



# Dietary handbook

Managing dietary symptoms for people  
with **pancreatic cancer**



The information in this booklet has been adapted from material listed in the 'Resources' section. It has been reviewed and modified by a dietary working group formed by the Pancare Foundation:

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## Note to reader

The information contained in this booklet is appropriate to follow if you are undergoing treatment for your pancreatic cancer, are in the early stages following treatment, or are underweight or losing weight. If you have recovered from your cancer, you should speak to your dietitian about the most appropriate diet to follow for longer-term health.

All care has been taken to ensure that the information in this booklet is accurate at the time of publication. No sponsoring organisation has had any input into the contents of this booklet.

Information relating to pancreatic cancer is constantly being updated by the medical profession and the research community. 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/general) symptoms, questions or concerns with your health care professional as soon as possible. The Pancare Foundation excludes itself from all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

## Pancare Foundation

The Pancare Foundation is Australia's not-for-profit pancreatic cancer organisation. Our purpose is to increase survival and provide support to people affected by pancreatic and other gastrointestinal cancers, including liver, biliary, oesophageal and stomach cancer.

When a patient is diagnosed with cancer, it affects the whole family and the community in which they live. The Pancare Foundation supports world-leading research and delivers programs designed to address individual and changing patient needs, from the point of diagnosis through to recovery or bereavement.



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# What is this handbook about?

**Cancer is a life-changing event, but advances in medicine mean that patients are living longer, better lives after cancer treatment. These advances include understanding how cancer affects the diet, and how you can change your diet to help you feel better. This handbook highlights important information about managing your diet if you have or have had pancreatic cancer.**

If you have been given this handbook, you or someone you know has probably been diagnosed with pancreatic cancer.

Cancer and its treatments and side effects can affect how you live day to day. This handbook explains what a normal pancreas does, how it is involved in digestion and absorption, and the effects that pancreatic cancer and its treatments can have on pancreatic function. It also provides suggestions about what you can do to feel better during and after treatment, to make it easier to manage during this difficult time.

The potential side effects of pancreatic cancer and its treatment include:

- problems with gaining or maintaining weight
- changes in taste and smell
- differences in bowel or bladder habits
- loss of appetite and feeling full early

- changes in blood sugar levels
- nausea (feeling like you are going to throw up) and vomiting.

You may experience all, some or none of these side effects at some point during your cancer journey. This handbook provides dietary tips to help manage these symptoms. You may also benefit from seeing a dietitian, who can alter the advice to be specific for you, to help you manage your diet and weight. Your doctor may prescribe medicines, such as pancreatic enzymes, or anti-nausea or anti-vomiting (anti-emetic) medicines, to help with some of your symptoms.

Eating is often enjoyable for people, and you should try to keep it this way during your treatment. Yes, you may have to make some changes, but, if you follow the advice offered in this handbook and from doctors, nurses and dietitians, it can help make eating and maintaining your weight a bit easier, and make you feel better.

**Cancer journey refers to the entire journey you will take, including the diagnosis, the treatments and life after treatment ends.**



# How does the pancreas work?

**The pancreas is a part of the digestive system that produces pancreatic enzymes and hormones. Any disease or treatment targeting the pancreas can affect digestion, nutrient absorption and blood sugar regulation.**

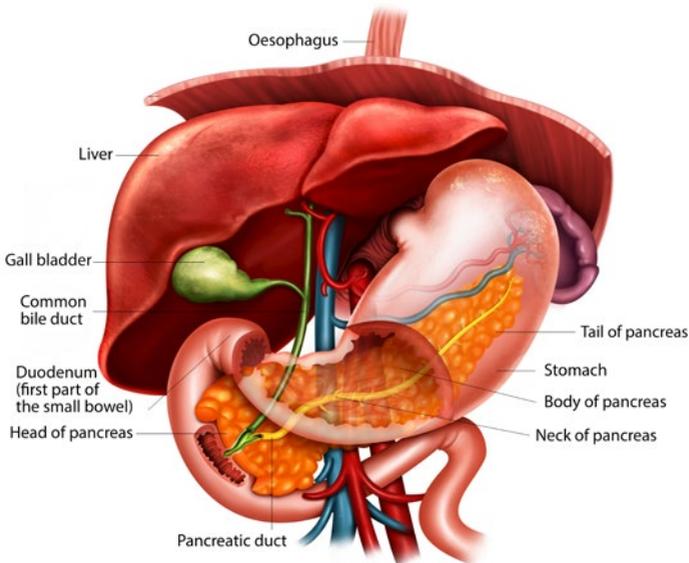
The pancreas is a gland that has a 'head', 'body' and 'tail'. It is part of the digestive system, and is found in the abdomen with other organs involved in digestion and absorption, such as the stomach, liver, gall bladder, and small and large intestines (also

called the small and large bowel) (Figure 1). The pancreas serves two main functions in the body:

- It produces enzymes that are important for helping you to digest your food.
- It produces hormones, including insulin and glucagon, that are involved in regulating 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 levels and/or digestion.

**Figure 1 The main organs of the digestive system**



## Insulin and glucagon

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. Problems with blood sugar levels can indicate a problem with the pancreas, such as diabetes.

Having a normal blood sugar level is important for good health and wellbeing. Consistently having 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.



**Hyperglycaemia** is when you have too much sugar in the bloodstream. **Hypoglycaemia** is the opposite – too little sugar in the bloodstream.

## Digestive enzymes

When we eat, we first break up food in our mouth by chewing. The food passes from our mouth down our oesophagus and into our stomach, where it is further churned up and broken down into small pieces. These small pieces of food slowly enter the small bowel where they mix with pancreatic enzymes (released from the pancreas), other pancreatic juices and bile.

The enzymes, pancreatic juices and bile work together to help digest and break down the food into carbohydrates, proteins and fat so that it can be absorbed.

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 well with the food (which can happen after surgery), this can affect the digestion of nutrients.

Poor digestion and absorption can lead to malnutrition (the body not getting enough nutrients), weight loss and change in bowel habits.



**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.

**Pancreatic juices and enzymes** are the liquids secreted by the pancreas that help to break down and digest food.

**Malnutrition** is a term commonly used as an alternative to undernutrition, as done in this guide. However, note that it can also mean overnutrition.

# What therapies are used to treat pancreatic cancer?

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



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 ([www.pancare.org.au/wp-content/uploads/2016/07/Pancare-Patient-Handbook-digital\\_Final\\_3.pdf](http://www.pancare.org.au/wp-content/uploads/2016/07/Pancare-Patient-Handbook-digital_Final_3.pdf)).

Pancreatic cancer is often treated using surgery, chemotherapy and radiation therapy (sometimes called radiotherapy). Your doctor will recommend which treatment(s) may help you, based on your diagnosis.



A **prognosis** is the likely outcome for you, depending on your diagnosis and the treatments you have. 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.

## Surgery

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

## Whipple 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)
- part of the stomach
- the gall bladder and a portion of the common bile duct.

Whipple surgery also removes some lymph glands in the area.

The surgeon will then reconnect 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/juices and bile (Figure 2).

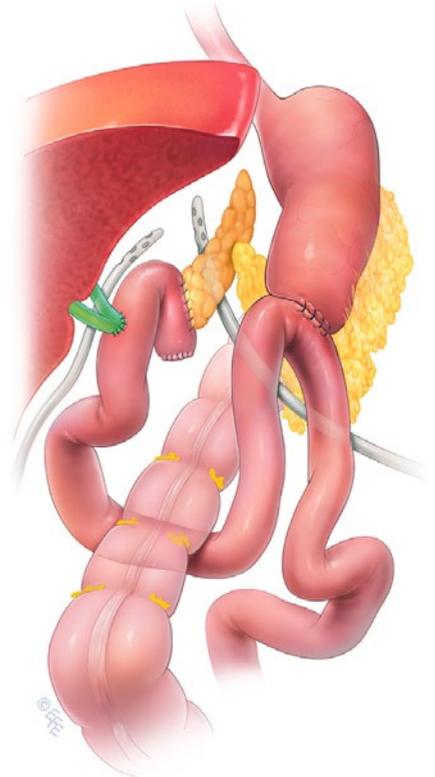
## Total pancreatectomy

‘Ectomy’ refers to the surgical removal of a body part or portion of a body part. In the case of 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 the tail of the pancreas – the head of the pancreas is left intact.

Figure 2 The Whipple procedure



## Bypass surgery

You may need bypass surgery if the cancer is more advanced and cannot be removed, or is discovered to have spread at the time of your operation. 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 gall bladder, which will bypass the blockage. This will relieve symptoms of jaundice when it is present.



**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.

## Chemotherapy

Chemotherapy 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 neo-adjuvant 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).

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

## Radiation therapy

Radiation therapy 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



**Curative treatments** refer to treatments that aim to cure the cancer, or put it in remission (where some or all of the symptoms of cancer disappear). Surgery, chemotherapy and radiation therapy are all curative treatments.

**Palliative treatment** helps patients deal with pain or symptoms, but does not treat the cause of the pain or symptoms.

**Advanced cancer** refers to cancers that are not likely to be cured. Patients with advanced cancer often have palliative treatment to help them feel better.

directed to a smaller area of the body where the tumour is, so that other parts of the body are not affected.

The radiation often comes from a machine directed at the pancreas (external radiotherapy). This treatment will not make you radioactive.

Depending on your type of pancreatic cancer, you may be injected with a radioactive therapy (internal radiotherapy). This type of treatment may make you radioactive for a few days after the injection. Your doctor will let you know what to do if this is the case.

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

# How can I manage the symptoms of pancreatic cancer and treatments?

**Pancreatic cancer and the associated treatments change how your pancreas functions. Managing these effects is important to maintain your weight, help you recover from the cancer, minimise other symptoms and make you feel better in general. The side effects can affect people differently. You may have none, some or all of the symptoms discussed below, but there are plenty of things you can do to help manage these side effects and increase your general wellbeing.**

This chapter explains the side effects of cancer and its treatments, and how to manage them. Pancreatic cancer and its treatment tend to affect how much you eat, what you need to eat (your dietary requirements), your appetite and your general wellbeing. You may also find it more difficult to digest or absorb some types of foods (especially fatty foods), but your doctor and dietitian can help with this.

Cancer itself often makes people feel tired, nauseous and generally unwell. Your weight, appetite and bowel movements may change. In the case of pancreatic cancer, you may also experience changes in your blood sugar levels, because the pancreas is important for

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

regulating these levels. If this is the case for you, you may need diabetes medicines.

Pancreatic surgery often leaves you feeling tired and sore, and may give you diarrhoea and make it hard to put on weight. You will probably also find it hard to eat big meals.

Chemotherapy can often leave your mouth feeling very dry, give you mouth sores, change your appetite, make you feel nauseous or make you vomit.

Radiation therapy can have several diet-related side effects, such as bowel problems (diarrhoea), loss of appetite and nausea.

## Weight changes

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

It is important to maintain your weight and eat well. Maintaining your weight will also help you cope better with the treatments, recover faster, feel less tired and reduce your chances of becoming unwell. If you struggle to keep weight on, see a dietitian.



Use these tips to help you maintain your weight:

- Try to eat nourishing foods and fluids (those that are high in energy and high in protein). See Box 2 in 'How do I maximise my nutritional intake?'
- Full-cream dairy, meats and meat alternatives are the best to eat and incorporate into your diet to make it nourishing (see Box 2 in 'How do I maximise my nutritional intake?').
- Try to eat the most nourishing part of the meal first.
- Ask about using pancreatic enzyme replacement therapy (see 'Malabsorption and pancreatic enzyme replacement therapy').
- Ask about using nutrition supplement drinks (see 'Do I need to see a dietitian?').

Don't worry about low-cholesterol, gluten-free or sugar-free diets, and other restrictions (unless your doctor or dietitian tells you otherwise). Making sure you are eating a variety of nutritious foods and maintaining a good weight is the most important.

## Loss of appetite and feeling full

Loss of appetite is a common problem in people with pancreatic cancer, not just during treatment. Early satiety (feeling full quickly) is also a common problem.

Remember to try to eat things you enjoy. Don't force yourself to eat things you'd rather not;

**Kilojoules, or calories, are a measure of how much energy is in a food. High-energy foods will also be high-kilojoule foods, and low-kilojoule foods will be low-energy foods.**

for most people, eating can be pleasurable, and there is no reason why it should not be this way for you.



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

- Eat small meals throughout the day. Try to eat every 2 to 3 hours, rather than having 3 large meals at morning, noon and night.
- 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?').
- When you do feel hungry – eat! If you find yourself to be hungrier than usual at certain times of the day or from day to day, take advantage and eat a bit more when you feel like it.
- Try to drink fluids separately from your meals so you have more room for food at meal times. If you do need to drink with your meals, make sure you drink 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.

**Early satiety is when you feel full quickly.**

## Changes in taste or 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.



Follow these 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 items. Alternatively, you may find 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 foods with plastic (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 things. 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 may also help with this.
- Avoid strong flavours, such as alcohol.



Follow these tips to help you cope with changes in smell:

- Choose cold food or food at room temperature that doesn't have a strong smell.
- 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 stomach meat, try it in different ways, such as in a mince dish or slow cooked with vegetables. If this doesn't help, try other protein sources, such as cheese, eggs, nuts, dairy foods or legumes.
- See the tips in 'Nausea and vomiting' if strong smells or some foods make you feel ill.

## Nausea and vomiting



Nausea and vomiting can be caused by both pancreatic cancer and its treatments. Dealing with nausea and vomiting as someone with cancer is much the same as for anyone who feels nauseous or has problems with vomiting:

- Talk to your doctor about trying an anti-nausea medicine.
- Eat small, frequent meals throughout the day. Don't skip meals or snacks – not eating can make nausea worse.
- Eat dry and salty snacks, such as dry crackers or toast with vegemite or cheese.
- Eat and drink slowly, and chew food well.
- Choose cold foods instead of hot, fried, greasy or spicy foods. Cold food tends to have less smell than heated foods. (Also see Box 1.)
- Avoid strong odours and cooking smells. If possible, stay away from the kitchen if

someone else is cooking, or 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.

Vomiting is a bit more serious than nausea. Vomiting can cause dehydration and, if it goes on for a few days, can increase the risk of malnutrition. See a doctor if you are vomiting for more than a day, especially if you find you can't even keep water down.



To manage vomiting at home, try the following:

1. Take small sips of water or flat drinks, such as ginger ale, soda water or 'sports drinks' such as Gatorade. You can dilute the sports drinks if you prefer. If you want to try a fizzy drink, open it and let it sit for 10 minutes or so, and drink it a bit 'flat'.
2. Once you are handling step 1 okay, try some different drinks, such as consommé and clear broths, weak tea, fruit drinks, beef and chicken stocks, or even ice-cream in soda water. Have small, frequent meals and snacks throughout the day.
3. Start eating bland, dry foods, such as plain biscuits, bread or toast with honey or jam, peanut butter, rice, low-fat yoghurt or fruit. Keep trying to have small, frequent servings.
4. Keep eating a bit more until you are eating a well-balanced diet. Follow the tips outlined in this chapter.

### Box 1 Food safety

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

It is important that you ensure that everything you eat and drink is prepared and stored properly to minimise any risk of food poisoning.

You can find easy-to-read information about food safety and food poisoning on the Better Health Channel website – [www.betterhealth.vic.gov.au/health/healthyliving/food-poisoning-prevention](http://www.betterhealth.vic.gov.au/health/healthyliving/food-poisoning-prevention).

### 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.

## 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 smell of your stools.

## Diarrhoea

Diarrhoea is when you pass four or more loose, watery stools per day. Frequent loose stools can occur because you are not digesting food or absorbing nutrients properly, because of the treatment side effects, after surgery, or because of a completely different cause.

Diarrhoea can result in dehydration, so it is important to stay hydrated by drinking extra fluids. For each loose bowel movement you have, you should drink an extra cup of non-caffeinated fluid. If you have diarrhoea for several days, see your doctor so they can determine the cause of your diarrhoea. Your doctor may decide to prescribe you anti-diarrhoea medicine or an over-the-counter medicine that will help symptoms.

It is best to consult your doctor or dietitian before making big changes to your diet, but several foods can make diarrhoea worse, and it can be beneficial to avoid or limit these until the diarrhoea stops. These are:

- foods that are fatty, greasy or fried
- foods that have a lot of insoluble fibre, such as wholegrain breads and cereals, raw fruits with thick peels, raw vegetables, nuts and seeds
- fizzy drinks; if you want to drink them, leave them open for at least 10 minutes before drinking
- foods and drinks that are high in sugar, such as cordial, soft drinks and lollies (especially if you've recently had a Whipple surgery)
- hot drinks
- large quantities of foods sweetened with sugar alcohols, such as sorbitol, mannitol and xylitol – these are often marketed as 'sugar-free' but they are still sweet.

**There are two types of fibre – soluble and insoluble – that we need to eat in our daily diets. Both are beneficial to the body, and most plant foods contain a mixture of both types.**

**Soluble fibre** includes pectins, gums and mucilage, which are found mainly in plant cells. One of its major roles is to lower LDL (bad) cholesterol levels. Good sources include fruits, vegetables, oat bran, barley, seed husks, flaxseed, psyllium, dried beans, lentils, peas, soy milk and other soy products. Soluble fibre can also help with constipation.

**Insoluble fibre** includes cellulose, hemicelluloses and lignin, which make up parts of plant cells. A major role of insoluble fibre is to add bulk to faeces, and to prevent constipation and associated problems such as haemorrhoids. Good sources include wheat bran, corn bran, rice bran, the skins of fruits and vegetables, nuts, seeds, dried beans and wholegrain foods.



Some foods have been found to help improve diarrhoea in some cases (depending on the cause of the diarrhoea) and may be worth trying as part of your diet. These are:

- soft, well-cooked, peeled vegetables and fruit
- white bread, white rice and pasta
- corn- or rice-based cereals
- lean meat, fish or chicken
- eggs.

It may also help to eat small, frequent meals throughout the day, rather than 3 large meals.

## Pale or smelly stools

Stools that are smellier than usual, floating, oily, pale coloured (often yellow, cream or white) or difficult to flush often indicate that your body is not absorbing food well, especially the fat in food. Instead, the fat is passing through the bowel, which often causes 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 (see 'Malabsorption and pancreatic enzyme replacement therapy').

## Mouth sores

Chemotherapy can cause mouth sores, which can make eating uncomfortable or even painful.



To lessen discomfort or pain from mouth sores, try the following:

- Suck on ice cubes.
- Eat soft or cold foods, or soups.

- Avoid 'coarse' foods that can irritate your mouth.
- Avoid spicy or very hot foods.

## Recovering from surgery

The surgeries used to treat pancreatic cancer may result in some of the symptoms described already, including weight loss and diarrhoea. In the short term, they may also cause delayed gastric emptying, which is where food moves from the stomach to the small bowel much slower than normal. This usually only lasts for a short time, but it means you may have to make some changes to your diet to ensure that you are getting enough nutrition, and to minimise the symptoms. If you experience this, speak to your dietitian for advice.

To help you recover from your surgery, your body needs enough nutrition. If you are not able to eat or drink enough, the hospital may prescribe you nutrition supplements. These will help you maintain weight, and give you an energy boost to help you recover from the surgery. You may want to weigh yourself once or twice a week to make sure you are maintaining a good weight or gaining weight.

**Nutrition supplements are high-kilojoule, high-protein products that will add energy to your diet in an easy-to-digest drink or food. These are not the same as pancreatic enzyme supplements.**

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

You may eventually be able to get back to a normal diet, although what was normal for you before the surgery may have to change! If you used to have a poor diet, you may have to consider defining a 'new normal' for yourself.

## Malabsorption and pancreatic enzyme replacement therapy

Changes to your pancreas, from either the cancer or the treatment, can mean that the body does not produce pancreatic enzymes, or does not produce enough of them. It can also mean that the pancreatic enzymes don't mix well with food. All of these things can lead to poor digestion and absorption of food. This is known as pancreatic exocrine insufficiency (PEI).



**The inability to digest or absorb nutrients, even if you are eating them, is called maldigestion or malabsorption.**

There are several symptoms of malabsorption:

- floating, pale stools
- more frequent or loose bowel movements
- bloating or pain (because the large bowel is not used to dealing with these 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're eating enough
- weak muscles.

If you are experiencing these symptoms, you should speak to a doctor about taking pancreatic enzymes, sometimes called pancreatic enzyme replacement therapy (or PERT). Taking pancreatic enzymes with your food will ensure that the enzymes are present to mix well and digest food properly so that it can be absorbed by the body.

Pancreatic enzymes come in capsules. These capsules contain a mixture of the different pancreatic enzymes – lipase (to digest fats), amylase (to digest carbohydrates) and protease (to digest proteins).

Your doctor will decide how much pancreatic enzyme replacement you need, and adjust the dose as required. Some people only need pancreatic enzyme replacement therapy for a short time, but others may need it long term. This depends on whether you have symptoms of malabsorption.

### 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. By the time the surgery arrived, most of my symptoms had disappeared.**

For more information, please refer to the *Pancreatic Patient handbook: for people affected by pancreatic cancer* ([www.pancre.org.au/wp-content/uploads/2016/07/Pancreatic-Patient-Handbook-digital\\_Final\\_3.pdf](http://www.pancre.org.au/wp-content/uploads/2016/07/Pancreatic-Patient-Handbook-digital_Final_3.pdf)).

## Do's and don'ts of taking pancreatic enzymes

If you are prescribed pancreatic enzymes:

- be sure to swallow the capsule whole – don't crush or chew it. The capsule is full of tiny beads, which hold the enzymes. The capsule will be broken down in the stomach, which releases the beads containing the enzymes. In the small bowel, the beads break open and the enzymes are activated. Crushing or chewing the capsule will break open the beads in the mouth, which is too early
- be careful about where you keep them. Room temperature is best. High temperatures will make them inactive, so don't store them near a heat source, in the car or in your pocket
- take them at the start of each meal or substantial snack. 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 and soft drinks
- take them with a cup of coffee if you have a lot of milk in it (such as lattes, cappuccinos or flat whites)
- don't take them with over-the-counter antacids that contain calcium or magnesium, such as Gaviscon® or Mylanta®. However, you may need a medicine called a 'proton pump inhibitor' to help the pancreatic enzymes work properly. If this is the case, your doctor will prescribe one for you
- do not take them if they are past their expiry date.



## Proper doses

Your doctor will prescribe a dose for you, so you know how much to take for each meal. You may find you need a higher dose if you are still experiencing the symptoms of malabsorption described earlier in this section.

You might also need to increase the dose if you are eating a particularly fatty meal, such as takeaway or deep-fried meals – this is okay. If you are eating a meal that has multiple courses and is spread across several hours, you may need to take extra pancreatic enzymes and/or spread the total dose of pancreatic enzymes across the meal time.

If you feel that your dose of pancreatic enzymes is not working, discuss this with your doctor or dietitian. If you are prescribed pancreatic enzymes, it is important to take them regularly and at the right dose; otherwise the enzymes will not be able to do their job and your symptoms will not go away. Symptoms could even get worse.

If you forget to take your enzymes, or forget to take them with you while eating out, there is not much you can do. You cannot ‘make up’ the dose later, as you can with some medicines. If you find you are always forgetting to take your enzymes, speak to your doctor, dietitian or pharmacist for tips to help you remember to take them. It is important to take the enzymes if you are prescribed them.

## Side effects and allergies

Pancreatic enzyme supplements can have some side effects. The most common ones are constipation, diarrhoea, nausea and pain in the stomach. Most of these will go away after using the enzymes for a while.

The pancreatic enzyme supplements are made from pigs. Unfortunately, a suitable

alternative is not available in Australia. If you have any allergies to pork products, speak to your doctor. If you have religious restrictions on eating pork, speak to your religious leader about seeking dispensation to receive treatment.

## What if I can't swallow the capsule?

Some people find it hard to swallow medicines. If this is the case for you, 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 also be able to get a smaller-dose capsule, which means the size of the capsule is also smaller. However, this means you will need to take more of them.

## Diabetes

The pancreas produces hormones, including insulin and glucagon, that help to regulate your blood sugar levels. Having a chronic unbalanced blood sugar level is known as diabetes. 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, be sure to see a doctor if you:

- have blurred vision
- are very thirsty and drinking a lot of water
- are going to the toilet to wee a lot
- are hungry
- are losing weight.

Most people with diabetes manage the symptoms by controlling their blood sugar levels with a suitable diet and small, frequent meals. You may need to take medicine to help manage your blood sugar levels. Your doctor will prescribe this for you if needed. An endocrinologist and dietitian can help you with your diet if you are diagnosed with diabetes.

Endocrinologists are doctors who specialise in hormonal problems, and you will see one 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 instead. As well as seeing your cancer doctors, you will see an endocrinologist, a diabetes educator and a dietitian to help you adjust your insulin dose and your diet. Dietary advice for someone who has both pancreatic cancer and diabetes can be quite different from the advice for someone with only diabetes, so it is important that you see a dietitian to help you with this.

### **Patient story: Becoming a diabetic overnight**

**When I was diagnosed with pancreatic cancer, I had a Whipple 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 diabetic 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 can often struggle to maintain their weight, or lose weight when they don't want to. The treatments and their side effects can make it hard to get enough nutrition.**

The treatments and side effects described in the previous chapters can make it very hard to maintain weight or to put weight on. Maintaining a healthy weight is very important. This chapter combines some of the advice outlined already to provide ways to get the most nutrition out of your diet while recovering at home.

A complete, nutritionally balanced diet is important for everyone. However, 3 things are particularly important for people with pancreatic cancer:

- energy to provide fuel for the body, and help you to gain weight and be healthy
- proteins to build and repair the cells in your body
- vitamins and minerals for the body to use with other nutrients so your body can function at its best.

## Nourishing diets

A nourishing diet is one that contains extra kilojoules and protein where possible.

You may also hear the term 'high-energy, high-protein diet'.

There are several foods you can add to your usual diet to make it more nourishing (see Box 2). Try to choose a variety of these foods. Variety will help make your meals more interesting, and ensure that you have good nutritional balance. Boxes 3 and 4 contain some meal ideas.

**A high-energy, high-protein (HEHP) diet is one that contains foods that are high in energy (or kilojoules) and high in protein. High-energy foods tend to contain a lot of fat and carbohydrates, including sugars.**



## Nutrition supplement drinks

Nutrition supplement drinks are drinks that are high in energy and protein, but are liquids so they are easier for many people to stomach when they don't feel like eating. You can sip on them slowly and still get good nutrition when your appetite is low.

Nutrition supplement drinks come either in powder form or ready-made, and there are

**Box 2** High-energy and high-protein foods and condiments to add to your diet

**High-energy foods**

- Avocado
- Butter and margarine
- Oils
- Coconut cream or coconut milk
- Cream
- Creamy sauces
- Dips made with cream cheese, or hummus
- Dried fruit
- Gravy (made with meat juices)
- Jam
- Honey, maple syrup and golden syrup
- Sugar
- 'Trail mix' – a snack of mixed nuts, dried fruits and seeds, and sometimes chocolate bits

**High-protein foods**

- Meat, chicken and fish
- Eggs
- Beans, chickpeas and legumes
- Full-cream milk
- Cheese
- Custard
- Yoghurt
- Ice-cream
- Peanut butter and other nut spreads
- Nuts (whole and ground up) and seeds such as sunflower or pumpkin seeds
- Nutrition supplement powders, as well as protein powders and bars, such as those that weightlifters or body builders might use
- Evaporated milk
- Condensed milk
- Fortified milk

Fortified milk is easy to make yourself. Just sprinkle 2/3 cup (or 75 grams) of skim milk powder onto 2 cups (or 500 millilitres) of full-fat milk, and mix until the powder is dissolved. Try to make it 2 hours before using it, and store it in the fridge. Use fortified milk wherever you would use regular milk, such as on your cereal, in your tea or coffee, or to make a milkshake or smoothie.

several brands on the market. A dietitian can let you know which ones are best for you.

You can also easily make your own, as a smoothie or a milkshake. Use combinations of fruit, dairy products and sweeteners such as honey or maple syrup. Make sure to add foods from Box 2 to make it high energy and/or high protein. See Box 3 for some smoothie ideas.

### **Patient story: Nutrition supplements**

**Nutrition supplements can be vital if you're struggling to eat much protein and maintain your weight. At times 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 ensure that I eat a nourishing diet?**

As mentioned in the previous chapter, there will 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 the following:

- Eat a variety of foods.
- Don't eat foods that you hate; try something new, even if it's something you didn't like before you had cancer. You may find your tastes have changed.
- Eat 6 small meals throughout the day, rather than 3 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.
- Use prepared frozen foods and tinned foods if you need to. You may find you are too tired to make a meal, so keeping a supply of pre-made foods on hand is important. You can also make large batches of foods and freeze them in small portions.
- If you find you feel full very quickly during a meal, eat the most nourishing (high-energy/protein) part of the meal first and try not to drink within an hour before your meals. If you are used to drinking with your meals, make sure you sip on nourishing fluids such as a smoothie or milkshake. If you feel like drinking something after a meal, try eating a bit more instead. Fluids can make you feel full even when you're not.

### **Box 3** Smoothie and milkshake ideas

Milkshakes and smoothies can be good sources of energy and protein, as well as being easier to eat than more traditional meals. They are also easy to make yourself if you have a food processor or blender.

For a smoothie, start with a base of yoghurt, then add things like bananas, berries or mango, and fruit juice. Add some nuts or seeds to add some extra kilojoules and protein, and blend together.

For milkshakes, start with a base of fortified milk and ice-cream. Add things like chocolate powder, Milo, fruit and peanut butter.

Always consider adding high-energy foods from Box 2 to add kilojoules and flavour!

### **Box 4** Sample meals

These sample meals are only suggestions, but they can get you thinking about ways to increase the energy and protein in your diet. These meals are based on the types of things people often eat for breakfast, lunch and dinner, but of course you can mix them up.

#### **Breakfast**

Cereal or muesli with fortified milk, yoghurt, sugar or honey

Eggs (poached, scrambled, fried, boiled, omelette) with cheese

Buttered bread or toast, with cheese, avocado, peanut butter, honey, vegemite, Nutella or jam

Baked beans on buttered toast with grated cheese

#### **Morning tea**

Smoothie or milkshake (see Box 3)

Nutrition supplement drink

Yoghurt or custard with fruit

Creamed rice

## Box 4 continued

### Lunch

Meat or fish with a creamy sauce or gravy

Mashed vegetables mixed with butter, margarine, cream or cheese

Wraps or sandwiches made with meat, chicken, fish, eggs, beans or lentils, avocado, mayonnaise and cheese

### Afternoon tea

Smoothie or milkshake

Dairy-based dessert, such as custard or pudding

Yoghurt with dried fruit, nuts and honey

Biscuits with dip or cheese

### Dinner

Pasta with meat sauce, such as spaghetti bolognese or fettuccini carbonara, with grated cheese, and a dinner roll with butter or margarine

Burritos with meat, rice, beans and cheese, topped with sour cream

Meat, chicken or fish with gravy, or cream or cheese sauce, and mashed potato with butter and fortified milk or cream

Lentil or bean salad, with cold chicken or tinned fish, avocado, corn, cheese and dressing

### Evening snack

Crème caramel, pudding, rice pudding, ice-cream or chocolate mousse

Sweet biscuits or cookies, with fortified milk and chocolate malt powder (Milo)

# Do I need to see a dietitian?

**A dietitian is specially trained to help you know what to eat if you have cancer or are being treated for cancer. Cancer can affect many people's diet, and this is especially true for pancreatic cancer because of the role the pancreas plays in digestion, absorption and blood sugar regulation.**



**Accredited practising dietitians are health care professionals who are trained to provide nutrition- and diet-related advice to anyone who needs it. Dietitians are especially important for people who have specific dietary needs. They understand how the body works, and how a healthy diet can help you feel better.**

**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 Australia. If you need to see a dietitian, ensure that they are an accredited practising dietitian.**

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

If you are losing weight, if you have any questions about what you should eat, or if you are following the advice in this handbook but your symptoms still bother you, see a dietitian. They may be able to help pinpoint the problems, and provide you with individually tailored dietary advice depending on your issues or preferences. A dietitian can talk you through the advantages of eating a high-energy, high-protein diet, and how to maximise your nutritional intake.

If you have been diagnosed with diabetes, see a dietitian to help with your diet. Irregular blood sugar levels can lead to very serious complications.

You may have had dietary restrictions before being diagnosed with pancreatic cancer. If these are because of a medical condition, such as coeliac disease, make sure you talk to a dietitian, because you may need more specialised advice than this handbook can offer.

If you were following a diet for nonmedical reasons before your diagnoses (e.g. if you were vegetarian or vegan), you may need to reconsider these restrictions. The goals are to eat a nutritionally balanced diet and maintain your weight, and a restrictive diet may make this very difficult. It is best to speak to a dietitian about this.

### **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, not a strict diabetic diet. 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'.



# What should I ask my medical team?

**Your medical team is made up of highly qualified individuals specialising in different aspects of health care, also called a multidisciplinary team. This team will likely include oncologists, nurses, psychologists, pharmacists, and allied health clinicians including dietitians and physiotherapists.**

Ask your medical team any questions you may have. If you don't understand the answer, ask them again. It is important that you have 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?
- What treatments have I had?
- What side effects will I have? Can I have medicines to manage these (such as anti-nausea medicines)?
- What is my target weight? Do I need to put on weight?
- Do I need pancreatic enzyme supplements? How long will I need to take them for?

**Oncologists** are doctors who 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
- radiation oncologists, who specialise in radiation therapy.

**Allied health clinicians** are a subset of health care professionals other than doctors, nurses and pharmacists. Allied health clinicians include dietitians, physiotherapists, psychologists and speech pathologists, and are an important part of a multidisciplinary team.

**Psychologists** are health care professionals who study behaviour and mental processes. They can help anyone who might be struggling with dealing with cancer, including someone with cancer and their family.

**Physiotherapists** can help you to recover from injury or surgery, reduce pain and stiffness, and increase mobility.

- Do I have diabetes? Can I still get diabetes if I don't have it yet?
- Should I make an appointment with a dietitian?

# Resources

The following websites were used as information resources for this booklet.

Also check another Pancare booklet – *Patient handbook: for people affected by pancreatic cancer* – for information about pancreatic cancer.

[www.pancare.org.au/wp-content/uploads/2016/07/Pancare-Patient-Handbook-digital\\_Final\\_3.pdf](http://www.pancare.org.au/wp-content/uploads/2016/07/Pancare-Patient-Handbook-digital_Final_3.pdf)

## Australian resources

### **Cancer Council NSW: Pancreatic cancer – after treatment**

[www.cancercouncil.com.au/56300/cancer-information/after-treatment/when-treatment-finishes-after-treatment/pancreatic-cancer-nutrition-and-dietary-problems/](http://www.cancercouncil.com.au/56300/cancer-information/after-treatment/when-treatment-finishes-after-treatment/pancreatic-cancer-nutrition-and-dietary-problems/)

### **Cancer Council Victoria: Managing dietary problems**

[www.cancervic.org.au/about-cancer/cancer\\_types/pancreatic\\_cancer/pancreatic-diet.html](http://www.cancervic.org.au/about-cancer/cancer_types/pancreatic_cancer/pancreatic-diet.html)

### **Dietitians Association of Australia**

<https://daa.asn.au/>

### **National Prescribing Service: Consumer Medicine Information – Creon capsules**

[www.nps.org.au/medicines/digestive-system/supplements-to-aid-digestion/lipase-protease-amylase/creon-25-000-capsules](http://www.nps.org.au/medicines/digestive-system/supplements-to-aid-digestion/lipase-protease-amylase/creon-25-000-capsules)

## International resources

### **Cancer Research UK: Your diet**

[www.cancerresearchuk.org/about-cancer/type/pancreatic-cancer/living/diet-and-pancreatic-cancer](http://www.cancerresearchuk.org/about-cancer/type/pancreatic-cancer/living/diet-and-pancreatic-cancer)

### **Pancreatic Cancer Action: Diet and nutrition**

<https://pancreaticcanceraction.org/about-pancreatic-cancer/diet-and-nutrition/>

### **Pancreatic Cancer Action Network: Diet and nutrition**

[www.pancan.org/facing-pancreatic-cancer/diet-and-nutrition/](http://www.pancan.org/facing-pancreatic-cancer/diet-and-nutrition/)







