Pancreatic
CANCER UK

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

Contents

How to use this booklet

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

Use the colours 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, nurse or dietitian

Things you can do to help yourself

At the end of the booklet you will find:

- A list of common medical words on page 48.
- Contact details for organisations offering support on page 50.

Key words used in this booklet

You can find more medical words on page 48.

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 a diet to help someone lose weight.

Dietitian: A dietitian is a health professional who provides expert advice about diet and nutrition. Read more on page 16.

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

Enzymes: Enzymes are made by parts of the body, including the pancreas. Different enzymes do different things. Pancreatic enzymes help to 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 have and how it affects your health.

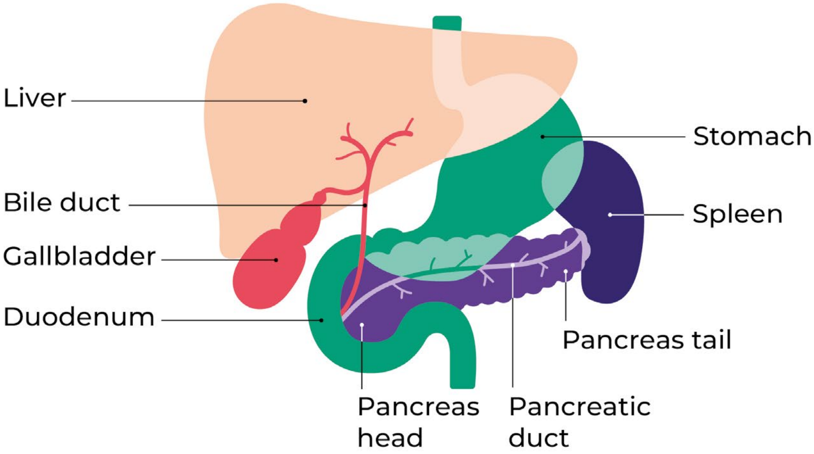
How does pancreatic cancer affect digestion and nutrition?

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 9).
- Problems with digestion can be managed with pancreatic enzyme replacement therapy (PERT). This replaces the enzymes normally made by the pancreas. Read more on page 17.
- 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 called diabetes (see page 7).
- There are many diets which claim to help cancer, but these are often not based on reliable 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 is called pancreatic exocrine insufficiency (PEI).

It means that food is not properly digested, and the nutrients are not absorbed. This is called malabsorption. It can be managed with **pancreatic enzyme replacement therapy (PERT).** Read more about PERT on page 17.

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 16) 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 type 3c really helped us to understand her condition.”
>
> **Mary**

> "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**

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 10.
- 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 cope 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 16) if you have any of the symptoms. They can work out what's causing them. The symptoms can often be managed with PERT (see page 17).

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 11)
- indigestion or heartburn
- frequent runny poo (diarrhoea) – see page 13
- finding it harder to poo (constipation)
- pale, oily, floating poo (steatorrhoea) – see page 12
- tummy pain or discomfort
- bloating or wind
- feeling full up quickly
- feeling sick
- needing to poo quickly, especially after eating.

Talk to your doctor, nurse or dietitian about any symptoms you have. There are ways to manage these symptoms, including PERT (see page 17).

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

Some treatments or medicines can hide symptoms. For example, medicine for diarrhoea may manage it, but the diarrhoea could be due to digestion problems and need PERT.

Your medical team will help you manage your medicines and any symptoms you have. Do not stop taking any medicines without speaking to your doctor, nurse or dietitian first.

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 31.

What can help with weight loss?

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 PERT (see page 17) 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 40.

Your dietitian may also recommend nutritional supplements, which have extra calories and protein in them (see page 30).

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 34) 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 more 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 be 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 notice any changes to your poo.

Diarrhoea (frequent runny poo)

Pancreatic cancer can cause diarrhoea. PERT can help manage this if it is caused by problems with 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 PERT, there could be another cause. **Bile acid malabsorption (BAM)** can happen if there is too much bile in the intestine. **Small intestinal bacterial overgrowth (SIBO)** is caused by too many bacteria in the intestine. Both can cause diarrhoea. Sometimes if you have constipation, some watery poo which looks like diarrhoea can leak out. This is called **overflow diarrhoea.** If you have diarrhoea and PERT isn't helping, speak to your doctor, nurse or GP.

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

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 open it, 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 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 PERT help my symptoms?

Could anything else be causing any of my digestion issues?

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?

What support is there for my family?

Who is the dietitian?

If you have problems with diet, 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.

> "Try to get a referral to a dietitian shortly after diagnosis. Getting the ball rolling is key." **Anne**

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 10.
- 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 19.
- You should take more capsules when you are eating larger meals, taking longer to eat, or eating fattier foods.
- PERT is available on the NHS. The brand names are Creon®, Nutrizym® and Pancrex®.

What is PERT?

Pancreatic enzyme replacement therapy (PERT) replaces the enzymes that your pancreas would normally make. PERT comes as capsules that you take when you eat. 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.

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 PERT, ask your doctor, nurse or dietitian about it. You could take this booklet with you to show them.

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

What is PERT made from?

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 it is acceptable to use pork based treatments. 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.

Taking PERT

PERT is normally taken as capsules that you take when you eat.

How much PERT should I take?

Some brands of PERT 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 PERT for each day. Take as much 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 Creon 25,000 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 about 720,000 units for a small meal.

> “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.”
>
> **Anne**

Getting the dose right

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

What can help?

- Take more PERT 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 PERT for what you are eating.
- For example, don't try to reduce fat. Just take more PERT if you are eating fatty foods.
- Speak to your doctor or dietitian before making any major changes to your diet.
- To begin with, you may find a food diary helps to work out if you are taking enough PERT. Note down what you eat, the dose of PERT, and if it helps your symptoms. Download our **Diet diary** at: **pancreaticcancer.org.uk/diet**

It may take a few days to notice an effect when you first start to take PERT.

Once problems with your digestion start to improve, you may start to eat more, and may need more PERT.

> “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 enzyme replacement therapy (PERT)

Make sure you take PERT properly, so it works well.

Do

- Take PERT with all meals and snacks. You should also take it with drinks that are made up of more than half milk.
- Swallow the capsules whole, with a couple of sips of a cool drink. The PERT won’t work properly if you take it with hot drinks. Read about what to do if you struggle to swallow capsules on page 23.
- Take half the capsules with the first few mouthfuls of food. Spread the other half out during the meal.
- You will need more PERT 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 30), you will need to take PERT 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 PERT. Just take the usual dose with your next meal or snack. You may get some symptoms but keep taking your PERT and this will soon 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 PERT 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.

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

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.

What can I do?

- 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 fruit 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. If the granules are not swallowed completely, they might get stuck around your gums or mouth and could cause ulcers.
- Do not chew the granules.
- Do not mix the granules with hot foods or drinks, as this will stop the PERT 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 PERT does not help?

PERT only works when it is taken with food and taken properly. See page 21 for some tips. If you are taking enough, your symptoms should get better. 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 PERT, and make sure that you are taking it properly. Some people may need to change the brand of PERT they take.

Proton pump inhibitors (PPIs)

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 PERT works.

Usually, PPIs are tablets or capsules that you take 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 capsules. 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 PERT at your next meal as usual.

Are there any side effects of PERT?

Side effects from PERT are not common. Some people get tummy pain, wind, or they may feel or be sick. This is often because the dose of PERT is too low, rather than a side effect.

Increasing the dose may help. Try keeping a food diary for a few days to see what dose helps. Or your doctor may need to change the brand of PERT you take.

Download our **Diet diary** at:
pancreaticcancer.org.uk/diet

Constipation and PERT

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 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 mealtimes. 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.

> "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."

What can help 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.
- 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.
- If you have any questions about how to take PERT, ask your dietitian, nurse or doctor.
- You can also get in touch with our specialist nurses on our Support Line.

Questions to ask your doctor, nurse or dietitian

Would pancreatic enzyme replacement therapy help with my symptoms?

How do I take PERT?

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

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

Get support with PERT and digestion

PERT can make a big difference to how you feel, but it can sometimes be hard to work out how 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 with any questions about how to take PERT or managing symptoms.

You can call them on **0808 801 0707**
or email **nurse@pancreaticcancer.org.uk**

We also run our diet webinars, where dietitians explain more about diet and PERT and you can ask questions. You can watch previous webinars or sign up to attend one.

Find out more about how we can support you at:
pancreaticcancer.org.uk/support

Nutritional supplements

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

Types of nutritional supplements

You need to take PERT with most nutritional supplements. Your dietitian can explain how to take them and how much PERT you need.

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

Vitamin and mineral supplements

If you are not digesting your food properly, you may not get enough vitamins and minerals. Ask your doctor or dietitian if vitamin and mineral supplements would help.

Don’t take very high doses of these supplements, and don’t take them 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 take any supplements containing oil (like cod liver oil), take PERT with these.

Coping with the emotional effects of diet symptoms

Key facts

- Problems with digestion and diet are hard to deal with and can affect how you feel. For example, you may feel worried about it or have low mood.
- Try not to feel pressured to eat when you are not able to as this may make you feel more stressed. Try explaining this to family and friends. Eat what you can, when you can.
- 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 34.
- 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 32.

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.

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

Get some support

Your family and friends can be a huge support. Talk to them about how the cancer has affected your digestion, and how this has made you feel. Let them know what can 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.

It may help to speak to others in a similar situation. We can help you connect and share your experience with others. We also have stories from people affected by pancreatic cancer on our website. No one understands the experience of pancreatic cancer quite like this community.

Find out more about the support we offer at: **pancreaticcancer.org.uk/support**

Read about the emotional impact of pancreatic cancer at: **pancreaticcancer.org.uk/coping**

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 gently and only do what you can 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. They left a printout 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**

How can physical activity help?

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.

How to get started

Find something you enjoy doing and take it gently. You might find it easier to exercise with a friend. 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, remember 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 manage illness and symptoms through movement and exercise.
- **Occupational therapists** provide equipment and help with everyday activities, such as dressing.

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 have a lot of information about keeping active.

What sort of exercise could help?

For most people, doing gentle exercise when they can 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) can help with digestion symptoms.** Don’t forget to take this when you eat. Read more on page 17.
- 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. Just make sure you take PERT with it.
- **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 42).
- **If you are eating a higher fat meal, you will need to take more PERT.**
- **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, dairy products, 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 tofu, hummus and dairy-free milk, cheese and yoghurt.
- Dairy alternatives, such as soya or oat milk, often have fewer calories and less protein than dairy. **Choose higher fat options that contain calcium and vitamins.**
- **If you have any special dietary needs, speak to your dietitian, doctor or nurse.** They can advise how to get more calories and protein into your diet.

Speak to your dietitian if you don’t put on weight. They may suggest nutritional supplements (see page 30).

> “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, salad cream or mayonnaise to meat, potatoes and vegetables.
- Add cream, evaporated milk or cheese to milk-based sauces.
- Add grated cheese to potatoes. Sprinkle it on top of dishes like shepherd’s pie, rice and peas or casseroles.
- Add cream, custard, evaporated or condensed milk, ice cream, honey, sugar, dried fruit or nuts to puddings.

If you are still struggling with eating, or 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 have ideas for high-calorie meals in their booklet, The building-up diet.

What if you have other health problems?

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.

> "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 and being sick can be a symptom of the cancer, or side effect of some treatments, like chemotherapy.

Speak to your medical team. There are anti-sickness medicines that can help.

- **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 can, 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 food or drink down, phone your doctor or nurse straight away. This can mean something is wrong. It can also lead to dehydration. Your medical team can treat this.

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

Tips for taste changes

You might find that some treatments like chemotherapy can make food taste different. These tips may help.

- **Try to eat what you can, when you can.** Try different foods to find some that you like.
- **If you no longer enjoy some foods, try them again** after a few weeks. 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 with pickle or chutney.**
- **If you can’t eat meat, there are other types of protein.** These 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 wooden spoons for cooking and plastic spoons to eat with,** rather than metal ones.
- **Ask your doctor or nurse to check for oral thrush.** This can cause taste changes but 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. They can also give you medicines to help with a dry mouth, such as a mouthwash, spray, gels or tablets.

- **Sip drinks frequently.**
- **Suck ice cubes or 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 if you have diarrhoea (frequent 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 13.

- **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 isotonic sports drinks. Or drink a rehydrating drink such as Dioralyte®.
- **You may worry about going out in case you can't find a toilet** when you need it. Macmillan Cancer Support have a toilet card that helps you access toilets in places like cafes and shops when you are out.

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 (frequent runny poo).

Glucose: a sugar found in food and drink. Our body turns all carbohydrates that we eat (such as bread, rice, pasta and cereals) 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

We are here for you

If you or someone you care about has pancreatic cancer, we are here to help.

Find out more at: **pancreaticcancer.org.uk/support**

Our specialist nurse Support Line

Our specialist nurses are experts in pancreatic cancer. They can talk for as long as you need, as often as you like. Whether you have a long list of questions or don't know where to start, they will provide practical, honest information to help you make the right choice for you.

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

Information about pancreatic cancer

Our website, videos and publications can answer your questions. The information can help you understand what you have heard from your medical team, and make decisions about your treatment and care.

Go to: **pancreaticcancer.org.uk/information**
Download or order our free publications at
pancreaticcancer.org.uk/publications or
call **0808 801 0707**

Webinars

Our regular webinars cover topics including diet, wellbeing and treatment. They are hosted by our friendly nurses and other experts, are informal, and you can ask questions. You can look back at previous sessions, or sign up to one.

Go to: **pancreaticcancer.org.uk/webinars**

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.

Macmillan Cancer Support

macmillan.org.uk
Support Line: 0808 808 00 00 (Every day, 8am-8pm)
Practical, medical and financial support for anyone affected by cancer.

Maggie's

maggies.org
Telephone: 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 medical advice and help you make decisions about treatment and care. This information should not replace advice from the medical team – please speak to them 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.

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