

# ***HEPATITIS C***

## ***PATIENT INFORMATION LEAFLET***

CLINICAL NURSE SPECIALIST, H ALLEN. JANUARY 2002

## **INTRODUCTION**

Hepatitis means inflammation of the liver. This may have a number of causes including viral infection. Hepatitis C is one of the more recently discovered Hepatitis viruses. It was first identified in 1989. Estimates suggest that there are around 250,000 people infected with Hepatitis C in the UK.

### **The Liver**

The Liver lies on the right hand side of the abdomen and has a number of important functions. These include making glucose and essential blood proteins, clearing toxic waste products from the blood, helping with the digestion of food (particularly fats) and also regulating the level of some medications in the body.

### **What is Hepatitis C ?**

Hepatitis C is a virus that infects liver cells and causes inflammation. Around 20% of people with Hepatitis will spontaneously clear the virus from their system and will go on to have no further problems.

In 80% of people, however, the virus is not naturally cleared. Unfortunately the virus stays in the system and continues to cause damage to the liver. This is known as Chronic Hepatitis. Chronic Hepatitis is defined by the virus still being detectable on a blood test six months after the initial diagnosis of Hepatitis C.

Of those people with Chronic Hepatitis, about 80% have no serious problems with their health and can live a normal life. Although in the majority of infected people the virus continues to live in their liver causing mild inflammation. In approximately 30% of people, however, damage progresses to scarring of the liver, which is called Cirrhosis.

The progression is very slow and it may take twenty to thirty years for Cirrhosis to develop. In a small percentage of people it will be quicker. It is very hard to predict who will go on to develop Cirrhosis. There is no one factor that influences prognosis and every case is individual. The longer a person has had Hepatitis C the greater their chances of running into problems.

The inflammation caused in the liver by the Hepatitis C virus marginally increases a person's chance of developing liver cancer in later life.

For all the reasons we have mentioned regular check ups by a specialist at the hospital and close monitoring of people with Hepatitis C (approximately every six to twelve months) is of the utmost importance.

## **Symptoms**

It is very common for people to have no symptoms at all from the Hepatitis C virus and it may go undetected for many years.

### **Acute illness**

An acute illness occurs when a person first contracts the virus. Only about 10% of people have any symptoms during the acute phase. The symptoms of acute Hepatitis C can be like having the flu, which may manifest with abdominal pain and vomiting.

### **Chronic infection**

Whilst some people will have no symptoms from the Hepatitis C virus, others may experience some tiredness and often feel unwell. It affects each individual quite differently and symptoms may not accurately reflect how severe any liver damage is. Some people experience symptoms whilst only having minor inflammation in their Liver, while others, with more severe disease, may have no symptoms.

Symptoms, when present, may be vague and include:

Mild to severe fatigue  
Anxiety and irritability  
Weight loss  
Anorexia, loss of appetite and nausea  
Alcohol intolerance  
Joint pain  
Pain and discomfort in the area of the liver  
Flu like symptoms such as fever, chills, night sweats and headaches

These symptoms often come and go in cycles this may be because the virus goes through stages of becoming more active and then more dormant.

### **At risk groups**

The Hepatitis C virus is carried in the blood so it is transmitted through blood to blood contact. The following groups of people are at risk of becoming infected.

**Any person who has received a blood transfusion** or blood products before 1991, for example Factor VIII for the treatment of Haemophilia.

Screening for Hepatitis C in blood donations commenced in 1991 and now all donations are screened for the virus in the UK.

**Intravenous drug users** sharing needles and injecting equipment. This is a high-risk group and it is estimated that 60 - 80% of intravenous drug users will be infected with the Hepatitis C virus.

**Health care workers** and others who have been put at risk through an accidental injury from an infected needle or sharp instrument.

**An infected person sexual partner.** The risk of contracting Hepatitis C from a sexual partner is considered low.

**Mother to baby.** A mother passing hepatitis C to her baby is highly unlikely and again is of low risk. This may be increased, however, if the mother's Hepatitis C infection is particularly active or she experiences a traumatic birth when having her baby.

There is no risk of transmission through breast milk.

Fathers will not pass the virus to their children purely by fathering them.

**Others.** People who have tattoos, acupuncture or their ears pierced with non-sterile equipment. It is also possible to catch the Hepatitis C virus through contact with the blood of an infected person while having a cut or open wound.

**To help prevent passing Hepatitis C on to others, infected people should:**

- Clean up blood spills promptly with undiluted household bleach
- Carefully clean cuts and wounds and cover with a plaster or dressing
- Not share personal items such as toothbrush, razor or scissors
- Make sure their General Practitioner (GP) and Dentist are aware of their Hepatitis C status and inform partners and other members of the household
- Not register as an organ donor or donate blood
- Consider barrier methods of contraception, especially when in a new relationship with a partner. You may wish to discuss this with your specialist
- Ideally avoid body piercing, tattoos and acupuncture or ensures sterile needles are used
- Not used intravenous drugs and especially not share needles or injecting equipment

If you have been tested positive for Hepatitis C it is recommended that you ask your GP to refer you for assessment to a liver specialist at the hospital.

## **Diet and lifestyle**

Alcohol is known to aggravate the Hepatitis C virus and cause it to attack the liver more aggressively. Many people find that alcohol, especially in excess, can make any symptoms they have worse and can make them feel quite unwell.

Alcohol consumption should be limited to the occasional drink only, and ideally no more than 21 units per week. 1 unit of alcohol is equivalent to half a pint of ordinary strength lager/beer/cider, a 25ml pub measure of spirits or a small glass of wine.

Diet and exercise are important. A good balanced diet which is low in fat, high in fibre with plenty of fresh fruit and vegetables plus regular exercise will be of benefit and can help your body to deal with what is effectively a continuous viral infection.

Some people may wish to seek help from alternative medicine for example herbal or homeopathic medicines. We do not object to anyone trying these alternatives especially if they feel it improves their symptoms, however it may be advisable to check with your specialist before starting any medication especially if you are on treatment for your Hepatitis C.

## **Cirrhosis**

Cirrhosis is the result of long term continuous liver damage. The normal healthy liver tissue is replaced by scar tissue called Fibrosis, resulting in hardening and impairment of function.

Cirrhosis may lead to a build up of fluid in the abdomen called ascites. The sufferer may also develop swollen veins in the oesophagus (gullet) which are at risk of bleeding and the liver and spleen may enlarge.

If Hepatitis C does eventually lead to severe cirrhosis and liver failure, liver transplantation may be an option.

## **Further Information**

Further information is available from:

### **Hazel Allen**

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C/O Dr P Winwood  
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### **British Liver Trust**

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## ***TESTS AND INVESTIGATIONS***

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**Blood tests:**

During your initial visit to the hospital a number of blood tests will be organised for you.

These tests look at how well your liver is functioning, if it is inflamed and to determine whether you still have an active Hepatitis C infection. This test is called a PCR test, which looks for the virus in the bloodstream. If this test is positive then this indicates a chronic infection.

The initial blood test which was taken to diagnosis Hepatitis C look for antibodies to the virus. If present this indicates a past Hepatitis infection but the PCR test is necessary to confirm whether the virus is still present. A small number of people, around 15% will have antibodies to the virus but will no longer be infected.

**Liver Biopsy:**

Liver biopsy is performed to assess the severity of liver disease, this necessary because it is the only accurate way of knowing how much damage and scarring you may have in your liver. The biopsy will only be necessary if the virus is still present on the blood tests.

A liver biopsy is performed using a local anaesthetic injection to numb the area. A small needle is passed into the liver on the lower right hand side at the level of the ribs. This is done in conjunction with an ultrasound scan so the doctor can see clearly where the needle should be placed. Two small samples of liver tissue are taken for analysis, both the size of a piece of thread.

When the biopsy is being done you should not feel any pain. After the procedure however some patients occasionally experience some pain in their side and this can radiate up into the right shoulder. You may also feel soreness in the area where the biopsy was taken as the local anaesthetic wears off. Painkillers will be available if you do have any discomfort.

Liver biopsy does carry a small risk of bleeding and possible localised infection. You will be required to lie on your right hand side for several hours after the procedure and to stay in over night.

If you have a blood clotting disorder for example Haemophilia then a biopsy will not be taken due to the risks of bleeding but a plain ultrasound scan of the abdomen may be arranged.

### **Ultrasound Scan:**

An Ultrasound Scan of the whole abdomen will also be arranged, and this will either be carried out at a separate appointment before the liver biopsy or on the day of the biopsy. This is to look at the shape, size texture and surface of the liver.

### **Further Information**

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## ***TREATMENT***

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## **Treatment for Hepatitis C**

The best-established treatment for Hepatitis C is with a drug called Alpha Interferon and Ribavirin. Interferon is a natural substance produced by the body in response to a viral infection; e.g. it is responsible for the flu like symptoms experienced when we have a viral cold. Interferon is given as a treatment for Hepatitis C as it mimics the body's natural responses and helps it to kill the virus. This combination of drugs is known to produce a sustained response in 50% of patients. Sustained response means that the virus is killed and does not reappear after treatment is finished.

Treatment is offered to people with moderate to severe damage as shown on liver biopsy, for these people are more likely to go on to develop problems in the future. If the damage to the liver is very severe with cirrhosis the effectiveness of treatment is reduced and it may even be harmful.

Patients with only minimal damage shown on biopsy will not require treatment. They will be observed and followed up every six to twelve months with blood tests to monitor liver inflammation and to ascertain how well the liver is functioning. A liver biopsy will need to be repeated every five years. If at any stage during follow up, treatment is considered necessary it can then be given.

## **Genotyping**

The Hepatitis C virus has many different strains, which are called Genotypes. Different Genotypes are found in different parts of the world. Some types may cause a more active disease than others and lead to damage of the liver cells at a greater rate.

The Genotype you have effects the length of treatment you require and the likelihood of it being successful.

If you have Genotype 1 then you will need a initial 24 week course of treatment and if you respond a further 24 weeks. The percentage chance of the virus being eradicated is around 40%.

If you have Genotype Non 1 then you will only need a 24 week course of treatment and the percentage chance of the virus being eradicated is around 70%.

### **How is treatment given?**

Interferon is given by an injection either once a week, or three times per week. The drug is injected into the body's fat layer just under the skin using a tiny needle. Most people give their own injections after appropriate teaching by the Nurse Specialist and no one will be expected to start self-injecting at home until they are happy and confident to do so.

Ribavirin is a capsule taken by mouth every day with foods, morning and evening.

### **Side effects of treatment**

As Interferon is the substance which produces symptoms when we catch a virus, Interferon given as treatment may cause flu like side effects such as:

- Chills
- Fever
- Shivers
- Muscle aches
- Headaches
- General weakness

These flu like side effects tend to last for about twelve hours after each injection and then subside. They are usually worse for the first two to three weeks of treatment and after that gradually become more tolerable. Some people, however, do suffer some flu like symptoms throughout the course of treatment.

The severity of side effects vary from person to person and can be helped by taking two Paracetamol tablets 1 hour before each injection and another 3 hours afterwards. It is quite safe to take Paracetamol as long as the recommended dose is not exceeded.

Other side-effects to be aware of are;

- Nausea, indigestion and vomiting
  - Loss of appetite and Weight loss
  - Irritable bowels, diarrhoea and stomach pain
  - Insomnia, difficulty falling asleep and staying asleep
  - Shortness of breath
  - Sore throat, dry mouth
  - Headaches
  - Muscular aches and pains
  - Redness of eyes and blurred vision
  - Increased sweating
  - Weakness and dizziness
  - Tiredness and lack of energy
  - Nasal congestion, sinusitis
  - Discomfort in the liver area
  - Slight hair loss
  - Dry, itchy skin and scalp and occasional rashes
  - Localised skin irritation and bruising at injection site
- 
- Irritability, anxiety, a lack of ability to concentrate, and depression. People with a history of depressive illness are at greater risk of becoming depressed while on treatment with Interferon. Even without a tendency to depression many patients complain of feeling down for no apparent reason, and can become emotional and tearful, (these side effects can be worse on combination therapy with Ribavirin.)

#### SIDE EFFECTS AFFECTING THE BLOOD

##### Interferon

- With Interferon there can be a reduction in the number of white blood cells in the blood stream, (these cells fight bacterial infection.) This could lead to a reduced immunity to infection.
- Reduction in the platelet cells in the blood (these cells help clot the blood when we bleed). This may make you bruise or bleed more easily.

## Ribavirin

- Ribavirin can cause temporary destruction of red blood cells leading to anaemia, (these cells carry oxygen around the body). The symptoms of anaemia are feeling weak, tired and lacking in energy. You may feel the cold more and can become dizzy and short of breath.

## Rare side effects

- Thyroid dysfunction causing low thyroid activity (disruption in the production of thyroid hormone.)
- Diabetes
- Pulmonary Fibrosis (scarring of lung tissues)

The medical team closely monitors all of the potential side effects listed. Regular blood tests and follow up appointments are necessary. Any patient undertaking treatment must be committed to the treatment programme, keep in regular contact with the hospital and be available to attend all the necessary appointments.

All the side effects listed usually resolve completely once the treatment is discontinued.

## **Treatment Outcomes**

Response rates to treatment are closely monitored throughout with the initial response to treatment being assessed with a blood test at week 24 of treatment.

Once the course of treatment is completed:

If the patient has responded to the drugs with no sign of the virus at the end of treatment. Blood tests will then be taken at regular intervals for 18 months to check that the virus does not reappear and that the response to treatment is sustained. A percentage of people who respond while on treatment will relapse and the virus will again be detectable in the blood after the treatment has been completed.

If the Hepatitis C virus is not detected in the blood six months after treatment this is considered a sustained response and there is only a very small percentage change that the virus will return after this point. However we do not have one test that can guarantee that a person no longer has the Hepatitis C virus. We can only keep looking for it in the blood and if it is consistently absent we assume that the body has, with the help of the drugs cleared the virus.

If the patient has responded to the drugs and the virus is still present at the end of treatment then they will be followed up 6 to 12 monthly until more effective treatment becomes available.

### **Advances in treatment for Hepatitis C.**

A great deal of research is being carried out on new treatments with combinations of drugs. A vaccine for Hepatitis C is not yet available but is being researched.



### **DO'S AND DON'TS**

**DO** Remember to take 2 Paracetamol tablets, 1 hour before your Interferon injection and a further 2 tablets, 4 to 6 hourly as necessary. As long as you do not exceed the dose of no more than 8 tablets in 24 hrs the paracetamol will have no ill effects on the liver.

The paracetamol tablets will help to reduce the flu like side effects of the interferon, even if you don't usually get these side effects after your injection it is still advisable to take the 2 paracetamol before the injection.

**DO** Keep a note of any side effects you are experiencing while on the treatment, their frequency and severity and inform us of any changes at your outpatient visits.

### **DO CONTACT US A.S.A.P;**

If any of your side effects become severe or intolerable.

If you notice that you are bruising or bleeding more easily.

If you develop any form of infection for example a severe sore throat and are feeling particularly unwell.

**DON'T** worry if you forget to have your Interferon injection. If you are on injections three times per week as long as there is 12 Hours between each injection you can always take it the next day instead but if you forget all together don't worry, just have the next injection as usual. Missing one dose will not have any effect on your overall treatment. If you are on weekly injections take it as soon as you remember even if it is a couple of days late. Similarly with the Ribavirin tablets if you forget a dose, just take the next one as prescribed. It is not advisable however to take the whole days medication together.

**DON'T** Hesitate to contact Hazel Allen or Dr Winwood's secretary at any time if you have any queries or questions regarding your treatment.

### **Contact Details**

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