

**SUPPORTING THOSE WITH
HEPATITIS C**

As Chapter Four demonstrated, the economic and social consequences of Hepatitis C can have profound consequences for individuals, families and carers yet as the Committee heard “Hepatitis C patients have very little support” (Pritchard-Jones evidence, 2 October 1997) and “people are often on their own” (Smart evidence, 26 February 1998). This Chapter looks at various support services available that are designed to assist people with Hepatitis C and identifies some of the gaps in this provision.

9.1 COMMUNITY-BASED ORGANISATIONS SUPPORTING THOSE WITH HEPATITIS C

In its submission to the Inquiry, the Hepatitis C Council noted that effective care and support in the form of counselling and information can make a significant difference to the impact of Hepatitis C on both individuals and the wider community.

Appropriate counselling and information can help an individual adjust to the demands of living with a chronic illness and to optimise their treatment. This may in turn reduce pressure on health and welfare services. The Council also points out that the provision of relevant information about the virus may also reduce the rate of transmission and reinfection (Hepatitis C Council submission). People with Hepatitis C need comprehensive information about the virus, including information about transmission, the prevention of reinfection, the availability and benefits of treatment and legal rights and responsibilities. Information should be updated regularly and presented in an accessible form (Hepatitis C Council submission).

The availability of counselling to assist people with Hepatitis C is, however, very limited. It may be provided by local general practitioners but as has been discussed in Section 8.3.3 there has been little training to assist general practitioners in understanding the virus and its management. Increasingly, the provision of information and support services has been provided by a range of community based agencies that specifically target those with Hepatitis C and even quite specific groups within the Hepatitis C community such as those with medically acquired Hepatitis C and injecting drug users who are HCV+. The following section reviews the agencies that provide support services to those with Hepatitis C.

9.1.1 HEPATITIS C COUNCIL OF NSW

The Hepatitis C Council of NSW is the key non-government agency providing assistance to people affected by Hepatitis C in NSW. The Council, which was incorporated in 1993 grew out of the Australian Hepatitis C Support Group which had been formed two years earlier. Its primary objectives are:

- to coordinate the community sector response to the Hepatitis C epidemic in NSW;
- to provide counselling, support and referral for people affected by HCV;
- to provide information and advice about HCV and, in liaison with other agencies, develop prevention and support strategies to reduce the spread and impact of HCV;
- to act as advocates for people affected by HCV and represent their interests on relevant bodies;
- to eliminate stigmatisation, discrimination and isolation of people affected by HCV through the promotion of community awareness by working to ensure that regressive policies and procedures do not occur; and
- to encourage, assist and promote both health and scientific research into the causes, prevention, treatment and cure of Hepatitis C and related conditions (Hepatitis C submission).

The Council is primarily funded by NSW Health. It has an annual operating budget of \$260,000 with an annual grant from NSW Health of \$215,000 providing its core operating income. Additional income sources include membership fees, individual and corporate donations and product sales. The Council employs four paid staff and has a team of 40 volunteers.

The Committee received numerous submissions from people with Hepatitis C who specifically identified the Hepatitis C Council as playing an important role in providing support, information and education:

The Hepatitis Council of NSW has been a real saviour to me. The first bit of real information I received was after diagnosis, using the telephone support line. I eagerly await the arrival, each quarter, of the 'Hep C Review' as it is the only source of reliable information. I have gained much from readers' stories and the articles about diet and general health have been invaluable (Submission 45);

I joined the Hep C Council of NSW and was given a lot of help from them with information which I needed (Submission 48);

and

The Hepatitis C Council is doing a wonderful job but needs more help (Submission 36).

During evidence, Committee Members heard that:

the Hepatitis C Council of NSW has been good to us all. It deserves every support and credit for its work (Smart evidence, 26 February 1998).

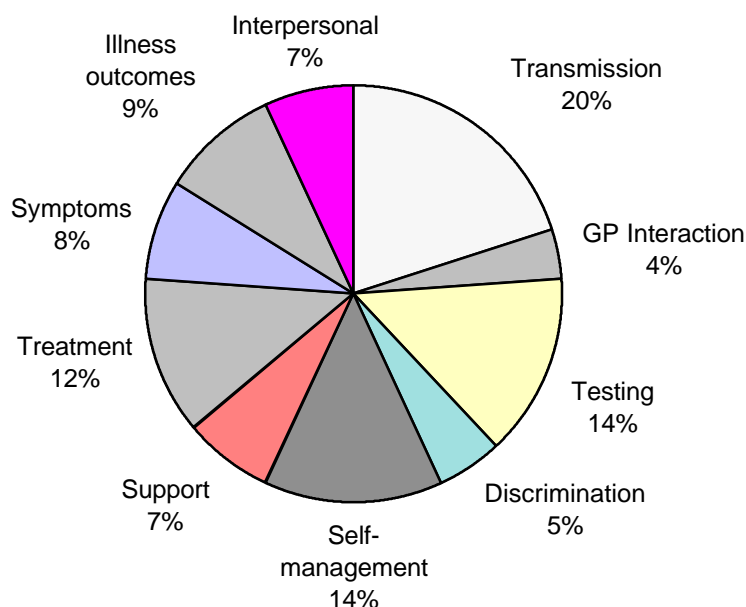
Specific activities of the Council include:

- operation of the NSW Hepatitis C Telephone Information and Support Service (TISS);
- production and distribution of information resources such as *Hepatitis C: a brief introduction* (over 200,000 have been distributed in two years); *Hepatitis C: what you need to know*; information videos and research packs;
- production and publication of a quarterly newsletter the *Hep C Review* which has a print run of 4,000 and an estimated readership of 16,000. This journal is Australia's "foremost regular publication" on Hepatitis C (Hepatitis C Council submission); and
- acting as the key Hepatitis C-specific agency in NSW, ensuring effective referral and networking (Hepatitis C Council submission).

A significant core activity of the Council is the Telephone Information and Support Service which is a 1-800 telephone service that receives over 3,000 calls annually. The service is staffed by a team of 8-15 trained volunteers who are supervised by a project officer who recruits, trains, supervises, manages and supports the volunteers.

Calls are often "extremely complex" and "require great skills to help an often distressed caller" (Loveday evidence, 30 March 1998). They also cover a range of issues. Figure Five shows the breakdown of topics discussed. The three most discussed issues in 1996-97 were transmission (20%); self management (14%) and testing (14%).

FIGURE FIVE
HEPATITIS C COUNCIL OF NSW INFORMATION AND SUPPORT LINE
1996-97



TISS operates 24 hours a week including three hour shifts every weekday morning, Monday and Tuesday afternoons and Wednesday evenings. Funding restrictions limit the hours of operation. The Executive Officer of the Council told the Committee that:

calls are being missed by this service through our ability to open 24 hours a week given our resourcing. We do the best we can to call back those who leave messages, but we know there would be some who are being missed through people not being able to speak to anybody at the time (Loveday evidence, 3 October 1997).

TISS is currently the only telephone information and support service available to those with Hepatitis C in NSW. The Committee considers the service to be vital in terms of the information and support it provides, particularly to those in rural and regional areas. The Committee therefore considers it appropriate that funding be increased to enable the service to operate from 9:00am to 6:00pm seven days a week and from 6:00pm to 10:00pm Monday to Friday evenings.

RECOMMENDATION 79:

That the funding allocation by NSW Health to the Hepatitis C Council of NSW be increased to enable the Telephone Information and Support Service to operate from 9:00am to 6:00pm seven days a week and from 6:00pm to 10:00pm Monday to Friday evenings.

9.1.2 SUPPORTING THOSE WITH MEDICALLY ACQUIRED HEPATITIS C

Two agencies currently provide services to those with medically acquired Hepatitis C: the Transfusion Related AIDS and Infectious Diseases Unit (TRAIDS), and the Haemophilia Foundation Australia (and its NSW counterpart). These agencies and the services they provide to the Hepatitis C community are reviewed in the following discussion.

- **Transfusion Related AIDS and Infectious Diseases Unit (TRAIDS)**

TRAIDS is a unit within the NSW Health Department which supports people infected with HIV and Hepatitis C as a result of a blood transfusion. The Unit, which is based in Parramatta, provides information and counselling on all aspects of Hepatitis C to individuals, families and health care workers. It also plays an important role in advocacy and policy development.

TRAIDS was initially established to support people with medically acquired HIV. In 1994 NSW Health broadened the scope of TRAIDS' services to include blood recipients who received HCV+ blood between the introduction of first and second generation HCV testing. The small number of affected people at the time, 52 in total, had little impact on the resources of TRAIDS as not all those diagnosed required or wanted intensive involvement (TRAIDS submission). The Hepatitis C Lookback program currently being undertaken by the Blood Bank (and reviewed in Section 3.3) is identifying a larger number of people who are HCV+. This is resulting in an increased number of referrals to the Unit.

Despite its increased role the Unit has not received any additional funding or resources to support people with Hepatitis C and all counselling and support is provided by the Unit's one social worker and the Director. According to the Director of the Unit, Ms Pam Shipway, TRAIDS has been able to cope with the additional caseload as the demands of HIV clients have reduced in response to new therapies (Shipway evidence, 10 October 1997). However, if the number of referrals were to increase Ms Shipway advised the Committee that the Unit would require additional counsellors and resources (Shipway evidence, 10 October 1997).

- **Haemophilia Foundation Australia**

The Haemophilia Foundation Australia (HFA) is the primary agency supporting those with haemophilia, von Willebrand Disorder and related bleeding disorders. The Foundation undertakes a range of activities including:

- funding for research;
- member education and interaction through activities such as workshops, family camps, family days; annual forums for doctors, nurses and counsellors;
- activities targeting youth including a Youth Newsletter, Peer Leadership workshops and the Haemophilia Youth Group's Internet home page, "Blood Brothers";
- community education including Haemophilia Awareness Week;
- resource development; and
- specific program development such as the Hepatitis C Program and the HIV/AIDS Program.

In 1996 a Member Needs Survey conducted by the Foundation found many members wanted more information and support on the issue of Hepatitis C. Later that year a decision was made to develop a program specifically addressing Hepatitis C related issues, particularly treatment and transmission. The overall aim of the program was to provide information to people living with haemophilia, related disorders and groups working with them (HFA, 1997:13). The Program was funded by a special grant from the Commonwealth Department of Health and Family Services along with individual HFA contributors.

According to the Foundation, people with haemophilia not only have to deal with the fear of illness and death, but with discrimination in the community, because they are a clearly recognisable group. Appropriate counselling is an important means of helping people to deal with the discrimination they experience:

All our families need help with the broad ramifications of Hepatitis C and haemophilia, even those new families who are uninfected, because they still fear the discrimination that belongs with our group (Ross evidence, 26 February 1998).

However, according to the Foundation, counselling services in NSW are inadequate:

our counselling services in New South Wales are definitely a problem. They need to be extended and maintained (Ross evidence, 26 February 1998).

There has been one counsellor, based at Royal Prince Alfred Hospital, providing support to those with haemophilia in New South Wales. However, as the Committee heard, the counsellor:

is employed with HIV funds and she is so outstanding that she has now been seconded to the position of acting in charge of HIV services for her hospital and region and she is only able to manage a few emergency cases for the haemophilia group. As you can understand, this is unsatisfactory for her and for the group (Ross evidence, 26 February 1998).

In other states it is the Haemophilia Foundation, rather than the Department of Health, which employs counsellors. As a result:

these counsellors cannot be whisked off, as happened here at Royal Prince Alfred Hospital, to do another job. The group employs them. Their time cannot be moved by placing them in other areas. The positions are protected (Ross evidence, 26 February 1998).

Not only are the positions of haemophilia counsellors secure in other states but more counsellors are available. The Committee understands that both Queensland and Victoria (which have smaller caseloads than NSW) have two full time counsellors - one dealing with haemophilia and HIV, the other with haemophilia and Hepatitis C.

The Foundation also offers care and support to its members through various programs, workshops and meetings. The ability of NSW to provide such services is limited by funding which enables the secretary to be employed only on a part-time basis. Again, other states employ secretaries for more hours or employ more people.

9.1.3 SUPPORTING INJECTING DRUG USERS WITH HEPATITIS C

In New South Wales the peak group representing those who use drugs illicitly is the New South Wales Users and AIDS Association (NUAA). NUAA is a community based, non-government organisation established in 1989 to provide health promotion and harm reduction education, information and support to illicit drug users. The Association's Coordinator likened the Association to a "union for drug users" (Madden evidence, 7 November 1997). NUAA employs 13 permanent staff members.

The Association is funded primarily by NSW Health receiving, for example, \$885,500 in 1997-98 (NSW Health submission). Ms Madden, NUAA's Coordinator, went to considerable lengths to assure Committee Members of the organisation's credibility:

we have a good working relationship with our funding bodies and we are a well-recognised and highly accountable organisation, which is important in this area, given that the organisation is run by and for drug users (Madden evidence, 7 November 1997);

and

NUAA is very much recognised as a professional organisation with a good reputation. I am sure you will appreciate that the Department of Health would not give us the budget it does and we would not have grown from one staff to 13 in eight years if we were not doing the work we were funded to do (Madden evidence, 7 November 1997).

The support provided by NUAA to its client base has a strong peer education and community development focus which is described in Section 10.1.1. The projects include TRIBES, CROWS and *NUAA News*, a quarterly newsletter which deals with information of interest to illicit drug users.

9.1.4 CONCLUSION

Mr Loveday from the Hepatitis C Council summed up the role played by community based support services during the course of his evidence:

with the current inadequate level of knowledge within the primary health care field, and with the vast majority of people receiving their Hepatitis C diagnosis with inadequate pre- and post-test counselling, if any at all, there is an urgent need to further fund and expand the community based information and support services (Loveday evidence, 30 March 1998).

The Committee concurs with his statement and fully appreciates the important role played by community based information and support services. While each of these four agencies spoke of inadequate resources, particularly funding, to meet the demands placed upon their services, the Committee found it difficult to recommend outright the allocation of additional funding.

The Committee appreciated the constraints under which these agencies operate and recognised the need for additional funding. However the Committee did not feel it was adequately equipped to make specific recommendations. It considers it more appropriate for a review of these four agencies to be conducted and the adequacy of

resources to meet the demand for services ascertained. Once the needs of each agency have been identified, the Committee wishes to see NSW Health ensure sufficient funding is made available to enable these services to meet the needs of the Hepatitis C community in New South Wales.

The Committee wishes to see the review include staffing needs, such as counselling, support, project, policy and volunteer management staff.

RECOMMENDATION 80:

That NSW Health commission an independent review and needs assessment of the services provided by the Hepatitis C Council of NSW, the Transfusion Related AIDS and Infectious Diseases Unit, the Haemophilia Foundation NSW, and New South Wales Users and AIDS Association to determine resource needs (including staffing needs for counselling, support, project and policy work and volunteer management) and demand for services. The Committee further recommends that the proposed review be conducted within six months of the tabling of this Report and that the results are with the Minister for Health no later than December 1999.

RECOMMENDATION 81:

That, upon receipt of the review proposed in Recommendation 80, NSW Health ensure sufficient and recurrent funding is made available to implement the recommendations of the review.

9.2 SUPPORT GROUPS

A number of those making submissions to the Inquiry mentioned the benefit they had received by being involved in a support group specifically designed for those with Hepatitis C. Rural people in particular, seemed to have appreciated this form of support. All of those that wrote of support groups however, wrote in the past tense. While a number of support groups have existed for short periods of time across the state, there have been no more than three or four at any one time and currently there would be no more than two or three (Loveday evidence, 30 March 1998). The mapping exercise of Hepatitis C education, prevention and training initiatives undertaken by NSW Health and updated in March 1998 identifies two support groups: a monthly support group in Wollongong; and the Hunter Hepatitis C Support Group which was scheduled to run for six 2-hourly sessions and would be repeated throughout the year (NSW Health, 1998b:22, 26).

Ms Shipway stressed the importance of support groups during the course of her evidence:

support groups can benefit some people by reducing their isolation and by identifying with others in similar situations and being more comfortable with their diagnosis (Shipway evidence, 10 October 1997).

The Hepatitis C Council told the Committee that:

it is very disappointing that when most people phone the information and support service to ask about whether they are able to meet with other people who have Hepatitis C, or talk to somebody who has been on interferon treatment, or join a formal support group to discuss issues brought up by their diagnosis, we have to tell them that there is virtually a complete absence of support groups across the state . . .

. . . This is true of both city and rural areas, but the need by people in rural areas, particularly for additional and appropriate local support is amplified by the general isolation and often reduced access to services, coupled with an often bigger potential for discrimination once their Hepatitis C positive status is disclosed (Loveday evidence, 30 March 1998).

The Council provides those interested in running a support group with information, material and guidelines on appropriate ways to run a small support service:

however, lack of local resources, both material and trained expertise, means that the burn-out rate is very high. No amount of community enthusiasm and voluntary input can sustain a support system to the level at which one is required (Loveday evidence, 30 March 1998).

To overcome the problem, Loveday proposed each Area Health Service allocate sufficient resources, both staffing and financial, to the establishment of local support services. He also considered it important that the local community be fully involved in determining the appropriate style of support system that would meet the needs of the local Hepatitis C community (Loveday evidence, 30 March 1998).

The Committee considers there to be a vital role to be played by support groups for those with Hepatitis C and their families. It wishes to see the Area Hepatitis C Managers proposed in Recommendation 40 take on the role of coordinating local support groups. The Committee does not envisage the Managers actually facilitating the support groups, but overseeing their establishment, ensuring necessary resources

are available (venue, photocopying, fax, etc), providing expert input and information as required.

RECOMMENDATION 82:

That the Area Hepatitis C Managers proposed in Recommendation 40 be responsible for instigating Hepatitis C Support Groups in their local Health Areas and, while not necessarily involved in the day to day operation of the groups, provide expert input and information as required, act as a resource/referral person and ensure necessary resources are available.

RECOMMENDATION 83:

That the review proposed in Recommendation 39 take into consideration the need for support groups in each Health Area and the role played by Area Hepatitis C Managers in facilitating these groups.

In terms of appropriate venues for the support groups, the Committee considers Community Health Centres to be well situated to provide a suitable venue. However, the Committee would rather this decision be made in conjunction with the development of best practice models for service delivery proposed in Recommendation 66. It is important though that consideration be given to the administrative needs of the support groups and ready access to basic office equipment such as photocopier, fax and Internet.

RECOMMENDATION 84:

That, in developing a model of best practice for the delivery of services to those with Hepatitis C (as proposed in Recommendation 67), the accommodation needs of local Hepatitis C support groups be taken into account.

9.3 FINANCIAL SUPPORT TO THOSE WITH HEPATITIS C

9.3.1 DISABILITY SUPPORT PENSION

While the Committee did not receive any first hand evidence concerning difficulties people with Hepatitis C have experienced in accessing the pension, the issue was raised during the course of evidence. Mr Mellors, for example, recounted two instances

he was aware of in which people with Hepatitis C, one with cirrhosis and moderate to severe depression, the other also with cirrhosis and on antidepressants, found it “very difficult” and “quite a struggle” to obtain the disability support pension (Mellors evidence, 26 February 1998).

The Hepatitis C Council informed the Committee that in 1996 the Committee understands that the Department of Social Security reviewed the impairment tables used by Commonwealth medical officers to establish the level of disability and, in turn, eligibility to receive the disability support pension. A series of changes to the tables was proposed which would have excluded many people with chronic illness, particularly those with an illness which was fatigue related. While Hepatitis C was not specifically identified, fatigue is one of the main symptoms of the disease and the proposed changes would have substantially reduced the numbers of people accessing this particular pension. Under the proposed changes, those with Hepatitis C would have been required to provide medical evidence in the form of liver function tests or liver biopsy results. However, as there is no direct correlation between the level of liver damage and the amount of symptomatic illness a person with Hepatitis C endures, the changes were considered to be inappropriate. The Hepatitis C Council strongly advocated against the changes which were not made as originally proposed.

Currently all those on a disability support pension are being reviewed.

The Hepatitis C Council anticipates that the new tables will provide some structured guidelines to the Commonwealth medical officers conducting the assessments for:

in some instances people’s ability to work appears to be measured at the whim of an individual Commonwealth medical officer. That is not true across the board certainly, but there is a lot of variation in the assessments. Hopefully these new tables will give clearer guidelines to the medical officers (Loveday evidence, 30 March 1998).

Given the assurances received from the Hepatitis C Council that the problem appears to have resolved itself, the Committee is satisfied that this is the case. However, it would be concerned if future changes were proposed that restricted those genuinely debilitated by Hepatitis C from accessing the disability support pension. It urges NSW Health to keep a watching brief on the issue and advocate on behalf of those with Hepatitis C should future restrictive changes be proposed.

RECOMMENDATION 85:

That NSW Health maintain a watching brief on the issue of changes to the Disability Support Pension. The Committee further recommends that, should changes be proposed in the future which would restrict those genuinely debilitated by Hepatitis C from accessing the Disability Support Pension, the Minister for Health, through the forum of the Australian Health Ministers Council, advocate on behalf of those with Hepatitis C.

9.3.2 FINANCIAL SUPPORT TO THOSE WITH MEDICALLY ACQUIRED HEPATITIS C

Approximately one-third of submissions received from those with Hepatitis C were from people who had acquired Hepatitis C either through medical procedures (including blood transfusions) or the workplace. Only a handful called for financial compensation or assistance. A nurse, for example, asked for compensation for those like herself “just to cover costs of medical treatment” (Submission 19). One other argued that:

Medically acquired HCV sufferers should be able to go on the interferon and riboviron treatment as some type of compensation. We are innocent victims of this virus and I feel strongly that this treatment should be given to us free (Submission 62).

TRAIDS recommend that financial assistance of a “limited nature” must be a consideration of the Inquiry (TRAIDS submission). Ms Shipway from TRAIDS considered such assistance would be helpful for people with Hepatitis C to “have more choices in their life” (Shipway evidence, 10 October 1997).

Towards the end of this Inquiry, the ACT government announced it would be providing financial assistance to those who contracted Hepatitis C through contaminated blood. The Committee understands that legislation is soon to be introduced into the ACT Legislative Assembly seeking a compensation package of between \$2.3 million and \$3.7 million over the next two years for 60-80 residents of the Territory who contracted Hepatitis C prior to the screening of blood and blood products by the Red Cross Blood Service (Jackson and Lawson, 1998). The maximum payout would be \$100,000 and recipients would waive their right to sue. As far as the Committee can ascertain, this is the first government in Australia to take such action. Similar measures are being taken by the Canadian government which, in March 1998, announced a \$1.1 billion package for approximately 22,000 people who received infected blood prior to the introduction of screening (CBC Radio News, 1998).

In 1990 this Committee conducted an Inquiry into medically acquired HIV. The Terms of Reference for that Inquiry were that the Committee report upon, as a matter of urgency:

- (a) *whether persons who have contracted HIV infection through blood, blood products, artificial insemination from a donor, or as a result of organ transplant, are receiving adequate and comprehensive health and welfare services;*
- (b) *whether persons who have acquired HIV infection through secondary transmission from spouses or parents with medically acquired HIV are receiving adequate health and welfare services; and*
- (c) *whether the Government should provide financial assistance to those persons described in paragraphs (a) and (b) above (Standing Committee on Social Issues, 1991:iv).*

The majority report of that Inquiry recommended that people with medically acquired HIV be entitled to financial assistance (Standing Committee on Social Issues, 1991:46). This recommendation was subsequently adopted by the government and financial assistance was provided.

The Committee is aware that its previous Inquiry and the resultant government action could be seen as setting a precedent for those with medically acquired Hepatitis C. However the Committee is reluctant, at this stage, to recommend similar action for two reasons. Firstly the Committee has been advised that litigation has commenced in relation to forty cases where allegations are made to the effect that NSW Blood Transfusion Service was negligent. With regard to these cases, the Committee was advised that:

litigation has been discontinued in three of these forty cases. Solicitors for the plaintiffs have indicated that litigation is to be discontinued in a further three of these cases . . . The claims involve complex legal and factual issues relating to the activities of blood banks throughout the world in the late 1960s, early 1970s up until 1991 . . . No claim involving the New South Wales Blood Transfusion Services has been resolved other than by discontinuance nor has any matter been listed for hearing (Benjamin evidence, 10 October 1997).

The Committee also took (in camera) evidence from the Queen's Counsel representing the Blood Bank.

Secondly, comments on financial assistance were made by only a very small proportion of those making submissions to the Inquiry. This is not surprising given the Terms of Reference of the Inquiry. However, the Committee concluded that, at this stage, it does not have sufficient evidence to come to any definitive conclusions concerning the appropriateness of providing financial assistance to those with medically acquired Hepatitis C.

The Committee fully recognises however that, at some point in the future, the issue may take on more prominence. Should that be the case, it may then be appropriate for the Committee to conduct an inquiry into the issue.

9.4 COMMUNITY SUPPORT FOR THOSE WITH HEPATITIS C

As has been discussed, the chronic nature of Hepatitis C impacts upon virtually all facets of people's lives. For many everyday tasks such as housework, caring for children, shopping, accessing public transport and paying bills become major chores requiring large amounts of energy and determination. The problem is exacerbated for those with limited support living in rural areas, isolated in the outer suburbs of Sydney and with limited English language skills.

In recounting examples from years of counselling people with Hepatitis C, Ms Lamb told the Committee of:

People [with Hepatitis C] living in Housing Commission areas, placed in a fourth-floor flat with two small children having to go up and down to put the washing on the line, so people in that situation do not do the washing. They cannot take the kids down to play because it is too tiring. In recent years the Housing Department has really tried to help (Lamb evidence, 30 March 1998).

From her own personal experience of utilising Home and Community Care, Ms Lamb suggested to the Committee that:

The Home and Community Care service should be extended. That service is regarded as only for the aged. I cannot see why it should be restricted to the aged. The set-up is there but young people also need help. When you ask for community transport, as I had to recently . . . all the questions focused on "are you continent?" (Lamb evidence, 30 March 1998).

As the long term manifestations of Hepatitis C become evident and increasing numbers of people are debilitated by the disease the Committee anticipates greater utilisation of essential services provided by a range of government agencies such as housing, community service, transport, in addition to health. In many instances, those requiring these services will be younger than those who have traditionally utilised these services. Their need will, however, be no less acute than that of the older members of the community. Given the long term and chronic nature of Hepatitis C, their reliance upon these services will extend over time.

The wide range of inquiries conducted by the Committee over the past ten years has given it considerable experience in observing the manner in which government

agencies provide services at the grassroots to address specific social issues. The Committee is very aware that, despite the best intentions of agencies and those in the field, gaps do appear and people with very real needs, do fall through those gaps. Often the problem is a lack of coordination between agencies, limited collaboration and poor communication. The Committee recognises that many people with Hepatitis C will have multiple needs for support, requiring contact with a number of government agencies. It is concerned that, unless coordinating mechanisms are put in place, these people will not be able to access the services they need when they need them.

The Committee therefore wishes to see mechanisms put in place to enhance the coordination and collaboration of government services utilised by those with Hepatitis C.

For much of 1998 the Social Issues Committee conducted an inquiry into parent education and support programs concurrently with this Inquiry. In the context of this second Inquiry, the Committee studied an interesting model: the Interagency Schools as Community Centres project. This project provides various forms of support, education and assistance to families and is based on the concept of full service schools, using the school site as an accessible point in the community where people can access a range of services. As the name implies, one of the features is the interagency component which involves a range of relevant government departments, such as Education and Training, Health, Housing and Community Services, working together to provide services.

A core group of programs are available at each of the project's four sites however one of the features of the project is that the range and type of programs offered is developed to meet local needs. The core group of programs includes playgroups, parenting information sessions, early childhood health clinics and transition to school programs. Individual sites have developed their own focus of activity ranging from nutrition and food co-operative programs, literacy support programs and a community-school bus service (Standing Committee on Social Issues, 1998:164).

The approach used in the Interagency Schools as Community Centres project was well supported by many participants of the parent education Inquiry. The main benefits cited were the collaborative approach between the government departments involved, the 'grass-roots' nature of program development which ensured services are relevant to the needs of parents, and the use of schools as an accessible venue for such services (Standing Committee on Social Issues, 1998:165).

The Committee saw considerable merit in this form of grass-roots, community development and felt there to be scope for the model to be adapted to meet the needs of those with Hepatitis C. Given the debilitating impact and the chronic nature of Hepatitis C many need services offered by a range of government departments such as Housing, Community Services, Health, Transport in addition to local government.

An interagency committee along the lines of the model discussed and operating at the local health area level could ensure these services are readily available and accessible. The Committee would like to see such an approach, to be known as the Interagency Hepatitis C Support Project, trialled by NSW Health.

RECOMMENDATION 86:

That NSW Health trial an Interagency Hepatitis C Support Project to ensure government services required by those with Hepatitis C are readily available and accessible. The Committee further recommends that the government agencies involved include the Departments of Health, Community Services, Housing and Transport in addition to local government representation.

The Committee envisages that the Area Hepatitis C Manager, proposed in Recommendation 40 would act as coordinator and chair of the Committee. The Committee also wishes to see the concept trialed for a two year period in three Health Areas: inner city, suburban and rural. Those considered most appropriate for the trial are the Health Areas of Central Sydney, South Western Sydney and Northern Rivers.

RECOMMENDATION 87:

That the Interagency Hepatitis C Support Project proposed in Recommendation 86 be trialed for a two year period in three Health Areas: Central Sydney Area Health Service (inner city), South Western Sydney Area Health Service (metropolitan) and Northern Rivers Area Health Service (rural). The Committee further recommends that the Area Hepatitis C Managers for each of these Health Areas proposed in Recommendation 40 act as project coordinator and chair of the Committee.

9.5 CONCLUSION

Committee Members have come to appreciate that those with Hepatitis C, and those who care for them, often need adequate and ongoing support. Such support is, however, limited. A range of community-based organisations, such as the Hepatitis C Council, TRAIDS, the Haemophilia Foundation and NUAA, provide a number of support services, but they are often underresourced and stretched to the limit. Accessing available government services such as appropriate housing, community transport and Home and Community Care is often confusing and difficult, particularly for those with limited English language skills or living in rural areas. The proposed recommendations of this Chapter attempt to address current inadequacies and provide a range of support mechanisms which will meet both current and future needs of those living with Hepatitis C.
