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## “Psychosocial questions in inhibitor care”

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# EMOTIONAL HEALTH & embracing change

It is difficult to say what exactly is good emotional health, but could you offer us some guidance for a patient with an inhibitor and their caregivers and how we can work to achieve good emotional health and live positively with a chronic illness?

I realise that all the people listening are actually experts in haemophilia with inhibitors, and particularly they are experts in their own condition. But I will share with you what I have learnt from other patients who have been living with haemophilia with inhibitors.

If we are thinking about emotional health, I would say that **the strongest emotional health often is present and demonstrated in the people who have had to undergo the most difficult situations.** So, ironically, it seems that good emotional health does not come out of having an easy life.

The simplest form is that good emotional health is probably a combination of two things: one is a degree of acceptance around things which are perhaps impossible to change, and it is equally a degree of optimism about the things which might not have changed yet, but are possible to engage with.

**So, it is both - acceptance and courage to make changes both in your own life but also in your own context.**

Those who are mostly affected by inhibitors are men, who do not necessarily tend to overly analyse their feelings, and the caregivers, mostly women, who by assuming the role of a caregiver often tend to forget about themselves. What is the solution here?

Let's take a couple as an example. The man has haemophilia with an inhibitor and his wife is the caregiver. **What often happens is that they are trying not to overburden and worry each other.** Therefore, the things that actually are happening do not get talked about and each is trying to second-guess the other. And sometimes it can feel quite difficult to make opportunities to have deeper conversations. **I think the first step, or the most creative part of it is to see, how to make an opportunity to have one of those conversations to actually try and find out what really is going on.**

I live in the UK, where the population are the masters of the understatement. When you ask them how they are, they say they are fine. Fine means not really good, but not really bad. Fine does not mean anything. Therefore, often I might ask people – *what kind of fine?* Just because people need encouragement to speak out.

**What are some of the worrying signs?** A sense that something is going on that is difficult, but not having a discussion about it. I think, for caregivers it can often be burnout, a sense of really **forgetting to look after themselves**, just in the most

minimal and basic kind of ways. But also **losing their joy in life.** When any of these things are happening, something needs to change.

### WORRYING SIGNS

- **Sense that something difficult is going on, but there is no discussion about it.**
- **Forgetting to look after themselves.**
- **Losing joy in life. Something that brought joy does not spark interest anymore.**

### How to motivate them to ask for help?

First of all, it is sometimes hard to admit that something is very difficult. One thing is the lowness of mood, but more challenging is that someone might find it difficult to identify feeling bad. They are not necessarily feeling bad, they are not feeling anything. They feel a kind of emptiness. And I always say that emptiness is a feeling. Because they find it difficult to talk about the emptiness, **they often find it difficult to reach out.** The first impetus might come from someone who cares about them and notices the changes, notices that their joy in life has diminished, that some of the things in life that they have enjoyed do not interest them anymore.



**I am fine**

Thinking of a couple I know who have a fantastic relationship, **I asked the husband what their secret is. He said when something is going on and his wife would say that everything is fine, he would persist and not give up until she talked about it. But it does not have to be the partner, it can be a family member, a sibling, a friend, whoever it is. It is just important that people are keeping an eye on each other and they are prepared to persist with a slightly uncomfortable conversation.** And often one of the things is just to say to people – you know, I really think you are suffering. Because people sometimes feel bad, they feel guilty about not being as joyful as they think they should be. It is just about acknowledging that underneath this all is actually quite a lot of pain.

**What kind of fine?**



**Now with emicizumab becoming more and more available, we see fantastic results in terms of clinical response. Also, gene therapy is on the horizon, which may completely alter the scene. But I have heard several things that may be difficult. For example, still avoiding doing sports or anything too intense, despite of emicizumab, just because of habit of caution. Another issue is being concerned about one's identity if gene therapy cures haemophilia. What would be your advice how to best embrace such radical changes?**

**It is about consciously taking the middle way.** We have a lot of new treatments coming. It is trying to pick your way down the middle of that. **You are finding yourself in a position where you have hopefulness, but you add in a huge dollop of realism as well - just to avoid disappointment.** So, it is about managing that swing between those two.

It seems that you get something, but you always lose something out of it. Because any change, oddly even the change to something that technically is better, has an impact. So, firstly acknowledging that there is change and that you may need time to readjust and that you may have ecstatic feelings that things have changed, but at some other times you may feel sad for no reason whatsoever.

I think that identity is a really interesting thing and that changing identity is a whole process.

**So, whatever new treatment you are on, just make a little space for the possible little ups and downs.** All of this is actually a bit challenging, because we are balancing between risk and potential gain. For somebody that is on emicizumab it may actually feel awkward about changing a pattern that they have been on for a very long time. So, it is going to be what I call a micro-experimentation. Because anything much more than that might bring up quite a lot of anxiety. It is trying to get the trajectory of moving the right way, but somehow the experiment is managed. Trying new things, but not swinging the pendulum too much to the other side without any regard.

**Any change, oddly even the change to something that technically is better, has an impact.**