



## Communication and Privacy

Issues relating to Cystic Fibrosis need to be treated sensitively. Some children, especially teenagers, do not want their friends to know they have Cystic Fibrosis and this must be respected.

However, families recognise that when done in a sensitive and safe manner, information sharing will mean better support and understanding within the school. All staff need to be aware of the student's needs.

Clear, regular communication between school and home is essential to good results for the student with Cystic Fibrosis. Have a Key Person the student can go to with any problems. Make this person the conduit of information to other teachers and school staff.

Support and guidance staff, in conjunction with the Key Person can address frustrations and general problems early on. They can also help with positive and realistic goal setting.



**Cystic Fibrosis Association of New Zealand**  
PO Box 8241, Riccarton, Christchurch  
Phone 03-341 8024 Freephone 0800 651 122  
email: [info@cfnz.org.nz](mailto:info@cfnz.org.nz)  
[www.cfnz.org.nz](http://www.cfnz.org.nz)



## Publications

- The Meaning of My Life by Carol Walsh a teenager's perspective on Cystic Fibrosis
- Educational Issues for Chronically Ill Students by Pat Jenner

For further information please contact:

Branch Details

Medical advances have dramatically improved the lives of people with Cystic Fibrosis and will continue to do so. The challenge to all educators is to enable people with Cystic Fibrosis to succeed at school, to be happy there and to make the transition from school to adult life successfully.

Children with Cystic Fibrosis have the same hopes, dreams and aspirations as everyone else. Schools are a vital link in the overall wellbeing of people affected by this condition and teachers have the power to have a profound effect on their lives.



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# Cystic Fibrosis

**Supporting Children with CF**  
A Guide for Teachers, Schools & Early Childhood Centres (ECC)



**1 in 25 people carry the CF gene**

**Cystic Fibrosis Association of New Zealand**

# Teachers Guide

## What is Cystic Fibrosis?

Cystic Fibrosis is an hereditary condition affecting 1:3500 births in New Zealand. Major symptoms include mucus in the body becoming thick and sticky - clogging airways and the digestive system, resulting in frequent and persistent infections and digestive problems.

## Specific effects which you may notice within school or ECG

- The need to cough to get rid of phlegm. The cough is not infectious and should not be discouraged as it is part of their daily routine for mucus clearance.
- Breathing difficulties - discuss action plans with parents and the child.
- The need to take enzymes every day to aid digestion of food.
- The need for frequent snacks and a high fat/calorie diet.
- Frequent visits to the toilet.
- Fatigue or lethargy (particularly in warm weather).
- Underweight appearance.
- Frequent absence from school for illness/clinic checks and hospitalisation.
- Strict physiotherapy routines which may include treatment during school.
- The need for specific and strict hygiene to be followed - this includes not sitting close to, or socialising with other children who have colds.
- The need to be aware and careful of medical aids such as picc lines/portacaths and gastrostomy tubes.
- Home therapy may impact on the child's ability to complete homework or assignments.

## Specific challenges for the young person with Cystic Fibrosis

- Getting behind in schoolwork because of frequent absences. Teachers and parents need to discuss strategies for dealing with this, including making school work available outside the classroom and flexibility with assignment deadlines.
- Struggling with the physical effects of the condition.

- Friendship - difficulty in keeping friendships may occur because of long absences from the school social environment.
- Stress and worry in times of illness.
- Growing awareness of the limited life span. This is an issue which begins to be more prevalent from adolescence onwards.
- Having to educate new teachers each year about their specific needs - this may be alleviated by teachers communicating as a group as to the student's specific challenges.

School is a very important part of the life of the child with Cystic Fibrosis. Teachers can make a significant impact on how well the Cystic Fibrosis child does in school by taking the time to learn about the condition and how best they can support the child and their parents to reach their educational goals.

## How can teachers help?

- Don't discourage or draw attention to coughing - it is a necessary part of their self-care routine. Let them leave the room if they wish.
- Be aware of the need to take medication during the school day - discuss with the child and parents the best way to facilitate this.
- When teaching regarding healthy eating - be aware that what is healthy for the well child may not be healthy for the child with Cystic Fibrosis.
- Allow toilet visits as needed and do not draw attention to this.
- Provide schoolwork when the child is hospitalised. If the child has email, encourage schoolmates to keep in touch. An email from the teacher can be a great boost. Faxes, videos of the class, anything that helps to keep in touch. Regional Hospital schools have itinerant teachers so be prepared to provide a work outline for them when asked.
- Have a plan for management on school trips/camps etc.
- Be flexible on assessment deadlines - find creative ways to help children catch up.
- Discuss transition from Primary to Intermediate or Secondary School with parents, to make sure everyone is confident to move forward. Be prepared to hand on your special information about your student to the next teacher, even if they are at another school.
- Ensure a safe and private place for medical treatment.
- Do not insist on outside lunches or breaks if the weather is cold.
- Do not assume that the child wishes for everyone to know they have Cystic Fibrosis.