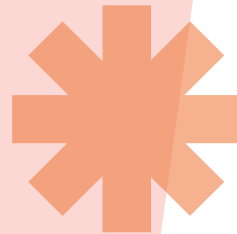




# YOUR SICKLE CELL DISEASE TREATMENT

# YOUR HEALTH DIARY



Consciously noticing any changes in your sickle cell disease can help you to play a self-assured role in the management of your disease.

It's only natural to have trouble remembering all the details sometimes. You might also have questions for your treatment team between appointments. This diary can help you with both of these things.

Your treatment diary has been created specifically for people with sickle cell disease.

You can contact your treatment team for advice between appointments or take the diary with you to your next appointment. You may want to use it to record your symptoms, your well-being and how you are finding any treatments you are having.

This digital resource was developed by Vertex Pharmaceuticals (CH) GmbH as part of the "Realtalk! Sickle Cell" campaign. This campaign to raise awareness for your disease is designed to support you in working together with your treatment team and finding the right path for you so that you can manage your sickle cell disease in a way that works with your own life.

For more information, visit <https://www.realtalk-sicklecell.ch/en>

**THIS DIARY BELONGS TO:**

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**DATE OF BIRTH:**

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**ADDRESS:**

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**TELEPHONE NUMBER:**

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# YOUR PERSONAL INFORMATION

## EMERGENCY CONTACTS

**BLOOD GROUP:**

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**LANGUAGE SPOKEN AT HOME:**

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**OTHER LANGUAGE(S):**

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**CURRENT MEDICATION AND DOSES:**

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**NAME OF PRIMARY CONTACT:**

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**RELATIONSHIP TO YOU:**

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**TELEPHONE NUMBER:**

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**NAME OF SECONDARY CONTACT:**

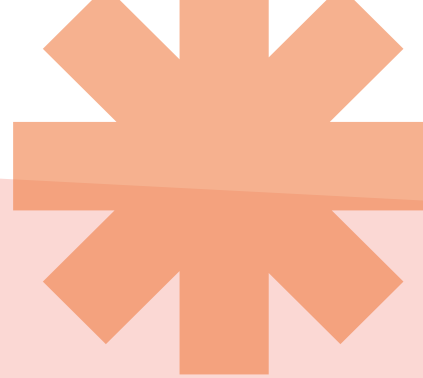
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**RELATIONSHIP TO YOU:**

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**TELEPHONE NUMBER:**

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# YOUR TREATMENT TEAM

**NAME OF THE HOSPITAL:**

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**ADDRESS:**

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**NAME OF YOUR NURSE:**

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**TELEPHONE NUMBER:**

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**EMAIL ADDRESS:**

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**NAME OF THE DOCTOR:**

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**TELEPHONE NUMBER:**

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**EMAIL ADDRESS:**

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**OTHER IMPORTANT CONTACT:**

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**TELEPHONE NUMBER:**

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**EMAIL ADDRESS:**

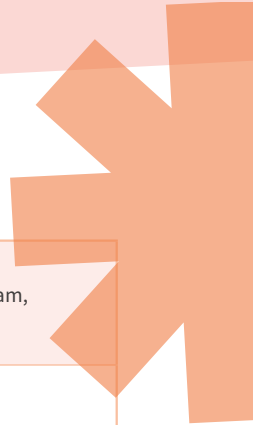
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# VISITS WITH YOUR TREATMENT TEAM



You can record all treatments that you receive in the table below – e.g., all check-ups, hospital visits for emergency care or other occasions where you see your treatment team.

Ideally, you should print out your diary and take it with you to every appointment.



Date and time	Doctor or therapist's name	Reason for contact Regular check-up (e.g., annual examination), treatment, hospital admission, other	Comments What was discussed/decided? (e.g., targets, referral to a different treatment team, arranging the next appointment, changes to the current treatment etc.)

# YOUR TREATMENTS

Month:

Treatment name	Scheduled time	Week 1	Week 2	Week 3	Week 4	Method of administration <small>(e.g., swallowing, injection, etc.)</small>	Time of administration <small>(e.g., after lunch/ before going to bed)</small>	Special instructions <small>(e.g., take with meals)</small>	Re-order at the pharmacy	Treatment target and/or personal target

# YOUR SYMPTOMS

You know best what you should note down between appointments with your treatment team.

Use these pages to record symptoms (e.g., exhaustion or chronic pain), hospital stays and treatments.

**Remember** that many factors can influence your sickle cell disease symptoms. Under “Unusual events”, you can record any specific details of the day in question, such as stressful events, a change in your diet or exercise, etc. Ultimately, recording your mood and your well-being is just as important as recording your physical health. The table contains an example entry.

<b>Date</b>	<b>What happened?</b> Symptoms experienced, incidents such as a hospital visit, etc.	<b>Unusual events?</b> Stress, lack of sleep, hectic week etc.	<b>How did you deal with the situation?</b> Treatments or other care that you received and/or other self-management techniques	<b>How do you feel in general?</b> Think about your mood and mental health	<b>Notes</b> Use this space for any other information or reminders
3 June	Back pain and severe fatigue since yesterday	Possibly did not eat enough today – I skipped lunch because I was too busy	Painkillers and phone conversation with a friend	Somewhat low mood, but looking forward to trip at the weekend	Remember to ask doctor whether he can recommend anything to combat fatigue

# YOUR SYMPTOMS

<b>Date</b>	<b>What happened?</b> Symptoms experienced, incidents such as a hospital visit, etc.	<b>Unusual events?</b> Stress, lack of sleep, hectic week etc.	<b>How did you deal with the situation?</b> Treatments or other care that you received and/or other self-management techniques	<b>How do you feel in general?</b> Think about your mood and mental health	<b>Notes</b> Use this space for any other information or reminders



## TIPS FOR YOUR TREATMENT APPOINTMENTS

Your treatment team is there to support you in finding the right balance between managing your sickle cell disease and living your life the way you want to. During appointments with the team, you can discuss how you are doing, what is going well and what you might like to change.

This guide will help you to make the best use of your appointments – with tips on what to do before, during and after appointments.

## BEFORE THE APPOINTMENT

There are a few things you can do to prepare for the appointment:

- ✿ Find out where the appointment is taking place and try to arrive a few minutes before the appointment so that you are relaxed.
- ✿ Prepare a list of questions for your treatment team. You will find a page with space for your notes/questions two pages down.
- ✿ Keeping a diary between appointments will make it easier to talk to your treatment team about your condition. There is space just before this page for you to make a note of any symptoms or thoughts to make sure you don't forget them at your next appointment.
- ✿ If you need support, ask a friend or family member to accompany you. This person can also take notes and remind you of any questions so that you don't forget them.

## DURING THE APPOINTMENT

You should view yourself as your treatment team’s partner so that you can be involved in decisions about your health in the following ways:

- \* At the start of the appointment, tell your treatment team what you would like to talk about.
- \* Use your list of questions to find out more or to steer the conversation in the right direction if you think that something important has been forgotten.
- \* If you have set yourself targets, you may want to talk about your progress. You may also have new targets that you want to discuss with your treatment team. Use the QR code to download our resource “Managing your sickle cell disease”.



- \* Ask questions if there is anything that you do not understand.
- \* Your treatment team will give you information. You can take notes on the next page.

## AFTER THE APPOINTMENT

After the appointment, there are a few things you can do to make the best use of the information discussed:

- \* Read through your notes and any information you received so you can remember any instructions or suggestions from your treatment team.
- \* Keep using this resource to monitor your health between appointments.
- \* Make sure that you have put your next appointment in your calendar and make a note of any questions that keep coming to mind. There is space for this on the next page.
- \* Keep your targets in mind so that you can take small steps in the right direction. Remember to discuss any changes to your targets with your treatment team first.
- \* Think about finding a support group that can help you between appointments.
- \* You do not have to wait until your next appointment to talk to your treatment team – ask your team whether an earlier appointment is possible if you need help or advice.

