

**HAPPY
1/2 HOUR**

with an expert in haemophilia care!

Join and have your questions answered!

Of course
I talk to myself.
Sometimes I need
expert advice.



“How to Become an Expert Patient? Communication with your NMO and HTC”
with expert patients Miguel Crato, Portugal and Jim O’Leary, Ireland

HOW TO COMMUNICATE WITH THE HTC’s?

First of all – you are the world’s greatest expert on you, and you should always remember this, but you need to share this with your care team, so that they also appreciate how important your knowledge about you is to them, while they are looking after your care. So how do we best do this?

Step one - understand the structure of your haemophilia treatment centre (HTC)

One of the first things is to understand the structure of your haemophilia treatment centre and the structure of the care team. Make some lists of who does what in the care centre and within the care team. **Who are the ones responsible?** Get their telephone and email contacts if you can, so that you know how to get to them quickly if you need to. The open lines of communication are very important. You need to know who the lead doctor or lead doctors in your HTC are. Who are the senior haemophilia nurses? Which ones are good for infusions and which ones to avoid? Who controls the supply of your products? Is there somebody in the centre who will make your product available to you, somebody who coordinates the deliveries etc.? Which secretary works for the lead doctor – it is very important to get to know the secretary, because you can’t always contact the doctor. Which secretary is reliable if you need to make contact with somebody? Make sure that there is a secretary who will put you through on the phone with somebody and make appointments for you, and write letters for you – if you need the letters for travel etc. These people are important.

If your haemophilia treatment centre has a dentist and a dental nurse- you need to get

to know who they are. You need to know who are the physiotherapists on your haemophilia care team- identify the good ones and get to know them. Physiotherapists can be very useful to you as they can provide really useful support, as well as they can speak with the doctor if you need something extra.

Now that you have identified the key people, you need to get to know them personally. It is not enough just to know their names. For example, they will often be speaking at the events that you could attend. If you are attending, go and sit in front, where you can ask them a question, and they will begin to identify you! When you see them at clinic or at the hospital, always say hello, even if you are not dealing with them on that day. **Always say hello and try to speak with them, so that they remember your face and start to recognize you!**

If you can, then use regularly their email and telephone contacts to send them questions about your treatment. This means you are maintaining a regular contact with them.

Reach out to other people with haemophilia and find out which people in the care team they find it the best to get things done, and use their experience and their knowledge. They will also have good information for you.

It is said that he who shouts loudest, is heard. So, make sure you are heard and you are seen by the key caregivers and you

will build a new relationship with them!

Step two - know your own condition

The second thing that is very important is to know your own condition. Every caregiver will respect you more and be more attentive to you if you will be able to discuss your own condition and needs intelligently with them. If the doctor does not know your particular needs, they will prescribe what is best for the average patient. But we are not average- each of us have a unique patient profile and a set of individual needs to be met. You need to take control of your medical care! Educate yourself about your condition and the treatment options available by reading leaflets or online publications which are produced by your NMO, EHC or WFH. These are excellent sources of information! Each time you meet with a caregiver from your care team, discuss your condition and ask relevant questions about your current treatment, as well as about what future treatment options you might need. Know what your status is now versus the last time you met with them – what has changed, what is better, what is worse, what new target joints do you have, what physiotherapy or other support might you be needing at this time. If you have not had or have failed ITI in the past, can it be tried again?

Why did it fail, could something be done differently? Could we try something new?

Be especially knowledgeable about the novel therapies, discuss them as an option for you and how useful they may be for you. If they are not available for you, find out what are the barriers for access and then work with your NMO to overcome these barriers and make pressure to the relevant stakeholders to make these novel treatments available.

The **Novel Treatment Product Newsletter** that is produced and updated by the EHC is an invaluable source of information and is available on the EHC website and also some NMO websites. It covers all the current novel therapies, both licensed and those on trial.

Always be ready to point out the areas where your treatment is not optimal and suggest changes which will help you to improve your quality of life.



Knowing your condition becomes even more important when you have to deal with clinicians who are not specialized in haemophilia. Most of them will not have encountered a haemophiliac before, let alone a haemophiliac with inhibitors. They will not understand even the basic facts about your condition, so you have to be alert and question them closely about any procedures or medication they are prescribing. Insist that they liaise with your HTC team before commencing with any procedure or medication. This is vital and can avoid some very costly mistakes. The more knowledgeable you are, the more attention they will pay to you.

Step three - get involved with other people who have bleeding disorders

The last and final point is to get involved with other persons with haemophilia. If you know somebody who is not involved in the NMO, encourage them to get involved. Because much of the information that you need is provided at the events organised by the NMO and by those who attend the events, be it the speakers or other patients. Build connections with other persons with haemophilia and persons with inhibitors, because they have knowledge. Volunteer for the events of the NMO when you can, volunteer to attend the EHC, WFH and even pharmaceutical company events. This will increase your knowledge and your confidence to advocate for yourself and for the others who need a voice to represent them.

You should also learn about other rare bleeding disorders, because they share many of the challenges that we do. They also have some different challenges that you may be able to help with. There are some very inspiring people in the women with bleeding disorders group, the von Willebrand Disease group and other. **Try to mix with young and old, and try to get different perspectives on living with rare bleeding disorder, because we all have different experiences from different times.** Encourage your loved ones and your caregivers to prompt you and to push you to do more for yourself and to take more control of your care, because it helps them as much as it helps you.



Is there a point of overdoing the “door that squeaks the loudest”? Is there a tipping point, when the healthcare professionals will think you are trying to do their job?

The communication is a two-way thing. You also need to listen to the doctor’s perspective. You need to find out what they are

thinking and what is their view and then you don’t tell them they are wrong. You can express your views and what you think can be best for you diplomatically. When I say “he who shouts the loudest...”, I don’t mean you need to shout at your doctor. I mean- ask a lot, talk to them a lot and they will then respect you. They will also pay more attention if they know you are somebody intelligent, who knows your condition and who knows what you need.

You are speaking from your Irish experience. How would you approach this in a different culture, different healthcare system, where the hierarchy is different and people may not be able to do this what you are describing?

What I am describing has taken a long time in my life to build up. Of course, in Ireland we are very lucky, we have very good system, very good care and treatment centres.

But I think basic principles still apply, for example, about learning how things work in your treatment centre, in your country, working with your NMO to improve things. Knowing your condition is the most important thing because every doctor, even the ones who don’t know haemophilia very well, will appreciate if you can tell them something or if you know some piece of information about something that is better in another country. You can then ask them if there is a way that this can be made happen in your country. These are all helpful things. Of course, we are all starting from different levels, but the principles are the same.

How would you stimulate people to educate themselves and to read the materials, in the time when people don’t have motivation to read or they say they find it very difficult to understand the science?

This is the very reason why the patients should engage with the NMO, who can then facilitate and provide support in this process of education, help understand about the novel treatments, how they work, what they are about etc. Also, getting to know other persons with haemophilia (and inhibitors) who are in your area, who you can discuss with and who can help you understand. But you need to reach out. If you don’t reach out, you will stay in your own box. The National Member Organisation is the central point – they can point you to other facilities.