

Pancreatic cancer if you can't have surgery (inoperable cancer)

A guide if you have just been diagnosed



Introduction

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

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

Contents

Diagnosing pancreatic cancer	4
Having treatment	14
When treatment to control the cancer isn't an option	27
Dealing with symptoms and side effects	32
Emotional support	47
Daily life with pancreatic cancer	54
What is my prognosis (outlook)?	59
Medical words explained	60
Pancreatic Cancer UK services	62
Useful organisations	63

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 60.
- Contact details of all the organisations we mention on page 63.

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.
- Pancreatic cancer can be hard to diagnose.
- Being told you have pancreatic cancer that can't be removed by surgery can feel overwhelming. You may still have treatment options, and there are ways to manage symptoms.
- There is support available for you and your family. You can get support from our specialist nurses by calling our free Support Line on **0808 801 0707**.



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**

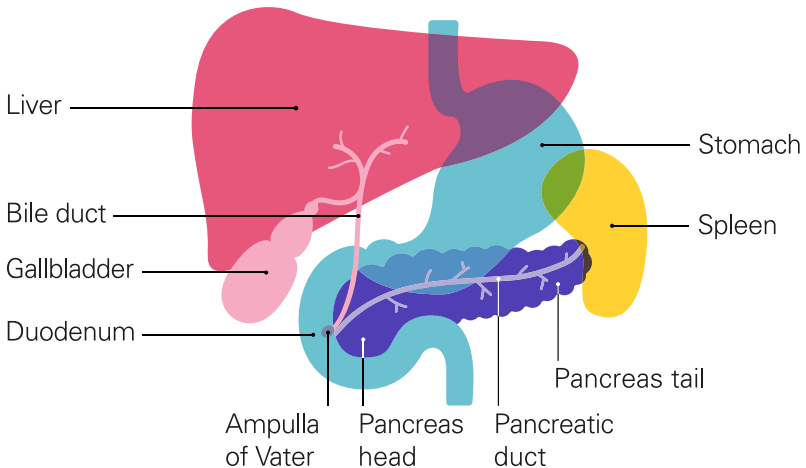
What is the pancreas?

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.

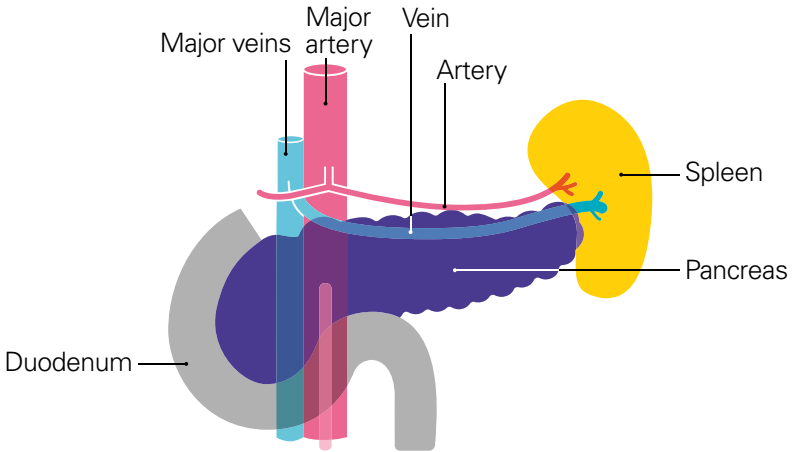
Your pancreas does two main things.

- 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.

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?

In the early stages, pancreatic cancer may not cause symptoms. Any symptoms may be vague, and may come and go to begin with. This makes it harder to diagnose early. It's often diagnosed at a later stage when it's started to spread.

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



Read more about the tests in our fact sheet:
How is pancreatic cancer diagnosed?
Or at: pancreaticcancer.org.uk/tests

What do my test results mean?

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

You may be told what stage your cancer is. This covers:

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

Read about the stages of pancreatic cancer on page 10.

Your doctors will tell you about the best treatments for you. Some doctors may focus on the treatment, and not tell you the stage.

Being told you have pancreatic cancer that can't be removed by surgery is upsetting and can feel devastating. There may be other treatments you can have, and there are ways to manage any symptoms. These can help improve the quality of your life.



What can I do?

- Use the diagrams and information on the next pages to help you understand more about your test results.
- Find out as much as you want to know – we have lots more information about pancreatic cancer on our website.
- Ask your doctor or nurse any questions you have. Read more about your medical team on page 15.
- Talk to family and friends about how you are feeling – sometimes just talking can help you make sense of things.
- Read more about the emotional support available on page 47.



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



Questions to ask your doctor or nurse

What do my test results mean?

Has the cancer spread? If so, where to?

What are my treatment options?

What happens next?

Where can I get support?

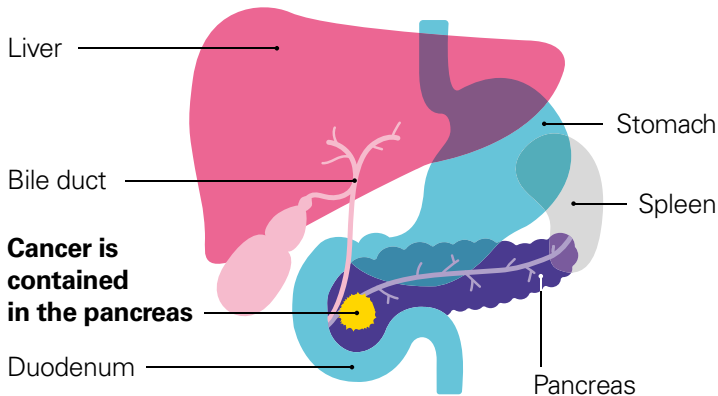


“ If possible, ensure there’s someone with you to help absorb the news. Go back to the consultant or specialist nurse and ask more questions.”

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.



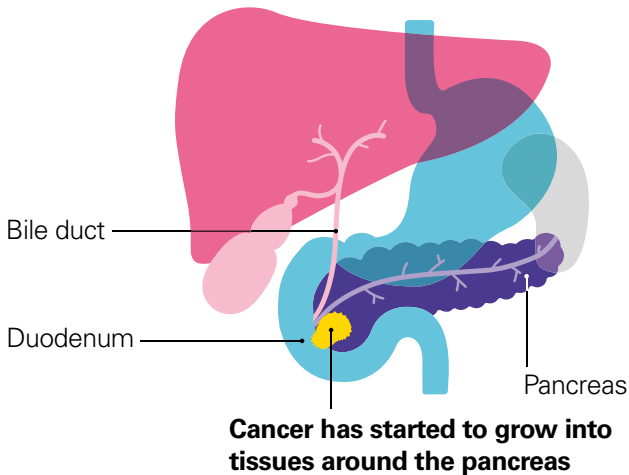
Possible treatments: Surgery to remove the cancer and chemotherapy after the surgery.



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

Stage 2 pancreatic cancer

The cancer may have grown larger. It may have 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 60.

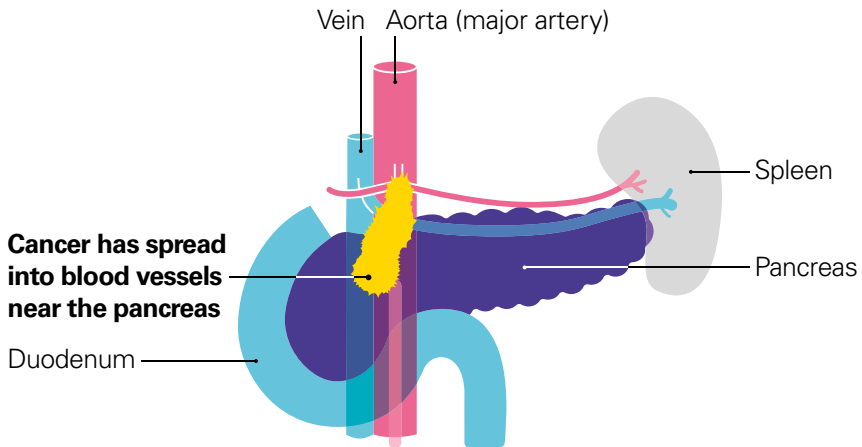


Possible treatments: You might be able to have surgery to remove the cancer, but this depends on how far it's spread. You might also have chemotherapy.

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**.

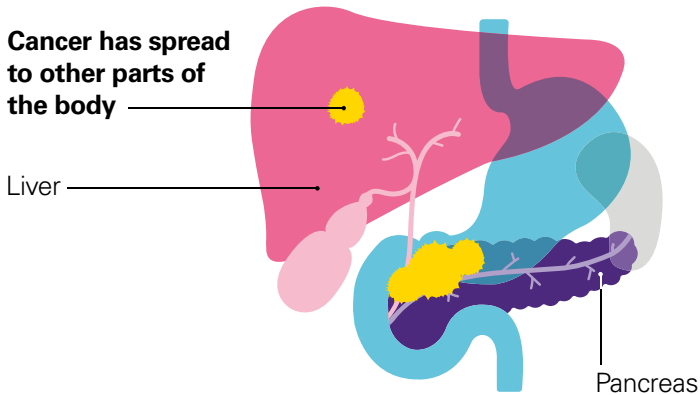


Possible treatments: If you have **locally advanced cancer**, it won't usually be possible to remove the cancer with surgery. You may be offered chemotherapy, sometimes with radiotherapy, to slow down the growth of the cancer. Find out more on page 24.

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 24.

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. Read more on page 25.

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

Having treatment

Key facts

- The type of treatment or care you have will depend on what stage of cancer you have.
- A team of medical professionals, called a multidisciplinary team (MDT) should review the information about your diagnosis.
- 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 have locally advanced cancer, you may be able to have chemotherapy, sometimes with radiotherapy.
- If you have advanced cancer, you may be able to have chemotherapy if you are well enough, as well as other treatments to control symptoms.
- You may be able to take part in a clinical trial, which might mean you can have new or different treatments.
- If you have advanced cancer then you may see a palliative care specialist, who can help manage your symptoms and provide emotional support.

What health professionals will I see?

Your medical team

If you are having treatment such as chemotherapy and radiotherapy, 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 won't necessarily have your treatment there.
- You might not meet everyone in the MDT, but your doctor or nurse should tell you what the MDT have decided.

You may see a **specialist nurse** (sometimes called a **clinical nurse specialist** or **CNS**). They are your main contact. They will provide expert support, care and advice. They will also coordinate your care if you are having treatment for the cancer. Not everyone will have a CNS – ask for details of who to contact if you have any questions. 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:

- 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 – a health professional who provides expert advice about diet and nutrition.

Palliative care and supportive care

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

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

Some people find the thought of palliative care upsetting. But these services aren't just for people at the end of their life. They are available at any point during treatment or care.

You may be able to have palliative care:

- in your own home – by Hospice at Home services (see below), palliative care doctors and nurses, Macmillan nurses or Marie Curie nurses
- at a hospice
- in hospital – by hospital-based palliative care or supportive care teams
- at a cancer centre.

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

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



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



Your support needs

Your doctors and nurses should regularly check how you are coping with any symptoms, such as pain, tiredness and problems with digestion. Read more about managing symptoms and side effects on page 32.

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



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.



What can I do?

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

What are my treatment options?

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

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



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

Getting a second opinion

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

Types of treatment you may be offered

Chemotherapy

You may be offered chemotherapy. If you have locally advanced pancreatic cancer, you may have this together with radiotherapy. (see page 24).

What is chemotherapy?

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

Side effects

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

Your medical team will closely monitor you, and there are ways to manage the side effects.



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

Radiotherapy

If you have locally advanced pancreatic cancer, you may have radiotherapy with chemotherapy (chemoradiotherapy).

If you have advanced pancreatic cancer, you may have radiotherapy to help with some types of pain.

What is radiotherapy?

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

Side effects

Radiotherapy can cause some side effects such as tiredness, feeling sick and runny poo (diarrhoea). Many people will only have mild side effects, and severe side effects are not common. If you have chemoradiotherapy, you may also get side effects from the chemotherapy (see page 21).



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

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



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



Treatment if you have locally advanced cancer

Locally advanced pancreatic cancer is cancer that has spread to areas near the pancreas, such as the stomach, spleen or large blood vessels.

If you have locally advanced pancreatic cancer, you may be offered chemotherapy on its own or together with radiotherapy (chemoradiotherapy). This is to try to shrink the cancer, slow down its growth, and control your symptoms. For a small number of people, this may shrink the cancer enough to make surgery to remove the cancer possible.

Treatment if your cancer is close to major blood vessels

If the cancer has grown close to major blood vessels, your doctors will look carefully at your scan results. They will try 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.

Whether you can have surgery depends on which blood vessels are affected by the cancer, and how close the cancer has grown to them. You may be offered chemotherapy and possibly radiotherapy. This can sometimes shrink the cancer enough to make surgery possible.

If your cancer is close to major blood vessels, speak to your doctor about your treatment options. Different medical teams may have different opinions about whether surgery is possible.

You can ask for a second opinion from a different medical team if you want one (see page 20).



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

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

Treatment if you have advanced pancreatic cancer

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

If you are well enough, you may be able to have chemotherapy. Chemotherapy won't cure the cancer, but it may help you to live longer and help your symptoms.

Treatments for symptoms

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

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



Speak to our specialist nurses on our free Support Line with any questions about your treatments.



Questions to ask your doctor or nurse

Who is my clinical nurse specialist?

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

Will chemotherapy help control my cancer?

Are radiotherapy or chemoradiotherapy suitable for me?

What side effects do these treatments have?

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

What treatments can I have for my symptoms?

When treatment to control the cancer isn't an option

Key facts

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



Being told you can't have treatment to control your cancer may be upsetting. You can speak to our specialist nurses on our free Support Line to talk through how you are feeling. They can also help with questions about symptoms and the support you can get.

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

Being told that you can't have any treatment to control your cancer can be a shock for you and those close to you. You may have a range of emotions, but there is support available. Read more on pages 47.

Your GP, community or district nurses will care for you and provide treatments to help with symptoms. They can also help you get care and support at home. Read more about this on page 55.

What medical care can I have?

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

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

Specialist palliative care

If you can't have treatment to control the cancer, you may be referred to a specialist palliative care team. They can help manage symptoms, as well as supporting you and your family.

If you haven't seen a palliative care team, ask your GP to refer you.

Read more about palliative care on page 16.

Thinking about your future care

If you have been told that you can't have treatment to control the cancer, you might want to think about what care you would or wouldn't want if your cancer got worse. This is called advance care planning. This can be difficult to do, but it may help you feel more prepared and in control.



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

Knowing what to expect

Sometimes pancreatic cancer can grow and spread quickly. If you have been told you only have a few months to live, you may want to know what to expect. We have information and support available if you want to find out more.



Find out about care and support for people in the last few months in our booklet: **Pancreatic cancer and end of life care. Information for people in the last few months, weeks or days of life.**



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

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

If you don't want to have treatment

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

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



Questions to ask your doctor or nurse

What treatments can I have to help with my symptoms?

How can I see a palliative care specialist?

What support can I get at home?

What emotional and practical support can I get?



“ I think the most difficult aspect of dealing with pancreatic cancer is the uncertainty that inevitably comes with it. But all of this has brought my family closer together.”

Dealing with symptoms and side effects

Key facts

- Not everyone will have the same symptoms of pancreatic cancer or side effects from treatments.
- There are ways to manage most symptoms and improve your quality of life.
- If you have any symptoms or side effects, speak to your doctor or nurse for help managing them.
- 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 your doctor or nurse for help with pain as soon as possible – there are treatments that can help.
- Extreme tiredness is a common symptom. There are things that can help, like balancing rest with activities.

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

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

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 intestine where they help with digestion.

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

Symptoms

Problems with digestion can cause symptoms, including:

- losing your appetite
- 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 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.

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



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 x. 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 33, 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 you deal with the symptoms of the cancer, and how treatments such as chemotherapy affect you (see page 20). It can also be upsetting.

Your doctor or dietitian will work out what is causing the weight loss, and how to manage it. Taking pancreatic enzymes (see page 34) may help you digest your food and maintain your weight.

Making changes to your diet so that you get more calories and protein can also help. Speak to your dietitian about this.



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

Diabetes

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

Symptoms of diabetes include feeling very thirsty, passing more urine 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. You may need to take tablets or have insulin injections. 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.



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 a side effect of treatments.



What can I do about fatigue?

- Get support for symptoms that might be causing fatigue, such as diabetes, pain, being sick or depression (see page 48).
- 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 can help with fatigue. Read more on page 58.



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

Pain

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

Treatments include:

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

There are also other things that can help you deal with pain, such as complementary therapies (see page 58).



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

Bowel problems

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

Diarrhoea

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

Taking pancreatic enzymes can help with diarrhoea caused by problems digesting food. Speak to your doctor, nurse or GP if the diarrhoea isn't getting better. You may need to see a gastroenterology team, who are experts in problems with the stomach and intestines.

If you have diarrhoea:

- drink plenty of fluids so that you don't get dehydration
- Macmillan Cancer Support has a **toilet card** that may help you access toilets in public
- your doctor or nurse may be able to prescribe you medicines.

Constipation

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

If you have constipation:

- medicine called laxatives may help
- make sure you eat enough food and drink enough fluids
- be as active as you can.



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

Feeling and being sick (nausea and vomiting)

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

There are treatments for sickness, including anti-sickness medicine. If the sickness is caused by the cancer blocking the bowel, you may be able to have a stent or bypass surgery (see page 43).



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



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).

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

Your doctors may put a small tube (called a stent) into your bile duct. This should open up the blockage and improve your symptoms.

If you are having chemotherapy, this will be delayed until the jaundice has been treated.



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

Treatment for a blocked duodenum

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

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

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



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

Blood clot in a vein

People with pancreatic cancer may be more at risk of a blood clot forming in a vein – especially if you have advanced cancer. Some chemotherapy drugs can increase the risk of a blood clot.

A blood clot in a vein is serious, and needs to be treated straight away. It often happens in the lower leg (calf), thigh, pelvis (area below your tummy button) or arm. This is known as deep vein thrombosis (DVT). Symptoms include pain, tenderness and swelling in one of your legs. It can block the normal flow of blood through the veins. Part of a clot can also break off and travel in the blood to the lungs. This is called a pulmonary embolism. Symptoms include feeling short of breath and sudden chest pain. This isn't common, but it can be very serious.

Blood clots don't always cause symptoms. But if you have any of the symptoms tell your medical team as soon as possible.



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



What can I do about symptoms?

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



Questions to ask your doctor or nurse

How can my symptoms be treated?

Are there things I can do myself?

Will taking enzymes help my problems with digestion?

Can you give me advice about how to put on weight?

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



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

Emotional support

Key facts

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



You can contact our specialist nurses on our Support Line for emotional support. Call **0808 801 0707** or email **nurse@pancreaticcancer.org.uk**

Your feelings

If you've been told you have pancreatic cancer, it's normal to go through a range of emotions, including distress, shock, fear, sadness and anger. There's no right or wrong way to feel, and you may have a range of emotions. But there is support available.

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.

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 anything that might be worrying you can help, such as symptoms or financial issues. Counselling may help you deal with your feelings (see page 49). Taking medication 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.

Get support from a palliative care team – they are experts at supporting people with advanced cancer. They can help you manage emotional symptoms, such as depression and anxiety.

Ask to be referred for psychological support. Psychological support services help people with emotional (psychological) 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 60. 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, hospice, 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.



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

Getting spiritual support

Spirituality means different things to different people – whether you follow a religion or not. Being diagnosed with pancreatic cancer may mean you think more about the meaning of life, death and loss. 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, hospice or palliative care team may have a chaplaincy service. Chaplains are trained specialists who work with people of any or no religion to help them find meaning and explore what's important to them.

“ My faith was a very important factor in my journey with pancreatic cancer.”

Speak to others affected by pancreatic cancer

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

- 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 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 also support groups across the country, and local cancer centres and hospices may run cancer support groups. Speak to your GP or nurse about what's available locally.



Find groups specifically for people with pancreatic cancer on our website 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.

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. For example, you may feel less worried about the future if your family know how and where you would like to be cared for. Read more about this on page 29.

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



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

Support for family and friends

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



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



Questions to ask your doctor or nurse

How can I get emotional support?

How can I see a counsellor?

Is there a local cancer centre that can provide support?

Is there support for my family and friends?

Daily life with pancreatic cancer

Key facts

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

Getting practical support

Getting practical things organised may help reduce worries.

Support at home

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



Read more on our website:
pancreaticcancer.org.uk/care

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

Equipment and changes to your home

An occupational therapist (OT) is a professional who provides advice and equipment to help you stay independent and carry on doing the things you want to do. They can visit you at home to help you get equipment. This might include ways to raise a seat to make getting up easier, or grab rails to get out of the bath.

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



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

Financial support

Get support with financial issues and find out about benefits and grants you might be entitled to. Macmillan Cancer Support and Citizens Advice can provide expert information and advice about this.

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



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

Physical activity

Gentle physical activity like walking can:

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

Speak to your doctor or nurse before starting any exercise. They can advise you on what type of activities are best for you, and any safety issues to be aware of. Some cancer support services 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



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

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.

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

How can I get support at home?

How do I get in touch with a community nurse?

What support can social care provide?

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

Where can I get financial advice and support?

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

What physical activity would be helpful for me?

Would complementary therapies help with my symptoms or side effects?

What is my prognosis (outlook)?

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

The prognosis will be different for each person, and depends on several things, including how far the cancer has spread (see page 10), and what treatments you can have.

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

How long do I have left to live? How accurate is this?

I don't want to know my prognosis, but how will my cancer and symptoms change?

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

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

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

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 34.

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

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

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

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



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

Pancreatic Cancer UK 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.

Hospice UK

www.hospiceuk.org

Tel: 020 7520 8200

Information about hospices, and a database of hospices in the UK.

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.

Marie Curie

www.mariecurie.org.uk

Support line: 0800 090 2309

(Mon-Fri 8am-6pm, Sat 11am-5pm)

Provides care and support for people living with a terminal illness and their families, including nurses and hospices.

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 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

- Emma Ainsworth, Clinical Nurse Specialist Upper GI/HPB Oncology, Freeman Hospital, Newcastle
- 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
- Steph Gooder, HPB Clinical Nurse Specialist, Stockport NHS Foundation Trust
- Jonathan Hartley, Consultant, Counsellor and Supervisor, Rixon Therapy Services
- Jo Harvey, Macmillan Upper GI/HPB Advanced Clinical Practitioner, Sandwell & West Birmingham Hospitals NHS Trust
- Adele Hug, Macmillan Oncology Dietitian, Royal Surrey NHS Foundation Trust
- Justin Waters, Consultant Medical Oncologist, Kent Oncology Centre
- 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)