Pancreatic Enzyme Replacement Therapy

This information was sourced from materials produced by Pancreatic Cancer UK

The NET Patient Foundation: supporting the neuroendocrine cancer community.

For further information and to make contact telephone 0800 434 6476 or visit our website: www.netpatientfoundation.org

@netpatientfound

www.facebook.com/NetPatientFoundation

Proud to be part of the International Neuroendocrine Cancer Community (INCA)

www.netcancerday.org

© NET Patient Foundation May 2014
**What is the pancreas?**
The pancreas is part of your digestive system. It is a gland organ that produces a fluid containing digestive enzymes. These enzymes are needed to break down (digest) your food so it can be absorbed. Your pancreas also produces a hormone called insulin which helps to control the amount of sugar in your blood.

**Why do I need to take pancreatic enzymes?**
If you have chronic pancreatitis, a pancreatic neuroendocrine tumour (PNET), had surgery for other cancer types or have had some of your pancreas removed, your pancreas may not produce enough enzymes to digest your food. As a result you may not be able to absorb the food you eat very well. This is called malabsorption.

**How do I know if I have malabsorption?**
If you are not fully absorbing some of the food you eat – particularly fat or carbohydrates – you may have symptoms including:

- Pale, orange or yellow coloured stools, which may float and be difficult to flush away. They may be oily and foul-smelling (steatorrhoea)
- Your stools may also be loose and you may need to go frequently
- You may experience bloating, abdominal pain, cramping and excessive wind

These symptoms may result in weight loss or failure to gain weight.

To help you absorb food properly again you will need to take replacement pancreatic enzymes.

**What are pancreatic enzymes?**
We treat malabsorption by replacing the enzymes you lack. There are a few different brands of enzymes that may be prescribed including: Creon®, Nutrizym®, Pancrease HL® or Pancrex®. Most come in capsule form. Each capsule contains a mixture of enzymes:

- Lipase to digest fat
- Amylase to digest starchy carbohydrate
- Protease to digest protein

They come in different strengths, for example, Creon 10000, Creon 25000 and Creon 40000. The number shows the amount of lipase in each capsule. So each Creon 25000 capsule contains less lipase than a Creon 40000 capsule. The higher the strength the larger the capsule size.

**How do I take pancreatic enzymes?**
- You need enzymes to digest food, so take your enzyme capsules with all meals, snacks and nutritious drinks (such as milkshakes and oral nutritional supplements, for example, Fortisip, Build-up Shakes). Some of these may cause further diarrhoea so please do contact your team if this is the case
- Take the enzyme capsules at the start of your meal, snack or nutritious drink
- Take them with a cold drink as hot ones may make them less effective
- For large meals or meal times lasting longer than 30 minutes take half your enzyme dose at the start of your meal and half in the middle of your meal
- You may need a higher enzyme dose with meals containing more fat. Your dietician can advise you on how many enzyme capsules you need to take
- If you find enzyme capsules difficult to swallow you can ask for a smaller capsule size. Please note this will be a lower dose so it is likely that you will need to take more capsules
How many capsules do I need to take?
The dose will depend on:
- Why you have reduced pancreatic function – for example, how much of your pancreas is working, and if you have had surgery, how much of the pancreas remains
- The amount of food you are eating
- The fat content of the food
- You, as everyone is different
- Suggested starting dose: your dietician, specialist nurse or doctor will tell you your starting dose. It is vital that the dose is high enough to provide you with the enzymes that you require.

You will need to take into account the fat content and size of each meal or snack. For example, if you are having a larger meal or a higher-fat meal or snack you may need to take more enzyme capsules, e.g:
- One Creon capsule with a snack/small meal.
- Two Creon capsules with a meal.

All pancreatic enzymes should be taken with a proton pump inhibitor (PPI) for example: omeprazole.

What about enzyme granules and powdered formulations?
Some people need to take granulated or powdered enzymes. You may need these if you find the enzyme capsules difficult to swallow or if your dietician or doctor has advised you to take them. Both the granulated and powdered enzymes can lead to mouth ulcers if they get stuck in your mouth. It is important to follow the steps below to reduce the risk of this happening:
- Mix your prescribed enzyme dose in fruit puree or apple sauce
- Swallow immediately and don’t chew
- Follow with a cold drink to ensure enzymes are washed down
- Eat your meal or snack immediately

How do I know I am taking enough enzymes?
If your weight is stable and you do not have any of the symptoms of malabsorption listed on page 1, then it is likely you are taking the correct enzyme dose. Your dietician can advise you if you need more help.

Are there any side effects?
The information leaflet that comes with your enzymes will give you more detailed information. The most common side effects are nausea, abdominal pain, diarrhoea and constipation. However, only some people taking enzymes will experience these side effects.

Your anal area may become red and sore (anal excoriation) if you take too many enzymes or if the enzymes pass through you too quickly because you have diarrhoea (that is not directly related to taking the enzymes). If you have any concerns or feel unwell contact your doctor.

How do I store the enzymes and how long can I keep them?
Store them at temperatures below 25°C/77°F. Do not keep them in a car, particularly the glove box, because the temperature may often exceed this limit.

Keep them in their original container or a special enzyme holder. If they have passed their expiry date, return them to your pharmacy who will dispose of them appropriately.

Will I need to take any other medications?
You may need to take medication that reduces your gastric acid (such as omeprazole) to prevent your stomach acid making your pancreatic enzymes less effective.

Vegan, vegetarian and other restrictive diets that avoid pork
Please be aware that all pancreatic enzymes are pork-based; there are currently no alternatives available. Please discuss any concerns with your dietician or doctor.

Do I need to take nutritional supplements?
If you have lost weight and/or have a poor appetite you may need to have high-energy and/or high-protein supplement drinks. You will need to take your enzymes with each supplement drink. Your dietician will let you know if you need to start on these.

What can I eat and do I need a low-fat diet?
It is useful to know which foods and snacks are higher in fat so you can adjust your enzyme dose. Unless you are overweight and have been advised to, you do not need a low-fat diet.

You should not need enzymes with fat free sweets such as mints, wine gums and fruit and vegetables.
About us

The Foundation has the following aims:

• To provide support, education and information to anyone affected by neuroendocrine cancers
• To advocate for neuroendocrine cancer patients so that they may achieve the best possible outcomes
• To encourage standardised care for all NET patients
• To provide community supportive care to patients and their carers or family members
• To raise awareness of NETs throughout the UK
• To raise funds for clinical research projects.

Did you know?

• Over 50% of patients are diagnosed when the cancer has already spread
• Early diagnosis significantly improves outcomes for patients
• There are dedicated NET clinics around the UK. Find out where at www.netpatientfoundation.org

Why the moth?

We have chosen the moth as our logo to symbolise this ‘camouflaged’ condition. We aim to encourage medical professionals to consider an uncommon alternative when symptoms persist (i.e. a NET rather than IBS).

“When you see an insect beating its brightly patterned wings against your window, don’t assume it’s a butterfly. It could be a moth.”

If you found this booklet useful and would like to make a donation to the NET Patient Foundation, please contact us.