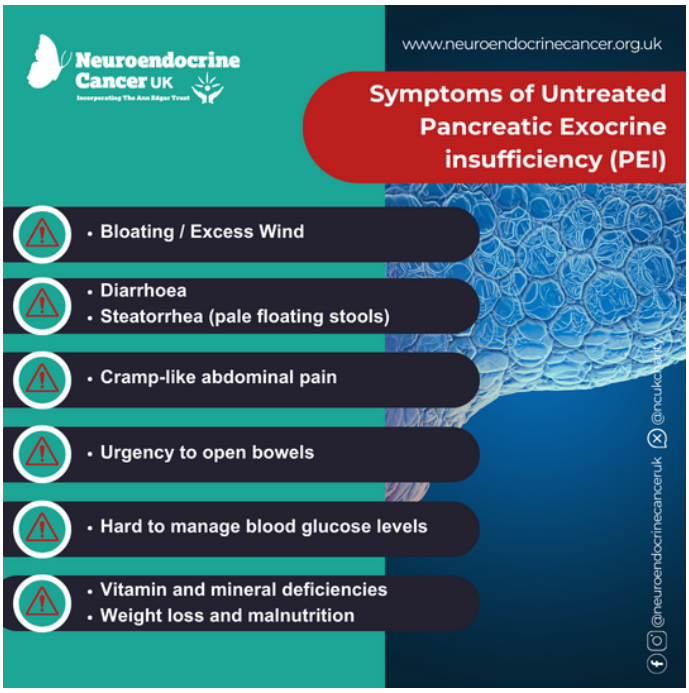
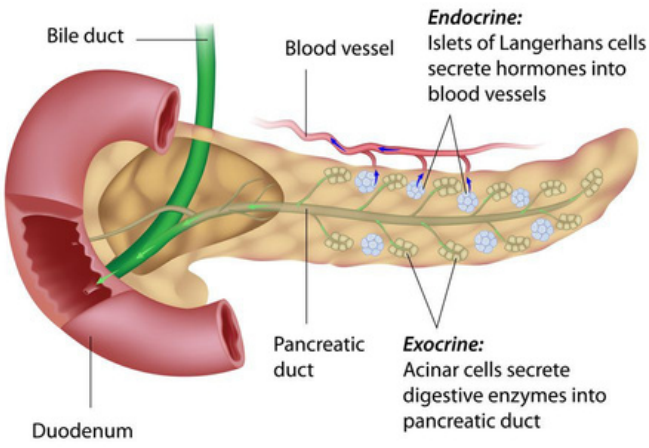
Factsheet: P.E.R.T Phase 3: Limited Supplies & PEI Symptoms

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.

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

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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.

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®.

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

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

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.

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.

Neuroendocrine Cancer UK
Incorporating The Ann Edgar Trust

www.neuroendocrinecancer.org.uk

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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.

The Position Statement offers the following advice - if supplies are short and you are experiencing worsening or new symptoms of PEI:

- If you are struggling with PEI-related diarrhoea, consider taking some loperamide / Imodium® before your main meal. This may help to slow down your gut and reduce diarrhoea. The longer food is within your gut, the greater the opportunity there is for more of it to 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 next page - table a). This is likely to improve some of your gut symptoms but will not mean you absorb more nutrition or prevent malnutrition, so keep a close eye on your weight and strength.
- If you eat a lot of high-fibre foods – consider reducing these as very high-fibre foods can bind to enzymes and make them less effective (see next page - table b). Healthy eating guidelines recommend adults try to eat 30g of fibre per day: however many with neuroendocrine cancer already follow a low fibre or soluble fibre diet. The advice provided recommends not exceeding 40g at this time.
- If you do not have diabetes, you could use sugary foods and drinks to increase your energy intake. Table sugar does not require enzymes to be absorbed in your gut, adding sugar/honey / syrup to foods and nibbling on sugary sweets/marshmallows (not chocolate), and soft drinks e.g. Lucozade, can help keep your energy levels up. But these do not provide any other nutrition so do ensure you are having protein, vitamins and minerals from other sources.

Handy Hint: if you find carbonated soft drinks, like Lucozade are too ‘gassy’ - loosen the lid for a little while and allow it to go almost flat. Sipping this ‘flat pop’ may also help alleviate nausea.

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

Table a

	REDUCE portion sizes of these	REPLACE with or use these instead
Fats and oils	Butter, Lard, Ghee, Margarine, Cooking oils	Small portions of low-fat spread Use spray on cooking oils - if needed
Dairy products	Full fat milk / yoghurt Cream Creme fraiche Cheese	Semi-skimmed or skimmed milk (To increase your protein intake add skimmed milk powder to skimmed milk and use in place of milk throughout the day: 4 tablespoons per pint) Low-fat yoghurt Use small amounts of grated cheese instead of slices.
Meat and Fish	Fried foods or foods cooked in batter Skins or visible fat on meat Tinned fish in oil	Meat or fish steamed, grilled, roasted - without added oil Remove skin and/or trim fat Tinned fish in spring water or brine
Plant-based protein sources	Nut butters	Pulses (e.g. lentils, chickpeas) Quorn / Tofu - up to 100g
Fruit and vegetables	No restrictions	
Carbohydrate-based foods	Croissants, pastries Chips / Fried Roast potatoes	Bread, breakfast cereals Potatoes, rice, pasta - cooked without added fat / oils
Sauces and condiments	Cheese-based sauces Creamy sauces e.g. bearnaise, hollandaise, etc) Large portions of mayonnaise	Gravy, mustard, tomato-based sauces, ketchup, mint jelly, vinegar or low-fat salad dressings.

Table b

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

Fibre can be categorised into soluble, insoluble and prebiotic fibres (including resistant starch).

- Soluble fibre attracts water and turns to gel-like material during digestion. This slows digestion and can help us feel fuller for longer. It is found in oat bran, rye, barley, nuts, seeds, beans, lentils, peas, and some fruits and vegetables e.g. onions, leeks, root vegetables, aubergines, citrus fruits, apples and bananas..
- Insoluble fibre does not dissolve in water and passes through the small bowel into the large bowel, where it adds bulk to the stool and appears to help food pass more quickly through the stomach and intestines. It is found in foods such as wheat bran, wholegrain bread and cereals, brown rice, quinoa, nuts and seeds, leafy green vegetables, pumpkin, cauliflower, green beans and potatoes with their skin on.
- Resistant starch is not digested by the small bowel and moves into the large bowel, where it acts as food for the large intestine (prebiotics). Sources of resistant starch include oats, wheat bran, lentils, chickpeas, almonds, hazelnuts, artichokes, beetroot and pomegranate seeds.

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.