

## Pancreatic Enzyme Replacement Therapy (PERT) Guidance

This information is for anyone who has been prescribed pancreatic enzyme replacement therapy (PERT). This guidance will explain when and how the medication should be taken, along with guidance on how to store this medication. Additional advice can be sought from your Dietitian, Nurse or Doctor.

### What are pancreatic enzymes?

Following surgery to the pancreas, or as a result of disease your pancreas may be unable to produce pancreatic enzymes. Pancreatic enzymes are a group of enzymes (proteins) which are used to help the body digest (break down) important nutrients such as fat, carbohydrate and protein. These enzymes are called

- **Lipase** which helps to break down fat
- **Protease** which helps to break down protein
- **Amylase** which helps to break down carbohydrate.

If these enzymes are not available you can get fatty diarrhoea (steatorrhoea) when your stools can look paler than usual, float due to the fat in them and can be smelly. They can be difficult to flush away. If you have eaten a fatty meal or snack, you can get pains or cramps in your tummy along with excess wind.

These enzymes usually come in a capsule form, but are also available in a powder form. The most common PERT used in the UK is called Creon® and comes in different strengths. The number in the product relates to how many lipase units the product contains, for example Creon® 25 000 has 25,000 units of lipase.

All Pancreatic enzymes are made from the pancreas of pigs. **Organisations representing Jews and Muslims have stated using these products is acceptable, as there is no alternative.**

The Doctor will prescribe the dose for you, but you may need to alter the number you take depending on what you eat and other symptoms you have. A usual starting dose may be 4-5 Creon® 25 000 at meals and 2 - 3 Creon® 25 000 with snacks.

For some people, the capsules are too large for them to swallow and they prefer to take a higher number of lower dose capsules for example 2-3 x Creon® 10 000 rather than 1 x Creon® 25 000.

### Storage - Keeping the enzymes viable (useable)

As the enzymes are natural products, they are affected by heat and will denature (break down) if not stored correctly. Aim to **keep them in a cool place** rather than on a window sill that catches the sun or in a cupboard that can get warm. When taking them out the house, it is safer to put them in a handbag rather than keeping them in a pocket next to the skin, e.g. trouser pocket. Some companies provide holders for storing and carrying about your enzymes.

### Hospital admission

If you have to be admitted into hospital, ask to keep your enzymes with you, but always out of sight for everyone's safety – a bedside locker can be used. You will then be able to self-medicate, rather than having them locked away in the medicine trolley or cabinet. This means that you can take them when you are ready to eat a meal, or snack, and not have to wait for the nurse to dispense them (give them out).

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Some staff may be reluctant to let you do this, but explain that the dose you need can vary and you need to take them immediately before you eat. Having to wait may mean your meal could get cold and you don't eat it. This will not help in your overall care.

#### How do I take PERT?

- Pancreatic enzymes need to be taken immediately before a meal or snack with enough cold or room temperature liquid to swallow it completely, perhaps 2-3 sips.
- **If you cannot swallow the capsules**, open them and mix the enzymes with a teaspoon of soft acidic food or liquid for example pureed apple, pureed apricot, mashed banana, apple juice or orange juice. Follow this with a few sips of a cold or room temperature drink
- **Do not crush or chew the capsule or its contents and do not hold it in your mouth.** Any of these may cause irritation in your mouth
- **Don't worry if you forget to take it with your meal.** Just take your usual dose with your next meal or snack
- **Do not take them without then eating, or having a milk based drink** (more than ¼ milk) as this may be harmful
- Pancreatic enzymes need to be taken to break down the nutrients in the food you eat, ideally at the start of a meal. For larger meals, or ones that take a while to eat (more than 30 minutes or when eating out) you may need to split the dose between courses

They also need to be taken with most snacks; milk based drinks (more than ¼ milk) and with milk based nutritional supplements for example Complan Shake, Ensure Shake, Fortisip.

Evidence suggests that taking too many enzymes is not harmful, but just may make you feel sick (nausea), constipated and cause itchiness around your anus (bottom).

#### Do I have to take it with everything I eat or drink?

Some foods do not need to be taken with pancreatic enzymes, because they are low in fat and protein, but generally they need to be taken with any food containing fat. If a food is fat free enzymes may still be required to digest the protein.

Low fat and protein foods include:

- A small amount of fruit or vegetables (includes fresh, dried, tinned or frozen) with no added fat, e.g. butter, oil, mayonnaise or oil based dressing
- Boiled sweets or mints, Jelly Babies® and wine gums
- Non-milk based drinks e.g. fruit juice, squash, fruit smoothie (no milk or yoghurt, unless fat free)
- Tea or coffee with a small amount of milk added
- Fizzy drinks
- Low fat puddings e.g. jelly, sorbet, meringues (no cream)
- Bovril®, jams, marmalades

#### How do I know if I'm taking enough pancreatic enzymes?

If you are taking enough enzymes your stools may return to normal, you may suffer less wind or bloating and may even gain some weight. If your symptoms continue the dose of enzymes may need to be reviewed or other changes made. Please raise this with the Doctor, Nurse or Dietitian.

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