HEALTH BASICS

Cystic fibrosis - nutrition

Nutrition care in cystic fibrosis supports growth, nutrient absorption, and changing energy needs.

WHAT IT IS
Individual nutrition care for people living with cystic fibrosis

WHERE IT COMES UP
CF clinic visits, growth checks, enzyme use, and food choices

WHY IT MATTERS
Supports growth, nutrient absorption, bone strength, and lung health

WHAT IT IS NOT
Not a disease, diagnosis, or single prescribed diet

WHO TO ASK
A cystic fibrosis dietitian and specialist care team

HOW IT IS CHECKED
Growth, weight, blood tests, stools, and glucose testing

Overview

Cystic fibrosis is a genetic disease. Cystic fibrosis nutrition is not a disease or diagnosis. It is the tailored nutrition care used alongside other CF treatment.

CF can affect digestion, appetite, energy needs, salt balance, blood glucose, and bone health. These effects differ from person to person and can change with age, illness, pregnancy, activity, and CF treatment.

There is no single "CF diet." Some people need more energy, fat, protein, or salt than other people of the same age. Others may need help maintaining a balanced weight rather than gaining weight. Advice that was appropriate during childhood may need to change in adulthood, especially after starting a CFTR modulator.

A CF dietitian can assess food intake, growth or weight trends, digestive symptoms, pancreatic enzyme use, vitamin levels, and glucose results. The aim is to meet nutritional needs without making eating unnecessarily restrictive or stressful.

How it works

The pancreas normally releases enzymes into the small intestine. These enzymes break down fat, protein, and carbohydrate so nutrients can be absorbed.

In many people with CF, thick secretions block the pancreatic ducts. Too few enzymes then reach the intestine. This is called pancreatic insufficiency . It can lead to poor absorption, particularly of fat and the fat-soluble vitamins A, D, E, and K. Not everyone with CF has pancreatic insufficiency.

People with pancreatic insufficiency are usually prescribed pancreatic enzyme replacement therapy, often shortened to PERT. The enzymes are taken with meals, snacks, and nutritional drinks as directed by the CF team. The amount needed is individual and may change with meal size, fat content, age, symptoms, or treatment.

CF can also raise energy needs. Breathing effort, inflammation, lung infections, recovery from illness, and physical activity may all affect how much energy the body uses. Reduced appetite, coughing during meals, digestive discomfort, or the time required for treatments can make it harder to eat enough.

People with CF lose more salt in sweat. Extra salt or fluids may sometimes be needed during hot weather, exercise, fever, or heavy sweating. The right amount should be based on age, health, climate, activity, and advice from the CF team.

CF may also affect insulin production. Insulin is the hormone that helps glucose move from the blood into cells. This can lead to cystic fibrosis-related diabetes, or CFRD. CFRD is treated as a separate condition; it is not caused simply by eating sugar.

CFTR modulator medicines can improve health and may change appetite, digestion, body weight, and energy needs. They do not automatically remove the need for enzymes or vitamin supplements.

Why it matters for your health

Good nutrition supports growth in children and helps adults maintain muscle, strength, and a suitable weight. It also provides nutrients needed for immune function, bone health, and recovery from illness.

Weight alone does not show the whole picture. A person can gain weight while losing muscle, or have vitamin deficiencies despite eating enough calories. For children and teenagers, growth over time is more useful than a single measurement.

Fat-soluble vitamin levels matter because pancreatic insufficiency can reduce their absorption. Low vitamin D and K levels may contribute to weaker bones. Too much of some vitamins can also be harmful, so CF-specific supplements should be reviewed rather than

increased without testing.

Nutrition needs may move in either direction. Some people struggle with poor growth or unplanned weight loss. Others develop overweight, high cholesterol, fatty liver disease, or other cardiovascular risk factors. Modern CF care aims for adequate, balanced nutrition rather than assuming everyone needs unlimited high-calorie food.

Eating also affects quality of life. Plans should take account of culture, budget, food preferences, school or work, digestive comfort, and the burden of taking enzymes with food.

What can go wrong

Several named conditions or situations may affect nutrition in CF:

Arrange routine contact with the CF team for ongoing oily stools, repeated bloating, constipation, reduced appetite, unexplained weight change, poor growth, or difficulty coordinating enzymes with meals. These concerns usually need review, but they are not automatically emergencies.

Seek urgent medical assessment for severe or increasing abdominal pain, a swollen abdomen, repeated vomiting, or being unable to pass stool or gas. These can be signs of a bowel blockage.

Use emergency services for collapse, a seizure, severe confusion, or difficulty waking. If you have CFRD, follow your personal emergency plan for severe low or high blood glucose.

- Pancreatic insufficiency can cause poor absorption, oily or difficult-to-flush stools, bloating, and poor weight gain
- Malnutrition or poor growth can develop when intake or absorption does not meet the body's needs
- Fat-soluble vitamin deficiency can occur even when food intake seems adequate
- Cystic fibrosis-related diabetes can cause high blood glucose and unplanned weight loss
- CF-related bone disease may involve reduced bone strength and a higher risk of fractures
- Overweight or excess body fat may create metabolic or cardiovascular concerns
- Constipation or distal intestinal obstruction syndrome can slow or block the bowel
- Dehydration and salt depletion may occur during heavy sweating, heat, fever, vomiting, or diarrhea

What you can do

There is no single home test that shows whether CF nutrition is adequate. A pattern of measurements and test results is more useful.

Practical steps include:

Nutritional drinks or tube feeding may be considered when ordinary food is not meeting nutritional needs. Tube feeding supplies nutrition through a tube into the stomach or intestine. It can supplement meals rather than replace them and is not a sign of personal failure.

Avoid starting high-dose vitamins, digestive enzymes, salt tablets, or restrictive diets without discussing them with the CF team. "Natural" supplements can still cause side effects or interact with medicines.

- Keep scheduled CF reviews for height, weight, growth, and body composition when offered
- Ask whether pancreatic function has been tested and whether PERT is needed
- Take prescribed enzymes with food exactly as instructed; do not change the dose on your own
- Tell the team about oily stools, bowel changes, bloating, or meals that are difficult to cover with enzymes
- Ask which vitamin product is appropriate and when blood levels will be checked
- Follow the CF team's plan for glucose testing and CFRD screening
- Ask how salt and fluid needs change with exercise, fever, travel, or hot weather
- Record food, enzymes, stools, and digestive concerns for a few days if the dietitian requests it
- Review nutrition after starting or changing a CFTR modulator

Common questions

Does everyone with CF need a high-calorie diet?

No. Some people need extra energy to support growth, weight, or recovery. Others need a more balanced intake because their weight and metabolic risks have changed. Advice should follow current measurements rather than an old rule.

Does everyone with CF need pancreatic enzymes?

No. Enzymes are used when the pancreas does not release enough digestive enzymes.

Pancreatic function can be checked, often with a stool test called fecal elastase.

Can enzymes be mixed into food?

Some enzyme products can be opened and the granules given in a specific way, but instructions differ by product and age. The granules generally must not be crushed or chewed. Follow the prescribing information and CF team's instructions.

Are ordinary multivitamins enough?

Not always. People with pancreatic insufficiency may need a CF-specific preparation of vitamins A, D, E, and K. Blood tests help guide the plan and reduce the risk of taking too little or too much.

Do CFTR modulators replace nutrition treatment?

Not automatically. Modulators may improve appetite, absorption, or weight, but enzyme and vitamin needs must be reassessed rather than stopped without review.

Can someone with CF follow a vegetarian or vegan diet?

It may be possible, but meeting energy, protein, iron, vitamin B12, calcium, vitamin D, and essential fat needs can require planning. A CF dietitian can help adapt the diet without unnecessary restriction.

Sources

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