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Getting the most out of



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Remember, your healthcare team are there to support you in getting the balance right between managing beta thalassaemia and living life your way. Visits to them offer the chance to talk about how you're doing, what's going well and the things you might like to do differently.

Don't just feel it's a routine healthcare appointment. It's an opportunity for you to discuss any concerns that you may have about your wider experience living with beta thalassaemia. Your healthcare team are interested in hearing about the challenges you are facing, and are ready to help you get the care you may need to support your physical and emotional wellbeing.

Of course, the strain of managing your condition can sometimes leave you lacking motivation – so it's not always easy to talk to your healthcare team. This tool can give you some positive ideas and help you make the most of your visits with things you can do before, during and after your appointment.

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 thalassemiafindyourpath.co.uk

Before the appointment

There's lot's you can do before you get to your appointment:

- * Know where you're going and aim to arrive early for your appointment, so you feel relaxed.
- Have a list of questions ready to ask your healthcare team you might like to write these in Your Wellness Journal.

 Use the QR code to download a copy on the Resource Hub.
- If you want some support, ask a friend or family member to come with you. They can take notes and remind you of any questions you forget to ask.
- It can help to keep a journal between visits to help you discuss how you've been with your healthcare team. You can use Your Wellness Journal to jot down any symptoms and other important information that can help guide the conversation.

Follow this QR code to download a copy on the Resource Hub.







During the appointment

See yourself as partnering with your healthcare team so you can be part of decisions made about your health by:

- * Starting the appointment by telling your healthcare team the things you would like to discuss.
- We your list of questions to help you find out more about what your healthcare team are telling you or to help guide the conversation if you feel something important is being left out.
- If you have set goals, you might want to discuss any progress you've made. Or you may have new goals that you want to discuss with your healthcare team before you set them.

 Use the QR code to download our goal setting resource on the Resource Hub and start coming up with your own set of goals.





- You may need time to think things over after the appointment before you come to a decision.

 Take notes so you can remember what was said.
- * Ask for something to be clarified if you don't understand that's what your healthcare team are there for!
- As well as hearing your questions and concerns, your healthcare team will have information to give you.

 You can make notes in the space on the next page.

After the appointment

Even after the visit is over, there are things you can do to make the most of what was covered:

- Look back over your notes and any information you are given so you can follow up on any instructions or suggestions from your healthcare team.
- * Continue using Your Wellness Journal to monitor your health between visits. Let your healthcare team know if anything changes between appointments.
- * Make sure you have your next appointment in your calendar and start making a list of questions to ask at your next appointment.
- * Keep your goals in mind so you can take small steps towards achieving them. Or think about any updates to them as things change with your beta thalassaemia. Remember to discuss any changes to your goals with your healthcare team first.
- Consider finding a support group that could help you between appointments.
- You don't have to wait until your next appointment to speak to your healthcare team. If you need any support or advice between appointments, get in contact with them and they can give you the help you may need.

Remember,

your healthcare team are interested in hearing how you are balancing managing your beta thalassaemia and living life your way. Keep communicating with them to explore all the ways you can manage your physical and emotional wellbeing while living with beta thalassaemia. **Find your path and keep**

Find your path and keep moving forward.





Your notes

Use can use this space to take notes about anything important you're told during your appointment.

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