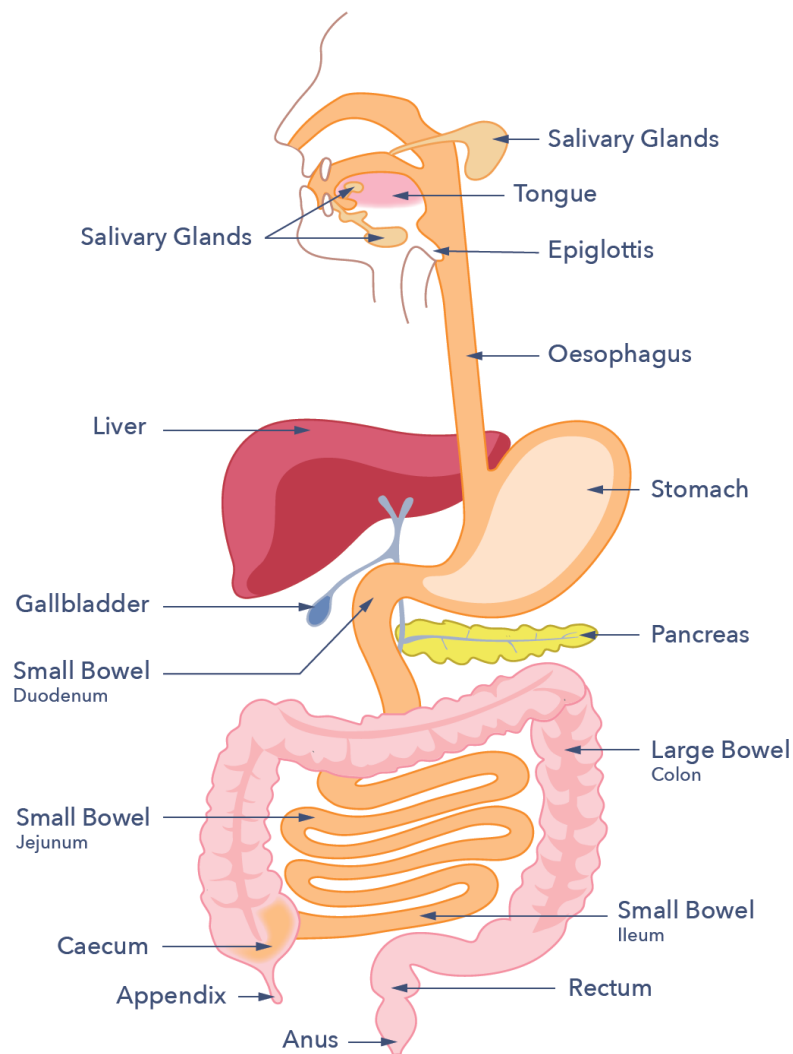




# How to deal with Creon, Nutrizym or Pancrex supply issues

Guts UK is the charity for the digestive system. Funding research to fight diseases of the gut, liver and pancreas.

## THE DIGESTIVE SYSTEM



## OVERVIEW

# THIS FACTSHEET IS ABOUT PROBLEMS WITH THE SUPPLY OF PERT.

**Issue date: 21<sup>st</sup> August 2024 (Version 4).** Please ensure you are reading the most up to date version.

The most up to date advice can be found on the Pancreatic Society of Great Britain and Ireland (PSGBI) website, the correct version of this document is version 3: <https://www.psgbi.org/position-statement-pert-shortage/>

If you would like a printed copy, you can e-mail us: [info@gutscharity.org.uk](mailto:info@gutscharity.org.uk) or call us: 0207 486 0341.

Viatrix, the distributor of Creon has started a consumer helpline for people who use Creon. This service aims to provide up-to-date information on Creon supplies and the pharmacies that have recently received a supply in your postcode area. They will require that you share your postcode on the call. Their free helpline phone number is 0800 8086410, opening times Monday - Friday, 9am to 5pm.

### 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 cared for by a specialist centre. We have highlighted that some of the advice in this leaflet is not for people with CF. If you have CF, you should contact your specialist team if you have any concerns.

### Advice for adults

Doctors prescribe pancreatic enzyme replacement therapy. It supports adequate digestion in people with pancreatic exocrine insufficiency (PEI). Most commonly PEI is caused by pancreatic cancer, pancreatitis and cystic fibrosis (CF). Many other clinical situations can cause primary or

secondary PEI. These include type 3c diabetes, and gastrectomy or gastric bypass surgery. PEI has many causes. But symptoms and their severity vary from person to person.

The ongoing supply issues surrounding pancreatic enzyme replacement therapy has progressed. PERT are supplied under the product brands: Creon®, Nutrizym® and Pancrex®. These supply issues are intermittent. They mean some people are running out of PERT. Or, they are having trouble getting PERT. This position paper gives advice to minimize the impact on your symptoms and quality of life. It is for times when you cannot access your normal PERT supply.

### Current supplies (August 2024)

For the most up to date information on current supplies please check this website [Prescribing and ordering available pancreatic enzyme replacement therapies - SPS - Specialist Pharmacy Service - The first stop for professional medicines advice](#). This website also has a tool to help healthcare professionals to change the type of PERT. Please contact us if you would like a copy on [info@gutscharity.org.uk](mailto:info@gutscharity.org.uk) or call [020 7486 0341](tel:02074860341).

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.

These symptoms are usually treated by taking PERT and will recur if you are unable to take enough.

We may update this advice as we get more guidance. And, as we get more experience in managing PEI without enough PERT. We have divided the advice for people with PEI into 4 stages. The stage depends on the supply available.

The advice for people with PEI has been split into 4 stages.

Stage 1 - There are supplies available.

Stage 2 - There are limited supplies available.

Stage 3 - There are not enough supplies, and you have belly symptoms. (See above)

Stage 4 - There are no supplies available.

PERT is still being delivered regularly into the UK. So, people will move back and forth between these stages. It is not expected for people to completely run out of PERT for long. So, if we do have to use the advice in phase 3 or 4, it is thought that this will only be for a short period of time.

## **STAGE 1 - THERE ARE SUPPLIES AVAILABLE.**

Whilst PERT supply issues continue, please do not stockpile them. Stockpiling will further drive the shortage.

The Department of Health and Social Care has recommended that only a 1-month supply is issued at a time. This is to try and regulate supplies. So, if you now get 2-3 months of your PERT at a time, you will need to refill your prescriptions more often.

If you pay for your prescription, you should consider applying for a pre-payment certificate. This will help to reduce the cost of prescription charges. You can find more at <https://www.nhsbsa.nhs.uk/help-nhs-prescription-costs/nhs-prescription-prepayment-certificate-ppc>.

If you take Nutrizym 22, and can't tolerate Creon 25,000, ask your GP to prescribe Pancrex 340mg.

You should place your prescription requests earlier. Do so 2 weeks in advance. This is to give the local pharmacist time to source your medication.

We suggest you request your prescription soon after you get your previous one. when the pharmacy has dispensed the medication. This should give the local pharmacist time to get your medication.

It is important that you check with your GP surgery that the prescription request has been authorised. This is because some GP surgeries have an automated system. It rejects repeat prescriptions if they are placed too early.

You may need a change in your repeat prescriptions. This is if what you usually get is not available. There are three brands of PERT available currently in the UK. Some Pharmacies may also be able to order in medicines from abroad.

Remember to store your PERT appropriately. All PERT should be stored below 25 degrees. Some brands recommend refrigeration, check the packaging. If PERT gets too hot it does not work properly, this damage cannot be reversed.

Taking the PERT throughout the meal is the best way. Rather than all at the start/ middle/ end of the meal. This is because it improves how well it digests what you are eating.

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

### **Stage 1 summary.**

Please make sure you:

- Use your PERT as effectively as possible. Store it correctly and make sure it does not go out of date.
- Put your next prescriptions in as soon as your previous one has been dispensed.
- Check each prescription. Make sure it was 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.

## STAGE 2 - THERE ARE LIMITED SUPPLIES AVAILABLE.

### How to reduce your dose to make your supplies last longer

If your pharmacist can't get PERT for you and you are waiting for a delivery, take these steps. They will help your existing supply last as long as possible.

Ensure you are taking a proton pump inhibitor. Examples include:

- omeprazole®
- pantoprazole®
- lansoprazole®

Or a (H<sub>2</sub>)-receptor antagonist. Examples include:

- famotidine®
- nizatidine®

These reduce the acid in your stomach and make the enzymes more efficient. This means a lower PERT dose 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.

If you don't take vitamins and minerals, we recommend that you take a calcium and vitamin D supplement. It should contain 800iu Vitamin D and at least 500mg Calcium. Also, take a multi-vitamin and mineral during this time.

For example:

- Sanatogen A-Z Complete®.
- Centrum Advance®.
- Or, a supermarket's own A-Z brand. Please ensure they have both vitamins and minerals.

People with CF should stay on their vitamins and minerals. They should discuss any concerns with their CF specialist dietitian.

#### First step:

- 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 small 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.

## Example meal plans

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

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



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, Orange juice 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

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 low dose capsules when you are at home to reduce the number of capsules you need to take out with you.
- 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) without any other medication, you do not need to change any of your diabetes management.

If you take insulin or medicines that can cause a hypo / low blood sugar please read the advice below carefully:

If you take less enzymes with your food, you are likely to absorb less starchy carbohydrate from food. 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: [https://trenddiabetes.online/wp-content/uploads/2022/03/A5\\_Hypo\\_TREND.pdf](https://trenddiabetes.online/wp-content/uploads/2022/03/A5_Hypo_TREND.pdf). You are only at risk of a hypo if you take medication that lower your blood glucose levels. It is not

usually possible to have a hypo if you have diet-controlled diabetes, or diabetes treated with **metformin/DPP-4 inhibitors (Gliptins)** 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 hypoglycaemic alarm set. If you are having more hypos than usual, you may need to contact your CF/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® Amyes®**, **Ensure®**, **Foodlink® Fortisip®**, **Fresubin®**), ask your dietitian if they can be changed to a peptide / semi-elemental preparation (i.e., **Vital 1.5kcal®**, **Survimed OPD 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 a fat-free nutritional supplements (**Actagain Juice®**, **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.

## STAGE 3 - THERE ARE NOT ENOUGH SUPPLIES AND YOU ARE HAVING BELLY SYMPTOMS.

If you reduce your dose and start experiencing symptoms such as diarrhoea, severe bloating, or urgency to need to have your bowels open, here are some other steps to try to reduce the symptoms:

- 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, infection should be ruled out before loperamide is used.*

*The above medicine 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 are on the oral contraceptive pill, a secondary form of contraception should be used at this time. Please talk to your doctor.

**Table 1: High fat foods and their lower fat alternatives**

	<b>Reduce your portion size of these.</b>	<b>Have these instead:</b>
Fats and oils	Butter, lard, Ghee, Margarine, cooking oils	Small portions of low-fat spreads Use spray on cooking oils if needed
Dairy products	Full fat milk / yoghurt Cream Crème Fraiche Cheese	Semi-skimmed or skimmed milk. Low fat yoghurts Use small amounts of grated cheese instead of slices of cheese - choose stronger cheeses to maximise taste. To increase your protein intake, make skimmed milk powder up using skimmed milk and use in place of milk throughout the day
1. Meat and Fish	2. Fried foods or foods cooked in batter 3. Skins / visible fat on meat 4. Tinned fish, tinned in oil	5. Meat and fish cooked without added oil 6. Tinned fish, tinned in spring water / brine
Plant based protein sources	Nut butters	Pulses (e.g. lentils, chickpeas, beans (note portion sizes in table 4) Quorn / Tofu - up to 100g
Fruit & vegetables		No restrictions for low fat, see Table 4 for fibre suggestions
Carbohydrate based foods	Croissants, pastries Chips / Fried Roast potatoes	Bread, Breakfast cereals Potatoes, rice, pasta, cooked without added fat
Sauces / Condiments	Cheese based sauces Creamy sauces (bearnaise, hollandaise etc.,) Large portions of mayonnaise	Tomato based sauces, gravy, mustard, tomato ketchup, soy sauce, mint jelly, vinegar or low-fat salad dressings

**\*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 tablespoons
Desiccated coconut	70g	Sweetcorn	7 tablespoons	Avocado pear	1 whole fruit

## STAGE 4 -THERE ARE NO SUPPLIES AVAILABLE.

If any one or more of these circumstances occur:

- You are unable to get hold of any PERT at all.
- You have not been able to get hold of enough PERT for more than 4 weeks and are:
  - Losing weight (more than 2kg a month, or you are already underweight, and losing more than 1kg a month).
  - Have uncontrollable bowel symptoms that are restricting your social / work / education activities.

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, this will be a short-term issue.**

**If you have had a total pancreatectomy or have difficult to control diabetes and have completely run out of PERT.**

Please contact your hospital team, it is important that we access some stock for you as soon as possible. Please monitor your blood sugars carefully.

**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 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.

### **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 <sup>®</sup> or Survimed OPD 1.5kcal <sup>®</sup> or Peptisip Energy HP <sup>®</sup> )
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 snack on the following:

- 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 can also try:

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

These foods will not give you many calories, but they should not make your symptoms 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:** 1 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

This table shows how each product compares to others

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

## APPENDIX 2: SUPPORT

Guts UK

Guts UK support people with pancreatitis and pancreatic exocrine insufficiency. This includes pancreatic exocrine insufficiency caused by stomach surgery and diabetes.

[www.gutscharity.org.uk](http://www.gutscharity.org.uk)

020 7486 0341 9am-5pm Monday - Friday

Email: [info@gutscharity.org.uk](mailto:info@gutscharity.org.uk)

Pancreatic Cancer UK:

[pancreaticcancer.org.uk](http://pancreaticcancer.org.uk)

email [nurse@pancreaticcancer.org.uk](mailto:nurse@pancreaticcancer.org.uk) or call our Support Line 0808 801 0707; we're open Monday, Tuesday, Thursday and Friday 9am to 4pm and Wednesday 10am to 4pm.

Cystic Fibrosis Trust:

[Cystic Fibrosis Trust Homepage | CF Trust](http://CysticFibrosisTrust.org.uk)

Call 0300 373 1000 or 020 3795 2184, Monday-Friday 10am-4pm

Email [helpline@cysticfibrosis.org.uk](mailto:helpline@cysticfibrosis.org.uk)

Chat on [Facebook](#), [Twitter](#) or [Instagram](#)

Message on WhatsApp on [07361 582053](tel:07361582053)

Neuroendocrine Cancer UK:

<https://www.neuroendocrinecancer.org.uk/>

Helpline 0800 434 6476 Tuesday - Thursday 10:00am - 4:00pm

Email: through contact form on the website

<https://www.neuroendocrinecancer.org.uk/contact-us/>