

Congress of Older People's Voices from the Margins

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Aboriginal people living with dementia, by Gwenda Darling

Dementia was listed in the DSM as a mental illness and people living with dementia were considered mad and somehow infectious. That was the start of stigmatisation of dementia. Some people still believe dementia is mental illness or that mental health issues cause dementia.

In some Aboriginal communities it is more acceptable to have mental health issues than it is a dementia diagnosis. Dementia has a lot of stigma. For some people it can be more acceptable for them to believe dementia is a mental illness and that they are mad because madness is curable. It's easier to say they have mental health issues than it is to say they have dementia.

When people ask me why I have a dog I say it's because I have epilepsy. I do have epilepsy, but I am not going to tell them that my dog is a dementia assistance dog. When I tell people I have dementia they often tell me I don't look like I have dementia. What does a person living with dementia look like?

There is shame in dementia. And there is no hope. It's all downhill. There is no way out. We are all on the way out. When I got my diagnosis, I came home and prepared to die. You can die slowly or quickly, and I decided to go quickly. I didn't get out of bed for four months. I didn't leave my front door. I have 32 rose bushes in my garden and I just left them. I gave up showering. I gave up on life.

There is so much shame and stigma around dementia. There is a misconception that you can't talk to someone with dementia because they won't understand. That's not true. I have a family I adore and sometimes they worry that I will stop remembering them. It's hard for them to keep fronting up when they are worried that I won't remember who they are.

I used to think people were worried they would catch dementia from me. But I think there is more worry that I won't remember them. Some people can't handle the decline, so they won't come. There is anticipatory grief. If I died today my children and grandchildren would receive sympathy. But if I had gone away and was still alive and breathing, there is no support. If you are diagnosed with cancer people will bring a casserole. No one ever brings you a casserole when you have dementia.

I get ageism a lot. I am a confident person, but I get intimidated in some circumstances. Whenever I go places with my carer - people talk to her and ignore me. I have to say: I'm over here. They don't take me seriously. That is particularly with health practitioners. You become invisible. People think I don't know anything. If you are there alone you are even more diminished, you are spoken down to like a child. That's the problem with people's responses to dementia. They speak very slowly and clearly, like I'm a 2-year-old.

I get judged because of what I wear and my hair. I have had pink hair for the past 20 years. Young people are dying their hair now and we ran out of pink hair dye during Covid. Some people say my pink hair is fabulous, some say I am so brave. It's like there is some symbolism in it for them, that they love that I refuse to be invisible. I don't do it to look young, I do it to rebel. My mother would never let me wear pink. People think I shouldn't do it because I am not young. My granddaughter said it is the essence of who I am.

If someone in your family has dementia – take a strengths-based approach. Focus on what we can do. Don't feel sorry for us. Be encouraging. And if we do something that you wouldn't do or something we might not have done in the past, don't take that on as a reflection on you. Don't be ashamed, it doesn't help.

I am blessed with the people who have come into my life since dementia, the ones who lived with a dementia diagnosis know how to support each other. We are all so busy living life. We know it's downhill, but we are going to have fun. The fact we don't have any filter means we can just be who we are. We don't have to worry about how we sit or walk or behave. We are just being ourselves with each other.

There is nothing like getting together with a group of other people living with dementia. There is instant connection and rapport. We all get it, we understand each other. We all value each other. There is total acceptance of who we are in that moment. Doesn't matter what happens, it's okay.

We meet in a local café and one of our friends used to go around the table and pick up our serviettes and then sit and fold them. It was never an issue for us, we totally accepted her. When she died, we all bought serviettes to place on her grave. Total acceptance. I wish we could have that in the broader community.

Some people who are diagnosed with dementia have anosognosia. They are living in denial. Families want to force them to accept their diagnosis and to accept help and support. There is an expectation that we will be dependent. We need to let people living with dementia be who they are. Sometimes the people around us feel helpless

and don't know what to do so they try to put order into our lives. They don't know how to react, so they try to take control. We need to be able to be who we are.

We need to check the tone we use when we talk to people living with dementia. Instead of sympathetic tone we need tone that says we are listening and ready to take our cue from the person living with dementia. I want to live every moment. So many people who are diagnosed feel trapped ... go with me, try to fathom what I am experiencing.

We need to take away the misinformation and fear. Dementia isn't contagious and we are not going to hurt you. Don't treat us like a child. Treat us equally. Our diagnosis doesn't define us. I'm not the same person. I will not be the same person. We can be unpredictable and that makes people upset. It can shatter family dreams, but we are the same people inside and please treat us with respect.

What's one thing people can do now? Go and talk to a person living with dementia about something that interests them. Please don't ask: do you remember me? Introduce yourself, tell us your story, find out what interests us. We don't all want to play bingo. What about a talk on plant hybridisation or patchwork mathematics perhaps?

Treat people living with dementia as if they didn't have a diagnosis. When the person living with dementia behaviours escalate, give them space, quiet, maybe offer hydration.