

The Haemophilia Society: Supporting you every step of the way

We're here for you and your family, no matter how old you are or what stage of life you're at. We aim to provide tailored, practical information and support, from the moment you or a loved one is diagnosed with a bleeding disorder, to help you live life well. Our approach is based on the help you need through seven key life stages.

Life Stage 1: Helping newly diagnosed children and their families

We provide 'whole family' support in many different ways, both practical and emotional – helping parents to navigate challenges like:

- Supporting mums (and dads) who carry the affected gene to process feelings of 'guilt' or a sense that they are responsible, addressing any tendency to be over-zealous in their care, which may in turn make their partner feel relegated to the sidelines.
- Nurturing their child's self-confidence and independence, resisting the temptation to 'wrap them in cotton wool'. Everyone is different and it can be hard to find the right balance, especially given that prescribed treatment regimes can vary between haemophilia centres.
- Helping brothers and sisters to understand, and not to feel excluded in any way when an affected child may command so much more time and attention.

Above all, families have asked us for dedicated time and space to meet and learn from medical experts and each other, sharing their experiences and parent-to-parent advice. Our weekends for newly diagnosed families have been designed to meet this need.

What parents say:

Kate

'My husband Dean and I knew nothing about haemophilia before our son Alfie was born. He was delivered with forceps and needed stitches to stop the bleeding from his scalp – that was the first sign that Alfie may have a bleeding disorder. After further blood tests, we received a diagnosis of severe haemophilia A. He had a bleed on the brain that led to a fortnight in hospital.

‘I wanted to understand how other mums felt, and how they coped with the guilt I was feeling for passing this condition onto my son. I also wondered whether it had affected their decision to expand their families further.

‘Having heard from other families coping with bleeding disorders, we now know that Alfie will soon be tearing around, being boisterous, and enjoying every minute of being a child.’

Claire and Chris

‘Although our comprehensive care team is brilliant, we still had lots of questions about Haemophilia. Our little boy Ellias has severe haemophilia A and has developed an inhibitor, so all our energy has been focused on his treatment plan, leaving very little time to discuss the future.

‘We were nervous about being away with the inhibitor, but couldn’t miss the opportunity to meet so many other families in similar situations. The weekend was the perfect way to bounce questions, knowledge and advice off other parents and learn about Haemophilia in a relaxed environment.

‘We loved meeting other families and expert presenters, and, most of all, seeing all the children play together and just get on with their day. We both found the separate breakout groups for mums and dads a useful chance to discuss our individual feelings, and were hugely reassured to know that we’re coping well and our emotions are normal.’

Viola and Ozgur are parents to Max, who has severe haemophilia A, and his younger sister Ruby:

‘My Dad has severe Haemophilia A, but the medication, approaches and processes have changed so much since he was young that he can’t advise us very much.

‘The weekend was an intensive lesson in the history of Haemophilia, current and future treatments, and UK treatment centres. My favourite part was the mums’ meeting, where we could express our feelings without guilt, or worry about being criticised or judged.

‘Children of all ages played together happily from the moment they met. They were able to see that they’re not the only ones with this condition, and could feel the same as everyone else.’

Find out more at www.haemophilia.org.uk or call us on 020 7939 0780 to request a place at an upcoming weekend.

We will be adding more information to our website in the coming months, so please check back for updates to this page.

Thanks to Bayer, sponsors of our work with newly diagnosed families.