

UW Medicine

# Living with Memory Loss

*A basic guide*



*First Edition, January 2017*

***“You go through the grief process and then you start living. Yes, there’s life after diagnosis.”***

*~ Myriam, living with dementia*



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UW Medicine

## Welcome

*From Dr. Tom Grabowski, Director of UW Medicine  
Memory and Brain Wellness Center*

Dear friends,

Welcome to the UW Medicine Memory and Brain Wellness Center. Our mission is to promote the well-being of people living with memory loss and their families.

Our care team in the memory clinic is made up of experts in memory and brain health. We aim to provide outstanding care for you, every step of the way.

We have created this handbook as a resource for your life after your diagnosis. It contains information and insights from our team members, community partners, and others living with memory loss and their family members and friends.

We hope that this handbook informs, encourages, and empowers you for your journey ahead. We welcome your ideas and feedback on this handbook as we work to make it even more helpful.

Sincerely,



Dr. Tom Grabowski  
Director, UW Medicine Memory and  
Brain Wellness Center



*Dr. Tom Grabowski*



UW Medicine

## The Memory Loss Journey

*A brief introduction*

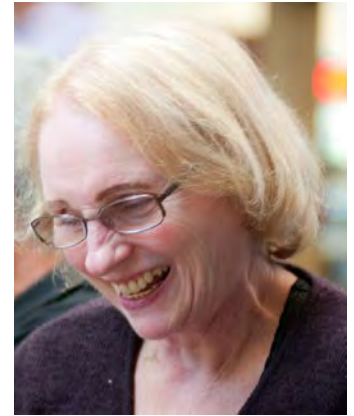
*From Alice, living with dementia:*

**“After hearing the news, I just felt totally lost. But you know what, I have a good life. That sounds crazy, but I do!**

**“I get out, and I have fun, and I don’t worry about Alzheimer’s. Because if you can’t fix it, then you have to find a way to live with it.**

**“I’ve got a group of people who love me, and who stand by me, and that is what life is supposed to be.**

**“I just want all the happiness I can have, and that’s what I go for.”**



*Photo by Rachel Turner,  
Alzheimer’s Association*



*From Vivian, a care partner:*

**“When my husband was diagnosed with Alzheimer’s, I didn’t have much information. The disease wasn’t in our family, so I was starting from scratch.**

**“Knowing that there’s a community out there to draw on was very important.”**



*A family meeting at the  
Memory and Brain Wellness  
Center*

## A Few Key Points

As you begin this journey, we offer a few key points about living with memory loss:

- **You are not defined by your disease.** You have people who love you, things you like to do, and gifts to offer.
- **Living with memory loss is not easy, but there are ways to cope with it.** Healthy habits can help you feel better and think more clearly. You have time to adapt. You can find ways to keep enjoying life.
- **You do not have to walk this path alone.** Your family, friends, and the MBWC team are with you as you move forward. People and programs are available in the community to help support you.

## A Letter from The Gathering Place

We would like to share a letter written to you by members of The Gathering Place. The Gathering Place is an early-stage memory loss enrichment program at Greenwood Senior Center in Seattle, Washington.

This group spent many months thinking about what they most want to tell others who are newly diagnosed with memory loss or dementia. Here is their heartfelt message:



*Members of The Gathering Place*

Dear friend,

We are a community of people living successfully with memory loss. We understand that you also have received a diagnosis of memory loss. We want to recognize your courage in finding out what is going on. It is normal to feel disbelief, anger, fear, and denial, but know that you are not alone.

Our hearts go out to you.

You may want to hide your diagnosis. Many of us did, too. But we have found that sharing what we are living with lightens the load. It also allows us to lessen the stigma around memory loss. We urge you not to hide. Connect with others who are living with memory loss, and encourage your family to get support. Acceptance is important. We are all in this together.

We have learned to live with our memory loss and still have productive lives with family and friends. We would like to give you hope that you too can live a full life. There will be obstacles to come, but you have an opportunity to give back to your community and yourself, and to experience beauty, happiness, and kindness.

Sincerely,

Walt, Mark, Bob, Sarah, Roger, Ron, Helene, Rick, and Midge

[illegible]

Your questions are important. Talk with your doctor or healthcare provider if you have questions or concerns.

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## My Diagnosis

*What is going on, and what does it mean for my life?*

*From Philip, living with dementia:*

**“The process leading up to being diagnosed took place over a period of years.**

**“My two children noticed the changes long before I did. Certainly, I was aware that I was being very generous with my life savings, thinking that treating myself to new clothes (buying up to 10 shirts at a time, for example), pledging funds to charitable organizations, and often taking my friends out to dinner, was just what people who were comfortably retired were supposed to do. But, my children were concerned and initiated my move to Seattle in 2015. There, I received my official diagnosis: ‘early Alzheimer’s.’”**



*From Katie, Philip's daughter:*

**“I was not completely shocked at the diagnosis. By the time we received the news that my dad had Alzheimer’s, I had already spent a little over a year researching what could be going on with him based on the symptoms I was seeing. I wasn’t surprised, but I still cried when we got the news.”**

In this chapter of your handbook, you will read a brief overview of memory loss and dementia. You will also find some worksheets to help you reflect on your own experience. Lastly, you can read a more detailed section about your diagnosis and what it might mean for your life.

### ***Key Points in This Chapter***

- *Conditions called “mild cognitive impairment” and “dementia” refer to changes in memory and thinking that are greater than are expected for a person’s age.*
- *Many types of brain disease can cause these conditions.*
- *If you have mild cognitive impairment or dementia, you can still live a meaningful life. Many parts of your brain will stay healthy. You will keep many of your abilities and strengths.*

## **What happens with memory as we age?**

Some types of memory and thinking stay stable or even improve with age, such as knowledge, wisdom, and long-term memory. Other types of memory and thinking can decline with age, such as short-term memory and the ability to do more than 1 task at a time.

The aging process is different for each person. But, it is common to have a harder time recalling names, thinking things through, or remembering details of events.

## **What is mild cognitive impairment?**

With mild cognitive impairment (MCI), a person has more memory and thinking changes than are expected for their age, but these changes do not interfere with their daily life. Someone living with mild cognitive impairment may still work, drive, do chores, and enjoy hobbies. These activities may just feel more challenging or take longer than they used to.

## What is dementia?

With dementia, a person has memory and thinking changes that interfere with daily life. These areas may be affected:

- Remembering things that happened recently
- Planning, problem-solving, and decision-making
- Knowing today's date or the time
- Finding their way in familiar places
- Doing tasks such as cooking, driving, and paying bills
- Communicating with others

Symptoms may differ from person to person. They often depend on the underlying cause of the dementia.

## What causes MCI or dementia?

Many things can cause changes in memory and thinking. Some of these are depression, a lack of some vitamins and minerals, and head injuries. But if these causes are ruled out or treated, and symptoms keep getting worse, the cause is likely a disease that slowly causes damage to brain cells. This is called a *neurodegenerative* disease.

There are 4 common types of neurodegenerative disease:

- **Alzheimer disease** (AD) is the most common cause of dementia. It results from the buildup of protein deposits (plaque) in the brain. The part of the brain that helps you form new memories is affected first.
- **Lewy body dementia** (LBD) occurs when protein deposits called *Lewy bodies* build up in areas of the brain. Symptoms include changes in movement, memory, and thinking. There are 2 types:
  - Dementia with Lewy bodies
  - Parkinson disease dementia

- **Vascular dementia** occurs when small blood vessels in the brain are damaged or when a stroke affects the brain.
- **Frontotemporal dementia** (FTD) can occur when there is damage to cells in certain sections of the brain. These sections are called the *frontal lobe* and *temporal lobe*. Symptoms can involve changes in personality, language, and social behavior. There may be less effect on memory.

Sometimes, more than one problem causes changes in memory and thinking. This is called *mixed dementia*. For example, someone could have protein buildup linked with Alzheimer disease and blood vessel problems that lead to vascular dementia. Or, someone could have the protein buildup of Alzheimer disease and also have Lewy bodies.

## What is a diagnosis?

Your doctor provides you with a *diagnosis* after examining you. Your diagnosis includes:

- A **description of your symptoms**, such as mild cognitive impairment or dementia
- The **name of the disease that causes the symptoms**, such as Alzheimer disease

Having a diagnosis helps you know what to expect going forward. It will also guide your treatment.

A diagnosis can change over time, as we learn more about your condition. You can ask your doctor or nurse practitioner how confident they are in your diagnosis and if they think it could change.

## Worksheet 1: My Questions Answered

It is natural to have many questions after receiving a diagnosis of memory loss. Take a moment to write down your questions on the lines below. Your doctor, this handbook, or others living with memory loss may be able to answer some of your questions. Other questions may not have an easy answer. But we encourage you to ask any questions you have.

[illegible]

Symptoms of memory loss and dementia are unique for each person. Some may struggle with finding the right word, while others may have a hard time finding their way around their neighborhood or keeping track of time.

You may want to use this page to talk with your family or doctor. You can also use it to think about ways to work with your own strengths and weaknesses.

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and extend across the width of the page. There are no margins, text, or other markings on the paper.

## My Diagnosis – Learning More

The rest of this chapter gives more details about different diagnoses. There is also a special section for people who are diagnosed with dementia at age 65 or younger. This is called “younger-onset dementia.”

You do not need to read all of the sections. Choose the ones that apply to you. If you have questions, ask your doctor.

The sections are:

|                                         |           |
|-----------------------------------------|-----------|
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| <b>Alzheimer Disease.....</b>           | <b>11</b> |
| <b>Lewy Body Dementia .....</b>         | <b>15</b> |
| <b>Frontotemporal Degeneration.....</b> | <b>20</b> |
| <b>Vascular Dementia.....</b>           | <b>24</b> |
| <b>Younger-onset Dementia.....</b>      | <b>28</b> |





From Sarah, living with mild cognitive impairment:

**“You have to develop some strength in yourself to feel like you’re going to live the best you can.**

**I work harder at doing basic things so that I can maintain as much independence as possible. And I get a little more creative as far as getting through life.”**

## Mild Cognitive Impairment

### What is mild cognitive impairment?

Mild cognitive impairment (MCI) means that you have changes in memory and thinking that are more than are expected for your age, but that do not interfere with your ability to do daily activities. MCI is also called *minor neurocognitive disorder*.

### What causes mild cognitive impairment?

Some of the causes of MCI include:

- Anxiety, depression, or other mood disorders
- Hormone levels that are out of balance
- A lack of important nutrients in your diet
- Bad reactions to certain medicines
- Diseases that damage brain cells, such as Alzheimer disease, Lewy body disease, or frontotemporal dementia

### What are common symptoms?

You may notice the most changes in your memory. This is called *amnesic* MCI. Amnesic means not being able to remember.

But, sometimes MCI causes changes in your thinking ability, such as difficulty with attention, decision-making, communication, or finding your way around. If you have these types of problems and your memory is good, this condition is called nonamnesic MCI. If many areas of your memory or thinking are affected, it is called *multidomain* MCI.

### Will my symptoms change over time?

Depending on the cause of your MCI, your memory and thinking may improve, stay the same, or get worse. Each year, about 10% of people with MCI (about 10 out of 100 people) find that their memory and thinking problems get worse. If these problems start to interfere with their daily life, their diagnosis changes from MCI to dementia.

## **What kinds of treatments or lifestyle changes might help?**

Some of the underlying causes of MCI might be treated with medicines or diet changes. For example, these treatments might be used if the cause is depression or a lack of certain nutrients. If the cause can be treated, your MCI may clear up over time.

If we think a *neurodegenerative* disease is the main cause of your MCI, we recommend healthy habits that may prevent or delay changes in memory and thinking. These include:

- Getting regular exercise
- Staying connected with family and friends
- Keeping your mind active
- Eating a healthy diet
- Reducing stress
- Sleeping well

See chapter 5 of this handbook, “My Daily Life,” to learn more.

## **How might MCI affect my life?**

You are not defined by your diagnosis. You still have people who care about you, things you like to do, and gifts to offer. You will likely be able to do most of your daily tasks without too much trouble. It may just take longer to complete things, or be a little harder to think things through. You may need to find new ways to stay organized, give yourself more time to finish tasks, or adapt some tasks so that you can do them more easily.

MCI does not affect all aspects of your memory and thinking. Even if it is hard to remember what you read or hear, you can often train yourself to learn new things through habit – by repeating an action many times. The parts of the brain that help you keep your balance, use your hands, use your senses, respond to others’ emotions, and even be creative, are also parts that still work well.

As you adapt and use your coping strategies, you can stay connected to the people and activities that bring you joy and meaning.

**Where can I find more information and resources on living well with MCI?**

Living with MCI may not be easy, but you are not alone. Others are on this journey, and there are people and programs in the community that can help. The list below will help you find some of these programs.

To discover more about living well with MCI, read other chapters of this handbook that interest you. Learn about more resources in chapter 9, “My Community.”

**Alzheimer’s Association**

*www.alzwa.org*

24-hour support line: 800.272.3900

Information and support for people living with MCI or any form of dementia and their families.

**Community Programs**

*www.momentiasseattle.org*

Arts, social, recreation, and community service opportunities for people living with MCI or dementia.

From Alice, living with Alzheimer disease:

**“Live your life as you always have.**

**Alzheimer’s disease isn’t going to get me down. What you have to do is live your life – live your life and enjoy it.”**



Alice and her husband, Paul

## Alzheimer Disease

Alzheimer disease (AD) is the most common cause of dementia. In AD, the brain cells that support memory and thinking begin to fail.

When we talk about “Alzheimer disease,” we are talking about both:

- The brain changes that cause the disease (called *amyloid plaques* and *neurofibrillary tangles*)
- The memory loss and thinking problems these brain changes cause

### What causes Alzheimer disease?

In AD, a protein called *amyloid beta* builds up between brain cells. Another abnormal protein, called *tau*, also builds up inside brain cells and causes damage. We do not know exactly what triggers these protein changes.

We do know that AD occurs more often in older people. It affects around 1% of people (1 out of 100 people) at age 65 and up to 30% (30 out of 100 people) at age 85.

A small number of people have a *genetic* (inherited) form of AD. For these people, disease symptoms can start when they are in their 40s or 50s.

But most times, AD is not caused by a single gene. Many factors could be involved. Scientists are studying the causes of the disease. We still have a lot to learn about it.

### What are common symptoms of AD, and how do these change over time?

Alzheimer disease is *progressive*. This means that over time, it will affect more of your memory and thinking.

The first symptoms of AD are subtle. They usually include having problems remembering things that just happened or that you just learned. Your loved ones may say that you are repeating the same question you just asked, even if it was already answered.

Later on, you may notice other changes. You might have a hard time making decisions, planning, problem-solving, communicating, or finding your way around. These symptoms vary from person to person.

AD symptoms usually develop slowly. If you are in the early stages of the disease, it may take 12 months to see clear changes in your memory and thinking. Your change in symptoms depends on how quickly your disease is progressing. These changes will usually continue at the same rate that you have already noticed.

### **What are the stages of Alzheimer disease?**

It's natural to wonder where you are in the process. The Memory and Brain Wellness Center defines the stages of dementia based on the amount of support needed in daily life:

- **Early stage:** A person may need support with daily activities such as finances, household chores, making meals, or taking medicines. But, the person can handle personal self-care.
- **Moderate stage:** A person may need some support or prompting with self-care activities like getting dressed, taking care of their appearance, taking a bath, going to the bathroom, and eating.
- **Late stage:** A person typically relies on others for all their daily needs.

Most people live for 8 to 10 years after being diagnosed with AD. But life span after diagnosis ranges from 2 to 20 years. Your healthcare provider may be able to tell you more based on your current health and other factors.

### **How is AD treated?**

We often use medicines to treat symptoms of Alzheimer disease. The purpose of these medicines is to help your brain cells work better, so you have fewer memory problems.

Some people find the medicines make a big difference in their memory. Other people may not notice much improvement. See chapter 4, “My Medical Care,” to learn more.

We do not have medicines that can slow down or stop brain cell loss caused by AD. Research on medicines to treat the disease is ongoing.

### **What lifestyle changes can help?**

We advise healthy habits that may delay changes in memory and thinking. These habits can also help you stay independent and get the most out of life. They include:

- Getting regular exercise
- Staying connected with family and friends
- Keeping your mind active
- Eating a healthy diet
- Reducing stress
- Sleeping well

Learn more about these healthy habits in chapter 5, “My Daily Life.”

### **How might AD affect my life?**

You are not defined by your disease. You still have people who care about you, things you like to do, and gifts to offer.

But, you may find that it is harder to do some things that require memory and thinking. You may notice that complex job tasks, hobbies, or chores take longer, or are harder to figure out. If this happens, you may learn new ways to do what you want to do. Or you may want or need some extra help.

Even if you have AD, some areas of your brain will still be strong. You will still be able to learn new habits, use your senses, respond to the emotions of others, keep your balance and dexterity, and be creative.

You can use these strengths to help make up for memory loss. There will be challenges ahead, but you can stay connected to the people and activities that bring you joy and meaning.

## **Where can I learn more about living well with AD?**

Living with AD may not be easy, but it can help to know you are not alone. Others are on this journey, and there are people and programs in the community that can help. Discover more about living well with AD by reading other sections of this handbook that interest you.

Here are some resources you may find helpful:

### **Alzheimer's Association**

*www.alzwa.org*

24-hour support line: 800.272.3900

Information and support for people living with MCI or any form of dementia and their families.

### **Community Programs**

*www.momentiasattle.org*

Arts, social, recreation, and community service opportunities for people living with MCI or dementia.

Learn about more resources in chapter 9, “My Community.”

From Julia, living with  
Lewy body dementia:

**“Don’t be afraid of change. A lot of people want to stay at home and hide – but it’s OK to be out, and to experience things.”**



Julia and MaryBeth

From MaryBeth, Julia’s  
sister:

**“Being proactive really pays off. Making a switch early – whether with driving, or a living situation, or getting involved in arts programs – gives you plenty of time to adjust. Wonderful things open to you if you can accept what’s going on. We faced everything early and we never looked back.”**

## Lewy Body Dementia

Lewy body dementia (LBD) is the 2nd most common type of dementia, after Alzheimer disease. It causes movement problems and changes in memory and thinking.

There are 2 types of LBD. The type you have depends on when you develop certain symptoms.

- **Dementia with Lewy bodies:** Changes in memory and thinking come earlier on, either before movement problems, or around the same time as movement problems.
- **Parkinson disease dementia:** Movement problems happen first. Changes in memory and thinking occur more than a year later.

### What causes Lewy body dementia?

LBD results when abnormal proteins called Lewy bodies build up in different parts of the brain. We do not know what makes this happen. We do not believe LBD is a genetic disease.

### What are common symptoms?

LBD is *progressive*. This means symptoms develop slowly over time. Symptoms depend on what areas of the brain are affected:

- If Lewy bodies are in the brainstem, there are changes in the way your body moves. This could include tremor, stiffness, balance problems, and overall slowing of movements.
- If Lewy bodies build up in other areas of the brain, there are changes in your memory and thinking. It gets harder to do things such as planning, paying attention, or solving problems.

Other symptoms may include:

- *Hallucinations*, where you see things that aren’t there
- Sleep changes, including *REM behavior disorder* where you act out your dreams
- Changes in your vision or sense of smell

- Drops in blood pressure, causing dizziness or fainting
- Memory and thinking abilities come and go during the day
- Depression or anxiety

### **What are the stages of LBD?**

It's natural to wonder where you are in the process. The Memory and Brain Wellness Center defines the stages of dementia based on the amount of support needed in daily life:

- **Early stage:** A person may need support with daily activities like finances, household chores, making meals, or taking medicines. But, the person is able to handle personal self-care.
- **Moderate stage:** A person may need some support or prompting with self-care activities like getting dressed, taking care of their appearance, taking a bath, going to the bathroom, and eating.
- **Late stage:** A person typically relies on others for all their daily needs.

If you are in early stages of the disease, it may take 12 months to see changes in your memory and thinking. The rate of change in your symptoms will likely be similar to what you have had up to now.

On average, a person lives for 5 to 7 years after being diagnosed with LBD. But, life span after diagnosis can range from 2 to 20 years. Your healthcare provider may be able to tell you more based on your personal situation.

### **How is LBD treated?**

We do not have any treatments that stop or delay the brain changes caused by LBD. Instead, treatment focuses on managing your symptoms and helping you enjoy your life.

LBD is linked with many different symptoms. That is why many types of treatment can be used at the same time. It is important to work closely with a team of healthcare professionals that specialize in movement disorders.

Medicines are often used to help with movement symptoms. They may also be helpful with memory and thinking, hallucinations, emotional changes, and sleep problems.

About 50% of people (50 out of 100 people) living with LBD are sensitive to some of the drugs that are used to treat hallucinations and other similar symptoms. For these people, side effects can be strong or even dangerous. This is why it is vital to get a clear diagnosis and to stay in close touch with your doctor during treatment.

Other kinds of treatments may also be used to help manage your LBD symptoms. These include physical therapy, speech therapy, occupational therapy, psychotherapy, and support groups.

### **What kinds of lifestyle changes might help?**

We advise healthy habits that may delay changes in memory and thinking. These habits can also help you stay independent and get the most out of life. They include:

- Getting regular exercise
- Staying connected with family and friends
- Keeping your mind active
- Eating a healthy diet
- Reducing stress
- Sleeping well

Learn more about these healthy habits in chapter 5, “My Daily Life.”

### **How might LBD affect my life?**

You are not defined by your disease. You still have people who care about you, things you like to do, and gifts to offer.

But, you may find that it is harder to do things in your daily life that rely on movement, memory, and thinking. Some tasks, hobbies, or chores may take longer, or may be harder to figure out. If this happens, you may find new ways to do the things you want to do. Or, you may want or need some extra help.

Even if you have LBD, some areas of your brain will still work well. You can still learn new habits, stay socially connected, respond to the emotions of others, and be creative. You can use these strengths to help you cope. There will be challenges ahead, but you can stay connected to the people and activities that bring you joy and meaning.

### **Where can I learn more about living well with LBD?**

Living with LBD may not be easy, but it can help to know you are not alone. Others are on this journey, and there are people and programs in the community that can help. Learn more by reading other sections of this handbook that interest you.

Here are some resources you may find helpful:

#### **Lewy Body Dementia Association**

*www.lbda.org*

LBD Caregiver Link: 800.539.9767

Information and support for people living with LBD and their families.

#### **Alzheimer's Association**

*www.alzwa.org*

24-hour support line: 800.272.3900

Information and support for people living with any form of dementia and their families.

#### **American Parkinson Disease Association (Washington Chapter)**

*www.waparkinsons.org*

206.695.2905

Information and support for people living with PD and their families.

#### **Northwest Parkinson's Foundation**

*www.nwpcf.org*

Toll-free: 877.980.7500

Seattle area: 206.748.9481

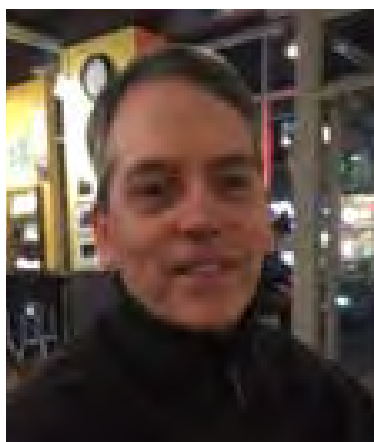
Information and support for people living with PD and their families.

## **Community Programs**

*www.momentiasattle.org*

Arts, social, recreation, and community service opportunities for people living with dementia.

Learn about more resources in chapter 9, “My Community.”



*Eric*

*From Eric, living with frontotemporal dementia:*

**“Do what you love.”**

*From Debbie, Eric's wife:*

**“Try not to worry so much about the future that you aren't taking advantage of every moment.”**

## Frontotemporal Dementia

Frontotemporal dementia (FTD) is a group of conditions caused by cell loss in one or more lobes of the brain, called the frontal and temporal lobes. Two common types of FTD are:

- *Behavioral variant FTD* (bvFTD), which affects your personality and social interactions.
- *Primary progressive aphasia* (PPA), which affects your ability to communicate well

FTD tends to affect people who are in their 40s or 50s. It can also occur in older people.

### What causes frontotemporal dementia?

Brain cell loss in FTD is related to the buildup of different kinds of proteins. For most people with FTD, we don't know what makes this buildup happen. Up to 30% of people (30 out of 100 people) with FTD have a gene change that causes the condition.

### What are some common symptoms?

FTD is progressive, meaning symptoms develop over time.

- **If you have bvFTD:** The areas of the brain that control your personality and behavior are affected. You may find that you care less about what others might think. You may act on impulses more often. You may socialize less, or become very friendly toward strangers. Planning, decision-making, organizing, and judgment may also be affected. You may find yourself getting stuck in habits or routines that repeat.
- **If you have PPA:** You may have a hard time understanding the meaning of words. It could be hard to come up with words or to pronounce them. It may be hard to form a sentence.

### How do these symptoms change over time?

As the disease progresses, if you have mostly language issues, you may develop changes in behavior, or vice versa. You may also notice changes in movement, and have Parkinson-like symptoms.

Changes in language and behavior usually happen slowly. Your rate of change depends on how quickly your disease is progressing. It will likely continue at the same rate that you have already noticed.

### **What are the stages of FTD?**

It's natural to wonder where you are in the process. The Memory and Brain Wellness Center defines the stages of dementia based on the amount of support needed in daily life:

- **Early stage:** A person may need support with daily activities like finances, household chores, making meals, or taking medicines. But, the person is able to handle personal self-care.
- **Moderate stage:** A person may need some support or prompting with self-care activities like getting dressed, taking care of their appearance, taking a bath, going to the bathroom, and eating.
- **Late stage:** A person typically relies on others for all their daily needs.

If you are in the early stages of the disease, it may take 12 months to see clear changes in your memory and thinking. Most people live for 7 to 10 years after being diagnosed with FTD. But life span after diagnosis ranges from 2 to 20 years. Your healthcare provider may be able to tell you more based on your current health and other factors.

### **How is FTD treated?**

We do not have any treatments that stop or delay cell damage in the brain. Instead, we focus on managing symptoms. For example, treatments might help reduce anxiety or depression, or build skills to help with communication. If you have PPA, speech and language therapy can help you learn communication tools and strategies.

If you have a genetic form of FTD, we may also suggest genetic counseling and testing. This can help you and your family members find out if the disease runs in the family.

## **What lifestyle changes can help?**

We advise healthy habits that may delay changes in memory and thinking. These habits can also help you stay independent and get the most out of life. They include:

- Getting regular exercise
- Staying connected with family and friends
- Keeping your mind active
- Eating a healthy diet
- Reducing stress
- Sleeping well

Learn more about these healthy habits in chapter 5, “My Daily Life.”

## **How might FTD affect my life?**

You are not defined by your disease. You still have people who care about you, things you like to do, and gifts to offer.

### ***If you have bvFTD:***

Your reaction to people or social settings may be different than it used to be. You may not be as emotionally affected by others, or may feel OK doing things that others find unusual. This could affect your relationships or how people react to you. Knowing that these are symptoms of a brain disease can help. But it may take some time for you and your loved ones to adjust to these changes.

You may also find that it is harder to do things that require thinking and organization. Some tasks, hobbies, or chores may take longer, or be harder to figure out. If this happens, you may need to learn new ways to do what you want to do. Or you may want or need some extra help.

Even if you have bvFTD, some areas of your brain will still work well. The parts of the brain that support memory, movement, dexterity, and creativity can stay strong. You can use these strengths to help you. You and your loved ones will need to make some changes in how you relate to each other, but you can stay connected with the people and activities that bring you joy and meaning.

### ***If you have PPA:***

Some parts of your life may stay the same. You may still do your hobbies, work, or other things you enjoy. But, it may be harder to communicate with others, or to take part in activities that involve language. You may feel frustrated and lonely sometimes. But you can learn new ways to communicate and connect. As you do, you can keep enjoying your family, friends, hobbies, and more.

### **Where can I learn more about living well with FTD?**

Living with FTD may not be easy, but it can help to know you are not alone. Others are on this journey, and there are people and programs in the community that can help. Learn more by reading other sections of this handbook that interest you.

Here are some resources you may find helpful:

#### **The Association for Frontotemporal Degeneration**

[www.theaftd.org](http://www.theaftd.org)

Helpline: 866.507.7222

Information and support for people living with FTD and their families.

#### **National Aphasia Association**

[www.aphasia.org](http://www.aphasia.org)

Information and support for people living with *primary progressive aphasia* and their families.

#### **Alzheimer's Association**

[www.alzwa.org](http://www.alzwa.org)

24-hour support line: 800.272.3900

Information and support for people living with any form of dementia and their families.

#### **Community Programs**

[www.momentiasattle.org](http://www.momentiasattle.org)

Arts, social, recreation, and community service opportunities for people living with dementia.

Learn about more resources in chapter 9, “My Community.”



From Barbara, living  
with vascular dementia:

**“I would tell  
someone newly  
diagnosed with  
vascular dementia:  
‘Don’t be alarmed. It’s  
one of those things  
you run into in life.’”**

## Vascular Dementia

Vascular dementia is a fairly common type of dementia. The term *vascular* refers to the blood vessels that carry blood from your heart to the other parts of the body. In vascular dementia, damage to the blood vessels in the brain causes changes in memory and thinking.

### What causes vascular dementia?

Vascular dementia can be caused by anything that harms the blood vessels in the brain. This keeps blood from getting to some of the brain tissue. Common causes include:

- **Stroke:** With a stroke, brain tissue is damaged by a clot or bleeding. More rarely, the damage occurs when not enough blood reaches the brain.
- **High blood pressure:** Over many years, high blood pressure damages the smallest blood vessels in the brain, making them work less well so that blood does not get to some areas. This is sometimes called *microvascular disease*.
- **Diabetes, smoking, obesity, and high cholesterol:** These health problems are also linked to damage to the small blood vessels in the brain.

### What are some common symptoms of vascular dementia? Do they change over time?

Symptoms of vascular dementia vary from person to person. If you have vascular dementia, your symptoms may get better, stay about the same, or get worse. It all depends upon where in the brain the damage has occurred and what caused it. Your provider can tell you more about your situation and what to expect.

#### *If you have a stroke:*

A stroke can cause symptoms to appear suddenly. These can include confusion and loss of speech or movement. These symptoms may stay the same, or slowly improve over time. About 20% of people (20 out of 100 people) who have a stroke then develop *progressive* dementia. This means they have a slow decline in memory or thinking abilities.

### ***If you have microvascular disease:***

Symptoms of microvascular disease often begin with very slow changes in how your brain works. For example, you may find that you are having a harder time planning ahead or making decisions. Memory loss tends to come later.

### **What are the stages of vascular dementia?**

If your vascular dementia is progressive, you may wonder where you are in the process. The Memory and Brain Wellness Center defines the stages of dementia based on the amount of support needed in daily life:

- **Early stage:** A person may need support with daily activities like finances, household chores, making meals, or taking medicines. But, the person is able to handle personal self-care.
- **Moderate stage:** A person may need some support or prompting with self-care activities like getting dressed, taking care of their appearance, taking a bath, going to the bathroom, and eating.
- **Late stage:** A person typically relies on others for all their daily needs.

### **How is vascular dementia treated?**

Memory medicines can be helpful for some people. There are also medicines that treat mood.

Most often, treatment for vascular dementia focuses on controlling the diseases and lifestyle factors that affect the health of the blood vessels in the brain. It is important to:

- Have stable blood pressure (not too high or too low)
- Keep cholesterol within normal range
- Control blood sugar

### **What kinds of lifestyle changes might help?**

To keep vascular disease from getting worse, it is very important to exercise often and drink plenty of water. Other healthy habits are:

- Staying connected with family and friends
- Keeping your mind active
- Eating a healthy diet
- Reducing stress
- Sleeping well

Learn more about these healthy habits in chapter 5, “My Daily Life.”

### **How might vascular dementia affect my life?**

You are not defined by your disease. You still have people who care about you, things you like to do, and gifts to offer.

But, you may find that it is harder to do some things that require memory and thinking. You may notice that complex job tasks, hobbies, or chores take longer, or are harder to figure out. If this happens, you may learn new ways to do what you want to do. Or you may want or need some extra help.

Often in vascular dementia, only certain parts of the brain are affected. Other parts of the brain may still be healthy. It is important to understand what parts of your memory and thinking remain strong. These can help you keep doing what you like to do.

Your healthcare team can help identify these areas of strength. Your life will need to adapt, but you can stay connected with the people and activities that bring you joy and meaning.

### **Where can I learn more about living well with vascular dementia?**

Living with vascular dementia may not be easy, but it can help to know you are not alone. Others are on this journey, and there are people and programs in the community that can help. Learn more by reading other sections of this handbook that interest you.

Here are some resources you may find helpful:

**Alzheimer's Association**

*www.alzwa.org*

24-hour support line: 800.272.3900

Information and support for people living with any kind of dementia and their families.

**Stroke Association**

*www.strokeassociation.org*

Information and support for stroke survivors.

**Community Programs**

*www.momentiasattle.org*

Arts, social, recreation and community service opportunities for people living with dementia.

Learn about more resources in chapter 9, “My Community.”

From Myriam,  
diagnosed with  
younger-onset  
Alzheimer disease:

**“I would tell people,  
don’t be afraid.”**



*Myriam*

*Photo by Alzheimer's  
Association*

## Younger-onset Dementia

Younger-onset dementia is also called *early-onset dementia*. The term is used when a person has symptoms of dementia before age 65. About 10% of people (10 out of 100 people) with any type of dementia, and about 5% of people (5 out of 100 people) who have Alzheimer disease have younger-onset dementia.

### What causes younger-onset dementia?

People living with younger-onset dementia usually have the same form of a disease that older people have. We do not know what causes the symptoms to occur at a younger age in these people. It is rarely hereditary.

### How might younger-onset dementia affect my life?

As with any form of dementia, younger-onset dementia brings challenges. At the same time, there are ways to live well and to keep pursuing the relationships and activities that make life meaningful.

Here are some things to think about, and some ideas for taking action:

### *Adjusting to the Diagnosis*

Most people think of dementia as a problem faced by older people. If you are under 65 when you get this diagnosis, you, your friends, and family may be very surprised. You may feel shock, denial, anger, and grief. You might also feel very alone. Friends or family members may question the diagnosis or not know how to react.

If you have received a diagnosis of younger-onset dementia:

- Learn about younger-onset dementia and share what you learn with others.
- Take care of yourself. Keep doing the things you enjoy. Stay physically active, eat a healthy diet, and connect with others.
- Think about joining a support group, or finding support through an online forum. Some support groups are designed for people living with younger-onset dementia. One online forum is *ALZconnected.org*, hosted by the Alzheimer’s Association.

- Talk with friends and family about how you're feeling. Talk with a trusted counselor, too.

### ***Family and Friends***

As a younger person with dementia, you may have to adjust plans and dreams with your partner or family much earlier than you would have expected. You may still be raising children, and find yourself concerned about their futures. At the same time, children may have a range of emotions, wondering if they might get the disease, or feeling embarrassed or resentful about the changes that are occurring.

Some friends may know how to be supportive, but others may not know what to do or say. You may find some of your friends withdrawing even if they want to support you.

To support your ongoing relationships:

- Talk openly about what is going on.
- Share what you feel comfortable doing, and what you would like support with.
- Invite others to educational events so they can learn more, too.
- Work together with your family to plan ahead.
- Encourage your family members to find their own support.
- If you find yourself feeling isolated from friends, reach out to others living with dementia.

### ***At Work***

People with younger-onset dementia may still be in the midst of their careers. If you choose to remain at your job, there may be ways to make it easier for you:

- Talk with your employer or a vocational rehab specialist about your options through the Americans with Disabilities Act. You may qualify for a job accommodation, such as changing to a different job in the same company, or being assigned a job coach who can help you figure out strategies.

- If your current job gets too complex, try asking your employer about switching to another position that can be a better fit.
- Try new ways to help you stay organized on the job: Use a daily calendar, write down all job tasks, and try other memory aids.
- Use the employee assistance program, if you have one.
- Find out what benefits are open to you. Look into Family Medical Leave Act (FMLA) for taking an extended break, or Disability Insurance.

If you retire early or are laid off, you may have these options:

- **Disability insurance**, either through your employer or through a private plan
- **COBRA health insurance** for a while after leaving your job
- **Early retirement benefits**
- **Social Security Disability Insurance or Supplemental Security Income** (visit [alz.org/ssdi](http://alz.org/ssdi))
- **Medicare**, after 24 months on SSDI

### ***Financial and Legal Issues***

People with younger-onset dementia may have extra financial concerns, often if their career was interrupted due to the disease. Putting legal documents in place can be helpful.

- Talk to a financial counselor about your plans for the future.
- Review all the benefits available to you, including those listed above.
- Think about your desires for future care or treatment. Ask someone you trust to take on the role of power of attorney for healthcare or finances when needed.

### **Where can I learn more about living well with younger-onset dementia?**

Living with younger-onset dementia may not be easy, but it can help to know you are not alone. Others are on this journey, and



*Members of a local Alzheimer's Association support group for people with younger-onset dementia share these thoughts:*

- **You are not alone.**
- **Make your own rules.**
- **Don't panic. It's scary and you won't always know what's going on, but don't panic. It will get better.**

there are people and programs in the community that can help. Learn more by reading other sections of this handbook that interest you.

Here are some resources you may find helpful:

### **Alzheimer's Association**

[www.alzwa.org](http://www.alzwa.org); [alz.org/alzheimers\\_disease\\_early\\_onset.asp](http://alz.org/alzheimers_disease_early_onset.asp)  
24-hour support line: 800.272.3900

Information and support for people living with MCI or any form of dementia. In some areas, the Alzheimer's Association has support groups specifically for people living with younger-onset dementia.

Alzheimer's Association brochures:

- "Younger-onset Alzheimer's"
- "I Have Younger-onset Alzheimer's Disease"

### **Community Programs**

[www.momentiasattle.org](http://www.momentiasattle.org)

Arts, social, recreation, and community service opportunities for people living with MCI or dementia.

Learn about more resources in chapter 9, "My Community."

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Your questions are important. Talk with your doctor or healthcare provider if you have questions or concerns.

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## My Next Steps

*What can help me process this news, and who do I tell?*

*From Philip, living with dementia:*

**“Feeling ashamed is one of the great enemies of a healthy approach to Alzheimer’s and dementia. That shame can cause us to hide, to stop telling the truth, to avoid our friends, to fail to take care of ourselves.**

**“The more I talk openly with others, the more I learn. I have gained support from many people, including a therapist, doctors, people in my place of worship, and above all, my children and grandchildren.**

**“Together we are learning that none of us should hide in the dark out of fear.”**



*From Katie, Philip’s daughter:*

**“For me, the hard part of Alzheimer’s disease came after the diagnosis. I’ve struggled with making the best decisions for my father and sometimes feel alone. It helps to read blogs written by persons living with Alzheimer’s disease or their family members, or go to a caregiver support group. General websites provide information, but I learn the most from personal stories.”**

In the pages that follow, you will find ideas to help you adjust to your new diagnosis. You will also find a worksheet to help you decide who you want to tell about your diagnosis, and how.

### ***Key Points in This Chapter***

- *It can take time to process your diagnosis and what it means.*
- *It can help to become aware of your feelings, learn more, and reach out for support.*
- *It is your choice who to tell about your diagnosis, and when. There's no rush. When you are ready, share the news with those you trust. Telling others may help you build a team of companions for your journey.*

## **What can help me process my diagnosis?**

These steps can help you adjust and move forward:

### ***Acknowledge your feelings.***

After receiving a new diagnosis, it is very normal to have a wide range of feelings. You may have a hard time believing the diagnosis, and think that your doctors are wrong and your symptoms will improve. You may also be angry about the diagnosis and feel irritated with others who do not seem to understand.

As the information sinks in, you may feel sad or want to be by yourself. It is common to grieve the plans and dreams you had for your future, or to feel sad about possible loss of independence. These feelings may come and go throughout your journey.

Your family members or friends may also have strong emotions. They, too, can feel angry or sad, and not know what to expect.

As you go through this time of adjustment, it is important to know that each person deals with their feelings in their own way and at their own time. You and your loved ones may be at very different places in the process. But as you move forward, you will learn how to support each other and share meaningful time together.

### ***Learn more about your diagnosis.***

You may find it useful to attend educational seminars, read articles, or talk to others living with memory loss. Your friends and family may also benefit from reading information or attending workshops. The more you understand your diagnosis and how to live with it, the more confident you can feel moving forward. You can find useful links online at [www.depts.washington.edu/mbwc](http://www.depts.washington.edu/mbwc).



*Loved ones can help you process your feelings and prepare for the road ahead.*

### ***Find support.***

Sometimes it can feel hard to reach out to other people. But a good support system is vital. Others can help you process your feelings and prepare for the road ahead.

It is valuable to have a few people who understand what you are going through and who you can rely upon when needed. Among these trusted people might be a therapist, a support group, friends, and family members. After you have decided who you want to tell about the diagnosis, you may choose to ask them to support you in specific ways. With others at your side, you can move forward with the goals, relationships, and activities that make your life fulfilling.

For more information on finding support, read “My Community,” chapter 9 of this handbook.

## **Who do I tell, and how?**

It is your choice who you tell about your diagnosis of memory loss. Take your time to make this decision. Some people tell many of their friends and relatives. Others want to go slowly and tell only those they feel closest to.

Some may be concerned about how others will react to the news. But telling others is a way to start building a team who can understand what you are going through and support you along the way. Not everyone will rush to help you. But as you tell others about your concerns and challenges, you may find the people who will be there when you need them.

Below is a worksheet to help you think about which family members or friends you may want to tell, and how to share the news with them. To learn more about memory loss and relationships, read “My Relationships and Activities,” chapter 6 of this handbook.

### Worksheet 3

## Telling Others About My Diagnosis

The first person I want to know about my diagnosis is ...

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It’s important for them to understand that ...

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The best time for me to talk with them about this is ...

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One of the best ways they could support me on this journey is by ...

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### Questions?

Your questions are important. Talk with your doctor or healthcare provider if you have questions or concerns.

- To learn more about the Memory and Brain Wellness Center, visit [depts.washington.edu/mbwc](https://depts.washington.edu/mbwc)
- To set up clinic visit, call 206.520.5000

# UW Medicine

## My Medical Care

*What treatments are there for memory loss?*

*From Alice, living with dementia:*

**“Whenever I go to the doctor’s or something, I just tell them my situation, that I have Alzheimer’s. I just get it out. And then the people are really very nice and gentle.”**



*From Sarah, living with mild cognitive impairment:*

**“Today at the eye doctor, I just decided I wanted more information than they give you. So I said, ‘I’m diagnosed with mild cognitive impairment – is there anything you can give me to take with me?’**



**“When the technician came in to schedule my surgery, the doctor said, ‘Sarah has a little memory issue, and she’d like to have a copy of all her scans and everything.’ It just fell into place.”**

In these pages, you will learn more about medical care for people living with memory loss. We will explain treatment options, rehabilitation and therapy, other health concerns, and ways memory loss might affect aspects of your healthcare. To learn more about staying healthy, also read “My Daily Life,” chapter 5 of this handbook.

Your care team at the Memory and Brain Wellness Center will partner with your primary care provider (PCP) to create a special care plan for you. We will talk with your PCP about your visit and give you a report that you can take with you. We want to support you and your PCP so that you receive the very best care for your overall health.

### ***Key Points in This Chapter***

- *Treatment for memory loss focuses on easing symptoms and helping you feel better.*
- *Rehabilitation can help you cope with memory changes.*
- *Treating other health problems may help your memory and thinking.*
- *Memory loss, and the medicines you take to treat it, can affect other aspects of your healthcare.*

## **What can I expect from treatment?**

Some causes of memory problems can be treated and resolved. These include depression, or a lack of certain vitamins or minerals.

If these issues are resolved or ruled out, but memory problems keep getting worse, the real cause could be a *neurodegenerative disease*. This type of disease damages brain cells over time.

At this time, there is no cure for this type of disease. We cannot stop the ongoing damage to your brain cells. Instead, we focus on treatments that help you remember better, think more clearly, feel good, and stay healthy.

Most times, treatment goals include:

- Easing your **symptoms**.
- Creating a **care plan** to help you cope and live well. This plan may include rehabilitation, education, support groups, and more.
- Treating **other health problems** that could make your memory or thinking worse.

## What medicines help treat symptoms?

The U.S. Food and Drug Administration (FDA) has approved these drugs to treat the memory and thinking symptoms of Alzheimer disease:

- *Cholinesterase inhibitors* such as donepezil (Aricept), rivastigmine (Exelon), and galantamine (Razadyne). These medicines:
  - Stop the breakdown of *acetylcholine*, a chemical in the brain that helps attention and memory
  - Help your brain cells work better by keeping your levels of acetylcholine high
  - Work for about half the people who take them, keeping their symptoms from getting worse for 6 to 12 months
- *Memantine* (Namenda). This medicine:
  - Is often prescribed if a person has more advanced symptoms
  - Controls the activity of *glutamate*, a chemical involved in learning and memory
  - May help reduce symptoms in the middle and late stages of the disease
- *Namzaric*. This medicine:
  - Is a single pill that combines the 2 kinds of medicines listed above

## Do these medicines work for all types of dementia?

These medicines may be used to treat symptoms of Alzheimer disease and other dementias, such as *vascular dementia* and *Lewy body dementia*. But these medicines do not help treat a type of dementia called *frontotemporal dementia*.

These medicines are also not used if you have *mild cognitive impairment*. This condition is not dementia, but it does involve problems with memory, language, thinking, or judgment.

We will talk with you about what medicines may work best for you. Your PCP may also prescribe other medicines if you have other health issues that affect memory and thinking. Talk with your PCP if you have questions.

## How can rehabilitation help?

Most people think that rehabilitation (“rehab”) is to help people recover after an injury, a stroke, or surgery. But rehab can also be very helpful for people living with memory loss and dementia.

Rehab specialists work together to support your physical, mental, environmental, and emotional needs. Goals of rehab may include:

- Helping you stay strong, flexible, and able to move around. You may learn exercises that help with muscle strength and heart health.
- Teaching you to use *adaptive devices* that help with your daily activities, such as finding your way around, managing your medicines, and taking care of finances.
- Helping you communicate with others.
- Helping you learn how to use calendars, cues, and other memory aids.
- Finding ways to help you stay involved in work or volunteering.
- Helping you stay active in your hobbies, interests, and leisure activities.

At the Memory and Brain Wellness Center, we work with physical therapists, speech and language therapists, occupational therapists, and other rehab providers. Our goal is to help you live as well as possible, and to help you adapt when your needs change. Rehab can be very helpful for both you and your care partner.

## **Do other health problems affect memory and thinking?**

Other health problems can affect your memory, thinking abilities, and how you feel. Treating these problems can help you think a bit more clearly, feel better, and get more out of life.

If you have other health problems, we may treat you for them. Or, we may talk with your PCP and suggest a care plan.

Health issues that can affect memory and thinking include:

### **Depression and Anxiety**

We all feel sad or worried sometimes. But depression and anxiety are serious issues that can make it harder for you to remember or to think clearly. They can also affect your sleep, your diet, or your desire to stay involved in activities. It is important to treat depression and anxiety. There are very safe medicines that can help.



*If you are having trouble sleeping, talk with your PCP.*

### **Sleep Disorders**

Getting good sleep is very important for memory, and for your physical and mental health. While you sleep, memories are formed and your body may get rid of certain proteins that cause damage to the brain.

Pain, bladder problems, or *sleep apnea* are some issues that might keep you up at night. If you are having trouble sleeping, talk with your PCP. Find out what is keeping you from sleeping, and what treatments can help.

### **Delirium**

*Delirium* is a condition in which you suddenly become confused, drowsy, or less aware. The symptoms may look like dementia, but they happen all at once and are caused by a different health issue.

Delirium can be caused by dehydration, an infection, or a side effect of a drug you are taking. People with dementia have a higher risk for delirium.

If your family or caregivers see that you suddenly are having much more problems talking or doing daily tasks, they should take you to your PCP or the emergency department **right away**. If delirium is the cause, it can usually be treated.

### **Seizures**

When a person has a *seizure*, their brain activity changes. Their thinking is affected and their arms or legs may jerk. This can last for a few minutes before the person returns to normal.

Seizures may be linked to Alzheimer or similar diseases, or other causes. Most times, seizures can be controlled with medicine.

### **Thyroid Disorders**

The thyroid is a gland in your neck. If there are problems in the thyroid, it can make too much, or too little, of the thyroid hormone. This may cause memory loss and mood changes.

A simple blood test can show how your thyroid is doing. Thyroid problems are treated with medicine.

## **What do I need to know about memory loss and my general healthcare?**

To help all your healthcare providers give you the best care, and to get the most out of your visits:

- **Tell your medical, dental, and vision providers that you have memory loss.** When your providers know about your memory loss, it helps them give you the best care.
- **Advocate for yourself.** Care providers are often busy. Most are learning how to better serve people with dementia, but some may not take the time to focus on you. They may assume you cannot speak or decide for yourself, and may start talking to your care partner instead. If this happens, your care partner can politely remind the doctor to talk directly with you.

- **Bring your medicines with you to every healthcare visit.**

This includes drugs your doctors prescribed, medicines you bought at the drugstore (over-the-counter), vitamins, and other supplements. These are important to review because some medicines:

- May make memory or thinking worse and should not be taken if you have memory problems
- Can work against the medicines you take to help your memory
- Might interact with your medicines and cause harmful side effects

Your providers need to know everything you are taking so that they can avoid these problems.

- **Know that having surgery may affect your memory loss.**

Surgery is very stressful for your body and your brain. It is hardest on you if you need *general anesthesia* (drugs that make you sleep). It can take some time after surgery for the effects of these drugs to go away.

Also, your medicines for memory loss may need to change for a short time after surgery or during your hospital stay. If you are planning a surgery and will stay overnight in the hospital afterward, ask our team to review the medicines we have prescribed.

## This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

Your questions are important. Talk with your doctor or healthcare provider if you have questions or concerns.

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UW Medicine

## My Daily Life

*What can I do to be as healthy as I can?*

*From Mary, living with mild cognitive impairment:*

**“At one point, my doctor told me, ‘Stay active, and stay social.’**

**“That’s the best advice I’ve gotten anywhere.”**



*From Myriam, living with dementia:*

**“I did all my research when I was first diagnosed.**

**“Staying socially active is important. Diet is important. Taking your memory meds as directed is important. And exercise is important because it gets the blood flowing up to the brain.”**

From Dr. Kimiko Domoto-Reilly, neurologist:

**“Staying physically, socially, and mentally active is very important for brain health.”**

Healthy habits in your daily life can help with your memory and thinking. They can also help you feel better overall.

In this chapter, you will learn about some of the best things you can do to take charge of your brain health: getting regular exercise, staying socially connected, keeping your mind active, eating well, getting quality sleep, and reducing your stress. You will also find some tips to help you remember better and stay safe.

### ***Key Points in This Chapter***

- *Maintain healthy habits to manage your symptoms.*
- *Try to do something physically, socially, and mentally active every day.*
- *Address any safety concerns you may have.*

## **What can I do to stay as healthy as possible?**

### **Get Regular Exercise**

Staying physically active is good for many reasons. Studies suggest that *aerobic activity* (exercise that increases your breathing and heart rates) may help your brain work better. But, any kind of movement that is safe for you is good for your health.

Exercise every day so it becomes one of your habits. Choose something you enjoy doing. Think about doing it with a friend to help you stay motivated.

### **Stay Socially Connected**

Connecting with others has a positive effect on your physical health and your mood. Memory loss can sometimes make you want to be by yourself, but make it a habit to reach out to others. Spend time with people you enjoy, or seek new friends who share your interests.

### **Keep Your Mind Active**

Challenge your mind every day. This could mean learning something new, taking a class, playing games or puzzles, or playing computer games that make you think.

Do something that challenges you, but is not so hard that you get too frustrated. One way to make a simple task harder is to time yourself.

## Eat Well



A diet that is good for your heart is also good for your brain. The best diet for protecting your brain is the Mediterranean diet. This diet includes:

- Eating plenty of vegetables, legumes, fruits, whole grains, fish, and olive oil
- Eating less simple sugars, red meat, and dairy

This diet includes 1 or 2 glasses of red wine a day, except for people who have problems with alcohol.

Your healthcare provider can support you in your healthy eating habits. Pick a diet that is right for you, one that will help your other health conditions, and one that you can live with.

## Get Good Sleep

Good sleep keeps you healthy, and may help your memory and thinking abilities. Adults need 7 to 8 hours of good sleep every night. If you are having trouble getting the sleep you want and need, talk with your doctor to make sure there isn't anything physical going on. Do these simple things to help improve the quality of your sleep:

- **Create a relaxing nighttime routine.** About 30 minutes before your bedtime, put away work, turn off the computer and TV, and do something that is quiet and helps you relax.
- **Make sure your bedroom helps you relax and sleep.** The room where you sleep should be quiet, cool, and dark. Avoid using TV, computer, and digital book readers in the bedroom. Be aware if pets are making it hard for you to sleep.
- **Go to bed at the same time and get up at the same time every day.** Doing this helps set your inner "sleep clock." If you must nap during the day, try to sleep less than 1 hour and take your nap before 3 p.m. in the afternoon.

Try creating a sleep plan for yourself, stick with it for a month, and then go over your results. Talk with a member of your care team about what you found out. We can help support your sleep strategies. You may still have sleepless nights from time to time, but most people find that these tips make a positive difference.

## **Reduce Stress**

Some stress can be helpful or give you a burst of energy. But ongoing stress can make it harder to remember or think clearly.

Find ways to reduce your stress level. Think about what helps you relax. For some people, it might be listening to music or spending time with animals or children. For others, it might be working on a hobby, going for a walk, working in the garden, meditating or praying, or laughing. See the next page for an example of one type of meditation.

Reducing stress will help with your memory and thinking. It can also just help you feel good!



*Kristoffer Rhoads, PhD*

## **UW Voices**

### **Mindfulness Meditation: One Tool for Reducing Stress**

*By Kristoffer Rhoads, PhD, Neuropsychologist, UW Medicine Memory and Brain Wellness Center*

Mindfulness meditation is one tool for reducing stress and living well with memory loss. It involves having a gentle, non-judgmental openness and curiosity about what's going on in the present moment, including its difficulties.

For example, you might notice what it feels like as your breath moves in and out of your nose, how different parts of your body are feeling, or what sounds you hear in the room. As you focus on “now,” your mind can quiet itself, releasing worries about the future or regrets about the past.

Mindfulness helps you accept feelings and situations, instead of avoiding them. It helps you learn to say, “It is what it is.” But acceptance does not mean giving up. Rather, it can be your first action step.

For example, you might not like that it's raining. If you deny that it's raining, you might walk outside and get wet. But if you accept that it's raining, you can take your umbrella when you go out. In the same way, accepting memory loss or dementia does not mean giving up. It means that you know what is going on, and can take active steps to adapt and live well.

Staying focused on the present and practicing acceptance rather than avoidance helps you feel more at peace. It also teaches you how to cope. Meditation is just one way to take care of yourself and build inner strength.

To learn more about mindfulness meditation, visit these websites:

- University of Massachusetts Medical Center for Mindfulness in Medicine, Health Care, and Society: [www.umassmed.edu/cfm](http://www.umassmed.edu/cfm)
- Mindfulness for Beginners, by Jon Kabat-Zinn, PhD: [soundstrue.com/store/mindfulness-for-beginners-4003.html](http://soundstrue.com/store/mindfulness-for-beginners-4003.html)
- Mindfulness Northwest: [www.mindfulnessnorthwest.com](http://www.mindfulnessnorthwest.com)

## **Worksheet 4: My Health, My Way**

Here are some questions to help you choose a “step to health” for yourself this week. Choose a new step each week, as you build new healthy habits!

This week, one thing I want to do for my health is:

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How many times will I do it this week?

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What day(s) and time(s) will I do it?

---

How long will I do it?

---

Who is one person I will tell about my plan? (Telling another person greatly increases the chances that you’ll reach your goal – plus you’ll have someone to celebrate with when you succeed!).

---



*From Mary, living with mild cognitive impairment:*

**"A regular routine helps me feel less frustrated with memory loss. I still make mistakes or get embarrassed, but having a predictable schedule for self-care, exercise, and outside activities helps."**

## **What can help me remember better and stay safe in my daily life?**

### **Memory Tips**

- Keep a familiar routine and schedule.
- Get a notebook. Write down things that you want to remember. Use only 1 notebook and keep it with you.
- Use only 1 calendar:
  - Add important things to it each night, and review it in the morning and often during the day.
  - Cross off each day before you go to bed each night.
  - Move items forward to the next day if you didn't finish them.
- Start and complete 1 thing at a time.
- Put items like your keys, wallet, and eyeglasses in the same place each time you put them down.
- Work on getting rid of clutter, bit by bit each day:
  - Get rid of things that you don't regularly use or need.
  - If you're not sure, put something in a box with a label.
  - If you haven't used an item in the last month, get rid of it.
- Use a clock and watch that has numbers on the face instead of hands.

## Safety Tips

Changes with memory and thinking can bring up some safety concerns. Most people need to find a new balance between independence and safety. In some areas of life, you may be able to do things on your own very well. In other areas, you may need to choose safety over independence.

Your decisions will change over time. Mark dates on your calendar when you will review your decisions about how much you can do on your own.

Here are some common safety concerns and tips for staying safe:

- **Emergency Information.** In case of emergency, you will want to be able to quickly access phone numbers and health information. This information will also need to be handy so that others can read it and help you if needed.
  - Keep a list of important phone numbers in your wallet and posted next to your phone.
  - It is a good idea to wear an ID bracelet that includes your name, emergency contact numbers, and health conditions.
- **Kitchen Safety.** One common safety concern is leaving the stove or other appliances on. Here are some tips:
  - When cooking, use a timer with an alarm that you need to turn off when it rings, instead of one that turns off by itself. This way, you will have to go to the stove to make sure burners are turned off.
  - Think about getting an electric kettle and coffee maker that turn off by themselves. This lessens the risk of leaving them on for a long time.
- **Medicine Safety.** Memory loss can make it harder to recall if you've taken your medicine, or when to take it. Taking too much or not enough medicine can be very harmful. Monitor your medicines so that you take the right amounts at the right times.
  - Use a pill box (*mediset*) to organize your medicines. Some have alarms to remind you it's time to take your medicines.

- **Driving Safety.** Safe driving includes making many decisions, both for your own safety and for the safety of others. Your ability to drive can be affected by changes in your memory or thinking. You may find that it is harder to react to unusual events, make quick decisions, or find your way around. Here are some tips for safe driving:
  - Put away your cell phone while driving.
  - Try using systems like a GPS to help you find your way around.
  - Have someone regularly assess your driving. Ask a friend or family member to drive with you and tell you if they see safety concerns. If there are concerns, ask yourself this question:

### **When should I consider retiring from driving?**

For your own safety and the safety of others, it is important to think about what would cause you to retire from driving. Some people choose to retire from driving soon after their diagnosis. Others ask a loved one to help them assess their driving skills over time.

The choice to retire from driving is often a hard one. The best approach is to begin trying out other ways to get around soon after your diagnosis. This gives you time to become familiar with them before you need to retire from driving.

- To find an occupational therapist who can assess your driving skills, visit [myaota.aota.org/driver\\_search/index.aspx](http://myaota.aota.org/driver_search/index.aspx).
- Read “At the Crossroads: Family Conversations about Alzheimer’s Disease, Dementia & Driving” by The Hartford Foundation. Find the free guide online at <http://hartfordauto.thehartford.com/UI/Downloads/Crossroads.pdf>.
- If you have retired from driving, find resources on getting around in chapter 9, “My Community.”

## What if I live by myself?

If you live alone, all of these daily life strategies are even more important. It is also vital that you build a good support system:

- Reach out to people you trust, who understand what you are going through. Ask if you can call on them if needed.
- Get involved in community activities or support groups.
- Think about where you live. Would it be a good idea to move into an apartment building or condo where people are close by?
- Think about what you'd like to do if it becomes a challenge to live on your own. You will be able to relax and enjoy life more once you know your options and preferences for the future.

### Questions?

Your questions are important. Talk with your doctor or healthcare provider if you have questions or concerns.

- To learn more about the Memory and Brain Wellness Center, visit [depts.washington.edu/mbwc](https://depts.washington.edu/mbwc)
- To set up clinic visit, call 206.520.5000.

## My Relationships and Activities

*How can I stay connected with the people and things I love?*

*From Myriam, living with dementia:*

**“When I was diagnosed, I made some choices about how I was going to live my life. Because I didn’t know – and none of us know – how many good years we have left. And so I just started to do the things that I love to do. I went to lots of places. I met wonderful friends. There is LIFE after diagnosis! And it can be really wonderful.”**



*From Mary, living with mild cognitive impairment:*

**“You kind of feel free. Because you have this situation that you can’t do a lot about, so you might as well do the things you really want to do – the things at the top of your list.**



**“I’ve tried new things, like folk dancing and drumming. So you don’t feel like your life is draining away – No, it can get richer in some ways.”**

*From Alice, living with dementia:*

**“My friends with Alzheimer’s, they are just wonderful. I love all these people. And since I don’t have family, I have a different family. They are my family.”**

As many people who are living with memory loss will tell you, “We’re still here!” You are still you, and your family and friends still care about you. There will be challenges ahead, but you can also keep enjoying the people and activities you love.

Changes in memory and thinking don’t happen overnight. You have time to adapt. This section explains more about staying connected and doing the things you enjoy when you have memory loss.

### ***Key Points in This Chapter***

- *Your relationships with others can stay strong as you adapt to changes in your memory.*
- *You can still do things you enjoy. You may need to adjust how you approach them.*

## **How can I stay close to loved ones, and find new friends?**

It is natural to wonder about how memory loss may affect your relationships. You may worry about losing respect in the eyes of your loved ones. You may not even want to tell your closest friends for fear of what they may think. And, some of your symptoms may put a strain on your relationships.

But, some people find that moving through challenges together can deepen relationships. They also find that they learn new things about each other along the way.

Here are some ideas for keeping your relationships strong:

- Learn more about your condition. Encourage your family and friends to learn more as well.
- Openly talk about any frustrations or worries that you have.
- Be clear about what support you want and don’t want.
- Find ways to have fun together. Many dementia-friendly activities are a great way to focus on something other than the disease.

*From Janelle Taylor, PhD,  
Sociocultural Anthropologist,  
University of Washington:*

**“Even with its challenges, dementia can provide opportunities for your relationships to grow. Friends describe learning new ways of doing things together, seeing new sides of their friend and of themselves, and developing new empathy and understanding. You can face dementia together, with love and shared laughter along the way.”**

- Be willing to show affection in new ways. Holding hands and hugging can work very well, even if you are forgetting words.
- Allow yourself to change and grow. Resisting change, or wanting things to remain “like they always were” will just be frustrating. Be curious about what is possible, and what new things you can find out about each other.
- If you’re in a rough patch with your loved ones, it may help to talk with a counselor. You may want to meet with the counselor by yourself, or with family members.

Along with connecting with friends and family, meeting others in the dementia community can be very helpful. It may feel uncomfortable or scary to think about joining a group for people living with memory loss. But, knowing you are not alone can provide a sense of relief. You can find true friendships among others who understand what you are going through.

If you are looking for some new connections and friendships, consider support groups, or community programs designed for people living with memory loss, such as walking groups or museum tours.

See more options for staying connected in chapter 9, “Community Resources.”

*From Mary, living with mild cognitive impairment:*

**“Look for groups of people who have similar diagnoses. And try new things! I try new things because I figure, it doesn’t matter if I make a mess of it – I have an excuse. If you don’t remember somebody’s name, they’re not gonna care, because they don’t remember yours.”**

## **Worksheet 5**

### **Staying Connected: Me, my family, friends and community**

The relationship that is most important to me right now is my relationship with ...

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I stay connected to this person by ...

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One thing I can do to enjoy this relationship is ...

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If I wanted more friendships or support, I could ...

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## Community Spotlight

### Finding Connections at an Alzheimer's Café

Roger Stocker says he looks forward to going to the Alzheimer's Café in Greenwood, Seattle, every month. A former architect, Roger has been living with Alzheimer disease since 2010. He actively looks for ways to connect with others living with memory loss. "When people like us get together – those with dementia – there's a lot of love there," he states.

An Alzheimer's Café is a way that people living with memory loss and their friends and family can enjoy getting together in a relaxed coffee shop or café setting. These groups started in the Netherlands in 1997 and came to the U.S. in 2008.

In 2010, Seattle's Greenwood Senior Center started the Alzheimer's Café that Roger attends. There are now 9 Alzheimer's Cafés in the Puget Sound area and more than 200 Alzheimer's Cafés in the U.S.

Daphne Jones and her husband have provided live music at the Columbia City Alzheimer's Café. Daphne shares, "It has really grown into a social thing. I've deepened friendships with the people who come. We can sit and talk and have a good time. I look forward to it. I know I'll get a hug from somebody and a smile from somebody."



*David and Daphne Jones perform at the Alzheimer's Café in Columbia City (photo by Full Life Care).*

If you'd like to start an Alzheimer's Café in your community, there are resources to help. Carin Mack, a social worker who helped start the Greenwood Alzheimer's Café, says, "In my opinion, it's the easiest thing to get started. There are a lot of people who are willing to help."

- To learn more and to get tips on starting your own Alzheimer's Café, visit [www.alzheimerscafes.com](http://www.alzheimerscafes.com).
- To see a list of Alzheimer's Cafes in the Puget Sound area, visit [www.momentiasseattle.org/alz-cafes](http://www.momentiasseattle.org/alz-cafes).

## **What are some ways to keep doing things I enjoy?**

While you may need to make some adjustments, there are ways to keep doing what you love to do:

- If you used to enjoy singing in a choir, you can get together regularly with a few friends to sing familiar tunes.
- If you liked getting outdoors on long hikes, maybe you can join a walking group.
- In the Seattle area, a growing movement called Momentia provides a variety of dementia-friendly activities. Offerings include the arts, recreation, connection, and ways to volunteer in the community. See [www.momentiasseattle.org](http://www.momentiasseattle.org) and learn more in section 9, "Community Resources."

## Worksheet 6

### Joy: What makes you feel good?

One thing I really like to do is ...

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The thing I like about this is ...

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Even if my memory and thinking change, I can still have this kind of experience by ...

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## Community Spotlight

### Exploring Creativity

Around the world, awareness is growing about the benefits of taking part in the creative arts, and about the creative potential of people living with dementia. In the Seattle area, we are seeing the growth of “dementia-friendly” programs that involve art, theater, music, and more.

In 2010, Seattle’s Frye Art Museum began an innovative program called **here:now**. The program helps people with memory loss and their families enjoy specially designed art gallery tours and art-making classes in an inspiring museum setting.

Mary Jane Knecht, program manager, says, “In the **here:now** program, we tap into the strengths of the person living with dementia. Our activities provide present-focus awareness and new possibilities of creative expression.”

Lee Burnside, a geriatrician with University of Washington, is on the advisory group for **here:now**. Lee explains, “Creative potential remains, and may even be enhanced, in persons living with dementia. Taking part in creative arts can be an effective tool for personal growth, discovery, and enjoyment.



*Frye Art Museum's **here:now** program.*

*Photo by Jill Hardy*

The Frye Art Museum also offers dementia-friendly arts programs in other settings, including people's homes. To learn more, visit [http://fryemuseum.org/creative\\_aging/](http://fryemuseum.org/creative_aging/).

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Your questions are important. Talk with your doctor or healthcare provider if you have questions or concerns.

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UW Medicine

## My Strengths

*How can I use my talents and skills to make a difference?*

*From Myriam, living with dementia, and a community advocate:*

**“It is crucial – very, very crucial – to get out of the closet, and become a warrior, or at least say, ‘I’m still here.’”**



*Photo by Alzheimer's Association*



*From Daphne, care partner, and member of Southeast Seattle dementia-friendly programs committee:*

**“I love coming together to try and make things happen in our neighborhood. And to actually have those things happen – it is just fantastic. It is my honor to serve.”**

We all want to feel that our lives matter. And we all have something to contribute. Memory loss does not change that. During your life, you have gained much wisdom and built many strengths. You can use your talents and gifts to help others and to give yourself an ongoing sense of purpose. In this chapter, we will review the kinds of strengths you may notice in yourself. We will also explore ways you can make a difference. This includes community service, advocacy, and building *dementia-friendly communities* – places that are welcoming and inclusive of people with memory loss.

### ***Key Points in This Chapter***

- *You have valuable strengths and gifts.*
- *You can advocate for yourself and help others understand more about memory loss.*
- *You can make a difference by building dementia-friendly communities.*



*Dr. Tom Grabowski,  
Director and Neurologist,  
UW Medicine Memory and  
Brain Wellness Center*

### **UW Voices**

## **What Strengths Are Maintained, What Strengths Are Gained?**

*By Dr. Tom Grabowski, Director and Neurologist, UW Medicine Memory and Brain Wellness Center*

A diagnosis of memory loss brings change into your life. But, it can also be a time of finding new strengths within yourself.

Most people who receive a diagnosis of *mild cognitive impairment* (MCI) need to make only a few changes in their daily life. Many people with MCI are fully independent. Some can keep working at their job. Even if your test results show signs of Alzheimer disease or other conditions that damage brain cells, you may not have many symptoms.

If you move from having MCI to dementia, many parts of your brain and your memory will still work well. These strengths can help you make up for problems you may have with memory loss.

Some common strengths you may notice in yourself include:

- **Doing or learning things by habit**

The parts of the brain that involve “muscle memory” – the memory of “how to do something” – often work well even when there is memory loss. For example, you will likely remember how to do physical things you’ve done throughout your life, like riding a bike, playing a musical instrument, or using a paintbrush. You can also train yourself to do something new by doing it over and over, the same way each time.

- **Finding new ways to communicate**

Memory loss can make it hard to find the right word. But, we share thoughts and feelings in many *nonverbal* ways – through body language, tone of voice, and gestures. You may find yourself becoming better at using these nonverbal ways to communicate.

- **Using your senses of vision, hearing, and touch**

The parts of the brain that help you see, hear, and feel things often keep working well. You can use these to enjoy nature, pet an animal, hold a friend’s hand, or listen to music.

- **Moving your body with balance, agility, and skill**

The parts of the brain that help you move around often also keep working well. You can use these abilities to walk around the neighborhood, dance with a loved one, or play with your grandchildren. But, some of the diseases that cause memory loss (like Lewy body dementia) may affect movement.

- **Being creative**

Your ability to see, hear, feel, or move your body can help you keep doing creative things like playing an instrument, singing, painting, or dancing. Some changes in the brain allow you to be more free to express yourself, and less concerned about what others think. They can also help you see the world a little differently. Even if you’ve never been a creative person, you may find that you come up with some new ideas and new ways to express yourself.

*From Elisabeth  
Lindley, Nurse  
Practitioner, Memory  
and Brain Wellness  
Center:*

**“I’ve seen amazing strengths emerge in people who have memory loss. Some people with dementia have a higher awareness of the emotions of those around them, and can respond in very caring and thoughtful ways. That emotional insight can be very powerful and humbling.”**

- **Responding to others’ emotions**

Even if you have a hard time understanding what someone says, you may still be able to tell how they are feeling. Their tone of voice or the expression on their face can say a lot. The ability to connect heart to heart can overcome any challenges with memory.

A diagnosis of memory loss is an opportunity to realize that your value is not based on your ability to think or remember. You can gain a lot by focusing on your ability to enjoy life in the moment, your connections with family or friends, and the wisdom you’ve gained in your life. These things do not depend on whether or not you have good short-term memory.

Living with memory loss or dementia can bring challenges. But, it is still possible to live well and to build new strengths going forward.

## **What can help me know my strengths and how to use them?**

### **Look Within**

You may know many of your strengths and gifts. But if you are not quite sure, try thinking about what has given you a sense of success in the past. You can also ask friends or family members what gifts they see in you.

Your healthcare providers can also help you think about your gifts. Some of your test results may show areas of strength.

To find ways to use your strengths, ask yourself what you care deeply about. Are you passionate about the environment? Do you want to help your grandchildren grow up strong and healthy? Once you know what you care about, consider what you could do to express that deep caring.

### **Look Outside**

To get started, you could choose a way to give back that you have found meaningful in the past. If it feels challenging to do exactly what you did before, change how you did it, or bring a friend with you for support.

You might also want to help an organization you already know – such as your congregation, a club, or a senior center. You could also see if there are tasks you can help with around the house or in the neighborhood. You can be of service in your family or community, and find a way to make a difference that feels good to you.

### **Worksheet 7: Giving Back**

I am good at:

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I feel strongly about:

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One way I can use this talent or this passion in my family or my community is to:

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## How can I advocate for myself and others?

In the months and years ahead, you may need to advocate for yourself from time to time. This is not always easy. It does not come naturally to many people.

Becoming more assertive can help you get what you need. It can also help your family and friends support you. Being confident can also help you share your opinions about how people living with memory loss are seen or treated.

Here are some ways to be assertive and advocate for yourself and others who live with memory loss:

- If you sense that you are being overlooked or “talked over,” tell others that you need a minute to say something.
- Explain what helps you feel included, such as, “Please address your questions to me, not my partner.”
- Plainly state what support you want and need, and what support you do not want or need. “Thank you for your help, but I can do this on my own.”
- Invite your friends and family to use terms that are respectful. For example, ask them to refer to someone as a “person living with memory loss.” This emphasizes that they are a person first.
- When you feel comfortable doing so, take opportunities to share with others that you are living with memory loss.
- If you see something in your community that does not support people living with memory loss, consider talking about changes you would like to see. For example, at your favorite restaurant, you could suggest that they have pictures of items on the menu, instead of just words.
- It may also help to connect with groups that are involved in advocacy:
  - Dementia Alliance International,  
[www.dementiaallianceinternational.org](http://www.dementiaallianceinternational.org)
  - Alzheimer’s Association, [www.alzwa.org](http://www.alzwa.org) or 800.272.3900



*Photo by Alzheimer's Association*

## **Community Spotlight**

### **Becoming an Advocate**

Myriam Marquez is a retired attorney who was diagnosed with Alzheimer disease in 2009. Since then, she has devoted herself to reducing stigma toward those living with dementia. She also advocates for policy change and research.

“I like to talk to people who are afraid of getting a diagnosis, because there is still such a stigma about Alzheimer’s. I know a lot of people who have symptoms, but they don’t want to tell anyone. Getting rid of the stigma is one of my biggest passions.”

Myriam is an advocate both locally and nationally. She is a speaker and advisor with the Alzheimer’s Association and the National Alzheimer’s Project Act.

She knows that not everybody may feel called to become a public figure. But there are many big and small ways to make a difference. Myriam suggests calling state and federal legislators and telling them, “We need a cure. We need services. What have you done to help with that?”

Other ways to become an advocate include creating a team for the Walk to End Alzheimer's or talking to your local senior center about programs they could offer for persons living with dementia. Myriam says, "There are many opportunities to be an advocate. Be persistent and find the one you like the best. You may find gold on your first try. But if you don't, don't give up."

Myriam is using her skills in advocacy to help others have a good life. You may have a different way of advocating and can find support in trying it. You can find resources for advocacy on the Alzheimer's Association website, [www.alzwa.org](http://www.alzwa.org), or by calling 800.272.3900.

## **How can I help build a dementia-friendly community?**

More and more people are becoming aware that those living with memory loss are a vital part of their community, and that they deserve the chance to stay connected and included. Sometimes, people living with memory loss can feel isolated because of stigma or barriers to staying involved.

The goal of a dementia-friendly community is to empower people with memory loss to stay active and feel included. To do this, these communities:

- Invite people with memory loss to define what would help them stay involved
- Reduce stigma and promote positive images of people with memory loss
- Make sure people with memory loss can easily access community areas and programs
- Teach staff who work with the public about how to best serve people with memory loss
- Create programs for people with memory loss to help them be active, stay connected, and use their gifts
- Provide other options that can help people with memory loss stay connected, such as transportation services or buddy systems

Ordinary people can help build a dementia-friendly community. If you'd like to be involved, you may want to talk with friends or neighbors about what can be done to make it easier or better to live with memory loss in your community. To learn more, visit the Dementia Friendly America website at [www.dfamerica.org](http://www.dfamerica.org).

Building dementia-friendly communities is part of our mission at MBWC. If you would like support in brainstorming how to be involved in building dementia-friendly communities, call the MBWC Program Manager of Community Education & Impact at 206.744.2017 or email [mbecker1@uw.edu](mailto:mbecker1@uw.edu).



### **Community Spotlight**

## **Building Dementia-Friendly Communities from the Ground Up**

In Southeast Seattle in late 2013, members of a few non-profit organizations had an idea. They invited a small group of neighbors who lived with dementia, their family members, and their friends to design their own dementia-friendly programs.

At the meeting, people used photos and objects to show what kinds of things brought them joy. Some talked about getting their hands

dirty. Others pointed to the photo of someone playing the piano. Next, they brainstormed how to transform their “boldest” ideas into dementia-friendly programs in their neighborhood.

Within a few months, the group had started a gardening program at Rainier Beach Urban Farm & Wetlands, a monthly drum circle at Southeast Senior Center, and an annual celebration at a local music venue. All the programs were designed to be accessible for people living with dementia.

Martha, one of the neighbors who dreamed up the gardening program, used to work in forestry. When asked if she enjoyed her first day at “Fridays at the Farm,” Martha replied, “I could live here!”

Connie, whose husband has dementia, also helped out. She said, “I liked the idea, because I wanted things to happen in Southeast Seattle. They had a lot of programs in North Seattle, and I liked the idea of things going on here, where we live. We just had to work at it.”

Some members from the original group continue to meet regularly. They help maintain what they started and plan yearly celebrations. In 2015 and 2016, their focus was on outreach to the large immigrant community in their neighborhood. Memory loss happens to people of many different backgrounds who all are part of the community.

To find more about dementia-friendly programs in Southeast Seattle and beyond, visit [www.momentiasseattle.org](http://www.momentiasseattle.org).

## Questions?

Your questions are important. Talk with your doctor or healthcare provider if you have questions or concerns.

- To learn more about the Memory and Brain Wellness Center, visit [depts.washington.edu/mbwc](http://depts.washington.edu/mbwc)
- To set up clinic visit, call 206.520.5000



*Photo by Seattle Parks and Recreation*

UW Medicine

## Support for Care Partners

*What should my family and friends know?*

*From Jane, former care partner:*

**“It’s about keeping yourself sane and healthy. I had very little time for myself, but it was important that I got that 30 minutes in the gym in the early morning. You’ve got to be healthy yourself in order to take care of someone else.”**



*From Connie, former care partner:*

**“Find a support group. It’s important to connect with people who are in a similar situation, who have ideas, and where you can laugh together. You need to laugh – you need to laugh a LOT – and you need to be around people who can help you laugh.”**



*From Gloria, former care partner:*

**“I became an advocate for my husband early on. And I tried to keep some normalcy in the relationship. I wanted my husband to know that even though you have this diagnosis, it does not have to consume you. You still have a wonderful life as it is. We’re still going to do things together.”**

People who care about you may feel a wide range of emotions when they hear about your diagnosis. Like you, they can gain from education and support.

**This rest of this chapter is directed to the people who are on your team.** Share this chapter with them. It includes tips from other family members traveling this path, and information on advocacy, being supportive, and how caregivers can take care of themselves while caring for a loved one.

### ***Key Points in This Chapter***

- *Care partners may feel both challenged and rewarded while supporting a loved one who has memory loss.*
- *Taking care of yourself as a care partner is important, too.*
- *Finding support through counseling, support groups, or dementia-friendly programs can really help.*

## **What does it mean to be a care partner?**

The term “care partner” is another way of saying caregiver. It refers to anyone who provides support or care to a loved one with memory loss.

As a care partner, you are still your loved one’s partner, husband, wife, daughter, son, or friend. But you also may take on extra roles such as advocate or helper during the journey with memory loss.

It can be very challenging to adjust to these changes in your relationship. It is an ongoing process. But as you shift your role, you can find new ways of relating to your loved one and keep learning about each other as you go.



*Carin Mack, MSW*

## **Community Voices**

### **Care Partner as Advocate**

*By Carin Mack, MSW, Social Worker, Greenwood Senior Center*

When a loved one is diagnosed with dementia or memory loss, a family member often must take on the important role of advocate. An advocate includes being a cheerleader, educator, coordinator, and planner. While the kind of support needed from a care partner evolves as the disease progresses, advocacy is vital throughout this time.

Advocacy by a care partner in the medical setting is critical starting from the time of diagnosis. A care partner must understand the complex information provided by the medical team and keep a record of appointments, medicines, and suggestions. In the hospital, a care partner is called upon to make sure that the right care is provided and that their loved one stays comfortable and aware of the treatment process.

Care partners often have to become a leader in the family and in the community to support the needs of a person with dementia or memory loss. They advocate so that all family members are in agreement about the treatment plan. This includes involving family members who may live in a different city or state. Family meetings, whether in person, on the phone, or online, are a good tool for sharing information and planning for the future.

When the person with dementia or memory loss is ready, the care partner can help tell others in their faith community, workplace, and social network about the changes their loved one is going through. This way, both can remain included in activities and receive much needed social support.

Professionals such as case managers, eldercare attorneys, healthcare providers, and social workers can help. Support groups are also a good way to learn about community resources.

Being an advocate for a family member or friend is a gift to them. You don't have to be perfect. Just remember to trust your instincts. You know your loved one best!

## **How can I best support my loved one?**

Ways of supporting someone with dementia or memory loss will change throughout the journey, and from person to person. Read the “Books” page in the Appendix for books that provide specific tips about caregiving.

Here are some ideas to help promote your loved one’s well-being:

### **UW Voices**

## **Supporting Your Loved One’s Well-being: 5 Key Approaches**

*By Dr. Abhilash Desai, geriatric psychiatrist and adjunct Associate Professor, University of Washington, Department of Psychiatry and Behavioral Sciences*



*Dr. Abhilash Desai*

### **Stay in the Moment**

As much as you can, focus on what is happening here and now between you and your loved one. Let go of your expectations, memories of what used to be, and worries about the future.

Embrace “what is.” As you stay present, you are more likely to find small joys and meaningful connection.

### **Validate Thoughts and Feelings**

When you acknowledge a loved one’s thoughts and feelings, they know that they are heard, valued, and respected. When a loved one says something, try nodding your head and rephrasing what they have said: “It sounds like you are angry about this.” You can also put words to the emotion that is showing on your loved one’s face: “You look upset. I know this is hard.”

### **Value Your Loved One’s Input**

Trust that your loved one has something valuable to offer. This may come through words, a gesture, or an expression on their face. Slow your pace and be curious about what your loved one may have to share. Even the invitation to try other ways to communicate – like touch – is a gift that a person with memory loss can bring to a relationship.



*From Katie, care partner:*

**“Mom and I often talk about what we see right in front of us, here and now. For example, we might look out the window and notice the birds together. What do you see? What does it make you think of? These kinds of ‘present moment’ interactions are a great way for us to connect.”**

## **It’s OK Not to Be Perfect**

There are no road maps for this journey. Your course is always changing, and it is impossible to be perfect.

Being a care partner is complex. Be gentle with yourself and your loved one will also benefit.

## **Keep Your Sense of Humor**

As much as you can, look for ways to bring humor into situations with your loved one. Laughing together can be a great way to relieve stress for both of you. It can also help you stay connected.

## **What can I do to take care of myself while I’m taking care of my loved one?**

Being with your loved one during this time can be one of the most rewarding and most challenging things you will ever do. It takes a lot of energy. It can bring up many emotions like sadness, anger, resentment, guilt, or worry.

It is vital to take care of yourself along the way. When you take good care of yourself, you are better able to care for your loved one.

Here are some ideas for self-care:

- Join a support group. It can be very helpful to have your own companions who understand, listen, and provide support. You don’t have to do it alone.
- Take breaks. Let go of any guilt you may feel about doing some things for yourself.
- Make a list of the help you need. Ask others to help you with specific tasks.
- Laugh!
- Let yourself not be perfect. Good enough is good enough.
- Every day, do at least one thing you like to do.
- Keep up with your own healthcare and healthy choices. Staying active, eating well, and getting enough sleep are as important for you as they are for your loved one.



*Daphne, Gloria, and Connie*

## **Community Spotlight**

### **Finding Support**

Gloria Roberts, Connie Bown, and Daphne Jones can't say enough about the value of having support while caring for a loved one with dementia or memory loss. These 3 Seattle-area women meet regularly for their own informal support group.

When they started meeting in 2013, it had been 10 years since Gloria's husband had been diagnosed with dementia. Daphne was newer to being a caregiver, and Connie was just getting started. Since they were at different places in the caregiving journey, they each had something valuable and unique to share.

Connie says, "It was a good fit. Gloria knew so much. It was also good for her to be able to share and enjoy laughter – that's what we brought to her."

Over time, they've helped each other think through many challenges, from how to maintain intimacy to finding options for long-term care. Gloria notes: "That sisterhood – being on a similar journey and being able to talk with someone – it's so important."

These women have some ideas for others who are looking for similar kinds of support. There are formal support groups, such as

those offered by the Alzheimer's Association or senior centers. You can also find support online, through websites like the caregiver forum on [www.alzheimerconnected.org](http://www.alzheimerconnected.org).

And, as these 3 women have shown, you can also build your own support group, with some effort and creativity. Faith communities and neighbors can also be a source of informal support.

Daphne suggests, "You have to really make an effort to get outside your 4 walls, meet people, and ask them if they have any experience with dementia. If they have, you can ask, 'What has helped you most?'"

All in all, finding support that works for you can make a huge difference as you care for a loved one with dementia or memory loss. As Daphne says, "You cannot do this by yourself. You have to find support."

Gloria agrees: "We're very lucky to have what we have. Reaching out is so important. You don't have to walk this road alone."



## **In Our Words**

### **From One Care Partner to Another**

We asked members of a care partner support group at Seattle's Greenwood Senior Center, "What is one thing you would tell another friend or family member just starting out on this journey?" This is what they shared:

- Don't sweat the small stuff.
- Have patience.
- "Let it go."
- Join a support group early!
- Expect the unexpected.
- Learn new communication strategies.
- Focus on the person, beyond the diagnosis.
- Take care of yourself.
- Learn as much as possible about dementia.
- Remind yourself that "This, too, shall pass."

### **Questions?**

Your questions are important. Talk with your doctor or healthcare provider if you have questions or concerns.

- To learn more about the Memory and Brain Wellness Center, visit [depts.washington.edu/mbwc](https://depts.washington.edu/mbwc)
- To set up clinic visit, call 206.520.5000

UW Medicine

## My Community

*What resources will be helpful on this journey?*

*From Sarah,  
living with mild  
cognitive  
impairment:*

**“I think it’s wise  
to let people  
know that there  
are a lot of  
resources, a lot  
of things you  
can do. I go to a  
class through  
Seattle Parks  
and Recreation**

**for people with memory issues. It’s called “Minds in  
Motion.” It’s a great class. And I’ve gotten so many ideas  
from our support group.”**



*“Minds in Motion” class*

*Photo by Seattle Parks and Recreation*



*From Myriam, living with dementia:*

**“It’s important to know about  
the options in your area – things  
like the Alzheimer’s Association,  
senior centers, and other groups  
that provide programs and  
services for people with memory  
loss.”**

*Photo by Alzheimer's  
Association*

Many people living with memory loss and their families tell us that connecting with others is the best thing they've done. They say it is worth the effort to find programs and reach out to people for support.

The Momentia movement promotes many kinds of dementia-friendly activities in Seattle and other cities in the area. Local programs may include support groups, walking clubs, art gallery tours, volunteer options, and more.

Try out the programs, groups, or services in your area until you find a good fit. If you cannot find a program that works for you, think about starting one that meets your needs. You may find others in your area who will also benefit.

This chapter includes resources that you may find helpful. Visit [www.depts.washington.edu/mbwc](http://www.depts.washington.edu/mbwc) for more ideas.

### ***Key Points in This Chapter***

- *Connecting with others who also travel this road is one of the best things you can do.*
- *There are people and programs to help support you, your family, and your friends.*

## **Organizations for Specific Conditions**

Some organizations offer information and support to people with specific health conditions and their families. Here are a few:

- **The Alzheimer's Association** – for those living with mild cognitive impairment or dementia and their families. To learn more:
  - Visit their website at [www.alz.org](http://www.alz.org). For support for different cultures, search for African American, Chinese, Japanese, Korean, Spanish, or Vietnamese.
  - Call their 24-hour helpline at 800.272.3900. Translation is provided in over 200 languages.

- **The Association for Frontotemporal Degeneration** – for those living with frontotemporal dementia and their families. Visit [www.theaftd.org](http://www.theaftd.org) or call 866.507.7222.
- **The Lewy Body Dementia Association** – for those living with Lewy body dementia and their families. Visit [www.lbda.org](http://www.lbda.org) or call 800.539.9767.
- **The Northwest Parkinson's Foundation** – for those living with Parkinson disease and their families. Visit [www.nwpcf.org](http://www.nwpcf.org) or call 877.980.7500.

## Support Groups

In a support group, people share their stories and their ideas. They also encourage each other. Some groups are for the person living with memory loss. Other groups are for their care partners.

- **The Alzheimer's Association:**
  - Early Stage Memory Loss support groups in Washington state: 206.529.3868.
  - Caregiver support groups for Alzheimer's disease, Lewy body dementia, and frontotemporal dementia in Washington state: 206.363.5500.
  - Online forum for persons living with memory loss or care partners, [www.alzconnected.org](http://www.alzconnected.org)
- **Community organizations** such as senior centers, libraries, faith congregations, or service clubs may offer support groups or be willing to start one.



*Support groups give you the chance to share your story with others who understand.*

## **In Our Words**

### **Reflections from the Memory Loss Journey**

Each person's journey is unique. But sharing stories can be very helpful. By joining a support group, you have the chance to share your story with others who understand. You can also learn new ways to adapt and live well.

Members of an Alzheimer's Association support group in Bellevue, Washington, shared these thoughts:

- "I'm still the same person I was before Alzheimer's."
- "I have made new friends through Momentia. We are facing similar things and can help each other."
- "Reading and writing have become harder. I make up for this by listening to audio books."
- "I've started going to the local senior center. No one there seems to mind that I don't remember their names or what I did the last time I was there. We are just in the moment and enjoy ourselves!"
- "It's hard to not be able to drive. But I get a lot more exercise because I walk everywhere."
- "I used to be the one cooking, but now I do the dishes."
- "When I can't find a word, my wife and I joke about it. That's how we get through it. It's important to let your partner know how you want them to handle it when you forget things. I like it when my wife and family help me. But, I know some people with memory loss who don't want help. Talk about it."
- "I can't change the fact that I have Alzheimer's, so I try to enjoy life to its fullest. I just have to find new ways to do so."

## Dementia-Friendly Activities

### Arts, Recreation, Volunteer Options, Social Activities

- **Momentia Seattle**, [www.momentiasseattle.org](http://www.momentiasseattle.org). This website has a calendar of dementia-friendly arts, fitness, social, and volunteer programs in Western Washington. Some programs are for persons living with memory loss, and some include their families and friends. Programs include:
  - **Arts:** Song circle, drum circle, art gallery tours, art-making classes, song-writing workshops, improv theatre workshops, folk dance classes, book groups, and movie programs
  - **Fitness/Recreation:** Neighborhood walking groups, exercise classes, and a walking program at the zoo
  - **Volunteerism:** Food bank program, gardening program, and activism groups
  - **Social activities:** Alzheimer's or Memory Cafes, special events
- **Alzheimer's Café**, [www.momentiasseattle.org/alz-cafes](http://www.momentiasseattle.org/alz-cafes). An Alzheimer's, dementia, or memory café is a social gathering for people living with memory loss and their families and friends. Restaurants reserve part of their dining area where the group can meet. Each group meets about once a month. Gatherings take place in many cities in the Puget Sound area, including Bellevue, Edmonds, Issaquah, Seattle, Silverdale, and Tacoma.
- **Museums and other arts and culture groups** may offer dementia-friendly tours and programs. For example:
  - The **here:now program** at the Frye Art Museum in Seattle offers art gallery tours and art-making classes. Visit [www.fryemuseum.org/program/here\\_now](http://www.fryemuseum.org/program/here_now) or call 206.432.8265.
  - **Taproot Theatre** in Seattle offers improv theatre workshops for people living with early stage memory loss. Visit [www.taproottheatre.org/earlystage-memoryloss-classes](http://www.taproottheatre.org/earlystage-memoryloss-classes) or call 206.529.3671.

- **Seattle Theatre Group** offers “Dance for Parkinson’s” dance classes. Visit [www.stgpresents.org/education/parkinsons](http://www.stgpresents.org/education/parkinsons) or call 206.467.5510, extension 1167.
- Some **parks and recreation departments** have dementia-friendly activities.
  - Seattle’s **Dementia-Friendly Recreation** programs offer many arts, fitness, social, and volunteer options for people living with memory loss and their families. Visit [www.seattle.gov/parks/find/dementia-friendly-recreation](http://www.seattle.gov/parks/find/dementia-friendly-recreation) or call 206.615.0100.
- **Senior centers** in your area may also offer programs for people living with memory loss. Here are some examples:
  - **Greenwood Senior Center** in Seattle has a Memory Loss Programs Coordinator. The center offers dementia-friendly programs like a chorus, yoga class, and more. Their early stage memory loss enrichment program, **The Gathering Place**, meets weekly for social and creative activities, exercise, and brain fitness. Visit [www.phinneycenter.org/gsc/social.html](http://www.phinneycenter.org/gsc/social.html), call 206.297.0875 or send an email to [socialwkr@comcast.net](mailto:socialwkr@comcast.net).
  - **Northshore Senior Center** in Bothell has a **Brain Fitness Club** for people with early stage memory loss. The club helps people stay mentally, socially, and physically active. Call 425.488.4821 or send an email to [candicew@seniorservices.org](mailto:candicew@seniorservices.org).
  - **Southeast Seattle Senior Center** offers support groups and a drum circle for people with memory loss. Call 206.722.0317 or send an email to [jaimec@soundgenerations.org](mailto:jaimec@soundgenerations.org).



*Nancy and Steve Olsen*

## **Community Spotlight**

### **Staying Active, One Step at a Time**

Steve and Nancy Olsen “walk the talk” when it comes to staying active! They have always loved to take walks, but when Steve was diagnosed with dementia, they felt walking was even more important.

In 2014, the Olsens started a program called “Out and About Walks.” This free walking group for people living with memory loss and their loved ones gives them the chance to connect with each other while getting exercise. The group is now one of Seattle Parks and Recreation’s “Dementia-Friendly Recreation” programs.

“Out and About Walks” meets 2 times a month. Each planned walk takes a 2- to 3-mile route through a different neighborhood. The walk begins with the reading of a poem and finishes with social time at a local coffee shop.

The group has been a huge success and has led to many new friendships. “Out and About Walks are very special for me – not only for the walking, but for the closeness of the group,” says one walker.

The Olsens’ love of walking has blossomed into a program that has helped many. If you want to start a program in your area, they suggest, “Look at what you love to do. Look at the needs of the people living with dementia and their families. Put those together and watch things take off!”

To find out more about “Out and About Walks” and other ways to stay active, visit [www.momentiasseattle.org](http://www.momentiasseattle.org).

From Michael Woo, Kin  
On Community Care  
Network, Seattle, WA:

**“In my work with the Chinese community, I reassure the person or family that this journey can be difficult, but it’s a journey they don’t have to travel by themselves. There are groups and services available to support them. And sharing with others who have similar challenges can be very powerful and useful.”**

## Caregiver Resources

Some programs help families who care for a loved one with memory loss. They may offer home visits, teaching, or counseling. Some may offer short-term *respite care*, which is planned or emergency care for someone with special needs. Respite care provides a short break for a family member who is also a caregiver.

- **Family Caregiver Support Program:** This is a State of Washington program that can provide information, support, and free counseling. The state contracts with agencies in each county to provide these services. To find the phone number for your county, visit [www.dshs.wa.gov/ALTSA/resources](http://www.dshs.wa.gov/ALTSA/resources) and enter your zip code. You can also call your local Department of Social and Health Services (DSHS) office.
- **Care Connections:** A program of the Alzheimer’s Association in King and Snohomish counties. Care Connections provides support for caregivers and may offer home visits and respite care. Call 206.363.5500.
- **El Portal Northwest:** A Latino outreach program from the Alzheimer’s Association and SeaMar Community Health Centers. It includes teaching designed for the Latino culture, support, and referrals to area resources. Call 206.529.3877 or send an email to [estela.ochoa@alz.org](mailto:estela.ochoa@alz.org).
- **Kin On Care:** Offers Alzheimer’s and dementia information, and support and respite care services for Cantonese, Mandarin, and Toisanese-speaking caregivers. Visit [www.kinon.org](http://www.kinon.org) or call 206.652.2330.
- **Online caregiver tools** can help with legal and financial planning, care options, safety, communication, and more:
  - Alzheimer’s Association: [www.alz.org/care](http://www.alz.org/care).
  - Family Caregiver Alliance: [www.caregiver.org](http://www.caregiver.org). Materials are in Chinese, Korean, Spanish, and Vietnamese.

## Adult Day Programs

These programs provide meaningful activities for people with memory loss. They also provide daytime respite for care partners. People usually attend these programs 1 to 5 days a week.

There are 2 types of these programs:

- **Adult day programs** are like senior center programs, but with extra support. They give people living with memory loss or other health problems a way to stay active and connected to others. The half-day programs may include activities such as social time, creative projects, exercise, and lunch.
- **Adult day health programs** have healthcare staff such as a nurse and occupational therapist. They provide wellness support, check blood sugars, manage medicines, and offer rehabilitation or other therapy.

Some adult day programs in the greater Seattle area include:

- **Circle of Friends**, an adult day health program in Bellevue that mostly serves adults who speak Russian. Others are also welcome. Call 425.454.8585.
- **Elderwise**, an arts-based adult day program in Seattle. Visit [www.elderwise.org](http://www.elderwise.org) or call 206.913.1757.
- **Full Life Care**, an adult day health program in King and Snohomish counties. Visit [www.fulllifecare.org](http://www.fulllifecare.org) or call 206.528.5315.
- **Kokoro Kai**, an adult day program in Seattle and Bellevue that serves Asian elders with Japanese focus. Visit [www.keironorthwest.org](http://www.keironorthwest.org) or call 206.726.6474.
- **Legacy House**, an adult day and adult day health program that serves Seattle's Chinatown neighborhood. Visit [www.legacyhouse.org](http://www.legacyhouse.org) or call 206.292.5184.
- **Old Friends Club**, an adult day program in Carnation and Kirkland. Visit [www.oldfriendsclub.org](http://www.oldfriendsclub.org) or call 425.681.9776.

- **Seattle Indian Health Board, Elders Program**, an adult day program in Seattle for American Indian and Alaska Native elders age 55 and older. Visit [www.Sihb.org/elders-program](http://www.Sihb.org/elders-program) or call 206.324.9360, extension 2813.

For more adult day programs in Washington state, visit [www.leadingagewa.org/members/adult-day](http://www.leadingagewa.org/members/adult-day).



*Many companies and agencies offer in-home care.*

## Living Options: In-home Care and More

**In-home care** staff are trained to help you with your daily activities. Many companies and agencies offer in-home care.

Some people choose to live in a **community** that includes activities and meals. This might be sharing a home with friends or family. Living with loved ones can be one way to give and receive support.

Other living options vary in the care and support they provide:

- **Senior apartments** may offer some activities, but they do not have medical staff.
- **Independent living retirement communities** may offer some activities, but they do not have medical staff.
- **Assisted living communities** provide some support for meals, personal care, chores, and taking medicines.
- **Adult family homes** are houses with 3 or 4 bedrooms. Staff may provide support or full care.
- **Memory care facilities** provide full, long-term dementia care. Some also provide respite care.
- **Skilled nursing facilities** provide short-term care after an injury, surgery, or hospital stay. Some offer long-term care.
- **Continuing care retirement communities (CCRC)** provide independent, assisted, and memory care. This is ideal for people who do not want to move to another facility if their care needs change.

Talk with a social worker or geriatric care manager about your living choices.

## Getting Around

If you do not drive, there are many other ways to get around.

- **Paratransit service** is a van service supported by the Americans with Disabilities Act. The fare is the same as the bus. If you qualify, they will pick you up at home.

You must apply for this service with your local transit service.

The name of the service depends on the county you live in:

- In King County ..... Metro Access
- In Snohomish County ..... DART program
- In Pierce, Kitsap, and other counties ..... Paratransit Services
- **Taking the bus** is also an option. To learn more, please see “Riding the Metro Bus” on page 12.
- **Taxis.**
- **Rideshare services** like Uber or Lyft.
- **Some nonprofit groups** offer free or low-cost transport services. Two of these programs are:
  - Sound Generations (formerly Senior Services) in Seattle:  
[www.soundgenerations.org/get-help/transportation/volunteer-transportation](http://www.soundgenerations.org/get-help/transportation/volunteer-transportation). Call 206.448.5740 or 800.282.5815 by no later than Tuesday if you want a ride the following week.
  - Catholic Community Services Volunteer Transportation program: [www.ccsww.org/site/PageServer?pagename=seniors\\_volunteertransportation](http://www.ccsww.org/site/PageServer?pagename=seniors_volunteertransportation). Call 206.328.5696.
- You may also have success asking friends and family for help with rides.



*The sign at a Metro bus stop gives the route number and tells where the bus is going.*

## Community Voices

### Riding the Metro Bus

*By Charlie Reidy and Sarah Parkhurst, Seattle, WA*

If you have retired from driving, a bus can help you get where you need to go. There are many good things about riding a bus:

- You can let the driver worry about traffic.
- You can read a good book or listen to music on your headphones.
- You may find that riding the bus is more relaxing than driving.

### Before You Ride

Metro is the bus system in King County, Washington. Visit [www.metro.kingcounty.gov/tops/bus/how-to-ride](http://www.metro.kingcounty.gov/tops/bus/how-to-ride) to learn about riding a Metro bus.

Metro offers riders with disabilities the chance to practice riding the bus. A support person can ride with you on the Metro bus or light rail until you are ready to travel safely by yourself. Call 206.749.4242 to learn more.

### Paying for Your Ride

If you are over age 65 or are living with dementia, you qualify for a **Regional Reduced Fare Permit (RRFP)**. Having an RRFP will lower your cost of riding the bus.

To apply for an RRFP:

- Visit [www.metro.kingcounty.gov/tops/accessible/reduced-fare-permits.html](http://www.metro.kingcounty.gov/tops/accessible/reduced-fare-permits.html). Click on:
  - “RRFP Eligibility Criteria Form” to read about the RRFP.
  - “RRFP Eligibility Application Form” to print the form.
- Ask your doctor to fill out and sign the last part of the form.
- Take the form to the Metro Customer Service Office. The address is 201 S. Jackson St., Seattle. You will need to pay a \$3 fee. They will give you the RRFP.

When you get on the bus, you can pay with either cash or an **Orca card**. An Orca card is a pass that can be loaded with money. It is helpful if you do not like to carry cash. To get an Orca card and load it with money, go to the Metro Customer Service Office at 201 S. Jackson St., or visit [www.orcacard.com](http://www.orcacard.com).

## **Planning Your Trip**

To find out what bus to take:

- Visit <http://tripplanner.kingcounty.gov> to use the **Metro Trip Planner**. Enter your starting address and the address you are going to. The planner will tell you which buses to take, what time they leave and arrive, and how much the ride will cost if you are paying with cash.
- Or, you can call Metro on weekdays from 6 a.m. to 9 p.m. at 206.553.3000. They will help you choose the right bus route for your trip.

## **Tips**

- If riding a bus is new for you, or if you just want support, ask a friend to ride with you for your first few rides.
- Give yourself plenty of time to get to the bus stop.
- If you have a smartphone, try the *One Bus Away* app. It will tell you if your bus is on time.
- When you get on the bus, feel free to ask the driver to lower the lift. This is helpful if you use a wheelchair or walker or have a hard time using the steps.
- To pay as you board the bus:
  - If you have an Orca card or RRFP, hold it up to the card reader.
  - If you are paying with cash, put it into the fare box. There is a place to insert dollar bills and a container for coins. You will need to have the exact amount for your fare. The bus driver is not able to give change.



*The arrow in this picture points to the sign in the front of the bus that tells where the next stop will be.*

- Learn the stops that your bus makes so that you know when it is getting close to your stop. A sign in the front of the bus tells where the next stop will be.
- When you see that your stop is next, pull the cord at the top of the window. This tells the driver that you want to get off at the next stop.
- Enjoy the ride!

## Questions?

Your questions are important. Talk with your doctor or healthcare provider if you have questions or concerns.

- To learn more about the Memory and Brain Wellness Center, visit [depts.washington.edu/mbwc](https://depts.washington.edu/mbwc)
- To set up clinic visit, call 206.520.5000

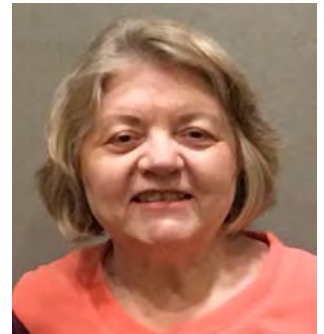
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## My Plans for the Future

*What plans can I make now that will help later on?*

*From MaryBeth, care partner:*

**“Being proactive really pays off. I don’t think there’s a single thing we’ve done that’s been bigger than that. Making a switch earlier – whether with driving, or a living situation, or getting involved in arts programs for those with memory loss – gives you plenty of time to adjust. There are wonderful things available if you can accept what’s going on. We faced everything early on, and we never looked back.”**



*From Myriam, living with dementia:*

**“I can still live independently, but I am thinking about the future, and when I can no longer live alone. I haven’t yet developed my plan - I need to sit down and do that.”**

After receiving a diagnosis of memory loss, some people want to start planning for the future right away. Others prefer to wait until they have adjusted to the news.

When you are ready, use the information in this chapter to guide you through the medical, legal, and financial decisions you may need to make.

### ***Key Points in This Chapter***

- *Advance care planning is a way to clarify your values and make decisions about your future ahead of time.*
- *Planning ahead helps you be in charge of your future.*
- *Legal forms and health insurance are 2 important areas for decision making.*

## **What is advance care planning?**

Advance care planning is planning for your future care needs. It is an ongoing process. It involves careful thought, conversations with your loved ones and doctors, and filling out paperwork. It helps you clarify your values, decide what treatments you want now and in the future, and know what your goals are for end-of-life care.

## **Why is it important to plan ahead?**

Planning ahead helps you be in charge of your future. Changes in memory and thinking can affect your ability to make decisions about things like healthcare and finances. If the time comes when you cannot make these decisions on your own, having a clear guide for your family and doctors will ensure your wishes are followed.

It's easy to put off these tasks. But, making some decisions now can bring peace of mind, and will help both you and your family later.



*Durable power of attorney gives someone you trust the legal right to make decisions for you, if needed.*

## What kinds of legal forms do I need?

There are 3 important legal forms to fill out when planning ahead: Durable Power of Attorney, advance directive, and POLST.

### Durable Power of Attorney (DPOA)

Durable power of attorney is the way to legally give another person the right to make decisions for you. These decisions can be about your healthcare, your finances, or both.

With a DPOA, you name this person in advance, but they only start making decisions for you if you cannot make them yourself. Make sure the person knows that you have chosen them, and that they know what kinds of decisions you want them to make for you.

The Durable Power of Attorney (DPOA) form is a legal document that you must fill out, sign, and have notarized. You can prepare this form in 1 of 2 ways:

- You can have your DPOA written by a lawyer. This allows you to make sure your specific concerns are included on the form.
- Or, you can use forms that you download from the internet.

For your DPOA to be legal, **you must sign it in front of a notary**. You do not need to have other witnesses present.

It is important to sign a DPOA at an earlier stage of memory loss. The law states that when you sign a DPOA, you must be able to understand what you are doing and to sign the form yourself. This is called having “decisional capacity.” Here is a legal definition:

*“Capacity” means an individual’s ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health-care decision.” (Uniform Health-Care Decisions Act of 1993, 1994)*

If someone does not have this capacity, they cannot sign a DPOA. Without a signed DPOA, your family may be limited in making some important decisions unless they go to court and apply to be your legal guardians.

Make sure to give a copy of your signed DPOA to your doctor.

## **Advance Directive (Healthcare Directive, Living Will)**

An advance directive is also called a healthcare directive or living will. This document states your wishes for the kind of healthcare you do and do not want if you become very ill.

For example, you can state that you would or would not want doctors to use a feeding tube to give you nutrition and liquids. Doctors are not legally required to follow your advance directive, but it will be used as a guide for making healthcare decisions if you cannot speak for yourself. Doctors will consult your healthcare directive, your family members, and your healthcare DPOA to get advice on what to do.

You can get a healthcare directive form at your doctor's office, from an attorney, or online. For the form to be legal:

- You must sign it.
- Your signature must be witnessed by 2 people who are not family members or hospital staff.

An advance directive does not need to be notarized. Make sure that you give a copy to your doctor.

## **Physician Order for Life-sustaining Treatment (POLST)**

The POLST form is used to guide your healthcare providers in an emergency. It tells first responders, doctors, and family members what you have decided about certain kinds of care, such as:

- Resuscitation and CPR
- Having a breathing tube placed to use a *ventilator* (breathing machine)
- Using a feeding tube to give you nutrition and liquids

Your POLST form is kept at home or with you so that emergency first responders will see it and follow the orders. Some people post their POLST form on their refrigerator or in another place where it can be seen easily if an emergency occurs.

If you want to fill out a POLST form, talk with your doctor about it. It must be signed by you (or your agent) **and** your doctor.

The POLST form is used in many states, including Washington, Oregon, Idaho, Montana, and California. To learn more, visit: [https://wsma.org/wcm/For\\_Patients/End\\_of\\_Life/POLST/For\\_Patients/wcm/Patients/POLST\\_for\\_Patients.aspx?hkey=79541052-8b1b-449c-944e-5ca7f2cf7dd1](https://wsma.org/wcm/For_Patients/End_of_Life/POLST/For_Patients/wcm/Patients/POLST_for_Patients.aspx?hkey=79541052-8b1b-449c-944e-5ca7f2cf7dd1).

## **Do I need health insurance? How do I get it?**

The Affordable Care Act (ACA) requires that everyone buy health insurance. If you already have Medicare or Medicaid, you do not have to buy any other health insurance.

Under the ACA, some people qualify for a subsidy that pays part of the cost of the insurance coverage. Many people get a full subsidy.

If you do not have health insurance, you can apply for it on the Washington Health Plan Finder website:

- Go to [www.wahealthplanfinder.org](http://www.wahealthplanfinder.org).
- Find the section on “Washington Apple Health,” and click on “Apply Now.”
- If you need the information in a language that is not English, click on “Language Assistance.”

A social worker or financial counselor at the Memory and Brain Wellness Center can help you with this, if needed.

On the website, you can choose from a list of insurance plans. You can see the price of the premium, your subsidy, and your cost for the coverage.

Think about your future health when you choose a plan. The plan that costs the least may not give you the coverage you need.

Under the ACA, you cannot be denied coverage because of a pre-existing condition. If you have Alzheimer disease or another form of dementia and do not have health insurance, you can still get coverage for your future healthcare costs through the ACA.



## **What kinds of health insurance are there?**

### **Medicare**

Medicare is excellent insurance coverage. It is usually the primary insurance for people age 65 and over.

Medicare pays 100% of most emergency medical treatment and 80% of most other care. It does not cover the cost of care for regular daily care such as bathing, dressing, and preparing meals.

**You must apply for Medicare.** It does not begin just because you turn 65.

You can apply online at the Social Security Administration (SSA) website: [www.socialsecurity.gov](http://www.socialsecurity.gov). The instructions will tell you what information you need. If you do not have access to a computer, you can visit a SSA office near you.

It is OK to have another person you trust help you apply.

### **Medicare Supplement Insurance**

Some people also buy a Medicare supplement insurance policy. You must pay for this yourself. It is not covered by a public program.

A supplement will usually pay for the 20% portion of a medical bill that Medicare does not cover. It can cover fees from a hospital stay, a doctor visit, home healthcare, or a nursing home. A supplement can be a good idea if you think your healthcare bills will rise and you can afford the monthly fees.

### **Private Health Insurance**

If you have private health insurance, read your plan booklet to learn what your plan covers. Review it carefully to see if any parts of care for dementia are not covered.

Under the ACA, you cannot be denied healthcare insurance if you have a pre-existing condition. But, your insurance plan might have limits on what it will cover. If you find that your plan will not cover treatment for Alzheimer disease or other forms of dementia, you could look at other plans on the Washington Health Plan Finder website ([www.wahealthplanfinder.org](http://www.wahealthplanfinder.org)).

## **Long-term Care Insurance**

Long-term care (LTC) healthcare plans vary greatly. If you have already bought a policy, review your policy booklet.

Insurance companies often give a memory test to rule out dementia care before they agree to cover someone's long-term care needs. But, if you develop dementia after you are already on the plan, they most likely will keep covering your care as long as you pay the premium. Most long-term care plans cover extended nursing home care, home healthcare, and some assisted living care.

There is no public program to help pay for long-term care insurance. If you have an LTC plan and the benefits are used up, you may be able to apply for Medicaid.

## **Medicaid**

Medicaid is a healthcare insurance program that is run by both the federal and state governments. Under the ACA, coverage for Medicaid has been expanded.

To apply for Medicaid, visit your local Community Service Office (CSO) of the Department of Social and Health Services (DSHS). To find your local office:

- Visit [www.dshs.wa.gov](http://www.dshs.wa.gov).
- Under “How Do I ...?” click on “Find a local service office.”
- Under “How to Find an Economic Services Administration Office,” click on “Community Services Offices.”
- Enter your zip code or country to see a list of offices in your area.

If you qualify for Medicaid, it will cover most treatment costs for dementia. This includes some in-home care, assisted living, and nursing home care. A social worker will give you an in-home assessment to find out if you qualify for these extra programs.

[illegible]

Your questions are important. Talk with your doctor or healthcare provider if you have questions or concerns.

- Page 8 of 8 | My Plans for the Future

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## Stepping Forward

*“Living in the possible”*

*From Philip, living with dementia:*

**“My journey through Alzheimer’s continues to be marked with alternating times of bravery and fear, expectation and resignation, clarity alternating with frustrating confusion, and one hell of a lot of paradox.**

**“Yet our journeys must not be kept in the dark, but rather, be brought out in the open, and in that way, the fear of death is challenged and ultimately can be broken.”**



*From Katie, Philip’s daughter:*

**“The answers are going to be different for everyone. There is no road map for how this plays out. I know that, but I also know this: If you are brave enough, especially when it is a difficult time, you can find a sense of gratitude that will do more than just keep you going.”**

Throughout this handbook, we have stressed that you are not defined by your disease. You have people who love you, things you like to do, and gifts to offer. Living with memory loss is not easy, but there are ways to cope with it. Healthy habits in your daily life can help you feel better and think more clearly. Meanwhile, you have time to adapt, and can find ways to keep enjoying life.

Most of all, you don't have to walk this path alone. Your family, your friends, and the team at the Memory and Brain Wellness Center are with you along the way.

As you step forward, we hope you feel informed, encouraged, and empowered for the road ahead.

We close with this poem, "Living in the Possible," written for our handbook by Mary Firebaugh of Seattle, Washington.



*Painting by Lenny, a member of the Elderwise adult day program*

## Questions?

Your questions are important. Talk with your doctor or healthcare provider if you have questions or concerns.

- To learn more about the Memory and Brain Wellness Center, visit [depts.washington.edu/mbwc](https://depts.washington.edu/mbwc)
- To set up clinic visit, call 206.520.5000.

## ***Living in the Possible***

*I used to spend holidays in the kitchen.  
Now my son makes pizza, and I do jigsaw puzzles.*

*I used to pump the gas and check the tires,  
Now I walk or bus or get a ride with friends.*

*I used to stay up late to get things done.  
Now I do gentle yoga to relax.*

*I used to greet my friends by name.  
Now they all get hugs, and Wow!, I get the same.*

*I used to read the paper every day.  
Now I sing (off key), and paint and drum.*

*I used to worry and feel down.  
Now I ask, get help, and help others when I can.*

*I used to think that life is earned by doing.  
Now I know it is a gift to pass around.*

We wish you well as you step forward from here!

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## Appendix

### *Living with Memory Loss*

|                                                                               |           |
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## My Workplace Rights

Changes in memory and thinking can make it harder to do some jobs. Some people living with memory loss find new tools and systems that allow them to keep their jobs. Others change jobs or choose to retire.

Here is an interview about workplace rights with Robert Fraser, PhD, Director of Neurology Vocational Services Unit at Harborview Medical Center.



Robert Fraser, PhD

### What rights do people with memory and thinking changes have in the workplace?

If you are diagnosed with mild cognitive impairment or dementia, you have the right to *reasonable accommodation*. This means your employer may change your work duties or your schedule to help you do the essential tasks of your job.

The Americans with Disabilities Act (ADA) requires that workplaces with 15 or more employees provide reasonable accommodation. But, the employer does not have to make changes that cause *undue hardship*. This means the employer does not have to make major changes that are too costly or disruptive, or that change the nature of the business.

### What can a worker expect?

Here are 3 types of accommodation and an example of each:

- **Changes in job duties:** A manager can no longer handle the many demands of her job. She transfers to a job with less involved tasks where she does not need to manage staff.
- **Work station changes:** A man who works on bicycles is misplacing tools. He forgets the right order of some tasks and has problems finishing his work on time. A special tool holder is set up for him. Each tool is color-coded to match the shelf it is on and placed in the order it will be used.
- **Assistive devices:** A carpenter cannot remember detailed instructions or the right order of some tasks. He is given a binder that lists the order of tasks for each project. He also uses a voice recorder when his boss gives instructions.

## **How do I know whether to keep working or retire?**

Answer the questions below to help you decide. Talk with your family, a vocational rehabilitation counselor, a neurologist, or a neuropsychologist about these issues:

- How quickly did your memory and thinking change? It may be easier to keep doing your job if changes are occurring slowly.
- Are your symptoms mild, or do they affect many areas of your life?
- What are your strengths and weaknesses with memory and thinking? Are you still able to do all of your job tasks?
- If your employer made some changes to the work you do or how you do it, could you keep doing your job?
- How do you feel about working at your current job? How does your job affect you physically?
- What is most important to you right now? How do you want to spend your time?

## **How can I get support with my job?**

To learn more about reasonable accommodation, contact:

- A vocational rehabilitation agency. These services may be offered through a local medical service or your state's department of vocational rehabilitation. To learn about UW Medicine's Neurological Vocational Services, call 206.744.9130 or visit [www.nvsrehab.org](http://www.nvsrehab.org).
- An ADA center in your area. Visit the Northwest ADA Center website at [www.nwadacenter.org](http://www.nwadacenter.org).
- The Job Accommodation Network. Visit [www.askjan.org](http://www.askjan.org).

If your employer is not making an effort to provide reasonable accommodation, contact one of these resources:

- The human rights commission for your state
- The U.S. Equal Employment Opportunity Commission
- An employment lawyer

## Disability Insurance and Benefits

People with memory loss or dementia may need to stop working or change the kind of work they do. This can mean a loss of income.

*Disability insurance* pays benefits to people who are not able to work for a long time because of a disability such as an illness.

- The Social Security Administration (SSA) has 2 disability programs:
  - Social Security Disability Insurance (SSDI) pays benefits to you and certain family members if you are “insured.” This means you must have worked and paid Social Security taxes for a certain length of time.
  - Supplemental Security Income (SSI) pays benefits based on financial need.

For the most recent information about these programs, visit [www.socialsecurity.gov](http://www.socialsecurity.gov).

- Some employers offer disability coverage. Talk with staff at your company’s human resources department.

### Who qualifies for SSDI?

SSA considers a person disabled if all 3 of these conditions are met:

- They cannot do the work they did before;
- SSA agrees they cannot adjust to other work because of their health condition(s); **and**
- Their disability has lasted or is expected to last for at least 1 year, or it is expected to result in death.

The SSA has a Compassionate Allowances (CAL) initiative that allows some applications for disability to be processed more quickly. This is done for applicants with certain conditions. The list of conditions that qualify for CAL includes:

- Amyotrophic lateral sclerosis (ALS)
- Creutzfeldt-Jacob disease (CJD)

- Younger-onset Alzheimer disease
- Frontotemporal dementia (FTD), Pick disease-Type A-Adult
- Lewy body dementia
- Mixed dementias

To learn more about Compassionate Allowances, visit [www.ssa.gov/compassionateallowances](http://www.ssa.gov/compassionateallowances).

### **How do I apply for SSDI or SSI?**

There are 2 ways you can apply:

- To apply online, visit [www.socialsecurity.gov](http://www.socialsecurity.gov).
- To apply in person, visit your local SSA office. To find your local office, visit <https://secure.ssa.gov/ICON/main.jsp>. Enter your zip code and click on “Locate.”

You can apply for disability even if you are still able to do some of your job. You can return to limited work after you are approved. If you return to work, SSA will look carefully at your work to be sure:

- It is not the same as your usual work; **and**
- You cannot do your usual work because of your disability.

When you apply, you must sign release of information forms. This allows SSA to contact your healthcare providers. They can also access your medical records to confirm your disability.

### **What happens after I apply?**

SSA will review your application. They will send you a letter restating what you wrote on the application. This is your chance to change anything that is not correct.

Some people request a letter from their provider to confirm their disability. This may not be needed, since SSA will have access to your medical records.

If your application is denied, you can apply again in 3 months.

## Research Studies

Scientists want to learn more about the diseases that cause memory loss and dementia. Many research studies are being done. The goals of these studies may be to:

- Help us understand more about how these diseases change the brain
- Help us understand what triggers these changes
- Test treatments that may prevent or delay these changes

Research studies work with volunteers who want to take part in the study. Some studies include people with a certain disease or who have certain symptoms. Others include people who do not have cognitive changes.

Taking part in a research study is one way you can make a difference. You can help build scientific understanding and help researchers find new prevention and treatment methods.

## Clinical Trials

One type of study is called a *clinical trial*. The goal of this kind of study is to see if a treatment works and if it is safe. In a clinical trial:

- Volunteers are assigned 1 or more treatments.
- Scientists monitor these people to see how the treatments affect them.
- Most volunteers also continue any treatments they are already using.

## Control Groups

Some volunteers in a clinical trial may be in the *control group*. This means they do **not** receive the trial treatment for at least the first part of the study. Instead, they may receive a *placebo* (a substance that does not have a medicinal effect), or no added treatment at all.

Scientists monitor people in the control group. They compare their health to the health of the people who receive the treatment.

## **If You Want to Take Part**

If you want to take part in a research study, please keep in mind:

- Research studies are separate from the care you receive from your healthcare providers.
- Taking part in research studies might **not** improve your health.
- Before you enroll, staff who are running the study will explain the study's goals, what it involves, and possible risks and benefits. You will receive a written copy of this information.
- You can choose to withdraw from a research study at any time.

Here are some places to learn more about research studies:

### **Memory and Brain Wellness Center Research Registry**

If you are a patient at UW Medicine Memory and Brain Wellness Center (MBWC), you can enroll in our Research Registry. This is a list of people who are interested in taking part in research studies. If you are interested, talk with your MBWC doctor or nurse practitioner.

It is your choice whether or not to enroll. Your choice will not affect the care you receive at MBWC.

### **Other Local Resources**

- UW Alzheimer's Disease Research Center:  
[www.depts.washington.edu/adrc](http://www.depts.washington.edu/adrc)
- Pacific Northwest Udall Center for Parkinson disease research and brain donation: [www.panuc.org](http://www.panuc.org)
- Memory and Brain Wellness Center clinical trials list:  
[www.depts.washington.edu/mbwc/research/clinical-trials](http://www.depts.washington.edu/mbwc/research/clinical-trials)

### **National Resources**

- Database of research studies maintained by the U.S. National Institutes of Health: [www.clinicaltrials.gov](http://www.clinicaltrials.gov)
- Research study matching service offered by the Alzheimer's Association: [www.alz.org/trialmatch](http://www.alz.org/trialmatch)
- List of research studies for people diagnosed with a form of FTD, offered by the Association for Frontotemporal Degeneration:  
[www.theaftd.org](http://www.theaftd.org)



## Books

Here are some books about memory loss and dementia that you may find helpful:

### ***Living Your Best with Early-Stage Alzheimer's***

By Lisa Snyder, MSW, LCSW

A practical guide to living well with memory loss. This book covers adjusting to the diagnosis, connecting with others, finding meaningful activities, planning ahead, tips for daily life, and more.

### ***What the Hell Happened to My Brain?: Living Beyond Dementia***

By Kate Swaffer

A powerful description of life with frontotemporal dementia (FTD). The author describes how FTD has affected her life. She also talks about social stigma and her own journey of self-discovery and empowerment.

### ***Alzheimer's from the Inside Out***

By Richard Taylor

A collection of essays about the author's experience of living with Alzheimer disease.

### ***Ten Thousand Joys & Ten Thousand Sorrows***

By Olivia Ames Hoblitzelle

One couple's journey with Alzheimer disease, from what gave them strength, to how they faced challenges and loss.

### ***I'm Still Here***

By John Zeisel, PhD

A discussion of a *strengths-based approach* to dementia care. This approach recognizes that the person with dementia is "still here" and can live a meaningful life.

### ***A Caregiver's Guide to Lewy Body Dementia***

By Helen Buell Whitworth and Jim Whitworth

Information and personal stories to support a caregiver's journey with Lewy body dementia.

***Dementia Beyond Disease: Enhancing Well-Being***

By G. Allen Power, MD

A framework for understanding and promoting overall well-being when dealing with dementia.

***Losing Clive to Younger Onset Dementia: One Family's Story***

By Helen Beaumont

A memoir written by a mother who is also an FTD caregiver. The author suggests ways for families to cope with younger-onset dementia.

***What If It's Not Alzheimer's?***

By Gary and Lisa Radin

A family's guide to managing daily care, adapting to changes, and finding resources in the days and weeks after a diagnosis of FTD.

***Living with Mild Cognitive Impairment***

By Nicole Anderson, PhD, Kelly Murphy, PhD, Angela Troyer, PhD

A guide to helping your brain stay as healthy as possible to prevent or delay changes in memory and thinking.

***Loving Someone Who Has Dementia***

By Pauline Boss, PhD

Ways for care partners to find hope as they deal with grief and loss.

***The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer Disease, Related Dementias, and Memory Loss***

By Nancy L. Mace, MA, and Peter V. Rabins, MD, MPH

A guide for care partners. It covers a wide range of issues including daily care, communication, behaviors, emotions, self-care, and living situations.

## Action Steps: A Checklist

There are many things you can do to take charge of your life when you are living with memory loss. The checklist below is a good place to start. You'll find action steps based on the different chapters in this handbook:

### My Diagnosis

- ☐ Make a list of questions about your diagnosis. Take your list with you to your next healthcare visit and share it with your provider.
- ☐ Learn more about your diagnosis and what it means. Research online or attend a workshop.

### My Next Steps

- ☐ Talk with friends, a counselor, or support group about your feelings.
- ☐ Decide who you want to tell about your diagnosis.
- ☐ Begin creating a support system for yourself.

### My Medical Care

- ☐ Tell your primary care provider, dentist, and other healthcare providers that you have memory loss.
- ☐ Ask your memory specialist if a referral to speech and language therapy, physical therapy, or occupational therapy might help.
- ☐ Bring your medicines with you to every healthcare visit.

### My Daily Life

- ☐ Create a daily schedule. Includes social, physical, and mental activity.
- ☐ Think about your safety. Use items you find helpful. Try a kitchen timer, an ID bracelet, pill boxes, and other tools.

### My Relationships and Activities

- ☐ Make a list of all the things you like to do. Every day, do at least one thing that makes you happy.

- ☐ Tell your friends and family what support you want. Also tell them what help you don't want.

### **My Strengths**

- ☐ Ask your healthcare team about your strengths.
- ☐ Find one way to regularly use your strengths and gifts.

### **Support for Care Partners**

- ☐ Write a list of what help you need as a care partner. Ask for support for these things.
- ☐ Call the Alzheimer's Association at 800.272.3900. Ask them what resources they have for care partners.
- ☐ Find a support group, online forum, or other program for people living with memory loss that you can attend with your loved one.

### **My Community**

- ☐ Call the Alzheimer's Association at 800.272.3900. Ask them what support groups or resources are in your area.
- ☐ Visit [www.momentiasseattle.org](http://www.momentiasseattle.org). Try out a community program for people living with memory loss.
- ☐ If you can't find the resources you want, think about what new programs or activities you might develop. Ask for help from others in your community.

### **My Plans for the Future**

- ☐ Talk with your loved ones about what kind of health care you do or do not want in the future. Fill out an Advance Directive form.
- ☐ Choose a trusted person to be your power of attorney so that this is in place if needed later. Fill out a Durable Power of Attorney form.
- ☐ Check what insurance benefits you might qualify for. Apply for them.

## **My Care Team at UW Medicine Memory and Brain Wellness Center**

The UW Medicine Memory and Brain Wellness Center team includes neurologists, neuropsychologists, geriatric psychiatrists, geriatricians, nurse practitioners, social workers, a science writer, and a community educator.

We also work with research teams at the Alzheimer Disease Research Center for Alzheimer disease and frontotemporal dementia, and the Pacific Northwest Udall Center for Parkinson disease.



*Some team members at the UW Medicine Memory and Brain Wellness Center*

Visit our website to learn more about our team:

[www.depts.washington.edu/mbwc/about/team/category/mbwc](http://www.depts.washington.edu/mbwc/about/team/category/mbwc)



## My Contacts

### UW Medicine Memory and Brain Wellness Center

- To make an appointment, call 206.520.5000.
- If you have feedback on this handbook, please call or email the Program Manager for Community Education and Impact: 206.744.2017, mbecker1@uw.edu.

### Primary Care Provider

Name \_\_\_\_\_

Phone \_\_\_\_\_

### Memory Care Provider

Name \_\_\_\_\_

Phone \_\_\_\_\_

### Other Doctor or Provider

Name \_\_\_\_\_

Phone \_\_\_\_\_

### Care Coordinator, Nurse, or Social Worker

Name \_\_\_\_\_

Phone \_\_\_\_\_

### Care Partner (Family Member or Friend)

Name \_\_\_\_\_

Phone \_\_\_\_\_

### Pharmacy

Name \_\_\_\_\_

Phone \_\_\_\_\_

### Emergency Contact(s)

Name \_\_\_\_\_

Phone \_\_\_\_\_

## Terms and Definitions

**Acetylcholine:** A chemical in the brain that helps with attention and memory.

**Activities of daily living (ADLs):** Basic things a person does during their day. ADLs include moving from place to place, bathing and showering, dressing, feeding oneself, personal hygiene and grooming, and toilet hygiene.

**Adaptive devices:** Tools that help with daily activities. These tools may include an electronic pill box that reminds you when to take your medicines, or a cane, walker, or wheelchair to help with balance.

**Adult day health programs:** Programs that have medical staff on site who can help with medicines, wellness activities, and rehabilitation.

**Adult day programs:** Programs for people with memory loss or other health issues to help them stay active and connected to others. Activities may include social time, creative projects, exercise, and meals.

**Advance care planning:** A process that helps you know and communicate your values and goals for medical care. This planning can help guide current and future decisions about your healthcare.

**Advance directive:** A form that states your wishes about the kind of healthcare you do and do not want if you become very ill. Also called a *healthcare directive* or *living will*.

**Aerobic activity:** Exercise that increases your breathing and heart rates.

**Amnesic:** Problems with short or long-term memory.

**Amyloid beta:** A protein that builds up between brain cells and forms *amyloid plaques*. This occurs in Alzheimer disease.

**Amyloid plaque:** A clump of the protein *amyloid beta* around brain cells. This occurs in Alzheimer disease.

**Care partner:** Anyone who supports or cares for a loved one with memory loss. Also called a *caregiver*.

**Cholinesterase inhibitors:** Medicines that stop the breakdown of *acetylcholine*, a brain chemical that helps with attention and memory.

**Clinical trials:** Research studies that assign 1 or more treatments to participants. Scientists monitor these people to see how the treatments affect their health.

**Dementia:** Changes in memory or thinking that interfere with daily life. For example, a person might have problems remembering what they did recently, figuring out how to do a common task like cooking or paying bills, or finding their way to a familiar place.

**Dementia-friendly:** Designed so that people with dementia can take part with ease and confidence. Also called *dementia-inclusive*.

**Dementia-friendly community:** A neighborhood, town, or city that welcomes and includes people with memory loss.

**Diagnosis:** A diagnosis has 2 parts: a description of your symptoms (such as mild cognitive impairment or dementia), and the name of the disease that is causing your symptoms (such as Alzheimer disease).

**Durable power of attorney (DPOA):** A legal document that gives another person the right to make decisions for you.

**Elder law attorney:** A lawyer who can help you plan for future care needs and finances.

**Frontotemporal dementia (FTD):** A condition caused by damage to the *frontal lobe* and *temporal lobe* of the brain. Symptoms can include changes in personality, language, and social behavior. There may be less memory loss than in other types of dementia.

**General anesthesia:** Drugs that cause a short-term loss of consciousness.

**Genetic:** Inherited.

**Glutamate:** A chemical in the brain that helps with learning and memory.

**Guardian:** Someone who is legally appointed to make healthcare and financial decisions for another person. If someone has *limited guardianship*, it means they can make decisions only in one area, such as only finances. Also called a *conservator*.

**Hallucinations:** When a person can see, hear, smell, taste, or feel something that is not there.

**Lewy body dementia (LBD):** A disease where protein deposits called Lewy bodies build up in the brain. Symptoms include changes in movement, memory, and thinking.

**Mild cognitive impairment (MCI):** A condition where a person has more memory and thinking changes than are expected for their age, but these changes do not interfere with their daily life. Also called *minor neurocognitive disorder*.

**Mixed dementia:** When more than 1 problem causes changes in memory and thinking. For instance, someone with mixed dementia may have both Alzheimer disease and vascular dementia.

**Multidomain:** More than 1 area of memory or thinking is affected.

**Neurodegenerative disease.** A *progressive* disease that causes more brain cell damage over time.

**Neurofibrillary tangles:** In Alzheimer disease, the clumps of a protein called *tau* inside brain cells.

**Placebo:** A substance that does not have a medicinal effect.

**Primary progressive aphasia (PPA):** A type of dementia that affects the ability to communicate.

**Progressive:** When symptoms increase or get worse over time.

**REM behavior disorder:** A condition where you act out your dreams. This disorder may occur with Lewy body dementia.

**Respite care:** Planned or emergency care for someone with special needs. Respite care provides a short break for a family member who is also a caregiver.

**Sleep apnea:** A condition where breathing is disrupted during sleep.

**Seizure:** A sudden change in brain activity. Seizures can cause jerking in the arms or legs, or short-term loss of awareness.

**Tau:** In Alzheimer disease, a protein that builds up inside brain cells to form *neurofibrillary tangles*.

**Vascular dementia:** A condition where brain cells are deprived of food or oxygen. A stroke or damage to small blood vessels in the brain may cause vascular dementia.

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## With Thanks

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### Questions?

Your questions are important. Talk with your doctor or healthcare provider if you have questions or concerns.

- To learn more about the Memory and Brain Wellness Center, visit [depts.washington.edu/mbwc](https://depts.washington.edu/mbwc)
- To set up clinic visit, call 206.520.5000.

