

CHAPTER 3

THE IMPACT OF HEPATITIS C

I am no longer the happy person my family and friends knew, I am now quiet and withdrawn most of the time. This disease has devastated my life and my family.¹

3.1 The diagnosis of hepatitis C is often accompanied by a severe emotional and psychological response. People with hepatitis C face deteriorating health and the prospect of an early death. They also face a range of social and economic problems. The impact is not limited just to those who have contracted HCV: their families and friends are also affected.

Health issues

3.2 For those with hepatitis C, the health issues vary as there is no single typical course or natural history of the disease. It is a broad spectrum of disease presentations and outcomes.² Hepatitis C has also been described as a 'silent' disease with many people being unaware that they have the infection. Most people will be free of symptoms for the first ten years or more after their initial infection.³

3.3 Hepatitis C infection involves an initial (acute) phase of infection, which usually lasts from two to six months. This phase is often asymptomatic with only about 20 per cent of cases having symptoms.⁴ Between 65 and 85 per cent of people infected will develop a long-term (chronic) infection. Many of those with chronic infection will have long term health consequences. For the remainder, the hepatitis C virus is cleared from the body. Antibodies to the virus persist after viral clearance, declining over time.

3.4 Chronic hepatitis C is determined by persistently abnormal serum enzymes and/or viraemia. People with chronic hepatitis C can remain well for some time without any liver damage or symptoms. The Hepatitis C Council of NSW advised that 'it is only in the relative long term – 10, 15 or 20 years later – that people start to notice an impact on their physical health'.⁵ For those with chronic hepatitis, some will progress to cirrhosis, liver failure or liver cancer. The Council provided the following information:

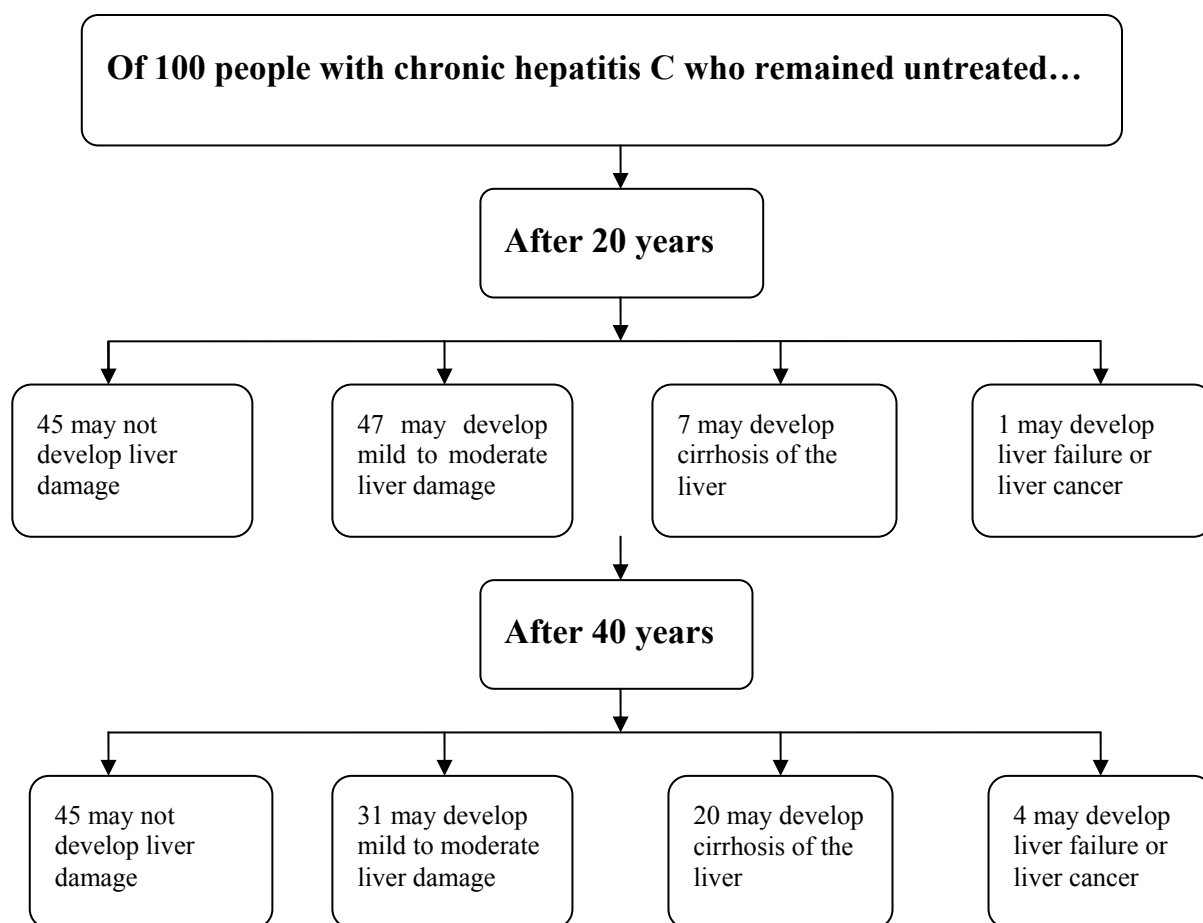
1 *Submission 8, p.5.*

2 Parliament of NSW, Legislative Council, Standing Committee on Social Issues, *Hepatitis C: The Neglected Epidemic Inquiry into Hepatitis C in NSW*, Report No 16, 1998, p.23.

3 www.heptatitisaustralia.com

4 *Committee Hansard 6.4.04, p.4* (Hepatitis C Council of NSW).

5 *Committee Hansard 6.4.04, p.4* (Hepatitis C Council of NSW).

Figure 3.1: Chronic hepatitis C outcomes chart (natural history)

Source: Submission 81 (Hepatitis C Council of NSW).

3.5 The hepatitis C virus does not directly damage the liver. The liver damage results from repeated attempts by a person's immune system to destroy infected cells within the liver. The liver forms scar tissue (fibrosis) in response to the hepatitis C related inflammation.

3.6 There are six main genotypes of hepatitis C which are generally recognised with many sub-types (around 10 in total). The most common genotypes in Australia are 1a, 1b and 3a.⁶

3.7 The symptoms of chronic infection can range from mild to severe. They can occur occasionally or can be continuous. The most common symptoms are fatigue and lethargy. Other symptoms include nausea, poor appetite, muscle aches, weakness, weight loss, abdominal pain and jaundice.

3.8 The symptoms of chronic hepatitis C are distressing and debilitating. Fatigue may be so persistent and overwhelming that it leads to diminution of quality of life as

employment and participation in family life becomes difficult. One hepatitis C sufferer described her situation:

I was always feeling unwell and fatigued, the fatigue would get so extreme that I would fall asleep while feeding or changing my baby. I would fall asleep so easily that I had advertently put my baby's well-being at risk on a number of occasions.⁷

Another witness stated:

I couldn't hold down a job any more! Too tired, very sensitive to noise, criticism, totally unbalanced, low energy, unable to concentrate for long, terribly sick when I drank alcohol, blurred vision due to fatigue, housework didn't get done, crying a lot, unable to get out of bed, didn't want to cook meals, low self esteem, muscle degeneration, pain in the body...dragging myself round for years and still do!⁸

And:

Most days I spend 14-16 hours in bed, I can barely think or read a book or follow events of any kind, I am clinically depressed, suicidal, I am extremely moody, volatile, angry, confused, in constant pain, my friends and family have no idea of how much I am suffering.⁹

Treatments

3.9 Treatment of hepatitis C depends on the different stages of the infection. Two conventional treatments are interferon (monotherapy) and interferon and ribavirin (combination therapy). To undertake monotherapy and combination therapy a person must meet certain criteria, including a liver biopsy showing evidence of fibrosis and raised ALT levels.

3.10 The Department of Health and Ageing (DoHA) stated that Pharmaceutical Benefits Scheme (PBS) and the Pathology Services Table of the Medicare Benefits Schedule (MBS) offer affordable access to hepatitis C treatments and investigation of hepatitis C infection. The hepatitis C antibody test may be reimbursed under the MBS. Qualitative nucleic acid testing which provides a measure of viral load can be reimbursed within certain criteria. Drugs for the treatment of hepatitis C are made available through the Section 100 arrangements (Highly Specialised Drugs Program) under the PBS. The Commonwealth approved Section 100 listing for pegylated interferon from 1 November 2003.¹⁰

7 *Submission 58*, p.1.

8 *Submission 51*, p.1.

9 *Confidential Submission 52*, p.1.

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

3.11 The Hepatitis C Council of NSW stated that the treatment can result in total viral clearance. Studies indicate that if the person does not have cirrhosis in the first instance, hepatitis C will not recur. Those people who have cirrhosis and who have successful treatment can go on to develop liver cancer or liver failure, even though the virus is not present in their bloodstream, but occurs only in a small percentage of cases.

3.12 The Hepatitis C Council of NSW indicated that the success rates for the majority of people treated with pegylated interferon and ribavirin average around 50 per cent. The result differs depending on what genotype of the hepatitis C the person has. The more common genotypes include genotype 1 which responds less well to hepatitis C treatment. Genotypes 2 and 3 respond much better to combination therapy. The success rate for these 'is around the 60 per cent, 70 per cent or 80 per cent mark. That averages out to between 50 per cent and 60 per cent sustained viral response'.¹¹

3.13 However, many people undertaking treatment report significant side effects. These include muscle aches, mood changes, fever, chills, headaches, nausea, dry mouth, loss of appetite, inability to sleep and depression. The side effects vary for each person but at their worst can be acute:

The side effects were very severe and debilitating, causing blinding headaches, extreme nausea and exhaustion...He suffered with deep depression and at times was suicidal.¹²

3.14 The side effects of treatment may impact adversely on work and social lives. The financial cost of treatment can also be high, placing further stress on hepatitis C sufferers:

I took 12 months off work to have treatment, so did my mum. (26 y.o. single male).¹³

And:

Whilst on treatment, the treatment for hepatitis C is about \$2,500 a month and then there are additional costs to the person being treated for things like sleeping pills just to be able to get to sleep at night, because it is very difficult to sleep. There is a cost at work...I was very close to forgoing work myself. There is no guarantee as to whether or not your job is going to be maintained whilst you take time off to complete your treatment, and there is the likelihood that you might not respond successfully...¹⁴

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

12 *Submission* 39, p.1.

13 *Submission* 82, p.22 (HFA).

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

3.15 However, the Hepatitis C Council of NSW noted that it was rare for people to come off the therapy because of the side effects. The Council stated that most of the side effects tend to lessen as the treatment progresses. Treatment lasts in cases of people with genotypes 2 and 3 for 24 weeks, and for 48 weeks for genotype 1.¹⁵

3.16 Unfortunately, not all those undergoing treatment successfully clear the virus. Witnesses informed the Committee that:

I have watched many people go through the horrendous side effects of treatment to try and clear the hep C virus and I have seen, at the end of 48 weeks, that the treatment has failed. Like many of these people, I have genotype 1 of the hep C virus, the most resistant strain to treatment. To undertake treatment is a very difficult decision to make, knowing the side effects that could occur and knowing that you will go through 48 weeks of sheer hell and possibly find at the end of it all that it had not worked.¹⁶

And:

I have had treatment twice, but it hasn't worked for me, so I really don't know what to expect in terms of my health in the future, I do worry about getting cancer because I have had hepatitis for so long (72 y.o. male)¹⁷

3.17 Another witness stated:

I have undergone treatment for hepatitis C. It was the most horrendous experience imaginable. I almost had to give up work so that I would be able to complete treatment. I managed to keep going, with the support of others and an incredibly tolerant workplace. Treatment was completed four months ago when I had a negative PCR at the end of treatment. However, I have since tested positive again. Most people with haemophilia in Australia have genotype 1, which requires longer treatment times and does not respond to treatment as readily as genotypes 2 and 3 – a further complication for people with haemophilia.¹⁸

3.18 A significant number of people with hepatitis C acquired through blood transfusion had pre-existing conditions, such as haemophilia and cancer. These pre-existing conditions often become complex to manage as a result of hepatitis C infection. In addition, many haemophiliacs have HIV co-infection. The Australian Haemophilia Centre Directors Organisation (AHCDO) stated that co-infection with HIV increases the incidence of cirrhosis. It also increases the severity of complications and affects the time taken to develop them with deaths from hepatoma having occurred.¹⁹ The Tainted Blood Product Action Group (TBPAG) noted

15 *Committee Hansard* 6.4.04, p.8 (Hepatitis C Council of NSW).

16 *Committee Hansard* 5.4.04, p.6 (HFA).

17 *Submission* 82, p.22 (HFA).

18 *Committee Hansard* 5.4.04, p.7 (HFA).

19 *Committee Hansard* 6.4.04, p.49 (AHCDO).

'haemophiliacs who had previously acquired HIV/AIDS from blood products face uncertain treatment scenarios when co-infected with HCV. Co-infected individuals are less likely to respond to drug therapies used to combat hepatitis C'.²⁰

3.19 The AHCDO also noted that 'it has been more difficult to assess the degree of disease associated with hepatitis C in haemophiliacs because the disorder makes liver biopsy, which is the trademark investigation technique, very difficult'.²¹

3.20 Many hepatitis C sufferers also seek out complementary and alternative therapies. One witness submitted that:

Over the years I have tried the following at an unbelievable cost. Physiotherapy, iridology, alternative medicine, chinese herbs, lymphatic drainage, homeopathic & osteopathic treatment, diets, vitamins, herbs, live blood tests etc.²²

However, these treatments may be expensive and further stretch limited budgets.

Psychological impact

3.21 The Committee heard that fear, apprehension, anxiety and depression are common responses to an initial diagnosis of hepatitis C infection. These feelings about hepatitis C infection may be exacerbated by anger as sufferers feel that they have been infected with a debilitating disease as a result of the standard medical procedure of receiving blood or blood products. These feelings are compounded by lack of knowledge about the virus, lack of specialised counselling services and negative attitudes of family, friends and health care professionals.

3.22 Having hepatitis C affects all aspects of life. One sufferer graphically described the impact of hepatitis C:

There is a psychological thing happening here – I have developed fears – fear about what the future holds for me, fear about liver disease, fear of cancer, fear about what I would do if I don't respond to treatment sometime down the track if I need to have treatment. All this affects me now – its just having to live with knowing you have hepatitis C and knowing the doctors don't really know enough about it still. The counsellor is helpful but it is really hard living with something that could be a time bomb – no-one really knows.²³

Another witness noted:

Not one day passes in which I am able to forget that I am the carrier of an infectious disease. The psychological impact has been devastating.

20 *Submission 70*, p.25 (TBPAG); see also *Committee Hansard 5.4.04*, p.7 (HFA).

21 *Committee Hansard 6.4.04*, p.50 (AHCDO).

22 *Submission 45*, p.5.

23 *Submission 82*, p.24 (HFA).

Hepatitis C is an isolating disease; the fear of rejection prevents you from disclosing it to family or friends.²⁴

3.23 Many witnesses also spoke of psychological symptoms, with depression arising from their hepatitis status being common. One witness stated:

I was suicidal, to tell you the truth. I am not coping very well at all anymore. I cannot work, so I am living on \$480 a fortnight. I have two children to support. I find it very hard to get the housework done and feed the children and cope with the utter fatigue that I suffer. I have clinical depression. I am not coping very well at all.²⁵

And:

...depression through the virus has had him contemplating suicide, something that would not have ever been in him prior to getting this virus.²⁶

3.24 The impact of both HIV and hepatitis C on the haemophiliac community has been particularly difficult. The AHCDO stated:

Psychologically, the haemophilia community suffer greatly with hepatitis C. Many were relieved not to be infected with HIV in the early eighties, but were then devastated by their hepatitis C infection.²⁷

3.25 Witnesses also pointed to the impact arising from the way in which they learned of their hepatitis C status. Some witnesses spoke of the anger they felt that they had not been contacted by the ARCBS about their infection. Rather they had learned from medical test results they had undertaken in an attempt to identify the cause of their health problems. Often a positive diagnosis had only occurred after many years of searching for a reason for their failing health. One witnesses stated:

I have been diagnosed as suffering hepatitis C after many years of unexplained symptoms. My deteriorating condition has lead me to numerous consultations with a variety of doctors and specialists together with endless tests conducted to ascertain the causes behind the degenerating condition of my health.²⁸

3.26 Other witnesses informed the Committee that they had been notified of their hepatitis C status by the Australian Red Cross Blood Service (ARCBS) by mail. For many, this means of notification added to their distress:

It was evening when I opened the letter and I couldn't call Lookback until the next morning. I found it hard to believe this was something they would

24 *Submission 65*, p.5.

25 *Committee Hansard 7.4.04*, p.4.

26 *Confidential Submission 53*, p.2.

27 *Committee Hansard 6.4.04*, p.50 (AHCDO).

28 *Confidential Submission 25*, p.1.

tell you by mail, or that they would tell you by mail and not include some information about the virus.²⁹

The ARCBS stated that it had changed the practice of notifying recipients by letter that they were HCV positive. Currently, the ARCBS uses a letter to contact patients or donors, who are likely to be infected with hepatitis C, for confirmation of identity and to invite them to contact the ARCBS. The ARCBS commented 'one of the things we have learnt through our management of lookback programs is that one of the initial means of contacting donors (i.e. by letter) was inappropriate and we are sorry for any distress this may have caused'.³⁰ The Hepatitis C Council of NSW noted that the ARCBS also notifies the recipient's medical practitioner who then contacts the recipient.³¹

Social and relationship issues

3.27 A diagnosis of hepatitis C brings with it many social consequences. Sufferers may lack the energy to undertake normal social activities and become fearful of how others will view their health status. This may lead to isolation and exacerbate depression and other psychological problems. Family and friends may also fear the infection due to lack of knowledge about how hepatitis C is transmitted.

3.28 The Committee was provided with examples of the social impact of hepatitis C:

It has impacted very much on my social life as once again the tiredness is a problem and I fear 'getting close to people' as I may have to tell them.³²

And:

I found that my personal relationships deteriorated as my hepatitis C progressed to cirrhosis. I think this is because I couldn't keep up with people, and they didn't understand the illness. I didn't have the energy for others and they didn't seem to care about me and I was fairly depressed about it. (male 50 y.o).³³

3.29 Family relationships often come under increased pressure with some family members being unable to cope with the infection. Witnesses stated:

My brother and sisters who are Catholics have shut all doors on me, I am an outcast, they don't want to know...I can't keep up with people, I'm basically

29 *Confidential Submission* 38, p.1.

30 *Submission* 64, Submission prepared for hearing 7.4.04, p.39 (ARCBS).

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

32 *Submission* 19, p.1.

33 *Submission* 82, p.23 (HFA).

friendless and get terribly lonely. I don't even enjoy the spirit of Christmas and yet I so much want to.³⁴

My sisters took the news in different ways, one was supportive and the other I now have no contact with as she fears the infection of herself and her children. The stigma of this disease stays with you always.³⁵

A member of our support group is in her 70s and has recently had a knee operation. She has not told her daughters that she has hepatitis C. She feels dirty. She will never tell her daughter, because she said her daughter would keep her grandchildren away from her.³⁶

3.30 The breakdown of family relationships is often particularly difficult. As the Australian Hepatitis Council noted:

Public life is one thing but, when you have trust in your family and friends, you think you have those relationships and that they will support you through thick and thin. People who end up with this diagnosis talk about family members not speaking to them; grandmothers talk about their children keeping their grandchildren away from them because they are worried about their grandchildren getting hep C.³⁷

Another witness reported:

I only have energy to work 3 days as my job is very demanding and my inability to have the energy to do daily housework, school events – life is very frustrating and hard on all my family. This in turn creates untold tensions and unhappiness.³⁸

3.31 Submitters also reported the breakdown of relationships and marriages as tiredness, irritability and depression take their toll. Witnesses stated:

A strong relationship, living together with my girlfriend of almost 3 years duration had been destroyed and therefore terminated due to the pressures of this condition.³⁹

I have no doubt that the diagnosis of hepatitis C destroyed the relationship I had been in at the time and had a significant effect on my partner, who bore the brunt of my anguish.⁴⁰

3.32 Some witnesses indicated that they feared having hepatitis C would mean that they would not be able to find a partner in life:

34 *Submission 51* p.3.

35 *Submission 70* p.1.

36 *Committee Hansard 6.4.04*, p.16 (Traids).

37 *Committee Hansard 1.4.04*, p.18 (AHC).

38 *Submission 3*, p.2.

39 *Confidential Submission 33*, p.2

40 *Committee Hansard 5.4.04*, p.7 (HFA).

I am still, and pretty much always have been a single man and at 34 yrs I wonder if I will ever find myself a wife and have children now I have got a second virus to deal with. One might say it's become a much bigger ask of someone (prospective partner) to accept me as I am.⁴¹

And:

Too tired for a relationship, have been on my own for 12 years, so gave up on men.⁴²

3.33 The Committee also heard evidence of the impact of hepatitis C on parenting. Parents feared infecting their children. Mothers in particular feared the transmission of the disease to children conceived after infection. One mother stated:

Following the initial HCV diagnosis my concern was for my family. Tests proved that none was infected. They were very fortunate in those 22 years, that I did not unwittingly infect them, particularly the breast fed baby.⁴³

3.34 Others expressed anxiety of transmission through the day-to-day care of their children. Witnesses submitted:

It is the little acts that occur within the family unit, that suddenly take on a more sinister meaning in the face of HCV infection. Sharing razors, accidentally using someone's toothbrush, your four year old putting a band-aid on your cut and kissing it better, the way you have done for him. You wonder at what point you may have compromised the safety and well being of those you care about the most.⁴⁴

And:

The constant fear of infecting my nearest and dearest is most confronting. I isolate myself by using personal crockery, cutlery, cooking utensils, toiletries, linen etc. This fear is magnified if a minor cut or abrasion occurs, during gardening or the like, causing me immense anxiety for the safety of others.⁴⁵

3.35 Other problems raised in evidence were the impact of fatigue and general ill health on the ability of HCV positive parents to interact with, and raise, their children in the way they would like. In addition, with high health costs and restricted incomes, many parents felt that their partners and children were being cheated by the disease. One witness stated:

My 16-year-old has gone to live with her father because of all the tension and the fact that sometimes I could not get up to cook a meal and do things

41 *Submission 47*, p.1.

42 *Submission 51*, p.2.

43 *Submission 10*, p.1

44 *Submission 65*, p.5.

45 *Confidential Submission 2*, p.1.

like that. She left to go and live with her father because I was not looking after her very well...My son is 31. He was 12 when I had the blood transfusion. Before that, I used to play soccer, basketball and netball. I would go training and take him to his football games. I came out of hospital and I expected to have a bit of time to get over it. I was in hospital for 2½ months when I had the blood transfusion. I came out...I was not the same mother after I came out of hospital. I was tired. I gave up all sport. I could not manage the sport. I was not doing the tuckshop for him anymore. I feel I have let him down. I feel that he has missed out a lot by me being sick.⁴⁶

And:

It has been hard on my family over the years. Instead of having a normal mum, they have had to put up with someone who is tired all the time, suffers from depression, and is always sick and sometimes unable to participate in planned activities.⁴⁷

Impact on earnings and career

3.36 The impact of hepatitis C on earnings and career is two fold. First, the chronic fatigue and other symptoms of the disease often make it difficult for people with hepatitis C to work to their usual capacity or to continue their chosen careers. Secondly, the cost of treatment is sometimes very high.

3.37 Witnesses provided evidence of the impact of their employment:

I could not perform a full days office work and always needed a "siesta" in the middle of the day to recharge my batteries. My income deteriorated substantially.⁴⁸

And:

I used to work full time but since contracting this condition I have not been able to work because of severe tiredness and pain...Trying to make ends meet is a daily battle for us because 1 salary is just not enough...It has stopped us from having children. It has turned our life inside out.⁴⁹

Another witness indicated:

I think employment is important because once you have used up your sick leave you start using leave without pay. If you are the sole provider for the family, that starts to affect your ability to support your family. Having odd days off here and there, you accumulate a large financial burden. You cannot get sickness benefits for that short term...If you are a mother, your partner is working and you have to attend appointments or you are unwell

46 *Committee Hansard* 7.4.04, p.8.

47 *Submission* 7, p.1.

48 *Confidential Submission* 1, p.5.

49 *Confidential Submission* 12, p.1.

you may have to use child-care services. There are a whole range of other things that you would normally not have to expend money on. This adds to the costs of people surviving with hepatitis C, or living with it.⁵⁰

3.38 Other witnesses spoke of the long term impact of hepatitis C on retirement plans:

I have tried to keep working over the years, but have had to give up a number of jobs because they became too strenuous and tiring. I am now earning less money than before because I cannot do the sort of work done previously. At the moment I am working full time, but cannot keep it up because of the stress and heavy work load. So instead of having reached the stage where my husband and I should be planning for retirement all I can manage is to take one day at a time, and because I will not be able to work much longer we are facing the prospect of not having enough money to retire on.⁵¹

3.39 Many witnesses indicated that having hepatitis C had resulted in them being unable to continue in their chosen field of work, this is particularly the case for those HCV positive people who are health care workers. The Committee received evidence from one nurse:

I am a registered nurse in operating rooms...I was informed after the discovery of Hep C that I could no longer be involved in exposure prone procedures ie I could not 'scrub'...I therefore was forced to cease working night shift with a subsequent loss of income...and a loss of job satisfaction.⁵²

Another witness submitted:

...I was an ambitious practitioner of my profession, looking forward to a developing career...I now find it necessary to retrain for a different, less physically arduous vocation.⁵³

And:

Prior to [contracting hepatitis C] I ran a successful building operation...for 30 years. I am now on disability pension and lost everything including friends.⁵⁴

3.40 The cost of medication and treatment for chronic conditions such as hepatitis C can be very high. Witnesses submitted:

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

51 *Submission* 7, p.1.

52 *Submission* 49, p.2.

53 *Submission* 4, p.1.

54 *Submission* 28, p.1.

It has been a very expensive time since I have learnt I have the disease. Medicare covers part of doctors bills but specialists costs are way over the Medicare rebate, plus prescription costs for various treatment is also expensive.⁵⁵

And:

Accessing medical care also present a big drain on me. After a while you feel like you are on a cattle truck and a lab rat to boot. You try any sort of care that may be available just to get some normality in your life.⁵⁶

3.41 Travel costs for those living outside metropolitan areas can also be substantial:

I just live on a pension, this gives me little money each week. With the running of my car, house, my medicine is up to \$100 per month. With the isolation from Tamworth and Newcastle to see a doctor or hospital in these centres you need at least \$200 each visit for petrol and for doctor's account.⁵⁷

Discrimination

3.42 Hepatitis C discrimination and stigmatism is well documented and has a profound impact on affected individuals.⁵⁸ Hepatitis C sufferers have reported discrimination in employment, education, health care, accommodation and insurance. The discrimination is often so distressing that people with hepatitis C have chosen to keep their health status private:

I don't tell people I have hepatitis C, but then I feel guilty and avoid them.

And:

I am an allied health professional and I don't tell people/colleagues of my hepatitis C status because so many are so judgemental about others with hepatitis C that I don't want them to know I have it.⁵⁹

Health care settings

3.43 Many witnesses referred to discrimination and insensitivity while receiving medical treatment. This is particularly distressing for people who are already trying to

55 *Confidential Submission* 10, p.1.

56 *Submission* 45, p.5.

57 *Submission* 40, p.2.

58 Parliament of NSW Legislative Council, Standing Committee on Social Issues, *Hepatitis C: The Neglected Epidemic Inquiry into Hepatitis C in NSW*, Report No 16, 1998; Anti-Discrimination Board of NSW, *C Change: Report of the Enquiry into Hepatitis C Related Discrimination*, 2001.

59 *Submission* 82, p.24 (HFA).

cope with a broad range of health problems. The discrimination ranges from refusal to provide services to breaches of confidentiality and disclosure issues.

3.44 The Committee was provided with examples of incidents of discrimination in health care settings. One witness reported that while in hospital signs had been placed on her room door indicating that the room was occupied by a hepatitis patient and that she was asked to wear a red band in front of a full ward of patients which made other patients think the person was a drug addict.⁶⁰ Another witness stated that their loved one had 'been exposed to all manner of verbal and inferred discrimination when he has been required to have any procedures or medical testing; basically considered unclean, a risk, a danger'.⁶¹

3.45 The Tainted Blood Product Action Group submitted:

Cancer patients who need to donate their own stem cells for possible autologous transplantation (self-donation) are denied tanks to store their stem cells, because they have HCV. Patients with chronic pain who have Hepatitis C frequently feel uncomfortable when asking for pain relief. There can on occasion be suggestions from medical practitioners that the patient may have used IV drugs in the past, because of incorrect assumptions that their HCV infection occurred as a result of sharing dirty needles, and that they should not be prescribed strong pain relief for fears that they are asking for medication under false pretences.⁶²

3.46 Other witnesses cited instances of insensitivity, particularly when they were being informed of their HCV status. One witness stated:

I found out through a routine pregnancy blood test in 1995 that I had hep C. I was unaware of the situation. The doctor really did not inform me; he told the medical student over my head, 'This patient has C antibodies and is also hep C positive,' at which point I sat up and said, 'Hepatitis C? I haven't got hepatitis C.' He just looked at me and said, 'Yes, you have,' but I was not informed.⁶³

3.47 Unfortunately, experiences of discrimination may lead to fear of accessing services which may have a detrimental impact on health outcomes for sufferers of hepatitis C. The Australian Hepatitis Council stated:

One of the big issues is that, if you have a negative experience within the hospital system or when you are first diagnosed by your GP, it actually discourages you from going back. So I guess an issue is that you may not actually seek treatment and you may not seek to have your condition monitored well, because you do not like being treated in that kind of negative way. I think that has quite an impact for a number of people,

60 *Submission 31*, p.1.

61 *Confidential Submission 17*, p.1.

62 *Submission 79*, p.25 (TBPAG).

63 *Committee Hansard 7.4.04*, p.1.

particularly people from marginalised groups who are affected by hepatitis C. They traditionally do not access health care services well, so again they do not access them around these issues too.⁶⁴

3.48 People who have acquired hepatitis C through blood transfusion also reported people did not understand that hepatitis C could also be acquired through blood transfusion. The Committee was provided with many examples:

I was made to feel dirty and constantly asked if I had been involved in drug use.⁶⁵

People with blood transfusion related hep C find it very difficult that they may also be judged to be an illegal drug user. Many face things like, 'I suppose you're going to tell us you got it through blood transfusion,'...As an excuse. It is not a condition that gets a sympathetic response in the wider community or within the health system.⁶⁶

There is a real stigma about having hepatitis C, when you say you have it you can see the look on people's faces and can almost hear them thinking "drug addict".⁶⁷

The general community

3.49 Discrimination in the general community adds to the distress of hepatitis C sufferers. One witness stated:

There is nothing more embarrassing than having someone not shake your hand, hug you, kiss you, touch something you've touched or pull a child away from you because you have Hepatitis "C" and they don't understand anything about the disease.⁶⁸

Witnesses, having experienced negative attitudes to their health status, reported that they chose not to tell people that they were HCV positive. One witness states 'I keep this [HCV status] a close guarded secret fearing that people may think I am a drug user'.⁶⁹

3.50 The Committee also heard of discrimination in the work place. One witness submitted:

I informed my work colleagues that I had been infected with hepatitis. The staff were very wary. A few members of my working team were concerned of being infected by body sweat and contact with me. A staff meeting was called and the Railways called in a doctor specialist to reassure the staff of

64 *Committee Hansard* 1.4.04, p.17 (AHC).

65 *Confidential Submission* 18, p.2

66 *Committee Hansard* 6.4.04, p.16 (Traids).

67 *Submission* 7, p.2.

68 *Submission* 8, p.6.

69 *Confidential Submission* 14, p.1

the limited risk involved. Regardless of the meeting my fellow workers were still distant in many ways [and] isolated me.⁷⁰

3.51 Other witnesses stated that they had been unable to obtain travel insurance, loss of income insurance or life insurance because of their hepatitis C and were distressed at the special arrangements that would have to be made for the funerals.⁷¹

3.52 Discrimination may also extend to the families of hepatitis C sufferers. One mother submitted:

My children have suffered discrimination at school and we have already changed from another school...My children are told to get out of class when they are bleeding and no adult supervision is offered to help them when they are injured or have nose bleeds. Both my children are HEP C negative.⁷²

3.53 The NSW Legislative Council Standing Committee on Social Issues reported in November 1998 on its inquiry into Hepatitis C. The report, *Hepatitis C: The Neglected Epidemic*, also detailed discrimination suffered by people with hepatitis C.⁷³ In 2001 the Anti-Discrimination Board of NSW, reported on its inquiry into hepatitis C related discrimination. This inquiry found that hepatitis C is a highly stigmatised condition and the discrimination against people with hepatitis C is rife. The discrimination takes many forms and is often motivated by stereotyped responses towards people on the basis of past, current or assumed injecting drug use.⁷⁴

Conclusion

3.54 Those who have been infected with hepatitis C from blood transfusion and blood products include adults, children, haemophiliacs, accident victims, mothers post childbirth and those having surgery. While many received these blood or blood products as part of life-saving medical measures, they also received the hepatitis C virus.

3.55 The Committee heard that, although some of those infected cleared the virus, for those who did not, hepatitis C is a 'life-changing' disease. Fatigue, pain and depression are the most common symptoms of hepatitis C. While in most cases, liver and other major organs also break down. Hepatitis C affects all aspects of the infected person's life from their working life to their relationships with their spouse, children, family and friends.

70 *Submission 15*, p.2.

71 *Submission 31*, p.3; *Committee Hansard 5.4.04*, p.14 (HFA).

72 *Confidential Submission 32*, p.1.

73 *Hepatitis C: The Neglected Epidemic*, pp.108-117.

74 *C Change: Report of the Enquiry into Hepatitis C Related Discrimination*, Executive Summary.

3.56 Many witnesses were distressed that they had lived with the symptoms of hepatitis C without it being diagnosed. Once diagnosed, sufferers face the prospect of undertaking treatment which may have distressing side effects or developing severe liver disease. The treatment of HCV positive people with other health conditions such as haemophilia and cancer may be more complex and co-infection with HIV increases the severity of complications.

3.57 People with hepatitis C also face ignorance, discrimination and stigma. The Committee heard many disturbing incidents of discrimination. Most distressing were those that had taken place in health care settings. As a result, people with hepatitis C often choose not to inform family or friends about their health status for fear of rejection and ostracism.

