

How to write and speak about epilepsy

Some epilepsy facts

- 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% of people will develop epilepsy at some stage in their life, around 85,000 people in Queensland.
- A much larger number of family, friends, class mates and colleagues may also be affected.
- 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 twenty people will have a single seizure at some stage in their life. One seizure is not necessarily seen as being 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.
- People with epilepsy in Queensland can drive provided they meet licensing regulations, their seizures have been controlled for a certain length of time,

they do not drink alcohol, and they take their epilepsy medication as prescribed.

Terminology and labels to be avoided, to help reduce stigma

- **Illness** - epilepsy is a condition, not an illness.
- **Disease** - epilepsy is a disorder, or condition, not a disease. It is not contagious.
- **Fit** - the term seizure, or epileptic seizure is preferred. There are many different types of seizures. A convulsion is the term for a seizure involving stiffening and jerking of the whole body. "Fit" implies mental derangement, willful emotional outbursts, 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, a person who happens to also have epilepsy. 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 what I am'.
- **Grand Mal or Petit Mal** - these are terms once used to describe seizures. We now understand that there are many different types of seizures, so these terms are too general, outdated, and inappropriate to use.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.

Although every effort has been made to ensure up to date and accurate information is provided, Epilepsy Queensland cannot accept any liability in relation to the information provided. It is strongly recommended that you discuss any information with your doctor or other relevant organisation.

