

Pancreatic Cancer UK



Pancreatic cancer
An overview of diagnosis
and treatment

Introduction

This booklet is for anyone who has recently been diagnosed with pancreatic cancer. Partners, family members and friends may also find it useful. It gives an introduction to pancreatic cancer, explains your diagnosis, and provides an overview of the treatment options. It also has information about the wider impact of being diagnosed with pancreatic cancer, and the support available.

There is a lot to take in at this time. This booklet has been designed so that you can dip in to get the information you need, when you need it.

- There are some questions that you may want to ask your medical team in each section.
- There is space for you to record the contact details of your medical team on page 57.
- You will find a list of common medical words on page 55.
- You can find the contact details of all the organisations mentioned on page 61.

If you have any questions about anything you read in this booklet, speak to your doctor or nurse. You can also speak to our specialist nurses on our confidential Support Line.



Call the specialist nurses free on **0808 801 0707**
or email **support@pancreaticcancer.org.uk**

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Section 1

About the pancreas and pancreatic cancer

The pancreas is a large gland that lies behind the stomach, at the back of the tummy (abdomen). It is about 15cm (6 inches) long and shaped a bit like a tadpole.



What is the pancreas?

The pancreas is often described as having a head, body and tail. It is surrounded by several large and important organs and blood vessels.

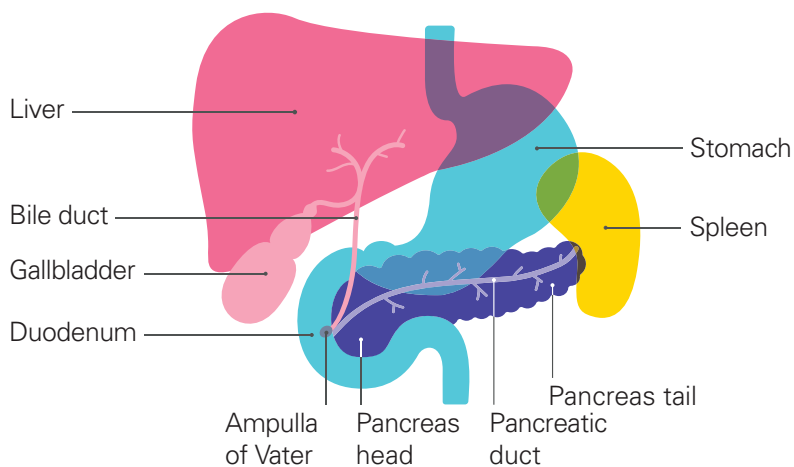
- The head of the pancreas is next to the duodenum (the first part of the small intestines).
- The common bile duct carries a fluid called bile from the liver. It passes through the head of the pancreas and empties into the duodenum.
- The blood vessels that carry blood to the liver, intestines, kidneys and lower part of the body are very close to the pancreas, and may touch it.

The pancreas has two main functions.

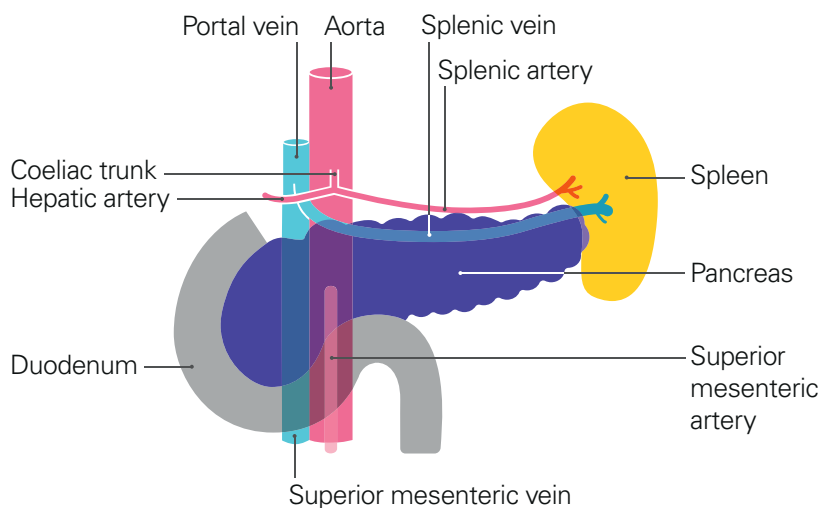
- It makes pancreatic juices containing enzymes. These enzymes help to break down food so the body can absorb it. The digestive juices flow down a tube called the pancreatic duct, which runs the length of the pancreas and empties into the duodenum.
- It makes hormones, including insulin, which control sugar levels in the blood.

Both of these functions can be affected if the pancreas isn't working properly.

The pancreas and surrounding organs



The pancreas with surrounding blood vessels



What is pancreatic cancer?

Normal healthy cells grow in a carefully controlled way. Pancreatic cancer develops when cells in the pancreas grow out of control, forming a lump (tumour). This can happen in the head, body or tail of the pancreas.

Pancreatic cancers are divided into two main groups.

- Exocrine tumours start in the exocrine cells. These cells make enzymes. About ninety-five out of a hundred pancreatic cancers (95%) are exocrine tumours. The most common type is pancreatic ductal adenocarcinoma – about eighty out of a hundred of all pancreatic cancers (80%).
- Endocrine tumours (also called neuroendocrine tumours) start in the cells that produce hormones. Less than five in a hundred (5%) of all pancreatic cancers are endocrine tumours.

Exocrine and endocrine tumours behave differently and are treated differently. The information in this booklet is mainly about exocrine tumours.



Read more about the different types of pancreatic cancer on our website at **pancreaticcancer.org.uk/types**



Questions to ask

What type of pancreatic cancer do I have?
Where in my pancreas is the cancer?

Section 2

Diagnosing pancreatic cancer

It can take a long time to be diagnosed with pancreatic cancer. It often doesn't cause any symptoms to begin with, and so may be diagnosed at a later stage when it can be more advanced.



You will have had a number of different tests to confirm your diagnosis of pancreatic cancer. And you may still need some tests, for example to find out exactly what type of pancreatic cancer you have and what stage it is (see page 10).



We have detailed information about the tests used to diagnose pancreatic cancer on our website, at **pancreaticcancer.org.uk/tests**

Waiting for tests

Sometimes you may have to wait a few days – or even as long as two weeks – for some scans or tests. If you haven't heard anything within two weeks, speak to your doctor or nurse. It may also help to speak to the consultant's secretary.

People with pancreatic cancer can start to feel very unwell quite quickly. If your symptoms get worse or you start to feel more unwell while you are waiting for tests, speak to your GP or specialist nurse. They can help you manage symptoms, and contact the medical team for you if necessary. If you have to go into hospital for any reason, ask if any of the tests you are waiting for can be done while you are there.

Symptoms to watch out for include:

- losing weight even though you are eating
- feeling or being sick (nausea and vomiting)
- bowel problems, including yellow, oily stools (poo) that smell horrible and are difficult to flush down the toilet (steatorrhoea), and loose watery stools (diarrhoea)
- pain
- jaundice, which causes yellow skin or whites of the eyes, and often, itching.

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

It may take from a few days to a couple of weeks for the results to come through. Ask how long you may have to wait when you go for the test. You can also ask who to contact if you don't hear anything.



Waiting for test results can be an anxious time. You might find it helps to talk things over with one of our specialist nurses on our free Support Line.

Test results

Your test results will give your doctors detailed information about your cancer, and help them to work out the best treatment for you.

You may be told what stage your cancer is. Staging describes the size of a cancer and how far it has spread. Your treatment is often decided based on the stage of the cancer.

One type of staging uses numbers to describe the stage of the cancer.

Stage 1

The earliest stage – the cancer is contained inside the pancreas. This is known as **early, localised or resectable pancreatic cancer**. It may be possible to operate to remove the cancer (resectable).

Stage 2

The cancer has started to grow into the duodenum, bile duct or tissues around the pancreas, or there may be cancer in the lymph nodes near the pancreas. Lymph nodes are small glands

found around the body, which are part of the immune system. This may be **resectable pancreatic cancer** – it may be possible to operate to remove the cancer, depending on how far the cancer has grown.

Stage 3

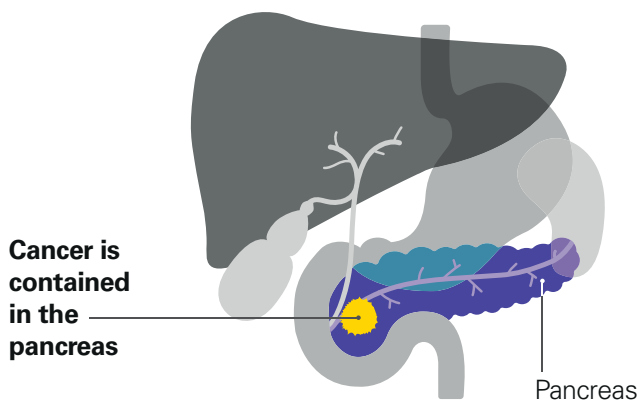
The cancer has spread into the stomach, spleen, large bowel or into large blood vessels near the pancreas. This is usually **locally advanced** or **unresectable pancreatic cancer**, which means it is not possible to remove the cancer with surgery (unresectable). However, it may very occasionally be **borderline resectable cancer** which means it may be possible to remove the cancer, but it depends which blood vessels are affected.

Stage 4

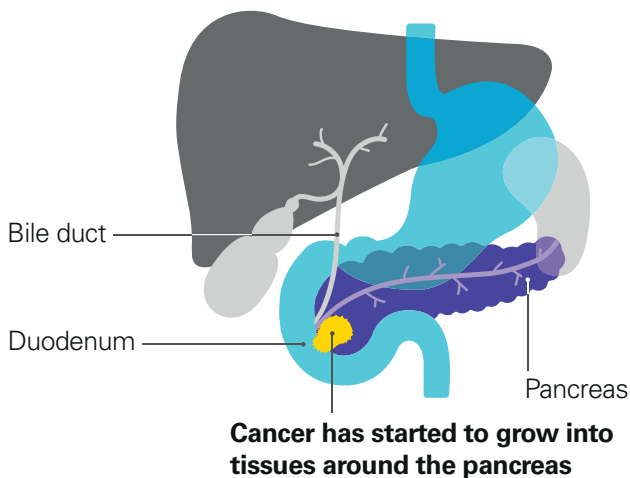
The cancer has spread to other parts of the body such as the lungs or liver. This is known as **advanced** or **metastatic pancreatic cancer**. It's not possible to remove the cancer with surgery (unresectable), as surgery can't remove all the cancer cells once they have spread to other parts of the body.

The diagrams on the next page show the different stages.

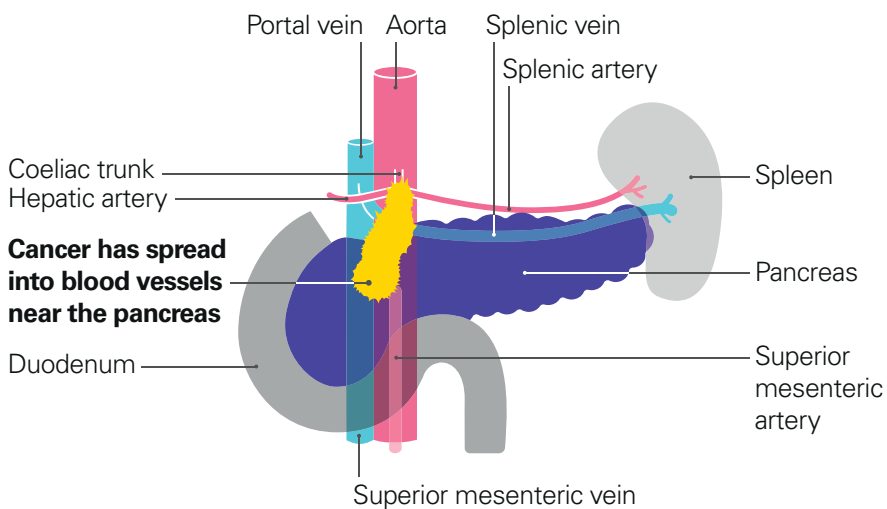
Stage 1 pancreatic cancer



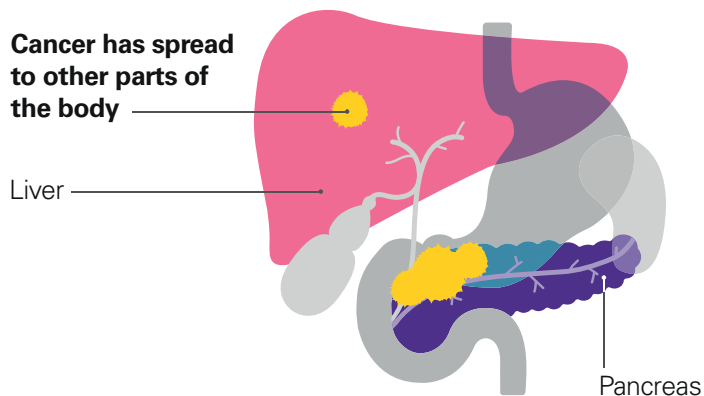
Stage 2 pancreatic cancer



Stage 3 pancreatic cancer



Stage 4 pancreatic cancer



Another system that is used is called TNM (Tumour-Node-Metastasis) staging.

T is the size of the tumour.

- **T1:** the cancer is contained inside the pancreas, and is smaller than 2cm.
- **T2:** the cancer is contained inside the pancreas, but is bigger than 2cm.
- **T3:** the cancer has started to grow into tissues around the pancreas, but it hasn't grown into the large blood vessels.
- **T4:** the cancer has grown into nearby large blood vessels.

N shows whether the cancer has spread to the nearby lymph nodes.

- **N0:** the cancer hasn't spread to nearby lymph nodes.
- **N1:** the cancer has spread to nearby lymph nodes.

M shows whether the cancer has spread to another part of the body (metastatic cancer).

- **M0:** the cancer hasn't spread to other parts of the body, such as the liver or lungs.
- **M1:** the cancer has spread to other parts of the body.

Your doctors will tell you the stage of your cancer and explain exactly what it means and how it affects your treatment.



You can read more about how pancreatic cancer is diagnosed and what your test results mean on our website at **pancreaticcancer.org.uk/diagnosis**

It may come as a shock to be diagnosed with pancreatic cancer. You may have all sorts of emotions, questions and concerns, and your family may also be struggling to come to terms with your diagnosis. There is support available to help you and your family cope – read more on page 47.

“My husband read everything and he knew exactly what was going to happen. He became my life line.”



You can speak to our specialist nurses on our free Support Line with any questions or worries about your diagnosis.



Questions to ask

Do I need more tests to confirm my diagnosis?

How long will I have to wait for these tests?

When will I get my test results?

What do my test results mean?

What stage is the cancer?

Has the cancer spread? If so, where to?

How does the stage affect my treatment?

Section 3

Being referred to a specialist centre

In the UK, anyone diagnosed with pancreatic cancer should have their case reviewed at a cancer centre where there is a specialist team to treat pancreatic cancer.



Specialist centres have been set up regionally across the UK, and hospitals in a region will work together with the specialist centres. In particular, surgery should only be carried out in specialist centres, as this gives people the best results.

You may not have to go to the specialist centre. Tests are often done at local hospitals, as is chemotherapy and radiotherapy treatment. But wherever you are treated, the specialist centre should always be involved in decisions about your treatment. Your doctor can tell you which specialist centre is involved in your care, and explain the decisions made by the specialist team.

If you take part in a clinical trial (see page 35), you may have your treatment at the specialist centre. This is because local hospitals may not always be involved in running clinical trials, or offer all the trials that are available at the specialist centre.



There is a list of hospitals with specialist pancreatic teams on our website at **pancreaticcancer.org.uk/specialistcentres**



You can also call our specialist nurses on our free Support Line to find out more about specialist centres.

Who will I be treated by?

The team of medical professionals responsible for your treatment and care is called the multidisciplinary team (MDT). You probably won't meet most of them, but they will discuss your test results and agree on the best treatment for you. They should also take your wishes into account.

The health professionals you are most likely to meet are the specialist nurse, gastroenterologist, oncologist, surgeon, and dietitian. You may meet others at different stages.

You will be given a main contact, often called a keyworker, who will usually be a specialist nurse. They will support you, and will be the person you speak to most. They will also be a part of the MDT, and will let them know how you are getting on.

There's more information about the people involved in the MDT on page 57. There's also space for you to note down their names and contact details.

Questions to ask

Is this a specialist pancreatic cancer centre?

Is my case being reviewed by a specialist pancreatic cancer centre? If not, why not?

Who are the members of my MDT?

Will I have a named specialist nurse?

If not, why not?

Who is my keyworker?

Who do I contact if I need to speak to someone in an emergency or out of normal hospital hours?

Section 4

What are my treatment options?

There are different treatment options for pancreatic cancer. These include surgery, chemotherapy, and treatment to control symptoms.



To work out the best treatment for you, your doctors will look at the type of pancreatic cancer you have, the stage of the cancer, where it is in the pancreas, and whether it's spread to any of the surrounding organs and blood vessels. They will also look at other things such as your age, and your general health and fitness.

Your treatment options will depend on whether it is possible to remove the cancer with surgery. But even if surgery to remove the cancer isn't possible, you may be able to have chemotherapy to slow down the growth of the cancer. And there are treatments available to help with symptoms.

The medical team will discuss your treatment options with you. It's a good idea to have someone with you – they can help you remember the discussion, or take notes. You may also want to have a list of questions to ask your doctor or nurse.

You don't have to make any decisions there and then. You will be given time to think about your options before deciding what you want to do. You may also want to discuss things with your family or GP. You will be given another appointment to discuss any questions you may have. Your treatment should start within 31 days of being diagnosed. But you won't start any treatment until you give your permission for it, usually by signing a consent form.

Can I get a second opinion?

You can ask for a second opinion if you wish. This means seeing a different doctor, possibly in another hospital, for their opinion about your diagnosis and treatment options.

A second opinion is free on the NHS or can be paid for privately. You don't have a legal right to a second opinion, but doctors usually won't refuse you.

Asking for a second opinion won't affect your care. But it can take time, so it's a good idea to start any treatment while going through the process, rather than delaying treatment.

Think about what getting a second opinion might mean. For example, if the doctors agree you may feel more confident. But if a different treatment is offered, you might worry about which treatment to choose.

NHS Choices, Citizens Advice and NHS Direct Wales have more information about getting a second opinion. If you live in England, the My Cancer Treatment website lists cancer services and the quality of care you can expect. See page 61 for contact details.

? Questions to ask

What treatment do you recommend for me?

What is the likely result of the recommended treatment?

What are the risks and side effects of the recommended treatment?

Can I get a second opinion? How do I go about getting one?

Section 5

When surgery to remove the cancer is possible

People who are diagnosed with early pancreatic cancer (see page 10) have more treatment options and a better chance of a good outcome. You may be offered surgery and chemotherapy, and occasionally radiotherapy.



Surgery

You may be able to have surgery to completely remove the cancer if:

- the cancer is small
- there are no signs that it has spread beyond the pancreas – especially to the large blood vessels nearby, and
- you are fit and healthy.

This is known as resectable (operable) cancer.

Surgery is the most effective treatment for early stage pancreatic cancer. However, only one to two out of ten people (10-20%) can have surgery. This is because pancreatic cancer is very hard to diagnose at an early stage when an operation may be possible.

Some tumours may be very close to the major blood vessels near the pancreas. These may be called borderline resectable tumours. This means that it may be possible to remove the tumour, but it depends which blood vessels are affected and how far the cancer has grown. Occasionally, you may be offered chemotherapy, and sometimes radiotherapy, before surgery to try to shrink the cancer and make surgery more successful. But the evidence for how well this works is still unclear.

Sometimes, the surgeons find once they have started an operation that it isn't actually possible to remove the cancer. They may still carry out other procedures to help relieve symptoms (see page 28), and you will usually have chemotherapy to treat the cancer. It can be very upsetting to find out that it wasn't possible to remove the cancer. Speak to your doctor or nurse about what your options are, and what support is available.



You can also call our specialist nurses on our Support Line to talk things through. See page 47 for more information about support available.

Types of surgery

There are several different operations. They involve removing all or part of the pancreas, and sometimes other structures around it. Your surgeon will discuss the best surgery for you, depending on where the cancer is and how much of the pancreas is affected.

- **Whipple's operation (pancreaticoduodenectomy or PD):** this is the most common type of surgery. It's usually used for tumours in the head of the pancreas (see page 6) that haven't spread beyond the pancreas. The surgeons remove the head of the pancreas, the lower end of the stomach, the duodenum (first part of the small intestines), the bile duct, gall bladder and surrounding lymph nodes. They then attach the remaining part of the pancreas, stomach and bile duct to the small intestines.
- **Pylorus-preserving pancreaticoduodenectomy (PPPD):** this is similar to the Whipple's operation, but the lower end of the stomach isn't removed. This means that the stomach valve (the pylorus), which controls the flow of food into the duodenum, isn't removed.
- **Distal pancreatectomy:** this involves removing the body and tail of the pancreas (see page 6). It may also involve removing the spleen, which is very close to the tail of the pancreas.
- **Total pancreatectomy:** this involves removing the whole pancreas. It's done where there is a large tumour, or more than one tumour. It's not used very often in the UK.

Benefits and risks

There are benefits and risks to having surgery. You should discuss these with your medical team. It's the most effective treatment for early pancreatic cancer. But it will take several months, and even up to a year to fully recover from surgery.

Removing all or part of the pancreas may affect how well it works. You may get side effects that affect how well you can eat and digest food. You will need to take pancreatic enzyme supplements to help you digest food (see page 39). You may also develop diabetes and need medication to help control this (see page 40). Speak to your doctor, nurse or dietitian about this.



Speak to your doctor or nurse about what surgery involves and the side effects. You can also speak to our specialist nurses on our free Support Line.



Read more about surgery in our fact sheet, **Surgery for operable pancreatic cancer**, or on our website at pancreaticcancer.org.uk/surgery



Questions to ask

Can I have surgery to remove the cancer?

Is the cancer affecting any major blood vessels?

Which type of operation do I need?

How much of my pancreas will be removed?

How experienced is the surgeon at doing this type of operation?

What are the benefits and risks of surgery?

What are the side effects of surgery?

How will surgery affect eating and digestion?

Will I need to take any medication after surgery?

How long will it take me to recover?

Will I need any other treatment?

Chemotherapy

Chemotherapy uses anti-cancer drugs to destroy cancer cells. You may have chemotherapy after surgery to remove the cancer, to try to reduce the chances of the cancer coming back. Occasionally you may be offered chemotherapy before surgery – see page 31.

The drug most often used after surgery to remove the cancer is gemcitabine. Capecitabine may also be used. Occasionally, fluorouracil (5-FU) may be an alternative option, but this isn't common. Clinical trials (see page 35) are looking at the best ways to use these drugs after surgery.

Side effects of chemotherapy

Chemotherapy can cause side effects, although everyone is affected in different ways. Most people get some side effects, but it's unusual to get all the possible side effects. Side effects include feeling and being sick (nausea and vomiting), extreme tiredness (fatigue), and low blood cell levels. This can make you more likely to get infections, and cause anaemia.

There are ways to manage the side effects, and you may be given medication to help with some of them. For example, you may be prescribed anti-sickness medication to deal with feeling sick.



Speak to your doctor or nurse about whether you will have chemotherapy, what treatment will involve, and the possible side effects. You can also call our specialist nurses on our free Support Line.



Read more about chemotherapy, the different drugs, and side effects on our website at **pancreaticcancer.org.uk/chemotherapy**



Questions to ask

Will I have chemotherapy after my surgery?

Why do I need chemotherapy?

Which chemotherapy drugs will I have?

What are the side effects of chemotherapy?

Are there any clinical trials involving chemotherapy that I could take part in?

Radiotherapy

Radiotherapy uses high-energy x-rays (radiation) to destroy cancer cells.

Occasionally radiotherapy may be offered before surgery, to shrink the cancer (see page 33). Or it may be offered after surgery, to try to make sure no cancer cells are left.

Radiotherapy may be given together with chemotherapy. This is called chemoradiotherapy.



Read more about radiotherapy on our website at **pancreaticcancer.org.uk/radiotherapy**

Section 6

When surgery to remove the cancer isn't possible

If it's not possible to remove the cancer with surgery, you will be offered treatment to control the growth of the cancer and any symptoms.



Because pancreatic cancer is so difficult to detect, by the time it is diagnosed, the cancer may have grown quite large or spread to nearby organs or blood vessels (locally advanced cancer – see page 11). Or it may have spread beyond the pancreas to other parts of the body (advanced or metastatic cancer – see page 11).

You may have been told that your cancer is inoperable, which means that surgery to remove it isn't possible. Instead you may have other treatment to help control the growth of the cancer, relieve any symptoms it is causing, and generally improve how you feel. The aim is to control your symptoms and give you the best possible quality of life.

Treatments to relieve a blocked duodenum or bile duct

The cancer might grow so that it blocks your duodenum (first part of the small intestines) or your bile duct (tube that carries bile from the liver).

- If your duodenum is blocked, food won't be able to get through to your bowel. It will build up in your stomach, and cause discomfort, sickness and vomiting.
- If your bile duct is blocked, you may get jaundice. Symptoms of jaundice include yellow skin and eyes, and itching.

In both situations a small plastic or metal tube (stent) can be inserted. This should open up the duodenum or bile duct.

Alternatively, you may be able to have an operation to bypass the blockage.

- For a blocked duodenum, the part of the small intestines just below the duodenum is connected directly to your stomach. This allows food to pass from the stomach into the intestines.
- For a blocked bile duct, the bile duct is cut above the blockage and reconnected to the small intestines. This allows the bile to flow into the small intestines.

Sometimes these two procedures are done at the same time.



Speak to your doctor or nurse about what having a stent inserted, or bypass surgery, involves. You can also call our specialist nurses on our free Support Line.



Read more about stents and bypass surgery in our fact sheet, **Surgery and other procedures to control symptoms**, or on our website at **pancreaticcancer.org.uk/surgeryinoperable**



Questions to ask

What treatment can I have for my jaundice?

What treatment can I have for a blocked bowel?

Which would be better for me – a stent or bypass surgery?

What are the benefits and risks of inserting a stent or bypass surgery?

What are the side effects of inserting a stent or bypass surgery?

Chemotherapy

If you have **locally advanced pancreatic cancer**, chemotherapy or chemotherapy combined with radiotherapy (chemoradiotherapy – see page 33) can be used to shrink the cancer, slow down its growth, and relieve your symptoms. For some people, this treatment shrinks the cancer enough to make surgery possible (see page 22).

If you have **advanced pancreatic cancer**, chemotherapy can be used to slow down the growth of the cancer and relieve your symptoms. Chemotherapy won't cure the cancer, but it may help people to live longer and improve the quality of their daily life.

Chemotherapy can cause side effects (see page 26), although there are ways to manage them.

Chemotherapy drugs for inoperable pancreatic cancer

The first chemotherapy drugs you have are called first-line therapy. Which chemotherapy treatment you have will depend on a variety of things, including how fit and well you are, your blood test results, and your own preference.

First-line chemotherapy includes some of the following options.

- Gemcitabine is one of the standard treatments for locally advanced and advanced pancreatic cancer. It can be effective in controlling pancreatic cancer and improving symptoms. It may be given on its own or in combination with other chemotherapy drugs.
- FOLFIRINOX is a combination of drugs (leucovorin, fluorouracil, irinotecan and oxaliplatin). It can shrink the cancer, and may sometimes shrink it enough to make surgery possible. It is only suitable for people who are fit and well enough to cope with several different drugs. This is because it can cause a lot of side effects which can be difficult to cope with.

- Nab-paclitaxel (Abraxane®) in combination with gemcitabine is an option for treating advanced pancreatic cancer. Access to nab-paclitaxel on the NHS is limited – speak to your doctor or nurse about whether it might be available for you. For up-to-date information see our website at **pancreaticcancer.org.uk/abraxane**
- Capecitabine is usually given in combination with gemcitabine (GemCap) to treat advanced pancreatic cancer. Occasionally it may be used on its own as second-line treatment for patients who have already had gemcitabine as first-line treatment.

There are clinical trials looking at different chemotherapy drugs and drug combinations (see page 35).

Speak to your doctor or nurse about what chemotherapy treatments might be suitable for you, the side effects and how to manage them, and any possible clinical trials.



You can also call our specialist nurses on our free Support Line.



Read more about chemotherapy in our fact sheet, **Chemotherapy for pancreatic cancer**, or at **pancreaticcancer.org.uk/chemotherapy**



Questions to ask

Will chemotherapy help control my cancer?

Will chemotherapy relieve any of my symptoms?

Are there any clinical trials I could take part in?

Radiotherapy

Radiotherapy may be an option if you have locally advanced pancreatic cancer. It is most commonly used together with chemotherapy (chemoradiotherapy). Studies have shown that chemoradiotherapy can be an effective treatment for locally advanced cancer.

Radiotherapy or chemoradiotherapy won't cure the cancer, but they may help control it and slow down its growth. In a small number of cases, treatment can shrink inoperable tumours enough to make it possible to remove them with surgery (see page 22).

Radiotherapy can also be helpful if you have advanced pancreatic cancer. The aim is to control and relieve symptoms, and improve the quality of your daily life. Radiotherapy used in this way is called palliative radiotherapy.

Radiotherapy can cause side effects such as tiredness, nausea and diarrhoea. Many people will only have mild side effects, and severe side effects are uncommon. Most side effects can be managed, sometimes with medication.

Speak to your doctor or nurse about whether radiotherapy is suitable for you, and what it involves.



You can also call our specialist nurses on our free Support Line.



Read more about radiotherapy at
pancreaticcancer.org.uk/radiotherapy

Questions to ask

Will radiotherapy help control my cancer?

Will radiotherapy help me live longer?

Will radiotherapy relieve any of my symptoms?

What are the benefits and risks of radiotherapy?

Where will I have the radiotherapy?

Are there any clinical trials involving radiotherapy that I can take part in?

“Don’t be ashamed to ask for help. Doctors and medical professionals understand and will do everything they can to provide support.”

Section 7

Clinical trials

Clinical trials are medical research studies that involve patients. They are very carefully controlled. Most trials in pancreatic cancer are looking at finding better treatments, including better ways of using surgery, chemotherapy and radiotherapy.



If your doctor hasn't mentioned clinical trials to you, ask if there are any trials that might be suitable for you. There are pros and cons to taking part in a trial. For example, it may give you the opportunity to try a new treatment – although there is no guarantee that it will be effective.

Before you decide whether or not to take part in a trial, you will need to know exactly what's involved. You should be given information about the trial. Talk to your doctor or nurse, and ask as many questions as you need, to help you decide. You can withdraw from the trial at any time if you change your mind, and it won't affect your care.



Read more about clinical trials and find trials that are available for pancreatic cancer on our website at **pancreaticcancer.org.uk/clinicaltrials**

Cancer Research UK also have a list of trials for pancreatic cancer.



Questions to ask

Are there any clinical trials I could join?

How do I find out about clinical trials?

What are the pros and cons of joining a trial?

Section 8

How does pancreatic cancer affect diet and nutrition?

The pancreas plays an important role in digesting food. Pancreatic cancer can affect this, which means that you may not be able to digest your food properly. But there are ways to manage this.



The pancreas produces enzymes that help to break down the food, so that nutrients from the food can be absorbed into the blood and used by the body. Pancreatic cancer can reduce the number of enzymes that your pancreas makes. It can also block the enzymes from getting to the duodenum, where they are needed for digestion. For example, the cancer can block the pancreatic duct, which carries the enzymes from the pancreas to the duodenum.

This means that food is not properly digested, and the nutrients in the food aren't absorbed. This can be treated with pancreatic enzyme supplements such as Creon® – see page 39.

The pancreas also produces hormones, including insulin, which control sugar levels in the blood. Pancreatic cancer can reduce the amount of hormones the pancreas produces. This can cause diabetes – see page 40.

Surgery for pancreatic cancer, where all or part of the pancreas is removed, will also affect the amount of enzymes and hormones produced by the pancreas.

What symptoms are related to diet?

It's common for people with pancreatic cancer to get symptoms caused by problems with eating and digesting food.

These can include:

- loss of appetite
- weight loss
- feeling and being sick (nausea and vomiting)
- loose watery stools (diarrhoea)
- yellow, oily, floating stools (steatorrhoea)

- tummy (abdominal) discomfort or pain
- bloating
- wind
- feeling full up quickly
- urgency in opening your bowels, especially after eating
- some people also develop diabetes.

Some diet problems can be caused by jaundice (see page 9), including loss of appetite, taste changes, feeling and being sick, and steatorrhoea. These usually improve once the jaundice is treated.

How can pancreatic enzyme supplements help?

Pancreatic enzyme supplements are capsules that replace the enzymes that your pancreas would normally produce. This is known as pancreatic enzyme replacement therapy (PERT).

They help to break down food, and can help to manage symptoms related to diet. Enzyme supplements can make a big difference to how you feel generally.

You should be told about pancreatic enzyme supplements by your doctor, nurse or dietitian. If you haven't been told about them, ask.

What support is there for problems with diet and eating?

A dietitian is a professional who provides advice about diet and nutrition. Specialist pancreatic or oncology dietitians are experts in diet and cancer, and can help with managing your dietary symptoms and preventing weight loss. They will also assess whether you need pancreatic enzyme supplements (see page 39) to help with digestion.

Finding ways to manage your dietary symptoms can help you feel better generally. If you haven't seen a dietitian, and you are having problems with your diet and eating, or are losing weight, ask your medical team or GP to refer you to one.

“If the person with pancreatic cancer needs to stop losing weight, it's important to always try new foods, and always have things available when the person feels able to eat.”

Diabetes

Your pancreas may not produce enough insulin if you have pancreatic cancer, or you have had all or part of your pancreas removed. This can cause diabetes, which is a condition where the amount of sugar in your blood is too high.

Symptoms of diabetes include feeling very thirsty, passing more urine than usual, rapid weight loss, headaches and tiredness.

If you are diagnosed with diabetes, you should see a doctor or diabetes nurse for help with managing it. It is important to get advice about diabetes that is relevant to you. There are different types of diabetes, and the information available on the internet may not be right for you, because of the pancreatic cancer.

You may need to monitor your blood sugar level, and take tablets or have insulin injections to stop your blood sugar levels becoming too high.



We have detailed information about issues related to diet, eating and nutrition, including how to take pancreatic enzymes and manage diabetes, in our booklet, **Diet and pancreatic cancer**, and on our website at **pancreaticcancer.org.uk/diet**



Questions to ask

Can I be referred to a specialist pancreatic or oncology dietitian?

How soon can I see a dietitian?

Would pancreatic enzyme supplements help with my diet symptoms?

How should I take pancreatic enzyme supplements?

Who should I ask for help with managing diabetes?

Section 9

Managing other symptoms and side effects

As well as problems with diet and eating, pancreatic cancer can cause a range of symptoms. Everyone is different, and people will get different symptoms at different stages of their cancer. There are ways to manage these symptoms.



Treatments for pancreatic cancer, such as chemotherapy and radiotherapy, can help with some of the symptoms – although they can also cause side effects (see pages 26 and 33).

Below are some of the common symptoms and side effects of pancreatic cancer.

- **Pain**, which can often start as general discomfort or pain in the tummy (abdomen) and can spread to the back. Pain can usually be well controlled. There are different treatments, depending on the cause of the pain. These include painkillers, radiotherapy, and a procedure called a nerve block (coeliac plexus nerve block), which destroys the nerves that supply the pancreas.
- **Feeling and being sick** (nausea and vomiting). Having a stent inserted or bypass surgery can help with feeling and being sick if it's caused by a blocked duodenum (see page 29). There are also anti-sickness medications available, which can help with sickness caused by chemotherapy. See page 38 for information about sickness caused by problems digesting food.
- **Changes to bowel habits** which can include constipation (problems opening the bowels), diarrhoea (loose watery stools) or steatorrhoea (see page 9). There are medications available to help manage constipation and diarrhoea. Make sure you drink plenty of fluids if you have diarrhoea.
- **Extreme tiredness (fatigue)**. Fatigue is common but there are ways to deal with it – read more on our website at [**pancreaticcancer.org.uk/fatigue**](http://pancreaticcancer.org.uk/fatigue)
Macmillan Cancer Support have a useful booklet called Coping with fatigue.

Some people find that complementary therapies can help them deal with some symptoms such as pain, and with the emotional effects of pancreatic cancer. See page 51 for more information.

If you are having any problems with symptoms or side effects, it's important that you speak to your doctor or nurse. They will help you find ways to manage them.



Read more about managing symptoms and side effects on our website at **pancreaticcancer.org.uk/managingsymptoms**



You can speak to our specialist nurses on our free Support Line if you have any concerns about symptoms.



Questions to ask

How can I manage my symptoms?

Will the treatment I'm having help with symptoms?

Who should I talk to if I get any new symptoms?

“Mum was anxious about changing symptoms. Some months there was no pain, but she vomited and had sweats, other times there was bad indigestion, sometimes there was pain in her abdomen. They seemed to shift a lot, and I urged her to keep track and make sure she told the doctors or Macmillan nurse. The nurse was amazing and really worked with her to get her symptoms sorted.”

Section 10

Help and support in the community

You may want to access community-based services at home, at some stage. For example, you might need help and support from a community nurse who can visit you at home, or from social services.



How services are organised varies in different areas. For example, community nursing might be provided by district nurses, palliative care nurses or Macmillan nurses. Ask your GP to help you access these services.

If you have been in hospital, before you are discharged you should have an assessment to work out what care and support you need at home. This may be called a care package. Your GP should be sent a letter explaining your condition. And you should be given a named person at the hospital to contact if you have any concerns or need more support.



You can read more about the nursing and social care available on our website at
pancreaticcancer.org.uk/practical



Questions to ask

How can I get support at home?

How do I get in touch with a community nurse?

And social care?

“The NHS organised for care nurses and a Macmillan Nurse to come to see Mum, and they have been really good. The nurse was a source of support as well as practical information, and has really helped my mother through some very rough times.”

Section 11

Coping with pancreatic cancer

Everyone reacts differently to being diagnosed with pancreatic cancer. You might feel that your world has been turned upside down, and feel shocked, numb, or frightened.



There is no 'right' way to feel. It's ok to be upset, angry, and to cry, shout or swear. If you have been unwell for some time, you may even feel a bit relieved that at least now you know what is wrong with you.

It can take time to come to terms with your diagnosis. You might find you have good and bad days. You will probably go through a range of emotions, from feeling positive and determined to get well again, to feeling low or worried about the future. People find different ways to cope, and there is support available. Your family and friends may also be struggling and need support.

What can help?

Finding out more

Some people find it helps to find out more about their cancer, treatment options and what the future might hold. Even if you don't want to know everything about pancreatic cancer, make sure you speak to your medical team, ask them questions, and understand what your diagnosis and treatment options mean.



We have information about pancreatic cancer, including treatments and side effects, on our website at **pancreaticcancer.org.uk/informationandsupport**



You can also call our specialist nurses on our free Support Line. They have time to listen to your concerns and answer questions about any aspect of pancreatic cancer. The service is available Monday-Friday, 10am-4pm. Call free on **0808 801 0707**. Or you can email **support@pancreaticcancer.org.uk**

Talking about it

When you are diagnosed with pancreatic cancer, it might seem that no one else understands how you feel, and some people tell us they feel isolated and alone. Some people find it helps to talk about their cancer and how they are feeling. Family and friends can be a fantastic support. But sometimes people just don't know what to say. Macmillan Cancer Support have information about talking about cancer.

Some people prefer not to talk to family or friends – for example because they don't want to worry them. You can also talk to your medical team. You will be given a main contact, or keyworker, who will usually be a specialist nurse. They can provide emotional support as well as medical care.

You might find it helps to talk to others affected by pancreatic cancer, who can understand what you are going through. We have an online discussion forum for anyone affected by pancreatic cancer. And there are support groups around the country where you can meet others.



Find out more about support groups and our online discussion forum on our website at

pancreaticcancer.org.uk/getsupport

Some people find counselling helpful. This gives you a safe place to come to terms with your feelings and find ways to cope. If you're interested in counselling, speak to your GP or nurse – they may be able to refer you. Cancer centres and Maggie's sometimes also have counsellors. You can find more information about counselling from the British Association of Counselling and Psychotherapy. See page 61 for details.

“We have used the counselling services of the local hospice. This has not been a ‘quick fix’ by any stretch of the imagination, but provides an environment to talk and try to understand the feelings that we have had.”

Looking after yourself

Many people find that sorting out symptoms around diet makes a big difference to how they feel, both physically and emotionally (see page 37). Getting help and support to manage other symptoms and side effects will also help you to feel better and more in control (see page 42).

You are bound to feel tired or exhausted at times, so be kind to yourself. Make sure you rest when you need to, and plan your time to make the most of when you have more energy. Don't be afraid to accept offers of help or ask for help if you need to.

Some people find that focussing on other things and making plans can help them cope. These might just be small things, like trying to live life as normally as possible, or planning something fun for the following week.

Simple ways to relax can help you cope with stress, pain and anxiety. For example, having a warm bath, deep breathing, or listening to soothing music are easy things to do at home.

Gentle physical activity can help to maintain or improve your strength and fitness. It may also help you feel better, deal with fatigue, and cope with treatment. It's important to exercise within your own limits. How much exercise you do will depend on how well you feel, and whether you are having treatment or recovering from it. Take it easy and only do what you are able to. It's a good

idea to speak to your doctor or nurse before starting any kind of exercise plan. Gentle exercise could include going for a walk around the block or garden, or walking up and down a few steps.



Read more about physical activity in our booklet, **Diet and pancreatic cancer** or on our website at **pancreaticcancer.org.uk/lookingafteryou**

“It is so overwhelming and it is so important to be kind to yourself, give yourself plenty of time, allow the emotions to come and go, and talk to anyone you can. No one will judge you and so many people will understand.”

Complementary therapies

Some people find that complementary therapies, such as acupuncture, massage, meditation, or relaxation therapies, can help them cope with anxiety, as well as pain and some side effects of treatments. Ask your GP or specialist nurse about any services available in your area – some may be available on the NHS. The Complementary and Natural Healthcare Council provide more information about complementary therapies, including a list of registered therapists.

It's important that you let your medical team know about any complementary therapy you are thinking about trying. And let your complementary therapist know about your cancer and treatment. While many complementary therapies are safe, some may affect how well your cancer treatment works. Cancer Research UK has more information about things to think about when deciding whether to use complementary therapies.

Depression

People with pancreatic cancer may be more likely to have anxiety or depression. Depression can have a big impact on the quality of your daily life, but there are ways to treat it. If you're feeling very down, low, hopeless, or have lost interest in things that used to give you pleasure, speak to your GP or doctor or nurse at the hospital.

There are ways to treat depression. For example, anti-depressant medications and talking therapies such as counselling can help.

"I think the most difficult aspects of dealing with pancreatic cancer is the uncertainty that inevitably comes with it. For me, it became a question of trust in the medical professionals. In all of this, it has brought my family closer together."

"I was determined to enjoy every minute I had with him, I didn't want to feel like I had wasted precious time being sad and looking back and having regrets. We also didn't want to make cancer the focus of our lives, as much for the kids as anything else."



Read more about coping with pancreatic cancer on our website at [**pancreaticcancer.org.uk/takingcare**](https://pancreaticcancer.org.uk/takingcare)

Dealing with practical issues

Practical issues may not have been the first things you thought about when you were diagnosed. But it's important to deal with things like your work or financial situation, so that they don't become something you worry about.

- Your diagnosis will affect your ability to work, even if only while you have treatment. Talk to your employer about sick leave, reducing your hours or working from home.
- Not working can lead to financial problems. Get advice about any financial help that's available, including any benefits you might be entitled to.
- Having cancer can have an unexpected financial impact – for example, the cost of travelling to and from treatment. Find out about any help that's available, such as whether your hospital charges for parking if you are having treatment for cancer.
- You are entitled to free prescriptions if you are having cancer treatment, including for symptoms and side effects. You will need to apply for a medical exemption certificate – ask your doctor for an FP92A form, which they will need to sign.



Read more about living with pancreatic cancer at
pancreaticcancer.org.uk/dailylife



You can also call our specialist nurses about any of these things on our free Support Line.

Macmillan Cancer Support provide information about work-related issues, benefits and financial help.

Section 12

Further information and support

In this section, we explain some key medical words, and provide information about our services and other organisations that can support you. There's also space to record the contact details of your medical team.



Glossary

We have explained some of the medical words that you may hear when you are finding out about pancreatic cancer and how it is treated.



You can find more medical words in our Medical A-Z fact sheet on our website at **pancreaticcancer.org.uk/publications**

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

Duodenum: the first part of the small intestines.

Enzymes: substances produced by different glands in the body, including the pancreas. Different types of enzymes have different roles in the body. Pancreatic enzymes help break down our food and drink.

Hepatobiliary: having to do with the liver, gall bladder and bile ducts. These are very close to the pancreas, and hepatobiliary doctors and nurses may specialise in treating pancreatic diseases as well.

Hormones: chemical messengers that are carried in your blood and affect different processes in your body.

Insulin: a hormone that is produced by the pancreas and helps to control blood sugar level.

Jaundice: a symptom of pancreatic cancer. It develops when there is a build-up of bilirubin in the blood. Symptoms include yellow skin and eyes, and itching.

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

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

Pancreatic enzyme replacement therapy (PERT): treatment with pancreatic enzyme supplements, which are capsules that can be taken to help break down food.

Small intestines: part of the bowel, where food is mostly digested and absorbed. The duodenum is the first part of the small intestines.

Steatorrhoea: caused by fat in stools. Symptoms include pale yellow or clay coloured stools, which can look oily or greasy, smell horrible, and are difficult to flush down the toilet. It can be a symptom of pancreatic cancer.

Stools: Poo. Also called faeces or bowel motions.

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

Multidisciplinary team (MDT) members

Use this space to record the names and numbers of the key professionals involved in your treatment and care.

Keyworker

The keyworker is your main point of contact. They will often be a specialist nurse.

Name:

Telephone:

Email:

Notes:

Specialist Nurse

A nurse who provides expert care and advice about a condition, such as pancreatic cancer. The specialist nurse may be your main contact or keyworker.

Name:

Telephone:

Email:

Notes:

Gastroenterologist

A doctor who treats diseases of the digestive system, including the pancreas.

Name:

Telephone:

Email:

Notes:

Oncologist

A doctor who treats cancer with treatments such as chemotherapy or radiotherapy.

Name:

Telephone:

Email:

Notes:

Surgeon

A doctor who carries out surgery.

Name:

Telephone:

Email:

Notes:

Dietitian

A professional who provides expert advice about diet and nutrition, including managing the symptoms of pancreatic cancer related to diet.

Name:

Telephone:

Email:

Notes:

Out of hours/emergency contact

Name:

Telephone:

Email:

Pancreatic Cancer UK services

We have a range of services to support you and your family in dealing with pancreatic cancer.

Our Support Line

Our Support Line is a lifeline for thousands of patients, families and friends. Our specialist nurses understand the issues you might be facing. They are there for you, giving you personalised information and support, when you need it.

Call us free on **0808 801 0707** (Monday to Friday from 10am-4pm), or email us at **support@pancreaticcancer.org.uk**

Our information

We have the most up-to-date information on everything you need to know about pancreatic cancer on our website. We can help you every step of the way, from explaining your diagnosis and treatment options, to managing symptoms, and questions to ask at your appointments.

Go to **pancreaticcancer.org.uk/informationandsupport**

Download or order our publications, for free, at

pancreaticcancer.org.uk/publications

Our online community

Our online community is a supportive place where everyone affected by pancreatic cancer can be there for each other.

Find us at **forum.pancreaticcancer.org.uk**

Support groups

We help set up local support groups in communities all across the UK. These groups provide the opportunity for sharing personal experiences, understanding and support.

Check to see if there's a group near you at

pancreaticcancer.org.uk/supportgroups

Useful organisations

British Association of Counselling and Psychotherapy

www.itsgoodtotalk.org.uk

Tel: 01455 883300 (Mon-Fri 8:45am-5pm)

Provides information about counselling and database of registered therapists.

Cancer Research UK

www.cancerresearchuk.org

Helpline: 0808 800 4040 (Mon-Fri 9am-5pm)

Information for anyone affected by cancer.

Citizens Advice

www.citizensadvice.org.uk

Tel: England 03444 111 444; Wales 03444 77 20 20;

Scotland 0808 800 9060

In person at your local Citizens Advice Bureau.

UK wide information and advice on a range of issues including work, benefits, NHS healthcare and patient rights.

Complementary & Natural Healthcare Council

www.cnhc.org.uk

Tel: 020 3668 0406

Information about complementary therapies and a register of therapists.

Healthtalkonline

www.healthtalkonline.org/Cancer/Pancreatic_Cancer

Personal and patient experiences presented in written, audio and video formats.

Macmillan Cancer Support

www.macmillan.org.uk

Support Line: 0808 808 00 00 (Mon-Fri 9am-8pm)

Provides practical, medical and financial support for anyone affected by cancer.

Maggie's Centres

www.maggiescentres.org

Centres around the UK and online offer free, comprehensive support for anyone affected by cancer.

My Cancer Treatment

www.mycancertreatment.nhs.uk

Directory of cancer services in England. Allows you to find and compare cancer services in your area.

NET Patient Foundation

www.netpatientfoundation.org

Call free on 0800 434 6476

Information and support for people with neuroendocrine tumours (NETs).

NHS 24

www.nhs24.com

Tel: 111 (24 hours a day, 7 days a week)

Health information and advice, including local services in Scotland.

NHS Choices

www.nhs.uk

Information about health conditions, living well, care, and local services in England.

NHS Direct Wales

www.nhsdirect.wales.nhs.uk

Tel: 0845 46 47

Health information in Wales, including local services.

nidirect

www.nidirect.gov.uk

Information about local services in Northern Ireland, including health.

This booklet has been produced by the Support and Information Team at Pancreatic Cancer UK. It has been reviewed by health professionals and people affected by pancreatic cancer.

References to the sources of information used to write this booklet, and a list of health professionals who reviewed it, are available on our website – **pancreaticcancer.org.uk**

Pancreatic Cancer UK makes every effort to make sure that our services provide up-to-date, unbiased and accurate information about pancreatic cancer. We hope that this information will add to the medical advice you have received, and help you make decisions about your treatment and care. This information should not replace information and advice from your medical team – please speak to your doctor, nurse or other members of your medical team about any questions or concerns.

Give us your feedback

We hope you have found this information helpful. We are always keen to improve our information, so let us know if you have any comments or suggestions.

Email us at **publications@pancreaticcancer.org.uk** or write to the Information Manager at the address on the back cover.

The photographs in this booklet are of people affected by pancreatic cancer, including family members, as well as people who haven't been affected by pancreatic cancer.

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© Pancreatic Cancer UK November 2015
Review date November 2017
Registered charity number 1112708

