



START

Best viewed in 'Books' on Apple devices or 'Acrobat' on Android devices





SCAN ME TO PICK UP YOUR OWN COPY OF THIS GUIDE





What is Hemlibra?

What is involved for me?



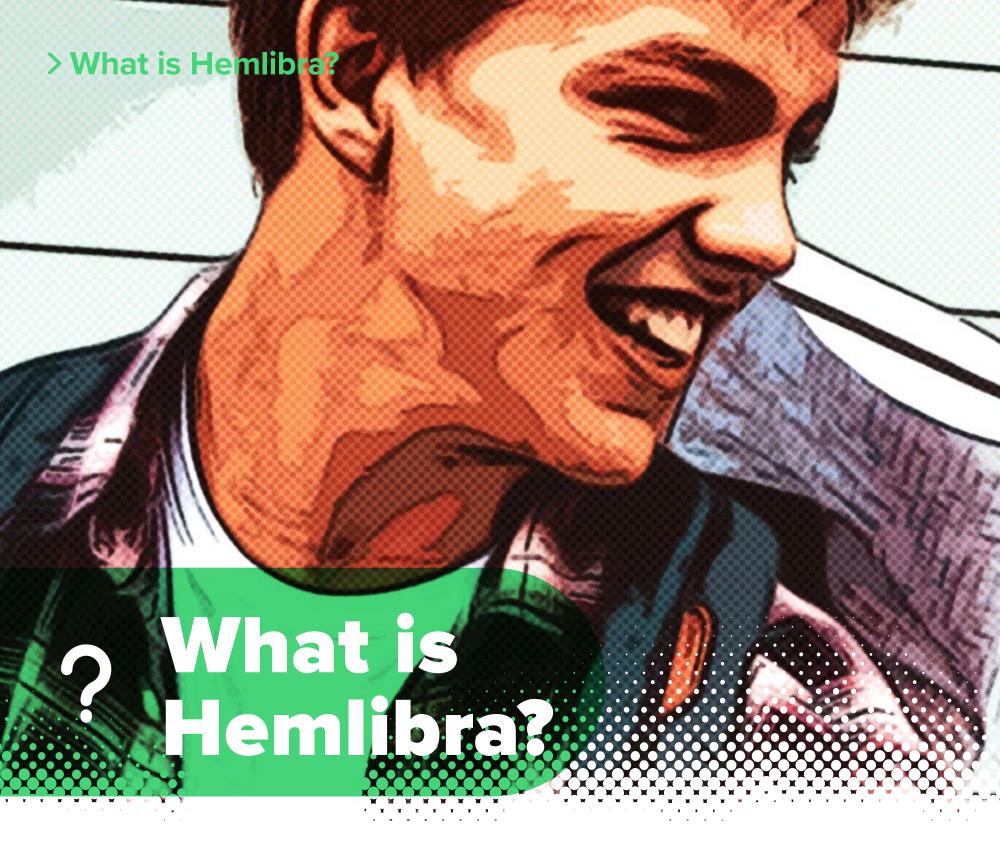
My activity & lifestyle



Transitioning







Understanding how Hemlibra works

Antibodies are proteins made by the body that stick to substances (antigens). Antibodies can be important in fighting infection. However, scientists can also design and manufacture antibodies in a laboratory.

These antibodies can bind to specific substances to help manage medical conditions, and are called monoclonal antibodies.

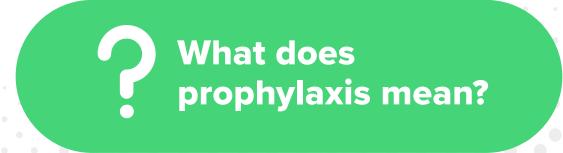


Hemlibra, also known as emicizumab, is a monoclonal antibody designed to help prevent bleeding in people with severe haemophilia A, people with moderate haemophilia A with severe bleeding phenotype, or people with haemophilia A and inhibitors to FVIII.

- Hemlibra is a bispecific antibody, meaning it can bind to two different substances
- Hemlibra creates a bridge between two clotting factors that you do have in your blood – activated factor IX and factor X. This allows the rest of your clotting factors to work together to form a clot.
- Hemlibra can only be used for prophylaxis and works in the same way whether you have severe or moderate haemophilia A, and whether you have inhibitors to FVIII or not









? What does prophylaxis mean?



Prophylaxis (pronounced pro-fi-lax-is) is the regular use of a treatment to prevent illness or preserve health.

For people with haemophilia A, prophylaxis is intended to prevent bleeding from occurring or reduce the number of bleeds that you may have.

















Hemlibra is quite different to your previous treatment, please click on the pages below to see how it differs to:























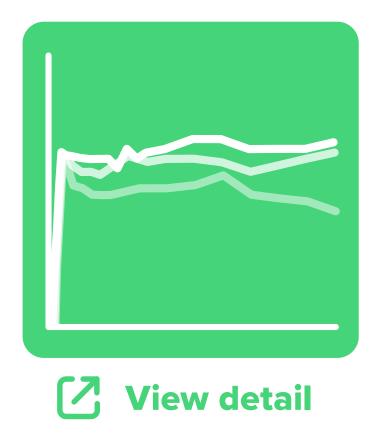




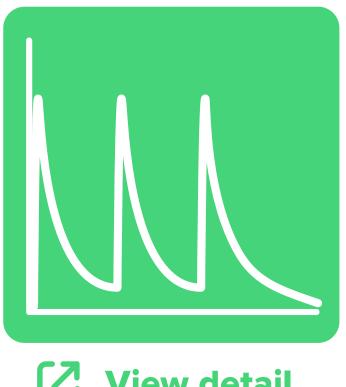
How Hemlibra is different to FVIII:

Hemlibra is different to FVIII concentrates, as it remains in your blood at a steady state. FVIII levels rise quickly after infusion and then decrease.





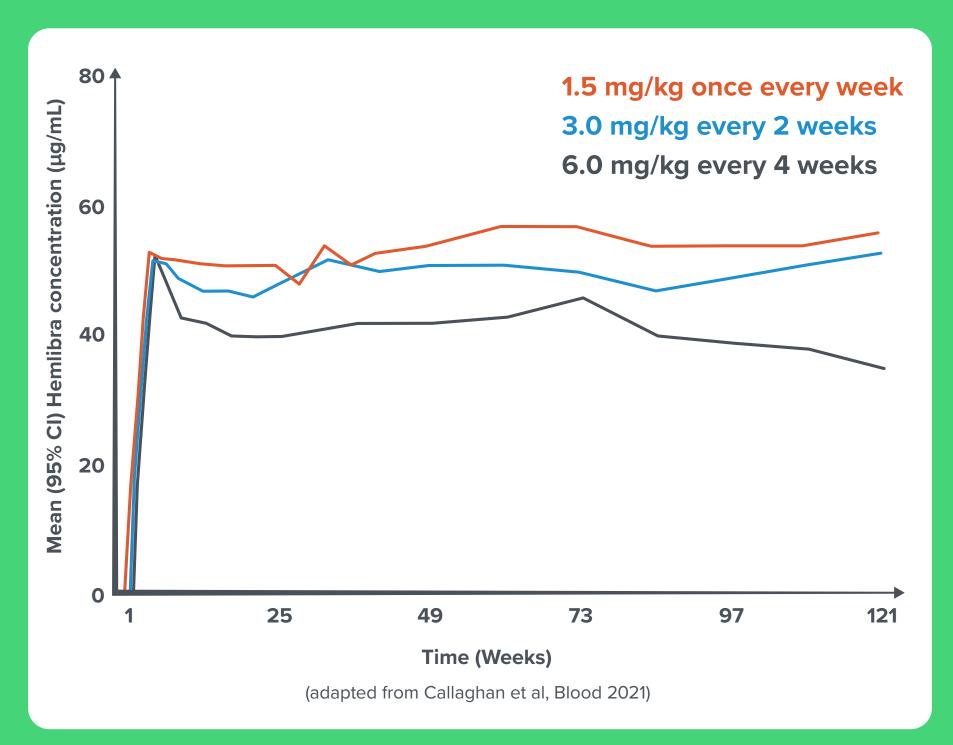
FVIII Peaks and Troughs



View detail







After the initial loading doses, blood levels of Hemlibra remain stable between doses, whether you are taking your ongoing dose once every week, every 2 weeks, or every 4 weeks. This is because Hemlibra has a long "half-life", which is the amount of time it takes for the drug's main active ingredients to reduce by half in your body.

This means that you do not need to take additional doses of Hemlibra to cover any planned physical activity.









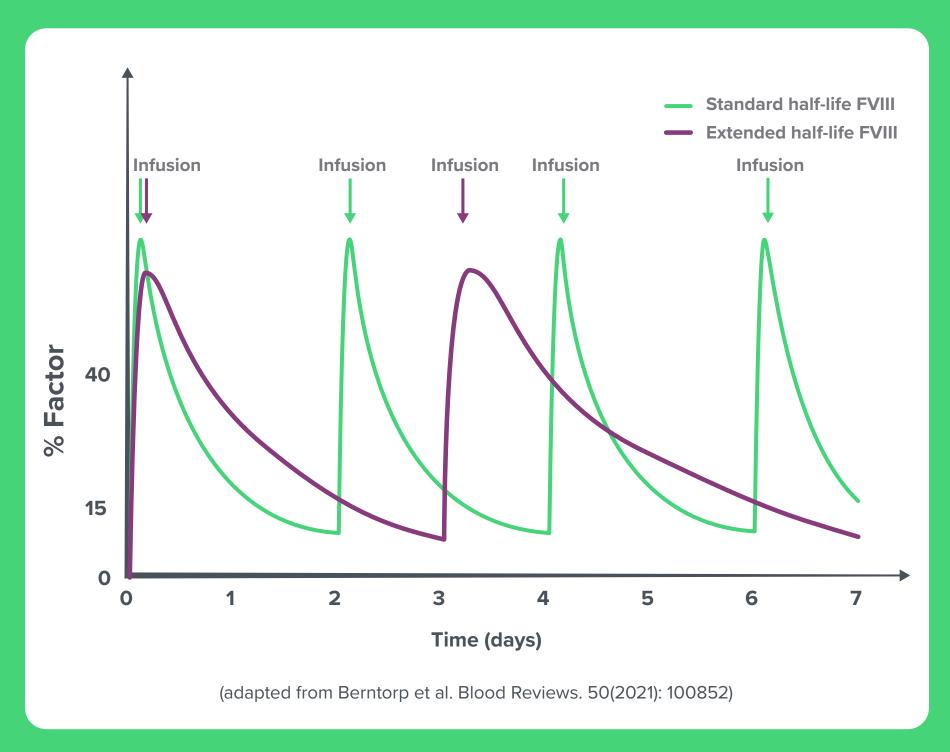












This graph does not represent a specific product

With FVIII replacement therapy, the level of FVIII rises quickly after infusion and then decreases, as shown by the peaks and troughs on the graph. The half-lives of standard and extended FVIII treatments are shorter than the half-life of Hemlibra.^{1,2} This means that if you were taking FVIII replacement therapy regularly, you may have needed to take additional doses, for example if you were playing sport.

https://pubmed.ncbi.nlm.nih.gov/26930418/. Accessed May 2023;
 Hemlibra Summary of Product Characteristics.



















How Hemlibra is different to FEIBA® and NovoSeven®:

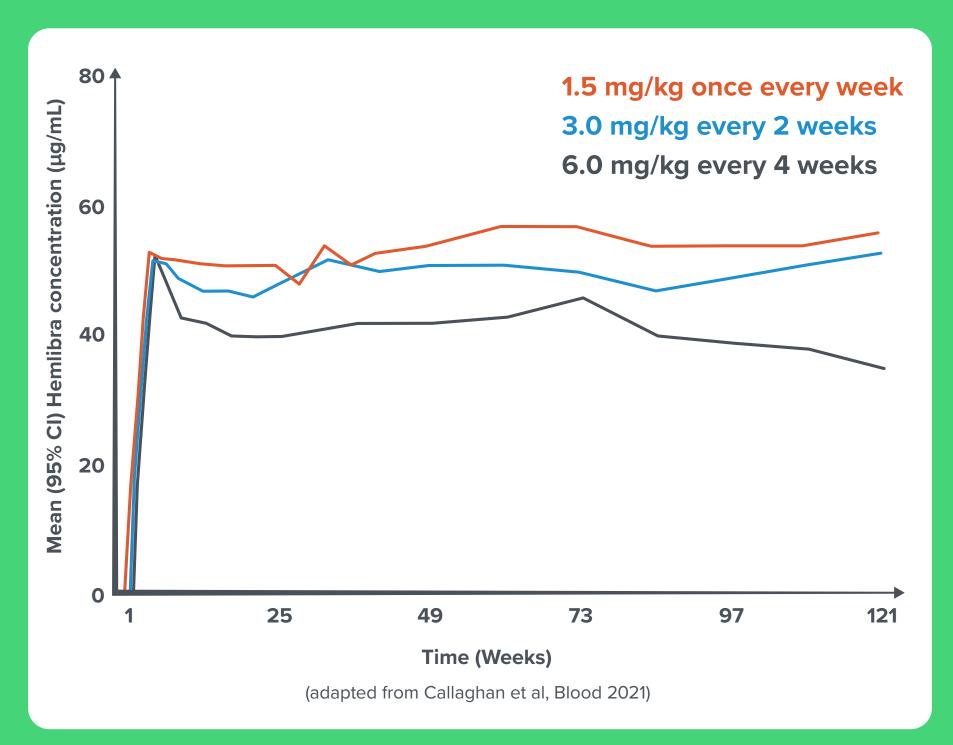
FEIBA and NovoSeven are treatment options for people with inhibitors to FVIII. Unlike Hemlibra, they can be used to treat bleeds in inhibitor patients, whereas Hemlibra can only be used for prophylaxis.











After the initial loading doses, blood levels of Hemlibra remain stable between doses, whether you are taking your ongoing dose once every week, every 2 weeks, or every 4 weeks. This is because Hemlibra has a long "half-life", which is the amount of time it takes for the drug's main active ingredients to reduce by half in your body.

This means that you do not need to take additional doses of Hemlibra to cover any planned physical activity.









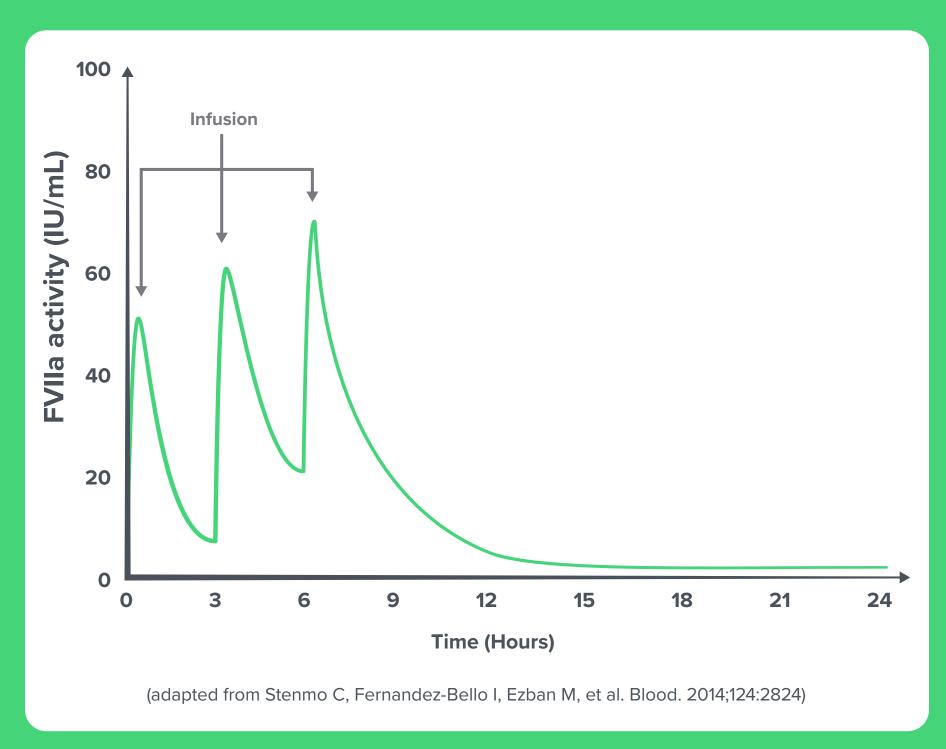












This example shows the peaks and troughs in recombinant NovoSeven therapy with repeat doses.

The levels of either FEIBA® or NovoSeven® fall following administration, meaning repeat doses may be required to manage bleeds.













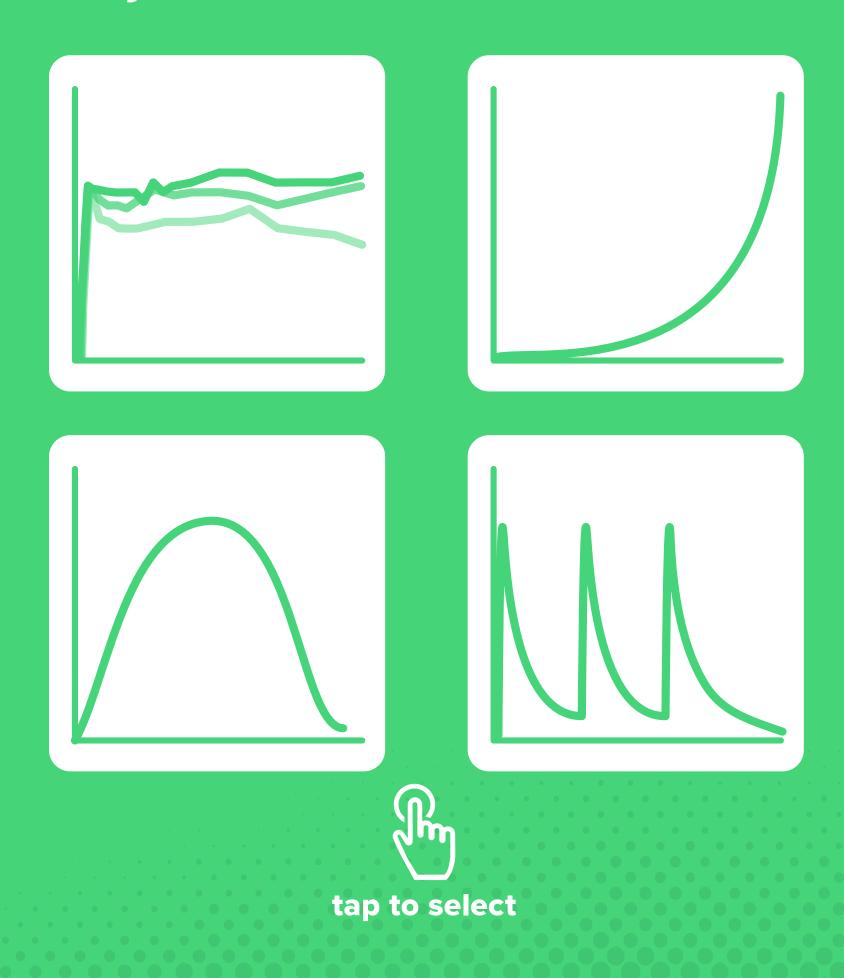






? What is Hemlibra quiz

Which graph best represents Hemlibra's time in your blood?





? What is Hemlibra quiz

Which graph best represents Hemlibra's time in your blood?



After the initial loading doses, blood levels of Hemlibra remain stable between doses, whether you are taking your ongoing dose once every week, every 2 weeks, or every 4 weeks.

This means that you do not need to take additional doses of Hemlibra to cover any planned physical activity.





Hemlibra is only for prophylaxis and it works the same way whether you have FVIII inhibitors or not, but if you want to see how it may change what you used to do, click the links below:



Q Without FVIII inhibitors



Unlike FVIII concentrates, Hemlibra can only be used for prophylaxis. It can't be used to treat a bleed like FVIII treatment.

Starting on Hemlibra could mean a change to your lifestyle, including when and how often you treat yourself.

If you have a bleed, <u>do not</u> take extra Hemlibra

It is crucial that you know how to recognise and manage a bleed while you are taking Hemlibra. If a bleed requires treatment you may have to take FVIII concentrate – ensure you know what dose your treatment centre recommends. If you have any doubts, call them.

What other things might change about your lifestyle? Your treatment team would love to chat about this with you!

? Q / 10 / 13 7 / 14

Q With FVIII inhibitors



Unlike FEIBA® and NovoSeven®, Hemlibra can only be used for prophylaxis. It can't be used to treat bleeds like your previous treatment.

Starting on Hemlibra could mean a change to your lifestyle, including when and how often you treat yourself.

If you have a bleed, do not take extra Hemlibra

There are risks associated with the use of FEIBA with Hemlibra – never use FEIBA to treat a bleed unless your treatment centre has specifically said so.

It is crucial that you know how to manage a bleed while you are taking Hemlibra. If your bleed requires treatment you may have to take NovoSeven — ensure you know what dose your treatment centre recommends. And if you have any doubt, call them.

What other things might change about your lifestyle? Your treatment team would love to chat about this with you!





Hemlibra is administered subcutaneously. This means that it is injected under your skin rather than into your vein, unlike like many other haemophilia therapies. This can be a change from what you're used to!

Here's a video to help you learn how to inject Hemlibra





If you have any questions, speak with your treatment centre to see how they can help.



Your Hemlibra dose

Your Hemlibra dose is based on your physical growth and development and may be adjusted at intervals throughout your life.

Regular contact with your treatment centre is key to ensuring your dose is correct.

There may be times when your dose requires you to use two syringes and it is important to remember not to mix the 30mg/ml vial with any of the other vial sizes.



Top tips for remembering your injections

Set reminders on your phone or computer.

Schedule your injection day around a regular activity.

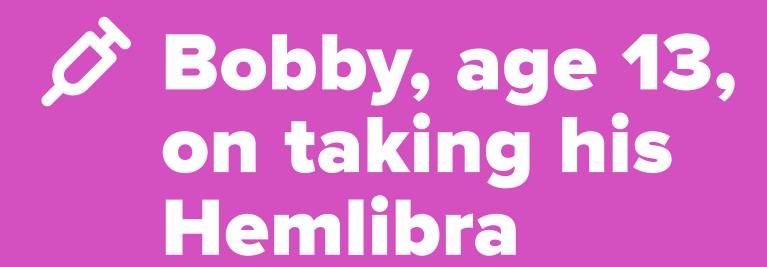
Continue to use Haemtrack® to keep a record of each time you use Hemlibra.



Hear from Bobby, age 13, about taking Hemlibra

Hear from Gabe, age 15, about taking Hemlibra





X

ON INJECTING HEMLIBRA:

Just do it nice and quick and try not to over-think it

And breathe while you're having it because it makes it a lot easier – just deep breaths

Mum just tried to tell me to not look at it and try to think of something else or look at the TV

ON REMEMBERING HIS INJECTIONS:

Because it's not so regular, maybe we need to start setting an alarm

We write it on the calendar and Mum does always check the calendar

ON EXPLAINING HIS TREATMENT
TO OTHER PEOPLE:

Lalso show people a lot if they're

I also show people a lot, if they're round on the day of my injection I just tell them to watch and then they realise what it actually is

BOBBY







I liked intravenous injections, I was so used to them, it [Hemlibra] took me a while at first, I didn't really like it but like the old injections they've just become part of my life now and I'm just used to them and I'm just trying to learn to do them myself

I just took my time, I took it step by step because I knew I'd done the FVIII injections, they took me a while. [My nurse] had to come over a bit but after a while I got there and then I started to grow confident and it was all fine

If I try to push it in too fast it hurts all at once, sometimes I do it slowly or I'm thinking about something else and I don't even notice it

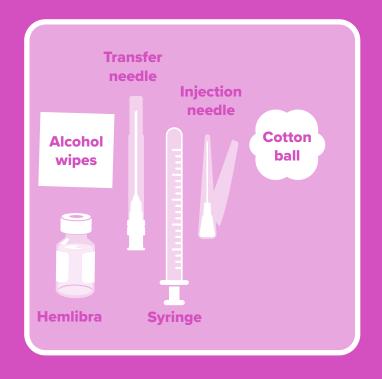
Sometimes I just have my phone there and just look at it then it'll be done

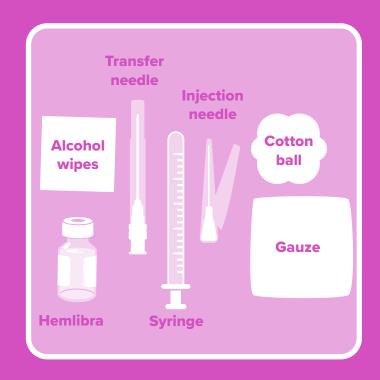
- GABE

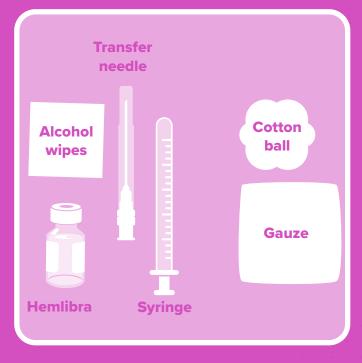


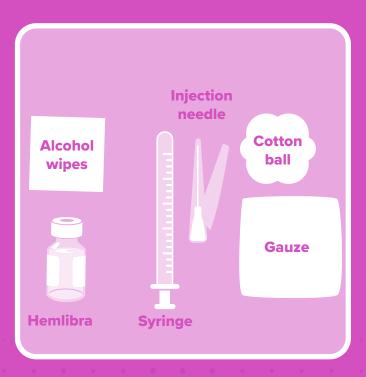
Hemlibra quiz

Which of the below options has everything you need to administer Hemlibra?



























Hemlibra quiz

Which of the below options has everything you need to administer Hemlibra?

Learning how to inject
Hemlibra yourself may take
some time, don't worry if
you don't get it straight
away. Your treatment team
may have some tips on how
to help — we also have a
video you can watch



Remember not to mix the 30mg/ml vial with any of the other vial sizes for correct dose measurement.









Exercise and activity are a great way to keep fit and healthy, but they all come with their own risks. If you're thinking of starting a new sport or activity, reach out to your haemophilia physiotherapist or nurse who can help you figure out the best way to approach it. This is a great step towards managing your own condition.

If you're going on holiday or away with your school, there may be things you need to do differently with your Hemlibra.



Top Tip!

Why not ask your nurses to help you plan and get the most out of your trip.





Having haemophilia is rare but it doesn't mean you're alone – it's sometimes good to talk to someone your own age about your treatment and maybe you could offer someone else support.

It would be nice as I don't have any friends that know what it's like to have haemophilia or have had any of the treatments, then we would be able to talk about it and talk about what we would do to deal with it and talk about what we do to make it better or make it easier.





> Hemlibra buddies

You can also reach out directly to a patient society, for example:





Please note these websites are not affiliated with Chugai or Roche

These societies should be able to put you in touch with one of their youth ambassadors — people with bleeding disorders who often share their stories on social media. Some places have different patient societies, speak to your centre about the best one to reach out to.



How about speaking to your treatment centre and ask if you can buddy up with someone





The word "transition" can mean a lot of things

– transitioning from an intravenous therapy to
subcutaneous, transitioning from parental care
towards self care and transitioning from a paediatric
centre to an adult centre, for example.



Take a look through the administration section for more info on the move to subcutaneous injections.



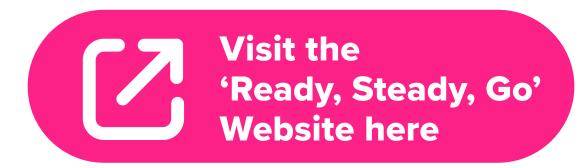


> Transitioning

Transitioning from parental care to self care and from paediatric to adult management are both processes where small steps are crucial in order to feel comfortable.

Ready, Steady, Go

The NHS have developed some resources to support the transition process towards adult care. If you'd like to read up on some of these materials then check out the 'Ready, Steady, Go' website.



Please note this website is not affiliated with Chugai or Roche





As with all treatments, using Hemlibra can cause side effects, although not everybody gets them. The table on the next page shows some of them from the studies.

If you experience any side effects you should inform your treatment centre ASAP.



> Safety & side effects

Very common: may affect more than 1 in 10 people

- A reaction in the area where the injection is given (redness, itching, pain)
- Headache
- Joint pain

Common: may affect up to 1 in 10 people

- Fever
- Muscle aches
- Diarrhoea
- Itchy rash or hives (urticaria)
- Skin rash

Uncommon: may affect up to 1 in 100 people

- Blood clot in a vein behind your eye (cavernous sinus thrombosis)
- Severe damage of the skin tissue (skin necrosis)
- Blood clot in a vein near the surface of the skin (superficial thrombophlebitis)
- Destruction of red blood cells (thrombotic microangiopathy).
- Lack of effect or decreased response to treatment
- Swollen face, tongue and/or throat and/or difficulty in swallowing, or hives, together with difficulty in breathing which are suggestive of an angioedema

If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at www.mhra.gov.uk/yellowcard. You should also report side effects to Roche Products Ltd by emailing the Roche Drug Safety Centre at welwyn.uk_dsc@roche.com or calling +44 (0) 1707 367554. By reporting side effects you can help provide more information on the safety of this medicine.



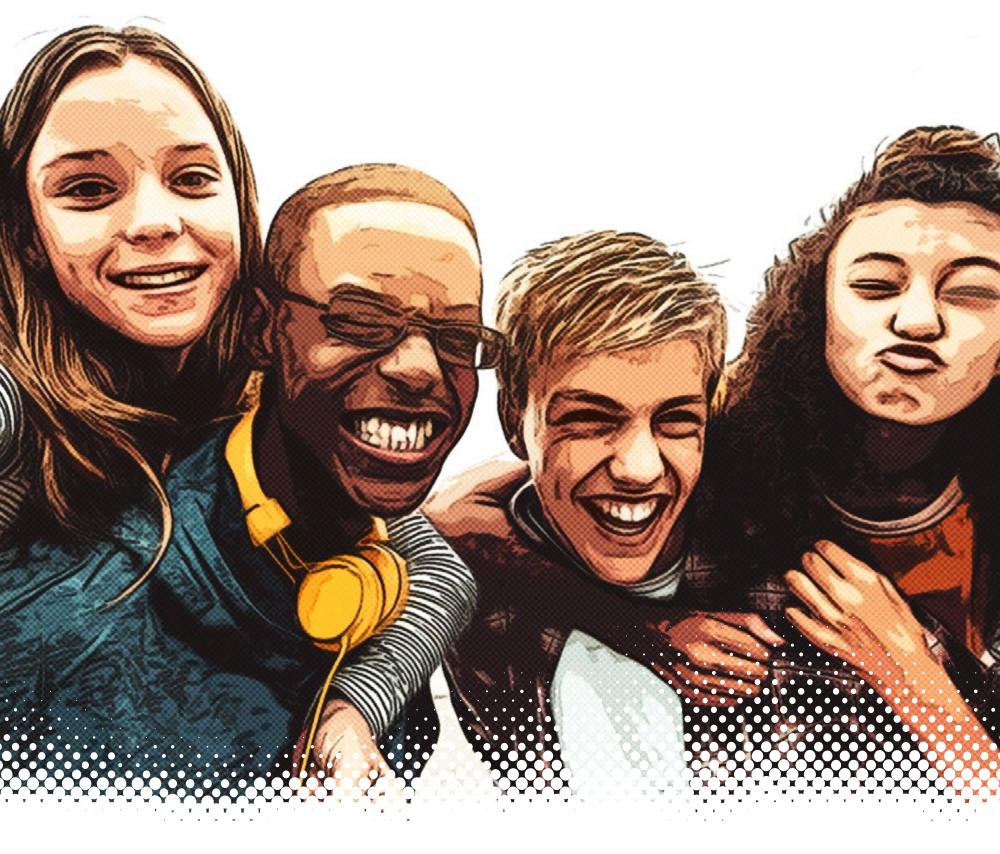


Remember – being proactive with your treatment centre is a great way to start managing your own condition

My paediatric centre:

My adult centre:





Special thanks to Lara, Trupti and the young persons with haemophilia who helped us develop this material

Lara Oyesiku,

Clinical Nurse Manager, Southern Haemophilia Network

Trupti Bhandari,

Haemophilia Physiotherapist, Evelina Children's Hospital







