

Patient Guide

Follow-up



What happens?

When your treatment is over, you may expect life to return to how it was before you were diagnosed with a brain tumour, but it takes time to recover, and many people find that although life never returns to normal, they start living a 'new normal' – a way of life that is normal to you now. Some describe this time as 'falling off the edge', and feel isolated and unsupported. It's important to know how you and those around you can feel resourced, supported and prepared.

What is the optimum standard of care according to the IOG?

- Imaging.
- Ready access to allied health professional assessment and rehabilitation services for problems such as epilepsy, headaches, speech or visual problems.
- Ready access to specialist neuropsychology and neuropsychiatry services.
- Immediate access to specialist equipment as necessary.
- Given clear information on who to contact and how, if you are concerned about your condition.
- Follow-up as close to home as possible.

What does *brainstrust* think I should expect?

- Regular, ongoing holistic support, which encompasses physical, emotional, spiritual and cognitive needs.
- If you are concerned your cancer might be returning, an urgent re-referral.
- Information on how to access Allied Health Professional assessment.
- Your primary care (such as your GP) to unlock resources for you.
- Support for your carer and close persons.
- Timely assessments so that you can be proactive, not reactive, based around functional and neurological assessments.

What questions could I ask?

- What follow up care can I expect?
- Who will look after me when I'm discharged back home?
- Which doctor should I see and how often?
- Are there any post-treatment symptoms I should be aware of?
- What do I do about symptoms that worry me?
- What can be done to relieve pain, fatigue or other problems after treatment?
- How long will it take me to feel more like myself?
- Is there anything I can do to stop the tumour coming back?
- When will my next scan be?
- Who can I get in touch with if I've any questions?
- When can I go back to work?
- When can I drive again?

Additional questions you may want to ask

- What are the chances that the tumour will recur?
- If it does, what are my options?

Follow-up sources

The Beatson, West of Scotland Cancer Centre, *Neuro Oncology*
www.beatson.scot.nhs.uk/content/default.asp?page=s18_1_10

Department of Health, *Living With and Beyond Cancer*, March 2013,
available at www.gov.uk/government/publications/living-with-and-beyond-cancer-taking-action-to-improve-outcomes

Getting Follow-up Medical Care, National Cancer Institute, available at
www.cancer.gov/cancertopics/coping/life-after-treatment/page3

National Cancer Peer Review Programme Manual for Cancer Services:
Brain and CNS Measures Version 1.2

NCAT, *Rehabilitation Care Pathway Brain CNS*, 2009, available at
ncat.nhs.uk/sites/default/files/NCAT_Rehab_BrainCNS.pdf

NICE, *Improving Outcomes for people with brain and other CNS tumours*,
June 2006, available at www.nice.org.uk/nicemedia/live/10905/28963/28963.pdf

