Diagnosing pancreatic cancer fact sheet

This fact sheet is for anyone undergoing tests or investigations for pancreatic cancer or wanting to find out more about how pancreatic cancer is diagnosed. It contains information on the routes to diagnosis, the tests that may be used to diagnose pancreatic cancer and staging of the disease.

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Introduction

Reaching a diagnosis of pancreatic cancer can be a lengthy and complex process due to the tests and investigations involved. When the disease first develops it often doesn’t cause many symptoms so people can have pancreatic cancer for some time without knowing. This means a diagnosis of pancreatic cancer can come as a shock.

Any symptoms people do have can be quite vague and may also be a sign of other more common illnesses that affect the gastro-intestinal system (gut) such as heartburn, pancreatitis, gallstones, irritable bowel syndrome or even stress. So it can be particularly difficult for GPs to detect and diagnose pancreatic cancer, especially in its early stages. As there is currently no easy way of detecting pancreatic cancer, diagnosis may sometimes be delayed while GPs or specialists spend time ruling out all the different possible causes.
for people’s symptoms. See our signs and symptoms of pancreatic cancer fact sheet for more information.

**Routes to diagnosing pancreatic cancer**

The difficulty doctors have in detecting and diagnosing pancreatic cancer means that people may arrive at a firm diagnosis by different routes.

**GP visit**

Most people start by seeing their GP. Sometimes people may see their GP several times because of vague symptoms that don’t get better over time. As with any illness, if your symptoms persist it’s important to go back to your GP until you get a firm diagnosis or a referral for further investigations.

Your GP will begin by asking you about your symptoms, which may or may not be obvious.

- They will usually look at your eyes and the colour of your skin for signs of jaundice.
- They may also examine your abdomen (tummy) for any swelling and to check if it is tender or painful.
- They will probably test your urine for bilirubin.
- They may also take a blood sample.
- They may ask you whether you have had any problems with eating, or digesting your food, and whether your bowel habit has altered.
- They may ask you whether you have been losing weight.

Your GP may decide to refer you to your local hospital for tests and to see a specialist.

Some symptoms indicate that your GP should refer you to a team specialising in pancreatic disease (an upper gastrointestinal or hepato-pancreatico-biliary team) straight away. These symptoms include jaundice, persistent unexplained abdominal pain and unexplained weight loss. This is known as an urgent referral for suspected cancer and means you must be seen by a specialist within two weeks. Being referred urgently does not necessarily mean that you do have cancer.

The National Institute for Health and Care Excellence (NICE) has produced guidelines to help GPs make this decision. (You can find these guidelines on the NICE website www.nice.org.uk/CG027 – *Referral guidelines for adults with suspected cancer*).
If you are very unwell when you see your GP they may decide to send you straight to hospital for assessment and further investigations as an outpatient, or they may feel it is more appropriate to arrange your admission as an emergency.

**Referral to your local hospital**

If your GP isn’t sure what is wrong with you they will probably refer you to your local hospital for tests and to see a gastroenterologist. Gastroenterologists are specialists in diseases and disorders of the digestive system, including the stomach, intestines, liver and pancreas.

The specialist will probably ask you the same questions you were asked by your GP before giving you a physical examination. They will then decide what tests and investigations you need to work out what is causing your symptoms. It may take several different tests before you are given a definite diagnosis.

**Getting admitted to hospital**

Sometimes people get admitted to hospital, perhaps even as an emergency, because they are very unwell but at the time the doctors don’t know what is wrong.

For example, jaundice may be the first sign that something is wrong and it can come on very quickly. Or someone might go into hospital because they have severe pain or persistent nausea and vomiting that can’t be explained.

It is only once they are there that the specialists can assess their symptoms and do whatever tests are needed to enable them to reach a diagnosis.

Depending on the hospital, people are usually admitted to a medical or surgical assessment unit. Or they might come in to Accident and Emergency if they’ve become ill very suddenly. The medical team will assess them, treat the pain or other symptoms and do some initial tests, such as an ultrasound scan. They will then be referred to a specialist (upper gastrointestinal or hepatopancreatobiliary (HPB)) team for further investigations.

**Being referred to a specialist centre**

Once someone has been diagnosed with pancreatic cancer they should have their case reviewed at a regional specialist centre where there is a dedicated...
team who assess and treat the disease. This may involve an appointment at the regional centre, or the local specialist and the specialist team at the regional centre may discuss the patient’s scans together without them having to attend the regional centre. Find out more about regional specialist centres and treatment teams on our website
www.pancreaticcancer.org.uk/specialistcentres

Tests and investigations

The tests used to confirm a pancreatic cancer diagnosis are described below. Doctors use the test results to work out the best treatment for anyone with pancreatic cancer. Different tests may be done at different times. People may have one particular test but then need another to find out exactly what type of pancreatic cancer they have and what stage it is. Most people won't need all the tests that are described here.

Most tests are done in the hospital x-ray or radiology department. Your hospital will usually give you a detailed information sheet about each test before your appointment so that you know whether you have to do anything to prepare for it and exactly what will happen on the day. You can ask your doctor or nurse for this information if you have not been given it.

Blood tests

Various blood tests are used to check your blood count, liver and kidney function, and your general health. The level of bilirubin in the blood can tell the doctors how severe your jaundice is. Blood tests can also check for tumour markers. These are chemical substances produced by cancers that show up in the bloodstream. For example, CA19-9 is a tumour marker linked to pancreatic cancer. Not all pancreatic cancers produce it and it may also occur with some other illnesses that are not cancer. This means blood tests are used together with other test results to make a diagnosis.

Most blood tests can be done straightaway and the samples are usually examined in the hospital laboratory within a day or two. Sometimes samples have to be sent away for analysis and it can take a few days to get the results. You may have to wait up to a week for results to be sent back to your GP.
Ultrasound scan of the abdomen

Ultrasound scans use sound waves to make a picture of the inside of the body. The images are collected on a screen – usually an outline of the liver, pancreas, gall bladder and bile ducts.

Ultrasound is simple, painless and relatively quick. 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 abdomen then a probe is passed over your abdomen to create the images. It can take anything from 5-30 minutes, depending on the extent of the scan, and you can go home as soon as it’s over.

If the scan is ordered urgently because of suspected cancer it should be done within two weeks. Otherwise you may have to wait two to four weeks for an appointment.

CT (Computerised Tomography) scan

A CT scan uses x-rays to build up a three-dimensional picture of the pancreas and the other organs around it. It is also usual to scan your chest and pelvic area to check for any signs of cancer outside the pancreas. It is more complex than an ultrasound and takes longer. A CT scan can also be used to guide the needle during a biopsy, a procedure where a tissue sample is taken for examination under a microscope (see biopsy section below).

The CT scan is done in the x-ray department at the hospital. It usually lasts approximately 30 minutes, depending on the exact area to be scanned. The scan is not painful but the couch you lie on is quite hard and can be uncomfortable. You will probably be able to go home straight afterwards.

As with an ultrasound scan you will be asked not to eat anything for six to eight hours beforehand and only drink clear fluids. You will be awake while the scan is done. You will lie on a couch attached to the scanner, which looks like a large ring. A computer moves the couch automatically through the scanner while a series of 360° x-rays are taken to build up a detailed picture. Before the scan you may be asked to swallow a liquid containing a dye, known as a contrast medium. This fills the stomach and intestines and provides a contrast to help identify the different organs. You may also be given an injection of contrast medium (providing you are not allergic to iodine) into a vein to help to show up the blood vessels in the area.
If the scan is ordered urgently because of suspected cancer it should be done within two weeks. Otherwise you may have to wait up to four weeks for an appointment.

**PET-CT scan**

This scan combines a CT scan (see above) with a PET (Positron Emission Tomography) scan, where a small amount of a radioactive substance is injected into a vein. On the x-rays the substance shows up areas where the cells are more active in the body. This type of scan can pick up small areas of active cells so it can help to give a clearer picture of the cancer.

You won’t be able to eat anything for a few hours before the scan, though you may be able to drink. The radioactive substance is usually injected into your arm. After that you have to wait for about an hour before the scan, which takes 30-90 minutes. You can usually go home straight after the scan.

These scans are usually done at specialist centres and aren’t routinely used. You may have to wait one to three weeks for the scan to be arranged. A national study has been looking at whether this type of scan should be used more widely, although the results aren’t yet available.

**MRI (Magnetic Resonance Imaging)**

MRI scans use magnets and radio frequency waves to build up detailed cross-sectional images of the pancreas and surrounding areas.

There is no special preparation for an MRI, but because it uses powerful magnets you have to fill in a safety questionnaire before your appointment. This asks you whether you have any metal implants in your body (such as pacemaker, eye or ear metallic fragments). 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; you lie on a table that moves into the tunnel for the scan. The magnets make it quite noisy so you may be given earplugs or headphones. You will also be able to hear and talk to the radiographer who operates the scanner from outside the room.

The scan usually takes 20-30 minutes, though it can be shorter or longer, and you will be able to go home straight afterwards. You may have to wait two to three weeks for an appointment.
MRCP (Magnetic Resonance Cholangio-Pancreatography)

This is a different type of MRI scan that is sometimes used to give clearer pictures of the bile and pancreatic ducts and any blockages in them. The pictures are similar to those from an ERCP (see below) but it is less invasive if no other procedures (such as inserting a stent) need to be done.

You will usually be asked not to eat or drink anything for two to three hours before the scan. This scan is usually done as an inpatient, though you may still wait up to two weeks for it to be done.

EUS (Endoscopic Ultrasound)

In this test a thin, flexible tube (endoscope) with an ultrasound probe at the end is passed through your mouth into your stomach. The ultrasound creates detailed pictures of the area that help show where the cancer is in the pancreas, how big it is and whether it has spread beyond the pancreas. A needle can also be passed through the tube to take tissue samples; this is a type of biopsy (see below) called fine-needle aspiration (FNA).

To prepare for the test you won’t be able to eat or drink for six to eight hours beforehand. The test takes between 30-60 minutes. You will be asked to lie down on your left side. You will be given a throat spray of local anaesthetic that helps to stop you coughing during the investigation. Then you will be given a sedative by an injection in your arm or the back of your hand. Although this won’t put you to sleep it will make you very drowsy and relaxed; most people don’t remember much about the procedure afterwards. It means the doctor can pass the endoscope easily into your stomach. During the procedure the doctor may see areas that need further investigation, in which case they will collect a small number of cells (an EUS FNA).

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

This test is usually done in specialist centres. You may have to wait two to three weeks for the test to be arranged.

ERCP (Endoscopic Retrograde Cholangio-Pancreatography)

This investigative test is used to diagnose problems of the liver, bile duct, gall bladder and pancreas. The doctors use an endoscope (like the EUS) but it
also involves taking x-rays. Dye is injected through the endoscopic tube directly into the opening (the ampulla of Vater) of the pancreatic duct. Any blockages will then show up on x-rays. While the endoscope is in place the doctor may take tissue samples for biopsy. If the x-rays show a blockage in your bile duct they may insert a small, flexible plastic or wire mesh tube (called a stent) into the duct. This keeps the duct open so that bile can drain into the duodenum (small bowel) as normal.

You may have to wait up to two weeks for your appointment. The ERCP will be done in the x-ray department or endoscopy suite at the hospital. You will be asked not to eat or drink for at least six hours before the test to make sure that your stomach and duodenum are empty. You will be given a sedative by an injection in your arm or the back of your hand. Although this won’t put you to sleep it will make you very drowsy and relaxed. The steps in this procedure are similar to those in the EUS. It takes about 25-30 minutes, and afterwards you will be taken back to a ward in your bed. The nurses there will monitor you until you are properly awake.

Most people have ERCP as an inpatient. If you are an outpatient and your ERCP is only to get x-rays and simple tissue samples you will be able to eat within a couple hours and will probably be ready 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. On leaving hospital you will be given contact details for the endoscopy department so that you can get in touch if you have any problems after the test.

**Laparoscopy**

This is a small operation done under general anaesthetic in the operating theatre at the hospital. A long tube with a camera at one end is inserted through a small cut in your abdomen so the doctor can examine you internally. Other small cuts may be made so instruments can be inserted to help with the examination. Carbon dioxide gas may be pumped into the abdomen to make it easier to see the pancreas. This test can help to clarify whether a tumour can be removed by surgery. Sometimes an ultrasound probe is also used (Laparoscopic Ultrasound) to help identify suspicious areas and take a biopsy (see below).

Because of the general anaesthetic you won’t be able to eat or drink for at least six hours before the laparoscopy. After it’s finished you will stay in the recovery area for a few hours until the anaesthetic wears off. You may be able to go home on the same day, although you’ll 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 on your abdomen are uncomfortable.

Laparoscopies are usually done at specialist centres. You may have to wait two to three weeks for your appointment.

**Biopsy**

A biopsy is when the doctor takes small tissue samples for a pathologist to examine under a microscope. A biopsy can be taken during a CT, EUS, ERCP or laparoscopy (see above). If the biopsy is taken during CT the doctor will put a needle directly through your skin into the tumour (cancer) under a local anaesthetic and remove a small sample of tissue. If it is taken during EUS the doctor may also aspirate (remove by suction) some tumour cells for the pathologist to look at. This may be referred to as a fine-needle aspiration (FNA) and is done while you are having a CT scan. Waiting times for biopsies will vary depending whether they are being done as part of another procedure.

In most circumstances you should have a biopsy as it is the only way of being absolutely certain about your diagnosis. You will need to have a biopsy to take part in a clinical trial as you may be ineligible to join if you don't have a definite cancer diagnosis. If you don't think you have had a biopsy you should discuss this with your specialist.

**Waiting for tests and investigations**

We have tried to give an idea of how long people may have to wait for different tests to be done, although this will vary between hospitals and areas. Waiting times also tend to be shorter for inpatients than outpatients.

Your doctor may be able to arrange for more than one test to be done before you go back to see them: this can help avoid having to wait too long between each test.

If you have been given an urgent referral for a particular scan or investigation because of suspected cancer it should be done within two weeks. If the test hasn't been requested as urgent you may have to wait several weeks for an appointment. This can be frustrating and worrying, especially if you are already feeling unwell.
Sometimes pancreatic cancer can make people feel very unwell quite quickly. If you are waiting for tests and you start to feel more unwell or your symptoms get worse you should contact your GP or the hospital. If you become acutely unwell you should go to your local Accident and Emergency Department. Symptoms to watch out for include: losing weight in spite of eating; pale, floating and smelly stools; nausea or vomiting; severe pain; jaundice; or itching.

**Waiting for test results**

Test results won’t be ready on the day of the test. Depending on the test you may have to wait from a few days to a couple of weeks for the results to come through.

Waiting for test results can be an anxious time. When you go for the test it’s a good idea to ask how long you may have to wait for the results. You may be able to make an appointment to get your test results.

Usually the doctor who does the test will write a report and send it to your specialist. If your GP sent you for the test the results will be sent to the GP surgery. You will need an appointment with your specialist or GP to find out what the test results show and discuss what will happen next.

If you haven’t had your results and think you’ve been waiting too long then contact your GP or specialist nurse to find out what’s happening.

**Staging**

Test results give the doctors a detailed diagnosis and also tell them what stage a cancer is. Staging is how doctors refer to the size of a cancer and whether it has spread around the tumour site or to other areas of the body. It is an important part of their assessment and contributes to treatment planning.

One system uses numbers from 1-4 to describe the stage of the cancer:

- **Stage 1:** the earliest stage when the cancer is only inside 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.

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For specialist information and support on pancreatic cancer contact our Support Line:
Telephone 020 3535 7099 or email support@pancreaticcancer.org.uk
• Stage 3: the cancer has grown outside the pancreas into the stomach, spleen, large bowel or into large blood vessels near the pancreas.

• Stage 4: the cancer has spread to other parts of the body such as the lungs or liver.

Knowing the stage of the cancer is important because it tells doctors whether or not an operation to remove the cancer may be possible. Doctors tend to classify pancreatic cancer into three groups:

• **Early stage or resectable cancer** – surgeons may be able to operate to remove the tumour. Because diagnosis is so difficult very few pancreatic cancers are diagnosed at this early stage (10%-20%).

• **Locally advanced or unresectable cancer** – the cancer has grown quite large or extensively involves blood vessels surrounding the pancreas and it is not possible to remove the cancer with surgery. About 35%-40% of pancreatic cancers are diagnosed at this stage.

• **Advanced, metastatic or secondary cancer** – the cancer has spread to other parts of the body such as the lung or liver. About 45%-55% of pancreatic cancers are diagnosed at this stage.

Another staging system is called TNM (Tumour-Nodes-Metastases):

• **T** is the size of the tumour

• **N** indicates if it has spread to the lymph nodes

• **M** indicates if the cancer has spread to another part of the body (metastatic cancer).
Questions to ask

• Do I need further tests to confirm my diagnosis?
• Have you done a biopsy as part of these tests?
• Who will perform the biopsy?
• How long will I have to wait to have these tests carried out?
• Who will contact me to arrange these tests?
• Where will I go for the tests?
• When will I get my test results?
• How will I get my test results?
• What do the results say about my cancer?
• What stage is the cancer?
• Has the cancer spread? If so where to?
• How does the stage affect my treatment?
• What kind of treatment can I have?
• What happens next?

Further information available from Pancreatic Cancer UK

• What is pancreatic cancer?
• Signs and symptoms of pancreatic cancer
• Types of pancreatic cancer

You can find this information on our website
www.pancreaticcancer.org.uk/publications

Glossary
You can find an A to Z of some of the common medical words that you may hear when you are finding out about pancreatic cancer on our website –
www.pancreaticcancer.org.uk/glossary
This fact sheet has been produced by the Support and Information Team at Pancreatic Cancer UK. It has been reviewed by healthcare professionals and people affected by pancreatic cancer.

References to the sources of information used to write this booklet and an acknowledgement of the health professionals who reviewed the booklet are available on our website - www.pancreaticcancer.org.uk

Pancreatic Cancer UK makes every effort to make sure that its 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 to take part in decisions related to your treatment and care. Please do continue to talk to your doctor, specialist nurse or other members of your care team if you are worried about any medical issues.

Give us your feedback We hope you have found this information helpful. If you have any comments or suggestions about this fact sheet or any of our other publications please complete our Information Feedback Form at www.pancreaticcancer.org.uk/informationfeedback or write to the Head of Support & Information at the address below.

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