



Know how to talk with your neurosurgeon about tissue collection

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 I need to have this conversation?

Following a brain tumour diagnosis, one of the treatment options that you may be offered is neurosurgery. The type of neurosurgery will depend on many factors, including tumour type and location. This will all be discussed with you by your clinical team beforehand.

For most types of tumours, the goal is to remove as much of the tumour as possible without causing harm to healthy tissue. This is called resection or debulking. Surgery also provides an opportunity to take a sample of tissue to learn more about the type of tumour and how it might respond to treatment. This is called a biopsy. A biopsy is a smaller surgery. Sometimes it is not possible to do a resection, so only a biopsy is done.

It is important to know what happens to the tissue that is removed. Knowing this will help you to think about any research that you want to be involved in. You may also want to think about potential future treatment options that are not currently available on the NHS.

What is my tumour tissue used for?

In some cases, there is only enough tissue to make a diagnosis. It may not be possible to collect extra tissue, due to technical reasons. This can be the case if a biopsy is done. The tissue might also be too poor in quality to be of use.

The first priority for the tissue that is collected is to find out what type of brain tumour it is (diagnosis). Any tissue that is left after enough has been taken for diagnosis may be stored in a tissue bank for use in the future. You may need to ask your surgeon to ensure that any tissue left over is kept. This tissue can be used for research purposes and, in some circumstances, for exploring potential treatments that may be available in the future.

How is my tissue stored?

Tissue taken at the time of surgery can be stored in a number of ways. The standard method for storing tissue used for diagnosis involves putting the tissue into paraffin blocks. This method is called formalin fixation. Sometimes there is enough tissue left over to allow part of the tissue to be frozen without formalin fixation. Not every hospital is set up to collect and store frozen tissue. Not having your tissue frozen will not impact the care you receive. There are currently no treatments available on the NHS for which frozen tissue is required.

What are the benefits of having tissue frozen?

Frozen tissue can be used for research purposes, as the genetic material in the tissue is better preserved when it is frozen, compared to tissue fixed in formalin. In the future, there may be treatments available for which frozen tissue is needed, e.g. a new treatment method involving an individualised anti-tumour vaccine. Currently, there are no treatments available on the NHS for which frozen tissue is required. If future studies of treatments that need frozen tissue show evidenced benefit, and these treatments become more widely available, then frozen tissue will be required.

What does this mean for me?

At the moment, it means you need to talk with your clinical team about what will happen to any tissue that is left over after tissue has been taken for diagnosis. If you have not talked with your neurosurgeon you need to ask. Some surgeons will raise the subject of storing your tissue, some don't. It is a difficult time and there is a lot of information to process. Ask your surgeon to keep any tissue not needed and ask how it will be preserved. Remember though, it isn't always possible to get enough tissue. Approaches to storing tissue vary. The standard approach is to fix tissue in formalin. In the short term, this will continue. However, it is likely that at some point in the future, freezing tissue will become routine, the advantage being that if a treatment becomes accessible and it requires frozen tissue, then that tissue will be available. In addition, frozen tissue could also be used for future research, if it is ethically approved.

Ask yourself

- How important is it to me that I discuss tissue preservation with my clinical team?
- What can be gained by storing my tissue?
- Does it make a difference to me how my tissue is stored?

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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