



Your ITP Discussion Guide

This guide is designed to help you have more focused discussions about your ITP care needs and preferences with your carer / care team

- 1 Reflect on your last month managing ITP** and note down what matters most to you. You do not need to complete everything: focus on the elements that are most important to you.
- Once completed, **tick the stars next to the questions that are most important to you.**
- 3 Bring your completed guide to your next appointment** and discuss it with a member of your care team:
 - Use the guide to outline your top care priorities and go through your other issues in turn
 - Help your care team to understand your goals and what's most important to you in your daily life.
- 4 Make a joint decision** on your future care plan.

Today's date:

Note down today's date so you can look back and track how you're feeling over time.

____/____/____

My goals

First, write down your short-term goals; the things that are most important to you right now (this week / month).

For example, having a nice walk with the dog this week.

Then, write down your longer-term goals; the things that are most important to you in the future (next 6 months).

For example, going on a cycling holiday in three months.

Living with ITP

Living with ITP can affect your wellbeing and how you cope with everyday activities. **Use the scales below to rate how ITP affects your day-to-day life. Circle the score that best reflects how you feel.**

Coping with ITP symptoms

How have ITP symptoms impacted your daily life in the last month (including fatigue, bleeding, bruising, etc.)?

1 2 3 4 5

Feeling on top of things

Do you feel able to carry out everyday tasks like washing yourself, dressing up, cooking, DIY, doing household chores and shopping?

1 2 3 4 5

Having emotional wellbeing

Do you feel positive (in control of your thoughts and feelings), or more negative (anxious, upset or depressed)?

1 2 3 4 5

Pursuing hobbies

Do you feel you can pursue the activities you enjoy the most?

1 2 3 4 5

Spending time with friends and family

Do you feel you can spend time with or care for family and friends in the way you want to?

1 2 3 4 5

Performing well at work or school

Do you feel you can excel in your work and/or studies?

1 2 3 4 5

Taking part in sports and exercise

Do you feel you can reach your sport and exercise goals?

1 2 3 4 5

Use this space to write down further details about how ITP affects your day-to-day life.

Managing ITP effectively

To enable you to live your life the way you want to, it's important to work with your care team to find a treatment that works well for you. **Use the scales below to rate how you feel about your ITP treatment. Circle the score that best reflects how you feel.**

How well does your ITP treatment help you to manage / prevent your symptoms (including fatigue, bleeding, bruising etc.)?

 1 2 3 4 5  

How satisfied are you that your treatment maintains or increases platelet production?

 1 2 3 4 5  

How satisfied are you with how often you take your treatment?

 1 2 3 4 5  

How satisfied are you with the number of blood tests needed to check your platelet count due to treatment?

 1 2 3 4 5  

How satisfied are you with the way your treatment is administered?

 1 2 3 4 5  

How easy is it for you to fit your treatment intake into your usual daily routine? (For example, commuting, working, eating, sleeping)

 1 2 3 4 5  

How easy is it for you to take treatment when your routine changes? For example, when on holiday?

 1 2 3 4 5  

Overall, how satisfied do you feel with your treatment and/or care?

 1 2 3 4 5  

Notes:

Use this space to write down further details about how your treatment and care impacts your daily life, or any wishes you would like to share with your care team.

ITP treatment and your goals

Does ITP or ITP treatment currently affect your ability to pursue your personal goals?

YES ☐ NO ☐

Use this space to write down how ITP affects your personal goals.

Priority discussion points for your next consultation

Look back over the questions and tick the stars highlighting the elements that are most important to you.

Use this space to write down the 1-3 most important topics you would like to discuss at your next ITP appointment.

And finally...

- Don't be afraid to say if you feel that you're not being heard, or your issues aren't being taken seriously
- Ask for an explanation of anything you don't understand