

# INFORMATION LEAFLET

# PRIMARY CENTRAL NERVOUS SYSTEM LYMPHOMA



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# WHAT IS PRIMARY PRIMARY CENTRAL NERVOUS SYSTEM LYMPHOMA?

This is a tumour that has grown from the tissue of the brain. Blood contains lots of different cells and some are used to fight infection. One of these cells is called a Lymphocyte. There are different types of lymphocytes. Some are called T lymphocytes and others are called B lymphocytes. The B cells are the type that generally cause Primary CNS Lymphoma. This tumour actually grow from cells within the brain rather than cells in the blood. It is called Primary because it has not spread from lymphoma elsewhere in the body.

These tumours usually grow around the Ventricles but can occur anywhere in the brain and can also occur in the eye. They can be associated with defects in the immune system.

## IS IT A MALIGNANT TUMOUR?

Malignant usually means that the tumour spreads to other parts of the body. The lymphoma grows locally but by the nature of its location behaves like a malignant tumour. It does not spread to other parts of the body.

# **HOW DO WE KNOW IT IS THERE?**

The tumour often causes problems with the brain Such as:

You may have had a seizure (fit)

It may be preventing part of the brain working (like a stroke)

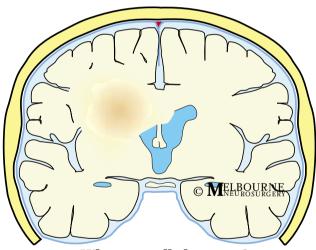
It may be causing headaches.

It very commonly causes confusion or inappropriate behavior.

The CAT scan is the first test and shows most tumours. If it does not show on the CAT scan an M.R.I. will be performed. Even when we know there is a tumour on the CAT scan we may still do an M.R.I. (more sensitive) to see how extensive the tumour is.

## **HOW DOES THE TUMOUR GROW?**

Unlike some tumours that grow as a lump (like a golf ball) the lymphoma has a tendency to also spread out into the surrounding brain. This means that the edge of the tumour is partly tumour and brain tissue.



What normally happens?

You have normally been seen by your local doctor and he has organised a CT scan otherwise you have presented to the emergency department. If your local doctor discovered the lesion in the brain he will send you for an opinion. At this stage it is only presumed that the lesion is a tumour (it could be infection or something else). Surgery is nearly always needed to find out exactly what the lesion is and the best way to treat it. You may either have a biopsy or total removal of the lesion depending on where it is in the brain.

Firstly you are started on DEXAMETHASONE. This is a steroid drug that will reduce the swelling around the tumour. Some of its' side effects are to make you hungry and also to give you the hiccups. Your symptoms of e.g. headache / weakness usually improve on these. The other drug we give you is an ANTI - EPILEPTIC. This is because the tumour may irritate the brain and cause a seizure (fit). The fit may have been the reason the lesion was found in the first place. Sometimes the tumour may disappear with Dexamethasone.

If you have not had an M.R.I. then this is organised. If you are not well and need urgent treatment the M.R.I. may be done after surgery and the CAT scan used for the procedure.

#### After the M.R.I:

- (i) If the lesion is near the surface, in a relatively silent area of the brain and can be reached then surgical removal is planned.
- (ii) If it is difficult to reach and remove safely then we would plan a stereotactic biopsy (computer guided needle biopsy)to confirm the diagnosis(see surgical leaflet).

# Why surgery?

The first step is to find out what type of tumour you have. The more that we can remove the less there is to treat with other methods.

The tumour cannot usually be removed totally with surgery.

If the tumour is large it may be compressing the brain to cause either weakness or drowsiness. Hopefully any weakness that you have is from compression and not invasion of the important parts of the brain.

Because of the nature of the tumour and the way it grows the aim is to remove what is safe.

The bulk can be removed and this will remove the pressure on the surrounding brain. With this the swelling in the brain goes down substantially. If your weakness is due to pressure this usually gets better in the next few days after the surgery.

The Surgery is usually a Craniotomy and Excision of the tumour (see Operation Leaflet CRANIOTOMY FOR LYMPHOMA).

#### After the surgery

The tissue is sent to the Pathologist. He will tell us what the tumour is. Once diagnosed further treatment is planned. You will be referred to a specialist Radiation Oncologist who will recommend the treatment course. The steroids are usually reduced to a small dose during your radiotherapy and then we try to remove them completely. It is common to remain on your anticonvulsant. There is usually the need for Chemotherapy as well. This may be given before the radiation in some cases and it may be the only treatment initially.

#### **RADIOTHERAPY**

Its aim is to slow down the growth of the tumour. The tumour usually responds well to irradiation. The radiation causes hair loss/some dizziness and makes you drowsy.

#### **CHEMOTHERAPY**

This is given to most patients. It is a specific type of chemotherapy (given by a Medical Oncologist). Some of the treatment may be experimental and you may be offered these when the established drugs fail. It is common to be involved in a trial for some types of drug.

# What happens next?

You will have a series of CAT scans to watch the tumour. A lumbar puncture may be done to follow up the response to treatment. If the tumour comes back you can have further surgery/chemotherapy/radiosurgery but radiotherapy can only be given once. If the tumour comes back quickly after the surgery/radiotherapy this is a bad sign. You will be followed up with CT scan at about 3 months. The timing of the next scan depends on the results of this. If your symptoms return early the scan is done earlier.

# Who follows you up?

Normally everybody involved. If you are stable the Neurosurgeon may have the Oncologist look after you but if there are any problems you will sent back to the Neurosurgeon. You will probably have three specialists watching your brain.

Neurosurgeon Medical Oncologist Radiation Oncologist And your Local Doctor will be keeping an eye on everything else.

#### **PROGNOSIS**

This depends on a few major criteria Your age has an effect in certain tumours. The location of the tumour, if it is in an important structure deep in the brain the prognosis is worse. If it comes back quickly after surgery the prognosis is worst.



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