

Getting older

Nicoletta Crollini

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Chair ~ Suzanne O'Callaghan

Personal story ~ Mike

Medical issues ~ Dr Liane Khoo

Hep C and liver health ~ Dr David Iser

Social connection ~ Marcia Fearn

Panel discussion and Q&A ~

*Speakers; and nurse: Jayne Treagust;
physiotherapist: Cathy Haley;
psychosocial worker: Kathryn Body*



I was eager to attend the Getting Older session as, thanks to advancements in treatment, people with inherited bleeding disorders are living longer and longer. This session was highly informative, and included stories from those with a lived experience and a panel of experts who are supporting the inherited bleeding disorder community as they get older.

The session began with Mike, who spoke about the challenges of growing up with severe haemophilia, how developments in treatment have allowed him to be more active and how his hope is for this to continue. Mike explained that he leads a very social life, which he enjoys and has found this to be a meaningful aspect of ageing.

The session continued with Dr Liane Khoo outlining medical aspects of getting older with an inherited bleeding disorder. Dr Khoo stressed the importance of health promotion, as good health and quality of life is a major goal for patients, their families and carers. Dr Khoo explained that upskilling general practitioners and educating other specialists are important for dealing with the complications of ageing associated with inherited bleeding disorders.



Ageing and Haemophilia

Advances in the development of effective and safer treatments for haemophilia over the last 50 years have resulted in a significant increase in the life expectancy of persons with haemophilia and other bleeding disorders

Life expectancy for persons with haemophilia has increased significantly from 11.4 years in 1920 to a potentially normal life span today^{1,2}

As life spans normalize with adequate haemophilia care, people with inherited bleeding disorders are now transitioning from a focus primarily on bleeding and its complications to a focus that includes health promotion and disease prevention.

1,2 : Shapiro and Marks, British Journal of Haematology, 2019, 164, 712-720; Larsson, S.A. British Journal of Haematology, 1985,59, 393-402.

Dr David Iser discussed the Australian experience of treating hepatitis C, which has been positive, particularly for those with inherited bleeding disorders, who were some of the earliest cured of the disease. Dr Iser explained that if a person is reinfected with hepatitis C, they can be re-treated and that treatment is still covered by the PBS. Dr Iser outlined the importance of testing and monitoring liver cirrhosis even after cure of hepatitis C, stressing that testing and monitoring is non-invasive.

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Benefits of befriending

"I love visiting John...It's not just in the immediate time that is spent with that person. People have told me they feel quite euphoric and happy for a few days after the visit."

"It's good because it gives yourself and also the person you're visiting, it gives you both a sense of purpose that maybe your lives didn't have before"

"It's nice to have a visitor. I mean my brothers visit. It's nice to have a visit from someone younger. She was more extraverted than him. She helped me open up a bit. I'm quite introverted at times. She helped me talk about myself."

"I felt very close and so did he to me and he said 'friends' the first day when he shook hands and he left."

"I think it's made me a little bit better...when there's no one around I used to just sit there and do nothing. Not talk to anybody or anything...I'll really tell you, she's very very helpful. Oh yeah (made me feel) much better...I always ask her when she's coming back."

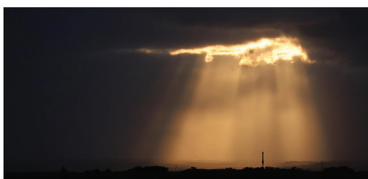
"As you get older, you don't have a lot of friends to make contact with...It's beneficial and I feel comfortable in her company."



Bringing research to life

Thank you!

- HCV remains curable for (almost) everyone living with chronic HCV
- Cirrhosis warrants ongoing surveillance for complications, especially HCC
- People with cirrhosis should be encouraged to remain in care



Marcia Fearn discussed the importance of social connection as loneliness has been identified as contributing to several physical and mental health issues. Supporting and maintaining existing connections, engaging in new social connections (such as joining a social group or volunteering) and supporting one's mental wellbeing were all identified as measures to help prevent loneliness.

The session concluded with a robust discussion amongst panel members: Mike, Dr Liane Khoo, Dr David Iser, Marcia Fearn, Jayne Treagust (Nurse), Cathy Haley (Physiotherapist) and Kathryn Body (Psychosocial worker).



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