Patient information

Suspected Brain Tumours

Cancer Services

The purpose of this leaflet

Being told that you may have a brain tumour can be frightening and may cause uncertainty. Your world may seem outside of your control, and you may not know what you want or need to know.

This leaflet is to help you understand:

- Primary and secondary brain tumours (Cancer)
- What will happen next?
- Steroid medication and how this will help?
- What is a seizure and medication to help?
- Where to find support

Following a scan an abnormality in your brain has been found, which may be a malignant brain tumour(s) (cancer).

We will try to answer some of the practical questions that you may have in terms of next steps and potential treatment options.

What is a brain tumour?

Brain tumours are a growth of abnormal cells within the brain that grow in an uncontrolled way.

Primary brain tumours (cancer) start in the brain or surrounding tissues and there are many different types.

Secondary brain tumours are called brain metastases or brain ‘mets’ for short. This happens when cancer spreads to the brain from another part of the body. Most people with a secondary brain tumour will have a history of cancer; however some people may not have been diagnosed with cancer previously.

To confirm your diagnosis we will need further tests (such as MRI scan) and you may need medication to help with your symptoms. The team looking after you will advise you on how to take your medications and when further tests will be performed.

What will happen next?

You will have had a CT scan because of the symptoms that brought you to hospital. Your scan will have been reviewed by a radiologist (a doctor that interprets scans) and may be discussed with a specialist at The Walton Centre in Liverpool (a specialist centre for brain tumours).

You will only be kept in hospital if you require inpatient hospital care. Any further investigations you may need will be arranged just as quickly whether you are in hospital or at home.

Whilst you are waiting for further tests you will be supported by the Acute Oncology Clinical Nurse Specialist team. They will be available to answer your questions, provide advice and keep you informed of what will happen next. (see the further information section of this leaflet for the contact number).

Once all of your test results are available they will be discussed at the multidisciplinary team (MDT) meeting. This is when a team of specialist doctors and nurses plan your care and treatment. This may take place at The Walton Centre depending on the results of your investigations.

Following the MDT meeting the Acute Oncology Clinical Nurse Specialist team will contact you as soon as possible. This will hopefully be no later than the day after the MDT meeting, to discuss the outcome of the meeting and next steps. The nurse specialists at the Walton Centre may contact you directly to arrange a clinic appointment.

Can I drive?

The DVLA has clear guidance around driving for people who are diagnosed with a brain tumour. The advice is not to drive and to inform the DVLA as soon as possible.
You can find further information at the brain tumour charity.
https://www.thebraintumourcharity.org/

What are steroids?

Brain tumours can cause swelling within the brain which may be causing your symptoms. You may have been started on steroid tablets, usually called dexamethasone which may improve your symptoms.

Steroids are helpful in managing symptoms but can have some side effects. You will be started on a high dose which will be reduced after a few days. This will help to minimise some of the possible side effects as well as following the advice below.

- **Take steroids before midday**. Steroids can keep you awake at night and can cause extremely light sleep.
- It is important to **take them with food**. Steroids can irritate the lining of the stomach and cause symptoms such as heartburn or acid indigestion.
- You will be given medication to protect the lining of your stomach**, take this half an hour before you take your steroids.**

- If you become **very thirsty or need to urinate more frequently, you should contact your acute oncology team or GP immediately** as steroids can cause diabetes.
- If you already **have diabetes you may need adjustments to your diabetic medication**. Please make an appointment with your GP to discuss.

For more support look at https://brainstrust.org.uk/brain-tumour-support/resources/downloads/.

There is specific information about what to expect, driving, recognising reliable websites, dealing with the overwhelm, knowing what to ask when newly diagnosed, plus so much more that can help.

What is a seizure?

Some patients may experience seizures (fits) because a brain tumour can disrupt the normal function of the brain. Where the brain tumour is may affect the type of seizure. For example, if it is within the area of the brain responsible for controlling movement this may result in twitching of your arm or leg or you may have a loss of awareness or feeling of absence which may last seconds.

It is important you tell your doctor or nurse as soon as possible **if you think you are having seizures.**

If you require urgent advice call NHS 111 or access NHS 111 via the website: http://111.nhs.uk/

If you have had a seizure your doctor will prescribe anti-seizure medication. It is extremely **important to take the medication** as directed by your doctor or nurse. If you **develop a rash not long after starting an anti-seizure medication, you must inform your doctor or nurse immediately. Do not stop the medication suddenly** as this may cause more seizures.

For further information please see the information sheet Seizures (epilepsy) and brain tumours available from your keyworker or the brain charity website: https://www.thebraintumourcharity.org/

Where to find support

We recognise that this is a stressful time for you and for your family. There are a number of support groups and patient guides that can offer you both support and useful information at this time. These charities support people who are affected by a brain tumour diagnosis. This includes people with secondary brain tumours. Whilst they cannot remove the uncertainty, they can help you manage your situation, and they support both patients and caregivers.

brainstrust “the brain cancer people’ :
Email: hello@brainstrust.org.uk
Telephone: 01983 292405 any time, day or night.
Website: https://brainstrust.org.uk/

Brain Tumour Charity:
Website: https://www.thebraintumourcharity.org/
Telephone- 0808 800 0004
support@thebraintumourcharity.org

The Brain Charity:
Website: https://www.thebraincharity.org.uk/

Macmillan Cancer Support:
Macmillan Support Line: 0808 808 00 00
Website: https://www.macmillan.org.uk/

Naseem's Manx Brain Tumour Charity:
Email Naseemscharity@manx.net
Telephone 07624499521
Website http://www.naseemsmanxbraintumourcharity.co.uk

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further Information

Local Support

Acute Oncology Clinical Nurse Specialist Team:

Aintree Hospital
Monday to Friday
8am – 4pm
Tel: 0151 529 8378

Royal Liverpool Hospital
Monday to Friday
8am – 4pm
Tel: 0151 706 3685

Your Specialist Nurse is ……………………………..

Your Clinical Support Worker is ……………………………………………………

Your Oncologist / Team are …………………………………………………………

Contact Details …………………………...

Walton Primary CNS Team Contact Details……………………………………

If your query is urgent, or you become unwell, outside of these hours please call NHS 111 or access NHS 111 via the website: **https://111.nhs.uk/**

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All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

يمكن توفير جميع المعلومات المتعلقة بالمرضى الموافق عليهم من قبل ائتمان المستشفى عند الطلب بصيغ أخرى، بما في ذلك لغات أخرى وبطرق تسهل قراءتها وبالحروف الطباعية الكبيرة وبالصوت وبطريقة برايل للمكفوفين وبطريقة مون والكترونياً.

所有經信托基金批准的患者資訊均可以其它格式提供，包括其它語言、 易讀閱讀軟件、大字體、音頻、盲文、穆恩體（Moon）盲文和電子格式，敬請索取。

در صورت تمایل میتوانید کلیه اطلاعات تصویب شده توسط اتحادیّه در رابطه با بیماران را به اشکال مختلف در دسترس داشته باشید، از جمله به زبانهای دیگر، به زبان ساده، چاپ درشت، صوت، خط مخصوص کوران، مون و بصورت روی خطی موجود است.

زانیاریی پێوەندیدار بەو نەخۆشانەی لەلایەن **تراستەوە** پەسەند کراون، ئەگەر داوا بکرێت لە فۆرماتەکانی تردا بریتی لە زمانەکانی تر، ئیزی رید (هاسان خوێندنەوە)، چاپی گەورە، شریتی دەنگ، هێڵی موون و ئەلیکترۆنیکی هەیە.

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Dhammaan warbixinta bukaanleyda ee Ururka ee la oggol yahay waxaa marka la codsado lagu heli karaa nuskhado kale, sida luqado kale, akhris fudud, far waaweyn, dhegeysi, farta braille ee dadka indhaha la', Moon iyo nidaam eletaroonig ah.