

# Emicizumab (for people without an inhibitor)

**The  
Haemophilia  
Society**

This factsheet is about a new treatment called emicizumab or Hemlibra® for people with severe haemophilia A. Emicizumab has been designed to mimic the way that factor VIII works in the body.

## Emicizumab (Hemlibra)

- A new treatment is available for people with severe haemophilia A. It is used as prophylaxis to prevent bleeds.
- Emicizumab is not a treatment for bleeds, serious injury or major surgery.
- You have emicizumab as an injection just under the skin either weekly, fortnightly or every 4 weeks. Most people however inject weekly or fortnightly.
- There is no viral infection risk as the product is entirely made in a laboratory.
- There have been some serious side effects reported and this treatment may not be suitable for everyone, you should discuss with your haemophilia team.

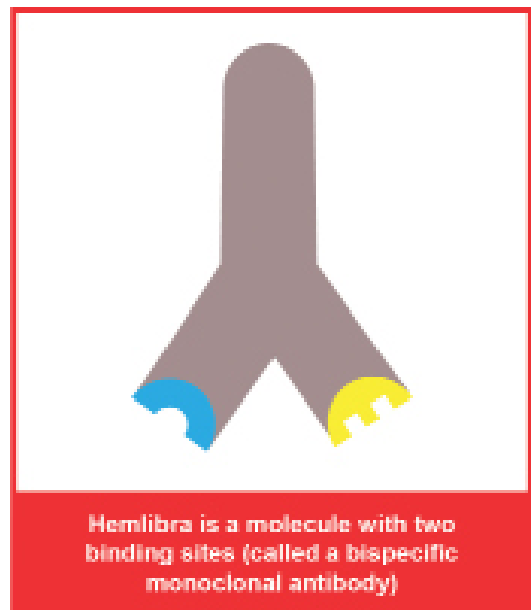
## What is emicizumab?

Emicizumab is a treatment called a monoclonal antibody. Monoclonal means single type. So it is a single antibody that has been manufactured in a laboratory in large quantities and designed to do a specific job in the body.

It isn't made from blood products so there is no viral infection risk.

Emicizumab copies the way factor VIII works. It brings activated factor IX and factor X together in the blood, which activates factor X.

This allows blood clotting to continue and ultimately form a clot and stop bleeding. Emicizumab is present in the blood at stable levels, helping to prevent most bleeds and gives protection against minor injuries.

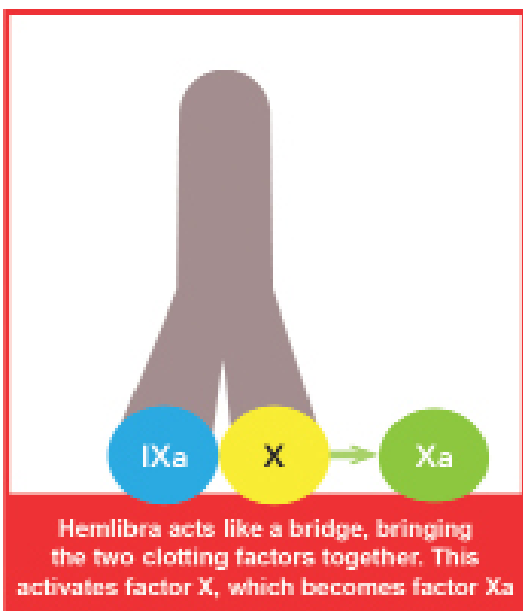
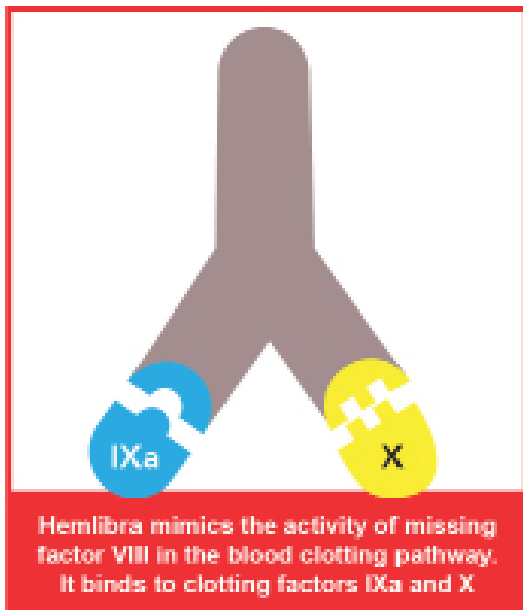


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This allows the clotting pathway to continue and the blood to clot

IXa = activated factor nine, X = factor ten, Xa = activated factor ten.

## Who can have emicizumab?

**Emicizumab is a treatment for anyone with:**

- severe haemophilia A without inhibitors
- haemophilia A of any severity with inhibitors

Because it is a newer treatment, we don't fully understand all the possible risks yet. Emicizumab helps your blood to clot. If the blood clots when it shouldn't, it can cause heart attacks, strokes and thrombosis. If you are older and have other risk factors for these conditions, or they run in your family, you will need to discuss whether emicizumab is right for you with your haemophilia specialist.

Emicizumab can be prescribed for very young babies. However, the clotting system doesn't fully mature until 6 months of age, so you will need to discuss with your haemophilia team what the best option for you and your child is. Some babies have been treated with emicizumab and research is still ongoing

## What are the benefits of emicizumab treatment?

You will have fewer injections. Your treatment to prevent bleeds (prophylaxis) will be by subcutaneous injection weekly or fortnightly. You may still need factor VIII or Tranexamic Acid if you do have a bleed.

Clinical trials have shown that emicizumab can prevent bleeding or reduce the number of bleeding episodes.

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## Are there any drawbacks to emicizumab treatment?

If your condition is stable on your current treatment and you are happy with your treatment plan and have good vein access there may be less reason to switch, particularly if you don't have bleeds.

You need specialist blood tests to monitor your factor level in an emergency if you are on emicizumab as normal factor level tests will not show the action of emicizumab. These are not available everywhere, so it may be an issue if you travel a lot and need treatment while abroad. Emicizumab takes up to 6 months to get out of your system.

## How you give emicizumab

Emicizumab is given as a subcutaneous injection. That means an injection you have just under your skin, not into a vein. You give yourself this injection once a week or once a fortnight, depending on your doctor's instructions.

The injection can be given under the skin in different areas of the body, these include upper arm, the tummy, and the thigh. Injections must be given at least 2.5cm from the site of the previous injection.

## What happens when you switch from your current treatment to emicizumab?

When you start on emicizumab, you have one injection of a 'loading dose' each week for 4 weeks. After 4 weeks, your dose of emicizumab will change to a smaller dose if you are having emicizumab weekly. Your dose will stay the same if you're having it fortnightly.

You should have your first loading dose at your haemophilia centre. This is so that the staff can teach you how to give the subcutaneous injections yourself and monitor you for any side effects. Some centres may ask you to attend the centre for all your loading doses.

FVIII prophylaxis can be given for the first 7 days of emicizumab treatment, please discuss this with your clinician.

## How will I be monitored on emicizumab?

Your centre will aim to keep the number of blood tests you have as low as possible – they'll discuss with you which ones are necessary.

### You are likely to need blood tests:

- After your loading doses, to monitor levels of emicizumab in your blood
- If you have a bleed and need treatment

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## You may need additional blood tests if:

- Your bleeding pattern improves but then worsens again – your team will want to check for antibodies against emicizumab (these are rare, but have been reported)
- You've had inhibitors in the past – your team will check for inhibitors twice a year and sooner than that if you need any FVIII for a bleed or injury
- You've never had an inhibitor but need FVIII for a bleed or injury – your team will check for inhibitors afterwards.

## What happens if I miss a dose?

If you miss a dose of emicizumab, call your centre. You may be advised to have a dose as soon as you remember, but **do not** have two doses in one day to make up for a missed dose.

## What happens if I have a bleed?

Emicizumab prevents bleeds, but it isn't a treatment for bleeding. When you switch to emicizumab, check with your haemophilia team how to manage a bleed or injury – it may be different to what you've done in the past or you may need a lower dose because you are having emicizumab.

In the first few months after starting emicizumab, it is best to contact your treatment centre for advice if you do have a bleed or injury.

Generally, for minor problems, you can take tranexamic acid and wait to see if that helps. But

don't do this without your teams' advice. If your bleed needs further treatment, you treat with factor VIII but only after discussing with your team.

Apart from your haemophilia medication, treat bleeds as you normally would, with PRICE – protection, rest, elevation and ice. Emicizumab may increase the risk of skin damage when ice is used, so take extra care to make sure the ice isn't in direct contact with your skin and report any skin discoloration or discomfort to your haemophilia centre.

## What happens if I need surgery?

If you need surgery you must ensure your haemophilia centre is involved in the planning of your care. For minor surgery such as simple dental extraction or endoscopy people have been able to have treatment without additional factor cover, but this decision must be made by your haemophilia team.

## Will I still have to fill in Haemtrack?

When you start on emicizumab, it is important that you keep a record of all your treatment and any bleeds on Haemtrack. This helps you and your haemophilia team to monitor how well emicizumab is working.

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

The most common side effect with emicizumab is irritation where you give the injection. This happens in around 1 in 5 people. You may have redness, soreness or itching or the area may feel hard. To avoid injection reactions, don't give two injections running in the same place.

Other common side effects are headache and aching joints.

**Tell your treatment centre if you have unusual headaches, joint pain or other new symptoms.  
Are there any serious side effects?**

Two potentially serious side effects have been reported in people having emicizumab. These are blood clots (thrombosis) and an unusual clotting condition called TMA or thrombotic microangiopathy.

Blood clots (thrombosis) can cause problems including heart attacks or strokes. They could happen to anyone taking emicizumab but are probably more likely in older people who have other risk factors for thrombosis.

**Contact your doctor immediately if you have any of these symptoms:**

- chest pain or tightness; shortness of breath or coughing blood
- confusion
- eye pain or swelling or difficulty seeing
- fast heart rate
- feel faint
- headache

- numbness in your face
- pain or redness in your arms or legs
- weakness in any part of your body

TMA means there are small blood clots and damage in the tiniest blood vessels in the body. TMA has only been reported in patients with inhibitors to FVIII on emicizumab, who used a bypassing agent called FEIBA at high doses to treat bleeding.

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