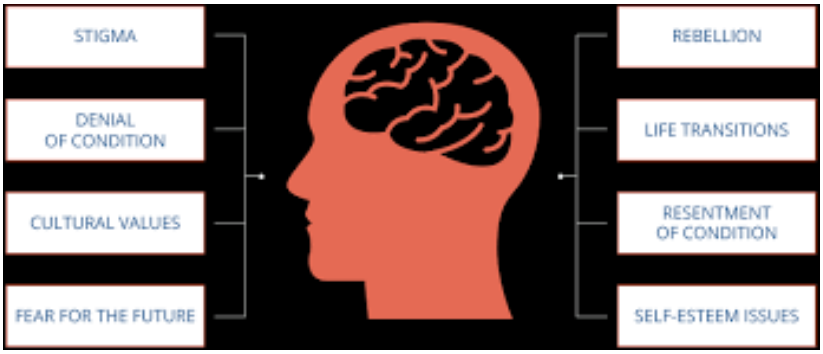
EHC NOW!

# Psychology in haemophilia: keeping one eye on the future, the other on what remains with us

*Interview with Nicola Dunn, Individual & Family Therapist, Specialist in Haemophilia, Katherine Dormandy Haemophilia Centre and Thrombosis Unit, Royal Free Hospital*

*By Raia Mihaylova, EHC Communications Officer*




Having haemophilia is a journey that can bring physical, mental, emotional and social challenges on top of the issues that come with everyday life. This makes psychosocial support all the more important for people with haemophilia, yet it is the least integrated area in comprehensive care. In an effort to shed more light on the topic, I sat down with Nicola Dunn, a psychotherapist in the field of haemophilia, to talk about the concerns the different age groups within the community have. While each experience is unique, there are many common traits that are present for everyone from diagnosis to adulthood.

***RM:*** *You have worked as a psychotherapist in the field of haemophilia for longer than 18 years. What are some changes you have observed over that time – are people reaching out more, have the issues changed?*

*Nicola Dunn*

**ND:** In terms of people's openness towards support for their emotional well-being, yes, it has changed quite a bit. I think there are general cultural factors that are operating in Europe, which have encouraged that. Whether that is through the media or through people in the public eye who appear to have quite successful lives coming out and talking about the fact that they struggle with their emotional well-being, I think there is a greater comfort with it, particularly for men, which is fantastic.

The issues have also changed. When I was doing my placement, the pressing issues were around the tragedy of HIV infection and later, with hepatitis C. In that situation, it was people having a diagnosis of HIV, whether that was in a family with their son or whether it was an adult man. They were coming to terms with the condition, which they had received through their treatment product. So it was the shock of that, it was dealing with not having a lot of information available, also for the local communities. There was a feeling of not being able to be "out" about their diagnosis. It was something that they had to hide in order to protect their family or in the case of parents, to protect their child from what might happen at school

and so on. It was a very difficult time for people in the haemophilia community. The treatments were new and not as sophisticated as they are now. People were losing friends who had haemophilia within their cohort. Some obviously weren't affected, which led to a kind of survival guilt as well.

There were a lot of things that were happening at that time period. We didn't have recombinant treatment products, they were only plasma derived. We didn't have prophylaxis in the same kind of way as we do now. If I am to contrast that with the issues that people come to me with now, the main one is the development of inhibitors. Something that the haemophilia community has always had to deal with is that not everybody gets dealt the same hand of cards, in a way. Their haemophilia is unique, the treatments that work for one person don't always work for another person. You are part of a community but it doesn't mean that you are all having quite the same success with the treatments that are available. I think that is something that we need to bear in mind. Also HIV has obviously not gone away and it is something for us not to forget about, because otherwise it feels as if we are leaving those patients behind. We are always focusing on what is new and I think that we need to keep one eye on the future and on what is unfolding and we need to keep another eye on what remains with us.

***RM:*** *As you said, the issues are very different whether they are based on the history of haemophilia or ones that come with different age groups. Can you share some of the most common psychosocial concerns that people with haemophilia have within each age group?*

**ND:** Because the patient cohort I work with is in London and London is hugely multicultural, our department is multicultural and our patient group is multicultural. We have a group of patients who have

been born in the UK and then equally, we have another significant group of patients who have come to the UK at a certain point of time – often as an adult or maybe as an older child – so they have had a different treatment history. We have people who have had the advantages and resources of excellent haemophilia care and we have others who have had to manage with what was available to them. Now they find themselves in the same patient group but with a very different impact on their body and on their psychological issues.


# Childhood

**ND:** If we were to go through the different age groups, starting out with the first years of a young boy's life (0-5 years old), I would say the challenges are having the whole family coming to terms with the haemophilia and the young boy's development within the context of friends and school. It is about "how active can I be?" and "how can I discover myself?" because to a large extent, you find yourself through your environment. How much is allowed and what is not allowed? Traditionally, when we had the plasma-derived products and it was basically on-demand rather than on prophylaxis, the general thought and advice was "no sport." So no football, none of the team sports that are popular in the UK and Europe were allowed. Now it is different, we even recommend sports. Probably not boxing or rugby because of the number of injuries, and while we do encourage involvement, it does require a commitment to prophylaxis. So it has gone from a "no" to a "yes, but…."

# Teenage Years

**ND:** When we get into teenage years, I always say that at this point, we have a new patient. We need to consider this because the treatment responsibility is being transferred over to the teenager. Often, the challenges are around prophylaxis treatment. If they had good treatment in the past, the young boy may not remember having particularly significant bleeds. Sometimes, unfortunately, it may be necessary for the patient to have an inconvenient bleed in order for them to think "I really need to commit to my treatment product."

Then there are some slightly new things – treatment was previously less effective and there was damage to joints at an earlier age. What we have now is an increasing pressure on young men around body image. They look to their icons, either from the sport or music industry or wherever, and body image is a big part of that. Particularly for patients who may have come from elsewhere and have had less availability of treatment, or even UK- based patients that maybe didn't adhere to their prophylaxis, if there was any change in their limbs or something else, they are very conscious of that. I think we really need to consider that this sort of pressure of body image that women are well aware of has also transferred over to our young men.

# Young Adulthood


ND: The issues that arise in the 20s and 30s are around building a career. Most young people these days have an interest in exploring the world and want to travel, and then they have to again consider their haemophilia when making a choice: availability of treatment product and treatment centres, could they work abroad and if so, where? So they are facing a wider world. Once again, at each transition the question

is “and how does my haemophilia impact me now?” Then of course it’s also about choosing a partner and answering questions about having or not having a family.

Another thing for young people is that, generally, it seems that anxiety is quite a big issue. Normally, when young men come to me, the words they would use are “I feel stressed.” So we would try to unpack what that stress is – whether it is about identity, whether it is about a feeling that the haemophilia is stopping them from doing something that they want to do, whether it is unhappiness about body image, whatever it is. That would often be the entry point and it is good that they have a word for it because that enables them to ask for help and support.


# Adulthood

**ND:** In the 40s to 50s there is a mid-life evaluation that happens to most people. People are thinking about how they want the second half of their life to be. Then we move on to ageing with haemophilia, which previous generations didn’t necessarily do, as their life expectancy was reduced. We are looking at joint health and for patients that didn’t have treatment products as young people, that is obviously more problematic. We are thinking about what point is the right point for someone to have a significant orthopaedic intervention, like a joint replacement. People normally choose it when they feel that the pain or the impact on their lifestyle is such that they are prepared to go forward with the process.

Understandably, there are concerns and it’s a little bit like the treatment – you don’t have any guarantee about how this intervention will turn out for you. We can talk about what happens in populations but we can’t say how it will be exactly for the individual. One guarantee, however, is that one knee, for example, will be different to the other knee. We don’t want people to be disappointed by the intervention but rather that they feel like they have chosen it with enough information. Part of my job is to accompany them through all these stages.

Overall, throughout all the age groups, patients sometimes come with a lack of trust, they just feel like they haven’t been given the full information. Or they have had a lot of trauma as a child. This can be something like being locked in during the day while their parents are working because it was a concern that they would hurt themselves and the family wouldn’t be able to pay for the treatment factor. All of these things impact who a person takes themselves to be and what it means to have value as a human being. For example I see patients who feel guilty because they have seen their families struggle financially to pay for treatment product. There are a lot of things to be worked through.

***RM:*** *Talking concretely about women who are carriers, they often feel a lot of guilt that they have passed on the gene to their child. What do you say to these mothers?*

**ND:** The first thing is I get them to tell me about their experience with that because it is often unique. Then I would really be in dialogue around two elements: one, we all know the scientific facts and the fact that it’s not the parent who chooses to pass on the gene. We know that but we need to stress it more. That’s the scientific side of it. Then we look at the emotional side. I would say that the reason they feel guilty is because that’s a natural process for a nurturer. Guilt gives responsibility and it is kind of built into us.

I would also look at it from the gender point of view. There was an interesting paper, which looked at male response to guilt and responsibility. Men are often more skilled then women at developing a narrative, which considers aspects like fate and destiny and actually puts responsibility outside of the parents.

Women need to have an opportunity to talk about it. It's about how we create a new narrative following the diagnosis and in going forward. It is looking at it from a perspective that your child's life comes with these opportunities and these challenges. They won't actually exist without having this particular genetic composition.

***RM:*** *I have read on a few occasions that some patients have noticed that when they are in a good mood and high spirits, they experience less pain or joint bleeds. Do you have any observations on that – can state of mind affect bleeds?*

**ND:** There is a physicality to pain. But my experience is that mood is a magnifier. A low mood would magnify pain and a more buoyant mood would actually ease it. There are things we can do in actually harnessing mood and creating buoyancy. We may very well therefore, not always but many times, get an accompanying effect in patients' experience with pain.

*For suggestions of additional resources or contact information of psychologists in the field of haemophilia, you can get in touch with the EHC at office@ehc.eu*