CYSTIC FIBROSIS

CF Fact
cystic fibrosis fact sheet

Nutrition for Children

Diet is particularly important in the management of cystic fibrosis (CF), as a child with CF who has a good diet may get fewer lung infections, recover more quickly from infections, maintain better lung function and have more energy for everyday activities.

Enzymes

Approximately 85% of children with CF are pancreatic insufficient. This means the pancreas is unable to produce or release enough digestive enzymes into the small intestine, and so food is not digested properly. If your child is pancreatic insufficient, they will need to take enzymes with most foods to help them absorb the energy and nutrients contained in the food. The dosage is calculated based in the amount of fat in the food. Forgetting or taking too few enzymes will result in diarrhoea, abdominal pain, and over time, weight loss or difficulty in gaining weight. Too many enzymes may lead to constipation.

Enzymes come as either microspheres, which are mixed with apple puree and administered with a spoon, or as a capsule once your child is able to swallow tablets.

Food

A balanced diet is important for children with CF. Most will need to eat 20-50% more calories in their daily diet than those without CF because they do not absorb food as easily and the body uses more energy to function.

The 'healthy food cube' is a good way to think about the CF diet.

The food cube does not limit intake of food sources, but rather encourages the addition of high fat, high calorie extras to food and drinks, such as oils/butter, cheese, nut butters and avocado. Dietary needs may again change with increased activity or diagnosis of CF Related Diabetes (CFRD).

Exactly how many calories your child needs each day should be directed by their CF dietitian, as each child has specific needs.

Vitamins and Minerals

Vitamins

Children with CF often have deficiencies in fat-soluble vitamins A, D, E and K, and will therefore require vitamin supplementation. VitABDECK is a CF-specific multivitamin that is commonly prescribed. It can be either swallowed

whole, crushed and mixed with apple or pear puree, or mixed with water and administered with a syringe.

Salt
Children with CF lose more salt through their sweat and need to replace this loss with extra salt in the diet and/or supplements. Salt supplements come in liquid form (salt solution) and can be added to milk, water, cordial, puréed fruit or other solids. They also come in tablet form which may be an option once your child learns to swallow capsules. You can also cut the tablet up and administer with yoghurt or another soft food your child enjoys eating. The amount of salt replacement needed varies for each child according to symptoms, dietary intake, climate and activity levels.

Gaining Weight

Often children with CF will struggle to gain weight despite the use of enzymes and increased caloric intake. Fat 'boosting' is often used to help with weight gain. This is simply adding more fat to a meal, so it is higher in calories, without having to consume more food. E.g. adding 2 tablespoons of peanut butter to celery adds an extra 20g of fat. Other tips include using full-cream milk, avoiding 'low-fat' food options, using supplement drinks, adding sauces to food and having ready-to-eat snacks on hand at all times.

Supplemental feeding directly into the stomach via a percutaneous endoscopic gastrostomy (PEG) may also be needed if, despite all other options, weight gain is still an issue.

Bowel Health

Children with CF can experience malabsorption (inadequate uptake of nutrients from food), which can be revealed by their bowel movements.

Signs of Malabsorption:
- Ulcers in the mouth or bottom.
- Excessive tummy pain, diarrhoea or wind.
- Very bad smelling bowel movements.
- Loose or greasy/oily bowel movements.
- Nappy rash.
- Mouth sores and irritation around the mouth (this can be common during the first month of taking enzymes).

These symptoms can occur from incorrect enzyme dosage. If this is a common recurrence, you should speak with the CF dietitian.

Seeking Help

Your child's CF care team should always be your first port of call when questions or concerns arise. They are a valuable resource you can reach out to at your clinic visits and in between those visits.

Useful Resources

- CFFood: A Guide for Feeding Children (CFWA)
- Cystic Fibrosis and High Energy Diet (NEMO)
- Information for CF Dietitian at Annual Review (Perth Children's Hospital)
- CFWA Factsheets

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