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## epilepsy and the young adult

This leaflet has been prepared for you as a young adult in the belief that, even if you have lived with epilepsy in childhood, there are certain facts that can be grasped only by a mature or maturing mind. Where epilepsy is diagnosed in the early or middle teens, knowing the facts can ensure a balanced attitude towards the condition. (Note that epilepsy is a CONDITION, not an illness or disease).

The medical management is in the hands of the family doctor and consultant; the domestic management is in the hands of the individual. Your daily living can play a large part in determining whether or not the condition becomes unnecessarily debilitating.

### WHAT IS EPILEPSY?

The information in this leaflet is grouped under three headings which cover most of the questions that are often asked. The first question must, of course, be "What is Epilepsy?" The text books say it is a repeated tendency to seizures or attacks. That may appear to be stating the obvious, but it is often the obvious that is overlooked. Epilepsy is a tendency to seizures. The number of seizures varies from person to person and, sometimes, the individual will experience periods in life when seizures occur with greater frequency. The important point is that having epilepsy does not mean having seizures all the time. You may be incapacitated by them when they occur, but don't let them dictate a life-style.

Medication is a constant factor throughout the duration of the condition. Certain simple precautions may also be a constant factor. The person who has, on average, say five seizures a year is, generally speaking, perfectly able to realise his full potential on the other 360 days. In the past there was a risk that anti-epileptic drugs might cause drowsiness or slowing down of reactions, but new forms of medication are less likely to do this and if you get any bad effects from your drugs you should report them to your family doctor (GP) or your Hospital Consultant.

### MEDICAL ASPECTS

It is becoming more widely recognised that epilepsy can affect anyone at any time of life. This fact is bound to cause you to ask the question: "**Why me?**" There will be a variety of answers to the question but the general answer is that you have a lower threshold than the majority of people. That is to say you have a lower resistance to electrical overcharging in the brain cells. The reasons are, again, varied. A blow on the head, or the effects of a high fever in babyhood or childhood may lower the threshold. Hormonal changes at puberty may affect it, or it may just be that you were born with a low threshold. Whatever the cause, a low resistance means that if you meet with a "trigger" or stimulus, you are more likely to have a seizure than someone whose resistance is higher. The stimuli also vary. Among the more widely known are flashing lights, sudden sharp sounds, extreme fatigue, alcohol, anxiety, stress, lack of sleep, boredom, lack of food, or forgetting to take the prescribed dose of anti-epileptic drugs. Some people will not be affected by more than one of these triggers - some may find that they react unfavourably to a combination of two or three.

### YOUR MEDICATION

The drugs you are prescribed are designed to build up the threshold so that you have increased resistance to such stimuli. The medication can sometimes have side effects, particularly in the early days. The Mersey Region Epilepsy Association is able to advise on the procedure if you find this happening and cannot, for some reason, get to a doctor.

## TESTS

One of the tests used in diagnosis, and sometimes in a hospital check-up is called an EEG (electroencephalogram). This is an absolutely painless investigation which entails having small electrodes fastened to the scalp. These electrodes are wired to a machine which measures the frequency of electricity and records the impulses on a "printout" in the form of a graph on a computer screen.

From the print-out the specialist can better assess the area that is causing the seizures. This information can be used in deciding the best type of medication for your particular kind of epilepsy. Various forms of brain scan can also be used, and may be referred to as an MRI (magnetic resonance imaging) scan or CAT (computerised axial tomogram). These are also quite painless. More often than not these scans are not needed to diagnose epilepsy.

The medical management of epilepsy is the concern of the GP, the Consultant and epilepsy specialist nurses but the individual has a part to play. Most children are not able to take responsibility for their own tablets, but as a young adult you should assume this responsibility as soon as possible. Work out a system that doesn't rely on chance or memory. Carry with you the exact dosage for one day and a "spare set" - just in case you can't get home overnight. The Mersey Region Epilepsy Association can advise you on types of containers that go easily into a handbag or pocket. It is important that you should take the prescribed dose at the prescribed time and it is important that you should note any changes that new medication may cause. This you can discuss with your GP or your Consultant at the next hospital check-up, which will probably be once a year, unless you are having particular difficulties. Incidentally, you can now assume responsibility for keeping a note of the dates and times of hospital appointments.

## SOCIAL ASPECTS

There are certain questions that are always asked about living with epilepsy.

**Can I drink alcohol?** Medication and alcohol don't mix - that's a recognised fact. There are some people with epilepsy who can take a drink without adverse effects and there are others who can't. Find your own level and make your own rules - always remembering that you're looking for a commonsense way that will avoid the risk of seizures. Sleep enough but not too much, eat regular meals, don't drink if alcohol sparks off attacks.

**Do I tell girlfriends, or boyfriends?** If you like. Generally speaking it's best to tell anyone close to you because it could avoid embarrassment in the event of a seizure. Remember that if you have a commonsense approach and an enlightened attitude towards epilepsy, so will those you are in touch with. Don't dismiss it too lightly, and don't exaggerate it. Get to understand it and then pass on your own understanding. The Association produces a series of leaflets from which you can find out what you want to know.

**Can I drive?** When you've been free from seizures, while awake, for one year, you can apply for a licence. In cases where the first attack is in sleep, it is necessary to wait for three years to establish that the pattern of attacks is only during sleep. The Association has a leaflet outlining the regulations concerning driving.

**Is it safe to swim?** Yes, bearing in mind that a seizure can incapacitate even the strongest swimmer. You must not, therefore, swim alone if you have an unpredictable seizure pattern. Again, it is a matter of commonsense. Someone who only has seizures when asleep, or who gets a long warning period, is less risk.

**What about sport?** Commonsense again - the type of seizure and their frequency at any time will dictate the answer. The only advice an outsider can give is: "Do what you CAN, and make sure that although epilepsy may be the REASON you can't do certain things it is never an EXCUSE."

**Can disco lights cause epilepsy?** No, but they may provoke a seizure in some instances. If you find they do in your case avoid flashing lights.

**What effect does television have on a person with epilepsy?** None at all on some - it depends again on the type of epilepsy. Some people have what is called photosensitive epilepsy and they find television more of an irritation than people with other types. If in doubt keep a light on above the screen and don't sit too close to the set. The Association can provide you with a leaflet about photosensitivity.

**Are there any restrictions on travel?** No. When flying it might be advisable to tell the stewardess if you think there's a risk of a seizure. Some people find it better to avoid night flights because of the disturbance to sleep. Whenever you're away from home, make sure that you have an adequate supply of medication with you.

*Can I emigrate?* Some countries impose restrictions. For details consult the Embassy of the country concerned.

*Can people with epilepsy marry?* Of course they can!

*What about starting a family?* If you're in doubt, go to your GP or Consultant and, through them, get advice from a genetic counsellor. The chances of any child developing epilepsy are 0.5%. If one parent has epilepsy the risk may be between 2.5% and 6%. If both parents have epilepsy the risk can increase to 25%.

## **EMPLOYMENT**

Before you start to train for a career it is advisable to consult a Specialist Careers Officer. At the Employment Office there is a Disablement Employment Adviser (DEA) who is responsible for all those who have any condition that may affect employment. Even if you get a job without the help of the DEA, he/she is still available for consultation and if you change your medication and think the adjustment period may put you at risk of increased seizures for a time, or cause you temporarily to slow down, the DEA can advise your employer. It is recommended that you tell your employer about your epilepsy because even if you've been free of seizures for some time, it's possible that the stress of starting a new job may provoke a seizure. If the employer is forewarned he will recognise that this is probably not the regular pattern and he will be more prepared to allow you time to adjust.

## **LIVING AWAY FROM HOME**

Most young people leave home and establish a degree of independence in their late teens, and unless seizures are frequent and severe, epilepsy should not be the cause of postponing this experience. There are one or two simple tips which, if followed, should ensure that you enjoy your independence without anxiety to your family or yourself.

*First you may need to find accommodation.* Much will depend on the area and, of course, on the type of accommodation you need. Bed sitters are advertised in most industrial areas. If your seizures are not controlled adequately it might be as well to see if you can arrange to share accommodation, either with someone you know, or with someone who understands epilepsy and can help if needed.

If you are able to think in terms of unfurnished accommodation there are in most areas single person flats available from the local authority agencies, or again you may prefer to share. In addition to local authority accommodation there are various types of accommodation available from housing associations. If you have particular difficulty, get in touch with Mersey Region Epilepsy Association, who will make enquiries on your behalf - but please give good warning as these arrangements take time.

### *Once you've moved in*

Remember the basic commonsense rules. Cookers, gas rings and fires should be guarded. A shower is often preferable to a bath, but if no shower is available keep the bath water to a maximum of six inches and there should be no reason for anxiety. If you have seizures in your sleep you're better off without a pillow, but if you find this uncomfortable you can buy a safety pillow.

### *Safety in the home*

If you follow the ordinary rules of safety you'll come to little harm. Avoid trailing leads from electrical appliances and lamps. Don't carry kettles and saucepans of boiling water or food - take the plate or teapot to the stove and leave the saucepans where they belong. A microwave oven can be invaluable as they do not require saucepans, and switch themselves off. If you have photosensitive epilepsy keep a light on above the television set and view from a distance rather than sitting too close.

Many of these tips will not apply to you - some may. It is, as always, a question of commonsense. If you take the necessary precautions in the first place you can then stop worrying.

## **FINAL NOTE**

We said earlier: "don't make epilepsy an excuse." Sometimes and in some circumstances it can be a handicap. It's up to you to develop skills that will outweigh the epilepsy - not only job skills, but skills in social contacts, forming relationships and presenting yourself in a good light. Aids to effective personal presentation are good deportment and appearance, oral and personal hygiene, clear confident speech and the realisation that you are a whole person, and epilepsy only a part.

You may go through a bad patch but it will probably pass and leave you greater freedom to live as you want to.

Let that time find you to be a balanced, well-adjusted person in your own right. There is no disgrace in having epilepsy. Scores of eminent people throughout history have had seizures.

In fact everyone is potentially epileptic - only most people have yet to have their first seizure.

It is not a tragedy to have epilepsy. It is a tragedy to let it dominate your life or make you less of a person than you would have been without it. If you have to live with epilepsy, make sure that **LIVE** is the operative word.

The Mersey Region Epilepsy Association exists for those who have epilepsy - AND those who don't.

More than 30,000 new cases are diagnosed every year in the UK. More than 350,000 people are already living with epilepsy in the UK. This means that **TWO MILLION PEOPLE ARE AFFECTED BY HAVING EPILEPSY IN THE FAMILY.**

Could you cope with epilepsy? The Mersey Region Epilepsy Association helps people to cope every day. We provide health education, social work and community support through our Liverpool office and growing network of support groups. The local groups are run by and for people with epilepsy. We can supply the contact for the group nearest you.

The biggest problem with epilepsy is **NOT KNOWING**. Your contribution will ensure that individuals, families, employers, schools and the public **DO KNOW** about epilepsy.