















THE AUSTRALIAN MEDIA GUIDE TO

2001 EDITION

HEPATITIS C

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Welcome to the first edition of the Australian Media Guide to Hepatitis C – produced by the Australian Hepatitis Council on behalf of the Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD).

The guide is designed for people working in the media, but is also a useful resource for a range of people dealing with hepatitis C related issues.

The launch of the National Hepatitis C Strategy 1999-2000 to 2003-2004, is an opportune time to provide a media resource to assist journalists in reporting this epidemic.

The first part of the guide deals with the history of the virus, its transmission, treatments and a chronological account of hepatitis C in Australia.

Other sections cover the range of challenges faced by governments and affected communities in their response to hepatitis C.

There is also a section dealing with terminology, comprising alternatives to common terms and suggested usage which describe more accurately people with hepatitis C, and which better inform the public about the nature of the virus and its effects.

This guide is designed to assist journalists and other media workers to continue their informed and considered coverage of hepatitis C-related issues.


Chris Puplick


Chair


*Australian National Council on AIDS,
Hepatitis C and Related Diseases*





Hepatitis C is a virus that causes liver inflammation and liver disease.


 Hepatitis C is transmitted by blood.


 Many people recently diagnosed with hepatitis C are often confused about the term 'virus' and what viral infection means. The word 'virus' is often linked with the Human Immunodeficiency Virus (HIV), the virus that can cause AIDS. Hepatitis C is not related to HIV, and infection with one cannot lead to the other.


 Hepatitis C is not commonly transmitted during sex and is not defined as a sexually transmissible disease.


 Hepatitis C was first identified in 1988. Before then, it was often called 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 most people does not result in serious disease or death.

 In 1997, approximately 200,000 Australians were estimated to have hepatitis C. There were an estimated 11,000 new infections in 1997.

 Approximately 25 per cent of people infected with hepatitis C will clear the virus within two to six months of becoming infected, but will continue to carry antibodies to the virus. The other 75 per cent of people who do not clear the virus will have an ongoing or chronic infection.

 The primary treatments for hepatitis C are interferon combined with ribavirin, or interferon monotherapy.

 About one person in every five will clear hepatitis C completely using the standard dose of interferon. Forty percent of people are likely to clear the virus when treated with a combination of interferon and ribavirin.

 As yet, there is no preventative vaccine for hepatitis C.



More Australians have been exposed to hepatitis C than any other notifiable disease over the past decade. An estimated 200,000 Australians are already infected with the hepatitis C virus, with a further 11,000 new infections occurring each year. Hepatitis C is the most common reason for liver transplant in Australia.

The impact of this epidemic will have major implications for the Australian healthcare system over the next decade and beyond.

From epidemiological research we know that, of the total number of infections, approximately:

- 80 per cent resulted from unsterile injecting drug use

- ten per cent contracted hepatitis C through blood transfusions or blood products (prior to the introduction of blood product screening in 1990)
- five to ten per cent are the result of other modes of transmission (including unsterile tattooing and body piercing)
- five to ten per cent of the total number of infections occurred outside Australia among people who migrated here from countries with a high background prevalence of hepatitis C. These infections are most likely the result of unsterile medical or dental procedures in their country of origin.

Prior to confirmed identification of hepatitis C in 1989, surgeons observed that people receiving blood transfusions and blood products were contracting hepatitis despite donated blood and blood products being screened for hepatitis A and B. The majority of these cases,

known as non-A and non-B hepatitis, have since been identified as hepatitis C.

Hepatitis C is thought to have been transmitted widely in Australia by blood-to-blood contact since the early 1970s.

As with any health issue, caution is suggested when reporting epidemiological data in isolation. For this reason, and to avoid potentially harmful or exclusionary generalisations, the National Hepatitis C Strategy speaks clearly in terms of risk behaviours, rather

than population groups.

With such a large and expanding base of people with hepatitis C in Australia, governments and health authorities are re-orienting health services to meet the future demand for treatment and support programs. Prevention remains a key priority.

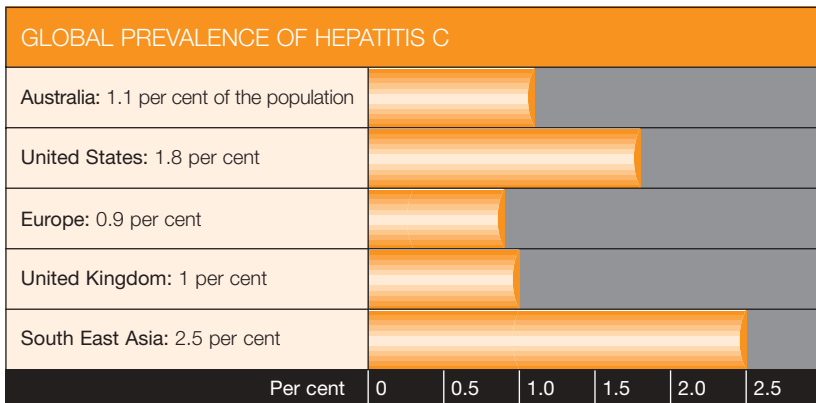
Australia's success in public health responses of this nature is world-renowned. As our response to the hepatitis C epidemic unfolds, we face particular challenges which need to be met with renewed commitment and vigilance.





Global hepatitis surveillance data and published studies have established that large numbers of people are chronically infected with hepatitis C and that significant numbers of new infections continue to occur.

The following graph illustrates the extent of hepatitis C infections worldwide:



Maintaining a secure blood supply system, infection control procedures in health care settings, and reducing unsafe injecting practices are the primary prevention strategies against further hepatitis C infections in both developed and developing nations.



Hepatitis literally means inflammation of the liver. The term applies to a specific set of liver disorders which can be caused by exposure to alcohol, chemicals, environmental pollutants, or one of several hepatitis viruses.

Viral hepatitis is referred to alphabetically according to the virus concerned. In Australia, the primary forms of viral hepatitis are hepatitis A, hepatitis B and hepatitis C. All three viruses have a distinct genetic makeup and are similar only in that they each infect and inflame the liver.

Hepatitis C is the name given to the inflammatory liver disease that results from chronic infection with the hepatitis C virus.

Hepatitis C infection involves an initial (acute) phase of infection which often goes unnoticed and lasts two to six months. During this

phase, levels of the virus in the blood can rise dramatically until the body's immune response begins to produce antibodies. Although these antibodies fight the virus, the virus is not eliminated in around 75 per cent of people infected, and they are left with a chronic hepatitis C infection.

People who clear hepatitis C from their bodies will still have antibodies in their blood and will experience no chronic liver disease unless they are reinfected.

For people who do not clear the virus, hepatitis C can cause long term liver problems including cancer of the liver. The mortality rate for people who reach this stage of liver disease is high.

There are six primary genotypes, or strains, of the hepatitis C virus worldwide. People who acquired the virus during the 1970s are more likely to be carrying genotype one. This genotype is typically the most resistant to treatment.

Other strains of the virus present in Australia, such as genotype three,

have a higher response rate to current treatments.

HOW IS HEPATITIS C TRANSMITTED?

Hepatitis C is transmitted by blood. For hepatitis C transmission to occur, the blood of a person with hepatitis C needs to enter the bloodstream of another person.

The transmission of hepatitis C through infected blood and blood products occurred prior to the screening of the blood supply from February 1990. This transmission was a common mode of infection until self-exclusion clauses were implemented in response to the transmission of HIV. Significant numbers of people who regularly receive blood products were infected with hepatitis C before 1990.

Sharing drug injecting equipment, including needles, syringes, spoons, water, filters and tourniquets, is currently the highest risk behaviour for contracting hepatitis C. Bleach, commonly used to clean injecting equipment to reduce the risk of HIV transmission, is not guaranteed to be an effective agent against hepatitis C.

Vertical transmission from mother to child is reported in approximately five per cent of cases where the mother has detectable hepatitis C virus in her blood. Transmission of hepatitis C from mother to child is most likely to occur at birth, rather than during pregnancy. There is no evidence of hepatitis C transmission through breastfeeding.

There have been documented cases of transmission of hepatitis C through tattooing and body piercing, following a failure to adequately sterilise equipment between clients. Commonwealth, State, Territory and local governments are working toward reducing the risk of hepatitis C transmission in these areas through improved infection control guidelines and work practices.

Hepatitis C is rarely transmitted through sexual contact; however, it may be transmitted where blood is present during sex - particularly as a result of sexual activity which breaks the skin.

There is a possibility of domestic transmission through the sharing of personal implements (such as razor blades and toothbrushes) which may carry one person's blood and create entry into another's

bloodstream - although this transmission route is considered a low risk.

Hepatitis C is not airborne and is not transmitted by social contact such as shaking hands. Similarly, sharing crockery, cutlery or shower and toilet facilities does not pose any risk for the transmission of the virus. Mosquitoes or other insects do not transmit hepatitis C.

SYMPTOMS

Symptoms of hepatitis C can include chronic debilitating fatigue, nausea and abdominal pain. Many people with severe symptoms are unable to carry out ordinary, everyday functions, including employment and home duties.

Other common symptoms include joint and muscle pain, general malaise, weight loss, hormonal irregularities in women, flu-like symptoms and depression.

Jaundice is not common in people with hepatitis C, although it may be present for some during the acute phase of infection.

Of 100 people who are infected by hepatitis C, about 25 people will clear the virus completely within

two to six months of infection, but will continue to carry hepatitis C virus antibodies for some time. People who clear the virus tend to be younger when first infected.

About 75 of the 100 people infected do not clear the virus, will have an ongoing or chronic infection, and are at risk of developing cirrhosis of the liver.

Of the 75 people who develop chronic hepatitis, about 20 people may never experience any noticeable illness or symptoms. Although they can transmit the virus to others, they won't develop illness or liver disease.

After an average of 15 years, between 40 and 60 people with chronic hepatitis C will experience some symptoms and develop some level of long term liver damage (see symptoms of chronic infection above).

After 20 years or so, between five and ten people with hepatitis C will develop cirrhosis of the liver. Between two and five of these people will experience liver failure or develop a form of liver cancer known as hepatocellular carcinoma.

ESTIMATED OUTCOMES OF HEPATITIS C INFECTION

100 people infected with hepatitis C at the same time



About 25 get rid of the virus within two to six months, but will have antibodies for a while



About 75 people develop chronic hepatitis



20 people don't develop liver damage or symptoms



40 to 60 people develop some long-term symptoms or signs of liver damage (on average after 15 years)



Five to ten people develop cirrhosis of the liver (on average after 20–40 years)



Two to five people who developed cirrhosis experience liver failure or cancer, 25 to 30 years after initial infection

The complexity of the hepatitis C virus means the development of a vaccine is unlikely for many years.

The primary treatments for hepatitis C are combination interferon and ribavirin therapy, or interferon administered as monotherapy.

About one person in every five will clear hepatitis completely using the standard dose of interferon. Forty percent of people typically clear the virus when treated with a combination of interferon and ribavirin.

Interferon is a natural protein produced by the body in response to infection - it has some direct anti-viral properties and stimulates the immune system to fight against foreign organisms.

The use of interferon as a single therapy has had limited success in treating hepatitis C. Due to its toxicity as a chemotherapy agent, its side effects are often potentially debilitating.

Positive outcomes of treatment include stabilisation of liver enzyme levels, reduction of symptoms, absence of detectable virus, and a potential improvement in quality of life.

It is common for people to experience a relapse during interferon treatment or one to six months after treatment ceases. This occurs in about 50 per cent of cases. Interferon monotherapy provides a sustained effective response in 15-20 per cent of people treated.

Ribavirin used in combination with interferon has been shown to be more successful than interferon monotherapy, with a sustained response in 40 per cent of people treated. This response rate increases to almost 70 per cent for people with favourable viral genotypes.

Ribavirin works similarly to common HIV anti-viral drugs of the same class, halting the replication of the hepatitis C virus by preventing the proper assembly of its genetic material.

COMPLEMENTARY AND ALTERNATIVE THERAPIES

Many people with hepatitis C report benefits from complementary or alternative therapies; however, their efficacy is difficult to establish.

In 1998, the results of a trial using traditional Chinese herbal medicines to treat people with hepatitis C at John Hunter Hospital in Newcastle were published. The study found the herbal treatment did improve ALT

(alanine aminotransferase) levels in a significant number of patients during treatment.

While these results were promising, they did not demonstrate any direct anti-viral activity attributable to the treatment.

People with hepatitis C commonly make use of complementary therapies to reduce side effects associated with medical treatments.



Hepatitis C became a notifiable disease in Australia in 1990. In the same year, the blood supply was secured following the development and availability of a diagnostic test for the virus.

Hepatitis C is now recognised as a significant public health issue requiring substantial planning and funding from governments, health professionals, researchers and community sector health services.

The National Hepatitis C Action Plan was developed in October 1994 to address four priority areas:

- surveillance and epidemiology
- testing
- clinical management and counselling
- education, prevention and research

In 1996, hepatitis C was incorporated into the Third National HIV/AIDS Strategy under the strategy's education, prevention and research initiatives.

The Australian National Council on AIDS (ANCA) became the Australian National Council on AIDS and Related Diseases (ANCARD) and in June 1997, the Intergovernmental Committee on AIDS and Related Diseases was reformed to ensure a joint approach between Commonwealth, State and Territory governments to policies and programs. Incorporation of hepatitis C into the Third National HIV/AIDS Strategy raised the profile of the epidemic as a serious public health concern. In 1998, the Commonwealth Government allocated a further \$1.7 m for research and national education programs targeting hepatitis C. It also established a partnership model for the response to hepatitis C, which sees communities most affected by hepatitis C sitting alongside governments, health care professionals and researchers in the development of policies and practice - a feature which has been one of the cornerstones of Australia's success in dealing with the HIV epidemic.

The Australian Hepatitis Council was established during the life of the

Third National HIV/AIDS Strategy, and specific hepatitis C funding was provided to the Australian IV League and the Australian Hepatitis Council for education to reduce the transmission and impact of hepatitis C.

In 1999, the Commonwealth government allocated \$12.4 m over four years to assist in preventing the transmission of hepatitis C, and to reduce the impact of hepatitis C on those people already infected.

That year, in recognition of the increasing importance of hepatitis C, ANCARD was replaced by the Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD).

A major component of the Commonwealth response to hepatitis C has been the development of the National Hepatitis C Strategy 1999-2000 to 2003-2004. Over a five-year term, the Strategy aims to reduce both the transmission and social impact of hepatitis C.

Despite these developments, new diagnoses and new infections remain high - indicating that existing initiatives are not enough to stabilise the epidemic. The human cost of hepatitis C infection is high, and the health care costs for people with hepatitis C, and for the healthcare system, are substantial.

COSTS TO THE COMMUNITY

In 1996/97, Australian governments spent almost \$50 m on the clinical management and treatment of hepatitis C. Additional costs include continued epidemiology and surveillance, blood screening, Commonwealth, State and Territory government spending on prevention programs, pathology testing funded through Medicare, Commonwealth spending on research and program evaluation, and the cost to the Pharmaceutical Benefits Scheme of interferon treatment. These costs totalled nearly \$75 m in 1996/97, making a total of \$125 m.

National and State/Territory level responses to hepatitis C involve a complex set of challenges for the future, including:

- reducing the number of new hepatitis C infections
- improving the range and availability of treatment and support options for people living with hepatitis C
- developing more comprehensive research and surveillance models
- improving hepatitis C related planning and healthcare infrastructures.

Australia's first National Hepatitis C Strategy provides for a strong and inclusive response from across the community, including: governments; community organisations; medical, healthcare, scientific and research services; and people affected by hepatitis C.

The Strategy promotes coordination between related public health initiatives by complementing existing government policies designed to address the impact of illicit drug use, and by detailing links between the public health responses to related diseases such as HIV/AIDS and other blood-borne viruses.

The National Hepatitis C Strategy promotes and supports the health, safety and wellbeing of all Australians affected by hepatitis C.

To achieve this, the Strategy aims to:

- reduce the transmission of hepatitis C in Australia
- minimise the personal and social impacts of hepatitis C infection.

The National Hepatitis C Strategy recognises that regardless of how hepatitis C infection is acquired, the social, medical and economic impacts for individuals and the broader community are profound, with significant implications for Australia's healthcare system.

An effective national response to hepatitis C will be achieved through addressing the challenges, and building on the opportunities, outlined in the Strategy's four Priority Areas for action.

These Priority Areas are:

- reducing transmission in the community
- treatment of hepatitis C infection
- health promotion, care and support for people affected by hepatitis C
- preventing discrimination and reducing stigma and isolation.

The Strategy is underpinned by six Essential Components considered fundamental in an effective response to the identified Priority Areas.

These Essential Components are:

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

The National Hepatitis C Strategy describes the risk factors and the specific contexts in which hepatitis C infection occurs. The Strategy acknowledges that it is participation in high-risk behaviours that exposes a person to hepatitis C infection, not a specific culture or ethnic identity.

While there are specific issues relating to Aboriginal and Torres Strait Islander communities and other culturally and linguistically diverse groups, the National Hepatitis C Strategy is inclusive of all people affected by hepatitis C.

The implementation of the National Hepatitis C Strategy will take place on several levels, involving a large number of organisations and consultative mechanisms. Although implementation must be coordinated, it must also remain responsive to specific contexts at

the local or community level, and be sufficiently flexible to respond to future challenges.

The Strategy will be put into effect through the work plans of the Australian National Council on AIDS, Hepatitis C and Related Diseases and the Intergovernmental Committee on AIDS, Hepatitis C and Related Diseases (and related sub-committees).

At the State and Territory level, the Intergovernmental Committee on AIDS, Hepatitis C and Related Diseases will coordinate efforts and develop nationally consistent reporting standards.

To ensure effective hepatitis C service delivery, local governments will be encouraged to become involved in the Strategy's implementation by developing and maintaining partnerships with local organisations.

THE COMMUNITY RESPONDS

Support groups for people with hepatitis C began to appear in Australian States and Territories during the early 1990s. Concerned individuals and healthcare workers organised these groups in response

to rising numbers of diagnoses, a lack of available information, and the confusion and prejudice encountered by many people with hepatitis C. A range of activities, including peer-based support, the provision of hepatitis C information, telephone 'buddy' systems, group meetings and public information seminars stimulated local communities to form incorporated associations.

Now known as State and Territory Hepatitis C Councils, these organisations define their primary business as the provision of information, referral and peer-based support services to people affected by hepatitis C.

Subsequent State, Territory and Commonwealth government funding has led to an expansion of the work

undertaken by Hepatitis C Councils. This includes the provision of telephone support and information services, resource production, volunteer training, awareness raising activities, advocacy and policy development, participation in healthcare worker training programs, inter-agency collaboration, and media work.

Hepatitis C Councils have also recognised the importance of establishing infrastructures to meet local needs. The involvement of people with hepatitis C, injecting drug users, health professionals, counsellors and researchers in management committees, projects and services are examples of continuing community involvement and empowerment.





HARM MINIMISATION

Harm minimisation is credited as one of the primary factors contributing to Australia's success in maintaining low levels of HIV infection among people who inject drugs and among the broader community. It is central to preventing the further transmission of hepatitis C.

Harm minimisation is a pragmatic approach based on a recognition of the reality of drug use, while aiming to reduce its harmful impact on individuals, communities and on society.

One of the most successful harm reduction strategies utilised in Australia has been the introduction of needle and syringe programs. Although established initially to reduce HIV transmission, needle and syringe programs play a broader role in reducing the harms associated with injecting drugs, including the transmission of hepatitis C. Beyond the provision of clean injecting equipment, these programs assist with referrals to drug treatment services, provide information on the

safe disposal of used injecting equipment, and advise people who inject on sexual health, housing and social support matters.

HEPATITIS C AND THE LAW

Hepatitis C carries a stigma that seriously threatens the rights of infected people.

Protecting individual rights and achieving balanced and appropriate law reform are necessary elements in an effective public health response to this epidemic.

Experience has shown that coercive public health strategies such as compulsory testing, quarantine, or the exclusion of people with hepatitis C from employment or education not only limit individual rights, but also undermine the effectiveness of public health efforts against hepatitis C. Punitive health strategies reduce participation in prevention programs, alienate people from health and social services, and are likely to increase isolation and suffering.

The HIV epidemic in Australia advanced the pace of public health law reform in some jurisdictions. The landmark Final Report of the Legal Working Party of the Inter-governmental Committee on AIDS, published in 1992, set out a blueprint for law reform which would enhance the effectiveness of the Australian response to the HIV epidemic and later, the hepatitis C epidemic.

The areas of law reviewed by this report include confidentiality, homosexuality, sex work, employment, law, and discrimination. Around half the reforms proposed have been implemented, however there is still significant work to be done in this area.

As yet there are no resource materials available which outline Australian law as it relates to hepatitis C infection. Journalists requiring specific details on hepatitis C related issues of law should contact the HIV/AIDS Legal Centre in Sydney or the Hepatitis C Council in their State or Territory.

DISCRIMINATION

People with hepatitis C experience discrimination in a variety of contexts. According to *Hepatitis C*:

A Review of Australia's Response, much of the discrimination is a result of beliefs, values and attitudes associated with injecting drug use, known as 'user phobia'.

Discrimination affects the quality of life of people with hepatitis C, and it compromises the effectiveness of our response to the epidemic. Many instances of hepatitis C discrimination are motivated by unwarranted fears or a desire to punish based on prejudice against people who inject drugs.

A person whose hepatitis C diagnosis becomes widely known may experience a broad range of discrimination from friends, local businesses, sporting groups, their workplace, institutions such as schools, hospitals, health and dental clinics, and child care facilities.

For a person with hepatitis C, discrimination can mean the loss of employment, promotion opportunities or accommodation, and can mean difficulty obtaining goods and services - including dental and medical care.

Myths, misrepresentation and misinformation about hepatitis C are commonplace. The many forms of

discrimination experienced by people with hepatitis C reflect the effects of this misinformation in the broader community.

All States, Territories and the Commonwealth have enacted anti-discrimination laws making it illegal to discriminate against people because they have a physical impairment or handicap, including hepatitis C. However, there is no protection under the law against discrimination based on a person's injecting drug use. This places many people with hepatitis C at risk of discrimination in employment and elsewhere, should their hepatitis C status become known.

The most commonly reported instances of discrimination occur within the healthcare system. People with hepatitis C who have a known or suspected history of injecting drug use may receive incomplete information relating to their treatment and support options. They may unofficially be ranked 'low priority' for places on hepatitis C treatment programs. Until recently, people who inject drugs were excluded from taking part in clinical trials of hepatitis C anti-viral medications.

CONFIDENTIALITY

Confidentiality is essential in the response to hepatitis C, particularly where affected communities have been disproportionately stigmatised and marginalised – most notably people who inject drugs or people with a history of drug injecting. These people are unlikely to come forward for education, testing, treatment or counselling unless confidentiality can be assured.

People with hepatitis C often face the prospect of serious discrimination if their status becomes known. The revelation that a person has been tested for the virus can be highly damaging.

A person's hepatitis C status should never be revealed without their consent. To do so risks legal action for defamation, negligence, breach of statute, or contempt of court.

INJECTING DRUG USE

While Australia has one of the lowest HIV infection rates in the world among people who inject drugs, hepatitis C infection rates are high. Less than two per cent of people who regularly inject drugs in Australia are infected with HIV; however,

researchers estimate that hepatitis C prevalence among people who inject drugs is currently around 50 per cent.

This variance stems in part from:

- i) the existing high prevalence of hepatitis C at the time of implementation of needle and syringe programs in 1983
- ii) the relatively late identification of hepatitis C (1989) and subsequent availability of testing procedures (1990)
- iii) the virulence and ease of transmission of hepatitis C.

Any contaminated item which is handled or which comes in contact with the site of injection can transmit the virus.

Hepatitis C infection has been endemic amongst people who inject drugs since at least the 1970s – hence a large pool of infection existed prior to the implementation of prevention measures. This has placed enormous pressure on current prevention programs.

The stigma associated with injecting often impacts on the ability of people to seek information, treatment and support for their hepatitis C infection.

A significant number of people infected with hepatitis C through injecting drug use no longer continue to inject. Hepatitis C can be a reminder of a lifestyle many have left behind. This can impact on people when they learn they are infected, and subsequently need to tell partners or family about lifestyle choices made in their past. Informing partners, family members and friends about a previous history of injecting drug use can be an extremely difficult experience.

HEPATITIS C IN PRISONS

According to *Hepatitis C: A Review of Australia's Response*, there remain significant areas of concern in relation to an effective response in prison settings.

The report outlines two priority issues:

- i) Inmates' lack of access "to effective preventative measures, such as sterile needles and syringes and methadone programs"
- ii) The preparedness of prisons for the future clinical needs of inmates with acute or chronic hepatitis C.

Factors such as limited education, restricted access to sterile injecting equipment, and the continuation of injecting drug use behaviour by a large proportion of prisoners while in prison, compound the risk of hepatitis C transmission in custodial settings.

In its position statement on the Health Care of Prisoners and Detainees (November 1998), the Australian Medical Association states:

"The AMA believes that prisoners and detainees have the same right to access, equity and quality of healthcare as the general population. Because prisoners return to society after their imprisonment, their health is an issue of concern to the general population."

NEEDLESTICK INJURY

Needlestick injuries occurring outside healthcare settings, particularly those involving children, often create a great deal of alarm across the wider community. Interestingly, there have been no reported cases to date of hepatitis C transmission occurring as a result of accidental exposure to a used syringe.

Nevertheless, the general community expresses fear and concern when incidents of this nature occur.

In reporting such cases, it is particularly important to outline the immediate options that are available to people exposed in this way.

These options include:

- administration, within 36 hours, of HIV anti-viral medications to reduce the risk of HIV transmission (known as Post Exposure Prophylaxis, or PEP)
- initiation of hepatitis B vaccination as a preventative measure against hepatitis B infection.

The three to six month waiting period to confirm hepatitis C test results often produces fear and uncertainty. However, the provision of counselling and support can considerably reduce such uncertainty during this time.

Economic Analyses for Hepatitis C: A Review of Australia's Response, A Report to the Commonwealth Department of Health and Family Services, Shiell A, 1998

Epidemiology of the Hepatitis C Virus, Communicable Diseases Intelligence, Commonwealth Department of Health and Aged Care, 1999

Estimates and Projections of the Hepatitis C Virus Epidemic in Australia, Hepatitis C Virus Projections Working Group, ANCARD Hepatitis C Sub-Committee, 1998

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Hepatitis C: The Neglected Epidemic, Inquiry into Hepatitis C in New South Wales, NSW Legislative Council Standing Committee on Social Issues, 1998

HCV Research Papers, NSW Hepatitis C Council, Issues 1 to 6

Hepatitis C Prevention Education for Injecting Drug Users in Australia, Australian Research Centre in Sex, Health and Society, La Trobe University, 1999

HIV/AIDS, Hepatitis C and Sexually Transmissible Infections in Australia, National Centre in HIV Epidemiology and Clinical Research, Annual Surveillance Report 1999

Meeting the Needs of People in Australia Living with Hepatitis C, Australian Hepatitis Council Education Reference Group, 1996

The Nationally Co-ordinated Hepatitis C Education and Prevention Approach, Australian Health Ministers' Advisory Council, 1996

National Hepatitis C Action Plan, Australian Health Ministers Advisory Council, 1994

The National Hepatitis C Strategy 1999-2000 to 2003-2004, Commonwealth Department of Health and Aged Care, 2000

A Strategy for the Detection and Management of Hepatitis C in Australia, National Health and Medical Research Council, 1997



ALT: alanine aminotransferase - a protein which, when found in the blood in elevated quantities, generally indicates liver damage.

ANCAHRD: Australian National Council on AIDS, Hepatitis C and Related Diseases – this council is appointed by the Federal Minister for Health and Aged Care to provide expert advice on issues relating to hepatitis C.

Antibody: A protein secreted by the immune system in response to infection. The antibody binds to an 'enemy' molecule - in this case, a specific part of the hepatitis C virus - in an attempt to destroy the virus or prevent it from infecting other cells.

Antigen: anything introduced into the body that is seen as foreign. An antigen stimulates the immune system into producing antibodies to attack it.

AST: aspartate aminotransferase - a protein which, when found in the blood in elevated quantities, generally indicates liver damage (although it is less specific than ALT).

Asymptomatic: having no symptoms.

Blood and blood products: components of blood including red cells, platelets and plasma that are separated out by blood banks.

Chronic active hepatitis: any form of liver inflammation lasting more than six months and causing continuing damage to liver cells. It often precedes cirrhosis.

Cirrhosis: a condition in which scar tissue develops on the liver - to the extent where such scarring becomes extensive and permanent. It interferes with the normal functioning of the liver.

DNA: deoxyribonucleic acid, the genetic material which determines a cell's activities and carries the cell's genetic code.

Epidemiology: the study of patterns of disease in a population.

Fibrosis: scar formation resulting from the repair of tissue damage. If it occurs extensively in the liver, it is called cirrhosis.

Hepatitis C antibody test: these tests were developed in 1990 to detect hepatitis C antibodies - the body's first response to the virus. The test searches for a limited number of signs of the antibody, such as the way its shell or envelope is made. These tests have been superseded by newer generation tests with improved sensitivity and specificity.

Gastroenterology: the branch of medicine specialising in diseases of the liver, stomach, intestines and oesophagus.

Genotype: different genotypes of the one virus are similar enough to be regarded as the same type, but have some minor differences in their genetic composition. These differences may mean the various genotypes react differently to our immune response or to drug treatments and natural therapies.

Haemophilia: a hereditary blood disease where the blood fails to clot and abnormal bleeding occurs. It is a chronic condition, treated by injections of Factor VIII.

Hepatocellular carcinoma: cancer of the liver. A malignant tumour arising in the liver, in most cases occurring as a complication following cirrhosis.

Hepatologist: a liver specialist, usually working in a liver clinic.

Incidence: the number of new infections occurring in a given period of time within a specific community.

Mutation: when cells divide or viruses multiply, their genetic material must be copied. Sometimes mistakes are made when this happens and the resulting new cell or virus is different in some way.

Non-A non-B hepatitis: the term for hepatitis shown not to be caused by hepatitis A or hepatitis B. In 1989, this form of hepatitis was shown to be mainly caused by hepatitis C.

Notifiable disease: any illness whose detection must be reported to State, Territory or Commonwealth health authorities for the purposes of epidemiological surveillance (in order to initiate investigative or control measures).

Prevalence: the number of cases of hepatitis C in the community at any one time, usually expressed as a percentage.

Pathogen: any organism or substance capable of producing a disease.

PCR: Polymerase Chain Reaction (PCR) is a process used to amplify pieces of the genetic make-up of a cell or virus. The amplified pieces are then detected and the presence of the virus itself can be determined.

RNA: ribonucleic acid, a genetic material similar to DNA. It often acts as a 'message' that is delivered to cells prompting them to change and prepare for reproduction.

Viral load: the amount of virus present in a person's blood stream. It is usually measured by the PCR quantitative test and the result is given in number of virus particles per millilitre of blood.

Virus: a vast group of minute structures, composed of a sheath of protein encasing a core of nucleic acids which are the building blocks of RNA and DNA. They are characterised by a total dependence on living host cells for reproduction and metabolism.



Hepatitis C is now the most commonly notified infectious disease in Australia. It is a comparatively new public health issue, not well understood in the community.

Misconceptions and misinformation about the virus and people affected by it are widespread.

The following section offers alternatives to common terms, suggesting usage which reflects more positively on people with hepatitis C, and which contributes to more informed public discussion about the nature of the virus and its effects.

| TERMS TO AVOID | ALTERNATIVE TERMS TO USE |
|---|--|
| <p>HEP C VICTIM, HEP C SUFFERER</p> <ul style="list-style-type: none"> This implies a person with hepatitis C is powerless, and has little control over their condition. | <ul style="list-style-type: none"> person / people with hepatitis C hepatitis C positive person person living with hepatitis C |
| <p>JUNKIE</p> <ul style="list-style-type: none"> This term is stigmatising, as it implies a stereotypical image of someone who injects drugs. Use of this term further marginalises people who are often disadvantaged socially, and prevents them from accessing health services or from being actively involved in their own and others' health promotion. | <ul style="list-style-type: none"> person / people who use drugs illicitly person / people who inject drugs injecting drug user (IDU) |

| TERMS TO AVOID | ALTERNATIVE TERMS TO USE |
|---|---|
| <p>INNOCENT VICTIMS</p> <ul style="list-style-type: none"> • This term is sometimes used to describe people with medically acquired hepatitis C infection, or children who have acquired hepatitis C transmitted from their hepatitis C positive mother during pregnancy or at birth. • It incorrectly implies that people infected in other ways are guilty. | <ul style="list-style-type: none"> • person / people with hepatitis C • people with medically acquired hepatitis C • children with hepatitis C • hepatitis C positive people |
| <p>CARRIER</p> <ul style="list-style-type: none"> • This term is stigmatising and offensive to many people living with hepatitis C and attempts to differentiate between people who have cleared hepatitis C and those who have not. • The term portrays the subject as a public health threat, rather than as a person affected by chronic illness. | <ul style="list-style-type: none"> • person / people with hepatitis C • hepatitis C positive person • person living with hepatitis C |
| <p>HIGH RISK GROUP</p> <ul style="list-style-type: none"> • This implies that membership of a particular group, rather than unsafe behaviour, is the significant factor in hepatitis C transmission. • This term may lull people who do not identify with any group into a false sense of security. It is high-risk behaviours, rather than high-risk groups, that can transmit hepatitis C infection. | <ul style="list-style-type: none"> • high risk behaviours (blood to blood contact with a person with hepatitis C; mainly through sharing any equipment used to inject drugs, unsterile tattooing, unsterile body piercing) |

| TERMS TO AVOID | ALTERNATIVE TERMS TO USE |
|---|---|
| <p>GENERAL POPULATION; GENERAL PUBLIC</p> <ul style="list-style-type: none"> • Implies that people engaging in risk behaviours are not part of the general population. It artificially divides the community into those who are infected and those who are not, and falsely implies that demographics, rather than behaviour, is the critical factor in hepatitis C transmission | <ul style="list-style-type: none"> • the Australian population • hepatitis C negative people • all Australians |
| <p>INJECTING DRUGS CAUSES HEPATITIS C</p> <ul style="list-style-type: none"> • It is blood to blood contact with a person with hepatitis C that enables transmission, not injecting drugs per se. • Hepatitis C transmission primarily occurs only when people share any equipment used to inject drugs, or when hepatitis C infected blood contaminates hands and surfaces in the environment where injecting takes place, or where there is unsterile tattooing or unsterile body piercing with equipment contaminated with hepatitis C. | <ul style="list-style-type: none"> • hepatitis C is transmitted by blood to blood contact |
| <p>A PERSON DESCRIBED AS 'BEING HEPATITIS C'</p> <ul style="list-style-type: none"> • Sometimes people with hepatitis C are described as 'being hepatitis C'. This is confusing, and implies that hepatitis C consumes their whole lives. | <ul style="list-style-type: none"> • person / people with hepatitis C • hepatitis C positive person • person living with hepatitis C |

Used with permission - Hepatitis C Council of NSW

The following listings represent the primary hepatitis C contacts working in Australian healthcare and academic settings.

The protocol for contacting listed government agencies is to approach the Director of the agency or unit involved. Other staff may not be authorised to speak to or answer media inquiries.

Similarly, contact with community based agencies (such as Hepatitis C Councils or Injecting Drug User Groups) is appropriately made through the President or Executive Officer of the organisation.

NATIONAL ORGANISATIONS

Australian Hepatitis Council

Canberra

Peak organisation representing State and Territory Hepatitis C Councils at the national level.

ph: 02 6232 4257

www.hepatitisaustralia.com

Australian IV League (AIVL)

Canberra

Peak organisation representing State and Territory peer based injecting drug user groups.

ph: 02 6281 7851/2

www.aivl.org.au

Haemophilia Foundation Australia

Peak organisation representing the State and Territory Haemophilia Foundations.

ph: 03 9572 5533

www.haemophilia.org.au

Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD) Secretariat

ph: 02 6289 4381

www.ancahrd.org

Commonwealth Department of
Health and Aged Care
Population Health Division
Media inquiries: 02 6289 9264
www.health.gov.au/pubhlth/strateg/h
iv_hepc/hepc

Human Rights & Equal Opportunity
Commission
Sydney
ph: 02 9284 9600
www.hreoc.gov.au

STATE AND TERRITORY ORGANISATIONS

NEW SOUTH WALES

Hepatitis C Council of NSW
ph: 02 9332 1853
www.hepatitisc.org.au

NSW Department of Health
Media Enquiries
ph: 02 9391 9121

New South Wales Users and AIDS
Association (NUAA)
(Peer based injecting drug user
group)
ph: 02 9557 1476

Traids (Counselling, Information and
Advocacy for people with medically
acquired HIV and hepatitis C Centre)
ph: 02 9843 3143

Anti-Discrimination Board of NSW
ph: 02 9268 5555

HIV/AIDS Legal Centre NSW
ph: 02 9206 2060

QUEENSLAND

Hepatitis C Council of Queensland
ph: 07 3229 9238
www.hepatitisc.asn.au

Queensland Department of Health
Communicable Diseases Unit
ph: 07 3234 1155

Queensland Intravenous AIDS
Association (QuIVAA)
(Peer based injecting drug user
group)
Brisbane
ph: 07 3252 5390

Sunshine Coast Intravenous AIDS
Association (SCIVAA)
(Peer based injecting drug user
group)
ph: 07 5443 9576

DUNES
(Peer based injecting drug user
group)
ph: 07 5520 7900

Anti-Discrimination Commission of
Queensland
ph: 07 3247 0900

VICTORIA

Hepatitis C Council of Victoria
ph: 03 9639 3200
email: hepcvic@vicnet.net.au
www.hepcvic.org.au

Department of Human Services,
Victoria
Infectious Diseases Unit
ph: 03 9637 4182

Victorian Intravenous AIDS
Association (VIVAIDS)
(Peer based injecting drug user
group)
ph: 03 9381 2211

Equal Opportunity Commission of
Victoria
ph: 03 9281 7111

SOUTH AUSTRALIA

Hepatitis C Council of South
Australia
ph: 08 8362 8443
www.hepccouncilsa.asn.au

South Australian Health Commission
Communicable Diseases Control
Branch
ph: 08 8226 7177

SAVIVE

(Peer based injecting drug user
group)
ph: 08 8362 9299

South Australia Equal Opportunity
Commission
ph: 08 8207 1977

AUSTRALIAN CAPITAL TERRITORY

ACT Hepatitis C Council
ph: 02 6253 9999

ACT Department of Health, Housing
and Community Care
Population Health
ph: 02 6205 1561

Canberra Injectors Network
(Peer based injecting drug user
group)
ph: 02 6262 5299

ACT Human Rights Office
ph: 02 6207 0576

TASMANIA

Department of Health and Human Services

Sexual Health Branch
ph: 03 6233 6227

Tasmanian Council on AIDS and Related Diseases

ph: 03 6234 1242

TUHSL

(Peer based injecting drug user group)
ph: 03 6234 1242

Tasmanian Anti-Discrimination Commission

ph: 03 6234 3599

NORTHERN TERRITORY

Territory Health Services Disease Control Centre

ph: 08 8922 8874

Northern Territory Anti-Discrimination Commission

ph: 08 8981 3813

WESTERN AUSTRALIA

Hepatitis C Council of Western Australia

ph: 08 9328 8538
www.hepccwa.highway1.com.au

Health Department of Western Australia

Media Enquiries
ph: 08 9421 4042

Western Australian Substance Users Association (WASUA)

(Peer based injecting drug user group)
ph: 08 9227 7866

Western Australia Equal Opportunity Commission

ph: 08 9216 3900

HEPATITIS SPECIALISTS

Prof. Robert Batey

Director
Gastroenterology Department
John Hunter Hospital, Newcastle
ph: 02 4921 3486

Dr. Greg Dore

National Centre in HIV Epidemiology and Clinical Research
University of NSW
St Vincent's Hepatitis Clinic
ph: 02 9332 4648

Prof. Bill Sievert

Department of Medicine
Monash University
ph: 03 9550 5521/5523

ASHM

Sydney
Society of medical and health care
professionals involved in hepatitis C
and HIV/AIDS
ph: 02 9368 2700

Gastroenterological Society of Australia

Sydney
Peak body representing the
disciplines of gastroenterology and
hepatology in Australia
ph: 02 9256 5454

RESEARCH

Australian Department of Health & Aged Care

Online Hepatitis C Research
Register
www.health.gov.au/pubhlth/strateg/hiv_hepc/hepc/register/index.htm

ARCSHS

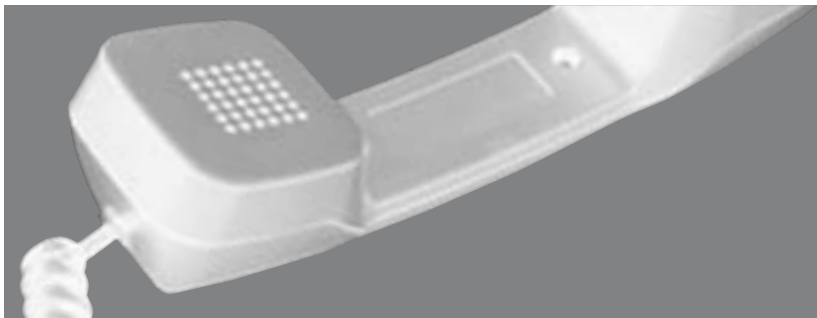
Australian Research Centre in Sex,
Health & Society
Melbourne
ph: 03 9285 5382
www.latrobe.edu.au/www/centstd/

NCHECR

National Centre for HIV
Epidemiology and Clinical Research
Sydney
ph: 02 9332 4648
www.med.unsw.edu.au/nchechr/

NCHSR

National Centre in HIV Social
Research
Sydney
ph: 02 9385 6776
www.arts.unsw.edu.au/nchsr/







Australian Hepatitis Council



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publications request line: 1800 022 863