

Liver cancer

Your guide to understanding and living with all types of liver and biliary cancer



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This booklet tells you about different types of liver cancer, what causes them and how they're diagnosed and treated. There is information on living with cancer and on where to find the support you need.

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There is no right or wrong way to deal with a liver cancer diagnosis, only your way.

Jackie was diagnosed with HCC liver cancer in 2021



You can read more detailed information on our website.

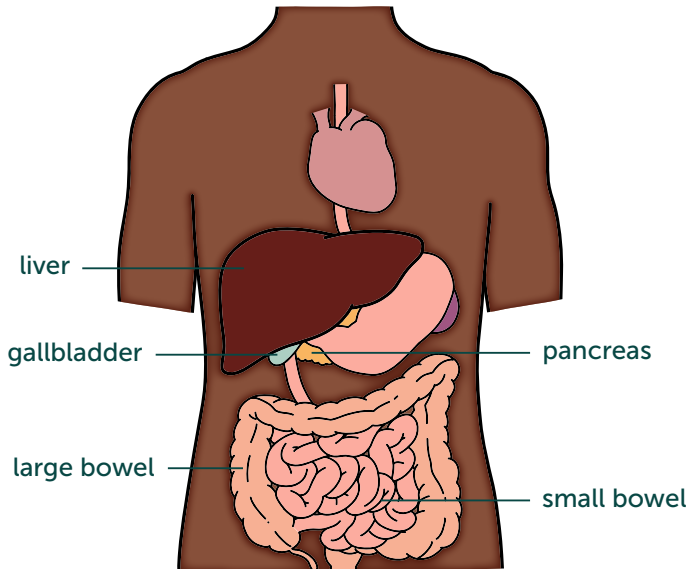
Scan the code with your phone or visit www.livercancer.org.uk



Liver Cancer UK is part of the British Liver Trust. We provide support and information for people affected by all types of liver and biliary cancers. And work in partnership to raise awareness, campaign for policy change and improve care.

About your liver

Your liver is on the right side of your tummy, just under your ribs. It works like your body's factory and carries out hundreds of jobs that help keep you alive and well.

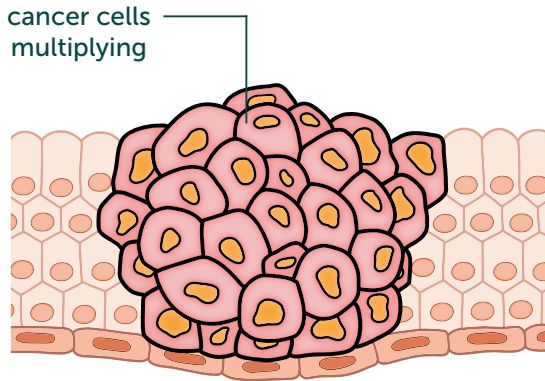


Your liver:

- turns digested food from your gut into all the different chemicals your body needs
- breaks down toxins, alcohol, drugs and other harmful substances
- helps control the amount of sugar in your blood
- makes the chemicals that help your blood clot.

What is cancer?

Cancer is a condition where body cells become abnormal. The abnormal cells grow and multiply in an uncontrolled way. Cancer can also be called a tumour, lump or lesion.



The cancer cells grow until they form a lump – a tumour. The tumour grows into surrounding areas of normal body tissue. They can sometimes break away and spread to other parts of the body.

There are as many different types of cancer as there are types of cells in the body. Where the cancer starts is called the 'primary' cancer. In liver cancer, it is liver cells or bile duct cells that have become abnormal. This booklet is about primary liver cancer.

Many people who say they have liver cancer will actually have a cancer that started somewhere else and spread to their liver. They have 'secondary' liver cancer.

Visit www.livercancer.org.uk/secondary-liver-cancer for more information.

Types of liver cancer

Over 7,300 people are diagnosed with cancer that started in their liver or gallbladder every year in the UK. There are several different types.

Hepatocellular liver cancer (HCC) is the commonest type. It starts in hepatocytes – the main working cells of the liver. It's diagnosed in men more often than women. HCC can affect people at any age, 7 in 10 cases are diagnosed in people over 65.

Bile duct cancer or cholangiocarcinoma starts in cells lining the bile ducts. These tubes carry bile from inside the liver to the gallbladder and on to the small bowel, where it helps us to digest fat. It may start inside (intrahepatic) or outside (extrahepatic) the liver. The commonest liver cancer in women is intrahepatic bile duct cancer.

Fibrolamellar liver cancer is sometimes called a subtype of HCC. It's much rarer and is usually diagnosed in younger people who have otherwise healthy livers.

Gallbladder cancer is sometimes called biliary cancer. It starts in cells lining the gallbladder.

There are some even rarer liver cancers:

Angiosarcoma starts in cells lining blood vessels.

Hepatoblastoma is a type of liver cancer most often diagnosed in very young children.

This booklet doesn't cover these rarer types.

Risks and causes of liver cancer

We can't always explain why some people get cancer and others don't. But there are things that we know increase risk. These are called risk factors. Having a risk factor doesn't mean you will definitely get liver cancer.

Age Most liver cancers are diagnosed in older people. Over 4 out of 10 people are 75 or more.

Damage to your liver Risk of HCC and bile duct cancer is increased if you have cirrhosis (serious liver scarring). This may be caused by:

- infection with Hepatitis B or C
- drinking alcohol
- other liver diseases, including primary biliary cholangitis (PBC) and non-alcohol related fatty liver disease (NAFLD)

Weight Being overweight may cause up to 1 in 4 liver cancers. It's linked to NAFLD, which is caused by a build up of fat in the liver. It also increases your risk of type 2 diabetes.

Diabetes This may cause liver scarring. Or the increased risk may be due to having higher levels of insulin than normal.

Smoking This can make other liver cancer risk factors such as hepatitis infection or alcohol more damaging.

Symptoms

Liver cancer may not have many symptoms to start with. If you do have symptoms, you are most likely to:



- feel sick
- lose your appetite
- lose weight without trying to

Other symptoms you may develop include:

- pain on the upper right side of your tummy (abdomen), which may spread to your shoulder or back
- feeling generally ill and lacking in energy
- a lump in your tummy
- a swollen tummy caused by fluid collecting – doctors call this ascites (say: ass-sight-ease)

If your liver cancer blocks the flow of bile into your small bowel, it can cause jaundice (say: jawn-diss). This causes:

- yellowing of the skin and whites of the eyes
- dark wee
- pale coloured poo
- itching

These symptoms can be caused by other conditions but you should see your doctor if you develop any of them.

Diagnosing Liver Cancer

There are a number of tests you may have if your doctor suspects you have a liver cancer.

There is more detailed information about liver cancer tests on our website at www.livercancer.org.uk/tests

Blood tests

If your GP suspects a problem with the liver, they'll do a series of liver blood tests. Or they may refer you straight to a specialist, who will do them.

These show how well your liver is working. If you already have liver disease, you may be having these done regularly already.

The doctor may also test for alpha fetoprotein (AFP). Blood levels of AFP can be raised in some people with hepatocellular cancer (HCC). It can be raised for other reasons, so doesn't necessarily mean you have cancer.

Ultrasound scan

This painless scan uses sound waves to build up a picture of the liver and bile ducts. The radiographer moves the ultrasound probe back and forth over the skin above your liver. It takes about half an hour.

If your ultrasound shows any suspicious areas in your liver, your doctor will ask you to have a CT or MRI scan.

CT scan

This scan takes a series of X-rays in cross section across your body. A computer joins them to give a detailed picture of your body organs. It takes about half an hour and is painless.

Your doctor may ask you not to eat or drink for a few hours beforehand. You may have a drink or injection of medical dye just before your scan, to help make it clearer.



MRI and MRCP scans

This scan uses strong magnets to create a very detailed image. It shows up soft tissues more clearly than a CT scan. Some people can't have an MRI because they have metal in their body.

The scan takes about 30 minutes. A special type of MRI, called an MRCP takes a little longer. This looks at your gallbladder, bile ducts and pancreatic duct in more detail.

MRIs are painless, but noisy. You will have earplugs and headphones to wear. The scanner is a tube that makes some people feel shut in (claustrophobic). Tell your doctor if you think it'll be a problem. The scan takes about half an hour.

You may have an injection of medical dye before your MRI scan or pineapple juice to drink before an MRCP. This helps to make the scan clearer.

Endoscopy

An endoscope is a long tube with a camera on the end that you swallow. Your doctor can use it to look at your digestive system from the inside. They'll ask you not to eat or drink for 4-6 hours beforehand.

The doctor will numb your throat before putting the tube in. They pass the tube down your throat, through your stomach and into the first part of the small bowel (the duodenum). They can see the liver and bile ducts through the wall of the small bowel and take tissue samples (biopsies) of anything that looks abnormal.

You can have a sedative beforehand if you're anxious. If you do, you'll need someone to take you home afterwards.

Endoscopic ultrasound

This is an ultrasound done from inside your body. The doctor attaches the ultrasound probe to the endoscope. Then the test is the same as having an endoscopy.

ERCP

This is another type of endoscopy. It takes about 2 hours.

Once the endoscope is in place, the doctor can put an even smaller tube right into the bile ducts and take tissue samples to check for cancer. They can also put a small tube (stent) in to help drain a blocked bile duct.

PET scan

This shows activity in body tissues, which helps doctors tell the difference between cancer and scar tissue. You can't eat for a few hours beforehand and mustn't exercise for a day before, as it affects the results.

First, you have a 'radiotracer' injection and then rest quietly for an hour. The injection contains a small dose of radiation which will be out of your body within a few hours. It doesn't keep long, so you must be on time or your scan may be cancelled.

The scan itself takes an hour. Afterwards, you shouldn't get too close to pregnant women or babies for a few hours, because of the radiation.

PTC

This test shows up abnormalities or blockages in your bile ducts. You will be in hospital for at least one night.

You have a local anaesthetic injection to numb the area over your liver. Then the doctor puts a thin needle through the skin and into the liver. They inject dye into a bile duct, so it shows up more clearly on X-ray. They can also take a tissue sample (biopsy) from the liver or put in a stent to help drain bile.

Having a biopsy taken

Your doctor may need a sample of your liver (a biopsy) to check for cancer. There are different ways of doing this. The doctor is most likely to do it by numbing the area and putting a needle through the skin, into the liver.

There's a risk of bleeding afterwards, so you have to rest in bed for 6 hours and may be in hospital overnight.

Molecular Profiling

This means testing a sample of your cancer to see which specific gene changes (mutations) the cancer cells have.

This tells your doctor which targeted therapy drugs are likely to work for you. These treatments will only help if your cancer cells have the target that each drug attacks.



After your tests

It can take a week or two to get your results. A 'multidisciplinary' medical team (MDT) will discuss them and decide on the best plan for you.

Waiting for results can be nerve wracking. It may help to tell a close friend or relative how you're feeling. Or you can call the British Liver Trust helpline on 0800 652 7330 and talk things over with one of our specialist liver nurses.

What your tests show – grade and stage

If you have liver cancer, your tests will show what type it is. A biopsy can show how abnormal the cancer cells looked. This is called the 'grade' of the cancer and may indicate how fast or slowly it is likely to grow.

Your tests will also show exactly where the cancer is and how far it's grown. This is the '**stage**.' This gives your doctors a guide to the best treatment for you.

The staging system your doctors use depends on the type of liver cancer. They may use the

- TNM system - Tumour, (lymph) Node and Metastasis (cancer spread)
- Bismuth-Corlette system for bile duct cancer
- Barcelona staging system, for HCC.

Child-Pugh score is a way of measuring the impact of liver disease. As well as your test results, it includes your general health and some symptoms of liver damage.

Questions to ask



Ask your doctor to explain your test results, stage and how this affects your treatment options.

Below are some suggestions.

- What kind of cancer do I have?
- Is it curable or controllable?
- Why did I get it – do I have liver disease that has caused it?
- Have my tests shown how far the cancer has grown?
- Can I have copies of my results sent to me?
- Should I have treatment at a specialist centre?
- Do I need surgery?
- What other treatments do I need?
- I've heard about personalised treatment – what is it and will I get that?

During your treatment you will be assigned a named clinical nurse specialist. They are your main point of contact and you can call them about results, follow ups, and to ask any questions you have.

Treatment for liver cancer

Your treatment will depend on the type of liver cancer you have, how far it's grown (the stage), how well your liver is working and your general health. Below, we've put a summary for each type of liver cancer. After that, there's an explanation of each treatment.

Treatment for hepatocellular cancer (HCC)

As with just about all types of cancer, the treatment you'll have depends on the stage of the cancer.

Early stage HCC (Barcelona stage 0-A)

The aim of treatment is to try and cure your cancer.

You are most likely to have surgery. The type of surgery depends on whether you have any other liver disease. Your surgeon may remove the part of your liver containing the cancer. This operation is called **liver resection**.

If your remaining liver would be unlikely to cope after a resection, your surgeon will suggest a **liver transplant** instead. While you are waiting for a donor, you may need other treatment to control the cancer. Your doctor may call this 'bridging therapy'. You may have treatments to destroy or shrink your liver tumours, called **radiofrequency ablation (RFA)** or **trans arterial chemo embolization (TACE)**.

If other health conditions mean you aren't well enough to have a major operation, you may have **radiotherapy** instead. This may be treatment aimed from outside the body (stereotactic radiotherapy). Or it may be internal treatment with radioactive beads, placed next to the liver tumour(s) – called **Selective Internal Radio Therapy (SIRT)** or **Trans Arterial Radio Embolization (TARE)**.

Intermediate stage HCC (Barcelona stage B)

The aim of treatment is to control your cancer. Sometimes the treatment can 'downstage' your cancer. This means that the treatment has reduced your cancer to early stage. Then you may be able to have surgery to try and cure it.

You may have treatment with **trans arterial chemo embolization (TACE)** or **trans arterial radio embolization (TARE)**.

Advanced stage HCC (Barcelona stage C)

The aim of treatment is to try and control the cancer for as long as possible. Your doctor is most likely to suggest a type of treatment called targeted therapy. You may have a combination of drugs called bevacizumab and atezolizumab. Or a drug called sorafenib.

Very advanced stage HCC (Barcelona stage D)

This means you are very unwell because of damage to your liver. This may be from the cancer or from other liver disease that you already have.

Because of this damage, you are unlikely to be well enough to withstand most of the treatments used for HCC. Your doctor is most likely to suggest treatment to control your symptoms and help you to feel better.

As well as medicines for symptoms such as pain or sickness, you may have **radiotherapy** if your cancer has spread to your bones and is causing pain. You may have **fluid removed from your tummy (ascites)** or a **small tube (stent)** put in to **help drain bile** and relieve jaundice.

HCC that comes back (recurrent HCC)

Your treatment will depend on whether the cancer has come back in your liver or has spread to another part of your body.

For cancer that's come back in the liver, you may have

- more surgery to remove it
- a liver transplant
- treatment to destroy the new liver tumours (ablation)
- TACE – localised chemo into the liver together with blocking the cancer's blood supply
- TARE – localised radiotherapy into the liver, together with blocking the cancer's blood supply

If the cancer has come back elsewhere, local treatment won't help. Your doctor is most likely to suggest targeted therapy. You may have a combination of drugs called bevacizumab and atezolizumab. Or a drug called sorafenib. This will circulate through your bloodstream. So it will treat the cancer wherever it is.

For more information about Barcelona staging for HCC liver cancer visit www.livercancer.org.uk/hcc-staging

And for more information about liver transplants visit www.britishlivertrust.org.uk/transplants

Treatment for bile duct cancer (or cholangiocarcinoma)

Your treatment will depend on whether it's possible to remove your cancer with surgery.

Bile duct cancer that can be removed

If you have an early cancer, it may be possible to cure it with surgery. The operation will depend on where the cancer is.

If you have intrahepatic bile duct cancer, you may have part of your liver removed.

If you have extrahepatic bile duct cancer, you'll have the bile ducts outside the liver and the gallbladder removed. You may need part of your pancreas or small bowel removed as well.

You may have chemotherapy after your surgery, to reduce the risk of the cancer coming back.

Bile duct cancer that can't be removed

If your cancer can't be removed, your doctor will concentrate on trying to control the cancer and slow its growth. You may have **chemotherapy** or **radiotherapy**. If your cancer is causing jaundice, you may have a **small tube (stent) put in to help drain bile** and relieve your symptoms.

Bile duct cancer that is advanced or has come back

The aim of treatment is to try and shrink the cancer and control it for as long as possible. You may have:

- a stent to unblock a bile duct
- chemotherapy
- radiotherapy
- a targeted (biological) therapy
- treatments to relieve symptoms

Treatment for fibrolamellar liver cancer

The treatment you'll have depends on whether it's possible for your doctor to remove the cancer with **surgery**.

This is more likely than with HCC because people with fibrolamellar cancer tend to be younger with otherwise healthy livers. The liver is able to grow back, so it's possible to have a lot of it removed safely.

If your cancer can't be removed, your doctor may suggest **chemotherapy**. Because fibrolamellar liver cancer is quite rare, your doctor may suggest joining a clinical trial to test new treatments.

Treatment for gallbladder cancer

The main treatment for gallbladder cancer is surgery. The aim of the treatment is to try and cure your cancer.

The exact operation you'll have depends on the size of the cancer and how far it's grown. You may have just your gallbladder removed for a very early cancer. But it'll be a bigger operation for most gallbladder cancers, which may involve removing part of your liver and your external bile ducts. For the largest tumours, your surgery may include removing part of the pancreas and small bowel (the duodenum) as well.

If you can't have surgery, your doctor may suggest **chemotherapy**. The aim of this is to shrink the cancer to try and relieve your symptoms and control it for as long as possible.

Types of treatment for liver cancers

Depending on your type of liver cancer, there are a number of different treatments you may have. Which is suitable also depends on how far your cancer has grown (the stage), your general health and the effect of any other liver disease you've had.

There is more detailed information about liver cancer treatment on our website at www.livercancer.org.uk/treatments



Surgery

The type of operation you'll have will depend on the type of cancer and its stage.

Preparing for your operation

It'll help you recover if you make sure you are as well as possible. If you smoke, you should stop if you can, or at least cut down. It'll lower your risk of complications after your operation, such as chest infections and blood clots.

You will have some tests before your surgery, to make sure you're well enough for the anaesthetic and to make a good recovery. These will include blood tests and a chest X-ray. A physio will teach you breathing and leg exercises to do after your operation. You may also have advice on diet and exercise.

You may not have much notice, but whatever you can do will help. If you're waiting for a transplant, your team can give you help and advice on getting fitter.

After surgery

When you come round, you'll be in the recovery room. Once you're fully awake, you'll go back to the ward or to a high dependency unit.

If you're in pain or feel sick, you can have medicines to help. Doing your breathing and leg exercises regularly will help lower the risk of infection and blood clots.

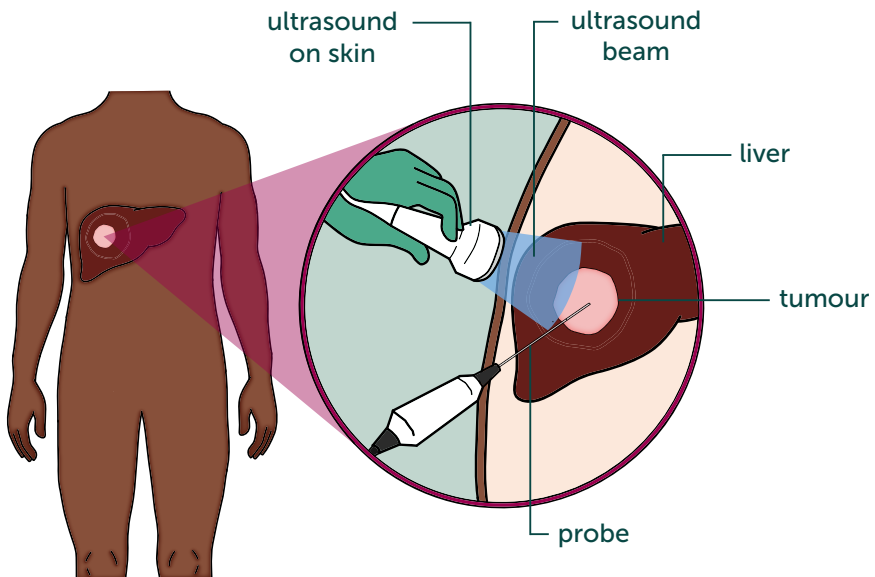
How long you'll be in hospital will depend on the operation you've had. Your nurse will give you an outpatient appointment before you leave. You'll also have a phone number to call if you have any problems.

Ablation

This is treatment to destroy liver tumours with heat, produced by either microwaves or radiowaves (radiofrequency ablation or RFA). You have treatment in hospital and usually stay overnight.

You may have a local or general anaesthetic, or a sedative to make you drowsy. Your doctor will ask you not to eat for 4-6 hours beforehand.

The doctor puts a needle through your skin and into the liver tumour. Once it's in place, the doctor switches on the power and the needle heats up.



Ablation side effects

These are caused by the cancer cells dying and breaking down. They may last for up to 10 days and include fever, feeling sick, tiredness, and aches and pains. Contact your doctor if your temperature goes above 38C – you might have an infection.

Embolization (TACE or SIRT/TARE)

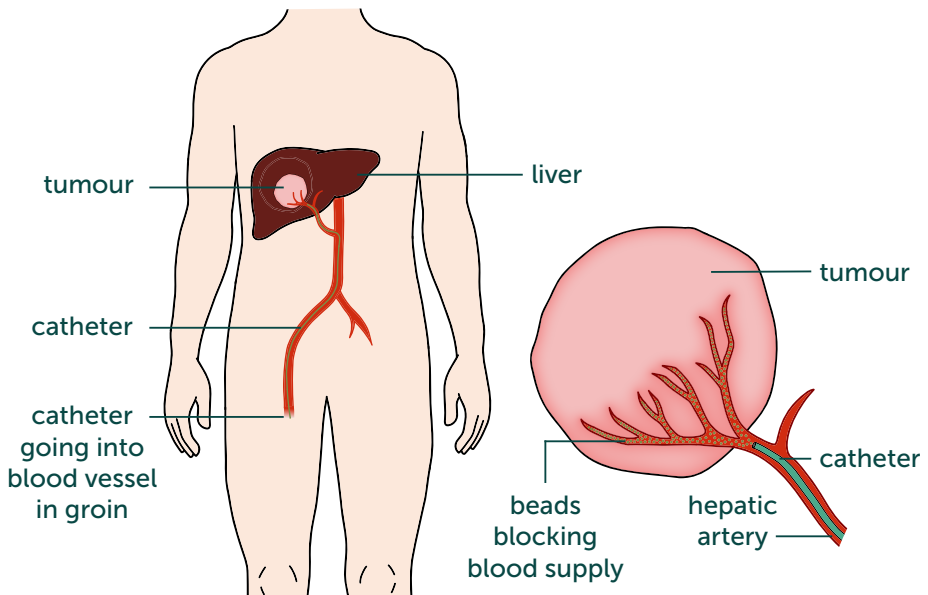
This is a treatment to cut off a tumour's blood supply, so it doesn't get any food or oxygen from your blood. The cancer may shrink or disappear completely.

The doctor uses tiny beads to block the blood supply. The beads may be plain (embolization). Or they may be loaded with chemo (TACE) or radiation (SIRT/TARE), which helps to kill the cancer cells.

Having embolization or TACE

First, you have a sedative, so you'll be drowsy during the procedure. The doctor puts a tube (catheter) into a major blood vessel (artery) in your wrist or groin. They feed this up until it reaches your liver, watching on an X-ray to make sure it goes to the right place.

Once the catheter is in place, the doctor injects the beads and takes the catheter out.



After these procedures, you have a pressure dressing put on to your wrist or groin. You'll need to rest in bed to reduce the risk of bleeding. You'll be able to eat and drink normally once you've got over the sedative. You may need to stay overnight.

Having SIRT or TARE

There's an extra step if you're having SIRT / TARE. You need to have a test called a planning angiogram about 2 weeks before you have the embolization. You may need to stay overnight for each procedure.

For the planning angiogram, the doctor injects dye that shows up on an X-ray. The dye highlights the cancer's blood supply. The doctor may then block some small blood vessels to make sure the beads stay in your liver when you have the embolization treatment a couple of weeks later. The procedure for that is the same as for TACE. The doctor injects radiation-loaded tiny glass beads instead.

Embolization side effects

You don't usually have side effects from the chemo or radiation, as it's blocked in your liver. But you may have side effects from the embolization for up to 10 days. These include fever, feeling sick or tired, and aches and pains. This is a sign that the cancer is breaking down. Contact your doctor if your temperature goes above 38C as you may have an infection.

Radiation safety with SIRT

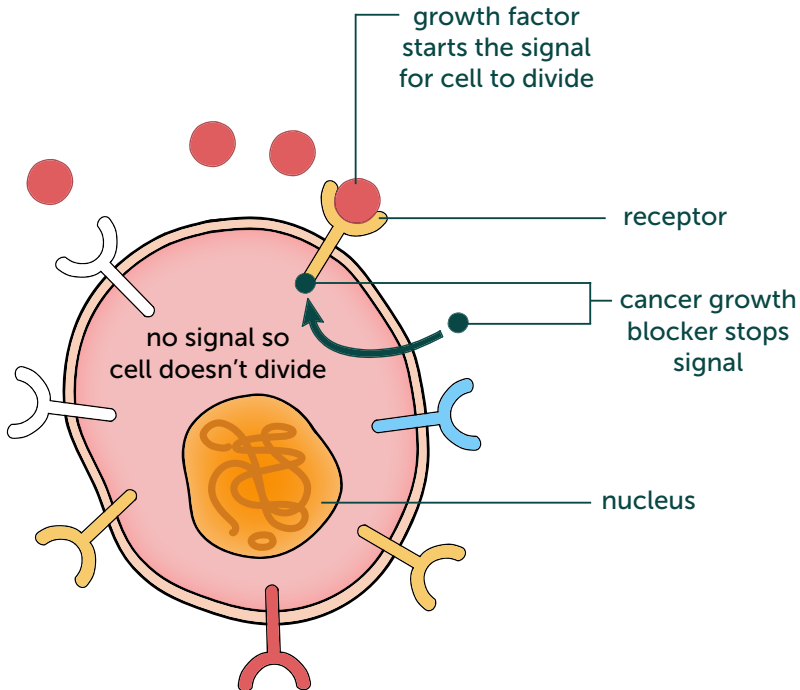
Although radiation from the beads only travels a few millimetres, your doctor may ask you to take a few precautions for a couple of days. You should wash your hands thoroughly after using the toilet. It's best not to have close contact with babies or pregnant women, just in case. Your doctor may suggest you sleep on your own for the first couple of nights too. All the radiation will be gone in a couple of weeks. The glass beads are harmless and can stay where they are.

Targeted therapy

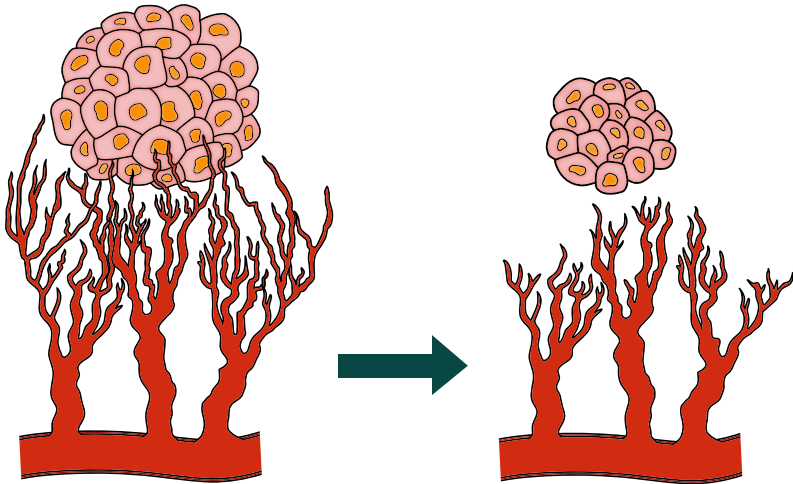
Targeted cancer medicines are also sometimes called biological therapies. They target altered genes (mutations) in cancer cells. Before you have treatment, your cancer cells may be checked to make sure they have the mutation the drug targets. This is called molecular testing.

There are a number of different types. Which you have depends on the type of liver cancer you have and on the results of the tests on your cancer cells.

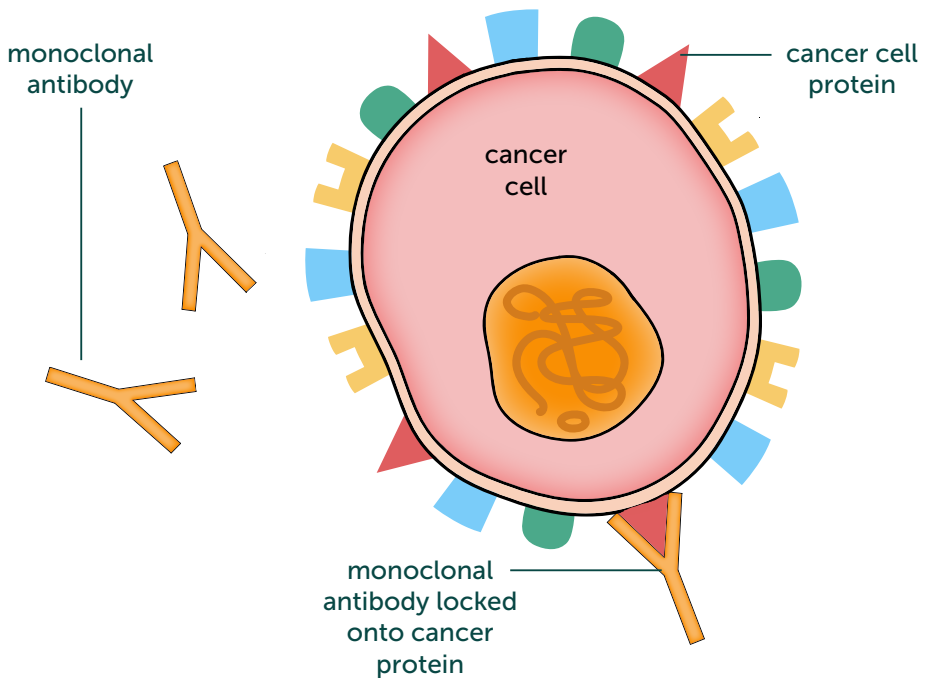
Cancer growth blockers block chemical signals that cancer cells need to grow and multiply.



Anti-angiogenics block tumour blood vessel growth.



Monoclonal antibodies find cancer cells by looking for proteins that they make.



How you have this treatment depends on the drug you're having. Many are tablets, but some you have through a drip (intravenous infusion) into a vein. You can usually continue with the treatment as long as it's helping and the side effects aren't too bad.

Side effects

Many different targeted therapies are used to treat liver cancer. Side effects vary, depending on the drug. Common side effects include tiredness, diarrhoea or sickness, rashes and a sore mouth. Ask your doctor for a list of the possible side effects of the drug(s) you're having.

Chemotherapy

Chemo drugs kill cancer cells while doing little harm to normal cells. The treatment circulates throughout your body in your bloodstream, so it can kill cancer cells wherever they are.

Depending on the type of liver cancer you have, you may have chemo before or after surgery. Or for an advanced cancer that has spread. For HCC, you usually only have chemo into your liver, as part of TACE.

How you have chemo

You may have tablets, a drip into a vein or both, depending on the drug(s) you're having. You have chemo in cycles – treatment over a few days and then a break of 2 or 3 weeks before the next cycle starts. You usually have 6 or more cycles, over several months.

Side effects

Chemo drugs have many side effects and they vary, depending on the drug. Common side effects include feeling or being sick, diarrhoea, tiredness, increased risk of infection and bleeding (such as nosebleeds).

Radiotherapy

This means using high energy rays (radiation) to treat cancer. As with chemo, cancer cells are more sensitive to radiation than normal cells.

You may have stereotactic radiotherapy (also called SABR or radiosurgery) to try and cure early stage HCC. This is highly targeted, with several beams aimed at the cancer from different directions. It's safe to have a higher dose of radiation because there is little normal body tissue in the treatment area.

You may have radiotherapy after surgery for bile duct cancer if there were cancer cells in your lymph nodes (glands).

Doctors also use radiotherapy to treat pain from cancer spread, for example in the bones.



How you have radiotherapy

Having external radiotherapy is a little like having an X-ray. You can't feel it and it doesn't make you radioactive in any way.

You usually have a course of treatments ('fractions') over 3 or 4 weeks. They may be daily or every 2 or 3 days.

You may have stereotactic radiotherapy in 1 – 3 treatments. How many treatments you'll have varies greatly. Ask your doctor for the details of your plan.

Before your treatment, you have a longer appointment for planning. You have a scan that the doctor uses with computer software to shape the beam(s) to fit your tumour. You may have marks made on your skin during planning. Don't wash them off or alter them! If they fade, your radiographer will redraw them.

Radiotherapy treatments take a few minutes. The radiographer lines up the machine very accurately with your skin marks. Then they'll leave the room for the minute or two that the machine is switched on.

If you're having stereotactic radiotherapy, your appointment will be longer – up to a couple of hours.

Side effects

These tend to start slowly and build through your course of treatment. You may have

- red, sore skin in the treatment area, similar to sunburn
- increasing tiredness
- sickness or diarrhoea
- loss of body hair in the treatment area

These will go a week or so after you finish treatment, although tiredness may last longer.

Controlling symptoms

This is sometimes called supportive care or palliative care. Palliation just means relieving symptoms. So it's not the same as terminal care. You can have cancer symptoms at any point.

Your doctor will use a range of treatments to relieve symptoms. For example, you may have radiotherapy for pain.

You can have medicines to control symptoms such as pain, sickness or diarrhoea. If they don't help at first, tell your doctor. There are many different types and a different medicine may work better for you.

You may find complementary therapies help you to relax and cope with symptoms. Some support groups and cancer centres now offer therapies such as massage and aromatherapy.

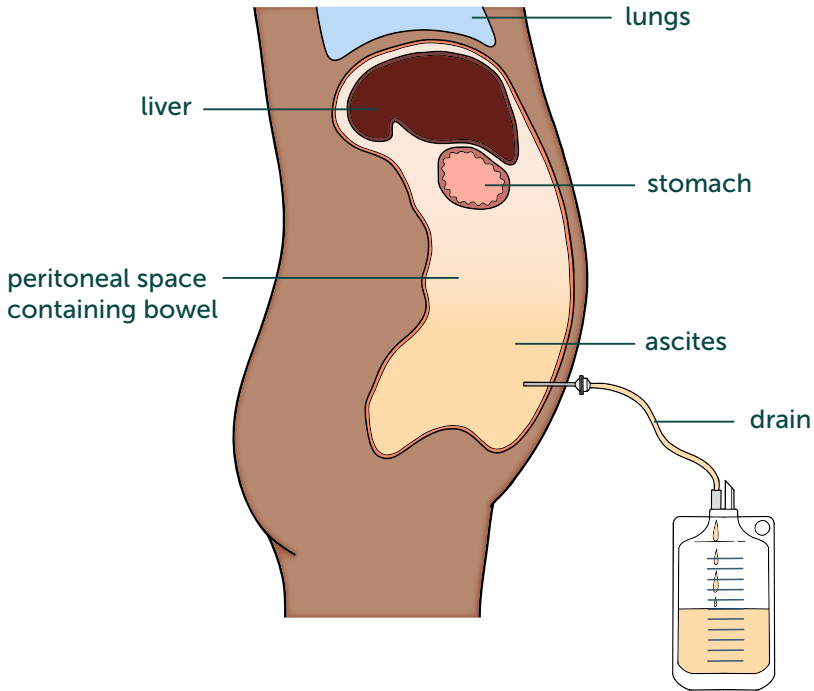
Relieving jaundice

If you have jaundice, it may be possible to unblock your bile duct and relieve your symptoms that way. Your doctor will put a small metal tube (a stent) into your bile duct. They may do this with a tube down your throat (an MRCP) or through the skin over your liver (a PTC). There is information about both of these in the Tests section of this booklet.

You may also have medicines to help with jaundice symptoms such as itching.

Draining fluid

With liver disease, you may get fluid (ascites) collecting around the organs in your tummy (abdomen). This can be uncomfortable and affect your breathing because it puts pressure on your lungs.



Your doctor can drain the fluid by putting a needle into your tummy and attaching it to a drainage tube. You have local anaesthetic before the needle goes in.

The fluid has to drain slowly or it can affect your blood pressure. Depending on the amount of fluid, it can take a few hours.



Living with liver cancer

Having cancer can bring a few challenges, affecting you and your family and friends. Hopefully the information here will help you cope, and covers finding support, diet, exercise and mental wellbeing.

Finding support

Everyone needs help at times. Those close to you will want to help but may not know how. So don't be afraid to ask.

Your GP can arrange for a district nurse if you need one. Or for a community physiotherapy or occupational therapist (OT) to help you manage at home. An OT can suggest small changes, such as raising the height of a chair to make getting up easier.

You may be able to get help at home from social services. Or local good neighbourhood schemes to help with shopping, dog walking, giving lifts, or sitting with someone if you're a carer and have to go out.

Local cancer support groups often have good information about sources of support. And it can really help to talk to others who know what having cancer is like. If you prefer, you could use a helpline or online forum. The British Liver Trust forum has thousands of members, including people with liver cancer.

Our helpline is staffed by specialist liver nurses who can help explain your cancer and treatment.

Visit www.livercancer.org.uk/support-for-you for information about our nurse-led helpline, support groups and online forum.

Diet

Liver cancer and its treatment can seriously affect your appetite. You may feel sick at times and an enlarged liver can make you feel full up before you've even eaten.

If you're very tired, it can be too much effort to prepare food or eat much. You may also have trouble keeping your weight up.

Everyone's needs and tastes are different, so ask for advice at your treatment centre. A dietician can help you to work out a diet programme that suits you. You'll need to pick and choose to suit the particular problems you're facing.



Here are a few general tips.

- Several small meals a day are easier to manage – aim for something every couple of hours
- Snacks are fine and may be easier to face. Healthy snacks include yoghurt, bananas, cereal or wholemeal toast and jam or honey
- Keep a stock of tinned or packaged foods that you like, or freeze portions of prepared foods.
- Have what you fancy – don't force yourself
- Cold foods may be more tempting if you feel sick.
- Low fat foods may suit you better: chicken, fish or eggs. Avocado and nuts are sources of healthier fats.
- To boost calories, fortify milk by adding 3-4 tablespoons of milk powder to a pint of whole milk.
- If you can't manage food, sip a nourishing drink. You can buy nutritional protein drinks or make your own milkshakes, smoothies or hot chocolate.

People with cancer sometimes turn to 'alternative diets' that claim to treat or cure cancer. This isn't true and the diets are often unbalanced and unhealthy. Speak to a dietician before trying them.

Exercise

Keeping active will help you to stay as well as possible. It can help to:

- combat anxiety and depression
- increase energy levels and improve sleep
- increase your general fitness

And you may even enjoy it! As with diet, we're all different. The ideal exercise depends on your age, fitness and medical history. Check with your doctor. As long as they agree, the general recommendation for people with cancer is 30 minutes of moderate exercise 3 times a week. This could include:

- brisk walking, fast enough to be a little out of breath
- cycling
- dancing
- water aerobics

If you can, also aim to strengthen muscles twice a week. This could be sets of exercises – or doing anything strenuous at home, such as carrying shopping or digging the garden.

The NHS has some online exercise videos. Search 'NHS strength and flex'.

Mental wellbeing

Cancer can seriously affect your emotions. At first, you may find it hard to think straight. At times you may feel angry, frightened or vulnerable. Often it becomes easier in time, as things calm down. But you may need help to get past these feelings.

Seeing people

Try not to become isolated. You might not feel like being sociable, but you may enjoy it if you do. Although you may feel the cancer sets you apart, other people can listen and understand. If those close to you are uncomfortable talking about cancer, you may find it helps to talk to someone outside your immediate circle.

Spotting depression

Depression is common in cancer and can creep up on you. If you feel low all the time and this has lasted a few weeks, you may be depressed. Talk to your doctor. They can refer you for counselling or may suggest a short course of antidepressants.

Relaxation

Relaxation has real benefits in helping you unwind and relieving stress and anxiety. If you have trouble relaxing, there are exercises you can learn. These may be simple breathing exercises or guided imagery - picturing a calming scene or happy memory. Search 'NHS breathing exercises for stress'. Or there are free apps you can download or books and CDs you can buy or borrow from the library.



Mindfulness

This means learning to stay in the present, rather than fretting about the past or the future. So it can be really helpful in coping with cancer. The first step is to spend time noticing the world around you and your thoughts and feelings. When walking, you might notice how the breeze feels on your skin or how it sounds walking on autumn leaves. If a negative or stressful thought comes to mind, you acknowledge it and let it go. Of course, this is harder than it sounds! It takes practice and a local course may help. Your cancer support group or cancer centre may have information. If not, check out MIND's information on learning mindfulness.

Counselling and cognitive behavioural therapy (CBT)

These are 'talking therapies' that can give you an outlet for your feelings and help you make sense of them. You can say things you wouldn't say to family or friends. Understanding yourself better can help you manage anxiety and come to terms with your feelings.

CBT also looks at how you react to situations. You can re-learn thought patterns that have become an unhelpful habit – self criticism for instance. The therapist helps you to develop more helpful coping strategies, focussing on the present rather than the past.

You have to feel comfortable to get the best out of these therapies. So don't stay with the first person you see if it doesn't feel right. A good therapist will explain their background and qualifications – if they don't, ask.

Useful words list

There is a longer Useful Words list on our website at www.livercancer.org.uk/useful-words

Ascites – fluid collecting around the organs in your tummy (abdomen). Can be a symptom of advanced liver disease.

Barcelona stage – a way of grouping hepatocellular liver cancers (HCC). It includes the number and size of tumours in your liver, your general health (performance status) and how well your liver is working. See also Child-Pugh and Staging.

Bismuth-Corlette stage – a way of grouping perihilar bile duct cancers. It helps your surgeon plan the surgery you need, according to where the cancer is in the bile ducts.

Cancer – a disease caused by a type of body cell becoming abnormal and growing uncontrollably.

Child-Pugh Score – a system to measure how well the liver is working. It includes results of blood tests, whether you have fluid in your tummy (abdomen) and whether your liver disease is affecting you mentally. A score of A is normal, B means some liver damage, and C a lot of liver damage.

Cholangiocarcinoma – another name for bile duct cancer.

Extrahepatic – means outside the liver. Some bile duct cancers are 'extrahepatic' because they grow in the bile ducts that connect the liver to the gallbladder and small bowel.

Fibrolamellar cancer – a type of cancer that starts in liver cells. Sometimes called a type of hepatocellular cancer (HCC). More often diagnosed in younger people who don't have any other type of liver disease.

Genes – genes are made of DNA. They carry information for making proteins and control how your body looks and works. Mistakes (mutations) in genes can lead to diseases, including cancer. The mistakes can be inherited, but are more often caused by environmental damage, such as smoking.

Grade – grade means how abnormal or normal cancer cells look under a microscope. The more abnormal they look, the higher the grade. High grade cancers are likely to grow more quickly than low grade.

Hepatitis – literally means inflammation of the liver. Hepatitis A, B and C are disease caused by viruses. Long term infection with Hepatitis B or C can cause liver damage and increase risk of liver cancer.

Hepatocellular cancer – a type of cancer that starts in liver cells (primary liver cancer). Often called HCC.

Insulin – a hormone made by the pancreas that controls blood sugar levels. Body cells can become resistant to insulin, particularly if you're overweight or eat a diet high in fat and sugar. Insulin resistance can increase risk of fatty liver disease and cancer.

Intrahepatic – means inside the liver. Some bile duct cancers are 'intrahepatic' because they grow in bile ducts that are inside the liver.

Jaundice – yellowing of the skin and whites of the eyes. May be caused by a blocked bile duct or advanced liver disease.

MDT – short for multi-disciplinary team. Group of medical experts who meet to discuss a patient's test results and decide on the best treatment.

Molecular profiling – tests done on cancer cells, to find genetic mistakes (mutations) that might be targets for treatment.

Mutations – mistakes in genes that mean they don't work properly. Usually a cell needs to have several mutations before it becomes cancerous.

NAFLD – stands for non-alcohol related fatty liver disease. A type of liver disease caused by a build up of fat in the liver. Related to diet and usually seen in people who are overweight. Having NAFLD increases risk of liver cancer.

Primary biliary cholangitis – a disease caused by your immune system attacking and damaging the liver. Relatively rare but more common in middle aged and older women.

Primary cancer – where a cancer starts growing is the primary cancer. So a primary liver cancer started when liver cells became cancerous.

Recurrence – means a cancer has come back.

Resection – surgery to remove something – in HCC, removing part of the liver.

Secondary cancer – where a cancer has spread to. A cancer that started in the bowel and then spread to the liver is a secondary liver cancer. The cells are cancerous bowel cells and will respond to bowel cancer treatments.

Stage – means the size of a cancer and whether it has spread.

Staging – tests to work out the size of a cancer and whether it has spread to lymph nodes (glands) or elsewhere in the body.

TNM – stands for Tumour, Node, Metastasis. The commonest system doctors use to stage cancers, but used less often for liver cancers. T is the size of the cancer, N shows whether there are cancer cells in lymph nodes. Metastasis means cancer spread to another part of the body. See also Stage and Staging.

Toxins – another word for things that are poisonous. Being exposed to toxins can help to cause cancer. Cigarette smoke is a toxin.

Tumour – a lump caused when a single type of body cell multiplies more than it should. Tumours can be non-cancerous (benign) or cancerous.

Special thanks

All our patient information is created with and reviewed by patients and clinicians. We would like to thank everyone involved in producing this booklet, especially our patient reviewers and those who took part in our focus groups.

Clinical reviewers

Mr Hassan Malik, Consultant Hepatobiliary Surgeon,
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If you have any feedback or comments, please share them with us by emailing publications@britishlivertrust.org.uk



More information and support

We have lots of more detailed information about liver cancer available on our website. Visit www.livercancer.org.uk or scan the code below with your phone.



People with liver cancer often also have a diagnosis of liver disease. For more information, including booklets to download or order, visit www.britishlivertrust.org.uk

Our nurse-led helpline, support groups and online forum are here to help you, your family and friends, whatever your diagnosis. Visit our website to find out more or you can call our helpline for information, advice or if you just need to talk to someone who understands.

Nurse-led helpline **0800 652 7330**

Online community
www.healthunlocked.com/britishlivertrust

Find out more www.britishlivertrust.org.uk/support

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After ten years of scans, I was told that I was officially cancer-free. And here I am, fourteen years later, still alive thanks to the fabulous surgeon who convinced me to have the operation and removed the tumour.



Beryl was diagnosed with bile duct cancer in 2008



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Company Limited by Guarantee Registered in England and Wales,
Company No 2227706
Booklet developed Oct 2022
Next review due Oct 2025