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This leaflet was produced by the Joint Epilepsy Council (JEC)

EPILEPSY - BE SAFE REDUCE RISK

LIVING WITH EPILEPSY

About this leaflet: This leaflet provides information about risks associated with epilepsy and suggests ways to minimise them. Because the causes and types of epilepsy vary so much from person to person, this leaflet is intended as an introduction.

Health Care Professionals and Epilepsy Associations can provide more specific information about increasing safety for each individual and can be contacted to discuss concerns about any of the issues raised here.

THE OUTLOOK

Epilepsy, for most people, is a long term condition but today the outlook for the majority is very good. With modern drug treatments, up to 70% of people diagnosed with epilepsy will not have seizures as long as medication is prescribed and taken correctly.

A few people are also able to benefit from epilepsy surgery which, in some cases, can cure the condition completely. As with other long term conditions such as asthma and diabetes, having epilepsy can impact on quality of life if seizures are not controlled. It can also carry with it associated health risks.

Epilepsy is common but can raise many issues and questions for someone, particularly when first diagnosed. Making informed choices about epilepsy and wider life issues can be made easier by talking things through with the medical team, epilepsy help-line staff or other people with epilepsy. Some local areas have an epilepsy specialist nurse as part of the local team.

Potential risks from having seizures are explained in the next section, followed by ways in which risks from seizures can be minimised. The key point is to assess if and how you might be at risk and to minimise those risks in a way most effective and agreeable to you. This leaflet may help you raise these issues with health professionals and epilepsy organisations.

POTENTIAL RISKS OF SEIZURES

People who continue to have seizures are more susceptible to the potential risks of living with epilepsy including:

Injury

The potential for injury will obviously depend on the type of seizure being experienced and where the seizures happen, particularly if they affect awareness or judgement or if they involve falling without warning. If this is relevant to you, information is available about safe participation in activities, including swimming and other sports.

Status Epilepticus

This is not common and refers to seizures that are prolonged or occur one after another in quick succession. In some seizure types status, if untreated, can cause brain damage and can be life threatening. It follows that it is important your doctor knows if you have experienced a seizure that is longer than normal.

SUDEP

Sudden Unexpected Death in Epilepsy is uncommon, but may affect about 500 people with epilepsy in the UK each year. Current research suggests that some people may be more at risk than others and that risk factors include:

- *young adults
- *generalised tonic-clonic seizures
- *seizures at night
- *abrupt and frequent changes in medication
- *people whose epilepsy is not well controlled

The overall risk for people with epilepsy relates to frequency of seizures and varies from up to 1:100 for those at highest risk to a general risk of about 1:1000 (similar to the risk of smoking 10 cigarettes a day). Although SUDEP is known to occur in children under 16 (mainly in children with other difficulties) it is rare among that age group.

REDUCED QUALITY OF LIFE

Epilepsy can be a difficult diagnosis for individuals to accept and so too for their family and friends. It can make some people feel angry, sad, isolated and fearful, unnecessarily leading to a sheltered or restricted life style. Talking to someone who understands can reduce anxiety and depression. The better your quality of life, the less likely you are to experience seizures caused by stress, boredom or anxiety.

PREVENTING SEIZURES TO MINIMISE RISK

Prompt Diagnosis, Treatment and Review

The most effective way of reducing any of the risk associated with epilepsy is to achieve complete control of seizures. Good medical diagnosis and treatment are vital and will usually require a referral to a specialist with an interest in epilepsy and then an agreed regular review, with a health professional who has a good knowledge and understanding of your epilepsy.

The Right Medication

Anti-epileptic drug treatment is recognised to be the most effective way to control seizures. For the right drug to be given at the right dose, the medical team will need to have precise information about the number, frequency and type of seizures. If you continue to have seizures ask to be referred again to an epilepsy specialist for a review of your diagnosis and treatment options.

A common reason why some people continue to have seizures is because they do not take their medication as and when prescribed. Sometimes side effects of a particular medication may deter people from taking medication. Epilepsy specialists can provide information on treatment options. Whatever the reason, however, the fact remains that while someone continues to have seizures the risk of injury and SUDEP is increased.

Avoiding Triggers For Seizures

Keeping a seizure diary is a good way of gathering reliable information. It helps identify some of the triggers for seizures, such as lack of sleep, too much alcohol and stress, forgetting tablets or other factors. Seizures can also be triggered by rapid changes in medication. Recreational drugs or excess alcohol may also play a part.

UNDERSTANDING YOUR EPILEPSY

A number of good books, leaflets, fact sheets are available about all aspects of epilepsy.

POSSIBLE CONSIDERATIONS FOR IMPROVING ENVIRONMENTAL SAFETY

*Using fireguards, smoke alarms and fire retardant materials and power breakers with electrical tools. In the kitchen using a microwave cooker reduces the risk of burns from direct sources of cooking heat.

*Using a well designed shower or having a shallow bath and fitting a thermostat so the water does not get too hot. If there are others in the house, it might be appropriate to use an occupied notice on the door rather than locking it.

*When swimming, asking the attendant at the pool to keep an eye out for you, or alternatively, going swimming with someone rather than going alone.

*Carrying identification that gives information about the condition, how it affects you and what someone needs to do if you have a seizure. It may also be helpful to include details of the medication you are taking.

FIRST AID

It is important for people to know what to do when a convulsive seizure occurs. First Aid procedures are simple to follow:

*Keep calm. Let the seizure take its course and do not do anything to stop it

*If possible, put something soft under the person's head and move away objects to prevent injury

*After the seizure, lay the person on their side (into the recovery position) and stay for 15-20 minutes to check their breathing and colour

*It is unnecessary to call an ambulance unless the person is injured; the seizure does not stop after a few minutes; a seizure follows closely after another or they are having trouble breathing

*Health professionals can properly inform family and friends about first-aid and additional information is available from epilepsy organisations on specific issues e.g. Status Epilepticus