

DAA Georgia Conference

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Each of you are living with different types and mixes of dementia symptoms. Could you describe what it's like to live with your dementia symptoms?

When I think about my symptoms of dementia I think of it as my roller coaster. You see my symptoms very daily, sometimes I'm up in the air, sometimes I am almost down at the ground, other days i'm on a level ground, then there's the other days when I had the really sharp corners This roller coaster ride that im on varies from day today some days I'm on that roller coaster from morning till night. There are other times when the roller coaster seems to slow down and take a week to get through the ride. So as you see it's very from day to day, minute to minute, hour to hour.

So I've learned to live around the variations in my life but this does become very hard for my family members and people around me in my life they never know when or what to expect.

Some of my symptoms are confusion, word finding difficulty, apathy. I find this very difficult because I seem to know what's

happening to me but I can't seem to express to others what's happening and that's where it becomes difficult for the other people in my life. When I'm having a good day I'm able to do all the things I used to be able to do. The funny thing is you learn ways around what you're experiencing so on days I'm having trouble with word finding difficulty I can frequently use my iPad and get the word that I'm looking for. I call my iPad my back up brain because I use it now for almost everything, I keep all my appointments in there, I can look things up on the Internet so that I'm still able to function. As an example when I'm having an off day with confusion and I'm wanting to cook something nowadays I need to look it up and it's usually on the iPad in one of the cookbooks that's there so that I'm still able to function in the kitchen but I just have to do it in a different way. One of the problems I have is doing laundry, it's not the procedure that I have the problem with it's remembering I'm doing it.

That's because it's on a separate floor and once I put it in and I come back upstairs it's gone out of my mind until the next time I have to go down and I could be a couple days so you know that's how it becomes a problem. So now I days I set the timer in my iPad with a note stating check laundry.

- What are your biggest hurdles and challenges living with dementia?

My biggest hurdle on my dementia journey was just getting the diagnosis. This process took a total of three years plus, it was during this time that I was very frustrated because I knew something was not right with me but trying to get the medical professionals can understand was very difficult.

The next hurdle came after diagnosis because I was told I had it and sent home so the hurdle was what do I do now. How do I get on with my life because none of this information was given. That is when I took to the Internet and went to the local Alzheimer society. I found helpful information on the Internet, the Alzheimer Society it was very instrumental for me through support and education.

Another thing that is very much a hurdle for me is the sense of feeling that things need to change and I feel a greater urgency for this because we all know that our time is limited and we don't know how much time we have.

Some of the other hurdles are smaller every day life hurdles like on the days that I am more confused, as I find this very frustrating I really feel I should be on my game at all times.

Or when I'm trying to find something and can't locate it and I can't describe what I'm looking for to my family, so it's these every day challenges that I find difficult.

- What was your experience getting a diagnosis of dementia?

In the beginning when I first started noticing little signs I always put it off to being tired after working a 12 hour shift or just having too much stress going on. As things progress and I started to notice more things I got more concerned so I did go off to the doctor. At first he said it was stress when it didn't get better he said it was depression you know what through the whole gamut, it was menopause but he didn't want to do any testing for dementia I really did find this difficult because I knew deep down inside something was going on and I really did feel it was Alzheimer's related.

I really did want to be seen by a specialist but I knew this was not going to happen so after what seemed like an eternity he did tell little white lie and told the doctor my migraines were back in that I'd like to be seen by my neurologist.

At this time I thought this is great I finally get to the bottom of this as she agreed something was going on and set me up to see you geriatrician. So at her first visit to see the geriatrician she kind of took a history and said welcome back in a year. So we did this and by this time I was really getting quite frustrated and I really felt like I was in a fog most of the time so we really push for the testing and she agreed to do it at this time so again your left wait for the testing to start which was nine months to a

year away again. On the day we return to this geriatrician it was like I wasn't even in the room she did receive the results and the results that I did have early onset Alzheimer's she spoke directly to my husband not to me and her conclusion was that I was still able to dress myself so for us to return when I couldn't do that.

This was very frustrating to me because after being a nurse for so many years I really believed in early intervention and this wasn't being done so I did return to my neurologist and explained the results and told her that I wanted to see someone else because I wasn't happy with this doctor and that I wanted early intervention so she did put me on medications at that time which to me worked they lifted the fog. On the other hand they gave me severe G.I. symptoms but I wouldn't quit them because I thought maybe that would settle out the longer I was on them and I didn't want to go back into the fog. So after losing approximately 45 pounds and feeling like I was going to end up in the ICU I did go off of them knowing that I have an appointment coming up with the new geriatrician in a couple of weeks. I must admit when I saw the new geriatrician I thought she was amazing she actually switch me to the medication in a patch form which works very well for me she redid all the testing and the results confirmed the same as this first set of testing I had done. I felt like I had been given my life back but there was

still areas I was having problems with but because my brain was in a fog I was able to think my way around and implement ways to do things so I could still function.

You know getting the diagnosis was like getting kicked in the gut and I was quite surprised that there was no other interventions offered so again I was back to the all Alzheimer's society to get the information I needed. It really did take me a year and a half to two years to get comfortable with the diagnosis and make sure my life is in order before I could MoveOn.

- What currently brings meaning and joy to your life?

One of the biggest things that brings meaning and joy to my life is my family. I am one of those very lucky ones whose family is very supportive in every aspect of my life and what I do. They do not try to smother me or take over my life they allow me to make my own decisions they allowed me to make my own mistakes but when I ask for help they are always there.

The next important part of my life are my friends. I have some really close friends who have stuck by me through this important time of my life. Through there if I need someone to talk, we still enjoy a full active life with our friends going to dinner going away and just join each other's company. My friends have gotten very good at telling when I'm getting tired or

just when I'm starting to have some difficulty. They have learned my signs and they have learned what to do during these times which to me means the world because they are there for me.

Although we all know all too well that with this diagnosis we also lose friends and family members who just don't understand and this is happened to but I've learned to compensate for that and that just makes my bonds closer to those who have stuck by me.

-ADD AL'S FRAMED QUESTIONS ABOUT

1. Language

The language that is used around dementia is sometimes not the nicest here and when I hear it being used I do try and use it to educate people. One of my biggest annoyance is around the language used is when I hear somebody use the word suffers with dementia, this can put me almost in a rage, so this is when I tell them that you know I don't suffer from dementia I have to measure but I am still able to be who I am and I am still able to live well with the diagnosis.

I was at a fundraising football game for all Alzhiemers a couple years ago. There was a group of young kids behind us and you know they were enjoying football game but at half time the guest speaker was a person living with dementia who is fairly

progressed in the disease process and he was also an ex-football player. These teenagers were making fun and saying things like why would they have such an idiot up there. I have my family with me at the time and I had my grandchildren there and I thought that this wasn't setting a good example for them. So I turned around and I ask the kids where they got their tickets and they had bought them through the all Psimer society at the discounted price so I explain to them that this was at a fundraiser for all Psimer's that person that was on the stage was a person with Alzheimer's and that it was a disease process that he could not help what has happened to him but what he is doing is trying to change the way people see the disease process so that more people will understand and hopefully will change the stigma surrounding it. After I spoke to them they really seem to settle down and understand more about what this football game was all about and they were more excepting of people with dementia. I did explain that they can't see dementia but that there was a number of people in the stands who have dementia and that the way they're talking is very belittling I did point out a number of people in the immediate area who I knew personally that had dementia and then I pointed out to them that I also had it.

Another term that is used with people with dementia is directed at my husband as my caregiver or you know he is my partner in

life more walking this journey together and it even bothers him when he's call the caregiver because he says I'm not your caregiver I am your partner, i'm your husband and I'm here to support you in any which way I can so when somebody says caregiver we turn around and say to them that we would prefer if they refer to him as my care partner you know there's all kinds of words that are use rounding people with dementia and I really think that we need to stand up and take notice of what we say in how we say it because language can be very hurting I can be there he derogatory and we need to turn it into a positive way of interacting.

2. Human rights and citizenship

The area of human rights very near to my heart because I feel that once we are diagnosed with dementia or Alzheimer's people no longer see us as an integral part of society. We lose all our human rights and this should not happen. A lot of people that are newly diagnosed become very isolated because of the way others treat them but if you look at the human right, They have the right to social engagement they have the right to life and they have the right to be treated with dignity.

I really feel that once somebody is diagnosed with Alzheimer's or dementia that because people feel they are not cognizant of what's happening that the best way to care for them safely is by

putting them in a nursing home and yes this may be required at in stage but there is such a vast area before this happens. It is during the time that they're declining to and stage that human rights should really play a part in how they are treated and cared for and to keep them in their homes and Society.

When the time comes that they need to go into a nursing home Worcester put on a locked ward and never see the light of day again.

Sent from my iPad

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