

living with evan

When a baby step is a milestone

BY ANNIE BOURGAULT



Lydia Gallant, Russell Harvey and their three children are an excellent example of how vibrant family life can be even in the midst of extreme adversity. In 2005 they had been happily married for more than 10 years and had two beautiful healthy boys: Kaden, three, and Evan, six months. Besides a few common childhood illnesses nothing had prepared them for what can only be described as any parent's worst nightmare.

LYDIA vividly remembers the day Evan became sick: "It was the 23rd of July 2005 and my whole life came apart at the time."

It was a beautiful Saturday morning. The brothers had finished playing cars and Evan suffered with a sudden high temperature spike. Lydia reflects, "I remember picking up the phone to call the medical centre and hanging up because I felt like a panicked mother." At that point Evan had been sick for only three to four hours.

After waking from a short sleep Lydia noticed his eyes were glazed, at which point, her husband rushed him straight to the doctor.

It wasn't until in the doctor's room that the "rash", so often characteristic of meningococcal illness, suddenly appeared.

"The worst part was there were no tell-tale signs – at least none that a six month old baby could tell us – in the few hours leading up to when the rash appeared at the doctor's, (the same time as) Evan's system collapsed," recalls Lydia.

Evan never recovered. He suffered cardiac and respiratory arrest in the local doctor's surgery, and the ambulance was immediately called but could not get him to Princess Margaret Hospital in time before irreversible damage had been done.

The result: severe brain damage – cerebral palsy. A few days later meningococcal septicaemia was confirmed as the cause. Doctors told Lydia and Russell their little boy would remain in a vegetative state for the rest of his life.

After nearly six weeks in hospital they finally brought their baby boy home. "He was still there but the 'presence' of a person in him wasn't," says Lydia. Their boy's body was completely floppy and he had no focal attention.

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But Lydia was determined to bring Evan out. "We decided to focus on what could be achieved rather than what couldn't. And it's been like that ever since. I remember thinking, 'This is what we've got to deal with! How can we best care for our son now?'"

They faced a steep learning curve. Their son suddenly required physiotherapy, speech pathology, occupational therapy and hydrotherapy, as well as neurology and paediatrician reviews.

Over the years being a mum to Evan also meant being a pseudo-therapist in every allied health discipline: a medical practitioner, nurse and advocate for services and care that he requires.

Lydia believes caring for Evan has drawn out her natural skills.

"Before someone is a mother

there are many skills left untapped within each person. We have had opportunity to challenge our existing patterns of behaviour and build knowledge to help ourselves and our family."

Now, five years old, Evan has been diagnosed with spastic quadriplegic cerebral palsy, as well as epilepsy and is considered to have a 'global development delay'. He is completely reliant on assistance from others for all care, including feeding and mobility.

But Lydia asserts, "He is very much aware, present and able to interact – all far from the 'vegetative' state that doctors assumed would persist. He just needs the tools that allow him to interact the way a "normal" child is able to." She adds that she has become accustomed to thinking outside the square to be creative in modifying activities for playtime and learning.

It is unlikely Evan will ever walk but Lydia says that she is continually motivated by the interest of what can be possible, and that with a child who has no mobility control or spoken language, any improvement is a milestone.

It is in the search for knowledge and support for Evan's development that she found Conductive Education (CE), a unique education that incorporates all therapies into a holistic educational approach for the minds and bodies of children with motor/physical disabilities.

This year Evan attends Melville Primary two days per week and spends the other three with a CE pre-

primary group run at Carson Street Primary School in East Victoria Park.

Russell and Lydia say that their son has improved immensely since starting CE at the age of two and that without the program, Evan's ability to swallow for eating, vocalise for communicating, observe, move deliberately and even pat the cat would be highly limited.

One would think that the mother of three who works as a freelancer in public relations and marketing would have enough on her plate already. However, a few years ago she decided to volunteer her help to Conductive Education Centre of WA (CECWA). To ensure its continuation she has assisted in growing the profile of CE and the charity, raising funds, and lobbying for greater Government support.

The Gallant-Harvey family also finds the time to do a great number of activities together as a family and on an individual basis. They try to keep a balance between Evan, who is included in everything they do, such as camping and eating out, while also giving Kaden, eight, and Sienna, three, individual time. "We want to give them the opportunity to be the kids that they are."

Even with such a busy schedule



Lydia takes time out for herself. "I draw, read, write, and take art workshops as well as care for the inner athlete in myself - I love to keep active."

And after 16 years of marriage Lydia and Russell appear happy and very much in love. Their experience has made them realise how much they need each other. But it isn't

always easy.

"You need to stop, talk and have empathy for others and realise that not everyone sees everything from your point of view," adds Lydia.

Their philosophy? It's quite simple really: "We haven't started to write a different book - it's just a new chapter in a dynamic life."



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