

Appendix

Living with Memory Loss

My Care Team at UW Medicine Memory and Brain Wellness Center 2

My Contacts 3

Disability Insurance and Benefits..... 4

My Workplace Rights 6

Research Studies 8

Books..... 10

Terms and Definitions 12

My Notes..... 16

With Thanks 17

Copyrights and Reprints 18



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, a nurse practitioner, a social worker, a geneticist, a science writer, and a community educator.

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



Some team members at the UW Medicine Memory and Brain Wellness Center celebrating a successful year of service

Visit our website to learn more about our team:

<https://depts.washington.edu/mbwc/about/team/category/memory-brain-wellness-clinic>



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 _____

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.

- 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’s 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.

How do I apply for SSDI or SSI?

There are 2 ways you can apply:

- To apply online, visit 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.

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.
- An ADA center in your area. Visit the Northwest ADA Center website at www.nwadacenter.org.
- The Job Accommodation Network. Visit 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



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:
<http://depts.washington.edu/mbwc/adrc>
- Memory and Brain Wellness Center clinical trials list:
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*
- Research study matching service offered by the Alzheimer's Association: *www.alz.org/trialmatch*
- List of research studies for people diagnosed with FTD, offered by the Association for Frontotemporal Degeneration:
www.theaftd.org/research-clinical-trials/ways-to-participate/



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 that covers coping with the diagnosis, finding meaningful activities, planning for the future, and more.

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

By Kate Swaffer

The author's personal story of living with frontotemporal dementia (FTD), from overcoming stigma to pursuing self-discovery.

Alzheimer's from the Inside Out

By Richard Taylor

A collection of personal essays on living with Alzheimer's disease.

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.

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.

What If It's Not Alzheimer's?

By Gary and Lisa Radin

A guide for families on managing daily care, adapting to changes, and finding resources after a diagnosis of FTD.

Diet for the MIND: The Latest Science on What to Eat to Prevent Alzheimer's and Cognitive Decline

By Martha Clare Morris, ScD

Advice on what to eat to help your brain work its best, from the creator of the MIND diet.

Mike & Me: An Inspiring Guide for Couples Who Choose to Face Alzheimer's Together at Home

By Rosalys Peel

A detailed account of how one couple pursues a full life together and nurtures their relationship in the midst of Alzheimer's.

Ten Thousand Joys & Ten Thousand Sorrows

By Olivia Ames Hoblitzelle

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

Creating Moments of Joy Along the Alzheimer's Journey: A Guide for Families and Caregivers

By Jolene Brackey

A practical guide for creating meaningful "moments" in the daily lives of people with dementia.

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

By Helen Beaumont

A memoir about caring for a husband with younger-onset frontotemporal dementia (FTD) and how the family copes.

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 complete guide covering dementia basics, daily care, financial and legal concerns, housing options, and more.

Dementia Beyond Disease: Enhancing Well-Being

By G. Allen Power, MD

A framework for understanding and promoting overall well-being in the context of dementia.

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.

Amnestic: 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's disease.

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



My Notes

With Thanks

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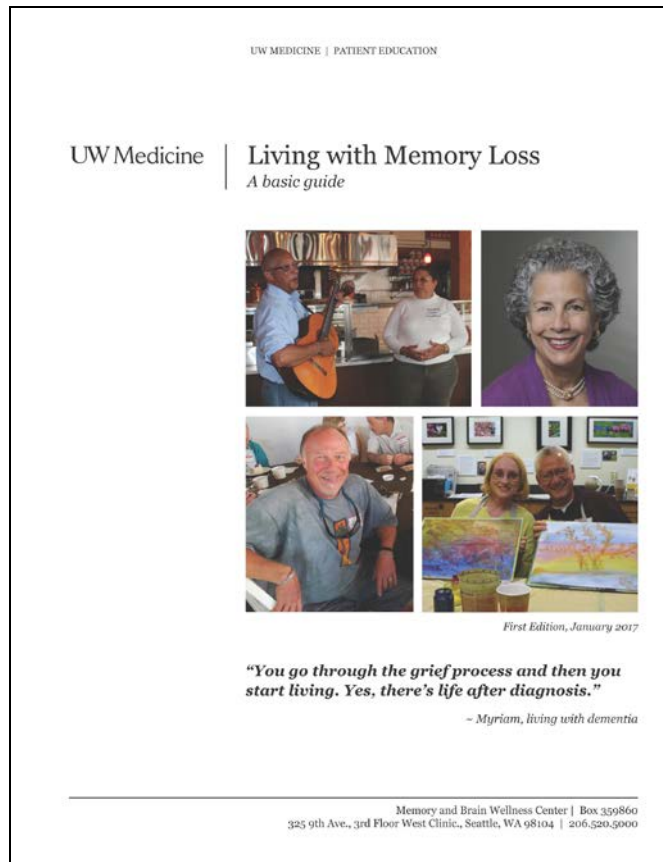
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Questions?

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 <https://depts.washington.edu/mbwc>
- To set up a clinic visit, call 206.520.5000.