

Emily's Story from her Dad

“As parents who have a child with a disability, there are many emotions you go through when your son or daughter is born with a disability. Sometimes these uncertainties can distract you from the joy of having a beautiful daughter.”



“Our beautiful daughter Emily is now a young woman who has just turned 20. Emily is non-verbal and has a dual disability of Down syndrome and autism. When I think about my daughter Emily, I think about her like every other

I don't see someone with a disability, I see a pretty young girl who will share many of the same feelings, hopes, interests and dreams that other girls have. She will also face the same challenges with friends, school, socially and at work. She has a unique personality with different likes and dislikes, just like the rest of us.

Communication has always been a challenge with Emily. Our communication approach has been multidisciplinary and we have tried everything including sign language, gestures, Picture Exchange (PECS), some basic words, and now an App called Proloquo to Go.

To any other parent or carer, I would say never give up, just because one approach doesn't work never hesitate to try something else as you never know what might work. Our successes came not only from our own knowledge of Emily, but we also partnered with numerous speech therapists, occupational therapists, exercise physiologists and many carers. Everyone needs to be on the same page including schools and support providers to help Emily to be the best person she can be.

From our perspective it's worth investing time to find the right school and supports for any child, and you only get out what you put in. Many of the schools and carers become like extended families, the teachers can be amazing, and you will meet lifelong friends.

Schools and your support network play a vital role. Emily started with Lifestart Intervention from newborn to 4 years old. She then attended St Lucy's Special Catholic School in Wahroonga for her primary years and moved to Giant Steps in Gladesville for high school. She now attends a mix of day programs from Sunnyfield in Dulwich Hill and Adult Services at Giant Steps along with home support workers.

Aged appropriate activities and community involvement are also a big part of Emily's family.

We had Emily in a learn to swim program when she was a one-year-old. She didn't swim for many years after, but now it's something she enjoys and can do unsupervised. Emily also needed over three years to learn to walk but if you saw her walk now you would never know as she loves walking. Both these activities have given Emily a sense of freedom and independence, so always plan for the long game.

Get involved, do whatever you can to help, join a disability group or committee, and if a program doesn't exist you want for your child go set one up like we did for dancing and swimming in our local area which still run today.

There are struggles and demands having a child with a disability, it can impact relationships and life is filled with challenges. However, the successes we have is what makes Emily special and we wouldn't want her to be someone else. We can see how hard she tries with everything, and how frustrated she is when she can't communicate what she wants from time to time. Emily is a young woman with feelings and emotions she wants to share, so being frustrated occasionally is understandable.

Always maintain your own sanity and relationships. Sometimes it can be a struggle and it's important to remember to put time aside for yourself and your relationships. We took our first holiday without Emily a few years ago after 18 years, it was fantastic, but we should have started doing that many years ago. Don't wait, just plan for it.

Regardless of the challenges, like every child Emily has brought us plenty of love, hugs, happiness and laughter. She has shown us what true love really is and has even started saying a few words from time to time."

Emily's Dad, John Collins, is one of the founding partners of Plan Manage Assist (PMA).

PMA are passionate about disability and pride themselves as being different from other providers. They have first-hand experience and knowledge as they have been through the journey and understand the frustrations and the challenges you can go through.

