

**Pancreatic cancer that can be  
removed by surgery**

A guide if you have just been diagnosed



# Introduction

This booklet is for anyone recently diagnosed with pancreatic cancer that can be removed by surgery. You might hear this called operable or resectable cancer. Family and friends may also find this booklet useful.

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

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# How to use this booklet

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

Use the symbols below to help you find out 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 53.
- Contact details of all the organisations we mention on page 56.

# Diagnosing pancreatic cancer

## Key facts

- The pancreas is a gland near your stomach.
- It makes enzymes which break down food. This is part of digestion.
- The pancreas also makes insulin which controls the sugar levels in your blood.
- Pancreatic cancer develops when cells in the pancreas grow out of control.
- Being diagnosed with pancreatic cancer can be overwhelming.
- 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 may 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?

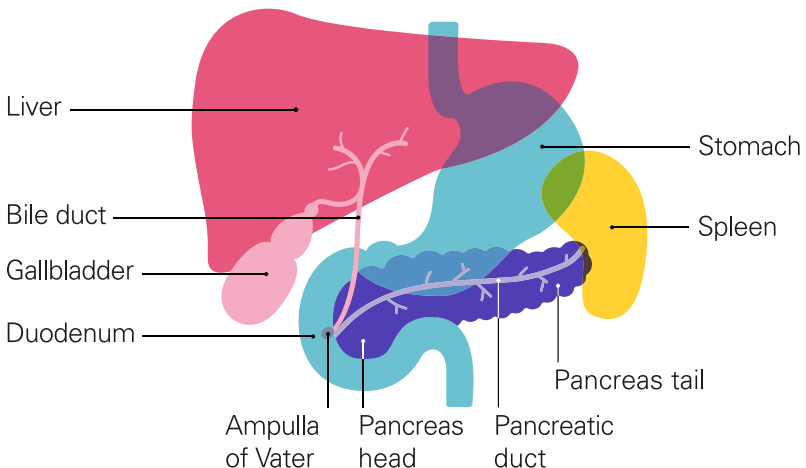
Your pancreas is a gland that sits behind your stomach, at the back of the tummy (abdomen). It is surrounded by several important organs, such as the liver, and also by large blood vessels and lymph nodes (part of your immune system).

Your pancreas does two main things.

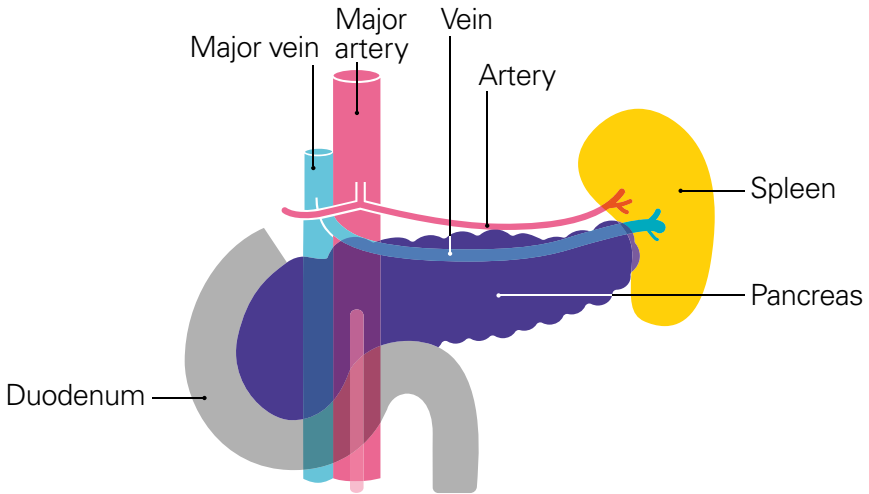
- It makes enzymes. Enzymes help to break down food so your body can absorb nutrients from it. This is part of digestion.
- It makes hormones, including insulin, which control sugar levels in the blood.

Pancreatic cancer can affect how well the 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 at:  
**[pancreaticcancer.org.uk/types](https://pancreaticcancer.org.uk/types)**

## How is pancreatic cancer diagnosed?

Pancreatic cancer can be hard to diagnose. This is because it often doesn't cause symptoms in the early stages. The symptoms may not be specific to pancreatic cancer, and they may come and go to begin with. This can delay diagnosis.

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



Read more about the tests in our fact sheet:  
**How is pancreatic cancer diagnosed?**  
And at: [pancreaticcancer.org.uk/tests](https://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 how far.

Your doctors will discuss with you what treatments would be best for you. Some doctors may just focus on whether your cancer can be removed with surgery, and not tell you the stage. Ask your doctor if you would like to know the stage.

Being told you have pancreatic cancer can feel devastating. You may have questions or worries about your diagnosis. You might find it helpful to speak to our specialist nurses on our free Support Line.



### **What can I do?**

- The diagrams and information on the next pages can help you understand 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.
- You might find it helpful to speak to our specialist nurses on our free Support Line.
- Read more about the emotional support available on page 38.



### **Questions to ask your doctor or nurse**

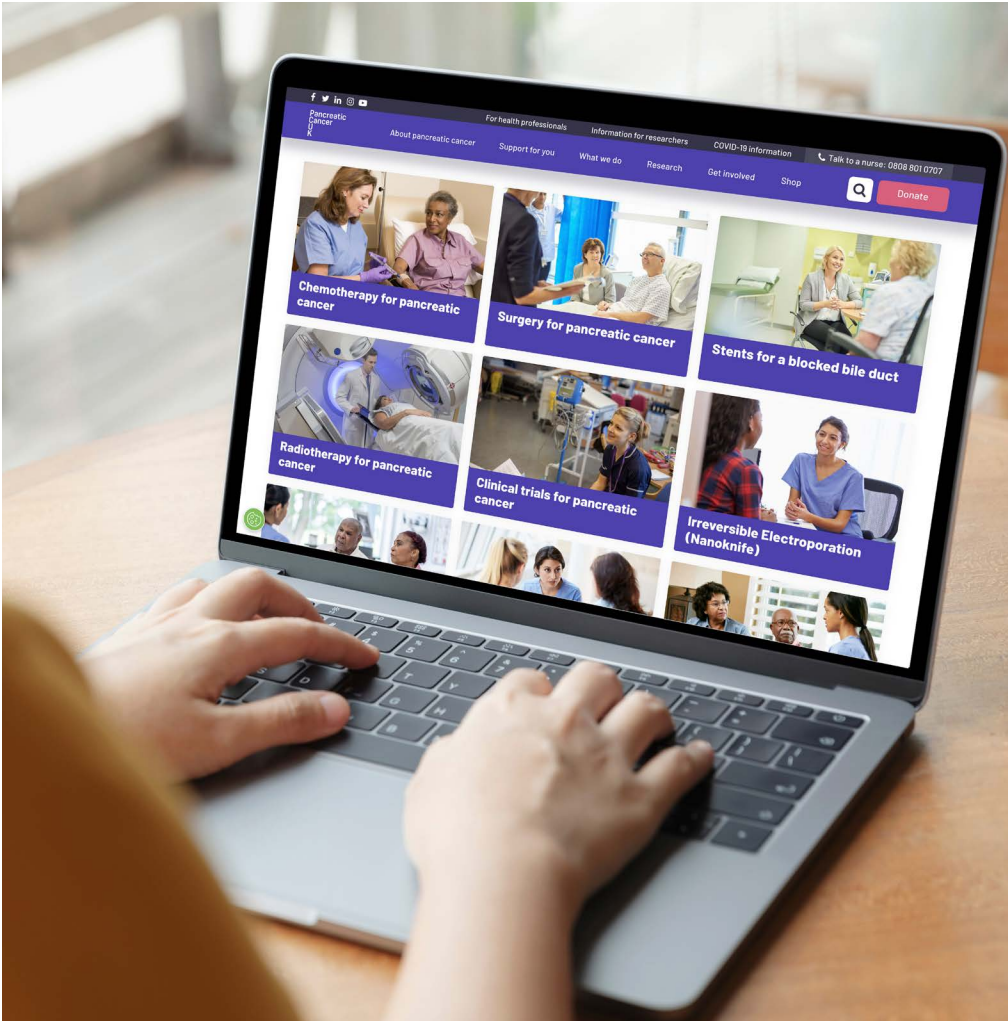
What do the test results mean?

What are my treatment options?

What happens next?

What should I do if my symptoms get worse while I am waiting for treatment?





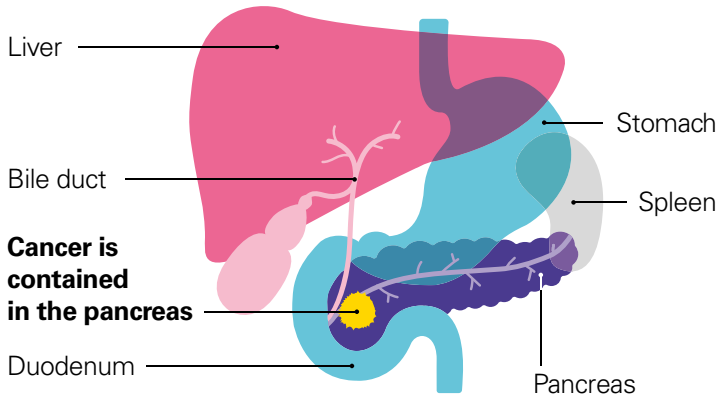
“ I went straight to the Pancreatic Cancer UK website to read up. I found it the most informative website, positive with clear information. I’ve used the forum and I love to read other people's stories.”

# What stage is my pancreatic cancer?

## Stage 1 pancreatic cancer

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

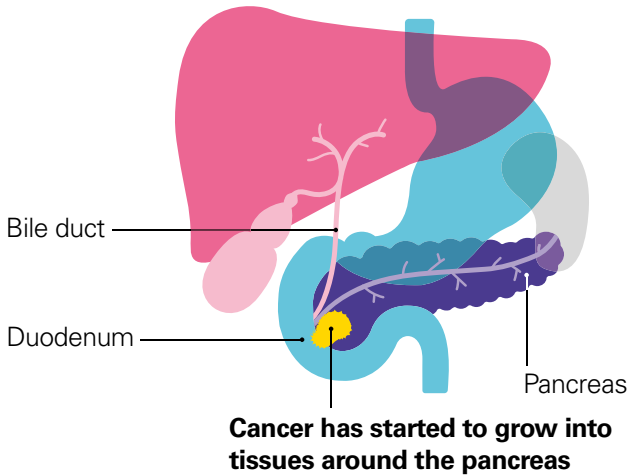


**Possible treatments:** You may be able to have surgery to remove the cancer. You may also have chemotherapy after the surgery.

## Stage 2 pancreatic cancer

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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 the pancreas.

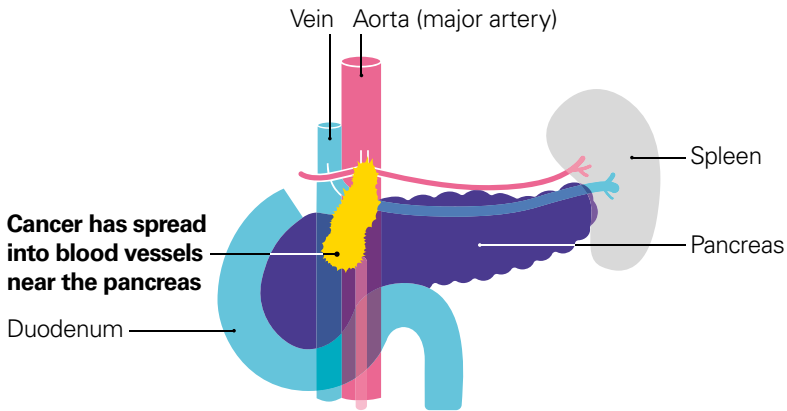


**Possible treatments:** You might be able to have surgery to remove the cancer, but this depends on how far it has spread. You might also be offered chemotherapy. This can sometimes be followed with chemotherapy combined with radiotherapy (chemoradiotherapy).

## Stage 3 pancreatic cancer

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



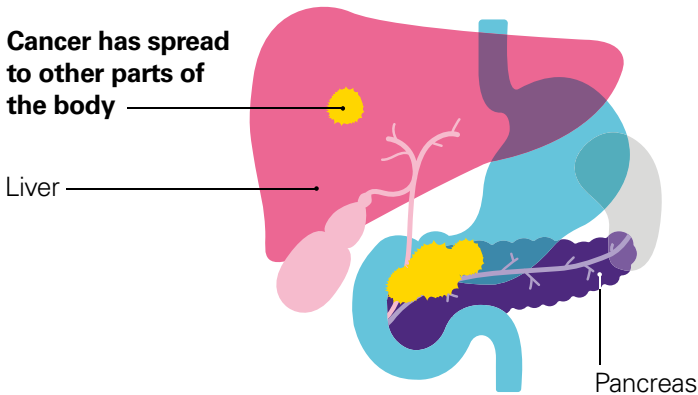
**Possible treatments:** **Borderline resectable cancer** is cancer that has grown very close to the major blood vessels near the pancreas. Some surgeons class borderline resectable cancer as stage 2 (see page 11). You may be able to have surgery to remove the cancer, but it depends which blood vessels are affected. Ask your doctor or nurse if you're not sure. You may have chemotherapy and possibly radiotherapy to try to shrink the cancer, before your doctors consider surgery. Read more on page 25.

If you have **locally advanced cancer**, it won't usually be possible to remove the cancer with surgery. You may be offered chemotherapy, sometimes with radiotherapy. For a small number of people, this may make surgery possible.

## Stage 4 pancreatic cancer

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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. There are also treatments to manage any symptoms.

Your doctor or nurse may call the cancer **inoperable** or **unresectable**, which means that surgery isn't an option.



If you have been told you have locally advanced or advanced cancer, you can find out more in our booklet: **Pancreatic cancer if you can't have surgery (inoperable cancer). A guide if you have just been diagnosed.**

# Having treatment

## Key facts

- A team of medical professionals should review the information about your diagnosis. The team is called a multidisciplinary team (MDT).
- 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 symptoms from your cancer or side effects from your treatment.
- If you have been diagnosed with early pancreatic cancer you may be able to have surgery to remove the cancer.
- Chemotherapy is usually recommended after surgery.
- If you have cancer that has grown very close to major blood vessels (borderline resectable cancer), you may be offered chemotherapy. If this shrinks the cancer, then surgery might be possible later on.

## What health professionals will I see?

### Your medical team

Your case should be reviewed by a pancreatic multidisciplinary team (MDT) at a specialist centre.

- The MDT is the team of health professionals who are responsible for your treatment and care.
- A specialist centre is a hospital where there is a team who specialise in pancreatic cancer.
- 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 are your main contact. They will provide expert support, care and advice and will coordinate your care. Where we talk about your nurse in this booklet, we mean the clinical nurse specialist.

You may meet other members of the team, including:

- a surgeon – a doctor who carries out surgery
- 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 – someone who works with the medical team to coordinate your care. They may only be available in some hospitals, or may be called different things.

Not all hospitals provide specialist pancreatic surgery. You should have your surgery at a specialist centre.



Find out more about specialist centres at:  
[pancreaticcancer.org.uk/care](https://pancreaticcancer.org.uk/care)



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



## Your support needs

Your doctors and nurses should regularly check how you are coping with any symptoms, such as problems with digestion, tiredness and pain. 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 28.

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 questions or concerns, contact your specialist nurse.



There are guidelines for cancer care across the UK. Find out more in our booklet: **The care you should expect and receive: Patient Charter.**

Read more about guidelines if you live in England, Wales and Northern Ireland in our fact sheet: **Explaining the NICE guidelines for diagnosing and managing pancreatic cancer.**

Read more about your care at:  
**[pancreaticcancer.org.uk/care](http://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 your doctor to refer you to one.
- 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 who you should contact out of normal hospital hours or in an emergency.

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

## What are my treatment options?

If you have been diagnosed with early pancreatic cancer you may be offered surgery, and also chemotherapy.

Whatever your options, treatment is **your** decision. It can feel overwhelming, but you don't have to decide anything straight away.



Speak to our specialist nurses on our free Support Line to talk through your diagnosis and treatment options.

## Clinical trials

Clinical trials are carefully controlled medical research studies involving people. Most trials in pancreatic cancer aim to find better treatments, including better ways of using surgery, 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 medical team whether there are any clinical trials that you could take part in.



Read more about clinical trials and find trials for pancreatic cancer at:  
**[pancreaticcancer.org.uk/clinicaltrials](https://pancreaticcancer.org.uk/clinicaltrials)**



## Questions to ask your doctor or nurse

Is surgery possible?

Which type of operation do I need?

Will I need to take any medicines after surgery?

How long might it take me to recover?

What are the risks and side effects of surgery?

Will I have chemotherapy after surgery?

What are the side effects of chemotherapy?

Who will help me deal with any side effects?

Are there any clinical trials that would be suitable for me?

Who do I speak to about appointments?

## Treatment for early pancreatic cancer

### Surgery for pancreatic cancer

Surgery to remove pancreatic cancer is a major operation.

#### Who can have surgery?

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

- there are no signs that the cancer has spread outside of your pancreas
- you are fit and well enough to have the operation.

#### Before you have surgery

You may need more tests to check whether you can have surgery. This might include another scan to check if it's possible to remove your cancer.

You will also need tests to check you are fit and well enough to have surgery. If you have any other major health problems, surgery may be higher risk for you. If you have lost weight, you may also need to put weight back on before surgery. Some hospitals offer programmes to help people get fit enough for surgery.

#### What does surgery involve?

This will depend on where the cancer is in the pancreas and how much of the pancreas is affected.

The surgeon may remove the whole pancreas, or part of it. They may need to remove other organs and tissues around the pancreas too. These may include part of the stomach or the first part of the small intestine (duodenum).

Your surgeon will tell you more about the type of operation that's suitable for you. There are several different types.

- **Whipple's operation (pancreatoduodenectomy or PD)**  
– this is the most common operation. It involves removing the head of the pancreas along with several other parts of the digestive system, including the lower part of the stomach.
- **Pylorus-preserving pancreatoduodenectomy (PPPD)**  
– this is similar to Whipple's operation, but none of the stomach is removed.
- **Distal pancreatectomy and splenectomy** – this removes the body and tail of the pancreas. The spleen is often removed too (splenectomy).
- **Total pancreatectomy** – the whole pancreas is removed, along with other parts of the digestive system.



Find out more about these operations in our fact sheet: **Surgery to remove pancreatic cancer.**  
Or at: [pancreaticcancer.org.uk/surgery](https://pancreaticcancer.org.uk/surgery)

“ The surgeon explained the Whipple's procedure. They remove the head of the pancreas and various other parts. It was major surgery.”

## **Does surgery cause side effects?**

It may take several months to a year to fully recover from surgery. This will be different for each person. As with any major surgery, there are some risks, such as bleeding or infection. Your medical team will check for these as you recover. Ask your medical team for more information about the risks.

Surgery for pancreatic cancer can cause side effects. Just after the operation this might include pain, constipation (when you find it harder to poo) or diarrhoea (runny poo), and feeling sick.

It will take time to get back to eating normally after surgery. Having part or all of your pancreas removed can cause problems digesting food. You may have to take capsules containing pancreatic enzymes to help manage this (see page 30).

Surgery may also cause diabetes, where your blood sugar level isn't well controlled (see page 33). You might have to take medicine to help with this. If your spleen is removed, you may need to take antibiotics for the rest of your life. You may also feel very tired for several months after surgery.

Different people have different side effects. How these affect you will partly depend on how much of your pancreas the surgeon has removed. There is more information on managing symptoms and side effects on page 28.

## **Chemotherapy**

Chemotherapy uses drugs to destroy cancer cells and slow down the growth of the cancer.

You will usually be offered chemotherapy after surgery, to reduce the chances of the cancer coming back.



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



## Side effects

Chemotherapy can cause side effects. Most people get some side effects, but it's unusual to get all of them.

Side effects include feeling and being sick, diarrhoea and extreme tiredness (fatigue). Chemotherapy can also make you more likely to get infections.

Your medical team will monitor you closely. There are ways to manage the side effects. It's important to tell your medical team about any side effects.



Read more in our fact sheet:

**Chemotherapy for pancreatic cancer.**

Or at: [pancreaticcancer.org.uk/chemotherapy](https://pancreaticcancer.org.uk/chemotherapy)

## Treatment if your cancer is close to major blood vessels

If the cancer has grown very close to major blood vessels near your pancreas, 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 whether it's possible to remove it.

This type of cancer is called **borderline resectable pancreatic cancer**. Your doctor may not call it this though. They may just talk to you about your treatment options.

### What does this mean for me?

You may be able to have surgery. It depends which blood vessels are affected by the cancer, and how close it has grown to them.

You may be offered chemotherapy on its own first. Some people then have chemotherapy with radiotherapy (chemoradiotherapy). This can sometimes shrink the cancer enough to make surgery possible. Radiotherapy uses high-energy x-rays (radiation) to damage cancer cells and stop them growing.

You will have scans before, during and at the end of your treatment to check how well it has worked, and whether surgery may be possible.

Different medical teams may have different opinions about whether surgery is possible. Ask for a second opinion if you want one (see page 27).

### **If your surgeon can't remove the cancer**

Sometimes your surgeon may start the surgery, but during the operation, they may find that they can't remove the cancer. This may be because it's spread outside of the pancreas or it's grown around blood vessels near the pancreas. It's not always possible to tell this from scans.

The surgeon may then do a different operation, called bypass surgery. They won't remove the cancer but this surgery can help control some symptoms. Once you have recovered, you may be able to have chemotherapy to help control the cancer.

It can be very upsetting to find out that it wasn't possible to remove the cancer. Support is available. Find out more on page 38.



Read more about bypass surgery on our website at: **[pancreaticcancer.org.uk/bypass](https://pancreaticcancer.org.uk/bypass)**



Speak to our specialist nurses on our free Support Line – they can provide emotional support, and talk through your treatment options.

### If surgery isn't possible

If surgery 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.



Read more in our booklet: **Pancreatic cancer if you can't have surgery (inoperable cancer). A guide if you have just been diagnosed.**

### Getting a second opinion

If you have any concerns about your diagnosis or the treatment recommended, you could ask for a second opinion from a different medical team. Don't delay your treatment while you get a second opinion, as it can take several weeks. Keep in mind that the second team's opinion may not be any different.



Read more about getting a second opinion at: **[pancreaticcancer.org.uk/secondopinion](http://pancreaticcancer.org.uk/secondopinion)**

# Dealing with symptoms and side effects

## Key facts

- Not everyone will get the same symptoms of pancreatic cancer or side effects of treatment.
- It's important that you tell your medical team about any symptoms. There are ways to manage most symptoms. This can improve how you feel both physically and emotionally.
- Taking capsules containing pancreatic enzymes when you eat can help problems with digestion.
- A dietitian can help you manage problems with digestion. 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 the doctor or nurse for help with any pain as soon as possible. There are treatments that can help.
- Extreme tiredness (fatigue) is common. There are things that can help, like balancing rest with gentle exercise.



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](https://pancreaticcancer.org.uk/managingsymptoms)

## Problems with digesting food

The pancreas makes enzymes which help to break down food. This is part of digestion. It is how you get the nutrients that your body needs from food. When you have pancreatic cancer:

- your pancreas may produce fewer enzymes
- the cancer can block enzymes from getting to your bowel where they help with digestion
- removing all or part of the pancreas may affect digestion.

This means that your body may not get the nutrients it needs.

## Symptoms

Problems with digestion can cause symptoms, including:

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

Speak to your doctor, nurse or dietitian about ways to manage these symptoms. Managing problems with diet and 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 milky drinks. They help to break down food so it can be absorbed, and can help to manage the symptoms on page 29. They can really improve how you feel.

Your dietitian, nurse or doctor can prescribe enzymes. In the UK, brands include Creon®, Nutrizym® or Pancrex®. If you haven't been told about pancreatic enzymes, ask your doctor, nurse or dietitian about them.



We have detailed information about diet and pancreatic enzymes 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](http://pancreaticcancer.org.uk/diet)**



## Support from a dietitian

If possible, you should see a dietitian to help manage problems with digestion. Specialist pancreatic or hepato-pancreato-biliary (HPB) dietitians are experts in diet and pancreatic cancer. They can help manage your symptoms and make sure you get all the nutrients you need.

Most specialist centres will have a specialist dietitian. You may also be able to see a dietitian at your local hospital if that's closer.



**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 your body copes with the effects of cancer, and with treatments such as chemotherapy or surgery. It can be upsetting, and affect how you feel generally.

If you are having surgery, the fitter you are beforehand the better for your recovery afterwards. Try to eat as well as possible in the weeks before your operation and be as active as you can. You may need to start pancreatic enzymes before surgery to help improve your digestion (see page 30).

If you have lost weight or muscle, you may need to put weight back on before you can have surgery. Check with your doctor or nurse. If possible, they will refer you to a dietitian (see above).



## 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, which is a condition where the amount of sugar in the blood is too high.

You may also develop diabetes after having part of your pancreas removed. If you have the whole pancreas removed, you will develop diabetes and will need to take insulin to manage this.

You will have support in managing diabetes. This may include your GP, a hospital doctor, a diabetes specialist nurse and a specialist dietitian. Speak to them with any questions about your diabetes.

**There are different types of diabetes. The type most people with pancreatic cancer have is not the most common type. A lot of the information you may find about diabetes, 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, your diabetes may now need to be treated differently.



Find out more on our website:  
[pancreaticcancer.org.uk/diabetes](https://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, other symptoms of the cancer, or it can be a side effect of treatments.



### What can I do about fatigue?

- Talk to your medical team about your fatigue. They can help you 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.
- 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 like acupuncture can help. Read more on page 49.
- Ask for help from friends and family 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](https://pancreaticcancer.org.uk/fatigue)



“ Spend time with people you wish to see,  
but give them a time guide to prevent you  
becoming too tired.”

## Pain in your tummy or back

There are lots of things that can cause pancreatic cancer pain. These can include the cancer itself, problems with digestion or constipation, and pain after surgery. It is normal to have some pain and discomfort for a few months after surgery.

### What can help?

Speak to your doctor or nurse if you have any pain. There are usually ways to manage it, such as taking painkillers. If you have pain or discomfort from problems digesting food, pancreatic enzymes should help with this. Read more on page 30.

It's important to speak to your medical team if you have any problems with pain when you get home after surgery. If you get sudden tummy pain or your pain gets worse, call your surgical team.



Read more about pain, including pain after surgery, in our booklet: **Pain and pancreatic cancer**.  
And at: **[pancreaticcancer.org.uk/pain](https://pancreaticcancer.org.uk/pain)**

## Jaundice

Pancreatic cancer can cause jaundice by blocking your bile duct. The bile duct is the tube that takes a fluid called bile from your liver to your duodenum (the first part of the small intestine).

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.

If your cancer can be removed with surgery and you are well enough to have the operation straight away, the surgery will treat the jaundice.

If you have jaundice but aren't fit enough yet for surgery, or you can't have surgery, you may need to have a small tube called a stent put into your bile duct. It 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 at: [pancreaticcancer.org.uk/biliarystent](https://pancreaticcancer.org.uk/biliarystent)

Read more about jaundice at:  
[pancreaticcancer.org.uk/jaundice](https://pancreaticcancer.org.uk/jaundice)



### Questions to ask your doctor or nurse

How can my symptoms be managed?

Are there things I can do myself?

Will my treatment help relieve symptoms?

Who should I talk to about symptoms?

Will taking enzymes help my problems with digestion?

# Emotional support

## Key facts

- You may go through lots of emotions from shock to sadness and fear. This is normal, and getting support can help.
- It's common for people with pancreatic cancer to have anxiety and depression. But there are ways to manage this.
- Talk to your nurse and medical team about how you feel. They can help you and refer you for more support.
- Try talking to others who have been affected by pancreatic cancer. They can understand how you are feeling.
- Getting support for symptoms, gentle physical activity and complementary therapies may all help you feel better.
- We have a range of services that can support you and your family and friends.



You can contact our specialist nurses on our Support Line for support and to talk through your feelings. Call **0808 801 0707** or email **nurse@pancreaticcancer.org.uk**



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

It can be a shock to be told you have pancreatic cancer. You may have a range of emotions which might include distress, fear, sadness and anger.

If you are having surgery, you might also be worried about the operation, recovery, changes to your body and what may happen afterwards. This is normal, as pancreatic cancer surgery is a major operation.

## 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.

There are ways to get help for anxiety or 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 40). It may also help to sort out any practical issues (see page 47).



Read more about anxiety and depression at:  
**[pancreaticcancer.org.uk/depression](https://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.

**Ask to be referred for psychological support.** Psychological support services help people with psychological (emotional) issues. You might be offered support from counsellors, clinical psychologists, psychiatrists or social workers. Read more about these professionals on page 53. 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, 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.

## Getting spiritual support

Spirituality means different things to different people whether you follow a religion or not. Being diagnosed with pancreatic cancer may mean that you think more about your spirituality. Your hospital may have a chaplaincy service. Chaplains are trained specialists who can help people of any or no religion find meaning and explore what's important to them.





“ 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.”

## Speak to others affected by pancreatic cancer

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

- Speak to trained volunteers on **Side by Side**. This is our telephone support service for people who are having or have had surgery to remove pancreatic cancer.
- Join one of our **online support sessions**, hosted by our specialist nurses to connect with others with pancreatic cancer.
- Talk to others and share experiences on our **online discussion forum**. There are also 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](https://pancreaticcancer.org.uk/stories)**
- Join a **support group** for people with pancreatic cancer. Local cancer centres may run support groups.



Read more about the support we offer at:  
**[pancreaticcancer.org.uk/support](https://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.



### What can I do to help me cope?

Finding ways to cope may help you feel more in control.

Try to sort out things that might be worrying you. For example, get help with any symptoms (see page 28) or financial issues (see page 47).

- 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 to deal with pancreatic cancer. Find out more on page 49.

“ I planned an ‘outing’ on the week that I was not having chemotherapy. Something to look forward to such as trip to the cinema or theatre or just meeting a friend for a coffee.”

## Talking to your family and friends

When you are diagnosed with pancreatic cancer you can feel isolated and alone. 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 your family and friends support you. Macmillan Cancer Support offer 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, finances and their own health. 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](https://pancreaticcancer.org.uk/families)**



### Questions to ask your doctor or nurse

How can I get emotional support?

How can I see a counsellor?

Are there any local support groups?

Is there a local cancer centre providing support?

Is there support for my family and friends?

“ I think it is so important to talk to others about how you're feeling, no one will judge you and so many people understand.”

# Daily life with pancreatic cancer

## Key facts

- It's important 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.
- Speak to your employer about ways you can carry on working if you want to.
- You are protected from discrimination at work if you have cancer.
- There are benefits and grants available, and other ways to get help with your finances.
- Gentle physical activity may help improve fatigue and boost your mood.
- Complementary therapies like acupuncture or massage can help with anxiety, pain and other side effects.

## Getting practical support

Sorting out any practical issues may help reduce worries.

### Work and finances

Get support with financial issues and find out about benefits and grants you might be entitled to. Contact Macmillan Cancer Support and Citizens Advice for information and advice. Some hospitals also have benefits advisors.

Talk to your employer about ways to keep working if you want to. They must make reasonable adjustments to support you at work. These might include changing your working hours, your duties, or working more from home. You have rights at work, and are protected from discrimination if you have cancer. Find out more from Macmillan Cancer Support.



Read more about financial support on our website at: [pancreaticcancer.org.uk/money](https://pancreaticcancer.org.uk/money)

*“ I told my boss immediately, and made sure people around me knew what was going on. It can be daunting but people in general are kind and caring.”*

### Support at home

Surgery to remove pancreatic cancer is a major operation. Think about the support you will need when you go home. Ask family or friends if they can help with shopping, cooking and cleaning. You might want to freeze some meals beforehand, and arrange online shopping.

Before you leave hospital, your medical team should give you advice on the care you may need at home. They will send your GP a letter and tell you who to contact if you have any questions.

The district or community nurse can visit you at home to help with things like changing the dressing on your wound. Ask the hospital team or your GP about this.

If you need extra help at home, tell your nurse. They should be able to arrange for social services to assess your needs. Most people manage well and don't need extra help.

## Physical activity

Gentle physical activity like walking can:

- help to maintain or improve your strength and fitness
- boost your mood
- improve fatigue
- help you to cope better with treatment
- help your recovery after surgery.

**Before you have surgery** – the fitter you are before surgery the better. If you exercise regularly, carry on with this. If you don't usually exercise, try to increase your level of activity. Try setting yourself small targets each day, such as increasing the number of times you go up and down the stairs. This will help you recover from surgery.

**After surgery** – gradually increase how much you do during your recovery. Make sure that you move around during the day. You should start to feel stronger and more active each week.



Speak to your doctor, nurse or physiotherapist before starting any new exercise. They can advise you on what type of activities are best for you. Some cancer support services run exercise classes for people with cancer. Ask your GP about any services available in your area.

**“ There may be local charities who provide advice and classes to build up general fitness and muscle after treatment.”**



Read more about physical activity on our website at: **[pancreaticcancer.org.uk/exercise](https://pancreaticcancer.org.uk/exercise)**

## **Complementary therapies**

Complementary therapies include things like acupuncture, massage, meditation and relaxation therapies. Some people find that they can help them cope with anxiety, pain and some side effects of treatments.

Local charities and occasionally some hospitals may offer some complementary therapies for free. The Complementary and Natural Healthcare Council has a list of registered therapists.

While many complementary therapies are safe, some may affect how well your cancer treatment works. Make sure you talk to your doctor or nurse before trying a complementary therapy, and tell your complementary therapist about your cancer diagnosis.



Read more about complementary therapies at:  
[pancreaticcancer.org.uk/complementarytherapies](https://pancreaticcancer.org.uk/complementarytherapies)



### Questions to ask your doctor or nurse

Where can I get benefits advice and support?

Where can I get advice if I want to carry on working?

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

What can I do to stay physically active?

Are there any complementary therapies that might be helpful for me?

# What is my prognosis (outlook)?

Everyone is different. Some people want to know whether their cancer can be cured, or how long they have left to live. This is called their prognosis, outlook or life expectancy.

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

Surgery is the most effective treatment for pancreatic cancer. If it is an option for you, it may help you to live longer. After surgery you will have check-ups to look for any signs that the cancer has come back. If it does come back, you may be offered further treatment with chemotherapy.

If you want to know more about your prognosis speak to your doctor. They won't know exactly but they should be able to give you an idea of what to expect. 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/operableprognosis](https://pancreaticcancer.org.uk/operableprognosis)**



### Questions to ask your doctor or nurse

What is my prognosis?

How accurate is this?

How successful is surgery likely to be?

If the cancer comes back, what other treatment can I have?

Can you speak to my family about my future if I or they want you to?

“ Hope is a word that I think sums up my journey. I never stop having hope, and sharing with others so that they have hope too.”

# 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.

**Bilirubin:** a yellow substance found in bile that comes from the breakdown of old red blood cells. A build-up of bilirubin in the blood can cause jaundice.

**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.

**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, where food begins to be digested and absorbed.

**Enzymes:** substances produced by different glands in the body, including the pancreas. Pancreatic enzymes help 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.

**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:** the upper part of the digestive system, including the stomach, pancreas, liver, gallbladder and bile ducts.



You can find more words on our website at:  
**[pancreaticcancer.org.uk/medicalwords](http://pancreaticcancer.org.uk/medicalwords)**

## Pancreatic Cancer UK services

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**

### Our online support sessions

Our online support sessions are hosted by our specialist nurses and will give you the chance to connect with others.

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

### Real life stories

Read other people's experiences of pancreatic cancer.

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

## Useful organisations

### Action Cancer

[actioncancer.org](http://actioncancer.org)

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

### Cancer Focus NI

[cancerfocusni.org](http://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](http://cancerresearchuk.org)

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

Information for anyone affected by cancer.

### Citizens Advice

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

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

### Complementary and Natural Healthcare Council

[cnhc.org.uk](http://cnhc.org.uk)

**Tel: 020 3327 2720** (Mon-Fri 9am-5pm)

Information about complementary therapies and a register of therapists.



## **Macmillan Cancer Support**

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

**Support Line: 0808 808 00 00** (7 days a week, 8am-8pm)

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

## **Maggie's**

**[maggies.org](http://maggies.org)**

**Tel: 0300 123 1801**

Centres around the UK and online offering free practical, emotional and social support for anyone affected by cancer.

## **Mind**

**[mind.org.uk](http://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](http://111.wales.nhs.uk)**

Health information in Wales, including local services.

## **NHS inform**

**[nhsinform.scot](http://nhsinform.scot)**

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

## **NHS website**

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

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

## **NICan (Northern Ireland Cancer Network)**

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

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

## **nidirect**

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

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

## **Something to look forward to**

**[somethingtolookforwardto.org.uk](http://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](http://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.

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# Pancreatic Cancer UK

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