6. Discussion

6.1 Ageing and getting older

The language around getting older can make a considerable difference to how people with bleeding disorders perceive themselves.

At the beginning of the consultation for this needs assessment, HFA asked older community members about how to engage their peers in consultation about 'ageing'. Older people with bleeding disorders commented that they did not identify with the term 'ageing' and thought it was negative and discriminatory and put them in an 'old person' box where they did not belong. A social worker noted:

> *'We talked at camp recently and it was really interesting. "No one is ageing. We are all getting older." The word "ageing" is not a good word. They talk about others; "I am not getting old". That is how we are wired, because if you are seen as older or frail, you are seen as broken in our society. Our whole community is wired as young and beautiful – that is what we must aspire to.'*

After some discussion, HFA changed the terminology for the needs assessment, so that the 'Ageing Project' became the 'Getting Older Project'.

6.1.1 'EARLY AGEING'

During the scoping for the needs assessment, 'early ageing' was identified as an issue for many people with bleeding disorders. However, younger people with bleeding disorders thought this term was problematic: that their physical issues were more related to disability than being an older person.

One younger man with haemophilia outlined the dilemma facing younger people with joint and muscle damage from their bleeding disorder. He could see that explaining this damage by comparing it to the kind of joint damage you might see with ageing helped others to understand it. At the same time, he pointed out how this muddied the understanding of the issues specific to younger people with haemophilia and the complications arising from it.

> *'"Ageing" is a word, like that we have an "ageing population". The word "ageing" misses the mark. It feels mainstream. Everyone ages eventually. I don't think we feel mainstream. I think we feel like we are a very unique group with very unique needs and experiences… One thing that I can say is that the results of haemophilia, joint deterioration and bleeds into the joints, can look like early ageing. So the younger person with haemophilia effectively has the mobility of an older person.'*

This dilemma around the language of ageing and being 'old' was also acknowledged by a physiotherapist:

> *'We've got an 18-year-old with joint damage that we would expect to see in the general community in an 80-year-old. So they are not ageing but their joints are [like] old joints, they are deteriorating because of bleeding.'*

WHAT WILL HELP?

It would be valuable to give careful consideration to the use of the words 'ageing' and 'old' when discussing getting older with a bleeding disorder and the disability in younger people related to the complications of their bleeding disorder.

6.1.2 HOW OLD IS AN 'OLDER PERSON'?

When is a person with a bleeding disorder 'ageing' or an 'older person'? The needs assessment consultation highlighted that this can vary widely between individuals.

Haemophilia Foundation and peer support workers and the health professionals at Haemophilia Treatment Centres were asked at interview at what age a person with a bleeding disorder is 'ageing'. Their answers were consistent: while they noted that the Australian Government My Aged Care portal generally defines 'an older Australian' as 65 years or older[30], 'ageing' can be both younger or older for a person with a bleeding disorder. With health challenges such as joint and muscle damage and bloodborne viruses, like HIV or hepatitis C, they could see 'early ageing' occurring for some people from their 40s onwards, and in people with inhibitors, where their treatment is not effective, even as young as their late teens. However, other people with bleeding disorders were functioning well, and were active and independent into their 70s and 80s, particularly people with mild disorders.

Foundations and health professionals also consistently associated 'early ageing' with inadequate treatment during the childhood years. They pointed out that the generation aged over 40 years had grown up not having prophylaxis factor replacement therapy or with insufficient clotting factor treatment to stop bleeds and this had resulted in significant joint and muscle damage, particularly for people with severe haemophilia.

6.1.3 WHAT DEFINES 'AGEING'?

This definition of 'ageing' was related to physical and mental functioning rather than a chronological age. One psychosocial worker explained,

> *'For me the ageing process starts when people are starting to need support from others, or they feel that they can't manage to do things that they have always done in their life. That may be the physical things or cognitive things.'*

For physiotherapists, 'ageing' was closely related to the physical impact of joint damage. It could start 20 years earlier or more in the person with haemophilia than in the general community.

Another psychosocial worker commented that people with haemophilia had created phrases such as 'the haemophilia shuffle', which they used to explain how they could identify the disability associated with early ageing in themselves and others.

The workers also associated 'ageing' with a state of mind. They noted that some elderly people with bleeding disorders could be engaging meaningfully with their world, had a strong social network, were proactive in managing their health care and treatment needs and were thriving. Others were 'not looking after themselves' and were not following up their regular health checks. Some might be struggling with grief and loss. As one nurse commented,

> *'Some of the older fellows have planned for their future, thinking that their partner is going to be looking after them and then their partner is suddenly gone. No one wants to plan for that. Preparing different options to what they had in mind is sad as well.'*

6.2 Aspirations and goals

HFA's vision is for 'active, independent and fulfilling lives for people in our bleeding disorders community' – but what does this look like for older people with bleeding disorders? Understanding the aspirations and goals of older people with bleeding disorders is an important first step in achieving this.

WHO's *World report on ageing and health* points out that a person's goals, priorities and what motivates them change as they grow older. Some changes may be a way of dealing with the loss of physical functioning and social roles they held previously as well as the loss of close personal relationships and social networks. WHO also notes that other changes reflect an 'ongoing psychological development in older age': for some this involves moving away from materialistic to more spiritual perspectives, but for many this is related to developing new roles and

viewpoints and a period in their life where they have a better sense of wellbeing.[32]

In both the interviews and the Getting Older Community Survey, older people with bleeding disorders were asked about their aspirations and goals as they grew older. Their partners and families were also asked what aspirations they had for the person with a bleeding disorder, and their responses often related to a future they would share together.

Most pictured themselves as actively involved in their life and their future. For many this involved participating in and contributing to the community or their family in some way. In psychological literature, this optimism and use of social networks is associated with 'resilient coping'.[112] For others, however, there was a sense of being alone, which made maintaining optimism and resilience more challenging.

6.2.1 GOOD HEALTH AND INDEPENDENCE

By far the most commonly expressed aspiration for the future was to maintain their quality of life, be healthy and remain independent. This involved maintaining their mobility, reducing stiffness and pain, and being able to participate in family life, travel, pursue their interests and to 'be useful'.

> *'To remain fit, healthy and well. Travel. Support my children in caring for their future children, who may have haemophilia. Volunteer work.'*
>
> *'Maintaining my quality of life as I am noticing my health is getting more challenging year by year.'*
>
> *'To continue to be active and find a way to reduce stiffness and pain.'*
>
> *'As I get older I hope to have a comfortable life. Still having quality of life. As I said I am young at heart.'*
>
> *'I hope to maintain a good standard of health, improve my health and to be worthwhile in society.'*

For partners and family, to remain healthy was important to sharing a future together.

> *'That it [haemophilia] can be managed. That he will get older with me!'*

For some individuals, the lack of a partner reduced their goals for the future.

> *'I will be probably be a bit of a unique case. I do live alone. I don't have a partner. So my only hope when I get older is to continue to enjoy good health.'*

6.2.2 TRAVEL

Being well enough to travel was high on their priority list and was associated with visiting family and friends as well as having adventures and enjoying themselves.

> *'To be well enough to enjoy time with family and friends and be able to travel overseas to where close family members now live.'*
>
> *'To travel with my husband and not have to worry about my bleeding disorder.'*
>
> *'Remaining active and continuing to be able to explore the world.'*
>
> *'When I grow older, I want to be fit enough to do a few trips and active enough to go on outings and be with our family.'*

6.2.3 PURSUING PERSONAL INTERESTS

Another high priority was being able to follow their interests, whether they were related to sports, or other activities like gardening, art, writing, singing in choirs or helping their family. This reflected a change in their priorities, from paid or domestic work, to being able to give more time to their recreational interests.

'Be as healthy as I can be so that I can participate and be involved with my husband and wider family and friends and be able to continue to paint.'

'Comfortable and safe accommodation, travel, engaging in enjoyable pursuits, being active and fit, quality family time, reading for fun.'

'Have more time for reading and for my artwork. I would like to spend less time on my domestic tasks. That's the hope for the future.'

For some, the vision of the future involved retirement or reducing work, while remaining comfortable financially. For others, while they were hoping to stop or reduce work, they saw their social role evolving and wanted to stay involved in the community and continue to work or contribute as a volunteer.

'In general, I hope for things like financial security. Being able work long into older age. Staggered hours.'

'To be able to choose how much I work after 60. Then to live an active and enjoyable retirement in good physical condition.'

'To get out more. Be more social. Try to contribute more to the community. Experience new things. Enjoy life.'

'Golf, travel, spend time with family and stay involved with the industry that I worked in (a few hours each week).

'The word retire doesn't mean anything to me. I rather not retire and just keep doing things that are worthwhile, whatever that may be.'

Partners were sometimes more prepared to acknowledge the value of what older people with bleeding disorders could contribute.

'I want them to have the opportunity to use their brilliant mind to tutor others and write.'

6.2.4 RELATIONSHIPS WITH FAMILY AND FRIENDS

Looking to their future, some people reflected on the importance of family and friends to provide a network of support and comfort into their old age. Many who were parents to adult children saw a role for themselves helping with care for their grandchildren.

'Enjoyment of my grandchildren. The relationships that I do have with people. They will be comforting and reassuring in my lucky years, however few they may be or how many.'

'And for me it's a sense of family. I think the Royal Commission into Aged Care really show how bad it can be! For me it is important to think how will I live in my old age, how will I have supports around me and the social networks and family around me. So you don't lose that.'

'I would like to be able to be more active with the grandkids, to be able to garden, shop, gym and bike ride with a minimum of pain being generated.'

6.2.5 TAKING LIFE AS IT COMES

Some were more philosophical about letting life unfold rather than worrying about or planning for their future.

'I just get up every day and do what I've got to do and get on with life. I don't think about getting older. I am 58 years old now. I don't worry about it. If it happens it happens.'

6.2.6 BARRIERS TO ACHIEVING ASPIRATIONS

Health concerns were perceived as the greatest barrier to achieving the aspirations of people with bleeding disorders who are getting older.

6.3 When stoicism isn't enough

HFA's consultation for the Double Whammy hepatitis C needs assessment highlighted a culture of stoicism among people with bleeding disorders. This was prominent in the generations who had grown up before prophylaxis treatment and recombinant factor products were readily available.[20] Several of the health professionals from Haemophilia Treatment Centres commented on the older generation's resilience and determination to overcome challenges. As one psychosocial worker said,

> *'The haemophilia community have been so resilient and stoic; they continue that one into their ageing as well. So they manage and push through a lot of things when other people need extra help.'*

For this older generation, there was a sense of a tipping point where the health conditions of ageing combined with their bleeding disorder could prove too much of a challenge for them to manage, even with their usual determination and positive approach. Some voiced their concern about this in the interviews, for example saying,

> *'I always had to deal with issues all my life, but I deal with them. If I lose that ability, I feel that's the place I am not really happy about to go to.'*

There was some similarity between their comments and a Canadian research study on the perspectives of older people with bleeding disorders, where their pain and physical limitations had exhausted their ability to stay positive.[28]

6.4 Living with multiple health conditions

When asked about their greatest concerns at present, the most prominent worries for older people with bleeding disorders were the complications of their bleeding disorder and the challenges of living with multiple health issues as they aged. This could impact on many aspects of their life.

Some were unsure how much their health issues were related to their bleeding disorder and how much to ageing. Others were only too conscious of the impact of the diseases of ageing, when they were already struggling with the joint and pain problems from their bleeding disorder.

> *'It's still murky to know what it is, depending on how your body is.'*
>
> *'I am hoping to slow the decline in my health. The last four years have seen me declining a lot, having several more medical conditions I haven't had before.'*
>
> *'At times it's hard. The only thing that stops me from doing things is my physical being – that being hip replacements and lately I have a heart condition. I am finding with this heart condition, it's more doing shopping. I am finding it little bit more difficult.'*
>
> *'I have learned that things change as you get older and they are worsened by the effects of having a bleeding disorder.'*

Health professionals recognized the burden of the increasing number of health conditions as their patients aged. One haematologist commented,

> *'Lot of patients have got complex multi-system disorders. This has an impact on their quality of life, which is compounded by the bleeding disorder, which needs regular treatment.'*

Health professionals also considered that having multiple health conditions had an impact on ageing and the associated needs. As a psychosocial worker noted,

> *'The issue really is around what other comorbidities they have as well, haemophilia and a heart condition and an inhibitor and something else going on. For me that's where I see differences. Comorbidities impact on your health and take a greater toll on your ability to manage. Comorbidities push the ageing needs.'*

6.5 Mild conditions

There has been little research on the impact of ageing on mild conditions such as mild haemophilia and VWD. However, health professionals at the HTCs reported that they were seeing their patients with mild conditions much more often as they aged. These patients were presenting to the HTC with complications such as coronary artery disease and needing liaison and advice about anticoagulant treatments or requiring preventive treatment to cover for surgery and medical procedures – or dealing with prolonged bleeding if the health care provider outside the HTC had not commenced preventive treatment in liaison with the HTC before administering treatment or undertaking an invasive procedure. Some older people with mild haemophilia were also presenting with joint problems.

Most people with bleeding disorders in Australia have mild conditions and data from the Australian Bleeding Disorders Registry highlights that people with mild conditions are currently the largest proportion of those surviving into old age. They are likely to experience fewer bleeding episodes in their lifetime and have less contact with an HTC. Some receive treatment for their bleeding disorder in the community instead, from general practitioners and private haematologists.[4] As a result they may have had fewer opportunities for HTC review and education. Some are also not diagnosed until later in life and may already have had a number of unrecognised bleeding episodes.

There is much still to be understood about the effect of ageing on VWD, including whether the rising factor levels with Type 1 decrease bleeding episodes as the person ages.[69] The clinicians in the HFA Getting Older Project Advisory Group noted that they would expect to see similar issues in VWD as in haemophilia in relation to ageing, with the exception of joint problems in mild forms of VWD. People with VWD who responded to the Getting Older Community Survey commented that they were experiencing more problems with their bleeding disorder as they grew older:

> *'As I age I was led to believe that von Willebrands would not be such an issue. I have NOT found this so. My body says otherwise!!!!'*
>
> *'Von Willebrands seems to impact more now. I didn't know I had it till I was 40 but did realise something wasn't right.'*

This lack of engagement with the HTC in mild haemophilia and VWD raises a significant concern about the impact it may have on the health and wellbeing of older people with mild disorders at a point when they will require more medical and surgical interventions and care for their joint problems. It also highlights the potential for breakdown in the communication flow between the HTC and medical and surgical health care providers in the community.

6.6 The rarer bleeding disorders

A small number of older people with rare clotting factor deficiencies, inherited platelet disorders and acquired haemophilia responded to the Getting Older Community Survey. Their responses were consistent with other older people with bleeding disorders, although they focused more on the health issues specific to their bleeding disorder. Those with rare clotting factor deficiencies and acquired haemophilia noted their goals of improving health, fitness and pain management, but were less likely to comment on joint and mobility problems than older

people with haemophilia who responded to the survey. Those with inherited platelet function disorders also pointed to the impact of anaemia on their working life.

However, their comments also highlighted the clinical management issues related to having a rarer bleeding disorder. For example, several highlighted difficulties with having their bleeding disorder taken seriously by the health professionals who provided their other care outside of the HTC.

There is increasing recognition of the rarer bleeding disorders at an international level and this may support more research into the area and the development of evidence-based education materials. Addressing the knowledge base of the wider group of health professionals who provide their care will be important for the health and wellbeing of older people with rarer bleeding disorders into the future.

WHAT WILL HELP?

Connection with an HTC

Encouraging people with mild bleeding disorders to connect to an HTC is an important way to ensure they have access to best practice treatment and care and the latest information about bleeding disorders as they grow older. This may also involve engaging with their general practitioner or other clinicians in the community to ensure the person has a referral to the HTC and that ongoing comprehensive care can take place. This will also assist with integrating their care for their complications and preventing unnecessary bleeding episodes.

Further research

Further research to understand the impact of ageing in mild conditions, VWD and the rarer bleeding disorders will be valuable to support specialised treatment, care and support into the future.

One aspect of connecting to an HTC is the use of the **ABDR** to collect clinical data. This would be an effective way to aggregate evidence about the impact of ageing on people with mild disorders, VWD and the rarer bleeding disorders and to study the outcomes of particular treatments and care programs. Encouraging all people with bleeding disorders to participate in the ABDR will be imperative to improving knowledge, treatment and care.

The **PROBE study** has been another effective way of gathering evidence about the impact of haemophilia and the related health-outcomes, from the perspective of the person with haemophilia. Promoting the PROBE Australia study to people with haemophilia will increase the evidence base about people with mild haemophilia in comparison to those with moderate and severe haemophilia. There has also been discussion at an international level about extending PROBE to other bleeding disorders, such as VWD, and Australia's proactive support for this work will be required for us to enable a similar collection of data in VWD and other rare bleeding disorders.

Community surveys targeted at people with mild haemophilia, VWD and/or other rare bleeding disorders could also be another tool for collecting information about the impact of ageing on people with these health conditions and the health and quality of life outcomes that they report.

Education

It will be important to include evidence-based information about ageing with these conditions in both education for the community and for health professionals.

6.7 Costs of delayed or inadequate treatment

6.7.1 PROPHYLAXIS AND ADHERENCE

The aim of prophylaxis is to keep factor levels high enough to prevent bleeding episodes, and treatment regimens are individualised to achieve this.[8] When the individual does not adhere strictly to their treatment regimen, their factor trough levels will drop and this is associated with experiencing more bleeds, further joint deterioration, pain and other complications.[124]

In the Australian prophylaxis study, leading Australian haematologists had expressed their concern about the low uptake of prophylaxis in adults, particularly those aged 60 years and over.[59] In the interviews nurses commented that some older people with haemophilia were *'not keen on prophylaxis'*: they had difficulty organising themselves to manage the 2-4 infusions required per week with prophylaxis on standard half-life products and worried about injecting themselves: *'organising to do prophylaxis on the whole is difficult, and again there is the anxiety, pain that comes with an infusion.'* Prophylaxis with standard products could add to their stress levels and sense of being overwhelmed by their health conditions. However, if they were not adherent to their regimen or preferred on-demand treatment, this could leave them open to more health problems and complications.

6.7.2 TIMELY TREATMENT

Nurses and psychosocial workers were particularly concerned about health complications for older people who were less engaged with the HTC: people with mild or rare disorders, who have fewer bleeding episodes and require specialised treatment for their bleeding disorder less often, or others who for various personal reasons did not connect as often with the HTC. This could mean that they did not realise they needed to organize preventive treatment to cover surgery or did not contact the hospital for treatment until a bleeding episode was well advanced, and as a result of the delayed treatment, bleeding complications could be worse.

'Those that are less engaged, those that care less, or those that have problems less tend to have larger problems when they occur. They don't call the HTC, they don't call their doctor, they don't call the Emergency Department.'

'The lack of timeliness in treatments amplifies the problems they are presenting with. That bothers me.'

Partners also expressed their concern about the cumulative impact on older person with a bleeding disorder if they did not take care of all aspects of their health:

'Not constructively tackling his haemophilia-related health issues and poor decision/non-compliance on treatments from the past, (including his poor care of his teeth!)'

WHAT WILL HELP?

Education and support

HTC health professionals highlighted the need to educate people with bleeding disorders about the importance of adhering to treatment, attending their regular reviews and seeking treatment early.

Education strategies would need to be innovative to reach the various target groups and could perhaps demonstrate the health problems that are caused by missed or delayed treatment and the value of recording treatments and bleeds.

Nurses also suggested 'value-adding' to clinical reviews, for example, with referrals to general practitioners (GPs) or other mainstream services in relation to their patients' specific issues.

Target groups include:

- People with mild conditions and rare clotting factor deficiencies who do not usually engage with the HTC regularly
- Young people on prophylaxis – to prevent future joint and muscle complications
- People with severe disorders who for various reasons do not connect regularly with the HTC.

The promise of new treatments

Both community members and health professionals commented on the potential of newer and emerging treatments to solve some of the treatment issues

for older people with haemophilia. In particular, they mentioned extended half-life (EHL) factor products, treatment products that are injected subcutaneously rather than infused into a vein, and gene therapy. These products are administered less often and studies indicate they may be more effective than standard half-life factor products.[60,61] In the case of gene therapy, a single course of treatment could mean that the person has very few or no breakthrough bleeding episodes.

- Treating less often would assist the older person to adhere to their treatment regimen more easily and make prophylaxis more attractive or workable
- It would also make infusion by a partner or carer or an external provider such as a GP or a community nurse more viable
- Subcutaneous treatments would be particularly beneficial for:
  - older people with dexterity or vein issues who have difficulty infusing into a vein
  - where the older person has dementia and may require a carer to administer the treatment and may potentially be distressed by an infusion
  - and where nurses with expertise in infusions are not easily available, for example, in a residential aged care facility or a home environment.

'Having to treat less could help. Getting the half-life products might reduce having to treat from every 3 or 4 days, but with the subcutaneous product I could treat once a month. Accessing veins will become an issue the older you get, also with my elbow getting worse – and I think about getting dementia or something like that.'

'I am keen to see the long acting factor coming. That will be life changing.'

Nurses noted the value of these products for encouraging the uptake of prophylaxis in older people with haemophilia:

'There is the benefit of being on prophylaxis, which with standard product is good, but the benefit of being on an EHL and also being on prophylaxis is even better.'

'The impact of EHLs on patients particularly on haemophilia B patients has been 99% positive. This is the best thing that has happened to them and they have never had a bleed again. Prophylaxis treatment is tedious for patients.'

'The impact of prophylaxis is encouraging. Even people who were never brought up with prophylaxis are encouraged to do prophylaxis or continue to do prophylaxis. Ok their joints are bad, but even EHLs are much better than taking 4 to 5 injections per week.'

'Subcutaneous injections do make much difference to life – two-weekly, monthly injections, not into veins.'

6.8 Physical functioning and quality of life

6.8.1 LOSS OF INDEPENDENCE

Both community members and health professionals described the loss of independence that could come with ageing and the increasing complexity of health conditions as a major challenge for the older person with a bleeding disorder. This was heightened because so many had worked very hard over their lifetime to maintain their independence in spite of the disability from joint and muscle damage. Memory loss, increasing frailty and injuries relating to falls were identified as particular challenges.

'The thought of me losing my independence is not something that I look forward to.'

'I have a number of disabilities that I have to cope with every day. I walk funny, I do all that stuff, but it doesn't bother me. I parked my car and walked into this office and I am very happy. If I lose that ability, I don't know whether I will be so happy.'

'I am worried that my arthritis will restrict what I could do independently. So, I could go to a nursing home younger than I would like to go.'

A psychosocial worker highlighted that this loss of independence could prevent the social interaction and activity so necessary to resilience:

'They can't take part in the community activities other people may have. For example, one was bound to his house as he couldn't get in and out of his car, because his joints didn't move. So, he was trapped with a lot of pain and the physical side of it as he could not get out.'

6.8.3 JOINTS AND MUSCLES

Joint and muscle damage related to bleeding episodes over a lifetime was often raised as an issue. It was recognised by all as a very important factor in the quality of life and physical functioning of many older people with bleeding disorders, particularly those with haemophilia.

A nurse explained:

'When it comes to pain management and declining mobility, we start to see them much earlier on than in the general population. Haemarthrosis is the issue. Rather than seeing normal arthritic changes, we are seeing degradation due to multiple bleeds within their joints.'

By the time they reached their senior years, some people with severe disorders had developed a number of target joints prone to bleeds, which caused pain and stiffness and restricted their movement. This could also impact on their mood, and memory loss could compound their problems.

'I've had haemophilia arthropathy since I was 9 years old. It started in my ankles and moved to my elbows. As I got older, it became more severe and more extensive. It restricts my movement, my dexterity, my range of movement and how long I can do things.'

'I have target regions in certain joints. My left elbow, my right ankle. Over the years they have become worse, in terms of repeated bleeding especially in joints in my 20s and 30s. Now I am left with accelerated arthritis and limited movement. It's really painful and that can change moods and the ability to work. Because pain is really tiring.'

'My joints have been a bit of a problem when getting older. I've had a knee and hip replacement and both my ankles are fused. I have problems with memory, misplacing the odd thing, can't remember people's names. I struggle with depression a bit, mood swings.'

In some cases, they had joint replacements or ankle fusions, which decreased the pain and sometimes improved their mobility. Others were concerned about the prospect of joint surgery, avoiding it because of the long waiting list and substantial recovery time. An Australian study noted that people with haemophilia often had joint replacements at a younger age than the general population.[79] If they had already had joint replacement surgery, some were now concerned about their options for the future.

'I started to lose my joint movements in my late teens. Because I had the operations they are better now. I do 4 to 5 kilometres every day now, with my dog. I feel I am in a better stage now, but there is bit of arthritis there.'

'I had my left knee replaced 27 years ago. That's been the best thing that ever happened to me, healthwise.'

'Facing the prospects of getting total care following a total knee replacement. Prospect of long waiting list as public patient for same.'

'I have two prosthetic knees. I worry that if one of them wears out my options are limited. I think the state of knowledge at the moment is that you either have to fuse or amputate below or above the knee.'

6.8.4 ARTHRITIS AND ARTHROPATHY

In the needs assessment consultation older people with bleeding disorders often described their arthropathy related to haemophilia as 'arthritis', but health professionals distinguished between the two conditions. Using the clinical definition of haemophilic arthropathy, the health professionals explained that the arthropathy resulted from repeated bleeding into a joint and noted that they were more likely to see it in older people with severe conditions who had grown up without prophylaxis, particularly men with haemophilia from the age of 35-45 years. This could also occur in younger men with haemophilia with inhibitors, which makes treatment less effective, and those with severe conditions who had not adhered to their prophylaxis regimen. They had noticed increasing numbers of older males with mild haemophilia who were starting to display arthropathy, but would not expect to see it in women with bleeding disorders, or only in a few, as they do not appear to have joint bleeds as often. They would, however, expect to see the same arthritis that you would see in the general population in both men with mild haemophilia and women.

In the interviews women commented that while they knew women were different in relation to the level of arthritis, they were unclear why this was: *'It's different for women. I don't know how different it is. I never understood.'*

Although it was a relatively small study, the PROBE Australia questionnaire showed some interesting results in relation to 'arthritis' in men and women with mild haemophilia (See Appendix 2). As would be expected, more than half (54% or 15/28) of the men with severe and moderate haemophilia 45 years and over reported target joints, as compared to around one-fifth (21% or 6/29) of the men with mild haemophilia and a small number (2/21) of women with haemophilia in the same age bracket. However, when asked about 'arthritis', men with mild haemophilia and women with haemophilia both reported this approximately twice as often as men and women without a bleeding disorder in the same age bracket. This raises the question of unrecognised haemophilic arthropathy and joint bleeds, especially as so few women reported target joints, and suggests that further investigation in this area may be valuable.

6.8.5 MUSCLES

Muscle contractures, weakness and other muscle damage were also a feature of living with a bleeding disorder for many older people.

This damage might have begun during their childhood:

'There are ongoing issues caused by previous damage due to haemophilia and Perthes disease [hip disease] that I had when I was eight: pain, restriction in joints and muscles caused through bleeding etc. I have had a hip replacement, but this has highlighted other physical issues.'

'When I start talking about my childhood, the pain, oh my God, the pain we went through you couldn't even imagine. When you bled into joints you would be immobilised for months. It was just like being paralysed, no muscle power to do anything. You had to build up your muscles and get back on your feet and it took forever. This happened over and over.

The simple act to get back on your feet and take a step - so many people take it for granted, that you can jump out of bed and play around. When you got back on your feet, it felt very good.'

Nurses commented that they also saw older people with VWD with muscle damage from bleeds, for example, compartment syndrome, particularly those with severe forms such as Type 3 VWD.

People with mild haemophilia could also be at risk of muscle damage from inadequate treatment and care in other health settings where they underestimated the bleeding complications for someone with a mild disorder. One older man with mild haemophilia described the outcome of a bleed in his hip after hip replacement surgery:

'Post-surgery I had a major bleed in the muscle, and that muscle was damaged. I was not given any factor VIII. None. I was in emergency ward for two nights and no treatment whatever. When I came back home after surgery, I was given a packet of factor VIII and a packet of syringes. I had no idea how to administer it. I had never needed to. While I was in emergency, my wife brought both of those into the hospital and gave it to them and I never saw it. Now I have got a permanent limp.'

6.8.6 MOBILITY AND PHYSICAL FUNCTIONING

For older people with bleeding disorders, a major concern was the increasing impact of joint and muscle damage on their mobility and physical functioning. This could interfere with all aspects of their life: their ability to undertake activities of daily living, to work, to socialise, to travel, and to achieve their aspirations in life.

They were worried about what this would mean for their future:

'As I get older, the harder it will be to do the simplest things. Already difficult, [my] concern is not being able to adapt like I have always in the past.'

'Physical and haematomas when doing physical work.'

'Ongoing loss of function that will prevent me doing the things I currently enjoy.'

'Restricted mobility combined with the possibility of some major medical issue that would necessitate confinement in an aged care facility.'

'My mobility issues will hinder my life and life plans will not eventuate.'

The PROBE Australia study compared physical functioning in men and women with haemophilia to people without a bleeding disorder. For this needs assessment the results were collated by age group: 19-44 years, 45-64 years, and 65 years and over (see **Section 5.6 Probe Australia Study results**).

In every age bracket men and women with haemophilia were much more likely to say they had used a mobility aid or assistive device or had difficulties with activities of daily living than people without a bleeding disorder. The proportions increased in each age bracket: from around one-sixth of those aged 19-44 years; to around one quarter of those aged 45-64 years; to nearly half of those aged 65 years and over.

In comparison, men and women without a bleeding disorder reported low numbers with problems in physical functioning. This ranged from none using mobility aids and one experiencing difficulties in activities of daily living in those aged 19-44 years to small numbers using mobility aids and just over a quarter reporting problems with activities of daily living in those aged 65 years and over.

The differences became more marked when analysed by age, gender and severity. More than three-quarters of men with moderate or severe haemophilia aged 45 years and over had problems with activities of daily living and more than half had needed a mobility aid or assistive device.

6.8.7 MILD HAEMOPHILIA IN MEN AND WOMEN

There has been little research into the issues around physical functioning for men and women with mild haemophilia. The PROBE Australia study results suggest that having a bleeding disorder may impact on mobility and activities of daily living for some people of both sexes in this group. Although men with mild haemophilia aged 45 years and over reported difficulties with physical functioning less often than men with moderate and severe haemophilia, a substantial number did experience problems in this area. More than a quarter of the men with mild haemophilia reported problems with mobility and approximately a third with activities of daily living, which is markedly higher than the equivalent age bracket of men without a bleeding disorder, none of whom reported problems with mobility and only a small number reporting problems with activities of daily living.

Women with haemophilia aged 45 years and over reported fewer mobility problems than men with mild haemophilia but a similar proportion reported difficulties with activities of daily living.

This suggests the need for further research in this area.

6.8.8 THE DOMINO EFFECT

Having a bleeding disorder and multiple joint and physical functioning problems could have a domino effect and exacerbate health complications. The experience of people with severe bleeding disorders aged 35 years and over who had acquired bloodborne viruses such as HIV and hepatitis C from their treatment was commonly given by community members and health professionals as an example. The interviews and the Getting Older community survey provided a picture of what this meant in daily life.

Some identified the impact of 'early ageing':

> *'For me complications are occurring earlier simply because of the number of medical conditions I have which can all be traced back to haemophilia. I don't know they are specific to haemophilia, but they have made worse because of haemophilia. I think we get the onset of arthritis earlier. So we face restrictions when we are younger, and then we worry about how bad our restrictions will be in the future. Some 70-year-olds may not have the lack of movement as we do. We have knee replacements earlier.'*

6.8.9 SELF-CARE AND DEPENDENCE

Both health professionals and people with bleeding disorders noted that the domino effect of bleeds and joint and muscle damage could lead to dependence in a very confronting way.

A psychosocial worker gave an example of the complexity:

> *'Men have problems as they age and get damaged joints - the complications of having target joints of shoulders and elbows and knees and hips and ankles. That's so complicated, when so many bits of them are grumbly. They can't manage normally the way they have managed in the past when they have a bleed. They have a bad elbow and they can't manage the crutches or weight bearing on one leg. How do you do an infusion when one arm is not working? That's tricky for our patients when they are getting older.'*

For the older person with a bleeding disorder, this could impact on the basics of self-care.

> *'Just restriction in movement. No being able to wash - I use a loofah now. I am a lot more careful not to fall in the shower now. Around 50 I started to think about it more. I am expecting my joints to get worse and worse. That's when I will have to make changes to my life. I am going to lose my lifestyle and certain level of independence.'*

A relatively young man with severe haemophilia noted:

> *'It's difficult to shave, I can't reach my top button. Brushing teeth, cutting up pieces of food, tying up shoelaces are a problem. I buy slip on shoes. My partner dries and dresses me.'*

One nurse commented on the effect on their dignity:

> *'Joint and muscle issues can mean some people can't wipe their bottom and [it's very difficult] if they are reliant on their partners and if they have no one.'*

6.8.10 WEIGHT MANAGEMENT

Recognised as an issue for people with bleeding disorders, community education about weight management has been a priority and a feature of bleeding disorder conferences in Australia over the last several years. People with bleeding disorders who are overweight or obese join the general community in being at higher risk of heart disease and stroke, diabetes, musculoskeletal problems and cancer.[125] In the interviews physiotherapists and nurses commented that education about weight management was important for older people because being overweight would also put more pressure on their joints and decrease their mobility. The physiotherapists noted that exercise was an important aspect of controlling weight: *'we need to keep them active, keep them moving. Because once they sit down, it's the "slippery slope" and it gets worse and worse.'*

For the older people interviewed, weight management could be a challenging issue. While they recognised the importance of not being overweight and some commented that they wanted to lose weight, they also struggled with the impact of joint problems on being active and the consequences for their weight. This was an area where they felt they needed ongoing support.

> *'Deteriorating joints makes exercise difficult, so I am gaining weight which I am concerned with.'*

6.8.11 BALANCE AND FALLS

Losing their balance and falling was a common fear for older people with bleeding disorders.

> *'I had a fall three years ago. So I am not even allowed to look at a ladder. My life has been dominated by health issues so that's what I focus on mainly. I can't see past it.'*
>
> *'Tripping over and losing balance. I do go to a fitness class focusing on balance.'*

The cascade of risk factors for balance problems and falls in older people with bleeding disorders with the potential for serious injury is well-recognised in the literature. Joint damage and muscle contractures and weakness in ankles, knees and elbows can lead to less activity and weight gain, as well as osteoporosis, and combined with gait problems make older people with bleeding disorders very vulnerable to falls.[80-84]

The older people interviewed were aware of the increased need for strategies to prevent falls. As one man with severe haemophilia explained,

> *'Your bleeding disorder makes it more challenging with your movement and stability. It's getting out of bed in the morning. I use a crutch and I only have been doing that about the last two years. I go to bed at night with crutch beside the bed. So, when I do get up, I feel more comfortable hopping down to the bathroom. Once I have been down there, I leave it down there until night-time.'*

Physiotherapists spoke about the difficulties of rehabilitation and the ongoing spiral of physical decline after a fall.

'They have poor balance because of their joints. Whereas somebody else without elbow issues will use their arms to push themselves up if they are getting older, when [older people with haemophilia] use their arms, because they've got the issues with terrible arthritis with their elbows, they can't rely on their arms as much. And if they have surgery, they are going to struggle a bit more with the frame. Post-surgery a fracture may happen, and they are going to be in a wheelchair for a short time. With that they can deteriorate further. If you put someone in a wheelchair, they are not going to use their muscles at all.'

While older people with mild haemophilia had joint damage less often, they were also less likely to be on prophylaxis treatment to keep their factor levels high enough to prevent bleeding complications, and health professionals noted that a fall for them could be catastrophic:

'If a patient with mild haemophilia is having any issues with balance, and they fall straight ahead, that has a massive implication if they have a head bleed. Not only that they are going to break their head, but they are going to have massive bleed with it.'

WHAT WILL HELP?

In the consultation older people with bleeding disorders were asked what would help them achieve their aspirations for the future. Most commonly they gave health-related suggestions that would enable them to stay active, mobile and independent.

Treatment approaches

Older people with bleeding disorders identified a number of treatment approaches that could assist with this:

- A cure or improved treatment that is longer-lasting or non-intravenous
- A cure or 'rejuvenation' for joints that were damaged or arthritic
- Holistic and integrated care to take the complexities of their complications into account.

'Non-intravenous treatment. My veins are not good and limit the amount of treatment I can administer. I cannot apply proactive treatment only reactive.'

'A cure for slowly deteriorating joints (the one that are not fused or replaced).'

'My ankles have progressively got worse in the past 20 years. I am managing - I had a steroid injection this year and that really improved my quality of life. I am trying to walk more and keep moving as much as I can.'

'Often a chronic illness such a bleeding disorder needs holistic care. Our current hospital and referral system is such that each specialisation acts as a silo rather than working together. This is fine if a person is treated for a one-off issue. But becomes a problem when an illness creates a myriad of issues that need examination.'

Programs and services to assist with physical functioning

Both community members and health professionals noted that programs and services to assist with mobility, exercise, balance and falls and pain management would be valuable for physical functioning and quality of life.

Specialised and individualised programs developed and monitored by haemophilia physiotherapists were a high priority and were provided through

the HTC as part of comprehensive care. Standard programs, such as falls and balance classes in the community, had their place. However, HTC physiotherapists underlined the need to ensure that the program suited the individual and that their patients were able to undertake the exercises and movements correctly so that the exercise program did not aggravate their problems.

'I am really not a fan of online therapies. Every patient's bleeding disorder affects them in a different way; every patient has different issues. And there is really isn't a one size fits all.'

HTC physiotherapists sometimes also provided exercises in online videos, but noted that uptake was very individual: *'people do them or don't do them'.*

Accessing programs and services in the community

Physiotherapy is an essential requirement for comprehensive care in a Haemophilia Treatment Centre and older people with bleeding disorders could access physiotherapy at their HTC hospital. Some older people with bleeding disorders said it was important to have the option to access physiotherapy programs and services in the community, closer to where they lived, and where they could park closer to the venue. This included therapies targeted at older people with mobility and balance problems and arthritis, for example:

- Hydrotherapy and aqua aerobics
- Massage
- Falls and balance programs
- Specialised sports physiology and pilates, yoga and T'ai chi for people with arthritis
- Weight management education and support.

'Access to aqua aerobics sessions, physio, massage - all those things I find myself accessing to keep moving and to keep as flexible and strong as possible. Anything that helps me to get on the floor and participate in those sessions is very valuable.'

'I think access to therapies to keep strong and mobile. I am talking about my local community support centres, so I don't have to go to the hospital to access my aqua-physio. Having access to parking spaces would help, so we don't have to walk too far.'

'I identified a gym that has a hydrotherapy pool. It has a good infrastructure - good steam rooms and things like that. That would help aches and pains. That's really important to me. I am really conscious that if things don't go well, and I have more injuries or more bleeds, my health could deteriorate.'

Some state and territory Foundations noted a problem with affordability with these programs when delivered outside the HTC and that subsidised access would also be important.

HTC physiotherapists had already been working with physiotherapists in the community and had found this worked well for some of their older patients.

During the consultation, the HTC physiotherapy and the rehabilitation experts had several suggestions to support this approach:

- Identifying a local physiotherapist who would accept and most benefit the person with a bleeding disorder in a reasonable timeframe
- The HTC physiotherapist may prepare an individualised program for the patient and liaise with the local physiotherapist to implement and monitor the program, including ongoing questions and concerns
- Or the HTC physiotherapist may refer to the local physiotherapist to assess the person for a program
- Supporting education resources on physiotherapy for an older person with a bleeding disorder would be provided to the local physiotherapist and could perhaps be available on the HFA website
- Older people with bleeding disorders may be able to access some government funding or support for physiotherapy sessions through community health and nursing home funding programs, including through My Aged Care.

For equitable access nationally, this approach would require adequate resourcing for specialised haemophilia physiotherapy in all state and territory HTCs.

Home modification and independent living aids

Another area that was raised by both community members and HTC health professionals were the strategies, aids and modifications that would enable older people with bleeding disorders to remain active and independent for as long as possible.

This included:

- Mobility aids, such as motorised scooters and wheelchairs
- Equipment such as shower chairs
- Medical devices such as arm supports and braces for elbows, modified footwear and orthotics, artificial limbs and other prostheses
- Home modifications, including ramps, rails throughout the house and disability-accessible bathrooms
- Independent living aids, for example, reaching aids to pick objects up from the floor
- Strategies developed to work around problems with physical functioning.

'So, these are the things I think would help in long run. For example, my stiff elbows mean I am having more trouble doing shaving, doing my teeth, doing my buttons up, wearing a tie. Each of these problems requires a unique solution such as a long-handled toothbrush, dressing more casually - I don't wear ties anymore.'

HTCs noted that referral to an occupational therapist for review was essential and needed to be integrated into comprehensive care.

While some older people saw their future as downsizing or moving to residential care, others saw more value in remaining in their current home.

'We have already modified the house so it's aged-care friendly and completely accessible. We have two bathrooms that have disabled access. Almost every entrance that it has is wheelchair friendly. I have done a lot of work to it. It may be easier to stay where we are than to move.'

'I don't want to go to a nursing home. I would prefer to stay in my home, and still do whatever I can for myself. We own our home. Since my knees went crook, we have recently put concrete ramps outside and also have done the flooring. We had carpet but put floating boards down to make it easier to clean.'

Some also found it helpful to reduce their home maintenance tasks.

'Fortunately, I planned years ago, so that my garden is almost maintenance free and there is minimal work to be done. I don't have any lawn at all so that I don't have worries about that. Life is a bit easier.'

HTCs also identified that funding for and access to specialised aids and equipment in a timely way needed to be addressed. This was an area where occupational therapists could assist and was an important reason for occupational therapists to be integrated into HTC comprehensive care teams.

'The funding model is an issue. For equipment they have to use another funding model, for example the State-wide Equipment Program. They might need to self-fund.'

'It is very difficult for men [with severe haemophilia]. They need scooters and something more permanent. Not all scooters fit all people. It is very difficult to have funding to provide that, you need support to access it.'

Physical functioning in mild haemophilia and women

Although men with mild haemophilia and women with low factor VIII or IX levels are the larger proportion of older people with haemophilia, little is known about the effect of their haemophilia on their joints and muscles and their physical functioning. The results of the PROBE Australia highlight the unexpectedly high proportion of 'arthritis' and difficulties with activities of daily living in both the men and women and problems with mobility in the men.

It would be valuable to have some larger clinical studies to look more closely at this area.

Physical functioning in VWD and rare bleeding disorders

There has also been little research into the impact of having a bleeding disorder on physical functioning in people with VWD and other rare bleeding disorders. Further study of this area will help to understand the issues for these groups.

6.9 Pain

Pain was often mentioned by both community members and health professionals as a significant issue for older people with bleeding disorders.

6.9.1 COMPARATIVE EXPERIENCES

Data from the PROBE Australia study suggests that the experience of pain in people with haemophilia may vary according to age, gender and severity (see **Section 5.6, Probe Australia Study results**).

People in the younger group aged 19-44 years were slightly more likely to experience acute pain rather than chronic pain, with more than half reporting acute pain and less than half reporting chronic pain. In the older age groups these proportions switched, with more than half reporting chronic pain. Interestingly, in the group aged 65 years and over, the proportion reporting acute pain dropped to a third.

When the pain experiences of people with haemophilia aged 45 years and over are further analysed by gender and severity, there are clear differences between the groups. The highest proportions were in men with moderate and severe haemophilia, where more than three-quarters reported acute and chronic pain. Men with mild haemophilia were less likely to experience pain than those with moderate and severe haemophilia, but nevertheless, more than a third reported acute pain, and nearly two-thirds reported chronic pain. The pain experience of women with low factor levels seemed to follow a different pattern, with more than half reporting both acute and chronic pain. The interviews did not reveal more information about the acute pain experience of women, and this will need further investigation to understand it better.

It might be expected that many people in the general community experience pain as they grow older but the PROBE Australia data highlighted the very much higher proportion of those with haemophilia who were affected by pain in comparison to the those without a bleeding disorder. This occurred in every age bracket. It was particularly remarkable in the 19-44 year age group, where for example, around a half of younger people with haemophilia reported chronic pain in comparison to about a quarter of younger people without a bleeding disorder when compared by gender. This may be related to some of the issues associated with early ageing.

6.9.2 THE INTENSITY OF PAIN

Understanding the intensity of this experience is important.

One man with severe haemophilia who was active in peer support observed that community members with bleeding disorders managed pain very individually.

'As you grow older medications are very individualised, how you cope with the pain is very individualised. I think after a lot of discussions over the years I have realised that a lot of people deal with their pain in different ways.'

For some the experience of pain was intermittent. An older man who was interviewed commented:

> *'There are pinch points in my life where you go through bit of pain to perform your tasks. Coming here today was not easy.'*

For many, the impact of pain was an immediate concern. Several Getting Older survey respondents described the need for more effective pain management as 'urgent' and partners and parents noted that the person's pain was increasing as they grew older.

> *'The bleeding can be controlled but the pain can't. Going to hospital to support pain relief can be difficult as drs don't respond to support patients who may use level of pain relief daily to sustain some type of normal life.'*

The national approach to reducing codeine use and dependence on other opioids was a cause of frustration for some older people with bleeding disorders, who had not found other ways of managing pain. A partner noted:

> *'Pain related to bleeds - a serious inability to control pain, now that codeine is unavailable over counter. And most GPs have no clue what REAL PAIN is.'*

6.9.1.1 Pain management approaches

For the person with a bleeding disorder, medication options for managing pain were limited as they were not able to take some NSAIDs, such as ibuprofen, because these medications increased their bleeding tendency.

Cannabis is known to be used for pain management by some people with bleeding disorders. The value of cannabis in reducing pain was viewed quite differently by the various participants in the consultation. Some individuals with bleeding disorders spoke highly of its benefits in pain relief; some with HIV also used it for stimulating appetite. On the other hand, health professionals were concerned about its impact on decreasing their patients' motivation and ability to organise themselves. Parents of middle-aged children who were frail and dependent, particularly if they had HIV and had cognitive changes, were concerned about their vulnerability to trafficking. Changes to legislation in 2016 have meant that medicinal cannabis is available for chronic pain in some states and territories under the Special Access and Authorised Prescriber schemes.[126] A large 2019 Australian study found that most cannabis users surveyed had continued to obtain marijuana from illicit sources rather than accessing medicinal cannabis through an authorised medical practitioner[93], and this was also the case with participants in the HFA consultation. The ongoing study of medicinal cannabis will be important to this debate and to finding effective pain management approaches.

Health professionals were very conscious of the need to determine the cause of the pain to manage it more effectively. Being able to assess whether the pain was related to haemarthrosis or a bleed using diagnostic tools such as Point-of-Care Ultrasound was crucial to the type of treatment required - would they treat the bleed with factor or the arthritic pain with an appropriate anti-inflammatory or neuropathic medication? In some cases, physiotherapists noted that exercise may be beneficial, but would need to be carefully monitored not to aggravate the problem. A physiotherapist remarked that their patients' stoic approach to pain could in this case be a disadvantage:

> *'And they just brush it off as haemophilia not knowing that it could be something else and engaging with their teams. It is very difficult for a person who has haemophilia to tell whether or not the pain in their knee is due to a bleed or due to rheumatological inflammation - their haemarthrosis flaring up. It's very difficult to get the message across that they don't need to accept this and there is help.'*

WHAT WILL HELP?

Specialised pain management is clearly a high priority and will need to be a significant aspect of comprehensive care into the future.

Several Haemophilia Treatment Centres spoke of the value of liaising with specialist pain management services and rheumatologists to reduce pain and find alternative and more effective pain management strategies. This could then become a pain management plan to be implemented with the support of the person's general practitioner.

Education for older people with bleeding disorders about pain was a common recommendation to assist with self-management:

- Understanding the experience of pain
- Differentiating arthritic pain from pain related to a bleed
- Strategies for managing pain, including specialist pain management services and alternative medication options to opioids
- Benefits of exercise for pain.

Physiotherapists also noted the benefits of having access to Point-of-Care Ultrasound for diagnosing the cause of the pain, both at the HTC and at local health care services.

6.10 Veins and skin

As they aged, people with bleeding disorders were very aware of the complications of increasingly fragile skin, loss of dexterity and having a bleeding disorder.

Both men and women, particularly those with moderate and severe bleeding disorders, were concerned about the difficulty of infusing their replacement factor product into a vein and the damage to their veins with scar tissue, both from many years of infusion and from unskilled venipuncture from some health care professionals.

'I can find myself getting a bit shakier now which can make intravenous injections little bit harder. I am lucky, I have got good veins. I have issues with the veins in my right arm, but I use the other arm - but I can inject right-handed or left-handed.'

'I can't use the other arm. I can't straighten this arm.'

'I still give injections myself and the veins are getting very tired - there is lot of scar tissue. I have been injecting myself since I was age 13. That's 40 years. I try and rotate the veins, but especially with the little bit of weight on, it is little bit more difficult too. When I was in the hospital my vein was damaged due to all the blood tests.'

Some found accessing veins psychologically daunting. Partners took an increasing role in undertaking the infusions for them.

'I just put it in the same vein. It's frustrating if you miss it twice - you feel like throwing it away.'

'Each time you go to different location for vein access, it's like starting over psychologically.'

'I have [plasma-derived factor VIII] three times a week. My husband does it for me. I tried to do it myself but no.'

Health care professionals in some states commented on the difficulty of accessing community nurses with appropriate skills to help with infusions at home and wondered about the possibility of using schemes such as hospital-in-the home programs to provide assistance with infusions.

'When people who are on prophylaxis treatment can no longer infuse into their arms - if they have elbow issues and they can't access themselves adequately - we don't have any means in the community where they can have somebody go into their house and help them. No community nurse would do that, and then they are required to come to the hospital and with some severe physical ailments, it's really taxing to have to come into the hospital. Hospital resources could be used in these areas.'

Nurses also commented that skin integrity required extra care as their patients grew older. Some people with bleeding disorders had noticed increased bruising and were concerned by it.

WHAT WILL HELP?

Newer and emerging treatments that could reduce the frequency of infusions or be injected subcutaneously rather than into a vein were viewed by all as a positive solution to vein problems in older people with bleeding disorders.

This is discussed in **Section 6.7** under **The promise of new treatments.**

Other suggestions from HTC haemophilia teams and older people with bleeding disorders included:

- Education on vein care targeted at older people with bleeding disorders
- Teaching partners or carers to infuse
- Access to a skilled infusion nurse to assist with infusions in the home or residential aged care facility.

Venipuncture to provide infusions is a specialised area of nursing. Access to skilled infusion nursing in the community will be variable across Australia, and it will be important to explore the options available in each individual situation.

'Last night we talked about it [wife learning to do infusions]. She is reluctant but she thinks she probably could if she had to. If I was in residential care for example, she would be an advocate or learn how to do it herself. That is the possible solution to that residential care worry.'

'Vein health issues increase as they are getting older and it may well be to do with venous elasticity. They have been on treatment for so long, their veins are running out of places to puncture. Or they may be using veins over and over again and all of a sudden the vein gives up and then they may have no other alternative because they have never used another vein. We offer them education - to come in for training. It's not like you don't know what you are doing, it's more like a refreshing thing - do you warm up your arm, etc. Some of them might have a phobia accessing there. It also depends how they were trained when they were younger, for example with rotating veins. It's like reprogramming.'

6.11 Bleeding gums and dentistry

There was some discussion about dentistry in the consultation with community and health professionals. All agreed that dentistry for a person with a bleeding disorder could be fraught because of the potential for bleeding episodes. It could also be difficult to access a dentist, for financial reasons and because only certain dentists would agree to work with a person with a bleeding disorder due to the potential complications. Going to the dentist could also be a source of anxiety because of the pain and bleeding.

HTCs highlighted that preventive dentistry was very important.

Gum bleeds may be a symptom of a bleeding disorder or may also indicate periodontal or gum disease, often due to inadequate teeth cleaning and sometimes exacerbated by HIV and hepatitis C.[8,95] Some older people interviewed commented that they were having difficulty brushing their teeth because of problems with their elbows.

It is interesting to note that in the PROBE Australia data, people with severe haemophilia only reported gingivitis/ gum disease or bleeding gums at the same proportion as people without a bleeding disorder. However, men with mild haemophilia and women with low factor levels were more than three times more likely to report bleeding gums or gum disease. This suggests a need for increased education around dental hygiene with a bleeding disorder and a regular review by a dentist, and perhaps a review of their bleeding issues.

Access to a local dentist was becoming more of a priority as they grew older and travel was proving difficult. One woman with a severe disorder expressed her frustration with a drastic solution:

> *'I want all my teeth out. I have been going to the dentist in [capital city] since I was a kid. I have had enough of going down there. I have had 50 odd years of going back and forth. I would rather just stay home.'*

WHAT WILL HELP?

Increasing access to dentistry for older people with bleeding disorders was seen by all as important, but finding ways to achieve this remains an ongoing issue. A number of areas will need to be explored:

- Accessing appropriate local dentists who will treat patients with bleeding disorders and liaise with HTCs on their management
- Accessing specialist dentists in the capital city or the dental service co-located at the same hospital as the HTC
- Transport options to assist with visits to specialist dentists
- Financial support to pay costs of private dentistry.

HTCs noted that it was often difficult to know what dentists were available locally, and that it may work better to ask older people with bleeding disorders to source a local dentist and then for the HTC to liaise with the dentist. Promoting preventive dentistry was also a priority.

6.12 Bloodborne viruses

People with bleeding disorders commented that it was hard to separate the impact of a bloodborne virus such as HIV or hepatitis C from that of haemophilia as they grew older, but they were very aware that it led to earlier ageing.

> *'I have had HIV for 35 years. HIV is well suppressed, well managed. Certainly it is still there, but it is undetectable. But due to that antiviral treatment, I am aging faster than most people. For example, people have been asking me to produce my senior's card or my pension card from my early 50s.'*

Psychosocial workers noted the dramatic impact of bloodborne viruses on their clients' health and their relationship with their treatment and the health system generally.

> *'Those who have been infected with HIV and hep C have special needs depending on how these diseases have impacted them, not just emotionally and psychologically, but then also the trust they have in the treatment services, considering that more than likely these individuals were infected years ago by unscreened blood.'*

State and territory Haemophilia Foundations and psychosocial workers described the impact on some community members' life expectations and personal relationships.

> *'You have to recognise that the group with HIV are different cohort. One has spoken to me about "not being able to dream or plan for future" because three quarters of his community of friends died within six months, when they first had HIV. So all his life from his 20s, he was told not to expect much - "You probably have two years".'*

'HIV and hep C infection has affected their personal life due to stigma. Their sexual life is also badly affected and they refuse to be in relationships or have pretty much withdrawn from their friendship circle.'

6.12.1 HIV

Although it was recognised that HIV infection was now well-managed with treatment, both people with bleeding disorders and health professionals spoke about the accelerated effects on pain, mobility, complications such as osteoporosis, heart disease or cognitive impairment, and overall fragility when growing older was combined with HIV and a bleeding disorder.

Psychosocial workers commented that those with complex needs were well-serviced by a range of agencies specialising in HIV and providing case-management.

Some people with bleeding disorders had acquired HIV during childhood and were now in their middle years. While some felt they were managing reasonably well, others were particularly unwell and frail. When they had not established a long-term relationship and their parents were their primary carers, their parents were growing anxious about their care into the future – who would advocate for them and protect them when their parents were gone?

As they grew older and needed surgery and other medical and dental procedures for ageing-related problems, they experienced discrimination from health care professionals in the wider community:

'I understand where their fear is based. But it doesn't seem to be based on current practices. How if someone HIV positive is well treated the risk of infection is probably none. My GP is normally fine. [Discrimination is] normal from my dental surgeon, general surgeon, a neurosurgeon, people who might be operating on me. You can see it in the way they look at you, in the way they respond to administering a procedure.'

6.12.2 HEPATITIS C

The legacy of hepatitis C infection

Many had lived with hepatitis C infection in the past, although nearly all had successful treatment and were now cured. Some commented on hepatitis C symptoms they had experienced in the past, such as fatigue, or side-effects from interferon-based treatments, but often brushed over the enormous impact both had on their working and personal lives, with brief comments such as *'Hep C treatment (2012-13) had a negative impact'* or *'forced to retire early'.*

A stoic approach to hepatitis C was common. Some explained that hepatitis C was yet another medical issue that they had tried to take in their stride:

'It's funny getting older with hep C. It didn't affect me. I live quite happily. It happened years ago. That's 30 odd years. It didn't cause me any problems. I get the occasional liver scan. Slight anomalies, the next one will be clear. I didn't know I had it until the 1990s, by which stage I was married and had children. And suddenly they say you know you have hep C. That kind of hit me with a ton of bricks – when, where? But you get your head around it and go on.'

Some were grateful for successful hepatitis C treatment and the potential improvement to their health and lifespan:

'There are the added medical issues [of living with hep C] – the extra layer of appointments and medical management. Getting rid of hep C was a load off psychologically - one less thing to worry about. Also, my risk of liver cancer has dropped dramatically, which was a really happy thing. I have an ultrasound every six months for monitoring, surveillance for cancer. So, there is a layer of worry there about the risk of cancer. But that's what we live with I suppose. I am lucky to be here. And the

treatment for hep C came along in time for me. So, it's not so bad having an ultrasound every six months, when you are cured.'

However, those who cared for them - their partners and family and the HTC health professionals - were concerned about the health complications that some older people with bleeding disorders affected by hepatitis C were now experiencing. Several commented on their ongoing issues with liver damage and cirrhosis. Nurses noted that, while some of their patients had 'picked up their lives' after curative treatment for hepatitis C, others were having liver transplants and they anticipated that some of their patients would go on to develop liver cancer.

A psychosocial worker described the impact of living a large part of their life with hepatitis C infection and then having curative treatment:

'Of course, all that trauma is still there. Most have been treated for hep C and doing well. But 20 to 30 years of their optimal life have been affected. They were not feeling great and only realised after they had [successful] treatment. The early treatments had severe side-effects and caused psychiatric disturbances, for example, one had severe depression and his marriage nearly broke down.'

In some cases, the psychological impact was substantial. The legacy of these experiences continues into the present.

'My mind was going crazy in the years [19]84 -85. All these people I used to go into [the HTC] with, all passing away. I thought I am next. So, I have been fortunate in that regard. Anyway, with the tablets two years ago I cleared hep C. But I went through issues coping mentally and it's hard.'

'I think the issue now is that for the people who have liver damage, it's causing issues. Other things - a few people have started talking about the investigation happening in the UK around blood borne viruses [in the past] and that is impacting on their state of mind.'

The consultation for the needs assessment around the impacts of hepatitis C on older people with bleeding disorders underlined its negative impact on their working life and ability to earn an income during what would otherwise have been the most productive years of their life. As a result, some now had limited or no superannuation and their financial security in their senior years was becoming problematic. This is discussed in more detail under **Section 6.21, Working** below.

For some, the inability to sustain a career was having an increasing effect on their psychological wellbeing as they came closer to their senior years.

'I struggle with depression a bit. I am in a bad patch at the moment. Sometimes you have issues with your feeling of self-worth when you are not working any more. [15 years ago] I was pretty sick with hep C and had hep C treatment which worked. But my health at that time wasn't good. I did part-time and was working less and less and struggling for it. In the end I found that it's too much of an ask from the employer, arriving at work late and not going to work. I thought I had been letting my employer down.'

Foundations described their concern that the effect of a lifetime of complications with hepatitis C was being overlooked because many of their community members had a stoic approach of *'just getting on with it.'*

'If they have had successful treatment for hep C, I hear a lot of the older people with bleeding disorders say they just want to get on with their lives. But there's no doubt, when you look at the evidence and hear their stories, that hep C has had a huge impact on their work and income and their quality of life over the years. And now that they are getting older and having more complications, it's all starting to unravel for some people. They don't have much in the way of savings or superannuation, they have multiple chronic health problems, they have often moved away from the city to save money, and now they are really struggling. But they are stoic and uncomplaining and don't want to talk about it or ask for help. It just seems really unfair to leave them in this kind of position after all that happened because they try to make the best of things. You look at what can be done, in the services for HIV, for example, and think that's the sort of help they need.'

'Individuals have specific needs, such as anxiety and depression. More than 75% contracted hep C at one point. Some have liver cancer now. There are specific socio-economic factors that are related to hep C - the financial burden from unemployment and because they missed out on education. This needs to be addressed.'

Unlike the situation with HIV, there has been no government financial assistance for people with bleeding disorders who acquired hepatitis C from their clotting factor treatment products in Australia. The 2004 Senate Inquiry into Hepatitis C and the Blood Supply recommended that those who acquired hepatitis C through the blood supply should be offered financial assistance for out-of-pocket health care costs and case management for their treatment, care and welfare issues[127], but, in spite of repeated requests from Haemophilia Foundation Australia, this was never implemented. The needs assessment highlighted that these issues remain – in fact, are increasing for some – and still need to be addressed.

Ongoing medical concerns

The results from the PROBE Australia study highlight the high level of exposure to HCV among people with haemophilia in Australia through their treatment products. More than two-thirds of the men with mild haemophilia and nearly all the men with moderate and severe haemophilia aged 45 years and over had been diagnosed with HCV. Some women had also been affected, including small numbers of the women with haemophilia and one of the women who carried the gene and had a normal factor level.

In comparison, only one of the more than a hundred men and women without a bleeding disorder aged 45 years or over had ever been diagnosed with HCV: a male, who had cleared the virus spontaneously.

HTCs have reported high rates of treatment and cure among their patients. Nearly all of the men and women with haemophilia or carriers in the PROBE study who had been diagnosed with hepatitis C now reported that they had cleared the virus, either after treatment or spontaneously. However, there remained one man with severe haemophilia who had unsuccessful treatment, a reminder that there is still a small number of people who have not been able to clear the virus. It is also notable that there was one woman with normal factor levels who had been diagnosed with HCV but did not know her current HCV status. The PROBE study reflects results from the more engaged in the community; there would possibly be many more in this situation in the wider community. This raises another concern: HTCs were convinced that there were more older people with mild conditions and carriers who had not yet been diagnosed. This highlights that those who are not engaged with HTCs might not have had a review of their HCV status and be missing the opportunity to have treatment and be cured.

Haemophilia foundations and HTCs also expressed concern about the number of people with cirrhosis who were not being followed up with ongoing liver health monitoring. Many assumed that because they had been cured, their cirrhosis was no longer a liver health risk, when they actually needed to be monitored regularly for serious complications such as liver cancer. To some extent this may also be an accidental by-product of the relief of

one less co-morbidity to manage as you grow older, and demonstrates the need for continued health promotion messages as well as liaison with hepatitis clinics.

'I have been cured of hep C. Now it's not an issue. It is an issue with the long-term consequences, as you may get carcinoma or you might get liver damage. Because it is cured I don't worry about it. Once it is cleared, it's one thing you tick off and you worry about everything else.'

Another issue with managing advanced liver disease in an older person with a bleeding disorder was that it could have implications for bleeding complications and interactions with their medications. A haematologist noted that it would be important for other health services managing their liver disease to liaise with the HTC to alert the HTC and seek their advice.

WHAT WILL HELP

Acknowledgement

It will be important for the bleeding disorders community in Australia to have the traumatic experience of being exposed to HIV and hepatitis C and the ongoing impact on their life acknowledged formally, even if they have been cured of hepatitis C.

This acknowledgement will also need to be included in psychological care. Psychosocial workers considered that a trauma-based clinical practice approach may be appropriate. Understanding the experience of the bleeding disorders community in this framework may also be helpful for all of the health and community services who provide their care and support.

'Probably by validating their experiences. This person has been generous: he doesn't rage against [his experience with bloodborne viruses]. I think validating that it has occurred, not dismissing or diminishing their experience, but also being really aware how much damage physically their body has been through too. Having an awareness around such trauma – medically-induced trauma - and managing trauma at psychological level with trauma-informed practice. There is a group – the Blue Knot Foundation - they do trauma-informed care to manage, for example, childhood abuse.'

Further work

The needs assessment consultation clarified that there are several areas where further work needs to take place:

- Case management extended to people with bleeding disorders affected by hepatitis C, as is the case with those with HIV, to ensure their physical and psychosocial health and financial needs are being met, and that advocacy on behalf of individuals takes place when required
- Financial assistance for out-of-pocket costs with health and community care
- Continuing to work with HIV and hepatitis organisations on discrimination
- Health promotion and clinical follow-up for people with bleeding disorders exposed to hepatitis C. In particular, this relates to:
  - Ongoing monitoring for people with cirrhosis
  - Liaison between hepatitis specialists and HTCs for management of people with bleeding disorders who have advanced liver disease
  - Reaching men with mild conditions and women with bleeding disorders or who carry the gene for haemophilia to encourage testing for their current HCV status and to seek treatment if they have hepatitis C.

'There needs to be a concerted education campaign for health professionals to educate them about the low risks of HIV infection when the patient is well suppressed.'

6.13 Health conditions of ageing

Nurses in the HTCs commented that their older patients, both male and female, were experiencing many of the health conditions that occur in the general population as people age:

> *'What we are starting to see is more of natural ageing processes such as arthrosclerosis or cardiopulmonary ageing-related issues - people needing heart bypasses or stents or pacemakers. We are seeing other degenerative diseases and other problems such as gastrointestinal problems or cancer.'*

6.13.1 WORKING WITH OTHER HEALTH CARE PROVIDERS

Haematologists and nurses explained that these conditions would be managed by the appropriate specialist for the condition in a public or private health care setting, or in an ongoing treatment plan by a general practitioner. However, for the person with a bleeding disorder there were the added complications of needing to prevent bleeding episodes. This might require balancing anticoagulants with factor levels, preventive cover for surgery and medical and dental procedures, and other management of bleeding complications and would need careful liaison with the HTC. A haematologist commented that other health care services may sometimes overlook contacting the HTC for management advice when older people with bleeding disorders consulted with them about health conditions unrelated to their bleeding disorder. This could have significant implications for their health if bleeding complications and interactions with their bleeding disorder treatments were not taken into consideration.

For the older person with a bleeding disorder, there was not only an issue about preventing unnecessary bleeding, but also a need for their other health care providers to have a good understanding of the other complications with their bleeding disorder. Some described their frustration at having their health problems dismissed by health care providers in the general health care setting, for example, when doctors perceived their complications as a common problem of ageing. This often occurred when they had a mild condition such as von Willebrand disease or a rare bleeding disorder, such as an inherited platelet function disorder, and their bleeding disorder was unfamiliar to their health care provider.

> *'Medical staff dismissing symptoms due to ageism. Eg "What did you expect, you're fifty now." Rather than explore the reason why I have painful joints.'*
>
> *'Some agencies do not consider von Willebrands disease to be of any concern. They may need help to understand the problems that we face.'*

6.9.1.2 Heart disease and hypertension

In the PROBE Australia study all participants were asked if they had other specific health problems in the last 12 months, many of which were related to ageing. When the results for those aged 45 years and over were analysed, these produced some interesting results.

While the experience of some ageing-related health conditions was similar between the older people with haemophilia and those without a bleeding disorder, for example, stroke, diabetes and kidney disease, there were other health conditions where there were noticeable differences. Substantial numbers of men with haemophilia reported heart disease - for example, around one-fifth reported angina/chest pain compared to only one man without a bleeding disorder; and approximately half reported high blood pressure in comparison to the just over a third of the men without a bleeding disorder. There has been ongoing debate about heart disease and hypertension in men with haemophilia and these results underline the need for more research in this area to understand the underlying factors at work.

6.9.1.3 Dementia

Dementia was a common concern. Older people with bleeding disorders were worried about the impact developing dementia would have on their ability to

manage themselves and their treatment, 'not getting treatment on time' and having to go into residential care. In a nursing home, 'if I had a bleed how anyone is going to know. Because I am not able to tell them.' They were uncertain that they would be able to identify when they were developing dementia and needing extra care. If their partner was still at home, they worried about the extra burden on them.

Health professionals commented that with increasing numbers of people with bleeding disorders living on into older age, they were starting to see more of their patients develop dementia. This could impact on treatment management issues: forgetting instructions and appointments, making treatment management 'tricky', having problems with balance and walking. Although some of their patients were placed in nursing homes, most relied on relatives or partners as carers and health professionals were concerned about the extra burden on family, but they were also concerned about patients who were single and did not have anyone to advocate or care for them.

WHAT WILL HELP

Special issues for older people with bleeding disorders

The research to understand how having a bleeding disorder impacts on the health conditions of ageing is necessarily in an early stage, as this is the first generation where larger numbers of people with bleeding disorders are surviving into old age. It will be very important to prioritise specific research into this area, particularly in areas such as heart disease and hypertension where some studies show higher rates of prevalence in older people with bleeding disorders in comparison to the general population.

Australia is fortunate to have a strong database as a tool for research in the Australian Bleeding Disorders Registry (ABDR), the system used by HTCs for the clinical management of their patients with bleeding disorders. Aggregated data from the ABDR will be an essential element in research to understand ageing with a bleeding disorder. It will be crucial to maintain ongoing development of a robust national database by supporting:

- the collection of clinical data into the ABDR system
- the contribution of information about bleeds and home treatment from people with bleeding disorders and their carers through MyABDR
- The development of the ABDR to provide meaningful data reports
- The ability of researchers to access relevant and de-identified information in an appropriate and timely way.

Education and support

Both community members and HTCs identified the need for education and support around the special issues in health conditions of ageing for a person with a bleeding disorder. They thought this should be developed for different target groups:

- The older person with a bleeding disorder
- Their partner, family or carers
- Health care workers who provide their care outside the HTC.

Community education

Older people with bleeding disorders thought it would be useful to have education materials about growing older with a bleeding disorder, explaining what to expect and how they affect a person. The resources could be developed in such a way that they were not just for the person with the condition, but could also be suitable for partners and carers.

HTC health professionals and state/territory Foundations saw the value in educating not only about the medical conditions, but also about how to self-manage for the best health outcomes.

This could include:

- Understanding how getting older affects a person with a bleeding disorder
- Preparing for medical, surgical or dental procedures
- The value of attending a regular review at the HTC
- Falls prevention, pain management
- Preventing and managing health conditions associated with ageing such as heart disease, diabetes, hypertension, dementia, gum disease, obesity, cancer, osteoporosis
- Staying active, healthy eating and exercise habits
- Self-advocacy in the health setting
- Building resilience, participation, respite, self-care.

Some also suggested promoting apps that work as reminders about exercise or as mental activities to prevent cognitive decline.

Health care worker education

Education for health care providers in the community about bleeding disorders and issues of ageing would have a significant role in supporting integrated care and reducing unnecessary bleeding episodes and other complications in older people with bleeding disorders.

The strategies that would provide the most effective education for health care workers would need to be targeted to the particular specialities providing treatment and care and may involve:

- Best practice clinical guidelines
- Education at the undergraduate and postgraduate level
- Integrating information about bleeding disorders in relevant professional development courses
- Journal articles and conference presentations and abstracts
- Education materials developed specifically for particular procedures or services that could be supplied to support liaison between the HTC and the care provider, eg surgery, dentistry, podiatry, physiotherapy, residential care, dementia care, general practice
- Professional development sessions for particular interest groups, for example, general practitioners who have patients with bleeding disorders.

Older people with bleeding disorders thought it was important that education for health care workers outside the HTC recognises the experience of the person with a bleeding disorder and their knowledge of their own body.

'If a doctor gives me a diagnosis - I know my body better than the medicos sometimes. I have been in the hospital system for an awfully long time. You listen to what they say because they are medical people. If it sounds right, that sounds right. If it doesn't sound right, if it doesn't make sense to me, I will question the medical profession.'

Dementia

The consultation highlighted that the cognitive and physical decline associated with dementia complicated treatment and care, including managing infusions. Replacement factor therapy involving fewer infusions or subcutaneous rather than intravenous injections was suggested as one way of decreasing the difficulty of treatment.

Case management to support both the person and their partner and family or carers would be valuable for managing the transition period while they progress to high care and various primary care and community services are called in to play a role, and for appropriate management in high care facilities such as residential aged care, where education for care providers and advocacy may be required.

6.14 Women

Women with bleeding disorders also experienced female-specific problems as they grew older, particularly gynaecological problems such as heavy menstrual bleeding in the lead-up to menopause. Because bleeding disorders are rare and haemophilia has traditionally been associated with males, the health professionals providing their care could sometimes be unaware of the special needs of women with bleeding disorders. A nurse explained:

> *'We do see some women who have polycystic ovarian syndrome or other kinds of gynaecological issues. Their bleeding disorder does have an effect upon that and complicate those matters. The complications sometimes come when the medical professional they go to see does not have a full or in-depth understanding of their bleeding disorder and does not engage with their Haemophilia Treatment Centre haematologist.'*

Psychosocial workers pointed out that some women had the feeling that their bleeding problems were not recognised or anyone else's problem and the isolation that this could cause.

> *'I think older females are isolated in their bleeding. They are not very connected and feel it is their burden to carry.'*
>
> *'Women's issues: being believed is important. For some women it is definitely a major thing. We are used to it [bleeding in females], women menstruate - so I think there is a historical bias against women.'*

Women with bleeding disorders who were interviewed highlighted how often they had to advocate for themselves in the health care setting as they grew older and were concerned about how they would manage this as they grew frailer. Some had been diagnosed late in life and were still coming to grips with their bleeding disorder. Their primary care often came from a general practitioner, rather than the HTC.

> *'The radiology team are like, let's do the biopsy now. Then I have to say I have a bleeding disorder, I can't have the biopsy now… okay…then the nurse [from the HTC] calls and plans. My concern with getting older is the invisibility that you get. Older women are really invisible. Older people in general are so dismissed.'*
>
> *'I think there is general stuff with being older. I have one ovary sleeping, I am on high blood pressure medications and I am on the pill too. I am on a painkiller. I am on a cocktail of things. GPs generally forget that you have a bleeding disorder and need information about classes of drugs. Everyone has to advocate for themselves as they get older.'*

An older man with a bleeding disorder described his deep grief and feelings of powerlessness when surgical staff would not listen to his concerns about his mother's bleeding problems:

> *'I lost my mother 2 years ago. Mum was a bleeder and had a major operation. When I talked to doctors about her bleeding disorder, it fell on deaf ears!!! Because of their ignorance mother passed away.'*

WHAT WILL HELP?

Education

Older women saw education about women with bleeding disorders for the wider medical community as a high priority. As with education related to growing older with a bleeding disorder (see above), this would need to be targeted to the medical specialty providing care. Raising awareness among

health care professionals about bleeding disorders in females would play a significant role in improving treatment and care for older women and preventing unnecessary bleeding episodes.

Educating older women to recognise and manage bleeding complications will also be essential to ongoing community education through the HFA Female Factors project. This project involves the development of high quality evidence-based resources that women can also use as an education and self-advocacy tool with their health care providers in the community.

Comprehensive care and the ABDR

It may also be valuable for women to develop a relationship with their local HTC as well as their GP or the medical specialist who currently manages their bleeding disorder. This would enable co-ordinated and best practice care to manage the complications of their bleeding disorder as they age and increase the understanding of the complications that women may experience. Some HTCs in Australia and internationally have established women's clinics to achieve this. Collecting clinical data about women with bleeding disorders into the ABDR will also be important to develop an understanding of an area where there has been little research to date.

6.15 Transport

For older people with bleeding disorders and their partners, issues of ageing that impacted on their ability to drive or use public transport were a major barrier to access to specialized treatment and care and participation in the workforce. They were battling fatigue and finding the traffic too challenging to travel to attend reviews at the HTC or other specialist appointments. However, specialist healthcare services were often not available in rural or regional areas. If their partner was the driver, they were concerned about what would happen when their partner could no longer drive.

'Transport issues may affect us. Most of the time my partner drives me to treatment. It will be interesting to see whether the local hospital can help without going to the HTC. I have a general hospital 10 minutes away from here.'

'Location as driving to access services is more difficult as I get older. Services are not easily available where I live.'

'I use a mobility scooter these days. It's in the back of my car. If I lose the ability to drive, I am going to be relying on other people to take me places.'

Health professionals noted that some of their patients had moved to outer suburban or regional areas for financial reasons as they grew older or retired from work, which made access to the HTC more difficult. They also commented on the problems their older patients experienced with public transport, including volunteer driving services:

'But due to stiffness, their legs can't fit inside the [volunteer's] vehicle and they can't use public transport, or they don't know how to use public transport.'

WHAT WILL HELP?

The consultation identified options to assist older people with bleeding disorders who have transport problems that are discussed further under **Section 6.16, Clinical treatment and care services:**

- Innovations in comprehensive care to enable care to be managed locally
- Investigation of suitable options for parking and support to access it
- Information and support to access disability-appropriate transport.

'If there is some kind of organisation that you could call and drive you to the appointment. Public transport is difficult due to transferring to bus to train etc.'

6.16 Clinical treatment and care services

6.16.1 COMPREHENSIVE CARE

With the range and increasing complexity of issues faced by their older patients with bleeding disorders, the multidisciplinary HTC team was described as having an essential role in co-ordinating their care across the various care pathways. The consultation highlighted that as well as the standard individualised treatment plan and care for their patients' bleeding disorder, this role may also involve liaison with other health care professionals in both public and private health care settings to manage interventions related to their bleeding disorder complications or health conditions unrelated to their bleeding disorder. This could involve liaison around treatment to prevent bleeding with surgery or medical and dental procedures, or balancing factor treatment with anticoagulants for health conditions such as heart disease or stroke. There may be cautions for some of their existing bleeding disorder treatments that need to be taken into account. Advanced liver disease related to hepatitis C also needed careful management. For women, it may also involve liaison with women's health specialists for gynaecological problems. Specialist physiotherapy and psychosocial services continue to be central to the individualised and holistic management required, and could well be in higher demand as musculoskeletal complications and support needs increase. The HTC also needed to work closely with their general practitioner around primary and preventive care and with aged care services as their dependency increased. HTC health professionals identified key partners in comprehensive care at this stage of life as pain management, rheumatology, orthopaedic, geriatric, occupational therapy, dietitian, podiatry and dentistry services, and general practice.

The HTCs were also seen as having a crucial role in providing expert education about bleeding disorders to the health care professionals in the wider community who dealt with their patients' other health conditions as they aged.

6.16.2 ABDR/MYABDR

HTCs currently use the ABDR system as a tool to manage the clinical care of their patients and to assist with co-ordinating comprehensive care services. Their patients contribute to the system by recording bleeding episodes and home treatments with the MyABDR app and website and can upload photos of bleeds. MyABDR also operates as a tool to manage the inventory of their treatment stock at home.

With so much communication about bleeding episodes, treatment and care now taking place remotely, for example, through discussion between the HTC and the person with a bleeding disorder on the telephone and via email, MyABDR has become a vital source of accurate information for managing treatment and care and alerting HTCs to the possibility of bleeding complications.

Uptake and usage of MyABDR has been variable between the states and territories and anecdotal feedback suggests that this may be related to local cultural attitudes to treatment recording. However, health professionals in states with higher usage rates noted that their older patients were more likely to be compliant with using MyABDR, as they were used to recording treatments and could see the value of being able to track batches after their experiences with bloodborne viruses.

Aggregated and de-identified data from the ABDR will assist greatly with understanding the impact of ageing with a bleeding disorder and the outcomes of different treatments. Increasing MyABDR usage nationally to provide robust clinical data remains an objective for all partners involved: HFA, AHCDO, the NBA and Australian governments.

6.16.3 HEALTH-RELATED QUALITY OF LIFE

With new treatments coming to market and innovations in comprehensive care programs, evaluating their impact on quality of life will be important to understanding benefits for older people with bleeding disorders.

The PROBE study has been validated internationally as a tool to investigate health-related quality of life in people with haemophilia and the Australian PROBE study implementation has provided very valuable quality of life data for the Getting Older needs assessment. Canada uses an equivalent system to Australia for collecting clinical data on HTC patients with bleeding disorders, the Canadian Bleeding Disorders Registry (CBDR), and also provides MyCBDR, a patient recording tool that is linked directly to the CBDR. In Canada a number of innovations with PROBE are currently being trialled to increase uptake and improve specificity, including an app version and an option for participants to link their PROBE questionnaire to their MyCBDR record. These trials are currently being monitored to assess whether these innovations may also be an effective way for Australia to collect data on quality of life outcomes for haemophilia patients at HTCs. Patient recording systems also work differently in Canada to Australia and assessing these innovations will also involve investigating their feasibility in the Australian situation.

6.16.4 NEW CHALLENGES

Health professionals at the HTCs identified several new challenges:

- **Mild bleeding disorders:** They were seeing many more people with mild disorders who were experiencing complications of their bleeding disorder, but may not recognise the complications and seek care in a timely way. Patient education was important for this group, and also encouragement to attend a regular review at the HTC when this was something they had not had to do in the past.
- **New treatments** meant that their older patients with severe haemophilia were having few bleeding episodes. As a result, these patients needed less face-to-face contact, which could weaken their close relationship with the HTC team and make them less inclined to come for an assessment when needed.
- **Integrating new care programs:** with so many disruptions to their life with increasing health problems and medical appointments, and difficulties in travel due to ageing, their older patients were reluctant to visit the HTC to participate in new care programs or reviews, which would involve regular face-to-face visits. However, there still needed to be careful monitoring as their patients could be desensitised to issues such as pain after a lifetime of complications. Online programs could be helpful when taken up, but might not provide adequate monitoring.
- **Co-ordinating care in regional and rural areas:** while there were now a number of medical resources in regional areas, including haematologists, there may not be the ancillary services needed, such as physiotherapy, laboratory services, dentistry, professional psychosocial care, etc. It could be a challenge for HTCs to integrate or use these medical services well, as they often had other local priorities.
- **Financial costs to their patients for services provided privately,** such as dentistry, podiatry.

WHAT WILL HELP?

Innovation in HTC services

Options to provide easier access to comprehensive care were discussed by many.

HTC nurses commented that older people with bleeding disorders wanted to live life as normally as possible, but their increasing complications meant that for good care, they needed to attend more appointments with a range of services. Community members, health professionals and Haemophilia Foundations all noted the difficulties of travel to appointments for both the person and their partner.

Suggestions considered ways to expand the reach of HTCs and included:

- Use of telehealth
- Evening or weekend clinics
- Liaising with haematologists in regional services
- Liaising with local hospitals to manage some aspects of treatment and care

- Commencing or further developing outer suburban and regional outreach with the full primary HTC team of haematologist, nurse, physiotherapist and psychosocial worker.

Some states and territories have supported the use of telehealth to deliver comprehensive care at a distance for some years. A telehealth consultation with the HTC can also be provided during an appointment with the person's local GP. The recent COVID-19 crisis meant that many appointments at HTCs around the country were converted to video calls, where patients had the technology, or telephone calls, where they did not. This highlighted the number of patients who did not have suitable video technology available to them and the difficulties of managing consultations about bleeding disorders without visuals. Health professionals noted that they were still asking people with acute bleeding episodes to visit the HTC. Communication issues raised by the HTC experience with the COVID-19 crisis has provided valuable insights for exploring telehealth services into the future. HTCs will also need to define when it is important to attend a consultation or review face-to-face with the HTC team.

Given the difficulty with travel to the HTC for older people with bleeding disorders, patients would also need to see the value in attending the HTC clinical consultation, whether this was face-to-face or via telehealth. This may be assisted by ensuring that a face-to-face review is co-ordinated with the multidisciplinary team, or by including some of the other 'value-added' strategies discussed earlier, such as referrals to general practitioners or other providers for their patients' specific issues.

The nurses also commented that while local health care services could provide support and liaison, they were less likely to be proactive in initiating best practice multidisciplinary programs to manage bleeding disorders and this role would still need to be taken by the HTC. There would also need to be more work to identify the gaps in service provision in regional and rural areas and to find ways to co-ordinate comprehensive care for HTC patients, when suitable services are not available locally.

Co-ordinating care

Health professionals underlined that ensuring continuity and consistency in care was critical to the health and wellbeing of the older person with a bleeding disorder, particularly as their care needs became more complex with ageing and they became more vulnerable and dependent.

They noted that the HTC would need to play a strong role to co-ordinate the range of services and programs to support people with bleeding disorders with complexities of growing older, but, with the comprehensive care model, had the approach to make it possible to achieve best practice treatment and care.

'We work collaboratively and it's a very multi-disciplinary team. We meet regularly and we discuss patients and we collaborate with others.'

The development of best practice will rely on a national approach to comprehensive care so that access to specialities is expanded to accommodate the needs of the older person with a bleeding disorder. Australian haemophilia clinical management guidelines identify the essential members of a comprehensive care team as:

- A medical director who is a haematologist
- A nurse co-ordinator specialising in bleeding disorders
- Musculoskeletal experts, including physiotherapy, orthopaedics and rheumatology
- A psychosocial expert, preferably a social worker or psychologist
- Specialist medical laboratory services.[8]

The needs assessment consultation also identified other key specialities to include in comprehensive care for the older person with a bleeding disorder:

- pain management
- geriatric services
- occupational therapy
- dietitians
- podiatry
- dentistry
- gynaecology for women
- vocational counselling.

General practitioners were also identified as key partners in primary care.

This may involve strengthening the resourcing for comprehensive care, to ensure older people with bleeding disorders have access to key specialities as required.

Nurses highlighted that providing effective co-ordination of a range of different clinical services required good communication:

'You need seamless communication between the care teams: data co-ordination and a centralised system where each of the clinicians is able to access and see the patient records.'

There will also need to be ongoing work to evaluate the older person with a bleeding disorder's experience of health service provision. This should cover both their and their caregivers' perspective on the breakdowns and improvements that occur in their care pathways.

ABDR and MyABDR

The ABDR and MyABDR have a significant role in reliable and accurate HTC and patient communication. They can also support research into new areas such as ageing with a bleeding disorder and issues for older people with mild conditions and women with low factor levels. It will be important to promote and support the use of the ABDR and MyABDR nationally to ensure it is integrated into everyday practice and is able to collect comprehensive clinical data.

Health-related quality of life outcomes

For older people with bleeding disorders, quality of life is a very significant aspect of health and wellbeing. Evaluating the impact of particular health interventions, including new treatments or health programs, will need to include the effect on their health-related quality of life. While the ABDR will provide some data on quality of life, other tools will also be required to collect meaningful data. The PROBE Australia study has been able to deliver valuable information on health-related quality of life for this needs assessment. One approach would be to explore the potential to use the PROBE Australia study to link with the ABDR to collect data on health-related quality of life, for example, using the model trialled in Canada. This will involve investigating the feasibility of undertaking this with the ABDR system and the acceptability to patients using the ABDR, HTCs and governments.

Patient education

The consultation underlined the many areas that HTCs would need to cover in patient education into the future. They would also need to develop strategies to engage their older patients in working with their HTC and other partners in comprehensive care and developing knowledge and skills for self-management.

Resourcing HTCs adequately to undertake this work and provide innovative and multidisciplinary education programs and resources will be crucial to achieving this.

Education for health care workers

If education for health care workers around managing older patients with bleeding disorders is

to be effective, it will need to be led by those often described as 'key leaders', health professionals in relevant disciplines with recognised expertise. Members of the HTC multidisciplinary team are well-positioned to take on this role and already have established national groups to develop best practice around the disciplines of haematology medicine, nursing, psychosocial work and physiotherapy.

Developing appropriate education resources and programs will be time-consuming and will likely involve collaborations with other organisations, such as HFA, aged care services and relevant bodies among their health professional peers. Nurses commented, for example, that they had already developed education resources for residential care facilities on managing people with bleeding disorders: these resources were the result of a collaboration with the psychosocial workers, were reviewed by residential aged care nurses and were published by HFA. As with patient education, resourcing members of the HTC multidisciplinary team adequately will be required to ensure they have the capacity to undertake this work.

6.16.5 PRIMARY CARE: PARTNERSHIP WITH GENERAL PRACTITIONERS

General practitioners (GPs) were seen as providing a central role for people with bleeding disorders as they grew older, undertaking their age-related health checks, implementing their pain management plans, making decisions such as their safety to drive, and even infusing their treatment at times. They would see the person with a bleeding disorder for their hypertension or diabetes and make a referral to a specialist. They may be responsible for setting up a primary care management plan.

Nearly all people with bleeding disorders who completed the Getting Older survey said they accessed the services of a GP, more than those who accessed the services of an HTC. This is consistent with the findings in the 2016 Queensland Haemophilia Centre study, where around 90% of the men reported having a GP. However, as the study pointed out, having a GP was not necessarily an indication of undertaking preventive health checks, with only one-third in the study actively visiting their GP for a health check.[116] With the overload many older people with bleeding disorders experience in relation to the complications related to their bleeding disorder and the health conditions of ageing and the number of medical appointments, it would be easy for preventive health checks to be sidelined or forgotten. Older people with bleeding disorders would need a clear message that these health checks could prevent further serious health conditions. However, there would also need to be other strategies to ensure that preventive health checks are more likely to occur.

Building a relationship with a GP so that preventive health consultations become routine was a critical factor raised by the HTCs. The interviews and the survey underlined that the person's trust in their relationship with their GP was very individual and often appeared to be related to their GP's interest in understanding their bleeding disorder. Several described having a good relationship with their GP and felt confident that the GP understood their bleeding disorder. Others were not confident that their GP understood their issues. A haematologist also commented on the issues relating to lack of continuity:

> *'A patient's life needs to have a focus point or home base. Usually it's the treating Haemophilia Centre or in many cases their general practitioner. But not all of them have GPs. There is also a problem with the way GPs rotate and there are different doctors each week.'*

HTCs perceived this lack of continuity as a dilemma: the HTC was considering whether the GP could take a co-ordinating role with their patient's primary care as they grew older, but also were concerned that there would need to be very close liaison with the HTC for management of their bleeding disorder treatment and complications. This would be difficult if there was not a strong relationship with a specific GP.

WHAT WILL HELP?

HTC nurses highlighted the importance for HTCs of developing relationships with GPs who would be prepared to work with their older patients and understand their bleeding disorder and of involving the GP as part of the treating team. It would be important for there to be continuity with a particular GP, so that the GP knew their patient and their individual needs. This may involve recruiting GPs who were available at short notice and would bulk bill, for those patients with financial issues.

Suggestions included:

- Linking with GPs through GP organisations
- Providing workshops for interested GPs.

HTCs were committed to including patient education about preventive health checks in their regular reviews.

Education resources for both older people with bleeding disorders and GPs on relevant health checks and managing the health conditions of ageing with a bleeding disorder would also be valuable. It would also be important to have the associated health promotion messages reiterated in haemophilia foundation newsletters and education materials.

6.17 Aged care

6.17.1 RESIDENTIAL AGED CARE FACILITIES

While many older people with bleeding disorders recognised that they might need to move to a residential aged care facility in the future, most were deeply concerned about the level of care and expertise that would be available to them in these facilities. Would their treatment be stored properly? Who would have the venipuncture expertise to undertake their infusions? Or the expertise to follow their treatment plan? Would they know or notice if the person was having a bleed? What if the person fell out of bed? How long would it take them to respond? What would be the access to specialist treatment and care? They were particularly worried because they knew they would be frail or have dementia and be unable to advocate for themselves, and if they had a partner, they might be in a similar position.

Partners sometimes assumed that it would be better not to go into care:

> *'Concern about how long he can work and medical care in future. Nursing home will not cater for him so needs to be at home.'*

Nurses noted that the decision to go into residential care may have its own inevitable progress and the process may sometimes be put in motion by the person's partner or GP if the person could no longer be managed at home. They had already developed educational materials for aged care facilities and had liaised closely with facilities in the past, but acknowledged that managing people who needed residential care could have its challenges.

WHAT WILL HELP?

Given the great concern many older people with bleeding disorders and their partners and family have about entering residential aged care facilities, it may be valuable to develop education materials to explain what they can expect, services available, how the relationship with the HTC will work, and how they can best self-manage and advocate for themselves in the facilities.

Existing education materials for nurses, personal care assistants and other staff are currently available on the HFA website and could be promoted to both the facilities and the community. They may also need to be updated around new and emerging therapies when these become widely available in Australia.

These education materials are part of the education HTCs provide to residential aged care facilities when their patients enter the facility and are aimed at supporting integrated care and responsiveness to the special issues of living with a bleeding disorder into old age.

Newer therapies involving less frequent infusions and/or subcutaneous injections may also reduce the treatment burden for older people with bleeding disorders and be more manageable in a residential care facility.

6.17.2 AGED CARE SERVICES AND SUPPORT

In the Getting Older community survey older people with bleeding disorders were asked about the support services they currently access.

The largest number of services accessed were related to their health care: GPs, the HTC, physiotherapists, psychosocial services, and other health care workers, which could include complementary medicine such as acupuncture, chiropractic, or naturopathy. A substantial number (38%) also identified their local pharmacy. As with other health care workers in the community who provide their care, complementary therapists and community pharmacists may also provide therapies and medications that involve risks for a person with a bleeding disorder and it will be important to ensure they have access to information about this to prevent unnecessary bleeding and other complications.

A smaller number (12%) said they accessed a spiritual advisor or local church for support.

Of the survey respondents, 10% accessed homecare workers or cleaners. Only a very small number accessed community support services such as personal care or support workers, community nurses, or services such as meals or cooking.

With their high care needs, this is a surprisingly low use of aged care support services. The survey respondents gave a couple of reasons for this:

- They didn't know what was available
- Out-of-pocket costs for these services can be expensive.

The consultation also highlighted that many older community members found the number and complexity of their health conditions to be overwhelming and were struggling to organise themselves. This suggests that they would have difficulty initiating access to support services.

A psychosocial worker noted that My Aged Care was intended to provide information about resources available and some guidance to accessing them, but *'it will be overwhelming if you don't know the process, which most people don't.'*

WHAT WILL HELP?

Assistance with access to aged care services

When asked about services or supports that would help, suggestions from older people with bleeding disorders included:

- Home help such as cleaners, gardeners, a handyman for home maintenance
- Assistance with setting up and accessing aged care services
- Information about the services available
- Financial assistance with out-of-pocket costs for these services.

'Perhaps a social worker who deals with bleeding disorders in particular and who could give advice when needed. I feel a bit lost sometimes.'

'Knowing how to access in-home care that could assist with self-treatment.'

Psychosocial workers thought that it would be helpful to provide guidance to older people with bleeding disorders about aged care services in the community and what services they could access. Community members interviewed noted that their support needs had changed over time and they needed to increase their package and funding to accommodate this. Case management to manage their ongoing needs may also be important, along with investigation of options for funding if they are not able to afford the out-of-pocket costs for the services required.

It will also be important to provide older people with bleeding disorders and their partners and family with self-directed access to information about accessing aged care services and what services are available. This could include:

- Information about aged care services on the Getting Older Information Hub on the HFA website
- Articles in foundation newsletters.

Education for complementary therapists and pharmacists

The need to educate health care workers in the community about special issues if they care for an older person with a bleeding disorder has already been identified. It will be important to also include education and information for complementary therapists and community pharmacists to complete the loop of the care pathway.

6.18 Early ageing and disability services

6.18.1 NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

A major problem for the people with bleeding disorders under 65 years who experienced ageing-related issues was that they were not yet eligible for aged care services, but could also fall through the cracks of the National Disability Insurance Scheme (NDIS). A psychosocial worker commented:

> *'One of the other issues is the grey area with the NDIS. You can see benefit in the NDIS but the younger guys needing support do not qualify because they don't meet the criteria for the NDIS. I think with some small NDIS support they might thrive and have a better quality of life – also for their partners.'*

While younger people with bleeding disorders born in Australia might have disability problems due to lack of access to prophylaxis treatment when they were young or having inhibitors, which make their treatment less effective, HTC health professionals commented that more recent migrants might also have joint and muscle problems if they had not had access to regular prophylaxis in their country of birth.

The psychosocial workers noted that while a few of their clients had accessed the Scheme, others were deemed to be not impaired enough by NDIS assessors, which meant that they could not access disability services. There was consensus among the health professionals at the HTCs that NDIS assessors often did not have enough expertise or understanding of bleeding disorders to make appropriate assessments. Nevertheless, the NDIS application needed to be reflective of the eligibility criteria and presented in the format and language required to have a better chance of being successful. There was a role for members of the comprehensive care team at the HTC who had experience with the NDIS, such

as the psychosocial worker, to assist applicants with their application. An occupational therapist and physiotherapist could provide functional assessments to support their application.

The inability to access care services when aged under 65 years might also explain the low access to support services by older people with bleeding disorders in the Getting Older community survey: a large proportion of 'older' people with bleeding disorders are actually under 65 years. In the case of the survey, only 56/133 or 42% of survey respondents who identified themselves as 'people with bleeding disorders who are getting older' were aged 65 years or over – 57/133 or 43% were aged 45-64 years and a small number were even younger.

WHAT WILL HELP?

The consultation highlighted a number of areas to address with the NDIS:

- Assistance with completing NDIS applications to ensure eligibility criteria are addressed.
- Involvement of members of the comprehensive care team with experience in NDIS applications, including psychosocial workers and occupational therapists, to support people with bleeding disorders to make their NDIS applications. This could entail HTC support with reports and advocacy for services and modifications for those with higher needs.
- Assisting applicants with an appeal or review where they have been rejected initially or the approved package seems inadequate.
- Advocacy around modifications to the NDIS so that it supports applicants to continue working.
- Adequate resourcing of all HTCs to assist with NDIS applications.

It may also be relevant to have some discussion with clinical experts on the value of considering early ageing in people with bleeding disorders more definitively. This could consider whether there would be benefit in a policy shift to recognise early ageing in bleeding disorders as a reason for earlier access to aged care services, similar to the current proposal by HIV organisations. Some participants in the consultation drew attention to the advocacy work of HIV organisations to lower the aged care threshold for people who have had long-term HIV infection and live with complex co-morbidities and suggested that this might also be relevant to people with bleeding disorders who live with similar health issues.

Further investigation into sources of financial assistance for equipment and support services when people with bleeding disorders cannot access the NDIS is also required.

'Well, here is a radical idea. Maybe people with haemophilia need access to services earlier than at the retirement age. Maybe support those who are financially challenged. Some sort of dollar-to-dollar support to get things done. Orthotics, podiatry etc is expensive.'

6.19 Mental health

A number of mental health issues were raised during the consultation.

6.19.1 DEPRESSION AND ANXIETY

In the PROBE Australia study, men with moderate or severe haemophilia who were 45 years and over were twice as likely to report clinically diagnosed anxiety and depression as men with mild haemophilia and men without a bleeding disorder in the same age bracket.

The interviews highlighted several different causes. Many spoke of the traumatic years of the HIV and hepatitis C epidemics, the loss of friends and family and the pain of discrimination in their everyday life, of feeling 'like a leper' and for example, as a teenager being banned from a girlfriend's house when her father found out he had haemophilia. A less well-recognised source of trauma was their experience of pain and immobilisation when hospitalised with bleeds as a child, and the deaths of their fellow paediatric patients if they were hospitalised in an oncology ward.

> *'I had depression. They say I have something called PTSD. Some of my earliest memories are of kids dying in the hospital ward. Those children would normally have things like leukemia. So, I made friends and they died within a few weeks. I was in the hospital regularly as a child. And then I thought I was fairly tough.'*

Another source of trauma that was identified was having a very severe bleeding episode, which could be difficult for people with mild disorders for whom this was not a common experience. A psychosocial worker commented:

> *'Some of the mild patients have very traumatic memories. There is one who had a traumatic experience with blood in his mouth, a horrible bleed. Every time he needs an operation, he becomes super anxious. To the outsider he looks like an anxious man, but he is not and it's because of his strong memories. He may need a psychiatrist for his PTSD.'*

For some there were issues related to grief and loss. This was sometimes related to their increasing problems with mobility and pain and loss of independence, and not being able to undertake the activities that formerly gave them pleasure. Some had lost people close to them and were greatly saddened: their partner, family members or friends.

6.19.2 PERSONAL INTERESTS

Psychosocial workers were concerned about the inertia and lack of motivation that could accompany depression and spoke of the need to keep older people psychologically active with activities that they enjoyed, such as fishing, reading and gardening. It was interesting to note that some of the people interviewed who described themselves as having a positive approach to life had personal interests and hobbies – 'plenty to keep me busy' – including music and art, reading, fishing, walking the dog, going to films or eating out with friends.

Psychosocial workers also pointed out the importance for older people with bleeding disorders of feeling like they were doing something useful or constructive.

> *'The ones I know are loving the Men's Shed and creating things. One group I know of actually built aids for disabled. I know others who have projects like restoring furniture. Because men love to be doing stuff. Sitting and having coffee makes them depressed about how creaky and old they are.'*

6.19.3 PERSONAL STRENGTH AND RESILIENCE

Although some interviewees spoke about their depression, many prided themselves on their personal strength and resilience. They often attributed this to their experiences of managing their bleeding disorder over their lifetime and the personal strategies they had learned to overcome challenges.

> *'I feel like I can navigate myself around the system because of my health issues all my life rather than somebody who has had a reasonably normal life.'*
>
> *'A combination of strength, stoic nature and all of that. I am fiercely independent as guys tend to be. I think it's better to have a strict perspective on it.'*
>
> *'Resilience is my strength. It's a marathon and you've got to have resilience.'*

It is interesting to note the fragility of this resilience, particularly if the person felt isolated or vulnerable. This was demonstrated during the consultation, when some community members in remote areas were reluctant to participate in consultation because they found thinking about getting older too confronting.

6.19.4 SOCIAL CONNECTION

An important aspect of their resilience was social connection and being able to call on personal networks. In the *Don't go it alone* study, older Australians who often or occasionally experienced lack of companionship and loneliness also recorded lower life satisfaction.[108] In both the interviews and the Getting Older survey, older people with bleeding disorders spoke about spending time with their grandchildren and extended family. Psychosocial workers described individuals who were confident and content with their life as they grew older – for example, an elderly woman living in a retirement village, with relatives close by, and a strong social network of friends *'thriving quite well and not overly strained as a result of her bleeding disorder'.*

The consultation identified some challenges to social connection as people with bleeding disorders reached their senior years: loss of their partner, inability to participate in social or community activities, losing connection with their workplace and work friends. Many relied on strong relationships with their partner and a single man pointed out the difficulties of needing increased personal connection as he grew older:

> *'I believe it is unique to having a chronic condition and also being a single male. You have lived your life with it [haemophilia] and unless you have had this support throughout (i.e. a stable marriage, supportive friends etc.) you begin to crave it later in life as you see yourself as vulnerable and needy.'*

Psychosocial workers highlighted the importance of friendships in the senior years, whether the person had a partner or not.

> *'It is really important for men [with a bleeding disorder] to make sure that they have good male friendships. They don't often have them outside of their partner. When their partner goes, they might find themselves suddenly, totally alone, but if you have got few good male mates, then you have a real lifeline into life.'*

6.19.5 SUPPORT

In the Getting Older survey, both the person with the bleeding disorder and their partner and family were asked who supported the person getting older in their daily life. In most cases partners and family were identified as key sources of support. For some, close friends, neighbours and pets were also important. Few identified online buddies or paid or unpaid carers as providing support. A small number commented that no one provided support; some because they felt they were self-sufficient and did not need support, but others were conscious of not having support and being isolated.

Peer support

Face-to-face peer support activities are a major feature of state/territory Haemophilia Foundation work with their community. Activities may be aimed at the bleeding disorders community generally, such as family or community camps, or targeted at specific groups, such as men and women's groups, grandparent groups, men's retreats, youth camps and inter-generational activities such as men and boys activities, where an older relative may attend with a boy with a bleeding disorder.

Access to the range of peer support activities has been variable between states and territories, depending on the level of peer support development, size and geographical distribution of the community and resourcing. This has been discussed at a national level and as a result, some Foundations have offered places in activities such as camps to nearby states and territories. Some Foundations also described encouraging older community members to take on volunteer roles, for example, in fundraising activities.

The value of peer support

For the majority of older people with bleeding disorders who participated in the consultation, there was great value in connecting and sharing experiences with other older people with bleeding disorders. They found having a rare health condition very isolating, particularly if they did not know anyone else with a bleeding disorder.

'My experience is that other than brief shared discussions about medical issues the true value of meeting other haemophiliacs is not having to explain yourself. The networking and making new friends who are kindred spirits has been invaluable. Went to a haem retreat a few years ago, was awesome and was fortunate that one of the guys picked me up.'

'Any connection would be good as it can be very isolating.'

'I have never met anyone in Australia who has my bleeding disorder. Hence, my only contact is with people overseas over social media.'

For older people with bleeding disorders, it was an opportunity to share not only what they had experienced, but what they had learned and tips and strategies that had been successful for them in managing their bleeding disorder. They thought it was important to celebrate their achievements and what made life enjoyable and rewarding for them.

'It's always better to sit around a table and chat. We have a men's breakfast [in my local haemophilia foundation] and discuss how we manage with certain circumstances. That is something that is practical and relevant to me. People going through the same thing as you is reassuring - you can work it out when you are sitting down together and have a laugh about it.'

A psychosocial worker explained how the proactive approach of some community members supported others to have the confidence to follow in their footsteps:

'What I have noticed with the older guys if they are connected is that if one person does something and it works well, then they will talk about it and support each other. They need someone to make that first move. It's bit like mentoring - or gaining the confidence to deal with the services with the support that you get.'

In the community survey a smaller number of older people with bleeding disorders (12 of 102 or 12%) commented that they were not interested in meeting other people with bleeding disorders. This was for various reasons: they didn't feel they needed support; or they preferred to connect with people who shared their interests rather than their health condition; or they preferred to discuss their condition with their family rather than others.

'I have mild haemophilia. Discussing this with my wife and health practitioner is sufficient at the moment.'

'I choose friends/associates for their attributes, not because we share some medical condition.'

The definition of a 'peer' is very relevant to the motivation for social connection: is it someone who also has a bleeding disorder or someone who shares your interests? Engaging older people with bleeding disorders in social activities with their 'peers' will need to take both definitions into account.

Ways to connect

When asked about how they would prefer to meet other people in the bleeding disorders community, by far the most popular choice for older people with bleeding disorders was in face-to-face groups, with 60% giving this as their preference. Around 20-25% of people with bleeding disorders were equally interested in remote and online options, including social media platforms, online discussion forums and email. About one-fifth were interested in peer support via telephone.

For some distance was an issue and frailty and mobility problems would also make travel to face-to-face events problematic. Some state and territory Foundations undertake routine regional visits with social events to connect to community members and provide them with an opportunity to meet each other as well as Foundation leaders.

The community survey also asked about their interest in connecting with other people online or through social media. In response most older people with bleeding disorders commented that they were not interested or that they prefer face-to-face and it was not something they do. Reasons given included:

- Not active on social media, 'too old for that'
- Not interested in digital connections or computers
- Concerns about privacy/security
- Can be defamatory and 'stories snowball away from the truth'
- No internet connection.

'Personally, it would be an issue, as need to be able to talk to person face to face. Social media would be too much of a barrier as far as not making true connection. That said, I am sure others may find it useful.'

'Social media is a very lean and isolating forum to discuss sensitive topics.'

'I find using a computer difficult because of my eyesight and choose NOT to be on Facebook etc.'

A smaller group were already active in social media groups and thought it would be helpful to have online options available for peer support. They also liked the opportunity to communicate with each other in their own time. While some community members thought that it would be helpful for HFA to provide a national Facebook group, for example, others commented that they would not like a haemophilia foundation to moderate or 'be in the room' and thought that it would be better to have independent peer support groups.

'A group page would be good.'

'I like that you can take a little time to think about your answer rather than being rushed in real time.'

Although most older people in the consultation were not interested in online technologies for peer support, the COVID-19 crisis has exposed many older people in the community to VoIP (Voice over Internet Protocol) platforms such as Zoom and Skype to connect socially to their family and friends. As a result of this experience, their attitudes to using this type of technology for peer support may have shifted. In the disability and aged care sector there are also a number of innovative projects using digital technology for older people, for example using simple interfaces for a Skype product that are appropriate to older people and those with cognitive decline. Digital options for peer support may provide a way for older people with bleeding disorders to connect with each other, when they are unable to meet face-to-face for distance, mobility or other reasons.

Australian haemophilia foundations have described the challenges of maintaining engagement with their peer support groups and the need to use strategies such as personal invitations, meals and interesting guest speakers or activities to attract participants.[118] With the small size of the affected community, some survey respondents were aware that it could be difficult to maintain momentum in an online peer support group. However, it was clear that meeting each other face-to-face at some point to establish a friendly relationship was key to continuing the connection online or by telephone.

'We started a facebook grp (secret) for guys living with haemophilia and HIV but there is very little participation. I'm not sure why. I can only put it down to the guys being busy with work and young families. Also, some of them work with computers so probably don't want to be looking at a computer when they come home. I have made some strong connections with the guys who go to the men's retreat. But it tends to be individual contact by sms/email. I really value those connections I now have after many years of being rather isolated.'

Peer support for older people with bleeding disorders, whether provided face-to-face or online, will need to address strategies to engage them. In the digital space this will involve, for example, understanding how to create an attractive social event online and how to schedule it nationally across multiple timezones. Providing peer support on digital platforms is a new and evolving area and there is still much to be learned about how to provide peer support for older people, particularly those with dexterity and mobility problems.

WHAT WILL HELP?

Psychosocial care

The frequency of depression, anxiety and phobias in older people with bleeding disorders highlights the need for professional psychosocial care. This also involves resourcing for psychosocial workers in the HTC comprehensive care team to identify problems and provide support and referral. Post-Traumatic Stress Disorder has been identified in people with bleeding disorders and HIV and/or hepatitis C and may also be an important factor in the mental health issues of older people with bleeding disorders generally. It will be important to explore this further and to consider whether trauma-informed practice may be an appropriate approach for some people in this group.

Personal interests, social connection and peer support

Investing in strategies to encourage personal interests and facilitate social connection for older people with bleeding disorders will be an important way of keeping these individuals active and supporting their quality of life. It will also be a means to encourage their resilience, while providing less confronting avenues for them to ask for help.

Peer support activities with the bleeding disorders community are an opportunity for older people with bleeding disorders to meet, share experiences and strategies for self-management, support each other to ask for help or changes in their treatment and care and develop friendships. Foundations may also consider ways to enable older people to contribute their skills and experience to the community.

As one partner commented,

> *'I think he could share his general optimism and positive attitude, his resilience.'*

Other community services and activities that bring together older people with shared interests may also have much to offer, for example, Men's Shed, Rotary and Probus, University of the Third Age, special interest groups, and innovative interventions such as 'befriending', where volunteers keep regular contact with individuals.

It will be important for Foundations to continue to look for opportunities to bring older people with bleeding disorders together face-to-face so that they can get to know each other and establish relationships that they can continue outside these forums.

Continuing to investigate and trial digital peer support options may identify workable solutions for the bleeding disorders community, which may supplement face-to-face events and provide opportunities for those who cannot attend face-to-face events to connect with their peers. This will involve looking at what has worked for other similar organisations and how to engage community members on digital platforms and maintain engagement. Resourcing may be an issue and it may be helpful to collaborate with other organisations or use existing community resources, such as peer support training through organisations such as the Chronic Illness Alliance.

6.20 Carers

The physical and emotional burden for partners and family as carers was a common concern. Older people with bleeding disorders explained that the outcomes of their bleeding disorder complications often fell on their partner, if they had one:

> *'Mobility loss and loss of independence, rely on more full-time care from my wife.'*

They often worried that their partner may not have the physical strength to manage carer duties such as lifting, or that they would need to take the brunt of domestic tasks. Their partner's health may also be deteriorating; and their partner could be emotionally affected by the person's health problems, and several commented that their partner had experienced depression in relation to issues such as their HIV diagnosis or life-threatening health episodes.

Partners commented that they worried about the future with the person's ongoing loss of mobility and multiple health problems.

> *'Continuing loss of joint mobility and concerns for what the future looks like with loss of mobility.'*
>
> *'Joint care, pain management, dental health and psychological care are needed urgently now. We're barely coping now and expect it to worsen.'*

If the partner had problems with their own health, this was further complicated by trying to support the person with the bleeding disorder and manage their appointments.

> *'My own health is a bit "out of whack" at the moment (unbalanced blood tests) and I am having to struggle between my appointments and his and other family members'. How am I physically going to cope when his mobility decreases and [my] "caring role" gets more intense?'*

Some people with bleeding disorders were aware that their partner needed their own time to care for themselves. Health professionals commented that partners often found the carer role stressful and exhausting as they grew older and that it was important to provide them with opportunities to take time out from caring and to talk with others on their own about their experiences.

The partner/carer role could be a dilemma for both people with bleeding disorders and their partners. Partners felt guilty at wanting to have time and space for themselves while also wanting to demonstrate their love for the person with the bleeding disorder. Some people with bleeding disorders felt that their relationship would become unequal if their partner was also their carer – and not necessarily a role that their partner wanted. They were keen to maintain their independence and to take their share of responsibilities within their relationship.

WHAT WILL HELP?

When asked what supports or services could help them, partners and family who responded to the survey said:

- Someone to talk to
- Support with garden and home duties
- Transport services to the HTC
- More support to country patients visiting the HTC.

Some older people with bleeding disorders acknowledged the need of their partner to have time to care for themselves.

Health professionals also suggested:

- Access to information about getting older with a bleeding disorder and services available
- Acknowledgement of their role and the difficulties they face, including the emotional toll and lack of control over their own life in their caring role
- Finding ways to include the partner or carer, even if the older person with the bleeding disorder doesn't want to engage
- Respite.

It is interesting to note that around 29-46% of partners and family who completed the Getting Older survey said they would like to use social media, online discussion forums, email, and face-to-face one-on-one meetings for peer support. This was a much higher proportion than older people with bleeding disorders. It will be important to take the needs of carers into consideration with digital options for peer support.

6.21 Working

6.21.1 OLDER PEOPLE WITH BLEEDING DISORDERS

While the desire to contribute to society was a common aspiration, having a bleeding disorder had a noticeable impact on the working life of many older people who participated in the interviews and surveys.

The PROBE Australia study showed that from the age of 45 years onwards men and women with haemophilia were more likely to be working part-time or retired than their counterparts without a bleeding disorder. More than half (54% or 69/128) of older people with bleeding disorders who completed the Getting Older survey were retired or permanently unable to work. The greater majority of them (70% or 91/131) thought that their health had impacted on their work or study life in various ways.

This included:

- Disruption to study or work with time off and hospitalisation for bleeds
- Early retirement due to joint damage or HIV infection
- Difficulties with travel to work with mobility problems
- The negative impact of hepatitis C symptoms and treatment.

This is consistent with the results of the PROBE Australia study, where 70% (21/30) of men with haemophilia aged 45-65 years and 44% (12/27) of men with haemophilia aged 65 years and over had made education or career decisions due to their health. In contrast, only 19% (6/32) of men without a bleeding disorder had made an education or career decision relating to their health and none of the men 65 years and over.

The interviews underlined the impact of HIV and hepatitis C on employment, and some spoke of the symptoms of extreme fatigue and physical and mental side-effects of hepatitis C treatment that meant they struggled to keep working. They also pointed to the difficulty of separating symptoms such as hepatitis C-related fatigue from the experience of ageing with a bleeding disorder, although those who had curative treatment recently noticed they now felt better overall.

Some of the participants in the Getting Older survey commented on the strategies they used to manage the impact of their health on their work, such as using up their leave or having modified duties, and some attended work in spite of their bleeding episodes.

'Numerous joint bleeds over many decades (mainly ankles and knees) and the associated impact these have had in terms of reduced mobility and chronic pain.'

'I have worked from the age of 16 years to 66 years continuously. I mainly took sick leave and went to work many times with nose bleeds, heavy periods etc and raised two kids.'

'For 25 years I was on crutches 20% of my working time.'

Many of those who completed the survey (42% or 54/128) wanted to stay longer in the workforce. When asked about barriers to staying in the workforce, they largely described complications relating to their bleeding disorder: having a major bleed at work, arthritis, fatigue, and mobility and agility problems, the unpredictability of their bleeding episodes and the time taken to recover. Some commented that the impact of this increased as they grew older, for example, managing pain. Women were facing concerns about heavy menstrual bleeding associated with menopause.

'Arthritis may stop me from doing my work.'

'The inability to control when, where and how often I become ill. The inability of doctors to recognise fatigue caused by the bleeding disorder as opposed to getting older.'

'In my profession it is very physical. Knowing and feeling pain due to my duties not only affects my performance but mental health.'

'That my womanly bleeding and hormone issues do not impact on my ability to perform.'

Partners were concerned about the impact on their career:

'My partner has not undertaken a career he aspired to due to the physical limitations of his disease and I worry about his job security and job satisfaction for the future.'

The impact of mobility problems on travel to work was also identified as a barrier.

'Staying mobile enough to be able to catch public transport to work and move around for work.'

Several commented that employers had a low tolerance for absentia and unreliability and that this had impacted on their work.

'Employers will no longer tolerate absences due to bleeding treatment.'

Others had fewer concerns at present because they were able to manage their bleeding episodes, particularly if their treatment protocol was preventing bleeds successfully.

'None, I am healthy and on prophylactic treatment.'

'I am comfortable staying in the workforce as the interruptions are not yet too intrusive.'

Psychosocial workers commented that employment was a big issue for the older bleeding disorders community, and that it was important for people to be respected and to be able to maintain a connection with their workmates – to be given the 'disability tag' could mean they were diminished by the workplace.

The Productivity Commission noted that improved health and more integrated care could enable Australians to have more days that can be used in productive activities, such as employment, home activities and leisure, rather than being lost to ill health and time spent on attending appointments. It argued that this would improve their capacity to work, leading to higher workforce participation and increased personal income. This would also contribute to a gain in GDP.[128]

6.21.2 PARTNERS AND CARERS

Most of the partners and family who completed the Getting Older survey did not think they had stopped work or worked part-time before they wanted to because of the health demands of the person with a bleeding disorder. However, the person's health could affect a partner's leave and one commented:

> *'Have taken a number of days carer's leave to assist my partner getting to appointments after bleeding episodes where he is unable to drive himself or is in pain and has trouble absorbing information and making treatment decisions.'*

Around a third wanted to return to work or stay longer in the workforce, but several described their concerns about this:

- Their partner's care needs in the future, including mobility issues
- The supporting care for haemophilia is expensive: special needs aids, allied health care, medications, dental and psychological care
- Concerns about how to manage financially between casual jobs
- Being constantly tired and not being able to pursue any personal interests outside of work and carer duties
- The unpredictability of care needs for someone with haemophilia
- Loss in currency of skills if they had become self-employed to manage the person's care.

> *'I'm always tired and don't have any activities outside work and carer duties.'*
>
> *'You can go days or weeks without a problem but you just never know when you will need time away from work.'*

WHAT WILL HELP?

Older people with bleeding disorders

Older people with bleeding disorders who participated in the Getting Older survey had a range of suggestions to help them stay in the workforce:

- Improved treatment to reduce the number of bleeding episodes, or that did not need to be injected
- Better pain management, which would improve mobility
- Modified work activities or change the type of job to reduce the number of bleeds
- Flexible working arrangements to accommodate bleeding episodes
- Retraining for more suitable work
- More understanding of bleeding disorders in the workplace
- Disability-friendly workplaces
- Government-funded support, including support from the NDIS.

> *'Reduction in the work activities which are a risk of me sustaining a bleed.'*
>
> *'Programs for them [employers] to understand how better to deal with it. Many times they think you are faking it.'*
>
> *'Lots of things. Flexibility of work hours, having an understanding/supportive employer, career advice, support to retrain if required, pain management, physio, counselling, psychosocial support, you name it.'*

A psychosocial worker commented:

'I think employment is a huge issue in the community. Retraining to find suitable work is also an issue. Managing their work life is an issue. Some employers are good - if you've got a flexible workplace, it's really good.'

Vocational counselling is considered an integral element of comprehensive care in an HTC and it will be important to continue to introduce it at an early age so that appropriate career decisions can be made and to continue it throughout a person's working life. It would also be helpful to provide vocational counselling and mentoring through both the HTC and haemophilia foundations, to provide professional guidance, peer support and supported opportunities to gain workplace skills.

The Productivity Commission has highlighted the role of a patient-centred care approach and integrated care in improving workforce participation for people with chronic health conditions.[33,35,128] Support to implement the innovations to comprehensive care proposed in **Section 6.16 Clinical treatment and care services** would assist to achieve this, as well as the shorter waiting times for appointments raised by the Productivity Commission.

Around one-third of older survey respondents said they wished to reduce their working hours or retire early. Suggestions on what would help included:

- Slightly shorter working day
- Financial sustainability
- Being able to work part-time
- Fewer personal demands outside the workplace.

'What I hope to be able to do is to scale down from full-time work in about 10 years, when I turn 60. I hope I can concentrate on things like getting access to aqua therapy sessions to support my joints and to keep my weight down and things like that; get my orthopaedic needs addressed. I would like between now and when I am 60 to look at a 4-day working week if I can negotiate it and make it financially viable.'

Partners and carers

Partners and family who completed the survey agreed that resolving the person with a bleeding disorder's pain and mobility issues and having more understanding in the workplace would also help the partner or family member to stay in the workforce. Other suggestions included:

- Support with home help and a carer/volunteer to take the person to appointments and for companionship during the day
- A couple of partners and parents noted that they had become self-employed to have the flexibility they needed.

'We became full-time farmers and being self-employed helps a lot with this situation. Before this, it was very hard to be employed full-time and be there for my son at the same time.'

Support and advocacy

Working and feeling productive and useful are key aspects of many older people with bleeding disorders' quality of life. Resourcing the psychosocial workers in the HTC team to support them to negotiate the options available to them will be a major factor in maintaining this community's wellbeing into the future.

It would be difficult for a rare health area such as bleeding disorders to achieve change in the workforce on its own and it would be useful for HFA to consult with other community agencies in the chronic illness area who are investigating ways to support their community members to remain in the workforce and seek collaborations, where appropriate.

At the time of publication, the workforce adjustments to the COVID-19 epidemic were foreshadowing a shift in thinking regarding flexible working arrangements. Workplaces had accommodated working from home to assist with 'social distancing'. It would be valuable to consult further with the older bleeding disorders community about the impact of working from home and whether this was able to provide them with the benefits they hoped. Once again, due to the small numbers, collaborations with other community agencies on this issue would be helpful to gain a broader national perspective.

Education for workplaces

Education materials on managing a person with a bleeding disorder targeted at workplaces may also be valuable.

6.22 Finances

Both community members and health professionals drew attention to the financial costs of living with a chronic health condition. Finances were a concern for the future, both being able to afford their health care costs and having the financial security to be able to stop work and afford to live comfortably.

'Cost and availability of ancillary health care - eg physio. Degenerative disorders. No adequate carer.'

'I don't have much super due to an intermittent part time work history. I worry that I won't have enough $.'

Among partners, financial worries were also raised regularly: financial stability and having enough money to support the family; what would happen if the government stopped their financial assistance payments; the *'limited government budget (or willingness to find), to make living comfortably in old age a realistic/achievable goal.'*

As was noted in the HFA hepatitis C needs assessment, with an uncertain working life, many older people with bleeding disorders had looked to establish their financial security early in their working life.[99] The Getting Older survey highlighted the importance of owning their own home to participants, with 65% of the older people with bleeding disorders owning their own home outright and 17% with a mortgage.

As a sample of the wider community of older people with bleeding disorders, the Getting Older survey showed a more financially independent community than expected. Most received their main source of income from their employment, either in wages/salaries or business income. The next largest group received government benefits, such as the age or disability support pension. More than a third were self-funded retirees, whose income came from superannuation or other investments. A smaller number were supported by their partner or by family or friends.

6.22.1 SUPERANNUATION AND INSURANCE

Nearly all older people with bleeding disorders who completed the Getting Older survey had superannuation, although they did not indicate whether the amount of their superannuation would be adequate for a comfortable retirement. They also commented that their bleeding disorder and for some their bloodborne viruses meant that getting income protection, disability and life insurance could be problematic, with comments that they had been refused or that there were exclusions or much higher and unaffordable premiums. Many also described difficulty obtaining travel insurance. Some said they had not tried to get insurance. This could have significant implications for their financial situation in the future if they were forced to retire early due to disability from their health conditions.

'Yes, I have been refused life insurance, disability insurance as well as travel insurance.'

'I can't get income protection due to liver/Hep C prior history. I can't increase my base insurance cover for the same reason.'

'Difficult to get life insurance, so only have limited through my super.'

'Applied for TPD [Total and Permanent Disability Insurance] as a fit and healthy 55 year old. Premiums were outrageously high and anything I was every likely to need to claim for was explicitly excluded from the cover. They did not 'get' that being an asymptomatic carrier did not increase the risk of me needing to make a TPD claim.'

A partner described the impact of an interrupted working life on their superannuation and financial security:

'There have been always financial issues as he hasn't worked for a long time. He was on casual work and on disability support, I was working casual and on a carer's pension. We have always kept ourselves out of debt but it's not like we have got much in reserve. We are just living as we go. Things like super, he doesn't have. My super has been at a minimum as I was working part-time for a long time. And he hasn't got life insurance.'

With a fragile financial situation going into their senior years, this could make access to the services where there would be out-of-pocket costs much less available to older people with bleeding disorders because of the affordability issues. This would include many of the services proposed in this needs assessment, including home and community care services, community nursing, disability aids and equipment, and health services outside their HTC, including local services, such as physiotherapy, podiatry and dentistry, which would be accessed through the private system.

While private health insurance may assist with some of the out-of-pocket health care costs, HFA community consultation for the Private Health Insurance Inquiry in 2017 indicated that affordability and value-for-money issues made private health insurance unattractive to many people with bleeding disorders in Australia. Many community members said they used the private health system for some aspect of their health care – as a private patient in a public hospital, or to manage health issues not related to their bleeding disorder, or for extras such as optometry, hearing aids, dentistry, or physiotherapy. They were very concerned that the premiums for private health insurance were becoming unaffordable, even for those on middle incomes, while the benefits were decreasing sharply. Others commented that although they had private health insurance they were unsure of its value to them, as benefits were poor and they were largely required to use the public health system because of their bleeding disorder.[129] These concerns are likely to increase as people with bleeding disorders grow older, particularly if their financial situation becomes more precarious and they have to wind back their expenditure. However, this would mean they would be less likely to access the services that would improve their health and wellbeing as they grow older.

6.22.2 FINANCIAL PLANNING

The *Don't go it alone* study pointed out that if older Australians were satisfied with their perceived current financial situation, they often experienced higher life satisfaction.[111] It was interesting to see that older people with bleeding disorders who participated in the consultation were aware that they may need to make uncomfortable decisions in the future to manage their finances and had not yet sought financial planning to deal with this. People who completed the survey were more likely to comment on being careful with spending rather than formal financial plans.

'Probably a financial plan…I need to receive financial planning advice as my savings and superannuation are very limited. I am awaiting the opportunity to discuss this issue with a professional as I live day to day.'

'Having been through aged care process with her [wife's] mother and my mother, we are aware if I need residential care, it is expensive. So we need financial flexibility to afford that. That means planning ahead. That I think is fairly probable for me.'

WHAT WILL HELP?

The consultation highlighted the cumulative impact of living with a bleeding disorder on reducing income over a lifetime and increasing health care costs.

The greater majority of older people with bleeding disorders had acquired hepatitis C before the 1990s, which compounded their health and financial issues. In spite of the recommendation of the Australian Senate Committee that they should receive access to financial support for the costs that flow on from these health complications, this support has not been received. This financial support would make a considerable difference to alleviating some of their concerns about managing their care and home environment into the future.

Participants in the needs assessment consultation raised a variety of specific concerns around financial security as they grow older, depending on their individual situation. A range of options would be required to address their concerns, including:

- Information about financial planning and the services available promoted widely in foundation activities, for example, on the Getting Older Information Hub on the HFA website, in foundation newsletters and peer support activities and at education events such as the national bleeding disorders conference.
- Exploration of government financial safety net options and vigorous advocacy through HTCs and foundations to access all options under existing programs, including the NDIS and MyAgedCare.
- Support and advocacy from HTCs and foundations to enable older people with bleeding disorders and their partners to access existing programs providing assistance for disability aids and equipment, travel to medical appointments and community nursing. There is wide state and regional variation in how these programs are implemented and the options available would need to be investigated individually.
- Increased resourcing to HTCs and foundations to enable them to undertake this investigation and advocacy on behalf of their patients/community members and their partners and family.
- Government financial assistance with out-of-pocket health and welfare costs not covered by existing government programs. Where an older person has private health insurance and this could provide some assistance with defraying costs, the government financial assistance could cover the gap fees. However, as outlined in this section, the needs assessment highlighted the financial problems for some older people with bleeding disorders and their concerns about private health insurance, making it less likely they would have private health insurance as they reached their senior years.
- Government financial assistance to support people with chronic health conditions and disabilities to remain in the workforce, who are currently excluded from the NDIS and other disability financial support.
- Exploration of barriers to various types of insurance and superannuation and consideration to relevant advocacy.

6.23 Travel

The desire to travel, see the world and meet up with family and friends interstate and overseas was a commonly held aspiration. Underneath this aspiration lay an acknowledgement of the complexities of travel for a person with a bleeding disorder.

> *'Actually, there is clash between what you hope for yourself. I hope to travel around the world. But actually, it's not simple. I did it when I was young and didn't even think that I might need treatment. I went all over the place and didn't even consider that I should have a plan.'*

Although travelling internationally could offer a considerable challenge to an older person with limited mobility and who needed to take treatment product with them, this did not appear to deter them from their plans. Most of the concern about travel was the difficulty of obtaining travel insurance, either because companies would not insure them or had high premiums for pre-existing health conditions like haemophilia.

WHAT WILL HELP?

Education resources about travel targeted at older people with bleeding disorders may assist them to plan and travel more safely and comfortably. With the aftermath of COVID-19, this will need to take into account travel restrictions for older people and special considerations around safety and infection control, for example, on cruise ships, which are often an appealing option for older people with mobility problems.

Advocacy around lower costs for travel insurance for people with bleeding disorders may also be advantageous.

6.24 Future planning

When asked about planning for the future, older people with bleeding disorders and their partners would commonly discuss planning around their future accommodation, which may involve modifying their current housing or moving to a smaller residence or to residential care. Partners or family were more likely to comment that there were plans for increased family support in the future.

> *'I am expecting my joints to get worse and worse. That's when I have to make changes to my life. I am going to lose my lifestyle and a certain level of independence. First option is to move into a retirement village and get help to do bits and pieces. I never contemplated it before now I have start putting things in place.'*

For some people with bleeding disorders, planning for the future also involved improving their health and fitness and being proactive in their medical care.

Psychosocial workers were concerned about the lack of planning around end-of-life care. One commented, *'practical things are also required to help improve quality of life, such as planning with making a will, an advance care directive, having control over medical decision- making with a Medical Power of Attorney.'* Survey results highlighted this problem: only a quarter or less had prepared formal medical or legal documents, such as a will, a power of attorney or an advance care plan.

A considerable number said they had no plans. For some, this was a reflection of their personal situation and lack of financial security or family. Others commented on the psychological impact of making these types of plans. These are important issues which would need to be addressed through psychosocial support, such as counselling.

> *'The issue for me is I don't have any plans. I live on a day to day basis, I don't have a plan for when I get older. Why do I want to retire from work? Do I have enough money to retire?'*

'None. Neither own my own home. No superannuation. NO legal arrangements, no wills no dependents, no partner'

'None. Too stressful and neither of us are psychologically equipped to do so.'

WHAT WILL HELP?

Planning for the future is an important aspect of health and wellbeing. Given the psychological issues identified in the consultation, a considerable number of older people and their partners will require psychosocial support to deal with the issues confronting them with future planning. A case management approach may be beneficial.

Promoting education materials about future planning could also support community members. This could include:

- House modification, downsizing, residential care
- Powers of attorney
- Advance care planning
- Making a will.

6.25 Information and education

The consultation identified a range of areas on growing older with a bleeding disorder where education materials would benefit the health and wellbeing of people with bleeding disorders and their partners and family.

This included education resources targeted at:

- Older people with bleeding disorders
- Their partners, family and carers
- Health care and community workers who provide their care in the community
- Workplaces.

Topics for education materials included:

- Special issues related to growing older with a bleeding disorder in men and women, including what to expect with health conditions of ageing
- Self-management for best health outcomes
- Understanding pain
- Aged care services.

Getting older survey respondents also ranked their interest in particular topics and the results are summarised in order of popularity for older people with bleeding disorders below:

- Exercise and remaining active
- New treatments
- Pain management
- Travel
- Nutrition and weight management
- Safety at home when getting older
- Accessing aged care services and the NDIS
- Vein care
- Working with a GP
- Caring for mental health
- Financial management.

More than 85% of both older people with bleeding disorders and their partners and family who completed the Getting Older survey said they used a computer or a mobile device like a tablet or iPad daily. Most used their computer at home or their mobile phone to access online information, with older people more likely to say they used their tablet or iPad than partners or family. This may be a reflection of their manual dexterity.

When asked about how they would prefer to get information or education materials about getting older with a bleeding disorder, most preferred to get their information online. However, around one third of older people with bleeding disorders and one quarter of partners and family preferred printed materials. There was also a marked preference to receive this information from Australian haemophilia foundations, in the Haemophilia Foundation Australia journal, *National Haemophilia*, or the local foundation newsletter.

WHAT WILL HELP?

How to provide education materials

Developing a **Getting Older Information Hub** on the HFA website will be a valuable way to centralise access to information for both the bleeding disorders community and for the health care and community workers who provide their care. It would also support independent research by both groups.

The Getting Older survey underlined that the HFA website is trusted and well-respected in the community as a source of information on bleeding disorders. The website has an information partnership with the Australian Government health information portal, HealthDirect, and provides high-quality, evidence-based health information in plain language, most of which has been focus-tested with the target groups.

To reach the wider bleeding disorders community, it will be crucial to promote the Information Hub in the environments where people with bleeding disorders receive their treatment and care, for example, in HTCs and through the general practitioners and other clinicians who provide their care outside the HTC. Promotion will also involve investigating ways to rank the Information Hub higher in search engines and other online promotion strategies so that people undertaking independent online research are directed to it.

It will also be important to provide information in local foundation newsletters and the HFA journal, *National Haemophilia*.

Consideration will need to be given to what information to provide in print format, including brochures and booklets, to meet the range of needs in the community, and where it may be valuable to provide information both online and in print.

Approach

Ensuring that the information is presented in an accessible way for the target group will be essential if it is to be effective as an education resource.

The objectives of the education resources will be to improve:

- The health literacy of the older person with a bleeding disorder and their partner and family
- The understanding of care providers on how best to provide care to them.

A key aspect of creating a meaningful framework for the education materials will be to focus on the patient journey as they grow older, the issues they encounter, and how these can be managed for the best possible health and quality of life.

The education materials will also need to be tested with the target group to ensure that the language, concepts and format are accessible and meet their information needs.

Development

To develop relevant and effective education resources will involve collaborations between the community, HTCs and other organisations and individuals with expertise and experience in the area. In some cases, it may be more appropriate for HFA to lead development, for example, with consumer resources, while health professionals may need to lead the development for resources related to their specific discipline. These collaborations may also assist with sourcing education resources or strategies that could be adapted for the bleeding disorders community.

6.26 Hard-to-reach populations

The needs assessment identified that there needed to be further research to understand the special issues with ageing for some populations with bleeding disorders who were difficult to reach through the consultation. This included the people with mild disorders who were not connected to HTCs or haemophilia foundations and some particularly vulnerable people where there may have been barriers to participation in the consultation in the timeframes. This would include some people experiencing housing insecurity and not contactable via post, phone or email. Literacy problems, and/or cultural, language and connection issues may have been a barrier, for example, in some people of culturally and linguistically diverse (CALD) backgrounds or some Aboriginal and Torres Strait Islander people, or some people with mental health or other serious health issues.

As for the wider population with bleeding disorders, the experience of growing older will also be a new phenomenon in the more vulnerable groups and numbers are likely to be small. Early ageing is also likely to be a significant issue.

WHAT WILL HELP?

There are several opportunities to build further consultation around ageing onto existing and proposed work to connect to these groups.

HFA will be conducting a wider community awareness campaign around VWD in 2021 when the new national diagnostic and clinical management guidelines are released. Through this campaign, HFA, state/territory foundations and HTCs aim to connect to people with VWD not previously known to them. Many are likely to have a mild form as those with severe disorders are usually connected to an HTC early in life. Further consultation around the impact of getting older and their associated education and support needs could take place during the process of connecting with older people with VWD, either formally, for example, as questions in a membership survey, or informally as part of the welcome to the foundation or HTC services.

A variety of strategies will be required to consult further with the more vulnerable groups. HTCs and state/territory foundations have existing outreach with Aboriginal and Torres Strait Islander people and services and have been building connections and peer support for individual people of CALD backgrounds and their families. It will be important to link any further consultation to this existing work. Bleeding disorders occur in families and it may also be valuable to use 'snowballing' techniques through families that are already connected to communicate and consult with others who may be affected.

Discrimination is a common issue for people with bleeding disorders and this may make disclosure and connection more difficult, particularly in vulnerable groups. Because bleeding disorders are genetic and inherited, disclosure of a bleeding disorder in an individual can have implications for their entire family. It will be valuable to discuss strategies for overcoming this with international colleagues: this is a recognised issue and some will already have addressed this locally when undertaking consultation. It may also be helpful to consider the strategies adopted by other Australian agencies who consult with vulnerable populations around health conditions, which may be associated with social stigma.