Some things change, some things stay the same

"Pinch and a punch for the first day of the month . . ." Wait, it's March? We're already one sixth of the way through the year? Summer's over? Things change constantly. But summer or autumn, rain or shine, RECORD will be here to keep you up-to-date with the latest Adventist news and views.
A caring place

“Your son will probably never speak,” said the doctor. "He has very low muscle tone, so he may never walk . . ." With those few words, Louise Inglis' dreams for her family shattered into a thousand tiny pieces.

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I struggled to focus on the paediatrician’s words: “What do you know about autism?” I looked back blankly. The doctor continued: “Your son will probably never speak. He has very low muscle tone, so he may never walk . . . ”

With those few words, my dreams for my family shattered into a thousand tiny pieces.

That was seven ago now, though sometimes it feels as raw as if it were yesterday. Since then my husband, Michael, our eldest son, Matthew, and I have had to learn how to live with a severely disabled child. I wish I could tell you it’s easy. It isn’t. “The valleys are deeper and the mountains are steeper than I ever would have dreamed.”

Disability is something our society struggles with. Should we look at someone in a wheelchair or ignore them? Should we smile at the parent struggling with an intellectually disabled child or turn away? What is the polite thing to do? What is the right thing to do? What will help the most and hurt the least? How can our church community best respond to severe disability?

Early in our journey with Kevin, we were blessed to have several church friends with medical and educational backgrounds who understood the profound significance of our son’s diagnosis. As our hearts ached and as we tried to come to terms with our broken dreams, these friends provided understanding as they listened quietly while we shared our grief. It helped to talk, to cry and to have my feelings validated.

In the month leading up to Kevin’s diagnosis we had over 25 appointments: hearing and visual tests, specialist and therapy appointments. My days were consumed, busy and stressful. With the eventual diagnosis I was shattered. The practical support of our church family was immensely helpful during this time. We received many home-baked meals. Others covered our usual roles at church. Some took a special interest in our eldest son.

A friend offered to come for two hours, once a week, for a whole term and mind Kevin so I could have reading time. The amount of information to absorb when you have an autistic child is overwhelming and finding time to read while caring for young children is nearly impossible. Another friend acknowledged she knew nothing about autism but was willing to learn with me. She offered to watch DVDs and read books that I thought were relevant.
Friends cared for our children so Michael and I could attend an autism conference. Other friends bought books they thought might be useful. Another gave me CDs with beautiful music. One offered to come and babysit so Michael and I could enjoy some time out together. An early intervention teacher gave us ideas while we waited for appointments.

The youth leaders in our church offered to coordinate a roster of youth carers for Kevin so I could attend an adult discussion group and the church service. The youth enabled me to attend church and participate in a meaningful way. I doubt I would still be attending church if it had not been for their support. My parents moved to our church, always on standby.

One of the teachers from Kevin’s age group asked how they could include him. I sincerely appreciated that his different needs were recognised with a genuine desire to accommodate him as best as possible. This is what a church community looks like at its best—rallying around to show the love of Jesus in the ways that matter most.

Our church family has learned how to communicate with Kevin. He has never spoken but can understand basic language. “High five Kevin”—with the simultaneous hand action—is meaningful to him. We use photographs to show him where we are going, what he is going to do, who he is going to see. He likes to show others his visuals.

Parents provide simple explanations to their own children, such as, “Kevin’s brain works differently from ours. He cannot speak and he finds it hard to look people in the eye, but he still likes it when you say hello to him.”

"Losing" a child to disability brings a profound grief, one that is cyclical in nature. For me this grief is triggered at birthdays, Christmases and other milestones, such as starting school. While recently watching our older son race in a school cross-country running competition, I felt sad that our younger son could never participate in such an event. I wanted more for him. The sadness caught me unaware. Seven years on I still feel the loss acutely at times.

Our experience with church has been positive, but anecdotally it seems that many families with disabled children stop attending church. The obstacles feel insurmountable at times. Exhaustion from the week makes a morning at home particularly appealing. Children, who are highly sensitive to noise and touch, are prone to melt down in busy environments. Parents can question why it all happened and doubt God’s love and even His existence. Depression weighs heavily and just staying home feels easier. I experienced this for a time but I felt lonely. I wanted to worship collectively; I wanted to be part of the community and I am forever grateful to be part of a church that recognised most of our needs and supported appropriately.

Along our journey, not all "help" has been beneficial. Sometimes, in a genuine attempt to encourage, words have been spoken that hurt. It’s hard, when trying to support someone through unfamiliar territory to know what to say.

It did not help when someone commented, “Don’t worry, about Kevin. We all worry about our children.” That hurt me. It minimised Kevin’s condition by equating his needs with those of typically developing children.

“He will grow out of it,” said another. That hurt too. It was well intended but untrue. Autism is a lifelong condition. There is no cure and children do not grow out of it. Better to say nothing than make ill-informed comments.
The search for a silver lining in the tragedy is natural but it comes across as a way to dismiss the very real pain; as if saying something happy permits society to turn a blind eye to the deep, raw tragedy in this life.

I often dreaded arriving at church and being asked, cheerily, "How are you today?" How should I answer that question? Should I lie and say "I'm fine" or should I tell the truth and burst into tears, yet again, at church? I used to wish people would simply say, "Nice to see you."

Many Sabbaths I wanted to sit in church anonymously. To be in the midst of our church family, hear the music, be encouraged by the sermon and not have to interact. I felt too emotionally fragile. I longed for a quiet room with a video link, without children, without noise, without questioning but just to be blessed with tissues and God through what was being offered that day.

I also longed, on Sabbaths, for someone, just one person, to come and be with me privately, to listen to my pain and offer prayer and encouragement. I’ve since spoken to other grieving friends who have expressed similar yearnings.

Perhaps a "listening room" is something for churches to consider.

Personally, throughout this journey, I gain strength from thinking ahead to heaven. I imagine Kevin in full health, running, climbing trees, looking into Jesus' face, free of seizures and able to talk with us. Strong hope in the future gives me perspective and strength for dealing with the present.

There are many things I've gone through that I never imagined, let alone understood, before Kevin came into my life. I therefore understand why so many people lack the understanding and sensitivity necessary when interacting with families who have a child with autism or other profound disabilities, or with families who have lost a child. I hope, however, that my experience gives you just a little window into the serious issues we face, and how to respond to them. Christ reached out to those most in need and He didn't mind going to extraordinary lengths to meet them where they were at. We can do the same for disabled children and their families, if we are informed and intentional.


As we drove out of the Coral Coast Christian School grounds on January 23 and headed to Brisbane for staff development meetings, we never dreamt it would be a very different world we'd be returning to!

Cyclone Oswald was a lurking danger up north but very far from our beautiful rural town of Bundaberg on the east coast of Queensland.

But after reports of the storm damage in Bundaberg, we were anxious to get home and especially to our school. We listened to reports coming in of the waterway in front of our school rising and overflowing its banks. "Please, Lord, protect our school!" we prayed fervently. A parent living near the school spoke to me on her phone while she was wading in knee deep water on the school driveway. I could hear the sound of the water. She described it as one big brown lake around the school and the water was still rising. "Lord, put your hand over the school! You control the waters and determine their boundaries." This text kept ringing in my head.

The sun eventually came out and finally the highway was opened. We made our way home through devastation and mud and our hearts sank the closer we came to Bundaberg. Whole sections of the town were completely cut off. Everywhere the results of severe flooding from rivers overflowing their banks could be seen. The water was receding but left its unmistakable high water mark of debris and mud. It was an unbelievable sight—as if an artist had taken a brown brush and swept it across houses, fields, cars, everything in its path.

Pathetic piles of soggy furniture were being dumped in the streets outside each affected home by forlorn residents. Everyone just stared in stunned shock. The two main bridges were closed over to the north side where our school is situated and it became clear that it was the worst hit area.

The school chairman and I took a roundabout route via Childers to inspect the school. What would normally take 10 minutes over the bridge turned out to be a 370 km trip! As we drove up the muddy driveway, what a relief to see our precious school standing high and dry like a green oasis in a brown sea of muddy grass! We broke into spontaneous prayers of thanksgiving.

After thorough investigation of each building we were able to ascertain that no water had in fact penetrated any classrooms or the administration block. The damage was minimal. We were one of the few schools in Bundaberg that was able to open relatively unscathed.

Is our God able to deliver? Oh yes, He has a thousand ways of which we know nothing! Some of our staff and dear ones suffered severe losses. That does not mean that God was not with them. We do not understand the end from
the beginning. But what we do see is how God is turning a curse into a blessing in front of our very eyes.

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