Charlotte

Charlotte Woodward is a whirlwind of creative talent and she has no intention of letting anything get in the way of her passions. Not even her epilepsy.

"I love ballet, but I also do hip-hop and contemporary dance, and jazz is my favourite," says the nine-year-old enthusiastically.

In year four at Canberra Girls Grammar School, according to mum, Kirsty, it would seem Charlotte was literally born a performer.

"Almost as soon as she could walk, she wanted to dance," laughs Kirsty.

"Charlotte also loves to sing, write poetry and do drama. Along with completing her annual Royal Academy of Dance Ballet exams, she's about to compete in her first dance Eisteddfod and undertaking her first vocal exam later this year."

On top of training 14 hours a week with the National Capital Ballet School in Phillip, Charlotte sings in an school choir which won both platinum and gold prizes at the 2018 Australian National Eisteddfod.

She's also a fundraising dynamo and over the last three years, has raised almost $4,000 for Epilepsy ACT, holding a lemonade and bake sale in the front yard of the family's Canberra home.

That's a huge program for anyone, but when you're dealing with a condition that requires regular trips to Sydney to visit specialists, the commitment is far beyond expectations for someone so young.

"Charlotte was diagnosed with absence seizure epilepsy in 2013, when she was three," says Kirsty.

"There are no specialists in Canberra so we were taking quarterly trips to Sydney to see her neurologist. She's currently both medication and seizure free. However, we continue to travel to Sydney at various times throughout the year for therapy as Charlotte has visual processing issues, often linked to epilepsy."

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Absence seizures result in brief periods of blanking out or staring into space. They're previously known as petit mal seizures and are most common in children. "Seizures can often go unnoticed, people thinking that it's little more than daydreaming. After Charlotte's first episode though, she was having anywhere between 30 and 100 a day, particularly when we were trying to get the medication right," she explains.

"It's been two-and-a-half years since her last seizure, but of course, something could happen at any time, or it could progress to more serious things. It's a matter of vigilance and knowing what to look out for."

Charlotte's epilepsy was triggered on hitting her head after a fall from playground equipment. There had been a family history, with Kirsty's brother experiencing tonic clonic seizures, which can result in loss of consciousness and noticeable muscle contractions.

According to Charlotte, she has moments where her condition is of concern to her. "Sometimes it can be scary," she relates.

"Once,when I was about four, we were at the beach and I had a seizure and dad had to rush into the water to get me because I'd just walked in without knowing it."

Overall, the busy young lady feels she has more than enough other activities on which to focus to let it take up too much of her attention. "Sometimes I talk about it to my friends, but usually I don't worry about it or even think about it," she says.

Kirsty and Charlotte's dad, Glenn, both believe the best way to manage the condition from a family and friends point of view is to have good support and be informed.

"Having a network is really important," says Glenn. "We initially didn't know about Epilepsy ACT and they're such a valuable local resource. Through them we've been able to meet other families and this helps normalise things for kids."

"The other factor is education - people need to know more about epilepsy, what it is, and the various ways it might manifest."

Kirsty agrees that it's about awareness.

""We've always been honest and open with Charlotte - why she blanks out or looks at the light. That way she can explain for herself."

"The fundraising she wanted to do for Epilepsy ACT was also to help promote the profile of this wonderful organisation and the work they do."

"While we did have to make adjustments, we didn't stop ballet or dancing - we work around it because life shouldn't stop.

"When Charlotte is asked for her advice to anyone who might find themselves in a similar situation, she's very practical. "Stay calm and know that it might not go on forever," she says. "Having a good specialist helped me a lot and you should make sure that your school knows, in case something happens and so they don't think you're just not paying attention.

"It seems that Charlotte's only daydreams are all about her future ambitions. "I'd definitely like to continue with dancing, singing and drama," she enthuses. "And I might want to own a dance studio, be a writer or a nurse. So many things!"

epilepsy ACT

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