

# Hemophilia

**Queen Victoria of England, who ruled from 1837-1901, is believed to have been the carrier of Hemophilia B, and she passed the trait on to three of her nine children.**

British actor with seven Oscar nominations, Richard Burton was the first Hollywood star to reveal he had hemophilia. In 1964 along with his wife and actor Elizabeth Taylor, he created the Richard Burton Hemophilia Fund to help find a cure.

**Globally more than 2,00,000 people live with some form of hemophilia.** While China reports the third highest global number of hemophilia patients, like India it has a low prevalence of 0.7 per 1,00,000 population.

The Rights of Persons with Disabilities Act, 2016 recognizes persons with blood disorders among the 21 types of disabilities. Hemophilia is one of them.

**Hemophilia is a group of disorders related to blood that cause excessive bleeding and poor blood clotting and affects mostly males.**

- **Hemophilia is an invisible disability** that can cause symptoms like spontaneous bleeding from the mouth or nose, from the gastrointestinal tract, joints, muscles, other tissues, brain or skull or increased bleeding after surgery.
- This can cause pain, swelling, and limited movement.
- The severity of the disorder varies from person to person.

**Treatment for hemophilia includes** replacing the missing clotting factor through infusions of clotting factor concentrates. This can help prevent and manage bleeding episodes. They can benefit from physical therapy and other types of rehabilitation to improve joint mobility and muscle strength. This can help them lead more active lives.

- People living with hemophilia may require some accommodations or 'reasonable' accommodations as per the RPWD legalese.
- Pursuing education or employment, they may seek flexibility in timing, extra leave, extra time for assignments/examinations, posting and transfers and so on.
- These are of course fall outs of the symptoms one experiences and how they cope with it.

[The Hemophilia Federation of India](#), was the first patient organization founded in 1983, with only 12 families! Fortunately, doctors and health workers have been quite aware of the condition from the early 1960s and there is a lot of research and written material on it as well.

Despite the challenges they face, people with hemophilia can and do live full and fulfilling lives. Many become advocates for themselves and others with the disease.