

A GUIDE TO CYSTIC FIBROSIS FOR

PRIMARY SCHOOL TEACHERS



About this guide

This guide is for teachers in 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 impacted very differently** by this condition.

Cystic fibrosis is a chronic genetic disease 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, while at school, can seem daunting to an educator, especially when there are several children with medical and learning requirements 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.



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Cystic fibrosis summary for primary school teachers & relief teachers

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. You may need to remind the child 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 may not be 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 e.g. 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.**
- **Primary school 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 approximately 3100 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

Although everyone is different, there are some common symptoms that a child with CF may have:

- cough (not a cold)
- shortness of breath
- pale appearance
- frequent respiratory infections
- excessive appetite or no appetite at all
- poor weight gain, small in stature and distended belly
- unpleasant smelling stools and frequent flatulence
- tires easily
- sinus infections
- late onset of puberty
- reflux

LESS COMMON SYMPTOMS

- CF related diabetes
- osteoporosis
- incontinence
- arthritis
- occasionally the mucus coughed up can be tinged with blood
- rectal prolapse: bleeding or protrusion of the rectum
- bowel obstruction.

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 cystic fibrosis (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. The child's parents should also let the school know if the child's medication changes to something which may have mood-altering side effects.

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.

THE CHILD'S UNDERSTANDING OF CF

From the age of 6 to 12 the child will start to learn about CF, depending on how much information the parents have disclosed and how much the child is able to take on board. If the child has had a hospital admission he/she may have more of an understanding about being a bit different to other children. Some children with CF may be embarrassed about having to take medication, their toileting habits or will have needle phobias and issues with anxiety.

It is important for children with CF to be encouraged to take responsibility for their own treatment as much as possible, even when they are young, while also understanding that there may be times (for some children) when they might be resistant.

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 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.

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 of 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 or 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 may spend on their physio and nebuliser routine can range from 1 hour to 3 hours per day, depending on the child's health. Coughing should be encouraged in children with CF as it helps clear the sticky mucus from the lungs.

ABSENTEEISM

☐ Tick if relevant to the child in your class

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.

Keeping up with school work:

Discuss with the parents about a possible homework plan in advance, if it seems likely that the student may have time off during the year for hospital admissions. A combination of challenging and basic school work may be required, depending on the individual student. Information provided to the child's parents about good quality online education programs that the child can access if absent from school may also be of assistance.

Some children may be able to complete a little bit extra work during the times they are at school, so they don't have so much to catch up on when they are absent.

Hospital school services:

There is also a hospital school service available located in the children's hospital, who you can liaise with, in regards to school work. Please refer to page 24 for contact details.

Fitting back into school life:

Adjusting from hospital back to school can be tricky for the child, particularly if he or she is absent for a long period of time. Providing the opportunity for the child to email the teacher or the class to keep in contact, or encouraging the other students to write letters or cards, may help the child to feel more connected. The child could possibly keep a scrapbook of the admission to hospital for the teacher and class to see upon the child's return (depending on the capacity of the child and parents).

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 CF 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 parents 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 22 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 parents straight away or the child's CF clinic. In some cases an ambulance may need to be called. See page 22 for more details.

WHEEZING

☐ Tick if relevant to the child in your class

Some children with CF occasionally wheeze. This occurs when the airways in the lungs contract and narrow. The child might have a feeling of tightness in the chest. The bronchodilators, e.g. Ventolin and steroids used for children who have asthma, also work well in children with CF who are experiencing wheezing.



INFECTION CONTROL

Germ in the classroom:

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 who has 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 can significantly lower infection rates.

Many parents of children who have CF say that their biggest concern for their child while at school 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 a metre 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 preprimary 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 a metre apart from others with CF.
- Children with CF should not travel in the same vehicle such as buses or gather in common areas.
- At outdoor events such as sports days the children must maintain a 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.

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 school.

MINIMISE THE CHILD'S EXPOSURE TO THE FOLLOWING:

- **Fish tanks in class rooms : ok as long as they have a cover on them.**
- **Water play, water toys with holes in them.**
- **Spas**
- **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 ok for 15 minutes or less.**
- **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 or cordial with added salt, during and after exercise, are encouraged for people with CF to consume 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.

The child may not feel thirsty, even if dehydrated, so might need to be reminded to drink extra fluids during the day.



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. The enzyme capsules are not harmful to other children. Speak to the child's parents about how the child usually consumes the capsules.

The enzyme capsules are not harmful to other students if taken.

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's 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 for them to 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. The lunchbox needs to be somewhere cool and dry. The enzymes are required as a life-long medication to be

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.**

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's 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 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, please see the PEG section 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 parents to confirm what activities will be appropriate.

CF RELATED DIABETES (CFRD)

☐ Tick if relevant to the child in your class

By the age of 25, 30% of adults with CF will have cystic fibrosis related diabetes (CFRD). A few children in primary school are also being diagnosed. The reason people with CF are prone to getting CFRD is because their pancreas becomes scarred from being blocked by mucus and it can stop producing enough insulin.

CFRD has features of both type 1 and type 2 diabetes but is also distinct. People with CF are more at risk of high blood glucose levels as a result of a lung infection or oral steroid use. Sometimes this will be temporary and the CFRD will pass once the infection clears or the course of steroids is stopped.

From the age of 10 children with CF are screened for CFRD. The symptoms of onset are weight loss, increased thirst and the need to pass urine more frequently.

People with CFRD are still required to follow a high calorie, high salt diet but need to use insulin usually 2 to 5 times a day. Regular meals and snacks with a similar carbohydrate content consumed each day are recommended. Blood sugar levels need to be checked regularly to determine the insulin levels required.

It can be quite overwhelming for the child and the parents when a diagnosis of CFRD is given, especially when there is quite a lot of treatment required for cystic fibrosis already.

If your student with CF is diagnosed with CFRD and requires glucose and insulin at school, contact the CF clinic or the state CF organisation to find out further information about managing this in school.

Fact sheets about CFRD are available from:
www.health.qld.gov.au/masters/copyright.asp or
www.cysticfibrosis.org.uk



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.

e.g. Creon 10,000 = 1 capsule per 8g 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 parents about how many capsules the child needs while at school and how the parents 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, he or she may experience diarrhea.

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

Use antibacterial hand gel before handling enzyme capsules or granules.

Parent's contact details: _____

How many enzymes per grams of fat: _____

Other considerations

LIVER

1 in 6 children with cystic fibrosis (CF) can have problems relating to liver damage, more commonly these problems can occur between the ages of 9 and 15. When the liver disease worsens it can affect vitamin levels, reduce the effectiveness of enzyme capsules, result in poor appetite, enlarge the stomach or spleen and the whites of the eyes can become yellow. There can also be itching on the skin and bruising can occur more easily. There is medication the child can take to assist with ongoing liver damage.

REPRODUCTIVE SYSTEM

In approximately 97% of males who have CF, the vas deferens (which is a part of the male reproductive system) is missing. Infertility in males with CF can be treated by assisted reproduction techniques through IVF clinics. Boys with CF in primary school may not yet be aware of this, but older children who might start to research more into CF might come across this information. It may be worth discussing this information with the child's parents if he is in upper primary.

Many females with CF are able to have children, but close surveillance is required during the pregnancy by both the CF and antenatal specialists.

CF ARTHRITIS/OSTEOPOROSIS

Rheumatoid-like arthritis and osteoporosis are both symptoms that a person with CF may experience. While it is more likely for adults to be affected, some children and adolescents have also been diagnosed.

Children and adults with CF will take vitamin supplements and other medications to improve low bone density. Usually the vitamins will be taken at home before the child comes to school.

STRESS INCONTINENCE

Stress incontinence is more common in children who have CF, more so in girls than boys. The symptom of stress incontinence is leakage of urine during an activity which places stress or pressure on the internal pelvic floor muscles, such as coughing, jumping or laughing.

Stress incontinence can be quite embarrassing and children are usually reluctant to discuss this issue. If you notice any changes in how the child exercises, coughs or general toileting habits, please discuss with his/her parents and also the child. A physiotherapist (from the CF Clinic) will be able to assist with advice on how to manage the symptoms of stress incontinence.

RECTAL PROLAPSE

Frequent coughing or hard to pass stools can occasionally cause a rectal prolapse in about 20% of children who have CF. This means that part of the rectum protrudes, or sticks out through the anus. This is not a life threatening occurrence and can be treated successfully with a surgical procedure (see page 22 for details).

EXCURSIONS AND CAMPS

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

If the child is going on an excursion, the main things to consider are:

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, straws and spas.
- ☐ Maintain good hand washing practices.
- ☐ Take antibacterial hand gel, paper towel and tissues.
- ☐ The parent may want to come along to assist.

See the camp checklist on page 17, useful for older students with CF attending school camps.

CYSTIC FIBROSIS EVENTS & FUNDRAISING WITHIN THE SCHOOL

Some families, teachers and students are keen for their school community to learn more about CF and be involved in fundraising. The main event for CF in Australia is "65 Roses Day" which is held annually on the last Friday in May. This event is a great opportunity for teachers and students to take part in some fun, educational activities.

Take the
65 ROSES
CHALLENGE

Getting involved:

- 1.** Check that the student and parents are happy with the school doing a fundraising event for CF. Discuss how the information will be presented to the students.
- 2.** Choose a date in May or another date convenient for your school.
- 3.** Pick a theme such as 'Crazy Hair Day' or 'Go Red for CF' or '65 Roses Day'
- 4.** Contact your state CF organisation who may be able create a fundraising kit to meet the needs of your school with tips on how to plan the day and provide balloons, posters, stickers and educational activities for students.
- 5.** Visit www.cysticfibrosis.org.au or cfsmart.org for more details.

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. Each CF state organisation provides a variety of support services which may include counselling, respite and financial support.



School camp checklist

(Some points won't apply to all students with cystic fibrosis)

CHECKLIST

☐ Discuss specific requirements with the student and parents.

☐ Ask the parents for a copy of the student's daily treatment plan (physiotherapy and medication). Contact the cystic fibrosis clinic or cystic fibrosis state organisation if further information is required.

☐ Nominate a teacher (possibly someone the child knows and likes) to be the student's contact person and to assist with treatment or any issues.

☐ Provide a location where the student can conduct his/her physiotherapy and take medication in private, with minimal disturbance.

☐ The student may require salt supplements, salty drinks and water if participating in strenuous activity and in warm weather.

☐ Check the student's dietary requirements as he/she may require extra salt, cream, butter in meals.

☐ The student may require enzyme capsules during meals and snacks. Discuss with the student about taking the enzymes. Most students will be independent in this area but will require a staff member to subtly check that the capsules are being taken.

☐ Suitable storage for medication and physiotherapy equipment is required, somewhere dry and not too hot.

☐ Providing electricity for the use of the nebuliser. Some nebulisers can be operated by car batteries or normal batteries (for camping purposes).

☐ Hand washing and infection control procedures. Keep other students who are unwell e.g. gastro, vomiting etc. away from a student with CF if possible. Have antibacterial hand gel available, soap and paper towel for toilets etc.

☐ Locate contact numbers of the local medical centre closest to the camp location.

MEDICAL CENTRE CLOSEST TO CAMP LOCATION:

PHONE:

ADDRESS:

CYSTIC FIBROSIS CLINIC:

PHONE:

ADDRESS:

A summary for managing cystic fibrosis in the classroom

THINGS TO DISCUSS WITH THE CHILD'S PARENTS:

Medication:

- ☐ Medication required e.g. enzymes, salt tablets, Ventolin, salty drinks.
- ☐ Discuss with the parent what type of system will work for their child in terms of administering the enzymes and how many are required for different food items.
- ☐ Parents could provide a list of common classroom foods e.g. cupcakes, pikelets or popcorn and how many enzymes their child may need for these types of food so teaching staff are aware.
- ☐ Is any other medication required while the child is at school e.g.. Ventolin or antibiotics?
- ☐ Any side effects of medications that impact on the child while at school?

Exercise:

- ☐ How much exercise can the child participate in? Is he/she likely to tire easily?

Toilet habits:

- ☐ Easy (and quick) access to a toilet may be required.
- ☐ Be aware that the child may be embarrassed about the situation.

CF Diet:

- ☐ 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 or maintenance.

- ☐ 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 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 from 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.

Are there any specific CF symptoms that you need to be aware of?:

- ☐ Any potential emergency situations?
- ☐ Hospital admissions in the past?
- ☐ Likely to be admitted during the year?
- ☐ Psycho-social issues e.g. phobias, anxiety, embarrassment?

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 more frequently than normal.

THINGS TO CONSIDER IN THE CLASSROOM:

Infection control:

- ☐ All students should wash their hands with liquid soap and dry with paper towels or a 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 a metre 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. See cfsmart.org for lesson plan ideas

Exercise:

- ☐ Hydration for when participating in physical activity.
- ☐ Extra rest if the child needs it.
- ☐ Toilet breaks.
- ☐ Tissues if coughing up mucus.

Homework:

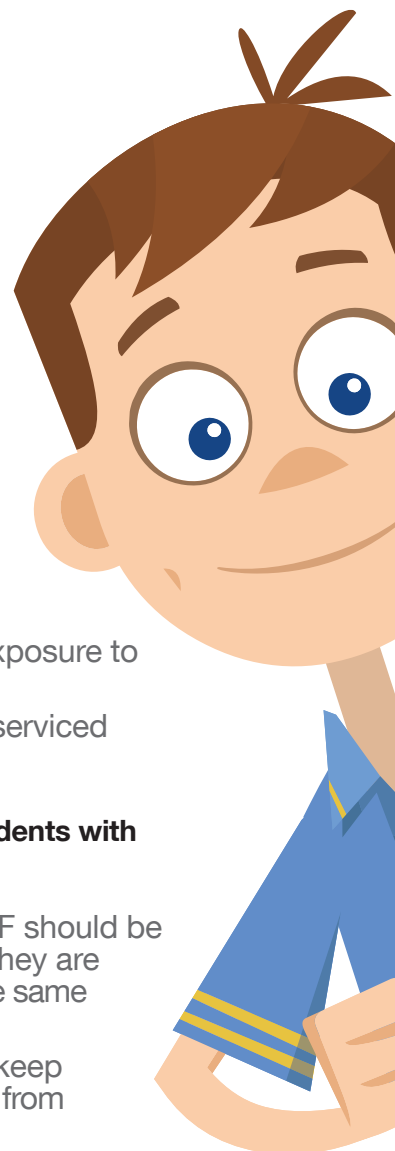
- ☐ Discuss with parents in advance about possible homework which could be undertaken if the child has to go to hospital or is at home on IV treatment.
- ☐ There is also a hospital school service available in each state hospital, to liaise with in regards to school work.

Minimise the child's exposure to the following:

- ☐ Fish tanks in class rooms: ok as long as they have a cover on them.
- ☐ Water play, water toys.
- ☐ Excursions, where hay, ponds.
- ☐ Swimming: avoid change rooms if possible.
- ☐ Soil: gardening, keep exposure to 15 minutes or less
- ☐ Air-conditioning : have serviced annually.

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 a metre apart from others with CF.
- ☐ People with CF should not travel in the same vehicle such as buses or gather in common areas.
- ☐ At outdoor events such as sports days the children must maintain a 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 (CF). A blank form is available from 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:	
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.	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.	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.	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.	Complaints of stomach aches or abdominal swelling.
<input type="checkbox"/> Lethargic, extra tired.	Markedly decreased or increased appetite.
<input type="checkbox"/> Increased coughing.	If child has eaten food without consuming enzymes.
<input type="checkbox"/> Small amount of blood in mucus.	Changes in child's behaviour.

MEDICATIONS	REASON USED	WHEN REQUIRED
<input type="checkbox"/> Enzymes	<i>To assist with digestion of food.</i>	<i>With most meals and snacks.</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 e.g., high fat CF diet.</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>	<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>May 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>
<input type="checkbox"/> CF related diabetes (CFRD)		
<input type="checkbox"/> Stress incontinence		
<input type="checkbox"/> Arthritis/osteoporosis		

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 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 or ambulance .</i> <i>Needs replacement - call parent.</i> <i>Apply pressure to area for 5 minutes to prevent / stop bleeding. Call parent/carer or 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 < 5 ml</i> <i>Moderate over 5 ml</i> <i>Large < 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/carer immediately, tube needs to be replaced ASAP. Country schools if close to hospital take child to ED and call parent/carer.</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>
CF related diabetes Low blood sugar levels	<i>Sugar levels low (one or more symptoms): trembling, shaking, excessive sweating, tingling of mouth and fingers, headache, difficulty concentrating, confusion, faintness, blurred vision, irritability and bad temper, palpitation, paleness.</i>	<i>Stop what doing, immediately take a quick acting sugar e.g. small glass of soft drink, sit down and relax for a few minutes, then take some more quick acting sugar if don't feel better. Check blood sugar levels if not sure.</i> <i>Check blood sugar levels before exercising. May need a carb snack before exercising.</i>
High blood sugar levels	<i>Thirst, passing a lot of urine, pins and needles, hot sweats, blurred vision, tiredness, weight loss.</i>	<i>Check blood sugar levels.</i> <i>Eat sugary foods in small amounts throughout the day, taken with or after meals.</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 or 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 not contagious but 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...
Influenza (Flu) 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.	If your child has a high temperature. If your child has the flu, it is usually ok to send them back to school after 5 days.
Common cold viruses 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.
Chicken pox 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.
Whooping cough 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 after 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.
Gastro 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

If you are after further general information about CF or have gained permission from the child's parents to ask for specific information, the CF 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	Royal Children's Hospital T: 03 9345 5522 Monash Medical Centre T: 03 9594 6666	Royal Children's Hospital Education Institute T: 03 9345 9700 E: education.institute@rch.org.au W: www.rch.org.au/education/students/learning-in-hospital/
NEW SOUTH WALES	The Children's Hospital at Westmead T: 02 9845 0000 W: www.chw.edu.au Sydney Children's Hospital T: 02 9382 1111 W: www.sch.edu.au John Hunter Children's Hospital Newcastle T: 02 4921 3670	The Children's Hospital School T: 02 9845 2813 E: childhosp_s.School@det.nsw.edu.au W: www.chw.edu.au/kids/school/ Sydney Children's Hospital School T: 02 9382 1510 John Hunter Hospital School T: 02 4985 5090
ACT	Canberra Hospital T: 02 6244 2222	
QUEENSLAND	Mater Children's Hospital T: 07 3163 811 Royal Children's Hospital T: 07 3636 3777	Mater Hospital Special School T: 07 3004 7888 E: mhss@eq.edu.au W: www.materschool.eq.edu.au
SOUTH AUSTRALIA	Women's and Children's Hospital T: 08 8161 7000	Hospital Education Service Women's and Children's' Hospital (WCHN) T: 08 8161 7262 E: HES.info652@schools.sa.edu.au
WESTERN AUSTRALIA	Princess Margaret Hospital T: 08 9340 8222	Principal and general enquiries: T: 08 9340 8529 E: hss@det.wa.edu.au W: www.hospitalschoolservices.wa.edu.au
TASMANIA	Royal Hobart Hospital T: 03 62 22 8475	Tasmanian eSchool Southern Campus T: 03 6282 8181 Northern Campus T: 03 6323 8999 E: tasmanian.eschool@education.tas.gov.au

Your state's CF organisation may have resources and staff available to answer specific questions.



Street/Postal Address: 80 Dodds St, Southbank, Victoria 3006

☎ 03 9686 1811

✉ admin@cfv.org.au

🌐 www.cysticfibrosis.org.au/vic/



Street Address: 51 Wicks Rd, North Ryde, New South Wales

Postal Address: PO Box 149, North Ryde, NSW, 2113

Free call: 1800 650 614

☎ 02 9878 2075

✉ general@cysticfibrosisnsw.org.au

🌐 www.cysticfibrosis.org.au/nsw/



Postal Address: PO Box 909, Civic Square ACT 2608

☎ 0401 990 111

✉ info@cfact.org.au

🌐 www.cysticfibrosis.org.au/act/



Street Address: 31 Kate St, Kedron, Queensland

Postal Address: PO Box 2245, Chermside Centre, Qld, 4031

☎ 07 3359 8000

✉ admin@cfqld.org.au

🌐 www.cysticfibrosis.org.au/qld/



Street Address: 143–145 Sturt St, Adelaide, SA, 5000

☎ 08 8221 5595

✉ cfsa@cfsa.org.au

🌐 www.cysticfibrosis.org.au/sa/



Street Address: The Niche, 11 Aberdare Rd Nedlands

Postal Address: PO Box 959, Nedlands 6909

☎ 08 9346 7333

✉ info@cysticfibrosiswa.org

🌐 www.cysticfibrosis.org.au/wa/



Postal Address: GPO Box 245, Hobart, Tasmania 7001

Street Address: Level 2, 38 Montpelier Retreat, Battery Point

Free call: 1800 232 823 (Tas only)

☎ 03 6234 6085







✉ general@cftas.org.au

🌐 www.cysticfibrosis.org.au/tas/

Other resources

CF SMART RESOURCES

A selection of resources for teachers and students are available online at 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.

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 ED Med 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>

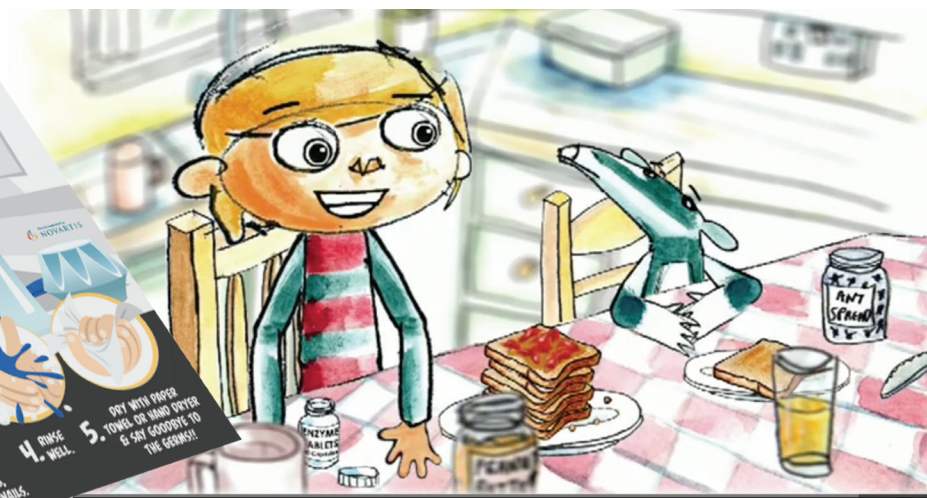
KIDS HEALTH

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

www.kidshealth.org

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.



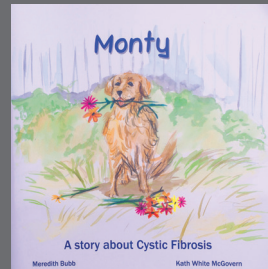
<https://www.youtube.com/watch?v=WuI72eMrIQI>

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.

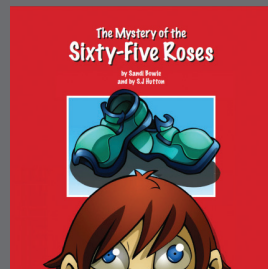
Cystic Fibrosis Queensland, \$11.00
www.cysticfibrosis.org.au/qld/allitems/



The Mystery of the Sixty-Five Roses by Sandi Bowie

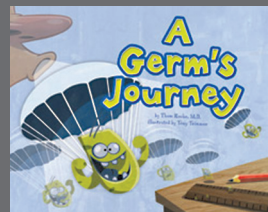
Jeremy is a curious 10 year old who likes to sneak and spy. He wants to find out why his neighbor Darcy has had the week off school. He slips into "Super Stealth Mode" to locate the mysterious sixty-five roses that Darcy tells him about, because he thinks they might just be the answer to getting some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

Cystic Fibrosis Western Australia, \$12.00
www.cysticfibrosis.org.au/wa/allitems?p=3



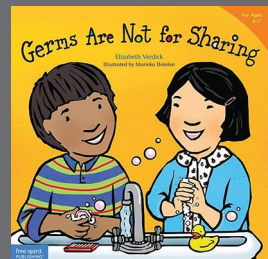
A Germ's Journey by Thom Rooke, MD

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.



Mega Man: Built to win by Dominique Gardiner

A story about three boys who enter an interschool robotics challenge and think they are going to win, but their chief designer has cystic fibrosis and has to go to hospital and things don't go as planned.



What's up with Beth? Medikidz explain cystic fibrosis

A book which explains CF to children aged 10 to 15 through the use of cartoon characters.



**Visit the CF Smart website for other resources and
information about individual CF state organisations.**

www.cfsmart.org