



Testimony of Sylvie, caregiver

My name is Sylvie and I'm from the Quebec City area. I've been retired for six years, and I live with my partner and daughter. Oh yes, I forgot, I'm also a caregiver! I'd like to share with you the story of my daughter Geneviève, who is 29 years old.

When she was around 2 years old, her father and I quickly realized that our daughter was not progressing at the same pace as other children her age in terms of language and motor skills. We consulted and were referred to the Centre Cardinal Villeneuve or IRDPQ, where patients with physical disabilities are assisted. There, a multidisciplinary team concluded that Geneviève had severe dysphasia. For those wondering what dysphasia is, it's a communication disorder that messes up the whole chain of communication, from hearing to

analyzing sounds and words, right up to oral expression at the very end. My daughter hit the jackpot...or at least a good 6 out of 7!

From then on, Geneviève was cared for at the Cardinal Villeneuve Centre, which became our 2nd home. Speech therapy, occupational therapy and physiotherapy sessions, both individual and group. During the 8 years of 2-3 weekly sessions, Geneviève was also evaluated by a neurologist, who informed us that she also had a mild intellectual disability. Following this diagnosis, our file was transferred to the CIUSSS to be managed by the intellectual disability team. We were called back 2 years later...so 2 years without services...

Geneviève attended special classes throughout her school years, until the age of 21. We were lucky in that, at the end of her schooling, she

was able to join a work group 5 days a week at the Fierbourg at the Polyvalente de Charlesbourg. She is part of a group of people who help out in the horticultural sector. Since her return to work, post-pandemic, last October, she's been working there three days a week, and loving it! In addition, she has been dating a boy for almost a year and a half. Every other Saturday, she goes to Patro Roc-Amadour, where she takes part in adapted activities with young adults in the same situation. Every two months, she stays at CampOCarrefour for a weekend of rest, where she enjoys taking part in the organized activities, but her favorite part is helping the educators!!

Despite her difference, which she is well aware of, Geneviève is good company, always smiling and very sociable. She has a playful side and loves to have fun.

This tall, blonde, blue-eyed beauty brightens up our lives, despite all the more difficult moments we occasionally experience. Some might say she chose us... and rightly so.

When you're a caregiver, it's also important to take care of yourself. I chose to get involved as a volunteer because it brings me so many benefits. I take time for myself, I don't think about everything that awaits me when I get home. Discussing, exchanging, giving my ideas, being listened to, appreciated and sharing my experience as a caregiver gives me the feeling of being useful and of being part of a team, a community of exchange and sharing. I'm a volunteer at the Valcartier Military Family Resource Centre, and I get nothing but positive out of it. As a member of the Committee for Special Needs created to support the staff who provide concrete expertise to parents of children with special needs, I hope that more and more caregivers will be able to benefit from the various services offered at the Centre.

Sylvie, caregiver, volunteer, mother

