

Diet and Nutrition for Pancreatic Cancer Patients



Dealing with malabsorption, advice for eating after surgery and while undergoing chemotherapy.



Understanding pancreatic cancer booklet 5

This booklet will cover pancreatic cancer and diet, and explain the treatments that are available to help this. It also covers helpful tips on lifestyle, coping with side effects and thoughts about life post treatment.

Understanding Pancreatic Cancer – Patient Information Booklets

Receiving a diagnosis of pancreatic cancer can be an upsetting, stressful and confusing time. We have listened to patients, relatives and carers to understand what information is useful. Our patient information booklets are easy to understand and beneficial to have at hand to answer any questions or concerns you may have.

All of these publications are produced under the Information Standard certified scheme and are reviewed by medical professionals and patients/carers who have been affected by pancreatic cancer.

To order further patient information, please visit: panact.org/patient-booklets



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What is the pancreas?

The **pancreas** is an organ about 6 inches long and shaped like a thin pear lying on its side. The wider end of the pancreas is called the head, the middle section is called the body, and the narrow end is called the tail. The pancreas is found deep inside your body, behind the stomach and in front of the spine.



The pancreas has two main jobs in the body, it makes:

Enzymes

These help to digest (break down) foods.

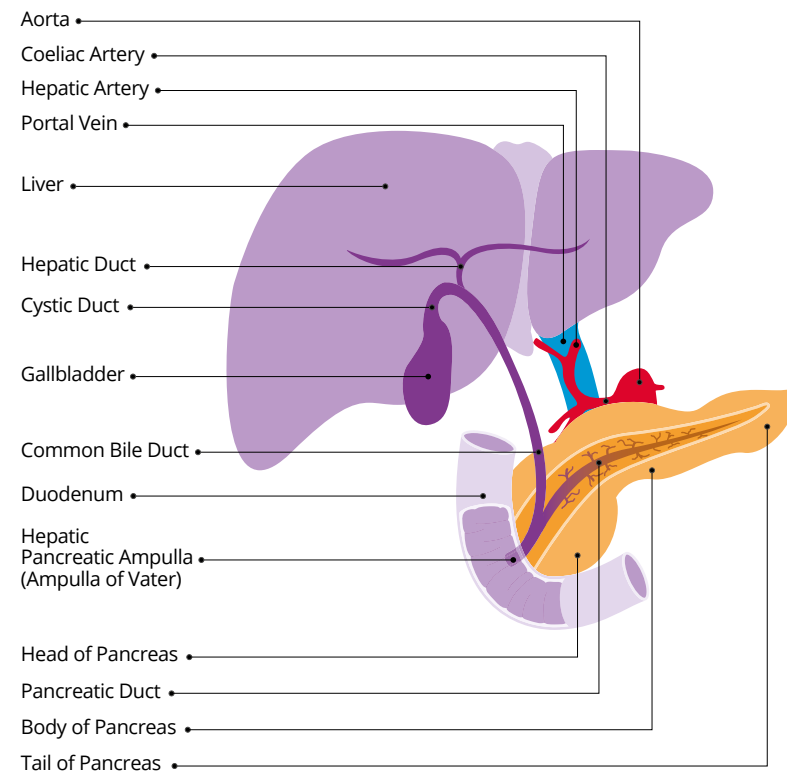
Hormones

Such as **insulin** and **glucagon**, which control blood sugar levels.

The pancreas helps the body use and store the energy it gets from food.

A tube called the pancreatic duct connects the pancreas to the first part of the small intestine, known as the **duodenum**. Digestive **enzymes** pass through this tube to help break down food. Another tube, called the common **bile duct**, passes through the head of the pancreas. This tube carries **bile** (a substance that helps to digest fats) from the liver and **gall bladder** to the small intestine. The bile duct may get blocked when a pancreatic **tumour** invades it. This causes **jaundice** (yellowing of the eyes and skin and dark urine).

The location of the pancreas



The pancreas contains two types of glands:

Exocrine glands

Create the enzymes which help digest (break down) foods.

Endocrine glands

Create the hormones such as insulin and glucagon, which control blood sugars.

What is pancreatic cancer?

Pancreatic cancer occurs when a **malignant** tumour forms in the pancreas.

Worldwide there are around 496,000 new cases each year; in Europe that figure is more than 104,000. In the UK, approximately 10,500 people are newly diagnosed each year.

Pancreatic cancer affects men and women equally with incidence increasing from the age of 45. The average age at **diagnosis** is 72.

There are two main types of pancreatic cancer:

Exocrine tumours

These make up the vast majority of all pancreatic cancers (around 95%) and come from the **cells** that line the ducts in the pancreas which carry digestive juices into the intestine.

These are called pancreatic ductal **adenocarcinomas**.

Other exocrine tumours of the pancreas are rarer, and include **adenosquamous carcinomas** and undifferentiated carcinomas.

Endocrine tumours

These are also known as **neuroendocrine tumours**, (NETS) and are much less common. The neuroendocrine tumours we discuss here are found in the pancreas and are called pancreatic neuroendocrine tumours (pNETS).

These are tumours that develop in our endocrine **glands** that release hormones (which regulate some processes in our bodies), these are then circulated around the body.

Other rare tumours that can affect the pancreas include **pancreatic lymphoma**, a cancer that arises from the lymphatic **tissue** in the pancreas; various **cystic tumours** and **pancreatic sarcomas**, which develop in the tissue that holds **cells** in the pancreas together.

Tumours that arise from tissues close to the pancreas, such as the bile duct (cholangiocarcinoma), **Ampulla of Vater** (ampullary adenocarcinoma), or **duodenum** (duodenal adenocarcinoma), may cause similar symptoms to pancreatic cancer but have different treatments and outcomes.

You will have undergone various tests such as ultrasound scans, CT scans and possibly had an endoscopy to determine that you have pancreatic cancer. These tests are important as they will inform the doctors about the size and position of the tumour and whether it's possible to have it surgically removed (resected).



80% of **pancreatic cancers** occur in the **head of the pancreas**, less commonly in the body (15%) and tail (5%)

Pancreatic cancer and your diet

Nutrition can be a major focus for people who have been diagnosed with pancreatic cancer. The disease itself, along with treatments such as surgery, **radiotherapy** and **chemotherapy**, can change your body's ability to digest and absorb nutrients from food. This booklet contains information on managing dietary symptoms such as poor appetite, weight loss and diarrhoea. The advice in this booklet aims to be general, but depending on the stage of your disease advice may vary. If you have any concerns, it's best to discuss these with your GP or specialist nurse.

How pancreatic cancer affects your diet

The main functions of the pancreas are to provide digestive **enzymes** to help break down food and hormones such as insulin and glucagon to control blood sugars. Cancer of the pancreas can interfere with this, which can lead to digestive problems and prevent you from absorbing all the nutrients from your food.

Treatment options such as surgery, to remove all or part of the pancreas and/or radio and chemotherapy, can also cause dietary problems leading to poor appetite, nausea and vomiting, diarrhoea and changes in taste and smell.

How to maintain weight

It is important to still enjoy food and to try and keep your weight stable, this may help you with treatments but also with how you are feeling.

If you are not losing weight, then stick to your normal diet. This will help to keep you strong and able to cope with treatments such as chemotherapy. If you are struggling to keep weight on, speak to your **dietitian**. Each individual has different requirements, and they will be able to give you advice on what will be helpful for you. It can seem confusing if you are being told the opposite to usual dietary recommendations but this advice is based on what your body needs.

If you are able to exercise normally then you should do so. Exercise, even if very gentle such as a small walk, or even just trying to move your body around when sitting, may boost your appetite, can help to prevent muscle loss and improve your mood.

See page 29 for more information and tips on diet and lifestyle, this expands on what you can do to be as healthy as possible and why that's important.

We have a recipe book designed for pancreatic cancer patients, which provides meal ideas that are easy to digest, are high in nutrition and will help you to keep weight on. To order a free copy go to our website:

panact.org or call us on **0303 040 1770**.

What dietary problems can pancreatic cancer or treatments cause?

- **Poor digestion of fats, carbohydrates and proteins** - This is caused by a lack of digestive enzymes which help to break down food and absorb nutrients from it. This is known as **malabsorption**. This is discussed on **page 11**, as well as the specific symptoms that can be caused by malabsorption
- **Flatulence (passing wind)** - Passing gas from the digestive system out of the back passage
- **Bloating** - When your tummy is stretched and uncomfortable and you feel full up
- **Change in bowel habits** - Pale, floaty stools which can be oily, foul smelling and difficult to flush away (also called **steatorrhoea**)
- **Loss of appetite** - When you do not feel like eating
- **Weight loss** - Weight loss is a common problem and is often caused by malabsorption along with poor appetite
- **Nausea and vomiting** - Feeling and being sick
- **Diarrhoea** - Passing of watery stools (poo) more than three times a day
- **Diabetes** - Occurs because your pancreas may not be making enough insulin, that is a hormone which helps regulate your blood sugar level. **See page 27** for more information on **diabetes**
- **Jaundice** - This is related to the tumour blocking the bile duct which leads to a build up of bile in the liver. It can cause your skin and the whites of your eyes to turn a yellow colour, make your urine a dark straw colour and your skin feel very itchy.
- **Malabsorption** - If the bile duct is blocked or the pancreas is damaged by the tumour it can also cause poor absorption of the nutrients from food, pale stools, loss of appetite, nausea and vomiting.

See a dietitian

While this booklet contains general advice on managing dietary issues, you will probably find it useful to talk to a **dietitian** about your specific needs.

What is a dietitian?

A dietitian is an expert in nutrition and dietitians are the only qualified health professionals that assess, diagnose and treat diet and nutrition problems. Registered dietitians are regulated by the HCPC – Health Care Professionals Council.

They will be able to give you advice on how to cope with nutrition problems or eating difficulties. This advice may include the use of pancreatic enzymes and nutritional supplements.

Where can I see a dietitian?

Dietitians are a key member of the Multi-Disciplinary Team (MDT) in hospitals that treat patients with pancreatic cancer. If you are not currently seeing a dietitian and think you may benefit from seeing one, ask your medical team or your GP to refer you.

Dietitian or nutritionist?

Dietitians and nutritionists may seem like similar roles, but it is important that you seek information and advice from a dietitian. These are the only health care professionals who are able to give dietary advice to people suffering from an acute illness such as pancreatic cancer. Dietitians can recommend or sometimes prescribe supplements and other medications to manage your condition. A nutritionist generally works in non-clinical settings, outside of hospitals or GP practices to advise people who are medically well about what makes a healthy diet. While they may be able to offer you some good advice, they are not in the same position as a dietitian, who is able to offer ways of maintaining or gaining weight specific to your pancreatic cancer.

Following the advice of a dietitian is the best way to make sure that you feed your body correctly when you have pancreatic cancer. You may read or hear about diets that can treat or cause cancer, but these have not been researched fully, and do not have sufficient scientific evidence to prove their effect, making them unreliable. Therefore they are not recommended by dietitians.

What causes malabsorption?

A blockage in the pancreatic duct caused by a tumour or removal of part of the pancreas during surgery, can cause a change in the flow and amount of pancreatic juice. Pancreatic juice contains enzymes that help the body to digest and absorb nutrients such as fat, carbohydrate and protein.



Without digestive enzymes, food passes through the digestive system without being broken down and absorbed. This is known as malabsorption.

Different enzymes have the job of breaking down different types of food:

- Proteins are broken down by **proteases**
- Starchy carbohydrates are broken down by **amylase**
- Fats are broken down by **lipase**.

What are the signs of malabsorption?

Some of the signs of malabsorption can include :

- Good appetite and food intake but with continuing weight loss
- Pale stools are a sign that there is fat in them. They also may be very smelly and difficult to flush away. Bowel movements may also be more frequent and looser than normal
- Bloating and abdominal pain after eating can be a result of starchy carbohydrates (bread, cereal, pasta and potatoes) not being absorbed
- Weaker muscles and loss of weight
- A lot of flatulence (passing wind)
- Lower than usual blood sugars in people with diabetes.

What can help control the symptoms of malabsorption?

If your dietitian thinks you may be suffering from malabsorption, they will usually prescribe pancreatic enzyme replacements to help you break down food and start to absorb the nutrients again.

Enzyme therapy

Pancreatic Enzyme Replacement Therapy (PERT)

What are pancreatic enzymes?

Pancreatic enzyme replacement therapy involves taking the digestive enzymes you need in the form of a capsule.

All enzyme replacements contain pancreatin – a mixture of the pancreatic enzymes: **lipase**, **amylase** and **protease**. These assist the digestion of fat, carbohydrates and proteins. Enzyme doses vary from person to person. A starting dose is 50,000 to 75,000 units of lipase with a meal and 25,000 units with a snack.

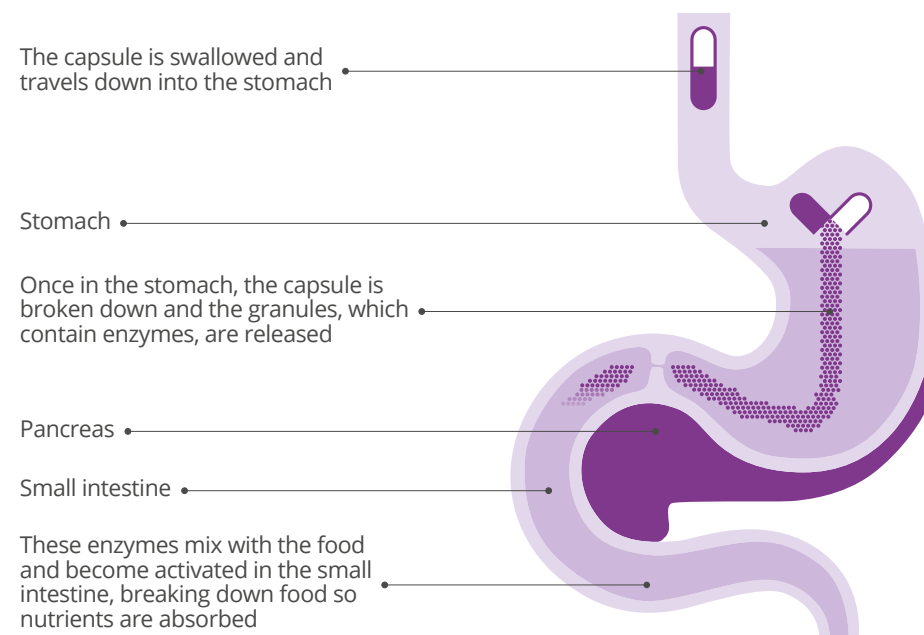
The different pancreatic cancer enzyme preparations include Creon®, Nutrizym®, Pancrease® and Pancrex®. They commonly come in 2 capsule sizes; 10,000 unit (mainly used in children) and 25,000 unit capsules. Each capsule has a different number or letter following the name to indicate the strength of the dose.

Most adults take either 2 or 4 of the 22-25,000 unit capsules per meal. Do not be alarmed by the high capsule units — the number relates to the amount of lipase units it contains. A healthy pancreas will release about 720,000 lipase units during every meal!

Pancreatic enzyme replacements are extracted from pig pancreas **glands** and there is currently no alternative to using pork products. However, it is important to know that for those who may have a religious objection to the ingestion of pork products, special dispensation to allow these products has been granted by religious organisations as they are a medicine.

How enzyme replacement works

The pancreatic enzyme capsule is swallowed and, along with food, travels down to the stomach. Once in the stomach, the capsule is broken down and the granules which contain the enzyme are released. The enzymes mix with food and become activated in the small intestine, breaking down food allowing the nutrients to be absorbed.



How should I take pancreatic enzymes?

You will need to take enough enzymes to allow your body to break down your food. Your dietitian, doctor or nurse specialist will recommend the amount to take. You may be given a low dose at first which will increase gradually until your symptoms are under control.

Capsules should be taken with all food directly – i.e. with the first mouthful of food. This includes meals, snacks and milky drinks including milk based nutritional supplement drinks such as over-the-counter shakes, homemade or prescription drinks. Your doctor and dietitian will advise you. It is important that you spread the capsules out throughout your meal.

If you don't take your enzymes with every meal or snack, the symptoms of malabsorption may return.

Capsules must be swallowed with a cold drink. Swallowing them with a hot drink can make them less effective as enzymes are damaged at high temperatures.

The capsules should be swallowed whole and must not be crushed or chewed.

If you are having a large meal with more than two courses, or one lasting more than half an hour, you will need to take your enzymes with each course.

When NOT to take enzyme replacements:

- On an empty stomach
- With drinks that contain less than half milk – such as tea, non-milky coffee, fruit squashes and fizzy drinks
- If you eat small quantities of fruit, vegetables, dried fruit, fat-free sweets (jelly babies, wine gums, mints)
- If you take a very small quantity of food such as an individual chocolate/square of chocolate or a small plain biscuit.

Do I have to restrict my diet?

No, it is not necessary to restrict your diet, but it is important to follow a balanced diet to help you maintain weight or gain weight. Some people find certain foods, especially fatty foods, may cause bowel motions to be smelly and loose. In this case, it may be necessary to adjust the dose of your pancreatic enzyme.

Foods higher in fat can be beneficial for those who have lost a lot of weight or are below an ideal weight. Your dietitian can give you advice on the diet that is best for you.

Can I vary the dose of the pancreatic enzymes myself?

While your doctor or dietitian will discuss what strength dose is best for you. You will be the best judge of your symptoms, so it may be appropriate for you to alter the dose yourself. For example, if you are experiencing persistent loose bowel motions and are failing to gain weight, you may want to increase your dose.

If you are eating a meal that is high in fat such as a takeaway curry or fish and chips, you will need to take more capsules. Your dietitian will explain how to do this.

If you are at all uncertain about what dose you should be taking, contact your doctor or dietitian.



You need to take enzymes whenever you eat a meal or a snack. Take them throughout your meal so they mix with the food in the stomach.

How long will I have to take pancreatic enzymes for?

If your pancreas has been damaged by cancer or you have had all of it removed through surgery, you will need to take pancreatic enzymes for the rest of your life.

If you have had surgery to remove part of the pancreas, your pancreatic function may improve, but this is unlikely. The majority of people will need to take these enzymes for the rest of their life. After surgery sometimes pancreatic function can decline and the dose may need to be increased.

Can I take too many pancreatic enzymes?

No - any additional enzymes that you take which are not needed to break down the food you eat will be excreted in your stools. Occasionally this may cause a little burning around the anus. Speak to your doctor if this occurs.

What will happen if I forget to take my pancreatic enzymes?

Sometimes it is difficult to remember to take your pancreatic enzymes but if you do not take them, your symptoms will not go away and may even get worse. If you stop taking them for long periods of time, then you will not be absorbing important vitamins that your body needs and you may lose weight. This may affect your ability to undergo some treatments such as chemotherapy. If you are worried that you are likely to forget, try setting an alarm or having a friend or family member to remind you at meal times.

Are there any side effects?

As some people will experience side effects from enzyme replacement, it is important that you read the medicine information leaflet produced by the manufacturers. The most frequent **side effects** are constipation, diarrhoea, nausea, and abdominal discomfort. These usually settle over time or, as the manufacturers use different coatings, it may be worth switching to a different brand of enzyme.

Let your doctor know if you experience severe diarrhoea.

What if I have difficulty swallowing the capsules?

In this case it is possible to open the capsule and mix the granules (do not crush them) into an acidic fruit puree such as apple sauce or with fruit yoghurt. This mixture needs to be swallowed straight away, without chewing.

It could be helpful to have a cold drink after this to help flush down any remaining enzyme granules and eat a snack or meal straight away.

It is also possible to ask for a lower-dose capsule which is smaller and easier to swallow. However, in order to get your required dose, you will need to take more of them.

My religion restricts me from eating pork, so can I still take pancreatic enzymes?

Currently, all enzyme replacement products are produced from pork-derived ingredients and no alternatives are available. However, pancreatic enzymes have been approved for use by Jewish patients by the Chief Rabbi. For Muslim patients, Dr Abdul Hamid Mohamed, London Central Mosque Trust, has advised the following:

"If, and only if, no other medicines than the ones containing prohibited substances are suitable to cure the illness or disease in the opinion of the physician, then the medicine containing the prohibited substance should be prescribed and taken by the patient."

Remember that if you are unsure about self managing pancreatic enzyme replacement therapy (PERT), or have any questions, you should ask your doctor or dietitian.

Things to remember:

- Pancreatic enzymes are damaged at high temperatures
- Store your enzymes at room temperature (they don't need to be refrigerated)
- Do not store enzymes in warm places such as near radiators, or in cars and do not carry enzymes in trouser pockets
- Never mix enzymes with hot drinks
- Carry the number of capsules you need in a pill box or small container so you do not have to carry the whole bottle with you.

Oral nutritional supplements

Many people with pancreatic cancer will find that they have difficulty maintaining or putting on weight. Nutritional supplements may be helpful to maintain weight and to ensure that you are getting enough vitamins and minerals.

Nutritional supplements are used to supplement your diet and where possible should not be used in place of ordinary foods.

There are many different types of products available – some you can buy (non-prescription) and others are only available on prescription. Some have a sweet taste and others savoury and some have no taste at all and can be added to other foods. Nutritional supplements come in three main groups:

- Nutritional drinks - juices, milkshake and high energy shots
- Energy and protein supplements - powders to add to milk, cream and soups
- Nourishing puddings - useful for people struggling to swallow.

If you are in doubt about whether you need a nutritional supplement and which one will be best for you, always consult your dietitian or GP.

Nutritional drinks

Nutritional drinks will come in either savoury, sweet or neutral (non-flavoured) varieties and can be served hot or cold. Other foods such as fruit and ice cream can be added to make them tastier. Non-flavoured drinks can be taken on their own or flavourings such as milkshake syrups can be added.

Nutritional drinks and supplements on prescription

Your medical team and dietitian will advise you if they feel you need nutritional supplements on prescription and how often you should take them. Many supplement products have a high sugar content and people with diabetes should seek advice from their doctor, diabetes nurse or dietitian before commencing on a course of nutritional supplements.



Eating after having a duodenal stent

Your duodenum is the first section of your small intestine. Your small intestine receives partly broken down food from the stomach, which is mixed with bile from the liver and pancreatic juice from the pancreas.

When you have pancreatic cancer, your duodenum may become partly blocked and food cannot pass through as quickly as normal. This can cause nausea, a feeling of fullness and loss of appetite.

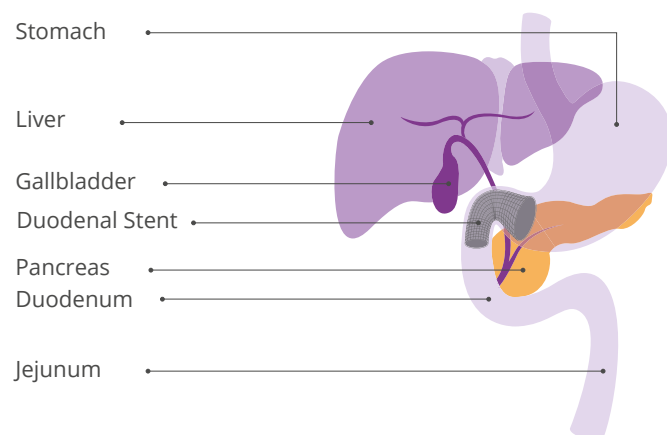
If the duodenum is completely blocked, food will not be able to leave your stomach and this may cause vomiting.

You may be too unwell to eat and yet, still feel sick. This may be because your stomach is always producing digestive juices, regardless of whether or not you have eaten.

When the duodenum is blocked, a tube (known as a duodenal stent) can be placed in that section of the duodenum to allow food to pass through the obstructed part. This allows your stomach to empty properly. If you have the duodenal stent placed it can take a few days for you to start eating well again.

We want you to be aware that having a blocked duodenum due to the tumour in the pancreas can be a cause of dietary symptoms with pancreatic cancer. For those that may be having or have had the duodenal stent placed, we have information on our website and a booklet specifically for eating after a duodenal stent. You can order free of charge from our website or you can call us on **0303 040 1770**.

Diagram showing location of a duodenal stent



For those with operable pancreatic cancer

Diet and surgery for pancreatic cancer

One of the most common surgical procedures to remove pancreatic tumours is known as the Pancreaticoduodenectomy. This involves removing the head of the pancreas, a portion of the bile duct, the **gall bladder**, the duodenum (the first part of the small intestine). Sometimes part of the stomach is removed - this is called a **Whipple operation**.

You will be assessed prior to surgery by your medical team. Other operations can be carried out to remove the tail of your pancreas (distal pancreatectomy) or to bypass the pancreas. If you have been losing weight you may be advised to try to build up your weight and strength before the operation. If you notice your stools become pale, floaty and smell offensive, notify your doctor/dietitian as you may not be absorbing the nutrients from your food and you could need pancreatic enzyme replacement therapy ([see page 12](#)).

Being healthy can make a difference to whether or not you are considered to have surgery, but also can aid your recovery from surgery. Eating healthy food, not smoking and drinking less alcohol can really help.

If you are losing weight then see below for tips to try and keep weight on.

Suggestions to help you gain or maintain weight are:

- Eat little and often, aiming for a small meal or snack every 2-3 hours
- Have your biggest meal when you are most hungry
- Eat more protein-rich foods (meat, fish, eggs, cheese, beans, lentils and pulses)
- Add extras to your basic meals such as milk powder to milky drinks and custards, cereals, sauces and mashed potato; add cheese to sauces, soup, vegetables and baked beans and add honey or golden syrup to cereal, fruits and drinks. Prescription supplements are available. Ask your doctor for a referral to a dietitian if you are struggling to maintain weight.

These changes to your diet will help you to maintain your weight and strength in preparation for surgery and for recovery from surgery. This may feel strange to you at first, especially if you are used to eating foods low in fat and sugar.

Eating after surgery

After some operations it may take a few days for you to be eating and drinking again, depending on how well you are feeling and your doctors advice. When you are ready you will be given water to sip, followed by a light diet. You will slowly build back up to a normal diet. How long this takes varies from person to person.

When you are able to eat enough, your doctors may prescribe pancreatic enzymes to help you digest your food. Your medical team and dietitian will tell you how to take these.

What is a light diet?

During the first week after surgery, your medical team and dietitian will help you to start eating a light diet. Nurses will be able to provide useful information about what foods to try. Generally this is soft, moist and easily digested food.

Suggested foods include:

Breakfast:

- Porridge, cornflakes or puffed rice cereal
- White bread and butter or spread
- Smooth apple or orange juice

Main meals:

- Soup, white bread and butter or spread
- White fish, mince, mashed potatoes, soft pasta
- Mousse, custard or milky puddings (e.g. creamed rice)
- Bananas or fruit compotes

Snack meals:

- Jelly, mousse or yoghurt
- Chocolate (no nuts or dried fruit)
- Crème caramel, soft crisps, bagel with soft cheese

Foods to avoid on a light diet

- Spicy foods
- High fat foods
- Foods that contain lots of cheese (e.g. pizza, lasagne)
- High fibre foods
- Food with bits and pips in.

You should be able to reintroduce these foods after two to three days on a light diet.



Fizzy drinks and alcohol

Avoid fizzy drinks until you are eating and drinking normally. This is because fizzy drinks can make you bloated (which can be sore after an operation) and reduce your appetite. Fizzy drinks can cause pain if drunk in the weeks immediately following surgery. You should avoid alcohol for the first few weeks after surgery to allow your pancreas a chance to heal.

Nutritional supplements

Some people need additional high protein or high energy supplements to help them recover from the operation. If you cannot manage to take in enough nourishment from your diet alone you may need to be referred to a dietitian for individual advice. Your dietitian may recommend that you try a high calorie protein supplement or drink and ask your doctor to give you a prescription for these. These boost your day-to-day calories and protein and help to give you the strength you need for your recovery.

It can take time to return to normal after some surgical procedures. It is advisable to try to eat little and often, with lots of small snacks and high energy drinks between meals.

You will need to ensure you are getting enough energy and protein from your food so try to avoid watery soups, meals of purely fruit and vegetables and large drinks at meal times.

Diet and surgery

Suggested foods for a soft diet after surgery include

Breakfast:

- Small bowl of porridge (add cream/ jam/honey)
- Small glass of fruit juice
- Creamy yoghurt
- Scrambled eggs
- Small bowl of cereal with full-fat milk

Main Meals:

- Small portion of meat with potatoes, rice or pasta
- Small portion of vegetables
- Fish in sauce
- Mince with mashed potato
- Corned beef hash
- Soft pasta with creamy sauce
- Jacket potato with cheese/tuna and mayo
- Ice cream with sauce
- Sponge and custard
- Mousse
- Crème caramel

Drinks:

- Hot chocolate (milk based)
- Fruit juice
- Milky coffee

Snacks:

- Small piece of cake
- Milky coffee
- Biscuits
- Glass of milk
- Crumpet with butter
- Scone with jam
- Mousse
- Yoghurt
- Packet of crisps
- Chocolate bar
- Cheese and biscuits
- Dried fruit and nuts

Snack Meals:

- Scrambled eggs made with full-fat milk and butter
- Creamy soup with croutons and toast and butter
- Thick and creamy yoghurt or mousse dessert



See our free recipe book for more helpful recipes that are easy to digest and help keep weight on. Visit: panact.org/patient-booklets

Always check with your dietitian or medical team if you are unsure of what type of diet you should be on.

Diet and chemotherapy

Chemotherapy can influence what you want to eat and how much you can eat. A common side effect of chemotherapy is feeling sick. Chemotherapy can change your senses of taste and smell which can affect your appetite. Some people suffer from mouth sores. **See section 12 on how to cope with physical symptoms and side effects.**

Eating smaller portions little and often may be helpful. The suggested foods in this booklet may be helpful, plus recipes in our cookbook for pancreatic cancer patients. To order our publications free of charge go to our website or call us on **0303 040 1770**.



Diabetes and nutrition

What is diabetes?

Diabetes is when the body is not regulating its blood sugar levels properly. When we eat fat and carbohydrates this is converted into glucose (sugar). Blood sugar levels are regulated by insulin, a hormone, found in the pancreas. Insulin converts the glucose into energy, if your body cannot make enough insulin, or use its own effectively, you have diabetes.

Pancreatic Cancer patients and diabetes

Type 2 diabetes is a risk factor for pancreatic cancer. Type 3c diabetes can be caused by pancreatic cancer or pancreatic surgery. The risks of developing diabetes can increase with time, so if you experience a dry mouth, increased thirst, feel the need to get up in the night to pass urine or lose weight suddenly you should ask your doctor to check your sugar levels.

You may get diabetes after pancreatic surgery as hormone and digestive enzyme production will be affected by removing all or part of the pancreas.

It is important to get advice relevant to your own circumstances. Some people may need tablets to manage their blood sugar levels, others may need insulin injections to replace the insulin the pancreas would have normally produced.

You may be referred to a diabetes specialist nurse who will help you manage your diabetes; by giving help and advice on any medications and managing your diet.

If you are at home following surgery and have symptoms of diabetes including thirst, rapid weight loss and you are passing a lot of urine, contact your GP.

To find our more information about the link between diabetes and pancreatic cancer, visit our website at panact.org

What foods may help control diabetes?

Talk to your dietitian or diabetes nurse about this, as each individual case is different. However, you can help maintain your blood sugar levels as close to normal as possible by maintaining a good balance between a nourishing healthy diet, nutritional supplements, medications and physical activity. These measures not only help to improve blood sugar control but also has an impact on physical healing, weight maintenance and quality of life. Remember if you forget to take your enzymes this can cause your blood sugar levels to fall.

No single food will supply all the nutrients a body needs, so good nutrition means eating a variety of foods. It is important to eat foods from each group throughout the day. Eating lots of fruit and vegetables is extremely good for your diet.

It is important that you get the balance right between healthy eating and maintaining your weight. If you are struggling to maintain your weight, you should not restrict your diet further to try and reduce your blood sugar levels. Ask your doctor, dietitian or diabetes nurse for advice.



Contact your dietitian, Diabetes Specialist Nurse or your doctor for specific advice on diet and diabetes

What is a balanced healthy diet?

A healthy balanced diet involves eating a variety of foods. Knowing about the different food types can help you plan and think about what foods you should have in your meals. You can always discuss this with your dietitian, GP or specialist nurse for advice.



Always drink plenty of fluids, it is recommended to have six to eight cups/ glasses of fluids a day.

Foods are divided into five main groups:

- **Fruits and vegetables**
These are a good source of vitamins, minerals and fibre, and are often low in fat
- **Carbohydrates** (starchy foods)
Such as whole grains, cereals, pasta, rice, potatoes and bread. These are a good source of energy and contain some nutrients. Try and choose wholemeal options when you can as this is healthier for you
- **Dairy products** (milk, cheese, and yoghurt). This also includes dairy alternatives such as soya milk yoghurt and cheeses. These are good sources of protein but also contain calcium, which helps keep your bones strong
- **Meat, fish, eggs, beans, pulses and nuts**
These provide you with protein which helps cells grow and repair
- **Fats, oils and sugars**
Some fats are better for us than others. Unsaturated fats such as avocado and olive oil are good for us. Foods containing saturated fats such as cheese are less healthy. Saturated fats in combination with sugar in foods such as cakes and donuts should be eaten rarely.

Try to ensure you eat regularly and have a mix of foods throughout the day, so the body has a proper balance of all the nutrients it needs to function.

Healthy food

Having a healthy diet can make a difference to your health. Research suggests that providing your body with all the nutrients it needs brings benefits during and after cancer treatments. A healthy diet helps to maintain muscle strength, keep a healthy weight and give you more energy, all of which can improve your quality of life. It may help you recover from the side effects of treatment sooner, helping to heal any wounds and damaged tissue (which is important after surgery, chemotherapy, and radiotherapy). It also helps you be stronger to fight off any infections as a healthy diet benefits your immune system

Making small changes to your diet can be helpful, rather than trying to change everything at once. [See page 29](#) for what is considered a healthy diet. Please be aware that this is general advice, and for specific advice relating to you, talk to your dietitian or GP.



Lifestyle

Your diet and lifestyle can make a difference to your overall health. While important throughout your life, changing your diet and lifestyle when you have a cancer diagnosis can make you physically stronger to cope with treatments. Importantly it can also influence how positive you feel.

Smoking

If you smoke it is strongly advised you give up. There is evidence that even after 72 hours of stopping, breathing becomes easier. After 2 to 12 weeks, there is evidence that stopping smoking improves your circulation.

The importance of exercise and tips on exercising

Exercise, even if very gentle, is good to help stop muscle loss and improve your mood. Even if you might not feel like doing any, exercise can make you feel better. There is a lot of research which supports the positive effect of exercise on mental health, this is because when you exercise chemicals are released in the brain that make you feel happy.

Alongside mental health benefits, exercise provides physical health benefits, such as preventing muscle loss, which can help your body cope with treatments.

Yoga and gentle walking or going up and down the stairs a few times can give you the same positive mental and physical benefits as more intense exercises such as jogging, cycling or swimming. If going out for a walk seems difficult then exercises at home can help. This can include stretching, such as stretching your legs out on your chair or bed and lifting them slightly for around ten seconds. You can also try lifting water bottles, or tinned cans - anything that is a comfortable weight in your hands - while lifting your arms up and down. Repeat these movements ten times each, rest, and then doing another cycle of ten if you can. Completing these small movements and stretches often creates a habit and can improve circulation and wellbeing.

Before starting on a new exercise routine, do talk to your doctor.

The influence of diet on your emotions and how you are feeling

Food can be an important factor in people's lives. Having and being treated for pancreatic cancer can change what you can eat, how much you feel like eating, and may make you feel uncomfortable when it comes to eating. This can be difficult to cope with.

Mealtimes can become an anxious time for you and your loved ones. Food that you have previously enjoyed may taste strange, metallic or make you feel sick. Your mouth may become very dry and sore from some chemotherapy treatment. You may be exhausted and unable to prepare meals. If you are the person in your family who has normally prepared the meals, it can feel strange to stand back and let someone else take charge.

Use support

Cooking and preparing food is often a way people try and help those who are ill because they feel it's a practical thing they can do. They want to help, so it's okay to let them. Many pancreatic cancer patients can struggle with eating. Your friends and family will want to help, so let them know what you are struggling with so they can understand your needs. Try not to feel guilty, maybe ask to serve your own portion or tell them that you are aiming for little and often. Eat what you like when you feel like it. Try and be positive about what you have managed to eat rather than worry about what you didn't eat.

Sometimes asking to use a smaller plate (side plate) instead of a dinner plate can help manage other people's expectations of how much you can eat in one go. Many restaurants will support you in ordering a children's portion, or just a starter dish rather than a full main course.

Helpful tips

What you fancy to eat may vary from day to day, so it's a good idea to keep stocked up on store cupboard meals and snacks, e.g. - instant milky puddings, jelly and tinned fruit, ice cream, savoury snacks such as nuts and crisps. When cooking make a bit more than you need and store in the freezer. Tinned meats and fish, UHT milk and fruit juice, dried mashed potato, tinned vegetables, packet/tinned soups are all great to have at home.

If food tastes bland, try experimenting with new tastes; spicy, very sweet or highly seasoned foods, may be more enjoyable. Toasted bread, crackers and rice offer a different texture to plain bread and potatoes. Cold food is just as nourishing and often has less smell so may be more enjoyable.

If your mouth is dry and sore, soft food will be easier to swallow. Sucking sweets, chewing gum, sucking ice cubes or frozen fruit such as grapes; satsuma or pineapple segments can all be soothing.

It can take time to get used to any change in diet and to any symptoms you may be suffering with. Please talk to your dietitian or GP about what may be most helpful to help manage these difficulties. If you are diabetic, you may need more advice on the best things to eat to help control your blood sugars. In the next section, we have tips on how to cope with some of the side effects of treatments such as chemotherapy, which may present themselves.

Macmillan Cancer Support is a very good support service if you would like to talk to someone about this. You can call them on **0808 808 00 00** Monday-Friday 9am-8pm.



Coping with physical symptoms and side effects of chemotherapy

Coping with nausea and vomiting

Treatments such as chemotherapy may make you feel sick (nauseous) or be sick (vomit). Your doctor will tell you if your chemotherapy treatment is likely to cause nausea and vomiting.

Anti-sickness medication (known as anti-emetics) can help.

Anti-emetics may be available as:

- Injections - usually given by the nurse before chemotherapy
- Tablets - can be taken regularly at home
- Wafers - dissolved under or on top of the tongue
- Suppositories - placed in the rectum where they dissolve
- Liquids - added to the chemotherapy
- Patches - worn on the upper arm
- Syringe driver - constant delivery through a needle, often placed in your thigh, which comes in a portable battery-powered box.

You may be prescribed medication before treatment to reduce the side effects. Some people find it takes some time before they find a medication that works for them. Let your nurse or doctor know if you still have nausea after a few days of taking the medication or if you have been sick for more than 24 hours.

Tips for coping with sickness and nausea:

- Eat little and often especially, before your treatment (e.g. soup and dry biscuits or toast), and drink as much fluid as possible
- Instead of drinking a lot at once, try sipping small amounts of liquid often. Sucking on ice cubes can also help to increase your fluid intake
- If you wake up feeling sick, eat a dry biscuit (ginger biscuits may help with nausea) or a slice of toast. This is better than skipping breakfast or forcing yourself to eat. If you are diabetic, consult your medical team

- Fizzy drinks such as ginger ale or soda water can often help relieve an upset stomach
- It is important to keep up your fluid intake to prevent you from becoming dehydrated if you have been vomiting a lot. You should contact your medical team if you are unable to keep fluids down
- Avoid strong odours and cooking smells, which can trigger nausea and vomiting
- Sometimes the taste of certain types of food can change. Your sense of taste should return to normal a few weeks after you have completed your treatment.



Speak to your dietitian for more detailed advice on eating and drinking while feeling or being sick.

Coping with physical symptoms and side effects

Changes in taste and smell

Some treatments for pancreatic cancer, such as chemotherapy, can alter your sense of taste or smell. Some people find that they like to enhance the taste of food using spices, herbs and sauces while others find avoiding strong flavours and eating bland, unseasoned food helpful.

Tips for coping with changes in taste and smell

- To add more flavour to your food, try using garlic, herbs, spices, cheese, pickles, mustards, sugar and salt. Marinate meat, tofu or vegetables to add more flavour
- If your food tastes too sweet, try adding lemon juice or salt – starting with a few sprinkles/drops and increase until you find the taste acceptable



- If food tastes metallic or too salty, try adding sugar or honey. Sucking on lemon sherbets or other sharp boiled sweets may also be helpful
- Some people find a drinking straw helpful to bypass your taste buds
- If you are affected by cooking odours, try to stay out of the kitchen while food is being cooked if possible
- Choose foods without a strong smell – sometimes the smell of a food can put you off eating. Cold foods tend not to smell as much as hot foods
- Sometimes it can be helpful to eat with plastic utensils to reduce the metallic taste and avoid drinking out of aluminium cans and storing food in metallic containers.

Coping with mouth sores

Some chemotherapy drugs can cause mouth sores such as ulcers and infections.

If you notice any change in your mouth or throat, such as ulcers or thickened saliva, or if you find it difficult to swallow, contact your medical team.

Tips for eating with mouth sores:

- Eat moist foods such as soup
- Avoid foods that are very hot, spicy or coarse
- Suck on ice cubes
- Add cream, fruit and extra sugar to ice cubes if you are trying to put on weight.



You may have finished treatment but now you are living with the effects that pancreatic cancer can leave. For example, you may now have diabetes to manage or you may need pancreatic enzyme replacement. Some find they have mental health difficulties following this diagnosis and treatment. Pancreatic cancer may have changed you physically and may affect relationships, particularly with people who are close to you. Below we discuss practical considerations you can take to help at this time, as well as the emotions that are usual to experience, and how to cope with these.

Practical considerations

Some people feel they are abandoned by the healthcare system after they have finished their cancer treatment. This is natural as the level of support decreases, but you can always ask questions and are normally followed up in the long term.

You can discuss with your doctor what your follow-up plan will be. You need to inform your doctor of the things you would like and need in your care. They know your medical history and can help you decide what to do about medical care in the future and how much treatment you want (ceiling of care). Do not be afraid to discuss any concerns and worries you have.

For example:

- Having regular check-ups with your GP or specialist about diabetes
- Having contact with dietitians
- Having contact with psychological support
- Ask to have your treatment summary, this will include all the treatments you have had and what side effects you may experience
- Be aware of any symptoms/side effects you may experience after treatments. Your doctor will discuss this with you, however, it is good to be aware of what these may be
- Tell your doctor if you are experiencing any side effects, whether these were expected or not.

Discussions about treatment depending on your prognosis

Ensure any new medical professional knows your medical history, or show them your treatment summary.

Emotions

Following diagnosis and treatment many people find it difficult to know how they are feeling because there are so many different and mixed emotions. It can be an extremely exhausting period, physically and emotionally. You may be relieved that you have finished treatment but also concerned at what the future holds.

Below are some of the common feelings after finishing cancer treatment

Feeling anxious

You may worry about how life will be after having pancreatic cancer.

Fear about cancer coming back

Fear about cancer returning is perfectly understandable. However, it is important that you do not let the fear take over your life. Many cancer survivors go on to live a full, happy and healthy life. It is important to continue to look after your body, exercise and eat right but if you have any concerns we advise you speak to your GP.

Feeling alone

Sometimes when treatment has finished you can feel strange and lonely, you're no longer seeing other patients or medical professionals you were seeing regularly. Sometimes when you're around family and friends you can feel alone as it doesn't feel like anyone else understands what you have been through.

Self-conscious

This may be of your body image. Cancer often causes weight loss and physical scars, even if others cannot notice this, it may be a big difference to you. This can also sometimes affect how you feel about sex and sexual intimacy as well as body image.

Sadness and depression

If you are having continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you might be experiencing depression. Depression is not a sign of failure or an inability to cope. Depression can be common with cancer diagnoses and can often be treated successfully. If you are feeling sad often but may not be depressed it is still important to seek help for this.

It is normal to feel these emotions. If you are struggling with any of these issues, do seek help. Go to your GP or call Macmillan Cancer Support or the Samaritans helpline. You are not alone.

How to move forward

If you feel you need help, do not be afraid to seek more support. What you have gone through is very difficult. Discussing this with someone you feel close to can be really helpful.

The Maggie's Centre runs a free 'What now?' seven week course for people who have just finished their cancer treatment as well as friends and family. This course provides information and support during this transition period, including discussions on exercise, healthy eating, emotional wellbeing, managing post-treatment challenges, partnering with your medical team and keeping momentum.

You can visit their website for more information: maggiescentres.org or call them on 0300 123 1801.

You can also call Macmillan Cancer Support to discuss any difficulties you are having or for any further advice. You can call them on 0808 808 00 00 Mon-Fri 9am-8pm.

If you are having some difficult thoughts or feelings you can call the Samaritans 24-hour confidential helpline 116 123.

Nutrition and finances

Sometimes people worry that the most expensive food is best for them and they may not be able to afford it. How much you decide to spend on your food is up to you, or whoever does the budgeting in your household. However, from a nutritional point of view, buying the home brand range or 'value' products are just as good. Do not feel pressured to spend more on food than is necessary due to having pancreatic cancer.

What is important is the type of food you're buying, and cooking from scratch if you are feeling well. This is the healthiest option. If you are struggling with fatigue, don't worry about using convenience foods. Batch cooking and freezing individual portions on days where you feel strong can help you manage on days where cooking feels a bit too much. Any prescribed nutritional supplements are free for cancer patients.



What is cancer cachexia?

Cancer **cachexia** is a condition caused by **metabolic** changes in the body that can't be changed by increasing the calories you eat – so once you lose weight, it can be difficult to put it back on again. Symptoms of malabsorption or undiagnosed diabetes can sometimes be confused with cancer cachexia.

Your doctor or a member of your medical team will inform you if you develop this condition.

Symptoms include:

- Significant unintentional weight loss
- Muscle wasting
- Loss of appetite
- Fatigue.

There are supplements which may be helpful in managing cancer cachexia. For specific advice about this condition, please talk to your doctor or dietitian.



Complementary and alternative therapies (CAMs)

As well as the main treatments given to pancreatic cancer patients, you might hear about some alternative therapies. This can be especially common when it comes to diets but can also be about other treatments in your cancer pathway. It is important you know the most you can about this to make the most informed and right decision for you.

What is conventional therapy?

These are used by doctors to treat cancer and have been scientifically proven through research.

What are complementary therapies?

These are treatments used alongside conventional therapies, often to help with side effects or emotional health. Some have been researched to see how safe they are.

What are alternative therapies?

These are typically used instead of conventional therapies and often have not been scientifically proven through research.

It is important to clarify that at present NONE of the alternative therapies are of proven benefit, and indeed may have no effect. Some people find alternative or complementary therapies make them feel better and can give them a feeling of control. Some feel these treatments are more natural and less toxic. Always discuss with your doctor if you are considering an alternative therapy.

Examples of alternative therapies include massage, green tea, acupuncture, meditation and visualisation techniques as well as Chinese herbs.

If they do not have an adverse effect on your treatment and do no harm then alternative therapies can be a helpful way of feeling in control of your body and treatment.

Ask your doctor before testing an alternative therapy to make sure it does not interfere with your current treatment.

We want you to do what is best for you but we cannot recommend the use of alternative therapies. We ask you to take caution if you are considering alternative therapies. Keeping weight on is very important and alternative diets, or other forms of medication, may not help with this. Always discuss this with your doctor and dietitian.

Pancreatic Cancer Action

We are a national charity dedicated to saving lives through early diagnosis and improving the quality of life for those affected by pancreatic cancer. Please call or go to our website for more free information on pancreatic cancer.

Tel: 0303 040 1700

panact.org

Health Care Professionals Council

Regulator of health care professionals. Register of health and care professionals who meet standards of training, professional skills, behaviour and health.

hpc-uk.org

Macmillan Cancer Support

Resources and information designed to provide physical, financial and emotional support to cancer patients and their families

Tel: 0808 808 0000

macmillan.org.uk

Maggie's Centres

Maggie's centres provide free practical, emotional and social support to people with cancer and their family and friends. They are often built next to NHS cancer hospitals.

maggiescentres.org

Samaritans

Samaritans is a charity that offers everyone a place to speak about anything that is getting to you.

Tel: 116 123 (UK) or 116 123 (ROI)

Email: jo@samaritans.org (UK) or jo@samaritans.ie (ROI)

samaritans.org

adenocarcinoma

This is cancer of the exocrine cells that line the pancreatic ducts. The majority of pancreatic cancers are this type.

adenosquamous carcinoma

A very rare aggressive form of pancreatic cancer.

Ampulla of Vater

The widened portion of the duct through which the bile and pancreatic juices enter the intestine.

ampullary adenocarcinoma

Cancer that develops in the ampulla of Vater (where pancreatic ducts and bile ducts merge).

Ampulla of Vater

The widened portion of the duct through which the bile and pancreatic juices enter the intestine.

Amylase

An enzyme made by your pancreas that helps to digest the carbohydrates you eat

artery

A blood vessel which delivers oxygen rich blood from the heart to the body.

bile

A fluid made in the liver and stored in the gallbladder that helps with the digestion of fats.

bile duct

The passage leading from the liver and gallbladder to the duodenum. Bile travels through the bile duct.

cachexia

Loss of body weight and muscle mass, and weakness that may occur in patients with cancer or other chronic diseases.

cells

The basic 'building blocks' of all living things. A human is made of billions of cells, which are adapted for different functions.

chemotherapy

The use of cytotoxic (cell killing) drugs to treat cancer by killing cancer cells or slowing their growth.

cystic tumours

Tumours that cause fluid filled sacs in the pancreas. Most are benign.

diabetes

A chronic disease in which sugars from food are not properly converted into energy in the body because the pancreas does not produce enough of the necessary hormone (insulin). Diabetes may be a risk factor for pancreatic cancer.

diagnosis

The identification and naming of a person's disease.

dietitian

A health care professional primarily concerned with the prevention and treatment of illnesses through proper dietary care.

duodenum

The first section of the small bowel (small intestine).

enzymes

Proteins that are essential for the normal functioning and performance of the body. Enzymes aid digestion.

gall bladder

An organ on the underside of the liver that stores bile. Bile is transferred from the gall bladder to the duodenum via the bile duct.

gland

Specialised organs or groups of cells that make various fluids that are used in the body or excreted.

glucagon

Is a hormone that is naturally made in the pancreas and works to raise blood sugar.

insulin

A chemical messenger (hormone) secreted by the pancreas to regulate the amount of sugar (glucose) in the blood. If the body does not produce enough insulin, diabetes will develop.

jaundice

A condition caused by increased amounts of bile in the blood. This causes the skin and the whites of the eyes to turn yellow, tiredness, loss of appetite and itchy skin.

Lipase

An enzyme made by your pancreas that helps to digest the fats you eat.

malabsorption

A condition in which there is a difficulty digesting or absorbing nutrients from food.

malignant

Cancerous. Malignant cells can spread (metastasis) and can eventually cause death if they are not treated.

metabolic

Complex physical and chemical processes occurring within a living cell or organism that are necessary for the maintenance of life. In metabolism some substances are broken down to yield energy for vital processes while other substances, necessary for life, are synthesised.

neuroendocrine tumours

Neuroendocrine tumours (NETs) start in the cells of the neuroendocrine system. The neuroendocrine system is a network of endocrine glands and cells throughout the body.

pancreas

An organ in the digestive system. The pancreas produces insulin and enzymes that help to digest food.

pancreatic lymphoma

Pancreatic lymphoma, or primary pancreatic lymphoma (PPL) is a cancer of the lymphatic system of the body that originates as a pancreatic mass. This is very rare.

prognosis

How you are expected to do after a disease is diagnosed.

Protease

An enzyme made by your pancreas that helps to digest the protein you eat.

radiotherapy

The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply. Also called radiation therapy.

side effect

Unintended effect of a drug or treatment.

tissue

A collection of cells that make up a part of the body.

tumour

A new or abnormal growth of tissue on or in the body. A tumour may be benign or malignant.

vein

A blood vessel that takes blood towards the heart.

This image shows a single sheet of white paper with horizontal blue or grey ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.This image shows a single sheet of white paper with horizontal blue or grey ruling lines. The lines are evenly spaced and run across the width of the page. There are approximately 20 lines visible. The paper has a slight shadow on the right side, suggesting it's resting on a surface.

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For sources and references used in the compilation of this booklet, please contact us at the address overleaf.

Pancreatic Cancer Action

This booklet has been funded through the generosity of supporters of Pancreatic Cancer Action, a UK charity founded by a pancreatic cancer survivor, Ali Stunt, who was diagnosed with pancreatic ductal adenocarcinoma in 2007. With a focus on early diagnosis, it is Pancreatic Cancer Action's mission to improve survival rates by raising awareness of pancreatic cancer and its symptoms among the public, medical education, improved information and by funding research specifically to improve early diagnosis of the disease.

If you would like to support us or find out more, please contact us at enquiries@panact.org or visit panact.org




Phone us on
0303 040 1700



If you would like to help us by either holding an awareness event or by fundraising, please email enquiries@panact.org or call 0303 040 1770. For more information or to donate directly please visit panact.org



 0303 040 1770

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 OfficialPCA

 PancreaticCancerAction

 pancreatic_cancer_action

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Saving lives through early diagnosis

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