

hemophilia myths & facts

Hemophilia is a disorder that impairs the body's ability to control bleeding. There are about 20,000 people with hemophilia in the United States and with the disease being so rare, many people may not know much about it. Below are 10 common myths to help people better understand the disorder.

MYTH

FACT

If a person with hemophilia gets a minor cut, they'll bleed to death.



People with hemophilia don't bleed faster, but they do bleed longer because they're missing a protein in their blood that assists in forming stable clots. Minor cuts are not a cause for concern and will usually heal on their own.

Only males have hemophilia.



While many people assume hemophilia affects only males, females who are carriers can also suffer from bleeding symptoms. Though extremely rare, a daughter who is born to a father with hemophilia and a mother who is a carrier can inherit the severe form of the disease.

People with hemophilia always have a family history of the disease.



Nearly one-third of hemophilia cases are not genetically based and have no family history of the disease.

All people who have hemophilia are diagnosed at birth.



Due to a lack of bleeding at birth or because the family doesn't have a history of hemophilia, some people who have hemophilia are not diagnosed as newborns.

Children with hemophilia will grow out of it.



Hemophilia is a lifelong condition, a bleeding disorder caused by the absence of an essential blood clotting protein that has no cure.

MYTH

Hemophilia is the same for all patients.



People with hemophilia shouldn't exercise or play sports.



Hemophilia is a "royal disease."



Hemophilia causes AIDS.



People with hemophilia can't live normal lives.



FACT

People can have hemophilia A, which is defined by low levels of clotting factor VIII (8), or hemophilia B, defined by low levels of clotting factor IX (9). The severity of the disease can be categorized as mild, moderate, or severe. Additionally, about 15% to 20% of people with hemophilia will develop an antibody—also called an inhibitor—which is one of the most serious complications of the disease.

Exercise is important for people with hemophilia because it strengthens muscles, which helps protect joints, and reduces the risk of being overweight, which places added stress on joints. They should work with their health care professional to create a fitness plan that's right for them.

While it's true that in the 1800s, hemophilia did affect the royal family of Queen Victoria of England, anyone can have hemophilia.

Hemophilia doesn't cause HIV/AIDS. Unfortunately, from 1978–1985, many people with hemophilia did contract HIV when they received treatments made from tainted blood donations. The blood supply is now much safer due to improved donor screening and advanced purification methods, and also, many newer treatments aren't made from donated human blood. There hasn't been a documented case of HIV from the use of hemophilia treatments since 1987.

With proper treatment, most people with hemophilia lead long, full, and productive lives.