

Three perspectives on an incident that happened to someone living with dementia.

“You don’t look like you have dementia”

An Alzheimer’s educator’s perspective

In dementia education, we frequently refer to the journey of dementia, highlighting that the experience for each person is unique. The specific diagnosis, the stage of the illness, and support available through family or community all influence a person’s lived experience. Even beyond those factors, every person affected by dementia is an individual, in the same way that we are all individuals, products of a lifetime of experience, learning, culture and personality. We tend to hold in our minds a “typical” view of what dementia should look like, and we frequently assign certain expectations of behaviours and abilities. One aspect of dementia that I have learned as an Educator is that for every feature of dementia that I talk about, there is someone who can provide an exception to the usual presentation.

Even I was stunned to read the personal reflections of Dr. Jennifer Bute, a former General Practitioner now living with Younger-Onset Alzheimer’s Disease. She describes it as a “glorious opportunity”. How is it possible that anyone can describe living with Alzheimer’s Disease as glorious? But Dr. Bute feels privileged. She can combine her professional knowledge of dementia with her own insights from living with the disease, and she finds herself in a unique position to educate the public about dementia. I would offer a parallel example that many people are familiar with, that demonstrates how we can use exceptional individuals that don’t necessarily fit our stereotypical view of a disease pattern to show how we can learn important lessons. Stephen Hawking was known for his brilliant mind but he also gave voice and recognition to the condition of Amyotrophic Lateral Sclerosis (ALS), another degenerative neurological disease that typically leaves people isolated and vulnerable. Professor Hawking lived with ALS for 55 years. This was dramatically atypical for this disease, but we don’t question the validity of his experience and his contribution to raising awareness of ALS has been invaluable.

It is very common for diagnosis to occur late in the disease process, but most people recognize that changes had been apparent long before diagnosis, often years before. Under these circumstances, many people have progressed to a stage where they are no longer able to provide a voice for dementia. As more people receive an earlier diagnosis, we do see more individuals able to speak up and articulate their needs and the needs of others living with dementia. Phyllis Fehr Dementia Alliance International board member, MaryBeth Wighton Ontario Dementia Advisory Group chairperson, and Kate Swaffer Dementia Alliance International chairwoman are all articulate speakers who have shared the lived experience of dementia, even if they don’t fit the profile that many people would view as “typical” of dementia. Only through listening to these individuals though, can we formulate meaningful policies and standards for care provisions that meet the needs of individuals with dementia.

Phyllis Fehr has made it her passion to use the ability that she retains for the benefit of others and to represent individuals living with dementia, including those unable to express themselves. She and others like her from around the world are speaking up, insisting that we respect the needs of those with dementia. If we want to say that we respect the rights of people with dementia, we are obligated to pay attention, and listen to what Phyllis has to say.

A person with dementia's perspective

Can you tell me what someone who has Alzheimer's look like?

Is he/she old or are they young, does he/she look a certain way, does he/she look disabled or like everyone else?

Is the way person's with dementia are viewed different than others, if so, why is this? Is this due to lack of public awareness, lack of education or the lack of knowledge about this disease.

My name is Phyllis, I am a registered nurse, grief and bereavement councillor, researcher and a person living with Alzheimer's. I speak on many topics about Alzheimer's from a personal perspective. I will take a moment to tell you about an incident that happened recently.

At a recent day in geriatric education I gave my speech and I thought things had gone very well. When we opened it up to the floor for questions a physician got up and asked the first question: Do you still drive? "Yes, I still drive," I replied.

He retorted, "If you were my patient, I would be hard-pressed to diagnose you with mild cognitive impairment, let alone Alzheimer's." At this point he also stated that if I were his patient he would be hard pressed to diagnose me with Alzheimer's.

It was at this point that I started to feel like I was being questioned as to the validity of my diagnosis and left me feeling like I was being attacked. In order for me to continue to take more questions I gently told him I would take no further questions I directed my attention to the next hand that went up.

The truth is I don't believe he wanted to hear this... plus, his manner was so off-putting I didn't have the presence of mind with dementia to inform him that due to Alzheimer's, it takes me longer to digest and understand information and questions.

I could have said that that I have self-imposed limitations, for driving. These include not driving at night, routinely driving with family members who will let me know if I can still drive or not. I don't drive on major highways... but I did not say any of this.

During the break he approached me at the booth for the Alzheimer's Society. Again he began asking questions. He was very dismissive to what I was saying as if he had his own agenda and again I became dismissive and walked away after handing him pamphlets on Alzheimer's.

The way I was questioned about my disease and the validity of my diagnosis happens more frequently to those of us living with Alzheimer's and dementia than most people would like to believe.

This upset me deeply, and I dwelled on it for about five day. I thought how can I turn this negative into a positive experience. That is when I decided I need to write about this incident so we can all see and understand what happens.

Understanding the experiences of people with dementia

A member of the Behavioural Supports Ontario Team

At a recent educational event, I observed an interaction between an audience member and Phyllis – a speaker living with dementia. The audience member quizzed the speaker about her diagnosis and ability to drive, without providing a rationale for why the information would be helpful. The approach was abrupt, but not unlike the way many healthcare providers interact with clients/ patients/ residents and their families.

It wasn't until well after the event that I spoke with Phyllis, and she expressed that the questions had left her feeling troubled. I then reflected on the interaction and realized that Phyllis walked away feeling bothered, while I felt that the questions and tone were quite ordinary. How many interactions like this occur every day, where people walk away feeling upset? I cannot assume how the audience member felt after this interaction, but I can state that, as a health care provider, the exchange did not seem atypical. Phyllis is a fierce advocate with the capabilities and connections to use this interaction as a learning experience. While Phyllis used this interaction to fuel her efforts to change perspectives and practices for people with dementia, not all clients would have reacted this way. Some might have retreated away from health care providers, potentially missing opportunities to access support and resources. Others might have become discouraged about their diagnosis.

As a community of providers, neighbours, friends, and relatives, we can only do better for people living with dementia by reflecting on our (or others') missteps and considering how we can improve in the future. This conversation prompted me to consider how I can be more caring, empathic and helpful to clients I meet in the future. It wasn't until I spoke with Phyllis and we talked through her experience that I was able to appreciate why it left her feeling poorly. In my future work, when I encounter a person with dementia, or any condition that requires interaction with the health and social care systems, I will ask: 'can you tell me about a time when you had a positive interaction with a health care provider? What made it positive?' By learning about the experiences that stand out to clients for positive reasons, I will build my ability to contribute to helpful interactions.

The above pieces show how incorrect beliefs and assumptions about people with dementia persist in our community, including in the minds of health care providers. These beliefs influence thoughts, which then affect providers' words and actions. Through addressing the root cause of these interactions by identifying, exploring and addressing such beliefs, other people living with dementia may avoid conversations like the one Phyllis experienced.

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