

## How are you feeling?

Being diagnosed with haemophilia or carrying the gene can affect people in very different ways. There is no right or wrong way to feel. How you react will depend on your individual situation and what this news means to you.

You may have been tested because your baby or child has been diagnosed with haemophilia – or because haemophilia is in your family. Your testing may result from bleeding symptoms that suggest haemophilia. Or it may be your daughter who is being tested.

Feelings and reactions can be very complex. The diagnosis may have been something you expected and perhaps a relief to have your symptoms confirmed or it may have been a shock to you. You may feel guilt about your child having haemophilia or worry about the future. There can be a ripple effect to partners and family.



## Support

Whatever your experience, you may need time to digest the information while you consider what this means to you or your daughter.

If you would like to talk to someone about your questions or feelings, don't hesitate to reach out for support.

Your Haemophilia Treatment Centre is there to provide information and support at any time along the way and also in the future, if issues come up for you later. They are also available for your partner and family and can talk to them separately if that works better.

The Haemophilia Treatment Centre can refer you to a genetic counsellor or other counsellors.

You can also talk to your GP and they can refer you to counselling and other services to support you.

## Talking to other women – you are not alone

You may find it valuable to talk to other women with the gene alteration, who have faced similar challenges and understand how you are feeling. The Haemophilia Treatment Centre, your local Haemophilia Foundation or Haemophilia Foundation Australia may be able to put you in contact with other affected women.



**Finding out you carry the gene – what does this mean to you?** is a free HFA booklet which explores feelings after diagnosis, support and information, with tips and personal stories from Australian women.

Available from:

- The HFA website – [www.haemophilia.org.au](http://www.haemophilia.org.au)
- Haemophilia Treatment Centres
- Or ask HFA to post you a print copy – [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)

# Sources

## References

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NB: All photos in this booklet are stock images.

# Acknowledgements

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

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## 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 Furnedgedge, 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](mailto:hfaust@haemophilia.org.au)

Or visit the HFA website: [www.haemophilia.org.au](http://www.haemophilia.org.au)

## 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.

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