

# Should I have proton beam therapy?

How do I make the right decision?



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## How do I make the right decision?

This resource will not tell you whether you should or shouldn't have proton beam therapy. It is more a resource to explore the approaches that can be taken to help you make a decision.

Communication is central to human interaction, to everything we do. Without it, people cannot relate to those around them, make their needs and concerns known, or make sense of what is happening to them. A survey<sup>1</sup> involving the brain cancer community highlighted gaps in its support. The community has very simple asks about communication.

They want:

- clear signposting of care in the community
- the right information at the right time
- public understanding
- clear expectations
- a more equal relationship with their doctor
- more honest discussions sooner
- to know how to get what they want out of a discussion
- to not feel alone
- to feel in control
- to know how to deal with death and dying

A cancer diagnosis, whether it is a new diagnosis or a recurrence, is frightening. A common theme is the sense of isolation, a lack of voice and the disempowerment that the cancer community feels. Patients and caregivers aren't sure

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<sup>1</sup> Bulbeck, H. (2015). *Quality of life: what the brain cancer community needs*. Cowes: braintrust.

to whom to turn, when, and for what, and there is a general feeling of loss of control. Patients do not know what support is available to them, where to seek help, or what questions they should be asking. A shift to being empowered begins at the point of diagnosis, with a collaborative and interactive relationship between patients and healthcare professionals, which empowers patients to take on responsibility for their condition with the appropriate clinical support. This is called **shared decision making**.

There remain major challenges to this change, for example, from moving from the position of seeing the healthcare professional just as an expert giving advice, to seeing them as an enabler who supports the person they are caring for to achieve their goals. There is also the challenge of patients moving from seeing themselves as passive recipients of care, to becoming activated and taking responsibility for their own contribution to improving their health and wellbeing outcomes, and being empowered to do so.

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## What is shared decision making (SDM)?

Shared decision making (SDM) ensures that individuals are supported to make decisions that are right for them. Only the patient and their family know what their context is, what their appetite for risk is and what their values are. The patient is the expert on them, and the clinician is the expert on treatment options, and whether the options are appropriate. SDM is a collaborative process through which a clinician supports a patient to reach a decision about their treatment.

The conversation brings together:

- the clinician's expertise, such as treatment options, evidence, risks and benefits
- what the patient knows best: their preferences, personal circumstances, goals, values and beliefs.

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## Why is SDM important?

Shared decision making is important because:

- It can create a new relationship between individuals and professionals based on partnership.
- People want to be more involved than they currently are in making decisions about their own health and healthcare.
- Both individuals and clinicians tend to consistently overestimate the benefits of treatments and underestimate the harms.
- It has the potential to enhance the way resources are allocated and reduce unwarranted clinical variation.

Even if individuals spend as much as 6 hours a year in a clinic or health professional's office, that leaves them 8,760 hours when they are 'on their own' to manage their diet, physical activity, medications, stress and other factors. Shared decision making helps the patient to stay connected to clinical care so that conversations are more focused, have clarity and enable the patient to:

- be an enabler for others
- be secure with uncertainty
- be open with not knowing, and taking risks

- ensure that their inner dialogue is constructive
- be non-defensive by having nothing to prove and no agenda

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## How does SDM happen?

Shared decision making focuses on achieving specific, immediate goals that relate to precise challenges. For example, weighing up the pros and cons of having a particular treatment, overcoming a problem with caring, or coming to terms with entering the next stage of treatment. All of these are effective forms of self-management, and all rely on effective communication, which is in our DNA.

There are a variety of tools available that enable shared decision making. People can use decision aids when there is more than one option and neither is clearly better, or when options have benefits and harms that people value differently. Decision aids may be pamphlets, videos or web-based tools. They state the decision, describe the options and help people think about the options from a personal view (e.g. how important possible benefits and harms are).

The two simplest and most accessible tools are outlined here.

The **'Ask 3 Questions'** approach encourages people to ask 3 simple questions, which evidence shows lead clinicians to provide higher-quality information about options and their benefits and harms. The questions are:

- What are my options?
- What are the possible benefits and risks?
- How can we make a decision together that is right for me?

**Decision aids** (also called **Option Grids™**)<sup>2</sup> are being developed across various cancers. These are simple grids, one side of A4, based on the most current evidence available, and are focused on the questions patients most frequently ask when they need to make decisions based on their preferences. Clinicians can select 2 to 3 options to compare and, for select topics, fill in patient-specific data to customise the grid.

There is a 6-step process that is then followed:

1. *Describe*: the patient is informed that the goal of using the grid is to initiate a conversation about options, that it is organised as a table to enable comparison, and that it uses questions that other patients have found useful.
2. *Check*: patients are asked if they wish to read it themselves or whether they prefer the comparisons to be read aloud.
3. *Handover*: the patient is given the grid so that they can mark their copy and jot questions if they wish.
4. *Create space*: if they wish to read the grid themselves, patients are asked if they mind if the clinician does other things during this time, so the patient does not feel ‘observed’ as they take time to assimilate the information.
5. *Ask*: the patient is encouraged to ask questions and discuss.
6. *Gift*: patients are told they should take the grid with them as an aid to memory and an opportunity to discuss their options with others, as well as to look for more information.

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<sup>2</sup> Seal, R.P., Kynaston, J., Elwyn, G. and Smith, P.E.M. (2013). Using an Option Grid in shared decision making. *Practical Neurology*, 14(1), pp.54–56.

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Funded (in part) from EPSRC EP/N027167/1 Grand Challenge Network + in Proton Therapy.

*brainstrust* would like to acknowledge the invaluable input of the patient, caregiver and clinical communities who have given their time to ensure that the information in this guide is as relevant and useful as possible.



Registered charitable trust – *brainstrust* is a registered charity in England and Wales (1114634), and Scotland (SC044642).

Published January 2019.

Due for review January 2022.

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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**