

community nursing service who could deliver this? Would they be open to education from the HTC on managing a bleeding disorder?

With so many new challenges in this area, the experience of the expert presenters in this session provided some really relevant and practical points, both from the perspective of the patient and the HTC. The session wrapped up with encouragement to view the HFA Getting Older Info Hub, where there is information covering many of these new issues.

My thanks to Jenny Lees from HFACT for chairing the session. Jenny has been a valued member of the HFA Getting Older Project Advisory Group and continues to support its work.

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## Pain and haemophilia

*Nicola Hamilton*

### Plenary 3 – Pain

Chair ~ Dr Liane Khoo

Pain in haemophilia ~ Paul McLaughlin, UK

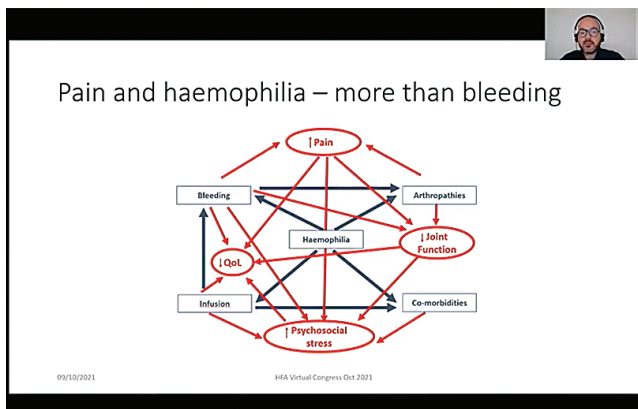
I enjoyed this presentation on pain and haemophilia as Paul McLaughlin, a leading haemophilia physiotherapist at the Royal Free Hospital in London, skilfully took us through an overview of pain and its complexities.

Paul explained that pain is complex and pain in haemophilia is even more complex. Pain can be acute from a joint or muscle bleed or it can be chronic from haemophilic arthropathy. For people with haemophilia, historically pain has been seen as a sign of bleeding and this has been taught from an early age.

Often pain is seen only through a biomedical lens and seeing pain ONLY as a correlation between joint health and joint status could be limiting.

Pain, however, can be distressing and it can interrupt your life and become a real problem.

In haemophilia, pain is more than just bleeding. Pain can be both acute and chronic and both acute and chronic pain can happen at the same time. Pain can be distressing and interfere with daily mobility and being able to attend school and work.



Pain can increase with age and can increase with the number of joints affected by haemophilic arthropathy. It can increase when mental health and wellbeing is affected and it can increase when your quality of life is impacted or activities of daily living become more difficult.

Paul explained that pain is not linear. Yes, it can be caused by an injury or bleed, but it can also be influenced by personal, social, psychological, familial, and medical issues.

And what I thought was incredibly important is that pain is always a personal experience, and everyone’s experience of pain is different.

## ASSESSING PAIN

Paul highlighted that when looking at pain, assessment is important and best addressed in a comprehensive care setting by a multidisciplinary team. Because pain in haemophilia can be complex, it is very important that we try and ascertain which pain we are assessing e.g., is it acute pain from a bleed or an arthritic pain or is it a pain from another cause. A thorough physical assessment is essential and as a physiotherapist, this for me is paramount. Working out what pain we are assessing can be difficult, so an assessment also means listening and talking to the person with haemophilia and trying to gain an understanding of their pain and how it is affecting them and their story.

## MANAGING PAIN

Paul made some key points about managing pain and drew on not only the haemophilia world when it comes to pain management but the wider pain community. I think as clinicians we need to get better at looking beyond the haemophilia space, especially when it comes to chronic pain and its complexities.

Managing acute pain in haemophilia can be relatively straightforward. Acute bleeding episodes tend to happen at home and over time the person with haemophilia develops strategies that work for them. In a sense they become the expert in treating their bleeds and what works for them should not be discounted. It is important however that when the pain management strategies being used at home are not working, the person needs to contact their Haemophilia Treatment Centre (HTC) for further help and advice.

Managing chronic pain in haemophilia needs to be a partnership between the person with haemophilia and the comprehensive care team. It should be framed as health maintenance and person-centred, and consider the biological, psychological, and social influences that there may be on that person's chronic pain. It is about finding what matters to the person with haemophilia and working towards it, being goal orientated and potentially using a mix of approaches. People with chronic pain should be encouraged to move every day, even if it is just a little bit. Pain is not always as sign of damage or that things are getting worse - remember exercise is safe for most people with haemophilia.

The take home messages for me from this presentation were:

- Good chronic pain management takes time – it is not a quick fix.
- It is important that the comprehensive care team and the person with haemophilia work in partnership in a person-centred way and that it needs to be a team effort.
- Pain is burdensome and everyone one has their own lived experience with pain and everyone's experience of pain is different.
- We need to be open to looking outside the haemophilia world when it comes to looking at chronic pain management.

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