Brain pathway patient experience survey

In order to improve our services and provide high quality care to all of our patients, we would welcome your views and experience of the care you received at Mersey and West Lancashire Teaching Hospitals NHS Trust following your recent attendance at the hospital.

Participation in this survey is voluntary; if you do not wish to take part you do not have to and this will not affect the care or treatment you receive.

The QR code below is a link to a survey for completion about your care/ experiences. The survey will take approximately 10 minutes to complete and can be completed by the patient, carer or family member.

If you would like a paper copy of the survey, please contact the brain pathway navigator on:

Telephone: 01744 646 773

Email: naomi.hanley2@sthk.nhs.uk

Southport Hospital
Town Lane, Kew,
Southport,
Merseyside,
PR8 6PN
Telephone:
01704 547 471

Ormskirk Hospital
Dicconson Way,
Wigan Road,
Ormskirk,
Lancashire,
L39 2AZ
Telephone:
01695 577 111

www.MerseyWestLancs.nhs.uk

Mersey and West Lancashire Teaching Hospitals
NHS Trust

Suspected brain tumours

Patient information

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

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

Jeśli niniejsza ulotka ma być dostępna w innym języku lub formacie,
proszę skontaktować się z członkiem personelu, który ją dla Państwa przygotuje.

Dacă aveți nevoie de această broșură într-o altă limbă sau într-un format accesibil,
vă rog să discutați cu un membru al personalului să se ocupe
de acest lucru pentru dumneavoastră

如果您需要本传单的其他语言版本或无障碍格式，请联系工作人员为您安排。

إذا احتجت إلى هذه النشرة بلغة أُخرى، أو بتنسيق
يسهل الوصول إليه، يرجى التحدث إلى أحد الموظفين لترتيب ذلك لك.

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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 (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 a tumour 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.

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. The aim of this leaflet is to explain what will happen next and to help you feel a little more in control whilst we are gathering information.

Local support

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).

Telephone:

01704 705237

If no-one is able to take your call, please leave a message and a member of the team will call you back. Please be advised this may not be until the following working day.

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/

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/

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/

What will happen next

You will have had a 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.

Whether you stay in hospital or go home, if you are not already known to a specialist team you will be given a keyworker (a nurse in the acute oncology team) who you can talk to you about your care and they will keep you informed of what will happen next (see page 6 of this leaflet for contact numbers).

If you already have a key worker (a clinical nurse specialist who looked after you if you previously had a cancer diagnosis), they will be updated and take over your care.

Your investigations will be discussed at a 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, your keyworker will contact you as soon as possible. This will hopefully be no later than the day after the MDT meeting, to discuss any potential care or treatment options. The nurse specialists at The Walton Centre may contact you directly to arrange a clinic appointment.

Your care or treatment plan will depend on the symptoms that brought you to hospital and the results of any investigations.

What are steroids

You may have been started on steroid tablets, usually called dexamethasone, which will help to reduce any swelling within the brain.

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 the 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 can 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 GP or keyworker immediately, as steroids can cause diabetes.
- If you are already diabetic you may need adjustments to your diabetic medication, please make an appointment with your GP to discuss.

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 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:

https://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 tumour charity website:

https://www.thebraintumourcharity.org/

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/