Pancreatic
CANCER UK

A guide if you have
just been diagnosed

Pancreatic cancer if you can't have surgery

(inoperable cancer)

Introduction

This booklet is for anyone recently diagnosed with pancreatic cancer that can't be removed by surgery. You might hear this called inoperable or unresectable cancer. Family and friends may also find this booklet useful.

Being diagnosed with pancreatic cancer can be overwhelming. You probably have lots of questions and worries, and it can be hard to take everything in. This booklet gives you key information about pancreatic cancer, diagnosis, your treatment options, managing symptoms, support and practical tips on coping.

Contents

How to use this booklet

You don't have to read this booklet all at once. Look at the contents on page 2, read the sections that feel most helpful, and come back to it if you want to know more. There is more information and support on our website. Find out more at: **pancreaticcancer.org.uk**

Use the colours below as a guide to where you can get more help.

Call our Support Line free on **0808 801 0707**
or email **nurse@pancreaticcancer.org.uk**

Read more on our website at:
pancreaticcancer.org.uk/information

Order or download our free booklets at:
pancreaticcancer.org.uk/publications

Questions to ask your doctor or nurse

Things you can do to help yourself

At the end of the booklet there is:

- A list of common medical words on page 61.
- Contact details of all the organisations we mention on page 64.

Diagnosing pancreatic cancer

Key facts

- The pancreas is a gland near your stomach.
- The pancreas makes enzymes which break down food. This is part of digestion.
- It also makes insulin which controls the sugar levels in your blood.
- Pancreatic cancer develops when cells in the pancreas grow out of control.
- Pancreatic cancer can be hard to diagnose.
- Being told that you have pancreatic cancer that can't be removed with surgery can feel overwhelming.
- You may still have treatment options, and there are ways to manage symptoms.
- You and your family can get support from our specialist nurses by calling our free Support Line on **0808 801 0707** or emailing **nurse@pancreaticcancer.org.uk**

Our **easy read booklets** use pictures and simple words to help people who might struggle with written information.

Download or order at: **pancreaticcancer.org.uk/easyread** call **0808 801 0707**, or email **publications@pancreaticcancer.org.uk**

What is the pancreas?

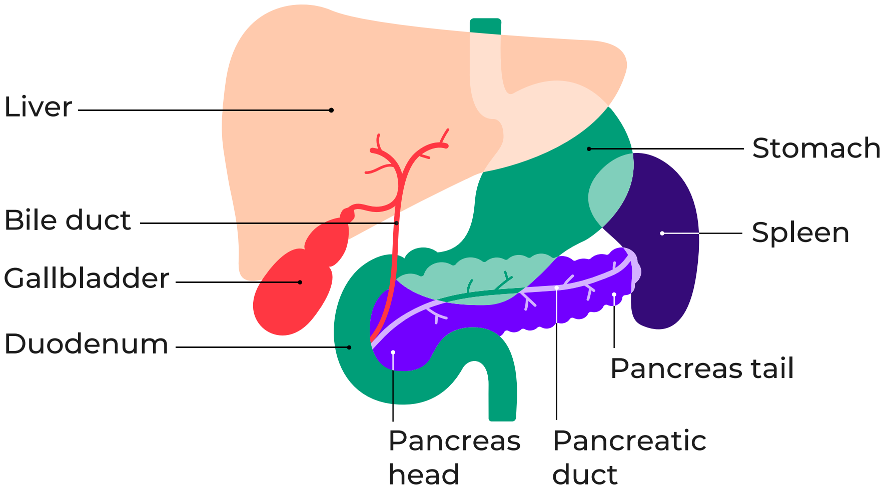
Your pancreas is a gland that sits behind your stomach, at the back of your tummy (abdomen). It is surrounded by several important organs, such as your liver, and also by large blood vessels and lymph nodes (part of your immune system).

Your pancreas does two main things.

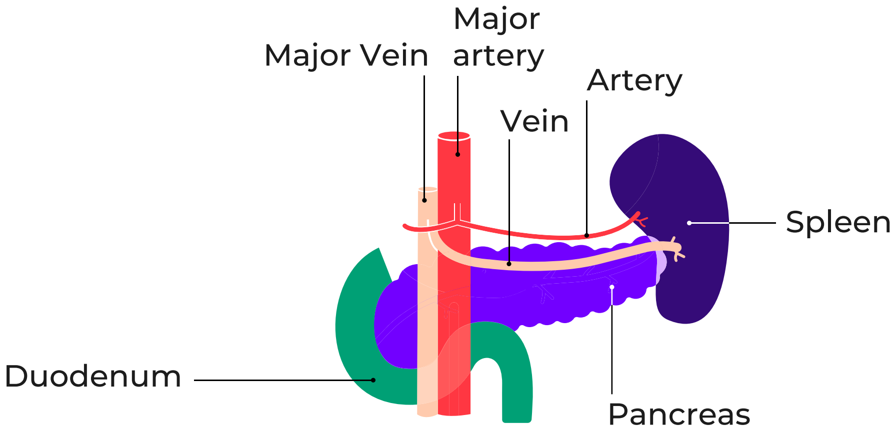
- It makes enzymes. Enzymes help to break down food so your body can absorb the nutrients from it. This is part of digestion.
- It makes hormones, including insulin, which control sugar levels in the blood.

Pancreatic cancer can affect how well your pancreas works. This may mean you have problems digesting your food and controlling sugar levels in your blood.

The pancreas and surrounding organs



The pancreas and surrounding blood vessels



What is pancreatic cancer?

Pancreatic cancer develops when cells in the pancreas grow out of control, forming a lump. You might hear this called a tumour, lesion or mass.

There are different types of pancreatic cancer.
The information in this booklet is about the most common type called pancreatic ductal adenocarcinoma.

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

How is pancreatic cancer diagnosed?

In the early stages, pancreatic cancer often doesn’t cause symptoms. The symptoms may not be specific to pancreatic cancer, and they may come and go to begin with. This makes it harder to diagnose early. Pancreatic cancer is often diagnosed at a later stage when it has already started to spread.

You may have had several different tests to diagnose pancreatic cancer.

Read more about the tests on our website at:
pancreaticcancer.org.uk/tests

What do my test results mean?

The 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. This describes:

- the size of the cancer
- if it has spread outside the pancreas and if so, where to.

Read about the stages of pancreatic cancer on page 10.

Your doctors will discuss your treatment options with you. Some doctors may just focus on the treatment, and not tell you the stage. Ask your doctor if you would like to know the stage.

Being told you have pancreatic cancer that can’t be removed by surgery can feel devastating. There may be other treatments you can have (see page 14), and there are ways to manage any symptoms (see page 32). This can help to improve how well you feel.

What can I do?

- Use the diagrams and information on the next pages to help you understand more about your test results.
- Find out as much as you want to know. We have lots more information about pancreatic cancer on our website.
- Ask your doctor or nurse any questions you have. Read more about your medical team on page 15.
- Talk to family and friends about how you are feeling. Sometimes just talking can help you make sense of things.
- Read more about the emotional support available on page 46.

Speak to our specialist nurses on our free Support Line with any questions or worries about your diagnosis. Call **0808 801 0707** or email **nurse@pancreaticcancer.org.uk**

Questions to ask your doctor or nurse

What do my test results mean?

Has the cancer spread? If so, where to?

What does it mean if the cancer has spread?

What are my treatment options?

What happens next?

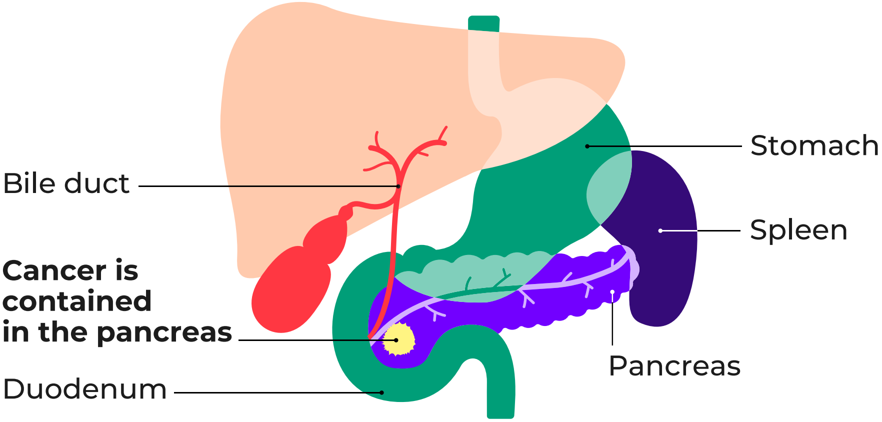
Where can I get support?

> "If possible, ensure there's someone with you to help absorb the news. Ask them to take notes. We found that important as a couple – so there was no ambiguity."
> **Jenny**

What stage is my pancreatic cancer?

Stage 1 pancreatic cancer

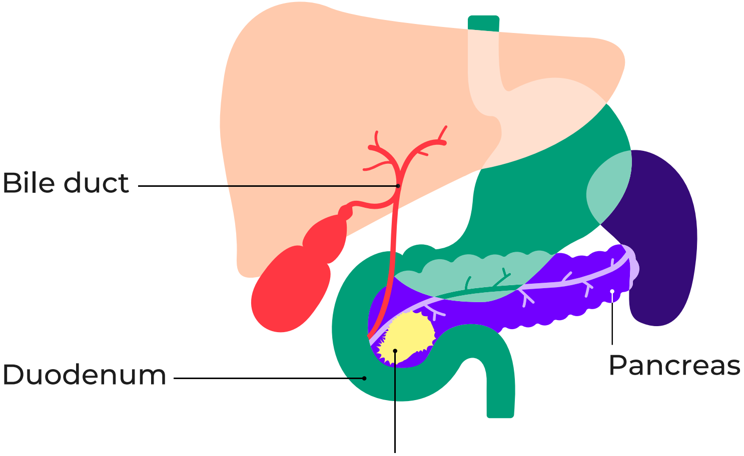
The cancer is contained inside your pancreas. This is **early, localised pancreatic cancer.** It is also called **operable or resectable cancer** because surgery may be possible.



Possible treatments: You may be able to have surgery to remove the cancer. You may also have chemotherapy after the surgery.

Stage 2 pancreatic cancer

The cancer may have grown larger. It may have spread to a small number of lymph nodes near your pancreas. It has not spread to large blood vessels near your pancreas.



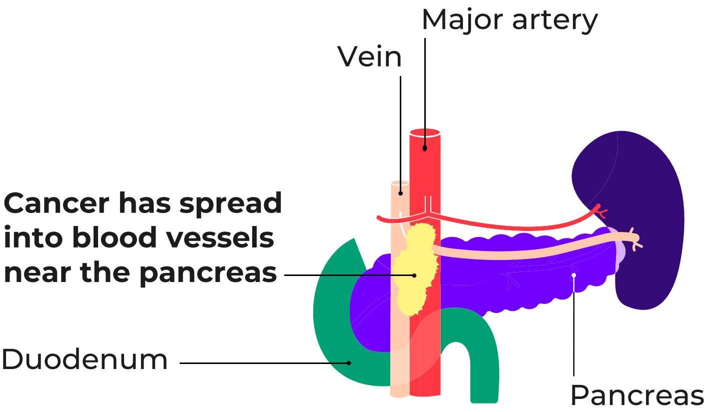
The cancer has grown larger

Possible treatments: You might be able to have surgery to remove the cancer, but this depends on how far it has spread. You might also be offered chemotherapy. This might sometimes be followed with chemotherapy combined with radiotherapy (chemoradiotherapy).

If you have been told you can have surgery to remove the cancer, read more in our booklet: **Pancreatic cancer that can be removed with surgery. A guide if you have just been diagnosed.**

Stage 3 pancreatic cancer

The cancer has spread outside your pancreas. It may have spread to the large blood vessels near the pancreas, or to a number of lymph nodes. This is usually **locally advanced cancer.** It may occasionally be **borderline resectable cancer.**

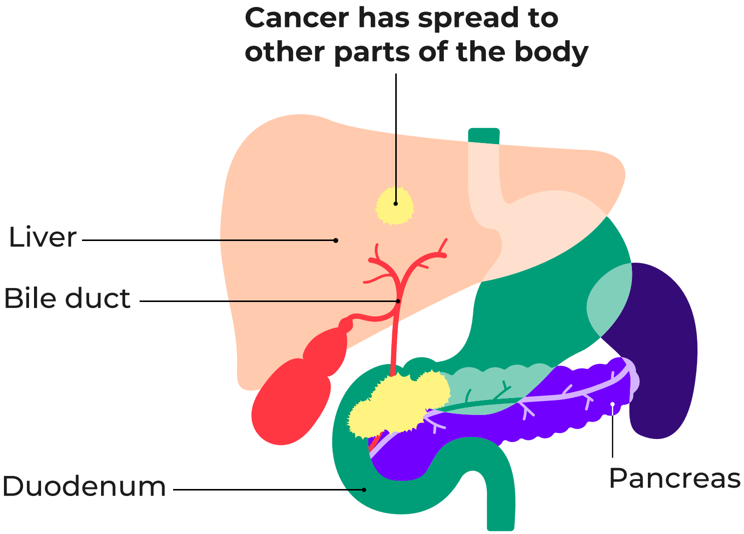


Possible treatments: It's not usually possible to remove **locally advanced cancer** with surgery. You may have chemotherapy, sometimes with radiotherapy. Find out more on page 21.

Borderline resectable cancer is cancer that has grown very close to major blood vessels near the pancreas. Some surgeons class borderline resectable cancer as stage 2 (see page 11). You may be able to have surgery to remove the cancer, but it depends which blood vessels are affected. Ask your doctor or nurse if you're not sure. You may have chemotherapy and radiotherapy to try to shrink the cancer before your doctors consider surgery. Read more on page 21.

Stage 4 pancreatic cancer

The cancer has spread to other parts of the body. It may have spread to your lungs, liver or lining of your tummy (peritoneum). This is **advanced** or **metastatic cancer.**



Possible treatments: You may be able to have chemotherapy to slow down the growth of the cancer. Treatment for stage 4 cancer won't cure the cancer, but it may help you live longer and generally feel better. You can read more on page 22. There are also treatments to help manage any symptoms – see page 32.

Your doctor or nurse may call the cancer **inoperable** or **unresectable**, which means that surgery is not an option.

Having treatment

Key facts

- The type of treatment or care you have will depend on what stage of cancer you have and how well you are generally.
- A team of medical professionals, called a **multidisciplinary team (MDT)** will review the information about your diagnosis.
- You should be given the details of a nurse called a **clinical nurse specialist (CNS)**. They can support you and answer your questions.
- Your doctor or nurse should regularly check how you are feeling. They can provide advice and support in managing any cancer symptoms or side effects from treatment.
- If you have locally advanced cancer, you may be able to have chemotherapy, sometimes with radiotherapy.
- If you have advanced cancer, you may be able to have chemotherapy if you are well enough, as well as other treatments to control symptoms.
- You may be able to take part in a clinical trial, which might mean you can have new or different treatments.
- If you have advanced cancer, you may see a palliative care specialist, who can help manage your symptoms and provide emotional support. Read more on page 16.

What health professionals will I see?

If you are having treatment such as chemotherapy and radiotherapy, your case should be reviewed by a **pancreatic multidisciplinary team (MDT)**.

- The MDT is the team of health professionals who are responsible for your treatment and care
- The MDT may be based at a specialist centre. This is a hospital where there is a team who specialise in pancreatic cancer. You won't necessarily have your treatment there
- You might not meet everyone in the MDT, but your doctor or nurse should tell you what the MDT recommend

Your team should include a **specialist nurse**, sometimes called a **clinical nurse specialist (CNS)**. They will be your main contact. They will provide expert support, care and advice. They will also coordinate your care if you are having treatment for the cancer. Where we talk about your nurse in this booklet, we mean the CNS. Not everyone will have a CNS. If you don't, ask for details of who to contact with questions or concerns.

You may meet other members of the team, including:

- an **oncologist** – a doctor who is an expert in treating cancer
- a **gastroenterologist** – a specialist in diseases of the digestive system, including the stomach, intestines, pancreas and liver
- a **dietitian** – who provides advice about diet and nutrition
- a **patient care coordinator** – who works with the medical team to coordinate your care. They may not be available in all hospitals, or may be called different things.

Palliative and supportive care

If you have advanced pancreatic cancer, you may be referred to a specialist palliative care team or supportive care team.

Palliative care and supportive care services provide specialist care to manage symptoms such as pain. They also provide emotional and practical support. They can help you live as long and as comfortably as possible. They will also offer support to your family.

Some people find the thought of palliative care upsetting. But these services are not just for people at the end of their life. They are available at any point during treatment or care for people with cancer that can't be cured.

You may be able to have palliative care:

- in your own home – from Hospice at Home services, palliative care doctors and nurses, district nurses, and Macmillan or Marie Curie nurses
- at a hospice
- in hospital – from palliative or supportive care teams
- at a care home.

Hospices provide palliative care for patients and families. Services are free and may vary. They may include managing symptoms, providing emotional, spiritual and social support, and offering financial advice.

If you haven't been referred for specialist palliative or supportive care, ask your medical team or GP for a referral.

Find out more about palliative care at:
pancreaticcancer.org.uk/palliative

Your support needs

Your doctors and nurses should regularly check how you are coping with any symptoms such as pain, tiredness and problems with digestion. There are usually ways to manage symptoms, so it is important to tell your medical team if you have any. Read more about managing symptoms and side effects on page 32.

Having pancreatic cancer can affect many parts of your life, not just your physical health. Your medical team should also talk to you about how you are feeling emotionally and ask about practical issues, like finances or help at home. Sometimes, this discussion may be part of a holistic needs assessment. Not all centres offer this. But if you have any concerns, contact your nurse.

The healthcare system can be confusing. Find out more about the care you should get at:
pancreaticcancer.org.uk/care

Speak to our specialist nurses on our free Support Line with any questions about your care and what to expect.

What can I do?

- Ask about the best way to contact your nurse with any questions.
- If you don’t have a specialist nurse, ask who to contact with questions.
- Keep a diary of your symptoms to help you explain them to your doctor or nurse.
- Write a list of questions to ask your doctor or nurse.
- Take someone with you to your appointment, and ask them to write down key things your doctor or nurse says.
- Talk to your nurse about your symptoms, feelings or worries.
- Ask your doctor or nurse if it would be helpful for you to see a palliative care or supportive care team.
- Ask who you should contact out of normal hospital hours or in an emergency.

What are my treatment options?

You may be able to have treatments for the cancer, such as chemotherapy. This will depend on the stage of your cancer and how well you are. You will also be offered treatments for any symptoms. The aim of treatment will be to control the growth of your cancer, control any symptoms and generally improve how you feel.

You can read about treatments for locally advanced cancer and borderline resectable cancer on page 21 and advanced cancer on page 22.

Whatever your options, treatment is **your** decision, and you don't have to decide anything straight away.

You can speak to our specialist nurses on our free Support Line to talk through your treatment options.

Getting a second opinion

You can ask for a second opinion about your treatment options from a different medical team, if you want one. Most doctors will help you do this if you ask them. But don't delay your treatment while you get a second opinion, as it can take several weeks.

Read more about getting a second opinion on our website at: **pancreaticcancer.org.uk/secondopinion**

Treatment if you have locally advanced cancer

If you have locally advanced pancreatic cancer, you may be offered chemotherapy on its own first, and then sometimes with radiotherapy (chemoradiotherapy) afterwards. This aims to shrink the cancer, slow down its growth, and control your symptoms. For a small number of people, this may make surgery to remove the cancer possible. Read more about chemotherapy and radiotherapy on page 24.

Treatment if you have borderline resectable cancer

If your cancer has grown close to major blood vessels (borderline resectable cancer), your doctors will look carefully at your scan results. They will try to work out if surgery is possible. But it can be hard to tell how close the cancer has grown to blood vessels and whether it is possible to remove it.

Whether you can have surgery depends on which blood vessels are affected by the cancer, and how close the cancer has grown to them. You may be offered chemotherapy and possibly radiotherapy (see page 24). This can sometimes shrink the cancer enough to make surgery possible. You will have scans before, during and after treatment to check how well it has worked and whether surgery may be possible.

Speak to your doctor about your treatment options. Different medical teams may have different opinions about whether surgery is possible. You can ask for a second opinion about your diagnosis or the treatment recommended from a different medical team, if you wish. (See page 20).

If treatment makes surgery possible, read our booklet:
Pancreatic cancer that can be removed by surgery: A guide if you have just been diagnosed.

Read more about surgery in our fact sheet:
Surgery to remove pancreatic cancer
Or: **pancreaticcancer.org.uk/surgery**

Treatment if you have advanced pancreatic cancer

Advanced pancreatic cancer is cancer that has spread from the pancreas to other parts of the body.

If you are well enough, you may be offered chemotherapy. Chemotherapy may help to control the cancer and help with symptoms. It won't cure the cancer but it may help you live longer and generally feel better.

Read more about chemotherapy on page 24.

Treatments for symptoms

If you have symptoms from the cancer there are also treatments to help control these. Find out more on page 32.

A specialist palliative care team or supportive care team can help manage symptoms. Read more on page 16.

Types of treatment

You will need to have a biopsy before you have chemotherapy.

Chemotherapy

Chemotherapy is one of the most common treatments for pancreatic cancer. It uses drugs to destroy the cancer cells and slow down the growth of the cancer.

Side effects

Chemotherapy can cause side effects, including feeling and being sick, diarrhoea (runny poo), constipation and extreme tiredness (fatigue). It can also make you more likely to get infections. Most people get some side effects, but it's unusual to get all the possible side effects.

Your medical team will closely monitor you. There are ways to manage any side effects.

Read more about chemotherapy, including the chemotherapy drugs you may be offered, in our fact sheet: **Chemotherapy for pancreatic cancer.**
Or at: **pancreaticcancer.org.uk/chemotherapy**

Radiotherapy

Radiotherapy uses radiation to destroy cancer cells. A machine directs beams of radiation at the cancer from outside the body.

Side effects

Radiotherapy can cause some side effects such as tiredness, feeling sick and diarrhoea. Many people will only have mild side effects. But they can be more common and severe if you are having chemoradiotherapy. If you have chemoradiotherapy, you may also get side effects from the chemotherapy (see page 24).

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

Clinical trials

Clinical trials are carefully controlled medical research studies that involve people. Most trials in pancreatic cancer aim to find better and new treatments, including better ways of using chemotherapy and radiotherapy.

Taking part in a clinical trial may give you the chance to try a new treatment. But there's no guarantee that it will be any better than current treatments.

Ask your doctor or nurse whether there are any suitable clinical trials that you could take part in.

Read more about clinical trials, watch videos of people's experiences of trials, and find pancreatic cancer trials on our website at: **pancreaticcancer.org.uk/clinicaltrials**

Questions to ask your doctor or nurse

Who is my clinical nurse specialist or main contact?

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

Who do I speak to about appointments?

Will chemotherapy help control my cancer?

Which chemotherapy drugs are suitable for me?

Can I have radiotherapy or chemoradiotherapy?

What side effects do these treatments have?

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

What treatments can I have for my symptoms?

Who should I contact if I have any questions?

When treatment to control the cancer is not an option

Key facts

- Some people with advanced pancreatic cancer may not be able to have treatment to control their cancer.
- Some people decide not to have treatment for different reasons.
- Whatever your situation, there is medical, emotional and practical support available.
- You will still be able to have treatment for any symptoms you may have, to help you feel better.
- A specialist palliative care team can help manage your symptoms, as well as providing emotional and practical support.

Being told you can't have treatment to control your cancer may be upsetting.

You can speak to our specialist nurses on our free Support Line to talk through how you are feeling. They can also help with questions about symptoms and the support you can get.

For some people diagnosed with advanced pancreatic cancer, it may not be possible to have treatment to control the cancer. This will depend on your situation. For example, you might not be physically well enough for treatments like chemotherapy.

Being told that you can't have any treatment to control your cancer can be a shock for you and those close to you. We explain the support available to help you deal with this on page 46.

What medical care can I have?

If you can't have treatment to control your cancer, you will still receive care from hospital or community teams. Community teams may include your GP, Macmillan nurses, a hospice team or district nurses. They will be able to assess your symptoms and provide treatments to help. They can also help you get care and support at home. Read more on page 16.

Treatment for symptoms

You will still be able to have treatments to help with any symptoms of the cancer. This might include:

- medicines and other treatments to help with pain
- capsules containing pancreatic enzymes to help any problems with eating and digestion (see page 33)
- medicines to help with sickness or bowel problems
- ways to manage fatigue
- other treatments and support to help with symptoms (see page 32).

Specialist palliative care

If you can’t have treatment to control the cancer, you may be referred to a specialist palliative care team. They can help manage symptoms, as well as supporting you and your family. If you haven’t seen a palliative care team, ask your GP or nurse to refer you.

Read more about palliative care on page 16.

Thinking about your future care

If you have been told that you can’t have treatment to control the cancer, you may want to think about your future care. This might include what care you would or wouldn’t want, and where you would like to be cared for. This is called advance care planning. This can be difficult to do, but it may help you feel more prepared and in control.

Read more on our website at:
pancreaticcancer.org.uk/planningcare

Knowing what to expect

Sometimes pancreatic cancer can grow and spread quickly. You may want to know more about what to expect in the future. You can talk to your team at the hospital or your palliative care team. We also have information and support available if you want to find out more.

Find out about care and support in the last few months of life on our website at:
pancreaticcancer.org.uk/end-of-life

You can speak to our specialist nurses on our free Support Line. They can explain what to expect, and how to get the support you need.

> "Knowing what to expect at the end would have made things a bit less stressful."

If you don't want to have treatment

Some people decide they don't want to have any treatment for the cancer. This can be for lots of different reasons, and will be a very personal decision to you. You can still have palliative care to control any symptoms (see page 16).

If you can, take some time to think this over and speak to your medical team and your family and friends. Macmillan Cancer Support have more information about making treatment decisions when you have advanced cancer.

Questions to ask your doctor or nurse

What help can I get with managing my symptoms?

How can I see a palliative care specialist?

What support can a palliative care specialist provide?

What support can I get at home?

What emotional and practical support can I get?

What issues may I face going forwards?

> “Make the most of times when you feel well. Seeing friends, family, trips away. We even had 2 trips to Greece (with careful planning). After the inoperable diagnosis, these times kept us going.”

Dealing with symptoms and side effects

Key facts

- Not everyone will have the same symptoms of pancreatic cancer or side effects from treatments.
- Tell your medical team about any symptoms. There are ways to manage most symptoms and help you feel better.
- Taking capsules containing pancreatic enzymes when you eat can help problems with digestion.
- A dietitian can help you manage problems with digestion and eating. If you haven't seen one, ask your doctor or nurse to refer you.
- Pancreatic cancer may cause diabetes. This can be treated with tablets or insulin injections.
- Ask your doctor or nurse for help with pain as soon as possible. There are treatments that can help.
- Extreme tiredness (fatigue) is a common symptom. There are things that can help, like balancing rest with activities.

This section explains the common symptoms of pancreatic cancer and side effects of treatment.

It’s important to talk to your medical team about any symptoms as they can help manage them. Getting treatment to manage symptoms can improve how you feel, both physically and emotionally.

Problems with digesting food

The pancreas makes enzymes, which help to break down food. This is part of digestion. When you have pancreatic cancer, your pancreas may produce fewer enzymes. The cancer can also block enzymes from getting to your intestine where they help with digestion. This means your body may not get the nutrients it needs from food.

Symptoms

Problems with digestion can cause symptoms, including:

- losing your appetite
- losing weight
- indigestion or heartburn
- runny poo (diarrhoea)
- finding it harder to poo (constipation)
- pale, oily, smelly, floating poo (steatorrhoea)
- tummy discomfort, cramps or pain
- bloating and wind
- feeling full up quickly
- feeling sick
- needing to poo urgently, especially after eating.

Speak to your doctor, nurse or dietitian about ways to manage these symptoms. Managing problems with digestion can make a big difference to how you feel. It can also help you cope better with treatments.

Pancreatic enzyme replacement therapy (PERT)

Pancreatic enzyme replacement therapy (PERT) replaces the enzymes your pancreas would normally make. They are capsules that you take when you eat or have a milky drink. They help to break down food so it can be absorbed, and can help to manage the symptoms on page 33. They can really improve how you feel.

Speak to your nurse, dietitian or doctor about getting a prescription for PERT. In the UK, brands include Creon®, Nutrizym® and Pancrex®.

If you haven't been told about pancreatic enzymes and have any of the symptoms on page 33, ask your doctor, nurse or dietitian about them.

We have detailed information about diet in our booklet: **Diet and pancreatic cancer**

And our factsheet: **How to manage problems with digestion using pancreatic enzyme replacement therapy (PERT).**

Or on our website at: **pancreaticcancer.org.uk/diet**

Support from a dietitian

If possible, you should see a dietitian to help manage difficulties with digestion. Specialist pancreatic or oncology dietitians are experts in diet and cancer.

Not all hospitals will have a specialist dietitian. Your doctor or nurse may help you with your diet and symptoms. Or they can refer you to a general dietitian at the hospital or a dietitian based in the community.

Speak to our specialist nurses on our Support Line for more information about getting support with digestion problems.

Weight loss

Weight loss is a common symptom of pancreatic cancer. Weight and muscle loss can affect how you deal with the symptoms of the cancer, and with treatments such as chemotherapy. It can be upsetting, and affect how you feel generally.

Your doctor, dietitian or nurse will work out what is causing the weight loss, and how to manage it. Taking pancreatic enzymes (see page 34) may help you digest your food and maintain your weight. Making changes to your diet so that you get more calories and protein can also help. Speak to your dietitian about this.

You can read more about weight loss and how it's managed at: **pancreaticcancer.org.uk/dietsymptoms**

Diabetes

The pancreas produces hormones, including insulin, which control sugar levels in the blood. Pancreatic cancer can reduce the amount of hormones the pancreas makes. This can cause diabetes, where the amount of sugar in the blood is too high.

If you have diabetes, you will have support in managing this. This may include your GP, a hospital doctor, a diabetes specialist nurse and a specialist dietitian.

There are different types of diabetes. The type of diabetes most people with pancreatic cancer have is not the most common type. **A lot of information you may come across, such as changing what you eat, may not be right for you.**

You may need to eat foods higher in calories and protein if you have lost weight. Your diabetes will be managed around this. If you already had diabetes before being diagnosed with pancreatic cancer, the cancer may mean that your diabetes now needs to be treated differently.

Find out more on our website:
pancreaticcancer.org.uk/diabetes

Extreme tiredness (fatigue)

Fatigue is extreme tiredness. It isn't the same as just feeling tired. You might feel drained or exhausted. Fatigue is a common symptom. It can be caused by the cancer itself, treatments or other symptoms of the cancer.

What can I do?

- Talk to your medical team about your fatigue. They can help you find ways to manage it.
- Plan your time, trying not to do too much and prioritising activities.
- Some people find it helps to track their energy levels and what triggers tiredness. You could use a fatigue diary or app.
- Gentle physical activity can help with fatigue.
- Have a bedtime routine. Try to go to bed at the same time each evening and find ways to relax before bed.
- Limit time on screens before bed.
- Try to avoid napping during the day if it affects your sleep at night. Or limit how long you nap to about 30 minutes.
- Some people find that complementary therapies such as massage and acupuncture can help with fatigue. Read more on page 57.
- Ask friends and family if they can help with things like laundry, cleaning and childcare.

Read more in our booklet: **Fatigue and pancreatic cancer: How to deal with tiredness.**
Or at: **pancreaticcancer.org.uk/fatigue**

Pain

Many people with pancreatic cancer will have pain at some point. You may find this worrying, but there are ways to manage pain. Tell your doctor or nurse about any pain. The sooner it is treated, the better the chance of getting it under control.

Treatments include:

- painkillers, including paracetamol and ibuprofen, and stronger painkillers called opioids, such as morphine
- medicines that are usually used to treat other conditions, such as steroids, antidepressants and medicines for epilepsy
- a nerve block, which blocks nerves from sending pain messages to the brain
- palliative radiotherapy
- palliative chemotherapy.

There are also other things that can help you deal with pain, such as complementary therapies (see page 57).

Read more about pain and how it's treated in our booklet: **Pain and pancreatic cancer.**
Or at: **pancreaticcancer.org.uk/pain**

Bowel problems

Many people with pancreatic cancer notice changes to their poo, including diarrhoea and constipation. Your doctor or nurse can work out what is causing these problems, and find ways to manage them.

Diarrhoea

Diarrhoea (runny poo) can be caused by problems digesting food, an infection or be a side effect of chemotherapy.

Pancreatic enzymes can help with diarrhoea caused by digestion problems. Speak to your doctor, nurse or GP if diarrhoea doesn't get better. You may need to see a gastroenterology team, who are experts in problems with the stomach and intestines.

If you have diarrhoea:

- drink plenty of fluids so that you don't get dehydrated
- Macmillan Cancer Support's **toilet card** may help you access toilets in public
- your doctor or nurse may be able to prescribe you medicines
- if you are on chemotherapy and have diarrhoea more than four times a day, call the 24-hour emergency number.

Constipation

Constipation (when you find it hard to poo) can be a side effect of some treatments, for example, morphine. Not moving around or eating much, and dehydration may also make constipation more likely.

If you do get constipation, medicines called laxatives may help. It's also important to make sure you drink enough fluids.

Read more about bowel problems on our website at: **pancreaticcancer.org.uk/bowelhabits**

Feeling and being sick (nausea and vomiting)

This can be caused by the cancer itself, but also by treatments such as chemotherapy. Speak to your GP, specialist nurse or palliative care team for help.

There are treatments for sickness, including anti-sickness medicine. If the sickness is caused by the cancer blocking the duodenum, you may be able to have a stent or bypass surgery (see page 42).

Read more about treating sickness on our website at: **pancreaticcancer.org.uk/sickness**

Jaundice

Pancreatic cancer can cause jaundice by blocking the bile duct. Your bile duct is the tube that takes a fluid called bile from your liver to your duodenum. We explain these medical words on page 61.

Jaundice turns your eyes and skin yellow. It can also make you feel itchy and causes dark urine and pale poo. Jaundice is serious and it's important to get treatment straight away.

You may need to have a small tube (called a stent) put into your bile duct. This should open up the blockage and improve your symptoms. If you are having chemotherapy, this will be delayed until the jaundice has been treated.

Read about stents in our fact sheet: **Stents to treat jaundice caused by a blocked bile duct.**

Or on our website at:
pancreaticcancer.org.uk/biliarystent

Read more about jaundice at:
pancreaticcancer.org.uk/jaundice

Treatment for a blocked duodenum

After you eat, food goes from your stomach into the duodenum. This is the first part of your small intestine (see diagram on page 5). Pancreatic cancer can block the duodenum, which means that food can't flow out of the stomach. This is known as gastric outlet obstruction. If this happens, the food can build up in your stomach. You may feel and be sick, feel bloated, and not be able to eat much.

You may be able to have a tube called a stent put into your duodenum. This should unblock the duodenum, and your symptoms should improve.

Some people may have bypass surgery. This is an operation to make a new way for food to flow out of the stomach into the duodenum, and bypass the blockage.

Read about stents for a blocked duodenum at:
pancreaticcancer.org.uk/duodenalstent

Read about bypass surgery at:
pancreaticcancer.org.uk/bypass

Blood clot in a vein

People with pancreatic cancer are at higher risk of a blood clot forming in a vein. Your risk of a blood clot is even greater if you have advanced pancreatic cancer. Some chemotherapy drugs can also increase the risk of a blood clot.

A blood clot in a vein is serious, and needs to be treated straight away. It often happens in the lower leg (calf), upper leg (thigh), or arm. This is known as deep vein thrombosis (DVT). Symptoms include pain, tenderness and swelling in one of your arms or legs. It can block the normal flow of blood through the veins.

Part of a clot can also break off and travel in the blood to your lungs. This is called a pulmonary embolism. Symptoms include feeling short of breath and sudden chest pain. This is a serious condition which needs immediate medical attention.

Read about blood clots, including the symptoms, at:
pancreaticcancer.org.uk/bloodclots

What can I do about symptoms?

- Tell your doctor or nurse about any symptoms as soon as you can.
- Find out more about how symptoms are managed on our website. This includes things you can do yourself.
- If you have any symptoms of digestion problems, ask about pancreatic enzymes. Ask to see a dietitian if you haven’t already.
- Be aware of the symptoms of a blood clot. Contact your doctor or nurse as soon as possible if you get any of these symptoms.

Questions to ask your doctor or nurse

How can my symptoms be treated?

Are there things I can do myself?

Will taking enzymes help my problems with digestion?

Can you give me advice about how to gain weight?

Are there other specialists who can help manage my symptoms? For example, a dietitian or palliative care specialist?

“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.”

Emotional support

Key facts

- If you have been told that you have pancreatic cancer, you may have lots of different emotions.
- Get support as soon as you can from your medical team, or ask to be referred for support.
- Anxiety and depression can be common in people with pancreatic cancer. But there are ways to help deal with this.
- If you have been told your cancer can't be cured, getting a referral to palliative care will help you get emotional support.
- We have a range of services that can support you.
- Family and friends might also find things difficult. They can also get support from our services.

Read more about emotional support and finding ways to cope at: **pancreaticcancer.org.uk/coping**

You can contact our specialist nurses on our Support Line for emotional support.

Call **0808 801 0707** or email **nurse@pancreaticcancer.org.uk**

Your feelings

If you have been told you have pancreatic cancer, you may have a range of emotions. These might include distress, shock, fear, sadness and anger. There's no right or wrong way to feel. But support is available to help.

Anxiety and depression

People who are dealing with a cancer diagnosis often feel low or anxious from time to time. But for some people with pancreatic cancer, these feelings can become more serious problems with anxiety and depression.

Speak to your doctor, nurse or GP about how you are feeling as soon as possible. They can support you and find ways to manage the anxiety or depression. This may include talking therapy such as counselling (see page 48). It may also help to sort out any practical issues (see page 54).

Read more about anxiety and depression and symptoms to look out for at: **pancreaticcancer.org.uk/depression**

Getting support

Talk to your nurse about how you're feeling. Being open with them will help them support you better.

Get support from a palliative care team – they are experts in supporting people with advanced cancer. They can help you manage emotional symptoms, depression and anxiety. Hospices can also provide a lot of emotional support.

Ask to be referred for psychological support. Psychological support services help people with emotional (psychological) issues. You might be offered support from counsellors, clinical psychologists, psychiatrists or social workers. Read more about these professionals on page 61. Your family can also get support.

Counselling or 'talking therapy' involves talking to a trained professional about your thoughts and feelings. It may help you work through your feelings and find ways of coming to terms with things. There are different ways to get counselling.

- Ask your GP or nurse to refer you. You can also refer yourself using the NHS website.
- Check what is offered through your local hospital, hospice, Macmillan information and support centre or Maggie's centre. If you live in Wales, you can get support from Tenovus Cancer Care. If you live in Northern Ireland, Cancer Focus NI and Action Cancer provide support.
- Mind have information about how to find a counsellor.

“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.”

Getting spiritual support

Spirituality means different things to different people, whether you follow a religion or not. Being diagnosed with pancreatic cancer may mean you reflect more on life and your future. Your hospital, hospice or palliative care team may have a chaplaincy service. Chaplains help people of any or no religion find meaning and explore what's important to you.

> "My faith was a very important factor in my journey with pancreatic cancer."

Speak to others affected by pancreatic cancer

Other people affected by pancreatic cancer may be more likely to understand how you feel.

- Talk to others and share experiences on our **online discussion forum**. You can also find social media groups for people with pancreatic cancer and their families.
- **Read about the experiences** of other people with pancreatic cancer on our website. Go to: **pancreaticcancer.org.uk/stories**
- Join a **support group** for people with pancreatic cancer. Local cancer centres and hospices may run cancer support groups.

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

Cancer centres

Cancer centres such as Maggie's centres or Macmillan information and support centres provide emotional support. They can also help with other things, such as dealing with the effects of treatment, and financial worries. Ask your nurse about local cancer centres.

Finding ways to cope

It may feel like lots of things are out of your control, and this can feel stressful and frustrating.

What can I do?

- Try to sort out things that might be worrying you. For example, get help with any symptoms (see page 32) or financial issues (see page 56).
- Make plans and have things to look forward to. The charity **Something to Look Forward To** provides gifts and treats to people with cancer.
- Focus on things you enjoy doing, and that might help take your mind off the cancer.
- Try breathing and relaxation exercises. There are guides on the **NHS website**, or apps for your phone.
- Some people find complementary therapies help them deal with pancreatic cancer. Find out more on page 57.

> "Listen to audio books, listen to music. Spend time with people you wish to see, but give them a time guide to prevent becoming too tired."

Talking to your family and friends

Telling your friends or family that you have cancer can be difficult. Everyone deals with difficult news in different ways. You may not want to talk to family and friends at all. Or you may worry that your family will find talking about it too upsetting.

But talking openly about your feelings or wishes can help people support you. For example, you may feel less worried about the future if your family know how and where you would like to be cared for. Read more about this on page 29.

Macmillan Cancer Support have useful tips on talking about your cancer.

Support for family and friends

Pancreatic cancer can have a big impact on the lives of those close to you as well – it can affect their emotions, their own health, and their finances. Let them know that they can also get support from our services.

We have lots of information for your family in our booklet:
Caring for someone with pancreatic cancer: Information for families and carers.
And at: **pancreaticcancer.org.uk/families**

Questions to ask your doctor or nurse

How can I get emotional support?

How can I see a counsellor?

Is there a local cancer centre that can provide support?

Is there support for my family and friends?

What support can a hospice provide?

Daily life with pancreatic cancer

Key facts

- It’s important that you get the right support to help you cope with the cancer and continue with your daily life as much as possible.
- Getting help for practical things may also help reduce worries and stress.
- You may be able to get support at home from a community or district nurse.
- If you need it, you can get an assessment from an occupational therapist. They can help you get equipment and make changes to your home.
- There are benefits and grants available, and other ways to help with costs.
- Gentle physical activity may help improve fatigue and boost your mood.
- Complementary therapies like acupuncture, massage or relaxation therapies may help with anxiety, pain and other side effects.

Getting practical support

Getting practical things organised may help reduce worries and stress.

Support at home

You may be able to get help and support from a community or district nurse who can visit you at home, or from social services. Ask your GP for more information.

Read more at: **pancreaticcancer.org.uk/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."

Equipment and changes to your home

Occupational therapists and physiotherapists can provide support in making changes at home. An occupational therapist (OT) provides advice and equipment to help you stay independent and carry on doing the things you want to do. They can visit you at home to help you get equipment.

Your GP or medical team can refer you to a physiotherapist and an OT. You can also get help through your local hospice or council.

Read more at: **pancreaticcancer.org.uk/equipment**

Financial support

Get support with financial issues and find out about benefits and grants you might be entitled to as soon as possible. Macmillan Cancer Support and Citizens Advice can provide expert information and advice about this. Some hospitals also have benefits advice workers.

If you have an illness that can't be cured, you may be eligible for benefits under the special rules for terminal illness (SRTI). Your claim might be fast-tracked and you could be paid at a higher rate. Marie Curie has more information about this.

Other ways to reduce costs

- **Apply for a parking permit under the Blue Badge scheme** – you may be eligible if you have cancer that can't be cured.
- **Free parking at hospitals** – some hospitals offer free parking to people with cancer. Check at the hospital's main reception.
- **Prescriptions** in Scotland, Wales and Northern Ireland are free. In England, prescriptions are free for cancer treatment, including medicines for symptoms and side effects.
- **Help with health costs** – you may be able to get help with various health costs, like dental treatment, eye tests, glasses and travel to hospital.
- **Refunds for health-related travel** – if you have a low income or receive certain benefits, you may be able to get refunds for your travel costs to hospital. Ask at the hospital.

Read more about these and other financial support on our website at: **pancreaticcancer.org.uk/money**

Physical activity

Gentle physical activity like walking can:

- help maintain or improve your strength, muscle mass and fitness
- boost your mood and improve fatigue
- help you to cope better with treatment.

Speak to your doctor or nurse before starting any exercise. A physiotherapist may support you with keeping active too. They can advise you on what type of activities are best for you, and any safety issues to be aware of.

Some cancer support services, including Maggie's centres and hospices, run exercise classes for people with cancer. Ask your GP about any services available in your area.

Read more about physical activity on our website at:
pancreaticcancer.org.uk/exercise

Complementary therapies

Complementary therapies include acupuncture, massage, meditation and relaxation therapies. Some people find that these therapies help them cope with anxiety, pain and some side effects of treatments. Tell your doctor or nurse before trying a complementary therapy, as some may affect your cancer treatment.

Read more about complementary therapies at:
pancreaticcancer.org.uk/complementarytherapies

Questions to ask your doctor or nurse

How can I get support at home?

How do I get in touch with a community nurse?

What support can social care provide?

Would it be helpful for me to see an occupational therapist (OT)? Can I be referred to an OT?

Where can I get financial advice and support?

Can I get help with hospital parking or travel to hospital?

What physical activity would be helpful for me?

Would complementary therapies help?

What is my prognosis (outlook)?

Some people want to know how long they have left to live. This is called your prognosis, outlook or life expectancy.

The prognosis will be different for each person, and depends on several things. These include how far the cancer has spread (see page 7), what treatments you can have, and how your health was generally before the cancer diagnosis.

You may not want to know your prognosis. But if you do, speak to your doctor. They won't know your prognosis exactly but they should be able to give you an idea of what to expect. They will base this on an average for people who have been in a similar situation.

There is a lot of information about pancreatic cancer online, and not all of it is accurate, so it's important to speak to your doctor about your own situation.

You can read more about prognosis at:
pancreaticcancer.org.uk/inoperableprognosis

Questions to ask your doctor or nurse

How long do I have left to live?

How accurate is this?

I don't want to know my prognosis, but can you tell me how my cancer will change?

What are my treatment options?

What difference will it make to my quality of life if I decide to have chemotherapy or not?

What's the benefit of having treatment? Are there any risks?

What are my treatment options if I decide not to have chemotherapy or other treatments?

Is there anything I can do to help me live longer?

If I don't want to know my prognosis but my family do, can you speak to them in confidence?

> "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."

More information and support

Medical words explained

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

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

Bile ducts: tubes that carry bile from the liver to the small intestine.

Clinical psychologist: a professional who treats people with emotional (psychological) problems to reduce their distress and improve their emotional wellbeing.

Consultant: a senior doctor – for example, a consultant oncologist. Read about the oncologist on page 15.

Counsellor: a professional who helps people deal with emotional problems by helping them talk through issues and find solutions. Also called a therapist.

Duodenum: the first part of the small intestine.

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 to break down food and drink.

Hepato-pancreato-biliary (HPB): this term covers the liver, pancreas and bile ducts. HPB doctors and nurses specialise in treating pancreatic diseases.

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.

Lymph nodes: small oval structures throughout the body that contain lymph fluid. They are part of the immune system.

Pancreatic enzyme replacement therapy (PERT): used if the pancreas isn't producing enough enzymes. It involves taking capsules containing pancreatic enzymes to help break down food. See page 34.

Psychiatrist: a doctor who treats people with mental health problems through medicines and recommending other treatments such as counselling.

Small intestine: part of the bowel, where food is mostly digested and absorbed.

Social worker: a professional who helps people deal with problems such as living independently, improving their wellbeing or accessing welfare support.

Upper gastrointestinal (Upper GI): the upper part of the digestive system, including the stomach, pancreas, liver, gallbladder and bile ducts.

Find more words on our website at:
pancreaticcancer.org.uk/medicalwords

Pancreatic Cancer UK support

We are here for everyone affected by pancreatic cancer.

Our specialist nurses are here to talk now

We can answer your questions, recommend practical steps, and provide emotional support when you need it most.

Call free on **0808 801 0707**
or email **nurse@pancreaticcancer.org.uk**

Expert information

Our free information can help you understand your diagnosis, ask questions, make decisions and live as well as you can.

Go to: **pancreaticcancer.org.uk/information**

Download or order our free publications at:
pancreaticcancer.org.uk/publications or call **0808 801 0707**

Our online forum

The forum is a supportive online space where everyone affected by pancreatic cancer can be there for each other.

Go to: **forum.pancreaticcancer.org.uk**

Real life stories

Read other people's experiences of pancreatic cancer.

Go to: **pancreaticcancer.org.uk/stories**

Useful organisations

Action Cancer

actioncancer.org

Provide early cancer prevention, detection and support services in Northern Ireland.

Cancer Focus NI

cancerfocusni.org
Cancer Nurseline: 0800 783 3339 (Mon-Fri 9am-1pm)
Provide support services to people with cancer and their families in Northern Ireland.

Cancer Research UK

cancerresearchuk.org
Helpline: 0808 800 4040 (Mon-Fri 9am-5pm)
Information for anyone affected by cancer.

Citizens Advice

citizensadvice.org.uk
Provide information and advice on a range of issues including work, benefits, NHS healthcare and patient rights.

Hospice UK

hospiceuk.org
Tel: 020 7520 8200
Information about hospices, and a database of hospices in the UK.

Macmillan Cancer Support

macmillan.org.uk
Support Line: 0808 808 0000 (7 days a week, 8am-8pm)
Provide practical, medical and financial support for anyone affected by cancer.

Maggie's

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

Marie Curie

mariecurie.org.uk
Support line: 0800 090 2309 (Mon-Fri 8am-6pm, Sat 11am-5pm)
Provide care and support for people living witha terminal illness and their families.

Mind

mind.org.uk
Infoline: 0300 123 3393 (Mon-Fri 9am-6pm)
Provide information and support to people with a mental health problem and their families.

NHS 111 Wales

111.wales.nhs.uk
Health information in Wales, including local services.

NHS inform

nhsinform.scot
Provide information about different health conditions and living well, and local services in Scotland.

NHS website

nhs.uk

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

NICan (Northern Ireland Cancer Network)

nican.hscni.net

Information about services in Northern Ireland to support people with cancer and their families.

nidirect

nidirect.gov.uk

Information about local services in Northern Ireland, including health services.

Something to look forward to

somethingtolookforwardto.org.uk

Support people with cancer and their families by providing a variety of gifts, such as tickets to attractions, restaurant meals, hotel stays and beauty treatments. They have gifts available specifically for people with pancreatic cancer.

Tenovus Cancer Care

tenovuscancercare.org.uk
Support Line: 0808 808 1010

Provide support, information and services to people with cancer in Wales.

This booklet has been produced by the Support and Information Team at Pancreatic Cancer UK.

We try to make sure that we provide accurate information about pancreatic cancer. We hope this will add to medical advice, and help you make decisions about your treatment and care. This information should not replace advice from the medical team – please speak to the medical team about any questions.

Email us at **publications@pancreaticcancer.org.uk** for the sources used to write this booklet. If you have any feedback, email us or write to our Information Manager.

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

We would like to thank the following people who reviewed this information.

- Prof Juan W Valle, Professor and Honorary Consultant in Medical Oncology, University of Manchester & The Christie NHS Foundation Trust.
- Lizzie Underhill, Upper GI Clinical Nurse Specialist, Frimley Park Hospital.
- Lou Keenan, UGI Nurse Practitioner, Southport & Ormskirk NHS Trust.
- Udita Mitra-Royhurst, Band 6 Research Nurse, Royal Free NHS Trust.
- Jonathan Hartley, Consultant, Counsellor and Supervisor, Rixon Therapy Services.
- Pancreatic Cancer UK Lay Information Reviewers.
- Pancreatic Cancer UK Specialist Nurses.

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Review date November 2025
Registered charity number 1112708 (England and Wales), and SC046392 (Scotland)