

# WHAT DOES TGCT MEAN FOR OUR FAMILY?



**This booklet has been developed by Deciphera Pharmaceuticals and is intended for adults living with TGCT to use with children in their lives. It is designed to support conversations about TGCT in a simple, age-appropriate way and should be read and discussed together, rather than used independently by children. It is for educational purposes only and is not intended to promote any specific product, treatment or service. Intended for people in Europe only.**

TGCT, tenosynovial giant cell tumor.

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# WHAT IS TGCT?

I have something called tenosynovial giant cell tumor (TGCT) that affects the joints in my body.

TGCT happens when when a lump starts growing in my joint.

### This can make it feel:

**Sore**

**Stiff**

**Hard to move**

**A little swollen or puffy**

You can't catch TGCT from someone else. Nobody caused it – sometimes it just happens.

### What is a joint?

A joint is a special place in your body where two bones meet.

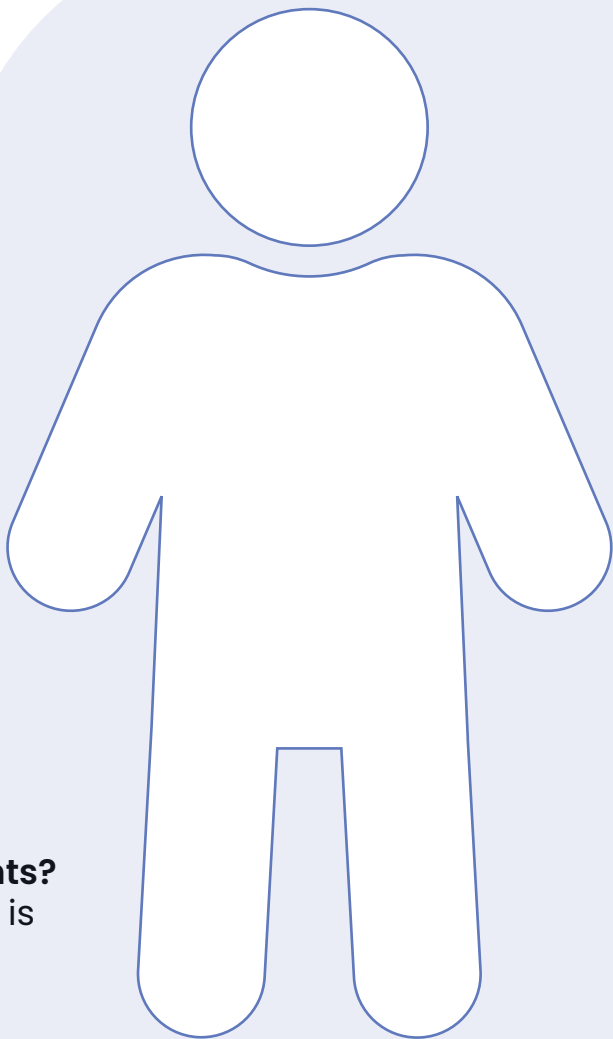
It works like a hinge, helping you bend, twist, and move.

Without joints, your body would be very stiff!

**Can you find and circle the joints?**  
Ask me to show you which joint is affected by my TGCT.

*TGCT MAY BE PART OF MY LIFE FOR A LONG TIME, BUT I HAVE A TEAM TO HELP ME TAKE CARE OF IT.*

## ACTIVITY



# WHY DON'T I ALWAYS LOOK SICK?

YOU CAN'T ALWAYS SEE TGCT, BUT IT IS STILL THERE.

Sometimes my body hurts even when it looks okay.

Some days I may need to rest more than other people. This helps me take care of my body.

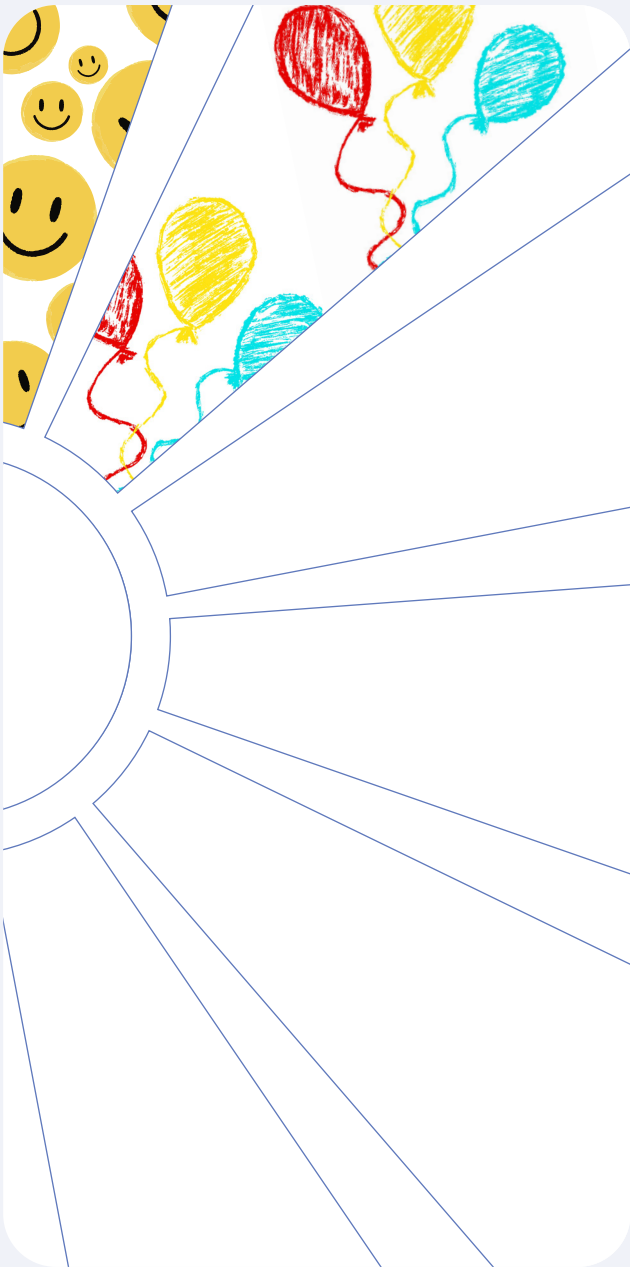
### How can you help?

- Drawing a nice picture before appointments
- Giving great hugs
- Making me smile
- Spending time with me

*YOU DON'T HAVE TO DO SOMETHING BIG TO MAKE A DIFFERENCE. SMALL ACTS OF KINDNESS, LIKE A HUG, CAN BRIGHTEN SOMEONE'S DAY.*

## ACTIVITY

**Can you help the sun shine?**  
Fill the rays with things that make someone smile. Some examples are already there to help you!



# WHY DO OUR PLANS SOMETIMES CHANGE?

## SOME DAYS ARE EASIER THAN OTHERS

The way my body feels can be different from day to day.

Sometimes my joint feels good, and other times it feels grumpy and needs a little extra care.

On some days, I may not be able to go on big adventures. Instead, we can enjoy a quieter adventure.

IF MY JOINT FEELS BAD, WE MIGHT NEED TO CHANGE OUR PLANS

-  We might stay at home instead of going out
-  We could choose a quiet activity, like reading, drawing or watching a movie
-  We can still find ways to have fun

## ACTIVITY

Match the animal with their special way of adapting.



The chameleon...



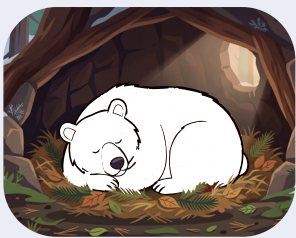
The bird...



The squirrel...



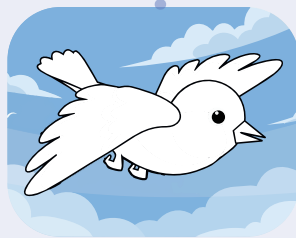
The bear...



...rests in its den during winter



...collects food to save for later



...flies somewhere warmer during winter



...changes color to blend in

## WHY DO I GO TO THE HOSPITAL?

### MY HELPING TEAM

Hospitals are places where people like doctors and nurses can take care of me.

They work together as a team to help me feel better and look after my joint:

- Some explain the disease and how we can treat it
- Some help me with movement exercises
- Together as team, they help me to get better

Sometimes they might use a really cool machine called an MRI to look inside my body and take special pictures of my joint.



## ACTIVITY

Can you be a hospital explorer?  
Find all three chameleons hiding in the picture.

SOME DAYS I NEED TO VISIT THE HOSPITAL BUT THAT'S OKAY. MY HELPING TEAM IS HERE TO SUPPORT ME EVERY STEP OF THE WAY.

MRI, magnetic resonance imaging; TGCT, tenosynovial giant cell tumor.

# WHY DO WE SOMETIMES HAVE BIG FEELINGS?

## LIVING WITH TGCT CAN BRING LOTS OF DIFFERENT FEELINGS.

Sometimes we may feel:

- Happy
- Excited
- Rested
- Hopeful
- Energetic

OR

- Cross/upset
- Worried
- Sad
- Tired
- Confused
- Angry

### ACTIVITY

Feelings can look different for everyone. Draw a picture to show how you're feeling today!



ALL FEELINGS ARE OKAY, AND TALKING ABOUT THEM HELPS.



# CAN WE STILL DO THINGS TOGETHER?

TGCT IS ONLY ONE SMALL PART OF OUR LIFE. IT DOESN'T CHANGE HOW MUCH I LOVE YOU.

TGCT might change the way we do things sometimes, but it doesn't change how much we care about each other.

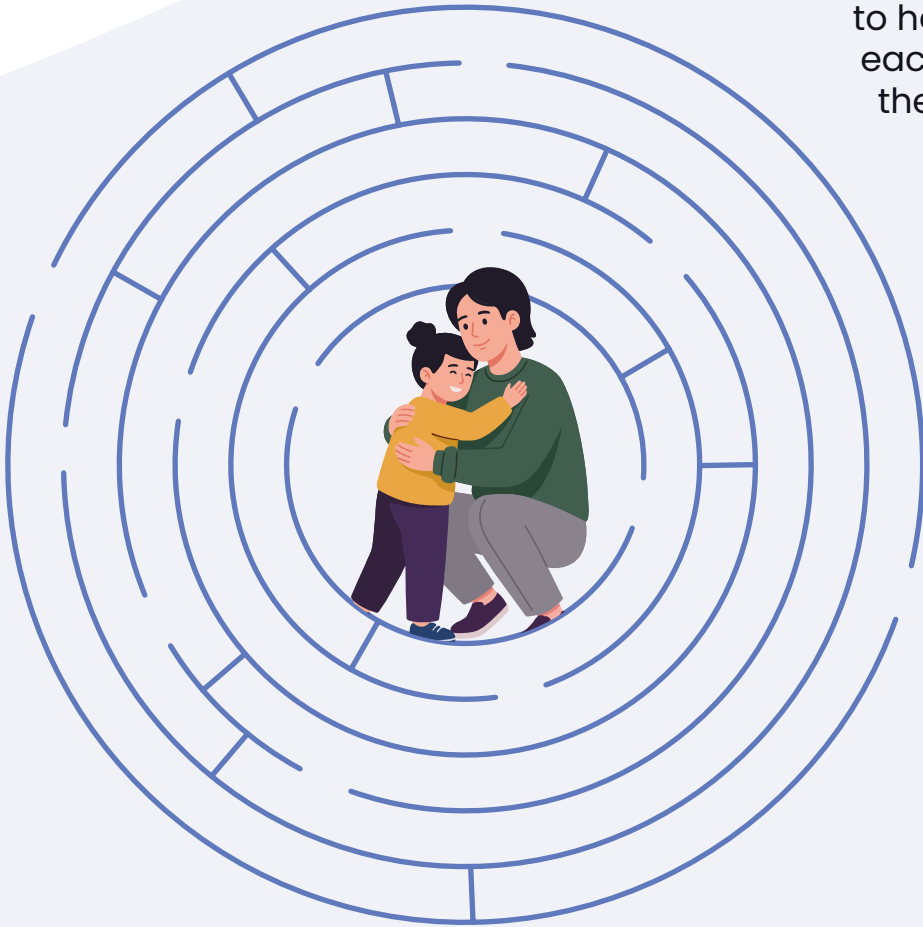
We may do some things differently.

We may do some things more slowly.

But we can still spend time together, laugh, and make special memories.

### ACTIVITY

Solve the maze to help us find each other in the middle.



# WHAT WOULD YOU LIKE TO ASK ME?

## SOMETHING YOU WOULD LIKE TO KNOW

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## SOMETHING YOU WOULD LIKE US TO DO TOGETHER

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