

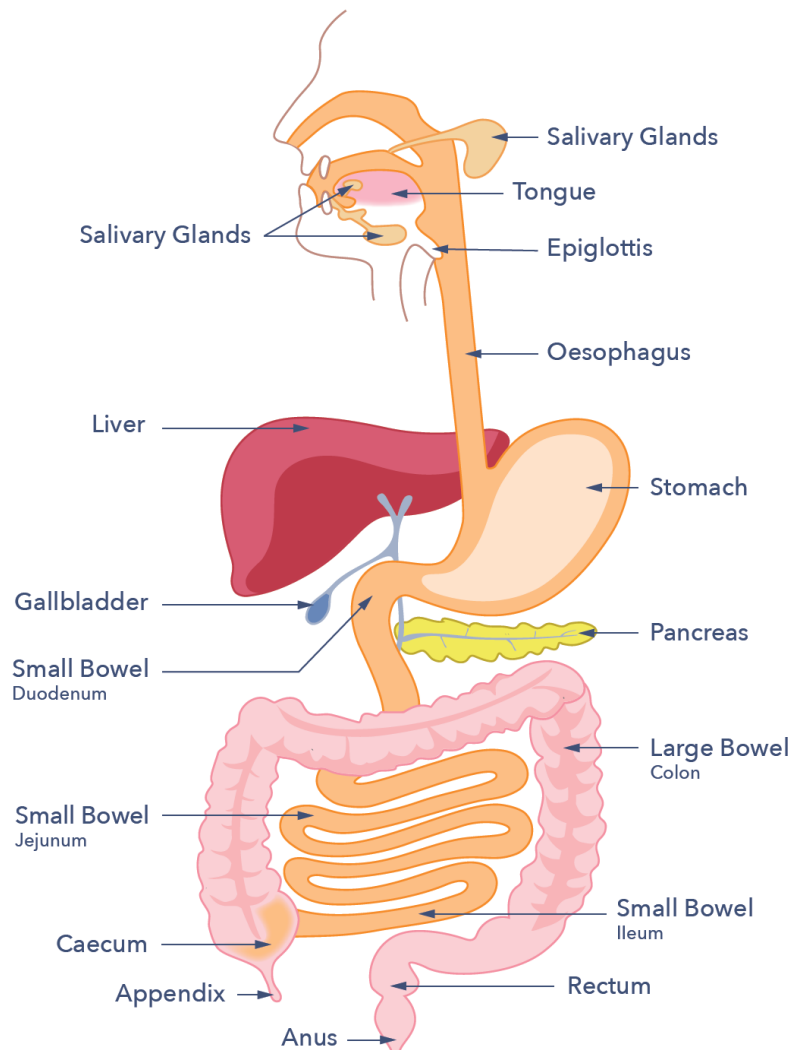


# Pancreatic Enzyme Replacement Therapy (PERT) supply problems.



Guts UK is the charity for the digestive system. Funding research to fight diseases of the gut, liver and pancreas.

## THE DIGESTIVE SYSTEM



## OVERVIEW

### THIS FACTSHEET IS ABOUT PROBLEMS WITH THE SUPPLY OF PERT.

You might have noticed supply issues with pancreatic enzyme replacement therapy (PERT), sometimes also called pancreatin. This situation has progressed. It has now caused some people who need PERT to run out of it. These medicines are supplied under the brand names **Creon®**, **Nutrizym®**, and **Pancrex®**. This advice is taken from a position paper written by dietitians and supported by doctors and charities who support people needing PERT. You can find a copy of it here [Position Statement: Pert Shortage | Pancreatic Society of Great Britain and Ireland \(psgbi.org\)](https://www.psgbi.org/position-statement-pert-shortage). If you would like a printed copy, you can contact [info@gutscharity.org.uk](mailto:info@gutscharity.org.uk) or call 020 7486 0341. This information will help you to reduce the impact of the shortage on your symptoms and quality of life.

Doctors prescribe PERT. It helps digestion in people with pancreatic exocrine insufficiency (PEI). It is most often needed due to pancreatitis, pancreatic cancer, and cystic fibrosis (CF). Several other medical situations may cause PEI. These are called secondary causes. These include:

- Type 3c diabetes
- Gastrectomy - surgery to remove the stomach.
- Gastric bypass surgery

The types of symptoms and their severity will vary from person to person. Symptoms do not depend on the cause of the insufficiency.

Symptoms of untreated PEI may include:

- Bloating.
- Excess wind.
- Diarrhoea.
- Crampy abdominal pain.
- Urgency to open bowels.

- Steatorrhea (pale floating poo).
- Hard to manage blood glucose levels.
- Vitamin and mineral deficiencies.
- Weight loss and malnutrition.

These symptoms are usually treated by taking PERT. They will come back if you can't take enough. Not having these symptoms does not mean you do not have PEI. Some people have PEI without symptoms.

The advice in this leaflet may be updated. It will be updated if there is more guidance. Also, if there is more experience of managing PEI without enough PERT.

Please note the advice in this document is designed for adults with PEI. Specialist advice should be sought for children with PEI.

People with cystic fibrosis (CF) will be under the care of a specialist centre. The Cystic Fibrosis Trust have produced specific information for people with CF. Some of the information in this leaflet is not suitable for people with CF. Please contact your specialist team for advice.

The advice for patients has been split into 4 stages.

Stage 1 - There are supplies available.

Stage 2 - There are limited supplies available.

Stage 3 - There are not enough supplies, and you have abdominal (belly) symptoms. (See above)

Stage 4 - There are no supplies available.

PERT is still being delivered regularly into the United Kingdom. So, people will move backwards and forwards between these stages. It is not expected for people to completely run out of PERT for long. So, if we do have to use the advice in phase 3 or 4, it is thought that this will only be for a short period of time.

## STAGE 1 - THERE ARE SUPPLIES AVAILABLE.

Whilst PERT supply issues continue, please do not stockpile them. Stockpiling will further drive the shortage.

The Department of Health and Social Care has recommended that only 1-month supply is issued at a time. This is to try and regulate supplies. So, if you currently receive 2-3 months of your PERT at a time, you will need to collect your prescriptions more often. If you pay for your prescription, consider applying for a pre-payment certificate. This will help to reduce the cost of prescription charges - <https://www.nhsbsa.nhs.uk/help-nhs-prescription-costs/nhs-prescription-prepayment-certificate-ppc>.

You should place your prescription requests earlier. Do so 2 weeks in advance. This is to give the local pharmacist time to source your medication.

If what you usually take is not available, you may need a change in your repeat prescriptions to another brand. Three brands of PERT are available in the UK. They are Creon<sup>®</sup>, Nutrizym<sup>®</sup>, and Pancrex<sup>®</sup>.

Remember to store your PERT appropriately. All PERT should be stored below 25 degrees. Some brands recommend refrigeration, check the packaging. If PERT gets too hot it does not work properly, this damage cannot be reversed.

Taking the PERT throughout the meal is the best way. Rather than all at the start/ middle/ end of the meal. This is because it improves how well it digests what you are eating.

Ensure that you use your PERT before it goes out of date. If you store PERT in different places (i.e. at work), rotate your supplies to prevent waste.

Table 1 shows how each enzyme product compares to others.

<b>Table 1: Conversion charts (2) Creon® 25,000 Dose</b>	Equivalent in Nutrizym® 22	Equivalent in Creon® 10,000	Equivalent in Pancrex® 340mg (8,000 units lipase)	Equivalent in Pancrex® 125mg (2,950 units lipase)	Equivalent in Creon® Micro*	Pancrex® V powder*
1 x Creon 25,000	1 x Nutrizym 22	3 x Creon 10,000	3 x Pancrex 8,000	8 x Pancrex 2,950	5 scoops Creon Micro	½ x 2.5ml spoon
2 x Creon 25,000	2 x Nutrizym 22	5 x Creon 10,000	6 x Pancrex 8,000	16 x Pancrex 2,950	10 scoops Creon Micro	1 x 2.5ml spoon
3 x Creon 25,000	3 x Nutrizym 22	8 x Creon 10,000	9 x Pancrex 8,000	24 x Pancrex 2,950	15 scoops Creon Micro	1½ x 2.5ml spoon
4 x Creon 25,000	4 x Nutrizym 22	10 x Creon 10,000	12 x Pancrex 8,000	32 x Pancrex 2,950	20 scoops Creon Micro	2 x 2.5ml spoon
5 x Creon 25,000	5 x Nutrizym 22	13 x Creon 10,000	15 x Pancrex 8,000	40 x Pancrex 2,950	25 scoops Creon Micro	2 ½ x 2.5ml spoon
6 x Creon 25,000	6 x Nutrizym 22	15 x Creon 10,000	18 x Pancrex 8,000	48 x Pancrex 2,950	30 scoops Creon Micro	3 x 2.5ml spoon

It may be most practical to combine medications. For instance, if the prescription is **Creon® 25,000 x 3 with meals and 2 with snacks**. These are all equal doses, using the different products:

**Creon® 25,000 x 3 with meals + Creon® 10,000 x 5, with snacks**

or

**Creon® 10,000 x 8 with meals + Creon® 10,000 x 5, with snacks.**

or

**Creon® 10,000 x 8 with meals, + Pancrex® 340mg x 6, with snacks.**

or

**Nutrizym® 22 x 3 with meals, + Pancrex® 340mg x 6, with snacks**

or

**Pancrex® 340mg x 10 with a meal, + Pancrex® 125mg x 16, with a snack**

## **STAGE 2 - THERE ARE LIMITED SUPPLIES AVAILABLE.**

The first steps if supplies are limited, meaning you have some PERT but less than your usual amount:

- Ask your doctor about taking a proton pump inhibitor (omeprazole® / pantoprazole®/ lansoprazole®) or an (H2)-receptor antagonist (Famotidine® / Nizatidine®). These reduce the acid in your stomach and make the PERT work better. This means a lower dose of PERT may work if you have a proton pump inhibitor. If this does not appear to be effective, they may be stopped.
- Reduce the dose of PERT you take with snacks before reducing your doses with meals. This is because meals tend to be more nutritious.
- Take one less PERT capsule with each meal and snack. Don't skip whole meal doses.

- If you have some high-dose PERT (eg Creon 25,000/ Nutrizym 22), take it with you when you go out. Use the low-dose ones at home. This will cut the number of capsules you need to take out.
- Prioritise taking PERT with the meals that have the most protein and energy in them.

If you do not take vitamins and minerals, it is recommended that you take a calcium and vitamin D supplement. Check the label. It should have 800 iu Vitamin D and at least 500mg Calcium. Also, take a multi-vitamin and mineral supplement during this time. For example:

- Sanatogen A-Z Complete®
- Centrum Advance®
- Supermarket own A-Z brand.

Please make sure these contain both vitamins and minerals.

People with CF should keep taking their vitamins and minerals. They should discuss any concerns with their CF specialist dietitian.

Please contact your dietitian, nurse, or doctor if you struggle with malabsorption or keep losing weight.

If you have diabetes:

Check your blood glucose levels regularly. They should be checked:

- Before meals
- Before bed
- If you are feeling unwell
- If you feel like you are having a hypo\*
- If you are more active than usual
- Before driving and every 1-2 hours if driving long distances.

If you take less enzymes with your food, you are likely to absorb less carbohydrate from it. Therefore, you may need to reduce the amount of quick acting or mixed insulin you inject to prevent a hypo\*.

\*A hypo is when your blood glucose level goes below 4mmol/l, typical symptoms include sweating, shaking, blurred vision, confusion, palpitations. Always keep hypo treatment on you.

You can find more information on recognising and treating a hypo from your diabetes team or by following this link:

[https://trenddiabetes.online/wp-content/uploads/2022/03/A5\\_Hypo\\_TREND.pdf](https://trenddiabetes.online/wp-content/uploads/2022/03/A5_Hypo_TREND.pdf) ([trenddiabetes.online](https://trenddiabetes.online)). If

you would like a printed copy of this information contact [info@gutscharity.org.uk](mailto:info@gutscharity.org.uk) or 020 7486 0341. You are only at risk of a hypo if you take medication that lower your blood glucose levels. It is not usually possible to have a hypo if you are not taking insulin or gliclazide.

If you have a continuous glucose monitor, ensure you have the hypoglycaemic alarm set. If you are having more hypos than usual, you may need to contact your diabetes team for advice on adjusting your insulin doses.

## **STAGE 3 – THERE ARE NOT ENOUGH SUPPLIES AND YOU ARE HAVING BELLY SYMPTOMS.**

This section is for people who do not have enough PERT and develop symptoms, such as diarrhoea, severe bloating, or a sudden need to have a bowel movement. Check the list of symptoms on page. Here are some other steps to try in addition to those above:

- If you have diarrhoea, take loperamide / Imodium® before you eat a meal. This should help to slow down your gut and reduce diarrhoea. The longer food is within your gut, the more chance more of it will be absorbed by your body.
- Reduce the amount of fat in your meal to ½ of your normal portion size of higher fat foods. See Table 3 for information on higher fat foods. This will likely improve some of your gut symptoms. But, it won't help you take in more nutrients. It also won't prevent malnutrition. So, keep a close eye on your weight and strength.
- If you eat a lot of high fibre foods, consider eating less of them. Very high fibre foods can bind to enzymes in PERT and make them



less effective (see Table 4 for information on higher fibre foods). Healthy eating guidelines recommend adults try to eat 30g of fibre per day. We recommended with less PERT you do not exceed 40g per day.

- **If you do not have diabetes**, use sugary foods and drinks to increase your energy intake. Table sugar is absorbed in your gut without enzymes. So, the following can keep your energy up:
  - Caffeine free energy drinks such as Lucozade.
  - Adding sugar / honey / syrup to food.
  - Nibbling on sugary sweets / marshmallows (not chocolate).
- These suggestions do not provide any other nutrition. So, make sure you get protein, vitamins, and minerals from other sources.

## STAGE 4 -THERE ARE NO SUPPLIES AVAILABLE.

If any one or more of these circumstances occur:

- You are unable to get hold of any PERT at all.
- You do not have enough PERT and are losing weight. If you are losing more than 2kg (4lb) a month. Or you are already underweight and losing more than 1kg (2lb) a month.
- You don't have enough PERT. Plus, you have bowel symptoms that are unmanageable and restricting your social, work, and education activities.

If you are under the care of a hospital team, contact them. See if they have enough supplies to issue 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. This is so your supplies can be prioritised if possible.

Try not to worry. Supplies are regularly coming into the country, so this should be a short- term issue.

Contact your GP. Ask for a prescription for a peptide nutritional drink. (Vital 1.5kcal® or Peptisip Energy HP®). Show them this leaflet. Or show them the position statement. Both could help. If you are known to a dietitian, they can be contacted too. But, because of the huge increase in

workload from this PERT shortage, you are likely to get them more quickly if you go directly to your GP. These drinks can be used instead of meals until you have your PERT again. If you do not have diabetes, you can keep having sugary foods and drinks. Table 2 shows how many supplement drinks you should take if you do not have any PERT at all.

Table 2 shows the recommended doses for peptide-based nutritional supplement drinks if you are unable to eat any food due to your malabsorption symptoms.

Body weight	Supplements needed per day (Vital 1.5kcal® or Peptisip Energy HP®)
Below 40kg (6st 4lb)	Contact a dietitian
40 - 50kg (6st 4lb- 7st 12lb)	4 x 200ml bottles = 1200kcal
50 - 60kg (7st 12lb - 9st 6lb)	5 x 200ml bottles = 1500kcal
60 - 70kg (9st 6lb - 11st)	6 x 200ml bottles = 1800kcal
70 - 80kg (11st - 12st 8lb)	7 x 200ml bottles = 2100kcal
80 - 90kg (12st 8lb - 14st 2lb)	8 x 200ml bottles = 2400kcal
Over 90kg (14st 2lb)	Contact a dietitian

This may under-estimate your needs. If you lose weight or are very active, add one more bottle per day. If you gain weight and were not intending too - reduce by 1 bottle per day.

They do not come in many flavours. But you can add milkshake mixes or coffee syrups to expand the flavours. Serve them chilled. Or freeze them into ice lolly moulds or ice cube trays for more variety.

Table 3 shows high fat foods and their lower fat alternatives.

	Reduce your portion sizes of these:	Have these instead:
Fats and oils	Butter, lard, Ghee, Margarine, cooking oils	Small portions of low-fat spreads Use spray on cooking oils if needed
Dairy products	Full fat milk / yoghurt Cream Crème Fraiche Cheese	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 your protein intake, make skimmed milk powder up using skimmed milk. Use it in place of milk throughout the day
Meat and Fish	Fried foods or foods cooked in batter. Skins / visible fat on meat Tinned fish, tinned in oil	Meat and fish cooked without added oil. Tinned fish, tinned in spring water / brine
Plant based protein sources	Nut butters	Pulses (e.g. lentils, chickpeas, beans (note portion sizes in table 2) Quorn / Tofu - up to 100g
Fruit & vegetables	No restrictions for low fat, see Table 4 for fibre suggestions	
Carbohydrate based foods	Croissants, pastries Chips / Fried Roast potatoes	Bread, Breakfast cereals Potatoes, rice, pasta, cooked without added fat
Sauces / Condiments	Cheese based sauces Creamy sauces (bearnaise, hollandaise etc.,) Large portions of mayonnaise	Tomato based sauces, gravy, mustard, tomato ketchup, soy sauce, mint jelly, vinegar, or low-fat salad dressings

Table 4 shows the fibre content of high fibre foods. Aim for less than 40g fibre per day.

Very high fibre foods		High fibre foods			
Food	Portion providing 10g fibre	Food	Portion providing 5g fibre	Food	Portion providing 5g fibre
All bran®	40g	Whole wheat pitta	1 large	Weetabix®	2 biscuits
Brown pasta	250g (cooked)	Rye based crackers (i.e. Ryvita®)	4 biscuits	Shredded wheat®	2 biscuits
Baked Beans	300g	Branflakes® / Sultana Bran®, Fruit n/Fibre®	30g bowl	Porridge / Readybrek®	Large bowl (60g oats)
Dried apricots / prunes	120g	Jacket potato with skin	1 medium	Pasta (white)	250g (cooked)
Nuts and seeds	150g	Wholemeal spaghetti	150g (cooked)	Wholemeal bread	100g
Dried lentils / chickpeas /Mung beans	100g (weight before cooking)	Baked beans	150g	Quorn®	75g
Dried soya beans / red kidney beans	70g (weight before cooking)	Green beans / peas (fresh or frozen)	120g	Spinach	5 tablespoons
Desiccated coconut	70g	Sweetcorn	7 tablespoons	Avocado pear	1 whole fruit

## For people who already have a gastric feeding tube.

If you have a PEG, RIG or NG (nasogastric) feeding tube, you could take your PERT using a powdered source. For example, Pancrex® V powder. You would take it through the tube. These can be dissolved in water and flushed down the tube, but this must be done at the time you eat. This does not work with a jejunostomy or naso-jejunal tube. The enzymes will not mix with your food. If you have a feeding tube, discuss this choice with your dietitian.

## SUPPORT

Guts UK

Guts UK support people with pancreatitis and pancreatic exocrine insufficiency. This includes pancreatic exocrine insufficiency caused by stomach surgery and diabetes.

[www.gutscharity.org.uk](http://www.gutscharity.org.uk)

020 7486 0341 9am-5pm Monday - Friday

Email: [info@gutscharity.org.uk](mailto:info@gutscharity.org.uk)

Pancreatic Cancer UK:

[pancreaticcancer.org.uk](http://pancreaticcancer.org.uk)

email [nurse@pancreaticcancer.org.uk](mailto:nurse@pancreaticcancer.org.uk) or call our Support Line 0808 801 0707; we're open Monday, Tuesday, Thursday and Friday 9am to 4pm and Wednesday 10am to 4pm.

Cystic Fibrosis Trust:

[Cystic Fibrosis Trust Homepage | CF Trust](http://CysticFibrosisTrustHomepage|CFTrust)

Call 0300 373 1000 or 020 3795 2184, Monday-Friday 10am-4pm

Email [helpline@cysticfibrosis.org.uk](mailto:helpline@cysticfibrosis.org.uk)

Chat on [Facebook](#), [Twitter](#) or [Instagram](#)

Message on WhatsApp on [07361 582053](https://www.whatsapp.com/channel/0029va28193012521451330)

Neuroendocrine Cancer UK:

<https://www.neuroendocrinecancer.org.uk/>

Helpline 0800 434 6476 Tuesday - Thursday 10:00am - 4:00pm

Email: through contact form on the website

<https://www.neuroendocrinecancer.org.uk/contact-us/>