

How to manage problems with digestion using pancreatic enzyme replacement therapy (PERT)

This fact sheet is for anyone who has been diagnosed with pancreatic cancer. Your family may also find it helpful. It explains how to manage problems with digestion, which are common if you have pancreatic cancer.

The pancreas plays an important role in digestion, as it produces enzymes that help to break down the food we eat. Nutrients from the food are then absorbed into the blood and used by the body. Pancreatic cancer and surgery to remove the cancer can reduce the number of enzymes your pancreas makes. This means that you can't digest your food properly, so the nutrients in the food aren't absorbed. This is called **malabsorption**.

These digestion problems can be managed by capsules that replace the enzymes your pancreas would normally make. This is called **pancreatic enzyme replacement therapy (PERT)**. This fact sheet explains how to take PERT.

Speak to your dietitian, doctor or nurse for support with digestion problems and PERT.



You can also speak to our specialist nurses on our confidential Support Line. Call free on **0808 801 0707** or email **nurse@pancreaticcancer.org.uk**

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What is pancreatic enzyme replacement therapy (PERT)?

Pancreatic enzyme replacement therapy involves taking capsules that replace the enzymes that your pancreas would normally make. These help you to digest your food. They break down the fats, carbohydrates and proteins in your food. Most people with pancreatic cancer will need to take these capsules.

Taking these enzymes can help manage the symptoms caused by digestion problems. Symptoms include:

- losing your appetite
- losing weight, or struggling to put weight back on
- indigestion or heartburn
- runny poo (diarrhoea)
- finding it harder to poo (constipation)
- pale, oily, floating poo that smells horrible and is difficult to flush – this is called steatorrhoea and is caused by fat in the poo
- tummy pain or discomfort
- bloating or wind
- feeling full up quickly
- needing to poo urgently, especially after eating.

If you have problems with digestion or are losing weight, you should see a dietitian. Dietitians give expert advice about diet and nutrition. They can help you deal with any problems with digestion, manage weight loss, and help you to eat as well as possible.



We have more information and tips for managing weight loss and the other symptoms in our booklet: **Diet and pancreatic cancer**
Or on our website at: **pancreaticcancer.org.uk/diet**

Pancreatic enzymes can help you cope better with treatments, such as chemotherapy, surgery or radiotherapy. Managing problems with digestion can also make a big difference to how you feel.

If you haven't been told about pancreatic enzymes, ask your doctor, nurse or dietitian about them. You could take this fact sheet 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.

What brands of enzymes are available?

Different brands of enzymes are available in the UK:

- Creon®
- Pancrease®
- Nutrizym®
- Pancrex®.

They are all made from pork products, and there is no other option. Talk to your doctor if you are allergic to pork products. Organisations representing Jewish and Muslim communities have said that these treatments are acceptable to use. The Vegan Society has also said that they are acceptable for vegans as there is no alternative.

Vegetarian enzymes are sold in some health food shops and online. But these don't work if you have pancreatic cancer, and won't help you digest your food. They are also expensive. Speak to your doctor or dietitian if you have concerns about taking enzymes.

What dose of enzymes will I need?

Some brands of enzymes have a number after the name, which shows the dose of the enzymes. For example, one capsule of Creon 25,000 contains 25,000 units and Nutrizym 22 contains 22,000 units.

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. Your dietitian, doctor or nurse can explain how to take the enzymes, and how to work out the best dose for you. They should check the dose regularly.

It is likely that you will need to increase the number of enzymes you take from the starting dose. You will also need to take more for some meals which need more enzymes to digest them. These include:

- larger meals
- meals which have more than one course
- meals high in fatty foods
- if you take longer than 20 minutes to eat your meal.

Don't worry if this sounds like a lot of enzymes – it's not as much as your pancreas would normally make.

Don't change what you eat to try to manage your symptoms as you may not get all the nutrients you need. Instead, make sure you take enough enzymes for what you are eating. For example, don't try to cut out 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.

You may find it helpful to keep a diary of what you have eaten, 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, especially when you first start taking them. There is a diary you can use on page 9.

“ The most obvious sign for me that insufficient enzymes have been taken is runny poo.”

How do I take pancreatic enzymes?

Enzymes are normally given as capsules, which you swallow with food. They are also available as granules or powder if you find it hard to swallow capsules (see page 6).

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

Do

- Do take enzymes with all meals and snacks. You should also take them with milky 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. If you are eating hot food, make sure you take the capsules with a cold drink first.
- Take the enzymes with the first few mouthfuls of food.
- If you are taking more than one capsule, or your meal will last more than 20 minutes, take half the capsules when you start eating, and spread the other half out during the meal.
- You will need more enzymes for larger meals, or if the food has more fat in it – for example takeaways, roasted or fried food, puddings, or food with lots of cheese or chocolate.
- If you take nutritional supplement drinks, you will need to take enzymes with these as well.

Don't

- Don't chew the capsules as this can cause mouth ulcers. Read about what you can do if you find it hard to swallow the capsules on page 6.
- Don't store the capsules in hot places as this can stop them working properly. For example, don't leave them in the glove box of your car, near radiators, in direct sunlight, or in trouser pockets.
- Don't worry if you forget to take your enzymes. Just take the usual dose with your next meal or snack.
- You don't need to take the enzymes when you're not eating – they only work when they are taken with food and some drinks.

There are some foods and drinks that you don't need enzymes for. These include:

- drinks with only a splash of milk (including tea or coffee)
- fruit squashes or fizzy drinks
- alcoholic drinks
- small amounts of fruit (except bananas and avocados) or dried fruit
- small amounts of vegetables (except potatoes, beans, and pulses such as lentils)
- sugary sweets – for example, jelly babies, wine gums, fruit pastilles or marshmallows.

“ I find that I do not need to take any enzymes with fruit – as advised by a dietitian.”

“ I suggest that people carry a small quantity of the capsules when going out for the day. It means that food can be consumed even when not planned.”

What if I can't 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 are smaller capsules available, but you may have to take more of these to make up the dose.

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

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

If you go into hospital

If you go into hospital, tell the staff that you need to take PERT with food, to help you digest your food. Sometimes hospital staff only give PERT when they come round to give other medicines – but this might not be at meal times.

Explain that PERT only works if you take it when you eat, and you will need to take different amounts depending on what you eat. **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 fact sheet.

What if the enzymes don't help?

If you are taking enough enzymes, your symptoms should get better, and for some people the symptoms may go. If your symptoms don't get better, speak to your doctor, nurse or dietitian. They can check that you are taking the enzymes properly and may increase the dose. Some people need to change the type of enzymes they take.

Sometimes, the doctor will give you medicines called proton pump inhibitors. These include omeprazole or lansoprazole. These medicines stop the stomach from producing too much acid, and help the enzymes work better. Speak to your doctor about these medicines and whether they would help.

Other causes of symptoms

If you are taking pancreatic enzymes and you still have symptoms, there may be other causes for these. For example, chemotherapy or antibiotics can cause changes to your bowel habits. Speak to your medical team about your symptoms and what might be causing them.

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

What happens if I take too many enzymes?

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

If you think you've taken too many enzymes and you feel unwell, speak to your medical team. 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 taking enzymes, but some people get tummy pain, wind, diarrhoea or they may feel or be sick. These symptoms are often caused by the dose of enzymes being too low, rather than a side effect of the enzymes. Increasing the dose may help, or you may need to change the type of enzymes you take.

Some people may have constipation (when you find it harder to poo). There could be many reasons for constipation. If you had diarrhoea because of digestion problems, taking pancreatic enzymes may stop this, and you might feel constipated. Other medicines, such as opioid painkillers like morphine, can cause constipation – you may need to take a medicine called a laxative for this. If you have constipation, speak to your doctor or nurse. They can work out what's causing it and how to manage it.

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

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



You can also speak to our specialist nurses on our free Support Line with any questions about your enzymes or symptoms.

“ My experience after 3 years of taking Creon indicates that a normal healthy diet, and eating and drinking habits can be maintained with them.”

Food and enzymes diary

You can use this diary to record what you have eaten, the enzymes you took, and any changes to your digestive symptoms. You might find this particularly useful when you first start taking pancreatic enzymes, to help you work out how many you need to take with different foods.

Meal	What I have eaten	Amount of enzymes I took	Any issues or symptoms – including symptoms that got better or worse	Things to think about
Example	<p><i>2 poached eggs on toast and butter</i></p> <p><i>Tea with a dash of milk</i></p> <p><i>Fortisip</i></p>	<p><i>2 Creon 25,000</i></p> <p><i>0</i></p> <p><i>1 Creon 25,000</i></p>	<p><i>Some bloating and increased wind</i></p> <p><i>Don't feel too bad</i></p>	<p>Include:</p> <ul style="list-style-type: none"> • Any changes to PERT and the difference this made • Things to discuss with the dietitian or nurse • Advice from dietitian or nurse
Breakfast				
Snack				

Meal	What I have eaten	Amount of enzymes I took	Any issues or symptoms – including symptoms that got better or worse	Things to think about
Lunch				
Snack				
Dinner				
Snack				

Pancreatic Cancer UK services

We are here for everyone affected by pancreatic cancer.

Our specialist nurses are here to talk now

If your world has been turned upside down by a pancreatic cancer diagnosis, we are here to talk now. We can answer your questions, recommend practical steps and provide the emotional support you and those close to you need, when you need it most.

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

Expert information

Our free information covers everything about pancreatic cancer to help you understand your diagnosis, ask questions, make decisions and live as well as you can.

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

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

Our online forum

The forum is a supportive online space where everyone affected by pancreatic cancer can be there for each other at any time.

Go to: **forum.pancreaticcancer.org.uk**

Living with Pancreatic Cancer Online Support Sessions

Our online support sessions are hosted by our specialist pancreatic cancer nurses and will give you the chance to connect with others who have also been diagnosed.

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

Real life stories

Read other people's experiences of pancreatic cancer to find out how they coped with their diagnosis and treatment and their tips on looking after themselves.

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

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

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

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

Give us your feedback

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

Email us at **publications@pancreaticcancer.org.uk** or write to our Information Manager at the address below.

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