

Care Partners

A Different Journey for Everyone

Written By: Charlene Heavener



A common comment heard from care partners is "My loved one is the one with the Parkinson's diagnosis, but I feel like I'm experiencing all these changes too."

Sharon Pangman is the care partner for her husband, Mike, who was diagnosed with Parkinson disease in 2019, and from his initial diagnosis until now, her experience has been a journey of learning and growth. After the initial shock of the diagnosis, she realized she needed to have a clear plan to move forward. For many in this situation, there is a quest to find information, while others may take a wait and see approach. Sharon and Mike were definitely in the quest for information category. Together they set out to learn, and understand, as much as they could about "our new diagnosis." She said "our diagnosis" because they were on this journey together!

Their plan was to educate themselves about PD, but they were not sure where to go to find the correct information, or even where their search should begin. They did know that just randomly searching the internet was not the best course, and they did not want to jump to anticipating, or predicting, what the future would bring. They needed reliable education, information, and connections. Soon, they found Parkinson Association of Alberta and were thrilled to learn that they both were able to take advantage of the programs, supports and services PAA offered.



But being a care partner for a loved one is not just a difficult journey, it is a completely different journey for everyone. Where Sharon and Mike were able to develop a clear plan together, others struggle with the idea that their partner has PD, and that both their lives will be changing. Sharon and Mike were hungry for information that would help them navigate their journey, while many others choose to not look too far ahead or have a more difficult time finding reliable information and supports.

Sharon quickly understood that a three-legged approach was important. The three legs were exercise; what should Mike be doing to be active, nutrition; what should he be eating, and medication; what does Mike need, and how can he keep to a schedule. All three legs acted as support and in the beginning, they focused on exercise, finding ways for Mike to be active and moving. It is a fact that exercise and activity can make a difference to those living with Parkinson's. Once they had introduced a consistent and realistic activity schedule into their plan, they added nutrition. Then they added the important medications and created a well-balanced schedule. Once they had all three support legs in place, it became all about attitude! How would they live well and remain positive.

At this point, the conversation moved from “what can we do” to “how can we best balance what we need to do”. Their lives became more of a balancing act, and Sharon realized part of that balancing act was adding in some self-care for the care partner – herself. Educational and Social programs were the answer.

PAA’s PD 101 provided the basic information they were looking for initially, and the social supports offered through the Organization such as the seasonal socials allowed them both to connect with other people living with PD as well as other care partners. These offered comfortable settings that allowed for connections with a common link.

Sharon and Mike also found the regular Friday Social Singing program helpful and enjoyable. It is a great activity for the voice but also a fun and engaging way to get to know other people in a casual way over zoom. Seeing familiar faces is a positive experience and they both look forward to Friday mornings!

NOW the conversation is based around, can we balance what we can do, and what we want to do! Part of the balancing act is self-care for the care partner.

Expectations can be a dangerous thing. Expectations that are not met can build resentment, harbor anger and lead to great disappointment. Being rigid can be disastrous: things don’t always go as planned and when you and your spouse are managing a chronic progressive neurological condition, no days seem to be the same. Allowing for flexibility is essential but can be very hard as well. PD evolves and changes and as the care partner, you must realize that you cannot stop the progression. Learning to work with PD instead of against it, accepting that some days will be great, and others will not, is a huge challenge and can be a difficult one for care partners. PAA is here to help care partners with those difficult challenges and Sharon acknowledges that asking for help is difficult but necessary.

It is highly recommended that care partners remember to nurture themselves so they can continue to care for the person with Parkinson disease. Sharon has built a team including health care professionals, friends, family, neighbors as these are the people that will build you up on a day that needs that or will help you

celebrate the wins. Nurturing oneself is different for everyone. Learning to care for oneself is an important part of the journey, as is caring for yourselves as a couple.

“Don’t save time for trips - take them now if able. Forge the path ahead. Think about what we can do and do it!” Living in the moment is hard when we start to think about the future – a future that can be unpredictable and unsteady at times.

This is where talking with others that are on the same path or have walked that same walk may be helpful. Support groups for care partners may provide that sameness factor. There are people that may have been in the same situation as a care partner and have information to pass along that can be very helpful.

Sharon had some recommendations that I thought were important to pass along. “As the disease progresses the demands on the care partner increase. Yes, it can be very terrifying if you only look at the negatives but look for the absolute awesome moments and celebrate those - be grateful and treasure those moments - big or small.”

“As part of a relationship - concentrate on how great can life be with PD right now. Yes, there will be low days, allow yourself as the care partner a break - and just make it through the day. On that day, you may not get everything done, but that’s ok. Again, set realistic expectations - give yourself a break!” Sometimes giving yourself permission to not do everything is necessary.

For Sharon, the top of the stool - ATTITUDE has been very important from the very beginning. Not allowing PD to take over but acknowledging that some days are better than others. “Moment by moment, step by step, day by day, fear of the future can be overwhelming but try to start to control that fear by realizing that things may not unfold the way you thought. Changes happen and not always by the book!” Even if there was a book, it would say that the only thing in common is the diagnosis. It can be hard to see things to be positive about when you are the person caring for a person with a Parkinson diagnosis. Just when you think you have things figured out, everything could change, and you wonder how you can find the joy in being a care partner.

“Positive attitude brings positive outcomes even when things are changing from day to day, hour to hour-never really knowing what it will be like.”

“Positivity makes the journey FUN!”

