

## Health Professionals, their connections and me

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Time: ~ 14 minutes

### SLIDE 2

My name is Mary Beth Wighton. I'm 50 years old and living well with a diagnosis of probable Frontotemporal dementia. It was in 2012 when a Geriatrician doctor pronounced that I had probable FTD and immediately revoked my license as I was told I did not have the ability to drive safely any longer. This was done without any due process but rather it was based on stigma. I remember looking at my partner, Dawn, and she at me. In the flash of a moment we began this journey that neither of us understands.

The ride home was very long and quiet. Dawn took my normal seat behind the wheel and I took hers – in the passenger side. Neither of us spoke – we were consumed by our own thoughts. We had never heard of FTD and the single brochure given to us by the doctor, did little to help us understand it or where to go for more help. The doctor told us that she would notify the Alzheimer Society and they would contact us and discuss support.

I immediately went into research mode and spent hours and hours trying to understand more about this disease that I would die from in 8-10 years. Most literature focuses on the behavioral issues that I can expect; being sexually inappropriate; problems with the law; living in long-term care; the loss of relationships due to my aggressiveness; depletion of family finances; etc.

I felt so alone – so isolated. There seemed to be little assistance for me and Dawn. Dawn worked the telephone trying to connect with anyone who could provide assistance of any kind. I kept my research up on the internet. There are lots of supports for the care partners but very few for PWD.

As you can quickly see, the important connections to health services were and still are not there. And this is why I am here today.

My connection to you is imperative. It needs to be one with clear responsibilities and lines of accountability. The stronger it is the better my understanding of this dementia will become. And of course, I will have the necessary support of which is critical to help me live well with FTD.

### SLIDE 3

Like many people with dementia, my diagnosis was what I call the long and winding road. From the year 2009 until 2013, I have been diagnosed with approximately 12 different diagnosis'. They are:

- PTSD
- Major Depression
- Forgetfulness
- No short-term memory impairment
- Probable Frontotemporal dementia
- Frontal lobe problems
- OCD
- Panic Attacks
- Conversion Disorder
- Over-reporting of memory complaints
- Pituitary cyst
- REM sleep Behavior disorder

From the year 2011, until now I have been through numerous sets of tests including:

- MRI's
- MMSE's
- SPECT
- EEG
- Beck Depression Inventory
- MOCA's
- Sleep Test, and
- Neuropsychological Testing

During this time of intensive testing, it was incredibly frustrating for me and my Partner. It really seemed that the so called right hand did not know what the left hand was doing. Much of the onus of ensuring information flowed from one doctor to another doctor was put on us. Dawn was constantly following up and ensuring faxes were sent, or resent. Tests were done and redone – even if I didn't need them. I was told that it was my Family Doctor who was ultimately responsible for me. Somehow, he was to manage all of the appointments with my specialists and follow-up on any tests. Juggling me with many other of his patients was obvious a difficult job.

#### SLIDE 4

One time when I was being tested for REM sleep Behavior disorder, the doctor who specialized in sleep – and not dementia, began to give me an MMSE test. Being that I had taken it numerous times, I immediately halted him and told him that I can tell time and read a clock. I then further educated him by stating that MMSE was a test to determine Alzheimer's and not FTD. His reply was a simple, "Oh it seems you know more about it than me." What's frightening is that this doctor obviously had no business giving me this test but still did. My Family Doctor had not ordered him to perform this test. He did not fully understand when and why it should be used. It was not something he was asked to do, but just went ahead on his own initiative. This disconnect between him and my other doctors was obvious. For me, it brought a sense of insecurity to think that I am relying on him to supply me with other answers. It also made me angry and I ended up walking out of the meeting.

Through out this intensive time of doctors visits, my Family Physician was a strong advocate for me and my Partner. Knowing there was something seriously wrong, he kept pushing for specialists to review my case. He always had my back. He defended me when my private insurance pushed to have me return to work. He told them in no uncertain terms, "No!"

#### SLIDE 5

During one of the many times he was reviewing a specialist's report with us, a serious incident occurred. As he read out loud the latest comments, my behavioral quickly escalated into a rage. The words were wrong – there was even some lies in the report. I began to shout at him and swear. He told me to stop it and that he wouldn't stand for me talking to him like that. I left his small room and went into the large waiting room, swearing and hitting the walls. My partner followed me quickly to remove me from the environment. Once again, it was just Dawn and I trying to manage things. I could only believe that my doctor, just like me, felt alone and frustrated. He wouldn't have even time to catch his breath as so many were waiting for him. I never did thank him for all that he did for me. And now it's too late as he suddenly passed away.

If there was a community approach to support, the scenario could look quite different. Someone would have reached out to Dawn and I and ask if we were OK. There would be

an inquiry on why I reacted like I did – for future conversations. And my family doctor would have received suggestions and counseling on what happened and strategies to prevent it or less it. Unfortunately, none of this occurred.

Just over two years ago, we moved from the busy city of Kitchener to the beautiful small town of Southampton on Lake Huron. We love it! People are great but yet it still has stigma regarding dementia. For instance, I hear the inevitable, "you don't look like you have dementia."

#### **SLIDE 6**

There was a time that my computer stopped working and we took it into the local computer store. When I don't have access to my computer, it make me very agitated. It is my life-line to others and it contains all of my advocacy work files. After having my laptop for 10 days, I went to pick it up only to find out that the owner did not send it away and said there was nothing wrong with it. He never bothered to call me to inform me of his results.

My reaction to this news was me heading straight for the owner and started yelling and swearing at him. We were chest to chest. With all of the commotion, including him yelling to call the police, my partner came running into the store and tried her best to get in the middle of the dual. Eventually, she was able to get me somewhat calmed down and moved me into our car. The owner then stuck his head out of the store door and smirked at me. That was it! I ran back into the store. I pulled out the phone system and started to throw items hoping to bust a big TV. The police arrived and I was put into our car. Dawn pleaded with them not to arrest me as I have FTD. She called our family doctor but the police didn't want to talk to him. Once again, we were alone – without the supports we needed. Dawn began to cry. As she drove us home, I reviewed my new police ticket for Do Not Trespass to the computer store.

The incident really shook up Dawn. For me – not so much. Dawn reached out to our Alzheimer Society worker for support. And this is where it gets good! She reached out to the local police and offered an education service for them on dementia and specifically FTD. She began the very important process of knitting our supports together so we all are better supported. She began the very important step of approaching this as a community where we help each other.

## SLIDE 7

As we all know, I am not the only person with dementia to experience loneliness. The question is: How can we systematically address the current lack of disconnectedness for both the medical and patient communities by linking our health services more closely to neighborhoods.

I am encouraged to find a number of initiatives in building caring neighborhoods. An excellent example from the UK called “Neighborhoods and Dementia” demonstrates that it can be done by focusing on people, spaces and places.

Another interesting project is a health network initiative in Los Angeles.

And I am so excited to hear that there will be a neighborhood approach to care in Toronto!

I truly hope that by listening to my stories today that you can appreciate the true impact a neighborhood approach to care can make a significant impact on both my partner, Dawn, and my life. And imagine your own struggles being addressed by the connections of a community.

It is wonderful to hear that you are huddling together and talking. And as good neighbors do – I am here to offer you my support and advice. And as a community lets figure out how to create and implement building, caring neighborhoods.

## SLIDE 8

Thank you for giving me an opportunity to talk with you.

I believe I can take a question?