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, and explains your diagnosis and the treatment options. It also has information about managing symptoms you may get, coping with being diagnosed with pancreatic cancer, and the support available.

There is a lot to take in when you have just been diagnosed. 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 60.

• You will find a list of common medical words on page 58.

• You can find the contact details of all the organisations mentioned on page 64.

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 Support Line. They can answer your questions and talk through any worries.

Call the specialist nurses free on 0808 801 0707 or email nurse@pancreaticcancer.org.uk
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Section 1

About the pancreas and pancreatic cancer

The pancreas is a large gland which is situated behind the stomach, in the back of the abdomen (tummy).
What is the pancreas?

The pancreas is part of the digestive system. It does two main things.

- It makes pancreatic juices which contain substances called enzymes. These enzymes help to break down food so the body can absorb it. The pancreatic juices flow down a tube called the pancreatic duct, which runs the length of the pancreas and empties into the duodenum (the first part of the small intestines).

- The pancreas also makes hormones, including insulin, which control sugar levels in the blood.

Both of these things can be affected if the pancreas isn’t working properly.

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 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 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.

There are different types of pancreatic cancer. About 95 out of 100 pancreatic cancers (95%) are called exocrine tumours. These start in the cells that make enzymes (exocrine cells).

Pancreatic ductal adenocarcinoma is the most common type of exocrine tumour. It starts in the cells lining the pancreatic duct. About 80 out of 100 of all pancreatic cancers (80%) are pancreatic ductal adenocarcinoma.

Endocrine tumours (also called neuroendocrine tumours or NETs) are a less common type of pancreatic cancer. They start in the cells that make hormones in the pancreas (endocrine cells). Fewer than 5 in 100 (5%) of all pancreatic cancers are neuroendocrine tumours.

Exocrine and neuroendocrine cancers behave differently and are treated differently. The information in this booklet is about exocrine tumours. The NET Patient Foundation has more information about neuroendocrine tumours. See page 65 for contact details.

Read more about the different types of pancreatic cancer on our website at pancreaticcancer.org.uk/types
What causes pancreatic cancer?
We don’t fully understand exactly what causes pancreatic cancer, but we do know some risk factors. There is good evidence that the following things may increase your risk of pancreatic cancer:

• smoking
• age
• being overweight
• having hereditary or chronic pancreatitis (inflammation of the pancreas)
• a family history of pancreatic cancer.

Read more about the risk factors for pancreatic cancer on our website at pancreaticcancer.org.uk/riskfactors

Questions to ask
What type of pancreatic cancer do I have?
Where in my pancreas is the cancer?
Diagnosing pancreatic cancer

Pancreatic cancer can be difficult to diagnose. It often doesn’t cause many specific symptoms in the early stages, and symptoms can be quite vague. So it 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 more tests, for example to find out exactly what type of pancreatic cancer you have and what stage it is (see page 11).

Waiting for tests

Sometimes you may have to wait a few days – or even as long as two weeks – for some scans or tests. Sometimes people have to wait longer than this. 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 your 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:

- loss of appetite
- indigestion
- losing weight even though you are eating
- feeling or being sick (nausea and vomiting)
• bowel problems, including constipation (problems opening your bowels), yellow, oily poo that smells horrible and is difficult to flush down the toilet (steatorrhoea), and loose watery poo (diarrhoea)
• tummy and back pain  
• jaundice (yellow skin or eyes and itchy skin).

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

It may take from a few days to a couple of weeks to get the test results. 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. The stage describes the size of the cancer and how far it has spread. It also helps doctors decide on the best treatments for you.

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 that it is not possible to remove the cancer with surgery (unresectable). However, it may very occasionally be *borderline resectable cancer*, which means that 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**

Cancer is contained in the pancreas

**Stage 2 pancreatic cancer**

Cancer has started to grow into tissues around the pancreas
**Stage 3 pancreatic cancer**

- Portal vein
- Aorta
- Splenic vein
- Splenic artery
- Coeliac trunk
- Hepatic artery
- Spleen
- Pancreas
- Superior mesenteric vein

*Cancer has spread into blood vessels near the pancreas*

**Stage 4 pancreatic cancer**

- Liver
- Pancreas

*Cancer has spread to other parts of the body*
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 the lungs.
- **M1:** the cancer has spread to other parts of the body.

Your doctors may tell you what the stage of your cancer is, and explain exactly what it means, and how it affects your treatment options. Some doctors may focus on whether or not your cancer can be removed with surgery, rather than the stage.
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 49.

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 the test results mean about my cancer?
- Has the cancer spread? If so, where to?
- What are the treatment options?
- What happens next?
Section 3

Being referred to a specialist centre

In the UK, anyone diagnosed with pancreatic cancer should have their case reviewed at a specialist cancer centre where there is a specialist team to treat pancreatic cancer.
There are specialist centres across the UK. Surgery should only be carried out in specialist centres.

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 37), you may have your treatment at the specialist centre. Local hospitals may not run clinical trials, or offer all the trials that are available at the specialist centre.

**Who will I be treated by?**

The multidisciplinary team (MDT) is a team of medical professionals who will be responsible for your treatment and care. 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. There’s more information about these professionals on page 60. There’s also space for you to write down their contact details.

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.
Your care plan

You should be offered an assessment, called a holistic needs assessment. Your keyworker should discuss a range of things with you, including:

- your physical needs – for example around symptoms and side effects
- any practical issues, such as work or any care you need
- emotional concerns, such as sadness, depression or spiritual questions.

Your doctor or nurse should develop a care plan, which includes how to manage anything raised in the assessment. If you haven’t been offered a holistic needs assessment, you can ask for one.

Macmillan Cancer Support has a useful booklet, called Holistic Needs Assessment: Planning your care and support.

Find out more about the care you should expect in our leaflet, Patient Charter: What you should expect from your care
Questions to ask

Am I being treated at 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?
Can I have a holistic needs assessment?

“The doctor referred me to the multidisciplinary team at the specialist centre on the Thursday or Friday and they were discussing it in the MDT the following Monday.”

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

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 try to slow down the growth of the cancer. There are also 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 straight away. 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 if you are fit and well enough to have it. But you won’t start any treatment until you give your permission, usually by signing a consent form.

“Don’t be ashamed to ask for help. Doctors and medical professionals understand and will do everything they can to provide support.”
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 you. 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. See page 64 for contact details of these organisations.

Questions to ask

What treatment do you recommend for me?
What are the benefits of this treatment?
What are the risks and side effects of the 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 12) have more treatment options, and a better chance of a good outcome. You may be offered surgery and also chemotherapy.
Surgery

You may be able to have surgery to completely remove the cancer if there are no signs that it has spread beyond the pancreas, especially to the large blood vessels nearby. This is major surgery, and you will need to be fit and healthy enough for it – you will have tests to check this.

Pancreatic cancer that can be removed with surgery is known as **resectable (operable) cancer**. Surgery is the most effective treatment for early stage pancreatic cancer. However, only around ten out of a hundred people (10%) have surgery. (This includes people with neuroendocrine tumours.) This is because pancreatic cancer is very hard to diagnose at an early stage when an operation may be possible.

Sometimes the cancer may grow very close to the major blood vessels near the pancreas. This is called **borderline resectable pancreatic cancer**. It may be possible to remove the cancer, but it depends which blood vessels are affected and how far the cancer has grown. Some people with borderline resectable cancer may be offered chemotherapy or chemoradiotherapy (radiotherapy together with chemotherapy) to try to shrink the cancer, and make surgery possible. Radiotherapy uses radiation to destroy cancer cells. There are clinical trials looking at this. Read more about clinical trials on page 37.

Sometimes, when the surgeon starts an operation, they find that it isn’t actually possible to remove the cancer. If this happens, the surgeon may do a smaller operation to help control symptoms (see page 31). It can be upsetting to find out it wasn’t possible to remove the cancer. Speak to your doctor about your treatment.

You may be offered chemotherapy to help control the cancer.

You can call our specialist nurses on our Support Line for emotional support.
Types of surgery

There are several different operations. They involve removing all or part of the pancreas, and sometimes other areas around it. Your surgeon will discuss the best type of surgery for you. This will depend 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 5) 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), part of the bile duct, the gall bladder and the 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 none of the stomach is removed. This means the stomach valve (the pylorus), which controls the flow of food into the duodenum, isn’t removed. The tail of the pancreas is joined to the small intestines or stomach.

Distal pancreatectomy

This involves removing the body and tail of the pancreas (see page 5). The spleen, which helps your body to fight infections, is also often removed.

Total pancreatectomy

This involves removing the whole pancreas, the duodenum, gall bladder, part of the bile duct and sometimes part of the stomach. It’s done where there is a large tumour, or more than one tumour.
Advantages and disadvantages

There are advantages and disadvantages to having surgery. You should discuss these with your medical team. Surgery is the most effective treatment for early pancreatic cancer. But it’s a major operation, and it will take several months, and even up to a year to fully recover.

Removing all or part of the pancreas may affect how well it works. You may get side effects that affect how well you can digest food. You may 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 42). Speak to your doctor, nurse or dietitian 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?
How much of my pancreas will be removed?
Will any other parts of my body be removed?
What are the advantages, disadvantages and side effects of surgery?
How will surgery affect eating and digestion?
How long will it take to recover?
Chemotherapy after surgery

Chemotherapy uses drugs to damage and kill cancer cells. You may have chemotherapy after surgery to remove the cancer to try to reduce the chances of the cancer coming back.

You may be given one chemotherapy drug on its own, or two different drugs together (combination therapy), depending on how fit and well you are. The drugs most often used after surgery are gemcitabine and capecitabine. Recent research suggests that using gemcitabine together with capecitabine (GemCap) can reduce the chances of the cancer returning, but they can also be given separately.

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, extreme tiredness (fatigue), and low blood cell levels. This can make you more likely to get infections and can cause anaemia. There are ways to manage the side effects, and you may be given medication to help with some of them.

Speak to your doctor or nurse about whether you will have chemotherapy, what treatment involves, and the possible side effects.

You can also speak to our specialist nurses on our free Support Line with any questions about chemotherapy.
Read more about chemotherapy, the different drugs used, 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?
When will I start chemotherapy?

“The surgeon explained the Whipple’s procedure. They remove the head of the pancreas and various other parts. It was major surgery – 8 or 9 hours in the end.”

“After surgery, I was told it was best that I have some chemotherapy – so I had 6 months of gemcitabine. I didn’t have major side effects with it – I just felt a bit under the weather, the main thing was the sickness.”
Section 6

When surgery to remove the cancer isn’t possible

If it’s not possible to remove the cancer with surgery, you may be offered treatment to control the growth of the cancer and any symptoms.
Because pancreatic cancer is so difficult to diagnose, the cancer may have grown quite large or spread to nearby organs or blood vessels (locally advanced cancer – see page 12) by the time it is diagnosed. Or it may have spread beyond the pancreas to other parts of the body (advanced or metastatic cancer – see page 12).

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, and generally improve how you feel. The aim is to control your symptoms and give you the best possible quality of life.

**Treatments for 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 – see diagram on page 6).

- If your duodenum is blocked, food won’t be able to get through to your intestines. 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 (called a stent) can be inserted. This should open up the duodenum or bile duct and improve your symptoms.
Another option may be 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 connected to the small intestines. This allows the bile to flow into the small intestines.

Sometimes these two procedures are done at the same time.

If you are offered a stent or bypass surgery, speak to your doctor or nurse about what it involves.

You can also ask our specialist nurses on our free Support Line any questions about stents or bypass surgery.

Read more in our fact sheet, Stents and bypass surgery for pancreatic cancer, or on our website at pancreaticcancer.org.uk/inoperable

Questions to ask
What treatment can I have for my jaundice?
What treatment can I have for a blocked duodenum?
Which would be better for me – a stent or bypass surgery?
What are the benefits, risks and side effects of having a stent or bypass surgery?
Chemotherapy

If you have **locally advanced pancreatic cancer**, you may be offered chemotherapy or chemotherapy combined with radiotherapy (chemoradiotherapy – see page 35) to try to shrink the cancer, slow down its growth, and relieve your symptoms. For a small number of people, this treatment shrinks the cancer enough to make surgery possible.

If you have **advanced pancreatic cancer**, chemotherapy can be used to try 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 28), but 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 the following options.

- Gemcitabine is one of the standard chemotherapy drugs 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 with other chemotherapy drugs such as capecitabine (GemCap).

- FOLFIRINOX is a combination of drugs (leucovorin, fluorouracil, irinotecan and oxaliplatin). 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 that can be difficult to cope with. FOLFIRINOX may help to control inoperable pancreatic cancer for longer than gemcitabine.
• Nab-paclitaxel (Abraxane®) together with gemcitabine may be an option for some people with advanced pancreatic cancer. Research has found that people with advanced pancreatic cancer who had nab-paclitaxel and gemcitabine lived on average about two months longer than people who had gemcitabine alone.

When one chemotherapy stops working, or if it hasn’t worked, different chemotherapy drugs may be used to try to control the cancer for longer. This is called second-line chemotherapy.

There are clinical trials looking at different chemotherapy drugs and drug combinations for inoperable pancreatic cancer. Read more about clinical trials on page 37.

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

You can also ask our specialist nurses on our free Support Line any questions about chemotherapy.

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

Questions to ask
Will chemotherapy help control my cancer?
Which chemotherapy drugs are suitable for me?
What side effects do these drugs have?
Are there any clinical trials that I could take part in?
Radiotherapy

If you have **locally advanced pancreatic cancer**, radiotherapy may be an option. It is most commonly used together with chemotherapy (chemoradiotherapy).

Radiotherapy or chemoradiotherapy won’t cure the cancer, but they may help control it and slow its growth. For a small number of people, treatment can shrink locally advanced cancer enough to make it possible to remove the cancer with surgery.

If you have **advanced pancreatic cancer**, radiotherapy can help relieve symptoms, such as pain. Radiotherapy used in this way is called palliative radiotherapy.

Radiotherapy can cause side effects such as tiredness, feeling sick and loose runny poo (diarrhoea). Many people will only have mild side effects, and severe side effects are uncommon. Most side effects can be managed, sometimes with medication. If you have chemoradiotherapy, you may also get side effects from the chemotherapy.

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

**You can also ask our specialist nurses on our free Support Line any questions about radiotherapy or chemoradiotherapy.**

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

Is radiotherapy or chemoradiotherapy suitable for me?
Will radiotherapy help control my cancer?
Will radiotherapy relieve any of my symptoms?
What are the side effects of radiotherapy?
Are there any clinical trials involving radiotherapy or chemoradiotherapy that I can take part in?

“The oncologist suggested I have chemotherapy, and there was a trial that was ideal for me, using two chemotherapy drugs.”
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 to take part in a trial, it is important that you have all the information that you need, and that you know exactly what is involved. Discuss the trial with 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, watch videos of people’s experiences of trials, and find trials that are available for pancreatic cancer on our website at pancreaticcancer.org.uk/clinicaltrials

Questions to ask

- Are there any clinical trials that are suitable for me?
- How do I find out about clinical trials?
- What are the pros and cons of joining a trial?
- What happens if I do decide to take part in 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 food. Nutrients from the food are then 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 you may not be able to digest your food properly, and the nutrients in the food aren’t absorbed. This can be treated with pancreatic enzyme supplements – see page 41.

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 42.

Surgery for pancreatic cancer that removes the head or all of the pancreas may also affect the amount of enzymes and hormones produced by the pancreas.

**What symptoms are caused by problems with diet and digestion?**

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 runny poo (diarrhoea)
- yellow, oily, floating poo (steatorrhoea)
• tummy discomfort or pain
• bloating and wind
• feeling full up quickly
• needing to empty your bowels urgently, especially after eating
• some people also develop diabetes.

If you have any of these symptoms, speak to your doctor or nurse. The symptoms can be managed using pancreatic enzyme supplements (see section below).

If you have diarrhoea, you may worry about going out, in case you can’t find a toilet when you need it. Macmillan Cancer Support has a toilet card that helps you access a toilet when out in public.

**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). Supplements available include Creon®, Pancrease®, Nutrizym® and Pancrex®.

The enzyme supplements help to break down food, and can help to manage symptoms related to diet. They 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 to help with digestion.

Finding ways to manage your diet 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 a specialist dietitian.

“If the person with pancreatic cancer needs to stop losing weight, try new foods, and always have things available when they feel able to eat.”

Diabetes and pancreatic cancer

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. Insulin controls your blood sugar level.

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 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](http://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 28 and 35).

Below are some of the common physical symptoms and side effects of pancreatic cancer. You can read more about how it can affect you emotionally on page 49.

- **Pain** can often start as general discomfort or pain in the tummy (abdomen) and can spread to the back. Pain can usually be managed so it’s important to ask for help as early as you can. There are different treatments, depending on the cause of the pain. These include painkillers, radiotherapy, and a procedure called a nerve block, which stops nerves sending pain messages to the brain.

- **Feeling and being sick** (nausea and vomiting) can be caused by several things, including the cancer itself, and treatments. There are treatments available, including anti-sickness medication and treatment for sickness caused by a blocked bowel. See page 40 for information about sickness caused by problems digesting food.

- **Changes to bowel habits** can include constipation (problems opening the bowels), diarrhoea (loose runny poo) or steatorrhoea (see page 11). There are medications available to help manage these symptoms. Macmillan Cancer Support has a toilet card that may help you access toilets in public.

- **Extreme tiredness (fatigue)** is common. It can be caused by the cancer itself, symptoms of the cancer, or be a side effect of treatments. There are ways to manage fatigue, including keeping a diary of your fatigue, and gentle physical activity.
If you are having any problems with symptoms or side effects, speak to your doctor or nurse. They will help you find ways to manage them.

Some people find that complementary therapies help them deal with some symptoms such as pain, fatigue and sickness. See page 53 for more information.

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

Read more about managing symptoms at pancreaticcancer.org.uk/managingsymptoms

Questions to ask

How can I manage my symptoms?
Will the treatment I’m having help relieve 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, other times there was bad indigestion, sometimes there was pain in her abdomen. 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 locally

You may want to get support at home at some stage. For example, you might need help and support from a community or district 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 services if you need more support at home.

If you have been in hospital, before you are discharged you should be given advice and information about what care and support you need at home. Your GP should also be sent a letter explaining your condition. Ask your medical team who 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?
How do I get in touch with social care? What support can they provide?

“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

Being told that you have pancreatic cancer may come as a shock, and everyone reacts differently.
It can take time to come to terms with your diagnosis. You might find you have good and bad days, and you may go through a range of emotions. 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 keyworker and medical team. Ask them questions, and understand what your diagnosis and treatment options mean. This will help you make decisions about your treatment and plan for the future.

We have information about pancreatic cancer, including treatment options, on our website at pancreaticcancer.org.uk/informationandsupport

You can also speak to 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. You can call free on 0808 801 0707, Monday-Friday, 10am-4pm. Or you can email nurse@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 that 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 has 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, and should be able to answer any questions that you may have.

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 we run Living with Pancreatic Cancer Support Days, where you can meet others. There are also support groups across the country.

Read more about the support we offer on our website at pancreaticcancer.org.uk/getsupport

Counselling and support
Some people find counselling helpful. This gives you a safe place to come to terms with your feelings and may help you find ways to cope. If you’re interested in counselling, speak to your GP or nurse – they may be able to refer you.
Hospitals, Macmillan Cancer Support and Maggie’s Centres sometimes also have counsellors that specialise in supporting people with cancer. The British Association of Counselling and Psychotherapy has information about counselling, and you can search for a counsellor who deals with cancer. Your GP or keyworker should also be able to put you in touch with any cancer support services and support groups in your local area.

“We have used the counselling services of the local hospice. This has not been a ‘quick fix’, but provides an environment to talk and try to understand the feelings 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 39). Getting support to manage other symptoms and side effects can also help you to feel better and more in control (see page 44).

Some people find that focusing on things other than the cancer 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 try 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. Speak to your doctor or nurse before starting any kind of exercise plan. Take it easy and only do what you are able to. Gentle exercise could include going for a
walk around the block or garden, or walking up and down a few steps. Some cancer support services run exercise courses for people with cancer. Ask your GP about any services available in your area.

““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.”

**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 that 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 and anxiety

People with pancreatic cancer may be more likely to have anxiety or depression. Depression can affect the quality of your daily life, and you may feel less able to cope with treatment such as chemotherapy. Symptoms of depression include:

• loss of appetite and weight loss
• negative thoughts and feeling hopeless
• loss of any interest or pleasure in daily life
• problems sleeping.

Some of the symptoms of depression can be similar to symptoms of pancreatic cancer. Speak to the medical team or your GP if you have any of these symptoms. They can find out what’s causing them and how best to manage them.

There are ways to deal with depression and anxiety. For example, support in dealing with what might be causing the anxiety might help – such as help with financial issues, or dealing with any symptoms or side effects. Speaking to the medical team or a counsellor may help you to come to terms with your cancer diagnosis and what that might mean for the future. Anti-depressant drugs can also help manage anxiety and depression.

Getting the right support can help you cope if you are struggling with anxiety or depression.

“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. We also didn’t want to make cancer the focus of our lives, as much for the kids as anything else.”
What is my outlook (prognosis)?

Everyone reacts differently to their diagnosis. Some people want to know whether the cancer can be cured, or how long they have left to live. This is called their prognosis. This will be different for each person, and depends on several things, including whether the cancer has spread, how far it has spread (see page 11), and the treatments they can have.

Not everyone will want to know this. But if you do, speak to your doctor. They won’t be able to tell you exactly what your prognosis is, but should be able to give you an idea of what to expect. There is a lot of frightening information about pancreatic cancer online, and not all of it is accurate, so it’s important to speak to your doctor.

Cancer Research UK has information about survival and pancreatic cancer, including survival for different stages of pancreatic cancer. But these are general statistics for large groups of people, so they can’t tell you what will happen in your own case.

Questions to ask

What does my diagnosis mean for my future?
What can I expect in the next few weeks, months or years?
Can my cancer be cured?

“I think the most difficult aspect of dealing with pancreatic cancer is the uncertainty that inevitably comes with it. But all of this has brought my family closer together.”
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. There is a wide range of practical support available for you.

- **Financial support.** Having pancreatic cancer can affect your ability to work and your finances. Macmillan Cancer Support and Citizens Advice can provide expert information and advice about finances and money, including any benefits that you may be entitled to.

- **Blue Badge scheme.** If you can’t walk or find walking very difficult, you may be able to apply for a parking permit under the Blue Badge scheme. This allows parking without a time limit or charge in restricted parking areas, disabled parking bays or yellow lines. You can apply from your local council or online at GOV.UK

- **Hospital parking and discounts.** Many hospitals charge for parking, but you may be able to get free or reduced parking. Check what the situation is at your hospital. The GOV.UK website has more information about hospital parking.

- **Free prescriptions.** Prescriptions in Scotland, Wales and Northern Ireland are free. In England, 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 practical issues at pancreaticcancer.org.uk/practical
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.

**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 food and drink.

**Hepatobiliary**: this term covers 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 levels.

**Jaundice**: develops when there is a build-up of a substance called bilirubin in the blood. It is a symptom of pancreatic cancer. You may get 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): used if the pancreas isn’t producing enough enzymes. It involves taking pancreatic enzyme supplements 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 poo. Symptoms include large, pale poo, which can look oily, smells horrible, floats and is 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.

You can find more words on our website at pancreaticcancer.org.uk/medicalwords
Multidisciplinary team (MDT) members
Use this space to record the contact details 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 or emergency contact

Name:

Telephone:

Email:
Pancreatic Cancer UK services

We are here for everyone affected by pancreatic cancer.

We’re here to support and to listen

Our free and confidential Support Line is a lifeline for thousands of people affected by pancreatic cancer. Our specialist nurses understand the issues you might be facing and their expert help will support you in coping with pancreatic cancer.

Call free on 0808 801 0707 weekdays 10am-4pm, or email nurse@pancreaticcancer.org.uk

We’re here with the information you need

We have the most up-to-date information on everything you need to know about pancreatic cancer. We can help you every step of the way through diagnosis and treatment options to managing your symptoms and the care you receive.

Go to pancreaticcancer.org.uk/informationandsupport
Download or order our free publications at pancreaticcancer.org.uk/publications or call 0808 801 0707

We’re here so you can share

Our Forum is a supportive place where everyone affected by pancreatic cancer can be there for each other online, any time of day or night: forum.pancreaticcancer.org.uk

Local support groups mean you can meet other people to share your experiences: pancreaticcancer.org.uk/supportgroups

And our Living with Pancreatic Cancer Support Days provide local face to face support in an informal setting for people diagnosed with pancreatic cancer: pancreaticcancer.org.uk/supportdays
Useful organisations

British Association of Counselling and Psychotherapy
www.itsgoodtotalk.org.uk
Tel: 01455 883300 (Mon-Fri 9am-5pm)
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.
Provide 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 (Mon-Fri 9am-5:30pm)
Information about complementary therapies and a register of therapists.

GOV.UK
www.gov.uk
Provides information about government services, including information about benefits, transport, money and guidelines for hospital parking.
Healthtalkonline
www.healthtalk.org
Personal experiences presented in written, audio and video formats, including people talking about pancreatic cancer.

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
Tel: 0300 123 1801
Centres around the UK and online offer free practical, emotional and social support for anyone affected by cancer.

mygov.scot
www.mygov.scot
Information about public services in Scotland, including health and social care services.

NET Patient Foundation
www.netpatientfoundation.org
Support line: 0800 434 6476
Information and support for people with neuroendocrine tumours (NETs).

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
Health information in Wales, including local services.

NHS inform
www.nhsinform.scot
Tel: 0800 22 44 88
Provides information about different health conditions and living well, and local services in Scotland.

NICan (Northern Ireland Cancer Network)
survivorship.cancerni.net
Information about services in Northern Ireland to support people with cancer and their families.

nidirect
www.nidirect.gov.uk
Information about local services in Northern Ireland, including health services.
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.