

Diet and pancreatic cancer

Support with eating and digestion



Introduction

This booklet is for anyone with pancreatic cancer. Your family may also find it helpful. It explains how pancreatic cancer and treatments for the cancer can affect eating and digestion.

We provide information on how to manage these problems, and who can help. There are also tips for dealing with these symptoms.

Contents

Key words used in this booklet	4
How does pancreatic cancer affect digestion and nutrition?	5
What symptoms are caused by problems with digestion?	8
Who is the dietitian?	15
Pancreatic enzyme replacement therapy (PERT)	16
Get support with PERT and digestion	27
Nutritional supplements	28
Coping with the emotional effects of diet symptoms	30
Physical activity	33
Tips for eating well and dealing with digestion problems	37
More information and support	47

How to use this booklet

You don't have to read this booklet all at once. Look at the contents on page 2, read the sections that feel most helpful, and come back to it if you want to know more. There is more information and support on our website. Find out more at: **pancreaticcancer.org.uk**

Use the symbols below to help you find out where and how you can get more help.



Call our Support Line free on **0808 801 0707**
or email **nurse@pancreaticcancer.org.uk**



Read more on our website at:
pancreaticcancer.org.uk/information
Order or download our free booklets at:
pancreaticcancer.org.uk/publications



Questions to ask your doctor or nurse



Things you can do to help yourself

At the end of the booklet there is:

- A list of common medical words on page 47.
- Contact details of all the organisations we mention on page 50.

Key words used in this booklet

You can find more medical words on page 47.

Absorption: Once your food has been broken down through digestion (see below), nutrients from the food pass into the blood. This process is called absorption.

Calories: A calorie is a measure of how much energy you get from the food you eat.

Diet: Your diet is the food you eat. When we talk about diet in this booklet, we are not talking about the kind of diet people often go on to help them lose weight.

Dietitian: A dietitian is a health professional who provides expert advice about diet and nutrition. Read more on page 15.

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

Enzymes: Enzymes are made by parts of the body, including the pancreas. Different enzymes do different things. Pancreatic enzymes help break down food.

Nutrients and nutrition: Your body needs nutrients, which you get from your food. They include protein, carbohydrates, fats, vitamins and minerals. Nutrition means the food and drink you take into your body and how it affects your health.

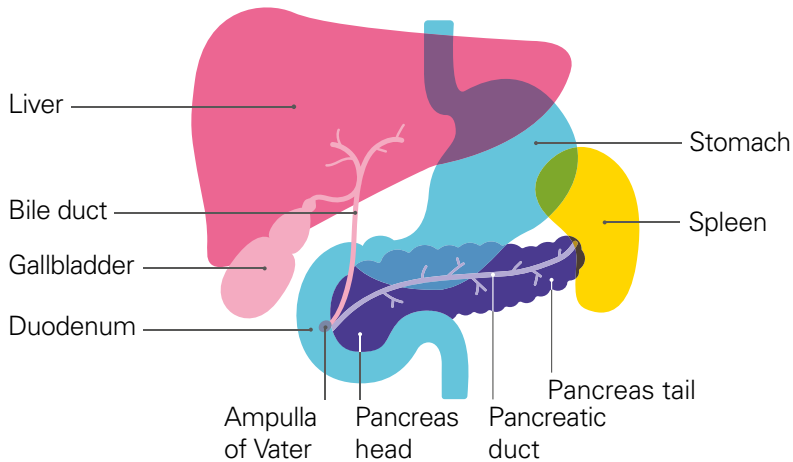
How does pancreatic cancer affect digestion and nutrition?

Key facts

- The pancreas plays an important role in digesting the food you eat. It does this by producing enzymes which break down food.
- Pancreatic cancer can affect this process. This means you don't get all the nutrients you need from your food.
- This can cause symptoms like weight loss, indigestion, tummy pain, feeling sick, bloating and wind, and changes to your poo (see page 8).
- Problems with digestion can be managed with pancreatic enzyme replacement therapy (PERT). This replaces the enzymes normally made by the pancreas.
- The pancreas also produces a hormone called insulin, which controls sugar levels in the blood. When you have pancreatic cancer, you may not produce enough insulin, which can cause high blood sugar levels. This is diabetes (see page 7).
- There are a lot of diets which claim to help cancer, but a lot of these aren't based on good evidence. Do not cut anything out of your diet or take any supplements without speaking to your doctor, nurse or dietitian first.

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. Different pancreatic enzymes help to break down foods containing fat, protein and carbohydrate.

The pancreas and surrounding organs



How does pancreatic cancer affect digestion?

Pancreatic cancer, or surgery to remove the cancer, can reduce the number of enzymes that your pancreas makes. It can also block the enzymes from getting to the duodenum (first part of the small intestine) 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.

This means that food is not properly digested, and the nutrients aren't absorbed. This is called **malabsorption**. It can be managed with pancreatic enzyme replacement therapy. Read more on page 16.

What is diabetes?

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. Diabetes is a condition where the amount of glucose (a type of sugar) in your blood is too high.

If you have pancreatic cancer, you might get a type of diabetes called type 3c diabetes. This is different to other types of diabetes that you may have heard of, like type 1 and type 2 diabetes.

There are treatments for diabetes. Your dietitian (see page 15) or diabetes nurse will help you manage it.



Read more about diabetes and pancreatic cancer at: **pancreaticcancer.org.uk/diabetes**

“ We didn’t know about type 3c diabetes before. Mum had been diabetic for some time and was following a diet and taking medication to manage type 2. The information on 3c really helped us to understand her condition.” Mary

What symptoms are caused by problems with digestion?

Key facts

- You may get symptoms caused by problems digesting your food.
- Symptoms include losing weight, tummy pain, losing your appetite and changes to your poo. There is a full list of digestion symptoms on page 9.
- Weight loss is a very common symptom. It can affect how you feel, and how you deal with other symptoms of the cancer. It can also affect how you deal with treatments such as chemotherapy or surgery.
- Some of the symptoms you may get can also be caused by other things, like treatments for the cancer, or medicines you may be taking.
- Speak to your doctor, nurse or dietitian (see page 15) if you have any of the symptoms on page 9. They can work out what's causing them. The symptoms can often be managed with pancreatic enzymes (see page 16).

“ I lost a lot of weight, but after advice from dietitians it has stabilised. I adjust the Creon dose and my food intake to keep it stable.” Clive

It is 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 10)
- indigestion or heartburn
- runny poo (diarrhoea) – see page 11
- finding it harder to poo (constipation)
- pale, oily, floating poo (steatorrhoea) – see page 11
- tummy pain or discomfort
- bloating or wind
- feeling full up quickly
- feeling sick
- needing to poo quickly, especially after eating.

Some of these symptoms can be caused by other things. For example, chemotherapy can cause side effects including sickness, diarrhoea and appetite loss.

Some treatments or medicines can hide symptoms. Your medical team will help you manage any symptoms you have alongside the medicines. Do not stop taking any medicines without speaking to your doctor, nurse or dietitian first.

Talk to your doctor, nurse or dietitian about any symptoms you have. There are ways to manage your symptoms. This includes taking pancreatic enzymes (see page 16).

Weight loss

Losing weight is a common symptom of pancreatic cancer. Diabetes (see page 7) can also cause weight loss.

Weight loss can affect how you deal with the symptoms of the cancer, and with treatments such as chemotherapy or surgery. Weight loss can be upsetting and affect how you feel generally. Read about emotional support on page 30.

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 16) 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 (energy) and protein. They may recommend enriched food, which has extra nutrients added to it. This can help you get more calories and protein, without needing to eat more. This is called a build-up or fortified diet. You can read more about this on page 39.

Your dietitian may also recommend nutritional supplements, which have extra calories and protein in them (see page 28).

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 33) can help rebuild muscle. This can help you to feel better and have more energy.

Jaundice

Jaundice makes your eyes and skin turn yellow, and you may feel itchy. It can also cause loss of appetite, taste changes, feeling and being sick, dark urine and pale poo.

Jaundice is caused by the cancer blocking the bile duct. The bile duct carries bile from the liver to the small intestine. Jaundice can be treated by putting a tube called a stent into the bile duct to open it up.



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

What is steatorrhoea?

Steatorrhoea is caused by fat in the poo. Your poo may be pale, oily, smell worse than normal, and 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. It is not caused by eating too much fat. You should not reduce fat in your food. Talk to your doctor or dietitian if you have signs of steatorrhoea.

Diarrhoea (runny poo)

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

Diarrhoea can be a sign of an infection. If you are having chemotherapy and have diarrhoea more than four times a day, phone the 24 hour emergency number that your chemotherapy team should have given you.

If your diarrhoea doesn't get better if you are taking enzymes, there could be another cause. Bile acid diarrhoea can happen if there is too much bile in the intestine. Small intestinal bacterial overgrowth (SIBO) can also cause diarrhoea. This is caused by too many bacteria in the intestine. Speak to your doctor, nurse or GP. You may need to see a gastroenterology team, who are experts in problems with the stomach and intestines. There are tests and medicines for bile acid diarrhoea and SIBO.

If the cancer blocks the duodenum

Pancreatic cancer can block the duodenum, which is the first part of the small intestine. This can cause symptoms such as feeling full quickly, feeling and being sick, and losing weight.

A tube called a stent can be put into the duodenum to hold it open so food can pass through. This should stop you being sick, and you should start to feel like eating again. You may need to change your diet to make sure the stent doesn't get blocked.



Read more about duodenal stents, including diet for a duodenal stent, at:
pancreaticcancer.org.uk/duodenalstent



What can I do about symptoms?

- Tell your doctor or nurse about any problems with digestion or eating.
- If you have lost weight, ask your dietitian or nurse for advice.
- Ask about pancreatic enzyme replacement therapy (PERT).
- The tips at the end of this booklet may help you deal with some of these symptoms.



Questions to ask your doctor, nurse or dietitian

Are my symptoms caused by digestion problems?

How can my symptoms be managed?

Will taking pancreatic enzymes help my symptoms?

Could anything else be causing any of my issues with digestion?

How can I keep my weight stable, or put weight on?

What sort of foods can I eat after having a stent put into my duodenum?

Who should I see for help with managing diabetes?



“ Try to get a referral to a dietitian shortly after diagnosis. Getting the ball rolling is key.”
Anne

Who is the dietitian?

If you have problems with digestion or are losing weight, you should see a dietitian. A **specialist dietitian** is an expert in pancreatic cancer and diet. They may be called a:

- pancreatic dietitian – an expert in diet and the pancreas
- hepato-pancreato-biliary (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 have a specialist dietitian. Your doctor or nurse may help you with digestion symptoms, or refer you to a general dietitian.



What can I do?

- If you haven't seen a dietitian and you have digestion problems, ask your medical team or GP to refer you to a specialist dietitian.
- Talk to our specialist nurses on our free Support Line. They can give you information about how to manage diet problems, and tips for speaking to your medical team.

Pancreatic enzyme replacement therapy (PERT)

Key facts

- Pancreatic enzyme replacement therapy (PERT) replaces the enzymes that your body needs to break down and digest food properly.
- It can help you manage the digestion symptoms on page 9.
- Most people with pancreatic cancer will need to take PERT. If you haven't been told about PERT ask your medical team.
- PERT can make a big difference to how you feel. It can also help you cope better with treatments like chemotherapy.
- You take PERT as capsules with your food. You should take it with most food, including meals, snacks, and milky drinks. Read more on page 20.
- You should take more capsules when you are eating larger meals, taking longer to eat, or eating fatty foods.
- PERT only works if you take it correctly. Read more about how to take PERT on page 18.
- PERT is available on the NHS. The brand names are Creon®, Nutrizym®, or Pancrex®.
- All pancreatic enzymes are made from pork. See page 17 for more information about PERT and religious or personal diets.

What is pancreatic enzyme replacement therapy?

Pancreatic enzyme replacement therapy (PERT) replaces the enzymes that your pancreas would normally make. The enzymes come in capsules that you take with food. These help you to digest your food by breaking down carbohydrates, fats and proteins in your food. Most people with pancreatic cancer will need to take PERT.

All pancreatic enzymes are made from pork products, and there is no alternative. You may see vegetarian enzymes in shops or online, but these are not used for pancreatic cancer as there is no evidence that they work. Organisations representing Jewish and Muslim communities have said that pork based treatments are acceptable to use. The Vegetarian Society and Vegan Society have also said that they are acceptable. Talk to your doctor or dietitian if you are allergic to pork products or have concerns about taking enzymes.

If you need PERT, you will need to take it for the rest of your life as your pancreas will not start making enzymes again.

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.



If you have any problems getting pancreatic enzymes, you can speak to our specialist nurses on our free Support Line for information.

Taking pancreatic enzymes

Enzymes are normally taken as capsules that you take with food. Read about what to do if you struggle to swallow capsules on page 21.

How much PERT should I take?

Some brands of enzymes have a number after the name, which shows the dose of enzymes in each capsule. For example, a capsule of 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 given a different brand.

There is no set dose of enzymes for each day. Take as many as you need. 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, you might take two or three capsules containing 25,000 units 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. A healthy pancreas would normally make up to 720,000 units for a small meal.

Most people will need to increase the number of enzymes they take from the starting dose. Your dietitian, doctor or nurse can tell you how to work out the best dose of enzymes for you. They should review the dose regularly.

You will need to take more enzymes for larger meals and for fatty foods, as these need more enzymes to digest them. Don't change what you eat to try to manage your symptoms, as you may not get all the nutrients you need. Just make sure you take enough enzymes for what you are eating. For

example, don't try to reduce fat. Just take more enzymes if you are eating fatty foods. Speak to your doctor or dietitian before making any major changes to your diet.

It may take a few days to notice an effect when you first start to take PERT. For the first few weeks you take PERT, you may find it helpful to keep a food diary (see page 48). Note down what you eat, the dose of enzymes you take, and if this makes your symptoms better. This can help you work out if you are taking enough enzymes with different foods.

Once problems with your digestion start to improve, you may start to eat more. So you may need more enzymes to digest your food.



Download our food and enzymes diary at:
pancreaticcancer.org.uk/diet

“ 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’ve regained a healthy weight. There’s nothing I can’t eat. If a meal looks a bit more fatty than the average I just take an extra capsule.” Iain

How to take pancreatic enzymes

Make sure you take PERT properly, to help it work well.

Do

- Take PERT with all meals and snacks. You should also take it with drinks that are more than half milk.
- Swallow the capsules whole, with a couple of sips of a cool drink. The enzymes won't work properly if you take them with hot drinks. Read about what to do if you struggle to swallow capsules on page 21.
- Take half the capsules with the first few mouthfuls of food. Spread the other half out during the meal.
- You will need more enzymes for larger meals or meals with several courses. You will also need more for fatty food. For example, take extra capsules with takeaways, roasted or fried food, puddings, or food with lots of cheese or chocolate.
- If you take nutritional supplements (see page 28), you will need to take enzymes with these as well.

Do not

- Do not chew the capsules as this can cause a sore mouth.
- Don't worry if you forget to take your enzymes. Just take the usual dose with your next meal or snack. You may have some symptoms for the next day or two, but this will improve.
- Do not store the capsules in hot places as this can stop them working properly. For example, do not leave them in the car, near radiators, in direct sunlight, or in pockets.
- You don't need to take the capsules if you are not eating or drinking. They only work when taken with food.

There are some foods and drinks that you do not need to take enzymes with. These include:

- drinks with only a splash of milk (including tea or coffee)
- fruit juice, fruit squashes, or fizzy drinks (except fruit smoothies)
- alcoholic drinks, unless they contain milk or egg
- small amounts of fruit or dried fruit
- small amounts of plain vegetables (except potatoes, beans, avocados and pulses such as lentils)
- sugary sweets like jelly babies, wine gums, mints, fruit pastilles or marshmallows.

What if I find it hard to swallow the capsules?

It is best to take the capsules whole as they work better this way. If you find it hard to swallow the capsules, speak to your doctor, nurse or dietitian. There may be smaller capsules available. You will have to take more of these to make up the dose.

You can open the capsules and mix the granules inside with a teaspoon of cold, soft, acidic food such as smooth apple sauce, fruit puree, apricot jam or yoghurt. Swallow this straight away, then rinse your mouth with a small amount of a cool drink. This is to make sure you swallow all the granules. Do not chew the granules. If the granules are not swallowed quickly, or get stuck between your teeth or dentures, they can cause mouth ulcers.

Do not mix the granules with hot foods or drinks, as this will stop the enzymes working. You should not sprinkle the granules on a plate of food, as they won't work this way either.



Speak to our specialist nurses on the Support Line if you have any questions about how to take PERT.

What if the enzymes do not help?

Pancreatic enzymes only work when they are taken with food, and taken properly. See page 20 for some tips. If you are taking enough enzymes, your symptoms should get better, and for some people the symptoms may go away.

If you still have symptoms or you are losing weight, speak to your dietitian, nurse or doctor. They can check if you are taking enough enzymes, and make sure you are taking them properly. Some people need to change the brand of enzymes they take.

Sometimes, the doctor will give you medicines called proton pump inhibitors (PPIs). PPIs include omeprazole and lansoprazole. They stop the stomach from producing too much acid, which can affect how well the enzymes work. Usually, PPIs are tablets or capsules that are taken once or twice a day. Speak to your doctor about these medicines and ask if they would help.

Other causes of symptoms

If you are taking PERT and you still have symptoms, there may be other causes for these. For example, opioid painkillers (such as morphine), antibiotics, iron supplements, some anti-sickness medicines or chemotherapy can all cause changes to your poo.

Speak to your medical team about your symptoms.



“ 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 straight away less discomfort on eating. My energy levels started to increase and I have very slowly started to gain some weight.”

What happens if I take too many enzymes?

Any extra enzymes you take will pass through your body and come out in your poo. They won't cause any harm. If you take lots more than you need it may cause some itching around your anus (bottom). This is nothing to worry about.

If you feel unwell, speak to your doctor or nurse. Make sure you take your enzymes at your next meal as usual.

Are there any side effects of pancreatic enzymes?

It is not common to get side effects from enzymes, but some people get tummy pain, wind, 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. Try keeping a food diary for a few days to see what dose helps (see page 48). Or your doctor may need to change the brand of enzymes you take.

Some people may have constipation (when you find it harder to poo). There could be many reasons for constipation. If you had runny poo before because of digestion problems, taking PERT may stop this, and you might feel constipated. Other medicines, such as opioid painkillers, can cause constipation. You may need a medicine called a laxative if you take opioids.

If you have constipation, speak to your doctor or nurse. They can work out what's causing it and how to manage it. Do not stop taking your PERT.

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

If you go into hospital

If you go into hospital, tell the staff that you need to take PERT to help you digest your food. Sometimes hospital staff only give PERT when they give other medicines, but this might not be at meal times. Explain that PERT only works if you take it when you eat, and that you need more if you are eating more.

Ask the hospital staff if you can keep PERT with you to take with any food, including snacks and milky drinks.

Some hospitals may let you do this. You could show them this booklet. If they don't let you keep it, speak to your medical team or dietitian as they may be able to help.



What can I do when taking PERT?

- If you have not been prescribed PERT and have any digestion symptoms, ask your doctor, dietitian or nurse about it.
- Take more PERT if you still have symptoms.
- Keep a diary of what you eat and how much PERT you take each time. This will help you find the right dose for different foods.
- If you have any questions about how to take PERT, get in touch with our specialist nurses on our Support Line.
- Tell your dietitian, nurse or doctor if you are still getting symptoms even when you are taking PERT. There may be another cause, which they can help you with.



Questions to ask your doctor, nurse or dietitian

Would pancreatic enzymes help with my symptoms?

How do I take pancreatic enzymes?

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

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

“ 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.”

Get support with PERT and digestion

PERT can make a big difference to how you feel, but we know it can sometimes be hard to get the right dose. Speak to your dietitian, nurse or doctor with any questions.

We also provide a lot of support to help you make sure you are taking it properly and deal with digestion problems.



Speak to our specialist nurses on our free Support Line about PERT or symptoms.

Our online support session, **Managing nutrition and pancreatic enzymes** is hosted by our specialist nurses. It's a chance to learn more about managing your diet and PERT and meet others affected by pancreatic cancer.

We also run our **Ask a Dietitian** webinar, where dietitians explain more about diet and PERT. You can watch previous webinars, or you can sign up to attend future sessions.



Book your place on a support session or webinar at: **pancreaticcancer.org.uk/support**

Nutritional supplements

If you are losing weight or struggling to eat, your dietitian will suggest some changes that you can make to get more calories (energy) and protein in your diet. If changes to your diet don't help, you may be given nutritional supplements. These can help you get the calories and nutrients you need.

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

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

Vitamin and mineral supplements

If you are not digesting your food properly, you may not be getting enough vitamins and minerals. Ask your doctor or dietitian if vitamin and mineral supplements would help, and how to take them.

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.

Vitamin and mineral supplements are often absorbed better if you take them with a meal. If you are taking any supplements that contain oil (like cod liver oil), take PERT with these.



Questions to ask your doctor, nurse or dietitian

How should I take the supplements?

Can I take them if I have a vegetarian, vegan or other special diet? Are there other options?



Coping with the emotional effects of diet symptoms

Key facts

- Food is an important part of everyday life for many people, and eating with friends and family can be an important social activity.
- Problems with digestion and diet are hard to deal with and can affect how you feel. For example, you may feel more anxious or down than usual.
- Try not to feel pressured to eat when you are not able to as this may make you feel more stressed. Eat what you can, when you can. Try explaining this to family and friends.
- Your family can be a huge support. Try talking to them about how you feel and things that you might find helpful, such as having smaller meals.
- Gentle physical activity may help to improve how you feel. Get medical advice before doing any exercise and only do what you can manage. Read more on page 33.
- You may find speaking to others in a similar situation helpful. Find out about how we can connect you with other people affected by pancreatic cancer on page 27.

Some people find that worries about eating and symptoms can affect their mood. 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. And low mood can also mean you don't want to eat as much.

Symptoms such as diarrhoea or sickness can be stressful and make it harder to eat. You may 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.

Finding ways to manage your diet and digestion problems 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.

Get some support

Your family and friends may worry about you, and whether you are eating enough. But they can also be a huge support.

Try talking to them about how the cancer has affected your eating and digestion, and how this has made you feel. Let them know what they can do to help. For example, some people with pancreatic cancer 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 to others in a similar situation helpful. We have an online discussion forum where you can connect with others affected by pancreatic cancer. We also hold online support sessions, hosted by our nurses, which provide a chance

to meet other people with pancreatic cancer. We often hold one on managing nutrition and pancreatic enzymes. Find out about how we can support you on page 27.



Read more about dealing with the emotional impact of pancreatic cancer at:

pancreaticcancer.org.uk/coping

Find out more about the support we offer at:

pancreaticcancer.org.uk/support



What can I do?

- Get support if your cancer or the symptoms are affecting your mood, or making you feel anxious, down or stressed.
- Dealing with any digestion symptoms can improve how you feel. If you are taking PERT but still have symptoms, speak to your dietitian, nurse or doctor.
- If you are not taking PERT, ask your dietitian or nurse whether it would help.
- Try speaking to a family member or friend about how you are feeling, and how they can help.

Physical activity

Key facts

- 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.
- But it can be hard to be active when you have pancreatic cancer.
- Try to do some gentle exercise when you can. This could be things like going for a walk, light housework or gardening.
- It is important to exercise within your own limits. Take it easy and only do what you are able to 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.

“ 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.”

“ I found that a little physical activity not only boosts mood and body image but can improve appetite.” Chris

If you are eating or drinking less, or doing less physical activity, you may lose some muscle and strength. Gentle physical activity can help improve your strength and fitness. This can help you to deal with symptoms, and improve how you feel generally.

Find something you enjoy doing, and take it easy. You may find that some days are better than others. You might find it easier to exercise with a friend or relative. But make sure you are in control of how much you do.

Speak to your doctor or nurse before starting any kind of exercise plan. They can advise on the best activities for you, and any safety issues to be aware of. If you have diabetes, be aware that exercising can affect your blood sugar levels.

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

Some cancer support services run exercise courses for people with cancer. Examples might include yoga, tai chi or walking groups. Ask your GP about any local services.

Macmillan Cancer Support has a lot of information about keeping active.

What sort of exercise could help?

For most people, doing gentle exercise when they are able to would be suitable. This could include:

- going for a short walk
- 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. Speak to your doctor or physiotherapist before doing vigorous exercise.

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



Questions to ask your doctor or nurse

Can physical activity help with my symptoms?

What sort of physical activity can I do?

Would it help to be referred to a physiotherapist?

Can I keep doing the exercise I did before?



“ For people who were very fit before their diagnosis it is hard to accept that only gentle exercise should be undertaken. I was advised that, although my external scars healed quickly, internal healing takes much longer and that helped me to be patient with myself.”
Chris

Tips for eating well and dealing with digestion problems

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



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

General tips

- Pancreatic enzyme replacement therapy (PERT – see page 16) can help with digestion symptoms. Don't forget to take this when you eat.
- People often think they need to follow special recipes when they have pancreatic cancer, but this is not usually the case. It's fine to eat the foods you would normally eat, or to try something new.
- There are no foods that you should stop eating because of the cancer.
- If you can't manage large portions, try eating smaller amounts more often, for example three small meals and three snacks a day.

- Use smaller plates so that your meals feel easier to manage.
- Every mouthful helps. If you feel sick or very full, have a break and eat some more an hour or so later.
- 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, so they are available 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 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 getting more calories and protein into 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 41).
- If you are eating a higher fat meal, you will need to take more enzymes.
- Use high fat foods in your usual recipes when you are cooking. For example, use full fat milk, margarine, butter or ghee.
- Try to have a pint of whole milk every day. You can add it to other foods and drinks, such as hot drinks, cereal, soups and sauces.
- 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 all three 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, and cheese. 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, ice cream or kulfi, sponge pudding, rice pudding, sweet pastries and pies or ready-made desserts.

- If you can, try to 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.
- 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 ice cream 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.
- Avoid low fat, fat free or 'diet' food.
- There are vegan options available if you need them. For example, Quorn, tofu, hummus and dairy-free milk, cheese and yoghurt products.
- Dairy alternatives, such as soya or oat milk, often have fewer calories and less protein than dairy. Try to choose options that are higher in fat and contain calcium and vitamins.
- Speak to your dietitian, doctor or nurse for advice on getting as many calories and protein into your diet as possible if you have a vegan diet or any other special dietary needs.

Speak to your dietitian if changes to your diet don't help you put on weight. They may suggest nutritional supplements (see page 28).

“ What’s needed is the nutrition and getting as many calories as you can. That was a game changer to know that information. It definitely helped when mum lost her appetite. It meant we could encourage her to eat doughnuts and anything else that she fancied. So she was very happy to have those things!” Mary

Enriched or fortified food

Enriched or fortified food 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, cream 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 it on top of dishes like shepherd’s pie, rice and peas, 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. You might want to choose options such as olive oil, nuts, seeds, and oily fish. Speak to your dietitian for advice about enriching your food.

If you are still struggling with eating, or you 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 high-calorie 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 dealing with feeling and being sick

Feeling sick (nausea) and being sick (vomiting) 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.

- Nausea is often worse when the stomach is empty. Even eating a little dry toast may help.
- Try plain foods, for example, toast, plain rice or biscuits.
- 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, ginger teas and ginger biscuits.
- Eat meals slowly and try to sit up for an hour afterwards.
- Drink plenty if you are able to, so that you don't get dehydrated. This is where your body loses more water than it takes in. This is especially important if you are being sick. Try to have nutritious drinks, such as milk, milkshakes, lassis, fruit juice, smoothies and soup.
- If the smell of cooking makes you feel sick, ask someone to cook for you, use ready meals, or get takeaways.
- Try eating cold foods, which smell less than hot food.
- Try getting some fresh air before a meal. If the weather is good, eat outside, or eat by an open window.

If you are being sick a lot and struggling to keep down food or drink, phone your doctor or nurse straight away. This can be a sign that something is wrong. It can lead to dehydration. Your medical team can treat this, so get their advice.



Read more about sickness at:
pancreaticcancer.org.uk/sickness

Tips for taste changes

You might find that some treatments like chemotherapy or surgery can make food taste different. You may find these tips helpful.

- Try to eat what you can, when you can. Try different foods to find some that you like.
- If there are foods that you no longer enjoy, try them again after a few weeks, as your taste may have returned to normal.
- If meat tastes bitter or like metal, try marinating it before cooking. For example, leave it to soak for a couple of hours in wine, soy sauce, barbecue sauce or sweet and sour sauce. Or cook it slowly at a low heat.
- Cold meats may taste better served with pickle or chutney.
- If you can't eat meat, other types of protein include fish, eggs, beans, lentils, tofu, milk, yoghurt and cheese.
- Try adding strong seasonings, such as herbs, spices, lemon or lime juice.
- Cold or warm foods may be easier to eat than hot food.
- If tea and coffee taste strange, try herbal teas, fruit juices or fizzy drinks instead.
- Try to drink plenty of fluids and keep your mouth and tongue clean.
- Use plastic or wooden spoons for cooking and to eat with, rather than metal ones.
- Ask your doctor or nurse to check for oral thrush. This can cause taste changes and sickness, but it is usually easy to treat.

“ I remember going to the store and just buying one of everything that she loves, just in case she fancied it.”

Tips if you have a dry mouth

Some treatments for pancreatic cancer can cause a dry mouth.

Tell your doctor or nurse if you have a dry mouth. They can check there are no 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, spray, gels or tablets.

- Sip drinks frequently.
- Suck ice cubes or ice lollies. Some nutritional supplements come as a fruit juice, which can be frozen into ice cubes or ice lollies.
- Suck sweets or mints, or chew sugar-free chewing gum to increase saliva.
- Have food with sauces, gravy, custard or cream.
- Keep your mouth clean. Brushing your teeth before and after meals might help.
- Use mouthwash regularly. If your mouth is sore, ask your dietitian which one to use.
- Use lip balm to soothe dry lips.
- Avoid alcohol, caffeine and smoking.
- Ask your doctor, nurse or dietitian about treatments for a dry mouth.

Tips for when you have diarrhoea (runny poo)

Speak to your doctor or dietitian for advice about diarrhoea. They can work out what's causing it and how to treat it. Read more about diarrhoea and how it is managed on page 11.

- Eat small meals often.
- Drink as much as you can manage, to help prevent dehydration.
- It can help to avoid spicy foods, alcohol, fruit juice, tea and coffee.
- Do not stop eating fruit and vegetables, unless your doctor or dietitian has told you to. They are important for your health and can help to make your poo more solid.
- If you have very bad diarrhoea, you may need to replace salts and fluids that you have lost. Eat salty and sugary foods, or drink sports drinks that say they are isotonic on the label. Or drink a rehydrating drink such as Dioralyte®.



Read more about diarrhoea at:
pancreaticcancer.org.uk/bowelhabits

More information and support

Medical words explained

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

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

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

Chemotherapy: treatment using drugs to destroy cancer cells.

Dehydration: when the body loses more water than it takes in. It might happen if someone is being sick a lot, or if they have diarrhoea (runny poo).

Glucose: a sugar found in food and drink. 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.

Insulin: a hormone that is produced by the pancreas and helps to control blood sugar levels.



You can find more medical words on our website at: **pancreaticcancer.org.uk/medicalwords**

Food and enzymes diary

Use this diary to record what you eat, the enzymes you take, and any changes to your symptoms. This may help you work out how much PERT you need to take with different foods. You can also download the diary at: pancreaticcancer.org.uk/diet

Meal	What I ate	Amount of enzymes I took	Any issues, including symptoms that got better or worse	Things to think about and note down
Example	<i>2 poached eggs on toast and butter</i> <i>Tea with a dash of milk</i> <i>Milk based nutritional supplement</i>	<i>2 Creon 25,000</i> <i>0</i> <i>1 Creon 25,000</i>	<i>Some bloating and increased wind</i> <i>Not feeling too bad</i> <i>Some discomfort - try 2 capsules tomorrow</i>	Include: <ul style="list-style-type: none">Any changes to PERT and the difference this madeThings to discuss with the dietitian or nurseAdvice from the dietitian or nurse
Breakfast				
Snack				

Meal	What I ate	Amount of enzymes I took	Any issues, including symptoms that got better or worse	Things to think about and note down
Lunch				
Snack				
Dinner				
Snack				

Useful organisations

Cancer Research UK

cancerresearchuk.org

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

Information for anyone affected by cancer.

Diabetes UK

diabetes.org.uk

Helpline: 0345 123 2399 (Mon-Fri 9am-6pm)

Information on managing different types of diabetes.

Healthtalk

healthtalk.org

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

Macmillan Cancer Support

macmillan.org.uk

Support Line: 0808 808 00 00 (Every day, 8am-8pm)

Provides practical, medical and financial support for anyone affected by cancer.

Maggie's

maggies.org

Tel: 0300 123 1801

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

This booklet has been produced by the Support and Information Team at Pancreatic Cancer UK.

We try to make sure that our services provide accurate information about pancreatic cancer. We hope this will add to the medical advice and help you make decisions about treatment and care. This information should not replace advice from the medical team – please speak to the medical team about any questions.

Email us at **publications@pancreaticcancer.org.uk** for the sources used to write this booklet. If you have any feedback, email us or write to our Information Manager.

The photographs in this booklet are of people affected by pancreatic cancer, as well as people who haven't been affected by pancreatic cancer.

We would like to thank the following people who reviewed this information.

- Anna Burton, Specialist Pancreatic Dietitian, Leeds Teaching Hospitals NHS Trust
- Chloé McMurray, Senior HPB Dietitian, Nutrition & Dietetics, North Tees and Hartlepool NHS Foundation Trust
- Emma Westmancoat, HPB Clinical Lead Dietitian, Nottingham University Hospitals NHS Trust
- Mary Phillips, Advanced Clinical Practitioner / Senior Specialist Dietitian (Hepato-pancreatico-biliary surgery), Royal Surrey Hospital NHS Foundation Trust
- Sarah d'Agar, Specialist Oncology Dietitian, University Hospitals Sussex NHS Foundation Trust
- Pancreatic Cancer UK Lay Information Reviewers
- Pancreatic Cancer UK Specialist Nurses

MI_14564514_05.12.2024_V_1

Review Date: 30.09.2027

Pancreatic Cancer UK

Queen Elizabeth House
4 St Dunstan's Hill
London EC3R 8AD

020 3535 7090
enquiries@pancreaticcancer.org.uk
pancreaticcancer.org.uk

© Pancreatic Cancer UK March 2023
Review date March 2025

Registered charity number 1112708 (England and Wales), and SC046392 (Scotland)