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epilepsy ACT

SAMUEL

Samuel has just celebrated his first birthday. The adventurous one year old knows no limits. He explores, plays and dotes on his big sister showing little sign that he can experience up to seven seizures due to epilepsy each day.

Samuel was diagnosed with epilepsy at around seven months of age – only a few months ago - however as Samuel's mother Leanne reflects on their journey so far, she notes that it 'feels like a lifetime'.

So far Samuel is on his fourth combination of epilepsy medication. His seizures seem to be now only occur once every 24 hours which makes the family feel that they are at least 'on the right track'.

"Trying to get the medication right is difficult", Leanne says. "I do feel that after just over three months we may be starting to control the seizures. I don't want to get my hopes up though."

Ensuring Samuel ingests the right dose of medication has become increasingly challenging. The attentive one year old knows that it is hidden in his food will pull his food apart or refuse to eat all together.

Life for any family with two children under three can be a juggling act. For the Fenton family the juggle includes a strict routine. Medication, medical appointments and round the clock monitoring. This has made socialising, daycare and returning to work really challenging.

"If Samuel is overtired or has a cold his epilepsy is worse. Making sure Samuel has his sleep and stays as healthy as possible is really important – it needs to be a priority," says Leanne.

"We do miss out on things because it will interfere with Sammy's sleep schedule. I do find it hard to explain to friends why we can't meet at a certain time or come to an event."

Samuel currently sleeps being held to ensure he sleeps well and his seizures can be monitored. Leanne admits that she has not had an uninterrupted night sleep since Samuel's first seizure. "It is exhausting, but it is all worth it if we can prevent a seizure, make sure he does not injure himself, and know that he is not alone when his awareness is restored," Leanne says.

"That is the way it has to be for now. I do wish there was some sort of monitor that could alert us to a seizure so we could respond immediately – but this simply does not exist yet for his type of seizures."

Samuel's older sister Lilah is 20 months older than her brother. "I think it is really hare on her" Leanne mentions. "Sometimes she will say – 'I need medicine too' or tell us about her sick dolls keen to have our attention. That is really hard."

As we were chatting Samuel's grandfather arrives to take a sleep shift'. He will hold Samuel and monitor him while he sleeps – giving Leanne precious time to focus her attention on Lilah.

Family support is really important for the Fenton family. Samuel's Grandparents and an aunt and uncle have expressed interest in completing Epilepsy ACT training to understand as much as they can about supporting him.

Taking the support where it is available is something that Leanne urges others to do if available. And if you ask Samuel's Grandfather, "we'd just do anything to be here for the kids".

The Fenton family tell a familiar story of the difficultly in recognising the signs of epilepsy being diagnosed. Samuel was meeting a lot of the regular developmental milestones, but the persistence of subtle signs such as: eye watering; calmness after he would fall; collapsing while crawling; and nodding his head, indicated to his parents that something may not be quite right.

After being sent home from Emergency after a fall with a clean bill of health, it was a chance visit to a different GP who recognised potential signs of epilepsy and recommended presenting to Emergency immediately if it happened again.. Further specialist appointments, testing and observation confirmed that Samuel was experiencing seizures which could be in several clusters each day from 2 minutes to 40 minutes.

"In hindsight, Samuel had probably been having seizures for a few weeks before he was diagnosed. We had no idea that there were different sorts of epilepsy and that the signs could be more subtle than a tonic-clonic seizure many people relate to epilepsy," Leanne said.

The Fenton family have a long journey ahead. Samuel is yet to have a full diagnosis of the type of epilepsy he has. "I don't think any of us realised when he was diagnosed that there were so many unknowns and it would be such a long process to work out the best possible treatment," reflects Leanne.

Like many families in the ACT, the Fenton family drive up the highway to Sydney to avoid waiting lists and to see a Paediatric Neurologist who are not available in Canberra.

There is a lot of waiting for answers, appointments, second opinions and medications to take effect. "The wait is frustrating and any time there is conflicting advice or an adjustment to the approach, you feel the guilty, questioning whether we been doing the right thing," Leanne points out.

Samuel's epilepsy does not seem to physically slow him down, however, Leanne says that, "it is difficult to tell what the effect of the medication and his seizures are on his cognitive development. The medication definitely makes him tired."

When asked what she had taken away from their difficult journey so far, Leanne reflected, "it is the way Sammy has surprised us with how much strength and resilience he has. Even during the periods where he was having six or seven seizures a day, he would just power through and still be the happiest, most affectionate and adventurous little guy again afterwards".