



# 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 or beyond a brain tumour can put a strain on both existing and new relationships.

When illness strikes, a number of structural and emotional skews will follow. Belief systems are challenged, roles are upended, and identities shift. The onset of a brain tumour diagnosis forcefully challenges the emotional and physical boundaries that we have spent a lifetime building. The tumour is an uninvited guest that we must somehow build into our lives while living with the undercurrent of threatened loss.

'The tumour has resulted in Paul and me taking on different roles. I dislike being seen as Paul's 'carer', even though I often use the term to describe myself. I am first and foremost Paul's wife, and he is my husband, not my patient. Getting the balance right can be difficult. Even more so where the tumour and treatment have impacted on speech and comprehension.' Caregiver

Behaviour and personality change is common for those diagnosed with a brain tumour. There are many ways in which people can be affected by behaviour and personality change, and it can have a significant impact on your life, including your relationships.

'I've known this man for 46 years and now feel as if I know nothing about him.' Caregiver

Fatigue can also affect relationships, and it is estimated that between 40% and 80% of people with a brain tumour experience severe fatigue.

If you are single, you may be considering whether to start a new relationship. If you do decide to start a relationship, you might worry about what and when to tell your new partner about your diagnosis and how your tumour and any symptoms you have will impact your relationship.

'My new relationship is going well ... but I'm insecure due to my health problems.' Patient

#### What does this mean?

If your relationship has been affected by a brain tumour diagnosis, this can be very distressing. If you would like support, there are a number of ways you can access this.

## What support is available to me?

#### Resources

Managing behaviour and personality change

If behaviour and personality change is affecting your relationship, *brainstrust* can help. Our behaviour and personality change resource has strategies to help you analyse and cope with this. We also run a webinar that complements the resource and is an opportunity to share experiences with others.

### **Fatigue**

Our <u>fatigue toolkit</u> can help you self-manage fatigue. This underpins our webinar on living well with fatigue. View our <u>events schedule</u> to see and sign up for upcoming events.

#### Difficult conversations

Our guide to <u>holding difficult conversations</u> can help you improve the quality and outcome of your conversations.

### Coaching

If you would like to talk about how a brain tumour diagnosis is affecting your relationship, contact us at *brainstrust*. Our support specialists will listen to what you are struggling with and work with you to produce a plan to move forward.

## Counselling

Relationship counselling can help you find a way through your difficulties. The Brain Tumour Charity has teamed up with Relate to offer a free counselling service <a href="https://www.thebraintumourcharity.org/living-with-a-brain-tumour/relationships/relationship-counselling-couples-affected-brain-tumour/">tumour/</a> for UK-based couples and individuals whose relationships have been affected by a brain tumour.

Some local Relate branches offer free relationship counselling to anyone affected by cancer, in partnership with Macmillan. You can find the contact details for your local Relate branch here <a href="https://www.relate.org.uk/find-your-nearest-relate">www.relate.org.uk/find-your-nearest-relate</a>.

The British Association for Counselling and Psychotherapy has a directory of private therapists, all of whom are registered members. You can find out more about how to find a private therapist here. <a href="https://www.bacp.co.uk/about-therapy/how-to-find-a-therapist/">www.bacp.co.uk/about-therapy/how-to-find-a-therapist/</a>.

## **Ask yourself**

- What relationship do I have/want to have with this person?
- What am I struggling with?
- What prejudices do I have towards the situation?
- What do I most need to be different?
- What do I want for the other person?
- What support do I need?

#### 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

Macmillan: <a href="www.macmillan.org.uk/cancer-information-and-support/diagnosis/talking-about-cancer/cancer-diagnosis-and-your-relationships">www.macmillan.org.uk/cancer-information-and-support/diagnosis/talking-about-cancer/cancer-diagnosis-and-your-relationships</a>

Relate: www.relate.org.uk

Men's Advice Line: mensadviceline.org.uk

Refuge: www.refuge.org.uk

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