



press clip

Maggie sheds light on a rare epilepsy

BY ANTHONY LONCARIC

MAGGIE Zeffiro goes to bed each night fearing her daughter might stop breathing if she has a seizure.

Her daughter Vanessa, 17, suffers from a rare type of epilepsy known as Dravet syndrome, which is difficult to control even with medication.

Vanessa has a seizure nearly once a week. She often has tonic clonic seizures, which cause her to stiffen, fall to the ground and jerk uncontrollably. She sleeps in the same room as her parents in their Keilor Downs home because a seizure could strike any moment.

"I had to give up my job to be her full-time carer. You really have to be by her side all the time because you never know when the next seizure is going to happen," Mrs Zeffiro said. "We've learned to live with it, but you never stop worrying."

Vanessa started having seizures when she was four months old but was only diagnosed with Dravet syndrome at age 12. "After that first one she had a lot of different seizures, all from fevers

associated with normal childhood illness, but they were prolonged and one lasted 55 minutes," Mrs Zeffiro said. "I was looking at some information on Dravet syndrome on the internet and it sounded like what my daughter had."

Mrs Zeffiro says there is a lack of awareness about different types of epilepsy and she is hoping to change that during Epilepsy Awareness Week (March 19-26). "Getting in touch with the Epilepsy Foundation has been fantastic because it's got me in contact with other families who have children with epilepsy."

Epilepsy Foundation of Victoria's chief executive, Graeme Shears, said Epilepsy Week and Purple Day (March 26) provided a chance to reduce the social stigma attached to epilepsy. "A large part of our work is about raising awareness of epilepsy so people have a better chance of being accepted in the community and getting on with life in a more positive way."

Mrs Zeffiro and her husband John have set up a website providing details on Dravet syndrome. Visit www.dravetsyndrome.com



By her side: Maggie Zeffiro with Vanessa, who has a rare type of epilepsy.

Picture: Paul Trezise