

LIBERATE  
LIFE

# my voice: talking with others about haemophilia

Introduction  
& tips

A new  
partner

Your partner's  
family

New friends  
and peers

People at  
work

Healthcare  
professionals

## you are **in charge**

Having haemophilia is part of who you are but it shouldn't define or limit you. **It's your choice when and how you tell others about it.** You may feel that it's important to share with certain people while you might decide not to share with others. It's completely your choice.

## a **positive mindset**

**Everyone is different and, therefore, will respond in their own way.** Some might take further interest and ask more questions while others might just want to listen. Nearly everyone you speak with about your haemophilia will want to be as understanding and supportive as possible.

## when to tell

Sometimes you may feel hesitant to open up about having haemophilia for your own personal reasons. Perhaps:

- You are a naturally private person
- You are not yet trusting enough of the other person
- You fear the information may affect a personal relationship or how others treat you

These are all perfectly valid reasons for wanting to wait. In most instances, **you can choose if and when the time is right for you.**

## who you might **want to talk to**



**A new partner**



**Your partner's family**



**New friends and peers**



**People at work**

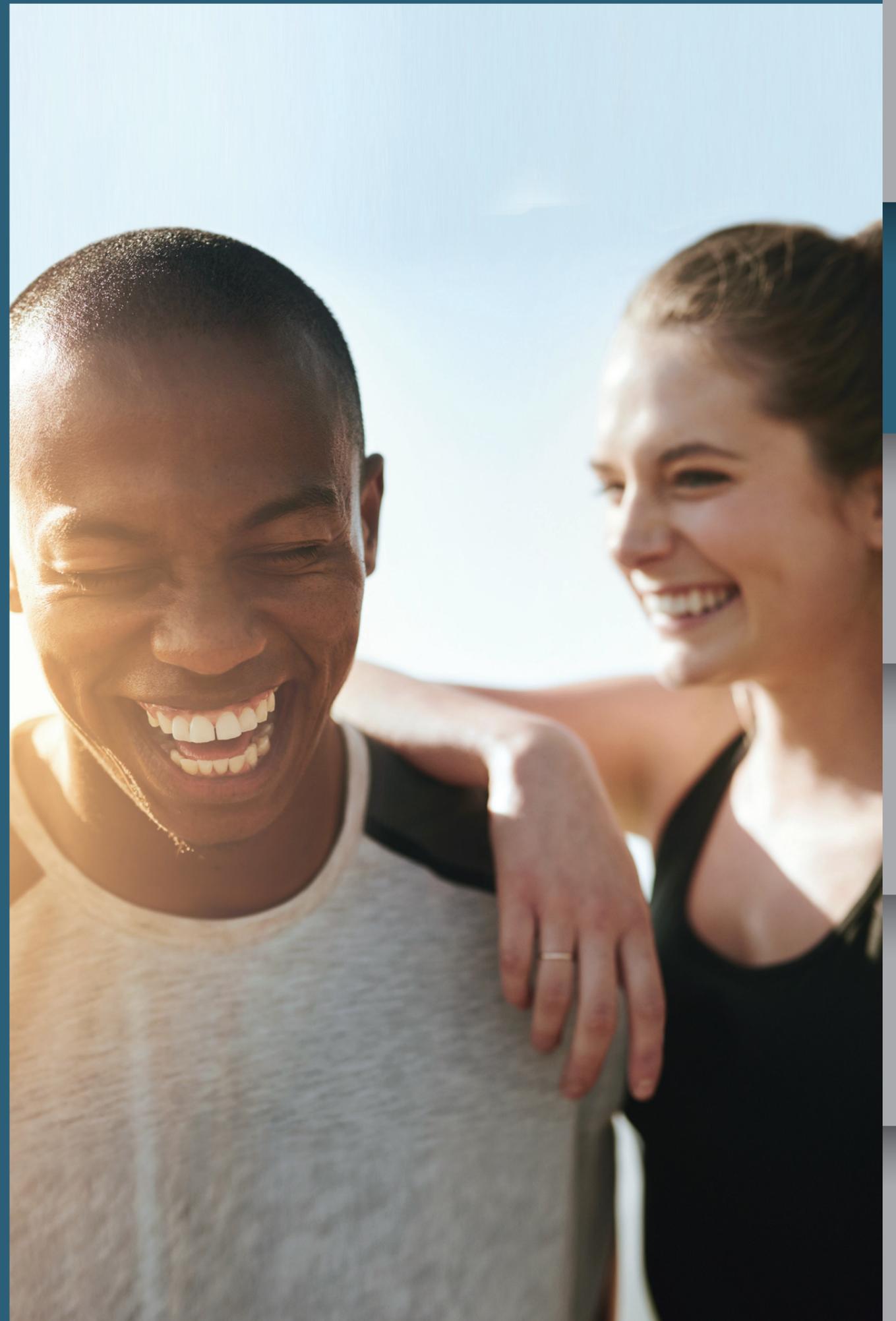


**Healthcare professionals who do not specialise in bleeding disorders**

Since these individuals will play different roles in your life, you may choose different approaches to talking with them about your haemophilia.

Whether or not you are already comfortable sharing your condition with others, you might find the following tips helpful.

●  
talking with...  
**a new partner**



# talking with... a new partner

New relationships can be an exciting time for everyone. Depending on how things are going, you may want to tell a new partner early on or wait until things get more serious – **this is an entirely personal choice.**

Having the conversation early can be helpful for your partner to understand your treatment needs, what they can do to help in emergencies and any considerations around sex.

Questions around family planning and becoming parents might come up as the relationship develops. It's helpful for you to know how to respond; your haemophilia care team can provide guidance and support, such as referring you for genetic counselling.

**Do you or your partner want to learn more?**  
Explore more Liberate Life content by scanning the QR code.



## Thoughts you might have

Will my partner be put off by my condition or find me less attractive?  
.....

Will my partner focus on all the activities we potentially can't do together?  
.....

How will this impact our relationship in terms of our future together?



## Talking tips

**Discuss the things that you already enjoy** doing together, as well as other activities that you'd like to do as a couple  
.....

**Share information and skills** with your partner that can help increase their confidence in supporting you – let them know what they can be doing to help, for example, coming along to your appointments  
.....

If you are considering starting a family, **have an open and honest discussion** with your partner around what this could mean for your relationship. There are many resources to help explain things in a simple manner; you might find this useful: [the inheritance of haemophilia \(www.LiberateLife.eu\)](#) <update with local URL>

● talking with...  
**your partner's family**



# talking with... your partner's family

If you are in a long-term relationship, your partner's family are likely to be an important part of your life. Concerns around how your partner's family might react are perfectly natural. All families are unique and will respond differently.

It's likely that your partner has already spoken with their family, though there may still be gaps in their understanding that you can help fill. **The key is helping your partner's family understand what haemophilia is (and what it isn't)**, as they are likely to know very little about it.

It's always a good idea to speak with your haemophilia care team and centre. They can offer support by recommending educational materials that you can use and share with your partner's family.

**Interested in ways to explain haemophilia to others?** Explore more Liberate Life content by scanning the QR code.



## Thoughts you might have

Will my partner's family treat me differently because of my condition?

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Will my partner's family be worried about haemophilia being passed on to our children?

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Will my partner's family be worried about what to do if I have a haemophilia-related emergency?



## Talking tips

**Share a simple explanation of haemophilia** with them (for example, types, severity, genetics, bleeds, treatments) and anything else that you feel is important for them to know

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**Share a brief list of things that your partner's family should do** in case of an emergency so they are able to help

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**Look for and use resources** from your haemophilia centre or local patient organisation. Some helpful online resources can be found here: [a lesson in haemophilia \(www.LiberateLife.eu\)](#) <update with local URL>

● talking with...  
**new friends and peers**



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Healthcare professionals

# talking with... new friends and peers

As you go through life, you will have many opportunities to meet new people and mix with your peers in various settings. Moving to a new area, attending university or joining a club/society, are all big life events that can give you a great chance to socialise and make friends. Haemophilia shouldn't be a barrier to having a busy social life or something to hide from friends or peers.

You may feel able to talk to friends or peers about the condition straight away or prefer to wait until you have known them for a while. Many people will never have met anyone with haemophilia before or understand what it means to live with the condition. More often than not, friends will be open-minded and supportive – some may be interested in learning more, whilst others will leave it up to you to decide how much to tell them.

Being part of a strong social circle, whatever the size, is important for your overall wellbeing. Having a few close friends and feeling part of a community or social group can have many benefits, to include helping to maintain a positive mind and balanced mood. It may even help reduce feelings of anxiety or low mood that can occur as part of living with haemophilia. Being able to talk openly about your condition, but also beyond that, is key for a happy and fulfilling life.

**Interested in ways to explain haemophilia to others?** Explore more Liberate Life content by scanning the QR code.



## Thoughts you might have

Will my friends feel responsible for looking after me when we are out together?

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Will my peers think I am unreliable when I can't take part in things (e.g. If I am in pain or attending medical appointments)?

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What if people think I am strange for injecting myself?



## Talking tips

**Share a simple explanation of haemophilia** with your friends/peers (for example, types, severity, genetics, bleeds, treatments) and describe how you manage and live well with, and beyond, haemophilia.

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**Be open to answering questions** from your friends or peers, if you feel comfortable doing so. As a rare condition, many people have limited knowledge of haemophilia and may want to know more, in order to make better sense of it and understand how they can support you.

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**Share with close friends a brief description** of what they can do to help you in an emergency. A few key actions on how they can help, if needed, may be empowering for them to know. Some helpful online resources can be found here: [a lesson in haemophilia \(www.LiberateLife.eu\)](http://www.LiberateLife.eu) <update with local URL>

### Reference:

PsychCentral. Supporting individuals with depression: The importance of self-care. 2018. Available at: <https://psychcentral.com/lib/supporting-individuals-with-depression-the-importance-of-self-care/> (accessed 10 March 2020)

● talking with...  
**people at work**



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# talking with... people at work

Starting out in your career or moving to a new job can feel like a huge step. You might have received advice from your haemophilia care team or patient organisation in finding a role that matches both your aspirations and activity levels. It's important to **remember that you were hired based on your skills, training, experience and what you can bring to the organisation**, so haemophilia should not be a focus at your new workplace.

You might not need to share anything about your condition if it does not affect your responsibilities and day-to-day tasks. If you do wish to tell the employer, you might choose to do so at the point of interview, when accepting the offer or once you've started your new role.

Depending on where you live and work, specific laws will be in place to protect you from discrimination in the workplace. If you feel that you are being discriminated against, you should contact your local advisory service <local markets can add in the appropriate service here>.

Remember, most people want to be helpful and supportive, so if colleagues ask you questions or make misinformed comments it's most likely from genuine interest. **In fact, think of it as an opportunity to correct any misunderstandings about haemophilia and to get their support and understanding.**

**Want to hear others' stories and experiences about work?** Explore more Liberate Life content by scanning the QR code.



## Thoughts you might have

Will my managers or colleagues think that haemophilia affects my performance or my ability to carry out my roles and responsibilities?

Will I be treated differently in the workplace based on misconceptions or misunderstandings about haemophilia?



## Talking tips

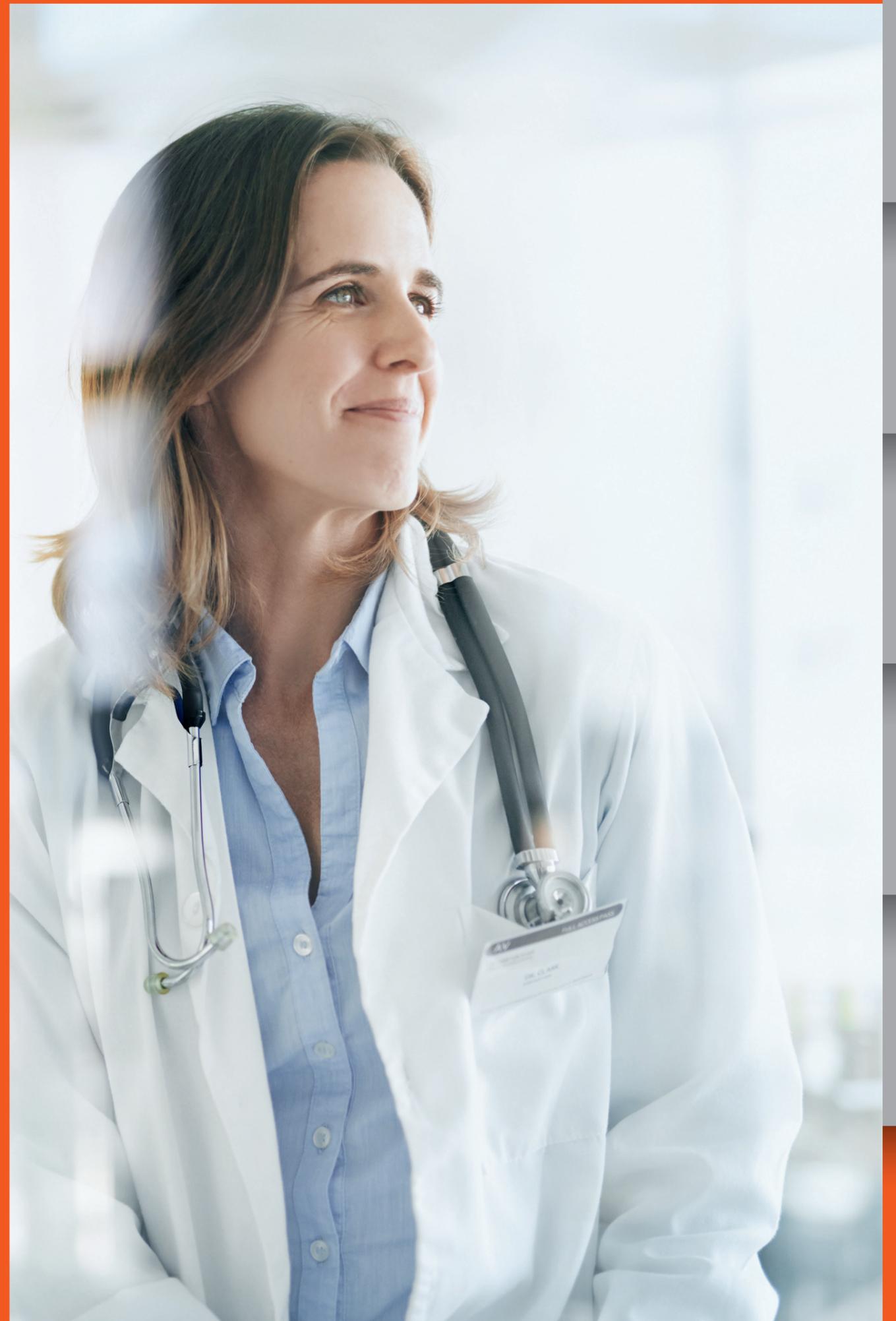
**Share a brief summary** with your manager about what haemophilia is and what your colleagues can do in case of an emergency

**Be open** to answering any other questions they may have at work if you feel comfortable doing so

**Discuss suggestions** on how your work environment or schedule could be adapted to fit your needs with your manager and teams

●  
talking with...  
**healthcare  
professionals**

*(who **do not** specialise in  
bleeding disorders)*



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# talking with... healthcare professionals

(who **do not** specialise in bleeding disorders)

Since haemophilia is a rare condition, many healthcare professionals (doctors, nurses, pharmacists, dentists, surgeons) outside of haemophilia centres may know little about it or may not have had any patients with haemophilia before. Therefore, in many instances, **you will find that you are the expert on your condition.**

It is essential to share information about your haemophilia so that these healthcare professionals can make the best treatment decisions for you. Your haemophilia centre can also provide any medical details that will be necessary for you to share.

Keep in mind that speaking with healthcare professionals beyond your haemophilia centre will be different from speaking with others about your haemophilia in your daily life, as they will need specific medical details.

**Interested in learning more about healthcare professionals and haemophilia teams?**

Explore more Liberate Life content by scanning the QR code.



## Thoughts you might have

What if I have an emergency bleed far away from my haemophilia treatment centre – will it be properly managed?

What if I am admitted for emergency surgery and am given a medicine that interferes with clotting?

What if my concerns about a bleed are not listened to or taken seriously?



## Talking tips

**Have to hand all the details about your haemophilia** and how it's treated, as well as contact details of a person from your haemophilia centre that can provide further information and that of a close relative or partner. [A bleeding disorder medical alert card you can use can be found here: *<local markets to indicate appropriate card>*]

Any of your medical concerns/complaints should be taken seriously, so **don't be afraid to urge the healthcare professional you are seeing to do so.** For example, a knock to the head may be more serious than is immediately thought given the nature of haemophilia

Before undergoing any medical, surgical or dental procedure and when getting prescriptions, **be sure to let the healthcare professional know that you have a bleeding disorder** and share with them relevant details. They will likely need to make adaptations should you undergo an operation or need over-the-counter medicine



If you would like to learn more about how to live well with haemophilia, you can explore information, advice and stories at [www.LiberateLife.eu](http://www.LiberateLife.eu) <local markets to update with relevant URL>.



***This booklet has been co-created with healthcare professionals and people with haemophilia.***



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