



Understanding Pancreatic Cancer

A guide for people with cancer,
their families and friends

Cancer
information

For information & support, call

13 11 20



Understanding Pancreatic Cancer

A guide for people with cancer, their families and friends

First published May 1995. This edition February 2020.

© Cancer Council Australia 2020. ISBN 978 1 925651 75 1

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

Editor: Ruth Sheard. Designer: Emma Johnson. Printer: SOS Print + Media Group.

Acknowledgements

This edition has been developed by Cancer Council NSW on behalf of all other state and territory Cancer Councils as part of a National Cancer Information Subcommittee initiative.

We thank the reviewers of this booklet: Dr Lorraine Chantrill, Head of Department, Medical Oncology, Illawarra Shoalhaven Local Health District, NSW; Marion Bamblett, Nurse Unit Manager, Cancer Centre, Fiona Stanley Hospital, WA; Prof Katherine Clark, Clinical Director of Palliative Care, Northern Sydney Local Health District Cancer and Palliative Care Network, and Conjoint Professor, Northern Clinical School, The University of Sydney, NSW; Lynda Dunstone, Consumer; Kate Graham, Accredited Practising Dietitian – Upper GI Dietitian, Peter MacCallum Cancer Centre, VIC; Dr Gina Hesselberg, Radiation Oncologist, St George Hospital Cancer Centre, NSW; Dr Marni Nenke, Endocrinologist and Mary Overton Early Career Research Fellow, Royal Adelaide Hospital, SA; Caitriona Nienaber, 13 11 20 Consultant, Cancer Council WA; A/Prof Nicholas O'Rourke, Head of Hepatobiliary Surgery, Royal Brisbane Hospital and The University of Queensland, QLD; Rose Rocca, Senior Clinical Dietitian – Upper GI, Peter MacCallum Cancer Centre, VIC; Gail Smith, Consumer. We also thank the health professionals, consumers and editorial teams who have worked on previous editions of this title.

This booklet is funded through the generosity of the people of Australia.

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.



Cancer Council Australia

Level 14, 477 Pitt Street, Sydney NSW 2000

Telephone 02 8063 4100 **Facsimile** 02 8063 4101 **Email** info@cancer.org.au **Website** cancer.org.au

ABN 91 130 793 725

About this booklet

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, your family and friends 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 what to ask your treatment team (see page 70 for a question checklist).

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 page 71). 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.¹⁻³

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. You can also visit your local Cancer Council website (see back cover).



**Cancer
Council
13 11 20**

Contents

What is cancer?	4
The pancreas	6
Key questions	8
What is pancreatic cancer?	8
What are the main types?	8
How common is it?	9
What are the risk factors?	9
How important are genetic factors?	10
What are the symptoms?	11
What can I expect after diagnosis?	12
Where should I have treatment?	13
Which health professionals will I see?	14
Diagnosis	16
Blood tests	16
Imaging scans	17
Tissue sampling.....	21
Staging and grading	23
Prognosis	25
Making treatment decisions	27
Treatment for early pancreatic cancer	29
Treatments before or after surgery	29
Surgery for early pancreatic cancer	29
What to expect after surgery	34
What if the cancer returns?	35

Treatment for advanced pancreatic cancer..... 38

Surgery to relieve symptoms.....	39
Chemotherapy.....	41
Radiation therapy	42
How palliative care can help	44

Treatment for pancreatic NETs..... 46

Surgery for early pancreatic NETs.....	47
Options for advanced pancreatic NETs.....	48

Managing dietary problems..... 53

Nutritional supplements	56
Enzyme replacement therapy.....	57
Vomiting	58
Diabetes	60

Looking after yourself..... 62

Living with pancreatic cancer..... 64

When the cancer is advanced.....	65
----------------------------------	----

Seeking support..... 66

Support from Cancer Council	67
Useful websites	68

Caring for someone with cancer..... 69

Question checklist..... 70

Glossary..... 71

How you can help..... 76



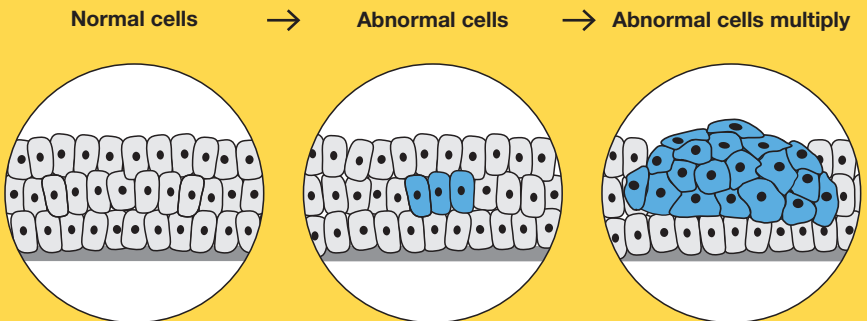
What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up tissues and organs. 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, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. In solid cancers, such as pancreatic cancer, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into cancer.

How cancer starts

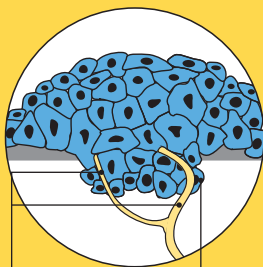


Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops is called the primary cancer. It is considered localised cancer if it has not spread to other parts of the body. If the primary cancer 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 called metastatic pancreatic cancer, even though the main symptoms may be coming from the liver.

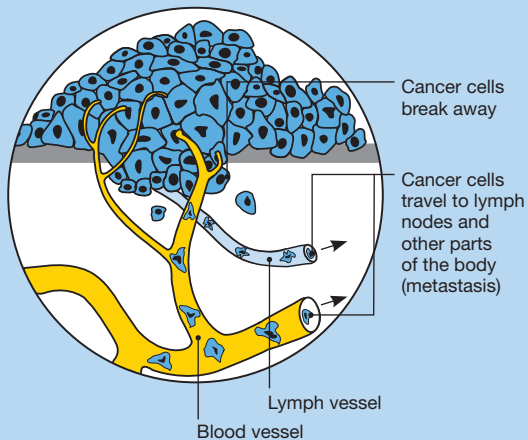
How cancer spreads

→ Malignant cancer



Grows own blood vessels (angiogenesis)

Invades surrounding tissue



Cancer cells break away

Cancer cells travel to lymph nodes and other parts of the body (metastasis)

Lymph vessel

Blood vessel



The pancreas

The pancreas is a long, flat gland about 13–15 cm long that lies between your stomach and spine. It is divided into three parts:

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

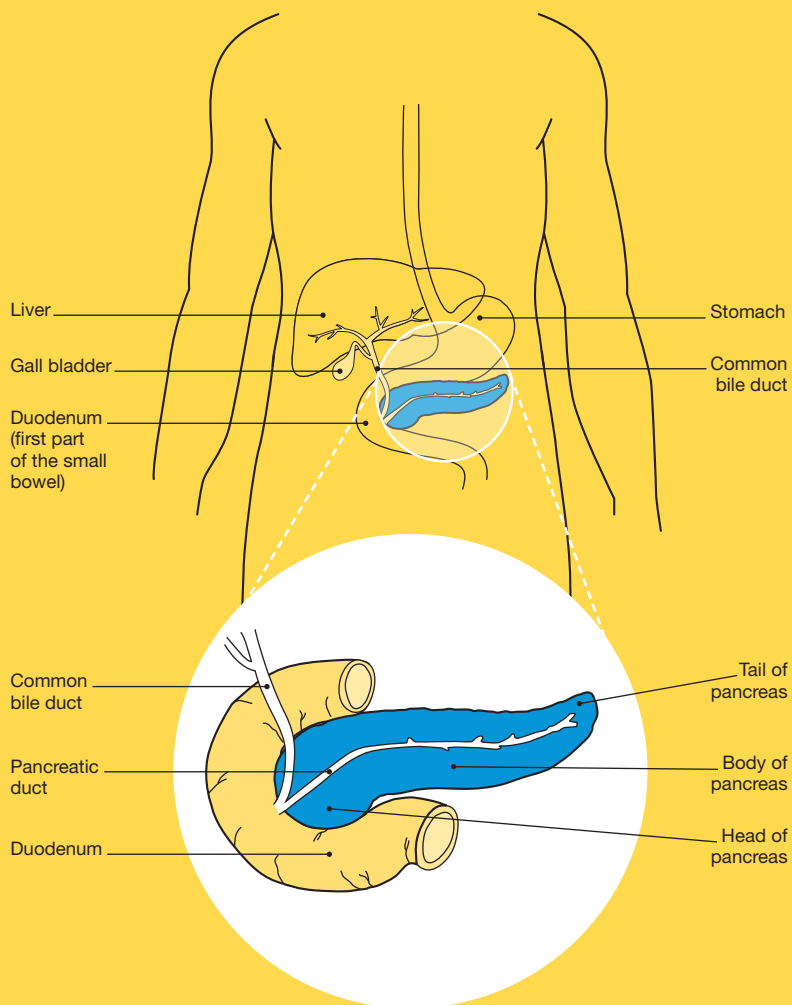
A tube called the pancreatic duct connects the pancreas to the first part of the small bowel (duodenum). Another tube, called the common bile duct, joins with the pancreatic duct and connects the liver and gall bladder to the duodenum.

What the pancreas does

Exocrine function – The pancreas is part of the digestive system, which helps the body digest food and turn it into energy. Exocrine cells make pancreatic enzymes, which are digestive juices. The pancreatic duct carries these juices from the pancreas into the duodenum, where they help to break down food. Most of the pancreas is made up of exocrine tissue.

Endocrine function – The pancreas is also part of the endocrine system, a group of glands that makes the body's hormones. Endocrine cells in the pancreas make hormones that control blood sugar levels, the amount of acid produced by the stomach, and how quickly food is absorbed. For example, the hormone insulin decreases the level of sugar in the blood, 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 any part of the pancreas. This may affect how the pancreas works, including its exocrine or endocrine functions. About 70% of pancreatic cancers are found in the head of the pancreas.

Pancreatic cancer can spread to nearby lymph nodes, blood vessels or nerves, and to the lining of the abdomen (peritoneum). Cancer cells may also travel through the bloodstream to other parts of the body, such as the liver.

Q: What are the main types?

A: There are two main types of pancreatic cancer:

Exocrine tumours – These make up more than 95% of pancreatic cancers. The most common type, called an adenocarcinoma, starts in the cells lining the pancreatic duct. Less common types include adenosquamous carcinoma and undifferentiated carcinoma. The different types are named after the cells they start in. Treatment for exocrine tumours is discussed in two chapters – see pages 29–45.

Pancreatic neuroendocrine tumours (NETs) – About 5% of pancreatic cancers are pancreatic NETs. These start in the endocrine cells (see page 6). Pancreatic NETs are categorised as either non-hormone producing (non-functioning) or hormone producing (functioning). Treatment for pancreatic NETs is discussed on pages 46–52.

Q: How common is it?

A: About 3300 Australians are diagnosed with pancreatic cancer each year. More than 80% are over the age of 60.⁴ It is estimated to be the eleventh most common cancer in males and eighth most common in females in Australia during 2019.⁵

Q: What are the risk factors?

A: Research has shown that people with certain risk factors are more likely to develop pancreatic cancer. Known risk factors include:

- smoking (cigarette smokers are about twice as likely to develop pancreatic cancer as non-smokers)
- obesity
- ageing
- type 2 diabetes
- 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 next page)
- workplace exposure to some pesticides, dyes or chemicals.



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

Q: How important are genetic factors?

A: Most people diagnosed with pancreatic cancer do not have a family history of the disease. About one in 10 people who develop pancreatic cancer have an inherited faulty gene that increases the risk of developing pancreatic cancer.

You may have an inherited faulty gene if:

- two or more of your close family members (such as a parent or sibling) have had pancreatic cancer
- there is a family history of a genetic condition, such as 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), neurofibromatosis (NF-1), Von Hippel-Lindau (VHL) disease or tuberous sclerosis.

Genetic testing aims to detect faulty genes that may increase a person's risk of developing some cancers. People with a strong family history of cancer can attend a family cancer clinic for genetic counselling and tests. For more information, talk to your doctor, local family cancer centre or Cancer Council 13 11 20.

“ My symptoms started with itchy skin. After a few days I was jaundiced and had dark-coloured urine and back pain. ” Leslye

Q: What are the symptoms?

A: Early-stage pancreatic cancer rarely causes symptoms. Symptoms may not appear until the cancer is large enough to affect nearby organs or has spread. Common symptoms are listed below. These symptoms can also occur in many other conditions and do not necessarily mean that you have cancer. Speak with your general practitioner (GP) if you have any of these symptoms.

Common symptoms of pancreatic cancer

Exocrine tumours and pancreatic NETs	Functioning pancreatic NETs
<ul style="list-style-type: none">• 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• newly diagnosed diabetes	<p>Because these rare pancreatic NETs produce excess hormones, they also have symptoms such as:</p> <ul style="list-style-type: none">• too much sugar in the blood (diabetes)• a drop in blood sugar• blurred vision• being very thirsty• needing to pass urine more often• reflux• severe watery diarrhoea

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.

Treatment for 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 the cancer.

Treatment for 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.

Treatment for pancreatic NETs (pages 46–52) – These tumours are uncommon and many are diagnosed at an advanced stage. There are additional treatment options for both early and advanced pancreatic NETs.

Managing your diet (pages 53–61) – 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. 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. This is especially the case with surgery for early pancreatic cancer (see pages 29–35). There is strong evidence that outcomes are better with an experienced surgeon who performs the operation at least several times a year.

Specialist treatment centres have multidisciplinary teams of health professionals experienced in treating pancreatic cancer (see pages 14–15). These centres see a lot of people with pancreatic cancer and are also associated with better outcomes. Visiting one of these centres gives you access to a wide range of treatment options, but it may mean you need to travel away from home for treatment. To find a specialist treatment centre for pancreatic cancer, talk to your GP.

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 trip. 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 general practitioner (GP) will arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a specialist, such as a gastroenterologist. The specialist will arrange further tests. If pancreatic cancer is diagnosed, the specialist will consider treatment options. Often

Health professionals you may see

pancreatic or HPB (hepato-pancreato-biliary) surgeon*	operates on the liver, pancreas and surrounding organs
gastroenterologist*	diagnoses and treats disorders of the digestive system, including pancreatic cancer and blocked bile ducts; may perform endoscopy
medical oncologist*	treats cancer with drug therapies such as chemotherapy, immunotherapy and targeted therapy (systemic treatment)
radiation oncologist*	treats cancer by prescribing and overseeing a course of radiation therapy
endocrinologist*	diagnoses and treats hormonal disorders, including diabetes
nuclear medicine specialist*	coordinates the delivery of radioactive iodine treatment and nuclear scans
radiologist*	analyses x-rays and scans; an interventional radiologist may also perform a biopsy under ultrasound or CT, and deliver some treatments

these will be discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting. During and after treatment, you will see a range of health professionals who specialise in different aspects of your care. Pancreatic cancer is challenging to treat and it is recommended that you are treated in a specialist treatment centre (see page 13).

cancer care coordinator	coordinates your care, liaises with other members of the MDT and supports you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)
nurse	administers drugs and provides care, information and support throughout treatment
palliative care team	a team of specialist doctors, nurses and allied health workers who work closely with the GP and oncologist to help control symptoms and maintain quality of life
dietitian	recommends an eating plan to follow while you are in treatment and recovery; helps with managing weight changes and digestive/bowel problems
social worker	links you to support services and helps you with emotional, practical and financial issues
psychologist, counsellor	help you manage your emotional response to diagnosis and treatment
physiotherapist, occupational therapist	assist with physical and practical problems, including restoring movement and mobility after treatment and recommending aids and equipment

**Specialist doctor*



Diagnosis

If your doctor thinks you may have pancreatic cancer, you will need some tests to confirm the diagnosis. These may include blood tests, imaging scans, endoscopic tests and tissue sampling (biopsy).

The tests you have will depend on the symptoms, type and stage of pancreatic cancer. You will not have all the tests described in this chapter. Some are only used to detect pancreatic NETs.

Blood tests

You are likely to have blood tests to check your general health and see how well your liver and kidneys are working.

Some blood tests look for proteins produced by cancer cells. These proteins are called tumour markers. Many people with pancreatic cancer have higher levels of the markers CA19-9 (carbohydrate antigen) and CEA (carcinoembryonic antigen). Other conditions can also raise the levels of these markers in the bloodstream, and some people with pancreatic cancer have normal levels.

The levels of tumour markers can't be used to diagnose pancreatic cancer on their own, but they may tell your doctor more about the cancer and how well the treatment is working. It is normal for the levels of these markers to go up and down a bit. Your doctor will look for sharp increases and overall patterns.

If your doctor suspects you have pancreatic NETs, you may have a blood test to check for high levels of certain hormones and a tumour marker called CgA (chromogranin-A).

Imaging scans

Tests that create pictures of the inside of the body are known as imaging scans. Different scans can provide different details about the cancer. You will usually have at least one of the following scans during diagnosis and 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

Most people suspected of having pancreatic cancer will have a CT (computerised tomography) scan. This scan uses x-ray beams to create detailed, cross-sectional pictures of the inside of your body.

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



Before having scans, tell the doctor if you have any allergies or have had a reaction to contrast during previous scans. You should also let them know if you have diabetes or kidney disease or are pregnant.

The CT scanner is large and round like a doughnut. You will need to lie still on a table while the scanner moves around you. The scan itself is painless and takes only a few minutes, but the preparation can take 10–30 minutes.

MRI and MRCP scans

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

An MRI or MRCP takes about an hour and you will be able to go home when it is over. Before the scan, you may be asked not to eat or drink (fast) for a few hours. You may also be given an injection of dye to highlight the organs in your body.

During the scan, you will lie on a treatment table that slides into a large metal tube that is open at both ends. The noisy, narrow machine makes some people feel anxious or claustrophobic. If you think you will be distressed, mention this beforehand to your doctor or nurse. You may be given medicine to help you relax, and you will usually

be offered headphones or earplugs. Also let the doctor or nurse know if you have a pacemaker or any other metallic object in your body, as this can interfere with the scan.

MRIs for pancreatic cancer are not always covered by Medicare. If this test is recommended, check with your treatment team what you will have to pay.

Endoscopic scans

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

You will be asked not to eat or drink (fast) for six 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.

Having an endoscopic scan has some risks, including infection, bleeding and inflammation of the pancreas (pancreatitis). These risks are uncommon. Your doctor will explain these risks before asking you to agree (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) is used to take an x-ray of the common bile duct and 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 bile duct to keep it open.

PET-CT scan

A PET (positron emission tomography) scan combined with a CT scan is a specialised imaging test. It may take several hours to prepare for and complete a PET-CT scan. Before the scan you will be injected with a small amount of radioactive material to highlight tumours in the body. The radioactive material may be either:

Fluorodeoxyglucose (FDG) – This substance is commonly used in PET scans. Some cancer cells may show up brighter on the scan because they take up more glucose solution than normal cells do. This scan can help doctors work out whether pancreatic cancer has spread or how it is responding to treatment.

68-Gallium DOTATATE (GaTate) – For most pancreatic NETs, the radioactive material used in a PET scan is 68-Gallium DOTATATE. This scan can help show the exact position of pancreatic NETs and may show tumours that don't appear on other scans. It may also 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.

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

If imaging scans show there is a tumour in the pancreas, your doctor may remove a sample of cells or tissue from the tumour (biopsy). This is the main way to confirm if the tumour is cancer and to 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). If you are having surgery to remove the tumour, your doctor may take the tissue sample at the same time. A pathologist will examine the sample under a microscope to check for signs of cancer.

Fine needle or core biopsy

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

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 done under general anaesthetic, so you will be asked not to eat or drink (fast) for six hours beforehand. If you take blood-thinning medicines or are diabetic, let your doctor or nurse know before the laparoscopy as they may need to adjust your medicines in the days leading up to the procedure.

A laparoscopy is done with an instrument called a laparoscope, which is a long tube with a light and camera attached. The camera projects images onto a TV screen so the doctor can see the inside of your body. 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.

●● 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

Staging and grading

The test results will show what type of pancreatic cancer it is, where in the pancreas it is, and whether it has spread. This is called staging and it helps your doctors work out the best treatment options for your situation.

Pancreatic cancer is commonly staged using the TNM (tumour–nodes–metastasis) system. The TNM scores are combined to work out the overall stage of the cancer, from stage 1 to stage 4 (see table on the next page).

Your doctor may also tell you the grade of the cancer. Grading describes how the cancer cells look under a microscope compared to normal cells and how aggressive they may be. 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 (low grade), 2 (intermediate grade) or 3 (high grade).

If you need help to understand staging and grading, ask someone in your treatment team to explain it in a way that makes sense to you. You can also call Cancer Council 13 11 20.

TNM staging system for pancreatic cancer

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)	Refers to whether the cancer has spread to lymph nodes. Exocrine tumours (N0–N2) and pancreatic NETs (N0–N1) are assessed differently. N0 means the cancer has not spread to nearby lymph nodes; N1 or N2 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.

Stages of pancreatic cancer

stage 1	Cancer is found only in the pancreas. This is sometimes called early-stage disease.
stage 2	Cancer is large but has not spread outside the pancreas; or it has spread to a few nearby lymph nodes (exocrine tumours) or nearby structures such as the duodenum or common bile duct (endocrine tumours).
stage 3	Cancer has grown into nearby major blood vessels (exocrine tumours) or nearby organs such as the stomach or colon (endocrine tumours). There may or may not be cancer in the lymph nodes. This is called locally advanced cancer.
stage 4	The cancer has spread to more distant parts of the body, such as the liver, lungs or lining of the abdomen. There may or may not be cancer in the lymph nodes. 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 hard to treat successfully. If the cancer is diagnosed at an early stage and can be surgically removed, the prognosis may be better, especially in the case of pancreatic NETs.

Discussing your prognosis and thinking about the future can be challenging and stressful. 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 situation. 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 about diagnosing pancreatic cancer

What it is

There are two main types of pancreatic tumours: adenocarcinomas and pancreatic neuroendocrine tumours (NETs).

Main tests

- Blood tests can check your general health and look for tumour markers.
- Imaging scans (ultrasound or CT), help show where the cancer is in the pancreas, and if it has spread to other areas of the body.
- Endoscopic scans can create detailed pictures of the pancreas and ducts. A long, flexible tube with a light and small camera is passed into your digestive system.
- A tissue sample (biopsy) may be removed and examined under a microscope to see whether cancer is present and, if so, what type it is.

Other tests

- Some people have a type of MRI called an MRCP. This can help show blockages in the common bile duct.
- Some people have a PET-CT scan to see if pancreatic cancer has spread.

Staging and grading

- The stage shows how far the cancer has spread throughout the body. Most pancreatic cancers are not found until they are advanced.
- The grade indicates how fast the cancer is likely to grow. The higher the grade, the faster the cancer cells are growing.
- Staging helps your treatment team decide on suitable treatment options.



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, or you might be anxious to get started. Check with your specialist how soon treatment should begin, as it may not affect the success of the treatment to wait a short time. Ask them to explain the options, and take what time you can before making a decision.

Know your options – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see page 15) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

Record the details – When your doctor first tells you that you have cancer, you may not remember everything you are told. Taking notes can help or you might like to ask if you can record the discussion. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

Ask questions – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 70 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

Consider a second opinion – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all of your

options. Specialists are used to people doing this. Your GP or specialist 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 second specialist.

It's your decision – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.

- ▶ See our *Cancer Care and Your Rights* booklet and “Making Treatment Decisions” podcast episode.

Should I join 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.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit australiancancertrials.gov.au.
▶ See our *Understanding Clinical Trials and Research* booklet.



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 only be suitable for 15–20% of people with pancreatic cancer, as most people are diagnosed at a later stage.

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 that a surgeon who specialises in pancreatic cancer does the surgery (see page 13).

Treatments before or after surgery

Your surgeon may recommend you have other 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 pages 42–43).

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.

The aim of surgery for early pancreatic cancer is to remove all the tumour from the pancreas, as well as a margin of healthy tissue. The type of surgery you have will depend on the size and location of the tumour, your general health and your preferences. Your surgeon will talk to you about the most appropriate surgery for you, as well as the risks and any possible complications. Types of surgery 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 pages 32–33 for more information about this 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 types of bacterial infection. Your doctor may recommend vaccinations before and after a distal pancreatectomy.

Total pancreatectomy – When cancer is large or there are many tumours, 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. It is possible to live without a pancreas. As the body will no longer produce insulin, you will have insulin-dependent diabetes and need regular insulin injections. You will also need to take pancreatic enzyme supplements to help digest certain foods (see page 57). It is important that an endocrinologist is part of your treatment team. They can help you adapt to life without a pancreas.

Surgery to relieve symptoms

During surgery to remove the cancer, the surgeon may find that the cancer has spread (metastasised) 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, they may be able to perform procedures (such as a double bypass) that will relieve some of the symptoms caused by the cancer. See pages 39–40 for more information.

How the surgery is done

Surgery for pancreatic cancer is carried out in hospital under a general anaesthetic. There are three main approaches:

- **Open surgery** involves one larger cut in the abdomen.
- **Laparoscopic surgery** involves several small cuts in the abdomen. The surgeon inserts a light and camera (laparoscope) into one of the cuts and performs the surgery using images from the camera for guidance.
- **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 best option in some situations.

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

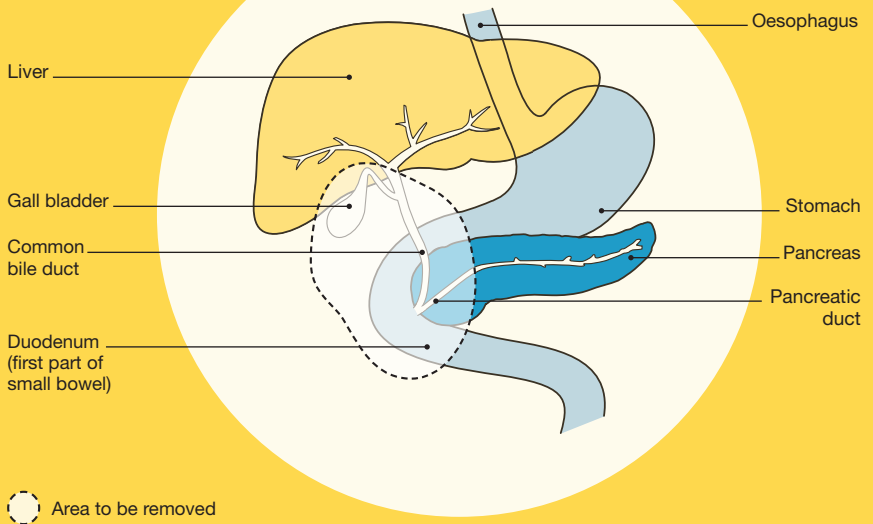
› See our *Understanding Surgery* booklet.

Having 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 common bile duct.

Before

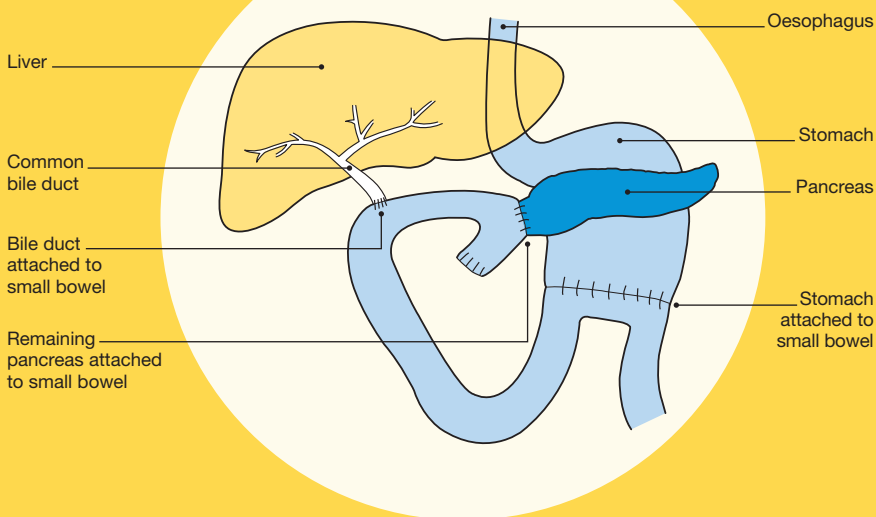


A Whipple procedure is extensive surgery and usually lasts 5–8 hours. As your surgeon will explain, there is a small chance of serious complications, such as major bleeding or leaking from one of the joins between the removed parts.

Then the surgeon reconnects the remaining part of the pancreas, common 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. Many people need to change their diet after a Whipple procedure.

After



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

What to expect after surgery

While you are recovering after surgery, your health care team will check your progress and help you with the following:

Pain control – You will have some pain and discomfort for several days after surgery. You will be given pain-relieving medicines to manage this. If you are in pain when you return home, talk to your medical team about prescribing pain medicine.

Surgical drain – You may have a thin tube placed in the wound to drain excess fluid into a small bag. The tube is usually removed after a few days, but may be left in for longer. Surgical drains are never permanent.

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 changes to eating.

Enzyme supplements – 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 57 for more information.

Insulin therapy – Because the pancreas produces insulin, people who have had all or some of their pancreas removed often develop diabetes after surgery. They may need regular insulin injections (up to four times per day). See page 60 for tips on coping with diabetes.

Moving around – Your health care team will probably encourage you to walk the day after surgery. They will also provide advice about when you can get back to your usual activity levels.

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 need rehabilitation to help you regain physical strength. This may be as an inpatient in a rehabilitation centre or through a home-based rehabilitation program.

What if the cancer returns?

If the surgery successfully removes all of the cancer, you will have regular appointments to monitor your health, manage any long-term side effects and check that the cancer hasn't come back or spread. Check-ups will become less frequent if you have no further problems. Between appointments, let your doctor know immediately of any symptoms or health problems.

Unfortunately, pancreatic cancer is difficult to treat and it does often come 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 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 get new treatments by joining a clinical trial (see page 28).



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.



Key points about early pancreatic cancer

What it is

Early-stage pancreatic cancer is an adenocarcinoma or other exocrine tumour that has not spread outside the pancreas.

The main treatment

The main treatment is surgery to remove the tumour (resection). This is an option for a small number of people with early pancreatic cancer.

Types of surgery

- A Whipple procedure treats tumours in the head of the pancreas. It 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.
- 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.

Other treatment options

- You may have chemotherapy, alone or in combination with radiation therapy, before or after surgery.
- After part or all of the pancreas is removed, you may need to take pancreatic enzymes to help digest fat and protein, or have insulin injections if you develop 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 without trying to cure the disease. This is called palliative treatment.

Some people think 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 as fully and comfortably as possible.

Palliative treatments may include surgery, chemotherapy and radiation therapy, either on their own or in combination. This chapter describes how cancer treatments are used to relieve some common symptoms of advanced pancreatic cancer, such as:

- jaundice caused by narrowing of the common bile duct
- ongoing vomiting and weight loss caused by a blockage in the stomach or small bowel
- pain in the abdomen and middle back.

Many people with advanced pancreatic cancer have digestive problems – for example, a blockage in the pancreatic duct can stop the flow of the digestive enzymes required to break down food. This can be treated with pancreatic enzyme supplements. See pages 53–61 for ways to change your diet to help manage some common dietary problems 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; dark urine; and pale stools (poo).

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. Surgical options for managing these 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 small bag on the 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

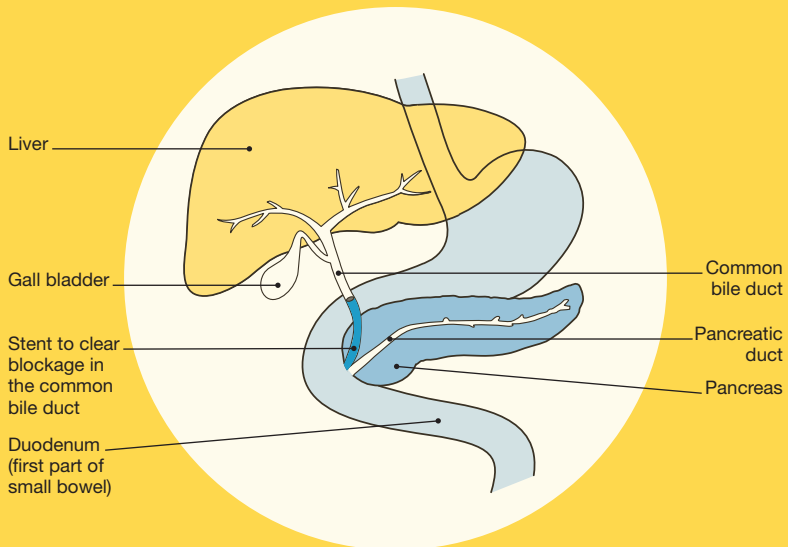
If the cancer cannot be removed and is pressing on the common bile duct or duodenum, you may need a stent. A stent is a small tube made of either plastic or metal. It holds the bile duct or duodenum open, allowing the bile or food to flow into the bowel again.

A bile duct 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 through your mouth,

stomach and duodenum. With the help of x-rays, the doctor places the stent across the blockage to keep the bile duct open. You may have the ERCP as an outpatient or stay in hospital for 1–2 days.

A duodenum stent is usually inserted through the mouth using an endoscope.

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



Chemotherapy

Chemotherapy uses drugs to kill or slow the growth of cancer cells. It is sometimes used in combination with radiation therapy (chemoradiation) to slow the growth of locally advanced cancer that has spread beyond the pancreas and cannot be removed with surgery. Chemotherapy is also used palliatively to relieve symptoms.

Chemotherapy is usually given as a liquid through a drip inserted into a vein in the arm or as tablets you swallow. To avoid damaging the veins in your arm, it may also be given through a tube implanted into a vein (called a port, catheter, central line or vascular access device). This will stay in place until all your chemotherapy treatment is over.

You will usually receive treatment as an outpatient. Typically, you will have several courses of treatment, and there will be a rest period of a few weeks between each course. Your medical oncologist will assess how the treatment is working based on your symptoms and wellbeing, as well as scans and blood tests. They will talk to you about how long your treatment will last.

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.



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.

Side effects of chemotherapy

Chemotherapy can affect healthy cells in the body, which may cause side effects. Some people have few side effects, while others have many. The side effects will depend on the drugs used and the dose. Most side effects are temporary and can be managed, so discuss how you are feeling with your medical oncologist and chemotherapy nurses.

Side effects may include fatigue and tiredness; feeling sick (nausea); vomiting; mouth ulcers and skin rashes; hair loss; diarrhoea or constipation; flu-like symptoms such as fever, headache and muscle soreness; and poor appetite. Chemotherapy can also affect your blood count. Fewer white blood cells can mean you are more likely to catch infections. Fewer red blood cells (anaemia) can leave you weak and breathless.

› See our *Understanding Chemotherapy* booklet.

Radiation therapy

Also known as radiotherapy, radiation therapy uses a controlled dose of radiation to kill cancer cells or injure them so they cannot multiply. The radiation is usually in the form of focused x-ray beams targeted at the cancer. Treatment is painless and carefully planned to do as little harm as possible to healthy body tissue near the cancer.

For locally advanced pancreatic cancer, radiation therapy is usually given with chemotherapy (chemoradiation). The chemotherapy drugs make the cancer cells more sensitive to radiation therapy. Chemoradiation may also be used before or after surgery for early pancreatic cancer (see pages 29–33).

Radiation therapy is delivered over a number of treatments known as fractions. Each fraction delivers a small dose of radiation that adds up to the total treatment dose. You will usually have treatment as an outpatient once a day, Monday to Friday, for up to five or six weeks. Each session takes 10–15 minutes. You will lie on a table under a machine that delivers radiation to the affected parts of your body. Your radiation oncologist will advise you about your treatment schedule.

Radiation therapy may also 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 both short-term side effects and late 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. Late side effects are uncommon, but may include damage to the liver, kidneys, stomach or small intestine. Talk to your radiation oncologist or radiation oncology nurse about ways to manage these side effects.

- ▶ See our *Understanding Radiation Therapy* booklet.



A newer radiation technique called stereotactic body radiation therapy (SBRT) delivers a higher dose of radiation per treatment session over a shorter period of time. SBRT is not currently standard practice for pancreatic cancer but is being investigated in clinical trials. SBRT may be a treatment option at some cancer centres.

Managing pain in pancreatic cancer

If pain becomes an issue, you may need a combination of treatments to achieve good pain control. Ways to relieve pain include:

- strong pain medicines such as opioids
 - nerve blocks – injecting anaesthetic or alcohol into nerves
 - anticonvulsants to help control nerve pain
 - chemotherapy and/or radiation therapy to shrink cancer pressing on nerves
 - complementary therapies such as acupuncture, massage and relaxation techniques.
- Tell your treatment team if you have pain, as it is easier to control if treated early. They can also refer you to a pain specialist if needed.
- › See our *Overcoming Cancer Pain* booklet.

How palliative care can help

The options described in this chapter are generally considered palliative treatment (see page 38). Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, emotional, cultural, social and spiritual needs. The team also provides support to families and carers.

Specialist palliative care services see people with more 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.

- › See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets, and listen to *The Thing About Advanced Cancer* podcast.



Key points about advanced pancreatic cancer

What it is	Advanced pancreatic cancer is an adenocarcinoma or other exocrine tumour that has spread from the pancreas to nearby organs or blood vessels (locally advanced) or to other parts of the body (metastatic).
Treatment goal	Palliative treatment aims to control the cancer for as long as possible, slow down its spread and relieve symptoms.
Treatment options	<ul style="list-style-type: none">• Advanced pancreatic cancer can be treated palliatively with surgery, chemotherapy or radiation therapy to ease symptoms.• Some people have a small tube (stent) inserted to relieve a blockage in the common bile duct or duodenum. This allows bile to flow into the bile duct, or food to move into the small bowel.• In some cases, the surgeon will need to relieve a blockage surgically by diverting different parts of the digestive system around the obstruction.• If you have pain, it can be relieved with pain medicines or palliative cancer treatments.• Complementary therapies may help you cope better with pain and other side effects caused by cancer and its treatment.• Palliative care helps to improve your quality of life by addressing your physical, emotional, cultural, social and spiritual 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). Some pancreatic NETs produce hormones (functioning), while most don't (non-functioning). About 90% of pancreatic NETs are non-functioning. This chapter focuses on the treatment of non-functioning pancreatic NETs.

Treatment of pancreatic NETs is complex. To ensure the best outcome it is recommended that you are treated by a multidisciplinary team in a specialist centre (see page 13). Your treatment team will discuss the best treatment for you based on the stage and grade of the tumour (see pages 23–24); whether the tumour is functioning or non-functioning; whether the tumour is associated with an inherited condition (see page 10); your general health; and your preferences.

Functioning tumours are very rare and are usually managed by an endocrinologist and surgeon (see pages 14–15). Types of functioning pancreatic NETs include insulinoma, gastrinoma, glucagonoma, somatostatinoma and VIPoma. The name of the cancer is taken from the type of hormone produced, for example, insulinomas produce too much insulin. Contact Cancer Council 13 11 20 or the Unicorn Foundation (see box below) for information about treating functioning pancreatic NETs.



Neuroendocrine tumours can also affect other areas of the body, including the bowel, lungs and stomach. 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).

Active surveillance

If you are diagnosed with a small, low-grade pancreatic NET that is not causing any symptoms or releasing hormones, your doctor might recommend active surveillance. This involves regular imaging and blood tests. If these tests suggest that the tumour has grown, you will be offered treatment (usually surgery).

Active surveillance might help to avoid the side effects of surgery.

It can also be a reasonable option if you are not well enough for surgery and the tumours are small.

You might feel anxious about not treating a cancer in your body right away. However, active surveillance will only be recommended if the doctor thinks it is the best thing to do. If you are worried, discuss your concerns with your specialist, GP or a counsellor.

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 of 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 done with the aim of cure. There are risks and potential complications involved in pancreatic surgery. For small pancreatic NETs, keeping a watchful eye on the tumour's growth may be preferable to major surgery (see active surveillance, above). Your treatment team will weigh up the benefits and risks of surgery, while taking into account your general health and your preferences.

Types of surgery

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 30).
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 30).

In some cases, you will be given somatostatin analogues (see opposite 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

Different surgical procedures 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. An SSA may be used for a functioning pancreatic NET to slow down the release of hormones and control symptoms, such as diarrhoea. In both functioning and non-functioning NETs, SSAs are also used to slow down a tumour's growth. The main SSAs used in Australia are octreotide and lanreotide. These are given as monthly injections into the thigh or bottom, and have very few side effects.

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, high-grade pancreatic NETs. It may be given on its own, with SSAs or before peptide receptor radionuclide therapy (PRRT, see next page).

Targeted therapy

This is a type of drug treatment that attacks specific features of cancer cells to stop the cancer growing and spreading. People with advanced pancreatic NETs may be offered targeted therapy drugs such as sunitinib and everolimus to slow the growth of the tumour. These are given as capsules that you swallow. Some may be taken daily for many months or even years. How long you take the drugs will depend on

the aim of the treatment, how the cancer responds and the side effects you have. Ask your doctor what side effects you may experience and discuss any side effects with your treatment team as soon as they appear, so they can be managed appropriately.

Peptide receptor radionuclide therapy (PRRT)

PRRT is a type of internal radiation therapy used to treat advanced pancreatic NETs that have large numbers of somatostatin receptors. These are proteins found on the surface of the tumour. If you have PRRT, you will be injected with a somatostatin analogue (SSA) that has been combined with a small amount of a radioactive substance (radionuclide). This mixture targets the somatostatin receptors and delivers a high dose of radiation that kills or damages the cancer cells.

You may have a dose of chemotherapy before PRRT to make the cancer cells more sensitive to the radiation. PRRT is available only in certain treatment centres. You will usually see a nuclear medicine specialist and a medical oncologist. PRRT is given as an outpatient treatment, with a session lasting around 4–5 hours. Depending on the grade of the tumour, you may have four sessions about 6–12 weeks apart. Your doctor will talk to you about possible side effects and safety precautions you may need to follow.



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 38 for more information.

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 as a guide, the doctor inserts a fine needle through the abdomen into the liver tumour. The needle sends out radio waves or microwaves that produce heat and destroy the cancer cells. The treatment takes about 15 minutes and you can usually go home after a few hours. Side effects, including pain or fever, can be managed with medicines.

Transarterial chemoembolisation – In this procedure, the doctor inserts a catheter 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 high dose of radiation to the tumour while causing little damage to normal liver tissue.



Key points about pancreatic NETS

What it is

Pancreatic NETs begin in the endocrine cells in the pancreas. They can be either non-hormone producing (non-functioning) or hormone producing (functioning). About 90% of pancreatic NETs are non-functioning.

The main treatments

- Active surveillance may be used to monitor small, low-grade pancreatic NETs.
- 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.
- Advanced pancreatic NETs can be treated palliatively with surgery, medicines or a type of internal radiation therapy called PRRT.

Symptom control

- 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 and help control some symptoms.
- Peptide receptor radionuclide therapy (PRRT) is given by injection and delivers a high dose of radiation directly to the pancreatic NET cells and any metastases.
- If cancer has spread to the liver, treatments include radiofrequency ablation, 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 essential nutrients. This chapter explains some common dietary problems and how to manage them.

During and after treatment, it's important to make sure you are eating and drinking enough to maintain your weight and avoid malnutrition or dehydration. Different foods can affect people differently, so you will need to experiment to work out which foods cause problems for you.

People who have a Whipple procedure (see pages 32–33) may have many questions and concerns about their diet after surgery. The suggestions on pages 54–55 may be helpful when you start to eat after surgery.

Changes to the way you eat may make you feel anxious, particularly when you know eating well is important. Some people find it difficult to cope emotionally with the changes to how and what they can eat. Finding ways to enjoy your meals can help you feel more in control and improve your quality of life. It may help to talk about how you feel with your family and friends.

If you have ongoing problems with food and eating, talk to a dietitian. 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 on page 56 for information on finding a dietitian.

- See our *Nutrition and Cancer* booklet or call 13 11 20 to speak with a Cancer Connect volunteer who has had a similar cancer experience.

Coping with some common dietary issues

Poor appetite and weight loss

- Eat small meals frequently, e.g. every 2–3 hours. Have a regular eating pattern rather than waiting until you're hungry.
- Ensure that meals and snacks are nourishing and include protein, e.g. meat, chicken, fish, dairy products, legumes (e.g. lentils, chickpeas), eggs, tofu, nuts and nut butters.
- Choose nourishing drinks such as milk.
- Add milk powder to cereals, sauces, mashed vegetables, soup, drinks, egg dishes and desserts.
- Add cheese to sauces, soup, baked beans, vegetables, casseroles, salads and egg dishes.
- Add sugar, honey or golden syrup to cereals, porridge or drinks.
- Talk to a dietitian before cutting out particular foods.
- It's okay to focus on eating foods you enjoy. Relax any low-cholesterol and other dietary restrictions. Gaining or maintaining weight is more important than avoiding extra fat and sugar.
- Have ready-to-eat food available for when you feel like eating or are too tired to cook (e.g. tinned fruit, yoghurt, frozen meals).

Changes in taste or smell

- If food tastes bland, add extra flavouring, 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 their 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 food smells bother 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, such as cheese, eggs, nuts, dairy foods or legumes (e.g. lentils or chickpeas).



Diarrhoea

- Talk to your doctor if your stools are pale in colour, oily, smell particularly bad, float and are difficult to flush, or you notice an oily film floating in the toilet. 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 (see page 57).
- 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. Hard cheese and yoghurt in small amounts are usually okay.
- If diarrhoea occurs 15–30 minutes after eating, you may be experiencing dumping syndrome. This happens when partially digested food moves into the small bowel too quickly. Speak to your treatment team about this.

Nausea

- Talk to your doctor about taking nausea medicine half an hour before meals.
- Snack on bland foods such as dry crackers or toast.
- Try to eat a little bit at regular intervals – not eating or skipping meals 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 pages 58–59 for tips on dealing with vomiting.
- Listen to our “Appetite Loss and Nausea” podcast episode.

Nutritional supplements

If you can't eat a balanced diet or are losing too much weight, your doctor or dietitian may suggest nutritional supplements, e.g. Sustagen, Ensure, Fortisip and Resource. These contain energy, protein and other nutrients that can help you maintain your strength.

Ask a dietitian where to buy supplements, and to advise you on the type and quantity best suited to your needs. Nutritional supplements should be taken in addition to the foods you are able to eat, and are best used as snacks between meals. They are available as:

- ready-made drinks, bars, puddings and custards
- powders to mix with milk or water, or to sprinkle on food.

Seeing a dietitian

A dietitian can prepare eating plans for you and give you advice about nutritional supplements.

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 find an Accredited Practising Dietitian who works

in your area and specialises in cancer. Visit 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. If you have private health insurance, you may be eligible for a rebate depending on your type and level of cover.

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

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 stools (poo) 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 diet. It may take time to get this balance right. A dietitian can help you and your doctor work out the correct dose.



Taking enzyme supplements

- Take enzyme capsules with water and the first mouthful of food to ensure adequate mixing. With larger meals, you may also need to take them halfway through the meal.
- Always take enzymes with 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.
- Take enzymes as prescribed. Do not change the dose without talking to your doctor or dietitian first.



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. There is a range of anti-nausea medicines that you can take regularly to control symptoms. If the one you are prescribed doesn't work, let your doctor or nurse know so you can try another medicine.

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. Signs of dehydration include a dry mouth, dark urine, dizziness and confusion.

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. You may need surgery to clear the blockage – 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 small amounts of drinks slowly and often. 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.

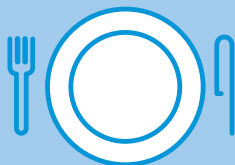
3.



Start solid food

Next, try to 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 amounts of food often, 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 both dietary changes and insulin injections. Sometimes medicines are given as tablets that you swallow.

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 changing your diet.



Coping with diabetes

- Eat small meals and snacks regularly to help control blood sugar levels.
- Talk to your endocrinologist or GP about medicines to help control the diabetes.
- If you are taking diabetes medicine, 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**.



Key points about managing dietary problems

Common changes

- Pancreatic cancer and its treatment can have a significant impact on eating and nutrition.
- 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 changes can cause you to lose too much weight.

Managing changes

- It is important to try 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, or ask your doctor for a referral.
- If you develop pancreatic exocrine insufficiency (PEI), you will need to take pancreatic enzymes to help you digest and absorb fats and proteins. Talk to a dietitian experienced in managing PEI. 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.



Looking after yourself

Cancer can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more, or visit your local Cancer Council website (see back cover).

Eating well – Healthy food can help you cope with treatment and side effects. See pages 53–61 for information about coping with eating problems after treatment and choosing the best foods for your situation.

➤ See our *Nutrition and Cancer* booklet.

Staying active – Physical activity can reduce tiredness, improve circulation and lift mood. The right exercise for you depends on what you are used to, how you feel, and your doctor's advice.

➤ See our *Exercise for People Living with Cancer* booklet.

Complementary therapies – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can 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.

➤ See our *Understanding Complementary Therapies* booklet.



Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

Work and money – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check with a social worker or Cancer Council whether any financial assistance is available to you.

➤ See our *Cancer and Your Finances* and *Cancer, Work & You* booklets.

Relationships – Having cancer can affect your relationships with family, friends and colleagues in different ways. Cancer is stressful, tiring and upsetting, and this may strain relationships. It may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening, and do the same for those around you. It may help to discuss your feelings with each other.

➤ See our *Emotions and Cancer* booklet.

Sexuality – 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.

➤ See our *Sexuality, Intimacy and Cancer* booklet.

Contraception and fertility – If you can have sex, you may need to use certain types of contraception to protect your partner or avoid pregnancy for a time. Your doctor will explain what precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, discuss the options with your doctor before starting treatment.

➤ See our *Fertility and Cancer* booklet.



Living with pancreatic cancer

Life after a diagnosis of pancreatic cancer can present many challenges. It is important to allow yourself time to adjust to the physical and emotional changes. Establish a new daily routine that suits you and the symptoms you're coping with. Your family and friends may also need time to adjust.

For some people, the cancer goes away with treatment. Other people will have ongoing treatment to manage symptoms. You are likely to feel a range of emotions about having pancreatic cancer. Talk to your treatment team if you are finding it hard to manage your emotions. Cancer Council 13 11 20 can also provide you with some strategies for coping with the emotional and practical aspects of living with pancreatic cancer.

➤ See our *Emotions and Cancer* booklet.

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

can get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call Beyond Blue on **1300 22 4636** or visit **beyondblue.org.au**. For 24-hour crisis support, call Lifeline **13 11 14** or visit **lifeline.org.au**.



The Thing About Advanced Cancer podcast

For information and insights that can help you navigate through the challenges of living with advanced cancer, listen to Cancer Council NSW's audio podcast series, *The Thing About Advanced Cancer*. To listen, go to cancercouncil.com.au/advanced-cancer-podcasts.

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 may include a social worker, counsellor or 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.

- See our *Living with Advanced Cancer* and *Understanding Palliative Care* booklets.



Seeking support

A cancer diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Cancer also often creates practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including:

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact of cancer treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs
- counselling services.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost.

To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.

“ 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*

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).



Information resources

Cancer Council produces booklets and fact sheets on over 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call **13 11 20** or visit your local Cancer Council website (see back cover).

Practical help

Your local Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.



Legal and financial support

If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council **13 11 20** to ask if you are eligible.

Peer support services

You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call **13 11 20** or visit cancercouncil.com.au/OC.



Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

Australian

Cancer Council Australia	cancer.org.au
Cancer Australia	canceraustralia.gov.au
Cancer Council Online Community	cancerCouncil.com.au/OC
Cancer Council podcasts	cancerCouncil.com.au/podcasts
Optimal Care Pathways	cancerpathways.org.au
Carer Gateway	carergateway.gov.au
Carers Australia	carersaustralia.com.au
Department of Human Services	humanservices.gov.au
Australian Pancreatic Cancer Genome Initiative	pancreaticcancer.net.au
Avner Pancreatic Cancer Foundation	avnersfoundation.org.au
GI Cancer Institute	gicancer.org.au
Palliative Care Australia	palliativecare.org.au
Pancare Foundation	pancare.org.au
PanSupport	pansupport.org.au
Targeting Cancer	targetingcancer.com.au
Unicorn Foundation	unicornfoundation.org.au

International

The Sol Goldman Pancreatic Cancer Research Center (US)	path.jhu.edu/pc/
Pancreatic Cancer Action Network (US)	pancan.org
NET Patient Foundation (UK)	netpatientfoundation.org



Caring for someone with cancer

You may be reading this booklet because you are caring for someone with pancreatic cancer. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a wide range of support available to help you with the practical and emotional aspects of your caring role.

Support services – Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local services, as well as information and resources, through the Carer Gateway. Call 1800 422 737 or visit carergateway.gov.au.

Support groups and programs – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

Carers Associations – Carers Australia works with the Carers Associations in each state and territory to provide information and services to carers. Call 1800 242 636 or visit carersaustralia.com.au.

Cancer Council – You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.

- See our *Caring for Someone with Cancer* booklet or listen to our “Cancer Affects the Carer Too” podcast episode.



Question checklist

Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

Diagnosis

- What type of pancreatic cancer do I have?
- Has the cancer spread? If so, where has it spread? How fast is it growing?
- Are the latest tests and treatments for this cancer available in this hospital?
- Will a multidisciplinary team be involved in my care?
- Are there clinical guidelines for this type of cancer?

Treatment

- What treatment do you recommend? What is the aim of the treatment?
- Are there other treatment choices for me? If not, why not?
- If I don't have the treatment, what should I expect?
- How long do I have to make a decision?
- I'm thinking of getting a second opinion. Can you recommend anyone?
- How long will treatment take? Will I have to stay in hospital?
- Are there any out-of-pocket expenses not covered by Medicare or my private health cover? Can the cost be reduced if I can't afford it?
- How will we know if the treatment is working?
- Are there any clinical trials or research studies I could join?
- Do I need the support of a specialist palliative care service?

Side effects

- What are the risks and possible side effects of each treatment?
- Will I have a lot of pain? What will be done about this?
- Can I work, drive and do my normal activities while having treatment?
- Will the treatment affect my sex life and fertility?
- Should I change my diet or physical activity during or after treatment?
- Are there any complementary therapies that might help me?

After treatment for early pancreatic cancer

- How often will I need check-ups after treatment?
- If the cancer returns, how will I know? What treatments could I have?



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. Also known as the belly.

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. It starts in the pancreatic duct lining.

adjuvant therapy

A treatment given with or shortly after the main treatment to enhance the main treatment's effectiveness.

advanced cancer

Cancer that is unlikely to be cured. In most cases the cancer has spread to other parts of the body (secondary or metastatic cancer). Treatment can often still control the cancer and manage symptoms.

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 produced by the liver and stored in the gall bladder. It helps the digestive system break down fats from food.

biopsy

The removal of a sample of tissue

from the body for examination under a microscope to help diagnose a disease.

catheter

A hollow, flexible tube through which fluids can be passed into the body or drained from it.

cells

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

chemotherapy

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

common bile duct

The tube through which bile travels from the liver and gall bladder to the bowel.

CT scan

Computerised tomography scan. This scan uses x-rays to create cross-sectional pictures of the body.

debulking

Surgery to remove as much of a tumour as possible. This makes it easier to treat the cancer that is left and increases the effectiveness of other treatments, such as chemotherapy.

diabetes

A disorder in which blood sugars are not taken up in the body properly because the pancreas does not make enough of the necessary 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.

endocrinologist

A doctor who specialises in treating 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 internal examination or diagnostic test. A thin, flexible tube with a light and camera (endoscope) is used to examine the inside of the body.

enzymes

Proteins that aid digestion and are essential for the normal functioning and performance 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.

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 type of neuroendocrine tumour that releases hormones that may 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 doctor who specialises in diagnosing and treating disorders of the digestive system.

genes

The microscopic units that determine how 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 the blood sugar levels.

glucagonoma

A type of 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. Hormones control many of the body's functions, including how you grow, develop and reproduce.

immunotherapy

A type of drug treatment that uses the body's own 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 may deliver some treatments.

jaundice

A condition caused by high levels of a substance called bilirubin in the blood. This can occur when the bile ducts are blocked or the liver is not working properly. Jaundice causes yellow, itchy skin; the whites of the eyes to turn yellow; pale stools (poo); and dark urine.

laparoscopy (keyhole surgery)

Surgery done through small cuts in the abdomen using a thin viewing instrument called a laparoscope.

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 vessels, nodes and organs that removes excess fluid from tissues, absorbs fatty acids, transports fat and produces immune cells.

lymph nodes

Small, bean-shaped structures found in groups throughout the body. They help protect the body against disease and infection. Also called lymph glands.

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 magnetic fields and radio waves to take detailed, cross-sectional pictures of the body.

neoadjuvant therapy

A treatment given before another treatment to make that treatment more successful.

neuroendocrine tumour (NET)

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

non-functioning tumour

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

nuclear medicine specialist

Coordinates the delivery of radionuclide therapy and nuclear scans.

outpatient

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

pancreas

An organ in the digestive and endocrine systems. It 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 enzymes 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.

radiation therapy

The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. 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 type of pancreatic neuroendocrine tumour 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.

stools

The bulky mass of waste material that normally leaves the body through the anus. Also known as faeces or poo.

targeted therapy

Drugs 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.

VIPoma

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
- cancervic.org.au/glossary
- 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, iss. 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, suppl. 5, 2015, pp. v56–v68 (incorporating ESMO Guidelines Committee, *eUpdate – Cancer of the pancreas treatment recommendations*, 15 March 2019).
3. Clinical Oncology Society of Australia, *Guidelines for the diagnosis and management of gastroenteropancreatic neuroendocrine tumours*. Available url: https://wiki.cancer.org.au/australia/COSA:NETs_guidelines (accessed 4/9/2019).
4. Australian Institute of Health and Welfare (AIHW), *Cancer Data in Australia; Australian Cancer Incidence and Mortality (ACIM) books: pancreatic cancer*, AIHW, Canberra, 2018.
5. Australian Institute of Health and Welfare (AIHW), *Cancer in Australia 2019*, AIHW, Canberra, 2019.



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.

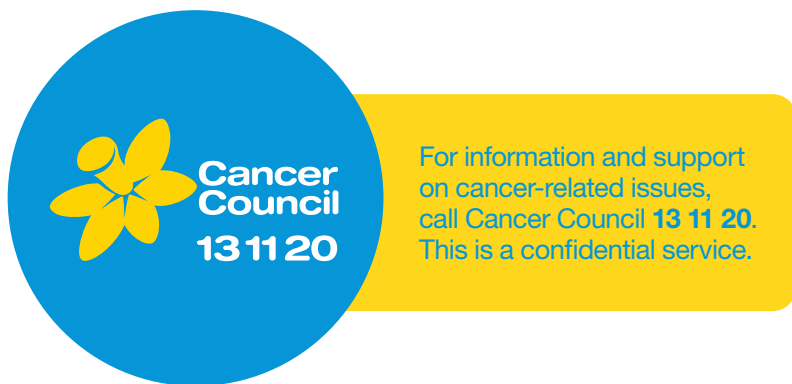
Cancer Council services and programs vary in each area.

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



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

*This booklet is funded through the generosity of the people of Australia.
To support Cancer Council, call your local Cancer Council or visit your local website.*