



Forget Me Not

Finding support

[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.

Some people hate asking others for help. They feel like it’s an admission of failure on their part – that they couldn’t do it by themselves. Why is it that so many of us would rather go it alone, rather than admit that we could use a little extra support?

People we consider to be great individuals have rarely ever achieved their success by themselves. Steve Jobs, the co-founder of Apple, had his ‘other Steve’, Steve Wozniak to thank for his tinkering that resulted in the creation of the Apple I which partly revolutionized home computing. Even Thomas Edison had a whole laboratory filled with people to come up with the next great invention.

These may be business examples, but they’re true for our own care too. We’re more capable to take better care of ourselves when we have the help of others. Because when it comes to our health, we need all the help we can get.

[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]

Thanks for listening to another episode of “Forget Me Not.” I’m Dr. Rhonda Collins, Chief Medical Officer at Revera. As a physician I rely on many people to help me make the best decisions for my patients. From the nurses I work with to

the pharmacists, each play an integral role in the health of the patient. Other groups that I lean on are the regional support networks who I can refer my patients to so they can get access to the tools and tips that will really help them succeed.

Today, I'm joined by Sarah Putman who is the Manager of Education with the Alzheimer Society in the Niagara Region.

Hi Sarah.

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

Hi Rhonda.

[Dr. Collins]

Glad to have you here.

[Sarah]

Thanks for having me.

[Dr. Collins]

Tell me about the mission of the Alzheimer Society.

[Sarah]

Well, the mission of the Alzheimer Society of Canada is to have a world without dementia. Each chapter across Ontario and Canada will have its own individual mission. I work for the Niagara region chapter, and our mission is to advocate for and with persons living with dementia and their care partners, and to provide access to a diverse range of appropriate resources and supports.

[Dr. Collins]

A world with no Alzheimer's, that's something to really look forward to. At what point in the journey of the patient do you get involved?

[Sarah]

The earlier the better. I think as soon as somebody is experiencing any change in their cognitive abilities, they're worried about their memory in any way, that's

when they want to give us a call. We can help them to navigate some of the important things they can do to keep their brain healthy and help them to figure out what the first steps are to getting an assessment.

[Dr. Collins]

So, I think that's potentially one of the concerns people might have, is that Alzheimer's Society only helps people with Alzheimer's disease, but that's not true.

[Sarah]

That is not true. Things have evolved a lot in the last few decades. We've been around for quite some time – in the Niagara region since 1984, and we support people with any type of dementia. Whether its Alzheimer's, which of course is one of the bigger blocks under the umbrella of what dementia is, but of course there are up to eighty to ninety different diseases that could affect someone's memory, and we can support all of those.

[Dr. Collins]

So, what do you do? How do you help a person living with dementia?

[Sarah]

Well, it depends on when they come to us, and at what point of the journey they're entering into our organization, and what they're doing. But 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. Whether that's their informal supports – their family, their friends, their community networks, or formal supports through agencies.

[Dr. Collins]

And when they come to you how do you figure out what supports can help them?

[Sarah]

It's about looking at the whole person and what their experience has been up to this point. Asking some great assessment questions around what they're looking for with regards to their life plan: do they want to stay at home? Do they want to be involved with a lot of community supports? Are they looking for extra help in their home or in their day-to-day lives? And helping them to navigate what that

might look like and connecting them with some peers that are experiencing similar situations.

[Dr. Collins]

When a person receives a diagnosis of Alzheimer's disease they can go through a lot of different emotions. I've experienced this in memory clinics, and I had the great pleasure of working with you in the memory clinics and having you there to support people when they're receiving the diagnosis. How do you help someone manage those feelings to get to a point where they can focus on the best way forward?

[Sarah]

So, absolutely we see a wide variety of reactions. For some people the diagnosis brings a relief. It's an absolute, "Thank God, I know there's something actually happening here", and they are fully prepared to move forward at that point. For some people, there is a point of denial which is all part of the grieving process. I think the first step is to allow people to grieve and help both the person living with the diagnosis and their family to find time to talk with each other, talk with others who can support them through that grief.

The other piece is then, to start the navigation process slowly. We're not going to throw everything at once at somebody. We want to start with the basics of: what does this mean? What does education around dementia mean? There's a lot of misconceptions about what it means to have that diagnosis. And connect them immediately to services as soon as possible.

[Dr. Collins]

Are there generally types of questions that patients and their families have when they come to you?

[Sarah]

The biggest one is: "What's the biggest difference between dementia and Alzheimer's disease?" - of course. Some of the others are: "do I have to stop driving?", "do I have to stop working?", "can I live alone?" There's a lot of questions and a lot of unknowns when you receive a diagnosis of a disease that is progressive and is going to be changing your life. We want to focus on how you can live well and adapt your lifestyle to be able to be independent, and hopefully change the perception that it's all gloom and doom and move towards a more positive action around the diagnosis itself.

[Dr. Collins]

So, you've talked about the things to focus on initially. As someone continues on with their dementia journey how does your involvement with them evolve?

[Sarah]

So, as people progress with an illness that changes their memory and their cognition, we see change in function. And as they're having change in their function, we have to worry about things like safety risks, along with what we see with some normal aging safety concerns around pain, mobility, and safety in the home.

We also are looking at some of the things that are related to memory. So what we do is help to make sure they're being introduced to the right services at the right time for them, and that they are aware of what the eligibility criteria and how they get through those referral processes - because it can be very overwhelming to have more than one agency come into your home, and that's typically what's happening with this type of disease.

And of course, we are also looking at supporting the ongoing education of what to expect and how to support somebody as those functional changes happen. Within that, we can see some changes in mood, personality, behaviors, that we can often look at environmental strategies and communication strategies and some of those interventions that can help on a day-to-day basis. If you have those in your toolkit, hopefully you are going to manage better.

[Dr. Collins]

You talked about one of the misconceptions being that people think that this is a diagnosis of doom and gloom. We want people to live a long and productive life, how can people with dementia lead the type of lifestyle they want for as long as possible?

[Sarah]

Well I think the first step is to make sure that they're involved from the very beginning in having conversations with the people around them about what their wish is, what their beliefs are, what they want out of life. The more the people around you know, the more they can plan to make sure that that happens. But the other piece is being open to making some of those environmental and daily changes in their life to keep themselves as safe and independent as possible.

People with dementia can continue to do all the things they used to do, as long they are supported with both environmental strategies or some modifications to activities to really make sure that they're being able to continue to participate. So, for instance, if they're having trouble remembering to take their medications, they can look at things like blister packing. If they're struggling out in the community, there may be GPS tools or tools that are found in cellphones or in other devices that can help them with navigation. They can continue to participate in all of the things they used to do as long as they are using some of those interventions.

[Dr. Collins]

We're talking a lot about the people who are diagnosed - the people living with dementia. It's hard for them, but sometimes it's just as hard for their families. How do you support them and what support do you find that they need?

[Sarah]

So ya, they say for every one person diagnosed with dementia, ten others are supporting or affected in some way. Of course, we're seeing a much larger population of people that are being diagnosed with these types of illnesses under that umbrella.

These people who are walking that journey with someone who's experiencing a cognitive change are going to need just as much support with regards to grieving - of course they're watching someone they respect, and love, and have been part of their life, change - and that's hard to watch and to be part of. But they also need some additional education on how they can adapt their approaches and communication to support that person.

The more they know about what to expect, what is normal within the journey of dementia, hopefully the better they'll cope and the less stress they'll have. We want to see them remain healthy and strong, so we want to make sure that they are participating in the same lifestyle interventions that we would recommend for someone with dementia - in staying involved, not isolating themselves either. So, we do a lot of navigation and support for them as well.

[Dr. Collins]

One of the philosophies of Revera is to fight the stigma associated with aging, and that pertains to people with dementia as well. There's a lot of stigma surrounding dementia. What are the biggest misconceptions about people with dementia that you see or hear?

[Sarah]

I think one of the biggest ones is the immediate diagnosis – that the point of diagnosis is incapacity. A diagnosis of dementia does not mean someone is incapable, and in fact, people who live with an early diagnosis of diagnosis and right through the dementia a lot of capacities and a lot of abilities. I think it's really hard to shift the focus from what they can't do to what they can do. Often, a lot of the misconceptions are they can't do something when in reality I think they can do a lot of things if we just give them the right tools and supports.

[Dr. Collins]

Statistics show the number of people living with dementia is on the rise. How do you educate people about dementia?

[Sarah]

I think we're doing a better job already of educating people about dementia. We need the government to buy in. We're looking at that national strategy, we're wanting to make sure that people are aware of what the symptoms are – that's the hard part: really getting out there and helping people understand that dementia is not a normal part of aging, and that when you're experiencing memory loss you're not always just getting old. It is important to get out and talk to your doctor. Those are difficult barriers to overcome. We're out there on an ongoing basis providing education to community partners, to community businesses, getting out there on news and podcasts and these kinds of things, and trying to get that word out there. Educating people about dementia is more than just helping them to know that there's a disease, it's about helping them to know that there's more to the disease than memory.

[Dr. Collins]

And, you sort of already spoke to this a little bit in that response, but as a society what should we know? How should we be caring for people with dementia?

[Sarah]

I think we need to know that the senior population is the largest growing population in Canada right now, and that we're going to see a lot more persons - as science allows us to live a little longer, we're going to see a lot more people who are experiencing not just dementia, but normal aging that includes some of these memory impairments and challenges. And as a society we need to know that in order to care for them, we are all going to have to adapt and change the way we do things. Whether that is a long term care home, a retirement home, or

just in a general business community, and how we approach, and talk to people, and support people who are living in our communities.

There is a lot to be done. Society has a lot of initiatives around building those dementia-friendly communities, and supporting the community at large, and knowing the strategies to support someone with dementia when they're out in the community so that they can live well.

[Dr. Collins]

So, dementia-friendly or dementia-inclusive communities are a safer environment. Are there other ways we can go about making our communities safer for persons living with dementia?

[Sarah]

I think we need to examine how things work in any situation – so whether it's a transportation system, or in a mall, or in an environment where persons with dementia may need support, and that's going to be anywhere that you or I need support. So, we need to really get the word out there around helping them to be independent. That means that we are allowing some of those environmental changes, and approach changes across the board to help them to live and engage in their community as long as they possibly can with minimal supports because the community itself is just equipped for them.

[Dr. Collins]

That's great. I want to thank Sarah for being here today. As previously mentioned, I've had the great pleasure of working with Sarah previously and I know that the people that have been referred to the Alzheimer's Society have so many great things to say about the resources available to them. Sarah, tell me about resources available for people living with dementia, their families, their care partners.

[Sarah]

So, the Alzheimer's Society of Canada has chapters across the country. You can access your local chapter and figure out which one is close by visiting the Alzheimer Canada website and just putting in your postal code– that will give you the local chapter. Some other great resources that are out there are at the findingyourwayontario.ca website, which will also link to other provinces as well to give some great information about living safely in the community, and how both persons with dementia, care partners, and businesses can support persons

living with dementia if they are using the spaces that they're in. And there are opportunities there to get some tips and strategies around locating technologies, and the MedicAlert system that is nationwide, around having identification with you all the time.

So, there's some great resources out there and I would encourage anyone with a diagnosis – whether it's early, or you've been living with your dementia for a while, to get in touch with your local chapter to see what sorts of services are available locally. It is important for both persons with dementia, and their partners in care, and for any of us really, to make sure that we're looking at some of the great maintenance and prevention pieces that are part of living well. Those are things like a good diet, exercise, socialization - which is so really important, to not be isolated. That old comment "if you don't lose, it you lose it," it's really important to get out there and involved. And so, chapters like ours in Niagara, we have programs that are like coffee clubs, day programs, things that any of the other chapters around Ontario and Canada can probably connect you to similar programs in your own community to make sure that people are staying involved.

[Dr. Collins]

And I encourage everybody to follow Sarah's advice, and look to see what's available, and take advantage of those resources, because they are so vital as the population continues to age and more people are diagnosed with dementia.

Thank you so much for being here today, Sarah. It's been really helpful.

[Sarah]

Thanks for having me!

[Dr. Collins]

When you were a young child do you ever remember losing your parents in a store? Do you remember that sense of fear you felt of being lost? For people that receive a diagnosis of dementia, many of them also are overcome by a sense of being lost and overwhelmed with fear. If anyone needs to be able to lean on someone for support, it's people with dementia. Connecting with agencies, like the Alzheimer's Society, can be a great relief. It's comforting to speak to someone that understands what you're going through. People living with dementia don't need our sympathy, what they need is for us to have empathy for what they're experiencing. They need us to have their backs. They need us to love them and be assured that we will always be there for them.

[Dr. Collins]

On the next episode of “Forget Me Not”.

[Johanna Weinzettl]

“I just thought well I’ll just take care of him, that’s what we promised each other. And we just go from there and I was more concerned to comfort him and encourage him and tell him that I’ll always be there for him.”

[Dr. Collins]

Family members often lead the support network that those living with dementia rely on. They also intimately experience the changes their loved ones undergo as time passes and can often find they need their own form of support.

[Aaron]

“Forget Me Not” is brought to you by Revera. It is produced, written and edited by Aaron Rathbone. Special thanks to Sarah Putman from the Alzheimer Society of Niagara for speaking with us today and sharing her expertise. If you’d like to learn more, visit the Alzheimer Society’s website at Alzheimer.ca. Thank you, and we’ll see you next time on “Forget Me Not”.