Information for patients, family and carers: Meningioma

What is a Meningioma?

A meningioma is a type of tumour that grows from the protective 'canvas-like' membrane (called the meninges) covering of the brain and spinal cord. These tumours are most commonly found in middle-aged or older people, and in particular in women.

Meningiomas in general are benign tumours, i.e., they are not cancers, are not fast growing, and will not spread elsewhere in the body. They are usually slow growing, e.g., often only increasing by about 2-3mm per year in their cross sectional diameter. Up to half of smaller meningiomas appear to be 'burnt out' and do not increase in size over many years. Because meningioma are usually slow growing tumours or not necessarily growing at all, not all meningiomas need to be treated immediately. Some meningiomas if very large and causing a lot of pressure on adjacent brain or nerve structures will need to be treated urgently.

Meningiomas tend to commonly grow inward, indenting and causing pressure on the brain or spinal cord. Occasionally, some meningiomas of the head can involve the adjacent skull causing thickening of the adjacent bone (known hyperostosis). Even when apparently completely removed surgically, a small percentage can have regrowth over subsequent years so follow-up brain scans are usually arranged. You can also have more than one meningioma.

What causes meningiomas?

For most people with a meningioma, the cause is unclear. These tumours are seen much more commonly in women and have an apparent relationship to female hormones.

Note that women with meningiomas may also at some point have other types of tumours that are female hormone driven at other body locations, e.g., breast cancer, fibroids of the womb. Thus regular checking for breast lumps and following up with the GP any breast lumps found, aswell as any low blood counts and irregular vaginal bleeding is important.

Rarely, there is a genetic cause or where there has been radiotherapy to the anatomic area concerned many years previously.

What symptoms may occur?

Symptoms are caused by compression of the adjacent brain. The brain tends to accommodate this compression over time and thus you may have noticed your symptoms appearing gradually over many weeks or months

The symptoms that occur depend on the location and size of the tumour within the brain or spinal cord. Patients may complain of any number of symptoms. These can include gradual worsening headaches over weeks to months, blurred or double vision, loss of smell and taste, fits (also known as seizures), personality changes (perhaps noticed by friends, family, or work colleagues), speech difficulty, bowel or bladder dysfunction, weakness in the face, arms or legs, or even pins and needles and numbness in the limbs.

Occasionally, an eye examination at an optician may reveal abnormalities, which then lead on to further investigation and diagnosis.

Sometimes meningiomas cause little or no symptoms and are discovered during a scan carried out for other reasons. This is called an incidental finding. As to whether a meningioma found in these circumstances needs treatment or simply follow-up with scans can depend on the size, location, and other scan features of the tumour.

How is my meningioma diagnosed?

You have been referred onto our care because a scan has been carried out to reveal a possible meningioma. Usually, a CT (computerised tomography) scan or MRI (magnetic resonance imaging) scan will be done to find the exact position and size of the tumour. The scan usually includes injection of a contrast material ('x-ray dye') into a vein to allow us to see the tumour better.

An MRI scan is often needed to allow us to evaluate the tumour in great detail and will also pick up any other small meningiomas. Generally, we have a good idea from an MRI scan that a particular tumour is a meningioma. Meningiomas do often have characteristic features on a scan

However, as and when such a tumour might be operated upon, we do send tumour to the pathologist at the time of surgery to confirm the exact type of tumour. Aswell as confirming a tumour is a meningioma, the pathologist will also grade the meningioma on the basis of its appearance under the microscope. Approximately 90% of meningiomas are 'grade 1' tumours. One in ten patients with this grade of tumour will have a small local recurrence of their tumour within ten years of surgery. About 10% of meningiomas are 'grade 2/atypical' and will have a higher chance of recurrence over subsequent years as compared to grade 1 tumours. This has a bearing on how frequent follow-up MRI scans are done over the years after surgery. Grade 2/atypical tumours will have an MRI every year. Whereas grade 1 tumours may have scans at longer intervals.

What are my treatment options?

If you have a meningioma of the floor of the skull underneath your brain, you will be seen by a consultant neurosurgeon of the skull base team. If you have a spinal tumour, you will be seen by a consultant neurosurgeon of the spinal tumour team. Otherwise you will be seen by a consultant neurosurgeon of the neuro-oncology team or if you are an acute hospital admission you will be dealt with by the consultant neurosurgeon on-call.

There are several options for your care once a meningioma has been identified. The most appropriate option depends on the size and location of the tumour; progression, extent, and reversibility of your symptoms; and your overall general health. Ultimately it is your choice to proceed with treatment once we have ensured that you fully understand the risks and benefits of each treatment option.

The main management options are observation, surgical removal, stereotactic radiosurgery (gamma knife), and occasionally radiotherapy.

Observation or interval imaging

Small, asymptomatic (i.e., with few or no symptoms or examination findings) meningiomas are often observed and followed with regular MRI scans with increasing scan intervals, e.g., starting with a 6 months gap, then 12 months, 12 months, and subsequently every two years. If the tumour remains unchanged on serial scans over years, no further treatment is required.

MRI is the best way of following meningiomas and does not involve any radiation exposure. Occasionally CT scans are used for interval imaging if MRI cannot be done, e.g., a patient has a pacemaker.

You should always keep your scan appointments even when your meningioma has not caused you problems for many years. Note please contact your consultant neurosurgeon's secretary if you have difficulties with making a scan appointment or your scan appointment is earlier than you anticipated or you do not receive an appointment for a scan when your scan date is due.

It may also be such that you do not need to come to a clinic appointment if your scan is unchanged as compared to previous and that the result of your scan can be communicated to in writing and arrangements can then be made for the subsequent scan. You should enquire with your consultant neurosurgeon or his secretary about the specific arrangements for communication of results and scan follow-up if you feel an appointment would not otherwise be required, in particular if you live at a distance.

Surgery

In many circumstances the principal form of initial treatment for a meningiomas is surgery. Surgical removal of meningiomas always has some risk, and growth or size of the meningioma or the progression of the symptoms should justify the risk

Surgery for a meningiomas within the skull involves a craniotomy, which means making a window in the bone in the skull to remove the tumour (see patient information leaflet on Craniotomy).

The general risks of cranial surgery include clot in the leg/clot in the lung ('DVT/PE') 1:100, infection 1:100, stroke/blood clot (with the possibility of permanent paralysis and also having a small risk to life) 1:100, brain swelling 1:100, and epilepsy 2-3:100. There maybe specific additional risks dependent on the nature and location of the meningiomas. There are a whole range of measures that the surgical team take to stop problems happening and a whole range of measures that are taken to reduce the impact when problems do happen. You will spend a day or two in the neuroscience intensive care/high dependency unit after your surgery (see patient information leaflet on Neuro-Intensive Care Unit).

We would expect you to be in hospital for about a week to ten days after your surgery.

After surgery we will carry out a further scan as an outpatient once you have recovered, usually an MRI around the three month mark. This will allow us to see if there is any tumour still left.

For meningiomas located near the surface of the brain, the tumour is usually completely removed. For meningiomas that are deeply located or adherent to important nerves or blood vessels, complete surgical removal may not be possible. Sometimes we have no choice but to leave a small piece of tumour if is stuck to important nerves or blood vessels. This is done to minimise the chance of complications. Any such remnant of tumour will likely be suitable to the other radiation-based treatment options described below.

Stereotactic Radiosurgery

Stereotactic Radiosurgery (STRS) is increasingly used instead of surgery to control small meningiomas in the head when growth on interval imaging is demonstrated. STRS involves the fixation of a stereotactic metal frame to the skull usually under local anaesthetic, repeating an MRI scan, and then treating the tumour using highly focused beams of gamma radiation.

Radiosurgery aims to stop the growth of the meningiomas, about a 90% chance, and occasionally does result in some tumour shrinkage. Radiosurgery does not get rid of the tumour and does not generally result in improvement in symptoms caused by the meningioma. Radiosurgery can be

given with less risk than surgery but the effects of radiosurgery take many months.

Radiosurgery is not suitable for all meningiomas either because the tumour is too large, is causing significant symptoms, or is close to a structure that could be harmed by radiosurgery (such as nerves to vision or brainstem).

Aswell as treating small incidental meningiomas that have been shown to grow on interval scans, radiosurgery is also sometimes used after surgery for larger meningiomas:

- In grade 1 meningiomas, if there is a small local recurrence or growth of a small post-operative tumour remnant on post-surgery interval scans.
- In grade 2 meningiomas, for any remnant seen on the baseline post-operative MRI scan or if a small local recurrence is identified on subsequent interval imaging.

Stereotactic radiosurgery is generally a single treatment planned and delivered all in one day with a one to two night hospital stay. This is carried out at the National Centre for Stereotactic Radiosurgery in Sheffield (see www.gammaknife.org.uk or patient information leaflet on Radiosurgery).

Radiation therapy

Radiotherapy, similar to that used in cancers elsewhere in the body, is occasionally used for meningiomas but is not a first line treatment. It is used for malignant meningiomas, which are rare. It may occasionally be used for 'atypical/grade 2' meningiomas when a tumour remnant or a tumour recurrence is too large for stereotactic radiosurgery or where your consultant neurosurgeon has additional concerns about risk of recurrence.

What should my expectations be over the long term?

We would expect that the majority of people with a meningioma to be able to have a normal life in terms of quality of life including employment and relationships and also to not have their lives foreshortened.

For example, approximately 95% of patients undergoing surgery for their meningioma will have no major problems.

You will likely require long term imaging follow-up over a number of years either because of the possibility of tumour growth or because there is a small risk of local tumour recurrence if you have had surgical removal initially.

Occasional patients will have additional issues that require assistance such as having to take anticonvulsant medication for epileptic fits. Depending on the meningioma location, a small proportion of patients may have permanent neurologic problems such as loss of smell/taste, visual impairment, limb

weakness or numbness, or gait unsteadiness. Such potential issues will be further outlined to you by your consultant neurosurgeon.

Is it safe for me to get pregnant if I have a meningioma?

Meningiomas can grow a little more during pregnancy because they are female hormone driven. It is normally safe to become pregnant and have a normal vaginal delivery if you have a meningioma or have had treatment for a meningioma but you should have a discussion with your neurosurgeon ideally when you are planning a pregnancy or as soon as you become aware that you are pregnant.

Note that if you have been put on an anticonvulsant medication for epilepsy, you should discuss with your neurosurgeon about coming off such medication prior to conceiving as there is a two to three times increased risk that such medication could negatively affect the development of a baby in the womb.

Can I take hormone replacement therapy?

There is evidence to suggest that hormone replacement therapy can encourage meningioma growth. You should avoid tablet forms of hormone replacement therapy and instead talk to your GP about other options.

How often and for how long will I be scanned?

If you have a meningioma that is being observed and not treated, you will generally be scanned at increasingly longer intervals for life or at least until you are at an age that you would not be fit for surgery or radiosurgery. If you have had surgery and there is no significant residual tumour and no subsequent local recurrence, you will usually be discharged after a ten period of follow-up.

Scan intervals vary depending on the nature of treatment and tumour location/grade. If disease is stable, initial scanning might be every year for two years, then every two years or even longer for example. Your particular interval scanning plan will be outlined to you by your consultant neurosurgeon.

Can I drive with a meningioma?

If you have been diagnosed with a meningioma, you will not be allowed to drive for a period of time if you have had an epileptic fit, have significant loss of vision, weakness in the arms or legs, episodes of confusion, or have had recent surgery.

You do need to contact the DVLA as early as possible after you have found out about your meningioma. If you have contacted the DVLA previously and they have permitted you to drive, you will need to contact them again if your condition with respect to your meningioma changes, e.g., you have an epileptic fit or you go on to have surgery for your meningioma.

The sort of period that you may not be allowed to for drive is six or twelve months. It is the DVLA that makes the decision concerning your driving including for how long you are not allowed to drive, **NOT** your consultant neurosurgeon. The hospital will not contact the DVLA. It is your legal responsibility to do so. You can contact the DVLA by phone on **0300 7906806** or at www.dvla.gov.uk. You should also contact your motor insurance company.

Is there anybody I can talk with to get further advice and information?

Your assigned 'key worker' can provide further advice and information. Your assigned key worker is usually either your consultant neurosurgeon or the specialist nurse or both associated with the specialist service relevant to your meningioma (i.e., Skull Base Service, Spinal Tumour Service, or Neuro-oncology Service). They should provide you with a means of contacting them. They can also provide you with copies of correspondence such as your clinic letters for your own records and additional information material such as further patient leaflets referred to within the text above.

You may wish to discuss your diagnosis with your GP.

The hospital also provides a chaplaincy service for different faiths or indeed if you do not belong to any faith group. Note that if you are an inpatient the chaplains will not automatically visit you, even if you belong to a particular faith group. If you would like to see a chaplain, please ask a nurse, relative or friend to leave a message on **0114 271 4999**.

In addition, there are some national patient information groups/charities who can offer further advice and information including:

- **Brain Tumour UK**
  Website: www.braintumouruk.org.uk
  Tel: **0845 4500386**
- **Meningioma UK**
  Website: www.meningiomauk.org
  Tel: **01787 374084**
- **Brain and Spine Foundation**
  Website: www.brainanspine.org.uk
  Tel: **0808 8081000**

This information sheet is to be used only in the context of attendance at or admission to the Department of Neurosurgery, Royal Hallamshire Hospital, Sheffield Teaching Hospitals NHS Foundation Trust. **Compiled by Mr Thomas Carroll, consultant neurosurgeon, 20th September 2012**