

# ***Hemlibra***<sup>®</sup> (emicizumab)



**START**

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This material is for people with haemophilia A who have been recently prescribed Hemlibra (emicizumab) and are transitioning from paediatric to adult haemophilia care

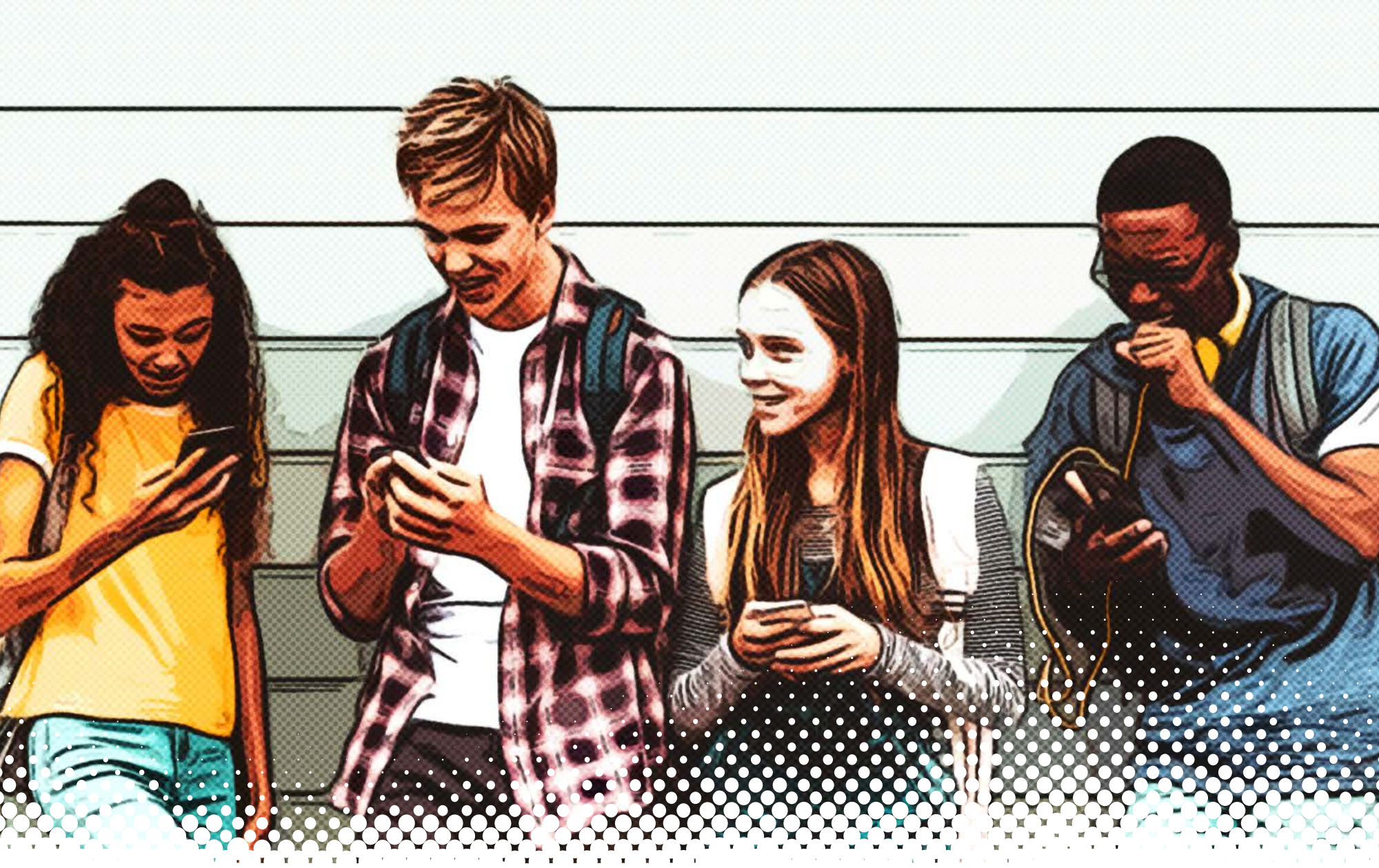
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This item has been developed by Roche Products Limited and Chugai Pharma UK Ltd

Job code: M-GB-00022908 | July 2025







**What is  
Hemlibra?**



**What is involved  
for me?**



**How do I take  
Hemlibra?**



**My activity  
& lifestyle**



**Hemlibra  
buddies**



**Transitioning**



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information**





> What is Hemlibra?

# ? What is Hemlibra?

## Understanding how Hemlibra works

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

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





## > What is Hemlibra?

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**



**To find out more about how Hemlibra works, visit our patient website**



**What does prophylaxis mean?**







# 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 or reduce the number of bleeds that you may have.



Hemlibra is quite different to other treatments for haemophilia A, 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 a constant amount of it stays in your blood. FVIII levels rise quickly after infusion and then decrease.



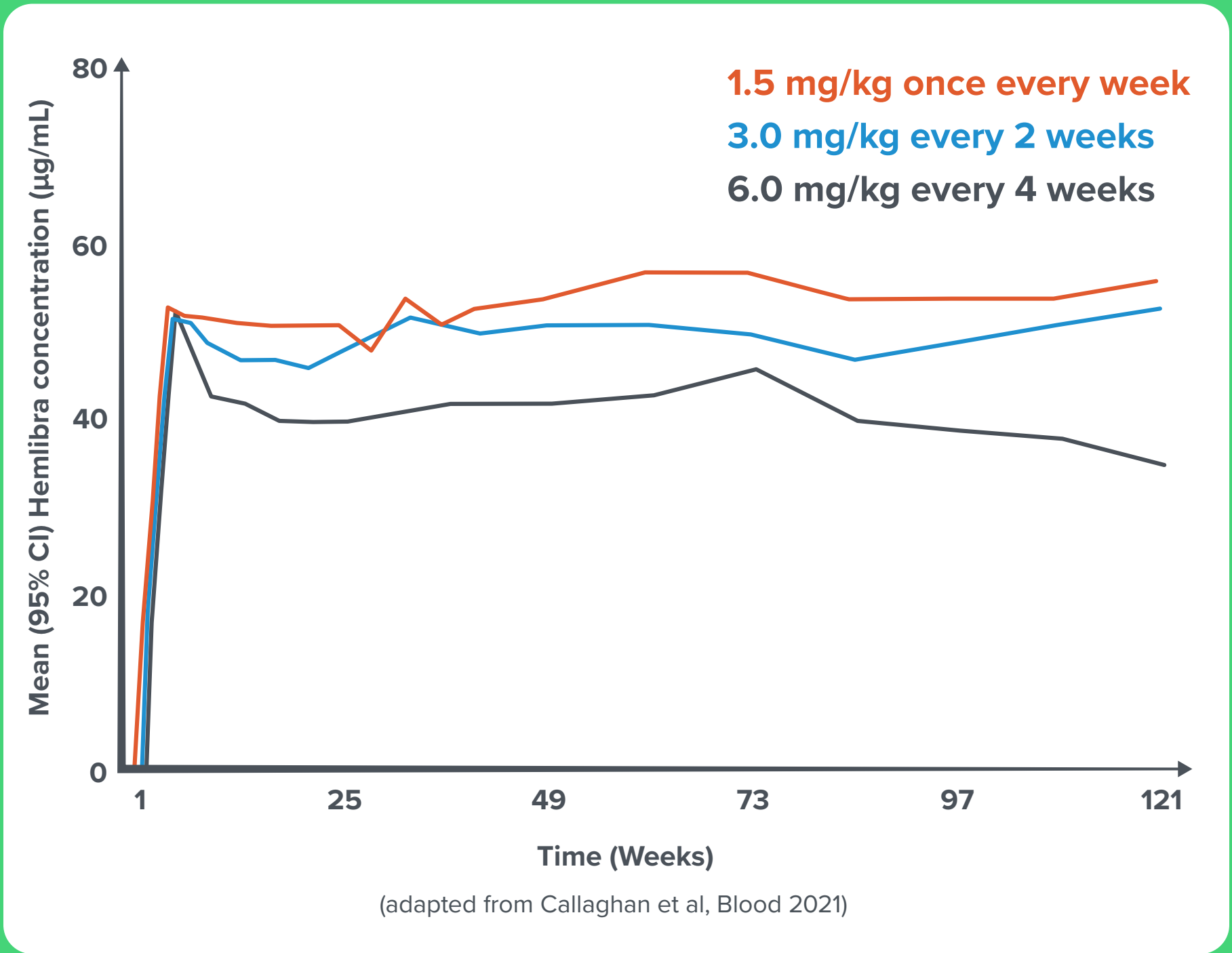
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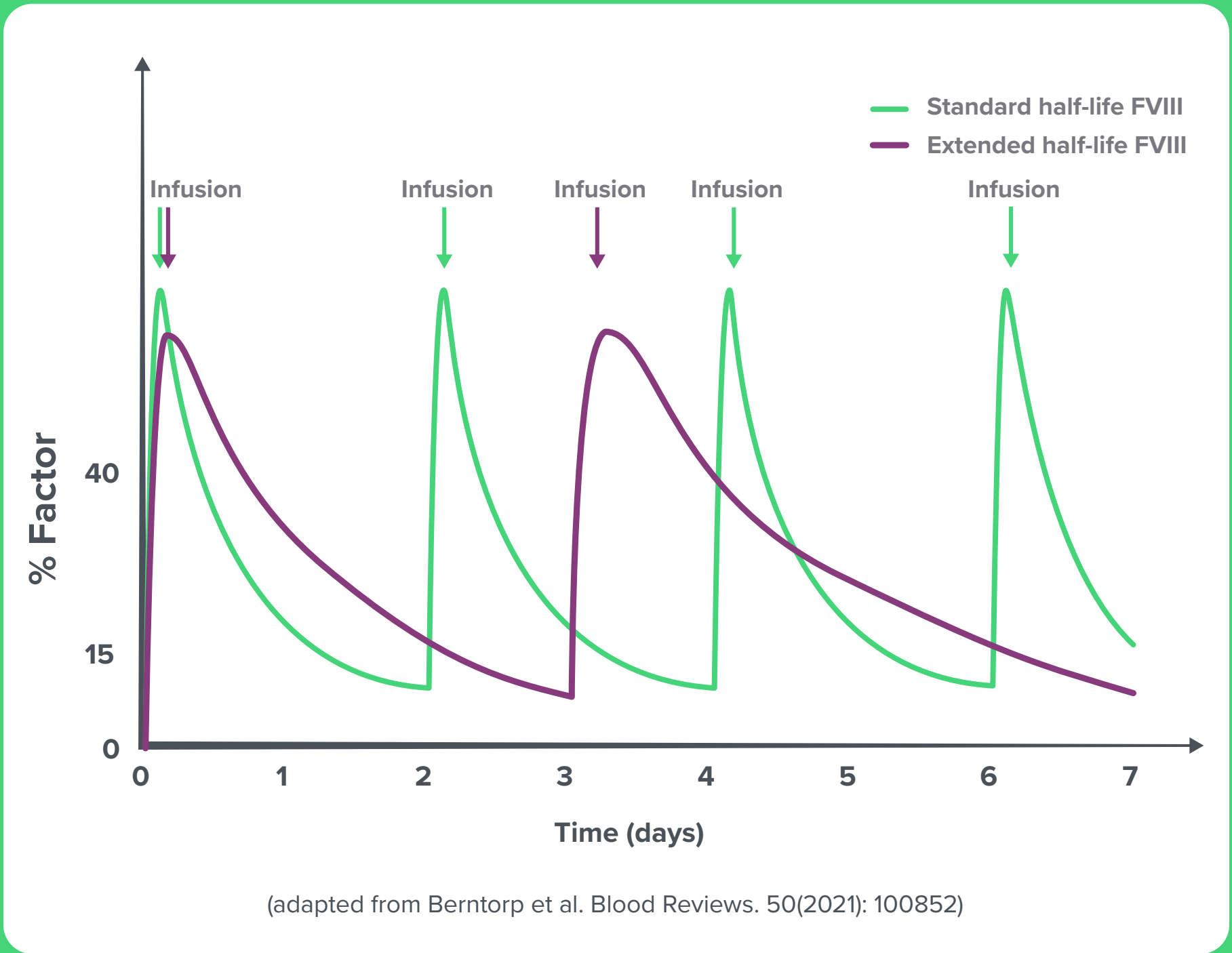
# Hemlibra Steady State



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.

# FVIII Peaks and Troughs



This graph illustrates the differences in peaks and troughs of FVIII replacement therapies. It does not represent any specific products and is not representative of all FVIII replacement products.

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.<sup>1,2</sup> 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.

1. <https://pubmed.ncbi.nlm.nih.gov/26930418/>. Accessed January 2025;  
2. Hemlibra Summary of Product Characteristics.



How Hemlibra is different to FEIBA<sup>®</sup> and NovoSeven<sup>®</sup>:

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

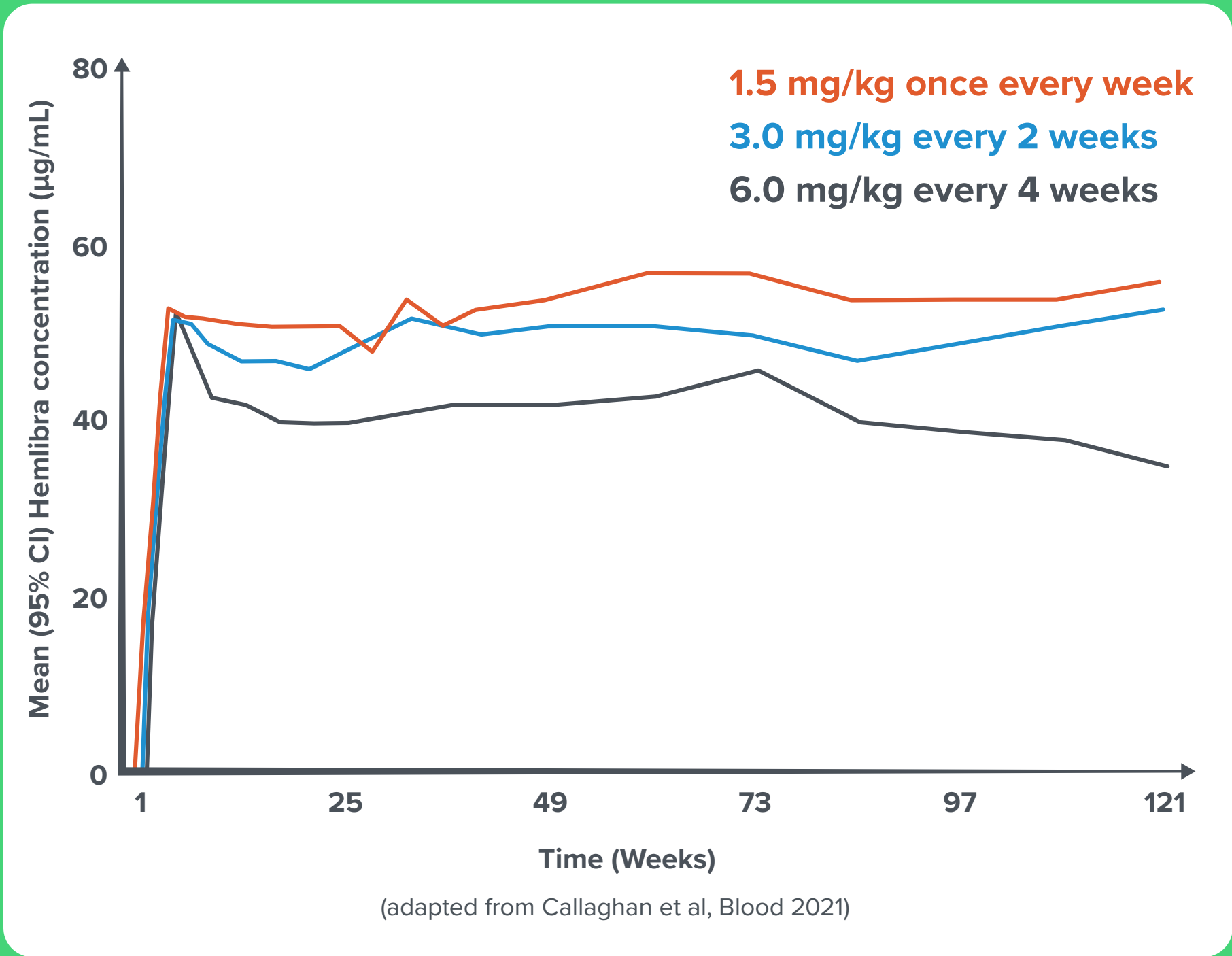


 View detail



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# Hemlibra Steady State

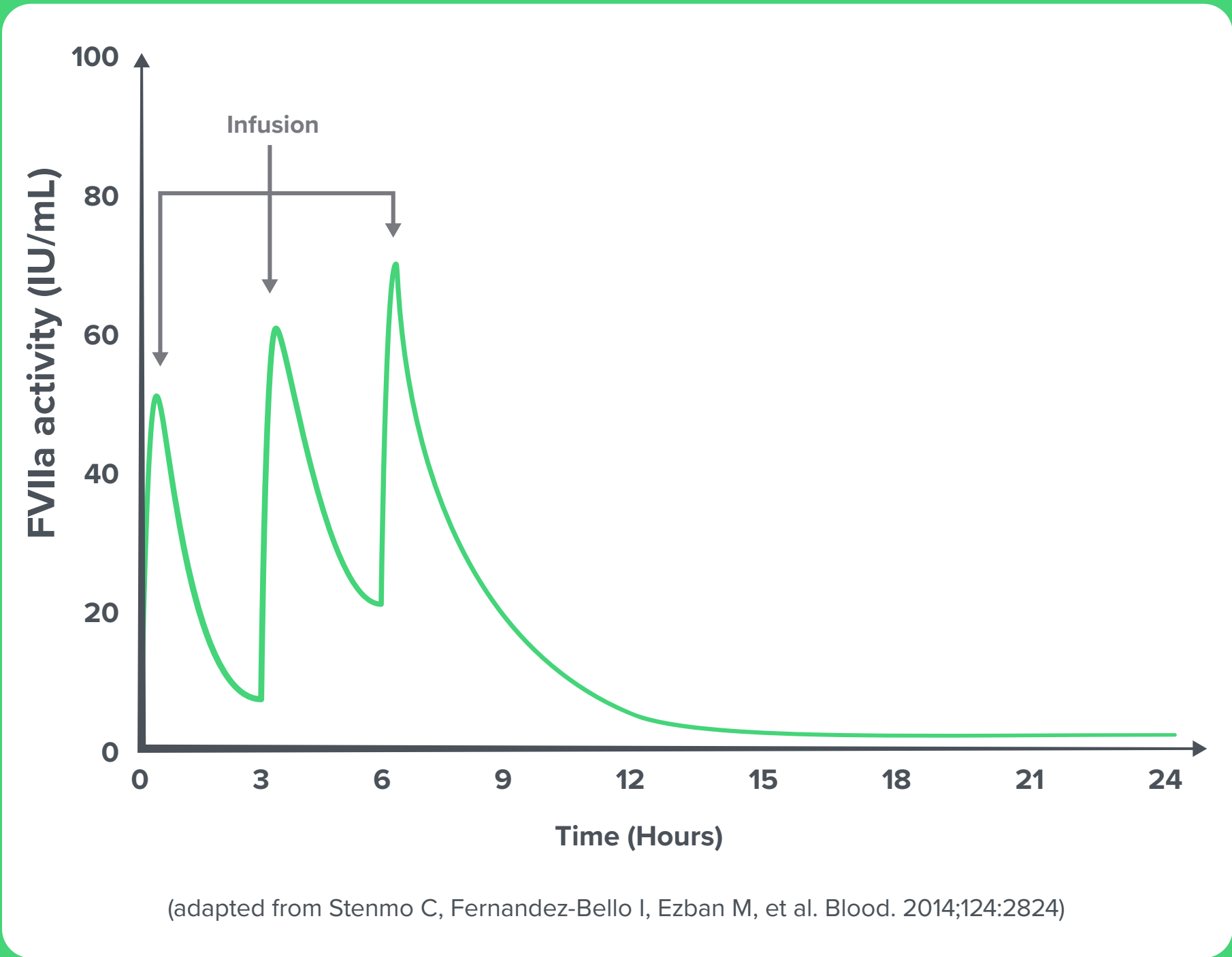


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# Bypassing Agents

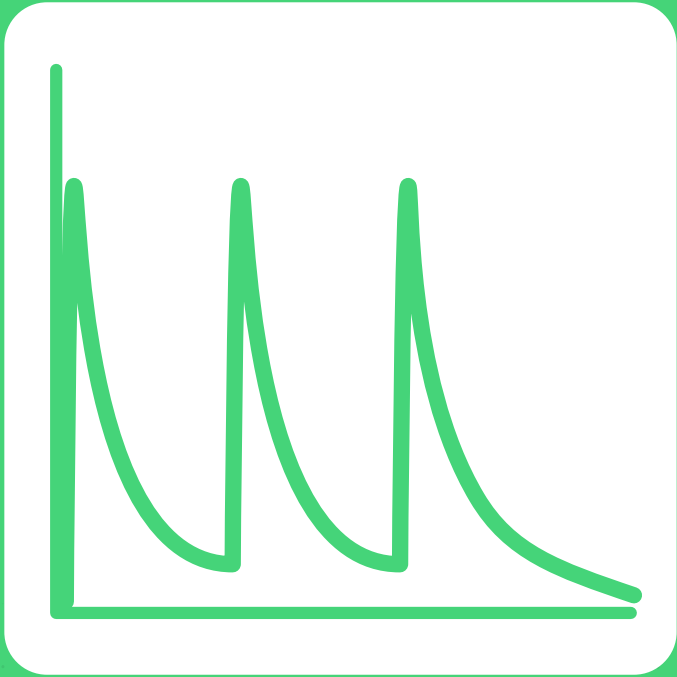
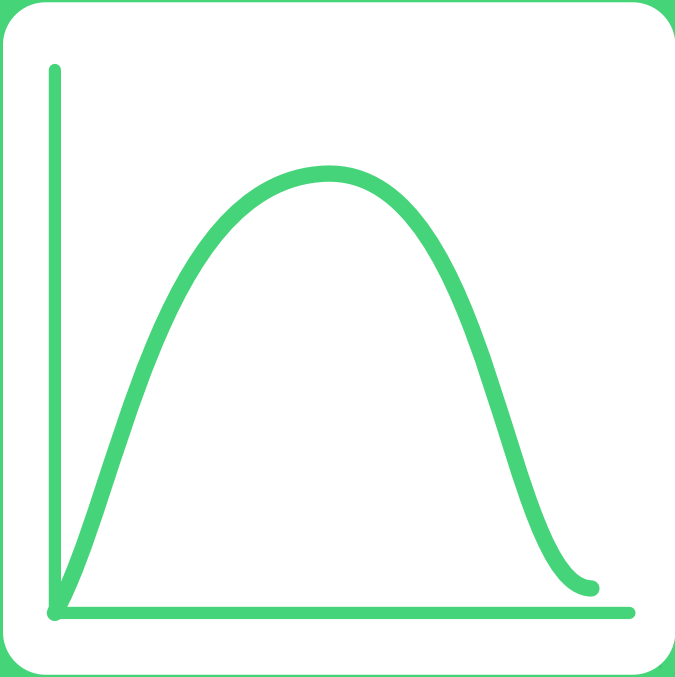
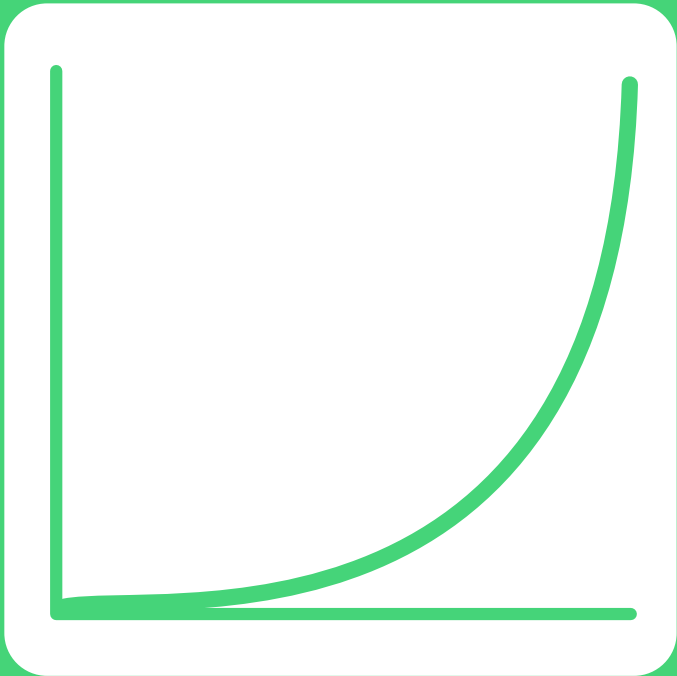
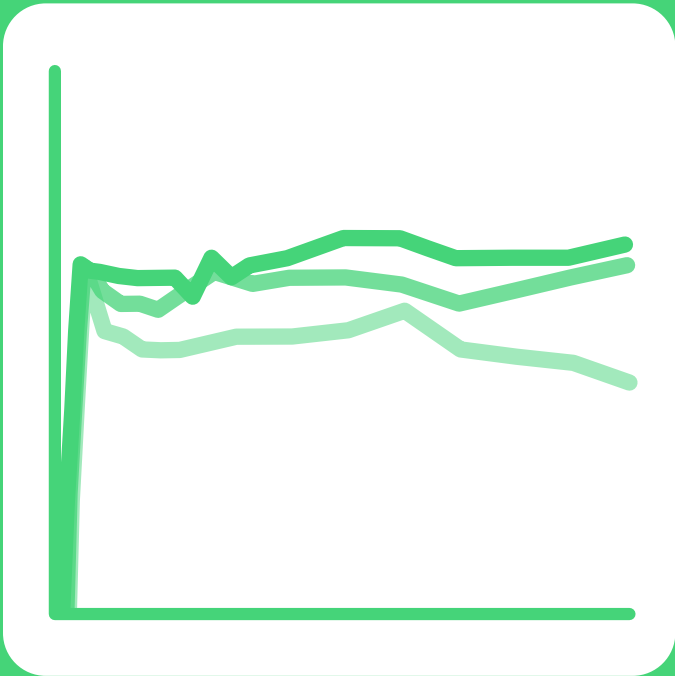


This example shows the peaks and troughs in recombinant NovoSeven therapy with repeat doses.

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?



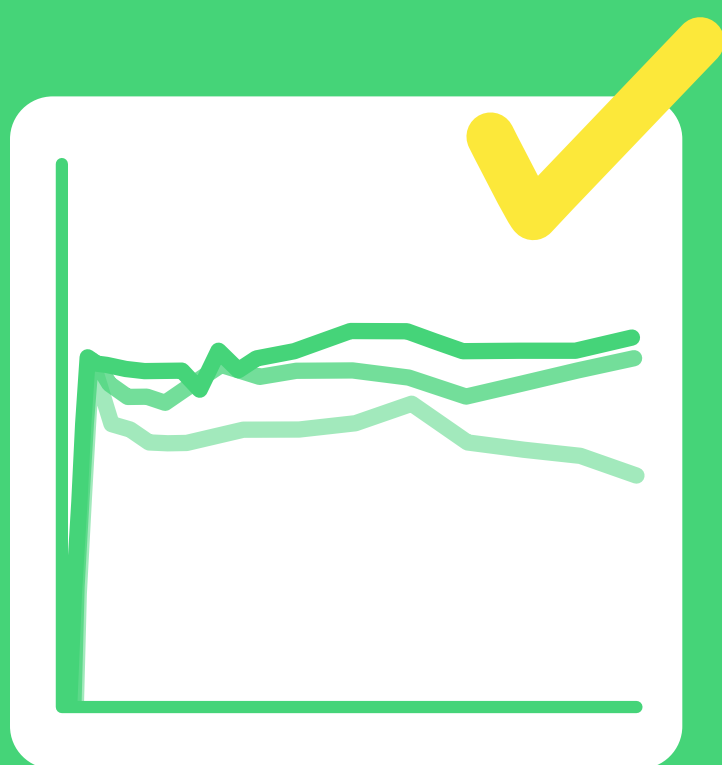
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These images are for illustrative purposes only



# ? 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.**



> What is involved for me?



**Q What is involved for me?**

**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:**

**INH-**

**Non-inhibitors**

**INH+**

**Inhibitors**





# 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, do not 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? Discuss this with your treatment team.**

# Q With FVIII inhibitors



Unlike FEIBA<sup>®</sup> and NovoSeven<sup>®</sup>, 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? Discuss this with your treatment team.**



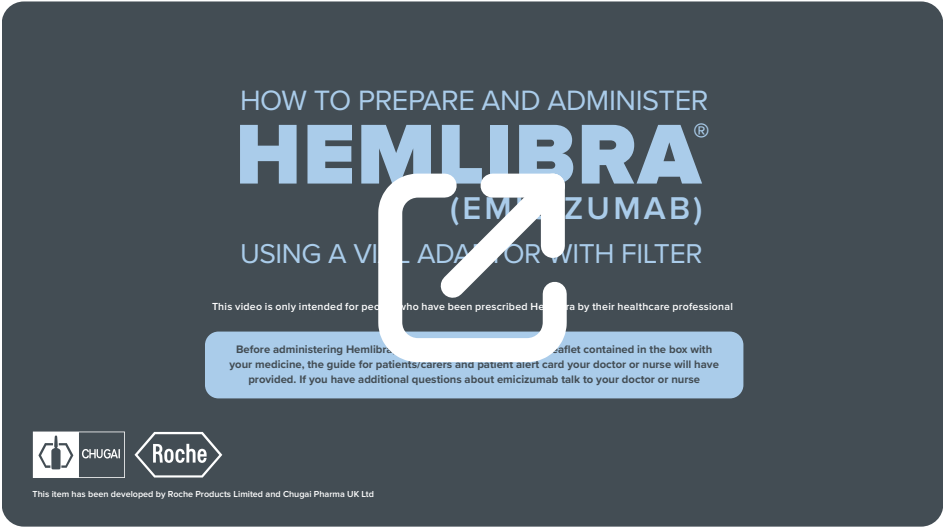
> How do I take Hemlibra?



# How do I take Hemlibra?

Hemlibra is administered subcutaneously. This means that it is injected under your skin rather than into your vein, unlike 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.





> How do I take Hemlibra?

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.

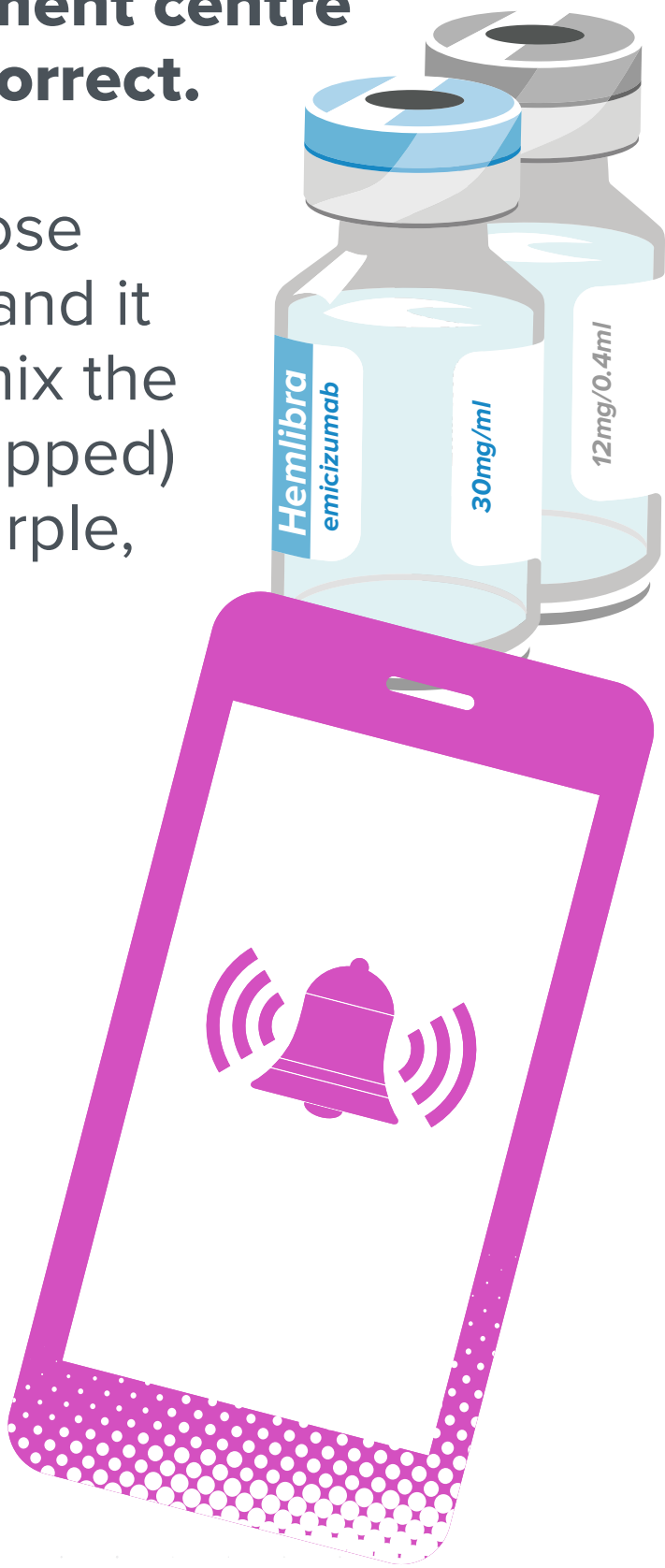
There may be times when your dose requires you to use two syringes and it is important to remember not to mix the 30mg/ml vials (grey or sky blue topped) with any of the 150mg/ml vials (purple, turquoise or brown topped).

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





# Bobby, age 13, on taking his Hemlibra



## 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:



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**





# Gabe, age 15, on injecting his Hemlibra



“

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







# How do I take Hemlibra quiz

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

Alcohol wipes

Injection needle

Cotton ball

Vial adaptor with filter

Hemlibra

Syringe

Alcohol wipes

Injection needle

Cotton ball

Vial adaptor with filter

Hemlibra

Syringe

Gauze

Alcohol wipes

Vial adaptor with filter

Cotton ball

Hemlibra

Syringe

Gauze

Alcohol wipes

Injection needle

Cotton ball

Hemlibra

Syringe

Gauze



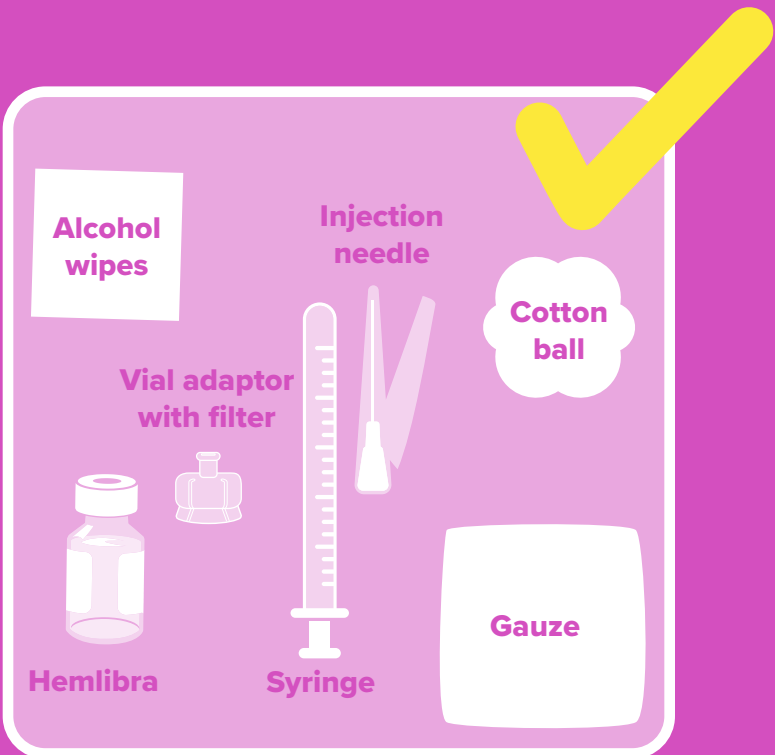
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# How do I take Hemlibra quiz

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 vials (grey or sky blue topped) with any of the 150mg/ml vials (purple, turquoise or brown topped) for correct dose measurement.



Watch our ‘How to administer Hemlibra’ video



## > My activity & lifestyle

*It's sort of the same,  
I feel confident now,  
a lot like I did with  
my FVIII*

*-GABE,  
AGE 15*



## My activity & lifestyle

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.**







# Hemlibra buddies

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."***

***-BOBBY, AGE 13***





> 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**







# Transition

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.**



**Watch our ‘How to administer Hemlibra’ video**






> 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.



Visit the  
'Ready, Steady, Go'  
Website here

Please note this website is not affiliated with Chugai or Roche







# Safety & side effects

**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
- Allergic reaction

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. Please report suspected side effects to the MHRA through the Yellow Card scheme, via the Yellow Card website [www.mhra.gov.uk/yellowcard](http://www.mhra.gov.uk/yellowcard), or the free Yellow Card app available in the [Apple App Store](#) or [Google Play Store](#).

You should also report side effects to Roche Products Ltd. by emailing the Roche Drug Safety Centre at [welwyn.uk\\_dsc@roche.com](mailto: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.





# Contact information

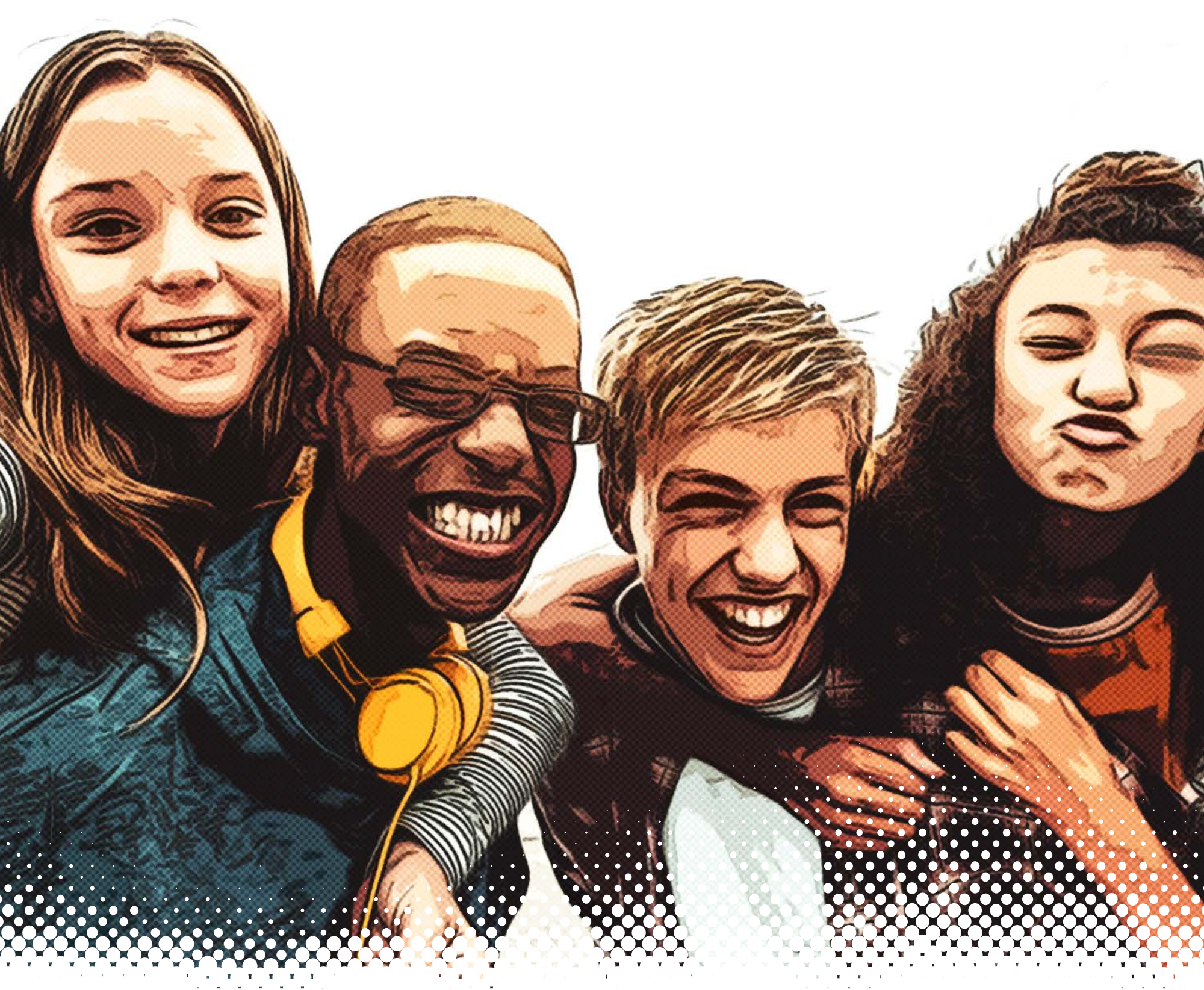
**Remember** – being proactive with your treatment centre is a great way to start managing your own condition

**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 Network Manager,  
Southern Haemophilia Network

**Trupti Bhandari,**  
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