PANCREATIC CANCER
AN OVERVIEW OF DIAGNOSIS AND TREATMENT
MY PERSONAL DETAILS

NAME:

TELEPHONE:

HOSPITAL:

HOSPITAL NUMBER:

NOTES:
INTRODUCTION

This booklet is for anyone who has recently been diagnosed with pancreatic cancer. Partners, family members and carers may also find it useful. It gives a general introduction to pancreatic cancer, information on tests and investigations that help confirm a diagnosis and overviews of possible treatment options and the wider impact of the diagnosis. The information may also be helpful for anyone who is undergoing investigations for pancreatic cancer and wondering what the next steps might be.

If you have only just been told about your diagnosis you may be feeling surprised or shocked, as many people diagnosed with pancreatic cancer have no idea they were seriously ill. You may have been feeling unwell for a while but without knowing what was wrong. You might feel frightened, angry or upset, but remember there isn’t any ‘right’ way to feel; everyone deals with things in their own way.

There is a lot to take in at this time, so this booklet is a good place to start.

- There are questions throughout that you may want to ask your doctors.
- There is also space for you to note down other questions or anything else you want to remember like contact details, telephone numbers or appointment dates.
- At the back you will find a list of explanations of common terms relating to pancreatic cancer and sources of further information and support.
Pancreatic Cancer UK is here to help so if you would like to know more about anything you read in this booklet, call our Support Line on 020 3535 7099, email support@pancreaticcancer.org.uk or go online at www.pancreaticcancer.org.uk.
WHAT IS THE PANCREAS?

The pancreas is a large gland that lies behind the stomach in the back of the abdomen. It is about 15cm (6 inches) long, shaped a bit like a tadpole and often described as having a head, body and tail.

The pancreas has two important functions. It makes:

- enzymes that are secreted in the pancreatic digestive juices and which help break down food so the body can absorb nutrients. These digestive juices flow down a tube called the pancreatic duct which runs the length of the pancreas.

- hormones that enter the body and flow around the bloodstream. The most important of these is insulin, which helps to regulate the amount of sugar in the blood.

If the pancreas isn’t working properly then both these functions can be affected.

The pancreas is surrounded by several large and important organs and blood vessels. The head of the pancreas is closely attached to the duodenum (the top part of the small intestines). The pancreatic duct empties into the duodenum. The common bile duct that carries bile from the liver also passes through the head of the pancreas to empty in the duodenum. The blood supply to the liver, intestines, kidneys and lower part of the body can all be in contact with the pancreas.
What is Pancreatic Cancer?

Pancreatic cancer occurs when abnormal cells in the pancreas grow out of control. It can occur in the head, body or tail of the pancreas.

Pancreatic cancers are divided into two main groups – exocrine and endocrine tumours.

- Exocrine tumours start in the exocrine cells that make enzymes to help digestion. Ninety-five per cent of pancreatic cancers are classified as exocrine tumours and about 90% of these are called pancreatic ductal adenocarcinomas (PDAC).

- Endocrine tumours (also called neuroendocrine tumours) start in the hormone producing cells and account for only 5% of all pancreatic cancers.

Within these two groups there are many different types of pancreatic cancer that behave differently, produce different symptoms and are treated differently.

You can read more information about the different types on our website – www.pancreaticcancer.org.uk/types

Questions

What type of pancreatic cancer do I have?
Where in my pancreas is the cancer?
DIAGNOSING PANCREATIC CANCER

Reaching a diagnosis of pancreatic cancer can be a lengthy and complex process, which is one of the reasons many people find the news such a shock. When the disease first develops it often doesn’t cause many symptoms so you may have had cancer for some time without knowing.

Some symptoms, for example jaundice, persistent abdominal pain or unexplained weight loss, indicate that your GP should refer you to a team specialising in pancreatic disease straight away. (Depending on where you live this might be an upper gastrointestinal or hepatobiliary team.) You can read more about the guidelines to help GPs make this decision on our website – www.pancreaticcancer.org.uk/ diagnosis/niceguidelines

However, any symptoms you do have can be quite vague and may also be a sign of other more common, less serious illnesses. This means you may have been sent for several different tests before pancreatic cancer was considered.

Alternatively, you may have been admitted to hospital, perhaps even as an emergency, because you were unwell and a diagnosis was made there. However you arrived at this point, by now you will probably have had a number of different tests to confirm your diagnosis.

Sometimes people with pancreatic cancer can begin to feel very unwell quite quickly. If you are waiting for tests and you experience any worsening symptoms you should contact your GP, or your specialist nurse if you already have one. Symptoms to watch out for include losing weight in spite of eating; nausea or vomiting; pale, smelly and floating stools (poo); pain; jaundice or itching.
TESTS AND INVESTIGATIONS

The tests used to confirm a pancreatic cancer diagnosis are described below. Your doctors use the test results to work out the best treatment for you. Although you will have had some of these tests you may need others to find out exactly what type of pancreatic cancer you have and what stage it is (see page 14 for more about staging). You may not need all the tests included here. You will be given more detailed information about each test before you have it.

**Blood tests**

Various blood tests are used to check your blood count, liver and kidney function and your general health. 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. Blood 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 several days to get the results.

**Ultrasound scan of the abdomen**

Ultrasound scans use sound waves to make a picture of the inside of the body. A probe is passed over your abdomen and the images are collected on a screen – usually an outline of the liver, pancreas, gall bladder and bile ducts.

**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. 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 page 12).

**PET-CT scan**

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

**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.

**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.

**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 called fine-needle aspiration (FNA).

**ERCP (Endoscopic Retrograde Cholangio-Pancreatography)**

Like the EUS this test uses an endoscope but it also involves taking
x-rays. Dye is injected through the 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 there is a blockage in your bile duct they may insert a small tube (called a stent) into the duct (see page 25). This keeps the bile duct open so that fluid can drain into the duodenum as normal, which also relieves any symptoms of jaundice.

**Laparoscopy**

This is a small operation done under general anaesthetic. 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. 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.

**Biopsy**

In most circumstances you should have a biopsy as part of these investigations as it is the only way of being absolutely certain about your diagnosis. Tissue samples for examination under a microscope can be taken during an EUS, ERCP or laparoscopy, or through your skin with local anaesthetic and guided by CT. If you don’t think you have had a biopsy you should discuss this with your specialist. You will need to have a biopsy to take part in a clinical trial (see page 31) as you may be ineligible if you don’t have a definite cancer diagnosis.

**WAITING TO HAVE TESTS CARRIED OUT**

Even if you have been given an urgent referral for a particular scan or investigation you may have to wait several days for your appointment, or perhaps as long as two weeks. This can
be frustrating and worrying, especially if you are already feeling unwell. If your symptoms get worse or you start to feel more unwell while you are waiting it’s a good idea to get in touch with your GP or specialist nurse if you already have one. They can contact the specialist team on your behalf if necessary. If you do have to go into hospital for any reason you can ask if any tests you are waiting for can be done while you are there.

**HOW LONG WILL I HAVE TO WAIT FOR MY TEST RESULTS?**

Depending on which tests you have had it may take from a few days to a couple of weeks for the results to come through. Waiting for test results can be an anxious time. It’s a good idea to ask how long you may have to wait when you go for the test. If you think you’ve been waiting too long then contact your GP or specialist nurse to find out what’s happening.

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 discuss the test results and how they might affect your treatment.

**QUESTIONS**

- 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?
- When will I get my test results?
- How will I get my test results?
- What do the results say about my cancer?
STAGING

Your test results will give your doctors a detailed diagnosis and also tell them what stage your 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 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.
- **Stage 3**: the cancer has spread 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 (metastatic cancer).

Another 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

*What stage is the cancer?*
*Has the cancer spread? If so, where to?*
*How does the stage affect my treatment?*
BEING REferred TO A SPECIALIST CENTRE

In the UK anyone diagnosed with pancreatic cancer should have their case reviewed at a cancer centre where there is a specialist team to assess and treat the disease. In particular, national guidelines state that surgery should only be carried out in specialist centres that see a high volume of pancreatic cancer patients. Research has shown that this gives patients the best outcomes.

These centres have been set up across the UK on a regional basis. Hospitals in a region work together with the specialist centres to try to ensure the best treatment and care for all patients.

Patients may not have to attend the specialist centre. Tests and investigations are often done at local hospitals and chemotherapy treatment can be given there too. Wherever a patient is treated, the specialist centre should always be involved in assessment and treatment decisions. Your doctor can answer any questions you may have about which specialist centre is involved in your care and explain the decisions made by the specialist team.

Local hospitals may not always be involved in running clinical trials or offer all the trials available at the specialist centre, so patients taking part in clinical trials may also have their treatment at the specialist centre. (See page 31 for more information on clinical trials.)

There is a list of hospitals with specialist pancreatic teams on our website –

www.pancreaticcancer.org.uk/specialistcentres
WHO WILL I BE TREATED BY?

You will be cared for by several different healthcare experts known as a multidisciplinary team (MDT).

Once all your investigations have been carried out your specialist team will meet to discuss the results with their colleagues. This MDT meeting will include doctors from the x-ray, pathology, surgery, medical and oncology departments and specialist nurses. Everyone will use their expert knowledge to review your case and agree on the best treatment options for you.

Below is a list of the health professionals likely to be most involved in your care, although you may not meet them all and there may be others in the team too. You will be given a main contact, or key worker, who will usually be a specialist nurse (either a hepatobiliary or upper gastrointestinal cancer nurse specialist). It’s their role to report back to you from the MDT and they will be the person you liaise with most.

There is space below for you to note down the names and contact details of the members of your MDT. It can be helpful to keep this list handy so that you have the information nearby when you need it.

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QUESTIONS

Is this a specialist pancreatic cancer centre?
Have I been referred to a specialist pancreatic cancer centre? If not, why not?
Where is the nearest specialist pancreatic cancer centre to me?
Who are the members of my MDT?
Will I have a named specialist nurse?
Who is my key worker?
Who do I contact if I need to speak to someone in an emergency or out of hours?
WHAT TREATMENT MIGHT I BE OFFERED?

Your doctors will consider several different factors when working out the best treatment for you. These include the specific type of pancreatic cancer you have, the stage of the cancer and where it is in the pancreas, as well as your age and your general health and fitness. They will also follow national guidelines outlining the best treatment for pancreatic cancer.

Once the team has decided on what treatment they would recommend they will discuss the plan with you at an outpatient appointment. If you are in hospital at this stage they may visit you on the ward. It’s a good idea to have someone with you when your treatment is explained as they can help remember the discussion or even take notes. You may also want to be ready with a written list of questions for your specialist or your specialist nurse.

You don’t have to make any decisions there and then; you will be given time to think about your options before deciding what you want to do. You may also want to discuss things with your family, carer or GP. You will be given another appointment to discuss any questions you may have after you have read all the information you have been given. Your treatment should start within 31 days of the MDT’s decision on treatment being made. But you won’t start any treatment until you give your permission for it to go ahead, usually by signing a consent form.

QUESTIONS

What are my treatment options?
What is the likely outcome of the recommended treatment?
What are the risks and side effects of the recommended treatment?
Can I get a second opinion? How do I go about getting one?
WHEN SURGERY TO REMOVE THE CANCER IS POSSIBLE

Because pancreatic cancer is so hard to detect it is much less likely to be found at an early stage than some other cancers. People whose pancreatic cancer is diagnosed early have more treatment options and a greater chance of a positive outcome. Treatment is most likely to involve surgery and chemotherapy.

SURGERY

If the cancer is small, there are no signs that it has spread beyond the pancreas and you are fit and healthy it may be possible for the tumour to be completely removed by surgery. This is known as a resectable (operable) tumour. Surgery is the most effective treatment for early stage pancreatic cancers but only a small number of people fall into this category.

Some tumours may be very close to the major blood vessels that pass under the pancreas or may even involve them. These are categorised as borderline resectable tumours. Surgeons may be able to remove the tumour, depending on how much of the blood vessels are involved. Sometimes, removing a tumour simply isn’t possible at the time of the operation. In this situation surgeons may still carry out other surgical procedures to help relieve symptoms (see page 25) and chemotherapy will normally be given to treat the tumour.

In some centres chemotherapy and/or radiotherapy may sometimes be used before surgery to improve the chance of successful surgery by shrinking the tumour first. Doctors are still investigating the effectiveness of this approach through clinical trials (see page 31).

Surgery for pancreatic cancer is complex and operations can last
for several hours. You may have one of the following operations to remove all or part of the pancreas, depending on where the cancer is and how much of the pancreas is affected.

- **Whipple’s operation (pancreatoduodenectomy)** This is the most common type of surgery for tumours in the pancreas. It may be done where the tumour is in the head of the pancreas, has not spread beyond the pancreas and does not extensively involve major blood vessels. The head of the pancreas, the lower end of the stomach, the duodenum (first part of the small intestines), the common bile duct, gall bladder and surrounding lymph nodes are all removed. The remaining part of the stomach, bile duct and pancreas are then reattached to the small intestines to allow normal digestion.

- **Pylorus-preserving pancreatoduodenectomy** This is a variation of the Whipple’s operation where the lower end of the stomach isn’t removed so the stomach valve (the pylorus) that empties into the small intestines is kept intact.

- **Distal pancreatectomy** This involves removing the left half (body and tail) of the pancreas, which is furthest away from the join to the duodenum.

- **Total pancreatectomy** For large tumours it may be necessary to remove the whole pancreas.

Removing all or part of the pancreas may affect its function and result in symptoms related to diet and nutrition, including diabetes. (Diabetes is inevitable if the whole pancreas is removed.) After surgery you may need to take pancreatic enzyme supplements to help with digesting and absorbing nutrients from food and nutritional supplements if you have lost weight. You may also need help with managing diabetes. (See page 32 for more information on dietary-related issues.)
Visit our website at www.pancreaticcancer.org.uk/surgery for more information on surgery and recovery from surgery.

QUESTIONS

Can I have surgery to remove the tumour?
Is the cancer affecting any of the major blood vessels?
Which type of operation do I need?
How experienced is the surgeon at performing this type of operation?
What are the benefits and risks of surgery?
How much of my pancreas will be removed?
What are the after effects of surgery?
Will I have to go on any medication after surgery?
Will I need to change my diet following surgery?
What other treatment options do I have?
Why can’t I have surgery? Was my case reviewed at the specialist centre?

CHEMOTHERAPY

One of the most common treatments for pancreatic cancer is chemotherapy – using anti-cancer drugs to destroy cancer cells. Chemotherapy can be used on its own or alongside other treatments such as surgery and radiotherapy.

If you have had surgery to completely remove your cancer you may benefit from a course of chemotherapy afterwards. This is to try to reduce the chances of the cancer coming back and is called adjuvant chemotherapy.
Following national guidelines the drugs most often used are gemcitabine and fluorouracil (5-FU). Capecitabine may be used instead of 5-FU. Other drugs and drug combinations such as gemcitabine with capecitabine (GemCap) are being tested in clinical trials (see page 31) to see whether they work better than the current standard treatments.

Chemotherapy can be given intravenously (as an infusion into a vein), orally (as tablets) or a combination of both. Because chemotherapy treats the whole body normal cells can be affected as well as cancer cells. This means you may experience side effects such as nausea, diarrhoea, hair loss and fatigue (extreme tiredness), although everyone reacts differently and most side effects can be well controlled.

The specific side effects of gemcitabine, 5-FU and capecitabine are listed on our website –
www.pancreaticcancer.org.uk/chemotherapy/maindrugs

**QUESTIONS**

*Will I have chemotherapy after my surgery?*
*Which chemotherapy drug will work best for me?*
*What can I expect the chemotherapy to achieve?*
*What are the side effects of chemotherapy?*
*Are there any clinical trials involving chemotherapy I could take part in?*
WHEN SURGERY TO REMOVE THE CANCER ISN’T POSSIBLE

Because pancreatic cancer is so difficult to detect, by the time a diagnosis is confirmed and treatment starts the tumour may have grown quite large or extensively involved the blood vessels near the pancreas. This is known as locally advanced cancer. Or it may have spread beyond the pancreas to other parts of the body – this is known as advanced or metastatic cancer. In these situations people may be experiencing symptoms that make them feel quite unwell.

You may have been told that your cancer is inoperable, which means that surgery to remove it isn’t possible. Instead you may have other treatment to help control the cancer’s growth, relieve any symptoms it is causing and generally improve how you feel. The aim is to control your symptoms and give you the best possible quality of life. This is known as supportive or palliative care.

STENT INSERTION AND BYPASS SURGERY

Some surgical and other interventional procedures are used that don’t remove the cancer but instead help relieve symptoms.

The cancer may have grown so that it blocks your duodenum or your bile duct. If your duodenum is blocked food can’t get through to your bowel and builds up in your stomach, causing discomfort, sickness and vomiting. If your bile duct is blocked you may get jaundice, with symptoms such as yellowing of the skin and eyes and itching.

In both these situations a small, flexible plastic or metal tube called a stent can be inserted to relieve a blockage and keep the duct or bowel open. Stents are most often put in during an ERCP (see page 11). If this isn’t possible an alternative procedure called a PTC (Percutaneous Transhepatic Cholangiogram) may be used. Here
the stent is inserted directly through the skin and liver into the top of
the bile duct using a needle and x-ray guidance.

Alternatively surgeons can carry out an operation to bypass the
blockage.

- When the bowel is blocked the part of the small bowel just
  below the duodenum is connected directly to your stomach
  so that food can pass from the stomach into the bowel.
- For a blocked bile duct the duct is cut above the blockage and
  reconnected to the small bowel, allowing the bile to flow again.

Sometimes these two procedures are done at the same time.

QUESTIONS

What treatment can I have for my jaundice?
Would a stent be better than bypass surgery?
Do I need to have bypass surgery?

CHEMOTHERAPY

If you have locally advanced or advanced cancer, chemotherapy
can be used to relieve your symptoms and to try to shrink the
cancer. The chemotherapy will not cure the cancer but may help
slow down its growth.

Because chemotherapy treats the whole body normal cells can be
affected as well as cancer cells. This means you may experience
side effects such as nausea, diarrhoea, hair loss and fatigue
(extreme tiredness), although everyone reacts differently and most
side effects can be well controlled.
Following national guidance the chemotherapy drug most often used for locally advanced or advanced cancer is gemcitabine, as clinical trials have shown that it is effective in controlling cancers and improving symptoms. Gemcitabine is given intravenously (as an infusion into a vein). Gemcitabine’s side effects are listed on our website – [www.pancreaticcancer.org.uk/gemcitabine](http://www.pancreaticcancer.org.uk/gemcitabine)

Doctors are constantly testing other drugs and drug combinations in clinical trials to see whether they give better results than gemcitabine. For example, trials with FOLFIRINOX (leucovorin, fluorouracil, irinotecan and oxaliplatin), and nab-paclitaxel (Abraxane®) with gemcitabine have shown increased survival time for people with advanced pancreatic cancer but also increased side effects. Talk to your specialist about other options that may be available and whether they are suitable for you.

You may be eligible to take part in a clinical trial testing alternative chemotherapy drugs or chemotherapy combined with other treatments. You can ask your doctors if any suitable trials are taking place (see page 31 for more information).

Visit our website at [www.pancreaticcancer.org.uk/ chemotherapy/ maindrugs](http://www.pancreaticcancer.org.uk/ chemotherapy/ maindrugs) for more information about different drugs.

**QUESTIONS**

*Will chemotherapy help control my cancer?*

*Will chemotherapy relieve any of my symptoms?*

*Which chemotherapy drug (or drugs) is most suitable?*

*Where will I have this chemotherapy?*

*Are there any clinical trials involving chemotherapy I could take part in?*
Radiotherapy uses high-energy x-rays to destroy cancer cells. Because modern radiation techniques target the cancer cells precisely it is called a localised treatment. Normal cells around the cancer cells are also affected, which is why radiotherapy can cause side effects such as tiredness, nausea and diarrhoea. Side effects usually resolve once treatment stops.

Radiotherapy isn’t used as often as chemotherapy for pancreatic cancer. It may be considered if your cancer is locally advanced, which means it can’t be removed surgically but it hasn’t spread to other parts of the body. Radiotherapy won’t cure the cancer but may help control it and slow its growth.

In this situation radiotherapy is usually given together with chemotherapy (chemo-radiation). The aim is for the chemotherapy drugs to make the cancer cells more sensitive to radiation. Trials are ongoing to find out how chemo-radiation can be used most effectively, so ask your oncologist if it is a suitable treatment for you and whether it is available in your specialist centre.

Radiotherapy can also be helpful when cancer has spread to other parts of the body (advanced or metastatic cancer). It is particularly effective in controlling and relieving pain.

Visit our website at www.pancreaticcancer.org.uk/radiotherapy for more information.
QUESTIONS

Will radiotherapy help control my cancer?
Will radiotherapy relieve any of my symptoms?
Which hospital will the radiotherapy be given at?
Are there any trials involving radiotherapy that I can take part in?

OTHER WAYS OF MANAGING SYMPTOMS

As well as the surgical interventions, chemotherapy and radiotherapy mentioned above, a range of other things can help manage any symptoms or side effects you may have. These might include:

- pancreatic enzyme supplements and nutritional supplements to help with digesting food and weight loss (see page 32 for more information on dietary-related issues)
- anti-sickness medication or complementary therapies to help with nausea
- morphine-based painkillers or a nerve block to relieve pain
- complementary therapies such as aromatherapy, reflexology, Reiki and relaxation therapy. These are sometimes available at NHS day centres and can help relieve specific symptoms and improve your general wellbeing.

If you are in hospital your care needs should be assessed before you leave. This may include a referral to the community based palliative care team, who are experts in managing pain and other cancer symptoms. Your GP should be sent a letter explaining your condition and you should be given a named person at the hospital to contact if you have any concerns or need additional support. You
may also want to be put in touch with a Macmillan nurse who will visit you at home, assess what support you need and help you to get it. If you are at home you can ask your GP to help you access these services.

**QUESTIONS**

What can I do to help me feel better during and after treatment?
How will I manage my symptoms day to day?
Who should I talk to if I get any new symptoms?
How can I make sure I get support once I’m out of hospital?
How do I get in touch with the palliative care team?
Can you put me in touch with a Macmillan nurse?
Clinical trials are medical research studies that involve patients. Most trials in pancreatic cancer are looking at different treatment options with the aim of finding more effective treatments to improve survival and quality of life.

Your doctor may already have asked if you are interested in joining a clinical trial. It is always a good idea to ask if there are any suitable trials for you so that you know all the treatment options that may be available.

Pancreatic Cancer UK maintains an up-to-date list of ongoing trials: you can read more about them online at [www.pancreaticcancer.org.uk/clinical-trials](http://www.pancreaticcancer.org.uk/clinical-trials)

Before you decide whether or not to take part in a trial you need to know exactly what is involved. Talk to your specialist and ask as many questions as you need to make your mind up. If you decide to take part you will have to sign a form saying you understand what is involved and agree to take part (this is called informed consent). You can withdraw from the trial at any time if you change your mind without it affecting your care.

**QUESTIONS**

*Are there any clinical trials I could join?*
*How do I find out about different trials?*
*What are the benefits and risks of joining a trial?*

For more questions to ask about clinical trials see the CancerHelp UK website: [www.cancerhelp.org.uk/trials](http://www.cancerhelp.org.uk/trials)
HOW DOES PANCREATIC CANCER AFFECT DIET AND NUTRITION?

Because pancreatic cancer affects the functioning of the pancreas it often has an impact on digestion and the body’s ability to absorb nutrients from food. This means people diagnosed with pancreatic cancer often have dietary-related symptoms. These can include losing weight, nausea and vomiting, diarrhoea and steatorrhoea (fatty stools which are large, pale, oily, floating and smelly). Another common symptom is jaundice, which can also cause loss of appetite, taste changes, vomiting and steatorrhoea. Some people may also have developed diabetes because of the cancer’s effect on the insulin producing cells in the pancreas. Symptoms of diabetes include weight loss, increased thirst and urination, and lethargy.

If you have surgery to remove all or part of the pancreas the body’s ability to digest and absorb nutrients from food will be affected. This can lead to dietary-related symptoms such as steatorrhoea and being unable to maintain weight. You may also develop diabetes as a result of surgery (definitely if the whole pancreas is removed), and you should seek advice on managing it from a diabetes nurse.

The dietitian is a key member of your care team at the hospital. You can seek expert advice and support from them and have your dietary needs assessed. They can help you to manage any dietary symptoms related to your pancreatic cancer or your treatment. They can give advice on nutrition and tips on increasing your calorie intake and may suggest you use pancreatic enzyme supplements and nutritional supplements.

If you are experiencing weight loss, steatorrhoea, diarrhoea, abdominal discomfort, bloating or flatulence it can be a sign that you aren’t digesting food and absorbing nutrients properly. Pancreatic
enzyme supplements help to break down food and can often control these symptoms. Your specialist can prescribe these supplements which you take immediately before you eat a snack or a meal. For larger meals you can take half the capsules before you start eating and half during the meal.

Dietary-related problems can have emotional impacts as well as physical ones. For example, you may feel pressure to eat more than you feel you can manage or be worried about weight loss and upset about how it has affected your appearance. You will probably feel much better overall if your dietary-related symptoms are properly managed so if you haven’t seen a dietitian yet you should ask to be referred to one, or talk to your specialist nurse. Whoever you talk to, try not to be embarrassed about discussing topics like diarrhoea or flatulence (wind) – the more information you can give your healthcare team, the more they can help.

You can read more detailed information about issues related to diet on our website – www.pancreaticcancer.org.uk/diet

QUESTIONS

Is there a dietitian in my MDT?
Can I be referred to a dietitian?
How soon can I see a dietitian?
Would pancreatic enzyme supplements help relieve my dietary-related symptoms?
Should I be taking nutritional supplements?
Who should I ask about help with managing diabetes?
HOW MIGHT PANCREATIC CANCER AFFECT MY OVERALL WELLBEING?

As time passes from your initial diagnosis you will find yourself dealing with the wider physical and emotional impacts of pancreatic cancer and its treatment. Everyone finds their own ways of coping, but whatever you do it’s important to take care of yourself.

Many people find that sorting out dietary-related symptoms makes the biggest difference to how they feel (see page 32).

- For example, if you can eat and maintain your weight you will feel better and cope better with any treatment.
- Feeling sick (nauseous) is another common symptom but you can be prescribed anti-sickness medication or try remedies such as ginger, peppermint or acupressure bracelets.

You will feel other physical effects from the cancer and its treatment and, as with dietary-related symptoms, managing these can play a big part in how well you feel.

- You are bound to feel tired, exhausted sometimes, so be kind to yourself. Make sure you rest, prioritise what you want or need to do, accept offers of help and ask for help if you need to.
- Simple relaxation techniques can help you cope with stress, pain and anxiety. Having a warm bath, deep breathing or listening to soothing music are easy things to do at home.
- You might want to try complementary therapies like reflexology or aromatherapy massage – ask your GP or specialist nurse about services available in your area.
- Physical activity can also make you feel better, though how much activity or exercise you do will depend on how well you feel and whether you are having treatment or recovering from...
Over time you will probably go through a range of emotions, from feeling positive and determined to beat the cancer to feeling low or despairing about the future. There are different strategies to help you cope and you don’t need to do it alone.

- If you feel the cancer is taking over your life, one way to cope is to focus on other things and make plans. For example, this might mean living life as normally as possible or changing your priorities.

- Feeling anxious or stressed is perfectly normal and one of the best ways to help is by talking – to family, friends or a trained counsellor. If the feelings become overwhelming you may be depressed, so talk to your GP about managing this with anti-depressant drugs or counselling.

- You can find support (and give it) from others going through similar experiences. Pancreatic Cancer UK runs online discussion forums and live chat sessions (see page 40), or you might want to join a local cancer support group.

- Your partner, family and friends will be experiencing different emotions too. Communication is essential for everyone's emotional wellbeing, so try to make time for talking and listening as your close relationships are important.

Practical issues won’t have been the first things you thought about when you were diagnosed, but dealing with things like your work or financial situation is important so they don’t become a source of stress.

- Your diagnosis will affect your ability to work, even if it’s only temporarily such as while you are having treatment. Talk to
your employer, HR department or union rep about sick leave, reducing your hours or working from home. Being unable to work can lead to financial problems, so get advice about benefits and other financial help.

- Having cancer can have an unexpected financial impact, for example if you can’t work or you have to pay for travel to and from treatment sessions. Again, get advice about any financial help or benefits you may be entitled to.

- There’s a lot of information about work-related issues, benefits and financial help on Macmillan Cancer Support’s website – [www.macmillan.org.uk](http://www.macmillan.org.uk)

You can read more about looking after yourself on our website as well as advice from others affected by pancreatic cancer – [www.pancreaticcancer.org.uk/takingcare](http://www.pancreaticcancer.org.uk/takingcare)
GLOSSARY

**Adjuvant treatment:** additional treatment, such as chemotherapy or radiotherapy given after surgery.

**Advanced cancer:** when cancer cells spread from where they first grew to other parts of the body. Also known as metastasis or secondary cancer.

**Ampulla of Vater:** the area where the pancreatic duct and common bile duct meet. Also known as the hepatopancreatic ampulla.

**Bile:** fluid which aids digestion that is produced by the liver and stored in the gall bladder.

**Biopsy:** when tissue is removed to be examined under a microscope.

**Chemo-radiation:** radiotherapy combined with a short course of chemotherapy. The chemotherapy makes the cancer cells more susceptible to radiotherapy.

**Chemotherapy:** treatment that uses toxic drugs to destroy cancer cells.

**Common bile duct:** tube that carries bile from the liver to the duodenum.

**Dietitian:** a specialist in promoting health through food and nutrition.

**Duodenum:** the first part of the small intestine where most digestion takes place.

**Gastroenterologist:** a specialist in diseases and disorders of the digestive system, including the stomach, intestines, liver and pancreas.
Hepatobiliary: having to do with closely related organs including the liver, gall bladder, pancreas and bile ducts.

Jaundice: yellowing of the skin/whites of the eyes and itchiness often caused by the bile duct being blocked.

Locally advanced cancer: when cancer cells have spread from where they first grew in the pancreas to structures around it such as blood vessels.

Lymph nodes: tiny oval structures throughout the body that contain lymph fluid. Part of the immune system.

Metastatic cancer: see ‘Advanced cancer’.

Nutritional supplements: specially formulated drinks, powders and foods to increase calorie intake and help weight gain.


Palliative treatment: treatment that controls symptoms and slows down the progress of the illness when a cure is no longer possible.

Pancreatic duct: the small tube that carries pancreatic juice containing digestive enzymes from the pancreas to the duodenum.

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

Pathology: examination of tissue and cells under a microscope. A pathologist is a doctor specialising in pathology.
Radiologist: a doctor specialising in using x-rays to diagnose and treat disease.

Radiotherapy: treatment using high-energy x-rays to destroy cancer cells.

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

Steatorrhoea: undigested fat in stools (poo). Stools are large, pale, oily, floating and foul smelling.

Supportive care: improving comfort and quality of life by preventing, controlling or relieving disease complications and side effects. Includes psychological, social and spiritual needs.

Upper gastrointestinal: the upper part of the digestive system, including the oesophagus (the tube between the throat and stomach), stomach, liver, pancreas, gall bladder and bile ducts. Often shortened to upper GI.
WHAT SUPPORT IS THERE FOR ME AND MY FAMILY?

PANCREATIC CANCER UK

Pancreatic Cancer UK is the only national charity fighting pancreatic cancer on all fronts: support, information, campaigning and research. We are striving for a long and good life for everyone diagnosed with pancreatic cancer.

DEDICATED PANCREATIC CANCER SUPPORT AND INFORMATION SERVICE

• We run a confidential Information and Support Line for anyone affected by pancreatic cancer. Our Specialist Nurses can provide individual specialist information about pancreatic cancer, treatment options and managing symptoms and side effects. We can also listen to your concerns and provide support.

Call us free on 0808 801 0707

Email support@pancreaticcancer.org.uk

The service is available Monday - Friday 10am-4pm

• We run online discussion forums and live chats for pancreatic cancer patients, their carers and families to enable them to share experiences, information, inspiration and hope.

http://forum.pancreaticcancer.org.uk

• We provide easy access to the best and most up-to-date information on pancreatic cancer –

www.pancreaticcancer.org.uk
OTHER SOURCES OF INFORMATION AND SUPPORT

CancerHelp UK
www.cancerresearchuk.org/cancer-help
Information for patients from Cancer Research UK. Cancer nurses answer questions 0808 800 4040 (Mon-Fri 9am-5pm).

Carers UK
www.carersuk.org, Advice Line 0808 808 7777
Support, information and advice for carers.

Citizens Advice
www.citizensadvice.org.uk
Practical, reliable information: online (www.adviceguide.org.uk), from local Citizens Advice Bureaux, or call 08444 77 20 20 in Wales, 08444 111 444 in England.

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

Macmillan Cancer Support
www.macmillan.org.uk
Freephone Cancerline 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.

NET Patient Foundation
www.netpatientfoundation.org
Call free on 0800 434 6476
Information and support for people with neuroendocrine tumours (NETs).
This booklet 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/newlydiagnosed

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 and Information at the address on the back of this booklet.