

Brain CARE in Focus

Issue 2



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Welcome to our second edition of the HCT Macmillan Brain CARE Team Newsletter!

Online Communities & Support Groups:

If you are facing brain cancer or taking care of someone who is living with the condition, you may wish to talk to and hear from others who are going through similar experiences. Online Communities and Support Groups provide the opportunity for people living with brain cancer to talk, share experiences and support one another.

In this edition of **Brain CARE in Focus** we provide details of Online Communities that may provide some of the support you are looking for.

Macmillan

Macmillan Cancer Support offers an Online Community providing support for people living with cancer. Support includes Groups, Blogs, Ask the Expert, News and Help.

A range of Groups are available for you to join, with a search facility to find appropriate Group for you. The Group which hosts discussions around [Brain Tumours is found here.](#)

'Blogs' provide an online space for posting your thoughts, ideas or activities on the subject of your choice — an opportunity to keep an ongoing journal of your experiences to share with the Community. If you would like to see an example, why not take a look at the Macmillan [Community News Blog](#)? This is where you can find out what's going on in the Macmillan Online Community, along with news and events.

'Ask the expert' provides the opportunity for you to pose a question to either a digital nurse, a dietician or financial guide. Questions are usually answered within 2 working days.

Check out Macmillan's Twitter Account: [@macmillancancer](#) which offers physical, financial and emotional support. Also their [Facebook page](#) which is monitored Mon-Fri 9am—11pm.

Useful information and support

[Macmillan Brain CARE Team](#)



We are a team of specialist therapists (Allied Health Professionals) working in Hertfordshire. We support the rehabilitation needs of people living with brain cancer.

[Macmillan Cancer Support:](#)

Provides physical, emotional and financial support for people living with cancer and their loved ones.

The Brain Tumour Charity is the world's leading brain tumour charity and the largest dedicated funder of research into brain tumours globally.

The Brain Tumour Charity provides online support services which include:

Online Support page available on the website offering support for individuals, families, young adults, benefits clinic, phone support groups and advice on local support groups.

Live Chat Service: Live Chat is available from 9am-9pm on Wednesdays and 9am-5pm on Thursdays and offers a way to ask questions or raise concerns about a diagnosis, treatments - including access to clinical trials, how a brain tumour can affect your daily life and how you can support a loved one.

Facebook groups: 4 Facebook groups are available for anyone affected by a brain tumour:

- for anyone facing a brain tumour diagnosis
- for adults 16-30 living with or beyond a brain tumour diagnosis
- for parents with a child under 18 living with a brain tumour
- for carers

Groups are moderated by members of a Support and Information Team and operate a code of conduct for your protection.

Twitter: @BrainTumourOrg

The Brain Tumour Charity also run the **HeadSmart Campaign** raising awareness of brain tumours in children and teens:

Twitter: @HeadSmartUK

brainstrust is a UK wide brain tumour charity and community which helps thousands of people who are affected by a brain tumour diagnosis.

brainstrust offer online community support through their **Facebook support group**. This is a closed group available for members only. Members can invite others to join the group but applications will need to be approved by brainstrust admin team.

Brain Tumour Support is uniquely dedicated to providing support for anyone affected by any type of brain tumour, at any point from diagnosis, and for as long as support is needed.

Brain Tumour Support offer online support through:

Members Forum on Facebook: a private Facebook Group set up to bring together anyone who may benefit from personal online contact with others affected by a brain tumour. A platform to keep members informed of support groups and other activities coming up, as well as a safe place to ask questions, share feelings and emotions and experiences. Essentially it's a place for friendship and peer support with the aim that no-one feels alone with a brain tumour diagnosis.

Facebook: Brain Tumour Support's public Facebook page is available for anyone who wishes to connect with the charity, raise awareness, get involved with fundraising or follow and support their work in any way.

Twitter: @BrainTumourSupp

The Brain Tumour Charity:

Offer an inclusive information and support service for everyone affected by a brain tumour.

brainstrust:

Provide help and support for people living with a brain tumour.

Carers UK:

Caring can be isolating. When looking after someone it is not always easy to find people who really know what caring is like and who are able to offer help and understanding.

Carers UK offer a warm and welcoming [online community](#) a place where you can share what's on your mind day and night. You can talk about real issues with people who understand and who can support you through everything caring has to throw at you.

The forum has different platforms for support that include: Support and Advice, Social Area for general chit chat, News and Campaigns and Specific disabilities and conditions.

Facebook: Carers UK public Facebook page is focussed on making life better for carers.

Twitter: @Carers UK

Macmillan Brain CARE Team—Service Update:

The Macmillan Brain CARE Team continues to support people in Hertfordshire living with high grade brain tumours. We are continuing to develop the service and can only do this with your involvement. In June we hosted a patient feedback group and we were really pleased to hear about what our team does well, and what we need to do more of. If you were unable to attend our group, but would like to share your experiences and ideas with us, then please get in touch and we will arrange to come and see you.

This newsletter focuses on the online support groups set up by the various charities. Getting support from people in a similar situation can be extremely beneficial. Please let us know if you think we should set up a Facebook group just for people in Hertfordshire. Also, if you have any experience in using social media that you would like to share with us then we would be happy for the help!

We may have the opportunity to set up a local support group, but we need to know if this is what you want. Maybe you would prefer a buddy service where we can put people in similar situations in touch with each other to share experiences and ideas. Please use the email link below to let us know what you think about this.

Finally, please remember we are here to help so don't forget to get in touch if you have questions or concerns.

Alison, Lesley and Lucy.

Carers UK:

Provide carers with expert advice information and support.:

including :

- Carers Assessments, practical support including:
- Managing someone's affairs
- Coming out of hospital
- Equipment and how to get it
- Planning for emergencies
- When caring changes or ends

The Macmillan Brain CARE Team

Welcomes your involvement. If you would like to share your experience of living with a brain tumour and help shape the service we offer, please get in touch:

Tel: 01727 732038

Email:

hct.braincare@nhs.net

Twitter: [@hctbraincare](https://twitter.com/hctbraincare)

Patient Feedback:

Would you attend a Support Group for people with high grade tumours (transport to the group could be offered) or use a buddy service?

[Yes](#)

[No](#)