

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.

The booklet explains what primary liver cancer is and how it is treated. There is also information about ways of controlling symptoms and coping with the emotional impact.

This booklet does not have information about cancer that starts. in another part of the body and spreads to the liver. This is called secondary or metastatic cancer. We have another booklet about this called <u>Understanding secondary cancer in the liver</u>.

We hope this booklet helps you deal with some of the questions or feelings you may have.

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

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 to help you.

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

At the end of the booklet, there are details of other organisations that can help.

Quotes

In this booklet, we have included quotes from people who have had primary liver cancer, which you may find helpful. These are from people who have chosen to share their story with us. To share your experience, visit macmillan.org.uk/sharevourstorv

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 Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

We have some information in different languages and formats. including audio, easy read, Braille, large print, interactive PDFs 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

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What is cancer?

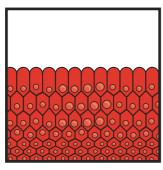
Our bodies are made up of tiny building blocks called cells. Inside every cell is a set of genes. Genes are the instructions the cell needs to work properly.

The instructions send signals to cells to grow and divide and make new cells. This is how our bodies grow and heal. Over time, cells become old or damaged. When this happens, signals tell the cell to stop working and die.

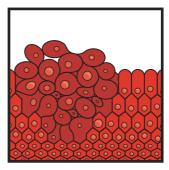
Sometimes genes in the cell can develop changes. If a gene is changed, it may not give the correct instructions anymore. A change in a gene is called a gene variant or mutation.

Gene variants in a cell may stop the cell working normally. Cancer may develop if cells like this multiply in an abnormal way and grow out of control. Over time, these cells can grow into a lump called a tumour.

Abnormal 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 to look for cancer cells. This is called a biopsy.

Tumours that are not cancer are called benign. Benign tumours cannot spread anywhere else in the body. But they can cause problems if they grow and press on nearby organs.

Tumours that are cancer are called malignant. Malignant tumours can grow into nearby tissue and spread to other parts of the body.

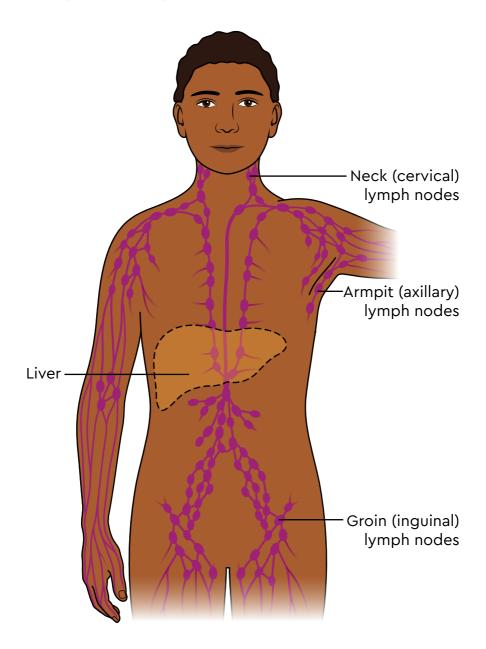
Cancer can spread from one place (the primary site) to another through the blood or lymphatic system. When cancer spreads and grows somewhere else, it is called a secondary cancer or metastasis.

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.

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. Sometimes, primary liver cancer may spread to the lymph nodes closest to the liver.

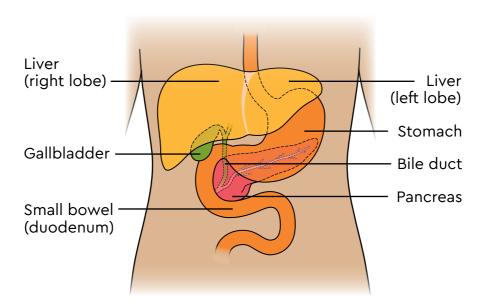
The lymphatic system and the liver



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 2 lobes.

The liver and surrounding organs



What the liver does

The liver does many important things for the body:

- It stores sugars and fats so they can be used for energy.
- It breaks down harmful substances so they cannot harm other parts of the body.
- It makes proteins that help the blood to clot. This prevents bleeding and maintains the balance of fluid in the body.
- It makes bile. Bile is a yellow fluid that helps break down fats so the body can absorb them. Bile travels from the liver to the gallbladder and small bowel through a tube called the hepatic duct – hepatic means relating to the liver.

The blood supply to the liver comes from 2 places:

- The hepatic artery takes blood full of oxygen away from the heart.
- The hepatic portal vein takes blood full of nutrients away from the digestive system.

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, the remaining liver can usually grow to replace it.

Primary liver cancer

Primary liver cancer is rare in the UK, but the number of people developing it is increasing. About 6,600 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

There are different 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. We have separate information on bile duct cancer on our website. Visit macmillan.org.uk/bile-duct-cancer
- Angiosarcoma is a very rare type of liver cancer. It starts in the blood vessels of the liver. We have separate information about soft tissue sarcoma in our booklet Understanding soft tissue sarcoma and on our website at macmillan.org.uk/ soft-tissue-sarcoma
- Hepatoblastoma is a very rare type of liver cancer that usually affects children. The Children's Cancer and Leukaemia Group has more information.

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

Benign tumours in the liver

There are some types of liver tumours that are not cancerous. These are called benign tumours. They are usually small and are often found by chance – for example, when a person is having a scan for another reason.

There are different types of benign tumours, including a hepatic adenoma. In some people, it might develop into a cancerous or malignant tumour over time.

Doctors can monitor these tumours and identify whether they are at risk of becoming malignant. If a tumour is higher risk, doctors usually advise having surgery to the liver as soon as possible to remove it.



Diagnosing primary liver cancer

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Finding out you have primary liver cancer

Being diagnosed can cause many different emotions. There is no right or wrong way to feel. You may have been worrying about having cancer for a while. Or your diagnosis might have been unexpected. Having tests and waiting for test results can be a difficult time.

This information is written for people who have already been diagnosed with primary liver cancer - this is called hepatocellular carcinoma (HCC). We have more information about:

- · causes and risk factors
- symptoms
- tests to diagnose primary liver cancer.

You can find this information at macmillan.org.uk/liver-cancer

Waiting for treatment to start can be a difficult time. You may be worried about telling people and about what treatment options you will have. You might choose to spend some time reading about the cancer, or you may prefer to wait until you meet with your cancer doctor. Do what feels right for you.

If you need support, you can contact our cancer support specialists on 0808 808 00 00. They will be able to talk to you about what has happened and help answer any questions you have.

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 different systems used to stage hepatocellular carcinoma (HCC). These include the:

- Barcelona Clinic Liver Cancer (BCLC) staging system
- TNM staging system.

Barcelona Clinic Liver Cancer (BCLC) staging system

This is the most common system used for liver cancer. It looks at different things to decide on the stage of liver cancer. This includes:

- the size and the number of tumours in the liver.
- how well the liver works this is measured by a system called the Child-Pugh classification system
- whether the cancer is affecting your activities this is measured by a scale called performance status.

Child-Pugh classification system

Doctors assess how well your liver is working using the Child-Pugh classification 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) - this is called ascites
- whether liver damage is affecting how the brain is working - this is called 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.

We have more information about ascites on our website. Visit macmillan.org.uk/ascites



Performance status (PS)

Performance status (PS) is a scale to rate how well you are. It uses the following scale:

- 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.

The BCLC staging system

The BCLC staging system has 5 stages:

- Stage 0 there is 1 tumour in the liver that is 2cm or smaller across. Your liver is working normally, and you are very well.
- Stage A there is 1 tumour in the liver that is smaller than 5cm across. Or there are up to 3 tumours and they are all 3cm or smaller 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 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. You are not as well, which might be affecting things like being able to work.
- Stage D you may have symptoms caused by liver damage such as a build-up of fluid in the tummy area (abdomen). You are very unwell and need some or a lot of help to look after yourself. Your liver is not working well.

Doctors sometimes describe HCC as being early, intermediate or advanced. This is linked to the BCLC stage:

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

The TNM staging system

This is another system used to stage liver cancer. When this system is used to stage HCC:

- T describes the size and the number of the liver tumours, and whether the cancer has spread into the blood vessels
- N describes whether the cancer has spread to any lymph nodes near the liver
- M describes whether the cancer has spread into organs near to the liver except the gallbladder or peritoneum.

This system gives detailed information about the tumour stage.

We have more information about staging and grading on our website. Visit macmillan.org.uk/staging-and-grading



Your data and the cancer registry

When you are diagnosed with cancer, some information about you, your diagnosis and your treatment is collected in a cancer registry.

The information is used to help understand cancer in the UK better. This is important for planning and improving health and care services. It can be used to ensure that people living with cancer get the best possible care and support.

Hospitals automatically send information to the cancer registry. There are strict rules about how the information is stored, accessed and used. Information about health is sensitive, so by law it has to be kept under the highest levels of security.

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





Planning treatment for primary liver cancer

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Treatment overview

There are different treatments for primary liver cancer. This information is about hepatocellular carcinoma (HCC), which is the most common type of primary liver cancer.

The treatment you have usually depends on:

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

Surgery

<u>Surgery</u> is the most effective treatment for HCC. This may involve an operation to remove part of the liver or a liver transplant. These are major operations, so you need to be well enough to cope with them.

There are 2 types of operation:

- A liver transplant is when the surgeon removes the liver and replaces it with a liver from another person (a donor).
- A <u>liver resection</u> is when the surgeon removes the part of the liver where the cancer is.

A liver resection might be open surgery, where the surgeon makes 1 large cut (incision). But surgeons often do a resection using keyhole (laparoscopic) surgery.

Unfortunately, surgery is not possible for many people. This might be because the cancer is too advanced. Or it could be because the liver is too damaged to cope with surgery. Your liver needs to be working well so that the remaining liver can cope after the operation. Sometimes other treatments are given before or during surgery.

Tumour ablation treatments

Some people have tumour ablation. This means destroying the cancer cells by applying heat, electrical pulses or sometimes alcohol directly to the tumour. The main ablation treatments include microwave ablation. and radiofrequency ablation.

Ablation may be used to treat small tumours instead of surgery. In tumours of 2cm or under, ablation can be as effective as surgery.

Ablation can also be used along with or after other treatments.

Embolisation treatments

Trans-arterial chemoembolisation (TACE) is when you have chemotherapy injected into a blood vessel going to the liver, and the blood supply to the tumour is cut off. Cutting off the blood supply is called embolisation.

Doctors may recommend TACE 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.

You might have trans-arterial embolisation (TAE) on its own without chemotherapy.

Radioembolisation is another treatment that works in a similar way but uses radiation to destroy cancer cells. It is sometimes called selective internal radiotherapy (SIRT).

Some people might have a treatment called portal vein embolisation (PVE) before a liver resection. It is usually done when surgery is possible but there might not be enough remaining liver left afterwards to work properly.

We have more information about embolisation treatments.

Targeted therapy and immunotherapy drugs

Targeted therapy drugs target something in or around the cancer cell that is helping it grow. Some targeted therapy drugs also stop the cancer developing new blood vessels. Immunotherapy drugs use the immune system to find and attack cancer cells.

Doctors may use targeted therapy drugs and immunotherapy drugs if the cancer is advanced in the liver or has spread outside it.

You might have a combination of the immunotherapy drug atezolizumab with a type of targeted therapy drug called bevacizumab.

Other targeted therapy drugs are also used. You might have a drug called sorafenib (Nexavar®) or a drug called lenvatinib. Other targeted therapy drugs can be used if these do not work well for you.

Radiotherapy

Some people have a type of high-dose radiotherapy that closely targets tumours in the liver. This is called stereotactic ablative radiotherapy (SABR). It is used to try to control areas of cancer in the liver.

Radiotherapy can also be used to ease symptoms such as pain. 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.

Chemotherapy into a vein

Less commonly, <u>chemotherapy</u> that is given into a vein (intravenously) or taken as tablets may be used. If other treatments have already been tried, your doctor might advise this to try to control the cancer or reduce the symptoms.

Clinical trials

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. We have more information on our website. Visit macmillan.org.uk/clinical-trials

Advanced cancer

If you decide not to have treatment, there is a still a lot that can be done to control symptoms and support you. 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 coping with advanced cancer in our booklet Coping with advanced cancer.

You can order our booklets and leaflets for free. Visit orders.macmillan.org.uk or call 0808 808 00 00.





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 reviews national treatment guidelines or the latest evidence for the type of cancer you have. We have more information about cancer types on our website. Visit macmillan.org.uk/cancer-types

If you have any treatment preferences, your doctor will tell them about this.

The MDT will usually include the following professionals:

- Hepatologist a doctor who treats liver problems.
- Hepatobiliary surgeon a surgeon who specialises in operating on liver cancers.
- Clinical oncologist a doctor who uses radiotherapy, chemotherapy and other anti-cancer drugs to treat people with cancer.
- Interventional radiologist a doctor who uses scans and x-rays to give treatments such as tumour ablation or embolisation.
- Clinical nurse specialist a nurse who gives information about cancer, and support during treatment.
- Radiologist a doctor who looks at scans and x-rays to diagnose problems.
- Pathologist a doctor who looks at cells or body tissue under a microscope to diagnose cancer.

It may also include:

- a palliative care doctor or nurse someone who helps with 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 meet with your cancer doctor and specialist nurse. They will talk to you about your treatment plan. It can help to write down your questions before you meet with 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 cancer 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 1 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.

We have more information about making treatment decisions in our booklet Making treatment decisions.



Choosing between treatments

Doctors sometimes ask you to choose between different treatments. This is usually when 2 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 to help you make your decision - these are called decision-making aids.

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 meet with 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/second-opinion



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 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 - research

Clinical trials are a type of medical research involving people. They are important because they show which treatments are most effective and safe. This helps healthcare teams plan the best treatment for the people they care for.

Trials may test how effective a new treatment is compared to the current treatment used. Or they may get information about the safety and side effects of treatments.

Some trials help answer questions about treatments we already use. They may test whether combining treatments is more effective. Or they may research different ways to give a treatment so it works better or causes fewer side effects.

Clinical trials also research other areas of cancer care. These include diagnosis and managing side effects or symptoms.

We have more information about cancer clinical trials on our website. Visit macmillan.org.uk/clinical-trials



Taking part in a clinical 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.

Joining a trial is always your decision. If you join and then change your mind, you can leave at any time. You do not have to give a reason. Your healthcare team will support you whatever you decide. You will always have the standard treatment for the type and stage of cancer you have.

Not all hospitals have the expertise or resources to take part in certain trials. This means for some trials you may have to travel to a different hospital.

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

They will explain the possible benefits and any possible risks of the trial. Clinical trials are designed with safety measures to keep any risks to you as low as possible.

Some trials involve collecting blood samples, or tissue samples from a biopsy. This often happens as a standard part of your treatment. But your research nurse or doctor will explain if they need to take extra samples for the trial.

Your samples can only be stored and used for research if you give your permission. Your name is removed from the samples before they are used. This means you cannot be identified.





Treating primary liver cancer

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Surgery for primary liver cancer

Surgery is the most effective treatment for hepatocellular carcinoma (HCC). The type of operation depends on:

- the number of tumours in the liver
- where they are in the liver
- how damaged the liver is from chronic liver disease.

There are 2 types of operation:

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

Only a few people with HCC can have surgery. Your surgeon and specialist nurse will tell you whether surgery is an option for you. They will explain what it involves and 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. We have more information about treatment decisions.

Liver transplant

The most common reason for a liver transplant is that you have liver disease that is too advanced for other treatments. A liver transplant is only suitable for some people with HCC. It is not suitable if the cancer has grown into blood vessels or spread outside the liver.

For example, it might be an option if you have:

- 1 tumour that is 5cm across or smaller
- up to 3 tumours and each is 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 liver surgeon 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 during this time:

- tumour ablation
- chemotherapy given directly into the liver called trans-arterial chemoembolisation (TACE)
- radiation using specialist techniques such as SIRT or sometimes SABR.

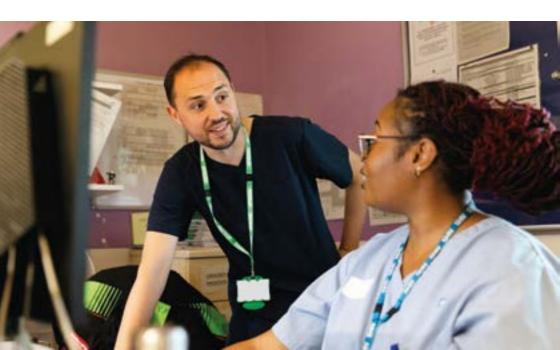
These treatments can help to control the cancer until you have your transplant. But for some people the cancer might progress. This means that a transplant is no longer possible. If you are no longer able to have a transplant, there are other treatments you can have.

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 part of their liver. This is transplanted into you after your 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 1 tumour or a limited number of tumours
- do not have cirrhosis or have early-stage cirrhosis.

Cirrhosis damages the liver and stops it from working properly. It is a risk factor for HCC.

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 this is called a hemi-hepatectomy.

The 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.

Some people also have <u>tumour ablation</u> during surgery. This uses heat to destroy cancer cells.

Some people may have a treatment called portal vein embolisation (PVE) a few weeks before a <u>liver resection</u>. PVE redirects the blood flow to the healthy part the liver and encourages it to grow. You might have this when surgery is possible but there may not be enough remaining liver left afterwards to work properly.

Keyhole (laparoscopic) surgery

You might have open surgery for a liver resection. This is where the surgeon makes 1 large cut (incision). But surgeons often do a resection using keyhole surgery. This is also called laparoscopic surgery.

Instead of 1 large cut, the surgeon makes several small cuts. They insert a thin tube called a laparoscope into a cut to see into and work inside the tummy (abdomen). The laparoscope has a camera that gives a 3-dimensional (3D) magnified view of the inside of the body. The images are shown on a video screen.

Sometimes during keyhole surgery, the surgeon uses a fluorescent dye called indocyanine green (ICG). It shows up the blood vessels and the areas of the liver to be operated on. This helps the surgeon make sure the surgery is done very exactly. Because keyhole surgery leaves small wounds, you usually recover quicker.

Keyhole surgery may sometimes be done using robotic equipment. But this is not common. The surgeon controls instruments attached to robotic equipment using the video images as a guide.

Before your operation

If you smoke, try to stop smoking 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 stopping smoking on our website. Visit macmillan.org.uk/stop-smoking

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.

At a clinic or when you are admitted to hospital, you will meet a member of the surgical team and a specialist nurse. They will talk to you about the operation. You may also meet the doctor who gives you the anaesthetic. They are called an anaesthetist.

Tell the surgical team if you have any questions or concerns about the operation. If you think you might need help when you go home, tell the nurses as soon as possible. This will give hospital staff time to help you make plans.

You will usually be admitted to hospital on the morning of the 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.

Preparing for surgery

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 guickly as possible.

For example, you may be given a diet plan to follow and exercises to do before surgery. You may also be given supplement drinks to take. This is to make sure you are as healthy as possible. After surgery, the nurses will get you out of bed and encourage you to start drinking and eating as soon as possible.

Getting fitter before an operation to avoid complications is called prehabilitation. It usually involves:

- stopping smoking, which reduces your risk of a chest infection
- stopping drinking alcohol, which helps your liver
- eating healthily
- being more physically active or exercising.

Your surgical team will tell you more about this and the support available to help you.

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 monitor you carefully for bleeding. Your nurse will check 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.

Drips and drains

For a short time after the operation, you may have some of the following:

- A drip going into a vein in your arm or neck. This is called an intravenous infusion. It gives you fluids until you can eat and drink again. It can also give you painkillers and other medications.
- 1 or more drainage tubes coming from your wound if you have had open surgery. These drain away extra fluids, such as blood. They are removed when the fluid has reduced.
- A fine tube that passes down your nose and into your stomach or small intestine. This is called a nasogastric tube. It drains fluids from your stomach so that you do not feel sick. You may need this for several days.
- A small, flexible tube in your bladder. This is called a catheter.
 It drains urine (pee) into a bag. This means you will not have to get up to pass urine. You usually only have this for a couple of days.

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.

You may have painkillers in the following ways:

- through a thin tube in your back (epidural)
- into a vein
- into the muscles 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 analogsia (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.

We have more information about managing pain in our booklet Managing cancer pain and online at macmillan.org.uk/pain

Your wound

For the first few days after surgery, you may have a dressing over your wound. The nurses will check your wound regularly to make sure it is healing well. You usually have stitches that dissolve. But if you need to have any stitches or staples removed, these can be taken out after 10 days.

If you have had a liver transplant, the stitches or staples will be taken out after about 3 weeks. 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. These are possible signs of infection. Contact the hospital straight away if this happens when you go home.

Going home

After a <u>liver resection</u>, most people can go home:

- 2 to 3 days after keyhole (laparoscopic) surgery for a smaller liver resection
- 4 to 5 days after keyhole surgery for a bigger liver resection
- 5 to 7 days after open surgery, if you have 1 large wound.

After a liver transplant, you will usually stay in hospital for 2 or 3 weeks.

Before you go home, you will be given painkillers to take for the next few weeks. Your nurse or pharmacist will talk to you about the tablets you need to take at home.

Recovering

It may take up to 3 months after a liver resection before you start getting back to normal. Recovery takes longer after a liver transplant. You will also need regular checks to make sure your body is not rejecting the new liver. Your doctor or nurse will tell you what to expect.

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

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. You will not be able to drive for a time. Your specialist will tell you when you should be able to drive again.

After any liver surgery, it is important to get enough rest and eat well. This will help your recovery.

Gentle exercise, such as regular short walks, will help build up your energy. You can gradually do more as you recover.

Your liver specialist will advise you not to drink alcohol for some time. How long this may be depends on your individual situation. This is to protect the liver while it is growing to replace the tissue that was removed.

If you had liver damage due to alcohol, then you will be advised not to drink alcohol again after a liver transplant. If you did not have this type of liver damage, you can usually drink within the recommended levels.

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.

Your check-up will be at the outpatient clinic. Your doctor will ask you about your recovery and talk to you about the results of your operation. This is a good time 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, electrical pulses or alcohol directly to it. It can be used to treat small tumours in the liver. If you have 1 tumour that is only 2cm or smaller, tumour ablation can be as effective as surgery.

It may be used in the following ways:

- instead of surgery, usually for tumours smaller than 3cm - if the tumour is nearly 3cm, you might have a treatment called trans-arterial chemoembolisation (TACE) followed by tumour ablation a few weeks later
- if you cannot have surgery, or if the tumour is small but very close to the outside of the liver, which makes it hard to remove with surgery
- with or after other treatments, such as surgery and TACE.

Tumour ablation can be done:

- during keyhole (laparoscopic) surgery the ablation needle is inserted into the liver tumour through the keyhole instruments
- during open surgery, usually a liver resection the ablation needle is put directly into the liver tumour
- as an injection with a needle directly into the liver through the skin (percutaneously).

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

Types of tumour ablation

Types of tumour ablation include:

- microwave ablation (MWA)
- radiofrequency ablation (RFA)
- cryotherapy
- irreversible electroporation (IRE)
- percutaneous ethanol injection (PEI).

The most common types are MWA and RFA. They use microwaves or radio waves to produce heat and destroy the tumour.

Cryotherapy produces very low temperatures, which freeze the tumour. This is less commonly done.

Irreversible electroporation uses a high voltage current to destroy tumours. It does not heat the nearby tissue, so it is useful for tumours that are close to vessels or bile ducts.

PEI uses alcohol to destroy cancer cells.

Your doctor will talk to you about the best type of tumour ablation for you.

What happens during tumour ablation?

You usually have ablation under a general anaesthetic. The doctor puts the ablation 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 target the tumours using ablation.

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 check how well it has worked.

We have more information about CT scans on our website. Visit macmillan.org.uk/ct-scan



Percutaneous ethanol injection (PEI)

This type of ablation uses alcohol and works in a different way. Percutaneous means given through the skin. The doctor injects pure alcohol (ethanol) through a needle passed through the skin 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 again, you can have the treatment again.

Side effects of tumour ablation

The side effects of tumour ablation are usually mild and may last up to 1 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 that goes to the cancer. This reduces the supply of oxygen and energy to the tumour, which can make it shrink or stop growing.

Embolisation on its own is called trans-arterial embolisation (TAE). But it is often given in combination with either of the following:

- Chemotherapy given into a blood vessel going to the liver is called chemoembolisation or trans-arterial chemoembolisation (TACE).
- A type of radiation called radioembolisation or selective internal radiotherapy (SIRT).

These treatments are used when the cancer is only in the liver but cannot be removed with surgery or treated with ablation. Sometimes they might be used before surgery or ablation.

Sometimes a type of embolisation called portal vein embolisation (PVE) might be done before a liver resection. We have more information about having a PVE.

Trans-arterial embolisation (TAE)

This is when embolisation is done without chemotherapy. The procedure is the same as for TACE, except you do not have chemotherapy into the liver

Chemoembolisation (TACE)

A chemotherapy drug is injected into a blood vessel going to the liver. This means the tumour gets a stronger dose of the drugs. You then have an injection of an embolising substance into the blood vessels (arteries) that carry blood to the liver. This blocks the arteries and cuts off the blood supply to the tumour (embolisation).

The chemotherapy drug most often used is doxorubicin. Some people might have another treatment of TACE several weeks later.

We have more information about doxorubicin on our website. Visit macmillan.org.uk/doxorubicin



How chemoembolisation (TACE) is given

You may need to stay in hospital for 1 to 2 nights. Before the treatment, the nurse or doctor usually gives you a mild sedative to help you relax. They then inject some local anaesthetic into the skin at the top of the leg (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 the groin. They pass the catheter along the artery, until it reaches the blood vessels that take blood to the liver and tumour. This is called the hepatic artery.

They also put a dye into the blood vessel through the catheter. This shows the blood supply on an x-ray and shows the doctor where the catheter is. This is called an angiogram.

After this, they inject the chemotherapy drugs or tiny beads coated with chemotherapy directly into the blood vessel going to the tumour. You usually then have an injection of an embolising substance to block these arteries. This cuts off the blood supply to the tumour or tumours in the liver (embolisation).

Some hospitals use beads that gradually release chemotherapy and also block the blood vessels. This is called DEB-TACE. DEB is short for drug-eluting bead.

Side effects

Chemoembolisation can cause side effects such as:

- a high temperature and flu-like symptoms
- pain in the upper right side of the tummy area (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 the liver. Serious complications are rare, but sometimes it can damage the liver.

We have more information about TACE on our website. Visit macmillan.org.uk/TACE



Radioembolisation (SIRT)

Radioembolisation uses radioactive beads to destroy cancer cells as well as the small blood vessels in and around the cancer. Destroying the blood supply may help shrink the cancer.

Radioembolisation is sometimes called selective internal radiotherapy (SIRT) or trans-arterial radioembolisation (TARE).

This treatment can be used if the liver cancer cannot be removed by surgery and:

- the liver is working well (Child-Pugh grade A)
- other treatments such as chemoembolisation (TACE) or targeted and immunotherapy drugs are not suitable.

If there is only 1 bigger tumour in the liver, SIRT might shrink it so that surgery to remove it is possible. It may take months, 1 year or more than a year before SIRT has had its maximum effect.

If there is only 1 large tumour in the liver, SIRT might be used instead of TACE. If the tumour is large and has spread into blood vessels, SIRT might be used instead of targeted or immunotherapy drugs.

How SIRT is given

You usually stay in hospital overnight to have SIRT.

You have different tests before the treatment. This includes an angiogram, which is an x-ray that checks the blood vessels. You usually have this up to 2 weeks before SIRT. It shows the doctor where the SIRT beads should go when they are injected.

You are awake during SIRT. You might have medication to help you to relax and feel sleepy before it.

You have SIRT through a fine tube (catheter). Your doctor puts the catheter into an artery in the top of the leg (groin). They guide it through the artery into a blood vessel that takes blood to the liver. They then inject tiny radioactive beads (microspheres) through the catheter into this blood vessel.

The beads stick permanently in the small blood vessels in and around the liver tumour. They also give off radiation. This damages the cancer cells and destroys the small blood vessels in and around the tumour. Without a blood supply, tumours shrink and may die.

The radiation from each bead only affects tissue nearby. This reduces the risk of damage to healthy cells. The beads lose their radiation quickly. They stay in the liver permanently but are harmless.

There are some precautions you will need to take for a short while after SIRT. These are to protect other people around you. Your doctors and nurses will explain this to you.

Side effects

Side effects can last for a few days and include:

- a high temperature and flu-like symptoms
- · tummy pain
- feeling sick (nausea).

Your doctor will prescribe drugs to control these side effects until they go away. Serious complications are rare. It takes about 1 to 4 months for the tumour to shrink.

We have more information about SIRT on our website. Visit macmillan.org.uk/SIRT



Portal vein embolisation (PVE)

The main blood vessel that carries blood to the liver is called the portal vein. A portal vein embolisation (PVE) is a procedure to block a branch of this vein.

This blocks the blood flow to the part of liver to be removed. The blood flow is redirected to the healthy part of the liver and encourages it to grow. This can make sure there is enough liver left behind after surgery for it to work properly.

You usually have a PVE in the x-ray department. You have a local anaesthetic injection to numb an area of the tummy (abdomen). The doctor uses an ultrasound scan to find the area of the portal vein that supplies blood to the part of the liver with the tumour(s).

They make a small cut in the skin just below the ribcage on the right side of the tummy. Then they gently push a fine tube (catheter) into the portal vein. When the catheter is in place, the doctor injects special glue or very small metal coils into it. This blocks the blood supply to that part of the liver.

PVE usually takes 1½ to 2 hours. You may feel some gentle pushing as the doctor inserts the catheter. Tell them if you feel any pain or discomfort, so they can give you painkillers. You usually stay in hospital overnight after this treatment.

Some people might have a PVE before a liver resection. It is usually done when surgery is possible but there might not be enough remaining liver left afterwards to work properly. If the liver has grown enough after a PVE, you have a <u>liver resection</u> operation about 3 to 6 weeks later. You may have more scans of your liver during this time.



Other treatments for primary liver cancer

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Targeted therapy and immunotherapy drugs

Targeted therapy or immunotherapy drugs might be used if the cancer:

- cannot be removed by surgery
- has spread to the blood vessels in the liver
- has spread outside the liver or other parts of the body.

Targeted therapy drugs target something in or around the cancer cell that is helping it grow. Some targeted therapy drugs also stop the cancer developing new blood vessels.

Immunotherapy drugs use the immune system to find and attack cancer cells.

To have these drugs, your liver still needs to be working well and you need to be generally well. This is because these drugs can have some serious side effects. You need to be well enough to cope with these side effects.

We have more information about how doctors use:

- the Child-Pugh classification system to understand how well the liver is working
- performance status to rate how well you are.

Atezolizumab (Tecentriq®) and bevacizumab

You might be given these drugs together as your first treatment for liver cancer that cannot be removed with surgery or has spread:

- Atezolizumab (Tecentrig®) is an immunotherapy drug.
- Bevacizumab is a type of targeted therapy drug called a monoclonal antibody. It also stops the cancer developing new blood vessels.

You usually have these drugs at a day unit as a drip into a vein. This is called an intravenous infusion. You have these drugs every 3 weeks. We have more information at macmillan.org.uk/treatments-and-drugs

Side effects

Some of the common side effects of this combined treatment are:

- feeling tired or weak
- feeling sick
- having pain in the tummy
- diarrhoea or constipation
- a cough and shortness of breath
- high blood pressure
- soreness of the skin on the palms of the hands and soles of the feet - this is called hand-foot (palmar-plantar) syndrome
- low platelets these are blood cells that prevent bleeding and bruising
- increased risk of bleeding
- thyroid changes.

Effects on the immune system

Immunotherapy drugs like atezolizumab can cause the immune system to become overactive. This can cause inflammation to organs in your body.

Some side effects may be mild to start with. But if they are not treated, they can become serious very quickly.

Always follow the advice your cancer team gives you about side effects. It is important to contact the hospital on the numbers they give you as soon as possible about any side effects.

Side effects can happen weeks, months, 1 year or more than a year after you have stopped taking the drug.

Your cancer doctor, specialist nurse or pharmacist will give you information about side effects. They will give you a card with information about your treatment on it. It is important to have this card with you during treatment and after treatment finishes. You should always show it to any doctor or healthcare professional you need to meet with or who prescribes any other medication for you.

Targeted therapy drugs

There are different types of targeted therapy drugs. Each type targets something in or around the cancer cell that is helping it grow and survive. Targeted therapy drugs called cancer growth inhibitors are often used to treat liver cancer.

Some cancer growth inhibitors are also angiogenesis inhibitors. This means they stop the cancer developing new blood vessels. The most commonly used targeted therapy drugs for hepatocellular carcinoma (HCC) are:

- sorafenib (Nexavar®)
- lenvatinib.

If you have sorafenib and it does not work or stops controlling the cancer, your cancer doctors often prescribe lenvatinib. Or they may prescribe a different targeted drug, such as:

- cabozantinib (Cometriq®, Cabometyx®)
- regorafenib (Stivarga®).

These drugs are taken as capsules or tablets.

Another type of targeted therapy drug called ramucirumab (Cyramza®) might be used if you have already had treatment with sorafenib. It is given as a drip (infusion).

Other targeted therapy drugs may be used in clinical trials. We have more information about clinical trials.

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 cancer doctor, specialist nurse or pharmacist about any side effects you have. They can give you drugs to help control side effects 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.

We have more information about these drugs on our website. Visit macmillan.org.uk/treatments-and-drugs



Side effects

Your cancer doctor or specialist nurse will explain the possible side effects of the drugs you are having. They will give you advice about how these can be managed.

Always tell them about any side effects you have so they can help.

Some common side effects include:

- tiredness
- feeling sick
- diarrhoea
- itchy rash or dry, sensitive skin
- soreness of the skin on the palms of the hands and soles of the feet - this is called hand-foot (palmar-plantar) syndrome
- high blood pressure
- muscle or joint pain
- thyroid changes.

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 ablative radiotherapy (SABR)

Stereotactic radiotherapy is a type of external radiation therapy that targets the tumour. It is also sometimes called stereotactic body radiotherapy (SBRT).

We use the term stereotactic ablative radiotherapy (SABR). Stereotactic radiotherapy is available in specialist centres. Your cancer doctor can give you more information.

You might have SABR instead of ablation treatments or surgery. This could be because the tumour is too large for ablation to work, or you have another medical condition that makes surgery difficult.

Some people have SABR before or after other treatments. It might sometimes be given instead of treatment with targeted and immunotherapy drugs. You usually need a few weeks to recover from any other treatment before you have SABR.

The radiotherapy machine delivers beams of radiotherapy from many different angles. This allows the doctor to give a high dose of radiotherapy to the tumour, while keeping the dose to surrounding tissues low.

You will have your treatment planned using a CT scan. You may also have an MRI scan or a PFT scan.

Some people might have small metal markers placed in or near the tumour. They are sometimes called fiducial markers. The markers help find the exact location of the tumour to make sure the treatment is given accurately.

You may also have markings made on your skin to help the radiographers position you for treatment.

Treatment is usually spread over a few days and may take up to 2 weeks. Your doctor or radiographer will explain how many sessions you need and over how many days.

Side effects

You might get some side effects during treatment or in the days or weeks after it finishes. These are usually mild and go away within a few weeks of finishing your treatment. Your cancer doctor, radiographer or specialist nurse will explain what to expect. They will tell you how the side effects can be managed.

You may have some of the following side effects:

- Feeling sick you will be given anti-sickness tablets to control this.
- Discomfort or pain in the tummy area your doctor can prescribe painkillers to take until this goes away.
- Tiredness make sure you get plenty of rest, but try to do some gentle exercise as well.
- Changes to the skin in the treatment area it might become dry or itchy. If you have white skin, it may become red. If you have black or brown skin, it may become darker. The radiographers will tell you how to look after your skin.

Some side effects can happen months or years after treatment is over. These are called late effects. Your cancer doctor will explain any of these.

We have more information about SABR on our website. Visit macmillan.org.uk/SABR



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, specialist nurse or radiographer will tell you what to expect.

You have the treatment as an outpatient in the hospital radiotherapy department. The radiographer positions 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 and on our website at macmillan. ora.uk/radiotherapy

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells

Chemotherapy for hepatocellular carcinoma (HCC) is usually given directly into the blood vessel that carries blood to the liver. It is often used together with a treatment that blocks the blood supply to the tumour. This is called chemoembolisation.

This information is about chemotherapy given into a vein (intravenously) or taken by mouth as tablets.

Giving chemotherapy into a vein or as tablets is a much less common way of treating HCC. It may be used to try to control the tumour and reduce symptoms. It is not suitable for everyone. The liver may not be working well enough to cope with chemotherapy drugs.

You might have a combination of the chemotherapy drugs oxaliplatin, leucovorin and fluorouracil (5FU). This is called FOLFOX for short. We have more information about FOLFOX on our website. Visit macmillan.org.uk/FOLFOX

How chemotherapy is given

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

Your doctor or nurse will tell you how you will have chemotherapy. You usually have chemotherapy on 1 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.

I had meals I could easily put in the microwave and prepare, because I didn't have the interest or appetite to cook anything. Once I stopped taking the chemotherapy drugs, my appetite came back.

Keith, diagnosed with primary liver cancer

Side effects

Your cancer doctor and specialist nurse will tell you about the likely side effects and how they can be managed.

If you are having chemotherapy directly into the liver, 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.

We have more information about the side effects of chemotherapy in our booklet <u>Understanding chemotherapy</u> and on our website at macmillan.org.uk/chemotherapy

You can order our booklets and leaflets for free. Visit orders.macmillan.org.uk or call 0808 808 00 00.



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.



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 diaphragm is the sheet of muscle under the lungs. The nerves below the diaphragm 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.

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.

We have more information about managing pain in our booklet Managing cancer pain and on our website at macmillan.org.uk/ pain

Sometimes drugs called steroids can relieve pain by reducing swelling around the liver. You usually take them for a few weeks or months. We have more information about steroids on our website. Visit macmillan.org.uk/steroids

Ascites

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

Ascites can be caused by the cancer in the liver. But in hepatocellular carcinoma (HCC), it is often caused by the effects of cirrhosis on the liver. Because the liver is damaged, it cannot make enough blood proteins, so fluid leaks out of the veins into the tummy.

Your doctor will usually prescribe water tablets (diuretics) to try to stop or slow down the build-up of fluid. They might also ask you to follow a low-salt diet.

If the ascites does not improve, you might need a small, fine tube put through the skin of your tummy to drain off the fluid. This usually happens in hospital as a day patient. This relieves the symptoms and helps you feel more comfortable. Your doctor can drain the fluid more than once if needed. Some people might need a drip (infusion) of protein fluids to replace protein that has been lost from the drained fluid.

We have more information about ascites on our website. Visit macmillan.org.uk/ascites



Jaundice

Jaundice in HCC can be caused by the liver not working properly. It can sometimes be caused by a blockage of the bile duct. The bile duct drains bile out of the liver. Bile is a yellow fluid made by the liver that breaks down fats.

When the bile duct is blocked, bile builds up in the liver and flows back into the blood. This causes the symptoms of jaundice. It makes the whites of the eyes and the skin turn yellow, and makes you feel itchy. Your stools (poo) may become pale and your urine (pee) may be very dark.

If you have black or brown skin, yellowing of the skin can be hard to notice. You might notice yellowing of the whites of your eyes, or a change in the colour of your urine first.

Treatments for HCC can shrink the cancer and help to improve jaundice. There are also different ways the symptoms of jaundice can be managed.

If the bile duct is blocked, some people might have a narrow tube put into the bile duct. This is called a stent. The stent helps keep the bile duct open. This allows the bile to flow into the small bowel and relieves the jaundice.

Doctors usually put the stent in using an endoscopic retrograde cholangiopancreatography procedure (ERCP procedure). This uses x-rays and a long, thin, flexible tube with a light and camera at the end called an endoscope.

If an ERCP is not possible, the stent is sometimes put in using a needle through the skin and liver. This is called a percutaneous transhepatic cholangiogram (PTC). We have more information about this procedure on our website. Visit macmillan.org.uk/ptc

You will have antibiotics before and after the procedure. This is to stop you getting an infection. If you have the stent using ERCP, you may be able to go home on the same day. If you have it done using a PTC, you might need to stay in hospital for a few days.

We have more information about jaundice on our website. Visit macmillan.org.uk/jaundice



Tiredness and weakness (fatigue)

Tiredness is a common symptom of cancer in the liver. It may be caused by:

- the cancer itself
- its treatment
- symptoms or side effects.

You may feel you do not have the energy to do everyday activities. Try to pace yourself. Save your energy for the things that matter to you and that you enjoy. Make sure you get enough rest. But try to balance this with some physical activity, such as short walks. We have more information in our booklet Physical activity and cancer.

Tiredness also makes 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 with tiredness in our booklet Coping with fatigue (tiredness).

You can order our booklets and leaflets for free. Visit orders.macmillan.org.uk or call 00808 808 00 00.



Loss of appetite

Some people lose their appetite. This might be a symptom of the cancer or side effect of treatment. If the liver is bigger, it can press on the stomach and make you feel full quickly.

It may help to eat small, frequent meals or snacks instead of 3 meals a day. Ask your nurse or a dietitian for advice. They can give you food or drink supplements. Your doctor may prescribe medicines called steroids to help improve your appetite.

We have more information on coping with eating problems in our booklet Eating problems and cancer.

Feeling sick (nausea)

Sickness may be caused by:

- cancer in the liver changing the chemical balance of the blood
- the liver being bigger and pressing on the stomach
- the 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. Tell your doctor if the tablet 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.

Extremes in body temperature

The liver makes a lot of the body's heat. Cancer in the liver can sometimes cause changes in body temperature. You may feel:

- hot and sweat more often than usual.
- cold and shivery.

If you notice these symptoms, 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.

Your doctor or nurse can prescribe lotions or medicines that can help reduce itching. If itching is affecting your sleep, tell your doctor. Here are some tips to help you cope with itching:

- 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 bathe or shower.
- Dry your skin by patting rather than rubbing.
- Apply non-scented moisturisers (emollients) after a shower or bath.
- If caffeine, alcohol and spices make the itching worse, try to cut down or avoid them.



After your treatment

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Follow-up care for primary liver cancer

After your treatment finishes, you will have regular check-ups.

Your check-ups may include a physical examination and a blood test. Depending on your treatment, you may have regular CT or MRI scans to check the tumour has not come back. Sometimes this might mean having 3 monthly scans for the first 2 years.

We have more information about:

- MRI scans at macmillan.org.uk/mri-scan
- CT scans at macmillan.org.uk/ct-scan

If you had a liver transplant, you will have check-ups more often. 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.

At your appointments, your cancer doctor will ask:

- how you are feeling and whether you have any ongoing treatment side effects
- whether you have any new symptoms.

If you notice any new symptoms between check-ups, tell your GP, cancer doctor or specialist nurse as soon as possible. Your doctor will check what may be causing your symptoms and whether they are caused by your treatment.

Many people <u>feel anxious</u> before their appointments. This is natural. It may help to get support from family or friends. You might also find it helpful to contact a <u>support organisation</u>.



Well-being and recovery

It can take time to recover from treatment. You may also still be coping with symptoms or side effects of your treatment. It is important to take care of yourself and to let your cancer team know if you are having problems.

Some people might also choose to make some positive lifestyle changes. You may have already followed a healthy lifestyle before you had cancer. We have more information about keeping healthy and adjusting to life after treatment in our booklets:

- Life after cancer treatment
- What to do after cancer treatment ends: 10 top tips
- Your feelings after cancer treatment.

Coping with tiredness

You are likely to feel very tired after treatment. 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 with practical tasks such as cleaning or cooking. 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 (tiredness).

Alcohol

It is important to check with your doctor before drinking alcohol. Alcohol can damage the liver and reduce its ability to work well. If you had cirrhosis before being diagnosed with liver cancer, continuing to drink alcohol can make the cirrhosis even worse. You will usually be advised to stop drinking completely.

<u>Surgery and some other treatments</u> also depend on how well the healthy parts of the liver are working.

Even if alcohol has not affected your liver, you might be asked to stop drinking for a time before and after treatment. Your liver may not be able to cope with alcohol.

Ask your specialist doctor or nurse for advice. They can give you advice and information about support to help stop drinking. <u>Drinkaware</u> has more information about drinking guidelines.

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 in our booklets:

- Eating problems and cancer
- Healthy eating and cancer
- The building-up diet.

Stopping smoking

If you smoke, talk to your doctor for advice on stopping.

We have more information on stopping smoking and tips to help you stop. Visit macmillan.org.uk/stop-smoking

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. We have more information in our booklet Physical activity and cancer.

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 about complementary therapies in our booklet Cancer and complementary therapies.

You can order our booklets and leaflets for free. Visit orders.macmillan.org.uk or call 0808 808 00 00.







Your feelings and relationships

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Your feelings

It is common to have many different feelings when you are told you have cancer. You may feel shocked, scared, depressed, guilty or angry. This can be difficult to cope with. Partners, family and friends may also have some of the same feelings.

We have more information about emotions in our booklet. How are you feeling? The emotional effects of cancer and on our website at macmillan.org.uk/emotions

Your healthcare team will usually give you support. But you may feel you need more help. Talk to your cancer doctor, GP or specialist nurse. They can refer you to a specialist doctor, psychologist or counsellor who can help.

You can also call the Macmillan Support Line on 0808 808 00 00 and talk to one of our cancer support specialists.

Talking to family, friends or other people affected by cancer may help. For more information or for help finding local support groups, visit macmillan.org.uk/supportgroups Or talk to other people on our Online Community at macmillan.org.uk/community

There is more information about other ways we can help you.

Relationships

Cancer and its treatment are stressful and may affect your relationships. Your experience of cancer may strengthen your relationships with people close to you. Or it may put a strain on relationships. Any problems usually improve over time, especially if you talk openly with each other.

We have more information about relationships in our booklets:

- Talking about cancer
- Cancer and relationships: support for partners, families and friends.

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 can support the person with cancer by listening and talking with them.

We have more information about supporting someone in our booklet Talking with someone who has cancer and on our website. Visit macmillan.org.uk/supporting-someone

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 and on our website. Visit macmillan.org.uk/carers

You can order our booklets and leaflets for free. Visit orders.macmillan.org.uk or call 0808 808 00 00.



Talking to children and teenagers

Deciding what to tell children or teenagers about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. It may be best to start by giving them small amounts of information, and then tell them more when they are ready.

Use simple, straightforward language to explain what is happening. You can encourage them to talk to someone they trust, who can support them. They may also find support online.

We have more information in our booklet Talking to children and teenagers when an adult has cancer.

You can order our booklets and leaflets for free. Visit orders.macmillan.org.uk or call 0808 808 00 00.







Money and work

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Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information on our website about Statutory Sick Pay and benefits you may be entitled to, as well as information for carers Visit:

- macmillan.org.uk/sick-pay
- macmillan.org.uk/carers-allowance

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- gov.uk if you live in England or Wales
- socialsecurity.gov.scot if you live in Scotland
- <u>nidirect.gov.uk</u> if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. You can get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland.

Our booklet Help with the cost of cancer has lots more information.

You can order our booklets and leaflets for free. Visit orders.macmillan.org.uk or call 0808 808 00 00.



Macmillan helped put me on Attendance Allowance, which I had not realised I was entitled to. They arranged everything for me. That was a great help. "

Keith, diagnosed with primary liver cancer

Grants

You may be able to get some financial help from other charities for example, a one-off grant. For further information, contact the Macmillan Support Line on 0808 808 00 00.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. We have information about insurance on our website. Visit macmillan.org.uk/insurance-cancer

We have more information about travel insurance in our booklet Travel and cancer. Our Online Community forum on Travel insurance may also be helpful. Visit macmillan.org.uk/community

You can order our booklets and leaflets for free. Visit orders.macmillan.org.uk or call 0808 808 00 00.



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 or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

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

Your cancer doctor, GP or specialist nurse can help you decide whether you should stop working, and when and if you should go back to work.

Our booklets have more information that may be helpful:

- Work and cancer
- Working while caring for someone with cancer
- Self-employment and cancer.

You can also find out more about your employment rights in our booklet Your rights at work when you are affected by cancer.

There is also lots more information online at macmillan.org.uk/work



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About our information

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

Our information has the PIF Tick quality mark for trusted health information. This means our information has been through a professional and strong production process.

Order what you need

You may want to order more booklets or leaflets like this one. Visit orders.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

- interactive PDFs
- 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 informationproductionteam@macmillan.org.uk or call us on 0808 808 00 00.

The language we use

We want everyone affected by cancer to feel our information is written for them

We want our information to be as clear as possible. To do this, we try to:

- · use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

To find out more about how we produce our information, visit macmillan.org.uk/ourinfo



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 support line is made up of specialist teams who can help you with:

- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our nurses about things like diagnosis and treatments from our nurse specialists
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on 0808 808 00 00. Or visit macmillan.org.uk/support-line to chat online and see the options and opening times.

Our trained cancer information advisers can listen and signpost you to further support.

Our cancer information nurse specialists can talk you through information about your diagnosis and treatment. They can help you understand what to expect from your diagnosis and provide information to help you manage symptoms and side effects.

If you are deaf or hard of hearing, call us using Relay UK on 18001 0808 808 00 00, or use the Relay UK app.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to macmillan.org.uk/talktous

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call 0808 808 00 00 and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Macmillan Information and Support Centres

Our Information and Support Centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

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

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. Please note the opening times may vary by service.

Financial advice

Our expert money advisers on the Macmillan Support Line can help you deal with money worries and recommend other useful organisations that can help.

Help accessing benefits

You can speak to our money advisers for more information. Call us free on 0808 808 00 00. Visit macmillan.org.uk/financialsupport for more information about benefits.

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 <u>macmillan.org.uk/work</u>

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 bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, family member or friend, 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

You can also use our Ask an Expert service on the Online Community. You can ask a money adviser, cancer information nurse or an information and support advisor any questions you have.

Macmillan healthcare professionals

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.

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

Liver cancer support organisations

British Liver Trust

Helpline **0800 652 7330**

www.britishlivertrust.ora.uk

Works to increase awareness of liver disease, including liver cancer. Provides information and support to people affected. Has a nurse-led helpline and produces leaflets on liver disease.

Guts UK

Tel 0207 486 0341

www.gutscharity.org.uk

Produces information and leaflets on common digestive diseases and illnesses, including liver cancer.

General cancer support organisations

Cancer Black Care

Tel 0734 047 1970

www.cancerblackcare.org.uk

Provides support for all those living with and affected by cancer, with an emphasis on Black people and people of colour.

Cancer Focus Northern Ireland

Helpline 0800 783 3339

www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland.

Children's Cancer and Leukaemia Group (CCLG)

Tel **0333 050 7654**

www.cclg.org.uk

Provides information for young people with cancer and their families. Brings together professionals, and funds research into childhood and teenage cancers.

Maggie's

Tel **0300 123 1801**

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 300 0118

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

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.

General health information

Drinkaware

www.drinkaware.co.uk

Provides independent alcohol advice, information and tools to help people make better choices about their drinking. Also has a web chat, for anyone concerned about their own drinking, or someone else's.

Health and Social Care in Northern Ireland

www.northerntrust.hscni.net

Provides information about health and social care services in Northern Ireland.

NHS.UK

www.nhs.uk

The UK's biggest health information website. Has service information for England.

NHS 111 Wales

111.wales.nhs.uk

NHS health information site for Wales.

NHS Inform

Helpline **0800 224 488**

www.nhsinform.scot

NHS health information site for Scotland.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel 0145 588 3300

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 the 'Therapist directory' page.

Emotional and mental health support

Mind

Helpline **0300 123 3393**

www.mind.org.uk

Provides information, advice and support to anyone with a mental health problem through its helpline and website.

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

adviceni.net

Provides advice on a variety of issues including financial, legal, housing and employment issues.

Citizens Advice

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

England

Helpline 0800 144 8848 www.citizensadvice.org.uk

Scotland

Helpline 0800 028 1456 www.cas.org.uk

Wales

Helpline **0800 702 2020** www.citizensadvice.org.uk/wales

Disability and Carers Service

Tel 0800 587 0912

Textphone 0800 012 1574

nidirect.gov.uk/contacts/disability-and-carers-service

Manages Disability Living Allowance, Attendance Allowance, Carer's Allowance and Carer's Credit in Northern Ireland. You can apply for these benefits and find information online or through its helplines.

GOV.UK

www.aov.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 1111**

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.

Living Made Easy

Helpline 0300 123 3084

www.livingmadeeasy.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

www.aaeuk.ora.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**

labt.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.

OUTpatients

www.outpatients.org.uk

A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. OUTpatients runs a peer support group with Maggie's Barts.

Support for carers

Carers UK

Helpline **0808 808 7777**

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 **0207 520 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**

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 is 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 a cancer registry in each country in the UK. They are run by the following organisations:

England - National Disease Registration Service (NDRS)

digital.nhs.uk/ndrs/patients

Scotland - Public Health Scotland (PHS)

publichealthscotland.scot/our-areas-of-work/conditions-and-diseases/ cancer/scottish-cancer-registry-and-intelligence-service-scris/overview

Wales - Welsh Cancer Intelligence and Surveillance Unit (WCISU)

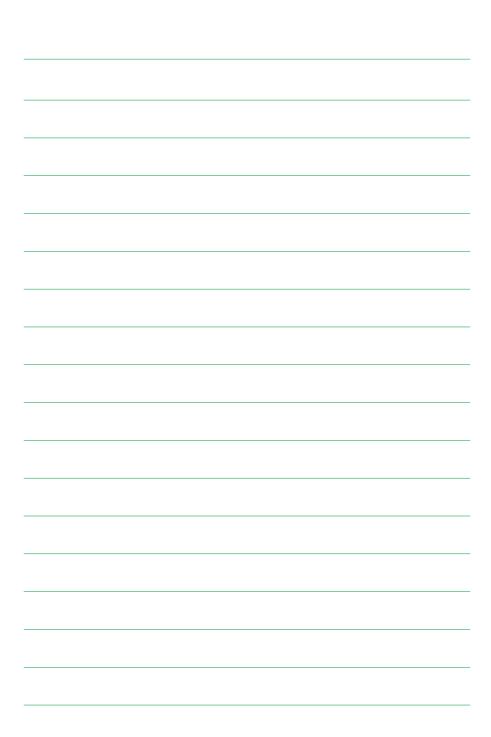
Tel **0292 010 4278** phw.nhs.wales/wcisu

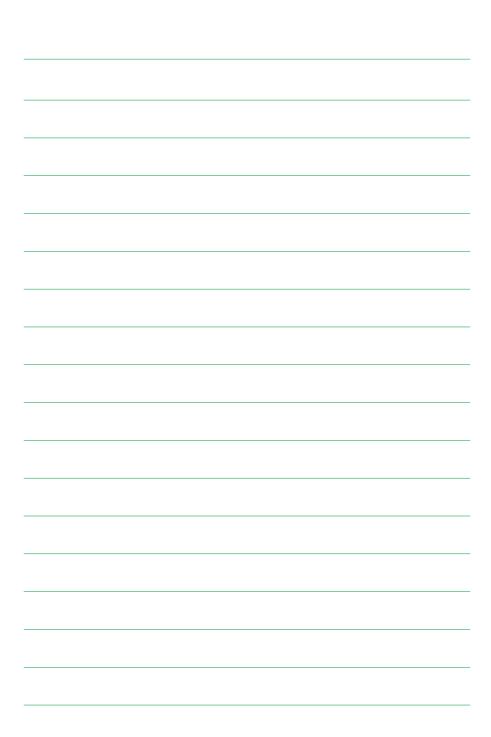
Northern Ireland - Northern Ireland Cancer Registry (NICR)

Tel 0289 097 6028

gub.ac.uk/research-centres/nicr/AboutUs/Registry

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, revised 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.

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

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

Sources

Below is a sample of the sources used in our primary liver cancer information. If you would like more information about the sources we use, please contact us at informationproductionteam@ macmillan.org.uk

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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, money 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 1.

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

2. 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 3.

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 4.

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

5. Give money

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

Please fill in your personal details	Do not let the taxman		
Mr/Mrs/Miss/Other	keep your money		
Name	Do you pay tax? If so, your gift will be worth 25% more to us -		
Surname	at no extra cost to you. All you		
Address	have to do is tick the box below,		
Postcode	and the tax office will give 25p for every pound you give.		
Phone	I am a UK tax payer and		
Email	I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the		
Please accept my gift of £ (Please delete as appropriate)			
I enclose a cheque / postal order /	last 4 years as Gift Aid donations,		
Charity Voucher made payable to	until I notify you otherwise.		
Macmillan Cancer Support			
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Date / /			







This booklet is about the most common type of primary liver cancer, hepatocellular carcinoma (HCC or hepatoma). It is for anyone diagnosed with HCC and for their carers, family members and friends.

This booklet explains what HCC is and how it may be treated. It also has information about controlling symptoms and coping with emotional, practical and financial issues.

At Macmillan we know cancer can disrupt your whole life.
We'll do whatever it takes to help everyone living with cancer in the UK get the support they need right now, and transform cancer care for the future.

For information, support or just someone to talk to, call 0808 808 00 00 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 Relay UK on 18001 0808 808 00 00, or use the Relay UK app.

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