NATIONAL

HEPATITIS C

RESOURCE MANUAL

ACKNOWLEDGEMENTS

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The project's Advisory Committee of Bob Batey, Gino Vumbaca, Helene Williams, Bridget Carrick, Jill Meade and Stuart Loveday, Jon Evans and Gai Wilson have provided much appreciated expertise in directing the shape of the project. The Melbourne-based Consortium Working Group of Nick Crofts, Campbell Aitken, Jia-Yee Lee, Jill Meade, Carlo Campora and Russell Renhard gave unstintingly of their time, energy and experience in fortnightly meetings and in the reading of yet another draft of the text.

More than 70 people, each with particular understandings of aspects of hepatitis C, contributed articles and review comments to the Manual in development. The relevance of this resource is a reflection of their expertise, and representative of Australia's outstanding position in responding to the challenges posed by this virus.

The Manual as a reality is the result of the exceptional skills which the Project Officer, Deb Sansom, brought to the complex task of compiling, writing, editing and formatting.

My appreciation and sincere thanks to all of you.

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INTRODUCTION

WHY IS HEPATITIS C SUCH A MAJOR PUBLIC HEALTH ISSUE?

When hepatitis C was first identified in 1989, there was a sense for many of 'here we go again'. In the 1980s, HIV and AIDS posed monumental challenges to accustomed ways of seeing the world, and to the design and delivery of a broad range of health services. Political commitment, prevention messages, provision of health care and ways of working with affected individuals and communities for better outcomes were all subjected to intense scrutiny and debate.

Since 1989, the hepatitis C public health pandemic has been acknowledged and mapped. Hepatitis C has become the major cause of primary liver cancer and the primary indication for liver transplantation in the world. The human costs of hepatitis C, in terms of reduction in quality of life and wellbeing and of occupational and social discrimination and isolation, is hard to quantify. The financial cost of the virus, in terms of medical and hospital care, lost productivity and social welfare, is immense.

AUSTRALIA'S RESPONSE TO HEPATITIS C

Australia's response to HIV/AIDS has, in some ways, enabled us to plan and implement a cohesive response to hepatitis C. All levels of government have shown leadership, and involvement of the affected communities has been more rapid, creative and profound than in any other country. Australia was the first country in the world to develop a national Hepatitis C Strategy, and to give support to this initiative through funding a number of ongoing community oriented projects.

In 1994, the Commonwealth Government produced the first position paper on hepatitis C, entitled the *National Hepatitis C Action Plan*. Since this time, there has been a significant increase in our understanding of the epidemiology of hepatitis C in Australia, and of transmission modes, natural history, management options and the efficacy and targeting of treatments for chronic infection. Our appreciation of appropriate prevention messages for educators has also been refined through peer-based behavioural research. In the health setting, one of the many challenges is to communicate the complexity and scope of this information to a diverse range of primary health care workers, who are ideally placed to practically apply their understanding for the benefit of those affected.

Hepatitis C is acknowledged as a major public health issue. However, the problems and challenges associated with hepatitis C have not yet been solved. There is still a great deal of work to be done in controlling the spread of the virus, in ensuring fair and equitable access to effective and safe treatments and in eliminating the associated discrimination and stigmatisation in all its forms. Multifaceted, fresh approaches are urgently needed to meet the various health, social and political challenges that this virus poses to our communities in the 21st century.

WHO DEVELOPED THIS RESOURCE?

The Centre for Development and Innovation in Health, in the Australian Institute for Primary Care at La Trobe University, has developed this resource in association with:

- The Hepatitis C Council of Victoria.
- The Melbourne Liver Group.
- The Blood Borne Virus Consortium, comprising
    - The Victorian Infectious Diseases Reference Laboratory;
    - The Macfarlane Burnet Centre – Epidemiology and Social Research Unit; and
    - The Victorian Infectious Diseases Service – Royal Melbourne Hospital.

The development of the Manual has involved wide community consultation. Contributing authors to the Manual include researchers, epidemiologists, clinicians, educators, counsellors and members of the affected community.

The Commonwealth Department of Health and Aged Care has funded the development and implementation of this resource through the Council of Australian Governments Illicit Drug Diversion Package.

WHAT IS THE AIM OF THIS RESOURCE?

The aim of the resource is to enhance the health outcomes of people affected or potentially affected by hepatitis C, by providing standardised, accurate and current information about hepatitis C and associated issues to a wide range of health care providers.

WHO IS THIS RESOURCE FOR?

This resource Manual has been developed with the following audiences in mind:

- alcohol and other drug agency workers;
- Needle and Syringe Program workers;
- carers and people providing community support;
- counsellors;
- nurses;
- educators; and
- emergency service personnel.

WHAT SHOULD THE MANUAL BE USED FOR?

This Manual has been designed to support individual and community understanding and knowledge, and to encourage reflection on service delivery and educational practice, so that the contributions of health care workers to hepatitis C prevention education, health maintenance, treatments, counselling and support are enhanced. This Manual has been developed as an educational resource, not as a training manual, nor as a source for academic research.

The Manual is not intended to replace expert medical advice about hepatitis C. It is recommended that any individual with hepatitis C or anyone at risk of contracting hepatitis C seek their own medical advice.

As a guide to enhance your understanding and enjoyment of this Manual, words that appear for the first time and are explained in the glossary appear in bold type.

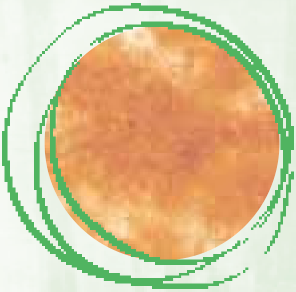
The Manual is also available for download at the Department of Health and Aged Care's website: *www.health.gov.au*

CHAPTER 1

HEPATITIS C: ALL ABOUT THE VIRUS

Contributors: Campbell Aitken, Australian Hepatitis Council, Australian Intravenous League (AIVL), Scott Bowden, Nick Crofts, Margaret Macdonald, NSW Hepatitis C Council, William Sievert, Victorian Hepatitis C Helpline.

- Hepatitis C is a blood-borne virus that affects the liver.
- Transmission occurs when the blood of someone who is already infected with hepatitis C enters the bloodstream of another person.
- Current estimates suggest that there are over 200,000 Australians infected with hepatitis C, and that 11,000 new infections occur each year.
- Hepatitis C is a slow-acting virus, and for the majority of people infection will not result in serious disease or death.



SUMMARY OF IMPORTANT POINTS

- There is currently no vaccine for hepatitis C, though there are options for treatment.

THE LIVER

The liver is a vital organ, located under the ribs in the upper right area of the abdomen. The liver has many different functions, including to:

- fight infection in the body;
- process digested food from the intestine;
- control levels of fats, amino acids and glucose in the blood;
- manufacture bile, an important substance for the digestion of fats;
- neutralise and destroy drugs and toxins;
- break down food and convert it into energy;
- store iron, vitamins and other essential chemicals;
- manufacture, break down and regulate numerous hormones; and
- make enzymes and proteins that are responsible for most chemical reactions in the body, e.g. those involved in blood clotting and repair of damaged tissues.

STRUCTURE AND FUNCTION OF THE LIVER

- The liver is the second largest organ in the body (after the skin) and weighs approximately 1.25 kg.
- It has a unique blood supply from two independent sources. It is supplied with oxygen-rich blood from the hepatic artery and with blood from the portal vein, coming from the intestines. All blood leaving the intestines reaches the heart and lungs only after passing through the liver, which enables the liver to filter nutrients, food and other substances absorbed from the bowel.

- The liver can grow new cells if existing ones are destroyed. Depending on the extent of damage to the liver, up to three-quarters can be removed and the remainder will re-grow to its original size and shape within a relatively short time.

FIGHTING INFECTIONS

- The liver plays a vital role in fighting infections, particularly infections arising in the bowel. It does so by mobilising part of the body's defence mechanism called the **macrophage** system. The liver contains over half of the body's supply of macrophages which can destroy any invading bacteria.
- If the liver is severely damaged, its ability to fight infections is impaired.

WHAT IS HEPATITIS?

- **Hepatitis** means inflammation of the liver.
- Inflammation is the body's natural reaction to injury. Inflammation is sometimes associated with swelling and/or tenderness.
- Hepatitis is caused by viruses and/or harmful consumption of alcohol and some chemicals.
- Five hepatitis viruses that can infect and inflame the liver have been identified to date; hepatitis A, B, C, D and E. These viruses are different and are transmitted in different ways, but their effect on the liver is similar.

When the liver is inflamed over a long period, it can develop scar tissue, which impairs its functioning. This scar tissue is known as **fibrosis**. Extensive scarring of the liver is called **cirrhosis**.

WHAT IS HEPATITIS C?

Hepatitis C was first identified in 1989. Before then, it was referred to as **non-A, non-B hepatitis**, or post-transfusion hepatitis. Hepatitis C affects millions of people around the world. It is a slow-acting virus and for the majority of people, infection with hepatitis C will not result in serious disease or death.

Of new infections in Australia:

- 90% result from the sharing or re-use of drug injecting equipment contaminated with infected blood; and
- 10% result from other risk behaviours which involve blood-to-blood contact (e.g. tattooing and body piercing with contaminated equipment, **needlestick injuries** and **vertical transmission** from mother to baby).

A test to screen the Australian blood supply for **antibodies** to hepatitis C was introduced in 1990. Prior to 1990, up to 10% of new infections resulted from blood transfusion and receipt of blood products.

Research has shown that approximately 25% of people with hepatitis C will clear the virus within 2 to 6 months of becoming infected; however, they will continue to carry antibodies to the virus. The other 75% of people who do not clear the virus will have an ongoing or **chronic infection**. After 20 years, up to 10% of people with chronic hepatitis C will develop cirrhosis. This rises to up to 20% of people after 40 years. *See Natural History, Estimated Outcomes of Hepatitis C Infection, p21 for details.*

Individuals who clear hepatitis C from their bodies are not at risk of chronic liver disease unless they are re-infected with the virus. There are approximately ten different strains of hepatitis C. These strains are called **genotypes**. A person can become re-infected with the same or with one or more genotypes. *See section on Genotypes below.*

Current treatments for hepatitis C use **interferon**, most commonly in combination with **ribavirin**. Approximately 20% of people will clear hepatitis C completely using the standard dose of interferon alone. However, treatment with interferon in combination with ribavirin provides an overall sustained response rate of 40% (rising to 65% for people with genotypes that are more responsive to treatment). *See Chapter 6: Treatments for Hepatitis C for details.*

As yet, there is no **vaccine** to protect against infection with hepatitis C, nor is it likely that one will be developed in the near future.

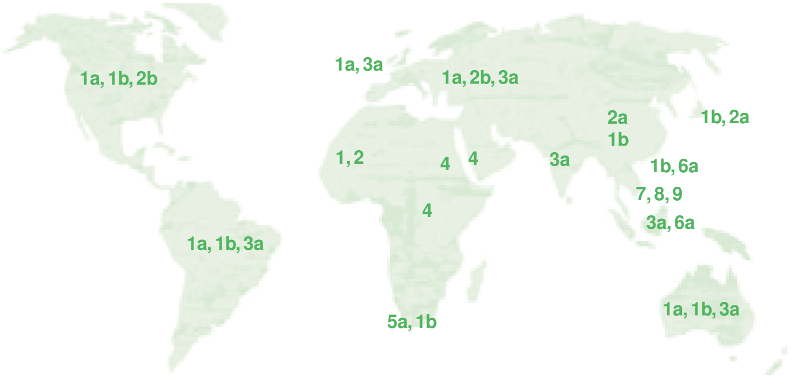
The hepatitis C virus is sometimes referred to as HCV, and commonly abbreviated to "hep C" in conversation.

HEPATITIS C GENOTYPES

Genotype is the term used to describe the specific genetic structure of hepatitis C. There are believed to be at least ten different hepatitis C genotypes, which are closely related in their genetic make-up but differ enough that scientists have classified them into distinct groups.

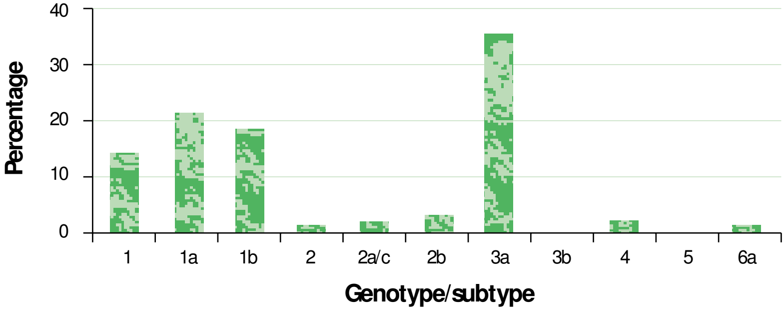
The classification scheme most often used divides hepatitis C into six major genotypes (1–6), each of which are further subdivided into subtypes (1a, 1b, 2a, etc). Genotypes 1, 2 and 3 are widely distributed in Western countries while other genotypes appear to be more geographically localised, e.g. genotype 4 is found predominantly in the Middle East and Central Africa.

HEPATITIS C VIRUS GENOTYPES – WORLD VIEW



In Australia, the predominant genotypes are genotype 1 (55% of notified infections) and genotype 3 (35% of notified infections).

DISTRIBUTION OF HEPATITIS C GENOTYPES IN AUSTRALIA (N=2176)



Victorian Infectious Diseases Reference Laboratory 1996–2000

Genotyping, the procedure for determining the specific hepatitis C genotype, is expensive because an initial Polymerase Chain Reaction or **PCR test** *(see Chapter 4: Hepatitis C Testing)* is required to generate sufficient genetic material of the virus for the test. Genotyping has little use diagnostically, and is mainly used in decision-making about whether to undergo treatment and in determining the duration of treatment.

VIRAL LOAD

Two commercial **viral load** tests are available – a quantitative PCR test and a branched chain DNA (**bDNA**) viral load test. Determining the load or amount of hepatitis C in the blood can be of use to predict an individual's response to treatment and as an estimate of the risk of transmission. These tests are expensive but are covered under Medicare in certain circumstances. *See Chapter 4: Hepatitis C Testing, for more information.*

PRINCIPLES: VIRAL TRANSMISSION

- The virus leaves the body of a person who is infected.
- The virus must be present in a body fluid. In the case of hepatitis C, the body fluid is blood.
- The virus must be concentrated enough (also known as **viral load**) to cause an infectious threat.
- The body fluid carrying the virus must enter the bloodstream of another person.

TRANSMISSION OF HEPATITIS C

- Hepatitis C is transmitted by blood-to-blood contact. This means that the blood of a person already infected with the virus must leave their body and enter the bloodstream of another person.
- Hepatitis C usually enters the body of a person via a rupture or opening in the skin.
- For transmission to occur, the virus must be concentrated enough (viral load) to present a threat of infection.
- Currently in Australia, the greatest risk for the transmission of hepatitis C is through blood-to-blood contact involved in the sharing or re-using of needles and syringes. Other injecting equipment, surfaces used for mixing up, disposal containers, hands and puncture sites can become contaminated during the injecting process and also pose a risk of transmission.
- The Australian Red Cross Blood Bank began screening for hepatitis C in February 1990. Before this time, some people were infected with hepatitis C when they received blood or blood products contaminated with the virus.
- Hepatitis C has been found in body fluids other than blood, but the viral load is thought to be too low for transmission to occur.

- Hepatitis C is not classified as a sexually transmissible infection (**STI**). Hepatitis C is transmitted through blood-to-blood contact, so sexual transmission is possible if there is blood-to-blood contact during sexual contact. *See Sexual Transmission, p18 for details.*

FACTORS INFLUENCING TRANSMISSION

Whether hepatitis C is transmitted in any particular situation depends on:

- the susceptibility of the recipient;
- the viral load or concentration of virus in the blood; and
- the amount of blood involved.

There is limited information available about variations in the concentration of hepatitis C circulating in blood and other body fluids throughout the course of infection. Current evidence suggests that around 80% of people with hepatitis C have detectable levels of the virus circulating in their blood. In particular, studies of mother-to-baby transmission and of needlestick injuries among health workers indicate that transmission is related to viral load.

DRUG PREPARATION AND INJECTING EQUIPMENT

The sharing or re-using of needles and syringes used during the drug injecting process is the most common mode of hepatitis C transmission in Australia. Transmission can also occur during the drug preparation and injecting process, through the sharing or re-using of other contaminated injecting items such as spoons, swabs, water, needles, syringes, syringe plungers and tourniquets. Hands and surfaces used for mixing up can also become contaminated during preparation and injecting.

It is important to remember that:

- blood does not have to be visible to the eye to transmit hepatitis C; and
- blood is often present when people inject drugs, and while it is safer to inject in the company of others because of the risk of overdose, the sharing or re-

using of **ANY** item of equipment poses a risk for hepatitis C transmission.

See Chapter 3: Section on Harm Reduction, p51, and section on Safer Using, p54, for more details.

BLOOD TRANSFUSION AND BODY TISSUE(S)

- Post-transfusion hepatitis C is relatively rare in most economically developed countries since donors with declared risk factors for blood-borne viral infections (e.g. injecting drug use, recent tattooing or piercing), and donors with hepatitis B, HIV or hepatitis C antibodies are excluded from donating blood, organs or body tissue. Donated blood is screened for hepatitis C antibodies.
- A commercial test for hepatitis C antibodies became available in 1990. Prior to this, the risk of acquiring hepatitis C (then called non-A, non-B hepatitis) through a transfusion was 0.19%. Since the test was introduced, the risk of transmission in Australia has dropped to 0.001%.

TATTOOING AND OTHER FORMS OF SKIN PENETRATION

- Contaminated equipment used in tattooing can transmit hepatitis C.
- It is recommended that people seeking a tattoo visit a practitioner who consistently uses standard infection control procedures. *See Chapter 3, section on Standard Infection Control Procedures, p52.*
- Other forms of skin penetration such as body piercing, acupuncture and electrolysis are thought to present a low risk of transmission.
- Some forms of beauty therapy involve skin penetration and if non-sterile equipment is used there is a risk of hepatitis C and other blood-borne virus transmission.
- No one having a tattoo or other skin piercing is legally obliged to disclose their hepatitis C status (except in Western Australia).

TRANSMISSION IN THE HEALTH CARE SETTING

- Transmission in the health care setting occurs mainly through needlestick or sharps injury, and through handling items contaminated with blood.
- In a health care setting, estimates of the risk of acquiring hepatitis C from a needlestick injury range from 2%–8%.
- In the absence of adequate precautions, blood spills may present a transmission risk. *See Chapter 2 for information about hepatitis B, and Chapter 3 for information on Standard Infection Control Procedures.*
- There have been reported cases of hepatitis C transmission through blood splashes to the eye. These events are rare but health workers should not ignore the risk.
- A small number of **nosocomial** (infections that occur in the hospital setting) transmissions have also been reported in people undergoing minor surgery, endoscopic procedures and kidney dialysis.

MOTHER TO BABY TRANSMISSION (VERTICAL 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.
- Current research about the timing of transmission from mother to baby is inconclusive. There is some evidence that transmission occurs during pregnancy, while other studies indicate that transmission occurs during delivery. In the absence of conclusive data about the timing of transmission, caesarean section is not recommended for women with hepatitis C, and the use of forceps and scalp electrodes should be avoided during delivery (if

clinically appropriate) as they can break the baby's skin.

- There is usually no benefit in testing babies for hepatitis C antibodies, but if parents are still concerned following counselling, then testing should only be carried out after the child reaches 18 months of age.

There is an increased risk of hepatitis C transmission from mother to baby when the mother:

- is in the **acute** (newly acquired) phase of hepatitis C infection. *See section on Acute and Chronic Infection, p19 for details*;
- has serious liver damage;
- has high levels of the virus in her blood; or
- is co-infected with HIV.

Transmission rates of 16% have been recorded for mothers co-infected with HIV and hepatitis C, versus a transmission rate of 2%–5% for those with hepatitis C only.

BREASTFEEDING

- Hepatitis C has been found in breast milk, but the levels of virus are not thought to be high enough to pose a transmission risk.
- Because the health benefits of breastfeeding far outweigh the low risk of hepatitis C transmission, women with hepatitis C are encouraged to breastfeed their newborn babies.
- Women with hepatitis C who have cracked or bleeding nipples are advised to express and discard milk from that breast until lesions are healed, as blood may be present in the breast milk.
- To learn more about breastfeeding positions and techniques that may help to prevent cracked nipples, health workers should advise women to consult with a lactation consultant or midwife at a maternity hospital or women's health centre.

TRANSMISSION IN THE HOME

- There is no evidence that people with hepatitis C transmit the virus to others with whom they share accommodation or household utensils such as cups, toilets or laundry facilities. Sharing personal grooming items, such as toothbrushes and razors, which are contaminated with infected blood can pose a transmission risk, though the risk is thought to be very low.

See Chapter 3, section on Household Transmission, p68.

SEXUAL TRANSMISSION

- Hepatitis C is not classified as a sexually transmissible infection (**STI**).
- While sexual contact is not dismissed as a route of hepatitis C transmission, the evidence from studies of sex-partners of people with hepatitis C suggests that the risk is extremely low, and exists when blood-to-blood contact occurs during sex.
- Reported cases of sexual transmission of hepatitis C have involved blood-to-blood contact in the course of sexual activities, e.g. through the use of sex toys, during menstruation, or during sex that causes abrasions in the delicate skin of the genitals or anus.
- There have been studies into sexual transmission, but many of these have been limited by small sample size, lack of control groups, or failure to exclude other risk factors, particularly histories of injecting drug use. Additional evidence is needed. In particular, **prospective studies** have not provided clear evidence of sexual transmission in the absence of other potential risk factors.

ACUTE AND CHRONIC INFECTION

ACUTE INFECTION

- The first stage of hepatitis C infection is called **acute** hepatitis.
- The term ‘acute’ does not mean ongoing and does not refer to the severity of the disease.
- This phase of infection is often very mild, lasts less than 6 months (often less than 12 weeks) and goes unnoticed in most people.
- Although only a very small minority of people experience symptoms in the acute phase, it is important for health workers to be alert to the symptoms of infection, such as nausea, dark urine, jaundice and abdominal discomfort.
- A person may have abnormal liver function tests at this time, even though no symptoms are present.
- A person with recognised acute infection should be referred to a liver specialist, an infectious diseases specialist or a specialist treatment centre for consideration of early treatment.
- Hepatitis C is cleared from the body without medical intervention in 25% of people within 2–6 months of infection.
- In this 25% of people, antibodies to the virus remain after viral clearance and will decline in time.

See Chapter 4: Hepatitis C Testing, and Chapter 6: Treatments for Hepatitis C.

CHRONIC INFECTION

- The term **chronic** refers to an infection that has been ongoing for more than 6 months.
- The term refers specifically to the duration of infection, not to the severity of the disease.
- Hepatitis C can live in the body for years without causing symptoms.
- Chronic infection with hepatitis C may lead to liver damage.

NATURAL HISTORY

The **natural history** of a disease is defined as its progression in the absence of any medical treatment or other intervention over a designated period of time.

The natural history of a condition includes interactions that occur between the person infected, the factor(s) causing the disease and the environment, beginning with the onset of the disease and finishing with either death or recovery. In the case of hepatitis C, recovery refers to viral clearance.

Understanding the natural history of a disease is important for two reasons:

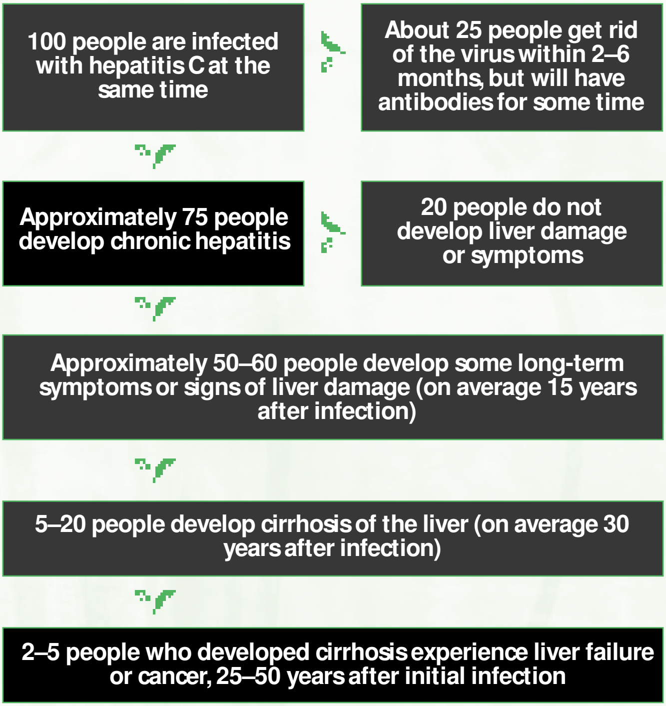
- it provides a way to make an informed prediction (**prognosis**) about what might happen in the future to the health of the person affected; and
- it helps to formulate effective treatment(s) for the illness.

It should be noted that the natural history of hepatitis C-related disease is difficult to document accurately in individual cases. Even with an ideal study population (i.e time and mode of exposure is known, the liver of each participant is normal before infection and participants are followed over time without any medical intervention), it is unethical to deny available treatment to people with symptomatic infection.

HOW IS NATURAL HISTORY USEFUL?

- There is debate regarding the conclusions from current studies because the findings are sometimes inconsistent.
- It is important to remember that, to date, natural history studies have concentrated on people who were infected through blood or blood products. Given that the majority of infections in Australia today are a consequence of sharing and re-using items of injecting equipment, tracking the progression of hepatitis C is still a challenge for the medical community.

ESTIMATED OUTCOMES OF HEPATITIS C INFECTION



100 people are infected with hepatitis C at the same time

About 25 people get rid of the virus within 2–6 months, but will have antibodies for some time

Approximately 75 people develop chronic hepatitis

20 people do not develop liver damage or symptoms

Approximately 50–60 people develop some long-term symptoms or signs of liver damage (on average 15 years after infection)

5–20 people develop cirrhosis of the liver (on average 30 years after infection)

2–5 people who developed cirrhosis experience liver failure or cancer, 25–50 years after initial infection

HEPATITIS C IN AUSTRALIA

The earliest evidence of hepatitis C in Australia can be found in stored samples of blood taken from people admitted to Fairfield Hospital in Victoria in 1971. All these people presented at Fairfield Hospital with acute hepatitis, and all had previously injected illicit drugs. Almost 60% of samples contained antibodies to hepatitis C, then known as non-A non-B hepatitis. In a similar **cohort** from Sydney in the early 1970s, 84% had hepatitis C antibodies.

Injecting drug use was probably introduced into Australia in the late 1960s by American military personnel on leave from the war in Vietnam, although by the early 1970s it was still relatively uncommon. Fairfield Hospital admissions data from 1971 to 1975 suggest that non-A, non-B hepatitis was spreading rapidly among people who were injecting drugs. Subsequent growth of the hepatitis C epidemic has been fuelled by increasing numbers of people injecting illicit drugs and sharing items of injecting equipment contaminated with infected blood.

DIAGNOSES AND EXPOSURE CATEGORIES

By the end of 1999, over 140,000 people in Australia had been diagnosed with hepatitis C antibodies; more than 80% had histories of injecting drug use. Of all hepatitis C cases notified to the Victorian Public Health Unit in 1993–94, reported actual or potential exposures were:

- history of injecting drug use – 85%;
- pre-1990 blood transfusions – 6%; and
- other blood exposures – 8%.

Transmission modes involving blood exposure were identified for almost all notifications, and other routes of transmission were rare.

The introduction of universal screening of blood donors in Australia in 1990 has virtually eliminated hepatitis C transmission via blood transfusions and blood products, which before this time were the only other major routes of transmission.

In 2000, there were 20,536 notifications of hepatitis C in Australia, making hepatitis C the most frequently reported infectious disease to the National Notifiable Diseases Surveillance System.

ESTIMATED PREVALENCE AND INCIDENCE

In 1997 a national working group estimated hepatitis C **prevalence** and **incidence** in Australia, based on estimates of the number of people injecting drugs. Given the difficulty of measuring the size of the drug-using population or its dynamics, these estimates should be treated with caution. The working group estimated that:

- 196,000 people in Australia were hepatitis C antibody positive by the end of 1997 (**prevalence**).
- There were 11,000 new hepatitis C infections in 1997 (91% among people who inject or have injected drugs) (**incidence**).
- Hepatitis C prevalence among blood donors was a low 0.29%.

Prevalence in women attending antenatal hepatitis C antibody screening is thought to be a useful estimate of prevalence in the entire adult population. The 1997 measure for hepatitis C prevalence in antenatal examination in South Australia was 1.1%.

PREVALENCE AND INCIDENCE IN PEOPLE WHO INJECT DRUGS

Most Australian studies of hepatitis C in people who inject drugs indicate prevalences of 50% or more. Annual measurements of hepatitis C exposure in people who have attended Needle and Syringe Programs since 1996 found hepatitis C prevalence between 51% and 54%, a significant decrease from the prevalence rate of 63% that was estimated in 1995.

Other Australian studies have confirmed that transmission of hepatitis C in people who inject drugs is continuing at a high rate. This is in marked contrast to HIV, which remains at a very low prevalence among this group in Australia.

Hepatitis C continues to spread among people who inject drugs in Australia while HIV does not, because of:

- the very high prevalence of hepatitis C existing before Harm Reduction Programs began in response to the emergence of HIV; and
- the high 'infectiousness' of hepatitis C compared with HIV. *See Chapter 2: Hepatitis C, Other Hepatitis Viruses and HIV.*

Current hepatitis C incidence among people who inject drugs is around 15 infections a year per 100 people, but up to 40 or more in some sub-populations, such as some young people who have spent time in prisons or juvenile justice settings.

There is some recent evidence that hepatitis C incidence among people who inject drugs may have decreased through the late 1980s and 1990s as a result of behaviour change in relation to HIV (this is also true for hepatitis B and hepatitis D). It remains to be seen whether this decrease is significant and sustained.

PREVALENCE IN OTHER POPULATIONS

Hepatitis C prevalence is high in populations of people detained in custodial settings. This is mainly because many inmates reported histories of injecting drug use. In addition, transmission of hepatitis C in custodial settings is facilitated by the absence of options for safer injecting. A study conducted in 1999 found that 47% of inmates (62% of women and 46% of men) in New South Wales correctional facilities were hepatitis C positive. Among male adolescents detained in the Melbourne Juvenile Justice Centre, all of whom had been heroin injectors for more than one year prior to detention, 21% were hepatitis C positive. *See Chapter 8: section on Hepatitis C Education in Custodial Settings, p172, for more details.*

High prevalence rates also exist among Australian men with haemophilia, who, as part of their treatment, received infected blood or blood products before donor screening for hepatitis C began in 1990. Many men with haemophilia also have HIV (acquired before donor screening for HIV antibodies was introduced in 1985). This state of infection with two, and sometimes three separate and unrelated viruses is known as **co-infection**. *See Chapter 2: Hepatitis C, Other Hepatitis Viruses and HIV for more details.*

Since the screening of donated blood was introduced into Australia, new hepatitis C infections have been almost entirely confined to people who inject drugs. A small number of transmissions related to tattooing or skin piercing have been recorded, and a few transmissions in medical and hospital settings have occurred through needlestick injuries. However, most new infections occur through blood-to-blood contact via activities associated with injecting drug use.

It is clear that efforts to prevent further infections must be a priority for people who currently have hepatitis C, and for those who are at risk of infection through behaviours that potentially transmit the virus.

COMMONLY ASKED QUESTIONS

I HAVE NEVER SHARED A NEEDLE WITH ANYONE: HOW DID I GET INFECTED WITH HEPATITIS C?

Hepatitis C is transmitted through blood-to-blood contact. If you have ever injected drugs, it may be that the virus was transmitted through sharing equipment contaminated with blood other than a needle or syringe (e.g. tourniquet, water, swab etc). If you have never injected drugs, then you may have been exposed to the virus in other ways, such as a pre-1990 blood transfusion or unsafe tattooing or body piercing practices.

SHOULD I BE CONCERNED THAT I HAVE HEPATITIS C?

Hepatitis C is not necessarily life-threatening, and you may not feel ill. However, it is very important to maintain your general health through reducing alcohol consumption, eating a balanced diet, exercising, taking adequate rest and having regular medical check-ups. Another reason to be concerned is the possibility that you could pass on the virus to others through unsafe behaviours. To avoid this, you need to be blood aware. Because it is possible to become re-infected with the same or another genotype, it is important always to practise safe behaviours. *See Chapter 3: Reducing Hepatitis C Transmission in the Community.*

I AM HEPATITIS C POSITIVE AND I HAVE A NEW BABY. HOW CAN I PREVENT TRANSMITTING THE VIRUS TO MY CHILD?

The advantages of breastfeeding far outweigh the risk of contracting hepatitis C. Breastfeeding should be discontinued if the nipples are cracked or bleeding and there is a possibility of transmission via blood. When the nipples have healed breastfeeding can be resumed. Advice about the best way to breastfeed can be sought from a lactation consultant.

See the section on Vertical Transmission in this chapter, p16 for additional information, and Chapter 4: Hepatitis C Testing, for testing information.

HOW MANY OTHER PEOPLE HAVE HEPATITIS C?

Current estimates suggest that more than 200,000 Australians have been infected with hepatitis C, and that there are approximately 11,000 new infections every year. It is estimated that 170 million people worldwide have hepatitis C (World Health Organisation, 1999).

HEPATITIS C:
THREE DECADES OF DEVELOPMENT

1971: Stored blood samples from people who had injected drugs (admitted to Fairfield Infectious Diseases Hospital, Melbourne in 1971; blood tested in 1990) show a majority have antibodies to hepatitis C. These people are diagnosed with non-A, non-B hepatitis.

NOVEMBER 1986: In response to the emerging HIV epidemic, the first Needle and Syringe Program opens in NSW.

1988: Scientists in the USA report the discovery of the hepatitis C virus, and patent its genetic make-up (the first time the genetic structure of a living organism is patented).

1989: Identification of hepatitis C is confirmed in Science, April 1989. The description non-A non-B hepatitis is discontinued.

1989: AusHep 1, the first of several Australian interferon clinical trials is initiated.

1990: Following the development of a diagnostic test for hepatitis C antibodies, Australia's donated blood supply is made safer from potential hepatitis C transmission with the introduction of screening in February 1990.

1990: Hepatitis C becomes a notifiable disease in Australia.

NOVEMBER 1991: Australia's first hepatitis C support group is established in NSW, to provide information, support and advocacy for people with hepatitis C. Haemophilia Foundations, already dealing with issues of haemophilia and HIV, also establish hepatitis C support groups.

OCTOBER 1994: The Australian Health Ministers' Advisory Council develop the *National Hepatitis C Action Plan* which recommends activities for **surveillance** and **epidemiology**, testing, clinical management, counselling, education, prevention and research.

OCTOBER 1994: Interferon monotherapy (6-month course) is funded under Section 100 of the Pharmaceutical Benefits Scheme (**PBS**), following Therapeutic Goods Administration (**TGA**) approval for use in Australia in December 1992.

1995: Australia's first State-based hepatitis C strategy is produced in Victoria.

AUGUST 1996: The Commonwealth Government sponsors a report entitled *Meeting the Needs of People in Australia Living with Hepatitis C*.

DECEMBER 1996: Hepatitis C is incorporated into the *Third National Strategy on HIV/AIDS*. The Australian National Council on AIDS becomes the Australian National Council on AIDS and Related Diseases (ANCARD), incorporating hepatitis C.

MARCH 1997: The National Health and Medical Research Council (NHMRC) launches the report, *Strategy for the Detection and Management of Hepatitis C in Australia*.

1997: The Australian Hepatitis Council is established as the peak body to represent state-based hepatitis C organisations.

1997: The Commonwealth Government allocates funds for research and national education programs on hepatitis C.

FEBRUARY 1998: Federal Health Minister, Dr. Michael Wooldridge, announces a funding allocation for social and behavioural research into hepatitis C.

MARCH 1998: The Commonwealth Department of Health and Community Services funds two distinct national education programs, administered by the national peak bodies, the Australian Hepatitis Council (AHC) and the Australian Intravenous League (AIVL).

NOVEMBER 1998: The world's first parliamentary inquiry into hepatitis C tables its first report in NSW, titled *Hepatitis C: The Neglected Epidemic*.

JANUARY 1999: The Commonwealth Department of Health and Aged Care publishes *Hepatitis C: A Review of Australia's Response*.

1999: The Commonwealth Government makes funding available over four years for community-focussed hepatitis C education and prevention initiatives.

MARCH 2000: The world's first mass media hepatitis C campaign to raise public awareness is launched in NSW.

JUNE 2000: Nucleic Acid Testing (**NAT**), capable of detecting minute amounts of hepatitis C genetic material, is introduced into Australian Blood Bank screening.

JUNE 2000: Australia launches the *National Hepatitis C Strategy 1999–2000 to 2003–2004*, a world first in terms of a comprehensive public health response to hepatitis C.

MARCH 2001: The world's first formal inquiry into hepatitis C-related discrimination is launched in NSW.

EPIDEMIOLOGY

June 2002

Contributor: Paul Harvey, *Hepatitis C Council of NSW*

Australia has experienced an alarming 45 per cent increase in estimated new hepatitis C infections - from 11,000 per annum in 1997 to 16,000 per annum in 2001.

The Third Australasian Conference on Hepatitis C, held in Melbourne, Australia, in March 2002, provided a forum for the presentation and discussion of new evidence about the prevalence and incidence of hepatitis C in Australia.

At this conference a research team, led by Dr Matthew Law of the National Centre in HIV Epidemiology and Clinical Research (in collaboration with hepatitis C clinicians, researchers and community representatives) formally revised the number of new cases of hepatitis C, from a previous estimated figure of 11,000 per annum, to an alarming 16,000 each year. The significance of the increase has set alarm bells ringing across the Australian hepatitis C sector.

Believed to be related to increased numbers of people using injecting as their preferred method of taking drugs, the increase puts further pressure on Australia's existing hepatitis C prevention strategies to do even more. Here in Australia needle and syringe programs have prevented the explosion in HIV cases and it was believed that they had capped the incidence of hepatitis C infections. But this is now open to speculation.

Health authorities are now aware of over 160,000 hepatitis C diagnoses that have been reported to State and Territory health departments.

Dr Law stated that of all people with hepatitis C in Australia in 2001, there were an estimated 124,000 with chronic hepatitis C and early liver disease (no or minimal fibrosis), a further 27,000 with moderate to severe fibrosis, and 6,500 people living with cirrhosis. He also estimated there were 175 people with liver failure and 50 with liver cancer.

Unless changes are made, and dependant on future patterns of injecting drug use, there are likely to be between 320,000 and 836,000 people with hepatitis C in Australia by 2020.

CHAPTER 2

HEPATITIS C, OTHER HEPATITIS VIRUSES AND HIV

Contributors: Australian Hepatitis Council, Scott Bowden, Nick Crofts, Haemophilia Foundation Australia, Ron McCoy, Leonie Mudge, Joe Sasadeusz, Bill Sievert.

- Hepatitis C is one of five hepatitis viruses, named A, B, C, D and E, that can inflame the liver.
- The effects of acute viral hepatitis range from no symptoms to severe illness with nausea, pain, abdominal discomfort and jaundice. Such symptoms indicate liver dysfunction.
- Vaccines have been developed to protect against infection with hepatitis A, hepatitis B and hepatitis D. Currently there is no vaccine for hepatitis C.
- Infection with two or more blood-borne viruses at the same time is possible, and is known as co-infection.
- Some viral hepatitis infections, such as hepatitis A, clear naturally from the body giving life-long immunity. This can also happen with hepatitis B, or it can become a chronic infection.

SUMMARY OF IMPORTANT POINTS

- Some hepatitis viruses can cause a chronic infection. Approximately 75% of people exposed to hepatitis C develop a chronic infection, and exposure to hepatitis C does not provide immunity.

OTHER FORMS OF VIRAL HEPATITIS

HEPATITIS A

- Hepatitis A is transmitted through food and water, and from person to person by contaminated faeces (called faecal-oral transmission).
- The time between contact with hepatitis A until symptoms develop is usually 4 weeks, but it can range from 2 to 7 weeks.
- This acute illness usually lasts from 1 to 3 weeks, but it may continue for several weeks or months (prolonged convalescence). Hepatitis A does not become chronic. Many people are not aware they have been infected.
- Complications with hepatitis A can occur for people with hepatitis C, for those over the age of 50 or for those with pre-existing liver damage. *See Co-infection with hepatitis A and/or hepatitis B, p39.*
- Once a person has been infected with hepatitis A and developed antibodies, they have life-long immunity from infection with this virus.

Transmission examples:

- food, drink and eating utensils that have been handled by a person infected with the virus;
- failure to wash hands properly after handling nappies, used condoms, linen or towels soiled with faeces;
- oral/anal sex;
- water contaminated by sewage; and
- food, such as shellfish, contaminated by sewage.

Symptoms of acute infection, if they occur, include:

- aches and pains;
- fever;

- nausea;
- loss of appetite;
- abdominal discomfort;
- yellowing of the eyes and sometimes the skin; and
- dark urine, followed by jaundice.

To avoid hepatitis A:

- get vaccinated; and
- wash hands thoroughly with soap and water:
  - after going to the toilet;
  - before preparing food;
  - after handling soiled or used objects such as nappies and condoms.

Avoid sharing the same food, eating utensils, cigarettes or drinks with people whom you know have the virus. Immunisation for hepatitis A is available. People who have recovered from hepatitis A have life-long immunity to the virus.

HEPATITIS B

- Hepatitis B is found in body fluids including blood, semen, vaginal fluid and breast milk.
- Hepatitis B can be transmitted through sexual activity, unsafe injecting practices, sharing toothbrushes or razors, tattooing or body piercing with contaminated equipment, and from mother to baby at birth.

Symptoms of acute infection, if they occur, include:

- general aches and pains;
- fever;
- nausea;

- loss of appetite;
- abdominal discomfort;
- yellowing of the eyes and sometimes the skin; and
- dark urine, followed by jaundice.

To reduce the risk of hepatitis B transmission:

- get vaccinated;
- use condoms and lubricant every time for anal and vaginal sex;
- use new and sterile injecting equipment every time and ensure that there is no blood contamination during injecting practices (e.g. on hands, tourniquets and surfaces); and
- wear disposable gloves if giving someone First Aid and when cleaning up blood or body fluids.

Most adults recover completely from hepatitis B, although between 3% – 5% of adults will not clear the virus from their body and will remain chronically infected. These people are sometimes called **carriers**. People who do not clear the virus are at risk of developing **cirrhosis** or liver cancer. They can help maintain their health by seeking advice from a liver specialist (**hepatologist**), a gastroenterologist or an infectious diseases specialist. Reducing or eliminating alcohol and following a balanced diet helps some people generally feel better, but it is important to emphasise that improvements to diet do not prevent the risk of developing cirrhosis.

See Chapter 5: section on Nutrition, p106 for information on diet.

Babies and young children infected with hepatitis B are much more likely (>95% risk) than adults to become chronically infected.

People who clear the virus and have normal liver function tests do not need any treatment. People with chronic hepatitis B who have no liver damage or active viral growth do not require treatment. However, if there is liver damage, anti-viral medicines such as **interferon** or **lamivudine** are often used. These can reduce the damage caused by infection in about 35% of people treated.

A vaccine is available for hepatitis B, and ***immunisation is the most effective way to protect against hepatitis B***. The hepatitis B vaccine is safe, inexpensive and effective in 95% or more of the population. However, people over 40 years of age and people who inject drugs are less likely to develop effective immunity. Combination hepatitis A and hepatitis B vaccination is recommended for those at risk of getting both infections: those at risk include people who inject drugs unsafely and people whose work involves a risk of blood-to-blood contact. *See Chapter 3: section on Vaccinations, p70 for more details.*

HEPATITIS D

- Hepatitis D only occurs when hepatitis B is also present.
- Hepatitis D can speed up liver disease and cirrhosis caused by hepatitis B.
- Hepatitis D is uncommon in Australia.

HEPATITIS E

- Hepatitis E is transmitted via water sources contaminated with faeces containing the virus (faecal-oral transmission similar to hepatitis A).
- Symptoms last for 2 to 3 weeks.
- Infection is not associated with chronic liver disease.
- Hepatitis E can be fatal for up to 35% of pregnant women, depending on the stage of pregnancy.
- Hepatitis E is rare in Australia and is seen only occasionally in travellers returning from areas of high hepatitis E prevalence, such as Asia, Africa and the Indian subcontinent.
- There have been reports of two other viruses, called hepatitis F and G. Hepatitis F is discounted as a hepatitis virus. There is no evidence that infection with hepatitis G causes significant liver damage.

HEPATITIS	TRANSMISSION	INCUBATION PERIOD	CHRONIC INFECTION	VACCINE
Hepatitis A	Faecal–oral	2–6 weeks	No	Yes
Hepatitis B	Blood and body fluids	4–24 weeks	Yes	Yes
Hepatitis C	Blood-to-blood contact	4–20 weeks	Yes	No
Hepatitis D	Blood and body fluids	2–6 weeks	Yes – when hepatitis B is also present	Yes – Hepatitis B vaccination provides protection
Hepatitis E	Faecal–oral	2–6 weeks	Yes	No

CO-INFECTION ISSUES

Co-infection occurs when a person is infected with two or more blood-borne viruses. In Australia, the most commonly recognised co-infection is hepatitis C together with hepatitis B. It is estimated that 2–5% of people with hepatitis C are co-infected with chronic hepatitis B. Treatment and management issues for a person with co-infection are complex, with the available research information constantly being updated. Information about management of co-infection is best provided by a liver specialist, a gastroenterologist or an infectious diseases specialist.

HEPATITIS C CO-INFECTION WITH HEPATITIS A AND/OR HEPATITIS B

In the presence of chronic hepatitis C, hepatitis A can become life-threatening. Chronic hepatitis B interacts with hepatitis C to increase the severity and rate of development of liver disease, and there is an increased death rate for people in this situation. If there is no prior evidence of infection with either hepatitis A or B in people with hepatitis C, immunisation against both is strongly recommended. *Also see Chapter 3: section on Vaccinations, p70.*

Health care workers should encourage people with chronic hepatitis A and hepatitis B to seek specialist advice from a liver specialist, gastroenterologist or an infectious diseases specialist.

CO-INFECTION WITH HIV

In the late 1990s, a highly effective anti-HIV therapy (known as **HAART**) transformed HIV/AIDS from a disease that was regarded as nearly always fatal to one that is potentially manageable long-term. With more people who have HIV able to manage their infection, other blood-borne virus issues have become more commonly recognised in the clinical setting.

The main implication of co-infection with hepatitis C and HIV is that the management of hepatitis C becomes a priority. Hepatitis C and HIV co-infection increases the risk of serious liver disease, because HIV infection causes decreased immunity, thus allowing hepatitis C to progress more easily. In the presence of HIV-related damage to the immune system, management aims to reduce the chances of hepatitis C becoming a life-threatening infection.

Who is at risk for hepatitis C and HIV co-infection?

- People who became infected with HIV through blood-to-blood contact via injecting drug use practices.
- People with haemophilia and HIV who were treated with blood products before 1990.
- Men who have sex with men and who inject drugs.
- Children born to women with co-infection.

The current number of people in Australia with hepatitis C and HIV co-infection is thought to be relatively low. It is estimated that less than 1% of people with hepatitis C also have HIV. In people who inject or have injected drugs and who are HIV positive, hepatitis C rates are as high as 91%. The majority of people with haemophilia who have HIV also have co-infection with hepatitis C.

People with co-infection have a high risk of developing liver disease. One study followed people living with HIV since August 1997 (a timeframe that encompasses the advent of HAART). This study found that 50% of deaths were non-AIDS-related and the most common cause of death was hepatitis-associated liver disease (13% of all deaths).

The United States Public Health Service officially declared hepatitis C as an **opportunistic infection** in people with HIV/AIDS in August 1999.

In terms of the interaction between these two viruses, most is known about the effect of HIV on hepatitis C, rather than the effect of hepatitis C on HIV.

The impact of HIV on hepatitis C

- The presence of HIV results in an increased amount of hepatitis C virus in the blood.
- Studies have also shown a direct correlation between transmission of hepatitis C and the degree of immune damage from HIV, as measured by the **CD4 cell** count.

- In individuals with co-infection it appears that the risk of transmission of hepatitis C is increased in the presence of HIV. This increased risk is probably related to **viraemia** and makes both sexual and **vertical transmission** more likely.
- The presence of HIV also decreases the accuracy of the antibody tests used to diagnose hepatitis C. This suggests that the hepatitis C **PCR test** should be the test of choice when a person is also infected with HIV. *See Chapter 4: section on Available Tests, p82.*

Much less is known about the effects of hepatitis C on HIV. Research results are inconclusive, some studies suggest a faster loss of CD4 cells and a more rapid progression from HIV infection to AIDS, and others indicate no adverse effect. An infectious diseases specialist should be consulted in such cases.

Development of disease in co-infected individuals

- Studies have consistently demonstrated that, in people with hepatitis C, those who also have HIV progress significantly faster to severe liver disease (cirrhosis) than those who do not have HIV. Their livers also fail more frequently due to this rapid disease progression.
- These consequences are directly related to the degree of immune damage caused by HIV.

CO-INFECTION IN PEOPLE WITH HAEMOPHILIA

Our current understanding of co-infection and its consequences comes largely from people with **haemophilia** who also have HIV and hepatitis C. Most of these infections were acquired through the use of infected blood or **blood products** before the introduction of HIV screening in 1985 and hepatitis C screening in 1990.

See Chapter 3: section on Blood Bank Strategies for Public Health Protection, p60.

In Australia, nearly all people with haemophilia who have HIV are co-infected with hepatitis C. The issues of managing co-infection for this group of people are generally the same as for others with co-infection (see above), with the additional considerations:

- people with haemophilia most likely received large quantities of blood products in the course of treatment for haemophilia and were potentially infected with higher viral loads of hepatitis C and possibly with multiple genotypes;
- it is not known whether or in what doses multiple drug combinations are appropriate for people with haemophilia who are co-infected;
- the side effects of some treatments for HIV and hepatitis C are further complicated by haemophilic bleeding; and
- liver biopsies are not always possible for people who have haemophilia, either because they may induce bleeding, and/or the lack of treatment products to cover such procedures.

See Chapter 6: Treatments for Hepatitis C, for more information on co-infection and treatments.

COMMONLY ASKED QUESTIONS

I WAS DIAGNOSED WITH HIV 15 YEARS AGO. I ALSO HAVE HEPATITIS C AND POSSIBLY CONTRACTED IT MORE THAN 15 YEARS AGO. WILL MY HEPATITIS C AFFECT THE PROGRESSION OF MY HIV?

Research is inconclusive, but liver disease may affect plasma levels of some anti-retroviral drugs. In this situation, health care workers should advise people to consult with their infectious diseases specialist.

I HAVE RECENTLY BEEN DIAGNOSED WITH BOTH HEPATITIS C AND HIV, BUT MAY HAVE BEEN POSITIVE WITH BOTH FOR SEVERAL YEARS. DOES HAVING HIV HAVE IMPLICATIONS FOR THE PROGRESSION OF HEPATITIS C?

Yes. With HIV, the level of hepatitis C in the blood and the rate at which liver damage occurs is often higher. People with co-infection experience a higher risk of toxicity when taking anti-retroviral drugs. You need to consult with your liver specialist.

I HAVE HEPATITIS C AND HEPATITIS B. I THINK THAT I CONTRACTED THESE AT THE SAME TIME I INJECTED DRUGS IN THE LATE 1980S. WHAT DOES THIS MEAN FOR MY HEALTH?

It depends on whether your hepatitis B infection is chronic. Consult your GP or an infectious diseases specialist.

I AM TAKING COMPLEMENTARY THERAPIES TO TREAT MILD DEPRESSION THAT MAY BE ASSOCIATED WITH HEPATITIS C. WILL THIS HAVE ANY IMPACT ON MY HIV?

Complementary therapies may impact on take-up and effectiveness of HIV treatments, particularly **Indinivar**. Consult a GP or infectious diseases specialist and a complementary therapist about the possible effects of combined treatments.

WILL THE FACT THAT I HAVE BOTH HEPATITIS C AND HIV INCREASE MY CHANCE OF TRANSMITTING EITHER OF THESE VIRUSES?

Yes. HIV causes an increased amount of hepatitis C virus in the blood, and consequently the blood of people with co-infection is more infectious to others through blood-to-blood contact. *See Chapter 3: Reducing Hepatitis C Transmission in the Community for details of safer behaviours.*

CO-INFECTION – HEPATITIS C AND HIV

July 2002

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In Australia there are differing rates of hepatitis C and HIV **co-infection** in different population groups. There is a higher probability of co-infection if a person who injects drugs is also at high risk of HIV infection. In Australia up to 2000 approximately 0.8% of people with hepatitis C were co-infected with HIV and about 14% of people with HIV were co-infected with hepatitis C (Peters 2002).

Having HIV often increases the amount of hepatitis C virus in the blood. This hepatitis C **viral load** is likely to be higher in those people with HIV who have a lower **CD4** (a type of immune cell) count.

If hepatitis C is going to seriously affect a person's liver this will happen more quickly in people who are co-infected with HIV and hepatitis C, than in people who have hepatitis C alone. There is debate about the effect of hepatitis C on HIV. Recent evidence suggests that having hepatitis C can result in more adverse outcomes for people who also have HIV infection (Dieterich 2002, Peters 2002).

TREATMENTS AND CO-INFECTION

Clinicians are increasingly recognising that it is important to consider the treatment of hepatitis C in people who also have HIV. This is mainly because, now that HIV treatments are helping people live longer and feel better, it is likely that hepatitis C is the infection which has a negative affect on health. Treatment is especially important for people who are shown to have liver fibrosis on liver biopsy. Some researchers believe that people who do not have fibrosis should be monitored with regular liver biopsies, although it is unclear how often these need to be performed (Peters 2002).

The antiretroviral treatments currently used to suppress replication of HIV have numerous side effects. These include impaired liver function and altered immune system responses to other infections (including hepatitis C). Some people with hepatitis C and HIV co-infection are more likely to experience these side effects than those people with HIV infection alone.

Expert clinical management is needed, given that up to 40% of people co-infected with HIV and hepatitis C will experience treatment side effects that impact on the functioning of the liver. They may need to change or even stop taking antiretroviral treatments.

TREATMENT OF HEPATITIS C IN PEOPLE LIVING WITH HIV

Recent research indicates that treatment with pegylated interferon and ribavirin leads to higher rates of viral clearance than does treatment with standard interferon and ribavirin combination therapy *(See Treatments Update, July 2002)*. These studies mirror what happens in treatment of hepatitis C in individuals without HIV.

All the evidence indicates that people with co-infection need to be monitored carefully while being treatment for hepatitis C. Some HIV treatments cause side effects, which make treatment with interferon or ribavirin a problem.

Further research is being undertaken to increase our understanding of co-infection, and to provide answers about whether treating hepatitis C will decrease the liver toxicities associated with HIV medications and hence provide better health outcomes for those who are living with HIV and hepatitis C.

ALCOHOL

A number of researchers stress the importance of ceasing alcohol consumption for people with co-infection. Health care workers need skills and sensitivity in addressing this issue, and should ensure that people are supported and provided with practical and realistic strategies to help limit alcohol consumption.

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CHAPTER 3

REDUCING HEPATITIS C TRANSMISSION IN THE COMMUNITY

Contributors: Campbell Aitken, Australian Hepatitis Council, Australian Intravenous League, Neil Boyce, Susan Carruthers, Robert Chen, Nick Crofts, Stephen Locarnini, Stuart Loveday, Andrew Mackintosh, Margaret McDonald, National Health and Medical Research Council Guidelines, Allison Ridge, Deb Sansom, Tamara Speed, Justin Woodruff.

- The transmission of hepatitis C and other blood-borne viruses can be reduced.
- It is important to be aware of the risks of blood-to-blood contact.
- For people who inject drugs, safer injecting behaviours can reduce the risk of becoming infected with hepatitis C. Safer injecting behaviours can also reduce the risk of passing on hepatitis C or other blood-borne viruses.
- For people who are considering having a tattoo or piercing, it is recommended that they visit a practitioner who consistently uses standard infection control procedures.

SUMMARY OF IMPORTANT POINTS

- Australia has a multifaceted prevention response to hepatitis C, based on the concept of harm reduction. A key component of the national response are Needle and Syringe Programs (**NSPs**).

BLOOD AWARENESS

WHAT IS BLOOD AWARENESS?

- Being blood aware means being alert to the potential or actual presence of blood in any situation or environment.
- It means being alert to the possibility of blood-borne organisms or viruses, and employing practices to prevent their transmission.
- Blood awareness acknowledges that blood can be exchanged in a range of situations outside the health care setting.

IMPLEMENTING THE CONCEPT OF BLOOD AWARENESS

In health care settings:

- always follow standard infection control procedures;
- always comply with First Aid guidelines; and
- always comply with occupational health and safety procedures.

Health care workers should adopt the concept of blood awareness to avoid discriminating against individuals on the basis of perceived or known virus status and in order to adopt better practice around blood issues.

See section on Standard Infection Control Procedures, p62, for more detailed information.

Outside the health care setting:

- **people who inject drugs:** be aware that even amounts of blood too small to see could pose an infectious risk. People who inject drugs are advised to practice harm reduction steps to avoid viral infection and re-infection;

- **within the home or workplace:** do not share any sharp grooming instruments and be aware of exchanges in which blood may be present (e.g. sharing toothbrushes or razors);
- **when dealing with blood or other body fluid spills:** gloves should always be worn and other people involved should be made aware of the presence of blood;
- **when having tattoos or body piercings:** people should be alert to the potential presence of blood, and ensure that their practitioner is adopting standard infection control procedures (see *section on Standard Infection Control, p62)*; and
- **sexual practices:** some sexual practices can involve blood-to-blood contact (e.g. sex when menstruating, use of sex toys, practices that involve ripping or tearing of the skin, rough sex).

WHAT ARE THE ISSUES FOR EDUCATORS?

Promoting blood awareness must be a key focus of educators' work. The concept of blood awareness complements and builds on earlier HIV prevention messages such as 'use a clean **fit** for every hit', which contributed to Australia's success in preventing the spread of HIV among people who inject drugs. However, to prevent the transmission of hepatitis C, information about new and sterile injecting equipment must be accompanied by information that creates a clear awareness of the possibility of blood in any interaction, situation or environment.

It is critically important that health care workers continue to use blood awareness as a pivotal concept to alert people to the risks of blood-borne viruses and to reduce hepatitis C transmission rates.

Educators should also be aware that blood has many different culturally-determined meanings that impact on their capacity to provide relevant education. These meanings may include:

- blood is often seen as symbolic of life and vitality;

- blood is associated with belonging, strength and pride in some cultures;
- blood features in many religious rituals and rites of passage, lineage and kinship traditions, in war and in emergency life-saving procedures; and
- issues around blood can generate strong emotional responses. In recent times, with increased awareness of blood-borne viruses such as hepatitis C and HIV, blood awareness has challenged our behaviours and ways of thinking.

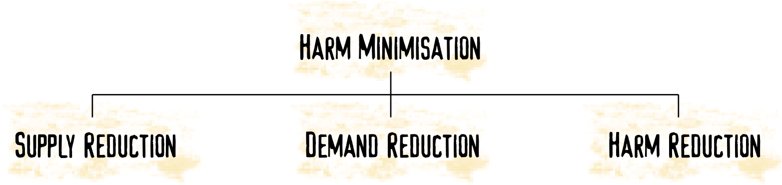
See Chapter 7: Education and Training for further details on key issues for educators.

HARM MINIMISATION

Harm Minimisation and **Harm Reduction** are terms at the core of hepatitis C prevention. The terms are not interchangeable and it is important to understand the differences between them. In this context, the 'harm' highlighted by these terms relates to associated consequences of drug use, which can include infection with blood-borne viruses such as hepatitis C.

Harm Minimisation is the official policy concept underpinning national and State public health strategies, such as the first *National Hepatitis C Strategy 1999–2000 to 2003–2004 and the National Drug Strategy 1998.*

Within the Harm Minimisation framework, there are three principles or streams: **Supply Reduction, Demand Reduction** and **Harm Reduction**.



Supply reduction aims to disrupt production and distribution of illicit drugs.

Demand reduction means reducing the demand for and the uptake of harmful drug use.

Harm reduction is about reducing drug-related harm in the community.

The effects of all proposed and implemented strategies must be examined to determine whether the nett impact reduces or increases overall harm. Many supply and demand reduction strategies may have unanticipated effects, or effects that are not immediately apparent.

For example, imprisonment of people for possession or use of injectable drugs may be considered to be part of a strategy for limiting supply and/or demand for drugs; however, it may result in the greater harm of increased transmission of blood-borne viruses in prisons.

Another example is a reduction in the street supply of a drug, perhaps due to increased surveillance by authorities. The resulting higher cost can lead to less reliable drug purity, with the consequent risks of contamination with other substances and possible overdose.

HARM REDUCTION

Harm reduction is a philosophy or approach that focuses on reducing the harm associated with potentially risky activities, not on preventing people from performing those activities.

Harm reduction is a pragmatic concept that recognises the reality of drug use. The harm reduction philosophy acknowledges that it can be more effective for individuals and communities to reduce the harms associated with drug use than to support attempts to eliminate drug use altogether.

Although the term is of relatively recent origin (in the last 15 years), harm reduction has been practised throughout history to address many different problems. For example, in medieval China many drunken people fell into canals and drowned or froze; preventing drunken behaviour proved impossible, but fences built around the canals prevented many deaths. More recently, Australia has led the world in making seatbelts a legal requirement in motor vehicles – a practical measure that reduces harm incurred in accidents without stopping people from driving.

HARM REDUCTION AND HEPATITIS C

Harm reduction applies directly to the prevention of hepatitis C transmission in relation to injecting drug use. As described in Chapter 1, hepatitis C in Australia is most often diagnosed in people who inject or have injected drugs. Hepatitis C is one of the most significant health problems affecting people who have injected or inject drugs, and thus it is a major target of harm reduction programs and policies.

HARM REDUCTION PROGRAMS

Harm reduction provides people who inject drugs with the capacity and resources to make informed decisions about their drug-using practices. Harm reduction avoids moral judgements about drug use, and instead accepts that – for a range of reasons – some people choose to inject drugs. The focus of harm reduction in this field is on reducing the harm associated with drug use, without necessarily reducing drug use itself.

Harm reduction programs often involve measures to encourage people to change the way they use drugs specifically to reduce related health risks. Perhaps the best example of harm reduction applied to drug use are Needle and Syringe Programs (**NSPs**). Operating in urban and regional suburbs and towns, these programs provide sterile injecting equipment and disposal facilities. The aim of NSPs is to enable people who inject drugs to avoid using borrowed equipment or re-using their own, and to provide a safe way of

disposing of used equipment, thus reducing risks of infection with blood-borne viruses such as HIV or hepatitis C. Australia's NSPs are a major factor in keeping rates of HIV very low in people who inject, and are a significant public health success in preventing the wider spread of HIV.

Methadone is the most widely and effectively used drug substitution treatment for heroin dependence. It has an effect that is similar to heroin but is taken orally. Commonly methadone is used in long-term maintenance programs where the goal is to reduce the harms associated with drug use and to improve the person's quality of life. Methadone is also used in withdrawal to ease the discomfort of withdrawing from heroin. There is reasonable evidence that longer duration of methadone maintenance treatment is associated with reducing the individual and social harms associated with illegal opioid use. Methadone treatment has been shown to significantly reduce the risk of death from overdose. The effectiveness of methadone maintenance programs in reducing HIV infections has been well-demonstrated.

Currently, **Naltrexone** and **Buprenorphine** are featuring more prominently in drug withdrawal and maintenance programs.

Harm reduction also includes programs that reduce harms to the wider community. Syringes discarded in public places pose a risk of injury and potential hepatitis C transmission to others; a harm reduction response is to provide syringe disposal facilities in appropriate public locations.

Peer education and outreach activities are additional examples of harm reduction strategies specifically aimed at reducing transmission of hepatitis C and other viruses among people who inject drugs. People who inject drugs generally keep a low profile and are hesitant to reveal their drug use if they feel that doing so will expose them to discrimination or prosecution. Peer educators are people with direct experience of drug use and drug-using cultures. They are well-placed to give information about reducing risks of hepatitis C transmission and other drug-related harms.

See Chapter 8: Education and Training.

HARM REDUCTION AND GOVERNMENT

Harm reduction is a fundamental national, state, local government and public health response to hepatitis C transmission among people who inject drugs in Australia. It features strongly in Australia's *National Hepatitis C Strategy 1999–2000 to 2003–2004 and the National Drug Strategic Framework 1998–1999 to 2002–2003.*

The *National Hepatitis C Strategy* defines harm reduction interventions as "interventions that aim to prevent anticipated harm… as well as interventions that aim to reduce actual harm".

In supporting harm reduction, Australian governments at all levels do not condone illegal drug use; instead they acknowledge that these behaviours occur and that government has a responsibility to reduce drug-related harm.

SAFER USING

WHAT DOES THE TERM SAFER USING MEAN?

Using the underpinning concept of harm reduction, the term **safer using** includes a series of precautions and practices aimed at preventing the occurrence of related harm when injecting drugs. Given that the quality, strength and content of any given street drug can never be assured, such harms can never be completely eliminated. Related harms can include those which relate to health such as blood-borne viruses and the possibility of overdose. They may also include social, psychological and legal harms.

The technique of safer using aims to prevent exposure to blood-borne viruses (HIV, hepatitis C and hepatitis B) and bacterial infections in the course of injecting drugs. The ability of an individual or group to practise safer injecting is, to some extent, dependent on the injecting event taking place in the context of:

- non-partisan political support for harm reduction;

- a government committed to providing accessible health and drug treatment services for people who inject drugs;
- needle and syringe provision; and
- a community that understands the health, social and political dynamics of injecting drug use.

SAFER INJECTING PROCEDURES

The safest way to avoid the transmission of hepatitis C and other blood-borne viruses is not to inject drugs. Some people choose other ways of consuming drugs, such as smoking, snorting, drinking, swallowing or absorbing them rectally.

- The safest way to inject is:
  - wipe down the preparation area;
  - wash your hands before and after injecting; and
  - use a new, sterile needle and syringe and clean or sterile injecting equipment, clean water (tap water is suitable), sterile swabs (one to swab the spoon and one to swab the injecting site), a tourniquet not used by others, a new filter, and an appropriate disposal bin.
- Sterile equipment has undergone a process that destroys bacteria, viruses and other infectious agents. It includes pre-packaged needles and syringes, water and swabs that are marked as sterile. It is not essential to have sterile water in order to inject safely; ordinary tap water is fine. All other equipment, the injecting space and hands need to be cleaned with soap and water or with swabs.
- Safer using is equally important for people who are already hepatitis C positive because they can become re-infected or can infect others with hepatitis C.
- Safer using means more than just using new and sterile needles and syringes. It includes being aware of how easy it is for blood to be transmitted. People may come into contact with someone else's blood when sharing any

injecting equipment. Blood from used needles and syringes, tourniquets and fingers – even in microscopic amounts – can get into a shared mix, filters or water and onto injection sites.

- If re-using a fit is the only option, it is important that it is cleaned and not shared with others. The same applies to any equipment such as spoons, tourniquets or water ampoules that are re-used.

The Australian Intravenous League (**AIVL**) and State and Territory peer-based drug user organisations produce booklets on safer using, cleaning fits and handy hints for people who inject drugs. *See Contacts, p236.*

OVERDOSE

For people with hepatitis C who inject drugs, the risk of overdose may be increased. A liver affected by hepatitis C is slower to break down drugs and this can lead to them having a longer life in the body. This is particularly true in polydrug use situations. To avoid overdose, health care workers should advise people to:

- not combine drugs – heroin overdose can result from mixing heroin (or other opiates) with other drugs. Alcohol and **benzodiazapines** have been shown to be of particular concern;
- test and go slow – wait at least five minutes (the longer the better) before another hit;
- think about tolerance – if a person hasn't used for a while or is using less, they should try a small amount first;
- think about what will happen if they drop (overdose) – using with others can increase the risk of sharing and re-using contaminated injecting equipment, but having someone else present when using could mean the difference between life and death in the event of overdose; and
- not consume alcohol or other drugs if they have already done so within the last six hours.

In overdose situations, health care workers should advise people to:

- take action before the situation escalates – monitor the casualty and call 000 if the person has stopped breathing;
- call for an ambulance – less than four breaths per minute means that an ambulance is required immediately; and
- acquire skills in mouth-to-mouth resuscitation – it could save a life.

ACCESS TO INJECTING EQUIPMENT

Programs

Needle and Syringe Programs (NSPs) exist in all States and Territories, although the range of services differ. Some of the services provided include access to needles and syringes (often free), disposal options, information and education about safer using, safe sex, blood-borne viruses, management and treatment programs (including methadone maintenance), overdose prevention education and referrals to user-friendly services. NSPs display this logo:

Health workers are advised to contact their local NSP or peer-based drug user organisation for more information about the range of services available from NSPs in their State or Territory. *See Contacts, p236.*

PHARMACIES

In many States and Territories, new needles and syringes, swabs and sterile water can be bought from some pharmacies. Some pharmacies also exchange, (without cost), new needles and syringes for used ones. Some pharmacies will accept used injecting equipment for disposal.

See Chapter 8: Education and Training for more information on pharmacies and injecting drug use.

PERSONAL SUPPLIES

It is recommended that people who intend to inject drugs keep a supply of new needles and syringes and safe, puncture-proof disposal containers. These should be stored in a dry place that will not be exposed to major changes in temperature, and is out of reach for children. Needles and syringes should be left in their sealed packages until they are to be used.

DISPOSAL

All items of injecting equipment should be disposed of appropriately to ensure that there is no risk of transmission through accidental contact with used items. Used needles and syringes should be put in an approved sharps container and disposed of in accordance with the specific requirements of the Environment Protection Authority in each State or Territory.

Specifically, needles and syringes should be:

- put in a puncture-proof, sealed container (not glass as it can break and needles are a hazard for recycling workers); or
- taken to a disposal service, such as an NSP, pharmacy or municipal council.

Some people who inject drugs do not have access to disposal facilities located at NSPs, or are unable to ensure safe disposal each time they inject. Health care workers should advise individuals about appropriate domestic disposal that meets with local and municipal requirements.

BARRIERS TO SAFER USING

There may be multiple barriers to people adopting safer injecting practices, including:

- **Cost of and limited access to equipment:** in some States and Territories, distribution programs have limited opening hours. In some States, needles and syringes are free, but in others a single syringe may incur a cost. In some States and Territories, pharmacies sell and exchange sterile equipment. The cost of and access to sterile water and other equipment also varies in each jurisdiction.
- **Discrimination by service providers:** *see Chapter 7: Preventing Discrimination and Reducing Stigma and Isolation, for more information*.
- **Peer and partner pressure not to adopt precautions**.
- **Limited appropriate locations for safer using:** people in custodial settings, for example, do not have access to sterile equipment or appropriate locations. Many other people also have limited choices about where they might inject, and often do so in public spaces such as toilets or outdoor locations. The threat of being apprehended by police can result in people injecting as quickly as possible and consequently they may take greater risks.
- **Inadequate knowledge about safer injecting practices:** access to appropriate and current information varies across the country, and access can be problematic for people with low literacy skills, those whose first language is not English and people in rural or remote locations.

The context in which injecting occurs may also present barriers to safer using. These can include:

- the level of a person's dependency on the drug being used, and therefore the haste with which they inject;
- the regularity or number of times a day that injecting occurs;
- the social dynamics of the injecting group – e.g. the person who has paid most for the drug may inject first and/or one person may be nominated to inject others, women often inject after men; and

- competing priorities, such as housing or income. Some people who use drugs may not be able to rate their own health as a high priority, and hence may not be committed to safer using.

Safer using is possible, but only if these necessary conditions are present:

- access to sterile equipment;
- a safe and secure environment in which to inject; and
- the knowledge about how to inject safely.

THE CHALLENGE FOR ALL WORKERS IS TO USE THE FRAMEWORK OF HARM REDUCTION TO DECREASE THE HARMS ASSOCIATED WITH INJECTING DRUGS, AND TO REDUCE THE TRANSMISSION OF BLOOD-BORNE VIRUSES SUCH AS HEPATITIS C.

For some, these essential conditions already exist; for others they do not exist and are not likely to in the future.

BLOOD BANK STRATEGIES FOR PUBLIC HEALTH

Hepatitis C was responsible for the majority of post-transfusion hepatitis infection in the 1970s and 1980s. Prior to identification of the virus and the availability of effective screening tests, hepatitis C acquired through the receipt of blood and blood products accounted for up to 10% of all hepatitis C infection per annum in Australia.

Improvements in donor selection, screening and viral inactivation of plasma products since 1990 have virtually eliminated hepatitis C transmission through blood or blood product transfusion.

DONOR SELECTION

Blood banks use a complex medical history and behavioural questionnaire to identify would-be blood donors who may be at risk of acquiring hepatitis C. Such careful scrutiny is a particularly important safety measure, as there are no laboratory tests that can totally eliminate the risk of hepatitis C transmission by blood transfusion. Testing technology can never be guaranteed fail-safe.

Blood banks have invested significant financial resources in minimising the risk of blood-borne virus transmission through blood and blood products. The annual Australian investment in viral screening of donated blood is more than $20 million. It is likely that any further improvements in donor selection, screening and/or viral inactivation will require additional investment and the co-operation of Australians who volunteer as blood donors.

NUCLEIC ACID TESTING

Nucleic Acid Testing (**NAT**) was introduced into Australian blood bank screening in June 2000. It is a powerful and sensitive test that is capable of amplifying a small part of viral or genetic material over a billion times. This means that it is now possible for Blood banks to detect minute amounts of hepatitis C and HIV that may be present in blood.

NAT screens directly for the virus, and as such is capable of identifying infection before antibodies are formed or are present at detectable levels. NAT is able to reduce the **window period** (the time between infection and detection of the virus or antibodies in the blood stream). In the case of hepatitis C, it has been estimated that NAT can reduce the window period from an average of 66 days to 22 days.

NAT is performed in addition to the current donor questionnaire and screening tests.

PLASMA PRODUCTS

Plasma products are subjected to a variety of processes that work to inactivate hepatitis C or other viruses that may have escaped detection through donor selection and screening. There have been no reported cases of hepatitis C plasma product transmission in Australia since the introduction of inactivation protocols in 1985.

STANDARD INFECTION CONTROL PROCEDURES

The Communicable Diseases Network of Australia and New Zealand (**CDNANZ**), in consultation with the National Centre for Disease Control (**NCDC**), has recently released, in draft form, revised guidelines relating to infection control in the health care setting, with particular emphasis on the transmission of infectious diseases, including hepatitis C. It is expected that the final document will be available in late 2001. *Check www.health.gov.au for the latest information.*

Note that the principles underpinning infection control should include:

- isolating the infectious organism, not the person;
- all practices, including any protective practices, should be non-discriminatory;
- there should be no testing without informed consent; and
- a commitment to protecting the privacy and confidentiality of all people using health care services.

Standard infection control procedures are designed to protect both the health care worker and the client from infection with a range of blood and other body fluid-borne viruses. By assuming everyone is potentially infectious and by treating all clients in the same way through following standard procedures, the risk of infection is reduced and the potential for discrimination is avoided.

For more information on standard infection control procedures see Chapter 7: section on Working with People who have Hepatitis C, p148.

HEALTH AND SAFETY IN THE WORKPLACE

Health care workers, laboratory staff, beauty industry workers, tattooists, body piercers, cleaners and other workers who may come into contact with blood or blood products need to be blood aware in order to avoid the risks of hepatitis C transmission.

PROTECTING STAFF AND CLIENTS

Under Occupational Health & Safety legislation in all States and Territories, employers have an obligation to ensure that workers are not exposed to any hazards while undertaking their duties, nor expose others to such hazards. Developing and implementing workplace protocols and guidelines around blood awareness issues is recommended.

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. *See section on Prevention in the Workplace, p64, for further information.*

A health and safety workplace policy should incorporate:

1. *Identification of work practices that may put people at risk of infection with hepatitis C.*

2. *Preventive measures:*

    - workers at risk should be offered hepatitis A and B vaccinations;

    - ensure that safe work practices are followed. *See the Commonwealth Government's Standard Infection Control Procedures at www.health.gov.au*;

    - provide appropriate protective clothing and equipment; and

  - ensure that all First Aid kits and equipment comply with the standards set by *First Aid in the Workplace Code of Practice No. 18, June 1995*.

3. *A reporting protocol for incidents:*
   - report all risk incidents immediately to management; and
   - fill out an accident report form.

This information should be treated as confidential. The employer is responsible for ensuring that the worker has access to appropriate support/medical services, where they can discuss the incident and possible infection issues.

4. *Staff training plan:*
   - access to the latest information on issues relating to HIV/AIDS and hepatitis in the workplace, and any appropriate training programs.

5. *Review:*
   - the policy should be reviewed on an annual basis.

Employees can contribute by complying with standard infection control procedures and reporting unsafe practices, incidents or risks to management.

PREVENTION IN THE WORKPLACE

GENERAL HYGIENE

Guidelines recommend that workers check their hands for cuts or abrasions each day and cover any breaks in the skin with a waterproof dressing. People are advised to wash hands before and after contact with each individual and after contact with used equipment. Thorough hand washing consists of:

- removing all jewellery;
- using soap and warm running water for 10–15 seconds to produce a good lather;
- rinsing all signs of dirt and soap away; and

- drying hands with a disposable paper towel.

Antiseptic products made for use in the absence of water can be used in emergency situations, when there may be insufficient time and/or lack of hand-washing facilities.

BLOOD AND BODY FLUIDS

Workers should wear gloves whenever:

- exposure to blood/body fluids is anticipated;
- handling any equipment or materials contaminated by blood or body fluids; or
- there is the possibility of contact with either broken skin or the mucous membrane of any person involved in an invasive procedure.

Gloves are not necessary when dealing with skin that is intact. Remember to wash hands after removal of gloves. Gloves should be changed and disposed of when moving from one client to another and between any of the above procedures. To prevent cross-contamination, gloves should be removed and disposed of before undertaking clinical or other tasks.

BLOOD OR BODY FLUID SPILLS

The following procedure is recommended:

- disposable gloves should always be worn;
- avoid using hot water because this will cause blood to congeal and adhere to the surface;

- if the spill consists of solid material first remove as much as possible with disposable towels;
- small blood spills can be managed easily by wiping the area of the spill with paper towels, then cleaning the area with water and detergent;
- for large blood spills use powdered bleach to contain the blood pool. A scraper and pan can then be used to remove the absorbed material. The area can finally be cleaned with a mop and a bucket of detergent diluted in water;
- if a spill occurs on carpet or soft furnishings, use detergent with cold water rather than bleach, which will damage fabrics;
- note: if there is any risk of skin contact with a previously bloodied area, such as a bathroom surface or a table, the surface should be wiped again with bleach solution; and
- wash hands.

CLINICAL PROCEDURES

Some procedures may involve splashes or sprays of blood. For eye protection, goggles or face shields must be worn. Please note that contact lenses do **not** give protection. Surgical masks provide adequate protection for the mucous membranes of the mouth.

Gloves should always be worn when collecting blood and other specimens for laboratory evaluations and these should be placed in leak- and spill-proof containers for transport. Containers should be checked for exterior contamination and, if necessary, be disinfected before sending and/or upon receipt. Transport between institutions should comply with carrier's conditions, and all relevant government and Environment Protection Authority guidelines.

FIRST AID

No one should be denied First Aid. If blood or body fluids are present, the precautions already outlined should be applied. For mouth-to-mouth resuscitation, specific airways or face masks should be provided to personnel likely to administer First Aid.

USED NEEDLES, SYRINGES AND OTHER INJECTING EQUIPMENT

Sometimes needles and syringes are inappropriately discarded in public places such as toilets. If employees are likely to come into contact with used needles, syringes and other injecting equipment in the course of their work, they should be well-informed and trained in how to safely handle these items.

- **Never** re-cap used needles found in public places or in the health care setting.
- Re-useable equipment must have all blood removed prior to disinfection and sterilisation.
- Dispose of used needles and syringes in an approved sharps container and dispose of in accordance with Environment Protection Authority requirements.

In the case of a needlestick injury:

- wash the affected area with warm soapy water;
- apply antiseptic and a waterproof dressing;
- consult your doctor as soon as possible, who will advise on testing and prophylactic treatment; and
- report the incident to management immediately.

OTHER WASTE

Waste such as used gloves, soiled dressings and body tissues should be treated as infectious and placed in impermeable bags. Handle with care and dispose of in accordance with Environment Protection Authority requirements.

TATTOOING, BODY PIERCING AND BODY ART

It is recommended that people undergoing a body art procedure, such as tattooing or piercing, visit a practitioner who consistently uses standard infection control procedures.

HEALTH AND SAFETY IN THE HOME – MANAGING THE RISKS OF TRANSMISSION

People with hepatitis C may be concerned that they can transmit the virus to their partners, their family, friends or other members of their household.

It is important to remember that hepatitis C is transmitted by blood-to-blood contact. This means that the blood of an individual who has hepatitis C must leave their body (e.g. via open wounds or sores) and enter the bloodstream of another person. *See Chapter 1: section on Transmission, p13.*

HEPATITIS C IS NOT TRANSMITTED THROUGH SOCIAL CONTACT. HUGGING, KISSING, SHARING FOOD, DRINKS, PLATES, EATING UTENSILS, SNEEZING, COUGHING, WASHING CLOTHES IN THE SAME MACHINE AND USING THE SAME TOILET FACILITIES DO NOT POSE A RISK OF HEPATITIS C TRANSMISSION.

Mosquitoes or other insects do not transmit hepatitis C. When a mosquito bites a person, it injects salivary fluid (which acts as an **anti-coagulant**) through one passage and sucks up blood through a different passage. Blood goes directly to a mosquito's stomach where it is broken down (and used as food), along with any blood-borne organisms.

People should be aware that there are some personal care objects that, if shared, **may** transmit hepatitis C from a person already infected to another person. These may include toothbrushes, razors, tweezers, scissors and nail clippers.

To reduce the possibility of hepatitis C transmission, everybody in a household should have, and exclusively use, their own personal care items, particularly toothbrushes and razors.

Another issue for the household relates to First Aid. Here are some basic infection control and First Aid hints:

- Skin acts as a barrier to infection with hepatitis C. To maintain this barrier, make sure that any cuts, abrasions, or dermatitis are covered with a waterproof dressing.
- Use disposable latex gloves when cleaning up blood and body fluids.
- Wash hands with soap and water before and after wiping up blood spills to reduce the chance of infection.
- Use disposable materials like paper towels when cleaning up blood or other body fluids and dispose of these soiled materials in a plastic-lined garbage bin.

Before giving First Aid:

- wash hands in soap and warm water;
- cover any cut or abrasions with a waterproof dressing; and
- put on a new pair of disposable latex gloves (latex gloves are available at pharmacists and some supermarkets).

During First Aid:

- be aware of any blood spills and splashes and try not to let blood or body fluids in contact with any broken or unprotected skin.

After First Aid:

- use soap and cold running water to wash hands and any other part of the body that may have blood on it;
- mop or wash blood-stained surfaces with detergent, then disinfect with diluted bleach;
- bag any blood-stained items used during the First Aid procedure;
- wash any blood-stained clothing in cold water and detergent;
- use detergent in cold water to clean up a spill on carpets or soft furnishings;
- dispose of all items stained with blood, including tampons and sanitary pads, by putting them in a plastic bag and into a plastic lined rubbish bin; and
- wash hands thoroughly with soap and water.

VACCINATIONS

Currently there is no vaccination for hepatitis C. Vaccinations against hepatitis A and hepatitis B are available and are important considerations for people with hepatitis C.

There are well-documented cases where co-infection with hepatitis A and/or B in people with hepatitis C has resulted in severe liver disease, including liver failure. There are also concerns that **co-infection** with hepatitis B can lead to a more rapid and severe course of disease progression for people with hepatitis C.

See Chapter 2: section on Co-infection, p38, for further information.

HEPATITIS A VACCINATION FOR PEOPLE WITH HEPATITIS C

The annual incidence of hepatitis A in Australia is approximately 0.01%, and universal vaccination is not warranted. It is recommended that people who may be at higher risk of acquiring hepatitis A, and especially those with hepatitis C, should consider vaccination. These people may include:

- travellers to areas outside Australia where hepatitis A is endemic;
- people who inject drugs;
- men who have sex with men;
- childcare workers;
- sewage workers;
- health care workers in paediatrics, intensive care and emergency departments who provide for substantial populations of indigenous children; and
- visitors and health care workers in rural and remote indigenous communities.

HEPATITIS B VACCINATION FOR PEOPLE WITH HEPATITIS C

The World Health Organisation (**WHO**) has recommended a policy of hepatitis B vaccination in all countries, particularly in those with a high prevalence of hepatitis B. The current recommendation in Australia is for universal vaccination of new-born babies and pre-adolescents. Hepatitis B vaccination is also recommended for those at high risk of acquiring hepatitis B and for people with chronic hepatitis C and/or liver disease.

HEPATITIS A & B VACCINATION FOR PEOPLE WITH CIRRHOSIS

People with chronic liver disease may have reduced liver reserve or stamina. The National Health and Medical Research Council (**NHMRC**) recommends vaccination for any person with chronic liver disease against other viruses (i.e. hepatitis A and /or B) that may be toxic to the liver. It recommends vaccination against hepatitis A and B for people with hepatitis C who are not immune to hepatitis A or hepatitis B.

GENERAL GUIDELINES

- Vaccination provides protection against hepatitis A infection and/or hepatitis B infection in people who have not yet been exposed. If a person has been infected in the past, vaccination is normally not necessary. The only way to be sure whether a person is already immune is by doing a blood test to look for specific **antibodies** associated with the particular infection. Antibodies indicating past infection with both hepatitis A and hepatitis B are common in people with hepatitis C.
- People with chronic hepatitis B and/or hepatitis C should be vaccinated against hepatitis A if they are not already immune to it.
- People with chronic hepatitis C should be vaccinated against hepatitis B if they are not already immune to it.
- People with more advanced liver disease including cirrhosis should be vaccinated against both hepatitis A and B if they are not already immune to both.

COMMONLY ASKED QUESTIONS

CAN I INJECT DRUGS WITHOUT GETTING HEPATITIS C?

Yes. As long as you do not share **ANY** item of injecting equipment with anyone, and follow the procedures for safer injecting, you can reduce the risk of transmission. However, the safest way of avoiding hepatitis C is not to inject drugs.

DO ALL PEOPLE WHO INJECT DRUGS GET HEPATITIS C?

No. However, if you have injected drugs with other people or have shared or re-used needles and syringes and any other injecting equipment (e.g. spoons, water, filters, swabs or tourniquets), you have been at risk of acquiring hepatitis C. Safer injecting behaviours can reduce the risk of acquiring or passing on hepatitis C.

I ALREADY HAVE HEPATITIS C. IS IT SAFE TO SHARE INJECTING EQUIPMENT WITH ANOTHER PERSON?

No. It is not safe. You can become re-infected with different strains of the hepatitis C virus, and you can infect other people. Ideally, people should not share any item of injecting equipment with another person, and if they are unable to get clean needles and syringes, should follow the cleaning guidelines produced by the Australian Intravenous League (AIVL).

WHAT IS THE LIKELIHOOD OF BEING INFECTED WITH HEPATITIS C AFTER A NEEDLESTICK INJURY?

In the health care setting, the risk of getting hepatitis C from a needlestick injury is estimated to be between 2% and 8%. This contrasts with a needlestick injury risk of 0.3% for HIV, and 30% for hepatitis B. The risk of needlestick and sharps injuries can be reduced through adopting standard infection control procedures, being blood aware and through the implementation of occupational health and safety guidelines.

Because of the very small amounts of blood and the likelihood that the virus has not survived in a public place such as a park or on a beach, the risk of transmission in this way is negligible. There has never been a proven case of hepatitis C transmission occurring through an injury from an improperly discarded needle and syringe in a public place.

I HAVE HEPATITIS C. IF MY CHILD GETS A CUT, CAN I ADMINISTER FIRST AID?

Yes. Unless you are also bleeding, there is virtually no risk of transmission from you to your child. However, it is advisable to always follow standard infection control procedures. Parents or carers may consider carrying waterproof dressings, spare plastic bags and disposable latex gloves with them in case of accidental blood spills.

CHAPTER 4

HEPATITIS C TESTING

Contributors: Scott Bowden, Sue Conrad, Hugh Harley, Paul Harvey, Rhonda McCaw, Jo Mitchell, Jack Wallace

- The decision to be tested for hepatitis C should be made by the individual, in the context of information and advice from health care workers, counselling and with informed consent.
- The initial screening test for hepatitis C looks for antibodies to the virus, and not for the virus itself.
- There are a number of tests used to monitor the liver and assess people for treatment.

SUMMARY OF IMPORTANT POINTS

- The aims of testing are firstly to determine whether the individual has been exposed to the virus, and secondly whether they have successfully cleared the virus or if a chronic infection has developed. Management of the individual will depend on these results.

PRINCIPLES FOR HEPATITIS C TESTING

The principles set out below are a core component of the National Hepatitis C Testing Policy, which is currently being finalised by the Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD) and the Inter-Governmental Committee on AIDS, Hepatitis C and Related Diseases (IGCAHRD). This is a strategic document that is intended to form the basis of how hepatitis C testing should be conducted in Australia. The *National Testing Policy* is expected to be available in early 2002.

- Testing is voluntary and needs to be accompanied by discussion about the test, the implications of being tested, post-test counselling and specific informed consent.
- Testing should be of benefit to the person being tested, either directly or indirectly.
- Test results need to remain confidential at the clinical level, in data management and in the notification process.
- Testing is accessible to those at greatest risk of infection.
- Appropriate standards are applied by laboratories undertaking testing for hepatitis C to ensure a high level of accuracy in test results.
- People with hepatitis C should have access to ongoing monitoring of their health status and, if needed, appropriate treatment.
- Testing and notification are critical to determine the extent and location of hepatitis C in the community.

TESTING CONSIDERATIONS

- There are many reasons why people decide to be tested for hepatitis C.
- Deciding whether or not to be tested is up to the individual, and testing must never take place without informed consent.

- Being tested can raise many psychological, emotional and social issues for the individual.
- For people who think they may have hepatitis C, knowing the result of a hepatitis C test may give them a sense of direction over aspects of their health and encourage them to seek more information and make informed decisions about their options.
- Being tested for hepatitis C may also motivate people to change particular behaviours to prevent further transmission of the virus.
- Some people who test positive choose to make important changes to their lives, such as reducing alcohol intake, improving diet and considering overall health maintenance.

ISSUES RELATING TO TESTING

- Each person will have different concerns before, during and after being tested.
- Some people find it useful to prepare questions before attending for an appointment with a doctor or health care professional, and health care workers should encourage people attending for testing to ask questions at all times.
- It is important that people receive clear and appropriate answers to all questions they may have about hepatitis C and the testing process.
- Individuals have the right to ask questions of their doctor or health care worker to determine their interest in, and knowledge of, hepatitis C and its implications.
- Individuals may consider talking to a Hepatitis C Council or seeing a liver specialist if they are not receiving helpful answers to their questions.

WHERE TO GET TESTED

- GPs can authorise a test for hepatitis C.
- State and Territory Hepatitis C Councils and peer-based drug user organisations can give information about doctors and clinics who have experience in hepatitis C testing.

WHO SHOULD CONSIDER BEING TESTED FOR HEPATITIS C?

Hepatitis C is transmitted through blood-to-blood contact. *See Chapter 1 and Chapter 3 for detailed information.*

Hepatitis C antibody testing should be offered to people when there is an identified risk of infection. While there are varying degrees of risk, it is possible to categorise particular behaviours and the context in which they occur according to the degree of associated risk.

HIGH LEVEL RISK OF INFECTION

Hepatitis C testing should be routinely offered to people who:

- have ever injected drugs unsafely. *See Chapter 1: section on Transmission of Hepatitis C, p13*;
- have been incarcerated in custodial settings;
- were transfused with blood or blood products prior to February 1990;
- have had a potential occupational or environmental exposure to hepatitis C (e.g. needlestick injury) and also, where possible, the person who is the source of the potential exposure, with their informed consent;
- engage in exposure-prone procedures, such as theatre staff and some health care workers;
- have abnormal liver function tests or evidence of liver disease with no apparent cause;
- have **extra-hepatic** manifestations of hepatitis C infection;
- are on renal dialysis treatment;
- are babies who are 18 months or older born to mothers with hepatitis C; and
- request testing in the absence of an identified risk factor.

MEDIUM LEVEL RISK OF INFECTION

The decision to test for hepatitis C when there is medium level risk should be based on an individualised risk assessment. People in these circumstances include:

- individuals with a history of tattooing and/or body piercing, and the settings in which these have occurred;
- people born in countries where there may be a high prevalence of hepatitis C; and
- sexual partners of people with hepatitis C.

ROUTINE TESTING NOT RECOMMENDED

Routine testing for hepatitis C is not currently necessary unless risk factors have been identified. The following people are not thought necessarily to be at risk:

- health care workers;
- pregnant women;
- people who have household (non-sexual) contact with a person with hepatitis C, unless there is a history of direct (**percutaneous** or **mucosal**) exposure to blood;
- elective surgery patients; and
- the Australian population as a whole.

AVAILABLE TESTS

ANTIBODY TEST

What does the test involve?

- The initial screening test for hepatitis C is a blood test. This is called an **antibody test**.
- With informed consent, a sample of blood is taken and sent to a laboratory to be tested.
- The antibody test is usually free for people who take their Medicare card to a doctor who bulk bills. In some States and Territories, sexual health clinics also provide this service.

What does the test look for?

- The human body produces antibodies to fight the virus and this initial test looks for antibodies, not for the virus itself.
- After infection, it can take up to 6 months before antibodies can be detected. This is known as the '**window period**'. During this time it is possible to get a false negative result. It is possible to transmit hepatitis C during this period, and health care workers should encourage people to be blood aware, regardless of known or presumed hepatitis C status.
- Blood samples that test positive are repeatedly checked before a report is given. Samples that test negative usually mean that a person has not been infected. However, the blood sample may have been taken in the window period before antibodies can be detected. In this situation, the Polymerase Chain Reaction (**PCR**) test *(see p86)* can be useful in early diagnosis because the virus is often present in blood two to three weeks after infection, well before antibodies appear.

- Babies born to mothers with hepatitis C will have maternal antibodies which usually disappear after about 18 months. A positive antibody test after this time may indicate that the child has been exposed to the virus. A PCR test would be useful at this stage to determine if the infection has cleared, or if it has become chronic. There is usually no benefit in testing a baby born to a mother with hepatitis C before the age of 18 months, because treatment is not an option.

Indeterminate test results

Antibody tests are usually clearly either positive or negative, but they can come back as **indeterminate**. There are at least four interpretations of an indeterminate test:

- **Sero-conversion:** the antibody response has not fully developed – it is expected that blood samples tested using PCR at this time would be positive.
- **Immunosuppression:** the blood sample may have been taken from someone with a reduced immune response, perhaps due to infection with HIV or drug treatments to prevent organ rejection. It is likely that PCR testing would return many of these results as positive.
- **Waning antibody response:** there is some evidence that for people who naturally clear hepatitis C, antibodies will remain but decrease over time. When tested with PCR, such samples would be negative.
- **False positive or non-specific reactivity:** the proteins made by molecular techniques are not identical to the proteins of natural infection, and sometimes cross-reactions with other antibodies can occur. These samples will test negative using PCR.

For most people, laboratory testing will provide a clear result. In cases where the antibody test result is difficult to interpret, as in an indeterminate result, PCR testing can provide important clarifying information. However, for some people further clinical information and follow-up testing may be necessary.

What if the result of the antibody test is positive?

Everyone reacts differently to finding out that they have hepatitis C; some people are angry, shocked, depressed or confused, while other people with acknowledged risk backgrounds and/or people who know about hepatitis C may have expected a positive test result.

Health care workers should ensure that all individuals who receive a positive result are offered a post-test counselling session. This provides the opportunity to:

- review information and assess how well a person understands the issues discussed at the time of testing;
- discuss questions and issues in detail; and
- consider the choices available for management and possible treatment.

See Chapter 5: section on Pre- and Post-Test Counselling and Information Provision, p96.

Some people find it helpful to take a friend with them when they receive their test result, or to have someone close by to talk to about the result.

Health care workers are advised to inform people who are being tested that free and confidential information and support is available from:

- Hepatitis C Councils and/or support groups in capital cities and some regional areas of Australia;
- peer-based drug user organisations;
- Haemophilia organisations for people with haemophilia who are affected by blood-borne viruses; and
- a range of community-based organisations and government agencies.

See Contacts, p236, for more details.

DISCLOSURE

- Often the biggest issue for people who have tested positive is whether or not to tell anyone, and who to tell. This issue is often referred to as **disclosure**.
- There is no legal requirement to disclose individual hepatitis C status to anyone, except to the Red Cross Blood Service.
- Disclosure may have an impact on personal and working relationships.
- It is up to the individual with hepatitis C to decide who to tell, when, how and why.
- In order to receive the best care and advice, it may be advisable for people with hepatitis C to disclose their hepatitis C status to their health care worker.
- Many people with hepatitis C have been discriminated against after disclosing their hepatitis C status to others, so careful consideration about who to tell and why is always advisable.
- If individuals require assistance on issues of disclosure, or in dealing with any resultant discrimination, health care workers can provide referral to a Hepatitis C Council or peer-based drug user organisation.

Who is notified of positive test results?

- It is a legal requirement in most States and Territories (Western Australia is the exception) that testing laboratories send all positive test results to the State or Territory health department. The results are used for statistical purposes only.
- Health departments are bound by law to keep personal information (i.e. names and addresses and other identifying details) confidential.

POLYMERASE CHAIN REACTION TEST (PCR)

What does the test involve?

- With informed consent, a sample of blood is taken and sent to a laboratory to be tested.
- The cost of the PCR (to detect the presence or absence of virus), genotype and viral load tests may be covered under the Medicare Benefits Schedule for those who meet certain criteria.

What does the test look for?

PCR detects the genetic material of the virus in the blood using a special molecular technique. In the case of hepatitis C, PCR can be used to detect the following:

- the presence or absence of virus in the blood (hepatitis C-specific RNA) – this is sometimes called a qualitative PCR test;
- the level of virus present in the blood (viral load) – this is sometimes called a quantitative PCR test; and
- the genotype of the virus.

See Chapter 1: section on Genotypes, p11, for more detailed information on viral load and genotype testing.

PCR tests are generally used when assessing people for treatment, but are also useful in confirming indeterminate antibody test results.

BRANCHED CHAIN DNA TEST (BDNA)

This is an alternative laboratory technique that can be used to estimate viral load. The viral load is expressed in different units, depending on which test is used and it is important to only compare results from the same type of test.

LIVER FUNCTION TESTS (LFTs)

What do the tests involve?

- With informed consent, a sample of blood is taken and sent to a laboratory to be tested.

What do the tests look for?

- LFTs are used to monitor the ongoing condition of the liver.
- LFTs detect abnormal levels of enzyme production in the liver, and the enzyme most commonly monitored using this test is alanine aminotransferase (**ALT**).
- LFTs alone do not identify liver damage. It is possible to receive normal liver function test results and still have liver damage. It is uncommon, except in cases of **cirrhosis**, to have LFTs within the normal range if the damage is severe.

Test results

- Due to differences in technology, 'normal ranges' quoted by laboratories may differ. This means that people should not compare results from different laboratories, but be guided by the normal ranges quoted by the laboratory that performed the test.

Generally, where LFTs are consistently elevated and/or fluctuating and the person has an antibody positive test result and a history of risk behaviour, it is almost certain that hepatitis C is circulating in the blood. In this situation, a PCR viral detection test is generally considered unnecessary.

It is recommended that people with hepatitis C have regular LFTs, as advised by their GP or liver specialist. Health care workers should provide photocopies of the results. This is particularly useful if people need or want to see a different doctor.

LIVER BIOPSY

Overview

LFTs give a snapshot of the health of the liver, but they cannot give an indication of how severe the damage is or whether the liver has developed scarring (fibrosis). The best way to determine this is to undergo a liver biopsy. Liver biopsies are a requirement for people who are considering treatment.

What does this procedure involve?

- A liver biopsy is considered to be a minor surgical procedure and involves a local anaesthetic. It is performed in a hospital or clinic.
- A liver biopsy involves removing a small piece of tissue from the liver with a special needle, which is inserted through the skin between the lower right ribs. The tissue is examined under a microscope by an experienced pathologist who can assess the extent of existing liver disease.
- People undergoing a biopsy will be required to lie still for approximately six hours after the procedure to ensure that complications do not occur.
- Some people experience persistent episodes of short-lived pain after the procedure. This can be reduced through the provision of appropriate pain relief.
- For some people, such as those with bleeding disorders, liver biopsies are not appropriate or possible.

MEDICARE BENEFITS SCHEDULE – (MONITORING TESTS)

The current **Medicare Benefits Schedule** covers two types of hepatitis C treatment assessment or monitoring tests:

- Hepatitis C virus antibody test.
- Hepatitis C virus RNA testing.

AVAILABILITY – PCR VIRAL DETECTION TEST

Since July 1998, the basic PCR viral detection test has been covered under the Medicare Benefits Schedule (under item no. 69444) for use in certain circumstances:

- people who have had a positive hepatitis C antibody test and who have normal liver function test results on two occasions six months apart; or
- people who have inconclusive hepatitis C antibody test results; or
- people who have weakened immune systems (e.g. HIV/AIDS) and want to confirm whether they are hepatitis C positive or not; or
- detecting acute hepatitis C, prior to sero-conversion in people who have signs of acute hepatitis yet other causes have been excluded (e.g. hepatitis A or hepatitis B).

PCR testing is made available in these cases (one PCR test annually per person) where PCR information is considered necessary for the clinical management of a person's hepatitis.

AVAILABILITY – VIRAL GENOTYPE AND VIRAL LOAD TESTS

Since November 2000, all three PCR tests and the branched chain DNA load test (bDNA) have been covered under the Medicare Benefits Schedule (see item numbers below) for use in certain circumstances.

Requests for these monitoring tests are limited to specialists and are for people with confirmed hepatitis C (by previous antibody or PCR test) who may undergo a course of antiviral therapy depending on the result of testing.

These additional funded access arrangements allow for:

- 1 x viral load test (PCR or bDNA) prior to therapy (Item no. 69442) – when the intention is to proceed with interferon or combination therapy.
- 1 x PCR genotype test (Item no. 69443) – when initially considering treatment options.
- Up to 4 x PCR viral detection tests (Item no. 69445) prior to and over a 12-month treatment/follow-up period – to help monitor treatment response.

The maximum number of PCR viral detection tests for any course of treatment is four, including any provided under Item 69444 (above).

Liver biopsy is also available under the Medical Benefits Schedule.

COMMONLY ASKED QUESTIONS

WHICH IS THE TEST THAT TELLS A PERSON THEY HAVE HEPATITIS C?

This is called an antibody test. This is a simple blood test that can show whether a person has produced antibodies to the hepatitis C virus. It can show whether a person has been exposed to hepatitis C in the past, but does not indicate a person's current viral status. A person who has been infected and has cleared the virus will test positive to hepatitis C antibodies for a period of time following viral clearance. *See Chapter 1: Estimated Outcomes of Hepatitis C Infection chart, p21.*

There are no tests that can tell how long a person has been infected with hepatitis C. Ideally, testing should take place only after a person has received pre-test information and counselling. It is strongly recommended that all test results, negative and positive, are given face-to-face.

WHAT DOES A PCR TEST SHOW?

The PCR test detects virus in the blood and can show whether a person is infected with hepatitis C. It can therefore indicate whether a person can pass the virus on to others. A negative test result means that the virus was not detected in the blood. The infection may have cleared or there may be very low levels of the virus undetectable by the test.

IS IT POSSIBLE TO FEEL TERRIBLE BUT HAVE NORMAL ALTS?

It is possible to receive LFT results that indicate normal ALT levels and still have liver damage and feel unwell because of this. However, it is uncommon (except in cases of cirrhosis) to have normal liver function test results if liver damage is severe. It is also possible to have elevated or fluctuating LFT results and feel quite well.

WHAT ARE LIVER FUNCTION TESTS (LFTs)?

LFTs are used to monitor the ongoing condition of the liver. LFTs detect abnormal levels of enzyme production in the liver, and the enzyme most commonly monitored using this test is alanine aminotransferase (**ALT**). People may consider having regular liver function tests so that they can monitor any changes and talk with their GP or liver specialist about the implications of these changes.

CHAPTER 5

HEALTH MAINTENANCE FOR PEOPLE AFFECTED BY HEPATITIS C

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- Health maintenance aims to promote physical, psychological, emotional and social wellbeing in people who are aware that they have hepatitis C.
- People with hepatitis C must have access to current, concise and appropriate information if they are to make informed decisions about their health.
- Partners, families and other non-professional carers of people with hepatitis C may need support from health workers. They may also have social and welfare needs in which hepatitis C needs to be taken into consideration.

SUMMARY OF IMPORTANT POINTS

- Having a sense of control over the experience of living with hepatitis C often enhances quality of life for many affected people.

PRE- AND POST-TEST COUNSELLING AND INFORMATION PROVISION

Thinking about being tested for hepatitis C may raise medical, psychological and social issues that individuals may not have anticipated or discussed previously. These issues may be of sufficient emotional significance that they need to be addressed in some depth before the individual is able to make an informed decision about being tested, and in this respect counselling skills may need to be used in the pre-test session. Some service providers use the term ‘information giving’ to describe the pre-test session.

The aims of the pre-test session are:

- to provide information about the process of being tested;
- to enable individuals to decide whether or not to be tested;
- to obtain **informed consent** if the decision is to go ahead with testing;
- to provide psycho-social support; and
- to help reduce the risk of further transmission of hepatitis C, through providing relevant information.

The aims of post-test counselling are:

- to discuss the meaning of the test result;
- to provide information about health maintenance and treatment options if the result is positive;
- to provide psycho-social support for people who test positive; and
- to reinforce transmission prevention messages.

Some people may choose not to have pre- and post-test counselling. The impact of a positive or a negative hepatitis C result will vary for everyone, as will the depth of understanding about the virus and its implications.

When testing for hepatitis C, pre- and post-test counselling is not a legal requirement in Australia.

BEST PRACTICE IN PRE- AND POST-TEST COUNSELLING

- Giving correct and up-to-date information (both oral and written) as part of a general discussion is an effective way of educating people. Printed information provided at the pre-test counselling stage can be particularly useful.
- It can be helpful if the same worker provides both pre- and post-test counselling. In this way, the potential for a trusting and respectful relationship is enhanced. This is most important in the context of educating people about Harm Reduction *(see Chapter 3 for more information)*. Providing continuity of care can improve people's opinion about the service they are receiving. It is often easier for health care workers to educate people about risk reduction and health maintenance if they have already established a rapport. The ability of the health care worker to make the person feel valued is vital.

PRE-TEST SESSION ISSUES

Confidentiality

Confidentiality is usually a major concern for people being tested for hepatitis C. It is important for health care workers to explain the sort of information that is recorded in a person's history and who has access to this information. It is helpful if health care workers can outline the meaning of confidentiality, and the processes for ensuring this in their particular agency.

Informed consent

To make an informed decision about being tested, people need clear and appropriate information about hepatitis C. Health care workers must be able to describe:

- how the virus is transmitted;
- the meaning of the window period;
- the meaning of a negative result;

- the meaning of a positive result;
- the meaning of a false positive result, a false negative result and an indeterminate result;
- possible outcomes if the result is positive;
- health maintenance strategies if the result is positive;
- the range of medical and non-medical support available; and
- how to reduce hepatitis C transmission – this applies to people who have received a positive or a negative result.

Because many people still believe that hepatitis C is always a fatal disease, failure to provide good information prior to testing increases the chance that the client will be traumatised by a positive result. The health care worker's role here is to assess how a person may react to the news of a positive result until a further appointment can be arranged.

Assessing risk factors

Health care workers must assess a person's risk of being infected. This involves taking a detailed history that includes questions about:

- current and past injecting drug use;
- tattooing, body piercing and body art;
- any blood transfusions in Australia before 1990;
- other possible risk activities; and
- time spent in other countries where hepatitis C may be endemic.

It is also important to determine the person's own understanding of their risk of infection. The pre-test setting is an ideal opportunity to identify any misconceptions that a person may have.

At times, health care workers may feel that the likelihood of a positive result is negligible. Given that hepatitis C can be viewed as a stigmatising disease, it is always worth considering that the whole story may not have been presented. A test should not be denied to an individual because the health care worker deems the risk to be low, or because information has not been forthcoming.

A more comprehensive personal history is often revealed in the post-test session. Sometimes the person being tested chooses not to reveal the real reasons for requesting a test in the pre-test session. The pre-test session is still an invaluable opportunity to provide clear information and education about hepatitis C and other blood-borne viruses.

Assessing a person's emotional state

Health care workers must informally assess a person's psychological and emotional state in the pre-test session. They must also help the person to decide whether or not to be tested at this time. This involves:

- checking how the person has coped with stress in the past;
- checking if there are other stressful events in the person's life at the present time;
- inviting the person to imagine how they would react to a positive result;
- inviting the person to imagine how they would react to a negative result;
- enquiring about existing support structures;
- determining whether anyone else knows that the person is being tested;
- determining if and when the individual can return in person for the test result; and
- exploring whether the person might want to share their result with anyone else, why and how.

If there are other stressful events for the person at the present time, it is often advisable to defer testing until a less stressful time.

If health care workers sense that a person has not been able to absorb essential information regarding the test, on account of recent drug or alcohol use, it is important that they talk about this and suggest they return at another time for an additional pre-test session. Health care workers must be aware that some people will only be able to attend under the influence of alcohol or other drugs and in this situation, testing/counselling should proceed.

POST-TEST SESSION ISSUES

A negative result

If the result is negative, there is an opportunity for the health care worker to re-visit some of the issues raised in the pre-test session and to clarify any misunderstandings. The person who has been tested may be grateful for information about available resources. They may also feel more inclined to return for future testing or other counselling and support if they feel that they have not been judged.

A positive result

If the result is positive, health care workers can provide support in a safe place and work through the initial issues raised by the person who has been tested. Few people will recall much of what is said following a positive test result. This is why it is good practice to provide information at the pre-test session. Ideally this should include clear and accurate printed resources that the client can take away and read.

The worker's roles at the post-test session are:

- to assess how a person may react to the news of having hepatitis C until a further appointment can be arranged; and
- to answer any immediate questions that the client has, ideally referring back to information and issues already covered at the pre-test session.

BEST PRACTICE IN POST-TEST COUNSELLING

Where possible, it is strongly recommended that the test result is given in person, and not over the phone or in writing. In some rural and remote areas, alternative arrangements may need to be negotiated, such as forwarding the result to another health worker to be given in person. The aim is to ensure that the individual being tested always receives appropriate and relevant information and support.

There is a tendency to bombard newly-diagnosed people with information. In many instances, it is more helpful to provide the person with concise information in small quantities. Giving complex medical information may have the effect of making a person feel powerless. Working through issues in a calm and orderly manner allows individuals a sense of control over what is happening. Printed resources can also be useful in this situation.

People who have received clear and accurate information about hepatitis C are better equipped to protect themselves and others and are also able to educate their peers and thus play an important role in the prevention of further transmission of hepatitis C and other blood-borne viruses.

While the information above provides recommendations about the content and process of pre- and post-test counselling, in practice a pre-test session is not always undertaken. If it is not possible to provide a pre-test session, health care workers should follow (to the best of their ability as the situation allows) the recommendations for both pre- and post-test information in the post-test session. The provision of printed information in this situation would be especially useful for the client.

QUALITY OF LIFE ISSUES

WHAT IS QUALITY OF LIFE?

The World Health Organisation defines health as:

> **A COMPLETE STATE OF PHYSICAL, MENTAL, EMOTIONAL AND SOCIAL WELLBEING, AND NOT MERELY THE ABSENCE OF DISEASE OR INFIRMITY**

Quality of life (QoL) is a term often used to describe the experience of overall wellbeing. When asked to define quality of life, many people say that it means being happy and content, being physically able to do what they want or need to, and having fulfilling, supportive relationships.

QUALITY OF LIFE IN THE HEALTH CARE SETTING

Experiences in the health care setting can influence a person's quality of life. In conventional medical and health service practice there is a continued focus on physical functioning – this focus does not acknowledge that QoL is complex and subjective, and that people with hepatitis C may have a broad range of needs, some of which can be addressed in health settings.

Many people with hepatitis C have no symptoms, but for others infection can be characterised by the unpredictable onset and progression of symptoms. As a consequence, people may experience a lack of confidence regarding their future health.

Physical symptoms undeniably affect QoL. Other issues, such as possible discrimination, loss of social support, inadequate income, uncertainty of the future and feeling 'infected' have also been identified as serious concerns for some people with hepatitis C. Pre- and post-test information provision and counselling sessions can be very helpful in alleviating the impact of being given a positive diagnosis.

STRATEGIES TO ENHANCE QUALITY OF LIFE IN THE HEALTH CARE SETTING

Strategies that can be employed to reduce the uncertainty associated with hepatitis C include:

- Health care workers contributing to the wellbeing of affected people through a genuine effort to understand their experiences, and by providing appropriate information and support. This is most crucial at the time of diagnosis, which may affect the way an individual interprets and internalises the concept of a 'person infected with hepatitis C'.
- Presenting information in an accessible way. This means not only using appropriate language and concepts, but also putting information into a context that is meaningful to the individual. *See Chapter 7: section on Discussing Risk Behaviours, p151, for more details on choice of language.*
- Prevention and transmission messages should be clear. When talking about transmission, it is important to shift the emphasis away from unknown or irrelevant factors onto known factors that can logically help to assess what the risk might be. This may provide health workers with the opportunity to debunk myths about how hepatitis C is transmitted, while reinforcing existing personal knowledge. *See Chapter 1: section on Transmission, p13, and Chapter 7: section on Discussing risk behaviours, p151.*
- People who have known of their infection for some time usually have different needs, such as developing strategies to limit feelings of uncertainty and reduce stress. Many people with chronic hepatitis C say that the virus has helped them realise what is important in their lives and to appreciate 'living in the present'.
- The concept of increased personal control needs to be considered in all discussions relating to hepatitis C. For many people, achieving a sense of control over their own health is crucial to their overall QoL. This can mean

increasing levels of exercise, taking adequate rest, managing stress, improving self-esteem, establishing healthier eating habits and using complementary therapies.

An increased sense of control may also be achieved by:

- clarifying expectations regarding health, correcting misbeliefs etc;
- discussing whether to disclose hepatitis C status, how and when;
- discussing whether health is currently affected and to what extent, and how to accommodate these changes into work and personal life; and
- discussing interactions with friends and family.

Addressing issues such as uncertainty can play an important part in helping people with hepatitis C to better manage their diagnosis and health.

SUPPORT AND CARE

Hepatitis C can affect all areas of life, including personal relationships, family dynamics, social situations, employment and plans for the future.

Systems that address the non-medical aspects of living with hepatitis C are crucial at all stages of service provision, including supportive counselling during pre- and post-testing, during treatment, and on an ongoing basis.

Support means different things to different people. Each person has individual support needs relating to specific experiences and circumstances. In order that support needs are defined and met, support must be able to encompass individual differences, and should also be informed and defined by those who require it. Effective support for the affected person, including the needs of partner, family and friends, comes in varying forms, including:

- accurate, evidence-based, and current information delivered by competent health care workers;
- telephone information and support services;

- magazines, newsletters and current pamphlets and brochures – particularly those produced by Hepatitis C Councils and peer-based drug user organisations;
- talking with others in a similar situation can be useful – a number of agencies (including Hepatitis C Councils and peer-based drug user organisations) run support groups and peer-based activities;
- health care workers may want to explore the possibility of setting up support groups specifically for those undergoing treatment, and also for those who are affected by hepatitis C, such as family and friends;

- peer-based education programs;
- support from family and friends can play a significant role in a person's quality of life;
- web sites and newsgroups;
- personal and/or relationship counselling;
- public forums and conferences;
- awareness campaigns;
- volunteering;
- employment re-training schemes; and
- indirect support is often available through service provision at Needle and Syringe Programs, Hepatitis C Councils, peer-based drug-user organisations, alcohol and other drug agencies, community health networks etc.

See Contacts, p236, for information on services in your State or Territory.

NUTRITION

Overall psychological and physical wellbeing is also influenced by nutrition. Although there is no evidence that improvements in diet have any direct virological effect, people with hepatitis C can optimise their nutritional status and their resistance to other infections through a healthy choice of food.

DO PEOPLE WITH HEPATITIS C NEED TO FOLLOW A SPECIAL DIET?

The majority of people with hepatitis C will not develop advanced liver disease and their lives will not be shortened by hepatitis C. This means that most of their nutritional considerations should be the same as those of the general population, i.e. high fibre and low fat.

Since most Australians are not yet eating a low fat, high fibre diet, most people, including people with hepatitis C, can benefit from making some changes to their eating habits.

Some people with hepatitis C may have intolerance to particular foods or alcohol, and individual assessment and modification of diet may be necessary.

Some resources on diet and hepatitis C recommend that people exclude all dairy foods, red meat, tea, coffee, foods containing added sugar, and artificial colours and preservatives. These recommendations are not supported by scientific evidence and following such a diet may have the following negative impacts:

- potential dietary deficiencies of iron, calcium and vitamin B12;
- difficulty with shopping and with eating or drinking away from home, which can be stressful and socially isolating;
- potential storage problems for preservative free foods; and
- extra costs – additive-free/organic products are always more expensive.

DIETARY GUIDELINES FOR ALL AUSTRALIANS

Guideline	Reason
Enjoy a wide variety of nutritious foods.	Nutritional requirements are easily met when food from a wide variety of sources is consumed. A diet containing only a few foods is likely to be deficient in one or more nutrients.
Eat more breads and cereals (preferably wholegrain), vegetables (including legumes), and fruit.	Most Australians do not eat sufficient fibre. Eating these foods will help to ensure an adequate intake.
Eat a diet low in fat and, in particular, low in saturated fat.	High intake of saturated fats increases the risk of cardiovascular disease.
Maintain a healthy body weight by balancing physical activity and food intake.	Being overweight or obese increases the risk of cardiovascular disease and diabetes.
If you drink alcohol, limit your intake.	Alcohol in excess is damaging to everyone. It causes damage to liver and brain cells when consumed at a rate greater than the liver can metabolise.
Eat only a moderate amount of sugars and foods containing added sugars.	Foods high in sugar tend to be low in other nutrients. Dental decay may occur if teeth are not brushed after consuming sticky foods and drinks.
Choose low salt foods and use salt sparingly.	Low salt diets are associated with lower risk of high blood pressure and cardiovascular disease.
Encourage and support breastfeeding by mothers of new-born babies.	Breastfed babies are more resistant to a number of infections, less likely to experience diarrhoea and are less likely to become overweight.

MANAGEMENT OF DIET AND HEPATITIS C-RELATED SYMPTOMS

It is important to note that many people with hepatitis C do not experience the symptoms discussed below. Others may experience some or all of the symptoms, either due to hepatitis C or as side effects of treatment. Note that nutritional priorities change according to health status. If people are having difficulty maintaining their weight, the nutritional priority is to consume high-energy nutrient-rich foods and not worry about issues like saturated fat intake until their weight has stabilised.

NAUSEA AND VOMITING

Tips for maintaining good nutrient intake when nauseous:

- eat small amounts often rather than big meals three times a day;
- eat most when you feel hungry (often this will be at breakfast);
- choose foods that contain lots of vitamins and minerals – eating small amounts of foods such as cheese, yoghurt, nuts, tofu, dried fruit, soy drinks, flavoured milk, milkshakes or smoothies can provide you with required amounts of vitamins and minerals;
- try different tastes to stimulate appetite, e.g. bitter, sour, salty or sweet;
- special nutritional supplements may be useful if people are not eating well or are losing too much weight. This should be discussed with a dietitian;
- drink ginger ale, or a mix of half ginger ale, half milk (which contains more nutrients than ginger ale alone), to combat nausea; and
- if you cannot tolerate food smells because of nausea, avoid being in the kitchen when foods are cooking, or prepare meals in advance when you are feeling at your best.

If vomiting persists for more than 24 hours, people are advised to seek medical advice.

LOSS OF APPETITE

- eat small amounts often;

- if possible, eat meals with other people;
- try to make meals look appetising – small serves with a variety of colour and texture;
- try and eat something small every two to three hours, rather than relying on appetite to prompt eating;
- use cold water as a mouth rinse before meals – this may help make food taste better;
- some food smells or cooking odours may enhance appetite;
- choose foods that contain lots of vitamins and minerals such as milkshakes or smoothies;
- try different tastes to stimulate appetite, e.g. bitter, sour, salty or sweet;
- ensure that all meals are eaten in a well-ventilated room;
- special nutritional supplements may be useful if people are not eating well or if they are losing too much weight. This should be discussed with a dietitian;
- cold foods may be better tolerated, such as sandwiches, salads, cold meats and antipasto; and
- try to have a number of snack type foods readily available such as dips, muesli bars, yoghurt, fruit cake, milk drinks or vegetable snacks such as carrot sticks. Pre-packaged snacks can often be expensive and buying in bulk or shopping for specials may help.

FATIGUE

The body's immune response to any infection can result in feelings of fatigue and eating a balanced diet is necessary to optimise the body's ability to fight infections. It should be noted that there is no nutritional 'quick fix' for fatigue. *Also see section on Managing Fatigue, p111.*

- Some people find that they become tired approximately 2 hours after eating sugary items such as chocolate – individuals should monitor and adjust their intake accordingly.

- Try to have a number of nutritious snacks readily available such as dips, muesli bars, yoghurt, fruit cake, milk drinks or vegetable snacks.

It can be helpful to seek further advice about diet and fatigue from a nutritionist or a naturopath.

DIET AND HEPATITIS C DRUG TREATMENTS

People using **interferon** or **combination therapy** may experience severe weight loss, nausea or vomiting. A dietitian at the treatment centre or hospital should be able to give individual advice.

WHO NEEDS TO SEE A DIETITIAN OR A NATUROPATH?

Qualified dietitians provide evidence-based dietary advice tailored to the individual. Professional advice from a dietitian is recommended for people with hepatitis C when they are experiencing one or more of the following problems:

- advanced liver disease;
- nausea, anorexia or unplanned weight change (including when these symptoms are the side-effects of treatment);
- other conditions such as coeliac disease or diabetes that require dietary modification; and
- loss of appetite, nausea or loss of energy, or generally feeling unwell.

Liver specialists and gastroenterologists, GPs, Hepatitis C Councils and peer-based drug user organisations can arrange referrals to a dietitian or a naturopath. A referral from a doctor is needed in order to claim a Medicare rebate if you see a dietitian in private practice.

For more information on available resources see Contacts, p236.

MANAGING FATIGUE

Fatigue is a common experience for many people with hepatitis C, but it is not a reliable measure of disease progression or severity of disease. Some of the factors contributing to fatigue may be:

- the reaction of the immune system to infection;
- impaired liver function through alcohol use;
- poor diet or toxic substances;
- drug use;
- stress, distress and other situational problems;
- medical treatments such as interferon; and
- poor sleep and lack of rest.

To some extent, fatigue can be managed. Some things to consider in trying to manage fatigue and maximise energy are to:

- validate the experience of fatigue and its symptoms;
- seek counselling to assist with the depression that can accompany fatigue;
- prioritise activities and plan the day carefully to avoid overload;
- ask for help, even on a regular basis;
- when fatigued, try relaxation or rest rather than attempting to go to sleep;
- have regular breaks and time out;
- avoid big meals and take time to enjoy food;
- avoid hot baths and showers and un-ventilated rooms;
- experiment with appropriate exercise; and
- ask for more ideas from a health professional.

Traditional Chinese Medicine is believed to help reduce some symptoms associated with hepatitis C, including fatigue.

See Chapter 6: section on Complementary Therapies, p128, for more information.

ORAL AND DENTAL HEALTH

People with hepatitis C may experience additional teeth and mouth problems. These can include dry mouth, tooth sensitivity and decay, gum infections and mouth ulcerations. These symptoms can also be associated with other conditions, and are not necessarily an indication of infection with hepatitis C.

Studies have shown that because of problems with the mouth, people avoid going out, are uncomfortable with their appearance, often have toothache and may have trouble relaxing. Poor oral health can affect speech, nutrition, body image and self-esteem.

DENTAL CARE CONSIDERATIONS FOR PEOPLE WITH HEPATITIS C

- Saliva helps to protect teeth and gums, and research has identified low levels of saliva among groups of people with hepatitis C. This may be a possible explanation of the high rate of decayed teeth and sore gums experienced by people with hepatitis C.
- Some medications, such as methadone and anti-depressants, can cause a dry mouth, and taking these medications may also contribute to dental problems.
- Some people, including those on interferon, have a lower resistance to gum infection than others. Smoking and use of methadone and other opioids can also lead to a worsening of gum conditions. Reduction or cessation of smoking is advised, and regular visits to the dentist for cleaning are recommended.

DENTAL HEALTH AND TREATMENTS FOR HEPATITIS C

People with **cirrhosis**, **platelet** abnormalities and other bleeding disorders should discuss their particular oral health needs with their dentist prior to treatment. People taking interferon or other therapies are also advised to see a dentist regularly.

There are simple remedies that can be carried out to improve oral health and reduce common dental problems. Health care workers should advise people with hepatitis C to visit their dentist regularly. Dentists will also be able to provide advice on specific problems such as dry mouth, tooth sensitivity and decay, gum infections and mouth ulcerations.

HEALTH CONSUMER RIGHTS AND RESPONSIBILITIES

Health care workers should be aware that consumers of health services are entitled to two basic rights:

- the right to give or withhold informed consent to treatment; and
- the right to receive competent care from health service providers.

Competent care should entail:

- treating people with care, consideration and dignity;
- giving clear information and explanations;
- informing people about the service they are dealing with – what it offers, who is eligible, what costs are involved and what their responsibilities are;
- encouraging people to ask questions about the service;
- answering questions about any proposed treatments or procedures, including any associated risks, alternative treatments or procedures as well as any costs involved;

- allowing people time to take in and understand the information provided;
- informing people about whether the proposed treatment or procedure is experimental or part of medical research;
- providing assistance from trained interpreters if requested;
- referring to a more senior person if a complaint is lodged;
- allowing a person to seek a second opinion, including when they are a patient staying in hospital (this may not be possible in an emergency);
- seeking informed consent before treatment begins;
- accepting withdrawal of consent or refusal of treatment at any time;
- allowing a person to appoint someone else to make decisions on their behalf, in the event that they are not able to make those decisions themselves;
- except in the case of some infectious diseases or psychiatric conditions, accepting a person's decision to leave the hospital or treatment centre;
- maintaining confidential personal records (except where the law requires that certain information be given to some person or authority, e.g. authorisation for methadone records from State or Territory health authorities or where health care records may be subpoenaed for court or police);
- accepting that consumers have the right to obtain legal advice if they think the way they are being treated is against the law, or they believe they have suffered harm as a result of the way they have been treated;
- dealing with any complaints in line with the individual services' complaints procedure; and
- allowing people access to their own medical records.

Health care workers should allow parents or guardians of children to:

- exercise all of the rights mentioned above on behalf of their own child; and
- stay with their child at all times unless separation is necessary for medical reasons.

CONSUMER RESPONSIBILITIES

Consumers also have a responsibility to treat health care workers with respect in order that they are able to provide optimum care.

In health care settings, consumers should:

- treat health care workers with care, consideration and dignity;
- tell their health care worker if they are unable or do not intend to follow the prescribed treatment plan;
- tell health care workers about any changes in their health, including any problems they may have with the treatment they are receiving; and
- keep appointments or let the service know if they are unable to attend.

COMMONLY ASKED QUESTIONS

IS PRE- AND POST-TEST COUNSELLING A LEGAL REQUIREMENT?

No. However, health care workers should encourage every person who is being tested to seek pre-test information and/or counselling, and best practice dictates that post-test counselling should be provided to everyone who undertakes an antibody test, regardless of whether the result of the test is positive or negative.

IF A PERSON HAS DISCLOSED THEIR HEPATITIS C STATUS TO FAMILY AND FRIENDS AND RECEIVED NEGATIVE FEEDBACK, WHAT CAN THEY DO?

Support means different things to different people. Each person has individual support needs relating to specific experiences and circumstances. In order that support needs are defined and met, support must be able to encompass individual differences, and should also be informed and defined by those who require it. Community-based organisations can provide information and support. *See section on Support and Care earlier in this chapter, p104.*

SHOULD PEOPLE WITH HEPATITIS C CHANGE THEIR DIET?

Not necessarily. A healthy balanced diet is recommended for all Australians, but it may be necessary for people with hepatitis C to change some aspects of their diet to manage symptoms such as nausea, fatigue or loss of appetite.

GIVEN THAT PARACETAMOL CAN CAUSE LIVER DAMAGE IN LARGE DOSES, IS IT OK TO TAKE?

Paracetamol is an acceptable painkiller for people with hepatitis C in usual doses. Individuals should check with their liver specialist or GP to ensure that all medications are appropriate for their particular circumstances.

DO PEOPLE WITH HEPATITIS C NEED TO TAKE SPECIAL CARE OF THEIR ORAL HEALTH?

People with hepatitis C may experience additional mouth and teeth problems, but the symptoms of poor oral health are not necessarily related to infection with hepatitis C. Regular check-ups by a dentist and attention to oral health is recommended.

WHAT SHOULD PEOPLE DO IF THEY ARE NOT GETTING THE ANSWERS THEY NEED FROM THEIR HEALTH PROFESSIONAL?

People with hepatitis C have the right to receive competent care from their health service provider, which includes relevant and meaningful information in reply to their questions. It is difficult for people to allow or withhold informed consent to treatment if they do not have appropriate information about factors that may affect their decision. People are advised to tell their health service provider that they are not satisfied with the information offered. If still dissatisfied, they should consider (where possible) changing service providers. Individuals can also contact the health service complaints authority or the Hepatitis C Council in their State or Territory for further information and support.

See Contacts, p236, for more information.

DISCLOSURE

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INTRODUCTION

At the time of diagnosis, many people feel a strong desire to seek support in disclosing the news to family or friends. Given the level of ignorance and discrimination around hepatitis C, it is natural that people would be worried about what to say, how to tell others and what their reaction will be. However, disclosure can elicit support from partners, family and friends and can have a positive affect on a person's quality of life, particularly at times of illness, stress and treatment.

It is important to remember that an individual with hepatitis C has control over who to tell. They may choose not to tell people about their hepatitis C. This is their right, and whatever decision they make about disclosure should be respected.

There is no legal requirement for an individual to disclose their hepatitis C status to anyone, with the following exceptions:

- If seeking to donate blood with the Red Cross Blood Service;
- within the Australian Defence Forces; and
- when applying for superannuation, life or health insurance, if the question is asked. *See chapter 7, section on Insurance, p147*.

However individuals can choose not to put themselves in any of these situations.

DISCUSSING DISCLOSURE DURING PRE- AND POST-TEST COUNSELLING

It is important to raise the question of disclosure during pre- and post-test counselling with a person being tested for hepatitis C. This can help to assess their psychosocial situation, their supports, and to inform them of their legal rights.

Discussion may include:

- whether the person has told anyone they are going to be tested;
- whether they are thinking of telling anyone while waiting for a test result; and
- who they might tell after getting the test result.

Some questions for the client to consider when considering disclosure:

- can this person be trusted with information about my being tested for hepatitis C?
- are they likely to offer me support?
- are they likely to judge me?
- will they respect my confidentiality?
- how might they feel after I tell them?

The person being told may also need time to accommodate this new information.

It is up to the individual to decide about disclosing, and to whom. However, a health care worker might think that a particular disclosure could put the client in a vulnerable position. In these circumstances it can be useful to spend time discussing the reasons for considering disclosure to a particular person, and the associated needs and expectations.

NEGATIVE RESPONSE TO DISCLOSURE

Disclosure to family and friends can result in negative personal and social responses. In such situations the health care worker may be able to provide further counselling, or referral to:

- another counsellor;
- a Hepatitis C Council;
- a support group; or
- a peer based drug user organisation.

These options may also be useful for anyone with hepatitis C, or for the person who feels unable to disclose their hepatitis C status to anyone they know, but would like to talk about it with other people. *See Contacts, p236 for more details.*

DISCLOSURE AND DISCRIMINATION

Many people with hepatitis C have experienced overt and serious discrimination from employers, health care providers, family, social contacts and friends. Discrimination is often fuelled by irrational fears about transmission or prejudice against past or current injecting drug use. It is never acceptable.

In order to decide whether to disclose, people with hepatitis C need to be informed about potential discrimination, be aware of their rights and know how to enact them. People with hepatitis C who believe that they have been discriminated against need to know:

- that they have the right to make a complaint; and
- the procedures through which to do this.

Health care organisations should have someone with the designated role of receiving complaints; for example, a hospital complaints officer.

Not all people will feel able to file and follow up a complaint without support. Referral to a Hepatitis C Council, peer community organisation, the Health Services Commissioner or the Equal Opportunity Commission can provide assistance for people who have experienced, or are concerned about, discrimination.

DISCLOSURE AND TREATMENT

The side effects of pharmaceutical treatment can be unpleasant, debilitating and difficult to manage. Interferon therapy may need to be taken for up to 12 months. Side effects, which can include mood alterations and depression, can impact on a person's personal and working life. Many people will need the support of family, friends, workplace managers and colleagues. Flexibility about working hours, and being able to schedule medical appointments to fit into a work schedule can make a big difference to the person being treated for hepatitis C.

This may be the time when a person considers telling someone else about their hepatitis C status. Professional counselling and support may assist during this process. If a person chooses not to disclose at work, they may need advice on useful strategies to manage the difficulties associated with treatment. Some Hepatitis C councils and liver clinics offer treatment support groups.

DISCLOSURE TO HEALTH CARE WORKERS

People with hepatitis C have the right to receive competent care from their health service provider. In order to receive the best and most appropriate care and advice, it may be advisable for people with hepatitis C to disclose their status to their health care worker. For example, some medications (for whatever health condition) may be contraindicated in cases where a person has liver damage and a health care worker would be able to recommend alternative medications for a person with hepatitis C.

Health care workers do not need to know the hepatitis C status of their patients or clients for infection control purposes. The unconditional practice of standard infection control procedures protects the health care worker and patients, no matter what their status.

However, many people with hepatitis C have experienced discrimination in the health care setting. Breach of confidentiality is an example of discrimination and is often a major concern for people with hepatitis C. *See chapter 7, p148-53, for more information.*

Health care workers have a legal and professional responsibility to maintain confidential personal records and to explain:

- the sort of information that is recorded in a person's history;
- who has access to this information;
- what confidentiality means; and
- the processes for ensuring this in the particular agency.

It is a legal requirement in all States and Territories that testing laboratories send all positive hepatitis C test results to the State or Territory health department. The results are used for statistical and epidemiological purposes only. Health departments are bound by law to keep personal information (i.e. names and addresses and other identifying details) confidential.

DISCLOSURE AND INSURANCE

When applying for superannuation, life or health insurance a person will be asked a range of questions about general health, and may be asked specific questions about their blood borne virus status or current or past liver illness. These companies are legally permitted to ask questions as part of their risk assessment. They are also allowed to discriminate in the provision of their services if:

- the discrimination is based on relevant statistical and risk assessment data (eg. it may be unreasonable for a person who has been hepatitis C positive for several decades yet whose biopsy shows minimal inflammation to be assessed similarly to someone with cirrhosis; or
- there is no relevant data, or this is difficult to assess, then the discrimination is reasonable, based on other relevant factors.

If a person discloses their hepatitis C status they may be refused insurance cover or be asked to pay a higher premium. For assistance with these issues see the list below.

HEPATITIS C POSITIVE HEALTH CARE WORKERS AND DISCLOSURE

Health care workers with hepatitis C who perform "exposure prone procedures" should be guided by their State or Territory health department's guidelines and by the policy of their professional body and relevant board.

For health care workers who do not perform exposure prone procedures, the use of standard infection control practices provides protection for both patients and health care workers.

In all other situations it is up to the individual health care worker to decide whether to disclose, to whom, when, how and why.

Disclosure to employers, colleagues and insurers can be professionally difficult. It may have unexpected impacts on working relationships and situations.

FURTHER ASSISTANCE

If individuals require assistance on issues of disclosure, or in dealing with any resultant discrimination, health care workers can provide referral to:

- Hepatitis C Councils and their support groups;
- Peer based drug user organisations;
- Haemophilia organisations for people with haemophilia who are affected by blood borne viruses;
- Community based and government organisations;
- Health Services Commissioner; and
- Equal Opportunity Commissions in capital cities.

See Contacts, p236, for further details.

CHAPTER 6

TREATMENTS FOR HEPATITIS C

Contributors: Robert Batey, Robert Chen, Jia-Yee Lee, Stephen Locarnini, Ron McCoy, Jacqui Richmond, William Sievert, Joe Sasadeusz.

- Interferon monotherapy was the first western medicine used in the treatment of hepatitis C. In Australia, interferon was approved for use in clinical trials in 1992, and became available under the Pharmaceutical Benefits Scheme in 1994.
- The standard therapy now used in the treatment of hepatitis C is interferon used in combination with ribavirin.

- Other treatments for hepatitis C, such as pegylated interferon, are currently being refined, and treatment regimes will continue to change as new findings, medical trial results and legislation inform their development.
- Treatment outcomes for many people with hepatitis C are encouraging.
- Many people choose complementary therapies to alleviate hepatitis C-related symptoms.

SUMMARY OF IMPORTANT POINTS

- Treatments for hepatitis C are not successful in clearing the virus for everyone, and for some people the side effects of treatment can be severe and difficult to manage.

WHAT IS THE AIM OF TREATMENT?

- To stop viral replication and eliminate the virus.
- To subsequently prevent the development of **cirrhosis**, liver failure and liver cancer.

WHO SHOULD BE TREATED?

Treatment is recommended for people who have a chance of clearing the virus and for people most at risk of developing cirrhosis. People with cirrhosis have a lower response rate to treatment, but it is thought that treatment will slow down the progression of liver disease.

CONSIDERATIONS PRIOR TO TREATMENT

The side effects of pharmaceutical treatment can be very unpleasant, difficult to manage and can sometimes be debilitating. Consequently, it is very important that people considering treatment are both fully informed about possible outcomes and side effects and also that they receive appropriate pre-treatment medical and psychological assessment.

In addition, personal commitments such as employment and domestic responsibilities should be considered and available psychosocial support options should be explored. This will enable each person to make a fully informed choice about whether to proceed with treatment.

CONVENTIONAL TREATMENTS: INTERFERON AND RIBAVIRIN

INTERFERON MONOTHERAPY

Interferons are proteins produced by the human body in response to any viral infection. The interferons used in the treatment of hepatitis C are synthetically manufactured and taken in higher doses than those which occur naturally in the body. **Interferon** therapy can boost a person's immune response and inhibit viral growth. The **sustained response rate (SR)** with interferon alone is between 15%–20%.

Interferon used alone, known as monotherapy, is given for a period of up to twelve months. Monotherapy will be used less frequently in the future as a consequence of the recent approval by the Pharmaceutical Benefits Scheme (**PBS**) of combination therapy for all people with hepatitis C who qualify for treatment. However, there will be some circumstances, such as for people who have a (known) severe reaction to ribavirin, where monotherapy is currently the only treatment option available. Treatment involves subcutaneous (under the skin) injections three times a week.

RIBAVIRIN

Ribavirin is a drug taken orally that alters the body's immune response to viruses. In the fight against hepatitis C, it has been shown to be most effective in combination with interferon rather than as a treatment on its own.

COMBINATION THERAPY

Combination therapy, now the preferred option for treatment of hepatitis C, consists of interferon and ribavirin. Treatment consists of a 6 or 12-month course of interferon injections, self-administered three times a week, plus ribavirin capsules taken twice daily. People with hepatitis C are more likely to have a sustained response to a course of combination therapy than to interferon monotherapy.

HOW EFFECTIVE IS COMBINATION THERAPY?

A person's response to treatment is related to several factors:

- genotype – people with genotypes 2 and 3 have been shown to have a higher response rate and in general need a shorter course of treatment than people with genotypes 1 and 4;
- degree of liver scarring (**fibrosis**) – people with advanced liver disease respond less well to therapy;
- amount of virus present in blood (viral load) – the lower the amount of virus, the more likely it is that therapy will clear the virus;
- age – younger people are more likely to respond to treatment; and
- sex – women are more likely than men to respond to treatment.

EFFECTS OF INTERFERON PLUS RIBAVIRIN IN PRODUCING A SUSTAINED VIROLOGICAL RESPONSE (SR) IN PEOPLE WITH HEPATITIS C WHO HAVE NOT PREVIOUSLY BEEN TREATED

Poynard, et al (1998) – International study, including 4 Australian centres			
	IFN + RBV For 48 weeks	IFN + RBV For 24 weeks	IFN + placebo For 48 weeks
SR	43%	35%	19%
By genotype			
1 or 4	31%	18%	11%
2 or 3	64%	64%	33%
McHutchinson, et al (1998)			
SR	38%	31%	13%
By genotype			
1 or 4	28%	16%	7%
2 or 3	66%	69%	29%

In two studies of people who had not previously been treated with either interferon monotherapy or combination therapy, the overall sustained response rate to combination therapy was 41% after 12 months. This compared to a 16% sustained response rate after 12 months with interferon alone. Long-term (over 7–8 years) follow-up studies of people with a sustained response show that almost all continue to be **PCR** negative.

People with genotypes 1 or 4 required a longer period of treatment (12 months), and had a lower sustained response rate (28%) than people with genotypes 2 or 3, who achieved a 65% sustained response rate after 6 months of treatment. People with more liver scar tissue also responded better to a 12-month course of therapy.

People who fail to respond to either monotherapy or combination therapy are more likely to have one or all of the following:

- genotype 1 or 4;
- high viral load; and/or
- cirrhosis.

It is thought that treatment with **pegylated interferon** (a slow release interferon) and ribavirin may produce better results for these groups.

HOW LONG SHOULD COMBINATION THERAPY CONTINUE?

Combination therapy can be demanding and it is important to monitor the overall health of the person undergoing treatment. Clinically, if a person still has detectable levels of virus in their blood after 6 months of treatment, they only have a 2% chance of achieving a sustained response and their treatment should be stopped.

WHAT ARE THE SIDE EFFECTS OF COMBINATION THERAPY?

Combination therapy can cause a range of side effects, which vary in intensity from person to person. Side effects can also be dose-related; higher doses are often accompanied by more severe side effects.

During the first few weeks of therapy many people develop a 'flu-like' illness (particularly pronounced after the first injection), together with fatigue, malaise, muscle aches and low-grade fever. This tends to subside as treatment continues. Interferon and ribavirin each have specific side effects.

SIDE EFFECTS OF INTERFERON

Interferon can lower the count of **platelets** and white blood cells, but reducing the drug dose or temporarily stopping treatment usually resolves this problem. Interferon can affect mood and concentration, and depression is the most common reason for stopping treatment. Mild to moderate depression can be treated with anti-depressants during the course of treatment. It is recommended that people with a history of severe depression or psychiatric disorder undergo a psychiatric assessment prior to making a decision about treatment. Some specialist clinics recommend that people be offered prophylactic anti-depressants while undergoing treatment.

Interferon may also cause temporary hair loss, problems in people with poorly controlled diabetes, weight loss, loss of concentration and sleep and a worsening of pre-existing **psoriasis**.

SIDE EFFECTS OF RIBAVIRIN

Ribavirin can cause red blood cells to break down **(haemolytic anaemia)**, which is a major concern in people with significant heart disease, and this treatment requires careful monitoring during the first few weeks. Other side effects of ribavirin can include a generalised rash and upper respiratory congestion. Ribavirin has also been associated with birth defects in animal studies. Although it is not yet known whether ribavirin causes birth defects in humans, it is a requirement of treatment that heterosexual women and men of reproductive age use adequate contraception during, and for up to six months after

treatment. Both the person undergoing treatment and their partner must use an effective form of contraception (i.e. one form for each partner). Women of child-bearing age must not be pregnant or breastfeeding. The female partners of men undergoing treatment must not be pregnant.

It is very important that people who are considering pharmaceutical treatment are fully informed about possible side effects, details of which are listed in the table below. Psychological and practical support, both during and after treatment, is also a very important consideration.

VACCINATIONS

Note that vaccination against hepatitis A and B is recommended for people with hepatitis C, or with hepatitis C/HIV co-infection, who are not immune to hepatitis A or hepatitis B. *See Chapter 3: section on Vaccinations, p70.*

ADVERSE EFFECTS OF INTERFERON AND RIBAVIRIN

Interferon

Systemic

- malaise, nausea, fever, weight loss, diarrhoea, temporary hair loss
- exacerbation of diabetes

Neurological

- loss of concentration, sleep disturbance, paraesthesiae (loss of sensation), exacerbation of epilepsy, visual loss (rare), deafness (rare)

Psychological

- depression, irritability, psychosis

Myelosuppression

- low white blood cell count, thrombocytopenia

Induction of autoimmunity

- autoimmune thyroid disease, haemolytic anaemia, thrombocytopenic purpura (bleeding disorder), psoriasis, worsening of psoriasis, worsening of autoimmune hepatitis

Cardiac

- arrhythmia, congestive failure

Susceptibility to infection

Ribavirin

Haematological

- haemolytic anaemia

Respiratory tract

- cough, dyspnoea, pharyngitis, sinusitis

Embryonic development

- possible birth defects

HEPATITIS C TREATMENT FOR PEOPLE WITH HEPATITIS C AND HIV CO-INFECTION

- Very few data exist about the effects of interferon monotherapy for people with co-infection. There is some evidence that interferon alone may achieve response rates similar to those for people who do not have HIV.
- There are fewer data available on the effects of combination therapy on people with co-infection.
- Response depends on the amount of damage caused to the immune system by HIV. People with **CD4 counts** above 500 cells/l have significantly better hepatitis C treatment results than people with less than 500cells/l.
- People with low CD4 counts are those in greatest need of hepatitis C therapy.

The aims of therapy in advanced HIV should be to delay progression of liver disease rather than to achieve eradication of both viruses.

- One major concern is the potential of ribavirin to inactivate some anti-HIV drugs, especially AZT and d4T. Inactivation of these drugs has been demonstrated during laboratory tests.
- Some recent data suggest that combination therapy does not increase HIV viral load, while achieving good responses to hepatitis C.

QUALITY OF LIFE ISSUES DURING TREATMENT

For some people, the physical and psychological side effects of combination therapy can be overwhelming. Given that treatment can last for up to twelve months, some people find it hard to continue to work, and many people experience difficulties in their personal and professional lives. Health care workers need to be aware of the social and psychological pressures that can result from a course of combination therapy and, where appropriate and available, refer people to treatment support groups.

To help people minimise the negative side effects that can be associated with treatment, appropriate support mechanisms should be an essential feature in the clinical setting. Additionally, Hepatitis C Councils offer confidential telephone information lines and support groups that people on treatment may find useful.

COMPLEMENTARY THERAPIES AND HEPATITIS C-RELATED SYMPTOMS

Complementary therapies have been used around the world for many years, in some cases for centuries, to treat and alleviate the symptoms of a range of health conditions. It is now widely acknowledged that complementary therapies have a role to play in the management of hepatitis C-related symptoms.

To date, there have been few controlled trials of specific complementary therapies in the treatment of hepatitis C. Current clinical research evidence indicates that some herbal medicines can alleviate hepatitis C-related symptoms and help to reduce high **ALTs**. Many other complementary therapies have not been formally studied. Some people report dramatic results and improvement in quality of life through the use of complementary therapies, while others observe no great benefits. When considering complementary therapies, it is important to be aware that as well as focusing on the functioning of the liver and related symptoms, many therapies are designed to address a person's holistic health needs.

Some of the more common types of complementary therapies used in the treatment of hepatitis C are:

- Traditional Chinese Medicine;
- Western herbal medicine;
- herbal medications such as St.Mary's Thistle, licorice root, dandelion;
- Acupuncture;
- Ayurvedic medicine;
- Naturopathy;

- massage;
- meditation; and
- vitamin and dietary supplements.

CONSIDERATIONS FOR PEOPLE USING COMPLEMENTARY THERAPIES

Health care workers should ensure that people considering complementary therapies are aware that:

- The best treatment outcomes are achieved when a person's GP or liver specialist works collaboratively with their complementary practitioner. This may include monitoring and discussing (with the permission of the person being treated) liver function on a regular basis, sharing case notes and assessing any adverse effects that might result through combining conventional and complementary therapies.
- As with any treatment, practitioners should give realistic (not overly optimistic) indicators of likely success. Treatment failure, be it complementary or conventional, can be devastating for some people.
- There are risks involved in self-medication, and a knowledgeable complementary practitioner should be involved in careful monitoring of any course of therapy.
- Some herbs are toxic to the liver.
- It is important to ask questions of the complementary practitioner about the possible outcomes or side effects of any particular treatment.
- In many States and Territories, complementary practitioners are unregulated. People considering such therapies are advised to use practitioners who have qualifications in the field, membership of a professional body, good communication skills and a sound knowledge of hepatitis C. *See Contacts, p236, for information on where to find a recommended practitioner.*
- Complementary therapies are not rebateable under Medicare, and some can be expensive. However, many therapies are covered by private health care policies.

Complementary therapists are encouraged to document their treatment regimes and outcomes in appropriate journals, so that a clearer understanding of their effect on hepatitis C-related symptoms can be achieved.

TREATMENT OPTIONS FOR PEOPLE IN RURAL OR REMOTE AREAS

A source of frustration for many people in remote and rural areas of Australia is poor access to services and treatment. Access to treatment for hepatitis C is currently restricted to specialist services linked to major regional hospitals. Many people live too far away from a regional-based treatment centre to have easy access to treatments under Section 100 of the Pharmaceutical Benefits Scheme (a government subsidised treatment schedule). **Shared Care** and **Enhanced Primary Care (EPC)** initiatives are gradually expanding through rural Australia, allowing more people with hepatitis C to access treatment and have their care managed in a partnership arrangement between specialists, GPs and other health care services. The expansion of these programs nationwide will ensure greater access to specialised care and treatment services. However, under current regulations, prescriptions for treatment can only be issued by the specialist centre.

ACCESS TO TREATMENT FOR PEOPLE WHO INJECT DRUGS

Discrimination, and fear of discrimination, have been identified by people who inject drugs as major barriers to accessing treatments. People who inject drugs and/or use methadone are no longer excluded from treatment under Section 100 of the Pharmaceutical Benefits Scheme. However, it is important to be aware that this does not necessarily translate into practice.

Unfortunately, many health care workers are not adequately trained or supported to work with people who inject drugs, and past experiences or current prejudices may lead them to treat people who inject drugs less favourably than others.

Compliance with treatment, cost of treatment and access to adequate medication while on treatment have also been identified by people who inject drugs as issues that require careful consideration by health care workers. Health care workers should remember that all people seeking treatment should be assessed using the same criteria.

See Chapter 7: Preventing Discrimination and Reducing Stigma and Isolation.

S100 PHARMACEUTICAL BENEFITS SCHEME

Interferon Alfa A-2a®, Roferon –A®, Interferon Alfa A-2b, Intron A® are listed as highly specialised drugs under Section 100 of the National Health Act. These drugs can only be prescribed by specialist hospital units and dispensed through pharmacies within hospitals that participate in the **Highly Specialised Drug Program**. Medical practitioners must be formally associated with specialist hospitals to prescribe these drugs as pharmaceutical benefit items. Prescriptions for highly specialised drugs are not generally supplied as pharmaceutical benefits by community pharmacies.

For information about PCR and other testing associated with treatments, see Chapter 4: Hepatitis C Testing.

S100 CRITERIA FOR TREATMENTS FOR HEPATITIS C – MAY 2001

INTERFERON ALFA-2A, ROFERON-A ®, AND INTERFERON ALFA-2B, INTRON A®

CAUTION: Treatment with interferon alfa has been associated with depression and suicide in some patients. Patients with a history of suicide ideation or depressive illness should be warned of the risks. Psychiatric status during therapy should be monitored.

Authority required.

Patients with chronic hepatitis C who satisfy all of the following criteria:

1. histological evidence of chronic hepatitis on liver biopsy (except in patients with coagulation disorders considered severe enough to prevent liver biopsy);
2. abnormal serum ALT levels in conjunction with documented hepatitis C infection (repeatedly anti-HCV positive and/or HCV-RNA positive);
3. no other forms of chronic liver disease;
4. female patients of child-bearing age, who are not pregnant, not breastfeeding and are using an effective form of contraception.

The treatment course is limited to 3 million units subcutaneously 3 times weekly for up to 52 weeks.

Treatment is to cease if plasma HCV RNA remains detectable by an HCV-RNA qualitative assay after 12 weeks' therapy.

The course of treatment must be continuous and excludes re-treatment of non-responders or patients who relapse.

NOTE:

Hospitals should adhere to the National Health and Medical Research Council's Taskforce report on hepatitis C regarding the facility requirements for the selection of treatment centres.

RIBAVIRIN AND INTERFERON ALFA-2B

(patients who have relapsed)

CAUTION: Treatment with interferon alfa has been associated with depression and suicide in some patients. Patients with a history of suicidal ideation or depressive illness should be warned of the risks. Psychiatric status during therapy should be monitored.

CAUTION: Ribavirin is a category X drug and must not be given to pregnant women. Pregnancy in female patients or in the partners of male patients must be avoided during treatment and during the 6-month period after cessation of treatment.

Authority required.

Treatment of chronic hepatitis C in patients who have relapsed following interferon alfa-2a/2b monotherapy where the monotherapy treatment would have complied with the criteria for PBS subsidy and who satisfy all of the following criteria:

1. histological evidence of chronic hepatitis on liver biopsy (except in patients with coagulation disorders considered severe enough to prevent liver biopsy);
2. abnormal serum ALT levels in conjunction with documented chronic hepatitis C infection (repeatedly anti-HCV positive and/or HCV RNA positive);
3. female patients of child-bearing age are not pregnant, not breastfeeding, and both patient and their partner are using effective forms of contraception (one for each partner).
4. male patients and their partners are using effective forms of contraception (one for each partner). Female partners of male patients are not pregnant.

The treatment course is limited to 24 weeks.

Treatment is to cease if plasma HCV RNA remains detectable by an HCV RNA qualitative assay after 12 weeks of therapy.

NOTE:
Hospitals should adhere to the National Health and Medical Research Council's Taskforce report on hepatitis C regarding the facility requirements for the selection of treatment centres.

RIBAVIRIN AND INTERFERON ALFA-2B

(patients who have not received previous treatment)

CAUTION: Treatment with interferon alfa has been associated with depression and suicide in some patients. Patients with a history of suicidal ideation or depressive illness should be warned of the risks. Psychiatric status during therapy should be monitored.

CAUTION: Ribavirin is a category X drug and must not be given to pregnant women. Pregnancy in female patients or in the partners of male patients must be avoided during treatment and during the 6-month period after cessation of treatment.

Authority required.

Treatment of chronic hepatitis C in patients previously untreated with interferon alfa-2a/2b and who satisfy all of the following criteria:

1. histological evidence of Metavir (or equivalent index) stage 2, 3 or 4 fibrosis or stage 1 with grade A2 or A3 inflammation, i.e. moderate to severe inflammation evident on liver biopsy (except in patients with coagulation disorders considered severe enough to prevent liver biopsy);
2. abnormal serum ALT levels in conjunction with documented chronic hepatitis C infection (repeatedly anti-HCV positive and/or HCV RNA positive);
3. female patients of child-bearing age are not pregnant, not breastfeeding, and both patient and their partner are using effective forms of contraception (one for each partner).

4. male patients and their partners are using effective forms of contraception (one for each partner). Female partners of male patients are not pregnant.

The treatment course is limited to 24 weeks, except for patients with genotype 1 hepatitis C and patients with hepatic cirrhosis or bridging fibrosis regardless of genotype, for whom the treatment course is limited to 48 weeks.

Patients eligible for 48 weeks' treatment may only continue therapy if plasma HCV RNA is not detectable by an HCV RNA qualitative assay after the first 24 weeks of therapy.

NOTE:
Hospitals should adhere to the National Health and Medical Research Council's Taskforce report on hepatitis C regarding the facility requirements for the selection of treatment centres.

COMMONLY ASKED QUESTIONS

ANTIVIRAL THERAPY SOUNDS TO BE A VERY DIFFICULT EXPERIENCE. WHY WOULD I CONSIDER IT?

You may choose to consider treatment to improve your health and sense of well-being. The aim of antiviral therapy is to stop viral multiplication in the short term, achieve viral clearance and thus limit damage to the liver in the long term. Both conventional and complementary therapies also aim to reduce other consequences of chronic hepatitis C that can reduce quality of life, such as fatigue and nausea.

IF I EXPERIENCE SIDE EFFECTS WHILE UNDERGOING COMBINATION THERAPY, WILL MY TREATMENT BE STOPPED?

Some people experience severe side effects while on treatment. It is a personal decision whether to continue with therapy. Certainly, some people decide that the side effects are too difficult to manage and they discontinue therapy. It is important that you discuss these and all other treatment-related decisions with your liver specialist and if you wish to, with a counsellor.

HOW IS THE TOTAL TIME OF THERAPY DETERMINED?

Therapy involves either a 6 or 12-month course of interferon and ribavirin, and length of treatment is determined by genotype. Each person should discuss all treatment options with their liver specialist.

HOW DO I LEARN TO GIVE MYSELF THE INTERFERON INJECTION?

Pre-filled, dose-measured, easy-to-use syringes are available from the pharmaceutical companies who supply interferon. Experienced service providers at your treatment centre will help you to develop confidence in your ability to self-inject.

WHAT IS THE MOST UP-TO-DATE TREATMENT AVAILABLE FOR HEPATITIS C, FOR PEOPLE WHO ARE CO-INFECTED WITH HIV?

Having HIV does not exclude you from treatment for hepatitis C. Consult with an infectious diseases specialist and a liver specialist, and refer to the protocol for combination therapy.

CAN I TAKE COMPLEMENTARY THERAPIES WHILE ON COMBINATION THERAPY?

It is important that details of all treatments are discussed with/between your liver specialist and your complementary practitioner. Some complementary therapies can be toxic to the liver and should be avoided at all times; however, some specialists support the use of particular complementary therapies during treatment to help alleviate side effects.

WHAT CAN COMPLEMENTARY THERAPIES OFFER ME?

There is no objective evidence that complementary therapies can eliminate the hepatitis C virus, but complementary therapies are widely used in the treatment of hepatitis C symptoms and many people report improved health from using these therapies. Consult a complementary therapist with experience and an interest in hepatitis C for more information. The Hepatitis C Council in your State or Territory will have a list of complementary practitioners.

I LIVE IN THE COUNTRY. MY NEAREST LIVER CLINIC IS IN THE CITY. IF I START TREATMENT, HOW OFTEN WOULD I NEED TO VISIT THE LIVER CLINIC?

The need to travel to specialist clinics will vary and depends on the relationship your GP has with the specialist. It is important to find a GP who will develop a shared care arrangement with the specialist clinic. Shared care is a system that operates between GPs/physicians in rural or remote areas and liver specialists in major regional centres. In some States and Territories, shared care is also practised in metropolitan and outer suburban areas. The aim of shared care is to provide optimum input for people who live in rural or remote areas by reducing their travel time and expenses, whilst still having access to medical interventions.

WHAT HAPPENS IF I CHOOSE NOT TO HAVE TREATMENT?

You can still be treated later if your decision or circumstances change. The effects of the virus on the liver may advance without treatment, but these changes occur very slowly over several years. Some people never require treatment.

COMPLEMENTARY MEDICINE UPDATE

July 2002

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Approximately half of the Australian population uses some form of non-medically prescribed **complementary therapy** each year. In addition, one in five Australians visits at least one complementary health practitioner annually.

Complementary medicine encompasses a wide range of therapies, each of which appears to play a significant role in health maintenance for an increasing number of people with hepatitis C. Complementary therapies aim to support people with hepatitis C by:

- enhancing or maintaining quality of life;
- reducing the effect of hepatitis C on the liver;
- helping to manage side effects of treatment;
- assisting with management of the symptoms of associated hepatitis C conditions. These include:
    - tiredness and lethargy
    - abdominal discomfort
    - nausea and vomiting
    - loss of appetite
    - pain in the joints (arthritis)
    - skin problems

HEALTH WORKERS AND COMPLEMENTARY MEDICINE

It is important that health workers provide honest, open, accepting environments in which people with hepatitis feel comfortable talking about the health choices they are making.

This also provides the health worker with a more accurate picture of the person's total health care, and enables the monitoring of all of the person's treatments.

Negative statements about complementary medicine or its place in health care may lead to people with hepatitis C hesitating to discuss their use of complementary therapies. Studies in Australia, USA and Europe indicate that only 35-40% of people using complementary medicine tell their doctor. There are many reasons why an individual may not want to reveal an alternative health choice. Fear of being judged is a major one.

Some approaches to inviting a discussion about complementary medicine:

- "Some people use complementary therapies to help with their hepatitis C. Are you using any of these to help you?"
- "I am interested in your overall health. It is important that we work together to monitor your progress. Is there another health practitioner you would like me to confer with?"
- "Are you using any other treatments or therapies?"
- "Are you interested in exploring how complementary medicine might support you?"

ASSESSING EFFECTIVENESS OF COMPLEMENTARY MEDICINE

There is strong historical and anecdotal evidence, plus growing expert opinion, that a range of complementary therapies can help people in managing their health problems. However, proving that therapies 'work' using commonly accepted Western research methods is difficult, for a number of reasons. Many complementary therapies tend to operate from a different ideological framework to western medicine. In some cases it is not possible to explain their effectiveness in terms of the biological mechanisms that underpin our understanding of western medicine (Arachne 2001).

In western medicine clinical research studies are used to demonstrate that drugs are effective and do not pose significant health risks. This research often uses standard trial dosing, placebos (preparations which contain no active drug component) and complex methodology to compare the results from people who do, and do not, receive the drug being studied. In order to try and get validly comparable results, these trials carefully control the type and dosage of the tested drug, and the criteria for accepting people into research trials.

In contrast, complementary therapies often use different doses and treatment approaches designed for the particular individual and their particular symptoms. This can make comparisons between people and their responses to treatment difficult.

SUMMARY OF LATEST RESEARCH

Continuing research into herbal medicine is providing an increasingly strong body of knowledge about application of particular herbals in the management of hepatitis C. Below is a brief synopsis of these research outcomes.

CH-100

An Australian study demonstrated that the use of the Chinese herbal medicine preparation CH-100 resulted in lowered ALT levels during the time it was being taken. In all but one person the ALT level rose when the treatment stopped. The researchers are now conducting a larger study to see if these results are repeated (Batey et al 1998).

Abnobaviscum Quercu

A German study has looked at the use of *Abnobaviscum Quercus*, a mistletoe preparation. While use of this preparation did not have any effect on ALT levels or on viral load, the frequency and intensity of clinical signs and symptoms decreased significantly. There was also a reported improvement in **quality of life** (Huber et al 2001).

Ginseng

A group of Japanese researchers are conducting a double blind, multicentre, randomised controlled trial on the effectiveness of Ginseng to see whether it inhibits the development of liver cancer. This planned five year study has only just commenced the recruitment phase of the research (The Ginseng-HCC Chemopreventative Study, Osaka Group 2001).

Silymarin

Listed as an hepatic herb, several studies have indicated that silymarin has hepato-protective qualities. Some studies clearly indicate its role in maintaining lowered ALT levels and other studies are looking at other properties of the herb.

Milk Thistle (St Mary's Thistle)

Researchers at Melbourne's Alfred Hospital and RMIT Psychology and Disability Studies Unit are currently conducting a trial into the effectiveness of Milk Thistle *(Silybum marianum)*.

The main active ingredients in this plant are silymarin and silibidinin. Milk Thistle is being used by many people because of its potential to minimise liver damage caused by the hepatitis C virus. Studies investigating the functions of silymarin and silibidinin indicate that Milk Thistle appears to:

- increase hepatocyte protein synthesis;
- have an antioxidant effect. This means it inhibits lipid peroxidation and destroys free radicals in the body, thus protecting cells from further harm;
- blocks various toxins from entering and injuring liver cells; and
- prevents inflammation (swelling) of the liver (NCCAM 2000).

WHERE TO FROM HERE?

People considering the use of complementary medicine in treating hepatitis C should:

- choose a health practitioner who has expertise in this area;

- encourage their health practitioners to communicate with and advise each other; and
- continue to monitor their hepatitis C viral load, liver function and general health.

It is important that all health care workers are aware of the potential support role of complementary medicine. As more evidence emerges about the effects of complementary medicine on hepatitis C and its associated conditions a wider range of treatment options will become available.

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TREATMENT OF ACUTE INFECTION WITH HEPATITIS C

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The aim of treating acute hepatitis C infection with antiviral drugs is to reduce the possibility that the infection will progress to chronic hepatitis C.

ACUTE HEPATITIS

The first stage of hepatitis C infection, which can last for up to 6 months, is called acute hepatitis. This does not refer to the severity of the disease or whether it might become chronic.

Only about one quarter to one third of people with acute hepatitis C develop symptoms. Only about 6% of people with acute hepatitis C develop jaundice, the symptom most commonly associated with hepatitis. Usually, acute hepatitis C infection will be evidenced through abnormal results of liver function tests. Although hepatitis C RNA can be detected in the blood 1-3 weeks after exposure, the time to the onset of illness is 2-16 weeks, with an average of 6-7 weeks. The time to the onset of illness is determined largely by the amount of virus received at the time of infection. People who are exposed to hepatitis C through a blood transfusion are likely to develop symptoms sooner than others, presumably due to the higher concentration of virus.

SYMPTOMS IN ACUTE INFECTION

Symptoms of acute hepatitis C are usually mild and variable, and can include:

- malaise;
- nausea;
- loss of appetite;
- weakness;
- abdominal discomfort, particularly around the liver;
- pale stools; and
- dark urine and jaundice are unusual.

During acute infection people are advised to have adequate rest, a healthy diet and to avoid or minimise alcohol. Some people feel more comfortable with a reduced fat intake.

VIRAL CLEARANCE AND PROGRESSION FROM ACUTE TO CHRONIC HEPATITIS C

It is currently estimated that 25-30% of people infected with hepatitis C will clear the virus from their body within 2-6 months of infection, without treatment.

While there is no way of predicting viral clearance on an individual basis, it appears more likely that people who are experiencing clinical symptoms of acute hepatitis C, including jaundice, are more likely to clear the virus (Poynard et al 2001). This is possibly due to the body's more vigorous immune response to the virus. It appears that women, babies and perhaps young adults are also more likely to clear the virus than are men (Farrell 2002).

The development of more sophisticated diagnostic tests may prove useful in distinguishing between acute and chronic hepatitis C, and in predicting viral clearance in response to interferon treatment (Buamert et al 2000).

For people who have cleared the virus, antibodies to the virus remain and act as indicators of past exposure to the virus. However PCR tests should return negative results. If an acute hepatitis infection becomes chronic (ie. lasting indefinitely), antibodies will remain detectable in a person's blood and their PCR tests will remain positive.

TREATMENT OF ACUTE HEPATITIS C – DILEMMAS

The treatment of acute hepatitis C is a relatively new area. While research from recent studies looks promising, particularly early treatment with interferon (Jaeckel et al, 2001), there are problems relating to the accurate and timely diagnosis of acute hepatitis C.

On the evidence so far a number of issues and dilemmas remain. These include difficulties in interpreting and comparing research results. There are only a small number of research studies in this treatment area, and it is difficult to compare results because of variables, including differences in:

- the type of diagnostic tools used, and lack of a consistent definition of acute hepatitis C;
- type of Interferon used. Some studies have used Interferon alpha 2a while others have used Interferon alpha 2b;
- the way the virus was acquired, i.e. blood transfusion, community, medical;
- dosage and length of time interferon is used as a treatment;
- timing of treatment commencement following infection;
- race; and
- hepatitis C genotype.

Randomised controlled trials in this area are increasingly difficult to conduct because of dilemmas associated with enrolling people into research studies. These include:

- ethical issues. It is difficult to justify withholding a treatment which may be effective, in order to conduct research; and

- the small number of people diagnosed with acute hepatitis C. In many individuals acute hepatitis C is asymptomatic, which makes it very difficult to conduct studies where the results are statistically significant (Hoofnagle 2001;Thevenot et al 2000).

WHEN TO INITIATE TREATMENT?

Another question concerns when to begin treatment. Given that 25-30% of people will spontaneously clear the virus, should treatment of acute hepatitis C be delayed 2-3 months after diagnosis or started immediately?

Starting immediately seems sensible, before the virus is established. On the other hand some recent research, which demonstrated favourable outcomes using Interferon alfa-2b (Jaeckel et al, 2001), had a mean treatment commencement time of 89 days post-infection, during which time the virus had presumably been multiplying. While these results look very positive, some questions remain. All participants had elevated ALT levels and over 2/3 had jaundice, and the researchers question whether their findings are transferable to people who have lesser degrees of liver injury, including those with normal serum ALT levels, or jaundice.

Overall, it is not known at this stage whether the best option is immediate treatment or treatment at 80-90 days post infection.

ASSESSING EFFICACY OF TREATMENT

Questions remain regarding the efficacy of both standard and pegylated interferon combined with ribavirin in the treatment of acute hepatitis C, as well as in chronic infection (Thevenot et al 2000).

One of the problems is that the research studies in this area have used different outcomes as indications of success. The current consensus on the definition of ‘treatment success’ is that the individual be hepatitis C PCR-free at 6 months after the end of the treatment regime.

In addition, Farrell (2002) suggests

> *"People who appear to have recovered completely from hepatitis C should be reviewed, with liver tests, on an annual basis by their general practitioner for up to five years. PCR should be repeated at the end of this time, or whenever liver tests show any abnormality".*

ADVERSE AFFECTS OF TREATMENT

Assessing the incidence of adverse events that are attributable to dose and duration of interferon treatment is difficult, due to variations between studies. However, it is known that interferon has many side effects and is not easily tolerated, especially in people who are ill with acute hepatitis (Hoofnagle 2001).

SUMMARY

Treating all acute hepatitis C infection means giving an expensive, difficult to tolerate therapy to many people who would possibly recover spontaneously (Hoofnagle 2001). The challenge remains, to identify the people with acute hepatitis C who will benefit from treatment and to determine what is 'optimal' therapy.

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TREATMENT FOR CHRONIC HEPATITIS C

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Until recently the treatment for chronic hepatitis C has been standard **interferon** alone or standard interferon combined with **ribavirin**. People treated have responded differently to these treatment regimes. A number of factors influence response rates.

People more likely to respond are those who:

- have genotype 2 or 3 of the virus;
- have lower levels of virus in their blood (**viral load**) before they start treatment;
- are 40 years old or younger;
- became infected with hepatitis C at a younger age;
- are female; and
- have less liver scarring (fibrosis) on liver biopsy.

WHAT IS INTERFERON?

Interferons are small proteins made by the body to help fight infections such as those caused by viruses. The body produces different types of interferon in response to different infections.

STANDARD INTERFERON

The standard interferon used to treat hepatitis C is a synthetic copy of the interferons naturally produced by the body in response to infection. It is given as an injection under the skin up to three times a week.

PEGYLATED INTERFERON

Pegylated interferon is an altered form of interferon recently developed and now available for use in certain circumstances, primarily when a person cannot tolerate the ribavirin component of combination therapy. A chemical called polyethylene glycol (PEG) is attached to interferon, which prolongs the effect of the drug in the body. There are two reasons for this:

- PEG protects the interferon molecule from the normal de-activation processes of the body; and
- the size of PEG-interferon is larger than standard interferon, which means it stays longer in the circulation.

There are two types of pegylated interferon, made by different drug companies:

- PegIntron alpha 2b is made by Schering-Plough;
- PEG Interferon alpha 2a is made by Roche.

Both of these pegylated interferons are given once a week, as a subcutaneous (under the skin) injection.

HOW DO WE TELL IF TREATMENT IS EFFECTIVE?

Currently successful treatment for hepatitis C is considered to be treatment that results in a **sustained viral response** (SVR). A sustained viral response is when there is no detectable hepatitis RNA in a person's blood 6 months after stopping treatment. Medical researchers are cautious about calling this a "cure". However, recent research in which people have been followed for 4 years after successful treatment suggests that a relapse is unlikely once viral clearance has been maintained for six months (Bernstein 2001).

NON-RESPONSE OR RELAPSE FOLLOWING TREATMENT

- ‘Relapsers’ are described as people who have a good response to treatment during therapy, but within six months of stopping treatment the virus can be detected again in their blood;
- ‘Non-responders’ are those who do not response to treatment, in that the virus is still detectable in the blood and the liver function tests (particularly for ALT) are abnormal. Combination therapy with pegylated interferon and ribavirin may result in a higher response rate for these people.

WHAT DOES THE LATEST RESEARCH SHOW?

PEGYLATED INTERFERON THERAPY

The effectiveness of both types of pegylated interferon as a monotherapy has been studied, and the results are similar. Treatment for 48 weeks resulted in a doubling of sustained response rates compared with standard interferon. However, relapse rates were the same as with regular interferon. People with genotype 1 did not respond any better to therapy with pegylated interferon. It seems that pegylated interferon alone will not replace the use of interferon ribavirin combination therapy (Mc Hutchison 2001).

COMBINATION PEGYLATED INTERFERON AND RIBAVIRIN

When pegylated interferon and ribavirin are combined the results are more positive, especially for people with genotype 1.

This table demonstrates the improved rates of sustained viral response for people using pegylated interferon and ribavirin compared with those using standard interferon and ribavirin. The way each study has been conducted varies because different research criteria are used.

	Poynard et al (1998)			**Hadziyannis et al (2002)**		**Manns et al 2001**
	Standard Interferon + ribavirin 48 weeks	Standard Interferon + ribavirin 24 weeks	Standard Interferon + placebo 48 weeks	Peg Interferon + ribavirin 24 weeks	Peg Interferon + ribavirin 48 weeks	Peg Interferon + ribavirin 48 weeks
Sustained Response: All genotypes	43%	35%	19%		61%	64%
By genotype 1	31%	18%	11%	41%	51%	54%
2 & 3	64%	64%	33%	78%	73%	89%

These clinical trial results have changed the way pegylated interferon and ribavirin combination therapy is prescribed for people with chronic hepatitis C. Treatment is now more likely to be 'tailored' to the individual, according to genotype, viral load, and body weight.

PEGYLATED COMBINATION THERAPY FOR PEOPLE WITH GENOTYPE 1

Pegylated interferon alpha 2a (Roche) is given as a dose of 180 micrograms (mcg) for 48 weeks. The PegIntron (Schering-Plough) dose is 1.5mcg per kilogram of body weight. The dose of Ribavirin is adjusted according to a person's weight - for people who weigh more than 75 kilograms the dose is 1200 mcg, and for those who weigh less than 75 kilograms it is 1000 mcg.

PEGYLATED COMBINATION THERAPY FOR PEOPLE WITH GENOTYPES 2 AND 3

Pegylated interferon is given as a dose of 180 micrograms (mcg) for 24 weeks (Roche dosage). The dose for Schering-Plough pegylated interferon is 1.5 mcg per kilogram of body weight. The dose of Ribaviron is 800 mcg, regardless of a person's weight (Hadziyannis et al 2002).

Because these are relatively new treatments, and different people respond differently to the same treatment regime, discussion about how to fine-tune this therapy continues. There may be different treatment regimes in different hepatitis C clinics in Australia.

RESULTS FOR PEOPLE WITH LIVER SCARRING

Combination therapy appears to offer encouraging results for people with scarring of the liver. One study which reported on the effects of using pegylated interferon and ribavirin showed a 73% decrease in liver necrosis and inflammation, in comparison to a decrease of 39% for people receiving standard interferon and ribavirin. The researchers suggest the need for further studies to confirm these findings (Berstein 2001). For people with cirrhosis of the liver, treatment with pegylated interferon and ribavirin resulted in an overall sustained virological response of 50% (Hadziyannis et al 2002).

ADVANTAGES OF PEGYLATED INTERFERON

People who take pegylated interferon seem to have reduced side effects compared with those who take standard interferon. This might be because the pegylated interferon provides a more constant dose level in the body, rather than the peaks and troughs of daily injections. The side effects associated with ribavirin remain the same regardless of the type of interferon used.

HOW CAN PEOPLE ACCESS PEGYLATED INTERFERON?

Pegylated interferon is available for use in Australia for treatment of hepatitis C where people may not be able to tolerate ribavirin. Since 1 August 2002, it has been available through the government subsidised PBS S100 scheme.

Pegylated combination therapy is available for use in Australia for treatment of hepatitis C. Applications have been made to have the treatment listed on the government subsidised PBS S100 scheme, although to date these have been unsuccessful.

There may be other ways that people can access this treatment, including trials or industry-sponsored special access programs. A specialist liver clinic will be able to tell people whether they may be eligible and whether they can have access to the medications.

THE FUTURE

Clarifying effective treatment regimes for hepatitis C remains a high priority on the research agenda. While much of the research is focused on combination therapies using interferon and ribavirin, some people are unable to tolerate these medications.

Other drugs and treatment regimes that may be more effective and have fewer side effects are being assessed. This research is at varying stages of development.

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CHAPTER 7

PREVENTING DISCRIMINATION AND REDUCING STIGMA AND ISOLATION

Contributors: Campbell Aitken, Julia Cabassi, Cheryl Delalande, Equal Opportunity Commission Victoria, Paul Harvey, Peter Higgs, Judith Jones, Helen Orcher, Jacqui Richmond, Deb Sansom, Jan Savage, Jeff Ward.

- Generally, discrimination in public life on the basis of infection with hepatitis C, actual or presumed, direct or indirect, is unlawful.
- Legislation, policies and guidelines developed at the National, State and Territory levels, aim to protect against discrimination and stigmatisation of people with hepatitis C, and to provide redress for people who have been discriminated against.
- Hepatitis C-related discrimination can arise from fear of transmission and/or from assumptions and judgements made about injecting drug use and people who inject drugs.

SUMMARY OF IMPORTANT POINTS

- Health care workers have an active and important role to play in reducing and responding to discrimination and isolation.

DISCRIMINATION AND HEPATITIS C

Discrimination on the basis of hepatitis C occurs when:

- a person who has, or is thought to have hepatitis C is treated less favourably than a person who does not have hepatitis C in the same or similar circumstances; or
- a requirement, condition or practice that appears to be neutral, in fact has a disproportionate impact on a person who has, or is thought to have hepatitis C, or is one with which they cannot comply, and is not reasonable in the circumstances.

Discrimination does not have to be intentional or obvious, and often results from unconsciously held beliefs and attitudes.

EXAMPLES OF DISCRIMINATION

Discrimination can be subtle or overt, direct or indirect, and can occur in all areas of life.

A factory employer refuses to employ a man as a mechanical assembly line operator because he has hepatitis C.

When a basketball player's past injecting drug use became known she was dropped from the team, her coach believing that she would infect others with hepatitis C or HIV.

A woman arrives at a hospital for a day procedure. Initially, she is advised that she will be going to the operating theatre within an hour and is asked to fill in some forms. She discloses her hepatitis C status. The nurse considers this information and advises her that she will have to be the last patient for the day.

All people have a right to not be discriminated against in public life.

In order to provide better access to health services for people with hepatitis C, it is particularly important that the discrimination common in health care settings is acknowledged and actively challenged.

THE EXTENT OF DISCRIMINATION AGAINST PEOPLE WITH HEPATITIS C

Discrimination relating to HIV/AIDS is better documented and researched than discrimination in relation to hepatitis C, although there are studies that highlight the existence of such discrimination. There is a growing body of information from a variety of sources that provides clear indication of the nature and extent of discrimination against people with hepatitis C.

In 1996 a national needs assessment of people with hepatitis C, *Meeting the Needs of People in Australia Living with Hepatitis C*, found that the majority of participants had experienced overt and serious hepatitis C-related discrimination from employers and health care providers. In addition, participants related experiences of discrimination from partners, family, friends and social contacts.

People with hepatitis C who participated in the report believed that the discrimination resulted from irrational fears about transmission or prejudice against current or past injecting drug use.

The report made recommendations to specifically address discrimination experienced by people with hepatitis C or people at risk of contracting hepatitis C. These included:

- improved access to legal services to enable people to respond to discrimination;
- funding for community-based organisations to provide education and advocacy programs – these will enable people with hepatitis C and those at risk of contracting the virus better access to existing complaint mechanisms; and
- funded education programs targeting doctors and health care workers to reduce the incidence of discrimination in the health care setting.

Another study that surveyed a group of people with hepatitis C found that 46% of discriminatory incidents reported by participants occurred in health care settings, and 20% of discriminatory incidents happened at work.

The NSW Legislative Council's Standing Committee on Social Issues undertook a comprehensive inquiry into hepatitis C in NSW in 1998. In its submission to the Committee, the Hepatitis C Council of NSW raised the issue of discrimination experienced by people with hepatitis C in health care settings, and drew the Committee's attention to the implications of such discrimination on people's willingness and ability to access information and health care services. The Committee's report, *Hepatitis C: The Neglected Epidemic, Inquiry into Hepatitis C in New South Wales*, recommended that the NSW Anti-Discrimination Board conduct an inquiry into discrimination and hepatitis C in NSW.

This inquiry is currently underway and will report toward the end of 2001. The terms of reference are to investigate the extent and nature of discrimination against people who have, or are thought to have, hepatitis C in NSW and to make recommendations for challenging and eliminating such discrimination and its adverse effects.

Hepatitis C: Informing Australia's National Response 2000 is a collection of commissioned papers written in support of the development of the *National Hepatitis C Strategy 1999–2000 to 2003–2004*. These submissions involved extensive public consultation on the significant impacts of hepatitis C, including discrimination.

LEGISLATION RELATING TO HEPATITIS C DISCRIMINATION

FEDERAL LAWS:

Disability Discrimination Act 1992

Administered by the Human Rights and Equal Opportunity Commission. The Act prohibits discrimination on the basis of disability.

In relation to hepatitis C, disability or impairment is broadly defined as:

- the presence in the body of organisms causing disease and illness; or
- disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
- a disorder, illness or disease that affects a person's thought processes, perceptions of reality, emotions or judgement or that results in disturbed behaviour.

Under the Disability Discrimination Act, it is unlawful to discriminate on the basis of disability or impairment in many areas of public life including:

- employment and work;
- education;
- access to premises;
- use of goods, services and facilities;
- accommodation;
- clubs and incorporated associations; and
- sport.

Reasonable Adjustments

Under the Disability Discrimination Act, unless an employer will suffer unjustifiable hardship, they are obliged to make reasonable adjustments for people with disabilities.

The Act prohibits both direct and indirect discrimination.

STATE AND TERRITORY ANTI-DISCRIMINATION LAWS

All States and Territories have laws prohibiting discrimination on the grounds of impairment or disability (including actual or presumed hepatitis C status) in areas such as:

- employment;

- education;
- accommodation;
- the provision of goods and services;
- clubs and club members;
- sport; and
- local government.

All State and Territory discrimination laws cover discrimination on the grounds of hepatitis C status, with the exception of South Australia. The meaning of 'public life' covered under anti-discrimination law also varies across the country. There is some doubt about whether the South Australian anti-discrimination law covers asymptomatic infection, and to date this has not been the subject of any judicial determinations. In terms of disability vilification, the NSW Act covers only HIV/AIDS and does not specifically cover hepatitis C. This contrasts with Tasmanian anti-discrimination law, which covers all disability.

See Contacts, p236, for more details on individual State and Territory services.

PRE-EMPLOYMENT MEDICALS

Although the use of pre-employment medicals are relatively common in recruitment procedures, they should **only** be used to assess a person's capacity to carry out the inherent or essential requirements of a job. They should **only** be used once the employer has identified the preferred candidate. Where the preferred candidate has a disability, such as hepatitis C, the employer is required to accommodate their needs so that they can carry out the inherent requirements of the job. The only exception to this is if an employer can demonstrate that making such adjustments would cause them unjustifiable hardship.

Example:

Paul applies for a job as a porter with a large hotel chain. He is selected as the preferred candidate and then asked to attend a pre-employment medical. Paul has hepatitis C and is currently on combination therapy. Paul's hepatitis C status does not affect his capacity to perform the essential requirements of the job. He requires some flexibility in shift allocations to ensure that he can attend relevant medical appointments. Given the rotating shift arrangements within the hotel, the employer can and should provide this degree of flexibility.

SUPERANNUATION AND INSURANCE

Fundamental to the process of insuring a person against future illness, injury or death is the need to assess the particular risk factors for injury, illness or early death. Insurance companies compare people in relation to such risks and this may lead to differential treatment.

It is not unlawful to discriminate in the provision of superannuation and insurance if:

- the discrimination is based on relevant statistical and actuarial data; or
- where there is no relevant data, or this is difficult to access, the discrimination is reasonable, based on other relevant factors.

Depending on the context and circumstances, refusal of insurance on the basis of infection with hepatitis C may be discriminatory. Health care workers should advise people to seek further advice from their State or Territory Hepatitis C Council or to seek legal advice.

Example:

Indigo has hepatitis C antibodies but she has cleared the virus from her system. She applies for life insurance. The insurance policy has a blanket exclusion clause for people who have hepatitis C and her application is refused. It is arguable that a blanket exclusion clause for all people with hepatitis C is not justified by current evidence about the natural history of hepatitis C, and therefore there may not be any actuarial data on which it is reasonable to rely.

Currently, State, Territory and Federal anti-discrimination laws do not explicitly prohibit discrimination on the grounds of injecting drug use. However, it is arguable that discrimination on the basis of actual drug dependency, past drug dependency and assumed drug dependency may amount to disability discrimination. Accordingly, such discrimination may form the subject of a complaint of disability discrimination under State, Territory and Federal anti-discrimination laws. This issue is yet to be judicially determined.

DEALING WITH DISCRIMINATION

People affected by hepatitis C and health care workers who need advice and support in challenging experiences of unlawful discrimination should contact the Anti-Discrimination Board or Equal Opportunity Commission in their State or Territory. *See Contacts, p236.*

WORKING WITH PEOPLE WHO HAVE HEPATITIS C

Two primary responsibilities of all health care workers are the provision of high quality and informed non-judgemental care, and self-protection. While health care workers have differing occupational capacities, access to different resources and different client groups, these principles should govern all health care practice.

STANDARD INFECTION CONTROL PROCEDURES

Standard infection control procedures (*see Chapter 3 for details*) should **always** be implemented. Judgements based on factors such as an individual's appearance, demeanour, personality, age or socio-economic status are unacceptable and may constitute discrimination.

COMPREHENSIVE IMPLEMENTATION OF STANDARD INFECTION CONTROL PROCEDURES GUARDS AGAINST POSSIBLE INFECTION AND PROTECTS PEOPLE WITH HEPATITIS C FROM BEING SUBJECTED TO DISCRIMINATION IN THE HEALTH CARE SETTING.

It is imperative that health care workers adopt a pro-active approach to standard infection control procedures. This involves assessing the potential for blood-spills/splashes prior to beginning any procedure, and responding appropriately, sensibly and sensitively to the risk of accidental exposure to infectious organisms.

Examples:

A nurse preparing to remove a drain tube must acknowledge the risk of an eye splash injury and put on a pair of protective glasses or a visor before beginning the procedure.

A worker in an NSP must assess the likelihood of accidental skin penetration before handling any item of used injecting equipment and decide on the appropriate way to handle the item.

STANDARD INFECTION CONTROL PROCEDURES SHOULD BE IMPLEMENTED AND PRACTISED WITHOUT JUDGING OR SPECULATING ABOUT AN INDIVIDUAL'S INFECTIOUSNESS.

ALL BLOOD SHOULD BE TREATED AS INFECTIOUS AT ALL TIMES

See Chapter 3: section on Standard Infection Control Procedures, p62, for more information.

DISCRIMINATION IN THE HEALTH CARE SETTING

In the health care setting, discrimination against people with hepatitis C can be subtle or overt. Best practice guidelines should determine the work practices and professional interactions of health care workers, and each individual worker should think about the circumstances in which discrimination might occur. As examples, hanging signs indicating infection status, or talking in public areas about infection or disease status is unacceptable.

Common examples of discrimination by health care and allied workers:

- *overt or open accusations of 'malingering' or hypochondria to explain symptoms of fatigue;*
- *negative reactions to disclosure of current or past drug use – including an assumption of ongoing illegal behaviour;*
- *refusing to provide service on the basis of a person's hepatitis C status or drug use;*
- *marking or 'branding' of people with hepatitis C in health settings (e.g. with coloured armbands or other tags);*
- *advice to terminate a pregnancy, or to discontinue breastfeeding even if no blood is present; and*
- *funeral workers refusing relatives permission to view the body of a deceased person who had hepatitis C.*

Good clinical and health care practice means having a sound knowledge of hepatitis C and applying this to any discussion about a person's current health status and their behaviours. It is important that service providers accept and monitor their own biases and personal attitudes, so that their behaviour does not have a negative impact on the person with whom they are working. This also allows the health care worker to concentrate on the person's clinical needs, assess and respond to them effectively, and provide appropriate education.

DISCUSSING RISK BEHAVIOURS

Discussing both current and past behaviour requires a great deal of sensitivity. A greater understanding of hepatitis C-related issues enables health care workers to answer questions and provide education on:

- transmission risks;
- social, physical and psychological effects of licit and illicit drug use;
- the effectiveness of and access to treatments; and
- the broad range of issues that affect people with hepatitis C and those around them.

Both the health care worker and the individual may be uncomfortable with questions about alcohol and other drug use, and about behaviours associated with the risk of hepatitis C transmission. People from marginalised groups, including people who inject drugs, may also fear that revealing current drug use will invite discrimination. Trust is an essential part of establishing an open and dynamic information exchange between the health care worker and the individual. Using exact, non-judgemental language (see below), combined with a sincere concern for the person's welfare, helps to build trust in the health care relationship.

Avoid the terms:

Addict, addiction, drug addict, drug abuse, drug abuser, and intravenous drug user.

Such terms may be offensive or misleading and could be considered as discriminatory.

Instead, use the terms:

- ***injecting rather than intravenous (not all drugs are injected into a vein, e.g. steroids);***
- ***drug use, not abuse;***

- *injecting equipment, not needles;*
- *re-used, (as in "have you ever re-used someone else's injecting equipment?");*
- *presence of withdrawal symptoms and/or dependence, not about addiction; and*
- *clarify meaning of any colloquial, sub-cultural terms associated with drug use using behaviour, such as fits, smack etc.*

Questions useful in evaluating health care practice

- *Does this action disclose the person's hepatitis C status without their consent?*
- *Do I need to know this to provide good care?*
- *Is this part of standard infection control procedures?*
- *Do I take this infection control procedure for everyone?*
- *Do my questions or comments imply negative opinions about the person's behaviour?*

STRATEGIES TO REDUCE DISCRIMINATION IN THE HEALTH SETTING

- Use standard infection control precautions with **all** people receiving care.
- Take care not to identify a person's hepatitis C status by speaking about it publicly, or 'branding' them, their case notes or their bed with a coloured band, tag, label or any other identification.
- Be aware of and implement your service's confidentiality policy.
- Acknowledge that pain relief for a current user of some substances, e.g. opiates, is complex. Involve the care team and the person in non-judgemental communication about current use and the level of dose required to achieve pain relief without overdosing.

- Be aware of the language used. Language carries all sorts of implicit messages.
- Work toward Harm Reduction and be careful to be non-judgemental when providing education to a person with hepatitis C.
- If you see discriminatory practice in your workplace, discuss the need for further staff education with your manager or the infection control consultant.
- Assume nothing about how a person may have acquired hepatitis C. Some people may not know themselves or they may have more than one risk circumstance; others may not identify with specific risks. All assumptions can further stigmatise people.
- Consider whether knowing how a person contracted hepatitis C is at all relevant or important.

Health care workers with hepatitis C who are involved in **exposure-prone procedures** need to check with their relevant State or Territory for policy and/or procedures for workers with hepatitis C, and ensure that standard infection control procedures are practised at **all** times.

PEOPLE AFFECTED BY HEPATITIS C

Australia is a culturally diverse nation. This is a consequence of a history of recent multi-cultural migration to a land previously inhabited by indigenous peoples. Subsequent community growth has predominantly been in coastal regions and there are vast differences between available health services in different areas of Australia. The diverse nature of the population has implications for health service planners and providers, in acknowledging and appropriately responding to the needs of particular communities living in Australia, some of whom are affected by hepatitis C.

People with hepatitis C come from a variety of backgrounds and have a very broad range of experiences and needs. Service providers should be capable of providing appropriate health education, care and support for all people affected by hepatitis C. They have a responsibility to provide optimal care for each client, be non-judgemental, and endeavour to minimise stigma and isolation. Issues associated with diversity and differing circumstances include:

- **History of injecting drug use** – people with a current, past or assumed history of injecting drug use are often subject to discrimination from service providers because of beliefs about deviant behaviour and self-inflicted harm. In addition, there are widespread community fears about needles and syringes and inappropriate disposal, apprehensions about blood, and the literal and symbolic threat of illicit drugs and drug use. Injecting drug use is also sometimes viewed as a threat to the health and wellbeing of others. The consequent stigma can affect self-esteem, personal life and relationships, including those with service providers, and often leads to social isolation and a reluctance to seek health care.
- **Medical history** – in the past in Australia, the treatment of some medical conditions has presented a transmission risk for hepatitis C. Examples are people who received blood transfusions in Australia prior to 1990 and people with haemophilia, and other bleeding disorders, whose treatment necessitated the use of blood products before screening for the virus was introduced in February 1990.
- **Hepatitis C acquired outside Australia** – many people now living in Australia became infected with hepatitis C in other countries, through mass vaccination programs or unsafe skin penetration practices with re-used equipment. For example, some people from Egypt, where hepatitis C became endemic following public health campaigns to vaccinate against **schistosomiasis**, and in which injecting equipment was re-used, may have acquired hepatitis C in this way. In Australia, most infection with hepatitis C found in older people from culturally and linguistically diverse backgrounds (**CLDB**) is not associated with injecting drug use. Groups in this situation may lack awareness of the risks of infection in their countries of origin and as a consequence, do not seek testing. They may be more likely to present with advanced liver disease when hepatitis C is identified.
- **Access to appropriate and meaningful information and services** – there is a current lack of information about hepatitis C for people with low literacy skills and for people from CLDBs. Hepatitis C screening is not generally included in immigration health checks, and publications in different languages are limited.

Some people from different cultural or language backgrounds are most comfortable with a service provider from a similar background; others who have confidentiality concerns prefer service providers to be from outside their cultural group.

- **Religious and cultural traditions** – in cultures around the world, blood is used as a symbolic agent in religious ceremonies. For example, some Aboriginal peoples in Australia have traditional practices that involve blood-letting or the exchange of blood between individuals. Members of these communities may be unaware of the infection risks associated with rites-of-passage and ceremonial practices, and also may not talk of these experiences to anyone outside the cultural group. Consistent sensitivity to the cultural circumstances of a person's history is required of health service providers working with blood-borne virus issues.
- **Cultural influences and beliefs in traditional practices** – some cultural activities, such as female circumcision, are illegal in Australia and practitioners, both in Australia and overseas, may not use adequate infection control procedures. People involved in such practices, including the subjects, risk stigma and possible punishment in disclosing this as an infection possibility.
- **Occupation and recreational procedures** – hepatitis C and other blood-borne viruses are not exclusively spread among injecting drug users through intravenous injecting practices. Health care workers may unwittingly discriminate, through ignorance, against people who inject substances intramuscularly, such as body builders. Intramuscular injecting, often practised with large needles and syringes, can involve a great deal of blood. Many steroid users do not visit NSPs, and may not have access to appropriate education or peer support. Targeted peer education and awareness programs, and appropriate methods of needle and syringe distribution and collection should be considered for this diverse group.

- **Existing stigma and isolation** – for some people, past or current experiences of social isolation and stigma may lead to increased risk of infection. Indigenous people, individuals with mental illness, some lesbians and gay men, those who have been abused, some CLDB groups (Vietnamese youth for example) and other marginalised populations may use alcohol and other drugs – sometimes in excess – as part of a response to personal and social experiences. Health care workers need to be sensitive to issues that may pre-dispose people to risk behaviours for hepatitis C, and to the vulnerability, anxiety and mistrust that can influence a person's ability to participate in decision-making around health care.
- **Geographic location** – people in remote or rural areas may experience a range of problems in accessing appropriate information and support services, including:
  - access to trained and experienced service providers;
  - access to sterile injecting equipment and information relating to injecting drug use issues;
  - access to current information about health issues for people with hepatitis C;
  - participation in regular monitoring and follow-up; and
  - trust in the confidentiality of services in small communities where everyone knows each other.

These are difficult concerns for health care workers and can challenge the provision of effective care. Health care workers in these locations can also experience inadequate professional up-dating and support which compromises their service provision. Better resourcing of agencies, adoption of partnership approaches and attention to improved effectiveness in shared care systems are urgent political, health and social issues.

- **Socio-economic disadvantage** – people who are already disadvantaged may experience further hardship in accessing health and support services. Those who are homeless, unemployed or educationally disadvantaged may have difficulties in co-operating in assessment, complying with treatment requirements and practising safer behaviours.

- **Negative experiences with the health care profession** – people who have been treated poorly in the past may be sceptical about any further management or treatment intervention by the health care sector.
- **Working with limited information** – discrimination often occurs as a result of misinformation or a lack of understanding.

With the exception of the medical specialist, most health care workers are generalists, with a broad knowledge of many health conditions. Staying up-to-date with current information and medical advances in hepatitis C can be challenging, and requires a commitment to reading, discussions with co-workers and in-service educational programs. *See Chapter 8: Education and Training.*

One of the greatest sources of information about hepatitis C can be a person with hepatitis C. People with hepatitis C often have a great deal of knowledge, and certainly have unique experiences, and hearing their experiences can offer a holistic and personalised insight into some of the real issues associated with this virus. Service providers can gain valuable information and understanding through listening to people affected by hepatitis C, and the affected person will benefit from the growing awareness and understanding of the health care worker. Similarly, it is vital that any single person with hepatitis C is not considered to be representative of all people who have the virus. The highly individual nature of this virus and its infection profile does not lend itself to generalisations about its effect on individuals.

It is important that health care workers are able to acknowledge that they don't know the answer to some questions. "I don't know the answer to your question, however I will find out for you", is a response that demonstrates respect and avoids problems that may arise from giving incorrect information or assuming knowledge. This is particularly important when decisions are to be made around treatment and in the pre- and post-test counselling sessions.

Ensuring that workers involved in the care of people with hepatitis C are aware of their role, are appropriately trained and skilled, have sufficient knowledge to act in that capacity and are able to access current information, will result in effective and collaborative management.

COMMONLY ASKED QUESTIONS

I WORK IN THE HOSPITALITY INDUSTRY, AND AFTER MY EMPLOYER FOUND OUT THAT I HAVE HEPATITIS C SHE RESTRUCTURED MY DUTIES SO THAT I HAVE MINIMAL CONTACT WITH THE PUBLIC AND WITH FOOD PREPARATION. WHAT CAN I DO?

First get advice and support from the Hepatitis C Council and/or contact the Equal Opportunity or Anti-Discrimination Board in your State or Territory. You may wish to speak directly with the person concerned and/or make a formal complaint. Whatever course of action you choose, make sure you have support, both personally and legally.

ON DISCLOSING MY HEPATITIS C STATUS TO A HEALTH SERVICE PROVIDER, HE CALLED ME A 'JUNKIE' AND HAS REFUSED TO WORK WITH ME. WHAT CAN I DO ABOUT THIS?

You are entitled to make a complaint about the way you have been treated, first to the original service provider, and then, if you choose, to the appropriate authority. You can also change your service provider. Your State or Territory Hepatitis C Council or peer-based user organisation can give you information about options and support in taking any of the above steps.

I HAVE BEEN DISCRIMINATED AGAINST IN A HEALTH CARE SETTING. WHERE SHOULD I TURN?

Firstly, try and talk with a manager or supervisor in the particular health care setting, describing the discrimination and its effect on you. Make it clear that you find this behaviour/procedure/policy unacceptable. If you feel dissatisfied with the outcome of such a meeting, you can make a further complaint through the Equal Opportunity or Anti-Discrimination Board in your State or Territory.

I'M A HEALTH CARE WORKER AND I'VE NEVER HAD TO WORK WITH PEOPLE WHO INJECT DRUGS BEFORE NOW. I FEEL NERVOUS AND DON'T WANT TO SAY THE WRONG THING. WHAT CAN I DO?

Time spent with more experienced co-workers, or your supervisor, will be useful. You need to reflect on the real fears that underlie your nervousness, talk about these together and practice how you would answer particular questions and handle specific situations. It may be possible for a co-worker to share the first few sessions with your clients who inject drugs.

C CHANGE – THE HEPATITIS C DISCRIMINATION INQUIRY

July 2002

Contributor:
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C Change, the report of the Anti-Discrimination Board of NSW on hepatitis C related discrimination in NSW, was released in November 2001, after a 10 month enquiry. Organisations and individuals made written or oral submissions about hepatitis C related discrimination issues and experiences.

> *"The evidence to this Enquiry clearly demonstrates that hepatitis C is a highly stigmatised condition and that discrimination against people with hepatitis C is rife. Such discrimination is often driven by irrational fears about hepatitis C infection, due to an inadequate understanding of how hepatitis C is transmitted. However, a perhaps more powerful driving force for discrimination than ignorance about hepatitis C transmission, is that infection is inextricably linked with illicit drug use, a highly stigmatised behaviour. Evidence to this Enquiry makes it abundantly clear that discrimination against people with hepatitis C is often motivated by stereotyped responses towards people with hepatitis C on the basis of past, current or assumed injecting drug use."*
>
> Executive Summary, C Change. Anti Discrimination Board of NSW, 2001. P.12.

C Change documents and analyses people's experiences of discrimination, examines the application of anti-discrimination and privacy laws to the issues raised during the enquiry, draws conclusions about the extent and nature of discrimination and makes a wide range of recommendations which aim to prevent and eliminate hepatitis C related discrimination.

The report examines discrimination in a wide variety of contexts and from the perspective of particular communities including:

- Health care settings
- Employment
- Custodial settings
- Insurance
- Funeral Services
- Autopsies
- Educational settings
- Accommodation
- General Community – family, friends, communities, media
- Stigmatisation of injecting drug use
- Aboriginal and Torres Strait Islander people
- Culturally and linguistically diverse communities
- Anti-discrimination and other complaint mechanisms.

The full report is available on **www.lawlink.nsw.au/adb**

For copies of *C Change* contact:

Anti-Discrimination Board of NSW
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CHAPTER 8

EDUCATION AND TRAINING

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- Hepatitis C education is diverse and takes place in many different environments.
- There are numerous strategies and tools available to the hepatitis C educator.
- Education in schools, Needle and Syringe Programs, pharmacies, custodial and police settings have been identified as key targets for hepatitis C prevention education and training.

SUMMARY OF IMPORTANT POINTS

- While the agencies above have been selected for specific discussion in this chapter, the educational principles and strategies outlined can be employed in a wide range of settings where professional and occupational education takes place. These might include alcohol and other drug agencies, hospitals, community health centres, universities, and peak and professional bodies.

PROFESSIONAL DEVELOPMENT FOR HEALTH AND COMMUNITY WORKERS

In today's evolving workforces, learning and working are inextricably linked. Learning strategies which integrate individual learning needs, work-based activities, organisational structures and professional partnerships can produce more dynamic and sustainable learning outcomes. This comprehensive and responsive approach to learning has the capacity to build a skilled, knowledgeable and adaptable workforce.

There is a broad range of activities and structures that support learning, program development and workplace systems. Many of these can easily be taken for granted or not appreciated as significant occasions where valuable learning can occur. For example, routine team meetings, unit changeovers or scheduled de-briefing sessions are common in health workplaces. These can be opportunities for information exchange and discussion about people's needs, workers' existing skills and knowledge, case management and referral options, brief intervention strategies, internal operating systems, critical incidents and new resources. Site visits to referring agencies can also be organised as a strategy to improve workers' knowledge of other local services and programs, and as a means of developing and improving partnerships with others.

The first *National Hepatitis C Strategy* is based on six components that are considered fundamental to developing effective responses to hepatitis C:

- developing partnerships and involving affected communities;
- access and equity;
- harm reduction;
- health promotion;
- research and surveillance; and
- linked strategies and infrastructures.

These components also serve as useful tools to guide workforce learning activities and the development of hepatitis C-related programs. A skilled, knowledgeable and adaptable workforce embraces a broad view of how, where and when effective workplace learning can occur.

REFLECTIVE PRACTICE

Regardless of whether the title 'educator' appears in their job description, most health care workers in the area of hepatitis C are involved in educational processes. However, many of these workers often have limited opportunities to reflect on their educational aims and practices. Evaluation of the effectiveness of educational outcomes is all too often limited to quantitative measures, such as numbers of people seen, fits distributed, events organised or pamphlets produced.

Reflective practice entails re-assessing activities for their underlying values and assumptions, and monitoring their effectiveness and appropriateness. This assessment can take place formally or informally, individually or with co-workers, and can incorporate a range of practices, such as:

- planning days;
- thinking in the car;
- chats over coffee;
- staff meetings;
- de-briefing sessions; and
- actively seeking new resources.

Objectives for reflective practice in the workplace can include:

- assessing how educators think and plan, what experiences they use, what ideas influence them, and how these ideas contribute to educational practice in the area of health and wellbeing;

- evaluating the impact of interactions with consumers and peers, and the uses of de-briefing; and
- managing workloads so that there is time for reflection.

Activities that may enhance collective reflection and can be built into workplace strategies include:

- regular staff meetings;
- documenting and discussing in teams;
- post-project de-briefs;
- considering the theory and principles of peer and education practice, and updating this knowledge on a regular basis;
- planning to make room for critical reflection time; and
- National, State and Territory workshops, where workers who provide education have the opportunity to meet with others working in the field.

PEER EDUCATION

DEFINITION OF A PEER

There is some debate about what or who constitutes a peer in relation to people with hepatitis C. Because of people's diverse backgrounds and beliefs, it is possibly a question without a definitive answer. In practice, the important thing is that those involved in the education process regard each other as peers. Peer educators usually have direct experience of drug use and an understanding of drug-using practices and cultures. They are well-placed to give information about reducing risks of hepatitis C transmission and other drug-related harms.

KEY PRINCIPLES OF A PEER EDUCATION PROCESS

Peer education is based on the principles of **community development**, and is usually facilitated from within the peer group. Peer education processes use an empowerment model of community development, and work with the culture of the group to encourage a bottom-up approach to decision-making and responsibility. Ownership of the learning process belongs to the group and is self-directed, which is fundamental to bringing about sustainable change among sub-cultures and their networks.

To be a useful and legitimate educational practice, peer education should include key principles, including:

- respect for the existing knowledge, skills and experience that people have;
- enabling people to define their own issues and develop their own solutions rather than giving pre-determined messages;
- recognition of the importance of the situation and cultural context, which may be unique to each network;
- provision of accessible and appropriate information;
- support for information-sharing in the context of continually evolving networks of people;
- delegation of power and responsibility for decision-making to the group involved, rather than placing peer educators (or project managers) in a position of authority and therefore outside the group;
- educational strategies that equally value the processes of learning, self-defined skill development, capacity-building, empowerment and participation; and
- strategies that incorporate a process of learning that is owned by those who are learning, including ownership of budget, reporting and other group processes.

Peer education is a crucial approach in preventing hepatitis C transmission, in maintaining the health of people with hepatitis C and in enabling communities as a whole to participate in their own health care.

Currently, peer education is a popular term applied to a range of projects within peer-based drug user groups and other organisations. The term 'peer education' is often poorly understood and is applied inappropriately to many initiatives. If an educational activity is not underpinned by the principles listed above, it is more accurately classified as education or information provision rather than peer education.

EDUCATION TARGETING PEOPLE WHO INJECT DRUGS

For a variety of reasons, traditional forms of education and health promotion have not been particularly effective when working with people who inject drugs. However, peer education has been shown to be an effective educational approach to increase knowledge about hepatitis C, encourage people to maintain health, and to prevent further transmission of hepatitis C. It can also effectively encourage behaviour change.

Peer education for people who inject drugs must be flexible and can be implemented in a number of different situations, including:

- workshops facilitated by peer educators;
- services that provide for people who use drugs, such as NSPs, where a peer educator can be based; this is known as 'opportunistic' peer education;
- conversations in the dealing, scoring and injecting environments;
- development and distribution of peer-based education resources (e.g. pamphlets, magazines); and
- formal peer education projects, usually located in an agency that has ongoing access to people who use drugs and their networks.

One example of peer education in practice is the series of Tribes projects, facilitated by the New South Wales Users & AIDS Association (NUAA). The projects aim to use relevant language, images, information and media as a peer-based educational resource for subcultures of people who inject drugs, with the primary aim of relaying information and encouraging debate about harm reduction and blood-borne virus issues. Projects have included the development of videos, pamphlets and stickers.

HEPATITIS C EDUCATION IN SCHOOLS

Schools play a critical role in hepatitis C education and prevention. Informing young people about blood-borne virus issues is regarded as a primary public health responsibility. Approximately 2% of young people in schools have ever injected drugs, and preventing the transmission of hepatitis C must begin with sound prevention and blood awareness education programs in the junior and middle secondary school.

Teachers have access to large populations of young people and are regarded by both parents and students as appropriate people to conduct hepatitis C education. Hepatitis C prevention education can be effectively taught by schools who are not afraid to tackle sensitive and contentious issues, and who work within the social realities of young people's lives (which may include testing of boundaries and risk-taking) to provide practical harm reduction messages. Additionally, blood awareness programs can be used in settings where a direct focus on specific injecting drug use issues is thought to be too sensitive.

Curriculum guidelines vary around Australia, but all States and Territories include some education around sexuality, drugs and hepatitis C prevention. These topics are often allocated into the broad learning area of Health and Physical Education. The more these areas are integrated into classroom learning, the more effective hepatitis C prevention messages for young people are likely to be.

A national survey of secondary school students conducted in 1997, demonstrated that knowledge of hepatitis C is very poor:

- less than half the students in Years 10 and 12 knew that hepatitis C could be transmitted through sharing and re-using injecting equipment; and
- 11% of same-sex attracted young people used illicit drugs, and those in the 14 to 18 age group were more likely to have shared items of injecting equipment than were older students.

This study illustrates that information about hepatitis C is not currently communicated effectively in school programs. Reasons for this include:

- Teachers may not be specifically trained or have the capability to teach about potentially contentious issues such as hepatitis C, and they may lack the support of the school administration or parents' and citizens' group.
- School drug education is often broad-based, covering both licit and illicit drugs. Although the topics of blood awareness and hepatitis C are relevant to its harm minimisation framework, they are not specifically included in the *National School Drug Education Strategy 1999*.
- Historically, hepatitis C and blood-borne viruses (such as hepatitis B that can be sexually transmissible), have been added onto the HIV/AIDS and STIs agenda. This has occurred for both political and educational purposes, but not necessarily with equal weighting. The recent ANCAHRD publication *Talking Sexual Health: National Framework for Education about STIs, HIV/AIDS and Blood-Borne Viruses in Secondary Schools 1999*, comprehensively addresses hepatitis C prevention education and suggests teaching strategies on the subject.

In a national survey conducted in 2000, secondary school teachers reported that there is little being taught about hepatitis C in their schools. Teachers themselves were reasonably well-informed, and believed that it was important for schools to include hepatitis C in the curriculum, but they felt they had few opportunities for professional development or appropriate curriculum resources to teach hepatitis C issues. Other barriers were structural, such as crowded curricula and timetables, lack of preparation time and inadequate training. Opposition from school communities was not identified as a barrier to hepatitis C education.

There are several major lessons from HIV prevention education in schools that are relevant to hepatitis C prevention education, including:

- explaining and promoting the harm reduction framework;
- helping students to develop an understanding of community values and opinions, and the effect of these on their own efforts to construct a personal ethic; and
- acknowledging that behaviours, including risk behaviours, are shaped by students' individual and personal values and beliefs.

In 1994 the Curriculum Corporation developed the following set of guidelines, entitled *Health and Physical Education for Australian Schools*. These national learning goals can be applied directly to hepatitis C prevention education in the school setting. They advise that young people:

- be guided to develop the knowledge and skills to make informed decisions, build and maintain effective relationships, and promote the safety and health of individuals and groups;
- be encouraged to accept themselves as they grow and change and promote their own and others' worth, dignity and rights, as individuals and members of groups;
- be taught the skills to evaluate the influence of diverse values, attitudes and beliefs on personal and group decisions and behaviour related to health; and
- be encouraged to take an active part in creating environments that support health and contribute to community debate and discussion on these issues.

A whole-school approach has been shown to be most effective in bringing about behaviour change in areas of health and wellbeing. In relation to hepatitis C prevention, this involves the development and implementation of policies relating to:

- the confidentiality and prevention of discrimination for anyone living with a disease;
- teaching students how to be blood aware; and
- adopting standard infection control procedures in all situations where blood is present.

All States and Territories have approved these guidelines and require schools to adopt and use them. The recent (2000) survey of secondary teachers indicated that only 29% were aware of these guidelines. This is clearly an area where more workplace capacity building, education and development is urgently needed, with the ultimate aim of reducing future hepatitis C transmission.

HEPATITIS C EDUCATION IN CUSTODIAL SETTINGS

Preventing the transmission of hepatitis C among people in custodial settings continues to be one of the most urgent public health issues for correctional administrators, custodial staff, prison inmates, health care providers and for politicians.

In general terms, Australia adheres to the principle that people in custody are entitled to the same standard of health care as citizens in the general community. Not all members of the community share this view. Some consider people in custody less deserving of equivalent standards of health care, while others have difficulty with the concept of health promotion and its implementation in the custodial setting.

In order to constructively address the challenges posed in custodial settings by hepatitis C, it should be noted that:

- individuals are incarcerated as punishment, **not for additional** punishment. People in custodial settings are entitled to health care of a standard equivalent to that of the community as a whole; and
- because the average length of a prison sentence in Australia is approximately 3 months, many prisoners return to the wider community after short periods of time. Consequently, health gains within custodial centres translate into health gains for the wider community. Similarly, adverse health outcomes in custody become health problems for the wider community.

Until the health issues of people in custody who were also living with HIV began to have an impact on occupational cultures and health care provision, little research had been conducted into the health needs of this group. Research now shows us that three main themes are emerging in this area:

- the health status of people living in custody is generally lower than that of the wider community;
- there are high rates of physical and mental health disorders among the custodial population; and
- social and economic disadvantage is identified as the major cause of ill health for people in custody.

Ill health among this population has been observed in the areas of mental health, substance use and communicable diseases. Examples of co-infection (e.g. with hepatitis B or HIV) and infection with hepatitis C alongside other health conditions (e.g. mental health problems) has also been observed.

INJECTING DRUG USE, CORRECTIONAL SETTINGS AND HEPATITIS C

Thousands of people who inject illicit drugs are incarcerated each year. Many of the custodial population are drug dependent, regardless of whether they were incarcerated for drug-related crimes.

A 1999 study found that a total of 47% of more than 4000 people tested in custodial settings in NSW were hepatitis C positive (62% of women and 46% of men). This figure highlights both the increased risk of transmission within these settings and the importance of providing inmates with comprehensive blood-borne virus education and the means for preventing further transmission of hepatitis C.

People in custody need information about hepatitis C transmission, treatment and management so that they can assess risk and make informed decisions about protection, testing and counselling. However, public health practitioners working in correctional settings suggest that while education is essential, it is not in itself sufficient to prevent the further transmission of hepatitis C.

As recommended in *Hepatitis C: The Neglected Epidemic*, people in custody need access to the same harm reduction strategies that are available to the wider community. In the custodial setting this means having reliable access to:

- methadone maintenance programs;
- bleach;
- sterile injecting equipment and clean water; and
- current and appropriate information.

Injecting drug use in custody occurs less frequently than in the general community, but given that injecting equipment is currently contraband and consequently scarce in all Australian custodial settings, needles, syringes and other equipment are shared more often than in the general community. To avoid detection and punishment, injecting is usually performed in secret and in haste, and because of pervasive surveillance, there is little incentive or opportunity to clean equipment. Equipment used for injecting and tattooing is often improvised. Given these circumstances, the overall risks associated with injecting drug use are greater in correctional centres than in the wider community.

An important part of prison culture is not to 'dog' on another inmate, i.e. report them to the authorities. This may limit the willingness of people to call for assistance from staff when their peers suffer accidental drug overdose. For these reasons people in custody often inject alone, and this increases the chance of accidental overdose.

RISK BEHAVIOURS FOR HEPATITIS C TRANSMISSION IN CUSTODIAL SETTINGS

Because of the higher prevalence of hepatitis C and the higher incidence of violent behaviour in custodial settings, the following risk behaviours, some of which are features of prison culture, have been identified:

- sharing and re-using injecting equipment;
- unsterile tattooing, body piercing and other skin penetration practices;
- accidental occupational needlestick injuries and blood exposures;
- blood exposures resulting from assaults and sports injuries;
- potential dental and medical transmission;
- sharing of personal grooming implements such as razors and toothbrushes; and
- unprotected anal sex where blood is present.

HOW IS EDUCATION BEST DELIVERED IN THE CUSTODIAL SETTING?

Correctional services differ in all States and Territories and differences in the custodial system are created through institutional security classifications and hierarchies. Organisational arrangements can also differ: some correctional health services are part of general health services (as in NSW), or they may be part of corrective services (as in Queensland). Health care provision in custodial settings also differs between each State and Territory. In addition, custodial staff and people in custody do not form homogeneous groups. Educational strategies must acknowledge and respond to these differences. Individual factors such as sex, age, indigenous status, ethnicity, possible pre-conceptions about injecting drug use, literacy, ideological beliefs and previous educational opportunities must be taken into consideration by educators when planning sessions.

WHEN AND TO WHOM IS BLOOD-BORNE VIRUS EDUCATION TARGETED IN CUSTODIAL SETTINGS?

People in custody:

- Generally at reception/remand centres.
- On admission to a new correctional institution.
- When progressing through the correctional system.

Blood-borne virus education for people in custody can be proactive when there is a specific health education curriculum in place, or reactive when an incident has occurred which demonstrates the need for education.

Peer educators:

- During initial peer supporter training and periodically thereafter.

Peer educators in custodial settings are people respected by both staff and inmates who volunteer to help other inmates stay safe and well. They receive some training and have access to staff support and debriefing. Peer education and support does not occur in all jurisdictions, and problems can be encountered when inmates are transferred or released, and when there are changes in the staff dedicated to supporting these programs. Additional problems may also occur due to the lack of confidentiality within such settings.

Educators working for Hepatitis C Councils and peer-based drug user organisations are encouraged to take part in advanced training of this group.

Peer educators/supporters should be encouraged to employ peer education principles (see above section) to enable them to better support their peers.

Custodial health care providers:

- During induction.
- Periodically throughout their careers. Regular on-site information updates can be organised from within the custodial service, or can involve an outside provider, e.g. Hepatitis C Councils.

There should be a formal mechanism in place for the distribution of current medical, nursing and public health journal articles. In addition, it is recommended that health care providers be given opportunities to attend conferences and off-site health promotion workshops with general community colleagues.

Other custodial staff and correctional administrators:

- During induction training.
- Periodically throughout their careers.

Peer education is also considered useful for these groups. Officers who are able to provide training for their peers can be an effective way to deliver training.

ADULT EDUCATION PRINCIPLES

Training and other learning activities in the custodial setting may be enhanced when the programs are interactive, informal, respectful of previous learning and enjoyable. Those with alternative views about complex and controversial aspects of harm reduction can be encouraged to share their views and present their arguments. By making links between theoretical models (e.g. harm minimisation), personal values and attitudes and work practices that reflect these, educators can highlight any discrepancies that may emerge. Often this involves lively debate, clarification of values and possible re-alignment of programs and activities that better reflect the organisation's position on issues such as harm reduction. *See section on Professional Development earlier in this chapter, p164.*

It is also important to allow space for personal stories, and a skilled educator can create learning opportunities using such stories. While it is difficult to ensure confidentiality in a custodial setting, it should be a guiding principle in the practice of education, e.g. information about the use of an illicit substance in custody should stay within the group.

The information presented in training materials must include the most recent epidemiological, transmission, prevention and infection control data available, and be presented in language that is easily accessible.

HEPATITIS C PREVENTION IN CUSTODIAL SETTINGS

An effective program of hepatitis C prevention education in custodial settings may include:

- pre-course assessment and analysis of training and education needs;
- detailed information about hepatitis C;
- guidelines for cleaning equipment used in injecting, tattooing and piercing;
- international, national and state custody hepatitis C epidemiology (i.e. prevalence and incidence rates);
- information on transmission myths and realities;
- current information on standard precautions;
- blood and body fluids protocols;
- practical harm reduction approaches;
- post-occupational blood-borne virus exposure risk assessment;
- a comprehensive testing policy;
- correctional policies regarding ethical behaviour, including non-discriminatory practice and confidentiality;
- information on differential sanctions in regard to the possession of different categories of drugs (as an example: cannabis is detected in urine for much longer than heroin. The absence of differential sanctions may inadvertently encourage a switch from smoking cannabis to injecting heroin, with an increase in overall harm);
- hepatitis A and B vaccinations;
- treatment, care and support options;
- acknowledging and challenging the institutionalised attitudes that stigmatise inmates, and can also marginalise empathetic staff;
- a permanent record of training undertaken; and
- post-training evaluation of risk prevention competencies, potential behavioural change and subjective feedback.

TESTING POLICIES

Policies around hepatitis C testing in the custodial setting often generate intense debate, and there are different requirements in each State and Territory. In some States there is routine testing on entry. In Queensland, testing for hepatitis C is based either on a clinical indication or at the request of the person in custody, and is performed without the need for individuals to specify the reason for their request.

Testing in the custodial setting is a complex issue that warrants further discussion at the highest levels.

HEPATITIS C EDUCATION ISSUES FOR POLICE

In all Australian States and Territories, the police, in collaboration with service providers and governments, are increasingly involved in diversion and cautioning strategies that aim to:

- reduce the number of injecting drug users held in custody; and
- improve their access to drug treatments.

Police interactions with drug users are no longer solely based on law enforcement, and the police can play an important role in health promotion, including hepatitis C prevention. An understanding of the individual, structural and cultural influences that shape police attitudes and interactions with people who inject drugs is a crucial part of a comprehensive public health response to hepatitis C-related issues.

In the course of their normal duties, operational police come into physical contact with people who inject drugs and this can bring with it the potential and perceived risk of hepatitis C and other blood-borne virus transmission. While the national number of blood-borne virus transmissions via needlestick injury, blood or other body fluid contact is not known, there is a real and ongoing risk of transmission for police officers.

A 1998 research study on stigma and discrimination against people living with HIV/AIDS (**PLWHA**), suggests that the more contact people have with any specific group, the less likely it is that they will harbour discriminatory attitudes towards them.

Changes to attitudes and practices do not come about overnight. A significant investment has been made in training operational police in the health and welfare issues of people who use alcohol and other drugs. This training occurs at a number of levels, involving recruit, probationary constable, sub-officer and officer, and includes blood-borne virus information and education about related issues.

As part of the comprehensive training process, it is beneficial for police to receive education about harm minimisation and harm reduction, and for officers to have contact with people who use drugs in order that they can understand the social and personal issues involved in drug use. One way in which this can be achieved is for police officers to hear a presentation from drug user organisations about the social and political issues that confront them. Initiatives such as those offered by the NSW Users and AIDS Association (**NUAA**) in 1999, aim to present to police a broad range of issues relating to injecting drug use. By challenging perceptions, such initiatives are likely to make a significant contribution to hepatitis C prevention and the prevention of discrimination.

Other constructive strategies that have been implemented in a number of jurisdictions include:

- the identification of individual police as community liaison officers in areas where drug dealing and injecting are common;
- the establishment of close working relations between NSP workers and police; and
- joint education programs for the police and local workers, such as NSP staff, alcohol and other drug workers and local government personnel.

The national commitment to hepatitis C prevention will be substantially strengthened by ensuring that all Australian police personnel have access to hepatitis C-related education and training.

NEEDLE AND SYRINGE PROGRAM WORKFORCE TRAINING, DEVELOPMENT AND NETWORKING

Of all Australian health care workers, Needle and Syringe Program (**NSP**) workers have contact with the largest populations of people who inject drugs. Throughout Australia there are over 3,000 NSP sites. In Victoria, more than 400,000 transactions were provided through NSPs in 1999 alone. Because of this front-line contact, NSP workers have a unique opportunity to play a key role in the prevention of hepatitis C transmission.

The success of NSPs in averting an epidemic of HIV among people who inject drugs and from the wider community has been well-documented. While the availability of sterile needles and syringes through NSPs remains a key component of preventing hepatitis C, new infections continue to occur at high rates. Because hepatitis C is much more infectious than HIV and because the epidemic was well-established before the virus was identified in 1989 and before the establishment and growth of NSPs, hepatitis C has been much more difficult to contain than HIV.

The prime strategy of HIV prevention for this population was to make sterile injecting equipment available. Coupled with a simple education intervention around the non-sharing and cleaning of needles and syringes, it was sufficient to impact significantly on the number of HIV transmissions. Despite every indication that new needles and syringes are being used more frequently than ever before for each injecting occasion, the impact on hepatitis C transmission rates has not been as significant. Each separate step of the injecting process needs to be considered for its potential to transmit hepatitis C. In turn, the implications for NSP workers are that far more intensive and interactive interventions are required to ensure that the more complex messages of hepatitis C transmission are delivered, understood and practised by NSP clients.

To educate effectively, NSP workers need:

- skills and knowledge to impart personalised safer using information;
- to be supported by a structure or organisation that enables them to spend adequate time with clients; and
- communication skills to interact effectively with clients from a variety of backgrounds.

Training programs for NSP workers also need to take into account existing differences, including individual differences in:

- skill levels;
- personal and occupational backgrounds;
- amount of time spent delivering NSP service;
- size of NSP client population; and
- level of commitment to providing services for people who inject drugs.

In addition, there are differing levels of support from State or local jurisdictions, and differences in the status of services, e.g. primary, secondary etc.

Primary NSPs are funded to provide specialist education and prevention programs to people who inject drugs, and are often stand-alone agencies. Secondary NSPs are located under the auspice of another agency, such as a community health centre or hospital, and their capacity to deliver service is often limited to the basic provision of injecting equipment, due to competition with other health service demands.

Given these issues, NSP workers have had difficulty in accessing appropriate training and professional development relative to their divergent needs and responsibilities. However, some recent important Commonwealth-funded initiatives have enhanced the resourcing of NSP workers, including:

- this *National Hepatitis C Resource Manual*;
- the booklet *NSPs: Needle & Syringe Programs: Your questions answered;* and *A Review of the Evidence* (ANCAHRD publications – requests to free call 1800 022 863); and

- the *National NSP Workers' Training Package*, currently being developed.

The *National NSP Workers' Training Package* is being developed by the Queensland Alcohol and Drug Research and Education Centre (QADREC), supported by the *Council of Australian Government's (COAG) National Illicit Drug Strategy NSP Supporting Measures Initiative*. This project has been specifically designed and developed to provide NSP workers in Australia with the essential knowledge and skill base to support their work. One of the key components of the package will be the production of a flexible-delivery training manual (due late in 2001), that utilises a competency-based framework in its development.

Another component of the *NSP Workers' Training Package* has involved the establishment of an e-mail discussion list, *NSP Forum*, administered by QADREC. NSP Forum provides an open forum for the discussion of any NSP related issues. This can include client intervention skills, blood-borne virus education techniques, law reform, policies and protocols, referral mechanisms or anything else of relevance to subscribers.

(To subscribe to the list, send an email to:listserv@lists.spmed.uq.edu.au with no subject, and the words "subscribe NSP-FORUM-L [Your Name]" in the message text box, and nothing else. Please note that NSP-FORUM-L must be in upper case. Your name is simply your first name and surname, not your e-mail address).

With the exception of Victoria, there are no State or Territory peak bodies who provide services, advocacy, representation, networking, support, training or conferences specifically for the NSP sector. In Victoria, the Association of Needle and Syringe Programs (ANEX) is the peak body that aims to address the needs of NSP workers. *See Contacts, p236.* The absence of a national body representing the NSP and its workers contrasts with the national organisational response to HIV and hepatitis C-related issues.

See Chapter 9: section on Needle and Syringe Programs, p198.

THE ROLE OF PHARMACIES IN THE PREVENTION AND MANAGEMENT OF HEPATITIS C

Pharmacists and their staff are some of the most frequently contacted of all Australia's community health workers, and have an appreciable impact on health care in Australia. Approximately 2.4 million pharmacy visits take place each week: 1.6 million are prescription-related and 0.8 million are for other health-related services, including retail.

The pharmacy profession has experienced major changes in the past 50 years. The advent of modern pharmaceuticals and pre-packaged products has seen pharmacists come out from the dispensary to the service counter where they have greater contact with their customers. They provide information, advice and counselling, which is often supported by take-home printed materials.

Pharmacies have the opportunity to play a key role in the prevention and management of hepatitis C by providing the following:

- specific illicit drug-related services such as Needle and Syringe Programs and methadone programs;
- sale of needles, syringes and other safer injecting equipment;
- information and advice on general physical and mental health;
- information on hepatitis C transmission, including injecting drug use;
- referrals to treatment and counselling;
- information to families and friends of people who inject drugs; and
- medication maintenance and review.

PHARMACIES AND INJECTING DRUG USE

Pharmacists and their staff are often the first point of contact for people who use drugs and can play a key role in reducing harm. They are in a unique position to provide and implement preventive health and medication management services to this client group.

Since the introduction of Needle and Syringe Programs in 1985, some pharmacies have played an important role in the provision of methadone, Needle and Syringe Programs, information, advice and referral. Many pharmacies also act as retail outlets for injecting equipment, and some offer disposal services for used injecting equipment. However, there are pharmacists who, in the absence of sufficient resources and training, remain reluctant to participate in prevention initiatives such as the provision of needles and syringes. There remains considerable scope to improve pharmacy services through developing more effective relationships between pharmacy staff and people who inject drugs, and local NSPs.

The Commonwealth Department of Health and Aged Care has funded the Pharmaceutical Society of Australia (**PSA**) to work with the Pharmacy Guild of Australia (**PGA**) to develop and implement a series of nationally consistent education and training programs. The programs are designed for pharmacists and their staff who come into contact with people who inject drugs and illicit drug issues. They aim to provide:

- education, training and support to pharmacists and their staff in relation to illicit drug issues and Needle and Syringe Programs;
- appropriate resources on injecting drug use for pharmacy staff to distribute to their customers;
- improved access to counselling, referral and treatment options for people who inject drugs; and
- a reduction in the transmission of hepatitis C through injecting drug use.

EDUCATION AND TRAINING FOR OTHER SERVICE PROVIDERS

Hepatitis C education and training is included in a number of professional programs, sometimes at the undergraduate and post-graduate levels and sometimes professional development programs. In some Australian States, hepatitis C and other blood-borne viruses (usually HIV) are the subject of training programs specifically developed for GPs, counsellors, nurses, community health workers and volunteer carers.

It is recommended that health care workers and health educators check with their State or Territory health department, Hepatitis C Council, peer-based drug user organisation and relevant professional bodies for up-to-date information on available training programs on hepatitis C and other blood-borne viruses.

COMMONLY ASKED QUESTIONS

I AM AN NSP WORKER, AND I AM WORRIED ABOUT CONTRACTING HEPATITIS C. WHAT CAN I DO?

Your NSP will have protocols and guidelines detailing how to handle used needles and syringes and items of injecting equipment. You need to be very familiar with these, and with the infection control guidelines appropriate for your workplace. Talk with other staff who are more experienced and less anxious. More information on drug-related issues can be obtained from organisations such as the peer-based drug user organisation or Hepatitis C Council in your State or Territory.

WHAT TRAINING TAKES PLACE FOR PEOPLE IN CUSTODY AROUND BLOOD-BORNE VIRUS ISSUES?

This varies greatly in each State and Territory. Check with your Hepatitis C Council, some of whom employ educators dedicated to correctional service programs, and with the health department and corrections office for details of current programs and initiatives.

I'M INVOLVED IN PROVIDING HEPATITIS C EDUCATION WITH PEOPLE WHO USE DRUGS. DOES THIS MAKE ME A PEER?

Some people believe a peer is a person who shares a detailed understanding of the culture of a group, while others believe that personal experience is the only true credential for being a peer. In practice, however, the important thing is that you are regarded as a peer, and are trusted by the people with whom you work as an educator.

I AM A RELATIVELY NEW WORKER IN AN OUTER URBAN SECONDARY NSP, AND I'M INTERESTED IN STRENGTHENING THE PROGRAM'S LINKS WITH THE COMMUNITY. WHAT ARE THE POSSIBILITIES?

Community development principles may be useful to guide your thinking. First talk with your program manager and fellow workers, and together decide how best to make contact with key people in the local community, such as your auspicing agency, the local government Environmental Heath Officer, youth leaders, a user advocate, pharmacists, GPs and a police representative. You might form a group that meets to discuss NSP-related issues that involve the whole community. Such groups can become self-directed and creative in their ideas for strengthening community links.

IF NSPS MAKE NEEDLES AND SYRINGES AVAILABLE FREE TO ANYONE WHO COMES IN, SURELY THEY ENCOURAGE INJECTING DRUG USE?

Injecting drug use is a part of our society, and is not the consequence of free needles and syringes, any more than readily obtainable beer glasses encourage the consumption of alcohol. NSPs are a public health initiative which aim to reduce the transmission of blood-borne viruses and drug-related harms for people who inject drugs and for the wider community.

NSP FORUM E-MAIL DISCUSSION LIST

July 2002

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The National NSP Workers e-mail discussion list was established to facilitate the sharing of information and opinion relating to the needle and syringe program (NSP), irrespective of people's geographical location.

Since 2001, the Association of Needle and Syringe Programs (ANEX) has maintained and operated this discussion list. ANEX is a community based non-government organisation in Victoria. It was established to facilitate effective networking between needle and syringe program (NSP) services, and to enhance the knowledge level of NSP workers and the general community regarding the provision of these services.

The National NSP Workers E-forum fulfils a variety of functions. It is an open forum for information sharing, problem solving, basic networking and discussion of NSP-related issues. Topics include the prevention of blood-borne viruses and other drug-related harms, drug pharmacology, current issues for the NSP, policies and protocols, service delivery and other practice issues.

The forum continues to be open primarily to current workers in Needle and Syringe Programs. However participation from other interested persons is always welcome.

To subscribe to the list, email: majordomo@onthe.net.au and in the body of your email type: subscribe nspforum. To post messages on the e-forum, simply send your message to: **nspforum@anex.org.au**

For more information email **info@anex.org.au** or visit **www.anex.org.au**

CHAPTER 9

NATIONAL, STATE AND TERRITORY AND LOCAL RESPONSES TO HEPATITIS C

Contributors: Commonwealth Department of Health and Aged Care, David Lowe, Geoff Woolcock.

- Since hepatitis C was first identified in 1989, Australia's national, State, Territory and local governments have worked collaboratively with organisations and communities to address the social, economic, psychological, and health issues faced by people affected.

SUMMARY OF IMPORTANT POINTS

- These responses are multi-faceted and have resulted in numerous local, State and Territory, and national initiatives, including the development of the world's first *National Hepatitis C Strategy* by the Commonwealth Government.

THE PARTNERSHIP APPROACH

Partnership is a fundamental principle of any successful population health policy. As with Australia's response to HIV/AIDS, the medical, health care, research and scientific communities, and people affected by hepatitis C are required to collaborate toward an effective response.

Another basic principle in the implementation of the *National HIV/AIDS Strategy 1996–1997 to 1998–1999* has been that education programs for the groups affected are most effective if designed and delivered at the community level by members of the target group themselves, in consultation with government agencies. The same approach is being taken in response to the challenges presented by hepatitis C.

Elements of the partnership approach, which are still evolving and developing, can be seen in the extensive consultation, communication, advocacy and sustained collaboration that have characterised Australia's response to the hepatitis C epidemic. Some of the outcomes of the partnership approach are illustrated in the responses outlined below.

SUMMARY OF NATIONAL RESPONSES

Australia is leading the world in responding to the hepatitis C epidemic.

Population health action relating to hepatitis C began in February 1990. Following identification of the virus and the development of a suitable test, screening of the blood supply was promptly introduced. As part of the continuing efforts to keep abreast of best international standards, Nucleic Acid Testing (**NAT**) was introduced from June 2000 to further reduce the risk of hepatitis C transmission through transfusion of fresh blood products.

In May 1993 a joint task force between the Australian Health Ministers Advisory Council (**AHMAC**) and the National Health and Medical Research Council (**NHMRC**) was established.

In October 1994, AHMAC released the *National Hepatitis C Action Plan*, a document detailing the first nationally co-ordinated approach. The plan identified four priority areas for action:

- epidemiology and surveillance;
- testing;
- counselling and treatment; and
- education and prevention.

The document described the roles and responsibilities of Commonwealth and State and Territory governments, the medical and research communities, and community organisations. It also acknowledged the vital role played by these groups in responding to hepatitis C.

In 1995, AHMAC released a document entitled *Nationally Co-ordinated Hepatitis C Education and Prevention Approach*, which described a program of educational activities and was developed in consultation with representatives of the AHMAC National Hepatitis C Education and Prevention Reference Group.

Inclusion of hepatitis C under the aegis of the *National HIV/AIDS Strategy 1996–97 to 1998–99* strengthened the commitment to tackle the epidemic. This strategy provided a basis for developing and extending partnerships in hepatitis C, emphasised collaboration, and raised the profile of hepatitis C as a priority on the population health agenda.

A review of the population health response to hepatitis C began in 1998 and the resultant report, *Hepatitis C: A Review of Australia's Response* was published in January 1999. The review assessed the performance of the *National Hepatitis C Action Plan* and the *Nationally Co-ordinated Hepatitis C Education and Prevention Approach*. The review found that the Action Plan had served Australia well by taking steps to deal with hepatitis C at a relatively early stage and mobilising the initial response to the epidemic.

The important role of State and Territory governments in providing hepatitis C-related health promotion programs and primary health care planning and infrastructure is also acknowledged. Throughout the 1990s the various jurisdictions have implemented a range of initiatives and interventions aimed at reducing the transmission of hepatitis C and minimising the impact for those already affected. In particular, inclusion of hepatitis C under the third *National HIV/AIDS Strategy* provided State and Territory governments with the opportunity to capitalise on established programs and infrastructures that targeted common risk factors (such as injecting drug use). This approach also broadened the scope of initiatives to incorporate issues relating to hepatitis C.

State and Territory governments also implemented *LookBack* programs designed to trace recipients, and, in some jurisdictions, donors of contaminated blood or blood products before the introduction of screening of the blood supply. These people were then offered counselling and testing and, where necessary, provided with information on hepatitis C treatments and health maintenance and monitoring.

The contribution of organisations representing affected communities has been critical in drawing attention to the needs of people with hepatitis C and those at risk of acquiring the infection. The prevention and education measures and the care and support services developed and implemented by affected communities and their organisations continue to be vital in reducing hepatitis C transmission and mitigating its effects.

The then Australian National Council on AIDS and Related Diseases (**ANCARD**) gave hepatitis C a platform at the national advisory level. The newly established (1999) Australian National Council on AIDS, Hepatitis C and Related Diseases (**ANCAHRD**) aims to build on this achievement by providing the Federal Minister for Health and Aged Care with independent expert advice on the national response to hepatitis C. The importance of hepatitis C as a significant population health issue is also demonstrated in its inclusion in the title of the ministerial advisory committee.

STATE AND TERRITORY RESPONSES

State and Territory governments and health authorities have responsibility for, and flexibility in, program delivery. Among their particular activities are the following:

- implementing the *National Hepatitis C Strategy* at the jurisdictional level;
- establishing State and Territory hepatitis C strategies, including treatment, care and support plans;
- establishing advisory forums with representation from all members of the partnership in their jurisdiction;
- establishing public policy and legislative frameworks consistent with the aims and objectives of the *National Hepatitis C Strategy*;
- investigating, analysing and monitoring the epidemiology of hepatitis C within their jurisdiction;
- developing, funding, delivering and evaluating a range of services, such as public hospital services (delivered on-site or as outreach services), health promotion, and care and support services provided by public and community-based organisations that reflect the prevalence and changing needs of people affected by hepatitis C;
- funding, supporting and evaluating the work of Hepatitis C Councils and peer-based drug user organisations;
- providing workforce infrastructure and professional development and training for workers who deal with hepatitis C related issues;
- funding and evaluating Needle and Syringe Programs;
- ensuring effective intersectoral co-operation between State and Territory and local government agencies;
- ensuring that resources are allocated in accordance with the priority areas, having regard to the essential components expressed in the *National Hepatitis C Strategy*; and
- measuring and reporting on the implementation of the *National Hepatitis C Strategy* within their jurisdiction.

LOCAL GOVERNMENT RESPONSES

The provision of services at the local government level has become increasingly important in meeting the needs of people affected by hepatitis C. Local government involves a wide range of agencies and services that can contribute to the health and wellbeing of people. It is well-placed to respond promptly and effectively to particular local needs. Furthermore, it is responsible for urban planning and development, which affects the location and operation of health promotion initiatives such as Needle and Syringe Programs, local health services and waste collection, including needles and syringes. Local governments are in a good position to become key partners in promoting population health initiatives, and their policies should reflect the principles and priorities of the *National Hepatitis C Strategy*.

COMMUNITY SECTOR RESPONSES

Central to the partnership approach is the involvement of individuals and communities in program and policy development. To date, this has been principally through community-based organisations supported by Commonwealth and State funds, and includes Hepatitis C Councils, peer-based drug user organisations, State and Territory haemophilia groups and Needle and Syringe Programs.

HEPATITIS C COUNCILS

The first Councils were formed in the early to mid-1990s, evolving primarily from hepatitis C support groups. The Councils were organised in response to the confusion and ignorance associated with diagnosis, the absence of reliable information, and the misunderstanding and discrimination encountered by many affected people. The development of support through the provision of information, telephone 'buddy' systems, meetings and public information seminars stimulated local communities to form incorporated associations.

The state-based Hepatitis C Councils define their principal tasks as the provision of:

- information;
- referral to appropriate agencies and expertise;
- peer-based support services to people affected by hepatitis C; and
- community representation at all levels of policy development and decision-making relating to hepatitis C issues.

All Hepatitis C Councils have recognised the importance of partnerships and of establishing infrastructure to meet local needs. Good examples of such community involvement and empowerment are seen in management committees, project co-ordination and provision of services to people with hepatitis C. These endeavours often involve people who use drugs, health professionals, counsellors and researchers, government representatives and people with hepatitis C, who work together for the benefit of affected people.

PEER-BASED DRUG USER ORGANISATIONS

The illicit nature of injecting drug use has meant that traditional public health promotion approaches are not always appropriate or effective. Consequently, peer-based drug user organisations have been funded to involve affected people in harm reduction initiatives that include:

- design, delivery and development of education programs;
- information provision; and
- participation in the development of health policy and programs.

These organisations have had interrupted histories, and in some jurisdictions have only recently received funding, or operate as semi-autonomous programs within other organisations. These factors and local conditions have resulted in variations between State and Territory organisations in terms of their size, the range of services provided, organisational style, and their capacity to participate in the partnership approach to prevent blood-borne virus transmission.

However, all of these organisations are characterised by their focus on facilitating involvement of people who inject drugs to manage their own health and that of their peers.

NATIONAL AND STATE HAEMOPHILIA FOUNDATIONS

These were formed to represent and address the needs of people with haemophilia, including complications in their treatment arising from blood-borne viruses. In 1990, these groups were in a position to respond immediately to the additional needs resulting from the identification and implications of hepatitis C.

NEEDLE AND SYRINGE PROGRAMS

The *National Hepatitis C Strategy* recognises the important contribution to hepatitis C prevention made by Needle and Syringe Programs, which were originally implemented under successive national HIV/AIDS strategies. The 1999 review of Australia's response to hepatitis C concluded that these programs represented a "blue-chip investment" in terms of cost-effectiveness, offering significant health gains, financial savings and other benefits. Support for this prevention mechanism has continued under the *National Hepatitis C Strategy*.

Needle and Syringe Programs (NSPs) are a key public health measure established to reduce the transmission of blood-borne viruses, particularly HIV and hepatitis C, among people who inject drugs. Known by alternative titles in different parts of Australia (clean needle programs in South Australia, and needle and syringe exchange programs in WA), NSPs are perhaps the most straightforward example of public health programs operating on the principles of harm reduction.

The NSW Health Department's *Needle and Syringe Policy and Procedures Manual*, in describing the underlying rationale of NSPs, reflects the national position on hepatitis C prevention imperatives. It acknowledges that:

- many people will continue to inject drugs, for varying periods of time, despite drug education and treatment programs;

- all people must be provided with the knowledge and skills necessary to make informed decisions about high risk behaviours; and
- the community as a whole faces a greater threat from the social and economic consequences of infections such as hepatitis C and HIV than it does from the adverse effects of drug use itself.

Types of NSPs

The first NSP was piloted in Darlinghurst, Sydney in 1986, following concerns about the rising prevalence of HIV among people injecting drugs. In 1987, NSPs were integrated into NSW government policy. Other States and Territories soon established their own NSPs, and currently there are over 3,000 NSPs in Australia.

Several types of NSPs operate across Australia, with distinct differences. Broadly, these are classified as:

- **Primary** – fixed, stand-alone agencies that specifically provide specialist services to people who inject drugs, including the provision of sterile equipment and appropriate disposal facilities, referral and sometimes primary medical care.
- **Secondary** – fixed outlets offering sterile equipment and appropriate disposal as one part of a range of health and community services. Examples of secondary outlets include those at community health centres and hospital-based accident and emergency departments.
- **Outreach/mobile** – equipment and disposal services provided by a team of workers, sometimes from a vehicle, or via 'foot patrols'. These outreach services are usually available after-hours and in the client's location, and often in response to requests for equipment and disposal in a specific location.
- **Pharmacies** – in some States and Territories, pharmacies dispense injecting equipment and provide support services.

Some NSPs also provide vending machines that dispense 'Fitpacks'. These packs contain several 1ml syringes (for a small fee) and are re-stocked by NSP workers.

See Chapter 8: Education and Training for more details on training and education issues for the NSP workforce.

Resources

GLOSSARY

Acute infection

Any infection characterised by signs and symptoms that last for a short period of time. Acute infection with hepatitis C is often very mild, lasts less than 6 months (often less than 12 weeks) and goes unnoticed for most people.

Alanine aminotransferase (ALT)

A protein which, when found in the blood in elevated quantities, generally indicates liver damage.

Antibodies

Proteins produced by the body in response to bacteria, viruses or other antigenic substances. In the case of hepatitis C, antibodies are produced in response to a virus.

Antibody test

Initial screening test. This is a blood test that looks for antibodies to the virus and not for the virus itself.

Antigen

A substance, usually a protein, that causes the formation of an antibody and reacts specifically with that antibody.

Benzodiazapines

Sometimes called ‘benzos’. They work by slowing down the activity of the central nervous system and alter physical, mental and emotional responses. Like alcohol, cannabis and heroin, they are depressants. They are produced through a process of chemical synthesis. The benzodiazepine group contains over 24 specific drugs. Each of these has a chemical or 'generic' name, and each drug is sold under one or more brand names.

Best practice

On the evidence available, the best intervention(s) to produce improved outcomes for an identified problem.

Blood awareness

Being alert to the potential or actual presence of blood in any situation or environment.

Blood-borne virus

A virus that is transmitted by blood or body fluids that contain blood. Examples include hepatitis B, hepatitis C and HIV.

Blood products

Component parts of blood (e.g. plasma, albumin etc.) that can be separated, virally inactivated and used by Blood banks and hospitals for specific medical requirements, e.g. treatment for people with haemophilia and other bleeding disorders.

Buprenorphine

New pharmacotherapy currently being trialed in Australia. Used with success overseas. Can be used as a withdrawal or maintenance drug, particularly in methadone withdrawal.

Carrier

Refers to a person who has a specific ongoing infection that can be transmitted to others through risk behaviours. The term is used in relation to hepatitis B.

CD4 cells (also known as T cells or T helper cells)

A type of blood cell that protects the body against viral, fungal or protozoal infection. HIV replicates within CD4 cells and destroys them in the process.

Chronic infection

An infection that is ongoing for more than six months. It does not refer to the severity of the disease.

Cirrhosis

Extensive and permanent scarring of the liver. Cirrhosis interferes with the normal functioning of the liver. Approximately 2% of people with hepatitis C develop cirrhosis.

Clinical trials

Research procedures that test the safety and efficacy of experimental medicines on groups of people, in order to identify who may benefit from a specific drug or treatment.

Co-infection

A general term referring to infection with two or more infectious agents. Hepatitis C co-infection refers to infection with hepatitis C and another blood-borne virus such as HIV and/or hepatitis B.

Cohort

Any designated group of people who are followed over a period of time and from whom data is collected.

Combination therapy

The use of two or more types of treatment in combination, alternately or together, to achieve optimum results and to reduce toxicity. In hepatitis C treatment, this term currently refers to a combination of the drugs interferon and ribavirin.

Complementary therapies

The various systems of healing that are not regarded as part of orthodox treatment by the medical profession. In relation to hepatitis C, complementary therapies are used to reduce symptoms.

Community development

Considered to be any activity that aims to empower the individual (within their own particular socio-economic context) to participate effectively, make decisions and take action to optimise their own health and quality of life.

Custodial settings

The various settings in which adults and juveniles are detained or imprisoned, including prisons, juvenile justice centres, remand and other detention facilities.

Demand reduction – see Harm minimisation.

Disclosure (hepatitis C-related)

The act of telling other people that you have hepatitis C. Apart from informing the Blood bank, individuals are not legally obliged to disclose their hepatitis C status. Disclosure to partners, family, friends, employers, insurers and health workers is a personal and potentially difficult decision.

Discrimination (hepatitis C related)

Any unfavourable treatment on the basis of known or implied hepatitis C status; any action or inaction that results in a person being denied full or partial access to otherwise generally available services or opportunities because of known or implied hepatitis C status. The definition includes discrimination on the grounds of known or imputed membership of particular groups that are commonly associated with hepatitis C.

Enhanced Primary Care (EPC)

A partnership arrangement between health care professionals, usually with expertise in different areas, designed to optimise the care of people with chronic disease. When caring for people with hepatitis C, the term is often used to describe an arrangement made between GPs and other health service providers such as complementary therapists, nutritionists, counsellors, etc.

Epidemiology

The study of the distribution and determinants of health-related states or events (such as likely routes of transmission and trends in epidemics) in specified populations, and the application of this knowledge to deal with health problems.

Exposure-prone procedure

Any situation where there is a potentially high risk of blood-borne virus transmission from a health care worker to a patient during a medical or dental procedure.

Extra-hepatic

Symptoms or manifestations of chronic infection which occur outside the liver.

False negative result

Incorrect result of test or procedure that indicates the absence of a condition or infection, when in fact the condition or infection does exist.

Fibrosis

Formation of scar tissue on the surface of the liver to replace normal tissue lost through injury or infection.

Fit

Colloquial term for a needle and syringe.

Genotype

A term used to describe the specific genetic structure of hepatitis C. The ten identified genotypes are believed to be closely related in their genetic make-up, but differ sufficiently that each genotype causes different immune responses and responses to treatment.

Haemolytic anaemia

A disorder characterised by chronic premature destruction of red blood cells. In the case of hepatitis C, haemolytic anaemia occurs in response to the use of anti-viral drugs.

Haemophilia

A group of hereditary bleeding disorders in which there is a deficiency in one of the factors necessary for coagulation of the blood. Haemophilia A (or Classical Haemophilia) is the most common form, and is due to the deficiency of factor VIII. Haemophilia B (or Christmas Disease) is due to the deficiency of factor IX. Haemophilia almost exclusively affects males.

Harm minimisation

The primary principle underpinning the National Drug Strategic Framework.

The term refers to policies and programs aimed at reducing drug-related harm. The underlying principle is the intention to improve health, social and economic outcomes for the community as a whole and for the individual. Various approaches are involved, including abstinence-oriented strategies. Both licit and illicit drugs are the focus of Australia’s harm minimisation strategy. Harm minimisation includes preventing anticipated harm and reducing actual harm, involving a balance between demand reduction, supply reduction and harm reduction.

Harm reduction

Harm reduction aims to reduce the harm associated with potentially risky activities, rather than preventing people from performing those activities. Harm reduction is a pragmatic concept; it recognises the reality of drug use, and maintains that individuals and the community may be better served by diminishing the harms associated with drugs than by attempting to stop drug consumption.

Health maintenance

A combination of activities, interventions and lifestyle choices which support continued management and monitoring of a person’s health, with the intention of reducing the severity and side effects of hepatitis C and delaying the onset of advanced liver disease.

Health promotion

The process of using health information, education, communication and community mobilisation to influence attitudes to health and behaviours of individuals or communities.

Hepatitis

A general term meaning inflammation of the liver.

Hepatitis C virus

An RNA virus transmitted through blood-to-blood contact.

Hepatologist

A doctor who specialises in the care of the liver.

Highly Specialised Drug Program

Highly specialised drugs are medicines for chronic conditions, which, because of their clinical use or other special features, are restricted to supply through hospitals which have access to appropriate specialist facilities. Highly specialised drugs must be prescribed by specialist hospital units and dispensed through pharmacies associated with hospitals that participate in the Highly Specialised Drugs Program.

Immune system

The body's defence against any foreign substance. A major function of the immune system is to combat infections caused by micro-organisms, and it also acts to protect against the effects of drugs, toxins and cancer cells.

Incidence

The number of new infections identified in a defined population in any specified period of time. For example, if 100 individuals were monitored for one year, and one event (e.g. an infection, or death, or accident) occurred during that year, then the incidence rate would be expressed as 1% per year or 1 per 100 person years.

Indeterminate

The result of antibody test that is neither positive nor negative.

Informed consent

Permission obtained without force, fraud or threat and with knowledge and understanding of the consequences of the matter to which consent relates. In this context, often meant as permission from a person to perform a specific test or procedure. In relation to hepatitis C, informed consent should be sought by the health care worker from the person involved before any medical intervention, e.g. testing, biopsy or prescribing of treatment takes place.

Indinavir

A protease inhibitor that blocks part of the HIV virus called protease so that no new infectious copies of the virus can be made.

Interferon

A substance produced naturally by the body to help defend itself against viral infection. The administration of synthetically manufactured interferon alpha in large doses can help to reduce the amount of hepatitis C in the blood and slow down or stop the disease process. See Combination therapy and Pegylated interferon.

Lamivudine

A commonly used drug in the treatment of hepatitis B.

Liver biopsy

A clinical procedure in which a small part of the liver is removed. Used to assess the health of the liver.

Liver function test

A blood test used to evaluate various functions of the liver.

Macrophage system

Large mononuclear phagocytic cells which are part of the population of white blood cells in the body.

Medicare Benefits Schedule

Professional services that attract Medicare benefits and include medical services rendered by or on behalf of a medical practitioner. Medical services that may be rendered 'on behalf of' a medical practitioner include services where a portion of the service is performed by a technician employed in accordance with accepted medical practice, acting under the supervision of the medical practitioner.

Methadone

Methadone is a synthetic substitute designed for the treatment of people dependent on heroin and other opioids.

Methadone maintenance

The effects of methadone are much longer lasting than heroin; a single dose being effective for approximately 24 hours (the effects of heroin may last only a couple of hours). In a treatment program, methadone is usually given out in syrup form and drunk with cordial or fruit juice.

Generally, there are two types of methadone programs:

- a maintenance or long-term program which may last for months or years, and aims to reduce the harms associated with drug use and improve quality of life; and
- a withdrawal or detoxification program, which lasts approximately 5–14 days and aims to ease the discomfort of coming off heroin.

Mucosal

Relating to the mucous membrane.

Mutation

A change in the genetic material (DNA or RNA) of a cell or organism such as a virus.

Naltrexone

New pharmacotherapy for the treatment of opiate addiction. The user must first be detoxed. It is taken daily to block the effect of opiates. Naltrexone is designed to take away the desire to use opiates and stops them working if they are used. There are overdose risks involved in taking this drug.

Natural History

The natural history of a disease is defined as its progression in the absence of any medical treatment or other intervention over a designated period of time.

Needlestick injury

Refers to an injury with a needle or other sharp implement.

Non-A, non-B hepatitis

Before hepatitis C was identified in 1989, this term was used to describe any hepatitis virus that was not caused by either hepatitis A or hepatitis B. It is now thought that the majority of cases of non-A, non-B hepatitis were hepatitis C.

Nosocomial

An infection that originates in a hospital. It may have been present at the time of admission or acquired during a stay in hospital.

Opiate

A narcotic drug that contains opium. Opiates have a strong analgesic effect. Narcotics such as codeine phosphate, morphine and heroin are made from opium.

Opportunistic infection

An infection that occurs when a person's immune system is impaired and where an infection would not usually cause disease in a healthy individual. The term is also used to describe a widespread infection by an organism that usually causes local infection only.

Peer education

An education process that is self-directed, devised, implemented and owned by members of a group or sub-culture, where the desired outcome is that peer support and the culture of the target group are used to effect and sustain changes in attitude and behaviour.

Pegylated interferon

Slow release interferon, administered once a week. Emerging as potentially the most effective treatment for hepatitis C, when used in combination with ribavirin.

People affected by hepatitis C

People at risk of acquiring hepatitis C, people who already have hepatitis C, or other people such as family members, friends and partners who are not directly infected with the virus, but who are affected by the experiences of others who have the virus.

Percutaneous

A procedure performed through the skin.

Person years

Describes the total amount of time that a group of people participating in a study has been exposed to or experienced a particular health issue.

Platelets

Components of blood formed in red bone marrow, which congregate at the site of an injury to form a clot. They are essential for coagulation or clotting.

Polymerase chain reaction (PCR)

A laboratory technique that amplifies the genetic material of a virus to a level that can be detected. The presence or absence of the virus can then be determined. In relation to hepatitis C, PCR consists of many stages and can be used to detect:

- the presence or absence of the virus in the blood;
- the level of virus present in the blood (viral load); and
- the genotype of the virus.

Prevalence

The number of all new and old cases of a disease in a given population at a designated point in time. Usually expressed as a percentage or a ratio (e.g. 1% or 1 in 100 people).

Prospective studies

An epidemiological study in which subsets of a defined population who are enrolled in the study and monitored over time may be exposed to a given disease.

Prognosis

A prediction of the probable outcome of a disease, based on the condition of the person and the usual course of the disease as observed in similar situations.

Psoriasis

A common skin condition, characterised by red patches and dry scales.

Quality of life

A complete state of physical, mental, emotional and social wellbeing, and not merely the absence of disease or infirmity.

Reflective practice

Re-assessing activities for their underlying values and assumptions, and monitoring their effectiveness and appropriateness.

Ribavirin

A drug that alters the body's immune response to viruses. Used in combination with interferon in the treatment of hepatitis C. Ineffective when used alone. See Combination therapy.

Safer using

A series of precautions and practices which aim to prevent the incidence of related harm during the process of injecting drugs.

Schistosomiasis

Parasitic infection transmitted to humans through contact with fresh water contaminated by human faeces.

Sexually transmissible infection (STI)

An infection that can be transmitted through oral, anal and vaginal intercourse.

Shared Care

A partnership arrangement between health care professionals, designed to optimise the care of people with chronic disease. When caring for people with hepatitis C, the term is often used to describe an arrangement made between liver specialists in regional centres and GPs in rural areas.

Standard infection control precautions

Work practices required for the basic level of infection control. These include good hygiene practices, particularly washing and drying hands before and after patient contact; the use of protective barriers which may include gloves, gowns, plastic aprons, masks, eye shields or goggles; appropriate handling and disposal of sharps and other contaminated or infectious waste; and use of aseptic techniques.

Standard precautions are recommended for the treatment and care of all patients, regardless of their perceived infectious status.

Subcutaneous injection

The introduction of a hypodermic needle inserted at a 45 degree angle into the tissue beneath the skin. Interferon is administered in this way into the fat of the abdomen or the outer thigh.

Supply reduction – see Harm minimisation.

Surveillance

The ongoing tracking of all aspects of a disease that are pertinent to effective control.

Sustained response (SR)

Refers to the elimination of the virus following treatment, which leads to an improvement in symptoms, and the reduction of potential long-term complications such as cirrhosis. Current research suggests that if a person has a sustained response for 6 months after a course of treatment, there is a good chance that their response will last indefinitely.

Vaccine

A substance that stimulates an immune response and renders a person immune to a particular infection. There is no vaccine for hepatitis C, but vaccines are available for both hepatitis A and hepatitis B.

Vertical transmission (hepatitis C-related)

The transmission of an infectious organism from mother to baby, during pregnancy, delivery or breastfeeding. It is very rare for hepatitis C to be transmitted in this way and only 2% – 8% of babies born to hepatitis C positive women will develop chronic hepatitis C.

Viraemia

The rapid multiplication of viruses in the blood, sometimes associated with symptoms.

Viral load

The amount of virus circulating in the blood. Usually measured by a PCR quantitative test. The result is given in number of viral particles per ml of blood.

Window period (or sero-conversion)

Describes the period of time between initial infection and when antibodies are measurable on testing. It usually takes at least 3 or 4 weeks before there is enough virus circulating in the blood to identify hepatitis C through a PCR test, but it can take up to 6 months for antibodies to appear in significant enough numbers to be detectable. A person may be able to transmit the virus to others via risk behaviours during this period.

ABBREVIATIONS

AHMAC	Australian Health Ministers Advisory Council
AIDS	Acquired immuno-deficiency syndrome
AIVL	Australian Intravenous League
ALT	Alanine Aminotransferase
ANCARD	Australian National Council on AIDS and Related Diseases
ANCAHRD	Australian National Council on AIDS, Hepatitis C and Related Diseases
BBV	Blood-borne Virus
bDNA	Branched Chain DNA
CDNANZ	Communicable Diseases Network of Australia and New Zealand
CLDB	Culturally and linguistically diverse backgrounds
COAG	Council of Australian Governments
DNA	Deoxyribonucleic acid
EPC	Enhanced Primary Care
HAART	Highly Active Anti-Retroviral Therapy
HIV	Human immuno-deficiency virus
IGCAHRD	Inter-Governmental Committee on AIDS, Hepatitis C and Related Diseases
LFT	Liver function text
NAT	Nucleic Acid Testing
NCDC	National Centre for Disease Control

NHMRC	National Health and Medical Research Council
NSP	Needle and Syringe Program
NUAA	NSW Users and AIDS Association
PCR	Polymerase Chain Reaction
PGA	Pharmacy Guild of Australia
PLWHA	People living with HIV/AIDS
PBS	Pharmaceutical Benefits Scheme
PSA	Pharmaceutical Society of Australia
QADREC	Queensland Alcohol and Drug Research and Education Centre
QoL	Quality of Life
RNA	Ribonucleic acid
STI	Sexually transmissible infection
TGA	Therapeutic Goods Administration
WHO	World Health Organisation

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Family Planning Victoria
Ph: 03 9257 0100 (admin)
Ph: 03 9257 0123 (clinic)
Email: fpv@fpv.org.au

Haemophilia Foundation Victoria
Ph: 03 9555 7595
Fax: 03 9555 7375
Email: hfvic@vicnet.net.au

Hepatitis C Council of Victoria
Suite 5
200 Sydney Road
Brunswick Vic 3056
Ph: 03 9380 4644
Fax: 03 9380 4688
Country: 1800 703 003
Email: hepcvic@vicnet.net.au
Web: www.hepcvic.org.au

Hepatitis C Helpline
Ph: 03 9349 1111
Freecall: 1800 800 241
TTY: 1800 032 665
Web: www.hepcvic.org.au

Office of the Health Services Commissioner
Ph: 03 8601 5222
Complaints: 03 8601 5200
Freecall: 1800 136 066
Web: www.health.vic.gov.au/hsc

Victorian Hepatitis C Educator
Ph: 03 9288 3586
Fax: 03 9288 3590
Mob: 0407 865 140
Email: richmoj@svhm.org.au

VIVAIDS
Ph: 03 9419 3633
Fax: 03 9415 7055
Email:drugsafe@vicnet.net.au

Youth Substance Abuse Service (YSAS)
Ph: 03 9415 8881
Fax: 03 9415 8882
Country: 1800 014 446

WESTERN AUSTRALIA

ADIS
Ph: 08 9442 5000
Freecall: 1800 198 024
Email: adis@health.wa.gov.au

Commissioner for Equal Opportunity
Ph: 08 9216 3900

Department of Health (Sexual Health Program)
Ph: 08 9388 4999
Fax: 08 9388 48/88
Web: www.health.wa.gov.au

Family Planning
Ph: (08) 9227 6177
Email: sexhelp@fpwa-health.org.au

Haemophilia Foundation Western Australia
Ph: 08 9420 7294
Fax: 08 9486 8966
Email: hfwa@iinet.net.au

Hepatitis C Council of Western Australia
PO Box 8060
Perth Business Centre
WA 6849
Ph: 08 9328 8538
Fax: 08 9227 6545
Country: 1800 800 070
Email: hepccwa@highway1.com.au
Web:
www.hepccwa.highway1.com.au

WASUA (Western Australian Substance Users Association Inc.)
Ph: 08 9227 7866
Fax: 08 9227 7855
Email: wasua@wantree.com.au

NATIONAL

Aboriginal Health

Office for Aboriginal and Torres Strait Islander Health
Ph: 02 6289 5334
Fax: 02 6289 1412
Email: oatsih.enquiries@health.gov.au

Blood Services

Australian Red Cross Blood Service
Ph: 13 14 95
Web: www.arcbs.redcross.org.au

Body Art

Professional Tattooing Association of Australia
Ph: 03 9314 1203

Complementary

Australasian College of Nutritional & Environmental Medicine Inc.
Ph: 03 9589 6088
Fax: 03 9589 5158

Counselling

Australian Institute of Professional Counsellors
Ph: 03 9602 3938
Fax: 03 9602 3832
Email: aipcvic@aipc.net.au

Drug Information and Services

Alcohol and Other Drugs Council of Australia (ADCA)
PO Box 269
Woden ACT 2606
Ph: 02 6281 0686
Fax: 02 6281 0995
Email: adca@adca.org.au
Web: www.adca.org.au

Government

Centrelink
Appointments: 13 10 21
Employment Services: 13 28 50
Disability: 13 27 17
Family Assistance: 13 61 50
Enquiries in languages other than English 13 12 02
TTY: 1800 810 586
Web: www.centrelink.gov.au

Commonwealth Ombudsman (Complaints against a commonwealth agency or federal police)
Ph: 03 9654 7355
Fax: 03 9654 7949
Freecall: 1300 362 072
Web: www.comb.gov.au

Human Rights and Equal Opportunity Commission
General enquiries: 1300 369 711
Complaints infoline: 1300 656 419
Web: www.humanrights.gov.au

Haemophilia

Haemophilia Foundation Australia
213 Waverley Road
East Malvern VIC 3145
Ph: 03 9572 5533
Fax: 03 9572 0622
Email: hfaust@haemophilia.org.au
Web: www.haemophilia.org.au

Healthcare

Commonwealth Department of Health and Ageing (CDHA)
Web: www.health.gov.au

Health Insurance Commission
Ph: 02 6124 6333
TTY: 1800 552 152
Fax: 02 6124 6100
Email: hic.info@hic.gov.au
Web: www.hic.gov.au

National Needlestick and Other Exposures Hotline
Freecall: 1800 804 823

Pharmaceutical Society of Australia
PO Box 21
Curtin ACT 2605
Ph: 02 6281 1366
Fax: 02 6285 2869
Email: psa.nat@psa.org.au
Web: www.psa.org.au

Royal College of Nursing Transcultural Nursing Society
Ph: 02 6282 5633
Fax: 02 6282 3565
Email: canberra@rcna.org.au

Hepatitis C

Australian Hepatitis Council
PO Box 357
Curtin ACT 2605
Ph: 02 6232 4257
Fax: 02 6232 4318
Email: info@hepatitisaustralia.com
Web: www.hepatitisaustralia.com

Australian Drug Foundation
Ph: 03 9278 8100
Fax: 03 9328 3008
Email: adf@adf.org.au
Web: www.adf.org.au

Australian Injecting and Illicit Drug Users League (AIVL)
Level 2, Sydney Building
112-116 Alinga St
Canberra City ACT 2601
Ph: 02 6279 1600
Fax: 02 6279 1610
Email: aivl@aivl.org.au
Web: www.aivl.org.au

HIV/AIDS

Australasian Society for HIV Medicine (ASHM)
Ph: 02 9368 2700
Fax: 02 9380 9528
Email: ashm@ashm.org.au
Web: www.ashm.org.au

Australian Federation of AIDS Organisations
Ph: 02 9281 1999
Fax: 02 9281 1044
Email: afao@afao.org.au
Web: www.afao.org.au

Nutrition

Dietitians Association of Australia
Ph: 02 6282 9555
Fax: 02 6282 9888
Email: nationaloffice@daa.asn.au
Web: www.daa.asn.au

Nutrition Society of Australia
Ph: 08 8363 1307
Fax: 08 8363 1604
Email: info@nsa.asn.au
Web: www.nsa.asn.au

Occupational Health and Safety

National Occupational Health and Safety Commission
Ph: 02 6279 1000
Fax: 02 6279 1199
Fax: 02 9577 9202
Email: info@nohsc.gov.au
Web: www.nohsc.gov.au

Pregnancy/ Childbirth/Breastfeeding

Australian Breastfeeding Association
Ph: 03 9885 0855
Fax: 03 9885 0866
Email: info@breastfeeding.asn.au
Web: www.breastfeeding.asn.au

Australian College of Midwives Inc.
Ph: 03 9804 5071
Web: www.acmi.org.au

Sexual Health

Family Planning Australia
217 Northbourne Avenue
Turner ACT 2612
Ph: 02 6230 5255
Fax: 02 6230 5344
Email: fpa@fpa.net.au
Web: www.fpa.net.au

Australian Acupuncture Association Ltd.
Ph: 07 3846 5866
Freecall: 1800 025 334 (Practitioner referral service)
Email: aacma@acupuncture.org.au
Web: www.acupuncture.org.au

Australian Complementary Health Association
Ph: 03 9650 5327
Fax: 03 9650 8404
Web: www.diversity.org.au

Australian Tradition Medicine Society (ATMS)
Ph: 02 9809 6800
Fax: 02 9809 7570
Email: enquiries@atms.com.au
Web: www.atms.com.au

Complementary Medicine Association Limited
Ph: 02 9894 5581
Fax: 02 9894 5581
Freecall: 1800 11 77 66
Email: admin@cma.asn.au
Web: www.cma.asn.au

Integrative Medicine Association
Ph: 03 9540 0226
Fax: 03 9540 0226

Steroid Users

For more information, please contact individual State and Territory peer-based drug user organisations or Hepatitis C Councils.

Superannuation and Insurance

Australian Prudential Regulation Authority
Superannuation Hotline: 13 10 60
Ph: 02 9210 3000
Fax: 02 9210 3020

Treatment Centres

For more information, please contact individual State and Territory Hepatitis C Councils.

Vaccination

Health care workers should refer to the Australian Standard Vaccination Schedule, National Health and Medical Research Council

Australian Psychological Society Ltd.
Ph: 03 8662 3300
Fax: 03 9663 6177
Email: contactus@psych.com.au

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