

ASK US...

Q & A's with Alex & Jane

QUESTIONS FOR THE ALFRED HTC TEAM

What do you believe are the most important health issues concerning men and women with bleeding disorders as they age?

The General Practitioner is so important for people with bleeding disorders as they age. They can do all other age related health checks as for the general population including cardiovascular, skin checks, prostate, bowel screening and the list goes on. We advise that if a test or procedure is bigger than a blood test to let the HTC team know. As people get older there are many other health conditions that can affect you, as well as the progression of any damage to joints that has happened.

What are the specific issues for men aged 35+?

Men over 35 are well known for not seeking medical care for themselves. They are usually busy with work or family commitments and prioritizing themselves is challenging. However we know that early action can reduce the severity of the problem, and shorten the recovery time. This stage of life is when many men and women have dependents relying on them, financially, with practical care and in their relationships. Taking time off for a medical appointment, a visit to the hospital or to recover can seem impossible. As for specific issues, this age group face the same challenges as the general population, including family planning. A common request by men is for a vasectomy which is complicated by their bleeding disorder.

Are there different issues for men aged 65+?

The haemophilia population aged

over 65 did not have access to adequate treatment as children. They may have significant musculoskeletal issues and may need to retire early which can cause significant financial stress. Some may also be carers for ageing partners.

They have also had long and complicated relationships with medical care, and not all of it has been easy. Many have negative or traumatic memories of hospital, recent and from long ago, and these can add to a reluctance to address any health concerns.

On the positive side they are able to put more time into their own health and can get good results from their own active involvement in their health and physical activity.

What are the issues or barriers that stop men from reaching out for support?

Unfortunately, financial issues limit choices and poor mobility restricts transport.

The barriers are less if patients have a good knowledge and understanding of their disease and plan for the long term from a younger age, such as thinking about suitable career choices. Some barriers can be very much dependent on their family situation.

Gender stereotypes exist and some men have been brought up to believe that it is a sign of weakness to address any health concerns. That they should just push on!

What other health conditions should people who are ageing with haemophilia be mindful of?

Again, people with haemophilia need to be mindful of all conditions that affect the general population as they age. This includes polypharma-

cy, alcohol and drug dependence and mental health issues such as depression and anxiety. Also, poor pain management can lead to other difficulties so it is important to have effective pain management in place.

Are aged care facilities educated in haemophilia care?

No. This is due to the rarity of the disease and the vast number of aged care facilities. Staff are provided with education on a needs basis.

Can nurses in aged care settings assist with intravenous treatments?

Rarely. Most are staffed by one registered nurse and care attendants. But often, as a person ages and becomes less active, the need for prophylaxis reduces.

Following the normal process of a nursing home, if a resident is unwell for any reason they are sent to their local emergency department.

If they were to have a bleed, again, the person would be sent to the emergency department.

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Thank you to Penny McCarthy, Megan Walsh & Emma Reiterer from the HTC team for their contributions to this article.

Please send your questions for the next edition to Jane, Alex or to the HFV team by the 1st August. You can remain anonymous, use an alias or just your first name. J.Portnoy@alfred.org.au, A.Coombs@alfred.org.au or julia@hfv.org.au