



LET'S
KEEP TALKING

MY WELLNESS JOURNAL

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

MY WELLNESS JOURNAL



No one knows better than you how sickle cell disease affects different parts of your life. And you'll have found your own ways of managing life with the disease. As things can change, how you manage your sickle cell disease might need to as well.

By taking notice of any changes to how sickle cell disease is affecting you, you can feel confident to be part of any decisions about the care and support you need. But it can be hard to remember what has happened or any questions you have between visits to your healthcare team. That's where this journal can help!

This journal has been specially designed for people living with sickle cell disease. It can be used to keep track of any symptoms, treatments, and your general health and wellbeing. Print it off and take it with you to your next appointment to help guide your conversations around your disease and how you want to live your life.

This downloadable resource has been developed by Vertex Pharmaceuticals as part of the Let's Keep Talking Campaign. This disease awareness campaign is designed to support you to work with your healthcare team to find your own way to live with sickle cell disease. For more information, please visit letstalksicklecell.co.uk

THIS JOURNAL BELONGS TO:

TELEPHONE NUMBER:

NAME OF SCHOOL / COLLEGE / EMPLOYER:

ADDRESS:

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 for future reference.

SICKLE CELL DISEASE TYPE: _____

BLOOD TYPE: _____

LANGUAGE SPOKEN AT HOME: _____

OTHER LANGUAGE(S):

CURRENT MEDICATIONS:

EMERGENCY CONTACTS

PRIMARY CONTACT NAME:

RELATIONSHIP TO YOU: _____

TELEPHONE NUMBER: _____

SECONDARY CONTACT NAME:

RELATIONSHIP TO YOU: _____

TELEPHONE NUMBER: _____

YOUR HEALTHCARE TEAM

This information is important, 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:

SICKLE CELL NURSE NAME:

TELEPHONE NUMBER:

EMAIL ADDRESS:

DOCTOR'S NAME:

TELEPHONE NUMBER:

EMAIL ADDRESS:

GP'S NAME:

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 treatment, 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 personal health record .

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

KEEPING TRACK OF YOUR SICKLE CELL DISEASE

You know best what is important to record between visits to your healthcare team. Use these pages to note down any symptoms you have (such as a pain crisis), any hospitalisations, and any treatment you receive (this might include your regular medications or other treatments such as vaccinations).

Remember that many things can influence your symptoms. Under triggers or notable events, you might include any stresses in your day, physical activity you do, your water intake or other diet factors 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. Why not print off your Wellness Journal now and get started?

Date	What happened? E.g., symptoms experienced, event such as going to hospital etc.	Any possible triggers? E.g., stress, physical triggers such as cold or heat, etc.	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	Pain in left lower leg since this morning, really tired	May not have had enough to drink or eat today as working hard on a work presentation	Painkillers and took a warm bath	Pretty stressed but excited about the new responsibilities at work	Remember to ask doc about other ways to manage pain at home

KEEPING TRACK OF YOUR MEDICAL CARE - REFILL



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

KEEPING TRACK OF YOUR SICKLE CELL DISEASE - REFILL



Date	What happened? E.g., symptoms experienced, event such as going to hospital etc.	Any possible triggers? E.g., stress, physical triggers such as cold or heat, etc.	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