Living with epilepsy

Adjusting and coping with your epilepsy diagnosis

Epilepsy is a disorder of brain function that involves recurring seizures. About 4% of the population will have epilepsy at some stage of their life and it presents as unique to every person. It is characterised by seizures, which can range from short episodes of loss of attention to intense convulsions.

Being diagnosed with epilepsy is a life-changing event. Like many people, you may respond to the news with strong emotions such as sadness, a sense of helplessness, or intense anxiety about what your diagnosis will mean for you and your family.

You may wonder about the changes it will bring to your daily routine, and feel discouraged about the challenges it can pose for your view of yourself and your life goals.

Adjusting to your diagnosis

After an initial period of adjustment, many people with epilepsy cope very well with the changes that they face. Around 70% of people achieve reliable seizure control with medication, and are able to live a full and active life. Although some modifications may have to be made to keep you safe, you are likely to be able to maintain most of your current activities, including work and hobbies. A diagnosis of epilepsy does not necessarily mean a more limited future.

You can help the process of adjustment along by learning more about epilepsy in general, as well as your own particular epilepsy diagnosis. Finding out more about your condition is not always pleasant, as it is likely to dispel some concerns but raise others. Nevertheless, gaining a greater understanding of your diagnosis will aid you in managing the challenges ahead, and help you to feel more in control. A good first step is to talk to your doctor or to the staff at the Epilepsy Foundation.
Coping

Some of the ways in which people choose to cope with epilepsy have more positive outcomes than others. Research has found that people who try to ignore their diagnosis, or who chose to deal with it by avoiding activities and social situations, are less likely to cope well. Making the choice to take action helps people manage their epilepsy better 1 (Westerhuis, W. et al., 2011).

Things to consider

Keeping safe

It is vital for everyone diagnosed with epilepsy to consider ways in which they can maintain their safety. In many potentially dangerous situations it is important to have another person with you if possible, including when you are bathing or swimming, driving, or around traffic. If you do have to travel without a companion it is worthwhile to carry a form of medical ID on your person, so that others know what to do in an emergency. Some people find that their epilepsy affects their memory, so setting up reminders to take your medication on time can be another way to keep yourself safe.

Taking control

One way in which you can make living with epilepsy easier for yourself and your family is to monitor your seizures. Writing down when your seizures occur and what happens around that time, may help you to find a pattern to your seizures. It may also help you to identify your seizure triggers, which means that you are more likely to be able to predict when a seizure will occur. You may want to keep a seizure diary to record and track your seizures or a mood diary, to help you express and monitor your feelings around epilepsy.

Another way in which you can take some control over your situation is to maintain a lifestyle that is likely to result in fewer seizures. This may mean making sleep a priority, abstaining from alcohol and recreational drugs, and avoiding venues where flashing lights may trigger seizures, as well as making sure that you take your medication as prescribed.

Self help

You may find that you cope with your diagnosis better if you pay attention to your state of mind, and look for personal support if you feel that you need it. If your mood is low, there are several ways in which you can improve it, including engaging in regular exercise and organising enjoyable activities. Many people find that connecting with other people who have epilepsy is helpful, whether on-line or through support groups. Using self-help techniques may be beneficial, including mindfulness, relaxation and self-hypnosis. It is important too, to keep in mind that professional help is available. This might mean calling a telephone helpline, talking to a mental health professional or phoning the Epilepsy Foundation.

Things to avoid

There are some coping behaviours which are likely to make adjusting to an epilepsy diagnosis more difficult. These include self-medicating with drugs and/or alcohol, giving in to pessimism, and keeping your diagnosis secret.

Conclusion

Epilepsy may affect your life, but it does not have to dominate it. As you gain knowledge and experience about how to manage your individual form of epilepsy, you are likely to develop an expanding sense of your ability to cope well with your diagnosis.

Other resources

Other helpful information including self-management information and seizure first aid advice can be found on our website http://www.epilepsyfoundation.org.au