

Living with a brain tumour

Information sheet 12

Introduction

A brain tumour may affect your life in different ways. Shock, fear and despair are some of the typical reactions to being diagnosed with a brain tumour.

The panic and anxiety you may feel is a natural response, affecting not only you but those close to you. There will have to be some changes in your daily routines and responsibilities and it will be easier if everyone involved understands what is going on and why.

Our information on living with a brain tumour will help you speak to your doctor or medical team about your condition. It should not be used as a substitute for professional care.

Quick facts about brain tumours

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.

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

Each year, more progress in research and treatments are made.

Common periods of emotional stress

We know from listening to people diagnosed with brain tumours that these periods caused them the greatest emotional stress:

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

Where to get information?

A vital step in coming to terms with your diagnosis, is to get accurate and understandable medical information about your tumour and your treatment options. Being able to participate in decisions about your treatment and care can help you feel more in control and less helpless. Ask your healthcare team to give you contact details for your key worker (this is likely to be a specially trained nurse or a doctor.)

Online, you will find a large amount of information about your condition and how to deal with it. Friends and others will also offer information. Choose the information carefully, looking for evidence that it is based on good quality research from reputable people.

Living with a brain tumour - physical effects

Learn more about potential physical symptoms and effects that a brain tumour can cause.

This question is the most difficult one to answer. The effects vary and depend on the type and location of the tumour(s).

General symptoms

You may find the stress you are under causes:

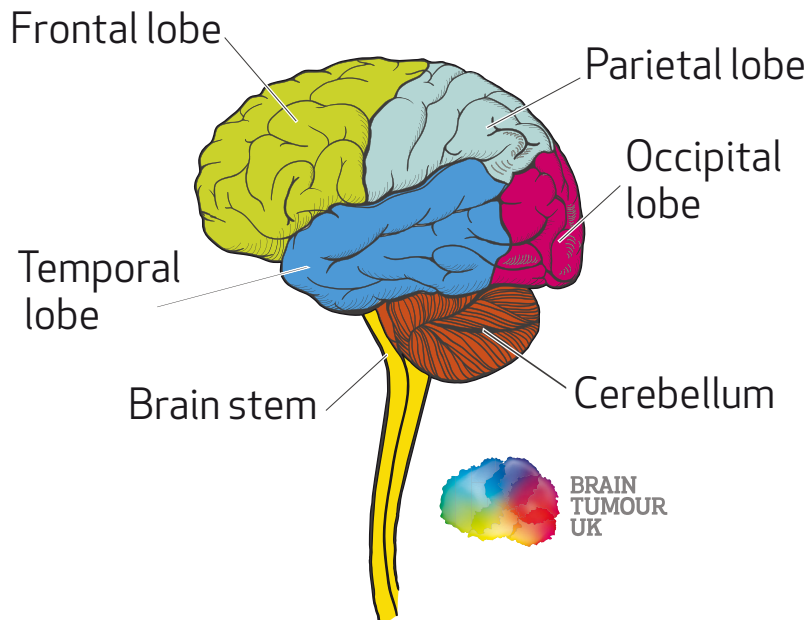
- A loss of appetite
- depression
- irritability
- fatigue
- sleeplessness
- erratic memory
- restlessness.
- Nausea, bladder problems or constipation can also occur. Your healthcare team can help you deal with these problems.

Symptoms caused by the tumour

There is a limited amount of space inside the skull, so the growth of anything that does not normally belong there causes changes in normal brain functions. These changes may be temporary or permanent. 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.

The brain is divided into lobes.

Tumours in the frontal lobe 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.



Tumours in the parietal lobe 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.

Tumours in the temporal lobe, which are frequently 'silent' unless they reach a significant size, can cause a dreamy 'deja vu' state. The loss of ability to understand language (aphasia), is associated with this area. Tumours in the occipital tumours can cause disturbance in vision and visual memory. Double vision, visual hallucinations or partial loss of vision could occur.

Optic nerve tumours reduce visual accuracy and can lead to blindness.

Tumours between the cerebellum and the pons – two parts of the brain at the base of the skull – are called cerebello-pontine angle tumours. They include acoustic neuromas and can cause pressure on the cranial nerve. Ringing in the ears or hearing loss (especially in using the telephone) can occur.

Tumours on the brain stem can affect tongue movements and cause difficulty with swallowing or speaking. Unusual eye movements can cause dizziness or unsteadiness in walking.

Tumours in the hypothalamus and pituitary gland can affect appetite and food intake.

Pituitary tumours can cause excess or under activity of some hormones. This can effect women's menstrual cycles and sometimes cause breast milk to flow. Growth hormones and thyroid hormones may also be affected.

Tumours in the Posterior Cranial Fossa 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. The Posterior Cranial Fossa is part of the intracranial cavity which contains the brainstem and cerebellum.

Side effects of treatment

Headaches are the most common discomfort associated with brain tumours.

Pain or discomfort following tumour removal or chemotherapy.

Skin problems & nausea are possible side effects of radiotherapy. However, most people feel it is worth tolerating the side effects to get the expected benefits. You can get medication to help with these effects.

Swelling of the brain prior to surgery and following radiotherapy 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 and offer temporary control over headaches. Side effects from steroids could include weakness of your legs, an increase in appetite, indigestion, thirst, frequency passing urine, the inability to sleep at night or agitation and anxiety.

Seizures may be one of the first symptoms of a brain tumour or may occur after surgery. Most seizures can be controlled with anticonvulsant medications.

Discuss side effects with your doctor or pharmacist. Blood tests help determine the level of drug needed.

Some seizures can be difficult to control, but those following surgery frequently decrease with time.

How will I change physically?

Losing your hair during treatment can be distressing. If you lose your hair your scalp will become sensitive and you can feel that people are looking at you. There are lots of options available from wigs through to scarves, ties and baseball caps. You might also lose your eyebrows and eyelashes and again this can make you feel self conscious. Your healthcare team can help you get through this period.

For more information about a free service run by specially trained volunteer advisors, offering practical information and support around hair loss due to cancer treatment, on an individual appointment basis, visit <http://www.breastcancercare.org.uk/about-us/our-services/local-support/headstrong/>.

You may lose interest in sex. Women may experience vaginal dryness, you might feel less desirable or be concerned about hurting or stressing yourself (or your partner may be afraid of hurting you).

You may feel tired, making it difficult to cope with your normal schedule. Deal with the fatigue having

frequent rest periods during the day. When you feel like cooking try and make batches of food to freeze for the times when your energy is low. Gentle exercise does help increase energy levels and physiotherapy can help maintain muscle tone.

What about my other medical conditions?

Medical conditions that existed before your diagnosis must continue to be treated, and keep up appointments to the dentist, optician etc.

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 other sites of your body.

My brain tumour has come back - what now?

Some brain tumours will recur. This may be because they are in a difficult area and cannot be removed entirely, or because tiny cells may remain following surgery, radiotherapy and chemotherapy. A recurrence can be emotionally devastating. No one is to blame and the choices that were made about your treatment were based on what was known at the time.

Living with a brain tumour - emotional effects

A change in life style, an acceptance of some degree of dependence, and dealing with a feeling of lack of control are some of the issues you may have to come to terms with. Every day we talk to people with brain tumours who are experiencing a wide range of emotions.

Common feelings after being diagnosed

Being in denial

Disbelief or a lack of concern is normal. Some may pretend it has not happened. Others may simply be in a state of shock. "Brain tumours happen to other people" or "Why me?" are common questions people ask themselves.

Feeling guilty

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?" You can also feel guilty if you feel you are causing disruption or distress to those close to you.

Being angry at spouses, family friends, employers, doctors or anyone is not unusual. Trying to hide your anger can lead to irritability, sleeplessness, fatigue, over-eating and over-drinking.

Feeling depressed or grieving about the way things used to be

This can last for a long time. Feeling restless and moodiness can also last for a long time. While physical activity may be the last thing you feel like doing – it can often be really helpful.

No two people are alike so the nature and type of responses will vary from person to person. Support from Brain Tumour UK along with that from your friends and family can help you get through. There are also specialist cancer counselling services available. Ask your key worker, or contact Brain Tumour UK for more information.

How can I cope with my feelings?

Allow yourself to feel and try to express your emotions through words, pictures or music – whatever works for you. Find someone to confide in. For patients and families, support groups can be invaluable. It helps to know you are not the only one dealing with this situation.

Accept help from others but don't feel guilty about it.

If you feel you are struggling then there are services like BTUK's helpline or specialist cancer counselling services which can help you.

Look after yourself, set your own limits and indulge yourself

Find out how others deal with things. You can use our social networking site, our support group or our Phone Pals groups to talk to people in similar situations.

If you can't find the information you are looking for, contact us at Brain Tumour UK.

Our confidential helpline 0845 4500 386 is open Monday to Friday 10am -1pm and 2pm-5pm. For other queries dial the same number and choose one of the options.

You can also get in touch by emailing us at support@braintumouruk.org.uk or by writing to Brain Tumour UK, Latimer Park, Chesham, Bucks, HP5 1TU.

Living with a brain tumour - other areas of life

For the time being, you may want to consider whether responsibilities such as managing finances, looking after children, managing the household can be handled by others. Consider asking friends or family members whom you may not have considered calling on for help.

Financial benefits information

More than £126.5 million in disability benefits is going unclaimed by people diagnosed with terminal cancer in the UK according to a report by Macmillan Cancer Support.

Macmillan's findings relate to unclaimed Disability Living Allowance (DLA) and Attendance Allowance (AA) by people diagnosed with terminal cancer. Terminally-ill cancer patients automatically qualify for DLA and AA, yet millions may be going unclaimed by people who do not have a terminal diagnosis but find claiming benefits more stressful than having cancer itself! They may also be entitled to other benefits such as housing benefit, council tax benefit, income support or Carer's Allowance (CA).

Macmillan Cancer Care provides financial information on their website, or call them free on: 0800 500 800.

What about my carers?

If you are being cared for by family members, remember they need time off to take care of their own needs.

Understanding relatives and friends can be called upon to help.

Will I lose my driving licence?

You will probably not be able to drive following your diagnosis.

How long you are not able to drive for depends on the type of tumour and its position, whether you have seizures and if you have had surgery.

Your doctor should have information from the Driver and Vehicle Licensing Agency (DVLA) and should be able to advise you. Explore more about losing and regaining your driving licence in our web pages.

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

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Brain Tumour UK is the leading, caring charity committed to fighting brain tumours. Our personalised support is available online, on the phone, by email and through our support groups. Our scientific research improves the quality of life for brain tumour patients and identifies better treatments. We raise awareness to change things for the better, for everyone affected by a brain tumour.

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*Providing support
Funding research
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