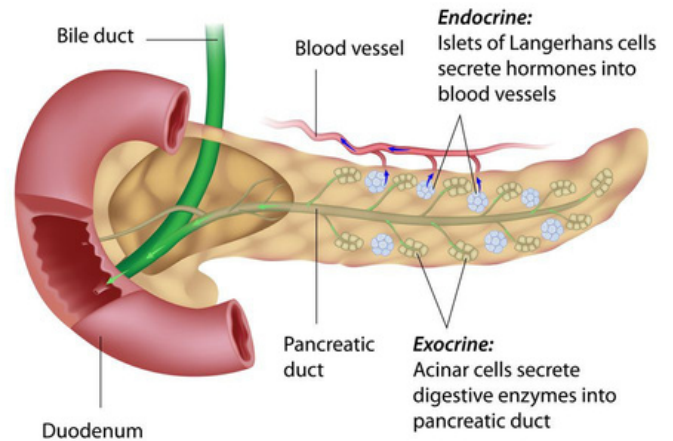


The pancreas is a large gland that is located behind the stomach and joins the digestive tract via the main pancreatic duct. It has several different types of cells that are responsible for producing substances (enzymes, peptides, hormones) that play an essential role in converting the food we eat into fuel for the body's cells – as well as regulating our blood sugars.

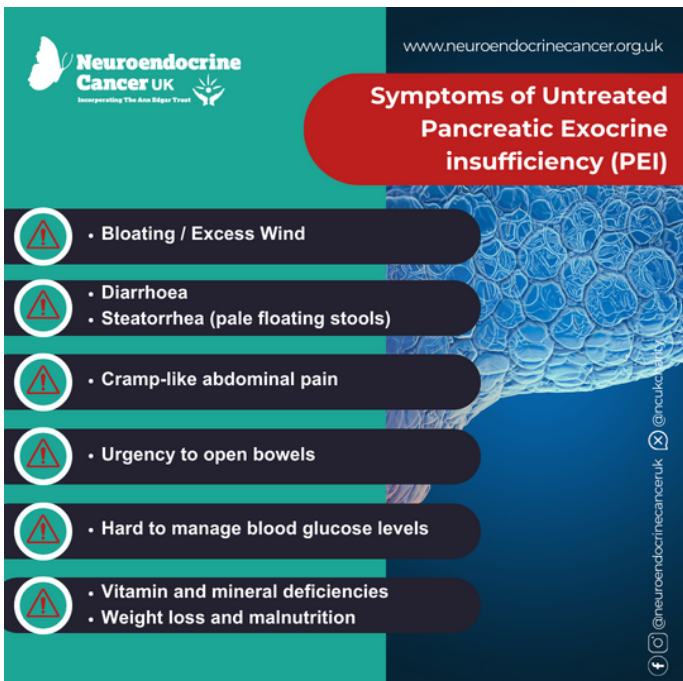
Exocrine function refers to the pancreas' ability to produce enzymes that are released into the ducts within the pancreas. These enzymes, mixed with digestive juices, help the body to absorb nutrients, by breaking down the food we have eaten when it reaches the duodenum.

Endocrine function refers to the pancreas' ability to produce certain gut hormones, such as insulin and glucagon, which are released directly into the bloodstream (rather than through ducts). These gut hormones aid digestion by controlling certain functions of the gut, as well as helping to regulate and control our blood sugar levels.



If the pancreas cannot produce enough enzymes this can result in Pancreatic Enzyme Insufficiency (P.E.I) which can, if left untreated, lead to malnutrition (due to malabsorption of nutrients, the effects of the underlying pancreatic disease and the impact of the symptoms on oral intake).

Pancreatic enzyme replacement therapy (PERT) is the cornerstone of treatment and is associated with improved survival and quality of life (QoL) in patients with PEI. Further information on PEI and PERT can be found on our website.



Symptoms of Untreated Pancreatic Exocrine insufficiency (PEI)

- Bloating / Excess Wind
- Diarrhoea
- Steatorrhea (pale floating stools)
- Cramp-like abdominal pain
- Urgency to open bowels
- Hard to manage blood glucose levels
- Vitamin and mineral deficiencies
- Weight loss and malnutrition

www.neuroendocrinecancer.org.uk
@neuroendocrinecanceruk

Position Statement:
Pancreatic enzyme replacement therapy (PERT) shortage – advice for the management of adults with pancreatic exocrine insufficiency
Phillips, McGeeney, Watson & Lowdon
Published March 2024
Full document available via the PSGBI website: <https://www.psgbi.org/> or by scanning QR code provided.

QR code to Position
Statement - March 2024

SCAN ME



When supply issues occur, it can be tempting to stock up on how much PERT you have at home (beyond 1 month's supply), we would caution against this, as it can drive up demand, which may increase shortages for others.

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

- 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.

This table shows how each product compares to others.

Table 1: Conversion chart

Creon [®] 25,000 Dose	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

*Please check the storage recommendations on the label
– Some products may need refrigerating*

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. Further information and advice is available via our website: www.neuroendocrinecancer.org.uk or scan QR code provided.

The Department of Health and Social Care has recommended that only 1 month's 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.

We suggest you place your prescription requests 2 weeks earlier than usual to give the community pharmacist time to source your medication.

You may need a change in your repeat prescriptions if what you usually have is not available. There are three brands of PERT available currently in the UK: Creon[®], Nutrizym[®] and Pancrex[®].



Scan QR code to visit our PEI & PERT page and watch our expert dietitian video

If you need help or information about how to deal with problems getting your PERT - we would suggest contacting your dietitian if you have one, GP or specialist nurse for support with digestion and PERT.

If you are having any difficulty in getting hold of your specialist healthcare professionals, please do contact our Helpline (Open Tues-Thurs, 10am-4pm): **0800 434 6476** or use the **"Contact Us"** form on our website and we will try to help.

Factsheet: P.E.R.T

Phase 2: Limited Supplies

First Step if supplies are limited:

- Ensure you are taking a proton pump inhibitor (PPI - such as omeprazole® / pantoprazole® / lansoprazole®) or an (H2)-receptor antagonists (Famotidine® / Nizatidine®) – these can help to reduce the acid in your stomach and make the enzymes more efficient. This means a lower dose than your usual dose may be more effective if you have a proton pump inhibitor as well. If this does not appear to be effective, the PPI may be stopped.
- If you have some high-dose PERT left, take this with you when you go out, and use the low-dose capsules when you are at home to reduce the number of capsules you need to take out with you.
- Prioritise meals that have the most protein and energy in them.
- Suppose you are not already taking vitamins and minerals. In that case, we recommend that you take a calcium and vitamin D supplement (containing 800iu Vitamin D and at least 500mg Calcium) and a multi-vitamin and mineral during this time (i.e. Sanatogen A-Z Complete® / Centrum Advance® / Supermarket own A-Z brand please ensure these contain both vitamins and minerals).

If supplies are low:

- Reduce the dose of PERT with snacks before reducing your doses with meals - as meals tend to be more nutritious (depending on content and amount).
- Reduce the dose of PERT by one capsule with each meal and snack, rather than missing whole meal doses.

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®, Peptisip Energy HP®) as many 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 fat-free nutritional supplements (Actagain Juice®, Altrajuce®, Ensure Plus Juice®, Fortijuce®, Fresubin Jucey® 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.

Please contact your dietitian/nurse specialist or doctor if you are struggling with malabsorption symptoms or are consistently losing weight.

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.

If you have diabetes - we recommend that you monitor your blood glucose levels regularly: before meals, before bed, if feeling unwell, if you feel like you are having a hypo*, or before driving. If you are driving long distances, make sure you check your blood glucose levels regularly.

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

You can find more information on recognising and treating a hypo from your diabetes team or by visiting <https://trenddiabetes.online/> (for the Hypoglycaemia explained PDF) or by scanning the QR code provided here.



You are usually only at risk of a hypo if you take medication that lower your blood glucose levels and it is not usually possible to have a hypo if you have diet-controlled diabetes, or diabetes treated with metformin/DPP-4 inhibitors (Gliptins).

However, this risk may also depend on the type of neuroendocrine cancer you have - and the treatment you may have undergone - or are continuing to receive (e.g. somatostatin analogues such as Octreotide or Lanreotide - both of which can alter blood sugar control).



You can visit our YouTube channel to view Dr Alia Munir's talk on Diabetes and Neuroendocrine Cancer - [@neuroendocrinecanceruk](https://www.youtube.com/@neuroendocrinecanceruk)

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 specialist team for advice on adjusting your insulin doses.

A "hypo" or 'hypoglycaemic episode' can occur when your blood glucose level goes below 4mmol/l.

Typical symptoms include sweating, shaking, blurred vision, confusion, palpitations.

Always keep hypo treatment on you.

If you need help or information about how to deal with problems getting your PERT - we would suggest contacting your dietitian if you have one, GP, or specialist nurse for support with digestion and PERT

If you are having any difficulty in getting hold of your specialist healthcare professionals, please do contact our Helpline (Open Tues-Thurs, 10am-4pm): **0800 434 6476** or use the **"Contact Us"** form on our website and we will try to help.