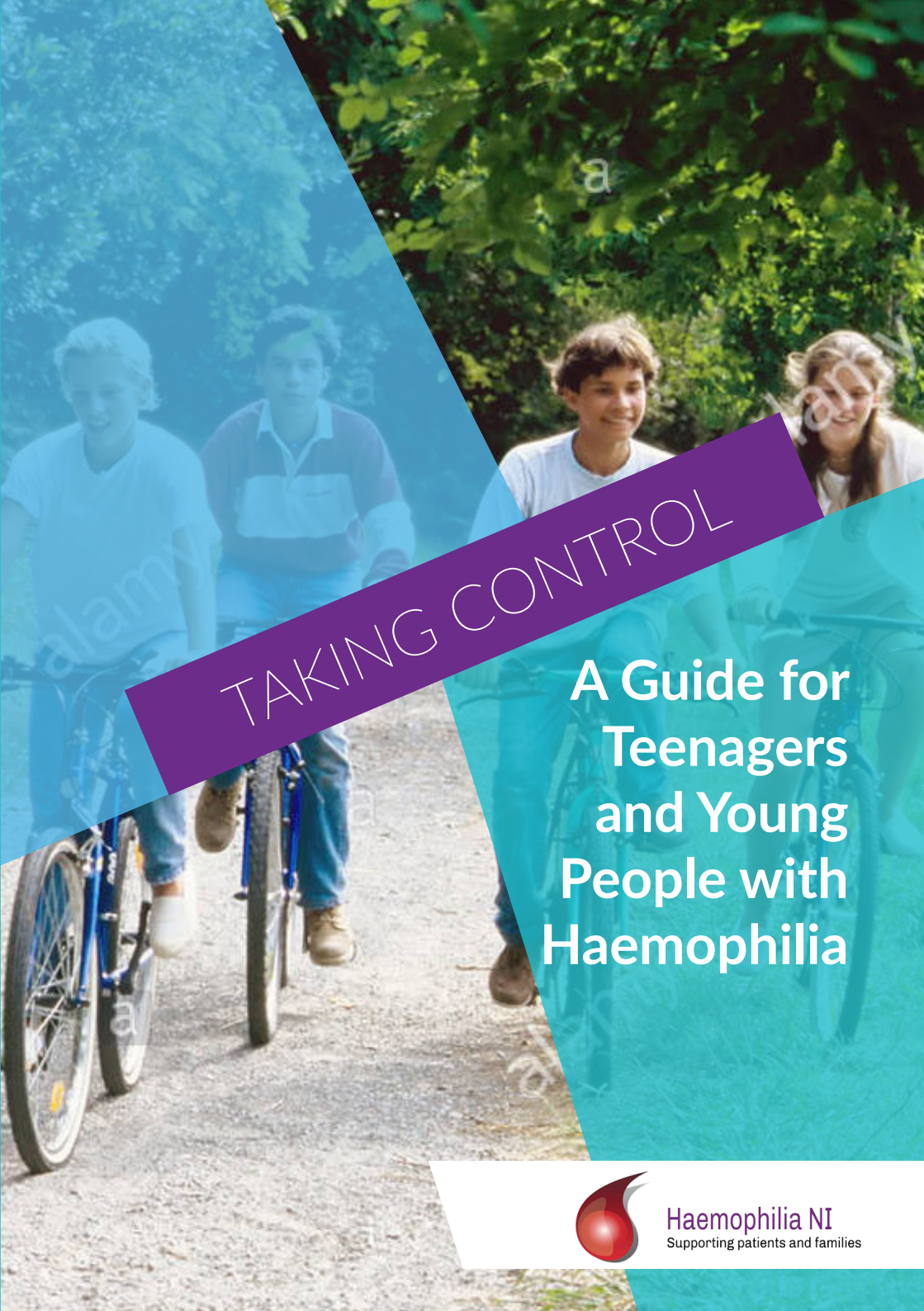


TAKING CONTROL

A Guide for Teenagers and Young People with Haemophilia

Haemophilia NI
Supporting patients and families

INTRODUCTION

Everyone with a bleeding disorder should aspire to live life to the full!

You can be in control of your bleeding disorder and not let it define you – for this it is essential to fully understand your bleeding disorder and know how to manage it safely, especially when things are going wrong or you have a bleed. That is exactly why this booklet was written, to help you understand your bleeding disorder better.

So many issues can come up and cause stress for teenagers with bleeding disorders; how to prevent bleeds, how to manage bleeds, how to tell friends you have a bleeding disorder; just to name a few. Hopefully you'll find some useful tips here from people with bleeding disorders who have been there and know what it can be like growing up with a rare bleeding disorder which hardly anyone else seems to understand.

It is important to remember you are not alone in looking after your bleeding disorder – bleeding disorders are a 'team sport' and you have to know who to go to for help when things are not going well; whether that be the haemophilia centre, family, friends or bleeding disorder groups like Haemophilia NI. There is almost no limit to what people with bleeding disorders can do – many work as lawyers, doctors and even as professional athletes – so what's your ambition?

The sky is the limit!

CONTENTS

HOW CAN I PREVENT BLEEDS?

There are two ways to help prevent bleeds – by sticking to your treatment plan and by keeping fit. Having regular factor replacement means you are much less likely to have spontaneous bleeds.[1,2]

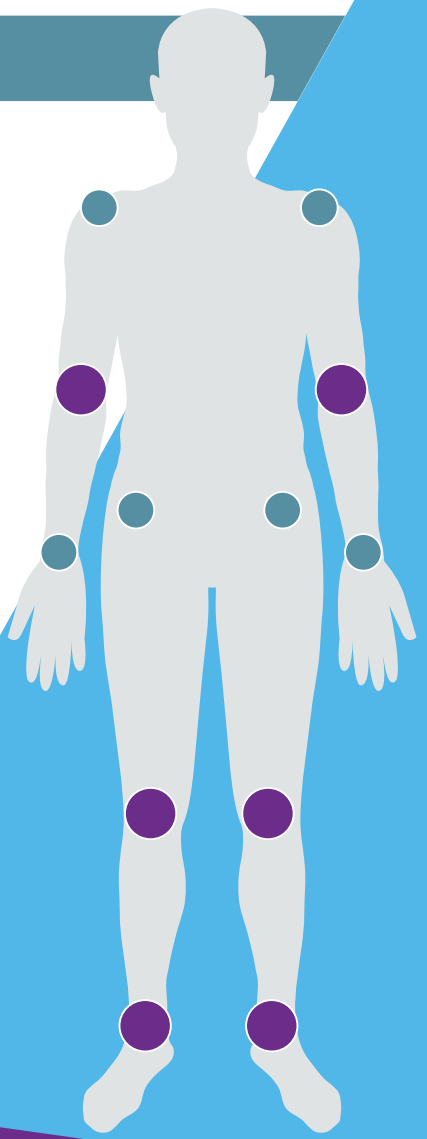
Most bleeds in haemophilia are into joints or muscles – between 7 and 8 out of 10 are inside a joint.[2] Bleeds are most common in knees, elbows and ankles.[2] But they can also happen in shoulders, wrists and hips.[2] Muscle bleeds are most often in the arms, legs or the iliopsoas muscles, which run from the groin to the lower back on each side.[3]

Muscles and joints have a rich blood supply with tiny blood vessels that are easily damaged. This can be from general wear and tear as you move around normally, or from knocks and falls.[4] Unfortunately a joint that has had a bleed is more likely to have another and each bleed causes more damage inside the joint.[1] So preventing them is really important.

There are different types of bleeds. Microbleeds are so tiny that you don't have any symptoms, but they can still cause damage inside a joint.[1] Spontaneous bleeds happen for no apparent reason.[2] Traumatic bleeds are caused by an injury or when you're very active, cycling, running or playing sports.[5]

Exercise is important because it strengthens your muscles and bones.[2] Keeping your muscles strong helps to support your joints and make bleeds less likely.[6] Some activities are more risky than others.[2] Contact sports such as boxing and rugby are not usually recommended.[2] But try and find something you enjoy – then you're more likely to keep it up. It's worth discussing this with your doctor and physio. They may recommend a dose of factor just before exercising.[2] With the right planning and preparation there's very little you can't do.[2]

Unfortunately, you may still have a bleed even if you're doing all the right things. If you're having bleeds often, talk to your haemophilia team. They can review your treatment plan and may be able to suggest ways to reduce your risk.[2]



Most common

- Elbows
- Knees
- Ankles

Less common

- Shoulders
- Wrists
- Hips

The **joints most often damaged** by bleeding in haemophilia

HOW DO I KNOW IF I'M STARTING TO HAVE A BLEED?

Some people can tell if they're having a bleed very early on.

They have a funny feeling, tingling, fullness or tightness in a joint or muscle that doctors call an 'aura'.[2] If you have this, do listen to it. It's an early warning sign that's telling you to act. Doctors think it best to start treating bleeds straight away, as soon as you think they're starting.[2] Treating early means the bleed will be easier to control and most importantly cause less permanent damage.[1]

Joints that are starting to bleed may feel warm or hot and be painful when you move.[2] Bleeding muscles may start to ache.[2] As the bleed continues you may have swelling.[2] The joint or muscle will be increasingly difficult to move and will be painful even when you're resting.[2] You may have bruising, but if you don't, you may still have started a bleed as bruising often develops later.[3]

Having pain doesn't necessarily mean that you are having a bleed. If you've already got joint damage from bleeds you've had in the past, that may be causing the pain. It can be difficult to tell that from pain caused by a new bleed.[1] Or you may have muscle aching because of a flu virus or after exercising, just as anyone else might.[7] But you do need to be careful. If you think you might be starting a bleed, treat with some factor straight away and then speak to your haemophilia centre for advice.[2]

WHAT DO I DO IF I HAVE SIGNS OF A BLEED?

Making sure you stick to your regular treatment plan is the best way to lower your risk of bleeds, but you may still have one from time to time.[2]

If you think you are having a bleed, the most important thing to do is have a dose of factor as soon as possible.[2] Doctors recommend having factor replacement within 2 hours of first suspecting you've got a bleed.[2]

If you are having a bleed, you need to protect the area so you don't make it worse. If it's in an arm or leg, rest with that limb up for at least 12–24 hours, or longer, depending on how well you recover.[4] Keep your limb in the most comfortable position - don't try to straighten it if it causes pain or discomfort.[4] Don't put weight on a leg that has a bleed.[2]

You don't have to be completely inactive. It's still OK to move around when you have to (going to the toilet, for instance). But you should move around as little as possible until pain and swelling begin to improve.[2] The more you are able to rest, the better.[4] Then, gradually increase activity until you're back to normal.[2] If you don't rest, you could risk another bleed in the same place.[2]

If you're not sure what's best to do at any point, call your haemophilia centre for advice. You should **always** contact them if the bleed doesn't seem to be getting better despite treatment with factor.[2]

Finally, you need to record the bleed in your Haemtrack records.[2] Your doctor uses this information to monitor your treatment and make any necessary changes.[8] So keeping this up to date is the best way to make sure you're on the right prophylaxis treatment plan.[8] And that's the best way to prevent bleeds.

WHY HAVE I GOT JOINT PAIN AND WHAT CAN I DO ABOUT IT?

Unfortunately, a lot of people with haemophilia have joint pain. It's worse for some than others.[9] Pain can be short term (acute) or long term (chronic).[9]

Acute pain is usually caused by a bleed into a joint.[9] You should be able to get that under control quite quickly by having some factor as soon as you can.[2,10] This will stop the bleeding and so relieve the pain.[10] Rest your arm or leg until things start to improve – then you need to start getting it moving again so it doesn't stiffen up.[2]

Blood inside a joint causes irritation and swelling.[11] If you have a series of bleeds, over time that can cause permanent damage inside the joint.[9] The damage is similar to arthritis and can cause chronic pain.[2,12] This type of pain usually starts when you are moving around and gets better when you rest.[9]

You can monitor your pain by using a pain rating scale,[13] which can be found in your Haemtrack record. You use this to score how bad your pain is, usually on a scale of one to 10.[13] This can help you to decide how best to manage it.[13] You can take painkillers but do check with your haemophilia team as some can increase the risk of bleeding so you shouldn't use them.[2] Exercise, massage and other complementary therapies can all help to ease pain.[9]

Pain isn't always caused by bleeding.[9] Like anyone else, you may be stiff and sore after exercising, for example.[7] But chronic pain can be miserable so if you feel it's holding you back, do talk to your haemophilia team. Your physio may be able to give you some treatment or some suggestions about how to manage it.[9] So don't be afraid to talk to them about it and how they can help.

WHAT DO I DO IF I HAVE A KNOCK OR A FALL?

We all bang into things, trip up or get injured playing sports from time to time. But with haemophilia, a knock, fall or other injury can cause bleeding inside a joint or muscle – even if you are really careful about having factor when you should.[1,14]

If you've hurt yourself, watch out for signs of a bleed – a funny feeling or tingling, pain, swelling, heat or tightness in a muscle.[1] If you have any signs at all, the best thing to do is have some factor as soon as possible.[2] Doctors say 'If in doubt, treat'.[2] It'll stop bleeding and help prevent any further damage.[1]

It's not always easy to treat quickly when you are away from home. Always having treatment with you will mean you can treat sooner rather than later. Then follow all the other usual advice for a bleed. Rest your arm or leg in as comfortable position as possible.[4] Keep your limb up as much as you can until pain and swelling have gone.[1] How long this takes will vary from person to person and also on how bad your injury is.

Let your haemophilia team know what's happened and follow their advice on managing your injury. Depending on where the bleed is and whether it is a muscle or joint, the advice may be different, so it's best to make sure.[2]

Accidents can happen to anyone so aim to be prepared. If you haven't already, talk to your haemophilia team about how to manage injuries. They can give you advice on how and when to treat with factor and what other steps to take. They may suggest altering the time of your factor treatments to better protect you when you are most active.[2]

Finally, do make sure you enter information about all bleeds in your Haemtrack record.[2] Your doctor uses this information to assess how well your preventative treatment (prophylaxis) is working.[8] If the pattern of your bleeds changes, they may need to alter your treatment plan to keep you in the best of health.[8]

PRICE

HOW CAN I REMEMBER TO HAVE MY FACTOR WHEN I SHOULD?

You've probably already started to take more responsibility for having your regular preventative treatment (prophylaxis).

You've learned to give yourself the infusions and should know how to spot the signs of a bleed and how to treat it.[15] The next steps are remembering to have your treatment (without being reminded by a parent!) and making sure you've always got enough factor.

You may be worrying unnecessarily. We know from research that four out of five UK teenagers and young adults do take their factor when they should.[16] However, it's a good idea to have some strategies in place. Having a routine should help.[15] If you always have your factor straight after showering in the morning for example, you'll be less likely to forget. You could also set reminders on your phone. There are memory tricks that may help. You train yourself to link having your treatment with another activity or object – picking up your keys or packing your sports kit.

The timing of your treatment may change as your lifestyle changes. For example, if you take up a new sport, your doctor may suggest having factor just beforehand to lower the risk of a bleed.[2] Remember that you can adjust the timing of your treatment plan to match when you're most active.[2] Do talk this over with your haemophilia centre though, just to check it's OK.

When you leave home, it's important to organise factor deliveries so that you don't run out. It's a good idea to start doing this early on – before you leave home.[17] Then your family can help while you get used to it. Make sure you have the phone number of your treatment centre. In fact, in case of emergencies you should always carry information with you that details your bleeding disorder, your treatment and the centre you go to.[2]

Don't beat yourself up if you do forget – these things happen. Just make sure you have some factor as soon as you remember. Thinking about why you might have forgotten can help you to make it less likely to happen in future.

- Get into a routine
- Set reminders on your phone
- Use memory tricks
- Change the timing of your treatment to fit around your lifestyle if necessary
- Start organising factor deliveries before leaving home

CAN I EXERCISE AND PLAY SPORTS IF I HAVE HAEMOPHILIA?

The short answer is 'yes'!

In fact, if you have haemophilia exercise and activity is really important. Exercising helps to keep your bones healthy and strong.[2] It strengthens your muscles and strong muscles help to support your joints and make injury less likely.[5]

Exercise has the same benefits for you as for anyone else, with or without haemophilia. Being active helps to keep your weight down, lowers your risk of many chronic physical illnesses and is good for your mental health.[5]

One of the reasons exercise makes you feel good is because it's sociable and fun. So it's important to choose activities that you enjoy. This doesn't have to be a sport – any activity will do. So dancing, going for a walk or even gardening all count.

There are some precautions you have to take if you have haemophilia. Some sports are not recommended, such as boxing or rugby.[2] The risk of serious injury is just too high. As you get older, you may find that your chosen sport, football for instance, gets a bit rougher and you may decide to switch to something else.[15]

If necessary, you can time your preventative treatment (prophylaxis) to give you the most protection when you're exercising.[2] If your factor levels are high, you will have the lowest risk of injuring yourself and causing a bleed.

Making sure you warm up properly will also help to prevent injury by loosening you up – stretching your muscles and flexing your joints.[9] Exercising with 'cold' muscles is more likely to cause an injury.[18] Warming up will also help to reduce muscle soreness after exercise.[9]

With modern preventative treatment and the proper planning, there is very little you can't do. If you have any concerns, talk it over with your haemophilia team – they'll be happy to help.

I FEEL DIFFERENT TO OTHERS MY AGE. I GET ANXIOUS AND FRUSTRATED ABOUT HOW HAEMOPHILIA AFFECTS MY LIFE. WHAT CAN I DO?

Having haemophilia can be stressful.[19]

You and your family have to cope with things that others don't – making sure you have your treatment, avoiding things in everyday life that increase your risk of a bleed and managing bleeds when you have them. Feeling different can make you anxious and upset, particularly when you're young.[20]

Talking about anxiety and stress is difficult. These aren't things that people talk about often and can be uncomfortable to bring up. If you're having trouble coping, speak to your treatment centre. They understand that looking after your mental health is just as important as keeping your body healthy.

Talking to someone who doesn't know you or your family may help. They may have a different take on things that can help you find a way through it all. Many people find 'talking therapies' such as counselling really can make a difference.[21]

It can also help to talk to people who really understand what you're going through. If there is a local patient support group near you, you can meet people who've grown up with a bleeding disorder, so they really know what it's like. You'll almost certainly find everyone has difficulty coping at times. You'll be able to find out how other people have managed and learn from each other.

People with long-term medical conditions often find mindfulness helpful.[22] You learn to live in the moment, rather than brooding about the past or worrying about the future.[23] You step back and begin to notice when negative thoughts are taking over.[24] It can really help you to understand yourself better and enjoy the world around you more.[24] Recognising anxiety and stress sooner can help you deal with it more effectively.[25] And learning to accept things as they are means you spend less time and energy wishing things were different.

The Belfast Haemophilia Centre can arrange for you to see someone to talk over your feelings and help you to learn to manage them. See the end of this booklet for useful links.

HOW CAN I EXPLAIN WHAT HAEMOPHILIA IS AND HOW IT AFFECTS ME TO OTHER PEOPLE?

As with any personal medical information, it's up to you what you tell people. You don't have to say anything if you don't want to. But it may help to have a handy, short way of explaining it when you need to.

You don't need to go into detail. You could say something like 'I was born without one of the proteins that blood needs to clot. So I give myself an injection X times a week to replace it'. Some people will ask questions and some will just say 'OK' and leave it at that. There are some suggestions for how to answer common questions on the next page.

There's a positive side to telling people. If your friends and other people in your life know about your haemophilia, they can be a source of support, listen when you want to sound off and most importantly, be in a better position to help if you injure yourself or have an accident.

There are people who do need to know. Your teachers will probably have been told by your parents when you started at school. You don't have to tell an employer but it is probably a good idea. For one thing, you have certain rights by law. Under the Disability Discrimination Act, they have to make 'reasonable adjustments' for you.[26] This could be giving you time off for medical appointments or somewhere to store factor or give yourself an infusion if you need to.

You'll probably want to tell a girl or boyfriend. It is a good idea to plan ahead. Choose a time when you won't be interrupted. Think about what to say – you can talk it over with your parents, brother or sister or a close friend. You can even role-play if that'll help. The most likely reaction of someone who cares about you is to worry. So be prepared to reassure them that, although there are some things you have to be careful about, you're fine as long as you have your factor infusions when you need to.

3 common questions that people may ask about your bleeding condition

1 Can you catch it?

No, never. It's not infectious. Haemophilia is something you're born with and there's absolutely no way I can give it to anyone else.

2 What happens if you cut yourself?

Usually I just have to press on the cut for a bit longer than anyone else would. If it's deep or won't stop bleeding, I just give myself an injection of my blood clotting medicine and that stops it.

3 Why do you have to give yourself injections?

I was born without one of the proteins that blood needs to clot and stop bleeding. To replace it I give myself an injection X times a week. I have to inject because the medicine is a protein. If I swallowed it as a tablet, my stomach would digest it before it had a chance to get into my bloodstream.

I need to have injections every few days because the body constantly uses up clotting proteins and I need to make sure I regularly top up the one that's missing.

I AM WORRIED ABOUT HAEMOPHILIA AFFECTING MY SCHOOL AND COLLEGE LIFE – WHAT CAN I DO?

Most people manage school and university well and live life to the full.

But it's natural to worry and there'll be times when hospital appointments, treatment or bleeds get in the way. With a bit of planning, you can make sure you don't miss out too much.

Firstly, talk to your treatment centre – they'll do everything they can to arrange your appointments so they interfere with school or college as little as possible. If you are open about your condition with your form teacher or personal tutor, they'll better understand the issues you have. They can help you arrange to catch up on anything you've missed. You should be able to get hold of assignments and work on them at home if you need to. They can give you longer deadlines when necessary too. They should also help to arrange somewhere private (and clean!) at school or college to give yourself treatment – for example before playing sports.

Starting somewhere new can be hard, whether it's a new school, going to uni or a new job. You'll have to explain your condition yet again, usually to people who won't know anything about haemophilia. This'll get easier in time. You'll get used to telling people and feel more comfortable with deciding what to say and who needs to know.

Going away to college is a big step for anyone. But you'll have a bit more to deal with than most. You may have a new treatment centre and this can be particularly daunting if you've always been to the same one. Do remember that everyone there wants to help and support you as much as they can. You'll have to take responsibility for organising supplies, remembering to have treatment and completing your Haemtrack records. Again this'll get easier with practice. You'll make mistakes sometimes, but that isn't the end of the world. You'll get into a new routine in time. Asking for help doesn't mean you've failed in any way. On the contrary – it's a sign of your growing maturity and independence. So don't try and manage alone if you're struggling.

USEFUL LINKS

https://hellohaemophilia.com

https://haemophilia.scot/information/living-with-a-bleeding-disorder

https://haemophilia.ie/living-with-haemophilia/teenage-boys-with-haemophilia

https://www.wfh.org/en/resources/young-voices

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