Liver cancer

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
- lobby 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 Helpline gives advice and support on enquiries about liver health. Call us on 0800 652 7330 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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This publication is for people diagnosed with primary liver cancer or those who would like to better understand the condition and associated risk factors.
The liver

Your liver is your body’s ‘factory’ carrying out hundreds of jobs that are vital to life. It is very tough and able to continue to function when most of it is damaged. It can also repair itself – even renewing large sections.

Your liver has around 500 different functions. Importantly it:

- fights infections and disease
- destroys and deals with poisons and drugs
- filters and cleans the blood
- controls the amount of cholesterol
- produces and maintains the balance of hormones
- produces chemicals – enzymes and other proteins – responsible for most of the chemical reactions in the body, for example, blood clotting and repairing tissue
- processes food once it has been digested
- produces bile to help break down food in the gut
- stores energy that can be used rapidly when the body needs it most
- stores sugars, vitamins and minerals, including iron
- repairs damage and renews itself.
Fighting liver disease

Liver damage develops over time. Any inflammation of the liver is known as hepatitis, 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 hepatitis.

Fibrosis is where scar tissue is formed in the inflamed liver. Fibrosis can take a variable time to develop. Although fibrosis is present the liver keeps on functioning quite well. Treating the cause of the inflammation may prevent the formation of further liver damage and may stop or reverse some or all of the scarring.
Cirrhosis is when inflammation and fibrosis has spread throughout the liver and disrupts the shape and function of the liver. Even at this stage, people can have no signs or symptoms of liver disease. When the working capacity of liver cells has been badly impaired and they are unable to repair or renew the liver, permanent damage occurs.

Cirrhosis can lead to liver failure or liver cancer. All the chemicals and waste products that the liver has to deal with build up in the body. The liver is now so damaged that the whole body becomes poisoned by the waste products and this stage is known as end stage liver disease. In the final stages of liver disease the build up of waste products may cause multiple organ failure and lead to death.

What is cancer?

The human body is composed of billions of cells that are continually ageing, dying and being replaced. Cell death, replacement, growth and development are normally tightly controlled. If this control breaks down, cells begin to grow and divide abnormally, clustering together to form a lump known as a tumour. These tumours are either benign or malignant. Cancer is the name given to a malignant tumour.

Benign liver tumours

Benign liver tumours stay in the liver and do not spread to other organs or parts of the body. Usually they only grow for a limited amount of time and produce no symptoms.
Most benign tumours are found by chance. Occasionally, they may need surgical removal if they are large, liable to bleed or cause any discomfort.

**Malignant tumours**

Malignant cancer tumours are cells growing without control, which go on to invade, erode or destroy normal, healthy tissue.

Cancer is not a single disease. In fact, there are more than 200 different types of cancer, each with its own name, cause and treatment.

**Liver cancer**

There are two broad categories of liver cancer: secondary and primary.

**1. Secondary liver cancer**

Secondary liver cancer, is a cancer that first develops elsewhere in the body and then spreads (metastasises) to the liver. It is sometimes called metastatic cancer.

**2. Primary liver cancer**

Primary liver cancers are cancers that start in the liver. The two main types are:

- Hepatoma, also called hepatocellular carcinoma (HCC)
- Biliary tree cancer, which includes cholangiocarcinoma (bile duct cancer) and gallbladder cancer.
How common is liver cancer?

In the UK, around 3,400 people every year are diagnosed with primary liver cancer which represents about 1% of all cancers in the UK. Secondary liver cancer is far more common than primary liver cancer. Most people in the UK diagnosed with tumours in their liver, will have secondary liver cancer.

Primary liver cancer is more common in men than in women. The reasons for this are not fully understood. It is more likely to affect people over the age of 60 and is rare below the age of 45.

Although primary liver cancer is relatively rare in the UK, HCC is the sixth most common cancer worldwide. It is common in sub-saharan Africa and parts of Asia such as China.

Causes of liver cancer

Secondary liver cancer

When a cancer forms in a part of the body, a few cancer cells may break off and find their way into the bloodstream. Because your liver filters your blood, any cancer cells in the bloodstream have a high chance of settling in the liver to form a cancer nodule (metastasis).

People who are most at risk of secondary liver cancer are those with cancers of the large bowel (colon), pancreas, stomach, lung or breast.

It is important to know where the cancer started as this will determine the type of cells which are causing the cancer and affect which treatment is best suited for you.
Secondary cancer diagnosed in the liver may be a sign of cancer in other organs. If the original (primary) cancer is too small to be detected, it is called carcinoma of unknown primary.

Primary liver cancer

1. Hepatoma (hepatocellular carcinoma, or HCC)
The main cause of HCC is cirrhosis of the liver, where the liver has become scarred as a result of damage over a long period of time. Any disease that causes cirrhosis of the liver can lead to a hepatoma, but certain causes of cirrhosis have a particularly strong link with HCC.

- Viral infections hepatitis B and C
- Excessive alcohol consumption
- Haemochromatosis: a rare hereditary disease caused by an overload of iron in the body. High risk if not treated.
- Non-alcoholic fatty liver disease (NAFLD): specifically the advanced form non-alcoholic steatohepatitis (NASH) is thought to be the cause of many cases of cirrhosis previously labelled as of unknown cause (cryptogenic). It is increasingly being associated with HCC.

Other causes of cirrhosis less frequently associated with HCC.

- Primary biliary cirrhosis (PBC): nine out of ten people with PBC are women and have a relatively low risk of developing HCC. However, the risk is greater for men with PBC, who have a risk of developing HCC similar to those with alcohol related cirrhosis.
- Autoimmune hepatitis: people with this condition have only a very low risk of developing HCC, even when cirrhosis is present.
Having cirrhosis does not mean you will get primary liver cancer. Around three or four people out of a hundred with cirrhosis will go on to develop HCC each year.

As well as cirrhosis, other factors can also increase your risk of developing HCC.

- **Infection with two or more viruses** (co-infection) such as hepatitis B, hepatitis C or HIV leads to a greater risk than a single infection.
- Both **obesity** and **type 2 diabetes** are linked with a higher risk of developing HCC, the risk being greater if both are present. This is often associated with NASH as part of a group of conditions called ‘the metabolic syndrome’.
- **Heavy smoking**, particularly in association with excessive alcohol consumption or infection with viral hepatitis is linked with HCC.
- Using **anabolic steroids** over a long period can lead to liver tumours. These are usually benign but can grow and rupture causing pain. These may in rare circumstances lead to HCC.
- Exposure over a long period to **aflatoxin B**, which may be present in mouldy rice, wheat, peanuts, corn and soybeans (particularly in areas of Asia and Africa) and the practice of chewing **betel quid**, also increase the risk of HCC.

If more than one of these apply to you, your risk of developing HCC will be greater.

**2. Biliary tree cancer (cholangiocarcinoma and gallbladder cancer)**

In most people, there is no clear reason why they develop cholangiocarcinoma or gallbladder cancer. However, people who have the following problems are more likely to develop cholangiocarcinoma:
• a liver problem called primary sclerosing cholangitis (PSC). The risk is increased by smoking.
• chronic inflammation of the bile ducts due to multiple stones within the liver
• parasitic infections (liver fluke) common in SE Asia
• cirrhosis of any cause but particularly due to viral hepatitis B and C.

3. Fibrolamellar carcinoma
A rare variation of HCC usually found in people between 20 to 40 years old without cirrhosis being present. It is usually well contained and can be removed with surgery.

Reducing the risk of liver cancer

Although it is not possible to entirely eliminate the risk of developing primary liver cancer, you can take steps to reduce your risk:

• Avoid infection with hepatitis B or C (both major causes of cirrhosis) by getting a hepatitis B vaccination, practising safe sex and not sharing items that might be blood-infected (such as needles, razors and toothbrushes).
• Talk to your doctor if you have a family history of HCC, or have spent extended time in areas of the world where hepatitis B or hepatitis C are very common (South-East Asia, the Middle and Far East, sub-saharan Africa) or received a blood transfusion before 1991.
• Ask for a blood test if you think you may have been at risk of infection with hepatitis B or C. Treatments are available which will reduce your risk of developing cirrhosis.
● Avoid drinking too much alcohol  
(recommended levels are no more than three units of alcohol per day for men (21 units per week) and two for women (14 units per week) as this increases your chance of cirrhosis, the major cause of primary liver cancer.

● Ensure haemochromatosis is treated.  
For those diagnosed with haemochromatosis, regularly having a unit of blood taken (venesection) to reduce iron overload significantly lowers the risk of developing HCC.

● Eat a healthy diet and take regular exercise  
to reduce the risks from obesity, type 2 diabetes, NAFLD or NASH. If you are diabetic, work with your GP to maintain good control of insulin levels.

● Stop or never start to smoke, particularly if you have viral hepatitis or PSC.

● Keep regular contact with your GP if you are diagnosed with any form of liver damage, such as fibrosis, and find out what you can do to stabilise or reverse the condition to prevent the development of cirrhosis.

● Continue to drink coffee. Several research studies have suggested that coffee has a beneficial effect on the liver and reduces the risk of developing HCC. For those with liver damage (who enjoy coffee) drinking two to five cups a day may be of benefit. The way in which coffee affects the liver is still being investigated.

Surveillance  
If you have been diagnosed with cirrhosis (particularly related to hepatitis B, C alcohol or haemochromatosis you should receive regular ultrasound scans and blood tests (every 6 to 12 months) to monitor your liver. Early detection of any tumours will give the best opportunities for successful treatment.
Surveillance may not be offered if you have alcohol-related cirrhosis and continue to drink, as the continued damage from alcohol would reduce the chances of any successful treatment.

In addition, should you develop cancer in another part of your body, especially if the primary cancer is in your stomach, oesophagus, pancreas, colon or bowel, screening for early symptoms of secondary liver cancer will give you a chance of finding this at an early stage when more treatment options are available.

**Symptoms of liver cancer**

Often there are no symptoms in the early stages of liver cancer because the liver can function very well when only a portion of it is working.

If you do notice any symptoms, they are usually vague and similar to symptoms for other liver conditions. They may include:

- fatigue (tiredness) and weakness
- a general feeling of poor health
- loss of appetite
- feeling sick (nausea) and vomiting
- loss of weight
- pain or discomfort over the liver area (place your right hand over the lower right hand side of your ribs and it will just about cover the area of your liver)
- itchy skin
- fine blood vessels visible on the skin in a radial pattern resembling the legs of a spider (known as spider naevi)
• enlarged and tender liver (you may feel tender below your right ribs)
• dark urine/grey pale stools (faeces)
• loss of sex drive (libido).

Do not be afraid to discuss these symptoms with your doctor they may be the first indication that something is wrong.

**Serious symptoms**

Some symptoms may be a sign of a serious problem. If you have any of these you should seek medical advice at once:

• skin and eyes turning yellow (jaundice) – often the first and sometimes the only sign of liver disease
• swelling of the abdomen, which can be due to the growing cancer itself or a build up of fluid within the abdomen (ascites)
• fever with high temperatures and shivers
• vomiting blood
• dark black tarry stools (faeces).

**How is liver cancer diagnosed?**

Your diagnosis will usually depend on whether you have secondary or primary liver cancer.

If you have secondary liver cancer it is quite possible that your liver cancer will be discovered when the primary cancer is diagnosed. For example, people with bowel cancer will also have tests to look for any spread to the liver. In this case your secondary liver cancer will usually be diagnosed by a specialist cancer doctor (oncologist) or a surgeon.
Primary liver cancer, including biliary tree cancer, is usually diagnosed in the following way:

- your GP will take your medical history – finding out about your symptoms – and perform a detailed clinical examination
- your GP will then take some blood samples and may arrange an abdominal ultrasound
- if blood tests and ultrasound indicate a tumour may be present, you will be sent to see a specialist doctor (surgeon or gastroenterologist/hepatologist) who may take more blood tests and arrange for you to have special imaging of your liver to examine it more closely (see page 16)
- you may be sent for a biopsy (see page 19) if the imaging is not conclusive.

Tests and investigations for liver cancer

Blood tests
A blood test provides information on the general health of your liver. In addition, if HCC is suspected, a protein found in blood called alpha-fetoprotein (AFP) will also be measured.

In around five to seven out of ten people with HCC, AFP levels will rise as the disease progresses. AFP levels usually come down if a treatment is working, so it is a useful tool to measure how effective treatment is. However, around one in five HCC tumours do not produce an elevated AFP, even when large.

In biliary tree cancer, blood tests for the tumour markers CA 19-9 and CEA may also be used.
However, these do not give a certain diagnosis as other conditions may also cause these markers to be raised.

**Consent**

Before you have any investigation or treatment you must give your consent (permission). No medical treatment will be given without you giving this. Before giving your consent you need to understand:

- why you need the treatment
- what will happen during the treatment
- the advantages and disadvantages of the treatment
- what the significant risks or side effects of the treatment are
- what the alternative treatments are
- what would happen if you did not have the treatment.

**Imaging**

**Ultrasound**

Ultrasound, the same technology used to confirm that all is well in pregnancy, sends sound waves into the body. The echoes are picked up and used to build a picture of the condition of the liver, bile ducts and gallbladder. Ultrasound is painless. If the ultrasound highlights any areas of tissue which could be a tumour you should be referred to a specialist liver unit for a CT or MRI scan. You should be seen by a specialist within two weeks.

**CT scan (computed tomography)**

A CT machine takes X-ray pictures of the body from different angles that are then fed into a computer. The computer processes the pictures as a series
of cross sections (or ‘slices’) giving a 3-dimensional image of the inside of your body enabling doctors to get an insight into the liver and other organs. This will show how far the tumour has spread and if it is present in other organs.

The scan is painless and takes approximately 20 minutes (even less with the latest fast scanners). Occasionally people may feel claustrophobic in a CT machine. If you think this may be a problem for you, discuss this with the radiographer beforehand so that they are aware. A dye, referred to as a contrast medium, is often used to help to make the images clearer. This may be given by injection or as a drink. You will be asked to drink lots of water after the scan to flush the dye out of your system. Rarely, some people may develop nausea or have an allergic reaction to the contrast dye. This can be treated immediately.

MRI (magnetic resonance imaging)

MRI uses radiofrequency waves and a strong magnetic field, not X-rays, to create a clear and detailed picture of internal organs and tissues and may be used where more detailed examination is required.

MRI is painless but rather noisy and some people may feel claustrophobic. Speak to the radiographer if this is a concern and ask about ear plugs or headphones through which you can listen to music. They may also be able to give you a sedative to help you relax if necessary. Because of the strong magnetic field, you must tell medical staff whether you have any piercings or have been fitted with anything metal, such as a pacemaker or pins.
When investigating possible bile duct cancer a particular form of MRI may be used called MRCP (magnetic resonance cholangiopancreatography).

**Chest X-ray**
You may also have a chest x-ray to detect the presence of any tumour spread to the lungs.

**Hepatic angiography**
Hepatic angiography is an X-ray study of the blood vessels that supply the liver and may be needed if the diagnosis is still doubtful after a CT and MRI scan. It may also be used as part of some treatment techniques such as chemoembolisation (see treatment section for further information). The procedure uses a catheter (a thin, flexible tube) that is placed into a blood vessel through a small cut in the groin. A dye is then injected through the catheter which ‘lights up’ the blood vessels in the tumour.

A hepatic angiogram is usually done under local anaesthetic and you are also likely to be given sedation. Because of this, you may be asked to stay in hospital overnight (the minimum stay is six hours). The test is usually uncomfortable, rather than painful. You should be able to drive the next day and continue with normal everyday activities.

**Endoscopic retrograde cholangiopancreatography (ERCP)**
This technique is used if you have suspected biliary tree cancer, to examine your bile ducts in more detail. It uses a small camera on the end of a flexible tube (endoscope). The camera is gently passed down your throat guided by an X-ray scanner to the bile ducts. A liquid will be injected to make your bile
ducts show up more clearly. A small needle may also be passed down through the endoscope to take a tissue sample for examination (biopsy).

**Laparoscopy**

A laparoscopy may be performed to assess damage to your liver and bile ducts and also to look for tumours in the abdominal cavity. In this procedure a tiny camera with a light on the end of a flexible fibre optic tube is inserted into your side through a small cut in your skin (‘keyhole’) to take pictures of your liver. If needed, a biopsy of your liver can be taken at the same time.

A laparoscopy is performed under a general anaesthetic. Afterwards it can be painful, but tablet painkillers are usually enough to dull the pain. You should not drive for 24 hours afterwards. A laparoscopy is often performed as a day case but an overnight stay is occasionally necessary.

**Liver biopsy**

Usually diagnosis can be made using imaging techniques but occasionally a biopsy may be required. 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 being withdrawn. In some circumstances it can be done using an endoscope (see above).

The test is usually done under local anaesthetic and may mean an overnight stay in hospital, although some people may be allowed home later the same day. 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 to eight hours is required. Ask your doctor for more information on this.

There is a small risk of spreading the tumour cells during this procedure and so it is only undertaken after specialist review by a multidisciplinary team.

Test results
When all the tests have been completed your consultant will review your test results with a medical team which may include specialists in surgery, liver disease (hepatologist), digestive diseases (gastroenterologist) and cancer (oncologist).

As well as diagnosing the presence of cancer, the tests will also provide information on how advanced the cancer is (size, number of tumours, location). This is referred to as ‘staging’ the cancer and is often measured using the TNM classification:

- Tumour (T) – the extent of the primary tumour
- Node (N) – whether the tumour has spread to your lymph nodes
- Metastases (M) – whether the tumour has spread to other organs.

The health of your liver will also be classified, using a scoring system called Child-Pugh (class A, B, C) which takes into consideration blood test results, the presence of fluid in the abdomen (ascites) and brain function (encephalopathy). A Child-Pugh class A, indicates the liver is working well, whereas class C indicates severe liver damage.

This information will help your medical team to decide on the most appropriate treatment options to discuss with you.
Primary and secondary cancer will require different approaches to treatment. The following treatments are used for primary liver cancer. Some of these may also be offered if your liver cancer is secondary, depending on the source of the primary cancer.

A number of treatment options are available. The aim of some treatments (surgery or liver transplant) is to get rid of the cancer to achieve a cure. If this is not possible then treatment will aim to shrink the size of the cancer to relieve symptoms, delay progression or to make surgery possible. Treatments may be used on their own or in combination.

Unfortunately a cure is only possible in a minority of people because liver cancer produces few symptoms and many people are not diagnosed until it is well advanced.

The treatment you receive will depend on a number of factors, including:

- the exact position of the cancer in the liver – sometimes there are several areas
- the stage of the cancer (size and extent of the tumour, whether it has spread to other organs)
- your general health, in particular the general state of your liver function (many people with primary liver cancer have a damaged liver due to cirrhosis).
Surgical treatments for liver cancer

Surgery is the only treatment which offers a chance of a cure, but may not always be possible. Whether you will be suitable for surgery will depend on a number of different factors, including:

- the size of the cancer and if it is contained in one part of the liver and no major blood vessels are involved
- if the cancer has spread beyond the liver
- whether the rest of your liver would be able to cope after an operation
- other health conditions which could hinder the operation or your recovery.

Resection surgery

The most frequent form of liver surgery is known as resection, where the part of the liver affected by the cancer is cut away and removed. The liver will then re-grow this section.
Resection surgery is only suitable for those who have very good liver function (Child Pugh class A). If you have a hepatoma (HCC) caused by damage to the liver through cirrhosis, then resection is usually not possible. This is because your liver may be too damaged to recover after the operation. A liver transplant may be considered, but only a few people are suitable for this.

Liver surgery is a major operation and there are some risks such as infection, bleeding or bile leakage. Nine out of ten people will recover from the operation however, unfortunately, around one in ten will die as a result of having this operation.

There is a risk that the cancer may come back as it is not always possible to determine if cancer cells have spread into the blood stream. In around half (50%) of people who have had resection surgery, liver cancer does not recur within five years.

For those receiving liver resection surgery, the long term success of the operation will depend on the size of the tumour which was removed. For those having a liver resection for cholangiocarcinoma, between one and four out of ten people (10 to 40%) live for more than five years.

For those having liver resection surgery for HCC, overall around one in five (20%) people will live for more than five years. However, five year outcomes may be considerably better for those who have small, well defined tumours. You should discuss your personal circumstances with your specialist.
Liver transplantation
A liver transplant may be considered if you have:

- a single tumour less than 5cms in diameter or
- up to five tumours, but all less than 3cms in diameter or
- a single tumour greater than 5cms but less than 7cms if there has been no tumour progression for six months.

Both CT and MRI scans are required to determine the number and size of the tumours, and measurements will be taken from whichever records the largest.

If you meet the criteria your consultant may recommend that you are put on the transplant waiting list. You will need to be assessed by a transplant team to check that you are well enough to go through this major operation. Unfortunately, there is a shortage of donor livers. It may be some time before a suitable liver becomes available and you may need other treatments to slow the growth of the tumour in the meantime.

Overall, about four out of five people (80%) live for at least four years after this type of surgery.

Liver transplantation is not recommended for those with cholangiocarcinoma as the cancer often returns very quickly.

Non-surgical treatments for hepatoma
If surgery is not an option, there are a number of treatments aimed at reducing the growth of the cancer. In some circumstances these may be effective at halting the cancer for several years.
Ablative therapies
These use a needle to deliver substances directly into cancer cells to kill them, and work best in small tumours which cannot be operated on. Two techniques commonly in use are radiofrequency ablation (RFA) and percutaneous ethanol injection (PEI).

Radiofrequency ablation
Radiofrequency ablation is a way of destroying a cancer tumour using heat. It is done by passing a needle into the tumour. When the needle is inside the tumour a high frequency current heats up and destroys the cancer. You may experience some tiredness or nausea following treatment.

Radiofrequency ablation is not suitable for all tumours, particularly if they are close to the gallbladder and biliary duct. Of the people whose small tumours are completely destroyed by this technique, around one in four (25%) live for at least five years.

Ethanol injections
Ethanol is a type of pure alcohol that can be injected into liver cancers to kill the cancer cells by dehydrating them. The ethanol is injected through the skin into the tumour using a very thin needle. You may need more than five sessions of injections to destroy the cancer and this may require a general anaesthetic.

Ethanol injections are often suitable if your tumours are few, well defined and easy to reach. For those people with small tumours and good liver function, five year survival rates are around one in two (50%).
Cryotherapy or cryosurgery
This technique uses a metal probe to deliver liquid nitrogen, which is extremely cold, into the tumour to destroy the cells by freezing them. It has been used for tumours up to 4cms where surgery is not suitable or to treat cancer which has recurred after resection surgery, there are uncertainties about how well it works and its use has declined. NICE (National Institute of Clinical Excellence) has recommended that it should only be used with special arrangement.

Embolisation
Embolisation is a technique used to cut off the blood supply to the cancer killing the cells. It works best for people who have good liver function.

Transarterial embolisation (TAE) and transarterial chemoembolisation (TACE)
Transarterial embolisation involves giving an injection into the main artery of the liver of a substance containing tiny gel-like beads or pieces of a gelatin sponge. This creates a seal that blocks the supply of blood to the tumour to stop it growing.

Chemoembolisation is a type of chemotherapy (see page 29) that directly targets a tumour. This reduces the side effects of using anti-cancer (chemotherapy) drugs directly in the patient’s bloodstream. In chemoembolisation a drug (such as doxorubicin) is mixed with an oily dye (lipiodol) and injected before the embolising substance. The drug is sealed in to make it attack only the tumour, and for a longer time. This therapy is given under local anaesthetic and requires a stay of up to two days in hospital. New methods aimed at improving delivery of the drug in this way are emerging. Your medical advisor can provide more information about these treatments.
Biological therapies
For those with advanced hepatoma but good liver function, and where other treatments are not suitable, sorafenib (a drug used to treat kidney cancer) has been shown to slow tumour growth, relieving symptoms and giving people some extra months.

NICE has issued guidance that sorafenib should not be prescribed on the NHS as it is not considered to be cost effective. However, if your cancer specialist believes you would benefit from a treatment not routinely available through the NHS they can apply to the local Primary Care Trust for exceptional funding. There are also proposals for other initiatives through which the Department of Health will cover the costs of cancer drugs, such as a Cancer Drugs Fund. Talk to your cancer specialist to see if any of these would be options for you.

You may also be able to receive sorafenib as part of a clinical trial in combination with other therapies (see page 31).

Non-surgical treatments for biliary cancer

Stents
In order to relieve symptoms of bile duct cancer your consultant may suggest inserting a stent. Biliary stenting is used to treat obstructions that occur in the bile ducts in order to allow bile to drain away and relieve symptoms. When there is a narrowing (stricture) in the bile duct the doctor can insert a small, thin wire-mesh
or plastic tube, called a stent, to open up the duct to keep it from collapsing. The stent can be inserted using **endoscopic retrograde cholangiopancreatography (ERCP)** and can remain in place permanently to help to drain away bile into the duodenum. Another common method of stent insertion is **percutaneous transhepatic cholangiography (PTC)** in which a hollow needle is inserted through the skin (after local anaesthetic and a sedative) into the obstructed duct area to guide and place the stent.

This may very occasionally be used prior to surgery but is not routinely recommended.

**Radiotherapy**

Radiotherapy may be used to treat bile duct cancer, either externally (using a machine to target the cancer with radioactive beams) or internally (using a wire inside your bile duct).

As well as damaging the cancerous cells, radiotherapy may also damage healthy cells causing side effects such as nausea and fatigue.

**Photodynamic therapy (PDT)**

PDT is a relatively new technique that aims to destroy cancer cells while minimising damage to normal tissue. Patients are given a ‘photosensitising’ drug intravenously that makes cells more sensitive to light. A low power red light, usually from a laser, is then directed onto the treatment area at the time of biliary stenting, up to two days after the photosensitising drug has been given. This activates the drug to attack the nearby cancerous tissue and thus improve the drainage of bile from the liver.

NICE has not recommended PDT as standard treatment on the NHS, however it may be available as part of a clinical trial.
Other non-surgical treatments for liver cancer

Chemotherapy
Chemotherapy is a treatment which uses drugs to kill cancer cells, or to stop them from multiplying. It aims to shrink the tumour down and slow the development of the disease. Drugs are given by injection or tablet form.

Chemotherapy will not cure your cancer, but it may control the cancer or even reduce its size. This can help to reduce symptoms and may also extend your life. In a very small number of cases chemotherapy may shrink a cancer sufficiently to make it possible to operate on it.

Not everyone will be able to have chemotherapy. Chemotherapy is not often used for HCC as this type of cancer does not respond well, but it is standard treatment for biliary tree cancer. However, if you have biliary cancer you may not be able to have chemotherapy if you have any signs of jaundice (yellow skin or eyes). This is because your liver may not be able to cope with the toxicity of the chemotherapy drugs. Other treatments, such as the use of a stent, may be needed to treat the jaundice before chemotherapy can begin.

Possible problems of chemotherapy include:
- anaemia
- increased risk of infections
- increased risk of bruising.

After receiving chemotherapy, you will need to have regular blood tests to monitor the effect of the drugs and to see how you are responding to treatment.
Emerging treatments and future research

Radioembolisation / Selective Internal Radiation Therapy (SIRT)
Like chemoembolisation, this technique uses tiny beads to block the supply of blood to the cancer. The beads contain a radioactive substance called yttrium-90, which helps to kill the cells using radiation. A course of chemotherapy may also be given at the same time. This may be an option if you have good liver function but resection is not suitable. Research is being undertaken to further evaluate the safety and effectiveness of the technique. You may be able to take part in the research as part of a clinical trial. The technique is available through the NHS with the condition that uncertainties, benefits and risks are fully discussed with patients before they consent, and outcomes of treatment are monitored.

Microwave ablation
This is a procedure, similar to radiofrequency ablation, which uses heat from microwave energy to destroy cancer cells. It can be used to treat primary liver cancer. Like other ablative therapies, it is not aimed at curing your cancer. NICE has approved this procedure for use in the NHS under the condition that patients fully understand what is involved and the results of treatment are recorded to provide more information on how well the procedure works.

Your specialist team will be able to advise whether these treatments are suitable for you and the possible risks and benefits compared with the other treatment options available.
Biological therapies and tumour characterisation

An area of active research is focussing on identifying elements in the process of tumour development which can be targeted with new drugs, used alone or in combination. Alongside this, work is ongoing to identify differences in the genetic make up of HCC tumours so that these can be grouped into types (characterised). Certain types of HCC tumours respond better to certain drugs. By characterising tumours in this way it should be possible to individualise a person’s treatment to maximise the effect on the tumour and minimise side effects.

Clinical trials

Doctors are always trying to find better ways of treating people. Your specialist may talk to you about the possibility of taking part in a clinical trial. This may involve treatment with new drugs or new ways of using drugs.

You do not have to take part in clinical trials and your care will not be affected if you do not. If you do take part, you may receive extra monitoring which may be beneficial to your treatment. The doctor involved in the research will give you specific information about any clinical trials.

You can find more information on trials which are currently running at www.controlled-trials.com
Follow-up and monitoring

Following treatment you will receive ongoing monitoring which usually involves the following:

- imaging tests every three to six months for two years and once a year thereafter
- alpha-fetoprotein (AFP) measurement every three months for two years and then every six months.

Supportive care

Sometimes no treatment may be suitable for you, perhaps because your cancer has progressed too far and treatment will not benefit you. And sometimes, after weighing up all the choices, people choose not to have any treatment. Whichever treatment choice you make, your cancer centre should support your decision.

Although treatment may not be an option, this does not mean there is nothing that can be done to help and support you and your family.

Coping emotionally

Being diagnosed with cancer is distressing and can be difficult to take in, particularly if you have experienced few symptoms. Many people go through a range of emotions before accepting their diagnosis, ranging from initial shock and disbelief that this is happening to them, to anger which can give way to depression. Your medical team will be able to direct you to counselling and psychological support to help you come to terms with your diagnosis. It is also worthwhile thinking of other sources of support, such as those in your local community, online support groups, ministers of religion and the organisations listed in the ‘Who else can help?’ section.
It is important not to push family and friends away. Try to explain to those close to you how you feel so they can help and support you. It can be helpful if you can give suggestions as to how they can help practically.

It can be particularly helpful for a friend or family member to attend medical appointments with you. Many people find they are too traumatised or anxious to ask questions. A second person can ask on your behalf and may get a completely different view of a meeting. It is of great benefit to be able to discuss this afterwards and agree what was actually said and by whom. Preparing a list of questions beforehand is a good idea.

**Diet supplements**

If you are finding it difficult to eat, there are plenty of dietary supplements available on prescription. Some are powders you sprinkle on your food and some are drinks that are complete meals in themselves. Sipping a supplement between meals throughout the day can really boost your calorie intake. Ask your doctor or dietician for help.

**Alcohol and smoking**

Alcohol is processed by your liver, and as a result, it can be dangerous for anyone with liver problems. Check with your doctor whether it is safe for you to drink any alcohol, and if so, how much.

Smoking is dangerous to everyone’s health. People with liver disease are more vulnerable to infection and to poor health overall, so smoking or exposure to passive smoking is not advisable.
Coping financially

Your GP or Macmillan nurse (if you have one) may be able to help you with grants for aids, heating costs, holidays and other household expenses related to your illness. They can also help you to claim benefits for yourself or for the person caring for you. It may be helpful to see a social worker. Again, talk to your GP or Macmillan nurse.

To obtain the services of a Macmillan nurse, you must be referred by your GP, your hospital consultant, a district nurse or a hospital ward sister.

Making your wishes known

If you are too ill to deal with your financial affairs you may wish to set up a document called an ‘enduring power of attorney’. This will enable someone you nominate to take legal decisions on your finances, and also your care and treatment, on your behalf.

You can also set up an ‘advanced directive’ or ‘living will’ which allows you to have a say in medical decisions if you are too ill to consent at the time. These are major steps and should be considered carefully. Discuss them with those closest to you, your medical team and a solicitor if possible.

The Trust’s publication ‘Living with liver disease’ provides further information which you may find helpful in coping day to day.

Coping with symptoms

As your illness progresses you may develop different symptoms. It is not certain that you will have all or any of them, but the following information may help you to realise that there is usually something that can be done to help you cope.
Ascites
Ascites is a build up of fluid in the lower tummy area (abdomen). There are several possible reasons for ascites including:

- cancer cells in the lining of the abdomen cause fluid to leak out into the abdomen
- pressure develops in veins around the liver because the liver is not working properly; this causes fluid to leak out into the abdomen.

Symptoms of ascites such as a large, uncomfortable abdomen, can be relieved by taking water tablets (diuretics) or by inserting a temporary tube into the abdomen to drain the fluid. Unfortunately, despite both of these treatments ascites may come back again.

Pain
Pain may develop in the abdomen and sometimes in the back. If pain affects you, there are a range of painkillers you can try. You will probably be started on some simple painkillers such as paracetamol or co-dydramol; some people do not need anything stronger than these.

However, if these are not effective then you may be offered a morphine based painkiller such as morphine sulphate tablets (MST). Do not worry about becoming addicted to morphine. Morphine taken to relieve pain works in a different way than morphine taken for ‘recreation’.
MST are taken in two doses daily, usually in the morning and at night before bed. The idea is that the morphine is released slowly into the bloodstream and so provides a background of constant pain relief. You will usually also be given liquid morphine or fast acting tablets in a bottle to take to ‘top up’ your pain relief if you experience a breakthrough in pain. It is important to make a note of how much liquid morphine you are taking, as this may be an indication to increase your morphine tablets.

Morphine-like drugs can also be given as a patch, similar to nicotine patches. This way of delivering painkillers may be used for patients who are not able to take tablets.

Remember that most painkillers can make you constipated. Constipation is not about how often you go to the toilet but how easily you pass the stool. If you find you are becoming constipated then drink plenty of water and have some laxatives at home ready to help you. Try to avoid becoming constipated as this can increase the amount of painkillers you need, and so increases the constipation; becoming a cycle that you need to break in order to become comfortable again. It is very likely you will be prescribed laxatives when you have your painkillers. There are many forms of laxatives, talk to your doctor about options and which are safe for you to use.

You may also find that painkillers, or even your illness on its own, may cause you to feel sick. If this is the case then a good anti-sickness medication to stop this feeling will be made available to you. You may also find that ginger or peppermint tea help to relieve symptoms.
Very rarely, your pain will not be controlled through the usual methods and you will be referred to an expert, such as an anaesthetist or specialist nurse, who will be able to offer special treatment.

**Complementary and alternative medicines**

Many complementary and alternative medicines are available that are suggested to ease the symptoms of liver disease. Most of these are processed by the liver, so can be toxic to people with liver problems. Some can damage the liver and make you more severely ill. At present, healthcare professionals are not clear on the role and place of some therapies in managing liver disease. More research needs to be done on the use of such therapies.

Many products are not licensed as a medicine and there is therefore no regulation of the product, which means you cannot be sure how much of the active ingredient you are getting or how pure it is. 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 a good idea to discuss the use of these remedies with your doctor.**
Useful words

Carcinogens – any substance that, when exposed to living tissue, may cause cancer.

Carcinoma – a cancer that forms in the tissue that lines the skin and internal organs (epithelium) of the body.

Cholangiocarcinoma – cancer of the bile ducts.

Gastroenterologist – a doctor who specialises in understanding and treating digestive diseases.

Curative – a treatment which offers a potential cure.

Hepatocellular cancer (HCC) – cancer of the liver cells.

Hepatologist – a doctor who specialises in understanding and treating liver problems.

Jaundice – a condition in which the whites of the eyes go yellow; in severe cases the skin does too. This is caused by the yellow pigment (bilirubin) which is normally disposed of in the liver.

Lymph nodes – glands found all over the body which are connected to form part of the lymphatic system (helps to fight infection). If cancer has spread to the lymph nodes it increases the chance of it spreading to other parts of the body.

Metabolic syndrome – a combination of medical conditions linked with cardiovascular disease including diabetes, high blood pressure, high cholesterol, obesity and also often associated with non alcoholic fatty liver disease.

Metastasis – the distant spread of a malignant tumour from its site of origin.

Oncologist – a doctor who specialises in understanding and treating cancer.
Palliative – treatment which is aimed at reducing symptoms and improving quality of life but does not offer a cure.

Primary sclerosing cholangitis (PSC) – an uncommon liver disease that causes the bile ducts (tubes inside and outside your liver that carry the digestive juice called bile to the bowels) to shrink in size. As they shrink, they block the flow of the bile which causes damage to the liver cells, leading to inflammation and scarring to the liver.

Resection – removal of some of a body part by surgery.

Surgeon – a doctor who specialises in treating people by operating on them.

Ulcerative colitis – a condition where ulcers and inflammation form in the rectum and the colon (part of your bowels).

Who else can help?

Bowel Cancer UK
7 Rickett Street
London SW6 1RU
Tel: 020 7381 9711
Fax: 020 7381 5752
Email: admin@bowelcanceruk.org.uk
Web: www.bowelcanceruk.org.uk

20 Queen Street
Edinburgh EH2 1JX
Tel: 013 1225 5333
Fax: 013 1225 2206
Email: scotadmin@bowelcanceruk.org.uk
Web: www.bowelcanceruk.org.uk
Cancer Research UK
PO Box 123
Lincoln’s Inn Fields
London WC2A 3PX
Tel: 020 7121 6699
Web: www.cancerresearch.org.uk and www.cancerhelp.org.uk
Cancer Research UK is the world’s largest independent organisation dedicated to research. They also provide support and information for people affected by all forms of cancer.

Macmillan Cancer Support
89 Albert Embankment
London
SE1 7UQ
Tel: 020 7840 7840 Monday to Friday 9am – Noon, 2pm – 4.45pm
Helpline: 0808 808 0000 Monday to Friday 9am – 8pm (interpretation service available)
Web: www.macmillan.org.uk
Macmillan provides practical, medical, emotional and financial support for people affected by cancer, as well as local information centres, support groups and nurses.

Marie Curie Cancer Care
89 Albert Embankment
London
SE1 7TP
Freephone: 0800 716 146 Monday to Friday, 9am – 5.30pm
Email: supporter.services@mariecurie.org.uk
Web: www.mariecurie.org.uk
Marie Curie Nurses provide free nursing care to cancer patients and those with other terminal illnesses in their own homes.
Further information

The British Liver Trust publishes a large range of leaflets about the liver and liver problems, specially written for the general public.

Leaflets that you may find particularly helpful include:

- Alcohol and liver disease
- Autoimmune hepatitis
- Cirrhosis of the liver
- Haemochromatosis
- Hepatitis B
- Hepatitis C
- Liver disease tests explained
- Liver transplantation
- Living with liver disease
- Primary biliary cirrhosis (PBC)
- Primary sclerosing cholangitis (PSC).

Information is also available in Urdu, Bengali, Hindi, Traditional Chinese, Gujarati and Punjabi which can be downloaded from our website.

Contact us for more information:
Tel: 01425 481 320
Helpline: 0800 652 7330
Email: info@britishlivertrust.org.uk
Web: www.britishlivertrust.org.uk

This leaflet is for information only. Professional, medical or other advice should be obtained before acting on anything contained in the leaflet as no responsibility can be accepted by the British Liver Trust as a result of action taken or not taken because of the contents.
Special thanks

Dr Simon Bramhall, Consultant HPB and Liver Transplant Surgeon, University Hospital Birmingham

Dr Steve Pereira, Reader in Hepatology & Gastroenterology, University College London & Hon Consultant Physician, University College Hospital and Royal Free Hospital

Dr Helen Reeves, Senior Lecturer & Honorary Consultant Gastroenterologist, Newcastle University & Hon Consultant Physician, Newcastle upon Tyne Hospitals NHS Foundation Trust
Did you find this publication helpful?

The British Liver Trust is always looking for ways to improve the information we provide. Please take a few minutes to let us know your views – we value your feedback.

How helpful did you find this publication? (please circle a number below)

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Fighting liver disease 43
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□ a relative / carer of someone with liver disease
□ other (please specify) ..........................................................

Would you be interested in any of the following:
□ sharing your story to help others
□ information about patient support in your area
□ fundraising for the Trust
□ reviewing updates to this publication
□ a list of all Trust patient information guides

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By giving the British Liver Trust your contact details (postal address, email address, phone number) you agree the Trust may contact you periodically with updates about its work.

Please tick the box if you do not wish to receive any further information from the British Liver Trust. □

The British Liver Trust does not give your information to other organisations for marketing purposes.

Please return this form to:
Freepost RLZS-RJXB-BYLX, British Liver Trust,
2 Southampton Road, Ringwood, BH24 1HY.
Tel: 01425 481320 Fax: 01425 481335
Email: info@britishlivertrust.org.uk
The need to do more for people with liver disease is greater than ever before.

The British Liver Trust is Britain’s only national charity for adults with all forms of liver disease. We rely on the generosity of others so that we can continue to improve the lives of people affected by liver disease.

A donation of just £3 a month can help us to plan and maintain our core services with confidence for the future. By filling in your contact details below, and the form on the reverse, you can set up your regular gift to the British Liver Trust.

**Your contact information (BLOCK CAPITALS)**

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**Please return this form to: British Liver Trust, 2 Southampton Road, Ringwood BH24 1HY**

**Tel:** 01425 481320 **Fax:** 01425 481335

**Email:** info@britishlivertrust.org.uk
Yes! I wish to make a monthly donation to reduce the impact of liver disease.

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To: The Manager  Bank/ Building society:

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☐ £5  ☐ £3  Other amount £ __________________________

By donating £2 or more a month you can become a Friend of the Trust, please tick here if you wish to sign up ☐

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To qualify for Gift Aid you must pay an amount of Income Tax and/or Capital Gains Tax for this tax year at least equal to the tax that we will claim from HM Revenue & Customs on your Gift Aid donations. This is currently 28p for each £1 that you give.

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