



Understanding Pancreatic Cancer

A guide for people with cancer,
their families and friends

Cancer
Information

For information & support, call

13 11 20



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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 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 understandably 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. 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.

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.



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What is cancer?

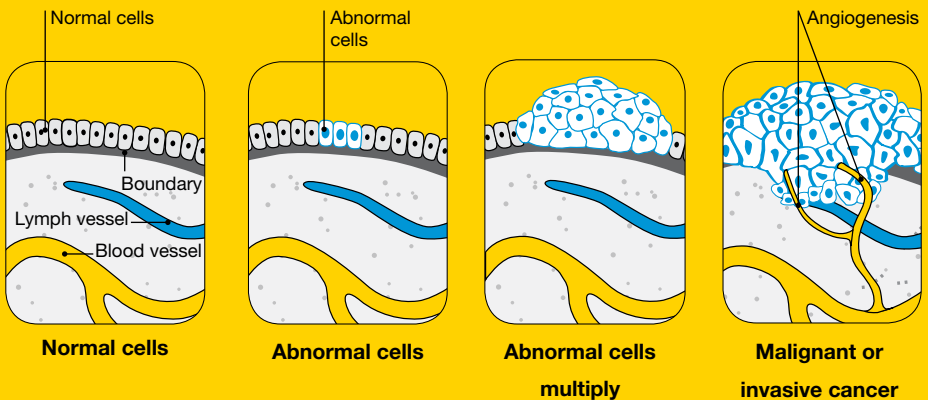
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

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 (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 pancreatic cancer, even though the person may be experiencing symptoms caused by problems in the liver.

How cancer spreads

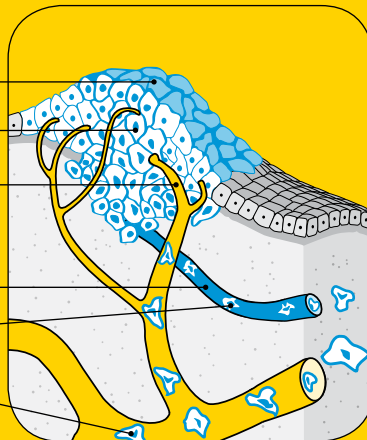
Primary cancer

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 the digestive system. It produces enzymes, which break down food so it can be absorbed and used by the body. It is a long, irregular shaped gland about 13–15cm long that lies between your stomach and spine.

The pancreas is divided into:

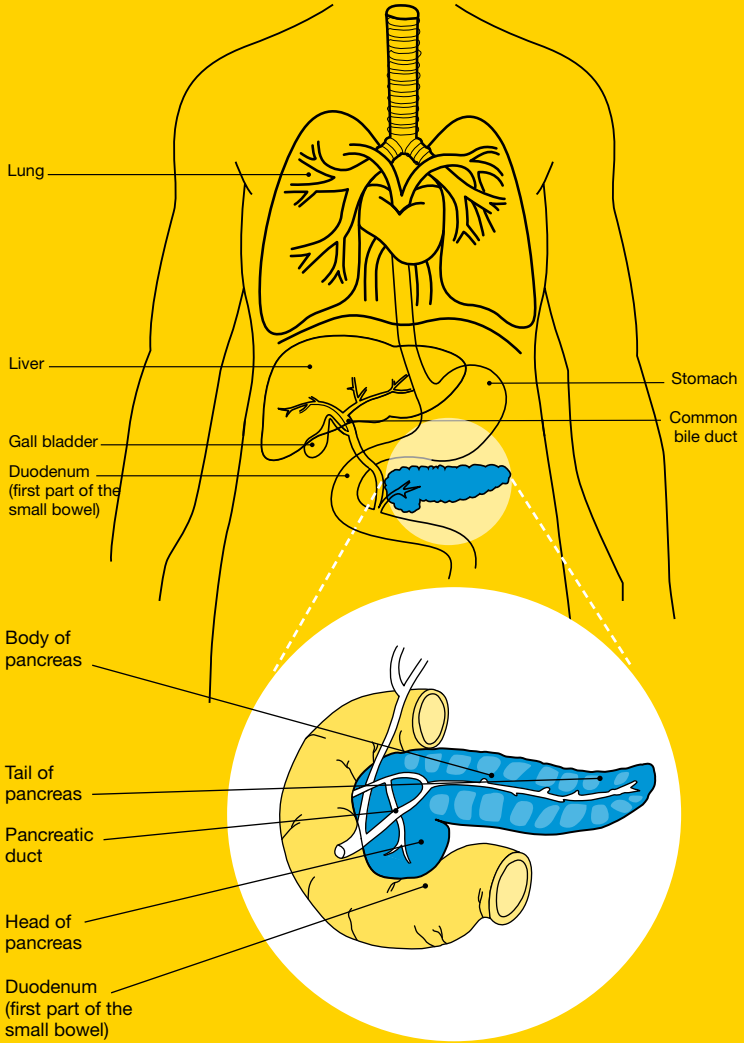
- a large rounded section, called the head of the pancreas
- the middle part, known as the body
- the narrow end, called the tail.

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 small bowel. The common bile duct carries bile, a substance that helps to digest fats.

The pancreas contains two types of glands: exocrine glands and endocrine glands. These release substances that help with digestion.

- **Exocrine glands** – These 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 glands.
- **Endocrine glands** – These are scattered amongst the exocrine glands in small clusters called pancreatic islets (or islets of Langerhans). They release hormones that control the amount of sugar in the blood. The hormone insulin decreases blood sugar levels, while the hormone glucagon increases blood sugar levels.

The pancreas





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 the functioning of the exocrine or endocrine glands.

Pancreatic cancer can occur in any part of the pancreas, but about 70% of pancreatic cancers are located 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 types?

A: There are two main types of tumours that occur in the pancreas:

Exocrine tumours – Make up the majority of pancreatic tumours. The most common exocrine tumour, called an adenocarcinoma, begins in the lining of the pancreatic duct. Other types of exocrine tumours include adenosquamous carcinomas and undifferentiated carcinomas. The name of the cancer is taken from the type of cells involved.

Pancreatic NETs (neuroendocrine tumours) – Pancreatic NETs begin in the endocrine cells. These cells produce


hormones that control the growth of cells in the body. Pancreatic NETs are categorised as either hormone secreting (functioning) or non-hormone secreting (non-functioning). Functioning tumours are usually named after the type of hormone they produce.

Types of functioning pancreatic NETs include:

- **gastrinomas** – produce too much gastrin
- **insulinomas** – produce too much insulin
- **glucagonomas** – produce too much glucagon
- **somatostatinomas** – produce too much somatostatin
- **VIPomas** – create a hormone-like substance called vasoactive intestinal polypeptide (VIP).

Q: How common is it?

A: About 2600 Australians are diagnosed with pancreatic cancer each year.¹ The average age at diagnosis is 72.² Pancreatic cancer was estimated to be the tenth most common cancer in both males and females in Australia during 2014.² The majority (more than 90%) of pancreatic cancers are exocrine tumours.³



This booklet contains information on neuroendocrine tumours affecting the pancreas (pancreatic NETs). 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 on **1300 287 363**.

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 itchiness of the skin
- indigestion (heartburn)
- appetite loss
- nausea and/or 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, foul-smelling stools that are difficult to flush away.

Additional symptoms of pancreatic NETs include:

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

These symptoms 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 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:

- **ageing** – pancreatic cancer is most common in people aged over 65
- **smoking** – cigarette smokers are 2–3 times more likely to develop pancreatic cancer
- **new onset type 2 diabetes** – about 15–20% of people with pancreatic cancer have newly diagnosed diabetes
- **pancreatitis** – chronic inflammation of the pancreas
- **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 gene (BRCA1 and BRCA2), familial atypical multiple mole melanoma syndrome, Lynch syndrome and hereditary pancreatitis.

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

If you are concerned about your family history or want to know more about genetic testing, talk to your doctor or visit the Australian Familial Pancreatic Cancer Cohort (AFPACC) website: pancreaticcancer.net.au/afpacc.



Diagnosis

If your doctor suspects you have pancreatic cancer or a pancreatic NET, you will undergo tests to confirm the diagnosis. The tests will also show where in the pancreas the cancer is, and whether it has spread to nearby organs or other parts of the body. This is called staging – see pages 19–20.

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 only used to detect pancreatic NETs.

Blood tests

Blood tests can check your blood count and determine how well your liver and kidneys are working. Blood tests are used together with other test results to diagnose pancreatic cancer.

- Pancreatic cancer may produce a tumour marker called CA19-9, which is a substance that shows up in the blood of some cancer types. Measuring the level of CA19-9 may give your doctor information about the cancer.
- Pancreatic NETs may produce high levels of certain hormones, which can also be detected in the blood. In addition, pancreatic NETs may make a tumour marker called Chromogranin-A. Measuring the level of Chromogranin-A may give your doctor information about the cancer and whether the cancer is responding to treatment.

Scans (imaging tests)

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 is a type of x-ray that takes pictures of several organs at the same time. These pictures are put together to create a three-dimensional picture of your body. CT scans are usually done at a hospital or a radiology clinic.

Before the scan, dye is injected into a vein to make the pictures clearer. You may feel hot all over and have a strange taste in your mouth for a few minutes. You may also feel that you need to urinate.



The dye that is injected into your veins before a CT or MRI scan may contain iodine, and may affect your kidneys. Tell your doctor if you are pregnant, have any allergies or kidney problems. You may need to have blood tests to check your kidney function.

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.

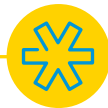
MRI and MRCP scans

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 the 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.

An MRI takes about an hour and you will be able to go home when it is over. During the test, the machine makes a series of bangs and clicks and can be quite noisy. 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 they can give you medication to help you relax.

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.



Endoscopic scans

Endoscopic scans can show blockages or inflammation in the bile ducts, 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.

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 page 18).

There are two main types of endoscopic scans:

EUS (Endoscopic Ultrasound) – This 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 any local spread of cancer.

ERCP (Endoscopic Retrograde Cholangiopancreatography) –

This test performs an x-ray of the pancreatic bile duct and/or pancreatic duct. The doctor uses the endoscope to guide a catheter into the bile duct, where a small amount of dye is inserted. The x-ray images show blockages or narrowing that might be caused by cancer. ERCP may also be used to place a stent into the duct.

Radionuclide scans

These scans use a mild dose of a radioactive substance, which is injected into a vein to show where tumours may be in the body.

SRS (somatostatin receptor scintigraphy) scan – This scan is an imaging method commonly used to stage pancreatic NETs. Over 90% of pancreatic NET cells have receptors for the hormone somatostatin. In the SRS scan, a radioactive substance that is similar to somatostatin is injected into your body. Over the course of a day, the drug travels to the tumour and attaches itself to the receptors. The scan will highlight the tumour by showing where the drug has attached.

68-Gallium PET scan – This specialised radionuclide scan can determine whether a pancreatic NET tumour has spread. The scan can be performed more quickly than an SRS, and is much more sensitive and specific in detecting pancreatic NETs. The scan is available in all states in Australia. However, it is not available at all hospitals with PET facilities.

It may take several hours to prepare for and complete these scans. Talk to your medical team for more information.

Tissue sampling

Fine needle biopsy

A biopsy means removing cells or tissue samples from an organ for examination under a microscope.

This procedure may be done during an endoscopy or endoscopic ultrasound. A fine needle is usually used to remove the cells.

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, sometimes 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. Another procedure, called peritoneal washing, may be performed at the same time to detect malignant cells within the abdominal cavity.

A laparoscopy is performed with an instrument called a laparoscope, which is a long tube with a light and camera attached. You will be asked not to eat or drink for six hours beforehand.



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

A general anaesthetic is given and a small cut will be made near your belly button through which the laparoscope will be guided inside your body through a tube. The doctor can insert other instruments through other small cuts (about 0.5–1cm each) to take the biopsy.

You will have stitches where the cuts were made, and you may feel sore while you heal. To help control the pain, you will be given medication during and after the operation, and to take home.

There is a small risk of infection or damage to an organ. Your doctor will explain the risks before asking you to agree to the procedure.

Staging pancreatic cancer

Results of the tests on pages 13–19 will help your doctors assign a stage to describe how far the cancer has spread. The tables on the next page show how pancreatic cancers may be staged.

The first table shows the most common staging system used for pancreatic cancer, which is called the TNM system. In this system, letters are assigned numbers to describe the cancer. Your doctor may also just use numbers to describe the stage. The second table shows this type of staging.

Ask your doctor to explain the stage in a way that will help you understand the best treatment options for your situation.

TNM system

T (Tumour) 1–4	Refers to the size of the primary tumour. The higher the number, the larger the cancer.
N (Nodes) 0–3	Shows if the cancer has spread to nearby lymph nodes. N0 means that the cancer has not spread to the lymph nodes; increasing node involvement is 1, 2 or 3.
M (Metastasis) 0–1	Cancer has either spread (metastatised) to other organs e.g. the liver (1) or it hasn't (0).

Staging

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 small bowel or common bile duct), or is large but has not spread to neighbouring organs.
Stage 3	Cancer has grown into nearby major arteries. There may or may not be cancer in the lymph nodes.
Stage 4	The cancer has spread to other organs, such as the liver, lungs or lining of the abdomen.

Prognosis

Prognosis means the expected outcome of a disease. You will need to discuss your prognosis and treatment options with your doctor, but it is impossible for any doctor to predict the exact course of your disease. Test results; the type, stage and location of the cancer; and other factors such as your age, fitness and medical history are all important when working out your prognosis.

As symptoms can be vague or go unnoticed, pancreatic cancers – especially exocrine tumours – are often not found until they are advanced. Cancer that is locally advanced or metastatic (i.e. has spread to nearby organs) 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.

If cancer is advanced, surgery and other treatments may relieve symptoms and help improve quality of life (see pages 35–44).

Which health professionals will I see?

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.

You will be cared for by a team of health professionals who meet regularly to discuss and plan your treatment. This multidisciplinary team (MDT) may include some or all of the health professionals listed on the following page.

Health professional	Role
pancreatic or HPB (hepato-pancreato-biliary) surgeon	specialises in surgery to the liver, pancreas and surrounding organs
gastroenterologist	specialises in diagnosing and treating diseases of the digestive system, including pancreatic cancer and blocked bile ducts
medical oncologist	prescribes and coordinates chemotherapy, hormone therapy and targeted drug therapies
radiation oncologist	prescribes and coordinates radiotherapy
endocrinologist	diagnoses, treats and manages hormonal disorders, including diabetes
nurses	support and assist you through all stages of your illness
dietitian	supports and educates patients about eating and managing weight changes at diagnosis, through treatment and recovery
social worker, psychologist and counsellor	provide emotional support and help manage anxiety and depression
physiotherapist and occupational therapist	assist you with any physical or practical problems associated with cancer and treatment
palliative care team	assist with symptom management and emotional support for you and your family



Key points

- You will have several tests to confirm the diagnosis.
- Blood tests can show how your liver and kidneys are working, and provide a full blood count.
- 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 a MRCP. This produces more detailed images.
- 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.
- An SRS scan is an imaging method that uses a mild dose of a radioactive substance to show where pancreatic NET tumours may be in the body.
- A 68-Gallium PET scan is a specialised scan used to show whether pancreatic NET tumours have spread.
- A biopsy means removing cells or tissue samples from an organ for examination under a microscope.
- A biopsy may be done during an endoscopy or endoscopic ultrasound, or during a surgical procedure called a laparoscopy.
- Staging describes how large the cancer is and how far it has spread.
- You may wish to talk to your doctor about your prognosis, this is the expected outcome of your disease.



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 more advanced 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 66 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.



Treatment: early pancreatic cancer

This chapter gives an overview of treatments used for early-stage pancreatic cancer, including treatment of early-stage pancreatic NETs. For information on the treatment of locally advanced and metastatic pancreatic cancer, see pages 35–44.

Surgery to remove the cancer, in combination with chemotherapy, and possibly radiotherapy, is generally the most effective treatment for early-stage pancreatic cancer.

Your medical team will discuss the best treatment for you based on the following factors:

- the stage of the tumour (the site, size and if it has spread)
- your general health
- your preferences
- for pancreatic NETs, whether the tumour is functioning (hormone producing) or non-functioning.

Travelling for treatment

Some people in rural and regional areas have to travel to attend appointments with specialists. If you need to travel a long way for 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 your eligibility or to apply, speak to your GP, the hospital social worker or travel department or call Cancer Council **13 11 20**.

Surgery to treat early pancreatic cancer

Surgical removal (resection) of the tumour is usually the most suitable 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-stage pancreatic cancer, particularly pancreatic NETs, is potentially beneficial, especially if the tumour is small. However, there are risks and potential complications involved in pancreatic surgery. Your surgeon will weigh up the benefits and impacts of surgery, while taking into account your wants, and your general health.

Surgeries for early-stage pancreatic cancer include:

- The Whipple procedure, or pancreaticoduodenectomy, which treats tumours in the head of the pancreas. This is the most common resection surgery for exocrine pancreatic tumours.
- A distal pancreatectomy, which removes tumours in the tail or body of the pancreas. This surgery is more likely an option to treat early-stage pancreatic NETs.

Where the cancer is large, or in multiple places in the pancreas, a total pancreatectomy, may be performed. This involves removal of the entire pancreas and spleen. If the cancer has spread (metastasised) or the surgeon is unable to safely remove the whole tumour, a double bypass may be performed, see page 36.

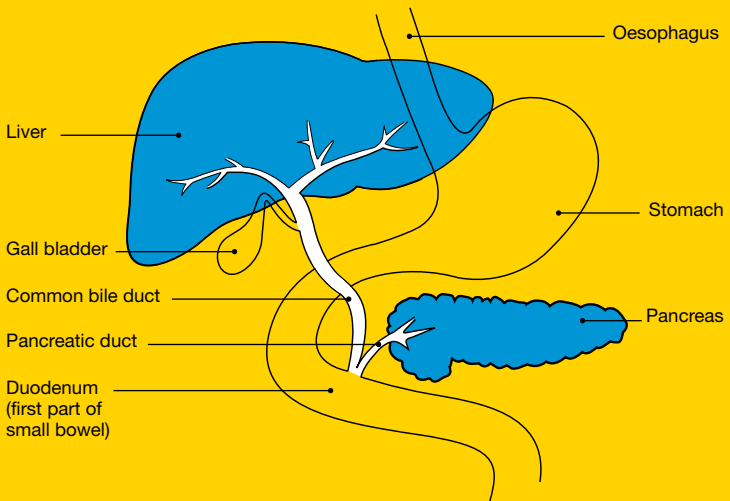
Whipple procedure

The Whipple procedure (pancreaticoduodenectomy) is a major operation that is done by specialised pancreatic or HPB surgeons.

During this procedure the surgeon will remove:

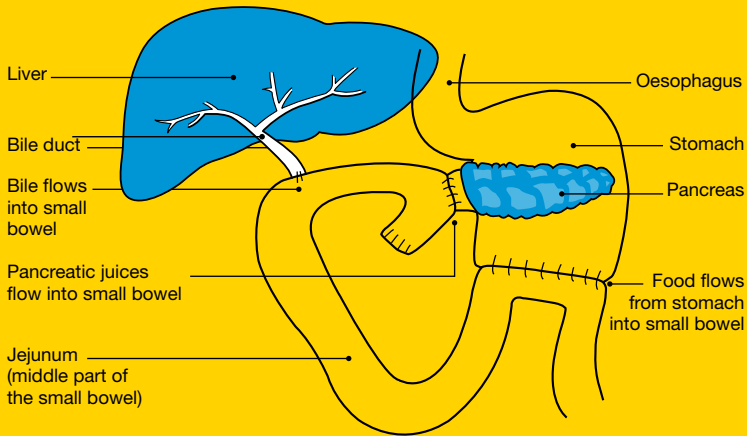
- the part of the pancreas where the cancer is (usually the head)
- the first part of the small bowel (duodenum)
- part of the stomach
- the gall bladder and part of the bile duct.

Before the operation



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. The surgery usually lasts 5–8 hours and most patients stay in hospital for 1–2 weeks afterwards. For tips on managing dietary problems after a Whipple procedure see pages 46–49.

After the operation



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 this surgery.

Total pancreatectomy

When cancer is large, or multiple tumours are found, the entire pancreas and spleen may be removed, along with the gallbladder, bile duct, part of the stomach and small intestine, 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 need to have regular insulin injections. It will also be necessary to take pancreatic enzyme pills to help digest certain foods.

Surgery to relieve symptoms

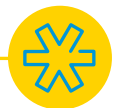
During the surgery to remove the cancer, the surgeon may find that the cancer has spread (metastasised) or grown into one or more of the major blood vessels in the area. This may occur even if you had several scans and tests beforehand.

If this happens, the surgeon will not be able to remove the tumour. However, the surgeon may be able to perform procedures that will relieve some of the symptoms caused by the cancer. See pages 35–38 for more information.

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 medication.
- **Drips and tubes** – When you are in hospital, you will have a drip (intravenous infusion) to replace your body's fluids. At first you will not be able to eat or drink (nil by mouth). You will then be restricted to 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 your ability to eat and drink is fully restored.
- **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 pages 52–53 for more information.
- **Insulin therapy** – A small number of people develop diabetes after surgery and may need insulin therapy. See page 51 for tips on coping with diabetes.
- **Length of hospital stay** – Most people go home within a fortnight, but if you have complications, you may need to stay in hospital longer.

For information on managing dietary issues that may be caused by pancreatic cancer and its treatment, see pages 45–55.





Leslye's story

My symptoms started with itchy skin. After a few days I was jaundiced and had dark coloured urine and back pain. I thought I had a problem with my gall bladder so I went to Emergency. The doctors did several tests and scans and couldn't figure out what was wrong, so they put a stent into my gall bladder to prevent it from becoming blocked.

The stent was changed four times over the course of a year. I had regular scans but no cancer was detected.

I wasn't feeling well and I had a bout of pancreatitis, so my surgeon removed my gall bladder and did a biliary bypass. They were then able to see that I had a carcinoid pancreatic neuroendocrine tumour on the head of my pancreas.

One good thing for me was that I didn't have to have chemotherapy or radiotherapy.

I had a Whipple procedure. It was a serious operation and I was in hospital for five weeks.

During recovery in hospital, I didn't have a feeding tube – I drank water and built up to other fluids. Over the next six months, I lost a lot of weight because I didn't eat a great deal.

I now eat a mostly vegetarian diet with meat 1–2 times per week. I take a digestive enzyme supplement called Creon® with food and increase the dose with a larger meal. I try to eat well most of the time.

I rarely eat sugary, fatty or dairy foods. I'm able to maintain a healthy weight.

Since I've learned to manage my diet, I was able to go overseas this year on a European river cruise. I was careful with what I ate and I rested a few days when I needed to, but I didn't have any serious problems.

Neoadjuvant and adjuvant therapies

Other treatments may be used before surgery to shrink the tumour, or after surgery to destroy any remaining cancer cells. These are known as neoadjuvant (before) and adjuvant (after) therapies.

Your doctor may suggest the following:

- chemotherapy to kill or slow the growth of cancer cells, either before or after surgery
- chemotherapy combined with radiotherapy (chemoradiation) after surgery to reduce the chance of the cancer returning.

For more information about chemotherapy and radiotherapy, including management of side effects, see pages 39–41.



Key points

- For early-stage cancer, surgical removal of the tumour (resection) offers the best potential outcome. This may not be an option for some patients.
- The most common surgery for pancreatic cancer is the Whipple procedure. This removes the gall bladder and parts of the pancreas, small bowel, bile duct and stomach.
- A distal pancreatectomy is sometimes used to treat pancreatic cancer and pancreatic NETs found in the tail and body of the pancreas.
- In a total pancreatectomy the entire pancreas and spleen is removed, along with the gallbladder, bile duct, part of the stomach and small intestine, 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.
- After surgery, you may need to take pancreatic enzymes to digest fat and protein, or receive insulin injections to treat diabetes.
- Chemotherapy is the use of drugs to kill or slow the growth of cancer cells. It can be combined with radiotherapy.
- Chemotherapy and/or radiotherapy may be used before or after surgery. This is known as neoadjuvant and adjuvant therapy.



Treatment: advanced pancreatic cancer

If the cancer is locally advanced to nearby organs or blood vessels, or has spread (metastasised) to other parts of the body, surgery to remove the cancer may not be possible.

Instead your treatment team will consider treatment to relieve symptoms including jaundice, digestive problems and pain. These treatments may include surgery, chemotherapy and radiotherapy, either on their own or in combination.

Other types of treatment for advanced pancreatic NETs include radiofrequency ablation, microwave ablation and chemo-embolisation.

Surgery to relieve symptoms

If the tumour is pressing on the bile duct, it can cause a blockage and prevent bile from passing into the small bowel. Bile then builds up in the bloodstream, causing symptoms of jaundice, such as:

- yellowing of the skin and whites of the eyes
- itchy skin
- reduced appetite, poor digestion and weight loss
- dark urine and pale stools.

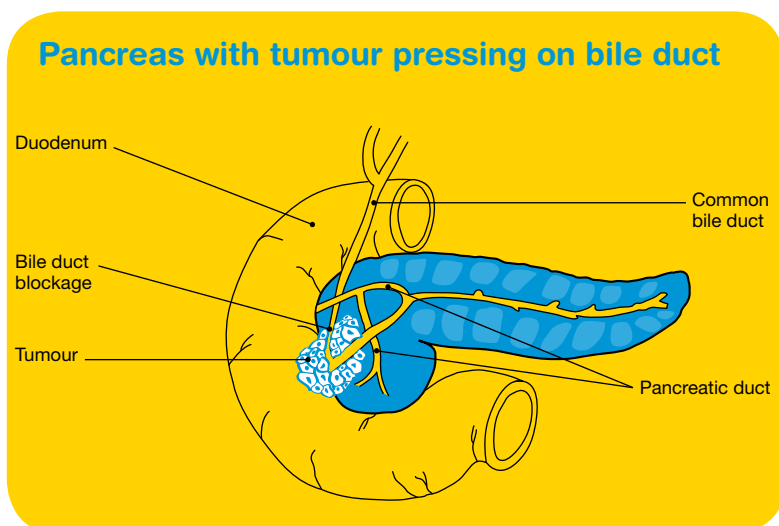
If cancer blocks the duodenum (upper part of the small intestine) food cannot pass into the bowel and builds up in your stomach, causing nausea and vomiting. Double bypass surgery or surgical insertion of a stent may be considered to relieve symptoms.

Debulking, removing as much of the tumour as possible, may be an option for relieving symptoms of pancreatic NETs.

Double bypass surgery

A double bypass surgery may be performed to relieve symptoms such as jaundice. This surgery is often carried out when the surgeon has planned to remove the tumour, but is unable to because the cancer has spread (metastasised) or has involved one or more of the major blood vessels in the region.

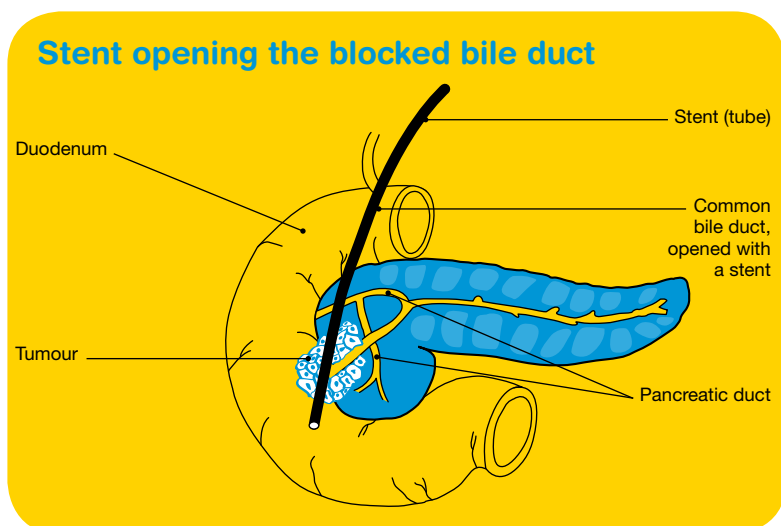
During a double bypass surgery, the surgeon connects a piece of your bowel to the bile duct or gall bladder to redirect the bile around the blockage. At the same time, the surgeon also connects a part of your bowel to the stomach, in order to bypass the duodenum. This will allow your stomach to empty properly. The surgery usually requires a hospital stay of 7–10 days.



Inserting a stent

If the cancer cannot be removed, and is pressing on the bile duct or duodenum, a stent may be inserted. A stent holds the bile duct or duodenum open, allowing the bile or food to flow into the bowel again.

The stent is inserted during a procedure known as an endoscopic retrograde cholangiopancreatography (ERCP). An ERCP involves passing an endoscope into the bile duct via your mouth, stomach and duodenum. X-rays are used to position the stent across the blockage to keep the bile duct or duodenum open. You can have an ERCP as an outpatient or you may stay in hospital for 1–2 days. You will be sedated for the procedure.



A stent is a tube made of either plastic or metal.

Plastic stents – These are sometimes used to temporarily relieve symptoms before surgery, then removed as part of the operation. They are generally short term and can be replaced when they become blocked, usually after a few months.

Metal stents – These are used when the tumour cannot be surgically removed. They usually remain open from several months to over a year. If the metal stent becomes blocked, another stent will be placed inside the blocked stent to open it up.

Following the insertion of a stent, symptoms of jaundice usually disappear over 2–3 weeks, but the itchy skin often goes away in 3–4 days. Your appetite should improve and you may gain some weight.

Debulking pancreatic NETs

Debulking is used for pancreatic NETs only. If the whole tumour can't be removed, the surgeon may still try to remove as much of it as possible. This surgery, called debulking, is not always possible and will depend on the position and size of the tumour.

Debulking may relieve some of your symptoms and, for functioning pancreatic NETs, reduce your hormone levels. If your hormone levels can be regulated, you will feel better and experience fewer side effects.

Chemotherapy

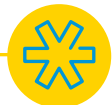
Chemotherapy is the use of drugs to kill or slow the growth of cancer cells.

Chemotherapy is sometimes used in combination with radiotherapy (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 and improve survival. Chemotherapy is not commonly used to treat pancreatic NETs.

You will probably receive chemotherapy by injection into a vein (intravenously) at treatment sessions over several weeks. In most cases you will receive the treatment as an outpatient. Most people have up to six courses of treatment. After each treatment session, you will have a break or rest period of 1–3 weeks at home. Your medical team will talk to you about how they will assess if the treatment has worked.

Tell your doctors about any prescription, over-the-counter or natural medicines you're 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, see page 56, or call Cancer Council **13 11 20** for a free copy of the *Understanding Complementary Therapies* booklet.



Side effects of chemotherapy

Chemotherapy affects fast-growing cells in the body, such as the white blood cells (which fight infections), hair cells and the cells lining the mouth and digestive system.

Chemotherapy can cause temporary side effects, which may include:

- fatigue and tiredness
- nausea and/or vomiting
- a low red blood cell count (anaemia), causing weakness and breathlessness
- a low white blood cell count, causing poor resistance to infection
- mouth ulcers
- diarrhoea
- flu-like symptoms such as fever, headache and muscle soreness
- poor appetite
- skin rashes.

You may have none or only some of the above side effects. Discuss how you are feeling with your medical oncologist, as there are ways to reduce or manage your side effects. For more information about chemotherapy, call the Cancer Council 13 11 20 for a free copy of the *Understanding Chemotherapy* booklet.

“ I found chemo a bit daunting – walking into the room with the chairs lined up. But the nurses were great and talked through it with me so I knew what to expect. ” Cheryl

Radiotherapy

Radiotherapy treats cancer by using x-rays to kill cancer cells or injure them so they cannot multiply. These x-rays can be targeted at cancer sites in your body.

Radiotherapy is usually used in combination with chemotherapy (chemoradiation) to treat locally advanced cancers, i.e. cancer that has spread beyond the pancreas and cannot be removed with surgery. Radiotherapy may also be given after surgery for early-stage cancer to reduce the risk of cancer recurring (see page 33).

Radiotherapy may also be used to relieve symptoms such as pain caused by tumours that may be pressing on a nerve or another organ. Radiotherapy is rarely used to treat pancreatic NETs.

Treatment is usually given Monday to Friday, for up to five or six weeks. Each session takes 10–15 minutes. Treatment is painless and planned to do as little harm as possible to healthy body tissue.

Side effects of radiotherapy

Radiotherapy can cause temporary side effects, including:

- tiredness
- nausea and vomiting
- diarrhoea
- poor appetite
- skin irritation.

Ask your doctor about managing these side effects or call Cancer Council 13 11 20 for a free copy of *Understanding Radiotherapy*.

Other treatments for advanced pancreatic NETs

Other treatments may be used to treat advanced pancreatic NETs that have spread to the liver. These treatments include:

- **Radiofrequency ablation and microwave ablation** – Using an ultrasound or CT, a needle is inserted through the abdomen into the tumour. The needle sends out radio waves that produce heat and destroy the cancer cells. The treatment is performed under local anaesthetic.
- **Chemo-embolisation** – 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 under local anaesthetic and you may need to stay in hospital overnight.
- **Peptide receptor radionuclide therapy (PRRT)** – This treatment is used for functioning and non-functioning pancreatic NETs that have receptors for the hormone somatostatin. You will be given amino acids to protect your kidney function. Then, a cell-targeting protein, or peptide, which is combined with a radioactive substance, is injected into the blood stream. Each session lasts around four hours and most people have a few sessions over several weeks or months.

Palliative treatment

Palliative treatment helps to improve quality of life by easing symptoms of cancer when a cure may not be possible. It is particularly important for people with advanced cancer, but it can be used during different cancer stages.

Often treatment focuses on pain relief and stopping the spread of cancer, but it can also involve the management of other physical and emotional symptoms, such as depression. Treatment may include radiotherapy, chemotherapy or other medication.

If pancreatic cancer has spread and it is not possible to treat it with surgery, your doctor may recommend treatment to relieve problems such as:

- **jaundice** – caused by narrowing of the bile duct
- **persistent vomiting and weight loss** – caused by obstruction in the stomach or small bowel
- **poor digestion** – caused by the 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.

See pages 45–55 for information on managing dietary issues that may be caused by pancreatic cancer and its treatment.



Key points

- When pancreatic cancer is advanced or cannot be surgically removed, treatment to relieve symptoms is still possible.
- A double bypass surgery may be performed to relieve jaundice or a blockage in the duodenum.
- Alternatively, a stent may be inserted to increase the flow of bile into the bile duct, or food into the bowel.
- The procedure to insert a stent is known as an endoscopic retrograde cholangiopancreatography (ERCP).
- Chemotherapy is the use of drugs to kill or slow the growth of cancer cells. It is sometimes used on its own, or in combination with radiotherapy (chemoradiation), to treat advanced cancer.
- Radiotherapy, which directs x-ray beams at the cancer, is sometimes used with chemotherapy (chemoradiation) for advanced cancer, or on its own as palliative treatment.
- Other treatments for pancreatic NETs may include radiofrequency ablation, microwave ablation and chemo-embolisation.
- Peptide receptor radionuclide therapy (PRRT) may be used to treat advanced pancreatic NETs that have receptors for the hormone somatostatin.
- Palliative treatment helps to improve quality of life by easing symptoms of cancer when a cure may not be possible.



Managing dietary problems

Pancreatic cancer, and treatments such as surgery, chemotherapy and radiotherapy, can affect your ability to eat, digest and absorb food. This can have a significant impact on nutrition, which can become a major focus for many people.

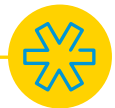
Common problems include:

- weight loss
- poor appetite and feeling full quickly
- nausea and/or vomiting
- changes in taste and smell
- changes in bowel habits
- 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 may vary from person to person. You may find it helpful to talk to a dietitian for individual advice.

Dietitians are experts in nutrition who can give you specialist advice on how to cope with nutrition-related problems and eating difficulties. See page 54 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.



Eating after a Whipple procedure

People who have a Whipple procedure (see page 28) may have many questions and concerns about their diet following the surgery.

The suggestions on the opposite page may be helpful when you start to eat after surgery.



Jan's story

I was diagnosed with pancreatic cancer when my third child was six weeks old.

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.

A month later I had Whipple's surgery. After the procedure, eating was hard and it was a real 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 natural the foods, the easier it was to handle. I found packaged foods were harder to deal with.

My tolerances have increased over the years, and trial and error has helped.



Managing food after a Whipple procedure

- Eat small meals every 2–3 hours rather than three large meals each day.
- Ensure that meals and snacks are nourishing and include protein, e.g. meat, chicken, fish, dairy products, eggs, tofu and nuts. This will help recovery and improve your nutrition.
- Sip only small amounts of liquids during meals to avoid filling up too quickly.
- Limit foods that produce wind (gas), e.g. legumes (dried beans, peas or lentils); vegetables such as broccoli, Brussels sprouts, cabbage, cauliflower or asparagus; and carbonated (gassy) drinks.
- Talk to a dietitian or your doctor about vitamin and enzyme supplements if you can't digest and absorb food properly. You may need a multivitamin supplement to provide calcium, folic acid, iron, vitamin B12 and the fat-soluble vitamins A, D, E and K.
- Ensure you take the right amount of digestive enzyme supplements, if prescribed (see page 52).
- Limit or avoid eating fatty, greasy or fried foods if these cause discomfort, even when taking adequate pancreatic enzymes.
- Nutritional supplements drinks, such as Sustagen[®] Hospital Formula, Ensure[®] and Resource[®], are high in energy and protein and have important vitamins and minerals. These may be prescribed after surgery.

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.
- Add extras to your basic foods at mealtimes.
- Add milk powder to cereals, sauces, desserts, mashed vegetables, soup, drinks and egg dishes.
- Add cheese to sauces, soup, vegetables, baked beans, casseroles, salads and egg dishes.
- Add golden syrup or honey to cereal, fruit and drinks.
- Use food-type nutrition supplements (see page 53).
- Relax normal low-cholesterol and other dietary restrictions. Gaining weight or maintaining your weight is more important than avoiding extra fat and sugar.

Change in taste or smell

- If food tastes bland, use seasoning, i.e. herbs, lemon, lime, ginger, garlic, soy sauce, honey, chilli, pepper, Worcestershire sauce or pickles.
- Some drinks may taste different or be off-putting because of the smell or texture. Choose non-alcoholic alternatives or try a milkshake, fresh juice or hot chocolate.
- 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 meat is less appetising, 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, have bad odour, 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 anti-diarrhoea medication.
- Drink plenty of liquids (e.g. water, fruit juice or weak cordial) to replace lost fluids.
- Avoid fried or greasy foods.
- 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.

Nausea

- Talk to your doctor about trying anti-nausea medication.
- Try snacks 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.
- Choose cold foods instead of hot, fried, greasy or spicy foods.
- Avoid strong odours and cooking smells.
- Suck peppermint or lemon-flavoured boiled lollies.
- Try drinking ginger beer, ginger ale or ginger tea, or sucking on candied ginger.
- See next page for tips on dealing with vomiting.

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.

See your doctor if vomiting lasts for more than a day or if you can't keep any fluids down, as you may become dehydrated. If you have persistent vomiting, the part of your body that connects your stomach to your small bowel may be blocked. This may be relieved with surgery – see pages 36–38.

How to cope with vomiting

Stage 1 – Small sips

Don't try to force food down. Sip small amounts of liquid as often as possible. Try dry ginger ale, cold flat lemonade, weak cordial, cold apple or orange juice. Ensure fizzy drinks are flat before you drink them.

Stage 2 – Introduce drinks slowly

If the vomiting has stopped but you still feel nauseated, 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.

Stage 3 – Introduce solid foods

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.

Stage 4 – Return to normal diet

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

Diabetes

Some people develop diabetes before pancreatic cancer is diagnosed or soon after surgery. Diabetes, or high blood sugar levels, can occur if your pancreas is not making enough insulin (a hormone responsible for regulating blood sugar levels).

The way diabetes is managed varies from person to person but usually includes a combination of dietary changes and medication. If needed, your doctor will advise you on medications and a dietitian will help you manage and change your diet.



Coping with diabetes

- Eat small meals and snacks regularly to help control blood sugar levels.
- If you are taking diabetes medication, you need to include high-fibre carbohydrate foods at every meal to avoid low blood sugar levels. These include wholegrain breads and cereals, vegetables and fruit.
- For more information about diabetes see diabetesaustralia.com.au

Pancreatic enzyme replacement supplements

The pancreas produces digestive enzymes to help break down the food you eat into basic nutrients that your body can use.

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 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 fatty bowel movements (stools) that are pale in colour, frothy, loose and difficult to flush
- weight loss.



Taking enzyme supplements

- Take supplements at the same time as food and drink to ensure adequate mixing.
- Always take supplements with food and drink that contains fat or protein.
- Slightly higher doses of enzymes may be needed if eating a high-fat meal, 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 the dose as prescribed. Do not change the dose without talking to your doctor first.

Your doctor may prescribe pancreatic enzymes to help prevent these symptoms. Pancreatic enzymes are available in varying strengths. The dose will be based on, and adjusted to your individual symptoms and dietary intake. It may take time to get this balance right.

Often people who take pancreatic enzymes will also be prescribed acid-suppressing medicine. This medicine helps the pancreatic enzymes work properly.

Nutritional supplements

If you are not able to eat a balanced diet, or are experiencing unintentional weight loss, your doctor or dietitian may suggest that you take nourishing fluids and/or nutritional supplements.

Nutritional supplements such as Sustagen® Hospital Formula, Ensure® and Resource® contain energy, protein and other nutrients in a concentrated source. Nutritional supplements should be taken in addition to eating your usual meals, i.e. as snacks between meals. They are available as ready-made drinks or in powdered form to be mixed with milk or water.

Glucose powder supplements can also provide energy, but shouldn't be used as a meal replacement as they don't provide protein, vitamins or minerals. Glucose supplements may not be recommended if you have been diagnosed with diabetes.

Ask a dietitian where to buy the most appropriate supplement for you, and to advise you on the type and quantity.

Seeing a dietitian

Dietitians work in all public hospitals and most private hospitals. There may be a dietitian connected to your cancer treatment centre.

The Dietitians Association of Australia (DAA) can also help you locate an Accredited Practising Dietitian in your area, who specialises in cancer or has experience with particular clinical conditions.

Visit daa.asn.au or call them on **1800 812 942**. Dietitians in private practice may also be listed in the Yellow Pages®.

If your doctor 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.



Key points

- Pancreatic cancer and its treatment can have a significant impact on eating and nutrition.
- The impact 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 unintentional weight loss.
- It is important to eat a nourishing diet with regular meals and snacks. Often a diet high in energy and protein is required to prevent or minimise weight loss.
- Some people will develop diabetes before pancreatic cancer is diagnosed or soon after surgery. Management usually requires a combination of dietary changes and medication.
- 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.
- Dietitians are experts in nutrition who can give you advice on eating problems. They are found in most public and private hospitals.



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. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful. For more information, call 13 11 20 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.

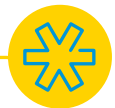
Give yourself time to adjust to what's happening, and do the same for others. People may deal with the cancer in different ways, for example by being overly positive, playing down fears, or keeping a distance. It may be helpful to discuss your feelings with each other.

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 *Sexuality, Intimacy and Cancer* and *Emotions and Cancer*, or download the booklets from the website.



Life after treatment

For most people, the cancer experience doesn't end on the last day of treatment. Life after cancer treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry if every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to 'normal life', but they don't want life to return to how it was before cancer. Take some time to adjust to the physical and emotional changes, and re-establish a new daily routine at your own pace.

Cancer Council 13 11 20 can help you connect with other people who have had cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

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 or medication – even for a short time – may help. Some

people are able to get a Medicare rebate for sessions with a psychologist. 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 or call **1300 224 636** to order a fact sheet.

After treatment: follow-up

After your treatment, you will need regular check-ups to confirm that the cancer hasn't come back.

Check-ups will become less frequent if you have no further problems. Between follow-up appointments, let your doctor know immediately of any health problems.

What if the cancer returns?

Unfortunately pancreatic cancer is difficult to treat, and it often comes back after treatment. This is known as a recurrence.

Most of the time, surgery is not an option if you have a recurrence. Your doctors may recommend you have other types of treatment, such as chemotherapy or radiotherapy.

If the medical team is unable to treat the cancer, treatments can be given to reduce symptoms and improve quality of life. This is called palliative treatment (see page 43). You may also find it helpful to read the following chapter, *Living with advanced cancer*.



Living with advanced cancer

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, or you may feel sadness, anger or disbelief. You might think:

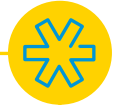
- Why me?
- It's not fair.
- How long do I have left?
- I am not ready to die. I have so many things I still want to do and achieve.
- How can I stop this happening?
- I don't want to live anymore. What's the point? I want it to be over now.

Some days will be easier than others. There will be days when you feel tired and unsure, while other days you will have more energy and feel more optimistic.

Some people find it important to stay hopeful during times of sadness or uncertainty. This may help you feel more able to deal with the situation. Your hopes may change over time – you may hope for a cure, to be around for a special event, or that your symptoms will be well controlled.

You might find it helpful to talk a palliative care team about what you are going through. For example, your doctors and nurses can help you cope with symptoms and side effects. You may want to talk to a social worker, counsellor or pastoral care worker about your feelings.

For more information, call Cancer Council **13 11 20** to obtain a free copy of *Living with Advanced Cancer* or *Understanding Palliative Care*, or visit your local Cancer Council website.





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.

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 in these support settings 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. This includes:

- **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 cancerconnections.com.au

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 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 Home Help, Meals on Wheels or visiting nurses can help you in your caring role. 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. Phone 1800 242 636 or visit carersaustralia.com.au for more information and resources.

You can also call Cancer Council 13 11 20 to find out more about carers' services and 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

Cancer Council Australia.....	cancer.org.au
Cancer Australia.....	canceraustralia.gov.au
Carers Australia.....	carersaustralia.com.au
Department of Health.....	health.gov.au
Health Direct Australia.....	healthdirect.gov.au
Australian Pancreatic Cancer Genome Initiative.....	pancreaticcancer.net.au
Pancare Foundation.....	pancare.org.au
Unicorn Foundation.....	unicornfoundation.org.au

International

American Cancer Society.....	cancer.org
Macmillan Cancer Support.....	macmillan.org.uk
National Cancer Institute (US).....	cancer.gov
Johns Hopkins Medicine Pancreatic Cancer Research Center.....	path.jhu.edu/pc/
Pancreatic Cancer Action Network.....	pancan.org
NET Patient Foundation.....	netpatientfoundation.org



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?



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.

adjuvant therapy

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

advanced cancer

Cancer that has spread from where it started (the primary site) to other parts of the body. If it has spread to distant parts of the body it is called metastatic advanced cancer.

anaemia

A reduction in the number or quality of red blood cells in the body.

anaesthetic

A drug that stops a person feeling pain during a medical procedure. A local anaesthetic numbs part of the body; a general anaesthetic causes a temporary loss of consciousness.

benign

Not cancerous or malignant. Benign lumps are not able to spread to other parts of the body.

bile

A fluid made in the liver and stored in the gall bladder that helps with the digestion of fats.

biopsy

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

carcinoid syndrome

Symptoms, such as diarrhoea, wheezing and flushed skin, that may occur in patients with carcinoid tumours.

carcinoid tumour

A type of neuroendocrine tumour that most commonly occurs in the appendix, small intestine, lung, kidney, colon or pancreas.

cells

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

chemotherapy

The use of drugs to treat cancer by killing cancer cells or slowing their growth.

common bile duct

The passage through which bile from the liver passes to the duodenum. Also called bile duct.

CT scan

A computerised tomography scan. This type of scan uses x-rays to create a picture of the body.

debulking

An operation 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 produce enough of the necessary hormone (insulin) or the body has become resistant to the effect of insulin.

diagnosis

The identification and naming of a person's disease.

dietitian

A health professional who supports and educates patients about nutrition and diet at diagnosis, and during treatment and recovery.

distal pancreatectomy

Surgery to remove tumours in the tail and head 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 which produce hormones.

endocrinologist

A doctor who specialises in treating people with disorders of the endocrine system.

endoscope

The flexible tube used during an endoscopy.

endoscopic retrograde cholangiopancreatography

A procedure used to examine the pancreas and bile duct, or insert a stent. Also known as ERCP.

endoscopy

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

enzymes

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

exocrine gland

A gland that secretes a substance through a duct.

exocrine tumour

The most common type of pancreatic cancer. It starts in the cells that make pancreatic enzymes that aid digestion.

functioning tumour

A type of neuroendocrine tumour that secretes hormones that may cause symptoms.

gall bladder

A small organ on the underside of the liver that stores bile.

gastrinoma

A pancreatic neuroendocrine tumour. It makes and releases (secretes) 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.

gland

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 secretes too much of the hormone glucagon.

hormones

Chemicals in the body that send information between cells.

insulin

A chemical messenger (hormone) secreted 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 secretes too much insulin.

jaundice

A condition caused by increased amounts of bile in the blood. This causes the skin and the whites of the eyes to turn yellow.

laparoscopy

Surgery done through small cuts in the abdomen using a laparoscope for viewing. Also called keyhole surgery.

liver

A large organ in the top right side of the abdomen. It has a number of functions including making bile, which helps digestion.

lymph nodes

Small, bean-shaped glands that form part of the lymphatic system. Also called lymph glands.

lymphatic system

A network of tissues, capillaries, vessels, ducts and nodes, which removes excess fluid from tissues, transports fat and fights infection.

malignant

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

metastasis

A cancer deposit that has spread from a primary cancer in another part of the body. Also known as secondary cancer.

MRCP scan

A magnetic resonance cholangiopancreatography scan. It is a type of MRI scan that produces more detailed pictures and can check the common bile duct for blockages.

MRI scan

A magnetic resonance imaging scan. A scan that uses magnetism and radiowaves to take detailed cross-sectional pictures of the body.

neoadjuvant therapy

A treatment given before the primary treatment to enhance the primary treatment's effectiveness.

NET (neuroendocrine tumour)

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.

outpatient

A person who receives medical treatment without being admitted into hospital.

pancreas

An organ in the digestive system. 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

A positron emission tomography scan. A specialised imaging test that uses a radioactive glucose solution to identify groups of cancer cells in the body.

prognosis

The predicted outcome of a person's disease.

radionuclide

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

radiotherapy

The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply.

recurrence

A cancer that comes back after treatment.

scintigraphy

A scanning method that uses a radioactive substance to locate tumours in the body. Types of scans include PET (positron emission tomography) scans, SRS (somatostatin receptor scintigraphy) and MIBG (metaiodobenzylguanidine) scans.

somatostatin

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

somatostatinoma

A type of pancreatic neuroendocrine tumour that secretes 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 tube made of metal or plastic that is inserted into a vessel or passage to keep it open.

tissue

A collection of cells 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 (not cancer) or malignant (cancer).

ultrasound

A non-invasive scan that uses soundwaves to create a picture of part of the body. An ultrasound scan can be used to measure the size and position of a tumour.

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.

References

1. Australian Institute of Health and Welfare (AIHW) 2015. Australian Cancer Incidence and Mortality (ACIM) books: Pancreatic Cancer. Canberra: AIHW. Available at aihw.gov.au/acim-books.
2. Australian Institute of Health and Welfare 2014. Cancer in Australia: an overview 2014. Cancer series No 90. Cat. no. CAN 88. Canberra: AIHW.
3. Cancer Australia 2014. Pancreatic Cancer. Available at canceraustralia.gov.au/affected-cancer/cancer-types/pancreatic-cancer.

Can't find a word here?

For more cancer-related words, visit:

- cancercouncil.com.au/words
- cancervic.org.au/glossary
- cancersa.org.au/glossary.



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 Pink Ribbon Day, 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.

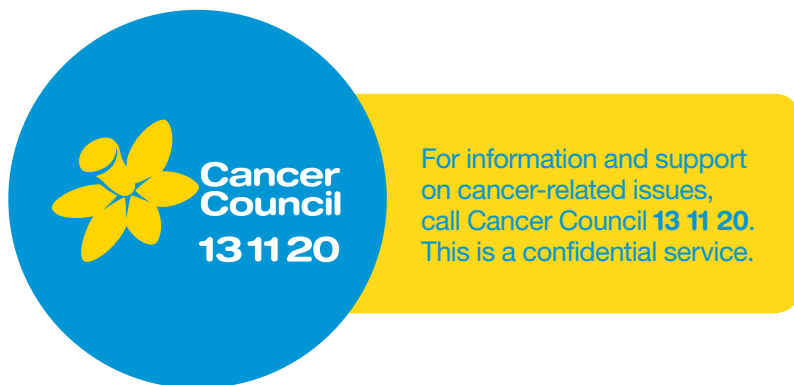
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



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, contact us through the National Relay Service.
www.relayservice.gov.au



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

Cancer Council Australia
cancer.org.au

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