MACMILLAN
CANCER SUPPORT

UNDERSTANDING PRIMARY LIVER CANCER

Hepatocellular carcinoma or hepatoma

About this booklet

This booklet is about the most common type of primary liver cancer, hepatocellular carcinoma (HCC). It is for anyone who has been diagnosed with primary liver cancer. There is also information for carers, family members and friends.

Primary liver cancer is cancer that starts in the liver. This booklet explains what primary liver cancer is, the symptoms, diagnosis and how it is treated. There is also information about ways of controlling symptoms and coping with the emotional impact. We hope it helps you deal with some of the questions or feelings you may have.

This booklet does not have information about cancer that starts in another part of the body and spreads to the liver (secondary or metastatic cancer). We have separate information about secondary liver cancer.

We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

We have a video on our website about primary liver cancer, which you may find helpful. You can watch it at **macmillan.org.uk/cancer-information-and-support/liver-cancer**

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 120 to 127, there are details of other organisations that can help. There is also space to write down questions and notes for your doctor or nurse on page 128.

Quotes

In this booklet, we have included quotes from people who have had primary liver cancer, which you may find helpful. Some are from our Online Community (**macmillan.org.uk/community**). The others are from people who have chosen to share their story with us. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

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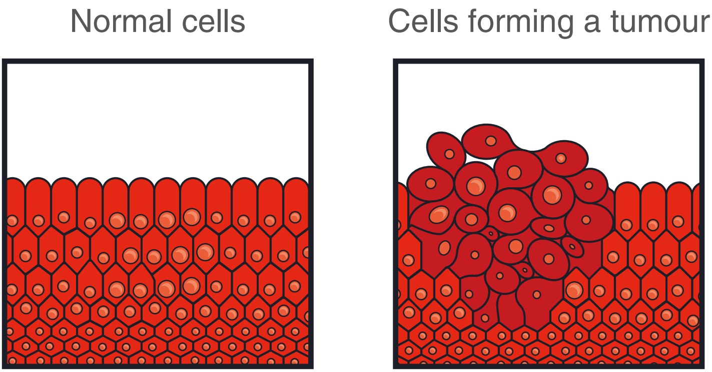
THE LIVER AND PRIMARY LIVER CANCER

What is cancer?

Cells are tiny building blocks that make up the body’s organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged, or no longer needed. When this happens, the cell gets a signal from the body to stop working and die.

Sometimes these signals can go wrong, and the cell becomes abnormal. The abnormal cell may keep dividing to make more and more abnormal cells. These can form a lump, called a tumour.

Cells forming a tumour


Normal cells

Cells forming a tumour

Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample of cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

A tumour that is not cancer (a benign tumour) may grow, but it cannot spread to anywhere else in the body. It usually only causes problems if it grows and presses on nearby organs.

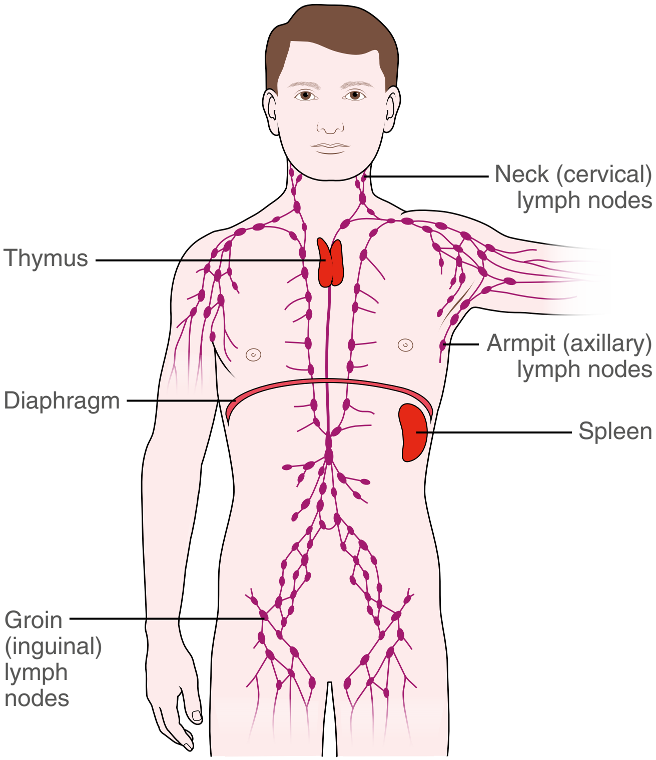
A tumour that is cancer (a malignant tumour) can grow into nearby tissue.

Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system (see page 8). When these cancer cells reach another part of the body, they may grow and form another tumour. This is called a secondary cancer or a metastasis.

The lymphatic system

The lymphatic system helps protect us from infection and disease. It is made up of fine tubes called lymphatic vessels. These vessels connect to groups of small lymph nodes throughout the body. The lymphatic system drains lymph fluid from the tissues of the body before returning it to the blood.

The lymphatic system

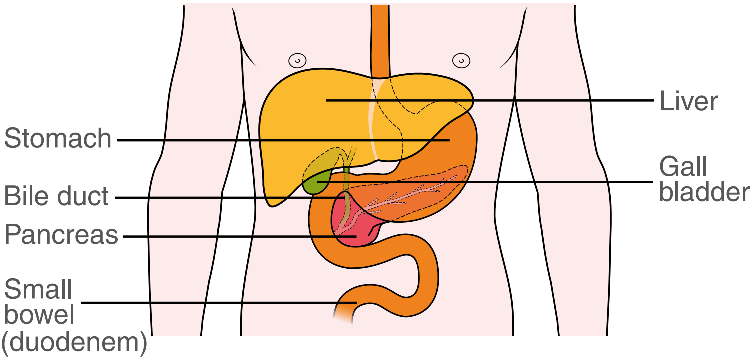


Lymph nodes are sometimes called lymph glands. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, some lymph nodes may swell as they fight the infection.

The liver

The liver is the biggest organ in the body. It is in the upper part of the tummy (abdomen) on the right-hand side, under the lower ribs. It is divided into two lobes.

The liver and surrounding organs



What the liver does

The liver:

- stores sugars and fats, so they can be used for energy
- makes different proteins that help the blood to clot, this prevents bleeding and maintains fluid balance in the body
- makes bile, which helps break down fats so they can be absorbed by the body
- breaks down harmful substances, so they cannot harm other parts of the body.

The liver is good at repairing itself. It can work well even when only a small part is working normally. If a part of the liver is removed, often the remaining liver can grow to replace it.

Primary liver cancer

Primary liver cancer is rare in the UK, but the number of people developing it is increasing. Around 5,700 people in the UK are diagnosed with primary liver cancer each year. In other parts of the world, such as parts of Africa and Asia, it is one of the most common cancers.

Types of primary liver cancer

- Hepatocellular carcinoma (HCC) is the most common type of primary liver cancer. It is sometimes called hepatoma. It starts in the main cells of the liver, called hepatocytes.
- Fibrolamellar HCC is a rare type of primary liver cancer that usually affects younger people. The causes and risk factors are not known.
- Bile duct cancer (cholangiocarcinoma) is another type of primary liver cancer. It starts in the cells lining the bile duct.
- Angiosarcoma is a very rare type of liver cancer. It starts in the blood vessels of the liver.

This booklet is about hepatocellular carcinoma (HCC). To make it simpler, we call it HCC.

We have more information about bile duct cancer and angiosarcoma on our website.

Benign tumours in the liver

Some tumours in the liver are not cancerous (benign). They are usually small and are often found by chance. This might happen when a person is having a scan for another reason. Benign tumours do not usually develop into cancer and doctors do not usually remove them.

Risk factors and causes

We do not know the exact cause of HCC. But certain things called risk factors can increase a person's chance of developing it. Having one or more risk factors does not mean you will get cancer. And not having any risk factors does not guarantee that you will not.

Risk factors for HCC include the following.

Age

HCC is more common as people get older. Most people diagnosed are over the age of 65.

Sex

HCC is more common in men than in women.

Smoking

People who smoke tobacco have a higher risk of developing HCC than non-smokers.

Hepatitis infection

Long-term infection with the hepatitis B virus (HBV) or hepatitis C virus (HCV) can cause HCC.

Cirrhosis

People who have cirrhosis have a higher risk of developing HCC. Cirrhosis is scarring all over the liver. It damages the liver and stops it working properly.

The risk factors for cirrhosis include the following.

Alcohol

Drinking a lot of alcohol over a long period of time can cause cirrhosis.

Non-alcoholic fatty liver disease

This is when fat builds up in the liver and causes damage.

Haemochromatosis

This is an inherited condition that causes iron levels to build up in the body. If diagnosed and treated early, it does not usually cause problems.

Primary biliary cirrhosis (primary biliary cholangitis)

This is when the body’s immune system, which normally fights infection, slowly destroys the small bile ducts in the liver (see page 9). Bile ducts are the tubes that connect the liver and gall bladder to the small bowel.

Diabetes

People with Type 2 diabetes have a higher risk of developing HCC.

Metabolic syndrome

People with metabolic syndrome have a higher risk of developing HCC.

Metabolic syndrome is a group of conditions that happen together. They include:

- high blood pressure
- high blood sugar levels
- high levels of unhealthy fats (triglycerides) in the blood
- extra fat around the tummy area (abdomen).

Family history

Having a close family member (father, mother, sister or brother) with primary liver cancer increases a person's risk of developing it. Doctors are not sure why this is.

Anabolic steroids

Taking anabolic steroids over a long period of time slightly increases the risk of developing HCC. These are mainly used by bodybuilders.

Mouldy peanuts and grains

A poison called aflatoxin, found in mouldy peanuts and grains, is a major risk factor for HCC in parts of Africa and Asia.

Symptoms

In the early stages of primary liver cancer (HCC), there are often no symptoms. If you have long-term (chronic) liver disease, you may have regular tests to check the liver. If you develop HCC, these tests may find it before you have any symptoms.

Possible symptoms include:

- loss of appetite and feeling full soon after starting to eat
- weight loss
- feeling sick (nausea) and being sick (vomiting)
- tiredness (fatigue)
- aching or pain on the right side of the tummy (abdomen) near the ribs, and sometimes in the right shoulder
- a high temperature and flu-like symptoms, such as aching all over
- a swollen tummy, which may be caused by fluid build-up (ascites)
- the skin and whites of the eyes looking yellow (jaundice)
- bruising or bleeding easily.

These symptoms can be caused by other conditions. But it is important to get them checked by your doctor or nurse. It is especially important to get them checked if you have risk factors for liver cancer.

DIAGNOSING PRIMARY LIVER CANCER

How primary liver cancer is diagnosed

You will usually start by seeing your GP. They will ask about your symptoms and examine you.

Your GP will usually take blood samples to check your general health. They may arrange other tests, such as an ultrasound. They will also refer you to a hospital for specialist advice. If your GP suspects you may have cancer, you should see a specialist within two weeks.

If you have long-term liver disease, you may have regular blood tests and ultrasound scans to check your liver. If you develop hepatocellular carcinoma (HCC), these tests may find the cancer at an earlier stage.

At the hospital

You may see a liver specialist (hepatologist) straight away. Or you may see a doctor who specialises in treating conditions of the stomach and bowel (gastroenterologist).

They will ask about your symptoms and your general health. They will also check whether you have risk factors for liver disease. The doctor will examine you by feeling your tummy area (abdomen). They may take some blood samples and explain which other tests you need.

Blood tests

You will have blood tests called liver function tests (LFTs). These check how well your liver is working. You will also have a blood test to check for a chemical called alpha-fetoprotein (AFP). AFP is called a tumour marker for HCC. This is because the level of it is sometimes higher in people with this type of liver cancer. But the level of AFP can also be higher if you have Hepatitis C.

Doctors may also check the AFP level after treatment. This is to check for signs of the cancer coming back (recurrence).

Liver ultrasound scan

A liver ultrasound scan uses sound waves to build up a picture of the liver. The doctors use it to look for the size and location of any tumours. It also shows them the health of the liver.

This test is painless and only takes a few minutes. It is done in the hospital scanning department.

You will be asked not to eat anything for at least 4 hours before your appointment.

You lie on your back and the person doing the ultrasound spreads a gel on your tummy area. They pass a small device, which produces sound waves, over the area. A computer then uses these sound waves to build a picture of your liver.

CT scan

A CT scan makes a three-dimensional (3D) picture of the inside of the body using x-rays taken by the CT scanner. It uses a small amount of radiation. This is very unlikely to harm you. It will not harm anyone you come into contact with.

You will get an appointment letter telling you if you need to do anything before the scan. You may be asked not to eat or drink for a few hours before the scan. If this is a problem for you, call the number on your appointment letter.

You have the scan at the hospital. The person who works the scanner is called a radiographer. They help you prepare for the scan. You may have a drink or injection of a dye. This is called a contrast. It helps show certain areas of the body more clearly. The contrast may make you feel hot all over for a few minutes. It is important to let your doctor know if you are allergic to iodine or have asthma. This is because you could have a more serious reaction.

The scan takes 5 to 10 minutes, but you may be in the department for longer. You will lie very still on a narrow bed. The bed moves slowly back and forward through the donut-shaped scanner.

Having a CT scan

MRI (magnetic resonance imaging) scan

An MRI scan uses magnetism to build up a detailed picture of areas of your body.

The scanner is a powerful magnet. You will be asked to complete and sign a checklist to make sure it is safe for you. The checklist asks about any metal implants you may have, such as a pacemaker or surgical clips. You should also tell your doctor if you have ever worked with metal or in the metal industry. Tiny fragments of metal can sometimes lodge in the body.

You have the scan in the x-ray department at the hospital. A person called a radiographer works the scanner. They may give you an injection of a dye, called a contrast. It helps show certain areas of the body more clearly.

During the test, you need to lie very still on a bed inside a long cylinder (tube). If you are worried about feeling claustrophobic, you may be able to have a sedative to help you relax. Talk to your GP or doctor about this before the scan.

The scan takes 15 to 90 minutes. It is painless but you may find it uncomfortable to lie still for that long. After the scan is finished you can usually go home.

Liver biopsy

You may have a small piece of tissue taken from the liver to be looked at under a microscope. This is called a liver biopsy.

Your doctor may take the biopsy from a growth in the liver to help diagnose a cancer. Sometimes you have a biopsy taken from the liver itself. This can help to check the health of the liver (how well it is working). Not everyone needs a biopsy. Doctors can often diagnose HCC with scans. Or they may diagnose it after surgery to remove the tumour.

You will have blood tests before the biopsy to make sure your blood is clotting properly. When you have the biopsy, you will have a local anaesthetic injection into the skin to numb the area. The doctor then passes a fine needle through the skin and into the tumour. A CT or ultrasound scan guides the doctor to the exact area to take the biopsy from.

After a liver biopsy you will need to stay in hospital for a few hours, or sometimes overnight. This is because there is a small risk of bleeding afterwards. The nurses will check you regularly and monitor your blood pressure. This is to make sure there is no bleeding and that it is safe for you to go home. You may have some pain in your tummy and right shoulder after the biopsy. Your doctor can prescribe painkillers for you.

There is a small risk of the cancer cells spreading when the doctor removes the biopsy needle. Your specialist will talk to you about this.

PET-CT scan

A PET scan uses low-dose radiation to check the activity of cells in different parts of the body. It is sometimes given together with a CT scan. This is called a PET-CT scan. It can give more detailed information about cancer or abnormal areas seen on x-rays, CT scans or MRI scans. PET scans are not suitable for everyone. Your doctor or specialist nurse can tell you whether they might be helpful for you.

PET scans are not available at all hospitals, so you may have to travel to a specialist centre to have one. If you are pregnant or breastfeeding, you should phone the scanning department before the test for advice.

About an hour before the scan, the radiographer will inject a radioactive substance into a vein, usually in the arm. This is called a tracer. While you wait to have the scan, you will be encouraged to drink. Drinking water helps move the tracer around your body. Very rarely, some people are allergic to the tracer. This can make them feel breathless, sweaty or weak. Tell the radiographer straight away if you feel unwell.

The person who works the scanner is called a radiographer. The scan takes about 30 to 60 minutes. You will lie on a narrow bed. The bed moves slowly back and forward through the donut-shaped scanner. You can usually go home after the scan. The amount of radioactive substance used is very small. But you will be advised not to have close contact with pregnant women, babies and young children for up to 24 hours after the scan.

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or a support organisation can also provide support (see pages 120 to 127). You may find it helpful to talk to one of our cancer support specialists on **0808 808 00 00** (7 days a week, 8am to 8pm).

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out.

Staging

The stage of a cancer describes its size and whether it has spread from where it first started. Knowing the stage of the cancer helps you and your doctors decide on the best treatment for you.

There are several systems used to stage HCC. Many doctors use combination staging systems based on:

- the size of the tumour
- the number of tumours in the liver
- how well the liver works (measured by the Child-Pugh scale, CPS)
- whether the cancer is affecting your activities (doctors call this performance status, PS).

The TNM staging system

- T describes the size of the tumour.
- N describes whether the cancer has spread to the lymph nodes.
- M describes whether the cancer has spread to another part of the body (known as metastatic or secondary cancer).

This system gives detailed information about the tumour stage. Numbers are added after T, N, and M. These give more details about each of these factors. Higher numbers mean the cancer is more advanced.

Child-Pugh classification

Doctors assess how well your liver is working using the Child-Pugh classification (CPC) system.

This looks at:

- the level of a waste product (called bilirubin) in the blood
- the level of a protein (called albumin) in the blood
- how quickly your blood clots
- whether there is any build-up of fluid in the tummy area (abdomen), called ascites
- whether liver damage is affecting how the brain is working (encephalopathy).

Based on this, people fall into 1 of 3 groups:

- A – the liver has some damage, but it is working normally.
- B – there is some damage to the liver, affecting how well it works.
- C – the liver is very damaged and not working well. It may not be able to cope with treatment for the cancer.

Performance status (PS)

Performance status (PS) is a scale to rate how well you are:

- PS 0 – you are fully active and can do much as you did before your illness.
- PS 1 – you cannot do heavy physical work, but can do everything else.
- PS 2 – you are up and about for more than half the day. You can look after yourself but cannot work.
- PS 3 – you have troublesome symptoms and are in bed or a chair for more than half the day. You need help to look after yourself.
- PS 4 – you are in bed or a chair all the time and need complete care.

Barcelona Clinic Liver Cancer (BCLC) staging system

This system considers the extent of the cancer, how well your liver is working (CPC) and how well you are (PS).

It has five stages:

- **Stage 0** – There is one tumour in the liver that is smaller than 2cm across. Your liver is working normally, and you are very well.
- **Stage A** – There is one tumour in the liver that is smaller than 5cm across. Or, there are up to three tumours that are smaller than 3cm across. Your liver is working normally, and you are very well.
- **Stage B** – There are many tumours in the liver. You are well, and your liver is working normally.
- **Stage C** – You are not as well. There is some damage to your liver, or the cancer has spread into main blood vessel of the liver. Or, the cancer has spread to nearby lymph nodes or other parts of your body.
- **Stage D** – You are not well, and your liver is not working well. You may have symptoms caused by liver damage such as a build-up of fluid in the tummy area (abdomen).

Early, intermediate or advanced

For the stages of HCC, you may also hear the terms:

- very early
- early
- intermediate
- advanced.

These terms are less specific than those used in the scientific staging systems. But the stages of the BCLC system can help explain them:

- stage 0 is very early
- stage A is early
- stage B is intermediate
- stages C and D are advanced.

TREATING PRIMARY LIVER CANCER

Treatment overview

The treatment you have usually depends on:

- where the cancer is in the liver
- the size of the tumour or tumours
- how many tumours there are
- whether the cancer has spread outside the liver
- whether any important blood vessels in the liver are affected
- how well your liver is working
- your general health.

Surgery may cure hepatocellular carcinoma (HCC) – see pages 44 to 54. This may involve a liver transplant or an operation to remove part of the liver. But often, surgery is not possible. This might be because the cancer is too advanced, or the liver is too damaged to cope with surgery.

Some people have tumour ablation (see pages 55 to 57). This is where a doctor applies heat to the cancer cells to destroy them. This may be used instead of surgery. It works well with small tumours.

Chemoembolisation is when you have chemotherapy directly into the liver and the blood supply to the tumour is cut off (see pages 58 to 60). Doctors may recommend this when the cancer is advanced in the liver but has not spread outside it. It may help to control the cancer and help you live for longer. Another treatment called radioembolisation works in a similar way (see pages 60 to 61). It uses radiation instead of chemotherapy to destroy cancer cells.

Some people have a type of high-dose radiotherapy that closely targets tumours in the liver. This is called stereotactic ablative radiotherapy. It is used to try to control areas of cancer in the liver. Radiotherapy can also be used to ease symptoms such as pain (see pages 73 to 74). You may have this treatment if the cancer has spread to another part of the body, such as the bones. This is called palliative radiotherapy.

Doctors may use a targeted therapy drug if the cancer is advanced in the liver or has spread outside it (see pages 62 to 64). Less commonly chemotherapy (see pages 65 to 72) may be used. You have these treatments to try to:

- control the cancer
- reduce symptoms
- help you live for longer.

Doctors are looking at newer treatments and different ways of giving treatments. Your cancer doctor may talk to you about taking part in a research trial.

If you decide not to have treatment, there is a still a lot that can be done to control symptoms and support you (see pages 75 to 85). Your cancer doctor can refer you to a team of doctors and nurses who specialise in controlling symptoms. This is called a palliative care team. We have more information about this in our booklet **Coping with advanced cancer** (see page 116).

How your treatment is planned

After your test results, you and your doctor start to talk about your treatment. Your doctor usually meets with other specialists to get their opinions too.

Multidisciplinary team (MDT) meeting

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT).

The MDT look at national treatment guidelines or the latest evidence for the type of cancer you have. If you have any treatment preferences, your doctor will tell them about this.

The MDT will usually include a:

- a hepatologist – a doctor who specialises in liver disease
- a surgeon who specialises in liver cancers
- a medical oncologist – a doctor who specialises in giving chemotherapy
- a clinical oncologist – a doctor who specialises in giving radiotherapy and chemotherapy
- an interventional radiologist – a doctor who uses imaging to help them give treatments such as ablation or embolisation
- a nurse specialist
- radiologists – who help to analyse x-rays and scans
- pathologists – who advise on the type and spread of the cancer.

It may also include:

- a palliative care doctor or nurse who specialises in symptom control
- a dietitian
- a physiotherapist
- an occupational therapist (OT)
- a psychologist or a counsellor.

Talking about your treatment plan

After the MDT meeting, you will usually see your specialist doctor and nurse. They will talk to you about your treatment plan. It can help to write down your questions before you see them. You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards. You need to know as much as possible before you can make any treatment decisions.

Your specialist doctor should explain:

- the aim of the treatment – whether it is to cure the cancer or control it
- the benefits of the treatment
- the disadvantages of the treatment – for example, the risks and side effects
- any other treatments that may be available
- what may happen if you do not have the treatment.

Cancer treatments can be complex. It can also be hard to concentrate on what you are being told if you are feeling anxious. If the doctor says something you do not understand, ask them to explain it again.

Most people worry about the side effects of treatment. Your doctor or nurse will explain how side effects can be controlled and what you can do to manage them. They can also tell you if your treatment is likely to cause any late effects and how these can be managed.

You may need more than one meeting with your doctor or nurse to talk about your treatment plan.

Making treatment decisions

You and your doctor can decide together on the best treatment plan for you. Your doctor is an expert in the best treatments. But you know your preferences and what is important to you. You can decide how involved you want to be in your treatment plan.

Sometimes doctors need to review a treatment plan. This may be when more information about the cancer becomes available – for example, when the doctor knows the results of surgery to remove the cancer. It may mean making more decisions with your doctor.

Choosing between treatments

Doctors sometimes ask you to choose between different treatments. This is usually when two treatments work equally well.

It can help to talk to your family or friends about your treatment options. Your doctor or nurse can help you with your decision. You do not usually need to decide straight away.

You could write a list of benefits and disadvantages for each treatment. When choosing a treatment, you may want to think about:

- how long you need to have it for
- how it may affect your everyday life
- how much time you will need to spend in hospital
- the different side effects and how they are likely to affect you.

Your doctor or nurse may give you printed information or show you videos about your treatment options. They may also show you web-based tools (decision-making aids) to help you make your decision.

We have more information about this in our booklet **Making treatment decisions** (see 116).

Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your specialist doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your specialist doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website. Visit **macmillan.org.uk**

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan.

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken (verbal) agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

Clinical trials

Clinical trials are medical research studies involving people. Doctors may use cancer clinical trials to:

- test new treatments to see if they work better than current treatments
- find which treatments have fewer side effects
- find new ways to combine treatments to see if they work better
- test new cancer drugs to find out more about them and their side effects
- improve the way treatments are given to try to reduce side effects.

Results from clinical trials can improve cancer treatments and help people live longer. Trials can also look at improving things like diagnosis and symptom management.

Taking part in a trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you. Usually, cancer clinical trials happen in several hospitals around the country. You may have to travel to take part in a trial.

A research nurse or doctor will give you information about the trial. It is important to understand what is involved before you agree (consent) to take part. You can ask the research nurse or doctor any questions you have.

They will also explain the possible benefits and any possible risks of the trial. Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

If you decide not to take part in a trial, your cancer doctor and specialist nurse will respect your decision. You do not have to give a reason for not taking part. Your decision will not change your care. Your cancer doctor will give you the standard treatment for the type and stage of cancer you have.

We have more information about cancer clinical trials in our booklet **Understanding cancer research trials (clinical trials)** – see page 116.

Giving blood and tissue samples

During your diagnosis and treatment doctors often take blood samples. They may also take a small piece of tissue or a sample of cells. These tissue samples are called biopsies. The samples can be looked at under a microscope. Your cancer doctor may ask your permission to store and use these blood or tissue samples for cancer research. This will only happen after they have done all the tests you need.

Your samples can only be stored for research if you give your consent. Your cancer doctor can answer any questions you have.

Your name is removed from the samples before they are stored. This means you cannot be identified.

The samples may be used to:

- find out more about the causes of certain cancers
- develop new cancer drugs or treatments.

This type of research takes a long time. The results may not be available for many years.

Surgery for primary liver cancer

Surgery is the most effective treatment for hepatocellular carcinoma (HCC). The type of operation you have depends on the number of tumours in the liver and how damaged the liver is from chronic liver disease. Only a small number of people with HCC can have surgery.

There are two types of operation:

- a liver transplant – the surgeon removes your liver and replaces it with a liver from another person (a donor)
- a liver resection – the surgeon removes the part of your liver where the cancer is.

Your surgeon and specialist nurse will tell you whether surgery is an option for you. They will explain what it involves and the possible complications or risks. An operation to your liver is major surgery. It is important to have all the information you need before you decide.

> ‘I was put on the liver transplant list and had a transplant 8 months later. I’m 4 years post-transplant now. It’s not been trouble free but the cancer has not come back.’

Martyn, diagnosed with primary liver cancer

Liver transplant

The most common reason for a liver transplant is that you have liver disease which is too advanced for other treatments. A liver transplant is only suitable for some people with HCC. It can only be done if you have:

- a single tumour that is 5cm across or smaller
- a single tumour that is between 5 and 7cm across, which does not grow over 6 months
- up to five tumours that are 3cm across or smaller.

You need to be quite fit to cope with a transplant. Your liver team will assess you very carefully to make sure it is a suitable treatment for you. Your specialist also needs to be sure that the cancer cells have not spread.

It can take time, sometimes months, for a donor liver to become available. You may have other treatments to help control the cancer during this time. Sometimes, the cancer may progress and a transplant is no longer possible.

It may be possible to have part of a liver transplanted from a living donor. This is a newer type of operation and is only available in a few hospitals. The donor has surgery to remove a lobe of their liver. This is transplanted into you after your diseased liver is removed.

After a transplant, you need to take drugs called immunosuppressants for the rest of your life. These stop your body from rejecting the new liver. But they also make your immune system weaker. This means it may be less able to fight any cancer cells that have spread.

Recovering from a liver transplant takes a long time. It will take time to build up your health and fitness. It can take many months before you get back to doing everyday activities.

We have not provided detailed information about your care before or after a liver transplant. Your liver team will talk to you about what to expect before and after the operation.

Liver resection

This operation is usually suitable for people who:

- have only one tumour or a limited number of tumours
- do not have cirrhosis or only have early-stage cirrhosis.

The surgeon removes the part of the liver where the cancer is. The amount of liver they remove depends on the size and position of the tumour or tumours. They may remove:

- only a small part of the liver
- a whole lobe of the liver (called a hemi-hepatectomy).

But your liver needs to be working well so that the remaining liver can cope after the operation. There are not usually any long-term side effects after a liver resection. This is because the remaining liver can grow bigger and work as it did before. This takes about 4 to 6 weeks. But you do not need to be in hospital while this happens.

In some hospitals, the surgeon may do a resection using keyhole surgery (laparoscopic surgery). Some people also have ablation treatment during surgery (see pages 55 to 57). This uses heat to destroy cancer cells.

Before your operation

If you smoke, try to give up before your operation. This will help reduce your risk of problems, such as a chest infection. It will also help your wound heal after the operation. Your GP can give you more advice. We have more information about giving up smoking on our website. The NHS also has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live.

You will have tests to make sure you are well enough to cope with the operation. You usually have these a few days before your operation at a pre-assessment clinic. They include tests on your heart and lungs.

You will see a member of the surgical team and a specialist nurse who will talk to you about the operation. You may see the doctor who gives you the anaesthetic (the anaesthetist) at a clinic or when you are admitted to hospital.

Make sure you talk to your team about any questions or concerns you have about the operation. If you think you might need help when you go home, tell the nurses as soon as possible. This means the staff can help you to make plans in plenty of time.

You will usually be admitted to hospital on the morning of your operation. You will be given special compression stockings (TED stockings) to wear during and after the operation. This is to prevent blood clots forming in your legs.

Enhanced recovery

Some hospitals have an enhanced recovery programme for certain types of surgery. Enhanced recovery programmes aim to reduce the time you spend in hospital and help you to recover as quickly as possible.

For example, you may be given a diet plan to follow and exercises to do before surgery. You may be given supplement drinks to take too. This is to make sure you are as healthy as possible. It is sometimes called prehabilitation.

After surgery, the nurses will get you out of bed and encourage you to start drinking and eating as soon as possible. Research has shown that this can help improve your recovery time.

After your operation

After a liver resection, you will be in intensive care or a high-dependency unit for about 24 hours. If you have a liver transplant, you will usually be in intensive care for a few days.

This is normal after major operations. There is a risk the liver may bleed after surgery. The doctors and nurses will check this by taking your blood pressure regularly.

Moving around

The nurses will encourage you to start moving around as soon as possible. They will usually help you get out of bed the day after your operation or sooner. While you are in bed, it is important to move your legs regularly and do deep breathing exercises. This helps prevent chest infections and blood clots. Your physiotherapist or nurse will show you how to do the exercises.

Pain

There are effective ways to prevent and control pain after surgery. For the first few days you are usually given painkillers through a pump. This gives you a constant dose of the painkillers.

The painkillers can be given in the following ways:

- through a thin tube in your back (epidural)
- into a vein
- into the tissue close to your wound.

You may have a button you can press to give yourself an extra dose of painkillers if needed. This is called patient-controlled analgesia (PCA). It is set so that you cannot have too much painkiller.

When you no longer need painkillers through a pump, you can take them as tablets. Tell your nurses and doctors if you are in pain. They can give you the dose of painkillers that is right for you.

Your wound

For the first few days after surgery, you may have a dressing over your wound(s). The nurses will check your wound regularly to make sure it is healing well. You will usually have stitches that dissolve. But if you need to have any stitches or staples removed, these can be taken out after 10 days (or about 3 weeks if you had a liver transplant). A nurse can do this in your own home or at your GP surgery.

Always tell your doctor if your wound becomes hot, painful or starts to leak fluid.

Going home

After a liver resection most people can go home:

- 5 to 7 days after open surgery, where you will have one large wound
- 2 to 3 days after laparoscopic (keyhole) surgery for a smaller liver resection
- 4 to 5 days after laparoscopic (keyhole) surgery for a bigger liver resection.

After a liver transplant, you will usually stay in hospital for 2 or 3 weeks. When you go home, you will have regular checks to make sure your body is not rejecting the new liver.

You will need painkillers for the next few weeks. It may take up to 3 months after a resection before you start getting back to normal. For at least 8 weeks, you need to avoid lifting heavy loads, such as shopping or laundry. You will also need to avoid activities like vacuuming or gardening. This is to give your wound time to heal. Your specialist will tell you when you should be able to drive again.

Recovery takes longer after a transplant. Your doctor or nurse will tell you what to expect.

> ‘I had radiofrequency ablation on a couple of liver lesions. It was successful as they haven’t returned and it has been almost 5 years now.’

Siobhan, diagnosed with primary liver cancer

Make sure you get enough rest and eat well. This will help your recovery. Your liver specialist will advise you not to drink alcohol for about 3 months. This is because your liver is growing to replace what has been lost. After a transplant, you need to avoid drinking alcohol and smoking.

Gentle exercise, such as regular short walks, will help build up your energy. You can gradually do more as you recover. It is usually fine to have sex when you feel ready. To begin with, you may be too tired or your sex drive may be low. This should improve with time.

Some people take longer than others to recover. It depends on your situation, so do not put pressure on yourself.

Your check-up will be at the out-patient clinic. Your doctor will ask you about your recovery and talk to you about the results of your operation. This is a good time for you to tell them about any problems you have had. Remember that you can contact your doctor or nurse before your appointment if you are unwell or worried about anything.

Tumour ablation

Tumour ablation means destroying the tumour by applying heat, cold or alcohol directly to it. Tumour ablation can be used to treat small tumours in the liver, usually smaller than 4cm across.

It may be used:

- instead of surgery for small tumours
- if you cannot have surgery, or choose not to have surgery
- after other treatments, such as surgery (see pages 44 to 54) and chemotherapy (see pages 65 to 72).

Tumour ablation can be done:

- during a laparoscopy
- during a liver resection
- as an injection with a needle through the skin (percutaneously).

Your liver specialist will explain if this type of treatment may be suitable for you. If your doctor thinks ablation may help you, they can refer you to a hospital that does this treatment. Ablation treatments are only available in some specialist hospitals, so you may have to travel for treatment.

We have more information about radiofrequency ablation, microwave ablation and cryotherapy on our website. Visit **macmillan.org.uk**

Types of ablation

Types of ablation include:

- microwave ablation
- radiofrequency ablation
- cryotherapy
- laser ablation
- percutaneous ethanol injection
- irreversible electroporation (IRE).

What happens during ablation?

Ablation is usually done under a general anaesthetic. The doctor puts a fine needle through the skin over the liver and into the centre of each tumour. They use an ultrasound or CT scan to guide them to treat the tumours using ablation:

- Radiofrequency, microwave or laser ablation produces heat, which passes through the needle and into the tumour.
- Irreversible electroporation uses a high voltage current to destroy tumours. It does not heat the nearby tissue and so is useful for tumours that are close to vessels or bile ducts.
- Cryotherapy produces very low temperatures, which freeze the tumour.

You may need to stay in hospital overnight. Afterwards, you will have 1 to 3 tiny holes in your tummy area (abdomen). These usually heal quickly. You usually have a CT scan a few weeks after ablation to see how well it has worked.

Percutaneous ethanol injection (PEI)

This is another type of ablation that works in a different way. The doctor injects pure alcohol (ethanol) through the skin and into the tumour. The alcohol destroys the cancer cells.

You have this done in the scanning department. The doctor gives you a local anaesthetic to numb the area. They use an ultrasound scan to help guide the needle into the tumour. You usually need several treatments, depending on the number of tumours and their size. If the tumour grows, you can have the treatment again.

Side effects of ablation

The side effects of ablation are usually mild and may last up to a week. You may have pain in the liver area. You can control this by taking regular painkillers. Other side effects include:

- a fever (high temperature)
- tiredness
- feeling generally unwell.

These side effects happen because the body is getting rid of the cells that have been destroyed. Try to drink plenty of fluids and get enough rest. Your doctor or nurse may ask you to contact the hospital if your temperature:

- does not go back to normal after a few days
- goes above 38°C.

These may be signs that you have an infection.

Embolisation treatments

Embolisation is a way of blocking the blood flow to the cancer in the liver. A substance is injected into a blood vessel in the liver. This reduces the supply of oxygen and energy to the cancer, which can make it shrink or stop growing.

Embolisation can be given in combination with:

- chemotherapy (called chemoembolisation)
- radiation (called radioembolisation or SIRT).

These treatments can be used when the cancer cannot be removed with surgery (see pages 44 to 54) or treated with ablation (see pages 55 to 57). Sometimes they are used before surgery or ablation. They are not used if the cancer has spread outside the liver.

Chemoembolisation

In chemoembolisation, a chemotherapy drug is injected directly into the liver. This means the tumour gets a stronger dose of the drugs. You will then have an injection into the blood vessels that carry blood to the liver (arteries). The injection blocks the arteries and cuts off the blood supply to the tumour (embolisation).

Chemoembolisation is sometimes called TACE (trans-arterial chemoembolisation) or CT-ACE (computerised tomography-guided arterial chemoembolisation).

The drugs most often used are doxorubicin and cisplatin.

How it is given

You may need to stay in hospital for 1 to 2 nights. Before the treatment, the nurse or doctor will usually give you a mild sedative to help you relax. They then inject some local anaesthetic into the skin at the top of your leg (your groin) to numb the area. After this, the doctor makes a tiny cut in the skin. They put a fine tube called a catheter through the cut and into a blood vessel in your groin (the femoral artery).

The doctor passes the catheter along the artery, until it reaches the blood vessels that take blood to the liver and tumour. You have an x-ray of the blood vessels at the same time This is called an angiogram. A dye is put into the blood vessel through the catheter. This shows the blood supply on the x-ray so the doctor can see where the catheter is. After this, they slowly inject the chemotherapy into the liver through the catheter. The doctor then injects a gel or tiny plastic beads to block the blood supply to the tumour. The beads may contain a chemotherapy drug.

You can have chemoembolisation several times. You will sometimes have it with radiofrequency ablation (see pages 55 to 57). Your doctor can explain this treatment to you in more detail.

Side effects

Chemo-embolisation can cause side effects such as:

- a high temperature
- pain in the upper right side of the abdomen
- feeling sick (nausea)
- feeling very tired (fatigue).

You will be given anti-sickness drugs and painkillers until the side effects get better. This usually takes 1 to 2 weeks.

It is unusual for chemotherapy given in this way to cause side effects outside of your liver. Serious complications are rare, but sometimes it can damage the liver.

Radioembolisation

Radioembolisation is sometimes called SIRT (selective internal radiotherapy).

It is done less often than chemoembolisation. It is not available in all hospitals.

> **‘There’s some nausea and some light fever. I was able to take care of myself when I got back home and was back to “normal” in about a week or two.’**
>
> **Martyn, who had chemoembolisation treatment**

How it is given

You will usually stay in hospital for 1 to 4 days to have this treatment.

A doctor injects tiny radioactive beads (microspheres) into a blood vessel close to the tumour. The radiation destroys the blood vessels and stops blood flow to the tumours. Without a blood supply, the tumours shrink and may die. The radiation only travels a few millimetres. This means that other parts of the liver are not affected and it does not make you radioactive. The beads stay in the liver permanently and are harmless.

You have radioembolisation through a fine tube (catheter) that is put into an artery in your groin. This is done in the same way as chemoembolisation. You have an angiogram about a week before the treatment, to check blood flow to the liver.

Side effects

Side effects can last for a few days and include:

- a high temperature
- tummy pain
- feeling sick (nausea)
- diarrhoea.

Your doctor will prescribe drugs to control these until they go away. Serious complications are rare, but sometimes radioembolisation can damage the liver.

It takes about 1 to 4 months for the tumour to shrink after radioembolisation.

We have more information about radioembolisation (SIRT) on page 74.

Targeted therapy

There are many different types of targeted therapy. Each type targets something in or around the cancer cell that is helping it grow and survive.

The most commonly used targeted therapy drugs for primary liver cancer (HCC) are:

- sorafenib (Nexavar®)
- lenvatinib
- regorafenib (Stivarga®).

Sorafenib and lenvatinaib can be used to treat HCC that is advanced or has spread to other parts of the body.

Regorafenib can be used if you have had sorafenib and need more treatment.

Other targeted therapy drugs may be used in clinical trials (see pages 42 to 43).

Targeted therapy drugs may help to slow the growth of the tumour and relieve symptoms. Doctors usually prescribe them for as long as they work well for you.

Always tell your doctor or nurse about any side effects you have. They can give you drugs to help control them and advice about managing them. For most people, the side effects are mild or moderate and get better after a few weeks. Sometimes side effects may be more severe, or may not go away after treatment finishes.

Side effects

Possible side effects of targeted therapy drugs include the following.

Diarrhoea

This is usually mild, but tell your doctor or nurse if you have diarrhoea. Your doctor can give you drugs to control it if it does not improve. It is important to drink plenty of fluids if you have diarrhoea.

Sore palms and feet

The skin on the palms of your hands and soles of your feet may get sore and red. Tell your cancer doctor or nurse if this happens, and if it gets worse.

Skin changes

You may get a rash, or notice that your skin is red, dry or itchy. Tell your doctor or nurse if this happens. They can advise you about creams or lotions to use.

Feeling sick

Any sickness (nausea) is usually mild, but tell your doctor if this happens. They can give you drugs to control the sickness. Try to eat lots of small meals or snacks regularly if you do not have much appetite.

Tiredness and lack of energy

It is important to get the right balance between having enough rest and being physically active. Going for regular, short walks will help you to feel less tired.

We have more information about tiredness in our booklet **Coping with fatigue** (see page 116).

Hair thinning

Some people notice that their hair becomes thinner while taking these drugs. This is usually mild.

Raised blood pressure

This treatment may cause your blood pressure to rise. Tell your doctor or nurse if you have ever had any problems with your blood pressure. Your nurse can check it regularly during your treatment.

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. Chemotherapy for primary liver cancer (HCC) is usually given directly into the blood vessel that carries blood to the liver (the hepatic artery). It is often used together with a treatment that blocks the blood supply to the tumour. This is called chemoembolisation (see pages 58 to 60).

This information is about chemotherapy given into a vein (intravenously) or taken by mouth as tablets. This is a less common way of treating HCC. It can be used to try to control the tumour and reduce symptoms. It is not suitable for everyone because the liver may not be working well enough to cope with chemotherapy drugs.

Chemotherapy drugs that may be used include:

- doxorubicin
- cisplatin
- fluorouracil (5FU) with oxaliplatin
- gemcitabine with oxaliplatin called GEMOX
- capecitabine.

How chemotherapy is given

Chemotherapy is usually given into a vein (intravenously) or taken by mouth as tablets.

Your doctor or nurse will tell you how you will have chemotherapy.

You usually have chemotherapy on one or more days, followed by a rest period of a few weeks. This is called a cycle of treatment. The rest period lets your body recover from the side effects before you start your next treatment cycle.

Your doctor or nurse will tell you how many cycles of treatment you will have.

Side effects

This information describes the main side effects that may be caused by having chemotherapy into a vein or as tablets. If you are having chemotherapy directly into the liver (intra-hepatic chemotherapy), the side effects will be different. The side effects depend on which chemotherapy drugs you have. Different drugs cause different side effects.

Some side effects are mild and easy to treat. Others can be harder to manage but can often be reduced or helped in some way. Most side effects stop or slowly go away when chemotherapy finishes. Chemotherapy can also make you feel better by relieving the symptoms of the cancer.

Your doctor or nurse will tell you about the side effects you may have.

Risk of infection

This treatment can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is called neutropenia.

Your doctor may give you antibiotics and other drugs to try to stop you getting an infection. These are called prophylactic medicines.

If you have an infection, it is important to treat it as soon as possible. Contact the hospital straight away on the 24-hour contact number you have if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- diarrhoea
- needing to pass urine often.

It is important to follow any specific advice your cancer treatment team gives you.

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time.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Bruising and bleeding

This treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. Tell your doctor if you have any bruising or bleeding that you cannot explain. This includes:

- nosebleeds,
- bleeding gums
- tiny red or purple spots on the skin that may look like a rash.

Some people may need a drip to give them extra platelets. This is called a platelet transfusion.

Anaemia (reduced number of red blood cells)

This treatment can reduce the number of red blood cells in your blood. These cells carry oxygen around the body. If the number of red blood cells is low, you may be tired and breathless. Tell your doctor or nurse if you feel like this. If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Feeling tired

Feeling tired is a common side effect. It is often worse towards the end of treatment and for some weeks after it has finished. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy. If you feel sleepy, do not drive or operate machinery.

Feeling sick

You may feel sick in the first few days of your treatment. The nurses will give you anti-sickness drugs regularly. If you still feel sick, tell your nurse or doctor. They can change the anti-sickness drug to one that works better for you.

Sore mouth

You may get a sore mouth or mouth ulcers. This can make you more likely to get a mouth infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

If your mouth is sore:

- tell your nurse or doctor – they can give you a mouthwash or medicines to help
- try to drink plenty of fluids
- avoid alcohol, tobacco, and foods that irritate your mouth.

Diarrhoea

This treatment may cause diarrhoea. Diarrhoea means passing more stools (poo) than is usual for you, or having watery or loose stools. If you have a stoma, it will be more active than usual.

If you have diarrhoea:

- try to drink at least 2 litres (3½ pints) of fluids each day
- avoid alcohol, caffeine, milk products, high-fat foods and high-fibre foods
- contact the hospital for advice.

Changes to your taste

You may get a bitter or metal taste in your mouth. Sucking sugar-free sweets may help with this. Some foods may taste different or have no taste. Try different foods to find out what tastes best to you. Taste changes usually get better after treatment finishes. Your nurse can give you more advice.

Helpful hints to improve taste

- Season food or add spices and herbs to add flavour when cooking.
- Use strong, flavoured sauces or gravies to make food tastier.
- Eat sharp-tasting fresh fruit and juices or try sugar-free sweets to leave a pleasant taste in your mouth.
- Try cold foods as they may have a stronger taste than hot foods.

Hair loss

Some chemotherapy drugs may cause hair loss. Some people may have complete hair loss including eyelashes and eyebrows. Others may only experience partial hair loss or thinning. It depends on what chemotherapy drugs you are having (your doctor or nurse can tell you more about what to expect).

If you do experience hair loss your hair should start to grow back within about 3 to 6 months of the end of treatment. It may grow back straighter, curlier, finer, or a slightly different colour than it was before. Your nurse can give you advice about coping with hair loss and how to look after your scalp.

Some chemotherapy departments may offer scalp cooling to reduce hair loss during chemotherapy. We have more information about this in our booklet **Coping with hair loss** (see page 116).

Numb or tingling hands or feet (peripheral neuropathy)

This treatment affects the nerves, which can cause numb, tingling or painful hands or feet. You may find it hard to fasten buttons or do other fiddly tasks.

Tell your doctor if you have these symptoms. They sometimes need to lower the dose of the drug. The symptoms usually improve slowly after treatment finishes, but for some people they may never go away. Talk to your doctor if you are worried about this.

Contraception

Your doctor will advise you not to get pregnant or make someone pregnant while having this treatment. The drugs may harm a developing baby. It is important to use contraception during your treatment and for a while after treatment finishes. Your doctor, nurse or pharmacist can tell you more about this.

Sex

If you have sex in the first few days after chemotherapy, you need to use a condom. This is to protect your partner in case there is any chemotherapy in semen or vaginal fluid.

Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells. It is planned by a cancer doctor called a clinical oncologist. The person who gives you the radiotherapy is called a radiographer.

Developments in technology mean that radiation can be given more precisely. This is to avoid damaging normal tissues as much as possible.

Stereotactic radiotherapy

Stereotactic radiotherapy is a type of external radiation therapy that targets the tumour. A specially adapted radiotherapy machine delivers beams of radiotherapy from many different angles. This allows the doctor to give high doses of radiotherapy to the tumour, while keeping dose to the surrounding tissues low.

You may have stereotactic radiotherapy if you cannot have ablation (see pages 55 to 57) or surgery (see pages 44 to 54). This might be because of other medical conditions, or because the tumour is too large for ablation to work.

Stereotactic radiotherapy is only available in a few specialist centres. Your cancer doctor can give you more information.

Internal radiotherapy

Sometimes a type of internal radiotherapy is used. This is called radioembolisation or selective internal radiotherapy (SIRT). SIRT is not available on the NHS for primary liver cancer (HCC).

You may have SIRT as part of a research trial (see pages 55 to 57). If your cancer team think it is suitable, you may have to travel to a specialist hospital to have it.

We have more information about what to do if a treatment is not available on the NHS at **macmillan.org.uk**

Radiotherapy to treat symptoms

Radiotherapy can also be used if the cancer has spread to another part of the body. The aim is to relieve symptoms.

For example, if the cancer has spread to the bones, radiotherapy can help relieve the pain. This is usually given as a single treatment. The main side effect is tiredness. Other side effects are usually mild. Your cancer doctor, nurse or radiographer will tell you what to expect.

You have the treatment as an outpatient in the hospital radiotherapy department. The radiographer will position you on the treatment couch. When you are in the correct position, they leave the room for a few minutes and you are given the treatment. You can talk to the radiographer through an intercom while you have your treatment.

We have more information about having radiotherapy in our booklet **Understanding radiotherapy** (see page 116).

Controlling symptoms

Treating the cancer will often improve your symptoms. Other treatments can also help control symptoms. This is sometimes called palliative treatment or supportive care.

Your doctor may refer you to a palliative care team, who are experts in controlling symptoms. You may have support from a palliative care team while having your cancer treatment. They will support you and your family. The team often includes a doctor and nurses. They often work closely with a local hospice and can visit you and your family at home.

> **We got good symptom control advice from the acute oncology nursing sister through our local hospice. She was so helpful and visited us at home.**
>
> **Sylvia, whose husband has primary liver cancer**

Pain

If the cancer stretches the layer of tissue surrounding the liver (capsule), it may cause pain. Some people get pain in the right shoulder. Doctors sometimes call this referred pain. It can happen if the liver stimulates the nerves below the diaphragm (the sheet of muscle under the lungs). These nerves connect to nerves in the right shoulder.

There are different types of painkillers your doctor can give you. If your pain is not controlled, tell your doctor or nurse as soon as possible. They can change the dose or give you a different painkiller that works better for you. Make sure you take painkillers regularly and as your doctor has prescribed.

We have more information about this in our booklet **Managing cancer pain** (see page 116).

Strong painkillers often cause constipation. Your doctor can prescribe a laxative for you. Eating foods containing fibre and drinking plenty of fluids will also help.Sometimes drugs called steroids can relieve pain by reducing swelling around the liver. You usually take them for a few weeks or months. Steroids can sometimes make you feel more energetic and increase your appetite. But they can also raise your blood sugar levels. So if you have diabetes, your doctor can give you advice on how to manage it while taking steroids.

Ascites

Ascites is a build-up of fluid in the tummy area (abdomen). Your abdomen becomes swollen and distended (bloated), which can be uncomfortable or painful. You may lose your appetite. You may also feel breathless. This is because the swelling can prevent your lungs from fully expanding as you breathe.

Your doctor may put a small, fine tube through the skin of your tummy to drain off the fluid. This usually happens in hospital. But sometimes it can be done at home. Your doctor can drain the fluid more than once if needed.

Your doctor may prescribe water tablets (diuretics) to try to stop or slow down the build-up of fluid.

We have more information about ascites at **macmillan.org.uk**

> **‘Hospice staff are very experienced at symptom control and do all they can to help people be comfortable at home if that’s what they want.’**
>
> **Sylvia, whose husband has primary liver cancer**

A blocked bile duct

The bile duct is a tube that drains bile out of the liver and into the small bowel. If it becomes blocked, bile builds up in the liver and flows back into the blood. This makes the whites of the eyes and skin turn yellow, and makes you feel itchy. Your poo (stools) may become pale and your pee (urine) may be very dark. Doctors call these symptoms jaundice. There are other causes of jaundice. So if you develop these symptoms, your doctor will do tests to check for the cause.

If your bile duct is blocked, you may need a narrow tube (stent) put into the bile duct. The stent helps to keep the bile duct open. This allows the bile to flow into the small bowel and relieves the jaundice.

The doctors usually put the stent in using an ERCP (endoscopic retrograde cholangiopancreatography) procedure. If this is not possible, they use a PTC (percutaneous transhepatic cholangiogram) and biliary stent.

You will have antibiotics before and after the procedure. This is to stop you getting an infection. You will probably stay in hospital for a few days. If you have the stent using ERCP, you may be able to go home sooner.

You may need to have the stent replaced every few months to a year. This is to stop it becoming blocked. How often you need the stent replaced depends on what type of stent you have. Your specialist can tell you more about this.

Ask your specialist who to contact if you have problems with your stent. If it becomes blocked, you may have a high temperature or jaundice, or both. It is important to tell a doctor as soon as possible if you develop these symptoms. You may need antibiotic treatment. Your specialist may suggest replacing the stent. This is usually straightforward to do.

Having a stent put in using ERCP

You will not be able to eat or drink anything for about 6 hours before the procedure. This is so the stomach and first part of the small bowel (the duodenum) are both empty. The doctor gives you a tablet or injection to make you relax (a sedative). They also use a local anaesthetic spray to numb your throat. Rarely, the doctor may use a general anaesthetic.

The doctor passes a long, thin, flexible tube with a light and camera at the end (endoscope) through your mouth, into your stomach and into the small bowel. Using the endoscope and looking at x-rays, the doctor can see the narrowing in your bile duct. They stretch the narrowed area using dilators (small, inflatable balloons). They then put the stent in through the endoscope so the bile can drain.

> **My dad had a stent fitted due to a blocked bile duct and it seems to be helping a lot! His appetite is improving, he is in much less pain and he is feeling more like himself.**
>
> **Nicola, whose dad had a stent fitted**

Having a stent put in using PTC

You will not be able to eat or drink anything for about 6 hours before the procedure. This is so the stomach and first part of the small bowel (the duodenum) are both empty. The doctor gives you a tablet or injection to make you relax (a sedative). They also give you an injection of local anaesthetic to numb the area to the right of your tummy (abdomen).

The doctor carefully passes a thin needle through the skin into your liver. They inject a dye which flows through the bile ducts. This helps them to see the blockage more clearly. You may feel some discomfort as the needle enters the liver. The doctor then passes a wire into the blocked area and guides the stent along the wire. Sometimes they put a drainage tube (catheter) into the bile duct. One end of the tube is in the bile duct. The other end stays outside the body, connected to a bag that collects the bile. This can help the doctor put in the stent. They usually leave the catheter in for a few days. When they remove it, the area heals in 2 to 3 days.

Tiredness and weakness (fatigue)

Fatigue means feeling exhausted all, or most, of the time.

It is a common symptom of cancer in the liver and can be difficult to cope with. It may be caused by:

- the cancer itself
- other symptoms, such as pain
- the treatment you are having.

Many people with cancer in the liver feel tired and do not have the energy to do day-to-day activities. If you feel tired, try to pace yourself. Save your energy for the things that matter to you and that you enjoy. It is a good idea to ask for help with housework. Letting other people help means you have energy for the things you really want to do. Often family members and friends want to help and are pleased that you asked.

There are no rules about how much you should or should not do. Just do as much as you want, and feel able, to. If you do too much, you will not hurt yourself. But you may need to rest a bit more the next day. Tiredness and weakness can make it harder to concentrate. If you have important things to do, try to do them when you feel less tired.

We have more information and tips to help you cope in our booklet **Coping with fatigue** (see page 116).

Loss of appetite

Some people lose interest in food. This may be a:

- symptom of the cancer
- side effect of the treatment.

You may not like the sight or smell of food. It may help to:

- have small, simple meals more often
- eat your favourite foods.

Your doctor may prescribe medicines called steroids to help increase your appetite. Your nurse or a dietitian can give you advice. We have more information on coping with eating difficulties in our booklet **Eating problems and cancer** (see page 116).

Feeling sick (nausea)

Sickness may be caused by:

- cancer in the liver changing the chemical balance of your blood
- the liver being bigger and pressing on the stomach – this can also make you feel full quickly
- cancer treatment
- some types of drugs, such as painkillers.

Your doctor can give you anti-sickness tablets to help with nausea. There are different types available. So tell your doctor if the one you are taking is not working. They can give you another type that works better for you.

Your doctor may give you steroids to reduce sickness and improve your appetite.

Extremes in body temperature

The liver makes a lot of the body's heat. People with cancer in the liver sometimes have changes in body temperature. You may feel:

- hot and sweat more
- cold and shivery.

If you have these changes, talk to your doctor. There may be medicines that can help.

Hiccups

If your liver is pressing on the nerve that leads to the diaphragm, you may have hiccups. The diaphragm is the sheet of muscle under the lungs that separates the chest from the abdomen.

There are medicines that can help reduce or stop hiccups. Your doctor can prescribe these for you.

Itching

If you have itching, tell your doctor about it. The treatment they give you depends on the cause of the itching. Itching may be caused by:

- jaundice
- cancer treatment
- medication.

Here are some tips to help you cope with itching:

- Keep your nails short and clean.
- Try not to scratch. It can damage your skin and make the itching worse.
- Wear loose clothing made of natural fibres, such as cotton. Avoid scratchy fabrics, such as wool.
- If possible, keep the temperature around you cool. Use slightly warm water when you have a bath or shower.
- Dry your skin by patting rather than rubbing.
- Apply non-scented moisturisers (emollients) 3 times a day, or as often as your nurse or doctor recommends. Put it on after having a bath or shower.
- Caffeine, alcohol and spices may make itching worse. If you notice this, try to cut down or avoid them.
- If itching is affecting your sleep, tell your doctor. They may give you medicine to take at night to help.

AFTER YOUR TREATMENT

Follow-up care for primary liver cancer

After your treatment finishes, you will have regular check-ups. You may also want to make changes to your lifestyle.

Your check-ups may include a physical examination and a blood test. Depending on your treatment, you may have regular CT scans to check the tumour has not come back.

If you had a liver transplant, you will have tests to make sure your body is not rejecting the new liver. Your doctor or nurse will tell you what to look out for.

Share your experience

Having cancer is a life-changing experience. When treatment finishes, you might find it helps to talk about it and share your thoughts, feelings and advice with other people. This can be helpful for other people with primary liver cancer who are about to start treatment. Someone in a similar situation may find it helpful to know how you have coped, which side effects you had and how you managed them.

We have more information about how you can share your story. Visit **macmillan.org.uk/cancervoices** or call our support line on **0808 808 00 00**

Looking after yourself

Coping with tiredness

After treatment you are likely to feel very tired. You may also still be coping with some side effects. It is important to take care of yourself and allow your body time to recover. Tiredness and feeling weak are also common in people with advanced liver cancer. Make sure you get enough rest and eat well. Ask family and friends to help. This can save you energy for the things you want to do.

Tiredness can make it harder to concentrate or be interested in what is going on around you. Try to pace yourself. Plan important things for when you are likely to feel less tired and try to rest before.

We have more information on coping with tiredness in our booklet **Coping with fatigue** (see page 116).

Making the most of your health

Some people want to make changes to their lifestyle after cancer treatment. Eating healthily, being active and giving up smoking can all help your recovery. Some people also find that complementary therapies can help too.

We have more information about keeping healthy and adjusting to life after treatment in our booklet **Life after cancer treatment** (see page 116).

Drinking less alcohol

Because the liver breaks down alcohol, your specialist doctor or nurse may advise you not to drink for a few months after treatment. They may ask you to reduce the amount of alcohol you drink, or stop drinking completely. Your liver may not be able to cope with alcohol, so ask your specialist doctor or nurse for advice.

Eating well

Try to eat a healthy diet, as this can help you recover. If you do not have much of an appetite, try to eat snacks regularly throughout the day. There are also supplement drinks you can take to get extra energy and nutrients. You can often get these on prescription. Ask your doctor or nurse to refer you to a dietitian if you need more advice.

We have more information on coping with eating difficulties in our booklet **Eating problems and cancer** (see page 116).

Stopping smoking

If you smoke, talk to your doctor for advice on giving up. We have more information on giving up smoking and tips to help you stop. Visit our website **macmillan.org.uk**

Being active

Regular, short walks can help improve your energy levels. They can also help reduce stress. You can build up what you do as you recover.

Complementary therapies

Some people use complementary therapies to help them relax. Your hospital or local support group may offer therapies, such as relaxation or massage. We have more information in our booklet **Cancer and complementary therapies**.

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

It is common to have many different emotions when you are told you have cancer. These can be difficult to cope with. We talk about some common feelings here. Partners, family and friends may also have some of the same feelings.

There are lots of different reactions to cancer. You might not have any of the emotions we talk about here. There is no right or wrong way to feel. You will cope with things in your own way.

Talking to family, friends or other people affected by cancer, may help. Or you may get support from your healthcare team.

Shock and denial

You may find it hard to believe that you have cancer when you are first diagnosed. It is common to feel shocked and numb. You may not be able to understand all the information you are given. You may find that you keep asking the same questions. At first, it can be hard to talk about the cancer. Or you might find it hard to think or talk about anything else. Both reactions are normal. Your mind is trying to process what is happening. These feelings usually get easier over time.

Fear and anxiety

You may be anxious or frightened about whether treatments will work and what will happen in the future. This can be one of the hardest things to cope with. It can help to try to focus on things you can control. You may want to find out more about the cancer, your treatment options, and how to manage any side effects. It can also help to talk about your feelings. Try to keep doing the things that are important to you and that you enjoy.

Sadness and depression

You may feel sad if you have to change your plans because of the cancer, or if your future feels uncertain. Feeling sad is a natural reaction to changes or loss. This feeling may come and go during and after your treatment. For most people, these periods of sadness get better. But for some people, the sadness may continue or get worse. If you think the sadness may be turning into depression, there are organisations that can help on page 122.

Avoidance

You may cope by trying not to find out much about the cancer. Or by not talking about it. If you feel like this, tell people that you do not want to talk about it right now. You can also tell your cancer doctor if there are things you do not want to know or talk about yet.

Sometimes, it may be hard to accept that you have cancer. This can stop you making decisions about treatment. If this happens, it is very important to get help from your healthcare team.

You may feel that your family or friends are avoiding you or avoiding talking about the cancer. This is usually because they are also finding it difficult to cope. They may need support too. Try to tell them how this makes you feel. It may help you, and your family and friends, to talk openly about how you are feeling.

Anger

You may feel angry about your diagnosis. You may also resent other people for being well. These are normal reactions. They are more likely when you feel frightened, stressed or unwell. You may get angry with your family, friends or partner. Tell them you are angry at your illness and not at them. Finding ways to relax can help with anger. This can include talking about or writing down how you feel, doing gentle exercise, having relaxation therapy or meditating. We have more information about these methods in our booklet **Cancer and complementary therapies** (see page 116).

Guilt and blame

You may feel guilty or blame yourself for the cancer. You may want to find reasons for why it has happened to you. Most of the time, it is impossible to know exactly what causes a cancer. Over time, a combination of different risk factors may cause a cancer. Doctors do not fully understand all these factors yet. Try to focus on looking after yourself and getting the help and support you need.

Feeling alone

You may feel alone or isolated. This could be because you do not think you have support. Family and friends may live far away, be busy, or feel uncomfortable talking about the cancer. Try to tell your family and friends how you feel. This can help them find ways to support you.

You may have times when you want to be alone for a while. But if you find you are avoiding people a lot of the time, try to talk to your doctor or nurse.

If you need more support, you can call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find local support groups. Visit **macmillan.org.uk/supportgroups** You can also talk to other people affected by cancer on our Online Community. Visit **macmillan.org.uk/community**

If you need more help

You may find it very difficult to cope with your emotions and may need more help. This does not mean you are failing in any way.

Talk to your doctor or nurse if:

- you feel anxious or worried a lot of the time
- you think you may be depressed.

They can refer you to a specialist doctor, psychologist or counsellor who can help. They may also prescribe medicines to help.

We have more information on the emotional effects of cancer in our booklet **How are you feeling? The emotional effects of cancer** (see page 116).

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You might think it is best to pretend everything is fine. You might not want to worry them. Or you might feel you are letting them down if you admit you are worried or scared.

But not talking to the person with cancer about how you feel may make them feel alone.

You can support the person with cancer by listening and talking with them. Do not feel you have to talk about the cancer. Often it is enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking. Visit **macmillan.org.uk/learnzone** to find out more.

We have more information about talking to someone with cancer in our booklet **Talking with someone who has cancer.**

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers in our booklet **Looking after someone with cancer** (see page 116).

Talking to children about cancer

Deciding what to tell children about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. Children do not always show their feelings, but their behaviour may change at home or at school.

Talking to children about the cancer can:

- help them understand what is going on
- help them feel supported
- prepare them for any changes.

It may also help with some of your own anxiety too. For example, not telling them about hospital appointments may cause extra stress.

How much you tell children will depend on their age and how mature they are. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Teenagers usually understand what cancer is. Some will want to know more.

Whether they are teenagers or young children, talking about the cancer helps them cope.

Teenagers

It can help to encourage teenagers to ask questions, ask them their opinion and try to give them time to think about what is happening. They may have to, or want to, take on more responsibilities to help – perhaps cooking meals or looking after younger children. This can be hard at a time when they may want more freedom and independence.

Sometimes teenagers may find it hard to talk about a cancer diagnosis. You can encourage them to talk to someone they trust, who can support and listen to them. This might be a grandparent, family friend, teacher or counsellor. They may also find support online. The website **riprap.org.uk** offers information and support for teenagers who have a parent with cancer.

We have more information in our booklet **Talking to children and teenagers when an adult has cancer**. We also have a video on our website about talking to children (see page 116).

Coping with your emotions

You may feel that the cancer has taken over your life. This is a common reaction. It can be very hard to cope with. But there are lots of things you can do to help you feel differently:

- You may find it helps to try to keep doing your usual activities.
- You may want to think about what is important to you. This could mean spending time with family, planning a holiday or starting a new hobby.
- You might decide to change your lifestyle. This could be eating healthily, being physically active or trying complementary therapies.
- Making plans can help you feel more in control.
- You might find knowing more about the cancer and your treatment options also helps you cope. It means you can make a plan with your healthcare team.
- Making choices and being active in your own care can help you feel more in control.

If you feel you are not coping well, or need more support, talk to your doctor or nurse.

Who can help?

Many people are available to help you and your family.

District nurses work closely with GPs and make regular visits to patients and their families at home if needed.

The hospital social worker can give you information about social services and benefits you may be able to claim. These may include meals on wheels, a home helper or money to help with hospital transport fares. The social worker may also be able to arrange childcare for you during and after treatment.

In many areas of the country, there are also specialist nurses called palliative care nurses. They are experienced in assessing and treating symptoms of advanced cancer. Palliative care nurses are sometimes known as Macmillan nurses. However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you are at a clinic or in hospital.

Marie Curie nurses help care for people approaching the end of their lives in their own homes. Your GP or hospital specialist nurse can usually arrange a visit by a palliative care or Marie Curie nurse.

There is also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.

WORK AND FINANCIAL SUPPORT

Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales or Scotland, or **nidirect.gov.uk** if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who have an illness or disability that affects how much they can work. There are different types of ESA, so it is a good idea to speak to a welfare rights adviser to see if you can make a claim.

Universal Credit

Universal Credit (UC) is a benefit for people under State Pension age who are either:

- out of work – for example, because of an illness or because they are caring for someone
- on a low income.

UC can include money for basic living costs, looking after children and housing.

Personal Independence Payment

This benefit is for people aged 16 to State Pension age who have problems moving around or looking after themselves. You must have had these problems for 3 months and expect them to last for at least 9 months, unless you are terminally ill.

Attendance Allowance

This benefit is for people at or over State Pension age who have problems looking after themselves because of an illness or disability. This could mean problems getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months, unless you are terminally ill.

Special rules

If you are terminally ill, you can apply for some benefits using a fast-track process called special rules. You can apply if your doctor thinks you may be reasonably expected to live for less than 6 months. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

Help for carers

Carer’s Allowance is a weekly benefit to help people who look after someone with a lot of care needs. If you do not qualify for it, you may still be able to apply for Carer’s Credit.

Carer’s Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

Macmillan Grants

Macmillan Grants are small, mostly one-off payments to help people with the extra costs cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. A grant from Macmillan does not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on **0808 808 00 00**.

We have more information in our booklets **Insurance** and **Travel and cance**r (see page 116). Our Online Community forum on Travel insurance may also be helpful.
Visit **macmillan.org.uk/travelinsurancegroup**

More information

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**

You can also get information about benefits and other types of financial help from Citizens Advice (see page 123).

Our booklet **Help with the cost of cancer** has lots more information (see page 116).

Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager soon after you are diagnosed. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others keep working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to do too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful (see page 116). There is also lots more information at **macmillan.org.uk/work**

Employment rights

If you have, or have ever had, cancer, the law considers this as a disability. This means you cannot be treated less favourably than people who do not have cancer because you have cancer, or for reasons connected to the cancer. That would be discrimination.

The law also says your employer must make reasonable adjustments (changes) to your workplace and their work practices to help you stay at work or return to work.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 116).

FURTHER INFORMATION

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more booklets or leaflets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**
If you would like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you would like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

Other useful organisations

There are lots of other organisations that can give you information or support.

Liver cancer support

British Liver Trust

Helpline **0800 652 7330** (Mon to Fri, 10am to 3pm)
www.britishlivertrust.org.uk
Works to increase awareness of liver disease including liver cancer, and provides information and support to people affected. Has a nurse-led helpline and produces leaflets on liver disease.

Guts UK

Tel **020 7486 0341**
Email **info@gutscharity.org.uk**
www.gutscharity.org.uk
Produces information and leaflets on common digestive diseases and illnesses, including liver cancer.

General cancer support organisations

Cancer Focus Northern Ireland

Helpline **0800 783 3339** (Mon to Fri, 9am to 1pm)
Email **nurseline@cancerfocusni.org**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Support Scotland

Tel **0800 652 4531** (Mon to Fri, 9am to 5pm)
Email **info@cancersupportscotland.org**
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Maggie's

Tel **0300 123 1801**
Email **enquiries@maggies.org**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 3000 118** (Mon to Fri, 10am to 1pm)
Email **helpline@pennybrohn.org.uk**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline **0808 808 1010** (Daily, 8am to 8pm)
Email **info@tenovuscancercare.org.uk**
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online ‘Ask the nurse’ service.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300** (Mon to Fri, 9am to 5pm)
Email **bacp@bacp.co.uk**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their 'How to find a therapist' page.

Emotional and mental health support

Samaritans

Helpline **116 123**
Email **jo@samaritans.org**
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271** (Mon, Tue, Wed and Fri, 9am to 5pm, Thu, 10am to 5pm)
Textphone **028 9031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Carer's Allowance Unit

Tel **0800 731 0297**
Textphone **0800 731 0317** (Mon to Fri, 8am to 6pm)
www.gov.uk/carers-allowance
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office by contacting:

England

Helpline **03444 111 444**
www.citizensadvice.org.uk

Wales

Helpline **03444 77 2020**
www.citizensadvice.org.uk/wales

Scotland

Helpline **0808 800 9060**
www.cas.org.uk

GOV.UK

www.gov.uk
Has information about social security benefits and public services in England, Scotland and Wales.

Equipment and advice on living with a disability

British Red Cross

Tel **0344 871 11 11**
Textphone **020 7562 2050**
Email **contactus@redcross.org.uk**
www.redcross.org.uk
Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disabled Living Foundation (DLF)

Helpline **0300 999 0004** (Mon to Fri, 10am to 4pm)
Email **info@dlf.org.uk**
www.dlf.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

Support for older people

Age UK

Helpline **0800 678 1602** (Daily, 8am to 7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030** ((Mon to Fri, 9am to 9pm, and Sat and Sun, 10am to 6pm)
Email **helpline@lgbt.foundation**
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Support for carers

Carers Trust

Tel **0300 772 9600** (Mon to Fri, 9am to 5pm)
Email **info@carers.org**
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline (England, Scotland, Wales) **0808 808 7777** (Mon to Fri, 9am to 6pm)
Helpline (Northern Ireland) **028 9043 9843**
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Advanced cancer and end-of-life care

Hospice UK

Tel **020 7520 8200**
www.hospiceuk.org
Provides information about living with advanced illness. Also provides free booklets and a directory of hospice services in the UK.

Marie Curie

Helpline **0800 090 2309** (Mon to Fri, 8am to 6pm, and Sat, 11am to 5pm)
www.mariecurie.org.uk
Marie Curie nurses provide free end-of-life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

Cancer registries

The cancer registry

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

National Cancer Registration and Analysis Service

Tel **020 7654 8000**
Email **enquiries@phe.gov.uk**
www.ncras.nhs.uk
Tel (Ireland) **021 4318 014**
www.ncri.ie

Scottish Cancer Registry

Tel **0131 275 7050**
Email **nss.csd@nhs.net**
www.isdscotland.org/health-topics/cancer/scottish-cancer-registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **029 2037 3500**
Email **general.enquiries@wales.nhs.uk**
www.wcisu.wales.nhs.uk

Northern Ireland Cancer Registry

Tel **028 9097 6028**
Email **nicr@qub.ac.uk**
www.qub.ac.uk/nicr

Your notes and questions

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Dr Paul Ross, Consultant Medical Oncologist.

With thanks to: Natalie Barratt, Hepatobiliary Clinical Nurse Specialist; Dr Rebecca Goody, Consultant Clinical Oncologist; Prof Michael Heneghan, Consultant Hepatologist and Professor of Hepatology, Dr Ashok Katti, Consultant Interventional Radiologist; Mr Hassan Malik, Consultant Hepatobiliary Surgeon; Mr Krishna Menon, Consultant Liver Transplant and Hepato-pancreatobiliary Surgeon; Jacquie Peck, Senior Clinical Nurse Specialist Lower GI Oncology; Mr Keith Roberts, Consultant Liver Transplant and Hepatobiliary Surgeon; Prof Giles Toogood, Consultant Hepatobiliary Surgeon; Dr Esther Unitt, Consultant Hepatologist; and Dr Kein Yim, Consultant Clinical Oncologist.

Thanks also to the people affected by cancer who reviewed this edition, and to those who shared their stories.

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

We have listed a sample of the sources used in the booklet below. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

BMJ. Best Practice Hepatocellular Carcinoma. 2018.

Melloul E et al. Guidelines for perioperative care for liver surgery: Enhanced Recovery after Surgery (ERAS) society recommendations. World J Surg 40:2425–2440. 2016.

NICE. Lenvatinib for untreated advanced hepatocellular carcinoma technology appraisal guidance (TAG 551). 2018.

NICE. Liver disease quality standard. 2017.

NICE Liver cancers overview. 2019. Available from: https://pathways.nice.org.uk/pathways/liver-cancers#content=view-node%3Anodes-liver-metastases [accessed February 2020].

NICE. Regorafenib for previously treated advanced hepatocellular carcinoma. Technology appraisal guidance (TA555). 2019.

Vogel A, Hepatocellular carcinoma: ESMO Clinical practice guidelines for diagnosis, treatment and follow-up. Annals of Oncology 29 (Supplement 4): iv238–iv255. 2018.

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 ways you can help someone with cancer

Share your cancer experience
Support people living with cancer by telling your story, online, in the media or face to face.

Campaign for change
We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

Help someone in your community
A lift to an appointment. Help with the shopping.
Or just a cup of tea and a chat. Could you lend a hand?

Raise money
Whatever you like doing you can raise money to help.
Take part in one of our events or create your own.

Give money
Big or small, every penny helps.
To make a one-off donation see over.

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Mr/Mrs/Miss/Other

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Surname

Address

Postcode

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Please accept my gift of £
(Please delete as appropriate)

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OR debit my:
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Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you would rather donate online go to **macmillan.org.uk/donate**

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Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

This booklet is about the most common type of primary liver cancer, hepatocellular carcinoma (HCC). It is for anyone who has been diagnosed with primary liver cancer. There is also information for carers, family members and friends.

The booklet talks about the signs and symptoms of primary liver cancer. It explains how it is diagnosed and how it may be treated. It also has information about controlling symptoms and coping with emotional, practical and financial issues.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or visit **macmillan.org.uk**.

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

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