

Nutrition & Cystic Fibrosis

A Guide for Feeding Infants
(Aged 0 to 2 years)

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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 birth to 2 years of age.

In the beginning stages of your baby's life, you will be learning about CF, the treatment involved and what it means for your baby. It can be a very daunting time and you may experience a whole range of emotions from anger to grief.

Be reassured that things will get easier as you learn to manage the treatment your baby requires. There is also support from a variety of sources available, so don't be afraid to ask for help.

Babies can be tricky little beings at the best of times, so give yourself the chance to learn about your baby's personality, quirks and needs and also enjoy your baby.

This booklet is designed to be a general guide only. Babies with CF can be affected very differently, so your baby will have individual dietary needs which vary from other babies with CF.

Your baby'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.

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1.

Nutrition for pancreatic sufficient babies

Babies with CF can be pancreatic sufficient or pancreatic insufficient.

If your baby is pancreatic sufficient, this means that his or her body is able to digest food naturally and therefore medication to assist with digestion is probably not required. This means that generally your baby can follow a normal, balanced diet.

When feeding a baby who is pancreatic sufficient there is usually no need to add extra fat or calories to the diet, unless recommended by the dietitian.

The diet for pancreatic sufficient babies from 6 months onwards should include a wide variety of nutritious foods from the 5 food groups:

- grain (cereal) foods such as breads, cereals, rice, pasta, noodles, polenta, couscous, oats, quinoa and barley
- vegetables
- fruit

- meat and meat alternatives such as lean meats and poultry, fish, eggs, tofu, nuts, seeds, legumes and beans at age appropriate textures
- dairy foods such as full cream milk, yoghurt and cheese

As your child grows, he may require a high energy diet to assist with growth, even if pancreatic sufficient.

Pancreatic sufficient babies and children may also need salt and vitamin supplementation, and there is a chance that they can develop pancreatic insufficiency at a later date.

2.

Nutrition for pancreatic insufficient babies

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 approximately 85% of people with CF, the pancreas is blocked with mucus, which affects its ability to secrete digestive enzymes and prevents the body from breaking down and digesting food normally.

This is referred to as pancreatic insufficiency or being pancreatic insufficient. If a baby is pancreatic insufficient, the baby will require enzyme supplements to assist with the digestion of food.

Without enzyme supplements, pancreatic insufficient babies are at risk of poor nutrient absorption leading to poor growth, poor weight gain and less positive health outcomes.

Most babies will need to start having enzymes as soon as they are diagnosed with CF.

The most commonly used enzyme supplement in Australia for babies, children and adults with CF is Creon, which comes in microsphere form for babies, or as capsules for older children and adults.

Babies begin with the microspheres (Creon 5,000) and transition to capsules once they are older and learn how to swallow tablets.

The dose required will vary from baby to baby as people with CF vary in their degree of pancreatic insufficiency. Enzyme supplements are made from the pancreas of pigs and are not a drug; they are not harmful to others.

PARENTS TIP

“Don't look too far ahead, or you can become overwhelmed. It is good to stay just one or two steps ahead of what you need to do to care for your child. Sometimes you just need tunnel vision to get through the first year.”

A glass of milk and a bowl of fruit, including kiwi and strawberries, are visible in the background of the top section.

PARENTS TIP

The first 6 months were a total fog but then I soon saw that I could do this. I became organised.

3.

Feeding babies 0-6 months

Good nutrition is the first defense against infections that can occur in the lungs.

In most cases, either breastfeeding or formula feeding your baby will provide enough nutrition during the first 6 months.

Your baby's dietitian will support you whether you decide to breastfeed or formula feed, and they should be your first port of call for all things relating to your baby's eating and growth.

MILK

BREAST MILK

Breast milk is considered the best option for most babies, with or without CF, as it contains everything needed for growth and development during the first 6 months of your baby's life.

Breast milk contains antibodies which offer some protection against certain infections, such as coughs and colds, ear infections and tummy upsets.

FORMULA

For some women breastfeeding can be very difficult. Be assured that feeding your baby formula is suitable for babies with CF.

It definitely has benefits, too, as you will know the exact amount of milk your baby is having at a feed. Formula also has a higher salt content than breast milk (which is a good thing for babies with CF). In most cases, babies with CF will be able to gain weight adequately on formula milk.

NUTRIENT DENSE INFANT FORMULA

Your baby's dietitian may recommend for your baby a special high protein, high energy formula if he or she needs assistance with weight gain.

This type of formula contains extra energy and other nutrients such as protein, vitamins and minerals.

The nutrient dense formula is only available on prescription from dietitians and neonatologists.

COW'S MILK & NON-DAIRY MILKS

Cow's milk does not have enough iron in it to cover a baby's requirements in the first year. After 12 months, your baby can switch to cow's milk instead of formula or breast milk.

This should be full cream. Non-dairy milks such as soy, oat, rice, almond and coconut are not nutritionally adequate to substitute for breast milk or formula.

ENZYMES

Babies with CF who are pancreatic insufficient will need to take enzymes with food (milk) from birth.

ADMINISTERING ENZYMES

Each time your baby has a feed they will require enzymes. The dose of enzymes is based on how many grams of fat is in the feed.

Generally speaking, 1 scoop of Creon 5,000 is recommended per 4g of fat, however, you should always consult with your baby's dietitian for individual recommendations. You may need to give quarter or half scoops depending on the amount of fat.

Enzyme requirements mean your baby will need to learn to eat solids (apple purée) much earlier than other babies. This is ok, and over time, both you and your baby will learn how to do this.

Be patient and try not to worry about how much your baby has consumed in terms of milk and enzyme mixture; it will get easier with time.

When administering enzymes, the microspheres need to be mixed with a room temperature, acidic mixture such as apple or pear purée to aid absorption and digestion of the medication.

Once the enzymes are mixed with the purée, they should be administered immediately as they are only effective for 30 minutes. If you find that the feeding sessions are taking longer, you may need to spread the dosage throughout the feed.

Use a flexible plastic spoon to administer the mixture (or place or pour it into the back of your baby's mouth) and then ensure there are no enzyme spheres left in your baby's mouth, as this can cause ulcers.

You can use a large cotton tip or small flannel dipped in sterile water to assist in clearing out any granules from their gums or teeth.

If your baby spits out the enzyme mixture, gently scoop it back into his mouth until the whole dose is consumed. Then carry on feeding your baby.

How do I know the dose is correct?

Weight gain is a good indicator of how well the enzymes are working and if your baby is digesting and absorbing the feeds.

If your baby experiences any of the following symptoms, it may be a sign that his or her enzyme dosage may need reviewing by your baby's CF care team.

PARENTS TIP

I would pump into a bottle every now and then, to measure how much I'd pumped and then to see how much my baby drank.

From this I could estimate approximately how much he would be drinking from my breast on an average feed and estimated enzyme dosage that way.

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)

What if I forget to give my baby enzymes?

Don't panic if you forget to give your baby enzymes before or after a feed. There is a lot to focus on just feeding your baby, let alone having to include medication into the picture.

There is nothing drastic that can happen if enzymes are forgotten during a feed, other than possibly some discomfort and extra runny poos.

However, if enzymes are not given regularly over a period of time, the baby will experience weight loss.

ENZYMES AND BREASTFEEDING

Breastfeeding is hard enough for some mums, let alone adding enzymes into the mix.

It can take a bit of practice and getting to know your baby's feeding patterns before getting the enzyme administration exactly right. Your baby will be ok while you work this all out and get to know each other.

Talk with your baby's CF care team to figure out a routine that works well for you and your baby, such as spreading the enzyme dose throughout the feed, e.g. half the dose at the beginning of the feed and the other half when changing sides or if your baby takes a break.

When babies start sleeping through the night, your milk supply will be more and your baby could have a bigger feed first thing in the morning, so extra enzymes may be needed. Your CF care team will suggest what enzyme dosage to use.

PARENTS TIP

“I put salt in my baby’s milk. If she needed 15ml of salt per day I would spread this over her feeds throughout the day.”

SALT

People with CF lose about 2-5 times as much salt in their sweat than other people.

Loss of salt can cause dehydration and also make the mucus in the lungs thicker and more difficult to clear. Dehydration can be an issue, particularly when the weather is hotter, or with fever or infection.

To prevent dehydration, salt supplementation is usually required from birth.

How much salt does my baby need?

You should always consult with your baby’s CF care team about individual salt requirements as her needs will differ depending on factors such as symptoms, body size, dietary intake and the climate you are living in.

Salt supplementation is particularly important for breastfed babies as human milk has a lower salt content than formula.

ADMINISTERING SALT

For infants, salt solution is usually recommended. This comes in liquid form and can be added to expressed breast milk or formula, or can be mixed with water in a syringe and given to your baby throughout the day.

SIGNS OF DEHYDRATION

If your baby is lacking salt they can become dehydrated.

Signs of dehydration include:

- fewer wet nappies than usual
- dark sunken eyes
- dry skin or lips
- tearless crying
- dark yellow urine
- lethargic and drowsy
- rapid breathing
- cold and blotchy looking hands and feet
- loss in skin elasticity
- vomiting
- loss of appetite
- salt crystals on the skin



If you think your baby is dehydrated, see a doctor as soon as possible or contact the CF clinic. Dehydrated babies often need to be re-hydrated in hospital via intravenous (IV) hydration therapy. In the interim, you can offer your baby plenty of fluids such as breast milk or formula.

Try giving them smaller amounts of milk feeds more frequently. Do not give water to babies under 6 months of age unless advised to do so by your doctor or the CF team, in which case, only use water that has first been boiled and cooled.

VITAMINS

Vitamins are needed to help your baby to grow, function and fight off infection. Babies with CF often have deficiencies in 'fat-soluble' vitamins A, D, E and K.

This is due to their limited or total inability to absorb these vitamins and is particularly prevalent in babies with pancreatic insufficiency. Deficiencies in these vitamins could affect the health

of a baby's bones and eyes, as well as the body's ability to fight infections; therefore, most babies with CF will need to take vitamin supplements.

Vitamin levels should be checked at least once a year at your child's annual review and more frequently if required.

VitABDECK is a CF-specific multivitamin that is generally prescribed to people, including infants, with CF.

Vitamin supplements should be mixed in with pear or apple purée or else dissolved in a syringe with water. To enhance absorption, the mixture should be taken with enzymes and a fat-containing food or drink (milk at this age).

BOWEL HEALTH

Checking your baby's bowel movements is normal for parents to do, but is particularly important for babies with CF. The signs of malabsorption (the inadequate uptake of nutrients from food) can be revealed by a baby's bowel movements.

PARENTS TIP

“I thought malabsorption was the worst thing in the world. I learnt over time that having the wrong enzymes for a day; she will be ok. Perspective comes with time.”

Signs of malabsorption include:

- poor weight gain despite having a good appetite
- frequent, loose and/or large bowel movements
- very bad smelling bowel movements
- mucousy or oily bowel movements

If your baby has diarrhoea, they can lose a lot of valuable fluids, nutrients and calories from their food, so it is important to pay attention to this.

Diarrhoea may result from not having enough enzymes, a viral or bacterial infection, or from antibiotic use.

A combination of dietary changes (depending on age) and fluid, can often help regulate your baby's bowel motions.

Constipation may result from having too many enzymes. If your child has regular bowel problems, the CF care team will investigate to find out what the root of the problem is. Some babies may receive regular bowel washouts in hospital. These help

to clean out the bowels by removing gas and fecal matter using a saline (salt) rinse.

MECONIUM ILEUS

Meconium is a baby's first bowel movement, formed in the intestine while the baby is still in the mother's womb.

In babies with CF, the meconium is much thicker and stickier than normal and can clog part of the intestine (ileum), preventing the baby from having a bowel movement once born.

Meconium ileus must be treated immediately and in most cases the meconium can be flushed out of the bowel using an enema. More severe cases may require surgery to remove the blockage.

DISTAL INTESTINAL OBSTRUCTION SYNDROME

Distal intestinal obstruction syndrome (DIOS) is a complication of CF. It occurs when fecal material and

intestinal contents stick to the lining of the intestines and cause a blockage. DIOS is not constipation and symptoms can vary. In suspected DIOS, symptoms can be similar to constipation, with cramps, abdominal pain, bloating, hard stools, a reduced amount of bowel movements, loss of appetite and vomiting.

In confirmed DIOS, there is usually a complete blockage of the bowel and the person can experience abdominal pain, bloating and vomiting. Sometimes a hard mass can be felt on the right side of the abdomen.

Babies who were born with a meconium ileus, have had bowel surgery, or have had DIOS previously are at an increased risk of DIOS. DIOS can occur with a change in diet, illness, exacerbation (chest infection) and dehydration in hot weather. DIOS is diagnosed with an abdominal X-ray.

Ways to minimize the risk of DIOS are:

- making sure the enzymes are matched to the daily fat intake
- ensure enough fluids are given to prevent dehydration
- giving enough salt in warm weather

REFLUX

Some babies, with or without CF, can have reflux, which is the regurgitation of the stomach contents (usually milk) into the esophagus and mouth. If a baby is coughing during or after feeds, vomits large amounts after feeds or during physiotherapy, he or she may have reflux.

For babies experiencing reflux, offering smaller, more frequent feeds is recommended, or medications may be prescribed. If reflux is an issue for your baby, speak to the CF care team for further guidance.



4.

Feeding babies 6-12 months

ENZYMES

Once your baby starts solids, you will need to increase his or her enzyme dosage. To work out how many scoops to give your baby, the amount of fat in the food needs to be calculated.

This can seem very daunting and time consuming to work out at first, but will become easier over time. Your baby's dietitian can help you figure out the best way to do this.

The Nutrition Information Panel on food packaging can guide you in calculating enzymes. Look at the 'Total Fat' in the 'per serving' column. For example, as seen in the table, a packet of Farex 'Breakfast on the Go Porridge with Apple' has a total of 2.3g of fat.

There are also some excellent apps for fat counting, such as 'Calorie King', which can be downloaded for free on your phone or iPad. You can add in almost any type of food and the app will give you the fat content automatically. It also lets you adjust the volume/weight of the food item.

Farex 'Breakfast on the Go Porridge'

SERVING SIZE: 120G	SERVING PER PACK	
	Per Serve 120g	Per 100g
Energy (kJ)	360kj	300kj
Protien (g)	2.5g	2.1g
Fat- Total (g)	2.3g	1.9g
Carbohydrate (g)	13g	10.8g
- Sugars (g)	6g	55
Sodium (mg)	21mg	17mg
Dietary fibre (g)	2.2g	1.8g

This is great to assist you in fat counting, and then being able to calculate the number of enzymes required.

Take caution to make sure that you calculate the fat content of the amount actually consumed, rather than the serving size as per the packet.

Sometimes a manufacturer's suggested serving size can be very different to the amount that is consumed. While you are getting used to calculating fat content of foods it may be useful to use kitchen scales to

Work out the calories and fat content of a few meals in advance to start with.

gain a better understanding of portion sizes. This will help you to be more accurate in your calculations.

FOOD PREPARATION

An easy way to manage what your baby is eating and how many enzymes he will need, is to come up with a meal plan for the week.

Spend some time cooking up the different items, freezing them into ice cube trays, then placing in plastic zip lock bags once frozen.

Calculate the enzyme dose required for each meal and write it on the zip lock bag.

This allows you to have lots of different meal options on hand so that you can easily add more cubes to the meal if your baby is hungry, or else quickly heat up something else if your baby won't eat the meal you have initially prepared.

You can also write down the enzymes for each meal on your meal plan. Check out the sample meal plan in the appendix of this booklet.

INTRODUCING SOLIDS

Many of the guidelines set for feeding babies solids apply to babies with CF, too. Breastfeeding is recommended to be continued to 12 months of age, and longer than that

if mutually desired, but other foods can be introduced starting from around 6 months of age.

It is a good idea to talk to your CF care team about starting solids as you will need information on enzyme dosage.

AGE	FOOD TEXTURE
0-6 MONTHS	liquid (and apple/pear purée for babies with CF)
6 MONTHS	puréed, mashed, then minced and chopped foods
8-12 MONTHS	finger foods
12 MONTHS ONWARDS	same foods as the family (but for some children with CF, a higher fat content)

6 MONTHS

As with most babies, it is recommended that solids are introduced by 6 months of age. In some cases, babies with CF may start solids earlier if this will assist in satisfying their energy needs.

At this age, your baby will still require formula or breast milk as an important source of nutrients, but gradually some milk feeds will be replaced by solid foods.

Introduce new foods one at a time to start with, over a couple of days, and monitor if there are any allergies.





Be aware that your baby's bowel movements will change colour and texture as new foods are introduced.

It is normal for babies to gag frequently as they learn how to eat solid foods.

Some babies can gag on purpose when they don't want to eat something, which can last into their toddler years. It is recommended to speak to a health care professional if your baby gags, coughs or splutters regularly when being fed.

Start with foods high in iron, as this is an important nutrient that is commonly low in babies and toddlers and can affect their development.

Examples of good dietary sources of iron include puréed red meat (the best source of easily absorbed iron), tofu, puréed chicken, puréed baked beans, puréed chickpeas or baby rice cereal.

Iron is most easily absorbed from non-plant foods. You can also steam or boil vegetables with water and if recommended by your baby's dietitian, you can add a little salt to the water and a little butter or avocado to the puréed vegetables to increase the salt and calorie content.

Feeding your baby solids plus the additional medication required for CF can be exhausting and also stressful, but it is also wonderful to

see your baby trying different types of foods and progressing through the stages until he or she becomes an independent eater. Plus it's a great time to take some funny photos.

FROM 7 MONTHS

Begin introducing foods from all of the different food groups: grains (cereal), vegetables, fruit, meat and meat alternatives, and dairy foods.

By this age, the texture of the food can be a little lumpier than purée, however, it does depend on your baby and how he or she copes with the texture.

If it seems your baby doesn't want to eat food that is lumpier, you can go back to puréeing it, as the main goal at this stage is to encourage your baby to have a good meal.

Keep offering foods that are lumpier so that your baby gets used to having foods with a more complex texture.

This will help your baby develop his eating skills as he gains more control over the muscles involved in chewing and swallowing. Mashed vegetables, porridge and eggs are good options for slightly chunkier meals.

FROM 8 MONTHS

This is a great time to introduce finger foods which your baby can hold herself and chew.



Try finger foods such as toast, rusks, pieces of cooked vegetables (e.g. carrot, broccoli and asparagus), fruits (e.g. banana, watermelon, rockmelon and strawberries), milk arrowroot biscuits, strips of cooked chicken, fish or meat.

Full fat dairy products are great and protein is also very important for the growth and development of your baby.

Nut pastes are ok to give to your baby on toast and bread (if your baby doesn't have nut allergies) but avoid giving her whole nuts until she is at least 3 years of age.

FROM 9 MONTHS

Your baby can start eating some of the same foods as the rest of the family, as well as continued breast milk or formula. Experiment more with finger foods and self-feeding.

Soft fruits can be given in pieces, with skin and seeds removed and other types of food can be given in pieces

or chopped. Changes in the texture of food is very important for your baby's jaw and speech development.

FROM 10-12 MONTHS

By 10 months, you can feed your baby 3 meals a day plus 3 snacks. Your baby can have high energy and protein rich foods and will still require about 3-5 milk feeds a day. If extra calories or high energy food is needed, you will be guided by the CF care team.

PARENTS TIP

Write the meals and fat content you are confident with into an exercise book. Save those recipes as your 'go to' meals.

Having a baby with CF made me become organised and develop good routines.

A GUIDE TO INTRODUCING SOLIDS

Below are some examples of the types of foods from each food group that fall into the different texture categories. If you would like more information regarding the introduction of solids foods, please contact your child health nurse, CF care team or GP. This is not intended for use as a meal plan.

	GRAIN FOODS	VEGETABLES	FRUIT	MEAT AND MEAT ALTERNATIVES	DAIRY FOODS
PURÉE	baby cereal	pureed sweet potato	pureed apple	blended tuna casserole	plain yoghurt
MINCED AND MASHED	porridge	mashed avocado	mashed banana	scrambled eggs	fruit and yoghurt
FINGER FOODS	toast fingers	cherry tomato and cucumber slices	watermelon slices	meatballs	cheese sticks



SALT

How much salt does my baby need?

You should always consult with your baby's dietitian about his or her individual requirements.

ADMINISTERING SALT

You can continue to administer salt either through a syringe or by putting it in your baby's milk.

If your baby is lacking salt he can become dehydrated. Be aware of the signs of dehydration as detailed on page 9.

VITAMINS

Continue to use whichever method works best for you and your baby. The vitamin mixture may be mixed in with pear or apple purée or else dissolved in a syringe with water.

Continue to administer vitamins along with enzymes and a fat-containing food or drink (milk or food depending on their age).

The table on page 19 shows each of the fat-soluble vitamins that people with CF are often deficient in, their health benefits and food sources.



PARENTS TIP

I had a chart for all my child's medications and would tick it off as I went.

PARENTS TIP

I had all the vitamins in syringes lined up on a tray.

VITAMIN	BENEFIT	FOOD SOURCES
VITAMIN A	<ul style="list-style-type: none"> • supports immune function, normal vision, bone and tooth formation, cell function and immunity. • also works to help fight infections and to keep the intestines healthy. 	<ul style="list-style-type: none"> • 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).
VITAMIN D	<ul style="list-style-type: none"> • helps build and maintain strong bones and teeth. Without enough vitamin D, bones can become thin and brittle. 	<ul style="list-style-type: none"> • 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). • dairy products may or may not be made with vitamin D fortified milks, so be sure to read labels.
VITAMIN E	<ul style="list-style-type: none"> • is an anti-oxidant and is important for nerve and muscle function. • helps keep red blood cells healthy and also helps fight infection and maintain the health of the intestines. 	<ul style="list-style-type: none"> • wheat germ, nuts, eggs, vegetable oils, green leafy vegetables and fortified cereals.
VITAMIN K	<ul style="list-style-type: none"> • important for blood clotting and bone health. 	<ul style="list-style-type: none"> • green leafy vegetables (e.g. spinach, broccoli), liver, soya beans and canola oils.

PARENTS TIP

My 12 month old started to play with his food and not really eat much. So I gave him half of his Creon at the start of his meal and then if he ate it all I would give him the rest during or at the end of the meal.

FUSSY EATERS

Food refusal and fussy eating are common behaviours in babies and toddlers. It is important to instill good nutrition and meal time behaviours from a young age to help reduce the incidence of problems later on.

Some tips:

- Test the temperature of food first before feeding to baby.
- Throw or pack away any uneaten food, don't force your baby to finish everything on their plate.
- Make sure baby is sitting comfortably and safely and is not too hungry or too tired.
- Use soft plastic spoons, not metal.
- Don't worry if your baby refuses a new food at first, try again another day - new foods may sometimes need to be offered more than 10 times before babies accept them.
- Don't leave your baby unattended when eating.
- Sit your baby with the family at meal times so they can watch and learn.
- Get ready for a mess, everywhere, which is all part of your baby learning about eating and enjoying food.
- A relaxed and comfortable atmosphere will assist in good eating practices, as it shows your baby that eating is an enjoyable and fun activity.
- Have alternative meal options available if your baby refuses certain foods.



PARENTS TIP

“I was so stressed in the toddler stage about how much food he was or wasn't going to eat and trying to match the enzymes. But you just have to let them try things.”

5.

Feeding babies 12 months to 2 years

ENZYMES

By the age of 2, your toddler is probably being defiant sometimes when it comes to taking enzymes, amongst other things.

You will need to be consistent and persistent with giving enzymes and work out a routine that works well for you and your child.

Remember that the Nutritional Information Panel on food packaging and calorie counting apps can help when calculating fat content and enzyme requirements.

FOOD

Your child should be eating a wide variety of foods now. Toddlers can manage various tastes, flavours and textures and they also know when they are hungry or full.

Toddlers need small meals and regular snacks. It is ideal to aim for 3 meals and 3 snacks at a regular time each day.

A BALANCED DIET

A high fat diet is often encouraged for children who have CF and are pancreatic insufficient, but it is also important to make sure your child's diet has variety and covers the 5 food groups.

Focus on making sure your 1-2 year old is meeting the suggested targets for each food group, as each food group provides different nutrients.

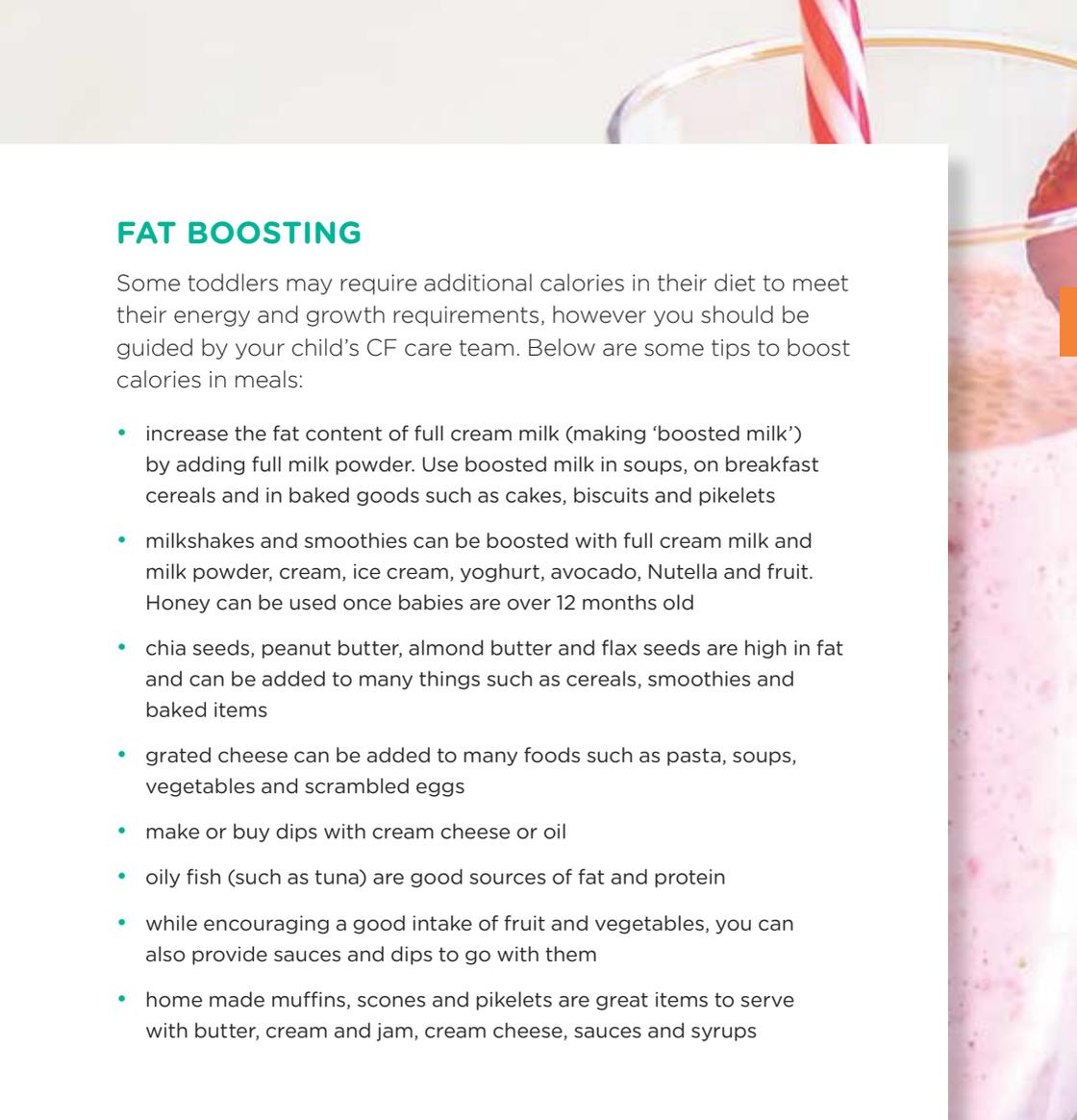
Your CF team will advise you on any extra nutritional requirements your child has and how many extra serves of foods to include. Alternatively, your child may not require extra serves, but may benefit from 'boosted' or fortified foods which will be discussed in the following pages.

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>

Suggestions for Maximizing Energy for 1-2 Year Olds

GRAINS (CEREALS) 4 SERVES PER DAY	GOOD SOURCE OF	EXTRA INFO
<ul style="list-style-type: none"> • breakfast cereals • bread wraps • rice • pasta • oats • quinoa 	<ul style="list-style-type: none"> • carbohydrates • fibre (if whole grain) • B vitamins • some minerals 	<ul style="list-style-type: none"> • include in most meals and snacks • add extra margarine or oil to servings • whole grain servings are the most nutritious choice, but it is ok to include some white products • not a good source of protein
VEGETABLES 2-3 SERVES PER DAY		
<ul style="list-style-type: none"> • fresh, frozen and tinned 	<ul style="list-style-type: none"> • fibre • antioxidants • vitamins • some carbohydrate 	<ul style="list-style-type: none"> • good for the bowels. Use in conjunction with a higher energy food. • include high fat veggies such as avocado • include a variety of different sorts daily, including veggies of different colours
FRUIT 1/2 SERVE PER DAY		
<ul style="list-style-type: none"> • fresh and tinned 	<ul style="list-style-type: none"> • fibre • antioxidants • vitamins • carbohydrates 	<ul style="list-style-type: none"> • good for the bowels. Use in conjunction with a higher energy food • not a good source of protein • include in meals and/or snacks
MEATS AND MEAT ALTERNATIVES 1 SERVE PER DAY		
<ul style="list-style-type: none"> • red meat • chicken and poultry • eggs • dried beans and lentils • nuts • fish - fresh and tinned 	<ul style="list-style-type: none"> • protein • iron and zinc • fish good for omega fats 	<ul style="list-style-type: none"> • include a variety of different types in age-appropriate textures • add sauces, oils and condiments to make sure these choices are high energy
DAIRY FOODS 1 - 1 1/2 SERVES PER DAY		
<ul style="list-style-type: none"> • milk • cheese • yoghurt • ice cream • custard 	<ul style="list-style-type: none"> • protein • fat • carbohydrate • calcium 	<ul style="list-style-type: none"> • add cheese in cooking • encourage dairy desserts • give milk after meals so there's more room for solids first



FAT BOOSTING

Some toddlers may require additional calories in their diet to meet their energy and growth requirements, however you should be guided by your child's CF care team. Below are some tips to boost calories in meals:

- increase the fat content of full cream milk (making 'boosted milk') by adding full milk powder. Use boosted milk in soups, on breakfast cereals and in baked goods such as cakes, biscuits and pikelets
- milkshakes and smoothies can be boosted with full cream milk and milk powder, cream, ice cream, yoghurt, avocado, Nutella and fruit. Honey can be used once babies are over 12 months old
- chia seeds, peanut butter, almond butter and flax seeds are high in fat and can be added to many things such as cereals, smoothies and baked items
- grated cheese can be added to many foods such as pasta, soups, vegetables and scrambled eggs
- make or buy dips with cream cheese or oil
- oily fish (such as tuna) are good sources of fat and protein
- while encouraging a good intake of fruit and vegetables, you can also provide sauces and dips to go with them
- home made muffins, scones and pikelets are great items to serve with butter, cream and jam, cream cheese, sauces and syrups

Sauces are a great way to get extra calories and salt and also provide flavour, such as dijonaise, mayonnaise, tomato and tartar sauce.

IDEAS FOR MEALS AND SNACKS

The following table (*right*) is not designed to be used as a meal plan, it is here to help with ideas for easy meals.

The number of servings from each food group may not be appropriate for your child. Speak with your CF team to understand the specific needs of your child.

When planning meals for your toddler, ensure you are including a variety of different types of food from all the food groups.

SALT

Salt solution can be added to milk, water, cordial, puréed fruit or other solids. It also comes in tablet form which may be an option once your child learns to swallow capsules.

You can try cutting the tablet up and administering with yoghurt or another soft food your child enjoys eating.

Some parents have found that the salt tablets can make their child vomit; this can be a normal reaction to the salty taste. Often these parents stick to giving their child the salt solution.

VITAMINS

Continue to use whichever method works best for you and your child.

This may be mixed in with pear or apple purée or else dissolved in a syringe with water.

Continue to administer the vitamins with enzymes and a fat-containing food or drink. See page 19 for details on each of the fat-soluble vitamins that people with CF are often deficient in, their health benefits and food sources.

BOWEL HEALTH

It is a good idea to have a look at your child's bowel movement every now and then; once your child is older and is toilet trained, encourage him to do the same.

This will help your child learn what a 'healthy' poo should look like. See page 10 for information on bowel health.

FUSSY EATERS/NON COMPLIANCE

It is definitely common for toddlers to be fussy with food.

Tantrums, obsessions with certain types of foods, refusal to eat other types of foods and playing with food instead of eating it, are all normal progressions for toddlers.

Toddlers can also eat more at some meals and less at others.

Ideas for Main Meals and Snacks

BREAKFAST	SNACKS	LUNCH	DINNER
<ul style="list-style-type: none"> cereals with full cream milk 	<ul style="list-style-type: none"> tuna salad and crackers 	<ul style="list-style-type: none"> toasted ham, cheese and tomato sandwiches 	<ul style="list-style-type: none"> quesadillas with guacamole
<ul style="list-style-type: none"> muesli (homemade or store bought) with full cream yoghurt and berries 	<ul style="list-style-type: none"> cheese bits, slices, sticks with fruit 	<ul style="list-style-type: none"> eggs on toast with sautéed veggies 	<ul style="list-style-type: none"> beef stew (slow cooker) with creamy mashed potato and broccoli
<ul style="list-style-type: none"> baked beans on thick buttered toast 	<ul style="list-style-type: none"> crumpets, muffins, raisin bread with margarine or cream cheese 	<ul style="list-style-type: none"> bacon, egg, lettuce and tomato sandwich 	<ul style="list-style-type: none"> fish in bread crumbs and potato wedges with mayonnaise dipping sauce and salad
<ul style="list-style-type: none"> scrambled eggs with milk and cheese on thick buttered toast 	<ul style="list-style-type: none"> Anzac biscuits with fruit smoothie 	<ul style="list-style-type: none"> chicken schnitzel with mayonnaise and lettuce roll 	<ul style="list-style-type: none"> fried rice with chicken and diced veggies
<ul style="list-style-type: none"> porridge with cream, crushed nuts, pears and Nutella 	<ul style="list-style-type: none"> celery sticks with peanut butter or cream cheese or full fat dip, like cheese and onion 	<ul style="list-style-type: none"> hummus, spinach, ham and cheese sandwich 	<ul style="list-style-type: none"> sausages (skin off), baked beans and creamy potato mash
<ul style="list-style-type: none"> peanut butter and banana sandwiches 	<ul style="list-style-type: none"> scones with cream and jam 	<ul style="list-style-type: none"> curried egg sandwiches with mayonnaise and lettuce 	<ul style="list-style-type: none"> cauliflower and cheese bake with roast lamb, roast vegetables and gravy
<ul style="list-style-type: none"> bacon with egg, fried tomato, mushrooms, hash browns 	<ul style="list-style-type: none"> cottage cheese with fruit 	<ul style="list-style-type: none"> cauliflower and lentil soup with warm Turkish bread 	<ul style="list-style-type: none"> baked potatoes with sour cream and cheese and lamb chops (meat removed from bone if under 2)
<ul style="list-style-type: none"> milkshakes with cream, ice cream, milk powder, bananas and berries 	<ul style="list-style-type: none"> custard, Yogo and fruit salad 	<ul style="list-style-type: none"> mini pizzas made from either mini pizza bases, pocket breads, English muffins, slices of bread, half a bread roll 	<ul style="list-style-type: none"> home made meat pie with puff pastry, peas, corn and mashed sweet and/or normal potato
<ul style="list-style-type: none"> French toast 	<ul style="list-style-type: none"> garlic bread with melted cheese 	<ul style="list-style-type: none"> mini quiches and salad 	<ul style="list-style-type: none"> meatballs and spaghetti
<ul style="list-style-type: none"> pancakes with whipped cream, crushed nuts and fruit 	<ul style="list-style-type: none"> fruit smoothie with cream and ice cream 	<ul style="list-style-type: none"> Vegemite and cheese toasted sandwiches with veggie sticks 	<ul style="list-style-type: none"> chicken or chicken drumsticks with salad and cheese

Involve your child in the cooking. They're more inclined to try it.

Likes and dislikes may change from day to day and it is important to keep offering foods even if they were previously refused.

However, do avoid food for which the child has an obvious strong dislike.

Toddlers and 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.

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, it is also important not to fall into the trap of using short-term strategies, such as coaxing them to eat or specially preparing their favourite

food, as these do not help to 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.

It is important to be consistent with your approach and make meal times a positive experience and an enjoyable family event.

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.

It is also useful to hide your anxiety. If you are anxious about your toddler 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, but other parents who have been through a similar experience may also be useful.



PARENTS TIP

If your child is sick, just focus on him eating and staying hydrated. Don't stress about fat boosting and enzymes. They just need to get better first.

Sharing tips with other mums, even if their child doesn't have CF can be handy, as many of these age related issues are universal.

Tips for managing fussy eaters:

It's your job to decide what foods are offered, when foods are offered and where foods are eaten, but allow your toddler to decide how much to eat and which foods to eat.

- offer a range of colourful foods on the plate and allow your child to choose what he or she wants to eat
- allow your child to help prepare some of the meal, which could encourage an interest in food
- encourage self-feeding and exploration of food from an early age
- offer alternative foods from each food group
- encourage your child to feed independently and to sit down while eating
- by the evening, toddlers can be very tired, so small meals of easy-to-eat foods can be more beneficial for your cranky toddler - sometimes if things are too tricky, a nutritious milkshake might be the way to go

- avoid using sweet food as a bribe, and keep out of sight, until savoury foods have been eaten at meal times

The Ellyn Satter website is a useful resource for learning about strategies to help your child to develop healthy eating behaviours from an early age.

<http://ellynsatterinstitute.org/>

LOSS OF APPETITE

Appetites tend to be erratic in childhood. Some days they will eat everything, other days they appear to eat almost nothing.

For a toddler with CF, there can be many reasons for a loss of appetite including antibiotic use or if they are unwell. During this time, they may eat less or refuse food altogether. Try not to panic.

As long as they are growing and gaining weight this is nothing to worry about. If you are particularly concerned, you can, of course, speak with the CF care team for advice.

6.

Appendix: Charts for meals and medications

MEAL AND ENZYME PLAN

	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							
VITAMINS							
ENZYMES							
BREAKFAST							
SNACK							
LUNCH							
SNACK							
DINNER							
NIGHT FEED							
PHYSIO							
ANTIBIOTICS							
OTHER							

MEDICATION CHART

7.

Recipe ideas

Here are some purée ideas which you can make and then freeze into ice block containers. If you are advised to fat boost the recipes with butter or cheese, you would need to consider the added fat content when calculating enzyme amounts:

Dhal Purée

PREP TIME	SERVES	FAT (PER TBSP)	CALORIES
25 mins	1 cup	0.1g (without butter)	16

INGREDIENTS

- 3/4 cup (180ml) water
- 1 small carrot, roughly chopped
- 200g pumpkin, roughly chopped
- 1 zucchini, roughly chopped
- 2 tablespoons red lentils

METHOD

1. Combine ingredients in a small saucepan and bring to the boil. Reduce the heat and simmer the mixture, uncovered for approx. 15 minutes until the vegetables and lentils are tender.
2. Blend or process the mixture until it is the desired consistency (smooth for babies starting out with solids).

Chicken, Corn and Risoni Purée

PREP TIME	SERVES	FAT (PER TBSP)	CALORIES
25 mins	1 cup	0.7g	38

INGREDIENTS

- 100g chicken breast fillet, roughly chopped
- 1 1/4 cups (310ml) water
- 1 cup fresh or frozen corn kernels
- 1 tablespoon risoni pasta

METHOD

1. Combine all ingredients in a small saucepan; bring to the boil. Reduce heat; simmer, uncovered for about 10 minutes or until the pasta is tender and the chicken is cooked through.
2. Blend or process the mixture until smooth, or desired consistency.



tablespoon of cheese	3g of fat and 37 calories
teaspoon of butter	4g fat and 34 calories

Macaroni Cheese				
PREP TIME	COOK TIME	SERVES	FAT (PER 1/2 CUP)	CALORIES
10 mins	20 mins	4	24.3g	687

INGREDIENTS

- 400g macaroni
- 1 1/2 cups (300ml) cream
- 3/4 cup (185mL) milk
- 1 1/4 cup cheddar cheese, grated
- 1/2 cup parmesan cheese
- 1/3 cup dried bread crumbs
- 1/2 cup cheddar cheese, extra
- paprika, salt, pepper to taste

METHOD

1. Pre-heat oven to moderate temperature. Grease a large baking dish.
2. Cook pasta in a large saucepan of salted, boiling water, following the packet instructions. Drain, place in another bowl and cover to keep warm.
3. Add to the same saucepan, cream and milk and bring to the boil over a medium heat. Reduce heat and add cheeses. Add salt. Once cheeses have melted return the pasta to the saucepan.
4. Mix pasta with the sauce then transfer to baking dish. Sprinkle bread crumbs over the mixture and add extra cheese. If suitable add a sprinkle of paprika.
5. Place dish into oven and bake for a few minutes until topping is golden and crispy.

8.

PARENTS TIPS

STARTING OUT WITH A BABY

- “I found the piece of writing “Welcome to Holland” (available online) by Emily Perl Kingsley very useful to read as it explains what it feels like to have a child with a condition like CF”.
- “Involve your extended family or close friends in any available CF education provided by the clinic or CF organisations, so that they can learn about CF and how to care for your baby- if you have a few support people available who you trust and who know about CF, this can make things more manageable”.
- “Don’t look too far ahead, or you can become overwhelmed, it is good to just stay 1 or 2 steps ahead of what you need to do to care for your child. Sometimes you just need tunnel vision to get through the first year”.
- “Cut yourself some slack and allow yourself time to find your groove”.
- “Listen to your baby”.
- “I found social groups on Facebook handy”.

ENZYMES

- “I started slowly by just getting him to taste the puree on my finger and getting him used to using his tongue and having the feel of the puree in his mouth. I then moved on to syringing the puree and enzyme mixture into his mouth. After this I started spoon feeding him the mixture”.
- “I would put enzymes, a pouch of apple puree and a spoon in a zip lock bag and make up a few of these so they were ready to go when we went out”. (Note: do not premix enzymes ahead of time with apple puree, as they will no longer be effective- keep enzymes and puree separate until it’s time to feed your baby).
- “Rafferty’s Apple Puree is great. It comes with a screw top lid so great for taking out too”.
- “Don’t feel bad about using packet food or food in jars when getting used to working out how much enzymes to give. It takes some of the stress out of the process as the calories and fat are already measured for you”.

FUSSY EATING

- “When my son became fussy I was told by the dietitian to give ‘tough love’; don’t give in and offer anything else. He didn’t eat much for two days then suddenly ate whatever I gave him. Although hard, tough love is sometimes the best for them”.
- “My 15 month old decided that food was really just to play with and would sit and squish everything and throw it all over the floor and pretty much ate nothing, so I put him back on purees. He gets a small bowl of meat and veg puree with extra butter and salt so I know the calories are going in. I have some pieces of more solid food for him to eat and play with afterwards and now he is eating more of the solid pieces of food again”.

Useful resources, websites, etc.

9.

STATE	CYSTIC FIBROSIS CLINIC	CYSTIC FIBROSIS ORGANISATION
ACT	<p>Canberra Hospital T: 02 6174 7373</p>	<p>Cystic Fibrosis ACT Postal Address: PO Box 909, Civic Square ACT 2608 T: 0401 990 111 E: info@cfact.org.au W: www.cysticfibrosis.org.au/act/</p>
NSW	<p>The Children's Hospital at Westmead T: 02 9845 0000 W: www.chw.edu.au</p> <p>Sydney Children's Hospital T: 02 9382 1111 W: www.sch.edu.au</p> <p>John Hunter Children's Hospital Newcastle T: 02 4921 3670</p>	<p>Cystic Fibrosis NSW 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@cfns.org.au W: www.cysticfibrosis.org.au/nsw/</p>
QLD	<p>Mater Children's Hospital T: 07 3163 8111</p> <p>Royal Children's Hospital T: 07 3636 3777</p>	<p>Cystic Fibrosis QLD 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/qlld/</p>
SA	<p>Women's and Children's Hospital T: 08 8161 7000</p>	<p>Cystic Fibrosis SA Street Address: 143-145 Sturt St, Adelaide SA 5000 T: 08 8221 5595 E: cfsa@cfsa.org.au W: www.cysticfibrosis.org.au/sa/</p>
TAS	<p>Royal Hobart Hospital T: 03 6222 8475</p>	<p>Cystic Fibrosis TAS 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/tas/</p>
VIC	<p>Royal Children's Hospital T: 03 9345 5522</p> <p>Monash Medical Centre T: 03 9594 6666</p>	<p>Cystic Fibrosis VIC Street Address: 80 Dodds St, Southbank VIC 3006 T: 03 9686 1811 E: admin@cfv.org.au W: www.cysticfibrosis.org.au/vic/</p>
WA	<p>Perth Children's Hospital (PCH) Hospital Avenue Nedlands, WA T: 08 9340 8222</p>	<p>Cystic Fibrosis WA Street Address: The Niche, 11 Aberdare Rd, Nedlands WA 6009 Postal Address: PO Box 959, Nedlands WA 6909 T: 08 9346 7333 E: info@cysticfibrosiswa.org W: www.cysticfibrosis.org.au/wa/</p>

<p>APPS</p>	<p><u>Calorie King*</u> 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>
<p>BOOKS</p>	<p><u>'Sense-ational Mealtimes! Making sense of tricky mealtime behavior, fussy/picking eating and feeding difficulties'*</u> By Gillian Griffiths and Denise Stapleton</p>
<p>FACT SHEETS</p>	<p><u>'Bone Health and Cystic Fibrosis' by NEMO:</u> https://www.health.qld.gov.au/nutrition/resources/cf_bonehealth.pdf</p> <p><u>'DIOS and Cystic Fibrosis' by NEMO:</u> https://www.health.qld.gov.au/nutrition/resources/cf_dios.pdf</p> <p><u>'Salt and Fluid' factsheet by Cystic Fibrosis Australia:</u> https://www.cysticfibrosis.org.au/media/wysiwyg/CF-Australia/Fact_Sheets/CF_Aust_Fact_Sheet_Salt_Fluid_Replacement.pdf</p>
<p>WEBSITES</p>	<p><u>Creon*</u> http://www.creon.com/</p> <p><u>Tips for CF Parents</u> A website with a range of articles and video clips which provide parents with practical tips and strategies for dealing with different issues www.TipsForCFParents.com</p> <p><u>CF Chef*</u> 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 www.chef4cf.com</p> <p><u>Ellyn Satter Institute</u> A website which provides information on creating healthy eating habits and attitudes in children ellynsatterinstitute.org</p> <p><u>Eat for Health</u> Information on the number of servings recommended for children and adolescents https://www.eatforhealth.gov.au/food-essentials/how-much-do-we-need-each-day/recommended-number-serves-children-adolescents-and</p> <p><u>Eat for Health</u> Information on what an appropriate serving size is https://www.eatforhealth.gov.au/food-essentials/how-much-do-we-need-each-day/serve-sizes</p>

BLOGS

Fun Fatty Foods*

Recipes from Katherine, a mum of a CF child living in Brisbane, focused on healthy, nutritious meals for children requiring high fat/ calorie diet

Blog <http://funfattyfoods.blogspot.com.au/>

Facebook <https://www.facebook.com/FunFattyFoods>

OTHER RESOURCES

CF Food:

A series of resources providing information about the CF diet and nutrition for people of all ages who have CF.

- Nutrition and Cystic Fibrosis: A Guide for Feeding Infants (0-2)
- Nutrition and Cystic Fibrosis: A Guide for Feeding Children (3-12)
- Nutrition and Cystic Fibrosis: A Guide for Young People
- Nutrition and Cystic Fibrosis: A Guide for Adults
- CF Cookbook : High Energy Recipes for Cystic Fibrosis

<http://www.cysticfibrosis.org.au/wa/cffood>

CF Smart:

A series of resources for teachers, students and parents providing information about CF, in a school setting.

- includes information booklets for Early Education, Primary and High School teachers
- a short animation about hand washing - 'Good Clean Hands'

www.cfsmart.org

CF Fit:

A series of resources designed to support adults and older children with CF to maintain an active lifestyle.

- 'A Guide for People Living with CF'
- 'A Guide for Personal Trainers'
- 'My Exercise Record'

www.cysticfibrosis.org.au/wa/cffit



CFsmart



CFfit



CFfood



www.cysticfibrosis.org.au

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