



Diet & nutrition for
people living with

PANCREATIC CANCER

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 with 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 pancreatic 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 pancreatic cancer and are underweight or losing weight.

The medical profession and research community are continually updating information about pancreatic 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.



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](tel:0800112775) to talk with our specialist support team, or visit www.gutcancer.org.nz

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, pancreatic cancer.

Cancer, its treatments and side effects can affect how you live day-to-day. This handbook explains the function of your pancreas and how pancreatic 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 pancreatic cancer and treatment side effects include:

- problems with maintaining or gaining weight
- changes in taste and smell
- differences in bowel or bladder habits
- loss of appetite
- feeling full quickly
- changes in blood sugar levels
- 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. You may benefit from seeing an Accredited Practising Dietitian (APD), who can tailor advice specifically for you. Your doctor may prescribe medication such as pancreatic enzymes, or anti-nausea (anti-emetic) medication, to help with some of your symptoms.



A good diet is essential to optimise 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

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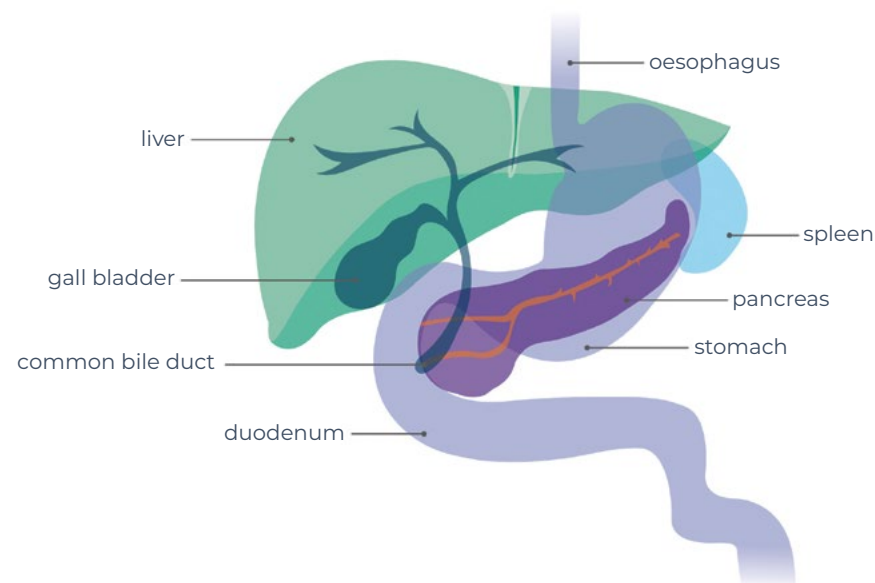
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How does the pancreas work?

People with pancreatic 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 pancreas is a gland that has a head, body and tail. It is found in the abdomen with other organs, such as the stomach, liver, gall bladder, and small and large intestines (also called the small and large bowel).

Figure 1: The main organs of the digestive system



The pancreas serves two main functions in the body:

- it produces enzymes that help you to digest and absorb food
- it produces hormones, including insulin and glucagon, which help to control your blood sugar levels.

Any changes to the pancreas, including those caused by pancreatic cancer and its treatment, can result in problems with blood sugar control and/or digestion.

Digestion

The first part of the digestive process involves chewing. Food passes from your mouth down your oesophagus and into your stomach, where it is broken down into small pieces. These small pieces enter the small bowel where they mix with pancreatic enzymes, other pancreatic juices and bile.

The enzymes, pancreatic juices and bile work together to help break down the food into smaller units that the body can absorb and use.

If the pancreas does not, or cannot, produce enough enzymes, if the enzymes are blocked from entering the small bowel, or if they don't mix with the food (which can occur after surgery), this can affect the digestion of nutrients.

Food and nutrients might not be properly broken down, leaving them too large to be absorbed. This can lead to signs of malabsorption, including:

- diarrhoea or loose stools
- floating or greasy stools (known as steatorrhea)
- pale coloured stools
- abdominal cramping, bloating and flatulence
- weight loss
- reduced energy levels and fatigue
- nutrient deficiencies.

Poor digestion and absorption can lead to malnutrition, weight loss and change in bowel habits. It is important to monitor for any of these signs so that pancreatic enzyme replacement therapy, such as Creon®, can be commenced if needed. Your dietitian and/or doctor will advise you on the correct amount, timing and administration of enzyme replacement.

Blood sugar control

The pancreas produces hormones, including insulin and glucagon, and releases them into the bloodstream. Insulin works by lowering blood sugar levels, and glucagon works by raising blood sugar levels. Together, they help to keep your blood sugar levels balanced. Problems with blood sugar levels can indicate a problem with the pancreas, such as diabetes.

It is important to have a normal blood sugar level for good health and wellbeing. Too much sugar in the bloodstream (hyperglycaemia) can result in blurred vision, being very thirsty, frequent urination, headaches, difficulty concentrating and tiredness. Too little sugar in the bloodstream (hypoglycaemia) can result in shakiness, nervousness or anxiousness, light-headedness or dizziness, confusion and a faster heartbeat. Both low and high blood sugar levels can have a negative effect on your health in the long term.



What therapies are used to treat pancreatic cancer?

Common treatments for pancreatic cancer include surgery, chemotherapy, immunotherapy and radiation therapy.

You may need to have just one or a combination of these treatments, depending on your diagnosis.

Surgery

Several types of surgery can be used to treat pancreatic cancer, depending on your diagnosis. Surgery that removes the cancer include the Whipple's procedure, a distal pancreatectomy and a total pancreatectomy. You may also hear the term 'bypass surgery', particularly in cases where the cancer cannot be removed or has spread.

Whipple's procedure

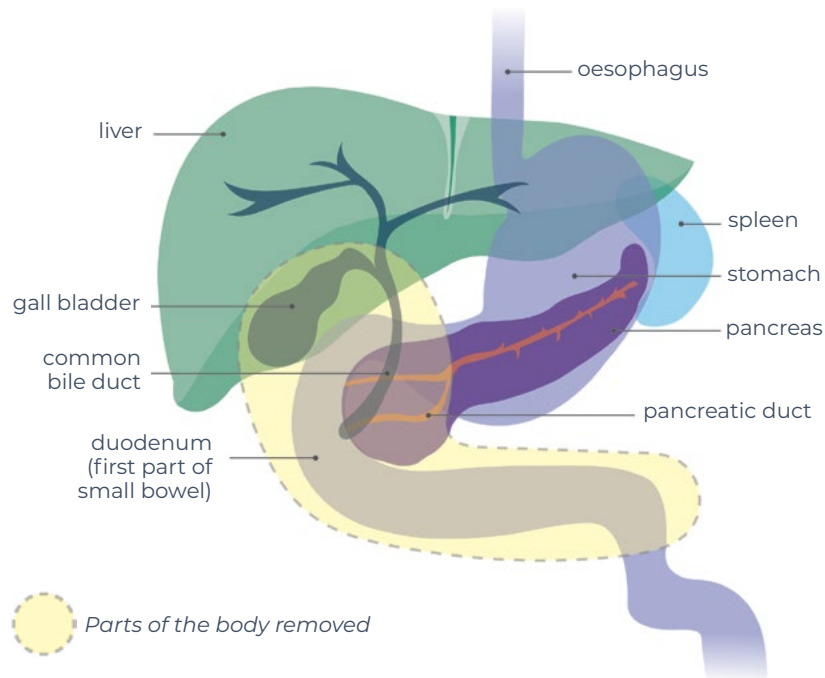
The Whipple procedure, or pancreaticoduodenectomy, is the most common type of pancreatic cancer surgery. It involves the removal of four main parts of your digestive system:

- the head of the pancreas
- the first section of the small bowel (called the duodenum)
- the bottom part of the stomach (called the pylorus), although sometimes this section is spared
- the gall bladder and a portion of the common bile duct.

Some lymph glands in the area are also removed.

The surgeon then reconnects your digestive system so that it still works without these missing parts. The remaining pancreas, bile duct and stomach are connected to the small bowel. Food will pass through the section of the stomach that remains and enter the small bowel, where it will mix with the pancreatic enzymes and bile.

Figure 2: The Whipple's procedure



Total pancreatectomy

If your doctor recommends a total pancreatectomy, the whole pancreas is removed. The surgeon will also remove the gall bladder, the common bile duct, parts of the small bowel and stomach, and often the spleen.

Distal pancreatectomy

Unlike a total pancreatectomy, a distal pancreatectomy removes the body and tail of the pancreas and often the spleen. The head of the pancreas is left intact.

Bypass surgery

If the cancer is advanced and cannot be removed or is discovered to have spread at the time of your operation, you may need to undergo bypass surgery. In this surgery, the tumour is not removed. Instead, surgery is performed to bypass any blockage or reduce the chances of future blockage. In the case of a blocked bile duct, the surgeon may connect a piece of the bowel to the bile duct or gallbladder, which will bypass the blockage. This will relieve symptoms of jaundice if it is present.

Chemotherapy

Chemotherapy is a systemic (or whole body) treatment and can be used to destroy cancer cells or shrink a tumour.

Depending on the type of pancreatic cancer, chemotherapy may be the only treatment used, or it could be given at different times:

- before surgery (known as neoadjuvant chemotherapy)
- after surgery (known as adjuvant chemotherapy)
- both before and after surgery.

Chemotherapy is usually given intravenously (through a drip into the veins) at the hospital or cancer clinic, although some chemotherapy medicines are given orally (swallowed as a pill or tablet). Because chemotherapy travels throughout the blood stream, its side effects can affect many parts of the body.

Chemotherapy can also be used for palliative treatment for someone with advanced pancreatic cancer, to relieve symptoms and to slow disease progression.



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

Pancreatic cancer and the associated treatments change how your pancreas functions. Managing these changes is important for your nutritional health, your recovery, and to make you feel better in general. Treatments can affect people differently. You may have no side effects, some, or all of them, but there are plenty of things you can do to improve your general wellbeing.

We describe several common side effects of cancer treatments, and how to manage them.

Pancreatic cancer may impact:

- your nutritional requirements and what you need to eat
- how much you eat
- your appetite
- your ability to digest and absorb foods
- your blood sugar control
- your ability to maintain your weight and muscle mass
- your energy levels and general wellbeing.

Radiation therapy

Radiation therapy is a targeted treatment that uses a radioactive source to destroy cancer cells or shrink a tumour. Like chemotherapy, it can be used before surgery, after surgery or as the only treatment. Unlike chemotherapy, radiation therapy can be directed to a small, specific area so other parts of the body that are not in the treatment field are not affected.

The radiation usually comes from a machine directed at your pancreas (external radiotherapy).

Like chemotherapy, radiation therapy can be used for people who have advanced pancreatic cancer to relieve symptoms and slow disease progression.

Immunotherapy

Immunotherapies are a type of targeted therapy, which means they only work for very specific cases. You may need to undergo some pathology testing to see if these treatments will benefit you.

Common side effects of pancreatic cancer treatment may include:

Surgery	Chemotherapy and immunotherapy	Radiation therapy
<ul style="list-style-type: none"> • Fatigue • Pain • Diarrhoea • Malabsorption • Weight loss • Loss of appetite • Feeling full quickly • Dumping syndrome • Malnutrition 	<ul style="list-style-type: none"> • Nausea and vomiting • Loss of appetite • Feeling full quickly • Diarrhoea and constipation • Fatigue • Weight loss • Sore mouth or throat • Taste changes • Malnutrition 	<ul style="list-style-type: none"> • Nausea and vomiting • Loss of appetite • Feeling full quickly • Diarrhoea and constipation • Fatigue • Weight loss • Malnutrition

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 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 (those that are high in energy and high in protein).

See *'How do I maximise my nutritional intake?'* on page 36.

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.

Try to eat the most nourishing part of the meal first.

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 (*refer to page 30*). If you are showing any of these signs, ask your doctor or dietitian about use of pancreatic enzyme supplement, such as Creon.

Ask about using nutrition supplement drinks (see *'Should I see a dietitian?'* on page 44).

Make sure you are eating a variety of nutritious foods and maintaining a good weight. This may mean reducing your focus on a previous diet, such as one that manages elevated cholesterol.



i What if I'm putting on weight?

Although weight loss is common in pancreatic cancer, some people find they gain weight instead. This can be caused by a number of factors, including:

- medications
- fluid retention
- changes in diet and food preferences
- altered taste
- fatigue and reduced energy levels and exercise
- hormonal changes.

If you are worried about weight gain, speak with your care team.

Loss of appetite and feeling full

Loss of appetite is a common problem in people with pancreatic cancer and during treatment. Early satiety (feeling full quickly) is also a common problem.

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

- Eat small nourishing meals, throughout the day. Try to eat every two to three 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 36).
- When you do feel hungry – eat! If you feel hungrier at certain times of the day or week (e.g. between chemotherapy cycles) eat a bit more.
- Try to drink fluids between 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.

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 fruits 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 (e.g., 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 you keep your mouth clean by cleaning your teeth and rinsing your mouth out regularly. Using mouthwash throughout the day can also help with this. If you use mouthwash, try to ensure it is alcohol-free to avoid drying out your mouth. 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, poultry or fish, try it in different ways, like 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), eggs, nuts, tofu, dairy or legumes, lentils and pulses.

Nausea and vomiting

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

- Talk to your doctor about trying an anti-nausea medication.
- Make sure you read the instructions on how and when to take this medication. 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 by the clock.
- Eat bland, starchy and salty snacks, such as dry crackers or toast with vegemite or cheese.
- 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 food and drink items, such as candied ginger, ginger beer, ginger ale or ginger tea. Talk to your dietitian doctor or pharmacist about ginger supplements.



A Note on food safety

If you are having chemotherapy, you will likely be immunocompromised, which means your body will not be primed to fight infection. 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 on the Ministry for Primary Industries website: www.mpi.govt.nz/food-safety-home

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.

Patient story: Nausea and vomiting



“ Sometimes when I'm having chemo, I can't eat dairy products, meat or good nutritional foods because they make me nauseous or make me vomit. I like to make up fresh fruit smoothies with a few scoops of powdered supplements to ensure I get as much nourishment as possible. ”

To manage vomiting at home, try the following:

1. 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.
2. Once you are managing or tolerating liquid as in Step 1, try some different drinks, such as consommé and clear broths, weak tea, herbal tea, fruit drinks, beef and chicken stocks. Include small amounts often throughout the day.
3. Introduce bland, starchy foods, such as plain biscuits, bread or toast with honey or jam, peanut butter, rice, yoghurt or fruit. Trying to attempt small, frequent servings.
4. Gradually increase your intake until you're eating a well-balanced diet.

Changes in bowel habits

Living with pancreatic 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.

Diarrhoea

Diarrhoea is the term for 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, surgical procedures, or because of a range 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 he/she can determine the cause and help to manage your diarrhoea. Your doctor may decide to prescribe you anti-diarrhoea or over-the-counter medication. In some cases, pancreatic enzyme supplements may be recommended.

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 recommended 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
- 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, '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 our 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, oat bran
- psyllium
- soy products
- garlic, onion, spring onion, leek 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 fruits 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 30) and/or a bile acid sequestrant.

Mouth sores

Chemotherapy can cause mouth sores (also referred to as 'mucositis'), which can make eating uncomfortable or painful.

Tips to lessen discomfort:

- suck on ice cubes
- eat soft foods such as stews, soups, scrambled eggs
- cold foods and fluids may be more comfortable than hot
- avoid 'coarse' foods that can irritate your mouth, such as crackers, toast, nuts and seeds
- be mindful of acidic, spicy or very hot foods as these may irritate a sore mouth



- use a straw and direct liquids away from the areas where mouth sores are most painful
- talk to your doctor about medication or mouth washes to help manage the pain and allow you to eat more comfortably.

Ulcers may also be present in your digestive tract, causing diarrhoea and discomfort in the stomach or bowel.

Recovering from surgery

Surgeries used to treat pancreatic cancer may result in a variety of side effects, including weight loss and diarrhoea. The side effects usually only last for a short period of time, but you may have to make some changes to your diet to ensure that you are getting enough nutrition and maintaining your weight.

Your body needs good nutrition after surgery. It's an important part of your recovery process. If you are struggling to eat or drink, the hospital may prescribe nutritional supplements, or recommend tube feeding, to help you to maintain weight and provide you with the nutrients you need for speedy recovery.

It's better to eat small, frequent meals after surgery so your digestive system only has to deal with a small amount of food at a time.

You may find that your usual way of eating changes after pancreatic surgery. This may take some adjustment and support. Make sure you are working with a dietitian to keep you feeling your best.



Tip for monitoring your weight

It's a good idea to weigh yourself once or twice a week to monitor for any weight loss. If you are losing weight, make sure you see a dietitian.

Dumping Syndrome

If you have had a Whipple's procedure, you may have had the lower part of your stomach removed. This may include the valve, or sphincter, that helps control the flow of food from your stomach to your small intestine. Removal of this valve can result in a condition called Dumping Syndrome.

Dumping Syndrome can occur when food moves from your stomach into your small bowel too quickly.

It can present as nausea, cramps and diarrhoea approximately 10 to 30 minutes after eating or sweating and dizziness one to three 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:

- avoid large meals
- avoid sugary drinks and sweets
- choose meals high in protein to slow the digestion of carbohydrates
- keep drinks separate to meals.

Fatigue

Fatigue and tiredness are common side effects of pancreatic 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:

- Eating regular meals. Try six smaller meals to spread your energy across the day.
- Include complex carbohydrates that provide you with a sustained release of energy across the day. Choose wholegrain breads and cereals, legumes, vegetables, fruit, full cream dairy products, including 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 refined grains, cordial and sugar. These cause a spike in your energy levels, followed by a drop (leaving you feeling tired).
- Ensure you are well hydrated, aiming for two litres of fluids per day. Water, herbal tea, soups, milk and milk drinks are good choices.

Malabsorption and pancreatic enzyme replacement therapy

Changes to your pancreas, from either the cancer or the treatment, 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:

- floating, pale, foul smelling stools
- more frequent or loose bowel movements
- bloating or pain (because the large bowel is not used to dealing with these undigested nutrients)
- excess flatulence (farting)
- stools that are oily in appearance
- stools that are difficult to flush and stick to the toilet bowl

- not gaining weight or losing weight, even if you feel you are eating enough
- fatigue and weakness.

In many cases, your specialist may recommend that you take pancreatic enzyme replacement therapy in a supplement such as Creon.

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).

On average, patients with pancreatic cancer need a minimum of 75,000 units of lipase per main meal to avoid symptoms of malabsorption.

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 consumed and your symptoms.



How much Creon do I need?

Your doctor or dietitian will assist you in determining a dosage to match your meal, snacks and fluids. It's important to note that there is no 'one size fits all' approach as the correct dosage for you may differ from someone else.

However, a common starting dosage is often 75,000 units of Creon per main meal and 25,000 units with snacks and nourishing drinks.

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

How to take pancreatic enzymes:

- Swallow the capsule whole with a glass of water – don't pull it apart, crush or chew it. The capsule is full of tiny beads that which 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 activated in the small bowel. Crushing or chewing the capsule will break open the beads in the mouth, which is too early for them to be effective.
- Store the capsules carefully. Room temperature is best and out of direct sunlight.
- Take them at the start of a meal or snack. If your meal or snack lasts longer than 20 minutes you will require another dose.
- Usually, enzymes are taken with meals or snacks that contain protein and/or fat. They are usually not needed for foods or fluids that contain no protein or fat, such as fruits, vegetables, juices, jelly, lollies, cordial, black or herbal tea and soft drinks.
- Take the capsule(s) when you have a milky drink, such as a latte, hot chocolate, flat white or a fruit-based supplement drink or any fluid other than those listed above.
- High fat meals, including fried foods, fatty meats, pastries, take-away foods, cakes, biscuits, desserts, milk drinks and creamy pastas and soups, will require larger doses of Creon.
- Don't take capsules with over-the-counter antacids that contain calcium or magnesium, such as Gaviscon® or Mylanta®.
- Do not take this, or any, medication if it is past the expiry date.

Dosage

- Your doctor or dietitian will prescribe a dose for you, so you know how much to take and when. You may find you need a higher dose if you are still experiencing the symptoms of malabsorption.
- 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.

Side effects and allergies

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

Pancreatic enzyme supplements are sourced from the pancreas 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, speak to your doctor or dietitian.

What if I can't swallow the capsule?

Some people find it hard to swallow medicines. 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. Do not chew the food or hold the food in your mouth – swallow it immediately.

You may be able to use a smaller-dose capsule in a smaller size. However, this means you will need to take more of them.

Speak with your doctor about the appropriate dosage.

Patient story: About Creon

“ After I was diagnosed with pancreatic cancer, the surgeon put me on Creon (a brand of pancreatic enzyme) while I was waiting for my surgery date. I couldn't believe the difference it made to my upset stomach, eating and bowel habits. ”



Blood sugar control

The pancreas produces hormones, including insulin and glucagon, that help to regulate your blood sugar levels. Pancreatic cancer and its treatments can cause diabetes, which may be detected before or after you are diagnosed with pancreatic cancer.

If you have not been diagnosed with diabetes and experience the following symptoms, be sure to see a doctor:

- blurred vision
- very thirsty and drinking a lot of water urinating frequently
- increased appetite
- losing weight.

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. A dietitian can help manage your blood glucose levels through dietary changes.

Endocrinologists are doctors that specialise in hormonal problems. They will be an important member of your team if you have been diagnosed with diabetes. If you have had a total pancreatectomy, you will be diagnosed with type 1 diabetes. This is because your body will no longer be able to produce its own insulin to control your blood sugar levels, so you will need to take insulin injections instead.

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



Patient story: Becoming a diabetic overnight



“ When I was diagnosed with pancreatic cancer, I had a Whipple’s procedure. Nine months later, another tumour came up in another part of my pancreas, so I had my pancreas and spleen removed completely. I became a diabetic overnight. The help I received from my endocrinologist and dietitian was invaluable. ”

Patient story:

Learning to manage blood sugar levels

“ Waking up to being an insulin-dependent person was a nightmare. I didn't understand any of the terminology, and learning about monitoring, finger pricking and so on was overwhelming. In hospital, I received so much verbal and written information from everyone looking after me. While this was all essential, it was way too much to take in, on top of the operation.

I was lucky that, on discharge, the endocrinologist in the hospital told me to text her my blood sugar levels before a meal, and she would text back the correct amount of insulin to inject. After I saw my local endocrinologist, I could continue texting my levels to the diabetes educator in his office until I felt comfortable working out the amount of insulin to inject. The whole team were so supportive.

Without that help in the early stages, I feel I could have totally lost my way. Now, 12 months later, adjusting the insulin dosage I need has become second nature. ”



How do I maximise my nutritional intake?

People with pancreatic 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 nutrients from your food.

A complete, nutritionally balanced diet is essential for everyone, but it's even more important if you are going through cancer treatment. A nourishing diet is one that contains enough kilojoules, protein, nutrients, vitamins and minerals to meet your needs.

You may also 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. Poor nutrition can result in healing taking a long time or problems with healing.

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.

Try making meals as enjoyable as possible. Variety will help make your meals more interesting and ensure you have a good nutritional balance. It can also help to have quick and simple meal or snack ideas for when you are feeling too tired or unwell to shop for food or cook.

These can include nourishing drinks, soups, and marinades that add or change the flavours in your meal.





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.

See *Smoothie and milkshake ideas* for some more inspiration.

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 41*
- 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 41*
- 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

Do I need to see a dietitian?

An Accredited Practising Dietitian (APD) is trained to guide your food choices. Cancer will usually affect people's diets, but the impact is greater for people suffering from pancreatic cancer because of the pancreas's role in digestion, absorption and blood sugar regulation.

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

If you are losing weight, have any signs of malabsorption, have questions about what you should eat, or your symptoms continue to bother you, see a dietitian. They may be able to help pinpoint the problem and provide you with individually tailored dietary advice depending on your issues or preferences.

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

i **Accredited Practising Dietitians** 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.

Patient story: The importance of a dietitian during hospital stays



“ *I'm a diabetic because I had my pancreas removed. I need to take insulin, and the amount of insulin I need has been worked out based on me eating a 'high energy / protein diet' as advised by my dietitian so I can maintain my weight.*

I always seem to have problems when I'm admitted to hospital for infections or other reasons because the doctors and nursing staff note that I'm diabetic, so they put me on a diabetic food plan. I always have to request a visit from the hospital dietitian to get those orders changed back to a 'high energy / protein diet'. ”

Merging dietary needs

If you are already on a restricted diet due to a previous medical condition, such as coeliac disease, 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 (e.g., if you were vegetarian or vegan), your dietitian can help you to adjust your intake to meet your needs. The key goals are to eat a nutritionally balanced diet and to maintain your weight.



Tips to finding an Accredited Practising Dietitian

- Request a referral through your treating hospital. Ask your doctor or nurse for more information.
- Find an oncology dietitian in your local area through Dietitians Australia at New Zealand at <https://dietitians.org.nz>
- Request a referral through your doctor.
- Ask the Gut Cancer Foundation team for more information on local services.

What should I ask my medical team?

Your medical team is made up of highly qualified individuals specialising in different aspects of health care. This multidisciplinary team will likely include oncologists, nurses, psychologists, pharmacists, and allied health clinicians 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, ask them again. It's important that you have all the information you want.

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

- What is my diagnosis?
- What treatments are available?
- What is my prognosis? Will it change if I do or don't have a particular treatment?
- What kind of surgery have I had? How much of my pancreas remains? Can the remaining pancreas carry out its usual function?
- What side effects can I expect? Can I have medications to manage these (such as anti-nausea medications)?
- Are there any concerns about my weight or muscle mass?
- Do I need 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 require insulin?
- Should I make an appointment with a dietitian?

Glossary

- **Advanced cancer** refers to cancers that are not likely to be cured. Patients with advanced cancer often have palliative treatment to help manage symptoms and improve their quality of life.
- **Allied health clinicians** are a subset of health care professionals other than doctors, nurses and pharmacists. Allied health clinicians include dietitians, physiotherapists, psychologists, exercise physiologists, occupational therapists, social workers and speech pathologists, and are an important part of a multidisciplinary team.
- **Bile** is a thick liquid produced by the liver and stored in the gall bladder. It is usually yellow, green or brown. Bile is ejected into the duodenum, where it helps to emulsify fats so they can be further broken down by pancreatic enzymes.
- **Cancer experience** refers to the entire journey you will take, including diagnosis, treatments and life after treatment ends (also known as 'survivorship').
- **Curative treatments** refer to treatments that aim to cure the cancer, or achieve remission (where some or all of the symptoms of cancer disappear). Surgery, chemotherapy and radiation treatments are all curative treatments.
- A **diagnosis** is the condition you have based on the cancer test results – in this case, whether you have pancreatic cancer or not. Diagnosis also includes the exact location of the tumour, and its grade and stage. The Patient Handbook: For people affected by pancreatic cancer explains more about diagnosing cancer available from the Pancare website.
- **Endocrinologists** are doctors that specialise in hormonal problems.
- **General wellbeing** is how you feel overall, and includes how you feel physically, mentally and emotionally.
- A **high-energy, high-protein (HEHP) diet** is one that contains foods that are high in energy (or kilojoules) and high in protein. HEHP diets help to meet your increased nutritional demands and assist in preserving your weight and muscle mass.
- **Hyperglycaemia** is when you have too much sugar in the bloodstream.
- **Hypoglycaemia** is the opposite – too little sugar in the bloodstream.
- **Jaundice** is a yellow discolouration in the skin and eyes, caused by blockages in the common bile duct. These blockages allow bilirubin (a yellow pigment) to enter the bloodstream, which causes the yellow colouring.
- **Kilojoules, or calories**, are a measure of how much energy is in a food. High-energy foods provide our bodies with lots of energy and can help weight managing weight loss and muscle wasting.
- **Malnutrition** is a term commonly used as an alternative to under-nutrition. However, it is important to note that people in larger bodies can also experience malnutrition.
- **Nutrition supplements** are high-kilojoule, high-protein drinks that provide you with extra nutrition.. These are not the same as pancreatic enzyme supplements.
- The inability to digest or absorb nutrients, even if you are eating them, is called **maldigestion** or **malabsorption**.
- **Oncologists** are doctors that specialise in treating cancer. There are many types of oncologists, such as:
 - surgical oncologists, who specialise in operating on tumours
 - medical oncologists, who specialise in chemotherapy and biological therapies (e.g. immunotherapy)
 - radiation oncologists, who specialise in radiation therapy.
- **Palliative treatment** helps patients deal with pain or symptoms but does not treat the cause of the pain or symptoms. Surgery, chemotherapy and radiation treatment can also be administered with palliative intent, also known as 'comfort measures'. The dose and frequency of palliative treatment will not be as aggressive as for curative treatment.

- **Pancreatic juices** are the liquids secreted by the pancreas that help to break down and digest food.
- **Pancreatic enzymes** include lipase, amylase and protease. These help to break down the fats, carbohydrates and proteins found in our food (respectively).
- A **prognosis** is the expected outcome for you based on the most up-to-date evidence. It is dependent on your diagnosis and treatment. A prognosis can change over time. For example, your prognosis may be improved if you have surgery and chemotherapy, if this is recommended for you, compared with surgery alone. Your prognosis can also change depending on how successful the treatments are. A prognosis is likely to be given as chance of survival, or chance of making a full or partial recovery.



Further information and support

Please visit our website www.gutcancer.org.nz

Email support@gutcancer.org.nz

Call 0800 112 775

International resources

- Cancer Research UK: Your diet: <https://www.cancerresearchuk.org/about-cancer/pancreatic-cancer/living-with/diet>
- Pancreatic Cancer Action: Diet and Nutrition for Pancreatic Cancer: <https://pancreaticcanceraction.org/get-help/ive-been-diagnosed/diet-and-nutrition-for-pancreatic-cancer>
- Pancreatic Cancer Action Network: Diet and nutrition: www.pancan.org/facing-pancreatic-cancer/diet-and-nutrition
- Cancer Council Victoria: Managing dietary problems: www.cancervic.org.au/about-cancer/types/pancreatic_cancer/pancreatic-diet.html
- Dietitians Australia: www.dietitiansaustralia.org.au



Diet & nutrition for people living
with pancreatic cancer.

gutcancer.org.nz

