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## “Psychosocial questions in inhibitor care”

with psychotherapist Ms Nicola Dunn, Royal Free Hospital, London, UK

# CHALLENGES OF THE OLDER GENERATION

One of the things that I feel as an older haemophiliac is that there is a big difference between how the older haemophiliacs deal with their haemophilia and how the younger haemophiliacs do so. When we grew up with no treatment and in a society where there was a lot of ignorance about haemophilia, including ignorance in the medical profession, we did not tend to broadcast the fact that we were haemophiliacs and we did not discuss it. The younger people have the advantage now that they can feel more confident to discuss this kind of things. Also, a lot of us went through the 80's when the contaminated blood scandal was going on, and at that point you definitely did not tell anyone that you had haemophilia. That was a bad time with employers etc. you did not discuss these kinds of things. So, if we think about psychosocial issues, I think there is a whole set psychosocial issues that revolve around the older generation of haemophiliacs and a different, maybe slightly less heavy set that revolves around younger people.

I am really glad that you have raised that issue! I think that some of our older gentlemen had to create kind of a wall, in which they presented a **version of normality out to the world in order to be able to work, to not create what they would call fear in the workplace**. They had to learn to have, in a survival sense, a separation off from these kinds of things and they got very good at that. I would also say that **this portion of patients are very stoic. They have really strong skills in that area**. They have actually had put up with a lot of pain, a lot of difficulty, a kind of feeling that if their communities knew what they were dealing with, they might be rejected. And **nobody ever wants to feel rejected by those who they work with or those who they love**. So, they have actually dealt with a lot. But then when we are asking-What is going on? Do you want to talk about it? – often that is the last thing that someone who has gone through those periods really wants to do.

However, it is about catching up a little bit with the fact that we are in different times and sometimes even the survivors of the difficult periods need support and need a bit of a help.

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**The divide then is contrasted with the younger patients, because they have not had to go through that. They have a different relationship with personal information and confidentiality, particularly online. And sometimes it serves them and sometimes it gets them into very painful places.**

But I think even though they have a very different experience, it is very important that we do not forget what the older patients have gone through and what are the learning points that they have to share with the community.



**I don't want to talk about it!**

**...my experience as a haemophiliac...**

