

## Enzyme refusal in children with cystic fibrosis

Cystic Fibrosis Trust is grateful to the dietitians from the British Dietetic Association Cystic Fibrosis Specialist Group who prepared the information in this leaflet.

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## Introduction

If a child is refusing or forgetting to take their enzymes it can be challenging and frustrating for parents. Parents may be concerned about the impact it may have on their child's weight, growth and health. This leaflet will help suggest ways you can support your child if they are refusing or forgetting to take their enzymes.

It's really important to try to understand why your child isn't taking enzymes and at what times of the day this happens. This can help you to work out solutions together, and with the support of your child's cystic fibrosis (CF) team.

## Helping your child remember to take their enzymes

Enzymes work best when taken with food. However, don't worry if your child missed enzymes with their food as they can still be taken up to 10–15 minutes after eating.

If you find that your child is forgetting to take enzymes with food, there are several things you can do to help them remember.

1. Identify the meal and/or snack times when they forget to take their enzymes.

2. Build some self-reminders into your family routines. For example:

- Put enzymes where you and your child are most likely to see or touch them (eg on or near the kitchen bench/table, plates or cups, where you keep the snacks)
- Write a note
- Draw a picture of enzymes for the fridge
- Draw a picture chart of meals and snacks eaten often, and write how many enzymes they need
- Always carry enzymes with you in your bag, even when your child is old enough to carry their own supply in their lunch box or pocket
- Have a supply of enzymes at the home of friends, relatives and/or neighbours if your child eats there regularly
- Create messages, songs or poems to aid your child's memory
- Have your child ask friends at school to remind them
- Use an enzyme container (ask a dietitian how to get one)
- Get your child to help decorate something to keep their enzymes in, an enzyme pot or little metal tin

3. Set your child a goal to remember to take their enzymes a specific number of times each week. Start with a small achievable goal, and then increase the goal each week. Monitor and reward your child as they progress.



## Rewarding their progress

Consider the following ways of rewarding positive steps forward.

- Each time your child takes their enzymes they can put an item (such as dried pasta or plastic balls) into a jar. Your child can see the amount increasing within the jar.
- Create a chart like the one below and ask your child to put a sticker, a tick, draw an enzyme or add a smile in any box when they have taken their enzymes.

Plan a reward for when the jar or reward chart is full (such as time spent together doing something the child enjoys, small prizes, or a lucky-dip box. (Make sure the reward jar/chart is achievable, eg a younger child may need a smaller jar or larger objects to fill it up. Avoid expensive rewards as you may want to reward new skills and achievements often).

|                    | Mon                                                                                 | Tues | Weds | Thurs | Fri | Sat | Sun |
|--------------------|-------------------------------------------------------------------------------------|------|------|-------|-----|-----|-----|
| Breakfast          |    |      |      |       |     |     |     |
| Morning snack      |                                                                                     |      |      |       |     |     |     |
| Lunch              |   |      |      |       |     |     |     |
| Afternoon snack    |                                                                                     |      |      |       |     |     |     |
| Dinner             |  |      |      |       |     |     |     |
| After dinner snack |  |      |      |       |     |     |     |

## Enzyme refusal in children

As a parent you will know the importance of taking enzyme supplements correctly. But does your child know why it's important? If not, you should explain why they need enzymes.

**For younger children, try explaining that their enzymes are needed to:**

- breakdown the food they eat
- help them grow taller and gain weight
- help them have the energy to play and run fast, and
- stop them getting tummy aches, and having loose oily poos or doing lots of farts.

For older children, it would be an idea to find out how much they know about enzymes and why they take them. This may just refresh their memory, but you may also find that there are things they don't know. The following are some points to remind them of.

- Enzymes are produced in the body's pancreas. The enzymes travel through tubes to the stomach, where they help to digest fat, protein and carbohydrates in food that they have eaten. In someone with CF, the tubes leaving the pancreas are often blocked with mucus, stopping the enzymes from leaving the pancreas. Anyone whose pancreas is affected in this way needs to take enzyme supplements (Creon®) to digest the food they have eaten.
- If you forget to take your enzymes, your food will not be broken down properly and you may get stomach ache, bloating, diarrhoea and wind (farting). You may not grow properly if you regularly forget to take your enzymes.
- Enzymes should be taken at the start of a meal or snack as they need to be in the stomach at the same time as the food. You can split the dose if you are unsure how much you will eat, or if the meal has several courses. If you forget to take enzymes at the start of a meal, it is not too late to take them at the end of the meal as they will still digest some of the food if taken up to 10–15 minutes after eating.

### Understanding why your child is refusing enzymes

If your child is refusing to take their enzymes, try to find out why and when. Do they refuse enzymes:

- |                                            |                                     |
|--------------------------------------------|-------------------------------------|
| • At every meal                            | • With certain foods                |
| • At school meal times                     | • At snack times                    |
| • Is it when they want to play             | • When they feel rushed             |
| • When they are distracted                 | • When taken from a certain teacher |
| • If taking them in front of their friends | There may be other reasons          |

**If your child refuses enzymes at every meal, discuss this with your child's CF team.**

**You could ask your child the following:**

- Which of their friends know about their enzymes?
- How do they feel about taking enzymes in front of friends or other people?
- What do they say if friends ask what they are taking?
- Can they tell you why they have stopped taking their enzymes?

If you find out why your child isn't taking their enzymes, try to work together to find some ideas which would help change that.

**You may find some of the following suggestions useful.**

- Some young people think taking enzymes is embarrassing or have been hurt by comments other people have made. It can help if your child has a response they can use if they are asked about taking enzymes. Help them to work out what they would like to say. They don't have to mention CF. They don't have to answer, but could say:

**"They help to digest my food when I eat"**

**"I need them to help my tummy work"**

- It's much better to be open about enzymes in front of friends and peers. Try to make taking enzymes a routine at home so that it is easier for your child to take them at school. It's better if, from the beginning, you are open and consistent about taking enzymes, and that your child feels that enzymes are a normal part of meal times.
- If your child doesn't want to take enzymes at school in front of their peers, you could talk with your child's school teacher and arrange for your child to take enzymes just before the rest of the class go for lunch, or in a separate room or office where they can take their enzymes in privacy.
- Is your child allowed to keep their enzymes with them in a lunchbox or bag? Does it make it easier if they have the responsibility of taking them themselves, instead of having to go to a member of staff before they can eat lunch? (You will need to inform someone at the school if your child is changing from getting their enzymes from a member of staff or in an office to keeping and taking their enzymes themselves.)
- If your child is happy for their teacher to discuss their medication and supplements, ask your child's teacher to give a lesson on special health needs of people (eg asthma, diabetes, CF) and ask the teacher to explain why people need their medications and supplements.

The CF team can often speak to school staff and offer support where needed.

### Tips for primary school aged children

For younger children refusing to take their enzymes, try some of the following ideas.

- Offer a choice of how they take their enzymes, eg with either apple puree or yogurt, or swallowing one or more at a time (if they can swallow them).
- Give your child a choice of taking their enzymes and eating the intended meal or snack, or eating a piece of fruit without enzymes. If your child chooses neither, tell them that these are the two choices available. If they still refuse, wait 15 minutes and ask again – they may have changed their mind.

### Further advice for young people at secondary school

Our resources about starting secondary school contain lots of tips and suggestions about taking enzymes at school. We have information for young people and a booklet for parents. Find out more at [cysticfibrosis.org.uk/life-with-cystic-fibrosis/secondary-school](https://cysticfibrosis.org.uk/life-with-cystic-fibrosis/secondary-school)

Some young people stop taking enzymes, or reduce the amount of enzymes they take, as they know it will affect their weight and body shape. If you are concerned about this, speak with your child's dietitian. There is some information on this in our body image booklet however it is aimed at adults and young adults. Find out more at [cysticfibrosis.org.uk/what-is-cystic-fibrosis/how-does-cystic-fibrosis-affect-the-body/body-image](https://cysticfibrosis.org.uk/what-is-cystic-fibrosis/how-does-cystic-fibrosis-affect-the-body/body-image)

## Further information

Find more information resources about living with cystic fibrosis at [cysticfibrosis.org.uk/information](https://cysticfibrosis.org.uk/information).

Our **Helpline** is open 10am – 4pm Monday to Friday. It's available to anyone looking for information or support with any part of cystic fibrosis, a listening ear, or just to talk things through.

How to reach us:

- Call **0300 373 1000** or **020 3795 2184**
- Email [helpline@cysticfibrosis.org.uk](mailto:helpline@cysticfibrosis.org.uk)
- Chat with us on Facebook, Twitter or Instagram
- Message us on WhatsApp on **07361 582053**

Visit [cysticfibrosis.org.uk/helpline](https://cysticfibrosis.org.uk/helpline) for more information.

We welcome your feedback on our resources.

You can also ask for this resource in large print or as a text file.  
Email [infoteam@cysticfibrosis.org.uk](mailto:infoteam@cysticfibrosis.org.uk).

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This leaflet has been designed to be given out by a CF dietitian, along with their advice. If you downloaded or requested it directly from Cystic Fibrosis Trust we would advise you to discuss this information with your CF dietitian.

The information in this leaflet is based on clinical best practice and a consensus of opinion by dietitians within the British Dietetic Association Cystic Fibrosis Specialist Group. For detailed guidance on CF nutrition, please see the **Consensus document on nutritional management of cystic fibrosis**. Our consensus documents as well as other publications about cystic fibrosis can be found at [cysticfibrosis.org.uk/publications](https://cysticfibrosis.org.uk/publications) or they can be ordered through our Helpline.

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

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The information in this resource does not replace any advice from your doctor or CF team. It is important that you seek your team's advice whenever you want to change your treatment.

# Cystic Fibrosis Trust

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

We won't stop until everyone can live without the limits of cystic fibrosis.

**[cysticfibrosis.org.uk](https://cysticfibrosis.org.uk)**

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