



## Forget Me Not

### Being a caregiver

[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.

Family is often described as the foundation for society. Most people rely on their family for support, whether it's emotional or physical. When we're hurting, we hope that our family will rally around us and help us through turbulent times in our lives. For people with dementia, there's no single moment but many moments where they will want to draw on the support of their family and loved ones. However, when it comes to supporting a person with dementia, it's important to make the distinction that we are working alongside them to continue to live well as opposed to taking over and controlling their lives. Instead of taking away things from people with dementia, we should be building them up with the support they need to maintain their independence and lead the life they've been spending their whole lives building towards.

[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, and it's my pleasure to be joined today by Johanna Weintzetti. Johanna and her husband, Herbert, have been married more than 65 years. They immigrated from Austria and built a new life for themselves and their family in Canada, settling in North York where they owned a beauty shop together. In 2011, their lives changed when Herbert was diagnosed with Alzheimer's disease.

Johanna, thank you for speaking with us today about yours and Herbert's experiences.

[Johanna Weintzettl]

You're welcome, Rhonda. I'm happy to speak to you.

[Dr. Collins]

Can you tell me a little bit about how you and Herbert met?

[Johanna]

Well, we were both working in the beauty salon in Graz, Austria, and he was basically my teacher. That's how we met, fell in love, and stayed together since - that was in 1948, I think.

[Dr. Collins]

And then you both came to Canada where you opened a business together. What's it like being husband and wife and also co-owners of a business?

[Johanna]

Well, like everybody said that's very unusual and they were thinking this isn't going to work but it works very well. We were working together until we retired - semi-retired - in '98, and we had no problems. He had the man's section. I had the lady section. We were together, but we weren't really working with each other. So, it was a wonderful time because as I say, I am not married 65 years. I am married 130 years because we were together 24-7 which doubles it! So, we have had a wonderful marriage and a wonderful life. And especially living in Canada, which was our dream, that was fulfilled.

[Dr. Collins]

What were your plans for when you retired?

[Johanna]

Well, we had a store we sold, and we moved some of our clients out to our house. We fixed up a little salon downstairs for men and women. We worked until the beginning of 2017. So, we were working practically all our life. We didn't work every day, but we just enjoy it and of course, you know, it was extra income and I just loved hairdressing and so did he. So, you know, making people beautiful is a wonderful thing. So, that's what we did. Retirement really was messed up a little bit with the diagnosis that Herbert had.

There wasn't too much travelling which we had planned, so we just stayed home and did what we had to do.

[Dr. Collins]

Leading up to his diagnosis, what were the signs that something wasn't quite right?

[Johanna]

Well, I noticed some personality changes. My husband was always a very quiet man and never raised his voice to the kids or anybody, and it was just wonderful to live with him. But he started a personality change where he got a little cross with me the odd time and he just wasn't himself - and of course forgetfulness. I thought maybe the doctor could give him some so-called "vitamins." So, I went to talk to the doctor by myself, Herbert was waiting in the waiting room, and when I told him he had the right questions, of course the doctor did, and I told him that you know, I was concerned. So he said, "would Herbert mind coming in?" I said, "no, I'm sure he wouldn't." So, he did come in and he gave him this basic Alzheimer test, which Herbert failed like every single thing. He couldn't do the clock, he couldn't answer when he was born, where he lived - which I had not noticed because I wasn't asking these questions. So, when we walked out, he of course with the diagnosis, was devastated. He says, "well now I'm going to kill myself" and I said, "no, you're not because I'm going to look after you until the end", which I'm still doing. Not at home, but...

[Dr. Collins]

How did you feel when Herbert was diagnosed with Alzheimer's disease?

[Johanna]

Well you know, I was upset of course. But you know, when you first get the diagnosis you think of other people doing it. I wasn't that devastated, as he was, I just thought "well, just take care of him. That's what we promised each other." We just go from there, and I was more concerned to comfort him, and encourage him, and tell him that I'll be always there for him.

[Dr. Collins]

It must have been really sad to hear him say that he wanted to end his life because of that diagnosis.

[Johanna]

Oh yes and he said it many times, even when he was in the nursing home. He still said it when he could still speak - which he can't anymore. So finally, you know, I tell him "you can't do that. There's no way!" So, it was hard.

[Dr. Collins]

How did your family react to the news that he had Alzheimer's?

[Johanna]

Well, they were naturally very sad. But because they knew that I would be the caretaker of everything they weren't as concerned. They were sad and upset, and also, you know, they had another issue to deal with and that's, "will we get it?" Cause that's, you know, people say offspring are usually are concerned about that part.

[Dr. Collins]

What did you do as a family to support him?

[Johanna]

There wasn't that much at the beginning because Herbert was still driving. The doctor let him still drive, he said [to me]: "As long as you're still in the car and you don't get lost." He was still fine, and we were still doing things. So, there was no need for any particular help. It was just a regular, you know, come see Mom and Dad and not that much to talk about it at that point.

[Dr. Collins]

Were there any resources or groups that you sought out to help navigate the journey with Alzheimer's disease?

[Johanna]

I got in touch after years. Of course, you know, he said he was diagnosed over eight years ago now, so the very first years everything was just normal, and it was just a little hard to deal with his personality change. So anyway, when the time came that I needed some help I got in touch with CCAC (Community Care Access Centre) and a couple of nice girls came and talked to me and let me know where I stand and what the possibilities are for me to access. So basically, CCAC was the only thing that I needed.

[Dr. Collins]

How has your relationship evolved with the changes Herbert has experienced?

[Johanna]

When you've lived together a lifetime, we were teenagers, and love never changed. As a matter of fact, even being in love never changed. So, that was basically what brought us through the whole thing until the time came when I had to let him go somewhere else.

[Dr. Collins]

When was the decision made that Herbert needed the support of long term care? How did you come to that decision?

[Mrs. Weinzettle]

Well first it's something I'm never going to do. This is what I hear other people say: "I'm never going to let him go. Never. I'll do this forever. I can do it. I can look after him." But then the time came when he started having a toilet issues where he couldn't go by himself, I had to take him. I couldn't make him sit on the toilet because he was afraid and I found out later in the nursing home, that our seats that are white are similar to the floor and people in that condition feel they are falling. So, in the nursing home they showed me, "This is why we have black seats, because people can distinguish where to sit." So, this was one issue. Herbert would go into the shower, you know, like he would get up every half hour at night and I would have to get up with him because otherwise it would be all over the floor and then I have more work washing the floor. He would stand in front of me sometimes and just wet himself in the living room. So, you know, that was the time when I really got serious about putting the name in for an eventual placement in a nursing home.

[Dr. Collins]

Now you live at Westney, which is incredible retirement residence -

[Johanna]

Absolutely.

[Dr. Collins]

A lot of our viewers get confused between a retirement residence versus a long-term care home. Can you tell me from your perspective what the difference is?

[Johanna]

I know, this is amazing that people are uneducated about it because a retirement home is just like moving in from one home to another. I mean, I moved from my home to retirement home and I actually changed homes because I wanted to have more independence and Revera is amazing that way because you have all the care, you have a wellness center, you have your food if you want it but you can also just buy it as you go, there are three eating areas - a dining room, Bistro, and a pub, so you can eat when you want. You can buy on your fob. You can buy let's say \$1,000 and then you just use it you never need to carry money or anything. So, it's just a wonderful setup.

The nursing home is something that is the stage after - when you can't look after yourself. In a retirement home, you still look after yourself although you do have the wellness center, which I am so pleased with, because sometimes when they don't see me all day they call me at 8:30 at night, "Johanna how are you?" Of course, I'm telling them I'm fine. So, you never feel alone. You have all the events that you want to go to, which I can't because I go to Herbert every afternoon. So, it's so different from a nursing home where you're taken care of, you have to - you know, diapers and being fed sometimes, and all the things that I see there which is also wonderful, you know, to be in a place.

[Dr. Collins]

How do you cope with supporting Herbert? Were there difficult moments you had to endure?

[Johanna]

Well right now he's at the stage where he can't stand any more or get up. He just lies in bed. Of course, the continence [is an issue, and he] has to be washed. He has to be cleaned. He has to be hoisted with one of those machines - it's like a swing, like a hammock - from bed to the chair and from the chair to the bed. So, it's hard to see that. When using the chairs, sometimes I'm in the hallway where he propels himself forward with his feet and it's an awful thing to watch. You know, when you remember him the way he was.

The hardest thing for me was, and still is, leaving him. Cause I'm there between two and two and a half hours in the afternoon. I lie down with him and we hold hands and he calms down and he's just very loving and still knows me which is a blessing. But leaving him, he always looks like a sad little puppy, you know leaving me now. I usually don't say I'm leaving, I just say "I'll see you later" or you know "I'll be back", because I'll be back the next day, but he doesn't remember.

So basically, leaving was for me from the beginning the hardest. At the very beginning I would cry half the way home. I still drive, so I would cry and now it's become, thank God, a routine. And this might be very helpful to some people when they're so frightened: he's been in there - this is his third Christmas, he was admitted on the 21st of December. So, it's two years and it's become a routine. I go every day and I look forward to seeing him as she does me. It's not as bad as you think, because I know he's taken care of and I can really encourage people to not be afraid to let the husband or wife or a spouse go into a place like that because when you go home, you feel a little bit of haven to be away from where you just left yourself. I also was a very strong believer in God. So, I have sight of the faith, which helps me a lot.

[Dr. Collins]

Have you and Herbert encountered any stereotypes about people living with dementia?

[Johanna]

Not really, no, I can't say that. I think people are educated enough today that they know it's a sickness. It's not it's not a mental thing. It's a sickness of the brain and it's not something that anybody can help. People are very supportive and trying to be helpful and sympathetic. So, I can't say that I have had any negative impact on that.

[Dr. Collins]

Has your perception of dementia changed?

[Johanna]

I don't know if I thought about it much before. And Since Herbert has it, I have just learned that it is what it is. It's not something that we can change. We can't change our destiny, or it would kill us if we try. So, I just live each day the way it comes my way and I don't look forward to the future but I know it is my future and it is Herbert's future and I have to live it. So, I'll live it to the end with him.

[Dr. Collins]

If you could say one thing to the people listening to this podcast, who maybe are going through the same experience you are, what would that be?

[Johanna]

Well, I think first of all, don't be as afraid as most people are. I think you have to allow yourself to be impatient, to get angry, because this is just a normal reaction to all the

things that are happening. When I had my husband at home, I don't get angry at him now of course because it sort of went right back to a very loving relationship, but when I first had to deal with everything myself, I would sometimes just cry. I'm not someone that cries too much - maybe that's too bad because maybe you should cry and talk to other people.

I've started, at Revera, an Alzheimer's support group. It's actually called Loss, Grief and Alzheimer's, because I've had a few people sharing with me their things that they go through and having to deal with their husbands. I decided that rather than stopping in the hallway and talking to each other, why don't we just meet downstairs in our lovely library area. And now we have a support group of about sometimes 5 to 10 or a little more. Everybody is very happy to share their thoughts and help each other.

[Dr. Collins]

That's excellent. And I really want to follow up on that by saying that it's so important for those people listening to understand that while certain things may not work for you, other things may. That's why it's so incredibly important to seek out the resources that are available and find what works for you, because we're all different, we all learn in different ways, we all respond to different things, and this is a great example of something that's working for you and for the people that you're providing the support group to. So, thank you so much for doing that Johanna.

[Johanna]

Thank you. Thank you for noticing it.

[Dr. Collins]

Johanna, I want to thank you for taking the time to speak with us today and sharing yours and Herbert's story. It's not easy supporting someone living with dementia or Alzheimer's disease, but you do with so much grace and humility. Thank you for sharing your experiences with our listeners.

[Johanna]

Well thank you very much, Dr. Rhonda. It was a pleasure talking to you.

[Dr. Collins]

My dad was my rock. He passed away almost six years ago after a sudden diagnosis of cancer. There was so much that I admired about him. Most of all, was the way he faced challenges.



As a child, he was diagnosed with glaucoma and knew it was only a matter of time before he would be completely blind. He attended the Ontario School for the Blind where he learned the skills he would need to succeed in life. He would go on to have a successful career as a darkroom technician in the x-ray department of our local hospital, and he was never held back by his quote, disability, un-quote.

I know what it means to take care of a loved one. I know the challenges it entails. I know the heartache of bad days and the joy of good ones. For many people supporting a loved one, whether they're fighting cancer or living with dementia, it can be a terrifying and exhausting experience. However, the thing that keeps us moving forward is the love that binds us to each other.

With my dad, I knew deeply the appreciation and love he had for me. Not just when he was sick, but during our whole time together. Being his daughter was the best gift I could have ever asked for. I love you, Dad.

[Aaron]

On the next episode of "Forget Me Not".

[Dr. Collins]

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 those people who may end up having to make that decision for you.

[Aaron]

There comes a point in a person's dimension journey where tough conversations need to happen. Who can you turn to for answers? How do you make the preparations you need? Where do you start? We'll answer those questions on the next podcast.

[Aaron]

"Forget Me Not" is brought to you by Revera. It's produced, written, and edited by Aaron Rathbone. Special thanks to Johanna Weintzettel for inviting us into her home and sharing her and Herbert's story. We hope our listeners were able to glean more insight into supporting a loved one living with dementia, and we hope you'll join us next time on "Forget Me Not."