

LIBERATE
LIFE



A GUIDE FOR HAEMOPHILIA
PATIENTS & CARERS

signs of a bleed

& how to treat it



This booklet has been written for parents
and carers of people with haemophilia who are
taking factor replacement therapy
This booklet has been developed by Sobi
NP-15112 March 2021

 **sobi**
rare **strength**





contents

What is haemophilia?	4
What happens when people bleed?	5
Where might someone with haemophilia bleed?	6
How do I know if the person I am caring for is bleeding?	8
What should I do if I think the person I am caring for is bleeding?	10

This booklet is only intended for parents and carers of people with haemophilia whose haemophilia has not been complicated by the development of inhibitors.



what is haemophilia?

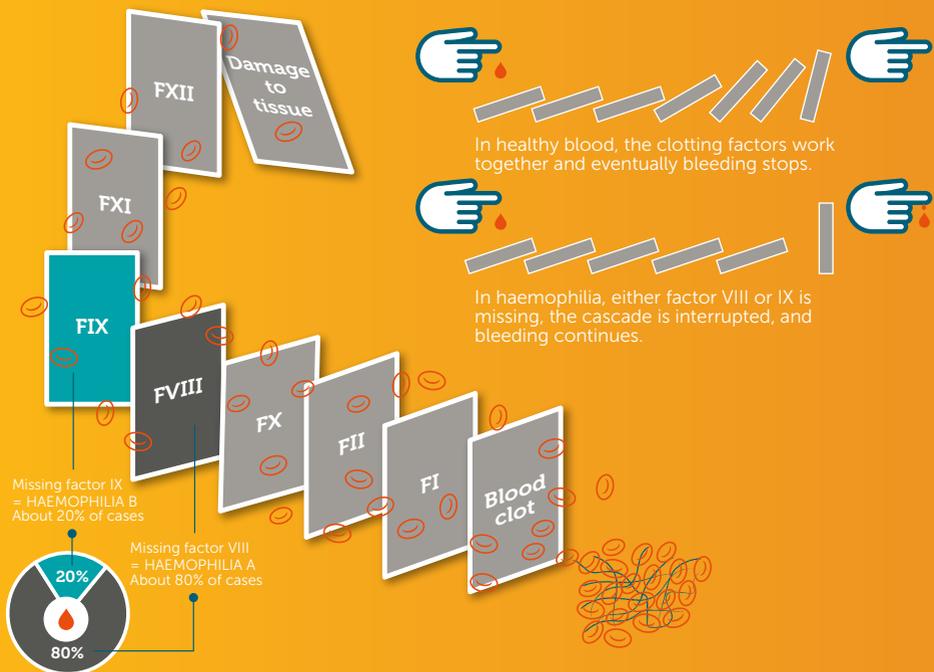
Haemophilia is a bleeding disorder in which the blood does not clot properly. When a person with haemophilia bleeds, it takes longer than normal for the bleeding to stop. This is because people with haemophilia don't produce enough of an important protein that helps the blood to clot, called a 'clotting factor'.

When caring for a person with haemophilia, recognising when they are having a bleed and what you should do if a bleed occurs is an important part of their long-term care. This guide aims to provide you with an overview of what a bleed looks and feels like, the actions you should take if you suspect a bleed has occurred and the importance of recording bleeds.



what happens when people bleed?

Normally, the body reacts to bleeding by triggering a series of events that helps the blood to clot. Proteins called clotting factors interact with each other to form a clot that stops the bleeding. People with haemophilia have reduced levels of, or lack an essential clotting factor, so when they start to bleed, the clotting process is disrupted. This process is shown in the picture below:

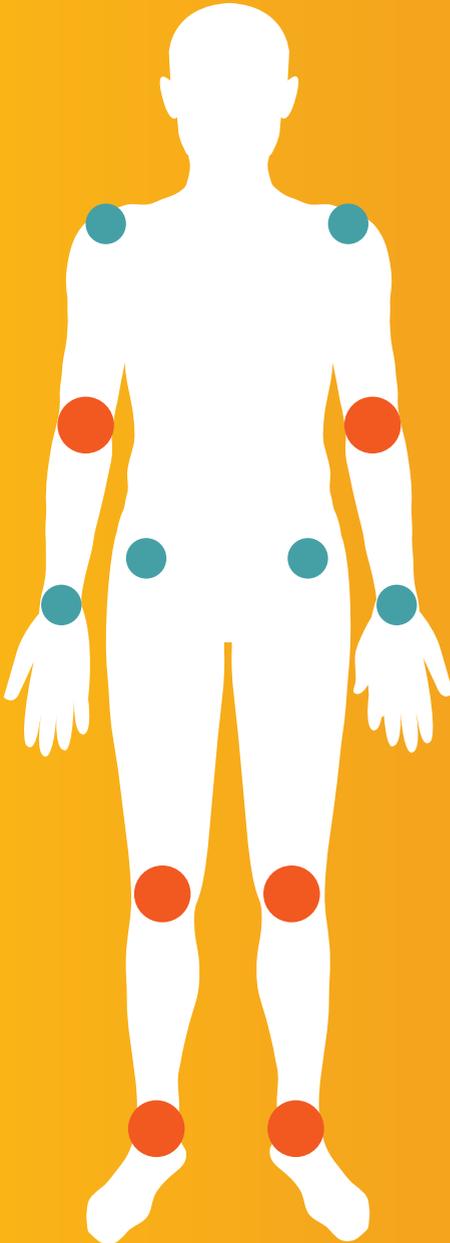




where might someone with haemophilia bleed?

Bleeding in people with haemophilia can happen anywhere in the body, including beneath the skin causing bruising. Bleeds inside the body are most common in the joints or muscles and may happen following an accident or spontaneously. This 'spontaneous' bleeding usually only happens in severe haemophilia. Spontaneous bleeding in the joints typically affects the ankles, elbows and knees. Bleeding in the head or brain is rare but can be serious.





Most common

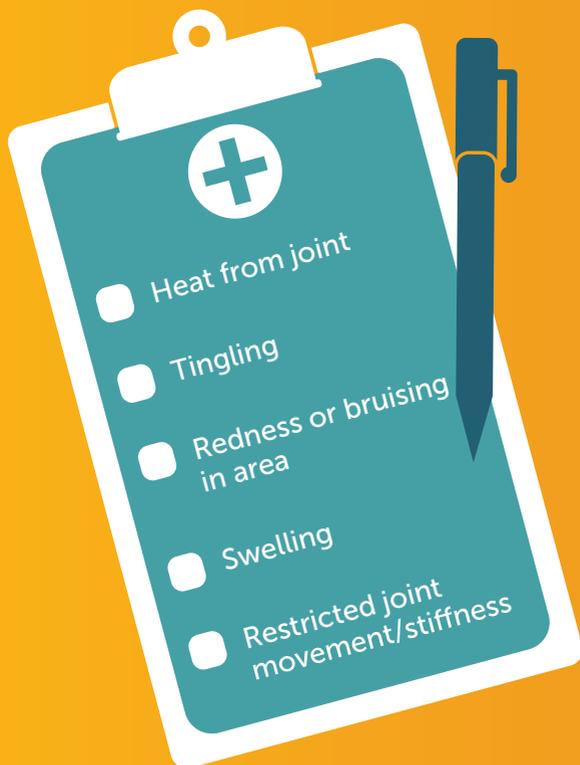
- Elbows
- Knees
- Ankles

Less common

- Shoulders
- Wrists
- Hips

how do I know if the person I am caring for is bleeding?

They might experience different types of bleeds;
these are most commonly in the joints and muscles:





Joint bleeds

Signs of bleeding in the joints include pain, stiffness, warmth and swelling. Once a joint becomes damaged, bleeding may occur more frequently. To prevent joint damage, it is important to treat bleeds quickly.

Muscle bleeds

Muscle bleeding can be difficult to see, as the muscles are beneath the skin and there might not be any bruising. Common signs of bleeding in the muscles include aching, tenderness, pain and restricted movement.

Brain bleeds

Bleeds in the brain are rare. Signs of bleeding in the brain include a sudden and severe headache, stiff neck, vomiting and confusion. If the person you are caring for has a head injury or you suspect a bleed in their brain, you should seek medical advice urgently.

External bleeds

If the person you are caring for has a cut or graze, applying pressure to the area should stem the bleeding. However, if the bleeding continues for more than 15-20 minutes, contact a Haemophilia Treatment Centre. For mouth and nose bleeds, standard first aid should be enough to stop the bleeding. However, if the bleeding does not stop after 15-20 minutes, contact a Haemophilia Treatment Centre. If the mouth bleed is related to a dental extraction, where the person you are caring for has not received factor first, then you should contact a Haemophilia Treatment Centre, where they might be given factor replacement or another suitable treatment.



what should I do if I think the person I am caring for is bleeding?

It is important to treat a bleed as soon as you suspect it, rather than waiting for pain and swelling. The goal of treatment is to stop the bleed as soon as possible to avoid long-term damage. Bleeding in haemophilia can be managed by replacing the missing clotting factor. The haemophilia team of the person you are caring for will tell you when and how often they need to take their factor to manage or prevent bleeds.

Should I keep a record of their bleeds?

It is important to record the bleeds of the person you are caring for, as their haemophilia team will use this information to monitor their treatment and joint health. If you have access to Haemtrack – an online system for recording treatment information, you should record their treatment and bleeds here so that you and their haemophilia team can monitor the treatment of the person you are caring for, and ensure that their treatment schedule is providing them with the best level of protection from bleeds.

thank you to our contributors

Sobi would like to express our warmest thanks to nurse consultant Dr Kate Khair. Dr Khair has extensive experience in haemophilia and has kindly helped us to fact-check the contents of this brochure.





for more information about
living with haemophilia,
please go to:

www.liberatelife.co.uk

Endorsed by:



**THE
HAEMOPHILIA
SOCIETY**

Registered Charity No. 288260

Charity registered in Scotland No. SC039732

Sobi is a trademark of Swedish Orphan Biovitrum AB (publ)
© 2021 Swedish Orphan Biovitrum AB (publ) – All rights reserved

Swedish Orphan Biovitrum (UK) Ltd, Suite 2, Riverside 3,
Granta Park, Great Abington, Cambridgeshire, CB21 6AD
www.sobi-uk.co.uk

 **sobi**
rare **strength**