



MANAGING YOUR SICKLE CELL DISEASE

YOUR LIFE WITH SICKLE CELL DISEASE

In your everyday life with sickle cell disease, you are constantly trying to find the right balance between managing your disease and living your life the way you want to. You see your treatment team for regular check-up appointments. Between appointments, you have to take charge of your life and your disease yourself. Additional tips may help you to do this.

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>



KEEP WELL INFORMED

A detailed understanding of sickle cell disease will help you in making decisions for your health and for yourself.



KEEP TALKING

Sickle cell disease is a complicated condition. For this reason, your search for information is likely to raise many questions. You should keep talking to your treatment team and ask them to explain anything you are not sure about.

KEEP PAYING ATTENTION

It is always good to be aware of your symptoms and to talk to your treatment team about them. This can help to find the right path for you together.

Tip: You can make a note of your symptoms in the “Your treatment diary” resource, which you can download here, so that you can remember them for your next appointment with your treatment team.



REMEMBER:

You make the decisions and are the best advocate for your own health – and you are not alone on this journey. You should view yourself as your treatment team’s partner so that you can make decisions together that will help you to live the life you want to with sickle cell disease.

As a parent of or caregiver for someone with sickle cell disease, you can help them to manage their disease between appointments. You can help them to find their path.

SET YOURSELF TARGETS AND STRUCTURE YOUR DAILY LIFE

Making plans for the future can be difficult when you have sickle cell disease. You can incorporate your targets into your daily life right away so they can continue to help you in the future as well.

Setting targets can help you to find your path. These targets can be as ambitious or as simple as you like.

HOW SHOULD YOU SET TARGETS?

Setting targets shows that you know what you want! Your treatment team can help you to define your own targets.

Achievable targets according to the SMART method:¹



You can find more detailed information about the SMART method and setting targets here:



SPECIFIC

Your target must be specific and clearly defined.

MEASURABLE

You must be able to measure your target and the steps involved in achieving it.

ACHIEVABLE

The target you set should be realistic.

RELEVANT

Your target should be consistent with your values.

TIME-BOUND

Define a deadline by which you want to have achieved your target.

¹ Mitschang T. Goal-setting for the chronically ill: Planning for an uncertain future. Immune Globulin Living, 2016. https://www.igliving.com/magazine/articles/IGL_2016-10_AR_Goal-Setting-for-the-Chronically-Ill.pdf. Last accessed: 30.05.2024

READY?

First of all, think about what you would like to improve in your daily life – your target is entirely dependent on your wishes, and it just needs to feel right.

In order to gather ideas, you can use this page as a map for your thoughts.

WHAT IS IMPORTANT TO ME?

Use the space on the right to note down ideas for possible targets in a structured way. Your ideas might relate to your diet or to targets involving your family or friends, work, school or your mental health. You can cover any topic that is important to you here.

There are no right or wrong answers here – just because you have made a note of something does not mean that this needs to become your target. You do not have to show anyone this first step. This means that you can be as honest and creative as you want.

MY TARGETS

You can print out the worksheet on the next page to turn the ideas from your mind map into achievable targets. If you want to, you can bring these with you to your next check-up appointment to discuss them with your treatment team. Below is an example of what a completed worksheet might look like:

If a target relates to your treatment, you should discuss this target with your treatment team so that they can support you in the best way possible.

My target (specific and clear)	How will I measure it and what achievable steps can I take?	Why is this relevant?	When do I want to have achieved my target by?
I want to improve my fitness by going out with the dog for 20 minutes every day.	I will start with a five-minute walk and then walk for longer each day. I will measure my success by extending the time.	Improving my fitness level may give me more energy and help me to improve my overall health.	By the end of the month.

Good luck with setting your targets and finding your path!



If you are looking for more ideas for how to play an active role in your health, take a look at the other resources in the resources library here.

<https://www.realtalk-sicklecell.ch/en/resource-hub>

MY TARGETS

My target (specific and clear)	How will I measure it and what achievable steps can I take?	Why is this relevant?	When do I want to have achieved my target by?