



# Getting older with a bleeding disorder

## Community report

### WHY A NEEDS ASSESSMENT?

In recent years 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 live with complications that usually come with growing older, including joint and muscle damage, arthritis, pain and mobility problems.

This impacts on many aspects of their life. 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.

### HOW TO ACCESS THE FULL REPORT

**This community report is a summary of the findings from HFA’s consultation. The detailed findings are in the HFA Getting older needs assessment report.**

The **Getting Older with a bleeding disorder needs assessment report** (full colour) is available on the HFA website: [www.haemophilia.org.au](http://www.haemophilia.org.au)

If you would like a print copy (black and white only), contact HFA:

T: 1800 807 173

E: [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)

## HFA NATIONAL CONSULTATION

To help understand the needs of older people with a bleeding disorder, HFA conducted wide consultation during 2019 and early 2020.

- 43 interviews nationally with older people with bleeding disorders, their partners and family, health professionals at Haemophilia Treatment Centres (HTCs) and other organisations with a common interest in chronic health conditions
- 2 community forums, one in the ACT and one in Queensland
- The HFA Getting Older Community Survey.

HFA also analysed age-related data from the PROBE (Patient Reported Outcomes Burdens and Experiences) Australia study.

The HFA Getting Older Project Advisory Group, which included bleeding disorder community members, specialist health professionals, peer support workers and researchers in the area of ageing, provided guidance and information for the needs assessment.



## 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**

## 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 wording 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. Although we did use the word 'ageing' sometimes, 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.'*

*'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 (preventive treatment), when there were treatment shortages. As a result many lived with joint and muscle damage. 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.'*

The most common challenges mentioned were health concerns.

Many older people 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. HTCs were seeing more of their older male and female patients with mild haemophilia and von Willebrand disease (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 HTCs 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.

*'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?

Both community members and health professionals shared their ideas for solutions and what could help.

### IMPROVING HEALTH AND QUALITY OF LIFE

Achieving 'patient-centred care' is an important part of this. 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 HTC's 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 HTC's 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.'*

*'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.'*

## 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. They 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. People with cirrhosis needed ongoing liver health monitoring. Some people with mild disorders, including some women who carry the gene, were thought not to know if they had hepatitis C. There was also a small number of people whose hepatitis C 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 assistance to explore 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 found that this would make a difference to managing the care and quality of life of older people with bleeding disorders affected by hepatitis C into the future. The findings 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.'*

*'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.'*

## MENTAL HEALTH AND SUPPORT

Mental health was identified as another important area. Both community members and HTC's discussed 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 consultation most older people said they found it helpful to keep up with other people in the bleeding disorders community. HTC's explained that peer support was very important to maintain 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. The senior years were seen as a time to seek out groups where new 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. 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 be 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.

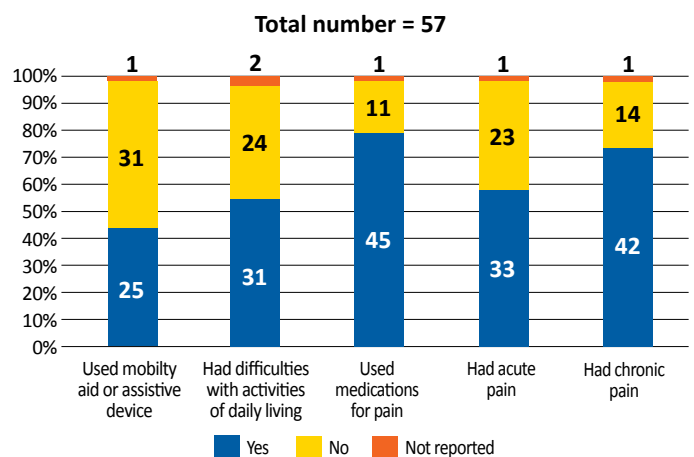
We looked at the results for some key areas, particularly for men and women aged 45 years and over:

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

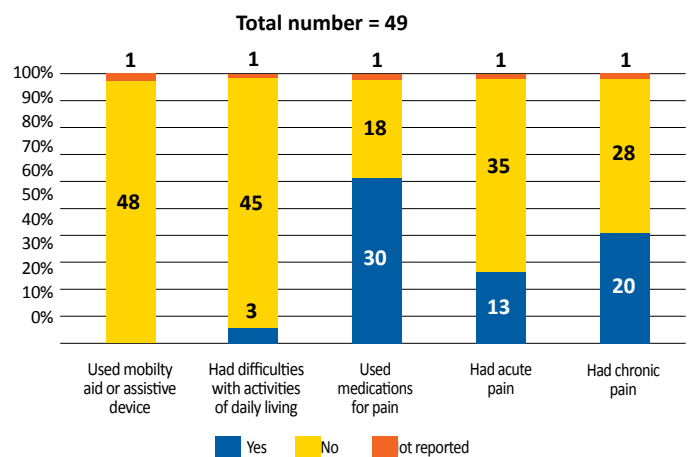
This was an important way to show the impact of haemophilia. For example, the results demonstrated very clearly how much having haemophilia can increase the experience of pain and problems with mobility or activities of daily living.

The graphs below are an example – you can see the full results in the needs assessment report.

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



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



## GETTING OLDER INFO HUB

Everyone agreed that there needed to be more information about getting older with a bleeding disorder, but where would you find it? A key result of the project has been to establish a **Getting Older Info Hub** on the HFA website.

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.

The Getting Older Info Hub has been developed from the report findings and with the input of the HFA Getting Older Focus Group. HFA will consult with health professional experts and the community on new information to include.

The Hub 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](http://www.haemophilia.org.au/getting-older)

## NEXT STEPS

### WHERE TO NEXT?

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

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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### Haemophilia Foundation Australia

7 Dene Avenue

Malvern East Victoria Australia 3145

Freecall: 1800 807 173

E: [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au)

W: [www.haemophilia.org.au](http://www.haemophilia.org.au)



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