Thank You!

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means teachers and nurses are now trained in seizure recognition and epilepsy first aid.

For me, they've been an amazing sounding board, especially when I don't know what to do next for my little girl or simply being able to have a chat with someone who understands the impact epilepsy has on a person.

The reality is more than 270,000 Australians have epilepsy. When you add in their family, friends and colleagues that's many thousands more.

Your support is vital.

Whatever you can give at this time, your donation will ensure families like mine receive the support, information, tools and care they need to live with this unpredictable and challenging condition.

Like any dad, I have hopes for my children. But my hopes may be considered a little different to other parents.

For Charlotte, I hope she can get through one week seizure free and experience the world as most other 10-year-olds do.

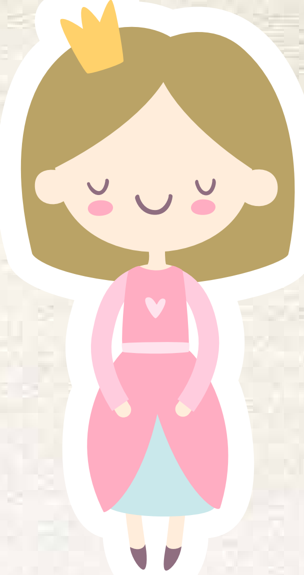
I hope her younger sisters don't have to see Charlotte put into the back of an ambulance, taken off to hospital, intubated, again.

And I hope one day we will find a cure for epilepsy.

Until then, I am grateful that the Epilepsy Foundation is here to support Charlotte, me and my family.

Thank you for caring. Wishing you and yours the very best.

Stephen &
Charlotte x



When I first held my daughter, Charlotte, in my arms, it was just amazing. I thought wow.

As I cradled her in my arms, my heart was bursting with love, joy, hope.

I couldn't wait to play, go bike riding, read or just watch television. Together.

I couldn't wait to see her crawl, walk, say her first words (hoping it would be dada, dad, papa), take Charlotte to her first day of school, lecture any future boyfriends.

I couldn't wait to just simply watch my beautiful girl grow into an amazing woman.

As a first-time dad, I just wanted to make sure everything would be perfect for my girl.

But that wasn't going to be the case.

Very early on we noticed Charlotte wasn't hitting milestones of babies her age.

Then, when Charlotte was around five months old, we noticed she would just stare off into space, unaware of her surroundings. We couldn't rouse her from that.

Occasionally, Charlotte would hold her breath. She would be breathing normally and then stop, to the point where she would turn blue.

We would find her blue in her cot. Or I'd look in the car's rearview mirror and see she wasn't breathing! Other times, her eyes would become pin-shot and she'd just look past you.

In a three-week period, I reckon we had six or seven presentations to hospital, where eventually her now paediatrician labelled what she was experiencing as absence seizures.

And where we also learnt Charlotte has what's called 22q11.2 duplication – a genetic condition where an extra copy of a small segment of chromosome 22 is present. There's no scientific name and worse, very little information with only 100 reported cases world-wide!

What we did learn is those with this chromosome duplication have a high risk of hearing loss, intellectual disability, and seizures.

It explains why Charlotte didn't walk until she was about three years old. Her first words were a while after that too. And although Charlotte is now 10, intellectually and physically she's around 4 years old. She still needs to wear nappies overnight, there are accidents during the day, her motor skills are not as developed as her younger sisters are.

When the paediatrician told us about Charlotte's condition, he was very upset for us. However, he gave us answers as to why our girl was experiencing developmental delays and seizures. Bizarrely, it gave us a sense of relief, yet we had so many questions, like:

Will she be able to drive?

Will she be able to work or hold down a job?

Will she be able to move out of home, be independent in any way?

Will she need supported living accommodation?

What will life be like for my Charlotte?

The mountain of appointments we have every week with paediatricians, occupational therapists, behaviour therapists, teachers, hospital staff, GPs. You name it, we see them.

Living with epilepsy has a huge impact - on Charlotte, on me, on our entire family.

I don't know any different, you see, as this has been my life as a parent since Charlotte was just a few months old. I just take each day as it comes.

Honestly, even though I have a background in fire and emergency services providing first aid training, there are moments where I just break down and cry with the enormity of what my little girl is going through.

Epilepsy is challenging. It's a rollercoaster. And it does take a toll on all of us.

It is really hard to see your daughter taken by ambulance to hospital, intubated, hooked up to all sorts of machines, with doctors trying to understand what's going on.

It's traumatic for her young sisters. They understand Charlotte has seizures – we call them 'brain hiccups'. Practically all of their lives, they've seen Charlotte taken by ambulance to hospital. Time, and time again.

When Charlotte was young, we were able to get her seizures under control with medication. She was still having tiny little short-lived microsecond absence seizures, but nothing major. As her seizures were under control, at around two and a half years old, we started to wean her off the medication.

Then I took Charlotte on a trip across Australia. We went across to Western Australia and then up to Cape York. We were at the very tip of Australia, camping out on a rooftop tent when she went all floppy and stopped breathing. We just rushed her straight to hospital.

Soon Charlotte was back on medication to control her seizures.

It wasn't until Charlotte was in Grade Prep, when she became unwell, that she experienced her first tonic-clonic seizure.

Since then, Charlotte has had about 10 tonic-clonic seizures that I've witnessed. Her eyes roll back, her tongue will poke out, her jaw will go stiff or tremble. And she'll stop breathing. I've got videos of her sitting there and still eating but she's in the middle of a seizure.

Last November, Charlotte had one of the worst tonic-clonic seizures she has ever had.

The hospital staff went through the first and second line of defence medications. They tried to get another IV medication into her. They then admitted her into ICU knocking her out to give her brain and body a break from all the seizure activity.

It was 90 minutes of seizure activity. How she came through this, we'll never know. But thankfully she did.

On top of that, Charlotte has hundreds of tiny microsecond focal onset awareness seizures, every single day.

I can't begin to imagine the impact these seizures are having on Charlotte. But what I am is grateful for you. Because...

You're the difference in my family's life.

If it wasn't for caring people like you, we would not have the support we need to understand and manage Charlotte's epilepsy. I dread to think who we would have turned to if there wasn't an Epilepsy Foundation.

Trying to manage a diagnosis of focal onset awareness AND tonic-clonic seizures is challenging. Trying to explain to people around us the impact they have on Charlotte is another thing. And then dealing with stigma, lack of understanding or awareness about the different types of seizures, is just on another level.

But the Foundation has given us the vital tools, support and information we need as a family to make sure Charlotte lives well.

They've been with us throughout our journey with epilepsy. Because it's not just Charlotte's journey – it's all of our journey with epilepsy. Parents, sisters, aunts, uncles, grandparents, friends...

They've provided us with highly personalised Epilepsy Management and Emergency Medication Plans.

These plans describe the symptoms and signs of each seizure Charlotte has. And then map out step by step a plan of action to keep Charlotte safe and help her recover. They provide details such as if the seizure goes on for more than 5 minutes what and how to administer midazolam and other medications.

And they constantly update these plans taking into account any changes in Charlotte's life.

They've also provided training to members of my family and provided epilepsy training at Charlotte's school, which