

#### LIVING WITH HEPATITIS C

Information about Hepatitis C for people with the virus, their family and friends

#### Hepatitis C Virus Infection

Inflammation of the liver is medically described as hepatitis and may be caused by a variety of drugs, disorders of the immune system and several viruses. Viruses are living cells which multiply in an individual's body and when the effect is mainly on the liver the disease is known as viral hepatitis. Several viruses have been identified as causing viral hepatitis and include Hepatitis A and B which were identified over two decades ago. In 1989 the Hepatitis C virus was identified and was recognised as being the cause of the so-called "non-A non B" viral hepatitis which had occurred in individuals receiving blood transfusions. It is now recognised that chronic Hepatitis C virus infection is a major cause of liver disease world-wide and is the commonest indication for liver transplantation in the United States of America. At present time treatment consists of the use of the anti-viral agents Interferon and Ribavirin and although the success of treatment is currently limited it can be anticipated that newer therapies will become available as our understanding of the nature of this virus increases. This booklet summarises some of our current knowledge about the Hepatitis C virus, its effects on the individual, the method of diagnosis and the treatments available, and is aimed at individuals infected with the Hepatitis C virus and their family members and friends.

While the specific Hepatitis C virus was first identified in 1989 it became clear that this virus was the cause of so-called "non-A non-B" hepatitis which had been recognised as a complication of blood transfusion for many decades. It is now recognised that chronic Hepatitis C virus infection is one of the commonest diseases in the world and it is the leading cause of chronic liver disease.

### What is the Hepatitis C Virus?

The Hepatitis C virus is a RNA (ribonucleic acid) virus of which there are at least nine genotypes. These genotypes are found in different parts of the world, with types 1 and 3 being the commonest in the western world. Each genotype may have several subtypes and within each subtype there may be minor variations in structure.

Each individual with Hepatitis C will have a specific genotype and subtype. Some individuals, particularly those who acquire the infection through intravenous drug abuse, have more than one genotype. Research has indicated that subtle changes in the structure of the Hepatitis C virus occur frequently and it is thought that these changes are at least partly responsible for the failure of the body's immune system to completely eliminate the infection. The genotype of the Hepatitis C virus is also important from the point of view of treatment with some genotypes, for example type 3, being more responsive to anti-viral therapy than, for example, type 1 a/b.

# How serious is Hepatitis C?

The consequences of Hepatitis C virus infection may be divided into those that relate predominantly to ongoing active virus infection, and those that relate to the liver damage caused by the infection. The severity of the symptoms present in individuals with Hepatitis C virus infection do not in any way relate to the presence of liver disease. Some individuals with mild liver disease have severe symptoms while others with advanced liver disease have no symptoms.

## What are the symptoms of Hepatitis C?

The physical symptoms of Hepatitis C infection vary considerably from individual to individual. Some individuals have virtually no complaints while others have debilitating symptoms which impact greatly on their social and occupational lifestyles. The symptoms of the Hepatitis C virus infection, rather than those attributable to liver disease, are usually non-progressive. In particular, the joint/muscle pains are not associated with any actual joint destruction. When individuals develop symptoms related to Hepatitis C chronic liver disease, the liver disease will usually be at the advanced stage. Such symptoms include fluid retention, muscle wasting, jaundice, sleep disturbance and inability to concentrate. There are a minority of individuals who do not have any symptoms related to either virus infection or liver dysfunction, even when the disease is at an advanced stage.

#### Some symptoms of Hepatitis C Virus

- Chronic fatigue which fluctuates in severity and which may be incapacitating.
- Joint/muscle pains
- Skin rashes
- Irritations/dryness of the eyes
- Abdominal discomfort
- Depression
- Fluid retention
- Sleep disturbance
- Difficulty in concentration
- Jaundice
- Muscle wasting.

### Natural history of Hepatitis C Virus infection

Following infection with Hepatitis C a patient may develop an acute hepatitis which may or may not be associated with symptoms. The majority of patients with acute Hepatitis C virus infection do not have any symptoms. If symptoms are present, they may include fatigue, nausea, loss of appetite, weight loss, jaundice and depression. Following an acute infection with the Hepatitis C virus the immune system may clear the virus and render the individual immune to reinfection with the Hepatitis C virus. Under these circumstances most if not all individuals do not suffer any permanent liver damage. In between 60% to 80% of individuals who develop acute Hepatitis C virus infection the virus persists and may be associated with development of a chronic hepatitis. Over several years the chronic hepatitis may remain as a minor inflammation within the liver without progression to more serious liver disease. However, in some individuals a progressive form of hepatitis develops which results in fibrosis and eventually cirrhosis of the liver. This advanced stage of chronic liver disease may then be associated with liver failure for which the only treatment currently available is liver transplantation.

In individuals with long standing Hepatitis C virus infection and cirrhosis the disease may be complicated by the development of hepatocellular carcinoma (liver cancer).

When chronic liver disease has reached an advanced stage patients may develop complications such as liver failure which is associated with fluid accumulation within the abdomen and in the lower limbs, or disturbances in intellectual function or sleep which result from failure of a diseased liver to clear toxins from the blood.

Does the Hepatitis C virus affect other body systems? In some people more often women than men, the Hepatitis C virus may cause disorders of the immune system, leading to complaints that seem unrelated to hepatitis, such as arthritis and thyroid problems.

Hepatitis C virus infection may also be associated with disorders in other organs which as the thyroid gland, and can produce a very troublesome possibly immune mediated fibromyalgia (joint and muscle pains). Rarely Hepatitis C virus infection is associated with disorders of the kidney and bone marrow. Many of these non-liver related effects are thought to be related to a disorder of the immune system. The consequences of acute and chronic Hepatitis C virus infection vary considerably from individual to individual. It seems likely that differences in genetic make up, gender, type of Hepatitis C virus, lifestyle, diet and alcohol consumption may all play a role in determining whether or not the virus will be eliminated, and whether the associated liver disease will be progressive.

Some people with fibrosis go on to develop **cirrhosis**. In the public mind, this is associated with alcoholism, but is only a medical term for scarring of the liver and does not suggest a particular cause.

In cirrhosis, the liver is scarred, thickened lumps (**nodules**) develop and some liver cells die, giving small patches of **necrosis**. Cirrhosis in Hepatitis C is usually progressive. Cirrhosis inevitably means that the liver works less effectively than 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. As cirrhosis increases it may cause serious problems in the gut and abdomen, in the blood system or in mental function. Some people with cirrhosis may eventually develop cancer of the liver

(hepatocellular carcinoma). This is a serious condition and requires a liver transplant.

While the effects of the liver disease in Hepatitis C are real and limiting most people cope with this serious illness. The future holds promise for people with Hepatitis C. Medical research throughout the world is searching for an effective treatment. The next decade should bring considerable improvements in the lives of all people with Hepatitis C.

#### Why are some people more affected than others?

We only partially understand the reasons for the individual variation in the amount and type of physical symptoms and in the extent of liver damage. It seems likely that differences in genetic makeup, gender, virus infection type, lifestyle, diet and alcohol consumption all play a part. The addition of another medical problem such as diabetes, kidney or heart disease may also affect the severity of Hepatitis C symptoms.

# How is Hepatitis C passed from one person to another?

The virus has spread to a large number of people world-wide through contact with blood containing Hepatitis C virus.

Throughout the world, people who have injected illegal drugs are at a high risk of developing Hepatitis C, by virtue of sharing contaminated needles. In Ireland, this is the most common route of infection.

Some medical and dental staff have become infected with Hepatitis C by inadvertently pricking themselves with contaminated needles.

Hepatitis C may also be acquired on a sporadic basis, that is, without an identifiable source. It may also be acquired, although rarely, by individuals who have had tattoos, body piercing, electrolysis and acupuncture procedures.

In Ireland in 1994, a national Hepatitis C screening programme identified a number of women who had contracted Hepatitis C as a result of the administration of Hepatitis C-contaminated Anti-D Immunoglobulin during or at the end of pregnancy. Additional Hepatitis C screening programmes identified individuals who had acquired Hepatitis C as a result of receiving contaminated blood transfusions. A number of people with haemophilia, and a number of kidney patients were also infected with Hepatitis C through contaminated blood and blood products. The current risk of contracting Hepatitis C from blood products administered in Ireland by medical personnel is considered minuscule.

Some people contract Hepatitis C during sexual activity although the incidence of sexual transmission is low. Body fluids (blood, semen, vaginal fluids, menstrual blood) that contain Hepatitis C may transmit the virus. **Evidence suggests that for couples in long-term, stable sexual relationships, where one partner has Hepatitis C, the virus rarely passes to the other partner.** Hepatitis C does not pass to the embryo at the time of conception. Transmission of the virus from mother to child is rare.

Any sexual activity that draws blood or causes tearing of the vagina, anus, rectum or mouth poses a risk of spread of the Hepatitis C virus. Menstrual blood may be a medium for passage of the virus to either partner. Open cuts, sores, genital herpes or warts may provide a means of transfer of the virus. Oral sexual contact may pose a risk if the person has bleeding gums, broken skin or mouth ulcers.

### Prevention of the spread of Hepatitis C

Infected blood is the means of spread of the Hepatitis C virus. Every one of us, whether diagnosed with Hepatitis C or not, should be alert to how to protect ourselves and others. Infection through routine social contact does not occur.

#### Be careful-about your own and other people's blood

**Cuts, wounds and nose bleeds.** Use gloves when tending to cuts and wounds. Keep your and your family's cuts and grazes covered to protect against chance contact with infected material. Wash up any spilled blood using bleach. The Hepatitis C virus can live in dry blood, so take precautions even with older blood stains. Wash bloodstained clothes in a hot wash, with detergent.

**Menstrual blood.** Treat menstrual blood with equal caution. Tampons or pads should be burned if possible or else tied in a plastic bag before disposal. Hands should be washed after contact with menstrual blood.

**Contact sports.** Some sports such as rugby or boxing may lead to bloody injuries. Be careful to avoid contact with other people's blood. Keep cuts and gashes covered.

**Needles.** If you inject yourself or a family member, for example for diabetes, haemophilia or while using Interferon, be careful to dispose of the syringes and needles in a proper Sharps Container.

**Donation of blood, sperm, eggs or body organs.** People with Hepatitis C should not donate blood, sperm, eggs or body organs. If you have Hepatitis C and are registered as an organ donor or carry a donor card you should cease to do so immediately.

Everyone should always obey common-sense rules of hygiene. Regular washing of the hands with soap and water and keeping cuts covered are routine protections against Hepatitis C and many other infections in everyday life.

Be careful – about your own and other people's personal items. Personal hygiene and cosmetic tools. Never share razors, toothbrushes or manicure implements such as tweezers and nail scissors. These tools may contain minute traces of your or someone else's blood. Ensure that everyone in your family has his or her own toothbrush, razor and manicure tools that no-one else ever uses. Tattoos and body piercing are other possible avenues of infection with Hepatitis C.

#### Infecting Illegal Drugs

Injecting illegal drugs using dirty syringes or needles or sharing syringes or needles are definite ways of contracting many serious diseases, including Hepatitis C. Needle exchange programmes help to cut down the spread of serious disease.

#### Should we continue as before?

All evidence shows that Hepatitis C is seldom transmitted between couples in long-term faithful sexual relationships and the advice is to continue their sexual activity as before. Some couples may decide that one or both would feel more comfortable using the physical protection of a condom or of altering sexual practices.

#### **Sexual Activities**

#### General advice on sexual activity

**Use condoms.** These give some protection to both men and women against a wide range of diseases, including Hepatitis C. You should always use condoms if you have casual sexual intercourse.

**Avoid sexual intercourse during menstruation** particularly if you have open genital sores or warts. Wish your hands thoroughly after any contact with menstrual blood. **Avoid any penetration that tears** the vagina, anus, rectum or mouth or that draws blood. **Avoid oral sex when there is a cut** or ulcer on the mouth or genitals or where there is bleeding from the gums.

# Other important questions and concerns about sexual activity

# Telling your partner(s)

Depending on the type of sexual relationship, you may find that deciding to tell a partner about your infection is difficult and may be a particular problem in a new relationship. If you tell your partner, he or she may wish to take a blood test to find out if he or she has the virus. Independent counselling may assist you in dealing with this issue.

#### Loss of interest in sex

For some people, the initial reaction to finding out that they (or their partner) have Hepatitis C is to lose interest in sex. This lack of interest may last for some time. If it becomes a problem for either partner, the couple needs to discuss it, consulting professional counsellors if necessary.

#### Planning a pregnancy

Some couples, where one or both partners have Hepatitis C may wish to have a child. The current evidence is that it is uncommon for Hepatitis C to pass from parent to child during conception or pregnancy. Seeking a medical specialist's view on the appropriateness of pregnancy, at a given time, is sensible.

#### Social contact does not spread Hepatitis C

Being in the presence of someone with Hepatitis C can <u>never</u> be infectious. Evidence shows that social contact, i.e., holding hands, kissing and hugging does not spread Hepatitis C. Coughing and sneezing does not transmit infection. Hepatitis C is not spread by food. Using common toilet or bathroom facilities or swimming in pools does not spread Hepatitis C. There is an extremely low risk of transmission of the virus from mother to child in the womb, at birth or through breastfeeding.

#### What health services are available for people with Hepatitis C?

People who contracted Hepatitis C through the administration in Ireland of contaminated blood or blood products are entitled to a range of health and related services, free of charge. Under the Health (Amendment) Act 1996, all are entitled to the **health** services card (commonly known as the blue card), which provides

free community-based health services, through the Health Boards. Each Health Board has appointed a liaison officer to ensure the smooth operation of the delivery of services under the Act, and to Act as a contact point for individuals. The names and addresses of The liaison officers are shown at the end of this leaflet.

The community-based health services include general practitioner services for all medical conditions, drugs and medicines for all medical conditions, home nursing services, home support services, dental and ophthalmic services and counselling services. Hospital services are provided in special units in six designated hospitals. These hospitals are Beaumont, the Mater, St. Vincent's and St. James's Hospital in Dublin, Cork University Hospital, and University College Hospital Galway. The services provided include access to both in-patient and out-patient treatment as required, prescribed medication, access to a specialist Liver Consultant, and prompt primary referral to other clinicians for conditions associated with Hepatitis C.

When the cause of the Hepatitis C infection is unknown, or if it is not because of contaminated blood supplied within the State, and if the infected person's income is below a certain threshold, she or he will be entitled to a medical card. If the income is above the threshold for public services, the person may have to pay for the investigation and treatment costs of their illness. Some of these people may have health insurance cover (in which case the normal rules of health insurance schemes will apply) or may qualify under one of the Community Drugs Schemes administered by the Health Boards.

# Tests for Hepatitis C

The presence of a Hepatitis C virus infection is initially identified by detecting the presence of antibodies to the virus. When these antibodies have been tested further analysis is performed to determine whether or not active virus infection is present. This is done using a polymerase chain reaction (PCR) test. Finally, tests are performed to determine the genotype and subtype of the virus. Tests for Hepatitis C virus infection are continually being upgraded to improve the sensitivity of the tests.

#### Antibody tests

Two main antibody tests, the **ELISA test** and the **RIBA test** are used.

# **Antibodies**

Antibodies are produced by the immune system in response to a viral infection. In the case of Hepatitis C the presence of antibodies may not be detected for some months after the infection, but they remain in the circulation for many years after an acute infection, and persists indefinitely during chronic Hepatitis C virus infection.

#### **ELISA** test

The first test performed in the diagnosis of Hepatitis C is the **ELISA (Enzyme Linked Immunosorbent Assay) test**. This tests the blood for antibodies to Hepatitis C. A positive ELISA test shows the presence of antibodies to Hepatitis C in the blood. This means that the person may currently have Hepatitis C infection, or have been exposed to the virus in the past.

#### RIBA test

If the ELISA test is positive, the person takes a second test to confirm the diagnosis. This **RIBA** (**Recombinant Immunoblot Assay**) test is a more complicated test than the ELISA test. It is highly accurate in confirming the presence of antibodies to four proteins found in the Hepatitis C virus. Each of these four proteins is represented in one of the four **bands** of the RIBA test material. The results of a RIBA test show whether a person has antibodies to any one, or more, of these four different protein bands. Some people have antibodies to two or three of the proteins and some have antibodies to all four proteins. Research is beginning to show the importance of these different findings for individuals, in relation to both increasing and decreasing levels of infection with Hepatitis C.

## Tests to identify the virus

If both the ELISA and RIBA tests are positive, another test, the **PCR** (**Polymerase Chain Reaction**) test, is used to find out whether the virus itself is in the blood. The PCR test uses a technique that examines the RNA structure of the virus. Some people have positive ELISA and RIBA test results, but a negative PCR result, i.e., they have antibodies to Hepatitis C but do not show the virus in their blood.

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

#### The viral load

Another test, called the **quantitative PCR test**, tells how much of the virus is in the blood; in other words, the viral load. This varies between individuals and even for individuals from time to time. How the viral load relates to the severity of the disease and the options for treatment is unclear. Some research suggests that when a person has a high viral load he or she is more infectious. Usually, a viral load test estimation is performed before starting treatment with Interferon. When more information becomes available, the implications of the test findings on viral load will become clearer.

#### Liver function tests

Liver function tests provide important information in relation to the function of the liver and the degree of inflammation. In individuals with very active liver inflammation the liver enzymes such as alanine amino transferase (ALT) may be significantly elevated. All of these tests require specialised interpretation.

#### Liver biopsy

A liver biopsy involves obtaining and examining a small piece of the liver which provides information as to the degree of inflammation and whether or not there has been any progression of the liver disease to fibrosis or cirrhosis. Analysis of the liver specimen also provides important information as to whether or not anti-viral treatment is indicated.

When visiting your general practitioner or liver specialist, think beforehand about any questions or concerns you have. Write down the questions you wish to ask in a simple way, which will allow the doctor to give you a clear answer.

### How a liver biopsy is performed

The biopsy is usually performed by inserting an ultrasound-guided liver biopsy needle between the ribs and extracting a small piece of the liver. The procedure is performed under local anaesthetic with some mild sedation if required.

Some individuals do experience pain at the time of biopsy or immediately following the procedure. The discomfort is usually transient and responds rapidly to the administration of painkillers. Very rarely the procedure is complicated by more severe and prolonged pain which may delay discharge from hospital following the biopsy. The liver biopsy is performed by experienced medical staff who are fully aware of the potential complications of the procedure.

People with haemophilia should consult with their consultant Haemotologist before undergoing this procedure.

#### What are the results from a liver biopsy?

The results of the liver biopsy should be available within a few weeks. A liver biopsy will show the degree of inflammation and whether it is mild, moderate or severe. In addition, it will show whether or not there has been any development of scarring (fibrosis) or cirrhosis. The liver biopsy will be graded to allow comparison with previous or future biopsies and to determine the response to Interferon therapy. You should make sure that you discuss the findings of the liver biopsy with the Liver Specialist and that you get a clear understanding of what the findings of the biopsy mean for you.

#### The aims of conventional medical treatment of Hepatitis C

- Elimination of virus infection
- Resolution of chronic hepatitis
- · Improvement in symptoms

# Treatment of Hepatitis C

The object of anti-viral treatment of Hepatitis C virus infection is to eliminate virus replication and thus prevent the progression of Hepatitis C related chronic liver disease. With the elimination of the virus infection and resolution of chronic hepatitis the symptoms associated with the disease should also disappear.

#### Interferon

Currently, anti-viral treatment is the main form of therapy for chronic Hepatitis C infection and the drugs in use at the present time include Interferon and Ribavirin.

#### Who is prescribed Interferon?

Interferon therapy is usually reserved for patients whose liver biopsies show evidence of moderate or severe hepatitis, or those with fibrosis. Some people with Hepatitis C are not given Interferon at present. In some instances, this is because the risks of the drug are too high, for example in pregnancy. For other people, their problems may mean the Interferon will be of little benefit and may actually do harm. There is ongoing research to find alternative means of treating people for whom Interferon is unsuitable.

### Taking interferon

Most people are prescribed Interferon at a dose of three million units, three times weekly, for six to twelve months. Researchers are investigating various dosages and durations of treatment to determine the best treatment to eliminate the virus. The Interferon is administered by way of injection. People with Hepatitis C

learn to inject themselves so that they can self-administer the Interferon at home.

Symptoms that occur quite often particularly at the beginning of treatment, include abdominal pain, constipation, diarrhoea, nausea, vomiting and heartburn and difficulties in sleeping. Occasional other side-effects may include dizziness, itchy skin, forgetfulness or dry eyes. Interferon can reduce bone marrow activity. About one in every hundred people may develop thyroid problems.

#### Side effects of Interferon

The dose of Interferon used to eliminate the virus is such that unfortunately it often has unwanted side-effects. Side effects vary greatly from person to person and are unpredictable. Many people develop flu-like symptoms, fever, sweating, tiredness, muscle/joint pains and aches, nausea, headaches, a sense of weakness and a feeling of depression. These symptoms may be transient, or may persist during the entire course of treatment. You may choose to stay in hospital for the first few days of your Interferon treatment so that any side-effects can be monitored.

#### Results of Interferon treatment

About half of all the people who take Interferon do not respond to the drug. Usually, their Interferon treatment stops after a couple of months when their condition has clearly not improved. In a small percentage of cases, Interferon treatment is stopped because of severe side-effects.

About half the people treated with Interferon respond during treatment. Unfortunately, in about 50% to 60% of individuals, this response is only temporary. The remaining individuals continue to show improvement even after the drug treatment has stopped, and this is known as a sustained response. In all, about 1 in 5 people who take Interferon for Hepatitis C has a sustained response.

What increases the likelihood of a temporary or a sustained response? Some factors appear to increase the likelihood of a positive response to Interferon. Some genotypes of Hepatitis C are more reactive to the drug than others. Interferon is more likely to be successful if the liver is functioning well and cirrhosis is not present. As with many treatments for disease, the younger and fitter the person, and the shorter the time of infection, the more likely the response to treatment.

Never take any product if you are unsure of its possible effect.

Ask your medical advisor whether it will harm you or possibly do you good

Never assume that a treatment that is beneficial to you will definitely be of benefit to another person with Hepatitis C.

#### Alternative medicines and approaches

Some individuals with Hepatitis C seek alternative medicine as a method of improving their symptoms and general health. Examples of alternative medicine include acupuncture and reflexology which may improve symptoms in some individuals. The use of alternative medicines should always be discussed with your medical advisors.

### Liver transplant

Hepatitis C chronic liver disease may progress to a stage where liver function is inadequate to sustain life, or complications of liver disease develop. In such circumstances there are no medical treatments available and the patient will be considered for liver transplantation. Over the last three decades the success of liver transplant has increased enormously with the majority of individuals returning to a normal social and occupational lifestyle. It is recognised that Hepatitis C virus does re-infect the new liver although research has shown that this does not appear to have a major effect on liver function, at least in the first ten years following surgery.

# Helping yourself

It is natural to feel vulnerable and powerless when you are first diagnosed with a serious illness for which there is no cure. It can be a frightening time and you may feel that Hepatitis C is, at times, taking over your life. It is possible to come to terms with Hepatitis C by understanding more about the illness and how it is affecting you as an individual. There are times when the support services that are available, such as professional independent counselling, may be important to help you, or others in your family, overcome a difficult time.

#### Stress

Stress and tension are natural reactions to anything that threatens to upset our health, safety and well-being. The knowledge that you have Hepatitis C provokes anxiety and tension. This may be exacerbated by other worries at home or at work. You may have to make adjustments now that you have Hepatitis C if you are feeling constantly tired or if you are on Interferon.

Some ways to relieve stress:

- Sometimes it helps to get away on your own for a while to relax and come to terms with your new situation.
- Anger may give you a temporary sense of righteousness but generally adds to stress. If you feel like lashing out, try curbing the impulse. Meanwhile do some physical activity to work off pent-up energy. Getting the anger out of your system leaves you better prepared to handle your problem constructively.
- Don't bottle up your worries. Talk to a family member or good friend. The friend should be someone level-headed whom you can put your trust in. The nurse and the Liver Specialist at the Liver Unit you attend are there to explain your medical condition and to discuss your fears and anxieties.
- Don't expect too much of yourself. You may now need to reassess your lifestyle and put more time into your own health and wellbeing. This may mean cutting corners or delegating certain responsibilities to others.

## Join a support group

Benefits of involvement include the opportunity to meet with other people in a similar situation. Support groups keep up to date with developments and can give you specific information or direct you to appropriate help.

### Join or keep in contact with support group

Join a support group for people with Hepatitis C. **Positive Action** looks after the interests of women infected with the virus through Anti-D treatment. **Transfusion Positive** represents people who contracted the virus by means of blood transfusion. **The Irish Haemophilia Society** supports people with haemophilia who have Hepatitis C. **The Irish Kidney Association** represents and supports people with kidney problems who are either on dialysis treatment or are organ recipients who have contracted Hepatitis C. All these organisations offer a range of supports and services, including counselling. Drug treatment organisations help people who have been or are drug users. Addresses of these organisations are printed at the end of this booklet.

#### Hepatitis C virus infection and diet

For the majority of patients with chronic Hepatitis C virus infection dietary restriction is not necessary. Individuals who do not have advanced liver disease do not require to restrict their intake of fat or protein and all such individuals should be encouraged to eat a **normal balanced diet** which provides sufficient calories for their daily requirements. Vitamin supplements are rarely required. Alcohol intake should be minimal and excessive iron supplements should be avoided. It is only in individuals with advanced liver disease that it may become necessary to restrict salt and protein intake.

If you feel you need special advice on diet, consult the dietician at your specialist clinic.

For most individuals with chronic Hepatitis C virus infection it is quite safe to use standard painkilling medication such as aspirin and Paracetamol and it is only where individuals have serious liver disease that precautions with medication are required.

If you have haemophilia, or kidney problems, you should ask your specialist whether special precautions are required.

#### Deciding to take the test

Some close family members may face a decision about whether to take the test for Hepatitis C. This is a major decision which should be carefully considered. Factors that may affect the decision include:

- It is one fewer thing to worry about;
- It helps to plan for the future;
- If you have the virus, there is no changing the fact;
- Treating a problem earlier, rather than later, is often better;
- We can deal with what we know, but not what we fear.

Testing positive, knowing that you have Hepatitis C, would inevitably change your life. It could possibly create problems in your work and in your opportunities for promotion. There may also be implications for life assurance and mortgage protection insurance. Applying for jobs where there is a medical examination might be impossible. If you are in a relationship, telling your partner might be difficult.

#### Deciding to test your children

This is a dilemma for some parents. On the one hand, if your child has Hepatitis C, diagnosis will help in proper treatment and care. If your child has contracted the virus through contaminated blood product, the child will receive any treatment at no direct cost. On the other hand, a diagnosis of Hepatitis C, for the child, brings many worries and unanswerable questions. It may mean that the child

experiences special problems at school or in everyday social contact. Independent counselling may help you to make the decision that is right for you and your family.

# Further information on Hepatitis C

# Reading

English, Richard and Foster, Graham (1997) *Living with Hepatitis C.*Robinson Publishing Ltd. 7 Kensington Church Court, London W8 4SP ISBN 185487 913 8.

Dolan M. (1996) *The hepatitis C handbook*. Catalyst Press, PO Box 13036, London NW1 3WG, England. ISBN 0 9529509 0 1.

The *British Liver Trust*, Central House, Central Avenue, Ransomes Europark, Ipswich IP3 9QG, England Tel 0473 276326, Fax 0473 276327 produces a range of booklets and other information about all aspects of liver disease.

#### Internet

You may have access to the Internet and wish to search for information about Hepatitis C.

Some reliable and responsible groups have useful information that you may find of benefit. However, there is also a lot of unreliable information on the Internet and you should never use any product, recommended on the Internet, without first consulting you own medical advisor.

# **Support group addresses:** Positive Action

56, Fitzwilliam Square, Dublin, 2

Tel: (01) 6762853 Fax: (01) 6620009 Irish Haemophilia Society

Block C, Iceland House, Arran Court, Arran Quay, Dublin, 7.

Tel: (01) 8724466 Fax: (01) 8724494

Positive Action provides support to those women who contracted Hepatitis C through the administration of Anti-D, and their families.

> The Irish Haemophilia Society provides support to people with haemophilia who have Hepatitis C, and their families.

#### Transfusion Positive,

162, Clonmacnoise Road, Crumlin, Dublin, 12

Tel: (01) 4538427 Fax: (01) 4538427

### **Irish Kidney Association**

Donor House, 156, Pembroke Road, Ballsbridge, Dublin, 4.

Tel: (01) 6689788 Fax: (01) 6683820

Transfusion Positive provides support to those persons who contracted Hepatitis C through a blood transfusion, and their families.

The Irish Kidney Association provides support to people with kidney problems who are either on dialysis treatment or are organ recipients who have contracted Hepatitis C and their families.

#### Liaison Officers in the health boards.

Ms. Sheila Marshall Eastern Health Board Dr. Steeven's Hospital Steeven's Lane Dublin 8

Tel: (01) 6790700 Fax: (01) 6710645

Mr. Pat O'Dowd Midland Health Board Tullamore General Hospital

Tullamore Co. Offaly

Tel: (0506) 46131 Fax: (0506) 46226

Ms Mary Healy Mid Western Health Board 87, O'Connell Street Limerick

Tel: (061) 483391 Fax: (061) 317407

Ms. Ann Coyle North Eastern Health Board Dublin Road, Dundalk Co. Louth

Tel: (042) 32287 Fax: (042) 33814 Ms Val O'Kelly North Western Health Board Manorhamilton Co. Leitrim

Tel: (072) 20400 Fax: (072) 20431

Ms Anne Marie Lanigan South Eastern Health Board Lacken

Dublin Road Kilkenny

Tel: (056) 51702 Fax: (056) 52813

Mr. Donal Murphy Southern Health Board Cork Farm Centre Wilton Road

Cork

Tel: (021) 278432 Fax: (021) 277293

Mr. Brian O'Donnell Western Health Board Merlin Park Regional Hospital

Galway

Tel: (091) 751131 Fax: (091) 752828

# If you are injecting drugs contact;

# Merchant's Quay Project,

Merchant's Quay, Dublin, 2.

Tel: (01) 6790044

# **Drug Treatment Centre Board**

Drug Addiction Treatment Centre, Trinity Court, 30 Pearse Street, Dublin, 2.

Tel: (01) 6771122