



MAKING DECISIONS TOGETHER:

A guide to support you and your healthcare
team make decisions about your haemophilia
care and treatment

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This Shared Decision Tool should not be used for diagnosing or treating a health problem or disease. It is not intended to substitute for consultation with a healthcare provider. Please consult your healthcare provider for further advice.

Intended for Europe and Canada HCPs and patients (outside of the UK).

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The aim of this booklet is to support people with haemophilia to make decisions about their care and treatment in partnership with their healthcare team. It was developed in collaboration with healthcare professionals and advocacy groups representing people with haemophilia. It does not support any particular approach to care and treatment.

INTRODUCTION

This aim of this booklet is to support you to make decisions about your care and treatment in partnership with your healthcare team.

It provides some tips to help you prepare for your appointments, and to think about what is most important for you to discuss with your healthcare team. It is intended to help you make the most of the time you have with your healthcare team, so that you can work together to agree a care and treatment plan that is appropriate to you and your lifestyle.

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EXPLAINING WHAT IS MOST IMPORTANT TO YOU IN YOUR DAILY LIFE

The time that you will have with your healthcare team to discuss your care and treatment may be limited, so it is important to prepare for your appointment and think about what you would like to talk about.

One way to do this is to think about what is most important to you in your daily life. For example, this might include things like:



Spending
time with my
family and
friends



My job or
career



Keeping fit,
playing sport
or undertaking
physical
activities



Going on
holiday or
seeing the
world

It is important for your healthcare team to know this so that they can take it into account when they are talking to you about the care and treatment options that might be appropriate for you.

To help you think about what is most important to you, it might be helpful to think about the questions below and share your answers with your healthcare team. Do not restrict yourself or presume that what is important to you is not achievable.

What did I do over the last few weeks or months that I particularly enjoyed?



Was there anything that I wanted to do over the last few weeks or months, but was not able to because of my haemophilia?



What are my ambitions for the next few...

...weeks?

...months?

...years?



Once you have thought about the answers to these questions, try to think about the top three things that are most important to you in your daily life, with number one being your top priority.

The top three things that are most important to me in my daily life are:

1. _____

2. _____

3. _____



COMMUNICATING WHAT YOU WOULD LIKE TO ACHIEVE FROM YOUR CARE AND TREATMENT

Once you know what is most important to you in your daily life, you can think about whether there are any specific goals you would like to achieve. For example, these might include things like:



I would like to go on a long holiday next year



I would like to play football with my children once a week



I would like to get a tattoo



I would like to cycle to work



I would like to go for long walks with my family and friends

Alternatively, your goals might include things like:



I would like to have fewer bleeds



I would like to need fewer infusions



I would like to improve my mobility



I would like to be in less pain



I would like to think about my haemophilia less

To help you think about what you would like to achieve, it might be helpful to consider the questions on the next page and share your answers with your healthcare team.

How would I describe my quality of life at the moment?



Is there anything I would like to do that I cannot easily do at the moment?



Is there anything I do regularly that is becoming more difficult, or that I have stopped doing because of my haemophilia?



You might also find it helpful to use the tables below to write down what you have done each day for the last week, or over the last few months, to help you see whether there is anything you are finding more difficult or that you have not been able to do.

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
What did I do?							
Notes							

	1 month ago	2 months ago	3 months ago	4 months ago	5 months ago	6 months ago
What did I do?						
Notes						



Once you have thought about the answers to these questions, try to think about the top three goals, with number one being your top priority.

My top three goals are:

1. _____

2. _____

3. _____



You can use these goals to start a conversation with your healthcare team about your care and treatment. For example, you might want to start by explaining why you have chosen your goals, or asking your healthcare team questions like:

- Do you think these goals are achievable for me?
- How long do you think it might take me to achieve them?
- What precautions will be necessary, if any?
- If you do not think these goals are achievable for me, what do you think we could achieve?



DISCUSSING THE APPROPRIATE CARE AND TREATMENT OPTIONS FOR YOU

Once you and your healthcare team have agreed on the goals that are achievable for you, you might need to have a conversation about what that means for your care and treatment.

If your healthcare team thinks there is a need to change anything about your care and treatment, there is an opportunity to ask questions and make sure you are comfortable with the changes that they suggest. This could include changes to your treatment, physiotherapy, mental health support, or a referral to a social worker.

If your healthcare team suggests a new treatment option, you might want to ask questions like:

- What are the advantages and disadvantages of the treatment?
- What alternative approaches are there?
- What would happen if we did not make any changes to my care and treatment?

If you feel like you need some more detailed information to help make a decision, you might also want to ask some more specific questions like:

- How often would I need to use the treatment?
- Would switching to the new treatment have an impact on the number of hospital appointments I have? Could I achieve the same impact with my current treatment? If so, what would I need to do to achieve that?
- How easy is it to learn how to use the new treatment myself? Are there any educational resources about the new treatment that I should be aware of?
- Are there any risks or side effects I should be aware of, and how common are they?
- What is the risk of developing inhibitors to the treatment and how common is this?
- Is the treatment easy to transport and carry with me?
- Can the way I use the treatment be tailored to my lifestyle?
- Is there anything else I should be aware of if I switch treatments?

You might find it helpful to make a list of questions that you believe would be most important to ask if your healthcare team were to suggest a change to your treatment. The time you have with your healthcare team may be limited, so try making a list of questions you would like to ask with the most important question at the top.

The questions that it is most important for me to ask my healthcare team about any potential change to my treatment are:

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____



There is space at the end of the guide for you to take notes of the conversations that you have with your healthcare team.

UPDATING YOUR HEALTHCARE TEAM ON ANY CHANGES TO YOUR HEALTH

During your appointment with your healthcare team, you might also be asked questions about any recent bleeds you have had, how well you are adhering to treatment, and your wider health and wellbeing.

To prepare for your appointments, you might find it helpful to think about this in advance. The following checklist might help:

Ensure you have information at hand on previous bleeds you have had, or any changes to your mobility

Ensure you take along tools such as diaries or apps with you when you go to the appointment, and make sure those are up to date

Note any recent changes to your health or lifestyle that you want to discuss with your healthcare team

Make a record of any health issues you have had with your haemophilia treatment, and any other medicines you might have been prescribed for other conditions



APPOINTMENT NOTES

Date of the appointment:

Who was the appointment with?

Key points to note:

Advantages of any changes we discussed:

Disadvantages of any changes we discussed:



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