

**THE SOCIAL AND ECONOMIC
IMPACT OF HEPATITIS C**

The Committee was specifically asked to inquire into the social and economic impacts of Hepatitis C. The following discussion attempts to identify the major impacts faced by Hepatitis C infected persons and their families. In doing so the discussion draws heavily upon submissions received during the course of the Inquiry.

Of the 123 submissions received by the Committee 91 (or over two-thirds) were private submissions from Hepatitis C infected persons many of which described the impact the disease has had on their lives and often the lives of their partners and children. Some of these people contracted Hepatitis C through infected blood, others through health care related work or by sharing infected injection equipment while others do not know the source of their infection. What they all have in common, however, is a chronic virus for which there is at present no cure, little public awareness and rarely adequate and available information.

The majority of those contacting the Committee requested that their submissions be treated as 'Private and Confidential' thus protecting them from public knowledge of their condition. The Committee also noted that many of the submissions were written by spouses or close relatives, rather than by the Hepatitis C infected person, suggesting that the task of preparing a written account of the disease and its impact may simply have been too physically and/or psychologically taxing. It was also noted that, while it has been estimated that less than 15% of infected persons contracted the virus in ways unrelated to intravenous drug use (see Chapter Three), almost one third of the private submissions the Committee received identified infected blood or blood products as the cause of their infection.

The following discussion looks at the social impact of Hepatitis C with particular reference to the impact of the disease on those with medically acquired HCV, those who live in rural areas and parents. Experiences of discrimination and stigmatisation are also recounted. The economic impact on both those who have HCV and the community in general is also discussed.

4.1 THE SOCIAL IMPACT OF HCV

The Committee has heard that Hepatitis C affects all aspects of an infected person's life. As one infected person noted:

My illness has limited my capacity to work, seriously questioned my ability to be an effective parent, partner or friend, and prevented me from participating in my community. I feel isolated and often through that isolation robbed of the necessary tools to combat negativity and hopelessness (Submission 67).

Another person wrote:

My life has changed. I was once full of energy, now I have none . . . My house work never gets done. I have lost interest in the world. I would

really love to get the spark back in my life, but it all seems so hard. Depression takes over. This is a result of not having the energy to do anything or go anywhere (Submission 7).

With dwindling energy levels everything, from close relationships with family members to social activities with friends, becomes increasingly overwhelming for the infected person. As a result, many become isolated at a time when strong networks of support from family and friends are needed the most.

In terms of relationships with family members, the Committee heard that:

My partner has been aware of my health situation since I first became aware of the specific nature of the illness in 1990. Whilst he has been very supportive, my illness has placed a significant burden on his life and upon our relationship (Submission 31),

and

I got involved with someone who found out from my ex about the Hep C. He ran a mile. . . . As soon as someone finds out you have Hep C they treat you like some kind of leper (Submission 40).

For some the pressure is just too much and the family breaks down:

My second marriage broke up as a result of my Hep C with the last words being "You're nothing but a diseased _____" (Submission 40),

and

my de facto relationship of 11 years, the result of which is a nine year old daughter, now seems doomed as my partner can't handle it anymore (Submission 50).

In appearing before the Committee Crofts referred to the "increasing number" of divorce cases where Hepatitis C has become a factor (Crofts evidence, 28 November 1997).

Others recounted incidents experienced with friends:

I have had friends tell me to stay away until I am better as they fear I may infect their children;

and

I have seen the questions in the eyes of the few close and trusted friends I have disclosed [it] to and feel a strong urge to reassure them that I'm not a "druggie" but an "innocent" victim - this then also appals me as no one

deserves this disease or the stigma associated with it. No one is innocent or guilty - HCV does not discriminate, people do!!! (Submission 81).

Even if the infected person has strong support from a partner and friends, the practical aspects of socialising, such as visiting or being visited by friends and family, can prove too much:

My social life is almost non-existent, as I am so fatigued that I cannot go out at night and I find that often I cannot get up (not because I don't want to), but through fatigue. I am at my best around lunchtime, but after that I need to rest again... We go visiting friends rarely, as I am too fatigued, nauseous or have bowel upsets and our plans fall apart (Submission 22).

Not only are difficulties commonly experienced with family and friends, but most feel unable to reveal their status to the general community:

this is a very isolating illness as there is a stigma involved and you can't talk about it openly - in fact you mustn't tell (Submission 1).

4.1.1 THE IMPACT OF THE VIRUS' PHYSICAL AND PSYCHOLOGICAL SYMPTOMS

As noted in Chapter Two, the most common symptom of Hepatitis C is fatigue while symptoms such as nausea, poor appetite, muscle aches, arthralgia, feverishness, weakness, and weight loss are also experienced. One HCV+ person told the Committee that:

I experience pain all the time in some part of my body. My abdomen is always very tender and painful to touch. I have extreme pain at night in the right upper quadrant (like a heart attack, heart checked thoroughly several times - normal). Other symptoms are: itchiness, rashes, headaches, bowel upsets, eye problems, stiff neck, feeling the cold much more, shivering spells, dry mouth, bleeding, nausea/extreme fatigue (Submission 22).

Participants asked to comment on their condition in a North Coast Hepatitis C study confirmed the range of physical symptoms along with a number of psychological symptoms. In evidence Sladden, of the Northern Rivers Institute of Health and Research, noted that:

...the fatigue and inability to continue with the usual lifestyle is the most commonly reported problem that people experienced in the study that we conducted . . . They suffered from poor sleep, stress and depression, which compounded the problem . . . people obviously have a lot of psychological impacts from this disease (Sladden evidence, 30 March 1998).

For many, the physical symptoms lead to depression, anxiety over the future, social isolation, depression and mood swings, loss of self esteem, the development of mild paranoia, acute stress regarding the decline of control over one's life, even a sense of "identity crisis" due to an inability to remain active socially, personally and professionally. The Committee heard from one HCV positive woman that living with the virus had had, and continues to have, a major impact on her. The virus and its symptoms has led to:

a loss of self-confidence..., loss of self-esteem, loss of energy, a loss of income, because I could not work full-time any more, difficulty with weight gain and self-image, difficulty with word finding when I am tired and not well and, above all, loss of self esteem that I can no longer count on myself to be dependable or reliable (Lamb evidence, 30 March 1998).

Another wrote that:

It is so hard to try and lead any sort of normal life because of other people's ignorance towards the condition. You try to explain but they don't want to know. You get that way that you can't trust anybody. With me, paranoia has set in in a big way (Submission 40).

Yet another HCV positive person had to give up a promising career as an artist when the symptoms started to dominate her life. Even a less physically demanding post-graduate degree could not be coped with:

I had to discontinue my studies for a year due to illness, which was difficult for me as I have been academically a high achiever all my life, and I am used to being energetic, involved and active. I have liver pain, fatigue, and chronic depression, and often feel like I don't have a future anymore (Submission 85).

For many, one of the most difficult aspects of the diagnosis of HCV was the lack of information available and the fact that they have battled with symptoms for many years before an accurate diagnosis was made. The stress and anxiety of not knowing, the Committee acknowledges, adversely affects a person's ability to cope with the disease. As one infected person writes:

[I] was undiagnosed for many years, and even after diagnosis in 1991 found that there was extreme ignorance on the part of even high level professionals as to the cause and effects of Hep C. It is only now that I have fortunately managed to overcome most of the distressing difficulties of the disease (thanks largely to Interferon and much hard work on my part) that I have ceased to feel like a leper and an outcast from society (Submission 42).

Debilitating symptoms are not confined to the disease itself. Interferon, the only approved and available form of drug therapy, often brings with it its own set of physical and psychological side effects (as will be discussed in detail in Section 7.2.1). The Committee heard from one infected person that:

Undergoing the interferon treatment was a very difficult period of my life. I experienced with it severe depression, terrible hives, which nothing would get rid of, increased weight some five stone and difficulty in losing it, lethargy and arthritis (Lamb evidence, 30 March 1998).

The dwindling energy levels and bouts of pain, depression, sleep disturbance and irritability affect all aspects of an infected person's life. Depending on the severity of the symptoms, Hepatitis C can radically affect an infected person's working life, family life, sex life and social life, often resulting in a loss of most aspects of a dignified life.

4.1.2 THE IMPACT OF THE DISEASE ON THOSE WITH MEDICALLY ACQUIRED HCV

- **Recipients of Infected Blood or Blood Products**

Those who contracted the Hepatitis C virus through infected blood or blood products often expressed a combination of frustration, anger, disbelief and bitterness at their diagnosis. As public perception of the virus is still, erroneously, often linked to the issue of "hygiene", several submissions stressed that the disease left them feeling "dirty". One person noted, "... you cannot imagine the shock and feelings of uncleanness that I experienced and still do when I think about it all" (Submission 29), while another recalled that "for a long time I felt dirty" (Submission 1).

The link between Hepatitis C and injecting drug use results in some respondents worrying that they will be stigmatised as users by those to whom they reveal their status. One person commented that she no longer reveals her status to anyone except health care workers because "they straight away think that you have been a drug addict. I don't think that I should have to keep explaining" (Submission 47). Another states that she feels "violated":

These feelings have calmed somewhat but I now find myself in great company. I have something in common with most NSW prisoners, most drug users and unfortunately I am now lumped into this group so I dare not tell anyone that I have HCV (Submission 20).

Others recognised that the issue is not how the disease was transmitted but "how to treat it" (Submission 29). As one person notes:

In my case, no one can blame me for what happened yet I still have the distinct feeling I am a social pariah and have been treated like shit. What hope, then, has some poor bod who experimented with intravenous drugs years ago got? (Submission 69).

- **Health Care Workers**

While Hepatitis C impacts upon the ability of most to work, the Committee has come to appreciate that HCV+ health care workers face additional questions. A positive diagnosis forced one health care worker who wrote to the Committee to ask:

Could I go on working as a registered nurse? Was I a risk to others? Had I already [prior to diagnosis] spread it unknowingly? Should I disclose [my status] socially and/or professionally? (Submission 81).

4.1.3 THE IMPACT ON THOSE LIVING IN RURAL AREAS

Infected persons living in rural NSW are another group who face difficulties in addition to those already discussed. Long distances, few resources, self employment (often as farmers) and small communities are just some of the aspects of rural life which have the potential to intensify the already existing problems for an infected person.

While some respondents describe their family support as good, the lack of resources – including support groups – and the fear of being rejected by the local community can, and often does, lead to isolation and alienation for infected people. As one submission noted “telling anyone other than immediate family about Hepatitis C is not an option in a country town” (Submission 45).

Furthermore, being situated far from tertiary medical centres often affects the infected person’s ability to find information confidentially. One person wrote that:

There are very limited support services down here [south coast], and because of the very nature of a small country town and the gossip grapevine, I feel even more isolated – nobody here wants to put their hand up and admit to this disease – our children may well be persecuted (Submission 38).

Another person added:

In the area I live in there is no support for Hep C people at all. My local doctor admits he knows very little about the virus; the Community Health Centre has no support group or even person; most of the time I feel alone, isolated and sick. Sick of being sick; sick of people’s ignorance, prejudice and paranoia (Submission 73).

The lack of information, confidentiality and support services are, according to the submissions received, the most common problems in rural areas. In addition, the travel to and from tertiary hospitals situated in major regional centres (mainly along the coastline) for tests and treatment is both exhausting and expensive. As a spouse of an infected person, currently living in rural NSW, wrote:

We had to travel to Sydney every two months (very difficult when one is on a pension with no back up finance). It was necessary for me to travel with him due to his condition. It was done for 12 months (Submission 36).

4.1.4 THE IMPACT OF HCV ON PARENTING

Numerous submission written by parents or grandparents highlighted a particular set of issues. For many the possibility of passing the Hepatitis C virus onto their loved ones has imposed enormous strain on their lives and the relationships they have with their partners and children. Lack of energy impacts upon the way they relate to their children and dealings with the wider, extended family can become complicated. These issues are examined in the following discussion.

- **Transmission**

The Committee received a number of submissions that expressed concern over the possible transmission of the Hepatitis C virus from parent (particularly mother) to child. As has been discussed in Section 3.6 research suggests the risk to be low, however, submissions from HCV positive parents and parents to-be still expressed much anxiety and concern.

Submissions referred to contradictory advice being given by medical specialists which only adds to the concern of parents. One woman recounted that the fertility clinic she was attending would not allow her to continue once they learnt of her Hepatitis C positive status despite her gastroenterologist advising the risk of transmission to her baby to be low (Submission 81). A worker with NUAA told the Committee that:

I have had a lot of contact with women . . . there are so many concerns, uncertainty, misinformation, fears, guilt factors . . . I have spoken to a lot of women who have terminated pregnancies on advice that they are Hepatitis C positive and therefore should not have children . . . This is advice from general practitioners, from friends and from people who they would think had the correct information . . . (Poeder evidence, 7 November 1997).

Ms Madden, also from NUAA, added:

there are reports of women being put last on lists for procedures during the day and of women having to fight to get caesarean sections rather than natural births because they might be worried about the amount of blood, tearing and so on, associated with natural birth. It is a real struggle (Madden evidence, 7 November 1997).

Many parents appeared to be overwhelmed by the possibility of having infected their children unwittingly. As one woman writes:

The horrible [fact] that I could have given it to my husband and children began to sink in... I cannot describe the guilt and sheer utter despair I felt in the next week waiting for their results to come back (Submission 21).

- **Family Issues**

In addition to the risk of transmission, the Committee heard that parenting and other family issues present a number of practical difficulties. The combination of pain, exhaustion and general unwellness which the HCV positive person typically experiences severely inhibits their ability to interact with their children. One parent describes it as follows:

I wake up every morning with permanent "morning sickness". Some days just getting out of bed is impossible. My little boys ask me "When will you be better again mummy", "Why can't you play mummy", " You're always too tired, it's not fair". And they're right - it is not fair - not for my children or my husband who has a wife who cannot do her home duties let alone her wife 'duties' (Submission 73).

Another parent adds:

The worst impact is on my family. My...children don't really understand except that Mum is tired and cranky and money is tighter because Mum can't even do as much part time work as before. My husband (an incredible support) is working longer hours to make ends meet as well as often coming home and making dinner or other jobs traditionally mine (Submission 12).

Mothers wrote that:

I see the change in my family. My husband had to stop work when he's a good hard worker. My 15 year old daughter feels she had to step in mum's shoes and had to grow up too fast. My nine year old can't understand why mum can't work in her canteen as I've been told everyone would have to know. I have also lost some family and friends due to not understanding (Submission 55)

and

there isn't a day in my life when I don't think about my prognosis, whether I will live to see my children [aged one and three years] become adults . . . I don't cope very well a lot of the time - emotionally (Submission 1).

These comments are characteristic of the general problems families face according to the submissions presented to the Committee. With smaller incomes, higher medical

expenses, less ability to work and additional duties to be undertaken by the partner, there is a great concern among parents that there is simply not enough time and energy left for their children.

Needless to say, the problems facing single parents with advanced symptoms are even more severe - particularly if the parent in question has had, or still has a drug dependency. During evidence given by a clinical psychologist, the Committee heard of one of such case:

I came across a young woman... who has hepatitis C. She was a drug user. She is now on methadone. She has to attend the methadone clinic six days a week because she has one free day when she is allowed to take a dose home. She has a child who is four and another child who is two. She has to travel seven kilometres each day by three buses, dragging those little kids with her, to get her methadone . . . The location of services is often so poor. Here is this woman with no support and two little kids... That is just one of the many examples around (Lamb evidence, 30 March 1998).

In evidence, Mr Harvey from the Hepatitis C Council told Members of a single mother who was faced with fostering out her children because she was so ill that she could not care for them:

I guess she did not have enough support from family and the community, so she was faced with a shocking decision (Harvey evidence, 3 October 1997).

Problems also arise when the family unit breaks down. Crofts told the Committee of a case he was familiar with in which one partner is refusing custody or access to the other partner on the grounds that the other partner is Hepatitis C positive (Crofts evidence, 28 November 1997).

The medical, economic and social impact of HCV on the family is extensive, particularly in already stressed family situations such as the above. The symptoms of the virus and their fluctuating behaviour radically undermine the energy necessary to hold together even families without special needs and thus put a serious pressure on children/parent relations as well as relations between the parents themselves.

- **The Extended Family**

The epidemiology of HCV in Australia suggests that a large proportion of those infected are 40 years and over reflecting injecting drug use practices engaged in during the 1970s. Consequently, many of these people have families and extended families who are also affected by the diagnosis, making the issue of extended families one of considerable importance. Again, the question of transmission is at the forefront of

concerns for infected people. As one person writes:

My main concerns were 1) did I give it to my wife? 2) Did I pass it on to my grandchildren? 3) Should I tell the rest of my family? ... 4) Where do I get good information on what to do – how not to pass Hep C on to others? (Submission 48).

Another person adds:

My relationship with my family has changed from the time I was diagnosed as they are living in fear that my grandchildren or themselves may be infected. Overnight stays for my grandchildren place everyone on alert as the kids may accidentally use my tooth or hairbrushes, (Submission 43).

While the issues are similar to those faced by the immediate family, the issue of Hepatitis C and the extended family is complicated by the fact that larger numbers of family members are involved and need to modify their behaviour without overreacting through fear. Furthermore, older people may experience great difficulties in admitting to the virus, partly out of fear of rejection from the family, as suggested in some submissions, and partly out of fear of accusations regarding its source. All these issues add to the complication of dealing with HCV in the extended family.

4.1.5 CONCLUSION

Hepatitis C is a condition which affects those infected in a number of ways. The numerous private submissions the Committee received highlighted the day to day reality of the disease and the impact it has had, and continues to have, in a number of contexts on people’s lives and on those of their families and loved ones.

Sladden et al have attempted to quantify the impact of HCV on personal circumstances. Their findings are reported in Table Eighteen below.

TABLE EIGHTEEN
IMPACT OF HCV ON PERSONAL CIRCUMSTANCES (%)

CIRCUMSTANCES	NO CHANGE	CHANGE: WORSENE	CHANGE: IMPROVED	OTHERS/ NOT STATED
Relationship:				
• with partner	69.4	16.1	4.3	10.3
• with household	76.7	11.1	3.9	8.4
Financial situation	69.8	22.7	1.9	5.6
Ability to perform daily tasks	54.4	39.0	1.5	5.1

CIRCUMSTANCES	NO CHANGE	CHANGE: WORSENE	CHANGE: IMPROVED	OTHERS/ NOT STATED
Fatigue	45.4	45.4	3.4	5.8
Diet	48.2	20.3	25.1	6.4

Source: Sladden *et al*, 1998:510

Part of the social impact of Hepatitis C is generated from the lack of general recognition of the problematic extent of the condition. The fact that few infected people knew anything about the virus before they became infected, combined with the widely reported lack of information available from general practitioners upon diagnosis, were described in many cases as contributing to long periods of extreme anxiety and a feeling of being 'in limbo'. One woman who has suffered from numerous serious conditions all her life, some life threatening, describes her reaction to her HCV diagnosis as follows:

I am a fighter, I should have died many times through my life and I have survived, I have an outrageously strong will, and can keep walking when most people would faint from lack of oxygen, from lack of blood. I have felt discomfort every day of my life, and accept that it is possibly true for the rest of it, but during this period [before diagnosis but after the symptoms set in], I was overwhelmed and wanted to die because I couldn't stand having so little control over my body and my life, and not knowing what was wrong with me... I sometimes thought of suicide, which was strange for I had spent so much of my life winning over death. It nearly sent me insane (Submission 88).

She concludes by stating that "feeling ill is unbearable when you are frightened about what and why" (Submission 88). Similar sentiments were expressed in numerous submissions. As these people point out, until an infected person knows what is at stake and what the condition involves and until adequate support is in place for coming to terms with this information, an infected person cannot start to relate to it in a way which may secure progress. Stress and anxiety are not unrelated to the physical aspects of the disease and are likely to undermine a person's ability to cope. It is precisely because HCV affects a person in so many facets of their lives that the well-being of the whole person must be secured in order to create the possibility of living a dignified life with HCV. Rejection and stigmatisation by health professionals, the general public or loved ones is extremely hurtful and only adds to the struggle to cope with the disease.

4.2 DISCRIMINATION AND STIGMATISATION EXPERIENCED BY THOSE WITH HEPATITIS C

The Committee is aware of two studies documenting discriminatory incidents experienced by those with Hepatitis C. The 1997 study by Crofts, Louie and Luff draws upon 37 case histories detailing 41 problematic incidents gathered as a result of information collected by members of Hepatitis C support groups, foundations and councils during the last half of 1994. The study made no attempt to quantify the frequency of discriminatory practices nor the resulting problems. Rather, the aim of the study was to highlight the existence of the problems and to gain some idea of the situations in which they occur (Crofts, Louie and Luff, 1997:89).

The issue of discrimination was also considered in the National Hepatitis C Councils' Education Reference Group's Report into the needs of people living with Hepatitis C (1996). This study records respondents' experiences of discrimination from health care workers, employers, family and friends, the local government, the local community, and government departments (1996:32-38). Many of the examples given are similar to those reported to this Committee by those making submissions and for this reason are not included in the following discussion.

In speaking at the First Australasian Conference on Hepatitis C President of the NSW Anti-Discrimination Board, and Chair of ANCARD, Mr Chris Puplick, referred to the discrimination experienced by people with Hepatitis C as "a secondary or underlying epidemic" which he considered to be "just as prevalent, just as virulent and just as threatening" as Hepatitis C itself (1997:224). In making their submission to the Committee, the Hepatitis C Council noted that the discrimination experienced by those who are HCV+ may be:

institutionalised through insurance and superannuation policies, employment programs, or through the practices of professionals such as doctors, dentists or funeral industry workers (Hepatitis C Council submission).

During the course of this Inquiry, the Committee heard considerable evidence concerning the extent of discrimination and stigmatisation against HCV positive people. Incidents reported included discrimination by health care workers (including nurses, general practitioners, medical specialists and dentists), friends of the infected person, and the general community. These distressing circumstances often result in the infected person opting for anonymity in all aspects of life. One HCV positive person wrote:

I have had a lot of bad treatment towards me by both friends and health professionals. I no longer disclose to friends, dentist, etc, my condition through fear of rejection and stigmatisation. This could be potentially dangerous to an unhygienic practitioner who does not thoroughly sterilise (Submission 54).

Another HCV positive person from a rural area added:

I constantly live in fear of 'someone' discovering my 'secret' and being automatically pre-judged and stereotyped. The guilt I carry is soul destroying! It creates an added stressful burden that intensifies my illness and interrupts what could be a reasonably 'normal' life (Submission 41).

Drawing upon their considerable experience, representatives from the Hepatitis C Council cited several examples of discrimination to Committee Members:

there was the case of one family whose son died of Hepatitis C and the funeral company refused to handle the body, refused to allow a viewing and even refused to carry the casket, . . . we have another case of a TAFE campus here in Sydney where a student's Hepatitis C status was made known to management. It was then made known to tutors and teachers, and those teachers refused to teach a class when that student was present (Harvey evidence, 3 October 1997).

4.2.1 DISCRIMINATION BY HEALTH CARE WORKERS

Before diagnosis, an infected person typically experiences a large number of fatigue related symptoms which may not necessarily be assumed to be of the one cause. Prolonged periods of being unwell and an inability to cope despite the fact that no tests provide any explanation (in cases where Hepatitis C screening is not performed) has, according to many submissions, lead to implicit or explicit accusations of "malingering" or hypochondria. The Committee received numerous descriptions of such accusations:

I knew that I was ill with something, because I would wake at night and vomit, wake in the morning and have continual bad headaches and nausea. The GP clinic I attended was hopeless, I believe because I confided to them that the only thing that stopped the nausea was cannabis. They told me that it was purely mental, not physical. I had no support, my husband did not know how to respond, he wanted me to be as I was before. If there was nothing wrong I should get better, or behave better. If the doctor was right it was mental and I should stop it, it was selfish and unattractive. It was a dreadful time for me as I knew that I was sick but couldn't get help (Submission 88).

Another person added:

...when I became ill I was a postgraduate student with a bright future. I have had to face the possibility of never working again and this has been very difficult to accept, particularly when other have disparaged me as "hypochondriac" and I myself have felt that my illness was psychosomatic

or mere "laziness". Many people (myself included) find it difficult to accept the existence of "invisible" illnesses such as Hepatitis C (Submission 67).

If liver damage is detected before correct diagnosis of the virus, excessive alcohol consumption is often assumed. Once the virus has been properly diagnosed, the assumption of injecting drug use is reported by many HCV positive people as a major obstructing factor in good relations with their doctors. These are concerns expressed both by those who contracted the virus through injecting drug use and those who received the virus through other means.

A number of submissions cited specific incidents of discrimination by their general practitioner or medical specialists. One woman wrote that her gynaecologist of six years no longer wanted to treat her once her HCV status became known (Submission 54). Another recounted that:

From the beginning every doctor I saw was hopeless; most were disdainful - I was just another junkie slag. I had a routine check for a congenital heart defect and remember the cardiologist doing the routine flirt then backing away when learning I was positive, telling me with disgust how skinny I was (Submission 15).

Loveday told Committee Members of an incident recounted to him by a gentleman who contacted the Hepatitis C Council's telephone service. The gentleman had visited his general practitioner "of longstanding" to have a full range of tests as he and his partner were considering starting a family:

He got all the test results and when his doctor got to the HCV result section, which was positive, his doctor said "now that you know that, I don't want anything more to do with you" (Loveday evidence, 7 November 1997).

Others recounted incidents experienced in hospitals where they felt "branded". Mr Loveday, from the Hepatitis C Council spoke of those who, upon disclosing their status within the health care setting, were "marked as having Hepatitis C through yellow armbands or through their new-born babies' bassinets being marked with a particular sticker" (Loveday evidence, 3 October 1997). In responding to these practices, NSW Health advised the Committee that:

the Department is aware of, but does not support, the routine use of coloured tags, sign posting or marking of patient records to indicate the presence of known infectious disease. The Department has advised Area Health Services of its position on this issue. The routes of diseases transmission and the unknown levels of infectivity in the general patient population make the use of armbands or prompts artificial protective measures. In addition, the use of surrogate markers potentially breaches

patient confidentiality as those persons who understand the code indicated by the marker immediately know the patient's condition, regardless of whether or not they require the information for the purpose of providing health care (NSW Health supplementary submission).

Other stories presented to the Committee include:

I was locked away in a little room somewhere [in the hospital], food was poked through a door and hospital staff would gown up and swathe themselves and come and talk to me (Smart evidence, 26 February, 1998).

One person wrote:

I remember in hospital once seeing my notes which were marked "drug addict". I never told anybody that. It just came from being Hep C positive (Submission 66).

Other incidents include:

When I was a patient in our local private hospital after the birth of our second son. The nursing staff had written on my bed notes and the baby feeding chart "Mother is HCV +ve" and had a large yellow contaminated waste bin at the door of my single room. This caused a lot of unnecessary stress and anxiety . . . had any of my visitors or nursing colleagues seen this? (Submission 81).

and

I recently went to hospital and was given a yellow toxic bag for my rubbish - nobody else on the ward had this. This told the other people on the ward that something was wrong with me . . . This was very upsetting (Submission 47).

Of the case studies reported to Crofts, Louie and Luff in their 1997 study, approximately one-half (46%) of the cases occurred in health care settings. In speaking on the results of his study during his appearance before the Committee Crofts referred to "many instances" of discrimination, some of which were "devastating":

stories of doctors advising women to have terminations of pregnancy because they are Hepatitis C positive, a lot of it around pregnancy and birth (Crofts evidence, 28 November 1997).

In commenting on the role of health care workers in addressing the issue of discrimination against those with Hepatitis C Puplick has stated that:

I stress the responsibility of people in the health care system itself to take a lead in the elimination of discrimination against people with Hepatitis C.

It is a sad fact that many people do not present for treatment, or receive inadequate treatment because they are intimidated by the attitude of the medical profession towards them. It is not the role of that or any other profession to be judgemental, but rather to act in accordance with the best standards and principles of their profession, treating people as human beings with the need for medical attention and rendering it accordingly (Puplick, 1997:228).

In appearing before the Committee Puplick spoke of the “extraordinary” amount of discrimination against those who are HCV+ and that “regrettably” a “large amount” of that is from health care workers and providers of health care services (Puplick evidence, 7 November 1997). In his opinion:

that is something which Area Health Services, the Department of Health, the professional colleges and unions need to address because it is a very serious problem (Puplick evidence, 7 November 1997).

The ANCARD Hepatitis C Sub-committee has recommended research into the knowledge and attitudes of health care professionals towards HCV (Hepatitis C Virus Projections Working Group, 1998:33). The Hepatitis C Council recommended the statewide implementation of general practitioner and health care worker education to address discrimination (Hepatitis C Council submission). It proposed that these programs cover values and attitudinal change and that they be both initial and ongoing (Hepatitis C Council submission). The Committee feels that the National Hepatitis C Education Program for General Practitioners currently being implemented (see Section 8.4.1 for discussion) may go some way to addressing the values and attitudes of general practitioners. However it does acknowledge that this program will only target medical practitioners and not other health care workers in hospitals. In the Committee’s opinion, there is a need for all those working in the health care sector to be aware of Hepatitis C related discriminatory practices, values and attitudes.

RECOMMENDATION 19:

That NSW Health design and implement an awareness campaign for all those working in the health care system addressing practices, values and attitudes that discriminate against those with Hepatitis C accessing the health care system.

In proposing this awareness campaign, the Committee saw merit in Puplick’s comment cited earlier in which he referred to the importance of the relevant professional colleges and unions addressing Hepatitis C related discrimination.

RECOMMENDATION 20:

That the Minister for Health meet with representatives of the various professional colleges (including the Royal College of Surgeons, Royal College of General Practitioners, and Royal College of Nursing) and unions and urge them to support the awareness campaign addressing Hepatitis C related discrimination in the health care system proposed in Recommendation 19.

- **Privacy Related Issues**

During the course of giving evidence the Committee heard of instances where breaches of confidentiality had occurred and people's Hepatitis C status made public. One witness told the Committee that:

my recent experience is in a large public hospital where I had been accessing treatment for Hepatitis C . . . An appointment for a biopsy was re-scheduled. A call was made to my home. To some degree there was a breach of confidentiality. The staff member from the hospital identified from which department he was calling, which pertained to liver biopsy. The caller pressed my flatmates for a further contact number, and my flatmates furnished the caller with a contact number at work. I work in public health. The call went to the front desk [of my work], then administration staff, where there was another breach of confidentiality, pertaining to which department, pertaining to a scheduled biopsy and my full name . . . the call then went to the nurse practitioners. More information was given to them. By that stage a staff member from the hospital became aware that I was not a client of the hospital, but a staff member. The call then went to my clinical supervisor who discussed the situation and became fully aware of my status. My clinical supervisor re-scheduled the biopsy for me.

In discussing the consequences of this incident with Members, the witness stated:

I did not give permission to anyone to disclose this information. Suddenly I am informing [my flatmates] of what Hepatitis C is about, and I feel I have to justify myself, defend myself and explain myself. As a part of the breach of confidentiality with administration at work, staff members have become aware of some of my injecting drug use history, my past history. Being from the nurse practitioner unit, they have also expressed concern and shock at the degree of disclosure that came from the staff member at the hospital at which I was accessing treatment. Furthermore, my clinical supervisor is aware of the situation and I have felt it necessary to discuss with him the pros and cons and the specifics of my drug use . . . My history is open to some discussion and hearsay, and I am at the

point at which my continued employment in that organisation is questioned. The director cannot give me assurances as to what will occur.

Mr Puplick raised the issue of privacy legislation during his evidence. He felt it was urgently needed to address many of the problems experienced by those who are HCV+. He noted that:

for 12 years the Privacy Committee of New South Wales has been pleading with this Parliament to enact privacy legislation, which has been promised ad nauseam. Attorney General Hannaford had a bill before the Legislative Council prior to the last election . . . This Government was elected promising the enactment of privacy legislation. Attorney General Shaw on four separate occasions has announced the imminence of the legislation. There is still no legislation and as a result the health status privacy issue remains one of the most sensitive. People whose health status is revealed improperly have absolutely no means of redress within New South Wales (Puplick evidence, 7 November 1997).

Mr Puplick added that:

if proper privacy laws were in place there would be at least some regime, some protocol, some redress. It remains extraordinarily unfortunate that the New South Wales Parliament just will not address this as an issue, and until the Parliament does address it, the providers of health care cannot be expected to do anything other than behave in the way they have traditionally done (Puplick evidence, 7 November 1997).

The Committee notes that the *Privacy and Personal Information Protection Bill* was introduced into the Legislative Council on 17 September 1998. During the Bill's second reading speech, Attorney General, the Hon J Shaw, MLC, noted that the purpose of the Bill is:

to promote the protection of privacy and the rights of the individual by the recognition, dissemination and enforcement of data protection principles consistent with international best practice standards (Shaw, 1998:7598).

He proceeded to identify the objects of the Bill:

to promote the protection of the privacy of individuals; to specify information protection principles that relate to the collection, use and disclosure of personal information held by public sector agencies; to require public sector agencies to comply with these principles; to provide for the making of privacy codes of practice for the purpose of protecting the privacy of individuals; to provide for the making of complaints about

privacy-related matters, and for review of conduct that involves the contravention of the information protection principles or privacy codes of practices; and to establish an office of Privacy Commissioner and to confer on the Privacy Commissioner functions relating to privacy and the protection of personal information (Shaw, 1998:7599).

The Bill was read a third time in the Upper House on 28 October 1998 and then referred to the Legislative Assembly. At the time of tabling this Report, the Bill was scheduled for debate in the Lower House.

4.2.2 DISCRIMINATION BY THE GENERAL COMMUNITY

Stories such as the following are typical of submissions received by the Committee:

I told one of my friends I have Hep C with only limited knowledge myself. I could not properly explain what it was all about. She assumed it was like AIDS and has had nothing to do with me, she won't have her kids play here either. I think she assumed I was a junkie, I don't really know. Her reaction stopped me telling anyone else (Submission 7).

Such an experience with a friend or acquaintance often stops HCV positive people telling others of their condition. Further, the realisation that one's children might be affected by local community perceptions only adds to their distress. As one person from a rural area commented, combatting the disease and the discrimination simultaneously and with so little public information at hand makes the condition almost unbearable (Submission 47).

One of the very severe cases of discrimination of which the Committee was informed involved a church-going couple from a metropolitan area:

[My wife and] I were forced to leave the ... church we started to attend, when the members learnt that I had HCV. They had some quite erroneous notions about HCV, such as "It leads to full blown HIV/AIDS"; or, I might suddenly have an accident and cut myself and they would all be infected by me. Disturbingly the opposition [to us] was fanned by one member, a GP! This really hurt us (Submission 22).

The Committee also heard of discrimination impacting upon work. During the course of evidence, the Committee heard from a young HCV+ woman:

I have had problems with work in a way. I was doing hospitality, and when they learnt that I was Hepatitis C positive they did not want me to work in the kitchen. If you put down that you are Hepatitis C positive you do not get the job. Then I changed and wanted to do child care, but I am not having much luck with that. So there is not really much I can do. If you put it down, you will not get the job; if you do not put it down, you are lying to them (Howell evidence, 7 November 1997).

Puplick has noted that discrimination against people with Hepatitis C is against the law (1997:227). In areas covered by legislation (such as employment, the provisions of goods and services, state education, the operations of registered clubs and in relation to accommodation) discrimination is contrary to the disability provisions of the NSW *Anti-Discrimination Act, 1997* and (in a slightly wider context) the provisions of the Federal *Disability Discrimination Act, 1992*. He also informed conference participants that the Anti-Discrimination Board of NSW has issued formal guidelines explaining the provisions of the state's legislation and making clear that discrimination on the basis of Hepatitis C constitutes an offence and provides a legitimate basis for people to make formal complaints (Puplick, 1997:227).

In their discussion on anti-discrimination legislation in Australia, Crofts, Louie and Luff also identified the *Disability Discrimination Act* along with the *Human Rights and Equal Opportunity Commission [HREOC] Act, 1986*. The HREOC Act gives the Commission power to investigate breaches of the Declaration of the Rights of Disabled Persons. Infringements of the Declaration are not of themselves necessarily unlawful. The Commission can therefore only hold inquiries into complaints of discrimination or violation of human rights. It has no power to conduct formal hearings or complaints (Crofts, Louie and Luff, 1997:94).

While the Hepatitis C Council suggested discrimination to be "relatively widespread" (Hepatitis C Council submission), the extent of discrimination against HCV positive people in the general community is almost impossible to estimate. During the course of this Inquiry, the Committee has come to appreciate the problem to be extensive.

Due to the present levels of ignorance and stigma surrounding the disease, those who choose to disclose their status are often treated with disrespect, hysteria, coldness or rejection. While most infected persons who contacted the Committee choose to inform medical practitioners of the virus, few inform more than very close loved ones. Many even express deep regret about having told friends, only to be abandoned and ostracised. HCV positive people have an important contribution to make to the promotion of public understanding of the disease, its transmission and prevention, but are often unable to make this contribution because of the public's response to them as infected people.

4.2.3 DISCRIMINATION EXPERIENCED BY INJECTING DRUG USERS WITH HEPATITIS C

For many people with Hepatitis C, discrimination relating to Hepatitis C is actually the least of their problems. Because of the discrimination relating to their injecting drug use status, Hepatitis C is just the icing on the cake - double stigmatisation (Crofts evidence, 28 November 1997).

The Hepatitis C Council noted that a "large part" of discrimination and stigmatisation is associated with injecting drug use and attitudes towards those who inject (Hepatitis C Council submission). As the submission notes, many people with HCV are assumed

to be current injecting drug users regardless of their mode of infection, or whether they had used some time ago. The labelling of drug user, or the more negative term “junkie”, can become barriers to people seeking assistance as they fear that they will encounter these reactions from health care providers.

The Council’s submission also notes that current injecting drug users in particular may experience an additional layer of stigmatisation associated with criminality, arising both from the criminal nature of drug use itself, and also the fact that a substantial amount of property crime is committed by people needing to finance their drug use (Hepatitis C Council submission).

Puplick also noted the impact of the illegal nature of injecting drug use during the course of his evidence:

the discrimination which has taken place against people who are Hepatitis C positive undoubtedly stems in a large part from the fact that they are perceived as part of a group of people who have engaged in illegal behaviour at some stage in their life although . . . that may have been a single incidence 20-odd years ago in an experimental situation, not since repeated. The attached stigma persists and very often has negative consequences in encouraging people to come forward to be tested and subsequently receive treatment (Puplick evidence, 7 November 1997).

Injecting drug users utilising the health care system also appear to experience difficulties. Puplick told the Committee that:

it frequently occurs in clinical situations that people who are HCV positive are those who are always attended to last, on the basis that junkies do not really matter in the provision of health care services (Puplick evidence, 7 November 1997).

Speaking more generally Puplick informed Members that:

there is also a considerable amount of complaint, arising from breaches of privacy, that people’s employment has been threatened or indeed terminated because they are HCV positive, on the assumption that they are a high risk because they are all current injecting drug users; which of course is not the case (Puplick evidence, 7 November 1997).

4.2.4 CONCLUSION

The Committee has come to appreciate that, particularly in relation to the issue of discrimination, Hepatitis C is a medical condition, not a political issue or a moral question of right or wrong. As such, the dissemination in the community and among the broader medical services of thorough and inclusive information about the condition will

be of help both as a ground for appropriate preventative strategies and as a step towards eliminating the kind of discrimination currently encountered on a regular basis by HCV positive people. The issue of education is considered in detail in Section 10.6.

Crofts, Louie and Luff note that the National Action Plan on HCV does not mention the issue of discrimination or examine strategies for its prevention, reduction or redress (1997:96). The Committee considers this to be most unfortunate. Members trust that any revision to the Plan resulting from the evaluation currently underway will take the issue of discrimination into consideration.

While the National Action Plan did not consider the issue or propose strategies to address the issue, a number of organisations have considered the issue and forwarded recommendations. The ANCARD Hepatitis C Sub-committee has, for example, recommended the systematic documentation of discrimination against HCV-infected people with investigation of underlying factors (Hepatitis C Virus Projections Working Group, 1998:33). Along similar lines, the National Hepatitis C Councils' Education Reference Group noted the impact of the NSW Anti-Discrimination Board's inquiry into discrimination and HIV/AIDS and its resultant report, *Discrimination: the other epidemic* (1992). This report recommended legal and administrative changes across a wide range of activities. The Reference Group proposed that similar inquiries need to be held in all states and territories to raise awareness about discrimination against people with Hepatitis C (1996:40). The Committee fully supports this recommendation.

RECOMMENDATION 21:

That the Attorney-General instruct the Anti-Discrimination Board to conduct an inquiry into discrimination and Hepatitis C in New South Wales. The Committee further recommends that the resultant report of this inquiry be distributed widely to relevant employer and employee organisations, trade unions, education institutions, hospitals and relevant community organisations (such as the Hepatitis C Council of NSW) across the state.

The Hepatitis C Council has proposed the development and implementation of public awareness campaigns to inform and educate people about HCV. This latter proposal is taken up in Section 10.6 which looks at a national education/information campaign. The Hepatitis C Council also recommended the design and implementation of private and public workplace education programs, both initial and ongoing, particularly in areas which impact directly on people with HCV such as social security, day care centres, funeral and prison settings (Hepatitis C Council submission). A similar recommendation was made by the National Hepatitis C Councils' Education Reference Group which called for education for employers, service providers and the general community (National Hepatitis C Councils' Education Reference Group, 1996:40).

RECOMMENDATION 22:

That the Premier direct an education campaign be designed and implemented across all sectors of the public service addressing practices, values and attitudes that discriminate against those with Hepatitis C and ensuring that those working for the government are aware of the illegality of discriminating against those with Hepatitis C.

It has also been proposed that people with Hepatitis C need information to ensure they are aware of their legal rights and of ways to address discrimination (National Hepatitis C Councils' Education Reference Group, 1996:40). A brochure addressing these issues entitled *Discriminating Against People Living with Hepatitis C* has been developed by the Equal Opportunity Commission Victoria (1996). The Committee is aware that the Anti-Discrimination Board of New South Wales has produced a factsheet entitled *Discrimination Against People with Hepatitis and Other Infectious Diseases* (undated). The Committee understands that the Board does not have the financial resources to produce factsheets aimed at people with specific infectious diseases and as a result, a factsheet specifically designed for those with Hepatitis C has not been available in the past.

The Committee also understands that when the factsheet was reprinted in 1997 all references to hepatitis were deleted and the generic term "infectious diseases" used instead. As the Board informed the Hepatitis C Council "hopefully this will encourage people to contact the Public Health Unit to find out about individual infectious diseases" (Dustmann correspondence, 21 July 1997). While fully appreciating the financial constraints of the Anti-Discrimination Board, the Committee does not consider it satisfactory that the only brochure addressing discrimination for Hepatitis C people now has no mention of the disease. The Committee wishes to see information specifically targeting those with Hepatitis C made available to ensure they are fully informed of their rights when experiencing discrimination.

RECOMMENDATION 23:

That the Anti-Discrimination Board of New South Wales design an information brochure informing those with Hepatitis C of their legal rights and action they can take to address discrimination. The Committee further recommends that the Hepatitis C Council of NSW be given responsibility (and adequate funding) to distribute this brochure.

RECOMMENDATION 24:

That the Attorney General provide adequate funding to the Anti-Discrimination Board of New South Wales for the design and development of the information brochure proposed in Recommendation 23.

In forwarding these recommendations addressing the issue of discrimination against those with Hepatitis C, the Committee is aware of the range of resources and services addressing the issue of discrimination that are available to those with HIV/AIDS such as the HIV/AIDS Legal Centre (HALC) run in conjunction with Community Legal Centres, the *HIV Legal Link* magazine, HIV-specific resources developed by the NSW Anti-Discrimination Board and specifically funded legal positions at ACON.

4.3 THE ECONOMIC IMPACT OF HCV

In considering the economic impact of Hepatitis C the Committee has looked at two aspects: the impact of the disease upon those who are HCV positive and the broader impact upon the community as a whole. Both of these issues are considered in the following discussion.

4.3.1 THE ECONOMIC IMPACT OF THOSE WITH HCV

Given the chronic nature of the Hepatitis C infection and the commonly experienced fatigue related symptoms, the disease has an economic impact upon many of those with Hepatitis C. The submissions received by the Committee suggest that many HCV positive people with serious symptoms are unable to continue working in their ordinary capacity. One gentleman who retired early as a result of his Hepatitis C wrote openly of the economic impact Hepatitis C has had upon his life:

My income dropped from around \$40,000 in 1995 to a Beneficiary Fund amount per annum of \$10,884. My wife worked at Hospital X but her worry about me caused her to seek a position closer to home. She was fortunate to find a position at Hospital Y but this meant a drop of \$3,000 in salary too. I require constant medication for the many complaints I have and this is quite a drain on resources. We keep up our MBF cover as this means less wait for tests to be done . . . and this is much too expensive. I do not qualify for any pension or benefits, but the Pharmaceutical Safety Net is no some help as I pay reduced amounts for prescriptions (Submission 22).

Another wrote that:

[T]o be honest, when I feel OK . . . there is no happier person, because I know that that day I will be able to work and to be active at home as well. This is a day for celebration, and I always do so, because I value every hour of being OK, having in mind that . . . the next day I won't be able to move from my bed for the rest of the week . . .

. . . out there in the job market there is no tolerance for such a fluctuated behaviour, no one will tolerate that their worker is OK one day, not OK for two days and [only] so-so for the rest of the week. No company will tolerate this kind of worker (Submission 51).

During the course of evidence the Committee heard that:

I have started working with handicapped people in a part-time job. That is all I could handle. I could not handle full-time work, because after a full-on day at work I need a day to recuperate. It is just that I am in a job in which I do some night shifts . . . or sleep-overs, and I do them when I have got time to recuperate. I could not work full-time.

The effect of chronic tiredness limits many from working full-time:

I do not think I can work a full day's work. It is just fatigue . . . I just get too tired . . . I cannot be up for eight hours.

HCV positive people in rural areas are also adversely affected by the fact that they are often self-employed on family run farming properties. Although this may initially provide some flexibility, the inability to work frequently puts already financially vulnerable businesses at risk:

living on a property some 200 kms from a major centre hindered by search for information. The thought of not working is an anxious one. We own a cattle property. Our sons are away at boarding school. Our economic situation would change (Submission 19).

Tim Sladden of the Northern Rivers Institute of Health and Research noted that:

people found it difficult to work and obviously their financial situation was affected by that (Sladden evidence, 30 March 1998).

Of all professions, the economic impact is possibly greatest upon those HCV+ people who are health care workers. As will be discussed in Section 10.3 surgeons who test positive are not able to perform exposure prone procedures. For many surgeons this eliminates many procedures they routinely perform forcing them to either retrain or retire from surgery. Other health care professionals such as dentists and nurses are often put in a similar situation. The Committee heard from one nurse that:

Because [among other things] the incredible stress associated with managing infected clients, I found I was unable to continue at work. The consequences for me are:

- *loss of employment*
- *my [very long term] relationship failed. Consequently my home and assets are now at risk due to a pending property settlement . . . The drain on my assets makes any potential future expensive treatment unlikely;*

- *stress and depression has resulted in the need to seek support from a psychiatrist on a regular basis (Submission 82).*

4.3.2 THE ECONOMIC IMPACT OF HCV ON THE COMMUNITY AS A WHOLE

The economic impact of HCV will, of course, depend on the number of people infected, the course of the disease and the cost of providing treatment, care and support. As will be discussed, various estimates were provided to the Committee but, as NSW Health pointed out, data on which such estimates are made are constantly changing (NSW Health tabled document, 3 October 1997).

the combination of a larger pool size of infected individuals and more protracted complications leads to the perhaps unexpected conclusion that the net health and economic cost of Hepatitis C may even be roughly comparable with HIV (Wodak and Crofts, 1996:182).

The cost of chronic Hepatitis C in the USA in terms of medical care and lost working days has been calculated to be approximately US\$600 million per year (cited in Schering-Plough submission).

The Committee is aware of three studies that examine the economic impact of Hepatitis C in Australia. Shiell, Briggs and Farrell (1994) model the costs of interferon therapy in the treatment of chronic, active Hepatitis C. Briggs and Shiell's 1996 study also looks at interferon in terms of its costs and benefits. Both of these studies are reviewed in Section 7.2.1. The third, and most pertinent to the question of economic impact of the disease (rather than the medication) has been prepared by Brown and Crofts (1998).

Applying a Markov cohort approach, Brown and Crofts estimated the health care costs of the Hepatitis C epidemic amongst injecting drug users in Australia. According to their calculations, **for every 1,000 injecting drug users newly infected with Hepatitis C in a given year, there is an implied \$14.32 million in health care spending over the years as the disease's sequelae become manifest** (Brown and Crofts, 1998:386; Crofts evidence, 28 November 1997).

They also calculate the exponential growth in the projected cumulative total costs to Medicare associated with the management and treatment of successive cohorts of 1,000 chronically HCV infected persons. According to their calculations, **after approximately 60 years, the cumulative total cost will be approximately \$0.5 billion (1994 dollars)** (Brown and Crofts, 1998:387).

As was discussed in Section 3.1, the current 8,000 - 10,000 new HCV infections each year give rise to approximately 6,500 - 8,000 chronic carriers of HCV. If such estimates are accurate, Brown and Crofts calculate that **HCV among injecting drug users is costing \$90-115 million per year (1994 dollars) in direct health care costs alone**

(Brown and Crofts, 1998:388). Such an amount equates to approximately 0.5% of the total 1994 health budget (Brown and Crofts, 1998:388).

Over the next 60 years, with an estimated 10,000 new HCV infections in Australia each year the total direct healthcare costs will be approximately \$4 billion over that period (Brown and Crofts, 1998).

Building upon Brown and Crofts findings, NSW Health's submission calculated that the implied health service spending for those currently infected in NSW would be \$601.44 million (expressed in 1994 dollars) over their lifetimes after infection (NSW Health submission). In terms of new HCV infections, the Department's submission proposed that 2,000 of the estimated 4,000 new infections estimated to occur in NSW each year will remain chronic carriers (a conservative estimate assuming 50% of those infected will remain chronic carriers), adding \$28.64 million to the state's long term health care bill for each year's cohort (NSW Health submission).

Brown and Crofts' estimate is considered to be conservative for a number of reasons including:

- their projections are based on numbers of injecting drug users only and do not take into account those who already have the infection from other sources;
- the costings are for direct medical costs only such as ambulatory visits associated with ongoing monitoring and in-patient admissions to hospital for treatment over the course of the disease (Brown and Crofts, 1998:385);
- direct and indirect costs incurred by patients and their families and the way in which the disease may impinge on the ability of individuals to participate in the paid workforce or the costs of premature mortality are not factored in; and
- public funds for disability pensions for those whose Hepatitis C precludes them from working is not factored into the model (NSW Health submission).

Brown and Crofts note that these limitations:

reflect both the limited epidemiologic data available for the purpose of assessing the impact of Hepatitis C infection and the need for further research in this area (Brown and Crofts, 1998:385).

4.4 THE IMPLICATIONS OF HEPATITIS C UPON FUTURE HEALTH FUNDING, PLANNING AND POLICY

Given the estimates proposed by Crofts and Brown and discussed above, the implications of Hepatitis C on future health funding are profound. If \$4 billion is to be

spent on Hepatitis C this money will not be available for services. Wodak noted this impact in his submission and commented that:

At the very least, the epidemic of Hepatitis C will have an impact on the general population of non-drug users by consuming large quantities of scarce health resources (Wodak submission).

If such significant resources are having to be spent on treating the Hepatitis C virus, there are profound consequences for health planning and, in turn health policy. Given the implications of Hepatitis C it is essential that governments at both state/territory and federal level get health policy right and get it right promptly. The Committee's proposals to assist in that process are outlined in Section 5.4.2. The Committee is not convinced that governments - at both the federal and state level - have as yet, fully grasped the enormity of Hepatitis C, its impact, particularly economic, and the implications it will have upon health funding, planning and policy. As will be discussed in the next chapter current policies addressing Hepatitis C in New South Wales are less than adequate and there is an urgent need for action.

4.5 NEED FOR FURTHER RESEARCH INTO THE SOCIAL AND ECONOMIC IMPACT OF HEPATITIS C

The Committee is aware of difficulties a number of researchers have experienced in attempting to conduct research into the economic impact of Hepatitis C. Shiell, based at the Department of Public Health and Community Medicine, University of Sydney, sought research funding from the NHMRC to evaluate the personal, social and economic impact of Hepatitis C. Although his grant proposal was "deemed fundable" he did not receive any funding (personal communication, 10 December 1997).

Dr Crofts told the Committee of two submissions for research that went before the NHMRC in 1997 and both failed (Crofts evidence, 28 November 1997). He also informed Members that the Commonwealth had tendered for groups to do work on the social and economic impact of Hepatitis C and then withdrew the tender (Crofts evidence, 28 November 1997). He concluded that "I think the money for that disappeared and I think the process has disappeared too". As a result there is "virtually nothing to go on" (Crofts evidence, 28 November 1997).

In appearing before the Committee, Crofts recounted the difficulties he experienced in getting his economic analysis study published. He informed Members that the paper had been sent to the *Medical Journal of Australia* but, despite receiving good referees' reports, was turned down on the basis that "it was not of sufficient general interest" (Crofts evidence, 28 November 1997). The Committee is somewhat amazed that a disease that will cost the health system an estimated \$4 billion was not considered to be of sufficient general interest.

In appearing before the Committee the Executive Officer of the NSW Hepatitis C Council, Mr Stuart Loveday, was specifically asked if the difficulties experienced by Crofts and Brown and Shiell were indicative of a general reluctance to quantify the economic impact of Hepatitis C. Mr Loveday indicated that he believed that to be the case, adding that:

one gets the feeling that if one delays the knowledge of the size of the problem then the problem does not seem as bad, but we know from past evidence that it is a major problem (Loveday evidence, 30 March 1998).

Numerous calls have been made for research to be undertaken into the social and economic impact of Hepatitis C. Loxley, for example, has observed that:

There are social costs and consequences to those who live with Hepatitis C and too little is known about these. Discrimination and public attitudes are a part of this, but beyond that there are relationships, employment, accommodation, parenting and a range of other issues to consider. All of these are amenable to, and deserve to be researched (Loxley, 1997:58).

Crofts commented during the course of his evidence that:

currently we are in that position where we are just not looking for the impact of Hepatitis C. It would be quite easy to do, but it would make very clear that there is a need for a lot more action, a lot more expenditure (Crofts evidence, 28 November 1997).

In March this year the Federal Minister for Health announced \$1 million would be made available for Hepatitis C research (Wooldridge, 1998). The Committee understands that a set of guidelines for grants have been developed by the NHMRC. The guidelines that will be used are:

The Australian National Council on AIDS and Related Diseases and the National Health and Medical Research Council, through its Strategic Research and Development Committee, are seeking research proposals that are rigorous and innovative and will result in making a difference in reducing the spread of Hepatitis C or improving the quality of life for people living with Hepatitis C.

Applications are called for in social and behavioural research which meet the following objectives:

- *research will be funded that is an intervention, or that will lead to an intervention, to reduce the spread of Hepatitis C in Australia;*

- *research will be funded that investigates ways to minimise the personal and social effect of Hepatitis C;*
- *epidemiological research will only be funded where it meets the first objective. Counting exercises will not be considered; and*
- *drug trials will not be considered for funding (Federal Parliament Liaison Group on HIV/AIDS and Related Diseases, 1998:3).*

ANCARD's Hepatitis C Sub-committee has called for investigations into the personal, social and economic costs of HCV infection to individuals, the health care system and to society (Hepatitis C Virus Projections Working Group, 1998:32). In its submission to this Inquiry, the Hepatitis C Council also recommended that studies into the social and economic costs of Hepatitis C infection be supported and funded (Hepatitis C Council submission). The Committee fully supports these recommendations which, Members feel, are broader than the research that will be funded by ANCARD and the NHMRC.

RECOMMENDATION 25:

That the Minister for Health direct research be undertaken into the personal, social and economic costs of Hepatitis C infection to individuals, the state's health care system and to society.

Given the extent of discrimination experienced by those living with Hepatitis C the National Hepatitis C Councils' Education Reference Group (1996:40) has specifically called for social research into the causes of Hepatitis C related discrimination to assist in formulating programmes to combat it. The Committee considers this proposal to have considerable merit and fully supports the recommendation.

RECOMMENDATION 26:

That the Attorney General request the NSW Anti-Discrimination Board conduct (or commission) social research into the causes of Hepatitis C-related discrimination.

The Committee further recommends that the findings of the proposed research be used in formulating programs to combat this form of discrimination including those programs proposed in Recommendations 19, 22 and 129.

4.6 CONCLUSION

From a number of perspectives, the impact of Hepatitis C is enormous. The social impact of the disease is, as has been documented, profound and touches every facet of life - social, sexual, economic, physical and emotional. The impact is not only felt by the person with Hepatitis C but their immediate and extended families, friends, work colleagues and neighbours. Many not only have to deal with the disease and its debilitating side effects but also discrimination and stigmatisation from a range of sources including (and often surprisingly) health care workers.

The economic impact upon the wider community is considerable. As Batey concluded:

we are looking at a cost of some billions of dollars into the new millennium when patients have had their disease for twenty, thirty or forty years (Batey evidence, 27 October 1997).

The Committee is not convinced that governments - be they federal or state - have as yet, fully grasped the enormity of Hepatitis C, its impact and the implications it will have upon future health funding, planning and policy. As will be discussed in the next chapter current state policies addressing Hepatitis C are not considered to be adequate and there is an urgent need for decisive measures to be taken to redress the current situation.