

Information Sheet 2: Epilepsy and Brain Tumours

This information document on epilepsy simply provides a basis for discussion with the healthcare professionals with whom you are in contact. It should not in any way be used as a substitute for professional care.

What is Epilepsy?

Primary Generalised Epilepsy

This is where the chemical and electrical disturbance occurs throughout all of the brain. These seizures come on without warning. This can result in a convulsion (grand mal or simply cause a momentary loss of awareness lasting seconds (absence) or sudden jerks (myoclonic).

Partial/Focal Epilepsy

In partial/focal seizures, the abnormal electrical discharge starts in one part of the brain and may spread to another part of the brain. The person may experience the symptoms of the abnormal discharge in the part of the body that is controlled by the brain area that is being affected by the seizure. For example, if the seizure arises in the part of the brain that controls movement there will be jerking of the limbs. If it involves the part of the brain that perceives sensation, it causes a strange tingling in the limbs. If it affects the temporal lobe of the brain, where thoughts and memories are stored, it may produce a feeling of disorientation, a funny smell, deja vu, panic attacks or strange recurring thoughts. These seizures can occur without any loss of awareness (simple partial seizures), or with loss of awareness for a short period (complex partial seizures).

Functions of the Cerebral Hemispheres

Frontal, Temporal, Parietal and Occipital Lobes

Occasionally the focus of electrical activity can spread from the localised area to involve the whole brain. When this occurs it causes a convulsion with loss of consciousness and movements of arms and legs (secondary generalised seizures). These convulsions usually differ from those of primary generalised epilepsy only in that there is frequently a "warning" before losing consciousness. Most people with a brain tumour and epilepsy will have partial/focal epilepsy because the tumour causes a focal disturbance in one part of the brain.

Is epilepsy a common problem?

Epilepsy is the most common serious neurological condition worldwide. At any one time, at least 1 in 130 people have epilepsy and 5% of all people will have a seizure at some time in their life. Most people with epilepsy have normal brain scans and only a very small proportion have a brain tumour.

What are the common types of brain tumour?

Primary brain tumours are those that arise from the brain cells directly, whereas secondary tumours are those that arise in another site in the body and spread (metastasise) to the brain.

Meningiomas arise from the coverings of the brain (meninges) and are usually considered benign. Neuromas arise from nerves and are benign. Pituitary Adenomas

arise from the glandular tissue of the pituitary and are benign.

If I have seizures does it mean my tumour is more severe?

No. About 80% of people with less serious glioma brain tumours, and only 20 - 30% of people with more serious brain tumours will have seizures. If seizures are present from the start, the overall outlook is better than in people who present with other symptoms such as weakness or headache. Seizures can also occur with benign brain tumours (such as meningioma) or tumours that have spread to the brain from another site of the body (metastases).

How is epilepsy diagnosed?

The diagnosis is made from a witness description of the precise features of the seizures, and the circumstances in which they occur. An EEG test may be helpful in determining the type of seizure and site of any problem. The EEG is a painless, safe procedure where thin wires are placed onto the scalp and these wires (electrodes) can demonstrate any irregularities in the normal activity of the brain. Frequently, however, the EEG is completely normal between attacks. A CT brain scan or MRI brain scan will produce pictures of the structure of the brain and will demonstrate where the abnormality is in the brain.

Can epilepsy be treated?

Yes. Treatment with tablets or medicines will control seizures in about 50% of people who have brain tumours and seizures. About 50% of people will continue to have seizures despite treatment, but the seizure severity and frequency is much less with medication. The treatment is aimed at trying to reduce seizure frequency and severity without causing too many side effects from medication.

The role of surgery in the treatment of epilepsy is still not completely certain. Sometimes surgery can cure the seizures. However seizures can continue or worsen following surgery. There are reports of radiotherapy reducing seizure frequency, but not enough evidence to say with any certainty that it does. The choice of medication usually depends on the seizure type, the possible side effects, and interactions with other medications that you may have to take.

What side effects could I have from the medication in general?

All medicines can cause side effects. Medication which prevents seizures (anticonvulsants) can cause side effects too, even though most people take them for long periods of time with no unpleasant side-effects.

Some people can have an allergic reaction to the medication (such as a rash, effects on the blood count or liver upset) and others may feel tired or nauseated when a course of tablets is first begun. The tiredness and nausea may settle when you become used to the tablets, but the drug should be stopped if there is an allergic reaction (contact your general practitioner or one of the medical professionals with whom you are in contact).

Another possibility is that if you take too much of the medication, you can get 'toxic' side effects, which may cause double vision, unsteadiness, dizziness, drowsiness, nausea, headache or changes in behaviour. If you have any of these symptoms, ask your general practitioner. They may want you to take a smaller dose of the medication or to give a blood sample to measure how much is in the blood stream. Each medication has its own list of possible side effects. If you are concerned ask a medical professional for

advice.

How will medical professionals try and help me?

General practitioners or the medical professionals with whom you're in contact will usually introduce medication gradually in small doses and advise you to take the medication regularly. Some medication has to be taken only once a day, while others need to be taken more frequently. The aim is to use the lowest dose of a single medication that will control seizures without toxic effects. Your doctor may wish to measure the drug levels to check if the dose is right and is being taken regularly, or for making planned increases in the dose of some medication.

In general doctors don't feel that the addition of a second drug to the first makes much difference, although there are some newer drugs that might be useful at reducing seizure frequency by 30-40%. There may be interactions between different anti-convulsants and frequently it is difficult to tell which one may be causing the side effects.

If the drugs you have been given are unhelpful, you may be advised to discontinue the medication. However, withdrawal of medication will be done gradually and new medication can be introduced slowly as the old one is removed. Stress, poor sleep and alcohol can make seizures worse and doctors may suggest methods of overcoming this. It is uncertain if antidepressants make matters better or worse. In some people, seizure control with available medication is not possible. In these cases the medication may be reduced to minimise side effects. In cases like this, surgery or vagal nerve stimulation to reduce the frequency of seizures (a pulse generator that sends small electrical impulses to the vagus nerve and this delivers electrical impulses to the brain where seizures are believed to start) may even be considered.

How can I help myself?

- Do not run out of medication. Stopping anticonvulsants quickly can lead to an abrupt increase in the number of seizures.
- A diary of seizure frequency and severity should be kept, as it will help when assessing any change in seizures related to changes in medication.
- If you have any other illness, anticonvulsants should be continued. If you are sick and only if you see the tablets in the vomit, you should repeat the dose a little later. Always let your medical team know if you are taking other medication, which may affect anything else you are prescribed for the epilepsy.
- Not taking prescribed medication regularly is the most common cause of treatment failure. Irregular therapy may be worse than no therapy at all. It may cause withdrawal effects, or it may make seizures or toxic side effects worse.
- Establish a routine about taking your medication at a set time of day and consider using a pill box divided into the days of the week. Follow closely the advice of your medical team, such as avoiding alcohol, make sure that you have sufficient sleep and eat regularly.
- Anyone may forget to take their medication at some time. If you miss a dose it is probably best to take an extra dose within the same 24 hour period, though again it's always best to check this with your medical team.
- Only take a bath if someone is in the house with you and leave the door unlocked. Otherwise take a shower as you are at risk of drowning if you have a seizure in the bath.

- Do not take additional anticonvulsants after a seizure but continue to take them at your regular time and dose. Ask your doctor for further advice if you are concerned.

What should my friends do if I have a seizure?

While the convulsion is in progress:

- They should not put anything in your mouth or force your teeth open
- They should not try to restrain your movements but let the seizure run its course.
- They can put a pillow under your head and loosen tight clothing or move sharp objects away from you.
- You should be moved only if you are in danger from injury, e.g. close to a fire or on the road.

After the seizure has finished:

- You should be turned on your side or put in the recovery position..
- Your airway should be checked and kept under observation.

After a major seizure:

- You may be confused and need reassurance.
- Friends shouldn't give you anything to drink, until you have fully recovered.
- Transfer to hospital is necessary only if the fit is prolonged or repeated - or if injury has occurred.

How will the seizures affect my daily life?

Driving

The law on the validity of your driving licence if you are affected by epilepsy and/or brain tumours depends on the type and grade of tumour. The period of time that you will not be able to drive can be as low as one year or up to four years, if you remain seizure-free. Your medical team should have up-to-date information from the Driver and Vehicle Licensing Agency (DVLA). You should notify the DVLA about your condition by writing to the Medical Unit, Longview Road, Swansea, SA99 1TU. For more information, they offer a website <http://www.dvla.gov.uk/drivers.aspx> or email eftd@dvla.gsi.gov.uk. You can also notify the DVLA of a medical condition by telephone. Please remember to quote your full name, date of birth and or driver number (if known). You must also give details of your specific medical condition in order that you can be sent the appropriate medical questionnaire Tel: **0870 600 0301**.

Some people with epilepsy who cannot drive may be entitled to additional help with the costs of travel to and from work, and also travelling whilst at work under the Access to work scheme.

You may be entitled to a free local bus pass if you have had a seizure in the last year as you would be refused a driving licence. You may also be entitled to 1/3 off rail travel if you purchase a Disabled persons rail card.

Contact the disability employment advisor at your local job centre for further information.

Work

You should not work with dangerous machinery, at heights, or in a job where, if you had a seizure, you could put yourself or others at risk. This is common sense, but also your employer may not be covered for any accidents that happen to you or others; if you

have not informed your employer, it is you that may be liable for any damages. In general, employers and work mates are very supportive and understanding. If your work involves any of the above, some alteration in the structure of your job may be possible. Computers, VDUs, discos and TVs are unlikely to precipitate seizures. If you are in the armed services, then it is likely that you will not be able to continue and you will be advised to take early retirement. The police and fire-service are a little more lenient, but it may mean a change in your job description.

If you wish to continue working, and your employer says this is not possible, it may be worthwhile discussing things in more detail with the person who makes the final decision. This will personalise things more. A supporting medical statement will be helpful. Many employers think there is only one kind of epilepsy (generalised seizures/convulsions). Employers may be more open to persuasion if you have "simple partial" or even "complex partial" seizures.

Home

Troublesome seizures can lead to all sorts of stresses and anxieties in the family. It is best that everyone in the family home is aware that you have occasional seizures, but that they should not over-react to them. Discuss things openly with your partner and children to ensure that they do not "overprotect" you. The well-meaning partner who does this can unwittingly find that they are contributing to a loss of confidence and self esteem that reduces your role within the family. This can lead to frustration and depression which may in turn aggravate your seizure frequency. Especially if you are losing sleep, there is good evidence that relaxation techniques can reduce seizure frequency. It is advisable to shower rather than bathe, use a smother proof variety of pillows in bed and when cooking and setting fires be aware of the possible dangers.

Sport

Do not swim alone, it is advisable to wear a distinctive cap and inform the pool attendant. Do not cycle by yourself. Do not box, canoe alone or rock climb. You can play rugby, karate and football as well as many other sports. Consult your doctor if you have any worries.

Contraception and pregnancy

Some contraception can interact with Epilepsy medication and therefore it is advisable to discuss options with your local GP or a specialist contraception health centre. It is also advisable to discuss a planned pregnancy as medication may need to be altered prior to conception and the risks discussed.

Should I tell people that I have seizures?

It is usually advisable to tell your family, employer and work mates. If you take a 'major' seizure, they should also be told what to do (see above), be reassured that the seizure is usually over in a short spell of time, and that you may be confused for a little while afterwards.

Do seizures injure the brain?

There is no evidence that the average seizure has any lasting effect on how the brain works. Many people with epilepsy have had hundreds of seizures in their lives, without any noticeable changes in their alertness or intelligence. Sometimes after a partial or generalised seizure, there can be a weakness on one side of the body for minutes or occasionally days (Todd's paresis), but this usually resolves completely. Rarely,

seizures that last an unusually long time, or a series of non-stop seizures, may produce changes in the brain that can affect the brain's abilities, but this is an uncommon occurrence.

Is epilepsy linked to mental illness?

Epilepsy and mental illness are separate conditions. Sometimes people with epilepsy experience fear that they may be mentally ill. They are usually relieved to hear that what is happening to them is merely the result of seizure activity in the brain. Of course some people with epilepsy do experience mental illness, just as some people do who have no physical problems, but there is no clear relationship between the two conditions.

Could I injure anyone during a seizure?

Although a seizure involving jerking of the limbs can look violent, the movements are undirected and it is therefore not possible to carry out a planned attack on anyone. Injury to others occurs only if they get in the way accidentally; when trying to suppress the limb movements, in the period after a seizure when you may be confused, or if you feel threatened (i.e. someone holding you down). Injury to yourself occurs rarely and almost always only if there is a loss of consciousness (generalised seizures) (especially when working at heights, with dangerous machinery or swimming unaccompanied). If you have generalised seizures you should be sensible and avoid situations where you could put yourself at serious risk.

If I lose my job what benefits might I be entitled to?

If seizures are a major problem or you also have a physical impairment, find out about eligibility for Disability Living Allowance (DLA) or Attendance Allowance (AA).

The Department for Work and Pensions is the Government's Benefit Agency. Their General Benefit Enquiry Line offers confidential advice and information for people with disabilities, and their carers and representatives, about social security benefits and how to claim them. Freephone **0800 88 22 00** or free textphone for people with speech or hearing difficulties **0800 24 33 55**. For specific advice on DLA or AA, call the DLA helpline on **08457 12 34 56**. Their website holds information on both DLA and the Carer's Allowance, explaining who is eligible and how to claim www.dwp.gov.uk/lifeevent/discare.

Alternatively, you may wish to ask your medical team to refer you to a Social Worker or Citizens' Advice Bureau to help you determine what benefits you may be entitled to. No one on regular anticonvulsants need pay prescription fees, for example, while you may be eligible to apply for a travel pass, depending on the area in which you live.

...and finally

Brain Tumour UK is unable to provide detailed or individual medical advice, and this information is intended to provide a basis for discussions with your medical team. For more detailed information on epilepsy, you may wish to contact one of the following organisations: the British Epilepsy Association in Leeds at www.epilepsy.org.uk Tel: 0808 800 5050 or the National Epilepsy Society at www.epilepsynse.org.uk Tel: 01494 601 300 or Epilepsy Scotland at www.epilepsyscotland.org.uk Tel: 0800 800 2200.

Alternatively, for more help or information on how your brain tumour is affecting you or someone you care for contact :

Brain Tumour UK, Tower House, Latimer Park, Chesham, Bucks. HP5 1TU
www.braintumouruk.org.uk
Helpline: 0845 450 0386.

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