

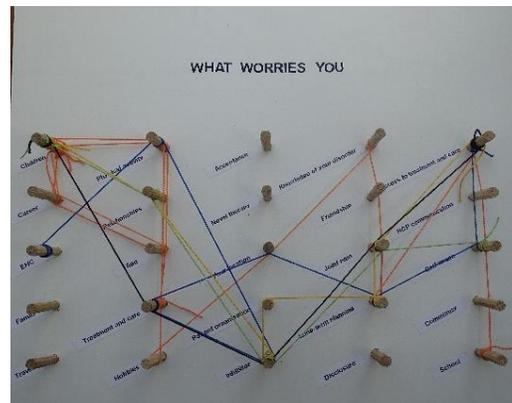
EHC NOW!



Comprehensive Care in Haemophilia: Intimacy and relationships

Interview with Greig Blamey, Senior Vice-Chair of the World Federation of Hemophilia (WFH) Musculoskeletal Committee, Interview taken by Alison Dougall, dentist and member of the EHC Medical and Scientific Advisory Group

Fighting for access to quality haemophilia treatment and care, frequent infusions and the worry of an inhibitor: though these issues are faced by all in the community, when filtered through experience everyone has their own story with rare bleeding disorders. What challenges you? What do you want to see changed, what makes you happy? At the recent World Federation of Hemophilia (WFH) Congress, the European Haemophilia Consortium (EHC) explored these questions for insight into what is important on an individual level. Tracing their answers with a piece of yarn, patients, health care providers and caregivers left a “footprint” of what matters to them in their experience with rare bleeding disorders. While taking part, many participants noticed one answer we had failed to include as an option - intimacy and sexual health. Often avoided as a topic, having a bleeding disorder impacts intimacy and leaves many questions on how to integrate it in personal relationships.



At the WFH Congress, Alison Dougall, dentist and member of the EHC Medical and Scientific Advisory Board, caught up with Greig Blamey, Senior Vice-Chair of the WFH Musculoskeletal Committee, after his presentation on intimacy and rare bleeding disorders. His message? Patient lives have more than one side, involving psychosocial concerns, dental concerns, musculoskeletal concerns, and so on. Just as important is the intimacy concern and it is time to broaden the conversation.

AD: First, congratulations on your recent role as Vice-Chair of the WFH Musculoskeletal Committee. What are your visions for the Committee?

GB: What I really want to see is the Musculoskeletal Committee to form stronger bridges and links with all of the other interprofessional committees that exist. We are seeing a real movement towards personalisation and individualisation of care for all people with haemophilia and other rare bleeding disorders and there is a lot more we could be doing if we connect our efforts. We can all learn from each other and find out what it is we can do to help each others' work.

AD: Yes, the care has to be completely comprehensive...

GB: It is interesting because patients have a full life that involves psychosocial concerns, dental concerns, musculoskeletal concerns. The conversation needs to be broadened. Just one example I heard today during a presentation of how elbow range of motion and upper arm mobility and

WORRIES IN MEN WITH BLEEDING DISORDERS THAT CAN AFFECT RELATIONSHIPS AND INTIMACY

- Management of different bleedings even when in prophylaxis during intercourse
- Management of treatment of HCV, HIV
- Pain management
- Disclosure
- Self-image

- Surgeries
- Fear of the future, ageing
- Chronicity and family planning

function impacts the ability to maintain proper oral health. It is just a perfect example of how two disciplines can be paired together.

AD: You did a presentation earlier on intimacy and relationships when having a rare bleeding disorder. Will you talk a little more about that?

WORRIES IN WOMEN WITH BLEEDING DISORDERS THAT CAN AFFECT THE WILL TO ENGAGE OR TO HAVE A RELATIONSHIP

- Facing cultural prejudices
- Self-image and perception
- Heavy periods and pain
- Post coitum bleedings
Nose and gum bleedings, lots of bruises
- Carrier of gene, marriage and family planning
- Pregnancy, postpartum bleeding

GB: Intimacy and the sexual health of people with haemophilia has been an interest of mine for a long time. It first appeared in the programme of the WFH Congress in 2006, so only 12 years ago did we really start talking about this openly. A lot of people have questions: the patients and the health care providers. This is something patients don't feel necessarily comfortable talking about and often we as treaters, feel that since they don't bring it up, they don't want to discuss it.

There is a range of issues to discuss: everything from the psychosocial barriers to communicating with partners, to the physicality of sex and just issues that come as a child develops into an adult, the way that their sexual development occurs.

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The elbows are maintained in close to full extension
As the body weight shifts forward this position is accentuated
This will tend to force the elbows further into extension potentially pinching existing synovitis and/or cause a new bleed

Passive stretch on the iliopsoas increases tension forces and active contraction will occur with the muscle in a lengthened position

AD: What is the best way in terms of going forward with educating the community?

GB: Maybe the best way is to make sure that your patients know that this is something we want to hear from them if they are comfortable to bring it up. They should choose who from the treatment team they are comfortable with - it may be that they are more comfortable with their physio, it may be their nurse, their haematologist or their dentist. Bring it up and if that person doesn't have the answers, they will help you connect with the right person. What matters is that these issues are

mentioned because knowing this information is important – what positions are more suitable for people with rare bleeding disorders, how to minimize your chance of a bleed during sex. There are many available resources.