Pancreatic Cancer UK

Diet and pancreatic cancer
Introduction

This booklet is for anyone with pancreatic cancer. Your family may also find it helpful. It explains how pancreatic cancer and treatments for it can cause problems with diet, eating and nutrition.

We provide information on how to manage these problems, and some tips for dealing with some of the different symptoms you may get (see page 41).

Not all the information in this booklet may be relevant to you. It’s been designed so that you can dip in to find the information you need, when you need it.

- There are questions to ask your medical team on page 51.
- We’ve explained some of the key words used in this booklet on pages 4 and 55.
- You can read other people’s experiences in the pink quotes.
- The yellow boxes tell you where to find more of our information on pancreatic cancer.
- You can find other organisations that provide support and information on page 57.

If you have any questions about anything you read here, or about diet and pancreatic cancer, speak to your doctor, nurse or dietitian (see page 11). You can also speak to our specialist nurses on our Support Line.

Call the specialist nurses free on 0808 801 0707 or email nurse@pancreaticcancer.org.uk
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Key words used in this booklet

We’ve explained some of the key words that we’ve used in this booklet here. You can find more medical words on page 55.

Diet
Your diet is the food you eat. When we talk about symptoms or problems around diet in this booklet, we mean problems that can affect your eating and digestion. We are not talking about the kind of diet people often go on to lose weight.

Digestion
Digestion is what your body does to break down your food so that you can get the nutrients from it.

Nutrients
Nutrients are the things you get from your food that your body needs for energy and to work properly. They include protein, carbohydrates, fats, vitamins and minerals.

Calories
A calorie is a measure of how much energy you get from the food you eat. People with pancreatic cancer often need to have more calories to help them maintain their weight, or put on weight.

Enzymes
Enzymes are substances produced by different parts of the body, including the pancreas. Different types of enzymes have different roles in the body. Pancreatic enzymes help to break down food.

Absorption
Once your food has been broken down, the nutrients pass into the blood so that they can be used by the body.
Section 1

How does pancreatic cancer affect diet and nutrition?

Pancreatic cancer can affect how well the body can digest food and absorb nutrients.
The pancreas plays an important role in digesting food, as it produces enzymes that help to break down food. Nutrients from the food can then be absorbed into the blood and used by the body (see page 4). Different pancreatic enzymes help to break down foods containing fat, protein and carbohydrate.

The pancreas also produces hormones, including insulin and glucagon, which control sugar levels in the blood. Pancreatic cancer can reduce the number of hormones the pancreas makes, which can cause diabetes (see page 32).

**How does pancreatic cancer affect digestion?**

Pancreatic cancer can reduce the number of enzymes that your pancreas makes. It can also block the enzymes from getting to the bowel, where they are needed for digestion. For example, the cancer can block the pancreatic duct, which carries the enzymes from the pancreas to the duodenum (the first part of the small intestine).

This means that food is not properly digested, and the nutrients in the food aren’t absorbed. This is called malabsorption. It can be managed with pancreatic enzyme replacement therapy (PERT). Read more on page 12.

Having surgery to remove all or part of the pancreas may also affect the number of enzymes that the pancreas makes. Read about surgery on page 22.
The pancreas and surrounding organs

What symptoms are caused by problems with diet and digestion?

It’s common for people with pancreatic cancer to get symptoms caused by problems digesting food. Symptoms include:

- losing your appetite
- losing weight, or struggling to put weight back on (see page 9)
- indigestion or heartburn
- runny poo (diarrhoea) – see page 50 for tips that can help
- problems emptying your bowels (constipation)
- pale, oily, floating poo (steatorrhoea – see page 9)
- tummy pain or discomfort
- bloating or wind
- feeling full up quickly
- needing to empty your bowels urgently, especially after eating.
Some people also develop diabetes (see page 32). Some symptoms can be caused by other things, such as jaundice.

Some treatments or medicines can hide these symptoms. For example, if you are taking strong painkillers called opioids (such as morphine), these may cause constipation and hide the symptoms of diarrhoea. Your medical team will help you manage any symptoms you have alongside the medicines you are taking. Don’t stop taking any medicines without speaking to your medical team first.

**What is jaundice?**

Jaundice is a symptom of pancreatic cancer. It can develop if the cancer has grown to block the bile duct, which carries bile from the liver to the small intestine (see diagram on page 7). Bile is a fluid that is made in the liver and helps with digestion.

Jaundice makes your eyes and skin turn yellow, and you may feel itchy. It can also cause a loss of appetite, taste changes, feeling and being sick, dark urine and pale poo. These symptoms normally get better once the jaundice is treated.

Read about treatments for jaundice in our fact sheet, *Stents and bypass surgery for pancreatic cancer*, or at pancreaticcancer.org.uk/stentsandbypass
What is steatorrhoea?
Steatorrhoea is caused by fat in poo. You may notice that your poo is often pale, oily, smells worse than normal, and is difficult to flush down the toilet. It happens if your body isn’t making enough enzymes to digest the fat in your food properly. It also happens if the enzymes are blocked from getting to the bowel, where they are needed for digestion. Steatorrhoea can be managed with pancreatic enzyme replacement therapy (PERT) – see page 12.

Weight loss
Losing weight is a common symptom of pancreatic cancer, and can be caused by problems with your digestion. Diabetes can also cause weight loss (see page 32).

Weight loss can affect how you deal with the symptoms of the cancer. It can also affect how you deal with treatments such as chemotherapy or surgery. Weight loss can be upsetting and affect how you feel generally. Read about emotional support that is available on page 36.

Your doctor, dietitian or nurse will work out what is causing the weight loss, and how this can be managed. You may need to take pancreatic enzymes (see page 12) to help you digest your food and maintain your weight.

Your medical team will also help you make changes to your diet so you can get more calories and protein (see page 43). When someone loses weight quickly, they often lose muscle and strength too. Having more protein in your diet and doing gentle physical activity (see page 38) can help rebuild muscle. This can help you to feel better and have more energy.
Your medical team may also recommend nutritional supplements, which are drinks or powders that have extra calories and protein in them (see page 20).

There are a lot of diets that claim to help cancer, but a lot of these aren’t based on good evidence. If you have pancreatic cancer it is important not to cut anything out of your diet, or take any supplements, without speaking to your doctor, nurse or dietitian first.

"In view of my weight loss it was suggested by a Specialist Nurse at Pancreatic Cancer UK that I may benefit from enzyme tablets. I started taking the capsules and noticed straightaway less discomfort on eating. My energy levels started to increase and I have very slowly started to gain some weight."
Who is the dietitian?

A dietitian provides expert advice about diet and nutrition. They can help you deal with any problems with your diet, reduce weight loss (see page 9), and manage diabetes (see page 32). A dietitian will look at the cause of your symptoms and help you to eat as well as possible.

It can be hard to manage the diet problems caused by pancreatic cancer. You may need to see a specialist dietitian who is an expert in pancreatic cancer and diet. A specialist dietitian for pancreatic cancer may have different job titles, such as:

- pancreatic dietitian
- hepatobiliary (HPB) dietitian – an expert in diet and the liver, gallbladder, bile duct and pancreas
- oncology dietitian – an expert in diet and cancer
- upper gastrointestinal (upper GI) dietitian – an expert in diet and the first part of the digestive system.

Not all hospitals will have a specialist dietitian. Your doctor or nurse may help you manage diet symptoms, or they can refer you to a general dietitian at the hospital or in the community.

If you haven’t seen a dietitian and you are having problems with your diet and eating, or are losing weight, ask your medical team or GP to refer you to a specialist dietitian.

You can also speak to our specialist nurses on our free Support Line. They can give you information about how to manage diet problems, and help you to speak to your medical team.
Section 2

Pancreatic enzyme replacement therapy (PERT) replaces the enzymes that your body needs to break down and digest food properly.
What is pancreatic enzyme replacement therapy?

Pancreatic enzyme replacement therapy (PERT) is capsules that replace the enzymes that your pancreas would normally make. These help you to digest your food by breaking down carbohydrates, fats and proteins.

Pancreatic enzymes can help manage the symptoms on page 7. They can also help you to cope better with treatments, such as chemotherapy or surgery. Managing problems with diet and digestion can make a big difference to how you feel.

Different brands of pancreatic enzymes are available in the UK:
- Creon®
- Pancrease®
- Nutrizym®
- Pancrex®

All pancreatic enzymes are made from pork products, and there is no alternative. Talk to your doctor if you are allergic to pork products. Organisations representing Jewish and Muslim communities have said that these treatments are acceptable to use.

Vegetarian enzymes are sold in some health food shops and online, but they provide very low doses of enzymes, are expensive and there is no evidence that they work. Speak to your doctor or dietitian if you have concerns about taking enzymes.

If you haven’t been told about pancreatic enzymes, ask your doctor, nurse or dietitian about them. You could take this booklet with you to show them.
How do I take pancreatic enzymes?

Enzymes are normally given as capsules that you swallow with food. They are also available as granules or powder if you struggle to swallow capsules (see page 17).

Some brands of enzymes have a number after the name, which shows the dose of the enzymes. For example, Creon 25,000 contains 25,000 units and Nutrizym 22 contains 22,000 units. We have used these brands as an example, but you may be prescribed a different brand.

You might start with a dose of at least 50,000 or 75,000 units for a main meal, and 25,000 or 50,000 units for a snack or milky drink. For example, if you are taking a capsule that contains 25,000 units you might take two or three capsules with a main meal and one or two capsules with a snack.

This may sound like a lot of enzymes – but it’s not as much as your pancreas would normally make. During and after a small meal, your pancreas would normally make up to 720,000 units.

Most people will need to increase the number of enzymes they take from the starting dose. Improving problems with your digestion can mean that you start to eat more, and need more enzymes to digest your food. Your dietitian, doctor or nurse can tell you how to work out the best dose for you. They should review the dose regularly.
There is no set dose of enzymes for each day. You will need to take more for larger meals and fatty foods, as these need more enzymes to digest them. Don’t change what you eat to try to manage your symptoms – just make sure you take enough enzymes for what you are eating. Speak to your doctor, nurse or dietitian before making any major changes to your diet.

You may find it helpful to keep a diary of what you have eaten, the dose of enzymes you took, and if this made your symptoms better. This can help you work out if you are taking enough enzymes.

**Taking pancreatic enzymes**

It’s important that you take the enzymes properly, to make sure they work well.

- Enzymes should be taken with all meals and snacks. You should also take them with milky drinks.
- Swallow the capsules whole with a couple of sips of a drink.
- Don’t take the capsules with hot drinks, as they won’t work properly. If you are eating hot food, make sure you swallow the capsules with a cold drink.
- Don’t chew the capsules as this can cause mouth ulcers. If you struggle to swallow capsules see page 17.
- You should take the enzymes with the first few mouthfuls of food. They won’t work properly if you take them after a meal.
- If you are taking more than one capsule, or your meal will last more than 20 minutes, take half the capsules when you start eating, and spread the other half out during the meal.
• You will need more enzymes for larger meals, or if the food has more fat in it – for example takeaways, roasted or fried food, puddings, or food with lots of cheese or chocolate.

• Don’t worry if you forget to take your enzymes. Just take the usual dose with your next meal or snack.

• If you take nutritional supplements (see page 20), you will need to take enzymes with these as well.

• Don’t store the capsules in hot places as this can stop them working properly. For example, don’t leave them in the glove box of your car, near radiators, in direct sunlight, or in trouser pockets.

**When NOT to take enzymes**

Pancreatic enzymes only work when they are taken with food. There are some foods and drinks that you don’t need to take enzymes with. These include:

• drinks with only a splash of milk (including tea or coffee), fruit squashes, or fizzy drinks
• alcoholic drinks
• small amounts of fruit (except bananas and avocados) or dried fruit
• small amounts of vegetables (except potatoes, beans, and pulses such as lentils)
• sugary sweets – for example, jelly babies, wine gums, fruit pastilles or marshmallows.
What if I can’t swallow the capsules?

It's best to take the capsules whole as they work better this way. If you find it difficult to swallow capsules, speak to your doctor, nurse or dietitian. There are smaller capsules available, but you may have to take more of these to make up the dose.

You can open the capsule and mix the granules inside with a teaspoon of cold, soft, acidic food – such as a smooth apple sauce, fruit puree, apricot jam or fruit yoghurt. Swallow the food straight away and wash it down with a cool drink to rinse your mouth. Don’t mix the granules with hot foods or drinks, as this will stop the enzymes working. Don't sprinkle them on a plate of food, as they won’t work this way either.

Don’t chew the granules. If the granules aren’t swallowed quickly, or get stuck between your teeth or dentures, they can cause mouth ulcers.

How do I know if I am taking enough enzymes?

If you are taking enough enzymes, your symptoms should get better, and for some people the symptoms may go.

If you still have symptoms or you are losing weight, speak to your dietitian, nurse or doctor. They may increase the dose of enzymes. They may also look at whether anything else is causing your symptoms (see page 18).

What if the enzymes don’t help?

If your symptoms don't get better, speak to your doctor, nurse or dietitian. They can check you are taking enough enzymes, and that you are taking them properly. Some people need to change the type of enzymes they are taking.
Sometimes, the doctor will give you medicines called proton pump inhibitors, that help the enzymes to work better. These include omeprazole and lansoprazole. These medicines stop the stomach from producing too much acid, which can affect how the enzymes work. Speak to your doctor about these medicines and if they would help.

**Other causes of symptoms**

If you are taking pancreatic enzymes and you still have symptoms, there may be other causes for these. For example, strong painkillers called opioids (such as morphine), antibiotics, or chemotherapy can all cause changes to your bowel habits.

If you have diarrhoea that isn’t getting better even after increasing your enzymes, you may need to have some tests to check what is causing the diarrhoea and how to manage it.

Speak to you medical team about your symptoms and what might be causing them.

**What happens if I take too many enzymes?**

Any enzymes that your body doesn’t need will pass through you. If you take one or two more capsules than you need, this won’t be a problem. If you take lots more than you need it may cause some itching around your anus (bottom).

If you think you’ve taken too many enzymes and you feel unwell, speak to your medical team. Make sure you take your enzymes with your next meal as usual.
Are there any side effects of pancreatic enzymes?

It’s not common to get side effects from taking enzymes, but some people get tummy pain, wind, diarrhoea or they may feel or be sick.

These symptoms are often caused by the dose of enzymes being too low, rather than a side effect of the enzymes. Increasing the dose may help, or you may need to change the type of enzymes you take.

You can find more information about side effects in the leaflet that comes with your enzymes.

If you have any questions about how to take your enzymes, speak to your medical team.

" Getting my Creon dosage right has been a challenge but advice I found on the Pancreatic Cancer UK website helped enormously and nearly two and a half years on I feel myself again."

" I do find eating little and often works best. The only foods that really give me problems are fatty, greasy ones and sometimes dairy. Since taking Creon I have noticed a big improvement."
Section 3

Nutritional supplements

For some people, it may be helpful to take nutritional supplements. This can help make sure you are getting all the calories (energy) and nutrients that you need. It can be helpful for people who have lost their appetite or are losing weight.
If you are losing weight or struggling to eat, your dietitian (see page 11) will suggest some changes that you can make to your diet to get more proteins and calories. If changes to your diet don’t help, your dietitian may recommend nutritional supplements. These are drinks or powders that can help you get extra calories, protein, vitamins and minerals in your diet.

You will need to take pancreatic enzymes with nutritional supplements – speak to your dietitian about what dose to take.

There are different types of nutritional supplements. Some are milk-based, some are similar to juices, yoghurts, or soups, and they can be savoury or sweet. Try different supplements to find one you like. Your dietitian can explain how to take them.

**Vitamin and mineral supplements**

If you are not digesting your food properly you may not be getting enough vitamins and minerals. Speak to your doctor or dietitian about whether vitamin and mineral supplements would be helpful.

Don’t take very high doses of these supplements and don’t start any vitamin and mineral supplements without talking to your doctor first. This is because they can affect the way some medicines work.

If you are taking pancreatic enzymes, you will normally take these and the supplement at the same time, together with a meal or snack. You should always follow the instructions from your doctor or on the supplement packet. Make sure you ask your doctor if you are unsure how to take them.
Section 4

Surgery to remove the cancer and diet

If you have surgery to remove the cancer (such as the Whipple’s procedure), you will have all or part of your pancreas removed. After surgery, most people need to take pancreatic enzymes to help them digest food.
How will my diet be affected by surgery?

Having all or part of the pancreas removed will affect how well the pancreas makes enzymes and hormones.

- It is likely that you will need pancreatic enzymes to help you digest food.
- You may also develop diabetes and need medicines to manage this (see page 32).

You may see a dietitian before and after your surgery. They can give you advice on managing any symptoms from the surgery, eating well and putting on weight, and taking pancreatic enzymes.

The National Institute for Health and Care Excellence (NICE) have guidelines for pancreatic cancer. They recommend that if you are having surgery your doctor should assess your symptoms to see if you need pancreatic enzyme replacement therapy before or after surgery.

Before surgery

Try to eat as well as possible in the weeks before your operation, as this will help you recover from surgery. Being active can also help you prepare for surgery (see page 38). If you have lost weight, you may need to put weight back on before surgery. Your medical team may suggest a build-up diet (see page 43). Speak to your doctor or dietitian about pancreatic enzymes if you are not already taking these.
After surgery

There are no foods which you should totally avoid after your surgery. To begin with, you will need more calories and protein in your diet to help you recover – see page 43 for tips on how to do this. You should also avoid alcohol and fizzy drinks for a few weeks.

Some people find that they can’t manage big portions after surgery, or feel full more quickly. Eating small amounts often can help with this. Try having three small meals and three snacks a day.

You may also find that some foods don’t taste the same. Taste can take some weeks to return to normal after surgery. We have tips on dealing with a loss of appetite and taste changes on page 47.

Speak to your doctor if you have any problems with your mouth after surgery. They can check for a mouth infection, such as oral thrush. Oral thrush causes white spots on your tongue, reduces your appetite and causes a sore mouth. It is common after surgery, but is normally easy to treat.

If you have any questions about managing diet problems before or after surgery, speak to your doctor, nurse or dietitian. If you are having chemotherapy after your surgery, it is important to speak to them about any eating problems to make sure these don’t delay the chemotherapy.

Gentle physical activity can help with your recovery. Speak to the physiotherapists at the hospital for more advice on this. Read more about physical activity on page 38.
Read more on eating and drinking before and after surgery in our fact sheet, *Surgery to remove pancreatic cancer*, or at [pancreaticcancer.org.uk/surgery](http://pancreaticcancer.org.uk/surgery)

If you haven’t seen a dietitian, ask your doctor or nurse to refer you to one – it is important that you get specialist advice about your diet.

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

"My weight is stable. I have not put back all the weight I lost post-surgery but think I look well and I eat well and healthily."

"I have continued with my steady progress since discharge after surgery and have increased my walking distance daily. My appetite has increased with my increased stamina."
Section 5

Managing your diet if you can't have surgery

If it’s not possible to remove your cancer with surgery (inoperable pancreatic cancer), you may be offered other treatment.
If the cancer can’t be removed with surgery, you may be able to have chemotherapy to help control the cancer. This may help you live longer and feel better generally. You may also have treatments to help with any symptoms.

Read about chemotherapy in our fact sheet *Chemotherapy for pancreatic cancer*, or on our website at [pancreaticcancer.org.uk/chemotherapy](http://pancreaticcancer.org.uk/chemotherapy)

**How should I manage my diet if I can’t have surgery?**

If you can’t have surgery to remove the cancer, keeping your weight stable and treating any problems with digestion (see page 7) can make a big difference to how you feel. It can also help you cope better with the cancer and treatment.

The National Institute for Health and Care Excellence (NICE) recommend that you should be offered pancreatic enzymes (see page 12). These can help improve your symptoms and help you to feel better. If you haven’t seen a specialist dietitian (see page 11), ask your doctor or nurse to refer you to one.

There are no foods that you should stop eating because of the cancer. If you are eating well and haven’t lost any weight, you can carry on with your normal diet.

If you have lost your appetite, are losing weight or are struggling to eat, speak to your medical team. They can help you manage these symptoms and give you advice about what to eat. There are tips that might help you deal with weight loss or a poor appetite on page 42.
Sometimes your doctor or dietitian may recommend nutritional supplements (see page 20). They may also suggest medicines to improve your appetite, such as steroids (for example, dexamethasone) or hormonal therapy (for example, megestrol acetate).

Speak to your doctor, nurse or dietitian if you have any questions about your diet.

You can also ask our specialist nurses on our free Support Line.
Section 6

Diet and a duodenal stent

Sometimes the cancer can block the duodenum (the first part of the small intestine). This can cause symptoms such as feeling full quickly, feeling and being sick and losing weight.
If your duodenum is blocked, this can stop food passing out of the stomach into the duodenum. You may need to have a small tube called a duodenal stent put into your duodenum. This unblocks the duodenum so that food can pass through. This should help with sickness, and you should start to feel like eating again.

**How should I manage my diet with a duodenal stent?**

Your dietitian will help you to increase what you eat after having the stent put in. You will have softer foods at first. It may help to start by eating foods like jelly or yoghurt.

Sometimes it can take a while for your stomach to start emptying properly again. You may be given medicine (such as metoclopramide) to help with this.

You will need to be careful about what you eat to make sure the stent doesn’t get blocked. The following tips may help.

- Eat smaller meals more often.
- Take your time eating, and make sure you chew your food well.
- Eat a variety of foods to make sure you get enough nutrients.
- Sit up when you eat and avoid lying down after meals. This will help to digest your food.
- Avoid drinking too much fluid before or with your meals as this can fill you up.
You will need to eat soft foods that are easy to chew, such as:

- porridge or cereal soaked in milk
- soup (add cream, milk or cheese for extra nutrients and calories)
- poached fish or minced meat
- eggs, including poached and scrambled eggs or an omelette
- soft pasta dishes, such as macaroni cheese
- mashed potato (add butter, cream or cheese for more calories)
- vegetables well cooked until they are soft
- rice pudding, stewed fruit, yoghurt, custard or ice cream.

Try to avoid foods that might block the stent. These include:

- raw vegetables or vegetables that are harder to digest, such as salads, celery, green beans and sweetcorn
- nuts and dried fruit
- citrus fruits like oranges or grapefruit – this is because of the skin around each segment
- tough or gristly meat
- bread, as it expands in your stomach
- wholegrain food, such as wholegrain pasta or rice, as they are more difficult to digest.

Speak to your doctor, nurse or dietitian for more advice about what to eat after you have had a duodenal stent put in.

If your stent gets blocked you will feel full and may be sick. If this happens contact your doctor or nurse. Or go to A&E if it is out of normal hospital hours.
Section 7

Diabetes and pancreatic cancer

Diabetes is a condition where the amount of sugar in your blood (blood sugar level) is too high. The pancreas plays an important role in controlling your blood sugar level.
When you digest food and drink, carbohydrates are broken down into glucose, which is a type of sugar. Glucose passes into your blood and is used by the body. Your pancreas makes hormones called insulin and glucagon, which help to control the amount of glucose in your blood (your blood sugar level).

If you have pancreatic cancer or you have had surgery to remove all or part of your pancreas, your pancreas may not make enough insulin or glucagon. This can mean that your blood sugar levels are not controlled properly. Diabetes is a condition where the amount of sugar in your blood is too high.

A high blood sugar level is called hyperglycaemia. It can make you lose weight, feel very thirsty, need to pass urine (pee) more often, get headaches and feel tired. Your blood sugar level can also become too low. This is called hypoglycaemia. It can make you feel hungry, shaky or sweaty.

**Managing diabetes**

Pancreatic cancer can make managing diabetes difficult. If you are diagnosed with diabetes, you should see a specialist dietitian (see page 11). If you haven’t seen a specialist dietitian, ask your doctor or nurse to refer you to one. You may also see a diabetes nurse for help managing any medicine you are given.

Your dietitian or diabetes nurse will help you control your blood sugar levels. You may need to monitor your blood sugar level regularly, and take tablets or have insulin injections to control it.

If you already had diabetes before you were diagnosed with pancreatic cancer, the cancer may make your diabetes more difficult to control. Your diabetes team may change your medicines, and you may need to monitor your blood sugar
level more often. Keep in regular contact with your dietitian or diabetes nurse, particularly when starting any new treatments.

If you are well, have a good appetite and haven't lost weight, you may be told to follow a healthy diet. Diabetes UK has information on this. If you have been on a particular diet for your diabetes, this may no longer be necessary, but talk to your medical team.

There are different types of diabetes, and information on the internet about changing your diet may not be right for you because of your pancreatic cancer. If you have lost weight or are struggling to eat, you may need more calories in your diet to help you put weight back on (see page 43). This may include eating foods that increase your blood sugar level. Your diabetes will need to be managed around this.

**Diabetes and pancreatic enzymes**

Problems with your digestion can affect your blood sugar levels. This is because you won’t be able to digest and absorb sugars from your food properly. Problems with digesting food should be managed with pancreatic enzymes (see page 12).

When you first start taking pancreatic enzymes, your blood sugar level may start to rise because you will start to digest your food properly again. This can change how your diabetes needs to be managed, and you may need more diabetes medicine.

If you forget to take pancreatic enzymes with food, your blood sugar level may drop. If this happens remember to take your enzymes with your next snack or meal.
What else can affect my blood sugar level?

If you are taking steroids, these can cause your blood sugar level to rise. Your doctor or nurse will need to monitor this, and they might change your diabetes medicine.

Infections can raise your blood sugar level. If you take insulin for your diabetes and have an infection, you will need advice on how to control your diabetes. If you take tablets for your diabetes, the tablets may not work properly if you are sick or have diarrhoea.

Some nutritional supplements (see page 20) are high in sugar, and your diabetes medicine may need to be changed.

Exercising can lower your blood sugar level, as your body uses the sugar for energy. You may need to eat more when you are exercising – even if you are only doing gentle activity (see page 38). If you take insulin for your diabetes, you may need to monitor your blood sugar levels when exercising.

Managing diabetes if you have pancreatic cancer can be difficult and confusing. If you have questions, speak to your dietitian, specialist cancer nurse, doctor or diabetes nurse.

You can also speak to our specialist nurses on our free Support Line with questions about diabetes.

Read more about diabetes and pancreatic cancer at pancreaticcancer.org.uk/diabetes
Section 8

Coping with diet symptoms

You may find that problems with digestion and diet are hard to deal with and affect how you feel. Food is an important part of everyday life for many people, and eating with friends and family can be an important social activity.
Some people find that worries about eating and symptoms can affect their mood – for example, they may feel more anxious or down than usual. People often worry about losing a lot of weight, losing their appetite, and feeling pressured to eat more than they can manage. If you have lost weight you may also worry about how you look.

Symptoms such as diarrhoea or sickness can be stressful and make it harder to eat. You may also worry about going out in case you can’t find a toilet when you need it. Macmillan Cancer Support has a toilet card that helps you access toilets in places like cafes and shops when you are out.

Your family may also worry about you, and whether you are eating enough. But they can be a huge support. Try talking to them about how you feel, and things that you might find helpful. For example, some people need smaller meals and more snacks. Others find that the smell of food makes them feel sick, so it helps if someone else cooks.

You may find speaking with others in a similar situation helpful. We have an online discussion forum where you can speak to others affected by pancreatic cancer. We also hold Living with Pancreatic Cancer Support Days which provide face to face support. Find out about how we can support you on page 56.

Finding ways to manage your diet and symptoms can help you feel more in control. If you are struggling at all, speak to your dietitian, doctor or nurse. They can provide emotional support as well as medical care.

You can also speak to our specialist nurses on our free Support Line.
Section 9

Physical activity

It can be difficult to be active when you have pancreatic cancer. Gentle physical activity can help to maintain or improve your strength and fitness. It may also help you feel better, and cope better with treatment.
If you are eating or drinking less, or doing less physical activity, you may lose some muscle and strength. This can affect how you deal with symptoms and side effects of the cancer and treatment, and how you feel generally. Gentle physical activity can help improve your strength and fitness and deal with symptoms such as fatigue (extreme tiredness) or losing your appetite.

It is important to exercise within your own limits. Find something you enjoy doing. It could be gardening or going for a short walk. Take it easy and only do what you are able to do. You may find that some days are better than others. You might find it’s easier to exercise with a friend or relative – but make sure that you are still in control of how much you do.

Speak to your doctor or nurse before starting any kind of exercise plan. They can advise you on what type of activities are best for you, and any safety issues to be aware of. If you have diabetes, be aware that exercising can affect your blood sugar levels and how you manage your diabetes (see page 35).

Your doctor or nurse may refer you to a physiotherapist or occupational therapist for more specialist advice. Physiotherapists help people manage symptoms through movement and exercise. Occupational therapists provide equipment and help with everyday activities, such as dressing or going to the shops if you are struggling with these.

Some cancer support services, such as Maggie’s Centres, run exercise courses for people with cancer, for example, yoga, tai chi or walking groups. Ask your GP about any services available in your area.
"The physiotherapist used to visit mum and do a few exercises with her and left a print out of what she could do in her own time at her own pace."

**What sort of exercise would help?**

For most people, doing gentle exercise three times a day would be suitable. This could include:

- going for a walk down the street or garden
- light housework or gardening
- sitting in a chair or lying on a bed or the floor, raising your leg, and holding it for a few seconds, before lowering it and repeating a few times
- lifting some small weights, tins of food or bottles of water, while sitting in a chair
- walking up and down a few steps.

If you usually do a lot of exercise, you may wish to do more than this. Don’t do any vigorous exercise without talking to your doctor or physiotherapist first.

Even if you are in hospital, doing some activity can help maintain your fitness. This can help you cope better once you leave hospital. For example, you could try walking along the corridor once a day.

Macmillan Cancer Support has a lot of information about different ways of keeping active that you may find helpful, such as their **Move More** tool.
Section 10

Diet tips

The following tips may help you manage different symptoms that can affect your eating and diet. If you have questions about any of these tips, speak to your doctor, nurse or dietitian.
General tips

Pancreatic enzymes (see page 12) can help with diet symptoms. Don’t forget to take them when you eat.

If you are having problems eating or you are losing weight, these tips may help.

- If you can’t manage large portions, try eating smaller amounts more often – for example three small meals and three snacks a day.

- Every mouthful helps. If you feel sick or very full, have a break and eat some more an hour or so later.

- Eating even a small amount can be a big achievement – try to set realistic goals for yourself. It’s normal to have good and bad days with how much you can eat.

- Freeze portions of homemade dishes if you don’t feel like cooking, or try ready meals.

- Keep snacks close by so that you can eat whenever you feel like it.

- How food is presented on the plate can help it look more tempting.

- Sometimes, the smell of food can put you off. If a family member or friend can cook for you that might be a big help.
"I managed to get her to eat more food simply by leaving time in between meals and snacks, and leaving snacks in front of her. I noticed that she would go back to them to take another mouthful from time to time."

**Tips for having more calories and protein in your food**

If you have lost weight or have a small appetite, you might need more calories (energy) and protein in your food to help you put weight back on. This is called a **build-up** or fortified diet. Your dietitian can help you to make changes to your diet.

- Have high calorie foods, such as full fat milk, yoghurt and butter. You can also enrich your food to increase the calories and protein (see page 45).
- If you are eating a higher fat meal, you may need to take more enzymes.
- Try to have a pint of whole milk every day.
- Try to eat more foods that are high in protein, such as meat, fish, milk, cheese, eggs, beans and lentils, nuts, and yoghurt. Try to include protein in at least two of your meals each day.
- Try to have snacks between meals. These can include sweet things like cake, fruit, teacakes and malt loaf. Or savoury things like crumpets, samosas, cocktail sausages, cheese and crackers. High protein snacks such as yoghurts, cheese, nuts or cold meats are particularly good.
- Have a snack instead of a main meal if this is easier.
• Have a pudding once or twice a day – for example, yoghurt, ice cream, sponge pudding, or ready-made desserts.

• Drink about eight cups of fluids a day. Try having nutritious drinks such as milk, fruit smoothies (made with yoghurt, ice cream or whole milk), hot chocolate and fruit juice.

• If you find that drinks fill you up at mealtimes, it may help to have your drinks in between your meals.

• Look at food labels when you’re shopping to help you choose foods that have more calories.

• Avoid low fat or ‘diet’ food.

• Eat what you feel like and try not to worry about ‘normal’ meals. It’s fine if you fancy breakfast cereal for supper, your pudding before your main course, or soup for breakfast.

• Have some fruit and vegetables every day – but don’t fill up on these if it means you can’t eat foods that are high in calories and protein.

Speak to your dietitian if changes to your diet don’t help you put on weight. They may suggest nutritional supplements (see page 20).

There are vegan options available if you want them. For example, Quorn®, tofu, hummus and dairy-free milk, cheese and yoghurt products. Be aware that dairy alternatives, such as soya or oat milk, often have fewer calories and less protein than dairy. Speak to your dietitian, doctor or nurse for advice on getting as many calories and protein as possible if you have a vegan diet.
"I remember going to the store and just buying one of everything that she loves, just in case she fancied it."

**Enriched food**

Enriched food is food that has extra nutrients added to it. This can help you get more calories and protein, without needing to eat more food.

- Enrich milk by mixing two to four tablespoons of skimmed milk powder into a pint of whole milk. Use this instead of ordinary milk in tea, coffee, cereals, porridge, soups, mashed potato and milk-based puddings.

- Add sugar, jam or honey to cereal, porridge, puddings and hot drinks.

- Add cheese, cream, milk powder, lentils or pasta to soup.

- Add grated cheese, cream, butter, margarine, mayonnaise or salad cream to meat, potatoes and vegetables.

- Add cream, evaporated milk or cheese to milk-based sauces.

- Add grated cheese to potatoes, or sprinkle on top of dishes like shepherd’s pie, fish pie or casseroles.

- Add cream, custard, evaporated or condensed milk, ice cream, honey, sugar, dried fruit, or nuts to puddings.

If you have other health problems, such as heart problems, you may have been told in the past to reduce the amount of fat in your diet. But if you have lost weight because of pancreatic cancer, eating some types of higher fat food can help you put weight on. Speak to your dietitian for advice about enriching your food.
If you are still struggling with eating, or are still losing weight on a build-up diet, speak to your dietitian. If you haven’t seen a specialist dietitian, ask your doctor or nurse to refer you to one.

Macmillan Cancer Support has ideas for meals that you may find helpful in their booklet, **The building-up diet.**

"I shopped for food for her and baked and cooked her favourite foods. She was eating but needed tempting now and again. It made me feel that I could do something for her."

**Tips for coping with feeling and being sick**

Feeling and being sick can be a symptom of pancreatic cancer, or a side effect of some treatments, such as chemotherapy.

If you are having problems with feeling and being sick, speak to your medical team. There are anti-sickness medicines that can help. If one type of medicine doesn’t work, try a different type, or a combination of drugs.

You may also find these tips helpful.

- Nausea is often worse when the stomach is empty – even eating a little dry toast may help.

- Try eating plain foods, for example, toast, bread and biscuits.

- Try eating cold foods, which smell less than hot food.

- If the smell of food cooking makes you feel sick, ask someone to cook for you, use ready meals, or get takeaways.
• Try sipping cold fizzy drinks between meals – it may help to let them go flat first.

• Try salty foods, such as crisps and salted nuts.

• Try food or drink containing ginger, such as ginger ale and ginger biscuits.

• Eat meals slowly and try to sit up for an hour after you have eaten.

• Try getting some fresh air before a meal.

• Remember to drink plenty so that you don’t get dehydrated, especially if you are being sick. Try to have nutritious drinks, such as milk, milkshakes, fruit juice, smoothies and soup.

Tips for coping with taste changes

Some treatments such as chemotherapy or surgery can make food taste different. Food may lose its flavour or you might be put off your favourite meal or drink. This normally gets better with time. You might find these tips helpful in the meantime.

• Eat the foods that you do like the taste of and avoid those that you don’t. Try different foods to find some that you like.

• If there are foods that you have gone off, try them again after a few weeks, as your taste may have returned to normal.

• If tea and coffee taste strange, try herbal tea, milky drinks, fruit juices or fizzy drinks.
- If meat tastes bitter or like metal, try marinating it before cooking – for example, leaving it to soak for a couple of hours in wine, barbecue sauce or sweet and sour sauce. Cold meats may taste better served with pickle or chutney.
- If you find you can’t eat meat, other types of protein include fish, eggs, beans, pulses, lentils, milk, yoghurt and cheese.
- Try seasoning your food with strong flavourings, such as mustard, herbs, pepper, spices or lemon juice.
- Or try sharp tasting foods or drinks such as grapefruit, lemon or boiled sweets which may help to stimulate your taste buds and leave a pleasant taste in your mouth.
- If you have a sore mouth or mouth ulcers, it may be best to avoid seasoned or sharp tasting food, as they can sting your mouth.
- Some people find cold or warm foods easier than hot food.
- Try to drink plenty of fluids and keep your mouth and tongue clean. Brush your teeth regularly, and try using a soft toothbrush to clean your tongue.
- Use plastic or wooden spoons for cooking, and reusable plastic cutlery to eat with, rather than metal ones.
- Ask your doctor or nurse to check for oral thrush. This can cause taste changes, but it is usually easy to treat.
Tips for coping with a dry mouth

Some treatments for pancreatic cancer can cause a dry mouth. You may find these tips helpful.

- Sip drinks frequently.
- Suck ice cubes or ice lollies.
- Suck sweets or mints, or chew sugar-free chewing gum to increase saliva.
- Make your food moist with sauces, gravy, custard or cream.
- Keep your mouth clean. Brushing your teeth before and after meals might help.
- Use mouthwash regularly. If you have a sore mouth, ask your dietitian which is the best mouthwash to use.
- Avoid alcohol, caffeine and smoking.
- Use lip balm to soothe dry lips.

Tell your doctor or nurse if you have a dry mouth. They can check you don’t have any problems with your mouth, such as oral thrush. They can also give you medicines which can help with a dry mouth, such as a mouthwash, gels or tablets.
**Tips for coping with diarrhoea**

Pancreatic cancer can cause diarrhoea. Pancreatic enzymes can help manage diarrhoea if it is caused by problems with your digestion. Treatments such as chemotherapy can also cause diarrhoea – your medical team can give you medicines for this.

Diarrhoea can be a sign of infection. If you are having chemotherapy check if you have a temperature over 37.5°C. If you do, phone the emergency number that your chemotherapy team should have given you for urgent advice.

Speak to your doctor or dietitian for advice about diarrhoea – they can work out what’s causing it and how to treat it. The following tips may help.

- Eat small meals often.
- Chew your food well and try to eat slowly.
- Drink plenty (at least two litres a day) to replace fluid you’ve lost, so that you don’t become dehydrated.
- It can help to avoid spicy foods, alcohol, fruit juice, tea and coffee.
- Do not cut out fruit and vegetables completely as they can help to make your poo more solid.
- If you have very bad diarrhoea, you may need to replace lost salts and fluids with salty and sugary foods, isotonic sports drinks, or a rehydrating solution such as Dioralyte®.
Section 11

Questions to ask your medical team

You might find it helpful to write down any questions you have for your medical team to ask at your next appointment.
? Are my symptoms caused by problems digesting my food?

Can I be referred to a specialist dietitian?

How soon can I see a dietitian?

Would pancreatic enzymes help with my diet symptoms?

How do I take pancreatic enzymes?

I still have some symptoms even though I am taking pancreatic enzymes. Should I increase the dose?

What should I do if my symptoms don’t get better?

How will my weight be monitored and managed?

Can you recommend foods to help me put weight back on?

Would nutritional supplements be helpful for me?

Am I at risk of developing diabetes?

Who should I see for help with managing diabetes?

What emotional support is available?
Section 12

Further information and support

In this section, we explain some key medical words, and provide information about our services and other organisations that can support you.
Medical words

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

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

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

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

**Duodenum:** the first part of the small intestine. It absorbs nutrients and water from food passing out of the stomach.

**Glucose:** a sugar found in foods and drinks. Our body turns all carbohydrates that we eat (such as bread, rice, pasta, cereals and sugar) into glucose, and uses it as energy.

**Hormones:** chemical messengers that are carried in the blood and affect different processes in the body.

**Pancreatic enzyme replacement therapy (PERT):** treatment with pancreatic enzymes, which are capsules that can help to break down food.

You can find more medical words on our website at pancreaticcancer.org.uk/medicalwords
Pancreatic Cancer UK services

We are here for everyone affected by pancreatic cancer.

We’re here to support and to listen

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

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

We’re here with the information you need

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

Go to pancreaticcancer.org.uk/informationandsupport

Download or order our free publications at pancreaticcancer.org.uk/publications or call 0808 801 0707

We’re here so you can share

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

Our Living with Pancreatic Cancer Support Days provide local face to face support in an informal setting for people diagnosed with pancreatic cancer: pancreaticcancer.org.uk/supportdays

Local support groups mean you can meet other people to share your experiences: pancreaticcancer.org.uk/supportgroups
Useful organisations

Cancer Research UK
www.cancerresearchuk.org
Helpline: 0808 800 4040 (Mon-Fri 9am-5pm)
Information for anyone affected by cancer.

Diabetes UK
www.diabetes.org.uk
Helpline: 0345 123 2399 (Mon-Fri 9am-6pm)
Information on managing different types of diabetes.

Healthtalk
www.healthtalk.org
Personal experiences presented in written, audio and video formats, including people talking about pancreatic cancer.

Macmillan Cancer Support
www.macmillan.org.uk
Support Line: 0808 808 0000 (Everyday, 8am-8pm)
Provides practical, medical and financial support for anyone affected by cancer, including family members.

Maggie’s Centres
www.maggiescentres.org
Telephone: 0300 123 1801
Centres around the UK and online offer free practical, emotional and social support for anyone affected by cancer.

National Institute for Health and Care Excellence (NICE)
www.nice.org.uk/guidance/ng85
NICE provide guidance, advice and information for health professionals. They have guidelines for the diagnosis and care of people with pancreatic cancer. Read more at pancreaticcancer.org.uk/NICE
This booklet has been produced by the Support and Information Team at Pancreatic Cancer UK.

We make every effort to make sure that our services provide up-to-date, accurate information about pancreatic cancer. We hope this will add to the medical advice you have had and help you make decisions about your treatment and care. This information should not replace advice from the medical team – please speak to your doctor, nurse or other members of your medical team about any questions.

Email us at publications@pancreaticcancer.org.uk for references to the sources of information used to write this booklet.

The photographs in this booklet are of people who have and haven’t been affected by pancreatic cancer.

**Give us your feedback**

We hope you have found this information helpful. We are always keen to improve our information, so let us know if you have any comments or suggestions.

Email us at publications@pancreaticcancer.org.uk or write to our Information Manager at the address on the back cover.
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