

## Life isn't easy with three children diagnosed with autism, Steve Butler writes

A few steps into the Bennett family's home in Perth's southern suburbs and everything points to them living the great Australian dream.

Three smiling kids play quietly in the living room, dad Peter is home after his day's work at the City of Armadale and mum Hayleigh is busily preparing a tray of biscuits for afternoon tea. But a closed cupboard above the fridge in an immaculately clean kitchen is filled with the wide array of medical products that reveals everything is not quite as normal as it seems.

Plastic containers, each labelled clearly with the names of the family's three children and also others separating the adult medication from the children's, sit neatly in the space. It has become the necessary evil of the Bennetts' life with autism, a condition which refers to a range of developmental disabilities called autism spectrum disorder or ASD.

The annual World Autism Day will be recognised this Thursday.

Nine-year-old Levi was the first to be diagnosed when he was just three. Then it was now six-year-old Maverick and then now 12-year-old Emily. Peter followed three years ago at the age of 39.

They all register at different levels on the spectrum, but the medical issues do not stop there.

Add secondary problems among the children such as three different types of epilepsy, hyperactive and impulsive ADHD, selective mutism, passive ADD, asthma and a range of skin allergies and it is easy to understand why the local pharmacy has become a regular place to visit.

The annual medications bill goes into thousands of dollars.

"It was purely survival... frantic," Mrs Bennett said.

"It wasn't about enjoying life, it was about getting through each day and making sure we got to medical and specialist appointments. The lack of sleep just made everything worse and then you'd start the next day and just go through the whole thing all over again."

Autism affects how a person perceives the world and how they communicate. People with autism can have difficulty with social interaction. They may display repetitive behaviours or react to sensations in a particular way. The symptoms vary significantly from person to person, both in terms of range and severity. No two people with autism are the same.

It is a lifelong disorder, but with appropriate treatment children can make significant developmental progress.

Before the births of their two boys, the Bennetts lost twins after 24 weeks of pregnancy. Levi's autism diagnosis then came when Mrs Bennett was 13 weeks' pregnant with Maverick, who was ultimately born 10 weeks prematurely.

Levi's parents were worried that he had not started talking by the time he turned three, a trait which remained for a further two years. They were told he may never talk. Fortunately that was wrong. But he has had the same dinner of chicken nuggets and chips every night for the past five years. He has the same fruit bites for breakfast every morning. An obsession for toasted cheese



Smiling through adversity: Peter and Hayleigh Bennett with their children Emily, 12, Levi, 9 and Maverick, 6. Picture: Steve Ferrier

# Family battles on despite the stress



They are who they are and we're proud of them

Hayleigh Bennett

sandwiches has passed and he has started drumming lessons.

Maverick's behavioural issues, which were sometimes violent, led to his diagnosis and he still requires sedation at night. He has taken up weekly swimming lessons.

Emily's core issue was a lack of social skills, but she is gifted in many other areas of her young life and has started embracing team sport in netball. All three have developed a new love of chess.

"It's an open book with us," Mrs Bennett said. "We've got nothing to hide and we can't change them. They are who they are, it is what it is and we're very proud of them."

"We want them to be happy and have all the experiences

typical families have."

All three children have an addiction to television's theatrical wrestling shows, in similar fashion to their father's fascination for all things sport. He gradually came to realise there was something not quite right in his life when he began obsessively counting bathroom tiles or drawing patterns on them with his finger.

"The more I knew about it, the more I could see some of the autism traits in myself," Peter said.

"Until Levi was diagnosed, I didn't really know anything about it and just lived through life. As I've got older, I think I've gone into my shell and more of it has come out. If a new person comes into the cricket club, is sitting at a table with people I've known for 15 years, I'll feel uncomfortable going across to that one table because there's one person I don't know.

"The diagnosis has definitely helped me explain a lot of things and why I am like I am, I guess." Mrs Bennett said she and her husband had been drowning in the emotional stress of their situation, which virtually had

them living from

minute-to-minute and suffering extreme sleep deprivation. But connecting 18 months ago with WA business Cam Can, which provides individually-tailored support to vulnerable people and their families and carers, has sparked new zest in their lives.

Cam Can was set up by WA couple Marc and Anthea Lema, who are the parents of seven children, one with an intellectual disability. Mrs Bennett was so moved by Cam Can's profoundly positive influence on her family's life, she nominated them for the Disability Support Awards, which will be held at Crown Perth tonight.

Now in a seventh year, the Disability Support Awards were conceived with the aim of raising the profile of an often-unheralded sector and to set standards of excellence for workers within it. This year, for the first time, people with disabilities were able to directly nominate their carers and support workers, resulting in a record 163 nominations.

NDS WA State Manager Julie

Waylen said the awards showcased disability sector work as an attractive career option.

"Working in the disability sector is more than just a job, it's a great career choice for those looking for meaningful challenges and those who want to have a real and positive impact on the lives of people with disability," Ms Waylen said. "Good support is not simply about doing a task, it is about recognising the person, respects their dignity and encourages them to live a good life."

"Not only are the awards an opportunity for us to recognise the outstanding contribution and achievements of support workers, it also provides a great stage to showcase the disability sector as a place of innovation and celebrates the achievements of people with disability."

Autism West will use today to mark World Autism Day in WA with the Team Sprint Cup, where about 250 school children will swim in a relay at Christ Church Grammar School to help raise money to promote awareness around the condition.