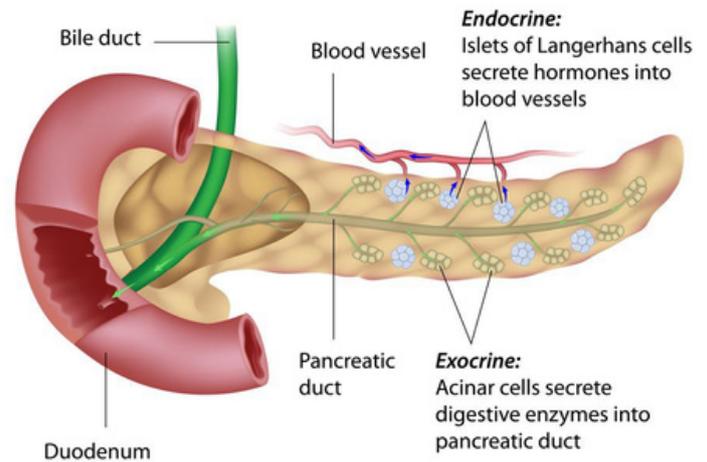


The pancreas is a large gland that is located behind the stomach and joins the digestive tract via the main pancreatic duct. It has several different types of cells that are responsible for producing substances (enzymes, peptides, hormones) that play an essential role in converting the food we eat into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

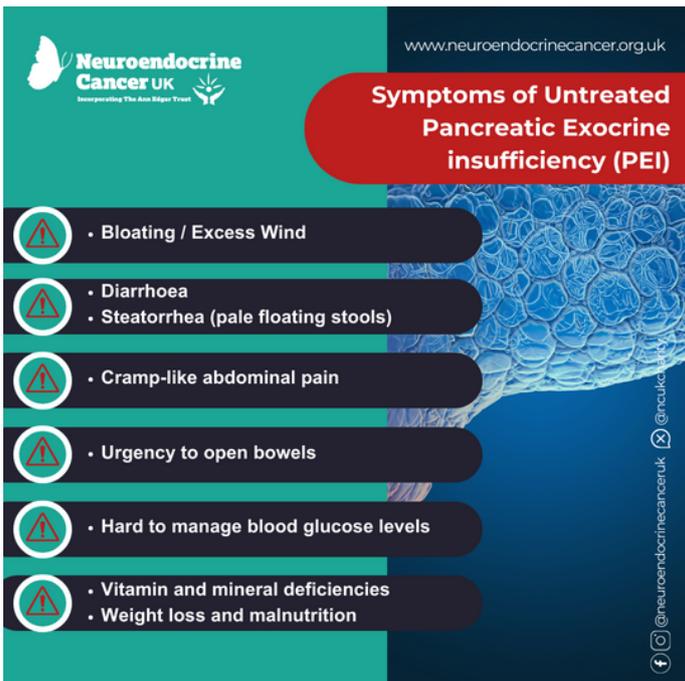
**Exocrine function** refers to the pancreas' ability to produce enzymes that are released into the ducts within the pancreas. These enzymes, mixed with digestive juices, help the body to absorb nutrients, by breaking down the food we have eaten when it reaches the duodenum.

**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.



**Neuroendocrine  
Cancer UK**  
www.neuroendocrinecancer.org.uk

**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

@neuroendocrinecanceruk @incuk

### 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 PSGB&I 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 <sup>®</sup> 25,000 Dose	Equivalent in Nutrizym <sup>®</sup> 22	Equivalent in Creon <sup>®</sup> 10,000	Equivalent in Pancrex <sup>®</sup> 340mg (8,000 units lipase)	Equivalent in Pancrex <sup>®</sup> 125mg (2,950 units lipase)	Equivalent in Creon <sup>®</sup> Micro <sup>*</sup>	Pancrex <sup>®</sup> V powder <sup>*</sup>
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](http://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<sup>®</sup>, Nutrizym<sup>®</sup> and Pancrex<sup>®</sup>.



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 4: No Supplies

In neuroendocrine cancer there may be more than one cause of diarrhoea - e.g., worsening Carcinoid Syndrome, bile salt/acid malabsorption (BSM/BAM), short bowel syndrome, Spontaneous Intestinal Bacterial Overgrowth (SIBO), etc. It is, therefore, important that if diarrhoea persists, worsens, or develops as a new symptom, this is reviewed and PEI is either confirmed or excluded as a factor, before changing your PERT dose or making dietary alterations. Other treatments may be more effective than PERT if PEI is not the cause or other causes are also present.

If any, or more than one of the following, occur:

- You are unable to get hold of any PERT at all: Creon®, Nutrizym® or Pancrex®
- You do not have enough PERT and are losing weight (more than 2kg a month or if you are already underweight - more than 1kg a month).
- You do not have enough PERT and have uncontrollable bowel symptoms that are restricting your social / work/education activities.

We know this can be worrying, however, supplies are being regularly restocked: if you run out, this should only be a short-term situation for you. It may help to:

- Contact your hospital team and see if they have sufficient supplies to issue a prescription for you – you may have to travel to the hospital to collect these if they have some available.
- Inform your pharmacist that you have completely run out so that your supply can be prioritised as stocks come in.
- 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 these particular nutritional supplements.
- You can also contact your dietitian if you have one, but you may be seen more quickly if you go straight to your GP.

These peptide\* nutritional supplements can be used instead of meals if dietary intake cannot be managed until you have your enzymes again. If you do not have diabetes, you can continue to have sugary foods and drinks alongside these, to increase your calorie intake.

Table c (next page) shows how many supplement drinks you should take if you do not have any PERT at all. It might be helpful to show your GP this information.

\*\*Peptides are partially broken down proteins, which makes them easier to digest and absorb in the gut than whole proteins.

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

Table c

Body weight	Supplements needed per day (Vital 1.5kcal® or Peptisip Energy HP®)
Less than 40kg (6st 4lb)	Contact a dietitian (or your specialist team if you do not have a dietitian)
40 - 50kg (6st 4lb - 7st 12lb)	4 x 200ml bottles = 1200kcal
50 - 60kg (7st 12lb - 9st 6lb)	5 x 200ml = 1500kcal
60 - 70kg ( 9st 6lb - 11st)	6 x 200ml = 1800kcal
70 - 80kg (11st - 12st 8lb)	7 x 200ml = 2100kcal
80 - 90kg (12st 8lb - 14st 2lb)	8 x 200ml = 2400kcal
More than 90kg (14st 2lb)	Contact a dietitian (or your specialist team if you do not have a dietitian)

This may under-estimate your needs:

- If you continue to lose weight or are very active - add one more bottle per day.
- If you start to gain weight and were not intending to – reduce by one bottle per day.

Vital 1.5kcal is suitable for people with disease-related malnutrition and malabsorption or for those who experience symptoms of poor feed tolerance. It is also suitable for patients with diabetes, provided that routine glucose checks are performed.

Peptisip Energy HP is suitable for those with disease-related malnutrition and malabsorption or for those who experience symptoms of poor feed tolerance.

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 variety.

**For patients who may have a gastric feeding tube:**

If you have a PEG, RIG or NG feeding tube, you could take your PERT from a powdered source (Pancrex® V powder). These can be dissolved in water and flushed down the tube, but this must be done at the time you eat. If you have a feeding tube, discuss this option with your dietitian.

Please note: this does not work with a jejunostomy or naso-jejunal tube as the enzymes will not mix with your food.

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.