

**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 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, read the sections that feel most helpful, and come back if you need to know more. There is more information available on our website and we provide a lot of support. Find out more at **pancreaticcancer.org.uk**

Use the symbols below to help you find out where and when 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 52.
- Contact details of all the organisations we mention on page 55.

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.
- It 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 might struggle with written information to understand pancreatic cancer. Download or order on our website, call **0808 801 0707**, or email **publications@pancreaticcancer.org.uk**

What is the pancreas?

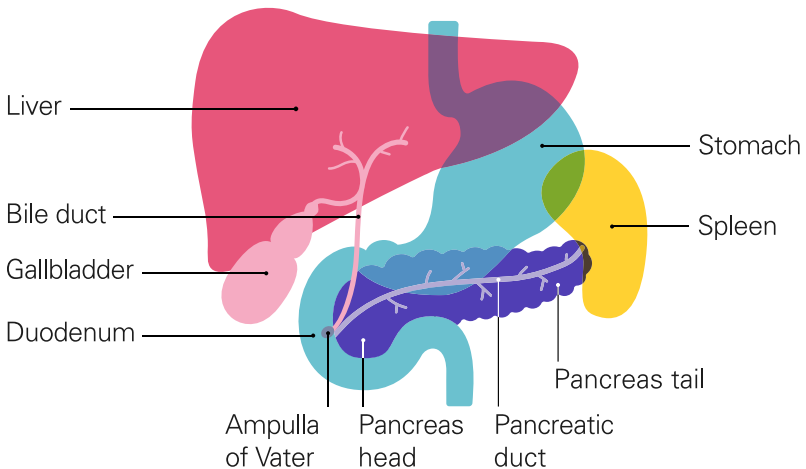
The pancreas is a large gland behind your stomach, at the back of the tummy (abdomen). It is surrounded by several important organs, such as the liver, and also by large blood vessels.

Your pancreas does two main things.

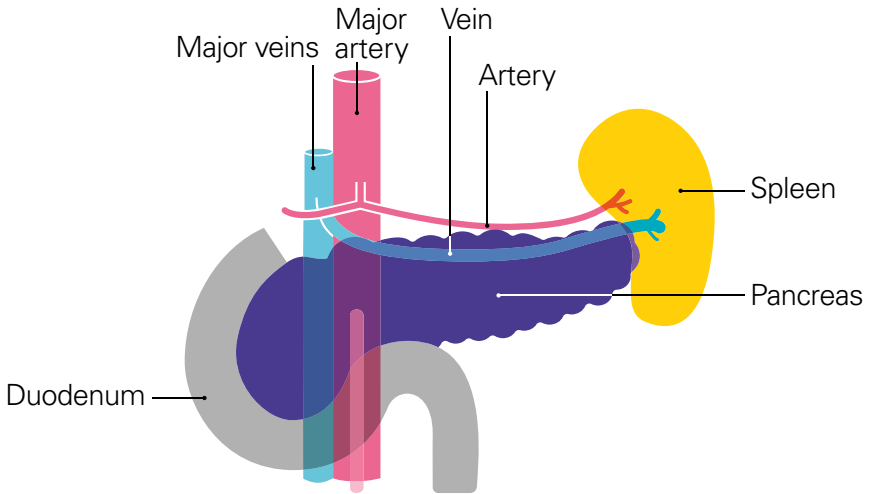
- It makes enzymes. Enzymes help to break down food so your body can absorb it. This is part of digestion.
- It makes hormones, including insulin, which control sugar levels in the blood.

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 or mass.

There are different types of pancreatic cancer. **The information in this booklet is about the most common type of pancreatic cancer 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?

Pancreatic cancer can be hard to diagnose. This is because it may not cause symptoms in the early stages. Any symptoms may be vague and may come and go to begin with.

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?
On our website: 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 covers:

- the size of the cancer
- if it has spread outside the pancreas and how far.

Your doctors will tell you about the best treatments for you. Some doctors may just focus on whether your cancer can be removed with surgery, and not tell you the stage.

Being told you have pancreatic cancer can be overwhelming. 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.
- Read more about the emotional support available on page 37.



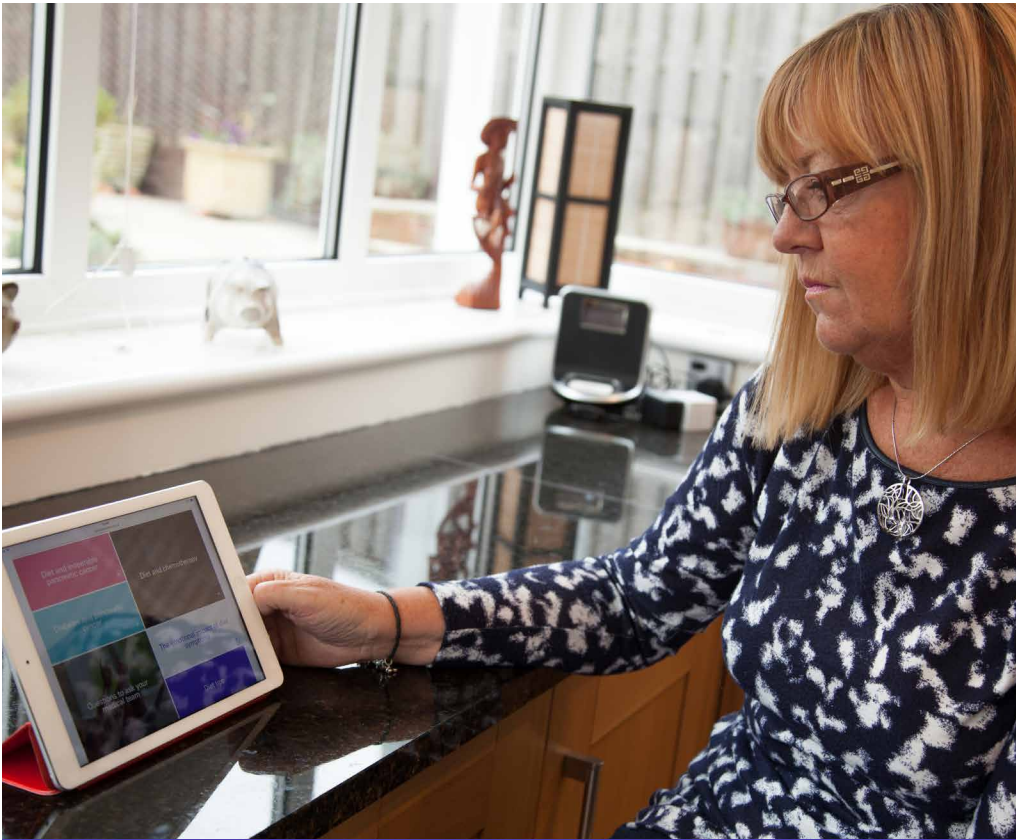
Questions to ask your doctor or nurse

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?

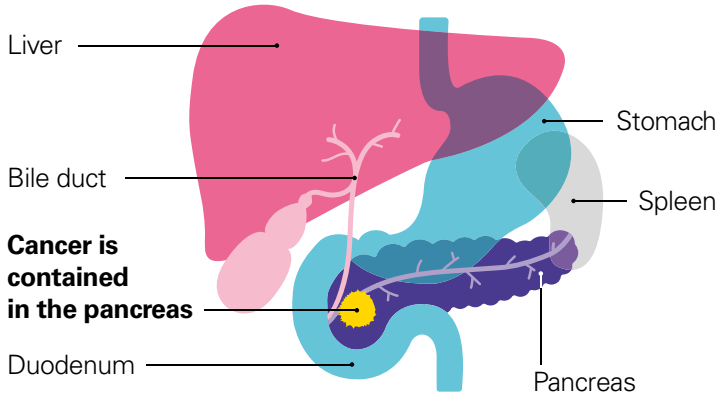


“ I went straight to the Pancreatic Cancer UK website to read up. I found it the most informative website, positive with clear information. I’ve used the forum and I love to read other peoples stories.”

What stage is my pancreatic cancer?

Stage 1 pancreatic cancer

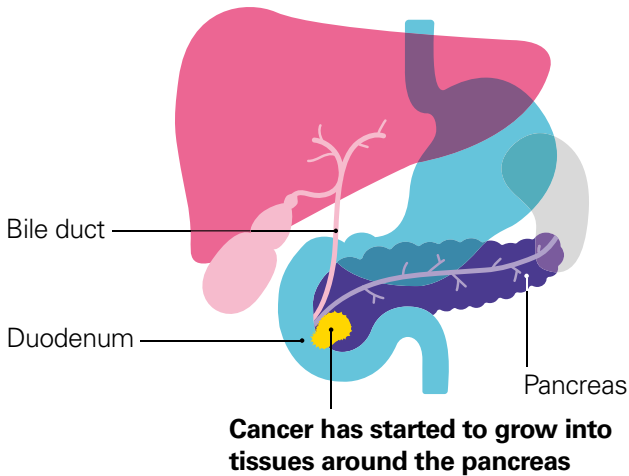
The cancer is contained inside your pancreas. This is **early, localised pancreatic cancer**. It is also called **operable** or **resectable** cancer because surgery may be possible.



Possible treatments: Surgery to remove the cancer and chemotherapy after the surgery.

Stage 2 pancreatic cancer

The cancer may have grown larger. It may have started to spread to a small number of lymph nodes near the pancreas. It hasn't spread to large blood vessels near the pancreas. We explain these medical words on page 52.

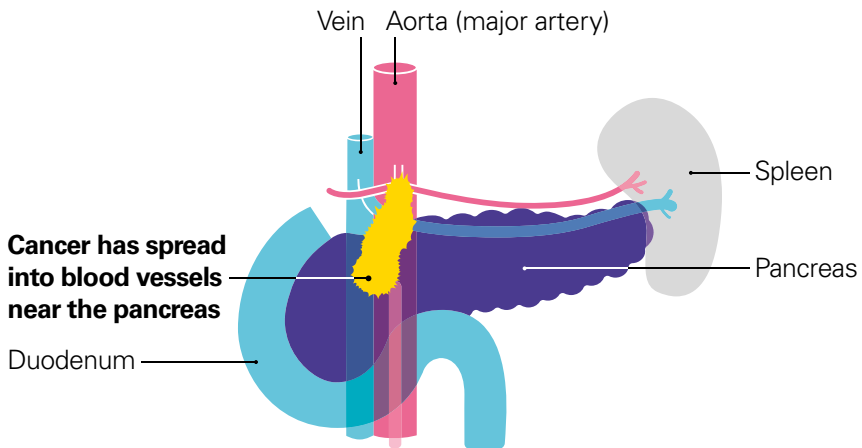


Possible treatments: You might be able to have surgery to remove the cancer, but this depends on how far it's spread. You might also have chemotherapy.

Stage 3 pancreatic cancer

The cancer has spread outside the 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** but it may occasionally be **borderline resectable cancer**.

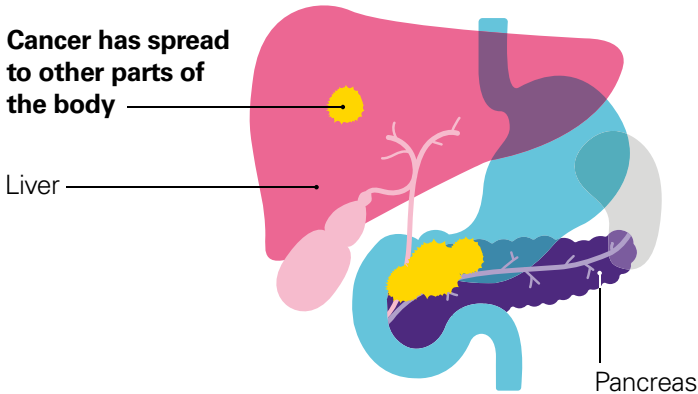


Possible treatments: **Borderline resectable cancer** is cancer that has grown very close to the major blood vessels near the pancreas. You may be able to have surgery to remove the cancer, but it depends which blood vessels are affected. You may have chemotherapy and possibly radiotherapy to try to shrink the cancer, before your doctors consider surgery. Read more on page 23.

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, to slow down the growth of the cancer. For a small number of people, this may shrink the cancer enough to make surgery possible.

Stage 4 pancreatic cancer

The cancer has spread to other parts of the body. It may have spread to the 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). They can support you and answer your questions.
- Your doctor or nurse should check with you about your symptoms and how you are feeling, and provide support.
- If you've been diagnosed with early pancreatic cancer you may be able to have surgery to remove the cancer.
- You should have chemotherapy after the surgery.
- If you have cancer that has grown very close to the major blood vessels (borderline resectable cancer), you may be offered chemotherapy to try to shrink the cancer so that there's a better chance of removing it with surgery.

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 have decided.

Your team should include a **specialist nurse** (sometimes called a **clinical nurse specialist** or **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 at different times, 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 and disorders of the digestive system, including the stomach, intestines, pancreas and liver
- a dietitian – a health professional who provides expert advice about diet and nutrition.

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



Find out more about specialist centres, the MDT, and the health professionals involved in your care on our website: pancreaticcancer.org.uk/care



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. Read more about managing symptoms and side effects on page 27.

They should also talk to you about how you are feeling emotionally and ask about practical issues, like finances.



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



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

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



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.

What are my treatment options?

If you've 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 that involve patients. 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 – although 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



Questions to ask your doctor or nurse

Is surgery possible?

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?

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

Treatment for early pancreatic cancer

Surgery for pancreatic cancer

Surgery is an operation to remove the cancer. This 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. You may have another scan to check if the cancer has spread outside your pancreas.

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. 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 your 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, such as part of the stomach or the first part of the small intestine (duodenum) that attaches to your stomach.

Your surgeon will tell you about the type of operation you're having. There are several different types:

- **Whipple's operation (pancreaticoduodenectomy or PD)**
– this is the most common operation
- **Pylorus-preserving pancreaticoduodenectomy (PPPD)**
- **Distal pancreatectomy and splenectomy** – splenectomy means the spleen is also removed
- **Total pancreatectomy** – the whole pancreas is removed.



Find out more about these operations in our fact sheet: **Surgery to remove pancreatic cancer.**
Or at: pancreaticcancer.org.uk/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 a risk of bleeding or infection. Your medical team will check for these as you recover from the operation. 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 hard to 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, and you may have to take capsules called pancreatic enzymes (see page 30).

Surgery may also cause diabetes, where your blood sugar level isn't well controlled (see page 31). You might have to take medicine to help with this. You may also feel very tired for several months after surgery – this is normal.

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 27.

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

Chemotherapy

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

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

Side effects

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

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

Your medical team will closely monitor you and there are ways to manage the side effects, for example with medicine. It's important that you speak to the medical team if you get any side effects.



Read more in our fact sheet:

Chemotherapy for pancreatic cancer.

Or at: pancreaticcancer.org.uk/chemotherapy

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

Treatment if your cancer is close to major blood vessels

If the cancer has grown very close to major blood vessels near the 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 how close the cancer has grown to blood vessels and whether it is possible to remove it.

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

What does this mean for me?

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

You may be offered chemotherapy on its own or together with radiotherapy (chemoradiotherapy). This can sometimes shrink the cancer enough to make surgery possible. Radiotherapy uses radiation to damage cancer cells and stop them growing.

You will have another scan to check how well the treatment has worked.

Different medical teams may have different opinions about whether surgery is possible. You can ask for a second opinion from a different medical team if you want one (see page 25).

If it's not possible to remove the cancer

Sometimes during the operation, the surgeon may find that they can't remove the cancer because it's spread too much. 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 tumour but the surgery can help control any symptoms. Once you have recovered from this surgery, you may be able to have chemotherapy to help control the cancer. Read more about chemotherapy on page 22.

It can be very upsetting to find out that it wasn't possible to remove the cancer. There is support available for you – find out more on page 37.



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



Read more about bypass surgery in our fact sheet: **Stents and bypass surgery for pancreatic cancer**. Or at: pancreaticcancer.org.uk/bypass

If your surgeon can't remove the cancer with surgery

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

You can ask for a second opinion from a different medical team if you want one. 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.



Dealing with symptoms and side effects

Key facts

- Not everyone will get the same symptoms of pancreatic cancer or side effects of treatment.
- There are ways to manage most symptoms and improve the quality of your life.
- Taking capsules called pancreatic enzymes when you eat can help problems with digestion.
- You should see a dietitian for help with problems with digestion and eating.
- Pancreatic cancer may cause diabetes, but 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 a common symptom. There are things that can help, like balancing rest with gentle exercise.

This section explains some 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.

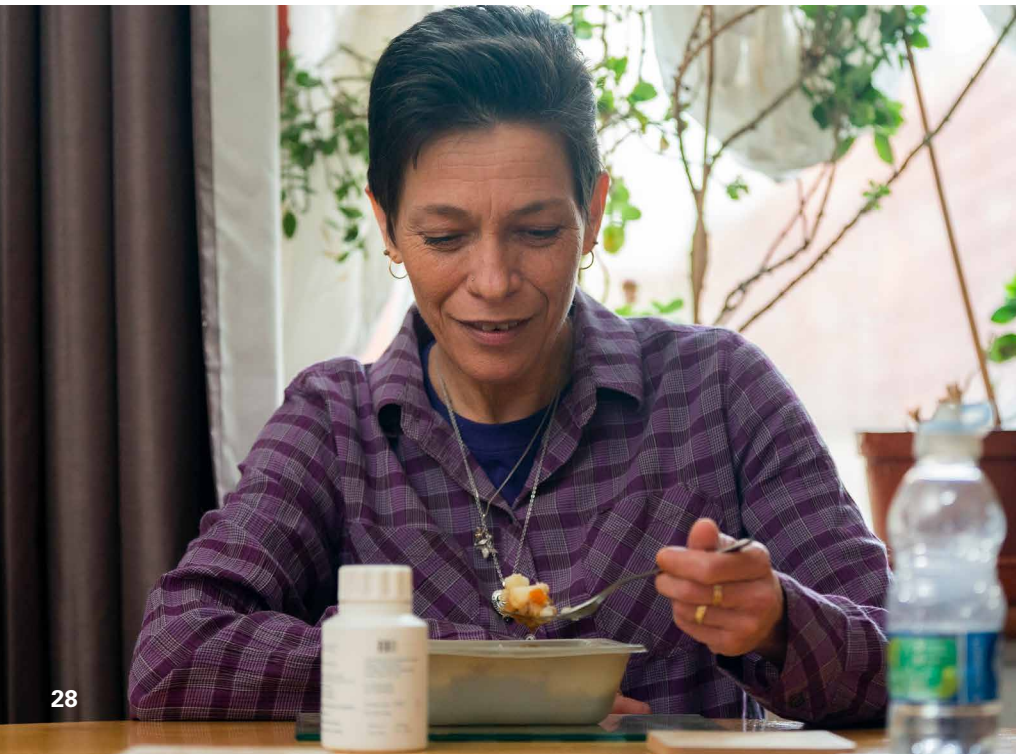
Getting treatment for symptoms such as problems eating and digesting food, tiredness and pain, can improve how you feel, both physically and emotionally.



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



Problems with digesting food

The pancreas makes enzymes which help to break down food (part of digestion). This is how you get nutrients, which are the things your body needs from food to work properly. 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
- having all or part of the pancreas removed may also cause problems with digestion.

These problems mean that your body may not get the nutrients it needs from your food.

Symptoms

Problems with digestion can cause symptoms, including:

- losing your appetite and losing weight
- feeling and being sick
- runny poo (diarrhoea)
- pale, oily, floating poo (steatorrhoea)
- tummy discomfort or pain
- bloating and wind
- feeling full up quickly
- needing to empty your bowels urgently, especially after eating.

Speak to your doctor, nurse or dietitian about ways to manage these symptoms.

It is important that problems with diet and digestion are managed. This can make a big difference to how you feel. It can also help you cope better with treatments.

Support from a dietitian

If possible, you should see a dietitian to help manage problems with digestion. Specialist pancreatic or oncology dietitians are experts in diet and cancer, and can help manage your symptoms and prevent weight loss.

Not all hospitals 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.



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

Pancreatic enzyme replacement therapy (PERT)

Pancreatic enzymes replace the enzymes your pancreas would normally make. They are capsules that you take when you eat. They help to break down food, and can help to manage the symptoms on page 29. They can really improve how you feel.

Your dietitian, nurse, doctor or GP can prescribe enzymes. In the UK, brands include Creon[®], Pancrease[®], Nutrizym[®] or Pancrex[®].

If you have any of the symptoms on page 29, ask your doctor, nurse or dietitian about enzymes.



We have detailed information about diet including how to take pancreatic enzymes, in our booklet: **Diet and pancreatic cancer**.
And at: pancreaticcancer.org.uk/diet

Losing weight

Losing weight is a common symptom of pancreatic cancer. Weight loss can affect how your body copes with the effects of cancer, and how treatments such as chemotherapy or surgery affect you. It can also be upsetting.

The fitter you are before surgery the better. 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 with any digestion problems (see page 30).

If you have lost weight you may need to put weight back on before you can have surgery – speak to your doctor or nurse. If possible you should also be referred to a dietitian (see page 30).

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.

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

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

You should see a specialist diabetes nurse and a specialist diabetes or pancreatic dietitian. They can help you manage your diabetes. If you can't see a specialist, then your doctor at the hospital or your GP should be able to help. There should also be a diabetes nurse at your GP surgery.

There are different types of diabetes. The usual information about changing your diet if you have diabetes may not be right for you because of your cancer. You may need to eat a normal diet, or you may need more calories in your diet to help you put weight on. Your diabetes will need to 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.

Speak to your dietitian, clinical nurse specialist or diabetes nurse about how to manage your diabetes.



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, other symptoms of the cancer, or it can be a side effect of treatments.



What can I do about fatigue?

- Get support for any symptoms that might be causing extreme tiredness, such as diabetes, pain, being sick or depression (see page 38).
- Plan your time, trying not to do too much and prioritising activities.
- Some people find it helps to keep track of when their energy levels are best and what triggers tiredness.
- Gentle activity can increase your energy levels.
- Have a bedtime routine – for example, try to go to bed at the same time each evening and learn ways to relax before bed.
- Try to avoid napping during the day if it affects your sleep at night. Or limit how long you sleep during the day to about 30 minutes.
- Some people find that complementary therapies such as massage help with fatigue. Read more on page 49.



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



“ It helped me to try and keep as fit and healthy as possible while dealing with symptoms, so I took walks and ate sensibly.”

Pain in your tummy or back

There are lots of things that can cause pancreatic cancer pain, including the cancer itself, problems with digestion, constipation or 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 pain, such as painkillers.

If you have pain or discomfort from problems digesting food, pancreatic enzymes should help with this (see 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**.
Or at: **pancreaticcancer.org.uk/pain**

Jaundice

Pancreatic cancer can cause jaundice by blocking the bile duct. The bile duct is the tube that takes a fluid called bile from the liver to the duodenum (which is the first part of the small intestine). We explain these medical words on page 52.

Jaundice turns your skin or eyes yellow. It can also make you feel itchy and causes pale poo and dark urine.

If you have jaundice and your cancer can be removed with surgery, you should be offered surgery – which will treat the jaundice.

If you have jaundice but aren't fit enough yet for surgery, or you can't have surgery, your doctors may put a stent into your bile duct. A stent is a small tube. 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 more about jaundice at:
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 the treatment I'm having 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 things that can help with this.
- Talk to your nurse and medical team about how you feel. They can support 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.
- There are other things that can help, like getting support for symptoms, gentle physical activity and complementary therapies.
- We have a range of services that can support you.
- Your family and friends might also find things difficult, but they can also get support from our services.



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**

It may be a shock to be told you have pancreatic cancer. It's normal to go through a range of emotions including 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 after. This is normal, as pancreatic cancer surgery is a major operation.

Anxiety and depression

It's common for people with pancreatic cancer to have anxiety and depression.

Symptoms of anxiety and depression include:

- negative thoughts and feeling hopeless
- loss of any interest or pleasure in daily life
- problems sleeping
- changes to your appetite.

There are ways to get help. 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.

Sorting out any issues that might be worrying you can help, such as symptoms or financial issues. Counselling may help you deal with your feelings (see page 39). Taking medicine called antidepressants can also be helpful.



Find out more on our website 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.

Ask to be referred for psychological support. Psychological support services help people with psychological (emotional) problems. You might be offered different types of support from health professionals such as counsellors, clinical psychologists, psychiatrists or social workers. Read more about these professionals on page 52. 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.
- Check whether your local hospital, Macmillan information and support centre or Maggie's centre have counsellors.
- Check the British Association of Counselling and Psychotherapy website for counsellors who deal with cancer.

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. Spiritual practice, including religion, may become more important to you. You may want to speak to a faith leader if you have a religion.

Your local 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.



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

Speak to others affected by pancreatic cancer

Other people affected by pancreatic cancer can really understand how you feel.

Side by Side is our telephone support service for people with pancreatic cancer who have had, or can have, surgery to remove their cancer. It gives you the chance to speak to a trained volunteer who has been in a similar situation.

You can talk to others and share experiences on our online discussion forum. Or join one of our Living with Pancreatic Cancer online support sessions. Hosted by our specialist nurses, you will be able to connect with others with pancreatic cancer, ask questions, share your experiences, and support each other.

You might also find it helpful to read about the experiences of other people with pancreatic cancer on our website.

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

There are support groups across the country. Local cancer centres may run support groups, where you can meet others with cancer. Speak to your GP or nurse about what's available locally.



Find groups specifically for people with pancreatic cancer at:

pancreaticcancer.org.uk/supportgroups

Read more about the support we offer 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.



What can I do to help me cope?

Finding ways to cope may help you feel more in control. Some people find these things helpful.

- Try to sort out things that might be worrying you. For example, get help with any symptoms (see page 27) or financial issues (see page 46).
- Make plans and have things to look forward to, even if it's just for the next weekend. The charity **Something to look forward to** provides gifts and treats to people with cancer, and have a specific project for people with pancreatic cancer.
- Find things that you enjoy doing, and that might help take your mind off the cancer.
- Try breathing and relaxation exercises. You can find apps and audio recordings to help with this on the NHS mental health apps library.
- Complementary therapies such as acupuncture or massage may help reduce stress and relieve symptoms such as fatigue. 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 about 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**



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 that can provide support?

Is there support for my family and friends?

“ It is so overwhelming and I think it is so important to be kind to yourself and talk to anyone you can, 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 help with your finances.
- Gentle physical activity may help improve fatigue and boost your mood.
- Complementary therapies such as 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.

Talk to your employer about ways to keep working if you want to. They may be able to make reasonable adjustments to support you at work. You have rights at work, and are protected from discrimination if you have cancer. Find out more from Macmillan Cancer Support.

“ 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.”



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

Support at home

Before you go into hospital for your operation, think about the support you will need when you go home. Surgery to remove pancreatic cancer is a major operation, and you will probably need some help. For example, who can help with shopping, cooking and cleaning? You might want to freeze some meals beforehand, and look into 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 let you know who to contact if you have any concerns or need more support.

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 GP if you think this would be helpful.

If you need some extra help at home, tell your nurse. They should be able to arrange for social services to look at what help you need. Most people manage well at home 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 – if you exercise regularly you should carry on with this. If you don't usually exercise, try to move about as much as possible. Try setting yourself small targets each day, such as increasing the number of times you go up and down the stairs.

After surgery – you can gradually increase what you do during your recovery and make sure that you move around during the day. You should find that you start to feel stronger and more active each week.

Speak to your doctor or nurse before starting any 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.



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



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

Complementary therapies

Some people find that complementary therapies, such as acupuncture, massage, meditation, or relaxation therapies, can help them cope with anxiety, pain and some side effects of treatments.

Hospitals and local charities 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.



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



Questions to ask your doctor or nurse

Where can I get benefits advice and support?

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, including whether the cancer has spread, how far it has spread (see page 10), and the treatments you can have.

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 check for any signs that the cancer has come back. If it does come back, you may be offered further treatment with chemotherapy.

You may not want to know your prognosis, but if you do, speak to your doctor. 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.



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 to.”

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 gall bladder.

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: pea sized structures throughout the body that contain lymph fluid. Part of the immune system.

Pancreatic enzyme replacement therapy (PERT): used if the pancreas isn't producing enough enzymes. It involves taking capsules to help break down food. (See page 30)

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 oesophagus (the tube between the throat and stomach), stomach, pancreas, liver, gallbladder and bile ducts. Often shortened to Upper GI.



Find more words on our website at:
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**

Living with Pancreatic Cancer 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

British Association of Counselling and Psychotherapy

www.bacp.co.uk

Tel: 01455 883 300

Information about counselling and database of registered therapists.

Cancer Research UK

www.cancerresearchuk.org

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

Information for anyone affected by cancer.

Citizens Advice

www.citizensadvice.org.uk

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

Complementary and Natural Healthcare Council

www.cnhc.org.uk

Tel: 020 3668 0406 (Mon-Fri 9am-5.30pm)

Information about complementary therapies and a register of therapists.

GOV.UK

www.gov.uk

Provides information about government services, including information about benefits, transport, money and guidelines for hospital parking.

Macmillan Cancer Support

www.macmillan.org.uk

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

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

Maggie's Centres

www.maggiescentres.org

Tel: 0300 123 1801

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

mygov.scot

www.mygov.scot

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

NHS 111 Wales

www.111.wales.nhs.uk

Health information in Wales, including local services.

NHS inform

www.nhsinform.scot

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

NHS website

www.nhs.uk

Information about health conditions, living well, care and local services in England. Includes a list of apps to help you manage your health – search for NHS apps library.

NICan (Northern Ireland Cancer Network)

nican.hscni.net

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

nidirect

www.nidirect.gov.uk

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

Something to look forward to

www.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.

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

We make every effort to make sure that our services provide up-to-date, accurate information about pancreatic cancer. We hope this will add to the medical advice you have had and help you make decisions about your treatment and care. This information should not replace advice from the medical team – please speak to your medical team about any questions.

Email us at **publications@pancreaticcancer.org.uk** for references to the sources used to write this booklet.

Give us your feedback

We are always keen to improve our information, so let us know if you have any comments. Email us at **publications@pancreaticcancer.org.uk** or write to our Information Manager at the address on the back cover.

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

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

- Natalie Barrett, HPB Clinical Nurse Specialist, The Christie NHS Foundation trust
- Debbie Clarke, Lead Macmillan Hepato-biliary Clinical Nurse Specialist, The Royal Oldham Hospital
- Dawn Elliott, Lead UGI Clinical Nurse Specialist, Northumbria Healthcare NHS Foundation Trust
- Paula Ghaneh, Professor of Surgery, University of Liverpool
- Simon Harper, Consultant HPB and Transplant Surgeon, Cambridge University Hospitals NHS Foundation Trust
- Jonathan Hartley, Consultant, Counsellor and Supervisor, Rixon Therapy Services
- Lena Loia, HPB Clinical Nurse Specialist, Cambridge University Hospitals NHS Trust
- Christian Macutkiewicz, Consultant HPB Surgeon, Manchester Royal Infirmary
- Pancreatic Cancer UK Lay Information Reviewers
- Pancreatic Cancer UK Specialist Nurses

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© Pancreatic Cancer UK September 2020
Review date September 2022
Registered charity number 1112708 (England
and Wales), and SC046392 (Scotland)