



Living with Barth Syndrome – How do you do it?



Nobody would ask to have Barth Syndrome but you can't choose to get rid of it. Having the right kind of help and information can make a difference to how you deal with it.

You may have questions, feelings and many different thoughts about Barth Syndrome. It can be hard to know how you feel, what might happen and what you might do. You may not feel comfortable talking about how you feel but if you are feeling upset you might need help to cope.

Talking about feelings

Being positive

Being optimistic can help, there may be many things about Barth Syndrome like the friends you make and social events that you go to which are fun. You may also get top tips from each other.



Sometimes I don't feel positive

You are not expected to feel happy all the time. Having Barth Syndrome can be very scary and it's okay to feel worried, angry or upset by it. Feeling sad won't make things worse, crying and talking about it can release stress and make you feel better.

Jealous

At times young people with chronic conditions feel jealous of brothers, sisters and friends that don't have an illness and can do normal stuff. It is okay to want to be like someone who doesn't have Barth Syndrome.

Feeling Lonely

You can feel lonely even if you are surrounded by people you love. You might feel that nobody really knows how it feels. You may need to help your family understand when you feel lonely and how they can help. It can help to spend time with other young people with Barth Syndrome.



Withdrawn

There might be a time when you feel really down and just want to be on your own. This is okay but if you are shutting yourself off most of the time you may be starting to feel depressed. You may need to talk to your parents or healthcare team to help you manage this.

Uncertainty

Although doctors and researchers across the world are finding out more about Barth Syndrome all the time currently there is no cure. It is impossible for your doctor to guarantee that everything will be okay and this uncertainty can be the hardest thing to cope with. But it is possible to live with this and cope with this.

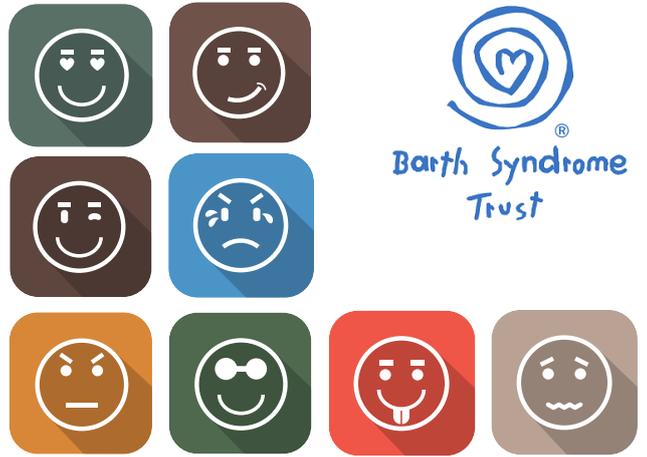


How do I cope?

You might need a few coping strategies or different ones at different times. It's important to find the best way to cope and only you know what that is. To get you started there are some ideas for you to try on page 2 of this factsheet.

Learn about your condition– you might feel more in control and less scared if you understand Barth Syndrome and what to expect in clinics or about treatments.

Ask questions you have – If you have worries, questions and concerns or anything you don't understand ask, it's better than not knowing.



Get involved – take control of your healthcare and decisions about treatments. Your parents and your healthcare team will give you your independence if you prove you can take control of your G-CSF and telling people if you are unwell.

Set goals –What is important to you in your life both today and in the longer term? Who can help you meet your goals?

Get organised – try writing a list or planning how to reach your goals. Be realistic and don't take on too much.

Getting upset – If you feel upset or sad and want to cry that is okay, it may even help.

Having good friends – spend time with people that support you and help you laugh, cry and have fun.

If talking is hard – write a letter, email or blog. Find cards and songs that say what you feel, leave signs on your bedroom door or draw pictures.

Try writing a journal – Sometimes writing down how you feel can help. You can keep this to yourself or share parts of it with people you trust.



Talk – Find somebody you can trust and talk to them or vent if you need to. Parents and friends don't always know how to help you or what you need from them so tell them.

Stay Positive – Barth Syndrome is part of your life but you are more than your Barth Syndrome. Find things that help you stay positive, this might be remembering to be hopeful or spending time with particular people or doing particular activities. Try and do something each day that is important to you or simply that you enjoy.

Talking to someone



You might find that talking to a psychologist, family member or friend can help you identify feelings or worries that you might have. It may help to talk about these and just have someone who can listen. They may also be able to help you find solutions and ways to cope with worries that you have.



Top tips from young people with Barth Syndrome

- Try to keep as busy as possible. Start by finding activities you can do by yourself, then look at finding things you can do with others, close friends and at school
- Think about asking somebody to help you role play situations you might not feel confident in, for example:
 - talking to new people
 - telling friends or colleagues about Barth Syndrome
- If school is difficult try taking a rest, try asking for a manageable timetable and get support from your teachers.
- Spend as much time with your friends as possible and try making new friends and finding new hobbies.



Cards for parents



To

It means a lot to me that you are there for me. When things are tough its hard to know what to do and say but here are things that might help.

- The best thing you can do is let me know that you are there for me. Ill ask for help when I need it.
- Just listen to me. I might laugh, cry or feel angry, you don't need to make things better but I would like you to listen.
- I'm sorry if I snap sometimes. I know you are trying to help. Give me time to work out what I am feeling.
- It's okay to ask me if I'm okay but sometimes I feel too upset to answer and I might not know why I am upset.
- Keep trying to talk to me. I might not always answer but please keep trying. Talk to me about the same stuff we always talk about.



To

It means a lot to me to have you as a friend at the moment. Things are tough and it's kind of hard to know what to do and say ... but here are some things that might help.

- Call me, email me, text me, face-book me. Just stay in touch. If I'm not in the mood to talk, I just won't answer (But keep trying!)
- Send me jokes, DVD's or music and do things with me that make us laugh. Everything's not always bad ...there are good days too.
- Come and hang out with me for a day at the hospital while I'm being treated.
- Talk to me about the same stuff we always talk about. We don't have to talk about Barth syndrome.
- Keep inviting me to things. I may not be able to go all the time, but ill go when I can.
- It's OK to ask questions. Don't worry too much about upsetting me. If I don't want to answer them, I'll let you know.
- Come and visit me at home. I'd like to just hang out.

