

When our son Braeden was born in 1995 he had great Apgar scores and everything seemed normal. But at about three months of age he still hadn't developed any head control so we took him to a physiotherapist at our local hospital who said, "We'll get him right." But nothing seemed to help.

After multiple physio visits, they finally gave us a diagnosis when he was five months old. It was athetoid cerebral palsy (also known as dyskinetic cerebral palsy), an extremely rare palsy caused by damage to the developing brain and characterised by constant involuntary movement. I remember the drive home from the hospital – my whole life had changed in an instant but everyone else was just going about an ordinary day.

Of course, we'd hoped there was nothing wrong but, on some level, it was a relief now knowing the situation. After processing his diagnosis and learning of its implications my husband Mark and I just got on with it and started the gruelling therapy routine necessary to help Braeden reach his potential.

We threw ourselves into it, with the assumption that if we worked hard enough, we'd get results. We had to buy lots of equipment we never knew existed before. Braeden's pram and his high chair, for instance, had to have specially constructed foam inserts to help him develop the skill to sit.

COMING TO TERMS

We also needed to learn a whole new language and understand child development milestones in a completely different way. In those first two years, we spent five days a week with occupational therapists, physiotherapists, speech pathologists, and eye therapists, who helped with his visual attention problem. All the professionals told us early intervention was key and it felt like we were in a race against time but we soon realised that, despite all our and Braeden's hard work, he would only make incremental, not massive, gains.

Eventually, at 20 months, he was able to sit on his own. It was a monumental achievement.

We'd been consumed with his therapy but we began to realise we needed to balance our life a little more. We came to terms with the fact that we'd have to pace ourselves for a marathon, not a sprint.



DON'T BE A SPECTATOR

Julie and Mark Jones's son, Braeden has cerebral palsy, is non-verbal and uses a wheelchair. However, that hasn't stopped him from travelling the world with his family.

AS TOLD TO SUSAN GOUGH HENLY

Part of that was realising how important it was to go on holidays with Braeden despite the obstacles. We learned that we needed to relax a bit and just be parents ... not advocates, not administrators, carers or therapists. The work is still never-ending but it's so important to stop and breathe out, and regain something of yourself.

I also went back to work as a travel consultant one or two days a week. It was nice to just be 'Julie' doing work that was fulfilling for me. Before Braeden was born, I'd been a special interest group travel consultant and Mark and I had travelled all over the world. My passion for travel started when I was nine and my parents took me out of school for six months and we travelled throughout Europe and Egypt, where my dad was from. We'd always planned to do the same with our kids.

At work, I spotted a South Pacific cruise special that I thought seemed doable for Braeden. It turned out really well. We enjoyed dinner with others and Mark and I remembered ourselves as a couple. It was great to carry on a conversation and not have

Above from left: The Jones family on holiday in Disney California Adventure Park, Port Macquarie, NSW, and quad bike riding in Fiji.



to talk about Braeden's disability. So often in those early days, people's questions took you to a place you were not really ready to go regarding the impact of his long-term disability.

BECOMING RESOURCEFUL

My husband Mark is incredible. We have a great partnership, which is so essential as everyday life is a phenomenal amount of work. He's always finding a way to support Braeden. He carried him in a travel backpack until he was seven. I have pictures of him crawling through the caves at Te Anau in New Zealand with Braeden on his back so he could see the glow-worms. He's also very good at coming up with practical solutions for our travelling needs. He custom built a plane cushion so that Braeden could travel more comfortably on long-haul flights and he welded together a portable toilet we could take on the road.

The athetoid cerebral palsy means Braeden has great difficulty sleeping. His constant movements wake him up every night around 1am and Mark does most of the shifts on the couch, while Braeden drifts off again in front of the television.

Our daughter, Amelia was born when Braeden was seven. He adored her from the minute she arrived and they've had a close bond ever since. It's so hard for him to control his movements but he puts so much effort into being gentle with her.

Today, at 26, Braeden is non-verbal, a wheelchair user and needs assistance with all his living needs. But that's only part of the story. While it's profoundly difficult for him, we all persevered and he took his first steps, unassisted, when he was 18.

"WE PERSEVERED AND HE TOOK HIS FIRST STEPS WHEN HE WAS 18."

JULIE JONES

He has an iPad to help him choose what he wants to do or eat. We inspire him with lots of options so he has plenty of choices in his life. We're always seeking what ignites the fire in him. He has a large collection of graphic T-shirts to choose from each day and he adores his Superman wheelchair, which offers a terrific way for people to engage with him. He has a massive desire to interact with people he meets and his memory is incredible. Once he knows you, he'll treat you like a rock star.

BEING RESOURCEFUL

As a family of four with not a lot of extra money to spend on travel I started entering competitions and was quite successful at it. With plenty of planning and research we took wonderful holidays to the Gold Coast and Cairns and eventually won a trip to Disneyland in 2011.

That trip really changed our lives. It was such a bonding experience for the entire family and Braeden absolutely loved sharing the adventures with us and everyone he met along the way. It was so liberating that I started my blog, 'Have Wheelchair Will Travel' to help other people with disabilities navigate the whole process.

WHERE TO GET HELP

Cerebral palsy is a condition that affects body movements due to brain injury. The injury can occur before, during or after birth. Cerebral palsy can affect movement, coordination, muscle tone and posture. It can also be associated with impaired vision, hearing, speech, eating and learning. For more information, visit healthdirect.gov.au/cerebral-palsy

Before every trip, we look at what's available at a destination for our family. Cairns, for instance, has waterfront boardwalks, accessible boat trips, the accessible Skyrail, helicopter tours, and beach wheelchairs. Overall, it offers plenty of opportunities for adventure activities as well as relaxing downtime.

As far as general accessible travel planning, I have two big tips:

1. Communication is key. Ask a lot of pre-trip questions about accessibility and tell the hotel, tour operator, airline, boat company, or transfer service exactly what you need. There's no 'one size fits all' in the disability world. Research, check, double check and check again. A hotel room can make or break your trip. Check measurements for bed clearance, toilet height, entrance dimensions, bathroom size. Ask for photos and talk to people who have been in the room.

2. Pack a friendly, positive attitude for a good travel experience. If something isn't working, make positive suggestions to develop constructive solutions. How you react affects the people you're dealing with. As an example, Fiji was one of the least physically accessible destinations we've visited but the locals have such a genuine warmth and can-do attitude. We enthusiastically contacted tour operators in advance explaining that we had a son who is a wheelchair user and that we all wanted to go quad biking. Their response was so inclusive. They strapped Braeden onto a quad bike with Amelia and Mark and we all had the biggest grins on our faces zipping through the muddy rainforest.

It certainly makes business sense to embrace the disability community. It's not a niche market. One in five Australians have a disability. A degenerative condition or an accident can mean at any time in life we could find ourselves with access needs. In Braeden's case, it was a blood clot or a kink in the umbilical cord that

deprived him of oxygen to the brain. Around one in every 700 children worldwide is born with cerebral palsy

As my understanding of disability issues in the travel space expanded, I decided (with my co-founder Janeece Keller) to create a biannual travel magazine called *Travel Without Limits*. Our goal is to raise awareness in the travel industry and help give travellers with a range of needs more visibility in the media. If people with disabilities are prepared to put aside discomfort

and indignities to experience the world, then the world should step up and meet their needs. In our current issue, we have stories showcasing accessible travel opportunities all around Australia, an autism trail in New York state, a first-person article about exploring London as a young blind man, Hawaiian travels with a wheelchair user, tandem skydiving adventures for people with diverse disabilities, travel tips for walking quadriplegics, and an article about an award-winning aerial drone photographer who is a wheelchair user.

MORE MUST BE DONE

The world is not well designed for people with disabilities. The general public's awareness is growing and resources like 'fat-tyre' beach wheelchairs are great, but we need more. Even though wheelchair users, including Paralympic teams, travel extensively, there are still basic barriers like the lack of accessible bathrooms on airplanes.

I've learned from talking to travellers with disabilities that everyone has unique requirements and it's vital to give space to lots of voices. Braeden is just one person but there's a whole spectrum of people with different needs. Along the way, we've built an engaged community where word of mouth is strong. I don't want anyone who is newly disabled or who are parents with disabled kids to feel as alone as I did. I see how empowering it is for this community to share travel tips and successes – they move from a sense of isolation to one of connection across the globe.

We knew we'd always love Braeden but we wanted the rest of the world to welcome him as well. And it does. So many people recognise him now, because of the blog and the magazine, and come over to give a big friendly hello. 🙌

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Disability representation has not been visible on toy shelves for the longest time, but now businesses big and small are responding to an ever-increasing demand for diversity. mindfood.com/disability-inclusive-toys

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