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# Survivorship

Patient Guide

## 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. Brain cancer brings a different set of challenges, specifically relating to behaviour, cognition and personality. These may require specific help. People living with a brain tumour can develop side effects months or years after treatment. These can include hearing loss, cognitive decline, epilepsy, as well as other side effects. 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. You might find this resource useful [brainstrust.org.uk/living-well](http://brainstrust.org.uk/living-well).

## What is the optimum standard of care according to the Improving Outcomes Guidance?

The optimum standard of care states the minimum level of care we should expect. Sometimes, for a variety of reasons, our health service may not be able to meet the standards.

- 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 6 weeks.

- Support to self-manage your condition, including advice on a healthy lifestyle, including exercise, a healthy diet and stopping smoking (if applicable).
- Advice on returning to work.
- 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 may occur after cancer.
- An assessment by a social care professional to determine your needs for social support.
- A named healthcare professional with responsibility for coordinating health and social care support, preferably someone who is known to you.

## **Recommendations from the NICE guideline 2018**

- Ongoing health and social care support needs will be discussed both with you and your relatives and carers (as appropriate). Complex care support needs, such as psychological, cognitive, physical, spiritual and emotional needs, will be taken into account.
- Enough time will be set aside to discuss your ongoing health and social care support needs.
- Information and support will be given empathetically in suitable formats and at appropriate times throughout your care pathway.
- Clinical results will be provided and explained as soon as possible.

- Neurorehabilitation assessment and options will be given throughout the care pathway. Potential neurorehabilitation needs include:
  - audiology
  - neuropsychology
  - occupational therapy
  - orthoptics (visual support)
  - orthotics (provision of devices such as supports and splints)
  - physiotherapy
  - speech and language therapy.
- Appointments for assessments will be arranged so that timing and frequency fit your neurorehabilitation goals (such as returning to work).

## What questions could I ask?

- For how many years going forward should I expect to have scans?
- Are there any long term consequences that I should be mindful of?
- Who supports me now I am at this point?
- What do I do if I am concerned in any way?
- What help is there for carers?
- I want to make the best of this phase. Is there anything or anyone who can help with me this?
- Can I drive again?
- An awareness of late effects should be present. Late effects may include:
  - cataracts
  - cavernoma
  - cognitive decline

- epilepsy
- hearing loss
- hypopituitarism
- infertility
- neuropathy (for example, nerve damage causing visual loss, numbness, pain or weakness)
- radionecrosis
- secondary tumours
- SMART (stroke-like migraine attacks after radiotherapy)

## Survivorship sources

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# Notes



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**Mike, Tom, Rebecca, Charlie & Sophie**

### ***brainstrust* patient guide**

This patient guide accurately reflects recommendations in the NICE guidance on [brain tumours \(primary\) and brain metastases in adults](#).

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