



Cancer of the pancreas

Patient information booklet

Delivering the best in care

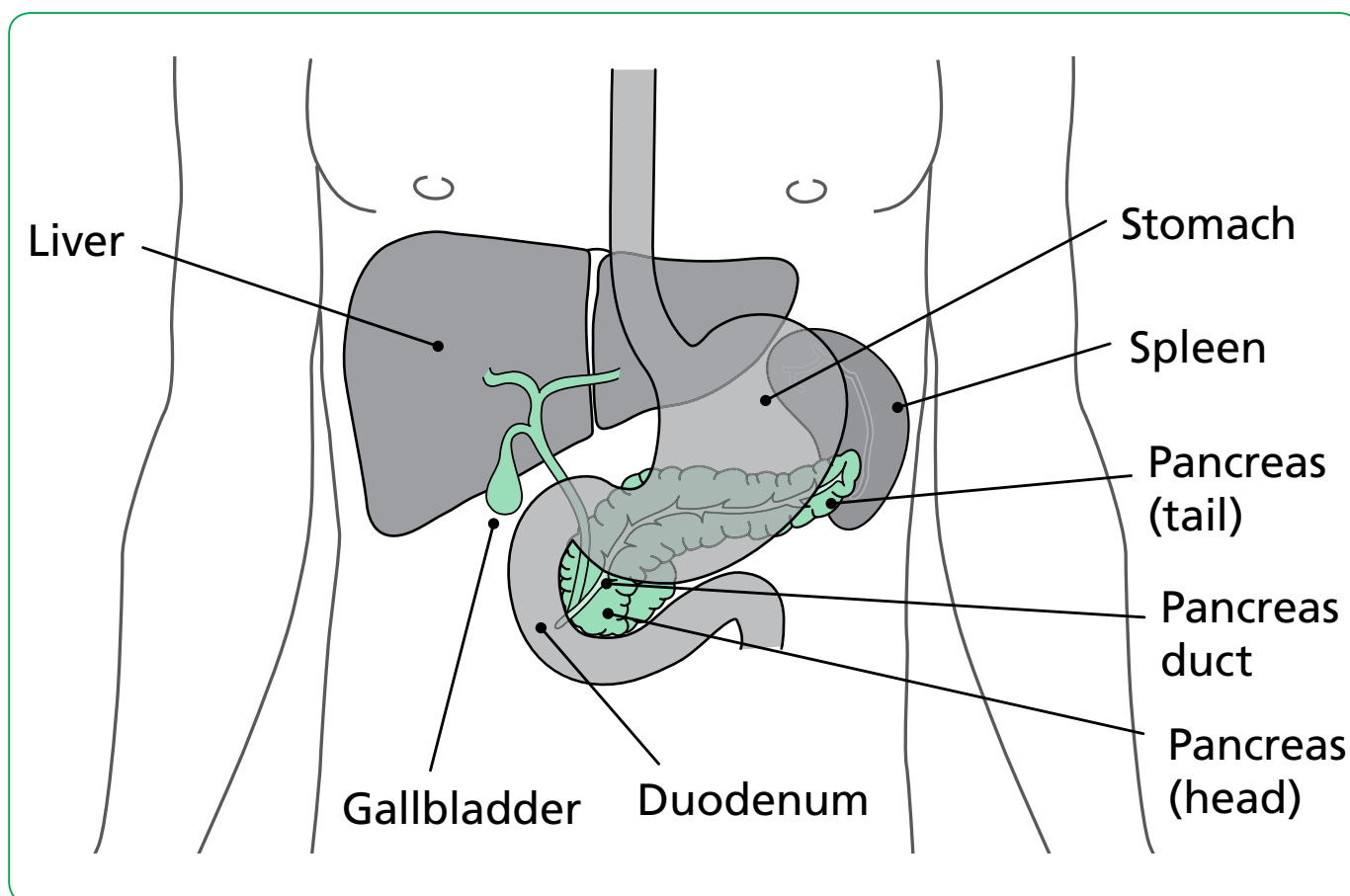
Introduction

This booklet contains information about cancer of the pancreas. There is also information about the treatment options available to you.

Please remember this booklet is not a substitute for asking questions of your doctor and specialist healthcare team. You are always welcome to ask questions and we would encourage you to do so.

The pancreas

The pancreas is a gland and part of the digestive system. It has two important jobs in the body. The first is to produce pancreatic juices that aid digestion. The second is to produce insulin and other hormones also connected with digestion.



Your pancreas is quite high up in your abdomen, just behind your stomach. It is about six inches long. The wide end of the pancreas is called the head. The thin end is called the tail. The part in the middle is called the body.

Risks and causes

We do not really know what causes cancer of the pancreas. At the moment, about 7,600 people in the UK get pancreatic cancer each year. About half of people diagnosed with pancreatic cancer are over 70 years old. Pancreatic cancer in people under 40 years old is quite uncommon. Please be reassured that this cancer is not your fault or the result of anything you have done.

Symptoms

The symptoms of pancreatic cancer can be quite vague. Symptoms can include;

- Jaundice – yellowing of the eyes and skin.
- Pale stools and dark urine
- Weight loss
- Loss of appetite
- General discomfort or pain around the stomach area
- Back pain

What should I eat?

During any illness it is essential to keep as strong and nutritionally well as possible. It is not unusual for your appetite and eating habits to be affected by pancreatic cancer. It is likely that your overall food intake will be less than normal but there are ways of working around this. For example it may be easier to take several small meals throughout the day. This food does not have to be 'proper' dinners but can be snack food instead. You could try;

- Toast, teacakes, scones, muffins with butter, jam or peanut butter
- Soups, either 'cream of' or with extra milk added to boost calories
- Cheese, beans tinned fish on toast or a jacket potato, or cheese and crackers

- Ice cream or a small dessert, full fat yoghurt or fromage frais
- Cereal with whole milk, milky drinks with biscuits, cake or flapjack

The suggestions above include high fat and sugar foods as these are much higher in calories to make up for what you are not eating at the moment.

Your dietician can give you further help with this.

Often people with pancreatic cancer have difficulty digesting fats. As mentioned earlier, the pancreas produces digestive juice called enzymes to break down foods, particularly fats. If you are not able to do this then you can develop digestive symptoms including indigestion and wind often described as a 'gurgly stomach'. Your bowel motions can also change they can be pale greasy and float in the toilet making them difficult to flush away, this is caused by undigested fats in the stools. It is important to control this if possible, as this can cause weight loss.

As your appetite may be poor, we do not want to restrict your food in any way, and so we ask you to take pancreatic enzymes in the form of a capsule. There are different makes of capsule Creon, Nutrizym and Pancrex, but they all work in the same way.

The capsules should be taken just before you eat, with cold water and the amount you need depends upon the amount and type of food you are going to eat.

Higher fat foods such as chips, sausages, pies, pastries, cakes and any fried food will need more enzymes to help digest them. The best way to judge how effective the capsules are is to monitor your bowel habits. If you still have signs of not digesting your fats, i.e. floating stools, then you need to increase the amount of pancreatic enzymes you are taking with your food.

It is important to find the right balance of pancreatic enzymes that work for you to ensure you are digesting your food. Your dietician, doctor or specialist nurse can give you further help.

Pancreatic enzymes also work better if taken while you are on an antacid medication called a PPI. Lansoprazole and Omeprazole are examples of these. Please ask your doctor to prescribe if you are not already taking these.

The stages of pancreatic cancer

The stage of a cancer tells the doctor how far it has spread. It is important because treatment is often decided according to the stage of a cancer. There are different ways of staging cancers. The two main ways are the TNM system and number systems. This booklet will discuss the number system, however if you want information on the TNM system please ask your specialist.

Number stages of cancer of the pancreas: There are four stages in this system – stage one to four.

Stage one: This is the earliest stage of cancer. The cancer can only be found inside the pancreas itself.

Stage two: The cancer has started to grow into the nearby tissues around the pancreas or the duodenum or bile ducts, but there is no cancer inside the nearby lymph nodes.

Stage three: The cancer itself can be any size and may have grown into the tissues surrounding the pancreas. Cancer is also found in the nearby lymph nodes, so it may have spread into other body organs through the lymph system.

Stage four: This is divided into 4A and 4B. 4A means the cancer has grown into the nearby organs such as the stomach, spleen, large bowel or nearby large blood vessels. There may or may not be cancer in the lymph nodes. 4B means the cancer has spread to other body organs such as the liver or lungs. Your doctor may call this advanced cancer.

Which treatment?

The type of treatment you will be offered for cancer of the pancreas depends on:

- The stage of the cancer
- The type of pancreatic cancer you have
- Your general health
- Your age and level of fitness

The stage of your cancer: Cancer of the pancreas is very difficult

to treat and may not be diagnosed until it has become quite advanced. The earlier cancer is diagnosed, the easier it can be to treat.

The type of cancer: Some types of pancreatic cancer are less likely to come back after surgery. They are not as fast growing and are not as likely to spread as other types. Cystic tumours and some endocrine pancreatic cancers are more likely to be curable with surgery.

Surgery: When you are diagnosed with pancreatic cancer, your specialist here at the Queen Elizabeth Hospital Birmingham will determine if surgery is possible. Surgery can also sometimes be used to relieve symptoms. Unfortunately for most people, pancreatic cancer is diagnosed too late for an operation to remove it to be effective.

Even if it is possible to try to remove the cancer, there is no guarantee that the cancer won't come back. Pancreatic cancer may spread to the liver before it is diagnosed. If this is the case, it is unlikely to be curable.

Surgery to remove the tumour: Surgery to remove cancer of the pancreas involves a long and complicated technique called a Whipples operation, therefore if it is possible to try to remove your cancer, you must also be fit enough to undergo the operation. If surgery is possible, you will be given another booklet which explains this in more detail. The name of this booklet is 'Surgery for pancreatic cancer' if you have not been given this, please do not hesitate to ask a member of staff for a copy.

Procedures to relieve symptoms: Other procedures aim to relieve symptoms of pancreatic cancer. Many people are troubled with jaundice. Jaundice is caused by cancer blocking the flow of bile through the bile ducts. Bile cannot follow its normal course and so it is excreted through the skin, causing you to go yellow. Your doctor can put a tube (stent) into the blocked bile duct to keep it open. A bile duct stent is the only way in which your jaundice can be relieved. This is not an operation as such. It is often done either during an endoscopy (ERCP) or the tube can

be placed through the skin using local anaesthetic (PTC). This last procedure is performed by specialist X-ray doctors and is likely to be done here at the Queen Elizabeth Hospital Birmingham. An endoscopy can be performed at your local hospital.

With either method of placing a stent there is a small risk of bleeding and infection. The risks for you will be discussed in detail by the doctor performing your procedure.

There is a possibility that the biliary stent can become blocked and/ or infected, it is important that you know the signs of this happening which are explained below.

An infected stent will cause you to develop a fever or high temperature. You may also shiver and shake, a feeling similar to bad flu. You may also develop symptoms of jaundice, such as dark urine and/ or pale stools. In both cases you need to contact your GP the same day so he/she can make the arrangements needed to help you. If this is problematic, please contact the ward 0121 371 7303. You will also have the contact details of your specialist nurse.

Chemotherapy

Chemotherapy is not recommended as the first type of treatment for the 15-20 people out of every 100 (15-20%) diagnosed with pancreatic cancer who can have surgery to try to cure their cancer. However, in May 2001 NICE (the National Institute for Clinical Excellence) recommended that chemotherapy should be considered for patients who cannot have their cancer removed by surgery. NICE recommend that a drug called Gemcitabine should be considered. In order to have chemotherapy you have to be strong enough to cope with the treatment. NICE do not recommend chemotherapy for anyone who is ill enough to need considerable help with day-to-day living and frequent medical care.

Side effects of chemotherapy

Generally Gemcitabine has few side effects. The usual side effects reported by patients are:

- Fatigue – needing to rest for a part of the day
- A feeling similar to flu for a day after chemotherapy is given (this is not to be confused with an infection or lowered blood count)
- Very occasionally nausea, medication will be given to you to counteract any feelings of sickness

Another other side effect is lowering your resistance to infection, this is called your 'blood count' or 'white cells'. Your blood count includes measuring other things than your resistance to infection such as platelets and how well your blood clots, haemoglobin or how much iron there is in your blood.

You will know if you have a lowered blood count if you become shivery or shaky like bad flu. It is very important you contact the hospital if this happens. You will be given a list of contact numbers when you start chemotherapy.

Do not worry about this now; you will be given very specific details about what to do when you start chemotherapy. We also monitor your blood counts very closely to stop this happening.

Although chemotherapy can have side effects there are usually ways in which we can reduce or avoid them with medication.

It maybe more convenient for you to have your treatment nearer to your home, in which case we will liaise with your local hospital for you to receive your treatment there.

Sometimes treatment is best given here. We can make that decision together.

Sadly, chemotherapy will not cure you of your pancreatic cancer, but it may control your cancer or even reduce its size. This can help to control any symptoms you may have and may also extend your life.

More information will be given to you about chemotherapy if

this is the treatment option that is best for you.

If you are offered chemotherapy, you may be asked to take part in a clinical trial so doctors can continue to learn more about treating this disease.

This may involve treatment with new drugs or new ways of using drugs.

You do not have to participate in clinical trials and your care will not be affected if you do not. The doctor involved in the research will give you specific information about any clinical trials.

Supportive care

Sometimes there are no treatment options available to you.

This may be because your cancer has progressed and treatment will not benefit you.

Sometimes people choose as an alternative not to have any treatment. We would support any decision you make regarding treatment.

Although treatment may not be an option this does not mean there is nothing that can be done to help and support you and your family.

The following are suggestions about how we can support you and your family. We would recommend that you be referred to a community cancer nurse usually called a Macmillan nurse. Your doctor or specialist nurse can arrange a referral for you. A specialist community nurse is essential to ensure you and your family has access to help and support at home.

Diet supplements

If you are finding it hard to eat, there are plenty of diet supplements available on prescription. Some are powders you sprinkle on your food and some are drinks that are complete meals in themselves. Sipping a supplement between meals throughout the day can really boost your calorie intake. Ask your doctor or dietician for help.

Coping financially

Your Macmillan nurse or GP may be able to help you get grants for aids, heating costs, holidays and other household expenses related to your illness. They can also help you to claim benefits for yourself or for the person caring for you. It may be helpful to see a social worker. We have a social worker available for patients.

Coping with symptoms

As your illness progresses you may develop different symptoms. It is not certain that you will have all or any of them, but the following information may help you to realise that there is usually something that can be done to help you cope.

Pain

Pain may develop in the abdomen and sometimes in the back. There are many painkillers or analgesics you can take to control pain. You will probably be started on some simple painkillers such as paracetamol or co-codamol, some people do not need anything stronger. However if these are not effective then we can introduce a morphine based painkiller, such as morphine sulphate in tablet form. Do not worry about becoming addicted to morphine. Morphine taken to relieve pain works in a different way than if it was taken for 'recreation'.

Morphine sulphate or MST is given in two doses daily 12 hours apart. This is usually in the morning and at night before bed. The idea is that the morphine is released slowly into the blood stream and so provides a background of constant pain relief. You will usually be given liquid morphine or fast acting tablets, in a bottle to take to 'top up' your pain relief if you experience a break through in pain control. It is important to make a note of how much liquid morphine you are taking, as this may be an indication to increase your morphine tablets.

Morphine like drugs can also be given as a patch, similar to nicotine patches. This way of delivering painkillers may be used

for patients who are not able to tolerate taking tablets.

Another important factor to remember when taking most painkillers is that they can make you constipated. Constipation is not about how often you go to the toilet but how easily the stool is passed. If you find that you are becoming constipated then you should ensure that you are drinking plenty of water and that you have some laxatives at home ready to help you. Try to avoid becoming constipated as this can increase the amount of painkillers you need and so increases the constipation, this becomes a cycle that you need to break in order to become comfortable again. It is very likely you will be prescribed laxatives when you have your painkillers.

You may also find that painkillers or even your illness on its own may cause you to feel sick. If this is the case then we can give you very good anti sickness medication to stop this feeling.

Very rarely we are unable to control your pain through the usual methods and so we can refer you to experts such as anaesthetist and other specialist nurses who will be able to offer special treatment.

Finding information

If you know what to expect, you may find yourself less anxious and worried. Talk to your doctor or nurse about your illness and treatment. It is important to know all your options.

If you would like to talk to someone outside your own friends and family, there are organisations that can provide information about cancer and treatment as well as cancer support groups, where you can talk to other people who have cancer and may have had similar experiences.

The Patrick Room is an Information Centre within the Cancer Centre at the Queen Elizabeth Hospital, where you can find information and support. Telephone: 0121 371 3539.

Difficult questions

A diagnosis of cancer may mean you will have all sorts of questions going around in your head that are not only difficult to answer, they are difficult to ask. We have tried to answer some of those questions here, but there will be other questions you can think of. Write your questions down and talk to your doctor or nurse, or contact one of the specialist nurses on 0121 371 4652.

It is very common in any family for some people to want to ask difficult questions and some not. Try to respect this and give each other the space to ask as much as you want to. This may mean giving your doctor permission to talk to your next of kin alone, or, if you are a relative, giving the patient time to talk to the doctors by themselves.

Please remember that you will undoubtedly have good and bad days and that during the bad days you are not alone but have a team of people, both in the hospital and community who are there to help you and your family.