

Know your rights

A simple guide to your rights and living with viral hepatitis in Victoria



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For more information on viral hepatitis, please visit the Hepatitis Victoria website or contact the Hepatitis Infoline on 1800 703 003

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Disclaimer

Information in this resource does not replace legal advice and acts as a guide only. We recommend that you seek expert advice from lawyer or an organisation located at the back of this booklet.

Introduction

Why do I need to know my rights?

Knowing your rights is important so you can make sure they are exercised properly and you are treated fairly. This applies to all parts of life, including at work, when receiving healthcare, and in your private and family life.

Our human rights are defined and protected by Victorian, Australian, and International charters and law. When human rights are respected, we can live free from discrimination, harassment, and unfair treatment.

How are the rights of people living with viral hepatitis protected in Australia?

When we are talking about human rights in Australia, we are most often referring to those protected in the Disability Discrimination Act 1992 and Australian Human Rights Commission Act 1986, both operating at a federal level. Victorians are also protected by the Equal Opportunity Act 2010.

“Viral hepatitis is manageable and doesn’t need to have a negative impact on your life. The best piece of advice I can give would be to educate yourself about the condition and be aware of your rights”

Person living with hepatitis B

Your right to privacy and disclosure

Who do I have to tell?

Disclosure is telling another person that you are living with viral hepatitis. In Australia, a person's viral hepatitis status is their business.

It is your right and personal decision to choose whether or not you disclose, and in most cases you don't legally have to. However, there are a few circumstances where you may be required to disclose.



At work

For almost all jobs, you do not need to tell your employer or colleagues that you are living with viral hepatitis. There are a small number of professions that may require you to disclose your status or have a blood test, such as:

- If you are a healthcare worker performing exposure prone procedures (EPPs).
- If you work for, or are applying to join the Australian Defence Force.

Some jobs may require you to provide evidence that you have been immunised for hepatitis B. If you are already living with chronic hepatitis B, you may want to consider seeing a doctor who can write a letter for your employer explaining the minimal risks involved with your condition and your suitability for the job.



What is an exposure prone procedure (EPP)?

EPPs involve a risk of injury to the worker resulting in exposure of the patient's open tissue to the blood of the worker. This usually involves the use of sharp instruments and surgical tools where the worker's hands are not visible.

People currently living with hepatitis B or hepatitis C cannot perform work involving EPPs.

Healthcare

It is the responsibility of all healthcare professionals to follow the same standard of infection-control precautions with every patient. An example of this would be wearing gloves when there is a risk of coming into contact with a patient's blood or bodily fluids - this means there is no reason to tell your healthcare provider (including doctors, nurses, paramedics, or any other healthcare worker) that you are living with viral hepatitis.

Depending on who you are seeing and what for, it may be a good idea to disclose in the best interest of your healthcare. In these situations, it's best to simply ask yourself 'does this person need to know my hepatitis status?'

Unfortunately, in some instances discrimination and unfair treatment does happen once viral hepatitis is brought up. Find out how to recognise and respond to discrimination later in this guide.

Your healthcare provider must keep your information safe and confidential. Confidentiality protects your right to privacy. It is illegal for anyone to pass on your medical records without your permission; including to your partner, family, friends, employers, or other healthcare workers.

What about donating blood?

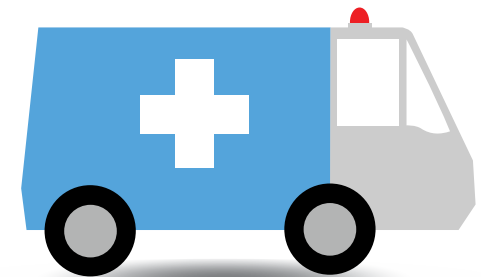
If you are currently living with viral hepatitis, you cannot donate blood.

If your body has cleared hepatitis A or hepatitis B, you can donate blood after 12 months.

If you have ever lived with hepatitis C, you are ineligible to donate blood.

"You have the right to be treated fairly and for your personal information to be kept confidential"

Person who used to live with hepatitis C



Friends and family

While there are no legal obligations for you to disclose among family and friends, often they can offer valuable support when needed. If you decide to disclose, they may react negatively at first, so be prepared.

Before disclosing, it's a good idea to educate yourself about your condition, so you can alleviate any uncertainties your friends and family may have and answer their questions. For example, you can assure them that it is perfectly safe to share food or hug somebody who is living with hepatitis B or hepatitis C.



Sexual partners

There is a high risk for hepatitis B to be sexually transmitted. For hepatitis C, there is a low risk. As long as you take precautions to avoid transmission, you do not have to tell a sexual partner that you are living with hepatitis. It is recommended that you always use barrier protection (condoms).

Disclosing your viral hepatitis status to a sexual partner is usually something to carefully consider for personal and ethical reasons, rather than for any legal obligations.

“I found out that I tested positive for hepatitis B. I was living with my parents and my two younger sisters at the time, but I kept it to myself for almost a year. It just never came up and I was afraid of how my family would react.

One night after dinner I sat down with my parents and said ‘I’ve got something to talk to both you about - last year I found out that I’m living with hepatitis B’. At first they were surprised, but afterwards their reaction was full of positivity and curiosity. They asked some questions and just we talked about it for a while. They were very supportive.

Since then my parents have taken my sisters to get immunised, but nothing changed at home. It was a huge relief knowing that everything was going to be okay.”

Person living with hepatitis B

Insurance

When applying for insurance, you are legally obligated to answer questions and disclose information correctly. Health and life insurance policies are most relevant to disclosing your viral hepatitis status.

Chronic hepatitis is considered a 'risk' to many insurance providers, and you may not be approved for a policy or the costs may be increased. Different insurance companies will have different criteria, so it's best to talk a professional advisor.



Sports

All sporting organisations should follow blood rules and infection control procedures when first-aid is needed.

Legally you are not required disclose your viral hepatitis status when participating in almost every sport.

Some martial arts and contact sports may require disclosure or a blood test before participating.

Education

If you are a student or you have a child living with viral hepatitis, you are not legally required to disclose that information to a school or university.

No educational institutions can treat someone differently or deny them admission based on their viral hepatitis status. If this occurs, it is discrimination and is illegal.



How should I disclose my status?

Disclosing your viral hepatitis status is not always easy, and there's no right or wrong way to tell. The main thing to keep in mind is that you are in control of who you tell and how you tell them.

Here's a straightforward example of how you might want to get the conversation started:

“There’s something I’d like to sit down and talk with you about, a while ago I found out that I have hep B. Do you know much about it?”

Some people will react differently to others, so it's best to be prepared. If you have decided to tell someone, here's a few suggestions to help you through the process:

- Be as informed as possible about your condition and the risks of transmission to alleviate any concerns the person might have
- Share information from websites or other resources to help answer any questions
- Make sure that you trust the person and you are comfortable with them knowing
- Ask the person to keep the information you have shared confidential.

Notifiable diseases

Viral hepatitis is a notifiable disease, meaning that if you see a doctor for a blood test, your positive test result and other details will be sent to the Victorian Department of Health and Human Services. This helps the department monitor and control infectious diseases. Not to worry though – your personal information is de-identified and kept confidential.

Electronic databases

In Australia, the main electronic record system is the *My Health Record*:

Name

My Health Record

What is it?

An electronic patient recording system.

What information does it hold?

Key patient information such as:

- Medications
- Allergies
- Medical diagnosis of conditions
- Blood test and scan results
- Immunisations.

Who can see it?

- Your doctor, pharmacist, or nurse, or specialist with your permission
- In emergency settings, healthcare professionals will have access to your my health record.



My Health Record fast facts – you're in control!

- You have the right to discuss with your doctor what documents should be added (or not) to the system
- You can control what information is visible
- You can keep track of who has seen your *My Health Record* using the app or website.

Your right to be free from discrimination

What is discrimination?

Put simply, discrimination occurs when someone is treated differently or less favourably based on who they are as a person. People are usually discriminated against based on their race, sex, or sexual preference, but it can also occur towards a health condition like viral hepatitis.



Did you know?

When we're talking about discrimination, we're referring to the Equal Opportunity Act 2010, which is the main legislation that prevents discrimination in Victoria.

The Equal Opportunity Act 2010 states that living with chronic hepatitis B or hepatitis C is considered a disability, and is therefore a protected characteristic. It is illegal to discriminate against someone based on a protected characteristic.

Stigma

Stigma is the negative social attitudes people have towards an individual's behaviour, appearance, or identity.

Unfortunately, people living with viral hepatitis are commonly stigmatised due to ignorance or fear about the condition.

“Stigma is always negative, but it can be stopped by challenging it and educating those around us.”

Hepatology nurse



You are not legally protected in all areas of life. Discrimination isn't illegal if it happens among family or friends in 'private life'. *Discrimination is illegal* when it happens in formal areas of 'public life', such as:

- Healthcare
- Education
- Government institutions
- Employment
- Good and services
- Sport

Discrimination against people living with hepatitis most often occurs in healthcare and in the workplace. The following are example of what would be illegal under the Equal Opportunity Act 2010:

Discrimination in healthcare

Health services cannot discriminate against someone on the grounds of living with viral hepatitis.

This includes:

- Refusal or lowering the quality of service
- Bullying or harassment
- Sharing of information about you outside of normal confidentiality laws
- Otherwise disadvantaging a patient.

Discrimination in the workplace

Employees cannot be treated differently and are protected through all stages of employment.

This includes:

- The recruitment process
- The terms and conditions under which someone is employed
- The way in training, promotions, and benefits are offered
- Dismissal, retrenchment, or demotion.

Reasonable adjustments

Under the Equal Opportunity Act 2010, employers, education institutes, and goods and services providers (including healthcare) are required to make changes so that a person with disability can do their job, participate in education or access goods and services. These changes are known as reasonable adjustments.

For example, it would be reasonable to allow an employee time off work to attend medical appointments for hepatitis B or hepatitis C.

Lawful discrimination

There are a few exceptions under the Equal Opportunity Act where it is legal for discrimination to occur:

- There is a real risk to your (or someone else's) health, safety or property and the discriminatory measures are needed for protection
- The discriminatory measures were taken to assist people with special needs or disabilities, such as providing accessible services and facilities
- An employer would have to make some unreasonable adjustments to their workplace so that you could apply for or perform a job
- You could not adequately perform a job even after an employer made reasonable adjustment to the workplace or situation.

Your right to complain

what happens when things go wrong?

If you feel that your human rights have been breached or you have been discriminated against, you have the right to call it out and speak up. It is important to first assess the situation and then consider your options.

Clarify the issue

It is recommended you take notes about the event(s), as soon as possible after it occurred, as it can be difficult to remember this information later on, including:

- Date and time(s)
- Who was involved
- What occurred
- Any other details you can think of

Next steps

If you do decide to complain, it's important to figure out what outcome you would like as a result of complaining (e.g. an apology or change in practice), and what it is that you need throughout the process (e.g. a lawyer or peer support).

Here are some outcomes people have achieved in the past:

Benefits of complaining in healthcare

- Receive an apology
- Financial compensation
- Anti-discrimination training for staff
- Change of services.

Benefits of complaining in the workplace

- Receive an apology
- Financial compensation
- Anti-discrimination training for staff
- Reinstated job.

Case study – challenging poor treatment

Emma had been living with hepatitis C for over 10 years and had recently started treatment. One day, she had a sore tooth and went to visit the dentist for a check-up. In the waiting room, she was given a questionnaire asking about different health conditions. She ticked 'yes' to having hepatitis C.

Everything seemed normal as the dentist was doing the routine check-up. The receptionist rushed into the room and whispered something to the dentist. The dentist then immediately changed his tone of voice and said "sorry I'm going to have to ask you to leave. I didn't realise you had hep C and our policy says we can't see you."

Distressed and still in pain, Emma contacted the Health Complaints Commissioner about her experience. The commission then contacted the practice on her behalf.

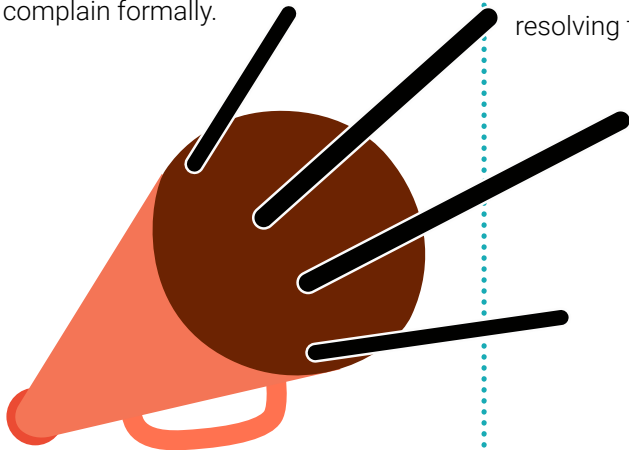
A week later Emma received a call from the owner of the dental practice, who apologised for what happened and said he will review the policy and have a meeting with staff. She received compensation to cover the costs for the check up and for the filling that she needed.

Lodging a complaint – call it out!

Informal complaint

If you feel comfortable doing so, sometimes it's possible to talk directly to the people involved without going through a formal complaints process. This can be done by speaking with them in person or writing a letter about your experience and can often save a lot of time and stress.

However, the person or organisation involved may refuse to listen, disagree, and not change their behaviour. In this case, you might decide to complain formally.



Internal complaint

Generally you can complain to the organisation that you feel treated you poorly. Most organisations will have a feedback form. Health services are legally required to offer a complaints/feedback process.

An advantage of internally complaining is that you can either provide contact details or remain anonymous.

The organisation should let you know that your complaint has been received and will begin the investigating and resolving the issue.

Complain with another organisation

There are several external organisations who can help you prepare a complaint or investigate matters on your behalf. In Victoria, the main complaints body is the Victorian Equal Opportunity and Human Rights Commission (VEOHRC) – they will take a complaint in relation to any kind of public service and are empowered to act on the Equal Opportunity Act 2010.

**Victorian Equal Opportunity
and Human Rights Commission**

1300 891 848

www.humanrightscommission.vic.gov.au

If VEOHRC is unable to assist your situation, they can refer you to a number of other state and federal based bodies that cater to specific situations or circumstances (see complaints bodies on the next page).

Important note!



In almost all cases, you will only have a limited amount of time to lodge a complaint. This could be as little as a few weeks to several months, depending on the circumstances and who you contact to lodge the complaint. Hepatitis Victoria recommends acting as quickly as possible after the event so you don't lose your right to complain.

Useful contacts and services



Australian Health Practitioner Regulation Agency

Investigates complaints if you are concerned a health practitioner behaving in a way that could present a risk to you, to other patients or members of the public.

1300 419 495 www.ahpra.gov.au

Australian Human Rights Commission

The main federal body that take complaints in relation to any kind of public service.

1300 891 848 www.humanrights.gov.au

Disability Discrimination Legal Service

Independent community legal centre that specialises in disability discrimination legal matters

9654 8644 www.ddsl.org.au

Fair Work Commission

Deals with employment related issues such as unfair dismissal and disputes.

1300 799 675 www.fwc.gov.au

Health Complaints Commissioner

Resolves complaints about health services and providers.

1300 582 113 www.hcc.vic.gov.au

Hepatitis Victoria

Provides information and support relating to hepatitis and liver health.

1800 703 003 www.hepvic.org.au

Independent Broad-Based Anti-Corruption Commission

Receives complaints in relation to corruption and police misconduct.

1300 735 135 www.ibac.vic.gov.au

Mental Health Complaints Commissioner

Resolves complaints about Victorian public mental health services.

1800 246 054 www.hcc.vic.gov.au

Victoria Legal Aid

A service that offers free legal advice for socially and economically disadvantaged people.

1300 792 387 www.legalaid.vic.gov.au

Victorian Ombudsman

Investigates and resolves complaints about Victorian state and local government actions.

9613 6222 www.ombudsman.vic.gov.au