Perspectives 2.0

A newsletter for people with dementia, about LIVING with dementia

ISSUE 1:
SUMMER
2025

WELCOME!

In 1995 Lisa Snyder, a social worker and dementia advocate, introduced the first issue of Perspectives, a newsletter for people living with dementia. At the time, there was very little information geared towards people living with dementia – most information was for care partners. This was a groundbreaking achievement – to create something that would reflect the issues important to people living with dementia themselves. Underlying this was the belief that people living with dementia were capable and curious – they wanted to learn about their conditions, and they wanted to know what they could do about it.

The 89th and last issue of Perspectives was released in 2017, due to the untimely death of Lisa Snyder. Years later, we recognize the epic impact of her work for people living with dementia, and her role in inspiring generations to hear their voices. We honor the role Perspectives has had in boosting efforts to provide support to people living with dementia based on what is important to them.

This is **Perspectives 2.0** – an evolution of this original newsletter.

In Perspectives 2.0 we will continue to elevate the lived experiences of people with dementia. We also strive to share another perspective of dementia – one that is not biomedically-centered, but rather, driven by a focus on the PERSON who is LIVING with dementia. While the types of dementia may be medical conditions, the experience of living with dementia is more than medical - it is about living as a WHOLE person.

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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)

Perspectives 2.0 offers perspectives on navigating dementia based on these principles/values that have been identified by people living with dementia:

- People are more than their dementia – they are full human beings with needs, wants, interests, and assets.
- People with dementia cannot be viewed through the lens of abnormalcy or deficits.
- Each individual living with dementia has their own story and experiences dementia uniquely.
- People with dementia are capable of many things.
- People with dementia are active and valuable participants in their own lives and society.
- Dementia can be life-changing in both negative and positive ways. And people can live well with it.
- “Treatment” of people living with dementia includes, and might even be driven by community, belonging, purpose, meaning, connection, and inclusion. These human needs are the basis for living well.

We are committed to sharing information and resources that highlight these values.

Perspectives 2.0 gives voice to the:

- Perspectives of people living with dementia
- Perspectives of research on living well with dementia
- Perspectives of resources that support people to live well with dementia
- Perspectives of the creative expressions of people living with dementia (books, articles, blogs, podcasts, music, dance, theater, paintings, etc.)

If you are living with dementia, we hope that these perspectives will remind you that you are not alone. There is more that is right with you than wrong with you. We see you, and we want to hear you!

To receive Perspectives 2.0 by email, you can sign up at www.perspectivesnewsletter.com or email us at perspectivesnewsletter@gmail.com.

Spotlight on a Person LIVING with Dementia

A Multigenerational Conversation between Arnie and Tiffany

Dr. Arnold Beresh, living with dementia since 2015, is an educator for physicians and students on dementia and an advocate for the Alzheimer's Association and National Council of Dementia Minds.
Tiffany, a graduate of Georgetown University, catches up with her previous classmate. The two met in Sonya Barsness's graduate Psychology of Aging course. The class, using her multigenerational learning model, unites older adults with undergraduate and graduate students in a learning environment focused on promoting shared learning and emphasizing reciprocity.

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Tiffany: How would you like to introduce yourself to the newsletter?

Arnie: Hi. I am Dr. Arnold Beresh, a retired podiatric surgeon, and a person who was diagnosed with mild cognitive impairment and early onset dementia in 2015... was that the introduction we are going for?

Tiffany: That's a great start! Tell me more about how you spend your time and the communities you are a part of.

Arnie: I'm an advocate for the Alzheimer's Association and National Council of Dementia Minds in helping to progress Alzheimer's legislation. I also am a resource for physicians and students within the medical field. Since dementia mitigation is not always clear, I think physicians must have these connections and resources.

Tiffany: What are some of your favorite things about life today?

Arnie: Taking part in support groups. Support groups are a great resource for creating safe spaces for those living with dementia or neurocognitive impairment. People can talk and ask questions freely and safely within a community of people who are also living with MCI or dementia, without the input of people from the outside. It is a great place to connect with people who are going through what you're going through.

A Multigenerational Conversation between Arnie and Tiffany

Continued

Arnie: However, social spaces for people living with dementia are an entirely different entity. People with neurocognitive diseases can get overwhelmed in social situations, especially when they may not know everyone. They may feel the need to get away from the noise or limit their conversation area. I find that limited background noise where I can interact with people I know makes for better social spaces.

Tiffany: Something I love about multigenerational conversation, which I remember from being in class with you, is that I learn that we are not that different. I can relate to many things you mentioned about uneasiness in large social gatherings.

Arnie: That is true; I believe many of those statements could also be true for people who are introverted. Conversations like these are another one of my favorite things - I get to present to the public what “life” is through my eyes.

Tiffany: Have your favorite things about life changed throughout your life?

Arnie: Definitely. Throughout high school, college, medical school, residency, practice and now, my favorite things about life were different at each point. We all pick what things at each stage of life are our favorite - like when people are in the process of building a family, at that time, their focus is on family, but when they’re in school, their focus might be on academics or friends. I mean, I guess the exception might be people who have firmly ingrained hobbies like golf.

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

Arnie: There are huge misconceptions. When people hear about those living with neurocognitive diseases, they think aout the terminal aspect of it; however, when someone is diagnosed with dementia, there is life after diagnosis... good quality of life. Of course, there is good quality of life until there isn’t. There aren’t specific starting points and ending points of dementia, and that is what a lot of people don’t understand.

A Multigenerational Conversation between Arnie and Tiffany

Continued

Arnie: For example, I can be spot on one day and the next day be totally confused. Or, the person can be good in the morning, but by the afternoon they may have to forget the rest of the day - that is the biggest misconception.

Another misconception is that people with dementia and neurocognitive disease cannot learn anything. This is not true. I know people living with dementia who have gone back to school and gotten other degrees. While, yes, it is not common, I know people who have. People living with dementia also discover things that they didn't know that they could do before. So, I would say that people living with dementia still have that fundamental ability to achieve things.

Tiffany: What wisdom do you wish you could impart to everyone in this world?

Arnie: One is to live your life to the fullest and enjoy your family and friends. Another is to maintain your identity.

Tiffany: I remember asking you this question in class, and this answer - your answer has stuck with me ever since. It's a whole different experience hearing this advice even just two years ago than hearing it now. I've learned much more about what it means to live fully now than before, and it seems like one of those concepts that I'll develop more as I get older.

Arnie: You're right - hearing it and living it are two completely different processes. It's not necessarily changing your way of doing A, B, or C - it naturally becomes a part of life.

Tiffany: Is there anything more you would like to add?

Arnie: If you meet one person with dementia, you've only met one person. Do not make assumptions about how someone lives with dementia by comparing them to another person - it presents differently depending on the person.

Research on LIVING with Dementia

When one thinks of “dementia research” the first thing that might come to mind is medical research – maybe studies that look at medications or other treatments for the various causes of dementia. This type of medical research is certainly important. And, there are a lot of other studies about dementia out there, particualrly non-medical research. Bottom line, as the experience of living with dementia is “more than medical”, research is also “more than medical”.

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

An example of this is a research project, called Improving the Experience of Dementia and Enhancing Active Life (IDEAL), which ran from 2014 through 2022.

There were many studies that came out of IDEAL. One study looked at how three types of psychological resources - self-efficacy, optimism and self-esteem - were related to whether a person might live well with dementia. Self-efficacy means person's belief in their ability to cope. Self-esteem refers to feelings of self-worth. And optimism refers to the tendency of a person to expect positive outcomes. Whether a person was living well with dementia was measured through how they rated their quality of life, well-being, and life satisfaction.

In plain language, the study found that having a good sense of self-efficacy, optimism and self-esteem could help a person to live well with dementia. This might not be surprising to some people. This also dispels any myths that people living with dementia lack emotional capabilities. These results confirm that there are things people CAN do to live well with dementia, and also remind us that “treatment” for dementia could also include people building their self-efficacy, optimism and self-esteem so that they can better live with dementia.

From the article “Psychological predictors of ‘living well’ with dementia: findings from the IDEAL study”.

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

Q&A
From People LIVING with Dementia

Dear Perspectives 2.0,
I have trouble finding the words I want to say. It takes me a while. I know my husband is trying to help but he sometimes will jump in before I have the chance to try to get it out. I get frustrated with him and then I feel bad. How can I handle this?
Paulette, a person living with dementia

This has happened to me. It is very frustrating. I have the thought in my head, know what I want to say, and I can't get it out. I cannot find the words. Sometimes I forget what I was trying to say whle I am searching for the word. I often want to keep trying to find the word, but after awhile I appreciate when my partner jumps in. He does give me some time to try to figure it out, and also worries that if he is quiet too long, it will seem like he is not listening to me. When I am with friends and I can't find the word, I will say to them "I'm sorry". And my friends will say, "Don't worry, it's okay".
- *Perspective of Lynda, a person living with dementia*

This could be an opportunity to talk with your husband about when you want and don't want help to find the words. Let him know that you know he is really trying to help and you want to help him help you. You might suggest to him that he ask you if you want help when you are having challenges. You might need to let him know what is helpful or not helpful to you - for example, maybe you need him to be quiet while you try to think of the word. Or maybe you want him to not look at you because that makes you anxious. Some people with dementia say that it helps them to "let go of the word" because the pressure of trying to think of it makes it harder - they say that sometimes the word comes back to them when they give themselves a break. This is frustrating for you both, so be sure to show yourself the same kindness you are showing your husband.
- *Perspective of Sonya, a professional working in dementia*

Perspectives 2.0 is for informational purposes and is not medical advice.

Resources

The Dementia Action Alliance (DAA) is is a diverse coalition of passionate people creating a better society in which to live with dementia. All DAA efforts and activities are shaped and informed by individuals living with dementia.

www.daanow.org

DAA also recently published a free guide called “Pathways to Well-Being with Dementia: A Manual of Help, Hope, and Inspiration”, which was written with people living with dementia. You can get it here: https://daanow.org/pathways-to-well-being-with-dementia/

Creative Expression from People Living with Dementia

Paddling

Living with dementia
Looks like a swan
Calm on the surface
Paddling faster and harder
Below the surface
To stay afloat

A poem by *Kate Swaffer, a person living with dementia*

From her book “Love Life Loss - A Roller Coaster of Poetry Volume 2: Days with Dementia”

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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 graduate of Georgeotwn University with majors in biology and music. She has been dedicated to exploring and promoting multigenerational learning since taking Professor Barsness’s Psychology of Aging course.