NHS
The Leeds Teaching Hospitals
NHS Trust

Low Grade Glioma Brain Tumours

Information for patients

Leeds Centre for Neurosciences

ı have been given an appointment in this
ic because you have been diagnosed with
ɔw Grade Glioma (LGG). This leaflet aims
ıelp you understand what this means and
at may happen in the future.

team that will be helping to care for you include:

r P. Chumas - Consultant Neurosurgeon

r J. Goodden - Consultant Neurosurgeon

r R. Mathew - Consultant Neurosurgeon

· M. Flatley - Consultant Neuro-Oncologist

· M. Maguire - Consultant Neurologist

· D. O'Hara - Consultant Neuropsychologist

anne O'Malley - Clinical Nurse Specialist Oncology

izabeth Wright - Clinical Nurse Specialist Epilepsy

nic, there will be a selection of people from the team and
may also include the Neurosurgical registrars, so when you
ıto the clinic there may be a lot of people in the room.
ɜe do not be concerned by this it is our normal practice.

What is a Low Grade Glioma?

A Glioma is a type of brain tumour that is made up from the supportive tissue of the brain, otherwise known as GLIAL cells. These glial cells support the nerve cells and help them perform their functions. Others have described these as the scaffolding cells holding the brain cells in place. Gliomas are classified into four grades (1, 2, 3 and 4) and the treatment and prognosis depend upon the tumour grade. Grade 1 or 2 tumours are termed low grade gliomas (LGG).

The word 'tumour' means a lump that would not be there normally. It is simply a descriptive word and does not imply any particular level of activity. It is therefore used to describe benign conditions such as warts and also for malignant cancers too. When we use the term 'tumour' it is therefore as a descriptive word.

The two main types of Glial cells that are involved in Low Grade Glioma tumours are:

1. **Astrocytes,** which provide the brain's framework and help to control the chemistry of the brain cells.
2. **Oligodendrocytes,** which help act as insulators in the transmission of messages to the brain.

The tumours made from these cell types are called Astrocytoma or Oligodendroglioma, or a mixture called an OligoAstrocytoma.

The World Health Organisation (WHO) has defined grades of brain tumour according to their activity and aggressiveness.

- **Grade 1** - These tumours occur most commonly in children and are classified as 'benign'.
- **Grade 2** - The majority of Low Grade Glioma tumours that we deal with are Grade 2 tumours. Tumours of this grade are not currently malignant.
- **Grade 3** - Tumours of this grade are more aggressive than Grade 2 tumours and are usually treated with radiotherapy after surgery. Some Grade 3 tumours may also receive chemotherapy as part of their initial treatment.
- **Grade 4** - These tumours are High Grade, malignant, cancerous tumours that are often treated with radiotherapy and chemotherapy following surgery.

Symptoms of a Low Grade Glioma

Symptoms of a LGG differ depending upon the site and size of the tumour.

The most common symptoms are seizures, with 70 - 80% of people being diagnosed following an epileptic seizure.

Because they are slow growing tumours, many people may have had their tumour for many years without any symptoms.

Other rarer symptoms of LGG can be limb weakness or numbness, speech disturbance, visual disturbance and sometimes, hearing disturbance, as well as memory or cognitive changes. Headaches are not often caused by these tumours.

Some people have their LGG diagnosed as a co-incidental finding after a brain scan for a different reason; for example, after a head injury.

Diagnosis of a Low Grade Glioma

When a patient presents with symptoms (as above), they often have a CT scan or an MRI scan of the brain. MRI scans are more detailed scans, and give us much more information about a tumour and its location. It is common to perform MRI scans to diagnose and follow-up LGG.

We can have a good idea that a tumour is a LGG because of how it looks on the scan but we cannot tell exactly which type of tumour it is unless we have a sample of tissue (called a biopsy - see below).

Low Grade Glioma and Epilepsy

As stated above, most people present with epilepsy as the first sign of a LGG. Medication can successfully control epilepsy for people with LGG, with up to 50% becoming seizure free on medication. Other treatments for the tumour itself can also help improve seizure control.

Antiepileptic drugs usually have to be started slowly and built up gradually to reduce the risk of side-effects. This is usually done by a Consultant Neurologist.

It is important to inform the Epilepsy Specialist Nurse if you have an increase in seizure frequency, change in seizure type or side-effects to your medication.

There are a variety of medications that can be used. If one does not suit you, we can try others.

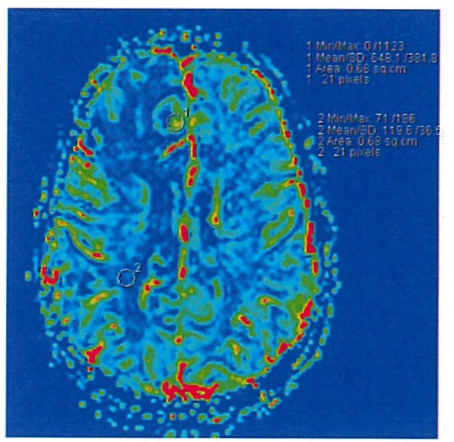
What happens next?

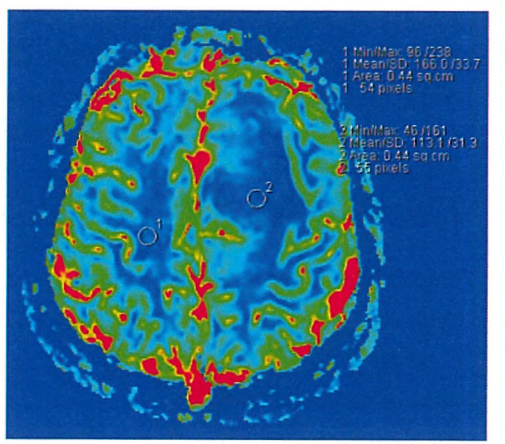
With just one MRI scan, we only have a snap shot of the tumour so we need to repeat the imaging to see if the tumour is growing. Most LGG grow by 1 - 2% per year, so we would arrange an initial repeat scan in 2 - 3 months. Then at intervals of six months and then 12 months.

We often include other specialists in your care:

1. **Neuropsychologist** - for assessment of memory and other thinking skills, and helping people adjust to the psychological aspects of diagnosis of a brain tumour.
2. **Neuro-oncology** (Radiotherapy / Chemotherapy experts) - if this needs to be considered for treatment
3. **Neurologist** - to manage seizures
4. **Clinical Nurse Specialists** to support and advise regarding Epilepsy and Tumour management
5. **Speech & Language Therapist** - Many tumours occur near speech and language centres in the brain, so these specialists are involved in monitoring and help with patients with LGG
6. **Physiotherapist** - Many tumours occur near movement-control centres in the brain, so these specialists are involved in monitoring this and help patients with their recovery after surgery

7. **Occupational Therapist** - These therapists work alongside the LGG team and neuropsychologists. LGG can often result in changes to higher functions and memory. The OTs assist particularly in post-operative rehabilitation but can also help with optimising function at other stages too.
8. **Ophthalmology** - eye specialists who are involved in monitoring and treatment if the LGG is near the vision pathways





How is my Low Grade Glioma monitored?

The best way to see and monitor a LGG is to do specialist MRI brain scans. You will normally have had an MRI scan to diagnose the tumour in the first place.

We also arrange for a Neuropsychology review. The Neuropsychologist is an expert at assessing memory, brain function and other abilities.

We recognise that most people will not have seen a neuropsychologist but this is an entirely routine part of your care before neurosurgery. They can check whether your tumour is causing any problems with memory, functioning or wellbeing. This assessment helps us to understand how things are for you, help you prepare for neurosurgery and your rehabilitation and allow us to monitor change in the future.

In order to provide a more comprehensive view of where your tumour is and what it is affecting within the brain, we may arrange some additional specialist 'Functional' MRI scans (fMRI). These scans enable us to map the important functional (eloquent) brain regions and see where they are in relation to your tumour. Other types of MRI scan are also done to examine the tumour blood flow and guide us in making treatment decisions.

When we first see you in clinic, we normally arrange a repeat scan to see if anything has changed since your initial scan. This is usually 2 - 3 months after your first scan. Further scans are then arranged with the timing decided according to whether the decision is for active monitoring or active treatment.

Does my Low Grade Glioma need treatment?

Our understanding of LGG has changed a great deal over the past 10 - 15 years. We have learned that neurosurgery operations have a significant role in treating these tumours and helping to control them.

Without any treatment, we know that LGG can grow and transform / change to become a High Grade (cancerous) glioma. For most patients, this change occurs within five years of initial diagnosis.

We have learned that surgery to remove significant parts of LGG can delay the time of transformation in LGG and can prolong quality and quantity of life. Unfortunately, this is not applicable for all LGG, and is dependant upon the location and extent of the LGG inside the brain. Where possible, we like to offer surgery at an early stage to try to control LGG. This is showing good results, with many patients' tumours controlled by surgery alone for long periods of time.

What are the treatment options?

In your clinic appointment, we would discuss possible options for the future these include:

1. **Active Monitoring or Watchful waiting** - where we perform regular scans to monitor for any change in the tumour, rather than planning up-front treatment.
2. **Biopsy** - where a small hole is made in the skull and a sample of the tumour is taken away for testing to define its type and grade.
3. **Craniotomy** - where a trapdoor is made in the skull and we try to remove some or all of the tumour.
4. **Radiotherapy and / or Chemotherapy** - these may be required alongside biopsy or craniotomy for some patients with LGG.

If a decision is made to monitor the LGG tumour, MRI scans are usually performed every six months in the first instance. If all is stable for the first two years, we will often then change to scans being done once every year.

Many, but not all tumours, may be suitable for surgery. This depends upon where the tumour is and if it is near a part of the brain that is vital for controlling part of the body or speech (a region called 'eloquent').

Because we know these tumours grow and change over time, it is our preference to consider surgery wherever possible, to remove as much of the tumour as possible. This is called 'craniotomy and debulking' - where we do an operation to remove as much as is **safe** and **possible** of the tumour.

From studies, we know that LGG tumours can extend into the brain deeper than may be apparent on the MRI brain scan. Individual tumour cells can be growing into the brain around the tumour, but this isn't shown on the MRI scan because only a microscope can show this. For a small number of patients, we may therefore try to remove an extra rim of brain around the LGG tumour during the surgery, to maximise the extent of resection. Where the tumour is beside a movement or speech area however, this is not a sensible thing to try.

Since LGG tumours are often close to important functional areas of the brain, we often need do these operations via a special technique called an 'awake craniotomy' (explained later); however, not all patients need this procedure.

After surgery, an initial post-operative MRI scan is performed 1 - 2 days after surgery. This is then repeated three months later. If all is stable on that scan, further MRI scans are usually performed every six months in the first instance. If all is stable for the first two years, we will often then change to scans being done once every year.

What are the benefits and risks of each option?

1. Watchful Wait

a. Positives to this approach

1. This is non-invasive and does not require surgery
2. It gives us time to be able to do our tests
3. It avoids the risk of surgery for tumours in difficult to operate areas.

b. Negatives to this approach

1. There is a risk of the tumour transforming into a high grade tumour over time.

2. Biopsy

a. Positives to this approach

1. Enables us to get a sample of the tumour to help with a formal diagnosis of which type of low grade glioma it is.
2. Useful for areas that are difficult to operate on as it is less invasive than a craniotomy.

b. Negatives to this approach

1. A biopsy is only representative of that part of the brain tumour and not necessarily representative of other parts of the tumour.
2. Carries a small risk of bleeding which may require further surgery or risk of stroke.

3. Craniotomy & Debulking

(Removing as much as safe and possible of the tumour via open surgery)

a. Positives to this approach

1. Studies show that if we can remove the majority of the tumour it has a smaller chance of transforming to a high grade glioma
2. It allows most of the tumour to be studied for diagnosis
3. May reduce or eradicate seizures

b. Negatives to this approach

1. Carries a small risk of bleeding and stroke
2. Small risk of causing seizures or making seizures worse
3. There is a small risk of damaging nearby areas of the brain which could affect speech or movement control depending upon its proximity to the tumour.

Biopsy

This procedure is normally performed under a general anaesthetic and is mainly done as a day-case operation. Before the biopsy, an up-to-date MRI scan is obtained. You are then admitted on the day of surgery to ward L28 where final pre-operative checks and an anaesthetic review are done. You are then taken around to the operating theatre for the operation itself.

The biopsy involves making a small cut (approximately 2 cm) in the skin and making a small hole through the skull. A small needle is then passed down into the part where the biopsy needs to come from and the biopsies are taken. The surgeons use a special surgical guidance navigation system to ensure that this is done very accurately. The biopsy is then sent to the laboratory. The incision is stitched closed (usually absorbable stitch) and you are woken from anaesthetic and taken to the recovery area.

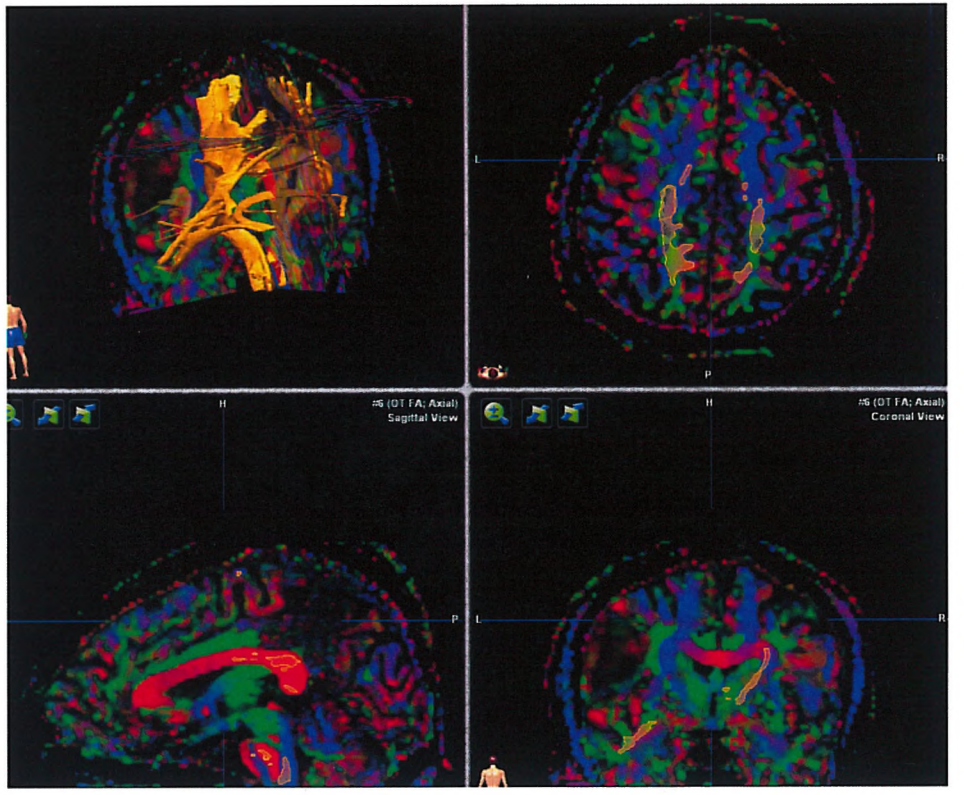
Once you have returned to the ward, the nurses will perform a series of checks to ensure you are alright after the surgery. A CT brain scan is also routinely performed approximately four hours after the biopsy to check there are no problems. If everything is alright, you will then be discharged that afternoon / evening.

Asleep Craniotomy

This is one of the two ways that we use to remove as much of the tumour as possible - a process called 'debulking'. It is used when the LGG tumour is away from the main functional areas of the brain. It involves open surgery with you asleep, under full general anaesthetic.

Prior to the surgery, an up-to-date MRI scan is obtained (within the preceding four weeks). You are then admitted on the day of surgery to ward L28 where final pre-operative checks and an anaesthetic review are done. You are then taken around to the operating theatre for the operation itself.

Just like with a biopsy, the surgeons use a special surgical guidance navigation system to ensure that this is done very accurately. This system is also used to help plan the best size and position for the surgical incision. After the incision is made, a trap-door is opened in the bone of the skull, and the surgeon then exposes the brain and tumour and starts removing the tumour. Once enough tumour has been removed, it is then sent to the laboratory. The trap-door in the bone is closed and secured with little titanium plates, and the incision is stitched closed (usually absorbable stitch) and you are woken from the anaesthetic. You are then taken to the recovery area and from there, you will go to one of the wards to recuperate. A post-operative MRI scan will be performed 1 - 2 days later and most patients are able to be discharged within 2 - 4 days of surgery.



Awake Craniotomy

This is the other way that we use to remove as much of the tumour as possible. It is used when the LGG tumour is close to, or even involving, one of the main functional areas of the brain.

Performing an awake craniotomy allows us to closely monitor brain function whilst removing the tumour. This means we can get the best balance between removal of as much tumour as possible and preservation of brain function.

Firstly, this is possible because the brain itself does not have sensation. The brain processes inputs from the body but doesn't actually feel things itself. You therefore, cannot feel us performing the surgery.

Whilst the surgery is being performed, your function is being closely tested and monitored by a Speech and Language therapist, and also a Physiotherapist. They provide constant feedback to the surgeon so that the best decisions can be made during the surgery.

The other important thing about LGG and awake surgery is that the brain can move functions from their normal control region to another. This is called plasticity and is happening because the brain is responding to the presence of the LGG tumour. This is why it is important to map out precisely where function is in relation to the tumour so that we can preserve it.

What happens in an awake Craniotomy?

Prior to the surgery, an up-to-date MRI scan is obtained (within the preceding four weeks). You will also be asked to attend an outpatient review with the Speech and Language therapist and Physiotherapist on the day, prior to surgery. You are then admitted on the day of surgery to ward L28 where final pre-operative checks and an anaesthetic review are done. You are then taken around to the operating theatre for the operation itself.

The surgeons use a special surgical guidance navigation system to ensure that this operation is done very accurately. This system is also used to help plan the best size and position for the surgical incision.

This procedure starts with you asleep under a general anaesthetic whilst the first parts of the operation are performed. After the incision is made, a trap-door is opened in the bone of the skull, and the surgeon then exposes the brain and tumour. At this point the anaesthetic is reversed in a controlled manner so that we can do our testing and then remove as much of the tumour as possible. The tumour specimens are sent to the laboratory for further analysis.

The process of awake craniotomy can be very tiring and it is normal for you to get tired during the procedure. A decision to stop further surgery is made when either enough tumour has been removed, or if you are too tired for the testing to be considered accurate enough to continue the surgery. At this point, we will assess whether to put you back under full anaesthetic or just let you drift off to sleep whilst the surgeon closes the wound.

The trap-door in the bone is closed and secured with little titanium plates, and the incision is stitched closed (usually absorbable stitch). You are then taken to the recovery area and from there you will go to one of the wards to recuperate. A post-operative MRI scan will be performed 1 - 2 days later.

Depending on what has been done during surgery and on whether any further rehabilitation is required, you may be able to go home 2 - 3 days after surgery but some patients can need a week or so of rehabilitation too.

What happens to function during awake surgery?

When operating on an LGG tumour, the surgeons use a special tool called a CUSA which shatters and removes tumour cells. This instrument is very effective at removing tumours. It also helps with us monitoring how close we are to the important brain regions. This is because it sends little ultrasound waves 5 - 10 mm deeper into the brain around where we are working and this disturbs the function of those cells in those deeper regions. This means that function can be disturbed temporarily and allows the surgeon to know where they are in relation to the functional areas.

The other thing that this raises is what happens to function during awake surgery? Due to the CUSA, function can gradually deteriorate during the surgery as we get closer and closer to the important control regions. Again, this is because those ultrasound waves are disturbing things deeper down. We know that this is temporary and reversible; however, sometimes, function can continue to get worse for up to 2 - 3 days after surgery due to cell-swelling as a secondary effect of the surgery. This usually then recovers but the recovery can take weeks or months and needs rehabilitation input too. This is something the surgeon will explain further and is not always the case for all patients.

Radiotherapy / Chemotherapy

If treatment with radiotherapy or chemotherapy is required, you will be referred for an individual appointment with a specialist for this treatment called a Neuro-Oncologist.

Radiotherapy is a treatment that uses high energy x-rays that are carefully aimed at the area of the brain affected by the tumour to stop or slow the growth of the cells. Radiotherapy is generally given in a series of treatments, and the dose of radiation administered per treatment is carefully calculated to maximise the killing of tumour cells and minimize the effect to the normal brain. For low grade gliomas, it is usually delivered in a total of 28 - 30 daily treatments, five days per week.

Chemotherapy is a treatment that uses drugs to stop or slow the growth of cells. Some chemotherapy can be taken by mouth with others given into a vein. A chemotherapy drug, often used to treat brain tumours is Temozolomide, which is effective if taken by mouth. Other common chemotherapy drugs, or combinations of more than one drug include 'PCV' combination (procabazine, lomustine, and vincristine), These treatments would only be considered once a tissue sample has been carried out. The treatment recommendation then mainly depends upon the grade, extent, and type of tumour you have.

Grade I tumours generally do not require treatment after surgery.

Grade II tumours may have radiotherapy / chemotherapy or both depending upon the type and extent of the glioma.

Younger adults whose tumours are small and not causing many symptoms may not have any treatment, unless the tumour shows signs of growing again. In some cases, second surgery may be tried.

In people who are older, or whose tumours are at higher risk of coming back for other reasons, treatment is more likely to be given after surgery.

Cytogenetic tests on the tumour can help to determine what combination of radiotherapy and / or chemotherapy is recommended. Occasionally, chemotherapy is used first to delay radiotherapy until signs of growing again. If, however, a Grade 3 or 4 tumour is diagnosed, treatment is given immediately after surgery. This is usually radiotherapy, with or without chemotherapy.

Other questions

Pregnancy and Low Grade Glioma

Having a LGG will not prevent you from getting pregnant; however, there are some issues with pregnancy and a LGG.

- MRI scans are not recommended in the first three months of pregnancy and as this is the main way in which we observe your tumour, we would need to try to provide scans after this time period but would prefer to wait until after you have had the baby.
- Some epilepsy-treatment medications can interfere with growth and development of the baby. If you are planning to get pregnant, please contact your epilepsy specialist as they will need to ensure that you are on the best and safest medication.
- Pregnancy is known to increase the rate of growth of LGG. It may therefore, contribute to the tumour changing into a more active tumour type.

Driving

Firstly, you MUST inform the DVLA immediately about your diagnosis. This is your duty by law and is written on your driving licence. The DVLA then decide whether or not you can continue to drive. Failure to inform the DVLA of your diagnosis may mean that your licence is not valid and therefore, you are driving illegally and therefore are not insured.

The DVLA publish their rules about driving online and update them every year. The guidance here is an outline to indicate what the DVLA might say but does not replace the DVLA guidance. There are different driving regulations for driving a car than for Public vehicles and HGVs.

Seizures and Driving

- If you have a single seizure but have an abnormality on scan (such as a tumour), then the DVLA will normally stop you from driving for one year from the date of your last seizure.
- If you are diagnosed with epilepsy and start epilepsy medication for it, again you must not drive and must inform the DVLA.
- If you make changes to your epilepsy medication, this may also affect your driving licence and you should also inform the DVLA.

Tumours and Driving

The DVLA decision will depend upon the tumour type, whether or not the tumour is growing and what treatment is being given. Below are the general principles of DVLA decisions but this is guidance and does not replace the DVLA decision:

1. If your tumour is not causing any symptoms and was found as an 'incidental finding', the DVLA will assess your case and might allow you to continue driving. However, you must check this with them first.
2. If no active treatment is being undertaken, scans show your tumour is stable and you have no seizures the DVLA might allow you to continue driving.
3. If you have any type of surgery, you will not be allowed to drive for at least one year from the time of surgery.
4. If you have treatment for a Grade 1 or 2 tumour this results in one-year off driving from time of completion of that treatment.
5. If you have treatment for a Grade 3 and 4 tumour, this will result in at least two years off driving from time of completion of that treatment.

Useful general information

Brain Tumour Research and Support Trust have a support group who meet on the first Thursday of every month, 630 - 830 at the Crowne Plaza, Wellington Street, Leeds. LS1 4DL

Website: **http://www.btrs.org.uk/Home**

Epilepsy Action Freephone: 0808 8005050

Website: **http://www.epilepsy.org.uk**

Epilepsy Society Helpline: 01494 601 400

Website: **http://www.epilepsysociety.org.uk**

Contact the team:

For general queries about appointments / scans / letters ring:-

Low Grade Glioma Secretary: Val Allerton
Tel: **0113 392 8413**

For general queries about epilepsy / medication ring:-

Epilepsy Specialist Nurses: Elizabeth Wright and Jo Geldard
Tel: **0113 392 8128**

For general queries about chemotherapy / radiotherapy ring:-

Oncology Specialist Nurse: Lianne O'Malley
Tel: **0113 206 8830**

Please consider supporting the Neurosurgery Research Fund by donating to Leeds Cares, official partner charity of Leeds Teaching Hospitals.

Donations can be made on the Leeds Cares website here: leeds-cares.org/donate/

Please quote the fund number 3T28 to ensure your donation is allocated to the Neurosurgery Research Fund.

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