

Pancreatic Cancer
Patient
Guide



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Your guide to pancreatic cancer

Finding out that you have pancreatic cancer is a life-changing experience. You're most likely feeling scared and confused. Not to mention the questions you have for which you don't have any answers. Don't worry, we're here to help!

We've created this guide to provide you with a general overview of pancreatic cancer. Some of the topics include diagnosis, treatment options and diet and nutrition. We want to remove some of the uncertainty you're feeling and help you to understand the path ahead.

Our guide is a tool to help you understand your diagnosis and how it may impact you and your family. We've kept the content as simple as possible as we know medical speak can be hard to understand.

This guide is not a replacement for medical advice. Please discuss any matters affecting your health immediately with your healthcare professionals.



About the Jreissati Family Pancreatic Centre at Epworth

Pancreatic cancer is the eighth most diagnosed cancer in Australia. In 2020, it was estimated that 3,933 people would receive a pancreatic cancer diagnosis. This would account for 2.7% of all cancer diagnoses in the country.¹

The Jreissati family knows the fear and uncertainty that follows a pancreatic cancer diagnosis. Knowing the impact the disease has had on their family, the Jreissati's want to change the patient and family experience for others. This has led to the establishment of the Jreissati Family Pancreatic Centre at Epworth. This ground-breaking project puts 100% of the funding it receives straight into research and clinical care.

What sets the Jreissati Family Pancreatic Centre at Epworth apart from other organisations in Australia is its structure. Our centre comprises of 3 distinct parts:

- > Clinical care
- > Patient experience
- > Research.



Clinical care is essential when trying to achieve better patient outcomes. We're a specialist centre offering centralised care for pancreatic disease. This means you can access all the different healthcare professionals needed for your care within our centre and hospital network. Overseas studies support the theory that centralised care improves patient outcomes.² Having patients come through one main centre increases case volume, which in turn increases clinical expertise. This expertise leads to breakthroughs that will improve patient procedures and treatment in the future.



The **patient experience** is another important feature of our centre. A pancreatic cancer diagnosis is an emotional time, and it raises a lot of questions. Knowing who you can turn to for support is important. Once referred to the centre, you will meet our pancreatic nurse coordinator. They'll be your first point of contact relating to your care at Epworth and will be able to answer any questions that you or your family may have.



Research forms the final part of the structure of our centre. There's been little improvement in patient outcomes because pancreatic cancer hasn't received the same level of research funding as many other cancers. To change the future of pancreatic cancer, our centre will be running many research studies and clinical trials for pancreatic disease.

One of the centre's primary missions is to find a way to diagnose patients in the early stages of pancreatic cancer. Early diagnosis will increase the number of patients with operable tumours. This will help achieve the centre's ultimate goal—to achieve better outcomes for patients diagnosed with this disease.



What is the pancreas?

The pancreas is a large, tongue-shaped gland that measures approximately 15 cm long. It sits deep inside your abdomen between your stomach, liver and spleen.

The pancreas comprises of 3 different sections:

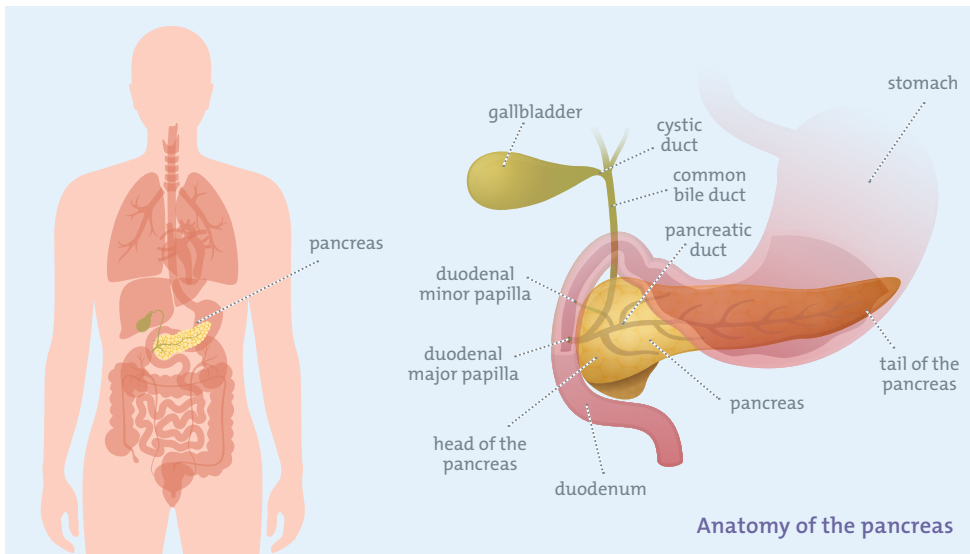
- ▶ head – the wide end on the right side of your body
- ▶ body – the middle section of the pancreas
- ▶ tail – the thin end on the left side of your body.

The pancreas has two important functions:

Exocrine function – most of the cells in the pancreas are exocrine cells. Exocrine cells produce enzymes released through a duct to help your body break down foods and absorb nutrients.

Endocrine function – the remaining cells in the pancreas are endocrine cells. Endocrine cells produce hormones, such as insulin, to help control blood sugar levels.

You are likely to notice issues with both of these functions if you have pancreatic disease.



Anatomy of the pancreas

What is pancreatic cancer?

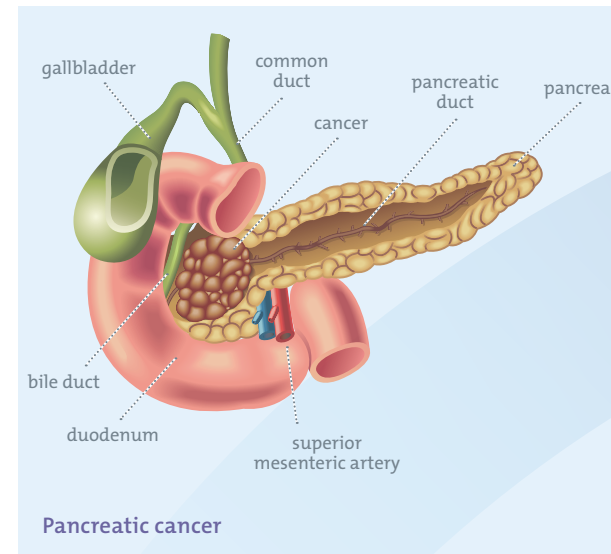
Cancer is a disease that starts in the cells of our body. When cells are working normally, they'll divide and multiply. When cells become damaged or are at the end of their life, they die, and new cells replace them. When cells don't die, they start to grow out of control, and a lump may form. This lump is more commonly known as a tumour.³

Pancreatic cancer occurs when abnormal cells grow out of control in the pancreas and form a tumour. Although pancreatic cancer can happen anywhere in the pancreas, approximately 70% of cases occur in the head of the pancreas.⁴

The two main types of tumours that develop in the pancreas are exocrine and endocrine tumours:

Exocrine pancreatic cancer – Exocrine tumours are the most common, accounting for 95% of pancreatic cancer cases. About 85% of these are pancreatic ductal adenocarcinomas (PDAC) which start in the lining of the pancreas ducts.⁵

Endocrine pancreatic cancer – Endocrine tumours are also known as pancreatic neuroendocrine tumours (NETs) or islet cell tumours. They start in the hormone-producing cells of the pancreas and account for approximately 5% of pancreatic tumours.⁶



Pancreatic cancer

How is pancreatic cancer diagnosed?

Symptoms associated with pancreatic cancer are also common symptoms of other less serious stomach issues, such as reflux and irritable bowel syndrome. This is one of the main reasons why the disease is difficult to diagnose early.

Your general practitioner (GP) will see hundreds of patients each year with stomach issues. Of those patients, they're only likely to diagnose 2-3 cases with pancreatic cancer. For this reason, your GP is unlikely to diagnose pancreatic cancer based on symptoms alone. GPs will use a combination of methods to determine if a patient has pancreatic cancer. These include:

- > risk factors
- > symptoms
- > imaging
- > endoscopy
- > laparoscopy.



What are the symptoms?

Symptoms may not appear until the disease is in the advanced stages. This is another reason why pancreatic cancer is hard to diagnose early. Symptoms that patients may experience include:

- > pain in the upper abdomen or back
- > jaundice
- > weight loss
- > appetite loss
- > nausea with or without vomiting
- > diarrhoea
- > constipation
- > recent type 2 diabetes diagnosis
- > existing diabetes that's getting harder to manage
- > blood clots.

What are the risk factors?

When referring to pancreatic cancer, a risk factor is an element that can increase a person's chance of developing the disease. When studying a patient's symptoms, a doctor will look for certain risk factors before investigating for pancreatic cancer. These risk factors include:

- > obesity
- > smoking
- > age
- > gender
- > diabetes
- > chronic pancreatitis
- > family history of pancreatic cancer.

What tests are available to help determine a diagnosis?

There are different tests available to determine if you have pancreatic cancer. They include imaging, endoscopy and laparoscopy.



Imaging

Medical imaging uses x-rays, magnetic fields, sound waves, or radioactive substances to create pictures of the inside of your body. Imaging is non-invasive (taken from outside of the body), and doctors use it to:

- › check suspicious areas to see if they're cancerous
- › learn how far the cancer may have spread
- › help understand if treatment is working
- › look for signs of cancer coming back after treatment.

Computerised tomography (CT) scan

A CT scan uses a series of X-ray images taken from different angles around your body. It builds a 3-D image of your pancreas and the organs around it. The scan can also identify if the cancer has spread to other organs and determine if surgery is a treatment option.

Positron emission tomography (PET) scan

A PET scan involves a dye injection into your body that contains radioactive tracers. A camera then takes pictures of the areas with radioactivity, as radioactivity can indicate the presence of tumours.

Specific imaging machines can create a PET and CT scan at the same time. A PET-CT scan gives more detailed images of the body than either scan could on its own. It can help determine the cancer stage and see if it has spread beyond the pancreas.

Magnetic Resonance Imaging (MRI) scan

MRI uses a magnetic field and radiofrequency waves to generate high-resolution, cross-sectional images of your pancreas and the organs close to it.

A magnetic resonance cholangio-pancreatography (MRCP), is a different type of MRI used to look at the pancreas, liver, gallbladder and bile ducts.



Endoscopy

A gastroenterologist performs endoscopic procedures using an endoscope. An endoscope is a thin, flexible tube with a tiny camera attached to it.

Endoscopic ultrasound (EUS)

An EUS test involves passing a small ultrasound probe on the tip of an endoscope through your mouth into your stomach. The endoscope allows your gastroenterologist to look inside your digestive tract. They can also take a biopsy sample if needed during this procedure.

Endoscopic retrograde cholangiopancreatography (ERCP)

An ERCP test involves passing an endoscope down your throat, through the oesophagus and stomach, into the first part of the small intestine. X-ray images are then taken of the bile and pancreatic duct to look for any blockages or narrowing of ducts. Blockages can indicate pancreatic cancer.

The procedure also allows for removing cells for biopsy or inserting a stent (a small tube) into the bile or pancreatic duct. A stent will keep the pancreas open if a tumour has created a blockage.



Laparoscopy

A laparoscopy helps to determine the extent of your pancreatic cancer. During a laparoscopy, your surgeon will make small incisions in your abdomen. Several long, thin instruments are then inserted, one of which has a small video camera on the end. The video camera allows your surgeon to look at your pancreas and the organs around it. The other instruments take biopsy samples of tumours and other areas that look abnormal.



The different stages and grades of pancreatic cancer

Staging

Once there is a confirmed diagnosis for pancreatic cancer, the next step is to determine the stage of the cancer. Doctors will run tests to work out the tumour's size and whether it has spread to other parts of the body. Determining the stage of the cancer will help your health professionals work out the best option for treatment.

TNM System

There are different staging systems used to determine the stage (extent) of cancers. The most common is the TNM system developed by the American Joint Committee on Cancer. The TNM system centres around three categories of information: tumour, nodes and metastasis.⁷

T (tumour)	<ul style="list-style-type: none">> provides information on the size and location of the original tumour> determines if the tumour has grown outside the pancreas into nearby blood vessels> a scale of T0-T4 will measure the tumour size<ul style="list-style-type: none">• T0 = no evidence of primary tumour• T1-T4 = size of the tumour (higher number means larger tumour).
N (nodes)	<ul style="list-style-type: none">> determines if the cancer has reached the lymph nodes> a scale of N0-N3 will measure the extent of spread to nodes<ul style="list-style-type: none">• N0 = cancer hasn't spread to lymph nodes• N1-N3 = cancer has spread to lymph nodes (higher number means more nodes).
M (metastasis)	<ul style="list-style-type: none">> determines if the cancer has spread (metastasised) to other parts of the body (lungs, liver, etc.)> a scale of M0-M1 will measure if the cancer has spread to other parts of the body<ul style="list-style-type: none">• M0 = cancer hasn't spread to other parts of the body• M1 = cancer has spread to other parts of the body.

Your treatment team at Epworth

The four stages of cancer

There is also a four-stage classification system for cancer. Like the TNM system, the four different stages are used to determine the cancer's size and spread in your body.

Pancreatic cancer stages range from numbers 1-4.

Stage 1	The cancer is small and is only located in the pancreas and hasn't spread to lymph nodes or other parts of the body.
Stage 2	The cancer has started to grow outside the pancreas into surrounding tissue and/or lymph nodes. It hasn't spread to nearby organs.
Stage 3	The cancer has spread into tissue, major blood vessels or nerves surrounding the pancreas. Cancer may be in the lymph nodes, but it hasn't spread to other parts of the body.
Stage 4	The cancer has spread to other organs, such as the liver, lung or bone.

Grading

The cancer's grading describes how the cancer tissue sample looks when examined in a laboratory under a microscope.

Grade 1	The cancer tissue looks most like normal pancreas tissue.
Grade 2	The cancer tissue is somewhere between normal and very abnormal pancreas tissue.
Grade 3	The cancer tissue is very abnormal pancreas tissue.

The grading of the cancer tissue gives your doctors an idea of how fast the cancer may grow. The higher the number is, the faster the cancer is likely to grow.

The team at the Jreissati Family Pancreatic Centre at Epworth will work in partnership with you and your family throughout your diagnosis and treatment. As cancer affects people differently, you will receive a personalised care plan suited to your individual diagnosis and needs.

As a specialised treatment centre, our team is here for you at all stages of your journey. This means help is on hand whenever you need it. It also means reduced wait times for diagnosis, treatment and/or surgery to ensure we achieve the best possible patient outcomes.

As part of our commitment to providing patients with centralised care, we have a multidisciplinary team working together on all aspects of your care. Not sure what a multidisciplinary team is? It's a group of specialised health professionals who meet as a group to determine the best treatment and care plan based on your needs.



What health professionals form the multidisciplinary team at the Jreissati Family Pancreatic Centre?

You will come into contact with many different health professionals during your treatment. Members of the multidisciplinary team will include people from the list of health professionals below.

Pancreatic nurse coordinator	Will oversee your pathway across Epworth cancer services. This includes the planning and coordination of your care in collaboration with your treatment team. They will also be available to answer your questions and will be your first point of contact during your care at Epworth.
Pancreatic or hepato-pancreatobiliary surgeon	Specialises in the surgical removal of benign (non-cancerous) and malignant (cancerous) tumours in the pancreas and surrounds.
Gastroenterologist	Specialises in diagnosing and treating diseases affecting the digestive system.
Medical oncologist	Will coordinate and prescribe chemotherapy treatments if they are part of your treatment plan.
Radiation oncologist	Will coordinate and prescribe radiation treatments if they are part of your treatment plan.
Endocrinologist	Will become involved in your treatment and care if your cancer results in hormonal disorders, including diabetes.
Medical imaging specialists	Responsible for carrying out and analysing the different imaging tests needed to diagnose your condition.

Pain team	Will provide options for managing cancer-associated pain. They will advise you on pain relief options to best manage your symptoms during treatment.
Nurses	A variety of nurses will support you and your family throughout your care. They will also administer your medication and provide support and information.
Dietitian	Will help you to maximise your nutrition by offering guidance and support in managing diet-related problems caused by your disease and/or its treatment.
Physiotherapist	Will help you to increase strength, movement and function. Can also create a tailored exercise program and help manage fatigue and pain.
Occupational therapist	Will work with you to develop goals and provide strategies to help adapt your living and working environments to achieve those goals.
Palliative care team	Will help you optimise your quality of life so you can live as comfortably as possible with your illness.
Pastoral care team	Provides spiritual, emotional and social support regardless of your religious or spiritual beliefs.
Social worker	Provides practical support and advocates for the needs of you and your family. Can also connect you with support groups and home care.
Psychologist/counsellor	Will help support you emotionally after your diagnosis and during treatment.
Clinical research coordinator	Will help you enrol in a research study and organise your research assessments, should you choose to take part.

Pancreatic cancer treatment

Treatment plans for pancreatic cancer are unique to each patient. Every diagnosis is different because pancreatic cancer presents differently in each patient. There's no one method to treat the disease. You will receive a treatment plan based on the stage and grade of your condition.

As part of our commitment to providing patient-centred care, our multidisciplinary team will work with you to develop a personalised care plan.

Making treatment decisions

Pancreatic cancer is a complex disease, making treatment a highly specialised field. It's important that you receive treatment from a multidisciplinary team within a centre or hospital network. They'll be using the latest research and technology to ensure you achieve the best possible outcomes.

As a specialised centre, we help a lot of people with pancreatic issues. Evidence suggests that specialised centres achieve better outcomes due to the volume of patients. Evidence also suggests better outcomes for patients when a surgeon is regularly performing pancreatic surgery.⁸



When making decisions about your treatment, make sure you discuss all the options available with your medical team. This allows you to make an informed decision about your treatment pathway. Questions to ask your doctor should include:

- > What is the stage and grade of my cancer?
- > How fast is the cancer growing?
- > How quickly can treatment start?
- > Is surgery an option to remove the cancer?
- > What is the aim of the treatment?
- > Will it cure or control my cancer?
- > Am I healthy enough to undergo the treatment?
- > What are the potential side effects of the recommended treatment?
- > Will the treatment improve my quality of life?



Surgery for early pancreatic cancer

Getting a diagnosis in the early stages—before the disease spreads to other parts of your body—means surgery to remove the cancer may be possible. Your doctor may recommend one of the following procedures listed below.

Whipple procedure

A Whipple procedure (or pancreaticoduodenal resection) is the most common surgery to remove tumours in the head of the pancreas. The procedure involves removing:

- > the head of the pancreas
- > the first part of the small intestine (duodenum)
- > the gall bladder
- > part of the bile duct
- > lymph nodes near the pancreas
- > part of the stomach, if required
- > the second part of the small intestine (jejunum).

After the procedure, your surgeon will reconnect the pancreas, bile duct and stomach to the small intestine. This allows digestion to start working again after surgery.

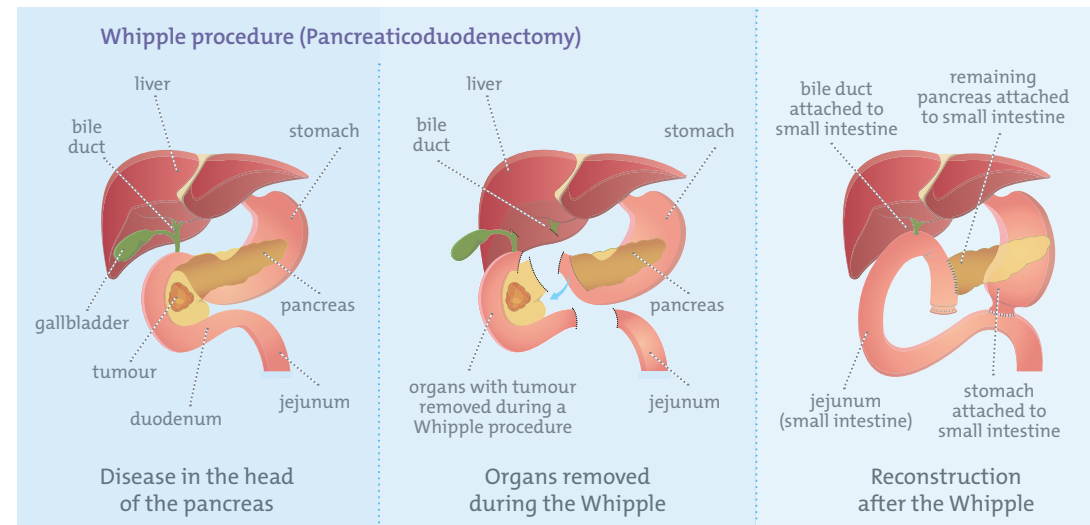
Distal pancreatectomy


A distal pancreatectomy is a procedure to remove tumours in the tail and body of the pancreas. The procedure involves removing the tail, or the tail and part of the body of the pancreas. Your surgeon will generally remove your spleen as well.

Total pancreatectomy

If the tumour is large or multiple tumours exist within your pancreas, your surgeon may recommend a total pancreatectomy. This procedure involves removing your entire pancreas. Your surgeon will also remove your spleen, gallbladder, part of the stomach, small intestine, bile duct and the lymph nodes close to the pancreas.

Living without a pancreas means that your body can no longer produce insulin. Without insulin, your body can't regulate your blood sugar levels. This means you will develop type 1 diabetes. Type 1 diabetes is a condition that will need to be managed for the rest of your life.





Surgery for advanced pancreatic cancer

If the cancer has spread (metastasised), the removal of the tumour may not be possible. In this case, your specialist may suggest surgery to relieve symptoms related to blockages caused by the tumour. This will help to improve your quality of life.

Surgical options for advanced pancreatic cancer include:

Stenting

Cancer in the head of the pancreas may result in a blockage of the bile duct or small intestine. A surgeon can insert a stent—a small metal or plastic tube—to open up the bile duct or bowel to allow food to pass through. This will also relieve pressure caused by a tumour. A stent is usually put in during an ERCP procedure.

Bypass surgery

Another method for relieving a blocked bile duct is bypass surgery. This procedure involves re-directing the flow of bile from the common bile duct directly to the small intestine, bypassing the pancreas. Bypassing the blockage will allow your stomach to empty and stop a future blockage to the first part of the small intestine (duodenum).

Gastroenterostomy

This procedure involves surgically connecting your stomach to the second part of your small intestine (jejunum). This allows food to pass straight from the stomach to the middle section of your small intestine. This procedure bypasses the first section of the small intestine (duodenum) if damage exists.

Venting gastrostomy

This procedure involves connecting the stomach to an artificial opening on the abdomen to insert a thin tube. This tube allows fluids to drain out of your stomach, vent air and give medicines if needed. The procedure also helps relieve nausea and vomiting, which improves quality of life.

Before any surgery, your care team at Epworth will provide you with detailed information about the procedure. This will include information on:

- > preparing for the procedure
- > what the procedure involves
- > what to expect after the operation
- > discharge from hospital and recovery
- > the possible side effects resulting from the operation.



Chemotherapy

Chemotherapy is one of the main treatments used to treat pancreatic cancer. It involves using drugs to kill cancer cells in your body. Chemotherapy can also damage healthy cells which often causes the side effects of chemotherapy. Side effects can be different depending on the type of chemotherapy drugs prescribed.

Depending on your treatment plan, you may receive chemotherapy on its own, or in conjunction with radiotherapy and/or surgery. Your treatment plan will depend on how advanced your cancer is.

Before chemotherapy, your medical oncology team will provide you with detailed information on your chemotherapy drugs and common side effects based on your individual treatment plan. This will include information on:

- > preparing for chemotherapy
- > what to expect after chemotherapy
- > how to best manage side effects.

There are various ways to use chemotherapy in your treatment. Your doctor may recommend chemotherapy to:

- > shrink a tumour before surgery for a better chance of removal (called neo-adjuvant chemotherapy)
- > destroy any remaining cancer cells after surgery to help prevent the cancer from returning (called adjuvant chemotherapy)
- > when surgery is not an option, it can slow down the cancer growth.

Chemotherapy is generally administered through a drip (intravenously) into the veins. Certain chemotherapy medicines also come in tablet form.



Radiation therapy

Radiation therapy (or radiotherapy) uses radiation to safely treat and manage cancer. Radiation therapy treats cancer by damaging cancer cells while limiting the impact to healthy cells.

Some damage may still occur to normal cells immediately around the treatment area. As with chemotherapy, damage to normal cells may cause side effects. These can include skin reactions and tiredness.

Radiation therapy won't cure the cancer. For this reason, it's not as common in the treatment of pancreatic cancer as chemotherapy. However, it can help to control the cancer and slow down its growth.

If radiation therapy is part of your treatment, your medical oncology team will provide you with detailed information, including potential side effects based on your individual treatment plan. This will include information on:

- › preparing for radiation therapy
- › what to expect after radiation therapy
- › how to best manage side effects.

There are various ways to use radiation therapy in your treatment. Your specialist may recommend radiation therapy to:

- › shrink the tumour before surgery to make it easier to remove
- › destroy the remaining cancer cells after surgery to help prevent the cancer from returning
- › help relieve tumour-related symptoms.

There are two different types of radiation therapy (for both procedures you will be awake):

- › **External radiation therapy** – this is the most common procedure. It involves an external beam targeting your pancreas from outside your body. You're not radioactive after this procedure.
- › **Internal radiation therapy** – you will receive an injection of radioactive material near the cancer. You may release small amounts of radiation for a few days after the procedure. Your doctor will tell you what you need to do if this is the case.

Managing your diet and nutrition

Pancreatic cancer can cause diet and nutrition-related problems. Managing your diet and nutrition issues is important because it can improve outcomes and quality of life.

As part of your care plan, you will receive guidance from a qualified dietitian through our centre. Our dietitians have the knowledge and expertise to advise you on what to eat to maximise your nutritional intake.

It's important that you consult with a dietitian, as dietitians can help you to:

- › manage your dietary issues resulting from symptoms of cancer, or it's treatment
- › create an individualised diet plan and provide nutritional counselling and education
- › manage diabetes
- › help you to gain or maintain your weight
- › improve your quality of life
- › assist in answering questions related to nutrition and cancer misinformation.

What does your pancreas do and how can pancreatic cancer affect it?

The pancreas is part of your digestive system. It has two main roles in the body:

- › it produces substances which help us to break down (digest) the food that we eat
- › it produces hormones (chemicals which send messages to other parts of the body) which help us to control our blood sugar levels (such as insulin).

Pancreatic cancer changes how your pancreas functions. These changes can affect your body's ability to digest and absorb nutrients from the food you eat.



Treatments for pancreatic cancer can also cause changes in how your pancreas works. As a result of these changes, you may experience the following symptoms:

- > nausea and vomiting
- > diarrhoea
- > no appetite
- > changes in taste and smell
- > mouth sores
- > changes in bowel habits
- > dry mouth
- > problems chewing and swallowing
- > heartburn or indigestion
- > fatigue
- > feel full quickly after eating (early satiety).

It's important to manage these symptoms so you have the best chance of maintaining your weight. This will assist in your recovery. Losing weight can impact the effectiveness of your treatment and draw out your recovery. You can help maintain your weight by ensuring you get the most nutritional value out of your diet.

Some ways to do that include:

- > eating smaller meals more often during the day
- > eat a variety of foods to get a range of different nutrients
- > choose foods that are high in protein as they can help your body repair and recover
- > sit up when you eat as this helps your digestion
- > avoid laying down straight after a meal as this can affect your digestion and increase the risk of suffering from reflux or nausea
- > try to stay physically active if possible as this will help boost your appetite
- > have meals ready in the freezer for the times you are too tired to cook
- > try new foods — pancreatic cancer and its treatment can change your taste.

How does diabetes affect my diet and nutrition?

Diabetes is a condition where your body can't control the glucose levels in your body correctly.

Your pancreas produces insulin and glucagon to help control the amount of sugar (also known as glucose) in your blood. Glucose is the primary energy source for our bodies. Insulin — a hormone — is released into the bloodstream when we eat, where it helps to move glucose from the food we have eaten into cells to be used as energy. People with diabetes are unable to produce enough insulin. This means that the glucose remains in your blood and causes high blood sugar levels. This can cause serious long and short term health complications if not treated.



Common symptoms of diabetes include:

- > feeling more thirsty than usual
- > blurred vision
- > feeling tired and lethargic
- > leg cramps
- > dizziness
- > sudden loss of weight
- > increased need to urinate.

Diabetes can occur in pancreatic cancer patients due to the disease, or the methods used to treat it — such as surgery. Although pancreatic cancer makes managing diabetes a little harder, it's still achievable. Some patients will be able to manage their diabetes by managing their diet. Others may need to take medication or have insulin injections to manage their condition. Members of your treatment team will provide you with the course of action you need to take.

Oncology rehabilitation



Epworth offers an oncology rehabilitation program. This 8-week program is for patients following their cancer diagnosis or treatment. The program's goal is to provide support for cancer patients and improve their physical and emotional well-being.

The program consists of an exercise program and education workshops. The exercise program can help restore movement, strength and fitness, and the education workshops help patients learn to understand their disease.

Our multidisciplinary clinical team delivers the program. Our team comprises of:

- > a specialist rehabilitation physician
- > an oncology nurse
- > an exercise physiologist
- > a psychologist
- > a dietitian
- > a social worker
- > an occupational therapist
- > a physiotherapist.

Once referred, our team will make a patient assessment. They will work with you to develop a specific program based on your individual needs. At the end of the program, our team can also link you to local support services, so you can continue to receive the support you need.

Palliative care



Palliative care is patient-centred care to improve quality of life. It supports, treats and cares for patients living with a serious illness. Palliative care also provides support to friends and family of the patient.

The symptoms of pancreatic cancer and the side effects can cause pain and suffering for the patient. Palliative care helps to relieve symptoms and side effects to keep the patient as comfortable as possible. Palliative care is holistic care that looks after a patient's emotional, physical and spiritual needs. Patients can receive palliative care at any stage after their diagnosis.

A palliative care team comprises of health professionals from various disciplines. These professionals may include:

- > doctors
- > nurses
- > cancer specialists
- > psychologists
- > spiritual advisers
- > occupational therapists
- > social workers
- > physiotherapists
- > dietitians.

Patients can receive palliative care at:

- > home
- > a hospital
- > a palliative care unit
- > an aged care facility.



Pain management

Pain associated with pancreatic cancer is common. Pain can result from the disease itself, or by treatments used to manage the disease. This makes pain management an essential aspect of pancreatic cancer patient care. Without pain management, your quality of life can worsen.

As soon as you start experiencing pain, you need to speak to your doctor immediately. The earlier you start treatment, the better chance you have of getting your pain under control.

There is a range of options available when deciding on the best way to relieve your pain. After an assessment by a healthcare professional, you will receive a tailored treatment plan to ensure you're as comfortable as possible.

Pain medications

Various medications can help treat your pain and make it manageable. Commonly prescribed pain medications include:

- > **non-opioids** – these are over-the-counter medications such as paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs) like ibuprofen.
- > **opioids** – these are stronger medications that need a script like morphine and oxycodone.

Surgery, radiation therapy and chemotherapy

Your tumour can be the cause of your pain. It may be pushing against your organs, nerves or bones. Surgery is a method used to relieve symptoms related to blockages caused by the tumour. Radiation therapy and chemotherapy are methods used to reduce your tumour's size to stop the source of pain.

Non-drug therapies

Other non-drug approaches to pain management can benefit patients, especially when combined with pain medications or other treatments. These can include:

- > acupuncture
- > massage
- > hypnosis
- > physical and occupational therapy
- > relaxation
- > meditation.

You must consult your doctor before taking any medications or supplements they have not prescribed. You should also consult with them before starting a new exercise, massage or physical therapy program.



Clinical research and trials

A clinical trial or research study aims to answer specific research questions and to find better treatment options. Clinical research can be an observational study that involves collecting data on a disease's history to better understand it. It can also be an interventional trial that aims to determine whether an experimental treatment is safe and effective. The main aim of clinical research is to see if discoveries made during the research phase are better than current treatment options.

Clinical trials need volunteers to test research questions. Testing will determine if the new treatments for pancreatic cancer work and if there are side effects. They're also an effective way for patients to gain access to the latest treatment options. Participation leads to advances in research, better treatments, and better patient outcomes.

One of the most important clinical trials we're participating in is a national screening study. The study is for patients who are at high risk of developing pancreatic cancer. The study aims to detect if someone has pancreatic cancer before developing any signs or symptoms of the disease. It will gather data from over 150 patients who will be actively monitored for more than 5 years. The aim is to build a knowledge base on how pancreatic cancer does/doesn't develop within these patients. By building knowledge around how and when the disease develops, we will be able to diagnose pancreatic cancer earlier.

The details of research projects and clinical trials currently being undertaken through the Jreissati Family Pancreatic Centre at Epworth are available at epworth.org.au/jreissaticentre. When deciding if you want to take part in a clinical trial, you need to be aware of what the trial involves. You should also seek advice from your specialist before taking part.

It is important to note that clinical trials are bound by Australian laws and regulations. All research is reviewed and approved by a Human Research Ethics Committee (HREC) and a Research Governance Office. Testing therapeutics requires the review and approval of the Therapeutics Goods Administration (TGA). These approvals and authorisations ensure that clinical trials are ethically and responsibly run. Participation in clinical research is entirely voluntary and confidential.

Advancements in pancreatic cancer diagnosis and treatment will happen as a result of clinical trials. Pancreatic cancer patients participating in clinical trials can achieve better outcomes. This demonstrates the importance of research in cancer care.



Clinical registries

A clinical registry is a database that collects health information from patients. The data collected comes from patients with the same or similar conditions, such as pancreatic cancer. Registries collect data from patients over a period of time and track their care. The types of information collected can include risk factors, response to treatment and outcomes.

Clinical registries in rare diseases benefit the wider research and healthcare community. Data sharing and collaboration across cancer centres and research laboratories helps to drive research findings from the laboratory into practice to benefit patients.

Clinical registries may also assess the quality of care patients are receiving. As with clinical trials, clinical registries need to pass a review and approval process by an HREC and a Research Governance Office. You do not have to share your data with clinical registries. Any information you share will have any identifying information removed and will remain confidential.

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Note to reader:

All care has been taken to ensure the accuracy of the information within this booklet at the time of its publication. Please remember that information pertaining to cancer is constantly being updated by healthcare professionals and the research community. This guide is intended as a brief introduction to pancreatic cancer. This handbook is not intended as a replacement for medical or professional advice. You must always consult with your healthcare professionals about any medical symptoms, questions or concerns that you may have. The Epworth Medical Foundation and the Jreissati Family Pancreatic Centre at Epworth exclude themselves from all liability for any injury, loss or damage incurred by the use of or reliance on the information provided in this booklet.



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