My Brain Tumour After Surgery

This article is a guide to the options for what can happen to your brain tumour tissue after your surgery and why it may be important to you. It is aimed at helping you make informed choices. As it's a complicated subject, we've added a downloadable guide of questions to ask your medical team pre-surgery. You can find it **here.**

Competing interests: this article was written by Michel Sadaka, founder of StoreMyTumor.com, a commercial tumour and fluid preservation service. We don't endorse any particular provider, and private storage comes at a cost. See the notes at the end of this article.

Key points

- Your diagnosis and safe clinical care always come first. Anything beyond that can only come from tissue that is surplus to what your team needs.
- Hospitals routinely keep diagnostic tissue (FFPE blocks and slides). Fresh-frozen tissue and viable cryopreserved tissue are different things, and not every hospital can offer them.
- In England, whole genome sequencing through the NHS Genomic Medicine Service generally needs fresh-frozen tissue, which is one practical reason to ask early whether your hospital can freeze some.
- Keeping tissue for your own possible future use and donating it to research are both valid choices.
- Private storage is a personal choice. It isn't part of NHS care, it costs money, and we don't endorse any provider.
- Raise it as early as you can, ideally when your surgery is first being planned, and ask who in the neuropathology team deals with tissue questions.

What happens to my brain tumour tissue after surgery?

If you're preparing for brain tumour surgery, you're probably thinking about the operation itself, what the surgeon will find, and what recovery looks like. One question that doesn't always occur to people straight away is what actually happens to the tumour tissue once it's removed. Why does it matter? Because tumour tissue can sometimes open the door to further options, such as clinical trials, genomic testing, drug-response testing and new treatments. Hospitals routinely keep diagnostic tissue, but not every hospital can also preserve it in ways that suit every kind of future test or trial, so it's worth asking what will happen to yours and how it will be stored.

Some of that tissue will always be needed by the pathology team, to confirm your diagnosis and carry out molecular or genetic testing. But depending on how much tissue can safely be taken, there's sometimes some left over, and you can ask what

will happen to that surplus and discuss what options may be available for it. Some people want tissue kept back for their own possible future use, whether that's a clinical trial, further genetic testing, or a personalised treatment further down the line. Others decide to directly donate to research to help others. Some do both.

This guide walks through what typically happens to brain tumour tissue in the UK, the different ways it can be preserved, what you can ask for so your own future options stay open, and how you can pass tissue on to research, when and if that feels right for you. Throughout, we've linked to further guides where relevant, including talking to your neurosurgeon about tissue collection and brainstrust's tissue donation campaign, both of which are useful for more information.

Why is tumour tissue taken during brain surgery?

Your clinical care comes first, always. When a biopsy or resection is carried out, tissue goes to a neuropathology laboratory, where a neuropathologist works out what type of tumour it is (there are over 100 types and subtypes of primary brain tumours) and what its characteristics are.

Diagnosis usually involves more than looking at cells under a microscope, it may include an exploration of its genetic profile, so that a more accurate diagnosis can be formed. Molecular and genetic features can help classify a tumour more precisely and, in some cases, guide treatment.

Enough suitable tissue must always be kept back for your diagnosis and any testing your team needs. That comes before anything else, and it should never be compromised by other plans for the tissue. Only what's left once that's covered could potentially be preserved in other ways.

What normally happens to my tumour tissue?

There isn't one answer that fits every patient or every NHS hospital. What happens depends on things like:

- how much tissue can safely be removed
- how much is needed for an accurate diagnosis
- the type and location of the tumour
- what molecular or genetic testing is required
- the facilities available at that particular hospital
- local pathology procedures
- whether you're taking part in a research study or tissue bank
- whether you've arranged another form of preservation in advance

The standard method used in pathology labs is formalin fixation and paraffin embedding, usually just called FFPE. Some hospitals can also preserve fresh or frozen tumour tissue, and it's worth knowing straight away that these aren't the same thing.

What is FFPE?

Formalin-fixed paraffin-embedded tissue has been the backbone of pathology for decades. The tissue is treated with formalin to preserve its structure, then embedded in wax, and thin sections can be cut from the block whenever they're needed and examined under a microscope.

It's a routine, well-proven part of diagnosis, and FFPE tissue can be used for a good number of molecular tests too, so it shouldn't be dismissed as “dead” tissue with no further use. However, it does have drawbacks. Formalin does change the tissue: fixation can cause cross-linking and fragmentation in molecules like DNA and RNA, and once tissue has been formalin-fixed, there's no going back to a fresh or viable state.

What does freezing tumour tissue mean?

Freezing is where the language gets confusing, because “frozen tissue” can mean more than one thing.

Fresh or snap-frozen tissue. Tissue can be rapidly frozen after removal. This kills the cells, but preserves DNA, RNA, proteins and other molecular features differently to formalin fixation, and can make a sample more useful for certain kinds of molecular analysis, research or clinical trials. The British Neuro-Oncology Society (BNOS) has specifically flagged how important it is to obtain enough fresh tissue during brain tumour surgery for diagnostic genetics and newer therapies. Its 2023 position statement, Guideline for tissue sampling of brain tumours, sets out an ideal of three samples: one formalin-fixed for diagnosis, one frozen at −80°C for whole genome sequencing, and one frozen at −80°C and stored for future therapeutic, diagnostic or research use. This still isn't standard practice everywhere: not every UK hospital has the same facilities or pathway for fresh-freezing brain tumour tissue.

Cryopreserved viable tissue. This is a further distinction worth knowing. Freezing a piece of tumour doesn't automatically mean the cells inside it stay alive. Specialist cryopreservation aims to keep cells viable so they can be thawed later and still be living, which needs particular collection, handling, transport, processing and storage methods. This matters because some potential applications need viable cells, not just DNA, RNA or a fixed sample.

It's also generally a one-way choice: viable tissue can later be processed into a fixed or frozen format if that's what a particular test needs, but tissue that's already been fixed or frozen without special care for viability can't be turned back into living cells. That's one reason viable cryopreservation is often described as keeping the widest range of future options open, though it's not widely used in the NHS either. Where a hospital can't offer it, some patients arrange it separately through a specialist private service instead.

All of which means that asking “will you store my tumour?” doesn't tell you much on its own. A more useful question is: ‘how will my tumour tissue be preserved, and what could that particular form of preservation allow it to be used for later?’

Paying for private storage?

Some storage methods may not be available on the NHS and may have to be paid for privately. Private storage is a personal choice: it isn't part of NHS care, it costs money, and this guide isn't suggesting that paying privately is the answer. If you're thinking about private storage, it's worth asking any provider:

- Do you hold the right Human Tissue Authority (HTA) license for storing human tissue?
- What does it cost to set up, and what will I pay each year after that?
- What happens to my tissue if your company stops trading?
- Who can authorise releasing my tissue, and how does that work?
- What rights do I keep over my tissue stored with you, and could it be used, shared or sold without my consent?
- Will NHS laboratories and clinical trials accept tissue stored with you?
- Can you send my tissue globally for trials, tests, and treatments?

Why might I want some tumour tissue preserved?

There are a few reasons this might matter to you.

Further molecular or genomic testing. Tumour tissue carries information about the genetic and molecular make-up of the cancer, and depending on your diagnosis, further testing may be useful now or become relevant later. Many modern molecular tests work perfectly well on routine FFPE material, so frozen tissue isn't required for everything, though appropriately preserved fresh or frozen tissue can have advantages for some kinds of analysis. One example is whole genome sequencing: in England, through the NHS Genomic Medicine Service, whole genome sequencing for eligible brain tumours generally needs fresh-frozen tissue, which is one practical reason to ask early whether your hospital can freeze some.

Clinical trials. Some trials need tumour tissue to be available, and requirements vary hugely, from accepting archived FFPE tissue through to needing freshly obtained or frozen material. Having stored tissue doesn't guarantee you'll be eligible for a trial, but how it was preserved can sometimes decide whether it's usable for one. brainstrust's own clinical trials information is a good starting point if this is something you want to explore, alongside NIHR Be Part of Research.

Personalised treatments. Some personalised or experimental approaches use material taken from an individual's own tumour, whether that's tumour antigens, proteins, genetic information or living cells. Certain personalised cancer vaccines and cellular immunotherapies, such as TIL (tumour-infiltrating lymphocyte) therapy, fall into this category. Not all of these are standard NHS treatments, and evidence, availability and regulatory status vary a lot, so it's best to think of preserved tissue as keeping future possibilities open rather than banking a guaranteed treatment. TIL therapy and personalised vaccines aren't established treatments for brain tumours,

so please be cautious of any clinic offering unproven treatments using your stored tissue, and talk to your clinical team first.

Drug-response (chemotherapy sensitivity) testing. There are companies around the world that can test living cells from your own tumour against a range of drugs, including chemotherapy, to see how the cells respond. Some people use the results to help them talk through their options with their oncologist. This kind of testing needs viable tissue, meaning cells that are still alive, which is one reason viable cryopreservation is sometimes discussed. These services aren't part of routine NHS care and usually must be paid for privately. It isn't yet established how well a result in the laboratory predicts how a person will respond to treatment, so it's best to talk any results through with your clinical team.

Research. Brain tumour tissue is hugely valuable to research: understanding why tumours develop and behave as they do, identifying biomarkers, investigating treatment resistance, and developing and testing new treatments. Once tissue your team needs for your diagnosis is secured, any surplus can be donated to research if you wish. Research tissue banks in the UK include BRAIN UK, a virtual archive of brain tissue samples and linked data, mostly left over from diagnostic work at NHS neuropathology centres, which researchers can apply to use.

Donating tissue to research and preserving tissue for your own potential future use aren't necessarily the same thing, so it's worth asking exactly what you're consenting to, and whether tissue donated to a research bank could later be made available for your own clinical use should you need it.

It isn't only the solid tumour that can be preserved

Tissue is the focus of this guide, but depending on your surgery, it isn't the only biological material that might be worth asking about.

Cerebrospinal fluid (CSF). This is the clear fluid that surrounds your brain and spinal cord, and during some brain tumour operations, surgeons already have access to it anyway, for example when the ventricles or cisterns are opened. It's worth knowing about, because CSF isn't just spare fluid: it can carry material from your tumour too, including DNA, RNA, proteins and, sometimes, tumour cells themselves, which researchers are studying as a possible complement to tumour tissue.

In 2023, the Response Assessment in Neuro-Oncology (RANO) working group recommended that CSF can be considered for storage if available during surgery without adding any risk to you, and that it can then be frozen at around −80°C for later analysis. In one small study of 22 patients, researchers looked at both the tumour tissue and the CSF taken during the same glioblastoma operations, and found that most patients (15 of 22, or 68%) had at least one genetic change picked up in the CSF that the tissue alone had missed. That's an interesting early result, but because the study was small, it remains an active area of research rather than routine practice.

Cyst fluid. Some brain tumours, including some glioblastomas, have a fluid-filled cyst as part of them. If yours does, that fluid can potentially be collected and

preserved during surgery too, alongside the solid tissue. It's obviously only relevant if your tumour has this cystic component in the first place.

Blood. Blood taken around the time of surgery can also be banked alongside tumour tissue and any CSF, for future molecular or immune analysis.

Does my NHS hospital already store my tumour?

You might assume your NHS hospital already stores your tumour. Almost certainly it stores some diagnostic material, though that may not be what you're picturing. Pathology departments keep tissue blocks and slides for a long time.

But “the hospital is keeping some of my tissue” and “my tumour has been cryopreserved for my future use” are two quite different things. It's worth asking exactly what material will be retained, how it will be preserved, roughly how much is likely to be kept, where it will be stored, what it could potentially be used for, and whether it could be accessed or transferred later if another laboratory or treatment provider needed it.

Can I ask the NHS to freeze my tumour?

Yes. You can absolutely raise this with your clinical team and ask what preservation options are available at your hospital. Many brain tumour charities encourage patients to bring up tissue collection and preservation with their clinical team, whether that means asking for tissue to be kept back for your own possible future use, or arranging for it to go to research.

Whether fresh-freezing is actually possible in your case is a separate question, and one worth asking early rather than assuming either way. Fresh-freezing capability isn't yet consistent across the NHS. In a written answer on 3 July 2026, the Department of Health and Social Care confirmed that although standard operating procedures for fresh-freezing tissue have already been developed across pathology networks in England, individual pathology services maintain their own procedures, reflecting local capabilities and practices, including access and storage capacity for neurosurgery services. In practice, that means one hospital may give you a different answer to another, which is exactly why it's worth asking rather than assuming.

How early should you ask? As early as you can, ideally when your surgery is first being planned or at your pre-operative appointment, rather than in the days just before. Start by speaking to your neurosurgeon or clinical nurse specialist.

Do I own my tumour once it's been removed?

Another common question is whether you own your tumour once it's been removed. This is more complicated than it sounds. Human tissue is governed by legislation, consent requirements, professional guidance and common law, with different legislation applying in different parts of the UK, so it isn't as simple as saying that because the tumour came from your body, it's automatically owned by you. In England, Wales and Northern Ireland, the Human Tissue Act 2004 regulates the removal, storage and use of human tissue for specified purposes; Scotland has its own equivalent in the Human Tissue (Scotland) Act 2006. Both place real weight on consent and on the purposes tissue is stored and used for, and hospitals also carry

clinical responsibilities around tissue needed for your diagnosis, review, further testing or future care.

So rather than asking whether you have a right to take your tumour home, it's more useful to ask what will happen to the tissue removed during your surgery, what needs to be kept for your diagnosis, what your options are for any surplus, and whether suitable surplus tissue could be transferred to a specialist facility if you wanted to arrange that. Tissue is biological material, not a personal possession you can simply collect from theatre.

Can I have tissue sent somewhere else?

Potentially, yes, depending on the circumstances. NHS pathology labs already have established routes for sending slides, sections or tissue blocks to other laboratories for specialist testing or a second opinion (brainstrust's own guide on seeking a second opinion is a useful companion here). Sending fresh or viable material elsewhere is more involved, since the speed of collection, sterile handling, temperature, packaging and transport all matter, along with the receiving laboratory's own requirements.

If you're considering specialist private storage, or a treatment that needs a particular tissue format, speak to that provider before surgery so they can explain their requirements and, where appropriate, liaise directly with your surgical or pathology team. Don't assume arrangements can be made once the operation is already done.

What if my surgeon says there might not be enough tissue?

That can happen, and it's worth being prepared for. The surgeon's priority is always to operate safely, not to obtain a particular quantity of tissue, so depending on the tumour's size and location, sometimes only a small biopsy is possible, and sometimes a much larger resection takes place. The pathology team needs enough suitable tissue to reach the most accurate diagnosis and carry out whatever testing is clinically necessary, and only after that is covered does any additional preservation come into play.

It's also worth knowing that a smaller tumour doesn't automatically mean there are fewer viable cells to work with. Several factors affect that, including any treatment you've already had, and even a small biopsy can sometimes be enough for certain kinds of testing or preservation. What counts as “enough” really depends on what it's needed for, which is worth asking about directly rather than assuming either way.

And remember, you can ask about collecting other material too, like CSF.

What if I've already had my surgery?

If you've already had your surgery, it isn't too late to ask. Get in touch with your clinical team and ask what tumour material was retained, whether there's FFPE tissue, whether any was fresh or snap-frozen, whether anything was stored in a research tissue bank, how long the material will be kept, and whether it could be released for further testing if that became clinically appropriate.

If a further operation is on the cards, you can have this conversation again before that one.

Does storing my tumour mean I'll have more treatment options?

Not necessarily, and this is worth being honest about. Preserving tissue can't guarantee that a new treatment will appear, that you'll be eligible for a clinical trial, that a stored sample will meet a future trial's requirements, that a personalised treatment will suit your tumour, that enough material will be available, that the sample will contain sufficient tumour cells, or that any treatment will actually work.

Tumour biology can also change over time, so tissue from an earlier surgery is really a snapshot of the tumour at that point. If a tumour recurs or progresses, a later sample can sometimes tell you something different, or more relevant, than the first one did.

Preserving tissue is about keeping possibilities open, not promising outcomes.

RECAP: Before surgery, ask how your tumour will be stored

A brain tumour diagnosis brings an enormous amount of information at once, and nobody expects you to become an expert in pathology or cryopreservation while also getting ready for neurosurgery.

Simply download our guide here and make sure to have a conversation with your neurosurgeon as soon as you can.

If you want support having that conversation or just want to talk it through with someone who understands, brainstrust's support team and wider downloads and resources are there for exactly this. Whether you're interested in preserving tissue for your own possible future use, donating surplus tissue to research, or understanding whether both might be possible, the important thing is to ask early enough to understand your options.

About the author: Michel Sadaka is the founder of StoreMyTumor.com, a commercial tumour and fluid preservation service that works with patients and clinical teams worldwide. It preserves tumour tissue in several formats for possible future diagnostic, research and therapeutic use.

A note from brainstrust: We've published this article to help people understand their options around tumour tissue preservation. brainstrust doesn't endorse or recommend any particular provider, product or service. Private tissue storage usually costs money, often including an upfront fee and ongoing storage charges. If you're thinking about it, ask any provider for a full breakdown of costs before you commit, and talk it through with your clinical team.