



# Invisible Illness

—an online resource about children and young people with chronic conditions for school communities



## *Hepatitis C Entry*

*Organisations who wrote / approved the information*

Hepatitis C Council of Victoria

*Date this entry was last updated*

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*Chronic Illness Alliance  
www.chronicillness.org.au  
03 9882 4654*

# Hepatitis C

## A: FACTS ON THE CONDITION

### ***1. General description, including different types, causes, prevalence, signs and symptoms***

It is estimated that around 210,000 Australians currently live with the hepatitis C virus.

Hepatitis C is a blood borne virus. It is one of several viruses that can cause inflammation of the liver. The virus was identified in 1989. Before that time it was called non-A/ non-B hepatitis. It is a very slow-acting virus. Hepatitis C involves an initial acute phase of infection that may not be noticeable, because in many cases people do not feel sick. A large percentage of people infected with the virus will experience impaired quality of life. The variety and intensity of the symptoms vary widely. Many people will have symptoms that are uncomfortable and significantly affect the quality of life, while others may not be as seriously affected. According to current estimates, only 3-5% of people infected may die through liver cancer or failure after 20 to 40+ years of infection.

The virus is transmitted through infected blood entering into another person's blood stream. Risk transmission factors are related to activities that involve this type of contact such as: sharing injecting equipment, transfusion of blood products before 1990 in Australia, unsterile mass vaccination programmes in many countries, non-sterile medical or dental procedures, non-sterile tattooing and body-piercing, and other accidental exposures where infected blood can transfer from the bloodstream of one person to another. The risk of transmission from mother to baby is relatively low (5%) while infection from a community needlestick injury is extremely rare.

Symptoms may appear a long time after infection to the virus (average of 10-20 years). Most common symptoms are bouts of extreme fatigue, flu-like symptoms, night sweats, nausea/indigestion, depression/mood swings, loss of appetite, itching, joint pain and pain in the liver region. Some people will present no symptoms, others will present some of the above symptoms but not necessarily all of them. It is important to note that the experience of the infection varies widely and people who are diagnosed with the infection face much uncertainty about its impact. Severity of symptoms are not necessarily related to the extent of liver damage.

Complementary or alternative therapies, such as Traditional Chinese and Western Herbal Medicine are used by many people to assist with managing the symptoms of hepatitis C. Research on the effectiveness of these therapies is increasing with some specific herbs being identified as having helpful properties.

### ***2. Treatments, including role of specialists, effects of treatments, use of devices, daily routines***

An antibody test has been available since 1990. A confirmatory PCR test is currently used to determine the presence or absence of the virus in the blood of a person as around 25% of people will clear the virus spontaneously within the first 6 to 12 months. A PCR test will also test for the genotype of the virus. As there are 10 different types of hepatitis C called genotypes.

Currently there is no vaccine for hepatitis C nor is there one expected in the near future.

Since November 2003 the approved treatment for hepatitis C is a course of two drugs - called pegylated interferon and ribavirin. Treatment requires regular monitoring by a health worker and involves daily administration of tablets and a weekly injection. Its aim is to reduce the virus to a non detectable level in the blood of the patient. Treatment success depends on the genotype. Genotype 2 and 3 have around 80% SVR ( sustained viral response) while genotypes 1 & 4 have a 48 - 52% SVR. It is useful to be aware that the treatment may be associated with some serious side effects for some individuals. Criteria need to be met in order to access this form of treatment free of charge under the Pharmaceutical Benefit Scheme.

While the role of general practitioners (GPs) is increasing in the management of hepatitis C, a referral from a GP to a gastroenterologist is usually required for specialist assessment. Complementary and/or alternative medicine practitioners also provide advice and support to people who choose to explore these forms of treatment. Counsellors have an important role in supporting people with the many issues that may arise at various stages of the infection.

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Disclosure of hepatitis C is only legally required in a small number of situations:

- when giving blood to the blood bank
- when PCR+ and working as a health care worker who conducts “exposure prone procedures”
- when applying for some insurance policies which require the disclosure of any infections
- When applying to join the defense force or the secret service.

## **B: THE CONDITION'S EFFECT ON THE CHILD/YOUNG PERSON**

### ***1. Effects on the individual***

It is estimated that around 150 children are currently born in Australia each year infected with hepatitis C. Research about the effects of the virus on children is increasing but is still limited.

Testing of children is a very delicate issue for which parents may require a lot of support and information. Current recommendations are that :

- diagnostic testing should be delayed until children are 18 months old, due to the probability of false/incorrect results
- children who do test positive are referred to a specialist paediatric gastroenterologist for ongoing monitoring and management..

Although there are some exceptions, children generally have a mild experience of the disease which features occasional abdominal pains, lack of appetite, nausea and fatigue.

Chronic paediatric HCV infection may be associated with development of autoimmune diseases, such as auto-immune hepatitis and arthritis. There appears to be a moderate influence on the child’s capacity to do normal activities for their age, including school work and some physical activities.

At the present time it is not possible to predict in the early stages which children will develop serious liver disease. Available treatments for hepatitis C have been used on children although there are still unresolved questions on the long term effects of some of the drugs used in these treatments. Nevertheless, if a child is starting to develop early liver disease, treatment can be commenced as early as six years of age.

### ***2. Effects on those close to the child/young person***

Children with hepatitis C may have significantly poorer health, which has an influence on family activities. Parents worry about the future and the long-term prognosis of their child’s health. Not knowing is a source of ongoing stress for parents. Due to the highly stigmatized nature of how hepatitis C is currently represented in our community some parents also worry about their child being discriminated against in the school, in social situations and in future work and education opportunities. There is no legal requirement for parents to disclose their child’s hepatitis C status.

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## **C: STRATEGIES FOR SCHOOLS/TEACHERS**

### ***1. Overview of strategies for schools.***

At school, in the classroom and on the playground, teachers are advised to follow standard infection control guidelines that are in place to manage all bodily fluid and blood spills regardless of the persons involved. It is also advisable that all children are taught these same principles as a matter of course in the early years. If these are followed no special arrangements or precautions need to be taken that identifies staff or children affected by the virus.

### ***Link(s) to other useful online resources for schools***

#### **What is this hep C thing?**

'*What is this hep C thing?*' is a new hepatitis C cartoon and quiz for school students, designed by a focus group of young people. Follow the story of Zoe, Matt and Sam and decide what happens to them.

Go to <http://www.hepc.com.au/>

This activity was produced by the Education Resource Centre and also comes as a stand alone CD with teacher's notes. It was mailed out to all Victorian state schools in 2008.

Copies can be ordered by contacting the Education Resource Centre on (03) 9276 6993 or go to their website: <http://www.hivhepsti.info/>

An educator from Hepatitis C Victoria may also be able to come out to your school to do an education session to both teachers and students in regards to hepatitis C. To contact Hepatitis C Victoria, go to [www.hepcvic.org.au](http://www.hepcvic.org.au)

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## D: FURTHER INFORMATION

### ***1. Organisations, including services and resources available***

#### **Hepatitis C Victoria**

Suite 5, 200 Sydney Road  
Brunswick 3056

Phone: (03) 9380 4644

HepCinfoline: 1800 703 003

Email Address: [admin@hepcvic.org.au](mailto:admin@hepcvic.org.au)    Internet Address: [www.hepcvic.org.au](http://www.hepcvic.org.au)

Hepatitis C Victoria provides information, education, support, advocacy and representation for people affected by hepatitis C. Hepatitis C Victoria also offers training services to health care workers and others in the community. It provides a monthly support group for people affected by hepatitis C and provides referrals to groups run by other services. By becoming a member, people receive Good Liver, the quarterly newsletter of the Council, the opportunity to participate in the organisation, and updates of all written information resources.

#### *Resources Available:*

Body Art Kit for school nurses.

Body Art Posters

'What is this hep C thing?' CD

"Impact": A general booklet on hepatitis C suitable for all the family.

A range of booklets, brochures, pamphlets, and fact sheets on the many aspects of life with hepatitis C.

#### **Hepatitis Australia**

<http://www.hepatitisaustralia.com/>

The peak body for all the state organisations, Hepatitis Australia provides an informative website including online resources about hepatitis C.

#### **Education Resource Centre**

The Education Resource Centre at The Alfred is a statewide resource centre for HIV/AIDS, Hepatitis and Sexually Transmissible Infections for the Victorian community (Australia). Community members can order research articles online.

Phone: (03) 9276 6993

Web: <http://www.hivhepsti.info/>

#### **Positive Counselling HIV/ Hep. C**

This service is for people with HIV and/or Hepatitis C, their families, the people they live with and the people who support them. For more information contact:

The Williams Road Family Therapy Centre

3 Williams Rd  
WINDSOR Victoria 3181

Phone: 95302311      Fax: 95294469

Email: [info@positivecounselling.org.au](mailto:info@positivecounselling.org.au)    Web: <http://www.positivecounselling.org.au/>

### ***2. Reading, including links to downloadable documents***

Hepatitis C Victoria website <http://www.hepcvic.org.au>

Hepatitis Australian website <http://www.hepatitisaustralia.com/>

Education + Resource Centre website <http://www.hivhepsti.info/>