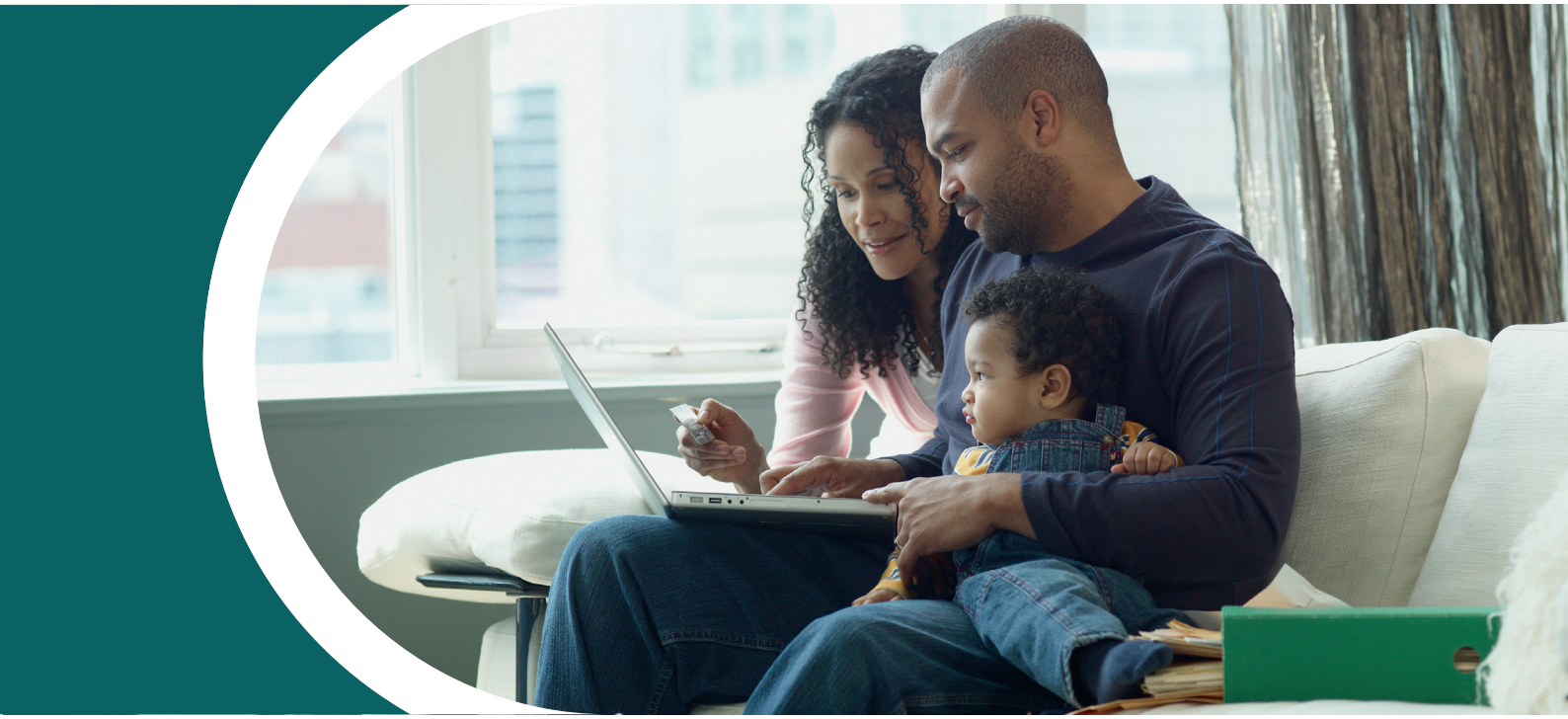
Living with cTTP



A diagnosis of congenital thrombotic thrombocytopenic purpura (cTTP) can lead to changes in your daily life. These changes can affect how you plan your routine, or prepare for the future and major life events.

This resource has practical information to help people with cTTP manage daily life and prepare for treatment. It is also useful for people who care for someone with cTTP.

Our resource ***"Information and support for people affected by cTTP"*** explains cTTP and supports you in coping with the emotional impact of a diagnosis. Ask your doctor or nurse for a copy of this resource.

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Adapting to change

Congenital thrombotic thrombocytopenic purpura (cTTP) can affect many different aspects of your daily life. This can include changes in your energy levels, or in your work, school, or social life as you manage the condition and have treatment.

These changes can affect people diagnosed with cTTP as well as those caring for someone with the condition.

Understanding how cTTP impacts you and preparing for change can help you cope with feelings of uncertainty, give you back a sense of control, and allow you to feel more organized and confident in living with cTTP. The information in this resource can help you prepare for and adapt to changes.



Responding to how you feel

You may have days when you feel tired or less able to think as clearly and quickly as usual. It is important to listen to your body and only do what you are able to do. Responding to how you feel and being flexible with your schedule can help you make the most of the days when you have more energy.



Taking precautions to stay well

People with cTTP may bruise more easily or need to take precautions to minimize injuries that could cause bleeding. Consider your usual activities, such as socializing, playing sports, or your hobbies. You can speak to your doctor about any precautions you may need to take while doing these activities, and how to manage any risks, to help you to stay safe and well.



Looking to the future

In the future, you may experience life changes such as moving house, going to college, or deciding to travel. If your child has cTTP, there may come a time when they learn to manage their care themselves. Thinking ahead to how you would like the future to look and how you might deal with any potential challenges can help you to feel more in control (see page 5).



Making time for the things you enjoy

Planning your day can help you schedule in time to rest. It can also help you focus on taking care of yourself and finding time to do the things you enjoy.

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Planning for your treatment

There are different treatment options for cTTP. If you have an acute TTP event, you will need treatment at the hospital. You may also have regular preventative treatment at the hospital, or sometimes in your home, to help avoid an acute TTP event.

Different arrangements will be needed depending on where and when you have your treatment. Thinking ahead can help you prepare any support you may need, feel more in control of your own care, and lessen any anxiety around having treatment. It can also help you prepare for potential emergencies, such as needing treatment when you are away from home. For example, you may want to add a "medical ID" to your phone with information about your cTTP diagnosis and your treatment, which a healthcare professional can read in an emergency.

The tool below can help you to think about your own situation. You can use the **"When, Where, What"** system to plan other areas of your daily life too, such as arranging childcare or making time to follow a hobby.

When?

It may help to set up reminders for your appointments, such as a list on the fridge or in your phone calendar.

You can talk to your employer or your child's teacher about organizing time off work or school. You could ask them about flexible working, or about how your child can be supported to continue learning.

Your doctor or nurse can support you with planning your appointments. If an appointment time does not suit you, they may be able to change it to a different time, such as when it will be quieter to travel to the hospital by public transport.

You may want to speak to your family and friends about how they can support you on the day of your treatment. For example, looking after your child or coming with you for support during the appointment.

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Where?

It can help to think ahead about how you will get to your appointment. For example, a family member or friend may be able to drive you, or if you use public transport, you can plan your route in advance.

What?

Your doctor or nurse can help you prepare for your treatment and support you in managing daily life with cTTP.

You can make a list of questions to ask your doctor. For example, questions about your treatment plan, or managing your treatment alongside your daily life. Remember that any question you have is important.

There may be items you need to take with you to your appointment. For example, a list of the medicines and any supplements you are taking or something to help pass the time, such as a book or music.

Support from your doctor or nurse

Being open about how cTTP affects you can help your doctor or nurse to offer you the best possible care. For example, they may be able to find you support with traveling to the hospital or with your finances.

If you have questions, or need support to manage the impact of cTTP, you can speak to your doctor or nurse. They may have a phone number that you can use to contact them between appointments.

Find more information about speaking to your doctor or nurse in our resource "***Information and support for people affected by cTTP***".

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Feeling prepared and in control

Alongside planning ahead for your treatment, there are additional tools and strategies you can use to help plan your time and overcome challenges you may face in managing cTTP. These tools may help you to feel more in control and able to continue doing the things that matter to you, like your hobbies, spending time with your family and friends, or traveling.

Taking action on what matters to you

Setting goals and planning how we can achieve them helps us stay positive when dealing with change.

If we set goals that are too big or ambitious, such as "I will manage my stress better," it is easy to be discouraged if things do not go to plan. Thinking of smaller, more specific goals can help us plan how we will achieve them. This may be finding time to do something you enjoy, or having 8 hours of sleep a night.



Activity: If you wish to set your own goals, try using the examples below as a starting point.

If you have goals, try keeping them specific. Consider what you want to achieve and why this is important to you, who may need to support you, and how you will know when you have reached your goal.

1
- **What:** I will find time in my day to go outside for a walk.
- **Why:** Getting some exercise clears my mind and helps me feel calm.
- **When or where:** In the morning after breakfast, to the local shop and back.
- **How:** I can set an alarm on my phone to remind me to go.
- **Who can support me:** My family can come with me if I need more support.

2
- **What:** I will change my bedtime routine to help me fall asleep more easily.
- **Why:** So I can get enough rest and do the things I need to do the next day.
- **When or where:** An hour before bedtime.
- **How:** I will turn off my phone and do the things that help me relax like having a bath or reading.
- **Who can support me:** My partner can help by not watching TV in the bedroom.

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Overcoming challenges

Living with cTTP can be unpredictable. Even with planning, challenges can still arise. For example, you may feel overwhelmed some days, or need support from others with childcare or getting time off work. Thinking ahead to any potential challenges can help you feel more prepared and positive about the actions you take to manage your condition.



Activity: It may help to think about challenges or things that could get in the way of your daily routine, treatment, or how you would like to live. These may be practical or emotional challenges.

If you think ahead to your own potential challenges, try to be as detailed as you can. This can help you to break down any challenges into manageable chunks. This activity can help you to write down your own challenges and potential solutions using the "If" and "Then" examples below as a starting point.

"**If** a situation arises, **then** I will do this action."

If I want to travel, **then** I will speak to my doctor to check how this may affect my treatment and care so that I am prepared in case of an emergency

If I am worried about my hospital appointment and how I will get there, **then** I will think about who I can ask for support, such as a family member or my doctor.

If I feel anxious about managing my condition, **then** I will be open with my doctor and nurse and ask for reassurance and more support.

If I feel overwhelmed about managing daily life, **then** I will speak to my family and friends about how they can support me with tasks such as doing the shopping or picking up my child from school.

Find information on how to ask for support in our resource ***"Finding support and connecting with others affected by cTTP"***.

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