

How to write and speak about epilepsy

Some facts about epilepsy:

- Epilepsy is a tendency to have recurring seizures.
- There are many different seizure types and seizure syndromes. Epilepsy is not just one condition; there are many forms of epilepsy.
- Epilepsy can affect anyone. Any age, any background, any level of intelligence.
- Around 2 per cent of people will develop epilepsy at some stage in their life, around 94,000 children and adults in Queensland.
- Epilepsy is not contagious.
- Many people with epilepsy still say the biggest problem they face is dealing with the attitude of others. Ignorance, stigma, discrimination and fear are still major problems.
- One in ten people will have a single seizure at some stage in their life. One seizure is not necessarily seen as epilepsy.
- A large proportion of children who have epilepsy will grow out of it by adulthood.
- Most people with epilepsy can live a perfectly normal life and do most things everyone else can do, with the help of simple safety measures where appropriate.

Terminology and labels to be avoided that may help reduce stigma:

Illness - epilepsy is a neurological condition, not an illness.

Fit - the term seizure is preferred. There are many different types of seizures. A convulsion is a term for a seizure involving stiffening and jerking of the body. 'Fit' implies willful outbursts, like a 'tantrum', or loss of emotional control.

Victim or sufferer – this implies someone who is helpless. Most people with epilepsy want your understanding, but not your pity.

Epileptic – the person is a human being first, a person with epilepsy second. A person with epilepsy is a more appropriate term to use. Like most of us, people with epilepsy dislike labels. These feelings can be explained by the phrase 'epilepsy is what I have, not who I am'.

Grand Mal or Petit Mal – these are terms once used to describe seizures. We now understand there are many different types of seizures, so these terms are too general, outdated and inappropriate to use.

Controlled – seizures may be controlled with medication. The term ‘controlled epileptic’ implies the person needs to be restrained in some way.

Reviewed by EQI Services Team October 2016

To be reviewed October 2018

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