

Pancreatic enzyme replacement therapy (PERT) for adults with Cystic Fibrosis

Who needs Pancreatic Enzyme Replacement Therapy?

About 85% of adults with Cystic Fibrosis (CF) are pancreatic insufficient. This means the pancreas is unable to produce or release enough digestive enzymes into the small intestine. As a result, food is not digested and cannot be absorbed in the gut. This can lead to weight loss and malnutrition. Replacement pancreatic enzymes need to be taken to digest food properly.

What are enzymes and how do they work?

Pancreatic enzyme replacements come in capsule form. Inside each capsule are many small “beads” that contain digestive enzymes. A special “enteric coating” covers each bead. This coating makes sure the digestive enzymes are released in the small intestine where they help digest food.

The main functions of enzymes are to:

- Digest carbohydrate, protein and fat (to supply the body with energy)
- Help with weight gain
- Promote nutrient absorption.

There appears to be a link between better lung function and higher body weights. Take enzymes with all fat containing meals and snacks to help you gain weight.

Dosing PERT

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

There is a wide range of strengths of pancreatic enzymes available. The most commonly used in Australia are Creon® 10000, 25000 and 35000.

Check your enzyme doses regularly and adjust them for the amount of food and drink you consume. Your doses will also be changed if there are signs of malabsorption. These signs

include stomach pain, excessive gas, bloating, frequent, loose and / or oily stools, poor weight gain and poor growth.

When should I take the enzymes?

- Swallow enzymes whole with every meal, as well as snacks or drinks containing fat. Do not crush or chew capsules.
- Spread your enzymes throughout the meal. Enzymes last in the small intestine (where they work) for 20 - 30 minutes.
- High fat meals will need more enzymes than low fat meals.
- Snacks will generally need fewer enzymes than a meal. Be cautious with high fat snacks, as these can need as many (or even more!) enzymes than a meal.
- Be flexible about the dosage and timing of enzymes. You need to adjust the amount of enzyme you take depending on how much fat is in your meal or snack.
- If you are prescribed CFTR modulator therapy you need to take enzymes with this to optimise absorption.

How do I know if I am taking enough?

- Stools should return to a more normal appearance and colour, and flush away easily.
- You should not experience stomach pains with eating and you should have less wind.
- If you are gaining weight, it is a good sign that you are taking enough enzymes to digest and absorb your food.

Note: Sometimes people with CF produce too much stomach acid and this can make pancreatic enzymes less effective. If you have heartburn, reflux or abdominal cramps, discuss this with your CF team.

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

Take enzymes with ALL food and fluids. The exception is foods that contain mainly simple sugars. Some examples include:

- Fresh, dried and canned fruit
- Non - starchy salad vegetables
- Lollies, jellies, sorbet, chewing gum
- Fruit juice, cordial, soft drink, electrolyte replacement drinks, water

- Clear soup
- Tea and coffee with a dash of milk

Remember that while enzymes are dosed according to how much fat is in food, enzymes also work on carbohydrate and protein. They are still needed with foods that are lower in fat such as milk drinks (e.g lattes), lean meat, baked beans, pasta and rice, and eggs.

How should the enzymes be stored?

- Store enzymes in a cool dry place.
- Enzymes will deteriorate if kept in a hot place for example; above your fridge or in the car.
- Top up enzyme carriers daily to avoid them deteriorating in hot weather.
- Check the expiry date of enzymes; use them while they still have a good shelf life (e.g. at least 6 months).
- Always keep the lid tightly sealed on the bottle of enzymes.
- Discard enzymes that:
 - are out of date
 - have changed colour or texture
 - have been exposed to hot temperatures.

My usual enzyme dose is _____ for every _____g dietary fat

Things I can do to improve my PERT

1. _____
2. _____
3. _____
4. _____

For further information contact your Dietitian or Cystic Fibrosis Centre