Noble's Hospital Patient Pathway Information Leaflet

Suspected Brain Tumours

manx care

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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). Manx Care is now following an agreed pathway to ensure you receive an accurate diagnosis that will determine the next steps and the care you will receive.

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 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.

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 who interprets scans) and may be discussed with a specialist at The Walton Centre in Liverpool (a specialist centre for brain tumours), or another hospital.
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, and 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 about your care and they will keep you informed of what will happen next. 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 Multi-Disciplinary 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 Clinical Nurse Specialist 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 visit:

https://braintumourresearch.org/blogs/types-of-brain-tumour/steroids-for-brain-tumours

https://www.thebraintumourcharity.org/brain-tumour-diagnosis-treatment/treating-brain-tumours/adult-treatments/steroids/

If you are unable to access this information online, please call or visit the Macmillan Cancer Information and Support Service, Noble's Hospital where the team will be able to print this information for you.

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 located 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 symptoms are urgent or life threatening or you think a person is having a seizure ring 999.

If you have had a seizure your medical team or 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 about seizures please see the information sheet: seizures (epilepsy) and brain tumours available from your keyworker or the brain tumour charity website:

www.thebraintumourcharity.org/living-with-a-brain-tumour/side-effects/seizures-epilepsy-and-brain-tumours/

Can I drive?

If you have a brain tumour, do not drive. You must follow medical advice from your consultant/medical team. If you are advised you can drive, you will need to inform your insurance provider and complete a Supplementary Medical Information form providing details about your condition. You can get this from any Post Office, from the Vehicle Test Centre, Tromode Tel: 01624 686843 or online via:

www.gov.im/categories/travel-traffic-and-motoring/drivers-and-vehicles/driving-licences/medical-fitness-to-drive/

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. The following services 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 carers.

Local support

Naseem's Manx Brain Tumour Charity

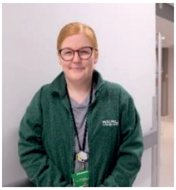
Support to Isle of Man residents who are suffering with a brain tumour by way of giving them financial support and providing the latest information about brain tumours.

Telephone: 07624 499521

Email: naseemscharity@manx.net

Website: naseemsmanxbraintumourcharity.co.uk

Acute Oncology



Acute Oncology, Manx Care support unwell adult patients who present with urgent needs as a consequence of their cancer or treatment, this includes a new diagnosis of cancer.

Telephone: 01624 650012

Clatterbridge Cancer Centre Neuro-Oncology Team

- Clinical Oncologists
- Clinical Nurse Specialists
- Cancer Support Worker

Telephone: 0151 556 5850

Email: ccf-tr.neuro.oncologynurses@nhs.net

Macmillan Cancer Information and Support Service

Based at Noble's Hospital. Providing a drop in service for anyone affected by cancer. The team can support you by listening to your concern and signpost you to local or national support services.

Open: Monday to Friday 9.30am - 4.30pm excluding bank holidays

Telephone: 01624 650735

Email: MCISS@gov.im

National Support

For specific information about what to expect, driving, recognising reliable websites, knowing what to ask when newly diagnosed, someone to talk to and much more.

Brainstrust
Telephone: 01983 292 405 24/7 helpline
Email: hello@brainstrust.org.uk
Website: brainstrust.org.uk

The Brain Tumour Charity
Telephone: 0808 800 0004 9am-5pm Monday to Friday
Email: support@thebraintumourcharity.org
Website: thebraintumourcharity.org

The Brain Charity
Telephone: 0151 298 2999 9am – 5pm Monday to Friday
Email: info@thebraincharity.org.uk
Website: www.thebraincharity.org.uk

Brain Tumour Research
Telephone: 01908 867200 - 9am – 5pm Monday to Friday
Email: supportercare@braintumourresearch.org
Website: braintumourresearch.org

Macmillan Cancer Support
Telephone: 0808 808 00 00 open 8am to 8pm, 7 days a week.
Website: www.macmillan.org.uk

Get In Touch

Macmillan Cancer Information and Support Service
Noble's Hospital
Strang
Isle of Man
IM4 4RJ
Telephone: 01624 650735
Email: MCISS@gov.im
Open Monday to Friday, 9.30am – 4.30pm excluding bank holidays

Feedback

Manx Care Advise and Liaison Service (MCALS) is a confidential service operated by Manx Care that's dedicated to driving positive change across our health and social care system by listening to your feedback and acting on it. The service aims to improve patient and service user experiences. If you would like to feedback on your experience or have suggestions on how you think we could improve please complete the Friends and Family questionnaire here:

Telephone: 01624 642642
Email: MCALS@gov.im

If you need this leaflet in a different language or accessible format please speak to the Macmillan Cancer Information and Support Service who can arrange this for you.

Printed: March 2025
Review: October 2026

Adapted from: Cheshire and Merseyside Cancer Alliance
Emergency Brain Pathway Patient Information Leaflet

Printed by BHW Print Group

Department: Cancer Services