



Welcome to the Neurosurgical/Oncology Clinic

This booklet aims to support and guide you and your family following your referral to the neuro-oncology team at the Queen Elizabeth Hospital Birmingham (QEHB).

In this clinic you may be seen by one or more of a core group of consultants/clinical fellow in neurosurgery, neuro-oncology and have access to a clinical nurse specialist (CNS).

You may come into contact with a variety of health care professionals who can offer expert advice, knowledge and experience in managing brain tumours.

Brain tumour specialists

Prof Colin Watts
Mr Ismail Ughratdar
Mrs Anwen White
Ms Victoria Wykes
Mr Vlad Petrik
Mr Andrew Kay
Mr Athanosis Zisakis
Mr P O'Halloran
Mr George Tsermoulas
Mrs Shani Samarasekara

Clinical fellow – this is a neurosurgeon gaining advanced specialist training in neuro-oncology

Dr Sanghera
Dr Benghiat
Dr Meade
Dr V Cheung
Claire Goddard
Frederick Berki
William Garratt
Sarah Freeth
Naomi Cole
Support workers: - Aimee Lawrence, Latoyah Smith

These professionals work within a multi-disciplinary team (MDT) structure, to include:

- Neurosurgeons
- Neuro-oncologists
- Neuroradiologists
- Neuro-histopathologists
- Neurologists with specialist interest in epilepsy
- Clinical nurse specialists (CNS)
- Research and trial team
- MDT Coordinator

Information for Patients

- Allied Health Professionals e.g. physiotherapists, occupational therapists, speech and language therapists and dietitians (access to other professionals as needed)
- Palliative care support

A Neuro-oncology MDT meeting is a multi-disciplinary team meeting which happens every Tuesday at QEHB. New cases and recurrent cases are discussed by a core team of expert clinicians to establish best plan of care for patients diagnosed with a brain tumour.

Your clinical history and scans will have been reviewed at a weekly neuro-oncology MDT meeting at QEHB and a plan for managing your care is discussed in this forum. You will be given an individualised care plan by the CNS team who will act as your key worker. This will outline how you will be managed including any treatment options.

Your key worker will act as your point of contact at QEHB to manage your symptoms, which may vary over time. However, if symptoms are severe, sudden or over weekends, bank holidays and out of hours, you should contact your GP, dial 999, or attend your local Emergency Department.

You may be invited to participate in a relevant clinical trial and if appropriate one of the trial team will speak with you about this.

It is important to let us know how you are feeling and if anything changes, particularly suddenly. These symptoms may include:

- Headaches (particularly early morning) with or without nausea and vomiting
- Seizures
- Weakness in arms, legs or face
- Slurred speech or communication difficulties
- Swallowing problems
- Blurred, double vision or visual loss
- Balance or coordination problems
- Memory, concentration and sudden mood swings
- Problems sleeping
- Fatigue
- Other changes in symptoms you feel we need to know about

This can impact on your quality of life or the ability to carry out your day-to-day activities independently. We can offer access to professionals who can support you with physical, psychological, social, spiritual, emotional and financial needs.

You may be prescribed steroid drug called Dexamethasone. This will reduce the swelling around the tumour.

All medication has a small risk of side effects but serious side effects are rare and usually get better once the medication is stopped.

We aim to reduce the dose as low as possible to reduce the side effects and gain the best effect on reducing the swelling. Steroids will be prescribed with an antacid drug to protect your tummy. Steroids are prescribed and taken either once or twice a day 08:00 and 14:00 hours and are best taken after a meal.

The most common side effects are listed below:

1. Increased stomach acid (which will be reduced by the antacid medication)
2. Poor sleep, difficulty sleeping and feeling too awake to sleep

Information for Patients

3. Increased blood sugar levels (Diabetics need special precautions and monitoring of their blood sugar levels)
4. Increased appetite/feeling much more hungry than usual
5. Feeling tense and anxious – sometimes serious feelings of agitation, hyperactivity and abnormal thoughts can occur which settle soon after reducing or stopping the steroids
6. Red rash – looking flushed
7. Build up of fat in the face and at the back of the neck
8. Allergy
9. Muscle weakness
10. If taking steroids for a very long time, bones can become weak – this is a form of osteoporosis
11. Steroids do dampen down the body's immune system, and this can increase the risk of infection, such as oral thrush or wound infections
12. **Never stop steroids suddenly** - and carry the steroid alert card at all times. Please contact CNS, GP or consultant if you have any side effects or if your symptoms worsen

You may be prescribed anticonvulsant medication and there are many that are used. This is to control seizure activity.

If seizures are problematic you will be referred to the epilepsy specialist team for advice and support. These drugs can cause drowsiness and rashes when started. Please let your CNS/GP or consultant know if you have any side effects or seizures are changing or increasing in frequency.

Frequently asked questions (FAQ)

Can I drive?

We will advise you about driving in clinic. Depending on your diagnosis you may have to stop driving and surrender your licence to DVLA for a period of time.

Is there financial support available?

Talk to your key worker/CNS and they can guide you on support available through Macmillan CAB and other support groups.

Are there any relevant clinical trials available?

The QEHB has a site specific neuro-oncology research team and can offer advice on research and trials available locally.

How long will surgery last?

Surgery lasts as long as it needs to, this is typically between 2–6 hours surgery time, but it can sometimes take longer.

How long will I be in hospital for?

You will likely go home the day after surgery if all is well. Occasionally discharge may be prolonged depending on the location of surgery and how well you are after the operation.

How long until I get my results?

You will come back to this clinic around 7–10 days post-surgery for results and are often contacted after the MDT meeting on Tuesday to come to clinic on Thursday.

Will I be in pain after surgery?

We do not expect you to experience pain after surgery which cannot be controlled with simple pain killers and steroids.

Information for Patients

What support is available for patients with a brain tumour diagnosis/cancer diagnosis?

You have access to the clinical nurse specialists and there are specific support groups available:

- Giles trust at QEHB charities
- Macmillan Cancer Support
- support@braintumoursupport.co.uk
- info@Braintumourresearch.org

Today you may go for:

- Pre-assessment visit to ensure you are fit for general anaesthetic
Yes No (Outpatients Area 2, Level 0, QEHB)
- Planning MRI/CT scan of brain.....
Yes No (Imaging, Level 0, QEHB)
- Other.....
- Information leaflets given.....
- Brain Tumour Support are present in the waiting area on a Thursday during clinic times for further support and guidance

You may have to have further appointments on another day

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Contacts

Contacts via key worker or secretary

Landline **0121 371 4740**

Claire Goddard **07799 096 061**

Frederick Berki **07767 442 101**

William Garratt **07901 951 008**

Sarah Freeth **07765 707 894**

Naomi Cole **07765 707 623**

Consultant Secretary

via Switchboard: **0121 371 2000**

Email: Braintumourspecialistnurses@uhb.nhs.uk

Support workers:-07880422965

Email:- btsw@uhb.nhs.uk

Neuro-oncology

Queen Elizabeth Hospital Birmingham

Mindelsohn Way, Edgbaston

Birmingham, B15 2GW

Telephone: 0121 371 2000

If you require this information in another format, such as a different language, large print, braille or audio version please ask a member of staff or email patientexperience@uhb.nhs.uk.