Perspectives 2.0

A newsletter for people with dementia, about LIVING with dementia

ISSUE 2: FALL 2026

WELCOME!

Welcome to the second issue of Perspectives 2.0, a newsletter, about and for people LIVING well with dementia.

Perspectives 2.0 is a revival of the original Perspectives newsletter, created by dementia advocate Lisa Snyder in 1995, and ended with her untimely passing in 2017.

Perspectives 2.0 highlights the lived experiences of people with dementia. We offer an alternative lens from which to view dementia – one that is person-centered, not defined by a medical model. Person-centered means that the focus is on the person as a whole, not simply as a "dementia patient".

If you would like to read more about the values behind Perspectives 2.0 and browse the original Perspectives newsletter, you can find that here.

Perspectives 2.0 is created by and for people living with cognitive change. Our Editorial Board, comprised of people with lived experience, reviews our newsletter content, shares personal experiences, and recommends issues important to them. Our goal is to explore more about living well with dementia.

We are so grateful for the time, energy, and wisdom of our Editorial Board: Arnie Beresh, Ellen Sue Moses, Seth Stern

Perspectives 2.0 is co-facilitated by Sonya Barsness and Tiffany Zhang. It is brought to you by Sonya Barsness Consulting, creator of Person-Hood™ which offers education and support to LIVE with dementia.

WELCOME!
(Continued)

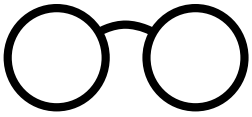
So, let's hear from our Editorial Board members.

What is a perspective about dementia that you wish other people living with dementia might have?

Celebrate your strengths, enjoy your people and laugh with yourself.
-Ellen Sue Moses

They need to know that there are others with the same problem and support groups to help them get their questions answered. There is life after diagnosis.
-Arnie Beresh

There are many different types of dementia. And there is no one aspect that covers all of them. People are experiencing different characteristics relating to their dementia. I have frontotemporal dementia, and one of the unfortunate aspects of it is, you experience significant apathy. So, even though you may enjoy doing or experiencing certain things, that is taken away from you. My example of that is that I'm a retired OBGYN physician after 37 years. I always loved practicing medicine and doing deliveries and performing surgeries and establishing a good rapport with my patients. I was the type of physician that enjoyed arriving in the hospital early in the morning, one of the first, and staying all day, and one of the last to leave. And then, all of a sudden in 2021, I was greatly affected by apathy. I no longer had that desire to be first in the hospital or last to leave. Not everyone experiences it, and people have different degrees that they may experience it, but that was the way I was affected. The unusual thing is I don't have constant apathy, and it is to different degrees. This past week, I had very significant apathy in which I didn't really want to participate in things. I'm very involved with different groups relating to frontotemporal dementia and other types of dementia, and I let the meeting leaders know in advance I may not be at the meeting, or, if I am at the meeting, I may not say much. So that they wouldn't be surprised. It's better to be open about what's going on. I have determined that this is what works best for me.
-Seth Stern



Spotlight on a Person LIVING with Dementia

A Multigenerational Conversation between Ellen Sue and Tiffany

Tiffany: How would you like to introduce yourself?

Ellen Sue: My name is Ellen Sue Moses, and I am an ambassador for people experiencing cognitive change. I am a retired pharmacist and have been living with vascular dementia diagnosed seven years ago. I attended pharmacy school at the University of New Mexico College of Pharmacy. Over the years, I have lived in several states and gained a broad range of professional experience, including working as a pharmacy consultant for skilled nursing facilities. These days, I live with my partner, Mark, and Oscar the Cat. I also love gardening and growing orchids, reading and taking walks.

Tiffany: What do you believe are some misconceptions about how people view life with dementia?

Ellen Sue: One of the biggest misconceptions is a dementia diagnosis means you can no longer have a full and rewarding life. The stigma created by family and friends, the media, physicians and well-meaning professionals often assume that we can no longer safely socialize with family, continue to learn, and participate meaningfully in the world around us.

I encounter people who do not understand that it takes me longer to process information and create a response. Sometimes, instead of allowing me that time, they repeat themselves, speak loudly as if not heard and get impatient. I have even had a family member become angry, yell at me, and walk away. Experiences like that can be very painful because what I need instead is patience, understanding and respect.

People often think that a diagnosis is the end of their life. Instead, it is the beginning of a new adventure for me in a life filled with adventures.

Tiffany: How do you manage or respond to those situations?

Ellen Sue: Sometimes I tell people directly that I have cognitive change, and I try to help them understand what that means and how best to communicate with those of us with cognitive changes. I have spent a lot of time speaking to groups about my journey through cognitive change because I think education is the best way to combat stigma.

Ellen Sue (continued): Sharing my story helps people see dementia differently. We are still people with skills and ideas. relationships, personalities, and lives. We need to be included and encouraged, not hidden away.

Tiffany: If there was one (or a few) pieces of information or wisdom you wish you could impart to everyone, what would it be?

Ellen Sue: Everyone has differences, and we need to see those differences as normal and celebrate them. Everyone deserves to be treated with respect and dignity. For me, the most important part of that is inclusion. But my definition of inclusion is not simply having a group and inviting someone into it. Real inclusion means that everyone has equal roles, equal responsibilities, and an equal voice. People living with cognitive change need to be involved in the conversations and decisions that affect them. That includes research, programs, services, and anything else being developed for our community. These things should be created with us, not just for us.
I have had the wonderful experience of working in research as a co-researcher on studies at Yale University. That has shown me how meaningful it is when people with lived experience are treated as partners, not just participants.

Tiffany: What is a difficulty in your life with dementia that you wish more people were aware of?

Ellen Sue: I've already mentioned that it takes me longer to process information. Reading books is impossible now, I can't follow the story line or characters anymore so short reads are the most I can handle. I also have a very difficult time sequencing. In cooking a meal, for example, there are so many steps that must be coordinated. And it comes up in other situations too. I get lost easily, even in familiar places. I cannot keep my calendar straight and miss appointments.
need people to speak slowly and clearly. If I am in a meeting, I need each topic completed, not have people interrupt each other, and be sure what was discussed is understood before moving on. When things move too quickly or jump around, I get lost and tune out. Large social events can also become overwhelming. And I get distracted and overwhelmed in restaurants with big screens everywhere.
One thing I want people to understand is that I only have so much cognitive energy in a day. Every task, every conversation, and every decision uses some of that energy. Once it is used up, I am done for the day. Some people call that energy "spoons." By late afternoon, I am usually out of spoons.

Tiffany: What is your favorite thing about life today?

Ellen Sue: The best thing about my life today is my partner, Mark. He is incredibly supportive and understanding, and he has helped me recognize that living with dementia has brought positive changes into our life. Mark does not finish my sentences—unless I want him to. If I become angry or confused, he asks whether I want to be heard, helped, hugged, or have some space. It is a system that works well for us. He is very patient and provides me with the opportunity to express what I need.

At some point, you realize dementia is not going to go away, so you learn to roll with the changes. I have integrated dementia into my life and into my being, but I am not identified by it. It informs my life, but it does not define me. By accepting it as part of who I am, I can continue doing the things I love to do.

One of those things is talking to people about living well with dementia. I want people to understand that life is made up of many journeys, and dementia is another one. We are on this journey together.

When I tell people I have dementia, they usually say, "Oh, I'm so sorry." And I say, "Well, I'm not, so you don't need to be!" Of course, I do not go around advertising it, but I share it with people when I feel they need to know.

One of the sayings that is important to me is, "Nothing about us, everything with us. It connects to what I said earlier about inclusion. If you do not give people agency, respect, and inclusion, then you are missing the valuable contributions we can offer. When everyone is not included, your perspective becomes narrow and full of bias.

We want dementia to be seen as and treated like a disability instead of a disease, so that legislation would give people greater access to support and resources at both the state and federal levels. It could also help strengthen research funding, which is already very limited.

Dementia is not a single diagnosis. It is a broad term used to describe many different diseases and conditions that involve cognitive changes, including but not limited to, Alzheimer's disease, vascular dementia, frontotemporal dementia, Lewy Body, traumatic brain injury, and Parkinson's disease.

I prefer the term cognitive changes because it is a continuum. Dementia is a static term. Cognitive changes affect everyone differently. It affects different parts of the brain, and each person experiences different changes and deficits. If you have met one person with cognitive changes, you have met one person with possibly one or more cognitive changes.

Tiffany: I didn't know that, thank you for teaching me.

Ellen Sue: Well, of course–that's what I'm here for!

Tiffany: What is a day in the life of Ellen Sue like?

Ellen Sue: I spend the day working on my orchids. Orchids are quite easy to raise, despite their difficult reputation. I like to buy the ones that are wilting, the ones nobody wants. People do not always understand that no matter what condition they may look like they are in, they will always bloom. So I take them home, baby them for a while, and then they bloom fully and beautifully. I also like to name my orchids after inspiring women. I have one named Frida Kahlo and one named Maya Angelou.
I am often in zoom meetings working on research projects, developing classes at LiveWell, writing my personal story or sitting on my deck enjoying a short read. On other days, I play Mah Jong with friends, go to class, attend meetings, and spend the day at LiveWell in Plantsville, CT. I might go for a walk and I love pampering myself by getting my nails done.

Tiffany: Finally, is there anything that you would like to add to conclude?

Ellen Sue: My conclusion would be that people with cognitive change need inclusion. We need to be an integral part of everything, especially anything that is done with us in mind.
We do not want people to simply do things for us, because doing something "for" us is infantilizing us. People with cognitive changes are not reverting to children. We are adults with life experiences which enrich everything we are involved in. We also do not want to be included just as a token person in a group. We want to be part of the whole process from the beginning. We want to be seen as valuable, capable, and equal contributors.

Ellen Sue Moses is on the Editorial Board of Perspectives 2.0.
Tiffany Zhang is a co-facilitator of Perspectives 2.0.

Research on LIVING with Dementia

In Perspectives 2.0 we focus on non-medical research that looks at LIVING with dementia.

"Perspectives on Living Well with Dementia"

This recent study, published in the Journal of Applied Gerontology (2025), asked people with dementia about "living well with dementia" and what this meant to them. People living with dementia shared that the moment of the diagnosis was life changing, and for some, very traumatic. They also said they might not have been living well right after the diagnosis as they came to terms with it. The process of acceptance took time. Some described it as a "back and forth" process. People living with dementia also shared:

- **Moving on** with their life and **carrying on** with the things they used to do.
- Wanting to be **included** and **treated normally**.
- Realizing they **needed help with things, but getting too much help was frustrating** and demoralizing.
- **Wanting to contribute** and be of help to others.
- Feeling the importance of **making every moment count**.
- Focusing on the things in life that **gave them joy**, even the ordinary things, and with the people they cared about.
- Accepting that there are **good days and bad days**.
- Trying to be **kind to themselves** when they have bad days or difficulties.
- **Coping by adapting** – trying to change their mindset, focusing on what they can do, maintaining activities, slowing down, and changing how they do things.
- Relying on their **social support** (family and friends) in helping them to live well.
- Trying to take care of both their **physical and emotional well-being**.

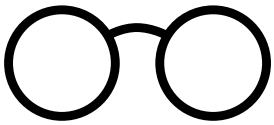
Research on LIVING with Dementia

Overall, study participants were clear in saying that each person with dementia is different, with a different experience. And that it is possible to live well, while experiencing the changes of dementia.

The study results called for broader “multi-dimensional” (more than medical) approaches to supporting people living with dementia, including physical, emotional, social, spiritual and daily living. It also called for professionals to develop strategies to support people living with dementia that are:

- Individualized
- Focusing on strengths, including inner strengths of people like resilience
- Creating physical and social environments that enable people to do the things they want to do
- Supporting overall well-being

This study was published in 2025 in the Journal of Applied Gerontology by authors Sheila Molony, Sam Fazio, Cynthia Barrere, Sheryl Zimmerman, Ricci Sanchez, Joseph Montminy, Maureen Rulison, Rachel Montesano & Kimberly Van Haitsma.

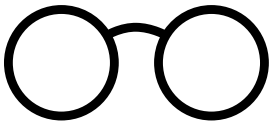


Q&A
From People LIVING with Dementia

Dear Perspectives 2.0,
Should I tell my friends I have dementia?
Jim, Person Living with Dementia

Dear Jim,
Only tell those you trust first. I think you have to process the diagnosis before telling other friends and family. Then you can anticipate how to answer their questions and understand their reactions.
Perspective, Person Living with Dementia

Dear Jim,
Yes, definitely. It allows people to know more about you, and you are in a better circumstance to improve understanding about you and your situation. For example, I play pickleball a lot, 3 times a week. Two hours a session. I'm considered a good player, and most people want to play with me. The situation occurs in which I'll meet someone for the first time today, and when I play the next time, which is 2 days from now, they'll come and say, oh, let's play again, and we had such a good time – we were good partners, we won a lot – and unfortunately, I won't remember it. Having played with them, I won't remember even meeting them. So, when I do meet someone for the first time, I explain to him, it's most probable that when we meet again, whether it's one or two days, I may not remember ever meeting you, or even playing pickleball with you. So, please don't be insulted. And I would appreciate that if you do see me in the future, instead of waiting for me to say, "Hi, John, Hi Mary", just come up and put out your hand and say, "Hi, my name is such and such. And you know what? Doing that has really improved my life. Because people are not surprised when I don't recognize them.
Perspective, Person Living with Dementia



Q&A
From People LIVING with Dementia (continued)

Dear Jim,

Telling people about your disability is a personal and difficult event. You may decide to tell some and not others depending on the social, employment or group participation. Most of the time, if I'm out, depending on the crowd, I may or may not say anything, because it may not mean anything if I'm only going to interact one time with that person. And there are other times that my wife will kind of cue me in to somebody that we go out more frequently with. She might say, you're withdrawing back, you really have to tell this person what's going on, because they're looking at you confused.

It also changes from moment to moment. In the morning, I might be good and more conversational about it. In the afternoon, I just may be knocked out, not willing to talk to anybody, and say, I've got Lewy body, and I just don't have enough cognitive reserve. And explain to them what it is versus Alzheimer's.

Perspective, Person Living with Dementia

Dear Jim,

This is a difficult thing to grapple with, as people living with dementia often tell me they are worried people will see them differently. This is a valid concern, because of how people misunderstand dementia.Maybe think about what could come out of sharing that you have dementia. What might be the benefits? It might be that your friend is grateful that you are sharing this so that they can support you. You might find that this person wants to be there for you, and you are giving them the chance to do that for you (you would probably do the same for them). It is very possible that your friend already suspects something is going on. They might be trying to piece it together, and they may or may not get it right. By telling them yourself, this empowers you to tell them what you want to tell them, on your terms, and with the language you want to use. You may need to educate your friend on what it means to have dementia. You might need to tell them that you are still you, just happen to live with a medical condition that affects your brain. On the other hand, if you tell your friend, and they don't react positively, you can feel good that you tried to be honest. You can't control their reaction, but you can decide moving forward what the friendship will look like. It also might take some time for that person to come to terms with what you have told them.

Perspective, Professional supporting people living with dementia

Resource Spotlight

National Council of Dementia Minds
https://dementiaminds.org/

The Vision of National Council of Dementia Minds:
We are people living with dementia transforming how the world views life with a neurocognitive disorder.

The Mission of National Council of Dementia Minds:
To develop and support a national corps of Dementia Minds™ groups—composed of persons living with dementia—who foster education and dialogue among individuals with neurocognitive disorders, families, care partners, healthcare providers, researchers, policymakers, and communities at large in order to empower more people to live well with dementia.

The website of the National Council for Dementia Minds has videos on a variety of topics, created with people living with cognitive changes. Examples of topics are: Dementia and Frustration, Dementia and Driving, Dementia and Cognitive Energy

Creative Expression from People Living with Dementia



Painted by Jane Kippenhan, a person who was living with dementia
Jane's work, created in a class at Elderwise, was a part of an exhibition called "The Artist Within" at Seattle City Hall in 2019.

Contact us with your ideas, comments, questions: perspectivesnewsletter@gmail.com or 757-828-7831



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PERSPECTIVES 2.0 INCLUDES CONTRIBUTIONS FROM, AND IS REVIEWED BY, PEOPLE LIVING WITH DEMENTIA. WE ARE DEVELOPING AN EDITORIAL BOARD OF PEOPLE LIVING WITH DEMENTIA. IF YOU ARE INTERESTED, PLEASE CONTACT US AT PERSPECTIVESNEWSLETTER@GMAIL.COM OR 757-828-7831

About the co-facilitators of Perspectives 2.0:

Sonya Barsness is a gerontologist, change agent, and advocate who works to support people with dementia to live well. To learn more about her work, visit her website www.sbcgerontology.com or her blog www.beingheard.blog.

Tiffany Zhang is a medical student at Darmouth College. She has been dedicated to exploring and promoting multigenerational learning since taking Professor Barsness's Psychology of Aging course while a student at Georgetown University.