

Explaining the NICE guidelines for diagnosing and managing pancreatic cancer

This fact sheet is for anyone diagnosed with pancreatic cancer and their family. It explains the guidelines that the National Institute for Health and Care Excellence (NICE) have produced for health professionals diagnosing and caring for people with pancreatic cancer. These guidelines are for the most common type of pancreatic cancer, pancreatic ductal adenocarcinoma. Health professionals don't have to follow these guidelines, but they must take them into account when making decisions about care. They should also take your needs and wishes into account.

These guidelines cover England, Wales and Northern Ireland. They are based on the best evidence available. There are no guidelines for pancreatic cancer in Scotland at the moment.

The guidelines cover the diagnosis of pancreatic cancer – including people who may be at higher risk of pancreatic cancer. They also cover the treatment of pancreatic cancer. And there are recommendations for managing symptoms. Your care will be individual to you, so not every recommendation will be relevant to you.

You can use these guidelines to help you understand the care you should have and make decisions about your treatment. You can also use them to speak to your doctors if you feel you are not getting the care you should have.

In this fact sheet we refer to our other information, which explains some of the tests and treatments mentioned in the guidelines. We suggest you read these guidelines along with our other information to make sure you have all the information you need. If you have any questions, speak to your doctor or nurse.



You can also speak to our specialist nurses on our Support Line. You can call them free on **0808 801 0707**, or email **nurse@pancreaticcancer.org.uk**

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1. Diagnosis

People with jaundice

Pancreatic cancer can cause jaundice. Signs of jaundice include yellow skin and eyes, dark urine, pale poo and itchy skin.



Read more about jaundice on our website at pancreaticcancer.org.uk/symptoms

- 1.1** If you have jaundice and suspected pancreatic cancer, you should be offered a computerised tomography (CT) scan before treatment for jaundice.

This is because it is easier to diagnose pancreatic cancer using a CT scan before you have treatment for jaundice.

- 1.2** If the diagnosis is still not clear following the CT scan, you should be offered an FDG-PET/CT scan and/or an endoscopic ultrasound scan (EUS) with a biopsy.

- 1.3** If you are having a stent inserted with an ERCP (endoscopic retrograde cholangio-pancreatography) to treat the jaundice and haven't had tissue samples taken, the doctor should take a tissue sample when the stent is inserted.

Tissue samples are used to help diagnose pancreatic cancer.



Read more about the tests used to diagnose pancreatic cancer in our fact sheet, **How is pancreatic cancer diagnosed?** and on our website at pancreaticcancer.org.uk/tests

People who have had scans that show something unusual in the pancreas but who don't have jaundice

- 1.4** If you don't have jaundice but have had a scan that showed a problem with your pancreas, you should be offered a CT scan.
- 1.5** If the diagnosis is still not clear after the CT scan, you should be offered an FDG-PET/CT scan and/or an endoscopic ultrasound scan (EUS) with a biopsy.
- 1.6** If tissue samples need to be taken, you should be offered an EUS with a biopsy.

People with pancreatic cysts

Pancreatic cysts are often not cancerous, but some can become cancer.

1.7 If you have a pancreatic cyst, you should be offered a CT scan or a type of MRI scan called an MRI/MRCP (magnetic resonance cholangio-pancreatography). If more information is needed after having one of these scans, you should be offered the other one.

1.8 You should be referred to have surgery if:

- you have jaundice and cysts in the head of the pancreas
- a scan shows that the cyst may have a solid part to it – this may suggest that the cyst could be cancer
- the main pancreatic duct (a tube in the pancreas) is 10mm in diameter or larger.

1.9 If you have had a CT scan or MRI/MRCP scan, you should be offered an EUS (endoscopic ultrasound) if:

- more information is needed on the chance of you having cancer or
- it's not clear whether you need surgery.

1.10 If more information is needed on the chance of you having cancer, your doctors should consider a biopsy with EUS.

1.11 If you have had a biopsy, your doctors should test for carcinoembryonic antigen (CEA).

CEA is a substance that helps to tell the difference between mucinous cysts (which could become cancer) and non-mucinous cysts (which don't become cancer).

1.12 If doctors think your cyst is cancer, they should follow the recommendations to work out how far the cancer has spread (see page 6).



Read more about pancreatic cysts on our website at pancreaticcancer.org.uk/cysts

Find out about the tests used to diagnose pancreatic cancer in our fact sheet, **How is pancreatic cancer diagnosed?** and on our website at pancreaticcancer.org.uk/tests

People with a family history of pancreatic cancer

1.13 If you have pancreatic cancer, your doctor should ask you if any of your first degree relatives (parent, brother, sister or child) have had it.

Your doctor should talk to you about any concerns you may have about an inherited risk of pancreatic cancer.

1.14 You should be offered monitoring for pancreatic cancer if you have:

- hereditary pancreatitis and a fault in the PRSS1 gene
- faults in the BRCA1, BRCA2, PALB2 or CDKN2A (p16) genes and one or more first-degree relatives with pancreatic cancer
- Peutz–Jeghers syndrome.

1.15 Monitoring for pancreatic cancer should be considered if you have:

- two or more first-degree relatives with pancreatic cancer, across two or more generations
- Lynch syndrome and any first-degree relatives with pancreatic cancer.

1.16 If you are having monitoring and don't have hereditary pancreatitis, doctors should consider regular MRI/MRCP (magnetic resonance cholangio-pancreatography) or EUS (endoscopic ultrasound scan).

1.17 If you have hereditary pancreatitis and a fault in the PRSS1 gene, doctors should consider regular monitoring with CT scans, rather than MRI/MRCP or EUS.

1.18 If you have hereditary pancreatitis, you shouldn't be offered an EUS to test for pancreatic cancer.

This is because pancreatitis can cause damage to the pancreas which may make an EUS less accurate than other scans.



Read more about genetic conditions and family history of pancreatic cancer, and monitoring people with a family history, on our website at pancreaticcancer.org.uk/familyhistory



If you have any questions about diagnosing pancreatic cancer, speak to our specialist nurses on our free Support Line.

2. Specialist pancreatic multidisciplinary teams

- 2.1** A specialist pancreatic cancer multidisciplinary team (MDT) should decide what care is needed, and involve you in this decision. Care may be delivered at either a specialist or local cancer centre, depending on the advice of the specialist MDT.



Read more about the MDT at
pancreaticcancer.org.uk/specialistcentres

3. Working out how far the cancer has spread (staging)

- 3.1** If you have recently been diagnosed with pancreatic cancer but haven't already had a CT scan, you should be offered one. The scan should include the chest, abdomen (tummy) and pelvis (area below the belly button).
- 3.2** If you have localised pancreatic cancer (cancer that is contained in the pancreas) and will be having surgery, chemotherapy or radiotherapy, you should be offered a FDG-PET/CT scan.

The FDG-PET/CT scan helps to confirm whether it is possible to remove the cancer.

- 3.3** If the doctors need more information to decide on your care, they should consider one or more of the following:
- an MRI scan to check if the cancer has spread to the liver
 - an endoscopic ultrasound scan (EUS) to help work out the stage of the cancer
 - a laparoscopy if surgery is a possibility, but there is a chance the cancer may have spread.



Read more about these tests in our fact sheet,
How is pancreatic cancer diagnosed? and on our website at
pancreaticcancer.org.uk/tests

4. Emotional (psychological) support

4.1 Your medical team should check the emotional effects of the following symptoms throughout your treatment and care:

- fatigue (extreme tiredness)
- pain
- problems with diet, digestion and nutrition, including changes to appetite
- anxiety and depression.

For example, your doctor, nurse or other members of your medical team should ask you about different symptoms and how you are feeling at different points during your care. This includes at diagnosis, and during and after treatment. They should support you in managing any issues you have.

4.2 People with pancreatic cancer and their families should be given information and support by the medical team, to help them manage the emotional impact of pancreatic cancer on their daily lives. This support should be tailored to their needs and the stage of their cancer (see page 6), and should continue to be available throughout their care.

4.3 NICE has made recommendations about providing information and support in its guidelines, **Patient experience in adult NHS services: improving the experience of care for people using adult NHS services.**



Read more about dealing with the symptoms of pancreatic cancer on our website at pancreaticcancer.org.uk/managingsymptoms

Read about coping with pancreatic cancer at pancreaticcancer.org.uk/coping



If you have any questions about managing the symptoms of pancreatic cancer, or about coping with the emotional effects of it, you can speak to our specialist nurses on our free Support Line. They have time to listen to your concerns and answer any questions.

5. Managing pain

5.1 A treatment called a coeliac plexus nerve block to manage pain should be considered if you:

- have pain that isn't controlled or
- have a lot of side effects from opioid painkillers or
- need increasing doses of painkillers.

A nerve block is a treatment that blocks nerves from sending messages to the brain, and so treats pain. The coeliac plexus is a thick bundle of nerves behind the pancreas. Pancreatic cancer can damage these nerves, causing pain.

A coeliac plexus nerve block blocks these nerves.

5.2 People with pancreatic cancer pain shouldn't be offered a treatment called thoracic splanchnicectomy.

This treats pain by cutting the nerves that send pain messages from the pancreas to the brain, as they pass through the chest. It has been used in the past to treat pancreatic cancer pain, but there is not much evidence that it helps.



Read more about managing pain in our booklet, **Pain and pancreatic cancer**, and on our website at pancreaticcancer.org.uk/pain



You can speak to our specialist nurses on our free Support Line with any questions about dealing with pain.

6. Managing diet and nutrition

The pancreas plays an important role in digesting food, as it produces enzymes that help to break down the food. Pancreatic cancer can affect this, causing problems with diet, eating, digestion and nutrition.

6.1 If you have pancreatic cancer that can't be removed with surgery, you should be offered pancreatic enzyme supplements such as Creon[®], Nutrizym[®] or Pancrex[®] to manage problems with diet and digestion.

6.2 If you are having surgery to remove pancreatic cancer, your doctor should assess whether you need pancreatic enzyme supplements before and after your surgery.

6.3 Fish oil supplements shouldn't be used to help manage weight loss for people with inoperable pancreatic cancer.

There has been some research looking at fish oil supplements for managing weight loss, but there is no evidence that it works.

6.4 If you have had a Whipple's operation or pylorus-preserving pancreaticoduodenectomy and are able to eat, you should be given food soon after the operation. You should have food either orally (by mouth) or through a feeding tube, rather than through a tube into a vein (parenteral feeding).



Read more about diet, digestion and nutrition in our booklet, **Diet and pancreatic cancer**, and on our website at pancreaticcancer.org.uk/diet

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



If you have any questions about managing problems with diet and digestion, you can speak to our specialist nurses on our Support Line.

7. Relieving a blocked bile duct or duodenum

Blocked bile duct (biliary obstruction)

Pancreatic cancer can block the bile duct, causing jaundice. A stent is a tube that can be inserted into your bile duct to relieve the blockage.

- 7.1** If your cancer can be removed with surgery and you have jaundice, you should be offered surgery rather than having a stent inserted first to treat the jaundice – if you are well enough and aren't on a clinical trial that requires a stent.
- 7.2** If a surgeon starts surgery to remove the cancer but finds it's not possible to remove it, they should carry out bypass surgery to treat the blocked bile duct.
- 7.3** If you have jaundice and can have surgery to remove the cancer but you aren't yet fit enough for the operation, you should be offered a metal stent to treat the jaundice. This should be inserted using an ERCP.
- 7.4** If you have suspected pancreatic cancer and are having a stent inserted to treat the jaundice which may need to be removed later on, doctors should consider using a covered metal stent, inserted using an ERCP.

A covered metal stent is a tube made of wire mesh, with a covering around the outside of it. Covered metal stents are easier to remove.

- 7.5** If you have jaundice and your cancer can't be removed with surgery, you should be offered a metal stent to treat the jaundice, rather than bypass surgery.



Read about stents and bypass surgery to treat a blocked bile duct in our fact sheet, **Stents and bypass surgery for pancreatic cancer**, and on our website at pancreaticcancer.org.uk/stentsandbypass

Blocked duodenum (duodenal obstruction)

Pancreatic cancer can block the duodenum (first part of the small intestine), causing sickness.

- 7.6** If a surgeon starts surgery to remove pancreatic cancer but finds that it's not possible to remove it, they should consider surgery to stop the cancer from growing to block the duodenum in the future.

7.7 If you have pancreatic cancer that can't be removed with surgery and have a blocked duodenum which is causing symptoms, the blockage should be relieved if possible.

7.8 If you have a blocked duodenum, your doctor should consider bypass surgery rather than a duodenal stent if you are likely to live longer.

This is because the evidence suggests that a stent may be more effective in the short term, and bypass surgery may be more effective in the longer term.



Read more about stents and bypass surgery to treat a blocked duodenum in our fact sheet, **Stents and bypass surgery for pancreatic cancer**, and on our website at pancreaticcancer.org.uk/stentsandbypass



If you have any questions about relieving a blocked bile duct or duodenum, you can speak to our specialist nurses on our free Support Line.

8. Managing resectable (operable) and borderline resectable pancreatic cancer

Resectable (operable) cancer is cancer that can be removed by surgery.

Sometimes the cancer may grow very close to the major blood vessels near the pancreas. This is called borderline resectable pancreatic cancer. It may be possible to remove the cancer, but it depends which blood vessels are affected and how far the cancer has grown.

Treatment before surgery (neoadjuvant treatment)

- 8.1** If you have borderline resectable pancreatic cancer, chemotherapy before surgery should only be considered as part of a clinical trial.
- 8.2** If you have pancreatic cancer that can be removed with surgery (operable cancer), chemotherapy before surgery should only be considered as part of a clinical trial.

Surgery

- 8.3** If you are having surgery to remove cancer in the head of the pancreas, your doctor should consider pylorus-preserving surgery, as long as it removes all the cancer.

Pylorus-preserving surgery doesn't remove part of the stomach or the stomach valve (the pylorus).

Chemotherapy after surgery (adjuvant treatment)

- 8.4** You should be given time to recover from surgery before starting chemotherapy. Chemotherapy should be started as soon as you are well enough to cope with six months of chemotherapy (six cycles).
- 8.5** You should be offered gemcitabine chemotherapy with capecitabine (GemCap) following surgery, once you have recovered from the surgery.
- 8.6** If you are not well enough to cope with GemCap following surgery, your doctor should consider gemcitabine alone.

This may have fewer side effects, but it may still help you live longer.

Follow-up after surgery to remove pancreatic cancer

- 8.7** You should have regular check-ups with the specialist team following surgery, to manage any side effects or problems from the surgery.
- 8.8** If you get new or unexplained symptoms following treatment, these should be investigated by the specialist team and you should be offered services to support you.



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

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



You can speak to our specialist nurses on our free Support Line with any questions about surgery.

9. Managing pancreatic cancer that can't be removed with surgery (inoperable or unresectable cancer)

Pancreatic cancer that has spread to nearby organs or blood vessels (locally advanced cancer)

- 9.1 If you have locally advanced pancreatic cancer, you should be offered a combination of chemotherapy drugs, if you are well enough to cope with the possible side effects.
- 9.2 If you have locally advanced pancreatic cancer and aren't well enough for combination chemotherapy, your doctor should consider gemcitabine chemotherapy.
- 9.3 If you are having chemotherapy with radiotherapy (chemoradiotherapy), you should be offered the chemotherapy drug capecitabine.



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

Read about radiotherapy at pancreaticcancer.org.uk/radiotherapy

Pancreatic cancer that has spread to other parts of the body (advanced or metastatic cancer)

First-line treatment

The first chemotherapy drugs you have are called first-line chemotherapy.

- 9.4 If you have advanced pancreatic cancer, you should be offered FOLFIRINOX chemotherapy if you are very fit and well enough to cope with the possible side effects.
- 9.5 If you have advanced pancreatic cancer and are not well enough for FOLFIRINOX, your doctor should consider gemcitabine together with other drugs such as capecitabine.

NICE have also previously recommended that nab-paclitaxel (Abraxane®) together with gemcitabine is an option for people with advanced pancreatic cancer who can't have FOLFIRINOX or GemCap (gemcitabine with capecitabine).

- 9.6** If you have advanced pancreatic cancer and are not well enough for a combination of chemotherapy drugs, you should be offered gemcitabine alone.

Second-line treatment

When one chemotherapy treatment stops working or if it hasn't worked, different chemotherapy drugs may be used to try to control the cancer for longer. This is called second-line chemotherapy.

- 9.7** If you need second-line chemotherapy and haven't already had chemotherapy that included oxaliplatin, your doctor should consider chemotherapy that includes oxaliplatin.
- 9.8** If you need further chemotherapy after FOLFIRINOX, your doctor should consider chemotherapy that includes gemcitabine.



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

Preventing a blood clot in a vein

People with pancreatic cancer may be at higher risk of a blood clot in a vein.

Doctors should consider giving people with pancreatic cancer who are having chemotherapy a drug called low-molecular-weight heparin (LMWH) to try to prevent a blood clot forming in a vein.



Read more about blood clots and pancreatic cancer on our website at pancreaticcancer.org.uk/bloodclots



You can speak to our specialist nurses on our free Support Line if you have any questions about inoperable pancreatic cancer.

Individual documents and selected extracts

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10. Further information and support

If you have any questions about these guidelines and your care and treatment, speak to your doctor or nurse.



You can also speak to our specialist nurses on our Support Line.

If you have any concerns about your care, speak to your doctor or nurse.



Read more about what to do if you have concerns about your care on our website at pancreaticcancer.org.uk/concerns

You can read the guidelines for health professionals on the NICE website.

Useful organisations

Cancer Research UK

www.cancerresearchuk.org

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

Information for anyone affected by cancer.

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

Tel: 0300 123 1801

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

National Institute for Health and Care Excellence (NICE)

www.nice.org.uk

NICE produce guidelines that make recommendations for the NHS care of people with different health conditions. The guidelines are based on the best available evidence, and aim to improve the quality of healthcare. The NICE guidelines for pancreatic cancer are available at www.nice.org.uk/guidance/ng85

Glossary

We have explained some of the medical words that you may hear when you have pancreatic cancer.

Advanced pancreatic cancer: cancer that has spread from the pancreas to other parts of the body. Also known as metastatic or secondary cancer.

Bile duct: a tube that carries fluid called bile from the liver to the duodenum.

Biopsy: procedure to remove tissue to examine under a microscope.

Borderline resectable pancreatic cancer: cancer that has grown very close to the major blood vessels near the pancreas. It may be possible to remove the cancer, but it depends which blood vessels are affected and how far the cancer has grown.

Bypass surgery: surgery to relieve a blocked duodenum or bile duct.

Coeliac plexus nerve block: a treatment that blocks nerves from sending messages to the brain, and so treats pain.

CT (computerised tomography) scan: uses x-rays to create a 3D picture of the pancreas and the organs around it.

Duodenum: the first part of the small intestine.

Endoscopic ultrasound scan (EUS): a thin, flexible tube (called an endoscope) is passed through your mouth and down into your stomach. The tube has a light at the end and a small ultrasound probe to create pictures of the pancreas.

Endoscopic retrograde cholangio-pancreatography (ERCP): a procedure used to diagnose problems with the pancreas or to insert a stent into a blocked bile duct to relieve the symptoms of jaundice. An ERCP uses an endoscope and the procedure is similar to an EUS, but also involves taking x-rays.

FDG-PET/CT scan: this scan combines a CT scan with a PET (positron emission tomography) scan to build up a clearer picture of the cancer and how it is behaving. A small amount of a harmless radioactive substance, called Fludeoxyglucose (FDG), is injected into a vein in your arm before the scan.

Genes: carry the information that controls our growth and how our bodies work. Occasionally, there may be changes in genes which means that someone is more likely to get a disease. This type of change in a gene is often called a fault or mutation.

Hereditary pancreatitis: pancreatitis is inflammation of the pancreas. Hereditary pancreatitis is a rare type of pancreatitis that runs in families. People with hereditary pancreatitis have a much higher risk of developing pancreatic cancer.

Laparoscopy: a small operation that is occasionally used to confirm a diagnosis of pancreatic cancer and check whether the cancer can be removed by surgery.

Localised pancreatic cancer: pancreatic cancer that is contained in the pancreas. Also known as early or resectable (operable) pancreatic cancer.

Locally advanced pancreatic cancer: pancreatic cancer that has spread to structures around the pancreas, such as blood vessels.

Magnetic resonance cholangio-pancreatography (MRCP): a type of MRI scan that looks at the bile duct, liver, gallbladder and pancreas.

Magnetic resonance imaging (MRI) scan: a scan that uses magnets and radio waves to build up a detailed picture of the pancreas and surrounding areas.

Metastatic cancer: see advanced cancer above.

Multidisciplinary team (MDT): a team of medical professionals who will be responsible for your treatment and care.

Pancreatic enzyme supplements: help to digest food when the pancreas isn't producing enough digestive enzymes.

Pylorus-preserving pancreaticoduodenectomy: similar to the Whipple's operation, but none of the stomach is removed. The stomach valve (the pylorus), which controls the flow of food into the duodenum, isn't removed either.

Resectable pancreatic cancer: cancer that is contained in the pancreas and can be removed by surgery. Also called operable cancer.

Stage: The stage of the cancer describes the size of the cancer and whether it has spread around the pancreas or to other parts of the body.

Stent: a small, flexible plastic or metal tube that can be inserted into the bile duct or duodenum to relieve any blockages.

Unresectable pancreatic cancer: cancer that has spread outside the pancreas and can't be removed by surgery. Also called inoperable cancer.

Whipple's operation: one of the most common types of surgery for pancreatic cancer. The head of the pancreas, duodenum, and part of the stomach and bile duct are removed.

Pancreatic Cancer UK services

We are here for everyone affected by pancreatic cancer.

We're here to support and to listen

Our free and confidential Support Line is a lifeline for thousands of people affected by pancreatic cancer. Our specialist nurses understand the issues you might be facing and their expert help will support you in coping with pancreatic cancer.

Call free on **0808 801 0707** weekdays 10am-4pm, or email **nurse@pancreaticcancer.org.uk**

We're here with the information you need

We have the most up-to-date information on everything you need to know about pancreatic cancer. We can help you every step of the way through diagnosis and treatment options to managing your symptoms and the care you receive.

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

Download or order our free publications at

pancreaticcancer.org.uk/publications or call **0808 801 0707**

Find an A-Z of medical words at **pancreaticcancer.org.uk/medicalwords**

We're here so you can share

Our Forum is a supportive place where everyone affected by pancreatic cancer can be there for each other online, any time of day or night:

forum.pancreaticcancer.org.uk

Our Living with Pancreatic Cancer Support Days provide local face to face support in an informal setting for people with pancreatic cancer:

pancreaticcancer.org.uk/supportdays

Local support groups mean you can meet other people to share your experiences:

pancreaticcancer.org.uk/supportgroups

Pancreatic Cancer UK

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 our Information Manager at the address below.

Explaining the NICE guideline for diagnosing and managing pancreatic cancer

This information supports the recommendations in the NICE guideline on pancreatic cancer in adults.

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