



How to make the best of the time I have left

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**.

'Whatever you do, be gentle with yourself. You don't just live in this world or your home or your skin. You also live in someone's eyes.'

Sanober Khan

Why do we need this Know How?

Time is our most cherished possession. It's a finite resource, and we should, therefore, cherish it. There can come a time when treatments no longer work and options have run out, and we are left facing the fact that our time is limited. This sense of time running out can bring unwelcome pressure that stops us living our best possible day. We believe that you can have your best possible day, even when you are at the end of life, but it needs a bit of planning and careful thought. It's therefore important to think about your wishes, make your wishes known and talk with loved ones about how you can make the best of the time you have left – communication is key.

The one certainty is that at some point we will all, inevitably, face death. We only have one chance to get our dying right; how we die lives on in the memories of those left behind. We owe it to ourselves and to our loved ones to spend the time we have left as we want to spend it – so that each day is our best possible day.

Making the best of the time you have left means finding out what matters to you, how to articulate what you want and how to achieve it.

What does this mean?

Finding out you have a life-limiting disease and that your options have run out can affect individuals differently, but how you approach this next stage and how you face up to it can have a massive impact on you and those around you.

If you are able to prioritise and articulate your wishes with your loved ones, it can help you feel more in control. Remember that this isn't all about the person who is diagnosed with the brain tumour; loved ones also have wants and needs, and so the best outcomes are those where there is trust, openness, understanding, confidentiality and honesty – TOUCH.

When

Knowing how to make the most of the time you have left is important, but when do you start thinking about this? The answer to this question will be individual to each person, but thinking about what matters to you the most can help you to prioritise and find the balance between what needs to be done and what you want to do.

How

What matters to you?

Talk to your family about what matters to you. What do you want to achieve in the time you have left? What are the values you hold dear? How can they help? Have a think about what a good day looks like to you. This could be spending time with loved ones, doing an activity that you are still able to enjoy, something as simple as walking the dog, baking a cake. Build something into each day if you can.

Who or what supports you when times are difficult?

We all have a source of comfort, and this can be family or close friends, but sometimes it can be difficult confiding in them when you're finding things difficult, as you don't want to worry them, but there are other people you can chat with. This could be a counsellor, your GP, an online support group (we have a very warm, welcoming and helpful Facebook community called [Brain Tumour Support *brainstrust*](#)), or arrange a chat with one of *brainstrust's* coaches.

Getting questions answered

There will inevitably be questions that you need answered. Your medical team is there to help answer questions and alleviate fears. If you're having difficulty articulating questions, remember that *brainstrust* can help. We have a set of patient guides. These are written in easy-to-understand sections and can give you a better understanding as well as help with questions you need to ask. You can download the guides at www.brainstrust.org.uk/patient-guides.

Sometimes all it takes is a simple conversation to help you articulate the questions. Email or call us. We can help.

Spending time making memories

How you want to spend your time is important, and making memories means doing things that you hold close to you. This can be as big or as small as you want. Making memories for you could be going somewhere with your family and loved ones, to a place that's special to you – it could be a restaurant, a beach, visiting friends. It could just be spending time watching a box set or playing board games, even looking through old photos. Sometimes building a memory box can be soothing and calming; building a legacy for family and friends can be life-affirming. This might be something to be done alone or with others.

Getting your affairs in order

Knowing that you have your affairs in order not only ensures your wishes are complied with but also means that you are not giving yourself the additional stress of worrying about leaving things for your family. It also means clearing the decks, leaving you time to spend doing what you want with those you love. We have produced a Know How on lasting power of attorney. This easy-to-read Know How will help you to consider whether it's something that you want to implement. You can find this at www.brainstrust.org.uk/knowhows.

The Conversation Project

The Conversation Project is a public initiative with the goal of every person's wishes for end-of-life care being expressed and respected. Conversations can provide a shared understanding of what matters most to you and your loved ones. It has produced a series of guides, including their starter kit and 'What Matters to Me' workbook, which has been produced to help you get ready to talk to your healthcare team about what is important to you.

You can find out more at theconversationproject.org.

Ask yourself

- What do I not want to regret? How do I want to think about these next few weeks/months/years?
- Who do I want to be with during the time left, and how do I want to spend that time with them?
- What will help me be prepared?
- What questions do I need to get the answers to?
- What do I and my loved ones want to remember about the next few weeks/months/years?
- What is important to get right?
- What don't I want?

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.**

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