

Haemophilia

A guide for parents of a newly diagnosed child



HAEMOPHILIA FOUNDATION AUSTRALIA

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This resource is the result of a substantial review and adaptation of *Haemophilia: for parents whose child has recently been diagnosed with haemophilia*, originally published by Haemophilia Foundation Australia in 2004, with revisions in 2014.

Some information and illustrations in this resource were originally published by the World Federation of Hemophilia (WFH) and the Royal Children's Hospital (RCH), Melbourne, and have been reprinted and adapted with permission. Neither WFH nor RCH are responsible for any inaccuracies in content different from the content of the original English edition.

Our thanks to the Physiotherapy Department at Lady Cilento Children's Hospital, Brisbane for photos of soft casts and exercises.

While some photos are stock images, some other photos in this resource were provided by parents and state/territory Haemophilia Foundations. Our thanks to them for permission to reprint the photos. These have not been identified individually for privacy reasons.

The content in this resource was redeveloped by the Centre for Community Child Health at The Royal Children's Hospital and the Murdoch Children's Research Institute for Haemophilia Foundation Australia.

This resource was reviewed by:

Australia/New Zealand Haemophilia Social Workers' and Counsellors' Group: Dr Moana Harlen, Lady Cilento Children's Hospital, Brisbane.

Australian Haemophilia Nurses' Group: Janine Furmedge, Royal Children's Hospital, Melbourne; Anne Jackson, Women's & Children's Hospital, Adelaide; Siew Lee, Princess Margaret Hospital for Children, Perth; Joanna McCosker, Lady Cilento Children's Hospital, Brisbane; Robyn Shoemark, The Children's Hospital at Westmead, Sydney; James Slade, Canberra Hospital and Health Services; Helen Starosta, Royal Hobart Hospital.

Australian and New Zealand Physiotherapy Haemophilia Group: Auburn McIntyre, Women's & Children's Hospital, Adelaide; Alison Morris, Princess Margaret Hospital for Children, Perth; Wendy Poulsen, Lady Cilento Children's Hospital, Brisbane.

Australian Haemophilia Centre Directors' Organisation: Dr Chris Barnes, Royal Children's Hospital, Melbourne; Dr Julie Curtin, The Children's Hospital at Westmead, Sydney

Haemophilia Foundation Australia: Sharon Caris, Suzanne O'Callaghan

Sandy Breit, grief and loss counsellor, Melbourne.

HFA Parents Consumer Review Group: bleeding disorder community representatives (names not listed for privacy reasons).

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Important note

This resource 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.

How to use this Guide

This Guide is intended for parents of children who have recently been diagnosed with haemophilia.

It aims to:

- Help you understand haemophilia and treatment, care and support in Australia
- Share experiences from other Australian parents
- Link you to further information.

The Guide does not replace medical advice from a qualified health professional. You should always discuss your child's individual situation with the treating team at your Haemophilia Treatment Centre (HTC).

Getting started

Everyone is different and you may find that you only want a small amount of information to start with and then find out more later – or you may want to read as much as you can from the beginning.

What to read first: the section in Chapter 1 *Haemophilia - what you need to know now* (pages 1.1-1.6) is intended to be your introduction to haemophilia.

Then dip into the rest of the Guide when you are ready.

Icons used in this Guide



Important information



Find out more information



Contact your Haemophilia Treatment Centre (HTC)