

TRANSCRIPT: More Talent Untapped

EPISODE 5 – Paul & Cathy Wing

AK: This program is brought to you by RBC. In order to speak up for inclusion, we need to speak about inclusion.

AK: I'm Anna-Karina Tabuñar and this is More Talent Untapped. Conversations about unconventional, sometimes underestimated talent... and the differences that connect us.

Paul: You just have to live moment by moment. Try not to dwell on your situation. Try to find something to distract you from the reality of the situation. There's always hope.

AK: Paul Wing has been living with Parkinson's disease for over a decade. The neurological disease affects every aspect of his life — from his movement and mobility, to his eating and memory. Paul and I share a special connection. It started as newsroom colleagues and progressed through our parallel journeys with disability. I reached out to him to see how he's managing Parkinson's and the pandemic. He and his wife Cathy work every day to consciously combat an isolating disease during an isolating time. Parkinson's has weakened Paul's voice. When it starts to fade, Cathy completes his sentences. When he loses his train of thought, she gives him a whisper. They recently celebrated 35 years of marriage. They've marked a lot of milestones together. Perhaps the most momentous was in 2015 — Paul's brain stimulation surgery. Paul remembers it vividly.

Paul: Well, being under anesthetic for five hours in the operating room and being conscious and having two plugs removed from my skull. They drill them out and they put two shocks down those holes into my brain and fed electricity to it. And I got up and started walking the next day. Amazing. It's like a heart, people with a heart condition have pace-makers. And mine is electrical. It supplies electrical currents to my brain. We don't know why it works so well, but it works.

AK: It's really changed the quality of your life?

Paul: Oh yeah. I was at the point where I was freezing in place for an hour at a time. I couldn't walk. I was using a cane. After the operation, I just threw that away. And just started living my life again.

Cathy: So physically he was in decline, and then the brain surgery gave him all his mobility back. It's been incredible. He's a lot more active, he became more independent. He did things on his own, joined clubs, played sports. So it was pretty life-changing.

Paul: My voice is deteriorating as you can tell. I have to learn to shout more. But with COVID, wearing a mask over my mouth doesn't help communication. The person I'm speaking with can't see my mouth. And it's muffled. That's pretty frustrating.

AK: And what do you do? How do you get your message across?

Paul: I SHOUT.

AK: That was super clear!

Paul: Ya, but to me that's rude. What's that guy shouting about?

AK: Apart from the physical distancing and the isolation, how else has it impacted your life?

Paul: It's taken away some of my independence because I'm nervous now when I go out. Not only... how do I say this? I've lost my independence. I feel nervous when I'm out there, outside of my house. But I have to go out, or I go stir-crazy.

AK: How do you overcome that? That fear, balanced with the need to go out and have some sense of normalcy?

Paul: I have a group of friends. We do social distancing dinners together once a week. That's something I look forward to. I just stay realistic. I have to go out. It's unpredictable. I set around to do a task and then half way through I have to stop it. So there's no sense of that completion. It's fragmented.

Cathy: We try to have some kind of routine, though. Like regular exercise working on his voice, and then trying to see people as much as possible. I think the social contact is so important for mental well-being.

Paul: Well, as I said, you just have to live moment by moment. And try not to dwell on the situation. Find something to distract you basically from the reality of the situation. There's always hope. When I had my brain operation, that was my hope. Hope that I recovered, and I did to a degree.

AK: So what's the next milestone for you?

Paul: Travelling. We bought a trailer. Do some travelling and go to the cottage. But, uh, we'll see. Cathy, my wife, is my trainer so...

AK: You said she's your trainer?

Paul: Yeah. She keeps on me. (Laughter).

Cathy: No, I think it's Cathy, his nagger. (Laughter). I have to be on him all the time to remember to practice his voice every day. To do exercises that improve his balance. And little things that need to be done regularly to improve those aspects he's having trouble with. So yeah, I feel like a mum again. Nagging my kid. (Laughs).

AK: I'm also curious about how the relationship tends to evolve. Because you referred to yourself as the nagging mom.

Cathy: Yes. (Laughs). Yes. I think there's certainly memory issues. Parkinson's is a neurological condition. Those things increase with age. So a lot of reminding Paul to keep him safe. And just trying to keep things safe around the house for him and make sure he's eating really well. Just keeping mentally and physically healthy.

AK: You said eating well. Is there also a swallowing component that's connected to Parkinson's?

Cathy: Well, yes there is. That's definitely an issue, helping him to eat safely because he has had choking incidents. And there's also been a lot of weight loss. So trying to pack in the carbs and the fat and protein into him. Not something most people worry about when we're retired because most of us put on weight. But it's the opposite for him.

AK: So you're looking after his eating, his memories, his exercise. When you're doing all that, how do you balance your own self-care?

Cathy: Well, there's a lot of things we do together, which is really good. We bike a lot, we go camping. We go to the cottage. So a lot of the activities. We both do yoga, I do more than he does — but these are activities that we do together so that's really helpful. I think with COVID it has been hard. All couples are struggling with the 24-7 month after month. And not being able to get away on their own. So, I think that's something that we're dealing with like everyone else.

AK: But in your case, there's that extra complication.

Cathy: Yes, the nagging as well. (Laughs). I think in fact our life is pretty good right now.

Cathy: Getting support is really important. When Paul's Parkinson's was worse before the surgery, we were quite involved in the Parkinson's community in Ottawa. We had groups that we went to. We had a dance group that we went to. We saw people who were in similar circumstances. So I think that's really important. If there's a symposium or conference happening in Ottawa. We'll go to it, get as much information as we can. And network with people. So that kind of thing is really important. And just keep up your social networks as much as you can.

AK: There was one thing I forgot to tell Paul. Can you bring him back on?

Cathy: OK. Here he comes.

AK: Remember a few years ago when I had a really hard time getting out of the house? My mobility wasn't great. My vision wasn't great.

Paul: Yup. I remember that.

AK: You were the one who dragged me out of my house to get me to overcome my own fear of falling. And you gave me that sense of security, that I could do this. So I don't think I had the chance to say thank you.

Paul: You're welcome. I'm glad I was able to do that. We would just talk. We didn't talk about our disability. We were just regular folks. No problem. Glad to help.

AK: I think my recovery would have been a lot longer if it weren't for Paul dragging me out saying, just two more steps. Come on, we can make it to the end of the block. That's what Paul did for me.

Cathy: So he was nagging you? (Laughs).

AK: I wouldn't call it nagging. He was encouraging me. He was nudging me forward. (Laughs). And do you see you playing that role for him?

Cathy: Yes. Yes. Maybe I could be a little more encouraging and less nagging. (Laughs). Ya, that just reinforces what I was saying, support networks are so important and reaching out and being with people. People who support you in a positive way, that's so important.

AK: So now in the spirit of giving back, what can I do for you?

Paul: Go for coffee.

AK: Your patio or mine?

AK: Paul and Cathy remind me how important it is to nurture our friendships and networks of support. Our family and friends, our neighbours and colleagues all help us combat the isolation that can affect both our physical and mental well-being. They also supply us with a healthy dose of laughter. So I want to send Paul and Cathy a huge Thank You for the much appreciated dose they've given me.

More Talent Untapped is a sequel to the documentary Talent Untapped. If you're interested in a special screening of the original film, send me a note through my website annakarinatabunar.com.

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The people who helped put together this show are: Lindsey Vodarek, Howard Sonnenberg, Ashley Wright, Colin Van Hattem and me, Anna-Karina Tabuñar.

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