

## 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's 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's 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's disease and blood vessel problems that lead to vascular dementia. Or, someone could have the protein buildup of Alzheimer's 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's 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.

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## **Worksheet 2: What I Notice About My Memory and Thinking**

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.

On the lines below, write what you notice about your memory and thinking. What is challenging? What is still fairly easy?

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.

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## 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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*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 *amnestic* MCI. Amnestic 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 nonamnestic 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 lifestyle 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 improve 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 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 MCI 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)*

24-hour support line: 800.272.3900

Information and support for people living with mild cognitive impairment or any form of dementia and their families.

#### **Community Living Connections (Area Agencies on Aging for Washington State)**

*[www.waclc.org/connect](http://www.waclc.org/connect)*

855.567.0252

Information and referrals to programs and services by county. In Washington state, connect to your local office by calling 855.567.0252 or visiting *[www.waclc.org/consite/connect](http://www.waclc.org/consite/connect)* and clicking on the map. You can also find local resources on the website.

#### **Momentia Seattle**

*[www.momentiaSeattle.org](http://www.momentiaSeattle.org)*

Arts, social, recreation, and community service opportunities for people living with dementia, offered by various groups.

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

From Alice, living with Alzheimer's 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's Disease

Alzheimer's 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's 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's 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's 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 Living Connections (Area Agencies on Aging for Washington State)**

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Information and referrals to programs and services by county. In Washington state, connect to your local office by calling 855.567.0252 or visiting *www.waclc.org/consite/connect* and clicking on the map. You can also find local resources on the website.

### **Momentia Seattle**

*www.momentiaSeattle.org*

Arts, social, recreation, and community service opportunities for people living with dementia, offered by various groups.

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 3rd most common type of dementia, after Alzheimer’s disease and vascular dementia. 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 (Pacific Northwest Chapter)**

*www.apdaparkinson.org/northwest*

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 Living Connections (Area Agencies on Aging for Washington State)**

*www.waclc.org*

855.567.0252

Information and referrals to programs and services by county. In Washington state, connect to your local office by calling 855.567.0252 or visiting *www.waclc.org/consite/connect* and clicking on the map. You can also find local resources on the website.

**Momentia Seattle**

*www.momentiasattle.org*

Arts, social, recreation, and community service opportunities for people living with dementia, offered by various groups.

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, or 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*

Helpline: 866.507.7222

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

**National Aphasia Association**

*www.aphasia.org*

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

**CurePSP**

*www.psp.org*

Information and support for people living with progressive supranuclear palsy, corticobasal degeneration, and related conditions.

**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.

**Community Living Connections (Area Agencies on Aging for Washington State)**

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**Momentia Seattle**

*www.momentiasseattle.org*

Arts, social, recreation, and community service opportunities for people living with dementia, offered by various groups.

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 Living Connections (Area Agencies on Aging for Washington State)**

*www.waclc.org*

855.567.0252

Information and referrals to programs and services by county. In Washington state, connect to your local office by calling 855.567.0252 or visiting *www.waclc.org/consite/connect* and clicking on the map. You can also find local resources on the website.

**Momentia Seattle**

*www.momentiaSeattle.org*

Arts, social, recreation, and community service opportunities for people living with dementia, offered by various groups.

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

From Myriam,  
diagnosed with  
younger-onset  
Alzheimer's 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's 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 [www.ALZconnected.org](http://www.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.

If you have children at home, you may find these resources helpful:

- Children and Alzheimer's Disease  
[www.alz.org/media/Documents/alzheimers-dementia-parent-guide-children-teens-b.pdf](http://www.alz.org/media/Documents/alzheimers-dementia-parent-guide-children-teens-b.pdf)
- Children and Frontotemporal Dementia  
[www.theaftd.org/living-with-ftd/kids-and-teens](http://www.theaftd.org/living-with-ftd/kids-and-teens)



*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.**

## **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 cannot keep working, you may have these options:

- **Disability insurance**, provided either by your employer or privately
- **COBRA health insurance** for a while after leaving your job
- **Early retirement benefits**
- **Social Security Disability Insurance** or **Supplemental Security Income** (Note: The Compassionate Allowances initiative allows SSDI applications to be processed more quickly for people with some conditions. This includes people with younger onset Alzheimer's disease and frontotemporal dementia. To learn more, visit [www.alz.org/ssdi](http://www.alz.org/ssdi), or see chapter 12, page 4).
- **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.
- If you haven't already done so, complete an advance directive and a power of attorney form for healthcare or finances. (See chapter 10, pages 3 and 4.)

### **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 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) or [www.alz.org/help-support/i-have-alz/younger-onset](http://www.alz.org/help-support/i-have-alz/younger-onset)*

24-hour support line: 800.272.3900

Information and support for people living with any form of dementia. It has some younger-onset support groups.

#### **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.

#### **Community Living Connections (Area Agencies on Aging for Washington State)**

*[www.waclc.org](http://www.waclc.org)*

855.567.0252

Information and referrals to programs and services by county. In Washington state, connect to your local office by calling 855.567.0252 or visiting *[www.waclc.org/consite/connect](http://www.waclc.org/consite/connect)* and clicking on the





