Support groups

There are both national and local brain tumour support groups running. There are also telephone support lines and internet forums available. Please ask your specialist nurse for a list if you are interested in attending a support group. They are open to family/carers as well.

Other formats:

If you would like this information in another language, large print or audio, please ask the department where you are being treated, to contact the patient information team: patient.information@addenbrookes.nhs.uk.
Please note: We do not currently hold many leaflets in other languages; written translation requests are funded and agreed by the department who has authored the leaflet.

We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site.
For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Document history

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Innovation and excellence in health and care
Addenbrooke’s Hospital I Rosie Hospital
About this leaflet
This leaflet explains the post-surgical care and follow-up advice for patients who have had an operation for a brain tumour. It includes frequently asked questions about everyday activities such as work and driving. Government guidelines state all patients need to have access to a key worker. For the purposes of this document, your key worker is your specialist nurse.

Wound care and hair washing
In most instances, your wound will be closed with self dissolvable (absorbable) sutures. This means you do not need to have any stitches removed as they dissolve over a period of a few weeks. During this time, a stitch or two may protrude from your wound as they begin to dissolve. This is normal and they should be left alone.

If you have skin staples in place, these will need to be removed by your practice nurse at your GP’s surgery. You will need to arrange for this to be done - usually seven-ten days after your operation. Please check with your specialist nurse for advice or check your discharge summary for further information.

Your wound will feel sore for a few weeks. It is normal for the skin around the wound to feel strange. This is a result of damage to the local nerves. It usually returns to normal in six to eight weeks. If you require any pain killers, please contact your GP for a prescription. Always contact your specialist nurse and GP if your headaches are not helped by simple painkillers, such as paracetamol.

You can start gentle swimming as soon as you feel able. However, we advise you to not submerge your head under the water if you are within six weeks from surgery. This is to ensure adequate wound healing and watertight closure of your wound. If you suffer from seizures (fits) we advise you never to swim alone. Always let a lifeguard or someone at the pool area know of your condition.

Help with the costs – are you entitled?
There are lots of benefits that may be available to you. This depends on your diagnosis and any other medical condition(s) you may have. For instance, if you have diabetes and/or epilepsy you are entitled to receive free medical prescriptions on all your drugs (apart from dental treatment or eye tests). Please fill in form FP92A which is available from your GP surgery. Macmillan produce a booklet titled ‘Help with the cost of cancer’. Please ask your specialist nurse for a free copy.

Contact numbers
Please do not hesitate to contact any of the numbers below if you have any questions or concerns regarding any aspect of your neurosurgical care. We are here to help.

Neuro Oncology Specialist Nurse (direct dial with answering machine): 01223 256246 or via Addenbrooke’s contact centre 01223 245151 via bleep 154-506.

Clinical Nurse Practitioner: 01223 216127 or via Addenbrooke’s contact centre 01223 245151 via bleep 152-090.

Team Secretary (direct dial with answering machine): 01223 216780.

Neurosurgical bed-manager via Addenbrooke’s contact centre 01223 245151 via bleep 156-0908 (out of hours only in an emergency).
**Sex and Alcohol**

It is safe to resume sexual activities once you feel able. However, if you have had Carmustine chemotherapy wafers inserted, we advise against becoming pregnant or fathering a child for at least six months after treatment. Please see our separate information leaflet titled ‘Carmustine Chemotherapy wafers (Gliadel)’ or contact your specialist nurse for advice if this applies to you. Drinking small amounts of alcohol both before and after your operation is safe. However, some people report feeling the effects of alcohol quicker when on Dexamethasone (steroids) and following surgery. There is an increased risk of you having a fit / seizure if you drink to excess. We advise drinking within safe, legal limits.

**Driving**

You are required by law to inform the DVLA of your established diagnosis. This will determine the length of time you are unable to drive. **Failure to notify the DVLA is a criminal offence and is punishable by a fine of up to £1,000.** We are bound by the DVLA legal restrictions and have no ability to influence their decision. For further information (including who to write to and what to say), please refer to our booklet entitled ‘DVLA driving regulations: Brain tumours’.

**Flying/Swimming**

We advise you avoid flying for six weeks after your operation. This is because the pressure difference and lower oxygen levels on-board the aircraft cabin can sometimes trigger a seizure. If you intend to fly within this time scale, discuss this with your specialist nurse. You will need to inform the airline and insurance company of your condition and operation.

You can gently wash your hair with a mild baby shampoo two days after surgery providing you have had no wound healing problems. Please do not use the antimicrobial wash on your wound. Mild shampoo is used to lessen any irritation of the skin around the scar. Please do not rub the wound dry with a towel as this can cause it to open up. Gently pat it dry. The steri-strips (the tape covering your scar) should be removed after your first hair wash at two days post-operatively. We recommend you avoid hair dyes for a month as they will irritate the scar.

All wounds heal differently, and this partly depends on the type of surgery you have had and the size/location of your tumour. If you have had Carmustine (Gliadel) chemotherapy wafers inserted, please refer to our additional patient information leaflet titled ‘Carmustine Chemotherapy wafers (Gliadel)’ as you will need to be aware of extra precautions.

Please contact your specialist nurse for advice if you notice any of the signs and symptoms below:
- Redness and increasing pain around the wound.
- Leaking/bleeding from the wound (especially a persistent watery leak – see CSF section below).
- A raised temperature.

We will liaise with your GP should you require any antibiotics, but we will need to be informed first.

**CSF leaks**

CSF stands for Cerebro-Spinal Fluid. This is the fluid that surrounds your brain and spinal cord. It provides it with nutrients and energy.
After an operation to your brain, this fluid can sometimes leak from your wound. Our concern is that whilst this CSF fluid can get out, bacteria normally living on your skin/scalp can get in. Sometimes this can cause significant infection problems, which in turn may cause delays to any further treatment you may require.

CSF leaks are normally easy to spot. It looks like a watery, persistent leak, sometimes described as trickling tears. It is usually colourless and odourless. It may leave a dried ringmark on your pillowcase for example.

Should you develop a CSF leak, **we will need to readmit you** to stop the leak and prevent an infection. We would like you to contact us straight away, as your GP will not be equipped to deal with a CSF leak. If you have had Carmustine chemotherapy wafers inserted and have a CSF leak, please also read our other information leaflet titled ‘Carmustine Chemotherapy wafers (Gliadel)’ as you will need to take extra precautions.

**Discharge advice and getting home**

You will be allowed home once the medical and nursing staff are happy with your recovery. This usually includes physiotherapy and occupational therapy assessment to ensure you can manage basic tasks at home, such as getting in and out of bed and climbing stairs.

Before you are discharged, you will need a post operative MRI or CT scan. This is to check on your progress and to ensure there are no surgical reasons for keeping you in hospital longer.

In East Anglia we currently have three centres that undertake medical/oncology treatment for brain tumours. They are Addenbrooke’s Hospital (CUHFT); Norfolk and Norwich Hospital (NNUH) and Ipswich hospital. Sometimes, we can arrange for further care to be undertaken at the Mount Vernon Centre in Hertfordshire. Addenbrooke’s hospital is the only hospital in East Anglia that offers surgery for brain tumours.

Because we are part of a region-wide team, we try to arrange for any further care to be carried out as close to your home as possible. Should you require further treatment, we will arrange for your onward referral to the appropriate centre. We will also advise them of the type of regime that has been recommended as part of our MDT discussions. Please speak to your specialist nurse if you have any queries or concerns regarding your ongoing care.

**Returning to normal**

You may return to light domestic work and exercise as soon as you feel fit. We recommend you avoid contact sport such as boxing, football and rugby for around three months. Rest when your body feels it needs to – be sensible and do not overdo it! It is normal to have good and bad days; this is part of your recovery process.

If you work, how quickly you are able to return to work will depend on the physical demands and skills required, as well as consideration for the health and safety of both yourself and others. If you intend to return to work, it is best to discuss this with your surgeon or specialist nurse. We can provide you with a sick note to cover your hospital admission and immediate period afterwards. Your GP will need to sign you off work for a longer period if required.
Getting your results

We appreciate that waiting for your results is a very stressful time filled with anticipation and uncertainty. For this very reason we never give results over the phone. Once your results are available, we will invite you to attend the clinic. This is usually the Thursday a week following your operation. It takes seven - ten working days for your results to become available to us.

We recommend that you bring a family member and/or a friend along with you to your appointment. This is so they can support you, listen to the conversation and ask questions. Often patients do not entirely remember what has been said about any further treatment which may be required. You may wish to bring a pen and paper with you. Please refer to our other patient information booklet entitled: ‘Undergoing Neurosurgery’ for further information about how results are obtained.

Onward referrals

Your results are discussed with a panel of experts in a multidisciplinary team (MDT) meeting before your results appointment with us. This means your diagnosis will have been established, and any further treatment which you may require will have been discussed. In some instances, this may mean further treatment such as radiotherapy or chemotherapy. In other instances, the operation and post-operative monitoring is all that you will require.

This will be arranged as soon as possible and will be done whilst you are an inpatient on the ward. In most cases, you will be allowed home one to two days after your surgery. Please ensure you are given a copy of your discharge summary as this contains information about all the drugs you need to take.

Should you require further care such as rehabilitation, we will arrange for you to have ongoing care at a place closer to home.

Please pre-arrange for a friend or relative to collect you on discharge from hospital. Hospital transport is only available in exceptional circumstances and for inter-hospital transfers. Please speak to your specialist nurse or nurse-in-charge as soon as possible if you think you will have problems with transport.

Repeat prescriptions

You will be discharged with a limited supply of drugs from hospital. Your GP will need to continue to dispense any drugs started by your neurosurgeon. Please ensure they are given adequate notice to arrange for any repeat prescriptions such as Dexamethasone. Please refer to our other information leaflet titled ‘Taking steroids’ for in-depth explanation of how/when to reduce your Dexamethasone dose.

If you have any queries or concerns about your drugs, please ring your specialist nurse for advice. It is important you do not run out of your medication. You will find all relevant contact numbers at the end of this leaflet.