FACT SHEET
Haemophilia

A lifelong bleeding disorder with evolving care and global disparities

novo nordisk haemophilia & haemoglobinopathies foundation

What is haemophilia?

Haemophilia is a genetic disorder in which blood lacks sufficient clotting factor proteins, leading to prolonged bleeding after injuries or surgery – and in severe cases, spontaneous internal bleeding.
It is inherited in an X-linked recessive pattern (meaning the gene is passed through the X chromosome), so males are typically affected while females are usually carriers.

Quick facts

- Haemophilia is a rare, inherited bleeding disorder where the blood does not clot properly.
- The two main types are Haemophilia A (factor VIII deficiency) and Haemophilia B (factor IX deficiency).
- It primarily affects males, but females can be carriers and experience bleeding symptoms.
- Haemophilia is not contagious and is present from birth.
- About 21 of every 100,000 males have hemophilia A. About 4 in 100,000 males have hemophilia B.

Haemophilia classification

Type	Cause	Prevalence	Notes
Haemophilia A	Factor VIII deficiency	~80% of haemophilia cases	Most common type
Haemophilia B	Factor IX deficiency	Less common	Also known as Christmas Disease
Acquired Haemophilia	Immune system attacks clotting factors	Very rare, non-genetic	Typically affects adults

Severity categories

- **Mild:** 5–40% of normal clotting factor
- **Moderate:** 1–5%
- **Severe:** Less than 1%

Severity affects bleeding frequency and risk. Most severe cases are diagnosed in early childhood, while mild cases may go unnoticed until a major injury or surgery.

Carrier status (females)

- Can have normal or reduced clotting factor levels.
- Around 20–30% experience bleeding symptoms.
- Common issues: heavy menstruation, bleeding during childbirth or surgery.
- Carrier testing is important for family planning and clinical care.

Symptoms and complications

Easy bruising

Prolonged bleeding from cuts

Joint swelling or pain
(from internal bleeding)

Bleeding into muscles or soft tissues

Heavy menstrual bleeding
(in female carriers)

Without treatment, recurrent joint bleeds can lead to chronic pain, disability, and reduced quality of life.

Who is affected?

About 21 of every 100,000 males have hemophilia A. About 4 in 100,000 males have hemophilia B[1]. Only 1 in 3 people with haemophilia are diagnosed, with the greatest gaps in low- and middle-income countries, where access to testing and treatment is limited[2]. Approximately 75% of people with haemophilia worldwide, primarily in low-income countries and lower-middle-income countries, have no or limited access to therapy[3].

Regional estimates:
- Africa: ~6% of global diagnosed cases
- South-East Asia: ~14%
- Europe & Americas: ~60%[2]

Diagnosis

Diagnosis is done by:
- Clotting factor tests (Factor VIII and IX levels)
- Activated partial thromboplastin time (aPTT)
- Genetic testing (especially for family planning or carrier screening)

Haemophilia is often detected in early childhood, particularly after circumcision, dental procedures, or abnormal bruising.
Carrier testing is recommended for women with a family history of haemophilia and is increasingly important not only for family planning but also for clinical management, as some carriers may have low factor levels and require treatment.

Treatment options

- **Clotting factor replacement therapy** (standard and extended half-life products)
- **Non-factor therapies**
- **Gene therapy** (approved for Haemophilia A; trials ongoing for Haemophilia B)
- **Plasma-derived treatments** (e.g. cryoprecipitate, fresh frozen plasma) – used in some low-resource settings
- **Supportive care:** physical therapy, pain management, joint protection

In high-income countries, prophylaxis is standard of care. In many low-income settings, treatment is often on-demand and relies on plasma-based products due to cost and limited access.

Living well with haemophilia

With proper care, people with haemophilia can live full and active lives.
- Regular infusions of clotting factor help prevent bleeding episodes.
- Preventive care and physical therapy support joint health.
- Early diagnosis and consistent treatment reduce long-term complications.
- Staying informed and connected to care teams improves outcomes.

References:
1. World Federation of Hemophilia, 2022, https://wfh.org/about-bleeding-disorders/#hemophilia Last accessed: November 2025
2. World Federation of Hemophilia, Annual Global Survey 2023, 2024. Available at: www1.wfh.org/publications/files/pdf-2525.pdf Last accessed: August 2025.
3. Pierce, G. et al (2022), Achieving access to haemophilia care in low-income and lower-middle-income countries: expanded Humanitarian Aid Program of the World Federation of Hemophilia after 5 years. The Lancet Haematology, 9(9), e689-697, https://doi.org/10.1016/S2352-3026(22)00209-5

Novo Nordisk Haemophilia & Haemoglobinopathies Foundation
The Circle 32/38, Postfach
8058 Zurich, Switzerland
nnhf.org

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