



A guide to understanding  
diagnosis and treatment:

# LIVER CANCER

## Gut Cancer Foundation

The Gut Cancer Foundation funds innovative research, is the voice of cancers of the digestive system, and provides vital information and education to improve and save the lives of all New Zealanders affected by cancers of the digestive system, which is pancreatic, liver, stomach, biliary, oesophageal, bowel and anal cancers.

The information in this booklet has been repurposed from our partners at Pancare Foundation Australia. We would like to extend our sincere gratitude to Pancare for generously sharing their patient support material and providing permission for us to adapt it to support Kiwis and whānau with liver cancer in Aotearoa New Zealand.

This booklet has been reviewed for the New Zealand system by relevant specialists in the New Zealand medical sector.

## Note to the Reader

The medical profession and research community are continually updating information about liver cancer. We have taken care to ensure that the information in this handbook is reflective of the clinical best practice at the time of publication. Sponsoring organisations have not had input into the contents of this document.

This handbook is not a substitute for professional help or advice from medical practitioners. It is important to discuss any medical (physical, emotional and/or general) symptoms, questions or concerns with your health professional as soon as possible.

Gut Cancer Foundation excludes itself from all liability for any injury, loss or damage incurred by use of, or reliance on, the information provided in this booklet.

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## Supporting you on your Cancer Journey

A cancer diagnosis can come as a terrible shock, but we are here to help you every step of the way and support you, your whānau and friends.

In this booklet, you will learn more about a recent diagnosis, your treatment options, working with your care team, managing symptoms, ways to nurture your health through diet, exercise and strengthening your emotional wellbeing and practical ways we can support you and your whānau.

## Talk to our team

To discover more or talk further with our team, visit [www.gutcancer.org.nz/support-service](http://www.gutcancer.org.nz/support-service) email [support@gutcancer.org.nz](mailto:support@gutcancer.org.nz) or call [0800 112 775](tel:0800112775)

# Your guide for using this handbook

This handbook contains key details in colour coded boxes.



ADDITIONAL  
DETAILS



PATIENT  
STORIES



FREQUENTLY  
ASKED QUESTIONS



HELPFUL  
TIPS



**Note:** At the back of this booklet, you will find a list of explanations of common terms relating to liver cancer and sources of further information and support.

## Introduction

This handbook is for anyone who has recently been diagnosed with liver cancer, and for their partners, family members and carers. It gives a general introduction to liver cancer, provides information on tests and investigations that help confirm a diagnosis, and offers an overview of possible treatment options and the wider impact of the diagnosis. The information may also be helpful for anyone who is undergoing investigations for liver cancer and wondering what the next steps might be.

If you have only just been told about your diagnosis, you may be feeling shocked; many people diagnosed with liver cancer would not have had any idea or suspicion that they were seriously ill. You may have been feeling unwell for a while and not known what was wrong. You might feel frightened, angry or upset. Just remember that there is no 'right' way to feel – everyone deals with things in their own way.

This handbook is a good place to start looking for up-to-date information relevant to your situation. You don't need to read everything in this handbook in one go. Please remember that you should always consult your doctor about matters that affect your health. This handbook is not a substitute for professional medical, legal or financial advice. You should seek appropriate independent professional advice relevant to your situation; you may wish to discuss anything raised in this handbook with these professionals.



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# About the liver

The liver is the largest organ inside of the body and forms part of the digestive system. The main functions of the liver are to help digest food and remove toxic substances from the body.

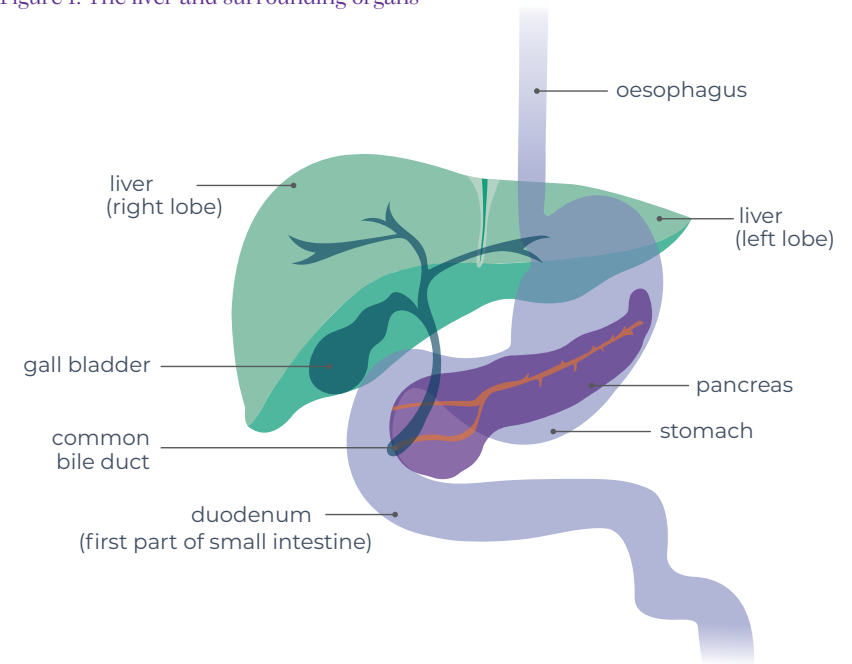
The liver sits just under the ribs on the right side of the abdomen. It has two large sections called the right and left lobes. Under the liver is the gallbladder, as well as parts of the pancreas and intestines (Figure 1). These organs work together to digest, absorb and process food.

The liver makes bile, a fluid that helps break down fats in food. Bile is made from cholesterol, water, bile salts and bilirubin (a yellow pigment formed when red blood cells break down). Bile is made in the liver and stored in the gallbladder until there are fats in the small intestine that need digesting.

The liver also:

- stores nutrients (carbohydrates, fats, proteins and vitamins)
- removes toxic chemicals from the blood
- metabolises drugs and alcohol
- makes proteins that are important for blood clotting and other functions
- helps regulate blood sugar levels by storing and releasing sugar.

Figure 1: The liver and surrounding organs



# About liver cancer

Liver cancer occurs when abnormal cells in the liver grow out of control. There are several risk factors for developing liver cancer.

Liver cancer can be:

- **primary**, meaning that the cancer started in the liver
- **secondary**, meaning that the cancer started in another part of the body and spread to the liver; most liver cancers are secondary.

Most liver cancers develop with no obvious cause, but some factors are known to increase the risk.

The information in this handbook focuses on primary liver cancer.

There are several types of primary liver cancer, depending on the type of cell that the cancer grows from:

- **Hepatocellular carcinomas** (HCCs; also called hepatoma) start in the main type of cells in the liver, called hepatocytes. This is the most common type of liver cancer
- **Intrahepatic cholangiocarcinoma**, starts in the cholangiocytes – the cells lining the bile ducts inside the liver. This is the second most common type of liver cancer
- **Hepatobiliary carcinomas** (Combined hepatocellular-cholangiocarcinoma) is a rare type of liver cancer that develops from cells that have features of both liver cells and the cells that line the bile ducts within the liver
- **Angiosarcomas**, a very rare type of liver cancer, start in the cells that line the walls of the liver's blood vessels
- **Fibrolamellar carcinomas**, a very rare type of liver cancer, develop from the tissues lining the liver.

## Risk factors

Most liver cancers develop with no obvious cause, but some factors are known to increase the risk.

### Health risk factors

Chronic (long-term) infection with hepatitis B or hepatitis C virus is the biggest risk factor for developing liver cancer. These viruses damage the

liver and cause scarring, which is called cirrhosis. People with cirrhosis have an increased risk of developing liver cancer.

Hepatitis can spread through contact with infected blood and other body fluids, including during childbirth. There are hepatitis B vaccines available that may prevent infection. If you are diagnosed with hepatitis B or C, you should make sure you've been referred to the Hepatitis Foundation for advice about caring for yourself and your family.

Those with chronic hepatitis B and C may be recommended anti-viral medication to treat the hepatitis itself and prevent cirrhosis.

Primary sclerosing cholangitis, a condition in which inflammation of the bile ducts (cholangitis) leads to the formation of scar tissue (sclerosis)

### Environmental risk factors

Environmental risk factors for developing liver cancer include:

- smoking tobacco
- drinking alcohol frequently
- obesity
- type 2 diabetes
- being exposed to certain chemicals.

Metabolic associated fatty liver disease (MAFLD) or metabolic dysfunction-associated steatotic liver disease (MASLD) is a build-up of fat in the liver. It can be caused by obesity, eating a high-fat diet or having diabetes. This condition can lead to liver cirrhosis, which increases the risk of developing liver cancer.

### Hereditary risk factors

Hereditary factors that increase the risk of liver cancer include haemochromatosis (where the body stores too much iron) and alpha 1-antitrypsin (AAT) deficiency. There are currently no genetic tests available to screen for liver cancer. Liver cancer may have been detected through cirrhosis screening programme aimed at detecting cancer at an early and curable stage.

# Towards a liver cancer diagnosis

Reaching a diagnosis of liver cancer can be a lengthy and complex process. When the disease first develops, it often does not cause any obvious symptoms, or the symptoms may be like those caused by common, less serious conditions. This means you may have been sent for several different tests before liver cancer was considered, and you may have had the cancer for some time without knowing.

Liver cancer is usually diagnosed because you have had symptoms such as:

- pain in the right side of the upper abdomen (stomach area)
- feeling sick (nauseous) with loss of appetite
- yellowing of the skin and eyes (jaundice)
- dark urine and/or pale stools
- itchy skin
- unexplained fatigue
- unexplained weight loss
- fever
- a swollen abdomen caused by a build-up of fluid (called ascites).

You may have gone to see your regular doctor, or general practitioner (GP), for these symptoms. More serious symptoms, like yellowing of the skin or eyes or abnormal blood test results, may have resulted in an emergency admission and further investigations.

Once less serious conditions have been ruled out, your GP may refer you to an upper gastrointestinal surgeon or gastroenterologist to investigate your symptoms further. You may need several different tests to confirm the diagnosis of liver cancer.

If any symptoms appear or get worse between appointments, or while you are waiting for tests or results, you should let your doctor know right away.

If you have been diagnosed with liver cancer and haven't had any symptoms, it is probably because you had another medical procedure and the cancer was found by chance. Liver cancer may have been detected through cirrhosis screening programme aimed at detecting cancer at an early and curable stage.



# Tests and investigations: what, why and how

The tests used to diagnose your liver cancer will help doctors understand your condition. You may need other tests to confirm the type of liver cancer, where it is, whether it has spread to nearby organs or other parts of the body, and what the best treatment will be for you.

You may not need all the tests described in this section, and you might have other tests that are not included in this handbook. Your specialist will give you more detailed information about the most appropriate tests for you.

## Initial investigations

The initial investigations will help doctors understand why you have certain symptoms, and whether they are being caused by a condition. This is called making a diagnosis.

### Physical exam and history

The doctor will ask you about your medical history and your health habits. The doctor will also check your body for signs of disease, such as lumps, swelling or anything else that seems unusual.

### Blood tests

You will have blood tests as part of the initial set of tests and during ongoing health checks. Blood tests are used to check your blood count, liver and kidney function, and general health.

Some blood tests can also check for tumour markers, which are chemical substances produced by cancers that show up in the bloodstream. For example, alpha-fetoproteins are tumour markers linked to liver cancer.

However, other conditions can also raise the levels of these markers, and some people with liver cancer have normal levels. These markers on their own cannot be used to diagnose liver cancer.

### Ultrasound

Ultrasound scans use soundwaves to create a picture of the inside of the body. The doctor will pass a probe over your abdomen and look at images of your liver, pancreas, gallbladder and bile ducts on a screen.

## Staging tests

If you have been diagnosed with liver cancer, you may need to have more tests to help the doctor work out the size of the cancer and whether it has spread elsewhere. To find out more about the stages of liver cancer, see 'Stages of cancer' on page 17.

### Biopsy

A tissue biopsy may be needed to confirm the diagnosis of cancer and to get as much information as needed for treatment planning. Tissue samples for examination under a microscope can be taken during an ultrasound (see 'Ultrasound'). A biopsy may not be performed when surgical removal is planned upfront. Diagnosis can be made on imaging alone in chronic liver disease cases.

### Computerised tomography (CT) scan

A CT scan uses X-rays to build a three-dimensional picture of your liver and the organs around it. Your CT scan will probably also include the chest and pelvic area, to check for any signs of cancer outside the liver.

## Magnetic resonance imaging (MRI)

MRI uses magnets and radio waves to build a detailed cross-sectional picture of the liver and surrounding areas. For more information visit our website: [www.gutcancer.org.nz/liver-cancer/#diagnosis](http://www.gutcancer.org.nz/liver-cancer/#diagnosis).

## Positron emission tomography (PET) scan

For a PET scan, a small amount of radioactive dye is injected into a vein. On the scans, the injected substance shows areas where the cells are more active in the body. This type of scan can pick up very small areas of active cells, so it can help to give a clearer picture of the cancer.

## Bone scan

If you have been referred for a liver transplant or have pain in your bones, you may need a bone scan to make sure the cancer has not spread to your bones. Like a PET scan, a small amount of radioactive dye is injected to show areas where cells are more active.

**i** Even if you have had an urgent referral for a test, you may have to wait days or weeks for your appointment. It is also common to have to wait for test results. Waiting can be frustrating and worrying, especially if you are already unwell. However, it is unlikely that your cancer will grow enough during this waiting period to cause you further harm if your symptoms are otherwise stable. It is still a good idea to ask your doctor how long you may have to wait. If you think you have been waiting too long or have any concerns, check with your doctor.

If your symptoms get worse or you start to feel more unwell while you are waiting, it is important to get in touch with your doctor. If you can't see your doctor, and you can't control your symptoms at home, you may need to go to the emergency department. If you have to go into hospital for any reason, you can ask whether any tests you are waiting for can be done while you are there.



# Stages of cancer

Your test results will give your doctors a detailed diagnosis and tell them what stage your cancer is at.

Staging is working out the size of a cancer and whether it has spread near the tumour site or to other areas of the body. It is an important part of the assessment and treatment planning. Sometimes, staging can only be done after the cancer has been removed during surgery.

There are two factors taken into account when planning liver cancer treatment:

- Child–Pugh score (Figure 2) – how well the liver is functioning
- Barcelona Clinic Liver Cancer (BCLC) system (Figure 3) – the extent of the liver cancer.

Figure 2: Child–Pugh score

- |          |                                                    |
|----------|----------------------------------------------------|
| <b>A</b> | The liver has some damage but is working well.     |
| <b>B</b> | The liver is working moderately well.              |
| <b>C</b> | The liver is very damaged and is not working well. |

Figure 3: BCLC (Barcelona Clinic Liver Cancer) system

## Stage 0

Very early liver cancer.

- There is only one tumour and it is less than 2 cm across
- You feel well and are fully active
- The Child-Pugh score is A.

## Stage A

Early liver cancer.

- There is only one tumour and it is greater than 2 cm across, or there are up to three tumours and they are all less than 3 cm across
- You feel well and are fully active
- The Child-Pugh score is A or B.

## Stage B

Intermediate liver cancer.

- There are multiple tumours in the liver
- You feel well and are fully active
- The Child-Pugh score is A or B.

## Stage C

Advanced liver cancer.

- The tumour has grown into one of the main blood vessels of the liver, or it has spread to the lymph nodes or other organs
- You do not feel well and are less active
- The Child-Pugh score is A or B.

## Stage D

End-stage liver cancer.

- The tumour has grown into one of the main blood vessels of the liver, or it has spread to the lymph nodes or other organs
- You do not feel well and are unable to look after yourself
- The Child-Pugh score is C.

## Treatment journey

After your tests are complete, a team of doctors will design a treatment journey that is specific to you. You should receive high quality care that aligns with your treatment goals and personal choices.

All patients in NZ diagnosed with liver cancer should have their case reviewed at a specialist health centre, where a specialist multidisciplinary team of health professionals can assess and treat the disease. There should be one key point of contact at every step of your treatment journey.



### Who in the multidisciplinary team will treat my cancer?

You will have a main doctor who will be managing your care, and they will consult with different doctors and other health professionals who are specialists in your cancer. This is called a multidisciplinary team, and may include:

- doctors from the radiology, pathology, surgery and oncology departments
- specialist nurses (oncology nurses) and other allied health professionals.

Once you have had all your tests and investigations, your specialist team will meet to discuss the results. The multidisciplinary team will use their expert knowledge to review your case and agree on the best treatment options for you.



## Treatments for liver cancer

Surgery is often used to treat liver cancer. The type of surgery depends on the type of cancer, size, location and extent of your cancer as well as your overall health. Other options for treatment may include chemotherapy, radiation therapy, targeted therapy, immunotherapy and liver transplant.

The order and type of treatment you will receive depends on your individual situation. You might have one or more of these treatment options. You may have chemotherapy or radiation therapy before or after surgery, or you might not have surgery at all. The order of the treatment options in this handbook is not necessarily the order you will receive them.

### Prehabilitation

Prehabilitation (prehab) means getting ready for cancer treatment in whatever time you have before treatment starts. This includes increasing your awareness of what you are eating, doing regular physical activity and looking at ways to improve your mental wellbeing through mindfulness. If you can stop smoking and cut down on your alcohol intake, it will benefit your cancer treatment, recovery and overall health.

Prehabilitation can be a program with your healthcare team (including doctors, nurses, dietitians, exercise physiologists and psychologists) or something you do by creating your own plan at home by yourself.

By getting support early to change health habits and ensure that you

are as healthy as possible before treatment, you are more likely to:

- leave hospital sooner after surgery
- cope better with the side effects of cancer treatment
- have fewer side effects
- have more treatment choices
- have better long-term health.

Prehabilitation continues as rehabilitation to help you recover from cancer treatment.

### Surgery

If you have been told that surgery to remove your cancer is possible, you may have been diagnosed with a cancer that has not spread to other organs and is not significantly attached to major vessels. Your doctor may call your cancer operable or resectable. You also need to have good liver function and be well in yourself.

#### Liver resection (hepatectomy)

Surgery that removes part of your liver is called a liver resection or hepatectomy. This can be done as a minimally invasive (keyhole) surgery or open surgery. The amount of liver that is removed depends on the size and location of the cancer. The liver can regenerate and adapt to work normally after a resection. Sometimes, the gallbladder and part of the diaphragm will also be removed.

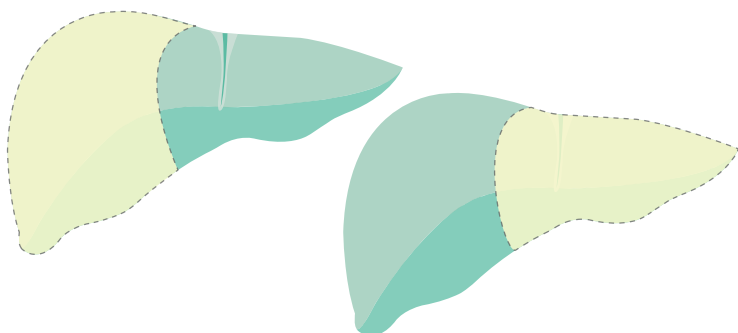
There are three types of liver resection (Figure 4), based on how much of the liver is removed:

- **Right-sided or left-sided liver resection** is when the right or left part of the liver is removed
- **Extended right-sided or left-sided liver resection** involves removing a large section of liver. This surgery is only recommended if there is enough healthy liver remaining to continue performing the liver's essential functions
- **Segmental liver resection** is when a small section of the liver is removed.

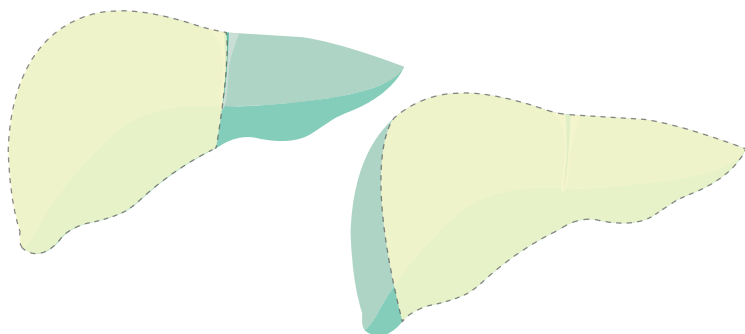
A hepatectomy is a complex surgery, and you may need to stay in hospital for 5 to 10 days. The liver has the ability to regenerate after surgery. In most people, the remaining healthy liver grows over time and is able to perform the functions needed to support the body.

Figure 4: Types of liver resection

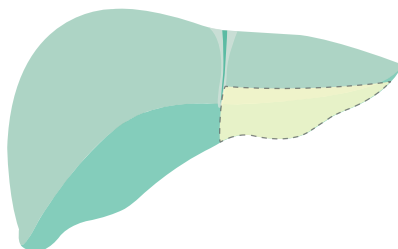
**A: Right-sided or left-sided liver resection**



**B: Extended right-sided or left-sided liver resection**



**C: Segmental liver resection**



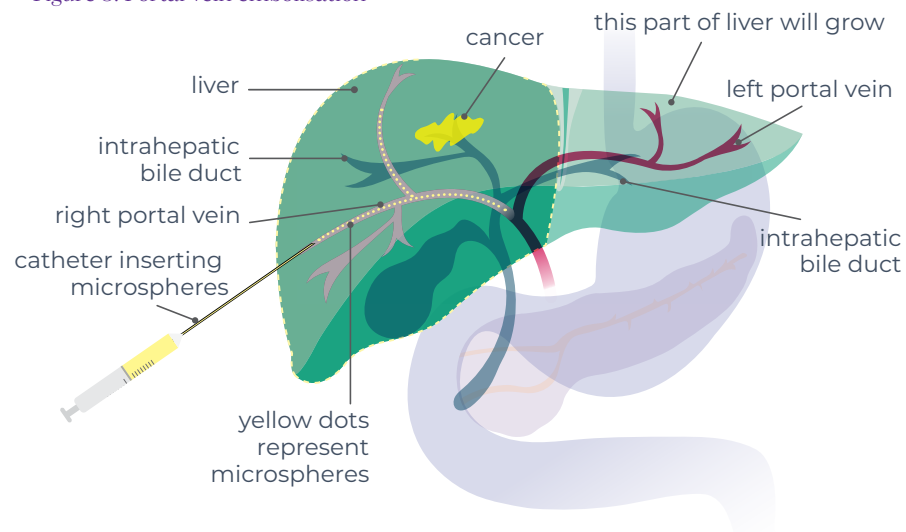
 Parts of the liver removed



**Portal vein embolisation (PVE)**

Before major liver surgery, the surgeon may suggest you have a procedure called portal vein embolisation (PVE) (Figure 5). PVE means blocking off part of the blood flow to the area of the liver that has liver cancer. During PVE, the blood supply to the part of the liver that will be removed is blocked by injecting tiny particles into a branch of the portal vein (the main blood vessels in the liver). This directs blood flow to the healthy part of the liver, encouraging it to grow before surgery. This is done about a month before you have surgery to remove the cancer.

Figure 5: Portal vein embolisation



## Liver transplant

If your tumour has not spread to other parts of your body but your liver is damaged, you may be referred to the liver transplant unit where decisions are made by a multi disciplinary team. This is when the whole liver is removed and replaced with a healthy liver from another person (called a donor).

Donor livers are rare, and it may be many months before a suitable liver is available. You may have other treatments to control the cancer while you wait for a transplant.

A liver transplant is a complex surgery. You may need to stay in hospital for up to 3 weeks, and it may take 3 to 6 months to fully recover. Your treatment team will watch you closely for signs that your body is rejecting the new liver or that the tumour has returned. You will need to take medications called immunosuppressants for the rest of your life to stop your body from rejecting the new liver.

## Tumour ablation

You may have a tumour ablation. Ablation destroys the tumour without removing it. The most common type of ablation is thermal ablation. A needle that uses radio waves or microwaves to create heat is inserted into the tumour and destroys it. This requires anaesthetic and requires a short hospital stay.

## Paracentesis

If you have ascites (a swollen abdomen caused by a build-up of fluid), you may need to have a procedure called paracentesis, or an ascitic tap.

Paracentesis won't treat the cancer, but it will help to relieve pressure in the abdomen caused by the cancer so that you are more comfortable.

Your doctor will insert a plastic tube into your abdomen that is connected to a drainage bag outside the body. When all the fluid has drained, the tube is removed. You may be prescribed medications called diuretics to slow down the build-up of fluid.

## Drug Therapies

### TACE

TACE is a treatment most commonly used for hepatocellular carcinoma (HCC). In some situations, it may also be used to treat other liver cancers, including selected cases of intrahepatic cholangiocarcinoma. TACE delivers high doses of chemotherapy straight into the tumour.

A catheter (a thin, flexible, hollow tube) is inserted through an artery in your inner thigh to a large artery in your liver. Medicines are injected through the catheter and into the artery. Small particles are then injected into the artery to block the flow of blood for a short time, so the chemotherapy stays in the tumour (*Figure 6 on page 26*).

Depending on the type of liver cancer, TACE may be the only treatment used, or it could be given before a liver transplant or major liver resection to control the cancer (known as bridging TACE).

### Chemotherapy

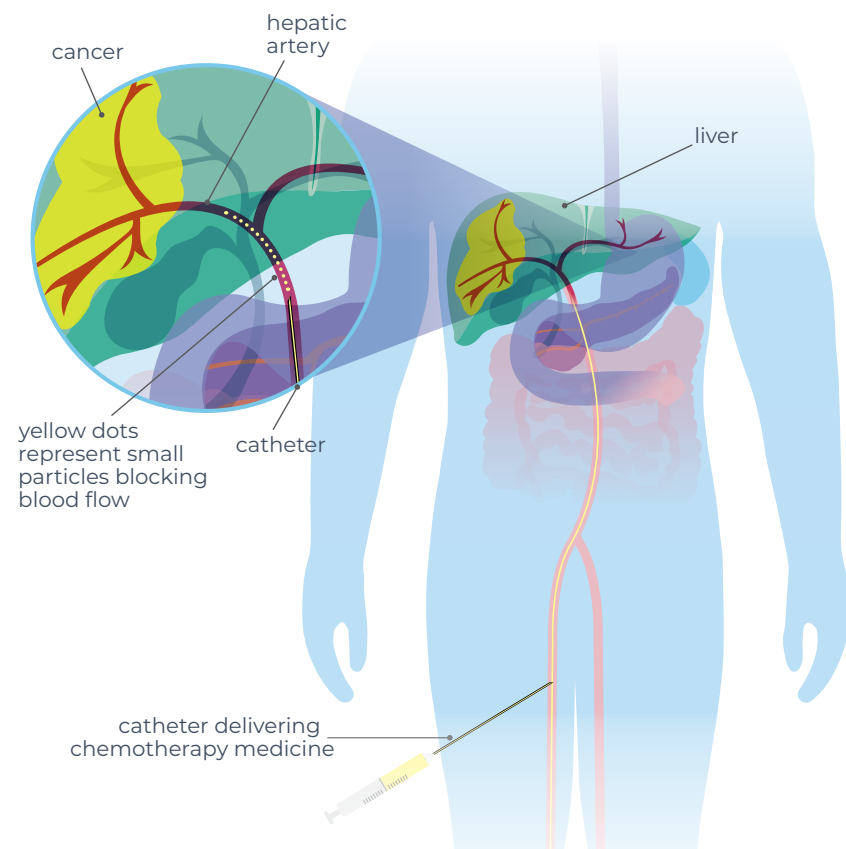
Chemotherapy may be offered to patients with intrahepatic cholangiocarcinoma either alone or in combination with other therapies. Chemotherapy is not recommended for HCC.

Chemotherapy could be given at different times, including:

- before surgery (known as neoadjuvant chemotherapy) – in these cases, the chemotherapy is given with the aim of shrinking the tumours or controlling the cancer growth for some time, to make surgical treatment more feasible or beneficial
- after surgery (known as adjuvant chemotherapy) – this has been shown to reduce the risk of cancer recurrence and is routinely offered after surgery
- both before and after surgery.

Chemotherapy is usually given intravenously (through a drip into the veins) at a hospital or cancer clinic, or can be given orally (swallowed as a pill or tablet). Because chemotherapy medicines travel throughout the bloodstream (systemic treatment), side effects can affect many parts of the body. Chemotherapy can also be used for palliative treatment, to relieve symptoms and slow progression of the disease.

Figure 6: Trans-arterial chemoembolisation (TACE)



## Radiation therapy

Radiation therapy uses high-energy radiation to damage or destroy cancer cells while limiting damage to surrounding healthy tissue. It may be used to treat liver cancer, relieve symptoms, or help control the growth of cancer. Some radiation therapy is funded in New Zealand and some is not, your treatment team will advise you.

### External beam radiation therapy (EBRT)

External beam radiation therapy delivers radiation from a machine outside the body directly to the tumour. Before treatment, you will have a planning appointment, which may include a CT scan, to help your radiation therapy team accurately target the cancer while protecting as much healthy liver tissue as possible.

Some people may receive a specialised form of external beam radiation therapy called stereotactic body radiation therapy (SBRT). SBRT delivers a high dose of radiation very precisely to the tumour over a small number of treatments.

Radiation therapy is painless. Each treatment usually takes only a few minutes, although your appointment may last 15–30 minutes to allow time for positioning and treatment preparation. The number of treatments you need will depend on your individual treatment plan.

Side effects vary depending on the area being treated and the dose of radiation. Common side effects may include tiredness, nausea, reduced appetite, diarrhoea, or discomfort in the treatment area. Most side effects improve after treatment has finished.

### Selective Internal Radiation Therapy (SIRT)

Selective Internal Radiation Therapy (SIRT), also known as radioembolisation, is a treatment that delivers radiation directly to liver tumours from inside the body. It may be an option for some people with liver cancer when surgery is not suitable. Your multidisciplinary team will discuss whether this treatment is appropriate for your individual situation.

During the procedure, an interventional radiologist inserts a thin tube (catheter) into an artery, usually in the groin or wrist, and guides it to the blood vessels supplying the liver tumour. Tiny radioactive beads are then injected through the catheter. These beads become trapped in the small blood vessels feeding the tumour, delivering radiation directly to the cancer while limiting exposure to the surrounding healthy liver.

Before SIRT, you will have tests to assess whether the treatment is suitable and safe for you. The procedure is usually performed as a day procedure or may require an overnight stay in hospital.

After treatment, you may experience tiredness, nausea, mild abdominal discomfort, or a low-grade fever for a few days. Your healthcare team will explain what to expect after the procedure and arrange follow-up appointments to monitor your recovery and assess how well the treatment has worked.

## Targeted therapy and immunotherapy

Targeted therapy works by blocking proteins or blood vessels that cancer cells need to grow and spread. Immunotherapy helps the body's immune system recognise and attack cancer cells more effectively.

In New Zealand, a combination of atezolizumab (an immunotherapy medicine) and bevacizumab (a targeted therapy medicine) is funded for those with advanced hepatocellular carcinoma (HCC). Both medicines are given by intravenous (IV) infusion, usually every three weeks.

Lenvatinib is available for those who are not able to have atezolizumab/bevacizumab. Lenvatinib is a targeted therapy taken as tablets once a day.

Both medicines aim to stop the cancer growing and spreading for a period of time.

The availability of these and other medicines depends on the type and stage of liver cancer, your liver function, your general health, and current funding criteria. Your hepatologist or medical oncologist will discuss which treatment options are most appropriate for your individual situation.



## About Immunotherapy and Targeted Therapy for Liver Cancer

Atezolizumab is an immunotherapy drug called a checkpoint inhibitor. Atezolizumab can make the immune system too active. This can cause varied side effects. Some of them are rare.

But it is important to know about them. Your treatment team will give you written information before you get started.

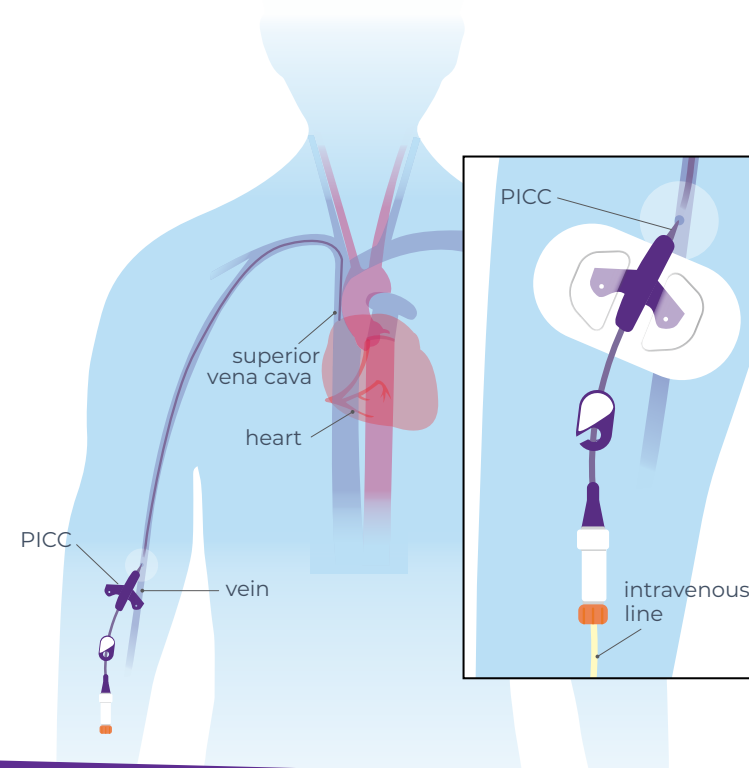
Bevacizumab belongs to a group of targeted therapy drugs known as monoclonal antibodies. It is also an angiogenesis inhibitor which makes it difficult for the cancer tumour to develop the blood vessels it needs to get a blood supply. It can cause high blood pressure and increases both clotting and bleeding risk.

Lenvatinib belongs to a group of targeted therapy drugs called angiogenesis inhibitors. These stop the cancer developing new blood vessels. It is also a cancer growth inhibitor which blocks signals in the cancer cells that make them grow.

Lenvatinib can cause fatigue, nausea, diarrhea, sore mouth, changes in taste, high blood pressure and skin changes. Your treatment team will give you written information before you get started.



Figure 7: Peripherally Inserted Central Catheter (PICC)



## i What is a PICC line?

A PICC is a peripherally inserted central catheter. It is used to give treatments, fluids, medicines or blood transfusions into your bloodstream and to take blood samples. A PICC is used instead of intravenous (IV) cannulas (needles in your arm) for your treatments. IV cannulas are put in for each treatment, but a PICC stays in for the duration of your treatments. This makes having frequent, repeated, continuous or at-home cancer treatments easier.

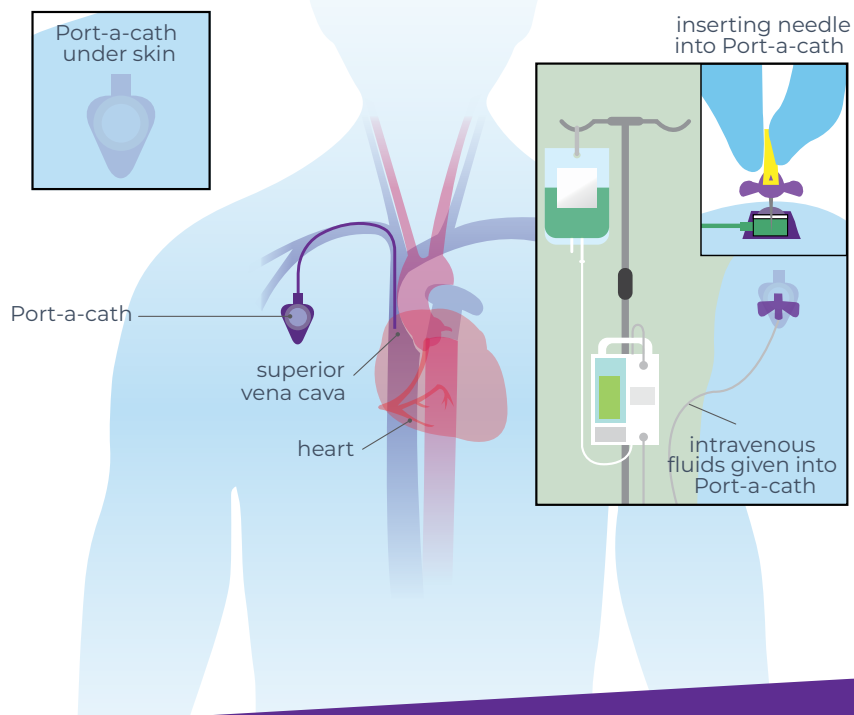
A PICC is a long, flexible, hollow tube. The tube is called a catheter. All PICCs have one end that goes through a vein in your upper arm up to a large vein near your heart (*Figure 7*). Outside your body, the PICC divides into 1, 2 or 3 smaller tubes, called lumens. Each lumen

may have a small clamp and has a cap on the end. A length of the PICC stays on the outside of your inner upper arm and is covered by a dressing. Your nurse will give your treatment, or take blood from you, through the lumen. Your treatment travels through the tube straight into your bloodstream.

Your PICC line will be put in by a specially trained member of your healthcare team. This can happen in a day unit or in the radiology department. A dressing keeps the area clean and dry, which is very important. A member of your healthcare team will advise of any restrictions on your activities.

Your PICC line can stay in as long as it is needed. This can be weeks, months or longer.

Figure 8: Port-a-cath (Port)



## Managing symptoms and treatment side effects

Because liver cancer affects the digestive system, your eating and drinking will be affected. Managing these changes is important for your recovery and will make you feel better in general. Treatments can affect people differently. You may have no side effects, or some or all of them, but there are plenty of things you can do to improve your general wellbeing.

Table 1 lists the most common side effects from the most common treatment options for all liver cancers: surgery, TACE, chemotherapy, radiation therapy, and targeted therapy and immunotherapy.

Rare, but serious, side effects can also occur with immunotherapies, such as immune-related symptoms, hormone changes and inflammation (swelling) of organs. It is important to contact your doctor and report these symptoms as soon as you are aware of them.

### *i* What is a chemo port?

A chemotherapy (chemo) port is a small device that is implanted under the skin, usually on the right side of the chest. It has a thin tube that is guided into a large vein above the heart (*Figure 8*). Chemotherapy medicines can be delivered straight into the port.

A port will make a visible 'bump' under the skin, but this can be easily covered with regular clothing. Many people who receive chemotherapy choose to have a port implanted, if recommended by their treatment team.

Table 1: Common side effects of liver cancer treatments

| Surgery                                                                                                                                                                                                | TACE and Chemotherapy                                                                                                                                     | Radiation therapy                                                                                                                                                                                                                                                            | Targeted therapy and immuno-therapy                                                                                                                                                                                       |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> <li>• Fatigue</li> <li>• Pain</li> <li>• Diarrhoea and malabsorption</li> <li>• Weight loss</li> <li>• Loss of appetite</li> <li>• Feeling full quickly.</li> </ul> | <ul style="list-style-type: none"> <li>• Nausea and vomiting</li> <li>• Pain</li> <li>• Fatigue</li> <li>• Fever</li> <li>• Flu-like-symptoms.</li> </ul> | <ul style="list-style-type: none"> <li>• Nausea and vomiting</li> <li>• Loss of appetite</li> <li>• Feeling full quickly</li> <li>• Diarrhoea or constipation</li> <li>• Fatigue</li> <li>• Weight loss</li> <li>• Skin changes in the area (redness or peeling).</li> </ul> | <ul style="list-style-type: none"> <li>• Skin rash</li> <li>• Flu-like symptoms</li> <li>• Abdominal pain</li> <li>• Diarrhoea</li> <li>• Weight changes</li> <li>• Joint pain</li> <li>• Shortness of breath.</li> </ul> |

Various options can help you manage any symptoms or side effects, including:

- anti-sickness medication or complementary therapies to help with nausea
- pain medication
- seeing an oncology dietitian, who can help with diet-related side effects
- complementary therapies such as aromatherapy, reflexology and relaxation therapy
- wellbeing support from a counsellor, psychologist or social worker.

If you are in hospital, your care needs should be assessed before you leave. These may include a referral to a community-based healthcare team (for example, community palliative care and a GP) who have expertise in managing pain and other cancer symptoms.

## Pain relief

If pain is your main issue, you may be referred to a pain specialist to help manage it. Your GP should be sent a letter explaining your condition, and you should be given the name of a person at the hospital to contact if you have any concerns or need additional support.

Pain relief may include:

- medication
- surgery, radiation therapy or chemotherapy to remove a tumour that is pressing on nerves or another organ.

Pain medication includes over-the-counter medicines such as paracetamol. The doctor may also prescribe anti-inflammatory medicines to help manage your pain. If your pain is severe, you may need strong pain medicines such as opioids.



## Nutritional support

Liver cancer and its treatment can place extra demands on your body, greatly increasing your nutrient and energy (caloric) needs, which can lead to weight loss. Weight loss can contribute to fatigue, delay and lengthen recovery, and negatively affect your quality of life. Also, because the cancer affects the digestive system, you might find it even more difficult to get enough nutrition to meet your needs and maintain weight.

You will probably have many questions about your diet and physical activity, and whether you should use dietary supplements or nutritional complementary therapies. You might seek or receive advice from family, friends, healthcare providers, the media, health food stores, magazines, books or the nutritional supplement industry. There are many claims about the use of dietary and nutritional supplements as alternatives to standard therapy. Making an informed choice can be difficult.

You should always tell your doctor or oncology dietitian if you intend to use any supplements, as they may cause certain side effects, interactions or interference when combined with standard therapies (including surgery, chemotherapy, radiation therapy and targeted therapies) and medications.



A dietitian can provide advice or supplementary information on managing your diet. You may wish to refer to the Gut Cancer Foundation's 'Diet & nutrition for people living with liver cancer' guide.



### Tips to help you maintain your weight and muscle mass

Try to eat nourishing foods and fluids, such as those high in protein and energy.



Include regular sources of protein-rich foods, such as chicken, fish, meat, eggs, tofu, legumes, dairy products, nuts and seeds. Aim to base each main meal around a high-quality protein. You may need to cook and prepare these foods so they are soft and gentle – for example, soups and stews, scrambled eggs, yoghurt, milk drinks, hummus dip and smooth nut butters.

Take advantage of when your appetite is the strongest. This might mean having a larger meal in the morning and a smaller meal in the evening.



Ask about using nutritional supplement drinks. When choosing a nutritional supplement for your needs, consider the different options, including milk based, juice flavoured, powder, yoghurt style, fortified foods and soups. You may need to try different products until you find one you prefer or tolerate better. Your dietitian can guide you.



Make sure you are eating a variety of healthy foods and maintaining a good weight.



## Physical wellbeing

Many people find that relieving dietary-related symptoms makes the biggest difference to how they feel. For example, if you can eat and maintain your weight, you will feel better and cope better with treatment.

Feeling sick (nauseous) is a common side effect of cancer treatment, but your doctor can prescribe you anti-nausea medication to help you feel better. You can also try remedies such as ginger, peppermint or acupressure bracelets.

You will feel other physical effects from the cancer and its treatment. As with dietary-related symptoms, managing these can play a big part in how well you feel.

Physical activity can make you feel better. The amount of activity you can tolerate will depend on how you feel and whether you are having treatment or recovering from it. Even a walk around the block or 10 minutes of stretching each day can help.

You may lose interest in sexual activity during cancer treatment, at least for a while. Talking to your partner or doctor, and sometimes seeing a relationship therapist, may help you find ways of overcoming difficulties.

## Emotional wellbeing

As time passes from your initial diagnosis, you will find yourself dealing with the wider emotional impacts of liver cancer and its treatment. Everyone finds their own ways of coping, but, whatever you do, it is important to take care of yourself.

Everyone will feel and react differently to treatment. What works for someone else may not always work for you. It is important to keep this in mind during your treatment.

Simple relaxation techniques can help you cope with stress, pain and anxiety. Having a warm bath, deep breathing or listening to soothing music are easy things to do at home.

You may want to try complementary therapies such as reflexology or aromatherapy massage. Ask your doctor or specialist nurse about services available in your area. Be sure to speak with your doctor, dietitian or pharmacist before taking any supplements, herbal remedies, powders, teas or tonics.

Over time, you may go through a range of emotions, from feeling positive and determined to beat the cancer to feeling low or despairing about the future. A cancer counselling service may support you with different strategies to help you cope.

If you feel overwhelmed by your cancer experience, you may find it valuable to focus some attention to other areas of your life. Making plans to do things you enjoy, spending time with loved ones, working or socialising as much as you feel able, and intentionally focusing some energy on things other than your diagnosis, treatment and recovery can help to bring some balance.

Communication is essential for everyone's emotional wellbeing. Try to make time for talking and listening, because your close relationships are important.

Your treating team will want to know how they can help, so please talk to them about your feelings.



Feeling anxious or stressed is perfectly normal and one of the best ways to help is by talking to family, friends or a trained counsellor. If the feelings become overwhelming and there are episodes of depression, talk to your doctor about managing this with antidepressant medications or counselling.

For more ideas and support, visit [www.gutcancer.org.nz/emotional-health](http://www.gutcancer.org.nz/emotional-health)

## Support for people with liver cancer and their families

You can find support from others who are going through a similar experience. You may want to join a local cancer support group, which can provide a safe place for you to share your feelings and experiences, and connect with others.

For more ideas and support, visit: [www.gutcancer.org.nz/patient-support-groups](http://www.gutcancer.org.nz/patient-support-groups)

## Practical support

You are bound to feel tired or exhausted sometimes, so be kind to yourself. Make sure you rest, prioritise what you want or need to do, accept offers of help, and ask for help if you need it.

Practical issues won't have been the first things you thought about when you were diagnosed, but it is important to deal with things like your work or financial situation so that they don't become a source of stress.

Your diagnosis will affect your ability to work, even if only temporarily (for example, when having treatment). Talk to your employer, human resources department or union representative about taking sick leave, reducing your hours or working from home. Being unable to work can lead to financial problems, so ask about any financial help or benefits you may be entitled to.

For more information on support available visit [www.gutcancer.org.nz/financial-support-and-assistance](http://www.gutcancer.org.nz/financial-support-and-assistance)

Health New Zealand Te Whatu Ora offer financial assistance for people who need to travel for medical tests and treatment. You may be able to get financial help for travel, for more information, go to [www.healthnz.govt.nz/hospitals-services/eligibility-subsidies/national-travel-assistance](http://www.healthnz.govt.nz/hospitals-services/eligibility-subsidies/national-travel-assistance)



# Clinical trials

Clinical trials for liver cancer look at different treatment options, with the aim of finding more effective treatments to improve survival and quality of life.

You may be eligible to take part in a clinical trial, so it is always a good idea to ask your specialist whether there is a trial suitable for your condition.

Before you decide whether to take part in a trial, you need to know exactly what is involved. Talk to your specialist and ask as many questions as you need to. If you decide to take part in a trial, you will have to sign a form saying you understand and agree to what is involved (this is called informed consent). If you change your mind, you can withdraw from the trial at any time – withdrawing won't affect your care.

The benefit of being involved in a clinical trial is that you can access the latest treatments before they are widely available. Often, your care and condition are also more closely monitored.

Several current clinical trials are looking at different ways to treat liver cancer, especially advanced liver cancer. Some trials are looking at new therapies, while others are combining various therapies to see whether they work better together.



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

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

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

For more information about clinical trials, please visit [www.gutcancer.org.nz/cancer-research-and-clinical-trials](http://www.gutcancer.org.nz/cancer-research-and-clinical-trials).



# What to ask your medical team

Your medical team is made up of highly qualified people who specialise in different aspects of health care. This multidisciplinary team will likely include oncologists, hepatologists, specialist nurses, surgeons, pharmacists, and allied health professionals including dietitians, physiotherapists and/or exercise physiologists. Some people may require support from counsellors or psychologists during this challenging time.

Ask your medical team any questions you may have. If you don't understand the answer, don't be afraid to ask them again.

There are some key questions that you should ask your medical team:

- What is my diagnosis?
- What treatments are available?
- What is my prognosis (expected outcome)? Will it change if I do or don't have a particular treatment?
- What kind of surgery have I had? How much of my liver remains? Did you have to place a bile duct stent?
- What side effects can I expect? Can I have medications to manage these (such as anti-nausea drugs)?
- Are there any concerns about my weight or muscle mass? (Also see Diet and nutrition for people living with liver cancer. This booklet is available to download at [www.gutcancer.org.nz/shop](http://www.gutcancer.org.nz/shop))
- How can I make an appointment with a dietitian? (Also see Diet and nutrition for people living with liver cancer, available at [www.gutcancer.org.nz/shop](http://www.gutcancer.org.nz/shop)).

# Glossary

- **Adjuvant treatment** is additional treatment, such as chemotherapy or radiation therapy, given after surgery.
- **Advanced cancer** is when cancer cells have spread from where they first grew to other parts of the body. Advanced cancer is also known as metastatic or secondary cancer.
- **Allied health professionals** are trained professionals who work with others in the multidisciplinary team to support cancer patients.
- **Bile** is a fluid that is made in the liver, stored in the gallbladder and secreted into the small intestine. Bile is transported through bile ducts. Bile is made from cholesterol, water, bile salts and bilirubin, and is used to help digest fats.
- **Bile duct** is one of a series of tubes that carries bile from the gallbladder, through the liver and to the small intestine. The tube through which bile travels from the liver and gallbladder to the small intestine is called the common bile duct. See also *Gallbladder*.
- **Bilirubin** is a yellow pigment that is formed when red blood cells in the body break down. See also *Jaundice*.
- **Biomarker** is a chemical substance in the bloodstream that can be tested by a pathology lab. See also *Pathology*.
- **Biopsy** is when tissue is removed so it can be examined under a microscope.
- **Caloric need** is the amount of energy that the body needs from food each day to maintain weight.
- **Chemotherapy** is treatment that uses toxic medicines to destroy cancer cells.
- **Diagnosis** is working out what condition you have based on test results – in this case, whether you have liver cancer. Diagnosis also includes working out the exact location of the tumour, and its grade and stage.
- **Dietitian** is someone who specialises in promoting health through food and nutrition.
- **Exercise physiologist** is someone who specialises in clinical exercise interventions for people with health issues.
- **Gallbladder** is a small, pear-shaped organ on the right side of the abdomen, just beneath the liver. The gallbladder stores bile, which is made by the liver.

- **Gastroenterologist** is someone who specialises in diseases and disorders of the digestive system, including the oesophagus, stomach, intestines, liver and pancreas.
- **Gastrointestinal** is a term used to describe anything that has to do with the digestive system (for example, gastrointestinal tract).
- **Hepatologist** is a specialist liver doctor who can diagnose, treat, and manage problems associated with your liver.
- **Immunosuppressants** are medications that stop the immune system from working. The immune system protects the body against illness and infection by attacking bacteria, viruses and abnormal cells. Immunosuppressants help stop the body from rejecting new organs after a transplant.
- **Immunotherapy** is treatment that activates the immune system to find and attack cancer cells. See also *Targeted therapy*.
- **Jaundice** is yellowing of the skin and whites of the eyes caused by a build-up of bilirubin in the blood. The excess bilirubin also makes the skin itchy. This can happen when bile ducts are blocked.
- **Localised treatment** is treatment that only affects a certain area of the body, such as radiation therapy.
- **Locally advanced cancer** is when cancer cells have spread from where they first grew in the liver to structures around it, such as blood vessels.
- **Lymph nodes** are tiny oval structures throughout the body that contain lymph fluid. Lymph fluid is part of the immune system. Cancer often spreads to lymph nodes.
- **Metastatic cancer** see *Advanced cancer*
- **Multidisciplinary team** is a team of health professionals with different skills who plan cancer treatment and provide ongoing care; this ensures that all your needs will be considered.
- **Neoadjuvant treatment** is treatment given before surgery, such as chemotherapy or radiation therapy.
- **Nutritional supplements** are specially formulated drinks, powders and foods that increase calorie (energy) intake and help you maintain weight.
- **Oncologists** are specialists in treating cancer. The main types of oncologists are:
  - surgical oncologists, who specialise in operating on tumours
  - medical oncologists, who specialise in chemotherapy and other systemic therapies (such as immunotherapies and targeted therapies)
  - radiation oncologists, who specialise in radiation therapy.

- **Oncology nurses** are nurses who work with you to identify and assess your supportive care needs, monitor your condition, give you medication and develop care plans. Oncology nurses also answer your questions and work closely with other members of the healthcare team to ensure that you receive the highest quality of care. See also *Supportive care*.
- **Palliative treatment** is treatment that controls symptoms, relieves pain where possible, and slows down the progression of an illness when a cure is no longer possible.
- **Pathology** involves looking at samples from the body to work out whether someone has a disease, and the nature of the disease. Pathology includes looking at tissue and cells from a biopsy under a microscope; testing blood, urine or stool samples; and genetic testing. A pathologist is a doctor specialising in pathology.
- **Prognosis** is the expected outcome for you based on the most up-to-date evidence. It depends on your diagnosis and treatment, and can change over time.
- **Radiation therapy** is treatment that uses high-energy X-rays to destroy cancer cells.
- **Recurrence** is when cancer comes back, even after responding to treatment previously.
- **Supportive care** is improving comfort and quality of life by preventing, controlling or relieving disease complications and side effects. Supportive care includes psychological, social and spiritual needs.
- **Targeted therapy** is treatment that blocks pathways that cancer cells need to grow and survive. A targeted therapy might work for one person but not another. You will likely need pathology tests to work out whether a targeted therapy will work for you. Immunotherapies are a type of targeted therapy.
- **Upper gastrointestinal** refers to the upper part of the digestive system, including the oesophagus, stomach, liver, pancreas, gallbladder and bile ducts.





## Further information and support

There are a range of international organisations that Gut Cancer Foundation is collaborating with. Due to differences in best practice care around the world, we have focused on resources and information available in New Zealand.

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Our website has information that complements what is in this booklet. You can get in touch with our specialist support team, find out more about clinical trials, learn about joining a support group and access other resources.

[www.gutcancer.org.nz/liver-cancer](http://www.gutcancer.org.nz/liver-cancer)

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To maximise your nutritional needs, we have developed a free booklet specially to focus on the topic of diet and nutrition.

[www.gutcancer.org.nz/shop](http://www.gutcancer.org.nz/shop)

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There are organisations that can support you with counselling to help patient and whānau work through a diagnosis.

**Cancer Society:** [www.cancer.org.nz/how-we-can-help/support-we-offer/psychology-and-counselling](http://www.cancer.org.nz/how-we-can-help/support-we-offer/psychology-and-counselling)

**Healthpoint:** [www.healthpoint.co.nz/community-health-and-social-services/cancer-support/cancer-counselling](http://www.healthpoint.co.nz/community-health-and-social-services/cancer-support/cancer-counselling)

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A guide to understanding diagnosis and  
treatment of liver cancer.

[gutcancer.org.nz](http://gutcancer.org.nz)

