

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

This fact sheet is for anyone 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 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.

Pancreatic cancer and surgery to remove the cancer may reduce the number of enzymes that the pancreas makes. The cancer can also block the enzymes from getting to the first part of the small intestine, where they are needed for digestion. This means that food is not properly digested, and the nutrients in it are not absorbed. This is called **malabsorption**.

These problems can be managed by taking 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 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 (PERT) replaces the enzymes that your pancreas would normally make. It helps you to digest 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.

PERT can help manage the symptoms caused by digestion problems. These 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 (steatorrhoea)
- tummy pain or discomfort
- bloating or wind
- feeling full up quickly
- feeling sick
- needing to poo quickly, especially after eating.

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

If you don't know 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.

Support from a dietitian

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 your diet, eat as well as possible, and manage weight loss. This can improve your quality of life, which may help you feel better. If you do not have a dietitian, ask your medical team or GP to refer you to one.

What brands of enzymes are available?

Different brands of enzymes are available in the UK:

- Creon®
- Nutrizym®
- Pancrex®.

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.

What dose of enzymes will I need?

Some brands of enzymes have a number after the name, which shows the dose of the 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. You should not 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, you should not reduce how much fat you eat. 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 that you are taking PERT, you may find it helpful to keep a food diary. There is a diary you can use on page 10. 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 will need more pancreatic enzymes to digest your food.

“ 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 if you find it hard to swallow capsules (see page 6).

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

Do

- Take the capsules with all meals and snacks. You should also take them 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 6.
- 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 if the food has more fat in it. 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, 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 during the summer, 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 you take them 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)
- fizzy drinks, fruit squash, or fruit juice (except 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.

“ 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 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.

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 come round to give other medicines, but this might not be at meal times.

Explain to the hospital staff 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 them 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. If they don't let you keep the capsules with you, speak to your medical team or dietitian. They may be able to help.

What if the enzymes don't help?

Pancreatic enzymes only work when they are taken with food, and taken properly. See page 5 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. They may also look at whether anything else is causing your symptoms (see below). Some people need to change the brand of enzymes they are taking.

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 pancreatic enzymes 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 what might be causing your symptoms.

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, or they may feel or be sick. These symptoms are often caused by the dose 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 10). 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 this. If you had runny poo before because of digestion problems, taking PERT may stop this. That might make you feel constipated. Other medicines, such as opioid painkillers, can cause constipation. You may need to take a medicine called a laxative to prevent or treat this if you are taking opioids.

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

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

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.

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

Get support with PERT

PERT can make a big difference to people with pancreatic cancer, but we know it can sometimes be hard to work out how to get the right dose. Make sure you speak to your dietitian, nurse or doctor with any questions.

We also provide a lot of support to help you take it properly.



Speak to our specialist nurses on our free Support Line with any questions 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 recordings of previous webinars, or if we have one coming up you can sign up to attend.



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



We have lots more information and tips for managing diet and digestion in our booklet: **Diet and pancreatic cancer**

Or on our website at: **pancreaticcancer.org.uk/diet**

“ It's been wonderful getting clarification on Creon and diet, and meeting other patients who shared their experiences and how positive they were. I feel more empowered now.”

Food and enzymes diary

You can use this diary to record what you eat, the enzymes you take, and any changes to your digestion symptoms. You might find this useful when you first start taking PERT, to help you work out how many you need to take with different foods. You can also download it 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	<p><i>2 poached eggs on toast and butter</i></p> <p><i>Tea with a dash of milk</i></p> <p><i>Milk based nutritional supplement drink</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>Not feeling too bad</i></p> <p><i>Some discomfort - try 2 capsules tomorrow</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 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				

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 booklet.

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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