Finding support and connecting with others affected by cTTP

If you are living with an ultra-rare condition like congenital thrombotic thrombocytopenic purpura (cTTP), support from family, friends, or other people affected by the condition can be an important part of living well. This type of support is equally important for people caring for someone with cTTP.

This resource aims to help people find support, connect with other people affected, and feel confident to ask for help when they need it. Although asking for support can feel overwhelming, it is important to remember that we all need help at times. There is a list of patient organizations providing information and support on page 5.

Getting support

Your doctors and nurses are key sources of information and support when managing life with cTTP. Alongside this, it can be helpful to get support from people you can turn to in times of need, or from patient organizations or people affected by the same condition who understand what you are experiencing.

Support often comes from a family member or friend, but it can come from anyone who is able to help you with daily tasks, to cope emotionally, or to understand new information about your condition. Support could also come from a neighbour, a member of your local community group, a colleague or teacher, a volunteer organization, or another person affected by cTTP.

Why is getting support important?

It is normal to seek support from people around you. Research shows that support from people around us can help us deal with health conditions, and allow us to feel more able to cope and do the things we want to do.

How can a support network help?

There are different types of support and they can all play different roles in your life.

Emotional. Listening to you and understanding how you are feeling, or sitting with you during your hospital appointments. This helps you to feel supported in making decisions, stay motivated in managing your condition, and feel more confident and positive.

Practical. Helping with day-to-day tasks such as shopping, childcare, driving you to your appointments, or reminding you to rest and eat healthily. This support can save you time and energy, allowing you to focus on living well with cTTP.

Information. Helping you understand new information about cTTP or your treatment. This could be from a patient organization, or from someone offering more general advice about coping with anxiety, feelings of isolation, or other emotional or practical issues you might be dealing with.

Companionship. Someone who you can do the things you enjoy with, allowing you to feel a sense of connection, belonging, and enjoyment.

Asking for support

Asking for help can sometimes make us feel vulnerable, or not fully in control. You may be the one who usually supports others and now find yourself asking for support for the first time. Feeling confident in asking for support is an important first step in overcoming some of these feelings and uncertainties. The information on this page can help you reach out for support.

Family and friends often want to understand more about how they can help you. If you find reaching out for help difficult, try asking people to check on you with a text or call.

Consider who can help. There may be people who can support you, or who have offered their support, including family and friends, volunteer networks, a local community group, or online social groups in your area.

Be specific about what you need. Consider making a list of tasks that you may need support with, such as being driven to the hospital, or going to the supermarket. This can help you give people specific tasks so they know how best to support you.

Share the details. The more details you share about what you need, the better people will be able to help. For example, you could let them know how long a task will take, whether they should wait with you during your appointment, or if there is anything you would like them to cook for you.

Be open about how you feel. People may not understand cTTP and the impact it may have. It can help those supporting you if you share how you feel. Think about what you are comfortable sharing. Maybe ask one person to communicate updates on your health and treatment to others, which will mean you do not need to repeat the conversation.

Find more information on living with cTTP and talking to colleagues, teachers, and your doctor and nurse in our resource **"*Information and support for people affected by cTTP*"**.

Talking to other people affected by cTTP

Connecting with someone else who has been diagnosed with cTTP, or is caring for someone with cTTP, can help you feel supported and build your coping skills. This kind of support can be helpful when used alongside support from your doctor and nurse.

As cTTP is ultra-rare, it can feel isolating at times, and finding other people affected can be a challenge. The information on this page can help you connect with people who understand your experiences.

Connecting with other people affected by cTTP

There are different ways you can connect with others affected by cTTP. Depending on where you live and what is available, you may be able to use support groups, phone calls, or social media groups.

You may want to think about what type of support you would like, the things you want to discuss, and whether you feel more comfortable speaking in a group or one-to-one.

cTTP is the inherited form of thrombotic thrombocytopenic purpura (TTP). Information or support for people affected by an acquired form of TTP, immune-mediated TTP (iTTP), can also help those affected by cTTP.

Your doctor or nurse may be able to give you information on how you can connect with other people affected by cTTP or iTTP, and if there are any patient organizations or peer-support networks available.

There may be support for people with rare diseases, or for more general conditions, that can provide practical or financial help. There may be a website that can offer information, or a group on social media with people who you can connect with.

You can also search for support yourself. Searching online for ”cTTP support” or ’’TTP support” can connect you with people who share similar experiences to you.

It is important to remember that other people may cope in different ways to you, and that it is OK to only share what you feel comfortable with when talking to others. Do not be afraid to ask questions before joining a group, such as what you might be asked to do or how many people may be there.

Additional support

Answering TTP
www.answeringttp.org

TTPnetwork
www.ttpnetwork.org.uk

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