

UW Medicine

## 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