Scottish Charity No. SCO 21490

Living with a brain tumour

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Information Booklet

publication in
association with

SANON
Scottish Adult Neuro Oncology Network

BTA
BRAIN TUMOUR ACTION

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

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Edinburgh EH4 1PL.
Tel: 0131 466 3116
www.braintumouraction.org.uk
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INTRODUCTION

“It’s a brain tumour........“

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

Perhaps it will help you to know that treatments are improving and people are surviving longer as our understanding of the condition improves.

Brain tumours can often be treated with surgery, radiotherapy and various chemotherapies, the aim of which is to keep people well, with a good quality of life, for as long as possible.

Each year, progress in developing new treatments for this disease is being made by dedicated researchers worldwide.

The fear 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 alleviated if everyone involved understands what is happening and has some idea of what to expect.

Understanding helps you feel more in control and decision-making becomes easier too.

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

- From suspicion of illness to diagnosis
- Immediately after completion of treatment
- Having repeat CT/MRI scans or follow-up medical appointments.

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

UNDERSTANDING AND COMMUNICATION

The first step in trying to come to terms with the diagnosis of a brain tumour is to be given 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. Never be afraid to ask questions or to seek explanations for words or terminology you don’t understand.

The feelings of helplessness and lack of control that are so common following diagnosis can often be reduced if you and your next-of-kin actively participate in decision-making regarding your care and treatment.

Once the diagnosis is confirmed 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 someone with you at every appointment actually serves two purposes: the second person can give you much needed moral support and they can be a great help reminding you of questions you may want to ask and noting down the information you are given. This is a stressful time for you and you may find you do not recall everything that is said by your doctor. But having a written record allows you to reflect on the appointment later on when you’re feeling more relaxed.

Being able to share your concerns with the doctor is very important; you will probably have many questions that require straightforward and honest answers.

The most commonly asked question, “What can we expect next?” is the most difficult to answer, as no one really knows how each individual will respond to treatment. This uncertainty can be very difficult to cope with.

It often helps to have a small notebook at each visit to write down information and to keep a record of doctors’ names and treatment options.

Patient information leaflets like this one can provide a basis for discussion with the doctor, by suggesting topics, important questions you might want to ask and explaining some medical terms.

Further information from Brain Tumour Action Publications is available on various aspects of the disease and its treatment.

At the back of this booklet is space where you can take notes, record important names and telephone numbers and find a list of useful contacts.

SOME EFFECTS OF BRAIN TUMOURS

The effects of a brain tumour are extremely varied. Many mimic other, far more common diseases, for example a migraine, which may delay the correct diagnosis. A brain tumour can only be properly diagnosed by having a brain scan and/or a biopsy – this is an operation to remove a small portion of the growth for cell analysis.

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 to normal brain function. These changes may be temporary or permanent, depending on the cause. Brain tumours may cause direct damage to brain cells, shifting the brain as they grow, or they can cause pressure that affects areas distant from the tumour and creates changes in their function too.

Some effects are emotional

You may experience several generalised symptoms - indeed your family and close friends may also experience similar problems. These can be due to the emotional stress caused by diagnosis and treatments. 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 will usually be able to help you deal with these difficulties.

Some effects are due to side effects of treatment

Whilst a headache, not necessarily severe, is the most common discomfort associated with a brain tumour, other discomforts may be caused by the procedures necessary to treat it. There may be pain following tumour removal or nausea from the side effects of chemotherapy, for instance. These can be controlled, however.

Radiotherapy is a painless procedure but it can have uncomfortable side effects, such as skin irritation, fatigue or nausea. If you are experiencing pain or discomfort, medication can be prescribed to reduce these symptoms.

Swelling of the brain may occur prior to surgery and following radiotherapy which may cause difficulty in walking or thinking clearly. Steroids prescribed by your doctor will control these symptoms and as the swelling decreases these side effects should fade.

Steroid medications have some side effects that may cause problems. These include; weakness of your legs, an increase in appetite, indigestion, thirst, frequency in passing urine, the inability to sleep at night or agitation and anxiety. For this reason your doctor may want to adjust the level of your medication very carefully and reduce it slowly over time. One of the positive effects of steroid therapy, however, may be temporary control of headaches.

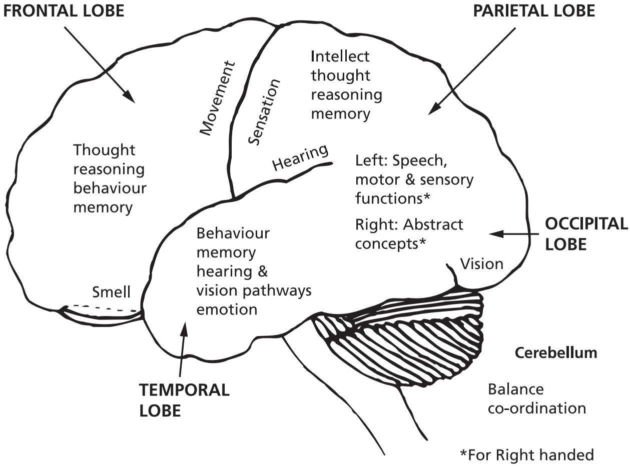
Seizures are caused by irritation to the brain. They may be one of the first symptoms of a brain tumour or they may occur for the first time following treatment such as surgery, which temporarily disturbs the normal function of brain cells.

Most seizures can be controlled with anticonvulsant medications. Some of the drugs used have side effects; you should discuss these with your doctor or neuro-oncology nurse specialist. Blood tests will be done from time to time to see if these drugs are at the right levels. In certain areas of the brain seizures can be difficult to control and different anticonvulsant medications may be tried. However those following surgery frequently decrease with time.

For further information refer to Brain Tumour Action Publications:

- Brain Tumours and Epilepsy No. 2.
- Radiotherapy for Brain Tumours No.3.

ILLUSTRATION OF THE CEREBRAL HEMISPHERE



*For Right handed individuals

Cerebral Lobes

SOME EXAMPLES OF PROBLEMS CAUSED BY TUMOURS IN DIFFERENT PARTS OF THE BRAIN

FRONTAL LOBE 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, weakness in opposite arm or leg, 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 ‘déjà vu’ state. The loss of ability to understand language, called ‘aphasia’ 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 vision 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. They can cause loss of sexual desire or changes in your opinion of your sexual desirability. (The latter may not be limited to this type of tumour.)

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.

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 behaviours 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 and this will take some time. For many it 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 such a crisis.

- **Denial:** disbelief or an apparent lack of concern over the diagnosis is normal for some people. 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 guilty. 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 says or does can make a tumour happen. Guilt may also occur if you feel you have disrupted the lives of others close to you.

- **Anger:** at spouses, family friends, employers, doctors, nurses, - anyone and everyone - is also not unusual. Hurting, bitter words may be said and then regretted. 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. You may worry about the future and how your tumour could affect you and your loved ones if it grows. While physical activity may be the last thing you feel like doing at this time, it can often help the most by lifting your mood and restoring your energy.

These are only some of the possible responses - each person will experience their own range of reactions. The nature, emergence and duration of these responses will vary according to personality and circumstances. However, those allowed to deal with their emotions in an unpressured atmosphere, with patience and understanding from friends, family and trusted confidants, will begin to accept the reshaping of their lives, facing the situation with a realistic amount of hope and a determined attitude to make the most of these altered circumstances.

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 for almost everyone.

Wigs can be uncomfortable, particularly if the skin is inflamed. But silk or cotton scarves and loose caps provide a comfortable alternative.

Sexual desires may be decreased due to tiredness, a feeling of not being sexually desirable or the fear of injuring or putting stress on yourself (equally your partner may be afraid of hurting you). Some people may choose to replace sexual activity for a while 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. Tiredness may be relieved by planning frequent rest periods during the day and conserving energy for special events or unavoidable, necessary chores. Physical therapy and non-strenuous exercise can help maintain muscle tone.

For some it may be necessary to make adaptations in the home, an unsettling experience and a daily reminder of your physical limitations but try to view it also as a way of making life easier for you and your family.

Diversions, such as hobbies or crafts, can help you avoid feeling lonely during your treatment. There may be a regular social or special interest group in your neighbourhood that would welcome a new member.
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, aromatherapist or hairdresser can lift your spirits.
A favourite, secluded place, such as a garden or park, can offer calming strength.

It should be remembered that while you are receiving treatment for a brain tumour, any medical conditions that existed before your diagnosis must continue to be treated. Dental visits, eye care examinations and the like should not be neglected.

If you have metastatic disease (a tumour that began in another organ which has now spread to the brain) you may require treatments to help control the original tumour as well.

SUGGESTIONS FOR COPING

- Allow yourself to cry. It's a good means of coping for both men and women.
- Find someone to confide in. You may not want to burden your loved ones with your more negative feelings and fears, nor they you. For both patients and families, outside support groups and telephone help lines run by brain tumour charities can be invaluable. It is a comfort to know you are not the only one dealing with this difficult situation and that other people understand what you are going through.
- Communication is especially important. If you have difficulty putting feelings into words, try using a tape recorder, letters or emails to share feelings or concerns with family or friends.
- Accept support from others without feeling that you have an obligation to repay the favour. Most people feel privileged to be able to help.
- If you are having a difficult time, consider seeking professional help such as a counsellor, psychologist, minister, doctor or nurse.
- Look after yourself. Set your own limits. Treat yourself to some small luxury or pleasure whenever possible. Try to keep positive but allow yourself to have bad days as well. Everyone does!
- Read about how others have dealt with this problem. There are a lot of patient stories online to inspire and encourage you.
- Contact BTA or some of the other organisations listed in this booklet. All are there to give you information and support.

COPING WITH STRESS

For most people fear of the unknown and sudden uncertainty about what the future holds causes great stress. For the time being, finances, work, family roles and medical decisions may have to be handled by others. It is important, however, for you to retain 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 wishes and abilities.

Daily routines may need to be altered, alternative financial resources explored or new responsibilities acquired. Activities that you once considered important may not seem so urgent now or they 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. Supportive relatives and friends can be called upon to help. Short breaks should be encouraged, even if it is only for an hour or two once or twice a week.

Birthdays, religious festivals and other anniversaries may be a difficult time for the whole family. Feelings of anxiety and irritability around these days is normal. Try to plan ahead to make activities both manageable and memorable. As a family member or friend, it is important to remember this special time.

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

There will always be acquaintances whose stories of miraculous treatments or opinions regarding your decisions you may not necessarily share. This need not produce conflict when you remember they are, in their own way, also trying to help. Expect that there will be some people who simply cannot ‘deal with the situation’ and will never call or offer to help.

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

SUPPORT GROUPS

Support groups can be invaluable. Realising that someone else shares similar difficulties is reassuring and meeting someone who has come through the experience provides hope. Learning how others work out practical, everyday problems is also helpful. There are many brain tumour support groups operating within the UK.

If you are unable to attend a support group but wish to talk to someone who has either had or cared for someone with a brain tumour, you can speak to one of our trained volunteers, or alternatively, join our ‘virtual’ support group. Details can be found on our website: www.braintumouraction.org.uk

ABOUT RECURRENCES

Some brain tumours will recur or continue to cause symptoms either because they are in a surgically difficult area and cannot be removed in their entirety, or because some malignant cells, too small to be seen even with a microscope, may remain following surgery, radiotherapy and chemotherapy.

The goal of treatment to reduce or eradicate these tumour cells is not always possible. The first sign of recurrence is emotionally devastating. You may blame your doctor or yourself for choosing one particular treatment plan over another, however the choice made at that time was probably the best one there was. No one is to blame – bad things happen.

DRIVING

You may not be able to drive for a time following your diagnosis. This is particularly likely if you have had any kind of seizure. You should be advised in hospital or by your GP.

If you do find you cannot drive, the length of time that you have to avoid driving will depend on factors such as the type of tumour and its position, whether you have had seizures and some types of surgery. **You should check with your doctor.**

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, Driver and Vehicle Licensing Agency, Swansea, SA99 1DL Further information can be found on www.dvla.org.uk

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

You may, however, be eligible for a bus pass or mobility allowance and 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 treatments necessary to deal with it will cause drastic changes in the lives of those affected. Friends, relatives and even acquaintances will amaze you with their generosity though there may be a small number, who, through fear, simply “don’t want to know.” Priorities will change and new relationships will begin.

This can be an enriching time, a time for growth, a time for closeness, a time for sharing with others.

You need never be alone.

USEFUL CONTACTS

Brain Tumour Research - A consortium of brain tumour charities throughout the UK.
Brain Tumour Research
The Business Centre
Padbury Hill Farm
Padbury, Buckingham, Bucks MK18 2BN

www.braintumourresearch.co.uk
Tel: 01296 733011

Brain Tumour UK
Tower House, Latimer Park, Chesham, Bucks HP5 1TU.
www.braintumouruk.org.uk <www.braintumouruk.org.uk/>
Helpline: 0845 4500 386

SamanthaDicksonBrainTumourTrust
Saddlers House
100 Reading Road, Yateley, Hampshire GU46 7RX

Tel: 08451309733 (mainswitchboard)
Fax: 08451309744
Email: enquiries@sdbtt.co.uk

Directgov: information about disability, carers, mobility and related allowances,
www.direct.gov.uk

Driver and Vehicle Licensing Agency
Swansea SA99 1DL
www.dvla.org.uk **www.dft.org.uk**

Disablement Income Group
5 Quayside Street, Edinburgh EH6 6EJ

www.digscotland.org.uk
Main Phone No: 0131 555 2811
Fax: 0131 554 7076

Epilepsy Helpline
UK freephone: 0808 800 5050
International: +44 113 210 8850
Email: helpline@epilepsy.org.uk
Twitter: epilepsyadvice
Txt msg: 07797 805 390 info

Epilepsy Scotland
Tel: 0141 427 4911
Fax: 0141 419 1709
Email: enquiries@epilepsyscotland.org.uk

International Brain Tumour Association
The Co-DIrector, IBTA,
PO Box 244, Tadworth, Surrey, KT20 5WQ

Email: kathy@theibta.org

Macmillan Cancer Support,
www.macmillan.org.uk

Tel: 020 7840 7840
Fax: 020 7840 7841

Write to Macmillan Cancer Support
89 Albert Embankment, London, SE1 7UQ

Marie Curie Cancer Care,
www.mariecurie.org.uk

Call us free phone: 0800 716 146

Supporter Services Team
Marie Curie Cancer Care
89 Albert Embankment, London SE1 7TP

Email: supporter.services@mariecurie.org.uk
www.mariecurie.org.uk

SANON -Scottish Adult Neuro -Oncology Network:

www.neurooncology.scot.nhs.uk

Lindsay Campbell
Email: lindsay.campbell@nhs.net
Tel: 0141 232 1034 or 07951 273920

Post: c/o West Of Scotland Cancer Network,
First Floor, St Mungo Building,
Glasgow Royal Infirmary, Glasgow G4 0SF

www.virtualtrials.com
An invaluable resource for everyone affected by a brain tumour. Includes survivors' stories.

A WORD ABOUT BTA

Brain Tumour Action has produced this booklet to help those affected by brain tumours.

Funds raised by Brain Tumour Action are used to:

- Increase public awareness about brain tumours.
- Support research into their causes and treatment.
- Operate a telephone helpline to give information and support. Help develop patient and carer support groups throughout the UK.
- Publish and distribute information through a range of leaflets and other publications.
- Fund training for health professionals working in the area of neuro-oncology.

To join us and become involved in our work, please complete and return the form overleaf. As a member you will receive our newsletter together with details of all our events and be encouraged to play an active part in the work of the charity.

Acknowledgments

We are indebted to the American Brain Tumour Association, 8550 W. Bryn Mawr Avenue, STE 550, Chicago, Illinois 60631, 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 Tumour Action Joining Form

The mission of Brain Tumour Action is to help relieve the suffering of those affected by Brain Tumours through education, training, support and research. We do this through a programme of social and fundraising events, our telephone helpline, virtual and face-to-face support groups and by providing free information literature.

To join us and become involved in our work, complete the undernoted form and as a ‘friend’ you will receive a newsletter together with details of all our events and be given the opportunity to play an active part in the work of the charity.

There is no membership fee but we welcome donations without which we cannot achieve our aims. We receive no statutory financial aid.
Brain Tumour Action, 25 Ann Street Edinburgh EH4 1PL.

Name (Print)..
....
Address...
Tel:-Home.......................................Business..
Fax:-Home.......................................Business...
E-Mail..

Patient/Carer/Friend/Relative/Medical/Employer
(Please circle)
I understand there is no membership fee but I wish to help by:-
Donation (Cheque/Money Order enclosed for £............)
Gift Aid - Payroll Giving/Covernant/Legacy (Please circle)
Justgiving
I wish to volunteer for - Fundraising/Support/ Business/Admin.
Other (Please circle or specify)..

Signature...Date...........................
Please send completed form to
Brain Tumour Action, 25 Ann Street, Edinburgh, EH4 1PL