



Living with **Hepatitis C**

Information for people with Hepatitis C
and their families and friends



Contents

1 Introduction

2 Viruses and the human body

Hepatitis and hepatitis viruses.

The Hepatitis C virus.

How many people have the Hepatitis C virus?

How serious is Hepatitis C?

3-7 Signs and symptoms of Hepatitis C

1. Signs at the time of infection

Clearing the virus at the beginning.

Having antibodies to Hepatitis C.

Most people do not clear the

Hepatitis C virus.

2. Long term infection with Hepatitis C

Hepatitis C gives variable symptoms.

3. Obvious symptoms

4. Liver problems

Scarring of the liver: fibrosis.

Serious liver problems: cirrhosis.

What is cirrhosis?

Liver failure.

Liver cancer.

8 How does Hepatitis C spread?

The main ways of spread of Hepatitis C.

Everyone can help stop the spread of

Hepatitis C.

9-13 Stopping the spread of Hepatitis C

1. Protect yourself and others from blood.

2. Protect yourself and others from needles and instruments that pierce the skin.

3. Protect yourself and others during sexual activity.

14 Deciding to be tested for Hepatitis C

Reasons to take the test.

Reasons not to take the test.

Speak to a counsellor before you decide.

Deciding to test your children.

15-17 Tests for Hepatitis C

Stage I: Have you ever had Hepatitis C?

The ELISA test.

The RIBA test.

Stage II: Do you still have Hepatitis C?

The PCR test.

The Quantitative PCR.

Finding out your genotype of the Hepatitis C virus.

Changing its shape.

Other liver tests

Liver Function Tests.

Liver biopsy.

How is a liver biopsy done?

Results from a liver biopsy.

19 Finding out you have Hepatitis C

Find out about your situation.

Don't try to cope alone.

Get professional support and help.

Who else needs to know?

General Practitioner (GP).

Dentist.

School and college.

20 Training and work with Hepatitis C

Vocational training.

Applying for jobs.

Employment.

21-23 Living well with Hepatitis C

Think positively about yourself.

Eat a balanced diet.

Avoid alcohol.

Take some exercise.

Let go of anger and guilt.

Deal positively with stress.

Don't bottle up your worries.

Keep in regular contact with your specialist centre.

Get vaccinated against Hepatitis A and Hepatitis B.

24-27 Treatments for Hepatitis C

Aims of treatment for Hepatitis C.
Treatments are improving all the time.
Deciding to take treatment.
Delaying treatment.
You may benefit from new treatments.

Combination therapy.

Side-effects of combination therapy.
Success rate of combination therapy.
Success for different genotypes.

Other drug treatments.
Liver transplant.
Complementary medicine.

28 What can't I do with Hepatitis C?

You can never be a blood donor.
You can never be an organ donor.
Your close family cannot donate blood or organs.
You may find it difficult to obtain life insurance.

29-30 Young people with Hepatitis C

Facts about Hepatitis C in young people.
Talking to your parent(s) or caregivers.
Young people and sexual relationships.

31-32 Health services for people with Hepatitis C

Going to a specialist centre.
Entitlement to services.
Hepatitis C from blood or blood products administered within Ireland.
 Special funding to hospitals.
 Hepatitis C Liaison Officers.
 Health Services Card.
 Counselling services.
 Children with Hepatitis C.

33-37 Useful addresses

1. Support groups.
 2. Specialist centres.
 3. Liaison officers.
 4. Do you need help?
 5. Other addresses.
- Further information on Hepatitis C.
 Recommended reading.
 The Internet: recommended websites.

Introduction

This booklet is for people who have Hepatitis C and for their families and friends.

Right now, these are the facts about Hepatitis C....

Hepatitis C is a common illness that can cause serious liver problems.

Millions of people all over the world have this virus infection.

Most people with Hepatitis C live as long as anyone else.

Many people with Hepatitis C never develop serious problems.

Some people with Hepatitis C need active treatment at some stage of the illness.

A small number of people with Hepatitis C have progressive liver disease that does not respond to existing treatments.

Doctors are making real progress in finding better treatments.

This booklet contains information on:

- the Hepatitis C virus,
- how Hepatitis C can affect health,
- how Hepatitis C is spread,
- the tests used to find out if a person has Hepatitis C,
- advice on how to keep well,
- the best treatments available now,
- concerns of young people with Hepatitis C,
- services available to people with Hepatitis C.

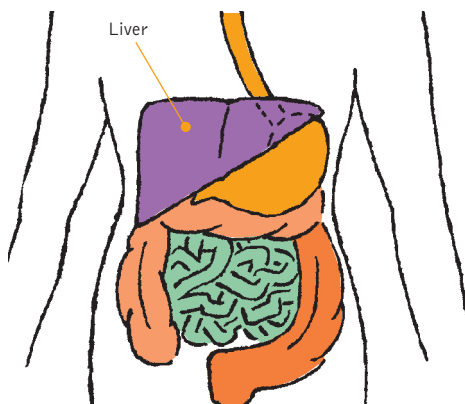
At the back of this booklet, there are names and addresses of services and support groups.

Some of the information in this booklet may have nothing to do with your life. You may even find some of the information is off-putting. This booklet is for all adults with Hepatitis C, regardless of their circumstances.

You may wish to share this booklet with your family or friends. You may also wish to use this booklet to help you get the best out of your visits to your doctor and especially to your liver specialist.

Not all of your questions can be answered here. If you have other questions, or if you do not understand any part of this booklet, ask your doctor or nurse.

There is no right or wrong way to come to terms with having Hepatitis C. People living with Hepatitis C may feel uncertain about their future. No-one knows for certain what the future holds. It is certain that we are making big strides in overcoming the Hepatitis C virus.



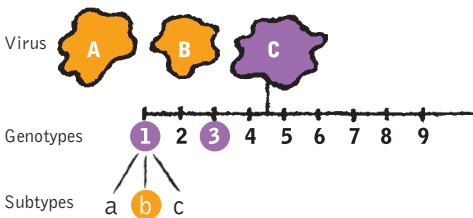
Viruses and the human body

A virus is a small organism that can attack one or more parts of the human body. Examples include the 'flu virus and the polio virus. The Hepatitis C virus lives in blood and passes into the liver where it can cause inflammation.

Hepatitis and hepatitis viruses

Hepatitis is the medical word for **inflammation of the liver**. There are many different causes of hepatitis. One cause is a group of viruses that attack the liver. **These hepatitis viruses are named by letter**. So we know of Hepatitis A, B, C, D, E etc.

Common forms of Hepatitis C in this country.



The Hepatitis C virus

The Hepatitis C virus was identified in 1989. Since 1991 tests can find it in blood. Hepatitis C is a complicated virus. It has at least 9 main subtypes, called **genotypes**. Each genotype can also have **subtypes**. No vaccine works against any form of this virus. The medical term for the virus is **HCV** (Hepatitis C Virus).

How many people have the Hepatitis C virus?

The Hepatitis C virus is one of the most common causes of liver disease in the world today. It has spread very widely because we did not know how to detect it until recently. Millions of people worldwide are living with Hepatitis C. Thousands of people in Ireland have Hepatitis C. Many people have

Hepatitis C but do not know they are infected.

How serious is Hepatitis C?

The Hepatitis C virus can cause liver problems. For some people, these liver problems become serious. It usually takes 20, 30 or more years before the Hepatitis C virus causes serious liver problems. In a small number of cases, the illness can become life-threatening. It is impossible to tell who will have few problems and who will have severe difficulties. Some people feel well but have serious liver problems. Other people can often feel unwell but have few liver problems. Staying in regular contact with the specialist centre or clinic, even if you are feeling well, means that regular tests will pick up any problems.

Doctors call it HCV. Is that because it's the same as HIV or AIDS?

No. Doctors use the term HCV for the Hepatitis C Virus but it has nothing to do with HIV (Human Immunodeficiency Virus) or AIDS (Acquired Immunodeficiency Syndrome).

Could I have this virus and not know?

Yes. Most people don't feel ill when first they become infected with Hepatitis C. Only one in every twenty people feel unwell. For these people, the main symptoms may be fatigue (extreme tiredness) Jaundice and joint pains, which can seem like the 'flu.

What's so important about my liver?

You have only one liver. It is on the right-hand side of your body, inside the lower ribs. It never stops its vital work. It converts the goodness from food into energy for the body. It makes proteins that create new cells and body tissues. It also makes proteins that fight infection and keep blood clotting under control. You cannot live without your liver.

Signs and symptoms of Hepatitis C

1. Signs at the time of infection

Most people do not become ill at the time of infection with the Hepatitis C virus. Only a few people are suddenly unwell with an acute inflammation of the liver (acute hepatitis) which gives signs (symptoms) like the 'flu. This lack of early signs is why so many people do not know they have the virus.

Clearing the virus at the beginning

In the first weeks of infection about one in every five people clears the Hepatitis C virus through the natural defence system of the body, the immune system. It produces antibodies that attack the Hepatitis C virus and get rid of it from the blood. People who defeat the Hepatitis C virus have these antibodies in their blood for the rest of their lives. Special blood tests that look for these antibodies can show that, at one time, they had the Hepatitis C virus.

Clearing the virus at the beginning.



Having antibodies to Hepatitis C

Some people have health problems which may be due to the presence of the antibodies to Hepatitis C in the blood.

If you had Hepatitis C in the past but defeated it, you need to stay in contact with your specialist centre to monitor your health.

Most people do not clear the Hepatitis C virus

Unfortunately, most people's immune systems fail to clear the virus. As a result, most people who come into direct contact with the Hepatitis C virus develop long-term (chronic) illness.

Most people do not clear the Hepatitis C virus



Why don't more people get rid of the virus at the beginning?

The Hepatitis C virus has the ability to change its shape. This may mean that it can avoid being destroyed by the immune system. Even if a person no longer has the virus it is important for that person to stay in contact with a specialist centre to monitor their health.

Can the immune system get rid of the Hepatitis C virus after the first few weeks?

Very occasionally. If it does not defeat the virus at the beginning, the immune system cannot usually overcome Hepatitis C on its own. Treatments for Hepatitis C often focus on giving the immune system help in fighting the virus.

Signs and symptoms of Hepatitis C

2. Long-term infection with Hepatitis C

For most people, the Hepatitis C virus infection becomes long-term (**chronic**). The inflammation of the liver becomes **chronic hepatitis**. Some people with Hepatitis C continue to feel well and have no obvious signs of illness for many years. Many people with Hepatitis C lead normal lives, sometimes with occasional illness.

Hepatitis C gives variable symptoms

The effects of the Hepatitis C virus in the human body give rise to two distinct concerns. First are the **obvious symptoms** of illness that a person may have. These include chronic fatigue, joint and muscle pains and headaches.

Second, and often more serious, are the **liver problems** the virus can cause. There are no clear links between the amount or type of obvious symptoms and the amount or type of liver problems. Each person with the virus has a unique pattern of **obvious symptoms** and a unique pattern of **liver problems**. This means that your experience of Hepatitis C is likely to be very different from other people's story. **No matter how you feel, stay in contact with your specialist centre.**

Feeling ill may or may not indicate liver problems. Feeling well is not a guarantee that the liver is unaffected. Discuss your situation with your doctors. Make a list of questions to find out what having Hepatitis C means for YOU.

It seems like Hepatitis C can be mild in some people and really serious in others. Why?

It is not clear why some people have more serious problems than others. It is likely that differences in genetic makeup, gender, the type of the infection, lifestyle, diet and alcohol intake all play a part. The overall picture may be complicated if a person with Hepatitis C has other problems, for example diabetes, kidney or heart disease, or has another viral problem, such as HIV infection. But most people cope with this serious illness.

Will I definitely get liver problems with Hepatitis C?

Most people with Hepatitis C have some evidence of liver problems. In most cases, these are mild and do not affect daily life to any great extent. People with Hepatitis C are at risk of serious liver problems. Right now, it is not possible to predict if a particular person with Hepatitis C will have serious liver problems or when these problems might start. This is why you should go regularly to the specialist clinic to pick up problems early.

How can I stop this illness from getting serious?

Right now, the best advice is to look after yourself well, eat a balanced diet, take moderate exercise and learn to cope with stress. You can also help yourself by attending your specialist clinic regularly to pick up any problems early. We know that alcohol reacts with Hepatitis C to increase the liver problems. People with Hepatitis C should avoid alcohol.

Signs and symptoms of Hepatitis C

3. Obvious symptoms

This section looks at the most common obvious symptoms of Hepatitis C infection. Remember, many people with Hepatitis C show no obvious symptoms at all. In some cases, people may gradually begin to notice obvious symptoms. Sometimes, it may be clear that these reflect liver problems. Sometimes, the symptoms may be general (**non-specific**) and do not clearly indicate a liver problem. The longer a person has Hepatitis C the more likely they are to notice symptoms.

Possibly the most common symptom is extreme tiredness or **chronic fatigue**. This can have a real effect on everyday life. The fatigue may be more noticeable at some times than at others. It is often worse at times of stress. **Joint and muscle pains** are also very common. Many people complain of **headaches**.

Some people with Hepatitis C have **skin rashes** or **irritation** or **dryness of the eyes**. Another complaint is abdominal discomfort, sometimes with fluid retention.

Depression is common and occasionally may be severe. Depression is a common side-effect of Interferon, a drug used to treat Hepatitis C. Some people complain of **difficulty in concentrating** and **sleep disturbance**.

Some people have **yellowing of the skin** or **of the whites of the eyes (jaundice)**. This is a common sign of liver problems.

If you have any of these symptoms make sure to talk about them when you visit your family doctor (GP) and your specialist centre. Ask about the best ways of coping with the symptoms and be prepared to try different approaches.

I've been told that my liver is in good condition. But I have a lot of symptoms that I find difficult to cope with.

The fact that your liver is in good condition is very good news. Your ongoing symptoms may be making life difficult. You can help yourself in a number of ways.

First, make your health and well-being a priority - your No 1 concern. Take plenty of rest and eat well.

Second, attend your clinic regularly and give serious thought to any suggestions they make about treatments for your symptoms.

Third, look at supports that could improve your sense of well-being. For example, physiotherapy may help aches and pains. Massage is another option. Through trial and error you may find a service that gives you some relief.

Signs and Symptoms of Hepatitis C

Tiredness.

Nausea.

Poor appetite.

Weight loss.

Flu-like illness.

Jaundice (yellowing of the skin and whites of the eyes).

Skin rash.

Dry eyes.

Depression.

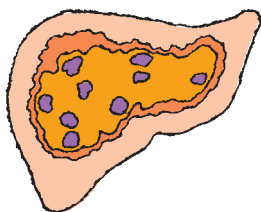
Signs and symptoms of Hepatitis C

4. Liver problems

This section talks about the liver problems that some people with Hepatitis C develop.

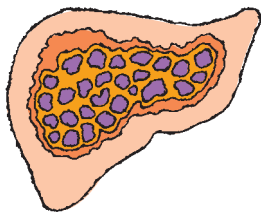
Scarring of the liver: fibrosis

For some people with Hepatitis C, the inflammation gradually gives scarring of the liver, called **fibrosis**. Occasionally, people in this situation show obvious signs of illness as already described.



Serious liver problems: cirrhosis

Some people with Hepatitis C may develop **cirrhosis** of the liver. This does not happen to everyone with the virus. It may take 20, 30 or even 40 years after infection for this serious liver problem to start. Very occasionally, cirrhosis develops quickly.



What is cirrhosis?

In cirrhosis, scarring of the liver (**fibrosis**) becomes widespread. Thick lumps (**nodules**) develop. Some liver cells die, giving small patches of dead tissue (**necrosis**). In cirrhosis, the liver does not

work as well as before. People may find that they become easily tired and sometimes feel unwell. Other symptoms

may include extreme sensitivity to heat or cold, easy bruising of the skin and loss of appetite.

Cirrhosis in Hepatitis C often gets worse over time. It may cause serious problems in the gut and abdomen, in the blood system or in mental function.

Liver failure

As cirrhosis progresses, the liver becomes less and less able to do its vital work. Gradually it may begin to fail. Symptoms of liver failure may include a build-up of fluid in the abdomen and in the legs, disturbances in intellectual function or in sleep.

No-one can survive complete liver failure. Treatments focus on not allowing the liver to get to this stage. One option in liver failure is liver transplantation. A small number of people never show obvious symptoms of liver disease even when the liver is close to complete failure.

Liver cancer

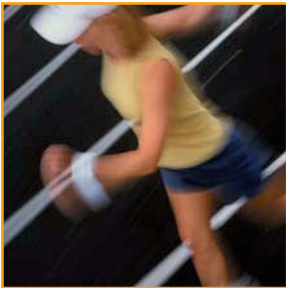
A very small number of people with progressive cirrhosis caused by Hepatitis C may develop liver cancer (**hepatocellular carcinoma**), usually many decades after the original infection. Liver cancer is an extremely serious condition. Treatments for all cancers are improving all the time. Liver cancer is now treated with drugs and in some cases with a liver transplant.

I thought that cirrhosis was a problem for alcoholics.

In the public mind, cirrhosis is associated with alcoholism, but it is only a medical term for scarring of the liver. It does not suggest a particular cause.

Is liver failure sudden or does it take time to develop?

Liver failure is usually gradual, taking a number of years to develop. Sudden liver failure can happen. If a person already has a liver problem, an extra problem, such as a chest or kidney infection, may tip the balance for the liver. It may not be able to cope and it may suddenly go into total failure. This is why people with liver problems must look after themselves properly.



How does Hepatitis C spread?

Hepatitis C is a virus that lives in blood. It is passed from one person to the next through **infected blood**. It is also passed in products made with infected blood, or body fluids that contain infected blood.

Unfortunately, the Hepatitis C infection was not recognised for many years. This allowed it to spread to a large number of people around the world. Many people with Hepatitis C are unaware they have the virus. They may pass it on without ever knowing.

The main ways of spread of Hepatitis C

Blood and blood-based transfusions. In Ireland, some people have Hepatitis C from infected blood products, for example, blood transfusions. Nowadays, every possible effort is being made to ensure that blood and blood products used in Ireland are safe.

Needle sharing. People who share needles when injecting drugs are at risk of Hepatitis C and other serious viruses, such as Hepatitis B and HIV.

Piercing of the body. A small number of people have Hepatitis C from tattoos, ear and body piercing, electrolysis or acupuncture with infected needles.

Mother to baby. The Hepatitis C virus can pass from mother to child at birth. Babies born to mothers with Hepatitis C antibodies will have their mothers' antibodies even if they have not contracted the virus. It is difficult to distinguish infection in the baby based on antibody tests in the first year to eighteen months of life. However, PCR tests for the Hepatitis C virus are usually accurate in

telling if the baby has or has not been infected, if performed at four months or older. Very rarely, Hepatitis C may be transferred through breast-feeding.

Sexual contact. The Hepatitis C virus can be passed through sexual contact. This is because body fluids such as semen, vaginal fluids and period blood (menstruation) can contain the virus. Any activity that tears skin or draws blood could be a route for Hepatitis C and other serious virus infection. Most experts consider that the risk posed by sexual activity is small.

Some health workers, including dentists, have Hepatitis C as a result of accidentally pricking themselves with infected needles.

Unknown. A certain number of cases of Hepatitis C have no obvious route of infection.

Everyone can help stop the spread of Hepatitis C

We have no vaccines to protect us against the Hepatitis C virus. It is up to each and every one of us to stop the spread of this virus. It is not just up to people who know they have Hepatitis C. Many people have this virus and don't know it. So **everyone** has to take commonsense precautions to protect themselves. **This is not difficult.** Hepatitis C is spread through blood. It is rare that we come in contact with the blood of other people.

There are 2 main rules

Protect yourself against other people's blood.

Protect others against your blood

Stopping the spread of Hepatitis C

1. Protect yourself and others from blood

Be careful about your own blood. Attend to all cuts immediately. Never leave cuts uncovered, especially on your hands.

Avoid all direct contact with other people's blood. Never touch even dry blood with your bare hands. Never suck another person's wound to clean it.

Wear gloves if you have to deal with another person's blood, including your own family. Have a pair of gloves ready at home and in the car.

If you come in contact with another person's blood, and are not protected by gloves, wash your hands immediately.

Teach your children that blood is a potential source of infection. Good habits start young.

Wash up any spilled blood, including your own, using bleach. The Hepatitis C virus can live in dry blood, so take care when handling older blood stains.

Tie blood-stained tissues or cloths in a plastic bag if you are cut or have a nosebleed. Do not leave blood-stained tissues or cloths for others to pick up.

If blood has gone on clothes, wash them in a hot wash with detergent.

Every girl and woman should be careful with period blood (menstruation). Wash hands carefully after any contact with period blood. Place used tampons or pads in a tied plastic bag before disposal. Burning tampons or pads is ideal. Wash blood-stained underwear in a hot wash with detergent.

Be careful during contact sports. Some sports can lead to injuries with bleeding, for example, boxing or rugby.

What about everyday contact with someone who has Hepatitis C. Could I be at risk?

If you avoid all contact with blood you are at absolutely no risk.

Hepatitis C is NOT spread by being near or with a person who has the virus.

Hepatitis C is NOT spread by coughing or sneezing.

Hepatitis C is NOT spread by shaking or holding hands, kissing or hugging.

Hepatitis C is NOT spread by contact with toilet seats or hand basins.

Hepatitis C is NOT spread by food.

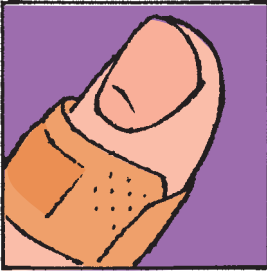
Hepatitis C is NOT spread by knives and forks etc. (cutlery) or plates, cups etc. (crockery).

Hepatitis C is NOT spread through swimming pools.

People with Hepatitis C need friendship as much as anyone else. If you know someone with Hepatitis C, you can support and accept them and socialise with them without any risk to yourself.

Stopping the spread of Hepatitis C

DO



Cover all cuts



Wash your hands



Wash up any spilled blood, including your own, using bleach.



Tie blood-stained tissues or cloths in a plastic bag.



Wear gloves if you have to deal with another person's blood.

Stopping the spread of Hepatitis C

2. Protect yourself and others from needles and instruments that pierce the skin

Be careful about needles. If you inject yourself, for example for diabetes, haemophilia or while using interferon (a drug that treats Hepatitis C), make sure you dispose of the syringes and needles in a proper sharps container. Be especially careful of children who might be curious to look at needles or syringes.

If you are injecting illegal drugs you are at real risk of Hepatitis C and other serious viruses, or of passing them to other users. Needle exchange protects you from the spread of Hepatitis C and other problems.

Never share a razor, toothbrush or manicure tools such as nail scissors or tweezers. Any of these could have small traces of blood. Everyone in the family should have their own toothbrush, razor and manicure tools that no-one else ever uses.

If you are having acupuncture or electrolysis make absolutely certain that the needles are safe. All clinics and salons should use disposable needles, which should be removed from sealed packaging within view of the client. A needle should only be used on one individual.

Think hygiene before getting body piercing or tattoos. Use only reliable professionals, with hygiene and safety guaranteed. If you are considering having body piercing, check that any piercing gun or other instrument is entirely safe. Disposable needles for piercing or

tattooing should be opened for first use in front of the client and used only with that client. Also ensure that tattoo inks are free from infection. Remember, it is impossible to be 100% sure that something is completely safe.

If you have Hepatitis C ask for the advice of your liver specialist before having body piercing or a tattoo.

Never become someone's 'blood brother' by mixing your blood. Never let anyone prick your skin or inject you with any needle or instrument unless they are fully qualified and competent and you are sure that the instrument is sterile.

What about blood transfusions in Ireland?

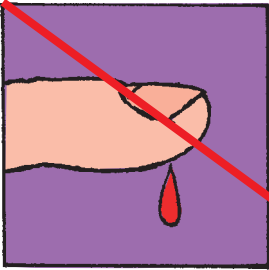
In the past, a small number of blood transfusions in this country were a source of Hepatitis C virus infection. Every effort has been made to eliminate known risks and to make blood and blood products as safe as they can be.

Most people have done at least one of these activities in their lifetime. How real is the risk of Hepatitis C?

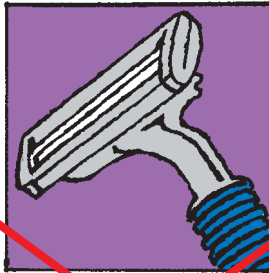
Most of us, at some time, have done something that, in theory, could spread the Hepatitis C virus. The most risky situation is direct blood contact with infected blood. Transfusion of infected blood and using infected needles are by far the most common ways of spreading Hepatitis C. Other ways mentioned here are far less usual.

Stopping the spread of Hepatitis C

DO NOT



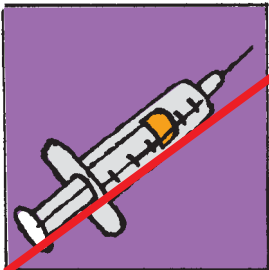
Avoid all direct contact with other people's blood.



Do not share razors



Do not share manicure tools



Do not share needles

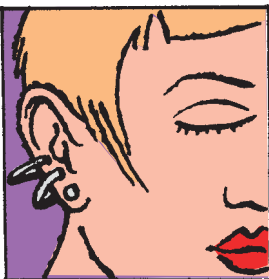


Do not share nail scissors

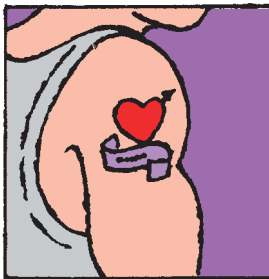


Do not share toothbrushes

THINK TWICE



before piercing



before getting a tattoo

Stopping the spread of Hepatitis C

3. Protect yourself and others during sexual activity

Condoms provide protection against the spread of Hepatitis C and other serious viruses.

Hepatitis C can be passed during sexual activity. Body fluids, including semen and vaginal fluids, may contain small traces of blood.

Any sexual activity that draws blood or tears the vagina, anus, rectum or mouth poses a risk of spread of the Hepatitis C virus.

Couples should be particularly careful if there are open cuts, sores, genital herpes or warts. These may provide a pathway for infection. Oral sex may pose a risk if the person has bleeding gums, broken skin or mouth ulcers.

Unprotected sex during a woman's period may pose a risk of spread of Hepatitis C to the man or woman.

Never have unprotected casual sex. If you do not know your partner's health or sexual history, do not take a risk. Use condoms for protection.

Couples in faithful, committed relationships are thought to be at low risk of passage of Hepatitis C. If you or your long-term partner has Hepatitis C, or if you are starting a relationship, you might like to talk with a counsellor, your liver specialist or a nurse to be clear about the risks involved.

I have Hepatitis C. I am in a steady relationship. Do we need to bother about safe sex?

All evidence shows that Hepatitis C is seldom passed between couples in long-term, faithful sexual relationships. The general advice is to continue your sexual activity as before. It may be best to avoid vaginal sex during the woman's menstrual period.

Some couples may decide that one or both of them would feel more comfortable using the protection of a condom or femidom. Some couples may decide to change their sexual activities.

If you use a condom you are protected from Hepatitis C and HIV and from many other sexually transmitted problems.

You also have some protection against unwanted pregnancy.

If you don't use one, you may spend a lot of time worrying.



Deciding to be tested for Hepatitis C

Are you having to decide about taking tests to find if you have Hepatitis C?

You may be concerned that you could have Hepatitis C. You may have been told by a doctor that you could have this infection. If a close family member or partner has Hepatitis C, you may have been asked to consider taking a test to find out if you have the virus. **Taking a test for Hepatitis C is a major decision. You need time to consider if you really want to do this or not.**

Reasons to take the test

Reasons to take the test include:

- It is one less thing to worry about.
- It helps you to plan for your future.
- If you have Hepatitis C, you have it. Nothing will change that fact.
- Looking after a problem earlier rather than later often gives better results.
- We can all deal better with what we know than what we fear.

Reasons not to take the test

Reasons not to take the test include:

- At the moment, just having the test, even if it turns out that you do not have Hepatitis C, can make your life more complicated.
- Taking the test, regardless of the result, will mean that you may have difficulty getting life insurance and you may find it more difficult to get a mortgage.
- You might also have to state that you have had a test for Hepatitis C for some kinds of employment.

- If you have Hepatitis C your life will inevitably change.
- Knowing that you have Hepatitis C might cause problems for you at work or in promotion.
- You might not be able to apply for any job that has a medical examination.
- If you are in a relationship, you will have to decide about telling your partner.
- If you have children you may have to decide to have them tested.

Speak to a counsellor before you decide

Before taking the test to find out if you have Hepatitis C you should take time to think about the pros and cons. You can ask to speak with a counsellor at one of the specialist centres.

Deciding to test your children

No parent wishes to be in the position of having to decide to test their child or children for Hepatitis C. On the one hand, if your child has Hepatitis C, you want to get proper care. On the other hand, a diagnosis of Hepatitis C brings many worries and unanswerable questions. You will have to decide when and how to tell your child. You will also have to deal with issues about school and social contact. Before making any decision to test your child you should consider getting independent professional counselling.

Tests for Hepatitis C

The main way to find out if you have Hepatitis C is to have blood tests. The tests for Hepatitis C are complicated. It takes time to get the full results. You will probably be worried and upset while you are waiting. The tests are in two stages.

Stage I: Have you ever had Hepatitis C?

The first stage finds out if you ever had direct contact with the Hepatitis C virus. Your blood carries a permanent memory of that infection. It does that in **antibodies** to the virus.

The ELISA test

The first test, the ELISA test, looks for antibodies to Hepatitis C in the blood. (ELISA is short for Enzyme Linked Immunosorbent Assay). **Taking the ELISA test, even if the result is negative, may affect your ability to get life insurance or a mortgage. Do not take this test without professional counselling.**

If your ELISA test is negative, you have never had any contact with the Hepatitis C virus and do not have Hepatitis C. You do not need more tests to make sure.

If your ELISA test is positive, it means that you have had Hepatitis C in the past. The test cannot tell if you still have the virus.

If the ELISA test is positive, a second test is needed to be certain. This is called the **RIBA (Recombinant Immunoblot Assay) test**. It is more complicated and gives more detail than the ELISA test.

The RIBA test

The RIBA test is extremely accurate in looking for antibodies to four proteins that are found in the Hepatitis C virus. The RIBA test looks to see if the blood contains antibodies to any one, some, or all of these proteins. Each person has a pattern of response to these proteins. We are still learning what the different patterns of response mean. The RIBA test confirms that you had Hepatitis C at some time. It cannot say if the virus is still in the blood.

Name of test	Purpose of test
ELISA, RIBA	Search for antibodies
PCR	Search for current signs of Hepatitis C
Genotyping	Determines type of Hepatitis C
Liver Function Tests	Indicates Liver Inflammation
Liver Biopsy	Identifies the condition of the liver

Stage 2: Do you still have Hepatitis C?

The second stage of tests for Hepatitis C looks to see if the virus is still in the blood. The main test is called the **PCR (Polymerase Chain Reaction)** test.

The PCR test

If the **PCR test is positive**, you have the Hepatitis C virus and are living with Hepatitis C. If the **PCR test is negative**, you are one of the few people who got rid of the virus in the early stages.

If you are **antibody positive, PCR negative** you have, and will always have, the antibodies to Hepatitis C in your blood. You need to keep in contact with your specialist clinic to ensure that you remain well.

The Quantitative PCR test

Doctors often use another test called the **Quantitative PCR** test. This measures the amount (the quantity) of the Hepatitis C virus in the blood. This amount is called the **viral load**.

If the **PCR test is negative**, you do not now have Hepatitis C, although you did have it some time in the past. So far as we know, the Hepatitis C virus will not come back. Because you have the antibodies to the virus, it is vital that you continue to attend appointments at the specialist centre to monitor your health.

If the PCR test is positive, you still have Hepatitis C. You will need to find out what this means for you. It will take time for the news to sink in. You will need support from family and friends. You may need the help of a counsellor.

Finding out your genotype of the

Hepatitis C virus. Hepatitis C was only identified in 1989, but it had been around for many years before that. Doctors have had problems getting to grips with this virus. This is because there are many different types of the Hepatitis C virus. At the moment, we know of at least nine main types. Each type is called a genotype. Each genotype has subtypes.

When you are told you have Hepatitis C, you are told which genotype you have. A very small number of people have more than one genotype of Hepatitis C. This is unusual.

Right now, some genotypes of Hepatitis C respond better to the treatments we can offer. People with the genotypes that are more difficult to treat should not feel that their situation is hopeless. We are making rapid progress on finding better treatments all the time.

Make sure that you talk about your situation to your liver specialist at each visit.

Changing its shape

The Hepatitis C virus is also able to change its shape. This is probably one reason why the virus is usually so long-lived. It may explain some of the difficulties in finding general treatments.

Other liver tests

People with Hepatitis C should keep in regular contact with their specialist centre. At each visit, medical staff check on the person's general health, including weight. At each visit, blood samples are taken. The blood is tested in various ways. The most important tests are **liver function tests**.

Liver Function Tests (LFTs)

Liver Function Tests give important information about how well the liver is working. If a person has active inflammation of the liver, the enzymes of the liver (e.g. alanine amino transferase (ALT)) may be raised. Liver Function Tests are specialised and can only be interpreted by trained staff.

If you are being medically tested, no matter for what, always ask what the test does and why it is being done. You are entitled to have medical information about yourself explained to you in a way you understand.

All these tests seem really complicated.

Yes, they are. Finding the Hepatitis C virus in the blood is complicated and takes time. It is easier to look for antibodies than it is to look for the virus itself. It is important to identify people who had the virus in the past, but who no longer have it. It is also important to be 100% sure before telling any person that they have Hepatitis C.

If you are being medically tested, no matter for what, always ask what the test does and why it is being done. You are entitled to have medical information about yourself explained to you in a way you understand.

Why do the antibodies stay in the blood?

Antibodies are made by the immune system to attack and destroy dangerous viruses. The immune system is designed to always remember how it defeats a serious infection. This means that, if the infection comes back, the immune system is ready for it.

I have been told that I am antibody positive. I am waiting for the PCR test results. Do I have Hepatitis C or don't I?

If you are antibody positive you have had direct contact with the Hepatitis C virus in your past. We cannot know for certain if you still have the Hepatitis C virus until we get the results of the PCR test.

Liver biopsy

At present, the only way we have to find out the exact condition of the liver is by liver biopsy. This means taking a tiny section of liver out of the body, to examine it under a microscope.

At some stage, many people with Hepatitis C have a liver biopsy. **You do not have to have a liver biopsy if you do not wish to.** If you are advised to have one, you can decide to delay it while you decide what is best for you.

Sometimes, people have more than one liver biopsy, over a period of years, to check on the health of the liver. Often, a liver biopsy is taken before and after a course of treatment. This lets doctors see how the treatment has worked.

How is a liver biopsy done?

The biopsy is done by inserting a special instrument between the ribs, into the liver, and taking a small piece of liver back out. The exact place in the liver where the biopsy is taken is usually decided by using ultrasound.

The liver biopsy is always done by highly trained and experienced medical staff. It is usually done while the person having the biopsy is under local anaesthetic, with sedation if required. This means that a person having this procedure is usually awake during it.

Many people feel pain during the biopsy or immediately afterwards. This usually doesn't last long and goes away with pain killers. Very rarely, the biopsy may give severe, prolonged pain and the person may need to stay in hospital for a while. Liver biopsy is a very well known procedure. All the staff are fully aware of all possible complications. People with haemophilia should talk with their consultant haematologist before having a liver biopsy.

If you have a liver biopsy, make sure you discuss the findings with your liver specialist. Make sure you understand clearly what the results mean for you. Sometimes it may help to bring someone along to take everything in.

Results from a liver biopsy

The results of a liver biopsy can take a number of weeks to come. They give details of the type and amount of inflammation of the liver and whether it is mild, moderate or severe. The results tell if there is scarring (fibrosis) or cirrhosis. The results of the liver biopsy are graded. This means that they can be compared with previous biopsies and future ones. This can be important, for example, to decide if a treatment is having a positive effect on the liver.

Fibroscan

The Fibroscan has been developed in the last decade as a non-invasive method of measuring liver stiffness (elasticity). The methodology is ultra-sound elastography and the degree of stiffness is correlated to the degree of liver fibrosis (scarring).

It is a machine similar in appearance to an ultra-sound machine and a probe is placed over the liver which takes readings in different positions. The Fibroscan generates an instant reading which relates to the degree of fibrosis. The Fibroscan is a European development and it is at present still being validated for its reliability and reproducibility in comparison to liver biopsies which will remain the gold standard in the assessment of liver damage (fibrosis). Difficulties remain in its development specifically regarding the probe size in relation to the individuals body mass.

As yet the Fibroscan can be used as an additional tool in patient assessment but does not replace a liver biopsy.

Finding out you have Hepatitis C

There is no right or wrong way to feel about having any illness. It is natural to feel vulnerable, empty and shocked at first. It can be a frightening time for you and for anyone close to you who knows your situation. You may find that, at times, the whole thing is like a bad dream. At other times, you may be overwhelmed by worry or anger.

Find out about your situation

Find out what having Hepatitis C means for YOU, not for others. Ask your doctors and nurses about YOUR situation. Make a list of questions to ask at each visit to the specialist centre.

Don't try to cope alone

You need someone in your life, other than your doctor, who knows you have Hepatitis C. You should trust that person to keep the information private and to support you when you are under stress. You may think of family members, good friends or neighbours who could support you.

Get professional support and help

You can talk in confidence with someone who is not directly involved but who understands your situation. A **counsellor or therapist** can give you information to help you understand your own situation and to deal with your fear and anger. Ask to speak with a counsellor at the specialist centre. Each time you visit the specialist centre look to speak with the counsellor.

Who else needs to know

General practitioner (GP)

You should tell your GP that you have Hepatitis C. This information will be treated as confidential. Your doctor needs to know about your Hepatitis C in order to treat you properly.

Dentist

You are not legally obliged to tell your dentist that you have Hepatitis C. Your dentist knows about the risks of Hepatitis C and should make sure that everyone in the dental surgery is safe. You may prefer to tell your dentist. This is up to you.

School and college

In general, school or college authorities have no automatic right to know that any student has Hepatitis C. Some training courses for dental or medical careers may ask if you have had Hepatitis C and other virus infections. It is important to answer these questions honestly. The next section looks at this issue in detail.

How can I tell my partner that I have Hepatitis C?

Telling someone close to you that you have Hepatitis C is difficult. Your partner needs to know. Your partner may need to be tested for Hepatitis C, which may have implications for insurance. You and your partner may need to think about safe sex.

What if I need an emergency operation or I'm in a car accident? How will people know I have Hepatitis C?

They may not. All ambulance staff and hospital staff are trained to approach all blood as a possible source of infection.

Training and work with Hepatitis C

In Ireland, the Employment Equality Act (1998) outlaws discrimination in employment and vocational training on nine separate grounds, including disability. Hepatitis C is a disability within the meaning of the Act. All aspects of employment are covered, including pay, promotion and dismissal. The Act also outlaws harassment of any person by an employer, employees or customers on the nine grounds, including disability.

If you feel that you have suffered discrimination in training or employment because you have Hepatitis C, you may have a case against the relevant body. You can get information from the Equality Authority about your rights and how to take a case. The address is at the back of this booklet.

Vocational training

In general, having Hepatitis C should not stop you applying to or being accepted for vocational training of any kind. One possible exception is training for employment that involves work with a risk of spreading the virus (Hepatitis C exposure-prone procedures).

Applying for jobs

When you apply for certain jobs you may be asked if you have any medical conditions, specifically if you have one of the hepatitis viruses. **If you are asked, you should say you have Hepatitis C.**

It is not sensible to try to hide the fact that you have Hepatitis C. Remember, except in very clear circumstances, having Hepatitis C is not a reason to reject your application.

Employment

Generally, if you are already in a job, you are not obliged to tell your employer that you have Hepatitis C. Healthcare workers are exceptions to this rule.

Healthcare workers form a special category, because of the infection risks of some healthcare employment. All new healthcare employees may be asked to read and sign a statement that they understand their ethical and moral duty to inform the appropriate authorities if they have Hepatitis C (or other serious virus infections) or are at risk.

Healthcare workers who have Hepatitis C are ethically and legally obliged to inform the relevant infectious disease physician or occupational health physician. Healthcare workers with Hepatitis C must stop performing exposure-prone procedures. Healthcare workers with Hepatitis C have confidentiality and employment rights.

I haven't told my employer that I have Hepatitis C. I'm taking time off work because I'm sick or for hospital visits. I feel uncomfortable about this.

You have entitlements in relation to illness and sick leave. Perhaps you could contact your trade union about your legal rights. This might make you feel more comfortable.

Are you considering telling your employer that you have Hepatitis C? Again, perhaps your trade union official could give confidential advice. You could also contact the Equality Authority, in confidence, to find out about your rights.

Living well with Hepatitis C

Think positively about yourself

Like everyone else you have strong and weak points. If you find you are focussing on negatives - give yourself a break. Take a look at the positives. Live life the way it suits you. Don't let others decide what you do or how you feel. Manage your energy when you feel well and when you don't.

Eat a balanced diet

General medical advice to most people with Hepatitis C is to eat a normal, balanced diet. Vegetarians should eat a normal, balanced vegetarian diet.

(see page 23)

Some people with Hepatitis C feel better avoiding some types of food (e.g. spicy foods) or big meals. If you are unsure that you are eating properly or if you need advice, talk to the dietician at your specialist clinic. If you have advanced liver disease, the dietician may recommend a low salt, low protein diet.

In general, it is not necessary for people with Hepatitis C to take vitamin or mineral supplements. You should **avoid iron supplements** as these tend to affect the working of the liver.

Avoid alcohol

Alcohol is a powerful, addictive drug. Too much alcohol has serious health effects. Alcohol is removed from the blood stream by the liver. Drinking alcohol, if you have Hepatitis C, increases the problems in the liver.

If you have Hepatitis C, it is safest not to drink alcohol at all. If you find this is not possible, you should try to drink only very small amounts of alcohol. **Avoid regular drinking.**

Take some exercise

Do something you enjoy! Get out into the fresh air. Go for a walk or a run, swim, join a gym, do a bit of gardening. Turn off your mind while using a few muscles. If you are going through a period of feeling tired, don't push yourself. Your body needs rest. Wait for your energy to pick up before going back to exercise.

Let go of anger and guilt

Knowing that you have Hepatitis C may leave you blaming and angry at others or yourself. You may know that you accidentally passed the infection to a partner or a child. Blame, guilt and anger are natural human emotions. They seldom help you to approach life in a positive way. You cannot change the past.

You may find yourself releasing your anger on other people, your family or your medical contacts. This may seem a good idea at the time, but it only builds up your stress and anger levels. Try not to vent your anger on other people. Instead, let it out in some physical activity that makes you feel better. Many people with Hepatitis C find that talking with a counsellor or psychologist helps them to sort out their feelings.

Deal positively with stress

Having Hepatitis C can be stressful. Knowing that your partner or close family member or friend has Hepatitis C can lead to anxiety. As well as the stress of Hepatitis C, you may have problems at home or at work. The pressures may come to a head if you are tired or unwell.

Try to keep a short period of every day just for you. You may like to put your feet up or to go for a walk, to meditate or pray. Whatever you do, do it for yourself. Sometimes it helps to get away on your own for a while, to relax and come to terms with your situation.

Don't bottle up your worries

Talk to a family member or good friend you can trust. Talk to the nurse or your liver specialist at the hospital. They can explain what is happening and can discuss your fears and anxieties. Talk with a counsellor who can help you sort out your feelings. Make contact with a support group for people in a similar situation to your own.

Keep in regular contact with your specialist centre

You need to keep in contact with your specialist centre, even if you are feeling well. Regular tests will ensure that problems will be noticed early. Your specialist centre can give you information about counselling, support groups and other assistance.

Get vaccinated against Hepatitis A and B

Having Hepatitis C means that your liver is already coping with a serious illness. Protect your liver from other viruses that can cause hepatitis. Get vaccinated against two of the most common viruses that give hepatitis. Remember that vaccination only gives protection for a certain time. Make sure you know how often you need to be re-vaccinated.

Hepatitis A is passed in food or liquids that are contaminated by contact with infected faeces. It can cause a sudden attack of liver inflammation (**acute hepatitis**) which is usually short-lived.

Hepatitis B is a liver virus that is transmitted by infected blood in the same ways as Hepatitis C. It is a serious illness, often with obvious signs at the time of infection. It can be fatal.

I know its best not to drink, but I want to be able to take a drink on my birthday or at Christmas.

That's very understandable. You may decide to drink on these occasions.

Try not to binge drink. If you can't stop after one or two, it may be more sensible never to start.

I had such high expectations of what I was going to do in life. Now, this has happened.

Many people aim high in life. Some people achieve their goals. Most people come to accept that their ambitions are never fully achieved. This does not mean they have failed. It means that life has taken a path they did not expect.

Often, it's not what happens in your life that is most important. It's how you react to it. A first step may be to try to accept what has happened. Gradually, you may be able to move along this new path.

Every time I get a cold or feel off-colour I get so frightened. I never seem to stop worrying about my health.

It is natural to be concerned about your health when you know you have an illness like Hepatitis C. Try to keep things in proportion. Having Hepatitis C doesn't stop the ordinary ups and downs in your health. You will get colds and 'flu, headaches and pains, just like everyone else.

Living well with Hepatitis C

Eat a balanced diet: The Food Pyramid

Sparingly.

Fats and oils, sugars,
confectionaery, cakes etc

2 Servings

Meat, fish, eggs,
beans etc

3 Servings

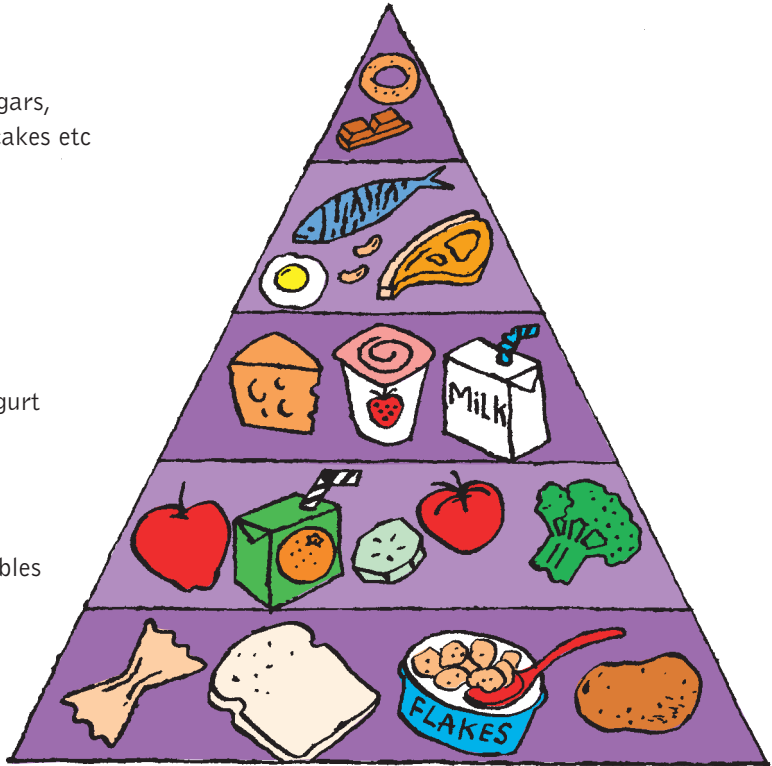
Milk, cheese, yogurt

4 Servings

Fruit and vegetables

6 Servings

Bread, cereals
and potatoes



Treatments for Hepatitis C

Some people need little, if any, special treatment. Other people need a lot of medical and other help. The best medical treatments for Hepatitis C are severe. They work better for some people than others.

Aims of treatment for Hepatitis C

Treatment aims to get rid of the virus, to stop the inflammation of the liver and to improve general well-being. The main medical treatment for Hepatitis C uses drugs designed to get rid of the virus, 'anti-viral' drugs.

Treatments are improving all the time

The treatment of Hepatitis C has improved in the last few years. The powerful drug interferon has been used from the beginning. Interferon is a natural, anti-viral substance found in the human immune system. It 'interferes' with the ability of viruses to reproduce. We have developed artificial forms of interferon to treat illnesses including Hepatitis C.

In the past, interferon was used on its own to treat Hepatitis C. It was injected, three times a week. Later, doctors added a second drug, called ribavirin, taken in tablet form. The two drugs together gave better results. This was the first form of combination therapy.

Now, we have a new type of interferon that lasts longer in the body. It is called **pegylated interferon** and only one injection a week is needed. **Ribavirin** is still used as well. Research continues to improve interferon and ribavirin and to look for other drugs that might help to stop the Hepatitis C virus.

Deciding to take treatment for Hepatitis C

At some stage of your illness you may be offered treatment. **Remember that taking any treatment is your decision.** Before deciding to start treatment, you may wish to be clear in your own mind what it involves, how long it would go on for, what the side-effects might be and how successful it usually is. Making decisions of this kind can be difficult. Perhaps you could talk with a counsellor to help you make a decision.

Deciding to take treatment.



Delaying treatment

You may feel that the time is not right for you to start treatment. If so, talk about this to your liver specialist. It may be possible to delay treatment until a time that is more suitable for you.

You may benefit from new treatments

In the past, you may have had unsuccessful treatment with interferon or combination therapy. It is likely that, as treatments get better, you will be offered treatment again, even if past treatment was not a success for you.

Making a decision to go back on treatment can be difficult, especially if you had a lot of side-effects in the past. Take time to think carefully about what you feel is best for you to do. Get the advice of your liver specialist. Discuss your feelings with a counsellor to help you to sort out what you feel is best for you to do.

If you go on the treatment try to stick with it even if you find it very difficult. Try to keep it up for as long as the doctors feel it is helping you.

Combination therapy

While many drugs are undergoing clinical trials in HCV, to date the following drugs; Interferon, pegalated-Interferon and Ribavirin only are fully licensed for its treatment. We await results of those drugs being trialed worldwide.

Right now, the recommended best medical treatment is a combination of the two powerful drugs **interferon** and **ribavirin** called **combination therapy**. Interferon is given as an injection, once a week, for up to twelve months. People learn how to give themselves the injection, which they can then do at home. Ribavirin is taken as a capsule, twice a day, for up to twelve months.

Side-effects of combination therapy

The combination therapy drugs can give **side-effects**. These may include 'flu-like symptoms, fever, sweating, tiredness, muscle aches, nausea and headaches. The side-effects vary greatly from one person to the next. We can't predict who will have side-effects and who won't. The side-effects may only last for a short time. For some people, they continue all during the treatment.

Success rate of combination therapy

The main aim of the treatment is to clear the virus from the blood. Treatment may be more successful for people whose liver is still functioning fairly well, with no cirrhosis. As with many illnesses, the younger and fitter the person, and the shorter the time of infection, the more likely the success.

About half of all people on combination therapy show no response. Their treatment stops when it is clear that it is not doing any good.

About half of the people on the treatment programme react positively. For about half of this group who start to improve the improvement is **temporary**. For the other half of the group the improvement continues after the treatment stops. This is called a **sustained response** and is a sign that the virus is being defeated. At present, about **two in every five people who complete the course of combination therapy have a sustained response**.

This figure is getting better all the time. Even if the treatment is not a complete success, it may slow down the problems caused by the virus.

Success for different genotypes

In general, treatment for some genotypes of Hepatitis C is more successful than for others. Even if you have a genotype that does not respond so well, you may still be offered the treatment because every person is individual. The treatment may have a positive effect for you.

Other drug treatments

Some people who are unable to take the combination therapy may be given **Interferon** on its own. The success rate is not as high as for combination therapy, but is improving with experience.

New treatments are coming available all the time. Each time a new treatment is found, it must first be tested to find out if it really is effective and what the side effects are.

Liver transplant

Each year, a tiny number of people with Hepatitis C develop liver problems that are so severe they are life-threatening. In such instances, a liver transplant may be considered. Over the past 30 years or so, liver transplants have become very successful. Most people who have one go back to a normal lifestyle. Hepatitis C will infect the new liver, but it takes a long time for serious symptoms to begin.

Complementary medicine

Some people with Hepatitis C use complementary medicine to help relieve symptoms and to improve their general health. Examples of complementary medicine include acupuncture and reflexology.

Some people find that **Traditional Chinese Medicine (TCM)** helps to relieve the symptoms of Hepatitis C. TCM uses herbs which have complicated effects on the body. The treatment means making changes to the diet, meditation and relaxation, and usually includes massage and acupuncture.

Can everyone with Hepatitis C get this treatment?

No. At the moment, combination therapy is given to people whose liver biopsies show moderate or severe chronic hepatitis or fibrosis. Some people are not given it because the risks are too high, for example, in pregnancy. A small number of people could be harmed by the treatment. It is never given in such cases.

Up till now I've been fine. But I've started combination therapy and I just can't cope any more. Don't despair. Starting treatment for Hepatitis C can be extremely tiring. Your body may get used to the treatment and, in time, you may begin to feel brighter. You can only cope with so much. Take a look at your life and let the unimportant things go. Let other people help a bit more too. Perhaps talking to a counsellor would help you.

What if you can't cope with the side-effects?

If the side-effects are severe, **do not stop the treatment.** It is not advisable to stop taking these drugs suddenly. Speak with your nurse and your liver specialist.

If you do have to stop, try not to feel upset or angry with yourself afterwards. You did your very best. The treatment did not suit you. Another treatment with fewer side-effects may become available and it may suit you.

If you are a HAA cardholder you may be entitled to certain services to help you cope. Please refer to your HAA guide for services or contact your Liaison Officer.

Remember, herbal products can be toxic to the liver. Never take any product without asking your liver specialist first.

Is complementary medicine safe?

If you are thinking about using complementary medicine of any kind, always, ask your liver specialist. Never assume that a treatment that has helped another person with Hepatitis C will help you. Also, never assume that a treatment that has helped you will help another person with Hepatitis C. In general, be careful about taking 'remedies' that could harm you or interfere with your medical treatment.

What about medicines for other problems?

If you are being prescribed other medication always make sure that your doctor knows you have Hepatitis C. You can take ordinary over-the-counter medication (e.g. paracetamol) for headaches, colds and 'flu.

I'm in the menopause and have been recommended Hormone Replacement Therapy (HRT). Would this have any effect on my Hepatitis C?

It is important to inform your gynaecologist about your Hepatitis C. Women with Hepatitis C who are going through the change of life (the menopause) should discuss their situation with a liver specialist before taking HRT. The liver is involved in the production of hormones. It may react to certain HRT products.

What can't I do with Hepatitis C?

You can never be a blood donor

You must never give blood, even if you have a rare blood type. If you have already given blood in the past you must inform the Irish Blood Transfusion Service (IBTS) (Tel:- (01) 432 2800) that you have Hepatitis C and that you have been a blood donor.

If you are ever called back to give blood, do NOT go. Explain the situation to the IBTS so that the mistake can be corrected.

You can never be an organ donor

Tell your next of kin and other family members that you cannot donate your organs. If you carry a donor card, stop doing so immediately.

Your close family cannot donate blood or organs

If you have Hepatitis C, your partner or anyone living in your home cannot donate blood or organs. The Irish Blood Transfusion Service (IBTS) has published a booklet, Eligibility to Donate Blood. This gives details about blood donation in relation to people with the Hepatitis C virus, people with antibodies to the Hepatitis C virus (people who are antibody positive) and people who are sexual or household contacts of these individuals. These rules are the same for organ donation.

You may find it difficult to obtain life insurance at normal premium rates

Right now, it is difficult for people with Hepatitis C to get life insurance from any of the main insurance companies at normal premium rates.

If you already have life insurance and when you took out the policy you answered about your medical history fully and honestly to the best of your knowledge at that time, you do not have to inform your insurers about any subsequent diagnosis of Hepatitis C.

If you wish to retain your current policy, you should be careful to keep your payments up to date. With some policies a lapse in payment (even for a month or two) may mean that your cover has expired and has to be re-instated by filling out another questionnaire. If that is the case you are legally obliged to disclose the Hepatitis C infection and any other relevant condition.

For HAA Cardholders

Under the Health (Amendment) Act 1996, those persons who were infected with Hepatitis C and/or HIV through the administration of blood or blood products within the state are entitled to access Life Assurance, Mortgage Protection Insurance and Travel Insurance without financial penalty.

The hepatitis C Compensation Tribunal (amendment) Act (No.22) of 2006 and Statutory Instrument (Regulations no 31) of 2007 allow for the implementation and operation of the Hepatitis C Insurance Scheme.

The most important aspect of the Scheme is that there is no financial penalty for having State Acquired Hepatitis C and/or HIV. This means that individuals who take out insurance under this scheme will only pay the standard premium to the Insurer, irrespective of existing health conditions. The Insurance Scheme allows (subject to certain limits) for the provision of :

Life Assurance Cover
Mortgage Protection Cover
Travel Insurance

The cover can be provided by any Insurance Company that has applied to and been approved by the Administrator.

If you think you are an eligible person you should contact the Administrator of the Scheme for more information:
www.hepcinsurance.ie
Free phone: 1850 211 570

Young people with Hepatitis C

This section is for teenagers and young adults with Hepatitis C. Like anyone else, you can look forward to completing your education, working, enjoying sports and recreation, having close relationships and a fulfilling life.

Having Hepatitis C may complicate some aspects of your life. Few people get through life without some complications on the way. Keeping a sense of perspective helps you carry on with life.

Let's look at the facts:
Hepatitis C usually takes many decades to give serious symptoms.

If you get Hepatitis C as a child or young person, the illness may be less severe and progress more slowly than if you get it as an adult.

If you face serious problems in the future, the treatments available by then will be more effective.

The likelihood is that you will live a full life. You can make plans about your future like anyone else.

You can help by keeping stress to a minimum, eating sensibly, avoiding alcohol and drugs and generally looking after yourself.

Talking to your parent(s) or caregivers

Your parents may let you get on with your life. They know you will come to them if you need help. Or you may find that your parents worry a lot about you and try to shelter you from life.

At some time, most young people find it difficult to talk to their parents, or the closest adult who cares for them, about

important issues. You may find that your parents are worried about issues that don't bother you. You may want to talk about issues that your parents don't feel are important or that they don't know anything about. If you find that you are having problems talking to your parents about things that are important to you, perhaps you could ask for help from the counsellor at your specialist centre.

Should I tell my friends?

This is entirely up to you. If you decide to tell someone, remember that they may know almost nothing about Hepatitis C. You may find that friends can help if things are not going well at home.

What about choosing a career?

Very few careers involve possible blood contact with other people. Hepatitis C should not stop you following a chosen career path. Some medical and dental careers hold a small risk of spread of Hepatitis C. It is likely that, if you apply to train in these areas, or if you apply for one of these jobs, you will be asked about any blood infection you have.

Having Hepatitis C means that you need to prioritise your health and well-being. In choosing a career, it may make sense to think about the physical commitments of the job.

Will I be able to work all my life?

None of us knows for certain if we will work all of our lives. Many people's lives change over the years. They may decide to opt for part-time work, for work from home or for early retirement. It is best to focus on the present and the near future, rather than using energy on concerns that may never arise.

Young people and sexual relationships

Young people may feel that all their friends are having sex and that they are abnormal if they don't. This is simply untrue. Much of the talk about sex is just that - talk. Sometimes, a young person can feel pressure from a boyfriend or girlfriend to start a sexual relationship. Never be pressurised into doing something you don't want. Never have sex because everyone else seems to be doing it or because someone else wants you to. For most young people, there comes a time when they feel ready to have a first sexual experience. Some young people have first sex with someone they know well. Other people have that moment with someone they don't know well. It is vital that all young people protect themselves and their partners during sexual activity. **Condoms protect against viruses like Hepatitis C and HIV. Condoms help to avoid unwanted pregnancy.**

My mother means well, but she's always on my case. I wish she'd give me a bit of space.

Your mother does mean well. The question for you is how to let her know that she's putting you under pressure. Could you talk to another adult who knows you mother well and might have a word with her? Perhaps you could talk to your mother at a time when you are both relaxed. You could start by saying that you understand that she is anxious about you and that you value her concern. You could then explain how you feel. Maybe having a talk with a counsellor at the specialist clinic might help.

I don't want to talk to my parents about how I feel.

That's understandable. You're entitled to your own space. Right now, your parents are not the people you want to talk with. But do you want to talk with someone? If your answer is yes, could you talk to a trusted friend? Next time you are at the specialist clinic could you talk with someone there?

Can I have a child?

Right now, our best advice is that Hepatitis C should not stop you having a child or children. There may be a very small risk of passing the virus to your child. There may be a very small risk of passing Hepatitis C through breast-feeding. You might like to discuss these matters with your liver specialist.

If you find that you are pregnant, or your partner is pregnant, make sure to tell the doctor as soon as possible.

If you give birth, your child does not have to be tested for Hepatitis C. Your permission must be given before your child can be tested.



Health services for people with Hepatitis C

Going to a specialist centre

When you are first told that you have Hepatitis C, your family doctor (GP) will arrange for you to see a hospital consultant doctor who is a **specialist** in treating this illness.

Most of the major acute hospitals in Dublin and around the country provide services for people with Hepatitis C. All people with Hepatitis C may attend one of the **specialist centre** clinics in Dublin (Beaumont Hospital, The Mater Misericordiae Hospital, St. James's Hospital, St. Vincent's University Hospital) or a designated specialist centre in one of the Health Service Executive areas. These include centres at Cork University Hospital, University College Hospital Galway, St. Luke's Hospital, Kilkenny and Our Lady's Childrens Hospital, Crumlin, Dublin.

Entitlement to services

When we talk about **entitlement to services** we are talking about the **type of services** a person may receive and the **extent to which a person is expected to pay for these services**.

In Ireland, everyone with Hepatitis C is entitled to receive certain core services. Not everyone is entitled to these core services free of charge. Other services, which are not classed as core services are generally not provided free of charge. However, some people are entitled to both the core services and a range of extra services, free of charge, because their Hepatitis C was caused by infected blood administered within Ireland.

First, let us look at the entitlements of people with Hepatitis C whose illness was not caused by the administration of blood

or blood products within the State. Your entitlement to Hepatitis C services is the same as your entitlement for any other health services. Most people fall into three main groups when deciding the extent to which a given person must pay for these services.

A person may hold a medical card.

A person may have income-related entitlements.

A person may have private insurance.

If you have a medical card, you will be covered for necessary core health services for Hepatitis C, in exactly the same way as for all other medical conditions. This means that visits to your GP, all hospital outpatient and inpatient services, drugs and other prescribed treatments will be provided free of charge to you.

If you do not have a **medical card**, you will have to pay for GP services. You will be entitled to claim back part of the costs of any drugs or medicines that your GP prescribes. You will be entitled to hospital outpatient and inpatient services in a public hospital but you will be expected to pay the minimum charge. If you are prescribed treatment with interferon, you may be able to avail of the DPS scheme that gives expensive medication, such as this, free of charge.

Under the Drugs Payment Scheme, an individual or family only has to pay a maximum amount monthly for approved prescribed drugs, medicines and certain appliances for use by that person or his/ her family in that month. The amount currently stands at a max of €90 per month. You should check the HSE website for the most up to date information www.hse.ie.

The scheme is aimed at those who don't have a medical card and normally have to pay the full cost of medication. You can get further details and registration forms from your local pharmacy.

If you have **private health insurance cover**, it is likely that your insurance will provide the same level of cover in relation to Hepatitis C as for any other medical condition. Check with your insurers to be certain about the extent of your cover. Regardless of your private cover, you may be entitled to services within the public health system.

Hepatitis C from blood or blood products administered within Ireland

Now, we will look at the services available to people whose Hepatitis C was caused by infected blood or blood products administered in Ireland. If you have Hepatitis C from this source, you are entitled to a range of health and related services, free of charge. These services include free GP services, free prescribed drugs, medicines and appliances, dental and ophthalmic services, home support, home nursing and counselling services. These services are provided under the Health (Amendment) Act 1996.

Special funding to hospitals

In addition to the hospital services mentioned at the start of this section, some hospitals have been specially funded by the Health Services Executive to look after your health care. Your GP will refer you to a specialist in one of these hospitals.

Hepatitis C Liaison Officers

Each of the Health Service Executive areas has appointed a **Hepatitis C Liaison Officer** whose job it is to ensure that all people with Hepatitis C from blood or blood products receive the services they are entitled to under the terms of the 1996 Act. A list of Hepatitis C Liaison Officers is provided at the back of this booklet.

Health Amendment Act Card

To avail of services under this scheme, you apply to the Hepatitis C Liaison Officer in your local H.S.E area for a **Health Amendment Card** (sometimes referred to as the H.A.A. card). This is not a medical card. It is a special card only for people with Hepatitis C from infected blood or blood products administered within Ireland.

If you are eligible, you will be given the Health Services Card. This will make it easy for you to obtain services. When you have the card, you should contact your Hepatitis C Liaison Officer if you have any difficulties getting services.

The liaison officers provide information and help only to people who have **Hepatitis C as a result of medical use of infected blood products**. The liaison officer is there to help you and will be able to send you an information guide that tells you everything you need to know about the services you are entitled to. The support groups listed at the end of this booklet will give advice to you as well.

Counselling services

Many people with Hepatitis C benefit from talking to a trained counsellor at some stage of their illness. The liaison officers have lists of qualified counsellors in each Health Service Executive area. Each support organisation has a list of specialist counsellors. You do not have to attend a counsellor in your area. You can choose to visit a counsellor in another area.

Children with Hepatitis C

Most children with Hepatitis C are looked after by a team at Our Lady's Children's Hospital, Crumlin, Dublin. Many young people continue to attend Our Lady's until the age of 18 years. Then, they transfer to one of the adult specialist centres in Dublin or in one of the Health Service Executive areas.

Useful addresses

1. Support groups

Positive Action

56, Fitzwilliam Square,
Dublin 2.

Tel: (01) 676 2853 Fax: (01) 662 0009
Web: www.positiveaction.ie
Email: info@positiveaction.ie

Positive Action provides information and support to women who have Hepatitis C from infected Anti-D products administered in Ireland, and to their families.

Transfusion Positive

3, Clanwilliam Square
Dublin 2.

Tel: (01) 639 8854/5
Fax: (01) 6398856
Email: transfusionpositive@eircom.net
Web: www.transfusionpositive.ie

Transfusion Positive provides information and support to people who have Hepatitis C from a blood transfusion in Ireland, and to their families.

Irish Haemophilia Society

1st Floor Cathedral Court,
New Street,
Dublin 7.

Tel: (01) 657 9900
Fax. (01) 657 9901
E-mail: info@haemophilia.ie
Website: www.haemophilia.ie

The Irish Haemophilia society provides information and support and services to all people with bleeding disorders who have Hepatitis C, and to their families.

Irish Kidney Association

Donor House,
Block 43A, Parkwest,
Dublin 12.

Tel: (01) 620 5306
Fax: (01) 620 5366
Lo-call: 1890 45 65 56
E-mail: info@ika.ie
Website: www.ika.ie

The Irish Kidney Association provides information and support to people and their families with end stage kidney problems, including people who have contracted Hepatitis C through haemodialysis or blood transfusions.

Hepatitis Information Point (H.I.P)

Tel: 01 473 6615
Web: www.hepinfo.ie

H.I.P is a self-help group set up by and for people living with Hepatitis C.

Useful addresses

2. Specialist Centres

Beaumont Hospital

Hepatology Unit Beaumont Road
Dublin 9
Tel: 01 8092220/ 8093000
Fax: 01 8092219
Contact: Emer Bolger
Ciara Corrigan
Mary McDonagh

St. James's Hospital

Hepatology Unit St. James Street
Dublin 8
Tel: 01 4103417 / 01 4103000
Fax: 01 4103418
Contact: Helena Irish
Carol Ann Brogan
Sharon Buckley
Barbara Hynes
Clodagh Quinn

Our Lady's Children's Hospital Crumlin

Hepatology Unit
Crumlin Hospital
Dublin 12
Tel: 01 4282527/ 01 4096742
Fax: 01 4096217
Contact: Eleanor Knopfler
Ursula McConnell

St. Luke's Hospital

Hepatology Unit
Kilkenny
Tel: 056 7785308 / 056 7785329
Fax: 056 7752232
Contact: Angela Buggy
Pauline Carroll
Noreen Maher

Mater Misericordiae Hospital

Centre for Liver Disease
55 Eccles Street
Dublin 3
Tel: 01 8032048 / 8032000
Fax: 01 8034058
Contact: Caroline Walsh
Mags Mc Andrew

St. Vincent's University Hospital

Liver Unit
Elm Park
Dublin 4
Tel: 01 2774713 / 01 2774000
Fax: 01 2218960
Contact: Sheila O'Toole
Aileen Murphy
Carol McNulty

University College Hospital

Hepatology Unit
Galway
Tel: 091 544370 / 091 524222
Fax: 091 520233
Contact: Margaret Scarry
Mary Bohan Keane
Sheenagh McLaverty

Cork University Hospital

Hepatology Unit
Wilton
Cork
Tel: 021 4922274 / 021 4922167
Fax: 021 4936383
Contact: Susan Corbett
Eleanor Healy

Useful addresses

3. Liaison Officers

HSE Area	Local HSE Area	Liaison Officer Name and Address	Telephone no	Email address
Dublin North East	Dublin North West/Dublin North/Dublin North Central (former community services areas 6,7 & 8)	Mr Larry Bathe Hepatitis C Section 2nd Floor Health Service Executive Mill lane Palmerstown Dublin 20.	01 6201758	Larry.bathe@hse.ie
Dublin North East	Cavan, Louth, Meath and Monaghan	Ms. Barbara Leech Primary Care Unit Railway Street Navan Co Meath	046 9076451	Barbara.leech@hse.ie
Dublin Mid Leinster	Dublin South West/Dublin West/Dublin South/Wicklow (former community services areas 3,4,5 & 9).	Ms. Anne Tiernan/ Ms. Valerie Whelan Primary Care Unit Block E Westland Park Nangor Road Dublin 22	01 460 9671	atiernan@hse.ie
Dublin Mid Leinster	Dublin South East/Dun Laoghaire/Bray/Wicklow (former community services areas 1, 2 & 10)	Ms Carmel Donohoe/ John Fennell Health Services Executive Civic Centre Main Street Bray Co. Wicklow	01 2744291	carmel.donohoe1@hse.ie j.fennell@hse.ie
Dublin Mid Leinster	Laois, Longford, Offaly, Westmeath	Ms Elaine Barry Primary Care Unit Health Services Executive St. Loman's Springfield Mullingar Co Westmeath	044 9384429	elainem.barry@hse.ie
South	Carlow/Kilkenny/Tipperary South/Waterford/Wexford	Mr Cathal O'Reilly/ Ms Breda Aylward Health Services Executive South Eastern Area, Lacken Dublin Road Kilkenny	056 7784160 056 7784113	cathal.oreilly@hse.ie breda.aylward@hse.ie

Useful addresses

3. Liaison Officers cont.

HSE Area	Local HSE Area	Liaison Officer Name and Address	Telephone no	Email address
South	Cork/Kerry	Mr Donal Murphy Primary Care Unit Health Services Executive Southern Area 26/27 South Mall, Cork	021 492 1872	Donal.murphy2@hse.ie
West	Clare/Limerick/ Tipperary North	Mr Michael Griffin Primary Care Unit Manager Health Services Executive Ballycumin Avenue Raheen Business Park, Limerick	061 464002 061 464004	michaelf.griffin@hse.ie
West	Leitrim/Sligo/ Donegal	Ms Phil Mulligan/ Sadie Flanagan Health Services Executive Iona Office Block Main Street Ballyshannon Co. Donegal	074 9122322 071 9834000	phil.mulligan@hse.ie sadie.Flanagan@hse.ie
West	Galway/Mayo/ Roscommon	Mr. Richard Broderick Health Services Executive Western Area Merlin Park Regional Hospital Galway	091 775416	Richard.Broderick @hse.ie

For all queries which cannot be resolved at local level in both primary / community services and within the eight hospital units, please contact the HSE Hepatitis C Liaison Officer as follows:

Michele Tait

Hepatitis C Liaison Officer

Tel: 01 620 1712 / 01 620 1750 Email: michele.tait@hse.ie

Useful addresses

4. Do you need help?

If you have a problem with alcohol contact:

Alcoholics Anonymous

General Services Office,
Unit 2, Block C, Dublin 8.
Santry Business Park,
Swords Road,
Dublin 9.

Tel: (01) 842 0700
Web: www.alcoholicsanonymous.ie

Alcoholics Anonymous is a voluntary worldwide group of men and women who meet to get sober and stay sober. Look in your regional telephone directory for the nearest meeting centre.

If you have a problem with drugs contact:

Merchant's Quay Project

Merchant's Quay,
Dublin 2.

Tel: (01) 679 0044
Fax: (01) 671 3738

Drug Treatment Centre Board

Drug Treatment Centre Board,
Trinity Court,
30-31, Pearse Street,
Dublin 2.

Tel: (01) 648 8600
Email: info@dtcb.ie

If you are a parent under stress contact:

Parentline

Carmichael Centre for Voluntary Groups,
North Brunswick Street,
Dublin 7.

Tel/Fax: (01) 878 7230
Helpline: (01) 873 3500
Web: www.parentline.ie

Parentline offers a support service to parents who are experiencing difficulties in parenting.

If you are despairing or suicidal contact:

The Samaritans

Republic of Ireland
Helpline: 1850 60 90 90 (cost of local call)

Northern Ireland
Helpline: 08457 90 90 90 (cost of local call)

Hearing impaired services (textphone):
Republic of Ireland: 1850 60 90 91
Northern Ireland: 08457 90 91 92

The Carers Association

Bolger House
Patrick Street
Tullamore
Co. Offaly

Tel: 057- 9322 920
Email: info@carersireland.com
Web: www.carersireland.com

Useful addresses

5. Other addresses

Equality Authority

2 Clonmel Street,
Dublin 2.

Tel: (01) 417 3333
LoCall: 1890 24 55 45
www.equality.ie

Irish Blood Transfusion Service (IBTS)

National Blood Centre
James's Street,
Dublin 8

Tel: (01) 432 2800
Fax: (01) 432 2930
Website: www.ibts.ie

The Professional Register of Traditional Chinese Medicine

Tel: (01) 855 9000
Website: www.chinese-medicine.ie

Further information on Hepatitis C

British Liver Trust

2 Southampton Road,
Ringwood,
BH24 1HY
England.

Tel: 0044 1425 481 320
Fax: 0044 1425 481 335

The British Liver Trust produces a range of booklets and other information about all aspects of liver disease.

Recommended reading

English, R. & Foster, G. (1997), Living with Hepatitis C. Robinson Publishing Ltd., 7 Kensington Church Court, London W8 4SP, England.

(ISBN 1 85487 913 8)

The Internet

You may wish to search the Internet for information about Hepatitis C. Some reliable and responsible groups have useful information that you may find of benefit. These sites can be useful to learn more about a topic or to reassure yourself.

Some sites are there to encourage you to use or buy products. Never use or buy a product recommended on the Internet, without first consulting your doctor.

Some sites are technical. They are really for doctors and other medical staff. You may not find these useful. Some sites are written by people with Hepatitis C. These may interest you. Remember that one person's experience is unlikely to reflect your own.

Recommended websites

Consultative Council on Hepatitis C at www.consultativecouncilonhepc.ie

Department of Health and Children at www.dohc.ie

Health Services Executive at www.hse.ie



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