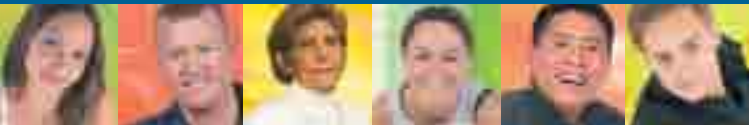


My Choice

My Rights

Hepatitis C



Disclosure,
anti-discrimination and
health complaints information
for people with hepatitis C

Contents

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Disclaimer

Hepatitis Australia takes care to ensure the information provided in this booklet is accurate, however, it is for general information only and not intended as medical advice. Hepatitis Australia encourages all readers to seek independent medical advice before making any decisions based on the information provided in this booklet.

Further information

For further information about hepatitis C please visit the Hepatitis Australia Website www.hepatitisaustralia.com or call the National Infoline 1300 437 222


Feedback

If you would like to provide feedback about the information contained in this booklet please email admin@hepatitisaustralia.com

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Introduction

 **D**isclosure means giving personal or sensitive information to other people; in this case, it means telling people you have hepatitis C. In most situations it is up to you to decide whether or not to disclose that you have hepatitis C. There are only a small number of instances where you may be required by law to tell others you have it. Many people find telling others they have hepatitis C is not easy. Others have few, if any problems. This booklet is designed to assist you to weigh up both the risks and benefits of disclosure. We hope it will help you to make decisions about disclosure that are right for you.

Everyone has the right to be treated fairly and with respect. Sometimes disclosing that you have hepatitis C can lead to a breach of confidentiality or discrimination. Being discriminated against can make you feel angry, humiliated, isolated and upset. The information in this booklet provides you with information about what discrimination means

under the anti-discrimination laws in Australia, when hepatitis C discrimination is against the law and also when people are legally allowed to discriminate. Information related to health care complaints and health care complaints commissions is also provided. If you wish to take action, information about who you can complain to and how to prepare a complaint is also provided.

The staff of your local hepatitis organisation are available to assist you with further information or help you think through your options and refer you to other agencies. Contact details of relevant agencies including your local hepatitis organisation and legal aid centres can be found at the back of this booklet.

Disclaimers

It is important to be aware that the information provided here is not a substitute for legal advice. There are many differences between the state, territory and federal anti-discrimination laws and between state and territory health care complaint laws. Working out which is the best agency to deal with your complaint depends on what happened in your circumstances. Should you decide to make a complaint, more legal advice can be provided by the legal aid commissions and/or disability discrimination legal centres in each state and territory.

Although the examples used in this booklet are fictitious, they are based on real experiences of discrimination and unfair treatment that were

reported to the New South Wales Anti-Discrimination Board's inquiry into hepatitis C- related discrimination in 2001. In addition, some comments related to the personal experiences of members of the Hepatitis Australia Community Reference Group have been included.



Do I have to disclose?



There are a small number of circumstances in which people with hepatitis C are required by

law to disclose:

- If you want to give blood to the Blood Bank and you know you have hepatitis C, or have had hepatitis C in the past you must tell them. Your blood will not be accepted for donation. The Blood Bank has to be careful that the blood they provide does not contain any blood-borne viruses such as hepatitis C. All blood will be screened (tested) for a range of infections, including hepatitis C.
- If you are a health care worker who performs exposure-prone procedures and you have hepatitis C and have tested positive on a PCR, or polymerase chain reaction test (which identifies viruses and genotypes and measures viral load), you are required to notify your employer. Confidential advice can be obtained from an



infection-control practitioner about whether or not you need to disclose, and how having hepatitis C could affect the work you do. A hepatitis organisation, your union, or the health department in your state or territory will be able to give you more information about this; requirements differ from state to state.

- Exposure Prone Procedure (EPP) is deep body cavity surgery with sharp instruments where there is not always a clear line of sight between the eyes of health worker and their hands. Applies to surgeons/dentists and any helper intimately involved in the operation.
- Some insurance policies, particularly for life insurance, require that you disclose any infections, disabilities or illnesses you have that might influence the insurance company's decision to insure you. If you do not provide this information, the company can refuse to pay any claim you make on the policy where hepatitis C is a contributing factor. Income protection insurance can also fall into this category. Be sure to read all insurance policies carefully and seek advice if you feel you need to.
- If you are a member of the Australian Defence Force, you are required by Defence regulations to declare your health status with respect to disease, illness or injury. The purpose of this declaration is to ensure that you receive appropriate health care and that you are employed in a manner which does not jeopardise your health or safety or that of others. If you want to join the Australian Defence Force, you are required by law to disclose any existing medical conditions on

application. If you are found to have hepatitis C whilst serving, you will be given appropriate clinical management and a decision on your future career is decided on a case by case basis taking into account factors such as the outcome of your treatment.

In the situations just described, the organisations concerned are exempt from discrimination laws concerning hepatitis C, but only in very specific circumstances. If you are not sure about whether or not you need to disclose that you have hepatitis C, the contacts at the back of this booklet can give you up-to-date information about when disclosure is necessary.





Disclosing to friends and family

She stated that she had disclosed to her sister-in-law ... and her sister-in-law responded by bursting into tears and saying that she also had hep C but didn't want to tell anyone.

When thinking about disclosing, perhaps the main question to ask yourself is, 'What will the benefits be for me if I disclose?'

Friends and family members can offer valuable support at a time when you might be feeling uncertain about your future and scared about your health. They can help you cope with your feelings when you find out you have hepatitis C; they can help you deal with the physical and mental challenges; and they can support you if you are discriminated against because you have hepatitis C.

Of course, there could be negative reactions when you tell family members and friends. Some people have found themselves isolated and shunned.

This kind of reaction from loved ones (and others) often happens because many people know little about hepatitis C; what it is, how it's transmitted and how it affects someone. Other negative reactions can be a result of people associating hepatitis C with injecting drug use and the preconceptions they have about this.

It is important that you find out as much as you can about hepatitis C before you tell others. Giving people accurate information (including booklets, pamphlets and information from the internet) often helps correct wrong ideas they may already have about hepatitis C and people with hepatitis C.

If you decide to disclose, you are not making a confession and you have nothing to be ashamed of, even though you might feel ashamed or embarrassed. You are simply sharing information about yourself.

You might want to practise disclosing in your mind first, with a friend who knows that you have hepatitis C, or with a counsellor or someone from your local hepatitis organisation. Whatever you decide, it is a good idea to be prepared for questions people may ask, including how you got hepatitis C.

A positive, supportive response is the best outcome, but it's important to be prepared for a negative reaction. If this happens, remember that it is because of the beliefs and knowledge of the person you have told. People react the way they do because of the information (or lack of it) they already have about hepatitis C and people with hepatitis C.

When I told my family, they were unsure what it meant. It was good to be able to give them information about hepatitis C, so that they could understand what it meant for me and them.

If possible, have a supportive person or people you can easily contact when you are disclosing to someone who is important to you. Sometimes you need support regardless of whether you get a negative or a positive reaction. It can be a big thing to share something you may have told very few, if any, people about.

When telling someone you have hepatitis C, no matter how they react, you might suggest they phone a hepatitis telephone information service or helpline, or give them some booklets containing basic information about hepatitis C.

It can be confronting for friends or family to find out that you have hepatitis C, so it's important to give the person time to come to terms with this new information about you and the virus. Give them a few days (or more if they need it) to absorb everything, including reading through the information you gave them.

Disclosing is rarely easy, so, no matter how those close to you react to being told, be proud of yourself for having had the courage to share something very personal with others.

My grandmother guessed. She's eighty and she loves to have a beer. I had two beers with her and said, 'Nan, I gotta lie down'; and she said, 'You only had two beers. Have you got that hepatitis C?' I asked her how she knew. She said, 'Well, you can't drink with that. Why didn't you tell me? This is silly. You are sitting there drinking beer to make me happy and you can't drink. You're nuts. You should have told me.' That was pretty amazing.

Sexual partners

There is no legal obligation to disclose your hepatitis C status to a sexual partner. Hepatitis C is not classified as a sexually transmissible infection, and transmission through sexual activity is considered unlikely in the absence of blood.

Blood-to-blood contact may occur due to the presence of menstrual blood, skin grazes, sores, cuts, scratches or blisters in the genital, anal or mouth region. In these circumstances, the risk of hepatitis C transmission through sexual contact is increased.

Transmission of hepatitis C among men who have sex with men is an emerging issue and is associated with both unprotected sex and HIV infection co-infection. Some men with HIV choose not to practice safer sex when having sex with other HIV infected men. These circumstances combine to create an increased risk for hepatitis C transmission. Around 13% of people with HIV in Australia also have hepatitis C.

All sexually active people should consider safer sex practices because of the risk of a sexually transmissible infection, and in certain circumstances, the risk of a hepatitis C transmission through sexual activity. Safer sex includes using condoms and water-based lubricants during penetrative vaginal or anal sex. Dental dams (squares of latex that can be used to cover the vulva and anus) during oral sex. Latex gloves should be used during penetration with the hands or fingers.

Lovers were a more confronting matter. If a partner was using, disclosing was not always easier — fear is fear. No matter what your intake or method of using drugs is, resources, referrals and information are good supports to call on. I found telling partners

who did not have similar using habits to me more difficult, and I must admit that shame and a pronounced fear of rejection did come into play. But I'm reasonably feisty when it comes to hepatitis C, so once again discussion and resources assisted enormously. This is not to say partners didn't find my being positive uncomfortable, difficult and frightening, but generally I feel I have not been hurt or stigmatised by disclosing to others.

You are under no legal obligation to disclose your hepatitis C status to your sexual partner, however, disclosure to a sexual partner should be actively considered to establish safer sex practices in circumstances where there is an increased risk of transmission. Additionally, your partner might be able to offer you valuable support in a way that is different from the support you receive from family members and friends.

If you prepare what to say before disclosing to your sexual partner, it will help both of you manage what can be a difficult or uncomfortable situation. Your partner might need more information about hepatitis C, its possible effects on your health, and how it is transmitted. Being able to give them this information might help them understand the feelings you are experiencing and any physical symptoms you have. Be sure to give them the time they need to digest all this new information.

I disclosed my hep C status to my partner in a pretty blasé fashion, thinking it was no big deal. He was taken aback & would use it against me, refusing to kiss me and saying things like he would go & see my friend because she didn't have hep C. It made me realise that disclosure was something to be managed carefully.



Disclosure and children

Kids interpret things as kids, not as adults ...

Several difficulties can arise with children and hepatitis C. It could be that you have hepatitis C and you're not sure if you should tell your child or children. You might have decided to tell them but aren't sure what to say. How much should you tell them? Perhaps your child has the virus but does not yet know: Do you tell them? When do you tell them? Do you tell their school? What about the parents of children they play with?

Remember that children do not think the way adults do. Small children in particular, tend to believe that what happens around them is because of something they have or haven't done. A change in your mood as a result of having hepatitis C, or being on treatment, can have a big impact on a child. If they do not understand the cause, they will probably think they are the cause of the mood change. This is just one example of how children can be affected by hepatitis C without adults being aware of it.

If you or your child has hepatitis C and you choose to disclose to them, it is worth noting that children can find it very hard to keep secrets. Placing the burden of secrecy on a child, even a teenager, can lead to problems for both them and you if or when that child does end up telling others.

When disclosing to a child, either that you have hepatitis C or that the child has the virus, there are a number of things to think about:

- why you are disclosing to them
- the age of the child and their level of maturity
- how much information you think they can understand
- how you think they might react
- what mental and emotional support they might need.

No matter how well you know your child or children, it might be useful to consult a child psychologist, school counsellor (or similar) or hepatitis organisation before disclosing, so as to have all the necessary information. Well-planned, informed disclosure can ensure that your children understand as much as possible about the virus. Ill-informed disclosure can lead to negative emotions such as confusion, anger, and feelings of betrayal and isolation.

During adolescence, my father explained things to me (about hepatitis C), so that I would not get the wrong information.

Although you do not have to disclose to schools or childcare centres that your child has hepatitis C, you might like to investigate education facilities to find one that has a helpful attitude to affected children or adolescents. You can do this by making anonymous phone calls to discuss the matter with the principal or school counsellor, or by contacting your local hepatitis organisation. In this way, you will not place yourself and your child in a difficult position by deciding on a school or childcare centre that does not have a practical (or caring) attitude towards children with hepatitis C infection.

A school that does not disclose your child's infection to anyone unnecessarily and does not treat your child differently from others will make things easier for all concerned, particularly your child. All schools should follow standard infection-control procedures.

Kids often cut, bruise and graze themselves when playing. If your child has hepatitis C and engages in play that may result in blood being present, you will have to decide whether or not to disclose to playmates' parents. This can be difficult, especially if you don't know the parents well. You might be able to gain an understanding of other parents' attitudes by initiating discussions about first aid precautions, drugs in school or chronic conditions (such as hepatitis B or HIV) and noting how they respond.


Remember, there is no legal obligation to disclose your child's status to their school, child carer or parents of playmates — using infection-control and first aid procedures that treat all blood as potentially infectious will reduce the risk of infecting other children.

After two or three months of fairly regular play dates, I told the other mother of my son's status. She was, at first, very sympathetic. However, after consulting her paediatrician, she decided that our children could no longer play together.

Being well prepared will help if you decide to tell other parents your child has hepatitis C. Have some written information you can leave with them. Encourage them to talk to a doctor you know and trust to pass on information that is accurate. Your school might be able to arrange information evenings about hepatitis C without disclosing the status of individual children or parents.



Disclosing at work

 **U**nless you work in, or are thinking of working in the Australian Defence Force, or are a health care worker who performs exposure-prone procedures, you do not have to tell your employer or anyone you work with that you have hepatitis C.

Occupational health and safety laws cover all places of work and state that employers must provide easy access to first aid materials and must treat all blood spills in the workplace as if there is an infection present. This means that all blood is assumed to carry a blood borne disease. For this reason there is no need to tell anyone at your work that you have hepatitis C.

If you are unsure about the quality of first aid at your work, you could volunteer to be the first aid officer. Then you can be sure that the first aid kit is always complete (with latex gloves, bandaging, and so on) and that proper first aid procedures are followed.

When applying for a job, you might have to fill out a form that asks questions about your health. You do not have to answer questions about hepatitis C, any treatments you have had, or time that you have had to take off from previous jobs because of your health. If your health history is required in order to determine whether you can meet the essential requirements of the job, your prospective employer must send you to a doctor who can then determine whether you are physically able to do the job. They cannot disclose specific health information. In most cases, having hepatitis C will not be relevant to your ability to do a job. In rare cases, though, such as health care jobs involving exposure-prone procedures, a person's hepatitis C status can be important.

Although there are many cases in which people with hepatitis C have been discriminated against at their place of work, you might want to consider disclosing if you think that could be of benefit to you. A caring and understanding employer or workmate can make things easier for you by giving you time off for treatment or when you're not feeling up to work. They can support you if others you work with are not understanding about your condition. They can help arrange your workspace and/or hours to ensure that you are comfortable, or they can make changes to the job you do so that you can cope more easily with being at work.

Although all this is certainly desirable, the reality is that quite often people who disclose to workmates or their boss find themselves discriminated against. You alone are in the best position to be able to predict how the people you work with will react to being told you have hepatitis C.

There may be circumstances in which you feel obliged to explain absences due to illness, attending doctors' appointments, or experiencing problems

as a result of treatment. While there is no requirement for you to provide details of your illness, some people find it best to deal with these situations by indicating that they have a 'liver problem', or a 'problem with their blood', rather than disclose they have hepatitis C.

Some people have income protection insurance or can draw on their superannuation to cover periods of unpaid absence from work. In these cases, the insurance or superannuation company will need to know why you need time off.

The information you give to insurance companies or Centrelink should not be passed on to your employer or people you work with. Your private health information is protected, and there is no reason for it to be given to anyone at your work.

You have control over your health information. If you feel you have lost that control at work, you could have grounds for making a complaint. See 'Health Complaint Laws in Australia' chapter.

I made a Workcover claim ... During the investigation the company legally obtained my medical records and were going to use my hepatitis C status as a case against my claim ... My claim was upheld, but two years later I am still treated with disdain and was isolated by my manager and some work colleagues.



Disclosing to health care workers



part from if you want to donate blood, you do not have to tell any health care worker you have hepatitis C. This means all kinds of health care workers, such as doctors, nurses, pathologists, dentists, osteopaths, and so on.

All health care workers are required to follow standard infection-control procedures. The only time they can be put at risk of contracting the hepatitis C virus through their work is by not following these procedures, or not being able to do so. If a health care worker becomes infected with hepatitis C at work, it is not the fault of the person whose blood infected them.

When it comes to disclosure, the decision you need to make is based on quality of care. You could ask yourself the following questions; if I disclose am I likely to receive better care? Does the health care worker need to know I have hepatitis C in order to give me the best care?

When completing a form which asks about your hepatitis C status for dental or medical reasons, remember there may be good health/medical reasons why you should disclose, e.g. poor oral health due to low saliva production, or liver unable to process medications, but from a legal point of view, you are under no obligation to disclose. Remember, all bodily fluids and blood is always treated as infectious if Standard Infection Control Procedures are being followed.

Some medications can be damaging to a liver that is trying to cope with the effects of hepatitis C. If you are given any medications, including things from an alternative health therapist, such as a herbalist or naturopath, ask them if the medicine is likely to stress your liver.

There are many reported cases of health care workers discriminating against people with hepatitis C. Sometimes pain relief can be withheld

or given reluctantly because the worker thinks all people with hepatitis C want drugs, not pain relief. Surgery has been delayed for people with hepatitis C and infection control has been exaggerated.

Although such discrimination might not happen to you, it is a possibility. If a health care worker does not need to know you have hepatitis C, think carefully about whether you need to tell them.

If you have been discriminated against by a health care worker and you want to make a complaint, See the section 'What is discrimination' or contact your local hepatitis organisation for more information.

I sought a Gastro (Gastroenterologist) some distance from where I lived. Upon meeting him, he virtually accused me of previously using drugs. The appointment was unpleasant and by no means friendly. I explained to the Gastro that his knowledge was poor and attitude unacceptable. I then angrily walked out. To my own detriment, I never went near a Gastro for seven years.



Disclosing to institutions



T

he general rule when dealing with institutions, such as government departments and insurance companies, is that you need to disclose that you have hepatitis C only if that information is essential to the service that is to be provided to you. For example, if you are applying for life insurance or income protection insurance, the insurance company can legitimately ask if you have any blood-borne diseases or other health conditions that could influence their decision to insure you.

Health departments

Hepatitis C is a notifiable disease. This means that when you receive a positive hepatitis C test result, the department of health (or its equivalent) in your state or territory will also have been informed. The information is used to help governments monitor how many people have the virus, what areas these people live

in, their age and sex, and how it was reported that the virus was transmitted. This helps policy makers make decisions about reducing hepatitis C transmission and informs them of hepatitis C's impact on the community. The departments are obliged to keep this information confidential; your personal details should not be passed on to anyone else without your permission.

Insurance

Insurance is a commercial activity, and companies have a right to find out how risky it is likely to be to insure a person. Insurers must use research and medical evidence to assess whether a person is more likely to make a claim, although it is usually against the law to have a policy of refusing people with hepatitis C.

Life and income protection insurance companies might refuse to insure you because you have hepatitis C, or they might offer you insurance at a higher premium (cost). These companies have a legal right to refuse you services or charge you more because you have hepatitis C, but only for the purposes of insuring you; not for any other reason.

Centrelink

If you apply to Centrelink for sickness benefits because you are unable to work as a result of hepatitis C, you will have to give a reason for your illness. In most cases this means that you will have to disclose that you have hepatitis C. Centrelink will ask for proof that you have a health condition that prevents you from working.

Any information you give to companies, government departments, and so on, about your health remains confidential and cannot be given to anyone else without your permission.

Sporting clubs

When playing sport, it is possible that you will experience an injury that results in cuts or grazes and the presence of blood. Do you have to tell your sporting club, team mates or opponents that you have hepatitis C?


The answer is no; you are not required by any law to disclose.

Although all sporting clubs and teams are obliged to use standard infection-control procedures in any first aid, many do not. You don't have to tell anyone you have hepatitis C, but it is worth remembering that you might have to take precautions against transmitting hepatitis C if you are injured and bleed. This could mean giving yourself a quick check after any falls or heavy body contact, acting quickly to remove yourself from the field or court and stopping any bleeding, or simply being careful about which sports you choose to play.

Ensuring that your team has a complete first aid kit (including latex gloves) is another precaution you can take without having to tell anyone you have hepatitis C. You can also contact the sport's local governing body to remind them that all registered clubs have obligations to follow standard infection-control procedures. This can be done anonymously.



My health information and privacy

 **Y**our private health information is just that — private. Health records can be passed from one person to another only in very limited circumstances that have to do with your personal care and the notifying of an infectious disease. In the vast majority of cases, no one can make use of, or pass on your health records without asking you first, and without you allowing them to do so.

If you think information about your health has been given to others without your permission, you can make a complaint to the health care complaints commission (or its equivalent) in your state or territory. This also applies if you have been tested for hepatitis C without your permission. All states and territories have arrangements for handling complaints made as a result of the misuse of private health information.

Usually, you need first to lodge your complaint with the organisation, company or government agency you believe has passed on, or used information about your health unnecessarily, or without your permission. This is best done by writing a letter or sending an email to the manager of the person you think has breached your confidentiality.

The letter or email should provide the name of the person, section or agency you have a complaint against. You should also detail the nature of the complaint (that is, what happened to make you want to complain), the date it happened and how you think the matter should be resolved. See the 'Contacts' chapter for details of contacts that can help you with your letter or, ask the hepatitis organisation in your state or territory for assistance.

If you are not happy with the way your complaint is handled at this stage, you can then pass it on to the state or territory body that handles such complaints.

Because there are differences in the way each state and territory handles complaints, it is best to contact the relevant authority in your area to find out exactly what you need to do.

Keep all letters, emails and other correspondence relating to your complaint. Writing down the dates and content of phone calls is also a good idea. This information can be used to support your claim if it is investigated.

For more information on privacy, contact the Office of the Privacy Commissioner for the National Privacy Principles. See the 'Contacts' chapter for details.




What is discrimination?

health care complaint laws. See 'Health Care Complaint Laws in Australia' chapter.

In this section we look at the following:

- what 'discrimination' means under anti-discrimination laws
- when hepatitis C discrimination is against the law
- what you can complain about under anti-discrimination laws
- when people are allowed to discriminate.

Anti-discrimination laws cover both direct and indirect discrimination. Usually, when people with hepatitis C are discriminated against, it is direct discrimination.



If you choose to disclose, you may experience some discrimination. The following information may help you deal with this.

Generally, discrimination occurs when someone is treated unfairly because of a particular characteristic they have, such as being infected with hepatitis C. Under Australian anti-discrimination laws, hepatitis C is considered a 'disability' or 'impairment'.

Sometimes discrimination is obvious; sometimes it's harder to notice. You might feel you were not treated fairly, or that a situation did not 'feel right'. The first step in deciding whether to make a discrimination complaint is working out when unfair treatment will be considered unlawful discrimination.

If you think a health care provider or service has treated you unfairly, even if it is not discrimination, you might be able to make a complaint under

Example: refusal to treat

Barbara, who had sprained her ankle, attended a country hospital emergency department. When she told the treating doctor she had hepatitis C, he refused to treat her.





Anti-discrimination laws in Australia



It is against the law to discriminate against a person with hepatitis C in many different areas of life, such as in employment, in the provision of goods and services, in education, and in the provision of accommodation.

All state and territory anti-discrimination laws make it illegal to discriminate against a person because of their disability or impairment. It is also against the law to discriminate against a person because they are thought to have a disability or impairment. Hepatitis C is covered by the definition of disability or impairment under these laws.

Some state and territory laws that deal with discrimination are called equal opportunity laws; they are basically the same kind of laws. In this booklet, 'anti-discrimination laws' refers to both anti-discrimination and equal opportunity laws. There are anti-discrimination or equal opportunity commissions in each state and territory; in this booklet, when we refer to

anti-discrimination commissions, we are referring to both anti-discrimination and equal opportunity commissions.

Federal legislation — the *Disability Discrimination Act 1992* — makes it unlawful to discriminate on the basis of a person's disability anywhere in Australia. The Human Rights and Equal Opportunity Commission (HREOC) handles complaints of disability discrimination made under the *Disability Discrimination Act*. The HREOC office is in Sydney, but the commission handles complaints from all over Australia.

In addition to the federal legislation, each state and territory has its own anti-discrimination law:

- New South Wales — the *Anti Discrimination Act 1977*
- Victoria — the *Equal Opportunity Act 1995*
- Queensland — the *Anti Discrimination Act 1991*
- Western Australia — the *Equal Opportunity Act 1984*
- South Australia — the *Equal Opportunity Act 1984*
- Tasmania — the *Anti Discrimination Act 1998*
- Australian Capital Territory — the *Discrimination Act 1991*
- Northern Territory — the *Anti Discrimination Act 1992*.



Hepatitis C discrimination

Hepatitis C is considered a disability or impairment in all state and territory anti-discrimination laws, as well as the federal law.

In South Australia, the definition of 'impairment' in the Equal Opportunity Act does not cover people discriminated against because of hepatitis C if they have no physical symptoms. So, if you were discriminated against in South Australia because you have hepatitis C but you do not have any symptoms or illnesses because of hepatitis C, you would need to make a complaint to the Human Rights and Equal Opportunity Commission under the *Federal Disability Discrimination Act*.

Drug use discrimination

Most people with hepatitis C in Australia were infected through unsafe injecting drug use, and people with hepatitis C are often discriminated against because of the link between the virus and injecting drug use. This discrimination can occur regardless of whether or not you have ever injected drugs.

It is unclear whether drug 'dependence' or assumed 'dependence' is considered a disability and whether anti-discrimination laws cover it. If you are discriminated against because of your past assumed or actual drug use, this could be disability discrimination. There might be better options, though, such as making a complaint under health care complaints laws. It is important that you obtain legal advice about the best option for you.



What you can complain about under anti-discrimination laws



As discussed, it is against the law to discriminate against a person with hepatitis C, or who is thought to have hepatitis C in many contexts, for example, in employment, in the provision of goods and services, in education, in the provision of accommodation, and by clubs.

Anti-discrimination laws cover only discrimination that occurs in public life. They do not cover things said or done in private, for example, offensive remarks made by a family member.

It is important to seek advice about whether your state or territory anti-discrimination law covers your situation or whether it would be better to make a complaint under the Federal Act. There are differences between the state, territory and federal laws; for example, trainees and volunteers are protected under some state and territory laws but not under others.

Employment

Anti-discrimination laws cover all kinds of employment relationships. You can complain if you are discriminated against when you apply for a job or are a current employee, a contract worker, or a member of a partnership. Some examples of discrimination at work are:

- refusing to employ a person with hepatitis C, even if they can do the job
- offering employment with less favourable conditions than the employer would offer to a person without hepatitis C
- denying a person with hepatitis C a promotion or access to training because they have hepatitis C
- letting work colleagues harass a person with hepatitis C, for example, excluding a person from a team meeting or calling the person offensive names
- dismissing a person because they have hepatitis C.

There are some exceptions and some occasions when it might not be against the law to discriminate against you in employment, so it is important to seek legal advice. See the next section; 'When is it Lawful to Discriminate?.'

Example: denied promotion

Ashley works as a graphic designer. Her boss, Margo, often used to give Ashley good feedback about her work and encouraged her to think about taking on a management role.

Ashley started to feel tired and weak at work and took sick leave to regain her energy. She worried that her boss would think she was not pulling her

weight and decided to tell Margo she had hepatitis C and that from time to time that meant bouts of fatigue. Margo appeared disturbed by the news and asked whether Ashley could manage her job. Ashley said she'd be fine, but she felt uneasy about Margo's reaction. She reminded Margo that she hadn't taken more sick leave than anyone else at work and that she'd only taken half her sick leave entitlement for the year.

During the next few months, Ashley's health improved considerably. Her liver function tests were normal, and she had much more energy. Her working relationship with Margo had, however, soured. Margo was much less interested in her work and offered little or no feedback, often allocating work by email rather than speaking to Ashley directly, as she used to do.

Later, a 12-month position as a manager in the company was advertised. Ashley applied. Another employee, George, was appointed to the position. He had been with the company six months and had only two years' experience as a designer; Ashley had seven years' experience and had been with the company for two years.

Ashley asked why she didn't get the position. Margo said she didn't think Ashley's work had been up to standard and that she was concerned Ashley would not be able to handle the stress of the job because of her health. Ashley decided to make a discrimination complaint.

Tips

- It is not necessary to show that the discriminatory conduct on the basis of hepatitis C was the only reason for Ashley not being offered the job. If one of the reasons Ashley was not offered the position was her hepatitis C status, this could be discrimination.
- Ashley's health had improved considerably, so it seems unlikely that the employer would be able to demonstrate that Ashley could not do the job because of her health.

Can I be made to have a pre-employment medical?

An employer has the right to ask you to have a pre-employment medical assessment, but they can do this only in order to determine whether you are capable of doing the job you are applying for. In most cases, having hepatitis C will not be relevant to your ability to do a job. If you are required to undergo a pre-employment medical, and the assessment reveals that you have hepatitis C, and you are not offered the job, this may be discrimination if having hepatitis C is not relevant to the requirements of the job.

The problem with such cases is that it is often hard to show that you were refused employment because you have hepatitis C. You might, however, be able to complain because the information about your hepatitis C status was requested. See 'Requesting information used to discriminate', at the end of this section.

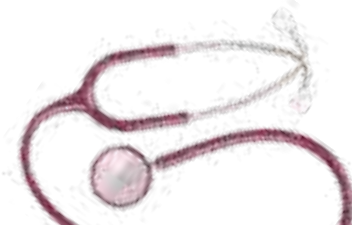
You may also have a case against the doctor who conducted your medical assessment for disclosing your hepatitis C status without your consent. A medical assessment should just give an indication of whether you are physically able to do the work or not — they should not disclose the specifics of your health history without your permission.

Provision of goods and services

It is against the law to discriminate against someone on the basis of hepatitis C when they are trying to gain access to, or are receiving most kinds of goods and services.

Anti-discrimination laws cover discrimination by all sorts of service providers, for example, health care providers such as dentists, doctors, nurses, hospital staff and physiotherapists. They also cover services provided by insurance companies, lawyers, government agencies and local councils. Discrimination in the provision of goods and services can take many forms, among them:

- refusing to provide the goods or services
- making it more difficult for a person with hepatitis C to obtain the goods or services than a person who does not have hepatitis C, for example, asking you to pay more, or to wait longer than a person who doesn't have hepatitis C
- discriminating in the manner in which the service is provided, for example, treating a person with hepatitis C rudely, or harassing the person in the course of providing a service.



Example: providing services on less favourable terms

Mario was to have a knee operation. Dr Jamieson, Mario's specialist, had told him to arrive early at the hospital and that he expected that the operation would be over by lunchtime. Dr Jamieson knew Mario had hepatitis C and had made a note of this on the front of Mario's file.

The anaesthetist saw Mario's file and told the hospital staff that Mario would have to wait until the end of the day to reduce the risk of hepatitis C transmission to other patients. Mario waited. Other surgery ran overtime and they could not operate on him that day. He was sent home. Mario waited a further three weeks before he was rescheduled for surgery, and again he was required to wait until the end of the surgery list on that day.

Educational settings

It is against the law to discriminate against a person with hepatitis C in an educational setting. This applies to primary and secondary schools, colleges, universities, TAFE, and other bodies that provide education or training. Discrimination in educational settings can involve:

- refusing an application for admission as a student
- offering admission on less favourable terms than the educational authority would offer to a person without hepatitis C

- denying a student with hepatitis C access or limiting their access to any benefit provided by the educational authority
- expelling the student
- harassment of a student with hepatitis C by other students or the staff of the educational authority.

Harassment

Harassment is any behaviour that is humiliating, offensive, intimidating, insulting or ridiculing. It is against the law to harass a person because they have, or are thought to have hepatitis C. Harassment is a form of discrimination in all areas covered by anti-discrimination laws, including at work, at your local club and at school or university.

Under anti-discrimination laws in some states (such as Tasmania), and under federal law, harassment because of a person's disability is specifically banned. In other states and the territories it is not covered specifically, but courts and tribunals have found that harassment on the basis of a person's disability is a form of discrimination and so is covered by anti-discrimination laws.



Example: harassment at work

Some of Martina's workmates have been making offensive remarks about her because they have found out she has hepatitis C. Dan said loudly to Nancy in the staffroom, in front of other staff members, 'Don't drink out of that cup. You'll get what Martina's got.'

Martina felt humiliated, isolated, upset and angry about the way she was being treated and spoke with her manager, Meng. Meng spoke with Don and Nancy, told them not to harass Martina, and told them the basic facts about hepatitis C transmission. Despite this, Don and Nancy continued to make offensive comments, and Martina again raised her concerns with Meng. He didn't take the matter any further. Martina decided to make a complaint.

Vilification

Vilification involves a public act that encourages others to hate or ridicule a person or group of people, in this case because they have or are thought to have hepatitis C. A 'public act' can include comments made on the radio, in printed materials such as newspapers, pamphlets and posters in public places, and in television broadcasts.

Only the Tasmanian Anti-Discrimination Act makes it illegal to vilify a person or group of people on the basis of their disability. No other state or territory anti-discrimination laws do so.

Victimisation

It is against the law to treat a person unfairly because they have said they might make a complaint of discrimination or because they have made a complaint of discrimination.

Example: victimisation

Madhu made a discrimination complaint because she was being harassed at work. When her manager found out about the complaint, he gave Madhu the worst shifts and the hardest cleaning tasks, which had previously been shared by everyone.

The requesting of information being used to discriminate

The *Federal Disability Discrimination Act* and anti-discrimination laws in the Australian Capital Territory, Victoria, Western Australia, Queensland and the Northern Territory all make it illegal to ask a person for information on which discrimination may be based. It might not, however, be discriminatory to ask for the information if the person seeking it can show they needed it for a reason that was not discriminatory.

There is no provision like this in the New South Wales, Tasmanian and South Australian legislation, but you could make a complaint under the *Federal Disability Discrimination Act*. You should also seek legal advice about your privacy rights.



When it is lawful to discriminate



A

lthough it is against the law to discriminate against a person with hepatitis C in a wide range of areas of public life, there are exceptions. They differ in the various jurisdictions and can be complex, so it is important to seek legal advice.

This section looks at two kinds of exceptions that can make it lawful to discriminate against a person with hepatitis C in some circumstances.

Public health

Generally, it is lawful to discriminate against a person with hepatitis C if it is necessary to protect public health, for example, not allowing the donation of blood.

If an employer or service provider discriminates against you in order to protect the health of the public, they need to demonstrate that they did this for sound reasons.

Example: protecting public health

David has hepatitis C and works in a childcare centre. When his employer found out that David had hepatitis C, David was sacked. His boss Danielle said she was sorry to see him go because he was a good worker, but she had to think of the health and safety of the children first.

David made a complaint, saying he had been discriminated against at work. The childcare centre's management tried to argue that it was necessary to discriminate against David in order to protect health and safety of the children.

This argument would be unlikely to succeed because the best way to protect the health of the public is to make sure that standard infection-control practices are always followed.

Insurance

For an insurance company to decide whether to insure you, they need to weigh up the financial risks. To do this they can ask for information about your health, and you are required to provide it.

Although under anti-discrimination laws it would usually be illegal for an insurance company to refuse insurance to all people with hepatitis C, there are two circumstances in which the company can discriminate:

- if the discrimination is based on relevant research, that is, actuarial and statistical data
- if the discrimination is reasonable on the basis of other relevant factors.

So, an insurer can't refuse to sell you life insurance just because you have hepatitis C antibodies. They need to take into account more information, for example, if you have antibodies to hepatitis C but have no viral activity, there may be no justification for refusing to insure you. Nevertheless, if the latest research and a person's medical history show the person is more likely to become sick in future because of hepatitis C, the insurer may be entitled to rely on this exception and refuse insurance or charge a higher premium.

Example: life insurance exception

Alleda applied for life insurance. Her health was good and her liver function tests were normal. She provided a medical report to the insurer. The report said that her prognosis was good, but her application was rejected. She contacted the insurance company and asked why. She was told that it was company policy to refuse to provide life insurance to applicants with hepatitis C.

The insurer would need to demonstrate that the decision to refuse Alleda life insurance was based on:

- up-to-date research or medical opinion that took into account the latest advances in hepatitis C treatment
- Alleda's medical records.

If Alleda's prognosis was good, but the company routinely refuses all people with hepatitis C without regard to current research and information about their health, this would be discrimination.

Complaints about discrimination in the provision of life insurance, including insurance for continuing disability, should be made to the Human Rights and Equal Opportunity Commission under the *Federal Disability Discrimination Act*.

The Australian Charter of Healthcare Rights

On 22 July 2008, at a meeting in Canberra, Australian health ministers endorsed the Australian Charter of Healthcare Rights.

The charter was developed after wide consultation by the Australian Commission on Safety and Quality in Health Care. It details the primary rights of patients and consumers when seeking or receiving healthcare services in Australia. These rights are:

- access
- safety
- respect
- communication
- participation
- privacy
- comment.

The charter will become the reference point for all healthcare organisations which will use it as the basis for informing patients and consumers of their rights. The purpose is to provide information to underpin the provision of safe, high-quality care and to promote a shared understanding of the rights of people receiving care.



Health complaint laws in Australia



In all states and territories there are specific health care complaint laws and health care complaints commissions.

You have a right to complain if you are treated unfairly or are unhappy with the quality of service you have received from an individual health care worker or a health care service. This includes unfair treatment that might or might not be covered by anti-discrimination law.

The commissions have differing names, for example, the Health Services Commission, the Health Care Complaints Commission and the Health Rights Commission. In this booklet we refer to all these agencies generally as 'health care complaints commissions'.

The purpose of the laws

The health care complaints commission's focus on protecting the health and safety of the community by making sure that health care providers and services maintain proper standards of care, and have the necessary skills and expertise. Handling complaints is just one of their roles.

Health care complaint laws provide guiding principles for the delivery of health care. The commissions develop codes of health rights which describe the standards of service you can expect from health care providers. To find out more about this, contact your state or territory health care complaints commission or check their website.

The applicable laws are as follows:

- New South Wales — the *Health Care Complaints Act 1993*
- Victoria — the *Health Services (Conciliation and Review) Act 1987*
- Queensland — the *Health Rights Commission Act 1991*
- Western Australia — the *Health Services (Conciliation and Review) Act 1995*
- South Australia — the *Health and Community Services Complaints Act 2004*
- Tasmania — the *Health Complaints Act 1995*
- Australian Capital Territory — the *Community and Health Services Complaints Act 1993*
- Northern Territory — the *Health and Community Services Complaints Act*.

Health care complaints commissions often work with state and territory health registration bodies, such as medical, nursing and chiropractic registration boards to maintain health care standards and respond to complaints about health care providers. Some registration boards can hold disciplinary inquiries into the conduct of a practitioner, and a health care provider can be deregistered if they are found to have engaged in serious misconduct.

When you complain to a health care complaints commission, the relevant registration board will be told of your complaint and will be involved in deciding who, either the board or the commission, will investigate your complaint. You can also make a complaint against a health care provider that is not registered with a health registration body. For more information, see 'Health Care Complaint Laws in Australia' chapter.

Usually, you must try to resolve your complaint directly with the health care provider or service before you make a complaint to the health care complaints commission.

It's a good idea to contact the health care complaints commission in your state or territory. They'll discuss your problem with you and give you advice about how to complain directly to the health care provider or service. If the problem isn't resolved, you can then make a complaint to the health care complaints commission.



and what you can complain about

The kinds of health services you can complain about

Generally, you can complain about the professional conduct of any person or agency providing a health service in any state or territory. This covers a wide variety of health care providers and services, including services provided in a hospital, community health centre, private clinic or pharmacy. It can also include complaints about particular practitioners, such as a doctor, dentist, nurse, physiotherapist, occupational therapist, pharmacist, psychologist, or practitioner of naturopathy, acupuncture or other alternative health care workers. Some health care complaint laws also cover social work, welfare and leisure services where these services are part of a health service.

If you are in any doubt about whether the person or organisation you want to complain about is covered by the health complaint laws in your state or territory, contact your health care complaint commission.

What you can complain about

The following are examples of what you can complain about in relation to the conduct of a health care provider or service:

- being refused a service
- not being treated in a professional manner
- denial of your right to make informed choices about your health
- unfair treatment in how the service was provided
- inadequate care, such as failing to provide information about your treatment options
- inappropriate behaviour, such as harassment
- inadequate diagnosis, such as provision of incorrect information about hepatitis C transmission
- denial of, or restriction of access to your health records kept by the provider.

In contrast with anti-discrimination laws, it doesn't matter whether any of these treatment failings occurred because you have hepatitis C, are thought to have hepatitis C, use illicit drugs, have ever used illicit drugs, or are assumed to have done so.

Many state and territory health complaints commissions also deal with complaints about breaches of confidentiality by a health care provider or service. For more information about disclosure, confidentiality and your right to privacy, contact your state or territory hepatitis organisation.

If a health care provider in Western Australia refuses you services, it's important to note that you can complain only about a refusal by a public provider. If you're not sure whether this applies to you, check with the Western Australian Office of Health Review.



Example: reasons for complaint

Sawat went to her doctor because she was feeling tired all the time. Dr Macey tested her for a range of things but did not tell her he was testing for hepatitis C. When Sawat returned to obtain the results, Dr Macey seemed uncomfortable, even though he had been her doctor for three years. He told her she had hepatitis C. He seemed angry and said he thought she must be really stupid to get herself in this situation and that she should wake up to herself. Sawat was shocked and upset by the news of the diagnosis, but also humiliated and intimidated by Dr Macey's manner. She started to cry. Dr Macey told her there was not much point in their continuing the consultation and she'd just have to live with the tiredness. Sawat walked out.

Sawat could complain about several things:

- testing without her informed consent
- inadequate delivery of test result information
- the health professional's unprofessional manner
- inadequate care — such as failing to confirm the diagnosis by further tests and, if the diagnosis was confirmed, discussing what treatment options were available to her.



Want to take action?

Why complain?

Being discriminated against or being treated unfairly can make you feel angry, hurt, humiliated, isolated, anxious and upset. It can be hard to know what to do, but doing something about discrimination when it happens can make you feel stronger, and it can also lead to changes that benefit other people.

You need to decide whether you will complain. The decision must be right for you. It's best to wait until you understand the different options that are open to you before you decide to complain.

Even if you don't think you want to make a discrimination or health care complaint, it is helpful to know your legal rights. All anti-discrimination and health care complaints commissions provide telephone information and advice.



Resolving the problem yourself

Every situation is different, and the steps you take to resolve the problem will depend on your circumstances. Not all adverse situations necessitate making complaints under anti-discrimination or health care complaint laws. There are other approaches to consider. You could:

- talk directly to the person involved, tell them their conduct is affecting you and outline your concerns
- talk to their boss or the manager of the organisation or service about your concerns
- find out whether the service or your workplace has a complaints policy and procedures, and then try to use those procedures to resolve your complaint
- if the problem relates to your workplace, talk to your union, your manager or another member of staff to obtain advice or support with what you might do to redress your concerns
- talk to your local hepatitis organisation.

Usually you need to try to resolve the complaint directly with the health care provider or service before making a written complaint to the health care complaints commission in your state or territory. The health care complaints commission will help you decide how best to do this.

If you can't resolve the problem, then you can make a complaint to the commission. Some commissions will help you prepare your complaint; many have fact sheets to help you prepare your complaint and will explain what happens once you complain. This

information is available on their websites, or you can call and ask for it to be sent to you.

Deciding whether to make a complaint

Making a complaint can be demanding. If you are thinking about making one, it's a good idea to make sure you have the support of someone close to you, either a friend, partner or family member. It can be useful to have someone who you can talk to about the process and your feelings about it.

You can also contact the hepatitis organisation in your state or territory. They can help you think through your options and refer you to agencies that can help. Some hepatitis organisations also provide ongoing support if you decide to make a complaint.

It's also important to remember that sometimes anti-discrimination and health care complaints commissions can help you resolve the problem quickly. Most complaints about discrimination and health care delivery are resolved before, or as a result of conciliation. For more information on conciliation see 'What is conciliation?' later in this section.

One frustration with making a complaint is that it can be a slow and time-consuming process. In some cases you can ask for your complaint to be expedited, or 'fast-tracked', especially if you are going to be sacked or if you are being harassed and it is affecting your health.

Getting information and legal advice

Anti-discrimination and/or health care complaints commissions in your state or territory are a useful resource. You can contact them to discuss your problem or to obtain more information to help you decide if you want to make a complaint.

If you decide you do want to make a complaint, it can be helpful to contact the anti-discrimination or health care complaints commission in your state or territory. They will discuss your situation, let you know whether you are likely to be covered by the laws they administer, and give you information about how to make a complaint.

This booklet is a guide only. If you're thinking about making a complaint, seek legal advice so you know which option is best for you. There may be other options you can consider, such as privacy and unfair dismissal laws. This booklet contains contacts details for legal aid commissions and disability discrimination legal centres in each state and territory. These agencies offer free advice.

You also need to find out whether it is better for you to complain under the laws in your state or territory or under the *Federal Disability Discrimination Act*. Some types of complaint, such as those about life insurance or complaints by Commonwealth employees need to be made under the Federal Act.

Who can complain

If you think you have been discriminated against because you have hepatitis C, or you are unhappy about the health service you have received, you can make the complaint yourself. If you want someone to complain on your behalf, you need to ask your anti-discrimination or health care complaints commission who can do this.

Time limits: when to make a complaint

Most anti-discrimination and health care complaint laws require that you make your complaint within a set period. The periods vary, so you need to check with the commission in your state or territory.

Under some anti-discrimination and health care complaint laws, your complaint may be accepted outside the specified period if you have a good reason for the delay. Nevertheless, it is always better to complain within the specified period rather than risk your complaint being rejected. Even if a late complaint is accepted, it can delay the investigation.

Preparing your complaint

The Human Rights and Equal Opportunity Commission, all state and territory anti-discrimination commissions and most health care complaints commissions have a standard form to help you prepare your complaint.



Discrimination complaints

You must make your discrimination complaint in writing. Usually no special format is required, although in the Australian Capital Territory you must use the form provided by the ACT Human Rights Office. They can send it to you; it's also available on their website.

Health care complaints

In general, you need to make a health care complaint in writing. Some state and territory health care complaints commissions say you can make a complaint by telephone, although this usually needs to be followed up in writing. Some of the commissions will help you prepare your complaint.

Apart from New South Wales, no special format is required. The NSW Health Care Complaints Commission can initiate a formal investigation only if your complaint is in the form of a statutory declaration. The commission can send you the form you should use; it's also available on their website.

Tips for preparing a complaint:

- Remember to include your name, address and telephone number.
- Include the name(s) and address(es) of the person, people or organisation you are complaining about.
- Provide important background information, for example, if you are making a complaint about discrimination in employment, describe what your job is and how long you have worked with the organisation.
- Say what happened to you in the order in which it happened. Be specific; for example,

rather than saying, 'I am being harassed', say what the person who is harassing you is actually doing, when and how often.

- Include the dates on which significant events happened or provide a general time frame if you don't know the exact dates, for example, if the harassment has been going on for a period, state how many weeks or months and give specific examples of what has happened.
- If you are complaining under anti-discrimination law, you need to say you think you are being discriminated against because you have hepatitis C, or are assumed to have hepatitis C.
- If you have tried to resolve the complaint, outline what you have done and what happened, for example, you complained to your boss about harassment by your co-worker; the complaint was investigated, but the harassment has continued.
- If you had any problems because you made a complaint, include this information too, for example, after you made a complaint to your boss, you were given less interesting work and excluded from team meetings.
- Remember to sign and date your complaint.



Lodging your complaint

There are no special requirements for lodging a discrimination or health care complaint; you simply post the documentation to the relevant commission. Your complaint is formally lodged when the commission receives it. If you want to complain by facsimile or email, you need to check with the commission about whether they accept complaints in this format.

Once your complaint has been made, you can withdraw it at any time.

About the complaints process

As noted, there are differences in the anti-discrimination and health care complaint laws in each state and territory. There will also be differences in the ways that each commission handles complaints. Most commissions provide fact sheets about their complaint processes; these are available on their website, or you can call and ask for information.

Discrimination complaints

Anti-discrimination or equal opportunity commissions are the agencies responsible for investigating discrimination complaints.

The person investigating your complaint (sometimes called a 'conciliation officer' or an 'investigator') is independent. They do not represent you or the person you have made the complaint against. Their role is to help you:

- understand what anti-discrimination law covers
- put forward your point of view

- try to reach an agreement on how best to resolve your complaint.

Usually the anti-discrimination complaint process involves assessment, investigation, and then conciliation.

Health care complaints

The types of health care complaints can vary from a concern about poor communication to serious professional misconduct, and the approach taken will depend on the nature of the complaint. The health care complaints commission in your state or territory will advise you about the process they propose to follow once they have considered your complaint.

Health care complaints commissions tend to conduct formal investigations only when a complaint is complex or serious. In less serious or less complex matters they are more likely to help the parties resolve the matter through conciliation or other informal strategies. Sometimes conciliation will be tried first, with a formal investigation following if necessary.

Assessment and investigation

When the commission receives your complaint they will contact you to let you know they have received it and explain what is involved. They might also ask you for more information.

An officer of the commission will be made responsible for handling your complaint. They will consider whether your complaint is covered by the

laws the commission administers and whether the complaint has been made within the time limit. The steps after this vary depending on whether you have made a discrimination or a health care complaint, so we consider what happens next separately.

Discrimination complaints

Assessment

If you delayed making your complaint, sometimes the commission has to decide whether you have a good reason for this, and you might be asked for more information. If your complaint has been made within the time limit, the commission decides whether to accept or reject your complaint (often called 'declining' a complaint).

If your complaint is declined, the commission must tell you why, and whether you can appeal against their decision or take your complaint to a relevant court or tribunal. If your complaint is declined, it's important to obtain legal advice about your options.

If your complaint is accepted, sometimes the commission will formally notify you of this. Once accepted, your complaint will be investigated. Throughout this process you will be known as the 'complainant'; the person or organisation you have complained about is known as the 'respondent'. Both of you might be referred to as 'the parties' to the complaint. The person handling your complaint is usually called the 'investigator' or the 'conciliation officer'.

Investigation

The investigation usually involves the exchange of written information between you, the person or organisation you have complained about and the commission. Sometimes, if the investigator thinks you and the respondent might want to resolve the matter, they can quickly arrange a conciliation conference.

The investigator will usually write to the respondent to tell them you have made a complaint and what your complaint is about. They will enclose a copy of your complaint. The respondent is then given the opportunity to provide a written response within a certain time. The investigator will send you a copy of the response and you will be given an opportunity to respond to anything the respondent has raised, again within a certain time. Both complainant and respondent might need to answer questions or provide more information.

Once all the necessary information has been gathered, the investigator will usually prepare a report to the president or commissioner about the complaint. The president or commissioner then decides whether to hold a conciliation conference. In most cases, complaints are referred to conciliation.

Health care complaints

Taking into account the nature of your complaint, the officer of the health care complaints commission will decide how best to deal with your complaint and contact you to let you know how they propose to handle it. If the complaint is about a registered health care provider, the commission will work with

the relevant health practitioner registration board to decide whether the commission or the board will handle the complaint.

The initial stage of the health care complaint process involves an investigation in order to determine the best way to handle the complaint.

Once the officer has contacted you, they will contact the respondent, advise them that you have made a complaint, and explain what the complaint is about. Often this will be done in writing, and a copy of your complaint will be provided. The respondent is given the opportunity to provide a written response, and the officer will send you a copy of that response. You will be given the opportunity to respond to anything the respondent has raised within a set time frame.

Sometimes it is necessary for the commission to seek further information. This might involve gaining access to your medical records with your consent, and obtaining an expert opinion.

The commission can:

- help you complain directly to the health care provider, or advise you how to do it if you have not already done so
- help resolve the matter informally
- refer the complaint to conciliation
- investigate the complaint
- refer the complaint to the relevant health practitioner registration board
- refer to another authority for action
- take no further action.

If the commission decides not to take any action on your complaint, they will tell you why they are doing this and whether you can appeal against this decision.

What is conciliation?

Most complaints are resolved by conciliation. Both anti-discrimination and health care complaints commissions can refer a complaint for conciliation.

A conciliation conference involves a 'round table', structured discussion between you and the person or representative of the organisation you have complained about. An independent conciliator, who is often the officer who has been handling your complaint, leads the conference. Conciliation conferences are usually face-to-face meetings, although they can be done by teleconference.

The conciliator will set the ground rules about how the discussion should proceed, make sure both you and the respondent have an opportunity to tell each side of the story, help both of you discuss options and reach agreement on how to resolve the complaint.

Usually, the parties are not legally represented. If you want to be represented by a lawyer or your union, or you would like to bring along a person for support, you need to seek permission from the commission before the conference. Anything said during conciliation is confidential and can't be used if the matter is formally investigated (in the case of health care complaints), or goes to a court or tribunal (in the case of discrimination complaints).

Resolution of discrimination complaints

Discrimination complaints can be resolved in a number of ways, including by the respondent agreeing to:

- provide a private or public apology
- give you your job back
- change a discriminatory policy or practice
- provide anti-discrimination and harassment training to staff
- provide financial compensation for pain and suffering and/or loss of income.

If your complaint is not resolved at conciliation, you will need to decide whether you wish to take it to court. See 'Formal investigations or hearings', below.

Resolution of health care complaints

Health care complaints can be resolved in a variety of ways, among them the respondent agreeing to:

- provide an apology
- change the way services are provided
- change policies or practices
- undergo training or professional development to redress a lack of knowledge or skills
- provide training or professional development to redress a lack of knowledge or skills on the part of staff
- provide financial compensation
- refer the complaint to the relevant registration board.

If the parties cannot reach agreement, or major problems emerge that need to be formally investigated, the conciliator can end the conciliation conference.

The conciliator will report to the commissioner on the progress of the complaint and recommend whether or not the commission should formally investigate it or take other action. Sometimes, if serious difficulties emerge during conciliation, the complaint can be referred for formal investigation, even though the parties have reached consensus.

Tips on preparing for conciliation

It is important to remember that the conciliator is impartial and is there to help you and the respondent talk about what happened and try to resolve your complaint. Keep in mind, too, that everything said in the conciliation conference is confidential.

You'll be given the opportunity to outline your complaint, so it's a good idea to prepare in advance a summary of what you want to say. Try to keep this to about five to ten minutes. You do not have to include everything that happened as the respondent will already have a copy of your complaint.

Just as it is important for you to be able to speak without being interrupted, you also need to listen carefully to what the respondent says, even if you disagree with it. Make notes of anything you want to respond to; you'll be given a chance to respond to anything you disagree with.



Stay calm. This can be difficult when you are confronted by a person or a representative of an organisation with which you are in conflict. Nevertheless, staying calm is likely to make the conciliation conference much more productive:

- It is more likely that the respondent will listen to what you are saying.
- It is less likely that they will respond defensively.
- It is more likely that the conference will enable you both to reach agreement on how to resolve the complaint.

It's also important to seek legal advice about your settlement options so that you are realistic about what you can expect in your circumstances. When it comes to deciding what you want in order to settle your complaint, you need to be flexible, realistic and willing to negotiate. It's also important to be clear about what your bottom line is when it comes to reaching a settlement.

Conciliation checklist

Before the conciliation conference, do these six things:

- Discuss any questions you have with the conciliator.
- If you want to bring along a support person, friend, lawyer or union representative, ask the conciliator.
- Prepare a summary of what you want to say.
- Make a list of the matters you think the respondent will raise and what you want to say in response to them.
- Obtain legal advice to help you decide what you might seek to settle your complaint.
- Decide what outcome you want.

Formal investigations or hearings

Anti-discrimination hearings

If your discrimination complaint is not resolved at the conciliation conference, you need to decide whether to take it to court.

Complaints made to state and territory commissions are usually referred to a tribunal for a hearing. If your complaint has been made under the *Federal Disability Discrimination Act*, you will need to make an application to have your case heard by either the Federal Court or the Federal Magistrate's Court.

The relevant court or tribunal will hear all the evidence and make a decision about whether the respondent has discriminated against you. If the court or tribunal finds that discrimination has occurred, they can order the respondent to take action to stop the discrimination, prevent the discrimination from being repeated, and pay you compensation.

If you want to take your complaint to court or a tribunal, you will need legal advice.

Health care complaint hearings

If the health care complaints commission decides to formally investigate your complaint, this will often be because the matters you raised are serious or complex, or the complaint raises problems that will affect other service users.

The purpose of the investigation is to find out what happened, whether the things you have complained about did in fact occur and, if they did, what action needs to be taken to redress the problem.

The investigation process is likely to involve:

- exchange of written information between you, the respondent and the commission
- gathering policies or professional standards relevant to the complaint
- obtaining expert opinions
- obtaining written statements from witnesses
- hearing evidence from witnesses.

The commissioner considers all the information and prepares a report of the investigation. The report usually provides conclusions about what occurred, a statement about whether the commissioner considers that the matters you raised have been proved, and, if so, what action the respondent needs to take to resolve the problem and improve the service in future.

Among the outcomes of investigation can be the following:

- an explanation of what happened and what went wrong
- changes to improve the way services are provided
- changes to policies or practices that contributed to the complaint arising
- referral of the matter to the relevant health registration board
- recommendations to the health minister, for example, for changes to government policy or law reform.

We hope this booklet is useful and answers your questions on discrimination and disclosure. For more information see the 'Contacts' section for a state by state listing of organisations that may be able to help you.



National

Hepatitis organisation Hepatitis Australia

The national organisation representing state and territory-based hepatitis organisations

Ph: 02 6232 4257
Helpline: 1300 437 222
Email: admin@hepatitisaustralia.com
Web: www.hepatitisaustralia.com

Health care information Australian Commission on Safety and Quality in Health Care

Ph: 02 9263 3633
Email: mail@safetyandquality.gov.au
Web: www.safetyandquality.gov.au

Discrimination information Australian Human Rights Commission

Ph: 02 9284 9600
Infoline: 1300 656 419 (Complaints)
Email: complaintsinfo@humanrights.gov.au
Web: www.hreoc.gov.au

Privacy Information

Ph: 1300 363 992
Email: privacy@privacy.gov.au
Web: www.privacy.gov.au

Other information

Australian Injecting and Illicit Drug Users League (AIVL)

The peak organisation representing state and territory peer-based drug user groups

Ph: (02) 6279 1600
Web: www.aivl.org.au

Haemophilia Foundation Australia

The peak organisation representing state and territory haemophilia foundations

Ph: 03 9885 7800
Email: hfaust@haemophilia.org.au
Web: www.haemophilia.org.au

Hep C Australasia

Web: www.hepcaustralasia.org

Telephone Interpreter Service (TIS), national

Ph: 131 450

Many of the agencies listed in this contacts directory will have arrangements with the TIS and can either arrange for a telephone interpreter free of charge or pay for the cost of a telephone interpreter.

Australian Capital Territory

Hepatitis organisation

Hepatitis ACT

Ph: 02 6230 6344
HelpLine: 1300 437 222
Web: www.hepatitisact.com.au

Health care information

Human Rights Commission

Ph: 02 6205 2222
TTY: 02 6207 0525
Email: human.rights@act.gov.au
Web: www.hrc.act.gov.au

Discrimination information

Disability Discrimination Legal Service

Ph: 02 6247 2018
TTY: 02 6247 2018
Web: www.communitylaw.org.au/ddls/

Legal information

Legal Aid Commission of ACT

Ph: 1300 654 314
After hrs: 0429 440 084
Web: www.legalaid.canberra.net.au

New South Wales

Hepatitis organisation

Hepatitis NSW

Ph: 02 9332 1853
HelpLine: 1300 437 222
Email: hnswh@hep.org.au
Web: www.hep.org.au

Health care information

NSW Health Care Complaints Commission

Ph: 02 9219 7444
Toll free: 1800 043 159 (NSW only)
TTY: 02 9219 7555
Email: hccc@hccc.nsw.gov.au
Web: www.hccc.nsw.gov.au

Discrimination information

Anti Discrimination Board of NSW

The board has offices in Sydney, Newcastle and Wollongong.

Ph: 02 9268 5544
Toll free: 1800 670 812 (NSW only)
TTY: 02 9268 5522
Web: www.lawlink.nsw.gov.au/adb

Australian Centre for Disability Law

TTY: 02 8014 7000
Email: adviceline@disabilitylaw.org.au

Legal information

Legal Aid Commission of NSW

There are many metropolitan and regional offices in NSW.

HelpLine: 1300 888 529
TTY: 1300 889 529
Legal Aid Youth Hotline: 1800 10 18 10
Web: www.legalaid.nsw.gov.au

LawAccess NSW

Ph: 1300 888 529
TTY: 1300 889 529
Web: www.lawaccess.nsw.gov.au

Northern Territory

Hepatitis organisation

NT AIDS and Hepatitis Council

Ph: 08 8944 7777 (Darwin callers)
1800 880 899 (NT regional callers)
HelpLine: 1300 437 222
Email: info@ntahc.org.au
Web: www.ntahc.org.au

Health care information

Health and Community Services Complaints Commission

Ph: 08 8999 1969
Toll Free: 1800 806 380
Email: hccsc@nt.gov.au
Web: www.hccsc.nt.gov.au

Discrimination information

Anti-Discrimination Commission

Ph: 08 8999 1444
Toll free: 1800 813 846
TTY: 08 8999 1466
Email: administrationadc@nt.gov.au
Web: www.adc.nt.gov.au

Darwin Community Legal Service

Specialist advice on disability discrimination issues.

Ph: 08 8982 1111
Toll free: 1800 812 953
Email: info@dcls.org.au
Web: www.dcls.org.au

Legal information

Legal Aid Commission

There are offices in Darwin, Katherine, Palmerston, Tennant Creek and Alice Springs.

Toll free: 1800 019 343
Web: www.ntlac.nt.gov.au



Queensland

Hepatitis organisation Hepatitis Queensland

Ph: 07 3846 0020
HelpLine: 1300 437 222
Email: info@hepqld.asn.au
Web: www.hepqld.asn.au

Health care information Health Quality and Complaints Commission

Ph: 07 3120 5999
Toll free: 1800 077 308 (outside Brisbane metro)
TTY: 07 3120 5997
Email: info@hepqld.asn.au
Web: www.hqcc.qld.gov.au

Discrimination information Anti-Discrimination Commission

There are offices in Brisbane, Rockhampton, Townsville and Cairns.

Ph: 1300 130 670 (Qld only)
TTY: 1300 130 680
Email: info@adcq.qld.gov.au
Web: www.adcq.qld.gov.au

Legal information Welfare Rights Centre

Specialist advice on disability discrimination
Ph: 07 3847 5532
Toll free: 1800 358 511 (outside Brisbane metro)
Email: wrcqld@wrcqld.org.au
Web: www.wrcqld.org.au

Cairns Community Legal Centre

Disability legal advocacy service for Far North Queensland

Ph: 07 4031 7688
Toll free: 1800 650 197
(DDLs clients outside Cairns)
Web: www.cclc.org.au

Legal Aid Commission of Queensland

Ph: 1300 651 188
Web: www.legalaid.qld.gov.au

South Australia

Hepatitis organisation Hepatitis SA

Ph: 08 8362 8443 (Adelaide callers)
HelpLine: 1300 437 222
Email: admin@hepatitissa.asn.au
Web: www.hepatitissa.asn.au

Health care information State Ombudsman of South Australia Consumer Health Complaints Unit

Ph: 08 8226 8699
Toll free: 1800 182 150
Email: ombudsman@ombudsman.sa.gov.au
Web: www.ombudsman.sa.gov.au

Discrimination information South Australian Equal Opportunity Commission

Ph: 08 8207 1977
Toll free: 1800 188 163 (country callers)
TTY: 08 8207 1911
Web: www.eoc.sa.gov.au

Legal information Central Community Legal Service

Statewide specialist advice on disability discrimination.

Ph: 08 8342 1800
Web: www.saccls.org.au

Legal Services Commission

There are a number of offices in the state.

Ph: 1300 366 424
TTY: 08 8463 3691
Web: www.lsc.sa.gov.au

Health and Community Complaints Commissioner

Ph: 08 8226 8666
Toll free: 1800 232 007
Web: www.hscs.sa.gov.au

Tasmania

Hepatitis organisation

Tasmanian Council on AIDS, Hepatitis and Related Diseases

Ph: 03 6234 1242
Information and support line: 1800 005 900
(Tasmanian country callers)
Email: mail@tascahrd.org.au
Web: www.tascahrd.org.au

Health care information

Health Complaints Commissioner

Ph: 1800 001 170
Email: health.complaints@ombudsman.tas.gov.au
Web: www.healthcomplaints.tas.gov.au

Discrimination information

Anti Discrimination Commission

Ph: 03 6233 4841
TTY: 03 6233 3122
Statewide local call: 1300 305 062
Email: antidiscrimination@justice.tas.gov.au
Web: www.antidiscrimination.tas.gov.au

Legal information

Launceston Community Legal Centre

Statewide specialist advice on disability discrimination
Ph: 03 6334 1577
Toll free: 1800 066 019
Web: www.lclc.org.au

Legal Aid Commission of Tasmania

There are offices in Hobart, Launceston, Devonport and Burnie.

Ph: (03) 6236 3800 (Hobart)
Ph: 1300 366 611 (statewide)
Web: www.legalaid.tas.gov.au

Victoria

Hepatitis organisation

Hepatitis Victoria

Ph: 03 9380 4644
HelpLine: 1300 437 222
Email: info@hepvic.org.au
Web: www.hepvic.org.au

Health care information

Office of the Health Services Commissioner

Ph: 03 8601 5200
Toll free: 1800 136 066
TTY: 1300 550 275
Email: hsc@dhs.vic.gov.au
Web: www.health.vic.gov.au/hsc

Discrimination information

Equal Opportunity and Human Rights Commission

Complaints advice line: 03 9281 7100
TTY: 03 9281 7110
Email: complaints@veohrc.vic.gov.au
Web: www.humanrightscommission.vic.gov.au

Disability Discrimination Legal Service

Ph: 03 9654 8644
Toll free: 1300 882 872 (country Victoria only)
TTY: 03 9654 6817
Email: info@ddls.org.au
Web: www.communitylaw.org.au/ddls/

Legal information

Legal Aid Commission of Victoria

There are a number of metropolitan and regional offices in Victoria.

Ph: 03 9269 0120
Toll free: 1800 677 402 (country Victoria only)
Web: www.legalaid.vic.gov.au

Western Australia

Hepatitis organisation HepatitisWA

Ph: 08 9227 9800
Fax: 08 9227 6545
HelpLine: 1300 437 222
Email: info@hepatitiswa.com.au
Web: www.hepatitiswa.com.au

Health care information Office of Health Review

Ph: 08 9323 0600
Toll free: 1800 813 583 (Country WA only)
TTY: 08 9323 0616
Web: www.healthreview.wa.gov.au

Discrimination information Equal Opportunity Commission

Ph: 08 9216 3900
Toll free: 1800 198 149
TTY: 08 9216 3936
Web: www.equalopportunity.wa.gov.au

Legal information Sussex St Community Law Service

Statewide specialist advice on disability discrimination

Ph: 08 6253 9500
Toll free: 1800 642 971
TTY: 08 9470 2831
Email: sscls@sscls.asn.au
Web: www.sscls.asn.au

Legal Aid Commission of WA

There are a number of offices in the state.

Ph: 1300 650 579
TTY: 1800 241 216
Web: www.legalaid.wa.gov.au



hepatitis
australia

Infoline: 1300 437 222