



Find
your
path

your

Wellness Journal

Provided as an educational service by Vertex Pharmaceuticals (UK) Ltd.

your

Wellness Journal

You'll have found your own ways of balancing managing life with beta thalassaemia and living life your way. Like any chronic condition, the effects of beta thalassaemia on your life go beyond just the physical symptoms. These effects and how that makes you feel may change with time.

Staying aware of how you're feeling is an important part of finding your path. Noticing any changes in how beta thalassaemia affects you can help you feel more confident being part of decisions about the care and support you need. Of course, it can be hard to remember what has happened sometimes and you may have questions between visits to your healthcare team. That's where this journal can help!

Your Wellness Journal has been specially designed for people living with beta thalassaemia. Print it off and use it to help you continue to find the right balance between managing your beta thalassaemia and living life your way. This might help you notice anything you want help and support with.

You can contact your healthcare team between appointments for advice or take your journal with you to your next appointment. You might like to use it to keep notes on your symptoms, how you're feeling and how you're getting on with any treatments you're taking and how your transfusions are going. This way your journal may be helpful in prompting your memory and guiding your discussions with your healthcare team.

This downloadable resource has been developed by Vertex Pharmaceuticals as part of the Find Your Path campaign. This disease awareness campaign is designed to support you to work with your healthcare team and find your own way to balance life with managing beta thalassaemia. For more information, please visit Findyourbetathalpath.com.

This journal belongs to: _____

Date of birth: _____

Name of school/college/university/employer: _____

Address: _____

Telephone number: _____

your

important information

It can be helpful to keep your details along with those of your healthcare team and contacts for people who may help support you all in one place. Use the form below to record this information.

Blood type: _____

Language spoken at home:

Other language(s):

Current medications and dose:

Emergency contacts

Primary contact name:

Relationship to you: _____

Telephone number: _____

Secondary contact name:

Relationship to you: _____

Telephone number: _____

your

healthcare team



This information is private, so please look after your journal to avoid losing it. You could also save important numbers on your phone as a back up.

Name of hospital:

Address:

Beta thalassaemia nurse name:

Telephone number:

Email address:

Doctor's name:

Telephone number:

Email address:

Other key contact:

Telephone number:

Email address:

Keeping track

of your medical care

You can use the space below to record the care you receive - you can include any regular check-ups, when you receive a transfusion (if you have transfusions), if you visit hospital for emergency care, or any other

times you may be meeting with your healthcare team. Print off your journal and take it with you to each of your healthcare appointments, to keep as a useful record.

Date/time	Name of healthcare team member seen	Reason for contact Regular check-up (e.g., yearly review), treatment, admitted to hospital, other	Comments What was discussed/decided, (e.g., goals set, referred to another healthcare team, next appointment booked and changes to current treatment etc.)

Keeping track of your medical care

Date/time	Name of healthcare team member seen	Reason for contact Regular check-up (e.g., yearly review), treatment, admitted to hospital, other	Comments What was discussed/decided, (e.g., goals set, referred to another healthcare team, next appointment booked and changes to current treatment etc.)

Keeping track

of your beta thalassaemia

You know best what is important to record between visits to your healthcare team. Use these pages to note down any symptoms you may have (such as fatigue or chronic pain), any hospitalisations, and any treatment you receive (this might include your transfusions - if you need them - or other regular treatments).

Remember that many things can influence your beta thalassaemia symptoms. Under notable events, you might include anything out of the ordinary for that day, such as a stressful event, a change to what you usually eat or the amount of exercise you did etc. Finally, keeping track of your mood and how you're feeling is just as important as your physical health. An example entry is included in the table. Make sure to print off your Wellness Journal now and get started.

Date	What happened? E.g., symptoms experienced, event such as going to hospital etc.	Any notable events? E.g., stress, lack of sleep, hectic week	How did you manage what happened? Treatments or other care you received and/or any self-management	How are you feeling in general? Think about your mood and mental health	Notes Use this space for any other information or reminders
3 June	Back pain and feeling really tired since yesterday	May not have eaten enough today - I missed lunch as it was a busy day	Painkillers and called a friend for a chat	A bit low but looking forward to going away for the weekend	Remember to ask doctor whether they have any advice to help me feel less tired

Keeping track of your beta thalassaemia

Date	What happened? E.g., symptoms experienced, event such as going to hospital etc.	Any notable events? E.g., stress, lack of sleep, hectic week	How did you manage what happened? Treatments or other care you received and/or any self-management	How are you feeling in general? Think about your mood and mental health	Notes Use this space for any other information or reminders

your
notes

This space is for any notes you might want to make during an appointment. You could also record any questions you have for your healthcare team ahead of your next visit.

Hopefully, using this journal can help you feel more confident about finding your path and achieving a balance between managing your beta thalassaemia and living life your way.