

Hepatitis C – Your Questions Answered

This leaflet has been produced to help answer some of the common questions surrounding Hepatitis C. It is estimated that 14,000 people in Wales have been diagnosed as Hepatitis C positive. If you or someone you know has been recently diagnosed, then this leaflet may be of some benefit to you. It is intended to supplement the information you receive from your hospital nurse or doctor.

What is Hepatitis?

Hepatitis is the medical term used to describe inflammation of the liver. Hepatitis can be caused by alcohol, certain medications or viruses. Hepatitis C is one of these viruses.

What does our liver do?

The liver is an important organ in the body. It lies behind the lower ribs on the right side of your abdomen. It is estimated to weigh 3-4lbs, and is the largest organ in the human body.

The liver has several functions: -

- To regulate and store nutrients in our blood, including fat, sugar, protein and vitamins needed by the body.
- To eliminate toxins or waste products from our blood.
- To make bile, which is a yellow liquid that helps digest the food we eat.
- To make substances in the blood which allows us to form clots when we bleed or injure ourselves.
- It turns food into energy.
- It regulates hormone levels in our body.

What are the symptoms of Hepatitis C?

Not everyone will be aware they have Hepatitis C. It is possible to have the disease for several years and remain relatively well and symptom free.

Some people however may develop one or several of the following symptoms: -

- Muscle aches and a high temperature
- Feeling tired
- Vomiting
- Loss of appetite, with possible weight loss
- Feeling depressed or anxious
- A pain or discomfort over the liver
- Jaundice (a yellow tinge to the skin)

- An intolerance to alcohol

If you have been diagnosed as hepatitis C positive, and have any or most of these symptoms, this does not mean you have any more of a problem with your liver than someone who is symptom free.

What will being positive mean to me?

For every 100 people who are found to be Hepatitis C positive, approximately 20 people will 'fight off' the virus themselves without medical intervention. The other 80 could, over a period of 20-40 years, develop chronic hepatitis, liver cirrhosis (scarring) and approximately 2 people could develop cancer of the liver.

How could I have got Hepatitis C?

Hepatitis C is primarily a blood-borne infection, although it has been identified in other body fluids. There are several ways in which people can become infected, these include: -

- Receiving a blood transfusion before September 1991 in the UK
- From a mother who is Hepatitis C positive to her baby
- Sexual transmission, although very rare
- Occupational injuries
- Receiving body art (tattoos or piercing) with non-sterile equipment
- Sharing personal items, such as a toothbrush, razor, tweezers etc which may be contaminated with the blood of someone who is Hepatitis C positive
- Having medical or dental procedures performed abroad using non-sterile equipment
- In some cases, the route of transmission is never known
- Sharing contaminated needles

It is not possible to catch Hepatitis C from normal social contact, including kissing, toilet seats, using cutlery etc.

How can Hepatitis C be prevented?

If you have been diagnosed as Hepatitis C positive, then you can prevent transmission to others by: -

- Practising 'safe sex' by using condoms.
- Not sharing personal toiletries such as a toothbrush, razor, nailbrush etc.
- Only having tattoos or body piercing using sterile equipment.
- Not sharing any needles or any other drug taking equipment.
- Avoiding blood exposure by covering cuts etc with waterproof plasters until healed.
- Do not carry a donor card, donate blood, semen or blood products.
- If you cut yourself, clean any spilt blood on floors or work surfaces using household bleach

If you have any worries about any possible risks, please discuss these with your nurse or doctor.

What will happen to me now?

An initial antibody test reveals if someone is Hepatitis C positive or negative. If you are found to be positive, you will need to have a follow-up blood test called a PCR to look for the active virus.

As the Hepatitis C virus has an incubation period of up to six months in the body, it is therefore possible from the time you are exposed to the virus until six months after; you could have a false negative result. If this is suspected, you will be advised to protect yourself from any further exposure using the precautions listed above.

You will then be re-tested after six months. If after this time your PCR test is still negative, then you should simply continue to protect yourself.

My PCR test reveals I am positive for the active virus – what happens next?

You will receive an appointment in the hospital or community, where you will meet the team who will be looking after you.

In order that we can give you the most appropriate help, advice and treatment, it is important that you are completely honest with us.

Please remember you will not shock us with anything you say or ask!

It will be necessary for further tests to be arranged.

This will include blood tests to establish your viral 'load' and Genotype (sub type of the Hepatitis C virus).

If your own immune system has not been able to 'fight off' the virus then you could still be cured using medication.

Before receiving any treatment, you will need further investigations including an ultra sound scan and then a special liver scan (fibro scan) will be arranged.

It is important that you attend for all your tests as these are required before you can be offered treatment.

The ultrasound scan provides information on your liver, kidneys, pancreas, spleen and blood vessels in your abdomen. This scan is done at either the Royal Gwent Hospital or Nevill Hall Hospital

Some people are put off having Hepatitis C treatment as they have heard they will need a 'liver biopsy' involving a needle. In the vast majority of people with Hepatitis C this is no longer required. This has been replaced with a Fibro scanner. This quick, simple and painless scan provides information on any damage or scarring in your liver. The scan takes a few minutes and is performed at County Hospital, Pontypool.

What can I do to help myself?

ALCOHOL - Alcohol can cause liver damage if taken in excess of the recommended daily allowance, (2 units a day for women or 3 units a day for men). However if you are Hepatitis C positive, alcohol can aggravate the virus, accelerating the progression of liver disease to develop cirrhosis. You should therefore not take any alcohol at all. If you feel you could experience difficulty in abstaining from alcohol, or are usually a 'heavy drinker' then please inform your nurse or doctor – they can arrange help if needed.

DIET - You should aim to eat regular meals and have a well balanced, healthy diet. This means low salt, sugar and fat. Plenty of fibre (i.e., Cereal, bran, etc). Two portions of protein a day (i.e., meat, fish, eggs, cheese, nuts, etc) lots of fruit and vegetables. Some carbohydrates (i.e., bread, potatoes, rice, pasta, etc) as a source of energy.

EXERCISE - You may be experiencing tiredness and lethargy as a direct effect of the virus on your body. Strenuous exercise regimes are not recommended, but gentle exercise which does not leave you feeling fatigued can be of benefit to your general well-being.

MEDICATION - Most medicines are considered safe, but it is recommended that you always check labels, instructions or warnings on packages and discuss any concerns with your doctor, pharmacist or nurse.

RECREATIONAL DRUG TAKING - If you feel that this could cause you problems, or like some help with this, then please inform your nurse or doctor.

What about Hepatitis C and Pregnancy?

If you are pregnant and have been found to be Hepatitis C positive then your specialist nurse can give you specific information.

What medication will I need to take?

Present treatment in the UK is described as combination therapy and is tailored to individual patients according to Genotype. There are currently many different treatments available and more treatments expected over the next 2 years.

INTERFERON - This is an antiviral drug. Interferon works in a similar way to your own body's immune system; it boosts your immune system allowing it to fight the Hepatitis C virus. Interferon is injected subcutaneously (into the fatty tissue just below the skin surface) once a week. Your nurse will teach you how to inject yourself, into your stomach or thighs.

RIBAVARIN - This is a capsule or tablet taken twice a day. Ribavarin, alone has not proven to be effective, but used with interferon, prevents the virus from multiplying. Most patients do experience some side-effects from the treatment they receive.

NEW ORAL AGENTS – these are Ledipasvir/Sofosbuvir, Ombitasvir-paritaprevir-ritonavir- dasabuvir, Sofosbuvir and Daclatasvir. These are well tolerated with minimal side effects and are used in combination as stated below per Genotype.

GENOTYPE 1

Ledipasvir/Sofosbuvir for 8-12 weeks

Ombitasvir-paritaprevir-ritonavir- dasabuvir/+/- Ribavirin for 12 weeks

GENOTYPE 2

Peg-interferon/Ribavirin for 24 weeks (no cirrhosis/fibrosis and has not had treatment in the past)

Sofosbuvir/Ribavirin for 12-16 weeks – cirrhosis or past treatment failure

GENOTYPE 3

Peg-interferon/Ribavirin for 24 weeks (no cirrhosis/fibrosis and has not had treatment in the past)

Sofosbuvir/Daclatasvir/Ribavirin for 12-24 weeks – cirrhosis only.

GENOTYPE 4

Ombitasvir-paritaprevir-ritonavir-Ribavirin for 12 weeks

Ledipasvir/Sofosbuvir only to be used in patients with cirrhosis

Other blood tests – during your treatment you will have a range of regular blood tests performed and treatment may be altered by your nurse or doctor to ensure you are receiving the most appropriate treatment for yourself.

How will I know if my treatment has worked?

After your treatment programme has been completed you will still require further blood tests. These will indicate if you have been 'cured'.

It is necessary to repeat this test again in a further 12 weeks to ensure the response is sustained. Having the virus once and being cured would offer you no future protection against the disease. You should therefore protect yourself in the future.

Who should I tell?

Unfortunately, there is still some stigma surrounding Hepatitis C, but support from close family and friends can help. Your hospital records are confidential and information to insurance companies etc can only be released on your authority. You may not be obliged to tell your employer although you may wish to do so in order to

gain support. Ultimately it is your choice who you tell. Your nurse will be happy to discuss this with you

Where can I get further information?

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01633 – 656069 (answer phone available)

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