Brain Tumours
High Grade Gliomas
Information for patients

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This booklet aims to provide information for anyone affected by this diagnosis wishing to understand more about high grade glioma brain tumours.

Types of Brain Tumours
This booklet addresses High Grade Gliomas only.

The High Grade Glioma’s are namely:-

- Anaplastic Astrocytoma (Grade 3).
- Anaplastic Oligodendroglioma (Grade 3).
- Anaplastic Ependymoma (Grade 3).
- Glioblastoma Multiforme (Grade 4).

What is a Glioma?
A glioma is a primary brain tumour. They arise from the supporting cells of the brain.

The brain substance is made up of nerve cells (neurons) and supportive tissue (glia). Glial tissue comprises of 3 cell types:

1. Astrocyte: These cells are thought to provide the brain’s framework and help control the chemistry of brain cells. The tumour arising from this cell type is called an astrocytoma.

2. Oligodendrocyte: These cells insulate and help in the transmission of messages in the brain. The tumour arising from this cell type is called an oligodendroglioma.

3. Ependymal cells: These cells line the ventricles (the fluid filled areas) within the brain. The tumour arising from this cell type is called an ependymoma.

Glioma’s are graded depending on how quickly they grow. Some glioma’s grow slowly, others more quickly. The growth rate determines the degree of malignancy.

Grades 1 & 2: Collectively called Low Grade Gliomas (slow growing tumours frequently treated differently from the higher grade gliomas).
Grades 3 & 4: Collectively called High Grade Gliomas. The specific name of your tumour and what this means, will be explained to you by your surgeon and your specialist nurse when you meet with them to discuss your results.

Grade 3: Commonly known as Anaplastic Astrocytoma; Anaplastic Oligodendroglioma; Anaplastic Ependymoma

Grade 4: Commonly known as Glioblastoma Multiforme or G.B.M in short.

High grade glioma brain tumours tend to only spread locally. Spread of these tumours outside of the brain or outside of the spinal cord is uncommon.
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.

Primary brain tumours are the second most common cause of cancer death in children ranging in age up to 15 years old.

- They are the 3rd most common cause of cancer death in males 35-54 and the fourth in females aged 15–34.
- Between 7 and 8 in every 10 cases of primary brain tumours are high grade gliomas.
- The cause of high grade gliomas remains unknown. Some instances of familial tumours have been reported, but research has not proved a hereditary cause.
- There do not appear to be any links with occupation, infections or head injury.
- High grade gliomas occur most often between the ages of 45 and 65, and affect men more frequently than women.
- 7 in 100 cases of childhood brain tumours are high grade gliomas.

What are the common symptoms?

Everyone is an individual and symptoms may be different in different people. The symptoms described below are a generalisation of common symptoms at the various sites within the brain. An individual may experience some of these, all of these or none.

Common symptoms include:

- Headaches: due to increased pressure in the head, these can be present irrespective of where the tumour is in the brain and will frequently be worse in the early hours of the morning and may be associated with vomiting.
- Seizures or ‘fits’.
Specific Symptoms

NB: this list is not exhaustive and you may experience symptoms not listed here.

Frontal Lobe Tumours

The most frequent symptoms are change in personality, mood and behaviour. There may also be weakness of one side of the body or seizures causing jerking of the body.

Temporal Lobe Tumours

Seizures in this area are a common symptom.

They may result in a number of sensations such as; ‘déjà vu’; Odd taste; Smell; feeling of panic or of ‘being outside your body’. These usually only last 1-2 minutes.

What happens to me when I have these seizures?

- You may seem or look vacant and sometimes chew and swallowing repeatedly.
- Some people make semi purposeful movements with their hands.
- Memory & speech can be affected if the tumour is on the same side of the brain which controls speech (the speech centre).

Parietal Lobe Tumours

- May cause loss of sensation and or power on one side of the body.
- Seizures may occur.
- If the tumour is in the speech area there may be problems such as;
  - Speaking or expressing oneself.
  - Understanding the spoken word and word finding problems.
Brain Stem / Cerebellar Tumours

- This can cause problems with balance and coordination.
- Double vision & problems with swallowing can occur.
- There can also be weakness in both arms and legs.

How is the diagnosis made?

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

**CT Scan** (Computed Tomography) – This is a specialised x-ray that will frequently identify the site and extent of a brain tumour. It will take approx 20 minutes and an injection of a contrast agent may be given to obtain the clearest picture.

**MRI Scan** (Magnetic Resonance Imaging) – This is a specialised imaging technique that gives very clear pictures of the anatomy and detail of the brain and will show the site and extent of an abnormality. This technique usually takes 30-40 minutes and uses powerful ‘magnets’ rather than x-rays. People with pacemakers cannot have this test and patients with any other metallic implant should inform the doctor well before the test.

**EEG** (Electroencephalogram) - This is a test that measures the electrical activity coming from the brain. It does not give pictures, but provides information about the brain functioning and is often used to diagnose seizures / epilepsy.

What treatments might be available?

A variety of options are available. The most appropriate for your case will be discussed with you to support you in making an informed decision about your choices.
Surgery

Please read this alongside the North Bristol Trust leaflet titled ‘Surgery for Suspected Brain Tumour’ which explains; what to expect; risks of surgery and other details associated with the operation and hospital stay.

The primary treatment for ACCESSIBLE tumours is surgery. (Accessible tumours are those which can be operated upon without a high risk of causing severe neurological damage).

The goals of aggressive surgery are to;

- Remove as much of the tumour as is safely possible.
- Relieve pressure within the head.
- Determine the full extent of tumour growth & to establish a diagnosis.

High grade gliomas are rarely able to be removed completely. This is because these tumours do not have a defined edge or border and the tumour cells are generally in amongst the surrounding normal brain tissue. The surgeon will remove as much as possible safely.

It is likely that you will be currently taking steroids (Dexamethasone). These are commonly used and very important in supporting your treatment.

Please read this alongside North Bristol leaflet titled ‘Understanding Steroids’.

Radiotherapy

Radiotherapy is usually recommended following surgery once the wound has healed. This will be discussed with you by your Oncologist. An Oncologist is a doctor who uses multiple approaches to treat brain tumours (such as radiotherapy and chemotherapy).
What is Radiotherapy?


It is used to try to destroy, control and contain the tumour. There will need to be some planning appointments before starting treatment.

This is given usually over a 2 - 6 week period attending daily as an outpatient (Monday - Friday). The treatment lasts for approx 10 minutes.

Please see additional leaflet on Radiotherapy for Brain Tumours by Cancer Backup & Macmillan Cancer Support in the information pack you have been provided with by your Specialist Nurse.

Chemotherapy

Chemotherapy may also be recommended as a further treatment and this will be discussed in detail with you, by your Oncologist.

What is Chemotherapy?

Chemotherapy are medications (tablets and or ‘infusion/drip’) which enter the blood system. It is used to try to destroy, control and contain the tumour.

The type of chemotherapy used is decided by the Oncologist looking after you.

Please see additional leaflet on Chemotherapy for Brain Tumours by Cancer Backup & Macmillan Cancer Support in the information pack you have been provided with by your Specialist Nurse.

Seizures/Epilepsy

Surgery, radiotherapy and chemotherapy are aimed at treating the tumour. Unfortunately it is common for individuals to experience seizures when diagnosed with a brain tumour. It is very likely anti convulsant or anti-seizure medication will have already been commenced. This will reduce the chance of further seizures but may not remove the risk completely. This will be monitored often by your GP, Oncologist and / or a Neurologist.
One of the most difficult issues for people diagnosed with high grade gliomas is that by law you are not allowed to drive. It is your responsibility to inform the DVLA of your hospital stay and who your Consultant Neurosurgeon is. The DVLA will contact your surgeon to seek more information. They will then contact you to advise you when you can reapply for your licence.

Please also see additional leaflet on Brain Tumours and Epilepsy by ‘Brain Tumour Action’ found in the information pack you have been provided with by your Specialist Nurse.

**How will it affect my life?**

A diagnosis of a brain tumour often causes many reactions including shock, fear, despair, frustration as the life as they know it has suddenly changed.

These are all normal reactions. We are all individual and we all react in different ways at times of stress and distress. There are many adjustments one makes following a diagnosis such as this.

Having family or close loved ones at difficult times, such as this, is often an enormous comfort.

Please see the leaflet by Brain Tumour Action on ‘Living with a Brain Tumour’ for more detailed information in the pack provided to you by your specialist nurse.

**Where can I get assistance and support?**

Once a diagnosis has been made and treatment begun, often one of the primary needs of the individual AND the family is emotional support.

Brain tumour support groups or local self-help groups are sometimes available, the local one in this area, who we work closely with, is called Hammer Out, they help to support patients and families in the South-West region diagnosed with a brain tumour (further details are at the back of this booklet and a leaflet is enclosed in the information pack provided by your specialist nurse).

There are other areas of support both practical and psychological. Your Specialist Nurse can always help to advise / guide you if you are experiencing difficulties.
Some of the teams the specialist nurse works with are:

- **General Practitioner (GP);** Remains central to your care in the community once you are home. Your Specialist Nurse will make contact with your GP to provide an update after you have been discharged from hospital and to provide their contact details.

- **District Nurses;** are integral to the services provided by your GP practice.

- **Social Workers;** are professionally trained staff who specialise in helping with social or emotional problems relating to illness, they are also familiar with local support groups, health care agencies, financial assistance, Hospice facilities, and special transportation and equipment available in your local area. Your Specialist Nurse, Oncologist or GP can discuss this with you if you need further information.

- **Clinical Psychologists;** Help to support individuals and families at times of extreme stress. They provide valuable support and help people work through complex personal difficulties, such as when you are diagnosed with cancer. Your Specialist Nurse, Oncologist or GP can discuss this with you if you need further information.

- **Community Specialist Nurses or Macmillan Nurses;** we work closely with this specialist team of nurses. They provide valuable support to people who have been diagnosed with cancer and can provide excellent support to individuals and families. Your Specialist Nurse, Oncologist or GP can discuss this with you if you need further information.

- **Speech and Language Therapists:** Depending on where the tumour is located sometimes it can be helpful to have advice from a speech and language therapist. They can advise, provide coping techniques if you are experiencing speech or swallowing difficulties related to the tumour. Your Specialist Nurse, Oncologist or GP can discuss this with you if you need further information.
Dieticians; Work in the field of nutrition. We sometimes refer or seek advice at specific times. Your Specialist Nurse, Oncologist or GP can discuss this with you if you need further information.

Physiotherapists; Specialise in the field of movement, and mobility. Your Specialist Nurse, Oncologist or GP can discuss this with you if you need further information.

Occupational Therapists; Specialise in the area of assessing individuals’ ability to be independent in their daily activities. They can advise on specialist equipment to help improve independence. Your Specialist Nurse, Oncologist or GP can discuss this with you if you need further information.

**Specialist Nurse in Neuro Oncology**

This is a specialist nursing service for patients with neurological cancers run jointly between North Bristol NHS Trust & United Hospitals Bristol North.

**Who should be referred to the Specialist Nurse in Neuro-Oncology?**

Any patient with a diagnosis of a cancer of the Central Nervous System. For example:

- Patients with Primary Brain Tumours.
- Patients with Primary Spinal Tumours.

**Who can refer to the Specialist Nurse in Neuro-Oncology?**

The specialist Nurse in Neuro-Oncology will accept referrals from Doctors, Nurses and other healthcare professionals in the hospital and community setting, with the consent of the Clinician in charge of their care.
What is the role of the Specialist Nurse in Neuro-Oncology?

- They complete nursing assessments to include the physical, psycho-social and emotional impact of a diagnosis of cancer.
- They provide support throughout treatments and the course of the illness.
- They liaise with the relevant support agencies to facilitate continuing care.
- They provide ongoing support, advice and information in person during inpatient stays and outpatient consultations and over the telephone as the patient and family wish.
- Facilitates discussion, communication, liaison and referral to other healthcare professionals and agencies as appropriate.
- They educate and support other healthcare professionals involved in the care of patients with neurological cancers.
- They provide support, in person or by telephone, in the early part of bereavement.

Team Details

Consultant Neurosurgeons:

- There are several Consultant Neurosurgeons in Bristol who specialise in surgery for glioma’s.

Consultant Oncologists:

There are Consultant Oncologists who are based at:

- The Bristol Haematology & Oncology Centre.
- Royal United Hospital, Bath.
- Cheltenham Oncology Centre.
Other Useful Contacts

**Hammer Out Brain Tumours**

Registered Charity 1102750

Unit One
Thornbury Office Park
Midland Way
Thornbury
South Gloucestershire BS35 2BS
0145 441 4355
www.hammerout.co.uk

Anne Coles
Family & Patient Support Co-ordinator
Hammer Out
0845 450 1039
support@hammerout.co.uk

**Brain Tumour Action**

Brain Tumour Action
25 Ann Street
Edinburgh EH4 1PL
0131 466 3116

Charity No. SCO 21490
www.braintumouraction.org.uk

**Macmillan Cancer Support**

www.macmillan.org.uk/Home.aspx

Any questions about cancer, need support or just someone to talk to, call free, Monday to Friday 9am - 8pm (interpretation service available). 0808 808 00 00 within the macmillan web site is the cancerbackup/macmillan information and support line for ‘cancer information’; www.macmillan.org.uk/Cancerinformation.aspx

Helpline:- Call free on 0808 808 00 00 Our cancer support specialists are available Monday to Friday, 9am-8pm. 
Calls from landlines and mobiles (3, O2, Orange, T-mobile, Virgin & Vodafone) are free.
Marie Curie
For more information for patients and carers call FREEPHONE 0800 716 146.
Registered in England and Wales with Charity Reg No. 207994 and registered in Scotland with Charity Reg No. SCO38731
www.mariecurie.org.uk

The National Society For Epilepsy
www.epilepsysoociety.org.uk
The National Society for Epilepsy is a Registered Charity (Registered in England No. 206186),
Helpline: 01494 601 400
NSE switchboard: 01494 601 300

Epilepsy Action
Main office: +44 (0)113 210 8800
Epilepsy Helpline: freephone 0808 800 5050 (UK only)
British Epilepsy Association is a registered charity in England (No. 234343) and a company limited by guarantee (registered in England No. 797997).
Registered office: New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY, United Kingdom
www.epilepsy.org.uk

Brain Tumour UK
www.braintumouruk.org.uk
For Support Call: 0845 4500 386
Brain Tumour UK is a registered charity (no: 1117538) and a company limited by guarantee, registered in England (no: 5983336).
Registered office is Cawley Priory, South Pallant, Chichester, PO19 1SY.
To contact, please write to the head office at Brain Tumour UK
Tower House, Latimer Park, Chesham, Bucks HP5 1TU (Tel: 0845 4500 386) or email enquiries@braintumouruk.org.uk.
DVLA
www.dft.gov.uk/dvla
Medical Enquiries
(Medical enquiries - including lorry or bus licences)
If you contact us by telephone, you will be greeted by our interactive voice system. Staffed telephone enquiry hours: Monday to Friday 8:00 am to 5:30 pm and Saturday 8:00 am to 1.00 pm. Outside these times you will be able to listen to a variety of messages covering the most commonly asked question on driver and vehicle licensing and vehicle registration.
Telephone: If you are a car or motorcycle licence holder: 0300 790 6806
If you hold a bus or lorry licence: 0300 790 6807
Fax: 0845 850 0095
Address: Drivers Medical Group, DVLA, Swansea, SA99 1TU
E-mail: eftd@dvla.gsi.gov.uk

Directgov
‘public services in one place’
www.direct.gov.uk/en/index.htm
Driving licence information;
www.direct.gov.uk/en/Motoring/DriverLicensing/index.htm

References
Information taken from the High Grade Glioma Brain Tumours booklet produced by Brain Tumour Action (BTA)
www.braintumouraction.org.uk


www.nice.org.uk Web site last accessed 04/05/10
NHS Constitution. Information on your rights and responsibilities. Available at www.nhs.uk/aboutnhs/constitution
If you or the individual you are caring for need support reading this leaflet please ask a member of staff for advice.

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