Media Room

The background below provides key facts about Epilepsy New Zealand, epilepsy and seizures.

Epilepsy New Zealand welcomes the opportunity to speak with media to raise community awareness of epilepsy, reduce and dispel the stigma associated with this condition, and share evidence-based information and statistics with the public.

EPILEPSY NEW ZEALAND – BACKGROUND

Epilepsy is a neurological condition that involves recurring seizures, which can greatly affect a person's education, employment and independence.

Our Mission is to improve the quality of lives of New Zealanders living with epilepsy.

Our Vision is a New Zealand that is free of discrimination and stigma, where the impacts of epilepsy on a persons life, and that of their whanau and community, are minimised.

Epilepsy New Zealand was founded in 1956 and works to ensure that no one with epilepsy goes it alone. We support people with epilepsy, and all those who care for them, right across New Zealand.

Epilepsy New Zealand works with medical specialists to ensure that the support we provide is current, grounded in evidence and impactful.

Epilepsy New Zealand hopes to further develop and deploy programmes to encourage all New Zealanders to learn about epilepsy and gain confidence in supporting people living with epilepsy and/or experiencing a seizure.

EPILEPSY NEW ZEALAND – OUR SERVICES

– **Information and Resources** – Our Information and Support Line is staffed by Epilepsy Educators with expertise in how epilepsy affects health, wellbeing and daily living, incorporating person-centred, self-management strategies.

– **Epilepsy Support Services** – Our Epilepsy Educators assist people with epilepsy and their whanau and support networks, providing advice and information about epilepsy, advice about risk management and living well with epilepsy, individualised support for people with epilepsy who require assistance with accessing supports and community resources and development of Seizure

Management Plans.

– Education and Training – We offer evidence-based, person-centred training programmes for families, schools, communities and workplaces to increase awareness and understanding of epilepsy.

– Peer Support – We run a number of peer support groups throughout the year for families, young people and adults living with epilepsy. Our website, Facebook page and blog provide opportunities for people living with epilepsy and their families to connect and share their stories.

EPILEPSY – DEFINITION AND RATES

– Epilepsy is a chronic medical condition that affects the brain and results in recurring seizures.

– Epilepsy can develop at any age, regardless of gender or cultural background.

– Around 1 percent of the New Zealand population, or 47,000 people, currently live with epilepsy. However, 1 in 25 New Zealanders will be diagnosed with epilepsy at some point in their life.

– Epilepsy is the most common serious brain disorder globally and more common than Parkinson's disease, multiple sclerosis, motor neurone disease and cerebral palsy.

– With an ageing population, people over the age of 60 are now the largest group of New Zealanders living with epilepsy.

– 1 in 200 New Zealand children live with epilepsy.

– 1 in 4 people with a profound disability also live with epilepsy.

EPILEPSY – CAUSES AND DIAGNOSIS

– Epilepsy is not contagious.

– The exact cause of epilepsy is unknown in approximately 6 out of 10 people living with the disorder. Some of the known causes of epilepsy are head trauma, central nervous system (CNS) infections, tumours, strokes and inherited, developmental or genetic conditions.

– Epilepsy is diagnosed if someone has at least two unprovoked seizures or one unprovoked seizure and a probability of further seizures happening.

EPILEPSY – SOCIAL AND ECONOMIC IMPACTS

– Due to the unpredictability of seizures, people experience them in public places, water, festivals, homes and on roads or public transport.

– People often don't talk about their epilepsy because they fear how they will be treated if they do so. Therefore many don't disclose their condition to others, including family, friends and co-workers.

– The stigma or social consequences of epilepsy is often worse than the disorder itself. People living with epilepsy can be publicly ridiculed, ignored when medical assistance is required and face employment and education challenges.

– Some people living with epilepsy are not allowed to drive vehicles and may even be restricted from pursuing certain jobs due to the risk of injury or death.

– Stigma and societal discrimination is largely due to a lack of public awareness or misinformation about epilepsy.

– There is a significant link between epilepsy, anxiety and depression.

– People living with epilepsy have a mortality rate two to three times higher than the general population. Epilepsy is within the top five causes of avoidable mortality for people aged 5-29 years.

– In New Zealand, epilepsy causes approximately 300 deaths per year. The most frequent cause is Sudden Unexpected Death in Epilepsy (SUDEP) where there is no other medical explanation for the death (e.g. cardiac arrest). Other causes of death include seizure-related accidents, drownings and even suicide.

EPILEPSY – MANAGEMENT

– Around 70 percent of people living with epilepsy can successfully manage seizure activity through anti-seizure medication, while the remaining 30 percent do not gain control through medication. Some people whose epilepsy is not controlled through medication may undergo neurosurgery, follow medically managed diets and/or trial new treatments to try to reduce seizure activity.

– Most people living with epilepsy can successfully minimise the effects of the disorder (including seizures) on their everyday life with a tailored epilepsy management plan involving:

- Taking medication as prescribed
- Visiting a neurologist to optimally manage the condition and any side effects
- Learning to identify and manage potential seizure triggers
- Keeping a seizure diary
- Developing and maintaining a Seizure Management Plan so family, friends, school or workplace colleagues know what to do in the event of a seizure
- Maintaining a healthy and balanced lifestyle
- Managing risks (such as fire, water, heights, operating machinery and driving)
- Learning more about epilepsy and their particular type

- Accessing available epilepsy support organisations and peer support networks.

EPILEPSY – SEIZURES

– Epilepsy is not just one condition, it is a diverse group of complex brain disorders resulting in recurrent seizures.

– Seizures occur because of a temporary disruption to electrical activity in the brain, leading to change in a person's movement, behaviour, level of awareness and/or feelings.

– During a seizure people are not capable of controlling their symptoms and behaviours and may not be aware that a seizure has occurred.

– Everyone's experience of a seizure is different. For example, some people will still be alert during a seizure and will be able to remember what happened afterwards. Others will be unaware and unable to respond to those around them during a seizure.

– Some seizures are considered a medical emergency, requiring medical intervention in hospital.

– A person can experience 'focal onset seizures' and/or 'generalised onset seizures'.

- Focal onset seizures include:
    - *Focal aware seizures* – the person is aware and may experience feelings such as déjà vu, an unpleasant smell or taste, or sensations such as 'butterflies' or nausea. These seizures may also involve motor activity (such as involuntary and brief jerking of an arm or leg) or autonomic behaviours (such as fiddling with clothing or pointing).
    - *Focal impaired awareness seizures* – the person may appear confused and dazed, and may do strange and repetitive actions (such as fiddling with their clothes, making chewing movements with their mouth or uttering unusual sounds).

- Generalised onset seizures include:
    - *Tonic-clonic seizures* – the person's body stiffens and, if standing, they fall to the ground (tonic phase – stiffening of the muscles) followed by their limbs jerking in strong, symmetrical, rhythmic movements (clonic phase – the shaking of the body). A person experiencing this type of seizure may produce excess saliva from the mouth, go blue in the face, lose control of their bladder and/or bowel, or bite their tongue and/or cheek. The person may also create vocal noises as the muscles in the chest contract and the air rushes through the vocal cords, making a sound.
    - *Tonic seizures* – cause the person's body, arms and legs to become very stiff and rigid (tonic – stiffening of the muscles) and may cause a person to fall and injure themselves.
    - *Clonic seizures* – involve repetitive, rhythmic jerks that involve both sides of the body at the same time and most commonly occur in babies.
    - *Atonic seizures* – cause a sudden loss or decrease of normal muscle tone, with the

person often falling to the ground if standing prior to the seizure and may cause an injury as a result.

- *Myoclonic seizures* – are brief, shock-like jerks of a muscle or a group of muscles, usually involving the upper body but sometimes the whole body as well.
- *Absence seizures* – cause a lapse in awareness and activity, and can be so brief that a person experiencing one is mistakenly thought to be ‘day-dreaming’ or ‘zoning out’.
- *Myoclonic absence seizures* – include rhythmic myoclonic jerks of the shoulders and arms and can also include rhythmic protrusion of the lips, twitching of the corners of the mouth, jaw jerking and/or elevation of the arms.