HAEMOPHILIA FOUNDATION AUSTRALIA

HAEMOPHILIA FOUNDATION AUSTRALIA SUBMISSION

AUSTRALIAN GOVERNMENT REVIEW OF AUSTRALIA'S WELFARE SYSTEM

AUGUST 2014

Background

Haemophilia Foundation Australia

Haemophilia Foundation Australia (HFA) is a not for profit organisation which represents people with haemophilia, von Willebrand disorder and other rare inherited bleeding disorders in Australia. It is the national peak organization for bleeding disorders. It provides advocacy, education and support to the bleeding disorders commmunity and works to promote Australian based research.

Bleeding disorders

There are more than 5800 people with inherited bleeding disorders in Australia, of whom approximately 3000 have haemophilia, largely male[1].

Haemophilia is a lifelong inherited condition and occurs in families. In one third of cases it is a spontaneous mutuation, appearing in families with no previous history of the disorder. Haemophilia is found in all races and socio-economic groups.

Haemophilia occurs when there are reduced levels of blood clotting factors VIII (eight) or IX (nine) in a person's blood or the clotting factors do not work properly. It is incurable and can be life threatening if not treated appropriately. Bleeding is internal, into muscles, joints and organs. Bleeding may occur as a result of injury, or as a result of surgery or invasive procedures; in severe haemophilia bleeding can occur spontaneously, from no obvious cause, up to several times a week.

The two main forms of treatment for haemophilia are 'on demand' or 'prophylaxis'. With 'on demand' treatment, people are only treated when a bleeding episode occurs, either as a result of an injury or invasive procedures or due to spontaneous bleeding. With prophylaxis the aim is to maintain near normal clotting factor levels, so that someone with severe haemophilia experiences bleeding similar to someone with a mild disorder. Prophylaxis involves regular factor infusions, for example, two to three times weekly. With appropriate treatment bleeding episodes can usually be stopped. Spontaneous bleeding can largely be prevented through prophylaxis treatment, but bleeding episodes may still occur due to injury. Small children in particular may also experience infections in the port in their chest used to administer clotting factor treatment, requiring a visit to the hospital.

Women and girls with haemophilia and symptomatic women who carry the altered gene causing haemophilia frequently experience menorrhagia and bleeding complications with childbirth. They may also experience other gynecological problems associated with their bleeding disorder. These are usually treated with hormonal medications but may require surgery[2,3].

Impact of haemophilia complications

Episodes of bleeding over the long term can cause permanent damage to joints and muscles, resulting in:

- Arthropathy, joint deformity, muscle atrophy and contractures
- Pain
- Disability and reduced mobility
- Decreased quality of life.

The likelihood of bleeds and the resulting joint and muscle damage is increased if the person has an inhibitor, a complication of treatment that reduces the effectiveness of treatments. A person who experiences repeated bleeding over their lifetime may start to experience these problems within the first 10 or 20 years of their life[2,3].

Today in Australia, children and young people who have been treated all their lives with the required replacement clotting factor are less likely to have the problems of older adults. However, many adults live with significant joint damage caused by inadequate clotting factor therapy in the past. Women may have

continual problems with very heavy menstrual bleeding and the resulting anaemia. Adults with bleeding disorders may require:

- Aids such as artificial limbs, crutches, wheelchairs, modified vehicles and home, work or school environments, orthotics and bracing
- Regular and specialized physiotherapy to improve muscle strength and balance and prevent falls
- Prescribed strengthening exercise such as swimming or gym work.
- Considerable support to manage the activities of daily life
- Time off work to manage bleeding episodes and attend clinic and allied health visits
- Hospitalization at times for serious bleeds or complications such as joint infections
- Surgical interventions including athroscopy, joint replacements, ankle fusion, soft tissue release.[3,4,5]

If bleeding complications occur often, it can impact on their ability to work and earn an income: they may have used up all their sick leave for the year and need to take unpaid leave, which in turn may mean they are unable to pay bills or support themselves adequately, causing a need for welfare support.

Von Willebrand disorder (VWD) is another inherited bleeding disorder caused when there is not enough of the von Willebrand clotting factor in a person's blood, or it doesn't work properly. It is thought that many Australians with VWD are undiagnosed as it is more common in a mild form, and most people do not need treatment unless they have invasive medical or dental procedures, surgery or an injury. However, some people have severe VWD with frequent bleeding episodes and joint and muscle bleeds. Women and girls with VWD may experience menorrhagia, affecting their ability to work, and bleeding problems after childbirth. Some people with VWD can only be treated with clotting factor VIII concentrates made from human plasma, while others can be treated with synthetic hormones[2].

Blood borne virus co-morbidities

Some adults with haemophilia or von Willebrand disorder may also have been living with blood borne viruses, including HIV and hepatitis C, for more than 20 years due to treatment with infected blood clotting products before safe blood screening tests and viral inactivation procedures were introduced. For many, their co-morbidities have increased the complexity of their health problems and need for health and support services. They may have co-existing hepatitis C symptoms, such as severe fatigue, pain, nausea, concentration and mental health problems, or advancing liver disease complicated by haemophilic bleeding, or other health problems associated with HIV and HIV treatments, including peripheral neuropathy, muscle wasting, diabetes and cardiovascular disease.

Many of those who have both a bleeding disorder and hepatitis C reported that it impacted on their ability to work and earn an income from the age of 35 onwards.

HFA's recent national hepatitis C needs assessment found that many experience overload with health problems and services, and need assistance to negotiate the health and social services system. Given affected community members' ill-health and disability, this assistance is required to help them understand and find the services that are available to them, support them in completing the applications and assessments, and advocate for them to receive the services they require when they do not fit the "one-size-fits-all" criteria, which is often the case[4,5].

Ageing

Each of these bleeding disorders is categorized according to levels of severity, eg mild, moderate and severe. The degree of disability as the person ages is specific to the individual. However, early ageing occurs for many people with haemophilia, particularly if the person has inhibitors or where clotting factor treatment was rationed in early life due to plasma supply shortages.

Improved treatment, treatment safety and quality of care in Australia has meant that people with bleeding disorders are now living longer and for the first time there is a generation experiencing the age-related medical problems also encountered in the general population. This includes diseases such as:

- Heart disease
- Cancer
- Renal disease
- Osteoporosis and degenerative or osteoarthritis.

Testing and treatment for all of these health conditions may be complicated by bleeding problems, for example, with the need for factor replacement with surgery or invasive diagnostic procedures, or with haemodialysis, or managing side-effects such as thrombocytopenia from chemotherapy[6].

Treatment and care for bleeding disorders in Australia

In Australia most people with bleeding disorders use recombinant or plasma derived clotting factor treatment products to treat their bleeding disorder. The financial cost of all clotting factor products is shared by Australian governments under the National Blood Agreement. Treatment and care for people with bleeding disorders is best managed though a model of comprehensive care which is provided by specialist Haemophilia Centres. These are currently located in major public hospitals around Australia.

However, the complications of people's bleeding disorders, their co-morbidities and the issues that occur as they age result in a need for a wide variety of health, social and support services. Most of these services have to be obtained through referral outside the Haemophilia Centre, and often outside the public hospital system.

Referral outside the Haemophilia Centre can result in extra costs for the individual:

- The cost of attending private services, or where co-payments exist
- The travel, parking and carer costs associated with these visits
- Costs of medications, aids or appliances.

Implications for financial costs and welfare assistance

A person with a bleeding disorder is living with a lifelong chronic health condition, often complicated with other health conditions.

Implications for income or reimbursement:

- Frequent bleeding episodes, surgery or health problems related to co-morbidities or complications can impact on their ability to work and earn an income
- They may have used up all their sick leave for the year and need to take unpaid leave, which in turn may mean they are unable to pay bills or support themselves adequately, causing a need for welfare support.
- They may have needed to retire early from work due to their health conditions and be living on superannuation, investments, a disability pension or their partner's income
- Parents of children with bleeding disorders or carers may be unable to work or need to take time off work to take their child or the person with a bleeding disorder to hospital or clinic visits, or to care for them at home.
- People with bleeding disorders often report that cover for life, travel, and income protection insurance has been refused or premiums are unaffordable due to their pre-existing health conditions; that they need to wait 12 months to upgrade health insurance. Private health insurance can be too expensive on a low income. If they experience a medical crisis they are financially unprotected and cannot obtain reimbursement through the private insurance system
- On a low income, the thresholds for Medicare and PBS gap payments and tax rebates are too high for them to reach. [4,5,6,7]

Every year this person also pays many out-of-pocket costs associated with their health care, depending on their current complications or co-morbidities:

- Health care costs with private general practitioners and medical, dental and allied health specialists; existing co-payments with public hospitals, including pharmacy dispensing costs
- Prescribed and over the counter medications, including pain relief and anti-inflammatory agents

- Travel, parking, and carer costs; meal costs for long clinic visits; airfare and accommodation costs if from rural/remote areas
- Gap costs for diagnostic tests
- Complementary therapies, herbal medications, dietary supplements
- Stress management activities, including meditation and massage
- Prescribed strengthening exercise activities, eg swimming, hydrotherapy, gym work
- Carers, home help, meals on wheels
- Large quantities of menstrual products for heavy bleeding
- Health aids and appliances, eg electric wheelchair.

People with bleeding disorders and parents and carers have reported relying on a range of welfare payments or supplements and concessions to support themselves, attend their health care appointments, and try to manage these out-of-pocket costs, including for example:

- Disability support pension
- Sickness allowance
- Mobility allowance
- Utilities and telephone allowances
- Carer, partner or parent payments
- Rental assistance
- Concessions and health care card[4,5,6,7]

They may also make use of payments such as Newstart, if they are able to work full-time but unemployed.

Outcomes of complexity and fragmentation

Co-ordination of health and welfare services is essential to the person's health and wellbeing, but as the systems are fragmented, services are split across state/territory and federal systems and communication between services is difficult, this very rarely occurs. A person with a chronic health condition such as a bleeding disorder and other co-morbidities will often have difficulty negotiating the health and welfare systems and the government support provided or advocating for themselves when they do not apparently fit the criteria, with the result that they cannot access government financial assistance schemes where they exist. They find this very stressful, which impacts negatively on their health. [4,5,6,7]

Haemophilia Social Workers and Counsellors have commented that even as a professional, it is difficult to ascertain which payments, supplements or reimbursements an individual with a bleeding disorder may be entitled to through the welfare system

Welfare Review Interim Report – Responses

In preparing this submission, Haemophilia Foundation Australia consulted with both specialist haemophilia social workers and counsellors and members of the bleeding disorders community. At times they offered a range of comments or suggestions, or had questions about the implications, and we have reflected this in the responses below.

Pillar One: Simpler and sustainable income support system

The current welfare system is complex and difficult to negotiate. This creates an environment where there are gaps in services, eligibility and ability to access welfare benefits. As a result some individuals with bleeding disorders "fall between the cracks".

> *"Most government schemes are based on "one size fits all". Haemophilia and hep C doesn't always fit the criteria. It's often very hard to convince the Centrelink and Patient Travel Scheme people that you should be considered, which is really stressful when you are sick."*

Bleeding disorders and their complications, including blood borne viruses such as HIV and hepatitis C or inhibitors to treatment, do not fit the current eligibility criteria neatly. This is due to:

- The episodic nature of bleeds
- The variability of the person's bleeding disorder or complications arising from it.

Individuals may experience different levels of severity with their bleeding disorder or the complication (eg, severe, moderate or mild haemophilia; inhibitors which have a varied impact on effectiveness of treatment in the individual; hepatitis C with few symptoms or advanced liver disease), and they may also have different symptoms or outcomes with the same level of severity or complication.

A simpler architecture to the welfare system that was accessible and enabled comprehensive support, without gaps, would be of great value to the bleeding disorders community.

Tiered working age payment
"People with disability who have current or future capacity to work could be assisted through the tiered working age payment to better reflect different work capacities."

While it is valuable to support the person with a disability who is able to work and can find suitable work, the reality is that it is a challenge to find flexible work that allows for the episodic nature of bleeding disorders, hepatitis C and HIV symptoms, and the pain, fatigue and mobility problems of haemophilic arthropathy.

Concerns:

- **How would "partial capacity to work" be measured and by whom?**
    - Individual assessment is paramount as people's lived experience of their bleeding disorder, complications and other comorbidities, such as blood borne viruses, inhibitors, arthropathy, and health conditions related to ageing etc, is very variable. People with bleeding disorders often experience ageing many decades earlier than the general population, many from their mid-30s[4,5,6]. It is important that this assessment is done by the person's treating medical specialists, who are familiar with these health conditions and the individual's experience of them.
- **Will people with a disability on a working age payment still be eligible for a health care card, mobility allowances and other concessions and supplements at the Disability Support Pension (DSP) rate?**

- **Will people with a disability on a working age payment have higher thresholds for income generated through work before the payment is reduced or stopped?**

    - In the current working environment, few people with bleeding disorders in this category are likely to be able to find suitable flexible work. Those who do would most likely be working part-time or casually.

    - Even if working, income levels are often very low. HFA surveys of people with bleeding disorders and hepatitis C, for example, found more than 50% surveyed already receive pensions or other government financial assistance. Those who are still working report cutting work hours, being obliged to take pay cuts or work at a lower level and have lost income due to unpaid sick leave[4,5,7,8]

    - Health care costs to manage chronic health conditions with complex co-morbidities are high. In HFA community surveys, people with bleeding disorders and hepatitis C, for example, reported paying more than $8,000 p.a. in out-of-pocket costs for basic health management, which is crippling on a low income. They rely on health care cards, concessions, allowances and supplements to attend clinic appointments and rehabilitation services and pay for basic medications. [4,5,7,8]

    - A mobility allowance is essential to manage the high transport costs of limited mobility, wheelchair access requirements, and parking that is close to the workplace, health care clinics and hospitals, shopping, Centrelink and other agencies or venues for managing the necessities of daily life.

    - A telephone allowance would be important for working from home or applying for jobs.

- **Would there be an income supplement for disability on top of the basic working age payment?**

    - At the moment the payment rates for Newstart are more than $200 less than the Disability Support Pension, which would be a considerable loss for someone with a chronic health condition and complex co-morbidities. As mentioned above, people in this situation have many health expenses. They may also require disability accessible accommodation and may be paying higher rental for this. They may need to have computer and internet facilities at home to enable them to work from home at times, or apply for jobs, and the costs for basic computer access and internet plans would need to be covered.

- **Would their disability be taken into account in the Activity Test requirements?**

    - The current Activity Test requirements assume that the person is able-bodied and able to travel to source technology such as computers or internet outside of the home to apply for a defined number of jobs and attend Personal Contact Interviews at Centrelink offices regularly. This would be very difficult for a person with a bleeding disorder and complications, who experiences pain, fatigue, limited mobility from joint damage, and other health problems; and is living on a low income with limited or no computer and internet capacity at home.

    - People with chronic health conditions are at a higher risk of depression and anxiety. In bleeding disorders this is particularly related to the relentless daily management of symptoms, the unpredictable nature of bleeding disorders and concerns about the future[9]. Increased pressure to procure and maintain employment combined with episodes of physical immobility and pain and treatment requirements will further inhibit health and wellness.

- **Would there be recognition of voluntary as well as paid work?**

    - The contribution to the community of a person with a bleeding disorder should not only be measured by earned income as there are many who provide voluntary service, as this can

be provided on a flexible basis and accommodate their health issues, unlike most paid employment. This also provides a very valuable service to the community.

Suggestions:

- **Eligibility assessment and reviews**
    - The current application and assessment forms and reviews for the DSP include a Medical/Treatment Report which is often an inadequate assessment with inappropriate questions for an episodic condition like haemophilia, with complications such as inhibitors, arthritis, blood borne viruses, etc. The Medical Report does not provide the opportunity to elaborate on the issues that confront people with haemophilia. In some cases, and if the applicants request a review of a negative decision, a Medical Assessment by a Centrelink doctor is required. This process could be shortcut at the time of initial application or review by accepting a letter from the person's treating medical specialist, who is more able, with expertise in the particular speciality, to make assessment of their patient's work capacity.
    - Regular reviews of people's health conditions, where their permanent disability is unchanged from year to year, increases their anxieties when they and their health are already very vulnerable. It may be appropriate to exempt some people from review, if, for example, they have already had a Job Capacity Assessment after this process was upgraded in 2011.
    - It may be appropriate to have a targeted review of DSP recipients eligible from 2008-2011, prior to upgraded Job Capacity Assessments, especially when the reasons for their eligibility are not clear. This would need to be handled sensitively and media coverage that attacks welfare recipients avoided.
- **Payments and allowances**
    - People with episodic conditions could be covered under 'working age payments' via a medical certificate, as is done with the current Sickness Allowance.
    - Rent assistance is very important to moderate the huge variations in living costs across Australia, eg rent in Sydney and Melbourne is very expensive.
- **Incentives and support for work**
    - It would be valuable to have extra support with work-focused education and training for people who are under 35, are candidates for the DSP and have a disability which impairs their ability to work. This would need to be developed and implemented carefully and target job opportunities realistically, or both candidates and employers would resent the program and not wish to engage.
    - Allowances that currently provide an incentive to work and recognize that people with bleeding disorders and their carers may face higher costs to work include:
        - Pensioner Education Supplement
        - Mobility Allowance
        - Carer Allowance.
    - Some carers of children with bleeding disorders, who are currently only eligible for the supplementary payment of Carers Allowance, would also benefit from recognition of their need for flexible work and income support to undertake work. Their ability to participate in work and their earning capacity is affected when their child is hospitalized due to a bleed, inhibitors, a port infection, etc.
- **Automatic transition to Age Pension**

- It would be helpful if the process to transition from working age payments, the DSP or other income support to the Age Pension was automatic if the person clearly qualifies by nature of their eligibility for their current income support and their age.

- **Simple and comprehensive information about eligibility for payments and allowances**

Pillar two: Strengthening individual and family capacity

Concerns:

- **The Review has an underlying assumption in 'mutual obligation' that productivity is achieved through 'paid work', and thereby risks devaluing the contributions of carers and volunteers.** In the bleeding disorders community carers and volunteers play an essential role in supporting the person with a bleeding disorder at a very basic level as well as improving their quality of life.

Suggestions:

- **Target carers for job-focused education and training**

  - Provide incentives like the Pensioner Education Supplement to assist them to transition to work when their caring role permits.

- **Government funding to support professional psychosocial and community volunteer roles in programs to equip people with skills for employment and increasing their self-reliance.**

  - The Haemophilia Foundation Australia Youth Leadership and Mentoring program and Parents Empowering Parents program are examples of programs specific to the bleeding disorders community which draw on haemophilia psychosocial professionals and volunteer community leaders to strengthen individual and family capacity.

Pillar three: Engaging with employers

Concerns:

- **There needs to be realistic employment models which do not overly burden employers or community agencies**

  - The draft Employment Services Model released by the Australian Minister for Employment in July 2014 requires job seekers to look for up to 40 jobs per month, and most job seekers under 50 years of age will be required to participate in Work for the Dole for either 15 or 25 hours per week for six months each year, depending on their age. This raises the question of the workload this will impose on employers and community agencies and their capacity to manage this.

Suggestions:

- **Wage subsidies for employers could provide incentives for employing people with disabilities or carers**

  - These could provide incentives to employers to provide a flexible working environment and assist them with restructuring the workplace to minimize the impact of employees with "erratic" health problems or carers of people with disabilities. Restructuring may include flexible working arrangements enabling employees to:

    - Job share or have paired roles
    - Work from home at times where appropriate

- Work flexible hours to meet caring needs and accommodate medical appointments
- Take sick or carer's leave when required.

- **Other wage subsidies such as the 'Restart Wage Subsidy' for those over 50, and the 'Job Commitment Bonus' for 18 – 30 year olds are also important initiatives.**

- **Information about various programs available at areas interfacing with people of working age on income support.**

Pillar four: Building community capacity

Suggestions:

- **Improve access to information and communication technology for low income groups**
    - This is extremely important to stay connected and build employment skills.
- **Develop a supportive employment environment with legal safeguards**
    - This is a fundamental context for assisting people on income support into employment and includes anti-discrimination law, workplace bullying protection, provisions for sick leave, carer's leave, and flexible working arrangements.
- **Using a strength-based approach to increase resilience**
    - Some older people with bleeding disorders have a reputation for stoicism and resilience in the face of multiple health conditions and sudden health challenges. Research has indicated that self-esteem is an important factor in their coping strategies[10]. If income support programs are to strengthen communities, it is essential that they encourage and recognize individual strengths rather than create impossible targets and punish those who are unable to meet them.
    - This involves developing programs that support and assist an individual to participate in their community, whether that is through paid or volunteer work, gives them simple and accessible pathways to acquire appropriate education and training and seek employment if possible, and rewards them with praise for their efforts at every level.
    - Language and attitudes also need to change so that being on a Disability Support Pension and seeking work are recognized as acceptable ways of participating in the community. It is concerning to see that people in these situations are being criticized for a role they have little power to change in an increasingly difficult economic environment.

References

1 National Blood Authority. Australian Bleeding Disorders Registry Annual Report 2012-13. NBA: Canberra, 2014.
2 National Blood Authority; Australian Haemophilia Centre Directors' Organisation. Evidence-based clinical practice guidelines for the use of recombinant and plasma-derived FVIII and FIX products. Australian Health Ministers' Advisory Council: Canberra, 2006.
3 World Federation of Hemophilia. Guidelines for the management of haemophilia. 2nd ed. WFH: Montreal, 2012.
4 Haemophilia Foundation Australia. *'A double whammy': living with a bleeding disorder and hepatitis C*. HFA: Melbourne, 2007.
http://www.haemophilia.org.au/documents/item/48
5 Haemophilia Foundation Australia. *Getting it right: hepatitis C needs assessment evaluation and implementation report.* HFA: Melbourne, 2009.
http://www.haemophilia.org.au/documents/item/151
6 Dolan G. The challenges of an ageing haemophilic population. Haemophilia 2010;16(Suppl 5):11-16.
7 Haemophilia Foundation Australia. Unpublished community survey results: Hepatitis C and bleeding disorder out-of-pocket costs survey. HFA: Melbourne, 2011.
8 Haemophilia Foundation Australia. Unpublished community survey results: Out-of-pocket costs – hep C and bleeding disorders survey. HFA: Melbourne, 2014.
9 Barlow JH, Stapley J, Ellard DR. Living with haemophilia and von Willebrand's: a descriptive qualitative study. Patient Education and Counseling. 2007;68(3):235-42.
10 Canclini M, Saviolo-Negrin N, Zanon E. Psychological aspects and coping in haemophilic patients: a case-control study.Haemophilia. 2003;9(5):619-24.