

# 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 people who have been diagnosed with cancer of the pancreas, or are having tests and investigations for it. There is also information for carers, family members and friends.

This booklet gives information about the most common type of pancreatic cancer, how it is diagnosed and treated. It also gives information about controlling symptoms for people with advanced pancreatic cancer. This booklet also has information about the feelings you might experience. You can find practical advice on dealing with work and finances towards the end of the booklet.

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.

We have included quotes from people who have had pancreatic cancer, which you may find helpful. Some are from **healthtalkonline.org**. The others are from people who have chosen to share their story with us. If you would like to share your story, visit **macmillan.org.uk/cancervoices** Or you can visit our Online Community at **macmillan.org.uk/community**

## How to use this booklet

The 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 the opposite page to help you.

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

At the end of the booklet, there are details of other organisations that can help (see pages 141 to 151). There is also space to write any questions or notes you may have for your doctor or nurse (see page 152).

If you find this booklet helpful, you could pass it on to your family and friends. They may want information to help them support you.

## 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 a foreign 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**.

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# CANCER OF THE PANCREAS

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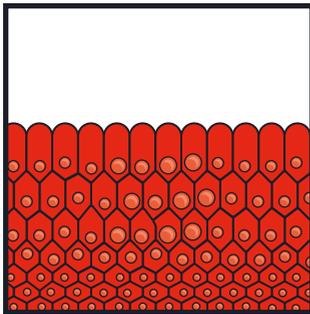
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# What is cancer?

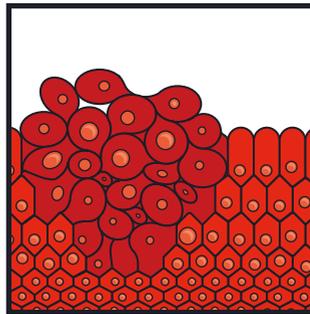
Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or can't be repaired, it gets a signal to stop working and die.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing making more and more abnormal cells. These eventually form a lump (tumour). Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

Normal cells



Cells forming a tumour



A lump that is not cancerous (benign) may grow but cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs.

A lump that is cancer (malignant) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system (see pages 12 to 13). When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary cancer or a metastasis.

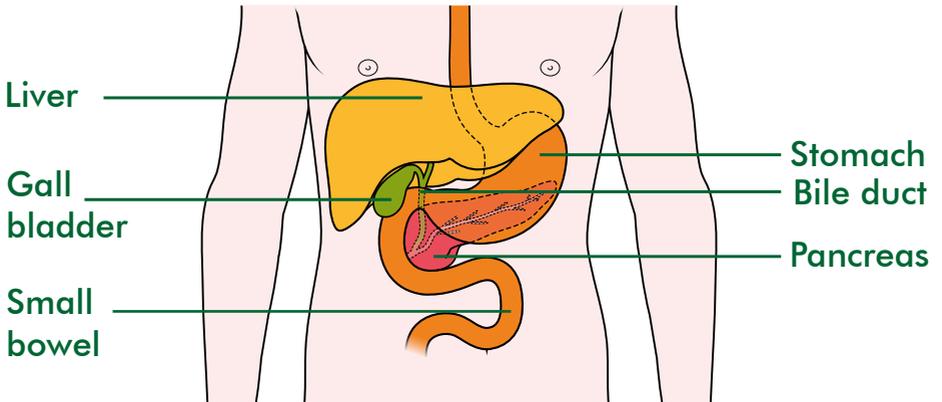
# The pancreas

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 pancreas has three 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.

## The position of the pancreas



## What the pancreas does

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

### Pancreatic juices

Pancreatic juices help the body digest food, especially fats. The juices are made in cells called exocrine cells. Most cells in the pancreas are exocrine cells.

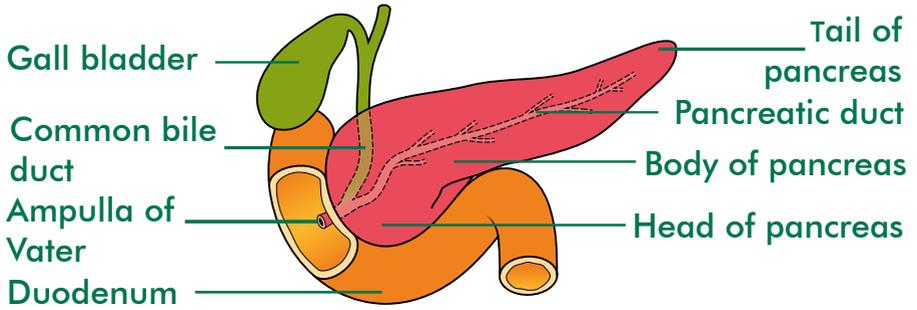
The pancreatic juices travel through small tubes (ducts) in the pancreas into a larger duct. This larger duct is called the pancreatic duct. It joins with the common bile duct, which carries bile from the liver and gall bladder. Together, they empty into the small bowel through an opening called the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

### Insulin

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.

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

## The pancreas

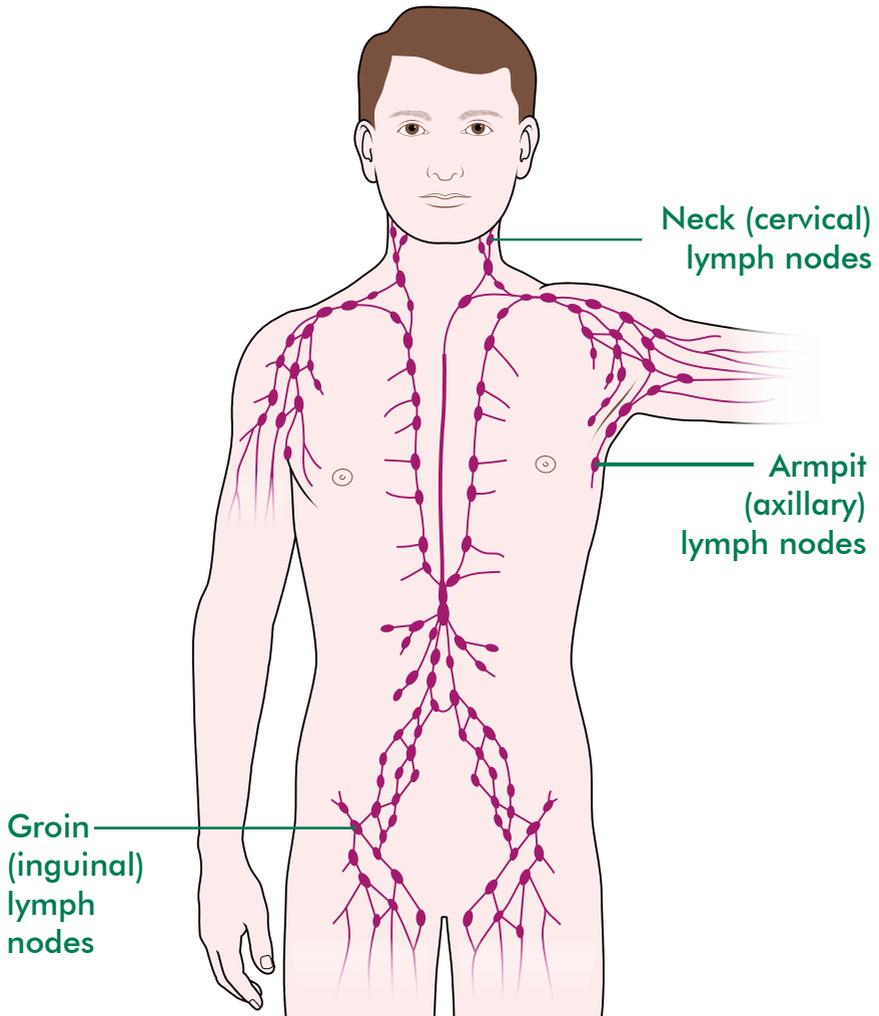


# The lymphatic system

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

Lymph nodes (sometimes called lymph glands) are small and bean-shaped. They filter out bacteria (germs) and disease from the lymph fluid. When you have an infection, lymph nodes often swell as they fight it.

## The lymphatic system



# Types of pancreatic cancer

There are several different types of pancreatic cancer. Pancreatic cancer types are described according to:

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

Cancer can occur 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 (see page 10). 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**. 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 juice
- ampullary cancer – this develops in the ampulla of Vater
- intraductal papillary mucinous neoplasms (IPMN) – these develop in the pancreatic duct and produce mucus.

## 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.

We have more information on neuroendocrine tumours (NETs) on our website [macmillan.org.uk](http://macmillan.org.uk)

## Other rarer pancreatic cancers

There are other rare types of pancreatic cancer:

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

Treatments for cancerous cystic tumours, acinar cell carcinomas and ampullary cancer are similar to those described in our treatment section (see pages 47 to 85). But the tests and treatments for neuroendocrine tumours, non-Hodgkin lymphoma, pancreatoblastoma and sarcoma of the pancreas may be different.

We have more information about these cancer types (see page 136).

# Symptoms of pancreatic cancer

Pancreatic cancer may not cause symptoms for a long time. Some people may have only one symptom.

## **Pain or discomfort**

This often begins in the upper part of the tummy (abdomen). Sometimes, it spreads to the back. The pain may come and go, or it may be there all the time. It may feel worse after eating or when you are lying down. It might feel better when you are sitting up or bending forward.

Remember, cancer is not the cause of most pain in the abdomen. But you should see your doctor if you are worried.

## **Jaundice**

If the cancer is in the head of the pancreas, it can block the bile duct. This means you may develop jaundice. Cancer in the tail or body of the pancreas is less likely to cause jaundice.

Jaundice happens when bile cannot drain away, but collects in your body. This can cause symptoms such as:

- yellowing of the skin and the whites of the eyes
- itchy skin
- dark yellow pee (urine)
- pale and smelly poo (stools) that is difficult to flush away (steatorrhoea).

Pancreatic cancer is not the most common cause of jaundice. Other illnesses, affecting the liver and bile duct, are more common.

## Weight loss

This is common and may happen even if you have not changed what you eat.

## Feeling sick

You may feel sick or be sick if you have jaundice, or if the pancreas is inflamed and swollen.

'Up until about a month before, I thought I was fit and well. I first had back pain, then abdominal pain that got increasingly worse, and pain when I ate.'

**Alison**

## Other symptoms

Pancreatic cancer can cause other symptoms, such as:

- losing your appetite
- having indigestion
- feeling bloated after meals
- having diarrhoea or changing bowel habits
- feeling very tired
- being newly diagnosed with diabetes
- getting a blood clot in the leg (deep vein thrombosis or DVT) or the lungs (pulmonary embolus).

Most people with these symptoms will not have pancreatic cancer. More common conditions can be causing them. But if you have any symptoms, it is important to get them checked by your doctor.



# Risk factors and causes

About 9,600 people are diagnosed with pancreatic cancer in the UK each year.

We do not know what causes pancreatic cancer. But things called risk factors can increase the chance of a person developing it. Having one or more risk factors does not mean you will definitely get pancreatic cancer. And if you do not have any risk factors, you may still develop cancer of the pancreas.

## Age

The risk of developing pancreatic cancer increases with age. It mainly affects people of middle and older age. Most people who develop pancreatic cancer are 65 or older. It is rare in people under 40.

## Smoking and tobacco

About 3 in 10 pancreatic cancers in the UK (30%) may be due to smoking cigarettes, cigars, and pipes. People who chew tobacco or use other smokeless tobacco products (such as snuff) also have an increased risk. Stopping smoking will help reduce the risk.

The NHS has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live.

## Diet

Eating lots of red or processed meat may increase the risk of pancreatic cancer. Processed meats include ham, sausages, bacon and burgers.

Having a diet high in fat and sugar, but low in fresh fruit and vegetables, can also increase the risk.

## Alcohol

Drinking a lot of alcohol regularly may increase the risk of developing pancreatic cancer. The risk is even higher for people who also smoke.

## Body weight and physical activity

Some studies have found that being overweight or obese, and physically inactive, may increase the risk of pancreatic cancer.

## Previous cancer

Pancreatic cancer is slightly more common in people who have had cancer before. Studies are looking at what may be causing this. It could be because of:

- previous cancer treatment
- a genetic link
- lifestyle factors, including diet or smoking.

## Family history

Most people with pancreatic cancer have no history of pancreatic cancer in their family. But about 1 in 10 pancreatic cancers (10%) may be linked to faulty genes that run in families. You may be at higher risk if you have any of these factors:

- You have two or more first-degree relatives that have pancreatic cancer. First-degree relatives are your parents, brothers, sisters and children.
- Some family members have the breast cancer gene BRCA2.
- Some family members have the condition Lynch syndrome/ HNPCC (hereditary non-polyposis colorectal cancer).
- Some family members have a large number of unusual moles (FAMMM – Familial Atypical Multiple Mole Melanoma).
- You have a condition called Peutz-Jeghers syndrome (PJS). This causes multiple growths (polyps) in the stomach and bowel. It also causes dark spots on the skin on the face and hands.

If your family history includes any of the above, you can be referred to a specialist clinic. They can give you advice and assess you. They may offer you regular screening tests to try to find the cancer early if it develops. Doctors are still researching the best way to screen for pancreatic cancer. You may be offered screening as part of a cancer research trial (see pages 58 to 59).



## Medical conditions

Some other conditions can increase your risk of pancreatic cancer.

### Chronic pancreatitis

People who have a condition called chronic pancreatitis are more likely to develop pancreatic cancer. Chronic pancreatitis means the pancreas is inflamed, tender and swollen over a long period of time. The risk is higher with chronic pancreatitis because of a rare inherited condition called hereditary pancreatitis. Inherited conditions are passed down through family members.

### Diabetes

Diabetes is linked to cancer of the pancreas. But it is not clear whether diabetes causes the cancer, or whether it is an early symptom. Diabetes is common and most people with diabetes will not develop pancreatic cancer.

We have more information in our booklet **Diabetes and cancer treatment** (see page 136).

## Infections

Some infections have been linked to a higher risk of developing pancreatic cancer. But the evidence supporting these links is weak. Many people have these infections and do not develop pancreatic cancer.

Studies have shown there may be a link between pancreatic cancer and an infection of the liver, called hepatitis B. Other research suggests there may be a link to tooth or gum disease. Researchers think a type of bacteria causes this.

*Helicobacter pylori* (*H. pylori*) is a common stomach infection that causes the stomach lining to become inflamed. There may be a link between *H. pylori* and a higher risk of pancreatic cancer, particularly in men. But the risk of stomach cancer is higher than the risk of pancreatic cancer.

Like all cancers, pancreatic cancer is not infectious. You cannot pass it on to other people.



# DIAGNOSING CANCER OF THE PANCREAS

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# How cancer of the pancreas is diagnosed

If you have symptoms, you usually begin by seeing your GP. They will examine you and look at your eyes and the colour of your skin. This is to check for jaundice (yellowing of the skin and whites of the eyes) – see pages 16 to 17. They may test your urine (pee) for bile and take some blood samples. They may also examine your tummy (abdomen) for swelling in the liver area. They will ask if you have noticed any changes in your poo (stools) or weight.

If your GP thinks cancer could be causing your symptoms (see page 16 to 18) they will refer you to hospital. At the hospital, you will have tests and get specialist advice and treatment. GPs have guidelines that help them know when to refer people to a specialist.

If you are aged 60 or older, your doctor may refer you urgently. They may arrange an urgent CT scan or ultrasound within 2 weeks.

If you are aged 40 or older and have jaundice, you should see a specialist within 2 weeks.

Sometimes, people are diagnosed with pancreatic cancer after being admitted to hospital because a symptom is making them unwell.

## At the hospital

The doctor will ask about your general health and any previous medical problems. They will then examine you and talk to you about the tests you need.

To diagnose you, doctors often use information from several tests, along with your symptoms and medical history. Sometimes, other medical conditions can give similar results. This makes it difficult to confirm whether cancer is the cause.

If you are diagnosed with pancreatic cancer, you may need more tests. These are to find out the size and position of the cancer. They will also let doctors know whether it has spread to other parts of the body.

## Blood tests

You will need to give blood samples to check your general health. They will also show how well your liver and kidneys are working.

Your doctor might also test for tumour markers. These are chemicals that can show up in the bloodstream. Many pancreatic cancers produce a tumour marker called CA 19-9. But some people who have pancreatic cancer do not have raised levels of CA 19-9. So if you have a normal level of CA 19-9, you could still have pancreatic cancer. Also, other conditions, such as jaundice that has not been caused by cancer, may cause high levels of CA 19-9. Doctors will consider these things when looking at the test results.

Doctors may measure your level of CA 19-9 during treatment and follow-up. This is to see how the pancreatic cancer is responding to treatment.

## Ultrasound scan

Ultrasound scans use sound waves to make a picture of internal organs, like the pancreas and liver. This test does not hurt and only takes a few minutes. You will have the scan in the hospital scanning department. Usually, you should not eat or drink anything for a few hours before the test.

You will lie comfortably on your back. A gel is spread on the skin over the area that will be scanned. A small device that makes sound waves is passed over the area. The computer then uses the sound waves to make a picture of the area.

## CT scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10 to 30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least 4 hours before the scan.

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It is important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to the injection.

You will probably be able to go home as soon as the scan is over.

## Having a CT scan



## Biopsy

Taking a small piece of tissue or a sample of cells from a tumour is called a biopsy. A biopsy may happen during an EUS or an ERCP (see pages 33 and 36). The biopsy is then looked at under a microscope.

To get a sample of cells, the doctor might insert a needle through the skin and into the tumour. This is called a **percutaneous biopsy** or **fine needle aspirate (FNA)**.

The doctor injects a local anaesthetic into the skin to numb the area first. They then guide the needle through the skin and into the tumour. This is to take (aspirate) a sample of cells. They are able to guide the needle using images from an ultrasound or CT scan.

The doctor will send the sample of cells to a laboratory to test for cancer. To help make an accurate diagnosis, they sometimes repeat the biopsy.

## Endoscopic ultrasound (EUS)

If your doctor finds a tumour, they may do an endoscopic ultrasound (EUS). This is to measure its size and see whether it has spread. They may also take samples of tissue (biopsies) from the tumour during the EUS.

You should not eat or drink anything for about 6 hours before the test. This is so your stomach and duodenum are empty. The duodenum is the first part of the small bowel. Your doctor or nurse will give you an injection to help you relax (a sedative). They will also spray local anaesthetic on to the back of your throat.

The doctor passes a thin, flexible tube (an endoscope) down your throat, into your stomach and then into your duodenum. An ultrasound probe is attached to the end of the endoscope. The probe produces a picture of the pancreas and other organs on a screen.

Most people are ready to go home a couple of hours after this test. It is a good idea to arrange for someone to collect you from the hospital. This is because you should not drive for 24 hours after having a sedative.

*'The thought of an endoscopy terrified me to be honest. But when I was given the sedative, it was a case of "have you done it yet?", and they had.'*

**Rani**

## MRI scan

This test uses magnetism to build up a detailed picture of areas of your body. The scanner is a powerful magnet so you may be asked to complete and sign a checklist to make sure it is safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins, etc.

You should also tell your doctor if you have ever worked with metal or in the metal industry as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body, it is likely that you will not be able to have an MRI scan. In this situation, another type of scan can be used. Before the scan, you will be asked to remove any metal belongings including jewellery.

Some people are given an injection of dye into a vein in the arm, which does not usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly. During the test, you will lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It is painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It is also noisy, but you will be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.

## MRCP (magnetic resonance cholangio-pancreatography)

This test uses magnetic and radio waves to get a detailed picture of your pancreas, bile ducts and liver. It is a type of MRI scan, but is not available in every hospital. You will have to lie still inside the MRI scanner for around 30 minutes. The scan shows any narrowing or blockages in the pancreatic ducts or bile ducts. But the scan cannot take biopsies.

### Preparing for an MRI scan



## ERCP (endoscopic retrograde cholangio-pancreatography)

For this test, the doctor passes a thin, flexible tube called an endoscope into your mouth. This goes down into your stomach and into the first part of the small bowel (duodenum). It allows the doctor to look at the pancreas and take a biopsy from a tumour (see page 32). An ERCP can also unblock the bile duct (see page 92).

You should not eat or drink anything for 6 hours before the procedure. This is so your stomach and duodenum are empty. The doctor or nurse will give you a sedative to make you feel relaxed and sleepy. They will also use a local anaesthetic spray to numb your throat. Sometimes, doctors do this test under general anaesthetic (while you are asleep).

Your doctor will look down the endoscope. This helps them find the openings where the bile duct and the pancreatic duct drain into the duodenum. This area is called the ampulla of Vater (see page 11). They can inject a dye into these ducts that will show on x-rays. This helps them find any abnormalities or blockages.

If there are any abnormal areas, the doctor will take a biopsy. They will then send the biopsy to the laboratory to be examined under a microscope. They may put a small brush down the endoscope and take biopsies from the tumour. They will then send the brush with the cells on it to a laboratory, to be tested for cancer.

## Laparoscopy

If other tests have not confirmed a diagnosis of pancreatic cancer, you may have a laparoscopy. You may also have this if you are going to have surgery to remove the cancer. It is a small operation that allows doctors to look at the pancreas and other organs in the tummy. They can see whether an operation to remove the cancer is possible. You will have a laparoscopy under general anaesthetic. This means you will have a short stay in hospital.

The doctor makes a small cut (incision) near the belly button. They then insert a thin tube (called a laparoscope) into your tummy. It has a tiny camera and light on the end, so doctors can look at the pancreas and surrounding tissues. They may also take a biopsy to look at in a laboratory, under a microscope.

To make it easier to see the pancreas, the doctor will pump gas into the abdomen. The gas can cause uncomfortable wind and shoulder pains for several days afterwards. Walking around or sipping peppermint water can help give you relief. After the laparoscopy, you will have one or two stitches in your abdomen.

'I wanted to know every tube that was going to go into my body and what to expect after the operation. It didn't scare me. I felt empowered because I knew what was going to be happening.'

**Helen**

## Laparotomy

If a laparoscopy is not suitable for you, a surgeon may do a laparotomy. You might need this if other tests have not given a diagnosis. But it is rarely needed, as most people can have a laparoscopy.

A laparotomy is an operation to look inside the tummy. It happens under general anaesthetic. The surgeon makes a larger cut into your tummy, so they can see the pancreas.

## PET-CT scan

This is a combination of a CT scan, which takes a series of x-rays to build up a three-dimensional picture (see page 30), and a positron emission tomography (PET) scan. A PET scan uses low-dose radiation to measure the activity of cells in different parts of the body.

PET-CT scans give more detailed information about the part of the body being scanned. You may have to travel to a specialist centre to have one. You cannot eat for six hours before the scan, although you may be able to drink. A mildly radioactive substance is injected into a vein, usually in your arm. The radiation dose used is very small. You will wait for at least an hour before you have the scan. It usually takes 30 to 90 minutes. You should be able to go home after the scan.

## Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, family listed on pages 141 to 151, can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.



# 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.

The staging systems most commonly used are:

- the number staging system
- TNM staging.

## Number staging

A common staging system uses numbers to describe the stage of the cancer.

### Stage 1

This is the earliest stage. The cancer is contained inside the pancreas. But it may be quite large. There is no cancer in the lymph nodes (see page 12 to 13) close to the pancreas. There is also no sign that it has spread anywhere else in the body.

Stage 1 is divided into two:

- **Stage 1A** – The cancer is smaller than 2cm.
- **Stage 1B** – The cancer is bigger than 2cm.

## Stage 2

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

Stage 2 is divided into two:

- **Stage 2A** – The cancer 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. It is in the lymph nodes but not blood vessels.

Doctors often call stages 1 and 2 resectable or early-stage cancer. Resectable means a surgeon may be able to operate to remove (resect) the tumour. About 2 in 10 cancers of the pancreas (21%) are diagnosed at stages 1 and 2.

## Stage 3

The cancer has spread to large blood vessels near the pancreas and may have spread to 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**. Usually, surgery is not possible for this stage. It is sometimes called unresectable cancer.

Occasionally, a person with stage 3 cancer may be able to have surgery to try to remove the cancer. It will depend on what blood vessels are involved. This is called **borderline resectable** cancer.

## 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 pancreatic cancers (79%) are diagnosed at stages 3 and 4.

## TNM staging

In the TNM staging system, TNM stands for tumour, nodes and metastases.

- **T** describes the size of the tumour and whether it has grown into nearby tissues or organs.
- **N** describes whether the cancer has spread to the lymph nodes and which nodes are involved.
- **M** describes whether the cancer has spread to another part of the body. These include the liver or lungs (secondary or metastatic cancer).

# 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.

## Grade 1 (low-grade)

The cancer cells tend to grow slowly and look similar to normal cells (they are well differentiated). These cancers are less likely to spread than higher grade cancers.

## Grade 2 (moderate-grade)

The cancer cells look more abnormal.

## Grade 3 (high-grade)

The cancer cells tend to grow more quickly and look very abnormal (they are poorly differentiated). These cancers are more likely to spread than low-grade cancers.



# 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. You can find more information at [macmillan.org.uk/cancerregistry](https://www.macmillan.org.uk/cancerregistry)



# TREATING CANCER OF THE PANCREAS

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# How treatment is planned

In most hospitals, a team of specialists called a multidisciplinary team (MDT) will meet to discuss your treatment. After the meeting, your specialist will talk to you about the types of treatment you may be able to have.

The MDT will include:

- a **surgeon** who specialises in treating pancreatic cancer
- **oncologists** – doctors who treat cancer with chemotherapy (see page 75) and other cancer drugs, and radiotherapy (see pages 82 to 83)
- a **pathologist** – a doctor who specialises in looking at cells under a microscope for signs of disease or cancer
- a **radiologist** – a doctor who reads x-rays and scans
- an **endoscopist** – a doctor who does the endoscopy, EUS or ERCP (see pages 33 and 36)
- a **specialist nurse** who can give information and support.

We have more information on the tests and scans mentioned above in the diagnosis section (see pages 28 to 39)

The MDT may also include other healthcare professionals, such as:

- a dietitian
- a physiotherapist
- an occupational therapist
- a palliative care doctor or nurse who specialises in symptom control and supportive care
- a psychologist or counsellor.



# Types of treatment

Surgery, chemotherapy and radiotherapy are all possible treatments for pancreatic cancer. These treatments are explained further in this section of the booklet. If you want to know more about these treatments, we have more general information available (see page 136).

People with pancreatic cancer often have treatments to control symptoms and make them feel more comfortable. This is known as supportive care (see page 87).

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 (see pages 58 to 59).

The treatment you have depends on the stage, grade and position of the cancer (see pages 40 to 43). It also depends on your general health and 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 plan of treatment. 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.
- If it is **borderline resectable**, an operation may be possible.
- If the cancer is **unresectable**, it means it has spread into nearby blood vessels (locally advanced) or to other parts of the body (metastatic).

## Resectable cancer

Surgery is the most effective treatment for early-stage pancreatic cancer (see pages 60 to 74). 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 a small number of people who are fit enough. You can only have surgery if the cancer is small and has not already spread.

You may have chemotherapy before surgery to shrink the tumour (see pages 75 to 81). This can also reduce the risk of the cancer cells spreading. This is called neoadjuvant treatment. You may have the treatment as part of a cancer research trial.

You might also have radiotherapy after surgery (see pages 82 to 85), to lower the chances of the cancer coming back. This is called adjuvant treatment.

## Borderline resectable cancer

Sometimes, the cancer spreads to 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 (a clear margin). If this is not possible, the risk of the cancer coming back is high.

You may have chemotherapy first to shrink the tumour. The surgeon then decides if they can remove the cancer along with a clear margin. Only a small number of people can have surgery in this situation. Otherwise, you will continue to have chemotherapy.

## Locally advanced (unresectable) cancer

Chemotherapy is the main treatment if the cancer has begun 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.

An operation is unlikely to be helpful if it is not possible to completely remove the cancer. However, you may have surgery to relieve symptoms. For example, this may be if the cancer is blocking the bile duct or the bowel (see pages 92 to 93).

## Metastatic or advanced cancer

If the cancer is advanced, 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.

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

You may need to have a stent (see pages 90 and 93). This will relieve jaundice or other symptoms caused by a blocked bile duct or bowel. To control any pain, you may have radiotherapy, painkillers and nerve blocks (on their own or combined). This is called supportive care (see pages 87 to 101).

# Talking about your treatment plan

After the MDT meeting, your cancer specialist or nurse will talk to you about your treatment options.

They will explain the main aims of treatment. These may be to try to cure the cancer, to help you live longer or to relieve symptoms. They will also tell you the possible short-term and long-term side effects of the treatments.

You and your cancer team will usually decide together which treatments are right for you. Cancer specialists have expert knowledge of the treatments. But you know your situation, beliefs and preferences.

If one treatment has been shown to work best, most people are happy for their cancer doctor to guide them. But there can be times when your treatment choice will depend on your preferences.

Sometimes, a cure is not possible and the aim of the treatment is to control the cancer. It may be more difficult in this situation to decide what to do. You may need to discuss this in detail with your doctor. If you choose not to have the treatment, you can have supportive (palliative) care. This will control any symptoms you may have.

## Making treatment decisions

When making treatment decisions, it is important to talk to your cancer team. It can help to make a list of the questions you want to ask them. You can take this to your next appointment. It is also helpful to have a relative or close friend with you at appointments. You may choose to keep notes about what has been said. You can use page 152 to write any questions or notes.

Our booklet **Making treatment decisions** has more information (see page 136).

## Giving consent

Before you have any treatment, your doctor will explain its aims. They will ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment.

No medical treatment can be given without your consent.

Before you are asked to sign the form, you should be given full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you don't understand what you've been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it's not unusual to need repeated explanations.

It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

People sometimes feel that hospital staff are too busy to answer their questions, but it's important for you to know how the treatment is likely to affect you. The staff will be willing to make time for your questions. You can always ask for more time if you feel that you can't make a decision when your treatment is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you don't have it. It's essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You don't have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.

## Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion.

Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you.

You may also find it helpful to have a list of questions ready so that you can make sure your concerns are covered during the discussion.



# Research – clinical trials

Cancer research trials are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials. These may be carried out to:

- test new treatments, such as new chemotherapy drugs or targeted therapies
- look at new combinations of existing treatments, or change the way they are given to make them more effective or reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- find out which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different type of surgery, chemotherapy, hormone therapy, radiotherapy, or other treatment is better than what is already available. You will find more information on these treatments in this section of the booklet.

We have more information on the treatments mentioned above, and about cancer research trials (see page 136).

## Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments. You will be carefully monitored during and after the study.

Usually, several hospitals around the country take part in these trials. It's important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments or to have side effects that outweigh the benefits.

If you decide not to take part in a trial, your decision will be respected and you don't have to give a reason. However, it can help to let the staff know your concerns so that they can give you the best advice. There will be no change in the way that you're treated by the hospital staff, and you'll be offered the standard treatment for your situation.

# Surgery

If you have early-stage pancreatic cancer, you may have an operation (called a resection) to remove it.

You may also have surgery to relieve symptoms if the cancer is blocking the bile duct or the bowel (see pages 93 to 94).

## Surgery to remove the cancer

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

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

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

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

We describe the different types of operations on pages 61 to 65.

## Pylorus-preserving pancreato-duodenectomy (PPPD)

In this operation, the surgeon removes:

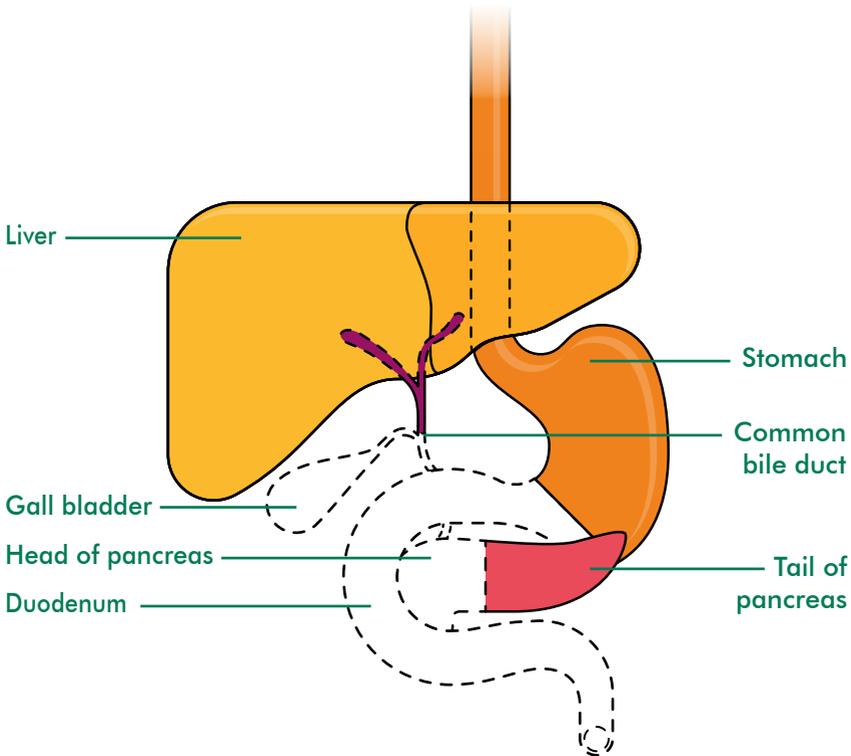
- the head of the pancreas (see illustration on page 11)
- most of the first part of the small bowel (duodenum)
- the common bile duct
- the gall bladder
- the surrounding lymph nodes.

It is also called a **modified Whipple's operation**. A PPPD is commonly used for people with cancer in the head of the pancreas.

## Pancreato-duodenectomy

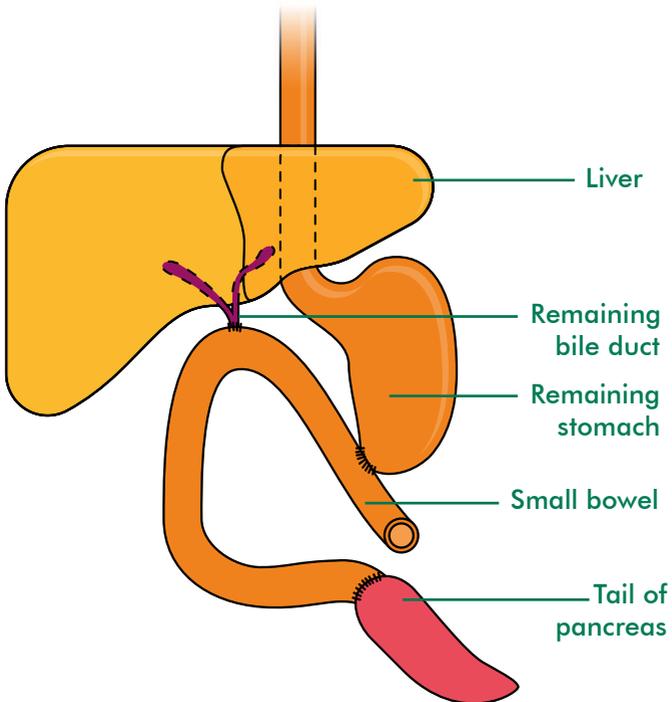
This is similar to a PPPD operation. But the surgeon will also remove the lower part of the stomach. It is also called a **Whipple's operation**.

### A Whipple's operation



The sections in white are parts removed during a Whipple's operation.

## After a Whipple's operation



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

## **Distal pancreatectomy**

This involves removing 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 is part of the lymphatic system (see page 12 to 13).

## **Total pancreatectomy**

Your surgeon will remove the whole pancreas. They will also remove:

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

This is a major operation and is rare.

## Keyhole (laparoscopic) surgery

In some specialist centres, the surgeon may do keyhole (laparoscopic) surgery. This can be used for a distal pancreatectomy (see page 64). Instead of one large cut (incision), the surgeon will make several small cuts. They use a special instrument called a laparoscope to see into and work inside the tummy (abdomen).

A small number of hospitals do keyhole surgery using robotic equipment. The camera on the end of the laparoscope gives a three-dimensional 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 a small wound. This means you usually recover quicker. This operation is not available in many hospitals and is not suitable for everyone.

Only surgeons who specialise in both pancreatic cancer and laparoscopic procedures can do keyhole surgery.

## Before surgery

If you smoke, try to give up or smoke less before your operation. This will lower your risk of chest 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 our booklet **Giving up smoking** useful (see page 136).

You will go to a pre-assessment clinic for 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.

Tell your nurse as soon as possible if you think you may need help when you go home after surgery. This may be because you live alone or care for someone else. 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. They will 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 stop 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 an intensive care or high-dependency unit for a few days after their operation. This is routine and does not mean your operation went badly or had complications. It is also usual in some hospitals for a machine (ventilator) to help you breathe for a few hours. You will probably feel quite drowsy and may not remember much about the first days after your operation.

The nurses 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. The nurses will encourage you to do regular leg movements and deep breathing exercises. A physiotherapist or a nurse can explain these to you.

## 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 (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 (catheter). This will drain urine from your bladder 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.

Painkillers can also be given through a tube into a vein in your hand or arm (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

Straight after the operation, you will not be able to eat or drink. Until you can, you will have fluids through a drip. Some people have extra nutrition through the drip. Or you may have a feeding tube (NG tube). This is passed through the nose and into the stomach.

You can usually 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.

## Wound care

The surgeon will close the wound with stitches, clips or staples. The stitches are usually removed 10 to 14 days after the operation. Your practice nurse can do this if you have gone home. If you cannot leave home, a district nurse can visit you.

You may have antibiotics to help prevent wound infection. You will have a dressing covering your wound. This may be left undisturbed 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, 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 (see pages 75 to 81) or radiotherapy (see pages 82 to 85).



## Replacing insulin and digestive juices

### Insulin injections

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 need to have insulin injections. This is usually only until the remaining pancreas recovers and starts to make insulin again.

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 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.

We have more information in our booklet **Diabetes and cancer treatment** (see page 136).

## Digestive juices

You may need to replace the digestive juices (enzymes) that the pancreas normally makes. This will depend on the type of operation you have had. Your surgeon or nurse or a 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, look pale and smell bad. 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 every time you eat or have a milky drink. Your nurse or a dietitian will explain how to take the capsules. You will need to take the capsules for the rest of your life.

Commonly used pancreatic enzyme replacement therapy drugs are:

- Creon®
- Nutrizym®
- Pancrease®
- Pancrax®.

Most replacement enzymes are made from pork. It is also possible to get enzymes from beef. Vegetarian based 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 (see pages 60 to 74), to reduce the chance of the cancer coming back (called adjuvant chemotherapy)
- if surgery is not possible, to shrink the cancer, relieve symptoms and prolong life (called palliative chemotherapy)
- to shrink a cancer before surgery (called neoadjuvant chemotherapy) – you may have this as part of a cancer research trial (see pages 58 to 59).

Sometimes, you may have chemotherapy with radiotherapy. This is called chemoradiation. If you have chemotherapy with radiotherapy before surgery, it is called neoadjuvant chemoradiation. This would usually be part of a cancer research trial. Your doctor or specialist nurse can give you more information about chemoradiation.

*'I started chemotherapy quite quickly. I was very lucky. I carried on life very much as normal. I lost my hair and lost a bit of weight. Now, I just have to go in every two months for maintenance.'*

**Alan**

## Chemotherapy after surgery

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

The most commonly used chemotherapy drugs are:

- gemcitabine (Gemzar®)
- capecitabine (Xeloda®).

You may have these together (called GemCap) or separately.

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

We have more information about chemotherapy drugs on our website [macmillan.org.uk](http://macmillan.org.uk)

### 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 half an hour 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.

## Chemotherapy for advanced pancreatic cancer

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

- gemcitabine on its own
- gemcitabine and capecitabine (GemCap)

gemcitabine and nab-paclitaxel (Abraxane<sup>®</sup>)

- a combination of drugs called FOLFIRINOX.

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

## Gemcitabine and nab-paclitaxel (Abraxane<sup>®</sup>)

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.



Having chemotherapy

## FOLFIRINOX

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

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

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

FOLFIRINOX can cause more side effects because it contains three chemotherapy drugs. So 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.

## Other drugs

Other drug combinations or new drugs may be used to treat pancreatic cancer. Sometimes, this will be as part of cancer research trials (see pages 58 to 59).

Cancer research trials are also looking at treatments called targeted therapies and immunotherapy. Targeted therapy drugs interfere with the way cancer cells grow. Immunotherapy tries to trigger the body's immune system to attack cancer cells. The body's immune system fights infection and disease. We have more information about targeted therapies and immunotherapy on our website [macmillan.org.uk](http://macmillan.org.uk)

Cancer research trials aim to improve the results of treatment 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 cannula
- a PICC line
- a central line
- an implantable port.

There are three videos about chemotherapy on our website [macmillan.org.uk/chemotherapy](http://macmillan.org.uk/chemotherapy) They show people having treatment inside a treatment centre and some of the different health professionals you will see. There are also two animations that show how PICC lines and central lines are put in.

## 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 tends to cause more severe side effects than single chemotherapy drugs. You can talk to your doctor or nurse about what to expect from your treatment.

We have more information about the side effects of chemotherapy (see page 136).

'Starting chemotherapy made me anxious, but it wasn't as bad as my imagination had led me to believe. Generally, during the three days following treatment, I had most side effects. But it would vary from day to day.'

**Carole**

# Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells, while doing as little harm as possible to normal cells.

Radiotherapy is not used as often as surgery or chemotherapy. 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 (called chemoradiation). This aims to shrink the cancer and control it for as long as possible. You may be offered radiotherapy as part of a cancer research trial (see pages 58 to 59).

You may also have radiotherapy to relieve symptoms that the cancer is causing. 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. So it is less likely to cause side effects.

You may also have stereotactic radiotherapy. This is a specialist way of giving radiotherapy, using a specially adapted radiotherapy machine. The machine delivers beams of radiotherapy from many different angles, which overlap at the tumour. This means the tumour gets a high dose of radiotherapy, but surrounding tissues get a low dose. We have more information about stereotactic radiotherapy on our website **[macmillan.org.uk](http://macmillan.org.uk)**

You will have radiotherapy in the hospital radiotherapy department. How you will have the treatment depends on your needs. Sometimes, a single treatment is all that 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.

We have more general information about radiotherapy on our website [macmillan.org.uk/radiotherapy](https://www.macmillan.org.uk/radiotherapy)

## Planning your radiotherapy

Radiotherapy must be carefully planned to make sure it is as effective as possible. A cancer specialist (clinical oncologist) will plan your radiotherapy. They may need you to visit a few times to do this properly.

On your first visit to the radiotherapy department, you will have a CT scan (see page 30). Your clinical oncologist will use this scan to design your radiotherapy treatment. Sometimes, they may ask you to lie under a machine called a simulator. The simulator will take x-rays of the area that needs treatment.

A radiographer will give you the treatment. You may need some small marks on your skin so the radiographer can position you accurately for treatment. The marks must stay visible throughout your treatment, so often these are like tiny tattoos. These are very small and you will need to give permission before having them. This may be a bit uncomfortable, but it is usually quick.



Preparing for radiotherapy

## 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 radiotherapy with chemotherapy (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.



# SUPPORTIVE CARE

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Controlling symptoms

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# Controlling symptoms

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

Chemotherapy (see pages 75 to 81) and radiotherapy (see pages 82 to 85) 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 known as supportive care.

Your GP or cancer specialist will refer you to a palliative care team. 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 the symptoms of cancer and coping with advanced cancer (see page 136).

## 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 promptly. Your medical team will work with you to find the best way to manage the pain

Our booklet **Managing cancer pain** has more information (see page 136).

### 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.

### Cancer treatments

Cancer treatments such as chemotherapy or radiotherapy can relieve pain. They work by shrinking the cancer to reduce any pressure 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:

- a nerve block
- relaxation techniques
- breathing exercises
- massage
- distraction techniques.

## Jaundice

If cancer blocks the bile duct (see pages 9 and 11), 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 an ERCP (see page 36).

You should not eat or drink anything for 6 hours before the procedure. You will have an injection to make you feel relaxed. The doctor will pass 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 (see illustration on page 11). Doctors then place the stent into the opening of the bile duct. The stent will keep 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. Once you are lying 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. Once 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.

The surgeon will make a cut in the bile duct (or occasionally the gall bladder) just above the blockage. They will 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 (see page 37).

'It's marvellous because the jaundice starts to disappear and the yellowness starts to fade. My rash stopped forming and I no longer felt very itchy. So it's a great relief.'

**Tony**

## A 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).

### Bypass surgery

An operation to bypass the blockage can help. 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. This operation may happen at the same time as an operation to relieve a blocked bile duct.

### Stents

If surgery is not possible, an expandable, flexible tube called a stent can often 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 (see page 33). You should not eat or drink for about 6 hours before the procedure. You will have an injection to help you to relax. 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.

## Tiredness (fatigue)

Many people with pancreatic cancer feel tired (fatigued). They have less energy to do the things they 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. Often, friends and relatives want to help and are 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. So 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.

We have more information in our booklets **Coping with fatigue** and **Physical activity and cancer treatment** (see page 136).

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 from you 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 about depression in our booklet **How are you feeling?** and on our website (see page 136).



## 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.

'I keep an eye on what I eat. I get a bit more tired, but I sometimes have an afternoon nap. I cycle and swim, but I've never pushed myself. It was a gradual process.'

**Kurran**

## Loss of appetite and weight loss

Pancreatic cancer can cause problems with eating and digestion. If your pancreas is not working properly, you may not be able to digest fats and proteins. 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. Your doctor may prescribe tablets to help you digest food.

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 three large meals.

If your appetite is not good, medicines such as steroids 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 about coping with eating problems and preventing weight loss (see page 136).



## 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 steroids for you to take. These can help relieve sickness and make you feel more energetic. They can also improve your appetite.

We have more information about controlling nausea and vomiting (see page 136). We also have information about steroids on our website ([macmillan.org.uk](http://macmillan.org.uk)).

## Ascites

If the cancer has spread to the liver, fluid can sometimes collect between the two layers of the peritoneum. The peritoneum is a membrane that lines the tummy (abdomen). 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 building up of fluid.

We have more information about ascites on our website ([macmillan.org.uk](http://macmillan.org.uk)).

## Itching

Sometimes, when people are jaundiced, bile salts are deposited in the skin. This causes itching. Having frequent showers can wash off the bile salts and provide relief. Try to avoid soaps that dry your skin. They may increase itching. You may find moisturising lotions helpful. Your doctor can also prescribe medicines to help relieve itching. Treating the cause of the jaundice will help relieve the itching (see pages 90 to 93).

## 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:

- pain
- redness and swelling in a leg
- breathlessness and chest pain.

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
- take short walks regularly
- 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.



# AFTER TREATMENT

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# Follow-up for pancreatic cancer

During your treatment, you will usually have regular talks with someone from your cancer team. This may be your specialist doctor or 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 check your care 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.

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 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.

These assessments, care plans and treatment summaries are not used everywhere. But more hospitals are starting to use them.

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 CA 19-9 tests (see page 29). Tell your doctor or specialist nurse as soon as possible if you have any problems or new symptoms between appointments.

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 (see page 141).

# Coping with advanced cancer

Coping with advanced cancer can mean living with doubt and uncertainty. You may be concerned about practical matters, such as your work or finances. Or you may be worried about your treatment, pain or other symptoms. You might also feel anxious about losing your independence or mobility. Sometimes, you may worry about how your loved ones will cope as the cancer develops. These are all common thoughts to have.

Uncertainty is one of the hardest things to deal with for you and your family and friends. It is especially tough when you are trying to live life as normally as possible. It can cause a lot of tension. You may feel irritable, angry and frightened. It is difficult to make plans when you do not know what is ahead. Even your doctors cannot say for sure what is likely to happen or give you full answers to your questions.

But many people find they can learn to live with uncertainty. One thing that can help is taking control of the things they can do something about.

We have more information about living with advanced cancer (see page 136).

## What you can do

One of the hardest things to cope with can be the feeling that the cancer and its treatment have taken over your life. This is a common feeling, but there are lots of things you can do.

There may be days when you feel too tired to even think about what could help. You will have good and bad days. But if you are overwhelmed by these feelings, let your doctor or nurse know. It may be that you have depression, and this is treatable. So they should be able to help.



## Finding ways to cope

You may find it helps to try to carry on with life as normally as possible, by staying in contact with friends and keeping up your usual activities. Or you may want to decide on new priorities in your life. This could mean spending more time with family, going on the holiday you have dreamed about or taking up a new hobby. Just thinking about these things and making plans can help you realise that you still have choices.

Some people want to improve their general health by eating a healthier diet, by getting fitter or by finding a relaxing complementary therapy.

Understanding about the cancer and its treatment helps many people cope. It means they can discuss plans for treatment, tests and check-ups with their doctors and nurses. Being involved in these choices can help give you back control of your life.

'I know this is a cliché, but truly your body tells you exactly what to do. And I listen to what my medical team has advised me.'

**James**

## 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.

Relatives or carers can give you complementary therapies such as gentle massage. This can also help them support you.

We have more information on complementary therapies (see page 136).

## If you live alone

It may be very hard to keep positive and optimistic if you live alone. Even though you may value your independence, being ill can make you feel lonely and frightened.

It is all right to ask for help. People who care about you will want to help in any way they can. Some people will find it difficult to talk. But they may want to help in practical ways, like doing your 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, you can show it to them. They can then choose to do something that will help you.

Other people may be able to listen to you and share your worries and fears.

Marie Curie has a free helper service available in parts of the UK. Someone can come over for a cup of tea and be there to listen when you need a friendly ear. They can also help you make appointments, or run any errands that you may need help with. For more information, you can contact Marie Curie (see page 151)

Your GP, social worker, or district (or community) nurse can also help you. They can tell you what support is available from health, social care and 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.

The hospital social worker can give you information about social services and benefits you may be able to claim. These include meals on wheels, a home helper or help with hospital fares. The social worker may also be able to arrange childcare for your family 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. But many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you are at a clinic or in hospital.

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

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

You can also contact our cancer support specialists on **0808 808 00 00**. They can tell you more about counselling and can let you know about services in your area.



# YOUR FEELINGS AND RELATIONSHIPS

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# Your feelings

It's common to feel overwhelmed by different feelings when you're told that you have cancer. We talk about some of these here. Partners, family and friends may also have some of the same feelings.

You might have different reactions to the ones we describe here. There is no right or wrong way to feel. You'll cope with things in your own way. Talking to people close to you or other people affected by cancer can often help.

## Shock and disbelief

You may find it hard to believe it when your doctor tells you that you have cancer. It's common to feel shocked and numb. You may not be able to take in much information and find that you keep asking the same questions again and again. At first, you might find it hard to talk to family and friends about the cancer. This usually gets easier as the shock wears off and it becomes more real to you. You may find you can't think or talk about anything but the cancer. This is because your mind is trying to process what you're going through.

## Fear and anxiety

People can be very anxious or frightened about whether treatment will work and what will happen in the future. This uncertainty can be one of the hardest things to cope with. It can help to try to focus on what you can control. You may want to find out more about the cancer, its treatment and how to manage side effects. It can also help to talk about your feelings and to take time to do things that are important to you and that you enjoy.

Doctors often know roughly how many people can benefit from a type of treatment. But they can't be sure what will happen to an individual person. Although they may not be able to answer your questions fully, they can usually talk through any problems with you and give you some guidance.

**'Cancer can turn your life upside down. You can experience just about every emotion a human being can feel.'**

**Iain**

## Avoidance

Some people cope by not wanting to know very much about the cancer and by not talking about it. If you feel like this, let your family and friends know that you don't want to talk about it right now. You can also tell your doctor if there are things you don't want to know or talk about yet.

Occasionally, this avoidance can be extreme. Some people may not believe that they have cancer. This is sometimes called being in denial. It may stop them making decisions about treatment. If this happens, it's very important for them to get help from their doctor.

Sometimes, avoidance is the other way around. Family and friends may seem to avoid you and the fact that you have cancer. They may not want to talk about it or they might change the subject. This is usually because they are also finding the cancer difficult to cope with, and they may need support too. Try to let them know how this makes you feel and that talking openly with them about your illness will help you.

## Anger

You may feel angry about your illness and sometimes resent other people for being well. These are normal reactions, especially when you feel frightened, stressed, out of control or unwell. You may get angry with the people close to you. Let them know that you are angry at your illness and not at them. Finding ways to help you relax and reduce stress can help with anger. This can include talking about or writing down how you feel, gentle exercise, breathing or relaxation therapy, yoga or meditation.

## Guilt and blame

Some people feel guilty or blame themselves or others for the cancer. You may try to find reasons for why it has happened to you. Most of the time, it's impossible to know exactly what has caused a person's cancer. Over time, several different factors may act together to cause a cancer. Doctors don't fully understand all of these factors yet. Instead, try to focus on looking after yourself and getting the help and support you need.

## Isolation and depression

There may be times when you want to be left alone to work through your thoughts and emotions. This can be hard for your family and friends, who want to share this difficult time with you. It may help them cope if you reassure them that, although you don't feel like discussing your illness at the moment, you'll talk to them about it when you're ready.

Sometimes, depression can stop you wanting to talk. If you or your family think you may be depressed, discuss this with your GP. They can refer you to a doctor or counsellor who specialises in the emotional problems of people with cancer, or prescribe an antidepressant drug for you.

## Feeling alone

Some people feel alone because they don't have enough support. Family and friends may live far away, have other commitments or feel uncomfortable because of their own fears about cancer. Try to let your family and friends know how you feel and how they could support you more.

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find out about local support groups – visit **[macmillan.org.uk/supportgroups](https://www.macmillan.org.uk/supportgroups)** You can also talk to other people going through the same thing on our Online Community at **[macmillan.org.uk/community](https://www.macmillan.org.uk/community)**

It's normal to have times when you want to be left alone to sort out your feelings. But if you find you're avoiding people a lot of the time, then try to talk to your doctor or nurse.

## If you need more help

These feelings can be very difficult to cope with and sometimes people need more help. This happens to lots of people and doesn't mean you're not coping.

If you feel anxious, panicky or sad a lot of the time, or think you may be depressed, talk to your doctor or nurse. They can refer you to a doctor or counsellor who can help. They may also prescribe medicine to help with anxiety or an antidepressant drug.

# Share your experience

Many people find it helpful to talk about things and share their thoughts, feelings and advice with other people.

This can be especially helpful for other people with the same cancer, who could be about to start treatment. Sharing how you have coped or what side effects you have managed can help someone in a similar situation.

We can help you share your story, visit [macmillan.org.uk/cancervoices](https://www.macmillan.org.uk/cancervoices)

## Support groups or online support

These offer the chance to talk to other people who have been in (or are in) a similar situation. You can share experiences and ways of coping. They can help if you do not feel able to talk with people around you or if you live alone.

You can go along to see what a support group is like before you decide to get involved.

Our Online Community at [macmillan.org.uk/community](https://www.macmillan.org.uk/community) is a social networking site where you can talk to people in our chat rooms. You can also write an online blog about your journey, make friends and join support groups. You can share your own experiences and feelings, and get support from others.



# If you are a relative or friend

Some people find it hard to talk about cancer or share their feelings. You might think it's best to pretend everything is fine, and carry on as normal. You might not want to worry the person with cancer, or you might feel you're letting them down if you admit to being afraid. Unfortunately, denying strong emotions can make it even harder to talk, and may lead to the person with cancer feeling very isolated.

Partners, relatives and friends can help by listening carefully to what the person with cancer wants to say. It may be best not to rush into talking about the illness. Often, it's enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking, to help friends and family support their loved ones affected by cancer. Visit [macmillan.org.uk/learnzone](https://www.macmillan.org.uk/learnzone) to find out more.

Our booklet **Talking with someone who has cancer** has more suggestions if you have a friend or relative with cancer.

If you're looking after a family member or friend with cancer, you may find our booklet **Looking after someone with cancer** helpful. It's based on carers' experiences and has lots of practical tips and information.

We have more information about supporting someone with cancer at [macmillan.org.uk/carers](https://www.macmillan.org.uk/carers)



# Talking to children

Deciding what to tell your children or grandchildren about your cancer is difficult. An open, honest approach is usually best. Even very young children can sense when something is wrong, and their fears can sometimes be worse than the reality.

How much you tell your children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information, and gradually tell them more to build up a picture of your illness.

## Teenagers

Teenagers can have an especially hard time. At a stage when they want more freedom, they may be asked to take on new responsibilities and they may feel over-burdened. It's important that they can go on with their normal lives as much as possible and still get the support they need.

If they find it hard to talk to you, you could encourage them to talk to someone close who can support and listen to them, such as a grandparent, family friend, teacher or counsellor. They may also find it useful to look at the website [riprap.org.uk](http://riprap.org.uk) which has been developed especially for teenagers who have a parent with cancer.



# WORK AND FINANCIAL SUPPORT

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# Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

## Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

## Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales and Scotland or **nidirect.gov.uk** if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.

## Employment and Support Allowance (ESA)

This benefit is for people under state pension age who cannot work because of illness or disability. There are different types of ESA:

- Contribution-based ESA may be available if you have paid enough National Insurance.
- Income-related ESA may be available if your income and savings are low, or if you cannot get contribution-based ESA. Income-related ESA is gradually being replaced by a new benefit called Universal Credit.

## **Personal Independence Payment**

This benefit is for people aged between 16 and 64 who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and expect them to last for at least 9 months.

## **Attendance Allowance**

This benefit is for people aged 65 or over who have problems looking after themselves because of an illness or disability. This could mean getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months.

## **Special rules**

If you are terminally ill, and your doctor thinks you may be expected to live for less than 6 months, you can apply for some benefits using a fast-track process called special rules. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

## Help for carers

Carer's Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you do not qualify for it, you can apply for Carer's Credit.

Carer's Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

## 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, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. The average grant is around £400. A grant from Macmillan would not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

## Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are looking into buying insurance or making a claim, one of our financial advisers can help. Call **0808 808 00 00**.

We have more information in our booklets **Insurance** and **Travel and cancer** (see page 136). Our Online Community forum Travel insurance may also be helpful.

Visit [macmillan.org.uk/travelinsurancegroup](https://www.macmillan.org.uk/travelinsurancegroup)

## More information

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 one 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 (see page 146).

Our booklet **Help with the cost of cancer** has lots more information (see page 136).



# 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 early on. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others carry on working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to take on too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful – see page 136. There is also lots more information at [macmillan.org.uk/work](https://www.macmillan.org.uk/work)

## Employment rights

If you have, or have ever had cancer, the law considers you to be disabled. This means you cannot be treated differently (less favourably) than other people at work because of cancer. If you are treated less favourably because of cancer, this is called discrimination.

The law also says your employer has to make reasonable adjustments (changes) to your workplace and their work practices.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 136).



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# 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 leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

## Online information

All of our information is also available at **macmillan.org.uk/information-and-support**. There you'll also find videos featuring real-life 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'd 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**.

## Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email [reviewing@macmillan.org.uk](mailto:reviewing@macmillan.org.uk) You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



# Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're 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. Our cancer support specialists 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.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

## Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

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

## 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's why we help to bring people together in their communities and online.

## Support groups

Whether you are someone living with cancer or a carer, 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](https://www.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](https://www.macmillan.org.uk/community)

## The Macmillan healthcare team

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.

'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal

## Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've 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 benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

### 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 a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area.

Visit **[macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport)** to find out more about how we can help you with your finances.

## Help with work and cancer

Whether you're 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](https://www.macmillan.org.uk/work)**

### My Organiser app

Our free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

# Other useful organisations

There are lots of other organisations that can give you information or support.

## Pancreatic cancer support organisations

### **Pancreatic Cancer UK**

**Support line** 0808 801 0707

#### **Email**

nurse@pancreaticcancer.org.uk

**www.pancreaticcancer.org.uk**

Provides support and information via nurse led helpline, a discussion forum and by putting people in contact with each other.

## General cancer support organisations

### **Cancer Black Care**

**Tel** 020 8961 4151

#### **Email**

info@cancerblackcare.org.uk

**www.cancerblackcare.org.uk**

Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

### **Cancer Focus**

#### **Northern Ireland**

**Helpline** 0800 783 3339

(Mon to Fri, 9am to 1pm)

#### **Email**

nurseline@cancerfocusni.org

www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

### **Cancer Research UK**

**Helpline** 0808 800 4040

(Mon to Fri, 9am to 5pm)

**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

(Mon to Fri, 9am to 5pm)

#### **Email**

[info@cancersupportscotland.org](mailto:info@cancersupportscotland.org)

**[www.cancersupportscotland.org](http://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](http://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 Centres**

**Tel** 0300 123 1801

#### **Email**

[enquiries@maggiescentres.org](mailto:enquiries@maggiescentres.org)

**[www.maggiescentres.org](http://www.maggiescentres.org)**

Has a network of centres in various 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

(Mon to Fri, 9.30am to 5pm)

#### **Email**

[helpline@pennybrohn.org.uk](mailto:helpline@pennybrohn.org.uk)

**[www.pennybrohn.org.uk](http://www.pennybrohn.org.uk)**

Offers a combination of physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

### **Riprap**

**[www.riprap.org.uk](http://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

(Daily, 8am to 8pm)

### Email

[info@tenovuscancercare.org.uk](mailto:info@tenovuscancercare.org.uk)

**[www.tenovuscancercare.org.uk](http://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.

## General health information

### Health and Social Care in Northern Ireland

**[www.hscni.net](http://www.hscni.net)**

Provides information about health and social care services in Northern Ireland.

## Healthtalk

**Email** [info@healthtalk.org](mailto:info@healthtalk.org)

**[www.healthtalk.org](http://www.healthtalk.org)**

**[www.healthtalk.org/](http://www.healthtalk.org/)**

**young-peoples-experiences**

(site for young people)

Has information about cancer, and videos and audio clips of people's experiences.

Also provides advice on topics such as making decisions about health and treatment.

## NHS UK

**[www.nhs.uk](http://www.nhs.uk)**

The UK's biggest health information website.

Has service information for England.

## NHS Direct Wales

**[www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)**

NHS health information site for Wales.

## **NHS Inform**

**Helpline** 0800 22 44 88  
(Monday to Friday, 8.00am to 10.00pm, Saturday and Sunday, 9.00am to 5.00pm)

**www.nhsinform.scot**

NHS health information site for Scotland.

## **Patient UK**

**www.patient.info**

Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

## **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** 020 7654 8000

**Email** enquiries@phe.gov.uk

**www.ncras.nhs.uk**

**Tel (Ireland)** 021 4318 014

**www.ncri.ie (Ireland)**

## **Scottish Cancer Registry**

**Tel** 013 1275 7777

**Email** nss.csd@nhs.net

**www.isdscotland.org/**

**Health-Topics/Cancer/**

**Scottish-Cancer-Registry**

## **Welsh Cancer Intelligence and Surveillance Unit (WCISU)**

**Tel** 029 2037 3500

**Email**

general.enquiries@wales.nhs.uk

**www.wcisu.wales.nhs.uk**

## **Northern Ireland Cancer Registry**

**Tel** 028 9097 6028

**Email** nicr@qub.ac.uk

**www.qub.ac.uk/nicr**

## Counselling

### **British Association for Counselling and Psychotherapy (BACP)**

**Tel** 01455 883 300

**Email** [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at [itsgoodtotalk.org.uk](http://itsgoodtotalk.org.uk)

### **UK Council for Psychotherapy (UKCP)**

**Tel** 020 7014 9955

**Email** [info@ukcp.org.uk](mailto:info@ukcp.org.uk)

**[www.psychotherapy.org.uk](http://www.psychotherapy.org.uk)**

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

## Emotional and mental health support

### **Mind**

**Helpline** 0300 123 3393 (9am to 6pm, Monday to Friday)

**Text** 86463

**Email** [info@mind.org.uk](mailto:info@mind.org.uk)

**[www.mind.org.uk](http://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](mailto:jo@samaritans.org)

**[www.samaritans.org](http://www.samaritans.org)**

Samaritans branches are located across England, Ireland, Scotland and Wales. Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

## Financial or legal advice and information

### Benefit Enquiry Line

#### Northern Ireland

**Helpline** 0800 022 4250

(Mon, Tue, Wed and Fri,

9am to 5pm, Thurs,

10am to 5pm)

**Textphone** 028 9031 1092

**[www.nidirect.gov.uk/  
money-tax-and-benefits](http://www.nidirect.gov.uk/money-tax-and-benefits)**

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

### 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 in the phone book or by contacting:

### England

**Helpline** 03444 111 444

**[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)**

### Scotland

**Helpline** 0808 800 9060

**[www.citizensadvice.org.uk/  
scotland](http://www.citizensadvice.org.uk/scotland)**

### Wales

**Helpline** 03444 77 2020

**[www.citizensadvice.org.uk/  
wales](http://www.citizensadvice.org.uk/wales)**

### Northern Ireland

**Helpline** 0800 028 1881

**[www.citizensadvice.co.uk](http://www.citizensadvice.co.uk)**

### Civil Legal Advice

**Helpline** 0345 345 4345

(Mon to Fri, 9am to 8pm,  
Sat, 9am to 12.30pm)

**Minicom** 0345 609 6677

**[www.gov.uk/civil-legal-  
advice](http://www.gov.uk/civil-legal-advice)**

Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English isn't your first language.

**Department for Work  
and Pensions (DWP)  
Personal Independence  
Payment (PIP) Helpline**

0345 850 3322

**Textphone** 0345 601 6677  
(Mon to Fri, 8am to 6pm)

**Carer's Allowance Unit  
Tel** 0800 731 0317

**Textphone** 0345 604 5312  
(Mon to Fri, 8am to 6pm)

**[www.gov.uk/carers-allowance](http://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.

**GOV.UK**

**[www.gov.uk](http://www.gov.uk)**

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

**Money Advice Scotland**

**Tel** 0141 572 0237

**Email** [info@moneyadvice.scotland.org.uk](mailto:info@moneyadvice.scotland.org.uk)

**[www.moneyadvicescotland.org.uk](http://www.moneyadvicescotland.org.uk)**

Use the website to find qualified financial advisers in Scotland.

**National Debtline  
(England, Wales  
and Scotland)**

**Tel** 0808 808 4000

(Mon to Fri, 9am to 8pm,  
Sat, 9.30am to 1pm)

**[www.nationaldebtline.org](http://www.nationaldebtline.org)**

A national helpline for people with debt problems. The service is free, confidential and independent. Has an online chat service with an expert debt advisor.

**NiDirect**

**[www.nidirect.gov.uk](http://www.nidirect.gov.uk)**

Has information about benefits and public services in Northern Ireland.

**Personal Finance Society –  
'Find an Adviser' service**

**[www.thepfs.org/yourmoney/find-an-adviser](http://www.thepfs.org/yourmoney/find-an-adviser)**

Use the website to find qualified financial advisers in your area of the UK.

### **The Money Advice Service Helpline**

0800 138 7777 (English)

0800 138 0555 (Welsh)

(Mon to Fri, 8am to 8pm,

Sat, 9am to 1pm)

#### **Typetalk**

18001 0300 500 5000

**Email** enquiries@

moneyadvice.service.org.uk

**www.moneyadvice.service.org.uk**

Runs a free financial health check service and gives advice about all types of financial matters across the UK. Has an online chat service for instant money advice.

### **Unbiased.co.uk**

**Helpline** 0800 023 6868

**Email** contact@unbiased.co.uk

**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.

### **Equipment and advice on living with a disability**

#### **British Red Cross**

**Tel** 0344 871 11 11

**Textphone** 020 7562 2050

#### **Email**

contactus@redcross.org.uk

**www.redcross.org.uk**

Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

#### **Disability Rights UK**

**Tel** 0207 250 8181

(Mon to Fri, 10am to 12.30pm, then 1.30pm to 4pm)

#### **Email**

enquiries@disabilityrightsuk.org

**www.disabilityrightsuk.org**

Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

## **Disabled Living Foundation (DLF)**

**Helpline** 0300 999 0004

(Monday to Friday,  
10am to 4pm)

**Email** [info@dlf.org.uk](mailto:info@dlf.org.uk)

**[www.dlf.org.uk](http://www.dlf.org.uk)**

Provides free, impartial advice about all types of disability equipment and mobility products.

## **Scope**

**Helpline** 0808 800 3333

(Mon to Sat, 8am to 8pm)

**Email** [helpline@scope.org.uk](mailto:helpline@scope.org.uk)

**[www.scope.org.uk](http://www.scope.org.uk)**

Offers confidential advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.

## **Support for older people**

### **Age UK**

**Helpline** 0800 055 6112

(Daily, 8am to 7pm)

**[www.ageuk.org.uk](http://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

(Mon to Fri, 10am to 6pm)

**Email** [helpline@lgbt.foundation](mailto:helpline@lgbt.foundation)

**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.

## Support for carers

### **Carers Trust**

**Tel** 0300 772 9600

(Mon to Fri, 9am to 5pm)

**Email** [info@carers.org](mailto:info@carers.org)

**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

(Mon to Fri, 10am to 4pm)

**Helpline (Northern Ireland)**

028 9043 9843

**Email** [info@carersuk.org](mailto:info@carersuk.org)

**www.carersuk.org**

Offers information and support to carers across the UK. Has an online forum and can put people in contact with support groups for carers in their area.

## Advanced cancer and end-of-life care

### Hospice UK

**Tel** 020 7520 8200

**Email**

[info@hospiceuk.org](mailto:info@hospiceuk.org)

**[www.hospiceuk.org](http://www.hospiceuk.org)**

Provides information about living with advanced illness. Has a directory of hospice services in the UK and free booklets.

### Marie Curie

**Helpline** 0800 090 2309

(Mon to Fri, 8am to 6pm,  
Sat, 11am to 5pm)

**[www.mariecurie.org.uk](http://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** 01962 712 690

**Email**

[rosie@naturaldeath.org.uk](mailto:rosie@naturaldeath.org.uk)

**[www.naturaldeath.org.uk](http://www.naturaldeath.org.uk)**

Offers independent advice on aspects of dying, funeral planning and bereavement.

## Bereavement support

### Cruse Bereavement Care

**Helpline** 0808 808 1677

(Mon and Fri, 9.30am to 5pm,  
Tue to Thu, 9.30am to 8pm)

**Email** [helpline@cruse.org.uk](mailto:helpline@cruse.org.uk)

**[www.cruse.org.uk](http://www.cruse.org.uk)**

Has a UK-wide network of branches that provide bereavement support to anyone who needs it. You can find your local branch on the website.



## 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 our Senior Medical Editor, Prof Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Dr Katherine Aitkin, Consultant Clinical Oncologist; Mr David Chang, Consultant Surgeon; Professor David Cunningham, Consultant Medical Oncologist; Wendy Martin, Senior Hepatobiliary and Pancreatic Nurse Specialist; Sophie Noble, Hepatobiliary and Pancreatic Nurse Specialist; Dr Naureen Starling, Consultant Medical Oncologist; Mr Adrian Steger, Consultant Surgeon; and Dr Kate Young, Clinical Research Fellow.

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](mailto:cancerinformationteam@macmillan.org.uk)**

## Sources

We've listed a sample of the sources used in the booklet below. If you would like further information about the sources we use, please contact us at **[cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)**

British Society of Gastroenterology, Guidelines for the management of patients with pancreatic cancer peri-ampullary and ampullary carcinomas. 2005.

European Society for Medical Oncology, Cancer of the pancreas: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. *Annals of Oncology*, Volume 26, Issue suppl\_5, pages v56 to v68. 1 September 2015.

Fernandez-del Castillo. Clinical manifestations, diagnosis, and staging of exocrine pancreatic cancer. UpToDate online. Jan 2018.

Fernandez-del Castillo C, et al. Supportive care of the patient with locally advanced or metastatic exocrine pancreatic cancer. UpToDate online. Feb 2017.

Winter JM, et al. Cancer of the pancreas, DeVita Hellman and Rosenberg's Cancer: Principles and Practice of Oncology (10<sup>th</sup> edition). Lippincott Williams and Wilkins. 2016.

# Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're 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're there 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.



## **Share your cancer experience**

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

## **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.

## **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?

## **Raise money**

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

## **Give money**

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

**Call us to find out more**

**0300 1000 200**

**[macmillan.org.uk/getinvolved](http://macmillan.org.uk/getinvolved)**

## 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

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Security number

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Signature \_\_\_\_\_

Date     /     / \_\_\_\_\_

## Don't 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'd rather donate online go to [macmillan.org.uk/donate](https://macmillan.org.uk/donate)

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

**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 explains the signs and symptoms of pancreatic cancer, and how it is diagnosed and treated. It also has information about emotional, practical and financial issues.**

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) 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.

# MACMILLAN

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