The Brain Tumour Charity Carers Facebook Support Group

Code of Conduct

The Brain Tumour Charity Facebook Support Group

This group is for anyone affected by a brain tumour diagnosis in anyway, including those living with a brain tumour, carers or friends and family. The group is designed to provide a safe and reassuring space where individuals can gain peer support, make lasting connection and become a member of the wider brain tumour community.

The group is a closed Facebook group, which means that anyone can see the group and who is in it, but only members can post and see posts. Anyone can add members to this group, but only admin can approve these members.

To prevent ‘spammers’ admin will use their discretion when approving new members.

The Administrators of this group are The Brain Tumour Charity staff and volunteers.

Through the group, The Brain Tumour Charity will inform you of our services and activities that you may find useful and may interact with posts within the group.

This group is owned by The Brain Tumour Charity, we would respectfully request that fundraising requests for individual causes or charities other than The Brain Tumour Charity are not posted in this group and we reserve the right to remove these posts.

The views and opinions expressed in this group are those of the authors and do not necessarily reflect the views and opinions of The Brain Tumour Charity. Advice received via the group is for general guidance purposes only. Appropriate professional advice should be sought before any course of action is pursued.

If you have an urgent medical enquiry we recommend that you contact your GP, call 111 or in the event of an emergency call 999 or attend A&E.

How we moderate

This group will be monitored and moderated by administrators, who are members of staff or volunteers of The Brain Tumour Charity. This moderation is not available 24/7, however we endeavour to remove unsuitable posts in a timely manner.

Almost 11,500 people are diagnosed with a primary brain tumour every year.
We do not allow anyone under the ages of 16 to become a member of this group. If you have any questions about this, please contact the Information and Support team on support@thebraintumourcharity.org

Moderation will cover the following topics, however we will evaluate each incident on a case by case basis.

Ensuring safe discussion

To ensure open and safe discussion on the group, we ask that you be tolerant and respectful of other member’s comments and experiences. The nature of our groups are sensitive so we understand that strong feelings are often expressed, but personal attacks are never acceptable, and will not be tolerated in The Brain Tumour Charity Facebook support group. This includes insults and inflammatory or discriminatory comments about:

- Age
- Disability
- Working status
- Gender
- Race, including colour, nationality, ethnic or national origin
- Religion or belief
- Political belief
- Sexual orientation
- Being or becoming a transsexual person
- Being pregnant
- Being married or in a civil partnership

Any posts which could encourage or condone unlawful activity may be removed.

Posts which encourage or endanger the safety of others may be removed.

Abusive comments will be deleted without consultation. Consistent criticism of a person’s comments or views will be seen as abuse. Initial offenders can expect to be issued with a warning, then a permanent ban if they continue to flout these rules.

If you are upset or suspicious of another member, please report it to the lead administrator and then ignore the member. For your own safety we ask that you do not try to address the matter privately, using direct messages or comments on the post as this may only exacerbate the situation. Please trust that the moderators will handle the situation appropriately and efficiently in line with our code of conduct.

Language used

We ask that all members please do not use excessive foul language/swearing, and any aggressive language or foul language towards other group members is prohibited.

Quoting from external sources

When quoting from other sources please ensure that you quote only the section of the source on which you are commenting. Any posts that fail to meet this requirement may be removed. If you would like to make the full quote available to the group please include the link.

Please do not post or private message any copyright material or intellectual property that is not your own without express permission of the copyright or intellectual property holder.

Spam, advertising or trading in the group

The group is intended to be a forum for discussion and support. Articles posted without context to promote discussion may be considered spam/advertising and removed from the group. Posts deemed to be irrelevant or unsuitable for the group may be removed.

Any posts deemed to be advertising will be removed at the discretion of our moderators.

The group is not to be used for a trading forum, and any posts thought to be trading goods, or to be promoting the trading of goods will be removed at the discretion of our moderators.
The source of the content

When providing information from other sources please give references or add links to the health/medical information you are quoting.

When the information provided is from your own personal experience we respectfully ask that you make this clear within your post.

All users must post information which is true and correct to the best of their knowledge.

You must not upload, post or transmit, or make available, any material that viruses or any other computer code, programs or files designed to destroy, interrupt or limit the functionality of any computer software or hardware or telecommunications equipment.

Posting images or photographs

It is the responsibility of all group members to protect their own privacy and we would ask that you are mindful of this.

Under no circumstances are pictures of a pornographic nature permitted.

We accept no responsibility for images hosted externally to The Brain Tumour Charity.

Please note that it is an offence to make copies of an illegal image. Please report any concerns about images/videos or contact the lead administrator who will deal with this appropriately.

Photos must only be posted with consent of the person who owns the photo and the person(s) in the photo.

Your privacy

Although the group is a Closed Facebook Group, we cannot control how other members choose to share or discuss posts outside of Facebook. Therefore, please be mindful of this when posting by self-moderating your content and respecting the privacy of other member’s experiences.

Looking after you

We are keen for this space to be an environment in which you are able to share your thoughts and feelings about what we know can often be a very upsetting and difficult time. We believe we are all responsible for ensuring the safety and wellbeing of our community.

Safeguarding is everyone’s responsibility, and therefore we have a duty, wherever possible, to share any concerns that we have about posts, messages or comments that indicate you or someone else might be at risk, with the relevant services. This includes posts regarding abuse or neglect.

Though we will always try to share our concerns with you, we reserve the right to share information with external agencies without checking first; especially if it is thought that by sharing our concerns this might put others at, or increase the risks identified.

If you are concerned about another user, please contact the lead administrator of the group immediately and do not contact the individual personally. Please trust that we will contact the relevant services to support the individual wherever possible.

Warnings or permanent bans

In extreme cases warnings or permanent bans may be issued

Protecting yourself on Facebook

The Brain Tumour Charity would advise that you do not accept any friend requests from people you do not know as this will give them access to your private information.

Please be aware of your privacy settings on Facebook and set them to a level that you are comfortable with.

If you choose to share images of scans or test results in the group, this should only be done with the explicit permission of the person to whom those scans or test results belong. We advise that any images shared do not include personal
identifiable information, including NHS or hospital numbers.

Do not share your bank details with anyone over social media and make sure that you’re using a secure website before entering any personal details. There are ways to spot that a website is secure, including:

- the website address starts with 'https’ - the 's’ stands for secure
- the address bar is green, which is an additional sign that you’re using a safe website
- a padlock symbol in the browser where the website address is (but don’t be fooled if the padlock appears on the page itself)
- a current security certificate which is registered to the correct address. (this appears when you click on the padlock)

Engaging outside the group

We are unable to verify member’s identity, contact details or any information they provide and therefore we advise exercising caution if members choose to engage in conversation or meet up with another member outside of the group.

We encourage all members to ensure that their online privacy settings are up to date.

Recording Personalised Data

Your personal details are held on our secure database and we promise never to share them with any other organisation for their marketing purposes. You can read our full privacy policy on our website:

https://www.thebraintumourcharity.org/about-us/privacy-policy/

The content you share will be used to provide you with information and support, as well as to ensure safeguarding of all members.

The health information you share will also be stored on our secure database, which we use to provide you with relevant information and support in the future as well as to monitor our services and make improvements, identify the needs of our community and the development of our information, as well as to ensure safeguarding.

You can withdraw your consent to us holding your personalised data at any time, simply email: support@thebraintumourcharity.org or call 0808 800 0004.

Recording Anonymised Data

We will securely store the content that is shared on the Groups anonymously in a separate internal database to help us identify the needs of our community and make improvements to our services and information.

About us

The Brain Tumour Charity is at the forefront of the fight to defeat brain tumours and is the only national charity making a difference every day to the lives of people with a brain tumour and their families. We fund pioneering research to increase survival, raise awareness of the symptoms and effects of brain tumours and provide support for everyone affected to improve quality of life.