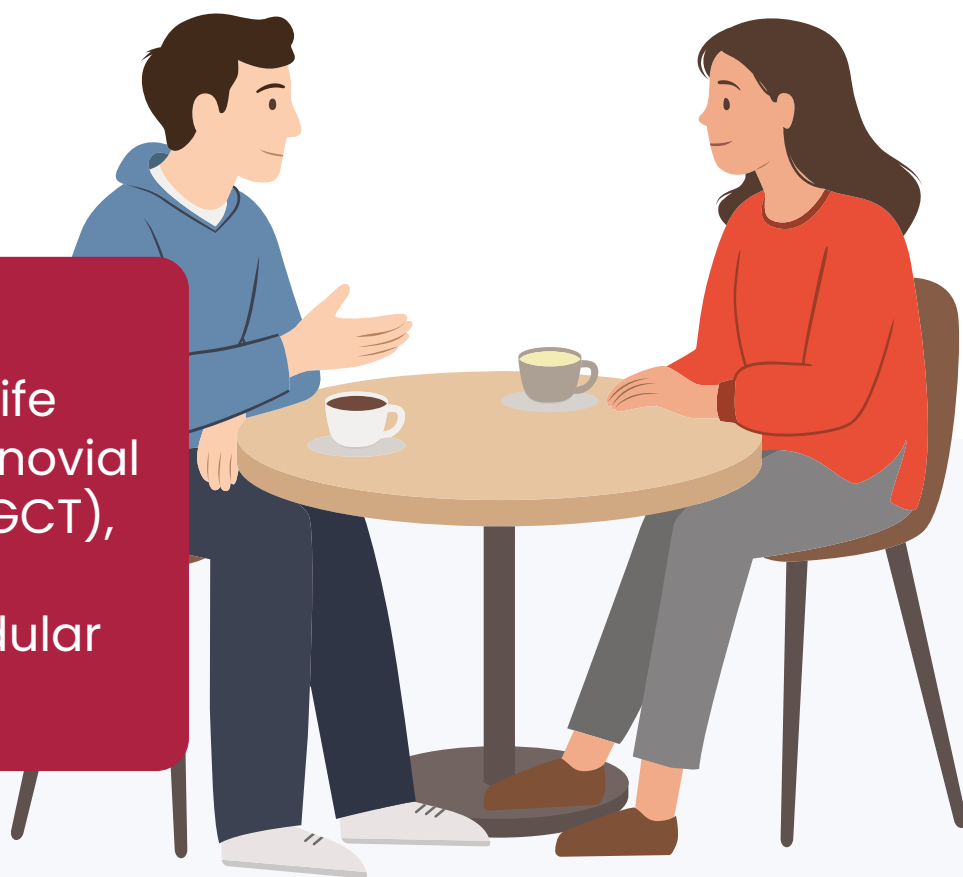


LIVING WITH TGCT

A guide to helping the people in your life understand tenosynovial giant cell tumor (TGCT), formerly known as pigmented villonodular synovitis (PVNS)



This leaflet has been developed by Deciphera Pharmaceuticals and is designed to help people living with TGCT explain their condition to those around them. It is not intended to promote any specific product, treatment or service. Intended for audiences in Europe only.

© 2026 Deciphera Pharmaceuticals. Deciphera, Deciphera Pharmaceuticals, and the Deciphera logo are registered trademarks of Deciphera Pharmaceuticals, LLC. All rights reserved.

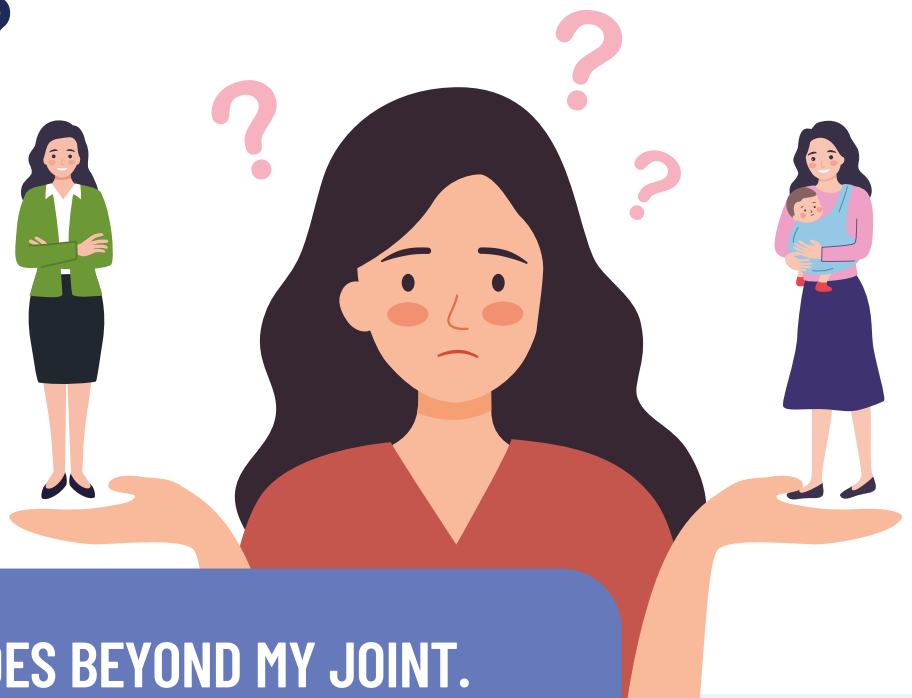
DCPH-P03683 | September 2026

deciphera[®]
a member of
ONO PHARMA

WHAT IS THE PURPOSE OF THIS LEAFLET?

I am sharing this because I want you to understand:

- Why I may be in pain even when I look well
- How TGCT affects me
- How you can support me



THE IMPACT OF TGCT GOES BEYOND MY JOINT. IT CAN AFFECT HOW I MOVE, WORK, SOCIALIZE, PLAN, AND EXPERIENCE EVERYDAY LIFE*

WHAT IS TGCT?



TGCT is a type of rare, non-malignant tumor occurring in the joints and sometimes the surrounding area



TGCT grows within or around a joint and in some cases, can damage surrounding tissues. Symptoms include pain, stiffness, and reduced mobility



Non-malignant means the tumor is not cancerous. It is a type of tumor that usually grows slowly and doesn't typically spread to other parts of the body, unlike cancer



Managing TGCT may involve ongoing appointments, treatment, or procedures, and some of us may continue to experience symptoms despite treatment



Although it is usually not life-threatening, TGCT is a chronic condition which can have a significant impact on daily life

*Fictional patient quote.
TGCT, tenosynovial giant cell tumor.

MY DAILY REALITY WITH TGCT

TGCT OFTEN LEADS TO PAIN, STIFFNESS, SWELLING, AND LIMITED MOVEMENT IN THE AFFECTED JOINT, AND CAN SOMETIMES CAUSE PERMANENT DAMAGE.



PAIN

Joint pain is one of the most commonly reported symptoms.

Pain affects more than physical comfort:

- It can interfere with day-to-day activities and enjoyment of life
- It can also impact family life, household tasks, social activities, and concentration



MOBILITY CHALLENGES

Simple activities can become difficult due to restricted movement.

The impact of TGCT is not the same for everyone, depending on the affected joint, symptoms, and severity of disease.

Things I may struggle with:

- Walking for extended periods
- Shopping or running errands
- Household chores
- Going up and down stairs
- Lifting or carrying things
- Reaching for objects



EVEN WHEN I LOOK WELL, I MAY BE DEALING WITH SYMPTOMS IN THE BACKGROUND*



WORK

For some of us, TGCT can affect work, including:

- Time away for appointments or treatment
- The ability to carry out certain physical tasks
- Career choices and financial planning

*Fictional patient quote.
TGCT, tenosynovial giant cell tumor.

LIFE WITH A CHRONIC LONG-TERM CONDITION

FOR MANY OF US, TGCT CAN SIGNIFICANTLY IMPACT QUALITY OF LIFE.

LIVING WITH UNCERTAINTY

- Symptoms may change over time and can be difficult to predict
- TGCT is associated with concerns about treatment, recurrence, and future symptoms
- Living with a chronic condition can affect independence, planning, everyday activities, and overall well-being

In addition to the physical symptoms, TGCT can also influence:



Relationships and family life



Hobbies and social activities



Plans and potentially important life decisions

LIVING WITH TGCT CAN SOMETIMES BE FRUSTRATING AND EMOTIONALLY CHALLENGING. I OFTEN HAVE TO ADAPT MY PLANS, ROUTINE, AND ACTIVITIES*

MANAGING TGCT OVER TIME

- For many of us, TGCT management involves appointments, scans, physiotherapy, treatment, and follow-up care
- Some of us may have had one or more surgeries; recovery and rehabilitation can take time. Reduced mobility and other symptoms may persist even after surgery
- Even when symptoms are not visible, daily life may require extra time, planning, and adjustment

*Fictional patient quote.
TGCT, tenosynovial giant cell tumor.



HOW CAN YOU SUPPORT ME?

SIMPLE WAYS TO HELP:



LISTEN

Listen without judgement and trust what I'm telling you, even if my symptoms aren't visible



BE FLEXIBLE

Symptoms may change unexpectedly, so I may need to change plans, take breaks, or ask for help at short notice



STAY CONNECTED

Keep checking in, even if I've had to cancel plans or seem quieter than usual



OFFER PRACTICAL HELP

Small things, like helping with shopping, transport, or household tasks can make a big difference



LEARN ABOUT TGCT

Learning about the condition can help you understand what I'm going through and reduce misconceptions

EVERYONE EXPERIENCES TGCT DIFFERENTLY, SO ONE OF THE BEST WAYS YOU CAN SUPPORT ME IS BY ASKING WHAT I NEED.

FIND SUPPORT AND HEAR FROM OTHERS LIVING WITH TGCT.



Visit livingwithtgct.eu to explore patient stories, resources, and more information about life with TGCT.