

This factsheet is about a bleeding disorder that is related to problems with a blood clotting factor called factor X (pronounced factor 10). It is written to go with our **Rare bleeding disorders booklet**, where you will find much more information on living with one of these conditions.

What is factor X deficiency?

Factor X deficiency is a bleeding disorder caused by the body producing less of the clotting factor than it should. This causes problems because the clotting reaction that would normally control any bleeding is blocked too early. So, your body doesn't make the blood clots it needs to stop bleeding. Factor X needs vitamin K from the liver to be activated.

Factor X deficiency is rare. Doctors estimate that it affects about one in a million people.

What causes factor X deficiency?

This is an inherited genetic disorder. It is what is known as recessive, meaning you must inherit the gene defect from both parents. It affects men and women equally. Inherited factor X deficiency cannot be cured.

If you carry one copy of the gene fault for factor X deficiency, you are known as a carrier. You can only pass the condition on to your children if your

partner also carries the gene fault. You will not have the condition yourself, but any children that inherit the gene fault from you will also be carriers of the condition.

It is also possible to develop a factor X deficiency later in life. This is called acquired factor X deficiency. Acquired factor X deficiency is not inherited and occurs in individuals with no family history of the disorder.

This is rare, but may be caused by other diseases, including severe liver disease, amyloidosis, cancer and infections.

Symptoms of factor X deficiency

Symptoms of factor X deficiency can be mild, moderate or severe, depending on the amount of factor X your body is able to make.

People with mild symptoms may have:

- nosebleeds
- easy bruising
- bleeding gums
- heavy periods or periods lasting for longer than normal (menorrhagia).

Together For Life

To find out more, visit haemophilia.org.uk or contact us on **020 7939 0780** or at info@haemophilia.org.uk

People with moderate to severe symptoms may also have bleeding:

- from the umbilical cord stump after birth
- after circumcision
- into joints
- into muscles
- into the gut (gastrointestinal bleeds)
- into the brain or spinal cord (central nervous system).

It is very important that you contact your doctor or haemophilia centre if you think you or your child are having a bleed. If you have frequent bleeds, such as nosebleeds, you can become anaemic.

This means you have low haemoglobin levels because of the frequent loss of blood. Anaemia can make you feel tired and breathless.

There is more information in our **Rare bleeding disorders booklet** about how to spot the different types of bleeds

Diagnosing factor X

If you have mild factor X deficiency, it may only be diagnosed because of family history or after routine blood tests, before surgery for example.

People with moderate factor X deficiency may be diagnosed because they've had bleeding after surgery or an accident. For girls, it may be when their periods start and are heavy or longer than normal.

People who carry one copy of the faulty gene are known as carriers. Most carriers are healthy, but

sometimes carriers may show mild symptoms of factor X deficiency, which may or may not need treatment.

Severe factor X deficiency is usually diagnosed soon after birth, because of severe bruising, bleeding from the umbilical cord stump or after circumcision.

Other people are diagnosed in childhood because of easy bruising or bleeds into muscles or joints.

Treatment for factor X

How often you need to have treatment will depend on how severe your condition is.

You should not take non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen or aspirin if you have factor X deficiency as they can increase the risk of bleeding. Other methods of pain relief should be used instead.

For minor bleeding such as nosebleeds, bleeding gums or heavy periods, your doctor may suggest you take tranexamic acid tablets (Cyklokapron).

These work by stopping the breakdown of blood clots. If you have very heavy periods, your doctor may suggest that you take the contraceptive pill to make them lighter.

You will probably only need other treatment if you have a more serious bleed or before planned surgery.

Factor X deficiency

Treatments include:

- factor X concentrate (FX) – which contains only factor X
- prothrombin complex concentrate (PCC), which contains factor X along with two or three other clotting factors
- fresh frozen plasma (FFP).

All are made from donated human blood – from plasma, the straw-coloured fluid that the blood cells are carried in.

All these blood products are now treated during manufacture to kill off any known viral infections such as hepatitis and HIV.

You have these treatments into a vein (intravenously). If you need treatment regularly, it is usually possible to teach you to give it yourself at home.

In the UK, everyone with severe factor X deficiency and unmeasurable levels of the protein will be offered regular treatment to prevent bleeds. Your doctor may call this prophylaxis (pronounced proff-ill-ax-iss).

You have treatment with FX, PCC or FFP concentrate two or three times a week.

Women with factor X deficiency should plan their pregnancy carefully as there is an increased risk of early miscarriage or extended bleeding after giving birth. Treatment for bleeding during the last three months of pregnancy, during labour and for a few days afterwards also can be given.

You should not use Non-Steroidal Anti-Inflammatory Drugs (NSAIDs such as ibuprofen) as this increases the risk of bleeding. Other methods of pain relief should be used instead. Speak to your doctor if you are unsure.

You should have immunisations or other injections subcutaneously (under the skin) rather than intramuscularly (into a muscle) to reduce the risk of a painful bruised swelling (haematoma) developing.

Coping with your condition

Finding out that you or your child has a bleeding disorder can be upsetting and bring on a range of different emotions. Of course, this will take time to accept. Finding out as much as you can about your condition can help you learn to cope with it.

How much your bleeding disorder affects your daily life will depend on how severe it is. For many people, it won't have much effect at all. It may only be an issue if you are having dental work, major surgery, are having a baby or have an accident.

Others may need treatment from time to time to treat minor or more serious bleeding. A small number may need regular treatment to prevent bleeding.

Any surgery (including dental) will need careful planning in advance so it is important that all health care professionals involved are aware of the condition.

Factor X deficiency

Regular follow up at a specialist haemophilia centre is essential to check that you or your child are responding to treatment and not experiencing any side effects. Regular check-ups with a dentist are also required.

If you or your child needs an injection or immunisations, caution is needed. Injections should be given subcutaneously (under the skin) rather than intramuscularly (into a muscle) to reduce the risk of a painful bruised swelling (haematoma) developing.

Contact sports, which carry a high risk of head injury, need to be avoided, but most day-to-day activities won't cause many problems. Your haemophilia centre can help you choose activities that are right for you or your child.

Factor X deficiency will require lifelong monitoring and treatment. As your child gets near to their teenage years, your haemophilia centre will start to talk to them about getting ready to move on to adult health services.

This is a slow process so that they become more independent as they grow older and more able to manage their own health.

It is possible to have genetic counselling before planning a family, both for affected individuals and unaffected carriers. You can discuss this with your haemophilia centre.

Do find out as much as you can about how to prevent bleeding and when it is likely to cause a problem. Our **Rare bleeding disorders booklet** has a lot of information about what to look out for and precautions you can take to keep yourself healthy.

There is information on:

- ways to make bleeding less likely
- how to spot the early signs of a bleed
- dental care
- carrying medical information with you
- information for girls and women about problems with periods and pregnancy.

A new diagnosis can feel scary or overwhelming but there's lots of great support available.