Fact Sheet 30

We are...

removing stigma, fear and prejudice around epilepsy

Epilepsy is a complex neurological condition that impacts on the quality of life for those living directly, and indirectly, with it. Epilepsy can be difficult to diagnose and to treat but, also importantly, it is a disease that can engender unnecessary stigma, prejudice, and fear within families and communities

1. Throughout the ages, epilepsy has been a misunderstood condition and, according to a recent international report, the perceptions, fears and stigma still exist within parts of our community today. Although most people with epilepsy do live with near-normal lives, quite a few carry the burden of their condition daily in many different ways. For example, they may have difficulties in education, employment, financial constraints, finding safe and affordable housing, and social isolation.

   Epilepsy is still the least understood and most maligned of all medical conditions and it continues to conjure up negative stereotypes of what epilepsy is. It is therefore important to improve public awareness of the condition at all levels of society if we are to eliminate that stigma. Removing terms such as ‘epileptic’ in preference to ‘a person with epilepsy’, is also important since, epilepsy is the medical condition and does not identify who a person is.

   Stigma can cause people living with epilepsy to feel shame, fear, rejection and discrimination.

2. We need the support of others in our community to provide the level of care necessary to improve the quality of life for those living directly, and indirectly with epilepsy. EWCT will continue to educate providers such as “Work and Income”, government ministries etc, on the many challenges affecting people living with epilepsy. Without their awareness of the epilepsy condition, people with epilepsy will continue to encounter stigma, fear and prejudice in New Zealand at that level.

   Collaborative endeavours are also important between organisations which represent related conditions such as with mental health, stroke and autism. EWCT regularly identifies common goals and carries our joint activities so that a person living with epilepsy is better supported.

   Despite the impacts and social cost of epilepsy, it generally has a low priority in many systems. The most likely reason for this will be the lack of understanding of what it is like to have epilepsy.

3. Epilepsy is a complex neurological disorder that is characterised by unpredictable seizures. It is considered a spectrum disorder since it affects people in many different ways. Some people live well with little, or no, impact from having epilepsy. Others feel that their lives are greatly affected by it. The challenge facing approximately 48,000 New Zealanders living with epilepsy is having access to a high-quality and coordinated health care system whilst dealing with stigma and common public misunderstandings. Epilepsy can impose immense burdens on individuals, families and society. To improve the quality of life for all we must learn to speak out about these challenges, and the most persuasive advocate to do this is the person living with the condition. See our "Postcard Project" (https://ewct.org.nz/postcard-project/) on what 32 New Zealanders shared about living with epilepsy.

   Barrier of fear, ignorance and stigma are broken down when people take the risk to break the silence and speak out.

4. Becoming a young adult is often a difficult time in a person's life and the path to adulthood can be a tricky one. Young adults will experience intense physical and emotional changes as a result of puberty. They will face parental, societal and school expectations, peer and social pressures, discovering new relationships, independence issues and they will be developing self- identity and self-esteem. In other words, it is a period of dramatic growth and personal development.

   Adults, especially parents, play an important role in helping to alleviate any negative impacts on the wellbeing of young adults living with epilepsy, by taking care of the physical and emotional health of them. Hopefully this help, guidance and support will help young adults feel empowered to face any challenges confidently.

   Stigma is associated with poor psychological health and it is keenly felt by teenagers with epilepsy

5. Many children develop epilepsy. Some types of childhood seizures are benign (the child grows out of them and his/her development and intellect are usually normal). Some types are more serious and are associated with other problems. These problems are often greatest for children whose epilepsy starts in the first two years of life.

   Children with epilepsy have a wide range of learning abilities. Epilepsy does not necessarily hinder learning and skill development, but many children do experience behavioural and learning issues which may include ongoing motor skills or cognitive functions, as well as a difficulty acquiring new skills or knowledge.

   Many children have problems with global delay, adaptive behaviours, such as learning to walk, talk or getting dressed etc, and they will have significant problems in sleep. The majority of children will also have significant difficulties with social and emotional development as featured in ADHD and autism.

   Unfortunately, many children with epilepsy do not fit the New Zealand Ministry of Education's criteria for funding help, with only 2.5% of children receiving support compared to children with other medical conditions, such as diabetes (38% of children). Having epilepsy can have a profound effect on a child but, the Ministry of Education's funding model sees epilepsy as an episodic event unworthy of support.

   The EWCT works with SENCOs in schools, writing up applications for HHN and ORS funding so that a child's voice is heard.

There are five laws protecting the rights of young people in New Zealand

- United Nations Convention on the Rights of the Child
- New Zealand Bill of Rights Act 1990
- Human Rights Act 1993
- Children, Young persons and their Families Act 1989
- Education Act 1989

Epilepsy affects 1 in 100 people, and most have their first seizure in childhood

6. About 15,000 New Zealanders have uncontrolled epilepsy and cannot achieve seizure control with conventional anti-epileptic medications and will have multiple hospital admissions. These people are considered to be drug-resistant and are more likely to have cognitive, psychological and social problems, and will require more help within health and education systems.

   Despite the addition of new anti-epileptic drugs, overall seizure control in newly diagnosed epilepsy patients has not fundamentally changed over the years. Surgery may help some of these people but, for most of them, the medications do not work, and surgery is not an option. Ketogenic diets, however, are proven, effective treatments in children and adults with intractable, medication-resistant epilepsy.

   We know that the ketogenic diet successfully treats children with epilepsy, with approximately 60% of children who start on the diet having a 50% seizure reduction, and with 30% of children having greater than 90% seizure reduction. Adults living with epilepsy also experience a dramatic decrease in seizures whilst using the diet.

   See https://ewct.org.nz/ketogenic-diet-therapies-for-epilepsy/ for more information about the ketogenic diet and epilepsy.

   At least 30% of people living with epilepsy have uncontrolled seizures

7. There is a ripple effect from having a person living with epilepsy in the family. Families will often struggle to find information about epilepsy, how it is treated, how to manage it and what services can be available to them for support. Families will discover that eligibility criteria come to play when trying to access some social service supports, which are governed by funding agencies. Generally, in funding models, there is an apparent lack of epilepsy awareness of what it is like to live with this condition. Epilepsy may be seen as an episodic event but the impacts can be ongoing. It is best to see beyond the seizure to the needs of a person living with the condition as there will be physical, social and emotional challenges.

   Family members can often live in ‘amber alert’ around when the next seizure may happen and this can cause severe anxiety and depression. There will be stress in all aspects of the family’s life.

   Education for people with epilepsy and their families therefore plays an important role in adapting to life with epilepsy, developing self-confidence, and becoming competent in self-management. By obtaining knowledge and skills related to epilepsy and its management can promote an enhanced quality of life for all and help prevent misconceptions about the condition and reduce concerns about stigma.

   Epilepsy has a significant impact on family functioning

8. Having epilepsy can be seen as a barrier to employment. However, many people living with the condition can participate in a variety of jobs because their epilepsy does not affect their ability to work. On the other hand, those with ongoing epilepsy issues face higher levels of unemployment or underemployment and were either on a Job Seeker's benefit or Supported Living.

   In all cases, people with the epilepsy label can face discrimination as employers often cite 'health and safety' laws as an excuse not to employ someone with epilepsy. See the "Epilepsy and employment" (https://ewct.org.nz/epilepsy-and-employment/) fact sheet for more information.

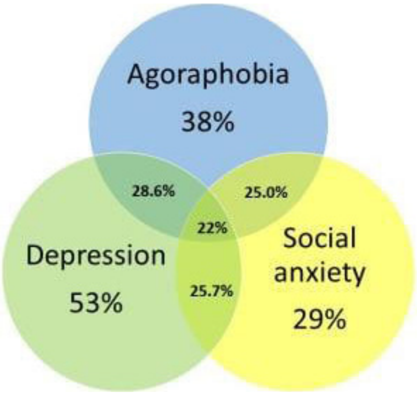
   Having epilepsy can be seen to be a barrier to employment

9. It is not uncommon for people with epilepsy to experience depression, anxiety or to sometimes feel suicidal. Some people may even develop personality disorders and psychosis. In fact, it is so common, that the overall rate of people with epilepsy experiencing a mood disorder stands at 25-50% higher than that of the general population.

   Many people with epilepsy experience social anxiety and agoraphobia (feeling scared of situations or places) which affects their quality of life. This can lead to social isolation and to lowering a person's self-esteem.

   Research suggests that people who have ongoing seizures are more likely to have agoraphobia compared to those who are seizure-free. Social anxiety disorder is more common in people taking multiple antiepileptic medications, which indicates poor seizure control. This condition is different from other anxiety disorders as it has a lot to do with seizure control, the outside environment and the way society sees epilepsy. People with epilepsy often feel ashamed and embarrassed about having seizures in public. The fear of being judged in a society that has a degree of ignorance about what to do when someone is having a seizure can be overwhelming. More epilepsy awareness is necessary to break down the fear, stigma and prejudice around the condition so that people living with epilepsy feel comfortable about being out in public.

   It is possible to be treated with social anxiety and agoraphobia but many people living with the conditions won't talk about it. It is therefore important that medical professionals are aware of the subject.



   Social isolation, stigma, anxiety or depression are frequently experienced by people with epilepsy.

10. Some people in New Zealand continue to experience poorer health outcomes because of where they live, who they are and their poorer socioeconomic status. Maori predominantly live in our deprived and rural communities, and they experience epilepsy at a higher rate than non-Maori. Maori with epilepsy have higher rates of hospital admissions, with many having four or more admissions in a year.

    Easily understood epilepsy education and support would help people with epilepsy, and their families, to develop skills and behaviours that would enable them to actively participate in patient-centred care. Having access to information on topics such as: what is epilepsy, how it is diagnosed, treatment options, strategies for injury prevention and healthy living, employment rights and protections, and self-management would increase the individual's (and family's) sense of empowerment and enhance their quality of life. Health literacy and attention to cultural considerations are particularly important if we are to reach all those living with epilepsy.

    People living directly, and indirectly, with epilepsy need to have the tools to understand how to deal with it.