

LIBERATE
LIFE

my voice, my care

for people living
with haemophilia

A guide to talking
with your healthcare
team about what
you want to achieve
and what you want
your treatment and
care to do for you.







starting the conversation

As a person living with haemophilia, you most likely have regular appointments with your specialist healthcare team at a haemophilia centre. Often these can feel like routine check-ups.

However, these appointments are also an opportunity to get involved in making decisions around your health that can help you reach your goals.¹

This booklet provides some tips on how you can get the conversation going about your goals and care preferences at your appointments and beyond.

what's inside

preparing for my appointments	4
discussion tips	6
what I want to achieve	7
conversation starters	10
my appointment checklist	13
haemophilia care team	14



preparing for my appointments

before



Making the most of every appointment

To help make every appointment meaningful to you, it's useful to have some things prepared ahead of time:

- During the months between appointments, keep notes of any questions you have as you think of them
- As your appointment approaches, identify the key points you'd like to discuss (at least a few days beforehand)
- Take a copy of your questions and key points with you. Alternatively, add the list to your phone so you don't forget

Doing this will help take the pressure off thinking on the spot and gives you enough time with your doctor to discuss your life and health priorities.



Educating yourself

You might have already gathered some information on haemophilia and treatments from the internet or other resources. Keep hold of any related notes and questions so that you can share and discuss them with your doctor.

If you are interested in learning more, you can explore advice on living well with haemophilia at our website: www.LiberateLife.co.uk.

during



Making your voice heard

Your doctor is likely to have questions for you but your appointment is also an opportunity to discuss your wants and needs. Just like with anyone else, your doctor will only know what's on your mind when you share it with them.

Aim to share your prepared questions during the appointment. **Discuss your key points and ask any urgent questions first to make the most of the time with your doctor.**

after



Continuing the conversation

Your care doesn't end after your appointment. If you still have questions, get in contact with your doctor or healthcare team.

Also follow up with any results you are waiting for from your centre – you can always get in touch with them. **You can also start thinking about what you'd like to get out of your next appointment and begin making preparations in advance.**



You can find some notes pages at the end of this booklet.



discussion tips

Here are some discussion tips that may be helpful when speaking with your doctor:



- **Challenge the norm**

If you feel that any part of your treatment or care is not working for you, **don't be afraid to speak up**. This is about getting the care that will help you do the things most important to you.



- **Be open and accurate**

Answer questions from your doctor as best as you can. **It will help to build your relationship**. It also means they are in a better position to support you.



- **Ask questions**

The appointment is an opportunity to ask any questions you have around your health, test results or treatment options. **There are no 'silly' questions**.



- **Bring support**

Though it's usual to go to appointments alone, **you could ask someone you trust to come along**. Not only will this help you feel supported, they may also have useful questions to add to the discussion.



- **Turn preparation into action**

Remember to keep your notes and questions to hand. **Be sure to share the ones most important to you with your doctor**.





what I want **to achieve**



What is important to you?

Sharing with your doctor and healthcare team what matters most to you means you can work together towards achieving the things you find meaningful.

Everyone is different and we all have different things that matter to us and that motivate us. **Try to identify what these are for you.**

Take a look at the sections on the following pages.² Remember, focussing on one area doesn't mean others aren't also important.



Enjoying my life and connecting with others

- Being able to do the things that bring me joy, pleasure and fulfilment (such as hobbies, sports, travel, fitness/exercise, career)
- Growing and strengthening relationships and connections that are important to me (including my partner, my friends, my family, my community)

Try thinking about:

- *How happy are you with your current lifestyle and close relationships?*

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- *Does your health limit how you spend your free time?*

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- *How confident do you feel in social settings and when meeting new people?*

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- *Do you feel able to talk about your haemophilia in your workplace?*

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Living independently and managing my health

- Being able to take care of myself and manage my care independently (such as administering treatment, keeping to my treatment schedule, recovery after a bleed)
- Looking after my mental and physical wellbeing (including pain, mobility and joint health, mental health and mood)

Try thinking about:

- *What is something I do now that I'd like to keep doing?*

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- *What is something that I'd like to start doing?*

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- *In what ways does my haemophilia and/or treatment impact my ability to do what matters to me?*

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- *In what ways does haemophilia-related pain and/or mental health issues impact my ability to do what matters to me?*

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conversation starters

If you have trouble sharing what's on your mind, take a look at the following suggestions on how to start a conversation with your doctor. **Feel free to personalise them and use your own words.** Your doctor will be able to help answer your questions.



Enjoying my life and connecting with others



What you might be thinking

I'm having a change in job/study and am not sure that my current treatment will be compatible

I've stopped doing an activity that I enjoy because I worry about bleeds

I don't think my current treatment fits into my day-to-day routine/family life

I will be travelling and am wondering how this could affect my care and/or treatment

I am worried about how having haemophilia could affect my relationships and sex life

I don't socialise as much as I would like to because of my haemophilia and/or treatment

I'm currently facing emotional or mental wellbeing challenges



Try asking your doctor

"How can we change my treatment to fit in with my new work/study commitments?"

"I'd like to get back to doing this particular activity – what changes can we make to help me feel protected against bleeds?"

"In what ways can we make my treatment fit in better with my current lifestyle?"

"What adjustments might I need to make to my treatment and care when travelling?"

"Who can I talk to for advice on relationships and sex for people with haemophilia?"

"I feel that my haemophilia and/or treatment is affecting my social life – what can we do to help improve this?"

"I'd like help coping with how I'm feeling emotionally/mentally – who can support me?"

Living independently and managing my health



What you might be thinking

My joint/joints aren't moving as well as they used to

I'm not sure what to do with my treatment in certain situations:

- when on holiday abroad
- during a bleed

I find that I often miss or skip treatments

I'm experiencing joint pain that is affecting my ability to do things and/or my mood

I've noticed that I've been having bleeds even though I've been sticking to my treatment

I've had a bleed that has hospitalised me

I'm not certain why I'm having a particular medical test



Try asking your doctor

"I've noticed that I'm losing mobility in my joint/joints (ankle, knee, elbow) – what support or treatment can I receive to help with this?"

"In what ways can I keep on top of maintaining joint health in my own time?"

"What should I do before going on holiday (for example, a long-haul flight or staying in a country with limited healthcare services) to keep me protected?"

"What should I do when I have a bleed while on treatment?"

"I'm having trouble sticking to my current treatment schedule – what are the options to help me with this?"

"I have pain in my joint/joints that is affecting my daily life and happiness – what can we do about this?"

"I'm not sure that my treatment is protecting me against bleeds as well as it could – could we go through my latest results and have a look at my options?"

"What could help prevent this from happening in the future?"

"Could you explain what this test is for and what the results mean for me?"



my appointment checklist

When it's time for your next appointment, you can use this checklist to remind you of what's useful to have ready.



Updates to your health

- Any bleeds you've experienced, any changes in mobility you've noticed, any issues with your haemophilia treatment and any new health conditions
- Also bring any updated results or health documents that you have



Changes in your medicines

- Any new prescriptions, over-the-counter medicines or supplements that you've been taking, even if they are not related to haemophilia
- Bring a note of the medicine names and doses, including those you have been taking regularly or even just once



App information

- If you use a haemophilia app you can bring the results or information from this with you



Notes and list of questions

- It's a good idea to keep notes or a diary between appointments to keep track of your symptoms, pain and mobility. Bring these to your appointment, along with a list of your priority questions



haemophilia care team

A haemophilia care team is made up of different types of healthcare professionals that each offer specific skills and expertise. Together they support the different needs of people with haemophilia to ensure you get the best care.

Understanding the roles of these experts will help you know the best source for answers and advice about your health or treatment. Remember, you may not need to see all of these healthcare professionals, but your haemophilia doctor can refer you to a specialist if needed.

Haematologist:

A doctor who specialises in diagnosing, treating and managing disorders of the blood, like haemophilia. As part of a healthcare team, the haemophilia doctor (haematologist) will create a personalised treatment plan, prescribe treatments and review and talk through test results. They will also provide referrals to other specialists if needed.

Haemophilia nurses:

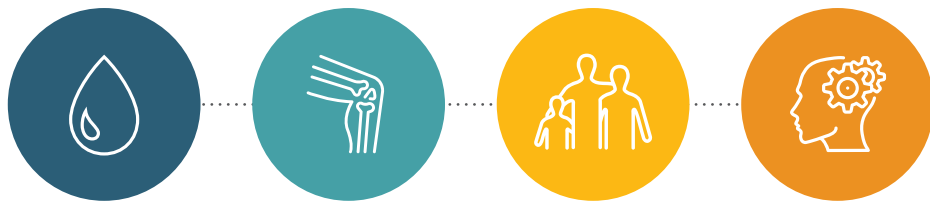
The haemophilia nurses are the healthcare professionals to contact for most issues. They support people with haemophilia in managing their treatment, such as teaching how to self-infuse and helping to organise home delivery.⁴ During appointments, a nurse may help carry out physical exams and blood tests, if these are needed.

Physiotherapist:

A healthcare professional who tests joints and muscles to measure how well they move. Physiotherapists use and teach techniques that can help manage joint and muscle problems.^{5,6} For people with haemophilia, physiotherapy can help restore joint movement and function, and reduce the risk of injury in the future.^{5,6}

Psychologist:

A healthcare professional who can help people with haemophilia cope with the emotional challenges they may be facing. Psychologists are trained to emotionally support people with their worries or concerns and to help improve their mental wellbeing.⁷



Orthopaedic surgeon:

A doctor who specialises in the diagnosis, prevention and treatment of bone, joint, muscle, ligament and tendon problems. Orthopaedic surgeons treat people with haemophilia who have severe joint problems and need surgery.⁸

Genetic counsellor:

A healthcare professional who educates individuals, partners and families on the likelihood of passing a genetic condition (like haemophilia) to their children. Genetic counsellors can answer questions around family planning and may also manage genetic tests during pregnancy.⁹

In addition to those listed above, you may also have other healthcare specialists involved in your care depending on your local centre (such as a chronic pain specialist, dentist or occupational therapist).¹⁰

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my appointment **notes**

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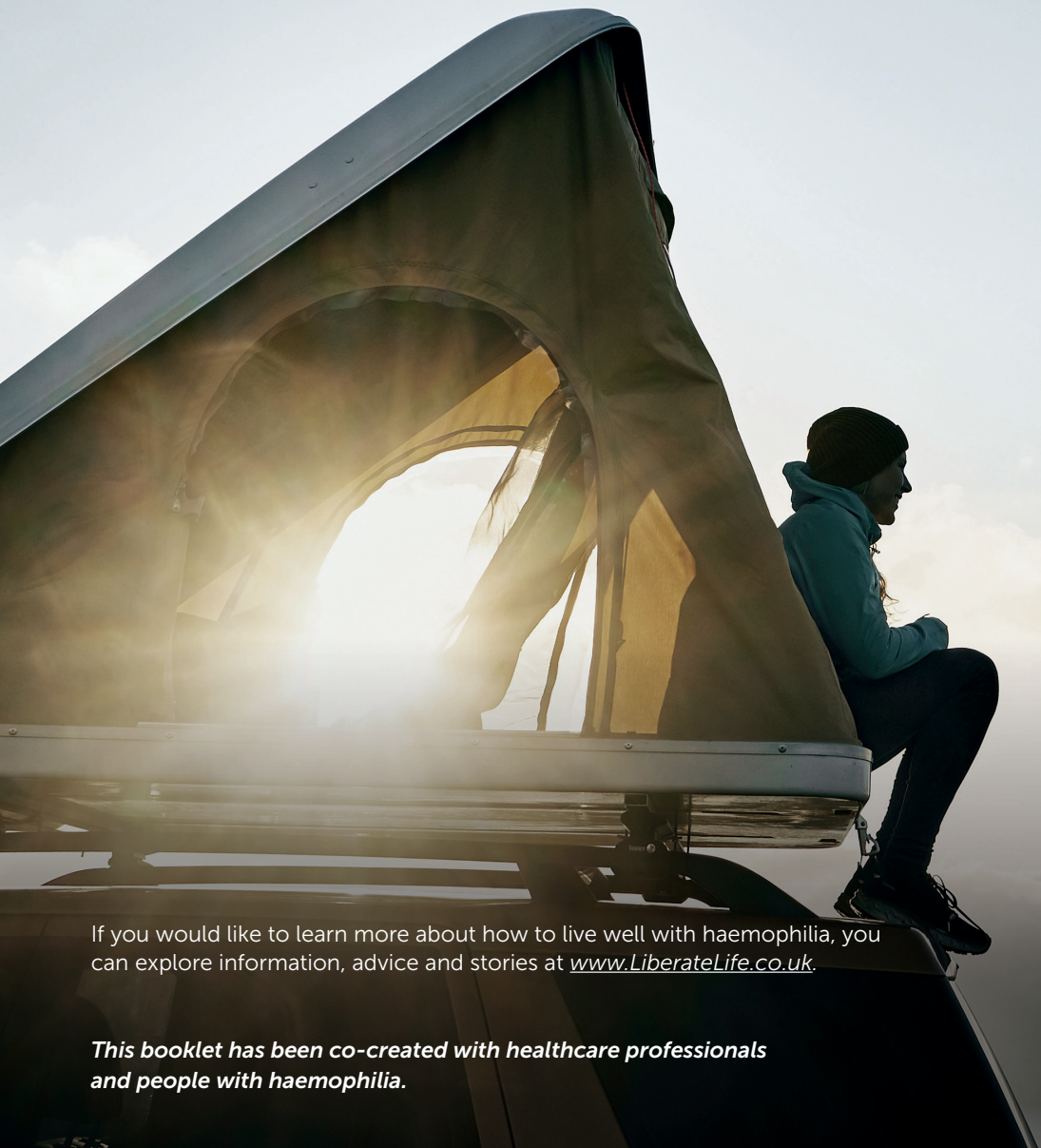
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If you would like to learn more about how to live well with haemophilia, you can explore information, advice and stories at www.LiberateLife.co.uk.

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

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