



Christine Thelker

At 61 years old, I am 6 + years into my diagnosis of Vascular Dementia. I often or normally don't look like I have dementia, but then again what does dementia actually look like? It is a look and a view based on old beliefs and stereotypes. It's outdated views that keep being passed down by people for either lack of interest or by people who find it easier to stay with the old than to venture into understanding the actual realities for those of us living with dementia.

For many reasons people do not generally like to accept change, either in their own lives or in their view points and perspectives. Over the course of history, we see how change has been thrust upon people. People have had to flee their home during wars and flee their countries. They had to establish a whole new way of life and living. Change was forced on them. People living with dementia have also had change forced on them – a new way of living, from the moment diagnosis is given – they have had to learn to adapt, sometimes on a daily basis. Other times we stay at a certain level until the next step down in our progression happens, but subtle changes happen constantly. We are always learning new ways to adapt and maintain our day to day functions, such as how we cook, how we dress, how we sleep, how we navigate our day to day. We learn to focus on the things we *can* do – even as we adapt how we do them – we become grateful for the small and simple things in our lives, like going for a walk or a drive.

The COVID-19 pandemic has, in a sense, forced change on the world, and in many ways, it is giving the world a taste of what it is like for those of us living with dementia. We live more isolated. We have for a long time been using tools like Zoom to keep us connected. However, there are some who are fighting the changes that are happening and they are unwilling to forge a new way of doing things. Instead, they focus on what they can't do anymore, and what has been taken away, instead of focusing on all they still have and can still do. Those of us living with dementia become very good at adapting and embracing the changes, if not our illness would be unbearable. We are a happy lot because we have chosen to be happy, to find joy in the simple things, to laugh at our own blunders, as we discover yet another thing that we at one time did with ease and now do with a lot more thought and improvising.

We have been blessed here in BC with a lovely winter and spring thus far, which allows us to be outdoors, walking and enjoying; we can go for drives with our families, or for me with my dog, or we can sit home and struggle with what we are being asked to do, to stay home in our bubbles and think about how awful it is. It oddly enough makes me once again look at how grateful I am for all that my dementia has given me instead of taken away, for I have already learnt to live in the manner that the rest of you are now being asked to, so although I feel deeply for all in the world effected by this pandemic, I believe there is lessons here for us all. Because I live alone, I have been totally isolated for a very long, extended period of time. Even though my dementia keeps me much more isolated than in the past, this is to the extreme but I have learnt through the challenges of my dementia, to keep it in perspective and manage what I can and let go of the rest. I use this time to be reflective, to do hobbies and get creative.

Another thing that has happened is that our advocacy work has changed, and we are having to be more creative in these times, just like everyone else. Research groups and many academics struggled to switch to online meetings, but soon realized we could effectively get a lot of work done this way. But for those people who normally work a full day, those of us with dementia, working more and more, trying to help in many different arenas in the dementia world, the only thing most did not take in to consideration was the toll this may have on us. And we are a group of people that push because we so strongly believe in our advocacy work. The toll has been that we have been left exhausted. Our brains are exhausted. We are struggling to keep up. We don't have to ability to put in full time hour and it takes us at least twice as long to do what most of you do in a day. Most of us don't have the help, either paid or volunteers to help us with this (most of us cannot afford to pay anyone to help us as we live on disabilities and all the advocacy work we do unfortunately is not paid) yet without those living with dementia stepping up and putting themselves out there, being vulnerable, using their voices, there is no hope of things ever changing.

It still amazes me, makes me sit back often and ponder why after 25 or 30 years so very little has changed with dementia. We still fight to change the stigma, the stereotyping, and we are still fighting to have academic programs include current and relevant information on dementia and living with dementia. It is strange to me that we are still so focused on a cure instead of shifting the focus to helping people live with their dementia while we look for a cure. We put effort and work into helping care partners and

caregivers who help those of us who live with dementia, and don't get me wrong they are so deserving of all of it, but we shouldn't focus so much on these things that we neglect the actual person living with the illness. We don't do that with any other illness and we should not do it to those of us living with dementia. We need to keep a sharp focus on having the academic world shift how and what these programs look like. Often dementia gets the least attention in program. We need to make sure that those who work in the field of dementia research are aware of all the new science surrounding the nutritional and exercise component of helping people live well for longer with dementia, how that along with a vast array of therapies can assist people to stay at home and live independently for a longer period of time.

I look forward to the day when my advocating finally sees some real change, until then I will keep fighting, after all if I don't who will.



Christine Thelker - Author For this I am Grateful-Living well with Dementia -
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