



## Forget Me Not

### The diagnosis

[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.

As we get older, we encounter many life changing experiences. Hopefully, many of these are happy, but sometimes life throws a curve ball that we never expected. Life is full of challenges to overcome. Sometimes we may find that a challenge is too big, too difficult, and we just can’t figure it out. But it’s struggles and the way someone chooses to face them are what make great people great.

The American singer Jimmy Dean once said, “I can’t change the direction of the wind, but I can adjust my sails to always reach my destination.”

[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]

Thank you for listening to another episode of “Forget Me Not.” I’m Aaron Rathbone and it’s my pleasure to be joined once again by Dr. Rhonda Collins. For those of you who don’t know, Dr. Collins is the Chief Medical Officer at Revera. In her practice, she specializes in Elder care with an emphasis on memory care, dementia, falls prevention and clinical quality improvement. Dr. Collins, thanks for speaking with us again.

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

Thanks for having me again.

[Aaron]

I want to talk to you about something that I think is very important, the doctor-patient relationship. As a doctor, you're on the frontline of a person's health and have the tremendous responsibility of treating them to the best of your ability. You also have the duty to give a diagnosis to a patient. Can you tell us what it's like for a physician to tell their patient that they have dementia?

[Dr. Collins]

It can be very difficult. Giving bad news is always tough. When you give somebody a potentially life-altering diagnosis, you recognize that you are changing the expectation they had for their own lives. Dementia is particularly challenging because so many people still don't really understand it. What everybody knows is that there is currently no cure, so they feel like they've just been given a death sentence. But this is where a physician can really make a difference. This is where I can focus on reminding patients that they can continue to live a full and meaningful life. It is a time to emphasize the things they can do, not the things they can't.

[Aaron]

When you were first starting out with your practice, do you remember the first time you had to deliver the news to a patient that they had dementia?

[Dr. Collins]

I do. It was devastating for the patient and his family. I remember him saying, "I wish you had told me I had cancer. At least I'd know what to do with that information. How am I supposed to explain this to people?". I was immediately shaken by this comment and I quickly realized that there is a huge lack of understanding that many people have about dementia. And of course, that leads to stigma.

[Aaron]

How does your relationship change with your patient from when you initially give that diagnosis and as their journey continues?

[Dr. Collins]

Well, it's an interesting paradox. I was in a memory clinic and patients were referred to me for an evaluation that included cognitive testing, history gathering, physical examination, and then provided a diagnosis and treatment plan. Because there can be resistance to a diagnosis of dementia and a variety of emotional responses, the referral allows the patient to maintain a good working relationship with his or her own physician - even if they're angry with me about the diagnosis. Interestingly though, as time progresses, their relationship with me often becomes stronger when a patient realizes that what is most important to me is their needs being met.

[Aaron]

I've heard some people that advocate for people with dementia refer to it as a disability. What does that distinction mean?

[Dr. Collins]

Well, the term disability is often seen as negative because its often thought of as a problem that exists in a person's body that requires medical treatment. But the social model of disability recognizes that people are disabled by barriers in society, not by their own impairments or differences. This can refer to physical barriers or the attitudes of others. We can use the social model of disability to help people understand that barriers make life more difficult.

Removing these barriers helps create equality and offers disabled people more independence and control over their own lives. Think about the incredible improvements to physical environments, education, transportation services, and employment opportunities for people with physical disabilities because of the Ontarians with Disabilities Act. The advantage of thinking of persons living with dementia as having a disability shifts the focus to thinking about their rights and addressing barriers - especially attitudes.

[Aaron]

Do you think that that goes far enough?

[Dr. Collins]

No, I think it's a good start. I don't believe that it goes far enough because what we really need is for people to understand. So, I think that this is a step in the right direction. Having legislation or acts that help people understand is just one piece of the puzzle. Having education and making the voice of persons living with dementia prominent is the next major step.

[Aaron]

What do you think are the best traits a doctor should have?

[Dr. Collins]

Well, number one is the ability to listen and support people to express their needs and concerns. Physicians need to be compassionate and empathetic. They need to be honest and patient and understand that people may be irritated, aggravated, angry, saddened, fearful - I've seen all of these responses to a diagnosis. The physician must be able to help them maintain their confidence and their self-esteem and ensure that ongoing support happens for the patients and their families.

[Aaron]

What you're describing sounds a lot like what most refer to as bedside manner. Is that something that doctors are taught in medical school? Is there a way to teach proper interactions that can help patients?

[Dr. Collins]

There is. I went to McMaster where we were required to learn patient communication skills with standardized patients. So, these were actors who represented patients with physical and psychiatric illnesses or difficult personal or medical situations. We approach them the same way we would an actual patient, and then we would receive feedback from them, as well as our classmates and our professors on how well we communicated and the things that we could be doing better. It gave us many opportunities throughout school to learn how to deal with the types of uncomfortable situations we would face as doctors and learn the types of things to say in those situations to be supportive and empathetic.

It is also born of experience. Asking yourself each time you have to news to a patient, "how would I feel is this was me, my mother, or my child?". When we've experienced certain losses or certain situations it makes it a little easier to relate to the person we're talking to.

[Aaron]

How do you relate to your patients?

[Dr. Collins]

I've always had a really good ability to establish a rapport with my patients. I've always tried to understand their needs and encourage them to express their feelings and emotions in a supportive environment. To me, the most important feature of the doctor-patient relationship is collaboration. It is pointless for me to recommend a therapy or prescribe a medication if you aren't interested. I need to know what you want, and we need to work together on a treatment plan.

[Aaron]

Is patient empowerment then something that is taught to doctors in medical school?

[Dr. Collins]

I don't think it's taught deliberately; I think it's a part of the learning process through the communication with our patients, through patience, through learning how to be honest and empathetic. What I do think is that we learn through that process to encourage our patients to be their own advocates.

[Aaron]

Speaking of advocacy, there's obviously a power dynamic between a patient and the doctor. Many patients feel vulnerable in any situation dealing with a medical professional. So how can they advocate for themselves?

[Dr. Collins]

One of the best ways to encourage a patient to advocate for themselves is to make sure that when they go to see their healthcare provider, they understand what they're going in for and have a list of questions and concerns in advance. It isn't to say that they can't go back after the fact and ask those questions, and often that's the case with dementia.

A diagnosis of dementia sometimes comes unexpectedly even when they're in a memory clinic. I've seen people really taken aback when I've given them a diagnosis although they were there to have their memory tested in the first place, but maybe weren't aware that things had progressed as much as they had. So, I always had a liaison from the Alzheimer's Society at every memory clinic appointment. That way if somebody wasn't able to ask the questions that they needed to ask at that time, they had a follow up within a couple of days to make

sure that they could ask questions. It gave them time to think about things and figure out where they wanted to go next.

[Aaron]

When it comes to supporting a person with dementia it's important to have empathy. I think you would agree with that.

[Dr. Collins]

Absolutely.

[Aaron]

How can we train doctors to have empathy for their patients?

[Dr. Collins]

I think the most important thing we can teach people, not just doctors but everybody, is how to listen. Listening is not just about hearing. It is about understanding. It is about being present in the moment, about not interacting, about not trying to formulate your next response, and it's about reflecting back on what has been said to make sure you truly understand. I think it's important to repeat a person's words back to them. That way they know you have truly heard what they've said.

We can teach empathy. People think of empathy as being an inherent trait – and it is – but there are studies that have shown we can teach empathy and that goes back to my previous statement of always asking the question, “if this were me”. I think that helps.

[Aaron]

Is that something that you learned in medical school? Or is it more of an inherent trait?

[Dr. Collins]

I think it's an inherent trait that can be enhanced with education and with experience.

[Aaron]

It's no secret that Canada's population is getting older. How can we prepare the next generation of doctors to be ready to treat older Canadians?

[Dr. Collins]

Well I think it's all about education. The piece about empathy and understanding needs to continue and probably needs to get even stronger than it is now, but education is so important because physicians and all healthcare providers and going back to the community and attitudes, everybody needs to have a better understanding. I think there's a little bit of fear, and I've heard this from family members, from staff members, "I don't know how to talk to somebody with dementia". It's very simple, you talk to them the same way you talk to anybody else. There shouldn't be a distinction between the way we communicate with somebody with any diagnosis including dementia. So that's where the education piece is so important. Physicians particularly need to continue to learn how to communicate effectively with everyone.

[Aaron]

How can health care providers better support people living with dementia and their families?

[Dr. Collins]

Well, there are several things that I think are important. First is talking directly to the patient. So many times, I've seen a healthcare provider speaking to a family member. Talking around the patient. That, to me, is extremely disrespectful, and I know from speaking to many people living with dementia, they find it extremely disrespectful as well.

It's also really important to be aware of resources in the community. One of the saddest situations I saw was a patient who was referred to our memory clinic, who had a diagnosis of dementia two years prior and was on medication for dementia. They came to the memory clinic and I wasn't really certain why. But, I found out that for two years this person had had no access to community resources. Neither the specialist who diagnosed her nor the family physician had asked, "have you been in contact with the Alzheimer's Society?", "do you know what's available in the community?". So, I think physicians need to know what resources are available to refer their patients to. They need to be able to explain the purpose of different tests and why we're doing them and what we hope to learn from them.

We need to take our patients' concerns seriously. What may seem trivial to us may be really important to the person asking the question. It's pretty easy to blow off a concern that seems unimportant, but this goes back to empathy. There's a reason a person's asking a question. There's a reason a person is expressing a concern. Take that seriously.

[Aaron]

In the example you just brought up, you mention how some physicians may not know about all the resources that are available to their patients. Is there a blind spot in our health care system that doctors could be unaware of things that will help support their patients better? Especially patients with dementia?

[Dr. Collins]

Absolutely. Yes, there is, and that has to take place at a societal level, at a regional level, and at a provincial level. We need to make sure that we're spending a lot of time. We're going to see more cases of dementia because we're going to see a continually aging population over the next couple of decades. And so, it's an absolute must that our physicians, and our health care providers in general, understand what resources are available. We need to put more emphasis on dementia care in medical school and in residency. It's underrepresented I think, at this stage.

[Aaron]

I think you kind of touched on it now, but do we need a political will in order to better address our aging population and the increase that is expected for dementia patients? You see certain governments bringing about a Minister of Seniors. Are these steps in the right direction and what further steps do you think we need to make as far as political advocacy to make sure that we have the resources in place that patients will need?

[Dr. Collins]

I think these are definitely big steps. There has been a push, a grassroots campaign, for a national dementia strategy over the past several years and it is gaining momentum. I see bringing on a Minister of Long Term Care and a Minister of Senior Services as definitely a step in the right direction, but this has to continue to move forward. It's nice to identify that we have issues that need to be addressed, but they need to continually move forward and this needs to be a sustainable program.

[Aaron]

Dementia is often thought of in terms of loss, but how can we empower people living with dementia?

[Dr. Collins]

We need to stop thinking about the loss and start focusing on the abilities. The truth is that life expectancy is shortened when someone has a diagnosis of



dementia, but that doesn't mean that they should stop living. First of all, 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. We need to celebrate life. We need to celebrate abilities. This is again a paradox, because I said it's a social disability but not a disability in terms of what someone cannot do.

[Aaron]

Dr. Collins, I just want to thank you again for speaking with us. I think these are important conversations to have and I think we frankly need to have more of them. Is there anything else that you would like to add?

[Dr. Collins]

Thank you, Aaron. It's a privilege to work with patients and have them trust you enough to know that you have their best interests at heart. For all the high points of being a doctor, there are also difficult moments as well, such as when we have to share some unpleasant news.

Empathy should be a key trait of all doctors. It's hard to teach, but it's something young doctors ought to learn to form better relationships with their patients and ultimately treat them better.

Millions of Canadians put their trust in doctors every year. Many times, we see patients at moments when they're feeling most vulnerable. The first thing we learn in medical school is "do not harm". I believe this goes beyond the danger of committing physical harm and should take into account a person's wellbeing. Neglecting the needs of our patients can also cause harm, so we need to understand those needs and protect the rights of our patients.

Doctors need to have empathy for their patients especially during difficult times. For some, a diagnosis can seem like a gut punch and we need to approach patients with compassion and understanding. As doctors and medical professionals, we must always take the time to deliver the care our patients deserve in an honest, empathetic, and respectful manner that recognizes them as individuals.

[Dr. Collins]

On the next episode of "Forget Me Not".

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

“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.

[Dr. Collins]

What does it mean to be on the receiving end of dementia and how do people prepare for the next stage of their lives? We’ll examine these questions and more on our next podcast.

[Aaron]

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