Nick

When you see eleven year old Nick carve up the tennis court with his best mate Jasper and sister Maddy, he looks like any other eleven year old budding sports star.

What you can't see is the challenges Nick and his family overcome everyday living with his epilepsy. This is why Nick's mother Mel calls it an 'invisible disability'.

The invisibility of epilepsy in talented and social children like Nick is one of the reasons why Mel thinks that it takes so long to recognise and diagnose the condition.

It took a number of years for a paediatrician to confirm Mel's long held suspicions about what her son was experiencing. Nick was diagnosed with absence seizures at age five.

An eyebrow twitch, vagueness, having to repeat herself, and a feeling that her son was on 'auto pilot', made it clear to Mel that something was not quite right. At the time Nick's behaviour was largely passed off as regular naughty behaviour by the professionals.

Further testing through MRI and telemetry monitoring did not show up any seizures, Nick's seizures were only picked up when he was 5 on an EEG. The EEG showed that Nick was experiencing 30 to 50 seizures a day before he was on medication.

Since his initial diagnosis, Nick has also experienced complex partial seizures He has been on many combinations of medication including medication for ADHD and anxiety.

Sport is undoubtedly Nick's super power and his loving and endearing nature mean that he gets along with everyone and can't go anywhere without bumping into a friend.

Learning in the classroom however has been a challenge for Nick and he has been diagnosed with a Learning Disorder in reading, writing and mathematics. He has difficulty with short term memory and it is clear that the combined effect of his seizures, fatigue and medication also make it hard to retain and process information and have seen him miss out on learning basic fundamentals.

Nick now works in the classroom with the support of a Chromebook with speech recognition and other support to scribe and read to him as required which takes some pressure off reading and writing in the traditional way.

Nick's sense of frustration learning can be exacerbated as his younger sister, eight year old Maddy, who learns with ease. Referring to the way that his condition impacts on the whole family unity, Mel says, "It is not only hard for Nick, it is tricky for Maddy too, she has in many ways had to become a big sister to support her brother".

When asked how Nick feels about his epilepsy, he says he is 'angry, sad, tired – every single mood'. Mel affirms this saying 'he can be angry, laughing and crying all within five minutes'.

For Nick's family, the impact on his mental health is the most worrying thing to deal with.
'I just don't want to live anymore. I just want to fly away and be a bird', Nick would tell his mum.

"It breaks your heart and you can't help but be completely on edge when your son tells you he doesn't want to go on," Mel says.

Nick needs constant monitoring. It is simple things like taking a shower or ensuring he is present when he is crossing the road. "I do worry about what his future will be like if I am not here. That is my main goal to give him the skills he needs to be as independent as he can,"
Mel says.

Mel talks about Nick's best mate Jasper and the immense support he provides Nick with a smile. "Jasper has been by Nick's side since kindergarten. Whenever he is admitted to hospital, Jasper will come to visit. He will also check on him through the day and ask 'is your brain ok mate?' To think that a young boy could have such a big heart and make such an impact is pretty heart-warming," Mel says.

Specialists refer to Nick's case as a complex one. This has resulted in an incredibly tough journey for Nick and his family. A road that has constant ups and downs and regular questioning and uncertainty about what is best for Nick.

What is certain, is that Nick is an incredibly talented, resilient, social and athletic boy who is surrounded by an incredibly supportive and loving family and friends.

Nick's struggle with school, his mental health and the ongoing challenge to effectively manage his seizures have led to the family's decision to start reducing his epilepsy medication after six years of various treatments.

With the hope that, while potentially increasing the chance of a seizure, Nick might have more energy, be able to start retaining more information and feel more functional.

When you ask Mel what advice she would have for other parents supporting their children diagnosed with epilepsy, she says, 'be vocal, keep seeking answers and if possible make sure you are not taking the journey alone' – whether it be support through family, friends or service providers like Epilepsy ACT.

If you would like to share your story please contact us on epilepsy@epilepsyact.org.au

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