

Flying Solo

An Interview with Olenka Melnyk

Interview by: Declan Beddow



Throughout this issue of Pulse magazine, we have been addressing topics that pertain to a unique group of individuals with Parkinson disease; those who are single and/or live alone without a primary care partner to rely on as they navigate this journey. In this article we get a firsthand account of what it is really like to fly solo with Parkinson's. The delightful and thoughtful Olenka Melnyk agreed to sit down with us and share her first-hand insights on managing Parkinson disease solo. Quotes have been modified for brevity.

Declan Beddow (DB): Could you please introduce yourself.

Olenka Melnyk (OM): My name is Olenka Melnyk. I'm 71 years old and have been retired for six years. I've worked as a writer and an editor for many years. I've lived in Edmonton for a long period of time, and I've got two grown children who both live in Edmonton as well. I was diagnosed with Parkinson's about a year ago, but I've had symptoms for much longer than that.

DB: We're here today to talk about Parkinson's as a single person or someone living alone. So, how are typical challenges approached differently in your situation?

OM: Parkinson's is challenging in any case, but I think it's particularly challenging when you live alone because you basically are responsible for yourself,

including day to day things, running a household finance, looking after yourself, socializing planning, and going to medical and therapy appointments. There isn't somebody to drive you, take you there, make the meals, clean up the house, and organize things. So, it is more challenging and there is always the fear, and the vulnerability, that comes as the condition progresses. The future can become more frightening because you must have a backup plan, and how do you make a backup plan when Parkinson's is so unpredictable? So, there is all the same responsibility, but there isn't that one person that kind of has your back.

DB: How has your family and social relationships changed since you've received your diagnosis?

OM: Well, it changes how I function overall as a person. I've been fortunate to enjoy what I call "mindless good

health”; to have had good energy and be active. It gave me a great deal of pleasure to be helpful to the people around me. This changes with Parkinson's. Your energy levels go down, your ability to focus, and do things. I'm not the one doing all the cooking for Christmas dinner anymore.

I think part of it is trying to educate and prepare my family. This is what Parkinson's is all about. Here's where I'm at. Try to be honest with what I'm capable of doing at a particular time and let them know how these things have changed.

It has shifted the balance quite a bit. And I think, like many people at my age, I'm finding that many of my friends are also dealing with health issues. Suddenly for many of us here, we're dealing with health issues and surgeries or chronic illnesses, and our aging all at the same time. So that changes the relationships a great deal and how you can rely on people. I think that has also forced us to dig deeper in our friendships and family relationships because you have to be honest with where you are, let each other know about your vulnerabilities, and kind of open up your heart more. For me it's been a big issue about how to be able to receive help and feel like your dignity is still intact and you're worthy of this. That you're not overburdening people.

DB: How does planning for the future look different for you?

OM: Well, I go after the bottom line. That's my way of dealing with issues when they come up. So, after I found out that I had Parkinson's, I immediately started looking up end of life care and provisions. My GP (general practitioner) watched me, and she says, you know, Olenka, this is a little bit premature. You've probably got a couple more years of a good kick at the can. She didn't quite phrase it that way, but I kind of went to the end of the road scenario, which I actually found very comforting to do. It made me feel better to go for the brutal, brutal planning.

Part of it is looking around and asking: how can I live independently as long as possible within my home?



But deciding when not to push it too far. Because if I'm pushing it too far, I'm not going to be capable of looking after myself and I will be a big burden for family and friends. Although I have two children in town, boy, they sure have a lot of challenges in their own lives, and I don't want to needlessly put more strain upon them.

So, it's been thinking ahead from A to Z. In essence, what can I do to make my house more livable than now? What do I do when I no longer can live there? What are the alternatives? And start to look at that. That's included, in my case, just hiring help like housekeeping, yard work, and snow shoveling. Because, physically, it's just become much more difficult to have the energy to do all those things. It's been important to me not to be afraid to look at the future. To say these things will come. They will happen. And to really try to make my children and people around me comfortable with that as well. To say to them, here's what I've planned, here's where my thoughts are, and to make it part of the normal conversation rather than something that seems morbid.

Do it while you can, while you're clear headed and then just focus on enjoying your life or going about it with as much meaning and care as you can.



DB: Can you talk a little bit more about how your perspective has changed since being diagnosed?

OM: Well, I think especially within my friendship group, it's been really dealing with our mortality, and I mean, we all have to deal with it. But when you have Parkinson's as well as other illnesses, it's there in your face. So that's been really important to share, to really find the humor about it, and to ask for help. That can be extremely difficult to do. It also means you have to let go of your ego, because our bodies are not functioning the way that we would like them to.

Sharing and remembering your values, the things that are important, and really letting go of the petty things and unnecessary things. Including in family relationships, and really making an effort to make sure my relationships are good and if there's been any misunderstandings to clear them up and just to really open your heart up.

And I'd like to just say that because Parkinson's is so unpredictable, I find that you really find a real sweetness in day-to-day life. Things become more

precious and more meaningful and it's a real gift every day. A lot of gratitude.

DB: Why is it important to talk about managing PD solo?

OM: It's beginning to change, but I still think that there's very much an emphasis on a more conventional approach to your living situation, that you're within a marriage and a family, and there's somebody there to pick up after you.

About a quarter of people over 65 are now living on their own. So, when you consider that about 100,000 people have Parkinson's in Canada, there's thousands of people who are on their own. And I think that it's really important that those particular needs are addressed.

So, you know, if you go to a support group and everybody's there with a spouse, and most people are, I mean, that's really lovely, but it kind of skews the dynamics a little. You are dealing with the same condition, but the circumstances are quite different. And it's really, really important that that be addressed, because I think when we're dealing with Parkinson's, it's really important that we all feel heard and understood. And not to feel sorry for yourself, but to really give yourself credit that you're trying and to hear from other people that, yes, this is typical, the feelings that you have are normal, and here are some ways that you can cope.

DB: Any last comments or anything you'd like to add before we wrap things up today?

OM: I'm really excited and pleased that the Association (PAA) is doing a support group for people living on their own with Parkinson's. I really welcome that and look forward to it. At this point in my life, I'm really searching for more support experience, and I'm really glad that we'll have the opportunity and to meet and talk and help each other out.

Thank you to Olenka for taking the time to sit down with us and talk through her first-hand experience living with PD solo.