

# Living with brain tumours - A Quick Guide



## Contents

This is a brief summary of the information on 'Living with brain tumours' from CancerHelp UK. You will find more detailed information on the website.

In this information there are sections on

- Coping with brain tumours
- Getting better after treatment for brain tumours
- Brain tumours and driving
- What to ask your doctor
- Brain tumour organisations

## Coping with brain tumours

It can be very difficult coping with a diagnosis of a brain tumour, both practically and emotionally. You are likely to feel very upset and confused. As well as coping with the fear and anxiety that the diagnosis brings, you have to work out how to manage practically. There may be money matters to sort out. Who do you tell that you have a brain tumour? And how do you find the words? There may be children to consider.

Most people find the thought of a brain tumour very frightening. But there are lots of different types of brain tumours and the likely outcome varies a great deal,

depending on the type and grade of tumour that you have.

The coping with cancer section contains lots of information you may find useful. There are sections about

- Your feelings
- Talking to people: who and what to tell
- Talking to children
- How you can help yourself
- Who else can help you
- Financial support including Government benefits and charity grants

## Getting better after treatment for brain tumours

Brain tumour treatment can feel like a long haul. It will leave you physically and emotionally drained. You will need time to recover your energy and spirits. Some people also have physical after effects. You may have

- A weakness on one side of your body, in an arm or leg
- Difficulty walking or moving in other ways
- Difficulty with speech or understanding
- Fits



You could have any number of different symptoms, depending on where your brain tumour was. In time, you may well overcome any problems that remain after your treatment. The human brain is remarkable. You may or may not get completely back to normal, but there will always be room for some improvement.

It is best to start any therapy you need as early as possible. For example, physiotherapy or speech therapy. Don't be afraid to push for this if it isn't arranged automatically. You have a right to it. It can make a lot of difference to your quality of life.

### Brain tumours and driving

You may not be allowed to drive for a while after you have had a brain tumour. This depends on the type of brain tumour you had and on where it was in the brain. For many types, you cannot drive for 2 years. With pituitary tumours, you can usually drive as soon as you have recovered from treatment. If you had a brain tumour as a child, but you have grown up without any recurrence, you can have a regular driving license.

On CancerHelp UK you will find more details about the rules on driving for different tumour types.

#### Fits

You cannot drive for at least a year after you have had a fit at any point, or been on anti fit medicines. But you may be able to keep your licence if you had a fit while you were sleeping and you last had a fit in your sleep more than 3 years ago. You must not have had a fit whilst awake during this time.

### DVLA driving regulations

By law, you have to tell the Driver and Vehicle Licensing Authority (DVLA) about your medical condition. They will take back your license and issue you with a new one, once you are declared fit to drive again by your doctor. You don't have to take your driving test again.

### Going back to work after treatment for brain tumours

Some people make a complete recovery from their brain tumour and unfortunately others won't. It isn't really possible to tell beforehand how things will turn out. Whether you get completely back to normal and how soon that happens depends on

- The type of tumour you had
- The treatment you had
- Your job

Some people find they have more difficulty concentrating or remembering things after having treatment for a brain tumour. If you had a job where your mental skills and abilities were very important, you may not be able to go back to the level you were at before your diagnosis and treatment. This is understandably devastating for many people. It will take time to come to terms with it and work out what else you would like to do.

If you have a job operating heavy machinery, you may not be able to go back to it straight away. The best thing to do is talk to your occupational health department, if you have one. If not, talk to your manager at work.

If necessary, most employers will arrange for you to take on another role until you are fully better. You may be able to go back



to work part time. Then you can go back to your regular hours once you have regained your strength.

If you don't think it likely that you will get back to the job you had before, then it may be helpful to ask to see a social worker or benefits adviser at your hospital. They will be able to advise you about your legal position and give you benefit information if you need it. Your local Citizens Advice Bureau can also help you with this.

### **Recovery for children with brain tumours**

Brain tumours and their treatment sometimes cause lasting physical and mental changes.

#### **Physical problems**

Over half of children treated for brain tumours probably have some sort of physical problem, such as weakness in a limb or poor balance. Physiotherapy and other rehabilitation strategies can help. Some children will occasionally have fits or blackouts, headaches or migraines. A few are left with sight or hearing difficulties.

#### **Growth, puberty and fertility**

Radiotherapy to the pituitary gland or nearby can leave children without enough growth hormone. Injections of synthetic growth hormone can correct this. Radiotherapy to the spine can affect the adult height a child will reach. Sex hormones can also be affected by brain tumour treatment. You may not know if this has happened until the child reaches the age when you would expect puberty to begin. They may be offered hormone replacement.

### **Educational problems**

Sadly, many children are permanently affected by having treatment for a brain tumour. They may have a drop in their IQ score and problems with learning. Some children will need extra educational support. Some children develop behavioural problems. For some these gradually improve, but for others they can be long lasting.

### **If your brain tumour cannot be cured**

Treatment may shrink the tumour and slow its progress. In some situations, your specialist may think that a long course of radiotherapy or major surgery may not help you, or may even make matters worse. If this is the case, your specialist will talk this through with you. You can still have treatment to help to control your symptoms. If you want a second opinion, you should go ahead. The best way is to ask your own specialist to refer you to another expert.

### **What will happen at the end with an incurable brain tumour?**

How the tumour develops will be different in every case. To find out more, it is a good idea to talk it over with your doctor and specialist nurse. They will be familiar with the medical details of your tumour and how it could affect you as it grows.

Once a brain tumour reaches a critical size, the increased pressure inside the head begins to cause headaches, sickness and drowsiness. At first, it will be possible to control these symptoms by increasing your steroids. But eventually, the steroids will not be able to reduce the swelling any further. You can have painkillers, and medication to control sickness. But you



may find you become increasingly drowsy. At this stage, many people can carry on with a relatively normal life. But as time goes on, you may find you are sleeping more and more. Gradually, it may become more difficult to wake you. Eventually most people slip into unconsciousness. You may be unconscious for days or weeks before you die.

### What to ask your doctor about living with brain tumours

- How long will it take me to recover from the effects of my treatment?
- Will I get back to how I was before the brain tumour?
- Can you refer me to physiotherapy or speech therapy to help me get better more quickly?
- Will I develop long term effects from my treatment and, if so, when would you expect this to happen?
- Can you put me in touch with someone to help me deal with my feelings about what has happened to me?
- Are there any counselling services here I could use?
- Will I have to pay for counselling?
- When will I be able to go back to work / college / school?
- Can I take up my usual sports, hobbies and activities again?
- Is there anything I shouldn't do?
- When will I be able to drive again?
- Is there anyone who can help me with my finances?
- Can anyone help me with claiming benefits and grants?
- Can I go abroad on holiday?
- Will you write a letter to help me get travel insurance?

- How likely is it that my brain tumour will come back?
- How will I know if the brain tumour is coming back?
- If my brain tumour is likely to come back, when is this likely to happen?
- What symptoms will I have?
- What help can you offer to help me cope with my symptoms?
- Can you refer me to a specialist nurse?
- What help can I get at home?

### Brain tumour organisations

Cancer Research UK  
 Main website: [www.cancerresearchuk.org](http://www.cancerresearchuk.org)  
 Patient information website:  
<http://cancerhelp.cancerresearchuk.org>  
 Cancer Information Nurses freephone:  
 0808 800 4040

Brain Tumour Action  
 Tel: 0131 466 3116  
 Website: [www.braintumouraction.org.uk](http://www.braintumouraction.org.uk)

Brain Tumour UK  
 Tel: 0845 4500 386  
 Website: [www.braintumouruk.org.uk](http://www.braintumouruk.org.uk)

British Acoustic Neuroma Association  
 Freephone: 0800 652 3143  
 Website: [www.bana-uk.com](http://www.bana-uk.com)

Brain and Spine Foundation  
 Tel: 0808 808 1000  
 Website: [www.brainandspine.org.uk](http://www.brainandspine.org.uk)

Chordoma support- online international support group  
 Website: <http://www.chordomasupport.org/>

Headstrong  
 Tel: 0808 808 1000  
 Website: [www.headstrongkids.org.uk](http://www.headstrongkids.org.uk)



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Headway  
Helpline: 0808 800 2244  
Website: [www.headway.org.uk](http://www.headway.org.uk)

## Notes

The Pituitary Foundation  
Support & information helpline: 0845 450  
0375  
Website: [www.pituitary.org.uk](http://www.pituitary.org.uk)

The Samantha Dickson Brain Tumour Trust  
Phone: 0808 130 9744  
Website: [www.braintumourtrust.co.uk](http://www.braintumourtrust.co.uk)

## More information

For more information about brain tumours, visit our website  
<http://cancerhelp.cancerresearchuk.org>

You will find a wide range of detailed, up to date information for people affected by cancer, including a clinical trials database that you can search for cancer trials in the UK. You can view or print the information in a larger size if you need to.

For answers to your questions about cancer call our Cancer Information Nurses on **0808 800 4040** 9am till 5pm Monday to Friday

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Adapted from Cancer Research UK's Patient Information Website CancerHelp UK in March 2012. CancerHelp UK is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through CancerHelp UK and our nurse team is not a substitute for professional care and should not be used for diagnosing or treating a health problem or disease. If you have, or suspect you may have, a health problem you should consult your doctor. © Cancer Research UK 2012. Cancer Research UK is a registered charity in England and Wales (1089464) and in Scotland (SC041666)