

A Difficult Balance: Letter From A Caregiver



Brain conditions have broadly impacted our family. Our 27-year-old daughter was diagnosed at age two with Rett syndrome. At age 38, I was diagnosed with Multiple Sclerosis. My husband's grandmother spent her last years of life challenged by dementia and my own grandmother had Parkinson's disease. I have also watched my cousin struggle to care for her son who has Prader Willi syndrome.

We are dairy farmers and have three children close in age. The diagnosis of our youngest child devastated our family. Our daughter, Kayleigh, seemed absolutely normal until 23 months of age. Rett syndrome is a cruel disorder. Parents believe their young daughter is healthy and between 6 to 24 months of age the symptoms will begin to appear. Throughout the years we have had to watch our daughter combat numerous comorbidities. Kayleigh needs daily physical, occupational and communication therapies. She also received hydro therapy weekly. She has had up to 80 grand mal seizures a day. She has a gastrostomy tube, is unable to use her hands purposely or walk, and needs constant care. Kayleigh also has osteoporosis and scoliosis. She has skin care issues, hyperventilation, breath holding, poor circulation and so much more.

Caring for a child with a severe neurological condition such as Rett syndrome can consume your entire life. Balancing the care of our other two children has been difficult. Many times they have had to take a back seat as we rushed to the emergency room to stop Kayleigh's continuous seizures. Given our challenges to simply get through each day, my diagnosis of MS seemed unbearable, but I have been fortunate that my MS has progressed slowly to date. I have tried to be the mother and wife I believe I should be for my family. It has been our goal to care for our daughter at home her entire life, but each day I worry if we can truly do this.

Once our daughter was 18 years of age, she had to leave the medical support provided by the local children's hospital. She was discharged from five specialists. A final report was sent to our family doctor. He became responsible for the management of her seizures; orthopaedic, cardiac, and urological issues; osteoporosis gastrostomy tube; pain, and so much more. Leaving the child sector for medical support has been devastating. Consultative physical, occupational and speech therapy was no longer an option through home care. Our daughter needs specialized medical interventions as an adult, but, in some cases, it took over a year for her to see a specialist. As a result, every medical challenge required more intensive interventions. Working towards a coordinated, comprehensive approach to support our daughter's ongoing challenges and family needs similar to what we experienced when she was a child would be valuable for us, as each stage of life brings additional challenges.

The financial impact our daughter's condition has had on our family has also been quite significant. The cost of medications, specialized equipment and home renovations that are not covered has been difficult to fund. There is also the upkeep on an accessible vehicle so our daughter can go to medical appointments. I could not work outside the home because our daughter seized over 60 times each day for more than a decade. She was medically fragile and I had to be available every moment. The lack

of a second income has put stress on our family. This financial impact is lifelong. I have not been able to contribute to my Canada pension; we do not have benefits or a supplemental pension to support us as we become seniors. We pray we will still be caring for our daughter at home as senior citizens, but are unsure how we will financially do this, and are also concerned about our physical ability to provide the care she requires.

When I had my most challenging MS attack I was unable to walk, speak, swallow properly or use my hands. I had double vision, severe pain in my head and continuous ringing in my ears. I was numb on one half of my body and in pain on the other side. Throughout this time period, I had to rely on my family for care and support. We were all frightened. Our oldest daughter had to assist in her siblings' care. At age 14 she became her siblings' second mother. There is no doubt our children have had to grow up quickly. It took our oldest daughter a long time to accept my diagnosis even though she is an occupational/physical therapist herself today. She was mad at me because "Mom" should always be there to provide support and not get sick. On top of accepting my diagnosis our children have had to accept their sister's. I continuously watch for signs of depression and mental illness in our adult children. This may occur among family members who have had to deal with many extraordinary challenges.

I believe there are solutions to assist families who are impacted by brain conditions, particularly those who dedicate their entire lives to their children who have a brain condition. In caring for our children at home, there is less stress on the system and the financial costs to the provincial and federal governments are decreased greatly. We also need to value the children who have a brain condition, such as my daughter. They too deserve the best supports and services Canada can provide. They are our heroes and the quiet teachers in society. I believe their parents, the caregivers, should also be supported. Deciding to care for your child in your family home should not mean a life that is full of battling systems, pleading for medical supports, being financially stressed and always dealing with extreme exhaustion. Today this is a reality for the majority of families who care for their children at home. Aging only compounds all these issues.

[*Mapping Connections: an understanding of neurological conditions in Canada*](#), the report of the National Population Health Study of Neurological Conditions, identifies many areas and opportunities for action which, if we work together to address them, will help to improve the quality of life of families such as mine, as well as the millions of others who are impacted by brain conditions in Canada.

Terry Boyd