Campaign for
Owain's Law

Ensuring Brain Tumour Tissue is Flash-Frozen

This document is designed to help patients, carers, or advocates ensure that brain tumour tissue removed during surgery is flash-frozen, enabling future use for **genomic testing**, **research**, **access to some clinical trials** or novel **personalised treatment**.
This document contains information and a template letter to issue to your medical team.

What is this?

Flash-frozen tissue is tumour tissue that is immediately snap-frozen (typically in liquid nitrogen or placed into a -80°C freezer), after removal in the operating room.

This process:

- Preserves DNA, RNA, and proteins
- Allows high-quality molecular analysis
- Is preferred for advanced research and genomic profiling

Why is it important?

There is only one chance to get this right.

Brain tumour tissue is typically and traditionally placed in formalin and preserved in paraffin wax; this is used for histology to confirm the diagnosis.

Diagnosis is important and very little tissue is required for this, but what can often happen is that the whole sample will be fixed in paraffin wax. Making what could be used for something else, unusable.

Your options to have **genomic testing, access to some clinical trials, options for novel personalised treatments** or **donation to research** would be unobtainable without flash-frozen tissue.

Freezing Tissue in Separate Aliquots

Aliquots are small, individual portions of a larger tissue sample, each stored in its own tube or cryovial. Instead of freezing one large piece of tissue, it is divided into multiple smaller samples before being frozen.

This helps to ensure tissue quality, minimises waste, and allows for multiple future analyses or uses without compromising the entire sample.

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Flash-Frozen vs Formalin-Fixed-Paraffin-Embedded (FFPE)

Feature	Fresh-Frozen / Snap-Frozen	Formalin-Fixed-Paraffin-Embedded (FFPE)
Preserves RNA / DNA	✅ Yes	❌ Partially degraded
Used for Genomic Testing	✅ Yes	❌ Limited utility
Required for Diagnosis	❌ Not essential	✅ Yes
Can be Donated for Research	✅ Yes, ideal	❌ Yes, less ideal

Final Tips

- Bring a **written note or letter** summarizing your request to pre-op meetings.
- Nominate a **family member or advocate** to follow up during or after surgery.
- Document all discussions and **get confirmations in writing** where possible.
- If denied, ask for a **written explanation** and request a second opinion if needed.

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Owain's Law is a campaign to propose a law to strengthen transparency, consent and best practice around how brain tumour tissue is handled, stored and used.

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Template Request Letter

Subject: Request for Preservation/Freezing of Surgical Tissue

Dear Dr. [Last Name],

I am writing respectfully to make a request for my upcoming neurosurgical procedure on [date of surgery]. Once the tissue has been removed and a small sample is taken for histology, I am requesting that the remainder of the tissue, as much as possible, be preserved as flash-frozen and placed into multiple aliquots.

The purpose of this request is to ensure that the tissue can be stored for my personal medical reasons. I would be grateful if the hospital could provide guidance on the process, requirements, and any consent forms necessary to allow for the tissue to be frozen and retained in accordance with applicable medical, ethical, and legal standards.

I understand that there may be institutional policies, regulations, and logistical considerations that govern tissue preservation, and I am willing to comply with any administrative steps required.

Thank you very much for your attention to this matter, as well as for your care and expertise in managing my treatment. I appreciate your guidance and support.

Sincerely,

[Your Full Name]