

# Being heard, achieving what you want and living well

In the UK, everyone with a diagnosed bleeding disorder has access to a consultant-led clinical team to support them in the choices they make.

One of the ways of being heard by your clinical team is by being able to advocate for yourself.

Self-advocacy is about knowing how to communicate what you need and want in a way that gives you the best chance of getting a positive result. It's also about knowing your rights and responsibilities.

Underpinning self-advocacy in your interactions with your clinical team is knowing that as a patient you have a right to:

- State your own needs and set your own priorities
- Be treated with respect as an intelligent, capable and equal human being
- Ask for what you want
- Express your feelings, opinions and values
- Say "no" or "yes"
- Make mistakes
- Change your mind
- Say "I don't understand" and ask for more information

When advocating for yourself, it helps to be prepared, be informed and be effective.

## BE PREPARED

Before your consultation, write down what you want to achieve from it (your objectives):

- What **must** you achieve?
- What would you **like to** achieve?
- What concessions could you make that would still enable you to feel happy with the result?
- What are the objectives of the clinical team and how much room do they have to meet your needs?

## BE INFORMED

Having identified your objectives, try to find out:

- The supporting information you will need (the Society will be a good start)
- The information your doctor/clinical team will need from you – remember, no-one knows your life better than you do!

## BE EFFECTIVE

To communicate confidently and effectively with your doctor:

- Be polite
- Stay calm
- Be objective and try to avoid making judgements
- Avoid personalising issues. For instance, if your consultation starts late, don't say "you really stress me out when you keep me waiting" instead, try saying "I get really anxious when my appointments run late"
- Be clear and specific in your requests: "I would like to speak to you about switching to an extended half-life factor" rather than "I was wondering whether I could change to a different product"
- Stay focused – stick to the point you want to make and remember the reason you are consulting the doctor. Don't be afraid to repeat your request
- If your doctor uses jargon or abbreviations you don't know – stop him/her and ask them to explain
- Reinforce positive results. When you get a response that shows you've been heard, acknowledging it can be helpful

### You can affect decisions

Be an equal partner in your own care

### Know what you want

Be well prepared and be specific

### Attention through information

You know most about your life and how to live it well

### Communicate effectively and assertively

Repeat and affirm and avoid aggressive/passive

ASKING  
FOR  
WHAT  
YOU  
WANT



# What is Haemnet?



**Haemnet is a registered charity (No 1152241) that was formed in 2013. We believe that excellent care should be an everyday experience for people with bleeding disorders. We want to see a vibrant, educated and interactive community of nurses, physiotherapists and other professionals sharing knowledge and engaging in research designed to improve the lives of those affected by bleeding disorders.**

To achieve this, we spend our time

- running training courses, conferences, workshops and meetings for healthcare professionals
- sharing peer-to-peer knowledge through publishing (we run *The Journal of Haemophilia Practice*, an open-access, peer-reviewed journal, that is available at [www.haemjournal.com](http://www.haemjournal.com)), and
- getting involved in patient-focused research.

Haemnet is governed by a board of Trustees, all of whom have a close connection with haemophilia care: Debra Pollard, Cathy Harrison, Paul McLaughlin, Dawn Prideaux de Lacy, Liz Rizzuto and Jamie O'Hara.

Day to day activities are run by a small team comprising Mike Holland, Sandra Dodgson and Luke Pembroke. They in turn work with a wider team of freelance consultants, writers, editors, researchers, statisticians, graphic artists and designers and web developers.

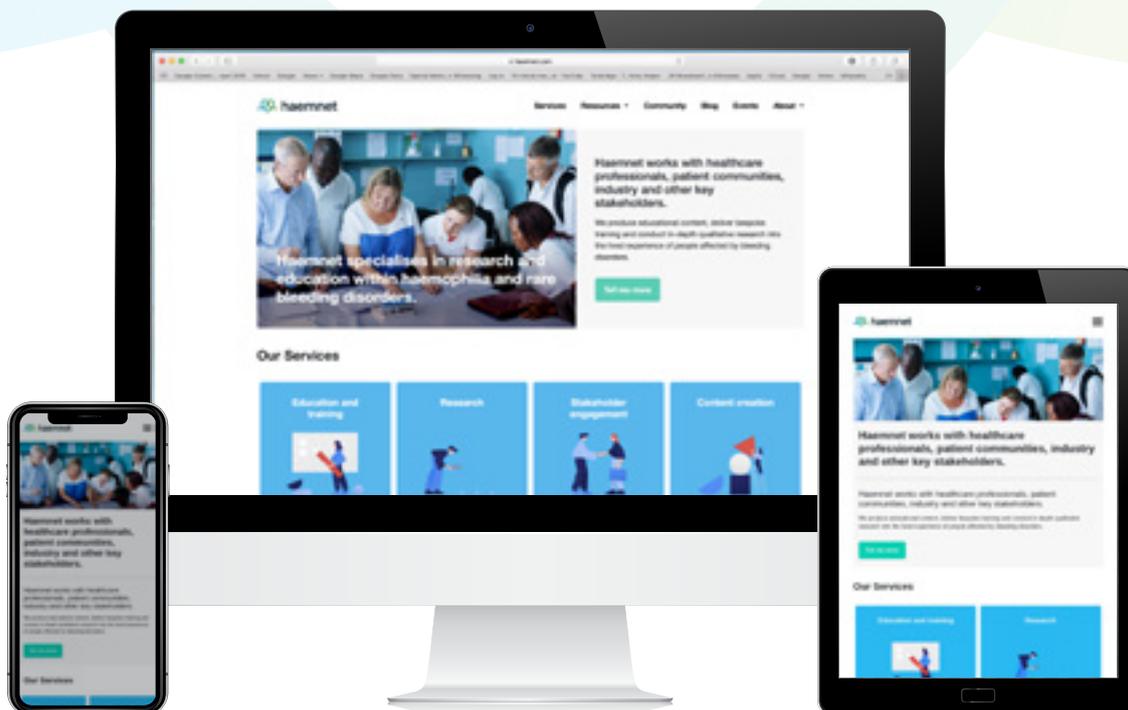
Dr Kate Khair recently stepped down as a trustee of Haemnet in order to become our Director of Research as we have a number of new patient-focused research studies about to get underway. Most of our research is based on capturing real-life stories from real-life people like you – and let's face it, who wouldn't want to sit down for a chin-wag with Dr Kate?

## Get involved

If you'd like to take part in our research projects, and to keep up to date with Haemnet activities, you can join our mailing list (<https://subscribe.haemnet.com/maillinglist>).

In addition to our education and research activities, we also try to fund investment in individuals (we're currently supporting one nurse to undertake a PhD) and their local projects, and sometimes this means we fund local patient events.

In December, the Haemnet team will be revisiting Uganda where we'll be teaching healthcare professionals and helping the Haemophilia Foundation of Uganda to run a patient awareness camp. While we are there, Luke Pembroke will also be making a documentary on the lives of people with haemophilia in Uganda. We'll be blogging and tweeting (@haemnet) all the way, so be sure to follow us.



If you'd like to know more about Haemnet, what we do and how to get involved in our projects, look at our website ([www.haemnet.com](http://www.haemnet.com)) or email us at [hello@haemnet.com](mailto:hello@haemnet.com)