

# STARTING SCHOOL WITH CYSTIC FIBROSIS



Published 2018

Special thanks to the parents who provided advice and input for this resource. For privacy reasons we have removed personal details.

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# CHOOSING A SCHOOL

Choosing a school for your child is a personal decision. There are many things to consider including location, public versus private and school size. When you have a child with CF, there will be other factors impacting your decision on which school will be best for your child.

If you are thinking about choosing a school, arrange a meeting to speak with a senior staff member, such as the deputy, to gauge if you feel comfortable with the level of support the school is able to offer your child. Some of the things you may wish to discuss are:

- Any other children with CF attending the school
- How does the school cater for students who have medical needs?
- Is the school interested in learning about CF and how it impacts a child in school?
- What is the school's policy for storing and administering medications such as enzymes, salt tablets or antibiotics?
- What is the school's approach to the health and wellbeing and pastoral care of students? How does the school assist students in these areas, e.g. what programs, staff, education provided for students and staff?

- Is there easy access to liquid soap and hand drying facilities for kindergarten, pre-primary and primary school classes? Is there a whole school approach to good hand hygiene?

*"I visited three different schools before deciding on our local primary school. I was looking for a good fit and liked the ethos at our local school"*

**Mum of a 6-year-old**

*"Our school was local to us, so was an easy choice. I think if they hadn't been so on board with helping us manage CF, we may have looked at other schools in the area"*

**Mum of a 9-year-old**



# COLLABORATING WITH THE SCHOOL

## Health Care Summary/ Health Care Plan

Schools require parents or carers to fill out a Health Care Plan which needs to be updated annually. The Health Care Plan is a helpful tool to communicate with teachers and staff about your child's health needs while at school. It should include treatment details, medications, dietary requirements, contact details for parent/carer and relevant health professionals as well as an emergency action plan if needed. A copy of the Health Care Plan should be given to the class teacher and will need to be updated if anything changes during the course of the year. Schools provide their own Health Care Plan and there is a CF specific example on the [www.cfsmart.org](http://www.cfsmart.org) website which is useful as a guide:

[www.cfsmart.org/wp-content/uploads/2017/01/CFF035I-CF-Health-support-plan-Primary.pdf](http://www.cfsmart.org/wp-content/uploads/2017/01/CFF035I-CF-Health-support-plan-Primary.pdf)

A GUIDE TO CYSTIC FIBROSIS FOR  
EARLY CHILDHOOD EDUCATORS

## 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 (CF) in child care, kindergarten or preprimary. A blank form is available from [cfsmart.org](http://cfsmart.org)



School:		Date plan created:	
Student's name:		Date for plan to be reviewed for following year:	
Date of birth:			
Year level:			
Student's teacher:		Medical Practitioner contact: Phone: Email: CF Clinic contact: Phone: Email:	
Parent/carer contact information:		Parent/carer contact information:	
Name:		Name:	
Relationship to student:		Relationship to student:	
Home phone:		Home phone:	
Mobile:		Mobile:	
Work phone:		Work phone:	
Address:		Address:	
Email:		Email:	
Parent responsibilities:			
Provide teacher with daily medications required.		Inform teacher of additional medications which may be required during the year.	
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 treatment or is unwell at home.	
Discuss appropriate location for storing medications.		Inform teacher if there are any changes in the child's health.	
Signs or symptoms to bring to parents' attention at end of the day:			
Toilet issues e.g. diarrhea, constipation, frequent trips to toilet or on toilet for a long time.		Complaints of stomach aches or abdominal swelling.	
Lethargic, extra tired.		Markedly decreased or increased appetite.	
Increased coughing.		If child has eaten food without consuming enzymes.	
Small amount of blood in mucus.		Changes in the student's behaviours.	

CFSmart | cystic fibrosis education program

WWW.CFSMART.ORG

"We have a health care plan in place but also have ongoing communication via emails and face-to-face discussions"  
Mum of a 5-year-old



### **Disclosure: Who Should Know About CF in the School Community?**

It is important to identify a key staff member who understands your child's needs at school. It is also important for your child's class teacher and teacher assistants to be well informed about CF.

Telling people within the wider school community is a personal decision. Some parents want the whole school community to understand about CF and others want only the class teachers to know. As your child journeys through school, you may decide to tell more people about CF.

These may include other teachers, parents and other students.

*"We were very upfront with all the school staff. We believe that CF is a medical condition that the school needs to consider, just as they need to consider allergies and other medical issues. We have found the school and the parents to be very accommodating and inclusive. We want to keep our daughter as healthy as possible and sometimes that takes more than us, it takes a community"*

**Mum of a 6-year-old**





### Educating the Teacher about CF

It is important the teacher understands the needs of your child while he or she is at school. They should have a copy of your child's health care plan; however, it is also beneficial to speak one-on-one with them. Try and set up a meeting before school starts, if possible, or within the first week of school.

#### Key points to discuss are:

- What is CF?
- Medications, e.g. enzymes, salt, Ventolin, antibiotics
- Dietary requirements e.g. extra snacks needed
- Bowel issues/toilet needs
- Infection prevention and control
- Dehydration: need for a water bottle/ salt tablets or solution or salty drinks
- Absences
- Anxiety or concerns that you or your child may have

Educating the class teacher is an ongoing process and will need to be revisited every year with new teachers, and sometimes again during the year if there is a change in teacher or your child's needs change.

*"The school have been very accommodating. At the beginning of each school year, our child's teacher and support staff meet with our local CF organisation to discuss CF in general, and some more specific information about our daughter's needs"* **Mum of a 7-year-old**

*"I print off the CFSmart booklet from the website and highlight the points relevant to my child. I give this to the teacher prior to my meeting and then go through it with them. I find them reading it beforehand is better as then they can ask me questions too"* **Mum of a 9-year-old**

## Educating Other Parents

Some people are very open about CF, whilst others are very private. Most people find that being open with other parents creates a more supportive community.

Schools are often happy to send a letter to other parents about why it's good to keep unwell children at home. It does not have to identify your child but can provide general information about CF and cross infection.

- There is a sample letter that schools can adapt or use available on the CF Smart website
- Download a sample bookmark to distribute to parents providing basic information about CF

Talk to your school about other ways to educate parents, which may include:

- Orientation Day – prior to starting school
- Parent Information Night - usually held in the first few weeks of school at the start of the year
- Written information
- Email explaining CF and the risks to their child in terms of unwell children coming to school

*"After much thought, I decided to be open with staff and parents at the school from the beginning, as I felt that people could make informed decisions based on this knowledge. For example, I couldn't be upset about other students being unwell around my daughter if the parents weren't aware of the risk involved. I have found the overwhelming majority of people to be understanding and very supportive"* **Mum of a 6-year-old**

## Educating Other Students

In some cases, particularly as children get older, other students may ask questions about enzymes, the high fat diet or why the student is away so much. It can be useful to provide basic information and be open to answering questions if the child with CF is comfortable with this idea.

There are short animated films available on YouTube and on the [www.cfsmart.org](http://www.cfsmart.org) website which are useful tools for explaining CF to children, as well as lesson plans for teachers, if it is appropriate to go into more depth.

- "Getting Nosed about CF with Olli and Nush"
- "Good Clean Hands"
- Lesson plans with topics covered such as "What is Cystic Fibrosis?", "What are lungs?", "What are Germs?" and "Hand Washing"



# MANAGING CF AT SCHOOL



There are many aspects of CF care that will need to be discussed with your school. Providing education about the CF diet, medications including enzymes and salt, dehydration, infection prevention and control and other medical issues, will help the school understand how to support your child while they are at school.

## The CF Diet

It is important that the school understands the high calorie, high salt diet as part of the treatment plan for most children with CF, and that sometimes your child's food may not be in line with the school's healthy eating policies. Learning

about the traditional healthy eating food pyramid, as well as 'green light' food and Crunch & Sip may cause confusion for your child and have them questioning why their diet might look different or be considered unhealthy. Other children might also have questions about why your child is allowed different foods. Many parents have found it helpful for the teacher to make reference to other diets (and the CF diet specifically if your child is happy with this) if the class is learning about healthy eating.





## Lunch Box Ideas

School lunchboxes are a challenge for most parents of children with CF, particularly if your child struggles to maintain a good weight. Involve your child in choosing their food for the coming week and if you have time, bake items which you can freeze in advance and pull out on the day, e.g. muffins, mini quiches, meatballs. The following ideas might help you when planning with your child:

- sandwiches with high energy filling e.g. cheese, avocado
- cheese sticks
- full fat yoghurt
- muesli bars (minus nuts if the school is nut aware or nut free)
- dried fruit, e.g. sultanas, apple
- plain biscuits with butter
- macaroni cheese
- banana bread
- vegie sticks with high calorie dip
- hard boiled eggs
- mini pizzas
- muffins
- popcorn with butter and salt
- crackers with butter, vegemite and cheese
- Milo
- instant pudding (vanilla, chocolate)
- pikelets cooked with cream, or buttermilk
- mini quiches, sausage rolls, meat balls
- soups, spaghetti bolognaise etc. in winter (in Thermos)

*"My son didn't eat very well when he first started school. He wanted to get out and play and food wasn't a priority. I was able to increase the calories in his meals before and after school to make up for this"*

**Mum of a 7-year-old**

*"I add crackers and pretzels for salt and sometimes give her basmati rice with lots of herb salt which she loves. On extra hot days I send a couple of Hydrolyte tablets with water"*

**Mum of a 6-year-old**

## Medications

Management of medication at school is often one of the major concerns for parents. All medications required at school must be included in their Health Care Plan and discussed with the school. There are many things to consider including where medication will be stored, how it will be administered, and the amount of assistance or supervision required. Each school will have their own medication policy and it is important to start discussions early to set up a system that works for you, your child and the school.





## Enzymes

Most children with CF need to take enzymes every day. Before your child starts school, it is important to work out a suitable system, so you can prepare them for taking their enzymes at school. Some of the things to consider when discussing enzymes with the school are:

- **Storage:** Some schools will be happy for a daily dose to be kept in the child's lunch box, whereas others will require them to be stored in a secure place such as the teacher's desk, front office or health centre. As they get older, having enzymes in their lunch box is ideal, however, at age 4 or 5, they might not be ready for that level of responsibility.
- **Dosage:** Work out a system for how your child and/or staff member will know how many enzymes are needed with each meal or snack. Many parents use stickers, ziploc bags and Tupperware containers to communicate enzymes required with each food item. Consider occasions where extra enzymes may be required, for example, birthday

cakes or class cooking. CFSmart has an enzyme chart that you can fill out and leave with the teacher for such situations.

- **Administering enzymes:** In Kindergarten, your child may require support from a staff member when taking enzymes. This will depend on your child's level of independence. If your child is taking enzymes with apple puree, assistance from the staff member may be greater. Often children starting Kindergarten haven't yet started to swallow enzyme capsules whole, so don't panic if this is the case.

*"In Kindy I provided a lunch box with all the items needed for Creon dispensing, and also provided a jar of apple purée. I went in and showed the teacher and education assistant how to give the Creon and ensured they knew to ask if they ran out of anything they needed to give the Creon"* **Mum of a 9-year-old**





*"I have little Tupperware containers that I pack with each thing. My daughter is now 12 and has been doing this from Kindy. I thought with high school she would want me to stop but she likes not having to think about it. She works out her dose herself (everywhere else), but I like that she has one less thing to worry about at school"* **Mum of a 12-year-old**

*"We're still at preschool - not up to capsules yet. We used stickers with the amount of enzymes required"* **Mum of a 4-year-old.**

## Salt

If your child requires salt supplements at school, it is important to discuss storage, dosage and how it will be administered with the school and relevant teachers. Some children will have salty snacks and possibly add salt to their water. Others will have a tablet or liquid supplement that will be part of their Health Care Plan and teachers may need to assist.

Remember, the important role of administering medication may be a bit daunting for the school. They will want to make sure they do it correctly and may be worried about getting it wrong, or the repercussions of your child not eating properly after taking their enzymes. It is important to provide guidance and reassurance. It is also vital to work out a good communication system that works for both you and the school, whether that be chatting to them at the end of each day (not always possible), emails, or a communication book. Once a good system is developed it becomes second nature.

## Exercise and Dehydration

It is important to discuss dehydration risks with the school and the class teacher in particular. Make sure they know that your child will need regular access to water, and possibly reminders to drink enough throughout the day. This is particularly important in warm weather or during physical activity. If your child needs extra assistance with hydration, such as extra water,



cordial, sports drinks, salty snacks or even salt supplements while at school, this should be part of their Health Care Plan and discussed with the class teacher.

Make sure the teacher is aware of signs of dehydration and how to act if they think your child is dehydrated. Your child might need:

- a water bottle on their desk at all times
- cordial or a sports drink
- to carry a water bottle to other subjects, including sport, library or art class
- salt tablets or liquid
- salty snacks

For further information on exercise and dehydration please see our Factsheets

*"My daughter carries her drink bottle at all times (e.g. to sport, library, assembly). The school schedules sport in the mornings for her class, in order to avoid the heat. On sport days, I put extra salt tablets in her lunchbox, with her enzymes. The class teacher also has a supply of salt tablets, in case she needs them"* **Mum of a 6-year- old**

*"My son takes three drink bottles to school with cordial. He has one with him at all times. The others are kept in a fridge. His teacher makes sure he has one with him for sport"*

**Mum of a 7- year- old**


## Infection Prevention and Control


### General Illness and Germs

Avoiding infection is a very common and valid worry among parents of children with CF, particularly in the school environment. Children often pick up germs such as colds and flus in school, especially in the younger years, and your child will undoubtedly pick up some of the usual bugs and illnesses that are going around. Risks can be minimised however by doing the following:

- Teaching your child good hand hygiene; how and when to wash their hands in all situations including at school.
- Encouraging your child to discreetly move away from other children who are coughing or sniffly. (Let the class teacher know your child may do this and why).





- 
- If appropriate, teach your child to use anti-bacterial gel while at school. You could also request the teacher encourages the rest of the class to use this.
  - Ask for your child to have separate equipment such as pencils, scissors, glue and separate play dough, rather than sharing.

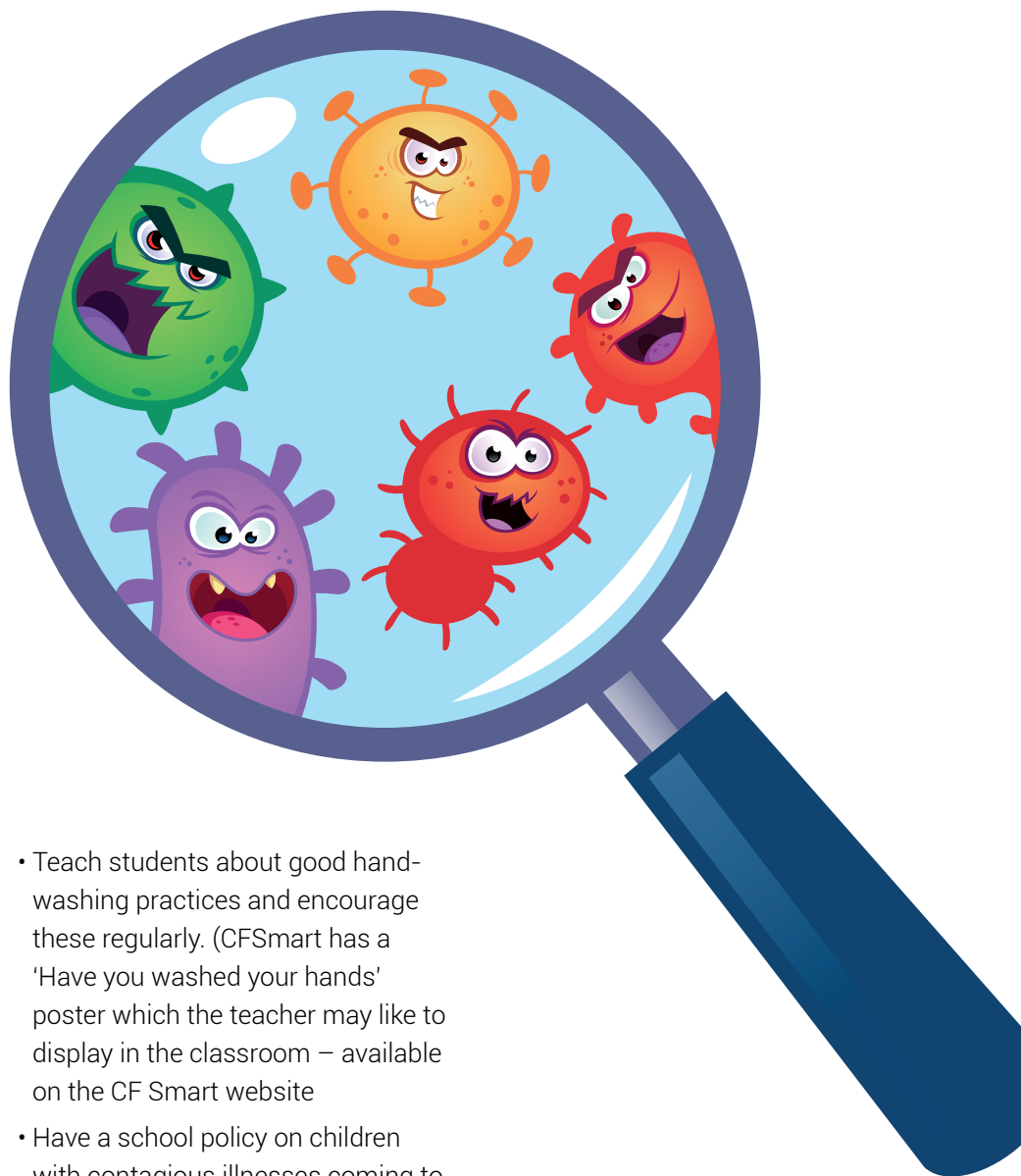


*"We have supplied a 'Germ Station' for my daughter's classroom with tissues, hand sanitiser and an enclosed rubbish bin. She has her own pencil case with all of her stationery, rather than using the shared ones"*

**Mum of a 6-year-old**

What the school can do:

- 
- Provide access to adequate hand washing and hand drying facilities which include liquid soap and either paper towel or hand dryer
  - Allow access to water bottle at all times and avoid using water fountains
- 



- Teach students about good hand-washing practices and encourage these regularly. (CFSmart has a 'Have you washed your hands' poster which the teacher may like to display in the classroom – available on the CF Smart website)
- Have a school policy on children with contagious illnesses coming to school
- Send a letter home to other parents about sending sick children to school, with specific reference to there being a child with CF in the school (if you wish to disclose)
- Staff complete the CFSmart E-learning modules to assist in their understanding of CF
- Develop a Risk Minimisation Plan with the school



*"My child has hand sanitiser in her school bag. The school makes the children wash hands before eating. I have asked the teacher to move my daughter if she is sitting next to any child that is coughing. My daughter is aware of this and she will often remove herself"*

**Mum of 6- year-old**

*"My son has started Kindergarten this year. The entire staff were asked to do the CFSmart education modules and ensure their class learns to wash their hands correctly (with help of CFSmart posters). Hand sanitiser is also available in his classroom"*

**Mum of a 5-year-old**

## **Environmental Risks**

As you probably know, there are germs in the environment which can affect the lungs of people with CF. Certain environments can pose a risk, including mud, stagnant water, rotting vegetation, hay and fungi. This has implications for certain pre-school activities such as playing outdoors in the mud, water play where the water is pumped through pipes and gardening, as examples.

Practical adjustments can help reduce the risk, such as ensuring water play is with fresh, clean water, and avoiding squeaky toys that can hold water.





You can speak with your CF team about activities you have concern with and get their advice. If you or they feel an activity poses a risk, then the school could encourage your child to be involved in a different way.

It is important to weigh up the risk of participation, wherever possible, your child should be included in activities, but perhaps in a different way.

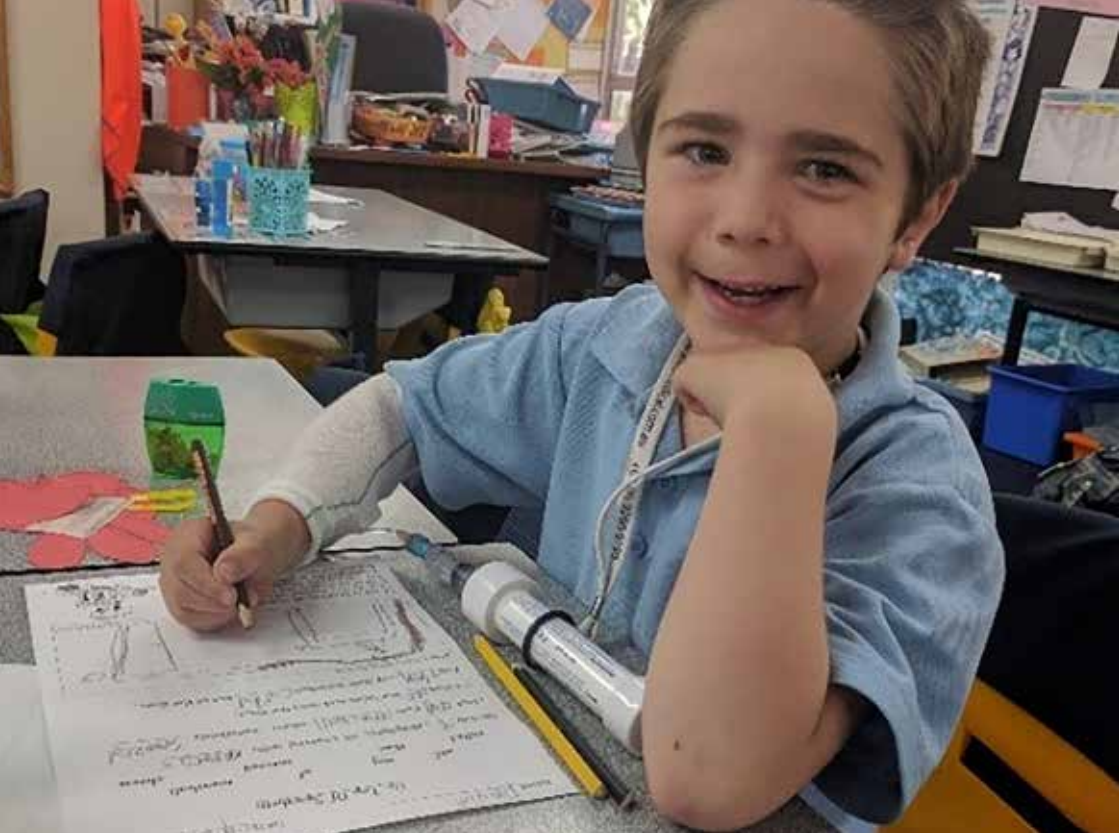
- For more information, see our Fact Sheets on the CF Smart website.

### **Cross-Infection**

It is important the school understands the risk of cross-infection if there is

more than one child with CF attending the school. This does happen occasionally and requires a Risk Management Plan to ensure that the risk of cross-infection is minimised.

Children with CF should not be in the same classroom, however children in different year groups can be managed. If you are aware of a potential cross-infection situation, discuss with the school administration as soon as possible to develop a plan. In the case of siblings with CF, this would not be a concern given that they live together.



## Absences

You child is likely to have some absences from school due to general illness, clinic appointments or hospital admissions. It is important to let teachers know in advance, if possible, if your child may be absent from school.

Don't worry too much about your child missing school at such a young age. As your child gets older, there is a hospital school support to help them keep up-to-date during admissions. The hospital school service at Perth Children's Hospital can liaise with your child's teacher to arrange school work.

Some children may return to school with a PICC line. This is a personal

decision, and if your child does this, the teacher should be provided with information about keeping the PICC line safe at school.

In most of the hospitals in Australia, there is a school hospital.

## PICCs, Ports and PEGs

If your child has a PICC line or Port for administering IV antibiotics, or a PEG for supplemental feeding, the school, will need general information about how to manage these at school. Although they will not need to be used at school they will need education about keeping them safe in the school environment.

For more information please see our Fact Sheets.

# PREPARING FOR THE FIRST DAY

It is important to prepare any child for the transition to school. You should talk positively and be excited about school. Show your child that you are happy and confident about them starting school, as this will positively influence their attitude.

*"Talk it up as much as you can! Talk about independence, being a big kid, making friends, activities they might do. Pack a lunchbox a week or so before so your child can practice taking their Creon (if they take capsules) and also eating their snacks at the right meal time"*

**Mum of a 9-year-ol.**

Tips to prepare your child for school:

- Encourage your child from a young age to have good hand hygiene, explaining when, why and how to properly wash their hands.
- Take your child to the school during the holidays or on the weekend. If possible, let them have a play on the playground and show them where their classroom will be.
- A week or more before school starts, practice the daily routine for school days and talk about what will be involved such as doing physio before school, getting dressed, packing their bag and lunch box and what will happen once they get home from school.







- Talk about what will happen while they're at school such as all the fun things they'll do, and discuss how CF related things will fit in, e.g. taking enzymes and washing hands.
- To prepare your child for eating lunch from a lunch box and taking their enzymes, have some picnics at home or the park. Discuss when they will take their enzymes and where they will be kept. Explain how they will know how many enzymes to take with each food item.

*"Try to have them as independent as possible before they start, and arm them with answers, just in case other kids ask questions (they probably will). Remember, they are kids first, and they are going to be at school for a long time. We want it to be a positive thing for them, as hard as it is for us"*

**Mum of a 6-year-old**

*"I took my son to the school one day during the holidays before he was due to start and let him play on the playground - he was sold!"* **Mum of a 7-year-old**




# PARENT ANXIETY

It's perfectly understandable, and normal, to feel anxious about your child starting school or when your child is unwell. You are not alone. Starting school is an important milestone for you and your child.

There are a few things you can do to help alleviate your anxiety:

- Provide the school with as much CF education as you can so they have a thorough understanding of your child's needs.
- Have a good communication system with the school and encourage them to contact you throughout the day if they have any questions or concerns.
- Have ongoing, short talks with your child about CF and what they need to do at school and why. Provide them with the opportunity to discuss any questions or worries they might have too.
- Do something on your child's first day or week of school to distract yourself if you are feeling anxious e.g. catch up with friends.
- Share feelings with other CF parents who have been through the process.



*"It's normal to feel anxious about handing care of your child over to the teachers at your school. I think meeting the teacher before school starts is a great way to ensure they understand how to care for your child. If you have any concerns make sure you address them as soon as you can, so the school can work with you to find a solution" **Mum of a 9-year-old***

*"Get time out, exercise, ask for help when you need it and try not to worry too much about things you can't control like your child catching colds" **Mum of a 5-year-old***

*"I don't think there is any way around not getting anxious or feeling worried. So, accept that this will probably happen. Talking about it with trusted family or close friends. Seek professional help if need be. I love a long hot shower, with no interruptions and a coffee catch up with friends" **Mum of a 7-year-old***



# MANAGING CONFLICTS



There may be times during your child's school life where there is an issue relating to their CF care. If you feel that the school is not adequately supporting your child's needs, it is important to address this early on with the class teacher.

Avoid contacting the school if you are angry. Wait to cool down and then make a plan about how to address the problem. Parents and teachers need to be partners with a shared goal of doing what is best for your child.

If you ever feel like you need support when approaching the school to discuss CF related information, your local CF organisation may be able to assist with support.

*"I have found that it is very important to maintain regular and honest contact, and feel confident raising concerns, but am also sure to praise assistance of staff and efforts of the school as a whole"*

**Mum of a 7-year-old**

# AVAILABLE RESOURCES & USEFUL CONTACTS



A website with downloadable resources about CF in school for teachers, parents and students.

**Teacher eLearning Modules:** Where teachers can learn about the needs of children with CF in early childhood, primary and high school and gain a certificate to show their professional development.

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

**A Guide to Cystic Fibrosis for Early Childhood Educators**

[www.cfsmart.org/wp-content/uploads/2017/02/Early-childhood-teacher-information-booklet.pdf](http://www.cfsmart.org/wp-content/uploads/2017/02/Early-childhood-teacher-information-booklet.pdf)

**A Guide to Cystic Fibrosis for Primary School Teachers**

<https://cfsmart.org/wp-content/uploads/2017/02/Teacher-information-booklet-for-primary-school.pdf>

**Good Clean Hands:**

Animation designed for school children aged 4-8 about hand washing and reducing the spread of germs.

[www.youtube.com/watch?time\\_continue=3&v=d-WVOBTW6iA](http://www.youtube.com/watch?time_continue=3&v=d-WVOBTW6iA)

**'I Am Starting School This Year' activity booklet**

[www.cfsmart.org/wp-content/uploads/2017/01/CFF072-CF-SMART-Activity-Sheets\\_HIRES.pdf](http://www.cfsmart.org/wp-content/uploads/2017/01/CFF072-CF-SMART-Activity-Sheets_HIRES.pdf)

**'Collaborating with Schools When Your Child Has CF' blog**

[www.cfsmart.org/collaborating-schools-child-cystic-fibrosis](http://www.cfsmart.org/collaborating-schools-child-cystic-fibrosis)

**What is Cystic Fibrosis and how do you get it?:**

A 1 min 20 animation which explains CF, handy for teachers and older children.



### **Cystic Fibrosis Western Australia**

**[www.cfwaw.org.au](http://www.cfwaw.org.au)**

CFWA have an Education Officer who can provide support and education to schools.

**Email:** [education@cfwa.org.au](mailto:education@cfwa.org.au)

**Phone:** 08 6457 7333

### **Cystic Fibrosis Community Care Victoria**

CFCC (Vic) have an Education Support coordinator who can provide support and education to schools and families

**Email:** [education@cfcc.org.au](mailto:education@cfcc.org.au)

**Phone:** 03 9686 1811

### **Cystic Fibrosis Community Care New South Wales**

CFCC (NSW) have a Regional Support Worker who can provide client specific CF education to school staff, to organisation staff that clients are linked in with, and to family members and support people.

**Email:** [regionalsupport@cfcc.org.au](mailto:regionalsupport@cfcc.org.au)

**Phone:** 02 4960 2922

### **Cystic Fibrosis South Australia**

When children first go to kindy or child care, the Women's and Children's Hospital usually offers to send the Respiratory Unit Nurse Manager out to talk to the staff about that child

Women's and Children's Hospital  
Respiratory Dept: (08) 8161 8492

### **Other Resources**

- "Getting Nosey about CF with Oli and Nush" from CF UK Trust:  
<https://www.youtube.com/watch?v=WuI72eMrIQI>
- UK DVD animation explaining CF to children [http://issuu.com/brentrg/docs/pulmozyme\\_story\\_book](http://issuu.com/brentrg/docs/pulmozyme_story_book)

**CF**smart  
cystic fibrosis education program



### **AUSTRALIAN CAPITAL TERRITORY**

Cystic Fibrosis Association ACT Inc  
P: (02) 6292 9866  
E: [info@cfact.org.au](mailto:info@cfact.org.au)  
W: [www.cysticfibrosis.org.au](http://www.cysticfibrosis.org.au)

### **NEW SOUTH WALES**

Cystic Fibrosis Community Care  
P: (02) 8732 5700  
E: [reception@cfcc.org.au](mailto:reception@cfcc.org.au)  
W: [www.cysticfibrosis.org.au](http://www.cysticfibrosis.org.au)

### **QUEENSLAND**

Cystic Fibrosis Queensland  
P: (07) 3359 8000  
E: [admin@cfqld.org.au](mailto:admin@cfqld.org.au)  
W: [www.cysticfibrosis.org.au](http://www.cysticfibrosis.org.au)

### **SOUTH AUSTRALIA**

Cystic Fibrosis South Australia  
P: (08) 8221 5595  
E: [cfsa@cfsa.org.au](mailto:cfsa@cfsa.org.au)  
W: [www.cysticfibrosis.org.au](http://www.cysticfibrosis.org.au)

### **TASMANIA**

Cystic Fibrosis Tasmania  
P: (03) 6234 6085  
E: [general@cftas.org.au](mailto:general@cftas.org.au)  
W: [www.cysticfibrosis.org.au](http://www.cysticfibrosis.org.au)

### **VICTORIA**

Cystic Fibrosis Community Care  
P: (03) 9686 1811  
E: [admin@cfcc.org.au](mailto:admin@cfcc.org.au)  
W: [www.cysticfibrosis.org.au](http://www.cysticfibrosis.org.au)

### **WESTERN AUSTRALIA**

Cystic Fibrosis Western Australia  
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E: [info@cfwa.org.au](mailto:info@cfwa.org.au)  
W: [www.cfw.org.au](http://www.cfw.org.au)



# HEALTH CARE PLAN

A GUIDE TO CYSTIC FIBROSIS FOR  
EARLY CHILDHOOD EDUCATORS



## 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 (CF) in child care, kindergarten or preprimary. A blank form is available from [cfsmart.org](http://cfsmart.org)

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

Medications	Reason used	When required
<input type="checkbox"/> Enzymes	<i>To assist with digestion of food.</i>	
<input type="checkbox"/> Salt tablets	<i>To reduce risk of dehydration and to replace loss of salt from body.</i>	
<input type="checkbox"/> Inhaler e.g. Ventolin	<i>To open airways and improve oxygen intake.</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>	
<input type="checkbox"/> Easy access to water bottle and drinks such as cordial or sports drinks	<i>To avoid dehydration, mainly needed in summer.</i>	
<input type="checkbox"/> Infection control	<i>Flus, colds, gastro, whooping cough etc can pose a greater risk to children who have CF.</i>	
<input type="checkbox"/> Easy access to toilet	<i>Bowel issues, embarrassment at amount of flatulence.</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>	
<input type="checkbox"/> Tired/lethargic	<i>Common for some children to be extra tired, lungs are working extra hard.</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>	
<input type="checkbox"/> Cross infection risk if another student with CF attending the school.	<i>Risk of passing germs to children with CF that don't affect other people.</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>	

Adapted from The Cystic Fibrosis Care Plan from DECS 2009, South Australia

# Student health support plan for cystic fibrosis: 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>Give fluids (gastrolyte or similar if available), keep cool out of sun Call parent/carer. If pulse remains above 110 beats per minute 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.  DAMAGE: cut line, lost cap on end  WET DRESSING.  PICC LINE accidentally pulled out.  Chest pain accompanied by shortness of breath</i>	<i>Call parent/carer.  Kink line so air does not get in. Call parent/carer or ambulance .  Needs replacement - call parent/carer.  Apply pressure to area for 5 minutes to prevent / stop bleeding. Call parent/carer or ambulance  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 Moderate over 5 ml  Large &lt; 240 ml</i>	<i>Inform parent the same day. Call parent/carer or ambulance if can't reach parents. Call ambulance.</i>
PEG feeding tube or button problems (not many students have this)	<i>Leaking around tube, pain.  Accidental dislodgement.</i>	<i>Call parent/carer.  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. Call parent/carer.</i>

# CYSTIC FIBROSIS BOOKMARK

**CF**smart  
cystic fibrosis education program

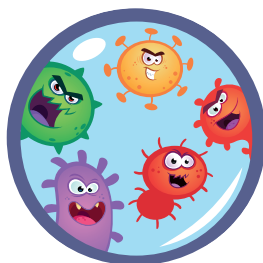
[www.cfsmart.org](http://www.cfsmart.org)

Cystic fibrosis is something that babies are born with, you can't catch it.

It sounds a bit like "65 Roses" and it's called "CF" for short.

Someone who has CF can have thick and sticky mucus in their lungs and also in their digestive system (for many people with CF).

Children who have CF can go to school, run, play and have fun with their friends but to keep as well as possible they have to take different tablets and medicines at school and at home.



**CHILDREN WITH CF CAN GET REALLY SICK AND SOMETIMES THEY HAVE TO GO TO HOSPITAL IF THEY CATCH THINGS LIKE COLDS OR THE FLU.**

**THINGS YOU CAN DO TO SAY GOODBYE TO GERMS WHICH MAKE YOU AND OTHERS SICK:**

- 1. WASH YOUR HANDS PROPERLY**
- 2. COUGH INTO YOUR SLEEVE INSTEAD OF YOUR HANDS**
- 3. KEEP YOUR FINGERS AWAY FROM YOUR MOUTH AND EYES**
- 4. STAY HOME FROM SCHOOL IF YOU HAVE A REALLY NASTY COLD, FLU OR GASTRO**



**[www.cfsmart.org.au](http://www.cfsmart.org.au)    [facebook/cfsmart](https://facebook.com/cfsmart)**  
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