

## Persistence and planning are key for parents

By Jennifer Briand, Caregiver Support Coordinator, Western Region

Many of us can remember how challenging our school years were and how important it was to remain focused and organized. Imagine trying to be part of a school system when you are having difficulty with activities of daily living. Imagine how hard it would be to focus, when you can't focus or when you can't comprehend what is being said to you. Imagine trying to get to class if you have to wheel your way through your peers. Every day is a challenge for children with physical or cognitive disabilities, as they need to work so much harder just to get through the day.

Years ago when I worked in clinics and schools, parents often told me that their children would go to bed every night, right after dinner, as they were so exhausted from trying to concentrate and from the effort it took to function, from the minute they woke up until the bus brought them home later in the day.

I was often amazed and humbled by these parents. From the moment their child came into the world, their lives changed. They went from Plan A to Plan B in an instant. They became not only parents, but also caregivers. Many quickly learned a great deal about their child's diagnosis; they also learned practical skills and could advocate when needed—which was often. Parents learned what it is like to grieve for their child and the life they may never have—never have their own independence or children of their own. But parents also know tremendous joy, with each new accomplishment and connection with their child.

When you become your child's caregiver, it takes an enormous amount of energy and fortitude on your part everyday. It is also important to take care of yourself and seek out support wherever you can. Parents should pay attention to their own nutritional, physical, and emotional needs so they can recharge their batteries. Some of these parents have made their way to our caregiver support groups, and I'm so glad they are accessing extra support for themselves. It does take a village to raise a child...and to take care of their parents too.

I have asked some of these special caregivers what advice they would pass on to new parents. I wasn't surprised to hear very similar advice from each of them: They all said, "It is ok to dream new dreams for your child and to adjust your own goals". "You will realize how much strength you have when you are advocating for your child in a system that does not always cooperate." *"Be persistent, you know your child and their needs. And most of all plan for the future, as you will not always be there, in their future."* Advance care planning will help prepare for your child's financial and life needs.

For more information regarding advance care planning for caregivers contact, the Caregivers Nova Scotia office at 1.877.488.7390.



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