

How to deal with problems with the supply of Creon, Nutrizym and Pancrex

We know there are currently shortages of Creon and Nutrizym brands of pancreatic enzyme replacement therapy (PERT). This information explains what you can do if you are having problems getting your usual PERT, including how to manage your diet.

We will update this information regularly if the situation changes. This information is for people with pancreatic cancer. If you have cystic fibrosis, please contact the Cystic Fibrosis Trust as some of the information will be different for you. If you have pancreatitis, Guts UK have information. If you take PERT for other reasons please contact your healthcare professional for advice.



We know this is a worrying situation. If you need help or information about how to deal with problems getting your PERT you can speak to our specialist nurses on our free Support Line. Call the nurses on **0808 801 0707** or email **nurse@pancreaticcancer.org.uk**

We would usually suggest you contact your dietitian if you have one, GP or specialist nurse for support with digestion and PERT. But we know the NHS is very busy at the moment. If you can't get hold of your healthcare professionals, please do contact our specialist nurses.

What is pancreatic enzyme replacement therapy?

The pancreas normally makes enzymes that help to digest your food and milky drinks. Pancreatic cancer can affect this. This means you don't get all the nutrients you need from your food, and may get symptoms (see page 4). Pancreatic enzyme replacement therapy (PERT) helps to manage this by replacing the enzymes the pancreas would normally make.

Brands of PERT in the UK are Creon[®], Nutrizym[®] and Pancrex[®].

Read more about PERT on our website at:
pancreaticcancer.org.uk/diet

What are the problems with the supply of PERT?

The companies that make PERT have told us about continued shortages of these brands. These shortages may affect different types of PERT at different times.

For example, we are aware that there have been particular issues with Creon 25,000, while there has still been supply available of Creon 10,000. The company that makes Creon is having problems making enough of it. This means people switch to other brands of PERT, and the companies that make these struggle to meet this demand.

Supplies are being regularly restocked, so shortages may only last for a short time. The shortages are a UK-wide problem, and we know other countries in Europe are also affected. Some areas in the UK may be affected more at different times. So it may be that you are not having problems getting your PERT.

We are putting pressure on the manufacturers, and also the UK government, which has responsibility for managing medicines across the UK. We want them to make sure they are treating PERT supply issues as a priority, and are taking urgent action to address the situation.

What should I do if my pharmacy is struggling to get my PERT?

It is a good idea to put in your prescription requests **2 weeks earlier** than usual to give the pharmacist time to get your PERT. You may also need to collect your prescriptions more often. Pharmacies are only supplying one month's supply at a time, to try to help supplies last longer.

If your normal pharmacy does not have supply of your PERT, you could ask them to try calling the company that makes your PERT to have more stock sent. Check back in a couple of days as we understand pharmacies are restocking with fresh supplies regularly.

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, and the doses are very low. The PERT needed for digestion problems caused by pancreatic cancer are only available on prescription.

Read more:

- What to do if you can get supplies of PERT (see page 5)
- What to do if supplies of PERT are limited (see page 7)
- What to do if you can't get enough PERT and you have symptoms (see page 11)
- What to do if you can not get PERT (see page 15)

Why does it matter if I do not take PERT?

If you need PERT to help you digest your food, but you can't take enough of it, you may get symptoms. These include:

- weight loss
- runny poo (diarrhoea)
- tummy pain and cramps
- pale, oily, floating poo (steatorrhoea)
- bloating and wind
- needing to poo quickly

You may not get enough nutrients from your food, including protein, vitamins and minerals. If you do not have PERT for some time you may develop symptoms people have from a poor diet, such as vitamin and mineral deficiencies.

If you have diabetes, you may find it hard to manage your blood glucose (sugar) levels. This is because you will release less glucose from your foods into your blood. It will make carb counting inaccurate. If you are on insulin, you will be more likely to have hypoglycaemia (a hypo). Read more about diabetes at: pancreaticcancer.org.uk/diabetes

These symptoms are usually treated by taking PERT.

Read more about these symptoms on our website at: pancreaticcancer.org.uk/dietsymptoms

What to do if you can get supplies of PERT

While you can still get your PERT, we know that you might feel worried about these supply issues. Please do not stockpile by getting extra supplies. This will cause further shortages.

It is a good idea to put in your prescription requests **2 weeks earlier** than usual to give the pharmacist time to get your PERT. Please do not ask for extra prescriptions, as this will make the shortages worse.

You may need to change your repeat prescriptions to a different brand if the PERT you usually take is not available. Speak to your GP about this. There are three brands of PERT available in the UK: Creon[®], Nutrizym[®] and Pancrex[®].

You may need to make up your usual dose using different types of PERT.

For example, if you normally take three Creon 25,000 capsules with meals and two with snacks, you can make up this dose using different products:

- three Creon 25,000 capsules with meals and five Creon 10,000 capsules with snacks, or
- eight Creon 10,000 with meals and five Creon 10,000 with snacks, or
- three Nutrizym with meals and two with snacks, or
- eight Creon 10,000 with meals, and six Pancrex 340mg with snacks, or
- three Nutrizym 22 with meals, and six Pancrex 340mg with snacks, or
- ten Pancrex 340mg with a meal, and 16 Pancrex 125mg with a snack.

Speak to your dietitian if you have one a, GP or pharmacist for more advice about this. You can also speak to our specialist nurses on our **Support Line**. They can talk through the doses you will need.

Tips to help you get the best from your PERT

- It is best to spread your PERT out during the meal, rather than all at the start, middle or end of the meal. This improves how well the PERT digests your food.
- Remember to store your PERT properly. All PERT should be stored below 25°C, and some brands recommend keeping it in the fridge.
- Make sure you use your PERT before it's expiry date.

What to do if supplies of PERT are limited

This information may help you manage your digestion if the supply of PERT is limited. You may be able to get some PERT but less than you usually do.

Taking a medicine called a proton pump inhibitor or an (H2)-receptor antagonist reduces the acid in your stomach. This can help make the enzymes work better.

- Proton pump inhibitors include omeprazole, pantoprazole, and lansoprazole.
- Brands of (H2)-receptor antagonists include Famotidine[®] and Nizatidine[®].
- Speak to your doctor or nurse about whether these medicines would be helpful.

If you can't get enough PERT for your normal dose, you will need to reduce how much PERT you take. These suggestions may help.

- Try reducing the amount of PERT you take with snacks, before reducing the dose with meals. This is because meals tend to be more nutritious.
- Reduce the dose of PERT by one capsule with each meal and snack. This is better than not taking any PERT with a meal.
- Try to make sure your meals have plenty of protein and energy in them.

If you are not already taking vitamin and mineral supplements, these can help you get these nutrients. You can take a calcium and vitamin D supplement containing 800iu Vitamin D and at least 500mg Calcium. Multi-vitamin and mineral supplements include Sanatogen[®] A-Z Complete, Centrum Advance[®] or a Supermarket own brand A-Z multivitamins. Make sure that these contain both vitamins and minerals.

Speak to your dietitian, specialist nurse or GP for support with reducing how much PERT you take. It is important you speak to them if you have any of the symptoms of digestion problems (see page 4), or are losing weight. You can also speak to our specialist nurses on our **Support Line** for help with this.

If you have some high dose PERT left, you may find it helpful to take this with you when you go out. Use the low dose capsules when you are at home. This will reduce the number of capsules you need to take out with you.

If you have diabetes

If you have diabetes and need to reduce how much PERT you take, you may find it harder to manage your blood glucose levels.

Monitor your blood glucose levels regularly, including:

- before meals
- before bed
- if you feel unwell
- if you feel like you are having a hypo (when your blood glucose level drops below 4mmol/l)
- if you are more active than usual
- before driving and every 2 hours during the journey.

Hypoglycaemia (a hypo)

If you take less PERT, you are likely to absorb less carbohydrate from your food. This means you may need to reduce the amount of quick acting or mixed insulin you inject to prevent a hypo. Make sure you know how to recognise and treat a hypo.

You are only at risk of a hypo if you take medicine such as insulin that lowers your blood glucose levels. It is not usually possible to have a hypo if you have diabetes treated with metformin or DPP-4 inhibitors (Gliptins), or if you manage your diabetes through diet.

If you have a continuous glucose monitor, make sure you have the hypoglycaemic alarm set.

Speak to your diabetes team about managing your diabetes if you are taking less PERT. If you are having more hypos than usual, contact your diabetes team for advice on changing your insulin doses.

You can contact our specialist nurses on our **Support Line** for more support with managing your diabetes.

Read more about diabetes and hypoglycaemia on our website at: pancreaticcancer.org.uk/diabetes

If you take oral nutritional supplements

Nutritional supplement brands include Fortisip[®], Amyes[®], Ensure[®], and Fresubin[®], Altraplen[®], and Foodlink[®]. If you take these, ask your dietitian if they can be changed to a peptide nutritional supplement. These include Vital 1.5kcal[®] and Peptisip Energy HP[®]. Many people find they can take these with less or no PERT.

These do not come in a wide range of flavours, but you can add milkshake mixes or coffee syrups for more flavours. To give you more options, you could have them chilled, or freeze them into ice lolly moulds or ice cube trays.

Sometimes you may be offered a fat-free nutritional supplement, such as Actagain Juce[®], Altrajuce[®], Fortijuce[®], Ensure Plus Juice[®] or Fresubin Jucy[®]. These usually need less PERT to be digested. Sip these slowly to give your gut more time to digest them without PERT. If you have diabetes, monitor your blood glucose levels closely when taking these.

Try not to worry if you feel bloated taking these supplements. This is a normal effect of taking these without PERT. But speak to your dietitian if you find the bloating hard to deal with, or if it is affecting your quality of life.

What to do if you can't get enough PERT and you have symptoms

If you cannot get enough PERT and you get symptoms such as diarrhoea, severe bloating, or needing to poo urgently (see page 4), speak to your dietitian, nurse or GP. Remember that you can also speak to our **specialist nurses**.

You could also try these steps to see if they help.

- If you are struggling with diarrhoea, consider taking some loperamide such as Immodium[®] before your main meal. This should help to slow down your gut and reduce diarrhoea. The longer food is in your gut, the more chance more of it will be absorbed by your body.
- You could try reducing the amount of fat in your meal to half your normal portion size of higher fat foods. The information on page 12 shows high fat foods. This is likely to improve some of your symptoms. But it will also mean that your meal contains less energy. So it's really important you keep a close eye on your weight and strength.
- If you eat a lot of high fibre foods, consider eating less of these. Very high fibre foods can make enzymes less effective. The information on page 14 shows high fibre foods.
- If you do not have diabetes, have sugary foods and drinks to get more energy in your diet. Table sugar does not need PERT to be absorbed in your gut. You could try Lucozade, or adding sugar, honey or syrup to foods. This may help keep your energy levels up. You could also have sugary sweets or marshmallows, but not chocolate. Be aware that these do not provide any other nutrition, so make sure you also have food with protein, vitamins and minerals.
- If you are not already taking one, it is a good idea to take an A-Z multivitamin and mineral supplement. Take this with a meal that you are taking PERT with.

High fat foods and their lower fat alternatives

Reduce your portion sizes of high fat food, and have lower fat foods instead.

Fats and oils

- Reduce the amount of butter, lard, ghee, margarine and cooking oils.
- Instead, have small portions of low-fat spreads. You could use spray on cooking oils if needed.

Dairy products

Reduce how much full fat milk and yoghurt, cream, creme fraiche and cheese you have.

Have these dairy products instead:

- semi-skimmed or skimmed milk
- low fat yoghurts
- use small amounts of grated cheese instead of slices of cheese – choose stronger cheeses to maximise taste.

To increase how much protein you have, add skimmed milk powder to skimmed milk. Use in place of milk throughout the day.

Meat and fish

Reduce your portion sizes of:

- fried foods
- foods cooked in batter
- skin or visible fat on meat
- tinned fish that's tinned in oil.

Instead, have meat and fish cooked without added oil. If you have tinned fish, make sure it's tinned in spring water or brine.

Plant-based protein

- Reduce how much nut butter you have.
- Instead, have pulses such as lentils, chickpeas and beans (see information on page 14 about fibre for portion sizes).
- Have up to 100g of Quorn or Tofu.

Fruit and vegetables

Have as much fruit and vegetables as you like. But be aware of high fibre foods – see page 14.

Carbohydrate based foods

- Reduce your portion size of croissants, pastries, chips, fried and roast potatoes.
- You can have bread, breakfast cereals, potatoes, rice or pasta, cooked without added fat.

Sauces and condiments

Reduce:

- cheese based sauces
- creamy sauces
- large portions of mayonnaise.

Instead have:

- tomato based sauces
- gravy
- mustard
- tomato ketchup
- soy sauce
- mint jelly
- vinegar
- low-fat salad dressings.

The amount of fibre in high fibre foods

Aim for less than 40g fibre per day.

Very high fibre food

These portion sizes provide 10g of fibre

- All bran - 40g
- brown pasta - 250g (cooked)
- baked Beans - 300g
- dried apricots and prunes - 120g
- nuts and seeds - 150g
- dried lentils, chickpeas and mung beans - 100g (weight before cooking)
- dried soya beans and red kidney beans - 70g (weight before cooking)
- desiccated coconut - 70g.

High fibre food

These portion sizes provide 5g of fibre:

- 1 large whole wheat pitta
- 2 Weetabix biscuits
- 4 Rye based crackers (such as Ryvita)
- 2 Shredded wheat biscuits
- 30g bowl of Branflakes, Sultana Bran, Fruit n Fibre
- A large bowl (60g oats) of porridge or readybrek
- 1 medium jacket potato with skin
- 250g cooked white pasta
- 150g cooked wholemeal spaghetti
- 100g wholemeal bread
- 150g baked beans
- 75g Quorn
- 120g green beans, peas (fresh or frozen)
- 5 tablespoons spinach
- 7 tablespoons sweetcorn
- 1 whole avocado.

What to do if you can't get PERT

This information explains what may help if:

- you can't get hold of any PERT at all, or
- you are losing more than 2kg of weight a month, or you are already underweight and losing more than 1kg a month, or
- you have uncontrollable bowel symptoms that are restricting your daily life.

We know this is a very worrying situation. Supplies are being regularly restocked, so if you do run out, this should only be a short term situation for you. We are putting pressure on the manufacturers and the government to try to make sure people can still get their PERT. But we want to provide information in case anybody can't get PERT. Remember that you can call our **specialist nurses** for support and information.

If you are under the care of a hospital team, contact them and see if they have enough supply to provide a prescription for you. You will have to travel to the hospital to collect these if they have some available.

Tell your pharmacist that you have completely run out, so your supplies can be prioritised if possible.

Contact your GP and ask for a prescription for a peptide nutritional supplement. This might be Vital 1.5kcal[®] or Peptisip Energy HP[®]. You do not need to take PERT with this nutritional supplement. It might be helpful to show your GP this information. You can also contact your dietitian if you have one, but you may be seen more quickly if you go straight to your GP.

The peptide nutritional supplement can be used instead of meals until you have your PERT again. If you do not have diabetes, you can continue to have sugary foods and drinks as well (see page 11).

How many peptide nutritional supplement drinks to have

This is a guide to how many supplements (Vital 1.5kcal[®] or Peptisip Energy HP[®]) to take, if you do not have PERT and cannot absorb your food. It is based on your weight.

- If you weigh below 40kg (6st 4lb), contact a dietitian.
- If you weigh 40 – 50kg (6st 4lb- 7st 12lb), take four 200ml bottles, which is 1200kcal (calories).
- If you weigh 50 – 60kg (7st 12lb – 9st 6lb), take five 200ml bottles (1500kcal).
- If you weigh 60-70kg (9st 6lb – 11st), take six 200ml bottles (1800kcal).
- If you weigh 70-80kg (11st – 12st 8lb), take seven 200ml bottles (2100kcal).
- If you weigh 80-90kg (12st 8lb – 14st 2lb), take eight 200ml bottles (2400kcal).
- If you weigh over 90kg (14st 2lb), contact a dietitian.

This may not be enough for you. If you lose weight or are very active, have one more bottle a day.

If you gain weight and were not intending too, have one less bottle a day.

These supplements do not come in a wide range of flavours. You can add milkshake mixes or coffee syrups for more flavours. Serve them chilled, or freeze them into ice lolly moulds or ice cube trays to give you more variety.

For people who have a gastric feeding tube

If you have a PEG, RIG or NG (nasogastric) feeding tube, you could take powdered PERT through this tube. Pancex V powder[®] is the powdered PERT available in the UK. This can be dissolved in water and flushed down the tube, but this must be done when you eat.

This does not work with a jejunostomy or naso-jejunal tube as the enzymes will not mix with your food.

If you have a feeding tube, discuss this with your dietitian.

We know this is a worrying time. It is important you contact your GP, dietitian or specialist nurse for help and advice. You can also contact our specialist nurses on our **Support Line**. They can provide information and talk through your options if you are struggling to get PERT.



Call our Specialist Nurses for free on **0808 801 0707** or email **nurse@pancreaticcancer.org.uk**

Pancreatic Cancer UK support

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**

This information is based on guidance developed by specialist dietitians from the Nutrition Interest Group of the Pancreatic Society of Great Britain and Ireland (NIGPS), Cystic Fibrosis Specialist Group and Gastroenterology Specialist Group, British Dietetic Association. We hope this will add to the medical advice you have had, 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.

We would like to thank the following dietitians for allowing us to use their guidance:

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