jim was diagnosed in 2010 with mild cognitive impairment. In 2014, he was re-diagnosed with Lewy body dementia with parkinsonism. In 2015, dissatisfied with previous healthcare experiences, Jim and Linda were introduced to the Cleveland Clinic Lou Ruvo Center for Brain Health in Las Vegas and their lives changed. Jim found a physician he felt connected with and started attending several programs offered by the Cleveland Clinic. Linda is also active with programs provided by the Cleveland Clinic as a care partner.

Jim is grateful to his wife for being a selfless care partner to him, and he wrote a song about his wife's dedication to show his gratitude. Jim and Linda have provided several interviews in the Las Vegas area to share their story of living with Lewy body dementia. Jim stays active by participating in programs at the Cleveland Clinic and volunteering at a local adult day center. He loves his volunteer work, which he does four days a week.

Chuck McClatchey

Recommended resource: Dementia Mentors, dementiamentors.org

Chuck spent 21 years in the US Air Force as a C-141 Flight Engineer. He flew in support of Vietnam, the invasion of Panama, Desert Shield, and Desert Storm. After Chuck's military service, he spent 22 years with the Arizona Department of Transportation. In 2013, Chuck began experiencing issues with his memory. Six months later he was diagnosed with younger-onset Alzheimer's disease.

Chuck worked with a therapist and discovered he could talk about his diagnosis to help others and himself. He is now a member of the Dementia Action Alliance (DAA) and hosts two podcasts for DAA, “Professional Insights” and “This Dementia Life.” Chuck also partners with Dementia Friendly Nevada to co-host a weekly, Zoom-based, supportive education group, “Dementia Conversations with Chuck and Jennifer.” Chuck lives in Las Vegas, Nevada with his life partner, Bobbie.

Nancy Nelson

Recommended resource: dangle & dot, dangledot.com

Nancy enjoyed a myriad of occupations throughout her career, and she believes they prepared her well for the journey of living with dementia. She worked in a mortuary, for AFLAC insurance, and finally in the airline industry for many years, even serving as a flight attendant on a plane on September 11, 2001. Nancy was diagnosed with younger-onset

Alzheimer's in 2013, and in 2017 her diagnosis was changed to mild cognitive impairment. The initial diagnosis catapulted her to express herself creatively, writing three poetry books that present her feelings about dementia and what it means to her. As a member of Dementia Action Alliance (DAA) and Dementia Friendly Nevada (through which she co-hosts a weekly Zoom-based discussion group, "Dementia Conversations with dangle & dot"), she has been powerfully vocal in speaking about her diagnosis and how she is living well with dementia. Recently, Nancy co-created *dangle & dot* along with Kat Hartley to open a place to inspire care partners and people living with dementia to live their best lives in a new way.

> "I will live with this diagnosis—
> a long, healthy life."
>
> — **NANCY NELSON**

Sam Simon
Recommended resource: Alzheimers.gov

Sam was diagnosed in 2018 with mild cognitive impairment and in 2021 diagnosed with early-stage Alzheimer's disease. Sam felt a sense of relief with the diagnosis, as it helped make sense of the changes in his cognition. He was encouraged by his theatrical colleagues to take his journey to the page and to the stage, and has written and now performs a one-man play, Dementia Man, An Existential Journey which is now touring throughout the US. It's Sam's goal to demonstrate that it is possible, even with a neurocognitive disabilitym like Alzheimer's, to live a meaningful and fully engaged life. He is using his theatre work to advocate for greater accommodations for people with neurocognitive disabilities. He imagines every store to have "Dementia Desks" and "Cognitive Navigators". Sam cautions folks to seek out trusted sources for information, and helps promote government resources from State and Federal agencies. Sam and his wife live in Mclean, Virgina. They have two children and four grandchildren. You can see information about the play and trusted resources at www.dementiaman.com.

Barbara Stockton

Recommended resource: Healing Dementia
by Kyrie S. Carpenter

Barbara taught developmental education at a college in Michigan for eighteen years, supporting the success of students. In the early 2000's, she completed her Doctor of Education (EdD) degree in Developmental Education. Barbara was diagnosed in 2017 with Alzheimer's disease, although she recalls experiencing forgetfulness which impacted her life starting in 2010. The diagnosis came as a shock because of the manner in which she received the news—abruptly and lacking compassion—and the fact that no one in her family had formerly been diagnosed with dementia.

Following her diagnosis, Barbara has participated in several clinical studies with the hope of finding a cure. Reno, Nevada is now home for Barbara, after she retired and relocated to live closer to her son, daughter, and grandchildren. She stays involved by volunteering at the Pioneer Center for Performing Arts and keeps her mind active by playing puzzle and word games. Barbara also participates in the Dance With Me program—a partnership between the Ballroom of Reno and Dementia Friendly Washoe County—and does Tai Chi, yoga, and weight lifting to stay physically fit.

Yvonne Sweeten

Recommended resource: Huntington's Disease Society of America, hdsa.org

Yvonne was a dedicated first-grade teacher for many years and is a member of Alpha Delta Kappa, a teacher sorority. Several members of Yvonne's family have had Huntington's disease and she was aware from an early age that she was at risk of developing it, too.

In 2016, the diagnosis finally came. Yvonne is now an active volunteer with the Huntington's disease (HD) Coalition of Patient Engagement (COPE), and in her work with HD COPE, she shares her perspective on living with Huntington's disease with pharmaceutical companies to increase awareness. As a result, Yvonne won the Huntington Disease Society of America Person of the Year award in 2021 in recognition of her advocacy for people living with Huntington's disease and the boundless inspiration she offers. Yvonne lives in Las Vegas, Nevada and enjoys being active in her community, traveling, hiking, and engaging in water sports with her husband, Jeff.

A very special ***thank you*** to all of our wonderful advisors and experts of lived experience. You made this book possible!

module title

module
shape

new section begins/ends
within the module ■

How to Use this Guidebook

Each module is organized by shape and color. For example, Module Three can be identified with the following:

★ **PLANNING YOUR LIFESTYLE**

star

yellow

Additionally, each section within the module begins or ends with that module’s shape.

The title of the module is in the upper left-hand corner. The section title within the module is in the upper right-hand corner.

There is a cover page for each of the six modules and for the Introduction and Connections sections. Every cover page matches the color scheme of its module.

space for
personalization
and note-taking

module color →

section title ↑

module shape ↑

Wide side margins provide space on each page to take notes about what you are learning, which helps you to personalize and apply key takeaways. →

To further enrich your experience with this Guidebook, at the end of each module, you will discover three Key Messages accompanied by three corresponding activities (“Key Message Activities”) designed to deepen your understanding and personalize your application of the content.

These Key Message Activities encompass a variety of engaging exercises such as fill-in-the-blanks, reflective discussion questions/journaling prompts, opportunities to brainstorm, and more.

Key Message

↑

space for
personalization
and note-taking

Their purpose is to facilitate the integration and application of new knowledge, bolstering your confidence in handling various situations related to dementia. By actively participating in the Guidebook's content through these Key Message Activities, you can develop personalized strategies to live your best life.

Applying what you learn and sharing it with others are important steps toward making your dementia self-management journey a success.

■

REFERENCES: INTRODUCTION

The Senses Framework, *page 4*

1. From the article “Using the Senses Framework to achieve relationship-centred dementia care services” by Ryan, Nolan, Reid, and Enderby

Healthy Brains, *page 5*

2. “How healthy is your brain?” on the *Cleveland Clinic* website: healthybrains.org

Six Pillars of Brain Health, *page 7*

3. “Six Pillars of Brain Health” on the *Cleveland Clinic* Healthy Brains website: healthybrains.org/pillars/

Additional Reflections and Notes

PART ONE

Learning and Planning

1

MODULE ONE

An Overview of Dementia

MODULE ONE

An Overview of Dementia

Welcome to your first step on the journey of dementia self-management. Yes, you have dementia, but dementia doesn't define who you are. Though this is a journey that you will be on for the rest of your life, it doesn't have to be one of only sadness and loss. A dementia-related diagnosis can be confusing and misunderstood. This Guidebook aims to help you live your best life with your diagnosis. At no point will your dementia take away

your personhood. This point bears repeating. **You are not your disease!** You are you, and now you happen to be living with dementia. The good news is that this Guidebook serves as a continued resource as you come to understand what living with dementia means for you. It is here to help you achieve a future in which you are truly living well with dementia. Today, millions of Americans live with dementia—as they live with other chronic conditions—for many years. There are many ways you can live well with dementia, and though there are countless answers to the question of how to live well, there are approaches that can help set you up for success. Use these pages to help you continue to live a life filled with meaning, purpose, and growth. Never forget that you are more than just your dementia. **You are you, and you always will be.**

> You are you, and
> you always will be.

What is Dementia?

Unfortunately, just because you've been diagnosed with dementia, it doesn't necessarily mean a medical professional has taken the time to talk with you in detail. Furthermore, our society is not well educated about brain health and dementia, so there's a good chance you have some questions about your diagnosis. You may have heard this; you may have heard that. We're going to try to put it all together for you.

Dementia is not a specific disease; it's an umbrella term that describes a set of symptoms brought about through a wide range of diseases. In this sense, dementia can more accurately be called a syndrome. You can think of dementia like a headache. There are plenty of reasons somebody might have a headache. They may be tired, stressed, or dehydrated. They may have a sinus infection. Maybe they hit their head. Dementia—like a headache—can be caused by a variety of different things.

Alzheimer's disease is the most common cause of the set of symptoms we call dementia, and represents about 60–80% of dementia cases, but there are many other causes. These include vascular dementia, Lewy body dementia, frontotemporal dementia, and many more. Currently there are over 100 different identified forms of dementia, with new ones being discovered each year. More often, experts are saying that the most common type of dementia is mixed dementia, meaning someone is living with more than one cause of dementia. It's not just brain diseases that can cause dementia, either; brain injury can play a role too. Traumatic brain injury in early life significantly increases one's risk of developing dementia as they age.

Each form of dementia is different and comes with its own unique characteristics.[1] Additionally, while there are some common experiences, the signs and symptoms of dementia may be different for each person.

However, some aspects of dementia occur most commonly. Those include memory loss that disrupts daily life, misplacing things and losing the ability to retrace steps to find them, challenges in planning or solving problems, and experiencing more changes in judgment, mood, and personality. Things such as confusion with time or place and trouble understanding visual information also occur.

▲

> "Life calls the tune; we dance."
>
> — **JOHN GALSWORTHY**

Types of Dementia

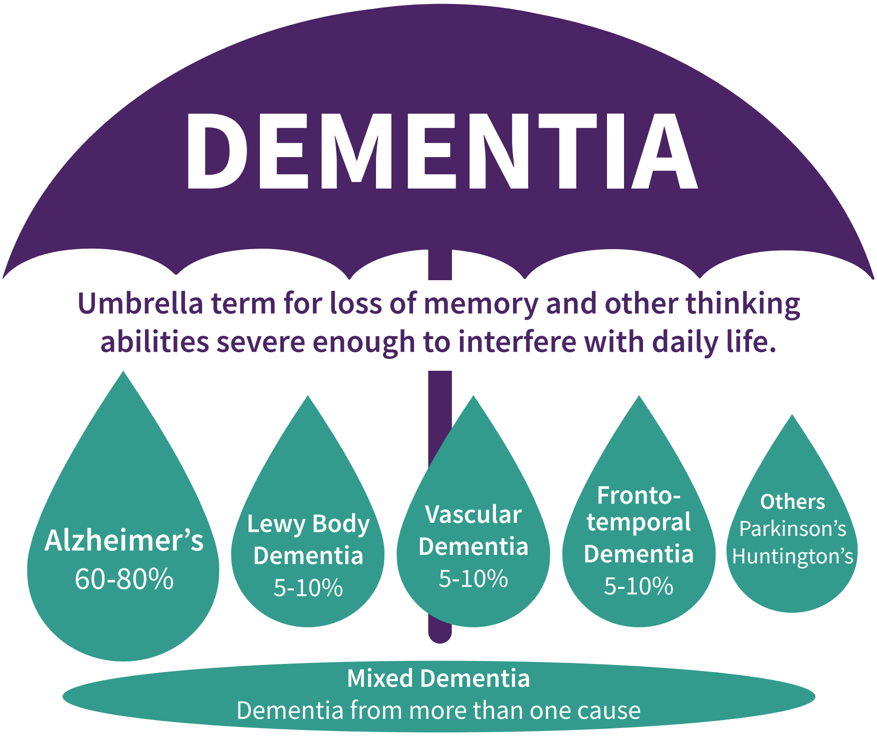
Here's a brief overview of a few different types of dementia:

- **Alzheimer's disease:**[2,3] With Alzheimer's disease, two different proteins cause plaques and tangles in the brain, both inside of brain cells and also in the space between those cells. These protein accumulations disrupt the neurons of the brain and cause them to die over time. Because of the way Alzheimer's disease affects the brain, information that normally should be stored as memory doesn't get stored. People living with Alzheimer's disease typically experience memory symptoms before changes in other thinking skills. Those challenges with memory impact more recently learned information rather than memories made long ago.

- **Vascular dementia:**[4, 5] This occurs when there is damage to the blood vessels that supply oxygen to the brain, whether it's one large blood vessel that is blocked (such as in the case of a stroke) or the accumulation of smaller damages over a longer period of time that produces a slow and steady loss of brain efficiency.

- **Lewy body dementia:**[6, 7] Like Alzheimer's disease, Lewy body dementia involves the accumulation of proteins in the brain, and also results in the loss of brain cells over time.

Different Types of Dementia



VISUALIZATION GRAPHIC alz.org/alzheimers-dementia/what-is-dementia

However, people living with Lewy body dementia experience certain symptoms that people living with Alzheimer's disease don't, such as cognitive fluctuations, visual and auditory hallucinations, dramatic and often rapid changes in attention and mood, and difficulty with coordinated movement resembling the symptoms of Parkinson's disease.

- **Frontotemporal dementia:**[8,9] Frontotemporal dementia is named for the regions of the brain affected, predominantly the frontal and temporal lobes. Changes in personality and difficulty processing language are typically the first symptoms to appear with frontotemporal dementia. This is the primary difference between frontotemporal dementia and other dementias.

- **Huntington's disease:**[10] Caused by a single defective gene, this rare condition produces symptoms that impact movement and thinking.

It is highly inheritable and does not have any known environmental causes. Symptoms usually start to show earlier than most other dementias, between the ages of 30 and 50.

Mild cognitive impairment[11, 12] is the term used to describe the state of cognitive changes that takes place between the expected shifts in thinking due to normal aging and the more significant cognitive changes associated with dementia. It is common that someone's diagnosis may be changed from mild cognitive impairment to dementia—and potentially back again—depending on the severity of symptoms.

Dementia is not considered a part of normal aging, but that doesn't mean it is an uncommon experience. Currently, one in nine people over the age of 65, and one in three over the age of 85, are estimated to be living with dementia. Dementia is even more common among populations of color, particularly Black, Latine, and Indigenous communities. According to the Alzheimer's Association's 2025 *Facts and Figures*,[13] there are currently over 7 million people in the United States living with dementia. That number is expected to increase by about 40% in the next 10 years, and approximately double by 2050. Much of this is driven by the fact that our population is rapidly aging, with more elders than ever before.

Someone's risk of developing dementia is affected by a wide array of factors. Age is the most significant risk factor for developing dementia—meaning that as people get older, they are more likely to develop dementia—but dementia is not just for "old people." Younger-onset dementia can affect people in their 40s and 50s. Even young adults sometimes develop dementia as the result of brain injury. Other contributors to dementia risk include lifestyle factors such as diet, exercise, sleep, and social engagement.

Eating healthy, being active, and staying intellectually and socially stimulated can all help reduce someone's risk of developing dementia in addition to helping people live well after a dementia-related diagnosis. We will explore these strategies in more detail later in this Guidebook. Environmental factors such as air quality can also play a role. For each individual, genetics will also come into play; each person's risk of developing dementia will be a complex interplay

between lifestyle, environmental, and genetic risk factors. Although it is more likely for someone to develop dementia if they have a history of dementia in their family, it isn't guaranteed. Similarly, a lack of family history doesn't mean a total lack of risk. Someone could be genetically at risk for dementia and not take any measures to reduce risk, but still never develop dementia. Alternatively, someone with no genetic risk who lives a radically healthy lifestyle might still develop dementia. **This is why we can only talk about reducing risk for dementia, not preventing it.** Still, by living as healthy and actively as possible, we can do a lot to reduce the risk of developing dementia.

▲

Dementia Misconceptions

Because of the stigma that surrounds dementia, people generally don't talk about the subject as much as they should. Therefore, there are a great many dementia **misconceptions**.

Here are a few misconceptions that Dementia Friendly Nevada members living with dementia highlighted as important to dispel:

- ***Misconception:* People living with dementia die soon after diagnosis.**
This is absolutely not the case. Increasingly, people are living with dementia as a chronic disease. People often live for 10, 15, even 20 or more years after their diagnosis. They can live well during that time.

- ***Misconception:* People living with dementia can't and don't communicate.**
Dementia may impact which forms of communication are most effective, but that doesn't mean that people living with dementia stop communicating or stop understanding. Though verbal communication may become difficult for people living with dementia—especially as dementia progresses—a large portion of what we communicate to each other as human beings is contained within

our body language and tone of voice, not within the vocabulary we use. This means communication is always on the table, even if it requires some creative approaches.

- ***Misconception:* People living with dementia can't and don't learn.**
The ability to learn new information and skills may also be impacted by dementia, but it doesn't prevent someone from continuing to learn. Different learning styles and methods may be needed, and adaptation is vital to staying independent and engaged.

- ***Misconception:* People living with dementia need to live in long-term residential care.**
Though an assisted living community, memory care community, or nursing home may be the right choice for some people living with dementia, not everyone living with dementia needs to live in long-term residential care. It is possible to live in a private home with proper supports in place.

In fact, the majority of people living with dementia live in their own home. The right living situation will differ for each person living with dementia, so conversations with support partners are important in figuring out just what the right situation is.

- ***Misconception:* People living with dementia can't make their own decisions.**

Everyone has a right to their own self-determination. This is no different for people living with dementia. People living with dementia can and do make decisions with forethought and purpose. Those decisions should be honored by support partners, ensuring the perspective of the person living with dementia is heard and prioritized within a strong partnership.

- ***Misconception:* Dementia can be treated through "magic pills" and "quick fixes."**

Though there is a great deal of work being done, there are no pharmaceutical options that prevent or cure dementia. For some dementias, prescription drugs may reduce symptoms or remove protein plaques from the brain, but there are no "fixes" to dementia. This is why learning to live well with dementia is important, and with the right support from family, friends, and community members, it is possible.

- ***Misconception:* Care and support partners deserve pity.**

Being a support partner for someone living with dementia isn't always easy.

That doesn't mean support partners resent the important role they play or should be pitied by friends and family members. It is an honor to provide support to a loved one, and the relationships people living with dementia and support partners develop over time can be extremely rewarding. In a true care partnership, the support partner grows alongside the person living with dementia. There is a giving and receiving of love and support in both directions.

- ***Misconception:* Dementia can be controlled through drugs and restraints.**
Too often, physical restraints and antipsychotic medications are used to control and sedate people living with dementia when they act or speak in ways that others do not understand. These measures do not address the underlying needs that a person living with dementia might be expressing in their words or actions. If behavior is viewed as communication and we get curious about those unmet needs,

then the root cause of distress can be addressed rather than reacting to a surface-level symptom. When the need is met, typically the troubling words or actions stop on their own.

▲

Diagnosing Dementia

Whether you have already received a dementia-related diagnosis or are considering getting checked out by a doctor or other healthcare provider, there are some important things you should know about the process of diagnosing dementia.

If your primary healthcare provider diagnoses you with Alzheimer's disease or another form of dementia based solely on a cognitive screen, it's best to follow up with a ***neurologist, neuropsychologist, or geriatrician.***

First, even though many people have been diagnosed with dementia by a primary care provider, most primary care providers cannot give a formal dementia-related diagnosis. Only providers with the proper training—typically specialists or those with advanced qualifications—should perform this function. Generally, primary care providers can implement what is known as a "cognitive screen," which helps you and your provider know whether a follow-up with a specialist is needed. To repeat: if your primary care provider diagnoses you with Alzheimer's disease or another form of dementia based solely on a cognitive screen, then we recommend getting a second opinion from a neurologist, neuropsychologist, geriatrician, or another qualified professional who can administer a comprehensive cognitive assessment, which often includes:

- Medical history and medication review
- Cognitive and functional assessment

- Depression screening
- Physical and neurological exam
- Brain imaging
- Cerebrospinal fluid analysis and blood tests

This thorough assessment is used to formally confirm or rule out a dementia-related diagnosis and, if applicable, identify the specific type of dementia. Meeting with a qualified provider is important, because this more detailed assessment might show that your symptoms are being caused by something that is treatable, like depression or prescription drug interactions.

Getting diagnosed early is one of the best steps you can take to support your well-being as a person living with dementia. It is undoubtedly a scary thing to confront the changes you may be experiencing, but having knowledge of your medical situation can help you and your support partners have the important conversations that will help you live well as your dementia progresses.

Early diagnosis can help you be proactive in generating solutions and plans ahead of time, rather than being reactive. That extra time can mean a more considered approach that truly honors your goals and wishes.

The next module of this Guidebook is devoted to helping you work with your healthcare providers to set your personal goals, make decisions collaboratively, keep up with the plan you develop, and communicate effectively along the way.

▲

SUMMARY: MODULE ONE

Throughout Module One, you've learned a bit about dementia and, most importantly, that you are not your disease! Dementia is a syndrome characterized by memory loss affecting your daily life, changes in planning and problem solving, difficulty in judgment, as well as mood and personality changes. Each form of dementia is different: Alzheimer's disease, vascular dementia, Lewy body dementia, frontotemporal dementia, Huntington's disease, and others. Although dementia isn't a part of normal aging, it is more common with increasing age. There are many stigmas associated with dementia, but it's vital to understand that people living with dementia can live well, communicate, learn, and make their own decisions. To get a diagnosis, it is important to have an assessment by a neurologist, neuropsychologist, or geriatrician.

Notes

Key Message #1: You are not your disease!

"I Am" Poem: Fill in the blanks to complete the following sentences by writing the appropriate word or phrase.

I am ________________________________
(your name)

I am ________________________________
(a food, game, or place you loved in childhood)

I am ________________________________
(something you are proud of)

I am ________________________________
(a place that is special to you)

I am ________________________________
(your name)

I am ________________________________
(a feeling you have now)

Key Message #2: There are many misconceptions about dementia.

Discussion/Journal: What are misconceptions about dementia that you'd like to dispel? What would you want others to understand instead?

Misconception	**Reality**
Example: People living with dementia shouldn't drive.	*Example:* People living with dementia should have their driving abilities assessed periodically.

Key Message #3: Getting diagnosed early is one of the best steps you can take to support your well-being as a person living with dementia.

Discussion/Journal: What was your diagnosis experience like? If you have not received a dementia-related diagnosis, what is the first step you can take toward receiving a comprehensive cognitive assessment from a qualified provider?

Additional Reflections and Notes

REFERENCES: MODULE ONE

Each form of dementia is different and comes with its own unique characteristics, *page 29*

1. “Understanding Different Types of Dementia” on *NIH: National Institute on Aging* website: nia.nih.gov

Alzheimer’s disease, *page 30*

2. “What Is Alzheimer’s Disease?” on *Alzheimers.gov* website: alzheimers.gov
3. “What is Alzheimer’s Disease?” on *Alzheimer’s Association* website: alz.org

Vascular dementia, *page 31*

4. “What Is Vascular Dementia?” on *Alzheimers.gov* website: alzheimers.gov
5. “Vascular Dementia” on *Alzheimer’s Association* website: alz.org

Lewy body dementia, *page 31*

6. “What Is Lewy Body Dementia?” on *Alzheimers.gov* website: alzheimers.gov
7. “Dementia with Lewy Bodies” on *Alzheimer’s Association* website: alz.org

Frontotemporal dementia, *page 33*

8. “What Is Frontotemporal Dementia?” on *Alzheimers.gov* website: alzheimers.gov
9. “Frontotemporal Dementia” on *Alzheimer’s Association* website: alz.org

Huntington’s disease, *page 33*

10. “Overview of Huntington’s Disease” on *Huntington’s Disease Society of America* website: hdsa.org

Mild cognitive impairment, *page 34*

11. "What Is Mild Cognitive Impairment?" on *Alzheimers.gov* website: alzheimers.gov
12. "Mild Cognitive Impairment (MCI)" on *Alzheimer's Association* website: alz.org

2025 Facts and Figures, *page 35*

13. Special Report, 2025 Alzheimer's Disease Facts and Figures online PDF on *Alzheimer's Association* website: alz.org

Additional Reflections and Notes

2

MODULE TWO

Planning Your Healthcare

MODULE TWO

Planning Your Healthcare

Upon receiving a dementia-related diagnosis, you might feel as though there are a lot of important decisions to make, and you would be absolutely right. The good news is that focusing on just a few decisions at the beginning of this healthcare experience can set the stage for a much easier journey later on. If you find the right medical providers and establish an effective method of communication with them, they can become incredible partners in your efforts to live as well as you possibly can. This module focuses specifically on making those important decisions so that your healthcare providers can work *for* you and can help you achieve *your* healthcare goals. Be aware that your goals and expectations may change as you continue your dementia journey.

Examining Your Goals

As you begin to think about your healthcare post-diagnosis, you

should always remember there are many ways to go about your care. What might work best *for you* may not be as useful for somebody else. **Each person's experience living with dementia is different, and each person's healthcare goals are unique.** Spending time reflecting on your healthcare goals—especially through conversations with your support partners—is essential before you and your providers work out a care plan.

These important conversations can ensure that your care plan will move you further toward your specific goals rather than in a different direction. For example, one person's goal may be to continue living in their own home for as long as possible, while another person's goal may be to identify some assisted living options. Somebody else's goal may be to avoid taking prescription medication for their dementia, while someone else may look for opportunities to engage in clinical trials for new medications. Still another goal could be to pursue the least financially burdensome care plan. Ask yourself: What are *my* healthcare goals?

In answering that question, it may help to expand on the term "healthcare," as it is a very broad term that means different things to different people. Many people benefit from varying levels of care to support their health and well-being across the life course. Some of these options are better suited for people with more functional challenges due to advanced dementia, but they are still important to learn about. Care options for people living with mild to moderate dementia include peer support groups, transportation help, meal delivery programs, and companion services, to name a few.

◆

> "A goal properly set is halfway reached."
>
> — **ZIG ZIGLAR**

Choosing Healthcare Providers

Once you have had the opportunity to outline your goals, the next step is to construct a team of healthcare providers who can help you achieve those goals in the best way possible. It is important to think of constructing a *team* of providers because there are many different types of providers who will offer different services for you as you move through your life with dementia.

Here is a list of key providers to consider adding to your team:

- **Primary Care Provider:** This will most likely be your go-to provider for most of your healthcare needs. Though primary care providers are not dementia specialists (nor are they meant to be), it is still possible to find a provider who is knowledgeable about dementia and—most importantly—who believes that there are opportunities for growth and well-being after diagnosis. This provider might be a physician, but could also be a nurse practitioner (NP) or a physician's assistant (PA).

- **Neurologist or Neuropsychologist:** As providers who specialize in diseases of the nervous system, a neurologist or neuropsychologist will likely be the best person to work with for all matters specifically related to your dementia. Find a specialist who will support you in living well as your dementia progresses.

- **Geriatrician:** A geriatrician specializes in the care of older adults and has a deep knowledge of dementia and how it relates to other health conditions. A geriatrician can help you set comprehensive care goals to help support you in staying healthy as you age.

- **Social Worker:** A social worker can help you navigate the services from all your providers, along with programs and resources available through community organizations in your area.

- **Mental Health Practitioner:** Living with dementia, like all complex human experiences, has its ups and downs. A good mental health professional—whether a psychologist, psychiatrist, licensed clinical social worker, or mental health nurse practitioner—can help you weather the downs and make the most of the ups.

- **Physical/Occupational Therapist:** Dementia often results in difficulties with physical movement and activities of daily living. Physical and occupational therapists can assist you in keeping as much control over your body's movements and everyday activities as possible.

- **Audiologist/Speech Therapist:** Some forms of dementia involve aphasia, or problems processing and/or using verbal language. Audiologists can step in to help maintain effective auditory processing, while speech therapists focus on supporting you in continuing to communicate verbally and nonverbally.

- **Opthamologist/Optometrist:** Vision changes happen for everyone as we get older, so finding a good ophthalmologist and/or optometrist can help to ensure that you see well for as long as possible.

- **Dietitian:** As we will explore in the next Module of this Guidebook, diet plays an immense role in your overall well-being, including the management of your dementia. Partnering with a dietitian can give you access to the most up-to-date expertise about how to support your health through the food you eat.

- **Dentist:** In the complexity of living with dementia, it can be difficult to make time for the little things, like going to the dentist. Yet dental visits are important, as maintaining good oral hygiene and ensuring healthy teeth and gums feeds into an overall healthiness that will support you in living well.

When finding providers to join your team, you might want to think of the process like a job interview; not for you, but for the providers! After all, they are (or should be) working for you. If you find that you—for any reason—aren't meshing well with a particular provider, it is absolutely okay to find someone to replace them. Living with dementia involves quite a bit of communication with your healthcare team, so it is important that you feel completely comfortable interacting with your providers and feel confident in the quality of their work.

Choosing Healthcare Providers

- ☐ Primary Care Provider
- ☐ Neurologist or Neuropsychologist
- ☐ Geriatrician
- ☐ Social Worker
- ☐ Mental Health Practitioner
- ☐ Physical/Occupational Therapist
- ☐ Audiologist/Speech Therapist
- ☐ Ophthalmologist/Optometrist
- ☐ Dietitian
- ☐ Dentist

◆

Common Care Options

There are a variety of care and support options available, ranging from community-based supports and services to residential long-term care. Here are some common options for people living with dementia to consider as their needs progress, depending on the nature and impact of one’s cognitive changes.

- **Adult Day Programs:** Usually located within senior centers or community not-for-profit organizations, these programs provide an opportunity for elders and people living with dementia to engage in meaningful activities together during the day. Adult Day Programs can serve as a good source of short-term respite for support partners.

- **Respite Care:** This is generally in-home care and support organized with the expressed purpose of providing a break for a primary support partner.

A professional or volunteer support partner will come and ensure continuity of care while the primary support partner attends to other matters.

- **In-Home Care:** This type of care consists of a professional support partner coming into your home to assist you with your activities of daily living, including assisting with or managing your medications, bathing, dressing, grooming, meal preparation or cooking,

housekeeping, and other services. Professional support partners can also provide companionship and transportation, which can be immensely helpful to people living alone with dementia.

- **Residential Care:** Long-term residential care—which encompasses assisted living, memory care, and skilled nursing—requires a person to move out of their home and into a new residential care community where care, support, and meaningful engagement is organized on a more continual basis.

- **Hospice Care:** This type of care is reserved for the end of life, and seeks only to make the person feel as comfortable as possible. Hospice care can either occur within a long-term care setting or within someone's private home.

These are just some of the more common care and support options.

Some people and some families find other creative ways to meet daily needs as dementia progresses, like through cohousing or neighbors caring for neighbors. It is important to make yourself aware of all the available options to determine which type of care and support will be most desirable and beneficial for you. Generally, a combination of multiple types of care can be employed for the best, most tailored approach.

◆

Communicating Effectively for Collaborative Decision-Making

There are a couple of reasons to think specifically about how you communicate with your healthcare providers. First, due to the cognitive changes that occur with dementia, communication may become more challenging over time. Miscommunications and misunderstandings may become more common, especially with people with whom you don't frequently interact.

Therefore, it becomes extremely helpful to find a healthcare provider willing to spend the time necessary to communicate with you, even as your communication abilities change over time. A provider only willing and able to spend 15 minutes may not be able to effectively work with you. It may be wise to find a new provider who can give the time you need to communicate. Even though you may not be experiencing communication challenges now, it is still useful to consider. Finding a provider who can offer the relationship you need *throughout* your care can help maintain a reliable continuity of care.

Second, the patient–provider relationship is one that may have a power dynamic; your provider holds expert knowledge and thus may be perceived to have greater power over decision making. This power dynamic can make it difficult for you to speak up in moments where you perhaps need additional information or when you might even disagree with what your provider is prescribing for you.

Always remember: ***You are the true expert of your life, not your provider!***

In these moments, always remember: you are the true expert of your life, not your provider! You are the one living with dementia and therefore you are the one who knows best what the experience of living with dementia is like. Your healthcare provider should always actively listen to you and value your essential perspectives. Some providers will naturally listen to what you have to say, while other providers might require you to assertively express yourself.

Below are several things to consider that might help you improve your communication with healthcare providers and thus ensure you receive the care that you truly want and need:

- **Always know that your healthcare is for *you*.** It is your right and responsibility as a patient to play an active role in the decision-making process about your care plan. Providers may present you with multiple care options, but the ultimate choice belongs to you.

These situations can help you gain confidence in your own healthcare advocacy.

- **Be honest with yourself and others.** Effective care and communication require you to openly and truthfully share how you feel, both physically and mentally.

- **Revisit your goals before each visit with your providers**, and ensure that you know what matters most to you and if you have preferences regarding what types or levels of care you want.

- **Make a list of questions and concerns** you have about your health to give to your provider. Make sure to not minimize or disregard the symptoms you are experiencing. The only way your providers can help you is if you are open and honest with them, just as you want them to be with you. If you find it hard to keep track of your health, you might try keeping a daily health journal.

Spend a few minutes each day writing notes specifically related to your dementia and your overall health.

- **Let your healthcare providers know if you have difficulty hearing, reading, speaking, or understanding** so they can make accommodations.

- **Don’t be afraid to ask for clarification** and detailed explanations if they would be helpful. Healthcare is full of complicated terms and you want to be sure not to miss any important information so you can make fully informed decisions.

- **Bring a support partner to your visit** to help you understand and remember information. If you bring someone you spend a lot of time with and who knows you well, they might also be able to help you accurately report some of the symptoms you’re experiencing.

- **Take notes throughout your visit** or ask for a verbal and/or written recap at the end of the visit.

- **Ask your provider questions** about how to access your health information, schedule follow-ups, pick up medications, and other necessary post-visit tasks.

- **If something isn't working for you, let your provider know.** There are very few catch-all solutions within healthcare, and everyone has their individual health and well-being differences. It's okay to try one approach, find it isn't working, and switch directions.

◆

A Note on Prescription Medications

No discussion of healthcare within the context of dementia would be complete without information about the available prescription medications designed to slow memory-related symptoms. Currently there are no identified cures for dementia and no treatments that reliably address the range of associated symptoms over the full course of the disease progression.

However, studies demonstrate modest cognitive benefits from cholinesterase inhibitors, memantine, and anti-amyloid antibodies in certain situations.[1] It is worth noting that the newer I.V. anti-amyloid medications do have some common and potentially serious side effects with only a small and temporary cognitive benefit. Ongoing extended clinical studies are occuring to better clarify the severity and frequency of side effects, as well as the duration of benefits.

All too often, prescription medications not designed for use by people living with dementia—such as sedatives and antipsychotics—

are administered in moments when people living with dementia are deemed to be "acting out." In the next module, we will talk more about how such labeling of people living with dementia is not only inappropriate but harmful in the next module. Use of prescription medication in this fashion should be avoided in nearly all cases. Many antipsychotic and sedative medications produce negative side effects for people living with certain types of dementia. This—along with all other reasons discussed in this module—is a good reason to ensure all your healthcare providers know you are living with dementia.

The American Geriatrics Society (AGS) developed the Beers Criteria[2] to outline five categories of medications that providers should reconsider when prescribing for older adults:

1. Potentially inappropriate medications in older adults;
2. Potentially inappropriate medications to avoid in older adults with certain conditions;

3. Medication combinations that may lead to harmful interactions;
4. Medications to be used with considerable caution in older adults;
5. Medications that should be avoided or dosed differently for those with poor renal function.

If your healthcare providers aren't familiar with the AGS Beers Criteria®, you might consider opening a conversation with them on the subject.

Visit **americangeriatrics.org** for more information (search "AGS Beers Criteria"). You can also find a downloadable "pocket guide" online to take to your healthcare appointments.

◆

◆

SUMMARY: MODULE TWO

To summarize this module, it is important to know that you deserve to be an active driver in your healthcare decisions. In fact, your direction of your own care is essential to ensure your goals are met as effectively as possible. Never be afraid to ask the necessary questions of your healthcare providers and spend the extra time to ensure your providers are genuinely working on your behalf. Again, there is no right way to approach your care, so you should feel supported in finding your way.

Module Two focuses on helping you navigate important decisions after receiving a dementia-related diagnosis. It's important to understand your life and healthcare goals before making major decisions such as choosing care options. After outlining these goals, you should also choose your providers—especially ones knowledgeable about dementia—like a neurologist, neuropsychologist, or geriatrician. When interacting with any provider, it's vital to use effective communication strategies to achieve collaborative decision-making. Also, understand dementia may cause you to react differently to certain prescription medications, so mention the AGS Beers Criteria® to your provider.

Notes

Key Message #1: Each person’s experience of living with dementia is different, and each person’s healthcare goals are unique.

Discussion/Journal: What are two of your healthcare goals?

1. ______________________________

2. ______________________________

Key Message #2: It is important to create a team of healthcare providers to help you meet your healthcare goals.

Discussion/Journal: What are some questions you might ask a potential healthcare provider when interviewing them about the possibility of joining your healthcare team?

Key Message #3: You are the true expert of your life, not your provider! Your healthcare is for **you**.

Discussion/Journal: What are three questions or concerns you have about your healthcare that you can ask your provider at your next appointment?

1. ____

____

____

____

____

2. ____

____

____

____

____

3. ____

____

____

____

Additional Reflections and Notes

REFERENCES: MODULE TWO

Temporary benefits of taking certain medications in early to moderate dementia, *page 76*

1. “How Is Alzheimer’s Disease Treated?” on *National Institute on Aging* website: nia.nih.gov

AGS Beers Criteria®, *page 77*

2. “For Older People, Medications Are Common; Updated AGS Beers Criteria® Aims to Make Sure They’re Appropriate, Too” on *American Geriatrics Society* website: americangeriatrics.org

Additional Reflections and Notes

3

MODULE THREE

Planning Your Lifestyle

MODULE THREE

Planning Your Lifestyle

Most of us likely understand the importance of keeping a “healthy lifestyle” on an intuitive level; fewer of us probably know exactly what choices we can make in our everyday lives to keep ourselves healthy and well. There are several steps each of us can take to protect our health and either reduce our risk for developing dementia or set ourselves on the best track for managing the symptoms of dementia. It’s never too late to support your brain health. Brain health is crucial for everyone to consider, not just as part of the dementia journey. It's important to think of health from a full-body perspective—what's good for the body is good for the brain.

★

Six Pillars of Brain Health

As mentioned in the introduction to this Guidebook, The Cleveland Clinic has a program they call *Healthy Brains.*[1]

VISUALIZATION GRAPHIC Cleveland Clinic. All rights reserved. https://healthybrains.org/pillars/

Their website—**healthybrains.org**—outlines six pillars that support good brain health. Below are summaries of these six pillars, as they are described on the *Healthy Brains* website.

* * *

GET MOVING.
Get into strength training.
Work on flexibility and balance.

Get Moving

Good heart health is good brain health. You can help to boost your mood, improve your sleep, and reduce your risk of many chronic diseases all by engaging in physical activity. Per week, the CDC[2,3] recommends older adults get at least 150 minutes of moderate-intensity activity, strength exercises on at least two days, and balancing exercises throughout.

It can be good to check with your healthcare provider before you start an exercise program, as they might be able to help you find a plan that works for you. If you haven't exercised in a while, it may benefit you to start small and work your way up to longer workouts. A regular routine can help you to workout consistently, especially with the motivation of someone else, like a friend or family member. Even if you can't meet the suggested physical activity goals, it's important to follow your plan to the best of your ability.

- **Aerobic Exercise:** Regular aerobic exercise—like brisk walking, running, swimming, biking, dancing, or just plain moving—can actually foster new brain cell growth and preserve existing brain cells. Experts recommend exercising at least five days per week for 30 minutes a day, and exercising at moderate-intensity activity, meaning that you can talk, but not sing, while exercising. Aim for a target heart rate that you and your healthcare provider decide upon.

- **Strength Exercise:** On the other end of the exercise spectrum, lifting weights or using a resistance band can help you build muscle and strengthen your bones while boosting brain power, enhancing concentration, and increasing decision-making skills. Aim for doing strength exercises twice per week and performing one set of exercises per muscle group with 8-12 repetitions of a particular exercise per set. Exercise all major muscle groups and then take a two-day rest before doing so again. Squats, lunges, planks, bicep curls, tricep press-downs, and shoulder presses are—among others—all good exercises to try.

- **Flexibility Exercise:** Flexibility can be honed through activities like Tai Chi, yoga, and stretching, all of which will help improve your posture and reduce your risk of injury; better flexibility means more energy! Try to practice your flexibility 3-5 times per week for 10 minutes each session. Hold each stretch for 30-90 seconds, and stretch muscles through their full range of motion.

- **Balance:** Lastly, balance diminishes progressively as you get older. Balance training—through simple exercises like standing on one foot or walking backward—isn't just about avoiding falls; better balance will improve your overall movement. Work on your balance 2-3 days per week with exercises such as: sit to stand, standing with your feet touching, standing heel to toe, walking sideways, walking on your heels and toes, and standing on one leg.

★

EAT SMART.
Enjoy a Mediterranean diet.
Cook fresh. Savor the taste.

Eat Smart

Eating a Mediterranean-style diet[4] can help maintain overall brain health, including helping to manage the symptoms of dementia. The Mediterranean-style diet prioritizes fish, whole grains, green leafy vegetables, olives, and nuts. Always aim to cook your own food when possible and to use fresh ingredients, and don't forget to savor the flavors you stir up! Eating slowly, intentionally, and with appreciation can do just as much to support your health as can the actual foods you eat.

Another component of a healthy diet is limiting foods that are high in saturated fats, which include red meat and dairy products. These foods are associated with the development and faster progression of various chronic diseases, including dementia. Also be moderate with your egg intake. Proteins in eggs may help to improve memory, but eggs are also high in cholesterol.

Finding good sources of Omega-3 fatty acids is an important element of a healthy diet, since your body can't produce this particular type of nutrient. Eating five ounces of fish at least twice per week can help keep your levels healthy, but if you'd prefer something else, walnuts, flaxseeds, and soybeans are also great options.

Fish is also packed full of vitamin D, which can help fortify your teeth and bones.

Of course, don't forget your fruits and vegetables. Plants like spinach, kale, broccoli, and other leafy green vegetables have an abundance of important nutrients for your brain. Berries—like blueberries, raspberries, and blackberries—are filled with antioxidants that can help to protect your brain as it ages. Try to eat some of these every day.

Foods like dark chocolate, spices, coffee, and tea can be great additions

to your diet as well. They contain compounds that help reduce inflammation in the brain and elsewhere in the body.

Regarding alcohol, red wine might have some protective effects when consumed in moderation. Stick to the maximum recommended daily amounts of one glass for women and two glasses for men. Red grape juice works, too.

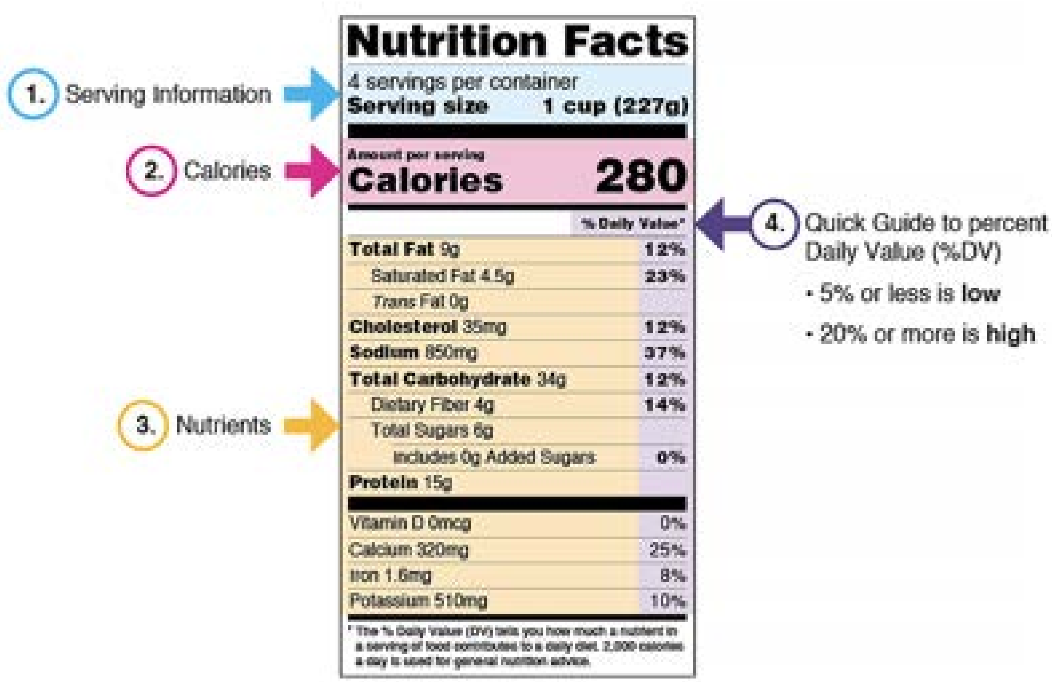
Whole grains like oats, barley, and quinoa are rich in B-vitamins that help to keep the brain running smoothly. For other vitamins, like vitamins C and E, supplements may prove to be beneficial for you.
Talk to your healthcare provider to see if you should add any supplements to your daily regimen. A daily multivitamin is often sufficient.

Keeping a food diary can help you to determine ways your diet can be improved, such as drinking more water, tea, or coffee instead of sweetened drinks.

While reading food labels, the percent daily value (%DV) can help you balance your meals through informed, healthy decisions.

★

How to Understand and Use the Nutrition Facts Label[5]



Nutrition Facts

4 servings per container

Serving size **1 cup (227g)**

Amount per serving

Calories **280**

	% Daily Value*
Total Fat 9g	**12%**
Saturated Fat 4.5g	**23%**
Trans Fat 0g	
Cholesterol 35mg	**12%**
Sodium 850mg	**37%**
Total Carbohydrate 34g	**12%**
Dietary Fiber 4g	**14%**
Total Sugars 6g	
Includes 0g Added Sugars	**0%**
Protein 15g	
Vitamin D 0mcg	0%
Calcium 320mg	25%
Iron 1.6mg	8%
Potassium 510mg	10%

* The % Daily Value (DV) tells you how much a nutrient in a serving of food contributes to a daily diet. 2,000 calories a day is used for general nutrition advice.

IMAGE *fda.gov/files/nfl-howtounderstand-labeled.png*

CONTROL RISKS.
Keep medical conditions in check.
Quit smoking.

Control Risks

There are a variety of medical conditions that negatively impact brain function. Keeping your blood pressure and your body weight at a healthy level is a great first step to reducing the risk of developing other chronic conditions that might worsen your dementia.

High blood pressure in particular can cause structural damage to the brain which can increase the cognitive changes associated with dementia. A healthy blood pressure is considered to be around 120/80 mmHg. You can help to keep your blood pressure at a healthy level by cutting down on salt, keeping active, maintaining a healthy weight, taking all of your medications as prescribed, and checking your blood pressure regularly.

In addition to helping you avoid hypertension (high blood pressure), keeping a healthy weight will also reduce your risk of developing diabetes, which has been shown to increase the risk of dementia significantly. To avoid becoming overweight, try to: avoid white sugar, white flour, and hydrogenated fat; eat more fiber and some protein with every meal; exercise for at least 30 minutes 5 times per week; and control the portion sizes you eat.

★

REST WELL.
Get at least six hours of sleep.
Stay positive. Relax.

Rest Well

We can probably all agree that waking up feeling rested is one of the best feelings. A quality night's sleep helps you to maintain a good mood while also sharpening your brain. It gives you the energy and the ability to move through your days and overcome any challenges you might face. According to the Centers for Disease Control and Prevention (CDC), here are a few tips for good sleep hygiene[6]:

- Try your best to be consistent in going to bed at the same time each night and getting up at the same time each morning, even when you don't have anything scheduled that day.

- Keep your bedroom as quiet, dark, and relaxing as possible, and maintain a comfortable temperature.

- Consider removing electronic devices like phones, televisions, and computers from your bedroom.

- Try to avoid ingesting caffeine or alcohol or eating large meals before bedtime.

- Get some exercise during the day, since being physically active can help you fall asleep more easily.

Much of our ability (or inability) to fall asleep quickly and stay asleep is tied to our overall stress levels. Stress is a natural part of life, and there’s no getting rid of it. So, the question isn’t truly about whether or not you have stress, but rather whether you are successful in riding the waves of stress that come your way. Developing your own strategies for managing stress can make a big difference in the overall health of your brain. Here are a few strategies that you might try:

- **Practice saying "no"** to requests to join in on activities that you'd prefer not to do.

- **Focus on the present**, and try not to worry about what has happened in the past or what may or may not happen in the future.

- **Keep a list of what's bothering you**, and schedule five minutes each day to read over your list and add or remove items.

- **Give your brain a 10-minute break** each day by finding a quiet place to simply sit and focus on your breathing. Consider adding meditation or mindfulness practice to your daily routine.

- **Think positively.** Even though it's hard to stay positive in a stressful situation, try telling yourself, "I can do this. I can figure this out. I'm going to be okay."

- **Allow events to unfold naturally.** This mindset may help to reduce the anxiety that comes with the unknowns of the future and that is made worse by our high—sometimes unrealistic—expectations.

- **Focus on the specific problem at hand** to protect yourself from making it into a bigger issue than it actually is.

- **Use imagery.** Consider placing a photo of a favorite spot where you can easily see it throughout your day. In the moments when you feel stressed, go look at that photo, and imagine for just a moment how the place feels, looks, sounds, and even smells.

★

Try It

Which activities will you use to prepare for sleep? Consider keeping a journal of the results.

KEEP SHARP.
Build your brain reserve. Use it or
lose it. Play, learn and study.

Keep Sharp

You may not know it, but you are powered by something called “brain reserve,” which helps your brain resist damage as well as adapt and respond to the challenges it faces. You begin to develop your brain reserve in childhood and it continues to grow stronger through your life. If you find ways to continue to support your brain reserve through learning, activities, and interests, you can set your brain up for success as it navigates the changes brought about by dementia.

Continuing to learn is one of the best ways to maintain your brain reserve. This can be through focused study or activities that challenge your brain; after all, you’re never too old to learn.

Consider taking an in-person or online class. The Osher Lifelong Learning Institute (OLLI) spans all 50 states, including programs at both the University of Nevada, Reno and University of Nevada, Las Vegas. However, learning can be informal too. Simply finding something you love and getting better at it counts as learning. Perhaps you might even find new activities and interests that you can delve into to keep your brain active.

As it turns out, enjoying artistic expression is good therapy for the brain.[7] It comforts and elevates the spirit and offers a sense of hope and affirmation. So, book tickets to local performances, organize some outings to your favorite museums, and listen to the music you love.

Lastly, play is an excellent way to stimulate the brain. Doing crossword puzzles, playing chess or cards, and even having fun with electronic "brain games" can help to improve your problem-solving ability and reaction time. It's important to find a game you will want to continue to play. Even though play is powerful, it takes time and commitment to make an impact.

★

Try It

What is one thing you always wanted to learn or experience?

STAY CONNECTED.
Treasure your loved ones.
Be social. Have purpose in life.

Stay Connected

Remaining engaged in the communities that matter to you is perhaps the best way to support your brain health and your overall well-being. A community might mean a geographic location—like a town,

county, or state—but it also might mean a book club, a church group, or simply a family. A rich social network provides sources of support, reduces stress, combats depression, and enhances intellectual stimulation, so always look around for opportunities to cultivate the important relationships you have developed with the people around you.

Shared hobbies are one great way to meet people who are probably like-minded. Think about what you enjoy doing, then do some research to see if there's a group of people who meet regularly near you and gather to do that very thing. You'll be surprised to find how easy it is to interact with others in a relaxed setting that you enjoy.

Don't forget that people aren't the only source of loving relationships; animals have proven to be excellent companions! Our pets make us feel good, but they also help keep us active, alert, and calm.

They can even serve to boost our immune systems, and—because they are so cute and attract attention—they can enhance our social life.

More detailed strategies for success to help you connect with others, and in particular with your closest support partners, will be covered in Part Two, Module Five.

★

Reframing So-Called "Behaviors"

There's a term that is sometimes used by scientific, medical, and residential care communities when discussing dementia: "Behavioral and Psychological Symptoms of Dementia" or BPSDs. In many instances, this notion of behavioral symptoms of dementia is shortened to "dementia behaviors." This term refers to the concept that the things people living with dementia do and say—such as taking a walk, getting angry, or crying—are directly related to the symptoms of dementia and are caused by the physical and chemical changes occurring in the brain.

Despite the fact that there are indeed very real changes happening in your brain if you are living with dementia, it is inaccurate to characterize all of your actions and speech as simply symptoms of your disease. The reality is that what most people label as “dementia behaviors” are actually legitimate attempts at communication and are often expressions of an unmet need. This means it may actually be dangerous for the people around you to think of your words and actions as “dementia behaviors.”

For example, imagine you are in pain due to acute appendicitis, and you are facing a challenge in finding the words to tell someone about it. The only way you can find to alert people to your emergency is banging on the table. If your banging is seen as nothing more than a "dementia behavior," it is likely to be ignored. However, if it is understood as communication, then people around you would seek the underlying meaning of your actions. By taking the time to explore and understand your nonverbal communication, they would be able to identify and meet your need for emergency assistance.

It is important for you to have conversations with your support partners about the fact that your words and actions have meaning, and always will. Make sure they know the risks associated with writing off the things you do and say as nothing more than the products of dementia. Consider thinking ahead to situations that may be easily misread.

For instance, if you like to take walks outside but may not always remember or be able to tell your support partners that you're going out, have a conversation with your support partners and neighbors so they understand that you are simply trying to go for a walk and don't instead assume you are "wandering." Conversations like this can help you continue to do what's important to you for as long as possible and can empower the people around you to support you in doing what keeps you living well.

★

Defusing Distress

Though following all of the strategies above can help you to proactively avoid finding yourself in distress, it is inevitable that distress will happen at some point. This is why it is a good idea to think about how you might respond to distressing situations in advance. That way, you have a game plan to follow and can defuse your distress as quickly as possible.

As an illustration of how having a plan might be beneficial, imagine you are at a dinner party and you begin to feel overwhelmed and anxious by the noise. In that moment, it can be difficult to think clearly and identify the next step to take. This might mean that you do nothing, and let the overwhelm and anxiety turn into extreme anger or fear, causing you to have to leave the party completely and making it difficult for you to sleep that night. This, of course, would continue to affect you the next day, perhaps making it more likely for you to find yourself in distress again since you aren't well-rested.

The good news is that with a little bit of planning, many distressing situations can be avoided. For example, think about how powerful it might have been for you to have a conversation ahead of time with the host of the party and let them know that you might need to excuse yourself to a quiet place in the house for 20 minutes at some point in the night if you start to feel overwhelmed. You could have politely stepped away and returned when you were ready. That is the power of planning, and here are a few things you might consider when working out your plan:

- **Tell people about your dementia**, if you are comfortable doing so. Having conversations with people around you about the things you might say or do can help them begin to understand the meaning behind your words and actions.

In the same way, talking with people about your needs ahead of time can help them help you in moments of distress. If someone sees that you are getting overwhelmed, they'll know why, and they may be able to offer support.

- **Think of middle-ground options.** It may be necessary to avoid potentially distressing situations altogether. However, there are usually ways to continue doing what you want to do, as long as you proactively consider ways to set yourself up for success. For example, if you love walks but often get lost, perhaps there are strategies you and your support partner can take to adjust the location or length of your walks. Don't let the fear of ending up in distress stop you from doing the things you love; always work to find the middle-ground between doing it the same way you've always done it and not doing it at all.

- **Try, and try again.** It can take a lot of trial and error to find the plan that works best for you and your support partners. So, as mentioned before, keep trying new ways to stay involved in the activities and communities that matter to you, but don't be disappointed if your plan doesn't work as well as you had hoped. You can learn from these experiences and adjust your approach for the next time. Eventually, you and your support partners will have a plan in place that truly promotes your well-being. It may take time, but it will be worth it in the long run.

- **Rest up!** The best way to avoid finding yourself in distress is to be well-rested when the challenging moments arise. This means getting enough sleep at night, but also finding opportunities throughout the day to relax and unwind. Stress can build up throughout the day if you are engaging in back-to-back activities.

If that stress is too high, it might lead to distress in a moment when it could have been avoided.

- **Be selective** in choosing the activities you want to pursue. Developing a plan can go a long way in helping you stay connected with the people, places, and things that you love. It is also wise to reflect on which activities are ones you truly want to maintain and which you may be able to forego in the name of ensuring you are well-balanced and prepared for the activities that *are* important.

★

Reflect on which activities are ones you truly want to maintain—those that **are important.**

★

SUMMARY: MODULE THREE

Module Three focuses on the Six Pillars of Brain Health as well as reframing so-called "dementia behaviors" and defusing distress. The Six Pillars of Brain Health are important to people of any age and ability, so everyone should consider these measures: get moving, eat smart, control risks, rest well, keep sharp, and stay connected. Instead of being solely attributed to dementia, so-called "dementia behaviors" can often stem from challenges or unmet needs that can be solved through thoughtful reflection and action. Understanding and planning for your needs may help you avoid many of the challenges and distressing situations that may arise.

This brings us to the end of Part One: Learning and Planning. You've learned more about brain health and dementia and have considered some ways you might plan your lifestyle to set yourself up for success in living well with dementia. In *Part Two: Pathways to Living Well*, you'll have the chance to further explore the many paths you might take in executing that plan.

Notes

Key Message #1: The Six Pillars of Brain Health are: (1) get moving; (2) eat smart; (3) control risks; (4) rest well; (5) keep sharp; and (6) stay connected.

Discussion/Journal: What is one thing you currently do to support your brain health?

Discussion/Journal: What is one action you've always wanted to take to better support your brain health?

Discussion/Journal: What, if anything, has held you back from taking action?

Discussion/Journal: What is one small step you could take to overcome that barrier?

Key Message #2: What some people label as "dementia behaviors" are actually legitimate attempts at communication.

Instructions: Read the quote below from a professional care partner. After reading, respond to the Discussion/Journal prompt provided on the next page.

"I am working in a 'memory care unit' in a nursing home. 'Jack' just moved in... He does not want to be there. He is repeatedly told he is staying in a hotel for a while. Occasionally he orders room service from me. One day I hear him yelling. His care partner went in his room to help him shower. He is appalled that someone would dare come into his room and suggest that he needs help bathing. When the care partner insisted, he pushed her out of the room. *Is this combativeness? Or a normal reaction to a really strange hotel service?*"[8]

Discussion/Journal: If you were to experience this kind of misguided labeling in the future, how might you respond to further communicate your needs and improve understanding?

Key Message #3: It is important to have a plan in place to avoid and defuse future distress.

Discussion/Journal: What is one stressful situation you sometimes find yourself in?

Discussion/Journal: What is a plan you can put in place to manage that distressing situation?

Discussion/Journal: To whom will you communicate this plan?

Additional Reflections and Notes

REFERENCES: MODULE THREE

Six Pillars of Brain Health, *page 91*

1. “Six Pillars of Brain Health” on the *Cleveland Clinic Healthy Brains* website: healthybrains.org/pillars/

CDC’s physical activity recommendations, *page 92*

2. “Adults” on *Centers for Disease Control and Prevention* website: cdc.gov
3. “Physical Activity for Different Groups” on *Centers for Disease Control and Prevention* website: cdc.gov

Mediterranean-style diet, *page 96*

4. “Take Your Diet to the Mediterranean” on *Johns Hopkins Medicine* website: hopkinsmedicine.org

How to Understand and Use the Nutrition Facts Label, *page 100*

5. “Sample Label for Frozen Lasagna” on *U.S. Food and Drug Administration* website: fda.gov

Good sleep hygiene, *page 103*

6. “Healthy Sleep Habits” on *American Academy of Sleep Medicine* website: sleepeducation.org

Therapy for the brain, *page 109*

7. “Mental exercise and dementia” online PDF on *Dementia Australia* website: dementia.org.au

Reframing so-called "dementia behaviors" as communication, *page 126*

8. "The Faces of BPSD" on *Being Heard* website: beingheard.blog/

Additional Reflections and Notes

PART TWO

Pathways to Living Well

4

MODULE FOUR

Making Sense of Dementia

MODULE FOUR

Making Sense of Dementia

One day you're just "you" and the next you're "you with dementia." In the blink of an eye, you've been granted a new piece of your identity. You have new peers, new healthcare providers, and—as we talked about in Part 1—new strategies to establish as you navigate life with dementia. If this Guidebook does anything, it should be to assure you that you are not losing yourself because of your diagnosis. Your life is still yours

to live according to your values, preferences, and needs. Dementia may change your approach, but you can still have aspirations and goals. However, it would be naive to claim that being diagnosed with dementia does not entail a necessary adjustment. This new piece of your identity needs to work itself into your mental image of yourself. Luckily, through conscious effort, you can help your new sense of self take shape. How are you going to think about yourself moving forward? What part does dementia play in constituting your self-image? How will you tackle the uncertainty that is central to a life with dementia? What will you do when you experience discouraging setbacks? This module is about making sense of your dementia-related diagnosis, and you will have the opportunity to answer all of these questions and more.

●

Managing Uncertainty

Any chronic disease is inherently uncertain to some degree. It is difficult to know which treatments or lifestyle modifications will prove beneficial and which will turn out to be fruitless. The symptoms of a chronic illness may or may not get worse over time, and the speed at which symptoms develop often differs dramatically for people. The uncertainty surrounding a dementia-related diagnosis can create some challenges. It is essential to develop skills to help you manage that uncertainty. A high level of uncertainty has been linked to a variety of negative health effects. These include increased stress and depression, decreased emotional well-being, difficulty maintaining relationships, overuse of healthcare facilities, and poor health outcomes.[1,2] Here are a few things you might think about as you work toward coming to terms with uncertainty:

- **Relationships and Effective Communication:** As mentioned in

Module Two, it is beneficial to stay connected in your relationships, even as the dynamics of these relationships might change. With these changes, it is important to foster strong relationships and practice effective communication with those around you. Talking through your emotions and feelings with others is a part of effective communication and can help you find hope. Module Five provides specific tips on connecting with others, understanding roles, and supporting your well-being.

- **Trust but verify.** There is no cure for dementia. The wide range of information available about drug treatments, therapies, and lifestyle modifications may make it overwhelming for you to determine what will work the best for you. This is a great opportunity for you to take charge of your healthcare. Speak with your healthcare provider, but don't hesitate to seek another opinion or two from other healthcare providers; trust but verify. Discuss your options with your support partners. Using trusted sources, do some research on the internet to see what has and hasn't worked for others in similar situations. In the end, it's your decision. You owe it to yourself to make an informed choice.

- **Knowledge isn't always power.** Sometimes, knowing something gives you the power to make a more informed choice, as mentioned above. Other times, knowledge doesn't grant you any power whatsoever. For example, it is natural to wonder how you developed dementia.

What did you do—or not do—in your life that increased your risk? Why did you develop dementia, but your sister didn't? To make meaning of your diagnosis, you might find yourself asking these types of questions. It is impossible to answer them with any confidence, but even if you could, what good would come of knowing exactly *why* you developed dementia? No effective treatments for dementia exist, so focusing on the cause of your dementia may lead to unnecessary stress. Although it can be difficult, learning to embrace the uncertainty of the origins of your dementia can help you focus on what you can control: the future.

- **Leave extra time.**[3] Whether thinking about the rest of your life, the remainder of the year, the end of the week, or just the day ahead, we can never know for sure what will happen. Knowing the course of your day is uncertain, it may be helpful to leave yourself additional time to complete your daily tasks. This allows for the unexpected to occur without derailing your plans. Giving yourself extra time allows you to take breaks and rest if you find you need some downtime in between activities.

> “The two most powerful warriors are patience and time.”
>
> **— LEO TOLSTOY**

- **Change isn’t always linear.** While your dementia may be caused by a progressive, chronic disease, the changes you experience may not be linear. In other words, individuals living with dementia may experience some days with less noticeable symptoms and other days when symptoms are more noticeable. The extent to which your dementia is a factor in your daily life can fluctuate hour-to-hour, or even minute-to-minute. The key is learning to adapt and to inform your support partners of your needs, which may change throughout the day.

- **You always have right now.**

Uncertainty doesn't just exist within the context of chronic disease. Everyone's future is uncertain. No one knows what the next day, year, or decade of their life holds. However, we all have one thing that is certain: this very moment. In the here and now, there is no uncertainty, no ambiguity, no room for the unknown.

In the moments when you find yourself becoming anxious about the future, take a few breaths and focus on the present. There's almost nothing as concrete in the world as the present. In a sea of uncertainty, *this moment* can be your anchor.

●

Identifying and Confronting Change and Loss

While it is possible to live well with dementia, a dementia-related diagnosis can be a shock that takes time to work through. You are likely experiencing many emotions about your diagnosis. Perhaps it feels like you're on a rollercoaster and the ups and downs can leave you feeling exhausted and unsettled. This may be particularly true if your diagnosis came at a stressful or uncertain time. There's no denying a dementia-related diagnosis can take a toll on your mental well-being.

It might be tempting to pretend you did not receive a diagnosis in the hope of escaping some of the difficulty. While this is understandable, according to the American Psychological Association[4], facing your diagnosis head on is the best way to cope. One way to do this is to keep a journal, like the daily health journal we discussed in Module Two. Use your journal to note how dementia impacts your daily life and your feelings about the changes you are experiencing. This information can assist you

with finding new coping strategies. Focusing on one challenge at a time can keep your dementia from feeling too overwhelming. While it is often easier to recall the low points, use this journal to take note of the good moments throughout your day or week.

In the beginning, you may blame yourself for your diagnosis. While there are strategies to reduce the risk of developing dementia, you are not to blame. In many cases, no single factor causes dementia, making it difficult to pinpoint the specific origin.

Try It

Do you currently keep a journal? How do you think this might aid in your journey?

As mentioned in the previous section, focusing on the potential cause of your dementia—or blaming yourself—does not give you any power to live well today or in the future. Focus on what you can do from this point on to live well with dementia. When you find yourself casting blame or thinking of what you could have done differently, write down one thing you can do to support your well-being moving forward. You can look back at this list when you need inspiration to help you live well.

Coming to terms with your dementia-related diagnosis may stir up emotions often experienced in the grieving process. While dementia does not mean you've lost who you are, it can mean a change in your sense of self. Changes will occur in your everyday life, which may cause anxiety and spark feelings of grief or loss. The American Psychological Association compiled a list of tips for handling grief.[5] While these tips were developed in the context of coping with the loss of a loved one, they can apply to navigating the grief associated with a dementia-related diagnosis:

- **Talk about what you have lost with your support network.** Being open about what you feel you have lost can help both you and the people closest to you better understand the changes you are experiencing. It may lead to productive conversations about how you can continue to do the things that are important to you. Don't be afraid to seek more structured help, such as support groups, counseling, or therapy. These activities are led by professionals who can assist you in navigating through the grief, stress, or anger you experience.

- **Accept and share your feelings.** It's okay to be sad, angry, frustrated, or whatever emotion you might be feeling. These emotions are normal and there is no right or wrong way to manage your dementia. However, it is important to seek support if you find yourself overwhelmed by your emotions.

Talk with your support partners to get you back on track to living well. Suppressing genuine emotion may lead to harmful reactions such as misplaced anger. Recognizing, accepting, and reaching a stage of emotional acceptance of your dementia may provide you with clarity in your own situation and emotions.[6]

- **Take care of yourself.** The strategies for good brain health discussed in Module Three can help keep you mentally and physically well. The grieving process can be a demanding one. Making sure to eat well, remain active, and stay connected to others can help your mind and body weather the difficulties. Feelings of grief and frustration have the potential to make you feel isolated or lost, therefore it is important to foster healthy lifestyle habits and relationships.[7]

- **Reach out and help others.** Do you know anyone else diagnosed with dementia? If you do, reaching out to offer your support can help you process your own diagnosis and feel more fulfilled. If you don't know anyone else living with dementia, the Connections section starting on page 247 of this Guidebook has tools and strategies to help make a positive impact on the lives of others by sharing your story.

- **Celebrate your life.** Don't forget to celebrate the wonderful moments in your life and the many good times ahead. Though life may look different now, it's not over, and there is much growth and happiness left to come.

Thankfulness Treasure Hunt

Write down some things for which you are grateful. Consider people, places, pets, events, experiences, and things.

●

Dealing with Discouraging Setbacks

Despite managing your dementia well, there are bound to be moments in which you experience setbacks. Experiencing a setback doesn't mean you've failed. In fact, setbacks can provide you with an opportunity to learn how to live well with dementia. It could be your symptoms progressing faster than you expected, or an unexpected break from your routine that throws a wrench into your plans. As mentioned previously, change isn't always linear. You will likely have good days and bad days with your dementia. The most important thing to know about setbacks is that they should not be feared or resented. Here are a few points to consider in the moments and days after you've had a setback:

- **Consider the context.** Take some time to think about your life leading up to the setback. Think about whether there was anything you might have been able to do differently to prevent it.

> “The real gift of life is not what you give, but who you become in the process of giving.”
>
> **— DEBASISH MRIDHA**

In some cases, nothing could be done to prevent the setback. When you experience an unavoidable setback, do your best to move forward and use the experience to help you develop strategies to live well. On the other hand, there are setbacks your actions might have influenced. For example, in a moment of distress, you might have yelled at your support partner, something you have not done in quite some time. Reflecting on the situation, you may realize you had a busy day and did not have the opportunity to rest. Or perhaps your support partner did not give you enough time to speak during a conversation, forcing you to assert yourself. Either situation may have led you to yell, which is an understandable reaction to a distressing situation. Setbacks like

these can help you see how people and your surroundings can influence your words and actions. Moving forward, you’ll be more aware of your personal needs on a busy day, or how to make your desire to speak known during a conversation.

- **Reset or adjust your strategy.**

Perhaps the reason you’ve experienced a setback is because the strategy you outlined for living well with dementia needs some adjustment.

For example, imagine that you altered your diet to promote good brain health and you ate more nuts. However, at a recent healthcare visit, you were informed your blood pressure is still high. After hearing this, you realized the nuts you added to your diet were salted, which affected your blood pressure. Setbacks—though disappointing—can be opportunities to reflect on whether your strategy is working for you. If your strategy is working, perhaps you can make it stronger.

If your strategy is not working, you can learn from the setback and adjust your strategy.

- **It's okay to be disappointed.** It's understandable to feel disappointed when you experience a setback. However, feeling disappointed is different than feeling discouraged. Feeling disappointed means that what you hoped would happen—presumably a future free of setbacks—didn't occur. Feeling discouraged means you've lost the confidence that you can live well with dementia. It is essential to know experiencing a setback today does not reduce your ability to live well with dementia tomorrow. As mentioned above, facing setbacks may increase your ability to develop strategies to live well. It's okay to be disappointed for a while, but if you find yourself being discouraged for a period of time, read this page again and reframe your setback into an opportunity to learn and adjust.

> *It is essential to always know that a setback today does not reduce your ability to* ***live well with dementia tomorrow.***

Reframe your setback into an opportunity.

In understanding ways to manage setbacks, it may be helpful to understand what **problem-focused** and **emotion-focused** coping mechanisms[8] look like and how to implement them. The previous sections have shown you examples of problem-focused coping mechanisms. Instead of being held back by emotional reactions to discouraging setbacks, try identifying the problem and focus on reframing the issue.

For example, you could be struggling to communicate with a friend or family member. This may cause you to feel frustrated when they don't understand you. Instead of remaining frustrated, try using some problem-focused strategies, such as ones in the "Identifying and Confronting Change and Loss" section of this module, or

Module Three's "Defusing Distress" section. Recognizing and confronting setbacks can lead you to new ways of understanding yourself and how you can live well with dementia.

Emotion-focused coping involves regulating your feelings and emotional response to the problem instead of addressing the problem. For example, you might journal when you feel frustrated to try to process what you are feeling, or you might practice mindfulness to manage the stress of daily life rather than implement strategies to reduce the number of daily stressors. Other emotion-focused coping strategies include art, walking, exercising, listening to music, or holding a beloved pet. Often the best method of coping is a combination of problem-focused and emotion-focused strategies.

●

"Identifying and Confronting Change and Loss" is on ***pages 145-151.***

"Defusing Distress" is on ***pages 115-120.***

SUMMARY: MODULE FOUR

This module shares ideas intended to help you make sense of your dementia-related diagnosis. Uncertainty often goes along with dementia, but now you have some specific tips to help you manage that uncertainty. A dementia-related diagnosis can lead to change, loss, and the need for adjustments in your life and relationships. However, not all of these changes will be expected or linear, and while some may be disappointing or discouraging, other changes might present unexpected opportunities. So, don't lose hope, and remain open to the possibility that you can live well with dementia. Accepting and facing your diagnosis head-on is essential. In the next module, we'll talk about how you do not need to face this alone. Through Dementia Friendly Nevada and other community-based initiatives and programs, there are many opportunities to connect with other people who are living with dementia, and living well. It’s important to find and stay connected to a supportive community.

Notes

Key Message #1: It is essential to develop skills to help you manage uncertainty.

Head-to-Toe Relaxation: Please read all steps before beginning or ask a support partner to guide you through the activity.

Head-to-Toe Relaxation[9] relaxes every part of your body and involves tightening your muscles, starting from your head and working your way down to your toes, releasing the muscles as you go.

1. First, get into a comfortable position, either sitting or lying down.
2. Close your eyes if you are comfortable doing so and focus on relaxing your body as much as possible.
3. Start by tensing your toes; curl them up into your feet and hold them tight for 3–5 seconds. Release your toes and repeat.
4. Next, tighten all your muscles from your feet up to your waist. Hold for 3–5 seconds, release, and repeat.
5. Next, tighten your stomach and chest muscles as much as you can. Hold for 3–5 seconds, release, and repeat.

6. Now, tighten your whole torso, including your shoulders. Hold for 3–5 seconds, release, and repeat.
7. Next, tighten both of your arms, including your hands. Hold for 3–5 seconds, release, and repeat.
8. Tighten your neck by turning your head as far to the right as possible without feeling any discomfort. Hold for 3–5 seconds, and then repeat to the left.
9. Finally, scrunch and tighten your whole face and hold for 3–5 seconds, release, and repeat.
10. Now that you've relaxed each part of your body, do a body scan to see how your body is feeling. Are you feeling more relaxed?

Discussion/Journal: When might you use Head-to-Toe Relaxation?

Key Message #2: Facing your diagnosis head-on is the best way to cope.

Discussion/Journal: How does dementia impact your daily life? How do you feel about the changes you are experiencing?

Discussion/Journal: What is one coping strategy you will try?

Key Message #3: A setback today does not reduce your ability to live well with dementia tomorrow.

Discussion/Journal: Think about a discouraging setback you've recently experienced. Is there anything you might have been able to do differently to prevent this setback?

Discussion/Journal: How can this setback be reframed into an opportunity to learn and adjust?

REFERENCES: MODULE FOUR

Managing Uncertainty, *page 138*

1. From the article “Uncertainty and psychological adjustment in patients with lung cancer” by Kurita, Garon, Stanton, and Meyerowitz
2. From the article “A loss of social eating: the experience of individuals living with gastroparesis” by Bennell and Taylor

Leave extra time, *page 142*

3. From the article “Managing uncertainty in chronic illness from patient perspectives” by Brown, Hayden, Klingman, and Hussey

Facing your diagnosis head on is the best way to cope, *page 146*

4. “Coping with a diagnosis of chronic illness” on the *American Psychological Association* website: apa.org

A list of tips for handling grief, *page 148*

5. “Grief: Coping with the loss of your loved one” on the *American Psychological Association* website: apa.org

Accept and share your feelings, *page 150*

6. From the article “Dementia grief: A theoretical model of a unique grief experience” by Blandin and Pepin

Take care of yourself, *page 150*

7. From the article “The relationship between self-blame for the onset of a chronic physical health condition and

emotional distress: A systematic literature review" by Callebaut, Molyneux, and Alexander

Problem-focused and emotion-focused coping, *page 158*

8. From the article "Balancing the struggle to live with dementia: a systematic meta-synthesis of coping" by Bjørkløf, Helvik, Ibsen, Telenius, Grov, and Eriksen

Head-to-Toe Relaxation, *page 162*

9. From the *Change to Chill* by Allina Health website: changetochill.org

Additional Reflections and Notes

5

MODULE FIVE

Connecting with Others

MODULE FIVE

Connecting with Others

Humans are social creatures. We naturally gravitate toward community and social connections. Unfortunately, people living with dementia often experience a dramatic sense of disconnection from their community following their diagnosis. Friends and family may reach out less frequently due to the stigmas and misconceptions about dementia. Participation in professional and social groups may seem increasingly overwhelming as the risk of making mistakes increases. Maybe these are feelings that you have recently experienced. You may have found it more difficult to connect with your community or you may fear this will happen in the future. This module will help make it clear that you should not have to feel cut off from your social connections. You can and should be a part of communities that are important to you for as long as you like. However, because many people know so little about dementia, staying connected with others might

take a bit of work on your end. This module will serve as your guide to help you remain socially connected.

♥

When and Where to Disclose Your Diagnosis

One of the most paralyzing questions you might find yourself asking after receiving a dementia-related diagnosis is, “Should I tell people about this?” It can be scary to be vulnerable and share your diagnosis with others.

However, inviting others to join you on your journey is a great way to gain support for your well-being. Here are some points you can use to determine when and to whom to talk about your dementia:

- **Will they be able to help?** Your closest friends and family members can certainly serve as a support system as you strive to live well with dementia. That support system can step in to lend a hand in times of need. It can be more challenging, though, to see how other community members—people you may not know—could be supportive as you navigate your dementia. However, if you start to consider who could help you during your daily life, the list of supporters begins to grow considerably. For instance, if your server in a restaurant knows you are living with dementia, they may show more patience as you take time to order from a long and complicated menu. If the TSA agent at the airport knows you are living with dementia, they may show less frustration if you are confused about how to navigate the security screening process. Of course, there may be some instances in which it isn't important to disclose your dementia. For example, the person sitting next to you on the bus might not need to know about your diagnosis. However, telling the bus driver could help them cue you at your desired stop. In many cases, being open and honest about your dementia will allow others to help you live well.

- **Get ahead of it.** The people around you, especially the people who love you most, might be scared or uncomfortable when they see the symptoms of your dementia. This fear or discomfort, often the result of a knowledge gap, may cause people to keep their distance because they do not know how to support someone living with dementia. It is easier to do nothing than to risk making a mistake. Therefore, it can be powerful to talk about your dementia with friends, family, neighbors, and anyone else with whom you interact frequently.

You may also consider providing them with educational resources. You can talk openly about your dementia, your goals, and your preferences for the future. Most importantly, tell your support partners you want them to continue to play an active role in your life. Being proactive and talking to your support partners early on will likely help you to avoid the isolation some people experience as their dementia progresses. Let people in and help them develop a deeper understanding.

- **Find your peers.** Dementia opens the door to a new community of peers: people living with dementia. All over the world, people living with dementia come together to share their experiences. You can be a valuable contributor. Your story of living well with dementia can help others do the same. Sharing your story can be the first step in making connections with other people living with dementia, which can grow your support system. Sharing your story is a powerful way to break the

stigma of dementia and shed light on the dementia-related myths and misconceptions.

♥

Communication Strategies

We connect with others through communication. Since dementia has the potential to affect communication, you might find it useful to proactively have conversations with your support partners about ways to keep the lines of communication open and clear.

Here are some strategies that have worked for people living with dementia and support partners that you can adopt, modify, or expand upon:

- **Set the stage.** The physical and auditory environment where a conversation takes place can make or break the communication. To ensure everyone can be heard, try to remove as many distractions as possible. Find a private, quiet place to talk where you know you won't be interrupted. Make the environment comfortable with the furniture and objects you love. Reduce clutter, and be sure you have the ability to sit down at eye level with whomever you are engaging. Try to avoid talking over the sound of a television or any other kind of background noise.

- **Have patience.** Your dementia may require extra time when communicating. Extra time may be needed in getting your words out, processing information, and responding to questions others ask you. Having patience in these moments is essential to preserve good communication. Be patient with yourself and take the time you need to say what you want to say, even if it takes longer than it once did. Ask your support partners to have patience with you when you take time to answer their questions. Consider asking them to wait at least 30 seconds while you consider their words and formulate a response. Sometimes silence—even if it's uncomfortable—can be very helpful.

- **Embrace body language.** Much of what we communicate to each other has little to do with the words we use and more to do with our tone of voice, facial expression, and body language. Dementia might make it more difficult for you to find the right words or to understand the words others are saying—a condition known as aphasia. Focusing on body language can be a great way to maintain good communication. Make sure your support partners know that if they can't understand you, there's no need to give up. Your support partners may need to shift their focus to your nonverbal communication to help them understand what you are communicating. Embrace the notion of "show, don't tell." You may want to ask your support partners to use good nonverbal communication skills as well.

- **Be truthful.** Your support partners may believe there are situations in which lying is harmless and potentially helpful in supporting your well-being.

However, even if lying is done out of the best of intentions, it can break down trust. Lying can also promote a dynamic in which your support partners hold the truth and therefore are the ones with more power in the relationship. You may want to consider asking your support partners to never lie to you, even when they feel it might be beneficial. For example, if a family member has concerns about you driving, ask them to sit down and discuss their concerns with you instead of hiding your keys or disabling your vehicle. It's best to negotiate issues *together.*

- **"With" not "to."** As your communication becomes slower and less verbal, you might find your support partners develop a habit of speaking *to* you rather than having a conversation *with* you. One reason for this is that we are not used to communicating slowly and in a less verbal manner. It might be helpful to inform your support partners that, regardless of your verbal ability, you want to remain an active participant in communication.

◆

Clarifying and Re-Establishing Roles

Throughout our lives, we settle into certain roles within the relationships we form. There is no universal format for how parents and children, spouses, significant others, siblings, or friends should relate to each other. Additionally, relationships and roles may develop and change over time. The way you communicate with others may also change.

Take a minute and think of someone very close to you. Consider how you act toward each other and the roles you play in each other's lives. Roles are central to the identities of the relationships we hold dear. It can be jarring when dementia makes it necessary to change or re-establish those roles. However, we should be mindful that while dementia takes, it also gives. Dementia can provide you with the opportunity to enter a new, perhaps even more meaningful stage in your relationships with others, and to do so in a way that is intentional and rewarding. It may require you to change or share the roles you play, but such evolutions can foster greater appreciation of the people in our lives.

One role everyone should embrace in the circle of care is "partner." Researchers from the University of Waterloo[1] in Canada worked in partnership with people living with dementia to better understand what it takes for people living with dementia and support partners to work in authentic partnerships.

Drawing on their own partnership experiences and interviews with other people living with dementia and support partners, the collaborative research team identified **three guiding principles and five enablers to authentic partnerships.** When supported, these principles and enablers can help people living with dementia and their support partners promote each other's empowerment and equality while building capacity for shared decision making. The "authentic partnerships" framework encourages people living with dementia and support partners to actively incorporate and value different perspectives and all relevant individuals in decision making.

> "Friendship ... is born at the moment when one man says to another 'What! You too? I thought that no one but myself...' "
>
> **— C.S. LEWIS**

Consider how this approach might work for you and your support partners as you clarify and re-establish roles.

The *guiding principles* of authentic partnerships are:

1. **Genuine regard for self and others:** Value and know each other. Honor individual uniqueness and abilities. Believe that everyone can learn and grow.
2. **Synergistic relationships:** Value interdependence. Include everyone who should be included. Hear all voices. Build on diversity and promote shared learning.
3. **Focus on the process:** Focus on the quality of your partnership. Stay flexible and responsive to change. Learn from mistakes. Embrace creativity. Remain open to new possibilities.

The *enablers* that support authentic partnerships are:

1. **Connecting and committing:** Bring together a group of support partners. Work together to determine goals and expectations.

Identify each person's strengths and resources. Develop mutually agreed-upon guidelines for supporting the partnership.

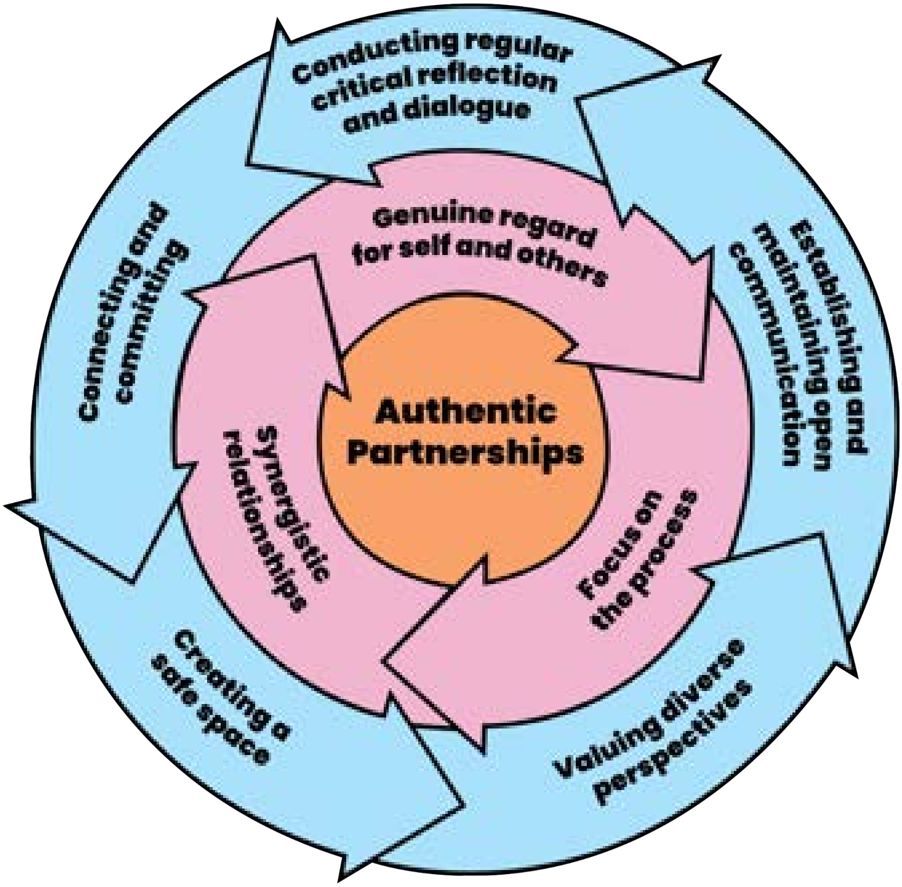
2. **Creating a safe space:** Create a space that is emotionally and physically comfortable. Build trust so everyone can openly express their opinions. Discuss how to foster strong relationships. Be attuned to indicators of discomfort or frustration. Provide a familiar environment free of distractions for effective communication.
3. **Valuing diverse perspectives:** Appreciate the contributions of all partners. Value different types of engagement. Act on everyone's insights. View differences as opportunities for greater understanding.
4. **Establishing and maintaining open communication:** Provide a range of ways for communicating. Provide time for people to process information. Use accessible language. Check for understanding. Keep everyone in the loop. Clarify meanings.

5. **Conducting regular critical reflection and dialogue:** Provide opportunities for self and group reflection and dialogue. Regularly ask how things are going. Reflect on what is working well and what you could be doing differently.

Dr. Tom Kitwood, psychologist and author of *Dementia Reconsidered: The Person Comes First*[2], outlined six basic psychological needs of people living with dementia: comfort, identity, occupation, inclusion, attachment, and love. When support partners help foster these psychological needs, they protect and affirm the personhood of the individual living with dementia. As a person who is living with dementia, it's important that you nurture these needs for yourself.

Building on these psychological needs, when support partners work in authentic partnership with the individual living with dementia, they do more than just protect personhood; they mobilize social citizenship[3] and then new possibilities emerge.

Authentic Partnerships Approach[4]



Mobilizing authentic partnerships in dementia care, support and services

In addition to supporting a person's sense of comfort, authentic partnerships open opportunities for growth. In addition to supporting a sense of identity, authentic partnerships open spaces for new social positions. Occupation manifests into a genuine sense of purpose. Inclusion is realized through active participation. Attachment blossoms into solidarity. And love for each other ensures freedom from discrimination.

In all, dementia should not relegate someone to being passively impacted by decisions made for or about them. That is not the role you have to play in your own life post diagnosis. Rather, your role can be an active one. Focusing on maintaining authentic partnerships between you and all your support partners is a good way to help you maintain an active role.

♥

> Authentic partnerships open opportunities for growth.

♥

SUMMARY: MODULE FIVE

Modules Four and Five explore new ways to think about the present, not just regarding yourself but also the connections you have to others. Module Five highlights that social connections and relationships may change as you go through your dementia journey. It is important to focus on maintaining and fostering these relationships and social connections. Deciding when and with whom to share your diagnosis, adapting your communication strategies, and anticipating potential changes that may occur can help you and your support partners strengthen and maintain your relationships. These approaches can help to uphold your well-being through meaningful relationships and authentic partnerships. Now, let’s think about the future. In Module Six, we will turn our sights forward and consider the myriad of possibilities that await you.

Notes

Key Message #1: In many cases, being open and honest about your dementia will allow others to help you live well.

Discussion/Journal: With whom have you shared your diagnosis or concerns?

Discussion/Journal: What is one approach that has been successful for you in sharing your diagnosis?

Discussion/Journal: Is there anything preventing you from sharing with others?

Additional Reflections and Notes

Key Message #2: Although your communication style may change throughout the journey of dementia, there are ways to ensure that communication stays open and clear. One of those ways is to embrace nonverbal communication.

Discussion/Journal: What is one approach that you and your support partner(s) can try to enhance communication beyond verbal expressions?

Match the Mood to the Face

Activity: Which expression(s) might be identified as:

1. Happy?
2. Upset?
3. Surprised?
4. Grumpy?
5. Laughing?
6. Nervous?
7. Sleepy?
8. Excited?
9. Skeptical?

Key Message #3: When support partners work in authentic partnership with people living with dementia, they do more than protect personhood. They strengthen social citizenship, and with it, new possibilities emerge.

Discussion/Journal: Think about a great partnership in your life, maybe with a friend or family member. What qualities of this partnership make it work so well?

Discussion/Journal: Now, imagine that someone has offered their help as a support partner. What are some qualities that you would want this person to possess?

Additional Reflections and Notes

REFERENCES: MODULE FIVE

Authentic Partnerships, *page 181*

1. From the article "Moving beyond patient and client approaches: Mobilizing authentic partnerships in dementia care" by Dupuis, Gillies, Carson, Whyte, Genoe, Loiselle, and Sadler

Dementia Reconsidered: The Person Comes First, *page 186*

2. Book by Kitwood

Broadening the dementia debate: Towards social citizenship, *page 186*

3. Book by Bartlett and O'Connor

"Authentic Partnerships" approach, *page 187*

4. From the article "Moving beyond patient and client approaches: Mobilizing authentic partnerships in dementia care" by Dupuis, Gillies, Carson, Whyte, Genoe, Loiselle, and Sadler

Additional Reflections and Notes

6

MODULE SIX

Focusing on Possibilities

MODULE SIX

Focusing on Possibilities

When we think of a dementia-related diagnosis, we may envision a death sentence, or even a fate *worse* than death. Often, a dementia-related diagnosis is steeped in sadness, loss, and fear of decline. For some, a future with dementia might suggest a lack of meaning, purpose, growth, or joy. These beliefs about dementia are part of a tragedy narrative. The fear and stigma these beliefs create limit our ability to imagine the possibilities that still lie ahead for people living with dementia. In actuality, the possibilities are endless. **People living with dementia are *living*.** As a person living with dementia, you wake up each morning, go about your day, pursue your goals, connect with people who matter to you, and lay in bed on your pillow each night ready for the sun to come up again. You're 100% alive, and with life comes possibility. This module is dedicated to that fact. No matter who you are, no matter what type of dementia you have or how advanced your dementia may be, your life is filled with possibilities. Let's explore some ways to seize your possibilities.

◆

> "I see dementia as a gift... It's a privilege to learn so much more from the inside, and a glorious opportunity to explain, educate, and inspire."
>
> **— DR. JENNIFER BUTE, *LIVING WITH DEMENTIA***

Unexpected Gifts of Dementia

Would you believe it if someone living with dementia told you they think of dementia as a gift?

As unbelievable as that might sound, it is the reality of many people living with dementia. Even the hardest things in life can teach us a great deal about how to be better humans and how to get more out of our time on this earth.

Considering the gifts dementia might offer can help shift your focus away from grief and tragedy and toward the possibility that you can live well. Here are examples of the gifts members of Dementia Friendly Nevada—including people living with dementia, family support partners, and professionals—believe they have received because of dementia:

- **Feelings over facts:** For people living with dementia, remembering facts can be challenging, but feelings are easier to access and remain longer. Bonds between people living with dementia and their support partners can strengthen by focusing on how they make each other feel rather than focusing only on facts. When we interact with each other, we tend to focus our attention on the substance of those interactions. What are we saying? What stories are we telling or hearing? What are we learning from each other? What are the problems that we are helping each other to solve? While the substance of our conversations matter, the manner in which we interact with others is perhaps more important.

- **Embracing the moment:** There is much to process and consider after receiving a dementia-related diagnosis. While this Guidebook encourages you to look toward your future, sometimes the best thing to do is to be present and live in the moment. Many members of Dementia Friendly Nevada have found living with dementia allows them to slow down and appreciate the here and now. Learning to take a step back from our fast-paced world can allow you to fully enjoy the moment.

- **New friends:** As mentioned in the previous module, a dementia-related diagnosis grants you entry into a new community of other diverse, vibrant, engaging people who are living with dementia. The people you will meet as part of this journey have the potential to become friends for the rest of your life.

While you didn't ask for dementia to come into your life, you might find it connects you with some of the most wonderful, creative, and kind people you have ever known. Most things in life are better when shared, including our struggles and our joys.

- **Serving others:** Speaking of joy, there's a great joy that comes from finding a purpose and impacting the lives of others. As a person living well with dementia, you can be an inspiration to other individuals who are just beginning their journey with dementia. Think of how you have learned from others' experiences throughout your life.

Now, you can be the mentor by sharing some of your own experiences. It can be a wonderful gift to see the impact you have on others' lives. Many members of Dementia Friendly Nevada believe this is one of the greatest gifts of dementia.

◆

Adapting to the "New Normal"

A life with dementia is likely different from the life you have been living. However, different does not necessarily mean worse. Change can be difficult, but eventually the change becomes the new normal. This is most certainly the case with dementia. As you continually strive to live well with dementia, you can look for ways to increasingly adapt to your "new normal." But how can you start to make your life with dementia seem normal?

Here are some approaches to help you:

- **Don’t abandon the old normal.** Just because you’ve been diagnosed with dementia doesn’t mean your entire life needs to change. In fact, the best way to make your life feel normal is to live it as normally as possible. Think about the things you love to do, the places you love to go, and the people you enjoy. How can you continue to do those things, go to those places, and be with those people now that you are living with dementia? If something seems impossible to do, talk to your support partners and others living with dementia about creative approaches to try. If your first approach doesn’t work, don’t give up. Keep trying to stay engaged and consider ways to adjust your approach. If you immerse yourself in experiences that foster your sense of self, your dementia will likely take a back seat.

- **Explore new interests.** You may find some of your favorite activities more challenging as your dementia progresses. It's certainly natural to grieve those lost activities. However, keep in mind the loss can make room for you to explore new ways to contribute to your well-being. In our busy lives, we may not have the time to try new things. Well, now can be that time. What have you always wanted to try? Try it! What new interests or curiosities do you find

blossoming within you? Following your inspiration can bring you unexpected joy.

- **Try not to "therapize" all aspects of your daily life.** After your diagnosis, you may have heard about opportunities such as "art therapy," "music therapy," "recreation therapy," "pet therapy," "nature therapy," and other "therapies" to try. While therapies can play an important role in supporting your well-being, there's no need to turn all aspects of daily life into a "therapy." Doing so can medicalize the normal and joyful aspects of your daily life. If there are activities you enjoy doing, engage with them freely without prescription. At the same time, if you have opportunities to participate in and benefit from non-pharmacological therapies, embrace the ones that appeal to you. But hold tight to your right to leisure, "the celebration of freedom at its crowning point."[1]

> "Leisure is the celebration of freedom at its crowning point."
>
> **— CHARLES SYLVESTER**

- **It's normal if you say it is.** There's a technique in improvisational theater called "Yes, and..." To summarize, if one actor on stage says something, other actors aren't allowed to contradict them and say "No." Rather, their only option is to accept what has been said and add to it. Hence, "Yes, and..." No matter what leaves someone's mouth, it's immediately adopted as part of reality. This technique can apply to your efforts to live well with dementia. Instead of focusing on what you can't do or don't have, celebrate and build on what you can do and what you do have. What a wonderful place to be—a radical acceptance of who, where, and how you are as "normal." From there, you can proceed in whatever direction best supports your well-being. Next time you find yourself wishing your life were different, give it a "Yes, and..." instead.

Embracing Leisure

What are some meaningful experiences that bring you peace, happiness, or a sense of freedom? How can you have more of those experiences?

____

____

____

____

____

____

____

Planning for Daily Life and Healthcare

To maximize the possibilities ahead, there are elements of your daily life and healthcare that are helpful to think about in advance. Dementia can lead to challenges with cognitive and physical skills and abilities.

Anticipating those changes will give you power to respond to them in the future. Each person living with dementia has different wishes and needs to create a safe environment. For this reason, it is important for you and your support partners to discuss how best to respond to the changes you are experiencing in a supportive manner.

Every person's journey with dementia is different, so while you're considering strategies to help you live well, always know there's no right answer; only the right answer for you. Both dementia and aging can negatively impact your balance and coordination, so it's necessary to think about accessibility. Some medications have side effects that can make it harder to balance, even causing dizziness or vertigo. Not all environments are built with accessibility in mind, perhaps including your own home and other important locations in your life. "Aging in place,"[2] or living in your

own home as you get older, may be important to you. You may need to take measures to maintain a safe environment to make aging in place possible. Here are some easy changes to make your home safe and accessible.

To avoid falls, ensure stairs have handrails and avoid using throw rugs. Good lighting throughout your home can help you see.

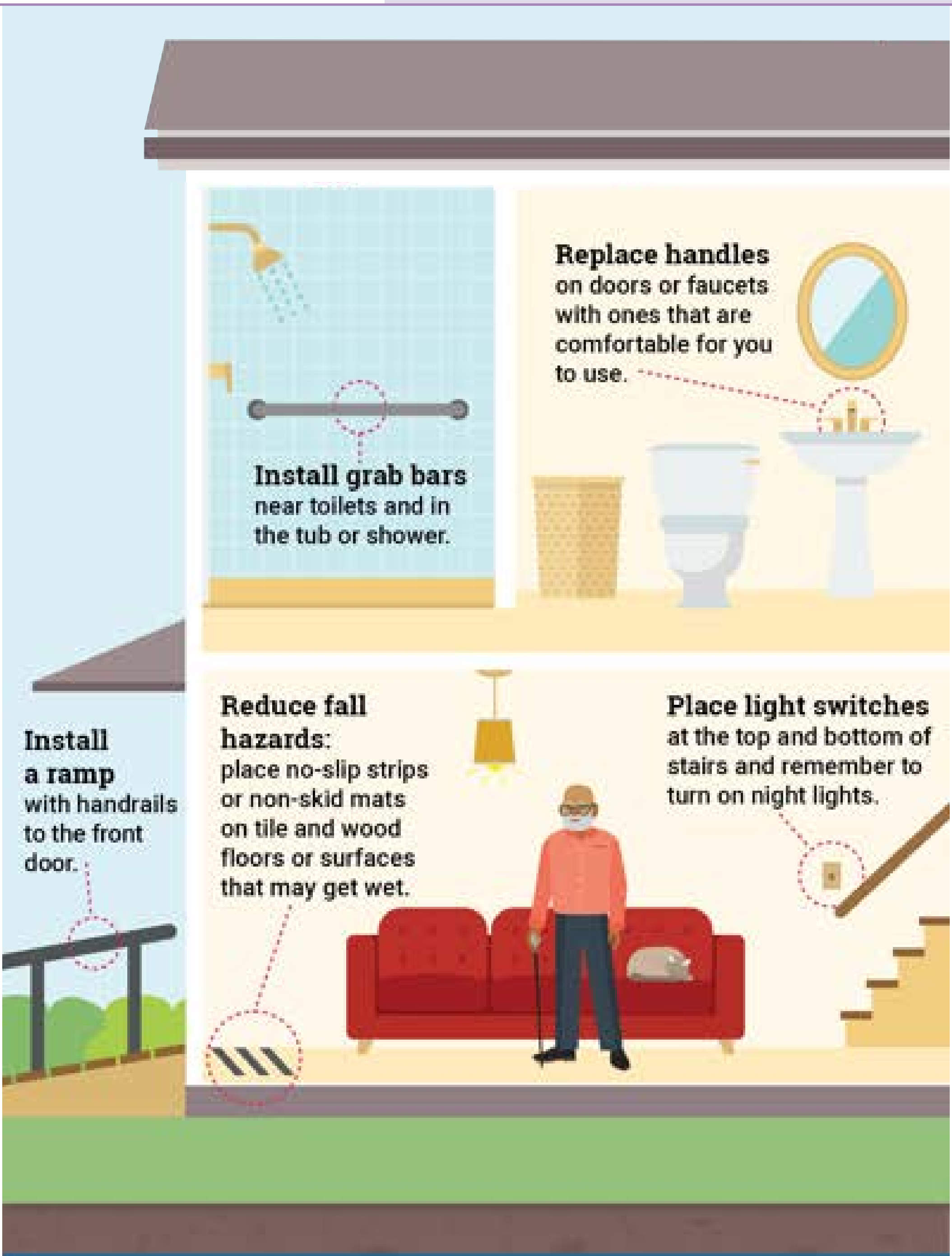
AGING IN PLACE[2]

TIPS ON MAKING HOME SAFE AND ACCESSIBLE

Many older adults want to "age in place" —stay in their own homes as they get older—but may have concerns about safety, getting around, or other daily activities.

A few changes could make your home easier and safer to live in and help you continue to live independently.

Don't use area rugs and check that all carpets are fixed firmly to the floor.



Install grab bars near toilets and in the tub or shower.

Replace handles on doors or faucets with ones that are comfortable for you to use.

Install a ramp with handrails to the front door.

Reduce fall hazards: place no-slip strips or non-skid mats on tile and wood floors or surfaces that may get wet.

Place light switches at the top and bottom of stairs and remember to turn on night lights.

For more information about aging in place, visit www.nia.nih.gov/aging-in-place.

NIH National Institute on Aging

Improving Accessibility to Help Maximize Independence[3]

Nightlights in dimly lit areas are especially helpful. Grab bars in the bathroom can help you balance on slippery surfaces. If bathroom grab bars aren't enough, a shower chair may help. Shoes or slippers with non-slip soles are better at preventing falls than socks or shoes with smooth soles. You, your support partners, and your healthcare team can help identify the approaches and tools that will work best in your situation. In some cases, you may not be able to significantly alter your physical environment to improve accessibility. However, there are still ways you can protect your physical health while living in your home:

- **Exercise:** As covered in Module Three—which focuses on brain health—physical activity has many benefits for your brain and body. Physical activity can increase your mood, improve your sleep, reduce the risk of chronic disease, help maintain balance and motor skills, and much more. Physical activity doesn't have to be intense or structured.

You can take a walk in your neighborhood, water your garden, or participate in your favorite recreational activity a couple of times a week. Depending on your ability, it may be beneficial to talk to a physical therapist, occupational therapist, or other providers to discuss safe physical activity options.

- **Mobility aids:**[4] Occupational and physical therapists can provide a mobility assessment to help you decide which mobility aids work best for you. Canes and walkers are commonly used mobility aids and are simple and often affordable. However, you may find canes and walkers aren’t a feasible option. Larger mobility aids like manual and power wheelchairs can be expensive but can make mobility possible if you need more support and safety. Check with Medicare and/or your insurance company to determine what costs may be covered by your plan.

- **Find new strengths:** As with many chronic diseases, living well with dementia may come with limitations due to your changing health needs. You may need to reexamine your personal strengths. Dementia can affect many aspects of your life, including home, work, driving, and your ability to schedule and plan.

Finding new strengths can be tricky, but it’s crucial to find strengths and strategies that align with what matters most to you. If you struggle with communication and love to talk to friends and family, you may communicate differently through tone, gestures, or creative arts. If one of your senses is impaired, try using other senses to experience the world. You may miss the sound of trees in the wind if your hearing is impaired. However, you may find new strengths and joys, such as smelling the woodsy scent of the forest and seeing the branches and leaves flowing with the breeze.

It can take creativity to identify and develop new strengths, but with determination you may discover a new normal.

Part of finding these new strengths and addressing limitations comes down to balancing safety and risk. Balancing risk isn't easy, but it's imperative to living well with dementia. Each person living with dementia has different wants, needs, and situations. The balance you create may not be the same as others.

As previously discussed, changes with dementia aren't always linear or consistent over time. Planning can help make these changes easier to navigate. A few common challenges have been expanded upon here:

- **Living independently:** Living independently may become challenging as your dementia progresses. It's important to prioritize safety in your home if aging in place, or what we like to think of as "aging in community," is a priority for you. The strategies mentioned earlier for improving accessibility in your home can help. However, you may need to adjust your sense of freedom to get extra support in your home. In addition to in-home supportive services, there are many devices available to make living independently possible. The devices include fall alert detectors, smoke and fire alarms, pill dispensers, accessible telephones and remotes, visible clocks, reminders, calendars, and more.

> ***If you find you can no longer live alone safely, it's important to discuss your options with your support partners and healthcare team.*** *Together, you can find the best option for you.*

If you find you can no longer live alone safely, it's important to discuss your options with your support partners and healthcare team. Together, you can find the best option for you.

- **Driving:**[5] It is true that living with dementia increases the risk of having an accident while driving. However, you aren't required to stop driving immediately. There are resources available through occupational therapists or your local Department of Motor Vehicles to assist you in determining your safety level while driving. Please note: in some states, healthcare providers are obligated to report to the Department of Motor Vehicles if it is believed the medical condition of an individual may affect their ability to drive. If possible, work with your support partners to determine an approach to driving that is safe and responsible. For example, consider asking someone you trust to provide you with monthly or weekly driving checks. These checks are

only helpful, however, if you accept the feedback provided. Losing the ability to drive can be difficult, as many individuals feel they are losing their independence. Planning for this possibility can make this transition easier and can provide you with a sense of control over this difficult decision.

- **Working:**[6] Just as in the cases of living independently and driving, a dementia-related diagnosis doesn't mean you have to stop working.

For many, work provides a sense of purpose and valuable connections in our lives. Staying engaged at work (or through volunteer work) can be a fantastic way to support your well-being. You may be able to work much longer with appropriate accommodations (which are required by the Americans with Disabilities Act). You may decide to retire early, take another job, or volunteer in your community. There are options available to provide you with opportunities to contribute and maintain your sense of purpose.

- **Wayfinding:**[7] For people living with more progressed dementia, navigation can become stressful. Once familiar places may be harder to find. Environmental cues, like a personalized sign outside your door, may help cue you to your home if you struggle with wayfinding.

> "Home is the nicest word there is."
> — **LAURA INGALLS WILDER**

Home Wayfinding Ideas

- ☐ Non-traditional front door color
- ☐ Unique mailbox
- ☐ Outdoor decor
- ☐ Favorite flower or plant
- ☐ Year-round wreath on front door
- ☐ Name-specific or one-of-a-kind welcome sign
- ☐ Flag displayed

Other ideas:

Putting environmental cues in place before they are needed will make them a normal part of your everyday life. Using environmental cues can help you remain independent for as long as possible. In addition, there are many navigation devices and technologies that can be helpful. These include location tracking devices, smartphone map applications, smartphone voice assistants, travel aids, and communications aids.

* * *

The Possibility of Living Well

No matter what, as you move through your life with dementia, you should always focus on the possibility of living well, even when it's hard. Researchers from the Murray Alzheimer Research and Education Program (MAREP), in partnership with people living with dementia, outline a set of **seven meaningful**

Staying connected to these meaningful experiences is what enables people who are living with dementia to live life to the fullest and celebrate each day.

Living and Celebrating Life through Leisure[8]

When people have opportunities to engage in the above meaningful experiences, they can ***live well*** *with dementia.*

experiences[9] (i.e., domains of well-being) that are essential components of living well with dementia:

1. **Being Me:** Opportunities for self expression and for simply being, including experiences that are personally meaningful and connected with current and/or past interests

2. **Being With:** Opportunities to be with other people, pets, and/or nature that foster a sense of connection and/or community
3. **Seeking Freedom:** Opportunities that provide a break from the norm; an escape from the stress of daily tasks and responsibilities; an escape from restrictive relationships and/or environments
4. **Finding Balance:** Opportunities to find or create a sense of balance between relaxation and keeping busy—too much or too little of either is not good
5. **Making a Difference:** Opportunities to fulfill a sense of purpose; to contribute and feel helpful and valued
6. **Growing and Developing:** Opportunities to grow and develop by challenging the mind and body, learning new things, and/or having novel experiences
7. **Having Fun:** Opportunities to feel pleasure, enjoyment, happiness, playfulness, and to share a sense of humor


NAVAJO CODE TALKER
WWII
5TH MARINE DIVISION

SUMMARY: MODULE SIX

Everyone has possibilities that lie ahead, no matter their diagnosis or the stigma surrounding that diagnosis. While dementia may require you to find your “new normal,” your “old normal” doesn’t need to be left behind, and you don’t need to change everything you do now that you have dementia. You will likely need to make some proactive adjustments and changes, but you may discover new interests and new ways to live well. Life is filled with possibilities, and so is your journey with dementia.

Notes

Key Message #1: As unbelievable as it might sound, some people living with dementia have referred to their dementia as a gift.

Discussion/Journal: What unexpected gifts can you envision receiving from your experience of living with dementia?

Key Message #2: As you strive to live well with dementia, you can look for ways to increasingly adapt to your "new normal."

Discussion/Journal: What are two changes or adjustments that might support you in living your best life with dementia?

1. ____

____

____

____

____

____

____

2. ____

____

____

____

____

____

____

____

Key Message #3: When people have opportunities to engage in meaningful experiences, they can live well with dementia.

The Possibility of Living Well: As this Guidebook has often stated, our relationships can help us to uphold our well-being. On the following pages are a few questions, based on MAREP's seven meaningful experiences, that you can answer and share with your support partners through writing or discussion. You can even start now and come back later to finish. Your answers will help guide your efforts to live well while strengthening your relationships with your support partners in the process.

1. Being Me

Complete the following sentence: I feel most like myself when…

____

____

____

____

What three things do I want my support partner(s) to know about me?

____

____

____

____

How can my support partner(s) help me maintain life according to my daily rhythms of waking, dressing, eating, leisure, sleep, and other activities?

____

____

____

____

____

2. Being With

Complete the following sentence: I share a special connection with…

(This connection could be with a particular person, place, pet, higher power, or something else.)

How can my support partner(s) help me maintain the connections that matter to me?

3. Seeking Freedom

What are three freedoms or choices that are important to me?

What is one change or improvement my support partner(s) can make to better support my freedom to choose and freedom to move?

4. Finding Balance

What helps me foster a sense of balance?

What is one thing my support partner(s) and I might try to better support my sense of balance across the span of a day?

What can I do to help my support partner(s) relax?

5. Making a Difference

What gives me a sense of meaning or purpose?

What do my support partner(s) and I appreciate and value about each other? How do we express or show our appreciation?

How can my support partner(s) and I incorporate opportunities for purpose into the physical environment and my daily routine?

6. Growing and Developing

Thinking back, what is one way that I have grown?

Imagining three years into the future, what is one way I would like to grow between now and then?

What are the essential things I need in order to grow and develop?

What is one thing my support partner(s) can do to support me in continuing to grow and develop?

7. Having Fun

What is one of my most joyful memories?

What things give me a deep sense of joy and fulfillment, even during hard times?

What simple pleasures provide me with a sense of joy? How can my support partner(s) help to ensure these simple pleasures are available every day?

REFERENCES: MODULE SIX

Leisure: the celebration of freedom, *page 211*

1. From the article “Therapeutic recreations and the end of leisure” by Sylvester

Aging in place, *pages 214–217*

2. “Aging in Place: Tips on Making Home Safe and Accessible” on *NIH: National Institute on Aging* website: nia.nih.gov

Fall prevention, *page 218*

3. “Improving Accessibility to Help Maximize Independence” modified from iStock graphic 1267691328.eps

Mobility Aids, *page 220*

4. “Expert Advice: How to Choose a Mobility Aid for a Senior” on *AgingCare* website: agingcare.com

Driving, *page 224*

5. “Dementia and Driving” on *Alzheimer’s Association* website: alz.org

Working, *page 225*

6. “Living with dementia series, Employment” online PDF on *Alzheimer’s Society* website: alzheimers.org.uk

Wayfinding, *page 226*

7. From the article “Creating a Supportive Environment using Cues for Wayfinding in Dementia” by Davis and Weisbeck on *National Library of Medicine* website: ncbi.nlm.nih.gov

Living and Celebrating Life through Leisure, *page 229*

8. From the article "Just dance with me: an authentic partnership approach to understanding leisure in the dementia context" by Dupuis, Whyte, Carson, Genoe, Meshino, and Sadler

Seven meaningful experiences, *page 229*

9. From the article "Just dance with me: an authentic partnership approach to understanding leisure in the dementia context" by Dupuis, Whyte, Carson, Genoe, Meshino, and Sadler

Additional Reflections and Notes

Connections

RESOURCES

Sharing Your Story

These six Guidebook modules focus on strategies to help you live well with dementia. Hopefully you are feeling empowered and ready to embark on your journey with dementia. You are not alone and have a lot of meaningful life ahead of you. Just as this Guidebook has—hopefully—been a positive influence on you, you can be a positive influence on others. “How?” you might ask. The answer is simple: by sharing your story!

It can be daunting to share your personal story with others. However, the beneficial impact of this modest act on the well-being of others living with dementia should not be underestimated. By sharing your story, you can help spread the word that it is possible to live well with dementia, and it’s being done, right here, right now, by you!

There's a term coined by activist living with dementia Kate Swaffer that describes what unfortunately happens far too often to people who receive a dementia-related diagnosis: "prescribed disengagement.™ "[1] This term describes the misconception that people living with dementia should give up the life they knew prior to their dementia-related diagnosis. This misconception can push people living with dementia to the edges of society, where they are left to internalize the story too often told: they can't continue to do the things they love, be with the people they love in the places they love, or actively contribute to their communities.

Even if a person living with dementia never hears this directly, the ways people act toward them communicate the message loud and clear. With dementia, you must disengage, or so we are told.

After engaging with this Guidebook for six modules, it should be abundantly clear this way of thinking about life with dementia is utterly false. Not only can people living with dementia contribute to society, but they do so every day. Just look at the advisors who helped develop this Guidebook! It would be a great disservice if we deprive our world of the wisdom and gifts held by people living with dementia.

This is why it is important that you help to break down the barriers that result in the disengagement of people living with dementia. It is only through the stories of people living with dementia—people like you—that we can ever hope to change the story about what living with dementia really means. Each of the advisors living with dementia who helped to write this Guidebook is a proud dementia self-advocate. Here's what some have to say about their experience sharing their stories:

Sam Simon: I remember the doctor's appointment as if watching a scene in a movie. The neurologist looked down at the test results, then mumbled, "early-stage Alzheimer's." The first thing I did when Susan, my wife, and I got home was to start telling people. First, it was our kids, my siblings, and then the clergy at our synagogue. Then anyone, if not everyone, I was dealing with, not for pity, instead for understanding. I was NOT going away; they just needed to be patient and aware. As I learned more about the likely arc of my unique situation – it is always unique – I realized that it could be 5 to 10 years. It did not take long for my phone to ring. "Sam, my husband has been diagnosed, he won't talk about it. You are so open, why?" or "Sam, I need to talk, I just got diagnosed with Alzheimer's and I'm devastated." And we talked. Sharing our story helps us. I love that I can be of help, and it helps others. And there is no shame in this disease, and I walk this path with love and pride.

Yvonne Sweeten: I have benefited from sharing my dementia story by becoming more comfortable and forthright. I have also become close to my circle of friends in Dementia Conversations because I've learned their stories. Finally, I have learned so much about dementia by researching it online. All in all, I have benefited by becoming extremely hopeful about a cure and/or better treatments.

Jim Loane: By working on this project, my eyes have been opened to all of the information about dementia that I didn't know before. I was diagnosed with Lewy body dementia 8 years ago and I learned so much more about myself, my disease, and my future. Initially, I was living with this diagnosis but felt I didn't know enough about it to be comfortable sharing with others. Now I volunteer at an adult day center, I discuss dementia openly with others, Linda (my wife and caregiver) and I have done interviews for local television on the topic, and I feel more confident in my knowledge and understanding of what I'm going through.

You, too, can become a dementia self-advocate. It doesn't require any special training or any experience that you don't already possess. Plus, there's no single right way to share your story; you could write a letter, call a friend, sing a song, paint a picture, or creatively express yourself in whatever way feels right to you.

Do you want to be a part of positive change for people living with dementia? Do you want to help others like you live fulfilling, meaningful lives?

If you answered yes, then we want to help you do just that. Whether you're interested in telling your story to the whole world, or just with your closest friends and family, the DEER Program would be honored to support you in sharing your lived experience. Let's have a conversation about what it might look like for you to share your dementia story! You can reach us at **deerprogram@unr.edu**.

Resources in San Diego County

Aging & Independence Services (AIS) is part of the County of San Diego Health and Human Services Agency. AIS offers free programs to help you stay healthy, safe, and engaged. The **AIS Call Center** can connect you to these programs and provide information and assistance about other community resources.

To learn more, call the AIS Call Center at 1-800-339-4661 or visit *aging. sandiegocounty.gov.*

AIS Call Center services include:

- *Meals and dining programs*
- *Help at home and personal care*
- *Fall prevention resources*
- *Free health and wellness programs*
- *Transportation*
- *Legal advice and support*
- *Planning for your care*
- *Adult Protective Services*
- *Referrals to other helpful organizations*

Stay Informed

Staying informed after a dementia diagnosis is important for managing the condition and improving quality of life. The organizations below offer classes, events, and support groups for people living with dementia and their care partners.

Alzheimer's Association
San Diego/Imperial Chapter
619-678-8322
alz.org/sandiego

Alzheimer's San Diego
858-492-4400
alzsd.org

Stay Connected

Staying socially connected can help people living with dementia maintain their overall well-being and cognitive function. The organizations below provide meaningful activities, opportunities for connection, and community programs that can help combat feelings of isolation and loneliness.

George G. Glenner Alzheimer's Family Centers, Inc.
619-543-4700
glenner.org

Jewish Family Service of San Diego
858-637-3210
jfssd.org

ElderHelp of San Diego
619-284-9281
elderhelpofsandiego.org

Help with Legal Planning

Legal, financial, and advance care planning before the onset of dementia, or in the early stages, allows individuals to make informed decisions about their future care and treatment. The organizations below can help you manage your affairs and ensure that your wishes are met:

Elder Law & Advocacy
858-565-1392
elaca.org

Legal Aid Society of San Diego
877-534-2524
lassd.org

Research and Clinical Trials

Research, including clinical trials, can lead to earlier and more accurate diagnoses and improved treatments and care. The UCSD Shiley-Marcos Alzheimer's Disease Research Center conducts research studies dedicated to understanding the causes, clinical features, and treatments for Alzheimer's disease and related memory disorders. To learn more about current research opportunities or to participate in a study, visit *adrc.ucsd.edu.*

Help for Care Partners

Care partners provide the best quality and most consistent care when they feel healthy, informed, and supported. The organizations listed below provide valuable programs and services designed to assist care partners, including friends and family, in their role.

Southern Caregiver
Resource Center
858-268-4432
caregivercenter.org

Caregiver Coalition of
San Diego
caregivercoalitionsd.org

* * *

Resources from the 2022 Advisory Team

Advisor: Chuck McClatchey

- Dementia Mentors. *Dementia Mentors.* dementiamentors.org/home.html
- DEER Program. *Dementia Conversations.* deerprogram.org/dementia-conversations/

Advisor: Jim Loane

- Cleveland Clinic. *Lou Ruvo Center for Brain Health.* my.clevelandclinic.org/departments/neurological/depts/brain-health

Advisor: Yvonne Sweeten

- Huntington's Disease Society of America. hdsa.org/
- Help 4 HD International. help4hd.org/
- HD-COPE (coalition for patient engagement). hdsa.org/hd-research/hd-cope/
- HD-Reach. hdreach.org

- HSG (Huntington Study Group). huntingtonstudygroup.org
- HD-Buzz. en.hdbuzz.net

Advisor: Sam Simon

- Alzheimers.gov
- Reimagining Dementia: A Creative Coalition for Justice. reimaginingdementia.com
- Being Patient. beingpatient.com

Advisor: Barbara Stockton

- Carpenter, K. S. (2017). *Healing Dementia* (2nd ed.). CreateSpace Independent Publishing Platform.

Advisor: Nancy Nelson

- *dangle & dot*. dangledot.com

REFERENCES: CONNECTIONS

Prescribed Disengagement™, *page 249*

1. From the article “Dementia and Prescribed Disengagement™” by Swaffer

Additional Reflections and Notes

Citations

PREFACE

Dementia Conversations Letter

Dementia Friendly Nevada. (n.d.). *Welcome to Dementia Friendly Nevada.* https://dementiafriendlynevada.org/

INTRODUCTION

The Senses Framework

Ryan, T., Nolan, M., Reid, D., & Enderby, P. (2008). Using the senses framework to achieve relationship-centred dementia care services: A case example. *Dementia, 7*(1), 71-93. https://doi.org/10.1177/1471301207085368

Six Pillars of Brain Health

Cleveland Clinic. (n.d.). *Six pillars of brain health.* Healthy Brains. https://healthybrains.org/pillars/

MODULE ONE

What is Dementia?

National Institute on Aging. (n.d.). *Understanding different types of dementia.* National Institute on Aging. https://www.nia.nih.gov/health/infographics/understanding-different-types-dementia

U.S. Department of Health and Human Services. (n.d.). *What is Alzheimer's disease?* Alzheimers.gov. https://www.alzheimers.gov/alzheimers-dementias/alzheimers-disease

Alzheimer's Association. (n.d.). *What is Alzheimer's disease?* https://www.alz.org/alzheimers-dementia/what-is-alzheimers

U.S. Department of Health and Human Services. (n.d.). *What is vascular dementia?* Alzheimers.gov. https://www.alzheimers.gov/alzheimers-dementias/vascular-dementia

Alzheimer's Association. (n.d.). *Vascular dementia.* https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/vascular-dementia

U.S. Department of Health and Human Services. (n.d.). *What is Lewy body dementia?* Alzheimers.gov. https://www.alzheimers.gov/alzheimers-dementias/lewy-body-dementia

Alzheimer's Association. (n.d.). *Dementia with Lewy bodies.* https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/dementia-with-lewy-bodies

U.S. Department of Health and Human Services. (n.d.). *What is frontotemporal dementia?* Alzheimers.gov. https://www.alzheimers.gov/alzheimers-dementias/frontotemporal-dementia

Alzheimer's Association. (n.d.). *Frontotemporal dementia.* https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/frontotemporal-dementia

Alzheimer's Association. (n.d.). *What is dementia?* https://www.alz.org/alzheimers-dementia/what-is-dementia

Huntington's Disease Society of America. (n.d.). *Overview of Huntington's disease.* https://hdsa.org/what-is-hd/overview-of-huntingtons-disease/

U.S. Department of Health and Human Services. (n.d.). *What is mild cognitive impairment?* Alzheimers.gov. https://www.alzheimers.gov/alzheimers-dementias/mild-cognitive-impairment

Alzheimer's Association. (n.d.). *Mild cognitive impairment (MCI).* https://www.alz.org/alzheimers-dementia/what-is-dementia/related_conditions/mild-cognitive-impairment

Alzheimer's Association. (2025). *2025 Alzheimer's disease facts and figures.* https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf

MODULE TWO

Prescription Medications

American Geriatrics Society. (2019, January 31). *For older people, medications are common; Updated AGS Beers® Criteria aims to make sure they're appropriate, too.* https://www.americangeriatrics.org/media-center/news/older-people-medications-are-common-updated-ags-beers-criteriar-aims-make-sure

National Institute on Aging. (2021, July 8). *How is Alzheimer's disease treated?* National Institute on Aging. https://www.nia.nih.gov/health/how-alzheimers-disease-treated

MODULE THREE

Six Pillars of Brain Health

Cleveland Clinic. (n.d.). *Six pillars of brain health.* Healthy Brains. https://healthybrains.org/pillars/

Get Moving

Centers for Disease Control and Prevention. (2021, July 29). *Physical activity for different groups.* https://www.cdc.gov/physicalactivity/basics/age-chart.html

Centers for Disease Control and Prevention. (2022, June 2). *Adults*. https://www.cdc.gov/physicalactivity/basics/adults/index.htm

Eat Smart

Johns Hopkins Medicine. (n.d.). *Take your diet to the Mediterranean.* https://www.hopkinsmedicine.org/health/wellness-and-prevention/take-your-diet-to-the-mediterranean

U.S. Food and Drug Administration. (2022, February 25). *How to understand and use the Nutrition Facts label.* https://www.fda.gov/food/new-nutrition-facts-label/how-understand-and-use-nutrition-facts-label

Rest Well

American Academy of Sleep Medicine. (n.d.). *Healthy sleep habits.* Sleep Education. https://sleepeducation.org/healthy-sleep/healthy-sleep-habits/

Keep Sharp

Dementia Australia. (2020). *Mental exercise and dementia.* https://www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-DementiaQandA06-MentalExercise_english.pdf

MODULE FOUR

Managing Uncertainty

Bennell, J., & Taylor, C. (2013). A loss of social eating: The experience of individuals living with gastroparesis. *Journal of Clinical Nursing, 22*(19-20), 2812-2821. https://doi.org/10.1111/jocn.12196

Kurita, K., Garon, E. B., Stanton, A. L., & Meyerowitz, B. E. (2012) Uncertainty and psychological adjustment in patients living with lung cancer. *Psycho-Oncology, 22*(6), 1396-1401. https://doi.org/10.1002/pon.3155

Brown, A., Hayden, S., Klingman, K., & Hussey, L. C. (2020). Managing uncertainty in chronic illness from patient perspectives. *Journal of Excellence in Nursing and Healthcare Practice, 2*(1), 1-16. https://doi.org/10.5590/JENHP.2020.2.1.01

Identifying and Confronting Change and Loss

American Psychological Association. (2013). *Coping with a diagnosis of chronic illness.* https://www.apa.org/topics/chronic-illness/coping-diagnosis

Blandin, K., & Pepin, R. (2015). Dementia grief: A theoretical model of a unique grief experience. *Dementia, 16*(1), 67-78. https://doi.org/10.1177%2F1471301215581081

Callebaut, L., Molyneux, P., & Alexander, T. (2016). The relationship between self-blame for the onset of a chronic physical health condition and emotional distress: A systematic literature review. *Clinical Psychology & Psychotherapy, 24*(4), 965-986. https://doi.org/10.1002/cpp.2061

American Psychological Association. (2020, January 1). *Grief: Coping with the loss of your loved one.* https://www.apa.org/topics/families/grief

Bjørkløf, G. H., Helvik, A. -S., Ibsen, T. L., Telenius, E. W., Grov, E. K., & Eriksen, S. (2019). Balancing the struggle to live with dementia: A systematic meta-synthesis of coping. *BMC Geriatrics, 19*, Article 295. https://doi.org/10.1186/s12877-019-1306-9

MODULE FIVE

Clarifying and Re-Establishing Roles

Dupuis, S. L., Whyte, C., Carson, J., Genoe, R., Meshino, L., & Sadler, L. (2012). Just dance with me: An authentic partnership approach to understanding leisure in the dementia context. *World Leisure Journal, 54*(3), 250-254. https://doi.org/10.1080/04419057.2012.702454

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

Bartlett, R., & O’Connor, D. (2010). *Broadening the dementia debate: Towards social citizenship.* Policy Press.

MODULE SIX

Adapting to the “New Normal”

Sylvester, C. (1987). Therapeutic recreations and the end of leisure. *Philosophy of Therapeutic Recreation, 1*, 76-89.

Planning for Daily Life and Healthcare

National Institute on Aging. (n.d.). *Aging in place: Tips on making home safe and accessible.* National Institute on Aging. https://www.nia.nih.gov/sites/default/files/aging-in-place-infographic-508.pdf

Bursack, C. B. (2022, May 13). *Expert advice: How to choose a mobility aid for a senior.* AgingCare. https://www.agingcare.com/articles/expert-advice-how-to-choose-a-mobility-aid-190138.htm

Alzheimer's Association. (n.d.). *Dementia and driving.* https://www.alz.org/help-support/caregiving/safety/dementia-driving

Alzheimer's Society. (2020). *Employment: Living with dementia series.* https://www.alzheimers.org.uk/sites/default/files/2018-10/Employment.pdf

Davis, R., & Weisbeck, C. (2016). Creating a supportive environment using cues for wayfinding in dementia. *Journal of Gerontological Nursing, 42*(3), 36-44. https://doi.org/10.3928/00989134-20160212-07

Dupuis, S. L., Whyte, C., Carson, J., Genoe, R., Meshino, L., & Sadler, L. (2012). Just dance with me: An authentic partnership approach to understanding leisure in the dementia context. *World Leisure Journal, 54*(3), 240-254. https://doi.org/10.1080/04419057.2012.702454

CONNECTIONS

Sharing Your Story

Swaffer, K. (2014). Dementia and Prescribed Disengagement™. *Dementia, 14*(1). https://doi.org/10.1177%2F1471301214548136

Advisor Resources

Dementia Mentors. (n.d.) *Dementia Mentors.* https://www.dementiamentors.org/home.html

DEER Program. (n.d.). *Dementia Conversations.* https://DEERprogram.org/dementia-conversations

Cleveland Clinic. (n.d.). *Lou Ruvo Center for Brain Health.* https://my.clevelandclinic.org/departments/neurological/depts/brain-health

Huntington's Disease Society of America. (n.d.). [Home]. https://hdsa.org/

Help 4 HD International. (n.d.). [Home]. https://www.help4hd.org/

Georgetown: Memory Disorders Program. (n.d.). *The Georgetown University Memory Disorders Program.* https://memory.georgetown.edu/

Carpenter, K. S. (2017). *Healing Dementia* (2nd ed.). CreateSpace Independent Publishing Platform.

dangle & dot. (n.d.). *dangle & dot.* https://dangledot.com/

This work is funded in part by the United States Centers for Disease Control and Prevention (CDC) Preventive Health and Health Services Block Grant #1NB01OT009412-01-00.

This work is funded in part by the United States Centers for Disease Control and Prevention (CDC) National State-Based Tobacco Control Programs Grant #1U58DP006009-01.

This work is funded in part by the United States Centers for Disease Control and Prevention (CDC) BOLD Infrastructure for Alzheimer's Act Grant NU58DP006924-01-00.

If you have been diagnosed with a dementia-related condition, then it is important to know: **you can live well with dementia.** This *Dementia Self-Management Guidebook*, based on the science of chronic disease self-management, was developed in partnership with six advisors who are living well with dementia. Specifically designed and formatted for people who are living with dementia, each module provides current information and aims to assist you in developing personalized strategies to live your best life. This Guidebook will also introduce you to helpful community resources recommended by our advisors to aid you in managing and adjusting to life after a diagnosis.

DEER
The Dementia Engagement, Education, and Research Program
School of Public Health