

Hello Friend,

**This is my little girl, Evelyn.** She loves playing with her three siblings, creating paintings for us to put around the house, and our family dog Rexie. She loves smelling and picking roses from the rose garden outside her bedroom. There's even a rose named Evelyn which we've planted for her.

**When I took this photo of my beautiful girl, at that very moment she was having an absence seizure.**

If Evelyn gets excited or happy, this will bring on a seizure. If her older brother gives her a bear-hug or she's playing with her siblings, this will bring on a seizure. Celebrating Christmas, Easter, Mother's or Father's Day, school holidays, will bring on a seizure.

She's only 6 years old, yet Evelyn knows when she's about to have a seizure. She'll come and stand right by me. Once her seizure is over, she becomes "postictal". This means she is mentally exhausted requiring between 1 and 3 hours of sleep to not only recover, but to function.

**Evelyn's seizures are uncontrolled.**

The seizures happen multiple times during the day, every day.

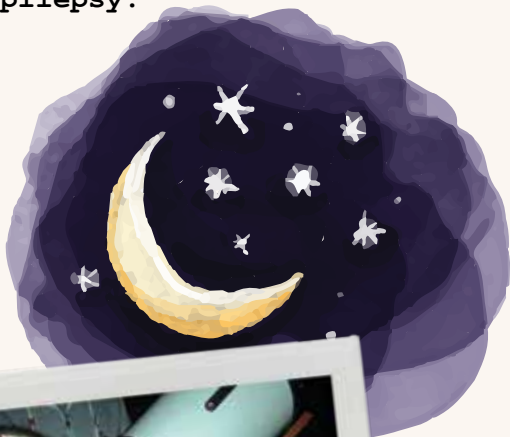
They happen throughout the night, every night.

Because of her night seizures, my beautiful girl is at risk of Sudden Unexpected Death with Epilepsy (SUDEP). A term we never knew before, a term that is a very real part of our lives now.

**Looking at the stars and the moon is one of the ways we all cope with Evelyn's epilepsy.**



*My beautiful girl having an absence seizure*



We have a nightly ritual in our family. Before Evelyn goes to bed, we all go outside to say "goodnight" to the stars and the moon. Evelyn loves to look up at the night sky through our telescope. Then each one of us gives her a hug and a kiss goodnight. Never far from my thoughts is - what if Evelyn didn't wake up one morning? How fast can I get to the phone to call 000? What would I tell her siblings?

**At least we would have all told Evelyn how much we love her.**

Evelyn is my second born. At the 20-week ultrasound something wasn't right.

I remember the ultrasound obstetrician saying to me that everything is perfect...

*"Except she's got a cyst on her brain."*

I was like, sorry, what? How can everything be perfect but?

The staff were at a loss. We had multiple MRIs, an amniocentesis, poking and prodding for more



*Evelyn looking through a family friend's telescope.*

information. We were told it wasn't uncommon for pockets of fluid to be visible in the baby's brain, however, they usually resolve themselves by about 28 weeks.

**Unfortunately, the pockets of fluid didn't resolve themselves - they got bigger and divided.**

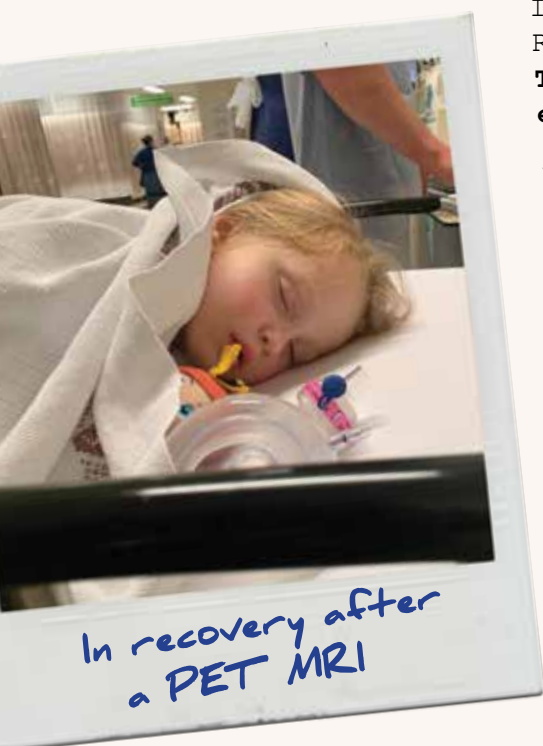
The first three months of Evelyn's childhood were uneventful. She was developing well, except she did not have very good neck strength. Then she stopped babbling. She was completely silent.

I was told not to worry... but...

**At about 4 months of age, Evelyn began to develop a twitch. It would happen when she was drifting off to sleep.** It really wasn't just a twitch - it was a full-on uncontrolled jerk.

The jerk didn't look like what I knew as a seizure. It was like she had a serious case of the shivers. This sense of dread came over me. I Googled "babies twitching in their sleep", "babies' legs jerking"... **and it came up with all these videos of babies having infantile spasm episodes.**

The spasm is very unique. Evelyn was raising her arms and jerking forward. She repeated that action. It's like a crunch. And her eyes would roll back and forth, left to right.



I took Evelyn to my GP, who told me to take her to the Royal Children's Hospital in Melbourne immediately. **That drive from home to the Children's felt like an eternity.**

Well, what was meant to be an overnight stay in Emergency became 6 long, hard weeks at the Children's. It was during this time that I remembered seeing the Epilepsy Foundation in my online searches about Evelyn's condition.

**Epilepsy has a major impact on me as her mother, on my beautiful girl, and on our entire family. It impacts her teachers and school, her learning and her ability to participate in after school activities. It impacts Evelyn's abilities to make friends...**

You see, Evelyn appears to be a "normal" little girl, but her health problems and behavioural challenges have seen her socially isolated. She struggles to engage in play with others and suffers severe frustration when trying to communicate.

**Sadly, Evelyn is well aware when people are judging or rejecting her.**

Living with epilepsy is hard. It's emotionally and physically draining. It's challenging. **More so, living with epilepsy is lonely.**

**When the neurologist told me that Evelyn has epilepsy, my head was spinning.**

**I blamed myself for causing Evelyn's condition.** I felt horrible.

I had this creeping dread that I was now going to have a child that was disabled. A child that my son will one day have the burden of looking after, when we're gone.

**I was mourning for the little girl I wanted and expected to have.**

I was full of hope for my little girl. I was going to have fun brushing and braiding her hair, choosing together the clothes she would wear, watching Evelyn

grow and become her own person. It may have been silly, but I had dreams of her following in my footsteps, playing the piano and taking a keen interest in horses, just like I did when I was a little girl.

**Realistically, Evelyn can still do all of those things.**

I was ashamed at how depressed I felt and I certainly didn't want to talk to about it. Even though that was probably a perfectly reasonable thing to say, that I was sad. But I was sad to the point that I just couldn't admit it.

**I was having to accept that she has epilepsy, she'd more than likely be intellectually disabled, delayed and highly dependent for life.** I remember thinking:

*What do I do?*

*Where do I get information?*

*Who do I talk to?*

*Who will help me and my little girl?*



At the time, my husband was away and my mum had just headed off overseas. **I felt very alone. I was sitting there thinking I can't ring my husband. I can't ring my mum. That was when I picked up the phone and called the Epilepsy Foundation.** And was put through to one of their amazing Epilepsy Support Workers, Lisa.

As I explained to Lisa what had been happening to Evelyn, she asked:

*Is it infantile spasms, have they mentioned infantile spasms?*

All I could tell her was they just said epilepsy. Lisa kept pushing and stated that we needed to find out what kind of epilepsy. Because of her experience and expertise, she knew it wasn't just epilepsy that I was describing to her.

Lisa kept asking - *Is it infantile spasms?*

It was Lisa's insistence that resulted in me insisting on the hospital staff to take better observation of Evelyn, as she was still having clusters of spasms and was not responding to the medications the hospital staff put her on.

**I need you to know that Lisa and the Epilepsy Foundation have been instrumental in our lives.** Lisa helped us understand what the future is going to hold for us and for Evelyn.

I remember Lisa saying to me when it was confirmed that Evelyn has infantile spasms:

**"You've got a long and lonely road ahead."**

She is so right.

Lisa, like everyone at the Foundation, truly understands what the loneliness of living with epilepsy means. She always checks to see that I'm okay. She has come to appointments with me and to our home on occasion to provide much-needed support. She organized the training for the staff at Evelyn's school to understand her epilepsy and know how to administer her emergency medication.

**The Foundation even picked up that the GP had made an error in their paperwork regarding Evelyn's dosage of her medication. They got it corrected!**

They encouraged me to share my perspective on Evelyn's epilepsy and even gave examples of what happens when we do or don't administer her emergency medication.



The Foundation has been critical in ensuring Evelyn's welfare at school. Today, her school is a proud Epilepsy Smart School.



We told Lisa our worries and concerns over Evelyn's risk of SUDEP. She has helped put together a support letter, quotes and information to assist us with the National Disability Insurance Scheme (NDIS) application for a nocturnal seizure monitor. If we didn't have her by our side, I really don't know who we would ask for help. We would have to find the time and become the experts ourselves.

**And the Foundation prepared and provided a detailed Epilepsy Management Plan and an Epilepsy Medication Management Plan.** Lisa was instrumental in making sure these two critically important documents were put together and that we understood them.

Whenever I need guidance, information, even moral support, I can call the Foundation. When I am after more practical support, such as the NDIS support letter, advice about traveling overseas with Evelyn, they will give me the advice I need.

The Epilepsy Foundation has been so supportive. They've treated me with respect and dignity - as a human being, a member of society, a carer, a mother. They provide unfiltered, unbiased assistance and advice. **At the end of the day, the Foundation is here for us. I am not alone.**

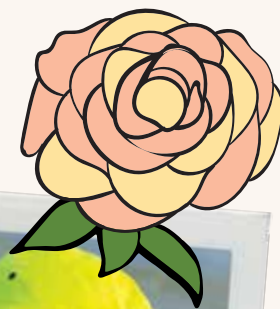
Thank you for reading my letter, and more importantly, for your kind, generous and most wonderful support of the Epilepsy Foundation.

I hope you can continue to give and help families like mine who will one day pick up the phone and call the Foundation for great support, information and care.

Yours sincerely,

Natalie x

Mum to Evelyn



My little girl will always be surrounded with the love and care she needs.



♡Xx