

Leaflet 1 - 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 knows that there are resources to support them.

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 removed by surgery.

Many brain tumours that are found and treated early cause little or no permanent damage to mental or physical abilities. However there are some brain tumours that may cause permanent disability or even death, depending on the grade of the tumour and where it is in the brain.

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 text 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 can often 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 questions you want to ask and the information you receive 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.

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 generalised symptoms. (Your family and close friends may also experience some of these problems.) These can be due to the emotional stress caused by treatments, or 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 EXAMPLES OF PROBLEMS CAUSED BY TUMOURS IN DIFFERENT PARTS OF THE BRAIN

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.

PARIETAL 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.

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.

HYPOTHALAMIC AND PITUITARY TUMOURS can affect appetite and food intake. Pituitary Tumours can cause excess or under activity of some hormones. This can effect women's menstrual cycle and sometimes cause breast milk. Growth hormones and thyroid hormones may also be affected.

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

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 are often prescribed to reduce the swelling. However, as with many medicines, steroids have some side effects that may cause you problems. These problems may include: weakness of your legs, an increase in appetite, indigestion, thirst, frequency passing urine, the inability to sleep at night or agitation and anxiety. 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.

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.

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. There may be a feeling of not being sexually desirable or a 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, and 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.
- 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.
- 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 friend to tape reading material for you to listen to, or make more use of the radio.
- Accept help from others without feeling guilty or obligated to repay the favours.

- If you are having a difficult time, consider seeking professional help, e.g. a counsellor, psychologist, minister or doctor.
- Look after yourself, set your own limits. Treat yourself to some small luxury or pleasure. Be positive.
- Read about how others have dealt with this problem.
- We are here to give you information and support. Call our helpline from 10am to 1pm Monday to Friday on **0845 4500 386** or email helpline@braintumouruk.org.uk.

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 and family roles 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. Anxiety 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 can- not '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 specialist nurse can advise you of the resources that are available in your area.

SUPPORT GROUPS

Support groups can be invaluable. Realising that someone shares similar difficulties can be reassuring, and meeting someone who has come through the experience provides hope. Learning how others work out practical everyday problems is helpful.

If you would like information about these groups please contact Brain Tumour UK.

If you are unable to attend a support group but wish to speak to someone who has either had a brain tumour, or cared for someone with a brain tumour, you can join a Phone Pals group – contact us through our website at www.braintumouruk.org.uk or email enquiries@braintumouruk.org.uk or phone 0845 4500 386.

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. The first sign 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.

DRIVING

It is likely that you will not be able to drive following your diagnosis. 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 dependant 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. It is usually around 6-12 months following treatment depending on the type of tumour. Many people find this difficult to come to terms with and it may mean changing some of your daily routines.

You have to notify the DVLA Adviser of your diagnosis. Drivers Medical Group, DVLA, Swansea, SA99 1TU. Telephone: 0870 600 0301 between 8am and 5.30pm Monday to Friday, and between 8am and 1pm on Saturdays. For more information go to www.direct.gov.uk/motoring - Medical rules for all drivers.

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.

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. Friends, relatives and even acquaintances may amaze you with their generosity. Priorities will change and new relationships may begin.

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

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