

New diagnosis of severe haemophilia: where to get support

Information for parents, guardians, and carers from the Haemophilia Centre

For you, having a child diagnosed with severe haemophilia can be a traumatic and lonely time, especially if there is no history of haemophilia in your family and you are unfamiliar with the condition. Some parents/guardians/carers have fallen under suspicion of abuse, having to prove to relatives, friends, or social workers that their child's bruises are a medical symptom, not a sign of abuse. At this stage, people often want information and reassurance about what lies ahead, and plenty of support from others who understand exactly how it feels to be in this position.

It is natural for parents/guardians/carers of haemophiliac children to worry about every bump or knock; and the instinct will be to 'wrap them up in cotton wool'. However, we know that doing all the normal things babies and toddlers do will make sure your child develops normally, and will protect them in the long term. The stronger and more active they are can protect them against joint bleeds. It is important to remember though, that accidents do happen.

How can the Haemophilia Centre help you?

We aim to offer you and your family as much practical and emotional support as we can. Our paediatric nurse will be able to spend time with you either in the Haemophilia Centre or at home during the coming weeks or months, to make sure you have enough information and help as possible.

Do not ever feel you are being a nuisance or bothering us if you get in touch with the Haemophilia Centre. Even if your concern seems minor, it is far better to ask questions, that is why we are here.

We regularly hold group meetings where you can meet other parents of children with haemophilia. We can also arrange for you to talk to another family who has already been living with haemophilia. This could be just to talk to them on the telephone or to meet up with them away from the Centre. If this is something you feel would help you and your family, please speak to a member of the team.



What help is available outside of the Haemophilia Centre?

The Haemophilia Society offers practical and emotional support for the whole family, including regular weekends for families with children aged 0 to 5 years. These weekends for newly diagnosed families are jam-packed with information, sessions with physiotherapists, paediatricians and specialist nurses, and are a time to swap stories and make new friends. More information is available on The Haemophilia Society website haemophilia.org.uk/support/newly-diagnosed

The practical challenges of living with a bleeding disorder are well documented, and yet there can also be a significant mental health impact on individuals and their families. This is not something that is often talked about, but it can be a concern for most people at some point, whether you yourself have a bleeding disorder or someone you love and care for does.

Very few people receive NHS treatment for the psychological impact of living with a bleeding disorder, which means that there is a greater need for emotional support from other sources. We hope the following information will help you find appropriate help if you find the need to seek emotional and mental health support.

Counselling and talking therapies offer a secure, confidential space to talk about life and things that feel confusing, stressful, or painful. Therapists are trained to be objective, attentive, and non-judgmental, they provide an “outside” pair of ears to help guide you towards new ways of coping. More information is available on The Haemophilia Society website haemophilia.org.uk/support/newly-diagnosed

How can I find the right counselling service for me and my family?

You may want to consider counselling services. If so, you can access free psychological therapies, including counseling for depression, through the NHS. You do not need a referral from your GP; you can refer yourself directly to a psychological therapies service through the NHS web site www.nhs.uk/conditions/stress-anxiety-depression/types-of-therapy/

If you wish to discuss further any of the topics raised above, please speak to a member of the Haemophilia Centre staff. They are available to offer support and help to both you and your family.

Always remember, you are not on your own

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff. You can ask someone to contact us on your behalf.

Any complaints, comments, concerns, or compliments please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 78 31 45, or email ekh-tr.pals@nhs.net

Further patient leaflets are available via the East Kent Hospitals web site www.ekhufft.nhs.uk/patientinformation