

OPTIMIZING TENOSYNOVIAL GIANT CELL TUMOR (TGCT) CARE: A PRACTICAL GUIDE*

BASED ON AN INTERNATIONAL EXPERT CONSENSUS
& SHARED DECISION-MAKING PRINCIPLES¹⁻⁴



TGCT patient management

Quality of life (QoL) should remain a guiding principle²

- TGCT can significantly affect QoL, even though it is rarely life-threatening¹
 - Ask patients about their symptoms, which may include pain, swelling, limitation in range of motion, joint instability or locking, or numbness¹
 - Ask patients about impact on daily life, including work, exercise and their mood¹
- Treatment decisions should always consider the potential impact on a patient’s daily functioning, wellbeing, potential morbidity or disability, and long-term outlook¹
- Shared decision making should be prioritized, empowering patients to choose appropriate care that aligns with their treatment goals and preferences^{2,4}



Referral to a sarcoma specialist

- Referral to specialized sarcoma centers is critical to ensure patients receive timely access to multimodal diagnosis and treatment approaches³
- Optimal management depends on evaluation by a specialized multidisciplinary team (MDT), where treatment decisions can be carefully balanced against recurrence risk and long-term outcomes³
- A collaborative approach between the patient and the MDT is critical to ensure the chosen path reflects both clinical best practice and individual needs³



Management options



Active monitoring, if:

Patient status and considerations:

- The patient is **asymptomatic** (no pain, swelling, or reduced function)¹
- The patient is **symptomatic but would likely experience significant morbidity with surgery** (This decision should be made in agreement with the MDT and the patient themselves. An individualized follow-up plan should also be implemented)¹
- The tumor appears **slow-growing or indolent** in nature¹
- The patient is at **risk of major morbidity or medical treatment** (e.g., chronic hepatitis or history of severe toxicity from previous treatment)¹

Expected outcomes:

- The **risks** of surgery or systemic treatment outweigh the potential benefits¹
- The **expected benefit of intervention is limited** due to tumor location or morbidity risk¹

Support and follow up:

- The **patient agrees** to active surveillance after a shared decision-making discussion^{1,2}
- Follow-up can be tailored to tumor behavior, location, and evolving symptoms¹
- The decision is supported by a **MDT**¹



Surgery, if:

Patient status and considerations:

- No critical anatomical involvement** (neurovascular bundles, major muscles, complex joint compartments)¹
- No extensive infiltration** requiring amputation¹
- Low recurrence risk**¹
- Consideration for the increasing risk of local relapse with multiple surgeries**¹

Expected outcomes:

- Expected **low morbidity and significant improvement** in QoL and symptoms¹
- Marginal resection achievable** (especially in N-TGCT)¹
- The expected benefits of surgery **outweigh** any potential loss of function¹



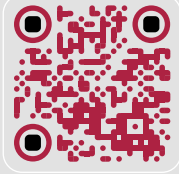
Systemic treatment, if:

- Tumor location is potentially life-threatening (e.g., cervical spine) in asymptomatic cases**¹
- Symptomatic disease is difficult to manage, or if moderate/severe functional impairment is present** (and if surgery would be associated with significant morbidity)¹

The **potential benefits** of any systemic treatment need to be **carefully weighed against side effects and impact on QoL**.¹

While the systemic treatment landscape for TGCT is rapidly evolving, the **availability of these therapies may differ across countries**.¹

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*TGCT is also known as pigmented villonodular synovitis (PVNS).¹ M-TGCT is not under the scope of this checklist.
D-TGCT, diffuse-type TGCT; M-TGCT, malignant TGCT; MDT, multidisciplinary team; N-TGCT, nodular-type TGCT; PVNS, pigmented villonodular synovitis; QoL, quality of life; TGCT, tenosynovial giant cell tumor.
References: 1. Stacchiotti S, et al. *Cancer Treat Rev.* 2023;112:102491. 2. NICE. About shared decision making. <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>. Accessed: September 2025. 3. CancerCare. Improving Resources and Support for Patients with Tenosynovial Giant Cell Tumor. https://media.cancercare.org/publications/original/431-2021_TGCT.pdf. Accessed: September 2025. 4. European Cancer Organization. Shared Decision-Making. Available at: <https://www.europeancancer.org/content/the-code-shared-decision-making.html>. Accessed: September 2025.
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