

UW Medicine

My Relationships and Activities

How can I stay connected with the people and things I love?

From Myriam, living with dementia:

“When I was diagnosed, I made some choices about how I was going to live my life. Because I didn’t know – and none of us know – how many good years we have left. And so I just started to do the things that I love to do. I went to lots of places. I met wonderful friends. There is LIFE after diagnosis! And it can be really wonderful.”



From Mary, living with mild cognitive impairment:

“You kind of feel free. Because you have this situation that you can’t do a lot about, so you might as well do the things you really want to do – the things at the top of your list.



“I’ve tried new things, like folk dancing and drumming. So you don’t feel like your life is draining away – No, it can get richer in some ways.”

From Alice, living with dementia:

“My friends with Alzheimer’s, they are just wonderful. I love all these people. And since I don’t have family, I have a different family. They are my family.”

As many people who are living with memory loss will tell you, “We’re still here!” You are still you, and your family and friends still care about you. There will be challenges ahead, but you can also keep enjoying the people and activities you love.

Changes in memory and thinking don’t happen overnight. You have time to adapt. This section explains more about staying connected and doing the things you enjoy when you have memory loss.

Key Points in This Chapter

- *Your relationships with others can stay strong as you adapt to changes in your memory.*
- *You can still do things you enjoy. You may need to adjust how you approach them.*

How can I stay close to loved ones, and find new friends?

It is natural to wonder about how memory loss may affect your relationships. You may worry about losing respect in the eyes of your loved ones. You may not even want to tell your closest friends for fear of what they may think. And, some of your symptoms may put a strain on your relationships.

But, some people find that moving through challenges together can deepen relationships. They also find that they learn new things about each other along the way.

Here are some ideas for keeping your relationships strong:

- Learn more about your condition. Encourage your family and friends to learn more as well.
- Openly talk about any frustrations or worries that you have.
- Be clear about what support you want and don’t want.
- Find ways to have fun together. Many dementia-friendly activities are a great way to focus on something other than the disease.

*From Janelle Taylor, PhD,
Sociocultural Anthropologist,
University of Washington:*

“Even with its challenges, dementia can provide opportunities for your relationships to grow. Friends describe learning new ways of doing things together, seeing new sides of their friend and of themselves, and developing new empathy and understanding. You can face dementia together, with love and shared laughter along the way.”

- Be willing to show affection in new ways. Holding hands and hugging can work very well, even if you are forgetting words.
- Allow yourself to change and grow. Resisting change, or wanting things to remain “like they always were” will just be frustrating. Be curious about what is possible, and what new things you can find out about each other.
- If you’re in a rough patch with your loved ones, it may help to talk with a counselor. You may want to meet with the counselor by yourself, or with family members.

Along with connecting with friends and family, meeting others in the dementia community can be very helpful. It may feel uncomfortable or scary to think about joining a group for people living with memory loss. But, knowing you are not alone can provide a sense of relief. You can find true friendships among others who understand what you are going through.

If you are looking for some new connections and friendships, consider support groups, or community programs designed for people living with memory loss, such as walking groups or museum tours.

See more options for staying connected in chapter 9, “Community Resources.”

From Mary, living with mild cognitive impairment:

“Look for groups of people who have similar diagnoses. And try new things! I try new things because I figure, it doesn’t matter if I make a mess of it – I have an excuse. If you don’t remember somebody’s name, they’re not gonna care, because they don’t remember yours.”

Worksheet 5

Staying Connected: Me, my family, friends and community

The relationship that is most important to me right now is my relationship with ...

I stay connected to this person by ...

One thing I can do to enjoy this relationship is ...

If I wanted more friendships or support, I could ...

Community Spotlight

Finding Connections at an Alzheimer's Café

Roger Stocker says he looks forward to going to the Alzheimer's Café in Greenwood, Seattle, every month. A former architect, Roger has been living with Alzheimer disease since 2010. He actively looks for ways to connect with others living with memory loss. "When people like us get together – those with dementia – there's a lot of love there," he states.

An Alzheimer's Café is a way that people living with memory loss and their friends and family can enjoy getting together in a relaxed coffee shop or café setting. These groups started in the Netherlands in 1997 and came to the U.S. in 2008.

In 2010, Seattle's Greenwood Senior Center started the Alzheimer's Café that Roger attends. There are now 9 Alzheimer's Cafés in the Puget Sound area and more than 200 Alzheimer's Cafés in the U.S.

Daphne Jones and her husband have provided live music at the Columbia City Alzheimer's Café. Daphne shares, "It has really grown into a social thing. I've deepened friendships with the people who come. We can sit and talk and have a good time. I look forward to it. I know I'll get a hug from somebody and a smile from somebody."



David and Daphne Jones perform at the Alzheimer's Café in Columbia City (photo by Full Life Care).

If you'd like to start an Alzheimer's Café in your community, there are resources to help. Carin Mack, a social worker who helped start the Greenwood Alzheimer's Café, says, "In my opinion, it's the easiest thing to get started. There are a lot of people who are willing to help."

- To learn more and to get tips on starting your own Alzheimer's Café, visit www.alzheimerscafes.com.
- To see a list of Alzheimer's Cafes in the Puget Sound area, visit www.momentiasattle.org/alz-cafes.

What are some ways to keep doing things I enjoy?

While you may need to make some adjustments, there are ways to keep doing what you love to do:

- If you used to enjoy singing in a choir, you can get together regularly with a few friends to sing familiar tunes.
- If you liked getting outdoors on long hikes, maybe you can join a walking group.
- In the Seattle area, a growing movement called Momentia provides a variety of dementia-friendly activities. Offerings include the arts, recreation, connection, and ways to volunteer in the community. See www.momentiasattle.org and learn more in section 9, "Community Resources."

Worksheet 6

Joy: What makes you feel good?

One thing I really like to do is ...

The thing I like about this is ...

Even if my memory and thinking change, I can still have this kind of experience by ...

Community Spotlight

Exploring Creativity

Around the world, awareness is growing about the benefits of taking part in the creative arts, and about the creative potential of people living with dementia. In the Seattle area, we are seeing the growth of “dementia-friendly” programs that involve art, theater, music, and more.

In 2010, Seattle’s Frye Art Museum began an innovative program called **here:now**. The program helps people with memory loss and their families enjoy specially designed art gallery tours and art-making classes in an inspiring museum setting.

Mary Jane Knecht, program manager, says, “In the **here:now** program, we tap into the strengths of the person living with dementia. Our activities provide present-focus awareness and new possibilities of creative expression.”

Lee Burnside, a geriatrician with University of Washington, is on the advisory group for **here:now**. Lee explains, “Creative potential remains, and may even be enhanced, in persons living with dementia. Taking part in creative arts can be an effective tool for personal growth, discovery, and enjoyment.



Frye Art Museum’s here:now program.

Photo by Jill Hardy

