

Nurses and Hepatitis C

Hepatitis C is a major public health concern in Australia. It is very likely that every nurse and midwife will care for someone with hepatitis C at some point in their career. This supplement presents an update on hepatitis C.

Introduction

Over the past decade the hepatitis C virus (HCV) has been Australia's most commonly notified infectious disease. In 2004, it was estimated that approximately 194,260 people living in Australia had been exposed to the virus and that 13,028 new diagnoses were reported in 2004.¹ The virus can cause long-term liver problems, including cirrhosis and hepatocellular carcinoma (HCC). However, there is still widespread misunderstanding about HCV – how it is transmitted, infectivity, who is at risk, management of the condition and prognosis.

The majority of hepatitis C notifications in Australia have been among young adults (20–39 years) with relatively few among children and the elderly. The prevalence of HCV infection in some countries in Africa, the Eastern Mediterranean, South-East Asia and the Western Pacific (when prevalence data are available) is high compared to some countries in North America and Europe.²

A person's HCV infection may be their primary reason for using a health service, or they may present with another condition unrelated to their hepatitis C status. In many instances, health professionals will be unaware of the hepatitis C status of a patient, who may themselves be unaware that they have the virus.

Before hepatitis C testing was developed in 1989, it became apparent that some people receiving blood transfusions and blood products were contracting hepatitis, despite the fact that blood products were screened for hepatitis B (HBV) and hepatitis A (HAV). The majority of these cases, known as non-A non-B hepatitis or post-transfusion hepatitis, have since been identified as hepatitis C (HCV).

The virus

Hepatitis C is a ribonucleic acid (RNA) virus, belonging to the flavivirus family.³ Genetically distinct viral groups have evolved, with nine different genotypes of hepatitis C identified⁴ and approximately 40 different subtypes. There are many predictive factors associated with the effectiveness of antiviral treatment. The HCV genotype is the most significant factor.

Impact of hepatitis C

Hepatitis C affects people in different ways. The vast majority of people with hepatitis C report no symptoms associated with the initial (acute) phase of infection. However, around 10% will be acutely ill for several weeks or months soon after infection. During the acute phase, levels of the virus in the blood rise dramatically until the body's immune response starts producing antibodies. Although these antibodies fight the virus, around 70 to 85% of people infected will develop a long-term (chronic) infection and could transmit the virus to others. Some people develop symptoms of liver disease, including tiredness, lethargy, nausea, headaches, depression, aches and pains in joints and muscles, and discomfort in the upper abdominal area. After many years the chronic infection may develop into serious liver illness, such as cirrhosis, liver failure and liver cancer.

Hepatitis C is now the most common reason for liver transplantation. With high numbers of existing chronic infections and most people with hepatitis C not yet seeking treatment or experiencing serious liver illness, compounded by the number of new infections occurring, hepatitis C may become a burden to Australia's health care system.

Transmission

Hepatitis C is primarily transmitted via the parenteral route – approximately 80% of Australian-born people with hepatitis C were exposed to the virus through unsterile injecting drug use.⁵ Hepatitis C can be spread unknowingly because many people do not realise they have the virus. The virus is not transmitted via hugging, kissing or touching unless there is blood-to-blood contact.

The main modes of transmission are:

- Reusing syringes and needles, and contact with other injecting equipment such as tourniquets, spoons, water, surfaces and fingers contaminated with blood. Blood contact may also take place with reused snorting devices⁶



How is hepatitis C different from hepatitis A and B?

Virus Type	Profile	Transmission	Vaccination	Treatment	Notifiable
Hep A (HAV)	Usually a mild disease that does not become chronic.	Orally via food and/or water contaminated with faecal particles from an infected person. Occasionally via oral/anal sexual contact. Rarely through blood-to-blood contact.	Yes	No specific treatment.	Yes
Hep B (HBV)	Can be mild, severe, acute or chronic. Less than 5% of adult HBV infections become chronic.	Most cases of chronic HBV infection worldwide occur through mother-to-child transmission. In Australia, most new cases of HBV are acquired through sexual contact with an infected person. Also transmitted through infected blood, including contaminated injecting equipment.	Yes	Antiviral therapy and post-exposure prophylaxis (PEP) are available.	Yes
Hep C (HCV)	Hepatitis C is likely to become a chronic condition in 70 to 80% of infected people, with 10% developing severe liver disease.	Transmitted when infected blood enters the bloodstream of another person (blood-to-blood contact). Unlike hepatitis B, it is very rare for hepatitis C to be transmitted by sexual activity or through mother-to-child. Hepatitis C is not transmitted by food or water contamination.	None for HCV. To prevent the complications of co-infection, people with hepatitis C should be vaccinated against hepatitis A and B.	Antiviral therapy and post-exposure prophylaxis (PEP) are available.	Yes

***Two other hepatitis viruses D (or delta) and E have been isolated, but both are uncommon in Australia.**

- Exposure through unsterile tattooing or body piercing
- Exposure via a penetrating injury (needlestick)⁷
- Receipt of a blood transfusion or blood product prior to 1990. Blood transfused after February 1990 is generally considered to be safe
- In many developing countries, where unscreened blood and blood products are still being used, the major means of transmission are unsterilised injection equipment and unscreened blood transfusions. In addition, people who use traditional scarification and circumcision practices are at risk if they use or re-use unsterilised tools²

Knowledge of the virus and understanding that nurses are at the forefront of the disease are vital for the effective management of hepatitis C.

The risk of transmitting hepatitis C via sexual contact is considered to be extremely low, but may occur if there is blood-to-blood contact during sex (for example, rough sex that could rupture the lining of the vaginal/anal or penis). There is also evidence to suggest that transmission rates may be higher if the patient is co-infected with HIV or other sexually transmitted diseases.⁸ The probability of transmission depends on the infectivity (viral load levels) of the infected person. A person with HCV infection should be advised to use condoms or dental dams where there is potential for blood contact (e.g. rough sex).

Household transmission (e.g. via razors or toothbrushes) is considered to be rare. Nevertheless, where the possibility of blood contact exists, these items should not be shared. There is no risk of viral transmission via cups, plates or other eating utensils.

Mother-to-child transmission

All babies born to women who are hepatitis C positive will test antibody positive at birth because they inherit their mother's antibodies. By the age of 18 months, 92–95% of babies will have cleared their mother's antibodies and test negative for hepatitis C.⁹

There is a very small risk of vertical transmission between mothers and babies. The risk is approximately 5%.^{10,11} In one study by the National Centre in HIV Epidemiology and Clinical Research, University of New South Wales, found the rate of vertical transmission to be 6% when women are positive for hepatitis C antibodies and have positive PCR (polymerase chain reaction). In contrast, those with negative PCR had no evidence of transmission.¹²

HIV/HCV coinfection in the mother increases the risk of hepatitis C transmission to the baby.¹³ Mode of delivery does not appear to affect the risk of transmission. However, care should be taken not to damage the skin integrity of the baby, (e.g. do not use scalp monitors).

Breastfeeding

The hepatitis C virus has not been found in samples of breast milk taken from hepatitis C positive women. Transmission via breast milk has not been shown to occur. There are many advantages to breastfeeding for the mother and baby, and the choice to breastfeed or not should be left up to parents. Breastfeeding mothers should check their nipples before each feed and avoid breastfeeding if they are cracked or bleeding.¹⁴

Testing

When assessing someone with possible HCV infection, a serum HCV antibody test should be performed first. A positive test usually indicates exposure to HCV, but does not prove active infection.¹⁵ However, the presence of a positive antibody test and an elevated alanine aminotransferase (ALT) level, particularly in the setting of risk factors for transmission, is sufficient to diagnose HCV infection and further testing is not required. In individuals with persistently normal ALT levels (PCR)¹⁶ test should be carried out to determine if viraemia is present, as some people in this situation may have cleared the infection. Viraemia can be detected in the blood one to three weeks after exposure. A liver biopsy may be performed to determine the severity of inflammation and fibrosis and guide treatment decisions.

Nursing people with hepatitis C

A large part of the job of any nurse working with people with hepatitis C is to provide support, advice and education. It is important that information is shared to ensure that patients do not fall between services and miss out on proper advice, support, testing and treatment.

Acute hepatitis C

In the majority of individuals exposed to hepatitis C, the onset of infection is unrecognised because acute hepatitis C is clinically mild and often not apparent. It is symptomatic in 25–35% of cases, and the clinical features resemble those of other forms of acute viral hepatitis such as malaise, nausea, abdominal discomfort, pale stools, dark urine and jaundice. These symptoms are usually mild, but this can be variable.¹⁷

Appropriate counselling of the patient is one of the most important measures that can be taken and this is discussed further below. In addition, patients should be advised to take adequate rest, a balanced diet and to avoid alcohol. There is no evidence that strict bed rest or a certain diet will alter the clinical outcome.¹⁸

Chronic hepatitis C

Between 70 and 80% of all patients infected with the hepatitis C virus develop chronic infection which is defined as infection persisting

for more than six months, usually with a degree of hepatitis. The term 'chronic' relates specifically to the duration of the infection not to the severity of the disease. Chronic HCV infection leads to a wide spectrum of liver disease ranging from minimal damage (even after 30 years) through chronic hepatitis (mild, moderate, severe) to cirrhosis, liver cell cancer and liver failure.¹⁹

Laboratory testing for chronic HCV infection will show positive anti-HCV and HCV RNA, with or without raised ALTs.

Tiredness and lethargy, often to the point of exhaustion after a normal day's work, can be experienced by patients with chronic hepatitis C. Once cirrhosis has developed, other symptoms may occur, including abdominal discomfort and swelling, nausea and anorexia, fluid retention and signs of coagulation disorder, such as bruising and epistaxis.

Discussing chronic disease, natural history and reassuring the patient is recommended. Understanding the patient's needs and what their next step is with their disease or treatment choices is helpful to ease anxiety around HCV.

Pre- and post-test counselling

A positive hepatitis C diagnosis can cause psychological distress, particularly if the test result is unexpected. It is quite common for people with a chronic infection to experience depression, as well as a considerable amount of fear, anger and anxiety. This can be compounded by the fact that there is considerable misinformation about hepatitis C in the general community. For some people a diagnosis of hepatitis C means they have to revisit something they may have done many years ago, e.g. injecting drug use. They may have never discussed this with their family, partner or friends.

In addition, the physical symptoms of chronic hepatitis C infection can lead to depression and mood swings, anxiety over the future, social isolation, loss of self-esteem, the development of mild paranoia and acute stress regarding the decline of control over one's life.²⁰ This can be compounded by antiviral treatment which can also produce psychological side-effects, including mood swings and severe depression. It is important to recognise the discrimination in the general community, faced by many people with hepatitis C.

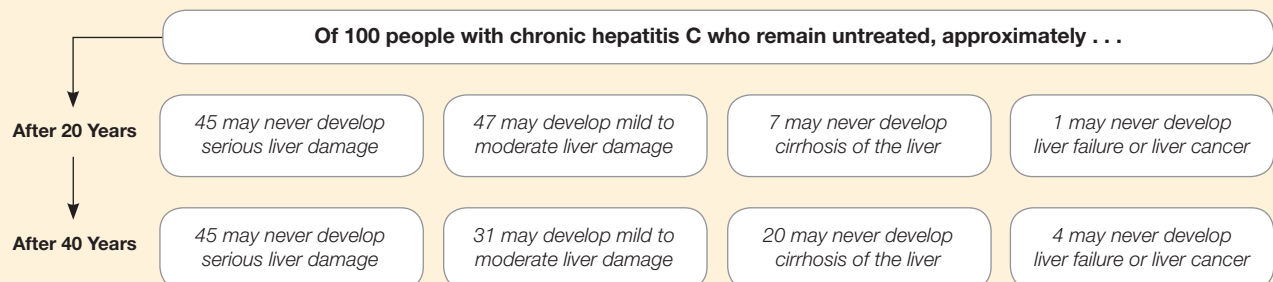
People with hepatitis C have reported being discriminated against when interacting with health professionals, which can have a considerable impact on the quality of their health care.

Disease progression of hepatitis C.

Hepatitis C outcomes (Natural History):
Factsheet, Hepatitis C Council of NSW October 2003

On average, one in four people who contract HCV will clear their infection naturally within the first 12 months. Three in four people experience a chronic (ongoing) hepatitis C infection.

This chart shows the different outcomes that may occur with chronic hepatitis C. It does not aim to show individual outcome (prognosis). Personal factors such as alcohol intake, age when HCV was acquired and current level of liver inflammation may influence a person's prognosis and individuals are advised to seek medical advice regarding their own situation.



Effective stress management is an important aspect of dealing with hepatitis C. Providing advice and education for the person with hepatitis C incorporates several elements²⁰:

- Information on the natural history of the virus
- Prognosis
- Prevention of transmission
- Assessment of lifestyle
- Advice on minimising impaired health from hepatitis C
- Explanation of the support services available for people with hepatitis C

Counselling injecting drug users

In counselling people with hepatitis C who inject drugs, advice can be offered about drug and alcohol counselling, detoxification and rehabilitation facilities, methadone clinics and prescribers. However, whilst avoidance of injecting drug use is the preferred option, it may not be the choice of the patient.

People with viral hepatitis should drink alcohol infrequently and at low levels.

The following information could be offered²¹:

- *Change to routes other than parenteral*
Although the same dose may have a slower and reduced effect, smoking, snorting or taking drugs orally carries a much lower risk of infection
- *Reduce risks if injecting*
Needles and syringes and other injecting equipment such as swabs, filters, spoons, water, utensils and tourniquets should not be reused, as these are potential sources of contamination. Advise people to wash their hands before and after injecting, use new equipment (new fit) for every injection (hit), and not to use an injection prepared by someone else. Information about local needle exchanges and safe disposal of needles should be offered (see page 8)
- *Reusing equipment is not safe*
Being infected with hepatitis C does not protect someone from reinfection. The antibody is not protective and a person who has cleared the virus may get reinfected. A person who has chronic hepatitis C may become infected with another genotype. Different genotypes are associated with different responses to antiviral treatment. Successful treatment does not mean immunity – re-exposure can lead to reinfection
- *Dispose of equipment safely*
Offer advice about the safe disposal of equipment to prevent reuse and needlestick injury

Diet

A well-balanced diet is recommended for all patients. There is no need to routinely limit the fat content of the diet or to supplement the diet with minerals or vitamins, unless nutrition is recognised to be inadequate. On the other hand, there is increasing evidence for interactions between hepatitis C, obesity and type 2 diabetes (NIDDM). Obese patients should be counselled on a weight-reducing lifestyle that incorporates diet and exercise.²²

Alcohol

Alcohol has an additive effect on the development of liver fibrosis. It is important to explore the alcohol intake of a person with hepatitis C and, if necessary, suggest they see a drug and alcohol counsellor, should they have difficulty in reducing alcohol intake.²¹

The Australian Alcohol Guidelines advise that people with health or social problems²³:

- Consider not drinking at all
- Are strongly advised to stop drinking for at least several weeks or months
- May then try drinking at low levels (well below the number of standard drinks recommended for adult men or women) under the supervision of their doctor
- Not drink at all if they have developed severe alcohol dependence
- Never drink if they have a severe health problem made worse by alcohol (e.g. cirrhosis of the liver, pancreatitis)
- Consider drinking infrequently (well below the number of standard drinks recommended for adult men or women) if they have hepatitis C, or another form of chronic viral hepatitis

Realistic guidelines about alcohol management, diet and stress management, information about appropriate counselling and support services and offering support for a person with hepatitis C, are all useful ways of providing an individual with the tools they need to manage their own health and well-being more effectively.

Treatment

Since 1990, when hepatitis C was first isolated as the major cause of non-A non-B hepatitis, rapid changes have occurred in the management of the virus. Initial clinical treatment includes an assessment of symptoms and signs of liver disease, and an assessment of the severity of disease. People with chronic hepatitis C infection will require regular monitoring, however not every person with a positive antibody HCV test result will necessarily require specialist referral. Not everyone with hepatitis C will choose to undergo treatment, in which case ongoing monitoring and support is essential to assist these people to maintain the best possible health. Management options include general practice, liver or hepatitis clinics in public hospitals or private specialists. These and other services, such as counselling, may be combined in a shared care model.

Antiviral therapy

Monotherapy with interferon alfa-2a and -2b is no longer the standard for HCV therapy. The longer-acting pegylated interferons have replaced them, except where the patient is intolerant to ribavirin.

Today, the most effective therapy for hepatitis C is a combination of once-weekly subcutaneously administered pegylated interferon plus twice-daily oral ribavirin.²⁴ This therapy is available in Australia under Section 100 of the Pharmaceutical Benefits Scheme (PBS) unless patients have failed to respond to previous interferon monotherapy or combination interferon plus ribavirin. The combination of pegylated interferon and ribavirin produces an overall sustained virological response (SVR) of greater than 50%,^{25,26} a significant improvement over the SVR rates achieved with interferon monotherapy (<10%) or standard interferon (given three times a week) plus ribavirin (40%). While HCV genotype is the most powerful predictor of response to combination therapy (80% SVR after 24 weeks for genotypes 2 and

3, 50% SVR after 48 weeks for genotypes 1 and 4), other predictors of SVR include low viral load, minimal hepatic fibrosis, female gender and age (younger than 40 years).²⁴

The benefits of achieving an SVR include a reduced risk of progression for patients at all stages of disease and probably a lower incidence of HCC development. Prior to specialist referral, patients should be informed that genotype testing is covered by Medicare. Patients with genotypes 2 or 3 can be counselled about the high chance of eradicating the virus with 24 weeks of treatment and patients with genotype 1 infection can also be informed of the likelihood of eradicating infection.²⁴

Patients with contraindications, or who may respond poorly to therapy include those with: HCV/HBV coinfection, HCV/HIV coinfection, chronic renal failure, cryoglobulinaemia, HCV recurrence after liver transplantation, psychosis or chronic depression. Decisions about therapy in these individuals are made on a case-by-case basis by the specialist.²⁴

Side-effects

Hepatitis C antiviral treatment produces a number of side-effects that often require intensive patient monitoring and support. Patients who are able to cope with side-effects and therefore adhere to therapy regimes are well placed to achieve successful outcomes to therapy. Patient preparedness, education and support are vital. Clinical Nurse Consultants (CNCs) work with multidisciplinary teams in clinical settings and specialise in this area of patient care.

Commonly experienced adverse events that occur early in interferon therapy are flu-like symptoms of fatigue, fever, lethargy, headaches arthralgia and myalgia. Other side-effects reported in 10-20% of treated patients may include anorexia, malaise, alopecia, neutropenia, thrombocytopenia, irritability, diarrhoea and weight loss.²⁷

Interferon can cause irritability and mood swings in some people. This can occasionally develop into a potentially serious psychiatric complication.²⁷ While a history of psychiatric illness is not an absolute contraindication for treatment, patients should undergo mental health assessment and be warned of the risks associated with interferon, particularly if they have a history of suicide ideation or depressive illness. Regular monitoring and early intervention can circumvent problems arising, as can the use of SSRI antidepressant therapy which is recommended where appropriate. Local patient support groups can also be useful. It is important to recognise and stabilise any underlying mental health illness. Nurses regularly work with patients and their families or carers, and can play a vital role in the early detection of mood and behavioural changes.

Ribavirin causes haemolysis²⁷ (breakdown of red blood cells) that may result in symptomatic anaemia. Haemolysis will lessen or stop after dose reduction or cessation. Because of this side-effect, ribavirin can be contraindicated if people have certain blood, cardiac or renal conditions.

Antiviral therapy is not always the most appropriate treatment for a person with hepatitis C and, even when it is deemed to be potentially beneficial, there is usually no urgency in beginning the treatment. The decision to commence therapy is made by the patient and doctor, taking into account the clinical, personal and lifestyle aspects of the patient.

Ribavirin is also a teratogen, meaning it may damage the developing foetus. Its use is prohibited in pregnant women, male partners of pregnant women, or if adequate contraception cannot be guaranteed.

Complementary and alternative therapies

Many people with hepatitis C are also keen to pursue non-pharmaceutical alternatives to control symptoms and modify liver inflammation, particularly when antiviral therapy is not an option.

Results from a double-blind placebo, controlled trial conducted by the John Hunter Hospital in Newcastle, indicate a Chinese herbal preparation (CH100) produced a 38% drop in ALT levels, compared with an 8.5% drop in the placebo group.²⁸ Attention is also focused on *Silybum marianum* (Silymarin, Milk Thistle, St Mary's Thistle), a herbal extract with few side-effects. A clinical trial – the Hep573 Study – is currently underway at the liver clinics of Westmead, John Hunter and Royal Prince Alfred Hospitals. The Hep573 Study is a randomised placebo controlled study of treatment with Silymarin alone, Silymarin with other antioxidants (vitamin C, zinc, alpha lipoic acid, selenium, green tea, grapeseed extract, tumeric among others) and placebo in patients with chronic hepatitis C. Patients receive treatment for six months and will be followed up for an additional six months. Markers of liver injury (F2-isoprostanes) and fibrosis (hyaluronic acid) and HCV RNA viral load will be monitored. 118 participants are enrolled in the study and results are expected in late 2007.

To date, there is limited information on the effectiveness of natural therapies in some areas. It is important to consult with a specialist clinical nurse, GP or qualified herbalist (accredited with the National Herbalists' Association of Australia) before taking a herbal preparation during antiviral therapy, as some herbs can be toxic to the liver.

In any treatment for HCV, good nursing support can be crucial. Management of side-effects, advice and education are key elements of this support and can make a substantial difference in outcomes for a person with hepatitis C.

Prevention and infection control

Hepatitis C is a notifiable disease. Transmission occurs when the blood of someone who is already infected with hepatitis C enters the bloodstream of another person.²⁹

The presence of antibodies to hepatitis C does not indicate infectivity and mandatory testing to detect the presence of antibodies to hepatitis C is not considered desirable, useful or cost-effective.

Standard precautions are recommended for the care and treatment of all patients, regardless of their perceived or confirmed infectious status, and in the handling of³⁰:

- blood (including dried blood)
- all other body fluids, secretions and excretions (excluding sweat), regardless of whether they contain visible blood
- non-intact skin, and
- mucous membranes

All blood and body fluids should be considered potentially infectious, so wearing gloves for procedures, including venepuncture, is mandatory. All health care workers should apply standard precautions to every patient.³¹

Needlestick injury

The risk of hepatitis C transmission through a needlestick injury is between 2% and 7% in health care settings. The risk depends on the viral load of the source patient, the first aid administered and the instrument involved (hollow bore needle, scalpel, trocar etc.). In the event of a needlestick or other blood accident, the Department

of Health and Ageing recommends establishing the HIV, HBV and HCV status of the source patient involved, after gaining informed consent and providing appropriate pre- and post-test counselling.³⁰ The recipient of the injury can choose to have Liver Function Tests (LFTs) and HCV RNA PCR testing four weeks after exposure, and antibody HCV testing at three and six months post-exposure. In order to establish a baseline measurement, it is also a good idea to have LFTs and a HCV antibody test on the day of the exposure or shortly thereafter.

At the time of a needlestick injury or other exposure:

- Wash your skin with soap and water
- Rinse your mouth, nose and eyes well with water or saline
- Report the incident and follow your local workplace Occupational Exposure Protocol

Health care workers with hepatitis C

Health care workers with hepatitis C who are involved in exposure-prone procedures should inform their employer of their infection status, and refer to their State or Territory policy and procedures for workers who are hepatitis C positive.³²

Infection control

What to advise people with hepatitis C about limiting transmission.

Health care workers:

- Using gloves, carefully wipe up any blood spills with a paper towel and then wash the area with soapy water. Where there is a possibility of bare skin contact, the surface should be disinfected with household bleach
- Completely cover any cut or wound with a waterproof dressing or bandaid
- Place blood-stained tissues, sanitary towels or other blood-stained dressings in a leak-proof plastic bag before disposal

Patients:

- People who inject should use sterile needles and syringes and new injecting equipment every time they inject drugs. They should dispose of equipment and wash hands immediately before and after injecting. Needle and Syringe Programs can be used to obtain sterile injecting equipment, education and referral advice on drug use. More information on safe injecting is available from the Australian Injecting and Illicit Drug Users League (AIVL) National Hepatitis C Education Program (see page 8)
- Use condoms or dental dams where there is the possibility of blood contact during sex
- When breastfeeding, milk from cracked or bleeding nipples should be expressed and discarded until the lesions are healed
- Do not share toothbrushes, razors, shavers, dental floss or barber's haircutting equipment
- Do not share or reuse injecting equipment, snorting devices, tattoo or body piercing equipment

It is never necessary to isolate the patient or insist that they use different eating utensils, toilet or washing facilities.

Discrimination

Hepatitis C is a highly stigmatised condition and many people living with the disease experience discrimination. The Anti-Discrimination Board of NSW states that discrimination in health care settings may take many forms and cause unfair treatment of patients.³³

Discriminatory behaviour in this setting may include:

- Refusal of care or treatment
- Lack of pre- and post-test counselling
- Giving a lower standard of treatment

Behaviours which reflect stigmatisation towards a patient can also reduce the standard of health care received and lower the quality of life for people with hepatitis C and should be avoided.³⁴

Such behaviours include:

- Breaches of confidentiality and disclosure related to hepatitis C, even among health care workers
- Assumptions about how a person acquired hepatitis C
- Assumptions about a person's past or present drug use

Choice of language when talking to patients

Avoid Terms	Use Terms
addict, drug addict, drug abuser	drug user
addiction	dependence (or inquire about the presence of withdrawal symptoms)
clean (equipment)	new (equipment)
drug abuse	drug use
intravenous	injecting
needles	injecting equipment
shared	reused (have you ever reused someone else's injecting equipment?)

Clarify the meaning of any colloquial, sub-cultural terms!

Avoiding discrimination

Health care workers should respect the rights of people with hepatitis C regardless of how they were infected. Everyone living with hepatitis C should have access to care and services regardless of transmission route, gender, race, culture, sexual orientation or lifestyle issues (such as drug use).

Discrimination and stigmatising behaviours can be avoided by:

- Continued health care worker education and continuing medical education³⁵
- Ensuring standard infection-control procedures are followed, thus reducing the need for disclosure or differential treatment
- Ensuring a person's privacy and confidentiality are protected
- Treating all patients with respect and compassion

Personal perspective

Jeff Ward has been living with hepatitis C for more than 10 years. Below he shares some of that experience.

Q: What sort of discrimination do you think people living with hepatitis C are up against?

Jeff: We are seeing institutionalised discrimination that is in breach of federal and state legislation – such as refusal of services or changes in employment conditions. Hepatitis C is not comprehensively recognised as a form of disability in itself – for many, especially those with disabling fatigue or advanced disease, this impacts on their ability to do full-time paid work, let alone domestic labour. But many others, such as those whose quality of life may be only marginally impaired, also experience discrimination upon disclosure of their status in the workplace. Many of these workplaces have poor occupational health and safety standards and hence a culture of ignorance, fear and panic is fostered. But much more pervasive in the community is the type of attitudinal discrimination that many of us experience. By this I mean judgmental attitudes that there are ‘types’ of people who have hep C or even that you ‘deserve’ to have hepatitis C. Many people internalise these feelings of shame or guilt. Others choose not to disclose to avoid these negative and narrow-minded attitudes.

Q: What were your initial feelings when you yourself were diagnosed with hepatitis C?

Jeff: I was diagnosed in the early nineties when the medical community knew very little, let alone the affected communities. I was shocked, confused and felt powerless over this virus. Looking back, I suppose I was angry with myself for being infected. In some ways I was relieved to put a reason to my tiredness, but I was also scared that I would have to live a life of illness and disability. I was also worried that I may have put others at risk as, back then, we didn’t have any quality information on the real risks of transmission. I also felt really alone and internalised a lot of shame and guilt that I knew I had to just deal with as, later on, I refused to be a ‘victim’.

Q: How does having hepatitis C affect your daily life?

Jeff: You know, most of the time I am OK. But some days I feel the tiredness and lethargy is so extreme that I can’t stop yawning and I feel overwhelmed by it. It’s like an attack of extreme exhaustion. After the working week, I just can’t do a big Friday night anymore! I have to put work into staying well, eating good food, sleeping properly and managing stress. For me, it’s the social stuff that I find the hardest to deal with: disclosing in relationships, worried about how people I care for will react. I still find it easier to talk publicly about having hepatitis C than to my family or my intimate friends.

Q: What factors affected your decision-making when you were deciding on the most appropriate course of treatment/management for your hepatitis C?

Jeff: In 2000, I chose to do a clinical trial of peg-interferon and ribavirin, which unfortunately didn’t result in viral clearance. The factors I found important in deciding to do the therapy were a big mix – obviously the biopsy result itself; my genotype (1); the timing of when to start the treatment; quality information about the side-effects and how to best manage them (especially the unpredictable depression that is common); and most of all my support networks and how I could best tap into them without feeling overly needy or demanding. I found the nurses absolutely invaluable and they reaffirmed my personal commitment to the treatment through their professional and personal conduct. For me, it revealed the great need for more resources for nursing and other support staff for our liver clinics and hospital services. These current treatments are not

easy going for everybody and certainly are not the only option for managing hepatitis C. I still feel that we need more self-management options for those who choose not to use these treatments or for people who can’t access them.

References

- 1 2005 Annual Surveillance Report, HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia, edited by National Centre in HIV Epidemiology and Clinical Research 2005;11-13.
- 2 World Health Organization (WHO). Hepatitis C Factsheet. WHO 2000;FS164 <http://www.who.int/mediacentre/factsheets/fs164/en/>
- 3 ASHM. HIV/Viral Hepatitis: a guide for primary care. Adelaide: ASHM, 2004;10.
- 4 Dev A, McCaw R, Sundararajan V, Bowden S, Sievert W. Southeast Asian patients with chronic hepatitis C: The impact of novel genotypes and race on treatment outcome. *Hepatology* 2002;36:1259-1264.
- 5 Crofts N, Dore G, Locarnini S. Hepatitis C: An Australian Perspective. Melbourne: IP Communications, 2001.
- 6 Hepatitis C Sub Committee of the Australian National Council on AIDS and Related Diseases. Estimates and projections of the hepatitis C virus epidemic in Australia. Sydney 1998;Aug.
- 7 MacDonald M, Wodak A. Preventing transmission of hepatitis C. *Hepatitis C Update: A management guide for general practitioners.* AFP 2003;28(Dec):9.
- 8 MacDonald M, Wodak A. Preventing transmission of hepatitis C. *Hepatitis C Update: A management guide for general practitioners.* AFP 2003;28(Dec):10.
- 9 Australian Institute for Primary Care. National Hepatitis C Resource Manual. La Trobe University, Melbourne: AIPC, 2001:16.
- 10 Dinsmoor MJ. Hepatitis C in pregnancy. *Current Women’s Health Reports* 2001;1;1(Aug):27-30.
- 11 Newell ML, Pembrey L. Mother-to-child transmission of hepatitis C virus infection. *Drugs of Today* 2002;38;5(May):351-37.
- 12 Dore GJ, Kaldor J M, McCaughan GW. Systematic review of role of polymerase chain reaction in defining infectiousness among people infected with hepatitis C virus. *BMJ* 1997;315(Aug):333-337.
- 13 Kumar RM, Shahul S. Role of breastfeeding in transmission of hepatitis C virus to infants of HCV infected mothers. *J Hepatol* 1998;29:191-197.
- 14 Hepatitis C Council of NSW. Hepatitis C: What you need to know. Sydney: Hepatitis C Council of NSW, 2001:10.
- 15 McCoy R, Watson K, Kosky M. Pretest counselling and diagnosis. *Hepatitis C Update: A management guide for general practitioners.* AFP 2003;32(Oct):23.
- 16 ANCAHRD. National Hepatitis C Testing Policy. 2003:32-43. www.ancahrd.org/pubs/pdfs/hepctestng.pdf
- 17 Farrell G. Hepatitis C other liver disorders and liver health: a practical guide. Sydney: MacLennan and Petty, 2002:47.
- 18 Marinos G, Post J. Acute hepatitis C. *Hepatitis C Update: A management guide for general practitioners.* AFP 2003;32(Oct).
- 19 Batey, RG. Chronic Hepatitis C. *Hepatitis C Update: A management guide for general practitioners.* AFP 2003;32(Oct)4:17.
- 20 Loveday S, Deakin G, Neophyton D. Meaning for the person. *Hepatitis C Update: A management guide for general practitioners.* AFP 2003;32(Oct).
- 21 Central Sydney Area Health Service. Hepatitis C Manual for GPs and other Health Care Workers 2000;(Mar):25.
- 22 Harley H, Shaw D, Steven I. Ongoing management of hepatitis C. *Hepatitis C Update: A management guide for general practitioners.* AFP 2003;32(Oct):31.
- 23 Population Health Division, Department of Health and Aging. Australian Alcohol Guidelines. 2003;(Oct):Guideline 4. <http://www.alcohol.gov.au/guidelines/groups.htm#guideline4>
- 24 ASHM. HIV/Viral Hepatitis: a guide for primary care (Chapter 10). Sydney: ASHM, 2006;10(revised):92 <http://www.ashm.org.au/uploads/File/hiv-hep-mono.pdf>

- 25 Manns MP, McHutchison JG, Gordon SC et al. Peginterferon alfa-2b plus ribavirin compared with interferon alfa-2b plus ribavirin for initial treatment of chronic hepatitis C: a randomised trial. *Lancet* 2001;358:958-65.
- 26 Fried MW, Shiffman ML, Reddy KR et al. Peginterferon alfa-2a plus ribavirin for chronic hepatitis C virus infection. *N Engl J Med*. 2002;347:975-82.
- 27 Sievert W. Antiviral therapy for chronic hepatitis C. *Hepatitis C Update: A management guide for general practitioners*. AFP 2003;10(Oct):829-30.
- 28 Batey RG, Bensoussan A, Fan YY, Bollipo S, Hossain MA. Chinese Herbal Medicine as an alternative therapy for HCV: A preliminary report of a double blind placebo controlled trial. *J Gastroenterol Hepatol* 1998;(13 Mar):244-247.
- 29 Australian Institute for Primary Care. *National Hepatitis C Resource Manual*. La Trobe University, Melbourne: AIPC, 2001:7.
- 30 Department of Health and Ageing. *Infection Control Guidelines for the prevention of transmission of infectious diseases in the health care setting*. Canberra: Commonwealth of Australia, 2004;1:10.
- 31 Royal Australasian College of Surgeons. *Infection Control in Surgery: Policy Document*. Melbourne: RACS, 1998:40.
- 32 Australian Institute for Primary Care. *National Hepatitis C Resource Manual*. La Trobe University, Melbourne: AIPC, 2001:63.
- 33 Anti Discrimination Board of NSW. *C-Change Report of the Enquiry into Hepatitis C Related Discrimination 2001;(Nov):36*.
- 34 Anti Discrimination Board of NSW. *C-Change Report of the Enquiry into Hepatitis C Related Discrimination 2001;(Nov):141*.
- 35 Anti Discrimination Board of NSW. *C-Change Report of the Enquiry into Hepatitis C Related Discrimination 2001;(Nov):53-57*.

Contacts

Hepatitis C and related organisations/groups can be contacted for further resources and support information

AUSTRALIA – HCV

Australian Hepatitis Council (AHC)

National

Tel: 61 2 6232 4257
 Fax: 61 2 6232 4318
 Email: info@hepatitisaustralia.com
 Web: www.hepatitisaustralia.com

Australian Capital Territory

Tel: 02 6257 2911
 Fax: 02 6257 1611
 Email: info@acthepc.org
 Web: www.acthepc.org

New South Wales

Tel: 02 9332 1599
 Freecall: 1800 803 990 (country)
 Fax: 02 9332 1730
 Email: hccnsw@hepatitisc.org.au
 Web: www.hepatitisc.org.au

Northern Territory

NT AIDS and Hepatitis Council
 Tel: 08 8941 1711
 Freecall: 1800 880 899
 Fax: 08 8941 2590
 Email: info@ntahc.org.au
 Web: www.ntahc.org.au

Queensland

Tel: 07 3236 0610
 Freecall: 1800 648 491 (country)
 Fax: 07 3236 0614
 Email: admin@hepatitisc.asn.au
 Web: www.hepatitisc.asn.au

South Australia

Tel: 08 8362 8443
 Freecall: 1800 021 133 (country)
 Fax: 08 8362 8559
 Email: admin@hepcouncilsa.asn.au
 Web: www.hepcouncilsa.asn.au

Tasmanian Council on AIDS, Hepatitis and Related Diseases

Tel: 03 6234 1242
 Freecall: 1800 005 900 (country)
 Fax: 03 6234 1630
 Email: mail@tascahrd.org.au
 Web: www.tascahrd.org.au

Victoria

Tel: 03 9380 4644
 Freecall: 1800 703 003 (country)
 Fax: 03 9380 4688
 Email: info@hepvic.org.au
 Web: www.hepcvic.org.au

Western Australia

Tel: 08 9227 9800
 Infoline: 08 9328 8538
 Freecall: 1800 800 070 (country)
 Web: www.hepatitiswa.com.au

NEW ZEALAND – HCV

Hepatitis C Support

Tel: 64 9 377 8500

The Hepatitis Foundation

Tel: 64 7 307 1259
 Freecall: 0800 332 010 (in NZ)
 Email: hepteam@hepfoundation.org.nz
 Web: www.hepfoundation.org.nz

For additional copies of this resource contact:

Australasian Society for HIV Medicine Inc (ASHM)

LMB 5057 Darlinghurst NSW 1300
 Tel: 61 2 8204 0700
 Fax: 61 2 9212 2382
 ABN: 48 264 545 457

AUSTRALIA – RELATED

Australasian Society for HIV Medicine (ASHM)

Tel: 02 8204 0700
 Email: ashm@ashm.org.au
 Web: www.ashm.org.au

Australian Injecting and Illicit Drug Users League (AIVL)

Tel: 02 6279 1600
 Fax: 02 6279 1610
 Email: info@aivl.org.au
 Web: www.aivl.org.au

Australian Drug Foundation

Tel: 03 9278 8100
 Infoline: 1300 858584
 Email: adf@adf.org.au
 Web: www.adf.org.au

Gastroenterological Society of Australia

Tel: 02 9256 5454
 Email: gesa@gesa.org.au
 Web: www.gesa.org.au

National Centre for Education and Training on Addictions

Tel: 08 8201 7535
 Email: nceta@flinders.edu.au
 Web: www.nceta.flinders.edu.au

Other ASHM resources, including the following hepatitis C-related publications, are available from the ASHM website: www.ashm.org.au

Journal Supplements

- *Ambulance Officers and Hepatitis C*
- *Dental Health and Hepatitis C*
- *General Practitioners and Hepatitis C*

Factsheet

- *Hepatitis C in brief – a factsheet*

Monographs

- *Coinfection: HIV & Viral Hepatitis – a guide for clinical management*
- *HIV and viral hepatitis C: policy, discrimination, legal and ethical issue*
- *HIV Management in Australasia: a guide for clinical care*
- *HIV/Viral Hepatitis: a guide for primary care*

Distance-learning kit

- *'Talking Together' Contemporary issues in Aboriginal and Torres Strait Islander health: HIV, hepatitis and sexual health*



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