



# Understanding Pancreatic Cancer

A guide for people with cancer,  
their families and friends

Cancer  
information

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**13 11 20**



## Understanding Pancreatic Cancer

A guide for people with cancer, their families and friends

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*Understanding Pancreatic Cancer* is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.

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### Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

### Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit [cancer.org.au](http://cancer.org.au) or call your local Cancer Council.



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# Introduction

This booklet has been prepared to help you understand more about pancreatic cancer. Many people feel shocked and upset when told they have pancreatic cancer. We hope this booklet will help you understand how pancreatic cancer is diagnosed and treated. We also include information about support services.

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, we hope this information will answer some of your questions and help you think about other questions to ask your treatment team.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary (see pages 71–75). You may also like to pass this booklet to your family and friends for their information.

## How this booklet was developed

This information was developed with help from a range of health professionals and people affected by pancreatic cancer. It is based on clinical practice guidelines for pancreatic cancer.<sup>1-3</sup>

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. Turn to the last page of this book for more details.



**Cancer  
Council  
13 11 20**

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# What is cancer?

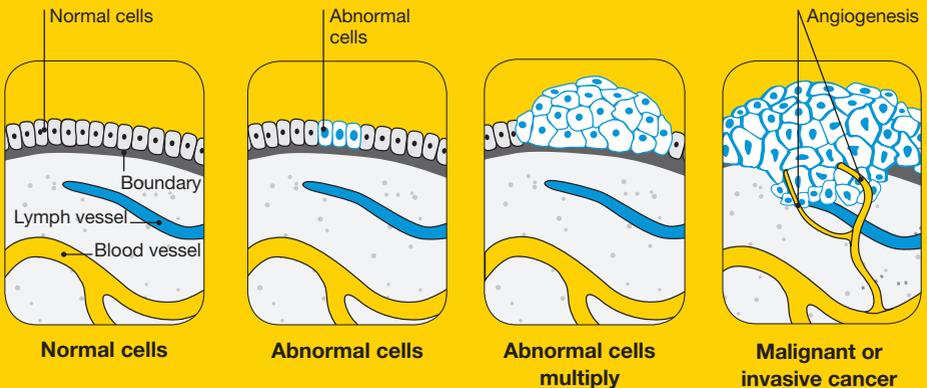
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

Sometimes cells don't grow, divide and die in the usual way. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.

**Benign tumour** – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

**Malignant tumour** – This is made up of cancerous cells, which have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid).

## How cancer starts



The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

A malignant tumour that has not spread to other parts of the body is called localised cancer. A tumour may invade deeper into surrounding tissue and can grow its own blood vessels in a process known as angiogenesis.

If cancerous cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, pancreatic cancer that has spread to the liver is still called metastatic pancreatic cancer, even though the person may be experiencing symptoms caused by problems in the liver.

## How cancer spreads

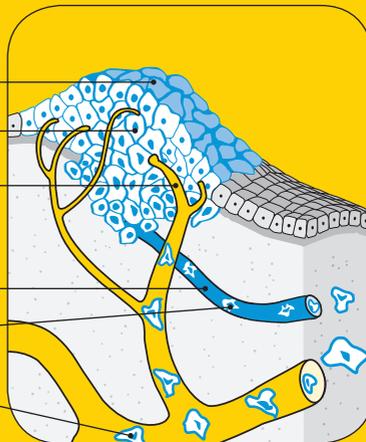
Primary cancer

Local invasion

Angiogenesis –  
tumours grow their  
own blood vessels

Lymph vessel

Metastasis –  
cells invade other  
parts of the body via  
blood vessels and  
lymph vessels





# The pancreas

The pancreas is part of both the digestive system and the endocrine (hormone-producing) system. It is a long, flat gland about 13–15 cm long that lies between your stomach and spine.

The pancreas is divided into three parts:

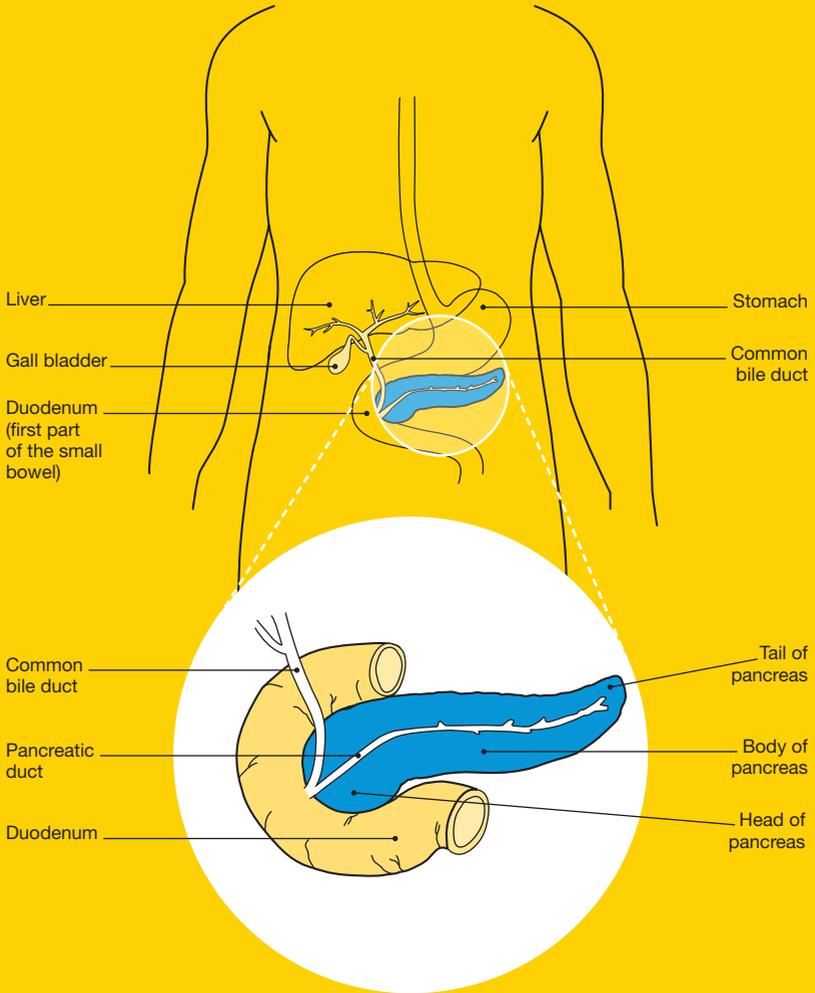
- a large rounded section, called the head of the pancreas
- the middle part, known as the body
- the narrow end, called the tail.

A tube called the pancreatic duct connects the pancreas to the first part of the small bowel (duodenum). Another tube, called the common bile duct, joins with the pancreatic duct and connects the liver and gall bladder to the duodenum. The common bile duct carries bile, a substance that helps the body to digest fats.

The pancreas acts as two glands in one – it functions as a gland to help with digestion (exocrine), and as a gland to control the amount of sugar in the blood (endocrine).

- **Exocrine function** – Groups of exocrine cells (acini) produce juices called enzymes that help break down food. The juices flow through the pancreatic duct from the pancreas into the duodenum. Most of the pancreas is made up of exocrine tissue.
- **Endocrine function** – Scattered among the exocrine tissue are small groups of endocrine cells called pancreatic islets (or islets of Langerhans). These release hormones that control the level of sugar in the blood – the hormone insulin decreases this level, while the hormone glucagon increases it.

## The pancreas in the body





## Key questions

### Q: What is pancreatic cancer?

**A:** Pancreatic cancer occurs when malignant cells develop in part of the pancreas. This may affect how the pancreas works, including its exocrine or endocrine functions.

Pancreatic cancer can occur in any part of the pancreas, but about 70% of pancreatic cancers are found in the head of the pancreas. Pancreatic cancer can also spread to nearby lymph nodes (part of the immune system), blood vessels or nerves. Cancer cells may travel through the bloodstream to other parts of the body, such as the liver.

### Q: What are the main types?

**A:** Two main types of tumours occur in the pancreas:

**Exocrine tumours** – These make up more than 95% of pancreatic tumours.<sup>1</sup> The most common type, called an adenocarcinoma, begins in the lining of the pancreatic duct. Less common types include adenosquamous carcinomas and undifferentiated carcinomas. The name of the cancer is taken from the type of cells involved. Treatment for exocrine tumours is discussed in two chapters – see pages 29–45.

**Pancreatic neuroendocrine tumours (NETs)** – About 5% of pancreatic tumours are pancreatic NETs.<sup>3</sup> These begin in the endocrine cells, which produce hormones to control blood sugar levels. Treatment for pancreatic NETs is discussed in a separate chapter – see pages 46–51.

## Q: What are the risk factors?

**A:** Research has shown that people with certain risk factors are more likely than others to develop pancreatic cancer.

Risk factors include:

- smoking (cigarette smokers are about twice as likely to develop pancreatic cancer)
- ageing
- type 2 diabetes
- obesity
- pancreatitis (long-term inflammation of the pancreas)
- certain types of cysts in the pancreatic duct known as intraductal papillary mucinous neoplasms (IPMNs) – these should be assessed by an appropriate specialist
- drinking too much alcohol
- family history and inherited conditions (see below).

### Family history and inherited conditions

Most people with pancreatic cancer do not have a family history of the disease. However, about one in 10 people who develops pancreatic cancer has a faulty gene that can run in families.

You may have an inherited family risk if you have two or more first-degree relatives affected by pancreatic cancer, or a history of an inherited syndrome. The “degree of relationship” describes how many genes are shared between two blood relatives. First-degree relatives, for example, your parents, siblings or children, share about half their genes with you.

Some inherited syndromes that may increase the risk of pancreatic cancer include Peutz-Jeghers syndrome, the familial breast cancer genes (BRCA1 and BRCA2), familial atypical multiple mole melanoma (FAMMM) syndrome, Lynch syndrome and hereditary pancreatitis.

Some pancreatic NETs are caused by a rare inherited syndrome, such as multiple endocrine neoplasia type 1 (MEN1) or neurofibromatosis.

If you are concerned about your family history or want to know more about genetic testing, talk to your doctor or call Cancer Council 13 11 20.

## **Q: How common is it?**

**A:** About 3080 Australians are diagnosed with pancreatic cancer each year. More than 80% are over the age of 60.<sup>4</sup>

Pancreatic cancer was estimated to be the tenth most common cancer in males and ninth most common in females in Australia during 2017.<sup>5</sup>



Screening tests help detect cancer in people who do not have any symptoms. There are useful screening tests for certain types of cancer, such as breast cancer and bowel cancer. However, there is currently no screening test available for pancreatic cancer.

## Q: What are the symptoms?

**A:** Early-stage pancreatic cancer rarely causes symptoms. Symptoms often only appear once the cancer is large enough to affect nearby organs, or has spread.

Symptoms of pancreatic cancer may include:

- jaundice – yellowish skin and eyes, dark urine, pale bowel motions and itchy skin
- indigestion (heartburn)
- appetite loss
- nausea with or without vomiting
- unexplained weight loss
- pain in the upper abdomen, side or back, which may cause you to wake up at night
- changed bowel motions – including diarrhoea, severe constipation, or pale, oily, foul-smelling stools that are difficult to flush away.

Because some pancreatic NETs produce excess hormones, they can also have symptoms such as:

- too much sugar in the blood (hyperglycaemia)
- a drop in blood sugar (hypoglycaemia)
- blurred vision
- excessive thirst
- increased urination.

The symptoms listed above do not necessarily mean that you have cancer; they can indicate other conditions. However, you should see your doctor if you have any of these symptoms.

## Q: What can I expect after diagnosis?

**A:** It's common to have many questions and concerns about what a diagnosis of pancreatic cancer will mean for you.

**Diagnosis stage (pages 16–26)** – You will have various tests to confirm that you have pancreatic cancer, and to work out which type and how far it has progressed. The results will help guide decisions about treatment.



### **Treating early pancreatic cancer (pages 29–37)**

About 15–20% of people with adenocarcinoma or another exocrine cancer of the pancreas are diagnosed at an early stage. They may be offered treatment that aims to get rid of all the cancer.



### **Treating advanced pancreatic cancer (pages 38–45)**

Most people with adenocarcinoma or another exocrine cancer of the pancreas are diagnosed at an advanced stage. Treatment will aim to manage symptoms, control the cancer and improve quality of life.



### **Treating pancreatic NETs (pages 46–51)**

About 5% of pancreatic cancers are neuroendocrine tumours (NETs). There are additional treatment options for both early and advanced pancreatic NETs.

**Managing your diet (pages 52–60)** – People with pancreatic cancer often need to adapt to changes in how their body processes food, either because of the cancer itself or because of the treatment.



For an overview of what to expect during all stages of your cancer care, visit [cancerpathways.org.au/optimal-care-pathways/pancreatic-cancer](https://cancerpathways.org.au/optimal-care-pathways/pancreatic-cancer). This is a short guide to what is recommended, from diagnosis to treatment and beyond.

## Q: Where should I have treatment?

**A:** Treatment for pancreatic cancer is highly specialised, so you may need to travel for treatment. This is especially the case with surgery for early pancreatic cancer (see pages 31–37). There is strong evidence that outcomes are better with an experienced surgeon who performs the operation several times a year.

Specialised treatment centres that see a lot of people with pancreatic cancer are also associated with better outcomes. Seeing a multidisciplinary team (see pages 14–15) at these centres allows you to access a wide range of treatment options. To find a specialised pancreatic centre, talk to your GP or call Cancer Council 13 11 20.

If you live in a rural or regional area and have to travel a long way for appointments or treatment, ask your doctor what support is available to coordinate your journey. You may also be able to get financial assistance towards the cost of accommodation or travel. To check whether you are eligible or to apply, speak to your GP or the hospital social worker, or call Cancer Council 13 11 20.

## Q: Which health professionals will I see?

**A:** Your GP will usually arrange the first tests to assess your symptoms. If you need further tests, you will be referred to a specialist, who will make a diagnosis and advise you about treatment options. Because pancreatic cancer is a challenging

### Health professionals you may see

|  |   |
|--|---|
| <b>pancreatic or HPB (hepato-pancreato-biliary) surgeon*</b>                       | specialises in surgery to the liver, pancreas and surrounding organs  |
| <b>gastroenterologist*</b>   | specialises in diagnosing and treating diseases of the digestive system, including pancreatic cancer and blocked bile ducts |
| <b>medical oncologist*</b>   | prescribes and coordinates chemotherapy, hormone therapy and targeted drug therapies  |
| <b>radiation oncologist*</b>   | prescribes and coordinates radiation therapy  |
| <b>endocrinologist*</b>  | diagnoses, treats and manages hormonal disorders, including diabetes  |
| <b>nuclear medicine specialist*</b>  | coordinates the delivery of radioactive treatment and scans   |
| <b>interventional radiologist*</b>   | analyses x-rays and scans, may do biopsy under ultrasound or CT, and delivers some treatments                               |
| <b>cancer care coordinator/clinical nurse consultant/clinical nurse specialist</b> | coordinates your care, liaises with other members of the MDT, and supports you and your family throughout treatment         |

cancer to treat, it is important to see a multidisciplinary team (MDT) in a hospital or treatment centre that regularly treats this disease. The MDT is a group of health professionals who meet regularly to discuss and plan your treatment. It may include some or all of the health professionals listed below.

|                                 |  |
|---------------------------------|--|
| <b>nurses</b>                   | administer drugs and provide care, information and support throughout your treatment                                     |
| <b>palliative care team</b>     | specialise in pain and symptom control to maximise wellbeing and improve quality of life                                 |
| <b>dietitian</b>                | supports and educates patients about eating and managing weight changes and digestive/bowel problems                     |
| <b>social worker</b>            | links you to support services and helps you with emotional, practical or financial issues                                |
| <b>psychologist, counsellor</b> | use counselling to help you manage your emotional response to diagnosis and treatment                                    |
| <b>physiotherapist</b>          | helps with restoring movement and mobility and preventing further injury, and can tailor an exercise program for you     |
| <b>exercise physiologist</b>    | assists people with medical conditions to exercise and improve their overall health, fitness, strength and energy levels |
| <b>occupational therapist</b>   | assists in adapting your living and working environment to help you resume your usual activities                         |

*\* Specialist doctor*



# Diagnosis

If your doctor suspects you have pancreatic cancer, you will need a number of tests to confirm the diagnosis. Together, the tests will show what type of pancreatic cancer it is, where in the pancreas it is, and whether it has spread to nearby organs or other parts of the body. This is called staging (see pages 23–24).

Tests may include blood tests, a CT scan and other imaging tests, endoscopic tests and tissue sampling (biopsy). The tests you have will depend on the symptoms, type and stage of the cancer. You will not have all the tests described below. Some are used only to detect pancreatic NETs.

## Blood tests

Blood tests are used together with other test results to diagnose pancreatic cancer. You are likely to have blood tests to check your general health and how well your liver and kidneys are working.

Some blood tests look for particular markers of pancreatic cancer. Many people with pancreatic cancer have higher levels of the markers CA19-9 (carbohydrate associated antigen) and CEA (carcinoembryonic antigen). Other conditions can also raise the level of these markers, and some people with pancreatic cancer have normal levels, so these markers can't be used to diagnose pancreatic cancer on their own. However, they may tell your doctor more about the cancer and how it is responding to treatment.

It is normal for the levels of these markers to go up and down a bit, but your doctor will look for sharp increases and overall patterns.

Pancreatic NETs may produce high levels of certain hormones, which can be detected in the blood. In addition, pancreatic NETs may make a tumour marker called CgA (chromogranin-A).

## Scans (imaging tests)

Tests that create images of the inside of the body are known as scans. Different scans can provide different details about the cancer. Depending on your individual situation, you may need only one or several types of scans. You are likely to have scans during the process of diagnosis, as well as throughout and after treatment.

### Ultrasound

An ultrasound uses soundwaves to create a picture of the inside of your body. An ultrasound of your abdomen will show the pancreas and the surrounding area, including your liver. It can show if a tumour is present and its size.

You will lie on your back for the procedure. A gel will be spread onto your abdomen and a small device called a transducer will be moved across the area. The transducer creates soundwaves that echo when they meet something solid, such as an organ or tumour. A computer turns these echoes into pictures. The ultrasound is painless and takes about 15–20 minutes.

### CT scan

A CT (computerised tomography) scan uses x-rays to take many pictures of the inside of your body and then compiles them into one detailed, cross-sectional picture.



The dye used in a CT or MRI scan can cause allergies. If you have had an allergic reaction to iodine or dyes during a previous scan, let your medical team know beforehand. You should also tell them if you are diabetic, have kidney function problems or are pregnant.

CT scans are usually done at a hospital or a radiology clinic. Before the scan, dye is injected into a vein to help make the pictures clearer. This may cause you to feel hot throughout your body and may give you a strange taste in your mouth. These sensations are temporary and usually go away in a few minutes.

The CT scanner is large and round like a doughnut. You will lie on a table that moves in and out of the scanner. It takes about 30 minutes to set up the machine, but the CT scan itself takes only 5–10 minutes.

## **MRI and MRCP scans**

An MRI (magnetic resonance imaging) scan uses magnetic waves to build up detailed cross-sectional pictures of the pancreas and nearby organs. An MRCP (magnetic resonance cholangiopancreatography) is a type of MRI scan that produces more detailed images and can be used to check the common bile duct for blockage (obstruction).

Before an MRI scan, you may be asked not to eat or drink for a few hours. You may also be given an injection of dye to highlight the organs in your body.

You may not be able to have an MRI if you have a pacemaker or another iron-based metallic object in your body, because the scan may damage these devices. However, some newer pacemakers are MRI-compatible.

An MRI takes about an hour and you will be able to go home when it is over. The test is painless, but some people feel anxious lying in such a confined space. If you think this will be a problem, let the doctor or nurse know beforehand, as there are medicines that can help you relax. During the test, the machine makes a series of bangs and clicks and can be quite noisy, but you will usually be given earplugs or headphones.

MRIs for pancreatic cancer are not always covered by Medicare, so check with your treatment team about whether you will need to pay for these tests.

## Endoscopic scans

Endoscopic scans can show blockages or inflammation in the common bile duct, stomach and duodenum. They are done using an endoscope, which is a thin, flexible tube with a light and a camera that is passed down your throat into your digestive system. This is also called an endoscopy. It will usually be performed by a specialist called a gastroenterologist.

You will be asked not to eat or drink for several hours before an endoscopy. The doctor will give you a sedative so you are as relaxed and comfortable as possible. Because of the sedative, you shouldn't drive or operate machinery until the next day.

An endoscopic scan to investigate pancreatic cancer has some risks, including infection, bleeding and inflammation of the pancreas (pancreatitis). Your doctor will explain these risks before asking you to consent to the procedure. During these scans, the doctor can also take a tissue or fluid sample to help with the diagnosis. This is called a biopsy (see *Tissue sampling*, pages 21–22).

There are two main types of endoscopic scans:

**EUS** – An EUS (endoscopic ultrasound) uses an endoscope with an ultrasound probe (transducer) attached. The endoscope is passed through your mouth into the small bowel. The transducer makes soundwaves that create detailed pictures of the pancreas and ducts. This helps to locate small tumours and shows if the cancer has spread into nearby tissue.

**ERCP** – The endoscopic scan known as an ERCP (endoscopic retrograde cholangiopancreatography) performs an x-ray of the common bile duct and/or pancreatic duct. The doctor uses the endoscope to guide a catheter into the bile duct and insert a small amount of dye. The x-ray images show blockages or narrowing that might be caused by cancer. ERCP may also be used to put a thin plastic or metal tube (stent) into the duct to keep it open.

### **PET scans**

A PET (positron emission tomography) scan is a specialised imaging test. It involves the injection of a very small amount of radioactive substance to highlight tumours in the body. It may take several hours to prepare for and complete a PET scan.

**FDG-PET scan** – This PET scan uses a radioactive substance called fluorodeoxyglucose (FDG). It can help doctors work out whether a pancreatic cancer has spread or how it is responding to treatment.

**68-Gallium PET scan** – For most pancreatic NETs, the radioactive substance used in a PET scan is 68-Gallium. It may be used to help work out whether a pancreatic NET has spread. For some pancreatic NETs, an FDG-PET is used instead of or as well as this test.

Another type of scan called an SRS (somatostatin receptor scintigraphy) scan was once commonly used to stage pancreatic NETs, but it has been largely replaced by the 68-Gallium PET scan. It uses a different type of radioactive substance to highlight the tumour in the scan.

These specialised PET scans are not available in every hospital and may not be covered by Medicare, so talk to your medical team for more information.

## Tissue sampling

While imaging scans can show the presence and location of a tumour in the pancreas, the main way to confirm that it is cancer is by testing a sample of cells or tissue taken from the tumour (biopsy). This sample can also be tested to help your doctor work out exactly what type of pancreatic cancer it is. The sample may be collected with a needle (fine needle or core biopsy) or during keyhole surgery (laparoscopy).

“ I went to the doctor because I was itchy and had constant diarrhoea. My GP initially thought it was gallstones and sent me for routine tests. After the CT scan I went into hospital for a laparoscopy and then had a biopsy, which confirmed I had cancer. ” Jan

### **Fine needle or core biopsy**

This method uses a needle to remove a sample from an organ for examination under a microscope. It is done during an endoscopy or endoscopic ultrasound (see pages 19–20). A fine needle biopsy removes some cells, while a core biopsy uses a thicker needle to remove a sample of tissue.

An ultrasound or CT scan can help the doctor guide the needle through the abdomen and into the pancreas. You will be awake during the procedure, but you will be given a local anaesthetic so you do not feel any pain.

### **Laparoscopy**

A laparoscopy, also called keyhole surgery, is sometimes used to look inside the abdomen to see if the cancer has spread to other parts of the body. It can also be done to take tissue samples before any further surgery.

This procedure is performed with an instrument called a laparoscope, which is a long tube with a light and camera attached. It is done under general anaesthetic, so you will be asked not to eat or drink for six hours beforehand.

The doctor will guide the laparoscope through a small cut near your belly button. The doctor can insert other instruments through other small cuts to take the biopsy.

You will have stitches where the cuts were made. You may feel sore while you heal, so you will be given pain-relieving medicine during and after the operation, and to take at home. There is a small risk of infection or damage to an organ with a laparoscopy. Your doctor will explain the risks before asking you to agree to the operation.

If you take blood-thinning medicines or are a diabetic, let your doctor or nurse know before the laparoscopy.

## Staging and grading

Using the test results, your doctors will assign a stage to the cancer. The stage describes how far the cancer has spread and can help your doctors work out the best treatment options for your situation. The tables on the next page show how pancreatic cancers may be staged using the TNM (tumour–nodes–metastasis) system and/or given a number for the overall stage.

Your doctor may also talk to you about the grade of the cancer. This is based on laboratory tests of a tissue sample (biopsy) and describes how quickly the cancer might grow. The higher the number, the more likely the cancer is to grow quickly. Grade is particularly important for pancreatic NETs, which may be described as grade 1, 2 or 3 (low, intermediate or high grade).

## Staging systems for pancreatic cancer

### TNM system

The most common staging system for pancreatic cancer is the TNM system. In this system, each letter is given a number that shows how advanced the cancer is.

#### T (Tumour)

Refers to the size of the tumour (T0–4). The higher the number, the larger the cancer.

#### N (Nodes)

N0 means there is no spread to nearby lymph nodes; N1 means there is cancer in nearby lymph nodes.

#### M (Metastasis)

M0 means the cancer has not spread to other parts of the body; M1 means it has.

### Numbers

Your doctor may just use an overall number to describe the stage.

#### Stage 1

Cancer is found only in the pancreas. This is sometimes called early-stage disease.

#### Stage 2

Cancer has either spread to lymph nodes or structures near the pancreas (such as the duodenum or common bile duct), or is large but has not spread to nearby organs.

#### Stage 3

Cancer has grown into nearby major arteries. There may or may not be cancer in the lymph nodes. This is called locally advanced cancer.

#### Stage 4

The cancer has spread to other organs, such as the liver, lungs or lining of the abdomen. This is known as metastatic cancer.

## Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis with your doctor, but it is not possible for anyone to predict the exact course of the disease.

To work out your prognosis, your doctor will consider:

- test results
- the type, stage and location of the cancer
- how the cancer responds to initial treatment
- your medical history
- your age and general health.

As symptoms can be vague or go unnoticed, most pancreatic cancers are not found until they are advanced. Cancer that has spread to nearby organs or blood vessels (locally advanced) or other parts of the body (metastatic) is difficult to treat successfully. If the cancer is detected at an early stage and can be surgically removed, the prognosis may be better, especially in the case of pancreatic NETs.

It is important to know that although the statistics for pancreatic cancer can be frightening, they are an average and may not apply to your individual situation, so talk to your doctor about how to interpret any statistics that you come across.

When pancreatic cancer is advanced, treatment will usually aim to control the cancer for as long as possible, relieve symptoms and improve quality of life. This is known as palliative treatment (see pages 38–45 for more information).



## Key points

- You will have several tests to confirm the diagnosis.
- Blood tests can check your general health and may identify tumour markers.
- During an ultrasound, gel is spread over your abdomen and a scanner creates pictures of your organs.
- CT and MRI scans involve an injection of dye into your body, followed by a scan. Some people have a type of MRI called an MRCP. This produces more detailed images and can help show blockages in the common bile duct.
- During an endoscopic ultrasound (EUS), a tube with a camera and ultrasound probe is passed into your digestive system.
- An ERCP is an endoscopic scan that takes x-rays rather than an ultrasound.
- A PET scan is a specialised scan involving an injection of a small amount of radioactive substance. It may be used to see whether pancreatic cancer has spread.
- A biopsy means removing cells or tissue samples from an organ for examination under a microscope. This can confirm that a tumour is cancer and what type of cancer it is.
- The sample may be removed during an endoscopy or endoscopic ultrasound with a needle, or during a surgery called a laparoscopy.
- Staging describes how large the cancer is and how far it has spread. Grade describes how quickly it may grow.
- You may wish to ask your doctor about your prognosis. Keep in mind that any statistics are averages and may not apply to you.



# Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast. Check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that's based on your personal values. You may also want to discuss the options with your doctor, friends and family.

You have the right to accept or refuse any treatment offered. Some people with incurable cancer choose treatment even if it only offers a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so that they have the best possible quality of life.

## Talking with doctors

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you are confused or want clarification, you can ask questions – see page 70 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

## A second opinion

You may want to get a second opinion from another specialist to confirm or clarify your doctor's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this.

Your doctor can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the doctor who provided the second opinion.

## Taking part in a clinical trial

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment.

Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

It may be helpful to talk to your specialist or clinical trials nurse, or get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call Cancer Council 13 11 20 for a free copy of *Understanding Clinical Trials and Research*, or visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).



# Treatment for early pancreatic cancer

This chapter gives an overview of treatments used for early-stage adenocarcinomas and other exocrine tumours of the pancreas, generally referred to as early pancreatic cancer.

The treatment options described in this chapter will be suitable for only 15–20% of people with pancreatic cancer, as most people are diagnosed at a later stage. For information on the treatment of advanced pancreatic cancer, see pages 38–45. For information on treatment options for pancreatic NETs, see pages 46–51.

Surgery to remove the cancer, in combination with chemotherapy and possibly radiation therapy, is generally the most effective treatment for early pancreatic cancer. It is important to have the surgery done by a surgeon who specialises in pancreatic cancer (see page 13). Your medical team will discuss the best treatment for you based on the stage of the tumour (the site, size and if it has spread), your general health and your preferences.

## Treatments before or after surgery

Your surgeon may recommend you see other specialists for treatments before surgery to shrink the tumour, or after surgery to destroy any remaining cancer cells. These treatments are known as neoadjuvant (before) and adjuvant (after) therapies and may include:

- **chemotherapy** – the use of drugs to kill or slow the growth of cancer cells (see pages 41–42)
- **chemoradiation** – chemotherapy combined with radiation therapy (see page 43).



## Phil's story

Two years ago, I had a couple of episodes of severe stomach pain a few months apart. I ended up seeing a surgeon and had blood tests, x-rays, CT scans and a PET scan. I got the news that it was pancreatic cancer about a week later.

I'd played and coached top level sport and thought I was bullet-proof, so the diagnosis really rocked me. I'll never forget that drive home, it was the quietest one I'd ever had.

The surgeon worked with a medical oncologist and radiation oncologist to plan the treatment. They hit me with everything they had. I had 18 chemotherapy sessions, then a month's break, 26 radiation sessions, then some weeks off, and then had surgery.

We'd hoped I might only lose part of the pancreas, but they had to take all of it as well as the spleen and gall bladder. I spent 12 days in hospital, then

went home for recovery. I had four months off work all up.

I pushed myself to keep walking every day to stay strong before and after the operation. The walking also takes your mind off things, it's better than sitting at home feeling sorry for yourself.

I had to make some slight changes to my diet, and avoid milk and red meat for a while. Now I can have lean meat, but I always have lots of fruit and vegies. Because I no longer have a pancreas, I'm diabetic and need to inject insulin three times a day and take pancreatic enzymes before meals. The diabetes has been easy to manage, no problems at all.

I don't take things for granted with my health now. My diet was good before but it's even better now, and I make sure I walk every day. I was 113 kg before the operation, and now I'm just on 80 kg and I feel great.

## Surgery for early pancreatic cancer

Surgical removal (resection) of the tumour is the most common treatment for people with early-stage disease who are in good health. Before the surgery, your treatment team may recommend that you have chemotherapy, with or without radiation therapy, to shrink the tumour. This is known as neoadjuvant therapy.

The aim of surgery for early pancreatic cancer is to remove all the tumour from the pancreas as well as the surrounding tissue. The type of surgery you have will depend on the size of the tumour and where it is located. All surgery has risks and potential complications, so your surgeon will weigh these up against the benefits, taking into account your general health and your preferences.

Surgeries for early pancreatic cancer include:

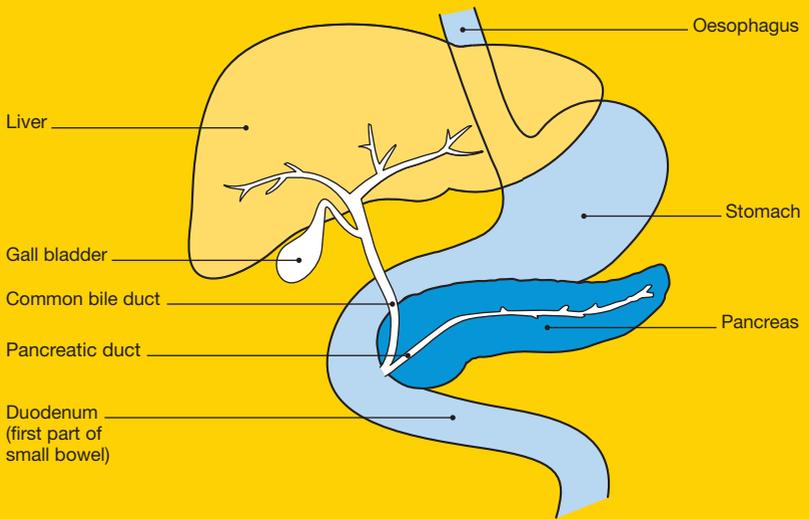
- **Whipple procedure** – This treats tumours in the head of the pancreas. Also known as pancreaticoduodenectomy, it is the most common surgery for pancreatic tumours. See the next two pages for more information about this operation.
- **Distal pancreatectomy** – This removes tumours in the tail or body of the pancreas and often also removes the spleen. See page 34 for more details.
- **Total pancreatectomy** – This removes the entire pancreas and spleen. This may be the best option if the cancer is large, or in multiple places in the pancreas. See page 34 for more details.

## Before and after a Whipple procedure

The Whipple procedure (pancreaticoduodenectomy) is a major operation that is done by a specialised pancreatic or hepato-pancreato-biliary (HPB) surgeon.

The surgeon removes the part of the pancreas with the cancer (usually the head); the first part of the small bowel (duodenum); part of the stomach; the gall bladder; and part of the bile duct.

### Before

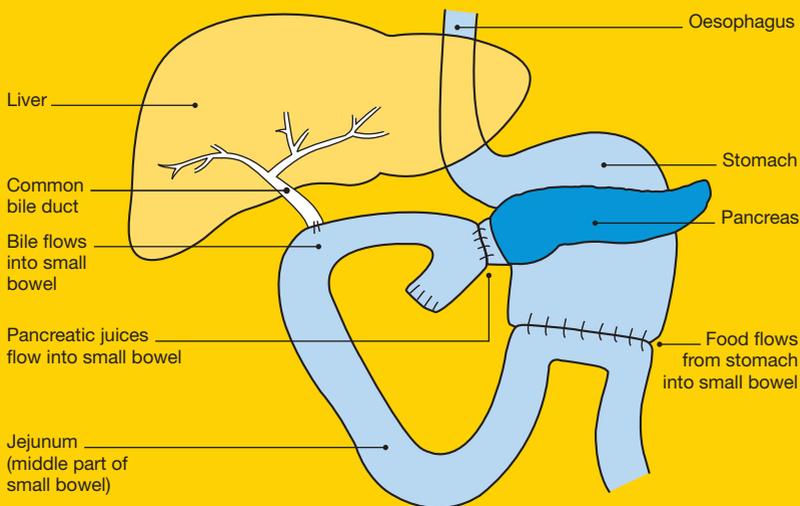


A Whipple procedure is extensive surgery and usually lasts 5–8 hours. As your surgeon will explain, there is a chance of serious complications, such as major bleeding or blood clots.

Then the surgeon reconnects the remaining part of the pancreas, bile duct and stomach (or duodenum) to different sections of the small bowel to keep the digestive tract working. This

allows food, pancreatic juices and bile to continue to flow into the small bowel for the next stage of digestion. Most people need to adjust their diet after a Whipple procedure.

## After



Most patients stay in hospital for 1–2 weeks afterwards, and full recovery takes at least 8–12 weeks. For tips on managing dietary issues after a Whipple procedure, see pages 54–55.

## **Distal pancreatectomy**

The surgeon removes only the tail of the pancreas, or the tail and a portion of the body of the pancreas. The spleen is usually removed as well. The spleen helps the body fight infections, so if it is removed you are at higher risk of some bacterial infections. Your doctor may recommend vaccinations before and after this surgery.

## **Total pancreatectomy**

When cancer is large, or multiple tumours are found, the entire pancreas and spleen may be removed, along with the gall bladder, common bile duct, part of the stomach and small bowel, and nearby lymph nodes. This is called a total pancreatectomy.

It is possible to live without a pancreas. However, the body will no longer produce insulin, so you will have type 1 diabetes and need regular insulin injections. You will also need to take pancreatic enzyme supplements to help digest certain foods (see page 59). It is crucial that an endocrinologist is part of your MDT to help guide your adjustment to life without a pancreas.

## **Surgery to relieve symptoms**

During the surgery to remove the cancer, the surgeon may find that the cancer has spread (metastasised) or grown into one or more of the major blood vessels in the area. This may occur even if you had several scans and tests beforehand. If this happens, the surgeon will not be able to remove the tumour. However, the surgeon may be able to perform procedures (such as a double bypass) that will relieve some of the symptoms caused by the cancer. See page 39 for more information.

## Surgical techniques

Surgery for early pancreatic cancer may be done using different techniques. Open surgery involves one larger cut in the abdomen. Laparoscopic surgery involves several small cuts in the abdomen. The surgeon inserts the instruments through these cuts and watches a screen to perform the operation. Robotic-assisted surgery uses a robotic device to help the surgeon perform laparoscopic surgery.

Compared to open surgery, laparoscopic surgery and robotic-assisted surgery usually mean a shorter hospital stay, less bleeding, a smaller scar and a faster recovery time. However, open surgery may be the better option in some circumstances.

Talk to your surgeon about what options are available to you and check if there are any extra costs involved.

## What to expect after surgery

- **Pain control** – As with all major operations, you will be given pain relief. If you are in pain when you return home, talk to your medical team about prescribing pain medicine.
- **Drips and tubes** – While in hospital, you will have a drip (intravenous infusion) to replace your body's fluids. At first you won't be able to eat or drink (nil by mouth). You'll then be on a liquid diet before gradually returning to normal food. A temporary feeding tube may be placed into the small bowel during the operation. This tube provides extra nutrition until you can eat and drink normally again. The hospital dietitian can help you manage these changes.

- **Enzyme and insulin replacements** – Some people will need to take tablets known as pancreatic enzymes after surgery. These are taken with each meal to help digest fat and protein. See page 59 for more information.
- **Insulin therapy** – Because the pancreas produces insulin, people who have had all or some of it removed often develop diabetes after surgery and may now need regular insulin injections. See page 58 for tips on coping with diabetes.
- **Length of hospital stay** – Most people go home within two weeks, but if you have complications, you may need to stay in hospital longer. You may also need to stay in a rehabilitation hospital to recover more before going home.

### **What if the cancer returns?**

If the surgeon successfully removes all of the cancer, you'll need regular check-ups to confirm that it hasn't come back. Check-ups will become less frequent if you have no further problems. Between appointments, let your doctor know immediately of health issues.

Unfortunately pancreatic cancer is difficult to treat, and it often does come back after treatment. This is known as a recurrence. Most of the time, surgery to completely remove the cancer is not an option if you have a recurrence. Your doctors may recommend other types of treatment with the aim of reducing symptoms and improving quality of life. The next chapter describes some of these treatments. You may also be able to access new treatments by joining a clinical trial (see page 28).



## Key points

- For early-stage cancer, surgical removal of the tumour (resection) offers the best potential outcome. This is an option for a small number of people with pancreatic cancer.
- Chemotherapy and/or radiation therapy may be used along with surgery. This is known as neoadjuvant therapy if done before surgery, and adjuvant therapy after surgery.
- The most common surgery for pancreatic cancer is the Whipple procedure. This removes the gall bladder and parts of the pancreas, small bowel (duodenum), common bile duct and stomach. Full recovery can take 8–12 weeks.
- A distal pancreatectomy is sometimes used to treat pancreatic cancer found in the tail or body of the pancreas. It removes part of the pancreas and often the spleen as well.
- In a total pancreatectomy, the entire pancreas and spleen are removed, along with the gall bladder, common bile duct, part of the stomach and small bowel, and nearby lymph nodes.
- If the surgeon finds that the cancer has spread, or is unable to remove the tumour, surgery to relieve symptoms may be performed instead.
- Surgery for pancreatic cancer may be done with open surgery, laparoscopic surgery or robotic-assisted surgery. Your surgeon will discuss the options with you.
- After part or all of the pancreas is removed, you may need to take pancreatic enzymes to digest fat and protein, or have insulin injections to treat diabetes.



# Treatment for advanced pancreatic cancer

Pancreatic cancer usually has no symptoms in its early stages, so many people are diagnosed when the cancer is advanced. If the cancer is in nearby organs or blood vessels (locally advanced), or has spread (metastasised) to other parts of the body, surgery to remove the cancer may not be possible. Instead treatments will focus on relieving symptoms such as jaundice, digestive problems and pain. This is called palliative treatment.

It is often assumed that palliative treatment is only for people at the end of life; however, it can help at any stage of a pancreatic cancer diagnosis. It does not mean giving up hope – rather, it is about managing symptoms as they occur and living for as long as possible in the most satisfying way you can.

This chapter describes treatments for managing common symptoms of advanced pancreatic cancer, such as:

- **jaundice** – caused by narrowing of the common bile duct
- **persistent vomiting and weight loss** – caused by a blockage in the stomach or small bowel
- **poor digestion** – caused by blockage of the pancreatic duct, which stops the flow of the digestive enzymes required to break down food
- **pain** – in the abdomen and middle back.

These treatments may include surgery, chemotherapy and radiation therapy, either on their own or in combination.

See pages 52–60 for information on managing dietary issues that may be caused by pancreatic cancer and its treatment.

## Surgery to relieve symptoms

If the tumour is pressing on the common bile duct, it can cause a blockage and prevent bile from passing into the bowel. Bile builds up in the blood, causing symptoms of jaundice, such as yellowing of the skin and whites of the eyes; itchy skin; reduced appetite, poor digestion and weight loss; and dark urine and pale stools.

If cancer blocks the duodenum (first part of the small bowel), food cannot pass into the bowel and builds up in your stomach, causing nausea and vomiting.

Blockages of the common bile duct or duodenum are known as obstructions. Options for managing obstructions may include:

- **stenting** – inserting a small tube into the bile duct or duodenum (this is the most common method, see next page)
- **double bypass surgery** – connecting the small bowel to the bile duct or gall bladder to redirect the bile around the blockage, and connecting a part of the bowel to the stomach to bypass the duodenum so the stomach can empty properly
- **gastroenterostomy** – connecting the stomach to the jejunum (middle section of the small bowel)
- **venting gastrostomy** – connecting the stomach to an artificial opening on the abdomen so waste can be collected in a bag outside the body.

Sometimes a surgeon may have planned to remove a pancreatic tumour during an operation, but discovers the cancer has spread. If the tumour cannot be removed, the surgeon may perform one of the operations listed above to relieve symptoms.

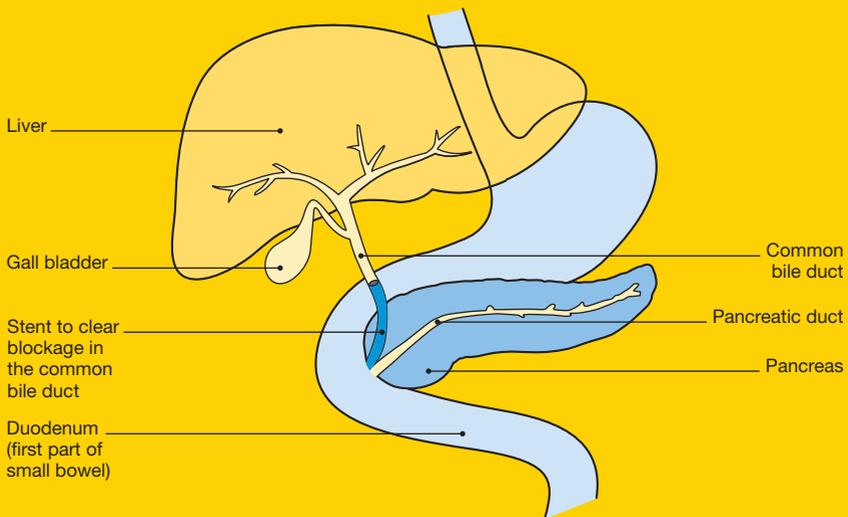
## Inserting a stent

If the cancer cannot be removed and is pressing on the common bile duct or duodenum, a stent may be inserted. A stent is a small tube made of either plastic or metal. It holds the bile duct or duodenum open, allowing the bile or food to flow into the bowel again.

The stent is usually inserted during a procedure known as an ERCP (endoscopic retrograde cholangiopancreatography). In

an ERCP, an endoscope is passed into the bile duct via your mouth, stomach and duodenum. With the help of x-rays, the stent is positioned across the blockage to keep the bile duct or duodenum open. You may have the ERCP as an outpatient or stay in hospital for 1–2 days.

Jaundice symptoms usually go away over 2–3 weeks. Your appetite is likely to improve and you may gain some weight.



## Chemotherapy

Chemotherapy is the use of drugs to kill or slow the growth of cancer cells. It is sometimes used in combination with radiation therapy (chemoradiation) to treat locally advanced cancers, i.e. cancer that has spread beyond the pancreas and cannot be removed with surgery.

If you have advanced pancreatic cancer, chemotherapy may be given as palliative treatment to relieve symptoms.

If you need chemotherapy, you will be referred to a medical oncologist. You will usually have the chemotherapy drugs by drip into a vein (intravenously). To avoid damaging the arm veins, it may be given through a small device called a port-a-cath. This is inserted under the skin near the collarbone and can stay in place until all your chemotherapy treatment is over.

Typically, you will have each course of treatment as an outpatient, and it will be followed by a break or rest period of 1–3 weeks. Your medical team will assess how the treatment is working based on your symptoms and wellbeing, as well as scans and blood tests.

Tell your doctors about any prescription, over-the-counter or natural medicines you are taking or planning to take, as these may affect how the chemotherapy works in your body. For information about natural medicines and other complementary therapies, visit your local Cancer Council website, or call Cancer Council 13 11 20 and ask for a free copy of the *Understanding Complementary Therapies* booklet.

## Side effects of chemotherapy

Chemotherapy affects all fast-growing cells in the body. As well as killing cancer cells, it can damage healthy fast-growing cells such as white blood cells (which fight infections), hair cells and the cells lining the mouth and digestive system. These healthy cells usually recover quickly, but until then, you may have side effects such as:

- fatigue and tiredness
- nausea and/or vomiting
- fewer red blood cells (anaemia), leaving you weak and breathless
- fewer white blood cells, causing poor resistance to infection
- mouth ulcers and skin rashes
- hair loss (only with some chemotherapy drugs)
- diarrhoea and/or constipation
- flu-like symptoms such as fever, headache and muscle soreness
- poor appetite.

You may have none or only some of these side effects. Most side effects are temporary and can be managed, so discuss how you are feeling with your medical oncologist and chemotherapy nurses. For more information, talk to your treatment team, call Cancer Council 13 11 20 for a free copy of the *Understanding Chemotherapy* booklet, or visit your local Cancer Council website.



Immunotherapy is a type of cancer drug treatment that uses the body's own immune system to fight cancer. So far, immunotherapy has had disappointing results for pancreatic cancer, but research is continuing and there are new clinical trials underway.

## Radiation therapy

Also known as radiotherapy, radiation therapy uses radiation to kill cancer cells or injure them so they cannot multiply. The radiation is usually in the form of x-rays and it can be targeted at the cancer. Treatment is painless and planned to do as little harm as possible to healthy body tissue.

If you need radiation therapy, you will see a radiation oncologist. The treatment is usually given Monday to Friday, for up to five or six weeks, and each session takes 10–15 minutes. With locally advanced pancreatic cancer, radiation therapy is usually given with chemotherapy (chemoradiation). Chemoradiation may also be used before or after surgery for early pancreatic cancer (see pages 29–37).

Radiation therapy may be used on its own over shorter periods to relieve symptoms such as pain caused by tumours pressing on a nerve or another organ.

### Side effects of radiation therapy

Radiation therapy can cause temporary side effects, which are mainly related to the area treated. For pancreatic cancer, the treatment is targeted at the abdomen. Side effects may include tiredness, nausea and vomiting, diarrhoea, poor appetite and skin irritation. Talk to your doctor or radiation oncology nurse about managing these side effects.

For a free copy of *Understanding Radiation Therapy*, call Cancer Council 13 11 20 or visit your local Cancer Council website.

## Managing pain in pancreatic cancer

A range of treatments can help to relieve pain in pancreatic cancer. These include:

- strong medicines such as opioids
- nerve blocks – injecting anaesthetic into nerves
- chemotherapy and/or radiation therapy to shrink cancer pressing on nerves.

Tell your treatment team about any pain, as it is easier to control if treated early. They can also refer you to a pain specialist if needed.

For a free copy of *Overcoming Cancer Pain*, call Cancer Council **13 11 20** or visit your local Cancer Council website.

## How palliative care can help

The options described in this chapter are generally considered palliative treatment because their main aim is to improve quality of life by reducing symptoms. Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, practical, emotional, spiritual and social needs. The team also provides support to families and carers.

Specialist palliative care services see people with complex needs and can also advise other health care professionals. Contacting a specialist palliative care service soon after diagnosis gives them the opportunity to get to know you, your family and your circumstances. You can ask your treating doctor for a referral. For free copies of *Understanding Palliative Care* and *Living with Advanced Cancer*, call Cancer Council 13 11 20 or visit your local Cancer Council website.



## Key points

- When pancreatic cancer is advanced or cannot be surgically removed, the aim of treatment is to control the cancer for as long as possible and to relieve symptoms. This is known as palliative treatment.
- Symptoms of advanced pancreatic cancer may include jaundice; vomiting and weight loss; poor digestion; and pain.
- The tumour may cause a blockage in the common bile duct or duodenum (first part of the small bowel).
- The usual treatment for a blockage is to insert a small tube called a stent. This allows bile to flow into the bile duct, or food to move into the bowel.
- The most common procedure to insert a stent is known as an ERCP (endoscopic retrograde cholangiopancreatography).
- In some cases, the surgeon will need to relieve a blockage by connecting different parts of the digestive system together. Operations that do this include double bypass surgery, gastroenterostomy and venting gastrostomy.
- Chemotherapy is the use of drugs to kill or slow the growth of cancer cells. For advanced pancreatic cancer, it may be used on its own or combined with radiation therapy (chemoradiation).
- Radiation therapy, which directs radiation such as x-rays at the cancer, is sometimes used with chemotherapy (chemoradiation) or on its own as a palliative treatment.
- Palliative care helps to improve your quality of life by addressing your physical, practical, emotional, spiritual and social needs. It also supports families and carers.



# Treatment for pancreatic NETs

This chapter discusses treatment for the rarest type of pancreatic tumours: neuroendocrine tumours (NETs). For information about treatment for more common types of pancreatic cancer, including adenocarcinomas, see pages 29–37 (early pancreatic cancer) and pages 38–45 (advanced pancreatic cancer).

Your medical team will discuss the best treatment for you based on the stage of the tumour (the site, size and if it has spread); the grade of the tumour (see page 23); whether the tumour is functioning or non-functioning; your general health; and your preferences.

Pancreatic NETs are categorised as either non-hormone producing (non-functioning) or hormone producing (functioning). About 90% of pancreatic NETs are non-functioning. This chapter focuses on the treatment of non-functioning pancreatic NETs.

Functioning tumours are very rare and are usually managed by an endocrinologist (specialist in hormone disorders) and surgeon. Most of these tumours are named after the hormone they overproduce, e.g. insulinomas produce too much insulin. Contact Cancer Council or the Unicorn Foundation (see box below) for information about how functioning pancreatic NETs are treated.



Neuroendocrine tumours can also affect other areas of the body, including the lungs, kidneys and bowel. For information about these types of tumours, call Cancer Council **13 11 20** or contact the Unicorn Foundation (**1300 287 363** or [unicornfoundation.org.au](http://unicornfoundation.org.au)).

## Surgery for early pancreatic NETs

Surgical removal (resection) of the tumour is the most common treatment for people with early-stage disease who are in good health. The surgeon will aim to remove all the tumour from the pancreas as well as the surrounding tissue. The type of surgery will depend on the size of the tumour and where it is located.

Surgery for early pancreatic NETs is often given with the aim of cure. However, there are risks and potential complications involved in pancreatic surgery. For small pancreatic NETs, observation to assess the growth of the tumour may be preferable to major surgery. Your surgeon will weigh up the benefits and impacts of surgery, while taking into account your general health and your preferences.

As with more common types of pancreatic cancer, surgeries for early-stage pancreatic NETs include:

- **Whipple procedure** – treats tumours in the head of the pancreas. Also called pancreaticoduodenectomy. See pages 32–33.
- **Distal pancreatectomy** – removes tumours in the tail or body of the pancreas and often also removes the spleen. See page 34.
- **Total pancreatectomy** – removes the entire pancreas and spleen. This may be the best option if the cancer is large, or in multiple places in the pancreas. See page 34.

In some cases, you will be given somatostatin analogues (see next page) before surgery.

## Options for advanced pancreatic NETs

Many pancreatic NETs have spread at the time of diagnosis. This is considered advanced cancer and the main aims of treatment will be to control the disease and relieve symptoms. People with advanced pancreatic NETs can live a long time with the disease.

### Surgery to relieve symptoms

Surgery can be used to treat blockages caused by the tumour and to reduce the size of the tumour.

**Stenting** – If the tumour has blocked the common bile duct or duodenum (first part of the small bowel), a small tube called a stent can be inserted. See page 40 for more information.

**Debulking** – If the whole tumour can't be removed, the surgeon may try to remove some of it. This surgery, called debulking, is not always possible and will depend on the tumour's position and size.

### Somatostatin analogues (SSAs)

The body produces a hormone called somatostatin, which controls how organs such as the pancreas release other hormones. Somatostatin analogues (SSAs) are medicines that are similar to somatostatin. They may be used when a pancreatic NET is making too much of a hormone and causing symptoms such as diarrhoea and dumping syndrome (see page 55). SSAs can slow down the release of the hormone and may also slow down the tumour's growth. The main SSAs used in Australia are octreotide LAR and lanreotide. These are given as monthly injections.

## Chemotherapy

Chemotherapy is the use of drugs to kill or slow the growth of cancer cells (see pages 41–42). It is rarely used for lower-grade pancreatic NETs, but may be used for advanced pancreatic NETs that are high-grade. It may be given on its own, with SSAs or before peptide receptor radionuclide therapy (PRRT, see below).

## Targeted therapy

Targeted therapy uses drugs that work in a different way to chemotherapy drugs. While chemotherapy affects all rapidly dividing cells and works by killing cancerous cells (cytotoxic), targeted therapy targets specific molecules within cells and often works by blocking cell growth (cytostatic). People with advanced pancreatic NETs may be offered targeted therapies such as sunitinib and everolimus to slow the growth of the tumour. These are given as capsules that you swallow.

## Peptide receptor radionuclide therapy (PRRT)

PRRT may be offered to some people with advanced pancreatic NETs, but it is available only in certain treatment centres. You will usually see a nuclear medicine specialist and a medical oncologist.

You may have a dose of chemotherapy before PRRT. For the PRRT, you will be injected with a cell-targeting protein (peptide) that has been combined with a small amount of radioactive substance (radionuclide). This mixture binds to the NET cells and delivers a high dose of radiation that kills or damages them. PRRT is given as a day treatment, with a session lasting around four hours. Most people have four sessions about 8–12 weeks apart.

## Treatment for liver tumours

Advanced pancreatic NETs often spread to the liver. The tumours on the liver are called metastases. Treatments to control them include:

**Radiofrequency ablation and microwave ablation** – Using an ultrasound or CT scan, a needle is inserted through the abdomen into the liver tumour. The needle sends out radio waves or microwaves that produce heat and destroy the cancer cells.

**Chemoembolisation** – In this procedure, a catheter is inserted into the hepatic artery, which supplies blood to the liver. A chemotherapy drug is released into the artery, along with tiny particles called microspheres, which block the flow of blood into the tumour. This causes the tumour to shrink. The procedure is performed by an interventional radiologist.

**Selective internal radiation therapy (SIRT)** – Also known as radioembolisation, this is done by an interventional radiologist. The radiologist inserts a catheter into the liver's main artery and then delivers tiny radioactive beads (SIR-spheres) to the liver through the catheter. The beads give a direct dose of radiation to the tumour while causing little damage to normal liver tissue.



The treatment options described for advanced pancreatic NETs are generally considered palliative treatment because their main aim is to improve quality of life by reducing symptoms. Palliative treatment is one aspect of palliative care. See page 44 for more information.



## Key points

- Pancreatic NETs can be either non-hormone producing (non-functioning) or hormone producing (functioning). About 90% of pancreatic NETs are non-functioning.
- Functioning pancreatic NETs are named after the hormone they produce and treated by both an endocrinologist and a surgeon.
- Small pancreatic NETs are not always treated immediately, but will be monitored for changes.
- The main treatment for early-stage pancreatic NETs is surgery to remove the tumour. The operation may be a Whipple procedure, distal pancreatectomy or total pancreatectomy.
- Treatments for advanced pancreatic NETs may include surgery, medicines, and a nuclear medicine treatment called PRRT.
- Surgical treatments to relieve symptoms include stenting for blockages and debulking to reduce the size of the tumour.
- Somatostatin analogues (SSAs), chemotherapy and targeted therapy drugs may be given to slow the growth of the tumour.
- Peptide receptor radionuclide therapy (PRRT) is given by injection and delivers a high dose of radiation directly to the pancreatic NET cells.
- There are also treatments to control cancer that has spread to the liver. These include radiofrequency and microwave ablation, chemoembolisation and selective internal radiation therapy (SIRT).



# Managing dietary problems

Pancreatic cancer, and treatments such as surgery, chemotherapy and radiation therapy, can affect your ability to eat, digest and absorb food. This can have a significant impact on nutrition.

Common problems include:

- weight loss
- poor appetite and feeling full quickly
- changes in taste and smell
- diarrhoea or other changes in bowel habits
- nausea and/or vomiting
- poor digestion (maldigestion) and absorption (malabsorption) of fats and proteins caused by a lack of pancreatic enzymes
- diabetes caused by inadequate insulin production.

This chapter provides general suggestions about how to manage these problems. What you can eat and drink will depend on your individual circumstances. People who have a Whipple procedure (see pages 32–33) may have many questions and concerns about their diet following the surgery. The suggestions on pages 54–55 may be helpful when you start to eat after surgery.

Dietitians are experts in nutrition who can give you specialist advice on how to cope with nutrition-related problems and eating difficulties throughout different phases of the disease. See the box opposite for information on finding a dietitian.

Call Cancer Council 13 11 20 for a free copy of *Nutrition and Cancer* or to speak to a Cancer Connect volunteer who has had a similar cancer experience.

## Nutritional supplements

If you can't eat a balanced diet or are losing too much weight, your doctor or dietitian may suggest nutritional supplements such as Sustagen Hospital Formula, Ensure, Fortisip and Resource. These contain energy, protein and other nutrients. Glucose powder supplements provide little nutrition and are rarely recommended.

Nutritional supplements should be taken in addition to your usual meals, i.e. as snacks between meals. They are available ready-made as drinks or bars, or in powdered form that can be mixed with milk, water and food. Ask a dietitian where to buy supplements, and to advise you on the type and quantity.

### Seeing a dietitian

Dietitians work in all public and most private hospitals. There may be a dietitian connected to your cancer treatment centre – check with your specialist or cancer care coordinator.

The Dietitians Association of Australia (DAA) can also help you locate an Accredited Practising Dietitian who works in your area and specialises in cancer or has experience with

particular clinical conditions. Visit [daa.asn.au](http://daa.asn.au) or call them on **1800 812 942**.

If your GP refers you to a dietitian, you may be eligible for a Medicare rebate. Most private health insurers provide a rebate depending on your type and level of cover.

The DAA has information on the typical fee for private dietitian consultations.

## Coping with dietary issues

### Poor appetite

- Eat small meals frequently, e.g. every 2–3 hours. Have your biggest meal of the day when you are hungriest.
- Ensure that meals and snacks are nourishing and include protein, e.g. meat, chicken, fish, dairy products, eggs, tofu and nuts.
- Choose nourishing drinks such as milk. Nutritional supplement drinks may be prescribed after surgery (see page 53).
- Add milk powder to cereals, sauces, desserts, mashed vegetables, soup, drinks and egg dishes.
- Add cheese to sauces, soup, baked beans, vegetables, casseroles, salads and egg dishes.
- Add golden syrup or honey to cereal, fruit and drinks.
- Talk to a dietitian before cutting out particular foods.
- Relax any low-cholesterol and other dietary restrictions. Gaining weight or maintaining your weight is more important than avoiding extra fat and sugar.

### Changes in taste or smell

- If food tastes bland, use seasoning, e.g. herbs, lemon, lime, ginger, garlic, honey, chilli, pepper, Worcestershire sauce, soy sauce or pickles.
- Some drinks may taste different or be off-putting because of the smell or texture. Choose milkshakes, fresh juice, hot chocolate and other non-alcoholic drinks.
- Choose cold food or food at room temperature without a strong smell.
- If cooking odours affect you, ask family or friends to cook.
- If you have a bitter or metallic taste in your mouth, eat moist fruits such as berries or suck boiled lollies.
- Try plain breakfast cereals with less added sugar, such as porridge or bran flakes, instead of cereals with added dried fruit, honey or other sweeteners.
- If you don't feel like eating meat, try other protein sources, e.g. cheese, eggs, nuts, dairy foods or legumes.



## Diarrhoea

- Talk to your doctor if your stools are pale in colour, smell particularly bad, or float and are difficult to flush. This may be a sign that you do not have enough pancreatic enzymes. You may need to start enzyme replacement therapy or adjust your dose.
- Talk to your doctor about whether to take anti-diarrhoea medicine.
- Drink plenty of liquids (e.g. water, fruit juice or weak cordial) to replace lost fluids.
- Avoid alcohol and limit caffeine and spicy foods as these can make diarrhoea worse.
- Try soy milk or lactose-reduced milk if you develop a temporary intolerance to the sugar in milk (lactose). This can sometimes occur when you have diarrhoea. Cheese and yoghurt in small amounts are usually okay.
- If diarrhoea occurs 15 to 30 minutes after eating, you may be experiencing dumping syndrome. Speak to your treatment team about this.

## Nausea

- Talk to your doctor about taking anti-nausea medicine half an hour before some meals.
- Snack on bland foods such as dry crackers or toast.
- Try to eat a little bit at regular intervals – not eating can make nausea worse.
- Eat and drink slowly. Chew food well.
- Avoid strong odours and cooking smells.
- Suck peppermint or lemon-flavoured boiled lollies.
- Drink ginger beer, ginger ale or ginger tea, or suck on candied ginger.
- See the next two pages for tips on dealing with vomiting.



## Jan's story

After I had Whipple's surgery, eating was hard and it was a balancing act getting it right.

I found that I would fill up quickly, but it helped to eat smaller meals. I also can't drink a lot of liquids. A lunchtime meal of a cup of tea and a soup is out of the question.

My taste buds had changed and chocolate was no longer appealing but ice-cream was okay. Fatty foods didn't settle well at all. The more unprocessed the food, the easier it was to handle. My tolerances have increased over the years, and trial and error has helped.

## Vomiting

Vomiting can occur as a result of the cancer or its treatment. For some people, just the thought of treatment or eating or the smell of food can make them feel unwell.

Let your doctor know if vomiting lasts for more than a day or if you can't keep any fluids down, as you may become dehydrated. There are a range of effective anti-nausea medicines (which are known as anti-emetics). If the one you are prescribed doesn't work, ask to try another type.

If you have persistent vomiting, the duodenum (the first part of the small bowel) may be blocked, so it is important to see your doctor as soon as possible. A blocked duodenum may be relieved with surgery – see pages 39–40.

## Steps to recovery after vomiting



### 1 Take small sips

Don't try to force food down. Sip small amounts of liquid as often as possible. Try flat dry ginger ale, cold flat lemonade, weak cordial, or cold apple or orange juice.



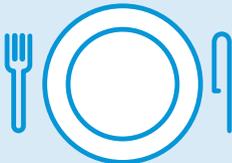
### 2 Introduce nourishing fluids

If the vomiting has stopped but you still feel sick, sip on drinks slowly in small frequent amounts. Start with cold or iced drinks. Prepare milk or fruit drinks with some water so they are not too strong. You can also try diluted fluids such as clear broth or weak tea.



### 3 Start solid food

Next, eat small amounts of solid foods, such as plain dry biscuits, toast or bread with honey or jam. Stewed fruits and yoghurt are also good. Aim to eat small regular food portions frequently, rather than three large meals a day.



### 4 Return to normal diet

As soon as you can, increase your food intake until you are eating a normal, balanced diet. Limit rich foods, such as fatty meats or full-cream dairy products. Your doctor or dietitian may suggest extra nourishment (such as supplements) on your good days to make up for the days you can't eat properly.

## Diabetes

Insulin is a hormone that controls the amount of sugar in the blood. Diabetes, or high blood sugar levels, can occur if your pancreas is not making enough insulin. This is why some people develop diabetes shortly before pancreatic cancer is diagnosed (when the cancer is affecting how much insulin the pancreas can make) or soon after surgery (when some or all of the pancreas has been removed).

The way diabetes is managed varies from person to person but often includes a combination of dietary changes and medicines. Your GP can help you manage the condition, but you will usually be referred to an endocrinologist, a specialist in hormone disorders. You may also be referred to a dietitian for help with adjusting your diet.



### Coping with diabetes

- Eat small meals and snacks regularly to help control blood sugar levels.
- Your GP or endocrinologist can prescribe medicines to help control the diabetes.
- If you are taking diabetes medicine, you need to include high-fibre carbohydrate foods at every meal to avoid low blood sugar levels. Wholegrain breads and cereals, vegetables and fruit are all suitable foods.
- For more information about diabetes, talk to your doctors and dietitian. You can also contact Diabetes Australia on **1300 136 588** or visit **[diabetesaustralia.com.au](http://diabetesaustralia.com.au)**.

## Enzyme replacement therapy

The pancreas produces digestive enzymes to help break down food. When you have pancreatic cancer, or have had pancreatic surgery, your body may not be able to make enough of these digestive enzymes. This affects the body's ability to digest food, particularly fat and protein, and to absorb vital nutrients. This is often referred to as pancreatic exocrine insufficiency (PEI). Signs of PEI include abdominal pain; bloating and excessive wind; diarrhoea or oily bowel movements (stools) that are pale in colour, frothy, loose and difficult to flush; and weight loss.

To help prevent these symptoms, your doctor may prescribe pancreatic enzymes, sometimes with acid-suppressing medicine. The dose will be based on, and adjusted to, your symptoms and dietary intake. It may take time to get this balance right.



### Taking enzyme supplements

- Take enzyme capsules with water and the first mouthful of food to ensure adequate mixing. With larger meals, you may need to also take them halfway through the meal.
- Always take enzymes when consuming any food or drink that contains fat or protein. Slightly higher doses may be needed with high-fat meals, e.g. fried foods and pizza. You don't need to take enzymes for simple carbohydrates that digest easily, e.g. fruit, fruit juice, black tea and coffee.
- Always take enzymes as prescribed. Do not change the dose without talking to your doctor or dietitian first.



## Key points

- Pancreatic cancer and its treatment can have a significant impact on eating and nutrition.
- The effect of surgery and other treatments on what you can eat and drink will vary from person to person.
- Common nutrition-related problems include poor appetite, feeling full quickly, nausea and vomiting, changes in taste, altered bowel patterns, and poor digestion and absorption of food. These factors can contribute to significant weight loss.
- It is important to eat a nourishing diet with regular meals and snacks. Often a diet high in energy and protein is needed to prevent or limit weight loss.
- You may be advised to take nutritional supplements if you are finding it hard to eat well or are losing too much weight.
- Dietitians are experts in nutrition who can give you advice on eating problems. They are found in all public and most private hospitals.
- Vomiting can be prevented or relieved with anti-nausea medicines. Once vomiting stops, gradually return to your normal diet.
- Some people will develop diabetes before pancreatic cancer is diagnosed or soon after surgery. Management usually requires both dietary changes and medicines. You may be referred to both an endocrinologist and a dietitian to help you control the condition.
- If you develop pancreatic exocrine insufficiency (PEI), pancreatic enzymes will be needed to help you digest and absorb fats and proteins. Talk to a dietitian experienced in managing PEI.



# Living with pancreatic cancer

Life after a diagnosis of pancreatic cancer can present many challenges. Take some time to adjust to the physical and emotional changes, and establish a daily routine that suits you and the symptoms you're coping with.

You are likely to feel a range of emotions about having pancreatic cancer. Cancer Council's *Emotions and Cancer* booklet offers strategies for coping with anxiety, fear, anger and other feelings.

You may also have practical concerns, such as what to do about work and finances. See Cancer Council's booklets *Cancer, Work and You* and *Cancer and Your Finances*.

## Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression.

This is quite common among people who have had cancer.

Talk to your GP, as counselling and/or medication – even for a short time – may help.

Some people are able to get a Medicare rebate for sessions with a psychologist or psychiatrist. Ask your doctor if you are eligible. Your local Cancer Council may also run a counselling program.

The organisation [beyondblue](http://beyondblue.org.au) has information about coping with depression and anxiety. Go to [beyondblue.org.au](http://beyondblue.org.au) or call **1300 22 4636** to order a fact sheet.

## Looking after yourself

Cancer can cause physical and emotional strain. It's important to try to look after your wellbeing as much as possible.

**Nutrition** – Eating healthy food can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Call Cancer Council 13 11 20 for a free copy of the *Nutrition and Cancer* booklet.

**Staying active** – Physical activity may help to reduce tiredness, improve circulation and elevate mood. The amount and type of exercise you do depends on what you are used to, how you feel, and your doctor's advice. Cancer Council's *Exercise for People Living with Cancer* booklet provides more information about the benefits of exercise, and outlines simple exercises that you may want to try.

**Complementary therapies** – These therapies are used with conventional medical treatments. You may have therapies such as massage, relaxation and acupuncture to increase your sense of control, decrease stress and anxiety, and improve your mood. Alternative therapies, such as coffee enemas and magnet therapy, are used instead of conventional medical treatments and can be harmful. Let your doctor know about any therapies you are using or thinking about, as some may not be safe or evidence-based.

For more information, call 13 11 20 and ask for a free copy of the *Understanding Complementary Therapies* booklet or visit your local Cancer Council website.

## Relationships with others

Having cancer can affect your relationships with family, friends and colleagues. This may be because cancer is stressful, tiring and upsetting, or as a result of more positive changes to your values, priorities, or outlook on life. Give yourself time to adjust to what's happening, and do the same for others. People may deal with the cancer in different ways – for example, by being overly positive, playing down fears or keeping a distance. It may be helpful to discuss your feelings with each other.

## Sexuality, intimacy and fertility

Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

If you are able to have sex, you may be advised to use certain types of contraception to protect your partner or avoid pregnancy for a certain period of time. Your doctor will talk to you about the precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, talk to your doctor before starting treatment.

Call **13 11 20** for free copies of *Emotions and Cancer*, *Sexuality, Intimacy and Cancer*, and *Fertility and Cancer*, or download the booklets from your local Cancer Council website.



## When the cancer is advanced

Many people diagnosed with pancreatic cancer think about what will happen if or when the disease progresses. You may question how much more time you have to live and begin going over your life and what it has meant for you. These thoughts are natural.

Being told that you have advanced cancer may bring up different emotions and reactions. You may not know what to say or think; you may feel sadness, anger, disbelief or fear. There is no right or wrong way to react. Give yourself time to take in what is happening, and accept that some days will be easier than others.

You might find it helpful to talk to your GP and the palliative care doctors and nurses about what you are going through. They can explain what to expect and how any symptoms will be managed.

The specialist palliative care team will usually include a social worker, a counsellor and a spiritual care practitioner (pastoral carer), and you can talk to them about how you are feeling. If you are not already in contact with a palliative care service, talk to your cancer specialist about a referral. You can also ask your specialist or GP about seeing a clinical psychologist, either through the treatment centre or in private practice.

## Advance care planning

If you have been diagnosed with pancreatic cancer, you may want to consider your wishes for your future care. This is called advance care planning, and it can be started at any stage, whether you are healthy or ill.



Call Cancer Council **13 11 20** for free copies of *Living with Advanced Cancer, Understanding Palliative Care or Facing End of Life*, or visit your local Cancer Council website.

Advance care planning mainly relates to decisions about your future medical care, but you may also want to appoint a trusted person to make financial and legal decisions for you if you're unable to make them yourself at some point in the future.

The law varies depending on where you live, and documents for appointing a substitute decision-maker may be known by different names, such as a power of attorney, enduring power of attorney, or advance care directive. For more information, talk to a social worker, call Cancer Council 13 11 20, or visit [advancecareplanning.org.au](http://advancecareplanning.org.au).

## The role of hope

A diagnosis of advanced cancer does not mean giving up hope. People with advanced pancreatic cancer can continue to enjoy many aspects of life, including spending time with their family and others who are important to them. Palliative care can be an important aspect of treatment for advanced pancreatic cancer, as effective management of symptoms is essential to quality of life.

As the disease progresses, the things that are hoped for may change. For example, a person might focus on living comfortably for as long as possible or being able to celebrate a particular event. You can have these hopes while acknowledging the reality of the situation.



# Seeking support

Cancer may cause you to experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. It can also cause practical and financial problems.

## Practical and financial help

There are many services that can help deal with practical or financial problems caused by the cancer. Benefits, pensions and programs can help pay for prescription medicines, transport costs or utility bills. Home care services, aids and appliances can also be arranged to help make life easier.

Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council offers free legal and financial services in some states and territories for people who can't afford to pay – call 13 11 20 to ask if you are eligible.

## Talk to someone who's been there

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone.

People often feel they can speak openly and share tips with others who have gone through a similar experience.

In a support setting, you may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be even more open and honest because they aren't trying to protect their loved ones.

## Types of support

There are many ways to connect with others for mutual support and to share information. These include:

- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums** – such as the Cancer Council Online Community at [cancercouncil.com.au/OC](https://cancercouncil.com.au/OC).

Talk to your nurse, social worker or Cancer Council 13 11 20 about what is available in your area.

“ My family members don't really understand what it's like to have cancer thrown at you, but in my support group, I don't feel like I have to explain. ” *Sam*



# Caring for someone with cancer

You may be reading this booklet because you are caring for someone with pancreatic cancer. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – give yourself some time out and share your worries and concerns with somebody neutral, such as a counsellor or your doctor.

Many cancer support groups and cancer education programs are open to carers, as well as people with cancer. Support groups and programs can offer valuable opportunities to share experiences and ways of coping.

Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local support services, as well as practical information and resources, through the Carer Gateway. Visit [carergateway.gov.au](http://carergateway.gov.au) or call 1800 422 737.

There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Visit [carersaustralia.com.au](http://carersaustralia.com.au) or call 1800 242 636 for more information and resources.

You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services and to get a copy of the *Caring for Someone with Cancer* booklet.



# Useful websites

The internet has many useful resources, although not all websites are reliable. The websites below are good sources of information.

## Australian

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|   |                                 |
|---|---------------------------------|
| Cancer Council Australia.....                           | <b>cancer.org.au</b>            |
| Cancer Australia.....                                   | <b>canceraustralia.gov.au</b>   |
| Carers Australia.....                                   | <b>carersaustralia.com.au</b>   |
| Department of Health.....                               | <b>health.gov.au</b>            |
| Healthdirect Australia.....                             | <b>healthdirect.gov.au</b>      |
| Palliative Care Australia.....                          | <b>palliativecare.org.au</b>    |
| Australian Pancreatic Cancer<br>Genome Initiative.....  | <b>pancreaticcancer.net.au</b>  |
| Pancare Foundation.....                                 | <b>pancare.org.au</b>           |
| GI Cancer Institute.....                                | <b>gicancer.org.au</b>          |
| Unicorn Foundation.....                                 | <b>unicornfoundation.org.au</b> |
| Avner Pancreatic Cancer Foundation.....                 | <b>avnersfoundation.org.au</b>  |
| International Centre for Community-Driven Research..... | <b>cc-dr.org/au</b>             |

## International

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|   |                                 |
|---|---------------------------------|
| American Cancer Society.....  | <b>cancer.org</b>               |
| Macmillan Cancer Support (UK).....  | <b>macmillan.org.uk</b>         |
| National Cancer Institute (US).....   | <b>cancer.gov</b>               |
| Johns Hopkins Medicine: The Sol Goldman<br>Pancreatic Cancer Research Center..... | <b>path.jhu.edu/pc/</b>         |
| Pancreatic Cancer Action Network.....   | <b>pancan.org</b>               |
| NET Patient Foundation.....   | <b>netpatientfoundation.org</b> |



## Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don't understand, ask for clarification.

- What type of pancreatic cancer do I have?
- How far has the cancer spread? What stage of cancer do I have?
- What treatment do you recommend and why?
- Are there other treatment choices for me? If not, why?
- What are the risks and possible side effects of each treatment?
- How long will treatment take? Will I have to stay in hospital?
- How much will treatment cost? Can these costs be reduced?
- Will treatment cause a lot of side effects? What will be done about this?
- How will treatment affect my nutrition and diet?
- Are the latest tests and treatments for this type of cancer available in this hospital?
- Are there any clinical trials of new treatments or other kinds of research that I could participate in? How frequently will I need check-ups after treatment?
- Are there any complementary therapies that might help me?
- Do I need the support of a specialist palliative care service?



# Glossary

## **abdomen**

The part of the body between the chest and hips, which contains the stomach, spleen, pancreas, liver, gall bladder, bowel, bladder and kidneys.

## **adenocarcinoma**

A cancer that starts in the mucus-producing (glandular) cells that form part of the lining of internal organs. Pancreatic adenocarcinoma is the most common pancreatic cancer and starts in the pancreatic duct lining.

## **adjuvant therapy**

A treatment given with or shortly after another treatment to enhance its effectiveness.

## **advanced cancer**

Cancer that is unlikely to be cured. It may be limited to its original site (primary cancer) or may have spread to other parts of the body (secondary or metastatic cancer).

## **anaesthetic**

A drug that stops a person feeling pain during a medical procedure. Local and regional anaesthetics numb part of the body; a general anaesthetic causes a temporary loss of consciousness.

## **benign**

Not cancerous or malignant.

## **bile**

A substance made in the liver and stored in the gall bladder. It helps the digestive system break down fats.

## **biopsy**

The removal of a sample of tissue from the body for examination under a microscope to help diagnose disease.

## **cells**

The basic building blocks of the body. A human is made of billions of cells adapted for different functions.

## **chemotherapy**

A treatment that uses drugs to kill cancer cells or slow their growth. May be given alone or with other treatments.

## **common bile duct**

The tube through which bile travels from the liver to the small bowel. Also called the bile duct.

## **CT scan**

Computerised tomography scan. This scan uses x-rays to create a detailed, cross-sectional picture of the body.

## **debulking**

Surgery to remove as much of a tumour as possible.

## **diabetes**

A disorder in which sugars are not taken up in the body properly because the pancreas does not make enough of the hormone insulin, or the body has become resistant to the effect of insulin. With pancreatic cancer, diabetes sometimes occurs shortly before the diagnosis or as a result of treatment.

## **diagnosis**

The identification and naming of a person's disease.

## **dietitian**

A university-qualified health professional who supports and educates patients about nutrition and diet during treatment and recovery.

**distal pancreatectomy**

Surgery to remove tumours in the tail and body of the pancreas.

**duct**

An enclosed tube or passage in the body.

**duodenum**

The first section of the small bowel.

**endocrine gland**

A gland that releases hormones that control the amount of sugar in the blood.

**endocrine system**

The system of the body that produces hormones.

**endocrine tumour**

A rare type of tumour affecting the glands that produce hormones.

**endocrinologist**

A specialist doctor who treats people with disorders of the endocrine system.

**endoscope**

A flexible tube with a light and camera on the end. It is used during diagnostic tests known as endoscopies.

**endoscopy**

A type of examination or diagnostic test. A thin, flexible tube called an endoscope is used to examine the inside of the body.

**enzymes**

Proteins that aid digestion and the normal functioning of the body.

**ERCP**

Endoscopic retrograde cholangiopancreatography. A procedure used to check the pancreas and bile duct, or insert a stent.

**EUS**

Endoscopic ultrasound. A test using an endoscope with an ultrasound probe on the end.

**exocrine gland**

A gland that releases substances through a duct.

**exocrine tumour**

A tumour that starts in the cells that make pancreatic enzymes to aid digestion. More than 95% of pancreatic tumours are exocrine tumours, and most of these are adenocarcinomas.

**functioning tumour**

A neuroendocrine tumour that releases hormones that cause symptoms.

**gall bladder**

A small, pear-shaped organ on the underside of the liver that stores bile.

**gastrinoma**

A pancreatic neuroendocrine tumour. It makes and releases abnormal amounts of a hormone called gastrin.

**gastroenterologist**

A specialist doctor who diagnoses and treats disorders of the digestive system.

**genes**

The tiny units that govern the way the body's cells grow and behave. Genes are found in every cell of the body and are inherited from both parents.

**glands**

Specialised organs or groups of cells that make various fluids that are used in the body or excreted.

### **glucagon**

A hormone that increases blood sugar levels.

### **glucagonoma**

A pancreatic neuroendocrine tumour that releases too much glucagon.

### **grade**

A score that describes how quickly a tumour is likely to grow.

### **hormones**

Chemicals in the body that send information between cells.

### **immunotherapy**

Treatment that stimulates the body's immune system to fight cancer.

### **insulin**

A chemical messenger (hormone) released by the pancreas to regulate the amount of sugar (glucose) in the blood. If the body does not produce enough insulin, diabetes will develop.

### **insulinoma**

A type of pancreatic neuroendocrine tumour that releases too much insulin.

### **interventional radiologist**

A specialist doctor who uses imaging scans to diagnose cancer, may perform a biopsy under ultrasound or CT, and delivers some treatments.

### **jaundice**

A condition caused by increased amounts of bile in the blood. Jaundice causes yellow, itchy skin; the whites of the eyes to turn yellow; pale stools; and dark urine.

### **laparoscopy**

Surgery done through small cuts in the abdomen using a tiny viewing instrument called a laparoscope. Also known as keyhole surgery.

### **liver**

A large organ in the top right side of the abdomen. Its functions include making bile, which helps digestion.

### **locally advanced cancer**

Cancer that has spread to nearby organs or blood vessels.

### **lymphatic system**

A network of tissues, capillaries, vessels, ducts and nodes that removes excess fluid from tissues, transports fat and produces immune cells.

### **lymph nodes**

Small structures that collect and destroy bacteria and viruses.

### **malignant**

Cancerous. Malignant cells can spread (metastasise) and eventually cause death if they cannot be treated.

### **metastasis (plural: metastases)**

Cancer that has spread from a primary cancer in another part of the body. Also called secondary cancer.

### **MRCP scan**

Magnetic resonance cholangiopancreatography scan. A more detailed MRI scan that can check the bile duct for blockages.

### **MRI scan**

Magnetic resonance imaging scan. A scan that uses magnetism and radio waves to take detailed, cross-sectional pictures of the body.

### **neoadjuvant therapy**

A treatment given before the main treatment to make the main treatment more successful.

### **neuroendocrine tumour (NET)**

A type of tumour that affects the endocrine and nervous systems. Some types of neuroendocrine tumours affect the pancreas.

### **non-functioning tumour**

A type of neuroendocrine tumour that does not produce hormones that cause symptoms.

### **outpatient**

A person who receives treatment without being admitted into hospital.

### **pancreas**

An organ in the digestive and endocrine systems. The pancreas produces insulin and some of the enzymes needed to digest food.

### **pancreatic exocrine insufficiency (PEI)**

The inability to properly digest food due to a lack of digestive enzyme made by the body.

### **pancreatic neuroendocrine tumour (pancreatic NET)**

A neuroendocrine tumour affecting the pancreas.

### **pancreaticoduodenectomy**

See Whipple procedure.

### **pancreatitis**

Inflammation of the pancreas.

### **PET scan**

Positron emission tomography scan. A scan in which a person is injected with

a small amount of radioactive glucose solution to find cancerous areas.

### **port-a-cath (port)**

A thin tube put into a vein with an opening under the skin so that medicine or blood can be given and blood can be taken.

### **prognosis**

The expected outcome of a person's disease.

### **radiation therapy**

The use of targeted radiation to kill or damage cancer cells. The radiation is usually in the form of x-ray beams. Also called radiotherapy.

### **radionuclide**

A radioactive substance that is injected into the body to locate or treat tumours.

### **recurrence**

The return of a disease after a period of improvement (remission).

### **somatostatin**

A hormone that helps to control the production of insulin by the pancreas and gastrin by the stomach.

### **somatostatin analogues (SSAs)**

Medicines similar to the hormone somatostatin that are used to treat some neuroendocrine tumours.

### **somatostatinoma**

A pancreatic NET that releases too much of the hormone somatostatin.

### **stage**

The extent of a cancer and whether it has spread from an original site to other parts of the body.

**stent**

A metal or plastic tube placed into a blocked organ to create a passage for substances to pass through.

**targeted therapy**

Treatment that attacks specific particles (molecules) within cells that allow cancer to grow and spread.

**tissue**

A collection of cells of similar type that make up a part of the body.

**tumour**

A new or abnormal growth of tissue on or in the body. A tumour may be benign or malignant.

**ultrasound**

A scan that uses soundwaves to create a picture of part of the body.

**VIPomas**

A type of pancreatic neuroendocrine tumour that produces a hormone-like substance called vasoactive intestinal polypeptide (VIP).

**Whipple procedure**

Surgery to remove the head of the pancreas and surrounding structures. Also called a Whipple operation, Whipple surgery or pancreaticoduodenectomy.

**Can't find a word here?**

For more cancer-related words, visit:

- [cancercouncil.com.au/words](http://cancercouncil.com.au/words)
- [cancervic.org.au/glossary](http://cancervic.org.au/glossary)
- [cancersa.org.au/glossary](http://cancersa.org.au/glossary)

**References**

1. RC Gandy et al., "Refining the care of patients with pancreatic cancer: the AGITG Pancreatic Cancer Workshop consensus", *Medical Journal of Australia*, vol. 204, issue 11, 2016, pp. 419–22.
2. M Ducreux et al. on behalf of the ESMO Guidelines Committee, "Cancer of the pancreas: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up", *Annals of Oncology*, vol. 26, issue 5, 2015, pp. v56–v68.
3. DS Klimstra et al., "The pathologic classification of neuroendocrine tumors: a review of nomenclature, grading, and staging systems", *Pancreas*, vol. 39, issue 6, 2010, pp. 707–12.
4. Australian Institute of Health and Welfare (AIHW), *Australian Cancer Incidence and Mortality (ACIM) books: Pancreatic cancer*, AIHW, Canberra, December 2017.
5. Australian Institute of Health and Welfare, *Cancer in Australia 2017*, AIHW, Canberra, 2017.



## How you can help

At Cancer Council, we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

**Join a Cancer Council event:** Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls' Night In and other Pink events, or hold your own fundraiser or become a volunteer.

**Make a donation:** Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

**Buy Cancer Council sun protection products:** Every purchase helps you prevent cancer and contribute financially to our goals.

**Help us speak out for a cancer-smart community:** We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

**Join a research study:** Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.



# Cancer Council 13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

Cancer Council services and programs vary in each area.

13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



**If you need information in a language other than English, an interpreting service is available. Call 13 14 50.**

**If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. [www.relayservice.gov.au](http://www.relayservice.gov.au)**



For information and support on cancer-related issues, call Cancer Council **13 11 20**. This is a confidential service.

## Visit your local Cancer Council website

**Cancer Council ACT**  
actcancer.org

**Cancer Council NSW**  
cancercouncil.com.au

**Cancer Council NT**  
nt.cancer.org.au

**Cancer Council Queensland**  
cancerqld.org.au

**Cancer Council SA**  
cancersa.org.au

**Cancer Council Tasmania**  
cancertas.org.au

**Cancer Council Victoria**  
cancervic.org.au

**Cancer Council WA**  
cancerwa.asn.au

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cancer.org.au

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To support Cancer Council, call your local Cancer Council or visit your local website.*