

Desmoid Tumour: Why Monitoring May Come Before Surgery

Understanding the reasons for surveillance and the questions to ask when a plan changes.

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A desmoid tumour can grow into the tissues around it, but it does not spread to distant organs. Its behaviour is variable: it may enlarge, remain stable or shrink. That combination explains why a diagnosis does not always lead straight to an operation.^[1]

This guide concerns a diagnosed desmoid tumour. If you have an unexplained lump, ask for an assessment rather than applying a surveillance plan yourself.

First, confirm what the tumour is

Your assessment usually includes examination, imaging and a tissue sample. MRI or CT helps show the size and location, but desmoid tumours can resemble other soft tissue growths. A pathologist examines the biopsy, commonly obtained with a needle, to establish the diagnosis.^[4]

You may see the terms **desmoid-type fibromatosis** or **aggressive fibromatosis** on the report. These are other names for the condition. "Aggressive" describes its potential to invade nearby tissue; it does not mean that the tumour has spread through the body.^[1]

Why might the team recommend active surveillance?

International consensus places active surveillance at the centre of initial care for many patients. It allows the team to learn how the tumour behaves before exposing someone to treatment and its consequences. An immediate threat to life or function calls for a different approach.^[2]

Some desmoid tumours stabilise or shrink without treatment, even after earlier growth. Evidence for this includes adults with newly diagnosed, sporadic tumours outside the abdominal cavity. Those findings support observation in suitable patients, but cannot establish that waiting is appropriate in every anatomical or inherited-disease setting.^[3]

More about the evidence

The researchers pooled three prospective observational studies of active surveillance. This was evidence about the course of selected tumours during monitoring, rather than a trial proving that observation is better than each treatment option.^[3]

What the monitoring plan should cover

- The next clinical review and scan.
- Changes that need contact before that appointment.
- Who will compare the scans and explain the result.
- What would prompt a recommendation for treatment.

A scan measurement is only part of the assessment. Worsening pain or function can matter even without enough growth to meet a study definition of progression. In the surveillance studies, symptoms sometimes prompted treatment for that reason.^[3]

Dr. Vishnu's perspective

I do not want observation to mean that you are left managing pain and worry until the next scan. We should agree how symptoms will be managed, when we will reassess and whom you can contact sooner. Tell me what has become harder in daily life, even if your main concern does not seem to be captured in the scan report.

What can change the decision?

Persistent growth, worsening symptoms and the tumour's relationship to important structures help guide the decision. The team weighs the harm the tumour may cause against the harm of treatment. Surgery remains an option for selected cases where removal can achieve useful control without disproportionate loss of function.^[2]

Other options include medicines, radiotherapy and selected ablation procedures. Cryoablation uses probes to freeze tumour tissue and may suit some smaller tumours outside the abdomen. Reconsidering treatment does not automatically mean having surgery. The choice depends on the tumour's position, symptoms and treatment goals.^[4]

Where does nirogacestat fit?

Nirogacestat, sold as Ogsiveo, is a medicine with a US approval for adults whose desmoid tumour is progressing and requires systemic treatment. "Systemic" means treatment with a medicine acting throughout the body, rather than a procedure directed only at the tumour.^[5]

The approval followed the DeFi trial, which compared nirogacestat with placebo in adults with progressing tumours that were not suitable for surgery. The drug delayed progression and improved patient-reported pain in that study. These results concern patients who needed treatment; they are not a reason to prescribe it for every newly diagnosed desmoid tumour.^[6]

The safety discussion is substantial. Risks include severe diarrhoea, liver problems, electrolyte disturbances and serious allergic reactions. Ovarian function and fertility may be affected, and long-term fertility effects remain uncertain. Pregnancy risks, interactions with other medicines and the required monitoring should be discussed before treatment.^[5]

Living with a plan that involves waiting

Surveillance can leave you with questions between appointments. Your results deserve an explanation in language you understand, and worry that affects daily life deserves support. A counsellor or a patient support group may help you talk through the uncertainty.^[4]

A short written explanation from the team should make the reason for monitoring and the next decision point clear: what are we watching for, and what will we do if it happens?

Frequently Asked Questions

Can a desmoid tumour spread to the lungs?

Desmoid tumours do not metastasise, meaning they do not travel to distant organs such as the lungs. They can still grow into nearby tissues and cause serious local problems. The tumour's location therefore matters. ^[1]

Can a desmoid tumour get smaller without treatment?

Yes. Spontaneous shrinkage has been documented, including after an initial period of growth. This does not predict what one person's tumour will do. The prospective surveillance evidence discussed here concerns adults with primary, sporadic tumours outside the abdominal cavity. [\[3\]](#)

Does growth on one scan mean I need surgery?

Not necessarily. Specialists consider whether growth persists, how symptoms are changing and whether important structures are threatened. Treatment may be needed sooner if there is an immediate threat to function or health. The treatment selected need not be surgery. [\[2\]](#)

Is nirogacestat suitable for every desmoid tumour?

No. Its US indication is for adults with progressing desmoid tumours who require systemic treatment. Suitability also depends on safety considerations, other medicines and reproductive plans. A stable tumour under surveillance does not automatically need this drug. [\[5\]](#)

Your consultation

Discussing your desmoid tumour monitoring plan

You can book a consultation with Dr. Vishnu Baburaj at Aster MIMS Kannur to discuss your desmoid tumour monitoring plan.

[Book a consultation](#)

[Plan your visit](#)

The evidence behind this article

1. National Cancer Institute. [Desmoid Tumor](#). Posted 27 February 2019. Definition, diagnosis and behaviour sections.
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4. Mayo Clinic. [Desmoid tumors: Diagnosis and treatment](#). 4 September 2026.
5. SpringWorks Therapeutics, Inc. [OGSIVEO \(nirogacestat\), full US prescribing information](#). Revised August 2026. Sections 1, 5, 7 and 8.
6. US Food and Drug Administration. [FDA approves nirogacestat for desmoid tumors](#). 27 November 2023. DeFi trial and approval summary.

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