

Meningioma

Information for patients



You have been referred to the Leeds Meningioma Service because your scan(s) have shown a lump (tumour) which we feel most likely represents something called a meningioma.

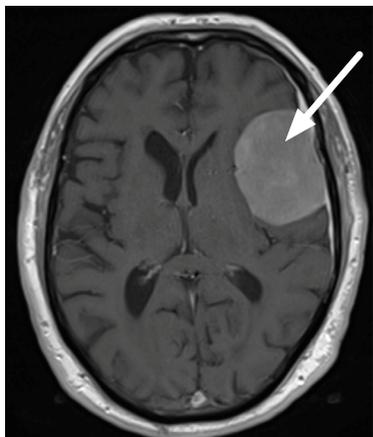
This booklet is to help you understand what a meningioma is and to answer some of the most common questions that patients have at this stage.

Our meningioma team will go through all this information with you when you come to see us in clinic and will explain the treatment options available in your case. You will have the opportunity to ask questions at every step along the way.

We have included some useful contact information at the end of this booklet. If you have seen us in clinic but then find that you have further questions or need more urgent advice, we hope that this contact information will enable you to get the answers you need. Please do note, there are some specific medical details that we can't always answer by telephone.

What is a meningioma?

A meningioma is an abnormal growth (a tumour) that arises from the linings that cover the brain and spine. Meningioma is much more common in the brain than the spine. Although usually considered a type of brain tumour, meningioma rarely grows inside the brain, rather it grows on the surface and presses against the brain. They are usually slow-growing and non-cancerous (benign).



Example of an MRI brain scan showing a large meningioma (arrow) causing some compression of the brain.

What causes a meningioma?

The causes of meningioma are not fully understood and most cases are what is known as idiopathic (meaning that we don't have a good reason why it happened).

There are some risks for developing meningioma which include:

- **Female hormones** – Meningiomas are more common in women and have sometimes been seen to grow during pregnancy, leading doctors to believe female hormones may play a role.
- **Radiation exposure** – Radiotherapy to the head may increase the risk of meningioma (especially if given in childhood).
- **Some genetic conditions** – These can often cause more than one meningioma, however some people without a genetic condition will also have more than one meningioma.

Patients often ask whether a previous head injury might have put them at risk of developing a meningioma. To the best of our understanding, head injury does not cause a meningioma.

Common signs and symptoms of meningioma

The signs and symptoms can be very varied depending on the size of a tumour and what structures it sits next to.

Some common presenting features are listed below:

- Headaches
- Seizures
- Visual problems
- Speech problems
- Changes to thinking skills
- Balance problems
- Weakness or tingling of the arms or legs

Even though meningioma can cause a variety of different symptoms, many patients have no symptoms at all or they have symptoms but the meningioma is not felt to be the cause. In these cases, we refer to the meningioma as an “Incidental tumour”.

If you have symptoms but these are not felt to be linked to your meningioma, the meningioma team may recommend you see your GP or neurologist to further investigate the cause for your symptoms.

Diagnosis and workup (tests)

A meningioma is almost always picked up during a scan of the head or spine. Some patients will have had a computed tomography (CT) scan, some will have had a magnetic resonance imaging (MRI) scan and some will have had both. If you require additional tests, your team will go through this with you in clinic.

Once you have had all of the tests that you need, your case will be discussed in a meeting called a Multi-disciplinary Team meeting (MDT). This is a gathering of lots of different health professionals who each has different areas of expertise and

different treatments to offer. The idea of the meeting is that every patient gets the benefit of the full range of options and opinions available to ensure the best possible care. Please see the *'Meet the Team'* section near the end of the leaflet for more information.

Treatment options

There are different ways that a meningioma can be managed. We want every patient to have the treatment that is best for them as an individual.

The meningioma team will discuss the suitable options with you in clinic; it is important that you feel able to be part of this discussion. We want to understand what your thoughts and wishes are.

Discharge

Sometimes a meningioma is so small that we don't think that it will become large enough to cause any problems in someone's lifetime and therefore it may be appropriate to discharge you.

There are also patients for whom treatment would simply be too invasive and in whom we risk causing more harm than good by intervening.

Surveillance

If a meningioma is not causing any problems and is relatively small, often the best strategy is to monitor it. This is done with MRI scans at regular intervals. If these scans show no change over several years, then often there is no need for further monitoring.

Radiotherapy

Radiation can be used to treat some tumours when they are in difficult to access locations, in cases where surgery is not the best option or if the tumour is small enough at the time of diagnosis. It can also sometimes be used in cases where you have had an operation to remove a tumour, but there is evidence on follow up scans that it is growing back. Radiation can be given in a traditional manner (to a larger area) or in a more focussed way (known as Gamma Knife or stereotactic radiosurgery). Should you require radiotherapy treatment you will be referred to a radiotherapy specialist for a discussion and further written information will be provided.

Surgery

Some tumours that are large, are causing symptoms or are growing on successive scans (e.g. during surveillance) will require surgery.

Depending on where the tumour is, this involves making an opening in the skull (called a craniotomy) to access the tumour with the aim to remove as much as is safely possible. Please see the craniotomy leaflet for more information about this.

In some cases, the tumours may be accessed via other routes. One example of this is using an endoscope (camera) to access the tumour through the nose. The surgical team will let you know if this is needed in your case.

Some tumours may be accessible via key hole surgery using eye brow incision. This allows for early recovery and discharge. If your tumour is suitable to be operated via eye brow incision and key hole (supra orbital craniotomy), your surgeon will discuss it in clinic with you.

Some meningiomas may involve bone of the skull, including around eye socket. The tumour may also extend into the eye socket itself; potentially requiring all of the involved bone to be removed. The defect in skull is then reconstructed using custom made 3D printed implants of a special PEEK (polyetheretherketone) material. These operations are jointly undertaken by Neurosurgery and Maxillofacial surgery teams.

Meningioma grading (results)

If a meningioma is surgically removed, we will send off samples of the tumour to our pathology laboratory for analysis. By carefully examining the cells under a microscope, it confirms an exact diagnosis and to give the tumour a grade (a measure of tumour aggressiveness). In general, the higher the grade of the tumour, the more chance it has to come back after surgical removal. This information guides your further treatment and follow up. The result can take between one and three weeks to come back.

Most patients are already back at home before we get the results. In this case, we will contact you to let you know the outcome, to explain what it means and to go over the next steps with you. You should not be kept in hospital just to wait for your results.

Preparing for Surgery

If you are listed for surgery, the process will start with sending you to the pre-assessment clinic. This may happen on the same day as your clinic appointment or some time after. This involves having your blood taken, checking your medications and going through some other simple checks to ensure you are ready for your surgery and that we can keep the risks of the surgery and the anaesthetic as low as possible.

If you are well enough to be admitted on the day of your operation, you will normally be asked to go to our on-day admission ward (full details will be in your admission letter) at the Leeds General Infirmary at 7:15am for final checks including meeting the surgical and anaesthetic team and filling in a formal written consent form. This is another opportunity for you to ask the surgeon and the anaesthetist any questions you may have. It can be useful to bring a list of questions in with you on the day. The risks of surgery will have been discussed between you and your operating surgeon prior to the day of surgery so that you have had time to consider and reflect but we will go over all of these again on the day of the procedure.

The time you will need to be in hospital after surgery varies between people and operations – an estimate of this may be available from your operating surgeon.

As you are having a general anaesthetic you should have nothing to eat (including chewing gum and mints) after midnight on the night before your operation. You can still continue to drink clear, still, unflavoured water freely until 6am. You must not drink anything after 6am.

Most of your usual medications can still be taken on the morning of surgery. However, some medications including blood-thinning medication, diabetic medication and some blood pressure tablets should not be taken. You will be advised about this in advance. If you are in any doubt, please contact us before your surgery to check.

Some patients will be asked to commence on steroids before the surgery, in order to counteract swelling in the brain.

In some circumstances, you may be admitted the day before your operation to one of the surgical wards.

After Surgery

After your operation, you will spend some time in the recovery area and then will return to one of the neurosurgical in-patient wards. In some cases, you may need to spend a day or so on our High Dependency Unit (HDU - Ward L02) or Intensive Care Unit (ICU - Ward L03) if you need some closer observation, but this is not always required.

You will be monitored on our ward for as long as is required and may have a further CT scan before you go home. You will have routine blood tests after your operation.

You will be reviewed by our medical staff daily, and specialist therapy teams (as required) on the ward, following which your discharge plans will be made.

If more recovery time is needed you may be transferred to a hospital nearer to your home for further rehabilitation.

The ward will send an electronic discharge advice note to inform your GP of the details of your surgery and any medication changes needed. You do not need to make an appointment to see your GP unless they have specifically asked you to do so or you have any problems.

A member of the Clinical Nurse Specialist team will contact you to provide telephone follow-up after your discharge home. (please contact us sooner if required).

You will also be sent an appointment for routine surgical follow up to discuss progress and ongoing management.

You will usually have a baseline MRI scan at three months following surgery.

Our Wards

Ward L24 (visiting 2-4pm and 6-8pm)

Tel: **0113 392 7424**

Ward L25 (visiting 2-4pm and 6-8pm)

Tel: **0113 392 7425**

High Dependency L02 (visiting 12-4pm and 6-9pm)

Tel: **0113 392 7402**

Intensive Care L03 (visiting 10-4pm and 6-9pm)

Tel: **0113 392 7403**

After Discharge

The Craniotomy leaflet goes through some of the commonest issues patients have after their operation. Please also refer to this for further information.

Common Questions After Discharge

- **Stitches/Clips** – Some stitches are absorbable and do not need to be removed. Some stitches are non-absorbable and these, along with any clips (staples) in the wound, would need to be removed after surgery. Removal can be arranged via your local GP Practice Nurse. The timing of suture/clip removal varies but is typically between 5 - 14 days after surgery and you will be advised of this before leaving. Absorbable sutures can take up to several weeks to disappear, so do not pull at any visible sutures; these will drop off as the wound heals.
- **Dressings** – Dressings can be removed a few days after surgery. Steri-strips are left on and usually fall off by themselves after a few days. If not, please ease them off gently when washing your hair.
- **Washing Wounds** – You can gently wash wounds 48 hours after surgery. If the wound is scabbed, these scabs should soften, lift and fall off with regular hair washing. If however you notice any fluid leaking from under the scab, then seek medical advice. Further information on who to call is at the end of this section.
- **Wound swellings** – Sometimes you may notice some swellings over the wound. These usually settle by themselves. If, however, these continue to grow in size and are painful, please seek medical advice.
- **Hair Dye** – Patients can dye their hair after six weeks if the wound is fully healed.

- **Length of Recovery** – This is different for everyone, but generally it can take anywhere from 6 -8 weeks and in some circumstances longer. Depending on what you do, you can return to work in 4 - 6 weeks. Please request a fit note (previously known as a sick note) from the ward before leaving, an extension to this can be obtained from your GP.
- **Exercise** – You can do light exercise two weeks after surgery and moderate exercise regularly in about six weeks. Avoid heavy lifting and straining in the first two weeks after surgery. Avoid swimming until your wound has completely healed (usually 4-6 weeks after surgery).
- **Fatigue** – Tiredness which is not fully relieved by rest can be experienced. This is common and usually improves over time. The outpatient Occupational Therapist (OT) is available to provide an individualised assessment, information and advice to help you manage these symptoms. Please contact **0113 206 7912**.
- **Emotions** - Brain surgery is a major event and can cause a variety of emotions alongside changes to your usual daily activities in the early stages after your operation. The health professionals involved in your care can discuss this further with you.
- **Sex** - You may have sex when you feel ready to do so.
- **Driving** – You should not drive after your surgery. The date that you can return to driving depends on the exact type or 'grade' of meningioma that was removed, on what type of driving licence you hold and on whether you have had any seizures. You need to contact the DVLA on discharge to let them know about your surgery. See Driving section later for DVLA contact details. We also advise informing your insurance provider.

- **Flying** – You should be safe to fly six weeks following surgery. You will need to disclose to your travel insurance company about your condition/treatment prior to travel to ensure you have appropriate cover.

Help and Advice

If you have the following symptoms you must seek medical advice:

- New seizures.
- Wound leak problems including clear fluid, pus or swelling
– Call the ward as soon as you notice this.
- Severe headaches or neck stiffness.
- Fevers above 38°C.
- Severe nausea and vomiting.
- New limb weakness.

For urgent advice or after hours

Female Neurosurgical Ward L24 **0113 392 7424**

Male Neurosurgical Ward L25 **0113 392 7425**

Admissions Unit L26 **0113 392 7426** (Only open on weekdays)

For non-urgent advice and support

Please contact your Meningioma clinical nurse specialist:

Roisin Darley and Alice Tonks Tel: **0113 206 7571**

Please do not leave any urgent messages on the answerphone. In case of an emergency, please attend your nearest emergency department.

Rehabilitation services

Patients are able to access rehabilitation services at any stage of their journey (before, during or after treatment). You can refer yourself to this service or ask a health professional to refer you.

Occupational Therapy. For difficulties with completing activities of daily living; caused by problems with vision, physical or thinking skills, or fatigue. Can also provide equipment to make things safer or easier at home.

Tel: **0113 206 7992**

Physiotherapy. For problems with mobility, movement or weakness.

Tel: **0113 206 8101**

Speech and Language Therapy. For problems with swallowing and / or communication.

Tel: **0113 206 7816**

Surgical Follow Up

You will require a baseline MRI scan 3 months after surgery. The MRI department will contact you with appointment details. For any enquirers related to scan imaging please contact: **0113 733 4974**

Driving

Please refer to guidance on DVLA website in the first instance:

<https://www.gov.uk/guidance/neurological-disorders-assessing-fitness-to-drive#benign-brain-tumours>

DVLA driver licensing enquiries:

Telephone: **0300 790 6801** Driving license and applications.
0300 790 6806 Driving and medical issues

Monday to Friday (8am - 7pm), Saturday (8am - 2pm)

Please note that the DVLA regulations are reviewed on a regular basis.

It is **your legal responsibility** to inform the DVLA of your diagnosis and any treatment/surgery you have received. You must not drive until the DVLA has written to you with their recommendation.

Meet the team

The MDT is comprised of the following staff:

- Consultant Neuro Surgeons
- Consultant Neuro Radiologists
- Consultant Neuro Oncologists
- Consultant Neuro Histopathologists
- Clinical Nurse Specialists
- Physiotherapists
- Occupational Therapists
- Speech and Language Therapists
- MDT Co-ordinators

Support Networks

Local

Leeds Neurosurgery Website

www.leedsneurosurgery.com

Yorkshire's Brain Tumour Charity

www.yorksbtc.org.uk/Home Twitter: @YorkshireBTC

YBTC Shop & Cafe No31

Tel: **0113 340 0111**

National

The Brain Tumour Charity

www.thebraintumourcharity.org

Tel: **0808 800 0004**

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Mon-Fri 9am-5pm.

www.citizensadvice.org.uk

Tel: **0800 144 8848**

What did you think of your care? Visit bit.ly/nhsleedsfft
Your views matter

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