GUT CANCER FOUNDATION

Diet & nutrition for
people living with

BILIARY CANCER

(bile duct cancer and gallbladder cancer)

GUT CANCER FOUNDATION

About 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.

Note to the Reader

The information contained in this handbook is appropriate to follow if you are undergoing or have recently completed treatment for biliary cancer and are underweight or losing weight.

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 as at the time of publication. Sponsoring organisations have not had input into the contents of this document.

This handbook is not intended as a substitute for professional help or advice by doctors, nurses or dietitians. It is important to discuss any medical (physical, emotional, and/or general) symptoms, questions or concerns with your healthcare 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 handbook.

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Supporting you on your Cancer Journey

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

Learn more about a recent diagnosis, your treatment options, working with your care team and ways you can nurture your health and wellbeing through diet, exercise and strengthening your mental health.

Talk to our specialist support team today

To discover more, email support@gutcancer.org.nz
or call 0800 112 775 to talk with our specialist support team,
or visit www.gutcancer.org.nz/support-service

What is this handbook about?

Cancer is life-changing, but recent advances in medicine mean that people living with cancer are now enjoying longer, fuller and healthier lives after treatment. These advances include a broader understanding of nutrition and how your diet can help you feel better.

This handbook highlights important information about managing your diet if you have, or recently have had, biliary cancer. Biliary cancer may also be called gallbladder cancer, bile duct cancer or cholangiocarcinoma (kol-an-geeoh-car-sin-oh-ma).

Cancer, its treatments and side effects of treatment can affect how you live day to day. This handbook explains the function of your gallbladder and bile ducts, and how biliary cancer and its treatments may affect your body. It also provides ideas on what you can do to feel better during and after treatment.

The potential symptoms of biliary cancer and treatment side effects include:

- problems with maintaining or gaining weight
- problems with eating and swallowing
- changes in taste and smell
- differences in bowel habits
- loss of appetite
- feeling full quickly
- nausea (feeling like you are going to throw up) and vomiting
- fatigue.

You may encounter all, some, or none of the above.

We share dietary tips to help manage the unpleasant effects of treatment. If you have biliary cancer, you should be referred to an Accredited Practising Dietitian, who will tailor advice specifically for you. If you have not seen a dietitian and would like to, please discuss this with your treating team. Your doctor may prescribe medication, such as anti-inflammatory or antinausea (anti-emetic) medication or pancreatic enzymes, to help with some of your symptoms.

Eating is a daily pleasure, but a good diet is essential to optimising your health outcomes during and after treatment. By using strategies and tips offered in this handbook, you may find eating, maintaining your weight and managing your side effects easier.

Your guide for using this handbook

This handbook contains key detail in colour coded boxes.

ADDITIONAL DETAILS

HELPFUL TIPS

PATIENT STORIES

FOOD IDEAS

Contents

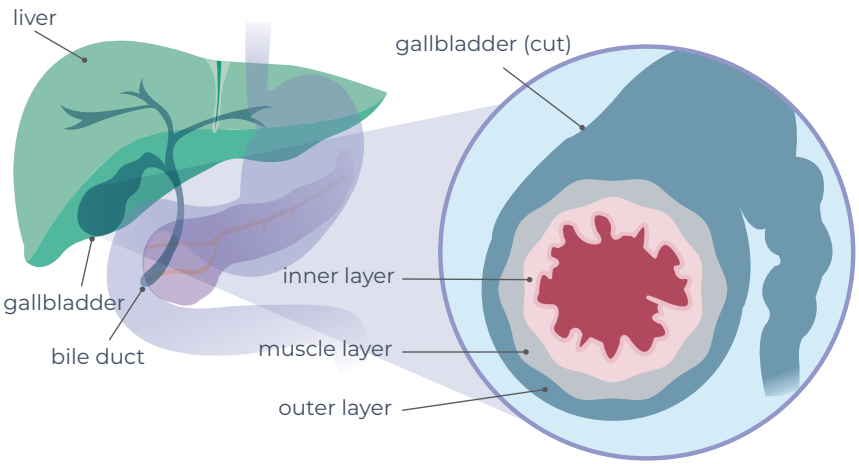
How do the gallbladder and bile ducts work?

People with biliary cancer often struggle to maintain a healthy weight. Cancer treatments and the associated side effects can also make it hard to take in, digest and absorb your food.

The gallbladder and bile ducts form part of the digestive system, specifically the biliary system. The function of the gallbladder and bile ducts is to store and transport bile, which is 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.

Figure 1: The three layers of the gallbladder



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.

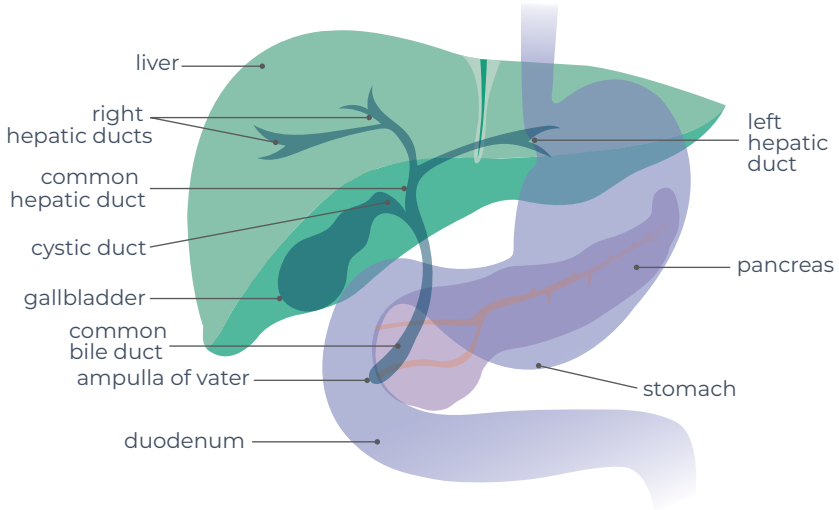
The gallbladder has three main layers *(See Figure 1)* These are the:

- 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 *(See 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 stricture (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.

What therapies are used to treat biliary cancer?

Common treatments for biliary cancer include surgery, chemotherapy and radiation therapy. You may need to have just one of these or a combination of treatments, depending on your diagnosis.

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.

The type of surgery that you have depends on the type of cancer and where it is located. Diagrams for each procedure can be found in Pancare Foundation's A guide to understanding diagnosis and treatment: Biliary cancer (bile duct cancer and gallbladder cancer). If you do not have this guide, you can order one through Gut Cancer Foundation.

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. 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.

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 *(see 'lymph nodes' in the Glossary on page 55)*. 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.

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.

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. The liver can regenerate (grow back to its original size) and work normally after a resection.

Portal vein embolisation

Before major liver surgery, the surgeon may suggest you have a procedure called portal vein embolisation (PVE). 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.

Biliary cancer surgery

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

Hilar Cholangocarcinoma

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 Cholangeocarcinoma

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.

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 (the first part of the small intestine). 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.

The two ways a stent can be inserted are:

- endoscopic retrograde cholangiopancreatography, where an endoscope (a thin, flexible tube with a camera on the end) 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).

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.

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. While you are sedated, your doctor will use an endoscope and a fine wire to insert the stent.

Duodenal bypass

You may need surgery to bypass the blockage in your duodenum if a stent has not worked. This is called a duodenal bypass. The surgeon will connect the stomach to the next part of the small intestine so that food can pass through.

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')* 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.

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. These may remain in place for several weeks, even months, with regular monitoring and care.

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.

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

How can I manage the symptoms of biliary cancer and the treatment side effects?

Biliary cancer and the associated treatments change how you eat. Managing these changes is important for your nutritional health and recovery, and to 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.

This handbook describes several common side effects of cancer treatments, and how to manage them.

Biliary cancer and its treatments may impact:

- your nutritional requirements and what you need to eat
- how much you eat
- your appetite
- your ability to digest and absorb food, nutrients and fluids
- your blood sugar control
- your ability to maintain your weight and muscle mass
- your energy levels and 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

Nutritional support after surgery

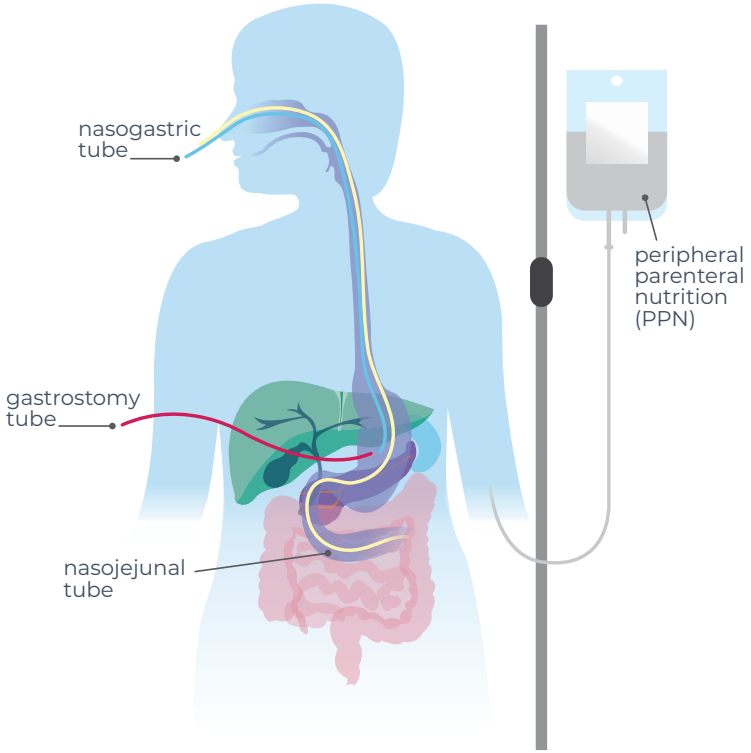
Your ability to eat and drink after your operation will depend on which surgery you have had and what the hospital recommends.

It is often difficult to meet your elevated nutritional needs with food alone. Your healthcare team may recommend a feeding tube for nutrition support. You may have a feeding tube placed directly into your stomach or small intestine before your surgery (called a gastrostomy or jejunostomy). This is used to ensure that you can meet your nutritional needs. You may have a temporary feeding tube up your nose (called a nasogastric or nasojejunal tube) during or after surgery if you are struggling to eat and drink *(Figure 3 on page 21)*.

Feeding tubes are an important way to ensure that your body receives the nutrition it needs to prepare for and recover from surgery. You can be given specially prepared feeding formula (called enteral formula) through this tube that will help you maintain weight and get the nutrients you need for a speedy recovery.

Once you begin eating, your surgeon or dietitian may guide you on any specific dietary needs or changes to follow.

Figure 3: Possible feeding tube options after surgery



Your surgeon or dietitian might guide you to eat several small meals or snacks throughout the day, rather than a few big meals. The hospital dietitian can prepare eating plans and work out whether you need any supplements to help meet your nutritional needs.

Fatigue

Fatigue and tiredness are common side effects of biliary cancer and treatment. Your food choices can help to balance your energy levels across the day.

Some tips to help optimise your energy levels include the following:

- Eat regular meals. Try six smaller meals to spread your energy across the day.
- Include complex, low–glycaemic index carbohydrates that provide you with a sustained release of energy across the day. Choose wholegrain breads and cereals, legumes, vegetables, fruit, and fullcream dairy products such as milk and Greek or natural yoghurts.
- Limit your intake of simple sugars and carbohydrates, such as soft drinks, juices, sweets, biscuits, cakes, white bread and other refined grains, cordial and sugar. These cause a spike in your energy levels, followed by a drop that leaves you feeling tired.
- Ensure that you are well hydrated, aiming for two litres of fluids per day. Water, herbal tea, milk and milk drinks are good choices.
- Have some nutritious ready meals in your fridge or freezer, you can buy these from the supermarket or from meal delivery services.

Mouth dryness

Some chemotherapy medicines and some pain medicines can reduce the amount of saliva (spit) in your mouth and make it feel dry. This is a condition called xerostomia. A dry mouth can increase your risk of tooth decay and infections such as oral thrush, which can make eating even more difficult.

Tips to help with a dry mouth

- Use mouthwash regularly to prevent infections (an alcohol-free mouthwash will reduce irritation)
- Gargle water mixed with a little salt or bicarbonate of soda
- Use a soft toothbrush when cleaning your teeth
- Ask your dietitian, speech pathologist, doctor or chemist about suitable mouth rinses, oral lubricants, artificial salivas and saliva stimulants
- Moisten the inside of your mouth at night with a small amount of grapeseed oil, coconut oil or olive oil
- Soften dry food by dipping it in milk, soup, tea or coffee, or add sauce, gravy, cream or custard
- Cut, mince or puree food with sauce or gravy so that it does not dry out when chewed
- Sip fluids with meals and throughout the day, or suck on ice cubes or frozen grapes to moisten your mouth
- Chew sugar-free gum or sour drops to stimulate the flow of saliva
- Limit alcohol and coffee, as these remove fluids from the body
- Avoid smoking.

Changes in taste and smell

Changes in taste and/or smell are common during cancer treatment, especially when having chemotherapy. You may find that you don't enjoy eating the foods you used to or that food has lost its taste.

Tips to help you cope with changes in taste

- If food tastes bland, try adding flavour by using herbs, lemon, lime, ginger, garlic, soy sauce, honey, chilli, pepper and other spices, sauces or pickled vegetables. You may also find that you can no longer stomach these things, and that bland food is more appetising. Do whatever works for you
- If you have a bitter or metallic taste in your mouth, eat fresh fruit or suck on hard lollies. Eat your food with plastic or wooden (not metal) utensils, and drink out of glass or plastic cups. Don't store food in metal containers
- If food is too sweet, add small amounts of lemon juice or instant coffee granules. Try plain breakfast cereals (for example, oats or wheat biscuits) that don't have any added sugar
- Try using a straw, where possible, as this can help food bypass the taste buds
- Continue to try different foods to assess your taste preferences. Variety is key!
- Ensure that you keep your mouth clean by cleaning your teeth and rinsing your mouth out regularly. Using mouthwash throughout the day can also help. If you use mouthwash, try to ensure that it is alcohol-free. Having a fresh, clean mouth before your meals can help.

Tips to help you cope with changes in smell

- Choose cold food or food at room temperature to minimise strong smells
- If cooking odours make you feel unwell, ask family or friends to help prepare food for you at their house, or when you are in another room or outside
- If you can't tolerate meat, chicken or fish, try it in different ways, such as in a mince dish, slow cooked with vegetables or blended through soups. If this doesn't help, try other protein sources, such as cheese (including ricotta and cottage cheese) and other dairy foods, eggs, nuts, tofu, or other legumes and pulses (including lentils and beans)
- If you use a slow cooker or crock pot to cook, try placing it in your garage or out of the main areas of the house.

Swallowing problems

Swallowing may be painful after biliary cancer treatment, especially after chemotherapy. Painful swallowing is called odynophagia.

You may also cough while eating or feel as though food is 'going down the wrong way'. If you feel as though food is going down the wrong way, or you are coughing or spluttering when eating or drinking, you should see your doctor right away, as these problems can be serious.

Tips to make swallowing easier

- Chop, mince or puree food to make smaller pieces that are easier to swallow
- Snack on soft foods between meals, such as avocado, yoghurt, custard, ice cream, diced tinned fruit and milkshakes. These are easier to swallow
- Try eating soft, nutritious foods, such as scrambled eggs, porridge, soup and casseroles
- Make tough food softer. Try using a slow cooker to keep food soft and moist, mash your food with a fork, or add extra gravy or sauce to your meals
- Sit upright, and chew carefully and slowly. Avoid lying down within 30 minutes of eating or drinking
- Wash food down with small sips of a drink
- Make changes in texture of food and thickening of fluids as guided by your dietitian and speech pathologist.

Loss of appetite and feeling full

Loss of appetite is a common problem in people with biliary cancer and during treatment. Early satiety (feeling full quickly) can also happen after having the Whipple's procedure.

Try the following to help with loss of appetite and early satiety:

- Eat small, nourishing meals throughout the day. Try to eat every 2 to 3 hours, rather than having three large meals. Eat by the clock. Regular meals can help to stimulate your appetite.
- Try to eat the most nourishing part of the meal first (before you become full), such as high-energy and high-protein foods and fluids *(see 'How do I maximise my nutritional intake' on page 43).*
- When you do feel hungry, eat! If you feel hungrier at certain times of the day or week (for example, between chemotherapy cycles), eat a bit more.
- Be mindful not to drink too much fluid during meals so you have more room for food. If you do need to drink with your meals, prioritise nourishing fluids, such as milk-based drinks, to help you get enough nutrition as well as hydration. Remember to keep hydrated by sipping on fluids between meals and snacks.
- Make your eating environment relaxed, positive and enjoyable. Distract yourself with family, friends or a good book.

Nausea and vomiting

Nausea and vomiting can be caused by biliary cancer and its treatments. Here are some ways to settle your stomach:

- Talk to your doctor about trying an anti-nausea medicine. Make sure you read the instructions on how and when to take this medicine. For example, metoclopramide is best taken 30 minutes before eating.
- Eat small, frequent meals throughout the day. Don't skip meals or snacks – not eating can make nausea worse.
- Eat bland, starchy and salty snacks, such as dry crackers or toast with vegemite or cheese. However, you should not eat these foods if you have a dry mouth *(see 'Mouth dryness' on page 23).*
- Eat and drink slowly, and chew food well.
- Choose cold food or food at room temperature to minimise strong smells.
- Reduce fried, greasy or spicy foods if these make you feel unwell.
- Avoid strong odours and cooking smells. If possible, stay away from the kitchen if someone else is cooking. It might also be easier if you cook and/or eat outside.
- Suck on hard lollies, especially those flavoured with ginger, peppermint or lemon.
- Try ginger-based foods and drinks, such as candied ginger, ginger beer, ginger ale or ginger tea. Talk to your dietitian, doctor or pharmacist about ginger supplements.
- If you find you wake up nauseous, try keeping a plain biscuit or two in a container, beside your bed to eat as you wake up.

Vomiting is more serious than nausea. Vomiting can cause dehydration and increase the risk of malnutrition. See a doctor if you are vomiting for more than one day, especially if you can't keep water down.

Tips for managing vomiting

- Take small sips of water or clear liquids, such as ginger ale, soda water or sports drinks like Gatorade® or Hydralyte®. Dilute sweet drinks. If you feel like a fizzy drink, open it and let it sit for 10 minutes or so, and drink it when it's a bit flat
- Once you can keep clear liquids down, try adding different liquids such as smoothies and milkshakes. Have small amounts of these frequently throughout the day
- When you are ready to try solid foods, start with bland, starchy foods, and other foods that are easy to eat – for example, plain biscuits, bread or toast with honey or jam, peanut butter, rice, yoghurt and fruit. Try to have small, frequent servings
- Gradually increase your intake until you are eating a wellbalanced diet.

Reflux

You may have some reflux after your treatments. Reflux can cause heartburn, nausea and discomfort in your chest.

Tips for managing reflux

- Limit spicy foods, fatty foods, fizzy drinks and alcohol
- Chew foods well, and eat slowly
- Remain upright for at least 30 minutes after eating. Try eating your evening meal earlier to allow more time for digestion before going to bed
- Try eating your main meal earlier in the day and have a small snack in the evening
- Avoid bending over or positions that worsen your reflux. Don't overexert yourself physically, as this can contribute to reflux
- Keep your chest higher than your abdomen when sleeping by using extra pillows or a foam wedge. Try to avoid lying on your left side, as reflux is often worse in this position
- Your doctor may prescribe medicines to reduce stomach acid, which may improve these symptoms. Over-the-counter antacids may also be helpful.

Weight changes

Cancer may result in weight changes – you may find it hard to gain weight or to keep weight on. This may be because of the treatments or the cancer itself.

It is important to maintain your weight and eat well. Maintaining your weight, particularly your muscle mass, will also help you to cope better, recover faster, feel less tired, and reduce the likelihood and severity of side effects. If you struggle to keep weight on, it is important to seek support from a dietitian.

Assess your risk of malnutrition

1. Have you lost weight recently without trying?
   No = 0
   Unsure = 2
   Yes, how much (kg)?
   1-5 = 1
   6-10 = 2
   11-14 = 3
   > 15 = 4
   Unsure = 2
2. Have you been eating poorly because of a decreased appetite?
   No = 0
   Yes = 1

If you scored 2 or more, you should visit a dietitian for a full assessment.

Speak to your treating team or find a dietitian locally using the resources page in this handbook.

(Reference the MST - Ferguson M, Capra S, Bauer J, Banks M. Development of a valid and reliable malnutrition screening tool for adult acute hospital patients. Nutrition 1999; 15: 458-64.)

Tips to help you maintain your weight and muscle mass

- Try to eat nourishing foods and fluids, such as those that are high in protein and energy. ***See 'How do I maximise my nutritional intake?' on page 43***
- 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. (See 'Swallowing problems' on page 26)
- Try to eat the most nourishing part of the meal first
- Take advantage of when your appetite is strongest. This might mean having a larger meal in the morning and a smaller meal in the evening
- Monitor for signs of malabsorption (see page 39). If you are showing any of these signs, ask your doctor or dietitian about the use of pancreatic enzyme supplements, such as Creon®
- 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 and soups. You may need to try different products until you find one you prefer or tolerate better. Your dietitian can guide you. ***(See 'When should I see a dietitian?' on page 52).***

Make sure you eat a variety of healthy foods and choose a supplement drink that suits your needs. Including it at breakfast or with your evening meal can work well as part of maintaining a healthy weight.

What if I'm putting on weight?

Although weight loss is common in biliary cancer, some people may find they gain weight instead. This can be caused by various factors, including:

- medicines
- fluid retention
- changes in diet and food preferences
- altered taste
- fatigue and exercising less
- hormonal changes.

If you are worried about weight gain, speak with a dietitian.

Changes in bowel habits

Living with biliary cancer and its treatments can result in changes to your bowel habits. This could be differences in the appearance, consistency and/or the smell of your stools. You may also have inflammation or damage to the lining of your digestive tract, called gastritis or enteritis, causing diarrhoea and discomfort in the stomach or bowel.

Diarrhoea

Diarrhoea is when you pass three or more loose, watery stools per day. Frequent loose stools can occur:

- because you are not digesting food or absorbing nutrients properly
- because of treatment side effects, an irritated gut lining, gastroenteritis or surgical procedures
- because of other causes, including stress and anxiety.

Diarrhoea can result in dehydration, so it's important to stay hydrated by drinking extra fluids. Every time you have a loose bowel movement, you should drink an extra cup of non-caffeinated fluid.

If you have diarrhoea for several days, see your doctor so that they can determine the cause and help to manage your diarrhoea. Your doctor may prescribe you an over-the-counter anti-diarrhoea medicine. In some cases, pancreatic enzyme supplements may be recommended *(see 'Malabsorption and pancreatic enzyme replacement therapy' on page 39).*

It is best to consult your doctor or dietitian before making big changes to your diet. Some foods can make diarrhoea worse or irritate your gut if you already have diarrhoea. You may be advised to limit some of the following until the diarrhoea stops:

- foods that have a lot of insoluble fibre, such as wholegrain breads and cereals, skins and seeds of fruits and vegetables, nuts, seeds and legumes
- foods and drinks that are high in sugar, such as cordial, soft drinks and lollies (especially if you've recently had a Whipple's procedure)
- large quantities of foods sweetened with artificial sweeteners (also known as sugar alcohols), such as sorbitol, mannitol and xylitol. These are often marketed as 'sugar-free'. Be aware of foods that may contain artificial sweeteners, including diet drinks and sugar-free lollies and chewing gum.

We need to eat two types of fibre – soluble and insoluble – for a healthy diet. Both are beneficial to the body, and most plant foods contain a mixture of the two.

Soluble fibre is found in the cells of plants. It absorbs water, acting like a sponge in your bowel, and can help reduce the amount of loose or watery stools. Soluble fibre is a source of prebiotics, which means it provides food for the healthy gut bacteria that live in your bowel (large intestine/colon).

Sources of soluble fibre include:

- fresh fruit and vegetables
- legumes such as lentils and peas (but not the skins)
- wholemeal bread and cereals
- grains such as barley, flaxseed and oat bran
- psyllium
- soy products
- garlic, onions, spring onions, leeks and shallots.

Insoluble fibre is found in the structural walls of plants. It does not absorb water and adds bulk to your stools. This can help prevent constipation and associated problems such as haemorrhoids. If you have issues with inflammation or infection in your bowel, you might need to reduce your intake of insoluble fibre in the short term.

Sources of insoluble fibre include:

- skins and seeds of fruit and vegetables
- nuts and seeds, including quinoa
- wholegrains.

Some foods have been found to help improve diarrhoea (depending on the cause of the diarrhoea) and may be worth including in your diet.

These are:

- soft, well-cooked, peeled vegetables and fruit
- white bread, white rice and pasta
- corn- or rice-based cereals.

It may also help to eat small, frequent meals throughout the day, rather than three large meals.

Pale, floating or foul smelling stools

(also referred to as 'steatorrhoea')

Stools that are smellier than usual, floating, oily, pale-coloured (often beige, tan, cream or white) or difficult to flush are often an indication that your body is not absorbing fat and other nutrients in your food well. Instead, these nutrients are passing through the bowel undigested, which can cause cramping, pain, bloating or changes in stool consistency. If you notice these symptoms, speak with your dietitian or doctor.

These symptoms can be treated by taking pancreatic enzyme supplements, such as Creon *(see 'Malabsorption and pancreatic enzyme replacement therapy' on page 39)* and/or a bile acid sequestrant.

Dumping syndrome

Dumping syndrome occurs when food moves from the stomach into your small intestine too quickly. This can happen after the Whipple's procedure. It can cause nausea, cramps and diarrhoea about 10 to 30 minutes after eating, or sweating and dizziness 1 to 3 hours after eating.

Be sure to speak to your doctor or dietitian if you are experiencing any of these symptoms.

Some tips to prevent dumping syndrome include the following:

- Avoid large meals.
- Limit sugary drinks and sweets.
- Choose meals high in protein to slow the digestion of carbohydrates.
- Keep drinks separate from meals.

Tips for managing dumping syndrome

- Eat small meals throughout the day
- Chew your food well
- Keep a record of foods that cause problems, and avoid them
- Limit foods and drinks high in sugar, such as cordial, soft drinks, cakes and biscuits
- Eat meals high in protein, such as lean meat, fish, eggs, milk, yoghurt, nuts, seeds, legumes and beans
- Drink between meals rather than at mealtimes
- Talk to a dietitian, who can help you work out how to change your meals to reduce the symptoms.

Symptoms usually improve over time. If they don't, ask your doctor for advice about medicines that may help.

Blood sugar control

The pancreas produces hormones, including insulin and glucagon, that help to regulate your blood sugar levels. If a large part of your pancreas was removed during a Whipple's procedure, you may develop diabetes.

If you have not been diagnosed with diabetes and experience the following symptoms, speak with your doctor:

- blurred vision
- very thirsty and drinking a lot of water
- frequent urination (peeing) · increased appetite
- weight loss.

You may need to take medication to help manage your blood sugar levels. This is often in the form of insulin. Your doctor or endocrinologist will prescribe this for you if needed. Endocrinologists are doctors that specialise in hormonal problems. A dietitian can help manage your blood glucose levels through dietary changes.

As well as your oncologist and endocrinologist, you will also see a diabetes educator and a dietitian to help you adjust your insulin dose (if required) and diet. Dietary advice for someone who has both cancer and diabetes can be quite different from that for someone with only diabetes, so it is important that you see a dietitian with cancer experience to help you with this.

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.

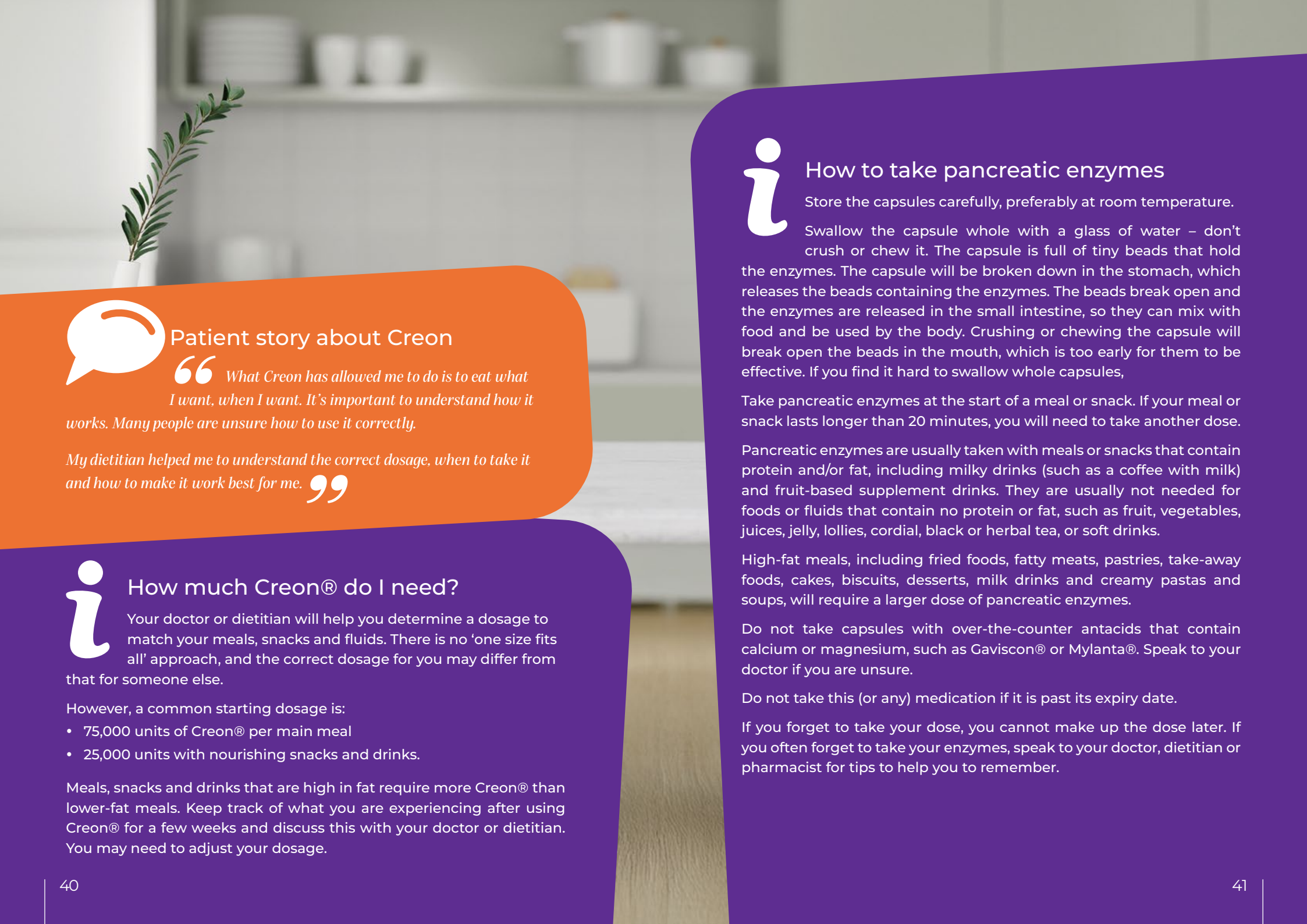
There are several symptoms of malabsorption, including:

- 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 adjusted according to the type and amount of food being eaten, and whether your symptoms persist.



Patient story about Creon

“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.”

How much Creon® do I need?

Your doctor or dietitian will help you determine a dosage to match your meals, snacks and fluids. There is no ‘one size fits all’ approach, and the correct dosage for you may differ from that for someone else.

However, a common starting dosage is:

- 75,000 units of Creon® per main meal
- 25,000 units with nourishing snacks and drinks.

Meals, snacks and drinks that are high in fat require more Creon® than lower-fat meals. Keep track of what you are experiencing after using Creon® for a few weeks and discuss this with your doctor or dietitian. You may need to adjust your dosage.

How to take pancreatic enzymes

Store the capsules carefully, preferably at room temperature.

Swallow the capsule whole with a glass of water – don’t crush or chew it. The capsule is full of tiny beads that hold the enzymes. The capsule will be broken down in the stomach, which releases the beads containing the enzymes. The beads break open and the enzymes are released in the small intestine, so they can mix with food and be used by the body. Crushing or chewing the capsule will break open the beads in the mouth, which is too early for them to be effective. If you find it hard to swallow whole capsules,

Take pancreatic enzymes at the start of a meal or snack. If your meal or snack lasts longer than 20 minutes, you will need to take another dose.

Pancreatic enzymes are usually taken with meals or snacks that contain protein and/or fat, including milky drinks (such as a coffee with milk) and fruit-based supplement drinks. They are usually not needed for foods or fluids that contain no protein or fat, such as fruit, vegetables, juices, jelly, lollies, cordial, black or herbal tea, or soft drinks.

High-fat meals, including fried foods, fatty meats, pastries, take-away foods, cakes, biscuits, desserts, milk drinks and creamy pastas and soups, will require a larger dose of pancreatic enzymes.

Do not take capsules with over-the-counter antacids that contain calcium or magnesium, such as Gaviscon® or Mylanta®. Speak to your doctor if you are unsure.

Do not take this (or any) medication if it is past its expiry date.

If you forget to take your dose, you cannot make up the dose later. If you often forget to take your enzymes, speak to your doctor, dietitian or pharmacist for tips to help you to remember.

What if I can't swallow the capsule?

Some people find it hard to swallow whole capsules. If this is the case for you, carefully open the capsule and pour the beads into something acidic and soft that you don't need to chew, such as apple sauce or pureed fruit.

Do not crush the beads; eat or drink whatever you put them in straight away and swallow it immediately.

You may be able to use a smaller-dose capsule, which will be smaller in size. However, this means that you will need to take more capsules to get your full dose of enzymes.

Speak with your doctor about the appropriate dosage.

Side effects and allergies

Like all medicines, pancreatic enzyme supplements may have side effects. You should discuss possible side effects with your specialist before starting any new medication. If you are experiencing persistent or ongoing side effects, speak with your doctor and dietitian.

Pancreatic enzyme supplements are sourced from the pancreases of pigs. Unfortunately, a suitable alternative is not available in Australia. If you have any allergies to pork products or cannot eat pork for cultural or religious reasons, or if you are vegetarian or vegan, speak to your doctor or dietitian.

Food safety

If you are having chemotherapy, you will likely be immunocompromised, which means your body might not fight infection as well as before. This makes food safety important.

Check that everything you eat and drink is prepared and stored hygienically to minimise any risk of food poisoning.

You can find easy-to-read information about food safety and food poisoning at www.mpi.govt.nz/food-safety-home.

How do I maximise my nutritional intake?

People with biliary cancer often struggle to maintain a healthy weight. Cancer treatments and the associated side effects can also make it hard to eat, swallow and absorb nutrients from food.

A complete, nutritionally balanced diet is essential for everyone, but it's even more important if you are going through cancer treatment. There will be many times when you don't feel like eating, but it is really important that you are well supported to maximise your intake.

A nourishing diet is one that contains enough kilojoules (or calories/energy), protein, nutrients, vitamins and minerals to meet your needs. You may hear the term 'high-energy, high-protein diet'. By including foods rich in energy and protein, and by fortifying the food that you already eat, you can make every mouthful more nourishing. This is often easier than eating extra food if you have a poor appetite.

Good nutrition is also important for wound healing. If you have had surgery, you want to make sure the wounds heal well. Make sure you get enough energy, choose foods rich in protein, and speak to a dietitian if you are concerned about meeting your vitamin and mineral needs.

High-energy and high-protein foods

STEP 1: Build your meal around a good source of protein.

STEP 2: Add extra kilojoules with high energy foods.

- High-protein foods:
- meat, poultry and fish
- eggs
- tofu
- beans, chickpeas, lentils and legumes
- full-cream dairy, including milk, yoghurt, cheese and custard
- nutrition supplement powders, as well as protein powders and bars, including whey or plant-based protein powders
- evaporated milk, condensed milk, skim milk powder or fortified milk
- avocado
- nuts, seeds, nut butters/pastes.
- butter, margarine and oils
- coconut cream or coconut milk
- cream
- creamy sauces
- dips made with cream cheese, or hummus
- dried fruit
- gravy (made with meat juices)
- honey, maple syrup, golden syrup, jam
- trail mix – a snack of mixed nuts, dried fruits and seeds, and sometimes chocolate bits.

Make your own fortified milk

Fortified milk is easy to make yourself with the following steps:

Sprinkle 2/3 cup (or 75g) of skim milk powder onto 2 cups (or 500 ml) of full-fat milk

Mix until the powder is dissolved

Try to make the fortified milk two hours before using it and store it in the fridge. Use fortified milk whenever you'd use regular milk – on your cereal, in your tea or coffee, or to make a milkshake or smoothie.

Nutritional supplement drinks

Nutritional supplement drinks are high in energy and protein and may contain additional vitamins and minerals. They're often easier to tolerate when you don't feel like eating a meal. You can sip the drinks slowly or throw them back like a shot. Ideally, nutritional supplement drinks are consumed between meals for extra nutrition or a 'top up', but they can also be taken as a meal replacement.

Nutritional supplement drinks come either in powder form or ready-made, and there are several brands on the market. A dietitian can provide advice on which supplement is best for you.

You can also make your own nutritional drink, such as a smoothie or milkshake. Use combinations of fruit, dairy products and sweeteners such as honey or maple syrup. Make sure to add foods from *High-energy and high protein foods* to make it high energy and/or high protein.

(For some more inspiration, see smoothie and milkshake ideas on page 47) .

Patient story: Nutrition supplements

"Nutrition supplements can be vital if you're struggling to eat much protein and maintain your weight. When I've found it hard to eat enough for good nutritional health, my dietitian has organised different types of supplement drinks to help me through those times."

How can I eat a nourishing diet?

We know there'll be many times when you don't feel like eating, but it is really important that you do.

Tips to help you eat a nourishing diet include:

- Eat a variety of foods
- Explore your preferred foods – try something new, even if it's something you didn't like before you had cancer. You may find your tastes and food preferences have changed
- Try eating six small meals spread throughout the day instead of three large main meals
- Eat at specified meal times, even if you are not really hungry. It is important not to miss meals. Take snacks with you if you are not going to be at home at a meal time
- Make the most of when you feel well and have an appetite, even if it's not when you would usually eat
- Figure out when you seem to have the best appetite and plan larger meals for those times. For example, you might find you are hungrier in the morning, so plan larger breakfasts and eat a bit less later on, and visa versa if you are hungrier in the evening
- Use ready-made frozen and tinned foods to reduce the need to cook. Enlist the support of family and friends. You may find you are too tired to make a meal, so keeping a supply of pre-made food on hand is important. You can also make large batches and freeze meals in small portions
- If you feel full quickly, eat the most nourishing (high energy/protein) part of the meal first and try not to drink beforehand (leave an hour in between). If you are used to drinking with your meals, make sure you sip on nourishing fluids such as a smoothie or milkshake. Fluids take up room in your stomach, making you feel full, so it's best to drink fluids separate from mealtimes.

Milkshake and smoothie ideas

Drinking milkshakes and smoothies is an easy way to increase your energy and protein intake.

Smoothie ideas:

- Start with a base of Greek or natural yoghurt
- Add fruit(s) such as bananas, berries or mango. Frozen fruit works well
- Fortify with nuts, seeds, peanut butter, coconut, coconut cream, protein or a nutritional supplement powder
- Add cinnamon, cocoa or cacao to taste
- Blend together with fortified milk and ice.

Milkshake ideas:

- Start with a base of fortified milk
- Add ice cream
- Include cocoa, chocolate powder, protein powder and/or peanut butter to taste.

SAMPLE MEALS

The following sample meals provide tips on how to increase the amounts of energy and protein in your diet. If you need a soft or pureed diet, you will need to consider which foods suit you best.

BREAKFAST

- Cereal or muesli with fortified milk, yoghurt, fruit or honey
- Eggs (poached, scrambled, fried, boiled, omelette) with cheese, plus wholegrain or rye toast
- Buttered wholegrain, rye or sourdough bread or toast, with cheese, avocado or nut butter
- Baked beans or four-bean mix on buttered toast with grated cheese.

MORNING TEA

- Smoothie or milkshake – ***see Smoothie and milkshake ideas on page 47***
- Nutritional supplement drink
- Yoghurt with fruit and nuts, or nut butter
- Fruit toast with butter or nut butter
- Boiled egg
- Bliss balls made with dates, nuts, seeds, cacao and oats (all well processed to form smooth balls)
- Wholegrain pita bread or wraps with dip, avocado, cream cheese or nut butter.

LUNCH

- Meat, chicken or fish with a creamy sauce or gravy
- Mashed vegetables mixed with butter, extra virgin olive oil, cream or cheese
- Wraps or sandwiches made with meat, chicken, fish, eggs, beans or lentils, avocado, mayonnaise, hummus or cheese
- Omelette made with your favourite vegetables and cheese
- Frittata made with eggs, vegetables, cheese and lentils
- Vegetable and lentil soup with grated cheese.

AFTERNOON TEA

- Smoothie or milkshake – ***(see smoothie and milkshake ideas' on page 47)***
- Wholegrain wrap with shaved turkey breast, tuna, avocado and ricotta
- Falafel or protein ball
- Hummus or tzatziki dip with wholegrain crackers, wholemeal pita bread or vegetable sticks.

DINNER

- Pasta with meat sauce, such as spaghetti bolognese with grated cheese
- Burritos with meat, beans and cheese, topped with avocado and sour cream
- Meat, chicken or fish with gravy, or cream or cheese sauce; mashed potato with butter; and vegetables or salad with a dressing made with extra virgin olive oil
- Lentil or bean salad, with cold chicken, tofu or tinned fish, avocado, corn, cheese and a dressing made with extra virgin olive oil
- Stir-fried vegetables with tofu, soy sauce and sesame seeds, served with basmati rice or soba noodles.

EVENING SNACK

- Hot chocolate or chai made with fortified milk
- Protein ball
- Yoghurt and fruit
- Frozen yoghurt
- Crème caramel, pudding, rice pudding, ice cream or chocolate mousse.

Vitamin B12 supplements

Bile and pancreatic enzymes play an important role in the absorption of vitamin B12. If you have a blocked bile duct or have had a large part of your pancreas removed, your body may not be able to absorb as much vitamin B12 as it needs. You may need to supplement your diet with vitamin B12 or have vitamin B12 injections.

Ask your doctor to monitor your vitamin B12 levels.

Oral health and hygiene

Some treatments for biliary cancer can cause side effects that affect your mouth and teeth. These conditions can make it hard to eat, and poor oral health can make them worse. It is important to have a check-up with your dentist before treatment starts so that they can check the health of your teeth and identify any problems early.

Some chemotherapy and targeted therapy medicines can damage healthy cells in the mouth, causing mouth sores or infections.

Your healthcare team will talk with you about the possible side effects of treatment and how to manage them. Most mouth problems gradually improve and go away after treatment is over.

It is a good idea to visit your dentist before starting treatment, especially if you already have mouth problems or tooth decay. There is a higher risk of infection and bleeding if you have dental work during cancer treatment.

Make sure to tell your dentist about the type of treatment you will be having so that they can develop an oral health care plan. This sets out any dental work you need before you start cancer treatment, and lets you know how to look after your mouth before, during and after treatment to help prevent tooth decay and manage any side effects that affect your mouth.

Tips to help you take care of your mouth before, during and after cancer treatment

- Try to eat a balanced, nutritious diet; limit how much alcohol you drink; and quit smoking
- Check your mouth, tongue and teeth daily during treatment for changes to the inside of your mouth. Tell your healthcare team if you notice any changes
- Clean your teeth with a mild toothpaste and a soft-bristled toothbrush. Replace the toothbrush at least every 3 months to prevent infection
- Rinse your mouth several times a day with an alcohol-free mouthwash (ask your doctor or nurse about what type of mouthwash to use and how often to use it). Use a mild mouthwash if your mouth is too sore or bleeds when you clean your teeth
- Check with your dentist before flossing, as this may not be recommended during treatment. Ask your dentist if they can apply fluoride treatments to help slow tooth decay
- If you wear dentures, make sure they fit properly, only wear them while eating, and clean them well using denture cleaning products that will not irritate your mouth.

When should I see a dietitian?

An Accredited Practising Dietitian (APD) is trained to guide your food choices. Cancer will usually affect a person's food and fluid intake, and the impact is greater for people suffering from biliary cancer because it can be harder to take in, digest and absorb food and fluids.

Cancer and its treatment can affect each person differently. What works well for one person may not work for another.

If you have biliary cancer, you should be referred to a dietitian. They will explore your unique situation, challenges and needs, and provide you with education about your current food and fluid intake.

If you have been diagnosed with diabetes or pancreatic enzyme insufficiency, it is essential that you see a dietitian. Irregular blood sugar levels can lead to very serious complications.

Accredited Practising Dietitians (APDs) are health professionals who are trained to provide evidence-based nutrition and dietary advice. APDs understand how a healthy diet can optimise health and minimise risk. They are uniquely placed to support people with complex and individual dietary needs.

Note that the term 'dietitian' is used throughout this handbook to refer to accredited practising dietitians. The term 'nutritionist' used on its own does not refer to a regulated profession in New Zealand.

If you need to see a dietitian, ensure they are an Accredited Practising Dietitian.

Tips to finding an Accredited Practising Dietitian

- Request a referral to a dietitian through your treating hospital. Ask your doctor or nurse for more information
- Find a dietitian in your local area through Dieticians NZ at www.dietitians.org.nz
- Request a referral to an oncology dietitian through your doctor
- Ask the Gut Cancer Foundation team for more information on local services.

How do I decide which diet is right for me?

If you are already on a restricted diet because of a previous medical condition, such as a low-cholesterol or low-salt diet, or if you have various symptoms that require different approaches, make sure you talk to a dietitian. You will need more personalised advice than this handbook provides.

If you were following a diet for nonmedical reasons before your diagnosis (for example, if you were vegetarian or vegan), your dietitian will help you to adjust your intake to meet your needs within your personal preferences. The key goals are to eat a nutritionally balanced diet and to maintain your weight.

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.

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.

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 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.

Gastrointestinal is a term used to describe anything that has to do with the digestive system (for example, gastrointestinal tract).

General wellbeing is how you feel overall, including physically, mentally and emotionally.

High-energy, high-protein diet is a diet that has foods high in energy (or kilojoules) and protein. A high-energy, high-protein diet helps you to meet your increased nutritional demands, and preserve your weight and muscle mass.

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 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.

Kilojoules and calories are measures of how much energy is in a food. High-energy foods provide our bodies with lots of energy, and can help with managing weight loss and muscle wasting.

Localised treatment is treatment that only affects a certain area of the body, such as radiation therapy.

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.

Malnutrition means that a person is not getting enough nutrients, such as proteins, vitamins, minerals and energy.

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'.

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.

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.

Pernicious anaemia is a condition where the body is unable to make enough red blood cells. Pernicious anaemia happens when the body cannot absorb vitamin B12 from food or oral supplements.

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.

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

Best-practice care differs around the world, so this handbook focuses on resources and information available in New Zealand.

Our Gut Cancer Foundation website has information that complements what is in this handbook. 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.

Please visit our website www.gutcancer.org.nz

Email support@gutcancer.org.nz or Call 0800 112 775

This booklet is available to download at www.gutcancer.org.nz/shop.

Dietitians New Zealand

It is important that you receive nutritional advice and support from a trained health professional who understands your complex and unique dietary needs. Dietitians New Zealand makes it easy to search for an Accredited Practising Dietitian in your local area.

To find an Accredited Practising Dietitian near you, go to www.dietitians.org.nz.

When searching you can use terms like oncology or malabsorption to find someone with the most appropriate experience.


Making a difference to the
lives of people with cancers
of the digestive system.

Diet & nutrition for people living with biliary cancer.

gutcancer.org.nz

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