NATIONAL DRUG STRATEGY CONSULTATION

HAEMOPHILIA FOUNDATION AUSTRALIA SUBMISSION

Haemophilia Foundation Australia (HFA)
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 body which advocates for the treatment, care and support needs of people with bleeding disorders. Its mission is to represent people affected by bleeding disorders through advocacy, education and the promotion of Australian-based research.

Support for ASHM submission
As an organisational member of the Australasian Society for HIV Medicine (ASHM), Haemophilia Foundation Australia (HFA) participated in the feedback process for ASHM’s submission to the National Drug Strategy Consultation. The ASHM submission gives a comprehensive response to the drug and alcohol strategy and its impact generally, as well as specifically on prevention, diagnosis and treatment of people with blood borne viruses and sexually transmissible infections and harm and prevention in selected communities. HFA endorses the ASHM submission, both generally and specifically in relation to blood borne viruses and sexual health.

Bleeding disorder specific issues
In addition the ASHM submission, HFA has further comments to make that relate to the specific needs of people with bleeding disorders in Australia. HFA will confine these comments to the three questions below.

Background to bleeding disorders in Australia
There are approximately 3600 people diagnosed with inherited bleeding disorders in Australia, of whom 2000 are males with haemophilia. Haemophilia occurs when blood clotting factors VIII (eight) or IX (nine) are missing in a person’s blood or don’t work properly. It is incurable and can be life threatening if not treated properly. Bleeding is internal, into muscles, joints and organs. Long term bleeding can cause permanent damage resulting in pain, disability and reduced quality of life. However, with appropriate treatment bleeding can usually be stopped. 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 and pain caused by inadequate clotting factor therapy in the past. Some of this group also live with blood borne viruses, including HIV and hepatitis C, due to treatment with unsafe blood clotting products before viral inactivation processes and HIV and HCV screening tests were introduced.

Alcohol and drug use issues also occur in the bleeding disorders community, but are further complicated by the day-to-day realities of living with a bleeding disorder and specialised treatment and care needs.
Where should efforts be focussed over the coming five years to increase the capacity of the generalist health workforce to identify and respond to substance use problems?

The complex care needs of a person with co-morbidities which include a bleeding disorder and alcohol and/or drug problems raise several issues in relation to this question.

The comprehensive care model is the preferred model worldwide for clinical management of bleeding disorders. This involves management by a comprehensive care team including a haematologist, nurse co-ordinator, social worker/counsellor and physiotherapist with expertise in bleeding disorders, usually co-located in a hospital-based Haemophilia Centre, and other specialists as consultants according to the patient's need. Key areas of management are:

- Prevention of bleeding;
- Long-term management of joint and muscle damage and other sequelae of bleeding;
- Management of complications from treatment including:
  - Inhibitor (treatment antibody) development; and
  - Viral infection(s) such as HIV and hepatitis C transmitted through blood products requiring long-term management.

Alcohol and drug problems may add to a person with a bleeding disorder's already complex needs. Haemophilia health professionals report that alcohol and drug problems among people with bleeding disorders often accompany mental health issues, such as anxiety and depression, and may also be associated with low income and unstable living environments. In this case, the comprehensive care team would be extended to include professionals with drug and alcohol, mental health and community care expertise. This may involve referral to a community case manager, to provide continuity of care in the long term. Haemophilia health professionals report that long term interventions have been the most effective but that cost and availability of services currently impact strongly on uptake. The Haemophilia Team would also rely on education from those with drug and alcohol expertise for guidance on how best to work with them in caring for the person.

To manage the person's general health needs, it may be more appropriate for the person to receive primary care through a low cost primary health care service which is attuned to the needs of people in vulnerable situations, e.g. a community health service. The person may present to primary health care services for clinical problems that also impact on or relate to their bleeding disorder. Anecdotal reports from health professionals suggest this could commonly include

- Injuries
- Other bleeding problems, including gastrointestinal bleeds from alcohol use, which may require clotting factor treatment. This is more likely to occur if the person has mild haemophilia, is less familiar with the procedures for treating bleeds and does not usually self-treat at home
- Other general health problems, where investigations and procedures may require liaison with the Haemophilia Centre for advice on preventing bleeding
- Dental care.

For effective care which takes into account the person's bleeding disorder, it is essential to maintain the comprehensive care model in the primary care environment.
and include the specialist Haemophilia Team in clinical consultation and planning, eg in a Chronic Disease Management Plan.

**Recommendations**

- Allocate increased resources to drug and alcohol services and community health services to ensure greater availability of free services, especially community case managers, counsellors and GPs. This should include resources aimed at staff retention. Services need to be spread across the community so that they are accessible to clients and promoted to generalist health professionals.
- Raise awareness among GPs of the need to include specialist expertise relating to co-morbidities in Chronic Disease Management Plans.
- Continue the development of the Chronic Disease Management Plan with a focus on co-ordination, co-operation and continuity of care.
- Increase free or low cost drug and alcohol related educational and professional development opportunities for the generalist health workforce. This should include:
  - Understanding risk factors and identifying affected patients/clients.
  - Where and how to refer affected patients/clients.

**How can efforts under the National Drug Strategy better complement the social inclusion agenda such as addressing unemployment, homelessness, mental illness and social disadvantage?**

Addressing social determinants of health is crucial to an effective response to drug and alcohol issues in the community. It would be valuable to also consider other appropriate structural responses to risk factors for drug and alcohol use. For example, among people with bleeding disorders, the following risk factors have been identified:

- Inadequate pain management related to joint problems, arthritis and intolerance of some pain medications due to liver damage with hepatitis C
- Deep psychological crisis in individuals and the community relating to negative diagnosis experiences during the HIV epidemic in 1984-5 and the subsequent wave of hepatitis C diagnoses in the early 1990s as a result of contaminated blood products. Experiences included:
  - Death of family members; fear of own death
  - Unresolved anger at the route of transmission and the lack of acknowledgement by health authorities
  - Unreasonably delayed information about own diagnosis (some children not informed until reached 16 years; many with hepatitis C were informed casually by other treating health professionals months to years after diagnosis)
  - Discrimination and resulting social isolation
  - Poor health, fatigue, mood disorders accompanied by loss of capacity to work/earn income/undertake education and financial hardship

- Increasing numbers of broken families leading to unstable home situations for younger people due to the pressure of managing a parent or child with a bleeding disorder in the family unit.

**Where should effort be focused in reducing substance use and associated harms among vulnerable populations?**

Effort should be focused on areas where it can have the most value and be most effective. Further research needs to be done to establish this.
Health promotion
The early success of the HIV prevention campaigns in Australia demonstrates the effectiveness of targeted health promotion messages in a harm reduction approach. Strength-based approaches with targeted and positive health promotion messages have also been effective in men’s health programs⁴. For those with chronic illnesses such as bleeding disorders, this may involve targeted health promotion messages aimed at reducing harm and self-managing health, eg planning self-treatment for times of the day when judgement or dexterity is not impaired by drug or alcohol use. It may also be useful to evaluate the effectiveness of strength-based approaches for smoking, which continues to be prevalent among people with bleeding disorders both in Australia and other countries, in spite of education about the risks of increased bleeding and other health problems⁵.

Reducing risks of substance use
The period of adolescence for a young person with a chronic illness such as a bleeding disorder is a time of crisis in personal development. Compliance with preventive bleeding disorder treatment often declines at people pass from childhood to adolescence and it is also a time of great vulnerability to the risk of commencing substance use⁶. Paediatric haemophilia specialists have highlighted the importance of understanding the balance of psychological risk and protective factors at this point and the need to develop a personalized health management strategy with the young person with a bleeding disorder that suits them and their lifestyle⁷. It may be valuable to increase education to parents/caregivers and paediatric health professionals on understanding this crisis, identifying risks and appropriate management strategies.

Reducing harm
Consultation with haemophilia health professionals has identified the lack of a stable living environment, lack of continuity of care and concurrent mental health issues as key vulnerabilities to increased harm among people with bleeding disorders and alcohol and drug problems.

To enable people in this situation to have the optimal environment for gaining control of their health and wellbeing, further public resources are needed to provide safe and stable living environments and ongoing case management for these individuals.

_HFA wishes to thank the members of the Australia/New Zealand Haemophilia Social Workers’ And Counsellors’ Group (ANZHSWCG) and the Australian Haemophilia Nurses’ Group (AHNG) who contributed to consultation for this submission._

*Haemophilia Foundation Australia, February 2010.*
REFERENCES

1 World Federation of Hemophilia. Guidelines for the management of hemophilia. WFH: Montreal, 2005
2 Canadian Hemophilia Society. Pain, the fifth vital sign: a resource on managing pain for people with bleeding disorders. CHS: Montreal [2007]