Mersey and West Lancashire Teaching Hospitals NHS Trust

Suspected brain tumours

Patient information leaflet

If you need this information in a different language or accessible format, please speak to a member of staff who can arrange it for you

Якщо вам потрібна ця інформація іншою мовою або в доступному форматі, зверніться до співробітника, який зможе це для вас організувати

إذا كنت بحاجة إلى هذه المعلومات بلغة مختلفة أو بصيغة ميسَّرة، فيرجى التحدث إلى أحد العاملين والذي سيقوم بترتيب ذلك لك.

如果您需要其他語言或無障礙格式的資訊，請聯繫工作人員，他們將為您安排。

இந்தத் தகவலானது உங்களுக்கு வேறொரு மொழியிலோ அல்லது எளிதில் அணுகக்கூடிய வடிவத்திலோ தேவைப்பட்டால், அதனை உங்களுக்காக ஏற்பாடு செய்துதரக்கூடிய பணியாளர் ஒருவரிடம் தயவுசெய்து பேசவும்.

Dacă aveți nevoie de aceste informații într-o altă limbă sau într-un format accesibil, vă rugăm să vă adresați unui membru al personalului, care va face demersurile necesare pentru dumneavoastră.

اگر به این اطلاعات به زبانی دیگر یا در قالب دسترس‌پذیر نیاز دارید، لطفاً با یکی از کارکنان صحبت کنید تا آن را برای شما تهیه کند.

Se necessitar desta informação numa língua diferente ou num formato acessível, por favor fale com um membro da equipa que poderá organizá-la para si

اگر آپ کو یہ معلومات کسی مختلف زبان یا قابل رسائی فارمیٹ میں چاہیے، تو مہربانی کرکے عملے کے کسی رکن سے بات کریں جو آپ کے لیے اس کا بندوبست کر سکتا ہو۔

Jeżeli niniejsze informacje mają być przekazane w innym języku lub dostępnym formacie, prosimy o kontakt z członkiem personelu, który może to dla Państwa przygotować

ئەگەر پێویستیت بەم زانیاریانە هەیە بە زمانێکی جیاواز یان شێوازێکی تر، تکایە لەگەڵ ئەندامێکی ستافەکە قسە بکە کە دەتوانێت بۆت ڕێکبخات

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The purpose of this leaflet

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

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?

Primary brain tumours are cancers that start in the brain or the tissues around it. There are many different types of primary brain tumour.

Secondary brain tumours happen when cancer spreads to the brain from another part of the body. They are also called brain metastases or brain mets.

Most people with a secondary brain tumour have already been diagnosed with cancer. However, for some people, the brain tumour is found before they know they have cancer elsewhere in their body.

Being told that you may have a brain tumour can be upsetting and worrying. You may feel uncertain about what is happening and what will happen next.

This leaflet explains what to expect while we carry out tests and gather more information. The results of these tests, such as scans, will help us confirm your diagnosis.

We understand that waiting for answers can be difficult. The doctors and nurses caring for you want to give you the right information, but it can take a few days to collect all the test results. We hope this leaflet helps you feel more informed and reassured during this time.

What will happen next?

You had a scan because of the symptoms that brought you to hospital. A radiologist (a doctor who looks at scans) will review your scan. The results may also be discussed with brain tumour specialists at The Walton Centre in Liverpool.

You will only stay in hospital if you need hospital treatment or care.

If you need more tests, these will be arranged as quickly as possible, whether you are in hospital or at home.

If you are not already under the care of a specialist team, you will be given a key worker. This is usually a nurse from the Acute Oncology Team. They will be your main point of contact, keep you updated, and answer any questions you may have. Contact details can be found at the end of this leaflet.

If you already have a key worker or a clinical nurse specialist from a previous cancer diagnosis, they will be updated and will take over your care.

The results of your tests will be discussed at a multidisciplinary team (MDT) meeting. This is a meeting where specialist doctors, nurses and other healthcare professionals work together to plan your care and treatment. Depending on your test results, this meeting may take place at The Walton Centre.

After the MDT meeting, your key worker will contact you as soon as possible, usually by the next day. They will explain the results and

discuss any care or treatment options with you. A nurse specialist from The Walton Centre may also contact you to arrange an appointment.

Your care and treatment plan will depend on your symptoms and the results of your tests.

What are steroids?

You may be given steroid tablets, usually called dexamethasone. These help to reduce swelling in the brain and can improve symptoms.

Steroids can be very helpful, but they can also cause side effects. You will usually start on a higher dose, which will be reduced after a few days. This helps to lower the risk of side effects.

Important advice when taking steroids:

- Take your steroids before midday. Steroids can make it difficult to sleep and may keep you awake at night.
- Take your steroids with food. They can irritate your stomach and may cause indigestion or heartburn.
- You may be given another medicine to help protect your stomach. Take this medicine 30 minutes before your steroids.
- Contact your GP or key worker if you become very thirsty or need to pass urine more often than usual. Steroids can sometimes increase blood sugar levels and may cause diabetes.
- If you already have diabetes, your diabetes medication may need to be adjusted. Please speak to your GP about this.

For further information please see the information sheet - Steroids and Adult Brain Tumours available from your keyworker or the brain tumour charity website: https://www.thebraintumourcharity.org/

What is a seizure?

Some people with a brain tumour may have seizures, which are sometimes called fits. This happens when the tumour affects the normal activity of the brain.

The type of seizure you have can depend on where the tumour is in the brain. For example, you may notice twitching in an arm or leg. Some people may become unaware of what is happening around them for a short time or have a brief "blank" episode lasting a few seconds.

It is important to tell your doctor or nurse as soon as possible if you think you may be having seizures.

If you need urgent medical advice, call NHS 111 or visit the NHS 111 website: https://111.nhs.uk/

If you have had a seizure, your doctor may prescribe anti-seizure medicine to help prevent more seizures. It is very important to take this medicine exactly as you have been told.

If you develop a rash soon after starting the medicine, contact your doctor or nurse straight away.

Do not stop taking your anti-seizure medicine suddenly, unless a doctor tells you to do so. Stopping it suddenly can increase the risk of having more seizures.

Can I drive?

If you have a brain tumour the DVLA will not allow you to drive, and you must notify them as soon as possible. For further information please see the information sheet - Driving and brain tumours available from your keyworker or the brain tumour 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 several 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.

Braintrust “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, the Brain Charity

Website: https://www.thebraintumourcharity.org/
Website: https://www.thebraincharity.org.uk/

Macmillan Cancer Support

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

Local support (St Helens and Knowsley)

Your local Macmillan Cancer Information and Support Centre is situated at St Helens Hospital, on the lower ground floor.
Telephone: 01744 646985 / 01744 647000.
Email: macmillansupport@merseywestlancs.nhs.uk

The centre is open between 8.30am and 4.00pm Monday to Friday except on bank holidays). If no-one can take your call, please leave a message and a member of the team will call you back.

The acute oncology team

If you have any questions you can talk to your keyworker in the Acute Oncology Team who are available between 9am and 5pm Monday to Friday (except on bank holidays).

Whiston and St Helens
Telephone: 01744 646794

Southport and Ormskirk
Telephone: 01704 705237

If no-one can take your call, please leave a message and a member of the team will call you back.

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/

Brain pathway patient experience survey

We want to make our services better and provide high-quality care for all our patients. We would like to hear about your experience of the care you received at Mersey and West Lancashire Teaching Hospitals NHS Trust during your recent visit.

Taking part in this survey is your choice. You do not have to complete it if you do not want to. Your decision will not affect the care or treatment you receive.

Use the QR code below to access a survey about your care and experience. The survey takes about 10 minutes to complete and can be completed by a patient, carer or family member.

If you would prefer a paper copy of the survey, please contact the Brain Pathway Navigator: Telephone: 01744 646 773

There may be students and observers present during your consultation as part of their ongoing training. Please let the staff know if you do not wish any students to be present during your attendance

Please ask a member of staff if you would like a chaperone present during your procedure.

MWL has a zero-tolerance approach to any form of abuse, violence or aggression shown to staff and patients, by patients, visitors or members of the public. We will not tolerate any form of bullying, victimisation, harassment, discrimination, unacceptable and inappropriate behaviour and/or unacceptable and inappropriate language.

All instances of abuse, violence or aggression, no matter how big or small, will be investigated and action taken if necessary.

Whiston Hospital
Warrington Road
Prescot
Merseyside
L35 5DR

St Helens Hospital
Marshall Cross Road
St Helens
Merseyside
WA9 3DA

Newton Hospital
Bradlegh Road
Newton-le-Willows
WA12 8RB

Southport Hospital
Town Lane Kew
Southport
Merseyside
PR8 6PN

Ormskirk Hospital
Dicconson Way
Wigan Road
Ormskirk
L39 2AZ