

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 an 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.

2. 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 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 with A 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.this will lead to living well, longer and In our own homes longer. You know if you look at all of this It is our human right to ave these things.

Human rights are basic rights and freedoms that all p
CONTEXT FOR HUMAN RIGHTS Describe the history of human rights and why working through the UN is a smart and powerful move to have society transcend treating dementia biomedically. Discuss your advocacy efforts.

People living with dementia or Alzheimer' have human rights. I know this is hard to believe by the way they are treated. it is my feeling and is of utmost importance that we start to look at human rights of people with Dementia. We sometimes hear people talking about dementia as a disability and this is important because when we're looking at human rights it really opens doors for people with dementia.

Dementia is included in the human rights under the title of cognitive impairment so as you see we are included we just didn't realize we were,so that is why people are working hard to get it included by name in the convention of rights.

Before we can understand why we need to have to mention included in the human rights we need to understand what human rights are so I'm going to take the next little bit to do my best to explain to you what human rights are and give you a little bit of history on human right.

Human rights are basic rights and freedoms that all people are entitled to regardless of nationality, sex, origin, race, religion, language or other status.

The Universal declaration was stopped by the United Nations on December 10, 1948. It was more faded by the experience of the preceding world wars. The Universal declaration was the first time that countries agreed on a comprehensive statement of inalienable human rights.

There are 30 human rights they are also referred to as articles or charters. Human rights cover the civil, economical and political rights of all people.

1. We are all born free we all have our own thoughts and ideals we should all be treated in the same way
2. Do not discriminate these rights belong to everybody what ever our difference.
3. The right to life we all have the right to life and to live in freedom and safety.
4. No slavery nobody has any right to make us a slave we cannot make anyone our slave.
5. No torture nobody has any right to hurt us or to torture us.

6. You have rights to matter where you go I am a person just like you.
7. We are all equal before the law the law is the same for everyone it must treat us all fairly
8. Your human rights are protected by law we can all ask for the law to help us when we were not treated fairly
9. No Unfair detainment nobody has the right to put us in prison without good reason you keep us there or to send us away from her country
10. The right to a trial if we are put on trial they should be in public the people who try us should not let anyone tell them what to do
11. We are all innocent until proven guilty he nobody should be blamed for doing something until it is proven when people say we did a bad thing we have to write show it is not true
12. The right to privacy nobody should try to harm our good need nobody has the right to come into our home opener ladders or bother us or her family without good reason
13. Freedom to move we all have the right to go where we want in our own country and travel as we wish
14. The right to seek a safe place to live if we are frightened to of been badly treated in our own country we have the right to run away to another country to be safe

15. Right nationality we all have the right to belong to a country
16. The right to marriage and family every grown it has the right to marry and have a family if they want to men in women have the same rights when they are married and when they are separated
17. The right to own your own things everyone has the right to own things or Sheridan nobody should take her things from us without good reason
18. The freedom of thought we all have the right to believe in what we want to believe you have a religion or change it if we want
19. Freedom of expression we all have the right to make up our own minds to think what we like to see what we think and
20. The right public assembly will have to write meet our friends into work together in peace and defend our rights nobody can make us join your group if we do not want to
21. The right to democracy will have the right to take part in government of our country every grown-up should be allowed to choose their own leaders
22. Social Security we all have the right to affordable housing medicine education child

care enough money to live on and medical help if we are ill or old

23. Workers rights every grown-up has the right to do a job to a fair wage for their work and join a trade union
24. The right to play we all have the right to rest from work and to relax
25. Food and shelter for all we all have the right to a good life mothers and children people ruled unemployed or disabled and all people have the right to be cared for
26. The right to education education is right primary school should be free we should learn about the United Nations and how to get on with others are parents can choose what we learn
27. Copyright copyright is the special law that protects one's own artistic creations and writings others cannot make copies without permission we all have the right to our own way of life engine and to enjoy the good things that arts science and learning brain
28. Affair and free world there must be a proper order so we can all enjoy rights and freedoms in our own country and all over the world
29. Responsibility we have a duty to others and we should protect their rights and freedom
30. No one can take away your human rights

So after hearing that list of your human rights as it brought forth any thought in your mind about how you yourself are being treated. I know for myself when I look at that and I think about me living now with dementia a number of my human rights are being violated. I think this is the main reason why we need to really work as a group together to get dementia included in name in the human rights so that we can fight harder and stand up to society so that we can live better lives with this disease