3. Literature review

3.1 A journey into unchartered territory

Growing older with a bleeding disorder is a relatively new development. Ongoing improvements in treatment and care since the advent of factor replacement therapy with clotting factor concentrate in the 1960s and 1970s and a comprehensive care approach to health care services have seen more people with bleeding disorders reaching older age than ever before. New and emerging therapies give hope that this increased lifespan can also be accompanied by improved quality of life.[12-19]

The road to increased life expectancy for people with bleeding disorders has had its backward steps: tragically over the last 40 years in Australia and worldwide there have been large numbers of premature deaths in this population related to the HIV and hepatitis C epidemics. Many people with bleeding disorders in Australia acquired HIV or hepatitis C infection from infected plasma-derived clotting factor concentrates before 1993, by which time blood supply screening and viral inactivation manufacturing processes had been introduced. Ironically it was the life-saving new clotting factor concentrates that also brought with them the blood-borne viruses that would have such an impact on recent generations of people with bleeding disorders. The fact that there is a current generation that is living on into senior years is also a reflection of the recent advances in HIV and hepatitis C treatment and care.[19-23]

Over the last decade there has been a growing body of literature that has focused on the emerging and anticipated medical, psychosocial and lifestyle challenges associated with ageing with a bleeding disorder. Many highlight the lack of evidence-based data and the limited experience in managing age-related concerns, due to the small population of individuals who have a bleeding disorder and have survived into old age to date.[17,18,23-27] One author described growing older with a bleeding disorder as a 'journey into unchartered territory'.[28]

3.2 Defining 'older person'

When is a person 'ageing' or an 'older person'? The World Health Organization (WHO) notes that most developed countries use the chronological age of 65 years as the definition of an 'elderly' or 'old' person, and that this is often associated with the age when a person becomes eligible for a government pension.[29] The Australian Government My Aged Care portal defines an 'older Australian' as being eligible for funded aged care services at 65 years or older or 50 years or older for Aboriginal or Torres Strait Islander people.[30] The current age at which a person is eligible for an Age Pension in Australia is 66 years; this will increase to 67 years by 1 July 2023.[31]

However, WHO points out that 'ageing' and 'older person' are only loosely associated with a person's years: the physiological and social changes experienced by an individual as they age are very variable, and one person at 70 years may be very active and still working while another is unwell and frail. Most noticeable is the change in the older person's goals, priorities and what motivates them. To deal with losses in close relationships and functionality, older adults may have fewer goals and use creative strategies to find different ways to achieve their daily tasks.[32] Interestingly, the Australian Government also requires a person to have a diagnosed medical condition or functional or mobility problems to be eligible for aged care services[30], on the assumption that some people will be well enough to remain active and independent without assistance.

3.3 A patient-centred approach

Making the patient the centre of care was a key recommendation of the Australian Productivity Commission for achieving better health outcomes for Australians and for developing a more efficient and cost-effective health system. In the 2017 review, *Shifting the dial*, the Productivity Commission identified a number of factors to improve care and the quality of health for Australians using this approach, including:

- more integrated and seamless care
- a better understanding of patient experiences and patient-reported treatment and care outcomes
- improved patient health literacy.

The Commission noted that achieving a higher level of integrated care would have broad-based benefits. It would 'lead to substantial improvements in the health of Australians, particularly those who are the most dependent on health services. This would bring welfare gains for the individuals concerned, savings for the health system and gains for the economy more broadly.' [33]

3.3.1 INTEGRATING CARE AND QUALITY OF LIFE

Bleeding disorders affect many aspects of life, both for the person with the bleeding disorder and those who are close to them. Understanding how growing older may impact on treatment and care needs is complex and needs to take account of how this relates to the person's quality of life. WHO identifies six broad domains of quality of life: physical health, psychological, level of independence, social relations, environment (including finances, leisure, opportunities to learn new skills), and personal beliefs.[34]

With its aim of addressing the wide-ranging physical and psychosocial health needs of people with bleeding disorders and their partners and families, the comprehensive care approach provides multidisciplinary treatment and care, co-ordinates the provision of care, including other medical specialities that need to be accessed, and provides education to the Haemophilia Treatment Centre patients, their partners and families.[8] As a result most of the review articles about ageing with a bleeding disorder produced by clinicians at Haemophilia Treatment Centres explored quality of life issues for older people with bleeding disorders and raised questions about the changes to HTC treatment and services that would be required to address their needs in an integrated way. This is discussed below under **3.6 Age-related health impacts**.

3.3.2 HEALTH LITERACY AND SELF-MANAGEMENT

The Productivity Commission also highlighted the importance of health literacy in improving health: enabling 'prevention, better self-management of chronic conditions, patient collaboration with clinicians, a greater capacity for informed choice and effective advocacy'.[35] The Australian Commission on Safety and Quality in Health Care has defined health literacy as 'health literacy is about how people understand information about health and health care, and how they apply that information to their lives, use it to make decisions and act on it'.[36]

While the Productivity Commission considered ways for health care providers to improve the health literacy of their patients, there is also a body of literature which underlines that some individuals seek information about their health condition as a way of taking control of their health. Being able to access that information independently of their health care provider is an important self-management strategy for them.[37,38] Information in plain language, that can be understood by the target population, was one aspect of accessible information identified by the Productivity Commission. The Commission also noted that the health literacy programs would need to be provided in environments accessed regularly by the patient target group.[35]

3.3.3 MEASURING QUALITY OF LIFE OUTCOMES

Having a bleeding disorder impacts on the range of quality of life domains. Tools to measure this need to address this in a way that is meaningful to the person with a bleeding disorder.

The PROBE (Patient Reported Outcomes Burdens and Experiences) study has been developed specifically to measure quality of life domains that are common to men and women with bleeding disorders globally. PROBE is a multinational independent project which has established a patient-led research network to develop standardised questionnaires to gather patient-reported outcomes. Haemophilia Foundation Australia joined the PROBE study in 2014 and was involved in the initial validation phases to ensure the study was appropriate to Australians with bleeding disorders.

The current PROBE questionnaire investigates health problems and health-related quality of life in men and women with haemophilia. It is comprised of four major sections (demographic data, general health problems, haemophilia-related health problems and health-related quality of life using EQ-5D-5L and EQ-VAS). Questions are intended to help understand the impact of haemophilia and treatment on quality of life including the number of bleeds, pain, mobility, activities of daily living and related surgical interventions. It also asks about the impact on education and employment. The study has been validated internationally.[39,40]

Australia was the first country to implement the real-world PROBE study, commencing in May 2019, and HFA has used age-related data sourced from the real-world implementation for this needs assessment (see **4.6 PROBE Australia study** and **5.6 PROBE Australia study results)**. The PROBE Australia data has shown a strong association between ageing and physical functioning, mobility problems and pain as well as lifetime impacts on working and education. An abstract from the PROBE investigators demonstrating the association between aging and health status in people with haemophilia using current PROBE study results, including Australian data, has been accepted for the International Society on Thrombosis and Haemostasis ISTH 2020 Virtual Congress in July 2020.[41]

3.4 Older people with bleeding disorders population

3.4.1 INCREASING LIFE EXPECTANCY

Several studies have documented the dramatic increase in life expectancy in haemophilia in high income countries over the twentieth century. Until the introduction of fresh frozen plasma in the 1950s, treatment for bleeding episodes was largely to manage symptoms using the management principles of the time, e.g. through rest, ice, compression and immobilisation. As a result most people with haemophilia did not survive beyond adolescence. Clotting factor concentrates became available in the 1960s and by the 1970s plasma-derived concentrates were being manufactured in enough quantities to make home therapy a reality.[16] A US study noted that, as a result, life expectancy for haemophilia had increased to nearly 68 years of age in the decade 1971 to 1980.[42]

3.4.1.1 Impact of HIV and hepatitis C

This progress was reversed sharply during the 1980s and 1990s, when the full impact of the HIV and hepatitis C epidemics on the bleeding disorders population became clear. Plasma-derived clotting factor concentrates were produced from the plasma donations of many individuals and the risk of infection was very high, particularly for people with severe haemophilia who treated often. In a government inquiry in Australia, the Australian Red Cross Blood Service (ARCBS) explained that each batch of concentrate was fractionated from the pooled donations of up to 10,000 donors and that one donation with HIV or hepatitis C virus (HCV) could infect the entire batch. They also acknowledged that a high proportion of Australians with haemophilia had been exposed to hepatitis B through blood products.[43]

In Australia the hepatitis B vaccine was introduced in 1983[44] and blood screening and viral inactivation manufacturing processes to prevent the transmission of HIV and HCV had been introduced by the early 1990s.[43] However, by this time a large proportion of people with bleeding disorders had already been exposed. The same US study noted that life expectancy for haemophilia declined from 68 to only 49 years of age in the decade 1981 to 1990, largely as a result of mortality from AIDS.[42] After highly active antiretroviral therapy (HAART) for HIV infection was introduced in 1996, Canadian, UK and German studies showed that HIV-related mortality rates in the haemophilia population dropped substantially. However, they also described the increasing impact of hepatitis C infection and noted that after 1998 the leading causes of death were haemorrhage from a bleeding episode and liver disease.[13,16,45,46]

There is limited published data on the prevalence of HIV and HCV infection among people with bleeding disorders in Australia. A 1993 survey of Haemophilia Treatment Centre (HTC) patients with haemophilia A in three Australian states found an overall prevalence of 23% with HIV infection, and up to 45% in some Haemophilia Treatment Centres. The prevalence of HCV exposure was higher – 74% overall.[21] Those with HIV were likely to be co-infected with HCV.[47,48] A more recent study of HCV infection in one Australian Haemophilia Treatment Centre found that exposure rates were very high for their patients with severe haemophilia (92%-94%) and type 3 (severe) VWD (83%), and also substantial for their patients with mild haemophilia (52%-61%) and type 1 (usually mild) VWD (16%).[22] By 2007 HTCs were reporting that more than half of their patients who had HIV had died, some of them from liver disease as they were co-infected with HCV.[48]

The last several years have seen some remarkable advances in treatment for HIV and hepatitis C. With the availability of highly effective antiretroviral therapy (ART), HIV infection is now described as a 'chronic manageable condition'.[49] In March 2016 new direct acting antiviral (DAA) treatments for hepatitis C were made available for all Australians. They have very high cure rates and few if any side-effects and there has been a high uptake by people with bleeding disorders.[50,51]

3.4.1.2 A new older generation

Over the last 10 years leading haemophilia clinicians have started to describe a new generation of people with severe as well as mild bleeding disorders who are living into old age.[18,24,25,28]

As well as more effective treatment for bloodborne viruses and access to co-ordinated comprehensive care through Haemophilia Treatment Centres, they have also pointed to more widespread use of prophylaxis to prevent bleeding episodes among people with severe haemophilia.[14,19] In previous decades there had been concern about the difference in lifespan between people with severe and mild haemophilia. For example, a UK study of people with haemophilia who did not have HIV from 1977 to 1999 found that those with severe haemophilia had a life expectancy of 63 years, compared to 75 years for people with mild haemophilia and 78 years for the general population.[13] A recent study, which also used data from national registries such as the Australian Bleeding Disorders Registry, found that overall there was still a 'survival disadvantage' for people with haemophilia even in well-resourced countries. It proposed that this indicated even for wealthier countries, that 'the quality of haemophilia care is still insufficient to close the life expectancy gap for patients with the disease.'[52]

While the improvement in survival rates among older people has been a cause for celebration, it has also led to a focus on the challenges of living into older age with the complications of bleeding and what else can be done to prevent bleeds, reduce the impact of complications and improve quality of life.[24,53]

3.5 Treatment

3.5.1 HAEMOPHILIA

3.5.1.1 Factor replacement therapy

Factor replacement therapy using clotting factor concentrates has been a standard treatment for haemophilia in Australia since it became available in the 1970s.[8,9,43]

During the 1980s there were major shortages of factor VIII concentrates in Australia. As a result, leading haematologists noted that Australians with severe haemophilia A were being treated with much less factor VIII than in Haemophilia Centres in the UK, the USA and West Germany.[54] At this time, Australia had a policy of self-sufficiency in blood and blood products. In spite of the efforts of Australian blood services to source enough plasma donations and the Commonwealth Serum Laboratories (CSL) to increase factor VIII yield, factor VIII concentrate production did not reach the levels required for recommended treatment standards until 1995.[43]

3.5.1.2 Recombinant product

Recombinant factor product was made available for children and previously untreated adults with haemophilia in Australia from 1994 to prevent further transmission of bloodborne agents and to overcome shortages of plasma-derived factor products. In 2004 recombinant factor was made available for all Australians with haemophilia regardless of age in response to a theoretical risk of variant Creutzfeldt Jacob disease (vCJD). Most Australians with haemophilia now use recombinant factor products for factor replacement therapy.

A small number continue to use plasma-based clotting factor concentrates.[4,43,55]

3.5.1.3 Prophylaxis

The aim of **prophylaxis** (prophylactic factor replacement therapy) is to keep factor levels high enough to prevent bleeding and joint destruction, with the goal of therapy described as being 'to preserve normal musculoskeletal function'.[8]

Since 1995 prophylaxis treatment to prevent bleeding has been available for children and younger people in Australia, and more recently for older adults as well.[56,57] With the standard half-life products currently available in Australia, prophylaxis with clotting factor concentrates usually involves infusions two to three times weekly, but the treatment plan is individualised to the patient. Individualisation is 'based on age, venous access, bleeding phenotype, pharmacokinetics, activity, and availability of clotting factor concentrate.'[8] Extended half-life products could reduce the number of infusions by one or two or more weekly. These are widely in use globally, but not yet funded for all in Australia. They are discussed below under **Newer and emerging therapies (section 3.5.1.6).**

The benefits of prophylaxis in preventing bleeds and the resulting damage to joints have been established through extensive study internationally, but the long-term outcomes for health and quality of life over the lifetime continue to be examined and debated, particularly as the impact of joint disease takes at least 5 years to be seen. Prophylaxis protocols and doses vary from country to country.[9,58] There has also been ongoing discussion about the value of 'tertiary prophylaxis', or prophylaxis which is started when the person with haemophilia has existing joint disease, usually as an adult, as compared to 'on demand' treatment.[8] For older adults with moderate and severe haemophilia in Australia, this would be the only relevant type of prophylaxis as they were adults when prophylaxis became available and would already have developed joint disease.

A 2018 international review of long-term outcomes compared prophylaxis to on demand treatment of haemophilia A. It found that sustained prophylaxis produced better control of bleeds, joint outcomes, health-related quality of life and attendance at school

and work than on demand treatment for both children and adults. However, it also pointed to the need for more improvement, even for those having consistent prophylaxis: the protocol used and how long the person had maintained prophylaxis had a significant impact on results. There were also issues with the development of inhibitors, the burden of regular treatment infusion over many years and the challenges of adhering to treatment.[58]

Prophylaxis in Australia

To understand current practice with prophylaxis in Australia, leading Australian haematologists recently reviewed national ABDR data on prophylaxis in people with moderate and severe haemophilia A and B. They found that prophylaxis rates in people with severe haemophilia were comparable with other developed countries, but were concerned that the current rates of prophylaxis in adults were too low to achieve the potential benefits with preventing bleeds and further joint deterioration, particularly those aged 60 years and over. The percentage having prophylaxis declined substantially from the age of 40 years, increased again in the 50-59 age group and declined again after the age of 60 years to less than half of those with haemophilia A and around a third of those with haemophilia B. The authors suggested the reasons for this 'may reflect the interplay of multiple factors, including patient acceptance (compounded by entrenched beliefs about their own therapy), physician preference, challenges around intravenous access and impact of other comorbidities'. They noted that people with haemophilia A who were over 60 also used far more factor than their expected dose. This was perhaps due to the need for surgical cover in this age group, or because this group found it difficult to distinguish between arthritic pain and pain caused by an acute bleed, or because their prescribed dose was too low to adequately prevent bleeds.[59]

3.5.1.4 Inhibitors

One of the challenges of factor replacement therapy is the development of inhibitors, or antibodies to clotting factor treatments, that make the treatment much less effective. The lifetime risk of developing an inhibitor in people with severe haemophilia is about 20-30%, while for people with moderate or mild haemophilia it is about 5-10%.

In recent years several treatment options for inhibitors have become available and many people are successful at overcoming inhibitors, while others have ongoing problems. The continuing bleeding is severe and results in significant disability. It can be life-threatening. People with inhibitors experience constant pain and increasing disability over time.[8]

3.5.1.5 Other products

The Australian clinical guidelines also describe a number of other products for treating bleeding problems in haemophilia. This includes desmopressin (DDAVP), which is often used to treat people with mild or moderate haemophilia A, tranexamic acid, and hormonal contraceptives for women to manage heavy menstrual bleeding.[8]

3.5.1.6 Newer and emerging therapies

Over the last several years a range of innovative new products have become available to treat haemophilia.

Extended half-life (EHL) clotting factor concentrates have been developed for factor VIII and factor IX and are described as having substantial advantages when used for prophylaxis. They have enabled clinicians to refocus on eliminating bleeding episodes in people with haemophilia entirely, with a much-increased rate of zero bleeds, especially for haemophilia B. The extended half-life reduced the frequency of infusions from 2-4 times weekly to 1-2 times weekly for people with haemophilia A and from 1-2 times weekly to once every 10-14 days for people with haemophilia B. This was associated with improved quality of life and reduced absenteeism from school and work. However, the development of inhibitors continues to be a problem.

Follow-up data from some factor VIII studies has also suggested that EHL treatments may improve musculoskeletal outcomes, even when there is existing joint damage. If this data is confirmed in other larger studies, it could offer new possibilities with tertiary prophylaxis for older people.[60,61]

Non-clotting factor concentrates, for example, emicizumab, fitusiran and concizumab, are another new class of product. These treatments are not based on factor replacement, but target other aspects of the blood clotting process, so they do not produce inhibitors and are effective for people who have inhibitors. They are injected under the skin, rather than into a vein, and have a long half-life, so that they can be given once every 1-4 weeks for prophylaxis. This is a major advance for ease of administration and adherence. Safety continues to be monitored, as a small number of thrombotic complications have been reported in some of these products.[60]

The recent advances in **gene therapy** for haemophilia A and B have led to great excitement internationally. Clinical trials using the adeno-associated virus (AAV) vector in small numbers of patients reported successful sustained results with few side-effects: reducing the patients' factor severity level from severe to mild, and even normal in some cases, and having few, if any, bleeding episodes over a 12-month period. While this has raised the question of whether gene therapy is a 'cure' for haemophilia, at present the conclusion with these therapies is that they are reducing the rate of bleeding to an equivalent of mild haemophilia rather than preventing bleeds altogether.

Some new studies are investigating ways to extend the groups who are suitable for gene therapy as a considerable number of people have been excluded; for example, whether the treatment can be modified so that it is effective in people with pre-existing immunity to AAV. These clinical trials are now being extended to larger groups and other new trials are starting. However, to monitor the effects of gene therapy in the longer term, the trials will need to follow participants for several years – on average 5 years.[62-67]

In Australia

At the time of publication EHL and non-clotting factor concentrate treatments were not publicly funded in Australia except for a limited early access program. Some people were using them following participation in clinical trials or through compassionate access schemes. There were several gene therapy clinical trials taking place nationally.

3.5.2 VON WILLEBRAND DISEASE (VWD)

There have been far fewer new developments in treatment for von Willebrand disease (VWD).

The Australian clinical management guidelines describe the intention of treatment for VWD as to restore the factor that is missing or does not work properly, in this case von Willebrand factor and sometimes factor VIII. Some people with von Willebrand disease require treatment with clotting factor VIII concentrates containing von Willebrand factor, which need to be injected intravenously. Others can be treated primarily with desmopressin (DDAVP).[68]

Treatment for VWD needs to be tailored to the individual and involves careful and complex testing of their VWD Type and response to treatment and reassessment over their lifetime. In Type 1, which is the most common Type, factor levels can increase with age but there is some question about whether this changes the bleeding pattern and therefore the need for treatment in older people.[69] DDAVP is not effective for all Types of VWD and some people do not respond well to it; there are also added risks of side effects with some health conditions associated with ageing and it is not recommended for people with existing heart or cerebrovascular disease.[68,69]

People with severe VWD (eg, Type 3) may require factor replacement therapy regularly for prophylaxis or to treat bleeds on demand. Most people with VWD usually have mild symptoms, and may need only to treat with factor replacement therapy when they have a substantial injury or as cover in preparation for surgery or medical and dental procedures.

For women, factor levels and bleeding issues with pregnancy, childbirth and menstruation need to be taken into account. As with haemophilia, hormonal contraceptives may be used to manage heavy menstrual bleeding.

Von Willebrand factor (VWF) recombinant clotting factor concentrates are not yet available in Australia and people with VWD who require clotting factor concentrate are treated with plasma-derived factor VIII concentrate that contains VWF.

Other additional treatments such as tranexamic acid and fibrin glue are recommended for mouth, nose and uterine bleeding, minor wounds and after dental procedures. The guidelines also note that occasionally some people may benefit from a platelet transfusion containing VWF.[68]

3.5.3 OTHER RARE BLEEDING DISORDERS

There is a diverse range of rare bleeding disorders other than haemophilia and VWD, including rare clotting factor deficiencies and inherited platelet function disorders. These disorders have symptoms which can vary widely from mild to severe, vary from one disorder to another, and from one affected person to another. They are very rare and affect small numbers of people in comparison to haemophilia and VWD.

Leading clinical experts have noted that this diversity along with the small numbers has delayed the development of new and effective treatments. Many rely on single-factor plasma-derived concentrates for factor replacement therapy and in some cases a specific factor concentrate is not available, for example, factor V deficiency where fresh frozen plasma is used. Treatment is usually on demand and preventive for surgery, although some may have prophylaxis if they have a severe disorder and a suitable treatment is available. Inherited platelet function disorders are often treated with platelet transfusion, or with desmopressin if the disorder is mild.

Women are at risk of gynaecological bleeding complications, with heavy menstrual bleeding, miscarriage and post-partum haemorrhage common across many rare disorders.[70,71]

A recent review of treatment notes that the development of new classes of treatment for haemophilia has had an important role in treatment for rare bleeding disorders. A number of early studies are pursuing the same focus on reducing the number of infusions and gene therapy is being explored in factor VII deficiency.[70]

3.6 Age-related health impacts

Over the last decade there have been a number of publications from leading haemophilia clinicians that have described the complications related to ageing with a bleeding disorder.[17,18,24-28,53]

More recently an editorial by a group of UK haematologists took a different look at these complications related to ageing, describing them in terms of a 'third age', or the period after retirement, and a 'fourth age' of partial or full dependency. Reviewing the issues of their current patients, they produced the list below:[43]

Third age: retirement
Cardiovascular disease
Renal disease
Hypertension, obesity, diabetes
Increasing tendency to falls
Decreasing visual acuity
Dementia
Malignancy
HIV and HCV coinfections
Mobility
Arthropathy
Bone health
Loss of social network

Fourth age: dependency
As in third age but worse
Seeking care/support outside the home or hospital

This list highlights both the bleeding disorder-specific complications, and the other age-related health conditions also seen in the general population including cancer, cardiovascular disease, hypertension, renal disease, vision problems, dementia, and issues with balance and falls.

Leading haematologists internationally point out that there is still much to learn about the impact of ageing on bleeding disorders and of bleeding disorders on age-related health conditions. This is a new population and gathering this evidence will take time: the numbers of older people with bleeding disorders are still relatively low, but increasing as the next generation ages as well. Moreover, most of the literature has focused on haemophilia and there is still much to be explored in ageing with VWD or a rare bleeding disorder.

However, it is well recognized in this group that managing the complications of ageing with a bleeding disorder will be complex, both medically and in its impact on quality of life. The authors underlined the importance of specialist haemophilia treatment centres in co-ordinating care between the various health care providers in the community, but also were concerned about the need to work with general practitioners to ensure regular screening relating to ageing is carried out.[17,18,24-28,53]

3.6.1 VEINS

Standard factor replacement therapy is administered through an infusion into a vein and vein care becomes increasingly problematic as a person grows older. Haematologists note that there are a number of difficulties for the person who is ageing: fragile or hidden veins, collapsed veins due to hydration, problems with dexterity in the hands, vision problems are some of these. As a result, a person may have to have multiple attempts to infuse, which could increase their anxiety and lead to avoidance or delay of treatment; some may switch back to on demand treatment from prophylaxis. All of this could have negative impacts on their health.[53]

3.6.2 JOINTS AND MUSCLES

For older people with bleeding disorders, some health and wellbeing problems are the direct result of having lived for many years with a bleeding disorder before prophylaxis and adequate supplies of treatment product were available. Joint and muscle damage and the resulting pain and disability are an example of this and are the most common complication experienced by older people with haemophilia.[17,18,24-28] A recent review of VWD pointed out that arthropathy can also be seen in people with severe VWD as a result of joint bleeds.[72]

Joint arthropathy (joint disease) is caused by repeated bleeds into a joint over time. Many people with moderate and severe haemophilia develop a pattern of bleeding into the same joint, typically a large load-bearing joint such as the ankle, knee or elbow.[73] When three or more bleeds have occurred in a particular joint within 6 months, the joint is known as a 'target joint'.[8] Older people with haemophilia often have several joints with arthropathy that have a limited range of motion with pain or stiffness and may also have muscle weakness and contractures, resulting in reduced daily activity. This may in turn increase the potential for the person to become overweight or obese, which can then put extra strain on their already damaged joints.[17,27] Over the years bony changes such as osteoporosis can also be caused and exacerbated by repeated bleeds and by the person's inactivity.[73]

3.6.1.1 Mobility, independence and quality of life

Studies on the impact of target joints have confirmed that they can have a very negative influence on the quality of life of a person with haemophilia.[74] By the time they reach their senior years many people with haemophilia are experiencing a life in which limited mobility, reduced joint function and chronic pain is beginning to dominate their lives.[25]

Two Italian studies have compared men with severe haemophilia aged 65 years and over to controls from the general population of the same age. They found that nearly all the men with severe haemophilia had joint arthropathy and had a bloodborne virus such as HIV, hepatitis C or hepatitis B. Two thirds of them reported moderate pain or discomfort compared to one quarter of men without haemophilia. They were much less physically active and more likely to have difficulty with transport, shopping, dressing and using the bathroom than the men without haemophilia. They had a similar cognitive status to men without haemophilia, but experienced depression more commonly. The second study confirmed these results, and also found that the men with haemophilia were more likely to be worried about the impact of their health on their future.[75,76]

Lifelong joint problems directly influence the person with haemophilia's independence and ability to manage their activities of daily living. This adds another layer of difficulty to their ability to manage their bleeding disorder and attend medical appointments, both at their haemophilia treatment centre and in the general community, and impacts on their overall health and wellbeing.[76] As age increases, these joint problems become more apparent and pronounced.[77]

3.6.1.2 Joint replacement and surgery

Because their joint and muscle damage occurred at a young age and the associated pain and disability is considerable, older people with haemophilia will often have had orthopaedic surgery, particularly if they have severe haemophilia or inhibitors. This commonly involves

hip, knee and sometimes elbow replacements, ankle fusions, and a range of other procedures to manage arthropathy in the bones and joints. Joint replacement surgery is usually delayed for as long as possible due to the limited lifespan of the prothesis (replacement joint), but if the person with a bleeding disorder had a joint replacement at a relatively young age, they are likely to need a revision operation to replace the prosthesis in another 10-20 years.[17,27,78,79]

3.6.3 FALLS AND BALANCE

As people with bleeding disorders age, they have a potential cascade of risk factors that could lead to balance problems and falls, and then serious injury as a result. Impaired mobility is a risk for overweight or obesity which can put additional strain on already damaged, painful joints. They have a higher risk of osteoporosis, which tends to progress with increasing age, and the low bone density is usually associated with increased fracture risk. They also can experience gait problems from arthropathy in their ankles and knees and muscle weakness around these joints with impaired proprioception (awareness of body position and movement), which put them at a higher risk of losing their balance and then falling.[80,81,82]

An Australian study which compared men with haemophilia to an age-matched group of healthy men found a much higher rate of balance problems in the men with haemophilia, with more than 50% of them reporting falls in the last 12 months, mostly while walking.[83] To improve balance and mobility, studies have suggested that individualized exercise programs of balance, strengthening and walking exercises would be valuable for men with haemophilia.[84] One study suggested that exercises that targeted hip strength and retraining ankle movement would be particularly helpful.[77]

3.6.4 EXERCISE

There have been many studies to show that exercise has benefits for people with haemophilia. A Cochrane review noted that most studies showed that exercise 'produced improvement in one or more of the measured outcomes including pain, range of motion, strength and walking tolerance'.[85] This was confirmed in another systematic review. Strength training, for example, has been shown to improve joint stability and decrease pain and disability. Combined with weight loss, it can reduce the impact on joints and lead to fewer bleeds. Several studies highlighted the benefits of hydrotherapy, e.g., exercise in a swimming pool, to provide resistance training for a person with haemophilia without putting extra load on joints.[86] Exercise has also been shown to be effective in reducing the age-related impact of arthropathy in older people with haemophilia.[87] Clinical management guidelines for older people with haemophilia also point out the value of physical activity in reducing the risk of cardiovascular disease, diabetes and some cancers, as well as improving mental health and mood.[25]

With existing joint and mobility problems, access to appropriate exercise is important. A large study of participation in sports and physical activity among people with VWD found that those with severe forms of VWD were also likely to have developed joint disease, which limited their ability to take part in the range of sports and physical activities.[88] Pain is also an issue which may prevent people with bleeding disorders from participating in exercise.[25] Recent work in arthritis has shown that, in contrast to people's fear that exercise will increase their pain with arthritis, the opposite is true: that with an individualized exercise program and education, pain and quality of life can be improved.[89] Haemophilia physiotherapists have encouraged their patients to participate in these programs.

3.6.5 PAIN

Pain is a very significant problem among older people with bleeding disorders. The Hemophilia Experiences, Results and Opportunities (HERO) study, which surveyed adult males with moderate and severe haemophilia from 10 countries, found that 31% those aged 40 years and over reported that pain had interfered with their daily life 'extremely' or 'quite a lot' in the last 4 weeks. Pain was associated with a higher frequency of bleeding episodes annually and impacted on mobility, quality of life and employment.[91]

Common sources of pain are the acute pain with a bleed and the chronic pain from arthropathy and inflammation in joints. Pain affects quality of life and mental health and can lead to dependence on alcohol, opioids and other substances used to alleviate pain, such as cannabis.[25,81]

There are a number of complexities in pain with a bleeding disorder. Australian clinical management guidelines note that the cause of the pain needs to be assessed for effective management – for example, while pain from a bleed may be alleviated by replacement factor therapy and an anti-inflammatory medication, this medication will have no impact on pain from arthropathy.[8] A US study highlighted the difficulty for both doctors and patients in determining whether pain was from a bleed or arthritis from symptoms alone and the need for other objective forms of assessment, such as musculoskeletal ultrasound.[92] In bleeding disorders there also needs to be caution with commonly used pain medications including aspirin and non-steroidal anti-inflammatory drugs (NSAIDS) such as ibuprofen as they can increase bleeding.[8]

An Australian study of people with haemophilia who had joint replacements over 23 years found the surgery was very valuable in relieving pain.[79] The value of medicinal cannabis in treating pain, however, is still debated. Although the law in Australia has been changed to allow medicinal cannabis to be prescribed through Special Access and Authorised Prescriber Schemes, medical professional groups have been cautious about support for it, while their patients describe benefits from its use that do not always align with the findings from the clinical trials. Many Australians using cannabis medicinally continue to obtain it illicitly through dealers, by growing it themselves or online rather than through prescription.[93]

An important aspect of pain management is understanding how and why pain occurs. The work of the NOI (Neuro Orthopaedic Institute) group to explain how to reconceptualise chronic pain has been very popular as a pain management approach in Australia and has figured regularly in recent Australian haemophilia conferences. This approach is supported by research demonstrating that it can reduce pain and disability and that activity-based pain treatments have better outcomes.[94]

3.6.6 EARLY AGEING

Early ageing is also a major problem in this population. The Australian clinical management guidelines note that arthropathy from haemophilia can develop any time from the second decade of life, and sometimes earlier.[8] Very early joint damage could occur, for example, if the person has had inhibitors, making treatment less effective.
A European study noted that the impact of target joints on health-related quality of life in people with haemophilia started being noticeable in the 25-34 year age group but was very marked in the 45+ age group.[80] In Australia people with haemophilia who are currently in their mid-30s and older have lived through periods where prophylaxis was not available and their access to treatment products was prone to shortages. As a result, many now live with significant arthropathy, mobility issues, pain and other complications due to joint and muscle damage from repeated bleeds in their earlier years. A substantial number have also been affected by added complications associated with bloodborne viruses such as hepatitis C and HIV, acquired through their treatment before 1993.

3.6.7 OTHER AGE-RELATED HEALTH PROBLEMS

As people with bleeding disorders grow older, they experience the same age-related health conditions as the general community. With so few people with bleeding disorders living on into old age in previous generations, information on the impact of these health conditions on people with bleeding disorders as they age is still being collected.[17] These complications are an extra challenge to clinical management and require some vigilance. The Australian guidelines highlight the importance of managing age-related health conditions appropriately: they may accentuate problems associated with the bleeding disorder and reduce quality of life even further.[8]

3.6.7.1 Heart disease and hypertension

In the community it is commonly thought that having a bleeding disorder protects against heart disease because of lower clotting levels, but there is much discussion and uncertainty in the literature about this.[8,17,24,78] Authors noted that people with bleeding disorders had the same risk factors as the general population, such as hypertension, kidney disease and reduced physical activity. They may also be at increased risk of heart disease if they have HIV.[24,78] Some more recent European studies compared people with and without haemophilia in older age groups and found similar or lower rates of heart disease and hypertension in older people with haemophilia. This may be reflective of the particular group they studied and highlights the need for more studies of older people with haemophilia to understand the range of experience.[95,96]

Several haematologists concluded that even if the rates of particular forms of heart disease, such as coronary artery disease, were lower in people with bleeding disorders than the general population, they certainly did occur and occurrence may be increasing because there are more people with bleeding disorders living on into senior years. Managing anticoagulant treatments such as aspirin and surgery when the person has a bleeding tendency creates further complications. They stressed that for good outcomes, there needs to be tight co-operation between the haemophilia and cardiology specialists.[17,24,27,78]

Some health conditions of ageing may be compounded by having a bleeding disorder. Lack of activity can result in a person becoming overweight. People with haemophilia are at increased risk of obesity as a result of decreased joint mobility and function and associated chronic pain. There is also a higher risk of developing diabetes in older people who are overweight.[8,24]

3.6.7.2 Bloodborne viruses

The added complications of having a bloodborne virus such as hepatitis C or HIV also create another level of complexity. The risk of developing cancer seems to be similar for people with bleeding disorders as for the general community and for everyone increases with age. However, people with long-term hepatitis C infection are at a higher risk of developing liver cirrhosis and liver cancer and this risk increases with older age.[97] HIV infection increases the risk of other specific cancers and at a younger age.[49] HIV and hepatitis C can also increase the risk of gum disease[8], which compounds the dental problems for older people with bleeding disorders in Australia. Even in the general population the Australian national health plan notes that periodontal (gum disease) increases with age and is the reason for dental extraction for 16.5% of people aged 45-64 and 20% of people over 65.[98]

As with heart disease, treating health problems like cancer and dental disease in people with bleeding disorders requires good co-ordination between the haemophilia and oncology, surgical or dental specialists. In particular, there needs to be care with managing factor replacement during surgical or medical procedures, including biopsies, and monitoring the side-effects of drugs and chemotherapy.[8,17,24,27,78]

3.6.8 WIDER IMPACTS OF HIV AND HEPATITIS C

The HIV and hepatitis C epidemics had an enormous impact on the bleeding disorders community and across many aspects of their lives.

HFA's 2007 hepatitis C needs assessment, *'A double whammy'*, revealed the depth of this experience. A large proportion were exposed through their treatment products, particularly to hepatitis C, and a significant number died, often at a young age. Multiple members of the same family could be affected. Discrimination in the community meant that there was a silence about this for people with bleeding disorders and their partners and families: many did not disclose their viral status, sometimes even within their own family, and were often careful of disclosing or proactively hid their haemophilia, as this was associated with HIV. HIV and hepatitis C symptoms and side-effects from treatment impacted not only on their quality of life and relationships, but their

ability to work and earn an income, and many retired early or took lower paying or part-time work. Some were forced to sell their house and move their family into rental accommodation; single people became more vulnerable and isolated.[20]

These bloodborne viruses also had a major impact on their self-management. Acquiring such a serious health condition from their treatment meant that many lost confidence in the safety of their treatments and some became suspicious of the health system generally.[20] HFA's 2009 follow-up report, *Getting it right*, noted that many experienced overload with health conditions and would prioritise what was affecting them immediately, sometimes to the detriment of their long-term health, for example, by not monitoring liver disease.[99] The 2019 National Association of People with HIV Australia (NAPWHA) report *HIV and ageing in Australia* describes some of the issues for people living with HIV as they grow older, including the complexities of managing multiple health conditions with particular problems such as developing physical frailty, unsteadiness when walking, and problems with managing an increasing number of medications (polypharmacy) from an earlier age than the general population.[100] These problems are already issues for many people with bleeding disorders as they age and are added to when they also have HIV or hepatitis C.

In more recent years advances in treatment safety and in HIV and hepatitis C treatments have had a number of positive effects for the bleeding disorders community in Australia. Most people with haemophilia now use recombinant products, which are synthetic and not at risk of infection by human diseases. With HIV a 'chronic manageable health condition' and curative hepatitis C treatments, many affected community members have been able to move beyond survival. Some have chosen to disclose their HIV status very publicly as a gesture of support to other affected community members.[101] When they were cured of their hepatitis C, some wrote personal stories about their treatment experience and how they felt afterwards to encourage others to have treatment. They were excited by the relief from the crippling fatigue of hepatitis C, using words such as 'exhilarating'.[102]

The understated comment of one young man with haemophilia highlighted just how much impact this had on their quality of life:

> *Having had the new treatment and being cured has also had a big impact on my quality of life and improved the quality of my leisure and personal time. I have noticed over the last few months that I have a lot more energy. I used to go to work and then go home and feel really tired, now I get home and tinker about in the shed or whatever for a couple of hours if I feel like it.*[103]

Although the treatments may have cleared the virus, the Australian hepatitis C clinical management guidelines note that people with cirrhosis will need to have ongoing monitoring for liver health complications such as hepatocellular carcinoma. Treatment may also be unsuccessful or unsuitable for some people with very advanced liver disease. Data on the long-term effects of the new treatments on liver health is currently being gathered.[51]

3.6.9 AGEING WITH MILD HAEMOPHILIA

Although the larger proportion of people with haemophilia have mild haemophilia, there are few publications that directly address ageing with mild haemophilia. A recent literature review of mild haemophilia found that the clinical issues of living with mild haemophilia had not been clearly delineated in haemophilia research studies, and as a result the impact of mild haemophilia is not well understood or addressed. It commented that further study will be very valuable, particularly as the new types of treatment for haemophilia could mean that in the future people with severe haemophilia live with sustained factor levels in the mild haemophilia range.[104]

A 2018 European article on clinical management of mild haemophilia noted that people with mild haemophilia have a good life expectancy and those with mild haemophilia are likely to predominate in the 60 years and over age group. The guidelines described several concerns with the risk of bleeding complications in this group: older people with mild haemophilia would have had few bleeding episodes in

their lifetime, often diagnosed in adulthood, and may not understand the need to raise their bleeding disorder with other health professionals to prevent bleeding episodes with surgery or medical or dental procedures. Although they may experience less arthropathy than people with severe haemophilia, using NSAIDs to manage the joint problems that occur with ageing may also increase bleeding problems. Discussion between their haemophilia and other specialists will be very important to work out the balance between medication for their various health conditions and the likelihood of it increasing bleeding, and the need to manage health issues such as hypertension to decrease the very serious risk of intracranial haemorrhage. The authors suggested that clinics via telephone may be useful for some in this group.[6]

3.6.10 AGEING WITH VWD AND RARE BLEEDING DISORDERS

As with mild haemophilia, there is little research on ageing with a bleeding disorder that is specific to VWD or other rare bleeding disorders.

In 2011 leading European haematologists pointed out that the population of elderly people with VWD was growing due to improved medical care, and that an evidence-base on ageing with VWD needed to be developed to support clinical management guidelines. They highlighted several clinical questions. One was whether bleeding symptoms would change with age: on the one hand von Willebrand factor levels can increase with age, but studies have also shown an ageing-related increase in some symptoms such as gastrointestinal bleeding. Treatment needs may change: treatment with desmopressin may no longer be suitable for older people because of its side-effects and is not recommended for people over 70 years of age; in fact, prophylaxis may be required more often due to increased bleeding with cancer, medications or surgery. They also noted a need for research to establish whether having VWD protected against cardiovascular disease.[105]

This was reinforced in a more recent review, with a call for more clinical trials in the older patient with VWD and that these consider common issues of ageing such as healing rates and management of pressure ulcers. It also recommended that these older patients be encouraged to participate in national bleeding disorder registries to help understand the ageing-related complexities of VWD.[106]

3.7 Women

The HFA women's project consultation found that many women had been treated for their bleeding disorder in the community, for example, by a general practitioner (GP) rather than a Haemophilia Treatment Centre. However, most doctors have not received training about managing bleeding disorders. As a result, many women had experienced problems with diagnosis and referral, with late diagnosis common, and had bleeding problems with surgery, medical and dental procedures, with menstruation and after childbirth. Many women also spoke about their difficulties in being 'taken seriously' by health professionals, as some of their non-haemophilia health professionals (eg, general practitioners, surgeons, dentists) didn't know that women can have bleeding disorders.[7] This is similar to the experience of women with bleeding disorders in other developed countries such as Canada.[107]

In Australia women with factor levels in the mild severity range were formerly described as 'symptomatic carriers' and have only recently been redefined as having 'mild haemophilia', when international definitions changed in 2014.[108] This shift in thinking about females with haemophilia has resulted in new questions about this population, for example, whether women develop arthropathy from joint bleeds as they age. A recent study of Swedish haemophilia carriers found that those with low factor levels had a significantly higher level of joint problems and earlier diagnosis with their first joint problem than women with normal factor levels, but did not publish age-specific results.[109] There remains much work to do to understand the impact of ageing on women with bleeding disorders and if and how this differs to men.

3.8 Sexuality

Several clinical reviews noted that older people with bleeding disorders may experience sexual dysfunction related to pain, problems with their joints and range of movement and concerns about causing bleeding. Medications and ageing-related health conditions can also contribute to this, along with concerns about transmitting bloodborne viruses.[18,25,27] Haematologists from the Netherlands pointed out that satisfactory sexual expression and intimacy are essential to wellbeing for many people and should not be abandoned simply because a person is older. They recommended that the HTC team should raise this proactively, as their patients will usually be too shy to bring up the subject, and consider the range of options for managing any problems.[27]

3.9 Mental Health

3.9.1 VULNERABILITY

Canadian research examining patient perspectives of ageing with a bleeding disorder found that many older people with bleeding disorders reported physical limitations, pain and mental exhaustion to be a major concern in their everyday lives. *'I am just tired of fighting,'* said one study participant. The participants were worried about their loss of independence. They were anxious about not being able to take care of themselves in the future because of their physical problems and whether other carers would have the expertise to provide their care safely. The researchers underlined the importance of recognizing depression in this population.[28] These findings are consistent with other reviews and studies, which raised concerns about quality of life and mental health in older people with bleeding disorders.[18,25,27]

Some reviews noted that people with bleeding disorders are likely to experience the same rate of dementia as in the general population.[18,25] A small number of older people with bleeding disorders who also have HIV may develop a condition known as HIV-associated neurocognitive disorder (HAND) which can affect thinking and concentration.[18,97] The incidence of dementia may nevertheless be a concern for older people with bleeding disorders, as it is estimated that nearly one in ten Australians over 65 years has dementia.[110]

3.9.2 STOICISM AND RESILIENCE

It is interesting to note that an international study of health-related quality of life in people with haemophilia found that, while their physical quality of life was significantly lower than people in the general population, their mental, emotional and social scores were similar to the general population and higher than other people with chronic health conditions. The authors speculated that this might be because they had been able to adapt to their health condition over their lifetime.[80] In contrast, the *Don't go it alone* study, a large study of life satisfaction in older Australians, found that health status was the second most important factor in life satisfaction and that those who perceived that they were in poor health displayed much lower levels of life satisfaction than those who described their health as excellent.[111]

The HFA *Double Whammy* report identified a culture of stoicism among Australians with bleeding disorders. Growing up they had been encouraged to *'carry on like anybody normal'* and not to complain about their bleeding disorder. They often dealt with health issues by downplaying them or making jokes about them. *'You learn to live with haemophilia. You're born with it, you grow up with it,'* commented one community member.[20]

An Australian study on the hepatitis C treatment experience described the self-management strategies of a participant with haemophilia as 'resilient coping': he drew on his past experience of living with haemophilia to deal with his hepatitis C treatment and took an optimistic approach to its challenges. '*With haemophilia… you tend to be a bit onwards and upwards in your approach to things,'* he explained. The authors noted that optimism and determination are acknowledged as assisting with

resilient coping.[112] It is important to note that in the Canadian research on older patient perspectives, many had not allowed their bleeding disorder to limit them, remaining physically active, working and travelling widely. However, for some their pain and physical limitations had exhausted them, and it was at this point that they were unable to keep up their positive approach.[28]

3.9.3 GRIEF AND LOSS

Grief and loss may occur in many ways for an older person with a bleeding disorder. They may have had to retire from work or lost their job; they may no longer be able to play sport or be physically active; they may be losing their independence.

A very significant impact is on relationships. In the HFA *Double Whammy* report, community members spoke about their ongoing sadness at having lost family and friends to HIV and hepatitis C. They may have chosen not to have children because of their bloodborne virus, or sometimes because of their haemophilia, and some described their difficulties in having a relationship as they felt they had very little to offer a partner.[20] UK haematologists drew attention to the narrowing social circle of the person with a bleeding disorder at this point in their life. If they then lost their spouse, family or friends, they would need extra support, both to manage their emotional health and often also to deal with the loss of their carer network.[53]

3.10 Comprehensive care

The value of comprehensive care for people with bleeding disorders and their families has been well established.[11,113] The literature highlights the ongoing importance of comprehensive care as people with bleeding disorders grow older, to manage both their bleeding disorder and the complications of other age-related health conditions in collaboration with their other health care providers.[8,17,18,25,27]

Older people with bleeding disorders have expressed concern about their future care if they are frail and unable to advocate for themselves effectively in community care facilities where they are totally dependent.[28] The Australian haemophilia nurse and psychosocial worker groups recognised the need to educate nurses and personal care attendants in residential care facilities about bleeding disorders and in 2018 published an information booklet and fact sheet targeted at care staff that can be used in conjunction with individual education from the HTC.[114,115]

Managing their ageing-related health conditions will also require older people with bleeding disorders to have treatment and care in the community, for example, with a GP. A 2016 Australian study considered how often local men with haemophilia attended a GP to undertake their preventive health checks associated with ageing. Around 90% of the men had a GP and two-thirds had seen their GP in the last 6 months, with two-thirds seeing the same GP for over 2 years. However, although they often knew about the preventive health checks for their age group, this did not necessarily mean that they undertook the recommended health check and only one-third actively visited their GP for a health check. The study highlighted the need for stronger integration between HTC and community-based services and proposed that HTCs take opportunities to educate their patients about working with their GP to access health checks appropriate to their age.[116]

With its multidisciplinary team and regular communication with older people with bleeding disorders, the HTC is also a good environment to trial innovative programs around ageing with a bleeding disorder. One example was a 2017 Italian project, which combined a physiotherapist-led exercise-based rehabilitation program with an occupational therapy program on skills and strategies to overcome problems with activities of daily life for older people with haemophilia.[117]

3.11 Social connection

The effect of social relationships and peer support on physical and mental health and wellbeing has been explored widely.

The *Don't go it alone* study found that the highest factor in the life satisfaction of older Australians was their social wellbeing, and that life satisfaction was reduced in people who often or occasionally experienced lack of companionship and loneliness.[111]

Peer-based support is recognised as a way for people with chronic health conditions to decrease loneliness and feelings of difference, while improving their competence in self-management and acceptance of their health condition.[118,119] Peer support groups can also be effective in improving self-care and complementing health care in people with haemophilia including those living in remote and regional areas.[120] Australian state and territory Haemophilia Foundations provide a range of peer support activities, but also acknowledge the importance of strategies to engage the bleeding disorders community in the activities. Their more successful strategies included having a focus to activities, such as a popular topic or invited speaker for a meeting, personal invitations to attend the meeting and making it a good social experience.[121]

Some new Australian studies are also considering the potential for peer activities using digital technology to provide support and education, particularly for those who have limited mobility or are geographically isolated. This includes interventions, such as 'befriending', where volunteers keep regular contact with individuals: this may be face-to-face, by telephone or using VOIP technology such as Skype.[122]

3.12 Carers

While there have been a number of studies that have investigated the impact of caring for a child with haemophilia on parents, there has been little work on the needs of partners and family of older people with bleeding disorders. Carers are an important part of the support network for older people with bleeding disorders and research to understand their experience and what could help them will be essential for the health and wellbeing of the bleeding disorders community into the future.

3.13 Finances

Financial security plays an important role in supporting the wellbeing of many Australians. The consultation for the HFA hepatitis C needs assessment highlighted that establishing yourself early financially was a key aspect of future planning for young men with severe haemophilia in earlier generations – that they *'only had so many years to work and try to get a good financial background happening'*.[99]

For many Australians, financial security involves owning your own home. A 2019 report on home ownership and rental from the Australian Institute of Health and Welfare commented, *'home ownership continues to be a widely held aspiration in Australia, providing owners with security of housing tenure and long–term social and economic benefits'.* The report noted that 67% of Australians were home-owners:

- 32% without a mortgage
- 35% with a mortgage.[123]

An important finding of the *Don't go it alone* study of life satisfaction in older Australians was that it was the perceived financial situation that made the most difference to older people: if they were comfortable with their current financial situation, this was associated with greater life satisfaction.[111]