



How to build a supportive team around you

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?

Living with a brain tumour is lonely, whether you are a patient or a caregiver. Because brain cancer is a less common cancer, it is hard to find anyone who has a shared experience, someone who really understands what it is like. And as a caregiver, this can be really hard. You have to be:

- an enabler for others
- secure around uncertainty
- open with not knowing
- sure that your inner dialogue is constructive.

All of this when most likely your world inside has fallen apart.

What does this mean?

In real terms, this means that caregivers also have losses of health, hopes, independence and also identity. One day you realise you are caring more for your loved one than you are for yourself. Poor self-care and prolonged periods of stress put caregivers at risk for their own mental and physical health, with 50% of caregivers reporting distress.^{1,2} These unmet needs could in turn impact on your ability to care.³

One way to address this is to make sure that, as a caregiver, you have a supportive team around you. Social support is important – it acts as a buffer and helps with general well-being. Being part of a community means that people have an improved quality of life, are better able to make decisions, bring improved satisfaction with care, have improved mood, and engage in healthier behaviour.

1. Sterckx W, Coolbrandt A, Dierckx de Casterlé B, Van den Heede K, Decruyenaere M, Borgenon S et al. The impact of a high-grade glioma on everyday life: A systematic review from the patient's and caregiver's perspective. *European Journal of Oncology Nursing*. 2013;17(1):107-117.
2. Choi C, Stone R, Kim K, Ren D, Schulz R, Given C et al. Group-Based Trajectory Modeling of Caregiver Psychological Distress Over Time. *Annals of Behavioral Medicine*. 2012;44(1):73-84.
3. Boele F, Bulbeck H, Browne C, Rooney A, Sherwood P. Interventions to help support caregivers of people with a brain or spinal cord tumour. *Cochrane Database of Systematic Reviews* 2017. Issue 3. Art. No. CD012582.

How can I build a supportive team around me?

Bottom line? People want to help. You'd do the same for someone who found themselves in a similar situation. In fact, you probably have.

So where to start?

A community has a life of its own, and you will find your cast of supporters changes over time – it isn't a fixed cast. Go with this. A community can be online and offline. Online support is not bound by geography or time, and accessibility is 24/7. Facebook has a wealth of support communities online. [brainstrust's Facebook support group](#) is a closed group and is carefully administered.

It also helps, though, if online interactions can be carried across to the real world – offline. Building a team around you can be daunting, but there are some simple things you can do to make a start.

1. Think of your support team as three separate teams – A, B and C.

The A team – this team consists of people who are good in crisis mode. This really is the A team – the dependable, non-judgemental, get-down-and-do team. These are your firefighters.⁴ You can count on them for anything, and because they are so special, you will only have a few in this team. They won't mind a 3 a.m. call, won't bat an eyelid if you need help in an emergency, will go to an appointment, aren't squeamish about the human condition. Look to close friends and family – people who have stood the test of time.

The B team – no less important. This resource is your maintenance. They will support you rather than the patient. They are happy to mow the lawn, pick up a prescription, look after the children for a couple of hours, walk the dog. You'll have more in this team.

The C team – these are people who you love but are no good for you in this situation. So you may wish to disconnect yourself from this team for the time being. This team is

made up of people who cannot handle the situation, may judge, may not understand what it means to be helpful and may make it all about them, and worst of all, they may undermine you. You will know who these people are, and there may be some surprises in there. It's amazing how a change in your life plan surfaces these people.

2. Start populating your teams. Look around you – family, friends, neighbours, work colleagues.
3. Think about other resources that could be part of your supportive team. Here are some ideas:

Thrive [brainstrust events](#), support groups, peer support ([brainstrust](#) has a great peer support programme – ask us), someone you have met in a clinic, a clinical nurse specialist, your GP.
4. Compile a list of all the things you are struggling with. Which of these things could you ask someone else to do? People are delighted to be asked – it makes them feel special. Have a look at our caregiver leaflet '[Walking a mile in our shoes](#)' for some ideas.
5. Accept people's limitations. Accept that people may move from team A to team C, and vice versa. Help them by reassuring them it's okay not to know what to say, that emotion is not directed at them but is the result of the situation, that the simplest things, such as a hand squeeze, helps.

Ask yourself

- What specifically am I struggling with?
- Who's in my teams?
- Who can I talk to?
- When can I weave my next 'pause' into my day?
- What could I pass on to someone else to do?
- Who am I tolerating?
- Who is not helping?

4. Taylor L, Umphrey A, Richard D. *Navigating life with a brain tumor*. New York: Oxford University Press; 2013.

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.**

Other helpful links

www.brainstrust.org.uk/brain-tumour-support

www.brainstrust.org.uk/wp-content/uploads/2018/01/how-to-have-difficult-conversations-guide.pdf

www.brainstrust.org.uk/brain-tumour-support/quality-of-life/practical-help/knowhows

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Production of *brainstrust*'s information is supported by the Anna Horrell fund. Anna, wife and mum, tragically passed away in August 2017 after a valiant fight against a glioblastoma. Throughout her life and her illness, she was an inspiration to us all, fighting bravely and cheerfully in the face of adversity. She was the beating heart of our family, and her loss left a hole in our lives that can never be replaced. In her incredible memory, we are passionate about helping others diagnosed with a brain tumour to navigate this most difficult of journeys.

Mike, Tom, Rebecca, Charlie & Sophie