



Mark today.

Marc's story

Our guest speaker at the recent Foundation Dinner was Mater Dei mum, Jan Verbinyecz, who shared the story of her son Marc and her family. At the request of many of those in attendance we reprint it with Jan's kind permission.

I'd like to share some of the experiences we have had with raising our autistic son. Marc is 17, in Year 11, has been at Mater Dei for six years and of course he's autistic. When Marc was four months old he became ill. Doctors found a rare heart condition and at 10 months he had heart by-pass surgery. Marc made an excellent recovery and was walking one month later. He continued to develop normally in all areas — speech, playskills, socially and verbally.

Now this is where the story takes a twist. What I'm going to say now is not meant to cause controversy, I'm simply telling our story. Because Marc had been ill, he didn't have his vaccinations until he was 16 months old. It was then that we believe we lost him. He completely shut down and stopped developing in every way. He no longer looked at us. He stared beyond us. Play and social skills went out the door, he stopped talking and today Marc is non-verbal. Friends and family would say "Don't worry. He'll start to talk when he's ready." But of course Marc was never ready. We take for granted that our children will always be able to tell us if anything is wrong, if they are ill or being bullied or hurt in some way. Marc isn't able to do that because of his autism.

Marc has absolutely no idea of danger of any description. Even now we have to make sure that someone is with him when he is crossing the road or walking through a busy

parking area. Marc is incredibly afraid of all animals, even birds, so his brother was never able to have a pet and we were never able to go anywhere where there were animals or pets, such as the depth of his fear.

We can't leave Marc alone at home and yet he is seventeen. Most seventeen year olds are working, learning to drive, going out with friends, having girl or boy friends. Marc won't be able to do any of those things.

When I take Marc shopping he is very happy and makes loud noises and flaps his arms around. So I spend my time saying, "Marc, no noise." I do that because so often, people around us are staring at him as if he was from another planet. Or they look at me with pity. That's something that I have never come to terms with.

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I remember when Marc was diagnosed as being autistic, I used to walk around thinking "We've got a handicapped child. What are we going to do? How are we going to cope?" Like every other family with a disabled child, one of our continuing worries is what will happen to Marc when we're not around. And we weren't the only ones to suffer. Marc's older brother, Alex, also suffered. He not only lost his brother, but his playmate and friend.

When Marc was ten years old, we found Mater Dei. When he was accepted into Mater Dei, we were thrilled because both my husband and I had gone to Catholic schools and Alex was at St Greg's (Campbelltown). Of course, we didn't think there were any Catholic schools that were solely for intellectually disabled children, especially one that was a high school as

well. He has been able to receive the sacraments of Communion and Confirmation at the Mater Dei Chapel.

Getting into Mater Dei was the making of Marc. He is now involved in a number of programs — Meals on Wheels and the workshop, which we hope will lead to paid work when he leaves school. He loves the swimming program, going bowling and generally being involved in a whole range of activities run by the school. He has a lot of untapped skills, one being that he is absolutely brilliant at jigsaw puzzles. He can do a 1000 piece puzzle in no time at all. It's almost spooky to watch. We're especially happy that the cooking lessons run by the school have taught Marc to eat a greater variety of foods. Being autistic, this was a real problem for him.



Alex and Marc (right) at 11 months, 4 weeks after his heart by-pass surgery.

You know, as difficult as it has been, we wouldn't trade Marc for anything. He is our beautiful son, and we love him very much. We are just so blessed and thankful to have Marc at Mater Dei. He is very well cared for by wonderful staff. He will have post-school opportunities for work. He will leave Mater Dei being the very best person he can possibly be. As parents we couldn't ask for anything more.