

Pancreatic Enzyme Replacement Therapy (PERT) for children and adolescents with Cystic Fibrosis

Who needs Pancreatic Enzyme Replacement Therapy?

Pancreatic Enzyme Replacement Therapy (PERT) is essential for everyone with cystic fibrosis (CF) who is pancreatic insufficient. PERT helps the body digest and absorb nutrients from foods and fluids. Without PERT, children are at high risk of poor nutrient absorption leading to poor growth and slow weight gain.

How does PERT work?

PERT comes in capsule form. Inside each capsule are many small 'beads' that contain digestive enzymes. Each bead is covered in a special 'enteric coating'. This coating allows the beads to dissolve in the small intestine. The digestive enzymes are then released in the small intestine where they help to digest and absorb food.

The main functions of enzymes are to:

- Digest fat, protein and carbohydrate (to supply the body with energy)
- Promote nutrition absorption
- Help with weight gain and growth
- Improve bowel motions

Dosing PERT

People with CF vary in their degree of pancreatic insufficiency. This means one person may require different amounts of PERT to another. Your dietitian will help you determine your dose. It is important to discuss any changes to your enzyme intake with the CF team before changing your dose.

A good guide for enzyme dosing is:

- 1 scoop of Creon Micro covers 3 – 5g of fat
- 1 Creon 10,000 capsule covers 6 – 8g fat
- 1 Creon 25,000 covers 15g fat

It is better to give a little extra enzyme than too little. For example, if a food has 10g fat, give 2x Creon 10,000 rather than 1.

If you are concerned about how much PERT your child is having, speak with your dietitian about your child's maximum recommended dose.

Enzyme doses need to be monitored regularly and adjusted based on the amount of food and fluid your child is consuming. Doses may also need to be changed if there are signs of malabsorption. These signs include abdominal pain, excessive gas, bloating, frequent, loose and/or oily stools, poor weight gain and poor growth.

When should I take PERT?

- At the beginning of a meal/snack or drink (if it contains fat).
- Redose PERT if you are eating/drinking for longer than 30mins (PERT only lasts 30mins in the small intestine)
- Capsules and beads should not be crushed or chewed. Beads should be given in and acidic food such as apple or fruit puree/gel.
- If you forget to take PERT at the start of a meal, it is safe to have it during or at the end of the meal.

How do I know if I am taking enough?

- Your bowel motions should return to a more normal appearance, texture and colour
- You should not experience any abdominal pain or excessive bloating after eating
- If you are gaining weight, it is a good sign that you are taking enough enzymes to digest and absorb your food.

Are there any foods and fluids that don't need PERT?

Enzymes need to be taken with ALL food and fluids that contain fat and protein. The only foods that do not contain fat are:

- Fresh, dried, canned fruit
- Vegetables (as long as they're not cooked in oil or butter)
- Lollies, jelly
- Water, juice, soft drink, cordial

Storing your PERT

- Store enzymes in the fridge (or a cooler bag + ice brick when leaving the house)
- Enzymes will deteriorate if left in a hot or damp place (eg school bag, kitchen table, car)
- Always check the expiry date of your enzymes to ensure they are in date – discard them if they are past their used by date or have changed colour/appearance
- Always keep the lid tightly sealed on the bottle of enzymes