Getting older

Suzanne O'Callaghan

Getting older

Chair ~ Jenny Lees

Personal story ~ Zev

Clinical issues with ageing
~ Professor Michael Makris, UK

Getting Older report – results and implementation
~ Suzanne O'Callaghan

Panel Discussion - What are the issues and challenges ahead? ~ Suzanne O'Callaghan, Frankie Mullen, Kathryn Body, Stephen Matthews

With a lively overview of what it means to him to be growing older with severe haemophilia, Zev set the scene for a multidisciplinary session on getting older that focused strongly on quality of life as well as health issues. Zev spoke about family, friendships and motivation, strategies for keeping fit and for maintaining a positive outlook – the power of the peer group. 'It's so therapeutic to be with someone where you don't have to explain,' was an important aspect for him.

CLINICAL ISSUES WITH AGEING

Professor Mike Makris is an international leader in ageing and haemophilia and outlined some key issues from a clinical perspective. He showed the remarkable change in life expectancy for people with haemophilia now – very close now to the general population. He also pointed out that numbers of people with mild haemophilia are much greater than those with severe.

Zev

Ages of life

He divided issues with ageing into two categories: issues at the third age or retirement and issues at the fourth age or dependency – where a person can no longer live at home independently. By the fourth age, problems are increasingly non-haemophilia related and may involve hospital admissions. He highlighted the increased prevalence of hypertension, musculoskeletal problems and hepatitis C in older people with haemophilia. He recommended that older people with severe haemophilia consider prophylaxis treatment, presenting data showing bleeds reduced dramatically with prophylaxis.

HIV and hepatitis C

Bloodborne viruses remain an issue. Sadly, very high proportions of people with haemophilia who acquired HIV have died, but with new highly effective antiviral treatments, for those who live on with HIV, it is now essentially a chronic disease. New treatments offer the potential for a cure for nearly all people with hepatitis C; however, the risk of liver cancer continues for those with cirrhosis and they need regular monitoring.

Health conditions of ageing

For older Australians with bleeding disorders, weight management is important as risks for cardiovascular disease are increased with obesity and being overweight can be a higher risk for musculoskeletal problems. They also now need to be aware of the risk for thrombosis, such as heart attack, stroke or

atrial fibrillation, which is common in the general population of older people. Usually treated with anticoagulants, it will need careful management in people with haemophilia. Other health conditions of ageing such as cancer or musculoskeletal problems, which would require medical procedures or surgery, need to be managed in liaison with the HTC to prevent bleeding complications. Osteoporosis is also more common in haemophilia. With such a range of problems, an important development in the future will be comprehensive geriatric assessments that include haemophilia specialists in the team.

During the Q&A at the end of his presentation, Prof Makris pointed to a number of current research projects exploring new areas: one in the Netherlands into bleeding-related arthropathy in older people with mild haemophilia and VWD; and some European studies on VWD and rare bleeding disorders, including a EUHASS thrombosis study, a study into whether you can grow out of VWD as you age, and a study to manage specific bleeding complications in some types of VWD.

ISSUES AND CHALLENGES AHEAD

I then had an opportunity to present the results of the HFA Getting Older report. This was a good springboard for the panel discussion, where we looked at some practical responses to questions that came up in the report and the issues and challenges ahead.

As a haemophilia nurse, Steve Matthews highlighted the challenges for HTCs:

- With such new territory, they are learning about the issues as patients present with them.
- Managing problems of ageing, such as heart bypass or stenting for cardiovascular disease, now commonly includes older people with mild haemophilia, who are not familiar with the range of treatments to prevent bleeding and need to learn about prophylaxis and personalised treatment to prevent bleeding, including the careful balancing with anti-coagulants.
- HTCs also need to look into strategies to help manage prophylaxis when older people can no longer self-treat or move into an aged care home, and whether the new sub-cutaneous treatments can be used - clinical trial results for people over 65 years are only now becoming available.

From a psychosocial perspective, Kathryn Body commented:

- Providing care for older people with bleeding disorders was quite time-consuming, which could be difficult for time-poor HTCs, and that it would be important to make the most of co-ordinated multidisciplinary appointments.
- Psychosocial workers may also need to have more of a role in researching for clients to connect them to services and advocating for them as they grow frailer and may not have the ability, the voice or the words.

Issues of ageing are an added complication for physiotherapy management, noted Frankie Mullen. However, this is also an opportunity to collaborate with community physiotherapists so that people can attend local programs for their regular health maintenance.

The panel discussed what makes a good GP for an older person with a bleeding disorder:

- Willingness to communicate and liaise with the HTC and with the patient
- Respecting the urgency of bleeding episodes
- Asking others who live locally about good local GPs.

For community physiotherapists there were similar criteria:

- A good physiotherapist was one who was willing to learn
- Where the patient felt comfortable with them
- And who understood the physical limitations of being older.

Keeping up physical activity as they grew older was particularly important for people with bleeding disorders to develop and maintain bone strength and prevent problems such as osteoporosis.

Self-advocacy can be more difficult as you grow older and more frail or develop dementia. Suggestions from the panel included:

- Taking a trusted person with you to appointments
- Before choosing an aged care home, visit a few and ask them questions about how they would manage someone with a bleeding disorder. If they do not support intravenous treatment, is there a local

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.

Suzanne O'Callaghan is HFA Policy Research and Education Manager

Pain and haemophilia

Nicola Hamilton

Plenary 3 – Pain

Chair ~ Dr Liane Khoo

Pain in haemophilia ~ Paul McLaughlin, UK

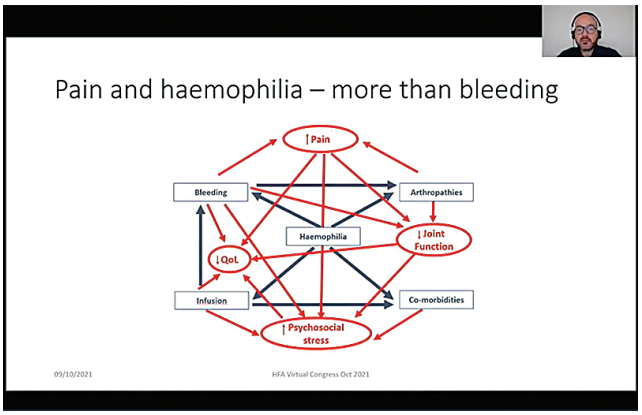
I enjoyed this presentation on pain and haemophilia as Paul McLaughlin, a leading haemophilia physiotherapist at the Royal Free Hospital in London, skilfully took us through an overview of pain and its complexities.

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 though was incredibly important is that pain is always a personal experience, and everyone's experience of pain is different.