

CHAPTER 6

SERVICES FOR PEOPLE WITH HEPATITIS C

The thing is that I am sick. I have a liver that is not working properly any more. I do not want to blame anyone; I would just like some help.¹

6.1 The Committee received much evidence from those who acquired hepatitis C through blood and blood products. This chapter outlines the services already provided by government, the Australian Red Cross Blood Service and support organisations. The chapter also considers what can be done to improve access to and the quality of these services.

Lookback program

6.2 For many people who have contracted hepatitis C through blood transfusion, identifying the event which led to their infection is an important step. The Australian Red Cross Blood Service (ARCBS), through its Lookback program, traces blood products which may have been contaminated.

6.3 The Lookback program was instituted by the ARCBS to identify recipients who may have been exposed to an infection via blood transfusion. The first Lookback program was undertaken for HIV. The ARCBS indicated that the process works in two ways:

- Donor triggered: if a blood donor is screened and found to be positive, prior recipients are traced by working sequentially backwards through the infected donor's prior donations and notifying recipients. These recipients are then tested to establish whether they are infected and referred to clinical and other services where appropriate.
- Recipient triggered: the process of attempting to identify an infected donor when a recipient develops a transmissible disease. This involves the recall and testing of all blood donors whose blood was transfused to the recipient.

6.4 The ARCBS indicated that it has identified 2,050 recipients of fresh blood products who have contracted hepatitis C. The ARCBS also estimated that, based on modelling² it had undertaken, that the number of people living with hepatitis C as a result of transfusion of blood and blood products was in the range of 3,500 to 8,000.³

1 *Committee Hansard* 7.4.04, p.6.

2 The modelling took into account survival rates of people receiving transfusions and estimated the possible number of Australians alive today with transfusion acquired hepatitis C. The upper limit was reduced by the number expected to have cleared the virus. The number of people with haemophilia who have hepatitis C was also included.

3 *Submission* 64, Submission prepared for hearing, 7.4.04, p.39; *Committee Hansard* 7.4.04, p.39 (ARCBS).

6.5 In evidence, some witnesses reported positive experiences of the Lookback program.⁴ However, other witnesses expressed concern about the program's effectiveness. Of major concern was that many recipients had discovered their hepatitis C (HCV) status through their failing health rather than through the Lookback program. The Tainted Blood Product Action Group (TBPAG) for example, stated that it had conducted its own survey of people who contracted HCV through blood transfusions. The TBPAG reported that 81 per cent of those surveyed had never been officially contacted nor offered any medical support by the ARCBS.⁵

6.6 Other areas of concern reported to the Committee included delays in notifying recipients of contaminated blood, with some witnesses reporting it was many years before they were contacted by the ARCBS. Witnesses also reported delays in the provision of information and provision of incomplete or incorrect information, for example, that they had not received a transfusion, once contact had been made with ARCBS. Of particular concern for some witnesses was the lack of accurate hospital records or the destruction of hospital records so that it was no longer possible to identify the blood or blood products they had received. Even when records were complete and donors could be identified, some witnesses reported that the ARCBS was unable to trace these donors to establish their HCV status.⁶

6.7 Suggestions were made in evidence that a form of universal lookback should be introduced. The TBPAG argued that all those who received blood transfusion in the high-risk blood transfusion era prior to the early 1990s should be traced. In particular, the TBPAG expressed concern at the number of mothers who received transfusions post childbirth and who may be unaware that they have hepatitis C.⁷

6.8 In evidence, the ARCBS voiced concern that, although it had identified 2,050 recipients of fresh products, there are others it cannot currently identify and who may never have been notified of their hepatitis C status.⁸ ARCBS indicated that both donor and recipient triggered Lookback have limitations:

I think the first important point to make is that Lookback, at its best, is an imperfect process. There is no form of Lookback available that will ever find all people who received or acquired non-A, non-B hepatitis or hepatitis C post transfusion. The Lookback that can achieve that does not exist. There are limitations with every form of Lookback that you undertake.⁹

6.9 The ARCBS identified a number of problems with the Lookback process. For instance, donor triggered Lookback may not be possible because:

4 *Committee Hansard* 7.4.04, p.2.

5 *Committee Hansard* 6.4.04, p.31; *Submission* 79, Reference E, p.1 (TBPAG).

6 *Committee Hansard* 6.4.04, p.27 (TBPAG); *Submissions* 3, p.2; 33, p.2.

7 *Committee Hansard* 6.4.04, p.21 (TBPAG).

8 *Committee Hansard* 7.4.04, p.39 (ARCBS).

9 *Committee Hansard* 7.4.04, p.69 (ARCBS).

- a large proportion of blood comes from the 10 per cent of donors who only ever donate once and, as they have not re-presented for a donation and been retested by the ARCBS after the introduction of screening, their hepatitis C status is not known to ARCBS;
- even though the donation may be traced to a particular hospital, it may not be possible for the hospital to link the donation to a particular patient as records may have been lost or destroyed, or patients may have moved and be uncontactable; and
- doctors may choose not to contact or test patients particularly if they are very elderly or terminally ill.

From international experience, only about one third of infected recipients are located using donor triggered Lookback.

6.10 There are also limitations to recipient triggered Lookback:

- many cases are not reported to the ARCBS as notification to the ARCBS is not compulsory;
- as with finding recipients, donors may have moved and be uncontactable or may be now deceased and therefore unable to be tested; and
- in many cases the recipient has received hundreds of blood products, particularly in the case of cancer or trauma patients, and the task of finding and testing all the donors is enormous and often impossible.

The ARCBS stated:

So clearly the lookback program can never be complete and there have been limitations to the programs in Australia. ARCBS is concerned that although in our submission we identified 2050 recipients, there are others who have not and cannot currently be found. ARCBS has however, pursued all cases as well as it has been able. That said, the lookback experience in Australia has the same difficulties as experienced in other countries and in fact, commenced well before many other countries, notably the USA which did not decide to commence lookback programs until 1998.¹⁰

6.11 The ARCBS emphasised that the Lookback process is 'a complex one and involves a number of key stakeholders. ARCBS must work together with these stakeholders (eg. hospitals for patient and transfusion records, tracing agencies) in order to ensure the process is successful'. In addition, the Lookback program varies in each State and Territory as Lookback was developed separately in each jurisdiction prior to the establishment of the ARCBS as a national organisation in 1996. As a result, the role of the Red Cross was and remains different in each program.¹¹

10 *Submission 64*, Submission prepared for hearing 7.4.04, p.17 (ARCBS).

11 *Submission 64*, p.88 (ARCBS).

6.12 The ARCBS also noted that the recommendation of a working party report to the Commonwealth Diseases Standing Committee on the National Health and Medical Research Council in 1991 was that only 'recipient (cases) triggered lookback' should be undertaken as other forms of lookback were too expensive and inefficient. The ARCBS indicated that it was not until a further application by the ARCBS that it was agreed by Health Ministers in December 1994 that donor triggered lookback would be undertaken. Funding for the program was only received from 1995 and the ARCBS stated that 'lookback programs were, by necessity, limited by resources available prior to this time'.¹²

6.13 The ARCBS concluded:

I think it is very important to resolve any confusion there may be about our ability to quickly identify recipients of blood or blood products once we know the donor. We do not have that capacity. We can identify the unit. We can then notify the hospital, but the Australian Red Cross Blood Service does not have the ability to instantly or even quickly identify once we know of a possible infective donor unit who the recipients of that unit were.¹³

6.14 The ARCBS indicated that it is attempting to harmonise the activity of all stakeholders involved with the Lookback process, and it strongly supported the replacement of individual State and Territory Lookback programs with a single Australian Lookback system.¹⁴

6.15 In relation to the suggestions for contacting all those who received blood transfusions prior to 1990 (universal Lookback), the ARCBS pointed to an extract from a National Health and Medical Research Council (NHMRC) paper on the difficulties of Lookback, including universal Lookback.¹⁵ The NHMRC paper considered the recommendations of the 1991 working party report 'in the light of improved knowledge of the epidemiology of hepatitis C and developments in diagnostic technology since then'. It went on to state:

Universal Lookback has not been conducted, ie, offering HCV screening to anyone who received a transfusion in the past. Although this may in principle provide a better indication of the number of people in the community with anti-HCV, it is unlikely that such a goal could be achieved. Based on experience in other settings, it is believed that it would be possible to contact only a proportion of those at risk, of which only a fraction will present for screening. Conversely, it is probable, especially if a publicity campaign is mounted, that many who are not at risk will present for testing. This would include, for example, people who had at some time been hospital inpatients. For these reasons, at this point in time, universal

12 *Submission 64*, Submission prepared for hearing, 7.4.04, p.17 (ARCBS).

13 *Committee Hansard 7.4.04*, p.70 (ARCBS).

14 *Submission 64*, p.88 (ARCBS).

15 NHMRC, *Report on the Epidemiology, Natural History and Control of Hepatitis C*, Nov 1993, pp.18-20.

lookback was regarded as ineffective as a public health measure in the control of hepatitis C.¹⁶

6.16 However, the ARCBS suggested to the Committee that if universal Lookback was to be further explored:

it would be worth focusing on younger patients transfused in the 1980's, or to give consideration to patients who were under a certain age when they were transfused. Unlike the majority of transfusion patients who were quite elderly when transfused, younger patients would be much more likely to be alive today. They may have experienced the burden of (perhaps undiagnosed) disease for a considerable part of their life. They would be likely to both qualify for treatment and be able benefit from treatment once diagnosed.¹⁷

6.17 The ARCBS also suggested that consideration be given to mandatory reporting to the ARCBS by medical practitioners or health care professionals of suspected transfusion transmitted cases of hepatitis C to enable more timely tracing and adequate support of those affected.

Conclusion

6.18 The Committee considers that it is imperative that an effective Lookback program is in place. Early identification and notification of recipients of contaminated blood and blood products ensures that they can seek treatment at the earliest opportunity and in so doing gain the maximum benefit from that treatment. Those people infected, whether notified through donor or recipient triggered Lookback, also need to receive information about HCV so that those exposed to HCV can be advised on ways to minimise the risk of passing the virus on to others. Many witnesses to the inquiry were very distressed that, because they were not diagnosed with the virus for some time, they may have inadvertently passed the virus on to others. It is also important that affected recipients have access to counselling, as hepatitis C can have a devastating impact on lifestyle, relationships and employment.

6.19 The Lookback program has identified many of those who have received blood contaminated with the hepatitis C virus. The Committee has also noted the time and effort put into searching through records by the ARCBS and hospital staff, particularly where records are old and incomplete. The Committee considers that to undertake a universal Lookback program would be logistically very difficult and there are doubts about its effectiveness, and that a more effective mechanism would be through the more specifically targeted education campaign undertaken on a wider scale.

6.20 The Committee also considers that mandatory reporting to the ARCBS by medical practitioners or health care professionals of suspected transfusion transmitted

16 *Submission 64*, Responses to questions, p.4 (ARCBS).

17 *Submission 64*, Submission prepared for hearing 7.4.04, p.21 (ARCBS).

cases of hepatitis C would improve tracing of contaminated blood and enable adequate support to be provided to those affected.

Recommendation 1

6.21 That the Australian Health Ministers' Advisory Council consider the introduction of mandatory reporting to the Australian Red Cross Blood Service by State and Territory health authorities of instances where a person is diagnosed with hepatitis C and it is judged that the infection was contracted through the blood supply.

Haemovigilance strategy

6.22 In order to ensure the safety and high quality of blood and blood products, the ARCBS recommended to the Committee that a national government sponsored haemovigilance system be established in Australia.¹⁸ The Australian and New Zealand Society of Blood Transfusion also supported the introduction of a national program.¹⁹

6.23 A haemovigilance system would collect information on complications arising from blood transfusions. The ARCBS indicated that 'such a system linking all hospitals with ARCBS would provide valuable data to detect hepatitis C transmission, other emerging blood borne infectious diseases and other non-infectious complications of blood transfusion. This would ultimately enable us to maximise patient safety and care for the longer term.'²⁰

6.24 The development of a haemovigilance system for Australia has been considered in a number of reviews. In 1997 a Haemovigilance Working Party was formed to advise on the development and implementation of a national haemovigilance system. The working party was composed of representatives from the ARCBS, the Australasian Society of Blood Transfusion, CSL Bioplasma and the National Centre for Epidemiology and Population Health.²¹

6.25 The 1999 review into the infection of a patient with HIV after a blood transfusion at Melbourne's Royal Children's Hospital by Professor Richard Smallwood also supported the establishment of a national haemovigilance system.²² The Review of the Australian Blood Banking and Plasma Product Sector (Stephen Review) examined the role of haemovigilance. The Stephen Review recommended the

18 *Submission* 64, Submission prepared for hearing 7.4.04, p.20 (ARCBS).

19 *Submission* 71, p.2 (ANZSBT).

20 *Committee Hansard* 7.4.04, pp.40,70 (ARCBS).

21 Stephen, Sir N, *Review of the Australian Blood Banking and Plasma Product Sector*, Department of Health and Aged Care, 2001, p.124.

22 Ministerial Inquiry conducted by Professor Richard Smallwood into the transmission of Human Immuno Deficiency Virus (HIV) to a recipient of a homologous blood donation at the Royal Children's Hospital, Melbourne in December 1998. Media release, Minister for Health, Mr J Thwaites, 9.12.99.

establishment of a national haemovigilance scheme to monitor untoward transfusion-related events and outcomes in hospitals, as a priority, with the purpose of identifying contributory factors; providing feedback to enable clinical practice and product improvement and providing data to place Australian transfusion risks in perspective. The Review further recommended that the scheme be developed as part of the national approach to improving patient safety led by the Australian Council for Safety and Quality in Health Care (ACSQHC). It was also recommended that the Council, with the National Blood Authority, provide Australian Health Ministers with a detailed plan for the scheme.²³

6.26 The Department of Health and Ageing (DoHA) stated that the Jurisdictional Blood Committee had considered organised options for a national haemovigilance system. As a result:

Given the on-going work by the Australian Council for Safety and Quality in Health Care (ACSQHC) and others to improve patient safety in the health care sector, the JBC [Jurisdictional Blood Committee] determined that there was further work to be done on drawing together the lessons to be learned from existing Australian safety and quality initiatives. Accordingly, work is under way with the ACSQHC to synthesise information from these initiatives...²⁴

Conclusion

6.27 The Committee notes that the Stephen Review recommended in 2001 that a national haemovigilance system be established as a priority. Work toward a national haemovigilance system is presently being undertaken by the Australian Council for Safety and Quality in Health Care and the National Blood Authority. However, the Committee considers that there is an urgent need for a national haemovigilance system to be implemented. A national haemovigilance system would be an important component of the overall quality assurance strategy of the health sector, would improve patient safety and would ensure continued public confidence in the blood supply in Australia.

Recommendation 2

6.28 That, in order to ensure the safety of patients and continued confidence in the blood supply, the Australian Council for Safety and Quality in Health Care and the National Blood Authority implement, as a matter of priority, a national haemovigilance system.

Government services

6.29 The Commonwealth Department of Health and Ageing (DoHA) collaborates with State and Territory Governments and community-based organisations in a

23 Stephen Review, pp.124-27.

24 *Submission 54*, Additional Information, 25.5.04 (DoHA).

national response to hepatitis C. This focuses on prevention of HCV transmission and increasing access by people living with hepatitis C to treatment, care and support services.

6.30 The delivery of health services through hospitals, health promotion, and care and support services provided by public and community-based organisations for people affected by hepatitis C are the responsibility of State and Territory Governments.

National Hepatitis C Strategy

6.31 By the mid 1990s the extent of hepatitis C infection in Australia was raising alarm. In response, the *National Hepatitis C Strategy 1999-2000 to 2003-2004* was launched in June 2000. The Strategy provides a comprehensive framework for national action to address hepatitis C. It is based on the approach taken to management and response to HIV/AIDS in Australia. The Strategy promotes and supports the health, safety and well-being of all Australians in relation to hepatitis C, both those infected and those affected. The two primary aims of the Strategy are to reduce transmission of hepatitis C in Australia and to minimise the personal and social impacts of hepatitis C infection. The four priority areas for action identified in the Strategy are:

- reducing hepatitis C transmission in the community;
- treatment of hepatitis C infection;
- health maintenance, care and support for people affected by hepatitis C; and
- preventing discrimination and reducing stigma and isolation.

6.32 The Strategy is based on six components that are considered fundamental to developing effective responses in the four priority areas. These components are:

- developing partnerships and involving affected communities;
- access and equity;
- harm reduction;
- health promotion;
- research and surveillance; and
- linked strategies and infrastructures.²⁵

6.33 DoHA reported that the Strategy is not a funding initiative. It is a comprehensive framework to guide Australia's response to hepatitis C.²⁶

25 *Submission 54*, pp.20-21 (DoHA).

26 *Submission 54*, Additional Information, 26.5.04, p.3 (DoHA).

6.34 The National Strategy was independently reviewed in 2002.²⁷ The Department noted that the review acknowledged that the Strategy had established a good foundation for action and has contributed to an increased awareness of hepatitis C as a serious public health problem.²⁸

6.35 However, the Australian Hepatitis Council (AHC) commented that no funding has been identified for the specific implementation of the strategy and resourcing for hepatitis C interventions from all levels of government is insufficient.²⁹

6.36 In relation to the review of the Strategy, the Australian Hepatitis Council stated that the review also found that implementation was constrained.³⁰ The review pointed to serious constraints to implementation including:

- lack of resources for implementation;
- absence of an implementation plan and performance indicators for monitoring it;
- failure to grapple with the complexities of treatment and care;
- inadequate research; and
- rudimentary surveillance.

6.37 In relation to lack of resources, the review stated that:

Commonwealth program funding for hepatitis C has been limited. The states and territories and the non-government and community sector are largely dependent on limited resources from the Commonwealth to contribute to the development of an effective national response to the epidemic.

Hepatitis C is not one of the strategies or programs covered by the PHOFAs [Public Health Outcome Funding Agreements].³¹ These Agreements contribute to the national population health effort by providing broadbanded Commonwealth funding to state and territory governments to support nominated population health strategies and programs.

27 Levy M, Baum F & Thomas H, *Review of the National Hepatitis C Strategies: A Road Not Taken*, July 2002.

28 *Submission 54*, p.21 (DoHA).

29 *Submission 75*, p.1 (AHC).

30 *Committee Hansard 1.4.04*, p.14; *Submission 75*, p.9 (AHC).

31 The PHOFAs are bilateral funding agreements between the Commonwealth and each State and Territory which provide broadbanded and special purpose funding from the Commonwealth to the States and Territories for a range of public health programs. These programs include the National Drug Strategy; National HIV/AIDS Strategy; National Immunisation Program and BreastScreen Australia.

In relation to treatment and care, the review pointed to the stringent eligibility criteria of S100 arrangements (Highly Specialised Drugs Program) and limited models of care.³²

6.38 Recommendations of the review included that:

- new governance structures be developed to support the national response to hepatitis C;
- equitable, sustained funding be provided to develop and implement an effective response to hepatitis C in Australia at all levels – federal, state and territory, local government and the non-government and community sector;
- the Commonwealth support a national hepatitis C public awareness campaign to increase knowledge of and reduce the stigma associated with hepatitis C infection;
- new research be commissioned including research into the treatment, care, support and costs for people affected by hepatitis C; and
- awareness of the availability and efficacy of hepatitis C treatments be increased by targeted information provision through primary care physicians, specialist liver clinics and needle and syringe programs.³³

6.39 The review concluded:

A second National Hepatitis C Strategy is essential for dealing with the hepatitis C epidemic in Australia.

The Strategy must be supported by effective partnerships, strong governance structures, equitable resource allocation, legislative and regulatory reform, committed professional action, and community advocacy...With hepatitis C, Australia has an opportunity to seize international recognition for its strong political leadership and innovation – just as it did in a previous century with HIV/AIDS.³⁴

6.40 ARCBS pointed to the review's finding that 'while Australia has had considerable success in tackling hepatitis C, there is a need for an invigorated and innovative approach to prevention of further cases and to counselling, treatment and care activities'.³⁵

6.41 DoHA stated that following the review of the Strategy, the Commonwealth announced that a second National Hepatitis C Strategy would be developed in consultation with all stakeholders and under the guidance of a new ministerial advisory body. The second Strategy will take into account priority areas for action

32 *Review of the National Hepatitis C Strategies*, p.85.

33 *Review of the National Hepatitis C Strategies*, pp.86-92.

34 *Review of the National Hepatitis C Strategies*, p.92.

35 *Submission 64*, p.72 (ARCBS).

identified through the review process and emerging needs identified in consultation with key stakeholders. The current Strategy expires in June 2004.³⁶

Health maintenance, care and support services

6.42 The Commonwealth funds a range of services available to a wide range of service providers including general practitioners, haemophilia foundations, Aboriginal and Torres Strait Islander primary health care services and specialist health services for people from culturally and linguistically diverse backgrounds.³⁷

6.43 For people with hepatitis C, making choices about antiviral therapy is assisted by targeted information and education resources produced with Commonwealth funding. The Department provided the following examples:

- *Contact 01: post-test information for hepatitis C* produced by the Australian Hepatitis Council. This booklet, designed for people who have been recently diagnosed with hepatitis C, provides important referral information. It has been distributed nationally through Hepatitis C Councils.
- The *National Hepatitis C Resource Manual*, produced by the Australian Institute for Primary Care at La Trobe University. The Manual is a concise source of standardised information for health care workers who provide services to people affected by hepatitis C.³⁸

6.44 Funding of treatments and investigations is provided through the Pharmaceutical Benefits Scheme (PBS) and the Pathology Services Table of the Medicare Benefits Schedule (MBS). The hepatitis C antibody test may be reimbursed under the MBS. Qualitative nucleic acid testing which provides a measure of viral load can be reimbursed within certain criteria.

6.45 In 2002-03, the Commonwealth provided \$16.7 million for the treatment of hepatitis C through the section 100 arrangements (Highly Specialised Drugs Program) under the PBS. In 2003-04, the cost of treatment for hepatitis C through the Program was estimated to increase to \$24.6 million, following approval of S100 listing for pegylated interferon from 1 November 2003.³⁹ The two new Medicare safety nets introduced in 2004 may assist some people with out-of-pocket, out-of-hospital medical costs.

6.46 The Commonwealth also provides funding to increase access to a wider range of services for people with hepatitis C including funding for the Education and Prevention Initiative announced in the 1999-2000 Federal Budget. Of the \$12.4 million over four years, \$6.6 million was allocated to State and Territory Governments

36 *Submission 54*, p.21 (DoHA).

37 *Submission 54*, p.21 (DoHA).

38 *Submission 54*, p.22 (DoHA).

39 *Submission 54*, p.23 (DoHA).

to develop and implement hepatitis C education and prevention programs. The remaining \$5.8 million was allocated to national hepatitis C education and prevention activities administered by DoHA. In the 2003-04 Federal Budget, the Government allocated funding to continue the Initiative. A total of \$15.9 million was allocated over four years, of which \$8.8 million will go to the State and Territory Governments and the remaining \$7.1 million will be allocated to national activities to be administered by DoHA.⁴⁰

6.47 Some national projects funded through this Initiative include:

- National Centre in HIV Epidemiology and Clinical Research (NCHECR) – *Surveillance of the long-term outcomes of chronic HCV infection*. These data will be used for research into the long-term outcomes of hepatitis C virus-related liver disease by using a longitudinal study of people with hepatitis C infection attending both primary care and hospital-based clinics.
- Australasian Society of HIV Medicine – *General Practitioner Education and Training* project, which aimed to provide training for GPs in relation to hepatitis C, as well as encourage medical training providers to expand their curricula to include hepatitis C and hepatitis C-related issues.
- Multicultural HIV/AIDS and Hepatitis Service – *Ethnic Media Campaign* which aimed to increase awareness of hepatitis C among people from culturally and linguistically diverse backgrounds.

6.48 Activities implemented by the States and Territories under the initiative include hepatitis C education for general practitioners (Victoria); rural/remote education and prevention pilot (South Australia) and hepatitis C information services (Tasmania).⁴¹

6.49 The Committee considers that many of the programs funded under the Budget Initiative appear to be used for the identification and management of hepatitis C rather than for education and prevention. The Committee considers that funding for such programs should be provided from the funding allocations provided to the professional medical organisations including the Divisions of General Practice and specialist colleges. The Committee further considers that public 'education and awareness' should be funded through this initiative and should be based on a broad campaign including the electronic and print media and a letter campaign to households. The implementation of an education and awareness campaign is discussed later in this chapter.

Organisations supporting those with hepatitis C

6.50 There are a number of support groups which provide assistance to those infected with hepatitis C. These groups provide a range of support services which

40 *Submission 54*, Additional Information, 26.5.04, p.3 (DoHA).

41 *Submission 54*, p.23; Additional Information, 1.6.04, p.2 (DoHA).

make a significant difference to the impact of hepatitis C on individuals. Services include counselling, information and advocacy.

Australian Hepatitis Council and State and Territory Councils

6.51 The Australian Hepatitis Council and the State and Territory Hepatitis Councils provide a range of services to people with hepatitis C including information, support, advocacy and representation. These organisations form a fundamental part of the national partnership response to hepatitis C.

6.52 The vision of the Australian Hepatitis Council is for:

- all people with hepatitis C and other chronic viral hepatitis reaching their potential;
- communities affected by hepatitis being valued and free from discrimination; and
- a society free from new infections of hepatitis C and other chronic viral hepatitis.

6.53 The Australian Hepatitis Council indicated that it and its members work in partnership with a range of agencies including community based agencies such as peer based injecting drug user groups, organisations representing people with haemophilia and Indigenous health services. In addition, the Council works with government at all levels, as well as research agencies such as the National Centre in HIV Epidemiology and Clinical Research, the National Centre in HIV Social Research and the Australasian Society of HIV Medicine.

6.54 The AHC considered that the hepatitis councils play a pivotal role in the provision of health maintenance and monitoring information to people with hepatitis C through a series of strategies. These include the development of resources, the provision of telephone information services, the facilitation of support and information groups, capacity building, particularly in the health care sector, and through websites and newsletters. However, it stated that the resources available to do this work are limited.⁴²

Haemophilia Foundation Australia

6.55 The Haemophilia Foundation Australia (HFA) is the primary agency supporting those with haemophilia, von Willebrand Disorder and relating bleeding disorders. Most services and activities are funded by donations, however the secretariat is funded by DoHA. Its primary objectives are to represent people affected by bleeding disorders through advocacy, education and the promotion of research. HFA is governed by a Council of delegates from State/Territory Haemophilia Foundations.

42 *Submission 75*, p.14 (AHC).

Traids

6.56 Traids is a NSW Health agency established in 1986 with a specific charter of providing support and advocacy for people with medically acquired HIV/AIDS and their families. Responsibility was subsequently extended to include people with medically acquired hepatitis C.

6.57 Traids services are available to residents across NSW. Services include counselling, information and support at its centre, by telephone, in homes and in hospital. The service facilitates support and information groups for people living with HIV and HCV. Traids also provides advocacy for its clients, liaison with medical practitioners and other health care workers for the benefit of clients and support to access travel and accommodation assistance for specialist and hospital treatment.⁴³

Tainted Blood Product Action Group

6.58 The Tainted Blood Product Action Group is a voluntary organisation which advocates special assistance for people injured by faulty blood products and transfusions in Australia. The TBPAG encourages people affected by tainted blood products to support one another.⁴⁴

Health services for those living with hepatitis C

Access to antiviral treatment

6.59 The Australian Hepatitis Council stated that 'Australia now has a world class standard of hepatitis C treatment, which unlike in many other countries, is fully funded by the Pharmaceutical Benefits Scheme subject to criteria'.⁴⁵ For those accessing treatment, combination therapy with pegylated interferon and ribavirin are now available. The Hepatitis C Council of NSW pointed to the benefits of combination therapy:

Success is measured in terms of sustained viral response, which for many people is a cure for their hepatitis C infection. It is total viral clearance...people who have a sustained viral response, if they do not have cirrhosis to start with, are in fact cured. Those people who have cirrhosis and who have successful treatment can go on to develop liver cancer or liver failure, even though the virus is not present in their bloodstream, but that is in a small percentage of cases. So we are confident as a community organisation in talking about cure for people with hepatitis C in certain circumstances.⁴⁶

43 *Submission 83*, pp.1-2 (Traids).

44 www.taintedbloodnetwork.com

45 *Submission 75*, p.7 (AHC).

46 *Committee Hansard 6.4.04*, p.7 (Hepatitis C Council of NSW).

6.60 However, the widespread uptake of antiviral treatment has not been without problems. Some barriers to uptake include:

- meeting section 100 criteria;
- public hospital waiting lists;
- lack of treatment services in rural and remote areas;
- lack of knowledge about antiviral treatment amongst general practitioners and people with hepatitis C;
- concerns around treatment side effects, particularly depression;
- lack of personal resources to support a significant period of ill health;
- disclosure issues when side effects are visible or people need to negotiate considerations in their workplace; and
- lack of culturally appropriate support for Aboriginal and Torres Strait Islanders and people from culturally and linguistically diverse communities.⁴⁷

6.61 In evidence, the AHC commented on the restrictive nature of the S100 criteria:

Obviously, the government are trying to target those people who will go on to have serious liver disease and they are trying to target those quite expensive treatments to those people. Basically, S100 criteria mean that you have to have a fibrosis score of one or two on a scale of one to four before you can access those treatments. A lot of people would like to access treatment for reasons apart from liver disease. Also, if you are suffering debilitating symptoms you may not have a high fibrosis score but you are still suffering significant effects from having the virus.⁴⁸

6.62 Witnesses stated that they were fearful of having a liver biopsy and that the procedure had its own morbidity and mortality.⁴⁹ The Review of the Hepatitis C Strategy also noted that many people are not eligible for treatment with some people not choosing to be treated.⁵⁰

6.63 Other witnesses recommended the extension of treatment with the HFA stating that full and unhindered access to free hepatitis C treatment should be made available irrespective of genotype and previous treatment outcomes.⁵¹ The Australian Haemophilia Centre Directors Organisation stated that while there have been recent changes which allow easier access to antiviral agents to treat hepatitis C, wider and

47 *Submission 75*, pp.7-8 (AHC).

48 *Committee Hansard 1.4.04*, p.21 (AHC).

49 *Committee Hansard 6.4.04*, p.13 (Traids); *Committee Hansard 6.4.04*, p.90 (Prof McCaughan).

50 *Review of the National Hepatitis C Strategies* p.116.

51 *Submission 82*, p.37 (HFA).

easier access to these treatments should be made available.⁵² The ARCBS also supported and recommended expediting consideration of, and access to, anti-hepatitis C drugs for Australian patients.⁵³

6.64 The DoHA commented that:

Improving treatments and widening their availability, as well as identifying the groups that are most suitable for treatment, are central to the response to hepatitis C infection in Australia. The primary goals of treatment are to eradicate the hepatitis C virus and prevent development of decompensated liver disease (scarring throughout the liver that gets progressively worse).⁵⁴

6.65 The Committee considers that it is imperative that as many people as possible who are suffering with hepatitis C have access to S100 drugs as soon as clinical evidence indicates that such treatment would be beneficial. The evidence suggests that the present criteria for access to S100 drugs is too restrictive and the need to undertake a liver biopsy may be discouraging people from undertaking treatment.

Recommendation 3

6.66 That the Commonwealth review the criteria access to S100 drugs for those people suffering from hepatitis C to provide for greater access.

Service delivery

6.67 During the inquiry there were a number of comments concerning the adequacy of service delivery to those infected with hepatitis C. These comments ranged from the availability of specialist clinics to information available from general practitioners and poor co-ordination of services in the health sector.

6.68 Subsidised antiviral treatment of hepatitis has been restricted to specialists in hospital settings. DoHA indicated that people who have acquired hepatitis C through blood transfusion (together with those who have acquired the infection through other means) have good access to treatments through liver clinics.⁵⁵

6.69 However, the Australian Hepatitis Council commented that 'the ability of healthcare infrastructures to provide the full range of treatment services to those who qualify for treatment is in doubt'. Extensive hospital waiting lists in some States mean that a person with hepatitis C may wait up to two years for assessment at a gastroenterology unit from the time of initial referral.⁵⁶

52 *Submission 72*, p.3 (AHDCO).

53 *Submission 62*, Submission prepared for hearing, 7.4.04, p.20 (ARCBS).

54 *Submission 54*, p.22 (DoHA).

55 *Submission 54*, p.22 (DoHA).

56 *Submission 75*, p.12 (AHC).

6.70 The AHC argued that an expansion of S100 prescribing into general practice would relieve some of the pressure on gastroenterology services to meet the demand for treatment, particularly in regional areas where no specialist gastroenterology services currently exist. This expanded framework would facilitate greater S100 availability, particularly in rural areas, and may encourage people who prefer to visit specific general practitioners to more fully consider their treatment options.⁵⁷

6.71 In early 2003, a pilot program for general practitioner S100 prescribing commenced in NSW, Victoria and the ACT. The pilot is conducted by the Australasian Society for HIV Medicine, funded by NSW, Victorian and ACT Departments of Health and approved by the Highly Specialised Drug Working Party. The Australian Society for HIV Medicine indicated that to date approximately 100 general practitioners had been trained and had entered the program.⁵⁸

6.72 Professor McCaughan pointed to shortages in the number of nurses required to manage patients with chronic hepatitis C. He noted that:

Many of these patients in treatment assessment and management during the treatment with interferon, which has quite a lot of side-effects, require quite intensive nursing hours, and there is certainly a limitation on the number of nurses who are experienced in that area. Many of these patients also require mental health services, drug and alcohol services and access to those services in a multidisciplinary team, which we try to run at our hospital. It certainly puts a lot of pressure on those services. I know that across Australia there are significant deficiencies in access to those areas of care.⁵⁹

6.73 Access to services for those living in rural and regional areas can also be difficult because of distance and expense involved.

6.74 Witnesses also pointed to the need to improve the co-ordination of services for those with hepatitis C. The Hepatitis C Council of NSW pointed to the lack of resources and disputes between the Commonwealth and States over funding for services on the ground – 'one blames the other, and it is community health and it is the public that suffers'.⁶⁰ The HFA was concerned about the lack of co-ordination of services between haemophilia treatment centres and those centres providing hepatitis C care. The HFA stated:

In proactive centres, patients would be referred to liver clinics and their hepatitis C would be monitored and probably well cared for. People would be given good education and would know how to respond to things that might be happening to them, they would get good advice and counselling

57 *Submission 75*, p.12 (AHC).

58 Personal communication with the Committee, Australian Society for HIV Medicine.

59 *Committee Hansard* 6.4.04, p.92 (Prof McCaughan).

60 *Committee Hansard* 6.4.04, p.10 (Hepatitis C Council of NSW).

about accessing treatments and when to have those treatments et cetera, but others would not. So there is some inconsistency in that respect.⁶¹

6.75 There was much comment in evidence concerning the adequacy of treatment provided by general practitioners. The AHC noted that general practitioners are often ill-equipped to offer appropriate information, support or referrals to people with hepatitis C.⁶² The AHC stated that:

...there are a lot of doctors who did their training a long time ago. Doctors, like anyone, reflect community values, and there has been general misinformation about hepatitis C. Certainly, a lot of work on the Hepatitis Council phone lines is around correcting misinformation that people have. There are a number of horror stories about what people have been advised in terms of getting a diagnosis. So there are still very poor practices around pre and post test counselling for people with hepatitis C when they are diagnosed.⁶³

6.76 Witnesses pointed out that for those receiving a diagnosis of hepatitis C, it is doubly traumatic if adequate information is not provided or the diagnosis is communicated poorly. However, the AHC noted that 'many people with hepatitis C report poor practices amongst general practitioners in providing a hepatitis C diagnosis'. There is a lack of knowledge, lack of communication skills and judgemental attitudes. This statement was borne out in evidence:

The lack of knowledge with regards to this disease is appalling to say the least. Most Hep "C" sufferers know more about their disease than the Medical professionals who are treating them. This is because we research this disease constantly. The Internet is a vast source of information including the latest medical studies and treatments. It can supply facts on the disease, side effects of the latest treatments and can correct the misinformation, which the Australian Medical Profession is currently handing out as fact...All of the above shows to me a sad lack of knowledge of this disease in all of areas of the Medical profession, Blood bank operators and the Health Departments.⁶⁴

Another witness stated:

The virus was only identified then and there was not very much knowledge. I had the virus for 10 years and, with the virus, I saw the same doctor for 10 years. He gave me virtually no information. To be fair to my doctor, he is a very knowledgeable doctor but in the hep C field he did not know very much at all. So, for 10 years, I carried this alone and isolated. I did not tell anyone in my family about it – I did not know much to tell other people about it. Whenever I went to my doctor for information, I would have a

61 *Committee Hansard* 5.4.05, p.16 (HFA).

62 *Submission* 75, p.5 (AHC).

63 *Committee Hansard* 1.4.04, p.15 (AHC).

64 *Submission* 8, pp.1-2.

liver function test – once a year – which was close to normal. He would say, ‘If it gets any worse, we’ll look at treatment; if not, you’re right.’ I had symptoms during those 10 years, and often I would say to my doctor, ‘Could it be the hep C virus?’ and he would just dismiss it and invalidate it.⁶⁵

6.77 Organisations noted that knowledge within general practice has improved but ‘they have a long way to go yet’.⁶⁶ The Review of the National Hepatitis C Strategy stated that:

Levels of professional education and training being undertaken at the national and state and territory levels are inadequate. Undergraduate training for medical and nursing students needs to be strengthened. Given the projected burden of hepatitis-C related disease, and the identified need to expand service delivery and models of care, it is critical that more resources are allocated to professional education and training at all levels.⁶⁷

6.78 One problem is the amount of information that general practitioners receive and as noted by Traids, if the professional is not dealing with the particular problem on a regular basis, it is difficult to retain adequate information levels.⁶⁸ In order to ensure that hepatitis C sufferers can obtain adequate care, hepatitis councils keep GP-friendly lists so they try to have available those doctors who have a good knowledge about hepatitis C and who are willing to see people with hepatitis C.⁶⁹

6.79 The Commonwealth also provides funds to the Australasian Society for HIV Medicine which provides education programs specifically for medical personnel, including general practitioners.⁷⁰

Support services for those with hepatitis C

6.80 Those suffering from hepatitis C require personal and medical support to manage their condition. Support is particularly important when undertaking treatment as the side effects, including depression, can be particularly debilitating. Support services can be particularly valuable in providing information. Australian Hepatitis Council stated in evidence:

People with hepatitis C need: access to correct current information so that they can make informed choices about their health; access to supportive, non-judgmental health care services to assist them to manage the physical and psychological impacts of hepatitis C; and access to the best available

65 *Committee Hansard* 6.4.04, p.12 (Traids).

66 *Committee Hansard* 6.4.05, p.10 (Hepatitis C Council of NSW).

67 *Review of the National Hepatitis C Strategies*, p.103.

68 *Committee Hansard* 6.4.04, p.14 (Traids).

69 *Committee Hansard* 1.4.04, p.15 (AHC).

70 *Committee Hansard* 1.4.04, p.32 (DoHA).

treatments to give them the optimal chance of clearing the virus, as well as a society that is much better informed and less fearful about hepatitis C. Obviously, there are many challenges in achieving these outcomes.⁷¹

6.81 Support is provided through specialist support groups including the hepatitis councils, the HFA and Traids. One witness indicated the benefits of support groups:

The support group is very important to me, because since mixing with other people with the virus I have found that all these symptoms that I had for a long time before I was treated for it were very real. Lack of information, invalidation, dismissal, carrying it alone and not telling my family – it would have been very nice to have had the information.⁷²

6.82 Unfortunately, support services are not always accessed by those who need them. Traids stated that people outside the health care system were not always aware that services that are available.⁷³

6.83 The Hepatitis C Council of NSW suggested that one problem is the lack of compulsory pre-and post test counselling. Counselling would provide people with information and assist them in relation to their diagnosis.⁷⁴ Counselling is also beneficial to those suffering depression and those undergoing treatment. The Triads Support Group stated:

Some patients experience significant depression. Counselling is possibly the only course of treatment, if they can't tolerate the combination therapy available to date. This type of support is very expensive if sought privately, and of very limited duration through Community Health Centres.⁷⁵

One witness undergoing treatment stated that she needed counselling and saw a psychologist on a weekly basis.⁷⁶

6.84 Many witnesses pointed to the cost of undertaking treatment and suggested the need for additional support. One witness indicated that whilst on treatment, the costs were about \$2,500 per month. This included visits to doctors and medication such as sleeping tablets.⁷⁷ The Traids Support Group stated that the cost of services associated with the disease can be exorbitant and 'some people just give up because they can't afford it'.⁷⁸ Many people with hepatitis C find alternative medicines of benefit. Traids stated:

71 *Committee Hansard* 1.4.04, p.14 (Australian Hepatitis Council).

72 *Committee Hansard* 6.4.04, p.12 (Traids).

73 *Committee Hansard* 6.4.04, p.12 (Traids).

74 *Committee Hansard* 6.4.04, p.10 (Hepatitis C Council of NSW).

75 *Submission* 84, p.1 (Traids Support Group).

76 *Committee Hansard* 6.4.04, p.12.

77 *Committee Hansard* 5.4.04, p.21 (HFA).

78 *Submission* 84, p.3 (Traids Support Group).

Some of the herbs have been found to ease some of the symptoms. Increasingly, when people find that the treatment is not going to work for them they seek alternatives to orthodox medicine.⁷⁹

This can add significantly to the costs of people with hepatitis C.

6.85 Witnesses noted that it was not only the cost of treatment but the impact on earning capacity. Those undergoing treatment may have to decrease their workload or give up work completely. The HFA stated:

An example is that at the moment some people who are having hepatitis C treatment are paying for scripts. They are actually having to take time off work and lose pay to have their treatment, but they are also having to pay for some of their medications. That is just one example of why it is difficult and why we are asking for free and universal treatment.⁸⁰

And:

There is a great need for support. Our people suffer in many ways: reduced wage earning capacity, dependency upon pensions and benefits, increased health care costs – even a health care card would be some help to some people – reduced capacity to complete education, complex treatments and side effects, and difficulties with social relationships and discrimination. There is a great need for financial assistance. People were infected with hepatitis C in the same way as those infected with HIV. A government trust was set up for people with HIV, but there has been no such financial assistance for people with hepatitis C. Governments and others have a moral responsibility to address the widespread financial impact on people with haemophilia who were let down by the very blood system which was meant to improve their health. For many, the system has caused them great harm. For some, it has resulted in death.⁸¹

6.86 In other evidence, witnesses suggested a range of other services that would be useful to those suffering from hepatitis C acquired through blood transfusion. As those with hepatitis C often suffer from debilitating fatigue, many pointed to the need for help within the home. Others also supported access to home nursing services and out-reach home visiting services. Help in the home was of particular concern for single people who did not always have other family members on hand to assist them.

6.87 Assistance with travel costs was also highlighted. As specialist liver clinics and haemophilia centres are located in capital cities and major centres, people in regional areas must travel to access services. Those on treatment with S100 drugs

79 *Committee Hansard* 6.4.04, p.15 (Traids).

80 *Committee Hansard* 5.4.05, pp.12-13 (HFA).

81 *Committee Hansard* 5.4.04, p.8 (HFA).

generally can only access specialists in larger centres. This adds to treatment costs. If accommodation costs are added the total cost may be substantially higher.⁸²

Need for further research

6.88 Witnesses to the inquiry stressed the need for further research to be undertaken in the area of hepatitis C. One witness commented that 'research is needed to find better treatments and a possible cure to give the sufferers of Hep "C" hope for a future free of pain and illness'.⁸³

6.89 Suggestions ranged from more funding for research already being undertaken to the establishment of a dedicated foundation targeting hepatitis C research.

Special needs of haemophiliacs

Haemophilia Treatment Centres

6.90 People with haemophilia and other related bleeding disorders have their condition managed by one of 16 comprehensive Haemophilia Treatment Centres (HTC). The HTCs offers medical services and a range of other professional services including counselling; advocacy and social work, and physiotherapy. The Australian Haemophilia Centre Directors' Organisation (AHCDO) stated that 'the holistic approach to the welfare of patients taken at the HTCs is greatly beneficial and the federal government should be encouraged to ensure that adequate funding is available to ensure provision of all the services provided'.⁸⁴ As HTCs are located in capital cities and major centres, some people with haemophilia must travel to their nearest centre and this may cause problems with access.

Recombinant products

6.91 As has already been noted in chapter 2, the high infection rate of hepatitis C in people suffering from haemophilia is related largely to the amount of Factor VIII or IX concentrates used in treatment. The amounts of Factor VIII or IX used by an individual is proportional to the severity of haemophilia and the frequency of bleeding. These Factors are manufactured from pools of thousands of donations of plasma.

6.92 The HFA noted that there have been problems with the supply of plasma derived Factor VIII with CSL being unable to produce sufficient quantities at various times.⁸⁵ ARCBS noted that every possible plasma donation currently has Factor VIII

82 See for example, *Submission 79*, p.26 (TBPAG).

83 *Submission 8*, p.2.

84 *Submission 72*, p.2 (AHCDO).

85 *Submission 82*, p.15 (HFA); see also *Committee Hansard 6.4.04*, p.49 (AHCDO).

manufactured from it, while Factor IX production is not limited by the supply of plasma and CSL is able to manufacture the amount required.⁸⁶

6.93 Factor concentrates manufactured using genetically engineered cells became available in Australia in 1994 when recombinant Factor VIII was imported. In 2001 recombinant Factor IX became available. People with von Willebrand disorder are unable to use recombinant Factor VIII as it does not contain von Willebrand factor.

6.94 Organisations expressed concern about the availability of recombinant products. HFA stated that recombinant Factor VIII and Factor IX has been restricted to children who were not already infected with hepatitis C and/or HIV and that 'government policy means that most people in Australia still must use plasma derived products even though safer alternatives are available'.⁸⁷ This is despite the recommendations of the Factor VIII and Factor IX Working Party of the AHMAC Blood and Blood Products Committee. The Working Party recommended that current restrictions on access to recombinant Factors VIII and IX be removed as rapidly as possible, and that these products be used whenever clinically indicated in order improve patient safety. The Working Party also recommended that a target of 85 per cent recombinant use be reached by 2004.⁸⁸ The Barraclough Report supported this recommendation. HFA concluded:

Despite the recommendations of these government agencies and committees, patients continue to be placed at risk by being forced to use plasma derived treatment products which are more likely to expose them to blood borne viruses and agents, known and as yet unknown...Countries with similar health care standards and expectations have accelerated programs to do this in recent years and now Australia falls well below international standards...If an alternative safer product can be supplied, it is reasonable and prudent to supply it and the government, doctors, hospitals and other bodies may be exposing themselves to potential claims for negligence if a new illness or infectious agent did emerge.⁸⁹

The HFA also stated that the policy was 'clearly discriminatory and unacceptable'.⁹⁰

6.95 The AHCDO noted that funding had been made available in 2003 for the importation of greater quantities of recombinant Factor VIII when CSL had not been able to produce sufficient supplies of plasma derived Factor VIII. However, AHCDO's policy on Factor VIII and IX concentrates expressed a preference for recombinant products as the treatment of choice for all patients.

86 *Committee Hansard* 7.4.04, p.47 (ARCBS).

87 *Submission* 82, p.15 (HFA).

88 Australian Health Ministers' Advisory Council Blood and Blood Products Committee, *Report on the Working Party on the Supply and use of Factor VIII and Factor IX in Australia*, April 2003, p.6.

89 *Submission* 82, p.16 (HFA).

90 *Committee Hansard* 5.4.04, p.4 (HFA).

6.96 The AHCDO added that many people, even those not infected with hepatitis C, are not able to access recombinant products. AHCDO stated that patients who have, for one reason or another, cleared the hepatitis C virus and are considered to be ‘virally free’ are often required, for lack of availability of recombinant products, to use plasma derived products to treat their bleeding disorders, thus subjecting themselves to the psychological distress of possibly acquiring another, as yet unknown, blood borne infection. This distress could be alleviated by improving access to recombinant treatment products.⁹¹

6.97 Witnesses argued that the availability of recombinant Factor VIII and IX is limited because of the cost to government and the policy of self-sufficiency in blood products.⁹² Witnesses were unable to provide an exact comparison of costs for plasma derived and recombinant products. However, HFA stated that it considered them to be close, while ARCBS noted that in international markets the price of recombinant product generally runs at \$A1 or more per international unit, whereas the price for plasma derived Factor VIII products generally runs at around A40c per unit.⁹³ Another witness indicated that the premium paid in the Netherlands for recombinant Factor VIII is 15 per cent (factor containing human albumin) and 24 per cent (factor without human albumin) above plasma derived Factor VIII and for recombinant Factor IX it is 21 per cent.⁹⁴

6.98 The ARCBS recommended that governments facilitate access to recombinant Factors VIII and IX as recommended by the Commonwealth Working Party and by HFA.

6.99 In response to concerns about the safety of plasma derived Factor VIII and IX, CSL stated that:

The current plasma derived factor VIII and factor IX both have excellent safety records. We have no evidence of transmission of any of these nasty viruses by those products – in fact, no evidence of transmission since the introduction of the 80-degree dry heat treatment in the late eighties or early nineties. Over the last eight years or so, with the introduction of recombinant factor VIII in Australia, we have seen a steady growth in demand and use of factor VIII in Australia.

6.100 CSL went on to state that very few countries had made the decision to use only recombinant Factor VIII. It was viewed that ‘the the haemophilic community would be best served by increasing the availability of factor VIII rather than just focusing on recombinant factor VIII’.⁹⁵

91 *Submission 72*, p.2 (AHCDO).

92 See for example, *Committee Hansard 5.4.04*, p.7 (HFA).

93 *Committee Hansard 5.4.04*, p.4 (HFA); *Committee Hansard 7.4.04*, p.47 (ARCBS).

94 Additional Information, Mr G Volk.

95 *Committee Hansard 5.4.04*, p.53 (CSL).

Conclusion

6.101 The Committee considers that the haemophilia community should have the choice of using either plasma derived products or recombinant products. The Committee also notes that the AHMAC Blood and Blood Products Working Party on the Supply and Use of Factor VIII and Factor IX recommend the increased use recombinant products by 2004 and that the Expert Advisory Group on Hepatitis C and Plasma supported the recommendations of the Working Party.

Recommendation 4

6.102 That the recommendations relating to the use of recombinant Factor VIII and Factor IX contained in the Report of the Working Party on the Supply and Use of Factor VIII and Factor IX in Australia be implemented as a matter of priority.

Education of the general community

6.103 Many witnesses emphasised the need to improve community awareness of hepatitis C.⁹⁶ Traids stated:

I think there has to be a wider media campaign and more awareness on a broader level. That role could be done in conjunction with someone like the Hepatitis C Council, who are very knowledgeable about awareness and how to raise it on a broader level. It needs to get out of the health system and into the general population so that people are much more aware. People who work in the area and share the knowledge know where to refer on, but when you are not in the health system—and clients are not—you do not know where to get support and information that would help you understand.⁹⁷

6.104 The lack of awareness in the community was seen as contributing to discrimination and stigma of those suffering from hepatitis C. This causes personal hardship for sufferers who may become isolated or fearful disclosing their condition. It can also mean loss of employment and promotion opportunities, denial of accommodation and difficulties in obtaining goods and services including dental and medical care. The AHC noted that 'the underlying causes of such discrimination are varied but are often the result of either a usually irrational fear of infection or the close link hepatitis C has with injecting drug use – an illegal and highly stigmatised behaviour'.⁹⁸

6.105 With hepatitis C infection in the general population on the increase, education is also vitally important to reduce the spread of hepatitis C in the community. An effective education campaign would alert those at risk of contracting hepatitis C about

96 See for example, *Committee Hansard* 6.4.04, p.98 (Prof McCaughan).

97 *Committee Hansard* 6.4.04, p.17 (Traids).

98 *Submission* 75, p.14 (AHC).

current dangers. It would also inform those who may have, in the past, undertaken activities leading to hepatitis C infection and encourage them to be tested. A public education campaign would also raise the profile of the disease and put it on the public agenda.

6.106 The review of the National Hepatitis C Strategy had recommended a national hepatitis C public awareness campaign. However, the AHC stated that the Commonwealth's response indicated support for 'education and prevention activities for hepatitis C' from within existing funding levels. The AHC commented that 'given the level of funding available to hepatitis C, this response indicated a lack of genuine support'.⁹⁹

Conclusion

6.107 The Committee considers that there is a great need for a community information campaign to raise awareness of hepatitis C. Hepatitis C can be acquired through a number of means and may remain undiagnosed for a long period of time. There are thus, potentially, many people in Australia who have hepatitis C and who are unaware of their condition. The Committee considers that an education campaign should emphasise the various ways in which hepatitis C is or was contracted including through blood transfusion. This would alert those people who may have contracted hepatitis C through the blood supply to have their HCV status investigated.

6.108 As noted earlier in this chapter, the Commonwealth provides funding for certain programs through its Hepatitis C Education and Prevention Initiative. The Committee considers that this funding would be more effectively allocated to a broad public awareness campaign including through the electronic media.

Recommendation 5

6.109 That the Commonwealth fund a national hepatitis C awareness campaign to increase the public's knowledge of hepatitis C and that such a campaign emphasise all the means by which the infection may be acquired and the need for early testing and treatment.

Apology

6.110 Many witnesses called for an apology to be made to those who have acquired hepatitis C through blood and blood products. An apology was seen as an acknowledgement by those involved in blood services – governments and the ARCBS – of the serious nature of the infection that had been acquired through their services and the devastating impact on many individuals. Witnesses stated:

99 *Submission 75*, p.8 (AHC). See also, *Australian Government Response to the 2002 Review of the National HIV/AIDS and Hepatitis C Strategies and Strategic Research*, p.15.

We feel we deserve an apology. All victims of contracting hepatitis C through tainted blood deserve an apology. No one asked to have this lifestyle passed to them.¹⁰⁰

And:

...many of the people I work with in the haemophilia community have said, 'If only some of the agencies' – so not just government – 'or the people involved in the blood system actually said sorry and said, yes, this did happen.' Hepatitis C has been very much underestimated. Even though people are suffering in the ways you have heard today and have been for some years, there has not been any acknowledgement of that.¹⁰¹

6.111 Some other witnesses argued that the apology should also admit responsibility and liability for the impact of hepatitis C on their lives:

That the Australian Red Cross admits responsibility and liability and publicly apologise to the victims and their families and that the Australian Government do the same.¹⁰²

6.112 Other witnesses suggested that an apology be accompanied by measures to address the needs of hepatitis C sufferers:

I think it is up to someone, the Red Cross or whomever, to put their hand up and say, 'Yes, we made a mistake. We're sorry' – of course, that has never been mentioned anyway – 'and we think you deserve some sort of compensation and help.' I am not really interested in blaming anyone.¹⁰³

6.113 On 27 May 2004, a meeting convened by the ARCBS and chaired by Sir Laurence Street was held at the NSW Parliament and involved representatives of organisations who had appeared before the Committee to speak on behalf of those affected with hepatitis C. Members of the Committee attended as observers.

6.114 At the meeting, the ARCBS indicated that it had 'listened carefully to the concerns of those who had made submissions to the inquiry and reflected upon what was said'. They had instigated the face to face meeting to express 'our sorrow at what had occurred', to establish a dialogue and 'to seek your input in terms of how best to move forward to support those affected by hepatitis C'. In a statement made on behalf of the ARCBS, Dr Brenton Wylie said:

The Red Cross has recognised that, in the past, some blood-transfusion recipients contracted hepatitis C virus from blood transfusions.

This is a terrible fact and we are sorry that this occurred.

100 *Submission 16*, p.2.

101 *Committee Hansard 5.4.04*, p.11 (HFA).

102 *Submission 8*, p.6.

103 *Committee Hansard 7.4.04*, p.6.

We are sorry that for some of those recipients contracting hepatitis C has resulted in often debilitating physical symptoms of this disease, and in some cases, unfair discrimination. We as individuals at the ARCBS have been distressed to hear of people's particular situations

6.115 The ARCBS acknowledged that 'it is clear that we have not always met the expectations of the people with hepatitis C in terms of how we have interacted with them' and hoped that 'we have learned from our experiences and intend to implement improved systems wherever practicable in our day to day dealings with those affected by hepatitis C'. The ARCBS maintained that it had 'acted and took decisions responsibly and in accordance with the best available scientific knowledge at the time and, accordingly we do not accept liability'.

6.116 The full text of Dr Wylie's statement is reproduced at Appendix 3.

6.117 As a result of the meeting, the ARCBS proposed that it would:

...establish a steering committee to review donor- and recipient-triggered Lookback programs with a view to making improvements in communication and engagement with blood donors and recipients. As a result of today's meeting, we will seek the participation of stakeholders representing groups such as those who appeared before the inquiry.¹⁰⁴

6.118 The Hepatitis C Council of NSW stated that it 'strongly welcomed the position taken and apology given by the ARCBS'. The Council concluded:

We believe this is a genuine attempt by the ARCBS to convey its sympathy to representatives of people who acquired hepatitis C from blood transfusions, and to address some of their concerns.

We consider that this is an honest and heartfelt gesture that will help us all move forward in the current debate.¹⁰⁵

Conclusion

Nobody can return our lost years or our good health, but, whatever help given would surely lighten our load.¹⁰⁶

6.119 For those who have hepatitis C, the impact is multifaceted. There are significant health issues; family and social lives are disrupted; and employment and career opportunities may be limited. It is therefore imperative that those suffering from hepatitis C receive optimal personal, medical and social support.

6.120 From the evidence received by the Committee it is clear that hepatitis C sufferers have found it difficult to access adequate medical support and access effective treatments. There was evidence that the services provided lack co-ordination

104 *Submission 64*, Supplementary Submission, 27.5.04, pp.1-2 (ARCBS).

105 *Submission 81*, Supplementary Submission, 31.5.04, p.5 (Hepatitis C Council of NSW).

106 *Submission 27*, p.2.

across the health sector. This is particularly a problem for haemophiliacs who attend both specialist haemophiliac clinics and liver clinics. Hepatitis C sufferers living in rural and regional areas also have problems in accessing specialist services and also face higher travel costs.

6.121 Many people who have acquired hepatitis C through blood transfusions indicated that they had problems with receiving services from general liver clinics and required services tailored to their particular problems. Many witnesses spoke of their distress when it was assumed, wrongly, that they had acquired hepatitis C through intravenous drug use or sexual activity. (This is discussed further in Chapter 3.)

6.122 Associated with this is the evidence of the discrimination and stigma related to hepatitis C status and the detrimental impact on those who have acquired it through blood transfusion. Many witnesses recommended a public education campaign to reduce discrimination and stigma.

6.123 The Committee has also found that there is a great need for counselling and referral services. Some of these services are currently available but many people do not access them. Wider circulation of information about the services as well as an increase in resources for services was recommended.

6.124 The Committee considers that further assistance should be provided to those people who have acquired hepatitis C through blood and blood products. The Committee has already stated in Chapter 5 of this report that it does not support an extension of existing compensation payments for those who have been infected with hepatitis C through blood and blood products. The Committee considers compensation schemes are not the best option when improved services would prove a more direct, efficient and beneficial vehicle to support a greater number of people.

6.125 The Committee therefore supports the establishment of a post-transfusion hepatitis C committee specifically tasked to improve the provision of services to those who have acquired hepatitis C through blood transfusion. Such a committee would be made up of representatives of the Commonwealth, State and Territory Governments, the ARCBS, representatives of organisations which supporting people with hepatitis C and individuals who have acquired hepatitis C through the blood supply. The Committee considers that the funding for the operation of the committee and the work it undertakes should be provided by the Commonwealth and State and Territory Governments. The Committee also believes that the ARCBS should consider contributing financial support to the proposed committee, to any extent it is able to do so.

6.126 The Committee considers that the post-transfusion hepatitis C committee should be established as a priority for the purpose of:

- formulating, coordinating and delivering an apology to be made to those who have acquired hepatitis C through the blood supply;
- establishing an effective Lookback program;

- improving service delivery to victims;
- establishing and managing a fund to provide financial assistance for certain services; and
- establishing criteria for accessing the fund.

6.127 The Committee acknowledges that a statement has recently been made by the ARCBS to those who acquired hepatitis C through the blood system. However, the Committee considers that an apology should also be made by governments as a further means of acknowledging the grave consequences of hepatitis C infection. The Committee, in supporting such a move, does not consider that an apology indicates guilt or liability on the part of government, or any other party.

6.128 The Lookback program currently in place, has identified some of those who have received blood contaminated with hepatitis C. However, a more effective program and greater resources are required to identify further victims. The Committee also considers that current Lookback programs are undertaken with goodwill and dedication but that the ARCBS should not be solely responsible for the program. Rather, increased coordination across the whole health sector is required.

6.129 Improved service delivery is fundamental to good health outcomes for hepatitis C sufferers. The Committee considers that the post-transfusion hepatitis C committee should formulate and implement strategies to improve service delivery to those with post-transfusion hepatitis C through case management. In this way, there would be greater liaison across various services and agencies to ensure those who have acquired hepatitis C through blood products receive appropriate and optimal medical, counselling and support services, including Home and Community Care services.

6.130 The Committee has carefully considered calls for financial assistance for the provision of services not normally covered by government. These include travel expenses for those sufferers living in rural and remote areas; psychology and counselling costs; the costs of medication not covered by the Pharmaceutical Benefits Scheme and recompense for lost income while undergoing treatment and as a result of curtailed employment due to symptoms.

6.131 The Committee recognises that these costs can be substantial and impose financial hardship on hepatitis C sufferers and their families. The Committee considers that the post-transfusion hepatitis C committee should be tasked with establishing a fund to provide financial assistance to cover the costs not covered through existing services. The proposed committee may wish to consider costs which are often not covered or fully covered including visits and transport to general practitioners; prescribed medication and surgical aids; dental, aural, optical, physiotherapy and chiropody treatments; home care and/or home help; and alternative medical treatments.

6.132 The Committee believes that the post-transfusion hepatitis C committee should be funded by the Commonwealth and the State and Territory Governments.

Access to the fund should be based on criteria established by the committee but it is the strong view of this Committee that access should be open to any person who is HCV positive and who can show that they received blood or blood products prior to the introduction of third generation tests. The Committee does not believe it should be necessary for a person to prove beyond a reasonable doubt that they have received hepatitis C through a blood transfusion. For example, the Committee received evidence that for some, records no longer exist which would prove that they had received a blood transfusion. For these people, the lack of records should not preclude them from accessing assistance. The Committee considers the committee should err on the side of compassion rather than require people who have acquired hepatitis C through blood products to undertake an exhaustive process to prove the means of their hepatitis C infection. In this way, many of the concerns of the haemophilia community would be addressed as well as those from people who became infected with hepatitis C in the 1970s and early 1980s.

6.133 The Committee considers the establishment of a post-transfusion hepatitis C committee tasked with improving services and providing some financial support will relieve some of the major concerns of people who have acquired hepatitis C through blood and blood products.

Recommendation 6

6.134 That a national post-transfusion hepatitis C committee be established as a priority with the purpose of:

- **formulating, coordinating and delivering an apology to those who have acquired hepatitis C through the blood supply;**
- **establishing an effective Lookback program; and**
- **improving service delivery through a case management approach that ensures that appropriate medical, counselling and welfare services are provided, sensitive to the needs of people who have acquired hepatitis C through blood and blood products.**

That membership of the committee include representatives of the Commonwealth, State and Territory Governments, the Australian Red Cross Blood Service, representatives of organisations which support people with hepatitis C acquired through the blood supply and individuals who have acquired hepatitis C through the blood supply.

That the committee establish and manage a fund to provide financial assistance for costs not covered through existing services, which could include the costs of visits and transport to general practitioners, prescribed medication and surgical aids, dental, aural, optical, physiotherapy and chiropody treatments, home care and/or home help, and alternative medical treatments, to the people who have acquired hepatitis C through blood and blood products.

That the committee, and the fund it establishes, be jointly funded by the Commonwealth and State and Territory Governments.

That the committee develop criteria for people to access the fund.

Senator Jan McLucas
Chair