

LIBERATE  
LIFE



# your voice, their care

for partners of people living with haemophilia



A guide on how you can support your partner in talking with their healthcare team about their life goals and what your partner wants their treatment and care to do for them.





# getting the conversation started

As a partner of a person living with haemophilia, you are likely aware of their regular appointments with their specialist healthcare team at a haemophilia centre.

Although these can often seem like routine check-ups, they are an opportunity for your partner to get involved in making decisions around their health **which can help your partner achieve what they want in life.**<sup>1</sup>

As their partner, and an important part of their life, **there are ways you can support these conversations.** This booklet provides some tips on helping your partner get the most out of their appointments.

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# preparing for **appointments**

## before

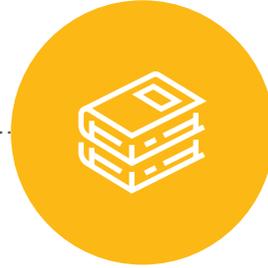


### **Making the most of every appointment**

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

- During the months between appointments, your partner can keep notes of any questions they have as they come to mind
- As your partner's appointment approaches, they should identify the key points they'd like to discuss (at least a few days beforehand)
- Encourage your partner to take a copy of their questions and key points with them. Alternatively, your partner can add this list to their phone

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



### **Being informed**

You and your partner 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 they can be shared and discussed with their doctor.

**If either you or your partner are interested in learning more, you can explore advice on living well with haemophilia at our website: [www.LiberateLife.eu](http://www.LiberateLife.eu) <local markets to update with relevant URL>.**



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

## during



### Making your partner's voice heard

The appointment should be a two-way conversation between your partner and their doctor. Therefore, your partner should see it as an opportunity to voice their goals, needs and questions.

Encourage your partner to share their prepared points or questions during the appointment. **Any key points or urgent questions should be discussed first to ensure these are covered by the doctor and to make best use of the time.**

## after



### Continuing the conversation

Your partner's care doesn't end after their appointment. If your partner still has questions, they should get in contact with their doctor or healthcare team.

Your partner can also follow up with any results they are waiting for from the centre – your partner should always be able to get in touch with them. **Encourage your partner to start thinking about what they'd like to get out of their next appointment and to make preparations in advance.**



There's also a conversation guide for people with hemophilia that contains tips and notes pages: [<local markets to update with relevant URL to My voice, my care booklet>](#).



# discussion tips

Here are some discussion tips that may be helpful when your partner speaks with their doctor:



## ● Be their support

If your partner asks, and if you can, join them for their appointment. Not only will this help them feel supported, **you might also have useful questions to add to the discussion.** Ask your partner how you can be most helpful.



## ● Challenge the norm

If your partner feels that any part of their treatment is not working for them, **they should not hesitate to speak up.** This is about getting the care that will help them do the things most important to them, whatever these might be.



## ● Being open and accurate is key

Your partner should answer questions from their doctor as best they can. **It will help to build the relationship between them.** It also means the doctor is in a better position to help your partner reach their goals.



## ● Practise questions together

Remind your partner that there are no 'silly' questions. The appointment is an opportunity for them to ask any questions they have around their health, test results, treatment and living well with haemophilia. **Before the visit, offer support by practising questions together.**



## ● Turn preparation into action

Suggest that your partner keep hold of their notes and list of questions. **Remind your partner to take these along to the appointment.** You can offer to store these together for safekeeping.





# what your partner wants to achieve



## What is important to your partner?

When your partner shares with their doctor and healthcare team what matters most to them, it means they can work together towards achieving the things your partner finds meaningful.

**Everyone is different and we all have different things that matter to us and that motivate us.** As a couple, you might have shared goals that you work towards together, as well as your own individual goals which you help each other pursue.

Take a look at the sections on the following pages.<sup>2</sup> Whether shared or individual, **which aspect of their life has your partner expressed to you as being the most important to them at the moment?**<sup>2</sup>



## Enjoying life and connecting with others

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

### Try thinking about:

- *How happy is your partner in their current lifestyle and close relationships?*

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- *Does your partner's health limit how they spend their free time?*

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- *How confident does your partner feel in social settings and when meeting new people?*

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- *Does your partner feel able to talk about their haemophilia in their workplace?*

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## Living independently and managing health

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

### Try thinking about:

- *Is there something your partner does now that they'd like to keep doing?*

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- *Is there something that your partner would like to start doing?*

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- *In what ways does haemophilia and/or treatment impact your partner's ability to do what matters to them? (perhaps they are hesitant to travel to far destinations)*

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- *In what ways does haemophilia-related pain and/or mental health issues impact your partner's ability to do what matters to them?*

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## conversation starters

Your partner might have trouble sharing what's on their mind with their doctor. If so, you can suggest these conversation starters to them. **Feel free to personalise them – their doctor will be able to help answer any questions.**



## Enjoying life and connecting with others



### What you might have noticed or discussed with your partner

When my partner has a change in job/study and are not sure whether their current treatment will be compatible

My partner has stopped doing an activity that they enjoy because they worry about bleeds

My partner feels their current treatment doesn't fit into their day-to-day routine/family life

My partner will be travelling and thinks it could affect their care and/or treatment

My partner worries about how having haemophilia affects our relationship and sex life

My partner doesn't socialise as much as they would like to because of haemophilia and/or treatment

My partner is currently facing emotional or mental wellbeing challenges



### Your partner could try asking their 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 health



### What you might have noticed or discussed with your partner

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

My partner is worried about finding veins when injecting themselves

My partner is not sure what to do with their treatment in certain situations:

- when on holiday abroad<sup>3</sup>
- during a bleed

My partner finds that they often miss or skip treatments

My partner is experiencing joint pain that is affecting their ability to do things and/or their mood

My partner is experiencing bleeds even though they are sticking to their treatment

My partner has had a bleed that has hospitalised them

My partner is not certain why they're having a particular medical test



### Your partner could try asking their 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?"

"I'd like support in giving myself injections and finding veins – who can help me with this?"

"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?"



# keeping **on track**

No matter how small or large you feel your role is in the management of your partner's haemophilia, **it's still important**. Perhaps you help them keep on track by:



Reminding your partner to take their treatment



Helping to prepare or give injections



Supporting your partner with at-home physiotherapy exercises



Joining your partner for their appointments, even if it's just to the centre or waiting room

When it comes time for your partner's next appointment, this checklist can help remind you both of what's useful to have ready:



## Updates to your partner's health

- any bleeds, changes in mobility, issues with treatment, new health conditions or updated results/health documents



## Changes in medicines

- any new prescriptions, over-the-counter medicines or supplements – even if unrelated to haemophilia



## App information

- results and information if your partner uses a haemophilia app, to track and record therapy



## Notes and list of questions

- it's a good idea for your partner to keep track of their symptoms, pain and mobility – your partner can bring these notes along as well as a list of their 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 they get the best care.

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

## Haematologist:

A doctor who specialises in diagnosing, treating and managing bleeding conditions 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.<sup>4</sup> 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.<sup>5,6</sup> For people with haemophilia, physiotherapy can help restore joint movement and function, and reduce the risk of injury in the future.<sup>5,6</sup>

## 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.<sup>7</sup>



## 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.<sup>8</sup>

## 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.<sup>9</sup>

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

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If you or your partner 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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