

Executive summary



Improvements to treatment and care over recent decades have created a new phenomenon: for the first time there is a generation of people with bleeding disorders who are living into their senior years. Newer and emerging therapies give hope that they will also be able to enjoy a better quality of life.

While this is a welcome change, it is challenging. This new older generation is entering into unknown territory: encountering the issues of ageing faced by the general population, and the first group to experience the impact of ageing on their bleeding disorder.

‘Early ageing’ is also a problem in this community. Many relatively young people with bleeding disorders experience complications usually associated with growing older: 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.

Haemophilia Foundation Australia (HFA) consulted with the bleeding disorders community, specialist health professionals and other relevant organisations to understand the needs of older people with bleeding disorders into the future. This **Getting Older needs assessment** report brings together the findings from that consultation.

ASPIRATIONS AND GOALS

Understanding the aspirations and goals of older people with bleeding disorders is essential to achieving the HFA vision of ‘active, independent and fulfilling lives for people in our bleeding disorders community’.

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.

ISSUES AND CONCERNS

Health concerns were perceived as the greatest barrier to achieving these aspirations.

There was a culture of stoicism and ‘getting on with it’ in this older generation, developed in childhood to overcome the outcomes of treatment shortages and the pain and disability they experienced over their lifetime. Many had also acquired hepatitis C and some also HIV from their treatment products during the early days of the epidemics and lived with the consequences. As they entered their senior years, they were concerned they were reaching a tipping point, where the health conditions of ageing combined with the complications of their bleeding disorder could be too difficult for them to manage, even with their usual determination and positive approach.

A significant worry was losing their independence. Joint and muscle damage, arthritis and pain resulting from bleeding episodes over their lifetime had a big impact on their mobility and dexterity, their ability to undertake activities of daily living and their quality of life. This could limit their working life, make it difficult to travel and prevent the social interactions and activity – catching up with family, friends, peers - so necessary to their

resilience. Memory loss, increasing frailty and injuries related to falls were identified as particular challenges. They worried about who would have the expertise and the vigilance to manage their bleeding disorder if they developed dementia and moved to a residential aged care facility. They did not know what aged care services were available or how to access them.

In bleeding disorders these multiple complications become increasingly complex when combined with issues of ageing and can also challenge treatment and care. Infusing treatment into veins was increasingly difficult and prophylaxis (preventive) treatment to reduce bleeding episodes, infused multiple times weekly, was unattractive. Compounding health conditions created a domino effect: mobility and weight problems could lead to a fall, joint problems could make rehabilitation challenging, leading to an ongoing spiral of physical decline.

Accessing care was also becoming more difficult. Some had moved to outer suburban and regional areas to save money. With stiff legs and increasing fatigue and frailty, travel to the HTC for appointments and programs, such as physiotherapy, could be a problem. They were overloaded with appointments to manage all their health conditions. Nearly all had a general practitioner (GP) for their general health care, but the continuity of care with GPs was variable. HTCs were concerned that they were missing regular preventive health checks.

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.

Most people with bleeding disorders have mild conditions, and usually do not need regular treatment for bleeding episodes. Many are not well-connected to HTCs. HTCs were now seeing their older patients with mild conditions more often, with joint problems and needing preventive treatment for surgery and medical and dental procedures. Bleeding disorders are rare and not well understood by many health care professionals outside the HTC. Men and women with mild and rarer bleeding disorders reported that some health care professionals in the community did

not take their bleeding disorder seriously. This resulted in unnecessary bleeding episodes and other health complications.

There has been little research into the impact of ageing on mild haemophilia, VWD, the rarer bleeding disorders and on women with bleeding disorders: this area will need further investigation. The PROBE (Patient Reported Outcomes Burdens and Experiences) Australia Study, for example, highlighted questions around arthritis, physical functioning and bleeding problems in older people with mild haemophilia, when this has traditionally been associated with severe haemophilia.

Mental health is key to maintaining resilience. Older people with a bleeding disorder and their partner and family could be affected by traumatic experiences with their bleeding disorder, or from HIV and hepatitis C, and the lifetime impact of the complications. Professional psychosocial care for both was vital, along with strategies to enable the older person to pursue personal interests, social connection and peer support.

Living with a bleeding disorder had a cumulative impact on increasing health care costs and reducing income over a lifetime. Most older people with bleeding disorders had acquired hepatitis C, compounding their health and financial issues, and becoming vulnerable in their senior years. Although the 2004 Senate Inquiry into Hepatitis C and the Blood Supply recommended case management and financial support for their health care costs, this was never implemented.



WHAT WILL HELP

For older people with bleeding disorders, solutions will need to address their goals of living the healthiest life possible, maintaining or improving quality of life, prolonging independence and contributing to society.

The Australian Productivity Commission *Shifting the dial* report pointed to the benefits of making the patient the centre of care for achieving better health outcomes and developing a more efficient and cost-effective health system. It also underlined that

integrated care could improve workforce participation in people with chronic health conditions.

Achieving integrated care for older people with bleeding disorders will involve strengthening and expanding the comprehensive care provided by HTC. This would enable HTCs to better co-ordinate the range of services and programs required to support the older person with a bleeding disorder and build a closer relationship with GPs. It would allow innovations to make access to HTC services and programs and other specialist services easier for older people with bleeding disorders or support liaison with local health and community services. It would support work to help younger people with bleeding disorders with 'early ageing' access disability support services and programs. However, this level of comprehensive care would require adequate resourcing for all HTCs.

Treatment with newer and emerging therapies could mean fewer intravenous infusions or subcutaneous injections and decrease the treatment burden for older people with bleeding disorders and their carers.

Access to robust data will be needed to support further research into ageing with a bleeding disorder and to evaluate related health and quality of life outcomes. This will require investment to develop and promote existing databases, including the Australian Bleeding Disorders Registry (ABDR), along with the patient recording tool MyABDR, and the PROBE Australia study. Ways of combining the data from the two databases could also be investigated.

Although vigorous exploration of government financial safety net options may assist 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. If the Senate Inquiry recommendations to extend financial assistance and case management to this group are implemented, it would make a considerable difference to managing their care and quality of life into the future.

Both professional psychosocial care and peer support are integral to the mental wellbeing and resilience of older people with bleeding disorders. It will be important to explore options enabling them to connect with other people with bleeding disorders or with shared interests, both face-to-face and in the digital space, and how they can contribute their skills and experience to the community. Support for partners, family and carers is also critical.

Achieving the best possible health and quality of life will involve education about the patient journey: the issues the person with a bleeding disorders will encounter as they grow older, and how these can be best managed. This will need to be targeted at people with bleeding disorders, the people who provide their care and other relevant settings such as the workplace.

An important way to support a patient-centred approach will be to centralise information about getting older with a bleeding disorder in an information hub on the HFA website. This will be an effective way to co-ordinate information for older people with bleeding disorders, their partners and family and their health and care services in the community. Producing targeted information online and in print will also be an effective strategy to reach older community members. Foundation newsletters were very popular as trusted sources of information and continue to be a valuable way to communicate with the community.

Recommendations



LANGUAGE AROUND GETTING OLDER

1. That careful consideration be given to the use of the words 'ageing' and 'old' when discussing getting older with a bleeding disorder or the disability in younger people related to the complications of their bleeding disorder.

PATIENT-CENTRED CARE

2. That there is a patient-centred approach to treatment and care for older people with bleeding disorders. This involves holistic and integrated care that takes the complexities of their bleeding disorder complications, their aspirations and quality of life, and their experience of service provision into account.

INTEGRATING CARE

3. That the role of the Haemophilia Treatment Centre (HTC) in providing comprehensive care and co-ordinating the range of services and programs to support older people with bleeding disorders is strengthened and resourced adequately in all HTCs to undertake this work statewide.

This involves resourcing to provide the essential elements of a comprehensive care team:

- 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.

It also involves expanding access to the following specialities:

- Pain management
 - Geriatric services
 - Occupational therapy
 - Dietitians
 - Podiatry
 - Dentistry
 - Gynaecology for women
 - Vocational counselling.
4. That general practitioners should be involved by the comprehensive care team as key partners in primary care and preventive medicine.
 5. That older people with bleeding disorders be provided with options to access appropriate treatment and care services and programs in relation to their complications with bleeding disorders. This may involve:
 - Some evening or weekend clinics or outer suburban or regional outreach from the HTC
 - The use of telehealth where appropriate and practicable
 - HTC liaison with local GPs and other local health care services
 - Investigation of all suitable transport and parking options available and support to access this.

6. That the role of the HTC, comprehensive care and the ABDR and the benefits of connection and ongoing management be promoted in particular to:
 - Men and women with mild bleeding disorders.
 - General practitioners (GPs) and other clinicians in the community who provide primary care to people with bleeding disorders.
7. That there 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

8. That HFA, the Australian Haemophilia Centre Directors' Organisation (AHCDO) and the National Blood Authority (NBA) collaborate to ensure:
 - There is ongoing development of the ABDR system and the MyABDR website and app to maintain a robust national clinical management system and database.
 - Proactive use of the ABDR and MyABDR is promoted to HTCs and to HTC patients.
 - Effective use of data by stakeholders for treatment and policy decision-making.

NEW AND EMERGING THERAPIES

9. That new and emerging therapies that require less frequent infusions, can be administered subcutaneously rather than intravenously, and will encourage uptake of prophylaxis to prevent bleeds be given strong consideration in older people with haemophilia, where clinically appropriate.

VEIN CARE AND INFUSIONS

10. That HTCs are resourced adequately:
 - to provide vein care and infusion education to older people with bleeding disorders and their carers
 - to investigate individual options for skilled nurses to provide infusions in the home.

DENTISTRY

11. That the following areas are explored:
 - Promoting preventive dentistry
 - 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.

INDEPENDENT LIVING

12. That older people with bleeding disorders be supported to continue living independently for as long as possible. This includes through:
 - Treatments and programs to support being active and to maintain mobility and physical functioning
 - Access to mobility aids and equipment, medical devices and other independent living aids
 - Information about and access to home modifications to enable independent living
 - Education about and opportunities to share strategies to work around problems with physical functioning and mobility
 - Inclusion of an occupational therapist in the comprehensive care team to facilitate and perform reviews, undertake education and support older people with bleeding disorders to apply for relevant aids and equipment, home modifications or other funding required.

INSURANCE

13. That barriers to various types of insurance and superannuation are explored and relevant advocacy is considered.

AGED CARE SERVICES

14. That older people with bleeding disorders and their partners, family and carers are provided with:

- Information about and assistance to access aged care services
- Case management and advocacy to access appropriate aged care services in a timely way, to explore government financial safety net options and to manage the transition to residential aged care if appropriate.

'EARLY AGEING' AND THE NDIS

15. That people with bleeding disorders with complex co-morbidities under the age threshold for aged care services are provided with:

- Assistance from members of the comprehensive care team, including psychosocial workers and occupational therapists, with completing National Disability Insurance Scheme (NDIS) applications to ensure eligibility criteria are addressed.
- Assistance with an appeal or review where they have been rejected initially or the approved package seems inadequate.
- Support and advocacy around employment.

16. That HFA explores the potential for modifications to the NDIS or other government income support schemes to enable people with chronic health conditions to continue working.

17. That there is adequate resourcing of all HTC's to assist with NDIS applications.

HIV AND HEPATITIS C

18. That the traumatic experience of being exposed to HIV and hepatitis C and the ongoing impact on the life of affected people with bleeding disorders is acknowledged by Australian governments, even if they have been cured of hepatitis C.

19. That Australian governments implement the recommendations of the 2004 Senate Inquiry into Hepatitis C and the Blood Supply, so that:

- Case management is extended to people with bleeding disorders affected by hepatitis C 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 is provided for costs with health and community care not covered through existing services.

20. That HFA continues to work with HIV and hepatitis organisations on discrimination.

21. That HFA continues to work with HTC's, hepatitis clinics and organisations and general practitioners to ensure there is health promotion and clinical follow-up for people with bleeding disorders exposed to hepatitis C. In particular, this relates to:

- Liaison between hepatitis specialists and HTC's for management of people with bleeding disorders who have advanced liver disease
- Ongoing monitoring for people with cirrhosis
- 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.

MENTAL HEALTH AND PEER SUPPORT

22. That psychological care by both health professionals and haemophilia foundations takes into account the traumatic experiences and the impact of a bleeding disorder over a lifetime, including the impact of HIV and hepatitis C, both for the older person with a bleeding disorder and their partner or family.

23. That haemophilia foundations and HTC's explore peer support activities to enable older people with bleeding disorders to connect with other older people with bleeding disorders or other people with shared interests, both face-to-face and in the digital space.
24. That haemophilia foundations consider ways to enable older people with bleeding disorders to contribute their skills and experience to the community.
25. That psychosocial and peer support should be extended to partners, family and carers of older people with bleeding disorders.

INFORMATION AND EDUCATION

26. That HFA collaborates with HTC's, specialist health professional groups and other experts on information and 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 services who provide their care and their employers.

Information provision

- A **Getting Older Information Hub** to be established on the HFA website to centralise access to this information and education.
- Education materials to be high-quality, evidence-based and appropriate to the target audience.
- Education materials to be provided online; some also to be provided in print, where appropriate to the target audience.
- Community education materials to be developed and tested with the target audience.

Community education

HFA to develop or source education materials for the older person with a bleeding disorder and their partner/family/carers that focus on the patient journey, the issues that may come up and how to self-manage for the best possible health and quality of life outcomes, including:

- Understanding how getting older affects a person with a bleeding disorder
- Working effectively with the HTC and other health services for good health outcomes
- Self-advocacy in the health care setting
- Preventing and managing health conditions and complications associated with ageing, including preventive health checks, weight management and exercise
- Pain management
- Staying active and involved, building resilience, self-care
- Recreation and travel
- Aids and strategies to assist with independent living
- Support and services available and how to access them
- Financial and future planning.

This information also to be published in *National Haemophilia* and state/territory haemophilia foundation newsletters.

Special issues for older women with bleeding disorders continue to be incorporated into the HFA The Female Factors education resources.

Education to young people with bleeding disorders to highlight the benefits of adherence to treatment and care and self-management strategies to prevent joint and muscle complications in the future.

Health care and community worker education

Education on special issues in ageing with a bleeding disorder for health care and community workers to be targeted to the particular specialities and settings providing treatment and care to older people with bleeding disorders. For this education to be effective, it would need to be led by key leaders in bleeding disorders in the relevant discipline and may involve a range of different strategies, including:

- Best practice clinical guidelines and fact sheets
- Integration in undergraduate and postgraduate education
- Relevant professional development, including for special interest groups
- Journal articles and conference presentations and posters
- Education materials for the point of care, for example, for an HTC to provide to a surgeon, a general practitioner or a community physiotherapist.

In addition,

- Educational resources about bleeding disorders in older people also to include mild conditions, VWD and the rarer bleeding disorders.
- These resources to acknowledge the experience of the older person with their bleeding disorder and to encourage a collaborative relationship between the health care provider and the patient.

Specialist health professionals at HTCs to be resourced adequately to undertake the development and delivery of these education resources.

Employers

HFA to collaborate with specialist health professionals and employer groups to develop education materials for employers.

Other information portals

27. That HFA explores how best to disseminate these education resources through HealthDirect and other relevant government and aged-care related information portals.

FURTHER RESEARCH

28. That there be further research:
 - To understand the impact of ageing in men and women with mild haemophilia, VWD and the rarer bleeding disorders, including health and quality of life outcomes and education and support needs.
 - To investigate arthritis and problems with physical functioning and mobility in men and women with mild haemophilia.
 - To investigate the occurrence of heart disease and hypertension in men with haemophilia.
29. That HFA undertakes further consultation around needs relating to getting older in harder-to-reach and more vulnerable populations. This might include people experiencing housing insecurity or literacy problems, or where cultural, language and connection issues are a barrier, for example, in some people of culturally and linguistically diverse (CALD) backgrounds, some Aboriginal and Torres Strait Islander people, and some people experiencing mental health and other serious health issues.
30. That HFA continues to develop and promote the PROBE Australia study and supports investigation into the potential to use the PROBE Australia study to link with the ABDR to collect data on health-related quality of life.