

Pain and bleeding disorders

Suzanne O'Callaghan



Pain is a significant issue for many people with bleeding disorders. It can be pain related to a bleed or pain from complications, such as the haemophilic arthropathy or arthritis that results from repeated bleeding into a joint. Pain is not limited to older adults: people with bleeding disorders experience pain over their lifetime, from childhood through to old age.

The session on pain at the recent Australian Conference was a great opportunity for presenters to explore issues around pain from different perspectives.

This is a summary of the discussion, but if you are interested, some of the presentations are available online for you to watch in full. Visit www.haemophilia.org.au/conference21 for more information.

Plenary 3 – Pain

20th Australian Conference on Haemophilia, VWD and Rare Bleeding Disorders

 <p>Dr Liane Khoo</p> <p>Paul McLaughlin</p>	<p>Chair ~ Dr Liane Khoo</p> <p>What's new in pain? Is it different now with new treatments? ~ Dr Liane Khoo</p>
 <p>Jane Portnoy</p> <p>A/Prof Carolyn Arnold</p> <p>Dr Christian Barton</p>	<p>Pain in haemophilia ~ Paul McLaughlin, UK</p> <p>A body and mind approach for pain management in people with bleeding disorders ~ A/Prof Carolyn Arnold</p> <p>Patient personal perspective on chronic pain ~ Jane Portnoy, social worker interviewing Dylan</p> <p>Osteoarthritis, exercise and pain: the GLA:D® program ~ Dr Christian Barton</p>

Dr Liane Khoo, Haemophilia Treatment Centre Director at the Royal Prince Alfred Hospital, Sydney, introduced the session by commenting that pain management is an important part of treatment and care for haemophilia.

'It is a biopsychosocial experience. It is beyond the mere concept of nociception, or the brain processing pain,' she said.

While the physical pathology at the site of an injury such as a joint bleed needs to be identified, this is not enough to explain 'the complex process by which pain is transformed into the physiological, cognitive, affective and behavioural responses labelled as pain. How we think, feel and act are integral to pain processing.'

Pain Complex

How the way we think, feel and act are integral to pain processing

Pain is a somatopsychic experience: a diagram indicating some of the nonphysical influences which modify perception of pain

Sensory: *what I'm feeling*

PHYSICAL

Cognitive: *how it makes me think*

DEPRESSION

Loss of Social Function
Loss of self-perception and esteem
Loss of role in family
Increase in Chronic Fatigue
Sense of Helplessness
Isolation

ANGER

Biomechanical Struggling
Delays in Diagnosis
Unrealistic Expectations
Communication Difficulties
Therapeutic Failure
Friends who do not Visit

TOTAL PAIN

Affective-emotion: *how it makes me feel*

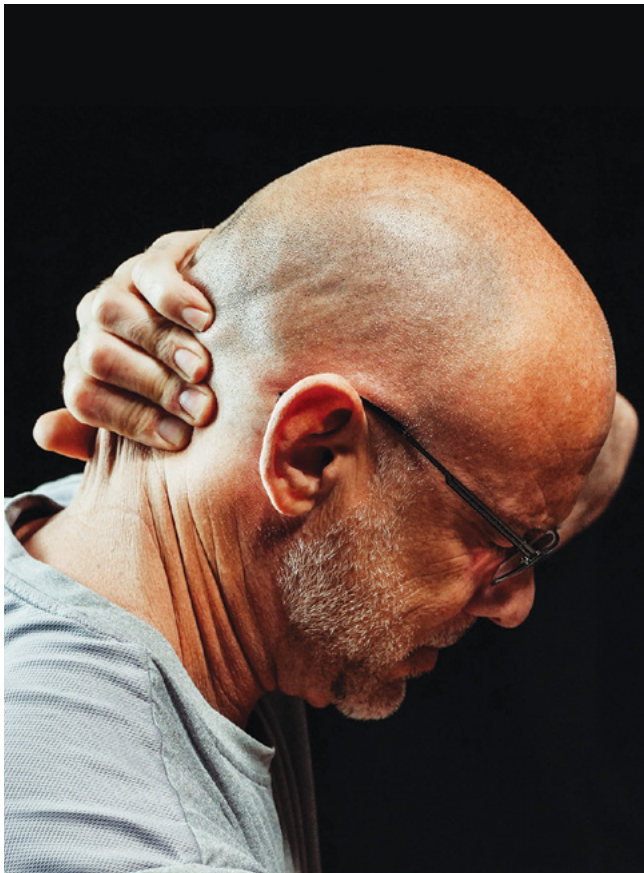
ANXIETY

Behaviour: *how it makes me behave*

Fear of Bleeding in Nursing Home
Fear of Pain
Worry about Family and Friends
Fear of Death
Normal Chronic Uncertainty about Future

20th AUSTRALIAN CONFERENCE ON HAEMOPHILIA, VWD & RARE BLEEDING DISORDERS
EMBRACING A CHANGING WORLD

Paul McLaughlin followed with a fascinating discussion of pain and its complexities from the point of view of a haemophilia physiotherapist. You can read more on his presentation in the December 2021 issue of *National Haemophilia* - <https://tinyurl.com/PM-pain>.



A BODY AND MIND APPROACH

A/Prof Carolyn Arnold specialises in pain management at The Alfred hospital in Melbourne and walked through some of the recent changes to pain management.

She highlighted that a holistic approach to pain management is essential.

New and innovative haemophilia treatments have made a substantial difference to the experience of acute pain, reducing the number and severity of bleeding episodes. This will also impact on joint degeneration from bleeding into joints.

Knowing the cause of pain is important – if it is a bleed, synovitis, haemophilic arthropathy or sensitisation. However, what can be seen on an X-Ray or other imaging is only one part of understanding pain.

As people with haemophilia grow older, the experience of pain can be disproportionate to what can be seen clinically, with the pathology of a joint, for example. This can be due to ‘sensitisation’ within the sensory system and it is important to manage pain and have pain free intervals to minimise this sensitisation.

With repeated episodes of injury with pain, the person's ability to recover reduces and chronic pain can result, along with an inability to tolerate as much activity – known as the 'boom and bust cycle'. 'The art is to find the right amount of activity to function better on every day and maintain your strength and mobility.'

How to do this?

- Consulting with your physiotherapist about recovery exercises to restrengthen muscles
- Varied options for exercises, including personalised gym exercises, swimming, hydrotherapy, modified T'ai Chi, walking (if appropriate)
- Overcoming fear of movement (relearning)

While medications may be used, they need to be used wisely and other non-drug options will be very important, as part of a 'healthy, happy, resilient lifestyle approach'.

This consists of:

- Strong opioid medications used early for severe acute pain, but then reduced and ceased quickly
- Seeking pain management services/programs outside the HTC team
- Understanding pain and perception of pain
- Mind-based tricks to manage tricky pain
- Reduce the body's over-protective response to pain
- Changes to lifestyle, including exercise and weight loss.

She spoke about avoiding the hazards of chronic pain – its impact on reduced fitness, strength and balance, on mental health, relationships, work, social isolation and over-reliance on drugs.

She also drew attention to the information about pain on the website www.painrevolution.org, which is a program for regional and rural Australia, but has valuable information for everyone.





A PATIENT VIEW OF CHRONIC PAIN

When our understanding of pain is so subjective, hearing the patient experience is crucial. Jane Portnoy, Haemophilia Social Worker at The Alfred in Melbourne, interviewed Dylan, a young man with haemophilia A, about pain and how it has affected him. Dylan's articulate comments on his experiences gave great insight into the day-to-day impact of pain.

Dylan explained that it is often difficult to explain his pain to the Haemophilia Team – what he is feeling, how long he has had the pain, how he would describe the pain. 'It can be a really frustrating experience when people don't seem to understand what you are going through as a haemophilia patient,' he said.

Another significant aspect was the impact of pain on limiting his life: his career, his social life, his mental health, exercising. 'It's hard not to put some blame onto yourself because you are constantly worrying that the things that you are doing everyday are causing your pain,' Dylan remarked.

How does he manage his pain?

- Listening to his favourite music as a distraction
- Working on his strength and muscle resistance with the help of his physiotherapist and personal trainer. This not only reduced his bleeds, but also helped with his mental health
- Having a chat with the social worker and psychologist at the Haemophilia Treatment Centre, for support and strategies and also just to vent.

His biggest barrier?

- Not knowing what help to ask for.
- It would be really valuable to have education on this for both patients and doctors.

His suggestion to others?

- Don't wait to ask for help. There is a multidisciplinary team at the HTC who can help you.



OSTEOARTHRITIS, EXERCISE AND PAIN

Surprisingly, the recommended first line treatment for osteoarthritis in the knee and hip is exercise, education and weight control, no matter what the severity of pain.

Dr Christian Barton walked through the research and the international GLA:D® program that is led in Australia by his team at LaTrobe University, Melbourne.

His key messages:

- Combining patient education with exercise improves patient outcomes with pain and function
- Exercise therapy is consistently beneficial for pain
- There are better outcomes if the exercise is tailored to the individual
- Aquatic therapy is good for people who cannot do land-based therapies
- There needs to be a program – preferably twice a week for at least 6 weeks
- Overweight and obese people can achieve great health benefits with weight-bearing exercise.

The GLA:D® (Good Life with osteoArthritis: Denmark) program is an education and exercise program developed by Danish researchers for people with hip or knee osteoarthritis symptoms. It is now available across Australia, delivered by physiotherapists who are trained and led by the LaTrobe team. The focus of this program is to change the way people think about their joints and pain, and the many factors that can affect and improve their pain and mobility, using exercise and education as strategies. Dr Barton explained there are a range of

exercises aimed at building confidence – you can find examples online at the free open-source website <https://nemex.trekeeducation.org/>.

An important take-home message from his session was that exercise therapy needs to address the commonly held myth that exercise is detrimental to arthritis and deal with the barriers to participating in exercise.

Q&A

The session finished with questions from the audience.

What can you recommend for family and carers who feel so helpless when our loved ones are in pain?

A/Prof Carolyn Arnold answered:

- It is valuable for the family and carers to understand the process of pain as well
- Then you can give positive guidance and support when the family member experiences pain
- Be aware of the impact of pain on their social relationships and emotional health, and support them.
- Sometimes you need to let young people learn, try things out and make their own mistakes.

This was a rewarding and enlightening session about an issue of concern to most people with bleeding disorders and the full presentations are well worth watching.

.....
Suzanne O'Callaghan is HFA Policy Research and Education Manager
