A practical guide to understanding cancer

UNDERSTANDING CANCER OF THE PANCREAS
About this booklet

This booklet is about cancer of the pancreas, which is also called pancreatic cancer. It gives information about the most common type of pancreatic cancer called adenocarcinoma of the pancreas. This booklet is for people who have cancer of the pancreas or are having tests or investigations for it. It also has information for family and friends.

We hope it answers some of your questions about diagnosis, treatment and living with this cancer and helps you deal with some of the feelings you may have. We can’t advise you about the best treatment for you. This information can only come from your doctor, who knows your full medical history.

If you would like to discuss this information, call the Macmillan Support Line free on 0808 808 00 00, Monday–Friday, 9am–8pm. If you are hard of hearing, you can use textphone 0808 808 0121, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit macmillan.org.uk

We have included some comments from people affected by pancreatic cancer, which you may find helpful. They have chosen to share their story with us on our online community macmillan.org.uk/community
We also have a website called The Source. It has comments and advice from people who have had cancer or have been affected in some way. Visit source.macmillan.org.uk Family and friends can find information to help them know what to say or do when someone they care about has cancer. You can also share your own tips.

Turn to pages 112–123 for some useful addresses and websites.

**How to use this booklet**

To help you find the information you need, we have divided this booklet into sections. You can either read it from start to finish, or you can go straight to any section in the booklet and start reading from there. For example, if you are having tests, you may want to go straight to that section for the information you need.

It is fine to skip bits of the booklet. You can always come back to them when you feel ready. You may also like to make notes and think of questions to ask your doctor or nurse. There is a section for this on page 124.
Contents

Cancer of the pancreas
Diagnosing cancer of the pancreas
Treating cancer of the pancreas
Your feelings and relationships
After your treatment
Work and financial support
Further information

5
19
35
79
91
99
105
Cancer of the pancreas

The pancreas 6
What is cancer? 8
What is pancreatic cancer? 10
Symptoms 12
Risk factors and causes 14
The pancreas

The pancreas is part of the digestive system. It has two main roles. It makes:

- **pancreatic juices** – to help digest food for the body to use
- **insulin** – to help keep sugar levels in the blood stable.

The position of the pancreas
The pancreas is in the upper part of the tummy (abdomen) just behind the stomach and in front of the spine. It is level with the V-shape where the ribs meet at the front of the body. It is about 15cm (6in) long and is shaped like a tadpole. The three main parts are:

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

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

Cancer cells can travel through the blood or lymphatic system. The lymphatic system is made up of fine tubes called lymphatic vessels that connect to groups of lymph nodes throughout the body. It helps to protect us from infection and disease. It also drains lymph fluid from the tissues of the body before returning it to the blood.
What is pancreatic cancer?

Types of pancreatic cancer can be described by where they are found in the pancreas and by the type of cell that they start from.

Cancer can occur in any part of the pancreas, but around 6 or 7 in every 10 pancreatic cancers (60–70%) start in the head of the pancreas.

There are several different types of pancreatic cancer. The most common type is ductal adenocarcinoma, which starts from cells in the lining of the pancreatic ducts. More than 9 out of 10 pancreatic cancers (95%) are ductal adenocarcinomas.

Cancer may develop at the ampulla of Vater (see page 6), where the bile and pancreatic ducts join up and enter the small bowel (duodenum). This is called ampullary cancer.

Other, less common, types of pancreatic cancer include:

- **cystic tumours** – cysts are fluid-filled sacs in the pancreas, which can be cancerous

- **acinar cell carcinomas** – these start from the cells that make pancreatic juice

- **neuroendocrine tumours** – these begin in the endocrine cells where insulin and other hormones are made

- **lymphoma** – this is a cancer of the lymphatic tissue in the pancreas.
The treatments for cancerous cystic tumours, acinar cell carcinomas and ampullary cancer are similar to those described on pages 36–77. But the tests and treatments for neuroendocrine tumours and lymphoma of the pancreas may be very different.

We can send you more information about lymphoma and neuroendocrine tumours.
Understanding cancer of the pancreas

Symptoms

Pancreatic cancer may not cause symptoms for a long time and some people may have only one symptom. The most common symptoms are:

**Pain or discomfort**

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

**Jaundice**

If you have ampullary cancer (see page 10) or if the cancer is in the head of the pancreas and blocks the bile duct, you may develop jaundice. Cancer in the tail or body of the pancreas is less likely to cause jaundice.

If bile can’t drain away, it builds up in the body. This can cause symptoms such as yellowing of the skin and the whites of the eyes, itchy skin, dark yellow urine and pale bowel motions.

Jaundice can be caused by illnesses other than pancreatic cancer.

**Weight loss**

This may happen even if there have been no changes in what you eat.
Other symptoms

Pancreatic cancer can cause other symptoms, such as:

• loss of appetite
• indigestion
• feeling sick (nausea) and being sick (vomiting)
• feeling bloated after meals
• diarrhoea or a change in bowel habits
• feeling very tired
• diabetes
• depression
• a blood clot in the leg (deep vein thrombosis or DVT) or the lungs (pulmonary embolus).

Remember: most pain in the abdomen is not caused by cancer of the pancreas. But see your doctor if you are worried.

‘Up until about a month before, I thought I was fit and well. I got the first symptoms, which were backache then abdominal pain that got increasingly worse, and pain when I was eating.’

Alison
Risk factors and causes

About 8,800 people are diagnosed with pancreatic cancer in the UK each year. Doctors don’t know what causes this cancer, but there is ongoing research into this.

Things that can increase your risk of developing a disease are called risk factors. Risk factors for pancreatic cancer include:

Age

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

Smoking and tobacco

About 3 in 10 pancreatic cancers in the UK (30%) may be due to smoking. People who chew tobacco are also at an increased risk.

Diet

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

Regularly eating a diet that is high in fat and sugar and low in fresh fruit and vegetables may also increase the risk.
Alcohol

Drinking large amounts of alcohol regularly may increase the risk of developing pancreatic cancer, especially in people who smoke.

Body weight and physical activity

Some studies have found that being very overweight (obese) and being physically inactive may increase the risk of pancreatic cancer.

Medical conditions

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 highest for people who have chronic pancreatitis due to a rare inherited condition called hereditary pancreatitis.

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

Infections
Some infections have been linked to a higher risk of developing pancreatic cancer. Studies have shown there may be a link to an infection of the liver called hepatitis B.
Other research suggests there may be a link between tooth or gum disease and an increased risk of pancreatic cancer. Researchers think this may be caused by a type of bacteria.

Helicobacter pylori (H. pylori) is a common stomach infection that causes inflammation and ulcers in the stomach lining. Over a long time, it can increase the risk of cancer developing. There may also be a link between stomach ulcers and the risk of pancreatic cancer, particularly in men.

But many people have ulcers and infections and do not develop cancer.

**Previous cancer**

Pancreatic cancer is slightly more common in people who have had cancer before. Studies are looking at whether this is because of previous cancer treatment, a genetic link or lifestyle factors such as diet or smoking.
Family history

Most people with pancreatic cancer have no history of pancreatic cancer in their family. But about 5–10 out of every 100 pancreatic cancers (5–10%) may be linked to faulty genes that can run in families. You may have a higher risk if:

• two or more people on the same side of your family have pancreatic cancer

• family members have the breast cancer gene BRCA2

• family members have the condition Lynch syndrome/HNPCC (hereditary non-polyposis colorectal cancer)

• family members have a large number of unusual moles (FAMMM – Familial Atypical Multiple Mole Melanoma)

• you have a condition called Peutz-Jeghers syndrome (PJS) which causes multiple growths (polyps) in the stomach and bowel and dark spots on the skin on the face and hands.

If your family history means you may be at a higher risk, you can be referred to a specialist clinic for advice and assessment. You may be offered regular screening tests to try to detect cancer of the pancreas early if it does develop. Doctors are still researching the best way to screen for pancreatic cancer, so screening may be offered as part of a research trial (see pages 42–43).

Like all cancers, pancreatic cancer isn’t infectious and can’t be passed on to other people.
DIAGNOSING CANCER OF THE PANCREAS

How cancer of the pancreas is diagnosed 20
Staging 30
How cancer of the pancreas is diagnosed

Usually, you begin by seeing your GP. Your GP will normally look at your eyes and the colour of your skin to check for jaundice, test your urine for bile and take some blood samples. They may examine your tummy (abdomen) to feel for any swelling in the area of the liver. They will also ask if you have noticed any changes in your bowel habits or in your weight.

Your GP will then refer you to hospital for tests and for specialist advice and treatment. If you are aged 60 or older and have symptoms, your doctor may arrange a referral and an urgent CT scan or ultrasound. If you are aged 40 or older and have jaundice, you should be seen at the hospital within two weeks.

At the hospital, a specialist doctor will ask about your general health and any previous medical problems. They will then examine you and organise some tests and scans.

Tests

To make a diagnosis, doctors often use information from several tests, along with your symptoms and medical history. Occasionally, other medical conditions can cause similar results, making it difficult to decide what is and isn’t cancer.

If you are diagnosed with pancreatic cancer, you may need more tests. These are to find out the size and position of the cancer, and whether it has spread to other parts of the body.
Other tests, such as blood tests and chest x-rays, will look at your general health and fitness. All these results will help when your doctor looks at the best treatment for you.

The following tests are often used to test for suspected cancer of the pancreas:

**Ultrasound scan**

Ultrasound scans use sound waves to show internal organs such as the pancreas and the liver. You will usually be asked not to eat or drink anything for a few hours before the test.

Once you are lying comfortably on your back, a gel is spread on the skin over the area to be scanned. A small device that produces sound waves is passed over the area. The sound waves are then converted into a picture by a computer. This test only takes a few minutes.

An ultrasound can also be used to guide a biopsy where a small sample of tissue is taken to be examined under a microscope (see page 27).
Endoscopic ultrasound (EUS)

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

You will be asked not to eat or drink anything for about six hours before the test, so that your stomach and duodenum are empty. Your doctor or nurse will give you an injection to help you to relax (a sedative). They will also spray some local anaesthetic on to the back of your throat.

The doctor passes a thin flexible tube called an endoscope down your throat, into your stomach and then into your duodenum. An ultrasound probe is put down the endoscope to produce 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 as you shouldn’t drive for 24 hours after a sedative.

CT (computerised tomography) 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 10–30 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 four hours before the scan. There is a photograph of a man having a CT scan on the opposite page.
Having a CT 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.

CT scans can also be used to guide a biopsy (see page 27). A biopsy usually involves an overnight stay in hospital, but you’ll be told if this is planned.

**MRI (magnetic resonance imaging) 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’s 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’ve 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’s likely that you won’t be able to have an MRI scan. In this situation, another type of scan can be used. Before the scan, you’ll be asked to remove any metal belongings including jewellery.

Some people are given an injection of dye into a vein in the arm, which doesn’t 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’ll 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’ll be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.
**MRCP (magnetic resonance cholangiopancreatography)**

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 (see page 24) but isn’t available in every hospital. You will have to lie very still inside the MRI scanner for around 30 minutes. The scan shows any narrowing or blockages in the pancreatic ducts or bile ducts but can’t be used to take biopsies.

**ERCP (endoscopic retrograde cholangiopancreatography)**

Doctors may carry out an ERCP to put in a stent (see pages 69–70) to drain a bile duct. This is a treatment for jaundice. They may also use an ERCP to take a biopsy from a tumour (see opposite page).

You will be asked not to eat or drink anything for six hours before the procedure, so that your stomach and duodenum are empty.

The doctor or nurse will give you an injection to make you feel relaxed and sleepy. After this, the doctor passes a thin flexible tube called an endoscope into your mouth, down into your stomach and then into the duodenum. They then put a small brush down the endoscope and take biopsies from the tumour. The brush with the cells on it is sent to a laboratory to be tested for cancer.

‘It’s not nice, the thought of having a tube down your throat. But it was not unpleasant at all.’

Phil
Understanding cancer of the pancreas

Biopsy

A biopsy is a small piece of tissue or a sample of cells that is taken from a tumour to be looked at under a microscope.

A biopsy may be taken during an EUS (see page 22) or an ERCP (see opposite page). Sometimes, the doctor inserts a needle through the skin into the tumour to get a sample of cells. 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 use images from an ultrasound or CT scan to guide the needle through the skin and into the tumour to take (aspirate) a sample of cells. The sample is then sent to a laboratory to be tested for cancer.
**Laparoscopy**

This may be done if other tests haven’t confirmed a diagnosis of pancreatic cancer or if surgery to remove the cancer is planned. It is a small operation that allows the doctors to look at the pancreas and other organs in the tummy. They can see whether an operation to remove the cancer is possible. A laparoscopy is done under a general anaesthetic. It will mean a short stay in hospital.

The doctor makes a small cut near the belly button. They then insert a thin tube with a tiny camera and light on the end, called a laparoscope, into your tummy. The doctor uses the laparoscope to look at the pancreas and surrounding tissues. They may also take a biopsy to be looked at under a microscope. Gas is pumped into the abdomen to make it easier to see the pancreas. The gas can cause uncomfortable wind and/or shoulder pains for several days afterwards. The pain is often eased by walking about or taking sips of peppermint water. After the laparoscopy, you will have one or two stitches in your abdomen.

**Laparotomy**

If a laparoscopy isn’t suitable, your surgeon may carry out a laparotomy. This may be done if other tests don’t give a definite diagnosis, but it’s rarely needed as most people can have a laparoscopy.

A laparotomy is an operation to look inside the tummy and is done under a general anaesthetic. The surgeon makes a larger cut (incision) in your tummy so that they can see the pancreas.
ERCP, biopsy and laparoscopy can cause problems for some people. Your specialist should discuss any possible risks with you before you have any of these procedures.

**Blood tests**

Many pancreatic cancers produce a substance called CA 19-9. This is called a tumour marker and can be measured in the blood. But some people who have pancreatic cancer don’t have raised levels of CA 19-9. And a normal level of CA 19-9 does not mean that someone definitely doesn’t have pancreatic cancer. Also, a high level may be caused by other conditions such as jaundice. Doctors will consider these things when they are looking at the test results.

Doctors may measure the level of CA 19-9 to see how a pancreatic cancer responds to treatment and during follow-up.

You may also have other blood samples taken to check your general health and how well your liver and kidneys are working.

**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, your family or a close friend. Your specialist nurse or one of the organisations listed on pages 112–123, 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 is a term used to describe its size and whether it has spread from the place in the body where it started. Knowing the stage of the cancer helps the doctors when they are looking at the best treatment for you.

Number staging

A commonly used 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, although it may be quite large. Stage 1A means the cancer is smaller than 2cm. Stage 1B means it is bigger than 2cm. There is no cancer in the lymph nodes close to the pancreas and no sign that it has spread anywhere else in the body.

**Stage 2**
The cancer has started to grow outside the pancreas into nearby tissues and/or there is cancer in lymph nodes near the pancreas. In stage 2A, the cancer is in nearby tissue but does not involve blood vessels or lymph nodes. In stage 2B, the cancer may have grown into nearby tissue and is in the lymph nodes but not in the 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. Fewer than 1 in 5 cancers of the pancreas (20%) are diagnosed at stages 1 and 2.
**Stage 3**
The cancer has spread to large blood vessels near the pancreas but hasn’t spread to other parts of the body such as the liver or lungs.

Stage 3 cancer is often called **locally advanced cancer**. Surgery may not always be possible for this cancer. 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. About 2 in 5 cancers of the pancreas (35–40%) are diagnosed at stage 3.

**Stage 4**
The cancer has spread to other parts of the body such as the liver or lungs.

Stage 4 cancer is often called **metastatic** or **advanced cancer**. This means the cancer has spread to other parts of your body. About half of pancreatic cancers (45–55%) are diagnosed at stage 4.
TNM staging

This number stage is then combined with a letter system called TNM, which gives the complete stage of the cancer:

- **T** describes the size of the tumour.
- **N** describes whether the cancer has spread to the nearby lymph nodes. For example, N0 is no lymph nodes affected while N1 means there are cancer cells in the lymph nodes.
- **M** describes if the cancer has spread to another part of the body. For example, M0 means the cancer has not spread (metastasised) to other parts of the body. M1 means the cancer has spread to other parts of the body.
Treatment overview

Planning your treatment

The type of treatment offered will depend on the stage and size of your cancer, and your general health. The treatment will be planned by a team of specialist doctors and other healthcare professionals. This is known as a multidisciplinary team (MDT), and may include:

• a **surgeon** who specialises in treating pancreatic cancer

• **oncologists** – doctors who treat cancer with chemotherapy (and other cancer drugs) and radiotherapy

• 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

• a **specialist nurse** who can give information and support.

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 may all be used to treat pancreatic cancer. An important part of the care of people with pancreatic cancer is using treatments to control symptoms and make you feel more comfortable. This is known as supportive care (see pages 68–77). Research is going on to find more effective treatments for pancreatic cancer and you may be invited to take part in a clinical trial of a new drug or treatment (see pages 42–43).
Treatment by stage of cancer

**Early-stage (resectable)**
The most effective treatment for early-stage pancreatic cancer is surgery to remove part, or all, of the pancreas. This may cure the cancer for some people but it is a major operation (see pages 44–55). It is only suitable for people who are fit enough to have the surgery and who have cancers that are small and haven’t spread.

Chemotherapy (see pages 57–63) may be given before surgery to shrink the tumour or to reduce the risk of the cancer cells spreading. This is called *neoadjuvant treatment* and may be given as part of a clinical trial (see pages 42–43).

Chemotherapy may also be used after surgery to reduce the chances of the cancer coming back. This is called *adjuvant chemotherapy*.

**Locally-advanced (unresectable)**
Chemotherapy may be used to control the cancer for some time and to relieve symptoms.

Sometimes, chemotherapy and radiotherapy are given together. This is called *chemoradiation*.

If the cancer is blocking the bile duct or the bowel, surgery (see page 56) or stents (see pages 69–70) may be used to relieve symptoms.
Locally-advanced (borderline resectable)
Very occasionally, it’s possible to operate to try to remove locally-advanced cancers. Chemotherapy (with or without radiotherapy) may be given first to shrink the tumour. However, this is rare.

Metastatic or advanced cancer
If the cancer is advanced, you may be offered treatment to control it. The main aim of this treatment is to reduce symptoms so that you feel as well as possible. This is called supportive care (see pages 68–77). Chemotherapy may be given to shrink the cancer and to relieve symptoms. Chemotherapy may also help some people to live for longer. Stents (see pages 69–70) may be used to relieve jaundice or other symptoms caused by a blocked bile duct or bowel. Radiotherapy, painkillers and nerve blocks (see pages 71–72) may be used on their own or in a combination to control any pain.
The benefits and disadvantages of treatment

Before deciding whether to go ahead with a treatment, you may want to know how well it is likely to work. If you’re offered a choice of treatments, you’ll need to think about the possible benefits and disadvantages of each to help you decide.

Some treatments have more side effects and risks than others. For some people, treatment will have no effect on the cancer and they’ll get the side effects with little benefit.

Making decisions about treatment can be difficult. Your doctor or specialist nurse can answer any questions you have.

Giving your consent

Before you have any treatment, your doctor will explain its aims. They will usually 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 is 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.

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 is 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, and 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.

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 is 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.

Clinical trials are described in more detail in our booklet Understanding cancer research trials (clinical trials). We can send you a free copy.

Current research

There are many research trials going on into pancreatic cancer. Some trials are looking into ways of improving treatments. Other trials are trying to improve screening tests for people at a higher risk of getting pancreatic cancer. This is so, if they do get cancer, it can be picked up at an earlier stage when it is more treatable.

Our website has details of databases you can search for trials for pancreatic cancer.
Surgery

Some people who have early-stage pancreatic cancer are able to have an operation to remove it. This operation is called a resection.

Surgery can also be used to relieve symptoms if the cancer is blocking the bile duct or the bowel (see page 56).

Before surgery

Before your operation, you will have some tests to check your general health. These may include blood tests, a chest x-ray or a recording of your heart (ECG). A member of the surgical team and a specialist nurse will discuss the operation with you. You will also be visited by the doctor who will give you your anaesthetic (the anaesthetist). This doctor may arrange more tests for you.

You will be given special elastic stockings (TED stockings) to wear during and after the operation to prevent blood clots forming in your legs.

Make sure you talk to your nurse or doctor about any questions or concerns you have about the operation.

If you smoke, try to give up or cut down before your operation. This will help reduce 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 and you may find it helpful to read our booklet *Giving up smoking*. 
Treating cancer of the pancreas
Some hospitals follow an enhanced recovery programme. This aims to reduce your time in hospital and to speed up your recovery after an operation. These programmes involve you more in your own care. For example, you will be given information about diet and exercise before surgery and any arrangements needed for you to go home will be put in place for you. Your doctor will tell you if an enhanced recovery programme is suitable for you and if it’s available – not all hospitals have them.

**Removal of the cancer (resection)**

Occasionally, it’s 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. It may cure the cancer in some people.

This type of surgery should be done by specialist surgeons who are trained and experienced in pancreatic surgery. You may need to be referred to a specialist centre for the operation.

It is important to discuss the benefits and risks with your surgeon before making the decision to go ahead with any surgery.
All or part of the pancreas may be removed during surgery. This will depend on where the cancer is, and how much of the pancreas is involved. One of the following operations may be done:

• A pylorus-preserving pancreatoduodenectomy (PPPD), also called a modified Whipple’s operation. This involves removing the head of the pancreas, most of the duodenum, the common bile duct, gall bladder and the surrounding lymph nodes. It is most commonly used for people with cancer in the head of the pancreas.

• A pancreatoduodenectomy or Whipple’s operation (see diagrams on pages 48–49) – this is similar to the PPPD operation, but the lower part of the stomach is also removed.

• Removal of the lower end (body and tail) of the pancreas (a distal pancreatectomy).

• Removal of the whole pancreas (a total pancreatectomy). This involves removing the pancreas, duodenum, part of the stomach, the spleen, gallbladder and part of the bile duct and some lymph nodes. This is a major operation and is rarely done.
A Whipple’s operation

The sections in white are the parts removed during a Whipple’s operation.
After a Whipple’s operation

The surgeon attaches the remaining part of the stomach, the remaining bile duct, and the tail of the pancreas to the small bowel.
Laparoscopic (keyhole) surgery

In some specialist centres, the surgeon may carry out laparoscopic (keyhole) surgery. This can be used for a distal pancreatectomy. Instead of one large cut (incision), you have several small cuts. The surgeon uses a special instrument called a laparoscope to see and work inside the tummy.

A small number of hospitals carry out keyhole surgery using robotic equipment. The camera on the end of the laparoscope produces a 3D magnified view of inside of the body on a video screen to help guide the surgeon. Instruments attached to the robotic equipment are then controlled by the surgeon.

The main advantage of keyhole surgery is that it leaves a small wound so recovery is usually quicker. This operation is not available in many hospitals and is not suitable for everyone.

Keyhole surgery is only carried out by surgeons who specialise in both pancreatic cancer and laparoscopic procedures.

‘I wanted to know everything. 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
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. How quickly you recover will depend on the type of surgery you’ve had.

Most people will be nursed in an intensive care or high-dependency unit for a few days after their operation. This is routine and doesn’t mean your operation has gone badly or that there are complications. A machine called a ventilator may be used to help you to breathe for a few hours – again, this is routine in some hospitals. You will probably feel quite drowsy and may not remember much about the first day or two after your operation.

The nurses will encourage you to start moving about as soon as possible. This is an important part of your recovery, as it helps to prevent problems such as chest infections or blood clots. If you have to stay in bed, the nurses will encourage you to do regular leg movements and deep breathing exercises. A nurse or a physiotherapist can help you do the exercises.

The ward staff will help you during this time as you may need help to wash and go to the toilet. Once you are moving about more freely, you’ll probably be able to manage this for yourself.

If you’re in an enhanced recovery programme or have had laparoscopic (keyhole) surgery, your nurse will encourage you to get out of bed and start moving around as soon as possible.
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 will give you fluids until you are able to eat and drink again. It may also be used to give you painkillers.

• One or more drainage tubes coming from your wound to drain away fluid or blood, or to drain away bile or pancreatic fluid. The drainage tubes will be removed when 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 don’t feel sick. You may need this for several days.

• A small flexible tube (catheter) to drain urine from your bladder into a collecting bag. This means you won’t have to get up to pass urine. It is usually taken out after a couple of days.

• A feeding tube that goes into the small bowel through a small cut in the abdomen. It is used to give you food and nutrients until you’re able to eat again.
Wound care

The wound is closed using clips or stitches. These are usually removed 7–10 days after your operation. Some surgeons use dissolving stitches that don’t need to be removed. These will dissolve completely when the area is healed. You may be given antibiotics to help prevent wound infection. You will have a dressing covering your wound, which may be left undisturbed for the first few days.

It is important to let your nurse or doctor know straight away if your wound becomes hot, painful or begins to bleed or leak any fluids, even after you go home.

‘The days slowly and surely get better, as various tubes and bags are removed and, eventually, you become more mobile and start walking with the physios.’

Colin
Pain control (analgesia)

After your operation, you’ll need painkilling drugs for a few days.

To begin with, you may have an epidural anaesthesia. This is given into the space around the spinal cord to numb the nerves in the part of your body where the surgery is carried out.

If you are having an epidural, before the operation an anaesthetist will put a fine tube into your back close to the spinal cord nerves. The tube is attached to a syringe in an electronic pump. The pump gives you a continuous infusion of medicines to numb your nerves and control pain.

Because the tube is very fine, you can still lie on your back when you have an epidural in place. You are also able to sit up and walk around while having this type of pain control.

Some people are given painkilling drugs into a vein (intravenously). These can be given continuously through an electronic pump.

You may have a hand control with a button you can press to give you a boost of painkilling medicine if you feel sore. This is called patient controlled analgesia (PCA). This is designed so that you can’t have too much painkiller (an overdose), so it’s okay to press it whenever you are sore.

It is important to let your doctor or nurse know if you are in pain so that the dose can be increased, or the painkillers changed, as soon as possible. When you are ready to go home, you’ll be given a prescription of painkiller tablets to take as needed at home.

Pain can usually be well controlled with painkillers.
Immediate complications of surgery

This will depend on the type of operation you have. The most common complications after surgery are a wound infection, bleeding in the operation area, a chest infection or developing a blood clot.

The nurses will monitor you for these complications. Let them know straight away if you have any bleeding, feel unwell, have symptoms of an infection such as a cough or discharge from your wound, or swelling and redness in a limb.

Insulin and enzyme replacement

If you’ve had a part of your pancreas removed, the remaining pancreas may not make enough insulin to control your blood sugar just after the operation. 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 an operation to remove your entire pancreas, you’ll need to continue with daily insulin injections. These are given under the skin (subcutaneously). If you already have diabetes, you may have to increase your insulin or tablet dose. A diabetes nurse specialist will give you support and advice about insulin replacement.

You may also need to take capsules containing the digestive enzymes (pancreatin) normally made by the pancreas. Digestive enzymes help your body to break down and absorb fats and protein. If you don’t have enough of them, you may have diarrhoea or your stools (poo) may float, look pale and smell bad. You will also find it difficult to put on weight because you can’t absorb nutrients from your food.
Surgery to relieve symptoms

**Bypass surgery for a blocked bowel**
If the first part of your small bowel (the duodenum) becomes blocked by the cancer, food or drink can’t pass from your stomach to your bowel. The food builds up in your stomach, and can make you feel sick (nausea) and be sick (vomiting).

An operation to bypass the blockage can help. The surgeon connects the part of your small bowel just below the duodenum directly to your stomach. This allows food to pass from the stomach into your bowel. This operation is often done at the same time as an operation to relieve a blocked bile duct.

Another way of treating a blockage in the duodenum is to place a tube called a stent in the duodenum (see pages 69–70).

**Bypass surgery for a blocked bile duct**
If cancer blocks the bile duct causing jaundice, your doctors may suggest you have a tube called a stent placed in the bile duct (see pages 69–70). This can be done during an endoscopy. If this is unsuccessful or not possible, you may be offered surgery to relieve the blockage.

The bile duct (or occasionally the gall bladder) is cut above the blockage and reconnected to the small bowel. This bypasses the blocked part of the bile duct and allows the bile to flow from the liver into the bowel. The jaundice will then clear up. In some hospitals, it’s possible to do this procedure during a laparoscopy (see page 50).
Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. It is one of the most commonly used treatments for pancreatic cancer.

Chemotherapy may be given:

- after surgery to reduce the chance of the cancer coming back. This is called adjuvant chemotherapy.
- if surgery isn’t possible to shrink the cancer, relieve symptoms and improve survival. This is called palliative chemotherapy.
- to shrink a cancer before surgery. This is called neoadjuvant chemotherapy. This may be done as part of a clinical trial for pancreatic cancer (see pages 42–43).

Sometimes, chemotherapy is given with radiotherapy. This is known as chemoradiation. If it is given with radiotherapy before surgery, it is called neoadjuvant chemoradiation. This would usually be as part of a clinical trial. Your doctor or specialist nurse can give you more information about chemoradiation.
Having chemotherapy
Some chemotherapy drugs are given as tablets, but most are given by injection into a vein (intravenously). Intravenous chemotherapy can be given:

- into a fine tube (**cannula**) in a vein in your arm or hand
- through a flexible plastic tube (**central line**) that sits in a vein just under your collarbone at the top of your chest
- through a flexible plastic tube (**PICC line**) that goes into a large vein in the bend of your elbow
- into an implantable port (**portacath**) that has an opening (port) under the skin on your chest or arm going into a vein.

We can send you more information about central lines, PICC lines and implantable ports. We also have animations on our website that explain how the lines are put in.
Some types of chemotherapy are given through a small portable pump, which is attached to your line or port. A controlled amount of the drug is given into the bloodstream over a set period of time. This means that you can go home with the pump, and spend less time in hospital.

Whether chemotherapy is given as tablets or into a vein, the drugs are absorbed into the blood and carried all round the body. The chemotherapy then destroys cancer cells wherever they are in the body.

Chemotherapy is usually given as several sessions of treatment. Each treatment is followed by a rest period of a week or two to allow your body to recover from any side effects. The treatment and the rest period together make up a cycle of treatment. The number of cycles you have will depend on the drugs that are used, and how well the treatment is working. This is checked by your doctor at regular appointments.

Most people can have their chemotherapy as an outpatient.

‘Three months after surgery I started chemotherapy. I did not feel ready or strong enough and on the first day of treatment I felt really nervous and anxious but it passed quickly enough and it wasn’t as bad as my imagination had led me to believe.’

Carol
Chemotherapy after surgery

If you’re having chemotherapy after surgery to remove the cancer, the treatment will usually last for about six months.

The chemotherapy drug that’s most commonly used for cancer of the pancreas is gemcitabine (Gemzar®). It is given as a drip into a vein (intravenous infusion) over 30 minutes.

Gemcitabine is usually given once a week for three weeks followed by a rest every fourth week. These four weeks make up a cycle of treatment and you will usually have six cycles of treatment.

Another drug that may be used after surgery is fluorouracil (5FU). It is given intravenously or as tablets. The fluorouracil tablet is called capecitabine.

Chemotherapy for advanced pancreatic cancer

Gemcitabine is sometimes used in advanced pancreatic cancer. It can be given on its own or with another chemotherapy drug. This may be capecitabine or another drug called paclitaxel albumin (Abraxane®). Your doctor will talk to you about what drugs are available and suitable for you.

Gemcitabine and paclitaxel albumin (Abraxane®)

Gemcitabine may be given with another chemotherapy drug called paclitaxel albumin. Paclitaxel albumin is given as a drip into a vein, usually over half an hour. Like gemcitabine, it will usually be given once a week for three weeks, followed by a rest every fourth week. These four weeks make up a cycle of treatment. Your doctor or nurse will tell you more about this and the number of cycles of gemcitabine and paclitaxel albumin you are likely to have.
**FOLFIRINOX**

Sometimes, a combination of drugs called FOLFIRINOX may be given. It is made up of folinic acid (leucovorin) and the chemotherapy drugs fluorouracil (5FU), irinotecan and oxaliplatin. Folinic acid is not a chemotherapy drug, but is often given with 5FU as it’s been shown to make it work better.

A recent study found that FOLFIRINOX may help to control advanced pancreatic cancer for longer than standard treatment with gemcitabine. However, FOLFIRINOX can cause severe side effects so it is only suitable for people who are well enough to cope with these.

Each cycle of treatment lasts for two weeks. On the first day of each cycle you’re given folinic acid, 5FU, irinotecan and oxaliplatin intravenously. The nurse then attaches a small portable pump to your line or port for you to go home with. The pump will give you continuous chemotherapy with 5FU for the next two days. After this, it’s disconnected from your line and you have a rest from chemotherapy for 11 days. This makes up a cycle of treatment. You may be given up to 12 cycles of treatment over about six months.

**Other drugs**

Other combinations of drugs, or new drugs, may be used to treat pancreatic cancer. Sometimes, this will be as part of cancer research trials. Treatments called targeted therapies are also being researched in cancer trials. These treatments interfere with the way that cancer cells grow. Research trials are carried out to try to improve the results of treatment for pancreatic cancer.

You may be invited to take part in a trial (see pages 42–43 for more information).
Side effects

Chemotherapy drugs may cause side effects, but they can also make you feel better by relieving the symptoms caused by the cancer. Most people have some side effects but these can usually be well controlled with medicines. The side effects will usually go away once the treatment has finished. Treatment with a combination of chemotherapy drugs tends to cause more severe side effects than treatment with a single chemotherapy drug. You can talk to your doctor or nurse about what to expect from the treatment that’s planned for you.

We can send you further information about the chemotherapy drugs mentioned here and their side effects. We can also give you advice about what you can do to reduce or control these side effects.

We also have a booklet called Understanding chemotherapy with more details.
Radiotherapy

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

Radiotherapy is used less often than surgery or chemotherapy. Sometimes, it is used to treat pancreatic cancer that hasn’t spread but can’t be removed by surgery. For this, it may be given with chemotherapy (chemoradiation) to shrink the cancer and keep it under control for as long as possible.

Radiotherapy can also be given to relieve symptoms caused by the cancer. This is called palliative radiotherapy. It is most likely to be used to treat pain. It works by shrinking the tumour and reducing the pressure that is causing pain. Palliative radiotherapy is given at lower doses than radiotherapy used to control the cancer. It is usually given as a shorter course of treatment so it is less likely to cause side effects.

Radiotherapy is given in the hospital radiotherapy department. How the treatment is given depends on your needs. Sometimes, a single treatment is all that is needed. Or, a course of radiotherapy may be given as a series of short daily sessions. Each treatment takes 10–15 minutes. A course of treatment is usually given daily, Monday–Friday, with a rest at the weekend. Your doctor will discuss the treatment and possible side effects with you. You may be offered radiotherapy as part of a clinical trial (see pages 42–43).
Being positioned for radiotherapy
Planning your radiotherapy

Radiotherapy has to be carefully planned to make sure it’s as effective as possible. It is planned by a cancer specialist (clinical oncologist) and it may take a few visits.

On your first visit to the radiotherapy department, you’ll be asked to have a CT scan or lie under a machine called a simulator, which takes x-rays of the area to be treated.

You may need some small marks made on your skin to help the radiographer (who gives you your treatment) position you accurately and to show where the rays will be directed. These marks must stay visible throughout your treatment, and permanent marks (like tiny tattoos) are usually used. These are extremely small, and will only be done with your permission. It may be a little uncomfortable while they are done.

Treatment sessions

At the beginning of each session of radiotherapy, the radiographer will position you carefully on the couch and make sure you are comfortable. During your treatment you’ll 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 will have to lie still for a few minutes during the treatment.
Side effects

Radiotherapy for pancreatic cancer can cause side effects such as sickness, diarrhoea and tiredness. These side effects are usually mild and depend on how much treatment you are having. Your cancer specialist will be able to advise you what to expect and can give you treatments to help with any symptoms.

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

We have a booklet called Understanding radiotherapy, which you may find helpful.
Supportive care (to control symptoms)

For many people with pancreatic cancer, the main aim of treatment is to control symptoms. Chemotherapy, radiotherapy and surgery can all be used to control symptoms. You may also be offered other treatments to help. These will help you feel better and have the best possible quality of life. This is known as supportive care.

You may be referred to a palliative care team by your GP or cancer specialist. This is a team of doctors and nurses who will work with you, your GP, and other health professionals to make sure that your symptoms are controlled. They are based in hospitals, hospices, palliative care units and pain clinics. They are experts in helping control symptoms such as pain, tiredness, changes in bowel habits, loss of appetite, weight loss and other problems caused by pancreatic cancer.

Our booklet Controlling the symptoms of cancer gives information about treating different symptoms.
Blockages and stents

If the cancer is blocking your bile duct or your duodenum, this can often be treated with a flexible plastic or metal tube called a **stent**. The doctor puts the stent into the bile duct or the section of bowel that is blocked by the cancer. The stent holds the duct or bowel open, so it’s no longer blocked.

Sometimes, a stent needs to be replaced if it becomes blocked or if an infection occurs. If a plastic stent has been in place for a long time, it may need to be replaced with a new one.

Stents for blockages in the duodenum are usually put in using an **endoscopy**. You will be asked not to eat or drink for about six hours before the procedure. Your doctor or nurse will give you an injection to help you to relax (a sedative). They will also spray some local anaesthetic on to the back of your throat. The doctor passes a thin flexible tube (endoscope) down your throat, into your stomach and then into your duodenum. An expandable, flexible tube is then put down the endoscope and into the duodenum to hold it open.

Bile duct stents are most commonly put in using an **ERCP** (see page 26) but can also be put in during a procedure called a percutaneous transhepatic cholangiogram (PTC).
PTC (percutaneous transhepatic cholangiogram)
If a stent can’t be passed into the bile duct during an ERCP, the doctor may do a PTC instead. This involves inserting the stent through the skin (percutaneous) and liver (transhepatic) into the top of the bile duct, using a needle and tube.

You will be asked not to eat or drink for a few hours before a PTC. The procedure is carried out in the x-ray department by a doctor called a radiologist. Once you are lying down, your doctor will give you a sedative so that you feel relaxed and drowsy.

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

Some people feel warm all over when the dye is injected. This is normal and the feeling wears off quickly.

The dye flows through the ducts, showing the area that is blocked. The doctor passes a fine guide wire along the needle into the blockage in the bile duct. A stent is then passed along this wire. The stent holds open the bile duct where it has narrowed, allowing fluid to flow through it again. You may feel some pushing when the wire and stent are being put in. If this is uncomfortable or painful, let the doctor know so that you can be given painkillers.

To help prevent infection, you will be given antibiotics before and after the procedure. You will probably need to stay in hospital for a few days.
Pain control

Pain caused by pancreatic cancer can usually be well controlled. If you are in pain, it’s important to let your nurse or doctors know as soon as possible so it can be treated. Your medical team will work with you to develop the best pain control plan for you.

Giving your doctor or nurse as much information as you can about your pain will help them to assess it and plan treatments. You may want to tell them:

- how your pain rates on a scale of 0 (no pain) to 10 (worst pain you’ve ever felt)
- what words best describe your pain – for example, is it dull, sharp, shooting or aching?
- what makes the pain better or worse
- how your pain affects the things you want to do.

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. Painkillers can also be given by injection or infusion into a vein. Your doctors and nurses will help you find the drugs that work best for you.

Cancer treatments

Cancer treatments such as chemotherapy (see pages 57–63) or radiotherapy (see pages 64–67) can also be used to relieve pain. They work by shrinking the cancer to reduce any pressure that is causing pain.
Nerve blocks
If your pain can’t be well controlled with painkillers, your doctor may suggest you have a procedure called a nerve block. This stops pain messages from getting to the brain by blocking the nerves. It is usually done by injecting an anaesthetic into the nerve. Sometimes, the nerve can be cut rather than injected. This can be done under sedation using an endoscope or under general anaesthetic during other surgery, such as bypass surgery.

Different nerve blocks can be used depending on which nerves need to be treated. Your doctor will talk to you about these.

Other treatments
Your pain team may talk to you about other possible ways of helping with your pain. These may include relaxation techniques, breathing exercises, massage or distraction techniques.

We have more information about these and other treatments in our booklet Controlling cancer pain. To order our booklets, call 0800 808 00 00 (Mon–Fri, 9am–8pm) or visit macmillan.org.uk
Managing tiredness

Many people with pancreatic cancer feel tired and have less energy to do the things they normally do. This may be due to the cancer or it may be a side effect of treatment.

Your body will tell you when you need to rest. When you do feel like doing things, try to pace yourself. Keeping a diary can help you record your energy levels and plan to do things when you’re feeling stronger.

Physical activity can be helpful for some people. One study found that, after surgery to remove pancreatic cancer, people who took regular walks had more energy and felt less tired.

Some causes of tiredness can be treated. For example, anaemia (low number of red blood cells) can be treated with a blood transfusion. Your doctor can take a blood sample from you to find out if you have anaemia.

Coping with pain is tiring and affects the quality of your sleep. If pain is causing or contributing to your tiredness, then good pain control will help you feel better and may improve your energy levels.

Many people find they can’t sleep because of worry or anxiety. It can help to try to share concerns by writing them down or talking 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 be very useful in reducing anxiety and stress.
Tiredness can also be a sign of depression. If you think you’re depressed, talk to your doctor or nurse. Talking about your feelings with a professional counsellor can often help with depression, and antidepressants may help you feel better.

Our booklet *Coping with fatigue* has tips to help you cope with tiredness.
Digestion and weight loss

Pancreatic cancer can cause problems with eating and digestion. If your pancreas isn’t working properly, you may not be able to digest fats and proteins. You may have diarrhoea and not absorb nutrients from food properly. This can lead to weight loss. If you have diarrhoea, it may help to avoid fatty or high-fibre foods. Try to drink plenty of fluids. Your doctor may prescribe tablets to help with digestion.

Try to maintain your weight by adding extra calories where you can. 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.

‘I found I had to eat little and very often at first. From eating three times a day, I had to go to six times.’
Mark

If your appetite isn’t good, medicines such as steroids may help to improve it. You may be referred to a dietitian at your hospital. Dietitians are experts in assessing the nutritional needs of people who are ill. They can advise you on which foods are best for you and also whether any food supplements would help. If you are at home, your GP can arrange this for you.

Our booklet The building-up diet has more information.
Body image

Cancer and its treatment can change how your body looks, works or feels. These changes can happen quickly or over time, and may be temporary or permanent. It is natural to have concerns about this.

You may feel embarrassed or anxious about changes to your body, or concerned that they may affect your relationships. It is normal to have these feelings when coming to terms with body changes.

It is important to remember that help and support is available. Talk to your doctor or nurse or with a trusted family member or friend. It may also help to share your experience with others in a similar situation through online community groups.

Our booklet Body image and cancer has more information and advice on how to deal with this. Or visit our online community at macmillan.org.uk/community talk to other people in similar situations.
**Blood clots**

Cancer can increase your risk of developing a blood clot (thrombosis), and some treatments may increase this risk further. A blood clot may cause symptoms such as pain, redness and swelling in a leg, or breathlessness and chest pain.

Blood clots can be very serious so it’s important to tell your doctor straight away if you have any of these symptoms. However, most clots can usually be successfully treated with drugs to thin the blood. 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
- keep your blood flowing by taking deep breaths and exercising the muscles in your legs regularly even when you’re 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 may be done to reduce your risk.
YOUR FEELINGS AND RELATIONSHIPS

Your feelings 80
If you are a relative or friend 86
Talking to children 89
Your feelings

It is 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 will 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 is 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.
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.

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
You can also talk to other people going through the same thing on our online community at macmillan.org.uk/community

It is 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.

Our booklet How are you feeling? The emotional effects of cancer discusses the feelings you may have in more detail, and has suggestions for coping with them.

Share your experience

Many people find it helps 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 are perhaps about to start their treatment. Just hearing about how you’ve coped, what side effects you had and how you managed them is very helpful to someone in a similar situation.

We can help you share your story. Call us on 0808 808 00 00 or visit macmillan.org.uk/cancervvoices for more information.
Support groups or online support

These offer a chance to talk to other people who have been or are in a similar situation. You can share experiences and ways of coping. They can help if you live alone, or don’t feel able to talk about your feelings with people around you.

You can go along to see what a support group is like before you decide to get involved. Call us on 0808 808 00 00 or visit macmillan.org.uk/supportgroups for information about cancer support groups across the UK.

Our online community at macmillan.org.uk/community is a social networking site where you can talk to people in our chat rooms, blog your journey, make friends and join support groups. You can share your own experiences and feelings, and get support from others.

‘It’s like walking off the end of a pier and if it wasn’t for Macmillan and other charities offering support, I wouldn’t have known what to do.’

Derek
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 to find out more.

Our booklet Lost for words – how to talk to someone with 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 is based on carers’ experiences and has lots of practical tips and information.
We have a website called The Source which has comments and advice from people who have had cancer or been affected in some way (source.macmillan.org.uk). You can find valuable information to help you know what to say or do when someone you care about has cancer. You can also share your own tips.

We have more information about supporting someone with cancer at 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 is 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 which has been developed especially for teenagers who have a parent with cancer.
After treatment – follow-up

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 and ask about any concerns and needs you have.

You may have a holistic needs assessment to assess your care needs. Then a care plan can be made up based on this. It should give information about the support you’re getting and other services that may be useful.

You should have a copy of the care plan to use at follow-up appointments or 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 produce a treatment summary which describes the treatment you’ve had, what you should expect and details of the follow-up care or tests you’ll have. You keep a copy and the hospital should send another to your GP.

These assessments, care plans and treatment summaries aren’t used everywhere, but more hospitals are starting to use them.

After treatment is finished, or if you are having supportive care, you will still have regular follow-up appointments. You may keep going to the hospital for these appointments, or you may go to your GP. This 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). If you have any problems, or notice any new symptoms between appointments, let your doctor know as soon as possible.

Many people find they get very anxious before appointments. This is natural and it may help to get support from family, friends or one of the organisations on pages 112–123 during this time.

For people whose treatment is over, apart from regular check-ups or symptom control, our booklet *Life after cancer treatment* gives useful advice.

‘Life changes all the time and that’s no bad thing. I would rather have not been down this road, but I certainly feel now that the road I’m on is the road to recovery. So that’s where I’m staying.’

Maureen
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’re 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’ve 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. Your cancer team and GP can give you advice on this.

Ask if there are any health and well-being clinics in your area. These clinics are run by volunteers and Macmillan professionals. They can give you support and advice on diet, lifestyle and adjusting to life after treatment.

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.
Complementary therapies

Some people find that complementary therapies can reduce symptoms and help them to feel better. It is important to discuss your planned therapy with your specialist or GP to check if there are any reasons why you shouldn’t go ahead. Many doctors are now comfortable with medical and complementary therapies being used together.

Many hospitals and hospices offer complementary therapies. Treatments may include acupuncture, massage, aromatherapy and relaxation techniques.

Therapies such as gentle massage can be carried out by your relatives or carers, and this can help them to support you.

We can send you our booklet about Cancer and complementary therapies.

‘I have gone from strength to strength and my outlook and approach to life is much more realistic and fun. I have been far more active over the 14 months or so than I have for many, many years.’

Colin
Who can help?

Many people are available to help you and your family.

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

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

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

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

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

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

If you are struggling to cope with the financial effects of cancer, help is available.

If you cannot work because you are ill, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks of sickness. If you qualify for it, they cannot pay you less.

Before your Statutory Sick Pay ends, or if you do not qualify for it, check whether you can get Employment and Support Allowance (ESA). This benefit is for people who cannot work because they are ill or disabled.

There are two different types of ESA:

• contributory – you can get this if you have made enough national insurance contributions

• income-related – you can get this if your income and savings are below a certain level.

Since October 2013, a new benefit called Universal Credit has started replacing income-related ESA in England, Scotland and Wales. This benefit is for people who are looking for work or on a low income.

Personal Independence Payment (PIP) is a new benefit for people under 65 who find it difficult to walk or look after themselves (or both). You must have had these difficulties for at least three months, and they should be expected to last for the next nine months. Since April 2013, PIP has started to replace a similar older benefit called Disability Living Allowance (DLA) in England, Scotland and Wales.
Attendance Allowance (AA) is for people aged 65 or over who find it difficult to look after themselves. You may qualify if you need help with things like getting out of bed, having a bath or dressing yourself. You don’t need to have a carer, but you must have needed care for at least six months.

If you are terminally ill, you can apply for PIP, DLA or AA under the ‘special rules’. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

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 don’t qualify for it, you can apply for Carer’s Credit. This helps you to build up qualifying years for a State Pension.

More information

The benefits system can be hard to understand, so it’s a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on 0808 808 00 00. We have just listed some benefits here, but there may be others you can get.

You can find out about state benefits and apply for them online at gov.uk (England, Wales and Scotland) and nidirect.gov.uk (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines (see page 117) or Citizens Advice (see page 117). In Northern Ireland, you can call the Benefit Enquiry Line Northern Ireland on 0800 220 674.
Insurance

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on page 118.

Our booklets Insurance and Getting travel insurance may also be helpful.
Work

You may need to take time off work during your treatment and for a while afterwards. It can be hard to judge the best time to go back to work, and this will depend mainly on the type of work you do and how much your income is affected. It is important to do what’s right for you.

Getting back into your normal routine can be very helpful, and you may want to go back to work as soon as possible. It can be helpful to talk to your employer about the situation – it may be possible for you to work part-time or job share.

On the other hand, it can take a long time to recover fully from cancer treatment, and it may be many months before you feel ready to return to work. It is important not to take on too much, too soon. Your consultant, GP or specialist nurse can help you decide when and if you should go back to work.

Employment rights

The Equality Act 2010 protects anyone who has, or has had, cancer. Even if a person who had cancer in the past has been successfully treated and is now cured, they are still covered by the act. This means their employer must not discriminate against them for any reason, including their past cancer. The Disability Discrimination Act protects people in Northern Ireland.

Our booklets Work and cancer, Working while caring for someone with cancer and Self-employment and cancer have more information that may be helpful. There is also lots more information at macmillan.org.uk/work
FURTHER INFORMATION

About our information 107
Other ways we can help you 109
Other useful organisations 112
Your notes and questions 124
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.

All of our information is also available online at macmillan.org.uk/cancerinformation

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. 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. No one should face cancer alone.

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 Monday–Friday, 9am–8pm. Our cancer support specialists can:

- help with any medical questions you have about your cancer or treatment
- help you access benefits and give you financial advice
- 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](http://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](http://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

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

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 advice
Our financial guidance team can give you advice 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 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

Macmillan’s My Organiser app
This 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 Research Fund
PO Box 47432,
London N21 1XP
Tel 020 8360 1119
Email info@pcrf.org.uk
www.pcrf.org.uk
A national charity funding research into pancreatic cancer throughout the UK.

Pancreatic Cancer UK
2nd Floor, 89 Camelford House, Albert Embankment,
London SE1 7TW
Tel 020 3535 7090 (general enquires)
020 3535 7099 (support and information)
Email enquiries@pancreaticcancer.org.uk (general enquires)
support@pancreaticcancer.org.uk (support and information)
www.pancreaticcancer.org.uk
Funds research and provides a support network for patients and carers.
Further information

General cancer support organisations

**Cancer Black Care**
79 Acton Lane,
London NW10 8UT
**Tel** 020 8961 4151
**Email** info@cancerblackcare.org.uk
www.cancerblackcare.org.uk
Offers information and support for people with cancer from ethnic communities, their friends, carers and families.

**Cancer Focus Northern Ireland**
40–44 Eglantine Avenue,
Belfast BT9 6DX
**Helpline** 0800 783 3339
(Mon–Fri, 9am–1pm)
**Email** hello@cancerfocusni.org
www.cancerfocusni.org
Offers a variety of services to people affected by cancer, including a free helpline, counselling and links to local support groups.

**Cancer Research UK**
Angel Building,
407 St John Street,
London EC1V 4AD
**Tel** 0300 123 1022
www.cancerhelp.org.uk
Has patient information on all types of cancer and has a clinical trials database.

**Cancer Support Scotland**
The Calman Centre,
75 Shelley Road,
Glasgow G12 0ZE
**Tel** 0800 652 4531
**Email** info@
cancersupportscotland.org
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

**Macmillan Cancer Voices**
www.macmillan.org.uk/cancervoices
A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.
Maggie’s Centres
20 St. James Street,
London W6 9RW
Tel 0300 123 1801
Email enquiries@maggiescentres.org
www.maggiescentres.org
Provides information about cancer, benefits advice, and emotional or psychological support.

Penny Brohn Cancer Care
Chapel Pill Lane,
Pill, Bristol BS20 0HH
Helpline 0845 123 2310
(Mon–Fri, 9.30am–5pm, Wed 6–8pm)
Email helpline@pennybrohn.org
www.pennybrohn.cancercare.org
Offers a combination of physical, emotional and spiritual support, using complementary therapies and self-help techniques.

Riprap
Maggie’s, The Stables,
Western General Hospital,
Crewe Road,
Edinburgh EH4 2XU
www.riprap.org.uk
Developed especially for teenagers who have a parent with cancer.

Tenovus
Head Office,
Gleider House,
Ty Glas Road,
Cardiff CF14 5BD
Helpline 0808 808 1010
(Mon–Sun, 8am–8pm)
Email info@tenovuscancercare.org.uk
www.tenovus.org.uk
Aims to help everyone get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, an ‘Ask the nurse’ service on the website and benefits advice.
General health information

Health and Social Care in Northern Ireland
www.hscni.net
Provides information about health and social care services in Northern Ireland.

Healthtalk
Email
info@healthtalkonline.org
www.healthtalk.org
www.youthhealthtalk.org
(site for young people)
Has information about cancer, and videos and audio clips of people’s experiences.

National Cancer Institute
National Institute of Health – USA
www.cancer.gov
Gives information on cancer and treatments.

NHS Direct Wales
www.nhsdirect.wales.nhs.uk
NHS health information site for Wales.

NHS Inform
www.nhsinform.co.uk
NHS health information site for Scotland.

Patient UK
www.patient.co.uk
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.

NHS Choices
www.nhs.uk
The UK’s biggest health information website. Has service information for England.
Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)
BACP House, 15 St John’s Business Park, Lutterworth, Leicestershire LE17 4HB
Tel 01455 883 300
Email bacp@bacp.co.uk
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor at itsgoodtotalk.org.uk

Samaritans
Freepost RSRB-KKBY-CYJK, Chris, PO Box 9090, Stirling FK8 2SA
Helpline 116 123
Email jo@samaritans.org
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

UK Council for Psychotherapy (UKCP)
2nd Floor, Edward House, 2 Wakley Street, London EC1V 7LT
Tel 020 7014 9955
Email info@ukcp.org.uk
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Financial or legal advice and information

Benefit Enquiry Line
Northern Ireland
Helpline 0800 220 674
(Mon–Wed and Fri, 9am–5pm, Thu, 10am–5pm)
Textphone 028 9031 1092
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers’ benefits.
Citizens Advice
Provides advice on a variety of issues including financial, legal, housing and employment issues. Find details for your local office in the phone book or on one of these websites:

England and Wales
www.citizensadvice.org.uk

Scotland
www.cas.org.uk

Northern Ireland
www.citizensadvice.co.uk

You can also find advice online in a range of languages at adviceguide.org.uk

Civil Legal Advice
Helpline 0345 345 4345
(Mon–Fri, 9am–8pm,
Sat, 9am–12.30pm)
Minicom 0345 609 6677
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)
Disability Living Allowance Helpline 0345 712 3456
Textphone 0345 722 4433
Personal Independence Payment Helpline
0345 850 3322
Textphone 0345 601 6677
Carer’s Allowance Unit
0345 608 4321
Textphone 0345 604 5312
www.gov.uk/browse/benefits
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
Has comprehensive information about social security benefits and public services.
The Money Advice Service
Helpline 0300 500 5000
(Mon–Fri, 8am–8pm,
Sat, 9am–1pm)
Typetalk
18001 0300 500 5000
www.moneyadvice
service.org.uk
Runs a free financial
health check service
and gives advice about
all types of financial matters.
Has an online chat service
for instant money advice.

Money Advice Scotland
Helpline 0141 572 0237
www.moneyadvice
scotland.org.uk

National Debtline
(England, Wales
and Scotland)
Tricorn House,
51–53 Hagley Road,
Edgbaston,
Birmingham B16 8TP
Tel 0808 808 4000
(Mon–Fri, 9am–9pm,
Sat, 9.30am–1pm)
www.nationaldebtline.org
A national helpline for
people with debt problems.
The service is free, confidential
and independent.

Personal Finance Society –
‘Find an Adviser’ service
www.findanadviser.org
Use the website to find qualified
financial advisers in your area.

Unbiased.co.uk
Email contact@unbiased.co.uk
www.unbiased.co.uk
On the website you can
search for qualified advisers
who specialise in giving
financial advice, mortgage,
accounting or legal advice.

Equipment and advice
on living with a disability

The Blue Badge Scheme
(Department for Transport)
Allows drivers of passengers
with severe mobility problems
to park close to where they
need to go. Local authorities
deal with applications and
issue badges.

England, Wales, Scotland
www.gov.uk/browse/
driving/blue-badgeparking

Northern Ireland
www.nidirect.gov.uk/blue-
badge-scheme
British Red Cross
UK Office,
44 Moorfields,
London EC2Y 9AL
Tel 0344 871 11 11
Email information@redcross.org.uk
www.redcross.org.uk
Offers a range of health and social care services such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK
Ground Floor,
CAN Mezzanine,
49–51 East Road,
London N1 6AH
Tel 0207 250 8181
(Mon–Fri, 10am–12.30pm and 1.30–4pm)
Email enquiries@disabilityrightsuk.org
www.disabilityrightsuk.org.uk
Provides information on social security benefits and disability rights. Has a number of helplines for specific support, including information on returning to work, direct payments, human rights issues, and advice for disabled students.

Disabled Living Foundation (DLF)
Ground Floor,
Landmark House,
Hammersmith Bridge Road,
London W6 9EJ
Helpline 0300 999 0004
(Mon–Fri, 10am–4pm)
Email helpline@dlf.org.uk
www.dlf.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

Scope
6 Market Road,
London N7 9PW
Helpline 0808 800 3333
(Mon–Fri, 9am–5pm)
Email helpline@scope.org.uk
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 young people

**CLIC Sargent**
Horatio House,
77–85 Fulham Palace Road,
London W6 8JA
**Tel** 0300 330 0803
[www.clicsargent.org.uk](http://www.clicsargent.org.uk)
Provides clinical, practical, financial and emotional support to children with cancer.

**Teenage Cancer Trust**
3rd Floor, 93 Newman Street,
London W1T 3EZ
**Tel** 020 7612 0370
**Email** hello@teenagecancertrust.org
[www.teenagecancertrust.org](http://www.teenagecancertrust.org)
A charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer, their friends and families.

**Youth Access**
1–2 Taylors Yard,
67 Alderbrook Road,
London SW12 8AD
**Tel** 020 8772 9900
(Mon–Fri, 9.30am–1pm and 2–5.30pm)
**Email** admin@youthaccess.org.uk
[www.youthaccess.org.uk](http://www.youthaccess.org.uk)
A national organisation providing counselling and information for young people. Support is given through local young people’s services. Find your local service through the website.
Support for older people

**Age UK**
Tavis House,  
1–6 Tavistock Square,  
London WC1H 9NA

**Helpline (England and Wales)** 0800 169 6565  
**Helpline (Scotland)** 0800 470 8090  
**Helpline (Northern Ireland)** 0808 808 7575  
(Daily, 8am–7pm)

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

Provides information and advice for older people across the UK through the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

Support for carers

**Carers Trust (Princess Royal Trust for Carers in Scotland)**  
32–36 Loman Street,  
London SE1 0EH

**Tel (England)** 0844 800 4361  
**Tel (Scotland)** 0300 123 2008  
**Tel (Wales)** 0292 009 0087

**Email** info@carers.org  
[www.carers.org](http://www.carers.org) and  
[www.youngcarers.net](http://www.youngcarers.net)

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–Fri, 10am–4pm)
Tel (Northern Ireland) 028 9043 9843
Email advice@carersuk.org
www.carersuk.org
Offers information and support to carers across the UK. Can put people in contact with support groups for carers in their area.

Advanced cancer and end-of-life care

Hospice UK
Hospice UK, 34–44 Britannia Street, London WC1X 9JG
Tel 020 7520 8200
Email info@hospiceuk.org
www.hospiceuk.org
Provides information about living with advanced illness. Has a directory of hospice services and practical booklets available free from the website.

Marie Curie
89 Albert Embankment, London SE1 7TP
Helpline 0800 090 2309
(Mon–Fri, 9am–5pm)
Email supporter.relations@mariecurie.org.uk
www.mariecurie.org.uk
Marie Curie nurses provide free end-of-life care to people in their own homes, or in Marie Curie hospices, 24 hours a day, 365 days a year.

The Natural Death Centre
In The Hill House, Watley Lane, Twyford, Winchester SO21 1QX
Helpline 01962 712 690
Email contact@naturaldeath.org.uk
www.naturaldeath.org.uk
Offers independent advice on aspects of dying, funeral planning and bereavement.
Bereavement support

Cruse Bereavement Care
PO Box 800,
Richmond TW9 1RG
Helpline 0844 477 9400
(Mon–Fri, 9.30am–5pm)
Email helpline@cruse.org.uk
www.crusebereavementcare.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, at cruse.org.uk/
cruise-areas-and-branches

You can search for more organisations on our website at macmillan.org.uk/organisations, or call us on 0808 808 00 00.
YOUR NOTES
AND QUESTIONS
Disclaimer

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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, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Professor David Cunningham, Consultant Medical Oncologist and Head of the Gastrointestinal Unit; Dr Jeff Evans, Clinical Oncologist; and Jeremy French, Consultant in Transplantation and Hepatobiliary Surgery. Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.
Sources

We have listed a sample of the sources used in the publication below.
If you’d like further information about the sources we use, please contact us at bookletfeedback@macmillan.org.uk

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
Please fill in your personal details

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Surname
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Postcode
Phone
Email

Please accept my gift of £
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I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

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Valid from

Expiry date

Issue no

Security number

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 taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that 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

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

27530
More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don’t have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you’re entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit macmillan.org.uk

Hard of hearing? Use textphone 0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available. Braille and large print versions on request.