

Cystic Fibrosis all about nutrition

Pancreatic enzyme supplement and cystic fibrosis

The Cystic Fibrosis Trust is grateful to the dietitians from the Cystic Fibrosis Dietitian Group UK (CFDGUK) who prepared the information in this leaflet.

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Why do I need to take pancreatic enzyme supplements?

The majority of people with cystic fibrosis (CF) are pancreatic insufficient. This means that the pancreas does not work as it should, and is unable to produce enough enzymes. These enzymes are normally released from the pancreas into the small bowel in response to eating; they help to digest the food eaten, breaking it down ready for absorption by the body.

Good use of enzyme supplements will help to control your bowels and improve your digestion, helping your body get the essential vitamins, minerals and energy you need to keep healthy.

The most commonly used enzymes in the UK is Creon®. Nutrizym 22® is an alternative enzyme supplement. These supplements are all prescribed by your doctor/GP.

Do I need to take enzymes with everything I eat?

Enzymes should be taken with all foods containing fat, protein or carbohydrate. This includes all meals, milk-based drinks and most snacks.

The only foods that do not need enzymes are:

- All types of fruit and fruit juices.
- Most vegetables and all vegetable juices
- Jelly and sorbet
- Fruit gums/jellies, pastilles, boiled sweets and mints
- Squash and fizzy drinks
- Alcohol (although creamy drinks such as Irish cream liqueur or milk-based cocktails do need enzymes).

How do I know if I am taking enough enzymes?

The amount of enzymes that you will need is very individual. You need to take enough for your body to fully digest and absorb your food. Weight gain is usually a good indicator of how well the enzymes are working.

Not taking enough enzymes will result in undigested food passing through your body. This can cause symptoms of abdominal pain, bloating, excess wind and loose stools that are pale, oily or difficult to flush away. You may lose weight or find it difficult to gain weight.

If you have any of these symptoms, discuss this with your dietitian or doctor.



How should I take my enzymes?

- Enzyme capsules should be swallowed whole, not crushed or chewed.
- They should be taken before or during snacks and meals.
- For meals eaten over a longer period (eg at a restaurant), enzymes should be spread throughout the meal, taking half at the start and others during the meal.
- You will need to take more enzymes with high fat foods.
- Some snacks are higher in fat than meals and will require more enzymes.

If you require more information about your own diet, discuss this with your dietitian.

What if I forget to take my enzymes?

Occasionally forgetting to take enzymes will cause nothing more drastic than possibly an upset stomach. If you forget to take them over a longer period of time, you will experience weight loss and nutrient deficiencies. This can affect your body's ability to fight off chest infections. You are also more at risk of developing distal intestinal obstruction syndrome (DIOS), a complication of CF that causes a blockage in the bowel. We have a leaflet called 'Gastrointestinal issues in cystic fibrosis' which gives more information about DIOS, see cysticfibrosis.org.uk/nutritionleaflets.

If enzymes are forgotten at the start of a meal, they can still be taken during the meal or at the end of the meal. Some people find it helpful to keep a supply of enzymes at places they often go, such as at work, or in their bag or jacket pocket. This way they always have a supply readily available.

Is there anything else I need to know?

- Enzyme capsules should be stored in an airtight container in a cool place, as exposure to heat and air can reduce their effectiveness.
- Check use by dates. You should rotate your stock of enzymes, using older stock first before starting new ones.
- It is important to drink plenty of fluid to keep your digestive system working well. A rough guide for adults and children with cystic fibrosis over 14 years of age is to try and have 2,000–3,000 ml/day. See the leaflet on Staying Hydrated for more information about fluid intake, see cysticfibrosis.org.uk/nutritionleaflets.

What if I sometimes choose not to take my enzymes?



Above, we have covered how enzymes work and why they are important. We know that sometimes people go through periods of time when they choose not to take the recommended amount of enzymes. If you are concerned about your enzyme use, eating or how you feel about your body, please discuss this with a member of the CF team.

We also have a booklet about body image which you might find interesting, visit cysticfibrosis.org.uk/bodyimage or order a copy from our helpline, details can be found on the back page of this leaflet.

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The information in this leaflet is general, please discuss it with your dietitian for a more personalised look at the topic.

This leaflet is part of a broad series on nutrition. Leaflets are available as online downloads and printed copies and can be found here: cysticfibrosis.org.uk/nutritionleaflets. You can also order the leaflets and our other publications from our helpline or download them here: cysticfibrosis.org.uk/publications.

Our helpline is open Monday to Friday, 9am–5pm, and can be contacted on 0300 373 1000 or by emailing helpline@cysticfibrosis.org.uk. Trained staff can provide a listening ear, practical advice, welfare/benefits information or direct you to other sources of support.

The information in this leaflet is based on clinical best practice, a consensus of opinion by dietitians within the CFDGUK and a consensus document on nutrition management of cystic fibrosis, which you can read here: cysticfibrosis.org.uk/publications.