



## Forget Me Not Living with dementia

[Aaron Rathbone]

“Forget Me Not” is a series that tackles living with dementia. When someone’s told they have dementia their mind often races immediately to the end and what that will look like. But just like in any story, you should never jump to the final pages. Because in life, if you focus only on the end, you’ll miss all the great opportunities to tell your story the way you want it to be told.

“If you fail to prepare you are preparing to fail.” This memorable quote from Benjamin Franklin rings true for most of life’s circumstances. Afterall, people spend their entire lives preparing in order to achieve their goals.

But what do you do when you are unprepared for an event that takes you completely by surprise? Are you inevitably doomed to fail? Of course not.

Nobody can see into the future to know what challenges lie ahead. In many cases you also don’t know how you’ll react until your faced with the situation. All we can do is take control of our decisions and surround ourselves with others who will support us unconditionally.

[Tom Wellner, President & CEO, Revera]

Hi, I’m Tom Wellner, President and CEO of Revera, and we’re proud to bring you this podcast. Revera believes in the importance of creating a world that allows older adults to live life to the fullest. Revera supports older adults and celebrates their contributions to our society. We believe it’s critical to be innovative, which is why we were the first company in the Canadian senior living sector to appoint a Chief Medical Officer and Chief Elder Officer. Together we’re improving the aging experience and changing the way we think about growing older.

[Dr. Rhonda Collins, Chief Medical Officer, Revera]

I’m Dr. Rhonda Collins, Chief Medical Officer at Revera. Throughout my medical practice I’ve had the pleasure and responsibility of treating my patients. As doctors, we’re accountable to our patients and must ensure that we empower them to live their best lives.

Today, I’m pleased to be speaking with Mary Beth Wighton. She’s the co-chair of Dementia Advocacy Canada and the chair of the Ontario Dementia Advisory

Group. Mary Beth is an excellent advocate for people with dementia because she herself is living with dementia – I want to emphasize “living.”

We spoke with her from her home via Zoom. Mary Beth, thank you for speaking with me today.

[Mary Beth Wighton, co-chair Dementia Advocacy Canada & chair Ontario Dementia Advisory Group]

Thank you very much for having me.

[Dr. Collins]

How old were you when you received the news that you had dementia?

[Mary Beth]

I think I was forty-five years old when I was actually given the diagnosis of probable front temporal dementia, but I had a number of years leading up to that.

[Dr. Collins]

Wow. How did you feel when you got that diagnosis?

[Mary Beth]

Well, it's interesting because there was such stress beforehand for years of knowing that I was cognitively impaired, that when I received the diagnosis it was like “oh, this is great!” You know, I have a diagnosis. My partner and I looked at each other and just said “now we know what to do.” My partner said, “is there a pill for this?”, and that's kind of when we learned there is no pill for this and realized that there was no cure.

[Dr. Collins]

So, can you describe that process? When you realized that there wasn't a cure, how did that feel for you? How did that change things for you, if it did?

[Mary Beth]

Oh, it definitely did. So, basically what came out of the doctor's mouth to us was: “Unfortunately, you have a diagnosis of probable front temple dementia, it is non-curable, it doesn't have a cure, and you can expect that your partner is going to

take care of you for the rest of your life. You're going to end up in long term care and you don't have a driver's license anymore." So, because it all came at me so quickly when I lost my driver's license on the spot, it almost overshadowed the powerful message of: you're going to die from this disease. Because I was thinking literally of the here and now, which is the keys in my pocket, that I became more concerned with my driver's license. It really wasn't until I had time to absorb what the other piece of information was, of not having a cure, that I went into a depression.

[Dr. Collins]

I'm sorry and it certainly doesn't sound like that was a very compassionate or empathetic way to deliver that news to you. If you were able to speak to a room full of medical professionals right now, what you would tell them about your experience when you were diagnosed?

[Mary Beth]

I would tell them that it was one of the worst experiences I've ever had in my life and that it could have been very, very different if the doctor had chosen to do that. It's about choice to me. It was about choice, and education, and empathy. And those particular things – and particularly for young doctors coming up – if there's anything I can recommend; it is talk to your patient as if that person isn't a patient, it's a person. Cause that's what we are. I think we can de-medicalize it when we're using the word patients but imagine if you were telling your friend that you have a disease and you're going to die from it. The language that you would use would be much more sympathetic and you would look for opportunities to say, "but there is some hope here." I think those are two very important words. Hope: it's talking about the many things that you can still do versus all the things you can't do.

[Dr. Collins]

Thank you. It's a difficult story to share and those are so important, the messages that you just shared with us. What about when you shared the news with your family and friends? How did they react to it?

[Mary Beth]

Well, it was shock for sure. Because my family and friends had gone through probably, I want to say, three years of a deep depression which actually ends up being fairly normal for the type of dementia I have. And my mom was diagnosed with Alzheimer's just a few months before I was diagnosed with FTD. So, my

family truly was spinning. We had to then go to my parents and say, “listen, Mary Beth too has a type of dementia.” For my friends, it was – you know, that’s when you really know who your friends are. They reach out to you and say, “what can I do?” It’s very much about how can I help you continue to live a great life and no matter what, you’re still my friend. Very much like my family, you know, “what can we do to help you?” It really makes you think of who could stand up for you, who wants to stand up for you, who isn’t afraid to stand up for you, and to ask those very tough questions. That’s where we started, with family and friends. We started about education.

[Dr. Collins]

So, you would say that your diagnosis did impact some of your relationships with people in your life. Do you think some of your relationships got stronger as a result?

[Mary Beth]

I do. I think some of my relationships got stronger because I knew I had to do a better job at communicating that I loved my friends! So - I don’t use the word very lightly, and so I started to tell my friends that I loved them. Which is kind of – you know, for some people it’s a little unnerving because we usually don’t use that word. So, I wanted them to know, even though I may have never said that to them, that I loved them. So yeah, they definitely have become deeper and stronger relationships for sure.

[Dr. Collins]

That’s good and good for you for recognizing that. Wouldn’t it be nice if we just all told the people around us how we felt about them all the time? Instead of having to wait until something happens in our lives this big.

[Mary Beth]

And that’s just it. I don’t feel like I have to wait anymore. So, when I say goodbye and give people a hug - which again, I’m more physical in that respect. I didn’t used to be like that. So, I can give friends a big hug and tell them I love them. I can give my brothers and sister big hugs and say I love them. It’s almost opened up this whole better ability to communicate, when in fact I don’t communicate that well, but it’s going back to that word “love” and big hugs.

[Dr. Collins]

Mary Beth, people often associate dementia with being an older person problem. But that's obviously not the case here. You've spoken about ageism being an issue for people living with dementia, especially for those with early onset dementia, can you please explain that?

[Mary Beth]

Yes. So, as we know, when I was diagnosed six or seven years ago, my role models in pictures when I went to the media and started to look through "what does it look like to have dementia?", every picture was of an old person looking forlorn out the window, and that person was in a wheelchair. Those were all the pictures that I ever saw. I really didn't see pictures of people living with dementia who were still working, for instance, or who were volunteering. I didn't see anyone under the age of 65, that's for sure. And so, it was very much a "well, I'm forty-five" and I'm starting to make friends from pretty much across the world, and they're in their fifties.

So obviously the stigma associated to dementia, that you just have to be eighty and over – be old – it's not true. And the more I talk to other people and the more other people started to stand up and say, "hey, I'm under sixty-five and I too have dementia" that I realized how much stigma was associated to it and how much of a large population of people living with dementia under the sixty-five there actually is.

[Dr. Collins]

You mentioned the word stigma, the purpose of this podcast is to challenge the stigma surrounding dementia. You mentioned one thing, and that is that it's an older person's disease, are there any other types of stigmas you've encountered? How would you educate people around living with dementia?

[Mary Beth]

Well, there's definitely lots of different types of stigma that are associated to dementia. When we say the word "dementia", there's a stigma that the person has Alzheimer's disease. And what it doesn't do, that stigma, is recognize that there's over 100 other dementias that someone may have. So, by doing that, what it enables people to do is stigmatize you according to the Alzheimer's symptoms. So, for instance, someone will make an assumption that if I say I have dementia, that I can't draw a clock on the paper, which is an indicator of Alzheimer's if you can't do that, whereas I can. And by the way, that affects a lot of the tests that are written in stigmatized language as well.

There's the stigma that "oh, well you must not be able to be very useful your family around the house." Whereas in fact, it's allowed me to kind of do things that I want to do around the house. So, for instance, I get to do more gardening. We do things a little bit differently around the house. So, there's this stigma that I can't take care of my family still, whereas I can but in a different way. There's a stigma around, I can only yell at people and communicate in a way that's mean, and in a physical way where I hit people, whereas that's not the truth. The stigma is that when we understand how people with dementia can communicate and how other people play into that, then that stigma will eventually start to disappear. I don't know about eventually – it's got a long way there.

So, can I communicate my love for family? Yes. Can I show how frustrated I am only in a way that's detrimental? No. There are many ways that I show that I'm hurt or I'm mad, for instance. So that whole language and physical stigma. There's a stigma that I have to take medication and there's a stigma that I should be locked up in a long term care ward. There's stigma that says I'm not going to be a very good researcher, for instance. Whereas actually, I can be a very good researcher. We do things just a little bit differently. There's stigma that I can't write, when actually I can, but it might just look a little bit different. You know, I might have to use different tools in order to do so. So almost every major component of your life feels stigmatized. It's what you do with it: you can accept the stigma or don't accept the stigma and really focus in on how to counteract that stigma and the issues that it causes.

[Dr. Collins]

That's a lot, thank you so much for sharing all of that. I think generally people think about some of the memory loss, but they don't think of all of those very valuable points that you just brought up. Keeping in mind that our audience may not be all that familiar with frontotemporal dementia, how it presents, and that memory is often fairly well preserved in the beginning, are you having issues with your memory at this point? Are there things that you're remembering better than others?

[Mary Beth]

I've been very fortunate. So, with frontotemporal dementia, it affects your lobes up and above your ears and then in the front part of your brain. What happens there, is as you mentioned, it doesn't affect my memory as quickly. Over the last, I would say, three months, my memory is definitely declining. For the most part, I can remember things that happened many years ago. Those long-term memories are still quite strong. It's the things that happened just yesterday, things that happen today, that I'm struggling with. So, I can present very well, it's like I can

walk and chew gum at the same time and things are fine, but where I'm struggling is, I'm very busy. As an advocate I have a lot of meetings and my schedule is very, very busy. So, this is where we're really seeing the impact of my changing ability to remember. I'm thinking that I need to be at a meeting when I'm not, I'm making mistakes in my calendar now. So that really affects you, because that's the here and now.

[Dr. Collins]

For the sake of our audience, who again may not understand that there are definitely differences between frontal temporal and Alzheimer's, for instance, whereas you know Alzheimer's affects short-term memory. Generally, that's the first symptom – short-term memory. Can you speak to what you noticed first?

[Mary Beth]

Sure. So, for me, I didn't notice it. It was my partner Dawn that as we started going through things noticed it. I had the inability to really understand finances. So, I was making huge financial decisions by myself and they were – I basically spent our savings, without my partner's knowledge. So that decision making really is affected in FTD. What's a good decision? With frontal temporal, many people like myself, make these crazy decisions to do finances that puts their family in crisis, immediately. Those are the types of things that we're dealing with versus I can't remember what I did today. We're dealing literally with "what do you mean you spent all our savings?"

So, you know, very different type of a diagnosis as well. We started to say these things to the many doctors that looked at me. And there was many of them. I think I ended up with about twelve different diagnoses. So, with all those different symptoms, well "you can't have dementia, you're too young." We heard that from every doctor. So those symptoms that I was showing that differs from Alzheimer's, including the ability to understand complex information which I needed to do for my job, I just wasn't understanding my job anymore. I wasn't having the ability to – I lead a team of people, and I couldn't really remember the long-term goals or the short-term goals that we had discussed, and it was starting to show in my emotions. I became easily very, very frustrated with people. I expected certain things and if that didn't happen, they would get an earful. Whereas that is a very different person from what I had normally been. We were being told, my partner was being told, that people at work were going "something's going on with her – God." So those were some of the big ones versus, again the Alzheimer's, that affected me.

[Dr. Collins]

And it has to be frustrating to know that something is going on and not be able to get an answer.

[Mary Beth]

Ugh! It - I can't even tell you how frustrating it was. So, I was put on long term care - or sorry, long-term leave from work, by my local doctor - who was an excellent doctor. He knew there was something wrong. He didn't have the ability to pinpoint it. So, he kept bringing in these different specialists and we would go to these different specialists, and it was requirement for the finances that I got due to long-term leave that I had to go to all these different doctors' appointments.

I went to psychologists and psychiatrists, and it just went on and on. They were very long and frustrating meetings, because they were trying to put me in a hole somewhere - pigeonhole me - and yet, it didn't make sense. Yet they kept trying to push me down into this "well, you must have" for instance, we had "marital problems." That's what one of the psychiatrists said to myself and Dawn. That I had marital problems. And I was like "What! There's nothing wrong with our marriage!" "Well, you know, there must be. You're making up stories," is really kind of what the person was saying. I was making up stories so that my partner felt sorry for me. That was one psychiatrist appointment.

[Dr. Collins]

That sounds horrible, that sounds really horrible. I hope that every one of my physician colleagues hears this podcast and recognizes how many things went wrong with this scenario. I'm so sorry. So, what are some of the tools or strategies you use to continue to be independent and continue to thrive as you have?

[Mary Beth]

I was very fortunate, actually my family was very fortunate in that when I was diagnosed eventually, I came to the "ok, now I know what I have, now I need to start back at living." You know, I had been in a depression for years and I was really tired of being depressed. I wanted to get out and make changes and so I met with the Murray Alzheimer's Research and Education Program out of the University of Waterloo, and they've been in the business now for 20 years working with people living with dementia. It's not all, "these are all the things you can't do"; they work with people on, "these are the things you can do", and it was the first real advocacy group that I met. They had just started producing a guide



called “By Us For Us Guides” and it gave me so much hope. I just thought, “that’s it! That’s what I’m going to do. I’m going to be an advocate.”

It was truly because of this organization that has led my way over the past seven years to really pushing Canadian society, and international society, and local society, and saying you need to challenge your own personal stigmas as a doctor. What do you believe as a cultural stigma for yourself versus really talking to your patient? And I forgot your question so I think I’m rambling, but it ignited a fire in me I think I can say, and then that was the beginning of advocacy, and that was the beginning of telling myself and showing myself that I can still be a very successful citizen. And a successful friend. And a warm and loving family member.

[Dr. Collins]

What other goals for the future? What do you want to do in the next several years?

[Mary Beth]

Um, one of the early goals I have to say – I accomplished it! So, about six years ago, Canada did not have a national dementia strategy plan. So, myself with many other, many other people across Canada said “we need to have one.” And you know, all of the effort that it took for us to make that happen.

I’m part of the Federal Ministerial Advisory Group, and I don’t think it gets much better than that to be able to help the Federal Minister of Health – provide advice to her for what a national dementia implementation plan will now look like. So as far as the goals are concerned, the Dementia Advocacy Canada is a really important organization that I think is going to do just tremendous work in this area of stigma. Its goal - it’s a national organization - its working with people living with dementia and care partners, and our goal is to work directly with the doctors. You know, we hope to be able to sit down some day in front of doctors and say, “this is a person who has dementia and look at all the things we can do.” So that goal is very much important to me and understanding that we can affect change. We can affect change through education at the university level, at the high school level, etcetera. I would say that’s probably one of my biggest goals.

My second one is I really wanted to write a book. So, over the years, I created what I call “journal articles” and I used to send them out to some family and friends. I now have, I think it’s about 160 journal articles from the point of diagnosis to about two years ago and lo and behold – I’m producing a book! So that book’s going to go out, I think I heard April. I think that can really help to

change the stigma too when people start to read it because it's – you know – it's written by a person living with dementia. My ups, my downs, my dementia work, my family, it's about any topic.

And then, I guess the other final one – I didn't think I had many, but I guess I do – I just want to be a really good grandma. My daughter Brianna, she's expecting in March, and this is going to be our first grandbaby and we're just so excited. So, I just want to be, you know, a really good, great grandma.

[Dr. Collins]

That's fantastic, congratulations! That's exciting!

[Mary Beth]

It is!

[Dr. Collins]

You know, I was going to ask you, you said in the beginning you felt helpless and vulnerable in the beginning of your journey. I wanted to ask how you feel now but based on everything you just said – I think I know! But go ahead and tell me how you feel now.

[Mary Beth]

I feel good in the sense of I know the tides are starting to change. One of the things that I did before this call is – I wanted to take a look at stigma as defined by the international world. They've done some really good work, as far as defining what it is. There's a picture and what it does is it shows, you know, the reducing stigma. It talks about – on the left-hand - more understanding and awareness, less negative connotations, societal empathy, and on the final one on the left-hand side it talks about the reduced stigma. And I thought to myself "how have I done with that? Where has my work led me? Am I on target?" And the things that I have done, and continue to do, are certainly inline on how to reduce stigma. So, I can't help but feel pretty good and feel pretty proud. I really do – I work with just unbelievable people that without them my journey would be different. So, I feel pretty proud with all the things that we've accomplished as teams and I feel pretty good. You know, like anyone I'm nervous on what lies around the corner for me, but you just have to stay focused.

[Dr. Collins]

Well you should be proud because you've just done so much, and you should be really thrilled with what you've been able to accomplish. More than that, what you've been able to share with your experience in reducing stigma. So, if we have the entire world listening right now and if you were to say one thing that you wanted every single person to know, what would that be?

[Mary Beth]

The person in front of you who has dementia, is a person. Treat them like that. Period.

[Dr. Collins]

Perfect. Beautiful. Mary Beth, I want to thank you so much for taking the time to speak with me today and for your advocacy for people living with dementia. We wish you the very best and look forward to continuing to hear from you as you continue to destigmatize dementia, and I want to hear about your grandbaby when he or she comes along!

[Mary Beth]

Well I appreciate the work that you do and thank you very much for having me today.

[Dr. Collins]

One of the most rewarding aspects of being a physician is the privilege of being part of my patients' lives, through a variety of challenges and triumphs. Not every diagnosis I give is one that a patient wants to hear, but I'm often amazed at the way bad news can become a catalyst for inspiring a positive response. Some people use lifechanging news as an opportunity to take control of their lives and live the life they want. I find this truly inspiring.

After we signed off with Mary Beth, she had one more point she wanted to leave the listeners with:

[Mary Beth]

One of the things that, as we were leading up to try and get my diagnosis and the many doctors that we were talking to, obviously Dawn and I were scared at this point. It had been years, and no one seemed to know what was going on. One of the doctors said to Dawn and I, after a long, grueling conversation, he said: "you better hope it's not dementia because if it is, it's game over." And that was my diagnosis. And so, I've walked into a diagnosis thinking "it's game over." I can't imagine talking to anyone like that.

I really want to suggest also to doctors and to anyone listening, about being an advocate for yourself. You know, if you are working with a person living with

dementia and a care partner, talk to them about advocating. And advocating for yourself simply means standing up for themselves and saying, “this is what I want, this is what I need, and this is how it should come.” It’s important to give people a voice and that’s done through advocacy work. Getting people to understand that it doesn’t have to be this big, national advocacy organization, but help enable them by being advocates and encourage them to join these organizations because this is where they can get peer support, this is where they will learn more about their disease, this is where they can affect policy. So definitely, there’s many things that can be done right at the point of diagnosis. And I would say, really think about that story. What is it that you want to help that person live the best life they can?

[Dr. Collins]

I couldn’t have said it better myself.

[Dr. Collins]

On the next episode of “Forget Me Not”.

[Sarah Putman, Manager of Education, Alzheimer Society Niagara]

The first step is to help them to understand they’re not alone on this journey, and to support them in getting the opportunity to build some circles of support.

[Dr. Collins]

Once you receive a diagnosis that you have dementia it’s time to figure out your next steps. There are many agencies and groups that can help support you as your needs change. We’ll learn how to navigate what can be a confusing time and find the solutions that fit your life.

[Aaron]

“Forget Me Not” is brought to you by Revera. It’s produced, written and edited by Aaron Rathbone. We want to give a special thanks to Mary Beth Wighton for speaking with us today. If you’d like to learn more about Mary Beth, you can follow her on Twitter @MaryBethWighton. Thanks for listening and we’ll see you next time on “Forget Me Not”.