

Going home after brain tumour surgery

A discharge guide for people with a brain tumour



Introduction

Going home after brain tumour surgery can feel quite overwhelming. We know there can be a lot of information to process and you may find that you have more questions, or need additional information or support.

This leaflet provides information and answers to questions often asked by people after brain tumour surgery.



CARE CAN'T WAIT

If you'd like to talk to someone about how you're feeling, or would like to find out where you can get further support (including details of support groups), you can contact The Brain Tumour Charity's Information and Support Team:

Phone: **0808 800 0004**

(free from landlines and most mobiles)

Email: **support@thebraintumourcharity.org**

Live chat: **thebraintumourcharity.org/live-chat**

Website: **thebraintumourcharity.org/getsupport**

Closed Facebook groups:

thebraintumourcharity.org/facebook-support

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The content of this guide was provided courtesy of Alison Rodway, Clinical Nurse Specialist at the Walton Centre NHS Foundation Trust, Liverpool. Additional material was provided by Collette Crompton, Macmillan Clinical Support Co-ordinator, and the Information and Support Team at The Brain Tumour Charity.

Going home - the next steps

When you get your biopsy results confirming your tumour type will vary between hospitals. Often, they won't be available before you go home.

Speak to your healthcare team about when you're likely to get them. If you haven't received them before you go home, the team will be in touch to arrange a time for you to go to the clinic and discuss your results. This appointment is usually arranged by your Clinical Nurse Specialist (CNS) or your consultant's secretary.

We understand that this can be a difficult time and you may want to talk about how you're feeling after surgery.

Please remember that your healthcare team are there to help and are always happy for you to contact them for advice and support, no matter what you need.



Any question is fine to ask - so don't be afraid to voice any worries or concerns you have.

You can also talk to The Brain Tumour Charity's Information and Support Team - contact details are on page 2 of this booklet. We can be a listening ear and also help you find further support (such as our closed Facebook groups and other support groups).

Holistic Needs Assessment (HNA)

You may have already had an HNA, either before or during your hospital stay. If not, and you're worried about how you'll cope when you leave hospital, you can ask for one before you leave (or at any time).

A Holistic Needs Assessment (HNA) is a chance to look, with your healthcare team, at your needs and concerns about the help and support you might need following diagnosis and treatment. Together, you and your healthcare team can work out how best to meet these needs and concerns and write it down in a care plan.

An HNA looks at all aspects of your life:

- physical
- emotional
- practical
- financial
- spiritual.

Speak to your CNS (Clinical Nurse Specialist) or key worker about this.

Some hospitals do this electronically using the Macmillan eHNA tool.

Symptoms

No two people will feel exactly the same after surgery. Some people may recover very quickly, while others may take longer. But, most people experience **some common symptoms**, which we've listed below:

- **Tenderness and numbness around the wound area**
- **Mild headache**

This should be relieved effectively with simple painkillers such as paracetamol. If not, contact your healthcare team or GP.

Both of these symptoms should improve a little each day.

- **Swelling/bruising**

This may be seen around the eyes and face. This can look alarming, but isn't a cause for concern. It will gradually fade in the days or weeks ahead.

- **Tiredness (fatigue)**

Tiredness is very common following any brain surgery and regaining good energy levels can take some time. Some tips to help with this are:

- Allow yourself time to recover and don't try to do too much too soon.
- Try to build up your stamina and exercise tolerance gradually – a gentle walk can be a good place to start, but take someone with you the first few times in case you need help. Gentle exercise is good for you and will help your overall recovery.
- Eat a balanced diet and keep yourself hydrated with regular sips of water or juice.



If you find that the following symptom continues in the months ahead, you should contact your Clinical Nurse Specialist (CNS) for further advice.

- **Noises or whooshing sensation**

During your recovery time, you may notice some unusual sensations in your head as things are settling down. These are often described as “crackles, pops, whooshes or drips”. If you’ve had surgery near your ear, you may experience a dull earache.

All these symptoms should usually settle down over time.

Remember everybody is different and the time you take to recover from any symptoms may not be the same as other people.

Symptoms to watch out for

You should look out for these symptoms once you've gone home. They may need medical attention.

- Your wound becoming red, sore or leaking any fluid or pus.

If it's leaking clear fluid or pus, you'll need to ring the hospital immediately, so that your healthcare team can assess it more fully.

- A soft fluid-like swelling behind or close to the scar may develop.

This is brain fluid collecting under the skin. It's called a pseudomeningocele. It will usually settle on its own, but ring your healthcare team for advice.

- Nausea or vomiting.
- Severe or worsening headache.
- New, worsening, different or more frequent seizures (epilepsy).
- Limb weakness.
- Aphasia (difficulty understanding and producing language).



If you experience any of the symptoms listed, you should contact your healthcare team straight away.

Make sure you have the contact numbers for your team (CNS or key worker) and out-of-hours service on your phone, or to hand. You can record them on the **Contacts you may need page of this booklet (p23).**



Frequently asked questions

When will the stitches (sutures) or clips be taken out?

Usually 7-10 days after surgery.

This will usually be done by district nurses who visit you at your home. Or you can go to your local treatment centre, depending on the services available in your area.

If you've had previous surgery or radiotherapy, the stitches may be left in a little longer. This will be discussed with you before you go home.

The ward staff will tell you the date your stitches or clips are due to be removed and who will be performing this.

If you have dissolvable stitches, these are usually inserted inside the scalp, so you're unlikely to be aware of them. Occasionally they will be inserted into the scalp. They usually dissolve after 2-3 weeks. Try to avoid touching the suture line (line of stitches).

See also the *When can I wash my hair after surgery?* section on page 12 of this booklet.

Do I need to keep taking my anti-seizure medication after my operation?

Yes – this is very important. You should keep taking this, even if you haven't had any further seizures. Some patients need long-term, anti-seizure medication; others for just a few months following surgery.



Anti-seizure medication should only be stopped on the advice of your medical team and should be continued unless you've been advised differently by your consultant.

Do I need to keep taking my steroids after I go home?

Yes. It's important that you keep taking your prescribed dose of dexamethasone (steroid).

You'll be given specific instructions to either:

- reduce the dose over a set time until you're no longer taking any steroids, or
- reduce to a specified dose of dexamethasone tablets until your clinic appointment.

DON'T stop taking steroids suddenly!



Make sure you continue with stomach-protecting tablets while taking steroids. If you need more detailed information, speak to your healthcare team.

The discharge team will explain all your medications, i.e. when, how often and how long to take them for. If you have any trouble taking them or experience severe side-effects, contact your healthcare team for advice.

While in hospital my blood sugar levels were checked every day. Will this continue?

Yes (while on dexamethasone). If you're still taking dexamethasone at home, the ward staff will arrange for your local district nurses or practice nurse to monitor your blood sugars at home.

Blood sugar levels don't necessarily have to be checked every day. How often they're checked will depend on what your blood sugar levels were during your hospital stay.

When can I wash my hair after surgery?

You need to wait at least 48 hours, but 72 hours is better.

Use a gentle shampoo, such as baby shampoo, or the hair wash provided to you before coming into hospital. And be careful not to rub around the wound area.

It's not a problem if some water runs onto the wound - you can gently pat the area dry with a clean towel.

If there's been any leakage from the wound, or you've had previous surgery, you may be advised to wait a little longer before washing your hair.

If you have dissolvable stitches in your scalp (rather than inside your scalp), you can wash your hair as above, but don't put shampoo over the suture line (line of stitches).

When can I dye my hair again?

You need to wait at least 6 weeks. This is to make sure your wound is fully healed.

However, if you're going to be starting chemotherapy or radiotherapy, you'll need to discuss this with your oncologist.

How long before I can fly?



It is strongly advised that you seek your doctor's advice on whether they believe that you're fit to fly, before booking any travel arrangements. And also speak to your airline.

There are no specific guidelines regarding the minimum time before you can fly.

However, brain surgery can leave air temporarily trapped in the skull. Due to the altitude and change in cabin pressure during a flight, this air can expand causing a notable headache. Most people prefer to wait to avoid this.

According to the Civil Aviation Authority (CAA), which is responsible for air travel safety, it's advisable to avoid air travel for approximately 7–10 days following brain surgery. This is because it generally takes 7-10 days for this air to dissolve away.

However, the general advice from the NHS is to wait until around 6 weeks from your operation and you've made a full recovery from your treatment before flying.

Different airlines may also have different rules, so it's advisable to talk to your consultant and your airline first.

It's also important to tell your travel medical insurance provider about your condition/treatment and to confirm that you would be covered in the event of any recurrence or complications arising from the tumour or treatment.

For more information about travelling abroad and travel insurance, see our Travelling series of webpages: **thebraintumourcharity.org/maintaining-your-independence**



If you're going to have any additional treatment, you should discuss this with your oncologist. This will make sure that your travel plans don't coincide with your treatment.

When can I drive again?

This depends on a range of factors including:

- the type of tumour you have/had
- the type of operation you had
- the symptoms you've been experiencing.

This can be very difficult to adjust to, but it's very important that you don't drive.

Driving restrictions are laid down by the DVLA (Driving and Vehicle Licensing Agency) in England, Wales and Scotland. In N. Ireland they're laid down by the DVA (Driver and Vehicle Agency).

You need to tell them, once you've been given your final results, about the type of tumour you have. It's advisable to surrender your licence at the same time.

The decision about how long you must not drive for will be made by the DVLA (or DVA), NOT by your doctor.

You can find more information about driving after a brain tumour diagnosis and treatment on our webpage and fact sheet: Driving with a brain tumour.

thebraintumourcharity.org/driving-and-brain-tumours

To contact the DVLA:

Tel: **0300 790 6806**

Mon-Fri, 08.00-17.30;

Sat, 08.00-13.00

gov.uk/driving-medical-conditions

To contact the DVA:

Tel: **0300 200 7861**

Mon-Fri, 09.00-17.00

nidirect.gov.uk/information-and-services/driver-licensing/medical-conditions-and-driving

When will I be able to return to work?

This will depend on:

- the type of tumour you've been diagnosed with
- your recovery following surgery, which is affected by:
 - the type of procedure used for surgery
 - the areas of the brain affected by the surgery
 - the location of the tumour
 - your overall health and age
- the type of job you do
- any future treatment planned.

Most people need at least 6–12 weeks off work. This can be longer, e.g. if you drive, work at heights or with machinery for your job, or if you're having any other treatment.

You'll be able to discuss this with your doctors and CNS to make plans that best suit your personal circumstances.

It's also useful to discuss this with your employer before your surgery. At The Brain Tumour Charity we have our Employment resources, which include tools to help your employer and colleagues understand the possible effects of a brain tumour and its treatment. They also include suggestions for 'reasonable adjustments' to help support you in your return to work, if you need them.

thebraintumourcharity.org/employment-support

If you're worried about financial issues, see the financial support section on our website:

thebraintumourcharity.org/financial-support

Will I need to have further scans after my surgery?

Yes. The frequency of these will depend on the type of brain tumour you've been diagnosed with and will therefore be individual to you.

Initially, scans may be done more frequently, but over time the interval between scans may become longer. Your healthcare team can advise you on this.

For more information, see our Scans webpage and fact sheet:

thebraintumourcharity.org/scans-adults



Other information

Your therapy team

You may have seen an occupational therapist (OT), physiotherapist (physio) or speech and language therapist (SLT) during your admission to hospital. They are healthcare professionals concerned with helping you to be as independent as possible with everyday activities, such as:

- walking
- balance exercises
- managing stairs
- dressing
- cooking
- shopping
- leisure activities
- work.

As well as giving you advice, the therapists may arrange for you to have equipment, such as walking aids, to assist your recovery.

If you saw a therapist during your stay, they'll have discussed with you any ongoing referrals or recommended treatment.

If you **didn't** see a therapist during your inpatient stay, you can discuss any concerns with your CNS (Clinical Nurse Specialist) or GP, who'll be able to refer you to your local area teams.

Long-term support

If you find you're having some lasting symptoms or worries following surgery, contact your CNS team, who'll be happy to see you in clinic to discuss this in detail.

You can use this consultation to update your Holistic Needs Assessment (HNA), if you've already had one. Or you can use this as a Holistic Needs Assessment. For more information, see page 5 of this booklet.

Many patients find this consultation very useful, as it provides time for you to talk about the things that are impacting your overall recovery. It's led by how you're feeling. This can be a positive step forward in your recovery process and can take place at any point after your operation.

The appointment can take place face-to-face or over the phone. Contact your healthcare team if you'd like more information about this.



Your CNS team should routinely offer an appointment for a Holistic Needs Assessment.

This doesn't depend on the type of tumour you've been diagnosed with and is entirely voluntary.

This is a good opportunity to talk about how you're feeling and any symptoms you may be experiencing following surgery.

Additional treatment following surgery

In some cases following surgery, it'll be necessary to have additional treatment. This could be radiotherapy, chemotherapy or a combination of both. Your treatment options will be discussed with you.

If such treatment is recommended, you'll be given an appointment with an oncologist once they have all the results about the tumour you've been diagnosed with.

Clinical trials

A clinical trial is an experiment that involves patients in a new way of managing a condition. This might include investigating a new treatment, a new way of giving an existing treatment, or a new approach to diagnosing illness or assessing an outcome after treatment.

If this is something you might be interested in, ask a member of your healthcare team about current research and clinical trials.

Please be aware that many people can't take part in a clinical trial. This can be for various reasons, such as lack of a suitable trial in your area or for your tumour, or your not meeting the strict eligibility requirements. Also the standard treatment may be most appropriate for you.

For more information, see our Clinical trials webpages and fact sheet:

thebraintumourcharity.org/clinical-trials

Alternative approaches to helping recovery

People often ask about alternative treatments to help in their recovery.

We understand that you may want to look at these options, but it's important to keep in mind that they're not fully supported by medical evidence and they may interfere with your standard treatment. Speak to your healthcare team.

Ketogenic diet

This is a diet that encourages low carbs (carbohydrates) and increased fats. It's being trialled by some specialist centres.

For more information, see our Diet and brain tumour webpage and fact sheet:

thebraintumourcharity.org/diet

Also, the charity Matthew's Friends, has a dietitian who specialises in ketogenic diet therapies.

matthewsfriends.org

Cannabis oil

The use of cannabis oil is highly publicised and many people want to know more about this option.

At this time, although there's evidence for cannabis treating some side-effects of a brain tumour, i.e. pain and chemotherapy-induced nausea and vomiting, there's no supporting evidence for the treatment of the tumour itself.

It's important to remember that cannabis-based products have NOT been licensed for people with brain tumours.

For more information, see our webpage about Cannabis derivatives: thebraintumourcharity.org/emerging-treatment/cannabis-derivatives

Your GP

Your GP will be told about your stay in hospital. They will receive a:

- treatment summary
This gives details of your surgery, progress to date and follow-up plans. It will be sent to your GP when you're discharged from hospital.
- medications summary
This gives details of any medications that have been started or changed during your hospital stay.

Contacts you may need

Use this section to record information about contacts you may need.

Appointments:

Scans:

Where can I turn for help and support?

CNS Team:

GP and Practice Nurse:

The Brain Tumour Charity website:

thebraintumourcharity.org/brain-tumour-diagnosis-treatment

thebraintumourcharity.org/living-with-a-brain-tumour/get-support

The Brain Tumour Charity closed Facebook groups:

thebraintumourcharity.org/living-with-a-brain-tumour/get-support/online-support-groups

Local support group:

About this information resource

The Brain Tumour Charity is proud to have been certified as a provider of high quality health and social care information by The Information Standard - an NHS standard that allows the public to identify reliable and trustworthy sources of information.

Written and edited by our Information and Support Team, the accuracy of medical information in this resource has been verified by leading health professionals specialising in neuro-oncology. Our information resources have been produced with the assistance of patient and carer representatives and up-to-date, reliable sources of evidence.

We hope that this information will complement the medical advice you've already been given. Please do continue to talk to your medical team if you're worried about any medical issues. If you'd like a list of references for any of our information resources, or would like more information about how we produce them, please contact us.

We welcome your comments on this information resource, so we can improve. Please give us your feedback via our Information and Support Team on 0808 800 0004 or support@thebraintumourcharity.org

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About The Brain Tumour Charity

Going further for a cure

As the UK's leading brain tumour charity, we're here to accelerate a positive change in how people affected by brain tumours are diagnosed, supported and cured.

At The Brain Tumour Charity, we believe that no-one should have to live with a brain tumour or lose a loved one to a brain tumour. Advances in both treatments and quality of life care need to be made - and they need to be made quickly.

We know that if we put our heads together, we're more than up to the challenge. So we're building a movement of people from every walk of life - all coming together to accelerate a cure.

Find out more and get involved:
thebraintumourcharity.org



**WE'RE
HERE FOR YOU
AT EVERY STEP**

thebraintumourcharity.org

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