



NTL MEDIA RELEASE

THURSDAY, MARCH 26, 2020
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1 in 10 Aussies with epilepsy sustaining serious physical injuries

Call to improve community awareness, support & response to seizures this Purple Day®

One in 10 Australians living with epilepsy experience a seizure-related injury each year, many of which are potentially life-threatening, according to an article just published in *MJA InSight* to mark Purple Day® (an international epilepsy awareness day).¹

The most commonly reported seizure-related injuries sustained by those living with the neurological (brain) disease include head (one-in-four of which require stitches), water immersion (almost 26 per cent), driving (14 per cent), burns (14 per cent), fractures (10 per cent) and dental-related injuries (10 per cent).^{1,2}

Doctors, advocacy groups, patients and their families are joining forces Australia-wide today to highlight the serious injuries caused by epileptic seizures, and call for heightened awareness, understanding and support for the 250,000 Australians living with epilepsy,³ to create calmer waters through which they can safely navigate their physical journey with the disease.

According to *MJA InSight* article co-author and Consultant Neurologist and Epileptologist, Royal Prince Alfred Hospital and Sharp Neurology, Dr Kaitlyn Parratt, Sydney, experiencing even one seizure a year can pose risk of serious injury.¹

“A seizure is the result of abnormal, excessive or recurring electrical activity in the brain,⁴ noting there is tremendous physical risk associated with experiencing seizures.

“One in three Australians living with epilepsy will sustain a seizure-related injury in their lifetime, more than 50 per cent of which will prove particularly dangerous to the head, or will occur at home in the bath or swimming pool,”² said Dr Parratt.

“Australians living with epilepsy are at 15-to-19 times greater risk of drowning than the general population,^{1,5} and are also at risk of sustaining a range of other injuries, including burns, serious fractures, dislocations and car accidents.^{1,6}

“It is therefore vital we improve community understanding of the physical dangers faced by those experiencing epileptic seizures, and educate people on how to react in the event of a seizure, to help maximise patient safety,” Dr Parratt said.

The epilepsy community's call today coincides with the launch of **'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 brain disease. The initiative urges Australians to lend their support to members of the epilepsy community by visiting lookforepilepsy.com.au, taking a selfie with a purple glasses filter on the site, and sharing the selfie on their social media channels to support epilepsy awareness, using the hashtag **#lookforepilepsy**.

MJA InSight article co-author and neurologist, epileptologist and epidemiologist, A/Prof Wendyl D'Souza, St Vincent's Hospital, Melbourne, who is supporting the *Look for epilepsy* initiative, hopes new and improved ways of predicting seizures will reduce risk factors for Australians living with epilepsy.

“Concerningly, people living with epilepsy have a mortality rate of up to three times higher than the general population.⁷ A frequent cause of epilepsy-related death is Sudden Unexpected Death in Epilepsy (SUDEP), where sudden death occurs in a person with the disease for no apparent reason.⁸

“However, according to emerging Australian research into seizure patterns, while long-considered to be unpredictable, there is, in fact, a person-specific long-term pattern to seizures in most (80 per cent) cases,”¹ said A/Prof D'Souza.

“The ability to forecast when someone may be at high risk of seizures through wearable devices, for instance, may help to reduce uncertainty, and allow for the implementation of preventative strategies to minimise the risk of physical injury, and SUDEP.”¹

Passionate cellist and Sydney Conservatorium of Music student, Amy, 20, Sydney, who was diagnosed with epilepsy in 2017, understands the severe physical and mental toll of experiencing seizures. She predominantly experiences absence seizures, during which she blanks out, or stares into space for between two-to-10 seconds.⁹ **more#**

During a high intensity interval gym training session one day however, Amy experienced her first and only tonic-clonic seizure (involving a loss of consciousness and alternating stiffness and jerking).⁹

She fell off the treadmill, and hit her head hard on the ground, and later learned that hyperventilation from over-exertion was one of her seizure triggers.

“Living with epilepsy is very challenging, both physically and mentally. The disease affects my memory and the seizures make me very tired.

“I love to run, snowboard and swim, but I'm always worried that having a seizure could cause me to fall, hit my head, or even drown,” said Amy.

“If I'm crossing the road while having an absence seizure, I could literally freeze for up to 10 seconds and a car could hit me.”

Fortunately, armed with the invaluable care and support from her family, neurologist, and anti-epileptic medication, Amy has been seizure-free for the past 14 months. She is not however, free from the strong, relentless shackles of uncertainty involving recurrent seizures.

“My friends see that I'm seizure free, and think my epilepsy has gone, and I'm fine now. What they often don't realise however, is just how much of my life epilepsy continues to consume.

“This Purple Day®, I'm calling for people to recognise the seriousness of epilepsy, the dangers of seizures, and the daily physical and mental challenges faced by people like me,” Amy said.

Epilepsy Action Australia CEO and Managing Director, Carol Ireland, hopes improving awareness of epilepsy will serve to address the abundant myths and misconceptions surrounding the disease.

“There are many common myths and misconceptions involving epilepsy. Epilepsy is something everyone has heard of, but that's usually the extent of their knowledge. Some people think it's psychiatric in nature, but it's certainly not. It's very physical.

“That's why the *Look for epilepsy* initiative is so important, because it allows our community to raise awareness of epilepsy, and reinforce the much needed support available to those in need,” said Ms Ireland.

Today (March 26) is Purple Day®, a global initiative that aims to heighten community awareness of epilepsy. Through the joint efforts of Epilepsy Action Australia, Epilepsy Australia, Epilepsy Queensland, Epilepsy ACT, the Epilepsy Foundation, Epilepsy Tasmania, The Epilepsy Centre (SA and NT) and Epilepsy WA, landmarks Australia-wide will turn purple this evening, to honour this important occasion, and applaud those living with epilepsy locally, and around the world. Some of the Australian illuminations will include the Story Bridge in Brisbane, The Royal Mint in Canberra, The Melbourne Star Observation Wheel, Government House in Hobart, Adelaide Oval and the Optus Stadium in Perth.

- **To join the *Look for epilepsy* initiative, head to www.lookforepilepsy.com.au.**
- **To access support, information and innovative services for those living with, and affected by epilepsy, head to www.epilepsy.org.au or call an Epilepsy Action Australia Epilepsy Nurse on Monday to Friday between 9am to 5pm on 1300 37 45 37.**
- **For counselling, support and information, head to Epilepsy Australia at www.epilepsyaustralia.net or call the Epilepsy Australia National Helpline on 1300 852 853.**

About epilepsy

Epilepsy is a common brain disease involving recurrent seizures¹⁰ caused by a temporary disruption of electrical activity in the brain.¹⁰ Epilepsy is not just one condition,¹¹ there are many different types, characterised by recurrent seizures,¹² noting not all seizures are epileptic.¹³

Epilepsy can develop at any age, regardless of gender or ethnicity.^{11,13} However, epilepsy is more likely to be diagnosed in childhood or senior years, noting children represent approximately 40 per cent of the epilepsy population.¹⁰ Epilepsy affects an estimated 50 million people world-wide,⁷ with an estimated three-to-four per cent of Australians will develop epilepsy in their lifetime.¹¹

Purple Day is a Registered Trademark of The Anita Kaufmann Foundation.

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For more information, or to organise an interview, contact Kirsten Bruce, Holly Hamilton Green or Bella Poidevin from VIVA! Communications on 02 9968 3741 or 0401 717 566, 0434 799 839 or 0423 041 631.

DIGITAL MEDIA KIT + VISION:

**Digital media kit – www.epilepsymediakit.com.au
Broadcast vision available for download –
<https://vimeo.com/400152677/f254845227>**

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