

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

Phillips M.E^{1,3}, McGeeney L.M¹, Watson K-L², Lowdon J².

Position statement and advice for patients from the ¹Nutrition 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.

Issue date: 17th November 2024 (Version 4)

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

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 type 3c diabetes or 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** – under the product brands: **Creon**°, **Nutrizym**° and **Pancrex**°) is going to continue until 2026. The current supply issues mean some people are running out of PERT, or experiencing difficulties or delays in accessing PERT. This position paper is designed provides advice to everyone who takes PERT.

Current supplies (October 2024)

- Creon[®] 25,000 is being delivered regularly into the UK, but at 90-95% of the usual stock levels.
- 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 can not tolerate Creon
- Pancrex[®] products are available, but there is not any extra supply, so they cannot fill the gap in the market
- Pharmacies have been provided with information to support them obtaining medication from abroad if they are not able to source any PERT from within the UK

Symptoms of untreated PEI may include bloating, excess wind, diarrhoea, crampy abdominal 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 are going to run out
- Phase 3 What to do if you have run out.

Pancreatic enzymes are still being delivered regularly into the United Kingdom, so we will move backwards and forwards between these phases. We are not anticipating that any individual patient will run out of PERT completely for very long. So, if we do have to use the advice in phase 2 or 3, we hope this will only be for a short period of time.

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 your previous prescription has been dispensed (the pharmacy have provided the medication).** 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.
- 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.
- Pharmacies should also be able to order in medicines from abroad.

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.
- □ Be prepared to receive a different brand of PERT to the one you are normally prescribed.

Phase 2: What to do if you are going to run out

If your pharmacist is unable to source PERT for you and you are waiting for a supply to be delivered, please take these steps to ensure your existing supply lasts as long as possible. Manufacturers have customer support lines that may help you find a pharmacist near by with stock: Creon: 0800 8086410, Nutrizym 08000 902408 (Mon-Fri 9-5).

- If you have cystic fibrosis please contact your specialist centre.
- If you are having Chemotherapy, preparing for surgery, recovering from surgery, having difficulty eating or struggling with malnutrition, it is important that you do not restrict your PERT dose as this may have an impact on the rest of your treatment. Please contact your managing hospital and request a rescue prescription.
- If you are not already taking one, speak to your doctor about taking a proton pump inhibitor (omeprazole[°] / pantoprazole[°] / lansoprazole[°]) or an (H₂)-receptor antagonists (Famotidine[°] / Nizatidine[°]) these reduce the acid in your stomach and can make the enzymes more efficient. 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.
- If you are not already taking vitamins and minerals, 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)
 - Patients with CF should remain on their prescribed vitamins and minerals and discuss any concerns with your CF specialist dietitian.

How to reduce your dose to make your supplies last longer

- First step:
 - \circ $\;$ Reduce the dose of PERT by one capsule with any snacks that you take.
 - Make the most of the meals you have and spread your PERT out throughout them to optimise digestion
- If this is not enough:
 - Reduce the dose of PERT by one capsule with each meal and snack, rather than skip whole meal doses.
- If this is not enough:
 - Reduce the dose of PERT by one capsule with each meal and only have a piece of fruit as a snack in order that you do not need to take any PERT with snacks.
- Please contact your dietitian / nurse specialist or doctor if you are struggling with malabsorption symptoms or are consistently losing weight.
- If you are taking other medication, be aware this may not be as effective as normal, speak to your doctor if this is the case. If you are on the oral contraceptive pill, you should use a second form of contraception

Example meal plan

Meal	Example of food consumed Usual PERT dose			
Breakfast	Bowl of cereal with milk and a yoghurt	2 x 25,000		
	Orange juice and cup of tea			
Snack	Cup of tea with 2 x rich tea biscuits 1 x 25,000			
Lunch	Tuna sandwich, packet of crisps, banana and a	3 x 25,000		
	chocolate biscuit			
Snack	Cup of coffee and a piece of cake	1 x 25,000		
Dinner	Cottage pie, vegetables and a scoop of ice cream,	4 x 2,5000		
	Glass of lemonade			

This is an example of a meal plan with adequate PERT (11 capsules per day)

Suggested changes if you do not have adequate PERT, but are nutritionally well (weight stable) or have diabetes. Here the PERT use is reduced to 5 capsules/day.

Meal	Example of food consumed	PERT dose	Explanation
Breakfast	Bowl of cereal with skimmed milk and a yoghurt and cup of tea	1 x 25,000	Dose reduced and milk & yoghurt swapped to a low-fat one to reduce any symptoms of insufficient PERT
Snack	Cup of tea with an apple	0	Biscuits swapped for an apple so PERT not required
Lunch	Tuna sandwich, packet of corn crisps (Skips®/Wotsits® /Quavers® etc.), banana and a sugar free jelly.	2 x 25,000	Dose reduction and reduction in fat content to reduce symptoms
Snack	Cup of coffee	0	No snack to reduce dose
Dinner	Cottage pie (made with lean mince and fat drained off / turkey mince), vegetables and a scoop of sorbet/low fat yoghurt, sugar- free lemonade	2 x 25,000	Dose reduction and reduction in fat content to reduce symptoms

Suggested changes if you do not have adequate PERT but are losing weight and do not have diabetes. Here the PERT use is reduced to 5 capsules/day.

Meal	Example of food consumed	PERT dose	Explanation
Breakfast	Bowl of cereal with skimmed milk and a low-fat yoghurt with	1 x 25,000	Dose reduction, low fat products to reduce symptoms and added sugar to
	honey, Orange juice, cup of		replace energy
	tea		
Snack	Cup of tea with	0	Fat free high sugar snack
	marshmallows, sugary sweets		
Lunch	Tuna sandwich, packet of corn		Dose reduction, low-fat products to
	crisps (Skips®/Wotsits®	2 x 25,000	reduce symptoms and added sugar to
	/Quavers® etc.), Jelly and a		replace energy
	chocolate biscuit		
Snack	Cup of coffee and banana	0	Low fat snack
Dinner	Cottage pie, vegetables and a		Dose reduction, low fat products to
	scoop of sorbet with syrup	2 x 25,000	reduce symptoms and added sugar to
	Glass of full sugar lemonade		replace energy

Tips if you are needing to take more capsules of a lower dose as your usual capsules are not available, and are struggling with the number of capsules you need to take

- If you have some high dose PERT left, take this with you when you go out, and use the lower dose capsules when you are at home.
- If swallowing the capsules is putting you off your meals take some of them at the end of the meal. For instance, if you need to take 20 capsules with your meals, take 5 at the start, 5 in the middle and 10 at the end.
- Ensure you do not chew or crush the tablets, this will make them less effective and can damage your gums or cause unpleasant mouth ulcers.

Advice for people with diabetes

If your diabetes is controlled by diet or you take Metformin / DPP-4 inhibitors (Gliptins) / SGLT 2 inhibitors (Gliflozins) without any other medication, you should not need to change any of your diabetes management.

If you take insulin or medicines that can cause a hypo / low blood sugar (i.e. Gliclazide) please read the advice below carefully:

If you take less enzymes with your food, you are likely to absorb less starchy carbohydrate from food, but simple sugar absorption is not affected by a lack of PERT. This will mean that usual carbohydrate counting techniques may be less reliable. Therefore, you may need to reduce the amount of quick acting or mixed insulin you inject to prevent a hypo*.

*A hypo is when your blood glucose level goes below 4mmol/l, typical symptoms include sweating, shaking, blurred vision, confusion, palpitations. Always keep hypo treatment on you. You can find more information on recognising and treating a hypo from your diabetes team or by following this link:

You are only at risk of a hypo if you take medication that increase the amount of insulin in your blood. It is not usually possible to have a hypo if you have diet-controlled diabetes, or diabetes treated with **metformin/DPP-4 inhibitors (Gliptins) / SGLT 2 inhibitors (Gliflozins**) alone.

Monitor your blood glucose levels regularly: before meals, before bed, if you are feeling unwell, if you feel like you are having a hypo* and before driving. If you are driving long distances, make sure you check your blood glucose levels at least every two hours. If you have a continuous glucose monitor, ensure you have the low alert alarm set. This will alert you if your blood sugars become low. If you are having more hypos than usual, you may need to contact your CF/NEN/diabetes team for advice on adjusting your insulin doses.

If you have had a hypo, please make sure you have enough PERT to take with the starchy carbohydrate snack you take to maintain your blood sugars (digestive biscuit / sandwich / scone / crumpet etc.). Speak to your diabetes team for advice on reducing your insulin or medication if you start having hypo's or need to reduce your PERT dose.

Advice for people taking nutritional supplement drinks

If you take oral nutritional supplements (i.e., Altraplen[°] Aymes[°], Ensure[°], Foodlink[°] Fortisip[°], Fresubin[°]), ask your GP or dietitian if they can be changed to a peptide / semielemental 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 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.

Advice for people taking other medication

Please be aware that other medication you take may be less effective if you are not absorbing. This is particularly important for people who take medications to prevent seizures, the formation of blood clots and the oral contraceptive pill.

If you are on the oral contraceptive pill, a secondary form of contraception should be used at this time. Please talk to your Doctor or specialist team.

Phase 3: What to do if you have run out

Do not worry – this should not last long.

Ask your GP what plans are in place in your local area to support people who have run out of PERT. You may be able to talk to a pharmacist at your GP surgery about this.

If you have had a total pancreatectomy or are taking insulin please **make an emergency (same day) appointment** with your GP. You can show them this document.

If you are under the care of a local hospital, please contact your local hospital team and ask for a rescue prescription.

Symptom management without PERT

- If you are struggling with diarrhoea, consider taking some **loperamide** / **Imodium**[®] before your main meal. This should help to slow down your gut and reduce diarrhoea. The longer food is within your gut, the more chance more of it will be absorbed by your body.
 - Please note if this is a new sudden onset of diarrhoea, that does not coincide with running out of PERT, infection should be ruled out before loperamide is used.
 - \circ This is not suitable for people with CF please contact your specialist CF Team
- Reduce the amount of fat in your meal to ½ of your normal the portion size of higher fat foods (Table 1). 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 (Table 2). Healthy eating guidelines recommend adults try to eat 30g of fibre per day. We recommend not exceeding 40g at this time.
- If you do not have diabetes, use sugary foods and drinks to increase your energy intake. Table sugar does not require enzymes to be absorbed in your gut, so Lucozade, adding sugar / honey / syrup to foods and nibbling on sugary sweets / marshmallows (not chocolate) can help keep your energy levels up. **But** these do not provide any other nutrition so make sure you are having protein, vitamins and minerals from other sources.
- If you are losing weight, please speak to your dietitian or GP about taking some peptide based nutritional supplement drinks. These are a specialist type of supplement drink that require a lot less enzymes for absorption, so can usually be taken without PERT. These are called Vital 1.5kcal[®], Survimed OPD 1.5kcal[®], Peptisip Energy HP[®]. They are more expensive than other supplement drinks, but really useful if you cannot take PERT.
- If you have enough PERT to take some with your main meal, eat this as usual and use half the dose of supplement drinks in place of your other meals

Advice for people taking other medication

Please be aware that other medication you take may be less effective if you are not absorbing. This is particularly important for people who take medications to prevent seizures, the formation of blood clots and the oral contraceptive pill.

If you take the oral contraceptive pill, a second form of contraception should be used at this time.

Please talk to your doctor or specialist team if you are taking medicines for other conditions.

If you take medication to stop your blood from clotting (anti-coagulation) please inform your doctor that you have run out of PERT. Vitamin K which helps control blood clotting is a fat-soluble vitamin and the absorption of this will be reduced whilst you are not on PERT. You may need more regular monitoring.

Advice for people with diabetes

You need a supply of PERT If you take insulin or medications that increase the amount of insulin in your blood (i.e. Gliclazide). You may be asked to travel to a hospital to collect this. In the meantime you should monitor your blood sugars more regularly.

If you have a continuous glucose monitoring device, ensure you have the low blood sugar alert set up.

Check your blood sugars more regularly when driving and ensure you carry "hypo" treatments with you. Sugary foods such as dextrose tablets, glucogel[®], and jelly sweets will still be absorbed, but your "long acting" carbohydrates (sandwiches/digestive biscuits etc.,) may not be as effective at maintaining your blood sugars when taken without PERT.

Table 1: High fat foods and their lower fat alternatives

	Reduce your portion sizes of these	Have these instead*	
	Butter, lard, Ghee,	Small portions of low-fat spreads	
Fats and oils	Margarine, cooking oils	Use spray on cooking oils if needed	
	Full fat milk / yoghurt	Semi-skimmed or skimmed milk.	
	Cream	Low fat yoghurts	
	Crème Fraiche	Use small amounts of grated cheese instead of slices of cheese – choose stronger cheeses to maximise taste.	
Dairy products	Cheese	To increase your protein intake, make skimmed milk powder up using skimmed milk and use in place of milk throughout the day	
	Fried foods or foods cooked in batter	Meat and fish cooked without added oil	
Meat and Fish	Skins / visible fat on meat	Tinned fish, tinned in spring water / brine	
	Tinned fish, tinned in oil		
	Nut butters	Pulses (e.g. lentils, chickpeas, beans (note portion sizes in table 4)	
Plant based protein sources		Quorn / Tofu – up to 100g	
Fruit & vegetables	No restrictions for	strictions for low fat, see Table 4 for fibre suggestions	
	Croissants, pastries	Bread, Breakfast cereals	
Carbohydrate	Chips / Fried	Potatoes, rice, pasta, cooked without added fat	
based foods	Roast potatoes		
Sauces / Condiments	Cheese based sauces Creamy sauces (bearnaise, hollandaise etc.,)	Tomato based sauces, gravy, mustard, tomato ketchup, soy sauce, mint jelly, vinegar or low- fat salad dressings	
*Diagon noto	Large portions of mayonnaise		

*Please note

Patients with Carcinoid Syndrome, please do not introduce foods you have previously been advised to avoid.

Table 2: High fibre foods. Aim for less than 40g fibre per day

Very high fibre foods		High fibre foods				
Food	Portion providing 10g fibre	Food	Portion providing 5g fibre	Food	Portion providing 5g fibre	
All bran®	40g	Whole wheat pitta	1 large	Weetabix®	2 biscuits	
Brown pasta	250g (cooked)	Rye based crackers (i.e. Ryvita [®])	4 biscuits	Shredded wheat [®]	2 biscuits	
Baked Beans	300g	Branflakes°/ Sultana Bran°, Fruit n/Fibre°	30g bowl	Porridge / Readybrek®	Large bowl (60g oats)	
Dried apricots / prunes	120g	Jacket potato with skin	1 medium	Pasta (white)	250g (cooked)	
Nuts and seeds	150g	Wholemeal spaghetti	150g (cooked)	Wholemeal bread	100g	
Dried lentils / chick peas /Mung beans	100g (weight before cooking)	Baked beans	150g	Quorn®	75g	
Dried soya beans / red kidney beans	70g (weight before cooking)	Green beans / peas (fresh or frozen)	120g	Spinach	5 tablespoon s	
Desiccated coconut	70g	Sweetcorn	7 tablespoon s	Avocado pear	1 whole fruit	

If you are without PERT for more than 3-4 days

If you are under the care of a hospital team, contact them and see if they have sufficient supplies to issue a prescription for you – you will have to travel to the hospital to collect these if they have some available.

Inform your pharmacist that you have completely run out, so your supply can be prioritised if possible.

Try not to worry, supplies are regularly coming into the country -

so running out completely will be a short-term issue.

If you are unable to eat food because of your symptoms

Drink plenty of fluids. Include Lucozade®, sports drinks or Dioralyte®.

Ask your GP for a peptide nutritional supplement to be prescribed (**Vital 1.5kcal**[°], **Survimed OPD**[°] **1.5kcal** or **Peptisip Energy HP**[°]) – you can show them this leaflet. If you are known to a dietitian – they can be contacted too, but due to the massive increase in workload this PERT shortage is generating, you are likely to get these more quickly if you go directly to your GP.

These can be used instead of meals until you have your enzymes again. If you do not have diabetes, you can continue to have sugary foods and drinks alongside these. The table below shows how many supplement drinks you should take if you do not have any PERT at all.

These do not come in a wide range of flavours, but you can add milkshake syrup 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. There is no real alternative to this, so it is important that you try your hardest to take these.

Recommended doses for peptide based nutritional supplement drinks if you are unable to absorb your food.

Body weight	Supplements needed per day. (Vital 1.5kcal° or Survimed OPD 1.5kcal° or Peptisip Energy HP°)
Below 40kg (6st 4lb)	Contact a dietitian
40 – 50kg (6st 4lb- 7st 12lb)	4 x 200ml bottles = 1200kcal
50 – 60kg (7st 12lb – 9st 6lb)	5 x 200ml bottles = 1500kcal
60 - 70kg (9st 6lb – 11st)	6 x 200ml bottles = 1800kcal
70 - 80kg (11st – 12st 8lb)	7 x 200ml bottles = 2100kcal
80 - 90kg (12st 8lb – 14st 2lb)	8 x 200ml bottles = 2400kcal
Over 90kg (14st 2lb)	Contact a dietitian

This may under-estimate your needs, if you lose weight or are very active, add in one more bottle per day. If you gain weight and were not intending too – reduce by 1 bottle per day.

Suitable foods to eat without PERT

Whilst you are on these supplement drinks you can consider the following snacks:

- Fruit a handful sized portion at a time
- Vegetable sticks (carrot, celery, cucumber)
- Small amounts of salsa / ketchup / balsamic vinegar / marmite / mustard tiny amounts can be used to give vegetable sticks a slightly different taste.

If you do not have diabetes, you could also try:

- Sorbet
- Marshmallows
- Sugary sweets (not chocolate / fudge or toffee)

Please note this is generic advice – do not introduce foods you have previously been advised to avoid.

These foods will not give you many calories, but they should not make your symptoms of malabsorption worse and will fill you up a bit more than having the supplement drinks on their own.

You can eat other foods, but these may worsen any abdominal symptoms you are experiencing.

A suggested daily meal plan for someone who weighs 80kg may look like this:

Breakfast: 1 x supplement drink, cup of black coffee and a banana

Mid-morning: I x supplement drink, carrot sticks

Lunch: 2 x supplement drinks flavoured with chocolate coffee syrup and served with ice, cucumber and celery sticks dipped in salsa

Mid-afternoon: 1x supplement drink and an apple

Dinner: 1 x supplement drink and some carrot sticks with a smear of marmite; 1 x frozen supplement drink served with a handful of strawberries, raspberries and a scoop of sorbet.

For patients who already 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) through this tube. These can be dissolved in water and flushed down the tube, but this must be done at the time you eat. This does not work with a jejunostomy or naso-jejunal tube as the enzymes will not mix with your food. **If you have a feeding tube, discuss this option with your dietitian.**

For all patients with feeding tubes

If you normally receive some of your nutrition through a feeding tube, or have one that you are not currently using, it may be beneficial to increase your feed through the tube whilst you do not have any PERT. Please speak to your dietitian about this.

Appendix 1: Conversion charts

Creon®	Equivalent	Equivalent	Equivalent	Equivalent	Equivalent	Pancrex [®] V
25,000	in Nutrizym [®]	in Creon [®]	in Pancrex®	in Pancrex®	in Creon®	powder*
Dose	22	10,000	340mg	125mg	Micro*	
			(8,000 units	(2,950 units		
			lipase)	lipase)		
1 x Creon	1 x Nutrizym	3 x Creon	3 x Pancrex	8 x Pancrex	5 scoops	1⁄₂ x 2.5ml
25,000	22	10,000	8,000	2,950	Creon Micro	spoon
2 x Creon	2 x Nutrizym	5 x Creon	6 x Pancrex	16 x Pancrex	10 scoops	1 x 2.5ml
25,000	22	10,000	8,000	2,950	Creon Micro	spoon
3 x Creon	3 x Nutrizym	8 x Creon	9 x Pancrex	24 x Pancrex	15 scoops	1½ x 2.5ml
25,000	22	10,000	8,000	2,950	Creon Micro	spoon
4 x Creon	4 x Nutrizym	10 x Creon	12 x Pancrex	32 x Pancrex	20 scoops	2 x 2.5ml
25,000	22	10,000	8,000	2,950	Creon Micro	spoon
5 x Creon	5 x Nutrizym	13 x Creon	15 x Pancrex	40 x Pancrex	25 scoops	2 ½ x 2.5ml
25,000	22	10,000	8,000	2,950	Creon Micro	spoon
6 x Creon	6 x Nutrizym	15 x Creon	18 x Pancrex	48 x Pancrex	30 scoops	3 x 2.5ml
25,000	22	10,000	8,000	2,950	Creon Micro	spoon

This table shows how each product compares to others (2).

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

Appendix 2: 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

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

- 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=10325 3 accessed 11/6/24