



Forget Me Not

Advance care planning

[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 want to succeed at something, it's best to have a plan. This can go for anything from your personal life to professional goals, and it's especially true when it comes to dealing with your health. There's some times when you can just wing it, but your health isn't one of them. Not only is it important to set an effective care plan in motion, it's important that you find a plan that meets your wants. Everyone is unique and has unique needs. Sometimes there are many different ways to go about completing something and it's not necessarily the case that any one way is better than another. You have to do it in the way that make sense to you and makes you most comfortable. Not only is it important to be comfortable with your plan, you need to be honest with yourself as you set out in making it. After all, it's only through being honest with yourself that you can find the right plan for 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]

I'm Aaron Rathbone and thanks for listening to “Forget Me Not”. This is our final episode and today we’re going to touch on a very important subject: how to make plans for your future care. Eventually dementia will progress to a point where these difficult conversations will be necessary to ensure your wants are known and can be fulfilled. We’re joined once again by Dr. Rhonda Collins, Revera’s Chief Medical Officer, to help guide us through this topic. Dr. Collins, thanks for being here.

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

Thanks again, Aaron.

[Aaron]

What is advance care planning?

[Dr. Collins]

Advance care planning is a process of thinking about and sharing your wishes for your future health and personal care and confirming and who will be making those decisions if you were unable to communicate. As a physician, I'm required to get informed consent before providing treatment. So, think about undergoing a procedure like a surgery. The doctor explains what is going to happen, what the benefits are, what the risks are, and then asks if you understand. If you understand, you can say yes or no to the procedure. This is called informed consent. If you're not capable of understanding your options, the physician will ask your substitute decision maker.

[Aaron]

Now you just mentioned if you're unable to communicate, but why is it important that a person have an advance care plan?

[Dr. Collins]

Well there are several reasons I can think of. First, it allows you to think about what you would really want if your health were to decline suddenly. Thinking about things like CPR and life support are important. It also gives you a chance to ask questions about how effective things like CPR would be in certain circumstances - what the potential outcomes would be if you chose for or against different types of treatments. It also gives you the opportunity to have a conversation with your family and let them know what you really want. Imagine if you had a stroke, or a heart attack, or you were in a car accident and couldn't speak for yourself. If you are unable to express your wishes, I will turn to your substitute decision maker - and this is so much easier when families have had these conversations beforehand. Many times, I've seen loved ones make decisions for a family member that they may not have wanted because they've never had the conversation and they want to ensure that they're doing everything they can. Dementia is one of those situations. In very advanced dementia, I've seen people undergo unnecessary and potential harmful treatments at the end of their life because a well-meaning family member is making a decision for them, holding out hope that the treatment will prolong their life a little bit longer.

[Aaron]

In your experience, why do some people struggle with making these preparations?

[Dr. Collins]

Well, nobody really wants to talk about death. Nobody wants to think about the end of their life. It's - we all struggle with our own mortality, and we particularly struggle with a loved one's mortality. Think about your mom coming to you with this conversation: "I want to talk about what's going to happen at the end of my life." You may not be open to that the first time. This is why it's so important to try and have these conversations more than once. Because we change. Our opinions change, our ideas change, there's more information that comes out about a certain procedure or treatment option. So, it's very difficult to talk about our loved one dying

[Aaron]

In your practice, have you found that your patient or their family typically struggle more with advance care planning?

[Dr. Collins]

It's often the families. So, in my practice at every checkup at age 65, at the end of the visit I would have the conversation: "If I were to tell you you had a year to live, have you given thought to what you would want? Have you discussed this with your family members?" And often times it's a very blunt question and it gives people pause. "No, I've never even thought about that", and then the realization that, "No I haven't thought about that" or "I know what I would want, but I don't know if my family knows what I would want." And so, it just encourages the conversation. This is an opportunity for us to encourage really good conversation between people and their substitute decision makers, their family members, their loved ones, their powers of attorney, to get a sense of what I really want at the end of my life.

[Aaron]

How does someone create their plan and who can they reach out to for help?

[Dr. Collins]

So, Speak Up Canada is a national campaign through the Canadian Hospice Palliative Care Association. This is an awesome organization who has a great [website](#) with all sorts of tools and resources. They have printable workbooks and quick guides on their website, they have podcasts, blogs, personal stories, they have conversation starters, how to get the conversation started with your loved one, there's decision aid tools to help

you make decisions. And I just want to point out that advance care planning is not about making decisions. It's about thinking and reflecting on your personal values and beliefs and what you want and sharing that information with the people who may end up having to make that decision for you.

[Aaron]

One of the things that you've brought up is having somebody who can help fulfill your wishes, also known as a substitute decision maker. What are the responsibilities of a substitute decision maker?

[Dr. Collins]

Well the substitute decision maker is the person who will make decisions about your health care if you are unable to. You can choose your own substitute decision maker by appointing a power of attorney for health care. If you have not appointed a power of attorney, the Healthcare Consent Act of Canada has a list of automatic substitute decision makers. These can be appointed, like a guardian or a representative from consent capacity. If none of these are in place it would be a spouse or partner first, then a child or parent who meets the criteria, a sibling or another family member, and finally the public guardian and trustee is a last resort.

There are certain responsibilities for this role: you have to be mentally capable of understanding the treatment or care being proposed and appreciate the consequences of consenting or refusing the treatment decision, you must be at least 16 years old unless you are the parent of the incapable person, you cannot be prohibited by a court order or separation agreement from acting as a substitute decision maker, you must be available in person, by phone, or via electronic communication, and you must be willing to act as a substitute decision maker. When your substitute decision maker (SDM) has to step in and make decisions for you, he or she is required to honor and apply the wishes, values, and beliefs that you communicated when you were still mentally capable. If your wishes are not known, your SDM is required to act in your best interest - and best interest has a specific meaning in law. It involves your substitute decision maker considering the values and beliefs you had when you were capable.

In addition, your substitute decision maker should consider your health condition: if you were likely to improve, remain the same, or deteriorate without the treatment, and the risks and benefits of the treatment options. By having these discussions with your substitute decision maker, it allows them to make decisions confidently, knowing that they are acting on your behalf.

[Aaron]

As a person's dementia journey continues and reaches a certain point, they'll rely more heavily on people for support - whether it's their family, or various services or agencies. How do you explain this to your patient who may be uneasy about challenges to their independence?

[Dr. Collins]

Of course it is important to understand what a patient's wishes are, but also to recognize the need for safety and security and the impact on family. Caring for a person with advanced dementia can be challenging. There's increasing physical care needs. I'm a huge proponent of individuals living independently for as long as they possibly can, and some people have the resources to achieve this.

Others often need to look for alternative options. Think, for example, of an older lady trying to take care of the physical needs of her husband's advancing dementia - like bathing, and assistance with walking or moving if he begins falling (which is not uncommon with dementia). Other things include becoming confused or agitated because he doesn't recognize his wife or his surroundings. Sometimes out of fear or confusion, people with dementia will strike out at caregivers because they see them as a threat. These situations can be unsafe for both the patient and the caregiver if they don't understand how to respond. In these cases, it is sometimes better for somebody to live in an environment, like long term care, where there is staff 24 hours a day that has been trained in how to prevent this from happening or know how to respond appropriately when it does.

[Aaron]

Now you just raised long-term care as one of those alternative options. For listeners who perhaps don't know, what is long-term care and why may it be a good option for some people?

[Dr. Collins]

So long-term care is congregated living, where people with physical or emotional psychiatric needs that can no longer be managed at home, because their needs are too great, have the ability to live in an environment where there's 24 hour staff that includes personal support workers, as well as registered nurses, registered practical nurses, dietary, culinary so that they can get their meals prepared for them, so their health care needs are being met and their day-to-day needs are being met. We know with advanced dementia, some of the abilities to complete activities of daily living like bathing, and dressing, and eating get lost, so having staff who know how to do these things can be very helpful and provide some respite to family members who may be getting challenged with all of these activities that they need to provide.

There's often confusion between retirement living versus long-term care. So, in retirement living, meals are prepared and there is opportunity for activities, group activities, and individual activities, but the care needs are not the same. So long term care is really advanced care needs for activities of daily living and health care.

[Aaron]

Advance care planning is all about allowing a person to have control over the decisions that need to be made when they're dementia journey advances beyond that certain point. Why is it important for people to have control over their own care decisions?

[Dr. Collins]

Because we're all different. Because we all have different ideas, and values, and beliefs, and experiences that shape our plans for our lives. I know what I do and do not want in certain circumstances, and I would not want somebody making a decision that contravenes these wishes out of either desperation or lack of knowledge. I think about advanced dementia and what I would want. I have a power of attorney for healthcare, but I've also shared my wishes with my entire family.

There's a few examples of questions you could ask yourself, and ask if you would be able to answer them for a loved one as well: where do I want to die? Do I want to die at home, or a hospital or hospice? A recent poll showed that about 90 per cent of people would prefer to die at home, yet more than 60 per cent of people die in hospital. Now the new numbers are showing that more people are dying at home than ever. So obviously the word is getting out and people are having these conversations, and that's great to me.

Ask yourself, "would I want a breathing tube or a feeding tube if I'm probably not going to survive or live independently? Why would I want or not want these procedures? Is there anything that scares me about dying – pain, trouble breathing, becoming confused and agitated, and is there somebody who can help me with these? Are there treatments available to prevent pain, to prevent trouble breathing, to prevent becoming confused? Talk to your doctor about that. Is there something that would make things better for me at the end of my life? Like having family present in the room, or listening to my favourite music, having somebody read to me or tell me jokes, having a spiritual leader like a priest or Rabbi present? These are all things we need to think about.

[Aaron]

Dr. Collins, thanks for helping our listeners to understand advance care planning. Just for anybody who might be struggling with having these conversations with her family, what were those resources that could possibly help them out?

[Dr. Collins]

So, there's several that I would turn your attention to. The first one I mentioned is advancecareplanning.ca as well as alzheimer.ca, this is the Alzheimer's Society of Canada website and they have advanced care planning resources on their website. There's also dyingwithdignity.ca, and finally if you can't find what you're looking for on the internet, speak to your family doctor. Your family doctor has probably had hundreds of these conversations and really knows what resources are available to you.

[Aaron]

I just want to thank you for being with us throughout this whole series and helping to shed a positive light on dementia, and helping people break down the stigmas that are impacting and holding people back. This is our final episode of forget-me-nots and I want to give you the last word.

[Dr. Collins]

Thanks Aaron. throughout my practice, I've met hundreds of people living with dementia. Every one of them is unique and vibrant. Dementia is many things, but it is not what defines a person.

For people living with dementia, they can continue to do the types of things they've always done and lead the lives they've always wanted. There is hope for people living with dementia, hope that we will one day find a cure, hope that we can provide the right type of support that will help them to be successful in their journey - according to however they define success. Above all else, I'm hopeful that through conversations, discussions, and education, we as a society can create a better world for people living with dementia. A world that will encourage their continued contributions and recognize their individual value. We need to show to people living with dementia that they are meaningful to us, that they are productive, and that they are loved.

I want to thank everyone for listening to "Forget Me Not." I encourage you to share it with your friends and family and I want you to be open to meeting with people living with dementia. They need our support on their dementia journey and we need to end the stigmas that are holding thousands of people back from leading their best life possible.

[Aaron]

"Forget Me Not" is brought to you by Revera. It's produced, written, and edited by Aaron Rathbone. We want to thank Dr. Rhonda Collins and all of the guests we've spoken to for sharing their stories and experiences, and for helping us to end the stigmas that

affect people living with dementia. And of course, we want to thank you for listening. We hope you found this podcast inspiring, and that it will spark more positive conversations around living with dementia. Thank you for listening.