



How to prepare for hospital discharge

brainstrust information sheet

Know Hows are published by *brainstrust* to help people living with a brain tumour to understand current topics. They are produced with input from relevant scientific and clinical experts and are written in a way that should help you to understand often complicated topics.

If you have an idea for a Know How, then please let us know.

If you have any queries, don't forget you can talk to one of our support specialists on **01983 292 405**, or email **hello@brainstrust.org.uk**.

Why do we need this Know How?

We know that there is a lot to think about when you or your loved one is being discharged from hospital. This can understandably leave you feeling quite anxious and not knowing where to start. This Know How will cover some ideas about how to ease this worry and help you feel more confident about the transition.

What can I do to feel prepared?

Adapting your environment

It is a good idea to make living at home as simple as possible. You can do this by ensuring easy access to all necessary items and areas and preparing ready-made meals. Being able to do things easily will help with settling back into living as independently as possible.

Creating a sanctuary as a space to rest in with a good selection of blankets and pillows can be helpful if you or your loved one is experiencing fatigue. You can find more information about how to create a sanctuary in our '[fatigue book](#)'.

Investing in a supportive pillow and covering any headboards can provide additional

reassurance and comfort. Synthetic coverings provide more support and less give, which may also allow greater comfort. Having this in the car for the journey home may provide an added sense of protection.

Practical arrangements

On being discharged from hospital, you may be given various medications. To make these easier to manage at home, you could create a space to store and organise medication. Pill organisers, calendars and labelled boxes are an excellent way to keep on top of medication. Additionally, writing a schedule of medication for the day can be useful, as doses can vary as the days progress, and you can tick them off as you go. Having someone to assist in administering medication may also help you to make sure that the correct doses are taken at the correct times.

A discharge plan will be agreed with the ward team before you leave the hospital. This is to identify things such as what to expect with the appearance of a wound, additional dressings, cleaning information and what assistance you will need at home so that it is a smooth transition. This may therefore include an

assessment with health professionals, such as an occupational therapist. They will be able to help you make adaptations to your home, such as installing handles or a shower stool, which can support you with unsteadiness or fatigue.

Arranging home care can also ease some of the pressure. Home carers can visit you weekly or even daily to ensure that you have everything you need and help with tasks. You can arrange this through your local authority or an occupational therapy assessment.

What can I do if the hospital stay is due to having surgery?

To-do list before surgery

	Date	Comments
Speak to my surgeon or a consultant on duty, and ask the questions I want to ask (e.g. How soon can I play football?).		
Speak to my occupational therapist to arrange an assessment.		
<ul style="list-style-type: none"> – Ensure that my house is ready: – Will I have food at home? – Have I removed any hazards? – Will my bed be comfortable enough? 		
Inform the nurses or the ward clerk if I need transport.		
Speak to my clinical nurse specialist about any concerns I may have.		

Knowing what to expect after surgery

General anaesthetic can affect memory, concentration, sleep pattern, energy levels, bowel movements and reflexes for a day or two. This can be quite exhausting, so you may find you sleep a lot to reset. It is important that there is a responsible adult around for at least 24 hours if you are discharged home during this time. Do not hesitate to contact your GP or clinical nurse specialist (CNS) if you have any concerns.

Paracetamol may be recommended to ease headaches, as there can be discomfort or a strange feeling where staples or stitches are in the wound. You may also be supplied with a staple-removing tool, ready for when it's time to visit your local clinic to have staples taken out.

There may be some loss of concentration to begin with. This is to be expected and will improve. The time frame of this may not be specific, depending on the location of the tumour.

There may also be a slight buzzing sensation and twitching of the body, which again will subside over time. Feeling nauseous or vomiting, hearing a gurgling noise when you move or experiencing pain when chewing is also completely normal.

Check with your clinical team about when you can wash your hair, as advice can vary depending on whether sutures or staples are used for your surgery. Baby shampoo can be gentler on the skin, as other products can sting and be uncomfortable. Pat your hair dry to avoid rubbing off any scabs, and avoid direct heat from a hairdryer for the first two weeks.

You may find it's best to avoid caffeine and alcohol for the first few weeks after surgery, or have these in small quantities or consume low-alcohol alternatives, as you will feel the effects sooner.

Symptoms following surgery that you need to raise with your clinical team:

- blurred vision
- confusion
- persistent vomiting
- high temperature/fever
- sleeping all the time
- severe headache
- wound problems (increasing pain, swelling, discharge or air escaping)
- development of new or worsening symptoms (weakness, numbness)

What can I do to adjust back to daily life?

Identify what matters most to you

Talk to your clinical team about any hobbies and pursuits that you would like to get back to, and find out when it is reasonable to expect to be able to do this. You may also wish to ask your clinical team about what they would advise around driving. You can find out more information about how to inform the DVLA in our '[Driving](#)' Know How.

Returning to work might be right at the front of your mind following a hospital stay, especially if you're self-employed. The amount of time that you will be off work will depend on the nature of your employment. Some people will go back sooner than they were initially signed off for. However, this will usually be at a reduced capacity or for shorter working days. You can find out more about reasonable adjustments in our '[Returning to work](#)' Know How.

Identify who is in your team

When returning to a family home, it is a good idea to speak together as a family to work out how you can support one another. You might also like to set up a messaging group to keep your loved ones updated.

If you live alone, it is a good idea to make neighbours and nearby friends and family aware. Everyone needs help every now and then, and it can be very comforting to know that there is someone nearby who can help if needed. You can find more information on how you can grow your support network in our '[How to feel part of a community](#)' Know How.

Keep the CNS team and neurosurgery ward telephone numbers to hand. Never feel like you're wasting the staff's time or causing trouble. They will be more than happy to assist you with any questions you may have.

Ask yourself

- What would help me to prepare?
- What do I commit to changing?
- What do I need?
- Where is my sanctuary?
- What matters most to me?
- Who's in my team?

Contact

Talk to *brainstrust*. We can help. You can call, write, type, text. Email for help and support: **hello@brainstrust.org.uk**. Telephone: **01983 292 405**.

Other helpful links

brainstrust.org.uk/brain-tumour-support.

brainstrust.org.uk/brain-tumour-support/resources/downloads.

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