

Ben's Story



If you were to meet Ben one of the first things you would see is his big beautiful radiant smile. When he smiles you can't help but smile too. He lights up a room with his smile.

For everything that he has gone through, for everything he has endured with his epilepsy, never once has Ben complained, and never once has he taken pity on himself.

Instead, if you were to meet Ben, you would meet one of the nicest, strongest and most positive young men I know. He meets every challenge that life has put his way with that big broad smile of his.

Ben was diagnosed with epilepsy when he was just 13 years old. He was in high-school when he had his first seizure. As is the case, his doctors waited to see if he would have another seizure before they diagnosed him with epilepsy.

Unfortunately, he not only had another seizure, he had so many seizures that he was rushed to hospital, admitted to the Austin Hospital's Epilepsy Unit to be monitored. His family were told that Ben had complex partial seizures.

Over the next 20 years his family tried everything they could to help Ben's epilepsy. He tried every form of epilepsy medication available but they didn't work. He also underwent so many different operations and procedures including having parts of his brain removed, (and ?) deep brain stimulation so as to find a way to manage his severe epilepsy. Unfortunately they too didn't work.

He loves coffee. In fact his favourite coffee is a large cappuccino, just warm. Every café owner in Bendigo, where Ben and his family live, knows Ben's order by heart! He loves Holden cars, and









doesn't mind the Ford now that his dad Darren has a Ford Ute. And his favourite colour is purple because it represents epilepsy.

More so he is grateful for the love and support he receives from his family – his mum Anthea, his dad Darren, and his two sisters Jess and Rebecca and their families. And he is thankful for the help his family gets from Epilepsy New Zealand.

Today Ben lives with tonic clonic seizures. They come in waves of clusters. Nights are the worst where he can have anywhere between 20 and 40 seizures. Because of this it's not unusual for Ben to sleep during the day. As Anthea says, "you can't wake Ben when he's asleep."

Epilepsy New Zealand has been with Ben and his family from the day he was diagnosed with epilepsy. And we will continue to be with them for the long haul providing all the support they need to best manage Ben's epilepsy.

Epilepsy New Zealand Support Workers have been instrumental in providing support, training and information to Ben, Anthea and their family for those 20 years. They have developed <u>epilepsy</u> <u>management plans</u>, delivered <u>training in Midazolam</u> and <u>epilepsy first aid</u> for every member of the family, and she's a rock of support for Anthea and Darren.

Anthea is grateful for the support Epilepsy New Zealand has provided to herself and her family. Read about Anthea's story here:

Anthea's Story (PDF booklet)Download

