

# 1. Introduction



## 1.1 Why a needs assessment?

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.

This is a welcome change, but it brings its own challenges. Although this generation of people with bleeding disorders has a longer life expectancy than ever before, they are also at the forefront of navigating issues associated with getting older with a bleeding disorder. They are entering into unknown territory: encountering the issues of ageing experienced by the general population, while also being the first group to experience the impact of ageing on their bleeding disorder.

At the same time there continues to be a problem with 'early ageing' in this community. Many relatively young people with bleeding disorders experience complications usually associated with growing older, particularly joint and muscle damage, arthritis, pain and mobility problems. This has implications for many aspects of their life, but also may create difficulties for accessing services as they will not fit the standard criteria for 'ageing' and may not fit the eligibility criteria for disability services.

## 1.2 Getting Older Project

Understanding the needs of older people with bleeding disorders and how best to address them is a priority for Haemophilia Foundation Australia.

**Haemophilia Foundation Australia (HFA)** is the national peak body for the bleeding disorders community in Australia. The Foundation provides national representation and advocacy, information and education, and support for those affected by a bleeding disorder in Australia. It promotes research and supports initiatives

in health care to promote high quality treatment and care, and better health outcomes for people affected by haemophilia, von Willebrand disease and other related bleeding disorders. With its vision of 'active, independent and fulfilling lives for people in our bleeding disorders community', a key objective for HFA is to enable people with bleeding disorders to overcome isolation and develop resilience and strategies for self-management as they grow older. This also involves support for the affected community: partners, family, friends and carers.

HFA commenced the **Getting Older Project** in February 2019. A major part of the Project was a needs assessment.

HFA needed to understand the key issues for older community members, including those experiencing the issues of early ageing.

- What are their aspirations and goals?
- What are their concerns about growing older?
- What planning is required for them to 'future proof' for getting older?
- What resources already exist that could be used to support an ageing community?
- What are the implications of their needs with growing older for their treatment and care and the comprehensive care provided through Haemophilia Treatment Centres?
- What would be required to support access to existing mainstream and local services?
- What information do individuals and their carers need to manage the issues of ageing?
- Are there ways of providing support for older community members apart from traditional face-to-face activities, such as digital support and information?

## 1.3 Approach

The HFA *Getting Older needs assessment* aims to understand community needs across a range of domains in people's lives. In line with best practice for a

community needs assessment<sup>1</sup>, HFA has used a systematic process involving:

- Scoping activities to gather input from the community and other stakeholders about the project design, frameworks, approaches and tasks
- Development of a data collection plan
- Collection and analysis of data to determine priorities and make decisions about addressing current and future needs.

The HFA needs assessment uses an ‘evidence-informed’ approach: a multipronged approach, which recognises that lived experience, expertise relating to practice and evidence from current research each play a role in ensuring a full range of issues are identified and explored.<sup>1</sup>

As expressed in its vision, HFA is committed to a strength-based approach with the bleeding disorders community. This is a positive approach, focused on working towards the goals of people with bleeding disorders and their partners, family and carers. A strength-based approach acknowledges the strengths and capacities of individuals, often arising from the adversity and difficulties they experience over their lifetime, and builds on these attributes to encourage resilience, to support people in self-management and to enable them to seek their own solutions. It identifies the resources individuals have both within themselves and around them to deal with problems and difficulties and what they themselves have to share with their community.<sup>2</sup>

An important element of this for the needs assessment has been to collect data and report on community ‘assets’, for example, on the services and supports people have available to them in their life, as well as the traditional financial and housing assets.<sup>1</sup>

The needs assessment also identifies areas where there are gaps or further development is needed to enable older people with bleeding disorders to achieve their goals.

## 1.4 Advisory Group

HFA established an Advisory Group to provide information and guidance for the project. The Group included representatives with relevant expertise from:

### **Bleeding disorders community**

- Older people with bleeding disorders
- Partner of an older person with a bleeding disorder
- Haemophilia Foundation Australia

### **Health professionals**

- Australian Haemophilia Centre Director’s Organisation (AHCDO)
- Australia/New Zealand Haemophilia Psychosocial Group
- Australian and New Zealand Physiotherapy Haemophilia Group
- Australian Haemophilia Nurses’ Group

### **Other organisations with a common interest**

- National Ageing Research Institute (NARI)
- Living Positive Victoria
- Gerontology/Physiotherapy research (Monash University, Melbourne)

## 1.5 Data collection

Scoping and data collection for the needs assessment has included:

- Information, review and advice from the Advisory Group
- Interviews with community members and relevant health professionals
- Community forums in Queensland and the Australian Capital Territory
- Consultation meetings with other relevant agencies
- Consultation with state/territory Foundations on key issues and priorities
- The HFA Getting Older Community Survey
- Age-related data from the 2019-20 PROBE (Patient Reported Outcomes Burdens and Experiences) Australia Study.