

## Patient information

# Going Home Discharge Advice for Patients with Thrombotic Thrombocytopenia Purpura

Haematology Liverpool

Discharge advice for patients newly diagnosed with Thrombotic Thrombocytopenic Purpura (TTP) or who have an acute episode of TTP due to relapse.

You will be discharged from hospital when your platelet count is within normal limits, and you no longer require plasma exchange. You will also need to be free from infection and the more serious side effects of TTP (Neurological, cardiac abnormalities).

During a new diagnosis or acute episode of TTP your body is placed under great strain during your illness. When you go home, although you **do not** have active TTP, you may still have a slightly low Haemoglobin (Hb) count (anaemia) so you will feel very tired whilst your body is recovering and trying to heal.

At this time, it is very important that you take things easy and gradually ease back into your usual routine. Accept offers of help and support from family and friends.

### Emotions

Getting a diagnosis of TTP, especially if it includes a hospital admission, is likely to affect a person in multiple ways. Everyone will experience their illness differently, but the psychological impacts can be broad, both for you and your loved ones. Psychological and emotional care is likely to be useful for you in managing these effects.

Alongside this discharge document you will be given a patient information leaflet outlining some of the common psychological impacts of having a blood condition, and how you can access support from our Clinical Psychology team. Not everyone will need additional support to help them process and manage the impacts of their condition, but help is available to you if you do need it.

Please speak to your specialist nurse if you or your family feel overwhelmed, anxious, uncertain, irritable, sad or hopeless, or any other psychological symptoms that might have developed since your diagnosis. You will also be offered an appointment with a Clinical Psychologist from our team 6-weeks after a new diagnosis to identify if you need any support, and to identify if you have noticed any changes to cognitive ability or functioning.

**Remember**, you are not alone. We are here to help even after you have been discharged from hospital.

## Going back to work

Consider going back to work only when you have been advised to do so by your Consultant. It may be that you consider going back part time at first if this is possible.

You may wish to ask your employer for a phased return to the workplace and it may also be helpful to speak to your employer/ manager about your diagnosis as you will need to attend regular appointments with your Haematologist.

There may some reasonable adjustments that could successfully support your return to work. We are able to provide certificates for your employer and letters as necessary for benefit support.

Your family doctor (GP) will be informed of your condition and your recent treatments during your hospital admission along with all the information you have been given. We will establish links with your local hospital if you live some distance from the Royal Liverpool University Hospital.

## Medication

On discharge, you will be given some medication to take at home. Most patients are given the medicines below.

- ❖ **(Low Dose Aspirin** – Given to help make your platelets less sticky)
- ❖ **Caplacizumab** – to be continued until ADAMTS 13 levels are acceptable – your TTP Team will decide this.
- ❖ **Prednisolone** – may be used short term to suppress the immune system. The dose will be gradually reduced as your condition improves.
- ❖ **Lansoprazole / Omeprazole** – To protect the lining of your stomach if taking steroids.
- ❖ **Folic Acid** – To speed up the production of red blood cells if you are still anaemic.
- ❖ **Cotrimoxazole** – an antibiotic to prevent certain chest infections whilst your immune system recovers.
- ❖ Additional medication may be supplied if necessary.

## What do I do if I feel unwell?

As previously discussed, when you first go home you will feel tired. There are some other symptoms, however, that you should look out for.

### If you have:

- ❖ Headaches, not relieved by paracetamol.

- ❖ Easy bruising without obvious cause.
- ❖ Rash.
- ❖ Blurred vision, dizziness or confusion or any altered behaviour.
- ❖ Dark urine.
- ❖ Feel unwell or are worried.

If you have any of the above, please contact your Specialist Nurse for advice on the number at the back of this leaflet.

You will require a blood test to check your platelet count to ensure it is within normal limits. In most cases, you will be absolutely fine.

You will not be wasting anyone's time – even if your blood test results are normal. We are here to help and support you with any worries or questions that you may have.

### **Dos and don'ts!**

- ❖ **Do** contact your Specialist nurse with any questions or worries that you have.
- ❖ **Do** please speak to your Consultant if you are considering starting or extending your family.
- ❖ **Do** let us know if you are planning to travel abroad.
- ❖ **Do** inform your Consultant or Specialist nurse about **all** medication you are taking including alternative remedies.
- ❖ **Do** speak to your Specialist nurse before receiving any alternative therapies. i.e. massage.
- ❖ **Don't** start any new medication without contacting us first, including the contraceptive pill, hormone replacement therapy or malaria prophylactic tablets.
- ❖ **Do** use a method contraception for a year post treatment with Rituximab.
- ❖ **Don't believe all you read on internet sites about TTP.** Some of the information about TTP and its treatments are not from reliable sources or up to date.

### **Clinic Visits**

Clinics are held on Thursday mornings between 9am and 1pm in OPD 3 which is situated on the ground floor of the Royal Liverpool University Hospital.

You will be seen by your Consultant Haematologist or Senior Registrar and the TTP clinical nurse specialist. At each clinic appointment you will be given the opportunity to ask any questions you may have and discuss any anxieties or concerns. You will also have blood tests taken to establish how your body is recovering. You can ask to meet a Clinical

Psychologist at this appointment too if you would like to ask any questions about what support they could offer you.

It is important that you attend these appointments to establish how you are doing and to collect valuable information. We can review how you have responded to treatment, and you can access further services that you may need.

## **Feedback**

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

## **Further Information**

**TTP Liverpool Support group meets every six months.**

**Please ask you specialist nurse for more information**

**[www.ttpnetwork.org.uk](http://www.ttpnetwork.org.uk)**

**Supports patients with Thrombotic Thrombocytopenic Purpura (TTP).**

**TTP Clinical Nurse Specialist:**

**Tel: 0151 706 3397**

**Text phone number: 18001 1051 706 3397**

**Mobile: 07917527423 (Office Hours Only)**

**Out of Hours:**

**Contact the Haematology Registrar on call**

**via switch 0151 706 2000**

**Author: Haematology Liverpool**

**Review date: January 2028**

All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

يمكن توفير جميع المعلومات المتعلقة بالمرضى الموافق عليهم من قبل انتمان المستشفى عند الطلب بصيغ أخرى، بما في ذلك لغات أخرى وبطرق تسهل قراءتها وبالحروف الطباعية الكبيرة وبالصوت وبطريقة برايل للمكفوفين وبطريقة مون والكترونياً.