

What are our aims?

To work towards better treatment conditions for people with a bleeding disorder and to provide support for their families by:

- Providing information about bleeding disorders to members and the general public.
- Maintaining contact with government and hospitals about the needs of people with a bleeding disorder.
- Contributing directly to the assistance of members in their education and welfare.
- Encouraging the public to become blood donors to the Australian Red Cross Blood Service.
- Supporting research and development of new and improved therapy.

The Haemophilia Foundation Western Australia employs a Secretary/Coordinator to assist in working towards these aims.

How can you help?

Join the Foundation – cost \$22.00 including GST per annum. We welcome interested, active members, who are willing to help with fundraising, social activities and support. All members receive regular local and national Newsletters.

Become a blood donor – To ensure continuing quantities of the factors essential for haemophilia treatment.

Make a financial donation – The Haemophilia Foundation Western Australia inc. is a voluntary charitable body. Donations of \$2.00 and over are tax deductible.

Related Condition

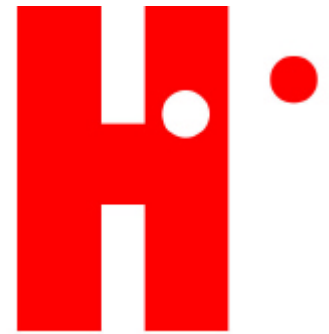
von Willebrand Disorder is a related bleeding condition, characterised by the inability of the blood's platelets to form an effective clot. It is also hereditary but differs from Haemophilia in that it affects both males and females.



Who are we?

A voluntary organisation of people with haemophilia or a related bleeding disorder, their families, friends and anyone who is interested.

Founded in 1985, we are a member of the Haemophilia Foundation of Australia (HFA). HFA is a member of the World Federation of Haemophilia.



HAEMOPHILIA FOUNDATION WA Inc.



MEMBERSHIP INFORMATION

Member of Haemophilia Foundation Australia

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Haemophilia What is it?

Haemophilia is a blood clotting disorder in which one of the essential clotting factors is deficient. There is no cure for haemophilia but the development of clotting factor concentrate has meant that it can be managed effectively.

Bleeding is mostly internal. The deficiency in clotting factor produces a wide range of bleeding episodes, usually into the joints or muscles. These bleeding episodes may be caused by injury, but in severe haemophilia can begin spontaneously.

The common belief that a person with haemophilia gushes blood from cuts or scratches and will rapidly bleed to death is a myth.

A person with haemophilia will bleed no more profusely than anyone else but they will bleed for a longer time. Small wounds or superficial grazes pose no problem because in these cases, healing does not depend on a clot forming.

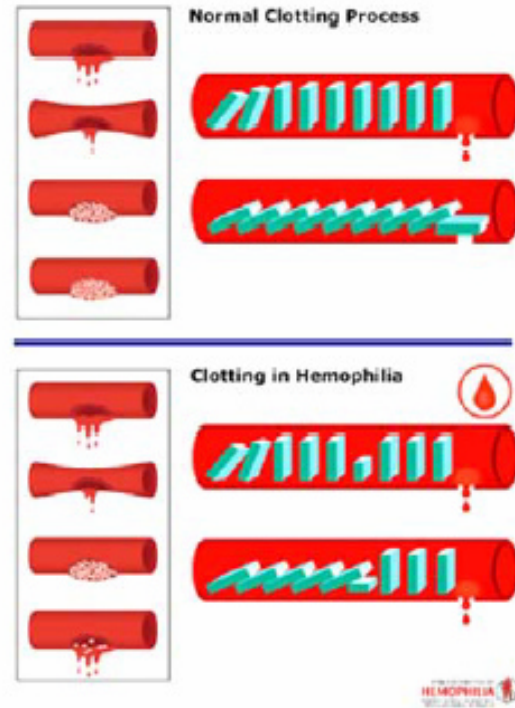


Who is affected?

Haemophilia is hereditary. It affects males almost exclusively, and is passed on through females who carry the defective gene. However, between one quarter to one third of all occurrences appear in families with no previous history of the disorder. Haemophilia is found in all races and all socio-economic groups. Men with haemophilia will have carrier daughters.

What causes it?

The haemophilia gene causes a shortage of the factors in the blood which make it clot (there are 12 factors). In Haemophilia A, the most common type, Factor VIII is missing or low. In Haemophilia B, Factor IX is missing or low. Very rarely another of the 12 factors is missing. Factor levels in the blood will vary – the lower the level, the more severe the bleeding problems.



How is it treated?

Treatment involves injecting the factor which is missing. These factors are taken from blood donated to the Australian Red Cross Blood Service. Also, recombinant, or “synthetic” clotting factor is being used to treat the majority of people. Home therapy is now widely used so that a person with a bleeding disorder (or parents) can give injections at home, at work or on holidays.

This reduces the amount of time spent at hospitals and so keeps disruption to people’s lives to a minimum.



How does this affect the lives of people with a bleeding disorder?

When toddlers begin to crawl, frequent bruising is often a problem. This is usually when a bleeding disorder is diagnosed.

When children start school, it is imperative that staff are well informed. Bleeds into knees or ankles may require rest at home, or the use of crutches at school until the joint recovers. Arthritis often occurs in joints which have had many bleeds. Physical fitness and participation in sports is encouraged, but body contact sports such as football should be avoided.

Normal working lives covering a wide range of occupations can be undertaken, but heavy manual labour is not advisable.

People with a mild bleeding disorder may have few problems and require treatment only a few times in their lives – for tooth extractions, surgery or serious injury.

