

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.alzconnected.org](http://www.alzconnected.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 <https://depts.washington.edu/mbwc/>
- To set up a clinic visit, call 206.520.5000