

Patient Handbook:

For people affected
by **pancreatic**
cancer



Pancreatic Cancer Handbook

An information booklet for people living with pancreatic cancer. An initiative of the Pancare Foundation and the Avner Nahmani Pancreatic Cancer Foundation



Published

The information in this booklet has been adapted from material compiled by the Pancreatic Cancer UK organisation. It has been reviewed and modified by the members of the Pancare Foundation Medical Advisory Board listed below and reviewed by the Avner Nahmani Pancreatic Cancer Foundation during its development.

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Note to Reader

All care has been taken to ensure that the information in this booklet is accurate at the time of publication. No sponsoring organisation has had any input into the contents of this booklet. Please note that information relating to pancreatic cancer is constantly being updated by the medical profession and the research community. This handbook is not intended as a substitute for professional help or advice by medical practitioners. It is important to discuss any medical (physical/emotional/general) symptoms, questions or concerns with your healthcare professional as soon as possible. Pancare Foundation and the Avner Nahmani Pancreatic Cancer Foundation exclude themselves from all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

Pancare Foundation

The Pancare Foundation is Australia's only charity providing awareness, research and support for those affected by pancreatic, liver, biliary and foregut cancers. When a patient is diagnosed with cancer it impacts on the whole family and the community in which they live. The Pancare Foundation

not only focuses on expediting scientific progress but also the delivery of programs that are designed to address individual and changing patient needs, from the point of diagnosis through to recovery and bereavement.

Avner Nahmani Pancreatic Cancer Foundation

The Avner Nahmani Pancreatic Cancer Foundation is the only foundation in Australia exclusively dedicated to pancreatic cancer. It was named after Avner, a dearly loved husband, father, friend and colleague. Avner was diagnosed with Pancreatic Cancer in September 2007 and passed away thirteen short months later. Prior to his passing, Avner wanted to do something that would offer future patients hope. In 2008, together with his wife Caroline, friends and colleagues, he established a research fund, which in 2010 became incorporated as a Foundation. The Vision of the Foundation is to break through 40 years of no progress by doubling the number of people who survive Pancreatic Cancer by 2020. Avner's wife Caroline carries on the work of the Foundation.



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that help confirm a diagnosis and provides an overview of possible treatment options and the wider impact of the diagnosis. The information may also be helpful for anyone who is undergoing investigations for pancreatic cancer and wondering what the next steps might be.

If you have only just been told about your diagnosis you may be feeling surprised or shocked, as many people diagnosed with pancreatic cancer have no idea they were seriously ill. You may have been feeling unwell for a while but without knowing what was wrong. You might feel frightened, angry or upset, but remember there isn't any 'right' way to feel; everyone deals with things in their own way.

There is a lot to take in at this time, so this booklet is a good place to start. Please however remember that you should 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 appropriate independent professional advice relevant to your specific situation and you may wish to discuss issues raised in this book with them.

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

Introduction

This booklet is for anyone who has recently been diagnosed with pancreatic cancer. Partners, family members and carers may also find it useful. It gives a general introduction to pancreatic cancer, information on tests and investigations

What is the pancreas?

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

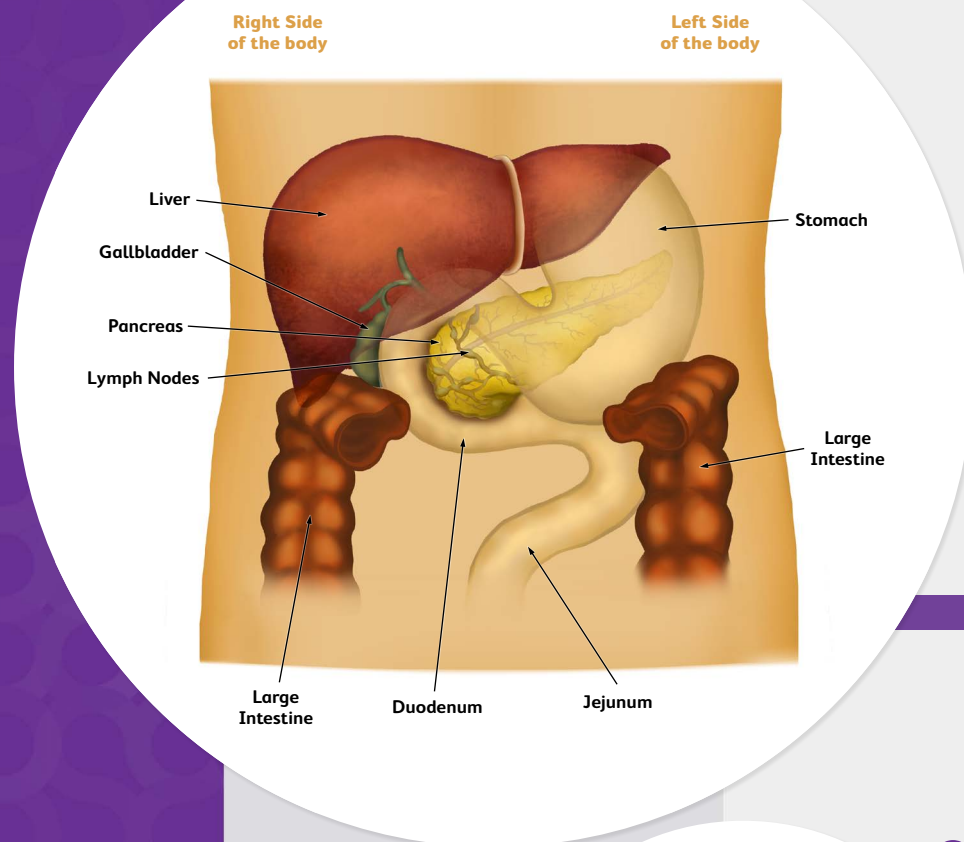
The pancreas has two important functions. It produces:

- Enzymes (protein substance produced that increase rates of reactions) that are secreted in the pancreatic digestive juices which help break down food so the body can absorb nutrients. These digestive juices flow down a tube called the pancreatic duct which runs the length of the pancreas.
- Hormones (chemical messengers) that enter the body and flow around the bloodstream. The most important of these is insulin, which helps to regulate the amount of sugar in the blood.

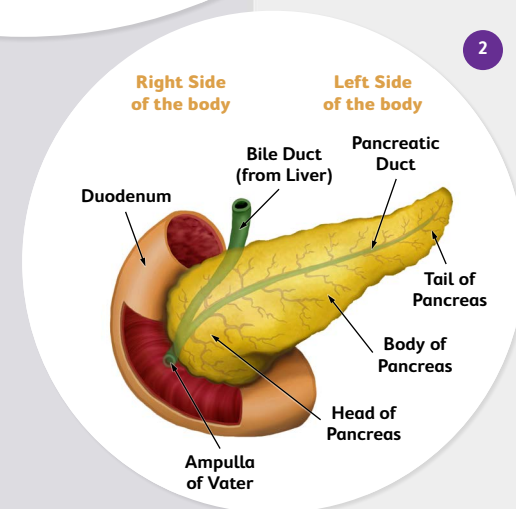
If the pancreas isn't working properly then both these functions can be affected.

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

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1. pancreas and liver illustration

2. pancreas diagram

What is Pancreatic Cancer?

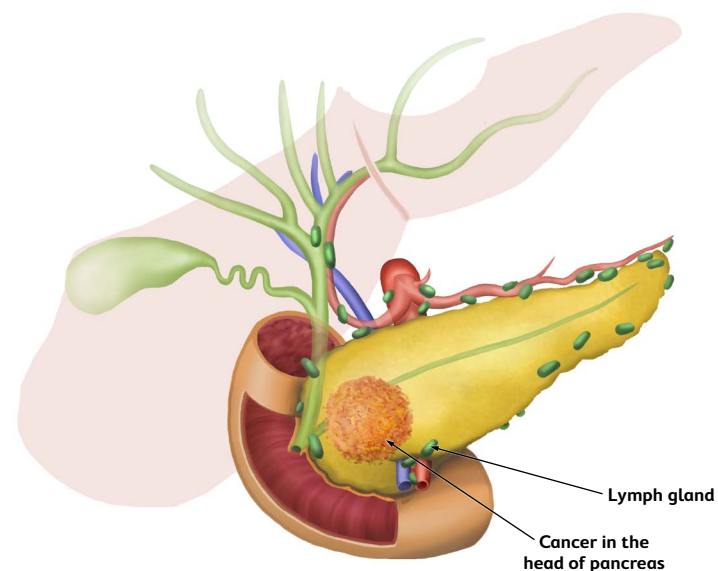
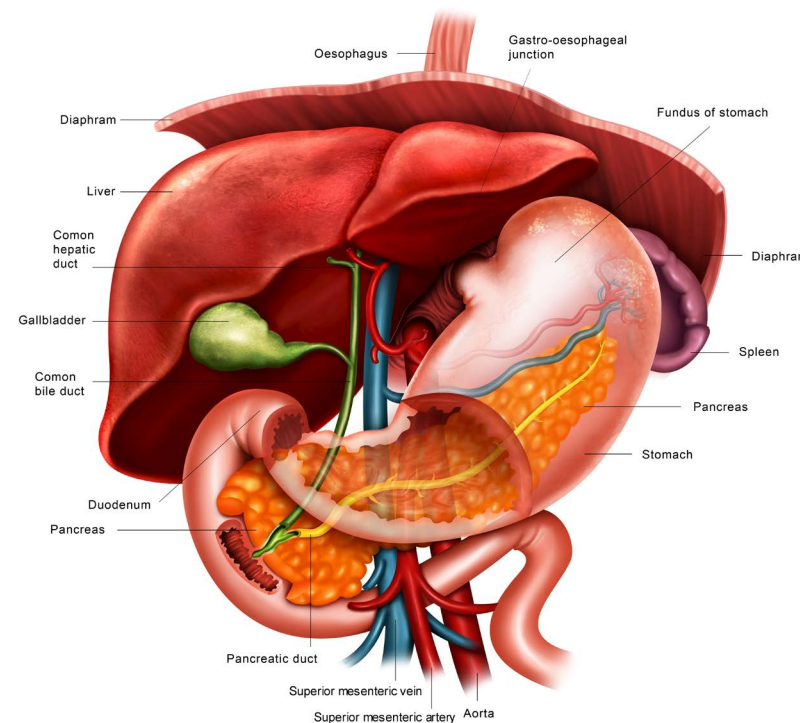
Pancreatic cancer occurs when abnormal cells in the pancreas grow out of control. It can occur in the head, body or tail of the pancreas.

Pancreatic cancers are divided into two main groups – exocrine and endocrine tumours.

- Exocrine tumours start in the exocrine cells that make enzymes to help digestion. 95% of pancreatic cancers are classified as exocrine tumours and about 90% of these are called pancreatic ductal adenocarcinomas (PDAC).
- Endocrine tumours (also called neuroendocrine tumours) start in the hormone producing cells and account for only 5% of all pancreatic cancers.

The symptoms produced by pancreatic cancer vary according to the location of the tumours and the tumour type. Exocrine tumours (PDAC) in general have a far worse prognosis (likely outcome) than pancreatic neuroendocrine tumours.

There is a 1 in 68 life-time risk of developing pancreatic cancer (PDAC) based on world-wide statistics. In Australia 2,780 new cases of pancreatic cancer were diagnosed in 2010 with 2,434 deaths occurring during the same time-period¹. Pancreatic cancer currently is the fourth leading cause of cancer death in our society.



Diagnosing pancreatic cancer

Reaching a diagnosis of pancreatic cancer can be a lengthy and complex process. When the disease first develops it often doesn't cause any symptoms so you may have had cancer for some time without knowing.

Some symptoms, for example jaundice, persistent abdominal pain or unexplained weight loss require urgent investigation by your GP or referral to a specialist for assessment. However, any symptoms you do have can be quite vague and may also be a sign of other more common, less serious illnesses. This means you may have been sent for several different tests before pancreatic cancer was considered.

Alternatively, you may have been admitted to hospital, perhaps even as an emergency because you were unwell and a diagnosis was made there. However, you have probably already had a number of different tests to confirm the diagnosis of pancreatic cancer.

Sometimes people with pancreatic cancer can begin to feel very unwell quite quickly. If you are waiting for tests and you experience any worsening symptoms you should contact your GP, or your specialist if you already have one. Symptoms to watch out for include losing weight despite eating well; nausea or vomiting; pale, smelly and floating stools; pain; jaundice or worsening itching of the skin.

What are the clues to the diagnosis of pancreatic cancer?

Some known risk factors for developing pancreatic cancer include:

- Smoking
- Obesity
- Diabetes
- Family history of pancreatic cancer

Possible symptoms may include:

- Jaundice – yellowing of the skin and eyes
- Dark urine
- Pale stools (faeces) which are foul smelling and difficult to flush
- Gradually worsening upper abdominal or back pain
- Unexplained weight loss
- Nausea and vomiting after meals

Tests and investigations

The tests used to confirm a pancreatic cancer diagnosis are described below. Your doctors will use the test results to work out the best treatment for you. Although you will have had some of these tests you may need others to find out exactly what type of pancreatic cancer you have and what stage it is. You may not need all the tests included here. Your specialist will give you more detailed information about what tests are most appropriate for your condition.

Blood tests

- Various blood tests are used to check your blood count, liver and kidney function and your general health. Blood tests can also check for tumour markers. These are chemical substances produced by cancers that show up in the bloodstream. For example, CA19-9 is a tumour marker linked to pancreatic cancer. Not all pancreatic cancers produce it and it may also occur with some other illnesses that are not cancer. This means blood tests are used together with other test results to make a diagnosis. Blood samples are usually examined in the hospital laboratory within a day or two. Sometimes samples have to be sent away for analysis and it can take several days to get the results.



Ultrasound scan of the abdomen

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

CT (Computerised Tomography) scan

- A CT scan uses x-rays to build up a three-dimensional picture of the pancreas and the other organs around it. It is also usual to scan your chest and pelvic area to check for any signs of cancer outside the pancreas. A CT scan can also be used to guide the needle during a biopsy that is performed in some cases. This procedure involves a tissue sample being taken for examination under a microscope.

PET-CT scan

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

MRI (Magnetic Resonance Imaging)

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

MRCP (Magnetic Resonance Cholangio-Pancreatography)

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

EUS (Endoscopic Ultrasound)

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

Laparoscopy

- This is a small operation done under general anaesthetic. A long tube with a camera at one end is inserted through a small cut in your abdomen so the doctor can examine you internally. Other small cuts may be made so instruments can be inserted to help with the examination. This test can help to clarify whether a tumour has spread to other regions and can be removed by surgery. Sometimes an ultrasound probe is also used (Laparoscopic Ultrasound) to help identify suspicious areas and take a biopsy. This test may or may not be performed depending on your surgeon's practices and the results of other tests.

ERCP (Endoscopic Retrograde Cholangio-Pancreatography)

- Like the EUS this test uses an endoscope but it also involves taking x-rays. Dye is injected through the tube directly into the opening (the ampulla of Vater) of the pancreatic duct. Any blockages will then show up on x-rays. While the endoscope is in place the doctor may take tissue samples for biopsy. If there is a blockage in your bile duct they may insert a small tube (called a stent) into the duct.

Biopsy

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

Waiting to have tests carried out

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

If your symptoms get worse or you start to feel more unwell while you are waiting, it's a good idea to get in touch with your GP or specialist if you already have one. If you cannot get in contact with them you may need to present to the closest emergency department if your symptoms cannot be controlled at home.

If you do have to go into hospital for any reason you can ask if any tests you are waiting for can be done while you are there.

It is important to obtain as much information as possible before embarking on a treatment strategy.

Several weeks of testing to confirm a diagnosis or awaiting appointments is relatively common and is unlikely to alter overall outcomes. Cancer growth is considered to be negligible over a period of weeks, and this waiting period is unlikely to cause you harm if your symptoms are stable.

How long will I have to wait for my test results?

Depending on which tests you have had it may take from a few days to a couple of weeks for the results to come through. Waiting for test results can be an anxious time.

It is a good idea to ask how long you may have to wait when you go for the tests. If you think you have been waiting too long then contact your GP or a specialist to follow up on the progress of your results. Usually the doctor who does the test will write a report and send it to your specialist. If your GP sent you for the test the results will be sent to the GP clinic.

You will need an appointment with your specialist or GP to discuss the test results and how they might affect your treatment. Usually your specialist will discuss your results and plan your subsequent care.

Staging

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

Staging is how doctors refer to the size of a cancer and whether it has spread around the tumour site or to other areas of the body. It is an important part of their assessment and contributes to treatment planning. In cases of cancers localised to the pancreas that are surgically operable, the staging, which includes whether there is spread to lymph nodes, often can only be determined once the cancer has been surgically removed.

One system uses numbers to describe the stage of the cancer:

Stage 1: the earliest stage when the cancer is only inside the pancreas.

Stage 2: the cancer is usually larger and may have started to grow into the duodenum, bile duct or tissues around the pancreas or there may be cancer in the lymph nodes near the pancreas.

Stage 3: the cancer is growing outside the pancreas into nearby major blood vessels or nerves, but has not spread to other parts of the body

Stage 4: the cancer has spread to other parts of the body such as the lungs or liver (metastatic cancer).

Another system is called TNM (Tumour-Nodes-Metastases):

T is the size of the tumour

N indicates if it has spread to the lymph nodes

M indicates if the cancer has spread to another part of the body (metastatic cancer).

Being referred to a specialist centre

Anyone diagnosed with pancreatic cancer should have their case reviewed at a centre where there is a specialist multidisciplinary team of doctors who are able to assess and treat the disease.

Guidelines from several countries suggest that surgery is preferably carried out in specialist centres that see and treat a “high volume” of pancreatic cancer patients. The outcomes of pancreatic surgery in particular appears to be better in high volume centres who perform at least 10–20 pancreatic operations per year, by surgeons that perform at least 5 pancreatic resections per year²⁻⁵.

Hospitals in a region often work together with the specialist centres to try to ensure the best treatment and care for all patients close to home. You may find it is not necessary for you to travel to a specialist centre for all investigations. Many tests and investigations can be done at your local hospital and standard chemotherapy can often be given there as well.

However, local hospitals may not always be involved in running clinical trials or offer all the treatments available at specialist centres. Therefore, if you are considering taking part in a particular clinical trial you may need to travel in order to have your treatment.

Who will I be treated by?

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

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

Treatment Options - Surgery

Pancreatic cancer is potentially curable when caught early, but the vast majority of cases are not diagnosed until too late. Pancreatic cancer (adenocarcinoma) is one of the most devastating cancers with generally a poor prognosis.

When imaging suggests that the entire tumour can be removed and has not spread to any other organs, surgical removal can be considered and may achieve a cure. No other therapy can cure pancreatic cancer. Up to 25% of patients with pancreatic cancer can gain significant benefit if the cancer is surgically removed, especially if the tumour is small and not yet spread to the lymph nodes.

Most curative surgery is designed to treat cancers in the head of the pancreas, near the bile duct. Some of these cancers are found early enough because they block the bile duct and cause jaundice. Cancer involvement of major veins (portal vein / superior mesenteric vein) should not preclude surgery, if portions of these blood vessels can be removed in order to completely remove the cancer and then be reconstructed. In some cases surgery is even considered when the cancer is attached to one particular major artery (hepatic artery). Complete encasement (wrapping around) of the superior mesenteric artery, however, is generally considered inoperable. About 10-25% of pancreatic cancers are contained within the pancreas at the time of diagnosis allowing surgery to be considered. In many cases, too few cancer cells to detect may already have spread to other parts of the body. This may explain why the cancer recurs in a large number of patients after surgical removal.

The type of surgery performed is guided

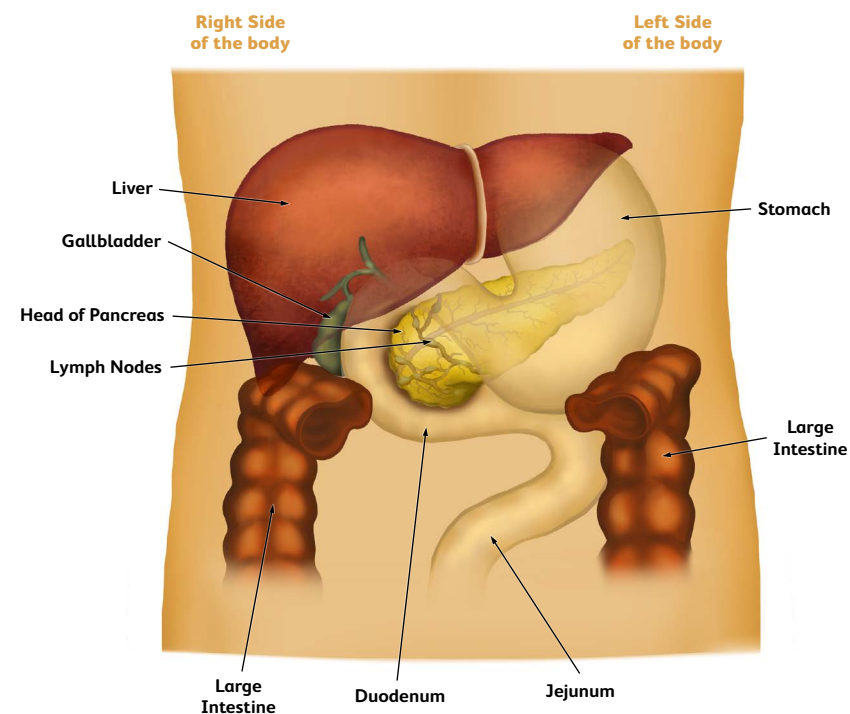
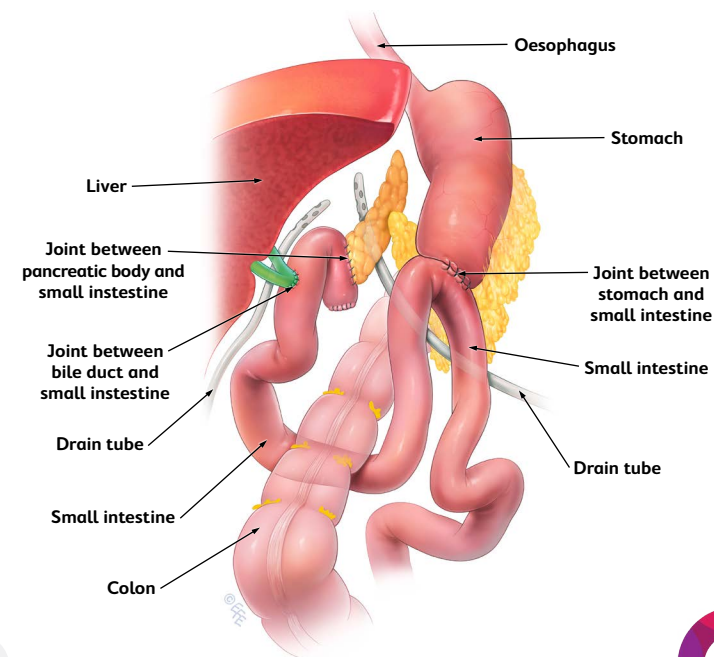
by the location of the tumour. In cases of cancers within the head of the pancreas, a pancreaticoduodenectomy is most commonly performed. Also known as the Whipple procedure, this operation removes:

- Head of the pancreas
- Lymph nodes near the pancreas
- Gallbladder
- Part of the common bile duct
- Part of the stomach
- Duodenum (first part of the small intestine)
- A small portion of the jejunum (second part of the small intestine)

This is a very complex operation and outcomes are generally optimal when the surgery is performed at a hospital and by a surgeon with extensive experience in pancreatic surgery. There is evidence that surgical complications are lower and survival is improved, when pancreatic cancer surgery is performed at specialised centres, compared to surgery performed at hospitals where pancreatic cancer surgery is not commonly performed.

In cases of tumours located within the tail or body of the pancreas a distal pancreatectomy may be indicated. This removes only the tail of the pancreas and a portion of the body of the pancreas. The spleen is often removed in this operation.

The entire pancreas may need to be removed in some cases of very advanced cancers or when multiple cancers are found within the pancreas. This is called a total pancreatectomy and removes the entire pancreas and the spleen. In such cases patients develop diabetes and require insulin injections.



Chemotherapy

Chemotherapy is usually considered in all patients with pancreatic cancer, even when tumor removal is achieved. This reduces the risk of the cancer returning. Chemotherapy is often used on its own to treat pancreatic cancer that has spread and may lengthen survival.

Radiotherapy

Radiation therapy combined with a low dose of chemotherapy may be used at times to reduce the chances of the cancer returning locally. Sometimes radiotherapy combined with chemotherapy is offered in instances of more locally advanced cancers to try and reduce the tumour size, with the hope of allowing subsequent surgical removal.



Stent insertion and bypass surgery

Some surgical and other interventional procedures are used that don't remove the cancer but instead help relieve symptoms.

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

In both these situations a small, flexible plastic or metal tube called a stent can be inserted to relieve a blockage and keep the duct or bowel open. Stents to unblock the bile duct are most often put in during an ERCP. If this isn't possible an alternative procedure called a PTC (Percutaneous Transhepatic Cholangiogram) may be used. Here the stent is inserted directly through the skin and liver into the top of the bile duct using a needle and x-ray guidance.

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

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

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

Sometimes these two procedures are done at the same time.

Chemotherapy

One of the most common treatments for pancreatic cancer is chemotherapy – using anti-cancer drugs to destroy cancer cells. Chemotherapy can be used on its own or alongside other treatments such as surgery and radiotherapy. If you have had surgery to completely remove your cancer you may benefit from a course of chemotherapy afterwards. This is to try to reduce the chances of the cancer coming back and is called adjuvant chemotherapy.

Chemotherapy can be given intravenously (as an infusion into a vein), orally (as tablets) or a combination of both. Because chemotherapy treats the whole body, normal cells can be affected as well as cancer cells. This means you may experience side effects such as nausea, diarrhea, hair loss and fatigue (extreme tiredness), although everyone reacts differently and most side effects can be well controlled.

Following national guidelines the drug most often used is gemcitabine. Gemcitabine is given intravenously (as an infusion into a vein). Other drugs and drug combinations such as gemcitabine with Nab-paclitaxel (Abraxane®) or FOLFIRINOX (Folinic acid,

fluorouracil, irinotecan and oxaliplatin) are more recently being used in patients with metastatic cancer, with improved results, but generally greater side-effects than gemcitabine treatment alone. Fluorouracil (5-FU) or its oral equivalent, Capecitabine may also sometimes be used for treatment of pancreatic cancer.

In patients with inoperable cancer that is locally advanced or metastatic, clinical trials have shown that chemotherapy is effective in controlling the growth of cancers and improving symptoms. It does generally increase survival, but cannot achieve a cure.

In some cases of cancers that are on the “borderline” between being able to be removed completely and those that are not, chemotherapy may be given before any surgery is considered (neoadjuvant chemotherapy). In these cases the chemotherapy is given with the hope of shrinking the tumours or controlling the cancer growth for some time, to make surgical treatment more feasible or beneficial.

Radiotherapy

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

Side effects usually resolve once treatment stops.

Radiotherapy isn't used as often as chemotherapy for pancreatic cancer. It may be considered if your cancer is locally advanced, which means it can't be removed surgically but it hasn't spread to other parts of the body. Radiotherapy won't cure the cancer but may help control it and slow its growth.

In this situation radiotherapy is usually given together with chemotherapy (chemo-radiation). The aim is for the chemotherapy drugs to make the cancer cells more sensitive to radiation. To find out how chemo-radiation can be used most effectively ask your oncologist if it is a suitable treatment for you and whether it is available in your specialist centre.

Sometimes radiotherapy may be used before surgery in combination with chemotherapy for patients who have pancreatic cancers that are on the “borderline” between being able to be removed completely and those that are not.

Radiotherapy can also be helpful on some occasions when cancer has spread to other parts of the body (advanced or metastatic cancer). It is particularly effective in controlling and relieving pain. It may also be considered if you have undergone surgery and there is evidence that there may be microscopic cancer cells left behind according to the pathologist that has examined the cancer specimen.

Other ways of managing symptoms

As well as the surgical interventions, chemotherapy and radiotherapy, there are a range of other things that can help manage any symptoms or side effects you may have. These may include:

- pancreatic enzyme supplements and nutritional supplements to help with digesting food and weight loss
- anti-sickness medication or complementary therapies to help with nausea
- morphine-based painkillers
- nerve block (often done by endoscopy) to destroy the nerves which convey pain from the pancreas
- complementary therapies such as aromatherapy, reflexology, relaxation therapy. This is sometimes available at day centres and can help relieve specific symptoms and improve your general wellbeing.

If you are in hospital your care needs should be assessed before you leave. This may

sometimes include a referral to the community based health care team, who have expertise managing pain and other cancer symptoms. If pain is your main issue, you may alternatively be referred to a pain specialist to assist in your management. Your GP should be sent a letter explaining your condition and you should be given the name of a person at the hospital to contact if you have any concerns or need additional support.

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



Pancreatic Enzyme Replacement

A blockage in the pancreatic duct or removal of part of the pancreas, can cause a change in the flow and amount of pancreatic juice. Pancreatic juice contains enzymes that help the body to digest and absorb nutrients such as fat, carbohydrate and protein.

If your body cannot produce enough pancreatic juice, you will have difficulty getting nourishment from foods and eventually you will lose weight. Studies have shown that taking a pancreatic enzyme supplement can improve the absorption of nutrients from the digestive system, help nutrition and prevent weight loss. It can also improve your overall quality of life.

Signs which indicate that taking enzyme supplements would be helpful are:

- Pale stools (bowel motions) that do not flush away easily and a greasy appearance on top of the water
- Loose bowel motions
- Abdominal pain and bloating after eating
- A lot of flatulence (wind)
- Good appetite and food intake but with continuing weight loss

What are enzyme supplements?

All enzyme supplements contain Pancreatin – a mixture of pancreatic enzymes lipase, amylase and protease. These assist the digestion of fat, carbohydrates and proteins. On average patients need a minimum of between 200–250,000 units of lipase a day to avoid symptoms of malabsorption. In situations following surgery to remove all or part of the pancreas or where the pancreatic duct is blocked, patients may require additional enzyme supplementation to control symptoms.

The proprietary drug “Creon” is by far the most common preparation used around the world (others include Panzytrat, Nutrizym, Pancrease HL, and Pancrex). Creon comes in 3 capsule sizes, 10,000, 25,000 and 40,000. These values indicate how many units of lipase there are in each capsule. Most adults take either 2 of the 25,000 capsules with a main meal and one 25,000 capsule with each snack to start with. The dosage is often adjusted according to the type and amount of food being consumed and the presence of continued symptoms.

These enzymes are extracted from pig pancreas glands and there is currently no alternative to using pork products. However it is important to know that for those who may have religious objections to the ingestion of pork products, special dispensation to allow these products has been granted by religious organisations as they are a medicine.

How should I take enzyme supplements?

Capsules should be taken with food – i.e. with the first mouthful of food. All food includes meals, snacks and milky drinks. Your doctor and dietitian will advise you.

If you are more comfortable eating smaller, frequent meals, with for example 3 snacks a day, it may be necessary to take 1 capsule with each snack. Your doctor will tell you how many and what dose capsules to take to suit your particular need.

Capsules should be swallowed with a cold drink. Swallowing them with a hot drink can make them less effective.

The capsules should be swallowed whole. If you find this difficult, you can open the capsule and mix the granules with fluid or soft food. Remember if you do this, it is important you take the fluid or food immediately, without chewing so you get the full effect of the granules.

The granules must not be crushed or chewed as they have a special coating to stop them dissolving until they have gone through the stomach and into the intestines where they work.

It is important that you try to drink plenty of fluid every day. You may find that some foods, particularly fatty foods, do not agree with you. If you are having a large meal with more than two courses, or one lasting more than half an hour, you may need to take half of your enzymes at the beginning and the other half in the middle of your meal.

When not to take enzyme supplements;

- On an empty stomach
- With drinks that contain less than half milk – such as tea, non-milky coffee, fruit squashes and fizzy drinks
- If you eat small quantities of fruit, vegetables, dried fruit, fat-free sweets (jelly babies, wine gums, mints)
- If you take a very small quantity of food such as an individual chocolate/square of chocolate bar or a small plain biscuit

A dietitian can provide advice or supplementary information on managing your diet.

How does pancreatic cancer affect overall diet and nutrition?

Nutrition can be a major focus for patients diagnosed with pancreatic cancer and subsequent treatment.

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

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

Tips to maintaining weight

- Use full fat products
- Eat smaller meals more often (aim for every two hours)
- If you have lost weight, have a poor appetite or can only eat small amounts of food you may find it helpful to take a nutritional supplement. Supplements can help make sure you are getting enough calories, protein, vitamins and minerals and medically proven supplements are available on prescription through your GP, hospital or dietitian.
- When choosing a nutritional supplement for your needs, consider the different options including milk-based, juice flavoured, powder, yoghurt style and soups. You may need to try different products until you find one you prefer or tolerate better. Some people find they prefer a savoury product to a sweet one.

- If you are finding it hard to eat or drink you may find it easier to take a nutritional supplement drink as small 'shots' (50ml doses) throughout the day. If you are diabetic you should be aware that these supplements can be high in sugar (in particular glucose).

Some of the changes that occur as a result of pancreatic cancer are unintentional loss of body weight and loss of lean body mass (muscle).

Problems with eating, digestion and fatigue can also occur. Any treatment for pancreatic cancer (surgery, radiation therapy, and chemotherapy) can alter nutritional needs and interfere with the ability to eat, digest, or absorb food. This is often due to side effects such as nausea, vomiting, changes in taste or smell, loss of appetite or bowel changes. At the same time, caloric intake needs are increased during any of these treatments.

When problems occur, usual food choices and eating patterns may need to be adjusted, when possible. Eating small, frequent meals

or snacks may be easier to tolerate than three large daily meals. Food choices should be easy to chew, swallow, digest, and absorb.

Choices should also be appealing, even if they are high in calories or fat. If it is not possible to meet nutritional needs through regular diet alone, nutritious snacks or drinks may be advisable. Commercially prepared liquid nutritional products can also be helpful to increase the intake of calories and nutrients.

How might pancreatic cancer affect my overall wellbeing?

- As time passes from your initial diagnosis you will find yourself dealing with the wider physical and emotional impacts of pancreatic cancer and its treatment. Everyone finds their own ways of coping, but whatever you do it's important to take care of yourself.
- Many people find that sorting out dietary-related symptoms makes the biggest difference to how they feel. For example, if you can eat and maintain your weight you will feel better and cope better with treatment.
- Feeling sick (nauseous) is another common symptom, but you can be prescribed anti-sickness medication or try remedies such as ginger, peppermint or acupressure bracelets.
- You will feel other physical effects from the cancer and its treatment and, as with dietary-related symptoms, managing these can play a big part in how well you feel.
- You are bound to feel tired, exhausted sometimes, so be kind to yourself. Make sure you rest, prioritise what you want or need to do, accept offers of help and ask for help if you need to.
- Both men and women often lose interest in sexual activity during cancer treatment, at least for a time. Talking to your partner or GP and sometimes seeing a sex therapist may help you to find ways of overcoming difficulties.
- Simple relaxation techniques can help you cope with stress, pain and anxiety. Having a warm bath, deep breathing or listening to soothing music are easy things to do at home.
- You might want to try complementary therapies like reflexology or aromatherapy massage. Ask your GP or specialist nurse about services available in your area.
- Each individual will feel and react differently to treatment. So what might work for someone else may not always work for you. It is important to keep this in mind during your treatment.
- Physical activity can also make you feel better, though how much activity will depend on how well you feel and whether you are having treatment or recovering from it. Even a walk round the block or 10 minutes of stretching each day can help.
- Over time you may go through a range of emotions, from feeling positive and determined to beat the cancer to feeling low or despairing about the future. A cancer counselling service may be able to devise different strategies to help you cope.
- If you feel the cancer is taking over your life, one way to cope is to focus on other things and make plans. For example, this might mean living life as normally as possible or changing your priorities.
- Feeling anxious or stressed is perfectly normal and one of the best ways to help is by talking to family, friends or a trained counsellor. If the feelings become overwhelming you may be depressed, so talk to your GP about managing this with anti-depressant drugs or counselling.
- You can find support from others going through similar experiences. You may want to join a local cancer support group.
- Your partner, family and friends will be experiencing different emotions too.
- Communication is essential for everyone's emotional wellbeing, so try to make time for talking and listening as your close relationships are important.
- Practical issues won't have been the first things you thought about when you were diagnosed, but dealing with things like your work or financial situation is important so they don't become a source of stress.
- Your diagnosis will affect your ability to work, even if it's only temporarily such as when having treatment. Talk to your employer, HR department or union rep about sick leave, reducing your hours or working from home. Being unable to work can lead to financial problems, seeking advice about benefits or other financial help may be beneficial.
- Having cancer can have an unexpected financial impact, for example if you can't work or you have to pay for travel to and from treatment sessions. Again, seek advice about any financial help or benefits you may be entitled to.

Clinical Trials

Doctors and researchers are constantly testing other drugs and drug combinations in clinical trials to see whether they give better results than gemcitabine.

Trials for example with FOLFIRINOX (Folinic acid, fluorouracil, irinotecan and oxaliplatin), and nab-paclitaxel (Abraxane®) with gemcitabine have shown increased survival time for people with advanced pancreatic cancer but also an increase in side effects. Talk to your specialist about other options that may be available and whether they are suitable for you.

You may be eligible to take part in a clinical trial, so it is always a good idea to ask your specialist if there is a trial suitable for your condition. Most trials test alternative chemotherapy drugs or chemotherapy combined with other treatments. For more information about current Australian cancer clinical trials visit the Australian Cancer Clinical trials website www.australiancancertrials.gov.au

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

Before you decide whether or not to take part in a trial you need to know exactly what is involved. Talk to your specialist and ask as many questions as you need. If you decide to take part you will have to sign a form saying you understand what is involved and agree to take part (this is called informed consent). You can withdraw from the trial at any time if you change your mind without it affecting your care.

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

Glossary

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

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

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

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

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

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

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

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

Dietitian: a specialist in promoting health through food and nutrition.

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

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

Hepatobiliary: having to do with closely related organs including the liver, gall bladder, pancreas and the bile ducts.

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

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

Lymph nodes: tiny oval structures throughout the body that contain lymph fluid. Part of the immune system.

Metastatic cancer: see Advanced cancer

Neoadjuvant treatment: A treatment, such as chemotherapy or radiotherapy given before surgery.

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

Oncologist: a doctor who specialises in cancer (oncology). A medical oncologist is an expert on drug treatments. A clinical oncologist also manages radiotherapy treatment.

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

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

Pancreatic enzyme supplements: help to digest food when the pancreas isn't producing enough digestive enzymes.

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

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

Radiologist: a doctor specialising in using x-rays to diagnose and treat disease.

Radiotherapy: treatment using high-energy x-rays to destroy cancer cells.

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

Steatorrhoea: undigested fat in stools (poo). Stools are large, pale, oily, floating and foul smelling.

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

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

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Extra sources of information

Cancer Council Australia
<http://www.cancer.org.au/about-cancer/patient-support/>

National Cancer Institute (United States)
<http://www.cancer.gov/cancertopics/pdq/treatment/pancreatic/Patient/page2#Keypoint14>

The Lustgarten Foundation
<http://www.lustgarten.org/get-informed/about-your-diagnosis>

<http://www.lustgarten.org/informationandsupportservices>

Whipple Warriors
<http://www.whipplewarriors.org/resources/documents>

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