

A photograph of two young boys playing on a grassy field. One boy, wearing a grey hoodie and blue jeans, is sitting on the ground and hugging another boy from behind. The second boy, wearing a bright green and black striped shirt and brown sneakers, is lying on his back on the grass, laughing joyfully with his mouth open. The scene is brightly lit, suggesting a sunny day. The text 'Jamie & Ben are on Prophylaxis' is overlaid on the right side of the image. At the bottom, there is a light blue decorative graphic consisting of several overlapping, slightly curved lines.

Jamie & Ben are on  
**Prophylaxis**

**BAXTER & YOU**

Shaping the future of haemophilia together

This booklet is designed for children with haemophilia who are about to start prophylaxis or are considering starting it in the future.

Parents may also find this information useful and benefit from reading it with their children.

We hope that the information in this leaflet will help to explain what prophylaxis involves and why it is worthwhile.

## What is prophylaxis?

The word prophylaxis means a treatment that prevents something happening.

For people with haemophilia prophylaxis means treatment to prevent bleeding.

The treatment is regular injections of factor, usually two or three times a week. Sometimes it can be a single injection before doing something which may cause a bleed such as playing football.

### How can prophylaxis help?

People with haemophilia who have regular injections of factor tend to have:

- Far fewer bleeding episodes
- Much less severe bleeding episodes
- Fewer days off school
- Less time in hospital
- Less need for operations on their joints later in life
- Less pain



Come on Oliver, let's have  
our prophylaxis. It hurts  
a lot more if we don't.



## Why has your doctor recommended prophylaxis?

Prophylaxis is given to children with severe haemophilia and it may also be considered for children with moderate haemophilia if they have had problems with bleeding. Prophylaxis helps most if it is started early in life as it is much better to prevent a bleed from happening than to treat one. This is because each time blood enters a joint it can do a little bit of damage. This can add up after several bleeds to leave the joint with some permanent damage.

Older boys and adults can benefit too because prophylaxis can still prevent damage to their joints in the future.

So, prophylaxis is usually recommended for:

- Young children – as soon as their haemophilia is identified (sometimes after their first joint bleed)
- Older children – instead of giving treatment only when a bleed occurs
- People with haemophilia who have a particular ‘target’ joint which bleeds easily
- People with haemophilia of any age who have a problem with regular bleeding

Jamie and Ben’s doctor decided that prophylaxis is the best way for them to receive treatment for their haemophilia.

## Jamie uses prophylaxis

Jamie is ten years old and has severe haemophilia A. When he was little, he didn’t have many problems other than the occasional lumpy bruise, but when he was 4 he started on prophylaxis after his first joint bleed in his left ankle. He has factor VIII three times a week, in the morning before school on Monday and Wednesday, and on Saturday (because he plays football on Saturday).

Sometimes Jamie finds it hard to get out of bed a little bit earlier on treatment days, but then he remembers that it means he can play football and join in lots of other games with his friends.

Jamie has just learnt to do his treatment all by himself, so he is really pleased.

His Mum or Dad used to give him his factor and they are always there if he needs help. Jamie goes to his haemophilia centre every 3–4 months for a check up to make sure his joints are healthy and he has not got an inhibitor.

Once he had a ‘breakthrough’ bleed, despite taking all his prophylaxis treatments. At the next clinic visit he was told to take more of his factor. Thankfully this did not mean any more needles – just different bottles.

Does prophylaxis mean I'll have fewer days off school?

Yes and you won't spend as much time in hospital as I did.

### Jamie's brother

Jamie's little brother Oliver is two. He has severe haemophilia A as well. Oliver has just started on prophylaxis because he's had a bleed in his elbow. The nurse at the haemophilia centre said it's best to start straight away before he has lots more bleeds. As he's very young and won't stay still, it was hard to find veins for the treatment three times a week. So last month Oliver went into hospital to have a special ‘port’ fitted under his skin. Now it's much easier for mum and dad to give him his factor.

### Jamie's uncle

Jamie's Uncle Pete has severe haemophilia A too. He used to have prophylaxis but stopped it after he left school and started taking ‘on-demand’ treatment just when he had a bleed. Recently Pete has had lots of bleeds in his elbow, so the doctor put him back onto prophylaxis for a while because of this target joint. To begin with, Pete had factor every day then every two days until his elbow felt better. Now he's having treatment three times a week like Jamie.

This should stop him having bleeds so his elbow won't get worse. Pete just started a new job. He'd really like to stay on prophylaxis because it means he doesn't have to worry so much about having a bleed or needing time off work.





Will I need my knees done  
like you Grandad?

Ben

Ben's a bit like Jamie, but he has severe haemophilia B.

His prophylaxis is factor IX twice a week, usually on Monday and Thursday mornings before school.

Factor IX lasts longer than factor VIII in the body so two treatments a week are usually enough to stop bleeds. Once he did have a breakthrough bleed, so the doctor told him to have factor three times a week for a month and then he could go back to his normal routine of twice a week.

When the doctor first told them about prophylaxis, Ben and his family were worried about the extra injections.

The nurse at the haemophilia centre encouraged them to try it and now they're glad they did. It's much easier and less painful to plan instead of having to rush to treat a bleed. Ben has to go to the haemophilia centre for a check up every 3–4 months just like Jamie does.

### Ben's Grandad

Ben's Grandad also has severe haemophilia B. When he was young, the treatment was not as good as it is now. Ben's Grandad's knees don't work properly because of this and he sometimes needs to use a walking stick.

Grandad has already had operations on his knees and he still needs more. He encouraged Ben to go for prophylaxis because it should help to keep his knees and other joints healthy as he grows older.

I shouldn't think  
so. Prophylaxis  
will keep your  
joints healthy.

# The meaning of some of the words in this leaflet

**Breakthrough bleed:** a bleed that sometimes happens even though you are using prophylaxis.

**Haemophilia:** a disorder in which one of the clotting factors is missing or in very low supply which can cause bleeds into muscles and joints.

**Haemophilia A:** the disorder where the missing factor is Factor VIII.

**Haemophilia B:** the disorder where the missing factor is Factor IX.

**Inhibitors:** substances in the blood that stop the factor from working properly.

**On-demand treatment:** replacement of missing factor only when a bleed happens.

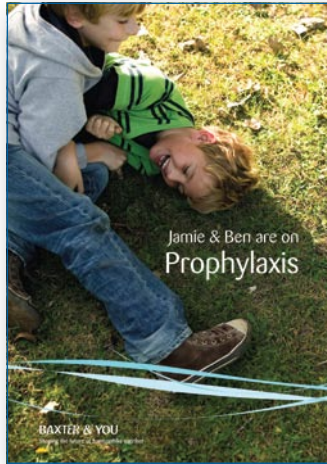
**Port:** a surgically implanted doorway into a vein, which can be accessed easily through the skin. It is intended for long term use.

**Prophylaxis:** regular injection of missing factor to prevent bleeding into muscles and joints.

**Severe, moderate and mild haemophilia:** normal levels of factor in the body are over 40%. In severe haemophilia the level is below 1%, in moderate haemophilia 1–5% and in mild haemophilia 6–40%.

**Target joint:** a joint such as a knee, ankle or elbow, where bleeds have occurred repeatedly.





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Haemophilia Society Helpline – 0800 018 6068

[www.haemophiliacare.co.uk](http://www.haemophiliacare.co.uk)

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