



How to feel part of a community

brainstrust information sheet

Know Hows are published by *brainstrust* to help people living with a brain tumour to understand current topics. They are produced with input from relevant scientific and clinical experts and are written in a way that should help you to understand often complicated topics.

If you have an idea for a Know How, then please let us know.

If you have any queries, don't forget you can talk to one of our support specialists on **01983 292 405**, or email **hello@brainstrust.org.uk**.

Why do we need this Know How?

In this Know How, we will explore more about what it means to be part of a community when living with a brain tumour diagnosis and how you can get involved and build a supportive network around you.

The term 'community' can be defined in a couple of different ways:

1. A group of people living in the same place or having a particular characteristic in common.
2. The condition of sharing or having certain attitudes and interests in common.

When you receive a brain tumour diagnosis, whether it is your own or that of someone you love, you may automatically find yourself being part of a community that you never intended to or wanted to become a part of.

What does this mean?

Although it is something that none of us has signed up for, and it may not feel like a community in the traditional sense of the word, feeling like you are part of a community of people who are sharing a similar experience with you can come with quite a lot of benefit in terms of how supported you feel to deal with your diagnosis.

Being able to connect with other people with a brain tumour diagnosis is crucial, as it is founded in shared experiences. The journey of a brain tumour diagnosis is unique in comparison to other cancers, often due to the treatment pathways and neurological symptoms that many experience. By being a part of a community of people in a similar situation, this can help you to:

- feel less alone and connect with others who understand what you are going through
- have access to resources that provide you with key information about your condition and possible treatment options
- know where to go and who to talk to for the right type of support

- know what your options are regarding your treatment pathway.

How can I become a part of a community?

The definition of a community is explained above, but what it means to you and what this looks like in practice may be quite different. Communities can be offline and online – for example, meeting someone for a coffee, attending a face-to-face workshop, being part of a group on social media, attending an online webinar. Communities come in all shapes and sizes, and connect in so many different ways.

Below are some ways in which you can feel part of a community:

Support from *brainstrust*

By getting in touch with *brainstrust*, you automatically become a part of our community and open the door to getting the support you need. Our support for you can come in many different forms, including providing you with resources and information, coaching, and signposting you to other services that may help. Our regional model means that we have support specialists covering different areas of the country, and they can be your key point of contact. Find out who your support specialist is [here](#).

Social media

There are lots of different ways to join online communities through social media platforms such as Facebook, Instagram and Twitter. Connecting with other people online gives you the opportunity to speak to other people outside your area and at different times of the day to suit you. When using social media to connect with others, it is important that any groups or forums that you join are moderated by an admin team and you know where and how to flag any concerns you may have.

brainstrust operates a private and moderated Facebook group specifically for people living with a brain tumour diagnosis. The group is nurtured by our support specialists and wonderful volunteers. It's a lively and supportive community of nearly 3,000 people. You can request to join our Facebook group [here](#).

Support groups and Meetups

Joining a support group or Meetup is another way in which you can feel part of a community. Our brain tumour hub is a database that includes details of support available in your local area – all you need to do is put in your postcode, and it will tell you what is happening near you. You can find this [here](#). In recent months, we have been able to add a number of monthly virtual Meetup groups to our support offering, as another way of enabling people to connect. Our virtual Meetups take place on Zoom and include groups for people living with different tumour types, such as meningioma, low-grade glioma and glioblastoma, as well as a group for family and friends of people with a brain tumour and a group for teenagers. To find out more about our virtual Meetups, visit brainstrust.eventbrite.com.

Peer support

If you would rather speak one-to-one with someone, then our peer support service is another way for you to join our community. The aim of this is to directly connect you with a peer supporter in order to help you feel better understood and supported. Peer supporters are trained volunteers who have been through a similar experience to you, whether you are a patient or caregiver. You can find out more [here](#).

Ask yourself

- What does being part of a community look like to me?
- How can I connect in a way that suits me?
- What are my boundaries when I join a community?
- What support do I need?
- Who is in my team?
- Who can I talk to?

Contact

Talk to *brainstrust*. We can help. You can call, write, type, text. Email for help and support:

hello@brainstrust.org.uk.

Telephone: **01983 292 405.**

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