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How is pancreatic cancer diagnosed?

This fact sheet is for anyone having tests for pancreatic cancer. Family members may also find it helpful. It explains the different tests that you might have, what they involve, and what your test results mean. There is also information about the support available.

Contents

Every hospital will do things slightly differently, so speak to your GP, consultant or specialist nurse if you have any questions.

☎ You can also speak to our specialist nurses on our confidential Support Line. Call free on **0808 801 0707** or email **support@pancreaticcancer.org.uk**

Why is pancreatic cancer difficult to diagnose?

Pancreatic cancer can be difficult to diagnose. This is because it doesn't usually cause many specific symptoms in the early stages, and symptoms can be quite vague. They can also be caused by more common conditions, such as pancreatitis (inflammation of the pancreas), gastritis (inflammation of the stomach lining) or gallstones.

If you have any of the symptoms of pancreatic cancer, it's important that you go to your GP.

We have information about the symptoms on our website at **pancreaticcancer.org.uk/symptoms**

Doctors will need to rule out all the different possible causes for your symptoms. This means that you will need several different tests to help diagnose pancreatic cancer (see page 4), and it can take some time to reach a diagnosis.

Visiting your GP

You may go to your GP because of vague symptoms that don't get better over time. Some people see their GP several times. If you have unexplained symptoms that last four weeks or more, go back to your GP until you get a firm diagnosis, or a referral for tests to find out what's causing them.

Tell your GP what symptoms you have, how often you have them and anything unusual, even if you're not sure it's relevant. It's important to give your GP a good description of your symptoms. You might find it helps to keep a diary of the symptoms so that you can describe them accurately to the GP.

> " From when you suspect a problem, just note down any symptoms, however vague or insignificant you feel they may be."

What will the GP do?

- Your GP may ask whether you have had any problems with eating or digesting your food, and whether you have had any changes with your bowels. Tell them about any pale, smelly stools (poo) that float and are difficult to flush down the toilet – this is called steatorrhoea, and may be a symptom of pancreatic cancer.
- They may ask whether you have been losing weight without intending to.
- They may examine your tummy (abdomen) for any swelling and to check if it is tender or painful.
- They may look at your eyes and the colour of your skin for signs of jaundice, which causes yellow skin and whites of the eyes, and itching. This can be a symptom of pancreatic cancer.
- They may take a urine or blood sample.

Will the GP refer me for tests?

Your GP may make a request (refer you) for you to have tests at hospital to work out what is causing your symptoms. There is information about the tests used to diagnose pancreatic cancer on pages 4 - 11.

If you have jaundice, your GP should refer you urgently. They should also refer you straight away for a CT scan (or ultrasound scan) if you are over 60 and have unexplained weight loss and **any** of the following:

- tummy or back pain
- nausea or vomiting (feeling or being sick)
- diarrhoea (loose, watery stools)
- constipation (problems opening the bowels) or
- have been diagnosed with diabetes in the past year.

Read more about the symptoms of pancreatic cancer at **pancreaticcancer.org.uk/symptoms**

In England and Wales, if you have been referred urgently you should be seen within two weeks of being referred. Being referred urgently does not necessarily mean that you have cancer.

If you are very unwell, your GP may send you straight to hospital. Or you may go to accident and emergency yourself. For example, you might go to hospital because you have severe pain. Once you are in hospital, the doctors can assess your symptoms and do tests to work out what's wrong. They can also treat any symptoms you have.

? Questions to ask

Will you refer me for any tests?

What tests will I have?

How long will I have to wait to have these tests?

Who will contact me to arrange these tests?

Where will I go for the tests?

Will I see a specialist?

Do I need to be referred urgently in case I have cancer?

Tests for pancreatic cancer

You may need several tests to work out what's wrong with you. If you are diagnosed with pancreatic cancer, your doctors will use the test results (see page 12) to help decide the best treatment for you.

Your hospital will give you detailed information about each test and where you need to go before your appointment. Ask your doctor for this information if you haven't been given it.

If you have any questions about the tests you are having and why you're having them, speak to your doctor.

☎ You can also call our specialist nurses on our free Support Line.

How long will I have to wait for my tests?

If you've been given an urgent referral for a test or scan because of suspected cancer it should be done within two weeks. If you haven't heard anything within two weeks, speak to your doctor. It may also help to speak to the consultant's secretary.

If your GP doesn't suspect cancer and you haven't been given an urgent referral, you may have to wait several weeks for tests.

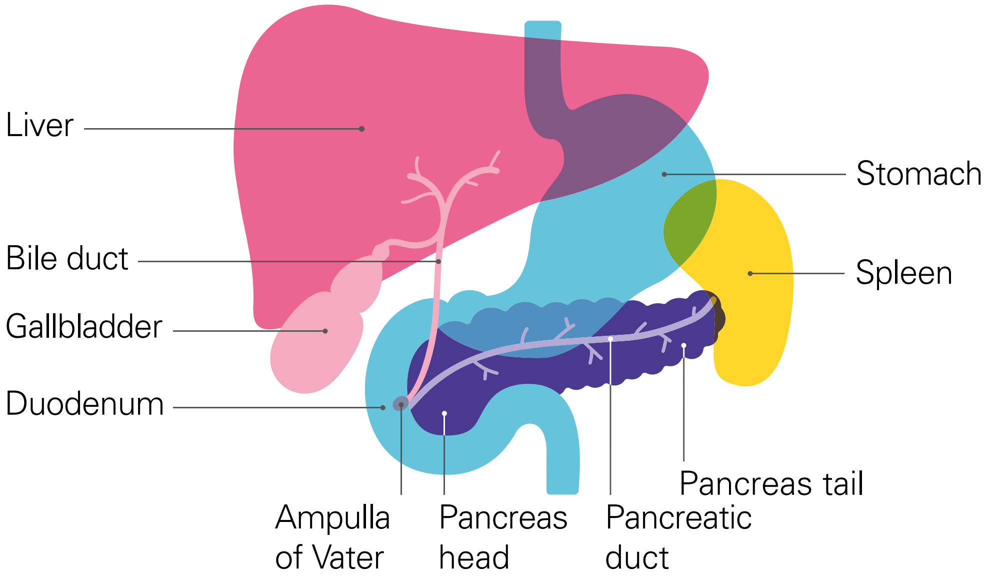
People with pancreatic cancer can start to feel very unwell quite quickly. If your symptoms get worse or you start to feel more unwell while you are waiting for tests, speak to your GP or specialist nurse, as you may need to be seen sooner. They can also help you manage symptoms. If you have to go into hospital for any reason, ask if any of the tests you are waiting for can be done while you are there.

What tests are used to diagnose pancreatic cancer?

You may have different tests at different times. For example, you may have tests which diagnose pancreatic cancer, but then need more to find out exactly what type of pancreatic cancer you have and what stage it is (see page 12). You probably won't need all the tests described here, and you may not have them in this order.

You may find this diagram helpful when reading about some of the tests.

Diagram of the pancreas and surrounding organs



Blood tests

Blood tests are used to check your blood cell levels (blood count), how well your liver and kidneys are working, and your general health. If you have jaundice (see page 3) the blood test will show how severe the jaundice is.

Blood tests can also check for tumour markers. These are chemical substances produced by cancers that show up in the blood. CA19-9 is a marker that may be used to help diagnose pancreatic cancer. But not all pancreatic cancers produce tumour markers, and other conditions that aren't cancer can also produce them. This means blood tests are used together with other tests to make a diagnosis.

Most blood tests can be done straight away. It may take a few days or up to a week to get the results.

Ultrasound scan of the tummy area (abdomen)

Ultrasound scans use sound waves to make a picture of the inside of the body. The images are displayed on a screen.

Ultrasound doesn't take long. You will probably be asked not to eat anything for six to eight hours before the test and only drink clear fluids. The scan is done while you are awake and lying on your back on a couch. Gel is spread on the skin of your tummy, then a probe is passed over the area. It can take from 5-30 minutes, depending on the extent of the scan, and you can go home as soon as it's over.

It may take one to two weeks to get the results of an ultrasound scan.

CT (computerised tomography) scan

A CT scan uses x-rays to create a 3D picture of the pancreas and the organs around it. It is also usual to scan your chest and pelvic area (below your tummy) to check for any signs of cancer outside the pancreas.

You may have a CT scan after an ultrasound scan. If you have jaundice, you may just have a CT scan. A CT scan is more complicated than an ultrasound and takes longer. If you have a biopsy (see page 9), you may have a CT scan to guide the needle.

The CT scan usually lasts about 30 minutes, depending on the exact area being scanned. You will probably be able to go home straight afterwards.

You will be asked not to eat anything for six to eight hours before your scan and only drink clear fluids. Before the scan, you may be asked to swallow a liquid containing a dye. This helps the different organs show up on the scan. You may also be given an injection into a vein (as long as you aren't allergic to iodine), to help to show up the blood vessels in the area.

You will be awake during the scan, and you won't feel anything. You will lie on a couch which moves through the scanner, and a series of x-rays are taken.

It may take one to two weeks to get the results of the CT scan.

MRI (magnetic resonance imaging) scan

MRI scans use magnets and radio waves to build up detailed pictures of the pancreas and surrounding areas.

As the MRI scan uses magnets, you will be asked whether you have any metal implants in your body, such as a pacemaker or pins in your bones. You will need to wear loose clothing and make sure you have no metal objects on you, including zips and buttons.

The scanner is shaped like a tunnel, and you will lie on a couch that moves into the scanner. The scanner is noisy so you may be given earplugs or headphones. You won't feel anything during the scan. You will be able to hear and talk to the radiographer who operates the scanner from outside the room. The scan usually takes 20-30 minutes and you can go home afterwards.

It may take one to two weeks to get the results of the MRI scan.

EUS (endoscopic ultrasound scan)

This test is usually done at a specialist centre, which is a hospital with a medical team that specialises in treating pancreatic cancer.

A thin, flexible tube (endoscope) with a light at the end and a small ultrasound probe is passed through your mouth and down into your stomach. The ultrasound creates detailed pictures that help to show where the cancer is in the pancreas, how big it is and whether it has spread outside the pancreas.

A needle can also be passed through the tube to take tissue samples. This is a type of biopsy (see page 9) called fine-needle aspiration (FNA).

You won't be able to eat or drink for six to eight hours before the EUS. The EUS takes 30-60 minutes. You will be given a throat spray of local anaesthetic to numb your throat and help stop you coughing during the procedure. Then you will be given a sedative by an injection in your arm or the back of your hand. It won't put you to sleep but it will make you feel drowsy and relaxed. This makes it easier for the doctor to pass the endoscope into your stomach.

You will probably be able to go home a couple of hours afterwards. You will need someone to take you home, as you can't drive for 24 hours after having a sedative.

Read more about specialist centres on our website at **pancreaticcancer.org.uk/specialistcentres**

ERCP (endoscopic retrograde cholangio-pancreatography)

An ERCP is sometimes used to diagnose problems with the pancreas. It is more usually used if your bile duct is blocked, to insert a small tube (called a stent) into the bile duct to unblock it. The bile duct is the tube that carries fluid (bile) from the liver to the small intestines.

Like the EUS (see page 7), an ERCP uses an endoscope but it also involves taking x-rays. Dye is injected through the endoscope into the ampulla of Vater, which is where the pancreatic duct opens into the duodenum (see diagram on page 5). Any blockages will show up on x-rays. While the endoscope is in place the doctor may use a small brush to take cells from the bile duct to check under a microscope. They may also take tissue samples for biopsy (see page 9).

If your ERCP is done to get x-rays and tissue samples, you will be able to eat within a couple hours, and will probably be able to go home after a few hours. You will need someone to take you home, as you can't drive for 24 hours after having a sedative. If your ERCP is to insert a stent, you will usually need to stay in hospital for a couple of days.

You will be given contact details for the endoscopy department in case you have any problems after the ERCP.

Read about how a stent is inserted, and possible side effects, in our fact sheet, **Surgery and other procedures to control symptoms,** or on our website at **pancreaticcancer.org.uk/surgery**

Biopsy

A biopsy involves taking small tissue samples to be examined under a microscope. A biopsy can be taken during a CT scan (see page 6), EUS (see page 7), ERCP (see page 8) or laparoscopy (see page 10).

A biopsy taken during EUS is called a fine-needle aspiration (FNA).

If the biopsy is taken during a CT scan the doctor will put a needle directly through your skin into the area where they think there may be cancer, and remove a small sample of tissue. This is done under a local anaesthetic, so you will be awake but won't feel anything.

A biopsy is the only way of being absolutely certain that you have pancreatic cancer. However, it can sometimes be difficult to get enough tissue to make a definite diagnosis, and a second biopsy may be needed.

The results can also show exactly what type of cancer you have, which may help the doctors decide on the most suitable treatment. You will need to have a biopsy to confirm your diagnosis before having chemotherapy, chemoradiotherapy (chemotherapy combined with radiotherapy) or starting a clinical trial. If you don't think you have had a biopsy, ask your doctor or nurse about this.

If you are having surgery, you may not have a biopsy. The tissue removed during surgery will be examined under a microscope to confirm that it is cancer.

Read about surgery in our fact sheet, **Surgery for operable pancreatic cancer,** or at **pancreaticcancer.org.uk/surgery**

Read about chemotherapy and chemoradiotherapy in our fact sheet, **Chemotherapy for pancreatic cancer,** or at **pancreaticcancer.org.uk/chemotherapy**

Read about clinical trials at **pancreaticcancer.org.uk/clinicaltrials**

MRCP (magnetic resonance cholangio-pancreatography)

This is a type of MRI scan (see page 7) that looks at the bile duct, liver, gallbladder and pancreas (see diagram on page 5). It can give clearer pictures of the bile duct and pancreatic duct, and any blockages in them. It gives similar pictures to an ERCP but it's less invasive if you don't need another procedure, such as a stent inserted (see page 8).

You will usually be asked not to eat or drink anything for two to three hours before the scan. You may have an injection of a dye to help make the pictures clearer.

PET-CT scan

This combines a CT scan (see page 6) with a PET (positron emission tomography) scan. It is not regularly done. If you do have one, it will usually be done at a specialist centre.

A PET-CT scan helps to build up a clearer picture of the cancer and how it is behaving. It may be used after you have been diagnosed if there is a chance of the cancer spreading, or to check how well treatment is working.

You won't be able to eat anything for a few hours before the scan, though you may be able to drink. A small amount of a radioactive substance is injected into a vein in your arm. This dye shows up on the scan, giving a clearer picture of the cancer. You will wait for about an hour after the injection to have the scan. The scan takes 30-90 minutes, and you can usually go home straight afterwards.

Laparoscopy

This is a small operation that can help to check that the cancer can be removed by surgery, before you have the actual surgery. It may also be used to confirm a diagnosis of pancreatic cancer, or to work out how far the cancer has spread. A biopsy (see page 9) may also be taken during a laparoscopy. A laparoscopy is only done occasionally.

It is done under general anaesthetic (so you are asleep). A long tube with a camera at one end is inserted through a small cut in the skin of your tummy area, so that the doctor can examine you internally. Other small cuts may be made so instruments can be inserted to help with the examination.

Sometimes an ultrasound probe is also used (laparoscopic ultrasound) to help identify areas where there might be cancer.

Because of the general anaesthetic you won't be able to eat or drink for at least six hours before the laparoscopy. You will need to recover from the anaesthetic before you go home, but you may be able to go home on the same day. You will need someone to take you home and look after you overnight. You may need to take painkillers for a few days if the small cuts are uncomfortable.

☎ If you have any questions about your tests, speak to your doctor, nurse or medical team. You can also speak to our specialist nurses on our free Support Line.

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

It may take from a few days to a couple of weeks to get the test results – ask how long it will be when you go for the test. You can also ask who to contact if you don't hear anything. You will need an appointment with your consultant or GP to find out what the results show and discuss what happens next.

Find out more about what your test results mean on page 12. Your test results will be sent to your GP, and you may be sent a copy of the letter.

☎ If there's anything in the letter that's not clear, your GP, nurse, medical team or our specialist nurses on our Support Line can help explain what it means. You might find it helpful to talk things over with one of our nurses, as waiting for test results can be an anxious time.

? Questions to ask

Have you done a biopsy as part of these tests?

When will I get my test results?

How will I get my test results?

What do my test results mean?

Your doctor will explain what the tests have found, and whether you have pancreatic cancer or not.

If you don’t have pancreatic cancer

If the tests show that you don’t have pancreatic cancer, you may be very relieved. But if you continue to have symptoms, make sure you go back to your GP. Sometimes the tests and scans can miss something.

If you do have pancreatic cancer

If you do have pancreatic cancer, the results give your doctor detailed information about the cancer, such as what type of pancreatic cancer you have and what stage it is.

There are different types of pancreatic cancer. You can read more about these on our website at **pancreaticcancer.org.uk/types**

The stage of your cancer describes the size of the cancer and whether it has spread around the pancreas or to other parts of the body. It also helps doctors decide on the best treatment options for you.

One type of staging uses numbers to describe the stage of the cancer.

Stage 1

The earliest stage – the cancer is contained inside the pancreas. This is known as **early, localised** or **resectable pancreatic cancer**. It may be possible to operate to remove the cancer (resectable).

- **Stage 1A** means that the cancer is smaller than 2cm.
- **Stage 1B** means that the cancer is larger than 2cm – but is still contained in the pancreas.

Stage 2

The cancer has started to grow into the duodenum, bile duct or tissues around the pancreas, or there may be cancer in the lymph nodes near the pancreas. Lymph nodes are small glands found around the body, which are part of the immune system. This may be **resectable pancreatic cancer** – it may be possible to operate to remove the cancer, depending on how far the cancer has grown.

- **Stage 2A** means that the cancer has started to grow outside the pancreas, but **has not** spread to the lymph nodes.
- **Stage 2B** means the cancer **has** spread to nearby lymph nodes.

Stage 3

The cancer has spread into the stomach, spleen, large bowel or into large blood vessels near the pancreas. This is usually **locally advanced** or **unresectable pancreatic cancer,** which means it is not possible to remove the cancer with surgery (unresectable). However, it may very occasionally be **borderline resectable cancer** which means it may be possible to remove the cancer, but it depends which blood vessels are affected.

If you can't have surgery, you will still be able to have treatment with chemotherapy or chemotherapy combined with radiotherapy (chemoradiotherapy).

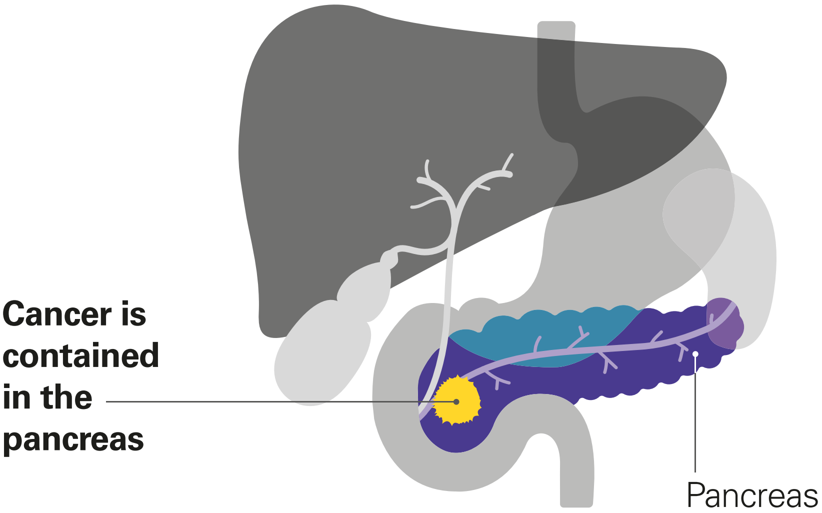
Stage 4

The cancer has spread to other parts of the body such as the lungs or liver. This is known as **advanced** or **metastatic pancreatic cancer.** It's not possible to remove the cancer with surgery (unresectable), as surgery can't remove all the cancer cells once they have spread to other parts of the body.

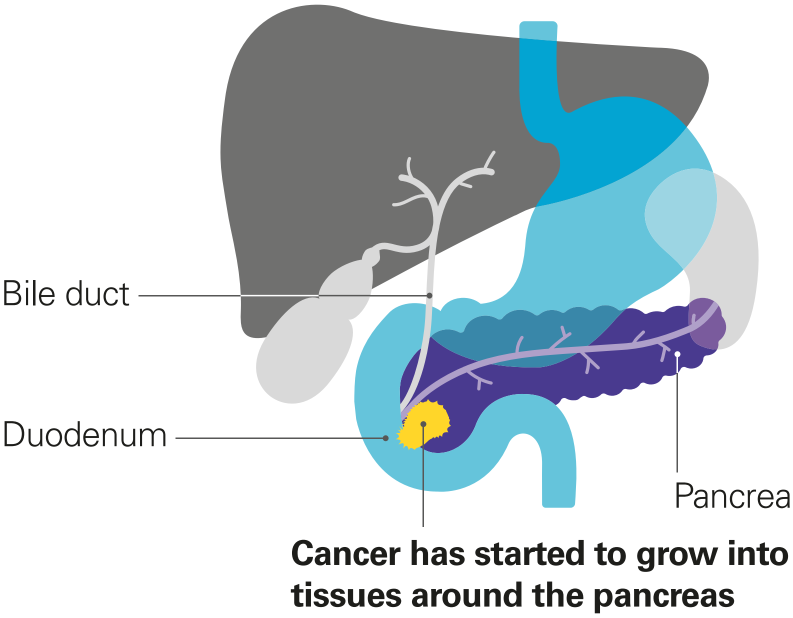
You may still be able to have treatment with chemotherapy to slow down the growth of your cancer.

The diagrams on the next page show the different stages.

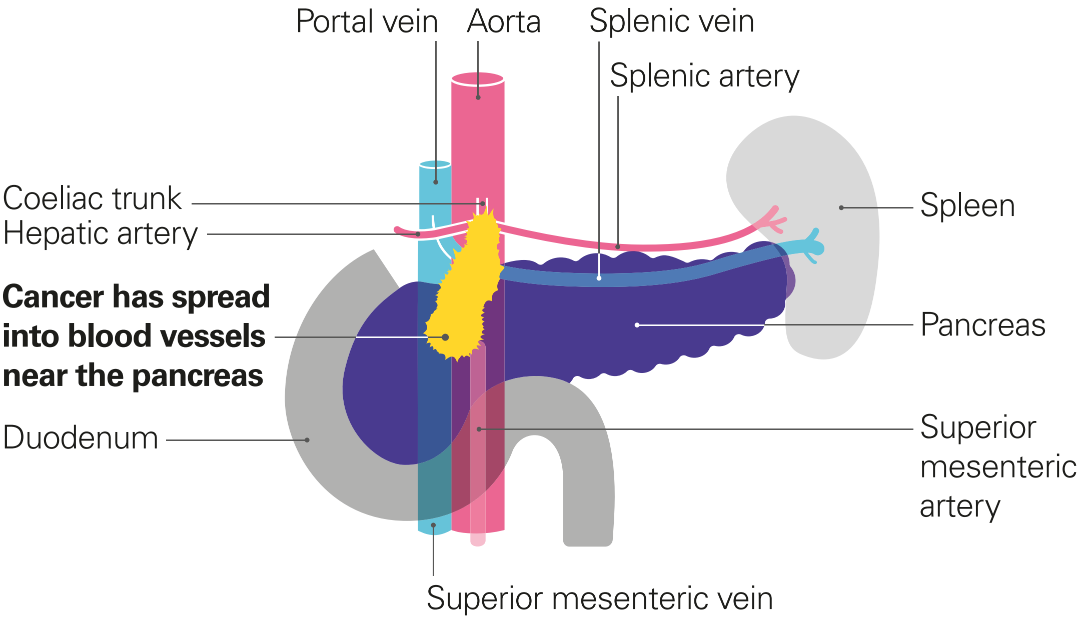
Stage 1 pancreatic cancer



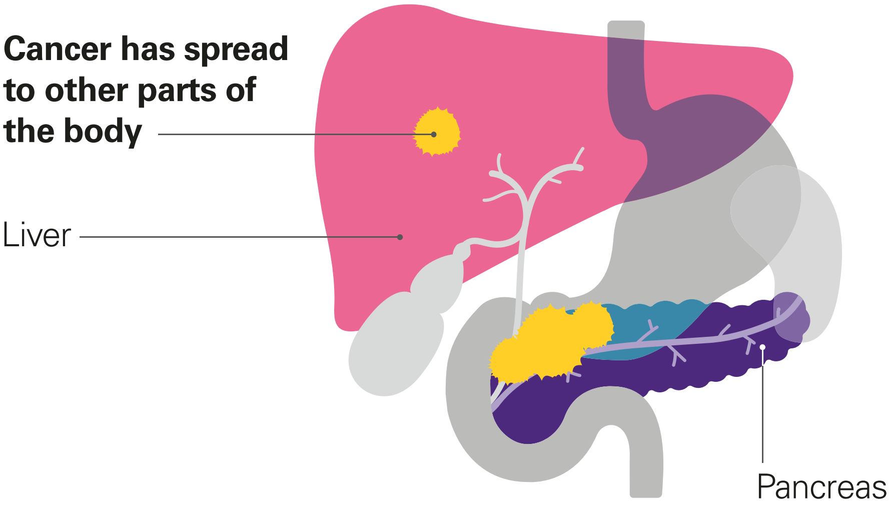
Stage 2 pancreatic cancer



Stage 3 pancreatic cancer



Stage 4 pancreatic cancer



Another system that is used is called TNM (Tumour-Nodes-Metastases) staging. You may only be given the TNM stage after you have had surgery to remove the cancer, if this is possible.

T is the size of the tumour.

- **T1:** the cancer is contained inside the pancreas, and is smaller than 2cm.
- **T2:** the cancer is contained inside the pancreas, but is bigger than 2cm.
- **T3:** the cancer has started to grow into tissues around the pancreas, but it hasn't grown into the large blood vessels.
- **T4:** the cancer has grown into nearby large blood vessels.

N shows whether the cancer has spread to the nearby lymph nodes.

- **N0:** the cancer hasn't spread to nearby lymph nodes.
- **N1:** the cancer has spread to nearby lymph nodes.

M shows whether the cancer has spread to another part of the body (metastatic cancer).

- **M0:** the cancer hasn't spread to other parts of the body, such as the liver or lungs.
- **M1:** the cancer has spread to other parts of the body.

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

Read about surgery to remove the cancer in our fact sheet, **Surgery for operable pancreatic cancer,** or at **pancreaticcancer.org.uk/surgery**

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

Read about radiotherapy at **pancreaticcancer.org.uk/radiotherapy**

? Questions to ask

What do the test results say about my cancer?

What stage is the cancer?

Has the cancer spread? If so where to?

What are my treatment options?

What happens next?

Coping with your diagnosis

Being told that you have pancreatic cancer may come as a shock. Everyone reacts differently and there is no 'right' way to feel. It's ok to be upset, angry, and to cry, shout or swear. If you have been unwell for some time, you may even feel a bit relieved that at least now you know what is wrong with you.

It can take time to come to terms with your diagnosis. You might find you have good and bad days. You will probably go through a range of emotions, from feeling positive and determined to get well again, to feeling low or worried about the future. People find different ways to cope, and there is support available (see page 18).

You will probably have lots of questions. You can speak to your doctor or nurse about these. We also have plenty of information about what to expect, including treatment options and coping with pancreatic cancer:

- on our website at **pancreaticcancer.org.uk/informationandsupport**
- in our booklet, **Pancreatic cancer: An overview of diagnosis and treatment.**

☎ You can also speak to our specialist nurses on our free and confidential Support Line with any questions or concerns.

Further information and support

Pancreatic Cancer UK services

We have a range of services to support you and your family in dealing with pancreatic cancer.

Our Support Line

Our Support Line is a lifeline for thousands of people affected by pancreatic cancer. Our specialist nurses understand the issues you might be facing. They are there for you, giving you personalised information and support that you need, when you need it.

Call us free and confidentially on **0808 801 0707** (Monday to Friday, 10am-4pm), or email us at **support@pancreaticcancer.org.uk**

Our information

We have the most up-to-date information on everything you need to know about pancreatic cancer on our website. We can help you every step of the way, from explaining your diagnosis and treatment options, to managing symptoms, and questions to ask at your appointments.

Go to **pancreaticcancer.org.uk/informationandsupport**

Download or order our publications, for free, at
pancreaticcancer.org.uk/publications

Our online community

Our online community is a supportive place where everyone affected by pancreatic cancer can be there for each other. You'll find others who understand what you're going through, because they are going through it too.

Visit our forum at **forum.pancreaticcancer.org.uk**

Support groups

We help set up local support groups across the UK. You can meet other people to get support and share experiences.

Find out if there's a group near you at
pancreaticcancer.org.uk/supportgroups

Useful organisations

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

Healthtalkonline
www.healthtalkonline.org/Cancer/Pancreatic_Cancer
Patient experiences presented in written, audio and video formats.

Macmillan Cancer Support
www.macmillan.org.uk
Support Line: 0808 808 00 00 (Mon-Fri 9am-8pm)
Provides practical, medical and financial support for anyone affected by cancer.

Maggie's Centres
www.maggiescentres.org
Centres around the UK and online offer free, comprehensive support for anyone affected by cancer.

My Cancer Treatment
www.mycancertreatment.nhs.uk
Directory of cancer services in England. Allows you to find and compare cancer services in your area.

Notes

Use this space to record anything you want to note down – for example, any questions for your medical team.

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This fact sheet has been produced by the Support and Information Team at Pancreatic Cancer UK. It has been reviewed by health professionals and people affected by pancreatic cancer.

References to the sources of information used to write this fact sheet, and a list of health professionals who reviewed it, are available on our website – **pancreaticcancer.org.uk**

Pancreatic Cancer UK makes every effort to make sure that our services provide up-to-date, unbiased and accurate information about pancreatic cancer. We hope that this information will add to the medical advice you have received, and help you make decisions about your treatment and care. This information should not replace information and advice from your medical team – please speak to your doctor, nurse or other members of your medical team about any questions or concerns.

Give us your feedback

We hope you have found this information helpful. We are always keen to improve our information, so let us know if you have any comments or suggestions. Email us at **publications@pancreaticcancer.org.uk** or write to the Information Manager at the address below.

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Health & care information you can trust
The Information Standard ✓ Certified Member

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