

Matt, 30

Father & graphic designer whose epilepsy continues to limit his career potential, **GOLD COAST**

Graphic designer and father-to-one, Matt, 30, Gold Coast enjoys creating illustrations and spending time with his five-year-old son.

At 10 years of age, Matt began to experience spells during which he would lose attention and stare into space. Over time these episodes became more frequent and intense, from which he would emerge speaking incomprehensibly and fiddling with his fingers. Questioning the cause of these spells, Matt's GP referred him for an electroencephalogram (EEG) and a consultation with a neurologist. The neurologist subsequently diagnosed Matt with epilepsy when he was in fifth grade.

Living with epilepsy is challenging for Matt, given his seizure triggers are stress and fatigue-related – common aspects of his daily life. Forced to leave high school early to avoid the stress of his senior school years, Matt's career aspirations have unfortunately been limited by his epilepsy.

Armed with strong support from his family and fiancé however, Matt has learned to manage his epilepsy and to overcome his struggle with depression. These days Matt insists on leading a full life, despite living with the uncertainty of his next potential seizure.

Matt is supporting *Look for epilepsy*, a UCB-led community engagement initiative designed to highlight the much-needed support available to those living with epilepsy, and their carers, while raising awareness of the neurological disease. He is a vocal advocate for those living with epilepsy, and lives in hope that with greater awareness and understanding, the Australian community will learn how to better support those living with the disease.

This is Matt's story.

Growing up in Sydney, Matt had a fairly typical childhood up until 10 years of age, when he began to experience attention lapses. As these episodes continued to increase in frequency and severity, Matt's concerned parents escorted him to their local GP, who expressed concern over his symptoms. Matt was subsequently referred to a neurologist after undergoing an EEG, which led to his diagnosis with epilepsy.

Initially, Matt experienced seizures once every three months. However, his seizures increased in frequency, heading into his teens. Growing up with epilepsy was challenging for both Matt, and his parents.

"I took a lot of my frustration out on my parents as a teenager. Looking back, I now realise just how concerned they were about me, and how much they helped me," said Matt.

Matt soon realised that his seizures were triggered by fatigue and increased stress. So, when he reached year 11, he chose to leave, in order to avoid the pressure-cooker of the final years.

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As an adult living on the Gold Coast, Matt's epilepsy grew even more challenging to manage when he became a father to River, now five. Lacking sleep with his then newborn child triggered more frequent seizures for Matt – up to two per day – leaving his wife at the time to care for both her husband and her son.

“Over time, our relationship broke down and we divorced. My epilepsy was a major contributor to these events,” Matt said.

Matt's epilepsy has proven career-limiting as a graphic designer. Due to his epilepsy, he is unable to drive, and is therefore reliant upon public transport to commute to and from work, which significantly restricts his job location options. In addition, given fatigue and stress serve as triggers for Matt's seizures, he has been unable to climb the corporate ladder.

“Despite my eight years' experience as a graphic designer, I need to be very selective about the jobs I choose to go for. I can't go for jobs that push my stress levels. It's extremely frustrating that I can't take a job at a level for which I'm qualified.

“My epilepsy also makes me feel extremely tired all of the time, especially after a seizure. I sometimes need to sleep for a couple of hours afterwards, which can really affect my day,” said Matt.

Matt continues to experience epileptic seizures, anywhere between once-a-week, to once-a-month. Fortunately, he is yet to sustain any physical injuries from having epileptic seizures. He remains concerned however, that should he not be in a safe place at seizure onset, this could prove dangerous. What Matt most struggles with however, is the hold that epilepsy has on his independence, and his need to rely on others for help and support.

“My memory is affected by my epilepsy. I have difficulty remembering small, everyday tasks, including work-related tasks or the need to take my medication, which can be a vicious cycle.

“Fortunately, I have a very supportive fiancé. She does a lot for me. She drives me to work and is very understanding of the ups and downs that come with living with epilepsy,” said Matt.

Matt is supporting *Look for epilepsy*, a UCB-led community engagement initiative designed to highlight the much-needed support available to those living with epilepsy, and their carers, while raising awareness of the neurological disease.

He is passionate about vocalising his journey with epilepsy to heighten community awareness, and to help minimise the abundant myths and misunderstanding associated with the disease.

“Epilepsy isn't widely discussed, although the disease affects so many Australians. The more awareness we create around epilepsy, the better informed our community will be, should they need to come to someone's aid if experiencing a seizure,” Matt said.

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MEDIA CONTACTS: Kirsten Bruce, Holly Hamilton Green & Bella Poidevin
VIVA! Communications
M 0401 717 566 | 0434 799 839 | 0423 041 631
E kirstenbruce@vivacommunications.com.au
holly@vivacommunications.com.au
isabella@vivacommunications.com.au