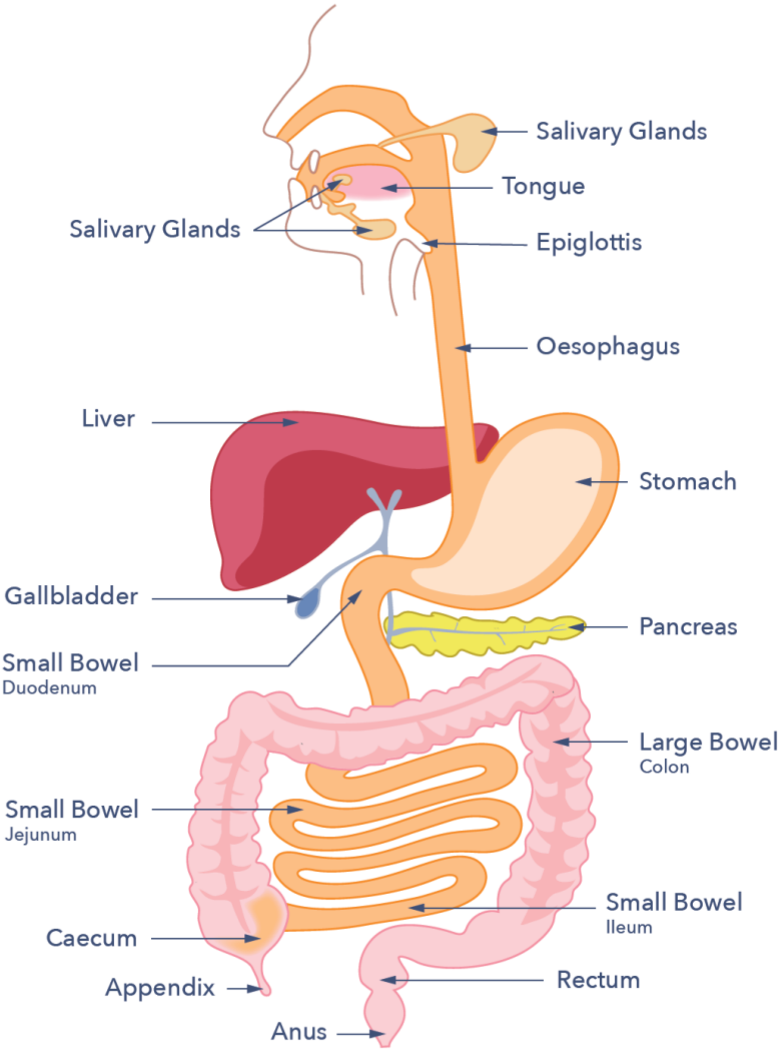
How to deal with Creon, Nutrizym or Pancrex supply issues

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.

Issue date: 14th April 2025 (Version 6). Please ensure you are reading the most up to date version.

The most up to date advice can be found on the Pancreatic Society of Great Britain and Ireland (PSGBI) website, the correct version of this document is **version 5**:

https://www.psgbi.org/position-statement-pert-shortage/

If you would like a printed copy, you can e-mail us: info@gutscharity.org.uk or call us: 0207 486 0341.

Manufacturers have customer support lines that may help you find a pharmacist nearby with stock. The numbers are for Creon: 0800 8086410 (Mon-Fri 9-5), for Nutrizym 08000 902408 (Mon-Fri 9-5).

Advice for children and those with cystic fibrosis

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 will be cared for by a specialist centre. We have highlighted that some of the advice in this leaflet is not for people with CF. If you have CF, you should contact your specialist team if you have any concerns.

Advice for those with (non-pancreatic) neuroendocrine neoplasms treated with somatostatin analogues.

Somatostatin analogues are the medicines Lanreotide (Somatuline®) / Octreotide (Sandostatin®). Please contact your specialist centre if your symptoms worsen, or you have any concerns.

Introduction

Please note this document has been extensively revised in view of the availability of imported alternatives to Creon®, Nutrizym® and Pancrex®. Everyone should now be able to get the enzymes they need but they might be a different brand.

Doctors prescribe pancreatic enzyme replacement therapy. It supports adequate digestion in people with pancreatic exocrine insufficiency (PEI). Most commonly

PEI is caused by pancreatic cancer, pancreatitis, pancreatic surgery, neuroendocrine cancers and cystic fibrosis (CF).

Many other clinical situations can cause primary or secondary PEI. These include:

- Gastrectomy (stomach removal surgery) or gastric bypass surgery.
- People who take the medicine somatostatin analogues [Lanreotide (Somatuline®) / Octreotide (Sandostatin®)] for the treatment of neuroendocrine neoplasms (NENs).

PEI has many causes, but symptoms and their severity vary from person to person.

The ongoing supply issues surrounding pancreatic enzyme replacement therapy (PERT) is going to continue until the end of 2026.

PERT are supplied under the product brands**:** **Creon®**, **Nutrizym®** and **Pancrex®**. These supply issues are intermittent. The current supply issues mean some people will need to be supplied with a different brand of PERT. This advice is designed for everyone who takes PERT.

Current supplies

- Creon® 25,000 is being delivered regularly into the UK, but at 90-95% of the usual stock levels. Up to 1 in 10 prescriptions will not be filled with their usual brand.
- Creon® 10,000 is available in limited supplies and should be prioritised for babies/infants and those unable who cannot swallow capsules and are unable to open them.
- Nutrizym 22® is available in limited supplies and should be prioritised for those who cannot tolerate Creon.
- Pancrex® capsules are available, but there is not any extra supply. So they cannot fill the gap in the market. These products are low dose and so most adults would need to take a lot of them to get what they need.
- Pancrex® powder is not usually suitable for taking by mouth. If you are provided with a prescription for this and you take it by mouth ***do not collect it from the pharmacy***. Once it has been collected, it cannot be reused. This product is used by people who have a feeding tube. Let your doctor or pharmacist know you will need an alternative.
- GP’s and pharmacies have been provided with information on ordering imported medicines to meet the gap in the supply. These should be ordered for anyone who may run out of PERT.

For the most up to date information on current supplies please check this website: Prescribing and ordering available pancreatic enzyme replacement therapies – SPS - Specialist Pharmacy Service – The first stop for professional medicines advice.

This website also has a tool to help healthcare professionals to change the type of PERT. Please contact us if you would like a copy on info@gutscharity.org.uk or call 020 7486 0341.

Symptoms of untreated PEI may include:

- bloating.
- excess wind.
- diarrhoea.
- crampy belly (abdominal) pain.
- urgency to open bowels.
- steatorrhea (pale floating stools).
- hard to manage blood glucose levels.
- vitamin and mineral deficiencies.
- weight loss and malnutrition.

These symptoms are usually treated by taking PERT and will recur if you are unable to take enough.

We have divided the advice for people with PEI into 3 stages. The stage depends on the supply available.

Stage 1 – What to do when you have a supply.

Stage 2 – What to do if you think you need to increase your dose.

Stage 3 – What to do if you have less than two weeks supply left.

STAGE 1 – WHAT TO DO WHEN YOU HAVE A SUPPLY.

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 a 1-month supply is issued at a time. This is to try and regulate supplies. So, if you now get 2-

3 months of your PERT at a time, you will need to refill your prescriptions more often.

If you pay for your prescription, you should consider applying for a pre-payment certificate. This will help to reduce the cost of prescription charges. You can find more at https://www.nhsbsa.nhs.uk/help-nhs-prescription-costs/nhs-prescription-prepayment-certificate-ppc.

Requesting your prescriptions:

- Place your prescription request **as soon as soon as you have picked up your last prescription.** This should give the community pharmacist time to source your medication.
- **It is important that you check with your GP surgery that the prescription request has been authorised.** Some GP surgeries have an automated system. It rejects repeat prescriptions if they are placed too early.
- If you still receive a paper prescription. Ask for your PERT prescription on a single script. This will let you take it to another pharmacy if needed, without disrupting your other medications.
- You may need a change in your repeat prescriptions if what you usually have is not available. There are three brands of PERT usually currently in the UK.
- Speak to your GP and pharmacist about the shortage, and make sure they are aware that you may need an imported medicine if your PERT is not available.

The following advice will make your PERT as effective as possible:

- Remember to store your PERT appropriately. All PERT should be stored below 25 degrees, and some brands recommend refrigeration. If PERT gets too hot it does not work properly, this damage cannot be reversed.
- Taking the PERT throughout the meal rather than all at the start/ middle/ end improves how well it digests the food and drinks you are eating / drinking.
- Ensure that you use your PERT before it goes out of date. If you store PERT in different places (i.e. at work), make sure you rotate your supplies to prevent any wastage.

Stage 1 summary.

Please make sure you:

- Use your PERT as effectively as possible. (Store it correctly and make sure it does not go out of date.)
- Put your next prescriptions in as soon as your earlier one has been dispensed.
- Check each prescription. Make sure it was approved by your GP surgery.
- Do not stockpile PERT – this makes the whole situation worse.
- Speak to your GP and pharmacist about the shortage, and make sure they are aware that you may need an imported medicine if your PERT is not available.

STAGE 2 – WHAT TO DO IF YOU THINK YOU NEED TO INCREASE YOUR DOSE.

Sometimes people may need to increase the amount of PERT they take as time goes on. If you are new to PERT, you may benefit from increasing your dose if:

- It has not yet brought your symptoms under control
- If you are experiencing worsening bowel symptoms as your appetite improves.

If you have cystic fibrosis – please contact your specialist centre.

Before increasing your dose, please check you are using your PERT as effectively as possible:

- If you are not already taking one talk to your doctor about taking a proton pump inhibitor. Examples include:
  - omeprazole®
  - pantoprazole®
  - lansoprazole®
- Or a (H2)-receptor antagonist. Examples include:
  - famotidine®
  - nizatidine®

  These reduce the acid in your stomach and make the enzymes work better. This means a lower PERT dose than your usual dose may be effective if you have a proton pump inhibitor as well. If this does not appear to be effective, they may be stopped. This may not be appropriate for everyone.

- Ensure you are spacing your PERT dose out throughout your meals unless you have been advised to do something differently. Advice may be different if you have a condition like gastroparesis or delayed gastric emptying.
- Ensure your PERT does not get too hot – it needs to be stored below 25 degrees. Make sure it is not left in the car on a sunny day, left in direct sunlight, on a radiator, in a warm pocket or close to an oven or kettle.
- Please contact your dietitian / nurse specialist or doctor if you are struggling with malabsorption symptoms or are consistently losing weight.

Advice for people taking nutritional supplement drinks

If you take oral nutritional supplements (i.e., **Altraplen**® **Amyes**®, **Ensure**®, **Foodlink**® **Fortisip**®, **Fresubin**®), ask your dietitian if they can be changed to a peptide / semi-elemental preparation (i.e., **Vital 1.5kcal**®, **Survimed OPD 1.5kcal**®, **Peptisip Energy HP**®) as most people can manage these without additional enzymes.

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

Sometimes you may be asked to try individual protein supplements or a fat-free nutritional supplements (**Actagain Juce®, Altrajuce®, Ensure Plus Juice**®, **Fortijuce**®, **Fresubin Jucy**® etc.,). You should 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.

If you feel bloated with these, don't worry - this is a normal effect of taking these without PERT, but if it is affecting your quality of life, please let your dietitian know.

STAGE 3 – WHAT TO DO IF YOU HAVE LESS THAN 2 WEEKS SUPPLY LEFT.

Try not to worry – Primary Care (GP surgeries and health centres) have made plans to reduce the risk of anyone running out.

Whilst there are plans in place to make sure PERT is available for everyone, there are a lot of medication shortages now, and your GP or local pharmacist may not be aware of the advice available within their area. They may need to contact their medicines management team to access this advice.

There are 2 steps for you to do if you have less than 2 weeks supply left and your Pharmacist is not sure if any more will come in time.

1) Check with the manufacturers customer support team to see if there is a supply near you: Creon: 0800 8086410, Nutrizym: 08000 902408 (Mon-Fri 9-5).
2) Speak to your GP and Pharmacist about accessing a prescription for one of the imported medications that have been brought into the UK to fill the gap in supply. There is a more complicated process to access these, so don't leave this discussion until the last minute. If you are seeing your GP for another reason, explain the issues when you see them and ask if you can have a prescription for the imported medicines in case you are unable to source any PERT. Also make sure your pharmacist is aware so they can check with their local medicines management teams how they can access this stock for you. The most common imported medicines are Pangrol® or Kreon® / Creon® from Germany or Canada.

If you have completely run out, please make an emergency (same day) appointment with your GP. You can show them this document.

They can access advice for health care professionals here:
https://www.psgbi.org/position-statement-pert-shortage/

If you are under the care of a local hospital, please contact your local hospital team and ask for a rescue prescription. This will only cover a short time and does not replace the use of an imported medicine for you. Hospitals no longer receive priority for ordering stock of PERT, so this may not be possible.

References available on request

APPENDIX - 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

Call: 020 7486 0341 9am-5pm Monday – Friday

Email: info@gutscharity.org.uk

Pancreatic Cancer UK:

pancreaticcancer.org.uk

email: 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

Call 0300 373 1000 or 020 3795 2184, Monday–Friday 10am–4pm
Email **helpline@cysticfibrosis.org.uk**
Chat on **Facebook**, **Twitter** or **Instagram**
Message on WhatsApp on **07361 582053**

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/