Australian Government

THE CARERS storybook

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THE CARERS
storybook

Stories of carers of children with severe disabilities and medical conditions

Around 4,000 carers described their experiences in submissions to the Carer Payment (child) Review Taskforce in 2007.

This book was inspired by and is dedicated to all those families who shared their moving and powerful stories through these submissions.

Introduction

Caring beyond expectations

An unforeseen diagnosis, an accident or a twist of fate — for each family in this storybook there was a moment when their lives changed forever.

'Anyone can become a carer really. We're all the same and you just never know when it could happen to you,' says Dianne who, with her husband Shaun, cares for their three children with special needs.

'I'm just a mother who is coping with a disabled child because he's ours and we have no other choice,' says Megan, echoing the sentiment of many of the families whose stories are told here.

Dianne, Megan and the other carers featured in *The Carers Storybook* may describe themselves as ordinary people — but their stories are extraordinary, touching and inspiring accounts of caring beyond expectations.

The book captures the experiences of 19 carers whose children have a severe disability, medical condition or terminal illness.

The families share their challenges, from the initial diagnosis to the complexities of living day-to-day.

They talk about how they cope with changed expectations, financial and emotional stresses, and lost plans for the future. They describe rebuilding their priorities and finding joy in the simplest of things.

They consider the life-long impact on the whole family, express their concerns for long-term care arrangements, and share precious insights and lessons learnt from their children.

For Bronwyn, it is the importance of 'living the days you are given'. She tells of catching waves in the early morning while her son Billy sits on the beach cheering her on. This is their short reprieve before heading back to hospital for Billy's latest round of chemotherapy. Billy has a brain tumour and the therapy is an attempt to halt its progress.

Daniel, whose three sons and partner have Asperger syndrome, finds pride in his role as a carer: 'It's hard for some people in the community to accept a young carer and they say, *Get a job.* I say, *I already have and it is full-time as a carer*… The main thing is you enjoy your children while you've got them and you appreciate what you've got, not dwell on what you need.'

The big message Lisa has learnt from her son Connaire is that 'all kids have a potential. And it might not be the one we think it is, but everyone's got a potential for something'.

Jenny is inspired by her daughter Teegan who can never be left alone due to her breathing difficulties and has spent most of her 18 years in a wheelchair. This hasn't held her back — she's about to graduate from mainstream Year 12 and is deciding if it will be TAFE or university next year.

Bianca finds comfort knowing she's not alone through her volunteer work with a support group. All three of Bianca's children have special needs, the two youngest with rare conditions.

This book provides just a glimpse into the lives of these carers whose love for their children helps them find the strength, humour and resilience to keep going. In doing so, it acknowledges the role, responsibilities and contributions made by the many carers within our community, each with a unique story to tell, as they take up the challenges of caring for their children with special needs.

making the best of it

Knowing you are not alone can bring an incredible amount of comfort to parents of special needs children, which is why Bianca is so passionate about her volunteer role with a support group.

'There is nothing harder than feeling isolated,' Bianca says.

'Having a special needs child can be very confining because you spend so much time at home trying to manage things.

'A lot of us feel trapped in our own individual worlds, not being able to get out and say, *I'm here, I need help and I need to know I'm not the only one.*'

All three of Bianca's children have special needs, the two youngest with rare conditions.

'Being able to contact people going through the same thing is a great help because it means I am not alone,' she says.

Co-running the support group also gives Bianca an outlet and a sense of worth.

'It makes me feel useful as I have been unable to fit work in around caring for my children, although I have tried. I started a nursing degree and tried a few different jobs but it was too much with the demands of the kids.'

Just getting on top of her children's medical conditions has proven to be a big enough job alone.

Seven-year-old Lachlann is autistic, intellectually impaired and incontinent. As part of his condition he is 'selective mute' and has anxiety issues, which makes it difficult for Bianca to take him anywhere.

Six-year-old Eleanor has Attention Deficit Disorder (ADD), a reactive attachment disorder and a condition called Type 1 Ehlers-Danloss. The attachment disorder leads her to form inappropriate attachments to males, so she needs constant supervision. Ehlers-Danloss weakens the muscles and ligaments and makes her hyper flexible and at risk of dislocating joints. Even school playgrounds are extremely dangerous.

Four-year-old Charlotte has a heart condition and a respiratory condition, which requires multiple medications and home oxygen for emergencies. She also has Asperger syndrome, epilepsy, suffers from weight loss and is being investigated for adrenal gland disorders.

All three are under the care of multiple specialists plus physiotherapy, occupational and speech therapists.

'It is all very expensive and I am so lucky I have a supportive partner in Korey. It's not just the financial support… it's incredibly important to have somebody who cares and understands what you are going through.'

Bianca has not always had that support. Her first relationship with the father of her two oldest children was an abusive one.

Bianca with her children Lachlann, Eleanor and Charlotte

Sometimes the most challenging times are the most rewarding.

'I fell pregnant at 17, straight out of high school and had two children within a year. I realised I had to get away from my partner when I was six months pregnant with Eleanor.'

Because there was so much going on in her life, it took a while for Bianca to realise what was happening with Lachlann.

'He was slow in reaching his development milestones, but I just put that down to our lives being so unsettled because we moved about 15 times in the first year of his life. However, when Eleanor was born it was immediately obvious things weren't right.

'With Charlotte, she stopped breathing when she was eight weeks old so we knew straight away there were problems.'

Already dealing with two special needs children it all became too much for Bianca, and she 'collapsed in a heap'.

'I drove straight to our local church and I remember just sitting there and crying. I felt like my world was falling apart from under me.'

But she knew she had to pull herself together.

'There was no other option. Days go on, medications have to be given, nappies have to be changed. You just have to get on with things. You become so entrenched in everyday life that there are days when you don't even think anything of it. But then there are days where you wake up crying for absolutely no reason and the emotion forces itself back into your reality.'

> *I'm stronger now than I ever could've been without my children.*

The challenge to get through each day gave her more resolve.

'I realised I had been a weak person. I had allowed myself to be hurt physically and emotionally because I didn't think I was worth anything. Now nothing stops me. I'm stronger now than I ever could've been without my children.'

Bianca needs that strength to tackle her daily routine which starts at 5am, getting the children ready for the day, administering medication, doing observations and taking up to two hours to give breakfast to Charlotte who has feeding difficulties.

After dropping the oldest two at school and the youngest at the special education unit, Bianca has an hour to tidy the house before picking up Charlotte again.

'Lunch is another two-hour battle and by the time I finish that, it's time to go back up to the school.'

The afternoon and evening routines are just as demanding. 'Eleanor doesn't go to bed before 11pm and in the middle of the night Charlotte usually needs medication. Then I'm up at 5am to do it all again so there's not a lot of downtime at all.'

Despite this, it has been an incredible journey.

'There are many times I look at my children and think there is no way I would change them.

'Sometimes the most challenging times are the most rewarding.

'There was a day when I took the kids to a massive reunion party for a young parents' program. There was a boy who kept teasing my son, but Lachlann was oblivious to the cruelty and just thought he was having fun with his new friend. It almost crushed me, but then I thought how great it was that he didn't understand the condemnation and wasn't worried about what anyone else thinks. That was a really big moment for me.

'He's really proud of the way he is and he thinks he's cool because he does things no-one else can do. It's sometimes hard for me to realise that I have to let go.

'But I accept that my children are unique. I enjoy them for what they are, not what I thought they would be.'

Bianca has a very pragmatic outlook on life — she has to.

'Charlotte's medical options are running out. Eleanor's condition could deteriorate and she may end up in a wheelchair with the possibility of suffering permanent dislocations.

'So, I only worry about the future in terms of a couple of months down the track. There's no point thinking too far ahead as I have enough on my plate right now.

'Let's just live our life, accept things as they are and see what happens — but at the same time make the best of it.'

a different path

In the early morning Bronwyn and her son Billy are at the beach. Bronwyn is really enjoying the surf, calling ‘Woo-hoo!’ as she catches waves while Billy sits on the sand clapping, ‘Good one Mummy, good one.’

This is their short reprieve each day before heading back to the hospital for Billy’s latest round of treatment.

Bronwyn didn’t intend to have a child. Nine years ago, she was helping to manage the family’s motor dealership when she was diagnosed with a malignant melanoma. ‘I thought I was very clever and I thought I was really somebody in my own little world. But things have taken a different path.’

Bronwyn met Billy’s father Doug during her treatment and unexpectedly fell pregnant. Billy was born in December 2000, at a time when Bronwyn was still adjusting to the fact that she might not live. ‘So Billy was a gift to us really, a very special child to a lot of people because we thought I was going to die.’

A rollercoaster year followed Billy’s birth. With her own future still uncertain, Bronwyn had to farewell her mother who passed away from pancreatic cancer, and support her sister who suffered post natal depression.

From the start, Bronwyn surrounded Billy with people she knew he could be close to if she died. ‘He’s got all of these people whose strengths he’s been able to draw from and as a result he’s quite an intelligent, well-rounded and very aware child.’

Then one Monday morning in April 2006, after a weekend involving two birthday parties, Billy announced he had a headache and began vomiting. Thinking it was just overload from the parties, Bronwyn kept him home from pre-school. He was sick on and off for several days before being taken to hospital with suspected meningitis. But when his vomiting and headache intensified the doctor recommended an MRI scan.

‘Billy was only five then and he had to lie perfectly still for half an hour, feeling sick with pressure in his brain. So we made an astronaut mask and said, *You’ll go into the spaceship, into the rocket and you’re going to blast off and you have to lie perfectly still.*’

Bronwyn is thankful that her brother and sister were with her when the doctor came into the room with the scan results. ‘He said, *Bad news I’m afraid. It’s a brain tumour.* I couldn’t believe it. I just collapsed, wailing. I said, *Is he going to die?* He said, *I don’t know.*

‘When Billy was diagnosed it was just devastating because he was so close to so many people and he was this little treasure that had taken us all out of the depth of the most horrible experience.’

Billy was quickly transferred to another hospital to prepare for surgery to relieve the pressure in his brain. Bronwyn and Doug were told there was a possibility Billy would not survive the operation.

‘The doctor said, *You have an option not to operate but I will guarantee you that he will die if we don’t operate. But he might die if we do operate.* It was terrible.’

Billy was a gift to us really, a very special child to a lot of people because we thought I was going to die.

Bronwyn and Billy like to enjoy family time in their garden

To their relief, Billy's operation was successful. They were told the growth, an Astrocytoma Brain Tumour Grade 2, was unlikely to bother him and that he should just be monitored.

But five months later Billy started to exhibit the same symptoms. 'I could just tell by his voice that things were not right. I had an immediate cold pulling pain in my stomach. He deteriorated quite rapidly.'

Another scan revealed the tumour had changed characteristics and spread rapidly. It was more serious than originally thought and Billy needed a major three-hour operation to remove as much of the tumour as possible. He then started on chemotherapy to stop the tumour's progress and 'buy time'.

The chemotherapy continued into the New Year when Billy was due to start school.

'His hair fell out the day before school started. He started school looking like a kid on chemo. Really terrible — really pale, really skinny, big dark circles under his eyes. His uniform, like every other Grade One, was three sizes too big for him. He went to school for two hours that day then went for treatment.'

Billy faces seven more rounds of treatment over 44 weeks to try to halt the tumour's progress. The treatment lowers Billy's blood count which increases the risks of slow bleeds from knocks or falls. He is also at high risk of getting infections.

Bronwyn must constantly calculate the risks. She provides antibacterial hand gel for Billy's entire class at school and keeps him home if other children are sick. Simple things like getting a haircut or buying a new pair of shoes require planning so they can go after normal hours or when the shops are least busy.

She also monitors Billy's daily activity levels as far as gentle exercise is concerned and has to ensure there is no rough and tumble play. A hospital bag is always packed and ready to go just in case.

'For his father it's very sobering because Billy now presents as a very well child and quite capable of these things but it's no laughing matter if the oncologist wants him in hospital and he has to stay overnight.'

As well as looking every day for signs that Billy's blood count may be low, Bronwyn is conscious of Billy's food intake, particularly from a nutritional point of view. He also requires daily antibiotics and frequent applications of sunscreen — one of the antibiotics carries a warning about excessive exposure to sunlight and the family has a strong history of skin cancer.

Many details of daily life take a back seat to Billy's health. For Bronwyn, there is little time or emotional energy for other things such as home maintenance, disputing bills, cleaning carpets or even continuing to properly monitor her own health issues.

Any plans for Bronwyn to return to work have been abandoned. Doug works full-time and Bronwyn says he is supportive in his own way. 'It's quite a common reaction amongst fathers of children with cancer. In a way he thinks that if he just keeps going to work everything will be okay. He really struggles to go to the hospital and witness what Billy has to endure.'

As well as support from her family and friends, Bronwyn has been buoyed by the response of her local community. 'When Billy was first diagnosed it came as such a shock to the community and we got so many cards and letters and gifts from people, even people we didn't know. Along the way, we have met some very beautiful, very kind and loving people, and some very dedicated people.'

The experience has had a big impact on Billy. 'He is different from his peers. He's aware that there is a world that he's been in that the other 649 kids at school haven't been in.'

But he is a bright and very happy child who enjoys simple things like kicking the ball across the street with Bronwyn, listening to Elvis Presley, and spending time with his friends and family.

'I have learnt from him to take one day at a time. Life becomes very small. It is literally a matter of life and death and if they are alive, you're lucky.

'Every day when he wakes up, I sit him on my knee and hug him and tell him that I love him. Every day I think, *Thank God you're alive and thank God I have this time to do this.*'

His hair fell out the day before school started. He started school looking like a kid on chemo.

For Bronwyn, her own experiences combined with Billy's mean she truly values her role as a parent. 'We live in a time where lots of people tend to get a nanny in for a week and go skiing and leave their kids at home, or go to Bali and put their kids in Kids Club from 8am to 5.30pm and have no concept of what they're missing out on.'

One of the family's favourite times together is story time at night. 'His father goes very early in the morning but he is here at night. I do the reading but we all lie on the bed and the boys play, and that is very precious as a family.

'I honestly think after someone saying to you, *You must realise your child could die* nothing else can really happen that's worse than that. Until he takes his final breath then nothing else can really match that.

'But there's a long way between where Billy is today and dying. There's a long way because I saw it with my Mum and my father — a long, long way. So, yes he may well die, I don't know, no one knows. But in the meantime there are a lot of days to live and so you've got to live the days you are given.'

an intriguing life

‘Look, you may have to give up work to become a full-time carer — not just for Megan but for Megan and for the three boys.’

With these words from his wife’s doctor, Daniel’s life changed completely.

‘I was shocked,’ says Daniel. ‘But no government department was going to fund a carer to come around here seven days a week so I said, *Right-oh, change of life. I’ll become my own boss.*’

Daniel gave up his job. Several financially and emotionally turbulent years followed. The family gave up all their luxuries, sold the house and cut up the credit cards. At one stage, Daniel went back to work but ‘the family started to fall apart again’ so he returned to the carers’ role. In the end, Daniel says ‘we went bankrupt just so we could survive’.

Six years earlier when Daniel and Megan married and started their family, they had no idea of the challenges that lay ahead.

Their first son Darian was born in 1995. He suffered a stroke at birth and was then diagnosed with epileptic seizures. A developmental delay was later recognised as Asperger syndrome. Twelve-year-old Darian also has gigantism, which means he is now taller and can be stronger than his father.

In 1997, before Darian was diagnosed, Alex was born. He was three when Daniel and Megan recognised that he also had developmental issues. Initially misdiagnosed, it took seven years before he was also diagnosed with Asperger’s.

By that time, the couple had had their third son, Mason. His arrival was dramatic. He survived SIDS and surgery at 10 weeks. ‘He actually had died, but the hospital brought him back to life.’

Now it appears that Mason also has Asperger syndrome.

The same year Mason was born and Darian’s diagnosis was coming to light, Megan became unwell. Megan was eventually diagnosed with a range of conditions including Asperger syndrome and depression.

Now Daniel and Megan share the role of looking after the children. ‘Even though Megan has a disability she is the most excellent Mum a child with special needs could have.’

Living with autism means there is no room for spontaneity. The day starts at 6.30am getting the breakfasts organised and boys ready for school. Housework, shopping, gardening, washing, ironing, cooking and other tasks like doctor’s appointments quickly fill in each day. Dinner always has to be at 6pm, even during daylight savings. The working day usually ends around 11pm after the boys finally go to bed. Daniel and Megan take it in turns if one of their boys has an ‘all-nighter’ and doesn’t sleep.

‘We need a routine that doesn’t change. Everything’s got to be concrete and step-by-step. I’ve always got to think a few days ahead. You can’t just do something in an instant.

Daniel and Megan with their boys Darian, Mason and Alex enjoying the foreshore

It’s hard for some people in the community to accept a young carer and they say, Get a job*.* *I say,* I already have and it is full-time as a carer, but with no wages unfortunately.

You have to explain to the children days in advance what you’d like to do. And you can’t then disappoint a child with autism because they go back into their own world.’

When this happens, Daniel has to ‘sit down and calmly speak to them. I’ve got to bring them out gently because they may be in their world just for five minutes or it may be a couple of hours, rocking and shaking their hands.’

Now, at least the family understands the condition and ways to deal with it. But getting to the heart of the problem was a frustrating task.

‘We had to fight with the hospital and ask the specialists to pursue the problem because we knew. Our gut feeling was that while there was a problem with their hearing and their speech, there were other problems also underlaying that — like a carpet underneath a carpet. Two or three doctors later we got on top of things and said yes, there is a problem with your children. We were right the first time.’

One of the adjustments for Daniel in taking on the role of carer has been giving up on socialising much outside the family unit. ‘With only myself to hold a car licence I’ve got to be alert. Megan is unable to hold one due to her disability. So I can’t afford to drink drive and I socialise very rarely. It’s hard for some people in the community to accept a young carer and they say, *Get a job.* I say, *I already have and it is full-time as a carer, but with no wages unfortunately* — but you just continue on as a carer.’

Last year, after a six year wait, the family moved to a regional coastal community and into a government house designed specifically for children with autism to minimise the chances of them hurting themselves. The move has been a real turning point.

‘It’s a different lifestyle down here. It’s more of a country town atmosphere. There’s more help and people are more open to the situation… they talk to us without a problem and ask how the boys are doing.’

All three boys are now at school, where they are in mainstream programs. Generally, the boys are enjoying this school and getting on well with the teachers and other children. But Megan says, ‘It’s still always in the back of your mind thinking that they’ll get into trouble somewhere along the line and they won’t know how to get out of it’.

Daniel has worked hard to help his children be accepted as ‘normal boys’. For example, he encouraged Alex to move from obsessively playing with spinning tops to spinning fishing reels. ‘He can interact with other children and socialise with them more often when he has something to talk about like how he’s been fishing with his Dad.’

After two terms, Darian has developed a ‘decent group of mates’. And Mason surprised both his parents recently when he came home from school with an honours certificate. It was for helping another child who’d hurt themselves in the playground. Daniel and Megan were so proud that, for a child with autism who doesn’t show much emotion, Mason had achieved something they hadn’t thought he could.

Through his experiences as a carer and parent, Daniel has learnt that patience is a virtue. ‘Strength, patience and I have a bit of humour in me at times,’ he says. ‘I speak to Mums and Dads and they say, *Where did that joke come from? Because we know you’ve been home all day.*

‘I’m also more open minded about what’s going on around me. I can stand back and see my children and where they are at and I can open my heart up to others who are going through a similar problem.’

Daniel also finds it helpful to talk to a counsellor from time-to-time, to ‘lay all my stresses on a person that’s neutral, and not part of the family’. And the family sincerely appreciates the support network of various government and community groups that provide assistance.

Megan describes the family’s life as ‘intriguing’ and says she stays positive for her boys.

Daniel also focuses on the positives to keep going. ‘I’ve got to keep pushing myself every morning. I’ve got to think of something like, it’s going to be a sunny day or the boys are going to achieve something different at school today, or we’re planning ahead for the weekend and we’re all going to go to the beach.

‘The main thing is you enjoy your children while you’ve got them and you appreciate what you’ve got, not dwell on what you need.

‘I give it all my best for my boys. They’re not very affectionate but they give me a lovely smile back and they let me know they’re happy where they are now, with their Mum and their Dad in this house that we’ve received.’

caring for Kate

Fifteen-year-old Kate loves life. She enjoys her swings, toys, swimming, school, shopping and time with her family and pets. She particularly loves her collection of hats.

'Sometimes she sits down beside you and puts on a large chef's hat with a serious face and just sits. I wonder if she is waiting for a reaction, which she usually gets,' says Kate's Mum, Dianna.

'I compare it to when you have a young child and you spend more time watching their antics than watching TV.'

Kate was born with a small head and subsequently diagnosed with a severe intellectual disability. She also has epilepsy, osteoporosis and some posture, feet and mobility problems. She doesn't talk but communicates well using sign language, photos and symbols. 'We say for a child who can't talk she talks non-stop!'

For Dianna, getting married and having children was something she couldn't wait to do. After working for a bank for 16 years, Dianna's 12 months at home with her first-born Grant was a joyful experience. 'Every stage that he went through I just loved and I couldn't wait to do that again.'

But the day after Kate was born Dianna was told something was wrong. 'I was in total disbelief. I did not want to believe that after having a perfect pregnancy and already having a gorgeous little boy that our baby girl had a disability.'

By the time Kate had her six week check up Dianna had to accept that she wasn't doing the same things Grant had at that age. 'I sort of broke down in the obstetrician's office and said, *Look I know OK, I had to find that out for myself.*'

A period of grieving followed, for the 'normal' baby they'd lost.

'I spent a lot of time crying in the shower. We didn't know how our lives would change and we sort of tended to take it a day at a time and deal with things as they came.'

Dianna resigned from her job soon afterwards, abandoning her 'five year plan' to eventually return to work.

The first six months were the hardest. 'She was a really unhappy baby. The first six months I spent carrying her around. She was a really fussy feeder and it was very hard to get her to gain weight. As well as me adjusting — babies sense a lot of things so maybe she could sense that — I kind of felt that she really wasn't ready to be born, you know that her brain wasn't ready.'

The family spent a lot of time going to therapists, early intervention centres, specialists and waiting for every milestone to come. But as Kate grew, she got further and further behind.

'Imagine you have a baby. Then they become a toddler, about two or three years old. Then imagine they can't talk and they are still at that same stage when they are 15 years old. You get older but they don't.'

Kate on her favourite swing with Mum, Dianna

A period of grieving followed, for the 'normal' baby they'd lost.

While each day is different depending on whether it's a school day, work day or weekend, they consistently revolve around caring for Kate. 'All days are spent dressing Kate, giving her breakfast and medication, toileting her and washing her face and cleaning her teeth.

'We have always tried to have our family dinner together, the four of us. Kate has improved a lot but still needs help to eat with a fork and spoon.'

A combination of well-organised planning and flexibility is needed to manage the daily challenges. 'You can plan, you can organise something then Kate will have a seizure and it'll all go out the door and you just have to go with it.'

With the rest of her family living interstate or some distance away, Dianna and her husband Craig depend on each other and work as a team.

'He is my best friend and we share the highs and lows of life. I have to say having a wonderful, supportive husband and a positive attitude and sense of humour has helped enormously. You don't have a choice you just have to do it.'

'All families have problems or health issues — no-one is without their own troubles but I guess when you have a child with a disability, it doesn't go away. It's a life-long impact on the family.'

Activities like shopping, going out for dinner or to the movies, having a coffee after work or planning a holiday are difficult and require lots of planning, if they happen at all.

'You can feel isolated because of this. Socialising with friends is very limited. It's difficult when their teenagers are independent and we still have to look after Kate like a baby.'

There is also the impact on Kate's brother, Grant. 'Grant has been a terrific brother. When he was little he used to let Kate push him and he would fall all over the place and have Kate laughing so much. He's always been really good with Kate.'

Dianna doesn't want Grant to feel that he has to be responsible for Kate down the track. 'I want him to be there and care about her, but I don't want her to have to live with him or for him to have that worry either. He has to have his own life… As long as he marries someone who likes Kate!'

The extra financial pressures are also never far from Dianna's mind.

'We have always purchased anything she has needed, like a special-needs pram and wheelchair, out of our own funds. I've had to make withdrawals from my superannuation for a swimming pool and bathroom renovations for Kate. And our housing loan seems to be getting bigger as it's impossible to save for large items or expenses.'

Dianna has been able to earn some income working at Kate's school, and she enjoys the job.

> *Imagine you have a baby. Then they become a toddler, about two or three years old. Then imagine they can't talk and they are still at that same stage when they are 15 years old. You get older but they don't.*

'It was only because I spent so much time at her school that they offered me a job! I have tried working at other schools but it was too difficult. If something happened, I couldn't get there.'

The next big challenge will be when Kate leaves school in three years. 'I'll have to retire then — no option, I have to be there for Kate.'

Looking further into the future can be daunting. 'No-one can look after your child like you can. But it's going to have to happen eventually. I don't know what kind of day places will be available to her or how many days she will have there. I just hope there are nice facilities with nice staff who want to work there.'

Dianna and Craig know that it's important not to get so caught up in the caring role that they neglect themselves. 'We have a very good GP who told me once I have to look after myself to be able to look after Kate. I try to remind myself of that because that is so true.'

Dianna finds it helps to have hobbies, like lead lighting and glass fusing. 'I call it my therapy.'

She and Craig also try to make a little time for each other, even though it's very limited. 'Having respite is great — a weekend here and there, but I still feel guilty leaving her.'

The joy that Kate brings to the family helps enormously.

'We get so much joy from Kate. She loves the simple things in life. She is cheeky, gorgeous, and beautiful. We are very proud of every small step she takes.'

Dianna also looks forward to the special quiet moment she and Kate share each evening.

'I love it at the end of the day when Kate comes and sits down next to me on the lounge. She's had a bath and she's in her pyjamas. She puts her feet up on the ottoman just like *I'm sitting there*, and watches TV.

'Nothing is said, she just sort of sits, like this is Mum and daughter time. And if it's winter she'll put a blanket over us. It's only for a short time before she goes to bed but it is precious.'

Rainbows and running races

Like many young couples, Dianne and Shaun's plans for the future centred on a happy and comfortable family life. After relocating to Perth from Sydney, they enjoyed their new lifestyle and worked hard to buy their first home.

'Our wedding song was *We've only just begun* and we felt that the world was at our feet — we were so very, very, happy,' says Dianne.

After several miscarriages, they were delighted their first son Ryan was born in 1997. However, it was clear straight away that something was wrong. Ryan was born with a congenital disorder called bladder exstrophy, which means that his bladder was outside his body. He needed an operation within 12 hours of being born.

'After a 21-hour labour, to be told there was something wrong with our newborn was shattering. We felt the elation of having our first born, but also suffered the distress, panic and worry that he may not make it through the night. He got through that first stage of surgery and that started a very long road for us.'

Afterwards Ryan was in the intensive neonatal care unit. 'I had to wait nearly a week for my first cuddle. It was worth it.'

At just three months, Ryan required major reconstruction surgery lasting nine-and-a-half hours.

Now a happy and determined 10-year-old, he has had 25 surgeries and faces still more operations in the future. He currently needs to be catheterised every three hours, including overnight, as his bladder capacity builds up.

After seeing a specialist to ensure Ryan's condition wasn't genetic, Dianne and Shaun decided to try to have more children. 'I had our lovely little boy Kieran in 1999. Kieran was a beautiful baby — quite perfect really.'

But Dianne soon noticed something wasn't right. 'He just looked at me one day and I thought it was as though he didn't see me, he was looking through me.'

Then Kieran started doing unusual things. He became obsessed with certain toys, especially balls, and he wasn't playing appropriately. So Dianne and Shaun started investigating what might be wrong.

'It was a very long process. Lots of waiting lists, lots of assessments from medical people and ultimately he was diagnosed with autism and intellectual delay. Emotionally, Shaun and I were drained and very distressed.'

By this time, the couple had already had their daughter Erin, who arrived a year after Kieran.

'Erin wasn't planned at the time, but we were delighted to have a little girl. Once again she was a lovely baby. But it got to a point where I personally thought she was just copying Kieran because I had both of them home, and I thought she was picking up his bad habits.'

Dianne and Shawn in their home

We felt the elation of having our first born, but also suffered the distress, panic and worry that he may not make it through the night.

To be on the safe side, Erin was checked by a paediatrician who suggested an assessment. Then she too was diagnosed as autistic.

'I had a breakdown instantly when they told us about Erin. I remember pleading with them. I said, *This can't be happening to us*. We just couldn't believe it. The look on my husband's face... I actually think part of us died that day.'

Feeling like they'd been thrown in the deep end, the couple became very resourceful, very quickly. Despite the stresses involved their relationship remained strong.

'We've been a bit like a tag team too. When I reached the point that I couldn't cope any more, Shaun and I spoke that night and I just felt extremely ashamed of myself — that I'd reached a point where I didn't think I could go on anymore, even for my beautiful kids. I just felt like the blood had been drained from me and I didn't know where I could find any more strength.'

So Shaun resigned from work and took over at home. 'There's not a lot of Dads who would give up work and just dedicate their lives to their kids. I don't think anyone has ever given him a pat on the back and said, *How fantastic for doing all that for your kids.*'

Dianne then went to work full-time to support the family financially. 'That's another thing that's quite draining for carers as well. Anyone can become a carer really. We're all the same and you just never know when it's going to happen to you. You know, you go through all of this and you don't want to burden anyone. The first time we applied for the disability pension, I felt embarrassed. I had always worked. We thought, *Fancy having to ask for welfare.*'

> *Anyone can become a carer really. We're all the same and you just never know when it's going to happen to you.*

However, they were at a stage in their lives where they were desperate for help. The funding they receive now pays for workers to come to their home sometimes. It also means the children can participate in activities like swimming lessons so that they can 'be part of their local community'.

Dianne and Shaun do all they can to help their children live as normal lives as possible. This includes deliberately breaking the routine for their autistic children sometimes. For example, they might swap the placemats at the dinner table or take a different route to the park to encourage them to be more flexible 'because that's what the real world is like'.

'We feel we can hold our heads up high for what we've achieved with our kids over the years.'

Sometimes the role of carer is overwhelming. 'Being a carer is a very demanding role. You're not paid for it and it is a 24-hour-a-day job. There are times when I feel we are just existing and not living a life. The reality is my caring role and my husband's caring role will be till the day we die. You do forget you're a Mum and Dad sometimes because you are just caring for the children who really can't help themselves.'

But their love for their children keeps them going. 'My love for them also keeps me alive.'

Having three children with special needs has changed their perspective on life enormously.

'You find joy, as simple and small as it is, and you hold onto it. It keeps you going, keeps you strong. The things we look forward to are very simple things in life.

'We just look forward to our children growing and being happy. We look forward to sunny days. Even when we see a rainbow, the five of us will run outside and enjoy looking at a rainbow. It's very simple things that make us happy now.

'I have become a very emotional person and don't think that people understand the reasons why I cry. Small things mean so much to me, and I absorb the moments such as when Ryan received his first certificate at assembly. I cried happy tears that day because we are so lucky that he is alive. He has his battles in hospital and he does his best when he's at school. And receiving that certificate was a reward for not only his good work, but his achievement in living a life. I am so very proud of him. Ryan is such a happy boy and he doesn't take anything for granted. He is also very determined to succeed and gets the most out of every single day. He's a lover of life and I adore that about him.'

Another special moment was when Erin, who for a long time had limited speech and wouldn't make eye contact or cuddle her, finally said 'Mummy'.

And Dianne will never forget the day Kieran took part in a running race with children from the mainstream school located on the same grounds as his Education Support Centre.

With Dianne's support, he waited patiently for an hour before his race. 'All those years of trying to get him to sit still, to listen, to focus, to remain calm… the reward was watching him act normal, just like the other children and blending in with the crowd instead of creating a scene and acting strangely because he couldn't cope with a situation'.

Then Kieran ran in his race. 'He held his head up high and he ran! He didn't just run though — he pranced like a ballerina. He enjoyed himself so very much. I was standing at the finish line calling his name, with my arms wide open waiting for him to finish. I was so very proud of him. He didn't come first of course but he was able to participate and it meant the world to me and to him.'

dancing with her hands

When Teegan was small she loved dancing with her sisters. She would often crawl into wardrobes to find tap shoes or ballet shoes and use her hands to dance in them.

Teegan was born with spina bifida and other complications, and has spent most of her 18 years in a wheelchair. But this hasn't held her back. She's about to graduate from mainstream Year 12 and is deciding if it will be TAFE or university next.

Her Mum Jenny couldn't be more proud. 'I really appreciate the fact that she's had to live with so many hurdles, there's been so much she's had to put up with and she's come out the other side smiling.'

The hurdles began towards the end of Jenny's pregnancy. After a routine 30-week scan, her obstetrician diagnosed spina bifida. However, because Jenny was living in country New South Wales she was sent to Newcastle for more scans. The original diagnosis was discounted and eight weeks of uncertainty followed, with specialists unable to reach a firm conclusion. While this was difficult, Jenny says in a sense she felt lucky. 'I was able to go through the stages of grieving — the anger, the denial, the *Why me?*'

Several weeks later, after an eventful early morning drive into hospital which included hitting a kangaroo on a deserted country road, Teegan was born blue and not breathing. 'If I'd had her in the middle of nowhere she wouldn't have survived.'

Teegan was resuscitated and put into special care. The original diagnosis of spina bifida was confirmed. On the first day, doctors had to sew up a hole in her back. 'You could see through to the spinal column so they had to sew that up to prevent infections.'

On day three she had a shunt put in for hydrocephalus. By day five, she was on oxygen due to a paralysed left vocal chord and a condition with her trachea that prevented her getting enough air, especially while feeding.

Jenny surprised medical staff with her no-nonsense, positive attitude. 'I'd gone through my grieving and I just wanted a baby at this stage. It's a really interesting situation when you have a child born with a disability. People expect you to fall apart and when you don't they're even more worried about you.'

For three years things were touch and go. Teegan spent nine of her first 14 months in hospital, including time in intensive care. Most worrying were her 'blue spells' where she would stop breathing for as long as eight minutes. 'She would go blue 20 or 30 times a day and there wasn't a great deal we could do about it… I had this child with all these problems but my biggest concern was that she may not make it.'

When Teegan was at home, her two sisters treated her just as the baby in the family, rolling around with her on the floor and pulling her legs, even though she was on oxygen. 'We had a lot of good times, even though it was hard times, it was good times.'

Enjoying family time – Jenny and Teegan

> *I really appreciate the fact that she's had to live with so many hurdles, there's been so much she's had to put up with and she's come out the other side smiling.*

Teegan turned a corner at three and the family had 'seven really good years'. But one day, inexplicably at the age of 10, Teegan's blue spells returned. 'She got worse for the next three or four years and then when she was 12 she developed epilepsy.'

After a particularly frightening night when Teegan was having blue spells and seizures every few minutes, tests also confirmed she had major sleep apnoea. The tests showed that she spent more time not breathing than breathing overnight.

Teegan has also had to have rods put in her back for scoliosis. An infection in the rods resulted in yet another trip to hospital. The weeks off school meant Teegan has had to extend her Year 12 studies over two years.

Supporting Teegan to be organised and succeed in her studies is just one aspect of Jenny's continuing role as carer. Because of her breathing problems, Teegan can never be left alone — something that is more frustrating for her now that she is 'a normal 18 year old who likes to go out with her friends'.

Jenny is still on call 24-hours-a-day, including being aware of Teegan's apnoeas overnight. She transports her wherever she needs to go, can never be more than 10 minutes away from her school and must be close by when Teegan is with her friends.

'I am relied on for much more physical and emotional support for Teegan to deal with everything in her life than would normally be required for a child her age.'

It is an intensive routine. 'She's at school by 8.30am but before that she has to get up, she has to have her medication, and she has to be showered. I have to dress her. I have to get her into the car and get her to school. Then I have to transfer her into the electric wheelchair and then an aid takes over at school. But because she's doing Pathways, she might only be at school an hour or an hour and a half so then the whole routine starts again. It is exhausting, some nights I just flop into bed.'

Challenging but worthwhile, rewarding but frustrating, and tiring but rejuvenating is how Jenny describes her experience as a carer.

There have been some dark times. 'When Teegan was constantly in intensive care I found many people felt sorry for me and the workload that came with a multiple disabled child, instead of supporting me in the battle to keep my child alive.'

Then when the family moved to Newcastle, Jenny had to fight for Teegan not to be automatically 'dumped in the bottom classes because she was in a wheelchair'.

Other experiences have been far more positive. 'Teegan's paediatrician said to me one time when I was down and Teegan was very ill, *I've got a bottle of wine I'm putting it into my cellar and we'll get it out and we'll celebrate when she turns 18.* And that was all I needed, that little bit of a hope from a medical professional to keep going. And he did it — he brought it to her 18th and gave it to her!'

From an early stage Teegan's sisters have also been involved in her care. 'They had to help me resuscitate their sister. They had to help me when I went to hospital with her. They also knew if they ever got sick that I'd be with them. I think everything we've gone through has given them that empathy for other people and yet they also can be light hearted about serious matters when they're able to be.'

Teegan's father has also played an important role by supporting all the family throughout the years.

A mischievous sense of humour runs in the family. 'When you have a child with a disability, you can actually joke about it. People don't really understand that side of it, but there are little things you can joke about.'

For example, Teegan's sisters will 'tease her and tell her the only good thing about it is we get disabled parking.'

Teegan gets her own back by jokingly complaining about tired legs after a day out shopping or pretending her feet hurt when trying on shoes, even though she can't feel anything.

And when Jenny explains that she keeps going because 'there isn't really a choice', Teegan says 'No you're supposed to say it's because I'm wonderful and gorgeous and it's not an effort!'.

> *I am relied on for much more physical and emotional support for Teegan to deal with everything in her life than would normally be required for a child her age.*

An 'eternal optimist', Jenny says she has realised that she is fairly strong and can deal with a lot. 'You need to be strong to keep going. The strength comes from the fact that I have three children developing and turning into wonderful human beings and you don't need more reward than that.'

determined to meet the challenge

Six-year-old Timmy has a great sense of humour and keeps everyone amused with his one-liners. He is also learning to play the keyboard and loves to entertain his family.

But this cheerful little boy is trapped inside an uncooperative body. Born 10 weeks premature, he has spastic quadriplegia cerebral palsy.

He relies on a wheelchair because he cannot stand or sit unassisted.

‘He is a good kid but he has the same care level as a baby, so it is very hard work looking after him,’ his Mum Jessica says.

‘He has poor trunk support, but relatively good head control. He can use his hands for some tasks like clapping and waving, but his fine motor skills for writing are poor.

‘Timmy can talk reasonably well. He is able to eat a small amount of some foods and manages fluids well, but has difficulty swallowing, so has a gastrostomy tube to ensure he gets enough nutrition to grow.’

Timmy is the youngest of five children and two of his sisters also have special needs. Eleven-year-old Talitha has Attention Deficit Hyperactivity Disorder (ADHD) and nine-year-old Mishael, who was also born prematurely, has developmental delay.

Jessica has her own medical issues and suffers from severe back pain so finds it difficult to lift Timmy.

She is also caring for her 90-year-old mother, Gwladys, who has dementia.

Gwladys lives just around the corner with Jessica’s two oldest children, 19-year-old Amanda and 21-year-old Brendan. They help out, but they find it difficult to deal with the demands of caring for someone with dementia.

‘She needs 24-hour supervision, so she is often at my house or I am over there. I spend a lot of time going back and forth. My Mum gets upset and disoriented very easily and I often have to put her at ease. It’s so hard because she used to be such a smart woman. She has to be prompted all the time to do everything, even eating. She is incontinent, so I also have to deal with adult nappies. Because she is a high-care dementia patient we do get some help from carers who come every day to shower her. But it mostly falls on us, and it’s either that or a nursing home and she always made us promise never to put her in a nursing home.’

The level of care for Timmy is also constant. He wakes frequently throughout the night. He is drip fed through a ‘kangaroo pump’, which needs to be flushed every three to four hours.

He also gets uncomfortable because he cannot roll over.

‘He calls out many times during the night to ask us to change his position. We are trying to encourage him to sleep in his own bed, but he needs someone close to feel reassured.’

Timmy embraces Michael

> *He is a good kid but he has the same care level as a baby, so it is very hard work looking after him.*

We presently receive respite care once every two to three weeks on an overnight basis. Michael and I use this time to try to catch up on sleep — not to go out as a couple.

This has meant years of disturbed nights for Jessica and her husband Michael. They now take it in turns to sleep in Timmy's room so the other one can get some rest.

'We presently receive respite care once every two to three weeks on an overnight basis. Michael and I use this time to try to catch up on sleep — not to go out as a couple.'

Jessica has been unable to work since Timmy was born.

Finding day care places for young children who required specially trained staff to give one-on-one time — in Timmy's case to ensure he had adequate nutrition — proved 'impossible' for Jessica.

'My husband left work in September 2004 to assist me as I simply could not manage alone any longer. Obviously, this greatly limits the type of employment is he able to undertake.'

Timmy now has access to the Early Intervention Special Education Developmental Unit through a local school. However, quite often the school calls to say that he is tired or sick and needs to go home early.

'He misses more school than regular children because he has difficulty overcoming respiratory infections.'

There are frequent appointments with Timmy's GP, paediatrician and dietician.

When he was younger, he had five operations in six years. A bilateral squint was surgically corrected, the muscles in his hips and legs needed to be cut and lengthened, he had a fundoplication to help stop reflux and then had a gastrostomy tube inserted.

His hips need to be continually monitored as they can move out of alignment.

Jessica's husband Michael has found it difficult to get jobs which allow him the time off to meet the many medical appointments, which are often in Brisbane, four hour's drive from their Bundaberg home.

Both Jessica and her husband have to travel with Timmy because of the potential risk of him gagging or vomiting.

'This is hard on the girls because they have to go to day care and they resent it.'

It has also put a huge strain on their marriage. 'Our relationship is falling apart. It's not just the emotional pressure, but financial too. What crushes me is not being able to afford the equipment he needs.

'By the time he received his Medical Aids Subsidy Scheme wheelchair, he had almost outgrown it. Tim had to wait seven months before his chair was modified. He could not sit in it properly and was experiencing severe knee pain. As he grows, his equipment must be modified, but it takes many months to have the modifications approved.

'The financial stress is really hard to cope with and I'm on the verge of putting Timmy into an institution or foster care because I just can't afford to look after him properly.

'I can't get things he needs for his development, things like a walker. He's capable of doing assisted stepping in a walker if I could afford one. He also needs a standing frame, leg wraps and a modified car seat. I can't afford any of those. That makes me feel like I'm not being a good mother and I just hate relying on charity.'

Jessica is trying desperately to secure the family's financial future and has enrolled in a law degree on an external basis with the Southern Cross University.

'It's not easy to fit the study in and there's so much reading. I still have to do the housework and organise numerous medical appointments for all the children and my mother.

'But I'm determined to finish so I can get a job and make some money to look after the needs of my children.'

giving Georgia a voice

Linda always knew she was somewhat stubborn and strong-willed. But she never knew how important those traits would become when it came to caring for her daughter Georgia.

Ten-year-old Georgia was born with an undiagnosed genetic condition which has left her with the intellectual and developmental age of an 18-month-old.

‘I’m still feeding her, changing her nappies, giving her a bath, brushing her teeth… all things I should have stopped doing eight years ago,’ her mother Linda says.

‘But not only do I have to look after her, my husband Kevin and I also have to be advocates for Georgia because she doesn’t have a voice. We have to give her a voice and fight for her and others with a disability.’

The dreams Linda had for her daughter before she was born have been replaced by a simple wish.

‘If we could have a fairy godmother who could wave her wand and grant a wish then all I’d ask is for Georgia to be self-sufficient and happy.’

The first sign that things were not as they should be was when Linda was 33 weeks pregnant.

‘An ultrasound picked up that she had a cleft lip and palate, and a heart condition. That actually gave us, our family and friends some time to get used to the idea. It also meant it wasn’t a big shock when everyone came to see her when she was born.

‘Our friends were great at the time, but as the years have gone on and Georgia’s problems have become more complicated they’ve tended to drift away and don’t exist anymore.

‘I’ve tried to keep in touch, but they don’t know how to deal with Georgia or what to say to me. It’s easier for them to keep away than to deal with her disabilities.’

The seriousness of Georgia’s condition became clearer when she was 18 months old and an MRI revealed abnormalities in her brain.

‘She’d been slow with all the usual milestones but I’d put that down to the fact that she spent a lot of time in hospital with her heart problems.’

However, the tests could not point to a particular diagnosis.

‘It is an unknown syndrome with no name to help us know what to expect. What we do know is that it isn’t degenerative, so she won’t go backwards. But we just don’t know how far forwards she can go and that’s difficult. There’s no crystal ball we can look into.’

So all they can do is deal with the present. ‘It’s pretty much like having a two-year-old child in a 10-year-old’s body. Georgia has to be closely supervised as she has no awareness of danger. She puts everything into her mouth. We have to keep the kitchen cupboards locked and put all the knives away. We have to lock the doors of the house. We have to make sure she doesn’t run out in front of cars on the road. She gets out of her seatbelt so we have to have a special harness for the car.

As parents we can never relax. We’re always on edge and trying to anticipate the next step.

Georgia full of smiles with Linda and Kevin

‘As parents we can never relax. We’re always on edge and trying to anticipate the next step.’

The daily regime begins early with a nappy change. ‘Even to get nappies for a 10-year-old isn’t easy. You can’t just pop down to the supermarket and pick them up if you run out. You have to plan ahead and order them as it takes a week for them to arrive.’

Once she has dressed Georgia, Linda sits her in a modified high chair and feeds her finely mashed food. ‘Then I do all personal care such as teeth and hair and get Georgia ready for the school bus.’

After school Georgia likes to spend time in her treasured swing in the backyard.

‘Georgia could spend all day in that swing and would let us push her for hours on end. Luckily Kevin is a hands-on dad and is great with her when he comes home from work.’

When Georgia is at school Linda is able to work, managing the promotional products section of her parent’s business.

‘I am fortunate my parents were able to restructure their business to employ me. Before that I had four jobs in two years. I couldn’t hold down a job as I was considered unreliable because I needed time off in school holidays or when Georgia had to go to an appointment.

> *Our friends were great at the time, but as the years have gone on and Georgia’s problems have become more complicated they’ve tended to drift away and don’t exist anymore.*

‘Working in the family business gives me a degree of flexibility for school holidays or when Georgia has doctor’s appointments. It also gives me a sense of self esteem, self worth and confidence and allows me to stay in touch with a different circle of people. In a way going to work is a bit of respite for me.’

Even with that flexibility it is sometimes difficult to cover school holidays and there are few options available for care. ‘Quite simply, with a high-needs child like ours, no one wants to know you.’

This also gives Linda and Kevin cause for concern looking to the future.

They plan to look after Georgia as long as they can, but they are realistic about the fact that they may not always be able to.

‘That’s frightening for us as we have set the bar very high when it comes to the standard of care we provide for Georgia.’

They have both vowed to fight for better conditions and continuity of care for people with disabilities.

‘We want Georgia and others like her to be treated as normally as possible.

‘Everything has been a fight for her and she has earned the right to be here — so we will help her continue to fight.’

in a heartbeat

In many ways Connaire is a typical 15-year-old boy. He loves heavy metal music and his favourite dish is corned beef and mashed potatoes. His moustache is just starting to grow and he can do 'the look' with attitude that teenage boys do so well. And his Mum Lisa says there are times when 'if he had a choice, I'm sure he'd walk five paces behind us all!'

Connaire has severe cerebral palsy. Lisa says his medical 'label' is spastic quadriplegic. He also has epilepsy and asthma. He has survived against the odds.

Connaire suffered a stroke five days before he was born by emergency caesarean in June 1992. He was bruised and had a swollen head from the fluid that had built up in his brain. At just six hours old he began having grand mal seizures and 'everything started going panic buttons'.

For Lisa the following hours were an unreal blur of conversations with doctors, paediatricians and even a social worker.

'They finally took me down to see him in the afternoon and I remember looking at him in this crib going *Well, where's my baby?* I couldn't relate at all.

'Then we saw the neurologist at 11 o'clock at night and at that stage they were saying that the damage looked as though it was quite extensive and he really wasn't going to live 24 hours. So my first major decision as a parent was how to tell our family about this and when to get him baptised and what funeral we were going to have.'

But Connaire defied everyone's expectations by surviving this critical time and then the following weeks.

'I remember sitting down with the paediatrician and neurologist and both of them saying, *Look he shouldn't be here. There is absolutely no reason why this is happening. We don't know what the prognosis is going to be, we'll just take one day at a time.*'

When Connaire was six weeks old, Lisa took him home to Meekatharra, a small country town 850 kilometres north of Perth. It was very hard to be so isolated from her family, but Lisa was grateful for the help she received there. This included visits from the child health nurse and the country Disability Services physiotherapist and occupational therapist, as well as support from the local community.

During those difficult first 12 months, Connaire had early intervention therapy 'until the funding stopped' at which point they tried alternative therapies.

He was also on a strict medication regime and Lisa kept extensive daily records of everything that happened including every bottle and medication because she was terrified that she would forget to give them.

'I remember craving going back to work. I did a stint of relief teaching at the district high school just to get back into something that I knew how to do.

> *So my first major decision as a parent was how to tell our family about this and when to get him baptised and what funeral we were going to have.*

Connaire surrounded by Lisa, his Mum, and Doreen, his Grandmother

I think about the future… where he's going to be, who's going to look after him. Sometimes that keeps me awake at night. If anything happens to me, what can I put in place to make it easier for people?

'My goal at that stage basically was to do country teaching and become a principal. The beauty of that is that's what I've actually ended up doing so I didn't lose that goal but it changed along the way. We did a little side detour!'

Lisa went back to work full-time when Connaire was 18 months old, becoming the family's main breadwinner. School holidays were spent in Perth for medical appointments and to visit Lisa's mother. 'That would be my two weeks respite.'

Eventually the strain of working full-time but having to take a lot of time off to care for Connaire took its toll and the family broke up.

Lisa and Connaire now live with her mother Doreen, in Perth. Lisa still works full-time as a school principal and Doreen helps to care for Connaire before and after school.

'Basically he's 24-hour care because he needs feeding, he's got no mobility at all and there's the bathing and things like that we need to do.'

All Connaire's food has to be pureed. 'We're doing everything we can for him not to be tube fed.'

The bathroom had to be renovated recently including adding a hoist. This replaced the old system which involved Lisa resting her foot on a milk crate in the shower and Connaire sitting on her knee.

On weekday mornings Lisa and Doreen get Connaire ready for school, where he enjoys activities like pool therapy and shopping trips. 'They've discovered if they can do some shopping and get some cappuccinos into him then he's happy.'

Doreen looks after Connaire after school until Lisa gets home by around 5.30pm. Then it is time for the bath and bed routine, which includes burping Connaire before he goes to sleep. 'He's discovered with me it's a rip off because I just pat him on the back and go, *Burp, that's it* whereas Mum sings him songs and tells him stories and all those Nanna things.'

Conniare might be non-verbal, but Lisa says he understands everything. 'It's more his eyes that communicate with you. But I tell you, you know when you're in the bad books!'

They share a 'warped sense of humour'. In particular Connaire loves slapstick. 'People falling over, he'll laugh at. He's at that 15-year-old boy stage where he'll burp and laugh. He thinks things like that are hilarious and of course he'll do it, like all kids, at the most inappropriate times.'

Lisa's own trademark humour and her love of gardening, quilting and sewing have also helped her cope — along with her work.

'I work full-time and I think that quite often that's enough to keep my sanity going. You can quite often just switch off with what's happening at home and just focus on something else.

'I can cope with most things, and I think being a principal of a school you learn that you just keep everything under control. Like emergency situations I do really well until someone says to me, *And how are you?* And that's generally when I start crying and the knees go and I fall apart quite nicely then.'

Over the years, there have been several emergencies and close calls. Twice, Connaire has almost died after catching the flu. 'Doctors have always said as he went along further that his big downfall is going to be his chest. In a heartbeat Connaire can go from being perfectly happy to sick. That's how quickly his asthma will come on or a chest infection will come on. In a heartbeat, things can change.'

One of the biggest changes for Lisa since having Connaire is that she had to stop planning. 'Even now, he's 15 and in three years he finishes school and I need to work out what I will do work-wise and what I'm doing with my superannuation and things like that. I find it really frustrating because he should be here, but we just don't know.

'I think about the future… where he's going to be, who's going to look after him. Sometimes that keeps me awake at night. If anything happens to me, what can I put in place to make it easier for people?'

For now, Connaire is enjoying school. 'He is very much accepted in the school and local community. You'll go out walking and people will stop and talk to him and talk to you.'

He also enjoys special relationships with his family.

'When we can have all the family together it's very, very special. Connaire gets his message across to every member of our family. All of them have a time when Connaire has touched their hearts — they just all love him to bits.

'He gives us back all the unconditional love you can cope with — he just oozes love. Those times when I'm thinking, *Oh, how am I going to go on?* and you look at him and the message in his eyes is, *I understand, it's okay.* Just that feeling, that communication there, that's a big thing I get from him.'

Living with Connaire has also taught Lisa patience. 'I have patience which as a classroom teacher I never had. And I listen. I actively listen a lot more to what people say.

'From Connaire the big message I've really learnt is that all kids have a potential. And it might not be one that we think it is, but everyone's got a potential for something.'

a ride into the unknown

When their second son Lachlan was born with uncontrolled epilepsy, Megan and Robert plummeted into the unknown.

'All of a sudden you are thrust into a world where doctors and nurses talk a whole different language and you're often too frightened to ask what they mean because you're afraid of the answer,' says Megan.

The couple's first child, Ben, had been a healthy baby. Megan instinctively knew something was wrong with the second pregnancy.

'I felt some unusual movements during the late stages, which we now know were seizures.'

But nothing prepared them for what was to come.

'Instead of taking our new baby home we faced an endless series of medical tests and hospital visits and had to accept our child was far from "normal".

'He was having seizures and it was totally devastating. We had no control. Everything was out of our hands because the doctors and nurses were looking after him and trying to diagnose his condition.

'The whole experience was frightening. The special care nursery was sterile and our baby was undergoing tests like spinal taps. It was just so far removed from the lovely experience we'd anticipated.

'While it was surreal for me, it was very hard on my husband Robert, who also had to look after Ben, who was only four at the time. The reality didn't really hit him until I brought Lachie home.'

Initially both parents hoped Lachlan might 'grow out of it'.

'We thought we were only dealing with uncontrolled epilepsy and didn't know the full extent of his condition until he didn't reach his milestones.'

Lachlan was finally diagnosed with global development delay, which affects all areas of development. He had such severe reflux and feeding problems he had to undergo surgery to have a gastrostomy button inserted into his stomach. He also has impaired vision which adds to his developmental delay because he sees so little and has no incentive to reach out for things.

'We are pretty grounded people and accepted things from the word go. However, you still cling to the hope they will find a drug to stop the epilepsy and give his brain a chance to develop better.'

As Lachlan grew the seizure patterns changed and became more physical.

'Sometimes they hurt him and he cries. It's nothing for him to have 40 seizures in a day.

'We accepted that we would have to take things as they came. It was hard because he looked like a normal baby. When he started rolling at 12 months old it was great. Now he's four and he's still lying on the ground. He can't sit unassisted or communicate at all.

Lachlan supported by Megan and Robert and a dotting Grandma

Instead of taking our new baby home we faced an endless series of medical tests and hospital visits.

It's emotionally difficult but you can't let yourself get too low because you have to keep going.

'It's emotionally difficult but you can't let yourself get too low because you have to keep going. Burying your head in the sand isn't going to help.'

Megan and Robert have made sure that Lachlan's older brother Ben, now nine, has been a part of things from the beginning.

'We didn't want him thinking he was getting pushed aside because of Lachie's problems so we always took him when we had to go to hospital in the middle of the night. We made sure we explained as much as we could to him.

'Ben is such a good little soul. He absolutely adores Lachie and is wonderful with him.'

The family is also fortunate to have an extensive support network of family and friends.

'I have a wonderful husband, great sister, terrific mum, a loving family and good friends who I can ring and say, *I've had a shocker of a day* and have a big cry.

'We have a diverse extended family, but it's brought us closer together and made us realise material things aren't important.'

Not everyone is as understanding.

'If Lachlan has a seizure when I'm out shopping people almost do a back flip to get away from him thinking they might catch it.

'Even during the times I spent time in hospital with him I got tired of explaining to other parents what was wrong with him, so I got to the point where I'd just draw the curtains because I didn't want to pour my heart out to strangers.'

Back in the security of his home things are different. 'We have a very open house so the kids in the neighbourhood come to see him all the time.'

Lachlan is often the centre of attention.

'What is really special is seeing my Mum, who is 83, rolling around on the floor and cuddling him. She just adores him.'

The family does worry about Lachlan's future.

'When he gets older and bigger he won't be as cute anymore and people might change towards him.

'I haven't even touched on what services are out there for him when he's a teenager or beyond. I just can't get that far because it would become too depressing.'

However, they are preparing for the immediate future and modifying their home to accommodate a wheelchair, which means reducing their four bedroom house to three bedrooms.

'He's getting quite hard to manage. Even though he only weights 14 kilograms, it's a dead weight and it's becoming more difficult to get him in and out of the car, so we are waiting on a wheelchair.'

Lachlan still has lots of medical appointments but is able to go to early intervention learning one morning a week and pre-school another half-day.

'I had to fight to get him into a normal pre-school. Looking after Lachie has made me more assertive because I have to be.'

But Megan is quick to reject any notion that she is a super mum.

'I'm just a mother who is coping with a disabled child because he's ours and we have no other choice.

'But I wouldn't change anything because our lives are so enriched.'

an unconditional investment

Jodie and Colin have given up a lot since their daughter Emily was born seven years ago with spastic quadriplegic cerebral palsy — but they say they have also gained so much.

'We have her unconditional love,' Jodie says. 'She's such a happy kid and wakes up every morning in a good mood. She hardly ever gets upset.'

When Emily was born 11 weeks early her parents were warned there was a high risk of cerebral palsy. They had no idea how badly she would be affected, but they resolved they would do the best they could by her.

'She had to fight for the first six weeks of her life just to survive and we decided we would do whatever it took for her to have a good quality of life. If that was going to mean pushing her around in a wheelchair then we would do it.'

For Jodie, it meant giving up her successful career as a financial planner's assistant and for the couple it meant selling their new home.

'We had built a house before Emily was born but it was unsuitable for a wheelchair. So we had to sell and build a new home, which put a huge financial pressure on us.'

Unfortunately, they sold just before a boom in the housing market. 'If we had sold it six weeks later would've got an extra $100,000.'

In some ways dealing with the financial strain has been tougher than handling Emily's condition.

'The expense is the hardest thing to cope with, especially with all the equipment you have to buy. For example, we have a specially modified car which will cost us in excess of $50,000 to replace. It's really hard bearing in mind that we are a one-income family.'

Jodie and Emily travel 1,000 kilometres from Mackay to Brisbane every few months for medical appointments. As Emily grows she needs surgery to relieve muscle tension in her limbs as well as corrective surgery.

'Because of the equipment that Emily needs, we mostly have to drive and that's time-consuming and expensive. On the last trip we were away for four days for a four-hour appointment and it cost us $1,500.'

But all the time and money they have invested in Emily has been worth it.

'Through all the operations she's had to undergo she never says anything about the pain and always comes through with a smile on her face. After one operation she was in a half-body cast for six weeks and not once complained. She is one of best patients you could ask for. She's such a great kid. She just happens to be stuck in a body that doesn't work.'

Emily cannot stand unassisted and has very limited use of her hands, so requires assistance to do everything including bathing, toileting, dressing and eating.

'With the constant attention Emily needs, the only time I have for normal home duties is when she is at school. This, together with regular trips to Brisbane, makes it impossible for me to work or study.'

> *She had to fight for the first six weeks of her life just to survive and we decided we would do whatever it took for her to have a good quality of life.*

Jodie takes time out to play with Emily while her baby brother Liam sleeps

'My husband works 38 to 45 hours per week, which leaves him little time to do things at home, and being a single-wage family we cannot afford to pay someone to do the trivial jobs such as mowing the lawn.'

As Emily grows she is becoming heavier and more difficult to manage. The couple have not found it easy to access respite care because of the level of training needed for Emily's particular needs.

'If we can't get help we do not go anywhere, which is often the case.'

Jodie's father used to be a great help, but he passed away 18 months ago with Motor Neurone disease.

'My mother and sister are all I have, and my sister has two young children of her own. Having Emily in a wheelchair makes it difficult to call on anyone else to collect her from school or accompany her to appointments.

'We lost most of our old friends when Emily was diagnosed. We do have new friends, in particular two families that we are pretty close to, one through school and one through swimming.

'It's good to be able to bounce ideas off each other and you can also help each other find out what services we can access, because it's not always that easy to know what's available. However, they have their own problems and are also under a lot of pressure so you can't ask them for help.

> *In some ways dealing with the financial strain has been tougher than handling Emily's condition.*

'But while it does get hard we are happy to do it for Emily. If we didn't do it she wouldn't be at the stage she's at now. She'd be curled up in a ball in the corner.'

Due to their efforts Emily is a switched-on child with a cheerful disposition and an amazing memory.

'She doesn't forget a thing. She remembers what people gave her as a birthday present years ago!'

She loves the outdoors and swimming, so much so that the family put in a backyard pool, even though they could not really afford it.

'After seeing what a difference just two swimming lessons made I came home to my husband and said, *I don't know how we are going to pay for it but we have to put in a pool.* It has made such a huge difference and it helps so much with her physio.'

Jodie and Colin do not know what lies ahead for Emily and that was one of the reasons they decided to have another child, Liam, who was born in mid-2007.

'Losing my Dad pushed me a little because it made me think about what would happen to Emily if we weren't around. It's not that we want Liam to be her carer, but more to be a companion and someone who can keep an eye out for her.

'It was something we couldn't contemplate until Emily was at school and we gave it a lot of thought.'

The early part of the pregnancy with Liam was very stressful for Jodie, who was constantly worried about the baby.

'I was worried he might be premmie too and counted every day of the first 29 weeks. Once I got past that I knew every week was a bonus.'

Jodie and Colin say they have grown so much because of Emily and they are now looking forward to continuing on that learning curve with baby Liam.

'We are both a lot stronger, you have to be. I appreciate kids in general and have great admiration for parents of special needs kids.'

as fragile as butterfly wings

His personality might be as cheeky as a monkey, but Connor's skin is as fragile as butterfly wings. The eight year-old has Epidermolysis Bullosa (EB), a rare genetic skin disorder characterised by fragile skin which blisters after the slightest trauma or friction. The condition also affects the eyes and the mouth so that even exposure to wind can cause pain. EB is a permanent condition with no cure.

Ever since Connor was diagnosed his parents Michael and Bree have been on a quest to find out everything they can about the condition.

'When we were given the results by our dermatologist he wrote the name on a piece of paper and sent us on our way,' says Bree. 'It was even misspelt. We then had to find out for ourselves what it really meant. We went to the Internet and it all became clear.'

'The Internet can be useful but it can also be a very scary place,' Michael says.

Connor needs 24/7 care and most of the load falls to Bree, allowing Michael to keep working to support the family.

'It is a very difficult condition to deal with. They are called cotton wool babies or butterfly children as their skin is so fragile,' Michael says.

For Bree one of the hardest things to deal with is the fact that Connor is often in so much pain. 'He has a lot of raw areas which cause an awful lot of pain. He has to take morphine to control it. It's not often you get through the night without him waking up.'

Connor's care is complicated by a tracheostomy to help him breathe, a gastrostomy for overnight feeds, medicine, and a catheter for toileting. All Connor's clothing has to be modified so that everything is flattened down, including the seams. Sometimes he needs a wheelchair to get around.

'Just bathing and doing dressing changes can take up to three hours. Family support is limited because he cannot be left with anyone who hasn't been specially trained in his care. Many respite or carer agencies do not have funding or staff trained to take on the responsibilities of Connor's high medical needs,' Michael says.

The daily routine begins at 6.45am when Connor needs a nebuliser for 40 minutes to clear his airways. EB can also affect internal organs and in Connor's case his upper airway is completely obstructed.

'Then he'll have to do his toileting, which has to be done carefully as he has a lot of tubes. This can be trying because he has chronic constipation as part of the condition which is not always helped by his medications,' Bree says.

'Then his top of the line silicone dressings, which are similar to burns-type dressings, around his neck and body have to be cleaned and changed, which takes an hour-and-a-half. After having something to eat it's off to school.'

The best and most effective dressings are very expensive and not all covered by the health system. Michael says many families living with EB spend hours trying to secure dressings and funding to pay for them, settle for less effective ones, pay for it themselves, or go without.

Connor needs 24/7 care and most of the load falls to Bree, allowing Michael to keep working to support the family.

Full of smiles — Connor with Michael and Bree

Connor attends a mainstream school but Bree has to be on call. She has unsuccessfully tried to find paid employment that is flexible enough, but has not even been able to manage volunteer work. She is now studying when she can fit it in at night.

'The school often calls if something is wrong and I'll go up there a couple of times a day. Luckily we live very close.'

After school Connor needs another nebuliser and more medication. 'He's really exhausted when he gets home and just lies on the lounge,' she says. 'We hook him up to a feed through a kangaroo pump like they have in hospital to give him some nutrition. Then we will tackle the homework.

'On the afternoons where we have to bathe him that takes about two to three hours because he has to have his bandages soaked off, which is very painful.'

Michael and Bree have tried to make Connor's life as normal as possible so they encourage him to have friends over and let him go out to play if the weather is okay.

'He might just ride along in his wheelchair. The kids in the street push him up the hill and down, which is kind of scary for us,' Bree says.

'Then he'll come in and have dinner and then more dressing changes, medication and toileting. That's a good day. We also often have to fit in appointments as he has about 17 specialists.'

> *On the afternoons where we have to bathe him that takes about two to three hours because he has to have his bandages soaked off, which is very painful.*

Connor is about to have a big change, with his parents deciding to move him to a new school where they believe he will have more opportunities to learn.

'Education is going to be the way ahead for him,' Michael says. 'He is going to need higher skills so he can take part in the workplace when he is older.'

While it will be hard for Connor to leave his friends behind, his parents believe he will quickly fit into his new school.

'He's very social. He's a bit of a larrikin and he's there to entertain. We've found other kids have been great accepting him,' Bree says.

It has not always been the same with adults, according to Michael. 'Reactions in public can be dreadful. One example was when I was in a video shop when Connor was only five and the guy asked what had happened to him. I told him he had a rare condition and he said, *That's a good story mate, stick to it.'*

Educating people about EB is something Connor's parents are passionate about. Michael is president of the support group DebRA Australia (www.debra.org.au) and spends at least 20 hours a week lobbying for improved services.

'The support group is just so important to parents like us. The networking alone provides you with as much valuable information as any text book or doctor can ever give you. Some days you can talk until the cows come home to educate people about EB… and other days someone will say something and you spiral into depression and defeat,' Michael says.

But both Bree and Michael try not to focus on the negatives.

'We value life more. Sure there are times I wish things were simpler, but we are blessed to have Connor,' Bree says. 'It's opened up a world to me. In the early days I used to think it was all too hard and I'd be really intolerant of people. I don't have time for trivial complaints and I'm really impatient and I don't like that about myself. You have to pull yourself in sometimes.'

Connor's own cheeky personality and outlook on life are a big help.

'He's a scream. His sense of humour is unbelievable,' Michael says. 'He is also very thoughtful and he'll ring me from a specialist's appointment to reassure me everything's okay and that's so precious to me. There are other times where he'll be watching a DVD or playing XBox and he'll ask me to sit with him. That's also special, because I can't go and kick a footy with him.'

Bree and Michael have learnt to let Connor find his own boundaries. 'It took us a long time to learn that. There were many times we'd be peering out the door watching him play with the other kids. You learn not to look,' Michael says.

Bree has made a point of exposing Connor to a range of experiences. 'Even when he was a baby he's done all the things everyone else has but I've spent more time cultivating each experience,' she says.

'Now it's amazing to see him mixing with people. He's very good at it. He can just blend in and I think life will be okay because he knows how to fit in. He's always looking out for others. He doesn't waste time on self pity. He can also be very naughty… He'll give them hell at school if he doesn't want to do something and he will speak up for himself. And that to me is good. No-one will walk over him. These are the skills he is going to need to get by. Hopefully we are taking him where he should be.'

the angel at the centre of our world

Odette believes she is blessed to have a special child who will always be her affectionate baby. Ten-year-old Lochie stopped developing when he was just four months old, but none of the medical experts know why and the underlying condition is undiagnosed.

‘He is my angel, who has the best smile in the world and a brother and sister who cherish and adore him beyond words,’ Odette says.

‘I feel so blessed to have Lochie. He can’t be naughty. He is the most perfect little being. Everything is so innocent with him. Not many people get the opportunity to cuddle their child forever.’

When Lochie was four months old he had a major seizure and was in a coma for two days in the Intensive Care Unit (ICU) at the Royal Children’s Hospital in Melbourne. He was initially diagnosed with epilepsy, but it became obvious that his condition was far more complex.

‘Our world changed at this point. He stopped developing and the search began for answers.’

There has been little change in Lochie’s development over the last 10 years. He is a 22 kilogram boy who cannot support his head, has spastic quadriplegia, has no speech and cries a lot through the night with cerebral irritations.

‘He didn’t ever babble like other babies or crawl. He can’t sit up independently and needs to be reclined so his head doesn’t fall forward.

‘He has been airlifted to hospital countless times, often ending up on full life support in ICU.’ Each time he comes out of a coma he has had a stroke and now requires a gastrostomy feeding tube.

Caring for Lochie is a full-time job for Odette, who has a background in nursing. She even has to sleep with him to make sure he gets through each night. ‘He can have a seizure so easily and the only indication is that his right eye blinks for a while. Then he’s unconscious and stops breathing.’

His condition deteriorated after hip surgery in June, when he had a stroke which affected the left side of his body. He is often in pain and some nights he only sleeps for two hours.

His medical conditions are complex. As well as epilepsy he has cardiac problems, an ulcerated oesophagus and asthma. He has bouts of vomiting so severe he brings up blood. He also is susceptible to chest and ear infections.

‘I try to look on the bright side. We live in the present and focus on making the most of every day.’

Odette has adopted a phrase that is written above the gate to the Starlight Garden at the Children’s Hospital which reads: Carpe Diem, or ‘seize the day’.

He can have a seizure so easily and the only indication is that his right eye blinks for a while. Then he’s unconscious and stops breathing.

Lochie at school with his siblings, Joeltyn and Skyler, and mum, Odette

I feel so blessed to have Lochie. He can't be naughty. He is the most perfect little being. Everything is so innocent with him. Not many people get the opportunity to cuddle their child forever.

It has not always been easy for Odette to be positive, particularly when her husband left her four years ago after 15 years of marriage.

'Financially it has made things difficult but the children and I are desperately trying to stay in our family home, which suits Lochie's needs.

'His costs are enormous — the trips to the hospital, medications three times a day, wheelchair, nappies — it's endless and all consuming. My car is old and becoming unreliable but a wheelchair van is out of the question at this stage.'

The marriage break-up was followed by a period when Lochie was particularly sick and had been airlifted to Melbourne four times in the space of six months.

'I had to get my act together to be stronger for everyone. Now we are in a much happier place but it took a while to find our feet. We live in a small community in Flowerdale, an hour-and-a-half from Melbourne, and people have really embraced us in a gentle way. The support has been wonderful.

'We are surrounded by many loving friends, who help me with babysitting when Lochie is in hospital. Unfortunately my parents live interstate and cannot offer the support they would like to give.'

Odette draws great strength from her other children, 12-year-old son Joeltyn and seven-year-old daughter Skyler.

'They have such an amazing connection with Lochie, who just loves being cuddled. Like everyone who gets to know him, they think he's an amazing little boy.'

Joeltyn and Skyler have had to grow up more quickly than other children. 'They've had to deal with lots of difficult things. Joeltyn is not your average 12-year-old. He can do a full gastrostomy feed. He knows how to do CPR. He's liaised with ambulance officers over the phone while I've been breathing for Lochie.

'I can't even begin to explain the closeness they have with Lochie. It's the most beautiful thing. Both of them love him so much. They are very tuned into him and know when he is sad or happy or in pain.

'They've also had to put up with a lot because we still try to go out and do things together as a family. This means wheelchairs on the beach, gastro feeds in public and things people aren't used to seeing.'

The family recently had a chance to spend a week together at the Gold Coast thanks to the Make a Wish Foundation.

'We went up to Queensland to do all the theme parks and it was the happiest week of our lives. It was something I couldn't ever have afforded to do. The kids didn't stop smiling for a whole week. We will never forget it. Lochie just loved it.'

Odette also has a very close friend, Annie, who has been hugely supportive.

'Annie has been there for me during all the difficult times. I met her at a parenting course when we first moved to Flowerdale and we connected straight away. She'd had experience caring for children with disabilities and now she works with Lochie four days a week at his school.'

When Lochie was in a coma Annie stayed with the family at Ronald McDonald House and looked after the other children.

'Lochie stays with her one night every month and she knows as much about him as I do. It is amazing to have such a person in your life. It takes the pressure off. She also comes to all the medical appointments so I don't forget things. When she can see I haven't slept for a couple of days she takes Lochie for a night. She has given me my strength.'

Lochie has a special bond with Annie, who is his integration aid at school. 'He just loves going to the local school with his brother and sister. Annie gives him one-on-one care.

'All the other kids love him to death and they all want to push his wheelchair. It's been a great thing to watch a whole generation of Flowerdale children growing up accepting a child with a disability and understanding that is not such a terrible thing.'

Without a diagnosis it is difficult to know what lies ahead for Lochie. He has vitamins and enzymes three times a day in an effort to slow down the episodes of epilepsy, coma and stroke.

'I watch, wait and hope that my beautiful boy does not have to endure any more painful procedures to his fragile body. He feels the cold terribly now and nappy changes are enough to make his heart rate suddenly drop dangerously low. He is unable to have further surgery due to the effects of the anaesthetics on his body.

'Lochie is the centre of our world. We are just so close and so connected. He gives us so much raw love. He communicates with his eyes. He's completely changed my life and the lives of everyone around him.'

a boy called Bodey

Most mornings 10-year-old Bodey wakes before the rest of his family, cheerfully calling out 'Hi Bodey, Bodey…' until someone answers him.

Bodey, short for Beaudaniel, has cerebral palsy, an intellectual disability and is visually impaired. He needs a wheelchair and has high medical needs due to epilepsy, a shunt and gastronomy tube.

His parents, Pamela and Dario, had everything planned before he was born, 'right down to the room decked out ready'.

The first sign of anything unusual was Bodey's large head size at birth, measuring 40 centimetres. 'Because there were so many people coming to us all the time and checking him we knew something wasn't right,' says Pamela.

'But to us he was the most beautiful looking child in the world because he was ours. He still to this day is a beautiful looking boy.'

Within a few days Bodey was sent for a CAT scan 'just to rule anything out'. But straight after the scan he was transferred to another hospital.

'That was hard for Dario because it was like his whole world had been taken from him. I had to go in the ambulance with Bodey and he couldn't. The ambulance was going at a certain speed and he couldn't keep up.'

Bodey had been born with gross hydrocephalus or fluid on the brain. Due to a blockage between the two ventricles of his brain his head was increasing in pressure. Arriving at intensive care, Pamela was told Bodey would need brain surgery to insert a shunt.

The surgery went well but the specialist couldn't say what the future held for Bodey. The couple was told their new son might have a 'vision problem' down the track but that all they could do was 'take him home and wait and see how his life turns out'.

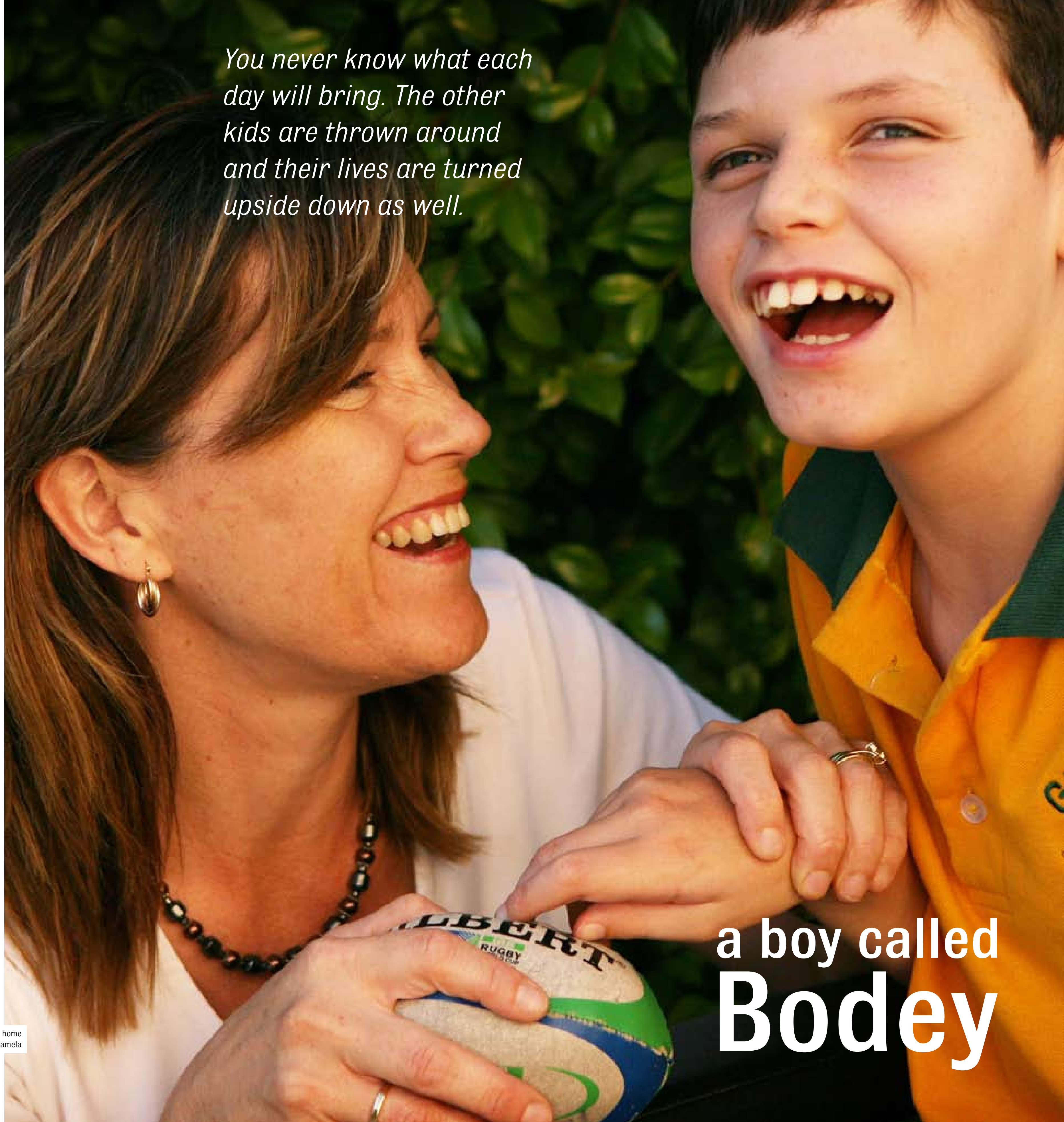
The complexity of his conditions was clear by the time he was 18 months old. From very early on, Pamela and Dario have had to work around Bodey's various hospital visits and appointments including regular physiotherapy. 'He wouldn't be where he is now if we didn't do what we did.'

An aircraft engineer, Dario does shift work. He worked nights up until Bodey was six. Now he does long-day shifts, four days on and four days off. Pamela gave up returning to her career as the director of a childcare centre. She now does supply teaching during Dario's days off. 'Basically that's what I have to accept otherwise I'd have to pay for carers to come after school and it wouldn't be financially viable.'

Other expenses include Bodey's equipment, medication and a new house, built to cater for his special needs.

For Pamela and Dario it was a 'huge decision' to have more children. They had extensive tests along the way and now have six-year-old Kiarah and four-year-old Caden. 'We were so grateful and we couldn't be happier.'

You never know what each day will bring. The other kids are thrown around and their lives are turned upside down as well.



Bodey at home with mum, Pamela

Like most parents, Pamela and Dario juggle the different needs of their three children. But their caring role for Bodey goes beyond usual parenting. He needs help to go to the toilet, shower, get dressed and eat.

His concentration span is limited to about five minutes unless he has adult interaction. He can't see the television and has no interest in listening to it.

He does love playing with his football, however. 'He'd happily throw it with someone 24 hours a day if he could! He also likes wearing hats and listening to music. It's still often the *Wiggles*, but we're gradually branching out into other music as well.'

Bodey chooses not to drink, so needs five tube feeds of fluid along with his medication each day. As he grows it is becoming harder to lift and transfer him or to visit places that don't accommodate his wheelchair.

When Bodey has to go to hospital, for example to replace his gastrostomy button or if he has a major seizure, he becomes distressed if one of his parents isn't there with him. 'He doesn't understand what is happening — his lack of communication and his vision impairment requires one of us to be at his bedside around the clock.'

Such concentrated time together means his parents have come to trust their own judgement about Bodey's health. 'We've learnt if we don't feel something is right, we just say it. They may be the specialist but they don't know your child like you do. We've learnt to stand our ground a little bit more.'

> *You will go that much further and miss out on things yourself to make sure he doesn't miss out. Sometimes it means running yourself a little bit ragged, but you just do.*

Other challenging times include school holidays when Bodey can't go to his special school. 'He loves it. He loves the routine of it all. Because he's intellectually impaired as well, he just doesn't understand the change of routine. School holidays can be challenging with Bodey often saying, *Ool, ool!* and you're saying, *No not today mate*. He does get bored and I think he misses the company of the other kids at school.'

And when Bodey gets bored, he has no trouble letting his family know. 'He'll start dribbling or making annoying sounds. The dribbling drives us insane because he does it to get attention. It will be like a tap.'

Due to his cerebral palsy, the right side of Bodey's mouth doesn't close properly. A saliva redirection procedure four years ago has had about a '50 per cent success rate' but Pamela says 'he's just so determined behaviourally. Where there's a will there's a way!'

While it is demanding caring for Bodey, Pamela says they would do anything for him.

'You'll go out on that extra limb. You will go that much further and miss out on things yourself to make sure he doesn't miss out. Sometimes it means running yourself a little bit ragged, but you just do.

'People always say, *I don't know how you do it*. But it's just that you don't know any different. Some days I wish I didn't have to do it, but I do. You've got to focus on the positives. Otherwise, if you dwelled on all the negatives you'd never get up in the morning. You've really got to look at what you do have.'

Pamela and Dario really appreciate the support of their own family members, some of whom live nearby while others are interstate. They also enjoy a strong circle of friends. 'We still have a very good social life but we tend to do it more as a family. We're determined not to shut ourselves away… I've learnt to be tougher now when people look or say things.'

Very occasionally Pamela and Dario organise carers so they can have a weekend away together. 'We don't want to lose sight of why we got together at the start.'

And this is something that keeps them strong. 'We know that there are a lot of single parents due to a having a disabled child. We just both know that we're a team and we couldn't do it on our own.'

Bodey's long-term future is their main concern. 'As we age, will everything be in place for him? And we know that no-one will ever love him like we do.'

Pamela is also sometimes concerned about the impact on her other two children. 'You never know what each day will bring. The other kids are thrown around and their lives are turned upside down as well.'

She doesn't want them to feel that they miss out on things because of Bodey. And while she tries to make time for each of her children it doesn't always even out, especially on the weekends when Dario is working. Like the recent occasion when Kiarah was invited to a friend's party.

'She said to me, *Does Bodey have to come?* And I said, *Well this is life darling, this is our family*. I was shattered. She's always been such a helpful child. The more I thought about it the more I realised it wasn't that she was embarrassed — she just wanted some time with me. But that's all part of their childhood with him.'

It's a childhood with plenty of love from their brother Bodey. 'He's very affectionate and he always wants kisses and hugs. He really loves his brother and sister. And they are so good with him — spending time with him and helping out in so many ways. There are some kids strapped to their chairs who hardly respond. Bodey can say, *Hi how are ya?* Repeated over and over again, but he can say it! He's very social. In a lot of ways we're lucky. He smiles, he laughs… he gives us all so much back.'

Raphael in charge

Any parents coping with three children under the age of five would find daily routine a challenge, but for Paul and Annie every day is a marathon.

As well as four-year-old Faith and three-year-old Zachariah, they have 18-month-old Raphael, who has CHARGE syndrome and needs special care round the clock.

'We have to be very organised, with a set routine and forward planning,' Paul says.

Paul and Annie both work part-time so they can manage. 'I look after the children from Saturday to Tuesday and Annie does it from Wednesday to Friday,' he says.

The couple thought they had prepared for parenthood, doing lots of research so they could raise their children well, but nothing equipped them for dealing with a special needs child.

'As soon as Raphael was born we knew something was wrong as he had a crooked mouth and ear and when he cried it was very raspy.'

It was 10 months before they were given the diagnosis of CHARGE syndrome, which is extremely complex and involves extensive medical conditions.

'For us having a label was a relief, because we are both confident people and once we knew what we were dealing with we knew we could start to help Raphael.'

Each initial of CHARGE stands for a different condition: C — Coloboma of the eye, which can lead to blindness, H — Heart defects, A — Atresia of the choanae, which means the nose is sealed shut, R — Retardation of growth and development, G — Genital abnormalities and E — Ear abnormalities and deafness. It varies from child to child and there are also other associated conditions.

Raphael has no sense of balance and his vision and hearing are severely affected.

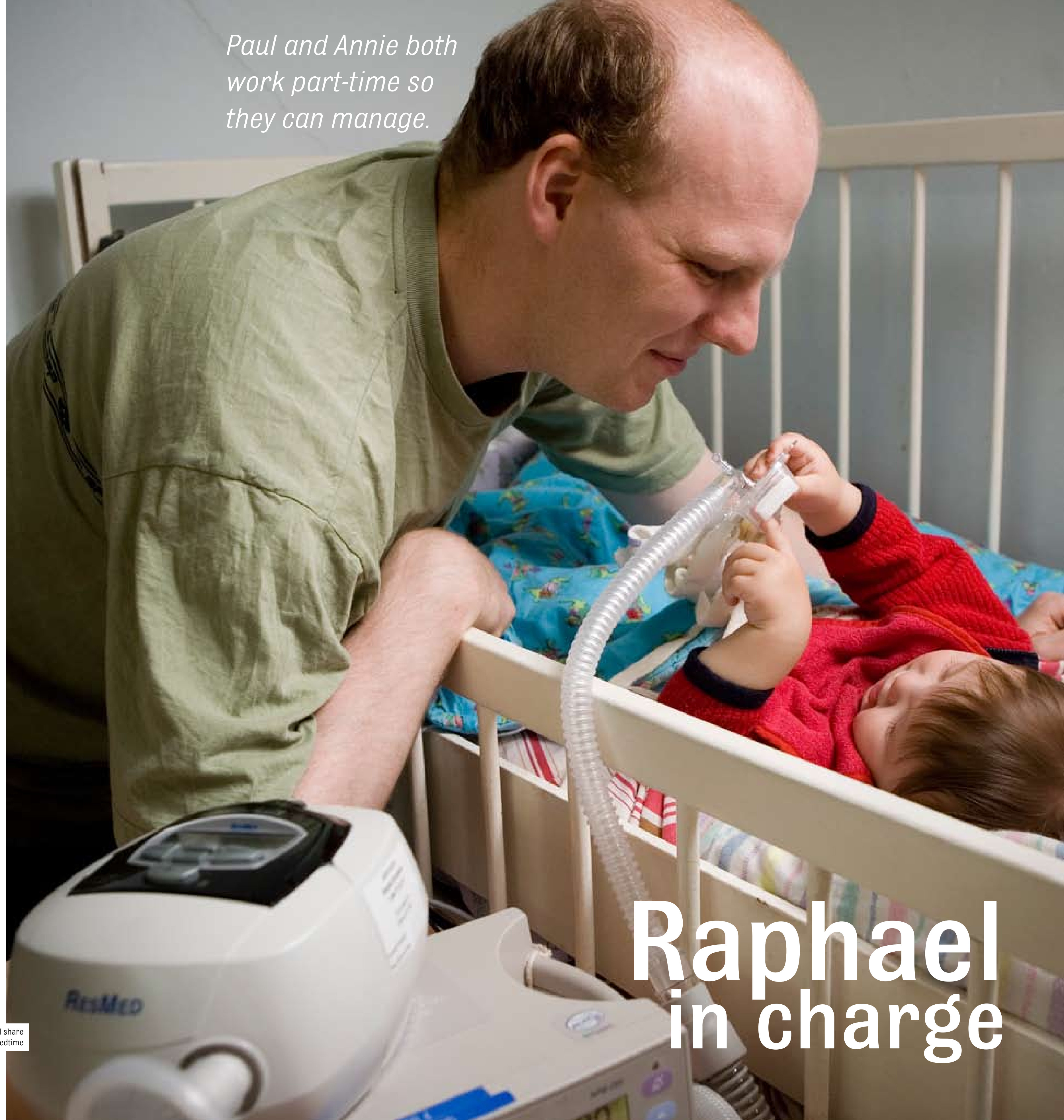
'We try to put him in hearing aids for most of his waking hours, but because his best ear is a funny shape the hearing aid doesn't lock in properly so it often whistles, which means he's not hearing anything at all.'

He has severe breathing problems and a minor heart defect. His growth and development has been slow and he has difficulty eating. 'He wasn't putting on any weight for a long time and we had to end up tube feeding him through a nasogastric tube, but that caused all sorts of other problems and he got sick a lot. So we have just recently started to feed him solids and milk to see if he can cope, otherwise he will have to have a more permanent (gastrostomy) tube placed directly into his stomach. We aren't keen on this idea because of developmental delays caused by tube feeding and his elevated surgical risk.

'Raphael is coping with his feeds, but it is very time consuming because he eats slowly and chokes and vomits easily.'

He has a schedule of 10 small feeds a day, which is complicated by the fact that he is often not hungry and he does not like the enriched formula necessary for his nutritional needs.

Raphael also suffers from sleep apnea and needs a blood oxygen monitor and CPAP machine to keep his airways open when he sleeps.



Paul and Raphael share some smiles at bedtime

Paul and Annie both work part-time so they can manage.

> *Alarms go off multiple times each night and we have to get up to check. There's only been two occasions in the last two months where we have had a whole night of undisturbed sleep.*

'Alarms go off multiple times each night and we have to get up to check. There's only been two occasions in the last two months where we have had a whole night of undisturbed sleep.'

Once he is up and disconnected from the equipment it is time for his first feed.

'I make sure the other kids have had breakfast and then get them doing an activity while I feed Raphael. Because he throws up so much I cover myself in cloth nappies. I'm an interesting sight! He has a bottle of high energy formula, which tastes disgusting. Then I feed him pureed solids, because anything lumpy makes him choke and vomit.

'After breakfast he'll watch a bit of television with his brother and sister and then it's usually time for another feed and morning tea for the other kids. He then has a sleep, but I have to keep the other two occupied while I connect him to the CPAP machine because it is quite traumatic and they get upset. While he sleeps I try to read to Faith and Zac.

'When Raphael gets up he's supposed to have another feed, although he usually just licks the top of the bottle and gives it back. So I give him custard or yogurt while the other kids have activity time. We have pictures on the wall showing them the different things they can do.

'Then it's lunchtime for the other kids and Raphael tries to raid their food, but we have to stop him because it makes him choke and vomit.'

The sleep and feeding pattern is the same in the afternoon then at 5pm the family sits down to dinner together.

'After dinner we do a family activity. This might be a game but we also do things like first aid, making it fun for the kids. This gives us a chance to practice what we would do in an emergency situation with Raphael. We also practice Auslan (Australian Sign Language).'

While his parents hope Raphael will be able to speak, he needs to learn sign language because he may need to rely on it when he is having breathing difficulties.

Raphael has to be weighed each Monday. 'We record every feed he has right down to the last drop to make sure he takes in adequate calories during the day.'

On other days Faith needs to be walked to kindergarten. 'We usually stop in the park on the way back for a play.'

There are also endless medical and educational appointments. 'Not a week goes by without a couple of appointments. We use eight educational and 22 medical professionals. Our busiest day so far involved eight appointments finishing at 11pm. Often the appointments are so important that we spend the whole evening before preparing questions.

Afterwards we go through an audio recording of the appointment to make sure we have understood everything. We write notes and do follow-up research if necessary.'

Because of the complexity of Raphael's disability both Annie and Paul need to go to the medical appointments. This means finding a babysitter for the other two children.

'Fortunately my mother-in-law is very helpful but we've burnt her out a bit. My parents help too, but I am one of six kids and everyone has their own lives.'

Paul and Annie are public servants and have been able to opt for part-time work.

Paul is a computer systems administrator and Annie is a statistician. However, they have given up on going for promotions while they focus on Raphael and their family.

'Raphael has added so much to our lives. He has brought us closer together. We've also learnt so much through him.

'He often brings us to tears with something he's done, like his first sign, which was, *All done* telling us he'd had enough to eat. Now we know we can rely on him to let us know if we give him another mouthful he'll throw up.

'It also gave us an insight into his mind and showed us he was operating alright, which was amazing for us. He surprises us every week. He has this cheeky crooked smile, which makes him look like he's getting away with something. He does get away with a lot, but because of his multiple sensory impairments we have to encourage him to explore so he can learn, which means he does things the other kids weren't allowed to do, like touch the remote control. But Faith and Zac don't mind as they are a tight little unit and they see themselves as the big kids and Raphael as the baby.

'It has been a real journey together as a family.'

what life offers

‘Look Ralphie, look at the foal’… These were the last words spoken by five-year-old Stephanie seconds before being kicked in the head by the foal’s mother, leaving her severely disabled.

The moment will forever be etched in her mother Paula’s memory.

‘She just adored horses,’ Paula says. ‘The day she was kicked we’d been for a ride together. When we got back I needed to go down to get a mare who had foaled and Steph was determined to come with me. She held my hand all the way there and back, but I let go to pick up the feed bin and she ran around to the back of the horse to call out to the neighbour Ralph. Bang! The mare kicked her.

‘I’ve often been asked do I blame myself and I’ve been through that. I knew she shouldn’t have been with me, but it was an accident.’

The little girl was rushed from the Kojonup Hospital to Princess Margaret Hospital in Perth, 300 kilometres away by the Perth Royal Flying Doctor. She was not expected to live.

‘After five days in intensive care, they suggested she be taken off life support and that she wouldn’t survive. When they took her off the ventilator she breathed by herself, but the prognosis wasn’t good. We were told she wouldn’t have any quality of life.

‘My husband Myles and I decided to take a walk and we went down to a coffee shop outside the hospital and next door there was a stationery store. They had daily saying on a whiteboard and on this particular day it said, *What life offers you today is not what you think you want, it is what you need.* It just hit home for me. We didn’t want this to happen to Steph but it had — and our life would never be the same.’

Paula and Myles have astounded everyone with their strength of character and positive attitude in the 10 years since the accident.

‘The past was gone and we knew we just had to get on with it. We have done it together. We were told it would make or break our relationship, but we pulled together and it has made us stronger.’

The accident left Steph with multiple physical and medical problems including uncontrolled epilepsy, for which she is on three different medications. She also has diabetes insipidus, requiring monthly blood tests to check her sodium levels.

‘We have to regulate her fluid intake and medication. The condition also means Steph has two large urine outputs a day which usually results in a wet wheelchair or bed.’

Due to the incontinence Steph needs to wear special nappies, which are expensive and have to be specially ordered.

She also has palsy in her throat, so is unable to drink. Her fluids and medication are given through a gastrostomy button five times a day. She is able to eat soft, easy-to-chew foods.

‘I quite often have to prepare a different meal to what the rest of the family is having. We choose to feed her, to save on the mess.’

Still fond of horses — Stephanie on the family property with parents Paula and Myles

Because of our remoteness I had to become Steph’s full time physio, OT and speech therapist.

Steph needs to wear a body brace for scoliosis 23-hours-a-day and an ankle and foot orthotic on her left leg.

While Steph does not speak, she comprehends everything. 'We've all had to learn Makaton sign language. She also uses a lot of gestures of her own, which I'm afraid only the family understands. We are also encouraging her to use a Minspeak computerised communication device.'

Before the accident Steph was about to start school and the family had made plans. 'We were hoping to renovate the house and I was going to go back to work in the bank or a local accounting business. But then the accident happened and none of that eventuated.'

Paula still has a job — and that is to look after Steph. 'It's difficult and relentless but I do the best I can. Human biology was always my favourite subject so I had a natural understanding of her medical needs. I'm much more knowledgeable now. Because of our remoteness I had to become Steph's full time physio, OT and speech therapist.'

The family lives in a small rural community 300 kilometres south of Perth and 160 kilometres north of Albany.

'We manage a farm west of Kojonup, which allows us to live and work at the same place, providing stimulation for Steph as well.'

However, this also means regular three-hour trips to hospital and specialists in Perth.

The past was gone and we knew we just had to get on with it. We have done it together. We were told it would make or break our relationship, but we pulled together and it has made us stronger.

'I have to attend regular monthly meetings with her therapists. We attend regular specialist clinics including neurology, endocrinology, rehab, orthopaedic and spinal — none of which can ever be arranged on the same day, let alone week.'

There are no respite services available for the family. 'Steph's needs are too great and complicated. My family were good when she was little, but Mum is now 75 and Steph weighs 45 kilograms, which is too much for her to handle.

'Our family is third generation in the community and I have beautiful friends but everyone is busy with their own lives. However, the acceptance we have is fantastic. I know if I want to call someone and pour my heart out they will be there to listen. That support is important.

'For example the local Lions Club is organising a walker for Steph. They touch you right in the heart with that strength of community spirit. We don't put our hand out for help but we know if we ever got to that point we would have the whole town behind us.'

Myles and Paula work as a team. 'Myles is actively involved in her care. He plans his day so he can help get her ready for school — showering, dressing and putting the brace on. He then gives her breakfast while I pack her lunch, write in the communication book for school and get her medication crushed and into the gastronomy button. She catches the bus at 8am.'

Their 17-year-old son Bayden has also been a great help. 'He has taken it all in his stride. He is far more thoughtful than any other teenager I know.'

Paula misses Bayden now that he is away at agricultural college. 'His help was invaluable — even if it was just playing with Steph or taking her for a ride on the motorbike. He would hold the door open for me, put the wheelchair in the car, bring the shopping in and carry her school bag. I didn't quite realise how much he did for me, without asking, until he went away last year.

'He brought normality into our lives. He'd come home and tell me what had happened at school and I just don't get that anymore. If they don't write in the communication book at school I don't have a clue what she's done.'

Despite the challenges, Paula believes their lives have changed for the better.

'You see the things that are important in life. I'm not religious but I have a spiritual side. I believe I have a better understanding of life and unconditional love.

'On the positive side it's a blessing that we still have Steph, but it's a paradox because caring for her is relentless. There's no let up and every morning when I wake up I know what I'm in for.

'We've got harder times to come, but I try not to go down that track. Steph is 15 now and is incredibly patient and extremely tolerant. She still has the same happy disposition. But we don't know what things will be like when she's 40.

'We take things a day at a time and stay firm in our belief that whatever happens we'll deal with it.'

strength from a smile

'I think I always knew I felt a bit for the underdog, I just didn't know we were going to be the underdogs,' says Rochelle.

Six years ago, Rochelle's life changed dramatically in the space of just five months. First her eldest daughter Georgia was diagnosed with moderate to severe autism with an intellectual disability.

Three months later, Rochelle's husband Scott died. Just five weeks after that, her other daughter Stephanie was diagnosed with a range of disabilities. They include motor and verbal dyspraxia, which manifests in poor muscle tone and poor balance, as well as global developmental delay with an intellectual disability and more recently ADHD.

'It wasn't a good year,' says Rochelle.

With a lot of support from her parents immediately after Scott died, Rochelle somehow managed to keep going.

'I think I'm just stubborn. I probably was ready to throw in the towel to begin with but you realise that no-one else is going to do it.'

While her girls are now eight and six, they are both yet to pass a mental age of around two-and-a-half. Rochelle still feeds, baths and dresses them. They both still need nappies, adding up to around 15 nappy changes a day. They also need constant supervision, in particular Georgia.

'Turning away for just a few minutes can result in Georgia escaping, flooding the bathroom with water or worse still, smearing poo over herself and the home and many other things.

'It's like they never grow out of being toddlers. When my girls are home I don't get to have a shower by myself, I don't get to go to the toilet by myself. I'm still taking things away from them so they don't put it in their mouths.'

Georgia was born after Rochelle and Scott turned to fertility drugs to start their family. 'As someone said I probably brought it on myself because when we were going through the fertility plan I said to God, *I'll take anyone, any baby will do.* He literally took me seriously. Twice.'

Rochelle says Georgia seemed fine until she had a seizure just after her first birthday. 'When she came out of the fit, she wasn't the same child.'

Stephanie's diagnosis was more of a shock because Rochelle initially thought her developmental delays were a reaction to the very stressful period surrounding Scott's death.

Caring for the girls is relentless and exhausting. Georgia sleeps only a few hours a night and is up early, usually by 5.30am.

Mornings are often a struggle. 'Most of the time I walk around behind Georgia trying to get her to eat breakfast because she won't eat it on her own. The next job on a school day is getting her bathed and in a school uniform. This usually proves quite hard work because Georgia only likes to wear purple and her school uniform is blue and she finds that extremely objectionable. I usually end up having to sit on her to get her clothes on and then we place purple over the top. Her poor teacher when we get to school has to take all the purple off. I don't envy her job.'

Rochelle with her daughters, Georgia and Stephanie

Being a carer is hard physical and mental work with no work cover or four weeks leave. It's a full-time job.

> *As an only child, Rochelle's parents do everything they can to help but this means they have no retirement. And they have also had to come to terms with a very different future to the one they had all imagined.*

Georgia is also a very fussy eater, having little meat and refusing fruit, vegetables and sandwiches. 'So her lunch box is extremely hard.'

Both girls have limited speech and Stephanie has a 'goldfish memory — she can forget five minutes after you've asked her not to do something.'

When Rochelle isn't helping out at the school, such as at the canteen, or taking the girls to therapy or other medical appointments, she tries to keep up with the housework, maintenance, gardening and supermarket shopping or just catch up on sleep. She also buys the girls' medications and special nappies and clothes, which often require alterations to accommodate comfort and fit.

The girls' behaviour, in particular Georgia's obsessiveness about certain things, limits what the family can do together. Even a simple trip to the shops can set off an uncontrollable tantrum. 'For example Georgia doesn't like anyone to wear a hat, but is improving with perseverance. I've also learnt to drive a path avoiding McDonalds, another obsession. Yet another obsession is balloons — one of every colour if possible as she is quick to spot a missing hue. And I can't go near a park with water because she'll break away from me with immense strength to get in. Even finding somewhere to place Scott's ashes was difficult because every cemetery had water.'

Security is a big issue. Everything has to be locked for the girls' safety and to prevent Georgia escaping. 'She's only ever got away from me once, thank goodness, where I didn't know where she was. And that was the scariest 45 minutes. That was just very bad luck. She hadn't slept all night. I was holding both of them on a chair and I dozed off with Stephanie and thought Georgia had too but she didn't unfortunately.'

A neighbour found Georgia at the nearby park because she'd taken a packet of chocolates with her and left a trail of wrappers on her way.

'But she was still cluey enough to pretend she didn't know who our neighbour was when they found her, saying *Stranger, stranger!*'

Rochelle has lost a lot of her earlier friends and socialises more now with other parents of children with a disability.

'We don't tend to go very many places. It's a shame because Stephanie, although she has an intellectual disability, is a very sociable child. So she misses out on a lot of things because I just can't take both of them on my own. Thankfully there are trusted people in our lives who understand Stephanie's special needs and take her to places she might not otherwise enjoy. Stephanie goes out with my parents regularly but Georgia and I mostly just stay home.'

When they do make the effort to go out together, Rochelle says people tend to stare and don't understand why her girls are still acting like babies. 'The worst case scenario was Georgia with a dummy when we went out on a weekend to get an ice cream. It took me all my energy to get her into the shop because she loves that ice cream and then this guy made fun of her about having a dummy. So she was becoming distressed, not really because she knew he was teasing her but because it upset me. People can be quite cruel.'

One of the hardest issues for Rochelle is the impact on her own parents. As an only child, Rochelle's parents do everything they can to help but this means they have no retirement. And they have also had to come to terms with a very different future to the one they had all imagined.

'When you get a child diagnosed with any disability you grieve for what might have been. In my case I know that my beautiful girls, who I went on fertility treatment to have and waited seven long years for, are never going to get married, go to university, drive a car or even probably get any job at all. They may never even leave home or become toilet trained. I grieve that loss every day.'

Worry about the future is constant and financially things are tight.

'If I didn't have Scott's life insurance, and that's not much, we'd be destitute. There's frustration which I never knew could happen until I had the girls. Like I'd never had one day of unemployment, I'd never been on the dole, I'd never been in a Centrelink office until I had a child.'

Rochelle has tried to work since having her daughters but it was a 'disaster'. Initially it was difficult to find a suitable position and proved very stressful trying to balance employment commitments with parental commitments and obligations. Filling out forms for her carers' payment became a 'confusing nightmare'. As it turned out she only earned a few thousand dollars that year anyway.

There's also the impact on her own personal life, including her current relationship. 'Scott's been gone five years and I'm dating someone now. It's very uphill for us as a couple, but luckily he understands that Georgia and Stephanie have special needs.'

Rochelle has her ups and downs. 'Being a carer is hard physical and mental work with no work cover or four weeks leave. It's a full-time job.'

However, she loves her daughters very much and manages to finds humour and rewards in each small step forward. 'Sometimes they'll surprise the living daylights out of you. Like when Georgia tries something new to eat. That's special when she does it for no reason. Or the first time Stephanie did a wee on the toilet. She was so excited she just about wet herself again.'

And there was Georgia's recent eighth birthday party, which was worth the effort organising several children with different disabilities to attend.

'They both had such a happy day and when they smile, I smile.'

Liam's gift

Liam might only be four years old, but he's already made a world of difference to the many people around him.

Liam has cerebral palsy. He is blind and he can't walk or speak. He has osteoporosis and seizures. And recently he was also diagnosed with a growth in his brain which is likely to be malignant.

Liam's mother Terresa believes it is fate that things have turned out this way. 'Liam was meant to be the way he was. He was meant to come to me to teach the people around me and myself. He's taught me to never, ever take things for granted — myself, kids, health, life. So yes it was fate. And I could curse fate sometimes and other days I'm so grateful for it because if I didn't have Liam, God knows where my life would be now,' she says.

One of 11 children, Terresa grew up with her grandmother while some of her siblings lived with her mother and others lived with her father. Her own relationship with her father has always been strained.

Her grandmother also helped care for Terresa's first son Tyler who was born straight after she left high school. 'I was very confused. I'd been through a bad relationship. I was a baby having a baby.'

Three years later, Terresa was married and she fell pregnant again. But at about 27 weeks, the baby stopped moving for 13 days. Scans showed the ventricles in the baby's brain were larger than normal, but not large enough to definitely indicate a disability.

'I think deep down inside I knew that Liam was going to have disabilities. I immediately called a family meeting and I said, *Look this child may have disabilities — we don't know how severe.*'

There was a mixed reaction. Her husband was very distant about it and she left him soon afterwards because she didn't feel she could bring a child with a disability into the world while being uncertain about how he felt.

Liam was born by emergency caesarean several weeks later and immediately placed in a humidicrib in the special nursery.

'Three days afterwards he started vomiting. He could not tolerate any fluids at all. They said to me, *Go and spend as much time with him as you can because he might not make it through the day.* I sat and held him for 23 hours. The day after, he started feeding.'

However, ongoing breathing and feeding problems meant that, up until he was six months old, the longest Liam spent at home with Terresa was 17 days.

At around three months he also started having seizures. One frightening seizure lasted 45 minutes. 'During that seizure his heart stopped four times and I had to resuscitate him. I brought him back… I've brought him back more times than I probably should have.'

A round of specialist appointments confirmed Liam couldn't see and that a lack of white matter at the back of his brain was the cause of the seizures, blindness, and global developmental delay that meant as a six month old he was still like a newborn baby.

At a local playground, Liam shares a slide with mum, Terresa

He's taught me to never, ever take things for granted — myself, kids, health, life.

Liam also began to develop chest infections. Finally, tests revealed that he was regularly refluxing into his lungs. He was immediately taken off all feeds and hooked up with a nasogastric tube. Liam became so sleepy he was asleep for 20 hours out of 24. Terresa was told he would need surgery to tighten his stomach muscles and insert a PEG feeding tube.

This was the last straw. 'I ended up having an emotional breakdown.'

Unexpected support from Liam's father helped her through the days leading up to the operation. The day of the surgery, they had to make a decision about whether or not Liam should be resuscitated if something went wrong. 'I said, *I don't want Liam resuscitated.* It was a hard decision but at the same time I feel comfortable knowing that if anything looks like it will lower his quality of life, they are not allowed to do anything.'

Terresa was convinced Liam wouldn't make it through the surgery, but he did. He has since had to have repeat surgery. 'He's come very, very close to dying quite a few times. He has this will to live and I could throttle him for it because it's so hard — at the moment he is living in pain more often than he's not.'

Looking after Liam, Terresa's days fill up quickly. 'As a carer for a severely disabled child, time is a rare thing. On a daily basis I PEG feed every few hours, do physio, OT, bathing, medicating and sensory stimulation.

> *During that seizure his heart stopped four times and I had to resuscitate him. I brought him back… I've brought him back more times than I probably should have.*

'There are times when you just look at him and he looks like a normal child, That's when it hits you like a ton of bricks because you can see what his physical body could have been. We've seen glimpses of what he could have been. I often think his brain understands more than his physical body can show. I'm positive that he has an element of understanding that he cannot show to us. It would be really interesting to experience the world through his eyes and ears just for one day.'

With emotional, financial and respite support from her family, particularly her mother and grandmother, Terresa now juggles Liam and Tyler's needs with those of their boisterous 12-month old sister, Hayley.

Watching Hayley's development is bittersweet. 'It's hard because Haley is learning to talk. I always thought that one day I'd hear Liam say, *I love you.* But he can only show me and if I don't open my eyes I miss it. And I'd be very stupid and very foolish to close my eyes to that just because I can't hear the words.'

An affectionate child, Liam enjoys kisses and cuddles. And there is something special about his smile. 'The smiles alone give you that strength just to pick up and carry on. It's amazing to see the changes in people, even people in the street, just because Liam has smiled at them. Liam has done so much for so many people.'

This includes bringing her mother and grandmother back together. 'They had actually never really gotten along my whole life until I said the word disability. And then they locked horns and now they are the best of friends.'

Terresa's stepfather, who 'can be very hard nosed man when he wants to be, very impatient' now has 'infinite patience'. And a friend of Terresa's who had jumped from job to job feeling that nothing suited her is now settling down to become a respite carer, based on her experience helping to care for Liam.

Even the community has rallied around him. When Terresa's car was stolen, one of the shopping centres began collecting money to help get a new car and a new wheelchair for Liam. Then there was the time Terresa contacted the community paper about children breaking the lock on the special Liberty swing at the playground. The paper's photographer took hundreds of photos of Liam and his friend Brayden, saying 'I can't stop taking pictures of these boys, they're just so beautiful'.

Through Liam, Terresa has also met two close friends — Brayden's mother and another friend she met when both their boys were sick in hospital.

More time in hospital seems inevitable for Liam, particularly after his brain tumour diagnosis. It is already impacting on his sleep and body temperature. If the tumour grows it will increase pressure on other things, but chemotherapy and radiation are not options for Liam.

'If they operate he could live through the surgery but he could lose everything he knows and I'm not prepared to risk that. I mean at the moment he has a quality of life — not as we know it but he has a quality of life — and I just don't know what is going to be the lesser of two evils.

'It's been a long road and the end is pretty close. Liam's body is getting very tired. There are days when Liam isn't awake by 10 or 11 o'clock in the morning and it is very scary going in to check on him. I'm very, very afraid of what I'm going to walk into one day.'

For now, Terresa is making the most of things. 'I'm very adamant about people not feeling sorry for Liam or for me. I've been so blessed and so honoured to have been given the opportunity to watch his life and to have a part in creating that quality of life.'

the long road

When four-year-old Jordan was diagnosed with a brain tumour it affected each of his family members differently. His Dad John fell apart, while his Mum Tracey-Jane took control and his older sister Kelly went into denial. But ultimately the experience has bound them more tightly together.

'Initially Jordan was diagnosed with a blind eye and that was traumatic enough but further tests showed he had a brain tumour known as an Optic Nerve Glioma,' Tracey-Jane says.

'Our world was thrown forever into that of people we had empathised with before but could never really imagine or understand.'

Two days later Jordan underwent emergency brain surgery at Sydney Children's Hospital. However, they couldn't remove the tumour as it was where the optic nerves cross, near the pituitary gland. It had taken the sight in his right eye and the risk was too great.

'My husband John broke down and went to pieces. He was not able to cope with the shock as it came out of the blue. But I just did what I had to do — I didn't have time for emotions. We were bombarded with so many different kinds of doctors and there was so much to take in.'

After dealing with the initial shock the family had to work out how to manage Jordan's chemotherapy over the next 12 months — especially the logistics and costs of regularly travelling between their Wagga Wagga home and the hospital in Sydney.

'At first John drove, but the trip was taking us up to eight hours because we had to stop often for Jordan to be sick. So we started flying, but that was too expensive.

'We also had to find people to look after Kelly but we'd only been in Wagga for four months and didn't have a good network of friends, and no family in Australia.'

The family ended up moving back to Richmond near Sydney when John managed to get a transfer through his job with the Royal Australian Air Force.

This was closer to the hospital but meant giving up the country lifestyle they had just begun to enjoy.

The regular hospital visits take a toll on everyone.

'It's not easy. When Jordan's in hospital, John still has to take me to and from hospital and still go to work. He also has to look after Kelly, so he can't always share the same emotions as me. I make sure I tell him exactly how things are so he can stay involved. We make sure we keep talking.'

Tracey-Jane had to give up plans to further her career in childcare and teaching to make sure she could always be there for her children.

'I was learning sign language and my dream was to work with deaf children once Jordan started school… But when Jordan was diagnosed everything changed.

Enjoying time together — Kelly, John, Jordan and Tracey-Jane

Our world was thrown forever into that of people we had empathised with before but could never really imagine or understand.

Tracey-Jane had to give up plans to further her career in childcare and teaching to make sure she could always be there for her children.

‘Financially and emotionally things became stressed and long-term friendships fell away. Some people cannot handle sick children even though we continually stressed, *Cancer is not contagious!’*

Despite Jordan’s gruelling treatment regime, they were still keen for him to start school. ‘I knew it would be tough for everyone, but the school was very good. It was important for Jordan to have a distraction from the treatment. We knew he’d miss a lot of school… but his teachers and a special sight support teacher worked very closely with him and he was able to keep up.’

But at the end of Year 1, Jordan’s tumour started to grow again and he had to undergo three months of intense radiation treatment.

‘Jordan fought it all the way. Treatment would start at 10am and he would have to fast because he had to have an anaesthetic every day. We decided to move into Ronald Macdonald House to avoid the travel. That set him back at school and he had to repeat Year 1.’

With a lot of determination, hard work and support from school and family, Jordan managed to catch up academically. Socially, however, things are still difficult.

‘He makes a friend and then goes away for treatment and the friend moves on.’

To help Jordan make friends outside school, Tracey-Jane takes him to indoor soccer and swimming. ‘As well as the social aspect it is important for his health to get some physical exercise.’

Jordan’s long-term prognosis is uncertain. It’s hard for Tracey-Jane not to constantly worry about him.

She’s also concerned about the impact on his sister Kelly.

‘She is very bright, outgoing and popular, but she’s had to grow up pretty quickly. We have tried to shield her from things as much as we can and have tried not to take her out of school too often. But it is important for us to spend time together as a family.’

Kelly has gone to special camps with Jordan and made friends with other children, some of whom have then passed away. She also lost her favourite teacher to breast cancer.

‘That was a double whammy for Kelly because she had a special bond with Julia, who was going through chemo at the same time as Jordan. Death is something she has had to deal with from a young age. It’s very tough.’

The next hurdle the family faces is growth hormone treatment for Jordan because his pituitary gland was destroyed by the radiation therapy and he has not grown in two years.

‘We are now applying for funding as the treatment is very expensive. He will have to give himself an injection every day for several years. We’ve been weighing up the risks as the side affects can be pretty shocking.’

The whole experience has changed the way that Tracey-Jane looks at life.

‘I don’t suffer fools easily and I’m incredibly honest. We also live for the day.

‘We changed a lot of things. We sold our house so we didn’t have to struggle with a mortgage. The dream of owning our own home was just not important.’

Now it is family time that is extremely important.

‘We make sure we talk to our children and at dinner we all sit at the table as a family.

‘Life is a challenge and you sometimes wonder how you are going to cope and rearrange things.

‘We keep going because our kids are just fabulous. Kelly has done very well academically. Jordan is full of life and has a go at everything. He tells jokes and laughs all the time. He’s good company.

‘There’s a special bond between us all. Each experience brings us closer together and makes us stronger, and it is a strange thing to say, but this bad experience has also brought great things to our family — especially the fantastic, inspirational people we meet all the time.’

Further Information

Information about assistance and support available to carers of children with disabilities or severe medical conditions is available from the resources listed here.

Department of Families, Housing, Community Services and Indigenous Affairs

www.facsia.gov.au/carers

Centrelink

Phone: 13 27 17
www.centrelink.gov.au

Australian Association for Families of Children with a Disability

Phone: 1800 222 660
www.aafcd.org.au

Carers Australia

Phone: 02 6122 9900
www.carersaustralia.com.au

Commonwealth Carelink Services

Freecall 1800 052 222
www.carelink.com.au

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