



## Forget Me Not

### What is 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.

Dementia can be a scary word. It’s a lifechanging event in a person’s life and the lives of their family and friends. There are over half a million Canadians living with dementia and every year about 25,000 new cases are diagnosed. It’s a huge number that’s changing the way our population looks and how health providers will deliver care.

Life is complex. When you’re young you can’t wait to be old, and when you’re older you wish you could go back to when you were young. You can’t turn forward or back the hands of time, you just have to learn how best to play the hand life gives you.

[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.

[Aaron]

Hi, I’m Aaron Rathbone. Thank you for listening to “Forget Me Not.” More and more we’re finding families’ lives being touched by dementia. It’s a growing issue around the world as our populations age.

We’re speaking with Dr. Rhonda Collins, the Chief Medical Officer at Revera. Dr. Collins is a family physician with a certificate of added competence in Care of the Elderly from the College of Family Physicians of Canada. Her expertise lies in memory care, dementia, falls prevention and clinical quality improvement.

So, Dr. Collins, what is dementia?

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

Thanks, Aaron. Dementia is not a disease, but a collection of symptoms that includes things like forgetfulness, misplacing things, difficulty completing tasks, trouble paying attention. The thing that separates it from normal memory loss is it affects one's ability to complete normal daily tasks like cooking, banking, shopping.

[Aaron]

So why is it so scary to people?

[Dr. Collins]

Well, there are a few reasons I can think of. One is fear of the unknown. We don't understand enough about something and we become nervous about what to expect. There's often fear of what others may think of them, there's fear of becoming a burden to their families, and there's fear about losing independence. We need to talk about dementia, this will help it become less scary – not only for people living with dementia, but for their friends and families, and others as well.

[Aaron]

Now, you mentioned forgetfulness. What's the difference between dementia and forgetting where you placed your keys?

[Dr. Collins]

Well, every one of us has moments where we forget things from time to time. The one I would hear most often in my memory clinic was: "I go to the fridge to get something and then I stand there with the door open for 5 minutes wondering what I was looking for, and as soon as I close the door, I remember what I was looking for". That's kind of normal forgetfulness. That's the day to day we have so much on our minds that we lose track of things. That's typical forgetfulness. When you can recall later on in the day what it was you were trying to remember, that's normal. The difference between cognitive impairment and forgetfulness is that that recall isn't there. And the difference between cognitive impairment and dementia, is that in dementia it becomes profound enough to interfere with our regular, daily activities.

[Aaron]

So, with cognitive impairment I think a lot of people tend to think about Alzheimer's disease. What is Alzheimer's disease and is it dementia? Are there different forms of dementia?

[Dr. Collins]

It's a question I get asked a lot. People say, "how do I know if I have Alzheimer's or dementia?". So again, dementia is lots of different things. There are many different types. The most common is Alzheimer's disease. It accounts for about 70-80% of all dementias. Other relatively well-known types include vascular - the type that can develop after you've had a stroke, Lewy body dementia, and Parkinson's dementia. There are also some very rare types as well. Most important, there are types of cognitive problems that can be reversed. There's certain vitamin and mineral deficiencies like vitamin B12, some metabolic abnormalities – thyroid disorder and excessive alcohol consumption. These are all types of memory loss that if they're caught and corrected, can be reversed. This is one of the reasons why it's so important when anybody's experiencing any memory loss to see their physician to determine if it's something that can be reversed.

[Aaron]

You've mentioned several factors that could lead to dementia, but how does somebody get dementia? Is there a trigger?

[Dr. Collins]

That's a great question. Dementia is caused by changes that happen in the brain. It is a bit different depending on the type of dementia. It can be due to an abnormal buildup of proteins, certain types of proteins, like we see in Alzheimer's disease. Or it can be due to damage, due to changes in blood flow and damage to the tissue like we see in vascular dementia. These changes affect the neurons – the nerve cells in our brains. When these cells become damaged, they don't work as well as they used to. Eventually they die, causing the brain to shrink in size. The changes to the neurons also affect the chemical messages that our brain sends telling us what we need to be doing. These are called neurotransmitters. So, in Alzheimer's disease for instance, the neurotransmitter that is affected is called the acetylcholine. It becomes important for treatment strategies. Symptoms are related to where the brain changes are most prominent. So, in Alzheimer's for instance, the hippocampus is usually affected early. The hippocampus is really important in consolidating short-term memory into long-term memory, which is why short-term memory is usually the first things affected in Alzheimer's disease.

[Aaron]

What are some of the early signs a person may have dementia?

[Dr. Collins]

Well, difficulty remembering new information like dates or events. Difficulty planning - I look for problems following a recipe or completing any tasks that has multiple steps. Trouble doing routine tasks either at work or at home - sometimes things get missed in one location or the other. Something that they've been doing for a long time, I get concerned for example when a patient gets lost on a familiar route. Communication can become affected. So, someone might have trouble following conversations, or difficulty finishing a sentence, or searching for the right word. Another concern would be somebody who spends less time socializing or engaging in activities they once enjoyed.

[Aaron]

How do these warning signs evolve as the disease or dementia takes route?

[Dr. Collins]

Well, the same symptoms continue but they become progressively worse. There's more memory impairment. In the early stages, short-term memory is lost while long-term memory is relatively well-preserved. As the disease progresses, long-term memory becomes affected as well. So, difficulty recognizing familiar people and places becomes an issue. Difficulty remembering more daily activities, including things like bathing and dressing. There can also be changes in mood and behaviors - sometimes people become agitated, fearful, anxious, or paranoid. This can be difficult for families to deal with.

[Aaron]

What do you know about decreasing our chances of getting dementia as we get older?

[Dr. Collins]

Well, the same things that we do for our physical health can actually be good for our cognitive health. There are some very good studies now looking at diet and exercise. For example, a Mediterranean-style diet, so eating a healthy, well-balanced diet that includes a variety of colorful fruits and vegetables, lean proteins like fish and chicken, heart-healthy fats like olive oil and avocados, and avoiding highly processed foods is good for our brains. Regular physical activity is not only good for our physical health, it's good for our cognitive health too. Socialization is equally important. Having conversations and participating in enjoyable activities stimulates our brains. And then

learning new things! Try learning a new language, or an instrument, brush your teeth or comb your hair with the opposite hand. Learning is really important to keep those neurons firing.

[Aaron]

After a person is diagnosed with dementia, what does a treatment plan look like?

[Dr. Collins]

Well, it's very individual. It depends on the person, it depends on what type of dementia they have, and where they are in their stage. In our memory clinics, we always had a liaison from the Alzheimer's Society to help ensure that the patient and their family had access to all of the wonderful resources available in the community so they could live their life to the fullest. Educational programs for patients and families help them to understand. The more we understand, the better armed we are. Community resources include things like Brain Wave Cafés through the Alzheimer's Society, where people diagnosed with dementia can get together in a social environment. And then there are medications that can help manage the symptoms of dementia, and a doctor in a memory clinic or someone who specializes in memory loss can help determine if those medications are right for you.

[Aaron]

Is there a cure?

[Dr. Collins]

No. There's not a cure at this time. There's so much research being done constantly but like other diseases, there's so many different factors and there's so many things they're still trying to figure out. For Alzheimer's, they've spent many years focusing on the proteins and how to eliminate those proteins as a potential cure. They're looking at new things now, like inflammation on the body and how it relates to cognitive loss and looking at new strategies. There's so much research being done on a regular basis; it's just trying to find the best strategy for each of the different types of dementia.

[Aaron]

Obviously, the brain is an incredibly complicated organ. Is there something that researchers are really tripping over and trying to unlock the key to maybe finding a cure one day?

[Dr. Collins]

No, I think once again because we know that there are different types of dementia that affect different parts of the brain in different ways - I highlighted two: the protein deposition in Alzheimer's disease and the vascular changes and damage to the tissue in Vascular dementia - but there's so many types of dementia and it's really important to make sure that we look at each of those types, figure out what the damage is, figure out how the damage is happening, and then tailor the treatment to that particular type.

[Aaron]

How many types of dementia are we talking about?

[Dr. Collins]

There are dozens. There's about 10 that are most common and most frequently seen. But we're learning new things all the time.

[Aaron]

Unfortunately, with issues that impact the brain, a lot of the time these tend to be hidden problems. You can see somebody that doesn't have an arm, but you can't necessarily see somebody that has trauma to their brain. Do you think that this leads to a stigmatization of people with dementia?

[Dr. Collins]

It's exactly that. There's often a stigma surrounding things that people don't understand or they cannot see. People who don't understand dementia are afraid to talk to somebody with dementia because they don't know what to expect. But the more they talk to somebody, the better they would understand. We need people talking about dementia. We need people to understand. That is the only way we're going to end the stigma. It's like any other mental health issue. It's taken us years to recognize that talking about it reduces stigma. It doesn't create it.

[Aaron]

Dementia is something that attacks a person's mind and by extension, a person's identity. So, what can physicians and people in healthcare do to help a person realize they're more than just their diagnosis? That they're more than just a person with dementia?

[Dr. Collins]

People living with dementia are just that: people. They should be treated the way we treat any other person with or without any other disease: with respect. We need to learn, we need to educate, we need to talk to people living with dementia, to their friends and

family, and to the general public. Let's ask them what they want. It's easy for me to sit here and tell you what someone living with dementia wants, but I might be wrong. We need to hear it from them, and we need others to understand.

[Aaron]

Dr. Collins, I just want to thank you for sharing your knowledge with us. The final word is yours – anything that you would like to say?

[Dr. Collins]

When you spend your life working around people living with dementia, it is inevitable to think about what you would want if you were to develop dementia. I think about it every day, as I am certain almost every family member, physician, nurse, PSW, social worker, housekeeper, environmental service worker and volunteer who works with people living with dementia does.

I think about the things I enjoy now. The things I enjoyed when I was younger. The feelings associated with certain people, places, songs, food, pets, memories. I know how it feels when somebody is rude or unkind. I know how it feels to be lonely. I know how it feels to be left out of conversations or not invited to things. I know how it feels when people don't understand what I am trying to tell them or when they simply don't listen. I know how it feels to be scared. I would guess that many of you share these feelings, and I wonder what others you might add.

[Aaron]

On the next episode of "Forget Me Not"

[Dr. Collins]

There's no cookie-cutter approach to dementia. Every person living with dementia is different and we need to treat each person with the dignity and the respect that we would want for ourselves and our family members.

[Aaron]

What does dementia mean to the doctor-patient relationship, and how can doctors learn from their patients? We'll examine these questions and more on our next podcast.

[Aaron]

“Forget Me Not” is brought to you by Revera. It is produced, edited, and written by Aaron Rathbone.