

IT'S NOT JUST AN “OLD PERSON’S” DISEASE

A Young Onset Perspective on Parkinson Disease

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Each person with Parkinson disease is fully unique, but we share our knowledge with each other as parts of our experiences overlap. This offers us a huge amount of support as we learn tricks and new ways to approach issues as they arise. We learn to be pre-emptive and learn what we can do to maintain a better future. Though this is something we can share with each other it is best to come from those that are in similar life stages as each other. There are many people with Parkinson's that are diagnosed early on and are what is commonly referred to as Young Onset. This is a term used to describe those that are diagnosed below the age of 50. About 10 to 20 percent of those diagnosed with Parkinson disease are under the age of 50, and about half of those are diagnosed before the age of 40 (Early Onset Parkinson disease: APDA, 2024). The disease itself does not change in the way of symptoms but what one is tackling at this time in their life often differs from many other people living with Parkinson's. For this article I spoke with some of our Young Onset clients to get their perspective on Parkinson disease.

For many people with Young Onset Parkinson disease (YOPD), the journey to diagnosis is filled with uncertainty. When diagnosed in earlier years, they

often experience subtle, early symptoms that are easy to dismiss. For some the process takes months or even years as they navigate a series of doctors and specialists before receiving a definitive diagnosis. The delay is partly due to a common misconception that Parkinson disease is most likely seen later in life. Younger patients are often told they're too young for such a diagnosis. Often hearing things like "It is just stress" or "some tremor is normal". When the confirmation does come, it's not just a medical revelation but a seismic shift in the trajectory of life.

Being diagnosed at a younger age means dealing with Parkinson's at a time when career ambitions, family responsibilities, and long-term goals are still the most prevalent thoughts on one's mind. Younger individuals with Parkinson's often feel the weight of explaining their condition to friends, family, and even colleagues. Speaking to children is one of these conversations that can be very difficult to broach. Kids often see what is happening but don't fully grasp what is wrong. Having these conversations with them is a balance between setting expectations and building understanding. Having a conversation with them will begin to build an understanding that sometimes things like fatigue, bad days, and other symptoms of Parkinson's could interrupt your time with them but helping them know that it doesn't change how much you want to be a part of their life will make those moments easier. Relationships can strain under the pressure of the disease, but they can also deepen as loved ones step up to offer support.

Many speak of having to adjust life plans, mentioning the difficult decision to adjust at work, "Balancing Parkinson's and my old work schedule just wasn't sustainable, but stepping back gave me space to manage my health better and take care of myself". Many have found great success by having a very



difficult conversation with coworkers, bosses, and other workplace connections about the disease, diagnosis, and what they might see moving forward. Along with this there may be times where one hits a wall of fatigue and needs to rest. This is a part of the disease that can be most disruptive to one's normal flow of the day, taking time and giving yourself patience is best in these moments. We will be tired sometimes and need to take a second to recover. This makes these conversations even more critical to build understanding or grace with those around us.

Honesty is always a good policy as things progress, we never know where our best supports will come from. The emotional and psychological toll of being diagnosed with Parkinson's at a young age cannot be overstated. Many expressed feelings of fear, anxiety, and grief. Being open about the diagnosis is another emotional hurdle. For some, going public with the diagnosis brings relief and allows them to educate others about the disease and find supports on days that are harder than others. For others it takes time before they have a conversation with their wider circles as they worry how being public with having Parkinson's could affect their life. Both are very valid ways for individuals to approach living with Parkinson disease where work, family, and life have high demands of them and their reaction to a diagnosis could vary greatly.

For those newly diagnosed with young-onset Parkinson's, the advice is consistent: take things one day at a time and lean on your support network. "It can become a lot, but you'll find a new normal. Don't be afraid to ask for help when you need it". Taking control of the disease early on, by incorporating exercise, seeking mental health support, and engaging with supports, is key to maintaining quality of life. Looking back, many wished they had reached out for help sooner or made lifestyle changes earlier. "Start exercising, get involved in your treatment, and don't wait. You're in this for the long run, so the sooner you take control, the better". Many encourage securing a good health care team, getting involved and informed, and connecting with others so that you can live as your best self with Parkinson's. Echoed by many young onset clients, despite the challenges, there is a shared sense of hope and resilience. Parkinson's may change life's trajectory, but it doesn't have to define it.

This proactive approach not only empowers individuals but also becomes crucial when considering long-term decisions, such as advanced care planning. While Parkinson's may alter life's path, thinking ahead about future care needs ensures that you remain in control, allowing you to shape how the disease will impact the later stages of your life. "At first, I didn't want to think about my future health needs, it felt too soon. But I've realized it's not about planning for the worse, it's about taking control of my future for the better". Advanced care planning is an important step in planning for the future and something everyone should be doing a lot earlier than we often do. It involves talking to your family and doctors about your preferences for medical treatments and setting up a plan to make sure your wishes are followed as your condition may change. Being pre-emptive with our care planning gives us the opportunity of choice and time to think through what we want in the future. Once complete it can offer a sense of security and allow you to focus on the now.



For those individuals diagnosed at a younger age, finding a supportive community can make a world of difference. Many Young Onset patients speak about the feelings of isolation that can accompany their diagnosis, especially since much of the focus in the public eye centers on older individuals. Accessing one-on-one support, support groups, or attending events, and participating in research can all be a good way to form connections and build a community that understand the challenges, complications, and victories that come with tackling Parkinson disease at an earlier age. If you are looking to get involved and connect with others there are Young Onset support groups that run monthly through us at the Parkinsons Association of Alberta.

While Young Onset Parkinson's presents unique challenges, it also highlights the resilience and strength of those living with the disease. The journey—from diagnosis to adapting to new realities—can be overwhelming, but through support systems, self-care, and exploring treatment options, many find ways to reclaim control of their lives. Whether it's through exercise, therapy, or leaning on family and peers, each person's story is a testament to how hope and determination can shine through the challenges. Parkinson's may change the path forward, but it doesn't diminish the capacity for joy, connection, and purpose.