

THE DRUG TREATMENT CENTRE BOARD

Information Booklet HEPATITIS C

A Guide for Drug Users and their Families



providing



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Dr. Shay Keating, MB, PhD.

Information Booklet
HEPATITIS C

A GUIDE FOR DRUG USERS AND THEIR FAMILIES

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FORWARD

Through our mission we aim to provide a specialist addiction service in a therapeutic, caring and collaborative way, whilst leading and informing on best practice.

As an organisation we are committed to providing a responsive, effective and progressive service. The delivery of Hepatitis information, education and treatment is vital in ensuring that we meet the needs of the client population we serve.

I warmly welcome the development of this timely booklet and would like to congratulate Dr. Shay Keating on its publication. I have no doubt that the information provided will be of benefit to those affected by Hepatitis C.

Sheila Heffernan
General Manager

June 2003



THE LIVER

WHAT AND WHERE IS THE LIVER?

The liver is the second largest organ in the body (the skin is considered an organ making it the largest). It is found on the upper right-hand side of the abdomen (belly) under the right lung and protected by the rib cage. It cannot normally be felt. If it becomes inflamed however, it might get bigger and your doctor may be able to feel it by pressing on the abdomen. Unlike the kidneys or lungs, you have only one liver. It is vital that you look after it. You can survive with only one kidney or even one lung but not without your liver.

WHAT DOES THE LIVER DO?

- It stores energy in the form of glucose. This acts as a rapid source of energy;
- It processes food absorbed in the digestive tract (gut);
- It makes certain proteins essential, for the control of body fluids;
- It stores excess amounts of vitamins and minerals, including iron, which are essential for the body to function;
- It helps in the destruction of old red blood cells;
- It makes a digestive juice called bile, (which is stored in the gall bladder) and coagulation factors (compounds that help the blood to clot if you bleed);
- It helps to regulate chemical, hormonal and cholesterol levels;
- It is essential for detoxifying the blood of many unwanted drugs and waste products;

WHAT HAPPENS IF THE LIVER IS BADLY DAMAGED?

In severe liver damage the liver –

- Cannot control fluid balance in the body. The abdomen (belly) and legs may swell up;
- Cannot excrete a compound called bilirubin effectively. Bilirubin is formed from the breakdown of old red blood cells in the body. The bilirubin level in the blood rises and the skin and eye membranes look yellow (jaundice). The urine may be very dark and the stools very pale;
- Cannot make clotting factors so you might bleed more easily;

- Cannot control the level of certain hormones. Men with advanced liver disease may lose body hair, their testicles may shrink and their breasts may get bigger;
- Cannot detoxify the blood of certain chemicals and drugs. Patients with advanced hepatitis may be extremely sensitive to the effects of certain drugs and chemicals;

Hepatitis C

WHAT IS HEPATITIS?

- Hepatitis means inflammation of the liver. It can be caused by alcohol, certain chemicals, drugs and viral infections;
- Viral hepatitis is very common in intravenous drug users;
- At present, six hepatitis viruses have been identified; they are named hepatitis A, B, C, D, E and G. They differ in how they are transmitted from person to person as well as how long and severely they can affect you. You may be infected with hepatitis A or E when travelling to developing countries without vaccination where water and sewage facilities are poor. You may also contract hepatitis A or hepatitis E when sanitation is poor - not washing hands after going to the toilet, eating contaminated food or after certain sex practices. Both hepatitis A and E cause acute illness, usually with jaundice and flu-like symptoms. They can be severe, especially in the very young or old but recovery is usually complete;
- The other four hepatitis viruses, B, C, D and G are transmitted mainly by blood and blood products or by sexual activity (mainly hepatitis B);

WHAT IS HEPATITIS C?

- Hepatitis C is a viral infection of the liver. A virus is a tiny organism that may cause disease, infection or inflammation if it enters the body;
- Hepatitis C was first identified in 1989.
- In Ireland, at present it is estimated that as many as 4 out of every 5 of intravenous drug users are believed to be infected with hepatitis C;
- World wide approximately 170 million persons are thought to be infected with hepatitis C;
- Hepatitis C infection is not caused by a single virus but by a family of viruses, that can be further divided into six different subtypes called

'genotypes'. Different genotypes infect different people worldwide. In Ireland genotypes 1 and 3 are the most common forms of hepatitis C seen in drug users, in approximately similar frequencies.

HOW CAN A PERSON BECOME INFECTED BY HEPATITIS C?

- Hepatitis C is a blood-borne virus. This means that it is carried in the blood and spread through blood-to-blood contact. In some cases, persons with hepatitis C have no idea how they became infected. The majority of people however can identify a likely way. Some practices are more risky than others;
- In Ireland sharing injection needles and equipment ('works') with someone who is infected is the commonest way to become infected with hepatitis C. Sharing filters, spoons or water, 'frontloading' and 'backloading' are also very risky practices. Snorting cocaine has recently been linked with hepatitis C infection. This is thought to be due to sharing of the straw;
- Not practising safer sex, for example not using a condom during intercourse is a possible risk for hepatitis C infection. This is thought to be a low risk. It is easier for women to become infected through unsafe sex than men. The risk of hepatitis C infection is higher in HIV positive persons;
- Hepatitis C can also be passed on from mother to baby. Once again this is thought to be a relatively low risk (1 in 20) but a risk nonetheless. The chances of a baby becoming infected are higher if the mother has both hepatitis C and HIV. Passing on Hepatitis C to your baby by breast-feeding is not thought to be a risk;
- Transfusion of blood and blood products can spread hepatitis C. Before 1990, no test was available for the detection of hepatitis C in blood. All blood and blood products are now routinely tested for hepatitis C and recent improvements in blood product screening have greatly reduced the risk of getting hepatitis C in this way;
- Sharing personal items such as toothbrushes and razor-blades where transfer of blood occurs are low risk ways to become infected, as are unsafe tattooing or body piercing when equipment is not sterile;
- Exposure to infected blood in the workplace can lead to infection with hepatitis C. Health care workers may have needle stick injuries or may be exposed to infected blood in other ways such as spills;
- Hepatitis C can be transmitted through dried blood because the virus can live outside the body for some time;

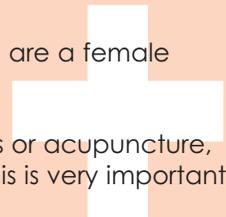
YOU CANNOT GET HEPATITIS C FROM:

- Hugging and kissing;
- Holding hands;
- Sharing toilets;
- Sharing crockery and cutlery;

HOW CAN A PERSON PREVENT THE SPREAD OF HEPATITIS C TO OTHERS?

Hepatitis C is very infectious. If you are infected with the hepatitis C virus, take the following steps to make sure that you do not spread the virus to others.

- Never share used needles or 'works' (barrel, filter, spoon, water, etc) with anyone else. Never share needles or 'works' cleaned with bleach. Unlike HIV, the hepatitis C virus does not appear to be killed in the works by bleach. As yet there is no known way of cleaning used works to kill off hepatitis C;
- Never share the straw if snorting drugs;
- Wash your hands after injecting. They might have tiny amounts of blood on them;
- Never donate blood, body organs, other tissues or sperm;
- Clean all blood spills with paper towels, followed by a detergent and water wash. Then disinfect the area with a solution made up of 10 parts water and 1 part good quality bleach. Dry the area with a clean paper towel;
- Blood stained articles, such as tampons (except sharp objects such as needles and razors) should be placed in a plastic bag, which is tied at the top before placing in an outside rubbish bin. All sharp objects should be placed in a special sharps container kept out of reach of children;
- Do not share personal items where blood may be present such as toothbrushes or razors;
- Cover exposed cut and sores;
- Use condoms with any new sexual partners. Talk to your doctor about the relative risks with long term sexual partners;
- Avoid sex during or immediately after your period if you are a female carrier. Hepatitis C is found in menstrual blood;
- For people receiving ear piercing, tattooing, electrolysis or acupuncture, check that new, disposable needles are being used. This is very important for those in foreign countries;



- Tell your doctor (if he or she doesn't know), your dentist or healthcare worker that you are hepatitis C positive. Anyone who is exposed to blood may be at risk;
- **Remember, unlike hepatitis A and B, there is no vaccine for hepatitis C at present;**

WHO SHOULD TEST FOR HEPATITIS C INFECTION?

- All drug users, especially those who have injected drugs or shared 'works' (even once) or snorted drugs from a shared tooter;
- Those who have been exposed to needle stick injuries;
- Babies born to hepatitis C positive mothers;
- Those who feel that they might have received contaminated blood or blood products before testing for hepatitis C in donated blood became routine in this country;
- Those who have had body piercing or tattooing using improperly sterilised equipment or contaminated ink;

DIAGNOSIS OF HEPATITIS C

HOW DO I KNOW IF I HAVE BEEN INFECTED WITH THE HEPATITIS C VIRUS?

- When persons are first infected with hepatitis C they may complain of flu-like symptoms, such as feeling feverish, shivering, nausea or loss of appetite. This is called acute hepatitis and usually lasts a few days or weeks. They may be jaundiced;
- These symptoms only occur in about 10 to 15% so many do not know that they have been infected;
- In some people the virus can no longer be detected. We don't know if the virus goes away forever or only for a short time;
- In most cases (approximately 80%), the infection becomes chronic. This means that the infection lasts for longer than six months;
- The best way to see if you have been infected is to have a blood test. The initial (first) test for hepatitis C is based on the detection of antibodies to the virus, not the virus itself. To help fight viruses, the body produces antibodies. These are found in the blood. Following acute infection it can take some time for these antibodies to appear, usually 2-3 months but in some cases up to 6 months – this is referred to as the 'window period'. If antibodies to

hepatitis C are found it means that the person has been in exposed to the virus at some stage. It does not tell however, if the person still has the virus in the liver or the blood. The virus may be gone but the antibodies can remain for years;

- Liver enzymes are proteins found in liver cells and are released into the blood if the liver is damaged. High levels of these enzymes in the blood suggest some sort of liver problem. They may be high in persons with Hepatitis C infection. Low levels however, do not necessarily mean that the liver is healthy. A person with hepatitis C and advanced liver damage may have normal liver enzyme levels;
- A PCR (polymerase chain reaction) test is a better test for the hepatitis virus itself. It will tell if the virus is still detectable in the blood and will show if a person has chronic hepatitis C, or on-going infection. Unfortunately, many persons who are Hepatitis C antibody positive have the virus in the blood and are actively infectious. You and your doctor will decide when is the best time to do a PCR test;
- Actively infectious means that hepatitis C may be causing liver damage and that you may pass the infection on to others by the ways already described.

WHAT ONGOING SYMPTOMS MIGHT I HAVE WHEN INFECTED WITH HEPATITIS C?

- Flu-like symptoms – fever, sweating, nausea, fatigue (tiredness), malaise (generally not feeling well), headache and night sweats;
- Pains in the joints;
- Pain around the liver area;
- Bowel problems such as diarrhoea or constipation;
- Mood swings, difficulty sleeping or depression;
- Loss of appetite, especially feeling unwell if you eat fatty foods;
- Bad reaction to alcohol and increased sensitivity to medication;

WILL MY HEPATITIS C INFECTION BECOME CHRONIC?

- For many patients with hepatitis C, up to 65%, the infection becomes chronic (persists). As mentioned earlier this means that the infection does not go away and the inflammation lasts for a minimum of six months and usually much longer;

- Chronic hepatitis C can lead to serious liver problems, such as fibrosis (scarring of the liver), cirrhosis (irreversible scarring of the liver) or cancer of the liver in some patients;
- Cirrhosis occurs when normal liver cells are damaged and are irreversibly replaced by scar tissue. At this stage the liver cannot heal itself. This occurs in a minimum of 1 in 5 of persons with hepatitis C, on average about twenty years after becoming infected;
- With cirrhosis, patients may complain of loss of appetite and weight loss, nausea and vomiting (sometimes blood), jaundice, itching, swelling of the abdomen, increased sensitivity to certain drugs and mental confusion often leading to coma;
- Approximately 6 – 8% of persons with hepatitis C develop liver cancer. This appears to develop in those persons with hepatitis C who have cirrhosis and will not generally occur until about twenty years after infection, but could occur earlier;

WHAT DO I DO IF I TEST POSITIVE FOR HEPATITIS C?

- Go to your doctor (G.P. or doctor in the drug treatment clinic). He or She may request a PCR test to see if you still have the virus in your blood. The PCR test must be sent to the laboratory within a couple of hours so your GP may need to refer you onto a specialist clinic for this test. It is most likely that this test will be positive meaning that you still have active infection. If it is negative it means that there is no virus detected in your blood. This means that the infection may be gone for good but it may also mean that the infection is still there but the virus is in very small amounts, which could not be measured in the laboratory. It is recommended that you get another blood test performed 1 year later to see if there is any virus present;
- Find out which genotype of hepatitis C you have. This may determine what therapy you take and for how long;
- The hepatologist (liver specialist) may organise an ultrasound test in the x-ray department for you to see if the liver is enlarged or scarred. He or she may also recommend a liver biopsy. This is a technique whereby a small sample of liver is obtained through a tiny cut in the skin above the liver. This is the best way to see how damaged the liver is. It is a relatively low risk procedure but like any medical procedure may have risks. Ask the liver specialist about these;
- After the biopsy you might feel some pain in the site of the biopsy or notice pain in the shoulder (referred pain caused by pressure on the nerves in the

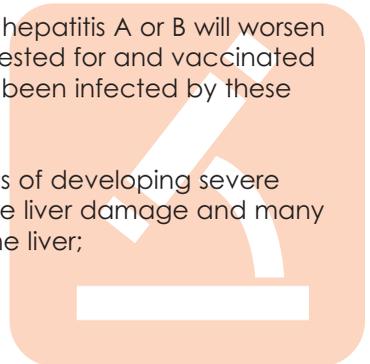
liver and surrounding tissue). If the hepatologist is considering offering you treatment, a biopsy is the best way to see the condition of your liver. It is well worth considering a biopsy. Talk to the hepatologist about any concerns you might have;

- Learn more about hepatitis C and how it may affect you. This is a newly identified virus. Doctors and scientists are learning more and more about it every day. Keep up to date with information;
- Talk to a counsellor. There will be questions you may need to ask about living with hepatitis C, it's effect on you and on your family;
- Learn good infection control practices to prevent the spread of infection;
- Look at your drug habit. On-going injection of drugs will lessen the chances of your staying healthy with the virus and it will affect your chances of getting treatment. It may also mean that you will infect others;
- Stop drinking alcohol or reduce your use to a minimum. Alcohol is another cause of hepatitis and may speed the development of liver damage;
- Look after your general health and diet. Eat sensibly and exercise regularly.

Will I develop severe liver damage from Hepatitis C?

Many factors can worsen the effect hepatitis C may have on you if infected.

- Excessive drinking of alcohol, as mentioned earlier is another cause of hepatitis, or liver damage. It is advisable for a person who is infected with hepatitis C to stop drinking alcohol. Alcohol worsens liver damage caused by hepatitis C and may speed up the development of cirrhosis (liver scarring) or liver cancer;
- Many recreational drugs are toxic to the liver and should be avoided. Persons infected by hepatitis C should avoid taking medication when it is not necessary and should consult their doctors or pharmacists when taking any medication even simple painkillers or antibiotics;
- Infection with another hepatitis virus, for example hepatitis A or B will worsen liver damage. At the moment it is possible to be tested for and vaccinated against hepatitis A and B if you have not already been infected by these viruses. Ask your doctor about this;
- Infection with HIV may also increase your chances of developing severe liver damage from Hepatitis C. HIV itself can cause liver damage and many of the drugs used to treat HIV are damaging to the liver;



- The hepatitis C virus has many different strains, or genotypes. In Ireland, genotypes 1 and 3 are the commonest. Patients infected with genotype 3 tend to respond better to treatment at present, than those infected by genotype 1;

Treatment of hepatitis C

IS THERE ANY TREATMENT FOR HEPATITIS C INFECTION?

Yes.

Current treatment for hepatitis C is with combination therapy with **interferon** and **ribavirin**.

- Interferon is a natural chemical that the body produces in response to viral infections. It is given by injection under the skin (subcutaneously) into a fatty area such as the thighs or stomach. It is a protein so it would be destroyed by the acid in the stomach if swallowed so it must be injected. In the past it was given three times a week for six months minimum. Now there is a new form of interferon available termed pegylated interferon. This need only be given once a week;
- Ribavirin is an antiviral drug currently originally used in the treatment of a particular type of viral pneumonia. Ribavirin appears to prevent the virus from multiplying. When used in the treatment of hepatitis C it works well in combination with interferon. It is taken twice daily in capsule form;
- The recommended length of treatment is 24 to 48 weeks. Those with genotype 'non 1' (any of the other five genotypes) are treated for 24 weeks. Treatment of genotype 1 may need longer;
- A response to treatment is shown by a negative PCR (no virus is found in the blood) at the end of treatment. The specialist will repeat the PCR test six months later to see if it is still negative – a sustained viral response. If the patient fails to respond to interferon within three months, therapy may be discontinued;

WHO IS OFFERED ANTI-HEPATITIS C THERAPY?

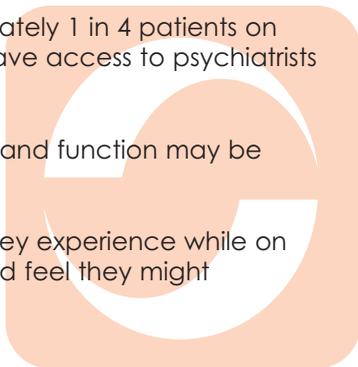
- Treatment of hepatitis C is recommended for those persons at greatest risk of developing liver cirrhosis. This includes persons with a positive PCR test;
- It is generally recommended that anti-hepatitis C therapy should be offered to those patients who have stable drug or alcohol habits, who are either drug and alcohol free or on a methadone maintenance programme and not drinking alcohol for a minimum of six months;

- Therapy is not routinely offered to a person who is still actively abusing drugs, such as heroin, benzodiazepines (for example valium) or alcohol. Recreational drugs or heavy alcohol drinking, as mentioned earlier are damaging to the liver and it does not make sense to treat one cause of liver damage, the hepatitis C virus and not treat another, the drug or alcohol abuse. It is also pointless to put a patient through the discomfort of interferon therapy if he or she is putting himself or herself at risk of reinfection by active drug use;
- A person's drug stability can easily be seen on routine urine testing. 'Dirty urines' (opiate or benzodiazepine positive) would suggest that you are not ready to enter into treatment;
- The treatment of hepatitis C can be uncomfortable for the patient. It is essential that the patient be in adequate accommodation before treatment is started. It would be very difficult for someone to stay on treatment if she or he were homeless;

ARE THERE ANY SIDE EFFECTS TO INTERFERON AND RIBAVIRIN THERAPY?

Yes.

- Many commonly used drugs have side effects. Painkillers can cause nausea and antibiotics can cause rashes;
- Interferon is a very strong drug, which is only given to a patient under the strict supervision of a hepatologist (liver specialist) or infectious disease specialist;
- Common side effects of interferon are flu-like symptoms such as fever, headache, chills, joint pains and weakness, usually 6 to 8 hours after injecting interferon. These symptoms usually lessen after the first few treatments. Some hair loss is seen in 1 in 10 patients. The hair usually grows back as soon as the course of the drug is finished;
- Patients on combination therapy may lose their appetites or interest in food;
- Depression while on interferon occurs in approximately 1 in 4 patients on combination therapy. All drug treatment clinics have access to psychiatrists who can help with this;
- Certain abnormalities in blood cells and thyroid gland function may be seen and regular blood checks are required;
- Unfortunately many patients feel the symptoms they experience while on interferon are similar to withdrawal from heroin and feel they might



need to take heroin to overcome these symptoms. If you are offered interferon therapy and experience unwanted symptoms, talk to your doctor. There are many therapies available, which will help to control these effects. Do not use non-prescribed drugs such as heroin;

- Patients on interferon often complain that they experience the 'needle buzz' again while injecting interferon and that this starts the drug injecting habit all over again. This may be avoided if the person discusses this with the doctor and counsellor. Interferon is now available in specially designed preloaded pens. This should overcome the 'needle-buzz' problem;
- Side effects of ribavirin are anaemia, which may be severe and may require treatment, dry mouth, nausea, indigestion and tiredness;
- Ribavirin is very toxic to the unborn baby. Women on ribavirin therapy should practice adequate contraception. They should avoid pregnancy during treatment and for at least four months after treatment is completed. Men should not have unprotected sex while on therapy and for seven months afterwards.

SHOULD I HAVE TREATMENT IF IT IS OFFERED TO ME?

- No two persons with hepatitis C are the same. One person may have ongoing symptoms from hepatitis C while another may feel very well. One person may have a good response to treatment while another may not. One person may find the side effects of treatment very difficult to cope with while another may experience little or no side effects;
- Unfortunately however, the reality for many persons with hepatitis C is that it will not go away and it's effects can only get worse with time. It is generally felt by liver specialists that treatment is available and should be offered to most patients who are stable, drug wise;
- With combination drug therapy for hepatitis C, there is a good chance of curing the disease. You should decide with the help of your doctor and counsellor, whether or not you should have treatment if it is offered to you by the liver specialist;
- Be aware of the risks of going on treatment, the chances of suffering side effects and the risk that your drug habit might destabilise and balance this against the obvious benefit of curing the disease;
- Do not start therapy until you are ready to do so.

Consider treatment sooner rather than later. Persons with low levels of the virus and mild liver disease respond best to treatment. In the long-term, those side effects of combination therapy, which only last a short time, will be a small price to pay for curing this disease.

CAN I USE COMPLIMENTARY THERAPIES FOR HEPATITIS C?

For some people with hepatitis C, complimentary (non-medical) therapies appear to be valuable tools, giving hope and health. They may not be proven to benefit dramatically but may help.

- Many herbal remedies have been reported as being helpful in the treatment of hepatitis C and it's symptoms. Unfortunately, these may not have undergone the same tests as medical therapies. Discuss this with your doctor. If you are offered medical treatment, do not take any other remedies without first discussing them with your liver specialist. There may be an interaction between both therapies;
- Massage can be very helpful in relieving stress. Regular relaxation can also make you feel better and control some of the symptoms of infection or side effects of medical therapy;
- Acupuncture may also relieve stress or help with sleep. If you go for acupuncture, make sure you go to a qualified practitioner and be sure the needles are sterile.

HEALTHY EATING WITH HEPATITIS C

A healthy diet is important for overall health and well-being. This is even more important if you are suffering from any illness such as hepatitis C or on treatment for this infection. Eating properly helps the liver to stay healthy and aids recovery.

Here are some healthy eating tips

- Eat a well balanced diet and take a vitamin and mineral supplement in times when you diet is not as good as it should be;
- Eat plenty of fresh fruit, vegetables and salads;
- Eat less red meats, Substitute with chicken or fish (preferably grilled);
- Reduce dairy products, use low fat milk and sunflower spreads;
- Limit eggs to 3 to 4 per week;
- Reduce salt and sugar intake. Season with herbs instead;
- Replace white bread, flour and pasta with whole meal alternatives;
- Avoid greasy, spicy, creamy and sugary foods;



- Cut down on tea and coffee. Drink herbal teas or fruit juices instead;

Do not drink alcohol.

Hepatitis C in Pregnancy

Many women who are hepatitis C positive and pregnant have special concerns regarding themselves and their unborn babies;

CAN I INFECT MY UNBORN BABY IF I AM HEPATITIS C POSITIVE?

Yes. It is possible to infect your unborn baby. Transmission is more likely if the amount of virus in the blood is high. Talk to your doctor about this.

CAN I RECEIVE TREATMENT FOR HEPATITIS C IF I AM PREGNANT?

No. At present the two commonly used drugs, approved for treatment of hepatitis C are interferon and ribavirin. Ribavirin is very dangerous to the unborn baby. If you are on combination therapy with interferon and ribavirin it is essential to avoid pregnancy with the appropriate contraception, if required. You must also avoid pregnancy for four months after treatment has ended. If you do become pregnant consult your doctor immediately. Men on combination treatment must avoid unprotected sexual intercourse for the duration of the study and for seven months after treatment has finished.

WHAT SHOULD I DO IF I AM HEPATITIS C POSITIVE AND PREGNANT?

Try to stay healthy for your own sake and the sake of your baby. Attend your ante-natal appointments as recommended. Do not use drugs if possible or maintain yourself on methadone only.

Family and Social Issues

HOW MIGHT HEPATITIS C AFFECT MY FAMILY RELATIONSHIPS?

- Living with hepatitis C isn't easy. Even if you don't have dramatic symptoms, the tiredness associated with hepatitis C infection may be frustrating;
- All family illness can lead to stress. Family relationships may suffer if a member of the family is infected by hepatitis C. This in turn may lead to tension in the home until all family members learn to adjust to the disease;
- Talk to a counsellor either on your own or with the members of your family. In Ireland at present there are many counsellors, trained in the support of

patients with hepatitis C and their families. Your problems are probably not unusual for a drug user infected with hepatitis C. There may be many questions you might like to ask. Feel free to do so;

- Try to maintain a normal lifestyle. If you are recently infected it may be years before you may feel unwell as a result of hepatitis C;
- Change your lifestyle if required. Try to ensure that you do not mistakenly infect a family member. Follow the prevention methods mentioned earlier in this booklet;

AS A FAMILY MEMBER, HOW CAN I SUPPORT A PERSON WITH HEPATITIS C?

- Learn about hepatitis C, how it is contracted and treated;
- Listen to the person. Don't try to take over and make all the decisions for him or her;
- Be supportive and not critical of the person;
- Expect the person with hepatitis C to be moody, worried or depressed from time to time. This is normal for someone with an illness even if he or she is physically well at the time.
- Try not to focus too much on the family member with hepatitis C, thereby neglecting others in the family;
- Discuss your concerns with the appropriate people, the doctors and counsellors involved in the care of your family member;



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