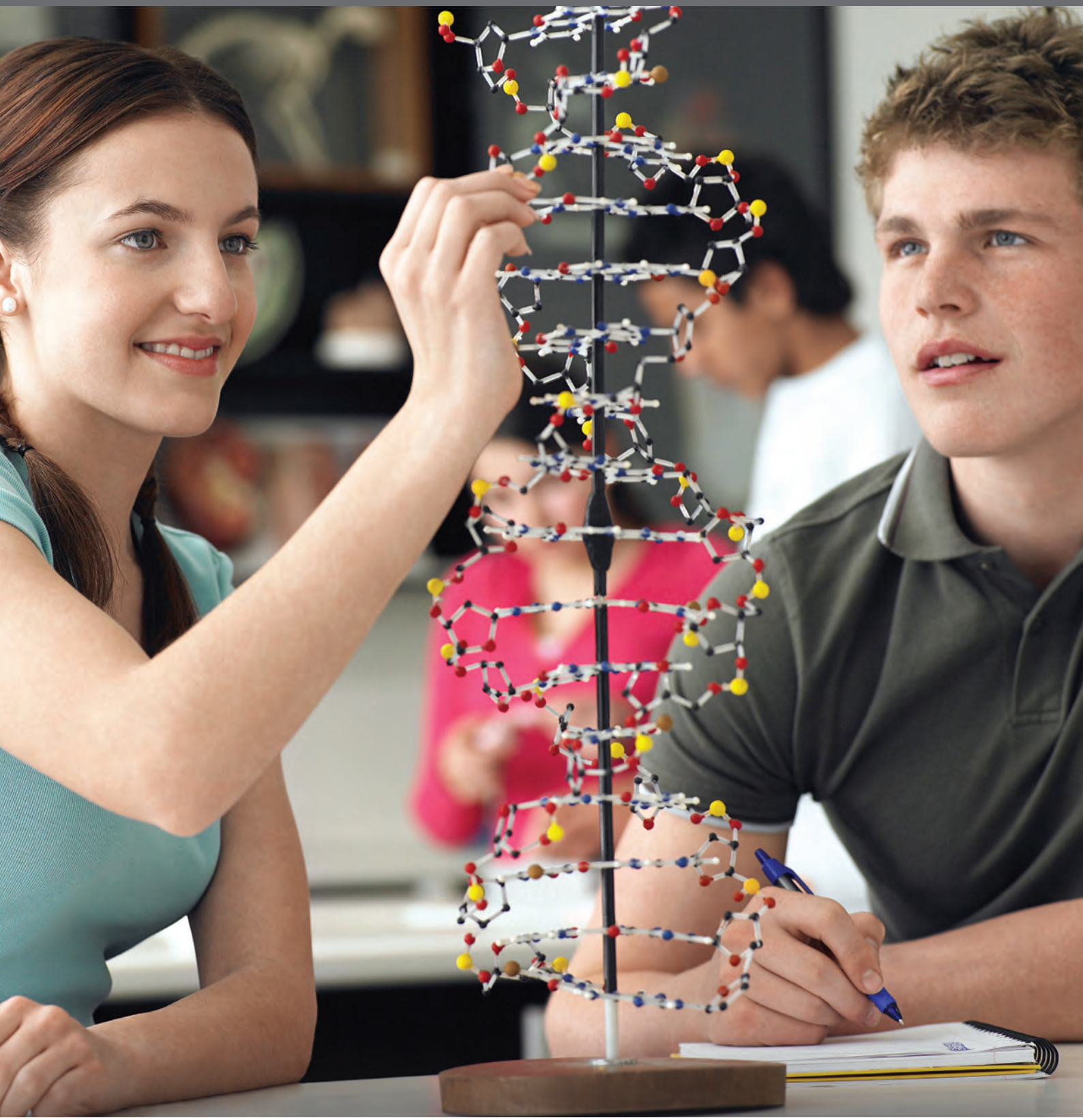
CFsmart
cystic fibrosis education program

A GUIDE TO CYSTIC FIBROSIS FOR

HIGH SCHOOL TEACHERS



About this guide

This guide is for high school teachers who have a student with Cystic Fibrosis in their school. 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 student you are working with. I**ndividuals 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. Students 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 at school.

Published by Cystic Fibrosis Western Australia
Authors from Cystic Fibrosis Western Australia.

CYSTIC FIBROSIS Western Australia

Special thanks to Cystic Fibrosis Community Care, Kylie Alford, Kim-Ellen Couch, Rosie Larmer, Nicki Smith and Jodi Wilmot.

Published with the generous support of

NOVARTIS | The Ian Potter Foundation | CYSTIC FIBROSIS Community Care *Incorporating CFV and CFNSW*

February 2014 | Reprinted 2017

Contents

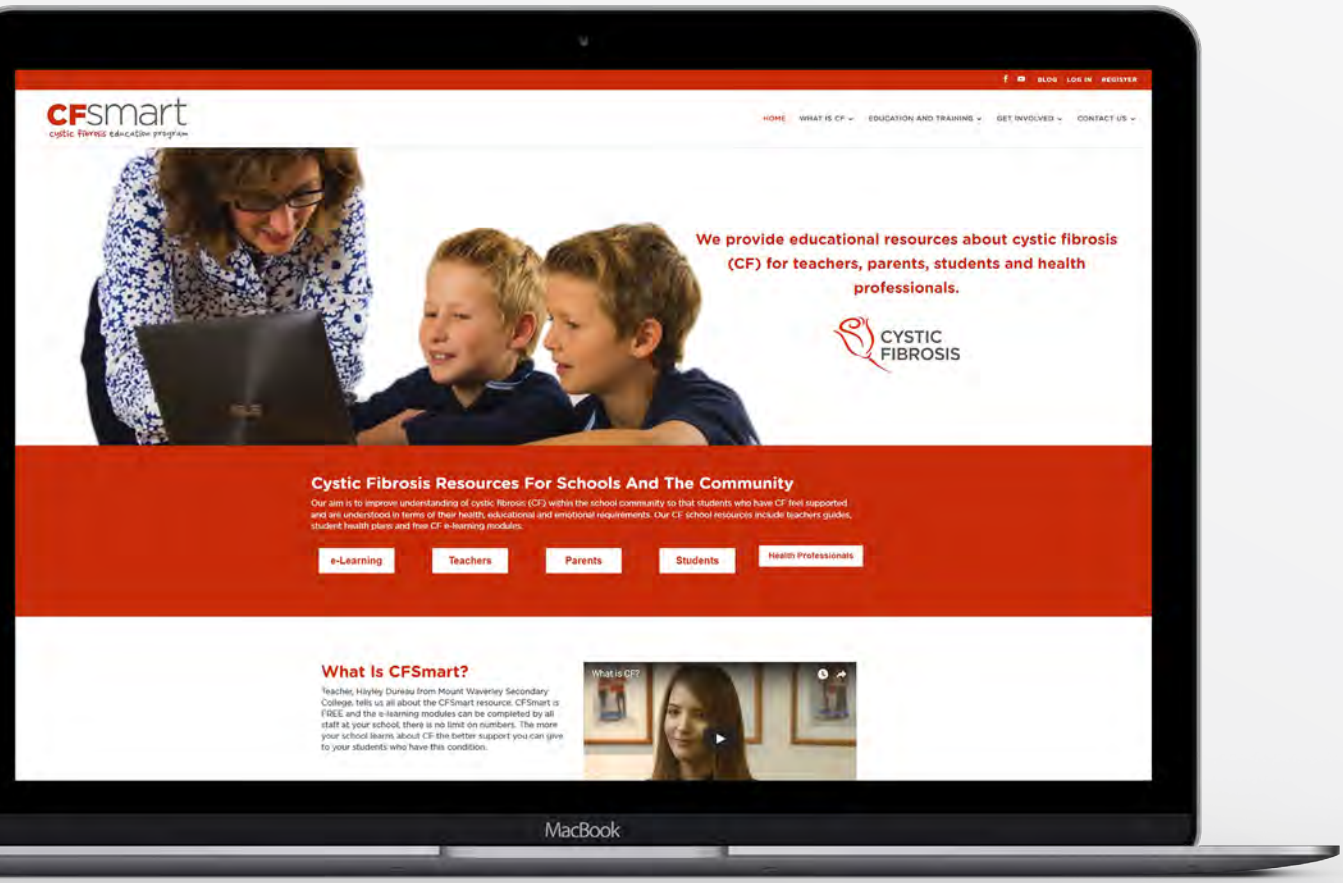
CFsmart
cystic fibrosis education program

Want your school to be CFSmart?

Find our e-Learning modules available on www.cfsmart.org

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

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



PHOTOCOPY
DOWNLOAD

Cystic Fibrosis summary for high school teachers & relief teachers

Cystic Fibrosis (CF) 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). Young people are affected differently by Cystic Fibrosis so their needs will vary.

The following things need to be taken into consideration when teaching a student with Cystic Fibrosis.

- **GERMS:** minimise the student's exposure to colds, flus etc. Students with CF should sit away from others who are unwell.
- **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 student is more at risk of dehydration so requires easy access to a water bottle and/ or salty drinks.
- **EXERCISE:**
  - the student may become more tired during exercise and need to rest
  - the student will need a water bottle for **extra hydration.**
- **COUGHING:** is common for some people with CF, it may not be a cold.
- **TOILETING:** the student may need to go to the toilet **frequently and urgently**.
- **CYSTIC FIBROSIS DIET:** most people with CF need **more calories** in their diet eg. food higher in fat and salt.
- **ABSENTEESIM:** some students with CF may go to hospital for several weeks at a time or may be unwell at home.
- **TIRED:** some people with CF can be very tired, especially in the mornings, if they have had sleepless nights coughing, or if they are coming down with a lung infection.

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.**
- **High school teachers can have the same expectations of the students behaviour and abilities as they would of other students in their care.**
- **Regular and good communication with the student'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 people experience more issues with some of the 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 person with CF may have:

- coughing
- shortness of breath
- pale appearance
- frequent respiratory infections
- dark rings under eyes
- excessive appetite or no appetite at all
- poor weight gain, small in stature
- unpleasant smelling stools, extra need for toilet
- frequent flatulence
- might take longer in the toilet due to constipation
- tires easily
- sinusitis
- late onset of puberty
- reflux
- absence of the vas deferens in males.

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.

Disclosure and compliance

DISCLOSURE

Students with CF deal with the everyday treatment and associated issues very differently. Some students will be comfortable with all staff and students having an understanding about CF, while others will want to keep things confidential. It is useful if the school nurse, the year coordinator and a few teachers have an understanding as well as some of the student's close friends.

How a student feels about disclosing details about CF may change as he or she moves through high school.

NON-COMPLIANCE WITH MEDICATION AND TREATMENT

It is common for some students with CF to go through a stage of non-compliance with their medication. Their reasons may vary from feeling frustrated at having to do their treatment and take medication every day or they may be embarrassed about being different from their peers.

It is good if there is a staff member in the school such as a nurse or year coordinator who can check from time to time how the student is going and whether he or she is taking the required medication correctly.

SOCIAL ISSUES

As a result of medical interventions, being more aware of their illness and comparing themselves to their peers, young people with CF may experience some issues with anxiety, depression, sleep disturbance, body image, anger, hypervigilence or non-compliance (as mentioned above). Having an illness or how the illness is perceived can also cause regression to the young person's development.

Professional help for the young person with CF is often available through a specialist clinical psychologist who is part of the respiratory team at the CF clinic.

BEHAVIOUR

In the majority of cases, you can have the same expectations in terms of the behaviour of a student with CF as you would of other students in the school. There are however certain medications that a few students with CF need to take which can affect their mood and behaviour. Discuss with the student's parents or with the student if there is a noticeable difference. The parents should let the school know if the student is taking medication with mood- altering side effects.

Steroids: Some young people with CF may require a course of steroids. The course is usually short, however some students 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: If the student is low in salt and dehydrated this can impact on his or her mood and behaviour.

COMMUNICATING WITH THE STUDENT AND PARENTS

Regular and ongoing communication between staff in the school e.g. deputy, year co-ordinator or school nurse, the student and parents is the best thing the school can do to assist in making sure the student's health and educational needs are being met while in high school.

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 student comes to school. Inhaled medications taken with a nebuliser may also be used at home as part of the routine.

The amount of time a person may spend on their physio and nebuliser routine can range from 1 hour to 3 hours per day, depending on the student's health. Coughing is a common symptom of CF and is also encouraged during physio as it helps clear the sticky mucus from the lungs.

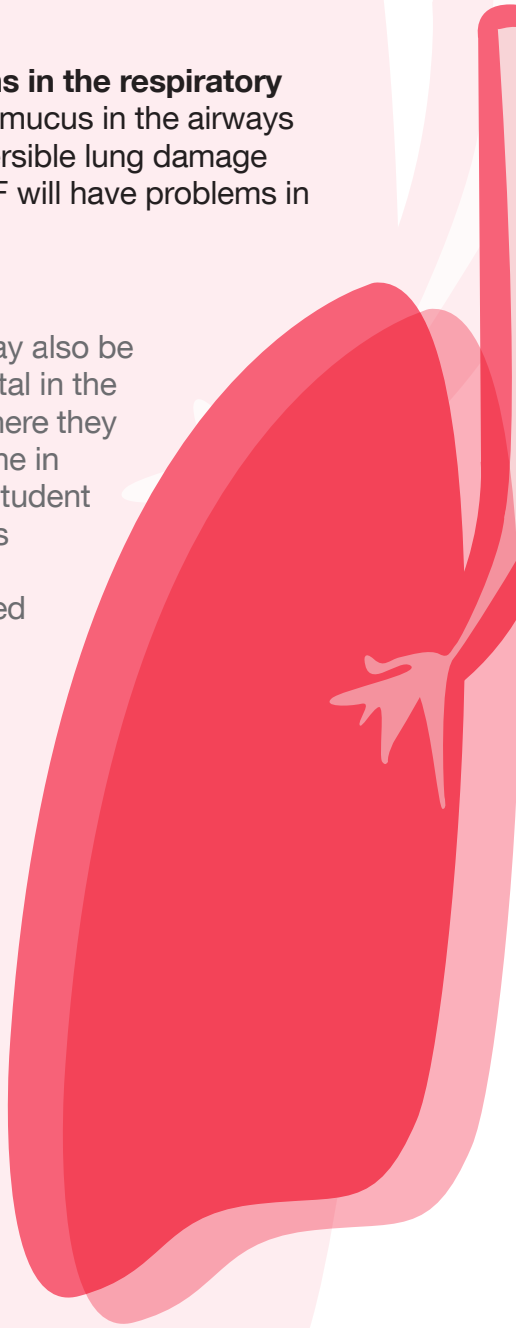
ABSENTEEISM

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

There will be times when a student with CF might be absent from school due to hospitalisation, clinic appointments or unwell at home. The student 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 (or more).

PICC lines:

Some students may also be placed on a Hospital in the Home program where they still have their IV line in but the parent or student administers the IVs at home through a peripherally inserted central catheter (PICC) line in the person's arm. The line is sealed and covered with a bandage which enables the student to continue on with their daily life, instead of staying in hospital to receive the antibiotics. Depending on the regime and how the young person is going, he/she may attend school or remain at home.



Tiredness:

Some students with CF can also struggle with tiredness due to having sleepless nights coughing. In some

cases the young person might find it very difficult to attend school in the morning. A lack of energy during the day may also affect some teenagers with CF, due to their lungs working extra hard to fight infections.

Keeping up with school work:

Discuss with the student about possible homework in advance if it seems likely that he/she may have time off during the year for hospital admissions.

Recordings of particular class lessons or power points etc may be useful if the student is in hospital or unwell at home.

Hospital school services:

There is also a hospital school service available at the hospital where the student will be admitted, who you can liaise with in regards to school work being sent to your student. Please refer to page 25 for contact details.

Flexibility:

There may be times when the required workload and scheduling of assignments is not possible for a young person with CF to achieve due to ill health, hospitalisation and tiredness. It could be more beneficial if teachers negotiated with the student, a suitable and realistic workload and timeframe for completing assignments.

For some students who are particularly unwell, more flexibility in when the student attends school allows more time for sleep, medical treatments and recovery while still enabling the student to be part of the school, attend lessons and see friends.

Some students are also able to maximise the times when they are well, by doing extra school work, so that they are ahead and prepared for the times when they are absent from school.

Schools of isolated and distance education (SIDE):

This could be an option for those students who are regularly absent from school, where they can complete a subject or two via distance education, from their home or the hospital.

Exams:

During exams, special provisions may be required such as easy access to the toilet, water, snacks, additional time required if the student is coughing a lot, rest breaks, an individual room (if the student is worried about coughing a lot during the exam in front of all the other students) and the possibility of doing a make-up exam if the student has been in hospital or is unwell at home.

Other students may not require any special provisions for exams initially, however things may change later on depending on the student's health.

4

PORTS

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

Some (not all) people with CF require 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 student and 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 24 for further details.

EXERCISE

Exercise has many benefits and is an **important** part of the daily treatment routine for people with CF.

Exercise is beneficial 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.

Many young people with CF are able to participate in sports and exercise, but this can vary depending on their health and how they feel from day-to-day and also the level of intensity of the exercise.

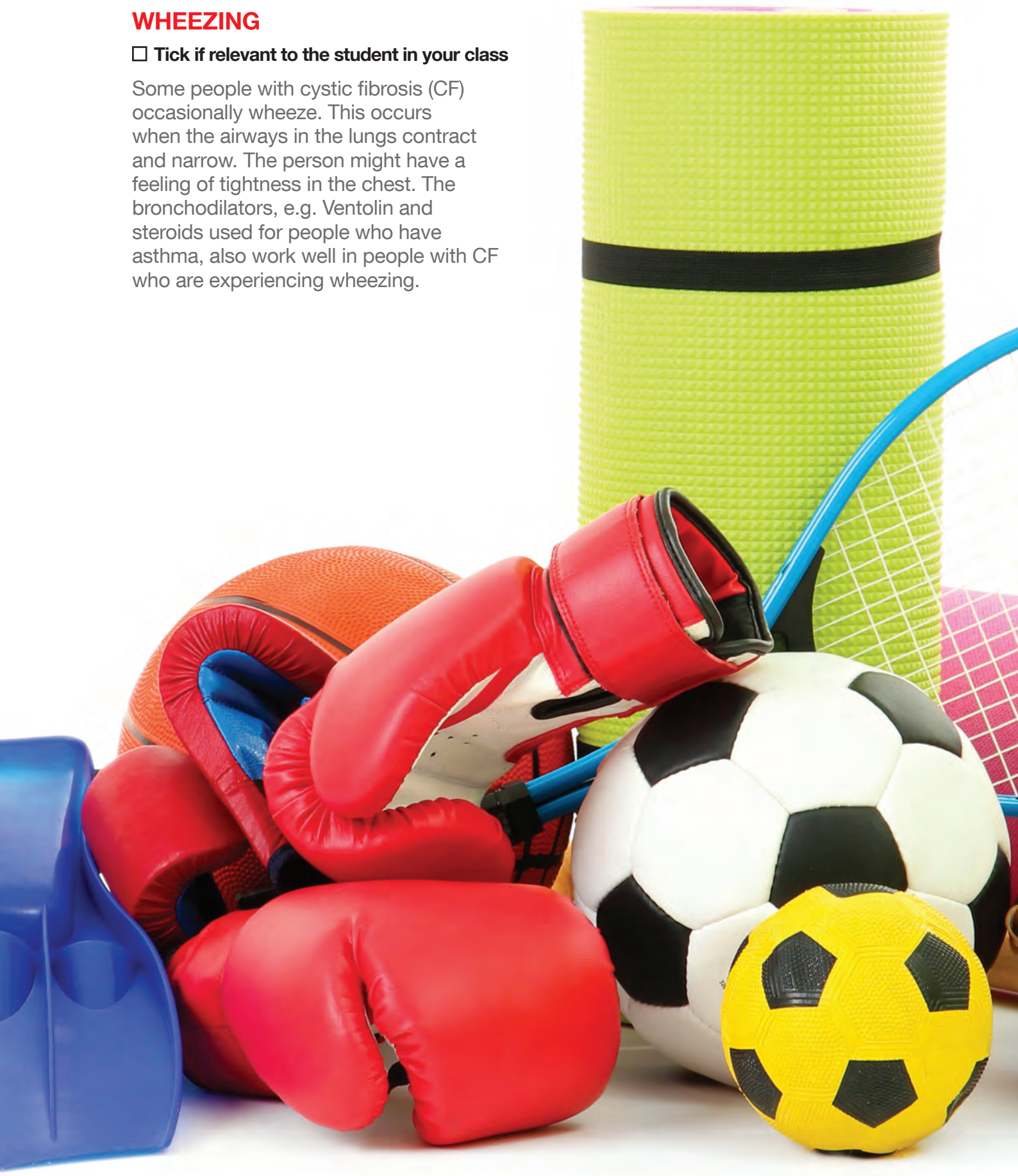
During sporting activities, some students may experience coughing, wheezing and/or breathlessness even though they are well. This does not always mean that they need to stop exercising. The teenager may need to rest for a moment until the breathlessness passes or may need to take some medication to help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

The student may also cough up mucus during exercise and swallow it or spit it into a tissue. Mucus may have some blood streaking or larger quantities of blood in it. Blood streaked mucus is quite common but may be distressing for the student (and teachers), particularly if it is the first time he/she has experienced it. Coughing up larger quantities of blood can be more serious. If this does occur, the student needs to stop exercising. Contact the parents straight away or the CF clinic. In some cases an ambulance may need to be called. See page 24 for more details.

WHEEZING

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

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



4

INFECTION CONTROL

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 person 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 person 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.

Good infection control within a school setting involves the following:

- All students have access to liquid soap and paper towels or hand dryer, to wash and dry their hands.
- A strong school policy about unwell students coming to school is in place.
- Provide access to antibacterial hand gel for students to use.

Cross infection between people 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. People with bronchiectasis or who are immunosuppressed, are also at risk of cross infection with people who have CF.

More than one young person 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 student in year 8 and another in year 12).

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:

- 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 students 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, discuss with both parties as soon as possible to develop a plan.

For further support or advice in this area, either contact the CF clinic or state CF organisation. See pages 25 and 26 for contact details.

Other germs affecting people with Cystic Fibrosis:

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

MINIMISE THE STUDENT'S EXPOSURE TO THE FOLLOWING:

- **Fish tanks in class rooms : ok as long as they have a cover on 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 student and 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 that is lost in the sweat. Some students will take salt tablets at school and easy access to water is also required. More salt is required in the warmer months.

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

Students with CF will need their water bottle with them during sport.

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 student in your class**

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

By the time the student reaches high school he or she should be able to swallow the capsules whole and take them independently with snacks and lunch. The capsules are required as a life-long medication to be consumed with most meals, so it is not advisable for the student to go to the office to receive them from a teacher- they should be able to keep them with their lunchbox and store in a cool, dark location.

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

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

THE CYSTIC FIBROSIS DIET

☐ **Tick if relevant to the student 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 student with CF may have a lunch box containing things like packets of chips, sandwiches spread thickly with margarine, and bars of chocolate. The student may worry about standing out with lunch boxes filled with high fat foods so might leave these items for home.

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

PEOPLE 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.**

GASTROSTOMY TUBE (PEG)

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

Some people with CF have a tube inserted into their stomach if they are experiencing severe malnutrition. This tube is called a PEG or gastrostomy tube and sits on the outside of the belly. High calorie liquids and enzymes are administered via the tube through a button. The feeds occur at home during the evenings before the young person 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 young person and the parents will have learnt about how to care for the tube. It is not common for complications to occur at school.

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 student and his or her parents to confirm what activities will be appropriate.

CF RELATED DIABETES (CFRD)

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

By the age of 25, 30% of people with CF will have cystic fibrosis related diabetes (CFRD). The reason people with CF are prone to getting CFRD is due to the fact that their pancreas becomes scarred from being blocked by mucus and stops 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 people 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 a teenager 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

PHOTOCOPY
DOWNLOAD

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 person 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 person takes in a day will depend on his or her body weight. Discuss with the student about how many capsules are needed while at school and how he or she calculates the amount 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.

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

If the student 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 people 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 more easily. There is medication the student 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 high school may not yet be aware of this.

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 adolescents have also been diagnosed.

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

If a student is affected by arthritis or osteoporosis this may affect his or her ability to participate in sports activities.

STRESS INCONTINENCE

Stress incontinence is more common in young people 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 young people are usually reluctant to discuss this issue. If you notice any changes in how the student exercises, coughs or general toileting habits, please discuss with him or her and the parents. A physiotherapist (from the CF clinic) can 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 people 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 24 for more further information).

CAREER PLANNING

Young people with CF, should be able to pursue many career choices. However there may be a few jobs which are less ideal and there are some jobs that people with a chronic health condition may not be permitted to do such as the armed forces, police force or ambulance officer.

When thinking about a career, young people with CF may want to consider a few things to make sure they choose a job which suits their health needs. Not everyone will want to consider their health

when making a career choice though, but choosing a career which allows the person to stay as healthy as possible and which has flexibility, means that the person can enjoy the career more.

Some considerations the student may need to think about when choosing a career path might be:

- Does the job involve chemicals, particles in the air or strong odours which may aggravate the lungs?
- Does the job require long hours, making it difficult to fit in medication and treatment?
- Does the job require a great deal of physical energy and strength, which may be too demanding if the person is prone to becoming unwell?
- Is the career flexible so the person can have time off to attend doctor's appointments, hospital admissions?
- Would part time work be more appropriate?
- Working for an employer means a certain amount of paid sick leave while being self employed means unpaid sick leave but more flexibility.
- Working from home may give the person more time for treatment, medication, exercise and rest.

UNIVERSITY AND FURTHER STUDY

The student may not be aware that some universities and TAFE's offer special entry or equity schemes which take into conderation factors such as illness, financial hardship or other issues which could have prevented the student from gaining the marks she or he is otherwise capable of.

The student might also benefit from knowing that universities and TAFE's also have services available which can assist with making adjustments such as special exam allowances, extensions for assignments and access to lockers.

EXCURSIONS AND CAMPS

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

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

EXCURSION CHECKLIST

- ☐ Easy access to toilet?
- ☐ Do they have their enzymes, salt tablets, Ventolin or other medications
- ☐ Are there extra foods to be consumed during the excursion?
- ☐ Have water or cordial and/or salty drinks readily available (particularly if hot weather).
- ☐ Avoid straw, stables and spas.
- ☐ Maintain good hand washing practices.
- ☐ Take antibacterial hand gel, paper towel and tissues.

CYSTIC FIBROSIS EVENTS AND 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 the month of May. This event is a great opportunity for teachers and students to take part in some fun, educational activities.

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.

Take the 65 ROSES CHALLENGE

PHOTOCOPY
DOWNLOAD

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 student 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:**

PHOTOCOPY
DOWNLOAD

A summary for managing Cystic Fibrosis in the classroom

THINGS TO DISCUSS WITH THE STUDENT AND PARENTS:

Medication:

- ☐ Medication required e.g. enzymes, salt tablets, Ventolin, insulin, salty drinks.
- ☐ Discuss with the student about his/her routine for taking the enzyme capsules and appropriate storage of them.
- ☐ Is any other medication required while the student is at school eg. antibiotics.
- ☐ Any side effects of medications that impact on the student while at school?

Exercise:

- ☐ How much exercise can the student 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 student may be embarrassed about the situation.

CF Diet:

- ☐ A high calorie diet may be eaten by the student while at school.

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

- ☐ If the student is extra tired or there is a big decrease in energy levels.
- ☐ If the student is coughing more than usual.
- ☐ If the student is on the toilet for long periods or going frequently (compared to normal).
- ☐ If the student's behaviour changes considerably.

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.
- ☐ Encourage appropriate use of antibacterial hand gel.
- ☐ The student with CF should be at least a metre away from other students who appear to be sick.

Exercise:

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

Homework:

- ☐ Discuss with student in advance about possible homework which could be undertaken if he or she 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. Please refer to page 25 for the CF clinic and hospital in the school service.

Minimise the student's exposure to the following:

- ☐ Fish tanks in classrooms: ok as long as they have a cover on them.
- ☐ Excursions, involving close proximity to hay or ponds.
- ☐ Swimming: Avoid change rooms if possible (may not be practical).
- ☐ Soil: gardening (limit exposure to 15 minutes) avoid dusty conditions.

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.
- ☐ 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.

PHOTOCOPY
DOWNLOAD

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 student with Cystic Fibrosis (CF) in high school. A blank form can be downloaded from www.cfsmart.org

School:	**Date plan created:**
Student's name: **Date of birth:**	**Date for plan to be reviewed for following year:**
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 phone:	**Mobile phone:**
Work phone:	**Work phone:**
Address:	**Address:**
Email:	**Email:**
Parent/Student 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 student 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 student's health.**
Signs or symptoms to bring to the parents' attention:	
☐ **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 student has eaten food without consuming enzymes.**
☐ **Small amount of blood in mucus.**	**Changes in student's behaviour.**

Medications	Reason used	When required
Enzymes	*To assist with digestion of food.*	*With most meals and snacks.*
Salt tablets	*To reduce risk of dehydration and to replace loss of salt from body.*	*Mainly needed in summer.*
Inhaler e.g. Ventolin	*To open airways and improve oxygen intake.*	*During sport, excercise.*
High fat drinks, extra snacks	*To assist with the amount of calories required for a person with CF.*	
Antibiotics	*To treat lung and sinus infections.*	
Vitamins	*To treat vitamin deficiency associated with CF.*	
Insulin	*For CF related diabetes.*	
Other		

Other considerations	Reason	Management in class
High fat diet	*To assist with the amount of calories required for a person with CF.*	*When discussing healthy eating, mention different diets eg, high fat CF diet.*
Easy access to water bottle and drinks such as cordial and sports drinks	*To avoid dehydration, mainly needed in summer.*	
Infection control	*Flus, colds, gastro, whooping cough etc can pose a greater risk to people who have CF.*	*Good hand washing practices of all students in class.* *Unwell students to stay home.* *Class learn about germs and good hygiene etc.*
Easy access to toilet	*Bowel issues, embarrassment at amount of flatulence.*	*Have an agreed signal with the student, so they can easily indicate when they need to go. Discuss with parents, or student the best strategy.*
Coughing	*Very common for people with CF to have a cough, clears mucus in lungs.*	
Regular absence from school due to hospitalisation and clinic appointments.	*If student has an infection in lungs or gastro issues, needs IV antibiotics etc. Can be up to two weeks in hospital.*	*Discuss with parent re: type of catch up work which would be suitable and achievable.*
Tired/lethargic	*Common for some people to be extra tired, lungs are working extra hard.*	*May need a few minutes to rest.*
Exercise	*Very good for CF, but sometimes student may not be able to perform consistently, depending on lung function.*	*May need to participate in less strenuous activities e.g.. helping setup equipment.*
Cross infection risk if another student with CF attending the school.	*Risk of passing germs to people with cystic fibrosis that don't affect other people.*	*Avoid two people in same year group with CF if possible (unless siblings).* *If big age gap, and wont cross paths, shouldn't be a problem.*
PORT, PEG or PICC line	*Increased calorie feeding via tube / administration of intravenous antibiotics while participating in a Hospital in the Home program.*	*Avoid certain activities.*
CF related diabetes (CFRD)		
Stress incontinence		
Arthritis/osteoporosis		

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

9 Student health support plan for Cystic Fibrosis: Emergency action plan

PHOTOCOPY
DOWNLOAD

Situation	Symptoms	Action required
Dehydration	*Lethargy, thirst, dry sticky mouth, decreased urine output- 8 hrs without urination (school aged student), fever, headache, rapid breathing, fast pulse, vomiting.*	*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.*
PICC/Port problems	*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 accidently pulled out.* *Chest pain accompanied by shortness of breath*	*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.*
Bowel obstruction	*Severe stomach ache, vomiting.*	*Call parent/carer.*
Blood in mucus (uncommon)	*Small < 5 ml* *Moderate over 5 ml* *Large < 240 ml*	*Inform parent the same day.* *Call parent/carer or ambulance if can't reach parents.* *Call ambulance.*
PEG feeding tube or button problems (not many students have this)	*Leaking around tube, pain.* *Accidental dislodgement.*	*Call parent/carer.* *Call parent immediately, tube needs to be replaced ASAP. Country schools if close to hospital take student to ED and call parent.*
Rectal Prolapse (uncommon)	*Rectal pain, bleeding, protrusion of rectum through anus.*	*Reassure student, lie quietly if painful to sit.* *Call parent/carer.*
CF related diabetes Low blood sugar levels High blood sugar levels	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. *Thirst, passing a lot of urine, pins and needles, hot sweats, blurred vision, tiredness, weight loss.*	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. Check blood sugar levels before exercising. May need a carb snack before exercising. Check blood sugar levels. Eat sugary foods in small amounts throughout the day, taken with or after meals.

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 2156 **W:** www.chw.edu.au **Sydney Children's Hospital** Randwick **T:** (02) 9382 1332 **W:** www.sch.edu.au **John Hunter Children's Hospital** Newcastle **T:** (02) 4921 3676	**The Children's Hospital School at Westmead** **T:** (02) 9845 2813 **E:** childhosp_s.School@det.nsw.edu.au **W:** www.chw.edu.au/kids/school/ **Sydney Children's Hospital School** Randwick **T:** (02) 9382 1510 **John Hunter Children's Hospital School** Newcastle **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 **Lady Cilento Children's Hospital** **T:** (07) 3068 2303 **E:** LCCH_CF@health.qld.gov.au **W:** www.childrens.health.qld.gov.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

CF SMART RESOURCES

A selection of resources for teachers and students are available online at www.cfsmart.org or contact your state CF organisation for more details.

USEFUL CONTACT DETAILS

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

CYSTIC FIBROSIS Community Care
Incorporating CFV and CFNSW

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

03 9686 1811
admin@cfv.org.au
www.cysticfibrosis.org.au/vic/

CYSTIC FIBROSIS Community Care
Incorporating CFV and CFNSW

Street Address: Unit 46 Homebush Business Village,
11-21 Underwood Road, Homebush NSW 2140
Postal Address: PO Box 4113, Homebush South, NSW, 2140
Free call: 1800 650 614

02 8732 5700
admin@cfnsw.org.au
www.cysticfibrosis.org.au/nsw/

CYSTIC FIBROSIS ACT

Postal Address: PO Box 909, Civic Square ACT 2608

02 6292 9866
info@cfact.org.au
www.cysticfibrosis.org.au/act/

CYSTIC FIBROSIS Queensland

Street Address: 30 Sylvan Rd Toowong, Qld
Postal Address: PO Box 86, Toowong Business Hub Qld, 4066

07 3359 8000
admin@cfqld.org.au
www.cysticfibrosis.org.au/qld/

CYSTIC FIBROSIS South Australia

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

08 8221 5595
cfsa@cfsa.org.au
www.cysticfibrosis.org.au/sa/

CYSTIC FIBROSIS Western Australia

Street Address: The Niche, 11 Aberdare Rd Nedlands
Postal Address: PO Box 959, Nedlands 6909

08 6457 7333
info@cfwa.org.au
www.cfwa.org.au

CYSTIC FIBROSIS Tasmania

Postal Address: GPO Box 245, Hobart, Tasmania 7001
Free call: 1800 232 823 (Tas only)

03 6234 6085
general@cftas.org.au
www.cysticfibrosis.org.au/tas/

Other resources

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 teenagers, 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 what Cystic Fibrosis is. Designed for children, but young adults may also enjoy.

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

LIVEWIRE

A safe and supportive online community for young people aged 10 to 20 affected by a serious illness, disability or a chronic health condition.

www.livewire.org.au

CF VOICE

An online community for people of all ages, living with Cystic Fibrosis. The website has age specific sections.

www.cfvoice.com

Books

What's up with Beth? Medikidz explain Cystic Fibrosis

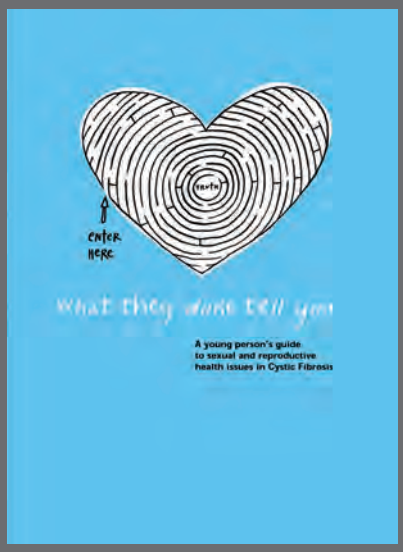
A book which explains CF to children aged 10 to 15 through the use of cartoon characters.

What they don't tell you: A young person's guide to sexual and reproductive health issues in Cystic Fibrosis

A booklet providing young people with CF, the basics about sexual and reproductive health and where to get more information.

Downloadable from:

http://www.rch.org.au/uploadedFiles/Main/Content/cah/What_they_dont_tell_you.pdf



CFsmart
cystic fibrosis education program

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

www.cfsmart.org