

Telling others

Who do you need to tell about the test results?

Family and partners

Diagnosis can be an emotional time. You may feel you need some time and support to come to terms with it, while you decide who you want to tell and how to tell them.

Family and partners can be a great source of support, but their reactions may also be challenging. You may feel unsure how to talk about your diagnosis with them.

Legally you do not have to tell your family or partner that you have the gene for haemophilia. However, telling others close to you may be very important to your relationship.

Are you the first person in your family to be diagnosed with the gene alteration for haemophilia? You may be asked to tell other family members so that they can have genetic counselling and think about testing for themselves and their children.

Telling others might be quite straight-forward or it may not be easy for you.

If you are concerned about telling your partner or your family about your diagnosis, consider getting some extra support.

Your Haemophilia Treatment Centre and genetic counselling services can assist with this:

- Information about who might be affected – your partner and in your family
- Helping you to plan how to tell them
- Support for your partner
- Support for all affected family members considering genetic or factor level testing
- Referral to other counselling services



Telling others about bleeding disorders is a free HFA information booklet for women, girls and their parents. It explores a range of situations - telling partners, family, friends, school, work and applying for insurance. Available from HFA

- Download from the website – www.haemophilia.org.au
- Or ask HFA to post you a print copy – hfaust@haemophilia.org.au



Employers

Generally you do not have to tell an employer or a prospective employer (eg, if applying for a job) about your health condition unless it will have a big ('fundamental') impact on your ability to do your job or will impact on your ability to do your job safely.

Some specific examples of situations where you need to tell an employer include applying to be employed by:

- The Australian Defence Force (ADF)
- The police force.

What do you need to do in this situation?

- When asked about your health conditions or genetic testing, you are required to answer honestly. Otherwise you may be discharged from the ADF or police force.

Insurance

Another common question is about telling insurance companies. When applying for insurance you may be asked if you have a **health condition** or have had **genetic testing**.

What do you need to do in this situation?

- If asked, you are required to answer honestly
- Let them know if you have been diagnosed as a *symptomatic haemophilia carrier*, even though this is not the medical condition *haemophilia*
- Otherwise your insurance may not be valid.

People with the medical condition *haemophilia* may need to pay a higher premium for **life insurance** (including income protection) and **travel insurance**. Shop around for an insurer who provides the best value for you.



More information

Haemophilia testing in women and girls: your questions answered – read the *Genetic testing and counselling* section of this resource on the HFA website – www.haemophilia.org.au

Talking to your employer about illness – under *Health Topics* on the HealthDirect website - www.healthdirect.gov.au