

## Madz - An Epilepsy

# Success Story.

**Two years ago, Madz Spence was one of the estimated four thousand people who every year face the shock news that they have epilepsy.**

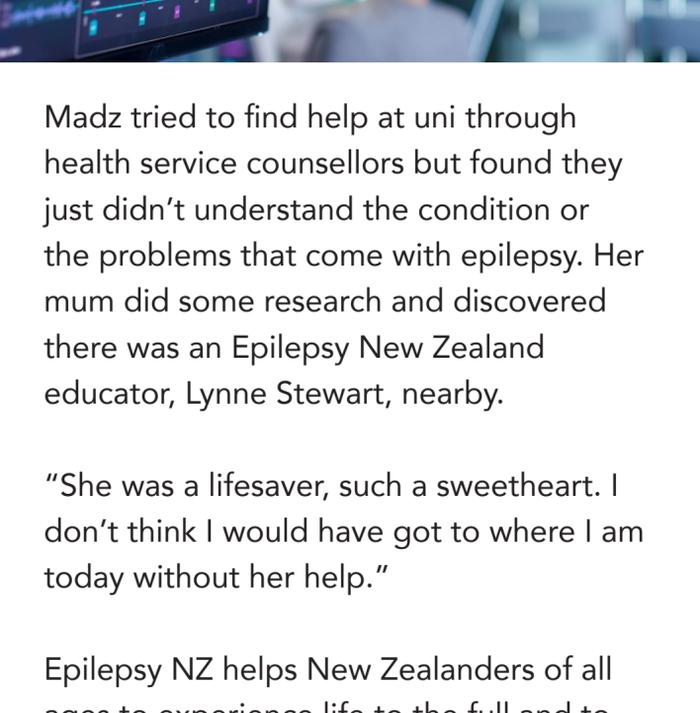
**F**or Madz, it was a moment she has described as “a spanner in the works,” which is probably something of an understatement.

In early 2018 she started having moments where she couldn’t speak or understand what people were saying to her. Then it was hospital tests and the diagnosis: epilepsy and anti-seizure medication. Madz says she has always been a “lively” person, but the struggles to deal with the condition and the lack of understanding from those around her made day-to-day life difficult. To make it worse, she was at university and living away from home. Madz couldn’t see how she could cope.

“There is still a lot of stigma around seizures and epilepsy. When I told people, I had epilepsy people would think ...she’s going to have a big seizure.”

And people are scared, they don’t know what’s going on, or how to deal with it. It can be difficult, even when you have epilepsy yourself.

“When I was in the hospital having EEG monitoring, I was put in a room with a young girl who had seizures that were worse than mine. Her first one was massive, and I was shocked. I didn’t know what to expect. But after that it was fine, I just held her hand and told her to breathe and that it would be OK.”



Madz tried to find help at uni through health service counsellors but found they just didn’t understand the condition or the problems that come with epilepsy. Her mum did some research and discovered there was an Epilepsy New Zealand educator, Lynne Stewart, nearby.

“She was a lifesaver, such a sweetheart. I don’t think I would have got to where I am today without her help.”

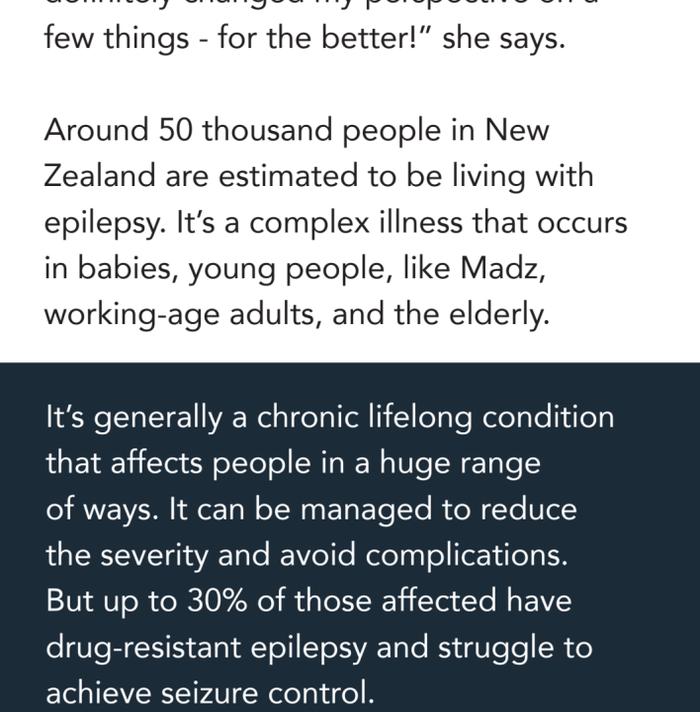
Epilepsy NZ helps New Zealanders of all ages to experience life to the full and to find their way to manage this generally lifelong condition.

Madz needed help and advice to get through university. Times of stress, such as exams, often made her epilepsy worse, as it does with many others. Lynne was able to speak to her lecturers and support Madz when she missed assessments and had to apply for aggregates.

**“100% if it hadn’t been for Lynne I wouldn’t have got through my degree,” Madz says.**

Life is now good for Madz. She works in Auckland, has a supportive partner who isn’t fazed by what she calls “her blips” and has a great flat and flatmates.

The one thing Madz would like, would be to get her driving license back, which would require a period without seizures. However, there are still treatment options on the table and surgery could well be a possibility soon.



To payback for the support she got from Epilepsy New Zealand and to help others facing similar challenges, Madz opened a Givealittle page to raise funds for ENZ by running in the 2020 Auckland marathon.

“I’m a firm believer that everything does happen for a reason, and this one definitely changed my perspective on a few things - for the better!” she says.

Around 50 thousand people in New Zealand are estimated to be living with epilepsy. It’s a complex illness that occurs in babies, young people, like Madz, working-age adults, and the elderly.

It’s generally a chronic lifelong condition that affects people in a huge range of ways. It can be managed to reduce the severity and avoid complications. But up to 30% of those affected have drug-resistant epilepsy and struggle to achieve seizure control.

Those living with epilepsy often experience significant discrimination when it comes to employment and there is a lack of understanding and stigma associated with the illness.

But Epilepsy New Zealand is doing what it can to help; offering support and advice to individuals and whanau, advocating for people with epilepsy, and challenging the misconceptions held about this complicated and often debilitating illness.



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*kia titiro ki te tangata - see the person*  
<http://epilepsy.org.nz/>