

# Speech to seating and mobility

## About Me

My name is Gary Schroeder. I am not trying to shock you, but I sleep on an electric chair. That is my seating choice. I have been married to my wife Karin for 42 years, but these days she isn't strong enough to kick me out of bed in the mornings. My chair helps raise me to an almost standing position since my body seizes up overnight.

I am the co-facilitator for the Abbotsford Parkinson's Group. My work history was 32 years for Safeway. I also owned two tax offices for 38 years. With my parkinson's group I did a number of their taxes. I found that many handicapped people do not know about the disability tax refund, gas tax rebate, ICBC discounts and caregivers discount. I have spoken to 10-12 groups about this information. These things are all on the internet but many people just do their tax returns themselves and miss out.

I am a person who enjoys being with people. I enjoy laughing and telling jokes. I am usually a positive person so I try to pass that attitude along to others. Thank you for offering this forum to share my seating and mobility tales.

I was diagnosed with Parkinson's in 2002, at the age of 52. I loved to golf and now I had an excuse when I took too many shots in a round. At first I did not need to change the things I did. The medicine helped to keep me moving. I used an old hand cart to carry my clubs. In 2006 I was having more trouble in my walking so I bought a 3-wheeled golf cart for my clubs. That was my first mobility change. Around 2010 I was facing more challenges walking the golf course, so I started taking a power cart.

Gradually my balance deteriorated, and my friends struggled to see me fall down on the course. Being the great friends that they are, they attempted to be my personal mobility aid and physically held me up while I was taking a swing. I will say my score improved as I only played a few holes and put 0's down for the holes I didn't play. Eventually I have had to stop playing golf, which has been a huge loss in my life.

Outside of golf, by 2012, I was stumbling more often, so a friend let me try his mom's four wheel walker, but it didn't work for me to use on my own. Even when I locked the wheels I could not stop the walker from sliding. Although it did not work well as a walker, we sometimes use it as a makeshift wheelchair. I sit down on the seat, and Karin pushes me while I try to keep my feet from dragging.

In 2015, my driver's license was expiring. ICBC sent me a letter asking me to come in for a 90 minute test with an ICBC driving examiner. I knew that even if I passed the test I would be endangering other people if I drove anymore. They gave me a free ID card and I gave them my license. Then I drove home...just kidding. Of all the things I have lost because of Parkinson's, driving is the thing that I miss most. Now I have to pay for a taxi or bus, or give up my pride and ask for rides from friends and relatives.

The reality of the situation caused me to mourn for a long time. I had driven for 50 years. I loved to drive. This was one more thing that Parkinson's had stolen from me. Soon after giving up my license, we moved closer to town. I was given a scooter, which gives me the ability to get out.



We live in the farthest unit from the elevator in our complex, so when I need to travel by car, I drive the scooter to the elevator and then park my scooter in the front lobby of our building. The scooter has a hole in the bumper where the canopy gets installed. My walker fits right in that hole, which is convenient, because I have to take my walker to get to the front door and meet my ride.

**When you were first diagnosed, or experienced a significant change in level of function that required an assessment for new or more complex seating or mobility technologies, how did you feel?**

In the summer of 2014, we were sent to see an OT at the Abbotsford Regional Hospital. The OT suggested a wheelchair, and I was measured to make sure the wheelchair was a good fit. The OT also helped with my balance and strength, teaching me to use walking poles. I went to numerous rehabilitation sessions that I found very helpful. The OT understood both Parkinson's and Seniors. So did the physiotherapist in the hospital.

All the previous physiotherapists I had seen claimed they could help me, but they mostly focused on core strengthening exercises. They could not help me prevent the increasingly frequent falls I was experiencing as my right leg seized up and refused to follow my brain's commands. For 6-8 months, the walking poles and physiotherapy made a significant positive impact but then my legs stopped listening to my brain again.

For a long time, I struggled to find a walker that fit my needs, testing out numerous designs. Eventually we settled on a walker with no wheels. Had Karin not worked in a seniors facility and already had a working knowledge of the varieties of walkers available, we would not have even known to try various walkers.

**What was handled well by the professionals working with you? What would have made the situation or the process better for you?**

One of the challenges I have encountered with Parkinson's is that I don't always know which questions to ask. It would be helpful if medical professionals had information about the purpose behind various mobility aid designs so that patients could better self-select the mobility aid to address their individual needs.

For the wheelchair, my OT did an excellent job. I had a clear plan of how to use the wheelchair to improve my lower body mobility. It is comfortable, easy to set up and take down. Karin can do so in about 2 minutes. However, in this case, the OT either did not know enough about walking aids or did not think we would want to purchase another walker.



People do not realize how they talk differently to handicapped persons. People will ask embarrassing questions about you right in front of you. Overall I have been treated very well by health care workers.

In spite of this, others fail to understand that every person is different. Sometimes frustration starts to set in and then you give up on the health care worker. Then you try a different one and start all over. Please remember who I am outside of Parkinson's disease. If I could, every sunny day I would be out on the golf course. Take time to get to know your patients.

I know health professionals' intentions are good, but if I could leave you with one piece of advice, I would say that it is important to listen to your patients' concerns and make them feel like mobility can restore the freedoms that patients have lost. Please remind patients that mobility aids should not be seen as embarrassing but life-enhancing.

It is hard to admit that I need these mobility aids and I often feel self-conscious that I am slowing others down. My family keeps reminding me that they want me to be with them even if it takes longer to get places. Please remind your patients of this when they feel awkward about transitioning to a new mobility device.

Thank you for allowing me to speak to you today.

Gary Schroeder