

Hepatitis C



Pioneering Liver Health



Hepatitis C

This publication is for adults diagnosed with, or experiencing symptoms of, hepatitis C and those who would like to better understand the condition and its risk factors.

The British Liver Trust works to:

- support people with all kinds of liver disease
- improve knowledge and understanding of the liver and related health issues
- encourage and fund research into new treatments
- campaign for better services.

All our publications are reviewed by medical specialists and people living with liver disease. Our website provides information on all forms of adult liver disease and our Information line gives advice about liver health. For more information call the Trust on 01425 481320, or visit www.britishlivertrust.org.uk

For the latest updates to this information, please refer to our website www.britishlivertrust.org.uk

A list of reference sources for this information is available on our website or by contacting info@britishlivertrust.org.uk

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The Liver

Your liver is your body's 'factory' carrying out hundreds of jobs that are vital to life¹. It is able to repair itself (even renewing large sections¹). However, the liver's ability to repair itself is limited, and continuous injury can lead to permanent scarring. Your liver is very tough and able to function even when most of it is damaged¹, which means you may not notice any symptoms for some time.

Your liver has around 500 functions¹.

Importantly it:

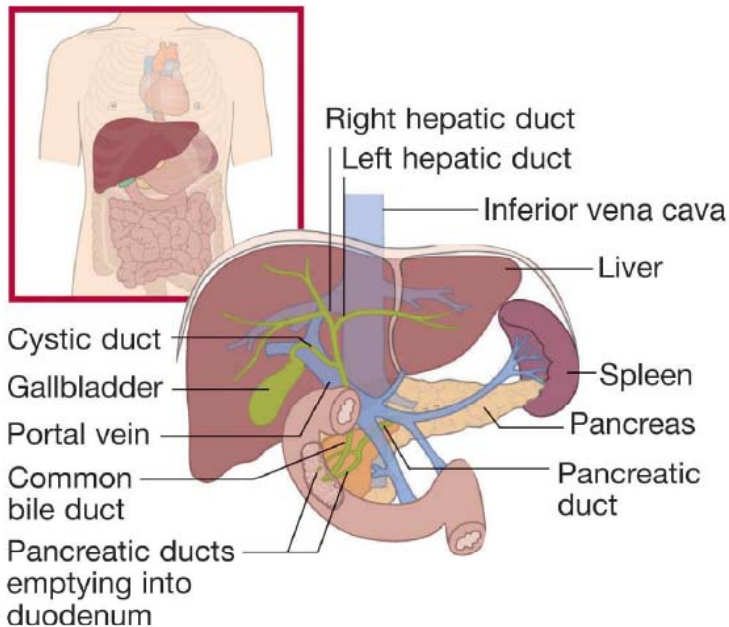
- filters and cleans the blood²
- fights infections and disease²
- destroys and deals with poisons and drugs¹
- makes vital proteins which make your blood clot when you cut yourself
- produces bile to help break down food in the gut³
- processes food once it has been digested³
- stores energy that can be used rapidly when the body needs it most¹
- regulates fat breakdown and distribution in the bloodstream^{1,2,4}
- stores sugars, vitamins and minerals, including iron^{1,3}
- gets rid of waste substances from the body⁵
- produces and maintains the balance of hormones¹
- produces chemicals – enzymes and other proteins – responsible for most of the chemical reactions in the body, for example, repairing tissue^{1,3}
- repairs damage and renews itself².

How liver disease develops

Your liver responds to injury by becoming inflamed. Any inflammation of the liver is known as hepatitis⁶, whatever its' cause. Sudden inflammation of the liver is known as acute hepatitis. Where inflammation of the liver lasts longer than six months, the condition is known as chronic hepatitis⁷.

Inflammation is part of the process of repairing damaged tissue. In a similar way to a scab forming over a skin wound, a temporary fibrous 'scaffold' forms while liver cells regenerate^{8,9}. If your liver is repeatedly injured, new liver cells cannot regenerate fast enough and the fibrous tissue remains as a scar⁹. This is called fibrosis and can take a variable amount of time to develop.

When fibrosis is present, the liver may be able to keep functioning quite well. Removing or treating the cause of the inflammation may reverse some or all of the fibrosis and prevent further liver damage^{9,10}.

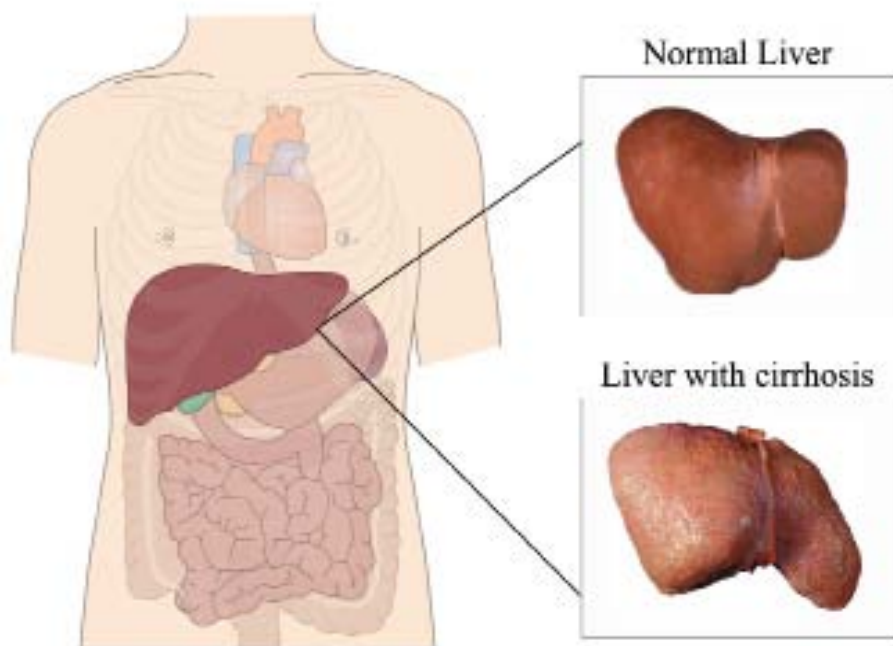


If damage continues, the inflammation and fibrosis can spread throughout your liver, disrupting its shape and affecting the working capacity of liver cells. This is known as compensated cirrhosis¹¹. Even at this stage, people can have no signs or symptoms¹¹.

The scar tissue in cirrhosis interrupts the blood flow through the liver. As a result the blood pressure in the veins around your gut is increased and may result in bleeding. Scar tissue in cirrhosis is difficult to remove and may be permanent¹². However, further progression can be halted and your cirrhosis stabilised, if the cause of the liver damage is removed.

Cirrhosis increases your risk of liver cancer^{2,11} and can lead to liver failure. If damage to your liver continues, it will become unable to function sufficiently (decompensated) and start to fail; this is sometimes referred to as end stage liver disease. At this stage chemicals and waste products can build up in the body, commonly causing jaundice (yellow colouring of the skin and the whites of the eyes), ascites (a collection of fluid in the abdomen) and hepatic encephalopathy (confusion and altered behaviour)¹³, see 'Useful words' section for more information, page 37.

In the final stages of liver disease the build-up of waste products may lead to multiple organ failure and loss of life.



What is hepatitis C?

Hepatitis C, sometimes called hep C or HCV, is a virus carried in the blood and body fluids which infects and damages the liver. A virus is a microscopic particle that needs to get inside living cells in order to live and reproduce (replicate)¹⁴.

The hepatitis C virus infects the cells in your liver, causing inflammation (swelling and tenderness) and fibrosis. In people with chronic (longer than 6 months) hepatitis C infection, inflammation and fibrosis can continue to spread. Over time, usually many years, this can lead to cirrhosis of the liver¹⁴.

What is hepatitis?

Any inflammation of the liver is known as hepatitis. Hepatitis can be caused by a number of things including¹⁵:

- drinking too much alcohol
- a viral infection, such as hepatitis C
- the body's own immune system – a liver condition called autoimmune hepatitis
- fatty deposits in the liver
- the side effects from some drugs and chemicals.

Other hepatitis viruses

There are a number of viruses that infect the liver. Best known are hepatitis A, B, C, D and E. The ways in which they are transmitted (spread or passed on), how they cause liver damage and the effects they can have on your health are different. Hepatitis B, C, D and E can cause chronic or long term illness¹⁵.

More information on hepatitis A, B, D and E can be found at www.britishlivertrust.org.uk.

How Common is hepatitis C?

It is not known for sure how many people in the UK have hepatitis C, but it is estimated that around 400,000 people may be infected¹⁴. Worldwide, more than 200 million people are estimated to be chronically infected¹⁶.

Injecting drug use is the most common risk factor for hepatitis C in the UK¹⁷. Other risk factors include mother to baby and unsafe sex. For more information see 'How is hepatitis C passed on'.

There are six main types (genotypes) of hepatitis C each with different subtypes. The most common types of hepatitis C in the UK, are genotype one and three¹⁶. Knowing your genotype is important in deciding the treatment you receive, as each genotype responds differently to treatment and requires a different treatment length.

It is possible to be infected with two types of the virus at the same time or to be infected with a different type of the virus at a later stage (this is known as re-infection). Before any treatment is started it is important to have a blood test to determine what type of the virus you have.

How is hepatitis C passed on?

Hepatitis C is a blood-borne virus (BBV); it lives mainly in the liver and moves around the body in the blood. It is spread by blood to blood contact.

The hepatitis C virus is highly infectious; this means you can get the virus even if you have only been in contact with a very small amount of it. It can be passed on through open cuts, wounds or scratches but cannot be passed on through unbroken skin¹⁴. In the UK the virus is often passed on by the sharing of drug injecting equipment.

The following activities all pose some risk of passing on the hepatitis C virus.

Injecting drugs (including steroids) – **high risk if you share needles, syringes or other ‘drug works’**

You are at the greatest risk of getting hepatitis C if you inject drugs or steroids, or share any ‘drug works’ including needles, syringes, filters, spoons, water cups or tourniquets. All of these may have a small amount of infected blood on them (it may be invisible to the eye).

Even if you think you have cleaned the equipment, if there is a small amount of the virus left behind, you could inject it without realising. The major route of HCV transmission (passing on the infection) in the UK is sharing equipment for injecting drug use^{14,15,17}. You only have to share infected ‘drug works’ once to be at risk of getting the virus.

Sharing cocaine straws – **medium risk**

Sharing a straw or a rolled bank note, to snort cocaine, could pose a risk as you may come in contact with the virus through nosebleeds or bleeding of the nasal mucosa (the tissue that lines the inside of your nose)¹⁵.

Mother to baby – **medium risk**

If you have hepatitis C and are pregnant, there is a small chance that your baby could become infected at the time of birth. Less than six per cent of babies born to mothers with the virus are infected with hepatitis C, although this is higher if you have a difficult delivery or if you also have another infection such as hepatitis B or HIV. Co-infection with HIV can increase the risk of passing the virus on by as much as 14 - 17%¹⁸.

Some research suggests the risk of passing on the virus (transmission) is higher at birth if you have a higher viral load at this time. Delivering your baby by caesarean section (also known as a C-section) is not thought to reduce the risk of passing on the virus to your baby during birth^{16,19}. As with any birth if there are complications, a caesarean may be needed. This should be discussed with your doctors and midwife.

It is common to find that babies have hepatitis C antibodies (protein in the blood produced by the body to try and fight infection), but these usually disappear by the time they are 12 months old. This shows they received the antibodies from you, but they have never actually been infected with the virus. Your baby should therefore be tested for hepatitis C RNA (see 'Useful words' section, page 37) and antibodies at four to six weeks and again at 12 months old¹⁸ to confirm if the virus has been passed on or not.

Although small amounts of the virus have been found in breast milk, there have been no reports of the virus being passed on through breast feeding²⁰. However, taking good care of your nipples to avoid cracking and bleeding, will help prevent any further risk.

Any concerns you have about passing on the virus to your baby should be discussed with your doctors or midwife.

Work and environment – medium risk in certain professions

Certain jobs or environments can put people at risk of hepatitis as they may involve contact with infectious blood or body fluids containing blood.

These include²¹:

- healthcare workers
- other workers who might come into contact with body fluids including morticians, sewage workers, those in emergency services, barbers or hairdressers, tattooists, acupuncturists, people in the fitness industry or in the building industry
- people who might have injuries and come into contact with others with injuries, such as those involved in contact sports
- foster carers and people who live or work in accommodation for people with severe learning disabilities
- prison staff and prison inmates.

To minimise the risk make sure all health and safety procedures for contact with bodily fluids and blood are followed. Ensure all cuts and wounds are covered with waterproof dressings or plasters before coming into contact with others for example, with patients and others you are caring for, before a sports match starts or as soon as an injury occurs during a match.

Personal items – medium to low risk

Personal items such as razors, hair clippers, toothbrushes, nail scissors and tweezers may have traces of blood on them sufficient to pass on infection. Sharing these items should be avoided¹⁴.

This is low risk in professional salons where equipment should be disinfected between customers.

Sex – Low risk^{18,22}

Hepatitis C can be passed on (transmitted) by having penetrative, anal or oral sex with an infected person if a condom or dental dam is not used.

Although passing on hepatitis C through sex is possible, it is unusual.

Transmission, where it occurs, is passed on by blood to blood contact.

Passing on hepatitis C is more common if you have a sexually transmitted infection. Also, anal or rough sex poses a greater risk of transmission, especially if this causes any bleeding. Oral sex is thought to be low risk.

Unless you are sure of your own status and that of your partner/partners, you may be at risk of BBVs if you do not have safer sex. 'Safer sex' is sex that doesn't allow body fluids to go from one person into another. Using a condom can help protect you as it provides a barrier between the body fluids, including blood.

If, as a couple, only one of you has hepatitis C and the other has tested negative throughout the relationship, it is unlikely that the virus will be passed on through your usual sexual practices, even after many years.

Women who have hepatitis C should ideally avoid penetrative sex during their periods.

Family – Low risk

The risk of infection to family members (i.e. parents or children) is very small.

It is fine to wash your everyday clothing along with those belonging to other family members. If you have hepatitis C and your clothes get blood or other bodily fluids on them, they should be washed separately, use a hot cycle (at least 60 degrees) and detergent (biological or non-biological), as a precaution²³.

It is important to maintain a high level of cleanliness of shared facilities, such as the toilet, especially for females during their period.

Social contact – No risk¹⁴

Hepatitis C is not passed on through social contact, for example holding hands, hugging, sharing towels, cups, and plates or cooking utensils.

Although hepatitis C can be found in bodily fluids such as saliva, it is not known to be transmitted through kissing, sneezing or coughing.

Travelling – Low risk

Travelling abroad poses a low risk but care must be taken to avoid putting yourself in a high risk situation. As hepatitis C can be passed on through sex, taking precautions such as having safer sex, avoiding rough sex and other activities likely to cause cuts or abrasions, which can increase the risk of transmission, is advised.

Anyone who receives medical or dental treatment, those who have had a tattoo, acupuncture, or come in to contact with blood or blood products in countries where hepatitis C is common and infection control may be poor; should be tested for hepatitis C. This is a significant source of infection abroad.

There have been no known reported cases, worldwide, of hepatitis C being transmitted through insect or flea bites²⁴.

Receiving blood in hospital (blood product infusions) – **very low risk in the UK since 1991**

Blood donations in the UK have been screened for hepatitis C since September 1991. This means that if you received blood or blood products before this time, there is a chance you may have been infected and should ask your doctor to be tested for hepatitis C. If you have had a transfusion after September 1991 you do not need to be screened.

In some countries, blood and blood products may not be screened and patients may be put at risk by medical equipment that has not been cleaned properly such as re-used needles and dialysis machines. Always ensure any needles or medical equipment being used is new from a sterile packet²⁵.

Acupuncture, tattoos, body piercing – **Low risk in professional parlours**

Having a tattoo, body-piercing or even acupuncture can pose a risk if unsterile equipment is used²⁵. The best way to protect yourself is to ensure that disposable needles are used and that they come straight out of a sterile packet.

If you have been diagnosed with hepatitis C and plan to have any of the above, you should inform the person performing the procedure so that they can take precautions to protect themselves and others from infection.

Co-infection

Co-infection is when a person is infected with more than one virus at the same time. Other blood borne viruses, such as HIV and hepatitis B, share similar routes of transmission (the way something is passed on) to hepatitis C and so some people may be infected with another virus as well. If you have been diagnosed with hepatitis C, you should be tested for other forms of viral hepatitis and HIV. Having more than one virus can affect treatment options, outcomes and can speed up the process of liver damage¹⁸. However, there is increasing experience in managing these conditions and being co-infected will not prevent treatment.

If you are diagnosed with hepatitis C, vaccination against hepatitis A and B is recommended as becoming infected with these can be much more serious in people who already have another liver condition.

Further information on hepatitis A, B, D and E can be found on the British Liver Trust's website: www.britishlivertrust.org.uk or by contacting the office.

What are the symptoms of hepatitis C?

Hepatitis C affects people very differently – many people have no symptoms at all and may never know they have the virus.

What is the difference between acute and chronic hepatitis C?

Hepatitis C can cause an acute or a chronic illness.

- An acute illness is a sudden illness that lasts for a short period of time (usually less than six months).
- A chronic illness is one that lasts longer than six months, possibly for the rest of your life. Sometimes symptoms may come and go.

Acute hepatitis C

About one in four of those infected with hepatitis C have symptoms during the first six months of infection. If symptoms do occur, they can take between two weeks and six months to develop after contact with the virus; this is called the incubation period^{14,25}.

Symptoms that may be present while the virus is in the acute stage are often common symptoms that can be caused by many different conditions.

This can make acute hepatitis C hard to diagnose.

These symptoms may include^{14,25}:

- fever (high temperature - 38°C/100.4°F or above)
- feeling sick/ vomiting
- loss of appetite
- stomach pains

- a general sense of feeling unwell
- jaundice, a condition in which the whites of the eyes go yellow and in more severe cases the skin also turns yellow (see 'Useful words' section, page 37).

About one in five people infected with hepatitis C will clear the virus, in its acute form, within two to six months. Younger people and women are more likely to recover from the infection this way. If this happens you should have no long term effects from the virus however, it may take a while for you to fully recover; you may still feel tired and lacking in energy for a few weeks^{14,16}.

Chronic hepatitis C

About 80% of people who are infected with hepatitis C will develop a chronic infection. About one third of people with chronic hepatitis C go on to develop cirrhosis and a small number of these will develop liver cancer¹⁴.

Chronic hepatitis C can be very different for each individual; many find some of their symptoms come and go and some find they have the following symptoms²⁶:

- mild to serious tiredness (fatigue)
- anxiety and/ or depression
- weight loss
- loss of appetite and/ or feeling sick
- inability to tolerate alcohol
- discomfort in the liver area (place your right hand over the lower right side of your ribs and it will just about cover the area of your liver)
- problems concentrating (brain fog)
- joint and muscle aches
- itchy skin (pruritus)
- indigestion or bloating
- flu-like symptoms such as fever, chills, night sweats and headaches
- jaundice (see the 'Acute hepatitis C' section, page 14).

It is not unusual for people with hepatitis C to be diagnosed as having ME or chronic fatigue syndrome. The liver has no nerve endings – meaning liver specific symptoms might not develop until the liver is in the advanced stages of cirrhosis. Even if you have mild or no symptoms, you can still pass the virus on.

Testing for hepatitis C

Blood tests

Hepatitis C is detected by a blood test that looks for antibodies (proteins - see 'Useful words' section, page 37) produced by your body's immune system to fight the virus²⁵. You can have the blood test at a GP surgery, a hospital clinic or a sexual health (genito-urinary medicine, or GUM) clinic.

It may take some time before you know whether your test result is positive or negative. In the time between the test and your results, you should take precautions not to transmit the virus to anyone else (see the 'Prevention' section, page 29).

If your test result is positive (there are antibodies in your blood); this means you have had the hepatitis C virus at some stage. However, it may not mean you are still infected as this test will remain positive even if you have cleared the virus (the virus is no longer in your body) - about one in five people who get hepatitis C will clear it.

If your result is positive there is a second test to determine if the hepatitis C is still active (reproducing) in your system, this is called a PCR test. It looks for the viral genes (HCV RNA) in the blood. In most laboratories the test will now be done automatically on any blood sample that tests antibody positive. The results of the HCV RNA are reported as a viral load, the number value of the amount of virus in the blood, you should receive the result of this test within two weeks²⁵.

It can take three to six months for antibodies to be made by the body; if you have recently come into contact with hepatitis C you may need to be retested after this time to ensure you have not been infected²⁵.

If you test positive for the viral genes (HCV RNA) your GP or other healthcare worker will refer you to either a liver specialist (called a hepatologist), a specialist in digestive diseases (a gastroenterologist) or a specialist in infectious diseases. Your GP will know who has the expertise locally.

A test result that finds you have the hepatitis C virus is known as a 'positive test'. Because of this, people with the virus are often called 'hepatitis C positive'.

Before referral to a specialist your GP will do some blood tests to find out the genotype of your hepatitis C and if you have another infection such as hepatitis A, B, D or HIV, as having one or more of these will influence your treatment options.

Assessing liver damage

Liver function tests (LFTs)²⁶

Liver function tests measure the chemicals in the blood made by the liver. An abnormal result may suggest a problem with the liver, and may help to identify the cause. Further tests may be needed to find the cause of the liver problem (see our 'Liver disease tests explained' publication for more information).

If you have hepatitis C, your doctor will look specifically at the level of enzymes: alanine aminotransferase (ALT), gamma-glutamyl transferase (GGT) and aspartate aminotransferase (AST) as values in your blood (see our 'useful words' section, page 37). However, having raised LFTs does not always mean you have liver damage. Sometimes raised LFTs can be an indication that there is a problem with another part of the body, such as an infection.

If you have hepatitis C your LFTs can go up and down. They can also be normal. Having normal LFTs does not mean that liver damage is not occurring and further tests may be needed.

Ultrasound scan

An ultrasound scan is a routine procedure; the same as used in pregnancy to examine an unborn baby. It is usually performed in the X-ray department of the hospital or in an outpatient clinic. The procedure is very safe and should not be painful, but it may take 10 to 15 minutes to complete.

For further information please refer to our 'Liver disease tests explained' publication.

Fibroscan

A Fibroscan is a non-invasive test (a test where the equipment used does not need to enter the body), it uses ultrasound technology to measure how stiff your liver is. The procedure usually lasts around 10 -15 minutes and is painless. A score is produced at the end of the consultation to help assess your liver health. You should not have a Fibroscan if you are pregnant or have a pacemaker.

For further information see our 'Liver disease tests explained' publication.

Liver biopsy

A liver biopsy assesses the amount of scarring that has occurred due to hepatitis C. During a liver biopsy, a tiny piece of the liver is taken for study. This usually involves a fine hollow needle being passed through the skin into the liver and a small sample of tissue (see the 'Useful words section, page 37) being withdrawn.

The test is usually done under local anaesthetic and most people will be allowed home later the same day, although for some it may mean an overnight stay in hospital. As the test can be uncomfortable and there is a very small risk of internal bleeding or bile leakage, a stay in bed of at least six hours after the procedure is required. Ask your doctor for more information on this.

The results of your biopsy are 'graded' according to the degree of liver inflammation and scarring.

Treatment of hepatitis C

Acute hepatitis C

The majority of those diagnosed with hepatitis C are not diagnosed until the condition is chronic, as many people are asymptomatic (have no symptoms) during the acute stage, some will be able to 'clear' the viral infection within six months; meaning they are no longer infected with hepatitis C however, their blood will always contain hepatitis C antibodies.

If you are diagnosed with acute hepatitis C, you will usually be monitored to see if your body can 'clear' the virus naturally. If your body does not fight off the virus you will be considered for a course of treatment (see 'Chronic hepatitis C' section, page 15). It is important to consider treatment in the acute phase as it is successful in clearing around 85% of cases²⁵.

'Clearing' the hepatitis C infection, does not mean you are immune (protected lifelong against the virus); this means you should take precautions to minimise the risk of becoming re-infected.

If you have had hepatitis C, you will always have the antibodies in your blood; this does not necessarily mean that the virus is active (reproducing) but that you have been infected in the past. This is also true for people who have been successfully treated.

Will my treatment be successful?

The main goal of hepatitis C treatment is to 'clear' or 'rid' the virus from your body. Successful treatment is called a sustained virological response (SVR). At the end of your treatment course, your virus levels – Hepatitis C RNA (see 'Useful words' section, page 37) will be tested to see if you have cleared the virus, and then again three to six months after treatment has stopped. If you still have no sign of the virus, you have achieved SVR.

Having an SVR means that you are no longer infected with the virus. However, it is possible to become re-infected at a later date; therefore it is important that you continue to take preventative measures to reduce the risk of re-infection.

Chronic hepatitis C

Effective treatment for hepatitis C is available and can result in you permanently clearing hepatitis C. Once you are diagnosed it is important to be referred to a specialist in treating hepatitis C (a hepatologist, gastroenterologist or infectious disease specialist), as they will be able to assess the virus and your current liver health. This information will help them establish if you should start treatment, and if so, the best treatment course for you.

For some it might be best to start treatment as soon as possible, while for others it might be appropriate to wait; this will depend upon an assessment of your liver health arranged by your medical team. There are many new drugs in development for hepatitis C, which may become available over the next few years. This means in future there may be different treatments available. This is something to discuss with your specialist, as they will be able to answer any questions you have on your treatment, and new developments in the field.

During the course of your treatment you could be taking up to three different drugs in combination, depending on your genotype. The usual treatment for chronic hepatitis C genotype 2 or 3 is a combination of two drugs; interferon and ribavirin. Evidence shows that treatment with these drugs has a clearance rate (SVR) of more than 70% in Western countries¹⁶.

For hepatitis C, genotype 1, interferon and ribavirin are combined with a third drug; a protease inhibitor (see 'Useful words' section). The protease inhibitor (Boceprevir or Telaprevir) enhances the effect of interferon and ribavirin. Studies show these drugs, used in combination with interferon and ribavirin can increase clearance rates to 80%. Both drugs were approved by NICE (National Institute for Health and Clinical Excellence,) a Government body which looks at the cost and clinical effectiveness of medications, within the NHS, at the beginning of 2012.

The duration of treatment will depend on your genotype, as well as how the virus responds to treatment (how quickly it becomes undetectable), and how advanced your liver disease is. Most treatment options are between 12 and 24 weeks, but can last up to 48 weeks, or rarely longer. Before you start treatment you should discuss with your doctor the best treatment option for you and how long it is likely to continue.

New drug treatments are being introduced that may mean changes in treatment for hepatitis C; the way treatment is given (tablets/ injection), the number of tablets taken, when they will be taken and length of time they need to be taken. The British Liver Trust encourages anyone with Hepatitis C to discuss trials and all new treatments with their specialist doctor or nurse.

Interferon alpha²⁷

This is similar to the interferon that your body's immune system produces naturally to fight infection. It is used to boost and support your immune system to mount a defence against the virus.

The form of interferon most commonly used is 'pegylated interferon'. Interferon is given for a set length of time, usually lasting between 24 and 48 weeks, depending on genotype and how the virus responds to treatment. It is taken as a weekly injection just under the skin. You should be shown how to inject yourself using a technique similar to that used to treat diabetes.

If you regularly drink over the recommended government guidelines for alcohol consumption, this may affect your treatment options. NICE does not recommend treatment with pegylated interferon for those who drink to excess. If you are receiving interferon combination therapy alcohol can have an impact on both treatment experience and treatment outcome.

Ribavirin²⁷

Ribavirin is an antiviral (see 'Useful words' section, page 37) and does not work in treating hepatitis C on its own, it must be used with another drug such as pegylated interferon. It aims to stop the virus from replicating (multiplying), by interfering with the viral replication inside your cells. This helps your body to fight the virus. Ribavirin is taken in tablet form, twice every day until your treatment is stopped by your specialist.

Telaprevir and Boceprevir^{28,29}

Both Telaprevir and Boceprevir are protease inhibitors and prevent the hepatitis C virus, genotype 1 multiplying (replicating); they do not work as well against other genotypes of the virus. They are used as well as ribavirin and pegylated interferon, similarly to ribavirin they help by stopping the virus replicating; making it easier for the immune system to fight the virus. It is still unclear which drug is more effective. They tend to have unpleasant side effects and Telaprevir has to be taken with fatty foods.

Telaprevir is taken as two tablets, every eight hours, or three tablets twice a day, with fatty foods for 12 weeks.

Boceprevir is taken as four tablets, three times a day (at meal times).

The length of treatment depends on how well your HCV RNA responds.

Monitoring during treatment

You will be closely monitored during treatment, with clinic visits as well as blood tests. Your virus levels (Hepatitis C RNA) will be checked at weeks 4, 12 and 24, and you will have regular blood counts (see 'Useful words' section, page 37) and liver function tests. Your treatment may be changed or stopped depending on these results¹⁶.

Treatments in development

More recently new antiviral drugs for hepatitis C treatment have been developed, which can be more effective, safer and better-tolerated than existing therapies. The aim for new hepatitis C therapies is to develop shorter and more effective treatment combinations, which have fewer side-effects. Through this it is hoped that therapy will be better tolerated, and more people can receive effective treatment.

These therapies, known as oral direct acting antiviral agents (DAA) therapies need less monitoring by professionals and have shown to increase cure rates. However, these drugs are not yet approved by NICE and therefore are not widely available³⁰.

Sofosbuvir

Sofosbuvir is licenced for the treatment of adults with hepatitis C, genotypes one to six and is taken in tablet form, as a once daily dose, for 12 weeks. It can be used alone or in combination with interferon and/ or ribavirin, this will depend on your genotype and the final NICE Guidance when it is issued³¹.

Simeprevir

Simeprevir is licenced for the treatment of adults with hepatitis C genotypes 1 and 4, it is taken in tablet form, as a once daily dose, with food, in combination with peginterferon and ribavirin, for 12 weeks³².

Daclatasvir

Daclatasvir is licenced for the treatment of adults with hepatitis C, genotypes 1, 3 and 4. It is taken in tablet form, as a once daily dose, for between 12 and 48 weeks. It is taken in combination with Sofosbuvir with or without ribavirin, or in combination with ribavirin and peginterferon, depending on your genotype.

It is important to discuss treatment options with your clinical team to see which treatment option is best for you.

Many new treatments and a vaccine are in development - please check the websites below for regular updates.

For the most up to date information and NICE Guidance on these treatment options please visit the British Liver Trust's website: www.britishlivertrust.org.uk, the Hepatitis C Trust's website: <http://www.hepctrust.org.uk/> or the NICE website: <https://www.nice.org.uk/>.

Will my treatment have side effects?

It is important to remember that side effects for each type of treatment can be very different from person to person. You may not experience those listed but being aware of them will help you to recognise them if they occur.

Interferon produces side effects in many people, especially in the early stages of treatment. Some people get flu-like symptoms such as²⁷:

- nausea (feeling sick) and vomiting
- headaches
- fever
- tiredness (fatigue)
- muscle aches.

Interferon can take between four and 36 hours to cause side effects. Once you know what the side effects are for you, and at what point they occur, often you can help ease them. For example, flu-like symptoms can be helped by taking paracetamol.

More severe side effects from hepatitis C treatment may include:

- depression
- skin irritation
- anxiety
- insomnia
- anorexia
- anaemia (low iron levels)
- hair loss
- aggressive behaviour.

Pregnancy and hepatitis C treatment

Family planning should always be discussed with your doctor before starting your hepatitis C treatment. It is important to use contraception when taking interferon and ribavirin, and for seven months after treatment, as there is a risk to the unborn child. If you become pregnant while taking interferon it is important to talk to your doctor, as soon as possible, to discuss your treatment options. If you are pregnant, or planning to become pregnant in the near future, you must delay treatment until after your baby is born²⁵.

Side effects of treatment can be made significantly worse if alcohol is consumed. For example depression, which is a common side effect of interferon treatment and is also commonly associated with excess alcohol consumption, can be made worse. Alcohol can also negatively affect the outcome of interferon therapy, although why this happens is not yet understood.

Telaprevir and Boceprevir may also cause you to experience other symptoms such as pruritus ani (an itchy bottom), dysgeusia (may affect how things taste), and increase the risk of skin irritation and anaemia (low iron levels).

Treating side effects

If you experience any side effects from your treatment you should talk to your doctor as they may be able to suggest something to help ease the symptoms. Some side effects may ease or go by reducing the amount (dose) of medication taken and others can be helped with other medication.

It is important not to use over the counter drugs to prevent side effects without talking to your doctor, as some can react with your hepatitis C treatment causing serious illness and possibly resulting in loss of life.

Please consult your doctor before taking any extra medications or herbal remedies.

Some people may have a higher chance of developing depression; you may be advised to see a psychiatrist before you start treatment to assess your risk and if this could stop you being able to complete treatment. If this is the case you may be asked to start taking anti-depressants before the hepatitis C treatment.

Low blood counts (low iron levels and low white cell count), caused by the treatment, are very common but rarely cause any problems, as long as they are monitored carefully.

It is important to go for regular check-ups during treatment so that any side effects can be carefully monitored. People who have very bad side effects may not be able to take a full dose or a full course of treatment. It is important not to stop your treatment before you have spoken with your specialist.

Coping with side effects

It is important to develop a good support system before starting treatment. There are many on-line or local support groups that can provide information and emotional support (visit the British Liver Trust's website to find a local support group near you).

Family and friends can also help you. Sometimes when you are feeling down, help with cleaning the house, making a meal or child care can help lift your mood.

Consider the time of day that you take your medication. Ask your doctor if you can take your medication before bed so that you can sleep through the worst of the side effects. If you feel nauseous (sick), try not to take your medication before food. Massage or relaxation techniques may help with anxiety or muscle aches. Make sure you drink plenty of fluids so that you do not become dehydrated.

Your doctor may prescribe other medications to help control some of your side effects if they are persistent or severe. It may also be helpful to discuss any side effects with your dispensing pharmacist or nurse specialist.

Cirrhosis

Long-term (usually after many decades of chronic infection with HCV) continuous damage to the liver caused by hepatitis C can result in the liver becoming scarred. Irregular bumps, known as nodules, replace the smooth liver tissue, the liver becomes harder and the normal shape and structure is changed. As a result, the liver runs out of normal liver cells and can stop working (this is sometimes referred to as liver failure).

The symptoms of liver failure are fatigue, jaundice, confusion (hepatic encephalopathy), fluid retention in the abdomen (ascites) and ankles (oedema) and major bleeding from swollen veins in the gullet (varices). These symptoms can be severe and may be fatal without a liver transplant¹³. Not everyone with hepatitis C will develop cirrhosis and in those that do, it usually takes many years of infection for it to develop.

You may not show any symptoms of liver damage until cirrhosis is quite advanced. Certain factors are associated with more rapid progression of liver damage such as^{7,16}:

- being over 40 years old at the time of infection
- alcohol consumption – particularly if you regularly drink more than the recommended weekly units
- being male
- having diabetes
- co-infection with HIV or another hepatitis virus such as A or B
- immune-suppressive therapy (treatment to stop your immune system fighting itself).

Liver cancer

If you have chronic hepatitis C and/or cirrhosis, you have an increased risk of developing primary liver cancer - hepatocellular carcinoma (HCC). In 25% of people who have liver cancer hepatitis C is the underlying cause^{20,33}.

For those with hepatitis C, co-infection with hepatitis B, HIV and/or drinking alcohol can further increase the risk of developing liver cancer³³.

Liver cancer initially has few symptoms. If you have hepatitis C and have been diagnosed with cirrhosis you should receive regular ultrasound scans and blood tests (every six to twelve months) to monitor your liver. Early detection of any tumours will give the best opportunity for successful treatment. If you have hepatitis C, the risk of cirrhosis is increased if you are co-infected with hepatitis B (HBV), HIV, consume too much alcohol or smoke³³.

Screening should also be considered if you are over 40 years old and have hepatitis C as you are also at an increased risk of developing HCC. Your doctor should discuss this with you.

Liver transplantation

For some people with cirrhosis, who develop life threatening complications, liver transplantation may be an option. Although this is a major operation, 89% of liver transplant recipients are still alive after one year and 86% after two years with a very good rate of long term survival³⁴.

Having a liver transplant does not cure hepatitis C; it will remove your damaged liver and should make you well again.

Hepatitis C is likely to infect your new liver but the virus can potentially be treated after you have received a transplant. In transplant recipients (patients who have received a liver transplant) the virus can become more active, due to the medication (immunosuppressant's) you will have to take after you have had a transplant to help your body accept your new liver, and can sometimes cause severe disease but this may take some years.

How can I prevent hepatitis C?

Whether you think you may have hepatitis C or not, you can reduce the risk of spreading the virus by following these simple steps.

- If you inject drugs and/or steroids, or snort cocaine you should never share anything you use for injecting or snorting this includes needles, syringes, straws or bank notes, filters, spoons, water, citric acid or vitamin C, tourniquets or any other equipment.
- When travelling abroad, make sure any medical equipment used to treat you is sterile.
- Make sure that only sterile needles are used if you are about to have acupuncture, a tattoo or a body piercing. (If possible see that the needles come from a new sterile pack).
- Always use your own toothbrush, razor, scissors, nail clippers and other personal items.
- Carefully clean cuts and wounds and cover them with a waterproof dressing.
- Clean up blood using undiluted household bleach for floors and work surfaces.
- Wash your hands and any skin that have been in contact with blood.
- Wear rubber gloves if handling anyone else's blood or any articles that might be contaminated with blood.
- Dispose of blood-stained items carefully in a sealed plastic bag.
- Have safer sex; use a condom.
- If you know, or suspect, you are hepatitis C positive do not register as an organ donor or donate blood or semen.

Preventative vaccines

If you have hepatitis C it is important to have your vaccines against hepatitis A and B as this will reduce the risk of co-infection.

There is currently no vaccine which can protect against hepatitis C.

Important issues to consider

The effects of hepatitis C are far reaching often affecting more than just your health. There can be financial implications and it can also affect those people close to you.

Will I have to pay for my treatment?

If you are found to have hepatitis C, your specialist will give you your medication on prescription. Usually you will have to pay a standard charge when collecting all prescriptions at the pharmacy. If you normally do not have to pay for your prescriptions you should not have to pay to get your hepatitis C medication. For more information about who is eligible for NHS care and free prescriptions visit: www.direct.gov.uk.

If you are a 'permanent resident' in the UK (this means that you are living in the UK legally and for a settled purpose) you will be able to see your GP, Consultant or Specialist nurse free of charge in your local area. If you have been in the UK for less than three months, you can still receive free medical treatment from your local doctor's surgery. They will register you as a 'temporary resident'.

Who should I tell?

If you are diagnosed with hepatitis C you will need to inform close friends and family members, such as your partner or children, so that they can consult a doctor to be tested and if needed in future they can prevent the virus being passed on.

It is important that you take the time to understand the routes of transmission (how the virus is passed on), as it will be clearer to you who else will need to know you have the virus; for example, previous sexual partners or anyone you have shared drug equipment with. When you are considering who to tell you may want to talk it over with your specialist nurse; they can help you decide who to tell and help you work out the best way to tell them.

Family and friends may also be able to offer comfort and support to you. Most people do not know very much about hepatitis C and how it is

passed on, so it is likely they will ask you questions about the virus. It will be useful to work out what they may want to know beforehand. Showing them a copy of this publication may also help them understand more.

Being able to answer their questions will help to calm any unnecessary fears about the risk to you and to them.

People may think you can catch hepatitis C like a cold or flu. They may think that shaking hands, hugging or even kissing an infected person will give them the virus. Letting them know that normal social contact cannot spread the virus can be reassuring to them.

Who else do I need to inform?

If you are having any other medical treatment, visiting the dentist, having a tattoo, body piercing or acupuncture; you must let the person doing it know that you have hepatitis C so they can take steps to protect themselves and others. You have no legal obligation to inform your employer. However, you do have a legal duty to ensure your own health and safety and that of others while at work³⁵. The type of work that you do will influence the level of risk to others. Working with your employer means you can prevent others being infected. If you do decide to tell your employer they are obliged to keep this information confidential and cannot pass it on without your consent.

Who can I talk to?

It is a good idea to talk about your own concerns with a professional. This might be a doctor, health advisor, counsellor or perhaps a drug worker. Clinical nurse specialists trained to help people cope with hepatitis, and its symptoms, are based at some hospitals. You can get advice by phoning the British Liver Trust's Information line (01425 481 320) or by contacting one of our support groups around the country (a list of support groups and their contact details can be found on our website www.britishlivertrust.org.uk or by contacting the Trust). The Hepatitis C Trust also provides support and information to anyone with or affected by hepatitis C. visit their website: www.hepctrust.org.uk or call their helpline: 0845 223 4424.

There will be helpful people involved in your day to day life who you may find it useful to tell. These include someone you trust at work or may be a person who is always willing to listen to your problems. Think about who these people are and make a list of them. Letting them know about your illness will help to build your support base as you progress with your treatment.

Confidentiality

Most drug agencies and genito-urinary medicine (GUM) clinics offer a confidential testing service and your GP can also arrange testing for you. If your test is positive, the clinic will forward on your result to your GP so they can arrange ongoing care and treatment.

Any doctor who diagnoses viral hepatitis is legally required to report this information^{22,36}, to the local public health doctors who are responsible for preventing the spread of infection. These doctors work under the strictest guidance about confidentiality. National data is reported anonymously to help monitor the number of people infected and to help the prevention and treatment of hepatitis.

Insurance & mortgages

Insurance companies must only ask information that is to do with the insurance you are taking out. They should not ask whether you have taken a hepatitis C test, had counselling due to the test or have received a negative hepatitis C test. However, an insurance company is allowed to ask you if you have had a positive hepatitis C test result or if you are receiving treatment for hepatitis C³⁷.

A positive test result may mean a life insurance policy or a mortgage linked to a life policy could be refused or the premium much increased³⁷. If this happens, it is worth talking to your doctor as many consultants are willing to write to a mortgage or insurance company stating your health and life expectancy. An insurance company may contact your doctor asking them to complete a medical report before accepting your application. Your doctor must obtain your consent before completing the report and is only allowed to disclose information to do with your application. Your doctor can choose not to answer any questions they find inappropriate.

When purchasing travel insurance, you must inform your insurance company of any conditions you have (including hepatitis C) and you should make sure that your policy will cover them. If the policy does not cover all the medical conditions you have your policy may be void; this means you will not be insured and may have to pay for any medical treatment or losses you have. You may need to contact a specialist insurance company who provide medical travel insurance. It is essential that anyone travelling to a European Economic Area (EEA) country has their European Health Insurance Card (EHIC) with them to get state healthcare at a reduced cost or sometimes for free. It will cover you for treatment that is needed to allow you to continue your stay until you come home. More information can be found at www.nhs.uk/ehic.

You can contact the British Liver Trust for a list of companies who are happy to cover people with liver conditions.

The Skipton Fund and Caxton Foundation

If you have hepatitis C as a result of receiving blood or blood products in a UK hospital, prior to September 1991, then the Skipton Fund and the Caxton Foundation have been set up to help.

The Skipton Fund has three payments; the first two are one off payments and the third is a yearly payment. Applications are considered individually and the stage two and three payments are available for those whose hepatitis C has progressed to cirrhosis.

The Caxton Foundation has been set up to assist those who are financially disadvantaged by having hepatitis C that was contracted from receiving blood prior to universal blood screening. To qualify for the Caxton Foundation payments you must have received your payments from the Skipton Fund. Both websites are easy to understand and take you through the application processes well. www.caxtonfoundation.org.uk and www.skiptonfund.org

Looking after yourself

Alcohol and smoking

Alcohol is processed by your liver and, as a result, it can be dangerous for anyone with liver problems. Alcohol can accelerate the rate of liver damage in those with hepatitis B and C and increase the risk of developing primary liver cancer^{33,38,39}. You may be advised by your specialist to reduce your alcohol intake or to stop drinking for a period of time.

Smoking is dangerous to everyone's health^{40,41,42} and can increase the severity of liver damage⁴³. People with liver disease are more vulnerable to infection and to poor health overall, so smoking or exposure to passive smoking is not advisable. If you smoke, speak to your doctor about what help is available with cutting down and giving up.

Diet and exercise

Being overweight or obese can affect your liver and the treatment of your liver condition. If you have a liver condition, there may be some special considerations you need to make in your diet to stay nutritionally well and to help manage your condition. Some of these are specific to certain liver conditions, others relate to how advanced your liver condition is (see our 'Diet and liver disease' publication).

For most people there is no special diet, however, eating a good, balanced diet is one of the most important things you can do to keep yourself well. Regular low calorie meals containing protein (such as meat, fish or beans), starch (such as bread, potatoes or rice) and vitamins (in fruit and vegetables) is the best approach.

It is vital that if you are concerned about your weight – whether it be under or over weight – that you discuss it with your specialist and discuss support from a dietician.

Exercise will help you to maintain a healthy weight. The Department of Health recommends adults should take at least half an hour's gentle exercise a day, leaving you warm and slightly out of breath. You can do this all at once or, if you find it easier, in shorter 10 minute bouts. If you are overweight, the amount of exercise you do may need to be increased from 30 minutes to 45-90 minutes a day to help you to lose weight⁴⁴.

Finding an exercise that you enjoy will help; try walking, swimming, cycling or dancing. If you are overweight, speak to your doctor about losing weight safely. Avoid crash diets and rapid weight loss as these rarely work and you are unlikely to maintain weight loss. They can also be dangerous and increase the risk of malnutrition and gallstones. A safe weekly rate of weight loss is between 0.5kg and 1kg (1-2lb)⁴⁴.

Complementary and alternative medicines (CAMs)

Many complementary and alternative medicines available suggest they can ease the symptoms of liver disease. Before taking any medicine you should check with your doctor that it is safe to do so as most of these are processed by the liver, so they can be toxic to people with liver problems⁴⁵. Some can damage the liver and make your condition worse. At present, healthcare professionals are not clear on the role and place of some complementary medicines in managing liver disease; more research is needed on their use.

Licensing has been introduced for some traditional herbal medicines⁴⁶ however, many herbal products are not classified as a medicine, meaning there is no regulation of the product. This means you cannot be sure how much of the active ingredient you are getting or how pure it is. Unregulated products are not monitored or assessed for how effective or safe they are. Some remedies can damage the liver and make you severely ill.

It is wise to be cautious about the claims made for herbal remedies, particularly those advertised on the internet, as they can offer false hope. It is important to discuss the use of these remedies with your doctor before taking them.

Some people choose to use complementary therapies alongside their conventional medical treatment, both to ease symptoms and emotional well-being.

Such therapies may include massage, aromatherapy, meditation or acupuncture.

To ensure your chosen therapy does not adversely affect your health or medical treatment, you should discuss any therapies you are thinking of using with your specialist doctor or nurse. Make sure the person doing the procedure is registered with an accredited body (qualified); your doctor may be able to refer you to someone who is locally recommended.

Always inform the person doing the procedure of your medical conditions as these may affect the type of therapies that are safe for you.

Useful words

Acute – a sudden illness that may be severe but lasts for a short period.

Alanine aminotransferase (ALT) – a liver enzyme, it enters the blood following liver damage. An ALT test is used to monitor and assess the degree of liver inflammation in patients with hepatitis of any cause.

Anaemia – a condition in which you have less than the normal amounts of red blood cells or haemoglobin in your blood resulting in a reduced amount of oxygen being carried around in the bloodstream, causing symptoms like fatigue, excessive tiredness and shortness of breath.

Antibody – a specific protein (immunoglobulin) produced by your body as part of a defence response against a foreign substance entering the body in order to render it harmless.

Ascites – accumulation of fluid in the abdomen (peritoneal cavity), which surrounds the bowel, leading to enlarged, swollen and tender abdomen.

Aspartate aminotransferase (AST) – is a liver enzyme, but it is less specific to the liver than ALT (see above). A raised AST level may also indicate muscle damage elsewhere in the body.

Antiviral – a drug or treatment for viruses.

Bile – a yellow-green fluid produced by your liver, which passes into your intestine. It contains chemicals, as well as waste products, and plays a central role in helping the body to process cholesterol and digest fat.

Bilirubin – a yellow pigment and waste product from the breakdown of haemoglobin. Increases of bilirubin in your blood can indicate liver disease, especially disease of the bile ducts (see jaundice).

Blood count – a full blood count is a test that measures the number of red cells, white cells and platelets in your blood.

Encephalopathy – altered brain function, leading to mental confusion and memory loss. Hepatic encephalopathy occurs when the liver is severely damaged and is unable to process toxins, as in the development of cirrhosis. Severe encephalopathy can result in a comatose state.

GGT – gamma-glutamyl transferase, a liver enzyme in your blood, it is measured to check for liver damage. Blood levels can also be higher in response to alcohol and various drugs, with the absence of liver disease.

HCV RNA – ribonucleic acid, found in the nucleus and cytoplasm of a cell, it is essential for protein production (synthesis). The genes of HCV and HIV are contained in the virus encoded as RNA and these are referred to as RNA-viruses. Other viruses such as HBV are DNA-viruses.

Inflammation – the body's reaction to acute and chronic injury or infection, commonly characterised by swelling, pain, redness and heat.

Jaundice – a condition in which the whites of the eyes go yellow and in more severe cases the skin also turns yellow. This is caused by accumulation in the blood of bilirubin; a yellow pigment and a waste product normally disposed of by the liver in bile (see bilirubin). Jaundice usually indicates a problem with the liver, though it can be caused by other conditions.

Protease inhibitor – a drug or treatment which can be effective in preventing the replication of a virus.

Protein – the active molecule in cells that determine the physical structure of the organs and tissue that make up your body. Proteins also control the biological and chemical reactions within your body.

Tissue – a group of similar cells that together carry out a specific function.

Vaccination – injection with a vaccine.

Vaccine – a substance containing treated parts of a virus (antigens) to stimulate the body to produce antibodies against a specific disease. Vaccines may be live or inactivated (very weakened or dead), both forms of the virus cannot cause disease. It is introduced into your body to cause an immune reaction to protect you against getting the virus.

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