



SETTING GOALS WITH BETA (β)- THALASSEMIA

WHAT DO YOU WANT TO ACCOMPLISH?

The answer to that question is different for everyone. Finding your own answer can start with setting goals today, helping you shape your ideal tomorrow.





SHARING YOUR GOALS with YOUR DOCTOR

THIS GUIDE IS DESIGNED TO HELP

you plan for a clear conversation with your healthcare team about your personal goals and your medical care. By discussing your personal goals and needs with your doctor today, you can help your doctor develop a medical plan **that will help shape your tomorrow.**



Actor portrayals
throughout.
Not real patients.



MY THAL. My today.

PICTURING YOUR STORY

Beyond "what do I want to be when I grow up," your life experiences—your best memories and most difficult challenges—can help you discover other life goals to discuss with your doctor. Since β -thalassemia affects each person individually, it is important for your doctor to understand what you personally would like to accomplish.

Let's start with your story up until now. It is made up of the people and experiences you've encountered along the way. It also includes all the ways you've lived with β -thalassemia. This is the story that explains how you became the person you are now.

Think of your life as a journey. What were the unexpected twists and turns? What were the successes and the challenges? How has β -thalassemia been a part of your journey?

Take a few moments to fill out the map of your journey on the next page.

When you're done, look at the map and answer the following questions:

- What people, events, and experiences in your life have been the most memorable? How has β -thalassemia been a part of these memories?
- Which experiences gave you the greatest inspiration?
- How have you learned from your challenges in life? How have you balanced β -thalassemia with your daily activities?
- Have you made any adjustments to your life as a result of your challenges?

These questions are designed to help you reflect on your journey so far and envision your future. Remember, this is about your own experiences; there are no right or wrong answers.

WHAT ARE THE MOST MEMORABLE MOMENTS in your journey?



REFLECT ON YOUR JOURNEY

I was inspired by:

Challenges I faced:

From my journey so far, I learned:

Can you see where your journey is taking you? Keep the answers to these questions in mind when you go to the next section.

LOOKING AHEAD

Now that you've had a chance to look back at your journey, it's time to look toward the future.

What do you want to do next? Where do you see yourself tomorrow?

Creating smaller goals in these specific areas can help you get to your ideal tomorrow:

- HEALTH AND WELLNESS
- FAMILY AND FRIENDS
- SCHOOL AND/OR WORK
- HOBBIES, SKILLS, AND PERSONAL DEVELOPMENT

Try to write down at least 1 goal for each area in the space to the right.

For my health and wellness, I aim to:

With my family/friends, I want to:

At school or work, I hope to:

This hobby, skill, or activity excites me, and I aspire to:

Which goal(s) matters to you most? Will you need assistance from your doctor to accomplish this? Take this into account before continuing.

TAKING THE NEXT STEP

Thinking of a goal, what is 1 small thing you could do to start moving toward it?
See the example on the right.

☐ My health and wellness goal:

I'm going to...

☐ My family/friends goal:

I'm going to...

EXAMPLE

☒ My health and wellness goal:

go on a walking tour with my family when they visit next month

I'm going to...

walk 20–30 minutes per day and plan some stops along the walking tour in case I need a break

☐ My school and/or work goal:

I'm going to...

☐ My hobbies, skills, and personal development goal:

I'm going to...

REMEMBER TO INCLUDE TIME FOR YOUR TREATMENTS

and doctor appointments in your goals and plans. It is important to stick to your treatment or medication plan, including iron-chelation therapy, to maintain your health and prevent health problems later in life. By talking with your doctor, you may be able to create a plan that helps to manage your disease while working to **meet your goals**.



RECORD YOUR PROGRESS

For most people, goals change over time. Your goals today may be different tomorrow or next month.

This is why it is a good idea to keep track of your progress on a regular basis. **Using a calendar or keeping a journal can help you stay focused on achieving your goals by a certain time.**

Remember, your healthcare team is there to help you manage your β -thalassemia. They can only help you if you talk with them about your experiences. If or when your goals do change, be sure to speak with your doctor about how to align your medical care to your needs.

TALKING TO YOUR DOCTOR

Now, let's organize all of the goals and thoughts you've been working on throughout this workbook in the space below. Having your goals, thoughts, and any questions you may have in one place will help you have a clear conversation with your doctor.

Goal(s) I would like to discuss with my doctor:

Any potential obstacles I may need to overcome:

Steps to achieve my goal(s):

Questions and/or advice I would like to ask my doctor:

CONVERSATION STARTERS

Here are a couple of ideas to help get you started speaking with your doctor about the goals that you wrote down on page 14.

- I want to accomplish a few personal goals that could impact my treatment plan. Could I get your thoughts on them?
- Can you help me plan out how to make my personal goals work within my treatment plan?

Notes from the conversation with my doctor:





MY THAL. My today.

I'M WORKING HARD TOWARD BECOMING A PASTRY CHEF, BUT SOMETIMES MY TEACHER THINKS I'M JUST BEING LAZY. EVEN WHEN MY THALASSEMIA MAKES ME EXHAUSTED, I WILL NEVER LET THAT BE A REASON TO QUIT.

THIS CULINARY PROGRAM IS GONNA TAKE A LOT OUT OF ME, BUT IT'S GONNA BE WORTH IT.

MY DOCTOR AND I ARE WORKING ON WHAT I CAN DO TO MANAGE MY DISEASE AND STILL ACCOMPLISH MY GOALS.

Aiden

I'M GOING TO
TALK TO MY
DOCTOR ABOUT
PLANNING FOR
my tomorrow.



REFERENCES

1. *Guidelines for the Management of Transfusion Dependent Thalassemia (TDT)*. Cappellini MD, Cohen A, Porter J, Taher A, Viprakasit V, eds. 3rd ed. Thalassemia International Federation; 2014.
2. Baer K. *A guide to living with thalassemia*. Cooley's Anemia Foundation website. <http://www.cooleysanemia.org/updates/pdf/GuideToLivingWithThalassemia.pdf>. Accessed April 9, 2019.