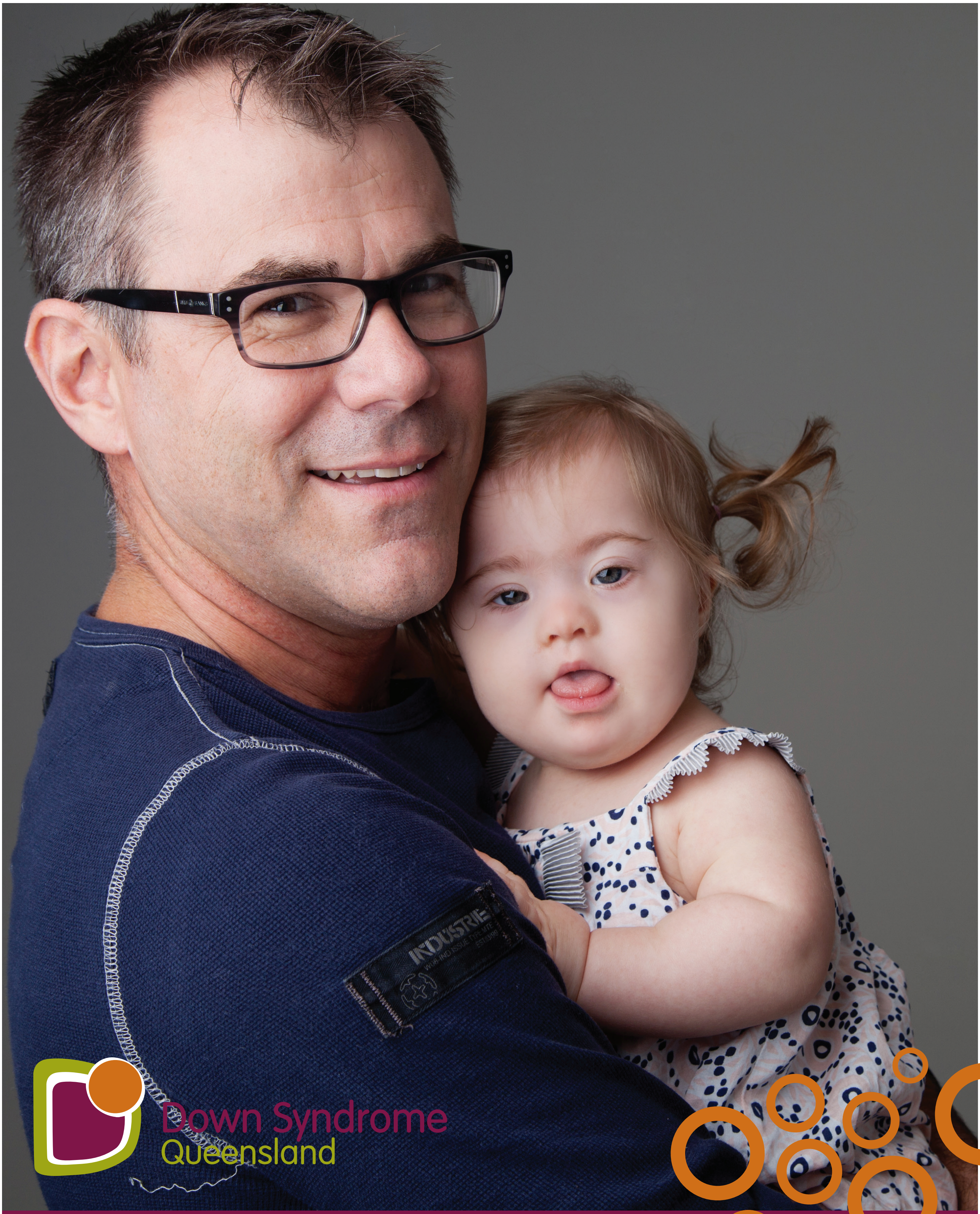


Down Syndrome
Queensland

Down syndrome

Information for New Dads

YOU HAVE JUST LEARNED THAT YOUR PRECIOUS NEW BABY HAS DOWN SYNDROME. AFTER THE EXCITEMENT, ANTICIPATION AND PLANNING DURING PREGNANCY, THE SITUATION HAS CHANGED AND NOW THERE IS A WORLD OF UNKNOWNS...

This can sometimes be a hard time for parents and family. Fathers in particular may have extra worries:

- Fathers often place expectations on themselves to be the stronger one - to support their partner.
- You may be worrying about whether there will be an extra financial burden with having a child with a disability.
- Some parents report feelings of inadequacy or embarrassment – what will others think?
- If this is the first-born child or son, there can be concerns about “carrying on the family name” or having grandchildren.

All these thoughts and more may be racing around in your head. Many of them are issues you will not need to think about for many years to come, some of them you will need to face straight away.

Many fathers have had similar reactions. They report feeling devastated, shocked, angry or lost. Others report not feeling any of these things and it is important to know that this is normal too. However you are feeling is perfectly ok.

It is also important for you and your partner to realise that there is nothing you could have done differently to change that your child has Down syndrome. It is nothing to do with your diet, lifestyle, and activities during pregnancy, fertility, or any other factor. It happens by chance to couples from all countries, lifestyles, backgrounds and ages.

You may have many concerns and questions. The material available in the New Parent Kit will help answer some of these. The staff at Down Syndrome Queensland and our Parent Support Volunteers are also available to answer any questions you have, provide information and be a listening ear.

The birth of any new baby is a time of adjustment for everyone. Allow yourself to explore your own reactions and talk them over with your partner and/or others.

Many men report that it was better to be able to do something constructive during this time. Try to stay involved in the care of your new baby. Attend medical appointments, gather information, help put them to bed, etc. This also helps you to get to know your child.

We hope to encourage you during this time, through these personal stories. If you would like to meet any other fathers or families, please let us know. They are living examples that there can be a ‘normal’ and happy life for your child and family.

If you would like any more information on Down syndrome, father’s perspectives, or activities in your area please contact the DSAQ on: 3356 6655.

The following quotes are from other fathers, about their reactions when they were first told that their baby had Down syndrome

"I felt as though my bubble was bursting …All my expectations were washed away …devastated … I didn't know what to think .. didn't know what to do."

"I wanted to blot it out …I felt we would never be a normal family … how will others react?"

"I cried – perhaps screamed – I can't remember."

"This was my worst moment … the peak of joy at the birth of my fine new son and the devastation at the death of my expectations."

"I needed to go home and see my family and my house. I needed to see something that was real and unchanged … I couldn't, I wouldn't believe that this could be happening to us."

"What did I do wrong?… why am I being punished? … why me?"

Those same fathers made the below comments after watching their new-borns grow into babies and toddlers…

"You have to let your feelings out …I learned to cope, to love, to adjust."

"I received a phone call … he said he had a five-year-old daughter with Down syndrome and that she was the apple of his eye. I thought if he can do it, so can I… If others can have a normal family life, so can we."

"There's going to be ups and downs … like all kids there's going to be a lot of work … but in return you get a lot of love… she's a real joy to us."

"When you have achievements there's a strong emotional tie and it's exciting."

"We have a lot of fun most of the time. She needs a bit more attention but it's not a big deal now. It's like the strains and stresses you have with all children."

"Remember there's still a new baby – they can bring a lot of joy to your home."

"If you are the father of a [child] with Down syndrome, be proud; he needs you more than anything. Don't be afraid to cry once in a while, but don't feel sorry for yourself or your son.
He is the way he is."

A Dad's story

It's OK to Cry

by Michael Harrison

By the end of 2006 I felt my life was in pretty good order. I had a beautiful little daughter, Laurel, who had jumped all the hurdles of good health.

While I know I'm biased, it has to be said that she was "up the front of the bus" when it came to intelligence. My wife, Vanessa, was pregnant with our second child, we had recently moved into our new house in the Brisbane suburb of Manly West and to me it felt that this was what life was supposed to be about. In 2006 I was the Rooms Division Manager at an award-wining corporate hotel. We were constantly exceeding expectations within the hotel chain; I felt good about going to work each day. Life was great and, to be honest, I could not have asked for anything more.

Perhaps it was a case of naivety or maybe being too casual about the subject of childbirth but I must admit I did not understand the entire process. I just assumed that everything would work out. In hindsight, maybe I should have spent some time reading the pregnancy books my wife had asked me to do on several occasions. When it came to the finer details of "the miracle of creation" I did not have a great understanding. Sure I knew the sperm and egg stuff but as to how many chromosomes we are supposed to have, and what would happen if the count were incorrect, I had no idea. Throughout my life everything had just fallen into place, so why would the birth of our second child be any different?

To be honest, the main thing I was expecting from our 12-week scan was a morning off work, and everything else would be a mere formality.

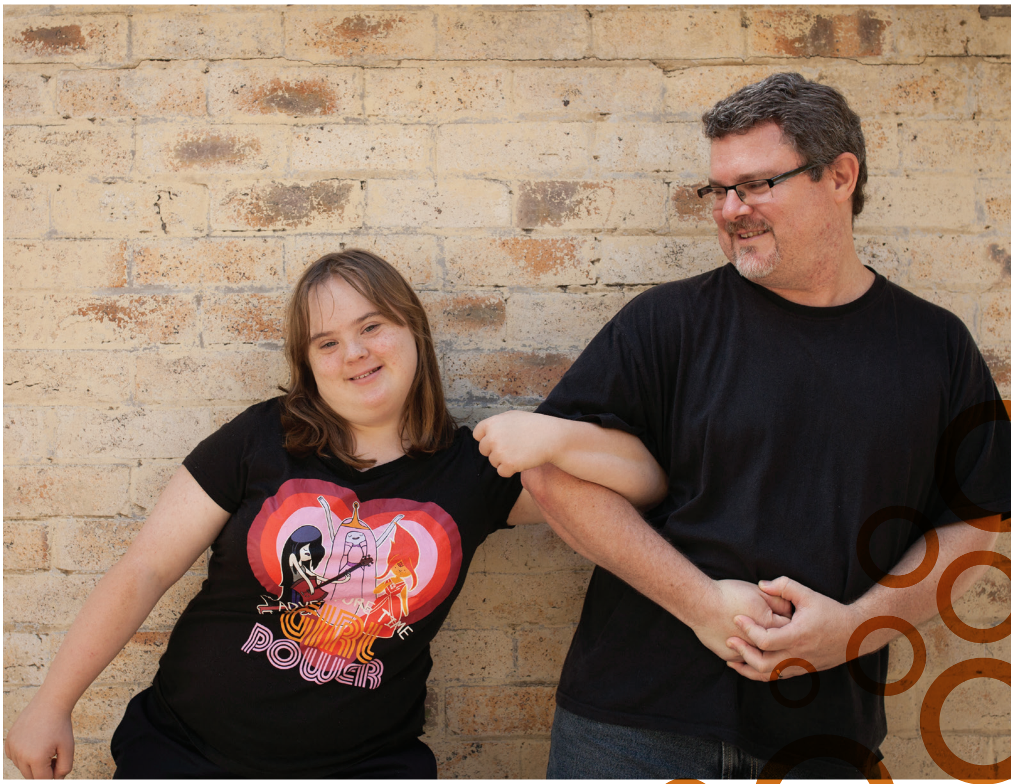
I can't remember a lot of what was said on that morning in the Redlands clinic, however I do remember the words "Down syndrome" and "one in three chance". The mood in the room turned very tense. I can also recall sitting outside a coffee shop after the appointment trying to put on a confident show for my wife, telling her "we had nothing to worry about" and "we would play whatever hand we were dealt". But just below the surface I felt a terrible sense of dread.

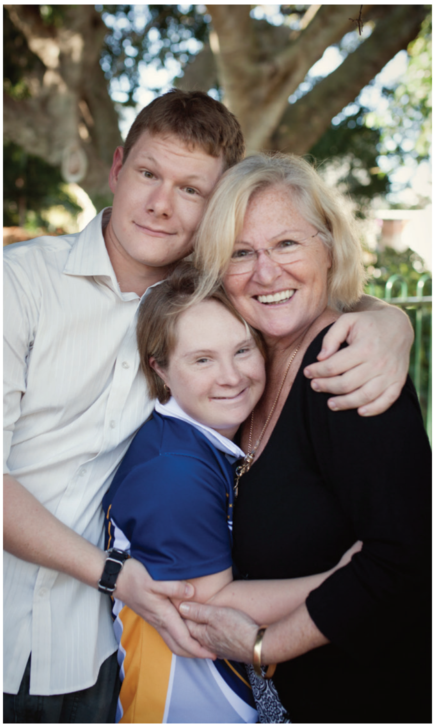
I must admit that my knowledge of Down syndrome did not extend any further than growing up seeing the people from the Northgate Sheltered Workshop on the train while I was going to school. They were overweight, wore thick glasses, dressed badly and sounded slow and simple. Worst of all, they were teased and laughed at by ignorant teenagers from the other schoo1-3ls. I remember thinking at the time how cruel it was but dismissed it as something that would never affect me. Now those images were coming back to haunt me and I was frightened. Was this going to be my child?

I think it was early afternoon on a Thursday, three weeks after the scan, when the phone rang and a distraught Vanessa asked me to come home. The waiting was over, we had definitive results, and the reality had begun: our child had been diagnosed with Down syndrome. We were devastated.

Why is it that men feel this compulsion to carry all the responsibility and have the misguided belief that they alone have to hold the family together in the hour of need?

I felt I had to be like the General of an army in the old war movies, standing tall on the hill, watching the battle play out in front of him, all the time remaining calm, emotionless and composed. This was my duty as the male in the household and for the good of the family I felt I could not let my emotions out because if I did I was being weak. When I look at these words now I think, “what a load rubbish!” This charade may work well in the old war movies but in reality I was not helping anyone.





I became distant and impatient with my wife who was struggling with the news. I was also hurting myself by ignoring my inner feelings. However, hindsight is a wonderful thing. During this emotional period I felt that bottling everything up and not speaking about the grief and fear I was feeling was what I had to do. I even stuck a note on my work computer with the words, “YOU MUST BE STRONG!”

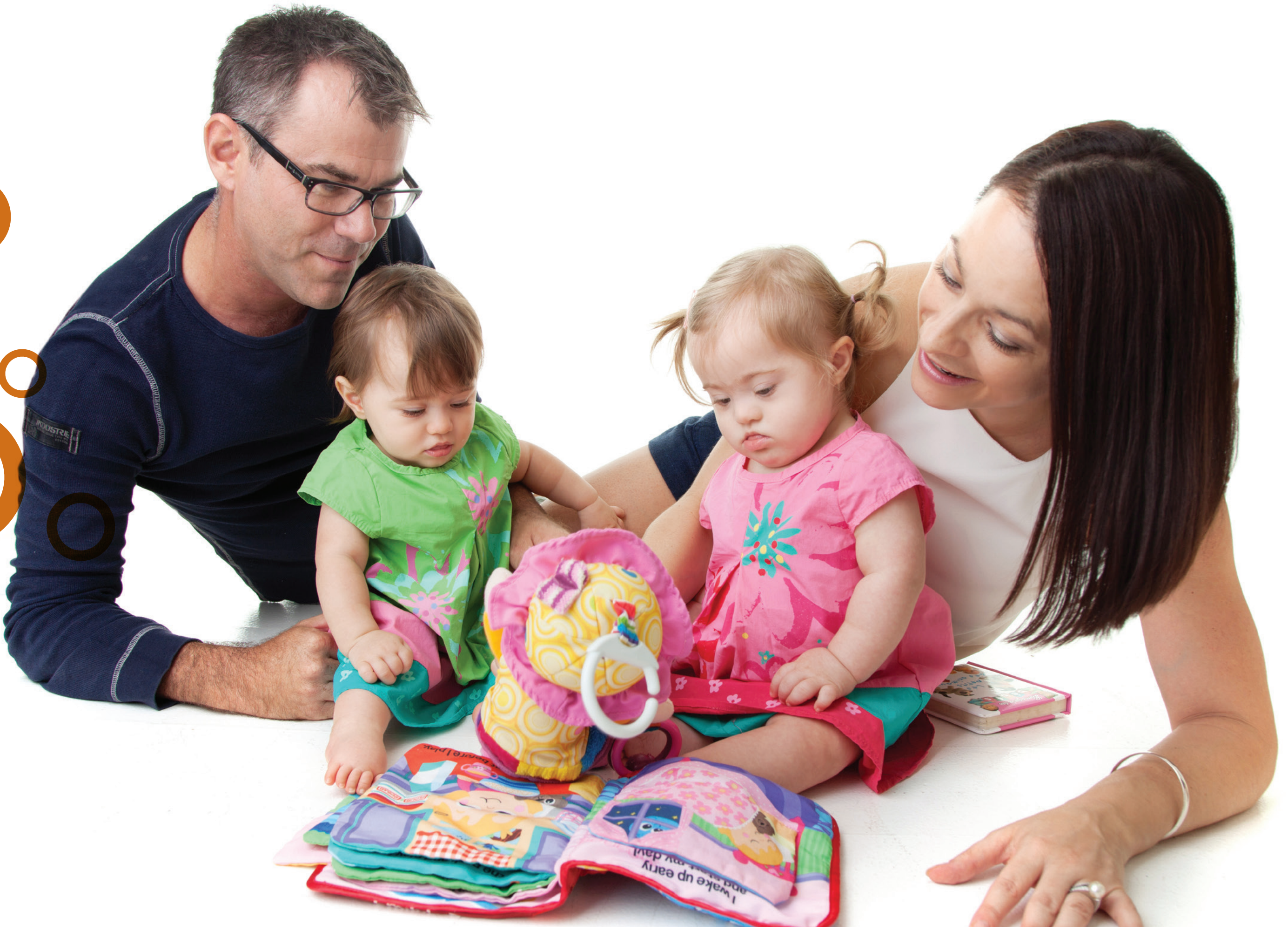
At times during that first month when I was alone in my office my eyes would fill with tears as images of the kids I had seen on the train and thoughts of my child’s lost opportunities filled my head. I would then repeat my mantra over and over again until I had buried the emotion that was trying to escape.

For good or for bad none of us has a crystal ball to know what the future holds. If I knew then what I know now, I would have done things very differently. I now know it is OK for a man to cry and accept how he feels; it is not easy but it is not weak to be honest with yourself.

In fact, it is a true sign of strength. I also know now that the family would not have gone to pieces if I had showed how I really felt, maybe we could have handled the news of our child’s disability as a family instead of as individuals; not really understanding how the other person was coping. For this I am truly sorry. Finally, I now have the knowledge that while I was hurting at the time the end result by far outweighs the immediate pain.

It was not until May 12, 2007, that the “emotional genie” finally escaped from the bottle. Compared to the birth of our first child, Laurel, the birth of our new son, Xavier, was easy. He was born just after midnight on the morning of May 12, 2007, and as I held him and looked into his eyes for the first time I couldn’t help but feel that he did not look right; that it was obvious he had Down syndrome. I did not feel that same euphoria I felt with the birth of Laurel. As with my daughter, I whispered to him the same promise that I would always be there for him and see him through, but inside I could not help but feel empty. Then as with the previous six months, I squashed my feelings back in the bottle and tried not to let my emptiness show.

The first day after the birth of any child is extremely busy as you operate on next to no sleep, run to and from the hospital and tell everyone about the new arrival. That evening at the hospital with my mother and grandmother, we discovered that Xavier had failed his hearing test. While these tests are in no way conclusive and would later prove to be incorrect, they did not help our emotional state.



On the way home from the hospital I had to listen to my grandmother ask what his name was every five minutes and my mother who meant well, telling me about the people she knew who had children with disabilities and how many people in her church parish were offering prayers. Unfortunately, the way I was feeling I did not want to talk to anyone and just wanted to be alone. The constant talk in the car was pushing me over the edge.

Finally, once home at the dinner table with the relatives, I hit the wall.

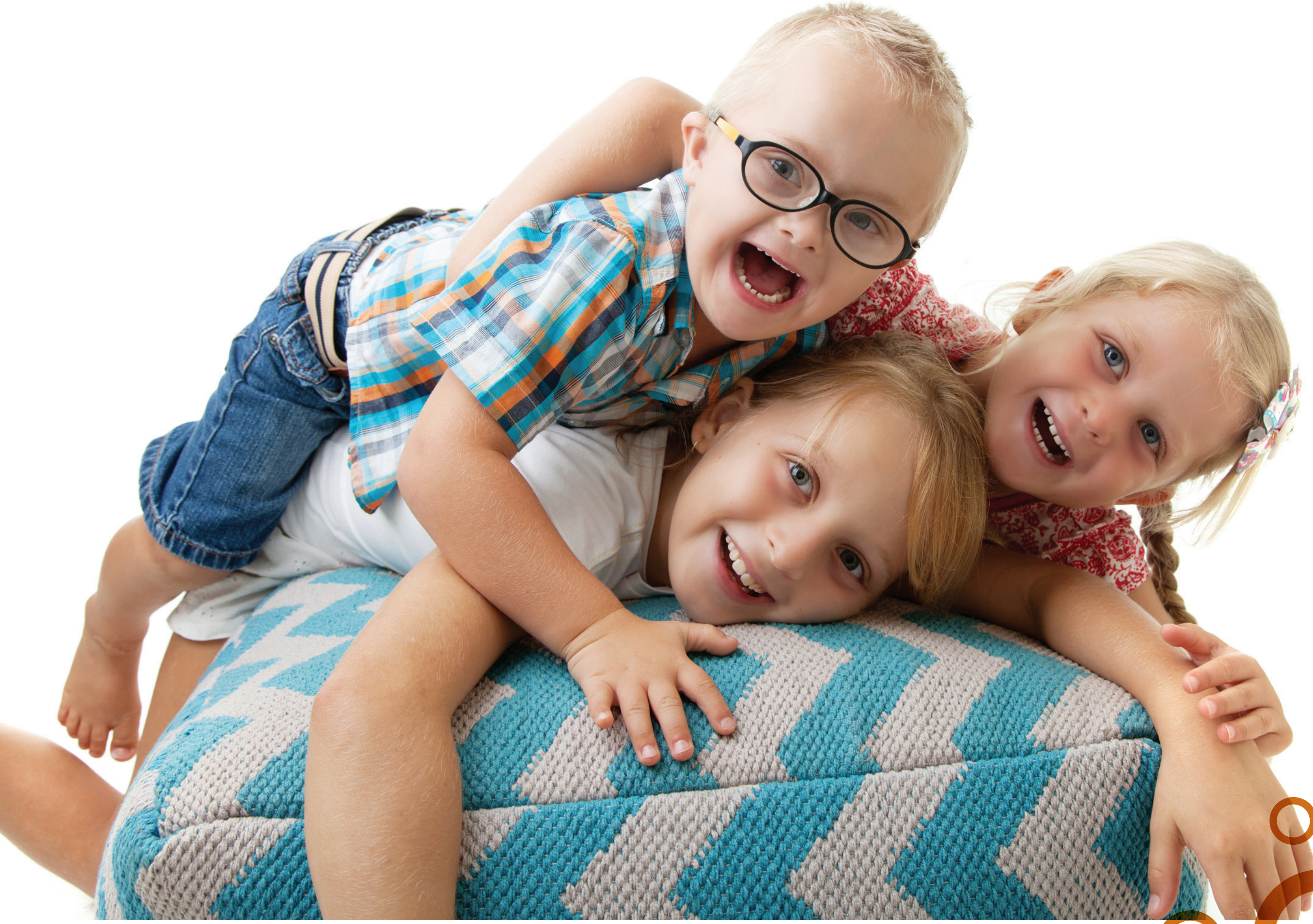
> ***Trying to keep it together I excused myself from the table and went out onto the balcony where six months' worth of emotion poured out. The reality that my child had a disability and would be different had finally hit home.***

How long I sat there sobbing I do not know. I just remember my mother coming out and telling me to have a good cry and my grandmother coming out and asking what his name was. That night in bed I shed a few more tears before drifting off to sleep, ending the first day of my new son's life.

Looking back now I feel that that moment on the balcony was the turning point. The dam had burst, releasing all my anxieties and sadness with it. The next morning I woke up feeling like a weight had been lifted. Since that night I have never felt empty about Xavier again and see him as the most amazing little boy. In saying this I must admit I sometimes have a tinge of sadness when I see that he is the oldest in the swimming class or when I read his low results on the physiotherapy report. However any sadness is quickly erased with love and warmth when I hear the words "there's daddy" followed by a huge hug. I have accepted who he is and would not change anything about him. My son is not Down syndrome; he is Xavier.

In the three years that Xavier has been with us he has been adorable but at the same time a challenge.

> ***He has not been a challenge because he has Down syndrome but because he is a little boy who likes to push the envelope with his mum and dad and torment his big sister.***



When I tell people he has Down syndrome I often smile when I am told “how loving these kids are”. Naturally, I agree but I also take a few minutes to set the record straight and assure them that being naughty comes just as naturally to Xavier as any other child. He is an adorable and loving child but he is also a little boy who has temper tantrums and knows how to press his parents’ buttons.

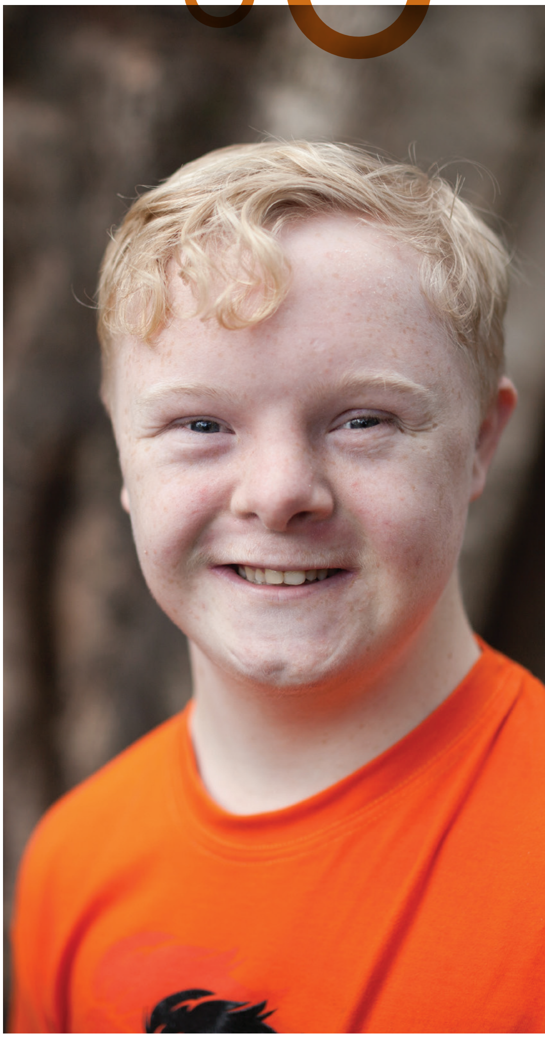
I recently had a work colleague say to me that it must be hard having a child with Down syndrome.

My answer to this comment was that I was the luckiest man in the world. While my reply may sound like a cliché, it was proved beyond doubt recently when Xavier spent a couple of nights in the Mater Children’s Hospital. As I sat on his bed watching the Wiggles with my little boy, I took a few minutes to look around the ward. Opposite us were a father and son who had been in hospital with problems for the last week, with no end in sight. Around the bed of a little girl next to us was a hive of activity and concern as alarms were beeping and hospital staff were talking gravely about her situation. Her mother had given me a smile when I saw her that morning and you could tell now that she had a lot on her mind.

As I scanned the room, I felt Xavier put his hand on my leg and noticed him give me a quick glance and smile. Maybe I am reading too much into it but the timing of it almost felt like in his own way he was saying, “Don’t worry about it dad, we’re sweet”. This moment reminded me that while our son may have a disability we are extremely fortunate.

Like any parent, not a day goes by when I do not worry about my children’s future. There is no question that at times it will be difficult. Life does not always go to plan and there will be bumps along the way. However, I also know that by staying positive with the right attitude life can be amazingly rewarding and a wonderful adventure. If we always remember to stick together as the loving and supportive family we are I know we will overcome any obstacles that confront us.

I would not change the little boy we were delivered for anything in the world. We have been truly blessed.



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