



A guide to understanding
diagnosis and treatment:
**PANCREATIC
CANCER**

Pancare Foundation

Pancare Foundation is one of Australia's leading not-for-profit organisations, committed to inspiring hope, raising awareness and funding research for upper gastrointestinal cancers – pancreatic, liver, biliary, oesophageal and stomach cancers.

To meet the needs of people living with pancreatic and upper gastrointestinal cancers, the information in this booklet has been collated from materials from reputable organisations and reviewed by a panel of experts, including:

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You can view the full reference list in the Resources section of this handbook.

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Note to the Reader

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

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

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Supporting you on your cancer journey

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

PanSupport is Pancare Foundation's dedicated support, resource and information service available for all Australians affected by upper gastrointestinal cancers, such as pancreatic, liver, stomach, biliary and oesophageal cancers.

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

Talk to our specialist support team today

To discover more or book a call with our specialist support team, visit pancare.org.au/pansupport



Introduction

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

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

This booklet is a good place to start looking for up-to-date information relevant to your situation. You need not read all the information in this booklet in one go. Please, however, remember that you should always consult your doctor about matters that affect your health. This booklet is not a substitute for professional medical, legal or financial advice. You should obtain appropriate independent professional advice relevant to your specific situation; you may wish to discuss issues raised in this book with them.

Your guide for using this handbook

This handbook contains key details in colour-coded boxes:



Additional details



Helpful tips



Patient stories



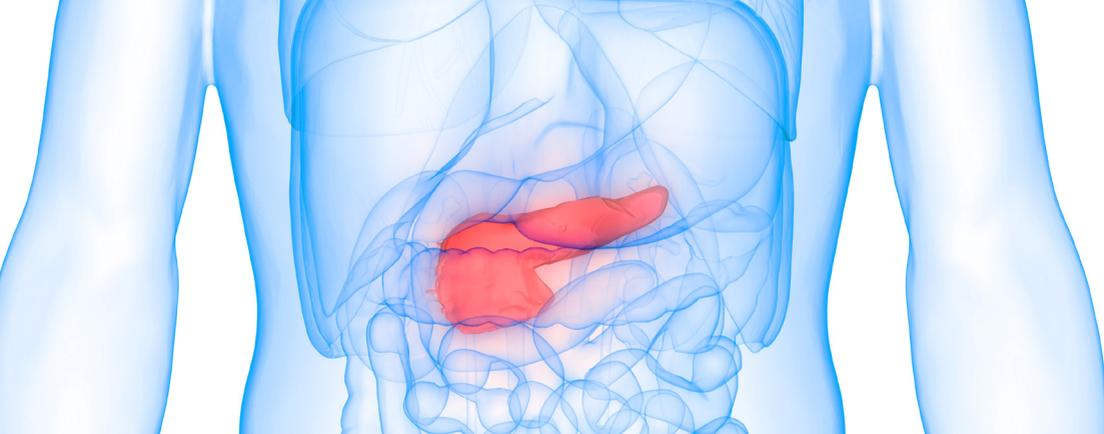
Frequently asked questions

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



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About the pancreas

The pancreas is a large gland that lies behind the stomach in the back of the abdomen. It is about 15 cm (6 inches) long and shaped a bit like a tadpole. It is often described as having a head, body and tail.

The pancreas serves two main functions in the body:

- It produces enzymes that help you to digest and absorb food. Partially digested pieces of food enter the small bowel where they mix with pancreatic enzymes and bile. The enzymes and bile work together to help break down the food further for the body to absorb and use.
- 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.

The pancreas is surrounded by several large and important organs and blood vessels. The pancreatic duct empties into the top part of the small intestine, which is called the duodenum. The common bile duct that carries bile from the liver also passes through the head of the pancreas to empty in the duodenum. The large blood vessels that carry blood to the liver, intestines, kidneys and lower part of the body can all be in contact with the pancreas.

Figure 1: The main organs of the digestive system

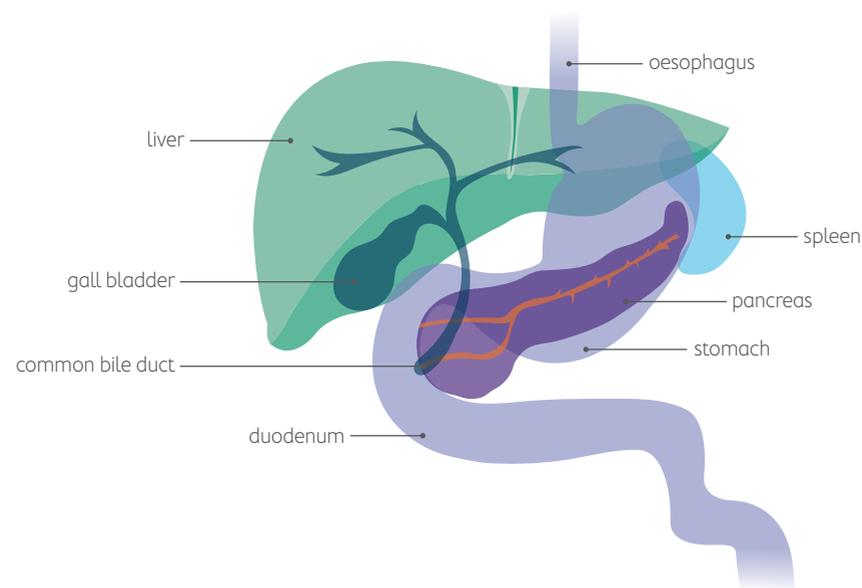
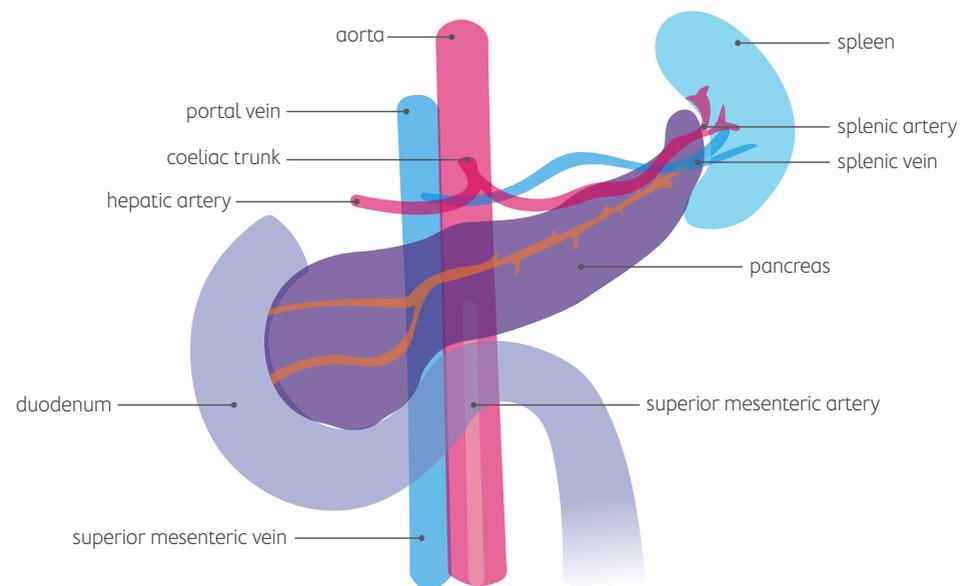


Figure 2: The pancreas





About pancreatic cancer

Pancreatic cancer occurs when abnormal cells in the pancreas grow out of control. It can occur in the head, body or tail of the pancreas.

Pancreatic cancers are divided into two main groups depending on the type of cell that the cancer grows from.

- **Pancreatic ductal adenocarcinomas** start in the cells that make enzymes to help digestion, called the exocrine cells. You may also hear this type referred to by your health professional as an “exocrine” tumour. Approximately 95% of all pancreatic cancers are of this type.
- **Pancreatic neuroendocrine tumours** start in the hormone-producing cells. You may also hear this type referred to as an endocrine tumour. Around 5% of pancreatic cancers are of this type.

The symptoms produced by pancreatic cancer vary according to the location of the tumours and the tumour type. Pancreatic ductal adenocarcinomas generally have worse outcomes than pancreatic neuroendocrine tumours.

Pancreatic cancer is caused by damage to genes, but it is not known exactly why this damage happens. The risk of pancreatic cancer is greater for smokers. It is also more common in people aged over 65 years and relatively uncommon in people under 50 years of age.

In Australia, 3,933 new cases of pancreatic cancer were diagnosed in 2020.



Other known risk factors for developing pancreatic cancer include:

- overweight and obesity
- sex of the person – men are more likely than women to develop pancreatic cancer
- family history – some genetic (inherited) syndromes are associated with increased risk; in other cases, the genetic change that causes the cancer to run in families is not known
- diabetes (especially type 2 diabetes) – Interestingly, pancreatic cancer can produce factors that can lead to high blood sugar levels.

Towards a pancreatic cancer diagnosis

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



Some symptoms, for example jaundice (yellowing of the skin and eyes), persistent abdominal pain or unexplained weight loss, would have required prompt and more targeted investigation by your doctor. New onset diabetes in a person without any risk factors – particularly when associated with significant weight loss – can also be a symptom of pancreatic cancer.

Alternatively, you may have been admitted to hospital, perhaps even as an emergency patient, because you were sufficiently unwell and hence, a diagnosis was made there.

Regardless, you have probably already had several different tests to confirm the diagnosis of pancreatic cancer.

Sometimes, people with pancreatic cancer can begin to feel very unwell quite rapidly. If you are waiting for tests and you experience any worsening symptoms you should contact your doctor. Symptoms to watch out for include unexplained weight loss, loss of appetite, nausea and/or vomiting, pale complexion, persistent abdominal pain, smelly and floating stools, dark urine, jaundice or worsening itchy skin.

“ I had not felt right for a few days prior, I couldn't sleep and started to lose my appetite and started to feel some abdominal pain, again I said to myself “it will be ok in a few days”. The abdominal pain worsened and after presenting to my GP, I was admitted to hospital and finally diagnosed with pancreatitis. Two months later, I underwent a series of tests including multiple PET, MRI and CAT scans which showed a lesion on my pancreas and diagnosis of pancreatic cancer. ”



Tests/investigations: what, why and how

The tests you have had leading to a diagnosis of pancreatic cancer will contribute towards the full picture of your condition. There will be other tests and together, these tests will show the type of pancreatic cancer, where in the pancreas it is, whether it has spread to nearby organs or other parts of the body, and what the best treatment will be for you. You may not need all the tests described here or indeed, there may be other tests you undergo that are not described in this booklet. Regardless, your specialist will give you more detailed information about the tests that are most appropriate for you.

Blood tests

Various blood tests are used to check your blood count, liver and kidney function and your general health. Blood tests can also check for tumour markers, which are chemical substances, produced by cancers, that show up in the bloodstream. For example, CA19-9 is a tumour marker linked to pancreatic cancer. Other conditions, however, can also raise the level of these markers, and some people with pancreatic cancer have normal levels, so these markers cannot be used to diagnose pancreatic cancer on their own.

Ultrasound scan of the abdomen

Ultrasound scans use sound waves to make a picture of the inside of the body. A probe is passed over your abdomen and the images are collected on a screen – usually an outline of the liver, pancreas, gall bladder and bile ducts.



Computerised tomography (CT) scan

A CT scan uses X-ray to build up a three-dimensional picture of the pancreas and the other organs around it. It is also usual to scan your chest and pelvic area to check for any signs of cancer outside the pancreas.

Positron emission tomography (PET)-CT scan

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

Magnetic resonance imaging (MRI)

MRI scans use magnets and radio frequency waves to build up detailed cross-sectional images of the pancreas and surrounding areas.

Magnetic resonance cholangio-pancreatography (MRCP)

This is a type of MRI scan is sometimes used to give clearer pictures of the bile and pancreatic ducts and any associated blockages.

Endoscopic ultrasound (EUS)

In this test a thin, flexible tube (endoscope) with an ultrasound probe at the end is passed through your mouth into your stomach.

Endoscopic retrograde cholangio-pancreatography (ERCP)

Like the EUS this test uses an endoscope but it also involves taking X-ray. The endoscope is used to guide a catheter into the bile and/or pancreatic duct(s); this is done to insert a small amount of dye. The X-ray images show blockages or narrowing of the duct(s) that might be caused by the cancer. ERCP may also be used to put a thin plastic or metal tube (stent) into the blocked duct to keep it open.

Laparoscopy

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

Biopsy

In some circumstances a biopsy is performed as part of the investigations. Tissue samples for examination under a microscope can be taken during an EUS, ERCP or laparoscopy, or through your skin with local anaesthetic and guided by CT. A biopsy may not be performed in certain cases when surgical removal is planned upfront. In cases when surgery is not planned at the beginning, you will need to have a biopsy before starting chemotherapy or taking part in a clinical trial, to obtain a definitive cancer diagnosis. **In these circumstances it is important to obtain as much information as possible before embarking on a treatment strategy.**

Even if you have been given an urgent referral for a particular scan or investigation you may have to wait days or weeks for your appointment. You may also have to wait days or weeks for your test results. This can be frustrating and worrying, especially if you are already feeling unwell.



If your symptoms get worse or you start to feel more unwell while you are waiting, it is a good idea to get in touch with your doctor. If that is not possible, you may need to present to the closest emergency department if your symptoms cannot be controlled at home. If you do have to go into hospital for any reason you can ask if any tests you are waiting for can be done while you are there.

This waiting period is common. Any cancer growth (which would be minimal) during this period is unlikely to cause you additional harm if your symptoms are otherwise stable. It is still a good idea to ask how long you may have to wait. If you think you have been waiting too long, contact your doctor.



Stages of cancer

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

Staging refers to the size of a cancer and whether it has spread around the tumour site or to other areas of the body. It is an important part of the assessment and treatment planning. Sometimes, the staging can only be determined after cancer has been surgically removed.

There are different staging systems but the common ones are:

- Numbered cancer stage system
- Tumour-Nodes-Metastases (TNM) system

Numbered cancer stage system

Stage 1	The earliest stage when the cancer is only inside the pancreas.
Stage 2	The earliest stage when the cancer is only inside the the cancer is usually larger and may have started to grow into the duodenum, bile duct or tissues around the pancreas or there may be cancer in the lymph nodes near the pancreas.
Stage 3	The cancer is growing outside the pancreas into nearby major blood vessels or nerves, but has not spread to other parts of the body.
Stage 4	The cancer has spread to other parts of the body such as the lungs or liver (metastatic cancer).

TNM system

T	Is the size of the tumour.
N	Indicates if it has spread to the lymph nodes.
M	Indicates if the cancer has spread to another part of the body (metastatic cancer).



Treatment journey

Cancer Council Victoria has developed detailed cancer care pathway guides for health professionals to provide optimal standard of cancer care. Based on the optimal care pathway, anyone diagnosed with pancreatic cancer should have their case reviewed at a centre where there is a specialist multidisciplinary team of health professionals who are able to assess and treat the disease. Regardless, there should be one key point of contact at every step of your treatment journey.

Hospitals in a region are often part of a network linked to these specialist centres. This ensures that the best treatment and care are available to all patients regardless of where in Australia they live. You may find it is not necessary for you to travel to a city-based specialist centre for all investigations. Many tests and investigations can be done at your local hospital, and standard chemotherapy can often be given there as well.

However, local hospitals may not always be involved in running clinical trials or offer all the treatments available at specialist centres. Therefore, if you are considering taking part in a particular clinical trial, you may need to travel for your treatment. Most clinical trials, however, cover the expense of travel for regional patients to participate. (See '*Clinical Trials*' on page 42).

Who in the multidisciplinary team will treat my cancer?

You should have a main doctor who will be coordinating your care. This doctor will consult with different doctors and other health professionals who are specialists in your cancer, known as a multidisciplinary team.

Once all your investigations have been carried out, your specialist team will meet to discuss the results. This multidisciplinary team will include doctors from radiology, pathology, surgery and oncology departments. It may also include specialist nurses and other allied health professionals. Everyone will use their expert knowledge to review your case and agree on the best treatment options for you.



Treatments for pancreatic cancer

Surgery

If you have been told that surgery to remove your cancer may be possible, you may have been diagnosed with a cancer that has not spread to other organs and is not significantly attached to major vessels. Your doctor may call your cancer operable or resectable. If the tumour partly surrounds some major vessels it may be referred to as borderline operable. You may be offered surgery in these cases depending on the vessels involved, but will more likely be offered chemotherapy prior to surgery being considered.

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

“ I suddenly fell ill in late 2019, presenting to hospital with jaundice and very dark urine, after 5 months of odd, vague symptoms and GP visits. On the day I was admitted to hospital, I was diagnosed with pancreatic cancer that was determined to be borderline resectable, with the tumour partly surrounding a major artery near the pancreas.



After three months of neoadjuvant chemo was completed with no change in tumour size, surgery remained an option, but I was uncertain about proceeding with surgery. After obtaining a second opinion, which was similar to the first, I decided to proceed with surgery, successfully completed in June 2020 and followed by nine rounds of chemo. Today I am doing well and eating healthily, despite continuing fatigue.”

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)
- 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 3: Extent of resection in Whipple procedure

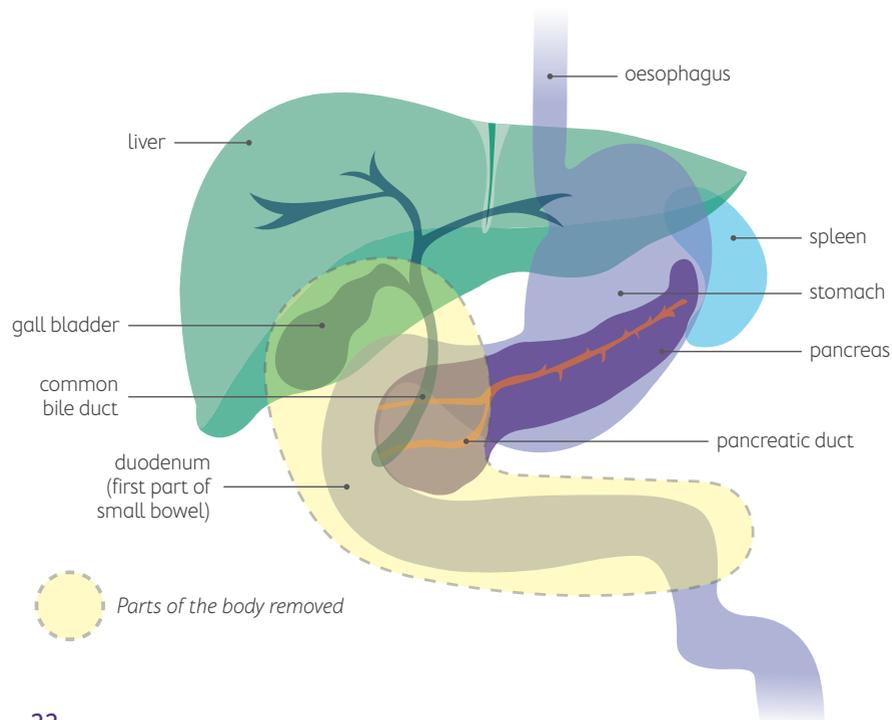
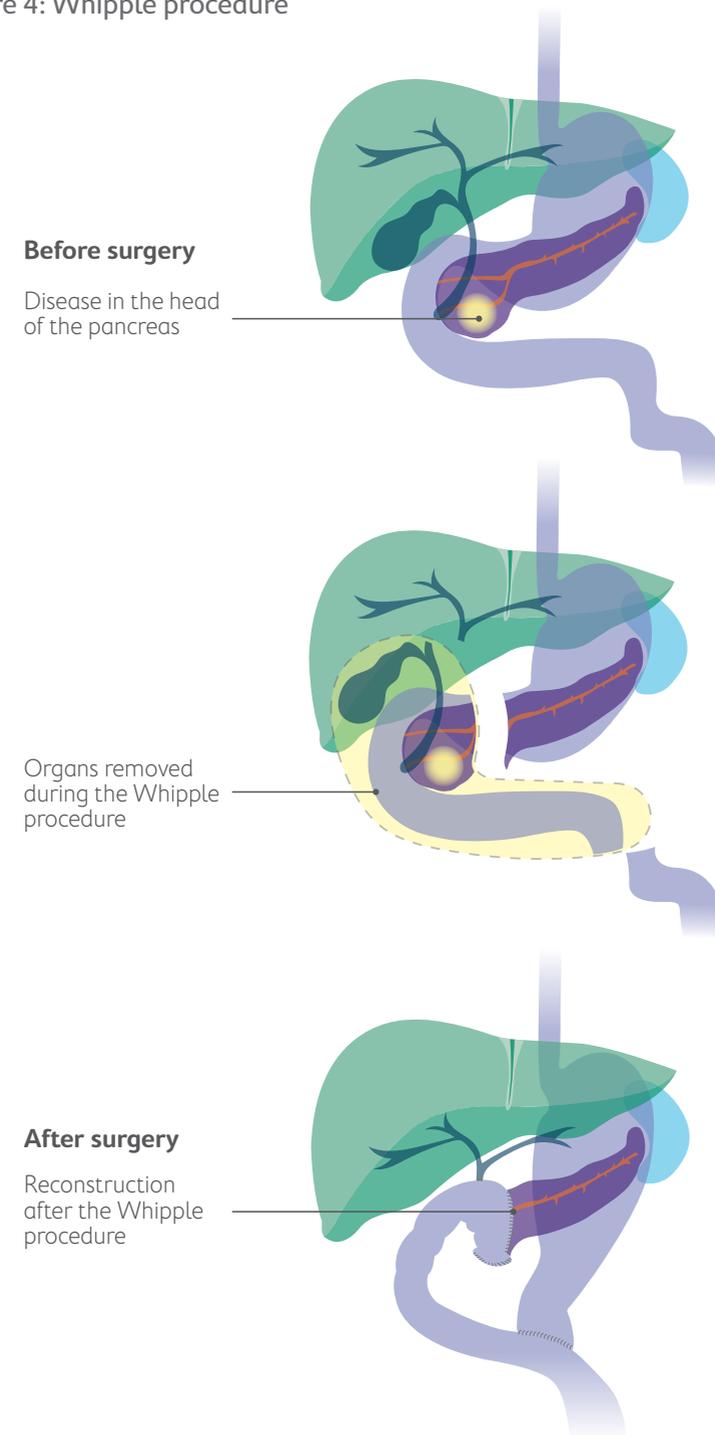


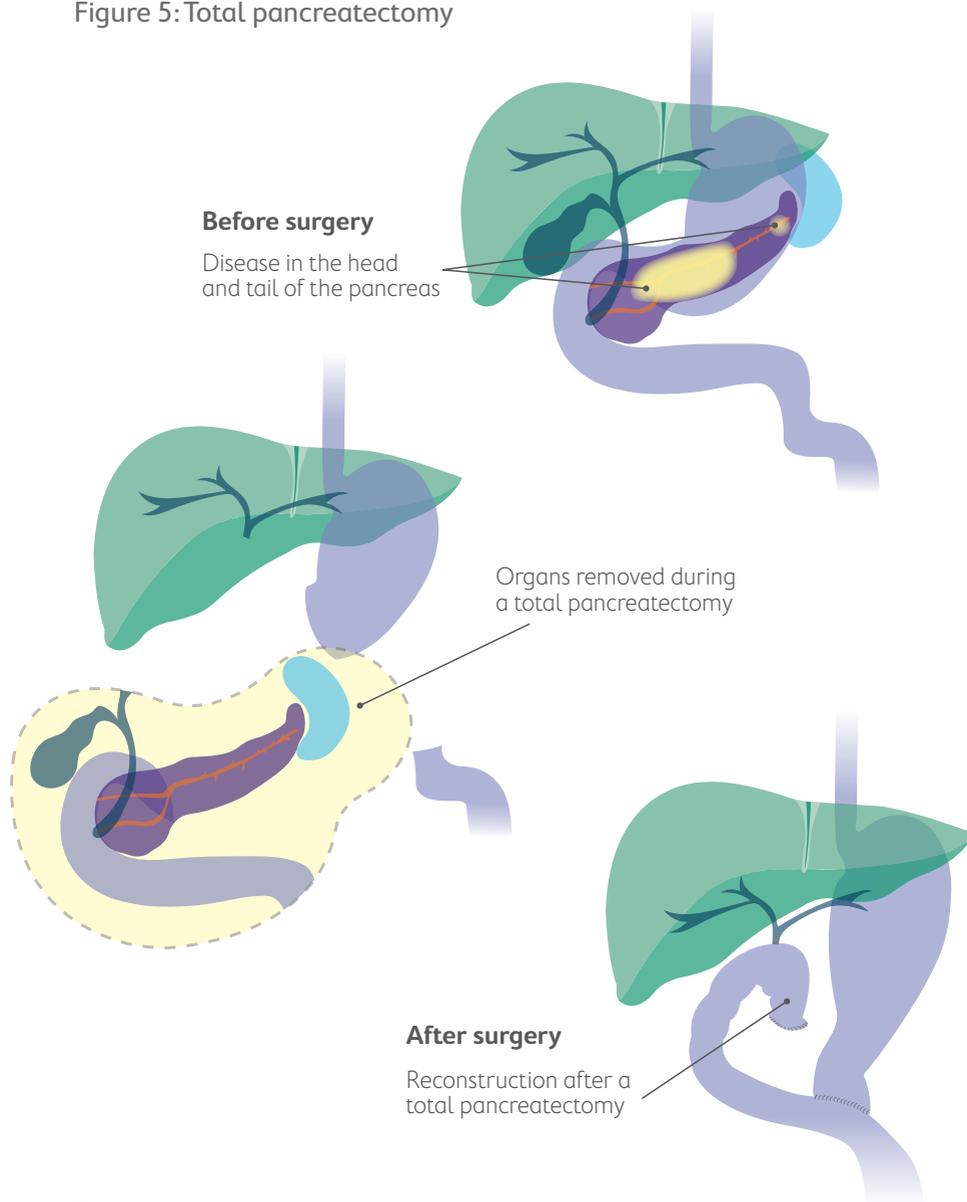
Figure 4: Whipple procedure



Total pancreatectomy

If your doctor recommends a total pancreatectomy, the whole pancreas is removed. The surgeon will also remove the gall bladder, part of the bile duct, parts of the small bowel and stomach, and often the spleen. In such cases patients develop diabetes and require insulin injections.

Figure 5: Total pancreatectomy



Distal pancreatectomy

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

Figure 6: Distal pancreatectomy

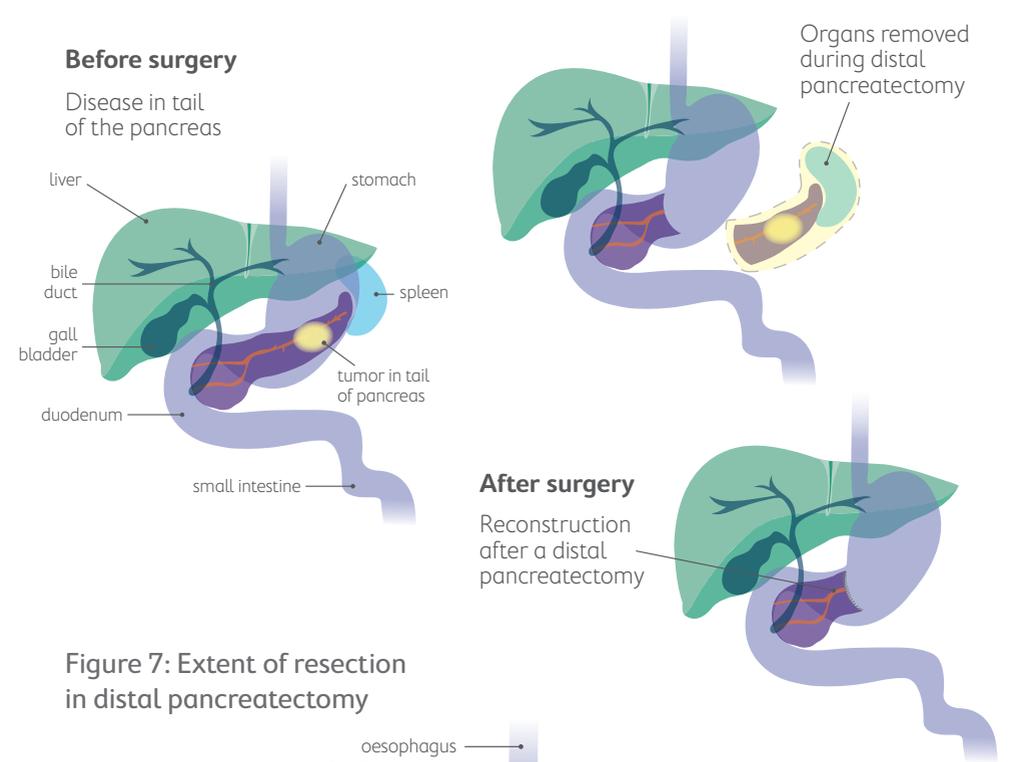
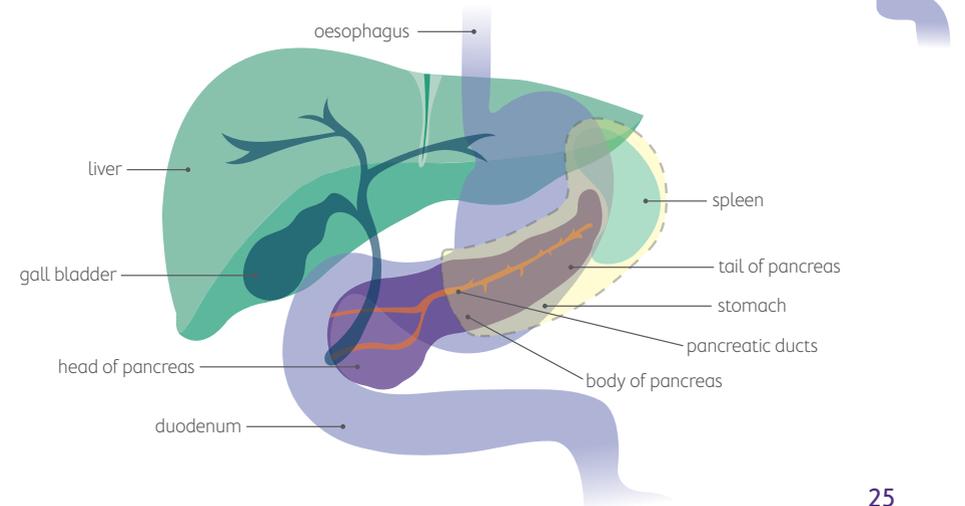


Figure 7: Extent of resection in distal pancreatectomy





Stent insertion and bypass surgery

Some surgical and other interventional procedures are used that do not remove the cancer but instead help relieve symptoms.

The cancer may have grown so that it blocks your duodenum or your bile duct. If your duodenum is blocked food cannot get through to your bowel and builds up in your stomach, causing discomfort, sickness and vomiting. If your bile duct is blocked you may develop jaundice, with symptoms such as yellowing of the skin and eyes and itching.

In these situations, a small, flexible plastic or metal tube called a stent can be inserted to relieve a blockage and keep the duct or bowel open. Stents to unblock the bile duct are most often put in during an ERCP (see *'Tests/investigations'* on page 14).

Alternatively, surgeons can carry out an operation to bypass an actual or anticipated blockage. This is also performed at the time of surgery to remove the cancer when cancer removal has proved not to be possible.

There are generally two components to a bypass operation that relates to pancreatic cancer and are as follows:

- When the stomach is blocked or at danger of blocking, the part of the small bowel just beyond the duodenum is connected directly to your stomach so that food can pass from the stomach into the bowel.
- For a blocked bile duct or a bile duct at danger of blocking, the duct is cut above the blockage and reconnected to the small bowel, allowing the bile to flow again.

Sometimes these two procedures are done at the same time.

Chemotherapy

Chemotherapy is offered to all patients with pancreatic cancer, even when tumour removal is achieved. This reduces the risk of the cancer returning. Chemotherapy is often used on its own to treat pancreatic cancer that has spread and may lengthen survival. You should strongly consider being involved in treatment trials if they are available. Always ask your oncologist if a clinical trial for treatment of pancreatic cancer is available in your region.

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)
 - In these cases, the chemotherapy is given with the hope of shrinking the tumours or controlling the cancer growth for some time, to make surgical treatment more feasible or beneficial.
- After surgery (known as adjuvant chemotherapy)
 - The use of adjuvant chemotherapy has been shown to reduce the risk of cancer recurrence and is routinely offered after surgery.
- Both before and after surgery.

Chemotherapy is usually given intravenously (through a drip into the veins) at 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.

What is a PICC line?

A PICC line (peripherally inserted central catheter line) is used to give someone chemotherapy treatment or other medicines. It is a long, thin, hollow, flexible tube called a catheter. It is put into one of the large veins of the arm, above the bend of the elbow. Then it is threaded into the vein until the tip is in a large vein just above the heart. The line is usually sealed with a special cap or bung. This can be attached to a drip or syringe containing your chemotherapy or medication. There may be a clamp to keep the line closed when it is not being used. Sometimes it divides into 2 or 3 lines. This allows you to have different treatments at the same time.

A specialist nurse or doctor will put in your PICC line at the hospital. It can either be done in an outpatient department or on a ward. They will talk with you about which arm would be better to use. Your doctor or nurse may use an ultrasound scan to help them find the best vein to use in your arm.



Figure 8: Peripherally Inserted Central Catheter (PICC)

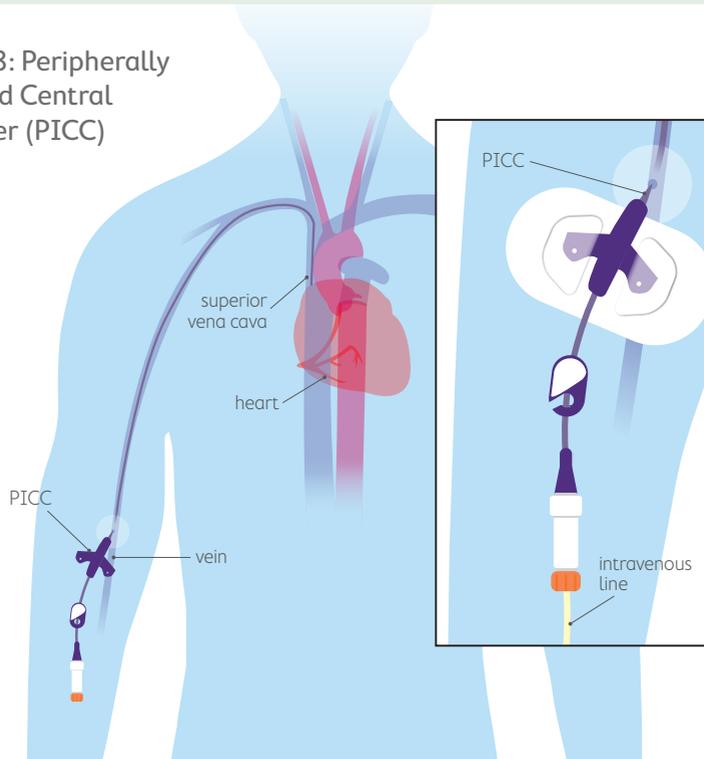
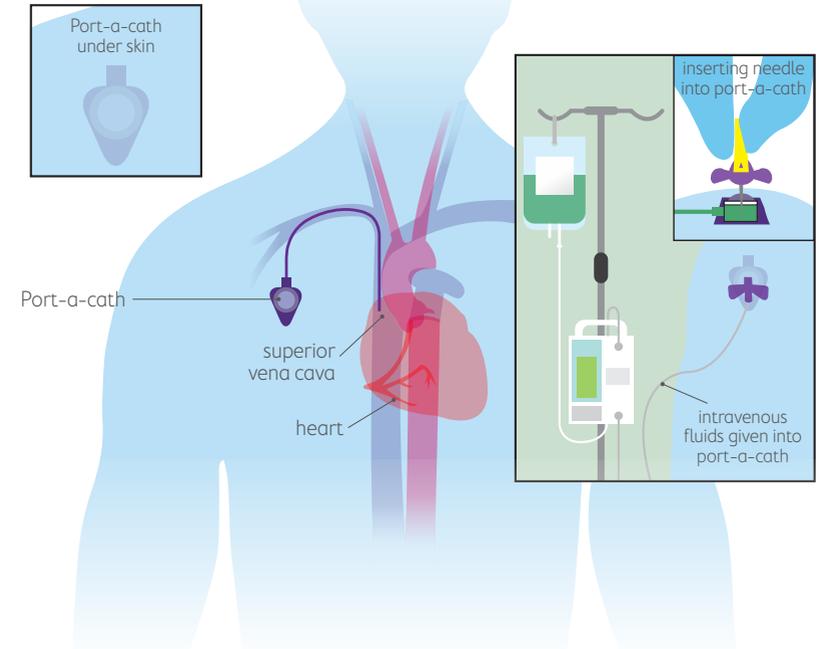


Figure 9: Port-a-cath (Port)



What is a Chemo Port?

A chemo port is a small, implantable reservoir with a thin tube that attaches to a vein. The main advantage of this is that chemotherapy medications can be delivered directly into the port rather than a vein, eliminating the need for needle sticks.

Many people who receive chemotherapy choose to have a port implanted, if recommended by their treatment team.

Usually, a chemo port is centrally placed under the skin near a large vein in the upper chest. This can be a good alternative to an intravenous catheter that is peripherally placed, as it is easily accessible by a patient's treatment team. While a port will produce a visible "bump" under the skin, it can be easily covered with regular clothing.



Radiotherapy

Radiation therapy, which is usually combined with low dose chemotherapy, may be used to reduce the chances of the cancer returning locally. Radiotherapy is rarely required for the treatment of pancreatic cancer. Sometimes radiotherapy is administered in cases of more advanced cases to try and reduce the tumor size, with the hope of allowing subsequent surgical removal. It may also be offered to treat certain symptoms or when there is residual cancer noted after surgical removal of the tumour.

Radiotherapy can also be helpful on some occasions when cancer has spread to other parts of the body (advanced or metastatic cancer).

Radiotherapy uses high-energy X-rays to destroy cancer cells. Because modern radiation techniques target the cancer cells precisely it is called a localised treatment. Normal cells around the cancer cells are also affected, which is why radiotherapy can cause side effects such as tiredness, nausea and diarrhoea.



Managing cancer symptoms and treatment side effects

Pancreatic cancer and the associated treatments change how your pancreas functions. Managing these changes is important for 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.

Common side effects of pancreatic cancer treatment may include:

Surgery	Chemotherapy and biological therapies	Radiation therapy
<ul style="list-style-type: none"> • Fatigue • Pain • Diarrhoea and malabsorption • Weight loss • Loss of appetite • Feeling full quickly 	<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 	<ul style="list-style-type: none"> • Nausea and vomiting • Loss of appetite • Feeling full quickly • Diarrhoea and constipation • Fatigue • Weight loss

You have a range of options that can help you manage any symptoms or side effects you may experience. These may include:

- pancreatic enzyme supplements and nutritional supplements to help with digesting food and weight loss
- anti-sickness medication or complementary therapies to help with nausea
- morphine-based painkillers
- nerve block (often done by endoscopy) to destroy the nerves which convey pain from the pancreas
- complementary therapies such as aromatherapy, reflexology, relaxation therapy.
- coping strategies as discussed with a psychologist or social worker.

If you are in hospital your care needs should be assessed before you leave. This may sometimes include a referral to the community-based health care team, who have expertise managing pain and other cancer symptoms.

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

If you have surgery to remove all or part of the pancreas the body's ability to digest and absorb nutrients from food is likely to be affected. This can lead to dietary-related symptoms such as steatorrhoea (the presence of excess fat in the stools) and being unable to maintain weight. You may also develop diabetes due to surgery (definitely if the whole pancreas is removed). You will be put in touch with a diabetic educator who can help you with an insulin regimen; s/he will be a point of contact once you are home.

Nutritional support

Pancreatic cancer and its treatment can place extra demands on the body, greatly increasing nutrient and caloric needs. Weight loss can contribute to fatigue, delay and lengthen recovery, and adversely affect quality of life.

Questions about diet may arise along with physical activity, dietary supplement use, and nutritional complementary therapies. Patients may receive dietary advice from a variety of sources including family, friends, and health care providers, as well as from the media, health food stores, magazines, books, nutritional supplement industry, etc. There are many claims about the use of dietary and nutritional supplements as alternatives to standard therapy. Making an informed choice can be difficult. You should always inform your doctor if you intend to use any supplements, as they may produce certain side-effects when combined with chemotherapy.

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



Malabsorption and pancreatic enzyme replacement

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).

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



On average, patients with pancreatic cancer need a minimum of between 25,000 to 50,000 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 often adjusted according to the type and amount of food being consumed and the presence of continued symptoms.

Creon (the brand name of a pancreatic enzyme supplement) may be prescribed if your body is not producing any or enough pancreatic enzymes, or if you are displaying symptoms of malabsorption. More information about Creon can be found in the Pancare Foundation’s ‘Diet & nutrition for people living with pancreatic cancer’ guide.





Tips to help you maintain your weight and muscle mass

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



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

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

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



Physical wellbeing

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

Feeling sick (nauseous) is another common symptom, but you can be prescribed anti- sickness medication or try remedies such as ginger, peppermint or acupressure bracelets.

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

Physical activity can also make you feel better, though how much activity will depend on how well you feel and whether you are having treatment or recovering from it. Even a walk round the block or 10 minutes of stretching each day can help.

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



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



Learn more about cancer counselling support at www.pancare.org.au/living-well/telehealth-support

Emotional wellbeing

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

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

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

You may want to try complementary therapies like reflexology or aromatherapy massage. Ask your doctor or specialist nurse about services available in your area.

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

If you feel the cancer is taking over your life, one way to cope is to focus on other things and make plans. For example, this might mean living life as normally as possible or changing your priorities.

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

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



Your diagnosis will affect your ability to work, even if it is only temporarily such as when having treatment. Talk to your employer, human resources department or union rep about sick leave, reducing your hours or working from home. Being unable to work can lead to financial problems, so seek advice about any financial help or benefits you may be entitled to.

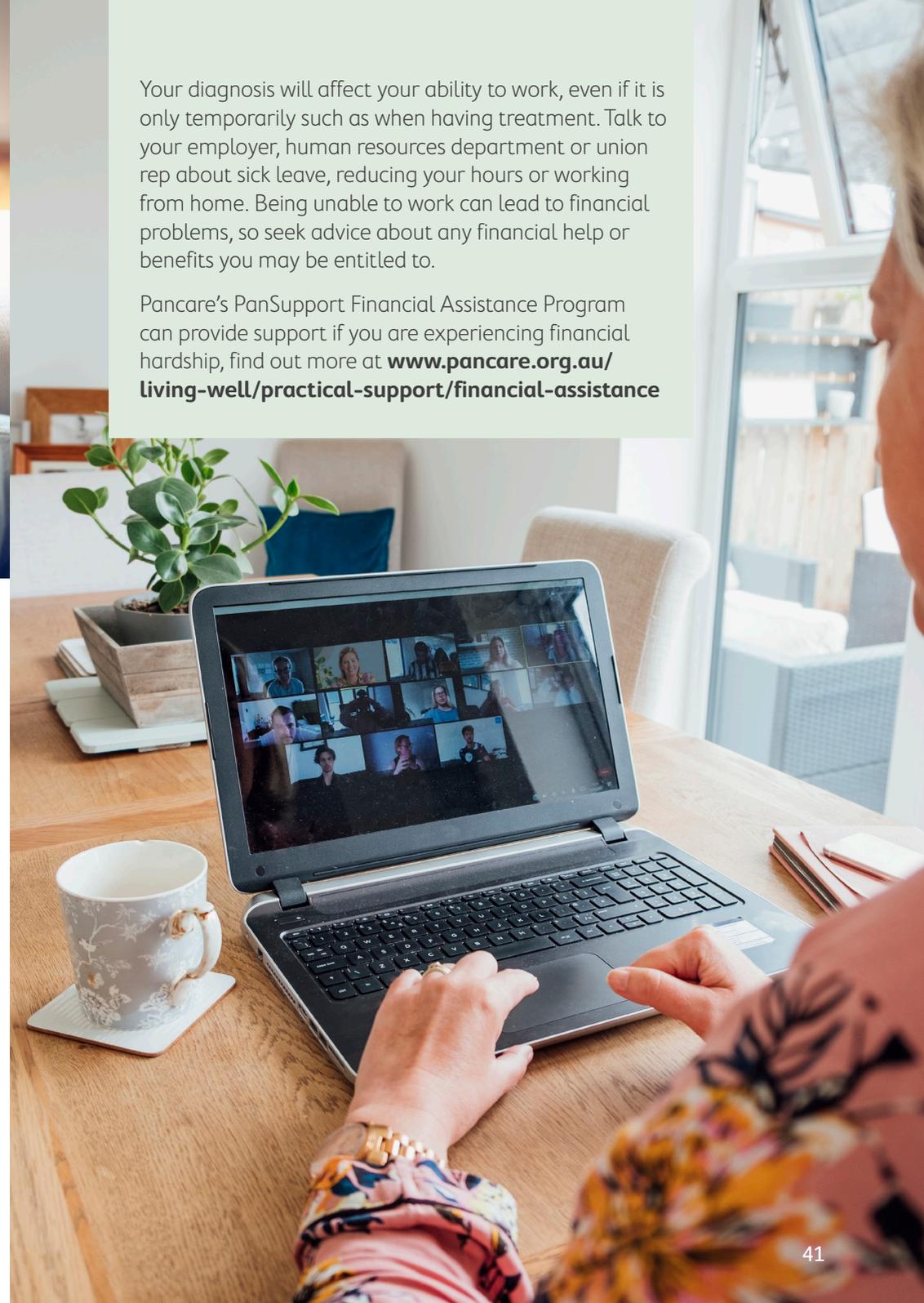
Pancare's PanSupport Financial Assistance Program can provide support if you are experiencing financial hardship, find out more at www.pancare.org.au/living-well/practical-support/financial-assistance

Practical support

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

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

You can find support from others going through similar experiences. You may want to join a local cancer support group which can provide a safe place for you to share your feelings and experiences and connect with others. Learn more about PanSupport patient and carer support groups and other online support groups at www.pancare.org.au/living-well/support-groups



Clinical trials

Most clinical trials for pancreatic cancer are looking at different treatment options with the aim of finding more effective treatments to improve survival and quality of life. Most chemotherapy trials compare a new treatment regimen with current best treatments.

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

Before you decide whether to take part in a trial you need to know exactly what is involved. Talk to your specialist and ask as many questions as you need. If you decide to take part, you will have to sign a form saying you understand and agree to what is involved (this is called informed consent). You can withdraw from the trial at any time if you change your mind without it affecting your care.

Being involved in a clinical trial has the benefits of allowing you access to the latest treatments before they become generally available. This is often combined with closer monitoring of your care and condition.

Several current clinical trials are looking at the influence of a range of genetic changes (mutations) on the development of pancreatic cancer. Results from trials of other types of cancer (e.g. breast, lung, blood) have shown that targeting these genetic changes with new types of medicines may significantly improve outcomes. Whether pancreatic cancer will follow these other cancers in the area of genetic testing and targeted treatment is yet to be fully uncovered but is the focus of numerous research studies and clinical trials.

Immunotherapy

The use of immunotherapy for the treatment of pancreatic cancer is not currently recommended for routine treatment.

Newer combinations of drugs with immunotherapy are being investigated in clinical trials. Speak with your specialist to find out whether there are suitable immunotherapy trials for you.



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

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

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

For more information about current Australian cancer clinical trials visit the Australian Cancer Clinical trials website, www.australiancancertrials.gov.au or the Australasian Gastro-Intestinal Clinical Trials Group (AGITG) website www.gicancer.org.au/community-clinical-trials





Genetic testing

Genetic testing and genomic-guided therapy for pancreatic cancer are emerging areas of study and are generally performed as part of research studies.

Genetic Testing for patients diagnosed with Pancreatic cancer

Pancreatic cancer is a genetic disease, meaning it is caused by changes in our DNA. Most cases occur by chance and are related to changes occurring to the DNA over a lifetime. However, 5% to 10% of cases are considered to be familial, indicating genetic faults may have been inherited.

Some families have multiple relatives affected by pancreatic cancer, often over a few generations. Individuals with two or more close relatives with pancreatic cancer may be at a higher risk of developing pancreatic cancer and, in turn, hold the key to valuable genetic information about the disease which one day could lead to a cure. A referral to a Familial Cancer Clinic should be considered for individuals newly diagnosed with pancreatic cancer, when there is a family history of multiple close relatives with pancreatic cancer, young age of diagnosis (<50 years), a personal and/or family history of melanoma, breast, ovarian or colorectal cancer or a family history of chronic pancreatitis.

Speak to your specialist about the options that are available and whether genetic testing is suitable for you. Your specialist may also recommend genetic counselling related to this testing.

Pancreatic cancer screening for people at high risk of pancreatic cancer

Pancare Foundation supports the National Familial Screening Program for Pancreatic Cancer, a research program that is looking at how regular screening for people at high risk of developing pancreatic cancer can drive early detection of cancer or identify changes in the pancreas that may progress to cancer.

The screening program aims to identify and screen high-risk people before they develop any symptoms. Specialists in the program use diagnostic tests such as endoscopic ultrasound and blood tests to detect any small changes in the pancreas. Research suggests that early detection and treatment of pancreatic cancer is likely to greatly improve outcomes.

Individuals most likely to benefit from pancreatic cancer screening in the setting of research studies include:

- people with at least two close relatives known to have pancreatic cancer
- people with Peutz-Jeghers Syndrome, a condition involving the development of multiple gastrointestinal polyps
- people who carry a BRCA2 gene fault and have a family history of pancreatic cancer
- people who carry a PALB2 gene mutation with a close relative known to have pancreatic cancer
- people who have a p16 gene mutation in families with familial atypical multiple mole melanoma syndrome (FAMMM) with a close relative known to have pancreatic cancer
- people with Lynch Syndrome (mismatch repair gene mutation carrier) and a close relative known to have pancreatic cancer
- people with confirmed hereditary pancreatitis.

Genetic testing of tumours and targeted therapies

Patients diagnosed with pancreatic cancer usually required a tissue diagnosis prior to chemotherapy treatment. Most pathology centres will perform a limited number of tests on tumour samples, which may alter treatment regimens.

It is estimated that a small percentage of pancreatic cancers involve targetable molecular or genetic changes, and there is growing evidence that targeting these genetic changes in pancreatic cancer with precision may improve survival over standard therapy. More effective targeted therapies in pancreatic cancer are, however, required. Pancare Foundation is highly invested in the discovery of novel therapies that can be used to target specific genetic and molecular changes.

Genetic testing of pancreatic cancer samples is relatively uncommon across Australia. It is most commonly performed as part of research studies and clinical trials. It may also be performed in centres involved in the PURPLE Translational Registry, which collects data to improve existing detection methods and develop more effective therapies for pancreatic cancer.

Your oncologist may request genetic analysis of your tumour in considering whether a specific clinical trial may be suitable for you. Self-funding genetic testing is becoming a more common option as the cost of genetic testing continues to reduce, knowing that in pancreatic cancer many patients will not have a genetically targetable alteration. People must also consider that the time between sample collection and receiving results from genetic tests can be several months. Awaiting genetic testing before commencing treatment may not be a reasonable option for many patients.

The Pancare Foundation is continuing to develop partnerships and collaborations across Australia that are helping to accelerate the clinical knowledge and development of new and specialised therapies that can make a significant impact for Australians living with pancreatic cancer in the future.

For more information on the National Familial Screening Program for Pancreatic Cancer, the PURPLE Translational Registry or Novel Therapies programs please contact info@pancare.org.au.



Glossary

Adjuvant treatment is additional treatment, such as chemotherapy or radiotherapy given after surgery.

Advanced cancer is when cancer cells spread from where they first grew to other parts of the body; also known as metastasis or secondary cancer.

Allied health professionals are trained professionals who work with others in the multidisciplinary team to support cancer patients.

Ampulla of Vater is the area where the pancreatic duct and common bile duct meet. Also known as the hepatopancreatic ampulla.

Bile is the fluid which aids digestion that is produced by the liver and stored in the gall bladder.

Biopsy is when tissue is removed to be examined under a microscope.

Chemo-radiation is radiotherapy combined with a short course of chemotherapy. The chemotherapy makes the cancer cells more susceptible to radiotherapy.

Chemotherapy is treatment that uses toxic drugs to destroy cancer cells.

Common bile duct is the tube that carries bile from the liver to the duodenum.

Creon® is a type of pancreatic enzyme supplement.

Dietitian is someone who specialises in promoting health through food and nutrition.

Duodenum is the first part of the small intestine where most digestion takes place.

Endocrine tumour starts in the hormone producing cells (also called **neuroendocrine tumours**)

Exercise physiologist is someone who specialises in clinical exercise interventions for people with health issues.

Exocrine tumour starts in the exocrine cells that make enzymes to help digestion (also called **pancreatic ductal adenocarcinomas**)

Gastroenterologist is a specialist in diseases and disorders of the digestive system, including the stomach, intestines, liver and pancreas.

Hepatobiliary means having to do with following organs: liver, gall bladder, pancreas and the bile ducts.

Immunotherapy are treatments that use the immune system to find and attack cancer cells (the immune system protects the body against illness and infection).

Jaundice is yellowing of the skin/whites of the eyes and itchiness often caused by the bile duct being blocked.

Locally advanced cancer is when cancer cells have spread from where they first grew in the pancreas to structures around it such as blood vessels.

Lymph nodes are tiny oval structures throughout the body that contain lymph fluid; part of the immune system.

Metastatic cancer see *Advanced cancer*

Multidisciplinary team are a team of health professionals who contribute differing skills to the planning of your treatment and provision of ongoing care; this ensures that all relevant aspects of your needs will be considered.

Neoadjuvant treatment is a treatment, such as chemotherapy or radiotherapy given before surgery.

Nutritional supplements are specially formulated drinks, powders and foods to increase calorie intake and help weight gain.

Oncologist are specialists in treating cancer; the main types of oncologists are:

- Surgical oncologists, who specialise in operating on tumours
- Medical oncologists who specialise in chemotherapy and biological therapies (i.e. immunotherapies)
- Radiation oncologists, who specialise in radiation therapy

Oncology nurses are nurses who work with you to identify and assess your supportive care needs, monitor your condition, administer medication, and develop care plans; they also act as patient educators and collaborate closely with other members of the team to ensure the highest quality of care to patients.

Palliative treatment is a treatment that controls symptoms and slows down the progress of the illness when a cure is no longer possible.

Pancreatic duct is the small tube that carries pancreatic juice containing digestive enzymes from the pancreas to the duodenum.

Pancreatic enzymes include lipase, amylase and protease. These help to break down the fats, carbohydrates and proteins found in our food (respectively).

Pancreatic enzyme supplements help to digest food when the pancreas is not producing enough digestive enzymes.

Pancreatic resection is surgical removal of a portion of the pancreas that is usually undertaken to completely remove a tumour.

Pathology is an examination of tissue and cells under a microscope; a pathologist is a doctor specialising in pathology.

Radiologist is a specialist in using X-ray to diagnose and treat disease.



Radiotherapy is a treatment using high-energy X-ray to destroy cancer cells.

Small intestine is part of the gastrointestinal tract, where food is mostly digested and absorbed.

Steatorrhea is undigested fat in stools (poo); stools are large, pale, oily, floating and foul smelling.

Supportive care is improving comfort and quality of life by preventing, controlling or relieving disease complications and side effects; includes psychological, social and spiritual needs.

Upper gastrointestinal is the upper part of the digestive system, including the oesophagus (the tube between the throat and stomach) stomach, liver, pancreas, gall bladder and bile ducts.

Further information and support

There are a range of international organisations that Pancare is collaborating with through our membership in the World Pancreatic Cancer Coalition. Due to differences in best practice care around the world, we have focused on resources and information available in Australia.



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

Pancare Foundation:
Pancreatic cancer.

www.pancare.org.au/cancer/pancreatic-cancer

To maximise your nutritional needs and learn more about pancreatic enzyme supplements, we have developed a booklet specially to focus on the topic of diet and nutrition.

Pancare Foundation:
Diet & nutrition for people living with pancreatic cancer.

<https://pancare-production.s3.ap-southeast-2.amazonaws.com/wp-content/uploads/2021/01/Pancare-Foundation-Pancreatic-Cancer-Dietary-Handbook-JAN2021-FINAL.pdf>

In conjunction with the Cancer Council, the “Optimal care pathway for people with pancreatic cancer” was developed to improve patient outcomes by facilitating a standardised pathway of cancer care that is consistent, safe, high-quality and evidence-based for people with cancer.

Cancer Council:
Optimal care pathway for people with pancreatic cancer.

www.cancer.org.au/assets/pdf/pancreatic-cancer-optimal-cancer-care-pathway

The Cancer Council provides support to people living with cancer and their carers. Pancare has supported the development of this service.

Cancer Council:
Support and supportive care.

www.cancer.org.au/cancercareguides/support-and-care

A woman wearing a dark blue headscarf with a pink and white floral pattern is shown in profile, looking towards the right. She is holding a white ceramic mug with both hands. She is wearing a light grey long-sleeved sweater with a perforated pattern on the shoulders. The background is a soft-focus landscape with a warm sunset or sunrise sky. On the right side of the image, there is a large, semi-transparent purple graphic element consisting of overlapping circles and shapes. Inside this graphic, the text "Making a difference to the lives of people with upper gastrointestinal cancers." is written in a white, sans-serif font.

Making a
difference to the
lives of people
with upper
gastrointestinal
cancers.



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