INVOLVEMENT CHAMPION



13%

of adults diagnosed with brain cancer in England survive 5 years or more (average across all cancers is 52%) 34

people in the UK
are diagnosed
with a brain tumour
every day



Our challenge

Our community are at the heart of everything we do, and we are committed to working in genuine partnership with those affected by a brain tumour diagnosis. Together, we aim to accelerate positive change in how people with brain tumours are diagnosed, supported, and treated, moving towards our vision – for everyone diagnosed with a brain tumour to live longer and better lives.

We want our Involvement Champions to reflect our brain tumour community, including both those living with low and high-grade tumours. We welcome carers of people living with a brain tumour, as well as those who have cared for loved ones who have sadly passed away. We value hearing from all relationships, including partners, parents, and siblings, as each perspective is very important to our work.

How can you help?

This three-year role gives you the chance to influence decision making across The Charity and act as critical friends to ensure community voices are embedded in all we do. As an Involvement Champion, you will help shape the future of brain tumour care and research. You will work on projects both within The Charity and across the wider brain tumour community, in-person and online, collaborating with researchers, healthcare professionals, and partner organisations to make sure those affected are at the centre of every decision.

What we're looking for

We are seeking passionate, collaborative members of our community who want to create change and improve outcomes for everyone affected by a brain tumour.

ABOUT THE BRAIN TUMOUR CHARITY

We are the world's leading brain tumour charity and the largest dedicated funder of research into brain tumours globally. Committed to saving and improving lives, we're moving further, faster to help every single person affected by a brain tumour. We're set on finding new treatments, offering the highest level of support and driving urgent change. And we're doing it right now. Because we understand that when you, or someone you love, is diagnosed with a brain tumour - a cure really can't wait.

Person Specification

We welcome applications from anyone affected by a brain tumour (carers and patients), but it's important this feels like the right time for you. By sharing your insight, you'll help strengthen and amplify the voice of our community.

We're looking for people who are:

- Passionate about improving outcomes for everyone affected
- Open to sharing their story while respecting different experiences
- Collaborative, empathetic, and supportive of others
- Able to balance involvement with their own wellbeing

The Brain Tumour Charity is committed to promoting diversity and inclusion in all aspects of our organisation. We particularly welcome applications from individuals belonging to minority ethnic groups, LGBTQ+ communities, people with disabilities, and other underrepresented communities.

As an Involvement Champion, you will:

- Use your lived experience to represent the wider brain tumour community and shape both internal and external work
- Listen to and respect different perspectives, recognising that others may face challenges different from your own
- Help ensure lived experience drives research, campaigns, policy and services in a meaningful way

You will be able to choose the projects you feel most passionate about and contribute in a way that works best for you.

Some of the ways you can get involved include:

- Taking part in focus groups sharing your lived experience to guide work and help ensure it reflects the real needs of those affected.
- Co-producing projects as a community partner collaborating with our team to create resources and initiatives that are suitable and fitting for our community.
- Feeding into research projects helping to ensure projects are understandable to the public, accessible, and relevant to the people who will benefit most in the future.
- Joining steering groups or advisory boards helping shape decisions and influence the direction of our work.
- Contributing to campaigns and events using your story and experiences to support reports, raise awareness, and engage MPs.
- Exploring and developing fundraising ideas supporting us in thinking about innovative ways to generate vital funds for our work.
- Being involved in service development and delivery ensuring the services we have/create are accessible, practical and focused on the needs of the community.
- Public speaking through press, conferences, media and blogsusing your voice to share your experiences publicly helping raise awareness of brain tumours and The Charity.

In addition to all of this, we are very open to hearing your ideas about how you would like to contribute and get involved.

Wellbeing and connection

Many previous Involvement
Champions have expressed that
one of the most rewarding parts of
being in the role is the strong sense
of connection and peer support
that develops with others in the
group.

A large proportion of your time will be spent working and collaborating with your fellow Involvement Champions and whilst this is a deeply meaningful and fulfilling role, we encourage you to consider whether you feel ready to hear and discuss a wide range of lived experiences.

Your wellbeing is our priority, and the Involvement /Support team are here to support you throughout the programme. The Charity also have a free counselling service that you have access to as a member of our community.

You can hear more about the role from our current Involvement Champions <u>here.</u>

Time commitment

This is a voluntary role with a term of up to three years, though we understand circumstances may change and you may need to step away earlier. We suggest a time commitment of around 1–2 hours per week, but this is flexible. You'll receive training, regular updates, and ongoing support to help you feel confident in your role.

- Induction: You'll start with an induction day on Thursday 22nd January at our offices in Fleet, Hampshire
- In-person meetings: Two further in person events will take place during the three-year programme.
- Online meetings: We'll meet monthly on Microsoft Teams during a weekday evening
- Other opportunities: You can choose activities that fit your interests, availability, and preferences. These will be shared via Volunteero, our volunteer app, which all Involvement Champions use. Opportunities may take place on both weekdays and weekends.

Please note, for in-person meetings, all travel, accommodation, and meal expenses are covered by The Charity.

Practical considerations

You will receive a full induction to The Brain Tumour Charity and any specific training for the role, as well as ongoing direction from one of the team, who will be your key contact. Volunteers must be over 18 and based in the UK. We encourage volunteers to claim for any reasonable expenses that are incurred in the course of their volunteering with The Charity. Find out more in our <u>Volunteer Expenses Policy</u>.

Application process

The application form will ask for information about your personal connection to brain tumours and any skills/qualities you would bring to the role.

Additionally, you will be asked to record a 2-minute video or provide a written statement (200-300 words) answering the following questions:

Motivation:

"Why do you want to be an Involvement Champion, and what does this opportunity mean to you personally?"

Vision & the Brain Tumour Landscape:

"Where do you think the biggest changes are needed in the brain tumour landscape?" – For this question, we ask you to consider what most interests you about The Brain Tumour Charity's work, and how would you feel about sharing your own experiences to help improve services, support, or research?

Need support with the application process?

We are committed to
being inclusive and recognise
that there may be a number
of ways we could support you
through
the application process.
If there's any adjustments we
can make to help
you fully engage in the
process, don't hesitate
to let us know by
getting in touch with the
Volunteering Team on

volunteering@

thebraintumourcharity.org

INTERESTED?

If you're ready to apply, please complete our online application form <u>HERE</u> by <u>9am on Friday 10 October 2025</u>. If we receive a high volume of applications, we may close the role early, so we'd encourage you to apply at your earliest opportunity. If you have any questions, please contact the <u>Volunteering Team</u>.