

Re-Imagine Life With Dementia - Dementia Action Alliance

Opening Panel

June 24 2017

I. PROVIDE THE AUDIENCE WITH CONTEXT FOR THE TOPIC
Describe the current norm of living with dementia (e.g., treated as a medical ailment, deficit-based, etc.) Provide a few personal examples you or others you know have experienced.

I would like to take you on a quick walk through my dementia journey. I am sure you can all identify with this experience.

I was first introduced to Alzheimer's at the age of approximately 14. On my school lunches, I would visit my grandparents to see if they needed anything. There would be notes on the fridge to someone who had stolen their butter or potatoes. Then one day I arrived to hear my bedridden grandfather yelling " Mary you left the stove on". Shortly after this my grandmother was diagnosed with Alzheimer's and she came to live with us. It was the silent elephant in the room. She was put on no medications. This was in the 60s she had a progressive decline, sitting there in her rocking chair.

Lets jump ahead to the late 80s early 90s my parents moved to Hamilton from BC. My mother was treated like a princess on a pedestal by my dad. It wasn't till my father passed away that we realize that my mother was showing signs of dementia. Again my parents had chosen to hide this, was this due to the stigma surrounding the disease or the lack of knowledge about the disease. Again, treatment was no medications, supportive treatment only.

Now I'm going to jump ahead to 2010. For a few years before this I started seeing some small signs, like walking into the kitchen and not remembering what I went in for. Or where are my keys, I would miss place things or forget things. I would put it off to having being tired after a 12 hour shift. In 2011 it started to show up at work and that scared me. I was there to help people not potentially harm them. I went to the doctors And was told it was stress, then depression, I knew

deep down it was more. So after a little lie I was off to see a neurologist. Who I knew well and she knew me from years of being a patient for migraines and I had also worked with her in the ICU. she was on the same page as me. I was sent to see a gerontologist. To make a long story short my testing showed positive signs but no treatment as I was still functioning. At this point it was like I no longer existed as she spoke directly to my husband. We were told to return when I could no longer dress myself. I was upset not because of the diagnosis but because of the lack of early treatment. Upon returning to the neurologist, we discussed the diagnosis and I requested early intervention so she started me on meds she also agreed to send me on to somebody else. I found this time very difficult as the medication caused serious G.I. complications but I persisted on thinking it would settle. Plus the fog had lifted.

After losing 30 pounds and feeling like I was going to end up in the ICU, I finally quit the medications. knowing I would be seeing the new doctor in a few weeks. Within a week I was physically feeling better but I could feel my mind was slipping. When I met my new doctor, she changed my life. she gave me the meds in a patch form, she treated me like a person not a disease, she gave me hope, she has given me the ability to help make changes to those living with dementia. Yes I do have dementia some of my symptoms are word finding difficulty, I have a apathy and forget things regularly. Something changed in the early part of my disease I developed a UTI. I slipped into what I felt at the time, was a really bad spot, my memory was not good and I would not speak. I became more uncommunicative, I could not process my thoughts, I couldn't understand some of the stuff others were saying to me. I knew I was on treatment for the UTI. All I could hope for is that I would return to a better spot. it took a while but I did return. When I returned, I returned a stronger person more determined to make change and to help others because that's what I've always done with my life, I'm a helper. So here I am now talking with you because I want things to change.

I would also like to tell you of the experience of a friend. Two years

ago a friend started having so symptoms that we're concerning. So she talked to her family doctor. At this time she had a couple of other problems going on so the doctor told her once the other issues were managed then they would deal with it. This never happened.

About a month ago while visiting her, her husband brought it up. She had made him promise that if he had concerns he would tell her. So she went back to the doctor. The doctors response was appalling. She was told why would you want to know, there's no cure, the medications don't work there is nothing that can be done. You are better off not knowing. Then told her she would not send her to a specialist.

Is this because of the doctors own feelings on dementia. When I think back to my nursing training we were only given a 30 minute talk on Alzheimer's/dementia.

1. WHAT IT MEANS TO CONSIDER DEMENTIA AS A DISABILITY

Discuss the benefits of treating dementia as a disability (e.g., strengths-based, comprehensive considerations for a chronic condition, etc.) Explain what is happening globally.

When we look at the treatment of dementia and Alzheimer's in today's society it is treated as a biomedical model so you are treated medically. You are given medications, you have blood work done and sometimes you even get routine visits to the doctor.

Whereas if we look at dementia as a disability it opens the doors for more treatment options. Let's look at another disease process and compare it to the treatment of dementia.

If you were given the diagnosis of cancer there is a whole care pathway that you follow. You are then followed by a whole team which includes cancer specialists your family doctor, occupational therapy, physiotherapy, speech and language therapy if needed you can also have a palliative care team for pain management.

So with Alzheimer's if we were treated as a disability we would see a family physician and a geriatrician who would then refer to the other health disciplines so that we would have physical therapy in the beginning this will help to keep us stronger and living at home longer this would also help to delay any weakness with occupational therapy you your occupational therapy assessment could include them coming to your home and assessing your needs in your home at the time of diagnosis and as your disease progresses because your needs change so they may come in and assess your needs in the beginning and say OK so you're have a little bit of difficulty walking let's get rid of the floor mats and just to make your hat home safe but as you decline and you're walking becomes more difficult they can come back into your home and assess and say OK now we need to put in more aids to help you in and out of the bathtub and they could also assessed for you no devices that would help you stay in your home longer like reaching sticks you know specialized feeding spoons in that type of thing the other thing is sometimes people end up with speech problems Judith due to dementia and if you how to speech therapy in the beginning this could help with this problem or they could teacher other ways to communicate which again would help us to stay stronger help us to stay in our own homes longer.

This is why it's so important for me to have it changed from a disease process to the disability. Around the world more more Alzheimer's organizations are really pushing to have it included as a disability. If you look at the UK or Australia even Japan are now taking a more disabilities approach. the world health organization has recently come up withA world dementia plan. Different countries are coming up for review at United Nations on the charter of rights of people with disabilities. This is important because civil delegation reports on how their country is doing and these civil delegations are trying to get Alzheimer's and dementia included in name right now it is included but under a cognitive disability or cognitive impairment. If they accomplish this it would give people with Alzheimer's and dementia in that country more latitude for treatment as a disability. Some of the things that this might include, better home care, a better care pathway,

better supports for care partners.

Sent from my iPad

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