



PREVENTING
DISCRIMINATION
AND REDUCING STIGMA
AND ISOLATION

- 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 people with hepatitis C against discrimination and stigmatisation and to provide redress for people who have experienced discrimination.
- Hepatitis C-related discrimination can arise from fear of transmission and/or from assumptions and judgements made about injecting drug use and about people who inject drugs.
- People with hepatitis C report discriminatory behaviour from some health service providers including general practitioners.



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

Many people with hepatitis C experience discrimination after disclosing their hepatitis C status to others, including health care workers, so careful consideration about who to disclose their hepatitis C status to and why is always advisable. Disclosure of hepatitis C infection may have an impact on personal and working relationships.

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 which may be difficult to comply with or may not be reasonable in the given circumstances.

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

EXAMPLES OF DISCRIMINATION

All people have a right not to be discriminated against in public life. Discrimination can be subtle or overt, direct or indirect, and can occur in all areas of life.

Examples:

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, the coach believing that she would infect others with hepatitis C virus 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.



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. Discrimination frequently follows disclosure of a person's hepatitis C status. See *Chapter 4: Hepatitis C Testing*.

THE EXTENT OF DISCRIMINATION AGAINST PEOPLE WITH HEPATITIS C

Hepatitis C-related stigma and discrimination is an added burden to a person with hepatitis C infection. It frequently has damaging health, financial, social and emotional consequences both for people living with hepatitis C and for the community.

The NSW Anti-Discrimination Board report "*C-change: the report of the enquiry into hepatitis C related discrimination*", released in November 2001 concluded that discrimination is driven by people's fear of contracting hepatitis C infection and a disdain for people who inject drugs, the population most affected by the infection. While this report made a number of recommendations for combating and eliminating discrimination against people who have hepatitis C in health care settings and in employment, the fear of discrimination following disclosure of hepatitis C infection remains a perennial concern for affected individuals.

In a 2006 study, most of the study participants receiving treatment chose a policy of non-disclosure in their workplace to minimise the likelihood of experiencing negative consequences. Others chose strategic disclosure to trusted friends, family or colleagues only while others found open disclosure as the most effective approach for gaining support. Disclosure of being treated for hepatitis C was identified as a bid to build supportive networks to make treatment easier to cope with and to avoid the stigma and discrimination that they fear they will encounter as a result of having hepatitis C.

Reported discrimination by health care workers towards those with hepatitis C covers a range of behaviours and actions including inappropriate comments

and unnecessary infection control procedures, breaches of confidentiality and refusal to treat. Research has shown that the attitudes of clients to their health care workers are related to their treatment experiences. People with hepatitis C report a less favourable treatment experience than people who do not have hepatitis C. The way health care workers relate to their clients who use illicit drugs, many of whom have hepatitis C, is an important factor in the quality of service provided.

➤ LEGISLATION RELATING TO HEPATITIS C DISCRIMINATION

FEDERAL LAWS

Disability Discrimination Act 1992

Administered by the Human Rights and Equal Opportunity Commission, this 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. Generally, any person who is treated unfairly because they have, or are presumed to have any form of a blood-borne infection can make a complaint of discrimination. 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 disabilities.

PRE-EMPLOYMENT MEDICALS

Although the use of pre-employment medicals is 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, and 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 council or to seek legal advice.

Example:

Indigo has hepatitis C. 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.

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, Human Rights and Equal Opportunity Commission, Health Complaints Unit, Medical Board, Dental Association or Nurses Board in their state or territory. *See Contact Section in Resources.*

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

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.

Standard infection control procedures (see *Chapter 3: Reducing Hepatitis C Transmission in the Community*) 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.

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.

Provided that standard infection control procedures are implemented, it is unnecessary to take any further precautions when treating a person with hepatitis C. A lack of confidence in standard control procedures can lead to action which could be viewed as discriminatory. A 2006 study of dentists *Discrimination or discretion? Exploring dentist's views on treating patients with hepatitis C* found that while the dentists surveyed had an appropriate attitude regarding patients with blood-borne viruses, some changed their practices when seeing a client with hepatitis C (e.g. double gloving). While discrimination may be unintentional, it is important to realise how the person may interpret comments and actions.

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 PRACTICED WITHOUT JUDGING OR SPECULATING ABOUT AN INDIVIDUAL'S INFECTIOUSNESS.

ALL BLOOD SHOULD BE TREATED AS INFECTIOUS AT ALL TIMES.

See Chapter 3: Reducing Hepatitis C Transmission in the Community.

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 a person's infection or disease status is unacceptable.

Common examples of discrimination by health care and allied workers:

- refusal to provide pain relief to people with a history of drug use;
- 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.

Health care workers living with hepatitis C may also experience discrimination. Hepatitis councils and counsellors can offer assistance in deciding who to tell and how to handle questions and reactions. Health care workers with hepatitis C can continue to carry out roles and functions they can perform safely in their job. However, health care workers who perform exposure-prone procedures (EPPs) have a professional and ethical obligation to know their hepatitis C RNA status and, if positive, must not perform EPPs. The issue of relevance in employing health care workers is whether they can safely fulfil the requirements of the position without putting a patient at risk of infection with the hepatitis C virus during medical or dental procedures.

Health care workers, who have cleared the hepatitis C infection with or without treatment, should continue to monitor their HCV status. *Refer to the National Hepatitis C Testing Policy and Infection Control Guidelines.*

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;
- access to and the effectiveness of NSPs;
- access to and the effectiveness of 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 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.

TERMINOLOGY

Avoid using the following terms: addict, addiction, drug addict, drug abuse, drug abuser, junkie 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;
- presence of withdrawal symptoms and/or dependence, not about addiction;
- person who injects drugs, rather than injecting drug user; and
- clarify meaning of any colloquial and/or sub-cultural terms associated with drug use, such as fits, smack, sharing 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 undertake 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 drug user of some substances may be complex as they may have a higher tolerance than others to pain medication e.g. opiates. 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 reducing harms 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 factor which has contributed to their infection; others may not be able to identify any specific risks. Making 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 health authority for policy and/or procedures for workers with hepatitis C and can seek confidential advice from their professional registration board.



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 in the availability of health services between various areas of Australia. The diverse nature of the Australian population has implications for health service planners and providers, in acknowledging and appropriately responding to the needs of particular communities, some of whom are affected by hepatitis C more than others.

People with hepatitis C come from a variety of backgrounds and have a very broad range of experiences and needs. Service providers should be able to offer 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 the inappropriate disposal of needles and syringes, 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** – some people may have acquired hepatitis C from medical procedures in the past before the introduction of standard infection control procedures. The effective infection control strategies now in place in health care establishments have reduced this risk and such events are now extremely rare in Australia.
- **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 may have acquired hepatitis C when hepatitis C became endemic following public health campaigns to vaccinate against schistosomiasis where injecting equipment was re-used. In Australia, most infection with hepatitis C found in older people from culturally and linguistically diverse backgrounds (CALD) 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 CALD backgrounds. 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 and Torres Strait Islander and African 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 themselves, risk stigma and possible punishment in disclosing this activity as a possible source of the infection.

- **Occupation and recreational procedures** – hepatitis C and other blood-borne viruses are not exclusively spread among people who inject drugs intravenously. Intramuscular injecting, often practised by body builders using large needles and syringes, can involve a great deal of blood. Many of these 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. Aboriginal and Torres Strait Islanders, people with mental illness, some lesbians and gay men, those who have been abused, some CALD sub-groups (e.g. Vietnamese or Sudanese youth) 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 access to professional development and support which compromises their service provision. Better resourcing of agencies, adoption of partnership approaches between service providers and improving the effectiveness of 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 have greater day-to-day priorities and may have difficulty in presenting for 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.*

People with hepatitis C often have a great deal of knowledge about the disease, and certainly have unique experiences. Hearing about their experiences can provide 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, while 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 do not have 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 discussions.

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 a hepatitis council and/or contact the Human Rights and Equal Opportunity Commission 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 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 Human Rights and Equal Opportunity Commission, Anti-Discrimination Board, Health Care Complaints Board, Medical Board, Nurses Board or Dental Association 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?

It will be useful to discuss your fears with more experienced co-workers, or your supervisor. 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.