

Your diagnosis and treatment

What does your diagnosis mean?

In the past women and girls with bleeding symptoms were generally all called 'symptomatic carriers'.

In Australia, diagnosis is now more specific – but you may be wondering the terms mean.





Diagnosis	Meaning
<p>genetic test negative</p>	<p>The genetic test did not find a gene alteration known to cause haemophilia.</p> <p>You are not a carrier and you do not have the medical condition <i>haemophilia</i>.</p>
<p>asymptomatic haemophilia carrier</p>	<p>You have the gene alteration for haemophilia but you do not have any haemophilia bleeding symptoms.</p> <p>You do not have the medical condition <i>haemophilia</i>.</p> <p>However, you can pass the gene alteration on to your children and some of your children may have haemophilia.</p>
<p>symptomatic haemophilia carrier (40-50% of normal clotting factor)</p>	<p>You have the gene alteration for haemophilia.</p> <p>Your clotting factor levels are on the borderline between normal and haemophilia, but you have haemophilia bleeding symptoms.</p> <p>You will be treated as having haemophilia.</p> <p>You can pass the gene alteration on to your children and some of your children may have haemophilia.</p>
<p>haemophilia and haemophilia carrier (less than 40% of normal clotting factor)</p>	<p>You have the medical condition <i>haemophilia</i>.</p> <p>Therefore you are also a <i>haemophilia carrier</i>. You can pass the gene alteration on to your children and some of your children may have haemophilia.</p> <p>Your male children may have more severe haemophilia than you do.</p>

Treatment plan

If you have been diagnosed with haemophilia, you will have an individual treatment plan.

The plan will be worked out with your haemophilia treatment team and will cover the best option for each situation. You may be prescribed different types of treatment at different times.

You may also be referred to a gynaecologist (specialist women's health doctor) if heavy menstrual bleeding is a problem for you.

If you have anaemia (low red blood cells or low iron levels) as a result of heavy menstrual bleeding, your doctor may suggest treatment such as iron supplements.


Australian Bleeding Disorders Registry (ABDR)

If you have bleeding symptoms, it is important to register and stay in contact with your local Haemophilia Treatment Centre (HTC), even if you receive most of your care from another doctor, such as your general practitioner (GP).

If you are diagnosed with haemophilia or as a 'carrier', you may be asked by your HTC to register in the Australian Bleeding Disorders Registry (ABDR). This is the online system used by HTCs across Australia to manage and record the treatment and care of their patients.

Ask your HTC about an ABDR patient card. This is a wallet card which explains:

- Your diagnosis and severity
- Your treatment plan
- Who to contact for further medical advice.

 <p>Haemophilia Treatment Centre City Hospital, OZ CITY, OZ Haemophilia Centre Ph: 01 2111 3111 On-Call Haematologist (A/H) Ph: 01 2111 3000</p> <p>Jane Citizen</p> <p>DOB: 1/1/2001 MRN: 0100101 ABDR ID: 100200</p> <p>Diagnosis: Factor VIII Deficiency (Haemophilia A) Severity: Mild Factor Level: 12%</p> <p>Card Issue Date: 16/03/2021</p>	<p>Treatment Guidelines</p> <p>Product: RECOMILISTATE (Extended Half-Life Recombinant Factor VIII)</p> <p>Treatment Comments: Treat PROMPTLY with Recombinant factor VIII (8) to avoid serious complications. Consult with Centre or Haematologist on call for dosing advice, and follow-up treatment. Will require cover for: trauma, medical or dental procedures or surgery.</p> <p>Factor doses rounded up to nearest vial size.</p> <p>MyABDR: www.blood.gov.au/myABDR MyABDR Support Ph: 13 000 25663</p>
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Keep your ABDR patient card on you for quick reference and to show to other health professionals treating you.





What can you tell your other doctors?

Haemophilia is rare. Many health care providers like doctors and dentists may not have treated female patients with haemophilia before and may not be familiar with the current treatment.

Planning is important! If you are going to have a procedure that will need preventive treatment, such as surgery, your doctors and HTC will need to organise the treatment ahead of time.



- Show your other doctors, dentist and health care providers your **ABDR patient card** if you have one.
- Ask them to liaise with your HTC.
- Always inform your doctor, dentist or surgeon you have a bleeding disorder before having any medical, dental or surgical procedures, no matter how minor.
- If you are planning surgery, contact your HTC beforehand and discuss the medical support you may need to prevent bleeding complications.
- Your HTC might also have specific brochures you can take with you, eg on surgery or dentistry.
- Before you start taking anything prescribed by your doctor, naturopath or other health practitioner, check with them or your pharmacy whether it is safe for someone with a bleeding disorder.

Pregnancy

If you are planning a pregnancy or are pregnant, speak to your HTC. You may wish to explore your reproductive options, such as testing for the sex of the baby, finding out if it has a gene alteration for haemophilia or options for having a child without haemophilia.

Ask your obstetrics team to liaise with your HTC.

Where can your other doctors get information?

If you consent, your treating haematologist (specialist bleeding disorders doctor) or the team at your HTC would be happy to speak with your doctors and other health professionals about your diagnosis and treatment plan and liaise with them about your care. HTC contact details are on the HFA website – www.haemophilia.org.au.

Your other doctors may find other useful medical information on the Australian Haemophilia Centre Directors' Organisation (AHCDO) website – www.ahcdo.org.au.