

Patient Advice and Liaison Service (PALS)

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Macluumaadkan waxaa lagu heli karaa qaabab kale, sida akhriska fudud ama daabacaadda wayn, oo waxaa lagu heli karaa luqaddo kale, marka la codsado. Fadlan la xidhiidh 02082238934.

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Bu bilgiler, okuması kolay veya büyük baskılar gibi alternatif biçimlerde ve talep üzerine alternatif dillerde de sunulabilir. İrtibat için lütfen 02082238934 numaralı telefondan ulaşın.

اس معلومات کو متبادل شکل، جیسے، پڑھنے میں آسان یا بڑے حروف، میں دستیاب کرایا جا سکتا ہے، اور درخواست کرنے پر اسے متبادل زبان میں بھی دستیاب کرایا جا سکتا ہے۔ براہ مہربانی 02082238934 پر رابطہ کریں۔

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Reference: BH/PIN/618

Publication date: May 2017

All our patient information leaflets are reviewed every three years.

Patient information

A guide to pancreatic enzymes in cystic fibrosis

Nutrition and Dietetics Department



What is the pancreas and what does it do?

The pancreas is an organ near your stomach; in addition to other functions it produces a fluid containing chemicals (enzymes) that digest your food.

In cystic fibrosis (CF) it is common for the pancreas to get blocked with mucus and not release these chemicals this is called pancreatic insufficiency. Therefore enzymes need to be taken artificially to do the job of the pancreas this is known as pancreatic enzyme replacement therapy (PERT).

Pancreatic enzyme replacement therapy (PERT) preparations contain 3 types of chemicals (enzymes):

LIPASE – to digest fat

PROTEASE– to digest protein

AMYLASE– to digest starchy foods

Everyone needs different amounts of enzymes. Therefore, this is only a guide and your CF dietitian will help you decide the dose suitable for you for different meals and snacks.

How can I tell if I need to take PERT?

We will test your pancreatic function on a yearly basis in clinic if you are not currently using PERT. We do this by asking for a stool sample and testing the level of a chemical called faecal elastase this indicates how your pancreas is functioning.

Notes:

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Name:

Date:

Dietitian:

Contact Number:

Hospital Site:

The amount of enzymes required varies enormously from person to person partly because of:

- The different levels of enzymes still secreted by the salivary glands, tongue, stomach and small intestine:
- The amount of food you eat e.g. large meals will require more enzymes than small meals. A meal with a pudding or dessert will require more enzymes
- The type of food you eat e.g. meals which contain a lot of fat for example: fried fish and chips will require more enzymes than a meal containing boiled potatoes and steamed fish which is much lower in fat. If you eat a meal that is high in fat (such as fish and chips) you will need to take more capsules.

If you find that you are taking very large doses of PERT capsules it may be possible to switch to a higher strength capsule and thereby decrease the number you need to take

Signs which may indicate that PERT would be helpful include:

- Pale colour stools
- Difficult to flush away
- Stool leaves a greasy appearance on top of the water.
- Loose/smelly stools
- Abdominal (stomach) pain and bloating after eating.
- Nausea and vomiting after eating.
- Increased wind (flatulence)
- Failure to increase weight despite good intake.

Type of PERT:

There are different types and strengths of pancreatic enzymes available. The strength indicates the number of units of lipase per capsule.

<u>Brand</u>	<u>Strengths available</u>
Creon	Creon 10,000 Creon 25,000 Creon 40,000 (these are currently not available on the market)
Pancrease HL	Pancrease HL (25,000)
Nutrizyme	Nutrizyme 22 (22,000)
Pancrex Powder	Pancrex V (25,000 units lipase per 1 g/2.5 ml)

These enzymes contain pork products; special dispensation may be granted for those who do not eat pork for religious reasons as the enzymes are classed as a medicine.

How should I take PERT?

- Although PERT digests protein, carbohydrate and fat, it is the amount of fat in the food or drink that will determine what dose of PERT you need to take. Fat can be found in:
 - dairy produce (butter/milk/cheese/cream),
 - vegetable oils and spreads
 - fried foods
 - chocolate/pastries/cakes/crisps/nuts
 - meat and fish (especially red meat and oily fish)
- Take PERT at the start of each meal, or if it is a long extended meal split the dose throughout the meal.
- Capsules will be active for up to 45 minutes after they have been taken. Therefore if you decide to eat extra more than 45 minutes after you took your initial meal PERT dose you will need to take more.
- Swallow the capsules whole, **DO NOT** chew them.
- If you have overnight tube feeds your enzyme dose will be discussed with you and it sometimes possible to have some at start and end of feed.
- **DO NOT** open up the capsules to put via the tube.
- If you take fat soluble vitamins (A, D, E and K) you should take these with PERT at a meal time to increase absorption, or take PERT with the vitamins.
- Take with a cold drink – swallowing with a hot drink can make them less effective.
- **DO NOT** store your enzymes in a hot room or on a window sill in direct light. Always check expiry dates, they may become less effective at the end of shelf life.

then it will be necessary to look at food labels. There are also Apps available such as Carbs and Cals app and MyFitnessPal that can be useful in identifying the amount of fat in a food and calculating the dose required.

What to look at on food labels?

Nutrition

Typical Values	Typical Values Per 30g(100kcal) serving	Per 100g
Energy	632kJ	2105kJ
-	151kcal(8%*)	504kcal
Fat	<u>7.9g(11%*)</u>	<u>26.3g</u>
of which Saturates	0.7g(3%*)	2.2g
of which Mono-unsaturates	6.2g	20.6g
of which Polyunsaturates	1.0g	3.4g
Carbohydrate	17.7g	58.9g
of which Sugars	1.1g(1%*)	3.7g
Fibre	1.2g	4.0g
Protein	1.7g	5.8g
Salt	0.47g(8%*)	1.57g

When reading labels look at the total fat content per serving, some labels may only have per 100g therefore you will need to calculate how much per serving you are eating.

Sample meal plan using Creon 10,000

THIS IS A GUIDE ONLY- the dose and strength you need to take may be different.

Breakfast

1 slice bacon/sausage/mushrooms/fried egg with toast and butter

Take 4-6 x capsules creon

or

1 bowl weetabix cereal with full cream milk with toast and butter

Take 2-3 x capsules creon

Nutritional supplement drink

Take 2 x capsules creon

Main meal

1 fried fish in batter and chips with mushy peas

Take 4-6 x capsules creon

1 cod in parsley sauce with mash and butter and carrots

Take 3-4 x capsules creon

Snack Meal

1 x cheese sandwich with crisps

Take 3 x capsules creon

Snacks

2 x chocolate biscuits and a cup of tea with milk

Take 1-2 x capsules creon

1 x toasted teacake with butter and a cup of coffee with milk

Take 2 x capsules creon

1 x fresh fruit

No capsule creon

1 full fat cappuccino

Take 1 x capsule creon.

If you are using a system of calculating a ratio of PERT: fat (g)

What happens if I don't take enough enzymes?

- You may find that your bowels open more than usual. Your stools may vary in colour (e.g. light/pale/brown/orange) or become looser, or float and difficult to flush away.
- If you consistently do not take enough enzymes or forget to take any at all you will have difficulty gaining weight as you are not able to use all the energy from the food you eat.
- If you consistently take too low a dose you may become constipated as the fatty deposits of the undigested food may cause a blockage. It may be difficult to notice this as you may still be having loose stools at the same time. If you have any abdominal symptoms such as bloating/cramping/changing stool habit you should contact your CF dietitian.

What happens if I take too many enzymes?

- If you consistently take too many enzymes with meals and snacks you may find your stools are a little hard.
- You may also notice you have an itchy anus (bum).
- It is unnecessary to take extra enzymes – this will not provide any extra benefits (i.e. gaining more weight).

Distal Intestinal Obstructive Syndrome (DIOS)

- You may develop severe constipation otherwise known as DIOS if you do not take enough enzymes over a long period of time or increase the amount taken too rapidly.
- This is where blockage of the bowel occurs due to a collection of stools and mucus.
- This may involve using a range of laxatives and potentially being admitted to hospital for treatment.

Do I need to take PERT with everything?

These foods you won't need to take PERT with:

- Fruit and dried fruits
- Vegetables (except potato, avocado and beans / pulses)
- Sweets such as chewing gum, mints, jelly babies, dolly mixtures,
- Marshmallows, fruit pastilles and wine gums
- Jelly
- Juice based nutritional supplements

Can I vary the dose of PERT?

Yes, you are the person who knows your symptoms best so it may be appropriate for you to alter the dose for yourself. Failure to gain weight and persistent loose bowel motions are the main reasons you may need to increase the dose. Increase gradually by one to two capsules per meal/ snack. Wait a few days to see if bowel motions become more formed and darker in colour before increasing further.

If you have noticed no benefit then please discuss this with your dietitian, specialist nurse, hospital clinician or GP

Do I have to restrict my diet?

No, you do not have to restrict your diet, but you may find that certain foods, especially those with a lot of fat in them, cause your motions to be loose and smelly.

If that is the case you may need to take a higher dose of PERT with those meals/ snacks.

It is important to stick to your normal diet which may include high fat foods to help maintain a good weight which is important in Cystic Fibrosis.

What happens if I don't take the PERT?

It can be difficult remembering to take the PERT with every meal, but if you do not take them your bowel symptoms will continue and may become worse.

You will find it more difficult to maintain a stable weight.

If you stop taking them for a long time you will not absorb some of the vitamins only found in fatty foods that your body needs (particularly vitamins A, D, E and K).

For how long do I have to take PERT?

Once you have been started on PERT you will require this as a life-long treatment. Your doses of PERT will be monitored regularly at clinic appointments by the CF dietitian.