



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?

This Know How is here to help you feel more in control and supported when you are young and taking care of someone.

Many people don't realise they are young carers, and yet you may have been helping someone for a while. You could be:

- doing the food shop
- helping someone to get dressed
- taking care of siblings
- helping with medicines
- making sure the person is not alone outside or inside their home
- doing the laundry
- cleaning the house
- preparing meals.

What does this mean?

If you are under 18 years old and are helping to take care of someone with a brain tumour, you are a young carer. If you are 18 or over but still young, you may be referred to as a 'young adult carer'. You could have a sibling, parent or relative with a brain tumour who you are helping to take care of.

You may have additional responsibilities when a loved one is diagnosed with a brain tumour. You may find that it is rewarding helping someone else and that you are managing well because you have support from the rest of your family, but it is super important to take care of yourself too.

Being a young carer, you may feel:

- you are struggling with your education
- you cannot keep up with friends
- you are missing social events
- you are struggling to concentrate
- you are angry that you are doing more than others

- you are resentful that you can't live the life you want
- you are frightened about the future
- you are struggling with mental health
- you are really rewarded
- you are closer to the person you are taking care of
- you have learned new skills
- you are more confident because you have more responsibilities
- you are more grown-up.

Supporting someone else can be draining physically and emotionally. You may feel you have to be strong for the rest of the family. We get it. Being a young carer can have ups and downs. Understand that you are not alone, and ask for help. We can help you find the best form of support for you, so please get in touch.

Looking after yourself

When you are busy taking care of someone else, sometimes it is easy to forget to look after yourself too. This is super important because if you are burnt out and exhausted, you will not be able to do a lot for others. Taking care of yourself is not selfish, and it will benefit you in the long run.

- Make time for things you enjoy. Make a list, and plan when you will do these things, so that you are less likely to get distracted or have clashing responsibilities.
- Take a break from caring, and do fun stuff.
 Organise for someone else to come and help you so that you can take some time off, or you can care together.

- Speak to others. Don't bottle up your feelings.
 You don't have to talk to a professional. It could be a close friend, family member, teacher or brainstrust. You would be surprised how many people are here to listen to you no matter how big or small your problem is.
- Find a local support group, as these are great to meet others going through something similar, so you don't feel alone. Or get in touch with *brainstrust*, and we can try to introduce you to other young people caring for a loved one with a brain tumour.
- Make sure you are eating and exercising well.
- Get enough sleep to help you feel energised the next day.

Ask yourself

- What specifically am I struggling with?
- What do I need to be different?
- What do I want for the other person?
- What do I want for me?
- What is important to me?
- What do I need for myself? For them?
- What does a good result look like?
- When's the right time to talk?
- What are the reasons to hold the conversation? And to not?
- What can go wrong?
- What do I sense?
- What do I know?

Contact

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

hello@brainstrust.org.uk. Telephone: 01983 292 405.

Other helpful links

brainstrust.org.uk/brain-tumour-support

How to have a difficult conversation

How to build a support team

How to have a voice as a caregiver

A guide for young people looking after someone with cancer

Maggie's young carers

YoungMinds resources

Know your Rights: Support for Young Carers and Young Adult Carers in England

Financial support for young carers

Who else can help?

Sometimes taking care of someone with a brain tumour can be overwhelming, so talk to someone. Get in touch with *brainstrust*, talk to your teacher, workmate, friend, counsellor or GP.

YoungMinds Crisis Messenger

This is a free text service for young people throughout the UK who are going through a mental health crisis. Texts are exchanged with trained volunteers and can be anonymous. However, if the volunteer feels you are at risk of harm, they may share your details.

Text: YM to 85258

Opening times: 24/7

Carers UK

This is a UK charity for all carers. They have support groups and carer assessment support.

Phone: **0808 808 7777**

Email: advice@carersuk.org

Youth Access

This advice and counselling network provides information and support for young people aged 12 to 25 about local counselling services.

www.youthaccess.org.uk

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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