This is our story...

A story of courage, determination and hope

My name is Anthea. I am a wife, a mum to three beautiful children, and a grandmother to three gorgeous grandchildren. I want to share our story with you.

I believe I am very lucky. I have the most beautiful and loving family anyone could wish for. And even though we've had very challenging and difficult times, it is the love of my family that keeps me strong and keeps me going.

My son Ben has epilepsy. He had a seizure when he was only 13 years old. At the time we were told not to worry unless he had a second seizure.

Well, he did have a second seizure. In fact, he had many seizures including in the doctor's office when we were told he had epilepsy. Ben was diagnosed with complex partial seizures.

Our GP immediately put us in contact with the Epilepsy Foundation. She realised that we were going to need all the support we could get. And she was right!

The Foundation helped us understand what Ben was going through, and they gave me so much support. I am so eternally grateful to the Foundation. But I'll share more about them a little later.

My son Ben, like my two girls and grandchildren, are my entire world. When Ben smiles, my heart just sings, and all the problems just seem to melt away.


Families
ARE FOREVER

Unfortunately, life has not been easy - not for Ben and not for us.

When Ben was first diagnosed he was placed on tegratol to manage his epilepsy. For two years Ben was seizure free. So the doctors started weaning him off the medication, as they do for all patients who have been seizure free for two years.

Unfortunately, within one week of being weaned off, his seizures came back. Unfortunately they weren't just complex partial seizures - they were also absence, simple partial, complex partial, drop attacks, tonic clonic, myoclonic and the majority being tonic. He would collapse all over the house, the road, wherever we took him.

Since then we have tried everything possible to help Ben control his seizures. Every type of epilepsy medication. Every kind of operation and procedure possible including removing 5cm from the right frontal and 5cm from the right temporal, even having deep brain stimulation.

Unfortunately, over the years the operations and infections in the brain have left his skull misshapen, but he's still our Ben.

Every time we tried something new I had a glimmer of hope. But every time the seizures came back and our hope diminished. It doesn't seem to matter to Ben though.

He just smiles and says everything will be okay. He thanks me for all the things I do for him. "Thank you for showering me, thank you for making my food, thank you for being my mum."
I cannot begin to tell you how many times I have cried - mainly they are tears of joy.

My beautiful Ben means everything to me, to his dad and to his entire family.


psy
foundation

Ben has just got this amazing strength.

It doesn't matter what he has gone through he just has a positive attitude. Like the time the doctor asked him why he wasn't angry that he had this awful condition. Ben just said, "Well, that wouldn't get me anywhere in life. Why would I do that when I've got the family I've got!" That brought tears to their eyes and still makes me cry today.

I've cried a lot with Ben – happy tears, sad tears. But he always makes me smile.

Ben loves cars. When he first started to talk we were waiting for him to say "mum" or "dad". But his first word was "CAR".

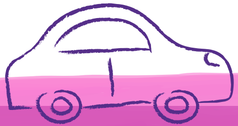
He would play with his matchbox cars all the time. Even when he was 13 he'd still play with them under the lemon tree. His dream was to become a mechanic but his epilepsy meant he would never realise that dream. For a few years he worked cleaning cars – he was so happy, and even if he had spent the night having seizures nothing was going to stop him going to work.

He especially loves Holden cars and the late Peter Brock was his idol. He just thought Peter Brock was everything.

Ben's wish was to have a hot lap with Peter Brock. And that came true for him in November 2004 when he got to do two hot laps with Peter Brock at Calder Park.

Peter Brock came up and shook his hand and Ben was like "Brockie!" I'll never ever forget it. I just couldn't stop crying. Ben has a cheeky sense of humour and told Peter Brock, "it's amazing that Bendigo is in a drought because my mum is in Bendigo and she cries all the time. She cries when she's happy, she cries when she's sad. I don't understand how we're in a drought!"

I'll never forget the look on Ben's face. The happiness and excitement in meeting his idol.



We are all so truly grateful for the Epilepsy Foundation and especially for Lisa Rath. Lisa is one of their Epilepsy Support staff. She has not only given me the support I needed over the last 20 years, but has always been there for me.

Lisa is absolutely amazing. She has provided our family with all the information, resources, and emotional support we have needed.

Over the years the Epilepsy Foundation has provided us with nurses to train every member of my family in Midazolam. Today, every one of us knows what to do when Ben has a seizure, because of the Foundation. Even Ben's nephew, eight year old Connor, knows what to do. Connor is just incredible.

When Ben has a tonic clonic seizure, Connor knows to get the Midazolam, he gets the phone to call the ambulance, he holds Ben's hand and he talks Ben through it, and tells him who's in the room with them. He's just inspirational.

We have a very close connection with the Epilepsy Foundation. They have been with us through all the highs and lows.

Over the years Lisa and other staff members have helped us better understand Ben's epilepsy, liaise with the medical profession so we understand the treatments and procedures for Ben, refer us to organisations for support services, and created epilepsy management plans.

Just as importantly has been the emotional support Lisa and everyone at the Foundation have given to me and my family.

I know that without the Epilepsy Foundation I don't think we would have made it through all of this.

My family is my world. Every day I am spoilt with love from my husband, children, and grandchildren. Every day Ben says to all of us, "I love you more than you will ever know."

And we all love him more than he will ever know.

And why I am reaching out to you.

Today, Ben lives with constant seizures. He is unable to work or even wash cars like he once loved to do. He does not get out as much as he used to.

But he still loves to drink his coffee every day - a large cappuccino, just warm. Then he sleeps during the day because of his night time seizures.

We're not sure how long we will have Ben with us. I don't want to think about that day. His epilepsy is now non-convulsive status epilepticus - a chronic form of epilepsy.

I hope you will give to the Epilepsy Foundation. They have been absolutely amazing and terrific for me, Ben and our entire family. I know of the support that they have provided to other families like mine.

We want everyone to be aware of epilepsy and to support the good work of the Foundation. We want everyone who lives with epilepsy to have all the support they need. Your donation can help one more family. And that would be wonderful.

Every minute of every day is a struggle from not being able to wake Ben for appointments and family outings, to Ben having seizures, collapsing and injuring himself while we are out and about. There are no words to explain how hard every day is but as long as we have Ben we get up each day and brave another day as he is our reason for living, and he is our everything.

He's just beautiful. And he's got this smile that just stops the world. Everybody talks about his beautiful smile.

You wouldn't believe what Ben has been through because he's so happy. He's just lived an amazing life. He's had so much love. And he gives so much love. ♥

Thank you for reading our story.

Your donation can help another family just like mine receive all the support they need.

Donate today:

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