



# Factor VII deficiency

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Information for patients, parents, and carers from the Haemophilia Centre

## What is factor VII deficiency?

Factor VII deficiency is a rare condition that affects blood clotting. It affects around 1 in 300,000 to 500,000 people in the UK.

People with a factor VII deficiency do not bleed any faster, but may bleed for longer than expected.

Having factor VII deficiency should not affect everyday life. Most of the bleeding problems that happen tend to be after an injury, surgery, or dental treatment.

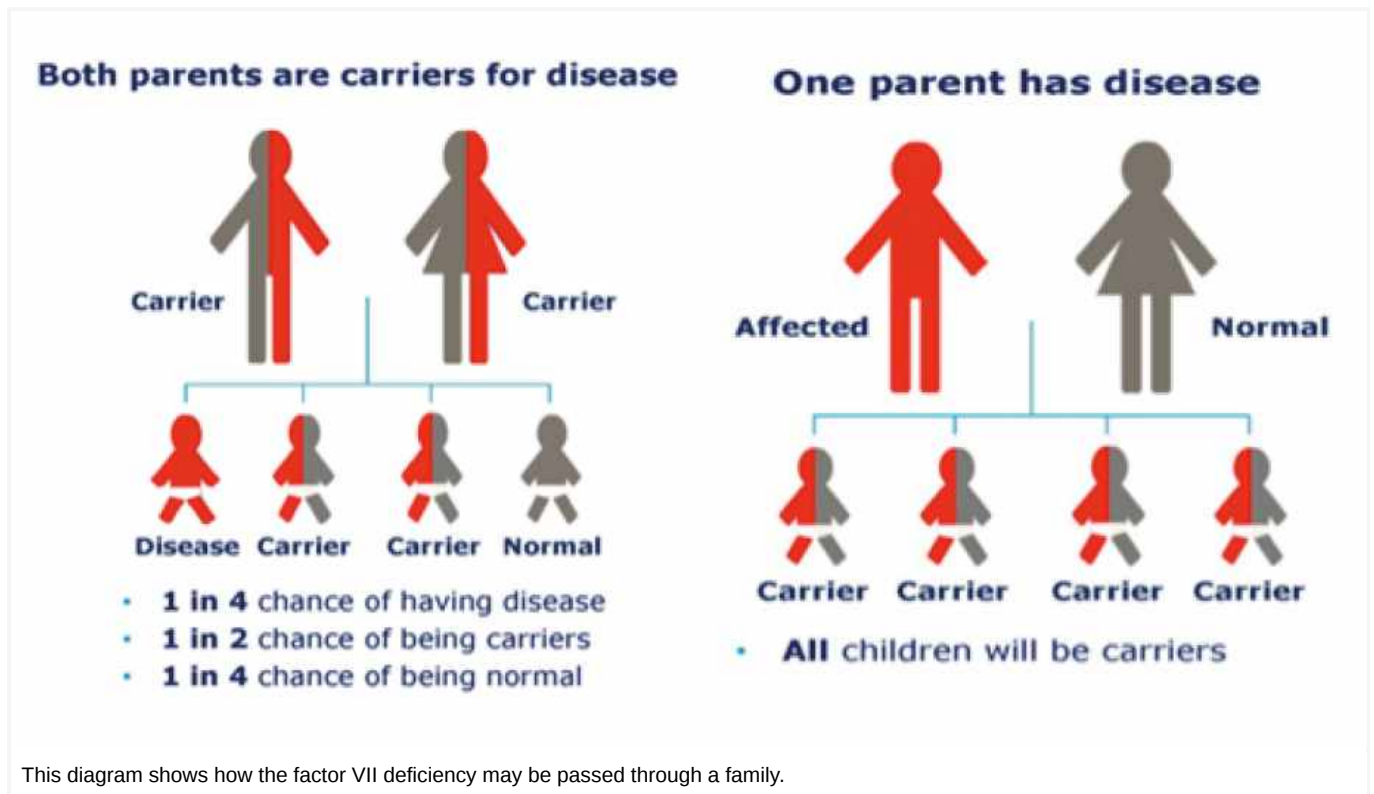
## How does factor VII affect clotting?

Factor VII is a protein made by the liver and helps to make your blood clot when there is injury to a blood vessel. If you have factor VII deficiency you do not make enough factor VII for your blood to clot normally, or what you do make might not work as well as it should.

## How do you get factor VII deficiency?

Factor VII deficiency is an inherited condition, you are born with it and both men and women can inherit it from their parents.

One set of our genes is inherited from our mother and the other set from our father. Both parents must carry the defective factor VII gene and pass it on for the child to have a more severe factor VII deficiency. Mutations can happen, which mean the gene is unable to make enough factor VII or that what it does make does not work as well as it should.



In conditions such as factor VII deficiency people who have one mutated factor VII gene may have a low factor VII level. Where both parents carry the mutated factor VII gene, there is a one in four chance their child will have both mutated factor XI genes and have a much lower factor VII level, making a more severe factor VII deficiency.

### What are the symptoms of factor VII deficiency?

Symptoms can vary and many people have very little in the way of bleeding problems. Spontaneous bleeding (bleeding that happens for no apparent reason) is very rare and usually only happens in those with severe factor VII deficiency.

Levels of factor VII can vary greatly in people too. It is thought that a level of 30% is sufficient for blood clotting. However, the bleeding problems do not always correspond to the levels of factor VII. Some people with very low levels of factor VII do not seem to have any problems with bleeding, whereas some people with a higher factor VII level may have problems. The reason for this variation may be due to how well the factor VII that you do have works.

### Common symptoms

- In women and girls, heavy and prolonged bleeding during menstruation (known as menorrhagia)
- Nose bleeds
- Bleeding from gums
- Easy bruising
- Bleeding after surgery
- Bleeding after trauma or injury

- Bleeding in the mother at childbirth.

### **Rare symptoms (usually in those with severe deficiency)**

- Blood in your urine (known as haematuria)
- Bleeding in your stomach or intestines (blood in stools (poo) or black tarry stools)
- Bleeding in to your muscle
- Bleeding in to your joints (known as haemarthrosis)
- Bleeding in to your brain.

### **How is factor VII deficiency treated?**

Day-to-day treatment is not needed for factor VII deficiency. It may however be necessary before and after surgery, dentistry, or trauma.

The need for treatment will depend on:

- how severe your bleeding is
- the type of surgery or dental treatment you are having
- your previous history of bleeding
- your family's history of bleeding; and
- your factor VII level.

### **What are the treatments for factor VII deficiency?**

- Antifibrinolytic Agents (Tranexamic Acid)
- Factor VII Concentrate

## **Antifibrinolytic Agents (Tranexamic Acid)**

Tranexamic Acid works by stopping the early breakdown of a clot that has been made after injury to your blood vessel. Fibrin is a protein that gives the blood clot stability. Tranexamic Acid stops the substances that destroy the fibrin within the clot.

Often it is the only treatment needed for some people with factor VII deficiency and for some procedures. It is particularly useful for mouth bleeding and therefore a very good preventative treatment when you are having a dental procedure.

This treatment is usually given as tablets. You may be asked to crush the tablets in a small amount of water and swish it around your mouth, before either swallowing it or spitting it out (you will be advised by the haemophilia team which is best for you).

Tranexamic Acid is not used when there is blood in your urine, as small clots can occur which can then block your urinary tract and cause you pain.

## **Are there any possible side effects?**

Common side effects are:

- nausea (feeling sick) and vomiting
- diarrhoea
- joint or muscle pain
- muscle cramps
- headache or migraine
- runny or stuffy nose
- stomach or abdominal pain.

Other side effects may include skin rash and changes to your colour vision.

## **Factor VII concentrate (NovoSeven)**

Factor VII concentrate is a treatment that replaces the factor VII you are missing. This treatment is recombinant, which means it has been made in the laboratory and does not come from blood donors.

It is given through either a small butterfly needle or a cannula (a small tube into a vein in your arm), directly in to your vein over two to five minutes.

## **Are there any possible side effects?**

Side effects are rare, but include:

- mild headache
- joint pain
- nausea (feeling sick) or vomiting
- swelling
- mild itching or rash
- pain, redness, swelling, or irritation where the medicine was injected.

## **Where can I find more information about factor VII deficiency?**

There are several sources of useful information about factor VII deficiency, including the following.

- The Haemophilia Society (<https://www.haemophilia.org.uk>)
- World Federation of Hemophilia (<https://www.wfh.org>)

**This leaflet has been produced with and for patients.**

**Please let us know:**

- If you have any accessibility needs; this includes needing a hearing loop or wanting someone to come with you to your appointment.
- If you need an interpreter.
- If you need this information in another format (such as Braille, audio, large print or Easy Read).

**You can let us know this by:**

- Visiting the Trust web site (<https://www.ekhuft.nhs.uk/ais>).
- Calling the number at the top of your appointment letter.
- Adding this information to the Patient Portal (<https://pp.ekhuft.nhs.uk/login>).
- Telling a member of staff at your next appointment.

**Any complaints, comments, concerns or compliments**, please speak to a member of your healthcare team. Or contact the Patient Advice and Liaison Service on 01227 783145 or email ([ekh-tr.pals@nhs.net](mailto:ekh-tr.pals@nhs.net)).

**Patients should not bring large sums of money or valuables into hospital.** Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property has been handed into Trust staff for safe-keeping.

**Further patient information leaflets** are available via the East Kent Hospitals' web site (<https://www.ekhuft.nhs.uk/patient-information>).

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