



Find
your
path

your
top tips for
self-management

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Living with beta thalassaemia:

your top tips for self-management

Living with beta thalassaemia can be a constant quest to find the right balance between managing your condition and living life your way. Everyone's experience is different, but you keep going even if you face challenges. Although you see your healthcare team regularly for check-ups, it's you that's managing your life in between. You're doing an excellent job but may appreciate some additional tips too.

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.

You've likely already learned many things that you can do to help you to live with your condition. And you can keep talking to your healthcare team about any support you might need to continue doing so. But no doubt you want to keep trying to reach a good balance between managing your beta thalassaemia and living life your way. Here, we share some top tips that can help you do that.

* **Keep yourself well informed**

Understanding your beta thalassaemia really well can help you to make informed choices for yourself and your good health. Take the time to read up about beta thalassaemia – our website, Findyourbetathalpath.com is a good place to start!

* **Keep talking**

Beta thalassaemia is a complex condition and it's likely that your research may throw up lots of questions. Plus, as your beta thalassaemia may change over time, you might find you have new questions. Being informed about your care is your right. Keep talking to your healthcare team and ask them to explain anything you're not sure about.

* **Keep an eye out**

Things can change for you (and your carer, if you have one) at any time. Keep an eye out particularly for any changes in your symptoms. By sharing these changes with your healthcare team, together you can find the path that's right for you.

If you are a parent or care for someone living with beta thalassaemia, you may also help to manage their condition between appointments. Your support makes all the difference. While these tips are aimed at people with beta thalassaemia, you should also find some useful ideas that can help you keep supporting your loved one. You can help them to find their path.

*** Keep track**

It's not always easy to remember how you've felt between appointments and when any changes in symptoms might have occurred. That's why it's really helpful to keep track in a journal of some kind. Make a note of how you're feeling mentally and physically and then you'll be in a good position to discuss it with your healthcare team when you see them. Your Wellness Journal can be helpful for this. Use the QR code below to download it!

These tips can help you keep track of your beta thalassaemia and make you feel more confident about achieving a balance between managing your disease and living life your way.

Remember, you are an important decision-maker and the best advocate for your health, but you are not on this journey alone. See yourself as partnering with your healthcare team so you can make decisions together that help you to live the way you want with your beta thalassaemia. With their support, you can be confident you will find your path to live the life you want with beta thalassaemia.

Scan the QR code to find more resources

Download Your Wellness Journal to start keeping track of your medical care. Also check out other resources available to help you take an active role in your health in our Resource Hub.

