

Step by Step: your interactive guide to life with a brain tumour

THE BRAIN TUMOUR CHARITY

Introduction

We know a brain tumour diagnosis can be devastating, and it's hard for our community to know what to expect. This can sometimes mean unfortunately our community receives care that falls short of what they're entitled to. The impact of Covid-19 meant this happened increasingly often, and many people in our community fell through the cracks, unaware of the support and care they should receive. This was reflected in an increased demand of our support services and the communities need for a clearer understanding of the right standard of care following a diagnosis.

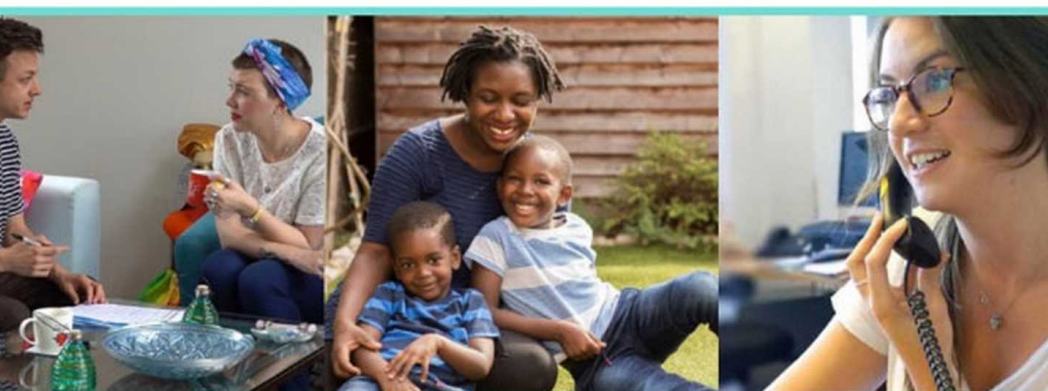
Involvement

The Brain Tumour Charity's Involvement Champions were central to the development of this guide. Involvement is all about our community using their experiences of being affected by a brain tumour and to help influence and shape our work. We want to ensure we are working in partnership with our community in all we do and to help us do this we've set up an Involvement Network. We also worked with medical professionals and our community, including 4 Clinical Nurse Specialists to set out the evidenced clinical standards for care of a high grade brain tumour patient. With their help, we produced our National Brain Tumour Standard of Care which details a typical journey for a patient following a diagnosis of a brain tumour.



Step by Step

Your interactive guide to life with a brain tumour



More about this guide

Click to get started

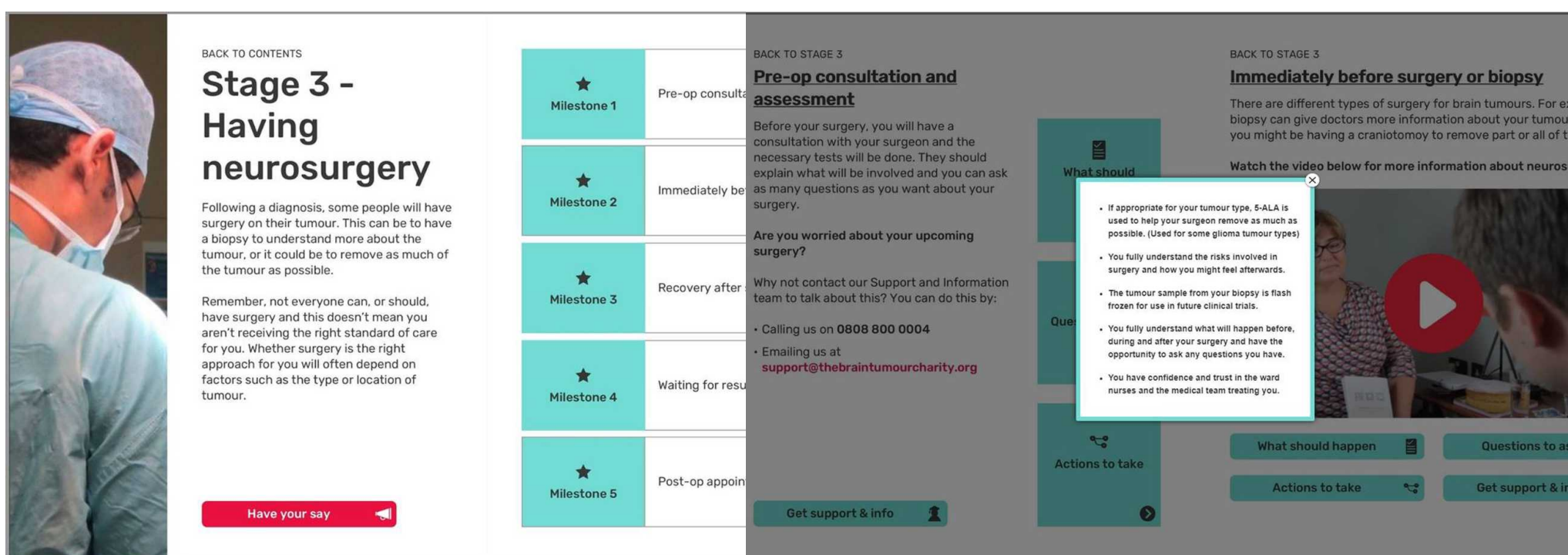
We asked our Involvement Network how they felt the guide has supported, informed, empowered and enabled our community.

SUPPORTED

We are all too aware that people don't always receive the level of care we would hope and find themselves feeling 'lost' and struggling to know their options. This Guide provides those answers and acts as a trusted navigator through what is always a difficult journey.

EMPOWERED

Brain tumours are a terrifying challenge for most people - they face all sorts of fears and often their care may fail to address the emotional and psychological aspects of finding out you have a tumour. This Guide helps you to understand the reality of situation and, most importantly, helps you to regain some element of control over what happens next.



"I found the new document really interesting and informative and I am so pleased to have had some input".

-Alanna, living with an acoustic neuroma.

Impact

Since launching the interactive guide we can report that-

- 1,370 individuals have used the guide
- 33,000 pages view have been reported within the guide.
- 77% of users are based in the United Kingdom.
- 13 individuals from our Involvement Network fed into this work and continue to support wider involvement opportunities at the charity.

Outcomes

Developing the Step by Step guide has shown what care and support is available for patients with a brain tumour and their families, and most importantly how to ask for it when it is missing. Patients and their families have been empowered to reach out to their healthcare team when they need support and understand what happens next. This project also showed how we can champion our community voice and their experience, where we continue to involve lived experiences in the development of our resources.

This poster was created in collaboration with the Involvement Champions at The Brain Tumour Charity who supported the development and promotion of the guide.