

# Nutrition & Cystic Fibrosis

A Guide For Children



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# About this guide

This booklet has been developed to provide you with practical, general and factual information about the nutritional needs of children with cystic fibrosis (CF) from ages 3 to 12 years of age.

Children with CF can be affected very differently, will have individual dietary needs based on symptoms and other factors such as gender, age, weight, height and physical activity levels.

Your child's CF dietitian, in conjunction with the CF care team, should advise you on your child's specific dietary requirements, and be your first port of call when questions or concerns arise.

They are a valuable resource you can reach out to, both at your child's quarterly visits and in between those visits.

This resource is designed to be a general guide only, so it is important to note that some of the information may not be relevant to your child.

Published 2016  
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Published with the generous support of Newman's Own Foundation

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# 1.

## Nutrition for pancreatic sufficient children

The pancreas is an organ in the digestive tract which produces digestive enzymes (which help to break down food) and hormones (which help to regulate blood sugar).

In CF, often the pancreas is affected and this is referred to as pancreatic insufficiency, or being pancreatic insufficient. About 85% of people with CF are pancreatic insufficient.

If your child does not suffer from pancreatic insufficiency, this is termed being 'pancreatic sufficient'. It means that their body is able to digest food naturally and, therefore, medication to assist with digestion is not required.

This means that your child can follow a normal, balanced diet, unless otherwise indicated by the CF team.

The diet is generally the same as what is recommended for the general population and should include a wide variety of nutritious foods from the five food groups:

- vegetables
- fruit
- grain (cereal) foods such as breads, cereals, rice, pasta, noodles, polenta, couscous, oats, quinoa and barley
- lean meats and meat alternatives such as poultry, fish, eggs, tofu, nuts, seeds and legumes/beans
- dairy foods such as milk, yoghurt, cheese and their alternatives

You should limit intake of foods containing trans and saturated fats and added sugars.

Some of the hints and tips included in this booklet may still be relevant for pancreatic sufficient people such as salt supplementation, vitamins and bowel issues.



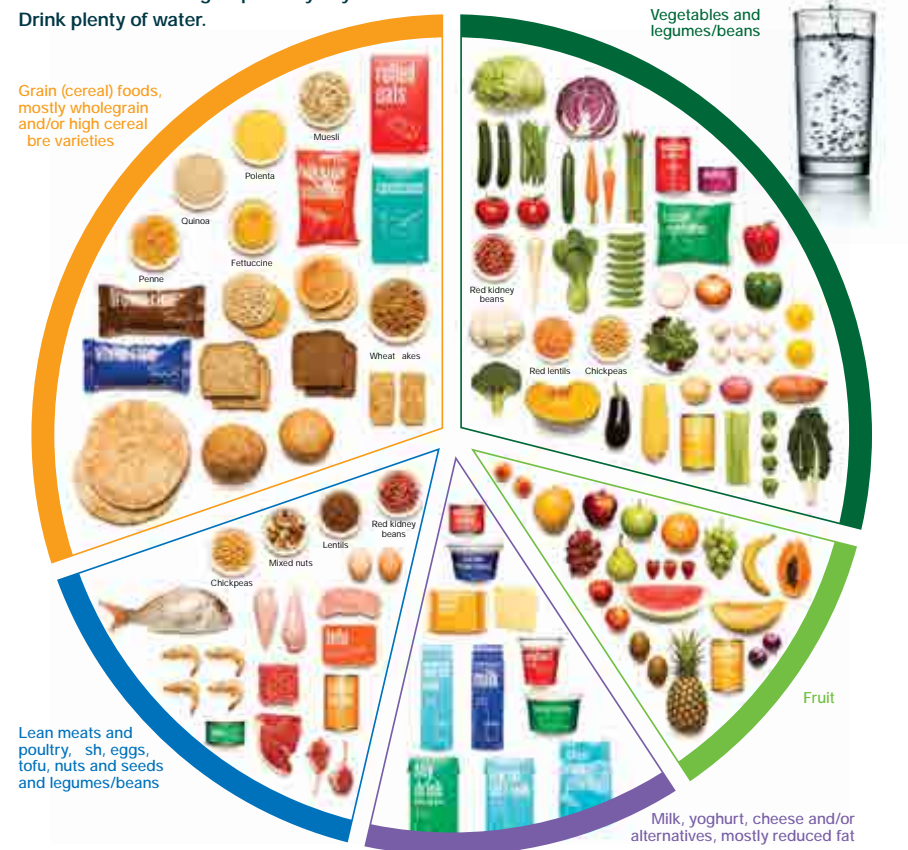
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Department of Health and Ageing

[www.eatforhealth.gov.au](http://www.eatforhealth.gov.au)

## Australian Guide to Healthy Eating

Enjoy a wide variety of nutritious foods from these five food groups every day.

Drink plenty of water.



Use small amounts



Only sometimes and in small amounts





# 2.

## Enzymes

### PARENTS TIP

We tell our daughter that the enzymes are a special medicine which help her grow and give her energy to play. We also explain that the medicine helps her tummy to work properly, so she doesn't get yucky poos and tummy aches.

### ADMINISTERING ENZYMES

Approximately 85% of people with CF suffer from pancreatic insufficiency.

This means the pancreas is blocked with mucus, preventing the body from breaking down and digesting food naturally.

Normally when food is eaten, it is broken down in the stomach and then passed into the small intestine where digestion takes place with the help of enzymes from the pancreas.

However, because the tubes in the pancreas are blocked with mucus, the pancreatic enzymes cannot be released. If the pancreas cannot work properly then Pancreatic Enzyme Replacement Therapy (PERT) will be required to assist with the digestion of food.

The main goal of treating pancreatic insufficiency is to optimize nutrient absorption, improve weight gain and growth and prevent nutrient deficiencies. If your child is pancreatic

insufficient they will need to take enzymes with most foods.

The commonly used enzyme in Australia is Creon. From about 3 years onwards, or when the child learns to swallow tablets, they will transition from the microspheres form of the medication to capsules.

Your child needs to take enzymes with any foods that have fats in them to help absorb the energy and nutrients contained in the food and prevent malabsorption. It is important to remember to:

- take the right number of enzymes based on the amount of fat in your food
- take them at the right time - enzymes only work for around 30 minutes, so if your child is eating slowly or snacking over a long period of time, you will need to take more enzymes after the 30 minutes is up
- take them the right way - they should be swallowed whole as a tablet, not crushed or chewed

There are some foods which don't require enzymes because they don't contain any fats, including:

- fresh, dried and canned fruit
- non-starchy salad vegetables
- some lollies, jellies and sorbet
- fruit juice, cordial, soft drink and water

### CALCULATING ENZYME DOSAGE

Enzymes come in different strengths. The dosage your child is on will be decided by your child's CF care team and depends on a few things, like age and level of pancreatic function.

To work out the dose for a particular meal or snack, you need to calculate the amount of fat in the food. This can seem very daunting and time consuming, however, it will become easier over time.

You should always consult with your child's dietitian for individual recommendations. Labels on food packaging can be helpful in working out how much fat is in a particular snack or meal.

On the Nutrition Information Panel on the food item or box, look at 'Total Fat' in the 'per serving' column. For

example, as seen below, an Uncle Toby's Muesli Bar has 4.3g of fat in one bar.

When looking at nutrition labels, it is important to remember that the serving size listed on the package is determined by the manufacturer, and may be very different to the serving size you consume.

It may also be different between similar products and brands. While you are getting used to calculating how many enzymes to take, it may be helpful to weigh your food on kitchen scales, or use measuring cups to determine what portion size you are consuming.

There are also some excellent resources for fat counting, such as the 'Calorie King' or 'My Fitness Pal' apps. They can be downloaded as a free app onto your phone or iPad. You can add in almost any food and it will give you the fat content automatically and adjust the volume/weight of the food item.

### Uncle Toby's Muesli Bar

SERVINGS PER PACK: 6	AVERAGE QUANTITY PER	AVERAGE QUANTITY PER
Energy	550kj	1770kJ
Protein	1.9g	6.1g
Fat - total	4.3g	13.7g
-saturated	1.4g	4.4g
Carbohydrate	20.5g	65.4g
-sugars	6.7g	21.3g
Dietary fibre	2.0g	6.5g
Sodium	4mg	13mg

These apps are a great tool to help you to fat count and calculate the number of enzymes required.

### *How do I know the dose is correct?*

The effectiveness of your child's enzymes should be routinely monitored by the CF care team.

Weight gain is generally a good indicator of how well the enzymes are working and if your child is digesting and absorbing his or her food.

You may also find it useful to monitor his or her bowel movements and note any gastrointestinal discomfort (gas and/or abdominal pain).

If your child frequently experiences any of the following symptoms, they may be a sign of malabsorption (inadequate uptake of nutrients from food) and his or her enzyme dosage may need review.

In this case, you should speak with your child's CF care team.

#### *Possible signs of malabsorption:*

- constipation, tummy pain, diarrhoea or wind
- loose, greasy or floating stools
- weight loss and poor growth
- very bad smelling bowel movements
- mucousy or oily bowel movements

### *What if I forget to give my child enzymes?*

If enzymes are forgotten at the start of the meal, you can still give them at the end, as long as it's within 5-10 minutes of eating.

Don't panic if you forget to give your child enzymes before or after a meal.

There is nothing drastic that can happen if enzymes are forgotten during one meal other than possibly some unpleasant bowel movements and some discomfort.

However, if enzymes are not given regularly over a period of time, the child will experience weight loss and loss of nutrients from their food. This is likely to result in poor health outcomes related to malabsorption and inadequate nutrition.

#### *NON-COMPLIANCE WITH ENZYMES*

Your child may start asking questions once he or she is old enough. Questions such as why they have to take enzymes all the time?

If you are open with your child, from a young age about what the enzymes are for and you are consistent in when they have to be taken, this can make things easier later on.



#### *Tips for encouraging compliance with enzymes:*

- Allowing your child choices for certain things may assist with reducing power struggles that can often be an issue, e.g. "Would you like your enzymes in apple sauce or pear sauce?"
- Don't give up on giving your child a dose of enzymes. If you give up, this can send your child the message that enzymes are not that important which can lead to more issues later on. The message you want to give your child is "Taking your enzymes is non-negotiable but how you take them is up to you."
- Expect your child to comply. Remain calm and as pleasant as possible while your child is having their enzymes. Children are masters at reading our body language and can pick up on our positive or negative attitude. If you have a positive expectation of "you can do it" your child will usually meet this expectation.
- Show empathy if your child refuses to take enzymes, e.g. "It is sad you don't want to take your enzymes. You will miss out on your pizza. I will leave it here and when you are ready to take your enzymes, you let me know." Once you have shown empathy but stated your case, leave the issue alone and in about 10 minutes check to see where things are at. Then try again: "I'm about to pop that pizza in the fridge now. Did you want to pop that pizza in the fridge now. Did you want it with your enzymes or did you want an apple instead?" (choose a snack that doesn't involve enzymes and is simple).

# 3.

## The CF diet

Your child's diet is a very important part of the management of CF.

In fact, nutrition is so important that a healthy body weight can be linked to better lung function.

Someone with CF who has a good diet and is well nourished may:

- have fewer lung infections
- have the ability to fight and recover quicker from infections
- have better growth
- keep better lung function and have more energy for everyday activities like going to school

In CF, the body has to work harder due to a range of things like fighting lung infections, the increased work of breathing and the malabsorption of food. This is why most people with CF will need to eat 20-50% more than the recommended daily intake of the general population.

### *What foods should my child eat?*

Our bodies get energy or calories from three main nutrients, or 'macronutrients'. These are: Fats, Proteins and Carbohydrates. Each of them is essential and they will be discussed in more detail below.

Diets, 'lifestyles', or eating plans which encourage the removal of any of these three macronutrients, are unbalanced and are not suitable for any children, but could present serious risks for a child with CF.

A balanced diet is important for people with CF. Generally, pancreatic insufficient children with CF will need to eat more calories than children who don't have CF.

Exactly how many calories your child needs each day should be directed by the CF dietitian as each individual with CF has different needs. 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 additions to food and drinks such as oils/butter, cheese, nut butters and avocado. Children with CF will often need extra serves of food per day.

The table (*on page 12*) is a starting point for ensuring that your child's diet is balanced and that he or she has intake of a variety of different foods. Focus on making sure your child is meeting the suggested targets for

each food group as each food group provides different nutrients.

Your child's CF team or dietitian will be able to advise you on extra nutritional requirements your child needs.

Alternatively, your child may benefit from 'boosted' or fortified foods which will be discussed in the following pages.

Information on what constitutes an appropriate serve size can be found at the following link:

<https://www.eatforhealth.gov.au/food-essentials/how-much-do-we-need-each-day/serve-sizes>

### FATS

To ensure adequate growth, most children with CF should get approximately 35-40% of their daily energy needs from fat.

Your child's dietitian will be able to recommend his or her specific daily requirements, in grams based on individual energy needs.

To help your child reach his or her daily target, you should use full fat options (rather than low fat),

aim for high calorie snacks and drinks between meals and add extra calories to meals.

For the general population, high consumption of certain fats can lead to health issues such as cardiovascular disease, obesity, diabetes and more, and many parents of children with CF also worry about the long-term health effects of a high fat diet.

Typically, pancreatic insufficient individuals with CF have been shown to have normal cholesterol levels, as well as minimal risk factors for cardiovascular disease despite their high fat intakes. This is thought to be most likely due to poor absorption of fat.

As individuals with CF are now living longer, the long-term effects on cardiovascular health are being considered, and concerns may exist, particularly for those adults with a higher body mass index.



## Servings of the 5 Food Groups

GRAINS	EXAMPLES	GOOD SOURCE OF	EXTRA INFO
<b>2-3 year olds</b> 4 x serves/day	• breakfast cereals • bread • wraps	• carbohydrates • fibre (whole grain) • B vitamins • some minerals	• include in most meals and snacks • add extra margarine or oil to servings
<b>4-8 year olds</b> 4 x serves/day	• rice • pasta • oats • quinoa		• wholegrain servings are the most nutritious choice but it is ok to include some white products
<b>9-11 year olds</b> Girls: 4 x serves/day Boys: 5 x serves/day			• not a good source of protein

VEGETABLES	EXAMPLES	GOOD SOURCE OF	WHAT TO DO
<b>2-3 year olds</b> 2.5 x serves/day	• fibre • antioxidants • vitamins • some carbohydrate	• fibre • antioxidants • vitamins • some carbohydrates	• good for the bowels • use in conjunction with a higher energy food • not a good source of protein
<b>4-8 year olds</b> 4.5 x serves/day			• include high fat veggies such as avocado
<b>9-11 year olds</b> Girls: 5 x serves/day			• include a variety of different sorts daily, including veggies of different colours

FRUIT	EXAMPLES	GOOD SOURCE OF	WHAT TO DO
<b>2-3 year olds</b> 1 x serve/day	• fresh, frozen and tinned	• fibre • antioxidants • vitamins • some carbohydrate	• good for the bowels • use in conjunction with a higher energy food • not a good source of protein
<b>4-8 year olds</b> 1.5 x serves/day			• include a variety of different sorts daily, including fruits of different colours
<b>9-11 year olds</b> Girls: 2 x serves/day Boys: 2 x serves/day			

MEAT/ALTERNATIVES	EXAMPLES	GOOD SOURCE OF	EXTRA INFO
<b>2-3 year olds</b> 1 x serve/day	• red meat • chicken and poultry • eggs	• protein • iron and zinc • omega fats (fish)	• include a variety of different types in age-appropriate textures
<b>4-8 year olds</b> 1.5 x serves/day	• dried beans and lentils • nuts • fish - fresh and tinned		• add sauces, oils and condiments to make sure these choices are high energy
<b>9-11 year olds</b> Girls: 2.5 x serves/day Boys: 2.5 x serves/day			

DAIRY FOODS	EXAMPLES	GOOD SOURCE OF	EXTRA INFO
<b>2-3 year olds</b> 1.5 x serves/day	• milk or milk alternatives • cheese • yoghurt • ice cream • custard	• protein • fat • carbohydrate • calcium	• add cheese in cooking • encourage dairy desserts
<b>4-8 year olds</b> Girls: 1.5 x serves/day Boys: 2 x serves/day			• give milk after meals so that babies are encouraged to eat
<b>9-11 year olds</b> Girls: 3 x serves/day Boys: 2.5 x serves/day			

### 'The Healthy Food Cube'

Adapted from 'More Please: A Guide to Eating for Children with Cystic Fibrosis', 2007



FATS CONTINUED...

There are four main categories of fats: polyunsaturated, monounsaturated, saturated and trans fats.

Polyunsaturated and monounsaturated fats are usually considered ‘healthier’ fats as intake of these types of fats are not associated with an increase in cardiovascular risk.

Intake of saturated fats are associated with an increase in LDL (low density lipoprotein) cholesterol in the general adult population, which is considered a cardiac risk factor – however this hasn’t been shown to be the case in people with CF.

Trans fats have been shown to cause an increase in LDL cholesterol, like saturated fats, but in addition to this they have been shown to cause a reduction in heart-friendly HDL (high density lipoprotein) cholesterol.

This makes trans fats the poorest choice of fats. Saturated fats usually don’t need to be strictly avoided by people with CF, as people with CF tend to have low cholesterol levels.

When feeding children, it is good to consider the type of eating habits that are being established in childhood, as these habits often influence eating habits that children take into adulthood. It is also important to consider the health of the rest of the family.

Here are some examples of different sources of dietary fat:

POLYUNSATURATED FATS	MONOUNSATURATED FATS	SATURATED FATS	TRANS FATS
fatty fish (such as salmon, tuna, herring and sardines)	olive oil	visible fat on meat such as: beef, veal, lamb, pork, poultry	commercially baked products such as biscuits and pastries
vegetable oils (such as sunflower, safflower and soybean oils)	canola oil	butter	deep fried takeaway foods
fish oils	peanut oil	cream	shortening
seeds (such as flaxseed, pepitas, sunflower seeds)	avocado	dairy made from whole milk such as yoghurt and cheeses	
legumes	natural peanut butter	plant fats including coconut oil, palm oil and cocoa butter	
soybeans	some nuts (such as almonds and peanuts)		
some nuts (such as walnuts and peanuts)	seeds		

PROTEIN

Protein is important to help with growth and repair body tissue. Muscle, skin, hair and fingernails are all made up of protein, as are antibodies, which play an important role in immune function. Your child’s dietitian will be able to recommend his or her specific daily requirement, in grams, based on individual needs. (Note: milk alternatives other than soy, such as coconut milk and almond milk are low in protein.)

FOOD	IDEAS
MEAT AND MEAT ALTERNATIVES	<ul style="list-style-type: none"><li>•meat, chicken, fish and meat alternatives such as baked beans, lentils, kidney beans, tofu</li><li>•include at each main meal and snacks as appropriate</li></ul>
CHEESE	<ul style="list-style-type: none"><li>•serve on crackers/sandwiches</li><li>•grate onto vegetables</li><li>•add to rice/pasta</li><li>•cut into small blocks as a snack</li><li>•make cheese sauce to add to meals/vegetables</li></ul>
FULL CREAM MILK	<ul style="list-style-type: none"><li>•try milk based drinks</li><li>•make soups, puddings, custards, desserts or packet mixes with milk instead of water</li><li>•soy milk as an alternative to cow’s milk</li></ul>
EGGS	<ul style="list-style-type: none"><li>•mash egg with mayonnaise as a sandwich topping or stir through potato salad</li><li>•try an omelette or quiche with chopped meat, vegetables and cheese</li></ul>
NUTS AND SEEDS	<ul style="list-style-type: none"><li>•use smooth peanut butter or other nut pastes rather than jam or Vegemite</li><li>•use hummus or tahini as a dip or spread</li><li>•eat whole roasted nuts as a snack</li><li>•use in baking (e.g. almond meal)</li></ul>

CARBOHYDRATES

Around 50% of all calories in a CF diet should come from carbohydrates. Your dietitian will be able to recommend your child’s specific daily requirement, in grams, based on their energy needs.

Low carbohydrate diets such as the ‘Paleo diet’ are popular in the media at the moment, however, these may be dangerous for people with CF, particularly children, who have difficulty with digestion and absorption of nutrients and energy.

Carbohydrates are the easiest form of energy for the body to digest. They are naturally found in breads, cereals, grains, legumes, dairy products, fruit, starchy vegetables, and in small amounts in non-starchy vegetables.

They are also found in other foods such as candies, sweetened drinks, sauces and condiments. The term carbohydrate refers to a chemical structure and it includes sugars and starches.



## CARBOHYDRATES CONTINUED...

Starchy foods such as breads, pastas, crackers, rice, legumes, and vegetables like potatoes, are great energy sources and should be included at most meals and snacks.

The energy from starches is released into the body more slowly than the energy from sugar because it takes the body longer to digest it; however, it is still digested faster than the energy from fats and protein.

Sugar has had a lot of discussion in the media lately and it has not always been portrayed accurately. Sugar is naturally occurring in many healthy foods (fruit and dairy products) and is a healthy inclusion in the diet.

Sugar that is added to food can be an issue if it is consumed in large quantities, but a small amount is ok.

As children with CF often have increased energy requirements, there can sometimes be more 'room to move' with intake of certain nutrients than for the general population. You are best off speaking to your CF team for individualized advice for your child.

## FIBRE

When we talk about dietary fibre, the term 'fibre' refers to the part of the food which is not digested by the body and remains intact throughout its passage in the digestive system.

It is a particularly important part of the CF diet as it helps form and move stools through the digestive tract, decreasing the chance of bowel blockages.

A high fibre diet not only helps prevent or minimize risk of DIOS (Distal Intestinal Obstruction Syndrome) and constipation, it helps to maintain a healthy microbiome – in other words it helps to keep the good bacteria (probiotics) that lives in your bowel, healthy.

As we learn more about the microbiome, we are learning that it may play an important role in supporting our immune system. Fibre is usually found in foods which contain carbohydrates and there are some sources of fibre in the table on page 17.

To maximize your child's intake of fibre, choose whole grain foods over white, leave edible skins on fruits and veggies, add nuts and seeds to dishes or enjoy them as snacks and choose pulses and legumes at least once a week.

Talk to your dietitian regarding how many grams of fibre per day to aim for.

## Sources of Fibre

EXAMPLES	GRAMS OF FIBRE PER 100G
oatmeal	10g
nuts, e.g. almonds	12g
beans	5g
lentils, e.g. red	8g
fruits, e.g. apple, skin on, and strawberry	2g
orange	2g
vegetables, e.g. carrot	3g
broccoli	3g
potato, skin on	3g
brown rice	2g
whole wheat bread	7.5g
whole wheat pasta, weetbix	10.5g

### PARENTS TIP

In order to neutralise the idea of taking vitamins, our whole family takes them too, so that it becomes a family routine and not just for my child with CF.

## VITAMINS AND MINERALS

### FAT SOLUBLE VITAMINS

People with CF, particularly those with pancreatic insufficiency, often have deficiencies in 'fat-soluble' vitamins A, D, E and K due to the body's limited or total inability to absorb these vitamins.

Deficiencies could affect the health of your child's blood, bones and eyes, as well as the body's ability to fight infections; therefore, most children with CF will need to take vitamin supplements.

The table on page 18 details each of the fat-soluble vitamins, their health benefits and food sources.

### VITABDECK

VitABDECK is a specific multivitamin that is generally prescribed to people with CF.

To enhance absorption, fat-soluble vitamins should be taken with enzymes and a fat-containing food or drink. If VitABDECK is not well tolerated, separate supplements may be used.

Your child's CF care team will be able to provide advice on your child's required vitamin supplementation. Vitamin levels should be checked at least once a year at annual review and more frequently if indicated.

## Fat Soluble Vitamins

VITAMIN	BENEFIT	FOOD SOURCES
<b>VITAMIN A</b>	<ul style="list-style-type: none"> <li>• supports immune function, normal vision, bone and tooth formation, cell function and immunity</li> <li>• it works to help fight infections and to keep the intestines healthy</li> </ul>	<ul style="list-style-type: none"> <li>• liver, egg yolk, whole milk and fortified low fat milk, fortified cereals, dark coloured fruits and vegetables (carrot, sweet potato, spinach, broccoli, apricot, rockmelon and peaches)</li> </ul>
<b>VITAMIN D</b>	<ul style="list-style-type: none"> <li>• helps build and maintain strong bones and teeth</li> <li>• without enough vitamin D, bones can become thin and brittle</li> </ul>	<ul style="list-style-type: none"> <li>• the major source of vitamin D in Australia is exposure to sunlight, while small amounts come from foods such as fortified cereals and fortified soy products, fish (e.g. mackerel and canned sardines), fish liver oils (e.g. cod liver oil)</li> <li>• dairy products may not be made with vitamin D fortified milks, so be sure to read labels</li> </ul>
<b>VITAMIN E</b>	<ul style="list-style-type: none"> <li>• is an antioxidant and is important for nerve and muscle function</li> <li>• helps keep red blood cells healthy, fights infection and maintains the health of the intestines</li> </ul>	<ul style="list-style-type: none"> <li>• wheat germ, nuts, eggs, vegetable oils, green leafy vegetables &amp; fortified cereals</li> </ul>
<b>VITAMIN K</b>	<ul style="list-style-type: none"> <li>• important for blood clotting and bone health</li> </ul>	<ul style="list-style-type: none"> <li>• green leafy vegetables (spinach, broccoli), liver, soya beans and canola oils</li> </ul>

### PARENTS TIP

We started by cutting the salt tablets into quarters with a tablet cutter and then put each quarter into a teaspoon with Yogo, which my daughter loves. Takes away the saltiness and adds some sweet.

## SALT

Children with CF lose large amounts of sodium and chloride (minerals that make up salt) in their sweat. As the body can not make sodium or chloride, it must be supplied through diet and/or supplements.

Not getting enough salt can interfere with growth, reduce appetite and cause stomach pain and dehydration.

*Signs of dehydration are:*

- feeling tired
- moody/grumpy
- headaches
- poor concentration
- salt crystals on the skin
- nausea/vomiting
- decreased appetite
- muscle cramps
- dark urine colour
- thicker, harder to clear mucus

If your child becomes dehydrated, see a doctor as soon as possible or contact your child's CF clinic. In the interim, give them plenty of fluids such as water, or sports drinks such as Hydrolyte which has a high sodium content.

*Tips for avoiding dehydration include:*

- add table salt to food
- encourage your child to always carry a water bottle

- eat salty foods like Vegemite, pretzels, soy sauce, tomato sauce, chips and nuts
- use plenty of sauces, gravies and condiments
- choose the 'salted' varieties of foods
- drink sports drinks such as Hydralyte
- take salt tablets
- crush salt tablets or use table salt in electrolyte drinks – freezing this will make an ice slushy

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.

Some parents have found that the salt tablets can make their child vomit which can be a normal reaction to the salty taste. Often these parents stick to using salt solution. The exact amount of salt replacement varies for different children according to their symptoms, dietary intake, the climate they live in and their level of physical activity.

Further increased amounts of salt may be required when they are unwell, if they are eating less or are having tube feeds, if they are engaging in excessive exercise or are living/holidaying in a hot climate.

Extra salt can be consumed by adding table salt to meals and eating high salt foods. Food labels will tell you how much sodium is in foods; foods that are higher in sodium are higher in salt.

*The adjacent table provides some ways to include salt in your child's diet.*

### CALCIUM

Calcium is needed daily by everyone. It is essential for strong bones and teeth.

As the body can not make calcium, it must be supplied through diet and/or supplements. If your child doesn't get enough calcium through his or her diet, the body will start taking calcium from the bones, increasing the risk of bone breakages.

Currently, the recommended daily intake for people with CF is the same as that for the general population, which is approximately 500mg per day for children aged 3 years of age, 700mg per day for children aged 4-8 and 1,000mg per day for children age 9-12.

Some children with CF may have calcium malabsorption so need extra calcium in their diet, particularly those with low bone mineral density.

You should be guided by your child's CF care team on his or her specific requirements. The main source of calcium comes from dairy foods and drinks, such as yoghurt, milk, cheese and ice cream. Dark green vegetables, calcium fortified orange juice and some cereals contain calcium, too.

### Salty Food Suggestions:

SALTY FOODS/ SUPPLEMENTS
chips
pretzels
rice crackers
white bread
salted nuts
sauces (e.g. tomato, soy)
stock cubes
bacon
cup a soup
baked beans
Vegemite
salt tablets
sports drinks

### Suggestions for Foods Containing Calcium:

Calcium	Approx. Calcium content in mg per 100g/100ml
calcium fortified milk (e.g. Lite Start, Shape, Pura tone)	120
yoghurt	100
tinned salmon with bones or sardines	277 – 382
cheese (cheddar)	721
calcium fortified soy milk	190
custard	145
ice-cream (full cream or low fat)	127
almonds	248
tofu	683
meat (beef)	20
eggs	25mg per egg
baked beans	31
oranges	38mg per orange
bread, whole wheat	138 (approx. 40mg per slice)
cottage cheese	61
broccoli	40
spinach	33 (approx. 3 cups)
dried apricot	55 (approx. 4mg per apricot)



# FAT BOOSTING

Often children with CF will struggle to gain weight and so eating foods which are higher in fat is the easiest way to achieve this.

Adding fats to your child's meals will increase the amount of calories without having to increase how much food is consumed. This is known as 'boosting' the calories in the food (for example, if you added 2 tablespoons of peanut butter to some celery, that's an extra 20g of fat in the snack).

Here are some items which can be used to add more calories to your child's snacks and meals:

FAT BOOSTERS
olive oil
coconut oil, sesame oil
avocado
chia seeds, flax seeds, pumpkin seeds
cashew nuts
natural peanut butter, almond butter
butter
mayonnaise
sour cream, grated cheese
cream, cream cheese

## Other fat boosting suggestions:

USE HILO OR FULL CREAM MILK	<ul style="list-style-type: none"><li>• Much higher in calories than skim milk. Use with everyday meals like porridge, cereal, or mashed potatoes.</li></ul>
AVOID 'LOW FAT' AND 'FAT FREE' FOODS	<ul style="list-style-type: none"><li>• You're better off with the normal versions of these foods. Always choose full fat dairy and salad dressings.</li></ul>
ENCOURAGE YOUR CHILD TO EAT MORE OFTEN IF UNABLE TO EAT A LOT	<ul style="list-style-type: none"><li>• Aim to give your child six smaller meals rather than three big meals a day, which may be too filling.</li></ul>
PROVIDE HIGH CALORIE DRINKS	<ul style="list-style-type: none"><li>• Milk, milkshakes, hot chocolate and nutritional supplements.</li></ul>
ADD SAUCES	<ul style="list-style-type: none"><li>• Sauces, gravies, dips or toppings can add lots of calories to food.</li></ul>
HAVE READY-TO-EAT SNACKS HANDY	<ul style="list-style-type: none"><li>• yoghurt, nuts, cheese, dips, mini muffins.</li></ul>
BOOST FRUIT AND VEG WITH HIGH CALORIE ITEMS	<ul style="list-style-type: none"><li>• Eat vegetables that are naturally high in fat (avocados, olives, coconut).</li><li>• Add butter or a cheese sauce to veggies (you can also add salt; this doesn't increase the calories but it does add more flavour).</li><li>• Make a smoothie by mixing fruit, whole milk (or non-dairy option if dairy isn't tolerated) and ice cream together. Chia seeds, flax seeds, pumpkin seeds, avocado or peanut butter can also be great additions to smoothies.</li><li>• Add items such as nuts, seeds, croutons, hard boiled eggs and cheese to salads.</li></ul>

## CYSTIC FIBROSIS-RELATED DIABETES AND DIET

Cystic fibrosis-related diabetes (CFRD) is a type of diabetes that some people with CF may develop.

It is different to other types of diabetes and is caused by damage to the pancreas over a period of time.

It is genetic and may be triggered by an exacerbation and treatment of an infection and/or be a gradual onset. CFRD is not related to diet.

One of the pancreas' main jobs is to make and secrete a hormone called insulin. Insulin is needed to move glucose from the blood into the body's cells to be used for energy.

A lack of insulin, or insulin resistance, causes blood glucose levels (BGLs) to rise. High BGLs are known as hyperglycaemia. In a person with CF symptoms may include:

- a lack of energy
- a decrease in lung function
- weight loss
- increased hunger
- excessive thirst
- increased urine output

Hypoglycaemia or a 'hypo' is when the opposite occurs and BGLs drop too low.

*Signs of a hypo can include:*

- hunger and feeling shaky
- sweating
- fainting
- restless/irritable
- anxiety

Insulin and other diabetes medications are used to keep BGLs at near-normal levels. This is very important as poorly controlled BGLs can lead to increased hospitalisations, worsening of lung function and poor weight gain.

If your child is diagnosed with CFRD, they will more than likely still require the high energy diet they needed previously, however, will now also need to monitor foods which affect BGLs.

Children over the age of 10 should be tested annually for the development of CFRD, and if there is a positive diagnosis, there will be a 6-monthly dietary review.

Everyone is different and so individualised dietary advice from a specialist diabetes educator experienced in the management of CFRD is essential.



## Dietary supplements

### PROBIOTICS

There are both 'good' and 'harmful' bacteria naturally occurring in the body.

The balance of these bacteria may be disturbed by antibiotics, infection, stress, poor diet and illness.

Probiotics are 'good' bacteria that can assist in balancing bacteria in the gastrointestinal tract and may also aid digestion, reduce intestinal inflammation and minimize symptoms of reflux.

Probiotics come in various forms including yoghurts, capsules or tablets, beverages and powders.

Probiotics have been found to be both safe and beneficial in people with CF, with results showing:

- reduced inflammation
- reduced exacerbations
- increased lung function
- increased gastrointestinal health

Probiotic supplements may be most beneficial during and immediately after, antibiotic use.

At times when your child isn't on antibiotics, daily sources of 'good' bacteria through his or her diet (e.g. yoghurt) should suffice instead of paying for supplements which become expensive over time.

It is important to note that probiotics will not affect the work of the antibiotics; if anything, antibiotics may affect the effectiveness of the probiotics.

It is highly recommended that you speak to your child's CF care team before starting any new supplements.

### FISH OIL

Fish oil has many great health benefits. It may be beneficial to your child's general health, however, there have been no significant biochemical or clinical improvements in CF symptoms.

## SUPER FOODS

Super foods are types of foods which are thought to have a very high content of certain nutrients.

Typically, these food sources are high in antioxidants and essential nutrients. However, there is no official definition of what a super food is and, quite often, the foods which are referred to as super foods contain similar nutritional profiles to other foods which are less expensive and less trendy.

For example, quinoa (\$2.00 per 100g) has a very similar nutritional profile to rolled oats (\$0.16 per 100g). If you enjoy these foods, then by all means continue to consume them.

If you are unable to afford the latest super food, you are not doing your child's body a disservice; remember that the key to good nutrition is having a variety of different foods.

Since the term has been introduced, many companies have abused the label in order to promote their products.

New products such as spirulina, wheatgrass, maca and so on may have certain health benefits, however, they have no specific proven CF nutritional benefits, and can be an unneeded costly expense for many families



# 5.

## Bowel health

### BOWEL MOVEMENTS

CF can cause your child to have runny, pale, bad smelling stools, however, good enzyme management should help to minimize these symptoms.

Sometimes it can be difficult to talk about bowel habits, particularly when having to describe them. A useful tool for this can be the Bristol stool chart which provides a reference framework for talking about stools.

It is a good idea to have a look at your child's poo every now and then and encourage your child to do the same as he or she gets older so they learn what a 'healthy' poo should look like.

Everyone has different bowel habits. The range for normalcy can vary anywhere from 3 per day to 3 per week.

Many factors can affect regularity from day-to-day such as diet, hydration, travel, medications, hormonal fluctuations, sleep patterns, exercise, illness, surgery, stress, and more.

Most children with CF will experience constipation or diarrhoea at one time or another. This is often due to a miscalculation of enzymes over a couple of days.

### DIARRHOEA

Diarrhoea can cause a loss of valuable nutrients and calories from food. It may result from not having enough enzymes, viral or bacterial infections from antibiotic use.

A combination of dietary changes and fluid can often help regulate bowel motions. Diarrhoea can lead to the inadequate uptake of nutrients from food which the body needs for maintenance and growth.

### CONSTIPATION

Constipation may result from having too many enzymes. Treatment of constipation may include increasing dietary fibre, sodium and fluid intakes. Your child's CF care team may prescribe laxatives.



## DISTAL INTESTINAL OBSTRUCTION SYNDROME

Distal Intestinal Obstruction Syndrome (DIOS) is a complication of CF. It occurs when faecal material and intestinal contents stick to the lining of the intestines and cause a blockage.

*Symptoms can include:*

- cramps
- abdominal pain
- bloating
- hard stools
- a reduced amount of bowel movements
- loss of appetite
- vomiting

Symptoms can be similar to constipation, however, DIOS is not constipation and can have very serious consequences. In confirmed DIOS, there is usually a complete blockage of the bowel. Sometimes a hard mass can be felt on the right side of the abdomen.

DIOS needs to be diagnosed with an abdominal X-ray. Children may be prescribed laxatives or stool softening medications by the CF care team to treat DIOS.

*Risk factors for DIOS:*








- babies born with a meconium ileus (bowel blockage at birth)
- children who have had bowel surgery

- previous cases of DIOS
- change in diet
- illness/exacerbation
- dehydration in hot weather

*Ways to minimize the risk of DIOS are:*

- ensure enzymes are correctly matched to fat intake
- ensure enough fluids are given to prevent dehydration
- ensure your child has enough salt in warm weather
- include adequate fibre in his or her diet

## BRISTOL STOOL CHART

TYPE 1		Separate hard lumps, like nuts (hard to pass)
TYPE 2		Sausage-shaped but lumpy
TYPE 3		Like a sausage but with cracks on the surface
TYPE 4		Like a sausage or snake, smooth and soft
TYPE 5		Soft blobs with clear-cut edges
TYPE 6		Fluffy pieces with ragged edges, a mushy stool
TYPE 7		Watery, no solid pieces. Entirely liquid

# 6.

## Nutrition when unwell

If your child is unwell they will need a lot more energy than normal, even though they may not feel like eating.

Food plays a vital role in recovery and in fact the body needs MORE food when a person is unwell.

## LOSS OF APPETITE

To increase your child's appetite, you can try the following:

- encourage to eat something every couple of hours during the day
- keep food on a small plate as a large full plate may be overwhelming - he or she can always take seconds
- gentle physical activity can stimulate appetite - take your child for a short walk around the house or the block
- Try including some nourishing drinks

## Snack ideas for a poor appetite:

- milk and milk drinks (smoothies, milkshakes, Milo, Sustagen, Quick)
- yoghurt, custard and ice cream
- fruche, Yogo and other dairy desserts
- fresh or dried fruit

- nuts and/or seeds
- cheese and biscuits
- peanut butter on bread
- cream soups
- hard boiled eggs
- crumpets, muffins, pikelets or scones with jam, honey, syrup, butter or cream
- dips made with cream cheese, beans or sour cream
- sandwiches
- cakes and biscuits

## NAUSEA

To combat nausea, you can try the following:

- encourage your child not to skip meals - an empty stomach can make nausea worse
- speak to his or her CF care team about anti-nausea medication
- to reduce bad mouth tastes, encourage your child (age 3 and upwards) to suck on sugar-free hard boiled lollies or peppermints
- encourage him or her to avoid laying down or leaning back in a chair for at least 1 hour after eating



**Snack ideas for nausea:**

- cold or room temperature food, as these do not taste or smell as strong, e.g. sandwiches, salads, custard, mousse, yoghurts, tinned fruit and jelly
- dry food such as biscuits, noodles, cereal, toast and crackers
- salty foods such as clear soup and potato crisps
- cold, clear fluids between meals such as cordial, lemonade, dry ginger ale or fruit juice
- foods or drinks that contain ginger such as ginger ale, tea or candied ginger

**MAKING UP FOR LOST CALORIES**

Following a period of nausea and/or loss of appetite, your child may need to make up for lost calories.

**Here are some tips to do so:**

- treat your child to his/her favourite foods and allow them the opportunity to eat them at any time of the day, e.g. breakfast foods at dinner
- choose drinks that are high in energy and protein, e.g. milk or milk-based drinks or commercial supplements such as Sustagen or Ensure
- there may be times of the day when your child feels more like eating - make the most of these times by encouraging him/her to eat well
- cook with higher energy foods so that the meals are higher in calories, such as:
  - » full cream dairy products, e.g. milk, cheese, yoghurt, cream, ice cream
  - » margarine, butter, salad dressings, oil

- » meat, fish, chicken, eggs, legumes
- » nutrition supplements

**SUPPLEMENTAL FEEDING**

If, despite having a good, high calorie diet, your child is struggling to put on weight, the CF care team may decide he or she needs a form of supplemental feeding to help gain weight.

Supplemental feeds can be delivered directly through a feeding tube via the nose, known as a nasogastric tube (or NG tube) or directly into the stomach through a surgically placed a feeding tube known as a Percutaneous Endoscopic Gastrostomy (or more simply, a PEG). A PEG may be used if the CF team thinks that supplemental feeding will be required for a longer period of time. This allows high calorie liquid meals to be delivered directly into the stomach.

Feeds can be given while your child is sleeping and allow more freedom to enjoy normal meals and activities during the day. Although having a PEG may seem daunting, it can be really helpful in enabling your child to gain weight and take off a lot of pressure around food and eating.

The procedure for inserting a PEG is usually uncomplicated and doesn't require extensive surgery or a long hospital stay. PEGs are also quite discrete and are likely to go unnoticed under your child's T-shirt.

**HOSPITAL ADMISSIONS**

During admissions, it is important for your child to eat well and maintain their weight (or gain). Here are some tips to help manage your child's weight during an admission:

<b>BREAKFAST IDEAS</b>	<ul style="list-style-type: none"><li>» choose a high protein choice everyday, e.g. eggs</li><li>» add cream to porridge and coffee</li></ul>
<b>MAIN COURSE IDEAS</b>	<ul style="list-style-type: none"><li>» eat the meat/meat alternatives and/or dessert before veggies (if appetite is poor)</li><li>» add butter or margarine to the veggies</li><li>» add cream to soup</li><li>» ask for a double serve of the protein part of the meal</li><li>» choose a sandwich as well as the hot meal or salad</li></ul>
<b>DESSERT IDEAS</b>	<ul style="list-style-type: none"><li>» order 2 or 3 dessert options</li><li>» order a side of ice cream, cream, or yoghurt</li></ul>
<b>SNACKS</b>	<ul style="list-style-type: none"><li>» ask for your child's favourite snacks</li><li>» ask visitors to bring favourite snacks</li><li>» keep snacks within easy reach</li><li>» don't rely on your child's appetite - encourage eating something every 2-3 hours</li></ul>
<b>NUTRITIOUS DRINKS</b>	<ul style="list-style-type: none"><li>» when your child's appetite is poor, it may be easier to drink than eat - nutritious drinks include:<ul style="list-style-type: none"><li>» plain or flavoured full cream milk</li><li>» Milo made with milk</li><li>» milkshakes</li><li>» nutrition supplements, e.g. Sustagen</li></ul></li></ul>

# 7.

## Learning to swallow tablets

Many children with CF are able to learn to swallow their enzymes whole between the ages of 3 and 7.

Some children learn faster than others and it is a skill which develops with practice. As a parent, you can help your child learn to swallow tablets. The lolly method is a frequently used training tool.

### THE LOLLY METHOD

Using different sized lollies as 'tablets', teach your child to swallow the 'tablets'. Start with small lollies and work your way up in size. Your child should be able to swallow water without dribbling before starting this process.

Lolly 'tablets' to use starting from the smallest:

1. Nerds/silver cake decorations
2. Mini M&Ms/Mini Skittles
3. Tic-Tacs
4. M&Ms/Skittles
5. Eclipse Mint/Jelly Belly
6. Jelly beans

### PARENTS TIP

When we were teaching our son to swallow enzymes, we would empty out the contents of a capsule and fill it with 100s and 1000s, which he loved.

1

Begin with the larger size lolly 'tablet' that you know your child can swallow. Tell him or her to place the 'tablet' as far back on the tongue as possible, take a drink of water from a cup and swallow the 'tablet'- have as many practices as needed.

Most children will manage swallowing these lollies easily- praise your child for trying and achieving. It is better not referring to them as lollies during practice as lollies rarely trigger anxiety and the skill may not be transferred to medications.

2

He or she should swallow the 'tablet' 5 times in a row. Continue using the same sized 'tablet' until this is achieved. If only successful 4 times, continue with the same sized lolly until you have 5 successes.

Sessions should last 10-15 minutes; do not prolong the practice if your child becomes upset. Keep in mind the amount of water your child drank and the degree of anxiety the procedure caused.

3

If you move to a bigger-sized lolly 'tablet' and your child is unsuccessful, return to a smaller size and end the session on a positive note.

4

In the next session, always begin with the first sized lolly 'tablet' used at the first session. If he or she has success on the first attempt, move immediately to the next size.

Try practice sessions, ensuring you always have five successes before re-trying the next size that he or she was unable to swallow. Some children are able to swallow all the sizes in one session; others need 2 to 6 practice sessions.

5

Progress from lolly 'tablets' to actual medications.



# 8.

## Food refusal and non-compliance

### PARENTS TIP

Little children like to be independent, so if time permits have a whiteboard you can write on and they can tick off when they have their meals and tablets.

Food refusal and non-compliance with eating are common behaviours in children and may make it difficult to achieve recommended daily food intake required for a child with CF.

Children with CF often have significantly longer meal and chewing times, and are often less willing to try new foods than children who don't have CF.

It is important to be consistent with your approach and make meal times a positive experience and an enjoyable family event (even if it doesn't feel like it!).

The Ellyn Satter Institute website has a wonderful collection of resources and articles for parents who are trying to establish healthy eating behaviours with their children.

[Ellynsatterinstitute.org](http://Ellynsatterinstitute.org)

### STRATEGIES

#### Ignore bad behavior

An appropriate strategy for dealing with a child's refusal to eat is to ignore the behavior and not offer anything more to eat or drink until the next scheduled meal or snack, even if enzymes have already been given.

Enzymes given without food occasionally will not harm your child. If food refusal is a big problem, it may be helpful to give a small amount of enzymes at the start, and if the meal is eaten, give more during the meal.

Although this may seem hard because of the importance placed on adequate growth and nutrition for children with CF, try not to fall into the trap of using short-term strategies, such as coaxing to eat or specially preparing favourite foods, as this will not help prevent long-term food issues.

Constantly telling your child to drink or eat more becomes stressful and adds to existing family tension triggered by food and eating.

#### Hide your anxiety

It is also useful to hide your anxiety. If you are anxious about your child not eating enough, he or she can pick up on this and realise they have power over meal times. If you are feeling really anxious and worried about your child's eating habits, it is worth seeking out someone to talk to, starting with your child's dietitian. Other parents often have lots of helpful advice, too.

#### Set meal time limits

Encourage your child when eating, but do not let meal times drag on, otherwise one meal quickly runs into the next. It may be helpful to set a time limit of no more than 20–30 minutes. Don't threaten, nag or yell. Use verbal praise and direct commands.

#### Have good meal time routines

Routines help your child know what is coming and allows them to be prepared.

#### Tips for good meal time routines include:

- encourage your child to sit down while eating
- aim for the family to eat together as much as possible as this models good eating habits
- if TV or other devices are distracting, keep them turned off while your child is eating
- avoid allowing your child to fill up on empty calories (such as lollies or juice) in between meals so they are hungry at meal times
- have set meal and snack times each day - 3 meal and 2 or 3 snack times each day is a good routine to have

#### Encourage food engagement

Allowing your child to help prepare some of the meal can encourage an

interest in food and eating. You can talk about the food, how it is grown, why it is good and so on. You may want to start a veggie patch in your garden and have your child help pick the food.

Continue offering new foods from all the food groups, but don't be disheartened if your child rejects the food. It can take over 10 tries for a toddler to accept a new food and this may be similar with older children too.

#### Use reward charts

Reward charts can be a great way to encourage a behaviour you want from your child or to change a tricky behaviour.

They can involve earning stickers, ticks or tokens (whatever your child will respond to) each time he or she completes the skill or behaviour you want.

A certain amount of stickers can equal an agreed reward. For younger children, make the collection of stickers or ticks a daily thing, with the reward being given at the end of the day. For older children, a weekly collection of points or stickers can then result in the reward.

Children can lose motivation if there is too much time between the stickers and the reward, so small, frequent rewards can work better for younger children.

Rewards should be discussed with your child and can involve simple things like family bike rides, staying up later, buying a new book or a small toy.

For younger children, a lucky dip box filled with very small prizes or rewards written on paper might work well.

For older children, you can set up a reward menu with a selection of rewards that your child can spend the stickers or ticks on. For example, 5 ticks = a trip to the park or time playing PlayStation.

As soon as the good behaviour occurs, give the sticker to your child and back it up with specific praise e.g. "You ate most of your breakfast without getting distracted, great job!"

If there are times when the behaviour is not shown, just move on and aim to stay positive.

You can say, "You can try again next time" instead of, "You won't get any stickers if you take so long to eat your breakfast."

If your child has improved the behaviour you were aiming for, you can move on from the chart and

gradually phase it out after a few weeks, or you could increase the time or the tasks required to earn the stickers. There is a huge range of reward charts available online.

With older children, where reward charts may no longer be enticing, education often becomes the main strategy to encourage compliance:

- › educate your child about the importance of nutrition and the medications needed
- › encourage a good relationship with the CF care team
- › empower your child - he/she can have the control to manage CF through a good diet and medications, and will experience the benefits of compliance or consequences of non-compliance
- › gradually increase your child's responsibility over his/her own health to develop good self-care skills in the future

#### PARENTS TIP

At age 3 we were struggling with compliance so started a lucky dip system. We went out and bought heaps of different little presents, wrapped them up, and once our son did the new behaviour he got a lucky dip prize.

## Exercise and diet

# 9.

Exercise is highly recommended for children with CF as it helps clear mucus, increases lung muscle strength and assists with bowel regularity.

Exercise does, however, also increase energy needs even further so it is important to replace the lost energy, water and salt through diet.

Ensure you speak to your child's CF care team so they can ensure your child is following a suitable diet for his or her activity levels.

### HYDRATION

Children with CF are more susceptible to dehydration because of the increased amount of salt lost through sweat. They are also known to have a lowered thirst drive so may need to be reminded to drink regularly.

Children should drink 2-3 litres of fluid a day to remain hydrated, and when playing sport or exercising should drink:

500-600mL 2 hours before exercise
150-350mL right before exercise
150-200mL every 15-20 minutes during exercise

Sports drinks are beneficial during exercise, especially in warmer weather. Benefits of use include:

- the salt content increases thirst drive and voluntary fluid intake
- improved fluid retention post exercise
- a good source of calories
- improves gastric emptying (the time it takes for food to empty from the stomach and enter the small intestine)

During exercise, hydration is a priority and if exercising for more than an hour, sports drinks and oral rehydration solutions are a good option.

It is important to be aware that although they have a place with exercise, sports drinks are not necessarily recommended on a daily basis due to the high sugar content in many of them.

They are also often not overly high in salt either. Hydralyte Sports is considered the most effective sports drink for rehydration because of the high sodium (salt) content (115mg/100mL).



## FOOD BEFORE AND AFTER EXERCISE

You should always make sure your child is well fed before and after exercise.

A light snack about one hour before exercising is a good idea, and another one within an hour of completing exercise. The snack should be a familiar food that is well tolerated (won't upset their stomach).

*Here are some snack ideas:*

Snack idea	Calories	Fat (g)	Carbs (g)	Protein (g)
mixed nuts (30)	285	26	9	6
Up and Go drink	198	3.8	30.2	8.5
muesli bar - Carman's Original	201	8.6	25.5	4
slice multigrain bread with banana	198	1.2	37	5.2
canned tuna (95g) Greenseas	94	1.8	6.7	12.2
Sustagen Sport chocolate flavour (60g)	225	0.7	39.2	14.7

Post exercise, you should aim to provide a snack which will help to replace all losses your child has sustained through exercise. The food should ideally contain some carbohydrates and protein.

## PARENTS TIP

“ Play schools at home before your child starts school. Eat lunch from a lunchbox with enzymes and talk about washing hands and what sort of things will happen at school. ”

# 10.

## Managing the CF diet at school

The thought of your child starting school can be very overwhelming as you have to trust another person to attend to your child's medical needs.

Communication with the school is key to set up good routines to manage your child's diet and enzyme needs while at school.

It is important to communicate regularly with the school, be clear about your child's needs, and be realistic about what teachers can do.

Educating the staff is an ongoing process and needs to be reviewed each year, or if there is a change in class teacher, during the year.

You will need to consider creating a medical plan with the school to discuss how your child's medication will be administered and ensure the staff understand your child's exact dietary requirements.

*You may wish to consider:*

- Does the school have 'crunch and sip' time? Will your child need an extra snack during this time and will the school support this?
- You may like the teacher to make reference to the CF diet if the class will be learning about healthy eating (as this can sometimes cause confusion for children with CF on a high calorie diet)
- Are flatulence/toilet habits an issue? Does he or she need easy access to the toilet?
- How will enzymes be administered? And where will they be kept?
- Will salt tablets need to be administered and reminders needed for your child to keep hydrated with water?

Go to [www.cfsmart.org](http://www.cfsmart.org) for more information on managing CF at school.



## PARENTS TIP

Plan meals in advance, have a weekly menu for meals for all family members.

## Making the CF diet work for the **whole family**

Many families face the challenge of cooking for family members with various dietary needs, including CF, and it is important to find ways to prepare healthy meals for all family members.

In order to make a meal that is suitable for the whole family, try making meals that combine good quality fats and carbohydrates so they contain good nutrients for everyone.

You may still need to adjust the serving size or ingredients used within the meal to ensure everyone is getting the amount of food that is right for their individual needs. It may also be useful to:

- › keep both non-fat and full fat options in the refrigerator such as milk, cream cheese, yogurt, salad dressings and cheeses
- › add salt to the meal of the person with CF once the meal is served to avoid adding too much to a family meal
- › add extra calories to the meal of the person with CF once the meal is served such as avocado, nuts, olive oil or butter

On the following page are a few examples of how to adjust recipes to cater for the whole family.

### Catering for the Whole Family

SPAGHETTI BOLOGNESE	
SOMEONE WITHOUT CF 712 CALORIES	1 1/2 cups pasta 3/4 cup sauce 2 large meatballs
SOMEONE WITH CF 925 CALORIES	1 1/2 cups pasta 1 1/2 cups sauce 1 teaspoon olive oil 2 tablespoons grated cheese 3 large meatballs
SANDWICH	
SOMEONE WITHOUT CF 323 CALORIES	2 slices of ham 2 slices of cheese low fat mayonnaise
SOMEONE WITH CF 509 CALORIES	4 slices ham 4 slices cheese full fat mayonnaise
FRUIT SMOOTHIE	
SOMEONE WITHOUT CF 242 CALORIES	1 cup fresh or frozen fruit as a base 1 cup low fat yogurt 1/2 cup non-fat milk and blend
SOMEONE WITH CF 454 CALORIES	2 cups fresh or frozen fruit 1 cup whole milk yogurt 1 cup whole milk 2 tablespoons of heavy cream
SCRAMBLED EGGS	
SOMEONE WITHOUT CF 276 CALORIES	scramble 1 egg using an oil spray in place of olive oil add 30g of low fat cheese wrap in a soft tortilla
SOMEONE WITH CF 548 CALORIES	scramble two eggs in 2 teaspoons of olive oil add 60g of full fat cheese wrap in a soft tortilla

This Creamy Chicken Fettuccine recipe shows how you can create a lighter version and a higher energy version at the same time:

LIGHT PASTA	CF PASTA
<ul style="list-style-type: none"> <li>fettuccine</li> <li>1/2 tsp garlic</li> <li>1 tub light cream</li> <li>2 tbsp parmesan cheese</li> <li>1 handful cooked fettuccine</li> <li>1/2 cup chopped chicken</li> <li>dash of white wine</li> <li>shallots or chives</li> </ul>	<ul style="list-style-type: none"> <li>fettuccine</li> <li>1 tsp garlic</li> <li>2 tubs full cream</li> <li>2 tbsp parmesan cheese</li> <li>1 handful cooked fettuccine</li> <li>1-2 cups of chopped chicken</li> <li>dash of white wine</li> <li>shallots or chives</li> </ul>



**STEP 1:**

Bring a saucepan of water to boil. Add a splash of olive oil and salt. Boil fettuccine as per directions on packet (~8-12 minutes)

**STEP 2:**

Pre-heat 2 deep frying pans

**STEP 3:**

Add 1/2 tsp garlic to light pasta  
Add 1 tsp garlic to CF pasta

**STEP 4:**

Add 1 tub of light cream to light pasta  
Add 2 tubs of full cream to CF pasta

**STEP 5:**

Add 2 tbsp parmesan to light pasta  
Add 2 tbsp parmesan to CF pasta

**STEP 6:**

Add 1 handful cooked fettuccine to light pasta  
Add 2-3 handfuls fettuccine to CF pasta

**STEP 7:**

Add 1/2 cup of chopped chicken to light pasta  
Add 1-2 cups chopped chicken to CF pasta

**STEP 8:**

Add a dash of wine to each and cook until cream thickens. Add some chopped shallots or chives.

MEMBER SUBMISSION FROM 'YUMMY NUMMIES FOR CF TUMMIES'

# Sample meal plans and ideas for meals

# 12.

## SAMPLE MEAL PLAN FOR 4-7 YEAR OLDS

APPROXIMATELY 1500 CALORIES PER DAY FOR A CHILD WITHOUT CF	APPROXIMATELY 2220 CALORIES PER DAY FOR A CHILD WITH CF
<b>BREAKFAST</b>	<b>BREAKFAST</b>
1 cup cereal with 150ml milk 1 slice toast with margarine and Vegemite 150ml milk	1 cup cereal with 150ml milk 1 slice toast with margarine with Vegemite and 1/2 cup grated cheese. 150ml milk and 2 tsp Milo
<b>MORNING TEA</b>	<b>MORNING TEA</b>
1 piece of fruit 2 plain biscuits	1 piece of fruit 2 plain biscuits with margarine or cream cheese
<b>LUNCH</b>	<b>LUNCH</b>
2 slices bread with margarine and cheese and tomato 1 banana	2 slices bread with margarine and cheese, tomato, salami and mayonnaise 1 banana 1 muesli bar
<b>AFTERNOON TEA</b>	<b>AFTERNOON TEA</b>
200ml milk 2 Anzac biscuits	200ml milk and 2 tsp Milo 2 Anzac biscuits
<b>DINNER</b>	<b>DINNER</b>
1 cup of pasta 1/3 cup bolognese sauce mixed green salad 1 tub yoghurt	1 cup of pasta and 2 tsp olive oil 1/3 cup bolognese sauce and 1 tbsp of parmesan or cheddar grated cheese mixed green salad 1 slice garlic bread 1 tub yoghurt
	<b>SUPPER</b>
	150ml milk

(ADAPTED FROM 'A GUIDE TO EATING FOR CHILDREN WITH CYSTIC FIBROSIS', 2007)



### SAMPLE MEAL PLAN FOR 7-12 YEAR OLDS

APPROX 1770 CALORIES PER DAY FOR A CHILD WITHOUT CF	APPROX 2650 CALORIES PER DAY FOR A CHILD WITH CF
<b>BREAKFAST</b>	<b>BREAKFAST</b>
1 cup cereal 200ml milk 1 slice toast with margarine and jam	1 cup cereal 200ml milk with 1 tbsp milk powder and 2 tsp Milo 1 slice toast with margarine and peanut butter
<b>MORNING TEA</b>	<b>MORNING TEA</b>
2 crackers with margarine and Vegemite	2 crackers with margarine, Vegemite and 1 slice of cheese
<b>LUNCH</b>	<b>LUNCH</b>
2 slices bread with margarine, 2 slices of ham and tomato 1 packet sultanas apple	2 slices bread with margarine, 2 slices ham, tomato and mayonnaise 1 packet sultanas apple
<b>AFTERNOON TEA</b>	<b>AFTERNOON TEA</b>
200ml milk 1 banana 1 muesli bar	200ml milk and 1 scoop ice cream with strawberry topping 1 banana 1 muesli bar
<b>DINNER</b>	<b>DINNER</b>
1 small chicken breast, grilled 1 potato corn on the cob broccoli 1 tsp gravy 100g custard	1 Chicken Kiev 1 potato and corn on the cob with 3 tsp margarine broccoli 1 tsp gravy 200g custard
<b>SUPPER</b>	<b>SUPPER</b>
200ml milk	200ml milk with 1 tbsp. milk powder and 2 tsp Milo 2 plain sweet biscuits

### MEAL IDEAS

Healthy fat containing meal ideas:

#### BREAKFAST

- » toast with eggs or avocado and sautéed veggies (mushroom, tomato, etc.)
- » buttered toast with Vegemite and a glass of milk
- » cereal with fruit and full cream milk
- » muesli with yoghurt
- » porridge with dates and walnuts
- » berry smoothie made with full cream milk and pumpkin seeds
- » vegetable omelette with cheese
- » pancakes with bananas and chopped almonds
- » bagel with salmon and cream cheese
- » beans, cheese and scrambled or fried eggs on toast

#### LUNCH

- » sandwiches with fillings such as: cheese, ham, chicken or tuna with avocado, chutneys/sauces and salad
- » veggie and feta frittata and a side salad
- » chicken and avocado salad with a slice of toast
- » tuna pasta bake with side salad
- » home made mini pizzas with cheese, meats and vegetables
- » chicken, tuna or egg & salad wrap with mayo, avocado, hummus or other dressing
- » home made nachos (with mince, kidney beans, cheese, salsa, sour cream)
- » baked beans, or sardines on toast with a piece of fruit, jacket potato with olive oil/ butter and baked beans or chili and sour cream

#### DINNER

- » quiche with meat, vegetables and cheese
- » spaghetti bolognese with grated cheese
- » fettuccini with chicken, mushrooms, onions, snow peas and creamy sauce
- » fried rice with egg, vegetables, meat and sesame oil
- » Thai style steamed fish with rice and sautéed green veggies and sesame oil
- » coconut cream curries with tofu or meat, veggies and rice
- » grilled chicken and sweet potatoes with sautéed spinach and pine nut pesto
- » steak with a creamy sauce, steamed veggies and mashed potatoes
- » fish and roasted vegetables with garlic bread
- » tacos, enchiladas or burritos with meat, guacamole, cheese, capsicum and onion





### SNACKS

- » nuts (almonds, pistachios, cashews) and seeds (pumpkin, sunflower)
- » fruit with yoghurt
- » muesli or protein bar
- » vege sticks with ricotta or peanut butter
- » tortilla chips with guacamole and salsa
- » whole grain crackers with Vegemite or avocado
- » toasted Lebanese/pita bread chips dipped in babaganouj/hummus/tzatziki
- » crackers with avocado, cheese, cream cheese, tuna, hummus or cream cheese dips
- » bread with avocado, peanut butter or other pastes thickly spread
- » hard boiled egg
- » tuna kit (comes with tuna, crackers and mayo)
- » dried fruit
- » cereal

### DRINKS

- » smoothie: full cream milk, fruit, ice cream/yoghurt - add honey or other flavourings
- » creamy milkshakes with ice cream, toppings or flavourings such as Milo
- » Sustagen and other supplement drinks

**ENRICH MILK RECIPE**

To every cup of milk add 1 heaped tablespoon of full cream milk powder and whisk until dissolved.

*OR*

To 2 cups of milk add 1 cup of evaporated milk

## Appendix: Charts for meals and medications

	MONDAY		TUESDAY		WEDNESDAY		THURSDAY		FRIDAY		SATURDAY		SUNDAY	
	MEAL	ENZYMES	MEAL	ENZYMES	MEAL	ENZYMES	MEAL	ENZYMES	MEAL	ENZYMES	MEAL	ENZYMES	MEAL	ENZYMES
BREAKFAST														
SNACK														
LUNCH														
SNACK														
DINNER														
SNACK														

	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
SALT SOLUTION/ TABLETS							
VITAMINS							
ENZYMES							
BREAKFAST							
SNACK							
LUNCH							
SNACK							
DINNER							
NIGHT FEED							
PHYSIO							
ANTIBIOTICS							
OTHER							

Useful resources,  
websites, etc.

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STATE	CYSTIC FIBROSIS CLINIC	CYSTIC FIBROSIS ORGANISATION
ACT	<b>Canberra Hospital</b> T: 02 6174 7373	<b>Cystic Fibrosis ACT</b> Postal Address: PO Box 909, Civic Square ACT 2608 T: 0401 990 111 E: info@cfact.org.au W: www.cysticfibrosis.org.au
NSW	<b>The Children's Hospital at Westmead</b> T: 02 9845 0000 W: www.chw.edu.au  <b>Sydney Children's Hospital</b> T: 02 9382 1111 W: www.sch.edu.au  <b>John Hunter Children's Hospital</b> Newcastle T: 02 4921 3670	<b>Cystic Fibrosis NSW</b> Street Address: Unit 46 Homebush Business Village, 11-12 Underwood Rd, Homebush NSW 2140 Postal Address: PO Box 4113, Homebush South NSW 2140 Free call: 1800 650 614 T: 02 8732 5700 E: admin@cfnsw.org.au W: www.cysticfibrosis.org.au
QLD	<b>Mater Children's Hospital</b> T: 07 3163 8111  <b>Royal Children's Hospital</b> T: 07 3636 3777	<b>Cystic Fibrosis QLD</b> Street Address: 31 Kate St, Kedron QLD 4031 Postal Address: PO Box 2245, Chermside QLD 4031 T: 07 3359 8000 E: admin@cfqld.org.au W: www.cysticfibrosis.org.au
SA	<b>Women's and Children's Hospital</b> T: 08 8161 7000	<b>Cystic Fibrosis SA</b> Street Address: 143-145 Sturt St, Adelaide SA 5000 T: 08 8221 5595 E: cfsa@cfsa.org.au W: www.cysticfibrosis.org.au
TAS	<b>Royal Hobart Hospital</b> T: 03 6222 8475	<b>Cystic Fibrosis TAS</b> Postal Address: GPO Box 245, Hobart TAS 7001 Free call: 1800 232 823 T: 03 6234 6085 E: general@cftas.org.au W: www.cysticfibrosis.org.au
VIC	<b>Royal Children's Hospital</b> T: 03 9345 5522  <b>Monash Medical Centre</b> T: 03 9594 6666	<b>Cystic Fibrosis Community Care (VIC)</b> Street Address: 80 Dodds St, Southbank VIC 3006 T: 03 9686 1811 E: admin@cfv.org.au W: www.cysticfibrosis.org.au
WA	<b>Perth Children's Hospital (PCH) Hospital Avenue Nedlands, WA</b> T: 08 9340 8222	<b>Cystic Fibrosis WA</b> Street Address: The Niche, 11 Aberdare Rd, Nedlands WA 6009 Postal Address: PO Box 959, Nedlands WA 6909 T: 08 6457 7333 E: info@cfwa.org W: www.cfw.org.au

<b>APPS</b>	<p><b>Calorie King®</b> A quick and easy way to check calories, carbohydrates and fats. This app contains over 22,000 Australia foods. Provides information including protein, fibre, fats, cholesterol and salt</p>
<b>BOOKS</b>	<p><b>'Sense-ational Mealtimes! Making sense of tricky mealtime behavior, fussy/picking eating and feeding difficulties®'</b> By Gillian Grieths and Denise Stapleton</p>
<b>FACT SHEETS</b>	<p>Bone Health Cystic Fibrosis Related Diabetes Dehydration Healthy Fats Nutrition for Children PEG Pill Swallowing</p> <p>All factsheets available from: <a href="http://www.cfwa.org.au/what-we-offer/resources/">www.cfwa.org.au/what-we-offer/resources/</a></p>
<b>WEBSITES</b>	<p><b>Creon®</b> <a href="http://www.creon.com/">http://www.creon.com/</a></p> <p><b>Tips for CF Parents</b> A website with a range of articles and video clips which provide parents with practical tips and strategies for dealing with different issues <a href="http://www.TipsForCFParents.com">www.TipsForCFParents.com</a></p> <p><b>CF Chef®</b> An online nutrition resource that allows those affected by CF to share, receive support, recipes and meal tips. There is also an online cook book, with meals and snacks submitted by the CF community <a href="http://www.chef4cf.com">www.chef4cf.com</a></p> <p><b>Ellyn Satter Institute</b> A website which provides information on creating healthy eating habits and attitudes in children <a href="http://ellynsatterinstitute.org">ellynsatterinstitute.org</a></p> <p><b>Eat for Health</b> Information on the number of servings recommended for children and adolescents <a href="https://www.eatforhealth.gov.au/food-essentials/how-much-do-we-need-each-day/recommended-number-serves-children-adolescents-and">https://www.eatforhealth.gov.au/food-essentials/how-much-do-we-need-each-day/recommended-number-serves-children-adolescents-and</a></p> <p><b>Eat for Health</b> Information on what an appropriate serving size is <a href="https://www.eatforhealth.gov.au/food-essentials/how-much-do-we-need-each-day/serve-sizes">https://www.eatforhealth.gov.au/food-essentials/how-much-do-we-need-each-day/serve-sizes</a></p>

	<p><b>Fun Fatty Foods®</b> Recipes from Katherine, a mum of a CF child living in Brisbane, focused on healthy, nutritious meals for children requiring high fat/calorie diet <b>Blog</b> <a href="https://funfattyfoods.wordpress.com/">https://funfattyfoods.wordpress.com/</a></p>
<b>OTHER RESOURCES</b>	<p><b>CF Food:</b> A series of resources providing information about the CF diet and nutrition for people of all ages who have CF.</p> <ul style="list-style-type: none"> <li>• Nutrition and Cystic Fibrosis: A Guide for Feeding Infants (0-2)</li> <li>• Nutrition and Cystic Fibrosis: A Guide for Feeding Children (3-12)</li> <li>• Nutrition and Cystic Fibrosis: A Guide for Young People</li> <li>• Nutrition and Cystic Fibrosis: A Guide for Adults</li> <li>• CF Cookbook: High Energy Recipes for Cystic Fibrosis</li> </ul> <p><a href="http://www.cfwa.org.au/what-we-offer/resources">www.cfwa.org.au/what-we-offer/resources</a></p> <p><b>CF Smart:</b> A series of resources for teachers, students and parents providing information about CF, in a school setting.</p> <ul style="list-style-type: none"> <li>• includes information booklets for Early Education, Primary and High School teachers</li> <li>• a short animation about hand washing - 'Good Clean Hands'</li> </ul> <p><a href="http://www.cfsmart.org">www.cfsmart.org</a></p> <p><b>CF Fit:</b> A series of resources designed to support adults and older children with CF to maintain an active lifestyle.</p> <p>3 Booklets:</p> <ul style="list-style-type: none"> <li>• 'A Guide for People Living with CF'</li> <li>• 'A Guide for Personal Trainers'</li> <li>• 'My Exercise Record'</li> </ul> <p><a href="http://www.cfwa.org.au/what-we-offer/resources">www.cfwa.org.au/what-we-offer/resources</a></p> <p><b>CF Cooking:</b> Healthy cooking demonstrations for people with CF, including how to boost energy levels, how to make healthy CF meals when tired, how to fuel up for exercise and more. <a href="http://www.cfcooking.org">www.cfcooking.org</a></p> <p>.....</p>





[www.cfwa.org.au](http://www.cfwa.org.au)

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