

After A Tenosynovial Giant Cell Tumor (TGCT) Diagnosis: Questions To Ask Your Doctor

A diagnosis of Tenosynovial Giant Cell Tumor (TGCT) can be overwhelming. This fact sheet will tell you:

- How to prepare for your appointments
- More about what TGCT is
- What questions will help you learn more about your diagnosis
- Treatment options for TGCT



The Importance of Communicating With Your Health Care Team

Your team of doctors, nurses and social workers are there to help. Here are some tips for your appointments.

- **Bring a list of questions.** This will help you remember important things to ask. Write down or record the responses so that you do not forget them.
- **Consider bringing a loved one with you.** A friend or a family member can help ask questions and provide emotional support.
- **Ask questions about costs.** Knowing how much your treatment and medications might cost can help you plan ahead and focus more attention on getting better.

If your doctors and nurses do not know every answer, they may be able to guide you to those who do.



What Is Tenosynovial Giant Cell Tumor (TGCT)?

TGCT is not a cancer. It is a rare, benign (non-cancerous) tumor that grows in the lining of joints or sheaths of your tendons. While it is non-cancerous, it can grow and cause damage in the tissue and surrounding structures of the affected area. This can cause pain, swelling and tenderness that can affect movement and stability of the affected joint.

There are two kinds of TGCT:

Localized: The tumor is slow-growing and typically confined to a small area, most commonly the fingers. Wrists and hands can also be affected.

Diffuse: More aggressive than the localized type and the tumor can spread outside the joint. Diffuse TGCT primarily affects large joints such as the knee, hip, ankle or shoulder. There may be multiple tumors at the same time and it has a higher rate of recurrence than the localized type.



Questions That You May Want to Ask Your Health Care Team

The following questions should help you learn key information about your diagnosis and situation.

“How is TGCT diagnosed?”

TGCT is diagnosed through a combination of physical exam, imaging tests such as X-rays and MRIs and biopsy.

“What stage is my TGCT?”

TGCT is not classified by stage, but instead by whether it is localized or diffuse-type.

“What are my treatment options?”

TGCT is often treated by surgery, radiation or targeted therapy. See below for more.



How Is TGCT Treated?

Although TGCT is not a cancer, it is often treated by an oncologist, as they understand how tumors grow and can guide treatment decisions.

Your treatment team will help decide what approach is best. Depending on type of TGCT and its location, they may decide to monitor, or watch, the tumor.

Surgery is the main treatment for TGCT. Most often, this means the tumor is removed along with any inflamed joint tissue.

Radiation or targeted therapy are sometimes used in cases of diffuse TGCT or TGCT that recurs (comes back).

Discuss with your health care team what options are best for you.

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