



A guide to understanding
diagnosis and treatment:

BILIARY CANCER

(bile duct cancer and gallbladder 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 biliary 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 biliary 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.

First published by Pancare Foundation Australia, 2015
Republished by ©Gut Cancer Foundation, 2026



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, email support@gutcancer.org.nz or call [0800 112 775](tel:0800112775)

Your guide for using this handbook

This handbook contains key detail 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 biliary cancer and sources of further information and support.

Introduction

This handbook is for anyone who has recently been diagnosed with gallbladder cancer or bile duct cancer (also called biliary cancer or cholangiocarcinoma, pronounced kol-an-gee-oh-car-sin-ohma), and for their partners, family members and carers. It gives a general introduction to biliary 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 biliary 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 biliary cancer would not have had any inkling 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.

This booklet contains references to, and visual depictions of, organs surgical procedures and treatments, please take care when reading.



Contents

Your guide for using this handbook	4
Introduction	5
About the gallbladder and bile ducts	8
Gallbladder	8
Bile ducts	9
About biliary cancer	11
Gallbladder cancer	11
Bile duct cancer (Cholangiocarcinoma)	12
Risk factors	13
Towards a biliary cancer diagnosis	14
Tests and investigations: what, why and how	16
Initial investigations	16
Staging tests	20

Stages of cancer	22
Treatment journey	24
Treatments for biliary cancer	25
Prehabilitation	26
Surgery	27
Intrahepatic biliary cancer surgery	31
Chemotherapy	37
Radiation therapy	40
Targeted therapy and immunotherapy	41
Managing symptoms and treatment side effects	42
Pain relief	44
Nutritional support	45
Physical wellbeing	49
Emotional wellbeing	50
Practical support	52
Clinical trials	54
What to ask your medical team	56
Glossary	58
Further information and support	63

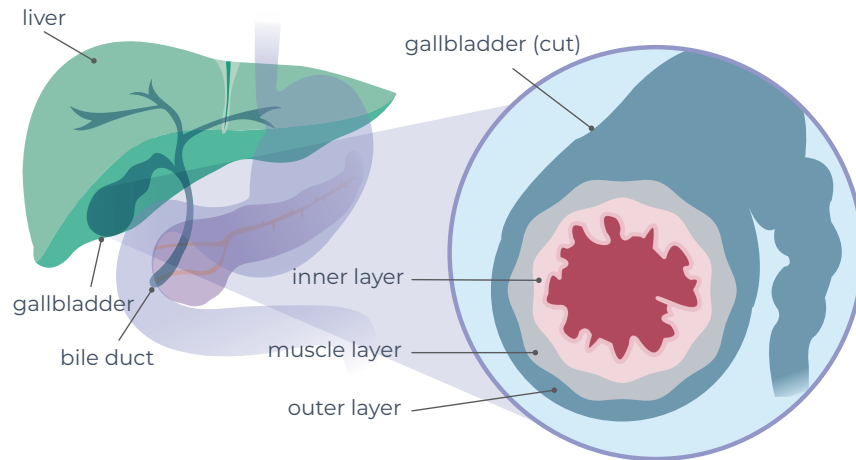
About the gallbladder and bile ducts

The gallbladder is a small, pear-shaped organ that sits under the liver. It stores bile that is made by the liver. The gallbladder is connected to the liver and small intestine by a series of tubes called bile ducts.

Gallbladder

The gallbladder is a small, pear-shaped organ that sits under the liver. It stores bile that is made by the liver. The gallbladder is connected to the liver and small intestine by a series of tubes called bile ducts.

Figure 1: The three layers of the gallbladder



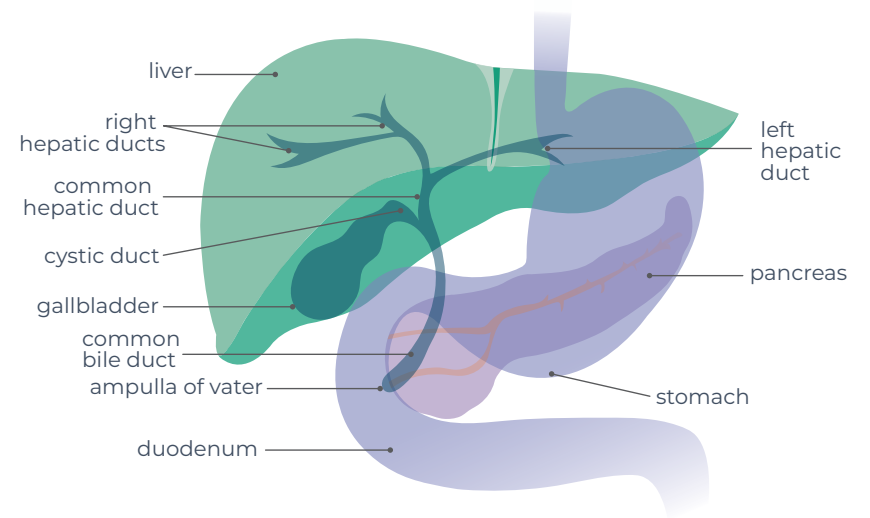
The gallbladder has three main layers (*Figure 1*). These are the:

- inner layer, known as the mucosa
- muscle layer, called the muscularis
- outer layer, known as the serosa.

Bile ducts

Bile ducts are small tubes that carry bile between the liver, gallbladder and small intestine. The common bile duct starts where the hepatic ducts (from the liver) and cystic duct (from the gallbladder) meet (*Figure 2*). The common bile duct passes behind the pancreas and joins the pancreatic duct. The combined ducts open into the small intestine, where bile is released.

Figure 2. Main organs of the biliary system





Biliary obstruction and jaundice

A blockage (obstruction) in the bile ducts can cause bilirubin to build up in the blood – this is called jaundice. Jaundice can cause the skin and whites of the eyes to turn yellow. You may also have itchy skin, pale stools (faeces) or dark urine.

Some common causes of biliary obstruction are:

- gallstones – these are the most common cause
- inflammation (swelling) of the bile ducts
- a biliary structure (narrowing of the bile duct)
- pancreatitis (inflammation of the pancreas)
- gallbladder or liver surgery
- tumours that have reached the liver, gallbladder, pancreas or bile ducts
- infections, including hepatitis
- cirrhosis (scarring) of the liver
- severe liver damage.

It is important to see your doctor if you have symptoms of jaundice. Your doctor may send you for tests to work out the cause.

About biliary cancer

Biliary cancer occurs when abnormal cells in the gallbladder or bile ducts grow out of control. Biliary cancer may also be called gallbladder cancer, bile duct cancer or cholangiocarcinoma.

Gallbladder cancer

Gallbladder cancers are divided into four main groups, depending on the type of cell that the cancer grows from:

- **Adenocarcinomas** start in the cells of the inner lining of the gallbladder (mucosa)
- **Squamous cell carcinomas** start in the flat cells that form the innermost layer lining the gallbladder
- **Sarcomas** start in the muscle layer (muscularis) of the gallbladder
- **Lymphomas** start in the lymph nodes (*see 'lymph nodes' in the 'Glossary' on page 59*) around the gallbladder.

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

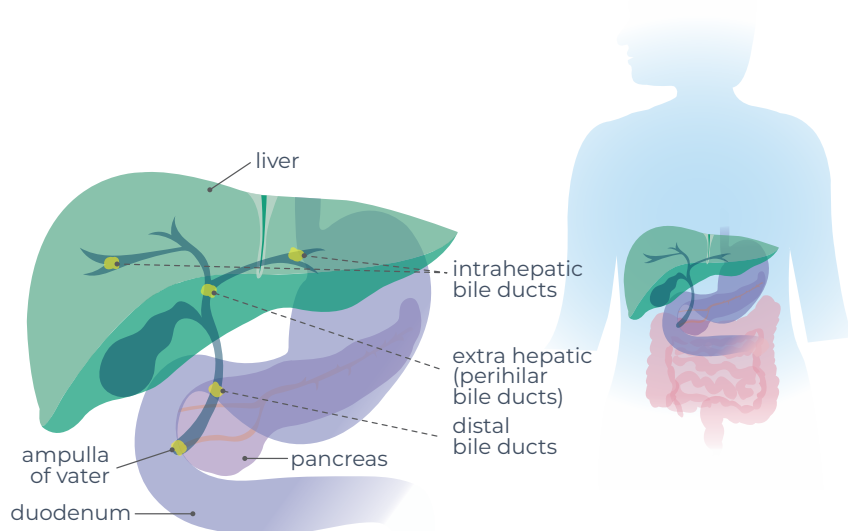
Bile duct cancer (Cholangiocarcinoma)

Bile duct cancer, or cholangiocarcinoma, is a rare type of cancer.

There are several types of bile duct cancer, depending on where in the bile duct the cancer starts (*Figure 3*):

- **Intrahepatic** bile duct cancers form in the liver. More on this in 'A Guide to Understanding Diagnosing and Treatment: [Liver Cancer](#)', available on our website.
- **Extrahepatic** bile duct cancers form outside the liver.
 - Perihilar bile duct cancers (also called hilar bile duct tumours or Klatskin tumours) form just outside the liver, where the right and left hepatic ducts (the two main bile ducts in the liver) meet
 - Common bile duct cancers form in the common bile duct
 - Distal bile duct cancers form in the bile ducts that run through the pancreas to the small intestine
 - Ampullary cancers form in the ampulla of Vater, where bile ducts from the liver and pancreas join and enter the first part of the small intestine (duodenum)
 - Multifocal bile duct cancers mean more than one tumour has been found in different locations within the bile ducts.

Figure 3: Locations of the main types of bile duct cancer



Risk factors

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

Health risk factors

Health risk factors for developing biliary cancer include:

- having primary sclerosing cholangitis, a condition in which inflammation of the bile ducts (cholangitis) leads to the formation of scar tissue (sclerosis)
- having other gallbladder and bile duct problems
- having inflammatory bowel disease
- older age (most biliary cancers are in people over the age of 65)
- being infected with hepatitis B virus or hepatitis C virus
- having gallstones or inflammation of the gallbladder.

Environmental risk factors

Environmental risk factors for developing biliary cancer include:

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

Hereditary risk factors

Having a family history of gallbladder cancer or bile duct cancer, particularly in first-degree relatives such as parents or siblings, can increase the risk of developing biliary cancer. However, the increase in risk is small.

Towards a biliary cancer diagnosis

Reaching a diagnosis of biliary 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 biliary cancer was considered, and you may have had the cancer for some time without knowing.

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

- pain around the abdomen or the right side of the ribs
- 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.

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 biliary cancer.

If any symptoms appear to 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 biliary cancer and haven't had any symptoms, it is probably because you had another medical procedure and the cancer was found by chance.



Tests and investigations: what, why and how

The tests used to diagnose your biliary cancer will help doctors understand your condition. You may need other tests to confirm the type of biliary 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, CA19-9 and CEA are tumour markers linked to biliary cancer. However, other conditions can also raise the level of these markers, and some people with biliary cancer have normal levels. These markers on their own cannot be used to diagnose biliary cancer.

Ultrasound scan of the abdomen

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 bile ducts, gallbladder, pancreas and liver on a screen.

Computerised tomography (CT) scan

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

Magnetic resonance imaging (MRI)

MRI uses magnets and radio waves to build a detailed cross-sectional picture of the gallbladder, bile ducts and surrounding areas.

Refer to the Gut Cancer website for more information www.gutcancer.org.nz/gallbladder-and-bile-duct-cancer/#diagnosis

Magnetic resonance cholangiopancreatography (MRCP)

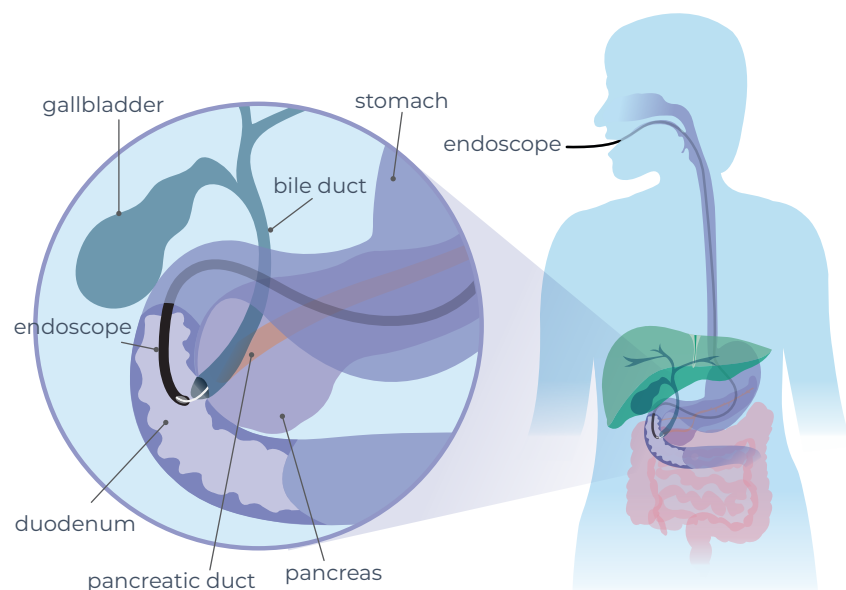
MRCP is a special type of MRI that is sometimes used to give clearer pictures of the bile and pancreatic ducts, gallbladder and any blockages. It can show whether a cancer is blocking the flow of bile or has grown around the vein to the liver (the portal vein).

Endoscopic retrograde cholangiopancreatography (ERCP)

ERCP uses an endoscope, which is a thin, flexible tube with a camera at the end. While you are sedated (asleep), the doctor will slide the endoscope down your oesophagus, through your stomach and into the first part of your small intestine. As well as looking for blockages of the bile ducts or signs of cancer, the endoscope is used to guide a catheter into the bile and/or pancreatic duct(s). This is done to inject a special dye called contrast medium into the ducts so that they are more visible on X-ray images (*Figure 4*). X-ray images are then taken of your pancreas, gallbladder and bile ducts. The doctor may also take a biopsy (a small sample) of any abnormal-looking areas during the procedure. The biopsy will be sent to a pathologist to look for signs of cancer or other disease.

If you have jaundice, ERCP may also be used to put a stent into your blocked bile duct to keep it open (*see 'Bile duct stents' on page 34*).

Figure 4: Endoscopy (ERCP) for examining biliary cancer



Cholangioscopy (Spyglass)

A cholangioscopy (kol-an-gee-os-copy) is sometimes done at the same time as an ERCP. A cholangioscope is a small tube with a camera that is passed directly into the bile ducts so the doctor can see if there are any abnormal areas. If there are, the doctor may take a biopsy that will be sent to a pathologist for further tests.

Endoscopic ultrasound (EUS)

You might have an EUS to look for a tumour or blockage in your bile ducts, to see how big the gallbladder or bile duct cancer is, or to see if the cancer has spread to other tissues or organs. EUS uses an endoscope with a camera and ultrasound probe at the end. While you are sedated, the doctor will slide the endoscope down your oesophagus, through your stomach and into the first part of your small intestine.

The ultrasound creates a picture of the inside of the body. The doctor may also take a biopsy of tissue during the procedure. The biopsy will be sent to a pathologist to look for signs of cancer or other disease. The result from the EUS can help doctors better assess the cancer.

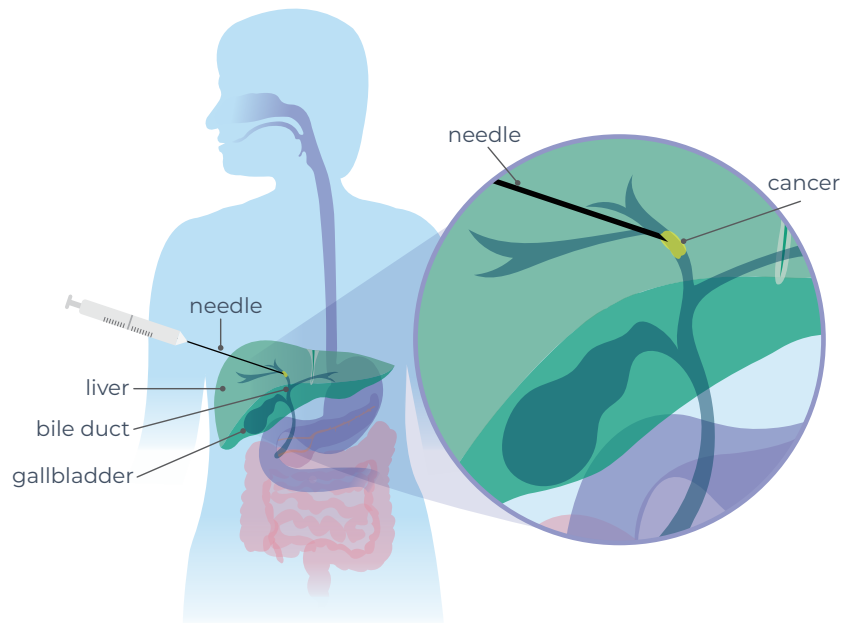
Percutaneous transhepatic cholangiography (PTC)

PTC uses X-rays to look for a blockage in your bile ducts. You usually have a PTC if you can't have an ERCP for some reason. Doctors can also use PTC to plan surgery to remove the gallbladder.

The doctor will put a long, thin needle through the skin and into the liver and bile ducts (*Figure 5 on page 20*). They will then inject a dye into your bile ducts that shows up any blockage on an X-ray. The doctor may also take a biopsy of any abnormal-looking areas. The biopsy will be sent to a pathologist to look for signs of cancer or other disease.

If you do have a blockage in your bile ducts, you might have treatment during the PTC. This may include draining the bile ducts or inserting a stent (see '*Bile duct stents*' on page 34).

Figure 5: Percutaneous transhepatic cholangiography and biopsy



Staging tests

If you have been diagnosed with biliary 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 biliary cancer, see *(‘Stages of cancer’ on page 22)*.

Biopsy

A tissue biopsy is 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 some tests such as an ultrasound, EUS, ERCP or a laparoscopy. A biopsy may not be performed in certain cases when surgical removal is planned upfront.

Positron emission tomography (PET) scan

During 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.

Laparoscopy

This is a small operation done under general anaesthetic. A long tube with a camera at one end (a laparoscope) is inserted through a small cut in your abdomen to see the cancer, and check whether it has spread to other parts of the body. Other small cuts may be made so instruments can be inserted to take a biopsy. Sometimes an ultrasound probe is used (laparoscopic ultrasound). Laparoscopy is sometimes called keyhole surgery.

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 different ways to stage cancer. In Australia, the common ones are:

- numbered cancer stage system (Figure 6)
- tumour-node-metastases (TNM) system (Figure 7).



Figure 6: Numbered cancer stage system

Stage 1

The earliest stage.

- For gallbladder cancer, tumours are found only in the inner layers of the tissues lining the gallbladder (the mucosa)
- For bile duct cancer, tumours are small and found only in one area of the bile duct. Also called localised cancer.

Stage 2&3

- For gallbladder cancer:

- tumours have grown through the muscle layer of the gallbladder wall (the muscularis) and into the connective tissue underneath, but have not spread outside the gallbladder
- tumours may have grown through the gallbladder wall and spread to nearby lymph nodes.

- For bile duct cancer, tumours are larger and may have grown into the surrounding tissues and to nearby lymph nodes. Also called locally advanced cancer.

Stage 4

The late stage. Tumours have spread to nearby lymph nodes or parts of the body, or to distant lymph nodes and parts of the body.

Also called secondary or metastatic cancer.

Figure 7: TNM (tumour–node–metastasis) system

T (tumour)	The size of the tumour
N (node)	Indicates whether the cancer has spread to the lymph nodes
M (metastasis)	Indicates whether the cancer has spread to other parts of the body (metastatic cancer)

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.

You will be cared for by a specialist multidisciplinary team of health professionals who can assess and treat the disease. There should be one key point of contact at every step of your treatment journey.

Rural and regional hospitals are often part of a network linked to metropolitan specialist centres. This ensures that the best treatment and care are available to all patients, regardless of where they live in New Zealand.



? 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 biliary cancer

Surgery and chemotherapy are often used to treat biliary cancer. The type of surgery depends on what type of cancer you have and where it is. Other options for treatment include radiation therapy and immunotherapy.

The treatments you will receive depend 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. Your doctor may call your cancer operable or resectable.

Because biliary cancers are often advanced when they are first found, the tumour may be referred to as borderline operable. You may be offered surgery in these cases, but it is more likely that you will be offered preoperative treatment, such as chemoradiotherapy or chemotherapy alone, before surgery is considered.



Gallbladder cancer surgery

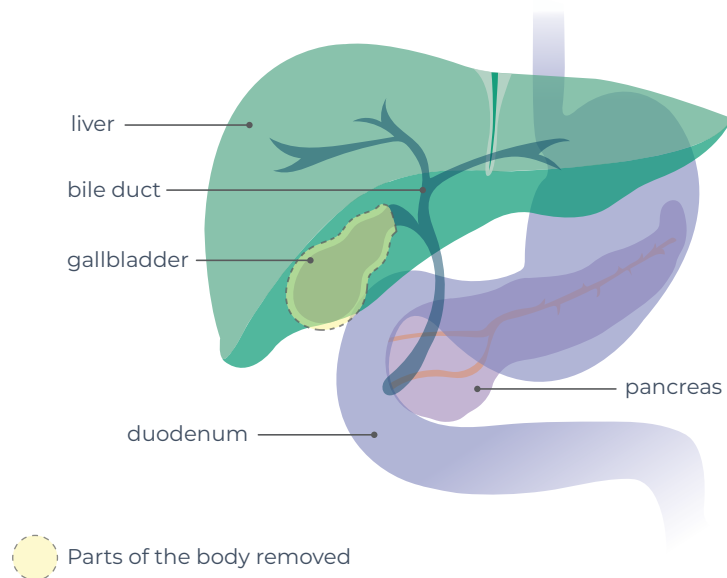
Surgery is the main treatment for biliary cancer inside the gallbladder.

Simple cholecystectomy

Surgery to remove the gallbladder is called a cholecystectomy (Figure 8). Surgery may be performed as either:

- laparoscopic (keyhole) surgery, where small cuts are made in your abdomen and a laparoscope is used to see and remove the tumour; most cholecystectomies are keyhole surgeries
- open surgery, where the gallbladder is removed through a large cut (incision) in the upper-right side of your abdomen.

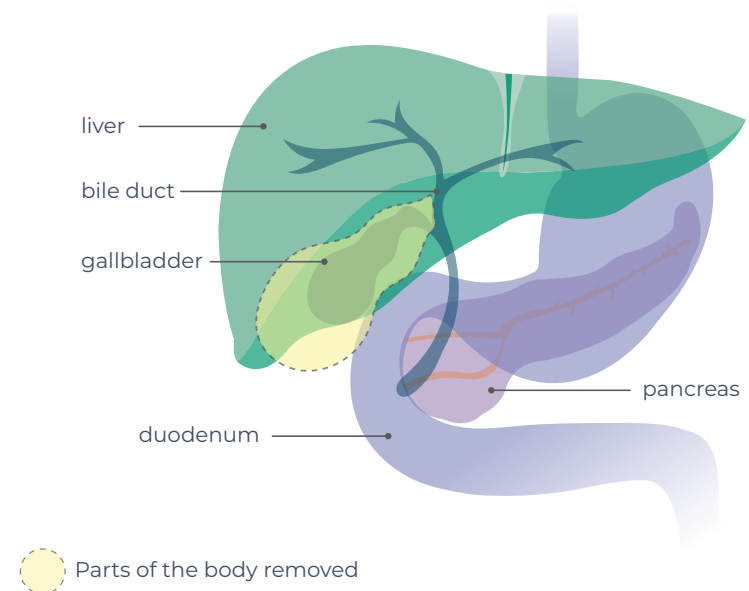
Figure 8: Simple cholecystectomy



Extended cholecystectomy

In an extended cholecystectomy, the surgeon will remove all of the gallbladder, part of the liver, and all of the surrounding lymph nodes (Figure 9). This is done if the cancer has spread throughout the gallbladder. The lymph nodes may be sent to a pathologist to check for signs of cancer.

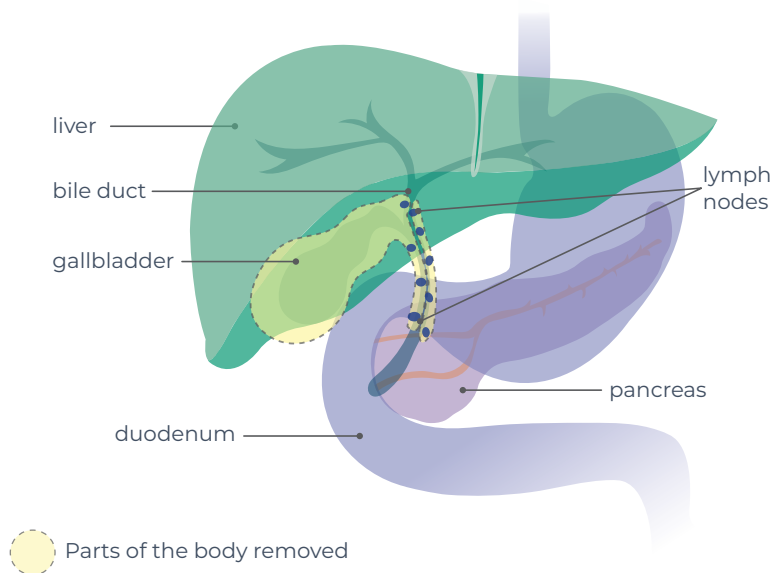
Figure 9: Extended cholecystectomy



Radical cholecystectomy

A radical cholecystectomy is done if the cancer has spread outside of your gallbladder to nearby lymph nodes. The surgeon will remove all of the gallbladder, part of the liver, the common bile duct, and the lymph nodes around nearby organs such as the liver, stomach, intestines and pancreas (Figure 10).

Figure 10: Radical cholecystectomy



Intrahepatic biliary cancer surgery

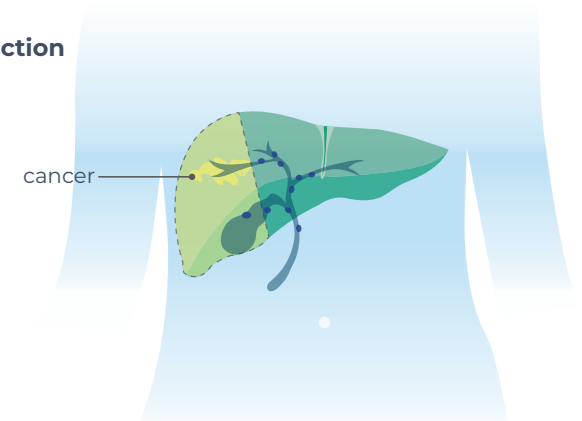
Surgery is the main treatment for biliary cancer inside the liver (called intrahepatic).

Liver resection (hepatectomy)

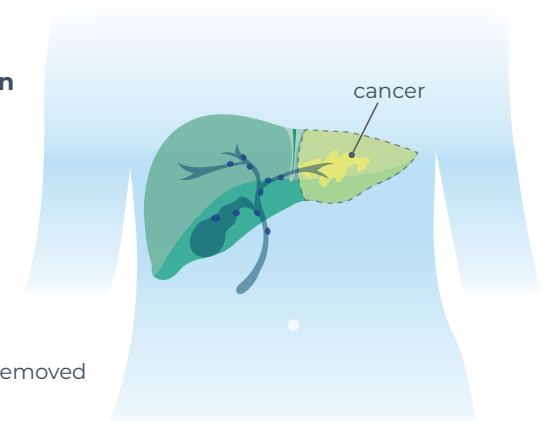
Surgery that removes part of your liver is called a liver resection or hepatectomy. How much of your liver is removed depends on the size of the cancer and where it is located (Figure 11). The liver can regenerate and work normally after a resection.

Figure 11: Liver resection (hepatectomy)

A: Right-sided liver resection



B: Left-sided liver resection

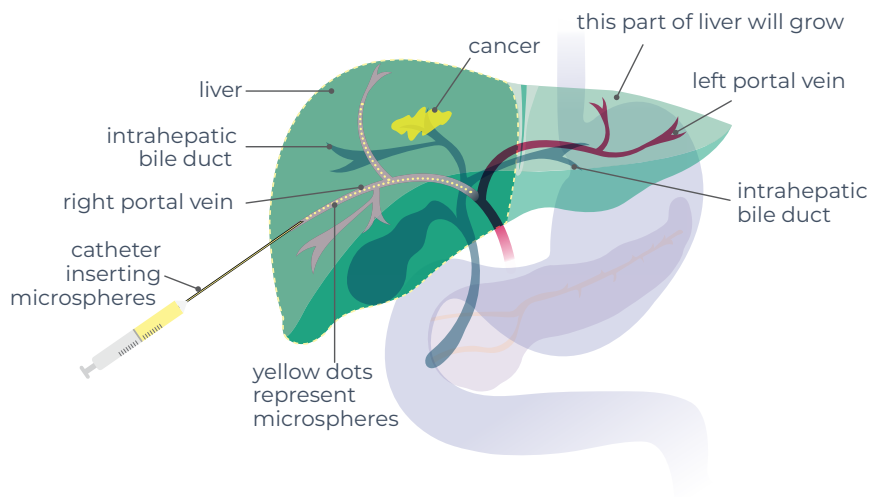


Parts of the body removed

Portal vein embolisation

Before major liver surgery, the surgeon may suggest you have a procedure called portal vein embolisation (PVE) (*Figure 12*). PVE means blocking off part of the blood flow to the area of the liver that has bile duct cancer. This is done by injecting microspheres into a portal vein (the main blood vessels in the liver). PVE increases the size of the healthy part of the liver by allowing it to grow. This is done about a month before you have surgery to remove the cancer.

Figure 12: Portal vein embolisation before a liver resection



Biliary cancer surgery

Surgery is the main treatment for biliary cancer outside the liver (called extrahepatic).

Hilar Cholangiocarcinoma

Resection of a hilar cholangiocarcinoma involves removal of the bile duct containing the tumour as well as the common bile duct, part of the liver, the gallbladder and nearby lymph nodes. Part of the pancreas and duodenum might also be removed. The remaining bile ducts are re-joined to the intestine, and blood vessels that supply the liver might also have to be reconnected. A procedure called portal vein embolisation

(PVE) may be offered to patients before resection (see above paragraph for information on PVE).

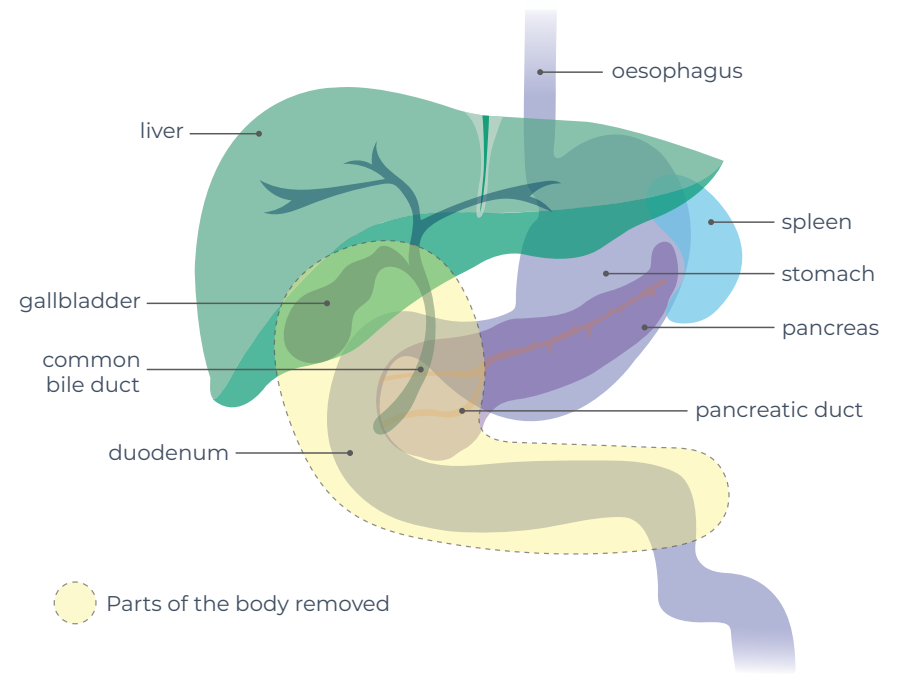
Extrahepatic Cholangiocarcinoma

Surgery for extrahepatic cholangiocarcinoma requires removal of the bile duct containing the tumour, nearby lymph nodes, part of the pancreas and part of the duodenum. The remaining pancreas and stomach are then reconstructed.

Ampullary cancer surgery

Ampullary cancer is typically removed by a type of surgery called pancreatoduodenectomy (also known as Whipple's procedure). This involves removal of the head of the pancreas, part of the small intestine, the gallbladder and part of the bile duct.

Figure 13: Whipple's procedure



Stent insertion and bypass surgery

Sometimes patients need to have other procedures that do not remove the cancer but instead help relieve symptoms.

The cancer may have grown so that it blocks your bile duct or duodenum. If your bile duct is blocked, you may develop jaundice and itchy skin. If your duodenum is blocked, food cannot move from your stomach and will cause discomfort, sickness or vomiting. In these cases, you may have a stent placed, or have surgery to bypass the blockage.

A stent or bypass won't treat the cancer, but will help relieve the blockage caused by the cancer so that you are more comfortable.

Bile duct stent

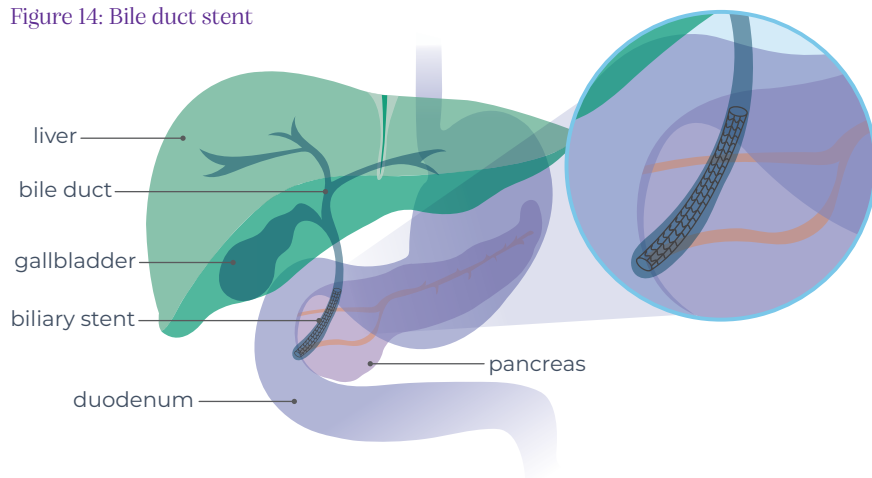
If you have a blockage in your bile duct, you might need to have a bile duct stent placed.

A bile duct stent is a small tube that sits in the bile duct. It helps keep your bile duct open so that bile can pass through the bile duct to the duodenum (Figure 14).

The two ways a stent can be inserted are:

- ERCP (see 'Endoscopic retrograde cholangiopancreatography (ERCP)' on page 18), where an endoscope is used to see the blockage and place the stent
- percutaneous stent placement, where the stent is placed through the skin of the abdomen using a long, thin needle (an ultrasound or X-ray is used to guide the needle).

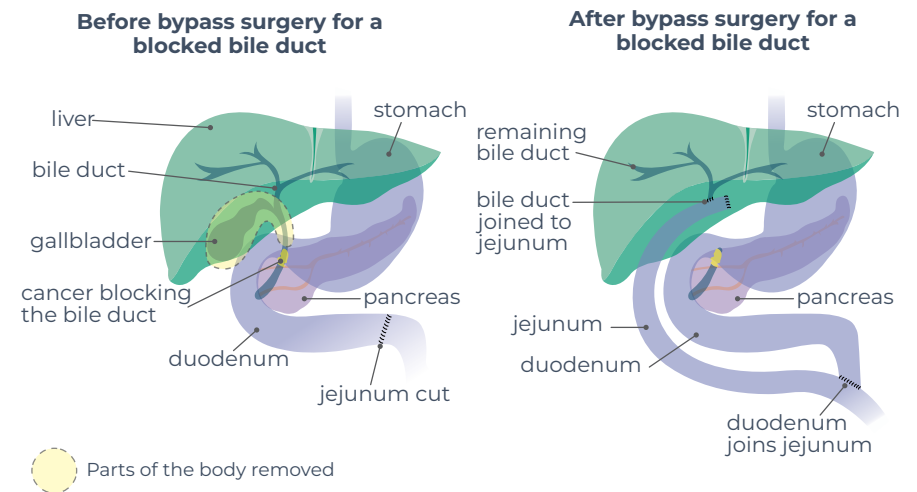
Figure 14: Bile duct stent



Biliary bypass

You may need surgery to bypass the blockage in your bile duct if a stent has not worked. This is called a biliary bypass. The surgeon will cut your bile duct above the blockage and reconnect it to a part of your small intestine (called the jejunum). They will also remove your gallbladder (Figure 15).

Figure 15: Biliary bypass



Duodenal stent

If the biliary cancer blocks your duodenum, you might need to have a duodenal stent placed.

A duodenal stent is a small metallic mesh tube that sits in the duodenum. It helps hold the sides of the duodenum open so that food and fluid can pass through the stomach into the intestines (Figure 16 on page 36). While you are sedated, your doctor will use an endoscope and a fine wire to insert the stent.

Figure 16: Duodenal stent

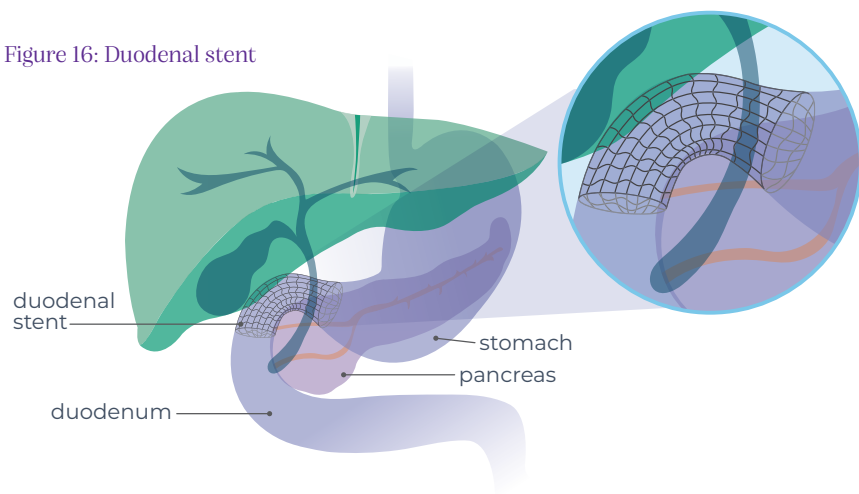
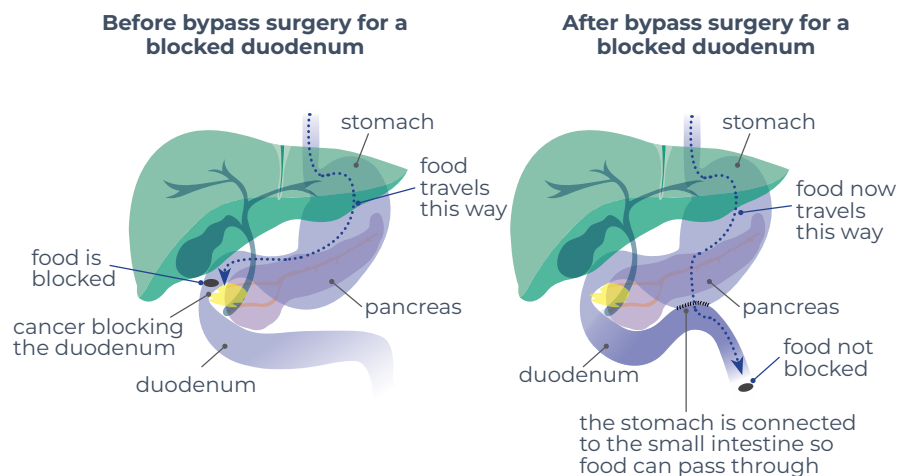


Figure 17: Duodenal bypass



Chemotherapy

Chemotherapy may be offered to patients with biliary cancer, either alone or in combination with other therapies such as radiation therapy. For biliary cancers that have spread and are not surgically resectable, chemotherapy on its own or in combination with immunotherapy (see *'Targeted therapy and immunotherapy'* on page 41) may improve symptoms and quality of life, and extend life expectancy. You should consider being involved in clinical trials if they are available. Ask your oncologist if a clinical trial for treatment of biliary cancer is available in your region (see *'Clinical trials'* on page 54).

Depending on the type of biliary cancer, chemotherapy may be the only treatment used, or it 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. For someone with advanced biliary cancer, chemotherapy can also be used for palliative treatment, to relieve symptoms and slow progression of the disease.

Often, patients are fitted with a temporary catheter that allows chemotherapy and other medicines to be administered intravenously without the need for multiple needle sticks. The most frequently used are either a PICC (peripherally inserted central catheter) line or a chemo port (see information boxes for more details). These may remain in place for several weeks, even months, with regular monitoring and care.



i What is a PICC line?

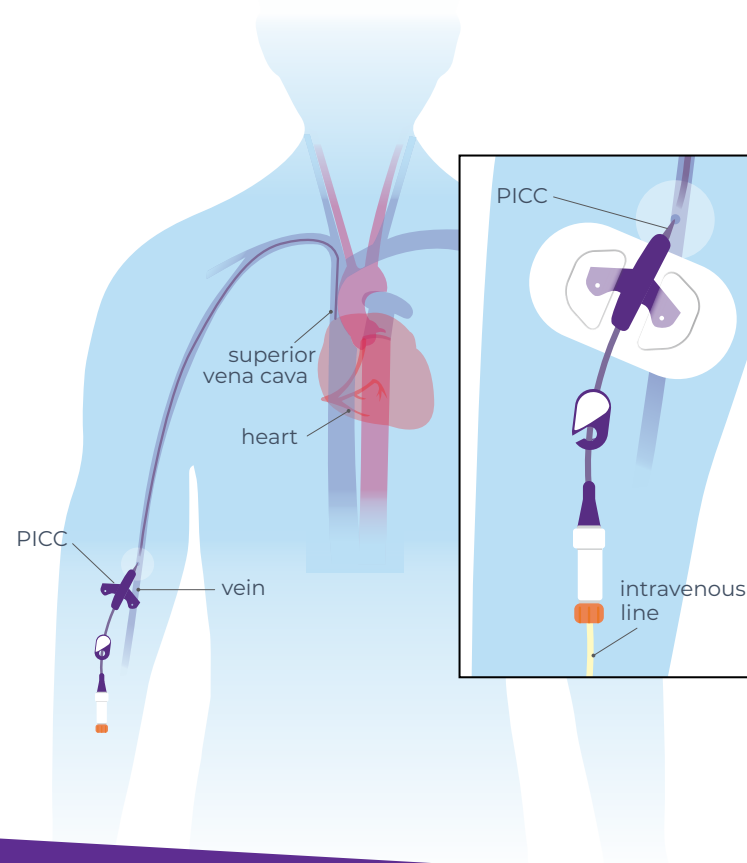
A PICC is a peripherally inserted central catheter. It is used to give treatments, fluids, medicines or blood transfusions into your bloodstream and to take blood samples. A PICC is used instead of intravenous (IV) cannulas (needles in your arm) for your treatments. IV cannulas are put in for each treatment, 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 18). 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 18: Peripherally Inserted Central Catheter (PICC)

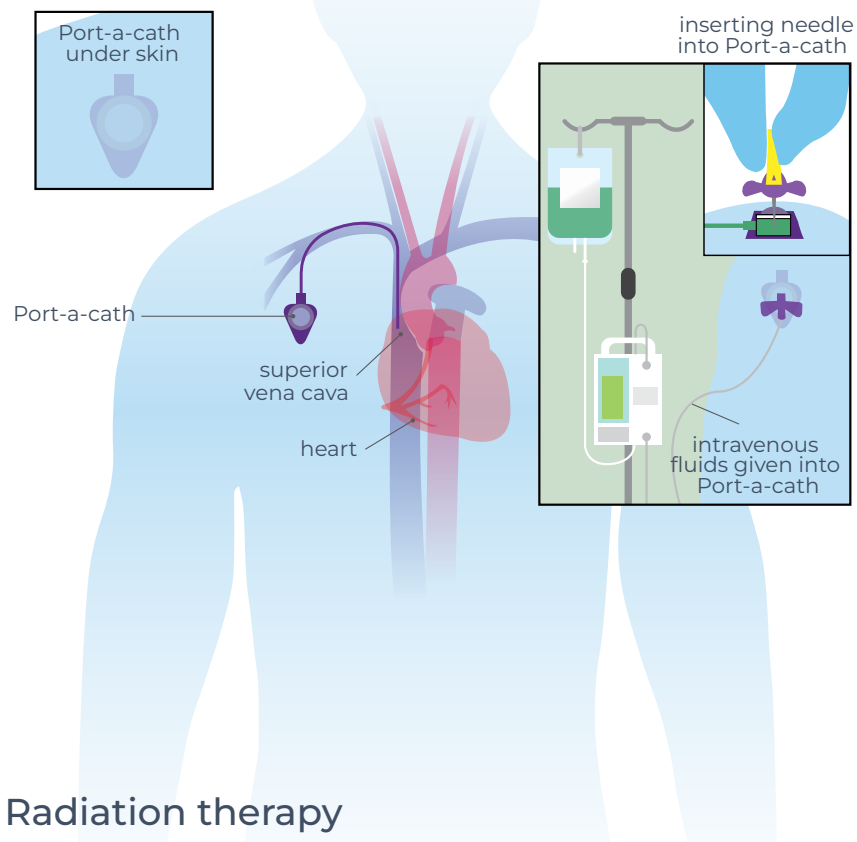


i What is a chemo port?

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 19 on page 40). 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.

Figure 19: Port-a-cath (Port)



Radiation therapy

Radiation therapy may be used by itself or combined with chemotherapy to reduce the chances of biliary cancer returning locally. Radiation therapy can be used to try to shrink the tumour before surgery, to increase the chance of successful surgical removal. It may also be offered to kill any cancer cells that are left after the tumour has been surgically removed.

Radiation therapy can sometimes be helpful when cancer has spread to other parts of the body (advanced or metastatic cancer).

Radiation therapy uses high-energy X-rays to destroy cancer cells. Modern radiation techniques target the cancer cells precisely, so it is called a localised treatment. Normal cells around the cancer cells can also be affected, which is why radiation therapy can cause side effects such as fatigue, nausea and diarrhoea.



Targeted therapy and immunotherapy

Targeted therapies are medicines that target specific genes and proteins involved in cancer growth. Immunotherapy is one type of targeted therapy.

Targeted therapies are only effective for some cancers, so you may need to undergo pathology testing to see whether they will benefit you.

Immunotherapy has shown promising results when used with chemotherapy for advanced biliary cancer. Immunotherapies are usually delivered as an injection or infusion, often over multiple sessions.

Immunotherapies and other targeted therapies are rapidly evolving, and the Therapeutic Goods Administration (TGA) approves new therapies all the time. The costs of these therapies can also change, if they are listed on the Pharmaceutical Benefits Scheme (PBS).

Your oncologist will let you know which therapies are available at the time of your treatment, and which might suit you.



Managing symptoms and treatment side effects

As biliary 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 might 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 biliary cancer: surgery, 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.

Table 1: Common side effects of biliary cancer treatments

Surgery	Chemotherapy	Radiation therapy	Targeted therapy and immuno-therapy
• Fatigue • Pain • Diarrhoea and malabsorption • Weight loss • Loss of appetite • Bleeding or blood clots • Leakage of bile (may be caused by an abnormal opening, called a fistula) • Infection.	• Nausea and vomiting • Loss of appetite • Diarrhoea or constipation • Fatigue • Fever • Weight loss • Hair loss • Higher risk of infections • Sore mouth or throat • Taste changes • Burning or prickling feeling in the fingers and toes • Weakness, numbness and pain in the hands and feet.	• Nausea and vomiting • Loss of appetite • Feeling full quickly • Diarrhoea or constipation • Fatigue • Weight loss • Skin changes in the area (redness or peeling) • Increased mucus production.	• Skin rash • Flu-like symptoms • Abdominal pain • Diarrhoea • Weight changes • Joint pain • Shortness of breath.

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

- anti-sickness medication or complementary therapies to help with nausea
- pain medication
- pancreatic enzyme supplements (if you have pancreatic enzyme insufficiency)
- nutritional supplements to help with digesting food and reduce weight loss
- 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

Biliary 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 biliary cancer' guide.

Malabsorption and pancreatic enzyme replacement therapy

Changes to your pancreas after a Whipple's procedure can mean that your body does not produce enough, or any, pancreatic enzymes. This can lead to poor digestion and absorption of food and is known as pancreatic exocrine insufficiency.

There are several symptoms of malabsorption, including:

- floating, pale, foul-smelling stools
- more frequent or loose bowel movements
- bloating or pain (because the large intestine is not used to dealing with these undigested nutrients)
- excess flatulence (passing wind)
- stools that are oily in appearance
- stools that are difficult to flush and stick to the toilet bowl
- weight loss
- not gaining weight, even if you feel you are eating enough
- fatigue and weakness.

In some cases, your specialist may recommend that you take a supplement to replace the pancreatic enzymes. Creon® is the brand name of one of these supplements.

Pancreatic enzyme supplements are available in capsules. These capsules contain a mixture of three different pancreatic enzymes: lipase (to digest fats), amylase (to digest carbohydrates), and protease (to digest proteins).

Your doctor or dietitian will help you to determine the dosage you require at each meal and snack, and when to take them. The dosage is often adjusted according to the type and amount of food being eaten, and whether your symptoms persist.




“What Creon has allowed me to do is to eat what I want, when I want. It's important to understand how it works. Many people are unsure how to use it correctly. My dietitian helped me to understand the correct dosage, when to take it and how to make it work best for me.”



Tips to help you maintain your weight and muscle mass

Try to eat nourishing foods and fluids (those that are high in energy and high in protein).



Include regular sources of protein-rich foods, including poultry, fish, meat, eggs, tofu, legumes, dairy products, nuts and seeds. Aim to base each main meal around a high-quality protein.

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.



Monitor for signs of malabsorption. If you are showing any of these signs, ask your doctor or dietitian about use of Creon.

Ask about using nutrition supplement drinks. When choosing a nutritional supplement for your needs, consider the different options including milk-based, juice flavoured, powder, yoghurt style and soups. You may need to try different products until you find one you prefer or tolerate better. Some people find they prefer a savoury product to a sweet one.



Some options are available on prescription - talk to your GP, specialist or dietitian to see which one might be right for you.



Physical wellbeing

Many people find that sorting out 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 another common symptom, but you can be prescribed anti-sickness medication or try remedies such as ginger, peppermint or acupressure bracelets.

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

Physical activity can also make you feel better, though how much activity will depend on how well you feel and whether you are having treatment or recovering from it. Even a walk round 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 time. Talking to your partner or doctor and sometimes seeing a relationship therapist may help you to find ways of overcoming difficulties.



i

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 gutcancer.org.nz/emotional-health

Emotional wellbeing

As time passes from your initial diagnosis, you will find yourself dealing with the wider emotional impacts of biliary 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.

i

Support for people with biliary 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 gutcancer.org.nz/emotional-health



Practical support

You are bound to feel tired, 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 to.

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

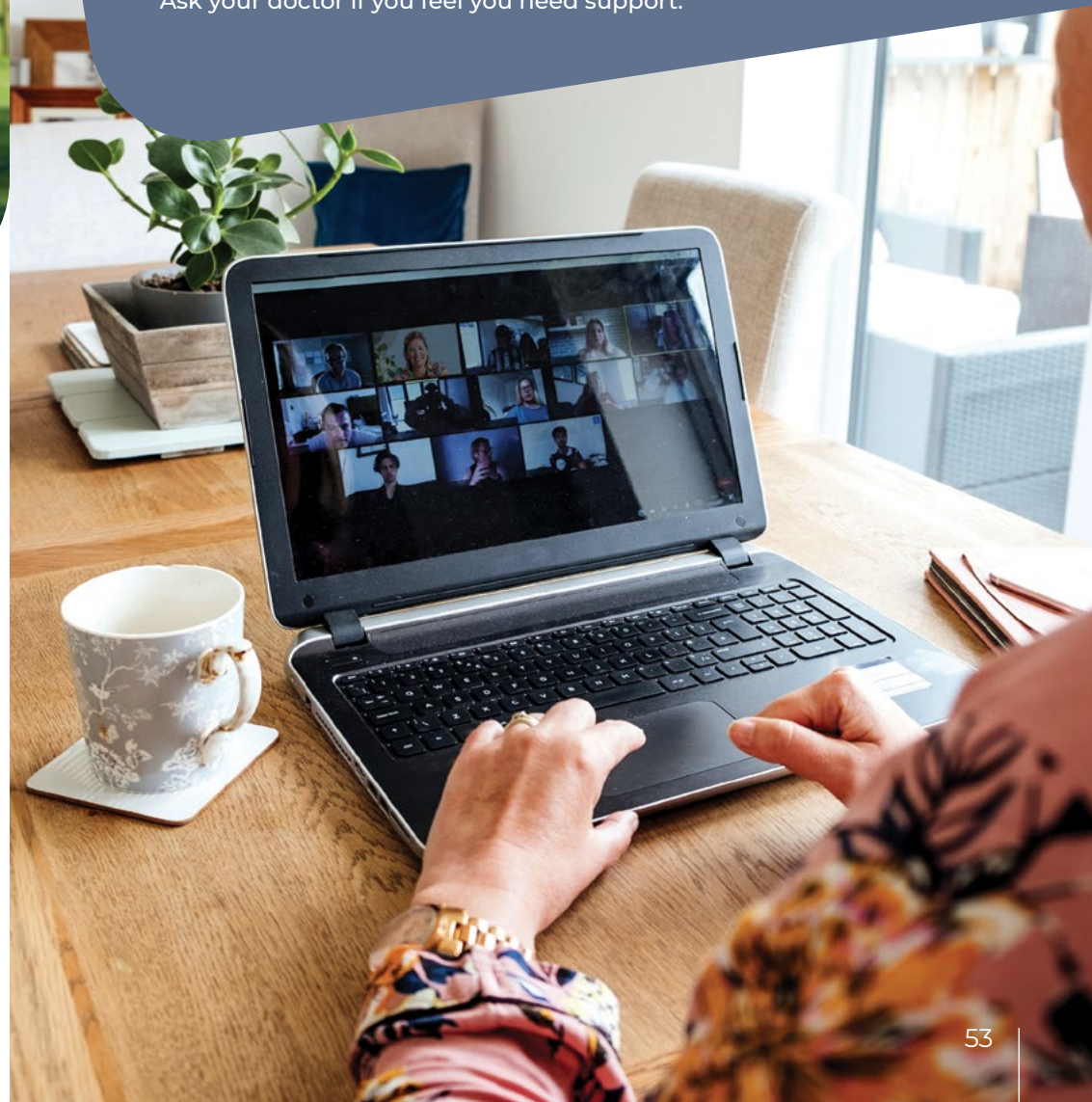


You can find support from others going through similar experiences. You may want to join a local cancer support group which can provide a safe place for you to share your feelings and experiences and connect with others. Learn more about cancer support at www.gutcancer.org.nz/support-groups



Your diagnosis will affect your ability to work, even if it is only temporarily such as when having treatment. Talk to your employer about sick leave, reducing your hours or working from home. Being unable to work can lead to financial problems, so seek advice about any financial help or benefits you may be entitled to. If you are needing information about financial support, find out more at www.gutcancer.org.nz/financial-support-and-assistance.

Cancer specific social workers are available at most Cancer Centres. Ask your doctor if you feel you need support.



Clinical trials

Clinical trials for biliary 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 biliary cancer, especially advanced biliary cancer. Some trials are looking at new therapies, while others are combining various therapies to see whether they work better together.

i

Clinical trials are medical research studies involving people.

Doctors may use cancer clinical trials to:

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

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

For more information about clinical trials, please visit 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, 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 remove part of my pancreas and small intestine? Did you have to place a bile duct or duodenal stent, or perform a biliary or duodenal bypass?
- 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? You may wish to refer to the Gut Cancer Foundation's 'Diet & nutrition for people living with biliary cancer' guide
- Do I need to take vitamin supplements or pancreatic enzyme supplements (Creon®)? How long will I need to take them for? How do I take them?
- Do I have diabetes? Can I still get diabetes if I don't have it yet? What is the likelihood I will need insulin?
- How can I make an appointment with a dietitian? You may wish to refer to the Gut Cancer Foundation's 'Diet & nutrition for people living with biliary cancer' guide.

Glossary

- **Adjuvant treatment** is additional treatment, such as chemotherapy or radiotherapy given after surgery.
- **Advanced cancer** is when cancer cells spread from where they first grew to other parts of the body; also known as metastasis or secondary cancer.
- **Allied health professionals** are trained professionals who work with others in the multidisciplinary team to support cancer patients.
- **Ampulla of Vater** is the area where the pancreatic duct and common bile duct meet. Also known as the hepatopancreatic ampulla.
- **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**.
- **Biliary** refers to the organs and ducts (including the gallbladder and bile ducts) that are involved in producing, storing and transporting bile.
- **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 to 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 drugs to destroy cancer cells.
- **Diagnosis** is working out what condition you have based on test results – in this case, whether you have biliary 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 a specialist in diseases and disorders of the digestive system, including the 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).
- **Immunotherapy** is treatment that activates the immune system to find and attack cancer cells. The immune system protects the body against illness and infection. See also **Targeted therapy**.
- **Jaundice** is yellowing of the skin/whites of the eyes and itchiness often caused by the bile duct being 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 gallbladder or bile ducts to structures around them, 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.
- **Oesophagus** is the tube that starts at the back of the mouth and ends in the stomach. After swallowing, food and liquids go down the oesophagus and into the stomach. It is sometimes known as the 'food pipe' or 'gullet'.

- **Oncologist** 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 biological therapies (i.e. immunotherapies)
 - 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 a treatment that controls symptoms and slows down the progress of the illness when a cure is no longer possible.
- **Pathology** is an examination of tissue and cells under a microscope; 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; includes psychological, social and spiritual needs.
- **Systemic treatment** is treatment that travels throughout the body in the bloodstream (for example, chemotherapy).
- **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.

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/gallbladder-and-bile-duct-cancer

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

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

Healthpoint: www.healthpoint.co.nz/community-health-and-social-services/cancer-support/cancer-counselling



A guide to understanding diagnosis and
treatment of biliary cancer.
(bile duct cancer and gallbladder cancer)

gutcancer.org.nz

