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LET'S TALK ABOUT GETTING OLDER

Suzanne O'Callaghan

When we first asked the nurses at Haemophilia Treatment Centres (HTCs) about the emerging issues related to ageing with a bleeding disorder, they said, 'Where do we start?'. And indeed, the Haemophilia Foundation Australia Getting Older needs assessment had a lot of ground to cover!

The *Getting older with a bleeding disorder needs assessment report* has now been completed, the result of many months of intensive work.

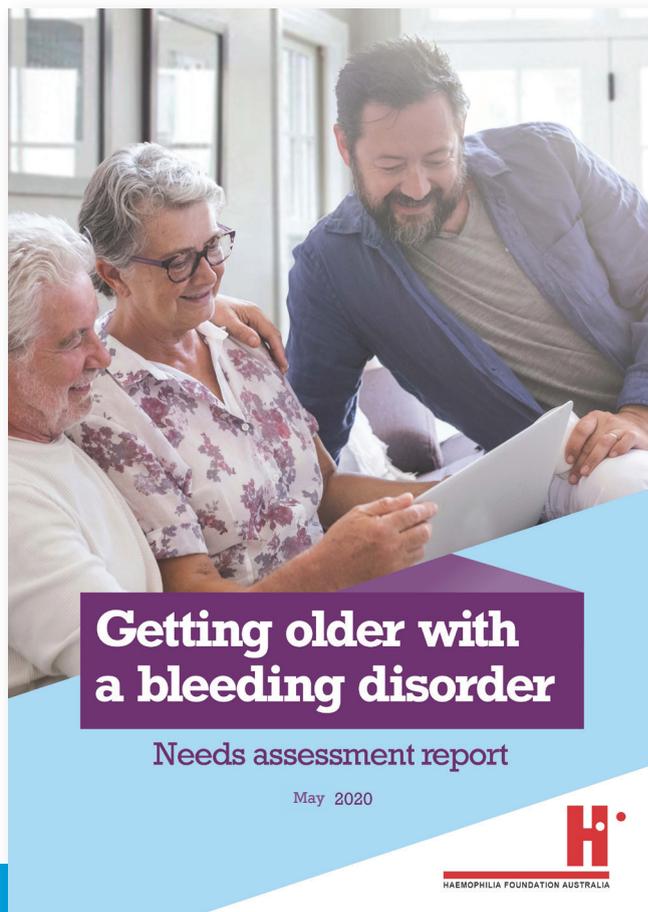
WHY A NEEDS ASSESSMENT?

Over the last several decades improvements to treatment and care have created a new phenomenon: for the first time we are seeing a generation of people with bleeding disorders who are living into their senior years. With the newer and emerging therapies, there is hope that they will also be able to enjoy a better quality of life.

This is a welcome change, but it has its challenges. This new older generation is entering unknown territory. They are encountering the issues of ageing faced by the general population and are also the first group to experience the impact of ageing on their bleeding disorder.

'Early ageing' is also a problem for some in our community. Many relatively young people with bleeding disorders experience complications usually associated with growing older, including joint and muscle damage, arthritis, pain and mobility problems. This impacts on many aspects of their life and many have difficulty meeting the eligibility criteria to access support services.

It was important for Haemophilia Foundation Australia (HFA) to understand the needs of older people with bleeding disorders into the future. HFA began work on the needs assessment in late 2018 and during 2019 consulted with the bleeding disorders community, specialist health professionals and other relevant organisations. The Getting Older needs assessment report brings together the findings from that consultation.



HOW TO ACCESS THE REPORT

The full report has been published in print (black and white) and online (full colour).

There is also a short community report, which is a summary of the findings.

If you would like a print copy of the report, don't hesitate to contact HFA and we will post you a copy:

E: hfaust@haemophilia
T: 1800 807 173

You can download the report from the HFA website – www.haemophilia.org.au

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WHAT DID WE DO?

Some of you have met or spoken on the telephone to Preetha Jayaram, who was employed by HFA on a 12-month project to undertake a needs assessment to help HFA understand the needs of older people with a bleeding disorder. Over the 12 months Preetha consulted widely:

- 43 interviews nationally with older people with bleeding disorders, their partners and family, health professionals at HTC's and other organisations with a common interest in chronic health conditions
- 2 community forums, one in the ACT and one in Queensland
- The Getting Older Community Survey, which had 169 respondents from all states and territories.

She transcribed all of the interviews and organised the data from the consultation into themes – a huge job.

We were also able to analyse some age-related data from the PROBE (Patient Reported Outcomes Burdens and Experiences) Australia study and we have included the results in the report.



WHAT DID WE LEARN?

'Ageing' and 'getting older'

The first thing that was made clear to us was that 'ageing' wasn't a very helpful word for the community. Older people with bleeding disorders thought that 'ageing' put them in an 'old person' box where they didn't belong, and that it was negative and often discriminatory. Younger people with joint and muscle damage are often referred to as having problems of 'early ageing' but they also pointed out that they were still relatively young and not actually aged in years; they had muscle and joint complications which looked like the problems of ageing.

So, after some discussion with the community about what terminology might work better, we changed the name of the project from the 'Ageing Project' to the 'Getting Older Project'. We were careful of the language in the report and, although we did use the word 'ageing' on occasion, this was as a medical term.

Aspirations and goals

HFA's vision is of '[active, independent and fulfilling lives for people in our bleeding disorders community](#)', but what does this mean to older people with bleeding disorders? Understanding their aspirations and goals is essential to achieving this.

When older people with bleeding disorders were asked about their aspirations for the future, most said they wanted to maintain their quality of life, be healthy and remain independent. This involved improving their mobility, reducing stiffness and pain, and being able to participate in family life and enjoy friendships, travel, pursue their interests and to contribute in a useful way to society. Some wanted to continue working as long as they were able to, other were hoping to stop or reduce work. Some were already retired or not working. Being comfortable financially was important.

'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.'

WHO DID THE GETTING OLDER SURVEY?

169 people completed the Getting Older Community Survey.

89 (53%) returned the **online** survey

80 (47%) returned the **print** survey

133 were **older people with bleeding disorders**

65% were male

34% were female

104 had **haemophilia** or carried the gene

19 had **von Willebrand disease**

15 had a **rare clotting factor deficiency**

7 had **other bleeding disorders**

Some had more than one bleeding disorder.

36 were **partners or family**

19% were male

81% were female

WHERE DID THEY LIVE?

All states and territories were represented.

45% lived in a **capital city**

13.5% lived in a **rural/urban fringe area**

28% lived in a **regional/rural/remote area**

'As I get older I hope to have a comfortable life. Still having quality of life. As I said I am young at heart.'

'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.'

Challenges and concerns

What could get in the way of achieving their aspirations and goals? What were they worried about?

The needs assessment covered a wide range of issues and concerns raised by community members and HTC's – you can see more in the full report. We touch on a few below.

There is a culture of stoicism and 'getting on with it' in this older generation. They had grown up in a time before prophylaxis, when there were treatment shortages, and as a result many lived with joint and muscle damage as a result. Many had also been exposed to hepatitis C and some also to HIV through their treatment products in the early days of the epidemics. Health professionals at the HTC's commented on their resilience and determination to overcome challenges.

'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.'

'Resilience is my strength. It's a marathon and you've got to have resilience.'

However, there is a limit to even the most positive and determined attitude. At a certain point, the combination of their complications with their bleeding disorder with the health conditions of ageing could be too much of a challenge to manage.

'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.'

Health concerns were mentioned most often by both the community and health professionals.

Many worried about losing their independence. They spoke about problems with their mobility and dexterity from the joint and muscle damage, arthritis and pain that were the result of bleeding episodes over a lifetime. This could limit their ability to work, make it difficult to travel and prevent them from being as active socially – catching up with family, friends, the foundation activities – all of which was important to their enjoyment of life.

Some talked about the trouble they were having infusing their treatment, with arthritic, shaky hands and scarred veins. Who would look after their bleeding disorder if they developed dementia and moved to a residential aged care facility? Some did not know what aged care services were available or how to access them.

Getting to the HTC for appointments was also becoming more difficult – and there were so many appointments to manage all their health conditions. As they grew older they had more health issues to deal with. This could require liaison with their HTC to manage factor cover for surgery or medical procedures like biopsies or dental work. If they had cardiovascular problems, the HTC would need to work out the best approach to anti-coagulant medications with their cardiovascular specialist.

HTC's were seeing more of their older male and female patients with mild haemophilia and VWD. Bleeding disorders are rare and some talked of the difficulties they had when health professionals outside the HTC would not take their concerns about bleeding complications seriously. Nearly all had a general practitioner (GP) for their general health care, but HTC's were concerned that some were not having regular preventive health checks and could miss out on treating a serious health condition early.

Younger people with the 'early ageing' complications of a bleeding disorder could slip through the eligibility cracks of the National Disability Insurance Scheme and other government safety net support programs.

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'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 can find myself getting a bit shakier now which can make intravenous injections little bit harder.'

'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.'

'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!!!!'

'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 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.'

WHAT WILL HELP?

Older people with bleeding disorders often develop strategies to work around their physical problems and share them with each other and they had a similar constructive approach to suggesting solutions for the needs assessment. HTCs also took the opportunity to explain the issues they had been managing and discuss their ideas on what else would help.

Patient-centred care

An important underlying principle was to achieve 'patient-centred care'. What will happen along the patient journey as the person with the bleeding disorder grows older? What services and help will they need? What will be the bumps along the way? What can be done to improve their experience – and their health and quality of life? What could help them to stay in the workforce longer?

Some suggestions were:

- Strengthening the role of HTCs in providing and co-ordinating comprehensive care for their older patients, which involves resourcing them adequately to undertake this work

- Innovations in comprehensive care to make access easier, eg telehealth, evening/weekend clinics, HTC outreach to outer suburban or regional areas, HTC liaison with local health care services
- Investigating all suitable transport options available
- Strengthening the relationship between HTCs and GPs
- Ongoing development and proactive use of the Australian Bleeding Disorders Registry (ABDR) and MyABDR, the patient recording app and website
- Education about the special issues of growing older with a bleeding disorder for
 - Older people with bleeding disorders
 - Their partners, family and carers
 - The health and community workers who provide their care
 - Employers
- Access to newer longer-acting and non-intravenous treatments for older people with haemophilia
- Treatments and programs to support being active and maintaining mobility and physical functioning
- Pain management
- Information about and support to access the range of aged care services
- Flexibility in the workplace, an understanding employer, vocational counselling.

'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 sub-cutaneous 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 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.'

'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.'

'Lots of things [will help to keep working]. 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.'



‘Resilience is my strength. It’s a marathon and you’ve got to have resilience.’

Hepatitis C and HIV

HFA also looked into the specific issues around hepatitis C and HIV in older community members. Nearly all who had been exposed to hepatitis C had been now been cured and were grateful for their successful treatment and the potential improvement to their health and lifespan. Although hepatitis C had a major impact on the working and personal lives of many, they often brushed it over and had tried to take it in their stride.

The needs assessment highlighted that there were still some medical issues with hepatitis C: the need for ongoing liver health monitoring for those with cirrhosis, and the unknown hepatitis C status of some people with mild conditions, including some women who carry the gene. There was also a small number of individuals whose treatment had been unsuccessful or could not have treatment and were living with advanced liver disease.

The consultation underlined the cumulative impact of living with a bleeding disorder on reducing income over a lifetime and increasing health care costs. Having hepatitis C or HIV added to this impact. Although vigorous exploration of government financial safety net options may help some older people with bleeding disorders financially, they will have out-of-pocket health and welfare costs not covered by existing programs. Most have been affected by hepatitis C. In 2004 the Senate Inquiry into Hepatitis C and the Blood Supply made recommendations to extend financial assistance and case management to this group which were never implemented. The report findings noted that providing this would make a considerable difference

to managing the care and quality of life of older people with bleeding disorders affected by hepatitis C into the future and supported the need for HFA to pursue these recommendations further.

‘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. 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.’

‘It’s funny getting older with hep C. It didn’t affect me. I live quite happily. It happened years ago. 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.’

‘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.’

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Mental health and support

Mental health was identified as another important area. There was much discussion from both community members and HTC's about the need for professional psychosocial care (eg from a psychologist, counsellor, social worker or psychiatrist) and that it should be extended to the person's partner and family as well, when required. However, there was also a big focus on how to support the older person to stay active mentally and socially, to do things that interest them, keep up with family and friends and contribute their skills and experience to the community.

In the Getting Older Community Survey most people said they found it helpful to keep up with other people in the bleeding disorders community. HTC's explained that peer support had a very important role in maintaining resilience. Older community members could share strategies that had worked for them and give each other confidence to take steps to try something different or to advocate for themselves. Friendships could make a big difference. This could be friendships with other people with bleeding disorders or with other people who shared the same interests, and getting older was seen as a time to seek out groups where friendships could be established.

COVID-19 has changed the way we socialise and many of us have tried out digital technologies like Skype and

Zoom to keep up with friends and family. Most people who completed the Getting Older Survey said they preferred face-to-face events and only a third were interested in online support. However, after being exposed to these digital platforms recently, their attitudes may have shifted. Although face-to-face events are clearly the first choice as an opportunity to meet and get to know others, digital options for peer support may provide another way for older people with bleeding disorders to connect with each other when they are unable to meet face-to-face because of distance, mobility problems, or other reasons.

'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.'

'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.'

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

WHAT DID WE LEARN FROM PROBE?

We were able to access age-related data from the PROBE Australia Study in February 2020.

PROBE is a multi-national validated community questionnaire to understand the impact of haemophilia and treatment on quality of life. It compares the experience of men and women with haemophilia or who carry the gene to men and women without a bleeding disorder.

We looked at the results for some key areas, particularly for men and women aged 45 years and over:

- Treatment regimen
- Target joints
- Physical functioning and pain
- Hepatitis C and other health problems
- Work

This was an important way to show the impact of haemophilia. For example, the results demonstrated very clearly how much having haemophilia can increase the experience of pain and problems with mobility or activities of daily living. We were able to compare results in the same age brackets between:

- moderate/severe and mild haemophilia
- men and women
- people with haemophilia and people without a bleeding disorder.

The graphs in figures 1 and 2 show the impact of haemophilia on physical functioning and pain. You can see the full results for severity, age groups and gender in the report.

Figure 1: Physical functioning and pain in the last 12 months - men with haemophilia 45 yrs and over

Total number = 57

- = Yes
- = No
- = Not Reported

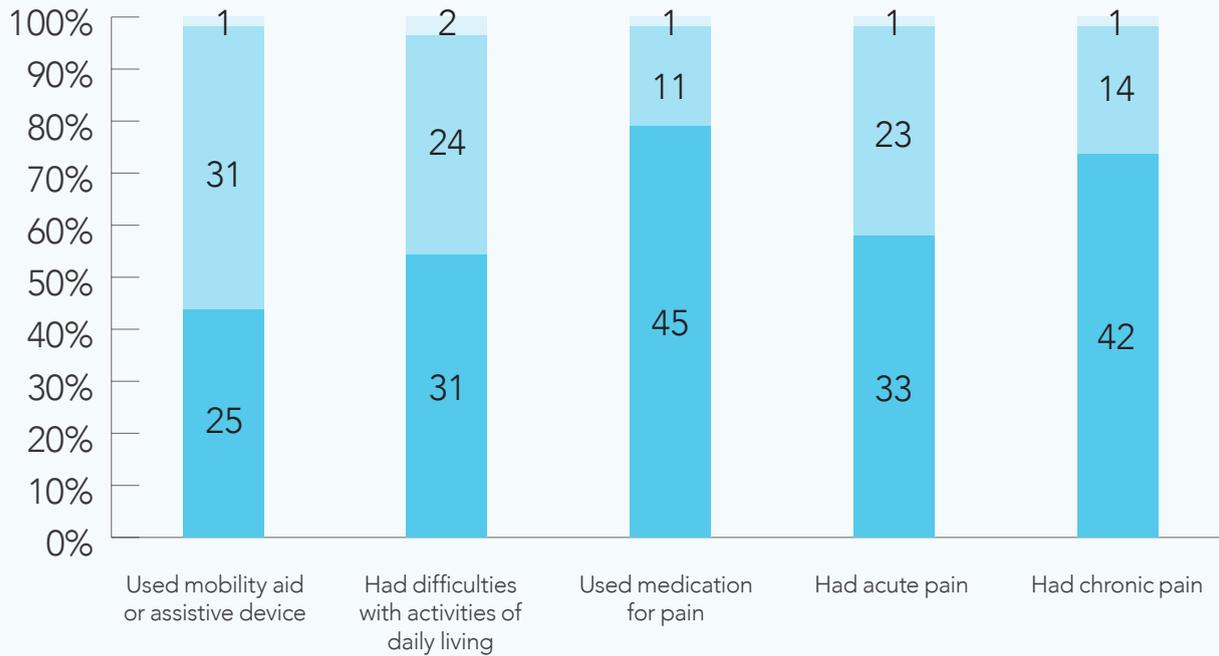
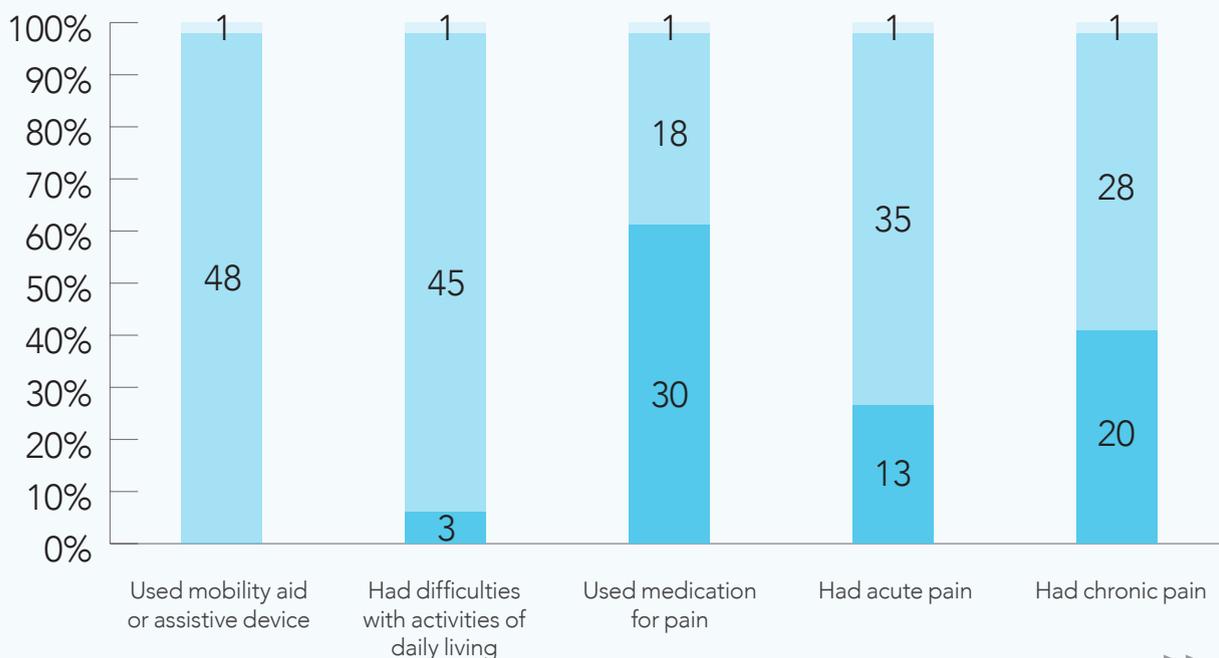


Figure 2: Physical functioning and pain in the last 12 months - men without a bleeding disorder 45 yrs and over

Total number = 49

- = Yes
- = No
- = Not Reported



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GETTING OLDER INFO HUB

Everyone was agreed that there needed to be more information about getting older with a bleeding disorder, but where would you find it? A centralised location was obviously important and a key outcome from the project has been to establish a **Getting Older Information Hub** on the HFA website.

Interestingly, more than 85% of people who completed the Getting Older Community Survey said they used a computer daily and most used it to access information online. Printed education materials were still important to many and HFA will continue to provide some information in print as well as online.

Over the last 6 months the Getting Older Focus Group – a group of older bleeding disorder community members – have been working with HFA on the concept and design for the Info Hub. They worked from the consultation findings and their own experiences to decide the topics and sections include:

- Health and wellbeing
- Services for getting older
- Work and finances
- Support
- Recreation and travel
- Planning for the future
- Connect to others
- For professionals

The Hub is available now and will continue to grow as more information is developed or sourced.

We would be interested to hear your feedback and ideas for more topics. You can find the Getting Older Info Hub on the HFA website – www.haemophilia.org.au/getting-older

NEXT STEPS

Where to next?

The report includes a number of recommendations for HFA to discuss and work through with other stakeholders such as state and territory Foundations, HTC's, other health care services and governments. You will find the recommendations at the front of the full report.

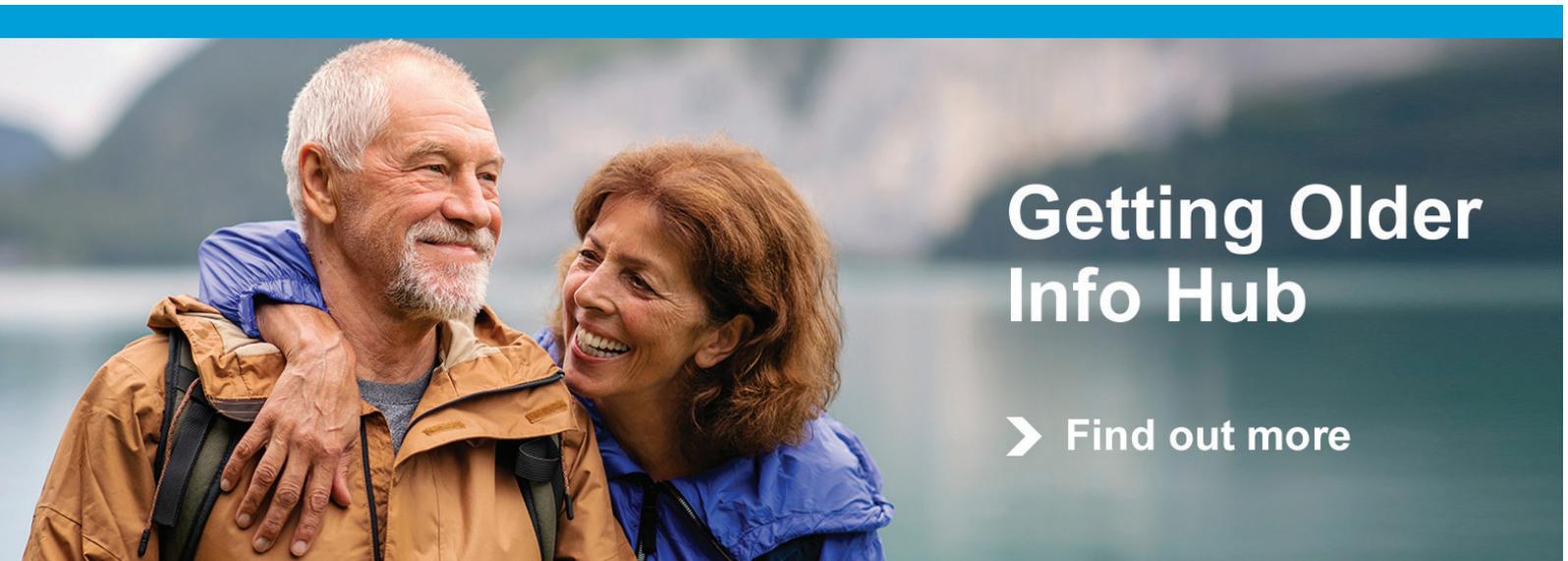
This is a priority area for HFA and we are excited to be embarking on the next stage of our work to achieve our vision of 'active, independent and fulfilling lives' for older people with bleeding disorders.

THANKS

There are many people and organisations who contributed to the report and we would like to thank them all. Please take a moment when you read the report to have a look at the Acknowledgements where they are listed.

A special thanks to the community members who participated in the interviews, the community forums, the Getting Older Community Survey, the PROBE Australia study and the Getting Older focus group; and the health professionals and other agencies who were part of the consultation; and the HFA Getting Older Project Advisory Group, for their guidance of the project.

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Getting Older Info Hub

➤ Find out more