

How to deal with problems with the supply of Creon[®], Nutrizym[®] and Pancrex[®]

We know there are currently shortages of Creon[®], and Nutrizym[®] and Pancrex[®] brands of pancreatic enzyme replacement therapy (PERT). This information explains what you can do if you are having problems getting your usual PERT.

We will update this information regularly if the situation changes. This information is for people with pancreatic cancer. If you have cystic fibrosis, please contact the **Cystic Fibrosis Trust** as some of the information will be different for you. If you have pancreatitis, **Guts UK** have information. If you take PERT for other reasons please contact your healthcare professional for advice.

We know this is a worrying situation. If you are having problems getting PERT, need help or information about how to deal with problems getting your PERT you can speak to our specialist nurses on our free Support Line. They 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

We know the NHS is very busy at the moment. If you can't get hold of your dietitian, GP or specialist nurse, please do contact our specialist nurses.

Contents

What is pancreatic enzyme replacement therapy?	<u>see page 3</u>
What are the problems with the supply of PERT?	<u>see page 4</u>
What should I do if my pharmacy is struggling to get my PERT?	<u>see page 5</u>
Why does it matter if I do not take PERT?	<u>see page 8</u>
What to do if you can get supplies of PERT	<u>see page 9</u>
What to do if you think you need to increase your dose	<u>see page 11</u>
What to do if you are going to run out of PERT	<u>see page 13</u>
What to do if you have run out of PERT	<u>see page 14</u>
What to do if you don't have PERT for three or more days	<u>see page 16</u>
Pancreatic Cancer UK support	<u>see page 19</u>

What is pancreatic enzyme replacement therapy?

The pancreas normally makes enzymes that help to digest your food and milky drinks. Pancreatic cancer can affect this. This means you don't get all the nutrients you need from your food, and may get symptoms ([see page 8](#)). Pancreatic enzyme replacement therapy (PERT) helps to manage this by replacing the enzymes the pancreas would normally make.

Brands of PERT in the UK are Creon®, Nutrizym® and Pancrex®.

Read more about PERT on our website at:
pancreaticcancer.org.uk/diet

What are the problems with the supply of PERT?

The companies that make PERT have told us about continued shortages of these brands. These shortages may affect different types of PERT at different times. The company that makes Creon is having problems making enough of it. This means people switch to other brands of PERT, and the companies that make these struggle to meet this demand. The shortages are a UK-wide problem, and some areas in the UK may be affected more at different times.

Supplies are being regularly restocked, so shortages of Creon, Nutrizym and Pancrex may only last for a short time. GPs and pharmacies can also order PERT from overseas ([see page 5](#)). This means that everyone should now be able to get the PERT they need, but it might be a different brand. If you are still having problems getting PERT, this information can help.

What should I do if my pharmacy is struggling to get my PERT?

Put your prescription in early

- It is a good idea to put in your prescription requests as soon as the pharmacy has provided the last prescription. This will give the pharmacist time to get your next prescription.
- Check with your GP surgery that the prescription request has been authorised. Some GP surgeries have automated systems that reject repeat prescriptions if they are placed too early.
- You may also need to collect your prescriptions more often. Pharmacies are only supplying one month's supply at a time, to try to help supplies last longer.

If your normal pharmacy does not have supply of your PERT, you could ask them to call the wholesaler that supplies it, to have more stock sent. Check back in a couple of days as we understand pharmacies are restocking with fresh supplies regularly.

Speak to your GP and pharmacist about imported PERT

- If your usual PERT is not available, you can have brands of PERT from overseas. These brands include Pangrol® and Kreon®.
- Make sure that your GP and pharmacist are aware of this. GPs and pharmacies have been given information on ordering imported PERT to meet the gap in the supply. They should order this for anyone who may run out of PERT.
- If your GP or pharmacist are not aware of advice in your area, they should contact their medicines management team for this advice.
- It may take a bit of time to access these imported brands, so speak to your GP and pharmacist early.
- You will need a prescription for imported PERT. This will need to include “(imported)” in the medicine name.

Contact the companies that make PERT

You can contact customer services at the companies that make PERT to find out about local pharmacies that have recently ordered stock. They cannot tell you about supply at those pharmacies, but you could contact the pharmacy yourself.

- To find out about Creon, contact Viatris on 0800 8086410 or email productenquiries@viatris.co.uk
- To find out about Nutrizym, contact Zentiva on 08000 902408 or email ukcustomerservices@zentiva.com

Try different pharmacies

You could try calling other pharmacies in the area to see if they have supplies. Make sure you try several different chains of pharmacy. One chain might be out of stock, but others might be able to get it.

If you get paper prescriptions, ask your GP to give you a separate prescription for PERT, without any other medicines included on it. This will make it easier for you to get PERT at other pharmacies, if your usual one does not have it.

Can I buy PERT online?

You may see PERT advertised online. It is important to be aware that there are genuine online pharmacies, but there are also many websites selling fake medicines.

- Make sure that the online pharmacy is registered with the General Pharmaceutical Council (GPhC).
- You need a prescription for PERT. If you use an online pharmacy, they should ask you questions to check that the medicine is appropriate for you. It is important to be honest when answering these. The pharmacy may also check your medical records or with your doctor.
- If the online pharmacy is not registered or does not ask questions about your health, it may not be genuine or safe to use.
- You may see vegetarian enzymes in shops or online. These are not used for pancreatic cancer as there is no evidence that they work and the doses are very low. The PERT needed for digestion problems caused by pancreatic cancer are only available on prescription.

The NHS and General Pharmaceutical Council have more information about buying medicines online. The GPhC and other regulatory organisations have also produced guidance about using online pharmacies safely.

- www.nhs.uk/conditions/medicines-information
- www.pharmacyregulation.org/patients-and-public/standards-you-can-expect-using-pharmacy-services/buying-medicines-safely-online
- <https://assets.pharmacyregulation.org/files/2024-11/how-to-keep-safe-when-getting-medicines-or-treatment-online.pdf>

Can I share spare PERT?

We are aware that people may be tempted to share PERT with others if they have some spare. We would not recommend this for several reasons.

- It is illegal to share prescription medicines, including PERT, with other people. This includes giving someone your PERT, or accepting PERT from someone else.
- You can't be sure that the medicine is genuine, even if it looks genuine.
- You don't know how the PERT has been stored. PERT can be damaged by heat and may not work properly if stored at the wrong temperature. Even a container that hasn't been opened can be damaged in this way. If the PERT does not work properly, your digestion symptoms will return.
- Always be careful about sharing your personal details or meeting someone you don't know. Make sure you stay safe.

We know it may be tempting to try to access PERT in other ways, but it is important to stay safe. If you are struggling to get PERT, you can speak to our specialist nurses for information.

Read more

What to do if you can get supplies of PERT	see page 9
What to do if you think you need to increase your dose	see page 11
What to do if you are going to run out of PERT	see page 13
What to do if you have run out of PERT	see page 14
What to do if you don't have PERT for three or more days	see page 16

Why does it matter if I do not take PERT?

If you need PERT to help you digest your food, but if you can't take enough of it, you may get symptoms. These include:

- weight loss
- runny poo (diarrhoea)
- tummy pain and cramps
- pale, oily, floating poo (steatorrhoea)
- bloating and wind
- needing to poo quickly.

You may not get enough nutrients from your food, including protein, vitamins and minerals. If you do not have PERT for some time you may develop symptoms people have from a poor diet, such as vitamin and mineral deficiencies.

If you have diabetes, you may find it hard to manage your blood glucose (sugar) levels. This is because you will release less glucose from your foods into your blood. It will make carb counting inaccurate. If you are on insulin, you will be more likely to have hypoglycaemia (a hypo). Read more about diabetes at: pancreaticcancer.org.uk/diabetes

These symptoms are usually treated by taking PERT.

Read more about these symptoms on our website at:
pancreaticcancer.org.uk/dietsymptoms

What to do if you can get supplies of PERT

While you can still get your PERT, we know that you might feel worried about these supply issues. Please do not stockpile by getting extra supplies. This **will** cause further shortages.

It is a good idea to put in your prescription requests as soon as the pharmacy have provided your previous prescription. This will give the pharmacist time to get your PERT. Please do not ask for extra prescriptions. Pharmacists have been told to only provide one month's supply at a time. Read more about talking to the pharmacist on [pages 5-6](#).

You may need to change your prescriptions to a different brand if the PERT you usually take is not available. Speak to your GP about this. There are three brands of PERT available in the UK: Creon®, Nutrizym® and Pancrex®. Your GP and pharmacy can also get you PERT imported from overseas.

You may need to make up your usual dose using different types of PERT.

For example, if you normally take three Creon 25,000 capsules with meals and two with snacks, you can make up this dose using different products:

- three Creon 25,000 capsules with meals and five Creon 10,000 capsules with snacks, or
- eight Creon 10,000 with meals and five Creon 10,000 with snacks, or
- three Nutrizym 22 with meals and two with snacks, or
- eight Creon 10,000 with meals, and six Pancrex 340mg capsules with snacks, or
- three Nutrizym 22 with meals, and six Pancrex 340mg capsules with snacks, or
- ten Pancrex 340mg capsules with a meal, and 16 Pancrex 125mg capsules with a snack.

Speak to your dietitian, GP or pharmacist for more advice about getting the right dose with the brands you are taking. You can also speak to our specialist nurses on our [Support Line](#). They can talk through the doses you will need.

Tips to help you get the best from your PERT

- It is best to spread your PERT out during the meal, rather than all at the start, middle or end of the meal. This improves how well the PERT digests your food.
- Remember to store your PERT properly. All PERT should be stored below 25 degrees centigrade, and some brands recommend keeping it in the fridge.
- Make sure you use your PERT before its expiry date.
- Read more about how to take PERT so it works as well as possible on our website at pancreaticcancer.org.uk/pancreaticenzymes

What to do if you think you need to increase your dose

People often need to increase the amount of PERT they take. If you still have digestion symptoms or your symptoms get worse, you may need more PERT.

Read our information about how to take PERT, to help make sure the PERT works as well as possible, at pancreaticcancer.org.uk/taking-pert

Taking a medicine called a proton pump inhibitor or an (H2)-receptor antagonist ([see page 17](#)) reduces the acid in your stomach. If you are not already taking one of these, it can help make the enzymes work better. This means you may be able to take a lower dose of PERT and it will still work well.

- Proton pump inhibitors include omeprazole, pantoprazole, and lansoprazole.
- Brands of (H2)-receptor antagonists include Famotidine® and Nizatidine®.

Speak to your doctor or nurse about whether these medicines would be helpful.

It is important to speak to your dietitian, specialist nurse or doctor if you still have digestion symptoms ([see page 8](#)) or are consistently losing weight.

If you take nutritional supplements

Nutritional supplement brands include Fortisip®, Amyes®, Ensure®, Fresubin®, Altraplen®, and Foodlink®. If you take these, your dietitian or GP may suggest you change to a peptide nutritional supplement. These include Vital 1.5kcal® and Peptisip Energy HP®. Many people find they can take these with less or no PERT.

These do not come in a wide range of flavours, but you can add milkshake mixes or coffee syrups for more flavours. To give you more options, you could have them chilled, or freeze them into ice lolly moulds or ice cube trays.

Sometimes you may be offered individual protein supplements or a fat-free nutritional supplement. These include Actagain Juce®, Altrajuce®, Fortijuce®, Ensure Plus Juice® or Fresubin Jucy®. These usually need less PERT to be digested. 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.

Try not to worry if you feel bloated taking these supplements. This is a normal effect of taking these without PERT. But speak to your dietitian if you find the bloating hard to deal with, or if it is affecting your quality of life.

What to do if you are going to run out of PERT

If you have less than two weeks' supply of PERT, make sure you read our tips on [page 9](#) if your pharmacist doesn't have enough stock.

- Contact the PERT manufacturers to find out if any local pharmacies have recently ordered PERT.
- Speak to your GP and pharmacist about getting imported PERT. Ask if you can have a prescriptions for these in case you cannot get your usual PERT.

It is important that you do not reduce your PERT dose if you:

- are having chemotherapy
- are about to have surgery or recovering from surgery
- have difficulty eating, or
- have malnutrition.

Reducing your PERT in these situations may affect your treatment. Contact your hospital and ask for a rescue prescription.

What to do if you have run out of PERT

Your pharmacist should be able to get your PERT for you now there are measures in place for using imported PERT. But this information explains what to do if there are any delays getting your PERT. We know it is very concerning if you have run out of PERT, but try not worry.

- Make a same day emergency appointment with your GP. You could show them this information. They can also get information about what to do from the Pancreatic Society of Great Britain and Ireland at: www.psgbi.org/position-statement-pert-shortage
- If you are under the care of a local hospital, contact your hospital team and ask for a rescue prescription. This is a short term solution, and your doctor and pharmacist should still order imported PERT for you. Be aware that the hospital may not have enough stock to give you PERT.
- Make sure you read our information about what to do if your pharmacy can't get PERT on [pages 5-6](#).

Managing symptoms

If you get symptoms such as diarrhoea, severe bloating, or needing to poo urgently (see [page 8](#)), speak to your dietitian, nurse or GP. Remember that you can also speak to our specialist nurses.

You could also try these steps to see if they help.

- If you are struggling with diarrhoea, consider taking some loperamide such as Immodium® before your main meal. This should help to slow down your gut and reduce diarrhoea. The longer food is in your gut, the more chance more of it will be absorbed by your body.
- But if the diarrhoea has started suddenly, speak to your doctor or nurse before taking loperamide. They should check you do not have an infection.
- You could try reducing the amount of fat in your meal to half your normal portion size of higher fat foods. This is likely to improve some of your symptoms. But it will also mean that your meal contains less energy. So it's really important you keep a close eye on your weight and strength.

- If you eat a lot of high fibre foods, consider eating less of these. Very high fibre foods can make enzymes less effective.
- If you do not have diabetes, have sugary foods and drinks to get more energy in your diet. Table sugar does not need PERT to be absorbed in your gut. You could try Lucozade, or adding sugar, honey or syrup to foods. This may help keep your energy levels up. You could also have sugary sweets or marshmallows, but not chocolate. Be aware that these do not provide any other nutrition, so make sure you also have food with protein, vitamins and minerals.
- If you are losing weight, speak to your dietitian or GP about taking some peptide based nutritional supplement drinks. These are specialist supplement drinks that need a lot fewer enzymes for absorption, so can usually be taken without PERT. Read more about this on [page 17](#).
- If you have enough PERT to take some with your main meal, eat this as usual. Use half the dose of supplement drinks in place of your other meals.
- If you are not already taking one, it is a good idea to take an A-Z multivitamin and mineral supplement. Take this with a meal that you are taking PERT with.
- Monitor your blood sugar levels carefully if you have diabetes.
- Some medicines may be less effective if you do not have enough PERT. This is particularly important for people who take medicines to prevent blood clots and seizures, and the oral contraceptive pill.

What to do if you don't have PERT for three or more days

As imported PERT is now available, your pharmacist should be able to get your PERT for you. But there can sometimes be delays in getting your PERT.

We know this is a very worrying situation. This should only be a short-term situation for you.

It is important to tell your pharmacist that you have completely run out, and ask them about getting imported PERT for you. Read more about talking to your pharmacist on [page 5](#).

Remember that you can call our **specialist nurses** for support and information. They can help with managing symptoms linked to a lack of enzymes.

If you can't eat because of your symptoms

Try to drink plenty of fluids. Try Lucozade®, sports drinks or Dioralyte®.

Peptide nutritional supplement drinks

Contact your GP and ask for a prescription for a peptide nutritional supplement. This might be Vital 1.5kcal®, Survimed OPD® 1.5kcal or Peptisip Energy HP®. You do not need to take PERT with this nutritional supplement. It might be helpful to show your GP this information.

The peptide nutritional supplement can be used instead of meals until you have your PERT again. If you do not have diabetes, you can continue to have sugary foods and drinks as well (see [page 15](#)).

How many peptide nutritional supplement drinks to have

This is a guide to how many supplements (Vital 1.5kcal® or Peptisip Energy HP®) to take, if you do not have PERT and cannot absorb your food. It is based on your weight.

- If you weigh below 40kg (6st 4lb), contact a dietitian.
- If you weigh 40 – 50kg (6st 4lb- 7st 12lb), take four 200ml bottles, which is 1200kcal (calories).
- If you weigh 50 – 60kg (7st 12lb – 9st 6lb), take five 200ml bottles (1500kcal).
- If you weigh 60-70kg (9st 6lb – 11st), take six 200ml bottles (1800kcal).
- If you weigh 70-80kg (11st – 12st 8lb), take seven 200ml bottles (2100kcal).
- If you weigh 80-90kg (12st 8lb – 14st 2lb), take eight 200ml bottles (2400kcal).
- If you weigh over 90kg (14st 2lb), contact a dietitian.

This may not be enough for you. If you lose weight or are very active, have one more bottle a day.

If you gain weight and were not intending to, have one less bottle a day.

These supplements do not come in a wide range of flavours. You can add milkshake mixes or coffee syrups for more flavours. Serve them chilled, or freeze them into ice lolly moulds or ice cube trays to give you more variety.

Foods you can eat without PERT

You can have these snacks as well as the supplement drinks:

- fruit – a handful sized portion at a time
- vegetable sticks, such as carrot, celery or cucumber
- small amounts of salsa, ketchup, balsamic vinegar, marmite or mustard.
You could have tiny amounts with vegetable sticks for a different taste.

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

- sorbet
- marshmallows
- sugary sweets (but not chocolate, fudge or toffee).

These foods will not give you many calories, but they should not make your symptoms worse. They will fill you up a bit more than having the supplement drinks on their own. You can eat other foods, but these may make any symptoms worse.

Suggested daily meal plan

This meal plan is for someone who weighs 80kg. Use the list above to change the amount of supplement drinks you have, depending on how much you weigh.

- **Breakfast:** 1 x supplement drink, cup of black coffee and a banana.
- **Mid morning:** 1 x supplement drink and carrot sticks.
- **Lunch:** 2 x supplement drinks flavoured with chocolate or coffee syrup and served with ice, and 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. For dessert: 1 x frozen supplement drink served with a handful of strawberries, raspberries and a scoop of sorbet.

We know this is a worrying time. It is important you contact your GP, dietitian or specialist nurse for help and advice.

You can also contact our specialist nurses on our **Support Line**. Although they can't help you access PERT, they can provide information and support if you are struggling to get it.

Call the nurses free on **0808 801 0707** or email **nurse@pancreaticcancer.org.uk**

Pancreatic Cancer UK support

We are here for you

If you or someone you care about has pancreatic cancer, we are here to help.

Find out more at: pancreaticcancer.org.uk/support

Our specialist nurse Support Line

Our specialist nurses are experts in pancreatic cancer. They can talk for as long as you need, as often as you like. Whether you have a long list of questions or don't know where to start, they will provide practical, honest information to help you make the right choice for you.

Call free on **0808 801 0707** or email nurse@pancreaticcancer.org.uk

Information about pancreatic cancer

Our website, videos and publications can answer your questions. The information can help you understand what you have heard from your medical team, and make decisions about your treatment and care.

Go to: pancreaticcancer.org.uk/information

Download or order our free publications at:
pancreaticcancer.org.uk/publications or call **0808 801 0707**

Webinars

Our regular webinars cover topics including diet, wellbeing and treatment. They are hosted by our friendly nurses and other experts, are informal, and you can ask questions. You can look back at previous sessions, or sign up to one.

Go to: pancreaticcancer.org.uk/webinars

This information is based on guidance developed by specialist dietitians from the Nutrition Interest Group of the Pancreatic Society of Great Britain and Ireland (NIGPS), Cystic Fibrosis Specialist Group and Gastroenterology Specialist Group, British Dietetic Association. We hope this will add to the medical advice you have had, and help you make decisions about treatment and care. This information should not replace advice from the medical team – please speak to the medical team about any questions.

We would like to thank the following dietitians for allowing us to use their guidance:

- Mary Phillips
- Laura McGeeney
- Jacqueline Lowdon
- Kerry-Lee Watson

Pancreatic Cancer UK

Queen Elizabeth House
4 St Dunstan's Hill
London
EC3R 8AD
020 3535 7090

enquiries@pancreaticcancer.org.uk
pancreaticcancer.org.uk