MACMILLAN
CANCER SUPPORT

Understanding cancer of the pancreas

About this booklet

This booklet is about cancer of the pancreas, which is also called pancreatic cancer. It is for anyone who has been diagnosed with cancer of the pancreas. There is also information for carers, family members and friends.

The booklet is about the most common type of pancreatic cancer and how it is treated. It also gives information about controlling symptoms for people with advanced pancreatic cancer. This booklet also has information about how to get advice and support about feelings, relationships, work and money.

We hope it helps you deal with some of the questions or feelings you may have.

We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 116 to 126, there are details of other organisations that can help.

Quotes

In this booklet, we have included quotes from people who have had cancer of the pancreas, which you may find helpful. These are from people who have chosen to share their story with us. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations.

To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

Contents

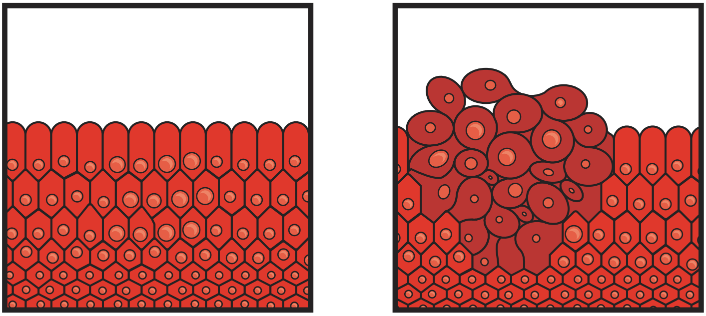
The pancreas and cancer

What is cancer?

Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged or no longer needed. When this happens, the cell gets a signal from the body to stop working and die.

Sometimes these signals can go wrong, and the cell becomes abnormal. The abnormal cell may keep dividing to make more and more abnormal cells. These can form a lump, called a tumour.

Abnormal cells forming a tumour



Normal cells

Cells forming a tumour

Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample of cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

A tumour that is not cancer (a benign tumour) may grow, but it cannot spread to anywhere else in the body. It usually only causes problems if it grows and presses on nearby organs.

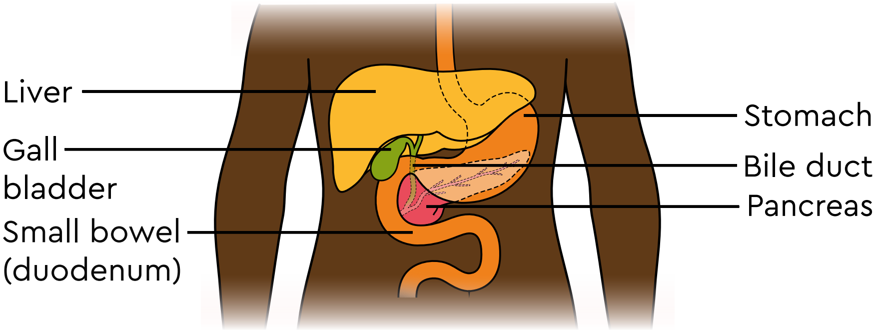
A tumour that is cancer (a malignant tumour) can grow into nearby tissue.

Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system (pages 10 to 11). When these cancer cells reach another part of the body, they may grow and form another tumour. This is called a secondary cancer or a metastasis.

The pancreas

The pancreas is part of the digestive system. It is in the upper part of the tummy (abdomen), behind the stomach and in front of the spine. It is level with where your ribs meet at the front of your body. It is about 15cm (6 inches) long.

The position of the pancreas



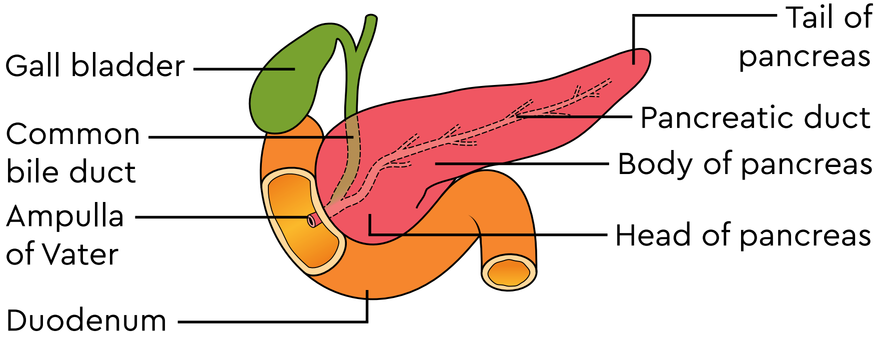
The pancreas has 3 main parts:

- **the head of the pancreas** – the large, rounded section next to the first part of the small bowel (called the duodenum)
- **the body of the pancreas** – the middle part
- **the tail of the pancreas** – the narrow part on your left side.

What the pancreas does

The pancreas makes digestive juices, called enzymes, and hormones including insulin. Hormones act as chemical messengers in the body. They control how different organs work.

The pancreas



Digestive enzymes help the body digest food, especially fats. The enzymes are made by the pancreas in cells called exocrine cells. Most cells in the pancreas are exocrine cells. The others are called endocrine cells.

The enzymes travel through the pancreas in small tubes called ducts. They move into a larger duct called the pancreatic duct. It joins with the common bile duct, which carries bile from the liver and gall bladder. Together they empty into the small bowel through an opening called the ampulla of Vater. The enzymes and bile flow into the duodenum, where they help digest food.

Insulin is a hormone that controls the amount of sugar in the blood. It helps move sugar into the body's cells, so we can convert it into energy.

The pancreas makes insulin in the endocrine cells. The endocrine cells group together in small clusters called islets of Langerhans. These cells release insulin directly into the blood.

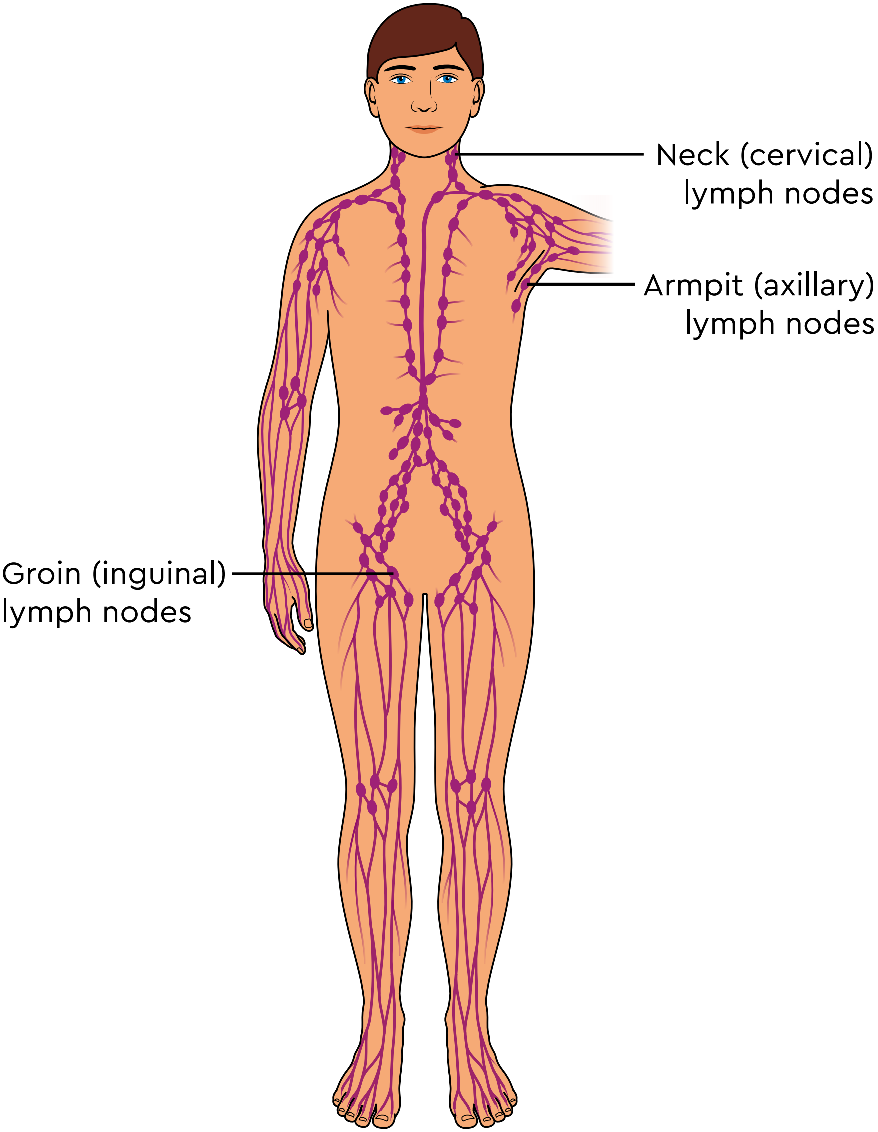
The lymphatic system

The lymphatic system helps protect us from infection and disease. It is made up of fine tubes called lymphatic vessels. These vessels connect to groups of small lymph nodes throughout the body. The lymphatic system drains lymph fluid from the tissues of the body before returning it to the blood.

Lymph nodes are sometimes called lymph glands. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, some lymph nodes may swell as they fight the infection.

If the cancer spreads outside the pancreas, it can affect the lymph nodes.

The lymphatic system



Types of pancreatic cancer

There are several different types of pancreatic cancer. Pancreatic cancer types are described based on:

- where they are in the pancreas
- the type of cell they start from.

Cancer can happen in any part of the pancreas. But around 6 out of 10 pancreatic cancers (60%) start in the head of the pancreas.

More than 9 out of 10 pancreatic cancers (95%) develop in the exocrine cells that make pancreatic juices. Cancers that develop in the endocrine cells can behave differently to those that develop in the exocrine cells. This means they can cause different symptoms.

Exocrine pancreatic cancer

The most common type of exocrine pancreatic cancer is ductal adenocarcinoma (PDAC). This cancer starts from cells in the lining of the pancreatic ducts.

Less common types include:

- cystic tumours – these cysts are fluid-filled sacs in the pancreas that can be cancerous
- acinar cell carcinomas – these start from cells at the end of the ducts that make pancreatic juices
- ampullary cancer – this develops in the ampulla of Vater
- intraductal papillary mucinous neoplasms (IPMN) – these develop in the pancreatic duct and produce mucus.

Our information is about the most common type of exocrine pancreatic cancer. But treatments for cancerous cystic tumours, acinar cell carcinomas and ampullary cancer are similar to those described in our treatment section.

Endocrine pancreatic cancer

Endocrine tumours of the pancreas are uncommon. They begin in the endocrine cells which make insulin and other hormones. They are also called pancreatic neuroendocrine tumours (PNETs) or islet cell tumours. About 4 in 100 (4%) of pancreatic cancers are PNETs.

We have more information about pancreatic neuroendocrine tumours (PNETs) at **macmillan.org.uk/nets**

Other pancreatic cancers

There are other rarer types of pancreatic cancer:

- **lymphoma** – a cancer of the lymphatic tissue in the pancreas
- **sarcoma** – a cancer of the connective tissues in the pancreas
- **pancreatoblastoma** – a rare type of cancer that mainly affects children
- **pseudopapillary neoplasm** – a rare, slow-growing tumour that mostly affects women.

The tests and treatments for non-Hodgkin lymphoma, pancreatoblastoma and sarcoma of the pancreas may be different to those in our information.

We have more information about non-Hodgkin lymphoma and sarcoma on our website. Visit **macmillan.org.uk/cancer-types**

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically.

There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out (page 126).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Planning your treatment

Finding out you have pancreatic cancer

Being diagnosed can cause many different emotions. There is no right or wrong way to feel. You may have been worrying about having cancer for a while. Or your diagnosis might have been unexpected. For some people, pancreatic cancer does not cause symptoms for a long time. Having tests and waiting for test results can be a difficult time.

This information is written for people who have already been diagnosed with pancreatic cancer. We also have information to support you if the cancer is advanced (pages 89 to 93). We have more information about possible causes, risk factors and symptoms of pancreatic cancer at **macmillan.org.uk/pancreatic-cancer**

Waiting for treatment to start can be a difficult time. You may be worried about telling people and about what treatment options you will have. You might choose to spend some time reading about the cancer, or you may prefer to wait until you see your cancer doctor. Do what feels right for you.

If you need support, you can contact our cancer support specialists on **0808 808 00 00**. They will be able to talk to you about what has happened and any worries you have.

Staging and grading

The treatment you have depends on the stage, grade, and position of the cancer. The doctors may already have some information about these things from the tests you had during diagnosis.

Staging

The stage of a cancer describes its size and whether it has spread. Knowing the stage of the cancer helps doctors decide the best treatment for you.

Staging can be confusing, so ask your doctor or nurse to explain if you are unsure.

The staging systems used are:

- TNM staging
- the number staging system.

The TNM and number stage are combined to give the complete stage of the cancer.

TNM staging

In the TNM staging system, TNM stands for Tumour, Nodes and Metastases.

T describes the size of the tumour.

N describes whether the cancer has spread to the lymph nodes and which nodes are involved:

- N0 means no lymph nodes are affected.
- N1 means there are cancer cells in between 1 and 3 of the lymph nodes tested.
- N2 means there are cancer cells in 4 or more of the lymph nodes tested.

M describes whether the cancer has spread to another part of the body (metastasised):

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

Number staging

This uses numbers to describe the stage of the cancer. The description of the stages in this section is for pancreatic ductal adenocarcinoma (PDAC), which is the most common type of exocrine pancreatic cancer.

We have more information about neuroendocrine tumours (NETs) at **macmillan.org.uk/nets**

Stage 0 or carcinoma in situ

This is a very early-stage pancreatic cancer, where the cancer is in the top layer of cells and has not grown deeper into the pancreas. It is also called **Tis** (tumour in situ). It is uncommon for pancreatic cancer to be diagnosed at this stage.

Stage 1

The cancer is contained inside the pancreas. But it may be quite large. There is no cancer in the lymph nodes close to the pancreas. There is also no sign that it has spread anywhere else in the body.

Stage 1 is divided into:

- **stage 1A** – the cancer is 2cm or smaller
- **stage 1B** – the cancer is bigger than 2cm but less than 4cm.

Stage 2

The cancer has started to grow outside the pancreas into nearby tissues. There may be cancer in lymph nodes near the pancreas (pages 10 to 11).

Stage 2 is divided into:

- **stage 2A** – the cancer is less than or equal to 4cm and is in nearby tissue, but has not spread into the blood vessels or lymph nodes
- **stage 2B** – the cancer may have grown into nearby tissue, and it is in up to 3 lymph nodes but not blood vessels.

Early-stage cancer

Stage 1 and 2 cancers are often called resectable or borderline early-stage cancers. About 2 in 10 cancers of the pancreas (21%) are diagnosed at stages 1 or 2.

Resectable means a surgeon may be able to operate to remove (resect) the tumour. Borderline resectable means that a surgeon may be able to operate, but they might not be able to remove all the cancer. In some borderline resectable cancers, you may have chemotherapy before surgery (neo-adjuvant treatment) to shrink the cancer, making it resectable.

Stage 3

The cancer has grown outside the pancreas and into nearly blood vessels. Or it has spread to 4 or more lymph nodes. But it has not spread to other parts of the body, such as the liver or lungs.

Stage 3 cancer is often called **locally advanced cancer**. Surgery is not usually possible for this stage. But it may be an option, depending on what blood vessels are affected.

Cancer that cannot be removed with surgery is called unresectable cancer.

If you have stage 3 cancer, you may have neo-adjuvant treatment. This would be chemotherapy or a combination of chemotherapy and radiotherapy (chemoradiation). Surgery may then be possible, but it would depend how well the cancer had responded to that treatment. It will also depend on what blood vessels are involved.


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Stage 4

The cancer has spread to other parts of the body, such as the liver or lungs. Surgery is not possible.

Stage 4 cancer is often called **metastatic** or **advanced cancer**.

Nearly 8 in 10 cancers of the pancreas (79%) are diagnosed at stages 3 or 4.

Grading

Grading describes how the cancer cells look when they are examined under a microscope. The grade gives doctors an idea of how quickly a cancer may develop and grow.

- **Grade 1** – low-grade or well differentiated. The cancer cells look similar to and behave like normal cells, usually grow more slowly and are less likely to spread.
- **Grade 2** – intermediate-grade or moderately-differentiated. The cancer cells look more abnormal and are slightly faster growing.
- **Grade 3** – high-grade or poorly differentiated. The cancer cells look very different from normal cells, they may grow more quickly and be more likely to spread.

How your treatment is planned

After getting your test results, you and your doctor start to talk about treatment. Your doctor usually meets with other specialists to get their opinions too.

Multidisciplinary team (MDT) meeting

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT).

The MDT look at national treatment guidelines or the latest evidence for the type of cancer you have. If you have any treatment preferences, your doctor will tell them about this.

The MDT will usually include the following professionals:

- **Surgeon** – a doctor who does operations (surgery).
- **Clinical oncologist** – a doctor who uses radiotherapy, chemotherapy and other anti-cancer drugs to treat people with cancer.
- **Medical oncologist** – a doctor who uses chemotherapy and other anti-cancer drugs to treat people with cancer.
- **Pathologist** – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.
- **Radiologist** – a doctor who looks at scans and x-rays to diagnose problems.
- **Interventional radiologist** – a doctor who uses scans and x-rays to give treatments such as ablation or embolisation.
- **Endoscopist** – a doctor who specialised in doing an endoscopy, EUS or ERCP.
- **Clinical nurse specialist (CNS)** – a nurse who gives information about cancer, and support during treatment.

Depending on the type of cancer you have, the MDT may also include:

- a **dietitian** – someone who gives information and advice about food and food supplements
- a **physiotherapist** – someone who gives advice about exercise and mobility
- an **occupational therapist (OT)** – someone who gives information, support and aids to help people with tasks such as washing and dressing
- a **palliative care doctor or nurse** – someone who specialises in symptom control and supportive care
- a **psychologist or counsellor** – someone who gives advice about managing feelings and behaviours.

Types of treatment

Surgery, chemotherapy, and radiotherapy are all possible treatments for pancreatic cancer.

People with pancreatic cancer often have treatments to control symptoms and make them feel more comfortable. This is called supportive care.

Research is going on to find more effective treatments for pancreatic cancer. You may be invited to take part in a cancer research trial of a new drug or treatment.

The treatment you have depends on the stage, grade, and position of the cancer. It also depends on your general health and your preferences.

It is important that you have the chance to discuss treatment with your doctors. They can help you understand why they have suggested a particular treatment plan. They can also explain how the treatment may affect you.

Your treatment will depend on whether surgery can remove (resect) the cancer.

- If the cancer is **resectable**, it means your doctors can remove the cancer with surgery (pages 40 to 54).
- If it is **borderline resectable**, surgery may be possible. But an operation usually follows other cancer treatment (neo-adjuvant treatment). This may be chemotherapy (pages 55 to 63), or a combination of chemotherapy and radiotherapy (chemoradiation).
- If the cancer is **unresectable**, it usually means it cannot be completely removed with surgery. But before describing the cancer as unresectable, the MDT (pages 25 to 26) may look at how close the cancer is to nearby blood vessels. They may discuss neo-adjuvant treatment with chemotherapy or chemoradiation. This may treat the cancer, or in some cases, it may shrink the cancer enough for surgery to happen.

Resectable cancer

Surgery is the most effective treatment for early-stage pancreatic cancer (pages 40 to 54). It involves removing part of the pancreas or the whole pancreas. For some people, this may cure the cancer. But it is a major operation. It is only suitable for people who are fit enough. You can only have surgery if the cancer is small, does not affect any large blood vessels, and has not already spread.

You might also have chemotherapy (pages 55 to 63) or radiotherapy (pages 64 to 67) after surgery, to lower the chances of the cancer coming back. This is called adjuvant treatment.

Borderline resectable cancer

Sometimes, the cancer has started to affect nearby blood vessels. This can make it more difficult for the surgeon to remove the whole cancer. It is important to remove the whole cancer and an area of healthy tissue around it. This is called a clear margin. If this is not possible, there is a high risk of the cancer coming back.

You may have chemotherapy before surgery. This is sometimes followed by a combination of chemotherapy and radiotherapy (chemoradiation) to shrink the tumour. The surgeon then decides if they can remove the cancer, along with a clear margin of healthy tissue. This can also reduce the risk of the cancer cells spreading. This is called neo-adjuvant treatment. You may have the treatment as part of a cancer research trial (pages 36 to 37).

Locally advanced (unresectable) cancer

Unresectable cancer is when the tumour has spread into the blood vessels around the pancreas. This usually means surgery is not an option.

Chemotherapy is the main treatment if the cancer has started to spread. You may have it to control the cancer for some time and to relieve symptoms.

Sometimes, you may have chemotherapy and radiotherapy together. This is called chemoradiation. Or, you may be offered radiotherapy on its own. Your doctor can discuss this with you.

Sometimes, chemotherapy or chemoradiation shrinks the tumour more than expected. This is not common, but may mean that it is possible to remove the tumour with surgery.

An operation is unlikely to be helpful if it is not possible to completely remove the cancer. You may have surgery to relieve symptoms. For example, if the cancer is blocking the bile duct or the bowel.

You may need other treatments to help with symptoms. If your pancreas is not working properly, you may need treatment called enzyme replacement therapy (page 52) to help your body digest fats and proteins.

Irreversible electroporation (IRE)

Sometimes the cancer cannot be removed by surgery following neo-adjuvant treatment because the nearby blood vessels are still affected. Irreversible electroporation (IRE) is a new treatment that might be used in this situation. A needle is inserted into the pancreas and an electric current is given through it to destroy the tumour.

IRE is only available in a few hospitals in the UK. Your doctor or specialist nurse can give you more information.

Metastatic or advanced cancer

If the cancer is advanced and has spread to the liver or lungs, or to other organs, you may have the option of treatment to control it. The main aim of this treatment is to reduce symptoms so that you feel as well as possible. This is called supportive care.

You may have chemotherapy to shrink the cancer and relieve symptoms. Chemotherapy may also help some people live for longer.

Depending on your symptomd, You may need to have a stent put in. This relieves jaundice or other symptoms caused by a blocked bile duct or bowel (page 73 to 76). To control any pain, you may have radiotherapy, painkillers, and nerve blocks (on their own or combined). You may need treatments to help with eating and digestion.

If your pancreas is not working properly, you may need treatment called enzyme replacement therapy to help your body digest fats and proteins (page 52).

Talking about your treatment plan

After the MDT meeting, you will usually see your specialist doctor and nurse. They will talk to you about your treatment plan. It can help to write down your questions before you see them. You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards. You need to know as much as possible before you can make any treatment decisions.

Your specialist doctor should explain:

- the aim of the treatment – whether it is to cure the cancer or control it
- the benefits of the treatment
- the disadvantages of the treatment – for example, the risks and side effects
- any other treatments that may be available
- what may happen if you do not have the treatment.

Cancer treatments can be complex. It can also be hard to concentrate on what you are being told if you are feeling anxious. If the doctor says something you do not understand, ask them to explain it again.

Making treatment decisions

You and your doctor can decide together on the best treatment plan for you. Your doctor is an expert in the best treatments. But you know your preferences and what is important to you. You can decide how involved you want to be in your treatment plan.

Sometimes doctors need to review a treatment plan. This may be when more information about the cancer becomes available – for example, when the doctor knows the results of surgery to remove the cancer. It may mean making more decisions with your doctor.

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan.

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken (verbal) agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your specialist doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your specialist doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website. Visit **macmillan.org.uk/getting-a-second-opinion**

Clinical trials

Clinical trials are medical research studies involving people. Doctors may use cancer clinical trials to:

- test new treatments to see if they work better than current treatments
- find which treatments have fewer side effects
- find new ways to combine treatments to see if they work better
- test new cancer drugs to find out more about them and their side effects
- improve the way treatments are given to try to reduce side effects.

Results from clinical trials can improve cancer treatments and help people live longer. Trials can also look at improving things like diagnosis and symptom management.

Taking part in a trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you.

Usually, cancer clinical trials happen in several hospitals around the country. You may have to travel to take part in a trial.

A research nurse or doctor will give you information about the trial. It is important to understand what is involved before you agree (consent) to take part. You can ask the research nurse or doctor any questions you have. We have more information about consent (page 34).

They will also explain the possible benefits and any possible risks of the trial. Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

If you decide not to take part in a trial, your cancer doctor and specialist nurse will respect your decision. You do not have to give a reason for not taking part. Your decision will not change your care. Your cancer doctor will give you the standard treatment for the type and stage of cancer you have.

We have more information about clinical trials on our website. Visit **macmillan.org.uk/clinical-trials**

Treating cancer of the pancreas

Surgery

Surgery can be used to remove a cancer from the pancreas. This is often the main treatment for early-stage pancreatic cancer.

You may also have surgery to relieve symptoms if the cancer is blocking the bile duct or the bowel.

Surgery to remove the cancer

Sometimes, it is possible to remove all of the cancer with surgery. This is a major operation. It is usually only suitable for people with early-stage pancreatic cancer. In some people, it may cure the cancer.

Only a specialist surgeon who has experience in pancreatic cancer surgery will do this type of operation. You may be referred to a specialist centre for it.

> **"The surgeon took us into a quiet room and explained the surgery. In fact, he actually drew a little sketch for us, to try to explain it as fully as possible."**
>
> Aziz, diagnosed with pancreatic cancer

It is important to discuss the benefits and disadvantages with your surgeon before deciding to have surgery.

The surgeon may remove part or all of the pancreas during the operation. This will depend on where the cancer is and how much of the pancreas it involves.

You may have one of the following operations.

Modified Whipple's procedure

In this operation, the surgeon removes:

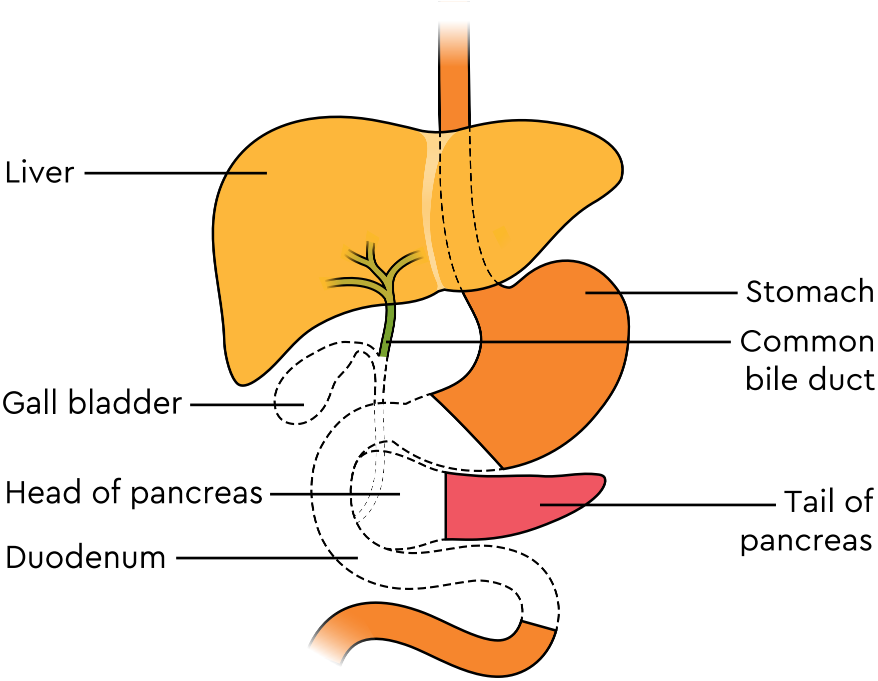
- the head of the pancreas
- most of the first part of the small bowel (duodenum)
- the common bile duct
- the gall bladder
- the surrounding lymph nodes.

It is also called a **pylorus-preserving Whipple's procedure** or **pylorus-preserving pancreatico-duodenectomy (PPPD)**. A modified Whipple's procedure is commonly used for people with cancer in the head of the pancreas.

Whipple's procedure

This operation is similar to a modified Whipple's procedure (PPPD). But the surgeon will also remove the lower part of the stomach. It is also called a **pancreatico-duodenectomy** or **PD**.

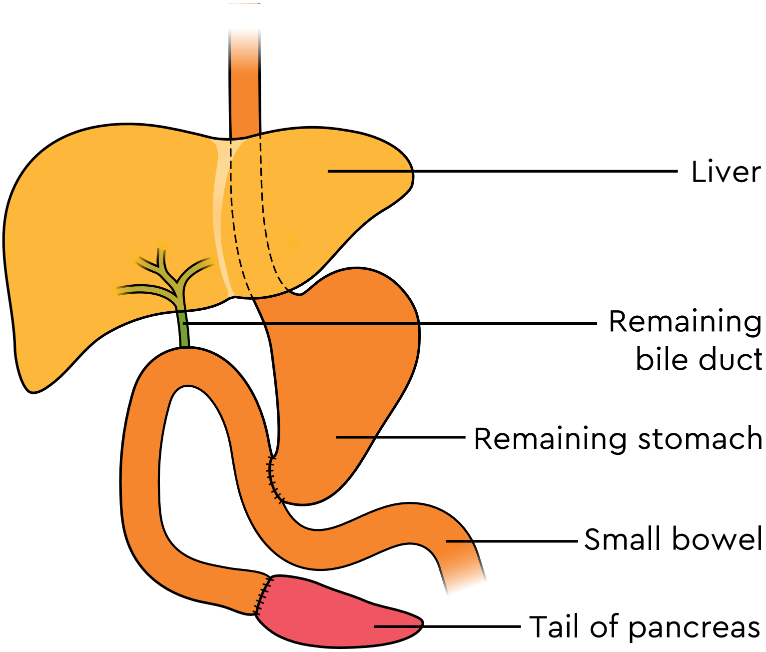
A Whipple's procedure



The sections in white are parts removed during a Whipple's procedure. These are the gall bladder, the head of the pancreas, and part of the duodenum, stomach and common bile duct.

> "I had a Whipple's procedure, which involved removing my gall bladder and parts of my pancreas, stomach and intestine before re-connecting the ends into a new digestive system. "
>
> Carole, diagnosed with pancreatic cancer

After a Whipple's procedure



The surgeon attaches the remaining parts of the stomach, the remaining bile duct, and the tail of the pancreas to the small bowel.

Pancreatectomy

A distal pancreatectomy is an operation to remove the lower end (body and tail) of the pancreas. The spleen is often removed at the same time. This is because it is close to the tail of the pancreas. The spleen helps you to fight infections. It is part of the lymphatic system (pages 10 to 11).

A total pancreatectomy is an operation to remove the whole pancreas. This is a major operation and is rare. The surgeon will also remove:

- the duodenum
- part of the stomach
- the spleen
- the gallbladder
- part of the bile duct
- some lymph nodes.

If your spleen is removed during a distal or total pancreatectomy, you will need to have some vaccinations for the rest of your life to protect you from infections. You may also need to take antibiotics for the rest of your life. When you see other healthcare professionals, it is important to mention that you no longer have a spleen.

Keyhole (laparoscopic) surgery

Surgery for pancreatic cancer is usually open surgery, where the surgeon makes one large cut (incision). But in some specialist centres, the surgeons may do keyhole (laparoscopic) surgery.

Instead of one large cut, the surgeon will make several small cuts. They use a special instrument called a laparoscope to see into and work inside the tummy (abdomen).

Keyhole surgery is only suitable for a small number of people. It is usually only possible for people having a distal pancreatectomy (page 45).

A small number of specialist centres do keyhole surgery using robotic equipment. The camera on the end of the laparoscope gives a three-dimensional (3D) magnified view of the inside of the body. This is shown on a video screen to help guide the surgeon. The surgeon controls instruments attached to the robotic equipment.

The main advantage of keyhole surgery is that it leaves small wounds. This means you usually recover quicker.

Before surgery

If you smoke, try to give up or smoke less before your operation. This will lower your risk of problems, such as a chest infection. It will also help your wound to heal after the operation. Your GP can give you advice. You may also find it helpful to read our information on giving up smoking. We have more information about giving up smoking at **macmillan.org.uk/stop-smoking**

Before surgery, you will have an appointment at the pre-assessment clinic. At the clinic, you will have tests to check you are fit for the operation. These may include blood tests, a chest x-ray or a recording of your heart (ECG). You will meet a member of the surgical team to discuss the operation. This is a good time to share any questions or concerns you have.

You may need help when you go home after surgery if you live alone or care for someone else. You should tell your nurse as soon as possible. This will give them plenty of time to make arrangements for anything you need to go home.

Some hospitals follow an enhanced recovery programme. This aims to reduce your time in hospital and to speed up your recovery. It also helps you become more involved in your own care. For example, you may get information about diet and exercise. The team will also make any arrangements you need to go home. Your doctor will tell you if an enhanced recovery programme is available and suitable for you.

You will usually be admitted to hospital on the morning of the operation. You will be given elastic stockings (TED stockings) to wear during the operation and for some time afterwards. This is to reduce the risk of blood clots in your legs.

After surgery

Knowing what will happen when you wake up after your operation can help you feel less anxious. It also prepares your family and friends for what to expect. Your recovery time will depend on the type of surgery you have.

Most people receive care in a surgical high-dependency unit for a few days after their operation. This is routine. Some people are cared for in the intensive care unit (ICU) if the operation was longer or more complicated. You will probably feel quite drowsy and may not remember much about the first days after your operation.

The nurses and physiotherapists will encourage you to start moving about as soon as possible. This is an important part of your recovery. It will help prevent problems such as chest infections or blood clots. You will be encouraged to do regular leg movements and deep breathing exercises. A physiotherapist or a nurse can explain these to you.

> **“Following the operation I was in intensive care for 2 days and in hospital for a total of 11 days. I went home with a drain in and at first found eating difficult.”**
>
> Pat, diagnosed with pancreatic cancer

Drips and drains

For a short time after the operation, you may have some of the following:

- A drip going into a vein in your arm or neck – this is called an intravenous infusion. This gives you fluids until you can eat and drink again. It can also give you painkillers and other medications.
- One or more drainage tubes coming from your wound. These drain away fluids, such as blood, bile or pancreatic juices. You will have these drainage tubes until the amount of fluid draining away has reduced.
- A fine tube that passes down your nose and into your stomach or small intestine. This is called a nasogastric tube. It drains fluids from your stomach so that you do not feel sick. You may need this for several days.
- A small, flexible tube called a catheter in your bladder. This will drain into a collecting bag. This means you will not have to get up to pass urine. You will usually only have this for a couple of days.

Pain control

It is normal to have some pain and discomfort after your operation. You can usually control this with painkillers. If you are in pain, tell the nurses. They may need to change the dose or type of painkiller.

You may have a spinal block during the operation. This is an injection of long-lasting painkiller into the fluid around the spinal cord. It gives pain relief for up to 24 hours. Or you may have an epidural. This is a pump that continuously delivers painkiller into the spinal fluid through a fine tube and can be left in for up to 5 days after the operation.

Sometimes a small, plastic tube is placed into the muscle around the wound, so that painkillers can be given through it for a couple of days.

Painkillers can also be given through a tube into a vein in your hand or arm. This is called a cannula. The tube connects to a pump. This is called PCA (patient-controlled analgesia). You can give yourself an extra dose of painkiller when you need it by pressing a button. The machine is set so you get a safe dose and cannot have too much.

Before you go home, your pain will be controlled by tablets or patches. You will get a prescription for painkillers you can take at home as needed.

Eating and drinking

You will not be able to eat or drink straight after the operation, . Until you can, you will have fluids through a drip. Some people have extra nutrition through the drip or a feeding tube.

Depending on the operation you had, you may be able to start drinking small amounts of fluid the day after the operation. The surgeon will tell you when you can. You may have supplement drinks for a few days. These will give you the nutrition you need to help your recovery.

If the operation you had means you will not be able to eat and drink for a few days, you will be given nutrition through a feeding tube. You may have a feeding tube called a nasogastric tube (NG tube) or a nasojejunal tube (NJ tube). An NG tube is passed through the nose and into the stomach. An NJ tube is passed through the nose and stomach, into the small bowel. It is used if you have a Whipple's procedure (pages 41 to 44).

Wound care

The surgeon will close the wound with stitches, clips, or staples. These are usually removed 10 to 14 days after the operation. If you have gone home, your practice nurse can do this at your GP surgery. If you cannot leave home, a district nurse can visit you. Sometimes, stitches are under the skin. These do not need to be removed as they dissolve on their own.

You may have antibiotics to help prevent wound infection. You will have a dressing covering your wound. This may be left in place for the first few days.

It is important to let your nurse or doctor know straight away about any problems with your wound. Tell them if the wound becomes hot or painful, or if it begins to bleed or leak fluids, even after going home.

Going home

Depending on the type of operation and your recovery, you can probably go home 5 to 10 days after surgery. Your doctor or specialist nurse will be able to give you more information.

You will have an appointment at an outpatient clinic for your post-operative check-up. This lets you discuss any further treatment you may need with them, such as chemotherapy (pages 55 to 63) or radiotherapy (pages 64 to 67).

Replacing insulin and enzymes

Insulin injections

Sometimes, if you have had part of your pancreas removed, your body may struggle to control blood sugar. This is because the remaining pancreas may not be making enough insulin. You may become diabetic and need to have insulin injections or tablets to control your blood sugar levels.

If you have had an operation to remove your whole pancreas, you will need daily insulin injections. You will need to have these injections for life. These are given under the skin (subcutaneously). You will also need to closely check your blood sugar level regularly. A diabetes nurse will give you support and advice about insulin replacement. If you already have diabetes, you may have to increase your insulin or tablet dose.

Enzyme replacement

You may need to replace the digestive enzymes that the pancreas normally makes. This will depend on the type of operation you had, whether you still have part of your pancreas and how well the remaining pancreas is working. Your surgeon, nurse or dietitian will give you more information.

Digestive enzymes help your body to break down and absorb fats and protein. If you do not have enough of them, you may have diarrhoea. Your stools (poo) may float, smell bad and be difficult to flush. This is called steatorrhoea. You will also find it difficult to put on weight, because you cannot absorb nutrients from your food.

You can replace the digestive enzymes by swallowing capsules.
You will usually take these capsules with every meal and snack.
Your nurse or a dietitian will explain how to take the capsules.
You will need to take them for the rest of your life.

Commonly used pancreatic enzyme replacement therapy drugs are:

- Creon®
- Nutrizym®
- Pancrease®
- Pancrex®.

Most replacement enzymes are made from pork. Vegetarian enzymes are not available.

The most commonly used supplement is a tablet called Creon, which is a pork-based enzyme replacement. There is no alternative that is not pork-based. It has been approved for use by Jewish patients by the Chief Rabbi. Previous rulings by Islamic scholars suggest that Muslims may use pork-based medicines if there is no alternative. If you have concerns about this, speak to your religious leader.

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It is one of the most commonly used treatments for pancreatic cancer.

You may have chemotherapy:

- after surgery, to reduce the chance of the cancer coming back – this is called adjuvant chemotherapy
- to shrink the cancer, relieve symptoms and prolong life if surgery is not possible – this is called palliative chemotherapy
- to shrink a cancer before surgery – this is called neo-adjuvant chemotherapy.

Sometimes, you may have chemotherapy with radiotherapy. This is called chemoradiation. If you have chemotherapy with radiotherapy before surgery, it is called neo-adjuvant chemoradiation. This may be part of a cancer research trial (pages 36 to 37). Your doctor or specialist nurse can give you more information about chemoradiation.

> **“3 months after surgery, I started chemotherapy. On the first day of treatment I felt really nervous and anxious. But it passed quickly and was not as bad as my imagination had led me to believe.”**
>
> Carole, diagnosed with pancreatic cancer

Chemotherapy after surgery

You may have chemotherapy after an operation to remove the cancer. The chemotherapy usually starts within 3 months of the operation and lasts about 6 months.

The most commonly used chemotherapy treatments are:

- gemcitabine and capecitabine (Xeloda®) – you may have these on their own or together in a combination called GemCap
- a combination of drugs called FOLFIRINOX.

Another drug that may be used is fluorouracil (5FU). You will have this as a drip (infusion) into a vein.

Gemcitabine

You have gemcitabine as a drip into a vein over 30 minutes. You will usually have this once a week for 3 weeks. You will then have a week of rest. These 4 weeks make up a cycle of treatment.

Capecitabine

You have capecitabine as tablets, twice a day. You should swallow them whole with a glass of water. You need to take them within 30 minutes after eating a meal.

You usually take the tablets every day for 2 weeks. This is then followed by a week of no tablets. These 3 weeks make up a cycle of treatment.

GemCap

If you are having gemcitabine and capecitabine together (GemCap), each cycle usually takes 4 weeks. You have a drip of gemcitabine once a week for 3 weeks and also take the tablets for 3 weeks. Then you will have no treatment in week 4.

FOLFIRINOX (FOLFOXIRI)

Sometimes, you may have a combination of drugs called FOLFIRINOX. It combines:

- folinic acid (leucovorin or calcium folinate)
- fluorouracil (5FU)
- irinotecan (Campto®)
- oxaliplatin.

Folinic acid is not a chemotherapy drug. But you may have it with 5FU, as it has been shown to make 5FU work better.

FOLFIRINOX can cause more side effects because it contains 3 chemotherapy drugs. It is only suitable for people who are well enough to cope with these side effects.

Each cycle of treatment lasts 2 weeks. Your doctor or nurse will tell you more about this and how many cycles you will likely have. You may have a PICC line put into into a vein to have this treatment (page 62).

Chemotherapy for advanced pancreatic cancer

People with advanced pancreatic cancer may have treatment with a single chemotherapy drug. Or they may have 2 or 3 combined. Common treatments are:

- gemcitabine on its own
- gemcitabine and capecitabine (GemCap)
- gemcitabine and nab-paclitaxel (Abraxane®)
- FOLFIRINOX.

Your doctor will talk to you about what drugs are available and suitable for you.

Gemcitabine and nab-paclitaxel (Abraxane®)

You will have both gemcitabine and nab-paclitaxel as drips into a vein. The treatment usually takes half an hour. You will have it once a week for 3 weeks. This will be followed by a rest week. These 4 weeks make up a cycle of treatment. Your doctor or nurse will tell you more about this and how many cycles you will likely have.

Other drugs

Cancer research trials aim to improve the results of treatment for pancreatic cancer (pages 36 to 37). Your doctor or nurse may talk to you about research trials if there is one suitable for you.

Sometimes research trials may use new drugs or drug combinations to treat pancreatic cancer. Sometimes the research trials may look at different ways of using existing treatments to see if they can be more effective.

Some research trials are looking at drug treatments called targeted therapy and immunotherapy for pancreatic cancer.

Targeted therapy drugs interfere with the way cancer cells grow. Olaparib is a type of targeted therapy called a PARP inhibitor. It is used to treat cancer of the pancreas that has a genetic change in the cancer cells called BRCA 1 or BRCA 2. It might be used after chemotherapy.

Immunotherapy tries to trigger the body's immune system to attack cancer cells. The body's immune system fights infection and disease. Immunotherapy is not yet widely used for pancreatic cancer.

How chemotherapy is given

You usually have chemotherapy as an outpatient. Most drugs are given into a vein (intravenously). You take some drugs (such as capecitabine) as tablets.

You may have drugs through:

- a short, thin tube the nurse puts into a vein in your arm or hand (cannula)
- a fine tube that goes under the skin of your chest and into a vein close by (central line)
- a fine tube that is put into a vein in your arm and goes up into a vein in your chest (PICC line)
- an implantable port.

We have videos to explain what chemotherapy is and how it is given at **macmillan.org.uk/chemotherapy** and **macmillan.org.uk/having-chemotherapy**

They show people having treatment inside a treatment centre and some of the different health professionals you will see. There are also animations that show how PICC lines and central lines are put in at **macmillan.org.uk/picc-lines** and **macmillan.org.uk/central-lines**

Side effects of chemotherapy

Chemotherapy drugs may cause some unpleasant side effects, but they can also make you feel better. This is because they relieve the symptoms caused by the cancer.

Most people have some side effects, but they can usually control these with medicines. The side effects usually go away once treatment has finished. Treatment with a combination of chemotherapy drugs may have more severe side effects than a single chemotherapy drug. You can talk to your doctor or nurse about what to expect from your treatment.

We have more information in our booklet **Understanding chemotherapy** (page 110) and at **macmillan.org.uk/chemotherapy**

> **"After each treatment I felt really shivery and cold, but I knew if I could get home and sleep, I would feel better by the next morning. Generally, the 3 days following treatment were the days I had most side effects."**
>
> Carole, diagnosed with pancreatic cancer

Radiotherapy

Radiotherapy uses high-energy rays to treat cancer. It destroys cancer cells in the area where the radiotherapy is given. Radiotherapy is not used as often as surgery (pages 40 to 54) or chemotherapy (pages 55 to 63). You may be offered radiotherapy as part of a cancer research trial.

You may have radiotherapy to treat pancreatic cancer that has not spread but cannot be removed by surgery. In this case, you might have it with chemotherapy. This is called chemoradiation. Chemoradiation aims to shrink the cancer and control it for as long as possible. The chemotherapy is usually a drug called capecitabine, which comes as tablets.

You may also have radiotherapy to relieve symptoms of cancer. This is called palliative radiotherapy. You will most likely have it to treat pain. It works by shrinking the tumour. This reduces the pressure that is causing pain.

If you are having palliative radiotherapy to control the cancer, you will have lower doses than usual. It is also usually a shorter course of treatment and is less likely to cause side effects.

You may have a type of radiotherapy called stereotactic body radiotherapy (SBRT). SBRT is a very precise way of giving higher doses of radiation with smaller number of treatments. You will usually have 5 treatments over 1 to 2 weeks.

You will have radiotherapy in the hospital radiotherapy department. How you have the treatment depends on your needs. Sometimes, for symptom control, a single treatment of palliative radiotherapy is all you need. Or you may have a course of radiotherapy as a series of short, daily sessions.

Each treatment takes 10 to 15 minutes. You usually have a course of treatment daily, Monday to Friday, with a rest at the weekend. Your doctor will discuss the treatment and possible side effects with you.

Planning your radiotherapy treatment

You will have a hospital appointment to plan your treatment (pages 27 to 28). You will usually have a CT scan of the area to be treated. During the scan, you need to lie in the position that you will be in for your radiotherapy treatment.

Your radiotherapy team use information from this scan to plan:

- the dose of radiotherapy
- the area to be treated.

You may have some small, permanent markings made on your skin. The marks are about the size of a pinpoint. They help the radiographer make sure you are in the correct position for each session of radiotherapy.

These marks will only be made with your permission. If you are worried about them, talk to your radiographer.

Treatment sessions

At the beginning of each radiotherapy session, the radiographer will position you carefully on the couch. They will make sure you are comfortable.

During your treatment, you will be alone in the room. But you can talk to the radiographer, who will watch you from the next room.

Radiotherapy is not painful. But you must lie still for a few minutes during treatment.

Side effects of radiotherapy

Radiotherapy for pancreatic cancer can cause side effects such as:

- sickness
- loss of appetite
- diarrhoea
- tiredness.

These side effects are usually mild. They will depend on how much treatment you are having. Having chemoradiation can make the side effects of treatment worse. Your cancer specialist will be able to advise you what to expect. They will also give you treatments to help with any side effects.

This treatment does not make you radioactive. It is safe for you to be with other people, including children, after your treatment.

We have more informationin our booklet **Understanding radiotherapy** (page 110) and at **macmillan.org.uk/radiotherapy**

Supportive care

Controlling symptoms

For many people with pancreatic cancer, the main aim of treatment is to control symptoms.

Chemotherapy (pages 55 to 63) and radiotherapy (pages 64 to 67) can sometimes help shrink the cancer for a time. This can help to control symptoms. You can also have other treatments that will help you feel better and have the best quality of life possible. This is called supportive care.

Your GP or cancer specialist can refer you to a palliative care team for supportive care. This is a team of doctors and nurses who will make sure that your symptoms are controlled. They will work with you, your GP, and other health professionals.

They are experts in helping control symptoms such as:

- pain
- tiredness
- changes in bowel function (poo)
- loss of appetite
- weight loss
- any other problems caused by pancreatic cancer.

Palliative care teams are based in hospitals, hospices, palliative care units and pain clinics.

We have more information about controlling cancer symptoms and coping with advanced cancer in our booklet **Coping with advanced cancer** (page 110) and at **macmillan.org.uk/advanced-cancer**

Pain

If pancreatic cancer causes you pain, it can usually be well controlled. If you are in pain, it is important to let your nurse or doctors know as soon as possible. This means they can treat it quickly. Your medical team will work with you to find the best way to manage the pain.

Painkilling drugs

There are many painkilling drugs available to treat different types and levels of pain. The drugs come in different forms including tablets, liquids and skin patches. You can also have painkillers by injection or into a vein (infusion). Your doctors and nurses will help you find the drugs that work best for you.

Nerve block

If painkilling drugs are not controlling the pain, or you have having side effects, your doctor or pain specialist may talk to you about having a nerve block. Nerves that cause you to feel the pain are injected with local anaesthetic and a steroid drug.

Before the treatment, you may be given some sedation to make you feel sleepy. During the treatment, you lie on your front and the doctor injects the drugs into the nerves through your back. They use an x-ray or ultrasound scan to guide them. Afterwards, your back may be sore for a few hours or days.

Sometimes an injection can be given through an endoscope during an endoscopic ultrasound (EUS). The injection is given into the nerves from inside the body using the endoscope. We have more information about endoscopic ultrasounds at **macmillan.org.uk/eus**

Cancer treatments

Cancer treatments such as chemotherapy (pages 55 to 63) or radiotherapy (pages 64 to 67) can relieve pain. They work by shrinking the cancer to reduce any pressure that is causing pain.

Other treatments

The team looking after you may talk to you about other possible ways of helping with your pain. These may include:

- relaxation techniques
- breathing exercises
- massage
- distraction techniques.

We have more information in our booklet **Managing cancer pain** (page 110).

We also have more information about managing cancer pain on our website. Visit **macmillan.org.uk/pain**

Jaundice

If cancer blocks the bile duct, you may develop jaundice. This happens because bile cannot drain away and builds up in the body. This can cause yellowing of the skin and the whites of the eyes. It can also cause itchy skin.

Your doctors may suggest they place a tube called a stent in the bile duct. Or they may suggest you have an operation to bypass the blockage.

Stents

Bile duct stents are most commonly put in using endoscopic retrograde cholangio-pancreatography (an ERCP).

You should not eat or drink anything for 6 hours before the procedure. You have an injection to make you feel relaxed and sleepy. The doctor passes a thin flexible tube with a camera on the end (called an endoscope) into your mouth. The tube moves down into your stomach and into the duodenum, which is the first part of your small bowel. Doctors then place the stent into the opening of the bile duct. The stent keeps the bile duct open and allow bile to drain.

Stents can be made of plastic or metal. If a plastic stent has been in place for a long time, it may need replacing. Metal stents do not usually need replacing. Sometimes a stent needs replacing if it becomes blocked or if you get an infection.

PTC (percutaneous transhepatic cholangiogram)

If doctors cannot pass a stent into the bile duct during an ERCP, they may do a PTC instead. During a PTC, doctors insert the stent through the skin (percutaneous) and liver (transhepatic) using a needle and tube. They then place the stent into the top of the bile duct.

Doctors will ask you not to eat or drink for a few hours before a PTC. You will have the procedure in the x-ray department. A doctor called a radiologist will do the procedure. After you lie down, you will have a sedative to make you feel relaxed and drowsy.

The doctor injects a local anaesthetic into the skin to numb it. Then they insert a long, thin, flexible needle through the skin and into the liver. The doctor looks at x-ray images on a screen to help them guide the needle to the bile duct. When it is in the bile duct, they inject a dye.

When doctors inject the dye, some people feel warm all over. This is normal and the feeling does not last long.

The dye flows through the ducts and allows doctors to see the blocked area. The doctor passes a fine guide wire along the needle into the blockage in the bile duct. A stent then passes along this wire. The stent holds the bile duct open where the blockage has narrowed it. This allows bile to flow through it again. You may feel some pushing when doctors put the wire and stent in. If this is uncomfortable or painful, let the doctor know. They can give you painkillers.

To help prevent infection, you will take antibiotics before and after the procedure. You will probably need to stay in hospital overnight.

Bypass surgery for a blocked bile duct

If a stent is unsuccessful, or if it is not possible, you might be able to have surgery to relieve the blockage. You need to be fit enough to cope with surgery and the anaesthetic.

The surgeon makes a cut in the bile duct, or sometimes the gall bladder, just above the blockage. They then reconnect it to the small bowel. This bypasses the blocked part of the bile duct. It allows the bile to flow from the liver into the bowel and stops the jaundice. In some hospitals, it is possible to do this procedure during a laparoscopy (keyhole surgery).

Blockage in the bowel

Sometimes, the cancer blocks the first part of your small bowel (the duodenum). This means food or drink cannot pass from your stomach to your bowel. The food collects in your stomach. This can make you feel sick (nausea) and be sick (vomit).

Stents

An expandable, flexible tube called a stent can often be used to treat the blockage. The doctor puts the stent into the section of bowel that the cancer is blocking. The stent holds the bowel open, so it is no longer blocked.

Stents for blockages in the duodenum are usually put in using an endoscopy. You should not eat or drink for about 6 hours before the procedure. You will have an injection to help you to relax and feel sleepy. The doctor passes a thin, flexible tube (endoscope) down your throat, into your stomach and then into your duodenum. They then put a stent down the endoscope and into the duodenum to hold it open.

Bypass surgery

If a stent is not suitable, you might be able to have surgery to relieve the blockage. You need to be fit enough to cope with surgery and the anaesthetic.

The surgeon connects part of your small bowel just below the duodenum, directly to your stomach. This lets food pass from the stomach into your bowel. In some hospitals, it is possible to do this procedure during a laparoscopy (keyhole surgery). This operation may happen at the same time as an operation to relieve a blocked bile duct (pages 73 to 75).

Tiredness (fatigue)

Many people with pancreatic cancer feel tired (fatigued). You may have less energy to do the things you normally do. The cancer itself may be causing this. Or it may be because of other symptoms, such as pain.

If you feel tired, it is important to get enough rest. You need to save your energy for the things that matter to you and that you enjoy. Try not to feel guilty if you need to ask for help with any daily activities or tasks. Letting other people do these can help you have energy for the things you really want to do. Friends and family may want to help and may be pleased if you ask them.

Just do as much as you feel like doing. You will not do any harm to yourself by doing too much. But you may need to rest and relax a bit more the next day. Tiredness and weakness sometimes make it harder to concentrate or fully take part in what is happening around you. If you have important things to do, save some energy so you feel less tired and more able to do them.

There is evidence that physical activity, like gentle strengthening exercises and walking, can help reduce fatigue.

Being active may help boost your appetite and give you more energy. It can also improve your general well-being. It is important to try to do some exercise, even if you do not feel like it. It is best to try to balance being active, exercising and getting plenty of rest.

You may be able to have treatment for some causes of tiredness. For example, if you have anaemia (low number of red blood cells) you may have a blood transfusion. Your doctor can take a blood sample to find out if you have anaemia.

Tiredness can also be a sign of depression. If you think you are depressed, talk to your doctor or nurse. Talking about your feelings with a professional counsellor can often help with depression. Antidepressant medication may also help you feel better.

We have more information in our booklet **Coping with fatigue (tiredness)** – page 110.

Other symptoms

Difficulty sleeping

Many people find they cannot sleep because of worry or anxiety. It can help to write down your concerns or to talk to someone about them. You may not be able to do anything about them immediately. But if you note them down, you can work through them the following day. Simple breathing and relaxation exercises may also be very useful in reducing anxiety and stress.

Sometimes pain can stop you from sleeping. Talk to your doctor or pain specialist about painkillers that can last through the night. Some medicines, such as steroids, can affect your sleep. Ask your doctor or nurse if you can take them earlier in the day. They may suggest you take them before 2pm.

Loss of appetite and weight loss

Pancreatic cancer can cause problems with eating and digestion.

You may have diarrhoea. This means you are not absorbing nutrients from food properly and you may lose weight. If you have diarrhoea, it may help to avoid fatty or high-fibre foods. Try to drink plenty of fluids, especially water.

Try to maintain your weight by adding extra calories where you can. If your food has more calories, it will give you more energy. For example, you can:

- add high-protein powders to your food
- supplement meals with nutritious, high-calorie drinks prescribed by your GP
- try eating several smaller meals and snacks during the day rather than 3 large meals.

If your appetite is not good, medicines such as steroids, or an appetite stimulant may help improve it. You may be referred to a dietitian at your hospital. Dietitians are experts in knowing what nutrition people need when they are ill. They can advise you on the best foods for you and on food supplements that may help. If you are at home, your GP can arrange for you to see a dietitian.

We have more information in our booklets **Eating problems and cancer** and **The building-up diet** (page 110).

Enzyme replacement

If your pancreas is not working properly, you may not be able to digest fats and proteins.

Digestive enzymes help your body to break down and absorb fats and protein. If you do not have enough of them, you may have diarrhoea. Your stools (poo) may float, smell bad and be difficult to flush. This is called steatorrhoea. You will also find it difficult to put on weight because you cannot absorb nutrients from your food.

You can replace the digestive enzymes by swallowing capsules. You will usually take these capsules with every meal and snack. Your nurse or a dietitian will explain how to take the capsules.

You will need to take them for the rest of your life.

Commonly used pancreatic enzyme replacement therapy drugs are:

- Creon®
- Nutrizym®
- Pancrease®
- Pancrex®.

Most replacement enzymes are made from pork. Vegetarian enzymes are not available.

The most commonly used supplement is a tablet called Creon, which is a pork-based enzyme replacement. There is no alternative that is not pork-based. It has been approved for use by Jewish patients by the Chief Rabbi. Previous rulings by Islamic scholars suggest that Muslims may use pork-based medicines if there is no alternative. If you have concerns about this, speak to your religious leader.

Feeling sick (nausea)

The cancer can make you feel sick. Some treatments may also make you feel sick.

Anti-sickness tablets (anti-emetics) can often relieve sickness. There are several different types of anti-emetics available. Your doctor will find the one that suits you best.

Your doctor may prescribe you steroids. These can help relieve sickness and make you feel more energetic. They can also improve your appetite.

We have more information at **macmillan.org.uk/nausea-vomiting**

Ascites

If the cancer has spread in the abdomen (tummy area), fluid can sometimes collect between the two layers of the peritoneum. The peritoneum is a layer of tissue (membrane) that lines the tummy. Your tummy may become swollen and distended (bloated).

This is called ascites and can be uncomfortable and painful. You may also have less of an appetite and feel breathless. The breathlessness happens when the swelling stops your lungs fully expanding as you breathe.

Your doctors may treat ascites by inserting a small tube into your tummy. This drains off the fluid. You usually have this treatment in hospital with a local anaesthetic. Your doctors can repeat this procedure when necessary. If needed, you can have a permanent drain.

Your doctors may give you water tablets (diuretics). These try to stop (or slow down) the build-up of fluid.

We have more information at **macmillan.org.uk/ascites**

Itching

Sometimes when people are jaundiced, bile salts are deposited in the skin. This causes itching. Having frequent lukewarm showers can provide relief. Try to avoid soaps that dry your skin as they may increase itching.

You may find moisturising lotions helpful. Your doctor can also prescribe or suggest medicines that may help relieve itching while you wait for treatment such as a stent. Treating the cause of the jaundice will help relieve the itching.

Blood clots

Cancer can increase your risk of developing a blood clot (thrombosis). Some treatments may increase this risk further. A blood clot may cause symptoms such as:

- throbbing pain, redness or swelling in a leg or arm
- suddenly feeling breathless or coughing
- sharp chest pain, which may be worse when you cough or take a deep breath.

Blood clots can be very serious. It is important to tell your doctor straight away if you have any of these symptoms. Drugs that thin the blood can successfully treat blood clots. Your doctor or nurse can give you more information about blood clots.

To help lower your risk of blood clots:

- drink plenty of water
- go for regular short walks
- take deep breaths to keep your blood flowing
- exercise the muscles in your legs regularly, even when you are not walking around.

Ask your cancer specialist for advice if you are worried about your risk of blood clots. They can talk to you about things that can reduce your risk.

We have more information at **macmillan.org.uk/blood-clots**

After treatment

Follow-up for pancreatic cancer

During your treatment, you will usually talk regularly with someone from your cancer team. This may be your cancer doctor or specialist nurse, or another health professional. They can talk to you about what to expect during and after treatment. You can ask about any concerns and needs you have.

You may have a holistic needs assessment to identify your care needs. It can help you to talk about any symptoms, worries or concerns, or practical needs. Your cancer team can make a care plan based on this. It should give information about the support you are getting and other services that may be useful.

> **"My tumour was found in time, and was operable. Although I underwent major surgery and chemotherapy, and have long-standing after-effects, I know how lucky I am to have had such a fortunate outcome."**
>
> Carole, diagnosed with pancreatic cancer

You should get a copy of the care plan to use at follow-up appointments. You can also use it when you see your GP (or other doctors) about anything not related to the cancer. You can update your care plan whenever you need to.

Some hospitals may give you a treatment summary. This describes:

- the treatment you have had
- what to expect from future treatment
- details of follow-up care or tests.

You keep a copy and the hospital should send another one to your GP.

After treatment is finished, you will have regular follow-up appointments. You will also have follow-up appointments if you are having supportive care. You may keep going to the hospital for these appointments, or you may go to your GP. Sharing the appointments between the GP and hospital is sometimes called a shared care agreement.

You may continue to have regular scans and blood tests, including blood tests for CA 19–9. CA 19–9 is a chemical produced by many pancreatic cancers. Tell your doctor or specialist nurse as soon as possible if you have any problems or new symptoms between appointments.

We have more information about these tests at **macmillan.org.uk/pancreatic-cancer**

Many people find they get anxious before appointments. This is natural, and it may help to get support during this time. This can come from family, friends, or support organisations such as Pancreatic Cancer UK (page 116).

> **"I was absolutely terrified for a good 12 months that it would come back. But as time goes on you're not as terrified, just scared then less scared, and you never take your life for granted. „**
>
> Pat, diagnosed with pancreatic cancer

Coping with advanced cancer

Coping with advanced cancer can mean living with doubt and uncertainty. You may worry about:

- your treatment, pain or other symptoms
- losing your independence or mobility
- the effect of the cancer on your family and friends
- how you will cope as the cancer develops.

You may be concerned about practical issues, such as your work or finances. It is understandable and natural to have these concerns.

Uncertainty can be one of the hardest things for you, your family and your friends to deal with. It may cause a lot of tension. You might feel irritable, angry or frightened. These feelings can make it difficult to live life the way you would like to.

It is difficult to make plans when you do not know what is going to happen. You can ask your healthcare team about this. But they may only be able to give you an idea of what will happen, because they do not know for sure.

Many people find they can learn to live with uncertainty. There are some things that can help.

We have more information in our booklets **Managing cancer pain** and **Coping with advanced cancer** (page 110).

Coping with your emotions

You may feel that the cancer has taken over your life.
This is a common reaction. It can be very hard to cope with.
But there are lots of things you can do to help you feel differently:

- You may find it helps to try to keep doing your usual activities.
- You may want to think about what is important to you. This could mean spending time with family, planning a holiday or starting a new hobby.
- You might decide to change your lifestyle. This could be eating healthily, being more physically active or trying complementary therapies.
- Making plans can help you feel more in control.
- You might find knowing more about the cancer and your treatment options also helps you cope. It means you can make a plan with your healthcare team.
- Making decisions and being active in your own care can help you feel more in control.

If you feel you are not coping well, or need more support, talk to your doctor or nurse.

Complementary therapies

Some people find that complementary therapies can reduce symptoms and help them feel better. It is important to discuss your planned therapy with your specialist or GP. This is to check that there are no reasons why you should not have the therapy. If they think certain therapies might interact with your treatment or cause harm, they will advise against having them.

Many hospitals and hospices offer complementary therapies. Treatments may include acupuncture, massage, aromatherapy and relaxation techniques. We have more information in our booklet **Cancer and complementary therapies**.

You can order our booklets and leaflets for free.
Visit **be.macmillan.org.uk** or call us on
0808 808 00 00.

If you live on your own

Living alone can add extra stresses. Even though you may value your independence, being ill may make you feel lonely and frightened.

People who care about you will want to help in any way they can. It is ok to ask for and accept their help.

Some people may be happy to help in practical ways, such as shopping or helping with your garden. You could make a list of practical things that would make your life easier. If people offer to help but are not sure what to do, they can choose to do something from your list.

Other people may be able to talk with and listen to you. This could help you to share your worries and fears.

Marie Curie (page 124) and Age UK (page 123) have free helper services available in parts of the UK. Some hospices may also offer this. Someone can visit you to have a chat over a cup of tea, help you get to an appointment or do a task. Your GP, social worker, local cancer information centre or district or community nurse can also tell you what help and support is available. This might be from health and social care, or voluntary organisations.

Who can help?

Many people are available to help you and your family.

District nurses work closely with GPs and make regular visits to patients and their families at home if needed.

The hospital social worker can give you information about social services and benefits you may be able to claim, such as meals on wheels, a home helper or hospital fares. The social worker may also be able to arrange childcare for you during and after treatment.

In many areas of the country, there are also specialist nurses called palliative care nurses. They are experienced in assessing and treating symptoms of advanced cancer. Palliative care nurses are sometimes known as Macmillan nurses. However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you're at a clinic or in hospital.

Marie Curie nurses help care for people approaching the end of their lives in their own homes (page 124). Your GP or hospital specialist nurse can usually arrange a visit by a palliative care or Marie Curie nurse.

There's also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families.

Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.

Your feelings and relationships

Your feelings

It is common to have many different feelings when you are told you have cancer. You may feel shocked, scared, depressed, guilty or angry. This can be difficult to cope with. Partners, family and friends may also have some of the same feelings.

We have more information about emotions at **macmillan.org.uk/emotions** and in our booklet **How are you feeling? The emotional effects of cancer** (page 110).

Your healthcare team will usually give you support. But you may feel you need more help. Talk to your cancer doctor, GP or specialist nurse. They can refer you to a specialist doctor, psychologist or counsellor who can help.

You can also call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists.

Talking to family, friends or other people affected by cancer may help. For more information or for help finding local support groups, visit **macmillan.org.uk/supportgroups** Or talk to other people on our Online Community at **macmillan.org.uk/community**

There is more information on pages 112 to 115 about other ways we can help you.

> "Cancer was the first thing I thought about when I got up, and the last thing I thought about when I went to bed. When my surgery was finished I went back to work, but mentally I still wasn't in a great place. I eventually got some counselling, and that helped a lot. „

Pat, diagnosed with pancreatic cancer

> **“I did get angry, and think, 'I don't want this.' But I realised that I was going through the process that you go through with a bereavement. And it's because, as I say, life will never be what it was. „**

Derek, diagnosed with pancreatic cancer

Relationships

Cancer and its treatment are stressful and may affect your relationships. Your experience of cancer may strengthen your relationships with people close to you. Or it may put a strain on relationships. Any problems usually improve over time, especially if you talk openly with each other.

We have more information about relationships at **macmillan.org.uk/relationships** and in our booklet **Talking about cancer**.

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You can support the person with cancer by listening and talking with them.

We have more information about supporting someone with cancer at **macmillan.org.uk/supporting-someone** and in our booklet **Talking with someone who has cancer**.

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers in our booklet **Looking after someone with cancer**.

You can order our booklets and leaflets for free. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Talking to children and teenagers

Deciding what to tell children or teenagers about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Use simple, straightforward language to explain what is happening. You can encourage them to talk to someone they trust, who can support them. They may also find support online.

The website **riprap.org.uk** offers information and support for teenagers who have a parent with cancer.

We have more information in our booklet **Talking to children and teenagers when an adult has cancer** (page 110).

Work and financial support

Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. We also have information for carers (page 110).

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- **gov.uk** if you live in England or Wales
- **socialsecurity.gov.scot** if you live in Scotland
- **nidirect.gov.uk** if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to them by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales (page 122) or Advice NI if you live in Northern Ireland (page 121).

We have more infomration in our booklet **Help with the cost of cancer** (page 110).

Macmillan Grants

Macmillan Grants are small, mostly one-off payments to help people with the extra costs that cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing or help paying heating bills, you may be able to get a Macmillan Grant. A grant from Macmillan does not usually affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

To find out more, or to apply, call on **0808 808 00 00** or visit **macmillan.org.uk/grants**

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on **0808 808 00 00**.

We have more information in our booklet **Travel and cancer** (page 110). Our Online Community forum on Travel insurance may also be helpful. Visit **macmillan.org.uk/community**

Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

Your cancer doctor, GP or specialist nurse can help you decide whether you should go back to work, and when.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful. You can also find out more about your employment rights in our booklet **Your rights at work when you are affected by cancer**.

There is also lots more information online at **macmillan.org.uk/work**

You can order our booklets and leaflets for free.
Visit **be.macmillan.org.uk** or call us on
0808 808 00 00.

Further information

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more booklets or leaflets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**

If you would like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

The language we use

We want everyone affected by cancer to feel our information is written for them.

We try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected. Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at **macmillan.org.uk/ourinfo**

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. We can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Our trained cancer information advisers can listen and signpost you to further support. Call us on **0808 808 00 00**. We are open 7 days a week, 8am to 8pm.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to **macmillan.org.uk/talktous**

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call **0808 808 00 00** and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with energy costs

Our energy advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to find out more about Macmillan Grants.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, family member or friend, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

You can also use our Ask an Expert service on the Online Community. You can ask a financial guide, cancer information nurse, work support advisor or an information and support advisor any questions you have.

Macmillan healthcare professionals

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

Pancreatic cancer support organisations

Pancreatic Cancer UK

Support line **0808 801 0707**
www.pancreaticcancer.org.uk
Provides support and information by putting people in contact with each other, and running a discussion forum and nurse-led helpline.

General cancer support organisations

Cancer Black Care

Tel **0208 961 4151**
www.cancerblackcare.org.uk
Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

Cancer Focus Northern Ireland

Helpline **0800 783 3339**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040**
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Cancer Support Scotland

Tel **0800 652 4531**
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices
A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's

Tel **0300 123 1801**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family and friends.

Penny Brohn UK

Helpline **0303 3000 118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Riprap

www.riprap.org.uk
Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

Tenovus

Helpline **0808 808 1010**
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

Emotional and mental health support

Mind

Helpline **0300 123 3393**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**
Email **jo@samaritans.org**
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people in distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**
Textphone **0289 031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Carer's Allowance Unit

Tel **0800 731 0297**
Textphone **0800 731 0317**
www.gov.uk/carers-allowance
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office by contacting:

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

GOV.UK

www.gov.uk
Has information about social security benefits and public services in England, Scotland and Wales.

Jobs and Benefits Office Enquiry Line Northern Ireland

Helpline **0800 022 4250**
Textphone **0800 587 1297**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).

You should be able to find your local council's contact details in your phone book or visit:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

www.wlga.gov.uk/authorities

Macmillan Benefits Advice Service (Northern Ireland)

Tel **0300 123 3233**

Money Advice Scotland

Tel **0141 572 0237**
www.moneyadvicescotland.org.uk
Use the website to find qualified financial advisers in Scotland.

NiDirect

www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.

Northern Ireland Housing Executive

Tel **0344 892 0902**
www.nihe.gov.uk
Offers help to people living in socially rented, privately rented and owner-occupied accommodation.

StepChange Debt Charity

Tel **0800 138 1111**
www.stepchange.org
Provides free debt advice through phone, email, the website and online through live chats with advisers.

Unbiased.co.uk

Helpline **0800 023 6868**
www.unbiased.co.uk
You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

Support for older people

Age UK

Helpline **0800 678 1602**
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030**
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Live Through This

www.livethroughthis.co.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBTIQ+ cancer experiences. LTT runs a peer support group with Maggie's Barts.

Support for carers

Carers Trust

Tel **0300 772 9600**
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline (England, Scotland, Wales) **0808 808 7777**
Helpline (Northern Ireland) **0289 043 9843**
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Advanced cancer and end-of-life care

Hospice UK

Tel **0207 520 8200**
www.hospiceuk.org
Provides information about living with advanced illness. Also provides free booklets and a directory of hospice services in the UK.

Marie Curie

Helpline **0800 090 2309**
www.mariecurie.org.uk
Marie Curie nurses provide free end-of-life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

The Natural Death Centre

Helpline **0196 271 2690**
www.naturaldeath.org.uk
Offers independent advice on aspects of dying, funeral planning and bereavement.

Bereavement support

Cruse Bereavement Care

Helpline **0808 808 1677**
www.cruse.org.uk
Provides bereavement support to anyone who needs it across the UK. You can find your local branch on the website.

Cancer registries

The cancer registry

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

National Cancer Registration and Analysis Service

Tel **0207 654 8000**
www.ndrs.nhs.uk
Tel (Ireland) **0214 318 014**
www.ncri.ie (Ireland)

Scottish Cancer Registry

www.ndrs.nhs.uk/cancer-registration-your-rights-and-privacy

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **02920 104278**
phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu

Northern Ireland Cancer Registry

Tel **0289 097 6028**
www.qub.ac.uk/nicr

Your notes and questions

Your notes and questions

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Chief Medical Editor, Prof Tim Iveson, Consultant Medical Oncologist.

With thanks to: Mr David Chang, Consultant Surgeon; Dr Charlotte Fribbens, Consultant Medical Oncologist; Becky Hart, Clinical Nurse Specialist; Wendy Martin, Senior HPB Clinical Nurse Specialist; Mr Sanjay Pandanaboyana, Consultant Surgeon; Dr Ganesh Radhakrishna, Consultant Clinical Oncologist; and Mr Colin Wilson, Consultant Surgeon.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

Below is a sample of the sources used in our pancreatic cancer information. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

European Society for Medical Oncology. Cancer of the pancreas: ESMO clinical Practice Guidelines. Volume 26. Supplement 5, V56-V68. 1 September 2015. Available from: doi.org/10.1093/annonc/mdv295 (accessed May 2021).

National Institute for Health and Care Excellence. Pancreatic cancer in adults: diagnosis and management. NICE guideline (NG85). Published 7 February 2018. Available from: www.nice.org.uk/guidance/ng85/chapter/Recommendations (accessed May 2021).

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 ways you can help someone with cancer

1. **Share your cancer experience**
   Support people living with cancer by telling your story online, in the media, or face to face.

2. **Campaign for change**
   We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

3. **Help someone in your community**
   A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

4. **Raise money**
   Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

5. **Give money**
   Big or small, every penny helps. To make a one-off donation see over.

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Do not let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

☐ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you would rather donate online go to **macmillan.org.uk/donate**

Registered with
FUNDRAISING
REGULATOR

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

MACMILLAN
CANCER SUPPORT

This booklet is about cancer of the pancreas, which is also called pancreatic cancer. It is for anyone who has been diagnosed with cancer of the pancreas. There is also information for carers, family members and friends.

The booklet talks about the most common type of pancreatic cancer and how it may be treated. It also has information about how to get advice and support about feelings, practical issues and money.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use.

Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app. Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

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