

One of the first steps in diagnosis will be to provide a bleeding history.

You will need to be seen in the clinic by the haemophilia team. Your doctor or haemophilia nurse will ask you a comprehensive range of questions about your medical history and your medications, including over-the-counter medications.

They may also ask you to complete questionnaires, known as Bleeding Assessment Tools.

The purpose of these questions is to identify if you have bleeding problems that suggest a bleeding disorder and what kind of bleeding pattern you have.

What are signs you might have a bleeding tendency?

- · Bruising easily
- Having more painful swelling and bruising than you would expect after an injury, eg falling off a bike, car accident, sporting injury
- Bleeding or oozing for a long time after dental surgery or extractions, other surgery and medical procedures, injuries or accidents
- Internal bleeding into joints, muscles, organs and soft tissues (more common in severe haemophilia)

Women and girls may also have:

- Heavy and/or long menstrual periods. This is called heavy menstrual bleeding or sometimes abnormal uterine bleeding or menorrhagia and may lead to low iron levels or anaemia
- Heavy bleeding for an extended time after childbirth (particularly with delayed or late postpartum haemorrhage)





References

1. van Galen KPM, d'Oiron R, James P, et al. A new hemophilia carrier nomenclature to define hemophilia in women and girls: Communication from the SSC of the ISTH. Journal of Thrombosis and Haemostasis. 2021;19(8):1883-1887. Accessed 24 March 2022. Available from https://doi.org/10.1111/jth.15397.

2. Australian Bleeding Disorders Registry data provided to HFA by the National Blood Authority in 2020, following an HFA request approved by the ABDR Steering Committee in 2020 and 2022.

3. Kasper CK, Lin JC. How many carriers are there? Haemophilia 2010;16:842. Accessed 24 March 2022. Available from https://doi.org/10.1111/j.1365-2516.2010.02210.x.

4. Hermans C, Kulkarni R. Women with bleeding disorders. Haemophilia. 2018;24(Suppl. 6):29-36. Accessed 25 March 2022. Available from https://doi.org/10.1111/hae.13502.

 Srivastava A, Santagostino E, Dougall A, et al. WFH guidelines for the management of hemophilia, 3rd edition. Haemophilia. 2020: 26(Suppl 6): 1-158. Accessed 24 March 2022. Available from https://doi.org/10.1111/hae.14046.

Other sources

Alabek M, Mohan R, Raia MA. Genetic counselling for hemophilia. Rev. edn. Treatment of hemophilia No 25. Montreal: World Federation of Hemophilia, 2015. Accessed 24 March 2022. Available from http://www1.wfh.org/publications/files/pdf-1160.pdf.

Australian Haemophilia Centre Directors' Organisation. Guidelines for the management of haemophilia in Australia. Melbourne; Canberra: AHCDO; National Blood Authority, 2016. Accessed 24 March 2022. Available from https://www.blood.gov.au/haemophilia-guidelines.

McLintock, C. Women with bleeding disorders: Clinical and psychological issues. Haemophilia 2018;24(Suppl. 6):22–28. Accessed 24 March 2022. Available from https://doi.org/10.1111/hae.13501.

World Federation of Hemophilia. Carriers and women with hemophilia. Montreal: WFH, 2012. Accessed 24 March 2022. Available from https://www1.wfh.org/publication/files/pdf-1471.pdf.

Acknowledgements

Written by Suzanne O'Callaghan, HFA Policy Research and Education Manager, and Marg Sutherland, health educator.

Quotes and personal stories in this resource were contributed by Australian women with haemophilia or who carry the gene alteration. We thank them for their generosity in sharing their experiences.

Our thanks also to the HFA Women's Consumer and Health Professional Review Groups for their suggestions on topics and content to include.

Reviewers

Australia and New Zealand Haemophilia Psychosocial Group: Nicoletta Crollini, Dr Moana Harlen, Jane Portnoy.

Australian Haemophilia Centre Directors' Organisation: A/Prof Chris Barnes, Dr Stephanie P'ng.

Australian Haemophilia Nurses' Group: Jaime Chase, Susan Dalkie, Janine Furmedge, Penny McCarthy, Joanna McCosker, Megan Walsh.

Genetics and genetic counselling: Clinical A/Prof Kristi Jones, Senior Staff Specialist in Clinical Genetics, and Lucy Kevin, genetic counsellor, The Children's Hospital at Westmead, Sydney.

Haemophilia Foundation Australia: Sharon Caris.

HFA Women's Consumer Review Group – individuals not named for privacy reasons.

Maurice Blackburn Lawyers: Katherine Bedford, Senior Associate.

More information

To find more information about haemophilia and carrying the gene alteration, or to find out how to get in touch with your local Haemophilia Foundation or a specialist Haemophilia Treatment Centre, contact:

Haemophilia Foundation Australia

7 Dene Ave Malvern East Victoria 3145

T: 03 9885 7800 Toll free: 1800 807 173

E: hfaust@haemophilia.org.au

Or visit the HFA website: www.haemophilia.org.au

NB: All photos in this booklet are stock images.

Important note

This booklet was developed by Haemophilia Foundation Australia for education and information purposes only and does not replace advice from a treating health professional. Always see your health care provider for assessment and advice about your individual health before taking action or relying on published information. © Haemophilia Foundation Australia, May 2022.

This factsheet may be printed or photocopied for education purposes.

