Position Statement: Pancreatic enzyme replacement therapy (PERT) shortage – advice for adults with pancreatic exocrine insufficiency

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Position statement and advice for patients from the [1]Nutrition Interest Group of the Pancreatic Society of Great Britain and Ireland (NIGPS), [2] Cystic Fibrosis Specialist Group and [3] Gastroenterology Specialist Group, British Dietetic Association.

Endorsed by the British Society of Gastroenterology (Pancreas section); Pancreatic Society of Great Britain and Ireland, Pancreatic Cancer UK, GUTS UK, CF Medical Association, Pancreatic Cancer Action, Neuroendocrine Cancer UK and the British Dietetic Association.

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Please ensure you are reading the most up to date version, which is available on the Pancreatic Society of Great Britain and Ireland Website:

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

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 under the care of a specialist centre, some of the advice in this leaflet is not suitable for people with CF, and this has been highlighted. 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 [Lanreotide (Somatuline®) / Octreotide (Sandostatin®)].

Please contact your specialist centre if you have symptoms that continue to escalate, 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.

Pancreatic enzyme replacement therapy is prescribed to support adequate digestion in people with pancreatic exocrine insufficiency (PEI), most commonly due to pancreatic cancer, pancreatitis, pancreatic surgery, cystic fibrosis (CF) or neuroendocrine cancers. There are many other clinical situations where people may have primary or secondary PEI, such as following gastrectomy or gastric bypass surgery (1). Patients who take somatostatin analogues [Lanreotide (Somatuline®) / Octreotide (Sandostatin®)] for the treatment of neuroendocrine neoplasms (NENs) are also at risk of PEI. Regardless of the cause of the PEI, the types of symptoms and their severity will vary from person to person.

The ongoing supply issues surrounding pancreatic enzyme replacement therapy (**PERT)** preparations under the product brands: **Creon**®, **Nutrizym**® and **Pancrex**® is likely to continue until the end of 2026. The current supply issues mean some people will need to be supplied with a different brand of PERT. This position paper provides advice to everyone who takes PERT.

Current supplies (March 2025)

- Creon® 25,000 is being delivered regularly into the UK, but at 90-95% of the usual stock levels, so 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 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 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 – do not collect it from the pharmacy – once it has been collected, it can not be reused. This product is used by people who have a feeding tube.
- 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.

Symptoms of untreated PEI may include bloating, excess wind, diarrhoea, crampy tummy pain, urgency to open bowels, steatorrhea (pale floating stools), hard to manage blood glucose levels, vitamin and mineral deficiencies, weight loss and malnutrition (1). These symptoms are usually treated by taking PERT and will recur if you are unable to take enough.

We have divided the advice for patients into 3 phases, depending on the supply available.

- **Phase 1 – What to do when you have a supply.**
- **Phase 2 – What to do if you think you need to increase your dose.**
- **Phase 3 – What to do if you have less than 2 weeks supply left.**

Phase 1: What to do when you have a supply.

Whilst the supply issues are ongoing, please do not stockpile these medicines, as this will further drive the shortage. The Department of Health and Social Care has recommended that only 1-month supply is issued at a time to try and regulate supplies, so you if you currently receive 2-3 months of your PERT at a time, you will need to collect your prescriptions more frequently. (If you pay for your prescription consider applying for a pre-payment certificate to reduce the cost of prescription charges)

Requesting your prescriptions:

- We suggest you place your prescription requests **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 that rejects repeat prescriptions if they are placed too early.
- If you still receive a paper prescription. Ask for your PERT prescription on a single prescription so you can take it to another pharmacy if needed without disrupting the supply of any other medication that you take.
- 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.

Phase 1 Summary

Please make sure you:

- ☐ Use your PERT as effectively as possible (store it correctly, make sure it does not go out of date)
- ☐ Put your next prescriptions in as soon as your previous one has been dispensed
- ☐ Check that each prescription has been approved by your GP surgery
- ☐ Do not stockpile PERT – this makes the whole situation worse.
- ☐ Speak to your GP and pharmacist about accessing imported medications so you are prepared in case you have less than 2 weeks supply left.

Phase 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 and it has not yet brought your symptoms under control, or you are experiencing worsening bowel symptoms as your appetite improves, you may benefit from increasing your dose.

- 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, speak to your doctor about taking a proton pump inhibitor (**omeprazole**® / **pantoprazole**®/ **lansoprazole**®) or an (H_2)-receptor antagonists (**Famotidine**® / **Nizatidine**®) – these reduce the acid in your stomach and can make the enzymes work better. This means a dose that is lower 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**® **Aymes**®, **Ensure**®, **Foodlink**® **Fortisip**®, **Fresubin**®), your GP or dietitian may ask you to change these to 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 syrups 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 suggested 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.

Phase 3: What to do if you have less than 2 weeks supply left.

Try not to worry – Primary Care 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 at the moment, 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, and 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.

Appendix 1: Other sources of advice for patients

Patient information is being produced by Pancreatic Cancer UK, GUTS UK, Neuroendocrine Cancer UK and the Cystic Fibrosis Trust, and is available on their websites:

Pancreatic Cancer UK

Pancreatic Cancer UK have information and tips on their website to help you manage if you can't get enough PERT. You can also speak to their specialist nurses on their free Support Line. The nurses can help with managing symptoms linked to a lack of enzymes. Please be aware though that they can't help you access PERT – they can only provide information. Call the nurses on 0808 801 0707 or email nurse@pancreaticcancer.org.uk

Pancreatic Cancer Action

https://pancreaticcanceraction.org/about-pancreatic-cancer/diet-and-nutrition-for-pancreatic-cancer/pancreatic-enzyme-replacement-therapy-pert/

Guts UK

https://gutscharity.org.uk/2024/04/pert-supply-problems/

Neuroendocrine Cancer UK

www.neuroendocrinecancer.org.uk/news/

Cystic Fibrosis Trust

www.cysticfibrosis.org.uk

References / sources of further information

1) Phillips ME, Hopper AD, Leeds JS, *et al* Consensus for the management of pancreatic exocrine insufficiency: UK practical guidelines *BMJ Open Gastroenterology* 2021 ;**8:**e000643. doi: 10.1136/bmjgast-2021-000643
2) https://bnf.nice.org.uk/drugs/pancreatin/ accessed 16/3/24
3) https://cks.nice.org.uk/topics/diarrhoea-adults-assessment/ accessed 16/3/24
4) Medicine Supply Notification: Creon 25000 MSN/2024/022 Issued 16/02/24
5) A5_Hypo_TREND.pdf (trenddiabetes.online) accessed 16/3/24
6) NPSA https://www.cas.mhra.gov.uk/ViewandAcknowledgment/ViewAlert.aspx?AlertID=103253 accessed 11/6/24