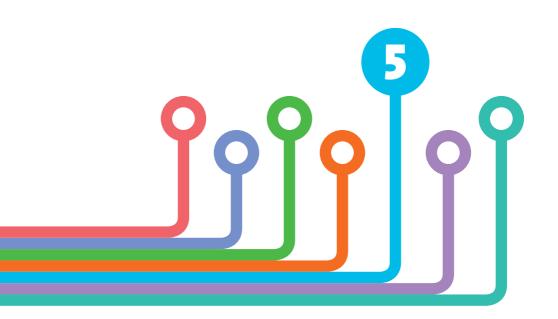


Patient Guide

Survivorship



www.brainstrust.org.uk

What happens?

If you are living with or beyond your brain tumour, you are a survivor. This can mean having an inoperable brain tumour, or living a brain tumour free life but having experienced surgery and adjuvant therapies. It is important that you and your loved ones have access to the support services you need. Cancer survivors can face all kinds of challenges as a result of their diagnosis and treatment, from physical, psychological, emotional, social and spiritual, through to financial challenges. Your wellbeing will be greater and the need for you to call upon services will be lower if you get the support that is relevant to your particular needs, specifically those that promote a healthy lifestyle and independence.

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

- A treatment summary.
- A personalised assessment and care plan, sometimes called a Holistic Needs Assessment. This should be copied to your GP.
- A care review within six weeks.
- Support to self-manage your condition, including advice on physical activity and weight management.
- Advice on vocational rehabilitation.
- Access to an education and support event, such as a Health and Wellbeing Clinic.
- Information on the long-term effects of living with and beyond your brain tumour.
- Access to specialist medical care for complications that occur after cancer.
- An assessment by a social care professional to determine your needs for social support.
- A point of contact, preferably someone who is known to you.

What questions could I ask?

- How often should I have scans?
- What might the consequences of my treatment be?
- What do I do if I am concerned in any way?
- Should I return to work?
- Where can I get help to support me in this next phase?

Survivorship sources

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

National Cancer Institute, *Getting Follow-up Medical Care*, 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

National Cancer Survivorship Initiative, www.ncsi.org.uk

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

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

