

## CHAPTER ELEVEN

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# CONCLUSION

The purpose of this Inquiry has been to inquire into and report on Hepatitis C in New South Wales. The Committee has examined, in detail, a range of issues that impact upon those with the Hepatitis C virus including diagnosis, treatment, management, support and prevention. This Report represents the findings of the Inquiry.

The evidence taken and submissions received from those with Hepatitis C portrayed the everyday realities of Hepatitis C: the overwhelming and debilitating fatigue; the fear of transmitting the virus to cherished partners, children and grandchildren; uncertainties over the future; and deteriorating health.

Hepatitis C must be viewed within an accurate epidemiological context, and an understanding of the profound social impact it is having (and will continue to have) upon the lives of those with the virus and their loved ones. This Report has attempted to provide such a perspective as well as recognise the economic impact the disease will have upon state and federal funding to health care and ancillary support services.

This Report demonstrates that Hepatitis C is a complex issue. Having considered and addressed all of the relevant issues, the Committee has formed a number of Key Conclusions. These include:

- the **need for policies to deal with all facets of Hepatitis C**: despite the current Hepatitis C epidemic there are no policies at the state level giving overall direction to the control, treatment, management and prevention of Hepatitis C. The Committee is critical of this situation and the limited response to Hepatitis C by NSW Health. The Committee's recommendations seek to provide an appropriate policy context to address all facets of Hepatitis C treatment and management (Recommendation 67) and prevention (Recommendation 88);
- the **provision of information**: there appears to be limited understanding in the community about Hepatitis C, in particular, about the way in which it is transmitted. Many assume it has the same transmission routes as other blood borne viruses such as HIV/AIDS. Health care workers, including medical specialists, often have a poor understanding of the disease. This lack of understanding manifests itself in a number of ways including discrimination and stigmatisation towards those with Hepatitis C, frustration by those with the disease as they struggle to learn about the disease and sort through conflicting information, and a lack of compassion and tolerance in the general community. To redress this situation, the Committee has called for the introduction of a number of strategies including education campaigns targeting all those working in the health care sector (Recommendation 19) and public service (Recommendation 22), the production of an information brochure informing those with Hepatitis C of their legal rights and action they can take to address discrimination (Recommendation 23), support for the National Hepatitis C Education Program for General Practitioners which seeks to inform and educate

general practitioners (Recommendation 65), and a national community education Hepatitis C campaign (Recommendation 129);

- the **need for research**: the Committee has forwarded a number of recommendations addressing the need for more research across a range of areas, including ascertaining the incidence and prevalence of Hepatitis C at both the national and state level amongst the general community and the two population groups at greatest risk of contracting the disease: injecting drug users and prisoners. Research is also required into the personal, social and economic impact of Hepatitis C (Recommendation 25), and the effectiveness of complementary therapies on treating the symptoms of Hepatitis C (Recommendation 69);
- a **multi-faceted approach to prevent the spread of Hepatitis C**: prevention strategies to limit the spread of Hepatitis C must be broad, multi-faceted and grounded in the principles of harm minimisation. These criteria are the basis upon which the Committee framed all recommendations directed at injecting drug users (both in the general community and the state's correctional system). In targeting those most at risk, the strategy builds upon services already in place to minimise the transmission of other blood borne diseases such as HIV/AIDS as well as new initiatives. Recommendations are also forwarded to address the transmission of Hepatitis C within the health care setting; and
- **Hepatitis C within the state's correctional system must be addressed as a matter of urgency**: the incidence and prevalence of Hepatitis C within prisons is unacceptable. Those entering prison face a high risk of contracting Hepatitis C and, on release, inmates pose a serious danger of transmitting the virus to the wider community. In the Committee's opinion, these circumstances warrant radical policies to reduce exposure to the Hepatitis C in correction establishments. Treating and managing inmates with Hepatitis C is also fraught with difficulties. The Report forwards recommendations for the development of a Best Practice Model for the delivery of health care (Recommendation 71) as well as the development and implementation of a strategic plan for the management of Hepatitis C in prisons (Recommendation 74).

## 11.1 ADVOCATING FOR THOSE WITH HEPATITIS C

Unlike HIV, Hepatitis C does not have a corps of articulate, professional, skilled and well connected people such as the gay community that lobbied so successfully in the early 1980s and on for services, support, community awareness and research funding.

The Hepatitis C "community" is much more disparate: current injecting drug users (with the stereotypes and prejudices associated with an illicit activity); past injecting drug users who are now far removed from previous practices which, for many, were just a

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passing phase; recipients of infected blood as young as eight years and as old as 80 years of age; and prisoners. The Committee is conscious that there is, in fact, no cohesive and united community - no one group to advocate for those with Hepatitis C. In the absence of an advocate, the Committee considers it to be the role of motivated Parliamentarians to come forward to fill the gap.

The Hepatitis C Taskforce noted the important role played by Commonwealth and State Parliamentary Liaison Groups during the formation and implementation of AIDS policies in the 1980s. The Taskforce report noted that:

*these groups had facilitated multi-party support in controversial areas and prevented a handful of Parliamentarians blocking views supported by a broad consensus* (NSW Health, 1995:20).

At the Federal level at least, the Liaison Group continues to function and has expanded its original brief to include other related diseases such as Hepatitis C.

The Taskforce concluded that it was "unclear" whether or not the HCV area could be considered "sufficient" to warrant such a mechanism, but that, in the absence of Commonwealth and State Parliamentary Liaison Groups a mechanism designed to facilitate multi-party support for control measures and minimise political obstacles to prevention was seen to be of "considerable merit" (NSW Health, 1995:20).

The Hepatitis C Council proposed the formation of a NSW Parliamentary Liaison Group considering that:

*Such a body is necessary to guide the process of specific policy development and prioritisation that may contain significant political challenges and risks. The group would guide the development and implementation of proposals which may be unpopular among some sections of the general community* (Hepatitis C Council submission).

The Council recognised that,

*Many Hepatitis C prevention strategies are contentious because they relate to injecting drug use. I do not need to point out examples of emotive public debate about the issue. We recommend that a Parliamentary Liaison Group be established - hopefully this will garner support from both sides of Parliament and the Independents - to facilitate some of those changes* (Harvey evidence, 3 October 1997).

Committee Members see merit in the Council's proposal. They fully appreciate the role multi-party support could play in minimising political obstacles seeking to limit the spread of Hepatitis C both within the general community and the corrections system.

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As was discussed in the introduction to Chapter Ten, the AHMAC Hepatitis C Education and Prevention Reference Group identified key decision and policy makers are a priority group for preventative education. It is anticipated that the formation of a Parliamentary Liaison Group would provide a very strong advocacy role and influence policy makers at the highest state level.

**RECOMMENDATION 132:**

That the Premier invite his Parliamentary colleagues, from both Houses and all political parties, to form a Hepatitis C Parliamentary Liaison Group. The role of the Liaison Group would be to advocate and support Hepatitis C related policies within the political domain with an overall objective to limit the spread of Hepatitis C in the general community and the corrections system.

## **11.2 IN CONCLUSION**

As this Report has demonstrated, Hepatitis C is a disease that has been neglected - neglected by politicians, health planners, bureaucrats, health care workers and the community in general. Committee Members have been overwhelmed with the enormity of the issue. Listening to and interacting with those who have Hepatitis C was moving. The death of one of the witnesses some seven months after giving evidence was sobering. This is a disease that debilitates. It is a disease that kills.

Committee Members have resolved to address current inadequacies and have unanimously proposed a framework for the state to respond appropriately and adequately to this disease. The Committee now seeks a similar resolve from the government: a resolve that is backed by political will and motivated by compassion. The Hepatitis C epidemic can no longer be neglected.