

Overview and Recommendations

Hepatitis C is a life changing disease. Infection is often accompanied by serious and debilitating symptoms such as fatigue, lethargy and pain. Some people with hepatitis C clear the virus naturally but this occurs only in a minority of cases. For many, there are uncertain long term health consequences with a number of sufferers developing cirrhosis of the liver, liver failure or even liver cancer. The infection does not only cause serious health problems but can also have a devastating impact on other aspects of the infected person's life, including tension within families, loss of friends, curtailment of social life, restrictions on employment and discrimination.

Infection with hepatitis through blood transfusion was observed during the Second World War. While hepatitis A and hepatitis B were both identified by the early 1970s, the virus causing non-A, non-B hepatitis, as hepatitis C was then known, remained elusive. During the 1980s scientists worked to identify the hepatitis C virus. At the same time debate was occurring world-wide as to the usefulness of surrogate testing of the blood supply. Two tests were suggested, both of which had limitations in identifying blood potentially infected with the hepatitis C virus. These limitations included a high rate of false-positive and false-negative results, markedly different epidemiological contexts between countries which had voluntary blood donors and those which paid donors, and a lack of consensus about the interpretation of test results. As a result, much controversy surrounded the debate on whether or not surrogate testing should be introduced.

The Australian Blood Transfusion Services, with the exception of the Queensland Service, chose not to introduce surrogate testing. The Committee is confident that due consideration was given to pertinent evidence at relevant times, and that decisions taken were reasonable in the circumstances.

It was not until 1988 that the virus was identified. The first specific test for hepatitis C became available in early 1990 and testing was immediately implemented in Australia.

The Committee considers that the most effective means of assisting people infected with hepatitis C through blood transfusion are improvements in services, including wider access to antiviral drugs and financial assistance for costs not covered through existing services. The Committee has recommended the establishment of a national post-transfusion hepatitis C committee. The proposed committee's membership would include representatives from government, the Australian Red Cross Blood Service, hepatitis C support groups and individuals who have acquired hepatitis C through the blood supply. The proposed committee should establish and manage a fund for additional services. Both the proposed committee and the fund should be funded by the Commonwealth and State and Territory Governments. The Committee has also recommended a broad public education campaign to increase public knowledge of hepatitis C. The Committee also considers that recombinant Factors VIII and IX should be available to haemophiliacs.

Over the last decade, major changes in the organisation of the blood service in Australia have occurred. The establishment of the National Blood Authority and the Australian Red Cross Blood Service have led to improvements in the management, safety and co-ordination of the blood supply. The Committee considers that the introduction of a national haemovigilance system would further improve safety of the blood supply.

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.

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.

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.

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.

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.

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.

