

A GUIDE TO CYSTIC FIBROSIS FOR  
**EARLY CHILDHOOD EDUCATORS**



## About this guide

This guide is for educators in child care, kindergarten and pre-primary school who have a child with cystic fibrosis in their care. We have covered most aspects of cystic fibrosis in this booklet but please be aware that **some sections may not be relevant** to the particular child you are working with. **Individuals are affected very differently** by this condition.

Cystic fibrosis is a chronic genetic illness which affects a number of organs in the body. Daily and ongoing treatment is required at home and at school to manage the illness and prolong the life of the person affected. Children with cystic fibrosis are able to **participate in most if not all school activities**, but some considerations do need to be made to ensure their health needs are met, while they are in your care.

The medical needs of a child with cystic fibrosis can seem daunting to an educator, especially when there are several children with medical and learning conditions to manage. Open and regular communication with the child's parents and establishing a routine which all parties agree to, can assist in the management of cystic fibrosis within the school.

**Throughout the guide please note we will refer to cystic fibrosis as CF for short.**

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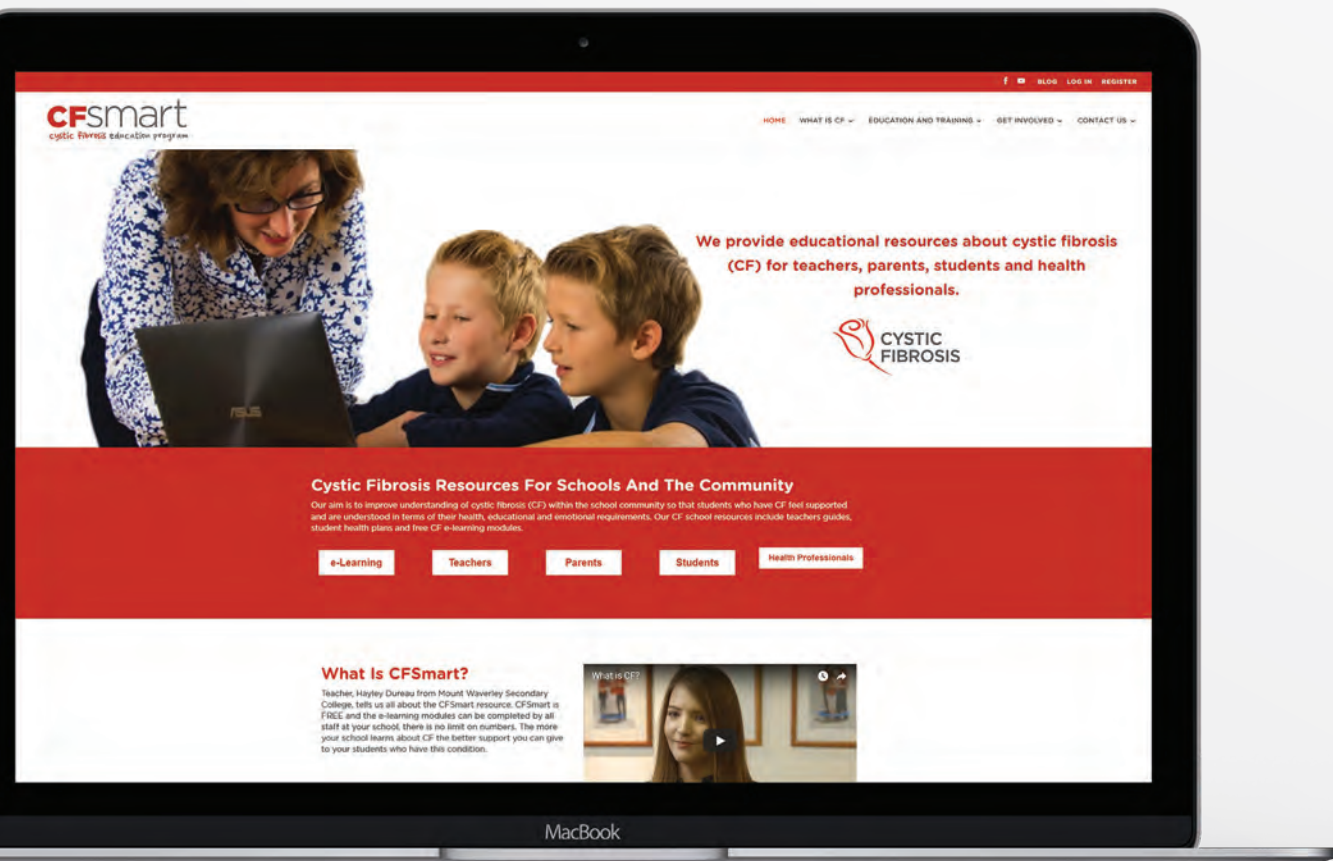
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## Want your school to be CFSmart?

Find our e-Learning modules available on [www.cfsmart.org](http://www.cfsmart.org)

Our e-learning modules have been created to support and educate teachers about cystic fibrosis (CF).

Each module takes around 30 minutes and you will only need to complete two modules; the first module 'What is CF?' and either module 2, 3 or 4 depending on the year levels you teach. On completion you will receive a certificate recognising one hour towards your professional development target.





# cystic fibrosis summary for early childhood educators

Cystic fibrosis is a genetically inherited condition that causes mucus in the body to be thick and sticky. The mucus mainly causes issues in the lungs and the pancreas (in the digestive system). Children are affected differently by cystic fibrosis so their needs will vary.

The following things need to be taken into consideration when teaching a child with cystic fibrosis.

- **GERMS:** minimise the child's exposure to colds etc. by keeping the child seated away from other children who are unwell and encourage good hand washing practices.
- **MEDICATIONS REQUIRED:**
  - enzyme capsules may be needed with snacks and lunch
  - salt tablets
  - other medications such as antibiotics or vitamins.
- **DEHYDRATION:** during warmer weather, the child is more at risk of dehydration so requires easy access to a water bottle and salty drinks. The child may need reminding to drink.
- **EXERCISE:**
  - the child may become more tired during exercise and need to rest
  - the child will need a water bottle for extra hydration.
- **COUGHING:** is common for some children with CF, it is not a cold.
- **TOILETING:** the child may need to go to the toilet frequently and urgently.
- **CYSTIC FIBROSIS DIET:** most children need more calories in their diet eg. food higher in fat and salt.

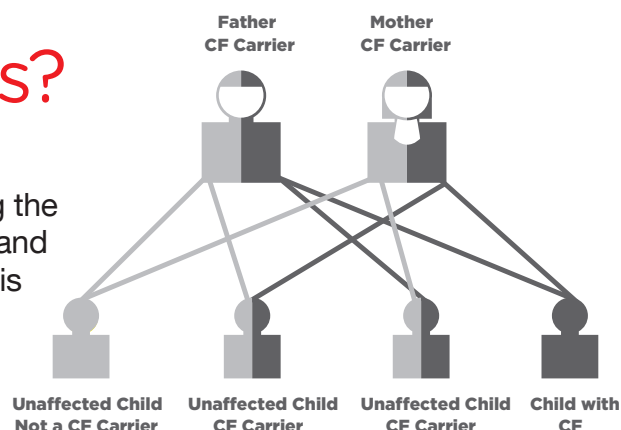
## SUMMARY

- **Cystic fibrosis (CF) is a complex chronic illness which requires a team of health professionals to assist in the management of it.**
- **CF affects people differently.**
- **Early childhood teachers can have the same expectations of the child's behaviour and abilities as they would of other children in their care.**
- **Regular and good communication with the child's parent/s is vital.**

## What is cystic fibrosis?

Cystic fibrosis (CF) is a **genetic condition** affecting the cells that line the lungs, pancreas, small intestines and sweat glands. In a person with this condition there is an imbalance in how salt moves in and out of the cells causing **mucus** in the body to become **thick and sticky**.

For most people with CF there are two main areas in the body affected, the **lungs** in the respiratory system and the **pancreas** in the digestive system. The **sweat glands** are also affected in a person who has this condition. Not everyone with CF experiences problems with their digestive system and some children experience more issues with symptoms than others.



The treatment regime for CF can vary between individuals, and may also change throughout the year.

In earlier years, babies born with CF rarely lived beyond childhood, whereas today thanks to a greater understanding of the condition and improvements in treatments, medication and research, the majority of babies born with CF in Australia are able to live well into adulthood.

In Australia there are almost 3500 people who have CF.

- CF is not contagious.
- In the Caucasian population, on average, 1 out of 25 people are carriers- they have one CF gene but do not have CF.
- For a child to be born with CF, the CF gene must be passed on by both parents.

### HOW IS CYSTIC FIBROSIS DIAGNOSED?

Most babies born in Australia who have CF are diagnosed within the first 2 months of life with a heel prick blood test as part of the newborn screening program.

### SYMPTOMS OF CYSTIC FIBROSIS

Most people with CF look healthy and have no obvious symptoms. Each CF journey is different however there are some common symptoms that a child with CF may have:

- cough
- wheeze or breathlessness, particularly with exercise
- frequent chest or sinus infections

If a child is becoming unwell they may experience other symptoms such as increased cough, temperature and fatigue. Children with CF who have more digestive issues may experience change in appetite, increased visits to the toilet, abdominal pain and vomiting.

# The child and the parents

## THE CHILD'S BEHAVIOUR

In the majority of cases, you can have the same expectations in terms of the behaviour of a child with CF as you would of other children in your care. Many children with CF wish to be treated the same as their peers and don't want to be seen as being different.

There are, however, certain medications that a few children with CF need to take which can affect their mood and behaviour. Discuss with the child's parents if the child's behaviour does change noticeably.

### STEROIDS:

Some children with CF may require a course of steroids. The course is usually short, however some children may be on a longer course and this can affect them in the following ways: trouble sleeping, low mood, increased temper, restlessness and disruptive behaviour.

### LOW IN SALT:

Some parents report that their child "acts up" when they are dehydrated and need more salt.

## DISCLOSURE

Parents of children with CF deal with the everyday treatment and associated issues very differently. Some parents will want all staff and other parents to know and understand CF, while others will want their child's illness to be completely confidential. Discuss with the parents who they want to know about their child's condition. Also consider in advance the types of questions that other students in the class may ask if

they notice the child taking their medication and have some appropriate answers prepared.

## COMMUNICATING WITH THE PARENTS

Individuals vary in their reaction to the stresses caused by cystic fibrosis (CF) and usually the initial diagnosis comes as a complete shock.

Caring for a child with CF can take up a lot of time with daily treatment and medications, clinic appointments and periods of hospitalisation. The uncertainty of how the child's health will progress over time is also very confronting and overwhelming for parents.

The early years of school or child care, can be **daunting for parents** and they may **feel anxious** about a new person (teacher) now being responsible for their child's health needs. The parents have had to provide medical care and treatment for their child, often since the first few weeks of birth. It can be difficult for others to believe that such a healthy looking child could have a chronic condition and it can seem like the parents are being overly protective when they are trying to maintain their child's health.

**Regular and ongoing communication** between you and the child's parents is the best thing you can do to assist in reducing the parents' anxiety. Also discuss with the parents how much the child knows about CF and any potential questions the child may ask while at school. Discuss with the parents the specific symptoms of CF which affect their child and how these can be managed.

## Lungs

For many people who have cystic fibrosis (CF), **complications in the respiratory system** are the most serious. The build-up of thick and sticky mucus in the airways and the lungs, leads to **infections and inflamed airways**. Irreversible lung damage occurs as a result of constant infections. Some people with CF will have problems in their upper airway (sinuses, nose and throat).

### PHYSIOTHERAPY

Daily physiotherapy, or "physio" for short, is essential for people with CF, and involves doing some form of airway clearance. The physio treatment is completed at home, before and after the child comes to school or child care. Inhaled medications taken with a nebuliser may also be used at home as part of the routine.

The amount of time a child spends on their physio and nebuliser routine will vary depending on their health, but may be several hours per day.

Coughing is an important part of all physio routines and should be encouraged in children with CF as it helps clear the sticky mucus from the lungs.

### ABSENTEEISM

There will be times when a child with CF might be absent from school due to hospitalisation, clinic appointments or unwell at home. The child may be admitted to hospital for a "tune-up" where they are given intravenous antibiotics (IVs) and extra physiotherapy. These admissions usually last for up to 2 weeks (sometimes more).

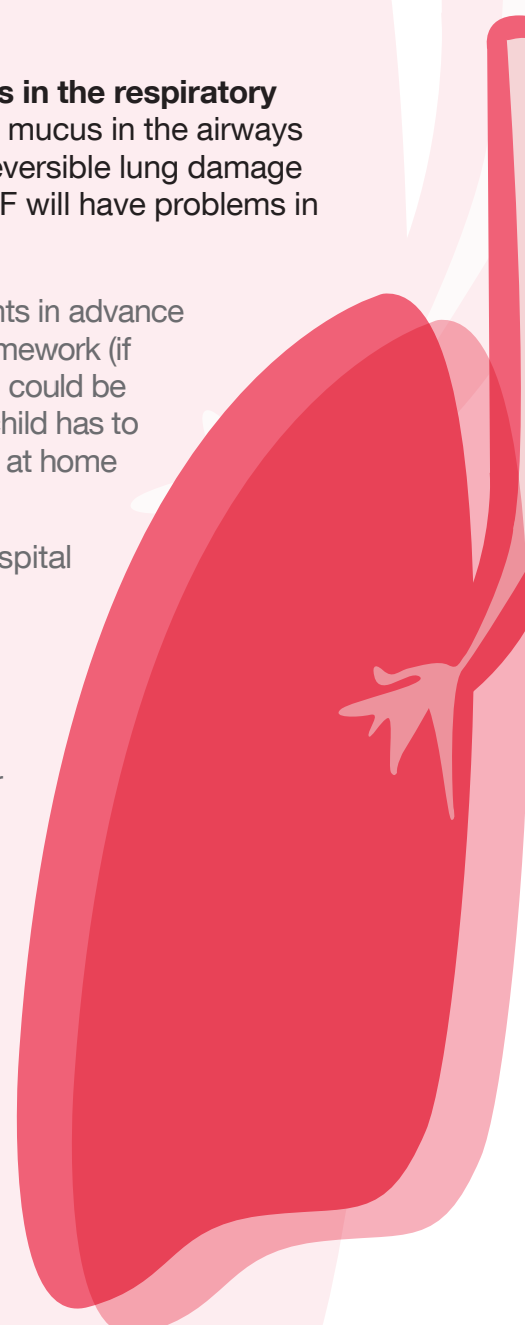
Discuss with parents in advance about possible homework (if appropriate) which could be undertaken if the child has to go to hospital or is at home on IV's.

There is also a hospital school service available in each state hospital, to liaise with in regards to school work. Please refer to page 22 for the CF clinic and hospital in the school service.

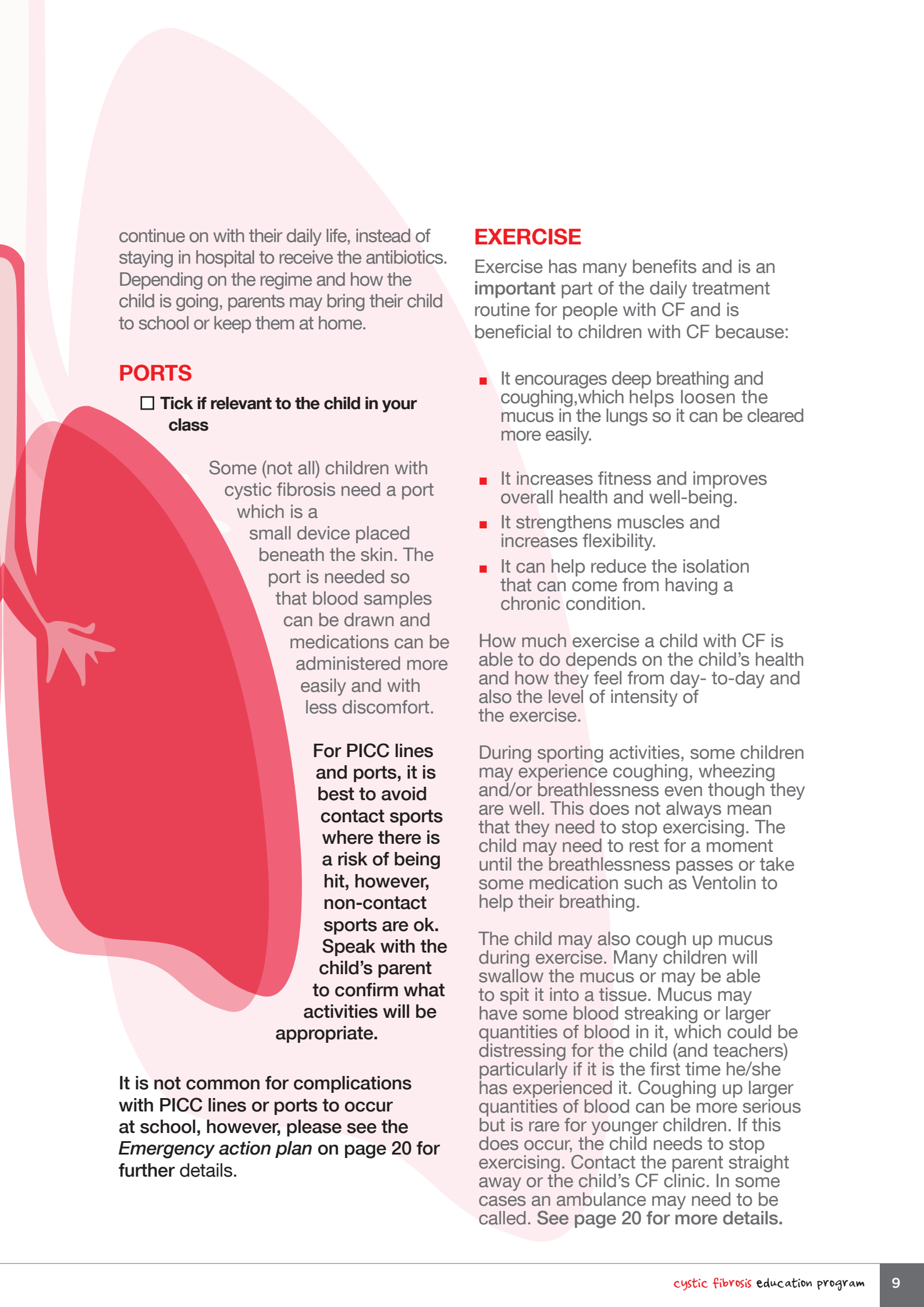
### PICC LINES

☐ **Tick if relevant to the child in your class**

Some children may also be placed on a "Hospital in the Home" program where they still have their IV line in, but the parent administers the IVs at home through a peripherally inserted central catheter (PICC) in the child's arm. The line is sealed and covered with a bandage which enables the child to







continue on with their daily life, instead of staying in hospital to receive the antibiotics. Depending on the regime and how the child is going, parents may bring their child to school or keep them at home.

## PORTS

☐ **Tick if relevant to the child in your class**

Some (not all) children with cystic fibrosis need a port which is a small device placed beneath the skin. The port is needed so that blood samples can be drawn and medications can be administered more easily and with less discomfort.

**For PICC lines and ports, it is best to avoid contact sports where there is a risk of being hit, however, non-contact sports are ok. Speak with the child's parent to confirm what activities will be appropriate.**

**It is not common for complications with PICC lines or ports to occur at school, however, please see the *Emergency action plan* on page 20 for further details.**

## EXERCISE

Exercise has many benefits and is an **important** part of the daily treatment routine for people with CF and is beneficial to children with CF because:

- It encourages deep breathing and coughing, which helps loosen the mucus in the lungs so it can be cleared more easily.
- It increases fitness and improves overall health and well-being.
- It strengthens muscles and increases flexibility.
- It can help reduce the isolation that can come from having a chronic condition.

How much exercise a child with CF is able to do depends on the child's health and how they feel from day-to-day and also the level of intensity of the exercise.

During sporting activities, some children may experience coughing, wheezing and/or breathlessness even though they are well. This does not always mean that they need to stop exercising. The child may need to rest for a moment until the breathlessness passes or take some medication such as Ventolin to help their breathing.

The child may also cough up mucus during exercise. Many children will swallow the mucus or may be able to spit it into a tissue. Mucus may have some blood streaking or larger quantities of blood in it, which could be distressing for the child (and teachers) particularly if it is the first time he/she has experienced it. Coughing up larger quantities of blood can be more serious but is rare for younger children. If this does occur, the child needs to stop exercising. Contact the parent straight away or the child's CF clinic. In some cases an ambulance may need to be called. See page 20 for more details.



## INFECTION CONTROL

### **Germ in the classroom or childcare centre:**

**Exposure to infections and viruses such as the flu, colds, measles, whooping cough, gastro and chicken pox can have severe and lasting effects on the lungs of a child with CF.**

In healthy people the mucus is a slippery watery consistency which helps to protect against infection. For a person with CF, the thick and sticky mucus creates a place where 'bugs' can easily grow, meaning the person is more prone to infections. Students and teachers who are unwell, should avoid close contact with a child who has CF until the infection has gone away.

Although germs are everywhere and can't always be avoided, there is evidence to suggest that infection control programs within schools and child care centres can significantly lower infection rates.

Many parents of children who have CF say that their biggest concern for their child while at school or a child care centre is how infection control is managed such as poor hand washing practices and sick children coming to school.

### **Good infection control practices:**

- All students wash their hands with liquid soap and dry with paper towels or hand dryer.
- A strong school policy about parents bringing unwell children to school is implemented.
- All students are encouraged to cough and sneeze into their elbow or sleeve instead of using their hands.
- Encourage students to use antibacterial hand gel appropriately such as after blowing their nose.
- Keep the child with CF at least 4 metres away from other children who appear to be sick.
- Avoid children in the class sharing eating utensils, cups or water bottles with other students.
- Include hand washing and germ lessons as part of the learning program.

### **Cross infection between children who have cystic fibrosis:**

Medical evidence shows that it is risky for individuals with CF to be in close contact as they can pass on germs existing in their lungs and sinuses to each other. Children with bronchiectasis or who are immunosuppressed, are also at risk of cross infection with people who have CF.

More than one child with CF may attend the same school if they do not share classrooms and the likelihood of being in close contact with one another is limited. (i.e one child in pre-primary and another in year 5).

According to the "Infection control guidelines for cystic fibrosis patients and carers" (2012) by cystic fibrosis Australia, the following guidelines should be applied within a school setting:

- Children with CF should keep more than 4 metres apart from others with CF.
- Children with CF should not travel in the same vehicle or gather in common areas.
- At outdoor events such as sports days the children must maintain a 4 metre distance from each other.
- Shaking hands, hugging or physical contact between children with CF is not recommended.

If you are aware of a potential cross infection situation, discuss with both parties as soon as possible to develop a plan.

For further support or advice in this area, either contact the CF clinic or state CF organisation. See page 22 for contact details.

### **Other germs affecting children with cystic fibrosis:**

There are **germs found in the environment which can affect people with CF**. The main type of germ is pseudomonas which can be found in stagnant watery environments such as lakes, spas and bathrooms. It is impossible for people with CF to avoid pseudomonas but the risks can be reduced at home and in a school or child care setting.

### **THINGS TO CONSIDER INCLUDE:**

- **Fish tanks in class rooms: ok as long as they have a cover on them.**
- **Water play and water toys with holes in them may pose an infection risk to children with CF.**
- **Excursions, where there is hay or ponds.**
- **Swimming: is great for people with CF, but pool change rooms can be a potential source of infection due to the presence of stagnant water. Often it is best if people with CF towel off at the poolside and then head home to shower. Discuss with child's parents about this.**
- **Soil: gardening at parent's discretion**
- **Air-conditioning in schools, if serviced on an annual basis, reduces risk of harmful bacteria**

## The sweat glands and hydration

People with CF are more susceptible to dehydration as they lose more salt in their sweat. Sports drinks (such as Gatorade, Powerade and Staminade) or cordial with added salt, during and after exercise, are encouraged for people with CF to help them replace the salt lost in the sweat. Some children will take salt tablets at school and easy access to water is also required. More salt is required in the warmer months.



**It is vital for people with CF to stay well hydrated because dehydration can cause the mucus in the lungs to become even thicker and stickier making it more difficult to clear. Dehydration and salt loss can cause irritability, cramps, headaches, lethargy and fatigue.**



## The pancreas and digestion

Approximately 85% of people with CF have **difficulty in digesting food** due to mucus blocking the pancreas in the digestive system. This causes low levels of fat being absorbed resulting in poor weight gain, low vitamin absorption and decreased lung function. These symptoms vary from person to person.



### ENZYME REPLACEMENT CAPSULES AND VITAMINS

☐ Tick if relevant to the child in your class

To assist with digestion of food, **enzyme replacement capsules called Creon or Panzytrat, are consumed with most foods and some drinks.**

How the enzymes are administered to the child depends on the age, level of independence and ability to swallow the capsules whole. Children with CF take between 20 to 24 capsules per day, depending on their weight and age. Speak to the child's parents about how the child usually consumes the capsules.

#### If the child is unable to swallow the capsules whole:

Young children who can't swallow enzyme capsules whole consume the small granules mixed with apple or pear puree. It is important to use food such as apple puree as it is acidic and aids in the digestion of the granules. The parent should supply the teacher with a container which includes the granules and the scoop. The container needs to be kept in a cool, dry place. A teacher assistant or teacher will need to assist the child to take the granules.

### CHILDREN WITH CF MAY HAVE THE FOLLOWING:

- ☐ foul smelling , excessive or urgent poos
- ☐ the need to go to the toilet often and for an extended time
- ☐ flatulence and stomach cramping.

Check the child's mouth and gums for leftover granules at the end of each feed and remove them as granules left in the mouth can cause ulcers. Teachers or teacher assistants should always use antibacterial hand gel before handling the enzyme granules.

#### If the child can swallow capsules whole but requires assistance:

The parent needs to provide a bottle of enzyme capsules which the teacher or teacher assistant can give to the child. Store the container in a dry, cool place. It is not ideal if the child has to go to the office to receive the enzymes as it makes it difficult to then transition to taking them independently.





### If the child is independent in taking the capsules:

The goal is for the child to be able to take his or her capsules independently and have them stored with the lunchbox. (But the lunchbox needs to be somewhere cool and dry). The enzymes are required as a life-long medication to be consumed with nearly every meal, so in the long run, it is easier for the school and also good practice for the child, if he or she can take them independently (but with light supervision from a teacher or teacher assistant).

Individuals may also require vitamin supplements due to vitamin deficiencies but these are usually given at home.

## THE CYSTIC FIBROSIS DIET

☐ Tick if relevant to the child in your class

Approximately 85 % of people with CF require extra calories in their daily diet for energy because of the demands that CF places on the body. The lungs need to work harder and the nutrients consumed are not always being absorbed properly. People with CF are encouraged to eat 20% to 50% more calories in their diet and the easiest way to do this is to eat foods with a higher fat content. An increased salt intake is also encouraged.



A child with CF may have a lunch box containing things like packets of chips, sandwiches spread thickly with margarine, and bars of chocolate. Some parents may worry that their child will stand out with lunch boxes filled with high fat foods so might leave these items for home.

It can be quite difficult for some children with CF to put on weight but being in a healthy weight range is important to maintain a better lung function.

Many parents have to work extremely hard to encourage their child to eat the extra calories they require to stay within a healthy weight range. It is advisable to discuss the child's lunchbox or meals with the parents.

## GASTROSTOMY TUBE (PEG)

☐ Tick if relevant to the child in your class

Some children have a tube inserted into their stomach if they are experiencing severe malnutrition. This tube is called a PEG or gastrostomy tube and sits on the outside of the belly. High calorie liquids and enzymes are administered via the tube through a button. The feeds occur at home during the evenings before the child goes to sleep or while asleep.

The gastrostomy site can be prone to infection and irritation so it must be kept clean and dry. The child's parents will have learnt about how to care for their child's tube. It is not common for complications to occur at school, however please see the PEG section under the Emergency action plan on page 20 for more details.

It is best to avoid contact sports where there is a risk of being hit in the stomach however, non-contact sports are ok. Speak with the child's parent to confirm what activities will be appropriate.



# Tips for enzyme capsules

**Enzyme replacement capsules are taken every time carbohydrates, fats and proteins are eaten to assist with digestion. The capsules are similar to vitamins and are made from the pancreas of pigs and will not harm other people.**

Forgetting a single dose is not catastrophic but if the child regularly misses taking the correct amount of enzymes over a period of time, his or her growth can be affected.

The enzyme capsules **do not** need to be taken with the following foods:

fruit juices	cordial	salad and leafy vegetables
lollies	fruit	icy poles
jelly	sugar	jam and honey.

The amount of capsules taken depends on how much fat is in the food and the strength of capsule being taken. The capsules come in different strengths.

## **Creon 5,000 = 1 capsule per 4g of fat in the food**

How many capsules a child takes in a day will depend on his or her body weight. Discuss with the parent about how many Creon the child needs while at school and how the parent calculates the amount of capsules needed per food item.

The capsules are only effective for half an hour after being taken, so food needs to be consumed within this time.

Sometimes children don't eat all their food or may take a long time to eat, so it can be better for the child to consume half the required dose at the beginning of eating and the remainder once the child is half way through the meal.

If the child takes too many enzymes each day over a week or so, constipation can occur.

If the child is not having enough enzyme capsules or forgets to take them when eating, the child may experience diarrhea.

Enzyme capsules need to be stored in a cool, dark place. Do not refrigerate.

## **BABIES AND TODDLERS**

Babies are given enzymes in granule form with a scoop and mixed with apple or pear puree.

Check the baby's mouth and gums for left over granules at the end of each feed and remove them. Granules left in the mouth can cause mouth ulcers.

Use antibacterial hand gel before handling enzyme capsules or granules.

Parent's contact details: \_\_\_\_\_

How many enzymes per grams of fat: \_\_\_\_\_



## Other considerations

### EXCURSIONS

It is very important for children who have cystic fibrosis to participate in all activities and they should be able to in most cases.

#### EXCURSION CHECKLIST

- ☐ Easy access to toilet?
- ☐ Do they have their enzymes, salt tablets etc.?
- ☐ Are there extra foods to be consumed during the excursion?
- ☐ Have water or cordial readily available.
- ☐ Avoid straw, stables and spas.
- ☐ Maintain good hand washing practices.
- ☐ Take antibacterial hand gel, paper towel and tissues.
- ☐ The parent may want to come along to assist.

### GET INVOLVED BY TAKING THE 65 ROSES CHALLENGE

The red rose is the symbol of cystic fibrosis (CF) because it sounds like “65 Roses”. Each year, the month of May is nationally recognised as CF awareness month and culminates with 65 Roses Day on the last Friday of May.

Individuals and community groups including schools, are inspired to take a 65 Roses challenge during the month of May to raise money for a great cause and to make a difference for people affected by CF.

### Take the 65 ROSES CHALLENGE

If your school or class are interested to get involved all you have to do is:

**1) Pick your date in May, or choose another date that suits your school.**

**2) Pick a challenge or create your own.** (What ideas can the students come up with?)

- ☐ Walk 6.5 km
- ☐ Make 65 cupcakes or 65 mini pizzas and sell them
- ☐ Run around the oval 65 times (between a few classes or students)
- ☐ Students could paint roses on mini canvases and create an art exhibition

**3) Contact your state CF organisation for a fundraising kit and support.** Check [www.cfsmart.org](http://www.cfsmart.org) under the “Get Involved” tab for more details about who to contact and for online resources.

#### Where does the money go?:

The money raised by schools participating in fundraising activities for CF goes towards providing services to people living with CF within your state as well as towards supporting critical research projects. Each CF state organisation provides a variety of support services such as counselling, treatment in the home, equipment subsidies, support of siblings and families living in country areas.



# A summary for managing cystic fibrosis in the classroom

## THINGS TO DISCUSS WITH THE CHILD'S PARENTS:

### Medication:

- ☐ Medication required eg. enzymes, salt tablets, Ventolin and antibiotics.
- ☐ A system for administering enzymes and how many are required for different food items.
- ☐ Parents could provide a list of common classroom foods eg. cupcakes, pikelets or popcorn and how many enzymes their child might need for these types of food. Or see the enzyme chart and bookmarks to download at [www.cysticfibrosis.org/CFSmart](http://www.cysticfibrosis.org/CFSmart) for lists of food and enzyme amounts.
- ☐ If the child is in child care, the parent could be provided with the menus in advance in order to work out the amount of enzymes required.

### Exercise:

- ☐ How much exercise can the child participate in?
- ☐ Do they need extra salt when exercising?

### Toilet habits:

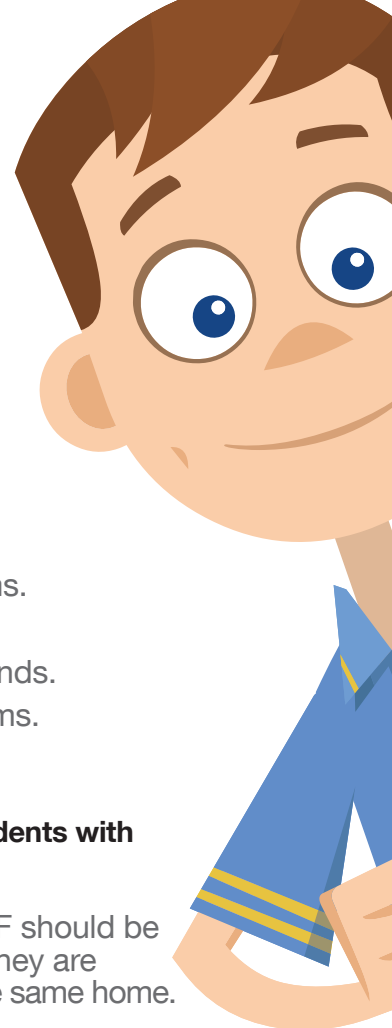
- ☐ Easy (and quick) access to a toilet may be required.
- ☐ The child may spend longer in the toilet than other children

### CF Diet:

- ☐ Extra high calorie drinks or snacks other than what the child might consume at recess or lunch may be needed to assist the child with weight gain.
- ☐ Some children with CF can take a long time to eat all their lunch, plus take their medication, so can miss out on part of their play time. Allowing the child to start eating their lunch a little earlier (to get a head start) can really help the child with CF with their nutritional needs and social needs.
- ☐ If your class is doing a healthy eating program it can be helpful if reference is made to the CF diet and how it is different to the healthy eating pyramid.
- ☐ Sometimes children with CF can become very confused when they learn about healthy eating habits at school and this can negatively impact on their calorie intake at home.

### Things to let the child's parent know about:

- ☐ If the child is extra tired or there is a big decrease in energy levels.
- ☐ If the child is coughing more than usual.
- ☐ Communicate with parents if the child is on the toilet for long periods or going frequently (compared to normal).



## THINGS TO CONSIDER IN THE CLASSROOM OR CHILD CARE CENTRE:

### Infection control:

- ☐ All students should wash their hands with liquid soap and dry with paper towels or hand dryer. Avoid shared towels and shared soap.
- ☐ Have a strong school policy about parents bringing sick children to school.
- ☐ Encourage all students to cough and sneeze into their elbow or sleeve instead of using their hands.
- ☐ Encourage appropriate use of antibacterial hand gel.
- ☐ Keep the child with CF at least 4 metres away from other children who appear to be sick.
- ☐ Avoid children in the class sharing eating utensils, cups or water bottles with other students.
- ☐ Include hand washing and germ lessons as part of the learning program.

### Exercise:

- ☐ Hydration and salt replacement.
- ☐ Extra rest if the child needs.
- ☐ Toilet break.
- ☐ Tissues if coughing up mucus.

### Homework:

- ☐ Discuss with parents in advance about possible homework which could be undertaken if the child has to go to hospital or is at home on IV's.
- ☐ There is also a hospital school service available in each state hospital, to liaise with in regards to school work.

### Environmental risks to discuss with parents:

- ☐ Fish tanks in class rooms.
- ☐ Water play, water toys.
- ☐ Excursions with hay, ponds.
- ☐ Swimming: change rooms.
- ☐ Soil and gardening.

### Cross infection if other students with CF in the school:

- ☐ Only one person with CF should be in a classroom, unless they are siblings who reside in the same home.
- ☐ People with CF should keep more than 4 metres apart from others with CF.
- ☐ People with CF should not travel in the same vehicle or gather in common areas.
- ☐ At outdoor events such as sports days the children with CF must maintain a 4 metre distance from each other.
- ☐ Shaking hands, hugging or physical contact between people with CF is not recommended.
- ☐ If you are aware of a potential cross infection situation, work with both parties ASAP to develop a plan.
- ☐ For further support in this area either contact the CF clinic or CF organisation.

# Student health support plan for cystic fibrosis

This document has been developed as a guide for principals, teachers and parents to use when completing a student health support plan for a child with cystic fibrosis in child care, kindergarten or pre-primary.

School:	Date plan created:
Student's name:	Date for plan to be reviewed for following year:
Date of birth:	
Year level:	Medical Practitioner contact:
Student's teacher:	Phone:
	Email:
	CF Clinic contact:
	Phone:
	Email:
<b>Parent/carer contact information:</b>	<b>Parent/carer contact information:</b>
Name:	Name:
Relationship to student:	Relationship to student:
Home phone:	Home phone:
Work phone:	Work phone:
Address:	Address:
Email:	Email:
<b>Parent responsibilities:</b>	
<input type="checkbox"/> Provide teacher with daily medications required.	Inform teacher of additional medications which may be required during the year. <input type="checkbox"/>
<input type="checkbox"/> Provide teacher with clear information about the medication e.g. how and when to be administered and side effects.	Inform teacher/school when child has to go to hospital, clinic appointments, is home on IV's or is unwell at home. <input type="checkbox"/>
<input type="checkbox"/> Discuss appropriate location for storing medications.	Inform teacher if there are any changes in the child's health. <input type="checkbox"/>
<b>Signs or symptoms to bring to parent's attention at end of the day:</b>	
<input type="checkbox"/> Toilet issues e.g. diarrhea, constipation, frequent trips to toilet or on toilet for a long time.	Complaints of stomach aches or abdominal swelling. <input type="checkbox"/>
<input type="checkbox"/> Lethargic, extra tired.	Markedly decreased or increased appetite. <input type="checkbox"/>
<input type="checkbox"/> Increased coughing.	If child has eaten food without consuming enzymes <input type="checkbox"/>
<input type="checkbox"/> Small amount of blood in mucus.	



Medications	Reason used	When required
<input type="checkbox"/> Enzymes	<i>To assist with digestion of food.</i>	<i>With most meals and snack.</i>
<input type="checkbox"/> Salt tablets	<i>To reduce risk of dehydration and to replace loss of salt from body.</i>	<i>Mainly needed in summer.</i>
<input type="checkbox"/> Inhaler e.g. Ventolin	<i>To open airways and improve oxygen intake.</i>	<i>During sport, exercise.</i>
<input type="checkbox"/> High fat drinks, extra snacks	<i>To assist with the amount of calories required for a person with CF.</i>	
<input type="checkbox"/> Antibiotics	<i>To treat lung and sinus infections.</i>	
<input type="checkbox"/> Vitamins	<i>To treat vitamin deficiency associated with CF.</i>	
<input type="checkbox"/> Other		
Other considerations	Reason	Management in class
<input type="checkbox"/> High fat diet	<i>To assist with the amount of calories required for a person with CF.</i>	<i>When discussing healthy eating, mention different diets eg, high fat CF diet.</i>
<input type="checkbox"/> Easy access to water bottle and drinks such as cordial or Gatorade	<i>To avoid dehydration, mainly needed in summer.</i>	<i>May have dark drink bottle to conceal if child having cordial instead of water.</i>
<input type="checkbox"/> Infection control	<i>Flus, colds, gastro, whooping cough etc can pose a greater risk to children who have CF.</i>	<i>Good hand washing practices of all students in class. Unwell students to stay home. Class learn about germs and good hygiene etc.</i>
<input type="checkbox"/> Easy access to toilet	<i>Bowel issues, embarrassment at amount of flatulence.</i>	<i>Have an agreed signal with the child, so they can easily indicate when they need to go. Discuss with parents, or child the best strategy.</i>
<input type="checkbox"/> Coughing	<i>Very common for children with CF to have a cough, clears mucus in lungs.</i>	
<input type="checkbox"/> Regular absence from school due to hospitalisation and clinic appointments.	<i>If child has an infection in lungs or gastro issues, needs IV antibiotics etc. Can be up to two weeks in hospital.</i>	<i>Discuss with parent re: type of catch up work which would be suitable and achievable.</i>
<input type="checkbox"/> Tired/lethargic	<i>Common for some children to be extra tired, lungs are working extra hard.</i>	<i>May need a few minutes to rest.</i>
<input type="checkbox"/> Exercise	<i>Very good for CF, but sometimes child may not be able to perform consistently, depending on lung function.</i>	<i>Mau need to participate in less strenuous activities e.g.. helping setup equipment.</i>
<input type="checkbox"/> Cross infection risk if another student with CF attending the school.	<i>Risk of passing germs to children with cystic fibrosis that don't affect other people.</i>	<i>Avoid two children in same year group with CF if possible (unless siblings). If big age gap, and wont cross paths, shouldn't be a problem.</i>
<input type="checkbox"/> PORT, PEG or PICC line	<i>Increased calorie feeding via tube / administration of intravenous antibiotics while participating in a Hospital in the Home program</i>	<i>Avoid certain activities.</i>

Adapted from The cystic fibrosis Care Plan from DECS 2009, South Australia

# Emergency action plan

Situation	Symptoms	Action required
Dehydration	<i>Lethargy, thirst, dry sticky mouth, decreased urine output- 8 hrs without urination (school aged child), fever, headache, rapid breathing, fast pulse, vomiting.</i>	<i>Call parent/carer. Give fluids (gastrolyte or similar if available), keep cool out of sun If pulse remains above 110 after 15 minutes rest consider ambulance if parent not able to come straight away.</i>
PICC/Port problems	<i>INFECTION: Skin around port / catheter is painful, red, hot swollen or oozing (pus / blood), fever.</i>  <i>DAMAGE: cut line, lost cap on end</i>  <i>WET DRESSING.</i>  <i>PICC LINE accidentally pulled out.</i>  <i>Chest pain accompanied by shortness of breath</i>	<i>Call parent / carer.</i>  <i>Kink line so air does not get in. Call parent/carer/ ambulance .</i>  <i>Needs replacement - call parent.</i>  <i>Apply pressure to area for 5 minutes to prevent / stop bleeding. Call parent/carer/ ambulance.</i>  <i>Call parent / carer or ambulance</i>
Bowel obstruction	<i>Severe stomach ache, vomiting.</i>	<i>Call parent/carer.</i>
Blood in mucus (uncommon)	<i>Small &lt; 5 ml</i> <i>Moderate over 5 ml</i>  <i>Large &lt; 240 ml</i>	<i>Inform parent the same day.</i> <i>Call parent/carer or ambulance if can't reach parents.</i> <i>Call ambulance.</i>
PEG feeding tube or button problems (not many students have this)	<i>Leaking around tube, pain.</i>  <i>Accidental dislodgement.</i>	<i>Call parent/ carer.</i>  <i>Call parent immediately, tube needs to be replaced ASAP. Country schools if close to hospital take child to ED and call parent.</i>
Rectal Prolapse (uncommon)	<i>Rectal pain, bleeding, protrusion of rectum through anus.</i>	<i>Reassure child, lie quietly if painful to sit.</i> <i>Call parent/carer.</i>

## Sample letter for other parents



## Dear Parents and Caregivers,

This note is being sent home to remind you of how we can help everyone in our school community to be as healthy as possible and reduce spreading germs by keeping children at home if they are unwell or still recovering from a recent contagious illness.

**Children who have suffered from vomiting, diarrhea, the flu, chest infections, chicken pox, whooping cough and other contagious conditions need to be kept at home until they are completely recovered.**

We also have a child in our class who has **cystic fibrosis**. Cystic fibrosis is a genetic illness that causes a build-up of mucus in the lungs and pancreas, causing problems with both breathing and digestion. Common colds and other viruses can have more serious consequences for people with this condition, possibly resulting in several weeks in hospital. Continuous infections for a person with cystic fibrosis can cause scarring on the lungs and decrease their capacity to function. One important part of the daily medical regime that a person with cystic fibrosis needs to follow includes minimising the risk of catching infections from others.

Illness/Virus	Contagious for...	Stay home when...
<b>Influenza (Flu)</b> Symptoms include headaches, high temperature, feverishness, chills, dry cough, muscle aches, sore throat, loss of appetite and chest pain.	A person with the flu can transmit the virus one day before they even begin to show symptoms of the virus. They will continue to be contagious for 5 days after they develop the symptoms even if they are still coughing and sneezing.	If your child has a high temperature. If you child has the flu, it is usually ok to send them back to school after 5 days.
<b>Common cold viruses</b> Several different viruses can cause colds. They usually affect the nose and throat.	The common cold is contagious between 24 hours before onset of symptoms until 5 days after onset.	If your child has green mucus.
<b>Chicken pox</b> Symptoms include fever, feeling ill, sore throat, and loss of appetite.	A person who has chicken pox is highly contagious and it can be passed on between 1 and 5 days before the person has shown signs of a rash. The person with chicken pox is contagious for 5 days after the onset of the rash until lesions crust over.	Keep at home until the sores have crusted over or the GP gives the all clear.
<b>Whooping cough</b> Symptoms begin like a cold with runny nose, tiredness, mild fever and poor appetite. Then bouts of coughing develops followed by characteristic "whooping" sound when breathing in.	A person with whooping cough can be infectious for up to 3 weeks after the onset of the cough. If antibiotics are taken the person will be infectious until 5 days of taking a 10 day course of antibiotics.	Keep at home until no longer infectious. Other members of the family may need to take antibiotics too.
<b>Gastro</b> Symptoms include stomach pain or spasms, diarrhea and/or vomiting.	After exposure to the virus, a person can become sick within 18 to 72 hours. Most people feel better after a day or two, but are still contagious for at least 3 days. If a person has gastro they should not prepare food for 72 hours.	Keep your child at home for at least 24-48 hours after he/she has been affected by gastro.

It is impossible to avoid all infections, but by taking precautions we can lower the risk of catching and spreading them to each other and to particularly vulnerable classmates with conditions such as cystic fibrosis. We appreciate your support and cooperation.

**Please contact me if you have any questions.**

Kind regards

**A.T.Eacher**

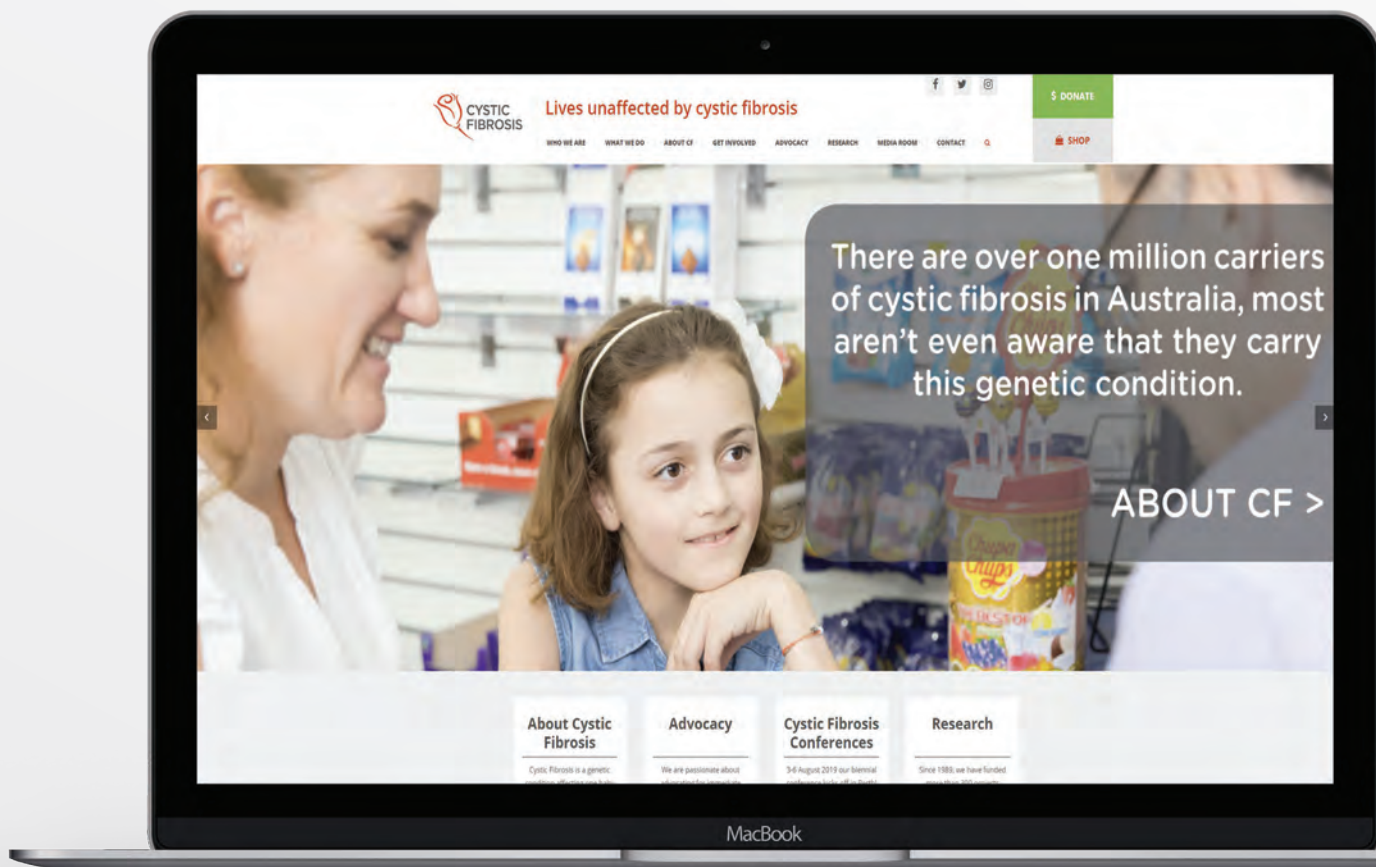
School principal/teacher

## Useful support resources

There are occasions when teachers need to find out more details about their particular student who has cystic fibrosis. The cystic fibrosis nurse specialist at your state's CF clinic will be the best point of contact. Also if you want to find out more about providing homework for the child while they are in hospital, the details of the hospital schools are below.

STATE	CYSTIC FIBROSIS CLINIC	HOSPITAL SCHOOL SERVICES
VICTORIA	<b>Royal Children's Hospital</b> T: (03) 9345 5522  <b>Monash Medical Centre</b> T: (03) 9594 6666	<b>Royal Children's Hospital Education Institute</b> T: (03) 9345 9700 E: education.institute@rch.org.au W: www.rch.org.au/education/students/learning-in-hospital/
NEW SOUTH WALES	<b>The Children's Hospital at Westmead</b> T: (02) 9845 2156 W: www.chw.edu.au  <b>Sydney Children's Hospital</b> Randwick T: (02) 9382 1332 W: www.sch.edu.au  <b>John Hunter Children's Hospital</b> Newcastle T: (02) 4921 3676	<b>The Children's Hospital School at Westmead</b> T: (02) 9845 2813 E: childhosp_s.School@det.nsw.edu.au W: www.chw.edu.au/kids/school/  <b>Sydney Children's Hospital School</b> Randwick T: (02) 9382 1510  <b>John Hunter Children's Hospital School</b> Newcastle T: (02) 4985 5090
ACT	<b>Canberra Hospital</b> T: (02) 6244 2222	
QUEENSLAND	<b>Mater Children's Hospital</b> T: (07) 3163 811  <b>Royal Children's Hospital</b> T: (07) 3636 3777	<b>Mater Hospital Special School</b> T: (07) 3004 7888 E: mhss@eq.edu.au W: www.materschool.eq.edu.au  <b>Lady Cilento Children's Hospital</b> T: (07) 3068 2303 E: LCCH_CF@health.qld.gov.au W: www.childrens.health.qld.gov.au
SOUTH AUSTRALIA	<b>Women's and Children's Hospital</b> T: (08) 8161 7000	<b>Hospital Education Service Women's and Children's' Hospital (WCHN)</b> T: (08) 8161 7262 E: HES.info652@schools.sa.edu.au
WESTERN AUSTRALIA	<b>Perth Children's Hospital</b> T: (08) 6456 2222	<b>Principal and general enquiries:</b> T: (08) 6456 0383 E: ssenmmh@education.wa.edu.au W: ssenmmh.wa.edu.au
TASMANIA	<b>Royal Hobart Hospital</b> T: (03) 62 22 8475	<b>Tasmanian eSchool</b> Southern Campus T: (03) 6282 8181 Northern Campus T: (03) 6323 8999 E: tasmanian.eschool@education.tas.gov.au

To see what your state's cystic fibrosis organisation provides for CF services and resources, please visit the Cystic Fibrosis Australia (CFA) website:  
[cysticfibrosis.org.au](http://cysticfibrosis.org.au)












## Other resources

### CF SMART RESOURCES

A selection of resources for teachers and students are available online at [www.cfsmart.org](http://www.cfsmart.org)

-  Sample letter to other parents about coming to school unwell.
-  Enzyme bookmark.
-  cystic fibrosis summary for relief teachers.
-  Student health support plan for cystic fibrosis.
-  Lesson plans and activities for students.
-  Hand washing poster for the classroom and bookmarks for students in the class.
-  “Good Clean Hands” a short animation available on YouTube about good hand washing practices and reducing the risk of spreading germs and why this is so important for children with CF, as well as everyone else.



### ED MED

ED Med is a one hour professional development session about long term health conditions provided free to schools for all staff. Each participant will receive an EDMed reference book and a teacher handout.

For more details look on the Ronald McDonald learning program website.

<http://learningprogram.rmhc.org.au/about/edmed-professional-development.php>

### KIDS HEALTH

A great website with trustworthy information about children and teenagers free of "doctor speak". For children, parents and educators.

[www.kidshealth.org](http://www.kidshealth.org)

### GETTING NOSEY ABOUT CF WITH OLLIE AND NUSH

An animation made by the CF UK Trust which helps explain to children what cystic fibrosis is.

<https://www.youtube.com/watch?v=WuI72eMrIQI>



<https://youtu.be/d-WVOBTW6iA>

## ACTIVITIES FOR YOUR STUDENTS

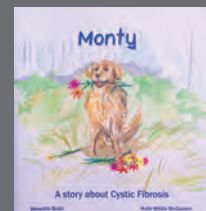
### KINDERGARTEN TO YEAR 3

- ☐ Lesson plans for K – Pre-primary, see [www.cfsmart.org](http://www.cfsmart.org)
- ☐ Colouring in sheet “Have you washed your hands”, see [www.cfsmart.org](http://www.cfsmart.org)
- ☐ Make a balloon car.
- ☐ Make a rose bush with 65 handmade roses.
- ☐ Games involving blowing (physio for children with CF involves different breathing games and breathing devices).
  - Blow pom poms through an obstacle course of blocks (physio).
  - Using a straw, have a race with other students to blow cups across a table.
  - Blow pom poms across a straight line of tape.
- ☐ Do a 65 Roses challenge such as jump 65 times, as a class read 65 books in 65 days (at school), run 65 metres, eat 65 cakes between the whole class.
- ☐ Book a visit from the education officer at CFWA to do a class activity and learn more about CF.  
[education@cysticfibrosiswa.org](mailto:education@cysticfibrosiswa.org)
- ☐ Watch the film “Good Clean Hands” on Youtube about hand washing and germs.



## Books

### Monty A story about cystic fibrosis by Meredith Bubb



Monty is a whimsical canine, whose owner has cystic fibrosis (CF). Through Monty we experience the daily routines of living with CF as well as heading off to hospital. The book deals with a number of concepts pertaining to the care and treatment of a person with CF, complete with information and suggested extension activities.

*cystic fibrosis Queensland*, \$11.00  
[www.cysticfibrosis.org.au/qld/allitems/](http://www.cysticfibrosis.org.au/qld/allitems/)

### The Mystery of the Sixty-Five Roses by Sandi Bowie



Jeremy is a curious 10 year old who likes to sneak and spy. He wants to find out why his neighbour Darcy has had the week off school. He slips into "Super Stealth Mode" to locate the mysterious sixty-five roses that Darcy tells him about, because he thinks they might just be the answer to getting some time off school.

*cystic fibrosis Western Australia*, \$12.00  
[www.cysticfibrosis.org.au/wa/allitems?p=3](http://www.cysticfibrosis.org.au/wa/allitems?p=3)

### A Germ's Journey by Thom Rooke, MD



Where did your cold germ come from? Where is it going next? A germ's journey is filled with shuffles, sniffles and sneezes. A great resource to teach children about how easily germs can spread. (More for children aged 5 and upwards)

### Germs are not for sharing by Elizabeth Verdick



A book especially for young children which teaches them the basics of not spreading germs.

## Notes

[illegible]



Visit the CFSmart website for more useful resources  
and information about cystic fibrosis for teachers,  
parents and students.

[www.cfsmart.org](http://www.cfsmart.org)