

A complete human being

Tony McDonald

As another birthday fast approaches for Rohan, I've been thinking about the events of the past 28 years since his birth. I remember that day well. First, there were the feelings of excitement and anticipation at bringing a new life into the world, and planning for its future glory. Then, there were the feelings of stunned shock, which came after I'd been told, coldly and unemotionally, that my baby boy had Down's syndrome. He was just 30 minutes old, and I was alone in the labour ward.

Rohan weighed just over 4 lbs, and had a major heart condition and two twisted feet. He spent 4 months in hospital. Then, absolutely terrified and with no information or support, we brought him home. Uncertain, inadequate, and frightened, we wondered how we could cope. Had our lives come to an end?

So began our long, lonely walk into an unknown future. We had lost control of our lives and needed to reclaim it quickly if we were to survive. We desperately needed information (which was almost non-existent at that time) and practical suggestions to help us make decisions for the future.

As we nurtured him, we discovered to our delight that we had a baby who had the same needs as any other infant. He was a child, a thing of joy, a person in the making ready to be moulded. He grew into a little boy, then a big boy, then a teenager, and finally a young man. He was himself; a rare, magical, unique person—an individual. There was no-one else like him, and we grew to love Rohan dearly.

I could tell you a million stories about him, his interests, things he has done—funny things, sad things, exciting things, and frustrating things. Things that made us laugh and things that made us cry. The wonder of his achievements never ceases to amaze me. And yes, we have also had problems. I could tell you all of the struggles we have had for services, and of all the difficult decisions that we, as his parents, have had to make over the years on Rohan's behalf. Relatives, friends, professionals, and, most importantly, other parents have helped us immeasurably.

Through the years, Ronan has blossomed. He is great to live with, has a tremendous sense of humour, and is full of fun and laughter. And when young, he also learned to kick, spit, and swear. Not because he had Down's syndrome, but because he was a child, and that's what children do.

Our son is very independent. He travels alone on public transport, and enjoys socialising. He has performed in concerts, has been a male model in a "normal" fashion

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Karyotype of individual with Down's syndrome

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show, has a healthy interest in the opposite sex, and would like to tell you all about "his type". He is a mine of information on so many topics (especially sporting matters). Rohan reads (not Shakespeare, but the daily sports pages and the TV guide), writes (letters to friends), handles money (uses the calculator on his watch), and has been working part time in a college library. His speech is not always clear, but he spells (another form of communication). In short, he is a complete human being.

But whatever I tell you (or myself), he still has Down's syndrome. The condition won't ever go away, and can't be cured. He will have it for the rest of his life. He still has funny feet, and has to wear orthotics to help him walk (and run and jump and ride a bike and kick a football). And now, because his heart condition was never fixed, he has developed Eisenmenger's disease too, and needs 16 hours of oxygen daily. We have set up his oxygen concentrator in the middle of the house and he links himself to it by 50 feet of tubing, which gives him unrestricted access to the whole place. I have even seen him, with his portable oxygen tank, out in the middle of the cricket oval, wicket keeping. Where there is a will, there is always a way.

There are some things that he will never do, though, and he will always need care. However, this young man has many abilities. He is capable and can achieve if given the opportunity, stimulation, and encouragement, and is valued for the person who he is. He needs to be accepted, included, and involved. He wants to participate in community life as independently, confidently, and competently as possible. My aim is the same as every mother's—to make sure that my son's potential is not wasted.

Nobody plans for or expects to have a disabled baby; you receive no training, but, one way or another, we have to learn to live with the situation. Everyone deals with the challenge in their own way. Personally, I have found the experience life changing. At times I've felt devastated and scared, exhilarated and challenged. Bringing up a disabled child is difficult and can make you feel like a martyr if you let it, but it can also bring out the very best in both yourself and the people around you. Never dull, never boring, however, never to be asked for. But, once there, not to be missed.



Tony McDonald, parent of 27 year old Rohan who has Down's Syndrome, is a foundation member and vice president of the Down Syndrome Association of Victoria, Australia. Tony is a teacher in the field of disability and also works with a number of disability groups.

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