Brain Tumour Action

Information Booklet

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Living with a Brain Tumour

Introduction

A brain tumour and the treatment necessary to deal with it will cause changes in the lives of those affected. Adjustment to these changes can be easier if everyone involved has some idea of what to expect and knowing that there are resources to support them.

"A brain tumour"

This diagnosis causes a host of reactions, among them shock, fear and despair. It means a plunge into unfamiliar medical surroundings and a future full of uncertainties. It is an emotional time.

Perhaps it will help you to know that there is hope for those with a brain tumour. Almost half of all brain tumours are non-cancerous and, if located favourably, can be cured by surgery. Many brain tumours that are found and treated early cause little or no permanent damage to mental or physical abilities.

Many others can be treated with surgery, radiotherapy and other therapies, resulting in prolonged life and a considerable amount of enjoyable time.

Each year, further progress in treating this disease is made by dedicated researchers.

The panic and anxiety you feel is a natural response, affecting not only you but those close to you as well. Changes in daily routines and responsibilities are often required. Adjustment to these changes can be easier if everyone involved understands what is happening and has some idea of what to expect.

Understanding helps you feel more comfortable and more in control.

As you begin to deal with your situation, it may help if you realise that others have found that some of the most difficult periods of time (those causing the greatest emotional stress) are:

- From suspicion of illness to diagnosis.
- Immediately after completion of treatment.
- Having any repeat CT/MRI scan, or follow up doctor visit.

In the information that follows we provide you with some basic information about brain tumours and a few hints on how to deal with the changes you and your family and friends are facing.

Understanding and communication

The first step in coming to terms with the diagnosis of a brain tumour is to seek accurate, understandable medical information about the disease and its treatment options. This information should be obtained from a doctor experienced in treating people with brain tumours.

The feelings of helplessness and lack of control that are so common following diagnosis often can be reduced if you actively participate in decisions regarding your care and treatment. Once the diagnosis is made it helps to share the news with those close to you. Whenever possible, you should be accompanied to the doctor by a family member or friend.

Having company actually serves two purposes: the second person can give you much needed moral support, and they can help you remember the information you are given. The ability to share your concerns with the doctor is very important; you will probably have many questions that require frank and honest answers.

The most commonly asked question, "What can we expect next?" is the most difficult to answer.

It often helps to take a small notebook along to write down the information and to keep a record of your visits and treatments. Patient information leaflets can provide a basis for discussion with the doctor, by suggesting topics, important questions and explaining medical terms.

Some examples of problems caused by tumours in different parts of the brain.

Frontal Tumours

Frontal Tumours can cause disinterest in your surroundings, mood swings, changes in moral and ethical judgement and intellectual impairment. Short-term memory (memory of recent events) may be affected.

Pareietal Tumours

Can result in sensory illusions (such as feelings of pins and needles'), inability to recognise objects by touch, inability to distinguish right from left and difficulty reading.

Temporal Tumours

Which are frequently 'silent' unless they reach a significant size, can cause a dreamy 'deja' vu' state. Also, aphasia, or the loss of ability to understand language, is usually associated with this area.

Occipital Tumours

Can cause disturbance in vision and visual memory. There may be double vision, visual hallucinations or partial loss of vision.

Hypothalamic and Pituitary Tumours

Can effect appetite and food intake. Pituitary Tumours can cause excess or underactivity of some hormones. This can effect women's menstrual cycle and sometimes cause breast milk. Growth hormones and thyroid hormones may also be affected.

Optic Nerve Tumours

Reduce visual accuracy and can lead to blindness.

Cerebello-Pontine Angle Tumours

(Such as acoustic neuromas) cause pressure on the cranial nerve. Ringing in the ears or hearing loss (especially in using the telephone) can occur.

Brain Stem Tumours

Can affect tongue movements and cause difficulty with swallowing or speaking. Unusual eye movements can cause dizziness or unsteadiness in walking.

Posterior Fossa Tumours

(Such as choroid plexus, fourth ventricle and cerebella tumours) may cause tremors or a lack of co-ordination in walking. Nausea (feeling sick) may also occur.

What can we expect?

The effects of a brain tumour are many and varied. Some of these effects may appear before the reason for them is known. Sometimes the reasons for them may never be known.

Some effects are emotional

You may experience several symptoms. (Your family and close friends may also experience some of these problems.) These can be due to the emotional stress caused by treatments, surgery, or by the tumour itself. A lack of appetite, depression, irritability, fatigue, sleeplessness, an erratic memory and restlessness are common complaints. Nausea, bladder problems or constipation can also occur. Your doctor can usually help you deal with these problems.

Some effects are due to the tumour

There is a limited amount of space inside the skull; therefore, the growth of anything that does not normally belong there causes changes in normal brain functions. These changes may be temporary or permanent, depending on the cause. Tumours may cause direct damage to brain cells, shifting of the brain due to growth, or cause pressure that affects areas distant from the tumour, resulting in changes in their function too.

Some effects are due to side effects of treatment

Whilst a headache is the most common discomfort associated with brain tumours, some discomfort may be caused by the procedures necessary to treat the tumour. There may be a pain following tumour removal or discomfort from the side effects of chemotherapy. Radiotherapy is a painless procedure but can have uncomfortable side effects, such as skin problems or nausea. However most people feel that it is worth tolerating the side effects of treatment in order to get the expected benefits.

If you are experiencing pain or discomfort, medication can be prescribed to help make these effects tolerable.

Swelling of the brain may occur prior to surgery and following radiotherapy and it may cause temporary difficulty in walking or thinking clearly. As the swelling decreases these side effects should fade.

Steroid medications, which are often prescribed to reduce the swelling, may cause a swollen appearance or hormonal disturbances. One of the positive effects of steroid therapy can be temporary control of headaches.

Seizures are caused by irritation to the brain. They may be one of the first symptoms of a brain tumour or may occur for the first time following treatment such as surgery, which temporarily disturbs the normal function of brain cells. Most seizures can be controlled with anticonvulsant medications.

Some of the drugs used have side effects, you should discuss these with your doctor or pharmacist. Blood tests will be done from time to time to see if these drugs are at the right levels.

Some seizures can be difficult to control. However, those following surgery frequently decrease with time. For further information, please see our other information pages on radiotherapy, epilepsy and chemotherapy.

Coping with your feelings

As children we are taught to control our emotions. In stressful situations we rely on what we have previously learned. Our ability to deal with stress is based on our upbringing, religious beliefs or methods that have been successful for us in the past. If this is your first experience of dealing with a crisis, you may have to learn new coping methods and, in particular, which ones work best for you.

Surviving a brain tumour emotionally means working through your various responses to the illness. For many this will involve a change in life style, an acceptance of some degree of dependence, and a means of dealing with a feeling of lack of control. There are many natural responses to crisis.

- **Denial:** disbelief or a lack of concern over the diagnosis is normal for some. It may take time for the news to become real. Some may pretend temporarily it has not happened. Others may simply be in a state of shock. "Brain tumours happen to other people" or "why me?", are common reactions. Refusal to discuss the situation is not unusual.
- **Guilt:** when something devastating happens, it is normal to try and place blame. When you blame yourself, you feel guilt. People often ask themselves: Is this a punishment? Did I do something to deserve this? The cause of most brain tumours is unknown; nothing anyone can do or say can make a tumour happen. Guilt may also occur if you feel you have disrupted the lives of others.
- **Anger:** at Spouses, family friends, employers, doctors or anyone and everyone is not unusual. Hurting, bitter words may be said and not meant. Hidden anger is sometimes shown by irritability, sleeplessness, fatigue, over-eating and over-drinking.
- **Depression** or grief at the loss of your previous lifestyle may occur. Restlessness and moodiness can last for many months. While physical activity may be the last thing you feel you have energy for at this time, it can often help the most.

These are some of the possible responses. Each person will experience their own range of responses. The nature, arrival and duration of these responses will vary according to personality and circumstances. Hopefully, those allowed to deal with their emotions in a natural unpressured way, with support from friends, family and trusted confidants, will begin to accept the reshaping of their lives, facing it with a realistic amount of hope and a determined attitude.

Coping with physical changes

Most people are upset by changes in their appearance and ability to function, regardless of whether these changes are permanent or temporary.

Brain swelling due to the tumour or radiotherapy may cause a temporary increase in symptoms. Loss of hair due to surgery, radiotherapy or chemotherapy is upsetting to almost everyone.

Wigs can be uncomfortable, particularly if the skin is reddened. Attractive scarves can be worn by women and loose caps, particularly baseball caps, are favoured by men.

Sexual desires may be decreased due to tiredness, a feeling of not being sexually desirable or fear of injuring or stressing yourself (or your partner may be afraid of hurting you). Temporarily, some may choose to replace sexual activity with non-sexual physical closeness, such as holding hands, kissing or hugging. For those receiving hormone replacement therapy, sexual desire may increase.

You may feel tired due to medications, treatments and the travelling required to reach your treatment centre, as a result you may not be able to keep up with your usual responsibilities - birthdays, Christmas, holidays, anniversaries.

Weakness may be overcome by planning frequent rest periods during the day and conserving energy for special events or unavoidable necessary chores. Physical therapy can help maintain muscle tone.

Diversions, such as hobbies or crafts, can help distract you from the loneliness of illness.

If you are 'bed-bound', some degree of independence can be achieved if all necessary equipment and personal belongings are moved within reach of your bedside. Home visits by a beautician or hairdresser can lift your spirits. A favourite secluded place, such as a garden, can offer calming strength.

It should be remembered that while under care for a brain tumour, medical conditions that existed before your diagnosis must continue to be treated. Dental visits, eye care examinations and the like should be continued.

If you have metastatic disease (tumours that began in other organs and spread to the brain) you may require treatments to help control the tumours in others sites of your body.

Suggestions for coping

Allow yourself to cry. It's a good escape valve for both men and women.

Know that symptoms usually worsen in the darkened evening hours. This is generally when everyone is tired and defenceless and at their worst.Arranging for outside support of visitors in the evening may help. Find someone to confide in. For both patients and families support groups can be invaluable. It helps to know you are not the only one dealing with this situation.

Sometimes it might be more comfortable to take your most private concerns to a trained counsellor. Your doctor or nurse can put you in touch with recommended counsellors.

Brain Tumour Action can give you information about local support groups and their befriending service. Communication is especially important. If you have difficulty putting feelings into words, try using a tape recorder or letters to share feelings or concerns with family or friends. If you have difficulty reading ask your friends to tape reading material for you to listen to, or make more use of the radio.

Don't deny yourself some small luxury or pleasure. Splurge once in a while if it makes you feel better.

Read about brain tumours, their treatment and about others who have dealt with this problem. Be positive and don't feel defeated.

If you are having a difficult time consider seeking professional help. For example a counsellor, psychologist, minister or doctor.

Accept the assistance of others without feeling guilty or obligated to repay the favours.

Set your own limits, not those suggested by others. It's OK to be selfish (up to a point!).

Coping with stress

For most people the fear of the unknown and the sudden uncertainty of the future causes great stress. For the time being, finances, work, family roles and medical decisions may be handled by others. It is important for you to have a sense of control and often this can be achieved if you help plan for your own care, treatment options or medical schedules.

Some people will continue to work as much as possible, assuming a flexible schedule can be arranged. Others may welcome the opportunity to give up their responsibilities to family members or friends. This should be a personal decision, based on your desires and abilities.

Daily routines may need to be shifted, financial resources explored or new responsibilities learned. Activities that you once considered important may not seem so important now or may be replaced by others.

Despite the confusion of the situation, family members need to permit themselves time off to take care of their own needs. Understanding relatives and friends can be called upon to help. A 'break' should be encouraged, even if it is only an hour or two.

Birthdays, Christmas, holidays, anniversaries etc. may be a difficult time for the whole family. Anxiousness and irritability around these days is normal. Plan ahead to make activities simple and memorable. As a family member or friend, acknowledge that you remember this special time.

Close friends, clergymen or your family doctor can be an excellent source of emotional and physical strength. Errands, child care, meals or housework can be handled by others. Friends may also be able to search for community or medical resources of value to you.

Unfortunately, there will always be acquaintances whose stories of miraculous treatments or opinions regarding your decision are best treated with a kindly 'thank you' and then forgotten. Also expect that there are those who simply cannot 'deal with the situation' and will never call or offer to help.

There are many health care professionals based in the hospitals and the community that can help you cope with the social and emotional aspects of your illness. Your doctor will advise you of the resources that are available in your area.

Driving

It is likely that you will not be able to drive following your diagnosis, at least for a time. **You should check with your doctor.**

If you find that you are not allowed to continue driving, the time that you have off driving is dependent on a few factors. These are the type of tumour you have and its position, whether you have seizures and if you have had surgery.

Your doctor has information from the Driver and Vehicle Licensing Agency (DVLA) and will be able to advise you.

You should notify the DVLA by writing to the Medical Adviser, Drivers Medical Unit, Longview Road, Swansea, SA99 1TU.

Many people find this difficult to come to terms with and it may mean you changing some of your daily routines.

You may be eligible for a bus pass or a mobility allowance; your doctor, nurse or social worker will be able to give you local information.

Support groups

Support groups can be an invaluable way for patients and family to benefit from the experiences of others in the same situation.

Becoming aware that someone shares similar difficulties can be reassuring. Meeting someone who has come through the experience provides hope. Learning how others work out the practical everyday problems are helpful.

Support groups are being set up in different parts of the country. If you would like information about your local support group please contact us.

Some people will not be able to attend a support group. For those who wish to speak to someone who has either, had a brain tumour or cared for someone with a brain tumour, you can telephone one of the trained befrienders.

About recurrences

Some brain tumours will recur. This may be because they are in a surgically difficult area and cannot be removed in their entirety, or because tiny cells, too small to be seen even with an operating microscope, may remain following surgery, radiotherapy and chemotherapy.

The goal of treatment to reduce the number of these 'left behind' cells to an insignificant amount is not always possible. Being told of recurrence is emotionally devastating. You may blame your doctor or yourself for choosing a particular treatment plan over another. The choice made at that time was the correct one for you. No one is to blame - it just happens.

Conclusion

No matter what the eventual outcome, a brain tumour and the treatment necessary to deal with it will cause major changes in the lives of those affected. Some friends, relatives and even acquaintances will amaze you with their generosity. Priorities will change and new relationships will begin.

This can be a very enriching time, a time for growth, a time for closeness, a time for sharing with others. You need not be alone.

Notes

It is helpful for you to write questions and important points for you to discuss with your doctor or nurse the next time you see them.

Other charities also offer support and information. Please see our page of links.

We are indebted to the American Brain Tumor Association, 2720 River Road, Des Plaines, Illinois 60018, USA for their permission to adapt their patient information leaflet and to the Western General Hospital, Edinburgh, Brain Tumour Support Group for their help in editing this booklet.

Brain Tumours and Epilepsy

Introduction

Most people with a brain tumour and epilepsy will have the epilepsy because the tumour causes a focal disturbance in one part of the brain. Drug treatments can reduce the frequency, severity and duration of seizures and sometime stop them completely.

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

This is where the disturbance in brain cell function starts at one specific site in the brain. The symptoms reflect the normal function of the part of the brain that is involved, 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).

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 relatively common. At any one time, at least 1 in 200 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.
- **Secondary Brain Tumours** are those that arise in another site in the body and spread (metastasise) to the brain.
- **Meningioma's** arise from the coverings of the brain (meninges) and are usually 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 will have seizures and only 20-30% of people with more serious brain tumours. 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 (e.g. meningioma) or tumours that have spread to the brain from another site (metastases).

How is epilepsy diagnosed?

The diagnosis is made from the description of the precise features of the seizures, and the circumstances in which they occur.

An **EEG** test (electroencephalogram) 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 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 improve 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 and occasionally seizures can come on or be temporarily worse after surgery. There are reports of radiotherapy improving seizure frequency, but not enough evidence to say that it does with any certainty.

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?

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, (e.g. rash, effects on the blood count, or liver upset) and others may feel tired or nauseated when a tablet is first started.

The tiredness and nausea may settle when you become used to the tablet, but the drug should be stopped if there is an allergic reaction (contact your doctor).

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. Ask your doctor, if you have any of these symptoms, as he may want you to take a smaller dose of the medication or to take 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 your doctor for advice.

How will the doctor try and help me?

Doctors will usually introduce medication gradually in small doses and advise you to take the medication regularly. Some medication only has to be taken once a day, others need to be taken three times a day. 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 nteractions between different anticonvulsants and frequently it is difficult to tell which one may be causing the side effects.

If drugs have been given which are unhelpful in your case it makes sense that they should be discontinued and subsequently avoided. Withdrawal of medication will be done gradually and new medication can be introduced slowly as the old one is removed.

Stress and poor sleep 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 it is worthwhile reducing the medication in order to minimise side effects. In cases like this sometimes surgery can 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 with medication. If you have any other illness, anticonvulsants should be continued. If the medication is vomited up, within a few hours of taking it, an extra dose should be taken. Avoid taking other medication unless it is really necessary and has been prescribed by a doctor.
- Not taking the 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, e.g. after breakfast and evening meal and consider using a pillbox divided into the days of the week. Don't take too much alcohol and get 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.

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.
- You should only be moved 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.
- 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.

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.

How will the seizures affect my daily life?

Driving

The law regarding epilepsy and brain tumours depends on the type and grade of tumour. The time that you will not be able to drive can be as low as one year or up to four years seizure free.

Your doctor has information from the Driver and Vehicle Licensing Agency (DVLA) and will be able to advise you.

You should notify the DVLA by writing to the Medical Adviser, Drivers Medical Unit, Longview Road, Swansea, SA99 1TU.

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, and 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 and if your job involves any of the above, some alteration in the structure of your job may be possible.

Computers, VDU's, discos and TV's 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 worth while discussing things in more detail with the person who makes the final decision, in order to personalise things more, or request a supporting medical statement. 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 and reducing 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

Don't swim alone, wear a distinctive cap and inform the pool attendant. Bicycle in company. Don't 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.

Should I tell people that I take 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 and be reassured that the seizure is usually over in 1 - 5 minutes, but 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, and 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 only occurs if they get in the way accidentally; when trying to suppress the limb movements or, in the period after a seizure when you may be confused, 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 take 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 (less than 65 years) or Attendance Allowance (over 65). Ask your doctor or nurse for advice or referral to a social worker.

Income Support may be available to you, as may Housing Benefit.

No one on regular anticonvulsants need pay prescription fees. Special travel passes can be applied for.

Radiotherapy for Brain Tumours

Introduction

Radiotherapy is an effective treatment for many brain tumours. It can stop a tumour growing and may cause it to shrink or in some cases disappear completely.

Why do you need radiotherapy?

Frequently brain tumours cannot be removed completely without interfering with normal brain structures and running the risk of causing permanent damage. Even if you have had surgery and the entire tumour seems to have been removed, small cells, too small to be seen by the surgeon may remain behind.

The cells of many malignant brain tumours are readily killed by radiotherapy and that is why this treatment is often recommended. It works by killing the cells directly or by interfering with their ability to grow. The tumour may shrink as tumour cells are destroyed. These cells are then disposed of by the body's natural process over a long time.

The operation and other medication such as steroid tablets and anticonvulsants (for seizures) may also have helped your symptoms and improved any disability. You may therefore be at a stage of recovery when the doctor suggests that you have radiotherapy.

Some tumours are very sensitive to radiotherapy and the hope is for a cure. Some tumours are less sensitive to it, in this case it may not be possible to effect a cure but radiotherapy will usually bring relief of symptoms and prolong life. Radiotherapy will also delay any tumour recurrence.

What is radiotherapy?

Radiotherapy is the use of high energy x-rays to destroy tumour cells whilst doing as little harm as possible to surrounding normal cells.

For various reasons the cells that grow and divide quickly are much more sensitive to radiation than non-dividing, resting cells.

In the brain most normal cells and certainly the important nerve cells (neurons) do not divide. This means that radiotherapy will be much more damaging to the tumour than the surrounding brain. Nevertheless a great deal of trouble is taken to minimise the amount of brain irradiated.

How is radiotherapy given?

Radiotherapy is given in a course of daily treatments called 'fractions'. It is given at different intervals; daily, twice daily or every few days. The number of fractions or daily treatments will depend on your tumour type and fitness.

Your doctor will plan the treatment individually for you taking all the factors into consideration.

Radiotherapy is painless, you will not feel anything during your treatment.

Planning radiotherapy

Before the radiotherapy can begin, the exact treatment plan, the radiotherapy dose, the number of fractions and the amount of brain that will be treatment is decided by the radiotherapist. A radiotherapist is a doctor who specialises in the treatment of tumours using radiotherapy. The treatment plan varies depending on the type of tumour.

Your doctor or nurse will fill in this section for your personal treatment plan.

Your radiotherapy will be given in:

- Number of fractions
- Frequency

Your first visit for radiotherapy

Your first appointment will be to the mould room.

To ensure that the radiotherapy is treating exactly the same area and that your position on the couch is the same each time, a Perspex mask is made. This is called a shell. It allows your head to be kept in the same position and helps to stop it moving during your treatment. In addition it has the advantage of allowing marks, for lining up the treatment machine, to be drawn on it instead of drawing on your skin. The mask is applied before each fraction of radiotherapy and removed immediately afterwards.

To make the shell an impression of your head and face is taken in the position that you will be in for your treatment. This could be lying on a couch on your back, on your side or even lying on your stomach. The impression is obtained using some strips of plaster of Paris bandage. Once the bandage starts to set it is removed and you can leave. The procedure takes about 20-30 minutes. Behind the scenes the mould room technician makes a plaster cast using this impression and a sheet of thin transparent Perspex is then moulded over this plaster cast. An alternative is to use a plastic sheet, which can be moulded when warm.

The shell needs to fit quite closely and it helps if you are relaxed during the taking of the impression. It does not hurt but most people say it becomes a little hot while the plaster bandage is setting.

The next step

Your next visit will be to the simulator machine. This is a special x-ray machine that can take films and reproduce the movements of the treatment machine and therefore 'simulate' the position of the x-ray beams that will be used for your treatment. You will need to lie in the treatment position wearing your newly made shell. The radiotherapist with the help of the radiographer plan the position of the radiotherapy beams using information from scans, operation and previous examinations. This session lasts about 30 minutes and is painless. It is often much longer than the treatment time on the machine.

At the end of this simulator session you will be given a date and time for starting treatment, this may be a few days later.

Whether you will be receiving radiotherapy as an outpatient or an inpatient will depend on how fit you are and your ability to travel. Your doctor will discuss this with you and any specific arrangements that need to be made.

You will be given a fixed appointment time for your treatment and every effort is made to keep closely to these times. However inevitably there may be some delays occasionally.

While some people find the shell and treatment machines intimidating at first, you can not feel the radiotherapy and there is no discomfort during treatment.

You are not radioactive and there is no need to take any special precautions for the safety of others. You are not a hazard.

The side effects

The side effects depend on how much of your brain is being treated or if the spinal canal has to be treated as well. Most side effects are quiet mild and all efforts are made to minimise them. However, some are inevitable.

Early side effects

- **Hair loss:**

  You will lose your hair in the area irradiated. Hair starts to fall out between the second and third weeks of treatment and will usually have grown back to its maximum extent by 3-6 months. It sometimes will not re-grow completely or it re-grows a slightly different colour and is usually finer than it was before the radiotherapy or it can re-grow curly. The part of your head that is affected will depend on the actual radiotherapy field arrangement, but for most people it will be such that a wig or hat will be required. Wigs are supplied on the National Health Service, your doctor or nurse will make arrangements for a fitting. Ladies often wear turbans, scarves and hats. Wigs are available for men, however most prefer to wear a hat or cut their hair very short or even shave their head.

- **Skin changes:**

  You may also notice some skin changes in the area being treated. After about 3 weeks it may become reddened, itchy and darkened, as sunburn might be. Do not try and treat this yourself. Check with your doctor, nurse or radiographer for advice on how to care for your skin. For example you will probably be advised to avoid the use of cosmetics and creams on the treatment area. It is also important that your head is protected in the sun with a hat. You should continue this practice for some years after the radiotherapy has finished. It is likely that the skin in the treatment area will be more sensitive to the sun.

- **Tiredness:**

  Most people will feel tired and a little sleepy towards the end of their course of radiotherapy. A sleep in the afternoon and periods of rest can help you cope with the tiredness. This feeling of tiredness can last for a few weeks. Additionally some people experience a period of increased tiredness around 6 - 10 weeks after radiotherapy has finished. If this happens to you it is advisable that you inform your doctor.

- **Nausea:**

  Very rarely people feel sick. This usually lasts just a few hours after treatment. For example, if your treatment is at 9am, you may feel queasy and not have much appetite for lunch, but by dinner time you are hungry again and ready to eat. Alternatively, it may be helpful to eat small but frequent meals throughout the day. Avoid fatty foods and keep your diet bland if you are feeling sick. If it is troublesome and persistent please tell your doctor as anti-sickness tablets can be prescribed and are effective.

- **Weight:**

  You may find that your weight has increased, especially if you have been on steroid tablets. In this case it is probably best to eat sensibly. Either way your doctor, nurse or dietician can give you advice.

- **Blood count:**

  The blood count is not usually a problem unless the spinal canal is being treated as well as the head.

Late side effects

There are some side effects that can develop many months or years after the radiotherapy. The degree and frequency will depend on the dose given, the amount of normal brain treated and sometimes the particular site of the brain that has been treated. If, for instance, the pituitary gland or the hypothalamus receives a high radiotherapy dose, regulation of some of the hormones can be upset. This may lead to a loss of periods or sexual function and sometimes an under active thyroid, but all of these can be treated by hormone replacements.

Most people are concerned about the effect of radiotherapy on their intelligence. Some damage to the normal brain will be inevitable. It must be remembered however that the tumour itself may cause damage and the best balance must be achieved between treatment effectiveness and side effects. All attempts are made to minimise radiotherapy injury to normal tissues and there are many people surviving well with normal life styles many years after treatment. If there is no tumour recurrence, many individuals can retain their ability to work and function within the lifestyle that they enjoyed before the illness began.

These notes are very general. If there are any questions about any aspects of your treatment, you should not hesitate to ask your doctor, nurse or radiographer.

When will I begin to notice results from the radiotherapy

The brain is not efficient at clearing away dead tumour cells. Also because the radiotherapy interferes with the tumour's ability to grow by damaging its reproductive cycle, cells die gradually over a period of time. Thus, it may be several months or even longer before the full effects of therapy are realised.

The results of scans taken during this time are often confusing. This is because of swelling caused by the treatment. Dead cells often appear as a mass larger than the original tumour, and this mass may cause symptoms similar to the tumour.

Don't be disappointed if the first scans do not show shrinkage of the tumour. The combined effects of your surgery and radiotherapy may mean that the positive results that you hope for will not be obvious for a while. The changes expected may show up on a later scan.

What is much more important is how you feel and whether there is improvement in your function and disability.

After the treatment

Most people feel an unexpected sense of depression after the treatment is over, even though they have been looking forward to its completion.

While you are undergoing treatment, you have a specific goal in mind and specific activities that have to be performed. You feel that you are contributing to the effort of your treatment.

Once radiotherapy is over you are no longer taking an active role. It may be a few weeks before you have to see your doctor and there is nothing to be done until then. No wonder you feel depressed - everyone does.

Your task now is to stay as healthy and as active as possible. Aim to lead an active life. Exercise. Eat well. Keep appointments for tests and check ups. See your doctor or nurse if you have any questions or notice any changes you think are important and are of concern. Think about joining a self-help group. The worst may well be over.

For Information / Support / Counselling contact:

Brain Tumour Action
25 Ann Street
EDINBURGH
EH4 1PL

High-Grade Glioma Brain Tumours

Introduction

This page contains information about high-grade brain tumours. It has been written as an addition to the information on the Living with a Brain Tumour page.

This information will provide a basis for your discussions with your doctors and nurses.

What is a Glioma?

The brain substance is made up of nerve cells (Neurons) and supportive tissue (Glia). Supportive tissue comprises of 3 cell types:-

- **Astrocytes**, which are thought to provide the brain's framework and help control the chemistry of brain cells.
- **Oligodendrocytes**, which help as insulators in the transmission of messages in the brain.
- **Ependymal cells**, which line the cavities in the brain.

Most primary brain tumours arise from the supportive tissue and are collectively called Gliomas. Gliomas can be separated further depending on their cell of origin:

- Astrocyte - **Astrocytoma**,
- Oligodendrocyte - **Oligodendroglioma**,
- Ependymal cell - **Ependymoma**.

The World Health Organisation grades astrocytomas into four grades. Grade 1 tumours are the least malignant and grade 4 the most malignant.

- Grade 3 are called Anaplastic Astrocytoma
- Grade 4 are called Glioblastoma Multiforme.

Together these grades are called High Grade Gliomas.

What are the common symptoms?

The symptoms will vary depending on the size and location of the tumour. Everyone is an individual and the symptoms may be different in different people. Some people may experience all, some or none of the symptoms.

The first symptoms may be headache, due to increased pressure in the head, seizures or weakness, numbness or speech problems. It may be helpful for you to read the information in the Living With a Brain Tumour page, which outlines the possible effects.

How is the diagnosis made?

Investigation of a suspected brain tumour follows a standardised procedure. A good neurological examination is essential, followed by some combination of the following tests, depending on the need and availability.

CT Brain scan (Computed Tomography) is a specialised x- ray. It will take 20-30 minutes and an injection, into the back of your hand, of a contrast agent (dye) may be necessary to give the clearest picture of the tumour.

MRI Brain scan (Magnetic Resonance Imaging) is a specialised imaging technique that gives very clear pictures of the brain and will show the site and extent of the tumour. It usually takes 30-40 minutes and uses magnetism instead of x-rays. People with pacemakers cannot have this test and those with any other metallic implant should inform the doctor well before the test.

How common are these tumours and who gets them?

There are about 8 new cases of primary brain tumour diagnosed for every 100,000 people every year. In other words about 4,500 new cases in the UK each year.

About 70-80% of primary brain tumours are **High Grade Gliomas**. They occur most often between the ages of 45 and 65 and effect men more frequently than women.

The cause of **High Grade Gliomas** remains unknown. Research has not proved a hereditary cause. There do not appear to be any links with occupation, infections or head injury.

What treatment might be available?

Your doctor will plan your treatment taking into consideration your general health, your symptoms and signs and the size and position of the tumour. In other words the treatment is planned for each individual.

Surgery

The first treatment choice for accessible tumours is surgery. Accessible tumours are those that can be operated on without a high risk of causing severe neurological damage. High Grade Gliomas may occur in sites that are not easily reached by surgery. In these instances, biopsy alone - examination of a surgical sample of the tumour- may be performed. Biopsy results help to establish the diagnosis and indicate whether the tumour is amenable to other treatments. Tumours that are located in the areas of the brain that control breathing, intellect or physical movement would possibly be considered inoperable.

Radiotherapy

This is the use of high energy x-rays to destroy tumour cells. It is often given after surgery; it may be used alone or given with chemotherapy. For further information see the Radiotherapy for Brain Tumours page.

Chemotherapy

Is treatment with drugs, which destroy tumour cells. It may be given alone or with surgery and/or radiotherapy.

For further information consult your doctor or the Chemotherapy for Brain Tumours page.

Low-Grade Glioma Brain Tumours

Introduction

This page contains information about low-grade brain tumours. It has been written as an addition to the information on the Living with a Brain Tumour page. This information will provide a basis for your discussions with your doctors and nurses.

What is a Glioma?

The brain substance is made up of nerve cells ***(Neurons)*** *and supportive tissue* ***(Glia)***

Supportive tissue comprises of 3 cell types:

- **Astrocytes**, which are thought to provide the brain's framework and help control the chemistry of brain cells.
- **Oligodendrocytes**, which help as insulators in the transmission of messages in the brain.
- **ependymal cells**, which line the cavities in the brain.

Most primary brain tumours arise from the supportive tissue and are collectively called Gliomas.

Gliomas can be separated further depending on their cell of origin:

- Astrocyte - **astrocytoma**.
- Oligodendrocyte - **oligodendroglioma**.
- Ependymal lining cell - **ependymoma**.

The World Health Organisation grades astrocytomas into four grades. Grade 1 tumours are the least malignant and grade 4 the most malignant.

- **Pilocytic Astrocytoma** is graded as 1
- **Astrocytoma** and **Oligodendroglioma** are grade 2 tumours.

Together these grades are called Low Grade Gliomas.

What are the common symptoms?

The symptoms will vary depending on the size and location of the tumour. Everyone is an individual and the symptoms may be different in different people. Some people may experience all, some or none of the symptoms.

A brain tumour that is slow growing, like **Low Grade Gliomas**, may be present for many years without symptoms. The first symptoms are usually seizures or headaches. 80-90% of people with Low Grade Gliomas of the cerebral hemispheres have seizures. Headaches, seizures and other symptoms such as numbness, weakness or speech problems can occur.

The information in Living with a Brain Tumour and Brain Tumours and Epilepsy pages will explain these points further.

How is the diagnosis made?

Investigation of a suspected brain tumour follows a standardised procedure. A good neurological examination is essential, followed by some combination of the following tests, depending on the need and availability.

- CT Brain scan (Computed Tomography) is a specialised x-ray. It will take 20-30 minutes and an injection, into the back of your hand, of a contrast agent (dye) may be necessary to give the clearest picture of the tumour.
- MRI Brain scan (Magnetic Resonance Imaging) is a specialised imaging technique that gives very clear pictures of the brain and will show the site and extent of the tumour. It usually takes 30-40 minutes and uses magnetism instead of x-rays. People with pacemakers cannot have this test and those with any other metallic implant should inform the doctor well before the test.
- EEG (Electroencephalogram) is a test that measures the electrical activity coming from the brain. It does not give pictures but instead tells a little about how the brain is functioning and it is useful in confirming seizures if there is a clinical suspicion of epilepsy.

How common are these tumours and who gets them?

There are about 8 new cases of primary brain tumour diagnosed for every 100,000 people every year. In other words about 4,500 new cases in the UK each year.

About 20% of primary brain tumours are **Low Grade Gliomas**. The cause remains unknown. Research has not proved a hereditary cause. There do not appear to be any links with occupation, infections or head injury.

Pilocytic astrocytoma mostly occurs in children in the cerebellum or brain stem, but a third occur in the cerebral hemispheres.

Astrocytomas account for **1O%** of adult primary brain tumours and most are situated in the frontal lobe.

Oligodendroglioma account for **5%** of gliomas. They often contain both oligodendrocytes and astrocytes and are therefore referred to as 'mixed glioma'. They occur most frequently in middle aged or young adults, but in rare cases also occur in children and the elderly.

Ependymoma occur most frequently in children in the brain stem and occasionally in the ventricles (fluid filled sacs in the brain).

The information in the Living with a Brain Tumour page illustrates the areas of the brain and its functions.

What treatment might be available?

Your doctor will plan your treatment taking into consideration your general health, your symptoms and signs and the size and position of the tumour. In other words the treatment is planned for each individual.

Surgery

The first treatment choice for accessible tumours is surgery. Accessible tumours are those that can be operated on without a high risk of causing severe neurological damage. **Low Grade Gliomas** may occur in sites that are not easily reached by surgery. In these instances, biopsy alone - examination of a small sample of the tumour - may be performed. Biopsy results help establish the pathological diagnosis and indicate whether the tumour is amenable to other treatments. Tumours that are located in the areas of the brain that control breathing, intellect or physical movement would possibly be considered inoperable.

Radiotherapy is the use of high energy x-rays to destroy tumour cells. It may be given after surgery, depending on tumour location, its size and the signs and symptoms produced. For further information see the Radiotherapy for Brain Tumours page.

Chemotherapy is treatment with drugs which destroy tumour cells. It is usually not necessary for this type of tumour. For further information consult your doctor or the Chemotherapy for Brain Tumours page.

Chemotherapy for Brain Tumours

Introduction

Chemotherapy is sometimes used in the treatment of Brain Tumours. Chemotherapy is treatment with drugs. It may be just one drug or several drugs depending on the type of tumour you have and the intended aims of the treatment.

Treating a Brain Tumour with chemotherapy is different from a tumour at other sites of the body.

A covering called the blood brain barrier surrounds the brain. This barrier can stop some drugs from reaching the brain tumour. This limits the number of drugs that can be used.

Often, to increase the effectiveness of the chemotherapy, a combination of drugs is used.

One of the most commonly used combinations is **PCV**. This is a combination of three drugs called: **Procarbazine**, **CCNU** and **Vincristine**. **PCV** is usually given every six weeks. Your doctor may use a slightly different combination and it may be helpful for the doctor or nurse to write down your specific treatment.

Chemotherapy may have side effects. If you are suffering with any of the symptoms in this leaflet you should contact your own doctor.

The side effects of PCV chemotherapy are outlined in this leaflet. However even if you are having a different combination (or even just one drug) it will give you an idea of what you may expect and advise you of what to do.

Procarbazine is taken orally and it can occasionally have some side effects: nausea, vomiting, diarrhoea, flu-like symptoms, a rash or possibly some dizziness. These side effects do not last long because tolerance usually develops over a few days.

In addition you should be aware that you should **avoid** certain foods and drinks, for the time that you are taking the Procarbazine tablets (5-7 days). These include alcohol, cheese, yoghurt, sour cream, chicken livers, banana, avocado and meat prepared with tenderisers. Eating or drinking any of these **may cause an allergic reaction**.

Vincristine is given as an injection into a vein, usually into the back of your hand. The side effects associated with this drug can include; hair loss, constipation and over long term use it can cause tingling of fingers and toes or some muscle weakness.

CCNU is given in tablet form. This may cause nausea and vomiting. Usually an anti-sickness tablet is given to help with these side effects.

Many chemotherapy drugs can cause bone marrow suppression. This may result in you feeling tired and lethargic. **There is also an increased risk of infection and a susceptibility to bruising and bleeding.**

Your blood count will be checked regularly but **if you are feeling unwell please see your own doctor**. It may make you more susceptible to infection.

New treatments

There are a number of new chemotherapy drugs that are under research investigation. New treatments are used initially in **clinical trials**. These are studies that are designed to answer specific questions about the drug being used. In this way the effectiveness of the new drug can be assessed.

Your doctor may discuss these with you or you may hear about them from the press or television. Do not hesitate to ask for information and explanation by your doctor.

Pituitary Gland Tumours

Introduction

This page contains information about pituitary gland tumours.

This information will provide a basis for your discussions with your doctors and nurses.

Pituitary tumours (adenomas) Pituitary tumours are almost invariably benign (non-cancerous). They are often called adenoma5 and are usually slow growing.

The pituitary is a small oval shaped gland found at the base of the brain below the optic nerve. The gland secretes hormones that control other glands in the body. It secretes a number of hormones such as:

- **Growth Hormone** which controls growth
- **Prolactin**, stimulates milk production after childbirth
- **ACTH** stimulates the adrenal glands to produce hormones
- **TSH** stimulates the thyroid gland
- **FSH** and **LSH** influence the production of hormones from the ovaries and testes.
- **ADH** controls the concentration of urine.
- **Oxytocin** stimulates the contraction of the womb in childbirth and the production of milk for breast feeding.

Symptoms

Most of the symptoms are a result of a hormone imbalance and can take a long time to develop.

Prolactin secreting tumours are most common and result in an absence of monthly periods and production of breast milk. Men may experience impotence. Infertility is common in both sexes.

Tumours secreting **FSH** or **LSH** are rare but would cause infertility also

Tumours that secrete an excess of growth hormones may cause a condition called gigantism or acromegaly, which is noticeable by the enlargement of the hands and feet.

Symptoms including weight gain, increase in facial hair and depression can result from an over-production of **ACTH**.

Sometimes a condition called diabetes insipidus is found, especially if there is disruption in the levels o f **ADH**. The main symptoms are passing large amounts of urine and continuous thirst.

Pituitary adenomas can cause pressure particularly on the **optic nerve** which leads to problems with vision and can cause headaches.

Diagnosis

Pituitary tumours are often discovered from a blood test; for example, as a result of routine blood samples taken to investigate infertility. If excessive amounts of hormones are detected in the blood then a CT scan or a MRI scan will be arranged. The scan will show the exact position of the tumour.

CT Brain scan (Computed Tomography) is a specialised x-ray. It will take 20-30 minutes and an injection, into the back of your hand, of a contrast agent (dye) may be necessary to give the clearest picture of the tumour.

MRI Brain scan (Magnetic Resonance Imaging) is a specialised imaging technique that gives very clear pictures of the brain and will show the site and extent of the tumour. It usually takes 30-40 minutes and uses magnetism instead of x-rays. People with pacemakers cannot have this test and those with any other metallic implant should inform the doctor well before the test.

The treatment of Pituitary tumours

Your doctor will plan your treatment taking into consideration your general health. In other words the treatment is planned for each individual.

Drugs: Some drugs to shrink the tumour can be given, depending on the hormones that are being secreted. (For example a prolactin secreting tumour can be treated with a drug called Bromocriptine.)

Surgery: Is a common treatment for pituitary tumours. The operation is technically easier than for other brain tumours. Generally the surgeon aims to remove most but not all of the pituitary gland. If the pituitary gland does not recover then medication will need to be given to replace the missing hormones. This is not a major problem and is usually managed by a doctor called an endocrinologist.

Radiotherapy: This is the use of high energy x-rays to destroy tumour cells. It is often given following the surgery.

Radiotherapy is usually given as a course of treatments called 'fractions'. This usually means 20-30 treatments, once daily, 5 days a week for further information see the Radiotherapy for Brain Tumours page.

Meningioma

Introduction

This page contains information about a type of brain tumour called a meningioma. This information will provide a basis for your discussions with your doctors and nurses.

Meningioma

Meningiomas arise from the leather-like layer of tissue covering the brain and spinal cord, called the meninges. Meningiomas can occur in any part of the brain or spinal cord but are usually sited on the inside of the skull. These tumours are usually benign (i.e. non-cancerous) and slow growing. They can grow quite large before they cause symptoms.

Symptoms

The symptoms are often due to increased pressure caused by the growing tumour, and often the first sign is a headache. Some people will feel nauseated and vomit. Others may have visual disturbances and some people will have seizures.

The symptoms will vary depending on the size and location of the tumour and may well be different in different people. Some people may experience all, some or none of the symptoms.

If you have a meningioma of the spinal cord you may experience pain, loss of sensation or weakness of the arms and legs. Some people may have problems with walking and some may have loss of bowel or bladder control.

Diagnosis

To come to a diagnosis the doctor will give you a neurological examination to assess the effect of your tumour on your nervous system. Then a **CT scan** or a **MRI scan** will be performed. The scan will show the exact position of the tumour. Other special x-rays may be performed, if the tumour involves the bone, skull x-rays may be taken. If the meningioma is in the spinal canal a **spinal MRI scan** may be done. Not infrequently an **angiogram** is performed. Sometimes an EEG test will also be done.

CT Brain scan (Computed Tomography) is a specialised x-ray. It will take 20-30 minutes and an injection, into the back of your hand, of a dye may be necessary to give the clearest picture of the tumour.

MRI Brain scan (Magnetic Resonance Imaging) is a specialised imaging technique that gives very clear pictures of the brain and will show the site and extent of the tumour. It usually takes 30-40 minutes and uses magnetism instead of x-rays. People with pacemakers cannot have this test and those with any other metallic implant should inform the doctor well before the test.

Angiogram is a special X-ray that shows up the blood vessels in the brain. This takes about an hour and involves a special injection of a dye.

Spinal MRI is another special scan of the spinal cord. It takes about 20-30 minutes and again may involve a small injection in the back of the hand. EEG (Electroencephalogram) is a test that measures the electrical activity coming from the brain. It does not give pictures but instead tells a little about how the brain is functioning and it is useful in confirming seizures, if there is a clinical suspicion of epilepsy.

The treatment of Meningioma

Your doctor will plan your treatment taking into consideration your general health and the size and position of the tumour. In other words the treatment is planned for each individual.

Surgery

The first treatment choice for meningeal tumours is surgery. Most can be operated on without a high risk of causing severe neurological damage.

Radiotherapy

This is the use of high energy x-rays to destroy tumour cells. Radiotherapy may be used when the meningioma is not completely removed by the surgery or can't be operated on safely because of the site of the meningioma. It can also be used to treat tumours that recur after surgery.

Radiotherapy is usually given as a course of treatments called 'fractions'. This usually means 20-30 treatments, once daily, over a few weeks. For further information see the Radiotherapy for Brain Tumours page. Stereotactic radiotherapy is being studied as a first treatment instead of surgery. This is a specialised form of x-ray treatment that uses narrow beams of high energy x-rays aimed at a small part of the head and is probably most useful for small tumours (<3 cm).

Steroids may be given to reduce any swelling around the tumour. Anticonvulsant medications can be used to control seizures. Refer to the Brain Tumours and Epilepsy page for further information.

Recurrence

Most meningiomas are benign and can be treated successfully with surgery. However sometimes the tumours regrow even when the tumour was thought to be totally removed. Treatment may be surgery again or radiotherapy. There may also be some new treatments available and you should discuss this with your doctor.

Even recurrent meningioma may not cause trouble and grow so slowly as not to interfere with life.

Children's Brain Tumours
Information and support for parents and others

Introduction

Brain Tumours are the most common solid tumour in children.

There are different kinds and grades of brain tumour.

Sometimes they may be described as benign or **low-grade.**

Others will be diagnosed as **high-grade.**

Some are curable but others may come back at some point.

Symptoms may include:

- Vomiting
- Headaches
- Clumsy movements
- Difficulties in walking
- Epileptic fits
- Sleepiness
- Squinting or other eye problems
- Ringing or buzzing in the ears
- Weakness on one side of the body
- Dizziness
- Problems with memory
- Difficulties with speaking, understanding or writing.

Diagnosis

As well as a neurological examination in the hospital several other tests are commonly used to make a diagnosis. These include:-

CT SCANS which combine an X-ray machine with a computer. A special dye is usually injected into the child's vein beforehand. This makes abnormal brain cells easier to see.

MRI SCANS also give clear pictures of the brain. They do not use X-rays but radio waves. They provide clearer pictures that CT scans in some parts of the brain.

EEG tests are often used to record electrical activity in the child's brain using electrodes attached to the scalp.

BIOPSY may be performed to make an accurate diagnosis of the type of tumour. This is an operation under anaesthetic where a very small hole is made in the skull and a piece of tumour is removed for analysis.

Treatments may include:-

Surgery

Depending on the position of the tumour it may be possible to remove most or all of it by surgery. However, it is too risky to operate on some brain tumours.

Chemotherapy

This is used to help kill the tumour or to delay its recurrence. Some brain tumours will stop growing and others may shrink with this treatment. There are many different kinds of chemotherapy and more than one may be prescribed. Very young children are often given chemotherapy instead of radiotherapy because it is considered to be safer.

Radiotherapy

There are various types of radiotherapy but the most common one lasts for several weeks. The aim is to destroy tumour cells as they are growing so radiotherapy is often prescribed for high grade tumours which grow quickly.

BTA's Paediatric (Children) sub-committee members all have children with a brain tumour. They have helped to produce this leaflet.

If you would like to know more or just feel like a chat please get in touch – at BTA we're all here to help each other. For ways of contacting us visit the contact us page on the website.

Facts and Figures

- Primary brain tumours are the most common solid tumour in children
- Brain tumours are the second most common cause of neurological death (stroke is the most common)
- Primary brain tumours are the 4th most common tumour in the under 45 age group
- Primary brain tumours are the 5th most common cause of cancer death in the working population
- Secondary brain tumours (metastasis) affect 20% of all people with cancer
- Primary brain tumours are the 8th most common in the working population