Living with pancreatic cancer

Information for patients and carers

Avner PANCREATIC CANCER FOUNDATION

Contact information

Name and contact number:

Emergency contact name and number:

My GP's name, contact details and out of hours contact:

My specialist/s' name, contact details and out of hours contact:

Location and contact details for my scans:

If lost, please return to the person listed under name and contact number

Notes

Living with pancreatic cancer
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Disclaimer: The information set out in this publication is current at the date of first publication. It offers general medical advice about pancreatic cancer. It may not apply to the individual circumstances of every patient and should be read in light of any specific advice or information provided by their medical practitioner. It is not a substitute for individual medical advice. It is current at the date of first publication and is to be reviewed two years from the date of first publication. Avner Pancreatic Cancer Foundation has no liability (including for negligence) to any users of the information contained in this publication.

This booklet is intended to be a living document and will be reviewed at regular intervals to reflect new changes in care and treatment for people with pancreatic cancer as they develop. We welcome your feedback for future revised editions of the booklet at info@avnersfoundation.org.au.

Patients quoted in this booklet are not associated with, and have not received any funding from, any pharmaceutical companies.

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Avner PANCREATIC CANCER FOUNDATION

We acknowledge the Traditional Custodians of the lands and seas on which we work and live, and pay our respects to Elders, past, present and future.

Avner Pancreatic Cancer Foundation mission statement

Our mission is to dramatically increase survival rates and quality of life of those impacted by pancreatic cancer. Pancreatic cancer is a complex problem that we are committed to tackling through a national, collaborative approach.

Our vision is to see a world free of pancreatic cancer.

About Avner Pancreatic Cancer Foundation

The core mission of the Avner Pancreatic Cancer Foundation is to improve the survival rates and quality of life for pancreatic cancer patients. We are achieving results through a strategic focus on raising awareness and investing in ground-breaking medical research to improve treatment.

We know from work with other cancers, such as breast, skin and prostate, that medical research is the single most important factor impacting patient survival. Due to extensive funding, these cancers now have 5-year survival rates above 90%. It's time to make the same improvements for pancreatic cancer.

The Avner Pancreatic Cancer Foundation is the only charity in Australia exclusively dedicated to pancreatic cancer and we invite you to join us on the journey to improve survival rates and the quality of life for the thousands of Australians affected by this disease every year.

Foreword

We are profoundly grateful to everyone who offered their time and expertise towards producing this comprehensive and well-informed publication, which we hope will be both useful and inspiring for everyone affected by pancreatic cancer.

We dedicate this booklet to everyone who has been touched by pancreatic cancer. We understand that it can be a much-feared diagnosis, but also recognise that many people find hope, solidarity, and moments of humour as they make their journey through diagnosis and treatment.

We extend our heartfelt thanks and respect to the researchers, carers, healthcare workers and allied health workers who contribute so much to supporting individuals with pancreatic cancer, particularly those who in 2020 have contended with the challenges of providing quality care during a global pandemic.

To the people living with pancreatic cancer, their carers, families and friends, we offer our sound belief that with expertise, resolve and a single-minded focus we will one day have developed the tools we need to combat the disease, and reduce the heavy toll it currently takes on so many lives.

Michelle Stewart
Chief Executive Officer
Avner Pancreatic
Cancer Foundation

Caroline Kelly
Founder and Director
Avner Pancreatic
Cancer Foundation

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Acknowledgements

Thank you to all those health professionals and consumers who generously gave freely of their time and expertise to help review and develop this booklet. Without you, the booklet would never have happened. We especially wish to acknowledge Jane Lathwell and Lynne McKenzie, who sadly both passed away from pancreatic cancer before publication but will always be remembered for their valuable insights and contributions to the production of this booklet. Our thoughts are with their families as they grieve.

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Living with pancreatic cancer

INTRODUCTION

The purpose of this book

This booklet is about pancreatic cancer. For most people, finding out they have pancreatic cancer comes as a huge shock. You and those close to you are likely to feel unsure about what this means for you and them – now and in the future. Avner Pancreatic Cancer Foundation has developed this booklet and other resources to help you navigate through your diagnosis, treatment and post-treatment. Our aim is to help you feel and live as well as possible.

The booklet aims to help you, your family, friends and carers understand how pancreatic cancer is diagnosed and treated. We also include information about how to live with having cancer, communicating with your medical team, who to turn to for support and how to best look after your physical, emotional and spiritual wellbeing. We guide you and those caring for you to support services that you may find helpful. Practical information about dealing with work, financial matters and looking ahead (e.g. advance care planning, Wills and superannuation) is also included.

The booklet has been written with a lot of input from people who have pancreatic cancer, and those caring for them. Avner Pancreatic Cancer Foundation want these people to be at the heart of the information we provide. We believe each person with pancreatic cancer should feel their personal needs, wishes and goals are understood. We are incredibly grateful to the patients and carers who took the time to share their personal experiences with us. Those who kindly contributed are listed in the acknowledgements of the booklet. We hope you will read their quotes throughout the booklet to gain a true insight into what having pancreatic cancer can be like, as well as the best ways to manage it.

We cannot tell you which is the best treatment for your situation. But we hope this booklet will answer some of your questions and help you think about other questions you may want to ask your medical team. This will ensure you get the best treatment and care for your specific situation.

You may like to pass this booklet on to your family and friends to help them understand your diagnosis as well as how to best help you through your treatment and afterwards.

This booklet can be read in sections according to your needs or interest at the time. The words in purple and **bold** are explained in the glossary.

For further information, visit Avner Pancreatic Cancer Foundation at www.avnersfoundation.org.au

About pancreatic cancer

Pancreatic cancer severely affects the lives of many thousands of Australians every year, although it is a relatively uncommon cancer (i.e. compared to breast or lung cancer). This section explains how it affects the body, the different types of pancreatic cancer, its symptoms and risk factors.

What is cancer?

Cancer is a disease of the body's basic building blocks known as our **cells**. A cancer starts when these cells begin to grow out of control. Our body is constantly making new cells to help us grow, replace damaged **tissue** and heal injuries. Normal cells grow, multiply and die in an organised way. However, sometimes things go wrong and they may form a lump called a **tumour**.

A tumour can be **benign** or **malignant**. Benign tumours are non-cancerous, which means they stay in one place in the body and do not spread to other parts of the body. Malignant tumours are made up of cancerous cells and they can travel through the bloodstream or lymphatic fluid. This means that the cancer can also spread from the organ in which it first began to other organs in the body. This is called a secondary, invasive cancer or **metastasis.**

The place the cancer first develops (either in the tissue or organ) is called the primary cancer site. If the cancer doesn't spread from this primary site, it is known as localised cancer. A cancer or tumour that spreads to nearby or deeper tissue or invades surrounding tissue can grow its own blood supply. This is called **angiogenesis**. The cancer may then spread (metastasise) further to other organs in the body.

Cancer that has spread to another organ keeps the same name as the original cancer. For example, pancreatic cancer that has spread to the liver is still called pancreatic cancer, with liver metastasis/es.

The pancreas

The pancreas is a large gland sitting high up in your **abdomen**. It is about 15 cm long and shaped a bit like a tadpole. It is made up of four parts:

- The head of the pancreas is on the right side of the body and is the widest part.
- The neck of the pancreas sits in front of the important vein that takes blood from the bowel to the liver (the superior mesenteric vein).
- The body of the pancreas sits behind the stomach.
- The tail of the pancreas is the thin end and is on the left side under the ribs and next to the spleen.

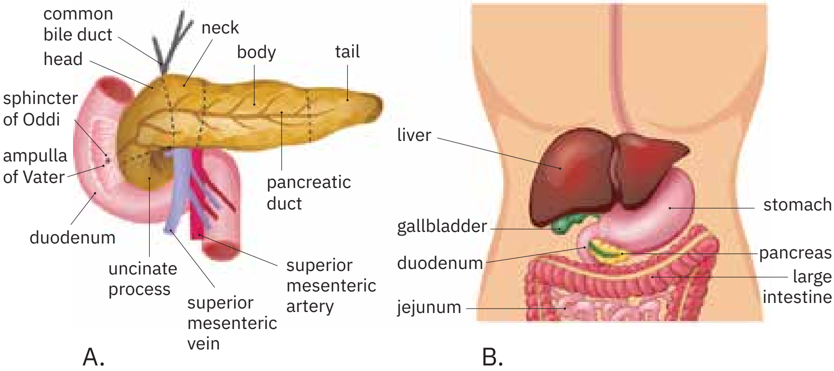


Figure 1: A. The pancreas and B. The digestive system

The pancreas is made up of two types of cells:

1. **Exocrine cells** cover 95% of the pancreas and make pancreatic enzymes that aid in food digestion. These cells flow down a tube (pancreatic duct) into the first part of the small bowel, which is called the duodenum.
2. **Endocrine cells** make up the remaining 5% of the pancreas, and produce hormones such as insulin and glucagon, which help control our body's blood sugar levels. This part of the pancreas is called the endocrine pancreas.

Cancers developing from these two cell types of the pancreas behave differently and cause different symptoms. As treatment management for each type is very different it is important to know what type of pancreatic tumour you have. See the section titled 'Types of pancreatic cancer'.

The bile duct is another duct coming down from the gallbladder and liver; it joins the duodenum next to the pancreatic duct, where it meets the bowel. This spot is called ampulla of Vater. This area is important as tumours in the head of the pancreas can cause a blockage of the common bile duct and cause jaundice.

The role of the pancreas in food digestion and insulin

Food digestion involves:

- chewing and mixing food in the mouth
- its movement through the digestive tract (from mouth to small intestine)
- the breakdown of large food molecules into smaller ones.

Once food has been in the stomach for a couple of hours, it is still only partly digested. From here it will move into the duodenum where the pancreas releases its digestive enzymes down the pancreatic duct. These enzymes help break down food into tiny parts so they can be absorbed into the body through the small bowel.

The pancreas makes the hormone insulin, which keeps the level of sugar in the blood within an acceptable range (after a meal glucose levels rise as do insulin levels). This allows the cells in our body to get the right amount of food (not too much). If our blood sugar levels become too high, the pancreas will release more insulin. If they become too low, it will produce and release less. If you don’t make enough insulin, you will develop **diabetes** (see the section titled ‘Symptoms of pancreatic cancer’). Diabetes is a disease in which your body has trouble producing or responding to insulin. This can lead to problems with lowered and elevated blood sugar levels.

What is pancreatic cancer?

Pancreatic cancer is cancer starting in the pancreas.

Pancreatic adenocarcinoma is the most common type of pancreatic cancer. Adenocarcinomas are a type of cancer starting in the glandular cells of your body. About 95% of pancreatic cancers are adenocarcinomas.

How common is pancreatic cancer?

Almost 4000 Australians are diagnosed with pancreatic cancer every year. More than 80% of people diagnosed are aged over 60 years.

Pancreatic cancer is rare in people under 40 years, but it can happen.

In 2018, pancreatic cancer was estimated to be the tenth most common cancer in men and the ninth most common in women. There are slightly more cases diagnosed in men than women.

Unfortunately, pancreatic cancer rates have increased over the past 10 years and it is thought they will continue to rise.

Types of pancreatic cancer

Pancreatic cancer can start in any part of the pancreas. About 65% of pancreatic cancers start in the head of the pancreas. Pancreatic cancer can start in the endocrine or exocrine cells (discussed earlier).

It is important for your doctor to find out where the cancer starts, as well as the type of cell the cancer started in. This will help them decide on the best treatment for your type of pancreatic cancer.

The different types of pancreatic cancers are:

- exocrine tumours
- cystic tumours and intraductal papillary mucinous neoplasms (IPMN)
- pancreatic neuroendocrine tumours (PNETs)
- other rare types.

Exocrine pancreatic cancers

Most pancreatic cancers (95%) are exocrine tumours and include:

- pancreatic ductal adenocarcinomas, which make up more than 80% of exocrine pancreatic tumours
- rarer types of exocrine pancreatic cancer, which include cancer of the acinar cells (usually diagnosed in younger people and slower growing) and adenosquamous tumours.

Cystic and intraductal papillary mucinous neoplasms (IPMN)

IPMN are abnormal growths of tissue (neoplasms) that happen within the cells of the pancreatic duct. Cystic neoplasms are fluid-filled sacs in the pancreas that are usually slow growing. Both types of neoplasms are benign (non-cancerous).

These types of tumours should be closely managed and monitored by a pancreatic specialist. If they grow to a certain size, they may need surgery, but generally it is curative surgery with no further treatment.

Pancreatic neuroendocrine tumours (PNETs)

Endocrine cells are found in various parts of the body including in parts of the digestive system (stomach, pancreas, bowel and rectum). They are also found in the lungs, ovaries and sometimes in the testes. The function of these cells depends on where in the body they are.

Tumours that develop in endocrine cells are called neuroendocrine tumours (NETs). About 50% of all NETs start in the digestive system. The tumour is named depending on where it started. For example, a NET starting in the pancreas is called a pancreatic NET or PNET.

PNETs are rare and only make up about 5% of pancreatic tumours. They develop in the islet cells of the pancreas, which produce hormones such as insulin and glucagon. Endocrine tumours generally have a better outlook (**prognosis**) than exocrine adenocarcinomas of the pancreas.

We do not discuss PNETs in this booklet. To find out more about PNETs, visit Neuroendocrine Cancer Australia (www.neuroendocrine.org.au) or call 1300 287 363.

Other rare types

Other rare types of pancreatic cancers include:

- pancreatoblastoma, which happen mainly in children and can be linked to **genetic** conditions but can sometimes develop in adults
- sarcomas, which happen in the connective tissue that holds the cells in the pancreas together
- lymphomas, which happen in the lymphatic system, which runs through the pancreas
- metastases from another cancer (e.g. cancer of the lung, kidney or skin (melanoma) can spread to the pancreas).

If you have a rare type of pancreatic cancer, speak with your specialist doctor about the best treatment for you, as this booklet is mainly about exocrine pancreatic tumours.

Symptoms of pancreatic cancer

In its early stages, pancreatic cancer tends to be painless and cause no ill effects. Symptoms often only appear once the cancer has grown large enough to affect nearby organs or it has spread to other parts of the body (e.g. liver, stomach, lungs, bones).

The symptoms listed in this section can occur with many other, less serious, conditions. But see your GP if you have any of the symptoms and they persist.

> ***'I only got symptoms one week before my diagnosis. I went yellow and went to my GP. I thought I had a tummy bug.'***
>
> **JANE**

Specific symptoms include pain, jaundice, indigestion and unexplained weight loss. Other symptoms include diabetes, nausea and vomiting, changes in bowel habits and blot clots.

Pain is often the first symptom people notice. It is a dull pain that feels like it is 'burrowing' into you. It can start in the stomach and travel around to the back. It is usually worse after eating and when you lie down. Relief is gained from sitting forward. Some people also experience back pain, especially at night.

Jaundice may occur due to blocked bile ducts. Urine may be darker and faeces may become clay coloured as bile gets into the blood-stream and out through urine, rather than going through the bowel. Your skin and eyes may become yellowish. If jaundice is bad, your skin may become very itchy due to increased bile salts in the blood.

> ***'My mum had had a number of tests and scans with no one seeing anything of concern. She presented at emergency department after becoming jaundiced. Even then they did not think that she had cancer, they thought maybe she had a gallstone that they could not see on the scans.'***
>
> **KAT**

Indigestion (dyspepsia) can sometimes be a symptom of pancreatic cancer. It causes a burning, painful feeling in your chest and may leave a bitter taste in your mouth. Indigestion is a common problem and usually isn't due to cancer.

Weight loss can be quite significant. It is thought to be due to a decrease in the key pancreatic enzymes that normally digest food: your body is no longer absorbing nutrients properly, so you lose weight. You will also lose weight due to loss of appetite.

Diabetes: Some people may develop diabetes before their diagnosis or at diagnosis. Or if you were already diabetic you may start to have problems controlling your diabetes.

If you have diabetes you are not producing enough insulin, which means you will have too much sugar in your body. The sugar will be passed out in your urine and you may feel very thirsty, weak and hungry. You will also pass more urine than usual. It is recommended that anyone who develops unexplained diabetes have an abdominal CT scan.

Nausea and vomiting: You may feel sick and vomit due to chemical imbalances in your body. These may be caused by jaundice or an inflamed pancreas. Blockages at the start of the bowel, caused by the cancer, or inflammation, can also cause vomiting.

Feeling nauseated and vomiting can also cause loss of appetite and weight loss.

'I lost a lot of weight before I was diagnosed. I also lost weight during the diagnosis process. I also found I could eat anything and not put on weight. I was putting it down to stress.'

SANDY

> *‘I saw my GP about some of my symptoms about nine months before I was diagnosed. I was feeling tired, having trouble digesting food and had lost 15 kg. I was overweight prior to this so the GP was happy with my weight loss and told me to keep doing what I was doing. I knew it didn’t feel right, after struggling with my weight for so long, for it to just fall off like that. I am glad I continued to pursue the cause of my symptoms through to diagnosis but frustrated at yet another block in the road that could have been an earlier diagnosis.’*
>
> **AARATHY**

Changes in bowel habits: Your bowel actions may become oily and float (steatorrhea), and appear pale, foul smelling and difficult to flush. This is due to the bile ducts blocking and not absorbing your food properly.

Blood clots: Sometimes pancreatic cancer is linked to blood clots in your legs (deep vein thrombosis) or other parts of the body. See your doctor immediately if you develop any pain, redness or swelling in your legs or other parts of your body. Being short of breath may also be a symptom.

Key message about symptoms

It is important to seek medical attention for any persistent, unexplained symptoms that may involve a combination of any of the following:

- abdominal bloating with or without discomfort
- indigestion (discomfort or pain in the upper abdominal area)
- changes in bowel habits
- loss of appetite
- weight loss
- loss of energy (malaise).

Risks and causes of pancreatic cancer

Anything that increases your risk of developing a disease, such as cancer, is called a risk factor. Different types of cancers carry different risk factors. Certain risk factors, such as smoking and sun exposure, can be prevented. But other risk factors such as a person's age, gender or family history can't be changed.

Doctors and scientists don't yet know the exact causes of pancreatic cancer. However, some risk factors, relating to lifestyle, the environment, genetics and other medical conditions, have been identified.

Many people who develop pancreatic cancer won't have any risk factors, while other people with some or all the risk factors may never develop pancreatic cancer. There is still a lot to learn about this disease.

Age, gender and race

Pancreatic cancer is more common in older people. The average age at diagnosis is 70 years, with 8 out of 10 people in Australia being over 60 years of age at diagnosis. Pancreatic cancer is rare in people under 40 years old.

There is a slightly higher risk for pancreatic cancer among African Americans, Asians and Pacific Islanders compared to Caucasians.

Lifestyle factors

Tobacco products: Pancreatic cancer risk is significantly increased by smoking cigarettes, cigars and pipes, as well as chewing tobacco. A recent study showed that 28% of pancreatic ductal adenocarcinoma in Australia is smoking related. Smokers are about twice as likely to develop pancreatic cancer as those that don't smoke.

Call Quitline on 13 78 48 for information and support to help you stop smoking. You can also text 'call back' to 13 7848 or book a time online (www.quit.org.au) for Quit to call you.

Diet, obesity and exercise: Some research suggests a possible link between pancreatic cancer and eating lots of red or processed meat and not enough fresh fruit and vegetables.

Obesity and being overweight have also been linked to pancreatic cancer risk. It's thought this may be because the pancreas makes more insulin in people who are overweight.

Being physically active might protect against pancreatic cancer. But this is not completely clear.

Alcohol: Pancreatitis is inflammation of the pancreas, which can either be acute (sudden and severe) or chronic (ongoing). Although other factors can cause pancreatitis, most cases of chronic pancreatitis are caused by heavy drinking over a long period of time.

Pancreatic cancer is more common in people with chronic pancreatitis. There may also be a direct link between drinking alcohol and pancreatic cancer, but more research is needed before we can confirm this.

> ***'The doctors kept asking me if I was a drinker, and I wasn't. I'm not a drinker at all, so this was frustrating when they kept asking me, as if they did not believe me.'***
>
> **LYNNE**

Genetic factors

Although rare, pancreatic cancer can run in families. Between 5% and 10% of people diagnosed with pancreatic cancer have a family history.

Your risk of pancreatic cancer is also higher if:

- you carry the faulty breast cancer gene **BRCA2** and to a lesser degree **BRCA1**
- your family has a family cancer syndrome (where an inherited family **gene** causes several types of cancers to develop in one family)
- you have an inherited syndrome including Peutz-Jeghers syndrome, familial atypical multiple mole melanoma syndrome (FAMMM) or Lynch syndrome/hereditary non-polyposis colorectal cancer (HNPCC).

We include two tables in the Appendix to this booklet that give more information about genes and pancreatic cancer.

Some medical services offer advice and screening to help find out if relatives may be at higher risk of developing pancreatic cancer, and what they can do to manage their risk.

For more information about family history and genetic testing for pancreatic cancer, call the Cancer Council on 13 11 20. You may also find it helpful to go to the Garvan Institute of Medical Research (www.garvan.org.au) and search for ‘familial pancreatic cancer’.

Read more about research trials for people at high risk of pancreatic cancer in the section titled ‘Clinical trials’.

Most cases of pancreatic cancer happen by chance, meaning they are not hereditary.

Other possible risk factors

Research in the following areas is ongoing.

Diabetes: Several studies show that having long-standing diabetes is a risk factor for pancreatic cancer. It has also been shown that developing unexplained diabetes after the age of 50 may be an early symptom of pancreatic cancer. If you develop diabetes with no other possible risk factors associated with pancreatic cancer, your GP should include a CT scan with your other tests to exclude pancreatic cancer.

Not everyone who has diabetes or who develops diabetes as an adult will get pancreatic cancer.

> *‘Sudden onset of diabetes was the first symptom for me and was one of the reasons my cancer was picked up early.’*
>
> **GREG**

Exposure to some chemicals: Being continuously exposed to certain workplace chemicals or other substances may increase your risk of developing pancreatic cancer. These include pesticides, dyes and chemicals used in metal refining.

Previous cancer: Having a previous cancer such as stomach, bladder or kidney cancer may slightly increase your risk of developing pancreatic cancer. Having had **radiotherapy** in the past to treat another cancer has also been linked to pancreatic cancer.

DIAGNOSIS

Diagnosing pancreatic cancer

Pancreatic cancer is diagnosed using a variety of tests. It can sometimes be difficult to diagnose and there may be many tests. This section describes the tests used and the process of staging the cancer, if cancer is found.

Seeing your GP when you have symptoms

If you develop persistent symptoms or you notice abnormal changes in your body, you should see your GP as soon as possible. Fear of what your symptoms mean may put you off going to see your GP. However, it is best not to delay.

Many pancreatic cancer symptoms can also be related to other, less serious illnesses. But if it is cancer, the earlier it is found, the much better outcome you will have. Giving your GP an overall picture of what is going on for you helps them decide with you the next best step.

Tell your GP about all your symptoms including:

- what makes your symptoms better or worse (e.g. eating, moving around, rest)
- how you are feeling
- if you have a known family history of cancer.

Make a list of your concerns and take it to your appointment. Taking a friend or family member who knows your situation can also be helpful.

Your GP will ask you about your general health, family history and current symptoms. They will want to examine you by feeling your abdomen and any other areas where you may be having discomfort. If you have shortness of breath, your GP will listen to your chest for any signs of fluid build-up. They may also ask about symptoms you were not aware of. Your GP may refer you to a doctor who specialises in treating disorders of the:

- stomach and intestines (a gastroenterologist)
- hormones or endocrine glands (an endocrinologist).

Or you may be referred directly to a surgeon and/or oncologist who specialises in treating pancreatic cancer.

Pancreatic cancer can be difficult to diagnose. Even if you have symptoms, and certain tests suggest you may have it, your doctors may want to do further tests so they can be sure of your diagnosis. Understandably, this will be a very stressful time. But your doctors need to gather as much information as possible so they can make the correct diagnosis. They can then confidently recommend the next step and appropriate treatment and care.

> ***‘My diagnosis has been complicated and it took a while to get a definite diagnosis.’***
>
> **AARATHY**

Optimal care pathway

The Department of Health and Human Services has developed up-to-date guidelines (called ‘optimal care pathways’) for doctors and consumers on a range of cancers.

The optimal care pathway for pancreatic cancer includes many important recommendations, including about when and what doctors should test for, and when and to which specialist to refer if a doctor suspects pancreatic cancer. For example, your GP should suggest you have certain urgent tests done (within 48 hours) if you are jaundiced. And they should refer people with suspected or proven pancreatic cancer to a specialist who is linked with a multidisciplinary team within one week.

You can read the optimal care pathway for people with pancreatic cancer at www.cancer.org.au/ocp. A consumer guide is available at https://www.cancerpathways.org.au/optimal-care-pathways/pancreatic-cancer.

Tests for pancreatic cancer

The tests you have will depend on your symptoms and where in the pancreas the cancer might be. Together the tests will help your doctors to diagnose the type of pancreatic cancer you have and whether it has spread to other parts of your body (to nearby tissue/ lymph nodes or other organs such as the liver, lungs and bones). Doctors call this **staging** a cancer (see later in this section).

You may not need all the tests mentioned in the following pages.

Blood tests: You will have blood tests to determine your overall general health. These tests can't show up cancer cells, but they can show how well your blood cells, liver, kidney and certain chemicals in your body are working. Pancreatic cancer can affect how well all these things work so if you have abnormal results it will help your doctor decide on what further tests you may need.

There are also blood tests that can detect certain markers in your blood which may be raised in someone with pancreatic cancer. These markers are called:

- **CA19-9** (carbohydrate associated antigen)
- **CEA** (carcinoembryonic antigen)
- **CA125** (cancer antigen).

The tests are not conclusive. Other medical conditions can raise the levels of these markers. Some people with pancreatic cancer will have normal CEA, CA125 and CA 19-9 levels. Sometimes there are 'false negative results' meaning your test will come back negative when it shouldn't.

These markers can't be used solely to diagnose pancreatic cancer, but they can help. It is a bit like a jigsaw puzzle – doctors need all the pieces of information to make a diagnosis. These tests can give your doctor an indication of the type of cancer you may have, and also how the cancer may be responding to treatment. Markers may also be used to assist your doctors decide if your treatment is working. CA19-9 is the most common marker in pancreatic cancer.

Ultrasound: Ultrasound scans use a small round device called a transducer. This creates soundwaves when it detects something solid inside the body, such as an organ or a tumour. It then makes pictures of these areas.

An ultrasound of your abdominal area will help exclude other conditions of the gallbladder (e.g. gallstones) and bile ducts that can cause jaundice (also a symptom of pancreatic cancer). It will also show up any tumours on the pancreas and nearby organs such as the liver.

To allow the transducer to move freely across the abdomen, the person doing the procedure will spread some gel on your tummy (abdominal area). The scan can take about 20–30 minutes.

Computed tomography (CT) scan: A CT scan is a type of x-ray that takes pictures of the inside of the body. Abdominal CT scans will show up swelling or fluid in the area. The scan can also detect the size or position of any tumours in the pancreas and if it has spread to nearby **lymph nodes** or other organs.

You will need to lie on a table while the scan moves around you and takes pictures. You will have an injection into a vein in your arm with a dye that will help make the pictures clearer and easier to read. This dye can cause some side effects including feeling hot all over your body and a bad taste in your mouth. Some people can have an allergic reaction to the dye, but your doctor will discuss the risks with you before the scan. You may be asked to fast before this procedure, but you will be given exact instructions before you attend. The procedure takes about 30–40 minutes and you can go home afterwards.

You may need to have more than one CT scan during your diagnosis and treatment. The CT scan should ideally be a ‘pancreas protocol’ CT, which includes three phases. Your specialist may want a CT done using a specific technique and it is important that each CT is compared to your previous one to fully assess any changes/treatment responses.

Magnetic resonance imaging (MRI) and MRCP scans: Your specialist doctor may order an MRI scan or another type of MRI scan called an MRCP (magnetic resonance cholangio-pancreatography). These scans can help diagnose pancreatic cancer or they may be used to determine the size of a tumour and whether it has spread. An MRCP is a more detailed scan and can help find any blockages in the bile duct.

These scans use magnetism and radio waves to make three-dimensional cross-section pictures of the inside of the body. These scans can show up soft tissue very well. You will have an injection of a dye and you may not be allowed to eat or drink for a few hours before the procedure. It can take about an hour and you will be able to go home after.

Not everyone with suspected pancreatic cancer will need to have an MRI or MRCP scan. Your specialist doctor will discuss the best choice of scans for you and possible risks and costs of having these scans.

Biopsy: A biopsy allows your doctor to take a sample of cells/tissue and look at this under a microscope to check for cancer cells. There may be rare circumstances where a biopsy may not be helpful, but for almost all people a biopsy will be recommended.

Taking a biopsy is usually the only way to really be sure someone has cancer. A biopsy alone may not give all the answers your doctor needs to make a definite diagnosis of pancreatic cancer. Your doctor will consider the results of all the tests you have.

There are several ways of taking a biopsy from people with pancreatic cancer. Your specialist will discuss with you which is best for you after they have reviewed all your other test results. It will depend on the type, and position of your pancreatic cancer as to which biopsy technique your doctor will choose to use.

A biopsy will give your specialists the information they need to decide on the most appropriate treatment plan for you.

You may have a biopsy:

- with endoscopic ultrasound and fine needle aspiration (see below)
- during an ERCP (see below)
- guided by ultrasound or CT scan
- by keyhole surgery (laparoscopy)
- using a small operation (laparotomy).

Endoscopic ultrasound: This test involves using a long flexible tube (endoscope) with a camera, light and ultrasound probe attached to the end. This is put into your mouth and guided down through the food pipe and into the stomach.

The probe uses high-frequency sound waves to create pictures of the pancreas, bile duct and other parts of the digestive tract including lymph nodes. A small piece of tissue will be taken out (aspirated) using a fine needle. The tissue will be examined in the laboratory under a microscope. This test can help diagnose pancreatic cancer and will clarify which type of cancer you have (exocrine or endocrine).

An anaesthetist will either sedate you or put you to sleep during this procedure, which means you will need somebody to drive you home afterwards. This test is done as a day procedure, and usually performed by an expert gastroenterologist.

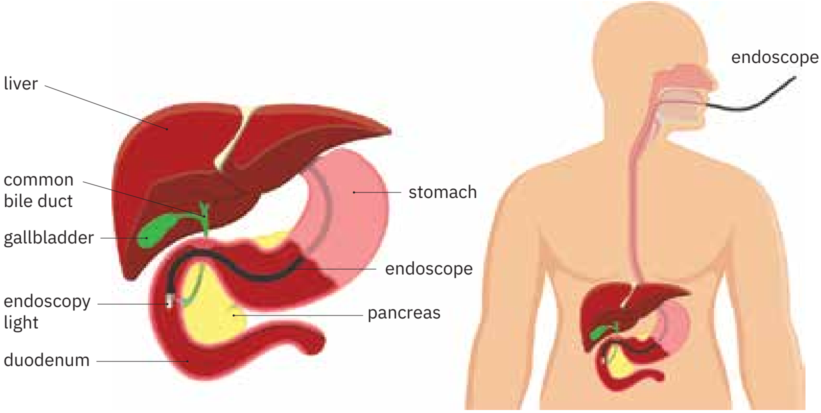


Figure 2: ERCP procedure

Endoscopic retrograde cholangiopancreatography (ERCP):
An ERCP is an x-ray used to help diagnose problems of the bile ducts, pancreas, gallbladder and liver. If you have jaundice, you will need this test.

A flexible tube (endoscope) is put into the mouth and down into the stomach and guides a catheter into the bile duct. The doctor will then put a small amount of dye into the area and it will show up any blockages or restrictions the cancer may be causing, especially in the duodenum or ampulla of Vater.

Sometimes an ERCP is used to insert a small tube (stent) into the bile duct to keep it open. At the same time the specialist will try to take some cells for a tissue diagnosis.

This test can take up to an hour but you will have it as an outpatient. You will be given some medication to make you sleepy during this procedure, which means you will need to stay for a few hours after the procedure.

Although rare, ERCP can cause side effects including pain, bleeding and infection (fever, increased temperature, shaking). If you develop these symptoms, it's very important to seek medical help immediately.

Positron emission tomography (PET) scan: Your specialist doctor will refer you for this test if necessary.

A PET scan involves injecting radioactive glucose solution into the body. Because cancer cells use more glucose than most normal cells, the PET scanner can find increased amounts of the radioactive glucose in areas of the body where the cancer is or has spread to.

A PET won't show up all cases of pancreatic cancer. However, it can sometimes help doctors understand the **stage** of the cancer so they can offer the most appropriate treatment options. It can detect if the cancer has spread, which may not show up on other imaging tests.

This scan is done in the nuclear medicine department in major hospitals.

Not all hospitals have a PET scanner. PET scans are not always covered by Medicare or private health insurance. Ask your medical team or private insurer for information.

Staging laparoscopy (keyhole surgery): This is a minor operation done under general anaesthetic. A small telescope is placed into the abdomen to see if the cancer has spread to areas within the abdominal area which are not visible using other imaging. Sometimes biopsies are taken if anything abnormal is seen. Your specialist will advise if this is necessary for you.

Other possible tests

Your doctor may do other tests to assess your level of fitness and ability to cope with certain treatment options. For example, you may need to have tests to see if your heart and lungs are functioning well.

Waiting for results

Waiting for test results is usually a worrying time. You and those close to you are likely to feel very anxious about what will happen if you have pancreatic cancer. It is natural to think the worst. But try to take things day by day.

Some results come back quickly, within a couple of days. Others can take up to a week or more. This can feel like a very long time. However, it important to get all the results to allow your specialist doctor to advise about the best treatment options for you.

> *'Waiting for results is such a stressful time.'*
>
> **SANDY**

Talk to your doctors and nurses about your symptoms, as well as about how you are feeling. Ask your doctor how long it might be before you will get your results so you at least have some idea about how long you will need to wait.

If you would like to speak with someone during this difficult time, call the Cancer Council on 13 11 20, Monday to Friday 9am–5pm, and speak with a cancer nurse.

Should people who don't have symptoms be tested?

Screening tests help detect cancer in people who don't have any symptoms. Screening cannot stop people getting cancer, but it can help to find cancer early when it is much easier to treat or cure. There are useful screening tests for certain types of cancer, such as breast cancer and bowel cancer. There is currently no reliable screening test for pancreatic cancer.

There are **clinical trials** underway in the United Kingdom and Australia testing people at high risk of pancreatic cancer. We need to wait for the results of these trials before we will know if this is effective and leads to a suitable screening test. See the section titled 'Clinical trials'.

If you think you might be at a higher risk than the average person of getting pancreatic cancer talk to your specialist or GP to consider referral to a genetic testing centre at a family cancer centre, or contact the Cancer Council on 13 11 20.

A note on germline testing

People are born with germline genetic mutations in every cell in their body. Germline testing examines a person's DNA for genetic changes (mutations), including those that can increase their lifetime risk of developing pancreatic cancer or other cancers.

Germline testing is not funded under Medicare, but patients with pancreatic cancer should be aware of the tests. Ask your specialist doctor about germline testing as having this testing can give patients and their doctors information that may help with decisions about the best types of treatments for your pancreatic cancer. Germline testing can also provide information about whether family members are at risk of developing certain types of cancer.

Staging the cancer

Staging your cancer helps your doctors work out the best treatment plan for you.

Cancer can spread into nearby surrounding tissue or to other, more distant parts of the body, including your lymph nodes. This is called metastasis or **secondary cancer**. Staging is a way of describing whether a cancer has spread, and if so, how far. It can range from stage 1, which means it has not spread, to stage 4, meaning it has spread to other organs in the body.

Pancreatic cancer can be staged in two ways:

- Pre-surgery staging is based on all the tests you have had to help your specialist diagnose pancreatic cancer (see Table 1 on the following pages).
- Post-surgery staging occurs after the operation to remove the tumour and surrounding tissue (see Table 2 on the following pages). It helps to guide your care after the initial treatment for your cancer.

Table 1: Pre-surgery staging

Group	What does it mean?
Resectable	Cancer has not spread outside the pancreas.
Borderline resectable	It is hard to tell from imaging tests if the cancer has spread to nearby tissues.
Locally advanced	The cancer has grown into or surrounded nearby major blood vessels.
Metastatic (unresectable)	Cancer has spread to distant parts of the body.

Source: Adapted from the National Comprehensive Cancer Network® (NCCN), Guidelines for Patients, Pancreatic Cancer, 2019

Can surgery be done?	Why?
Yes, tumour can be removed completely with surgery.	Tumour hasn’t grown into nearby arteries or veins.
It is unclear if the tumour can be removed with surgery.	Tumour may have just reached nearby blood vessels.
Unlikely, as the risk of leaving tumour cells behind on the vessels is substantial and risk of resecting vessels is high.	Very high likelihood of tumour cells being left behind on the vessels.
No, the tumour cannot be removed with surgery.	Tumour has grown into surrounding tissues and has spread to distant parts of the body.

In all groups there is the chance of microscopic cancer spread. This means single or small clusters of cells that cannot be seen by the eye will spread to nearby tissue or distant organs in the body. Therefore, it is important patients are given chemotherapy after surgery (adjuvant chemotherapy) to kill any cells left behind. Read the information in the treatment section about chemotherapy.

Table 2: Post-surgery staging

Stage	TNM* examples for each stage
1A	T1, N0, M0
1B	T2, N0, M0
2A	T3, N0, M0
2B	T2–T3, N1, M0
3	T1–T3, N2,M0
4	Any T, any N, M1

*The post-surgery staging system used for pancreatic cancer is known as the ‘TNM system’ (T= tumour, N = lymph nodes, M = metastasis)
(*see next page for more information*)

	Meaning
	The tumour is only in the pancreas (early stage disease) and is less than 2 cm in dimension. No spread to nearby lymph nodes or blood vessels.
	The tumour is still only in the pancreas but is greater than 2 cm but less than 4 cm in dimension. Still no spread to nearby lymph nodes or blood vessels.
	The tumour is greater than 4 cm in dimension but has not spread outside of the pancreas into nearby lymph nodes.
	The tumour is still only in the pancreas but is at least 2 cm in dimension and can be greater than 4 cm. The cancer has spread to local lymph nodes.
	The cancer has spread to **regional lymph nodes** (increasing the risk of systemic disease). It still hasn't spread to other organs in the body.
	Known as 'secondary' or 'metastatic' cancer. It means the cancer has spread from where it began in the pancreas to other parts of the body such as the liver, lungs or lining of the abdomen. **Note:** Stage 4 pancreatic cancer is not named by the organ it has spread to. For example, if the cancer has spread to the liver, it is not called liver cancer, but remains pancreatic cancer, as it is still pancreatic cancer cells that are in the liver.

The post-surgery staging system used for pancreatic cancer is known as the 'TNM system' (T = tumour, N = lymph nodes, M = metastasis).

- T – refers to the size of the tumour – the higher the number, the larger the tumour.
- N – refers to any spread into the lymph nodes (N0 means there is no spread into the lymph nodes, N1 means there are 1 to 3 lymph nodes that contain cancer cells and N2 means it has spread to 4 or more lymph nodes).
- M – describes whether the cancer has spread to other parts of the body and how far (M0 means there is no spread, M1 means it has spread to other organs such as the liver, bones or lungs).

Possible outcomes (prognosis)

Prognosis means the outlook for your disease and your life expectancy. Doctors are not able to predict exact outcomes for any individual. However, you can ask your doctor about possible outcomes for the stage, type and **grade** of your cancer. To work this out your doctor will review your test results and consider several things including:

- where your cancer is, its stage and type
- your age, general health and medical history
- how well your cancer responds to initial treatment.

Your specialist is the best person to talk to about your prognosis for your stage of cancer. They will know your individual situation best and be able to discuss likely outcomes.

Because pancreatic cancer is often diagnosed when it has spread to other parts of the body (**advanced cancer**), it can limit treatment options.

If pancreatic cancer is found early and can be removed with surgery as well as having **chemotherapy** and/or radiotherapy, the prognosis is more favourable. The intent is to cure the cancer (known as 'curative intent'). The best outcome is the cancer is no longer detectable – this is called **remission**.

When pancreatic cancer is advanced, treatment aims to slow down the growth/control the cancer and relieve symptoms such as pain and fatigue. The aim is first to maintain and improve your quality of life, and then to extend life. This is called **palliative treatment** or treatment with 'palliative intent' (see the section titled 'When cancer won't go away').

A note about statistics and survival rates

You may have seen some general survival rates for each stage of pancreatic cancer.

- We don’t include statistics on survival rates in this booklet as they are based on studies from large numbers of people and they can be confusing for individuals.
- Remember that statistics are averages and don’t consider things that can impact an individual’s prospects (e.g. age, fitness, other diseases).
- The terms ‘1-year’ and ‘5-year’ survival rates are used but this doesn’t mean a person will only live for one or five years. These numbers just show how many people are alive one and five years after their cancer diagnosis. Some people live much longer than five years.

The Cancer Australia website (www.canceraustralia.gov.au) has more detailed information about statistics.

> ***‘When I was first diagnosed, I was told to go home and smell the roses, which was a shock. Later I got a second opinion and well … here I am nearly a year later.’***
>
> **LYNNE**

Statistics can’t tell you what will happen in your individual situation. Although sometimes doctors may give you an estimated time frame of how long you have left to live, no one can really tell you exactly *how* long. It can depend on how you respond to treatment and will be an ongoing discussion with your specialist doctors.

> ***‘I was told at my diagnosis that I have 12 months to live. I didn’t feel this was appropriate to be told this at this time. He should not have told me this. I did not go back to him again.’***
>
> **JANE**

Some people don't want information about their prognosis. They prefer to focus more on quality of life and the here and now, rather than worrying they only have so many months or years left to live. Others want to know more, as they may have certain events or dreams they wish to fulfil while they are well enough. It is a personal preference as to what information is important to each individual and those close to them.

> ***'I try not to look too far ahead. I've never asked my doctor how long I have to live but I'm not stupid and I know I don't have infinite time to live. So, I try to just be grateful every day.'***
>
> **SANDY**

Please be careful about information on the internet and advice from well-meaning friends and relatives. Cancer treatments are changing rapidly, and information becomes quickly outdated. Ensure you are getting your information from the most up-to-date and reputable cancer websites and always check with your specialist medical team that what you are reading is accurate.

For more information, read the section titled 'Further information and support'. You can also call the Cancer Helpline on 13 11 20 and speak with a qualified cancer nurse.

Doctors and nurses are often working with statistics that are a few years old and there may have been improvements in treatments and survival since then.

TREATMENT

Deciding about treatment

After diagnosis, you will have some time to think about the treatment options presented to you. In this section we discuss some important things that will factor into your decisions.

Patient- and family-centred care

Patient- and family-centred care means that you and those close to you are at the centre of planning and decision-making around your treatment and care throughout all stages of your illness. It also means:

- you are treated in the way you choose to be treated
- your preferences about your care are recognised and respected
- you are treated with respect and dignity, whatever your age, cultural background, religion or sexual orientation.

This holistic approach to your care, and to those caring for you, allows you to feel more in control of your situation. Your treatment team will hopefully always aim to make this happen.

> ***'The best part about going to a specialist cancer centre for treatment was there was a team approach to mum's treatment. She saw the oncologist, nurse and a dietitian who told her about how to fuel her body – it was a holistic approach and it was supportive of us all as well as mum. We felt empowered and this continued throughout mum's treatment, even when she was at home, as I was able to talk to a Nurse Jenny on the phone about Mum's test results and what they meant. This helped a lot.'***
>
> **KAT** (cared for her mother with pancreatic cancer)

For further information about your rights as a patient or carer, read the Australian Charter for Healthcare Rights (www.safetyandquality.gov.au/).

Your multidisciplinary treatment team

It is important you are treated and cared for by a specialised team of health professionals (see Table 3 on the following pages). This is called a multidisciplinary team.

The multidisciplinary team will discuss your diagnosis and staging, and their treatment options, to ensure you get the best possible treatment for your individual situation. Being cared for by a multidisciplinary team improves communication and the coordination of your care between all the specialists involved in your care.

Ideally, all your tests and treatment will be available at one treatment centre, preferably as close to your home as possible, where you have support from loved ones. This may not be possible in some non-metropolitan areas. You may need to travel to a larger treatment centre specialising in pancreatic cancer. These centres are sometimes called ‘high volume hospitals or centres’ or ‘centres of excellence’. These hospitals have specialist cancer doctors who treat large numbers of people with your type of cancer each year. We recommend you ask for a referral to a ‘high-volume treatment centre’ or referral to a specialist who has links to a high-volume treatment centre close to where you live.

Your multidisciplinary team should keep your GP informed about all your test results and treatment. Discuss with your GP the role they will play in your multidisciplinary team. This can help you feel sure your GP understands your cancer and that they will be able to answer any of your questions in between appointments with your specialist cancer doctors.

Table 3: Health professionals who care for people with pancreatic cancer

Health professional	What they do
Hepatopancreatic-biliary surgeon	removes cancers that can be operated on and performs some biopsies
Anaesthetist	takes care of you during the operation to ensure your lungs and heart function well and manages your pain relief after the operation
Medical oncologist	prescribes chemotherapy and other treatments such as immunotherapy
Radiation oncologist	prescribes radiotherapy
Interventional radiologist	interprets some tests, biopsies and treatments
Gastroenterologist	specialises in treating disorders of the stomach and intestines
Pathologist	examines cells under the microscope to accurately define the type of cancer you have
Endocrinologist	specialises in treating disorders of the hormones, including diabetes
Specialist nurses	includes cancer care co-ordinators; clinical nurse specialists; palliative care nurses; surgical, radiation oncology and chemotherapy nurses; diabetic nurse specialists; and community nurses, who are all there to advise and provide care and support for you and your family throughout your treatment

Health professional	What they do
Palliative care team	assists with symptom management and emotional support for you and those close to you to obtain maximum quality of life
GP	helps you through all stages of your cancer and is a crucial part of the multidisciplinary team
Dietitians	advises about maintaining your nutritional status during and after treatment long term
Physiotherapist/ occupational therapist	helps you adjust to changes in your body and home and aims to get back to your normal activities
Psychologists/ counsellors	helps you and your loved ones with emotional and social concerns
Social worker	offers emotional support and advises on support services
Pastoral care	supports your spiritual needs
Exercise physiologist	assists you with your overall wellbeing – exercising and improving your health, fitness, strength and overcoming fatigue

Communicating with your treatment team

'My medical team, including our specialist nurse, were always willing to communicate with myself and my wife in times of our uncertainty and unsureness of what the next step involved along a long and at times mentally torturous road.'

TOM

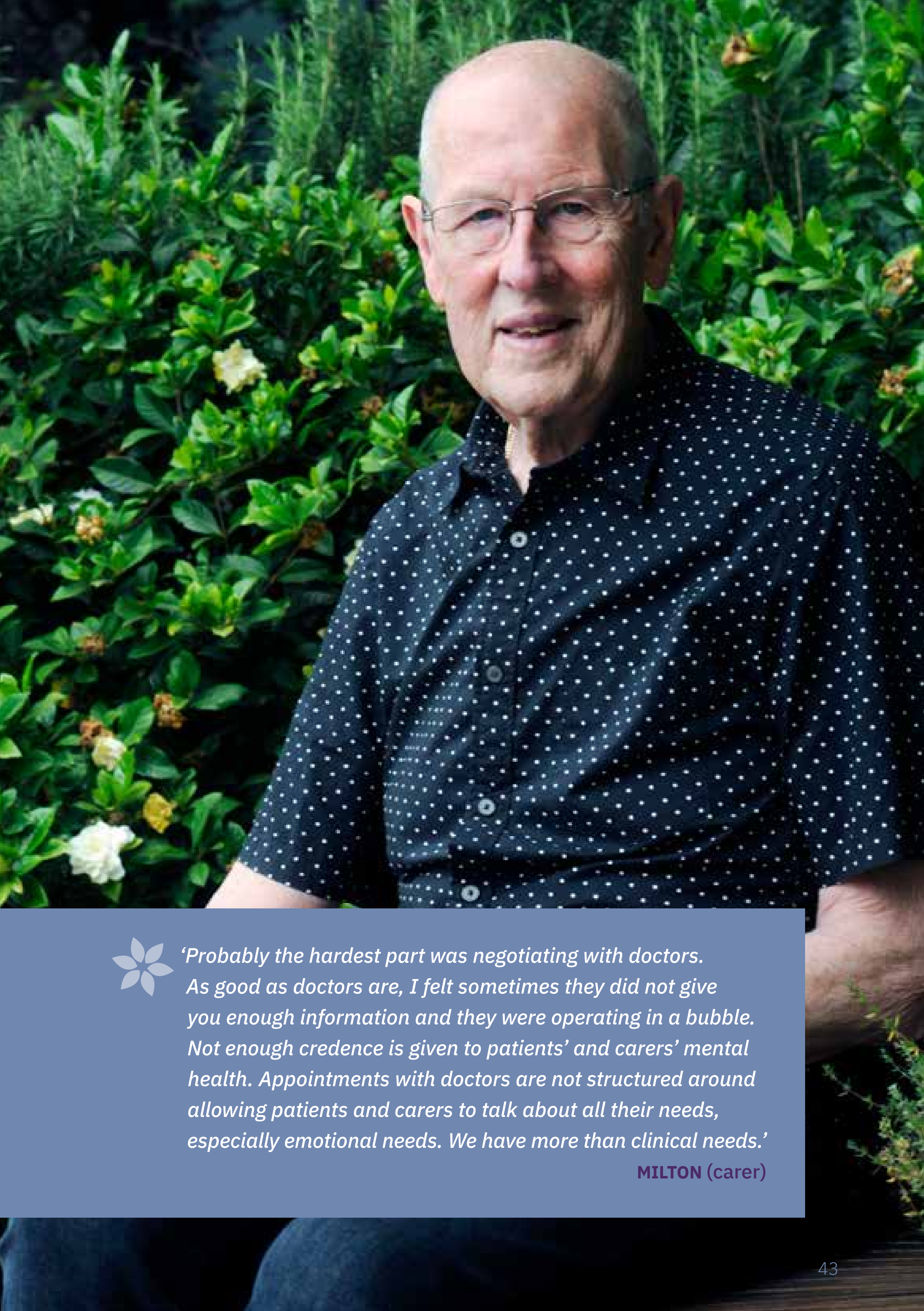
When you are first diagnosed with pancreatic cancer, you may see many different doctors, nurses and other health professionals (see Table 3, previous page). Communication with so many health professionals can be challenging during times of stress. Your treating team will hopefully communicate all the necessary information to you, in language you understand. But unfortunately, sometimes it doesn't always go as well as we would hope.

'I had a call from a receptionist confirming an appointment with a doctor I had never heard of, I assumed it was a mistake but then she had all my details so I queried the speciality of the doctor and found out it was an oncologist. And that's how I found out I had cancer. Through either bad communication or bad luck, over the phone from a receptionist.'

AARATHY

'I would get conflicting views on things to do with my cancer and treatment, especially about diet and sugar, and this was hard.'

JANE



> *‘Probably the hardest part was negotiating with doctors. As good as doctors are, I felt sometimes they did not give you enough information and they were operating in a bubble. Not enough credence is given to patients’ and carers’ mental health. Appointments with doctors are not structured around allowing patients and carers to talk about all their needs, especially emotional needs. We have more than clinical needs.’*
>
> **MILTON** (carer)

There are strategies you can learn over time about how to communicate well with your care team which can help have a positive impact during your treatment and beyond. Don’t expect to feel comfortable or understand everything immediately. It may take a few meetings with your doctors and nurses before you feel like you can work well together.

‘Communications were excellent. They gave us advance information of what we might expect in coming days as the treatments varied in time and type and I must give credit to the nurse who became my go-between in the early days and stuck with me through these three years. My nurse knew straight away, or found quickly, the answers I always needed, which helped Janice and myself understand where we were going, why and what was ahead of us.’

TOM

Be clear with your doctors about what you want and how you wish your care to progress. Even if you don’t want to know everything, it is still important your doctor has a discussion with you about the extent of your cancer and the possible treatment options and side effects (short and long term). It is your decision which treatment you go with, but you need the information in order to make an informed decision.

‘I like it when things are explained to me in detail about what is happening. I was told having a port put in was a “simple procedure”, but when I went to have it put in, I had a massive panic attack. Doctors need to be clear with patients. Getting a port put in was quite traumatic for me.’

AARATHY

Don’t be afraid to speak up and ask questions. A strong and honest two-way communication channel between you and your doctors will help build trust, which will enable you to feel more in control and empowered to make important decisions about your situation.

‘I have absolute confidence in the expertise of my oncologist and the nursing/support staff at my treatment centre. I do have concerns that the pressures and time constraints under which my oncologist works don’t afford me the opportunity to discuss as fully as I would wish, my test and scan results and my current and proposed treatment options. Perhaps I should be more assertive in my questioning, but it is not easy to break through the high powered, even frantic pace and atmosphere of the standard consultation. Further, there is always a lot of information, much of it emotionally charged, to be absorbed by my poor chemo-addled brain in a short period of time!’

DAVID

Tips to help with effective communication

- Don’t be afraid to speak openly and honestly or ask questions of your doctors and other health professionals.
- Be sure to tell your doctor about all your symptoms, even if you think they aren’t important.
- Let your doctor know how much or how little information you want. This may change at different times in your illness, but it is important your doctor is aware.
- Write down your concerns and take them along to your appointment so you don’t forget anything. Take notes during your appointment or ask your doctor if you can record it on your phone or other small device.
- Make sure your doctors listen to your concerns and they understand your needs.
- Repeat back to your doctor what you believe you heard them say to make sure you have interpreted them correctly.
- If your doctor talks and you are struggling to understand what they are saying, ask them to slow down.
- Take someone you trust with you to your appointments – two sets of ears will allow you to later discuss what you heard together and ensure it is correct.

- Ask your doctors and health professionals where you can find the most reliable and up-to-date information about your cancer and its treatment.
- Avoid asking ‘Dr Google’, as a lot of medical/cancer information on the internet has not been reviewed by experts. Some of it is wrong and can be dangerous to follow.
- Ask your doctor for copies of your test results or to write down/ provide you with written information about your cancer and its treatment.
- If possible, have all your scans at the same imaging place to keep things simple and allow for easy access and comparison of your results.
- Keep a health calendar (see Table 4) with all your good or bad days and the symptoms or emotions concerning you. It can be hard to remember all that happened yesterday, or in the past week or month. Take this with you to each appointment.
- Make a list of all your medications, dosages, times to take them and the reason you’re taking them. Prior to your appointments, check if you have enough medications or if you need a new script from the doctor. Remember to review your symptoms and related medications regularly with your doctor.

Effective communication is always a two-way process. Being a good communicator means you need to express yourself clearly. But it is also important to listen to what others have to say and be sure to give their ideas respectful and thoughtful consideration.

Table 4: Example of a three-day health calendar

Concern	Sunday 14 May	Monday 15 May	Tuesday 16 May
Energy levels	So tired, several naps.	Able to shower and go out to shops.	A lot more energy today – no naps.
Mood	Feeling sad and anxious most of the day.	Depressed and teary. Overwhelmed talking to anyone.	Feeling happy today and enjoyed chatting to my friend.
Symptoms	Nausea all morning but improved in afternoon. Headache.	Rash on arms and abdominal area. Vomiting.	Keep forgetting things and unable to concentrate for long.
Exercise	Stayed in bed most of day.	Short walk with dog – 10 minutes.	Few stretches and cleaning around the house.
Social activities	Nothing, did not want to see anyone.	Spoke on the phone to a friend but found it tiring.	Friend visited for coffee and brought homemade biscuits.

Telehealth

Telehealth (also known as eHealth) is the practice of caring for patients remotely when the health provider (e.g. doctor, nurse, counsellor) and the patient cannot be physically present with each other. This can be done using telephone and/or computer technology (e.g. video calls using Skype or Zoom).

Telehealth can improve access to healthcare for people with chronic illness and cancer. It is becoming a more accepted and frequently used way for patients to communicate with their treatment team, especially for those who must travel long distances.

For more information about telehealth and how it works, visit the Department of Health (www.health.gov.au).

Getting a second opinion

Seeing another specialist and asking for their view on your cancer and its treatment options is called ‘getting a second opinion’.

Most doctors understand why patients may decide to get a second opinion. It is your right to seek a second opinion, so don’t be scared or feel uncomfortable about asking for a second opinion. It may change things but often it doesn’t, as treatment for pancreatic cancer is standard across Australia. But for peace of mind, it helps some people. Sometimes knowing the same treatment has been recommended is reassuring.

‘It was organised for us to get a second opinion from another Doctor and we flew to Sydney and met with him. He did additional tests and my Mum had a biopsy. Mum then felt very safe and the best part was she was treated by a “team” which felt good.’

KAT (carer)

Your GP can refer you to another specialist. Ask for a copy of the results to be sent to the second opinion doctor.

‘I am so grateful I sought a second opinion. Not much changed clinically about my care, but I was significantly better supported mentally and emotionally. The team I transitioned to prioritised quality of life, it was the forefront of all our communication and made me feel like a person not a patient.’

AARATHY

Getting a second opinion doesn’t mean you won’t be able to have treatment with your first doctor. It is important you feel confident with who is treating you, but it is also important to be open and honest with both specialists as they will often need to make complex decisions about your treatment.

> *‘Later I got a second opinion, which helped a lot as when I was first diagnosed, I was pretty much told there was nothing that could be done, but it turned out there was a lot that could be done.’*
>
> **LYNNE**

Treatment decisions

Where should I have treatment?

Your GP can refer you to a specialist. In Australia, pancreatic cancer is treated both in the public and private system. Different states have different health systems. The key is the multidisciplinary team approach and it is important you discuss this with your GP/ specialist as every patient is assessed individually.

It is important to know how many patients a year your specialist sees with pancreatic cancer. There is evidence to suggest that specialists who treat a lot of people with the same type of cancer have better outcomes.

Many rural areas have specialists who have close ties to major metropolitan cancer teams. They may also have visiting specialists who come from the specialist cancer centres.

Avner Pancreatic Cancer Foundation recommends you initially gain an opinion about your treatment from a specialist at a high-volume cancer centre. You may also have your treatment here, especially surgical treatment. But quite often the same treatment (chemotherapy and other) will be available in a hospital closer to your home. Be reassured that most local oncologists have strong ties to the larger cancer centres. They are also able to enrol patients into clinical trials that are being done in larger, metropolitan centres.

- The most important question to ask your specialist if you are having surgery is ‘How many pancreatic cancer surgeries has the hospital performed in the last year?’

- It is also important for every patient to ask, whether having surgery or not: ‘Does the hospital have a multidisciplinary team?’ and ‘Are there any clinical trials suitable for my situation?’

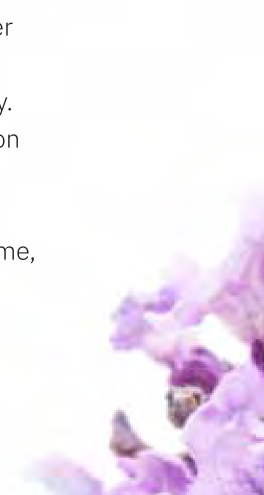
Depending on which treatment you will have, you should ask your GP to suggest a specialist suitable for your situation.

What if I live in a remote area?

For people living in remote areas it is not always easy to gain access to a high-volume centre to have your surgery. And travelling a long way for treatment can be stressful, and the costs involved difficult to cover. But there is often support available for people to travel to a high-volume surgical cancer centre. For example, you might be eligible for help through:

- the Royal Flying Doctor Service’s (www.flyingdoctor.org.au) patient transfer scheme
- Angel Flight (www.angelflight.org.au), a charity that provides non-urgent flights to those living remotely to deal with poor health, lack of finances and long distances
- the Country Women’s Association (www.cwaa.org.au) sometimes helps people in remote areas with travel and accommodation for healthcare.

To find out more about the best options for you and specific schemes available in your state or territory, speak with your GP or the social worker at the local hospital. You may decide you prefer to stay local to have your surgery as the inconvenience of travel and being away from home is too difficult for you and your family. This is your choice, but it is important you have all the information to be able to make an informed decision about where you have your surgery. Other treatments, such as chemotherapy and radiotherapy, can usually be given at hospitals closer to your home, which are linked to high-volume cancer centres.



Which treatment?

Which treatment you have for your cancer depends on:

- the type of cancer
- how far it has spread (the stage)
- what the cells look like under a microscope (the grade)
- your overall health and fitness level (see 'Performance status')
- your wishes.

For further details on staging your cancer before surgery, see 'Staging the cancer'.

Performance status

Performance status is a score of a person's ability to do certain activities of daily living without help from someone else (see Table 5). The score is an important part of cancer care and identifies the person's ability to tolerate treatments when seriously ill, especially treatments such as chemotherapy and radiotherapy. It is used by doctors when planning cancer treatment and is likely to contribute to the recommendation your doctors made regarding your treatment.

Table 5: Performance status

0	Able to selfcare, fully active
1	Able to selfcare, ambulatory but unable to undertake strenuous activities, able to carry out light and sedentary tasks
2	Able to selfcare, ambulatory and up and about more than 50% of waking hours, unable to do any work tasks
3	Limited selfcare, confined to bed or chair more than 50% of waking hours
4	Unable to selfcare, completely disabled, totally confined to bed or chair

Adapted with thanks from Eastern Cooperative Oncology Group

Your doctor will discuss with you the possible treatments, their side effects and benefits.

You may like to read the optimal care pathway for people with pancreatic cancer at www.cancer.org.au/ocp. This discusses in detail treatment options, care after initial treatment and recovery. But it is most important to ask your specialist about current advances in treatment as options are continually changing.

Stage 1 or 2

One of the first things your doctor will look at is whether your test results indicate they can remove your cancer with surgery. This operation is called a resection. If your cancer is stage 1 or 2, and the cancer is only affecting the pancreas, small bowel, stomach and bile duct and it isn't affecting any nearby blood vessels, a surgeon may be able take out the cancer (resectable).

Pancreatic cancer is potentially curable with multimodal treatment surgery (which may be a combination of surgery with other therapies such as chemotherapy and/or radiotherapy) when caught early.

Stage 3

Stage 3 means the cancer has spread locally to surrounding tissue, lymph nodes or to other more distant organs (metastatic cancer). In some situations, it might not be so clear if your cancer can be taken out with surgery. This is known as borderline resectable cancer, or locally advanced cancer. The intent of surgery for pancreatic cancer is to remove the cancer, as well as an area of tissue around the cancer that doesn't contain cancer cells (a clear margin). This will give you the best chance of the cancer not coming back.

For further details on staging your cancer before surgery, see 'Staging the cancer'.

You may also have chemotherapy before your surgery to shrink it or after your surgery to help stop the cancer coming back. Radiotherapy before surgery, along with chemotherapy, may also be offered to some patients. This is called neo-adjuvant treatment – treatment given before surgery to shrink a tumour.

If the cancer hasn't spread to other parts of the body, but it is blocking or surrounding nearby blood vessels, it is called a locally advanced cancer (stage 3). Chemotherapy is usually the choice of treatment for stage 3 cancers. If there is enough tumour shrinkage, surgery may then be an option for some people to take the cancer out.

Stage 4

Cancers that have spread to distant organs in the body, such as the liver or lungs, are called metastatic cancers (stage 4).

Surgery isn't usually an option for stage 4 pancreatic cancers as removing all the cancer isn't possible. Chemotherapy, radiotherapy and endoscopic treatments can all help control the symptoms, side effects and growth of advanced pancreatic cancer.

Treatments for all stages of pancreatic cancer are discussed in detail in the next section.

What if I decide I don’t want treatment?

If your cancer is advanced, you may wonder whether having treatment is worth it.

Even if the cancer can’t be cured, treatment may still help control it and relieve difficult symptoms and side effects such as pain and fluid build-up in the abdomen.

You always have the right to refuse any treatment you are offered. But before you refuse, it is important you understand the treatments on offer, their possible benefits and the possible outcomes without treatment. In some states, if you choose to refuse treatment, your doctor may ask you to fill out a ‘refusal of treatment certificate’.

Discussing your treatment and outcomes with those close to you

Talk to your specialist doctors and nurses first about possible treatments and outcomes. You can then talk to friends and family you trust to help you sort out which course of action is right for you. It can be a confusing and difficult time. It is important you feel safe and don’t have to worry about too many people suggesting what you do.

Gather the information and then take your time to make decisions about your treatment. You may also like to read the information on reputable cancer patient websites listed in the ‘Further information and support’ section.

Treatment for pancreatic cancer

Many years of treating people with cancer and testing different treatments in clinical trials has helped doctors know what is likely to work for a particular type and stage of cancer. Your specialist doctors will advise you about the best treatment for the stage, grade and type of pancreatic cancer you have. Their suggestions will take into account your overall health, how far the cancer may have spread and what you want. As the treatment plan is so individual, you may meet other people with pancreatic cancer with a similar story, who are receiving different treatment to you. Feel free to talk to your medical team about why your treatments have been recommended for you.

Treatment for pancreatic cancer may include one or a combination of the following:

- surgery
- chemotherapy
- radiotherapy
- endoscopic treatments (e.g. stents and bypass surgery to relieve pain and blockages)
- other treatments (e.g. ablation, targeted therapy, immunotherapy).

Surgery

The most common treatment for early stage pancreatic cancer is surgery, with chemotherapy and/or radiotherapy before and/or after the surgery.

Treatment for more advanced cancer is aimed at relieving symptoms such as pain and digestive problems.

It is important you discuss treatment options with your doctor and ask about the treatments that are selected in cancer centres that treat high volumes of patients each year. Your GP may be able to help you frame your questions to your specialist or find out this information on your behalf.

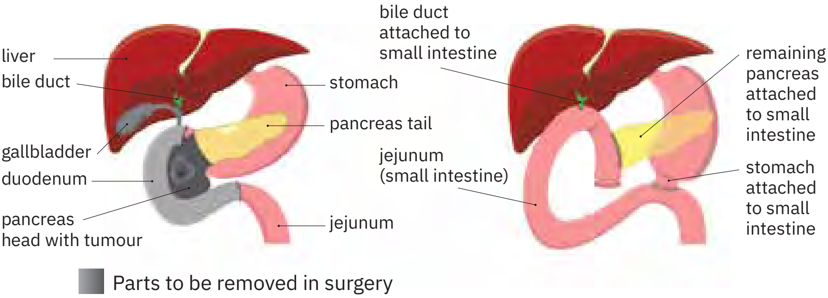
Types of surgery

About 25% of people with pancreatic cancer will have surgery. If your cancer is found in the early stages (i.e. stage 1 or 2) your doctor is likely to suggest you have surgery to remove the cancer (with chemotherapy and maybe radiotherapy as well before or after the surgery). Depending on where the cancer is, you may have one of the following operations:

- A distal pancreatectomy involves removing the tail and/or a portion of the body of the pancreas, but not the head, with or without removal of the spleen (splenectomy) for tumours in the tail of the pancreas.
- A Whipple procedure (pancreaticoduodenectomy) involves taking out part of your pancreas (usually the head of the pancreas), your duodenum (the first part of your small bowel), your gallbladder and part of your bile duct as well as removing a small part of your stomach.
- A total pancreatectomy is removal of the whole pancreas as well as your duodenum, part of the stomach, the gallbladder and part of your bile duct, the spleen and many of the surrounding lymph nodes.

The Whipple procedure is the most common type of pancreatic cancer surgery. It is major surgery and performed by a specialised pancreatic or hepato-pancreato-biliary (HPB) surgeon. The surgeon will remove the head, or right-hand portion, of the pancreas, which is where most tumours happen. Because of the difficult location of the pancreas, the surgeon will also have to remove part of the small intestine, gallbladder, bile duct and sometimes a part of the stomach.

The operations are complex. They take several hours to perform (between five and 12 hours), and you will be in hospital for one to two weeks if there are not any complications. The recovery time can take between six and 12 weeks.



A. What your surgeon removes

B. How the surgeon might repair what is left behind

Figure 3: Whipple operation

Surgery will affect your digestive system and you may have diarrhoea for a while. Although this is expected, it can be difficult to cope with. There are things that can be done to help with your diarrhoea, but it can take time to feel able to manage it. You may need to take digestive enzymes after the surgery to help digest food.

If you have a total pancreatectomy, you will develop diabetes. You will need to use insulin for the rest of your life. It is important you see an endocrinologist and connect with a specialist diabetic nurse, as well as a dietitian who specialises in this area. Your treating team will organise this for you after your operation.

If you have your spleen taken out, you will be more susceptible to infection and your blood clotting mechanisms may be affected. You may find it helpful to refer to Spleen Australia website (www.spleen.org.au) for further information about having a splenectomy.

Most people who have any of these operations will need help with their diet. It takes time (often months) before issues with your eating and drinking settle down. You can read more about diet in the section titled ‘Managing symptoms and side effects’.

In recent years, a new procedure using robotic surgery has been used in some hospitals to perform Whipple procedure. This surgery is more advanced and less invasive than using the usual laparoscopic keyhole surgery. However, robotic surgery and keyhole surgery are relatively new techniques and won't be available in all cancer centres. We need further research in the area before we are sure of their benefits.

Preparing for surgery

Preparing for surgery can be a very stressful time. You may be trying to imagine what the surgery will mean, about the pre-surgery tests and how you will prepare your home, pets, family and work for being 'out of action' for some time.

Your specialist doctors and nurses will inform you about any tests you need to have prior to surgery. This will usually include tests to determine your general health and fitness for such a big operation. You may need to have all or some of the following:

- blood tests to check general health, tumour markers (CA19-9) and kidney and liver function
- breathing tests and possibly a chest x-ray to check your lungs are okay
- electrocardiogram and echocardiogram to check your heart is functioning well.

You will need to have an appointment at a pre-hospital admission clinic. This may be a few days or a week before your operation. The order in which things happen may vary between hospitals. At this session you may see:

- your surgeon, to discuss the exact operation, its benefits and possible complications, as well as consenting to the operation
- nurses, to discuss your general health, recovery in hospital and what you will need when you go home
- a physiotherapist, to teach leg and breathing exercises you need to do before and after surgery to prevent blood clots and infections
- an anaesthetist, to assess you before the operation to make sure you are fit enough to have a long aesthetic

- a dietitian, to discuss the possible dietary problems after surgery and what can be done to help manage your diet. It's not uncommon to lose weight after major abdominal surgery. A dietitian will also help you get as well as possible before your operation and provide useful tips on how to increase your overall nutrition. This may include drinking some nutritional supplements before your operation.

You may go into hospital the day before, or the morning of the operation.

Before your operation, your doctors and nurses may suggest you make an advance care plan. This allows you to set out in writing your wishes for all your future medical care. Advance care plans are the best way to make sure important decisions about your care are carried out in the way you want them to be. You may also be asked to fill in a form called 'medical orders for life-sustaining treatment' and/or a 'goals of care' form. These forms allow you to express your preferences about your ongoing care and life sustaining treatments. There is more detailed information about advance care plans in the section titled 'Useful information'.

After surgery

Immediately after your operation you may be in an intensive care unit. This is so a team of doctors and nurses can monitor you very closely. You will need to have regular pain relief. Your doctors and nurses will want you to be as pain free as possible during your recovery time. You will have several drips and tubes in place to help keep your body hydrated and fed until you can return to eating normal food. You may also have some tubes draining blood or fluid. A urinary catheter will be inserted before the operation and removed a few days after your operation.

Most patients will also need to take pancreatic enzyme tablets after their operation. Your surgeon will discuss this with you. These are taken with each meal and help to digest fat and proteins. Because the pancreas produces insulin, some patients will develop diabetes if you have part or all your pancreas removed. This means you will need to have regular insulin injections. This will be managed by the endocrinology team. Both of these issues are discussed further in the section titled ‘Managing symptoms and side effects’.

You are likely to be in hospital for about 10–14 days. But if you develop any complications you may need to stay longer.

Possible complications after surgery for pancreatic cancer

After any operation there are risks and possible complications which can make recovery more difficult. Surgery to treat pancreatic cancer carries some serious risks. However, these risks are lessened if your surgeon works in a specialist cancer centre/hospital and performs a large number of these operations each year. It is important you and your doctor discuss the pros and cons of the surgery prior to the operation. A decision to go ahead with this type of surgery is based on your health, the size and location of your tumour and the risks involved. About 4 out of 10 (40%) people who have complicated pancreatic surgery will develop one or more complications. These complications can be serious but others minor. You may like to ask your surgeon how many of the type of operation you are having they do each year.

Possible complications and long-term issues include:

- bleeding (internal)
- anastomotic leak
- delayed gastric emptying
- blood clots
- infections
- bowel problems (diarrhoea or constipation)
- diabetes
- death.

‘My worst time in the first year after my diagnosis was finding myself in ICU after the Whipple operation. This was a dark room with a number of soft lights glowing behind readings that meant little to me. Alone, tubes and attachments all over me, and feeling quite claustrophobic I recall my hands running over the equipment in and around me and wondering if I could sit up and call someone – not because of aches or pain, because I didn’t have any. I was simply, I think, suddenly finding myself a bit out of my depth, out of my comfort zone, unable to be my usual independent self.’

TOM

Major internal bleeding after surgery is rare. But if it happens you may need to have a blood transfusion or have urgent surgery to stop the bleeding.

Anastomotic leak after surgery is a serious complication and happens in about 1 in 10 cases. This happens if the join (anastomosis) between the part of your pancreas that is left behind and your small bowel leaks. This means pancreatic digestive juices leak into your abdominal cavity. This is a serious problem as it can cause infections and, if not treated, death. Antibiotics and draining the fluid are options but sometimes it may mean further surgery.

Bowel paralysis (ileus) is when your bowel stops working for a few days, which often happens after major surgery. You will feel nauseous, bloated and uncomfortable in your stomach area. Treatment for this is to put a tube through your nose into your stomach (naso-gastric tube) and give you intravenous fluids until your bowel starts working again. The tube into your stomach is used to suction out extra air or material that you would otherwise vomit.

Delayed gastric emptying: Also called gastroparesis, delayed gastric emptying means the slowing or stopping of the movement of food from your stomach to your small intestine. It is a common problem after pancreatic surgery. It affects between 14% and 30% of patients after surgery. You will not be able to eat until the situation improves. Delayed gastric emptying is not life threatening but it can mean a longer stay in hospital.

Blood clots (also known as deep vein thrombosis or DVT) can occur after surgery as you are resting and not moving around much. A DVT will block normal blood flow through your veins. There is a chance it will dislodge from its position and travel to the lungs. This can be fatal if it causes a blockage in the lungs (pulmonary embolism).

To try to prevent blood clots, you may have daily injections of blood-thinning medication, physiotherapy and wear anti-embolic stockings. You may have to continue using these for short time once you are at home. Moving around soon after surgery can greatly help with preventing clots.

Infections can occur in the chest and surgical wound, and there may be leakage of bile internally around the operation site. Urinary tract infections caused by having a catheter or infections from other tubes used to give you fluids and medications (e.g. intravenous cannula) are also a risk. You will have antibiotics during and after surgery to try and prevent any of these infections. Physiotherapy and moving around as soon as possible after the operation can also help prevent chest infections and pneumonia. If bile or other fluids leak from the surgical wound, it may need to be drained. It is very important to prevent any internal/external fluid leakages, otherwise it could mean further treatment and a longer hospital stay.

Diarrhoea can happen because part of the pancreas is taken out during surgery and the part that remains may not be able to produce enough enzymes to properly help with food digestion and fat absorption from food. Undigested fat can cause diarrhoea.

Your dietitian and nurses will discuss ways to help you cope. You will most likely need to take a pancreatic exocrine supplement (see the section titled ‘Managing symptoms and side effects’).

Constipation can happen after surgery. It can take some time for the bowel to start working after you begin to eat again. The drugs used to help control your pain after surgery can also cause constipation. A specialist dietitian can help.

Diabetes can happen because the food pathway through your gut is shortened and food can pass through your small intestine quickly, causing diarrhoea and poor digestion of food. It may also occur if all or part of your pancreas has been removed, or the part of your pancreas that is left is scarred from inflammation caused by the tumour.

Death: With advances in surgery, death after pancreatic surgery is now very rare. It is still a risk. If you have a very experienced surgeon perform your operation at a specialised centre that does a large volume of cases each year, the death rates are very low (1–2%). This is why we suggest asking your surgeon how many operations were done at the hospital in the previous year, before deciding on where you will have your operation. We know that international guidelines state higher volume centres and higher volume surgeons have improved outcomes. Your GP will likely be a helpful and reassuring support for you if you need help asking this question.

Going home after your operation

During your recovery at home it is important to gently exercise to help build up your strength. Before you go home, your doctor and physiotherapist will advise you about the amount of exercise and best type of exercise for you.

You may have a community nurse visit you at home for a while after your operation. They will dress any wounds you have and help you with hygiene needs.

If you have any concerns at home, contact the hospital, specialist nurse (if you have one) or your GP. Always keep these numbers close by.

Make an appointment to see your GP soon after you are discharged from hospital. Your GP will play an important role in working as part of your multidisciplinary team to monitor you and ensure you are well supported.

Gentle walking and swimming after all the wounds have healed are often helpful.

‘At this stage, almost three years since my Whipple surgery, I feel 85% back to where I might have been otherwise.’

TOM

Stents and bypass surgery to relieve symptoms

Surgery can be used to relieve the symptoms caused by the pancreatic tumour (jaundice or bowel blockage).

Jaundice is a condition that happens due to a blockage in the bile duct. If this happens you may:

- feel sick (nauseous) and vomit
- feel very itchy, weak and tired
- have pain or discomfort in your abdominal area
- get a yellow colour in your skin and the whites of your eyes.

These symptoms can happen with localised disease, but they can also happen if your cancer is advanced and curative surgery isn't an option. Your doctor may decide to put a small tube (stent) into the bile duct to hold the duct open and relieve the blockage. This can be done using an endoscope and is usually successful.

If you can't have a stent, or it hasn't been successful (which is rare), your specialist may do it radiologically (percutaneous transhepatic approach), or suggest an operation called a choldochojejunostomy or hepaticojejunostomy. This means cutting the bile duct above the blockage and then reconnecting it to the small bowel. This allows bile to bypass the blocked bile duct and drain out. Although this means recovering from an operation, it is usually worth it, as it almost always relieves the jaundice and other symptoms.

Sometimes the pancreatic cancer causes a partial or complete **bowel blockage (obstruction)** in the small bowel (duodenum). This is a serious problem and can make you feel very sick. Anything you eat or drink can't pass into the bowel as it normally would. It sits in the stomach and eventually you will vomit it back up again. You may also get cramping pain and swelling in the abdominal area. To relieve this, your doctor may suggest putting a tube (stent) into the duodenum to keep it open. Or your doctor may recommend an operation to bypass the blockage. You would need to discuss the pros and cons of this operation with your doctor.

Chemotherapy

Chemotherapy uses anti-cancer drugs to destroy cancer cells. The aim is to kill the cancer cells while doing the least possible damage to normal cells. The drugs work by stopping cancer cells from growing and reproducing.

Your doctor may recommend chemotherapy for several reasons including:

- before surgery (neo-adjuvant chemotherapy) to try to shrink the tumour, which will make it easier to remove with clear margins
- after surgery for early stage cancer to get rid of any cancer cells left behind as well as trying to stop the cancer coming back (known as adjuvant chemotherapy)
- for advanced (metastatic) pancreatic cancer if the cancer has spread to other organs in the body, to help control the growth of the disease and maintain quality of life.

You usually start adjuvant chemotherapy six to eight weeks after surgery as your body needs time to recover before having more treatment.

Chemotherapy is given in cycles over a period of about six months. Depending on the stage of your cancer and your overall health, you may have one chemotherapy drug or a combination of drugs.

Before you begin your chemotherapy, a medical oncologist will discuss with you the best types of chemotherapy drugs for your cancer and you. A specialist will also talk you through your treatment and possible side effects.

Don't be afraid to ask questions: find out as much as you need to about the chemotherapy you will be having.

Some of the names of drugs you may have include:

- gemcitabine
- capecitabine
- fluorouracil (5-FU)
- irinotecan
- oxaliplatin
- nab-paclitaxel.

Examples of chemotherapy drugs given together are:

- FOLFIRINOX, which is a combination of four drugs: fluorouracil (5-FU), leucovorin, irinotecan and oxaliplatin
- nab-paclitaxel (Abraxane) with gemcitabine may be offered to people with advanced pancreatic cancer who can't have FOLFIRINOX, or gemcitabine together with capecitabine (GemCap).

It is important to know that if the first choice of chemotherapy drugs you have (first-line therapy) doesn't work well, you can have other drugs or combinations of drugs. These are called second-line drugs.

Your specialist doctor and nurses will tell you which specific drugs/combination of drugs you will have.

Most chemotherapy drugs are given directly into your bloodstream through a small vein in your arm or through a device (PICC line or porta-cath) inserted into a larger vein. Your specialist doctor will discuss these devices with you. If you are having chemotherapy over a long period, you will need to keep this device in place for several months or longer.

Your oncologist should discuss with you the proposed chemotherapy pathway based on:

- guidelines and protocols for your specific hospital
- the stage of your disease
- your general health and fitness levels
- your preferences.

Side effects of chemotherapy

All chemotherapy drugs can have side effects but not everyone having chemotherapy will get side effects. Chemotherapy drugs given for pancreatic cancer can cause:

- fatigue
- nausea and vomiting
- numbness in your hands and feet (**peripheral neuropathy**)
- bowel problems (diarrhoea and constipation)
- mouth problems (sore, dry or ulcerated mouth)
- dietary problems (loss of appetite, taste changes, weight loss)
- muscle and nerve problems causing numbness
- skin changes (rash and itchiness)
- hair loss/thinning
- changes in your memory and ability to concentrate which can improve once treatment finishes (chemo brain 'fog').

'I was fortunate to come through chemotherapy almost unscathed. I managed to avoid nausea, headaches, aches or pains, though I did feel the year of drugs were becoming a little challenging in terms of memory, concentration and being somewhat lethargic.'

TOM

'I had a lot of different chemo and then I had to come out of the chemo fog.'

SANDY

Chemotherapy also causes changes in numbers of different blood cells. A drop in the number of:

- white blood cells mean you are at an increased risk of getting an infection – tell your doctor if you have any symptoms of an infection, such as a change in your temperature, chills, muscle aching or feeling generally unwell

- platelets (which help blood to clot) can mean you will bruise more easily or get bleeding noses or gums
- red blood cells can cause **anaemia**, which can cause shortness of breath and tiredness.

‘My white blood cells/neutrophils crashed regularly the first few cycles and being neutropenic meant being hospitalised in isolation to protect me from getting sick while my body had no defences. We got good at recognising the symptoms and having a bag packed and ready to go in. There’s often an urge to just have a nap, take a Panadol and get on with it, but I had to remember my body wasn’t the same anymore, and I needed help.’

AARATHY

‘Frances was suffering so much from the side effects of her treatment that she could not take in too much information.’

MILTON (carer)

You will have blood tests before each treatment. If your blood cell levels are too low, your next cycle of chemotherapy may be delayed until your blood levels have recovered. It is not unusual for this to happen at some stage during your treatment. Your nurses will discuss this with you before you begin chemotherapy.

‘Chemotherapy was described to me in a way that implied I would still be able to function, play with the kids etc, but I was so nauseated, so tired and felt like I’d failed. I was not absorbing any nutrients, had diarrhoea and vomiting.’

AARATHY

‘My husband is fantastic. I came home from chemo yesterday and I was very cold and shivery. I didn’t feel like dinner, so he made me a piece of toast and told me to get into a warm bed. He knows what to do and cares for me so well.’

LYNNE

It is very important you contact your doctor or go to the nearest emergency department immediately if you have signs of an infection, including a temperature above 38 °C and you feel shivery or cold.

Your doctors and nurses will talk to you about possible side effects from the drugs you are having.

For more detailed information about chemotherapy, read the Cancer Council booklet ‘Understanding chemotherapy’ (available from www.cancer.org.au). You may also find it helpful to read about your specific chemotherapy protocol at eviQ (www.eviq.org.au).

Some dietary supplements and herbal medicines can be harmful and change the effects of chemotherapy or make the side effects worse. It is very important to let your doctor know about any herbs, vitamins, supplements and other products you have bought over the counter at health food stores, chemists or come from complementary or alternative practitioners. Read more about complementary and alternative therapies later in this booklet.

Radiation therapy

Radiation therapy (also called ‘radiotherapy’) treats cancer by using radiation to destroy cancer cells. Radiation can be targeted to where the cancer is in the body. Special techniques are used to minimise dose (and hence harm) to surrounding normal body tissues.

Not everyone who has pancreatic cancer will have radiotherapy. However, research is showing that radiotherapy before surgery may help shrink the cancer. In certain cases, radiotherapy may also be given after surgery to help stop the cancer coming back, but this is rarely done. Radiotherapy is also commonly used as a palliative treatment to help control symptoms such as pain from either the pancreatic cancer or from metastases elsewhere.

Radiation before or after the operation is usually given Monday to Friday for five to six weeks. It is often combined with chemotherapy (which may be in the form of tablet taken each day during treatment).

Palliative treatments are usually much shorter and often may involve just a single treatment.

Before starting your radiotherapy, you will meet with a radiation oncologist and nurses who will explain your treatment in detail with you. You will need to have scans and planning to map out the treatment to make sure you receive the doses of radiotherapy to the exact same spot each time. This is called simulation and can take a few hours to do. A radiation therapist and nurses will support you through this session. The spot on your body where the radiation is going to be directed at will be marked with a small dot of ink, which is permanent.

The treatment only takes about 15–20 minutes each time and it is not painful.

When receiving treatment to the pancreas area, many patients have some degree of nausea, abdominal discomfort and fatigue, which tends to get worse towards the end of treatment and settles a few weeks afterwards. It may help to have someone drive you to and from your appointment each time.

You won’t be radioactive after your treatments, so you are not a risk to anyone else. There may be a risk of late side effects, which your radiation oncologist will discuss with you.

Figure 4: A medical linear accelerator (LINAC) is the most commonly used machine for delivering external beam radiotherapy to people with cancer. It gives high-energy x-rays or electrons to the area where the tumour is.

There are new radiation techniques being used in clinical trials. One of these is called stereotactic body radiotherapy, which delivers a higher individual dose of radiation within a shorter timeframe.

Speak with your radiation oncologist about the most appropriate radiotherapy treatment for you.

> *‘I had radiotherapy for pain management, which helped a lot.’*
> **LYNNE**

Side effects of radiation therapy

Radiotherapy can cause side effects both during and after the treatment. Some will disappear within a few weeks once the course of treatment has finished. But others can continue for a while after.

The types of side effects depend on where in the body you are having the treatment. For example, if you are having radiotherapy to your abdominal area you may experience diarrhoea, nausea and vomiting. Tell your radiotherapy nurse if you are having side effects. Nausea and vomiting can be controlled with anti-sickness medications. Other possible side effects can include:

- skin changes such as redness, peeling and soreness (this is rare)
- tiredness and fatigue, which can last for many weeks after treatment finishes.

Your radiation oncologist and nurses will explain about the side effects to expect from your radiotherapy and suggest ways to manage them.

For more detailed information about radiotherapy, read the Cancer Council booklet 'Understanding radiotherapy' (available from www.cancer.org.au). You may also find it helpful to read about your specific radiotherapy protocol at eviQ (www.eviq.org.au).

Other treatments (immunotherapy/targeted therapies)

Immunotherapy uses substances to help stimulate an immune response in the body to help fight the cancer. Most immunotherapy drugs for pancreatic cancer are given in clinical trials (discussed below). They are not yet standard treatments for pancreatic cancer as their benefits have not been proven. They are usually given with other treatments such as chemotherapy.

Pembrolizumab (Keytruda) and nivolumab (Opidivo) are immunotherapy drugs that may be an option for a very small number of patients whose pancreatic cancer is inoperable. However, they will not be available to everyone and you need to ask your doctor if there is a clinical trial of the drug that you would be eligible for.

Clinical trials

Clinical trials are the most accurate way to determine the effectiveness of promising new treatments or new ways of combining cancer treatments. Your doctor may suggest that you take part in a clinical trial. It is important you understand the reasons for the trial and what it means for you. Clinical trials are beneficial because you will:

- have access to a potentially helpful treatment that isn't yet available as standard treatment
- get regular support and follow-up with specialist doctors and nurses who are experts in their field
- be contributing to research that may help save lives in the future
- feel you are taking an active role in your treatment and care.

Not everyone is eligible for all clinical trials. If your doctor thinks you might be suitable for a certain trial, they will ask you to speak with the trial coordinator/nurse who will explain the trial in detail.

You may want to ask your doctor:

- Which treatments are being tested and why?
- How long will the trial last?
- What are the possible side effects of the new treatment?
- Do I have to go into hospital to be on the trial?
- What is the standard (best existing) treatment for my cancer if I don't go on the trial?

If you are eligible and decide to join a randomised clinical trial, you will be given either:

- the best existing treatment, or
- a promising new treatment.

You will be allocated at random to receive one of these and you won't know which one you are taking. You have the right to withdraw from a clinical trial at any time. Doing so will not affect your cancer treatment.

There are four different phases of clinical trials:

- **Phase I:** Testing of a new drug/treatment for safety on a small group of patients; it involves testing different doses (dose-ranging).
- **Phase II:** Testing of the drug/treatment on patients to assess its effectiveness and side effects.
- **Phase III:** Testing of a drug/treatment on patients to assess effectiveness and safety, but with much larger numbers of people than used in phase II trials.
- **Phase IV:** Studies looking at drugs that have already been approved as standard treatment, but where important questions remain, like looking at safety over long periods of time. These trials involve thousands of people, and often from all around the world.

For more detailed information about clinical trials and trials underway for pancreatic cancer, visit the Australian Cancer Trials at www.australiancancertrials.gov.au. Ask your specialist about other websites they consider helpful to search for clinical trials.

Follow-up

After you finish your treatment you will most likely have regular check-ups with your specialist. Your doctor will decide how often you need check-up appointments – everyone is different, but it is usually every six to 12 weeks. If you stay well, your check-ups become less frequent but because pancreatic cancer is often diagnosed in the advanced stages, you will probably be seen regularly. This will vary slightly between specialists, but it is normally:

- every three months following surgery for the first 12–18 months
- then every six months until around three years after your surgery
- then every year.

You will usually have a CT scan and blood tests before each of your follow-up appointments. If your cancer has spread to other parts of your body (metastasised) your follow-up appointments are likely to be monthly.

Many people find the few days before going to a check-up appointment stressful. You may start to worry that your cancer has become worse or has returned. It is very normal to feel this way and it can be helpful to try to find ways to cope with your anxiety. The important thing is to make sure you attend all your follow-up appointments.

Read the information about fear of having a recurrence of your cancer in the 'Living well' section.

Complementary and alternative therapies, and finding reliable information

Complementary therapies

These are therapies used alongside scientifically proven conventional cancer treatment (e.g. chemotherapy, radiotherapy, surgery). There are many different types of **complementary therapies,** which include:

- body-based therapies such as massage and yoga
- mind–body therapies such as meditation, music therapy and counselling
- herbal treatments such as cannabis
- Chinese medicine practices such as acupuncture
- diet-related therapies.

There is no scientific evidence to prove these therapies can treat or cure any type of cancer. Some of the main reasons people with cancer use complementary therapies are to:

- feel more in control
- improve wellbeing
- relieve side effects such as pain, nausea and vomiting (e.g. acupuncture may help control nausea caused by chemotherapy).

These are positive outcomes, but it is important to remember that it doesn't mean the therapies have had any physical effect on the cancer (e.g. killing cancer cells or shrinking a tumour).

It is important to let your medical team know about any therapies you are using or thinking of using. Some are known to interact and cause side effects when used together with conventional treatments. If you are going to use complementary therapies, it is very important to find the right therapist. This may be someone who has had experience in working with cancer patients and is willing to communicate with your medical team.

Alternative therapies

If you are looking into using complementary therapies, it is likely you will come across the term ‘alternative therapies’ as well. Alternative therapies are very different to complementary therapies. They are used *instead of* conventional treatments. For example, someone may decide to stop having chemotherapy and treat their cancer using a special diet and herbal remedies that haven’t been scientifically proven to treat cancer. Along with being unproven, alternative therapies can be very expensive, have harmful side effects and possibly make your overall health worse.

We don’t recommend using alternative therapies. But if you do, we strongly advise you to discuss this with your doctor before refusing or stopping conventional treatments.

There is a lot of information on the internet and in the media about alternative therapies being ‘cures for cancer’. Be wary of anything you read about that is going to cost you a lot of money, has only patient testimonials and has no scientific evidence proving it helps and is claiming to ‘cure or treat cancer’. Always ask your doctor’s opinion, since some of these therapies can be promoted in a way that suggests they are effective or scientifically proven when in fact they are not.

Reliable websites and information booklets

For reliable information about complementary and alternative therapies, their benefits, dangers of individual therapies and choosing a safe therapist, we recommend:

- the Cancer Council booklet ‘Understanding complementary therapies: A guide for people with cancer, their families and friends’ (available from www.cancer.org.au or call the Cancer Council Helpline on 13 11 20 and ask for a copy to be posted)
- the Memorial Sloane-Kettering website ‘About herbs, botanicals and other products’ (www.mskcc.org). This website has excellent information about individual products and the scientific evidence regarding any benefits, adverse effects and interactions with other herbs and medicines
- National Centre for Complementary and Alternative Medicine, a US government funded institution that supports scientific research into complementary and alternative therapies (www.nccih.nih.gov/). This site also has useful information about evaluating medical resources on the web
- Quackwatch (www.quackwatch.com), an American non-profit organisation that aims to combat health related frauds, myths, fads, fallacies and misconduct. There is a lot of helpful information on this site about complementary and alternative therapies in cancer care.

MANAGING

Living with pancreatic cancer

Finding out you have cancer will have a huge impact on you and those close to you. This section discusses feelings you are likely to have and offers practical tips on managing symptoms and side effects.

> *‘My first questions were: “Am I going to live or am I going to die?”, “How long do I have?” and “What’s happening here?”’*
>
> **AARATHY**

Your feelings

> *‘Our world as we knew it was turned upside down.’*
>
> **KAT (carer)**

Some common first reactions to finding out you have cancer can include:

- fear of the future
- sadness, anger and disbelief
- uncertainty about everything in your life
- concerns about those you love, especially children
- wondering if you are going to die.

> *‘Day to day, I probably put on a brave face often, and don’t let people know how I really feel.’*
>
> **SANDY**

It is natural for you and those close to you to feel upset when you have been told you have cancer. But many people say these feelings reduce in intensity over time. There is no right or wrong way to cope. But acknowledging your feelings and knowing where to get help allows most people to work out strategies to help themselves and those around them to manage with the challenges.

Give yourself and others some time to adjust. Time, support from others and sharing your concerns will help enormously during your treatment and beyond.

‘The initial diagnosis is a shock; the sense of grief is so hard. A lot of the time I just put it to the back of my head because if it was at the front of my mind, I would need to be in a psychiatric hospital all the time.’

SANDY

Try and be kind and patient with yourself. Talk to those you trust about how you are feeling as these people will want to support you. But they may need your guidance about what you need at different times. It is also important not to feel afraid to ask for or accept help.

‘The diagnosis was shattering as I was always a fit and healthy person and envisaged I would have another few years to work and then my partner and I would have time to do things together like travelling. I was in a state of shock to start with.’

LYNNE

Women often say they find it helpful to chat to their girlfriends on the phone, or over a coffee or glass of wine. Men may seek support from their friends in different ways, for example, by going to a sporting event together or having a drink at the pub together.

Your GP can also be a good person to share your feelings with as they may be able to refer you to a professional counsellor/psychologist for counselling. These sessions may be subsidised by Medicare. Ask your GP about this.

‘There was no cancer in my family, and I had no risk factors – it was out of the blue. They kept asking me if I was a drinker which was very annoying and upsetting as I wasn’t. I was made to feel disregarded as if I was a drinker. This was hard.’

LYNNE

You may find it helpful to read the section titled ‘What patients feel’. This section is full of quotes from the perspective of people who have pancreatic cancer. It outlines what they have found most difficult to cope with since their diagnosis. It also provides suggestions and messages to people who are newly diagnosed with pancreatic cancer.

Managing symptoms and side effects

When you have pancreatic cancer and its treatment you may have various symptoms and side effects. Many of these can be controlled with medications such as pain-relieving drugs and anti-nausea drugs.

Some of the main symptoms are outlined below. But we encourage you to always discuss any symptoms with your medical team, no matter what the symptom is. There is usually something that can be done to help.

Fatigue

Fatigue means feeling very tired and lacking energy to do day-to-day things. It is one of the most common symptoms associated with pancreatic cancer and its treatment. This type of fatigue can be overwhelming and often doesn’t go away with rest. It can be very disruptive to your daily activities and you may feel completely exhausted after doing such things as bathing, dressing, cooking, eating and shopping – tasks that you would have normally have no trouble doing. Even talking to people can feel tiring.

Some people worry that fatigue means their cancer is getting worse or their treatment is not working. But this isn’t necessarily true. If fatigue is an issue for you, talk with your doctors and nurses. They will be able to suggest ways to help you cope better with this symptom.

> ***‘Fatigue is very difficult to cope with each day. It is a feeling you can’t explain to anyone. But I try to get up and “do” something each day, which helps me.’***
>
> **JANE**

Tips on coping with fatigue

- Plan your day and set manageable goals.
- Plan for regular rests throughout the day.
- Ask for help and take any offers of help from friends and family to cook, clean do the shopping or take you to appointments.
- Sit down when doing tasks such as cutting up vegetables, folding washing or talking on the phone.
- Eat nutritious meals when possible to keep up your energy.
- Say no to things you really don't want to do.

> ***'It's hard to accept not being able to do things for others that you would have normally done with no trouble. But you can't, you don't have the energy. This is one of the hardest things for me as I am naturally a person who wants to help others.'***
>
> **JANE**

Pain

Many people with pancreatic cancer will have some type of pain. The main causes of pain include:

- the cancer pressing on nerves in the surrounding areas and organs
- side effects from treatments such as chemotherapy and radiotherapy
- blockages in the bowel or bile duct
- bone pain if the cancer has spread to the bones
- infections.

Having pain can be frightening and worrying. But with the right medical care and nursing support, it is usually possible to reduce pain or relieve it completely. It may take a bit of time to work out the correct pain control measures for you. But it can be done.

It is important you know who to ask for help. Your specialist doctors and nurses, including palliative care specialists, are the best people to ask for help. The most common way of controlling pain is with medications such as morphine (for severe pain), codeine (for moderate pain) and paracetamol (for mild pain).

Tips on coping with pain

- Try complementary therapies such as massage and acupuncture (see the section titled 'Complementary therapies').
- Resting, heat packs, warm baths can sometimes help control pain.
- Distraction can sometimes help – listening to music or podcasts, chatting with friends, watching a movie or gentle exercise.
- Don't leave pain for too long before taking your pain-relieving medications as they won't work as well if you do.

There are many psychological strategies to help people cope with pain, for example, breathing exercises, progressive muscle relaxation and mindfulness. Ask your treating medical team about possible programs in these areas.

You may also find it helpful to read the Cancer Council booklet 'Overcoming cancer pain' (available from www.cancer.org.au).

A note on morphine

Morphine is one of the most common pain-relieving drugs used to help control moderate to severe cancer pain. It comes in fast- and slow-acting forms and is usually very effective. Unfortunately, many people are wary of using morphine. They associate it with drug addiction or people who are dying. A person does not become addicted to morphine if they are using it to relieve pain. And morphine is not only used to treat pain in people who are dying. It is used in lots of other situations such as post-surgery.

Bowel problems

You may suffer from constipation or diarrhoea. Both problems can be caused by side effects of cancer treatments or from other medications. Your bowel may be affected by the cancer as well causing changes in your bowel habits. Sometimes it can be due to more serious problems such as a **bowel obstruction**. It is important to tell your doctor if you have any changes in your bowel habits.

Diarrhoea: Some chemotherapy drugs, radiotherapy, surgery and antibiotics can cause diarrhoea. After surgery, diarrhoea can be a major problem for some people. This may be related to pancreatic exocrine insufficiency and you will need to take pancreatic enzyme supplements (see 'Nutritional and dietary problems'). Feeling anxious, and infections, can also cause diarrhoea.

Constipation: Pain-relieving drugs such as morphine and anti-nausea medications can cause constipation. Ask your nurse or dietitian how to reduce the chance of becoming constipated if you need to take these medications.

Constipation can also be the sign of something more serious, such as a bowel obstruction, which is discussed in the next paragraph.

Bowel obstruction: Symptoms of a bowel obstruction can include abdominal pain and cramping, constipation, feeling sick and vomiting. You can also sometimes get faecal fluid leaking from the bowel, which is very bad smelling. Talk with your doctor if you have any of these symptoms.

Bowel obstructions can be relieved. The sooner you seek help the easier it will be. You may need to go into hospital for treatment, which can include possible surgery.

If you do not have your bowels open for more than three days, let your doctors and nurses know.

Tips on coping with bowel problems

If you have diarrhoea, drink plenty of fluids to prevent dehydration. Avoid caffeine and alcohol and reduce the amount of fibre in your diet. If your diarrhoea is persistent and you sometimes have problems making it to the toilet in time, you may find it helpful to use pads. This is especially useful when you go out. Understandably, most people find it embarrassing to use pads but there are many on the market that are comfortable and not obvious.

With constipation, you also need to drink plenty of clear fluids to help soften stools in the bowel. Get regular exercise (if possible) and increase fibre in your diet with wholegrain foods, fresh fruit and vegetables.

If diet methods are not helping, talk to your doctor. They may suggest you take medications to help with diarrhoea (anti-diarrhoea) or constipation (laxatives such as Movicol and Coloxyl). Your doctor will tell you the correct doses to take. Your dietitian is also an excellent source of support for problems with your diet and bowels.

Breathlessness

Breathlessness can happen in people with pancreatic cancer due to:

- the cancer spreading to the lungs
- a fluid build-up (**ascites**) in the abdomen or around the lungs (pleural effusion)
- low red blood cells (anaemia), which can be a side effect of chemotherapy and radiotherapy.

Depending on the cause of your breathlessness, there may be medical treatment to help. This may involve having a blood transfusion for anaemia or draining the fluid from your abdomen or lungs.

Tips on coping with breathlessness

Being breathless is frightening. Whatever the cause, feeling anxious can make your breathing worse. Along with getting treatment, the following tips may help:

- If possible, try to relax by concentrating on slowing down your breaths.
- Relaxation techniques such as listening to meditation podcasts or music helps some people.
- Keep a fan in your room or open a window to help circulate air and prevent feelings of panic.
- Sit up when breathless and lean over a table to help expand the lungs as much as possible.
- If lying down to sleep makes your breathing worse, use lots of pillows to prop you up. If you have one, sleep in a recliner chair or adjustable bed.
- Morphine can sometimes help with breathlessness. Discuss this with your doctor.

Feeling sad, low in mood and anxious

It’s very common and natural for someone with cancer to have times when they feel very low in mood. Anxiety is also common and can come in waves. Sometimes you may feel like you are managing well. Yet at other times you are full of panic, fear and sadness. There are many reasons this may happen, including:

- visible changes the cancer has caused to your body (e.g. scars, hair loss, fatigue, weight loss)
- changes/losses the cancer has caused to your day-to-day life (e.g. work, hobbies, and relationships)
- fear of the future and/or fear of the cancer spreading or coming back
- challenges of coping with the symptoms and side effects of the cancer and its treatments.

Feeling sad or low in mood for a few days is very different to feeling depressed for long periods of time. Often people with cancer who are suffering depressive symptoms are diagnosed with 'adjustment disorder', rather than 'depression'. This is because symptoms of a low mood can be explained by your physical health (having cancer). Many people going through cancer treatment have difficulty adjusting and feel low in mood for prolonged periods. This is a normal response to an abnormal situation and doesn't mean you will have long-term depression or mental health problems.

Feeling depressed doesn't always go away with time and you may need to seek further help through your GP, psychologist or a counsellor. Some of the main symptoms of depression include:

- loss of pleasure or interest in things you used to like
- decrease or increase in appetite, weight loss or gain
- feelings of worthlessness, hopelessness
- constant feelings of fear, guilt, regret and anger
- withdrawing from your social life and wanting to be alone
- difficulty concentrating and problem solving
- sleeping problems (either getting to sleep or not sleeping for very long)
- thoughts of suicide.

'Sometimes I struggle to sleep due to the medication or my concerns about the future, but I think this is a good time to think. I solve world problems during this time and solve lots of my own problems during the night when I cannot sleep.'

SANDY

> *‘Mental health support is so necessary on this journey. I think I would have benefited from having a mental health professional sit with me post-diagnosis to help process. It’s all very clinical and medical, which of course it has to be, until it’s the middle of the night and you’re alone with your thoughts and what ifs. Cancer sucks, there’s no getting around that; along with the doctors, nurses, dietitians etc, it is important to seek mental health support too.’*
>
> **AARATHY**

Some people may have been diagnosed with depression, anxiety or other mental health issues before being diagnosed with pancreatic cancer. You may already be taking prescription medication for your mental health issues. If you are under the care of a mental health specialist (psychiatrist, counsellors, psychologist), it is important to link them with your cancer medical team. They can work together to ensure your physical, emotional and mental health are cared for in the best way possible during and after your cancer treatment. They can also manage your medications appropriately to prevent any negative drug interactions with your cancer drugs.

Low mood and feelings of depression are not a sign of weakness. There is a lot that can be done to help people with depressive symptoms. Sometimes antidepressant medications can be helpful. The important thing is to seek support so you can find the best way to help you feel better. If your mental health is suffering you will be less able to manage with your cancer and its treatment. Below are some tips on coping with low mood, which we acknowledge may not work for everyone.

Sometimes shifting the feelings of depression/low mood is impossible and overwhelming. You may even have thoughts of self-harm and/or suicide. If this happens, we strongly encourage you to seek medical help immediately either through your GP, or out of hours call Lifeline or Beyond Blue. See contact details in the ‘Further information and support’ section.

Tips on coping with low mood

- Eat a well-balanced diet with lots of fresh foods and drink plenty of water.
- Avoid caffeine, alcohol and recreational drugs, which all make it more difficult to cope with feeling low in mood.
- Try to get regular gentle exercise, even if it is just a short walk around the block each day. Many people say exercise lifts mood.
- Some types of complementary therapies may help improve mood (e.g. massage, yoga, meditation and acupuncture).
- Share your feelings with someone you trust, which can help you feel less alone.
- Try to have some structure and routine in your days. Some people use a weekly planner to make sure they are getting up, eating and socialising through the day.

> ***‘One of the main ways I found to help avoid depression was drawing on my inner self to avoid self-pity, itself a by-product. People need to encourage the patient with “We know you can do this …”, rather than platitudes of “I know how you feel”, because, sadly, the majority of them don’t.’***
>
> **TOM**

Getting support when you have continuing low mood or depression

The following organisations can help:

- The Cancer Council has cancer nurses and other health professionals who can offer specialised assistance Monday to Friday on 13 11 20.
- Visit Beyondblue (www.beyondblue.org.au) or call 1300 224 636 for information about coping with depression and anxiety as well as how to find a counsellor. The Beyondblue website has a symptom checker.
- Call Lifeline Australia on 13 11 14 if you are having suicidal thoughts.

- The Australian Cancer Survivorship Centre (available via www.petermac.org) has information about the emotional impact of cancer and its treatment and coping with fear of cancer recurrence.
- For ongoing face-to-face support with your emotional concerns, speak to your GP who can determine if you are eligible for Medicare rebates and/or provide a referral to a psychologist.
- Raise any concerns you have with your oncologist, nurse, surgeon or someone else in your cancer team. They have likely heard many patients express similar concerns and will be able to suggest local support services to you.
- Alternatively, to find a psychologist in your area, you can use the 'Find a Psychologist' tool on the Australian Psychologist Association website (www.psychology.org.au/Find-a-Psychologist). You can tailor the search to find a psychologist with experience working with people who have cancer and their families.

Concentration and memory loss ('chemo brain')

Chemotherapy and other treatments may affect your ability to concentrate and remember things day to day. Chemo brain is a common term used by people who have cancer and describes concentration and memory problems they may face during and after their cancer treatment. Another term is 'chemo fog' – meaning things in your brain are foggy and there is some cognitive impairment. This often improves once the treatment is finished but there may be some long-term problems with your ability to concentrate for long periods of time.

'I found I didn't have the ability to concentrate on podcasts, reading and music.'

AARATHY

‘I couldn’t concentrate to read, and I had to realise that studying and going back to my nursing work was no longer a reality for me. So, I had to develop another strategy – I called it my “save my sanity” strategy.’

LYNNE

Peripheral neuropathy

Some chemotherapy drugs can damage nerves that affect your feeling and movement in your hands and feet. Doctors call this peripheral neuropathy. This symptom can be mild but for some people it can be severe and affect quality of life. For example, it can be difficult to do simple things like do up buttons or tie shoelaces. You will also be very sensitive to hot and cold and need to take care when handling hot things as you may not feel something burning.

Unfortunately, there is no treatment for peripheral neuropathy that will improve the nerve damage. But there are still ways to help reduce the impact of the problem. These include using a combination of pain medications, vitamins, lotions and exercise to help you manage symptoms.

Sometimes drugs used to treat other conditions have been found to help with treating nerve pain. One example is the antidepressant duloxetine (Cymbalta). Anti-inflammatory drugs and other pain killers such as pregabalin (Lyrica) can also help. Some research suggests that the following treatments may also be helpful in preventing or controlling neuropathy related to chemotherapy:

- vitamin E cream
- vitamin B6
- calcium and magnesium
- anti-seizure drugs
- glutathione, a vitamin that is rich in antioxidants.

It is important to always ask your doctor before using any treatment for your neuropathy. The most important prevention tip is to tell your doctor immediately if you have symptoms. Your medical team will be able to suggest ways to help protect you from worsening symptoms and injury due to your neuropathy.

> ***‘I have so much peripheral neuropathy from chemotherapy that I can’t do my sewing and patchwork due to my fingers being numb.’***
>
> **LYNNE**

> ***‘I’m still on a learning curve on dealing with side effects. Neuropathy as an example is hard to treat and can be debilitating. I have found using a foot massager and diabetic neuropathy cream has helped stabilise the effects.’***
>
> **GREG**

Tips other than medications to help you cope with neuropathy

- Physical therapy/exercise can help with strength, balance and safety (e.g. regular finger or toe tapping).
- Occupational therapy can help some people improve motor skills to aid in daily activities such as buttoning shirts and picking up small objects.
- Low-impact exercise such as yoga, tai-chi and swimming may help, but consult your doctor before starting any new exercise program.
- Acupuncture and meditation have helped some people.
- Some evidence suggests eating a well-balanced diet that eliminates alcohol and smoking.

Finally, always be safe:

- Use gloves to protect your hands when doing gardening, household repairs and cooking with hot utensils/pans.
- Take extra care using sharp objects such as scissors, saws and tools.
- Regularly inspect your fingers and toes for any skin breaks, cuts, redness or soreness.
- Always turn the cold water on first and gradually add hot water.
- Don’t drive if you are having trouble feeling the pedals or steering wheel.
- Avoid walking barefoot on rough surfaces.
- Keep floors clear of mats and other obstacles you can easily trip on.

Nutritional and dietary problems

People with pancreatic cancer often face problems with their eating, drinking and overall dietary habits. This is not surprising, considering the pancreas is situated very near to our stomach and bowel. It is also responsible for making insulin and enzymes that are important in digesting food.

Weight loss is very common in people with pancreatic cancer. This may have started before your diagnosis. While some people may feel comfortable losing weight, others may find it very difficult.

‘I found it hard when people said things like “You look really good; you have lost a lot of weight”. I find comments about my weight very difficult to manage as I am this weight because I have cancer.’

AARATHY

‘I am finding my diet really difficult. I started at 64 kg and now 54 kg, I lost 6 kg suddenly when I was having a dreadful time with pain.’

LYNNE

People who have had a Whipple's operation will need to take enzyme supplements with each meal to help with digestion. You may also need insulin in the same way a diabetic person does, to help regulate your blood sugar level.

'After the Whipple's was interesting, but I always force myself to eat as I know it is important.'

SANDY

Other problems can include:

- loss of appetite
- nausea and vomiting
- loss of taste and taste changes
- mouth problems such as ulcers and thrush.

'My husband Bernie likes cooking, which is good as it's often more appealing when he has cooked me something to eat. It really helps if someone else can do the cooking occasionally.'

LYNNE

'Preparing suitable food was important as Frances' tastes changed and her ability to cook. She probably would not have eaten if I had not cooked for her and her nutritional needs would have suffered more.'

MILTON (carer)

The problems are related to several factors, including pain, depression, the cancer itself, side effects from treatments (e.g. chemotherapy, surgery) and fatigue. Feeling tired, depressed or being in pain can put someone off eating.

'Losing the ability to cook was very difficult for me; cooking was my happy place. But my tastes changed, and I found it difficult to be around certain smells, food courts would send me running to the nearest bathroom.'

AARATHY

Managing diet problems

Overall, managing your diet, blood sugar levels and weight can be challenging. It is important you seek information and support. Ask your specialist doctors and nurses, GP and a dietitian.

Because good nutritional care improves tolerance of treatment and outcomes, we recommend all patients with pancreatic cancer see a qualified dietitian, who has a special interest in people with cancer. Dietitians are experts in the body's nutritional needs. They can give you advice on how to manage problems related to eating, drinking, weight loss and gain, diabetic diet and nutritional supplements. They will be especially helpful immediately after surgery as you try to introduce eating again.

> ***'I used to be very food focused. I loved my food. But now I have to almost force myself to eat some days as it caused so many issues and I have lost my appetite.'***
>
> **LYNNE**

Building up your diet (high protein, high energy)

If you are losing weight, are unable to eat well or feel full even when you haven't eaten properly:

- have small, frequent meals and snacks
- use convenience foods if you are too tired to prepare food
- cook in bulk and freeze individual portions
- have foods rich in protein such as meat, poultry, fish, eggs, dairy products (milk, yoghurt, cheese), beans, legumes, nuts and seeds
- have energy-dense foods such as oils, avocado, nuts, seeds, peanut butter, butter, margarine, full-fat dairy products (full cream milk, full fat cheese, full cream yoghurt, double cream) (you may find too much of these foods can upset the gut if you're having problems with fat digestion and absorption, so increase gradually as tolerated and discuss with a dietitian)
- use supplement drinks.

Diabetes

Insulin is a hormone produced in the pancreas that helps control our blood sugar levels. If there are changes to how much insulin the pancreas is making, you can develop diabetes. Some people with pancreatic cancer may develop diabetes. This is because your pancreas may not be making enough insulin, either because of the cancer or after surgery when some or all the pancreas has been taken out. Doctors call this type 3C diabetes.

Controlling diabetes is very important because if your blood sugar levels go too low or too high you can become very sick, and even die if not treated. If you've had surgery to take out all or part of your pancreas, you may need to take insulin or tablets to regulate your blood sugar. You may also need to be careful with what you eat and the amount of sugar you have in your diet. Your GP and a diabetes specialist nurse will educate you and help you manage diabetes. You may also be referred to a doctor who specialises in hormone changes (an endocrinologist) and a dietitian to help you with adjusting to a diabetic diet.

If you need to use insulin to control your diabetes, you will have to take daily insulin injections to regulate your blood sugar levels. Your doctor will ask you to take regular blood sugar level readings. You do this by:

- pricking your finger and squeezing a small amount of blood onto a special strip, which is inserted into a small machine that will show you how much sugar is in your blood
- using a sensor and reader (e.g. FreeStyle Libre) – this is a newer development and is relatively costly.

These readings help your doctor to advise you how to regulate the type and how much insulin you need.

It can be difficult at first to adapt to being diabetic and having to regularly take your own blood sugar levels. A specialist diabetic nurse educator should teach you how to do this.

Nutritional supplements

Some people with pancreatic cancer may need to have nutritional supplements to help boost their calorie intake and maintain their weight. There are different types of supplements and a dietitian can help you choose the one most appropriate for you. They may come in powder form or in a ready-to-drink carton. You can also sip on one in between meals to help get some extra calories in. If you see a dietitian, they may be able to help you access the supplements for a lower price than buying them in a pharmacy.

> ***‘I find I can always eat vegetables and fruit. Otherwise when I am unwell, I just eat small amounts of foods. My “go to” is pumpkin soup as I can always eat this with no problems, so I always have some in the freezer.’***
>
> **LYNNE**

Enzyme replacement

Keeping your body well-nourished is key to your quality of life. Pancreatic enzymes can help to ensure that all the food you are eating can be used by the body and keep you nourished.

What are pancreatic enzymes?

In a healthy pancreas, the pancreatic juices are secreted into the duodenum (at the start of the small intestine). About one-and-a-half litres are secreted each day, and this fluid contains pancreatic enzymes. These enzymes help to break down fats, proteins and carbohydrates in our body and are essential for digestion. Without these enzymes present in the body, you will not be able to absorb the nutrients from what you eat and will have problems maintaining or gaining weight.

Reasons for taking pancreatic enzymes

If the pancreas is unable to secrete the enzymes necessary for digestion (there is an insufficiency) you may have the following symptoms:

- pain or feelings of indigestion after eating
- bloating and very foul-smelling gas and stools
- changes in your bowel actions (more frequent, loose stools)
- your stools may look oily or float
- changes in the colour of your stools (light coloured, yellow or orange)
- weight loss.

If you have any of these symptoms it is important you talk with your doctor about whether it would help you to take pancreatic enzyme supplements.

Pancreatic enzyme insufficiency is very common in people who have pancreatic cancer, especially if you have had surgery (Whipple operation). About one-quarter of people who have this type of surgery will have long-term problems with malabsorption and will need to take enzymes for life. Others may only need them for a few months or years after their surgery.

If you have radiotherapy after your surgery, you are more likely to have long-term problems with malabsorption, and enzyme replacement may only help to prevent weight loss and stop diarrhoea. Other conditions that can cause pancreatic enzyme insufficiency and the need to take enzyme supplements when you have pancreatic cancer include:

- blockages or narrowing of the tubes that carry the pancreatic juices and bile (pancreatic and bile ducts)
- pancreatic tumours blocking the flow of the juices
- pancreatitis (inflammation of the pancreas).

If your cancer is inoperable it is not uncommon to have bile duct obstructions. A combination of pancreatic enzymes, dietitian help and counselling, along with draining the blockages, can help to stop weight loss and improve symptoms.

Taking pancreatic enzymes will help your body digest the food so that it can be absorbed into the body. By letting your body utilise all the nutrients you are eating, it will allow you to maintain your weight or prevent further weight loss. The pancreatic enzymes will also ensure that you are able to absorb certain nutrients that are found in fats and oils, such as fat-soluble vitamins and essential fatty acids.

Types of pancreatic enzymes

Enzyme supplements contain pancreatin – a mixture of pancreatic enzymes lipase, amylase and protease. Each enzyme has a different effect on helping the body absorb different things.

For example:

- Protease breaks down proteins and helps keep the bowel free from parasites.
- Amylase breaks down carbohydrates (starch) into sugars.
- Lipase (with bile from the liver) breaks down fat molecules so they can be absorbed and used by the body.

Shortages of any of these can cause problems such as diarrhoea and increased risk of infections in the bowel.

> ***‘It is not just the pancreatic enzyme insufficiency that affects my appetite, but you also have to deal with the side effects of chemotherapy, which make you feel sick and not want to eat too.’***
>
> **LYNNE**

How to take pancreatic enzymes

Pancrelipase is the most widely prescribed pancreatic enzyme. It comes in capsule form and is taken orally with a glass of water with every snack or meal. The most effective way to take the enzyme supplements to ensure they work properly is to take them just before you eat or after the first mouthful. However, some people may take half a capsule at the beginning of the meal and the rest halfway through their meal. Your doctor or dietitian is the best person to ask about this. It is important to swallow the capsules whole and not let them sit in your mouth too long.

> ***'I have been very fortunate with diet. I have consciously lifted my game with increasing fruit and vegetables, but I otherwise manage it pretty well with taking [pancrealipase] and eating regular meals and exercise.'***
>
> **JANE**

> ***'I had to make changes to make sure I was getting enough nutrients. Liquids were often easier than chewing food. Fortisips and soups were good, and [pancrealipase] really does help.'***
>
> **AARATHY**

Your dose will depend on the size of your meals and how much fat is in the food. Everyone is different and therefore it is a good idea to consult with an experienced dietitian to get your dosage correct.

Sometimes it can take a few months to get the correct amount. You will know when you are taking the correct amount: when your symptoms disappear. Your doctor and dietitian will discuss the appropriate type and dosage of enzymes at each of your visits.

It is possible to buy over-the-counter enzyme supplements in pharmacies. These are not recommended for people with pancreatic cancer as there is no guarantee they are safe or contain the correct amounts of enzymes you need. Always ask your doctor for a prescription for your enzyme supplements.

Your doctor may also prescribe medications to help with acid reflux (heartburn) to help increase the effectiveness of your enzyme supplements.

‘I take [pancrealipase], 3/4 pills per meal, per half hour, works okay for me. Heard of one patient taking seven pills per meal, another just three pills per day. Obviously depends on the ultimate severity of each case.’

TOM

‘I have been on [pancrealipase] since Oct 2018 and have been using 25k capsules, three for a main meal and two for a small meal. I’m not entirely sure if they have helped with diarrhoea, but they may have at least helped with digestion and stemmed weight loss.’

GREG

Side effects of pancreatic enzymes

All medications can have side effects, but it does not mean you will experience any or all of them.

The most common side effect of pancreatic enzymes is constipation. They can also cause abdominal cramping and diarrhoea, but these are less common. People who have allergies, are vegan/vegetarian or follow strict religious rules regarding eating pig products may not be able to use some pancreatic enzyme supplements. This is because pig/porcine is used in preparing enzymes you get on prescription. Your doctor and pharmacist may be able to suggest an alternative enzyme preparation for you. If your religious beliefs prevent you from eating pig products, please discuss with your religious leader. Many will grant concessions for something essential to your health. Vegetarians and vegans may also decide to make an exception for these supplements to keep themselves well.

‘Whatever I can eat is a good thing for me, so if I feel I can eat a bowl of ice-cream, I do.’

LYNNE

‘The foods I used to love no longer bring me comfort. My Mum used to make this Sri Lankan porridge dish I loved when I was sick as a child, but now I can’t tolerate it or stand the smell of it.’

AARATHY

Finding a dietitian

Many people who have pancreatic cancer will have the opportunity to see a dietitian at the hospital where they are having treatment. But if there isn’t a dietitian connected to your cancer treatment centre, you can ask your specialist doctor or nurses where you can see one.

The Dietitians Association of Australia can guide you to where you can find an accredited practising dietitian who specialises in cancer care. They will be able to advise you about the costs associated with seeing a private dietitian. Visit www.daa.asn.au or call 1800 812 942.

Some people may be eligible for a Medicare rebate if they are referred to a dietitian through their GP. Or if you have private health insurance, you may be able to claim seeing a dietitian.

‘You learn what you can and can’t eat. I had a dietitian help to start with, which helped to reinforce what you can and can’t eat.’

SANDY

‘It really is a day-to-day thing. I would be really winning today as I was able to eat a kebab, whereas yesterday was definitely not a winning day.’

LYNNE

A note on cannabis oil

There has been a lot of international research and trials into the use of cannabis and cannabinoids (the active compounds in the cannabis plant) in helping control pain and nausea in people with cancer. The debate around this has been significant in recent years.

People with pancreatic cancer may think about using cannabis oil to help with dietary problems caused by their cancer or surgery.

Questions you may like to ask your doctor

You may find the following list helpful when thinking about the questions you want to ask your doctor about treatment and living with pancreatic cancer. If you have difficulty asking your specialist/s some of these questions, your GP may be able to help.

- What type of pancreatic cancer do I have?
- What stage of the disease do I have?
- Has my pancreatic cancer spread? If so, how far?
- Is my cancer in the advanced stages? If so, what can be done to help me?
- How is pancreatic cancer treated?
- Are there clinical guidelines for the treatment of pancreatic cancer? If so, how can I see them?
- What treatment do you advise for my cancer and why?
- Will my treatment be performed by a doctor who specialises in pancreatic cancer?
- How do I go about getting a second opinion?
- Are there other treatment choices for me? If not, why not?
- Will I have surgery, chemotherapy or radiotherapy?
- How many patients a year does my surgeon operate on with pancreatic cancer?
- What are the side effects from treatment?
- Will the treatment affect me sexually or physically? Will I be able to do normal things?
- Is there anything that can be done to help control the side effects?
- How will I know if the treatment is working?

- What are my chances of cure?
- What if I decide not to have any treatment?
- Will I have to stay in hospital, or will I be treated as an outpatient?
- How long will the treatment take? How much will it affect what I can do?
- Will I have follow-up appointments after my treatment is over?
- Who can I contact if I am worried in between my appointments?
- Who will be my main contact person?
- Are there any clinical trials of new treatments that I should know about?
- Will I have pain from the cancer? What will be done about this?
- I am feeling frightened about what will happen to me: who can I talk to about my feelings?
- Will others in my family also be at risk of developing pancreatic cancer if I have it?
- Is it harmful to take supplements or vitamins while I am having treatment?
- What practical help is available for me?
- Are there support groups specifically for people with pancreatic cancer? If so, how do I access these in the state or territory I live?

If you don’t understand any of your doctor’s answers, ask: ‘Can you explain that again?’ or ‘I am not sure what you mean by that.’ The most important thing is you feel you understand what is going on so you can make informed decisions about your treatment and care.

Living well

Having cancer is life changing and these changes are different for each person. The full impact of the challenges and losses can only truly be described by those people who have pancreatic cancer. Among the information given in this section, there are many quotes from people who have pancreatic cancer. We believe the quotes will give you a true insight into how to ‘live well’ with pancreatic cancer.

Health professionals caring for someone with pancreatic cancer will always try to prioritise the highest quality of life for their patient, so they can ‘live well’. This can sometimes mean putting the patient’s needs, as they express them, above what health professionals may see as the main concern. Your multidisciplinary team will want to see you as central to the care they are giving.

What is quality of life?

Quality of life is ‘the standard of health, comfort, and happiness experienced by an individual or group’. Quality of life means how satisfied you are with your life. This includes our physical health, emotional wellbeing, family, partners, friends, employment, wealth, safety, the environment and religious beliefs.

When you have cancer, how you view quality of life can often differ to how you saw it before your diagnosis. Time with family, leisure time, pursuing hobbies and feeling well and happy may become far more important than improving quality of life by having a high income and work satisfaction.

Exercise

Most people with cancer feel it helps to stay active and exercise regularly. If your cancer is too advanced, this may not be possible. You may feel too tired and unmotivated. However, if you are fit enough to exercise, it can help to improve:

- fatigue
- appetite
- sleep
- mood.

The amount of exercise you do will depend on what you are used to and how well you are. A short walk around the garden may be all you can manage some days, and this is okay. Gentle yoga and swimming can also help.

Discuss with your doctor what is the best amount of exercise for your situation. Always consult your doctor before starting any new exercise program, and stop exercising if you feel too tired or have pain. If your doctor has said that you can exercise, it may be worth consulting with a physiotherapist or exercise physiologist who has experience in cancer care. They can give you manageable exercises and help with energy conservation.

You can search for an exercise professional near you via Exercise and Sport Science Australia (www.essa.org.au/find-aep).

Hobbies

A hobby is an activity you do regularly in your leisure time because you enjoy doing it. Hobbies can range from running to more gentle exercises such as tai chi and yoga. Woodwork, sewing, knitting blankets for the homeless, gardening, reading, singing, listening to music, looking up things of interest on the internet or watching Netflix can all be hobbies. It is just something you enjoy doing.

> *‘I try to live as much as possible. Fundraising for pancreatic cancer research is important to me personally. Last year my family and friends raised $48,000 and this year we reached $53,000. And that is just events with family and friends. I want to improve someone else’s outlook. Last year’s money was able to buy a machine for the hospital.’*
>
> **SANDY**

‘For me it is exercise. I used to play tennis twice a week, walk the dog every day. After surgery I got back walking quickly and I walked the dog even when I was feeling yucky. I do it because it makes me feel better.’

JANE

Research shows that people who have hobbies are less likely to suffer low moods, anxiety and depression. Having a hobby can bring fun, self-achievement and freedom into your life. It can reduce the day-to-day difficulties of having cancer. Cancer patients often say that they don’t want their cancer to define them or it to be the only topic of conversation with their friends and family. It is important to have other things to talk about and do, other than having treatment and being asked about how you feel.

‘I garden and do Pilates twice weekly. Within 10 minutes into a Pilates class I feel better, even after chemo.’

JANE

‘Thoroughly recommend to anyone in a similar situation to find something to do. My craft and sewing saved me. I got a sewing machine and started to make clothes for friends’ children.’

LYNNE

Living with cancer can be draining and affect your mental health. It may feel like your cancer is dictating your life, which is understandable. You may feel you don’t have the time or energy to focus on fun things like hobbies and your own interests. But many people with cancer say the very thing that improves their mental health and quality of life is taking time out for their hobbies. If hobbies involve helping others, this can be even more rewarding.

‘If I do something, I then feel like the cancer is not ruling me – I am ruling it.’

JANE

‘When I am having a shitty day, I would go and set up the sewing machine and I can be lost in that for hours.’

LYNNE

‘Everyone does things to cope in different ways. Some go out and fundraise, set up charities. Whatever you do is okay as long as it makes you feel better and helps you cope.’

JANE

‘If you are not doing something creative, then it allows you to be indulgent. If you don’t have a hobby then it is easy to sit around and feel sorry for yourself but when you are doing something that takes up your mind, it eliminates feelings of self-indulgence – you can no longer just sit around and think about your problems. Sewing is almost like a mindfulness technique for me. I find it difficult to meditate but with sewing I can get lost for hours and be creative at the same time.’

LYNNE

10 ways hobbies improve your #mentalhealth

when living with a serious health issue

1. Provide a distraction from symptoms
2. Remind you of abilities you still have
3. Process of learning and getting better provides a sense of mastery
4. Provide a sense of achievement
5. Provide a sense of belonging thru socialising with others and/or looking after someone or something
6. Can provide a safe way to deal with unpleasant feelings linked to your health issue and changes in your life
7. Provide enjoyment
8. Reduce stress & increase relaxation
9. Provide meaning to your life
10. Restore a sense of normality to your life

#ReturnToWellness

www.returntowellness.co.uk

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Image: Courtesy Barbara Babcock, www.returntowellness.co.uk

Sexuality

Sexuality involves how you feel about your body, gender and your sexual feelings towards others. Your sexuality is shaped by many factors around you, such as your physical and mental health, religious and spiritual preferences as well as cultural influences. Whether you are in an intimate relationship or not, your sexuality can play an important part in how you feel about yourself and your self-esteem.

Having cancer, its treatment and side effects may greatly affect how you feel about yourself and your sexuality. It can be difficult to feel ‘sexy’ or good about yourself when you are unwell. And having sex may not be possible due to the cancer itself and side effects such as fatigue, decreased libido and pain. However, being close by sharing intimate conversations, cuddling, holding hands or kissing can still bring intimacy into a relationship.

> ***‘Intimacy has become daily hugs while the kettle is boiling for coffee. However, in most respects, life has never been as good.’***
>
> **TOM**

> ***‘Having non-stop diarrhoea for a while was not very romantic but it hasn’t affected our relationship.’***
>
> **AARATHY**

If you have cancer and aren’t in a relationship, you may still have fears about your sexuality. You may worry you won’t ever be able to have a relationship again or be attractive to someone. Even though this is unlikely to be true, it can be difficult to cope with. Speaking to someone you trust about your feelings may be helpful. You may also find it helpful to see a specialist oncology psychologist.

For further information, support and details about how to find sexuality counsellors who work with people with cancer, read the Cancer Council booklet ‘Sexuality, intimacy and cancer’ (available from www.cancer.org.au).

Your relationships

Having cancer can create more meaningful and lasting relationships with those close to you. But sometimes it can put huge strains on close relationships with friends, colleagues and family.

‘The dynamics of some friendships change.’

JANE

‘Caring for someone with cancer sorts out relationships with your friends and family. Some turn up and just help and others may not know what to do.’

MILTON (carer)

If you have children and are dealing with cancer, you may feel you want to hide children from the pain of what is exactly going on for you. But it is usually best to be honest with children, no matter what their age, as they often sense something is wrong. Listen to what your children are saying and give them explanations suitable to their age.

‘My wife and I introduced a journal for our 10-year-old son. He leaves it for us to read when he has something to share and then we write back an answer to him and leave it on his bed. No pressure to talk if he doesn’t want to. This has worked well and now he will talk to us more, which is good as he is not generally a “talker”. Whereas, our younger daughter, who is 6, implicitly believes Drs will fix me. She is very open to come and talk to us though and if she has a bad thought, she will come and tell us.’

AARATHY

‘I involve the kids as much as in that my health is part of everyday life, but it has not taken over our lives.’

JANE (three children aged 28, 30 and 33 years)

Reassure young children about who will care for them if you become too unwell. Be mindful of behaviour suggesting your child is struggling and needs more support. Close family and friends can be a great source of help and support to children. But sometimes it also helps children to speak to someone outside of the family such as a counsellor.

For more detailed information about talking to children about cancer and where to find support, download a copy of the Cancer Council booklet 'Talking to kids about cancer' (www.cancer.org.au). Canteen (www.canteen.org.au) is an excellent website for those aged between 12 and 25 whose lives have been changed by cancer.

'Even when my kids are cranky with me or what is happening for them in life, I am still so grateful I can be a Mum. I say to them, "Even though I have cancer I can still be your Mum and pick you up, tell you off".'

SANDY

Relationships with your partner can also come under a lot of strain when you have cancer.

'My husband has been so supportive, and he is an amazing father. But sometimes he takes on the role of carer and gets quite overzealous about it. But I know it is because he cares so much for me.'

SANDY

Problems you may face include:

- a reversal in your roles for some parts of your relationship (e.g. you may no longer be able to work, cook or look after the children as you used to, so your partner must take on one or all of these roles)
- wanting to protect each other from the difficulties around your illness
- financial difficulties if there is now only one income
- changes in how you communicate emotionally and sexually.

‘It took time to sink in that I had cancer and it was terminal, and it took my partner longer. There were stages when we were at a ‘mis-match’ in where we were at and what we were thinking. This was really difficult.’

LYNNE

If a relationship was stable before you had cancer it is likely to continue in this way. However, if you were having difficulties it may become worse, or some couples may become closer again as they choose to face such difficult times together. It can be challenging, but it is important to try and keep communicating with each other, even if your opinions differ. Some couples benefit from relationship counselling. You can ask your GP to refer you to a counsellor or psychologist.

‘I am very lucky to be with the person I am with, who understands me very well. We are a couple who talks to each other about everything. In public I might appear to be okay, but then when I get home and break down, my wife is always there to support me.’

AARATHY

How partners and friends can help

Watching someone you care for and love go through all the suffering of cancer and its treatment is heartbreaking. You may feel helpless at times and not know how to offer them the love and support they need. Sometimes it may feel like the person with cancer is pushing you out or doesn’t want or appreciate your help. But this is often because they feel overwhelmed, tired, upset or just unsure how to ask for the help they need.

Sometimes the help and support they need might not be exactly what you might have thought would be helpful. Ask how you can help and try not to feel hurt if the answer you get isn’t what you expected. Listen to what the person is saying and be open to helping, even if this means leaving the person alone for a while or having to tell family and friends not to visit at certain times.

‘It is important to talk to the person, don’t assume, ask them what they want.’

MILTON (carer)

People with cancer often say they understand their friends and family mean well and they greatly appreciate their support. But they also say there are times when they need those close to them to understand they might want to be alone, or not want others around them to express their sadness about their cancer. They don’t always want to be reminded about their cancer and would prefer to talk about other things. They say that having their cancer define them is difficult. Other times, they may be desperate for you to be close by and not to feel alone in their thoughts. They will want to know you feel sad and fearful too about their illness.

It can often be difficult to know the right words to use when you speak to someone with cancer. Comments such as ‘Wow, you look great, you have lost so much weight’ or ‘Gosh, you really look good, you don’t look like you have cancer’ may seem appropriate. However, it can be a shock and not always a good thing for someone with cancer to hear these things because the weight loss has been caused by the cancer. It can sometimes be hurtful to hear people sound surprised by the fact you are looking good, or you that you don’t ‘look’ like you have cancer. Other times, it can make the person feel frustrated as they think they may look good, but inside they feel terrible.

The following quotes provide a tiny glimpse into the feelings of some people with cancer and ways partners and friends can help.

‘I love it when a friend just rings and says “Coffee?”. This is lovely, and I feel better to know it is not always about my cancer.’ **JANE**

‘Much appreciation must go to my wife, Janice, for her concern, her love and support, her serious care and attention with food, drink and ensuring I got enough sleep with the right pillow and that I didn’t over-extend myself during recovery despite my natural penchant for some independence as I do try not to weigh heavily on my carers.’ **TOM**

‘When everyone was saying their goodbyes to us the day after the wedding, many people were openly sobbing and devastated – it’s like they were already grieving my passing and that was difficult for me, my wife and children.’ **ANON**

‘I know it is hard for people to try and figure out the right things to say to you.’ **AARATHY**

‘Everyone has good intentions, but you have to change the focus of your friends/family away from just your chemotherapy/illness. When friends would ask me all the time, when is your next chemo – I would try to change the subject and talk about going to the movies and other things I was doing in my life. I don’t want my whole life to be about my illness. And it can be exhausting dealing with friends even though you know they are well meaning. It is just draining talking about your illness all the time.’ **LYNNE**

‘I was always thankful for my wife’s daily visits while in hospital, but less happy with visitors other than close family. I sure didn’t want to share anything much of what I was going through, people have their own problems, and I wasn’t about to heap my misfortune upon them. Even today, among friends, if the conversations turn to medical matters, or more importantly, mine, I generally quietly leave the room and go looking for wherever the coffee is.’ **TOM**

‘I have an amazing family and friends’ support and I feel so lucky and often think how much worse it could be to have to do this alone.’ **SANDY**

‘When I go out with friends or am with family, yes, ask me about my cancer and treatment. But then move on to talking about our kids, what’s happening in the world, etc. I have to be able to keep some normality. I am just the same me. I still like to laugh and know about my friends’ lives and their problems too. It is not all about me.’ **JANE**

‘Telling people is a hard part too. Trying to explain to people what it means. I had some strange reactions – and then to try and explain to people it’s palliative and then people think you are dying. The whole meaning of palliative care needs to be re-written.’ **LYNNE**

‘I sense people looking at me. Some say things like, “You look amazing”, which I sense in their thinking that maybe I should look terrible. This can be hard.’ **JANE**

Going it alone

Some people find themselves coping with cancer alone. Perhaps you have recently moved interstate or from overseas, or have recently left a relationship during which you became estranged or separated from friends and family. Or perhaps you have always chosen a solitary path. Whatever the reason, your solitude doesn’t have to mean isolation. If you need help and support, you will be able to find it. It may be that the communication you have with doctors and other health workers is enough, but if you want to reach out beyond that, try talking with counsellors at the Cancer Council helpline (13 11 20) or a social worker or psychologist linked to the hospital where you are being treated. They will be able to suggest ways to connect or reconnect with others.

Cancer Council Australia has a telephone support group for people with pancreatic cancer. Call 13 11 20 to speak with a cancer nurse, who will be able to tell you more about this group.

Spirituality

Spirituality is often a very personal concept and has many perspectives. For many people it is the quality of being concerned with the human spirit or soul. It is above and beyond material or physical things. It often includes a sense of connection to something bigger than us.

Spirituality and religion have different meanings for some people. For others they may be closely intertwined.

People with cancer often rely on spiritual or religious beliefs to help them cope with their illness. Your spiritual needs depend on your own cultural and religious beliefs. For some, praying in a church or temple fulfils their spiritual needs. For others, it may mean being in nature, painting, writing in a journal or doing yoga. Your spiritual needs can change throughout life and illness often creates a space to connect more freely to your spiritual self.

Fear of recurrence

Cancer recurrence means cancer that has come back (recurred) following a length of time after treatment when you had no symptoms. Pancreatic cancer may come back in the same place or in another part of the body.

Understandably, people who have had cancer worry about a recurrence. You may worry that any ache, pain or symptom means your cancer has come back. This is very natural, but it can cause a lot of stress and affect your quality of life. The fear can be stronger at certain times, including just before follow-up appointments, at the anniversary of your cancer diagnosis and in the lead-up to special occasions such as birthdays, weddings or religious celebrations.

Don’t ignore your fears or any symptoms, but try not to let your fear overpower you. Share your fears with those close to you, and/or your doctors and nurses. They will be able to discuss ways to help you and reduce your fears. If you have symptoms that persist, see your GP, who will be able to assess if you need further investigations.

It can help to ask your doctor about which specific symptoms would need investigating and which are okay to leave. Ask how long you should wait before getting investigations. This can help prevent you constantly worrying about every niggle or pain you may have.

Joining a support group can also help some people as you can talk with others who have similar fears.

> ***‘It’s always there if you allow it to come through your everyday living. Just another instance where you have to push back, enjoy every day and strive to have something to look forward to.’***
>
> **TOM**

If your fears and anxiety about your cancer coming back become overwhelming, despite your efforts to try and control them, seek medical help as soon as possible. Your GP or oncologist may be able to refer you for counselling.

FEELINGS

What patients feel

When writing this booklet, the writer spoke to many people with pancreatic cancer and those caring for them. Three of the questions asked are outlined below with the many beautiful, heartfelt and, sometimes, sad answers. We feel this section is one of the most important in this booklet. We hope you will gain hope and reassurance that you are not alone, and your feelings are important. All quotes are anonymous in this section.

What has helped you most since being diagnosed with pancreatic cancer?

‘The love and support of my wife is the one thing that keeps me going and wanting more and more to try harder each day.’

‘Mum was always so positive, she always felt she had more time, that she would beat it, she had such a strong faith, that is what helped us as well. She didn’t allow us to dwell, which meant that we had so many moments where we could have conversations that were not bogged down in cancer.’

‘It has given me time to reflect on what a fortunate life I have led and that I am lucky enough to still have time to enjoy nature and the environment, my hobbies, the company of friends and family and to arrange a relatively orderly departure from this life.’

‘I have thrown myself into my work more and lucky to have good people around me at work and this has been really helpful as I feel like I am in control at work.’

‘I started to put together our family history as my generation knew it, which is ongoing, published a photo book of our youngest son’s first 50 years for him on his 50th birthday and made further contact with people from our teenage years, which previously had been fleeting and spasmodic. I still wonder why I hadn’t done that sooner.’

‘Reading the morning papers, monthly coffee meetings with friends and acquaintances gathered from my working days, eating out far too much with my wonderful wife and trying to get with my two sons (one in Qld) and their families at any excuse for a gathering.’

‘Working keeps my mind working, which helps me a lot.’

‘I can’t meditate. It is not in me to do it.’

‘What has helped me is that I actually do believe I am quite lucky.’

‘I was so lucky as we had each other’s backs and we talked a lot. We relied on each other for support.’

‘I try not to look too far ahead. I’ve never asked my doctor how long I have to live but I’m not stupid and I know I don’t have infinite time to live. So, I try to just be grateful every day.’

‘I try to be as normal as possible. There has not been a day I have not got out of bed. I may have gone back to bed when the kids leave the house or after I have dropped them at school. But I always get up.’

‘My first goal each day is to get out of bed and shower. Anything else after this is a bonus. I nap a lot but not in bed but on the couch. So, I don’t feel like I am a sick person. Being in denial like this helps me.’

‘When you make something for someone else you feel like you are contributing something to others. When I would see photos of the children in dresses that I had made it was a fantastic feeling.’

‘Having a hobby gives me something to strive for and I am always looking to improve my sewing skills. It does not matter what you do but I say you must have a hobby.’

‘I have met people I would never have met if I didn’t have cancer, and I’ve made some very good friends.’

‘I am enjoying being a part of a very new Pancreatic Cancer (Recovery) Group.’

'We have a kindness program here called 1000 hearts – at the hospital that mum was at for her final weeks (palliative care) we all got a pocket heart (or if you look in my four year old's bedside drawer she has about seven). The hearts are a symbol of compassion, care and love at a time of need. Mum's family (she is the eldest of 12 and so many aunts, uncles and cousins) were with mum when she died and the days leading up, we all have a heart, we all still remember and reflect on mum's journey, her strength, faith and courage. We remember with our own heavy hearts, as we hold our pocket hearts, that there is always hope and love.' (www.1000hearts.com.au)

What have been the most difficult things to cope with since your diagnosis?

'My children have had some major personal events happen in the 5 years I have been sick. These have been hard enough without their Mum being sick.'

'You find yourself having to educate people and telling them the chemo will only keep the cancer at bay, they can't operate. This was hard for people to understand that it could not be cured.'

'I am a pretty private person but now I spend a lot of my time talking to people about my bowel habits and being asked the colour, consistency of my stools. With pancreatic cancer you have to get used to things like this.'

'The hardest thing I will ever do is watch my children watch me be sick.'

'People expect because you have cancer, you just sit down but I didn't want cancer to become my identity.'

'The biggest struggle for me has been the not knowing. Not knowing how long for – survival, treatment, and when I will lose ability to do day-to-day things.'

‘Sometimes the offers of help and assistance can be overwhelming, and it is difficult to refuse assistance without the fear of, or actually offending people. My approach has been to explain that whilst I am able to do things, I would prefer to do them myself, as to accept help when I don’t really need it, reinforces the fact that I am ill. There will come a time when I really will need assistance, and it will be most welcome then. I have found that this works, and people accept and understand my mindset. No-one has said (so far) – “Well bugger you then” – and stormed off.’

‘People you meet seem to always focus on your cancer and ask: “How is your cancer affecting you today?”, but I have a business, a family and kids and not everything is about cancer.’

‘It is good to remember to focus on our own mental health too – and sometimes/often that means saying no to spending time with people who drain my energy. This is particularly difficult with family.’

What would be your advice to someone who is newly diagnosed with pancreatic cancer?

‘Give it time to sink in as there is so much to take in. My husband and I went into panic mode to start with. Trying to think of the best way to manage things in a panic state, but don’t make rash decisions. Sit back and absorb it for a while, as you may not make wise decisions when you are in a panic.’

‘Mental health is so important. We are always building up our kids to know it is ok to ask and get help and I wish I had sorted out earlier getting mental healthcare.’

‘It’s not always fun but you can’t sit back and let it get you. Don’t let the “big” picture take over from all the lovely things that can happen each day.’

‘Be positive, which is not everyone’s cup of tea, but it helps me.’

‘It’s about having a good life. Living with “it” and not dying.’

‘Make the most of your good days and then other days you have just got to surrender to it as you’re too tired and unwell. And I always remind myself – tomorrow is another day.’

‘My advice to someone else diagnosed with pancreatic cancer is to try and be as normal as possible. It is okay to get cross, yell and be cranky but what is important is how you deal with it.’

‘I would like people not to give up – have hope.’

‘I have never given myself a time limit and I have never asked for one.’

‘Stay positive, stay active, try and keep a routine. Enjoy everything.’

‘Don’t let your cancer take you over and it all be about cancer. Make memories even if it is just sharing a cup of tea with someone you care for. Making memories for others is as important as making them for yourself.’

‘Make times to have meals together with family. Just all sit around the kitchen bench and chat – whether you are dying or not.’

‘Do what your medical team tell you to do, they are a wonderful resource and can help manage your side effects and don’t get caught up in saying “Oh I don’t want to take that tablet”. If it is helping, deal with the long-term side effects later.’

‘You have to get through the now. People need to be honest about their side effects and listen to your Dr. I have tried to be the hero, but it is not worth it as you suffer for no reason and if a tablet helps with my nausea, pain, itchiness – then I now just take it. I advise others do the same to save themselves a lot of suffering.’

‘Your cancer and its effects need to be managed so you can feel normal because if you don’t, you are just in misery all the time.’

‘I have always taught my children that “the inner circle is very small”. And when you get sick with this kind of thing you quickly work out who that inner circle is. So, cherish that.’

CHALLENGES

When cancer won’t go away

Sometimes cancer stops responding to treatment, and it keeps growing and possibly spreading to other parts of the body. If this happens, there will usually still be treatment to help control your symptoms. But it can be very difficult to accept your cancer isn’t going to go away. This is called ‘advanced cancer’, which we discuss in this section.

What is advanced cancer?

Advanced cancer means your cancer has spread from where it began in the body into surrounding tissue and other parts of the body. Pancreatic cancer can spread to nearby lymph nodes. But it also most commonly spreads to the liver, the peritoneum (lining of the abdominal cavity) and the lungs.

Pancreatic cancer is often diagnosed when it is in the advanced stages of the disease (stages 3 and 4) (see ‘Staging the cancer’). This is because the symptoms of pancreatic cancer usually don’t show up until the cancer has spread or is pressing on other organs and causing pain.

When pancreatic cancer is advanced it isn’t curable. However, your doctor may still recommend treatment such as chemotherapy, radiotherapy, surgery or biological therapies. These treatments may help control and/or slow down the growth of the cancer and/or relieve symptoms such as pain. Treatment for advanced cancer, when cure is no longer possible, is called palliative treatment, which is discussed in the next section.

Read the section ‘Living with pancreatic cancer’ to find out about ways to help control the symptoms of advanced cancer.

Whether your cancer was advanced when you received your diagnosis, or it has become advanced over time, it is distressing to learn your cancer is incurable. Most people need a lot of support during this time. You may want to discuss your outlook (prognosis) and possible treatments with your doctor. For some people, treatment can keep the cancer stable for months or years. But the uncertainty can create times when you and those close to you will feel low in mood and frightened. This is very normal, and it is important to seek support to help you when you feel ready.

You may find encouragement by joining a support group for people with pancreatic cancer. While joining a support group is not for everyone, many people who join one say they are able to speak openly and share their concerns with others going through similar experiences. Not having to worry about upsetting those close to you with your real feelings can be a huge relief. Through support groups you can form close relationships and talk about your cancer, its treatment, relationships, fears and future hopes. Support groups can be face-to-face, online or by telephone. See the 'Further information and support' section.

The Cancer Council Australia has a telephone support group for people with pancreatic cancer. Call 13 11 20 to speak with a cancer nurse who will be able to tell you more about this group.

Palliative care

The World Health Organization defines palliative care as being for people with a serious or life-limiting illness, not just at the end of life or when disease is advanced. Many people worry when they hear 'palliative treatment' or 'palliative care'. They worry 'palliative' often means nothing else can be done to help the person with pancreatic cancer. Or it is time to 'give up' and the person is going to die. But palliative care is about finding ways to get support and resources from experts who know how to improve your quality of life. Palliative treatment is given to try to control a cancer that can no longer be cured. Palliative care is a specialist approach to care of the patient and those close to them. It involves expert support from a palliative care team, who are specialists in managing the difficult symptoms and side effects of your cancer and its treatment.

This can include help from:

- doctors (GP, palliative care consultant, other specialist doctors)
- nurses (specialist oncology, diabetic educator and palliative care nurses)
- family support workers (social workers, counsellors and pastoral care, psychologists)
- dietitian, physiotherapist and occupational therapist
- massage, music and art therapists
- biographers (volunteers who help to document your life history for you)
- other volunteers who can help with doing shopping, cleaning, providing respite for carers and taking you to and from appointments.

Their goal is to provide people in the advanced stages of an illness with care to control their symptoms caused by their cancer and its treatment. This will allow them to live as comfortably as possible. It involves looking after your physical, emotional, social and spiritual needs as well as supporting your family and other carers. They all work closely with each other, using their own expertise, to provide holistic care to help control symptoms and solve problems relating to:

- pain
- breathing problems
- fatigue
- bowel problems
- anxiety and depression
- dietary problems
- carers' exhaustion, fears and other concerns (see 'Caring for someone with pancreatic cancer')
- grief and bereavement concerns for all the family
- financial and practical problems (see 'Useful information').

'Nobody in the clinical area ever told me about how to go about dealing with palliative care.'

MILTON (carer)

> *'I remember panicking when I was referred to palliative care – was I terminal? But it was quickly explained to me that they need to manage my symptoms and quality of life as well as treat the cancer itself. I was having a lot of difficulty keeping anything down after my first two cycles of chemo, I ended up being admitted for eight days under the palliative care team who worked with me to prescribe medications to help me feel normal and withstand the onslaught of chemo.'*
>
> **AARATHY**

There is information in the 'Living with pancreatic cancer' section about how to cope with the symptoms and side effects listed above. Palliative care can be given at any stage of your cancer. And it can be helpful to think about palliative care before you become too unwell. This way you can be involved in your care and advise those close to you how you would like to be cared for. You may like to write up an advance care plan (see the 'Useful information' section). Care can be given in a hospital, hospice or home setting. It is all about what you want and what makes you feel most comfortable.

Palliative care can provide people with cancer and those caring for them a great deal of comfort and support. Palliative care is a medical speciality that helps people with life-threatening illness to overcome complex physical, psychological and spiritual issues related to their disease.

Generally, palliative care services are free. There may be small charges for hiring equipment, and for medications and dietary supplements. If you have private healthcare you will need to discuss with your insurance company what they do and don't cover.

If you would like to be linked in with palliative care services speak to your GP, specialist doctor or nurses at the hospital. You can also contact Palliative Care Australia (www.palliativecare.org.au) directly to find out about services available in your state.

What to expect as your cancer progresses

Most people diagnosed with cancer will worry about what might happen if their cancer gets worse (progresses). Even if it is not going to happen soon, you and those close to you may wonder about the end stages of life – death and dying. This is a very natural reaction and you may feel a lot of different emotions when you think about this: anger, sadness, fear, guilt, joy, denial and love for all the different stages of your life. Everyone will deal with these emotions in their own way. You may feel like crying a lot, want to be alone or not speak much to anyone. Other times you may find you want to talk, be with those you love and make the most of the time you have left. You may find you want to focus on getting your Will done and organising your financial affairs (see 'Useful information').

You may have many questions, some of which don't have answers. But it may help to talk with your medical team, family, friends, spiritual carers and anyone else you trust. You may find answers to some of your questions.

End-of-life care

Knowing you or someone close to you may be nearing the end of their life (terminal stages) is usually very confronting. And often difficult to talk about. You may have questions about when this will happen, how it will happen and what are the signs that someone is coming to the end of their life. The main goals and hope for caring for someone in the end stages of their life are to maintain:

- comfort
- choices
- legacy and memory-making
- quality of life.

Other important goals include:

- providing support for loved ones / family / caregiver
- being able to communicate honestly, but also maintain reasonable hope
- being able to adjust care and communication according to culture
- identifying goals when a patient is no longer able to.

It is important to follow 'patient- and family-centred care' (see 'Deciding about treatment') during end-of-life care, to support the dying person's individuality and dignity, as well as to care for the psychosocial and spiritual needs of the patient and those caring for them. It is crucial to encourage choice and control.

We have decided not to include in-depth information about end-of-life care in this booklet. But if you or someone close to you is at this stage and would like to know more, the links below take you to further information and support. These resources will be able to help answer your questions and give you and your family the support you may need during this difficult time.

The Cancer Council has produced booklets titled 'Facing the end of life: A guide for people dying with cancer, their families and friends', 'Understanding palliative care' and 'Living with advanced cancer'. Cancer Council booklets are available from www.cancer.org.au or call 13 11 20 for free copies.

The Cancer Australia booklet 'Finding the words: Starting a conversation when your cancer has progressed' can be found online or order a printed copy from www.canceraustralia.gov.au.

Palliative Care Australia has produced information about palliative care (www.palliativecare.org.au/what-is-palliative-care).

Hold on to hope

While many things can remain uncertain when you have cancer, one certainty is you can always continue to hope. Hope is very important to people with cancer and those close to them. Being hopeful allows you to cope during hardship and suffering. It lets you focus on what you can control and can help you find the strength and courage you need to face ongoing challenges. Look for hope!

Plan and keep setting goals for things that are important to you. Your hopes may vary from day to day and can be as simple as going to your friend's birthday party. Others may hope to be pain free or be able to continue pursuing a hobby that distracts them from their illness. Share these hopes with those around you, including your healthcare team. This allows others to plan care around things that most matter to you.

'We felt empowered with information, despite being in such a horrific place BUT most of all we had HOPE.'

KAT (carer)

Image: Courtesy 1000 hearts, www.1000hearts.com.au

INFORMATION

Useful information

Cancer can affect all parts of your life, including your work, finances and insurance policies. When you are unwell, having to deal with these issues can add extra stress to your life. But there is a lot of support available for people with cancer to help them manage their finances, work and other practical issues during this difficult time.

Working and cancer

It may be that you need to stop working for a while when you are first diagnosed with pancreatic cancer. For some people this may be temporary, but for others it may mean giving up work all together, either by choice or because your health will no longer allow you to work. Whatever the reason, this can be difficult to cope with, especially if you like your job and the people you work with. It can also create stress around financial issues. You may be able to return to work part time after your treatment finishes. A lot will depend on the stage of your cancer, your general health, energy levels, as well as how much you need the income.

If you can return to work either during or after your cancer treatment, you are likely to feel a bit nervous. Many people worry about what to tell their employer and colleagues and how it will change how people see them at work. You may also become anxious about managing your symptoms and side effects of the cancer and its treatment when you are at work. Most employers will be willing to help you in any way possible to make sure you can return to work and feel comfortable. But if you are having issues, you need to know your work rights and what support is available for you.

If your pancreatic cancer and its treatment means you are unable to work, you may be eligible to apply for certain Centrelink benefits. The process of applying for these benefits can be time consuming and frustrating. We advise you ask the social worker at the hospital where you are having treatment to help you apply for these types of financial support.

For detailed information, read the Cancer Council booklet 'Cancer, work and you: A guide for people with cancer, their family and friends' (available from www.cancer.org.au).

Travel and accommodation

Travelling to and from hospital for cancer treatment is exhausting, especially if you live far from your treatment hospital. You and your carer may need accommodation nearer to the hospital to avoid too much travel during treatment times. Travel, parking and accommodation costs can become expensive.

There are several organisations that provide some financial support to cover these costs for people with cancer who need to travel a long way to their treatment. Some hospitals have reduced parking rates for patients and their family members. Talk to your social worker or specialist nurses to find out more.

Call the Cancer Council on 13 11 20 to find out more about specific schemes to help with travel and accommodation costs when having to travel long distances for treatment.

Finances (insurance, loans and superannuation)

Having cancer can put a lot of financial pressure on you and your partner/family. If you are not able to work any more, you may need to find another source of income to help cover your usual bills, medical bills and overall lifestyle needs. You may need to consider reducing your outgoing costs, which can be difficult to do. There are several options available to people with cancer to help them with paying bills and reducing costs. There are also certain Centrelink benefits you and the main person caring for you may be entitled to.

You may find it helpful to read the Cancer Council booklet 'Cancer and your finances' (available from www.cancer.org.au).

Wills and enduring power of attorney

If you have not already done so, you may start to think about your Will and who you want to be your power of attorney. Many people with cancer often say: ‘I want to get all my affairs in order.’ This can mean:

- making a Will and preparing any other documents (e.g. an advance care plan) to allow those close to you to make decisions should there come a time when you can’t
- organising your legal and financial paperwork
- nominating a person to be your beneficiary – who you want to receive the benefits from your Will, superannuation and any insurance policies.

Being organised and preparing these matters means you can be sure your personal wishes are fulfilled. It also makes these often-challenging times much less stressful for your family and others close to you.

‘Put your financial and testamentary affairs in order as soon as possible. Settle up or resolve as best you are able, any personal issues that are worrying you. You can then close the books and concentrate on quality of life issues.’

DAVID

‘There is a lot of anger amongst carers whose partners die without a Will in place. These practical issues are often completely missed.’

MILTON (carer)

Download the Cancer Council factsheet ‘Getting your affairs in order: Information for people affected by cancer’ (available from www.cancer.org.au).

‘If you get a stage 4 diagnosis it is devastating but I sorted all my stuff like my Will so that is all done now, I feel I have all my ducks in a row and I can focus on more important things like being with my family.’

SANDY

Advance care planning

Advance care planning is when you talk about and plan for your future. It is about recording/documenting your personal values and wishes to do with your health, medical and personal care. This allows close family, friends, carers and medical staff know what your beliefs, preferences and instructions are for your ongoing and future care. By documenting this you will have peace of mind that what you want and how you prefer things to happen will happen. It helps you receive the care you wish to receive.

The documentation for advance care planning is called an Advance Care Directive. An Advance Care Directive may have different names in some states and territories of Australia. What can be included in an Advance Care Directive may also differ within each state and territory.

Anyone can make an Advance Care Directive, but it is particularly important for the elderly, unwell, mentally or physically impaired or if you have a terminal illness. An Advance Care Directive can be changed at any time during your life or illness. You will be able to nominate someone to make decisions about your healthcare if there comes a time you are too unwell to do this for yourself. This person will be called a 'substitute decision-maker'.

Advance Care Directives only come into effect if you get to the stage where you are unable to make your own decisions.

For more detailed information and advice about advance care planning, call the Advance Care Planning line on 1300 208 582 (9 am to 5 pm Monday to Friday).You can also find information at www.advancecareplanning.org.au

Leaving behind memories

Some people with cancer choose to leave behind messages, gifts, photos or recordings for their loved ones to read, listen to and look at after they pass away.

> *'It is about making memories and having those you love around you.'*
>
> **SANDY**

Making a memory box to leave for your partner, children or a friend can be a special and meaningful gesture. Items to include might be photos, sentimental items and written messages. Some people like to buy small gifts and wrap them for close family to have on the first birthday or Christmas after they die. It is a very personal thing and not something everyone will feel comfortable doing.

> *'I am writing cards and a journal for each of my children and they don't know about it.'*
>
> **ANON**

Some hospitals, hospices and community palliative care services offer a biography service. A volunteer will regularly visit you over a period to interview you about your life. This will be written down, edited and prepared into a copy of your biography for you and for your family to keep. Many people say this is an emotional, important and rewarding experience to go over their life history and have it documented for their family. Often facts or events come up that family have never been told.

A short holiday break

It can be extremely helpful and relaxing to get away from the routine of life and any stress, especially during treatment. But not everyone can afford to go away. The Cancer Council in some states has a holiday break program that gives people with cancer and their loved ones a once only chance to a free holiday house to spend quality time with those you love.

Contact the Cancer Council Helpline on 13 11 20 to find out more.

Help for people with language and cultural barriers

Being unwell and not being able to speak your own language with your health professionals is frustrating and difficult to cope with. The person can feel very alone and scared, not knowing exactly what is going on for them. If you know someone with cancer whose first language isn't English, there are services that can help to access information and support in various languages. There are also interpreter services that can be very helpful.

Contact the Translating and Interpreting Service National on 13 14 50 who provide a free interpreting service and will be able to provide you with further information if you need an interpreter to attend a doctor's appointment with you, or visit www.tisnational.gov.au

Aboriginal and Torres Strait Islander people may also feel isolated and uncertain about asking for help if they have cancer. Cultural differences relating to health and treating cancer play a big part in this. An Aboriginal health worker or liaison officer is the best person to offer support and explain the help Aboriginal and Torres Strait Islander people have access to.

Contact the Cancer Council on 13 11 20 to find out more about the range of information and support available.

CARERS

Caring for someone with pancreatic cancer

A carer is anyone, whether family or friend, who is helping to look after someone with cancer. Although caring for someone with pancreatic cancer is often rewarding, it can also be tiring and stressful, especially when it is someone you care about a lot.

As a carer you are likely to go through many emotions, which are similar to the emotions the person you are caring for may often feel, such as fear, anxiety, guilt, anger, frustration and shock.

It is tempting to ignore your own emotions and needs when you are caring for someone with cancer. However, it is important you try to care for yourself during this time. You will be able to care for the person much better if you are rested and cared for as well.

> ***'There is such a range of ways people cope caring for someone in this situation. The carer and patient are more aligned than people realise. If the carer doesn't do the best job, then the patient doesn't get the best result. And the first time around with my first wife, I didn't care for myself – I was much younger and had two young daughters. But with my second wife I was more selfish, and I focused on Frances and was not a support person for other family members, which worked better for me.'***
>
> **MILTON** (carer)

Your carer's role will depend very much on the wishes of the person you are caring for and how advanced their cancer is. Caring for someone in the advanced stages of cancer is quite different to caring for someone earlier on in their illness.

> ***'It would be great to train "cancer mentors" who have relevant skills and you are referred to one at the start of your journey to help you navigate the system – appointments, hospital maps, parking etc.'***
>
> **MILTON** (carer)

Carers often need to make a lot more decisions that you normally would about the person you are caring for. Attending doctors' appointments with them, along with possibly having to organise other services and support, can become overwhelming.

It can help to take notes to appointments or write down what doctors and other health professionals say. This means when you go home, you and the person you are caring for can discuss anything that is concerning you.

Another challenging thing carers often have to do is to keep up communication with other family and friends. This can often become exhausting.

'I was also the main communication point to all of mum's family and friends – this was a difficult task, and certainly something that in hindsight it would be great to have a resource around how you can be that person, who relays the good and the bad, and then ultimately that mum passed away.'

KAT (carer)

Cancer support groups are usually open to carers as well as patients with cancer. A support group often provides a place to feel safe to talk about your feelings with others going through similar experiences. There are also a range of other support services that can help take some of the pressure off carers, for example, meals on wheels and district and palliative care home nursing services.

'Being a carer for someone you love provides an environment where you are forced to examine your beliefs, emotions, and what underpins your relationship. I was lucky to have had 25 years with a person who was loyal, caring, loving, and who demonstrated courage, strength, and beauty in the most trying of circumstances.'

MILTON (carer)

Things that may help

- Make time for yourself to get out of the house and share your feelings with someone you trust.
- Be active each day if possible, even if only for a short walk outside.
- Eat a healthy, well-balanced diet and drink plenty of water.
- Rest when you can.
- Accept help from others where possible, and don't feel guilty if you can't do everything. Listen, but don't feel you always have to fix things.
- See your GP if you are feeling anxious, sad or low in mood all the time or have any other health concerns. Don't put off seeing a doctor if you have symptoms that won't go away.
- Accept your role as carer is difficult at times and there will be days you won't feel as positive or able to support the person you are caring for as well as usual. You may even feel resentful at times. It is very normal to have these feelings and doesn't mean you don't love or want to care for the person.
- Nominate a close friend or family member to be the person who communicates to others about the person with cancer. Using group emails, texts or a daily blog can be useful tools to update everyone on the person's health, treatment and support needs.

> ***'As a carer you run the risk of crowding or over protecting your loved one but finding a balance where they are cared for adequately, but you can't take over someone's life just because they are sick.'***
>
> **MILTON** (carer)

Carer support

There is a lot of support available to people caring for someone with cancer. Some carers find joining a support group comforting and a great source of information.

You may be eligible for a Carer Payment or Carer Allowance, which are funded through the government. Both these payments can provide carers with income support if you are not able to work or you are working but still caring for someone.

Contact Centrelink on 13 2717 to find out more about the Carer Payment and Carer Allowance or visit www.centrelink.com.au.

The following websites may also be useful:

- Carer Advisory and Counselling Service (1800 242 636) provides carers with referral services and practical written information to support them when caring for those close to them.
- Carers Australia (www.carersaustralia.com.au) works with carers' associations throughout Australia to help improve the lives of carers.
- The Cancer Council has a useful booklet 'Caring for someone with cancer' (available from www.cancer.org.au or call 13 11 20 and ask for a free copy to be posted).
- The Cancer Council also has a support group for carers (phone 13 11 20).
- Carer Gateway (www.carergateway.gov.au)
- Young Carers Network (www.youngcarersnetwork.com.au)

'I honour Frances' life by doing things that will help others in a similar situation.'

MILTON (carer)

'To be brutally blunt, upon your demise, your suffering will be over, but those who are left behind will have grief and other issues to deal with. The period of your illness and treatment are likely to have been just as, if not more stressful upon them as upon you, and their welfare needs to be considered and attended to throughout.'

DAVID (patient)

Finding information on the web

The internet is an easy source of information and it has a lot of information about pancreatic cancer. With such a vast amount of information available, it can be very difficult to know which information is reliable, backed up by research and up to date. We strongly advise that you don't use online information as a substitute for information you are given by your doctors and other health professionals. Ask your healthcare teams' opinion about information you find on the internet.

> ***'After my diagnosis, my children googled pancreatic cancer and said to me "Mum you will be dead in six months". But five years on, I'm still here!'***
>
> **SANDY**

Important things to watch out for are: Is the website promoting a cure for cancer? If the site is offering a cure or treatment for cancer, are they asking you for a lot of money to buy the product? Claims like this are unlikely to be backed up by any scientific evidence. This is called 'quackery', which means false promises and dishonest advertisers.

The American Cancer Society (www.cancer.org) has detailed information about finding cancer information on the internet.

A note on voluntary assisted dying

Voluntary assisted dying (sometimes called 'VAD') is a legal way of taking medication that you know will cause your death. It is governed by a strict set of guidelines. In Victoria, voluntary assisted dying is legal for someone who has an incurable disease and has been told by a doctor they have less than six months left to live.

Legislation for voluntary assisted dying came into effect in Victoria in June 2019. Currently Victoria is the only state in Australia where voluntary assisted dying is legal. You must have been living in Victoria for 12 months before you are eligible.

We recommend you speak with your GP if voluntary assisted dying is something you or someone you are caring for are thinking about.

RESOURCES

Further information and support

We have listed resources throughout the booklet. Here are some other resources you may find useful.

Australian resources

General

- Avner Pancreatic Cancer Foundation (www.avnersfoundation.org.au) has helpful information for patients and carers on a range of topics related to pancreatic cancer.
- The Living with Cancer Education Program is a Cancer Council program that provides information on cancer and ways of coping with it. The program runs over one day or several weeks. Groups are small, with plenty of time for talking. Courses are held at hospitals and community organisations throughout Victoria and other states and territories in Australia. Contact your hospital social worker or the Cancer Council Helpline on 13 11 20 Monday to Friday between 9 and 5 pm. The program is also conducted in languages other than English.
- Cancer Connect (13 11 20) is a free and confidential telephone peer support service provided by the Cancer Council that connects someone who has cancer with a specially trained volunteer who has had a similar cancer experience. 'A Connect volunteer can listen with understanding and share their experiences and ways of coping. They can provide practical information, emotional support and hope. Many people newly diagnosed with cancer find this one-to-one support very beneficial.'
- The Thing About Cancer podcast (www.cancercouncil.com.au/podcasts) has covered a range of topics about cancer, including 'The thing about advanced cancer', 'Coping with a cancer diagnosis', 'Cancer affects the carer too', 'Making treatment decisions', 'How to help someone with cancer' and 'Managing cancer pain'.

- Optimal care pathways are guidelines on a range of cancers developed by the Department of Health and Human Services for doctors and consumers. They cover optimal diagnosis, treatment and follow-up, among many other issues. You can read the optimal care pathway for people with pancreatic cancer at www.cancer.org.au/ocp. A consumer guide is available at www.cancerpathways.org.au/optimal-care-pathways/pancreatic-cancer.
- Cancer Australia (www.canceraustralia.gov.au) has a very wide range of information on its website.
- Australian Cancer Trials are listed at www.australiancancertrials.gov.au

Palliative care

- CareSearch (www.caresearch.com.au) is a palliative care knowledge network with many helpful resources.
- Palliative Care Australia (www.palliativecare.org.au) has local and national information for people having palliative care and their family and friends.

International resources

Following are some credible websites from the United Kingdom and United States. It is important to note that some information on international websites may not apply in Australia. Always ask your specialist healthcare team if you are unsure about something you have read.

- Pancreatic Cancer Research Center (www.path.jhu.edu/pc)
- Pancreatic Cancer Action (www.pancan.org)
- Neuroendocrine Cancer UK (www.netpatientfoundation.org)
- American Cancer Society (www.cancer.org)
- Cancer Research UK (www.cancerresearchuk.org)
- Macmillan Cancer Support (www.macmillan.org.uk)
- Pancreatic Cancer UK (www.pancreaticcancer.org.uk)
- National Comprehensive Cancer Network guidelines for patients with pancreatic cancer (www.nccn.org)

Appendix

These two tables expand on information given in the section titled ‘Genetic factors’.

Table A1: Faulty genes that are known to cause pancreatic cancer

Faulty gene	Condition	Lifetime risk of pancreatic cancer*
STK11	Peutz–Jeghers syndrome	11–32%
PRSS1	Hereditary pancreatitis	20–40% (higher in smokers)
CDKN2A	Familial melanoma	17%
BRCA2	Hereditary breast and ovarian cancer	3–8%
PALB2	Hereditary breast cancer	Not known
MLH1/PMS2/ MSH2/MSH	Lynch syndrome	3.6%

*Higher % number means a higher chance of getting pancreatic cancer by the age of 80

Table A2: Pancreatic cancer risk based on family history

Familial pancreatic cancer	Lifetime risk of pancreatic cancer
No relatives with pancreatic cancer	0.96%
One relative with pancreatic cancer	4%
Familial pancreatic cancer (two relatives)	8–12%
Familial pancreatic cancer (three relatives)	16–30%

Source: Garvan Institute of Medical Research, reproduced with permission

For more information about family history and genetic testing for pancreatic cancer, call the Cancer Council on 13 11 20. You may also find it helpful to go to the Garvan Institute of Medical Research (www.garvan.org.au) and search for 'familial pancreatic cancer'.

Glossary: What does that word mean?

abdomen/abdominal The part of the body between the ribs and the hips containing the stomach, bowel, pancreas, liver and bladder.

advanced cancer Cancer that has spread from where it began to other parts of the body and can no longer be cured.

anaemia A condition in which there is a deficiency of red cells or of haemoglobin in the blood, causing tiredness, breathlessness and pale skin.

angiogenesis The development of new blood vessels.

ascites The accumulation of fluid in the peritoneal cavity, causing abdominal swelling.

benign tumour A growth of abnormal cells that is not a cancer and cannot spread to other parts of the body.

biopsy Tissue taken from part of the body and examined under a microscope in a laboratory to help find out the presence, cause and extent of a cancer.

bowel obstruction A blockage in the intestines (bowel), which prevents the normal movement of stools through the body. It can be caused by the cancer and/or its treatments.

BRCA1 and **BRCA2** A gene change (mutation) that may be inherited from your mother or father. These gene changes are linked to higher risk of developing breast cancer and other types of cancers, including pancreatic cancer.

CA125 (cancer antigen) test This test measures the amount of a protein called CA125 (cancer antigen 125) in the blood. CA125 is a type of tumour marker. High levels can sometimes happen when you have certain types of cancer, including pancreatic cancer.

CA19-9 (carbohydrate associated antigen) test This test measures the amount of a protein called CA 19-9 (cancer antigen 19-9) in the blood. CA 19-9 is a type of tumour marker. High levels can sometimes happen when you have certain types of cancer, including pancreatic cancer.

CEA (carcinoembryonic antigen) test This test measures the amount of a protein called CEA (cancer antigen CEA) in the blood. CEA is a type of tumour marker. High levels can sometimes happen when you have certain types of cancer, including pancreatic cancer.

cancer A disease caused by cells in the body growing in an uncontrolled way that develop into a malignant growth called a tumour. If not treated, these tumours can spread to other parts of the body.

cells The building blocks of the body. Each human is made of trillions of cells, which are made for different functions in the body.

chemotherapy The treatment of cancer using chemical/cytotoxic substances, to slow the growth of or destroy cancer cells.

clinical trial A carefully designed research investigation to test new treatments, interventions or tests to prevent, detect, treat or manage various diseases or medical conditions such as cancer.

complementary therapies Therapies used alongside medical treatment to help manage symptoms and side effects.

diabetes A disease in which the body's ability to produce or respond to the hormone insulin is decreased, causing abnormal absorption of carbohydrates and raised levels of glucose in the blood.

DNA (deoxyribonucleic acid) The carrier of genetic information in all living organisms.

endocrine cells Cells that are responsible for producing and releasing hormone molecules into the bloodstream.

exocrine cells Cells in the pancreas that make enzymes, which aid in the digestion of food.

family cancer centre A place where you can talk to genetic counsellors about having genetic tests if you have a strong family history of cancer and you want to discuss testing for yourself and other family members.

genes A unit of heredity which is made up of DNA and transferred from a parent to offspring and determines some characteristics of the offspring. Your genes decide such things as hair and eye colour and your height. If you inherit a faulty gene, it may mean you have an increased risk of developing a certain type of cancer.

genetic Relating to genes. A genetic condition is one caused by a fault in one or more genes and may have been inherited.

Glossary (continued)

grade A term describing how similar cancer cells are to normal cells. Grades are defined as well, moderately or poorly differentiated. Well-differentiated cancer cells look more like normal cells under a microscope and usually grow and spread more slowly than poorly differentiated or moderately differentiated cells.

immunotherapy Treatment that stimulates the body’s own immune system to fight cancer.

local lymph node The first group of nodes to drain from the primary tumour.

lymph nodes Small bean-shaped structures that are part of the lymphatic system, which is part of the immune system. The immune system protects the body against infections and parasites.

malignant Cancerous. Malignant cells can spread (metastasise) and if not treated can cause death.

medical oncologist A doctor who specialises in treating people with cancer by using chemotherapy or other medications, such as targeted therapy or immunotherapy.

metastasis The development of secondary malignant growths at a distance from a primary site of cancer.

oncology nurse A nurse who specialises in caring for people with cancer.

palliative care or treatment A family-centred model of care and treatment given with the aim to relieve symptoms, provide emotional support and improve quality of life when an illness is no longer curable. Palliative care can be used alongside active treatment to help relieve symptoms and side effects.

pancreatic adenocarcinoma Cancer that usually begins in the ducts of the pancreas.

pancrelipase A drug that replaces enzymes that your pancreas isn’t able to make to help break down food properly.

peripheral neuropathy Numbness and tingling in hands and feet caused by certain chemotherapy drugs.

prognosis A doctor’s assessment of the likely outcome or course of a medical condition.

radiotherapy The treatment of disease, especially cancer, using X-rays or similar forms of radiation.

regional lymph node A lymph node that drains lymph from the region around a tumour.

remission When cancer can no longer be found in the body (undetectable) or is no longer progressing. Complete remission is when the cancer has not been detectable for some time. Partial remission means there is still cancer present after treatment, but it is less active than before, but it is likely to grow again in the future.

secondary cancer A cancer that has spread from where it started to another part of the body. Also called metastasis.

stage The stage of a cancer describes how advanced the cancer is and how far it has spread.

staging Investigations to find out how far the cancer has progressed, which is important for deciding on the best treatment.

tissue A collection of similar cells.

tumour A new or abnormal growth of tissue in or on the body which can be benign (non-cancerous) or malignant (cancerous).

tumour marker A chemical released from cancer cells which travels in the blood of the person with cancer.

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