

UW Medicine

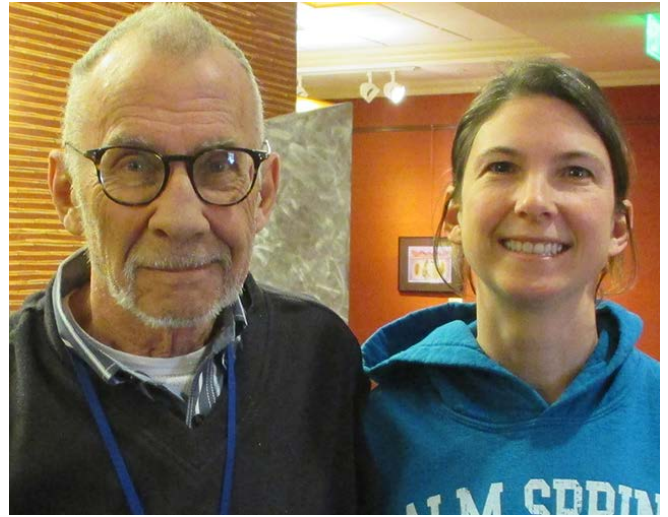
Stepping Forward

“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.

On the next pages, you'll find a checklist of action steps based on the chapters in this handbook. These can give you some ideas about what to do next.

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



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

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. Here are action steps for each chapter of 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. Include 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.momentiasattle.org. Try out a community program for people living with memory loss.
- If you can't find the resources you want, consider reaching out to a local senior center, library, faith community, service club, or other nonprofit group. Share what you envision. With your advocacy, they may be encouraged to start a new program or service.

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.

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

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!

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.

