

STARTING HIGH SCHOOL WITH CYSTIC FIBROSIS



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HELPING YOUR TEEN MANAGE AT SCHOOL

*"On the first day of high school, we were all sitting in the undercover area waiting for the principals to yell out our class. I had all my mates in my class which was a bonus. It was a bit scary and I felt nervous going to all these different teachers that I didn't know. At the end of the first day I thought "High school isn't that bad after all". But unfortunately, I got homework that I had to do. The second day wasn't too bad, all my nerves went away. High school is way different to primary school. We have to work harder and we have to study and do heaps of tests." **Brandon, 15***

Moving to high school can be a big transition. Your child will become more independent and will need to learn to manage all the normal high school requirements, plus CF treatments.

It is important to have open communication and prepare your child for high school as much as possible.

If you and/or your child are feeling nervous, there are a few things you can do to alleviate some of your anxiety:

- Provide the school with as much CF education as you can so you and your child feel confident with the systems you have set in place.
- Encourage your child to have a good communication system with the school. They may choose to have a key person they can speak to about any issues that arise, such as their Year Coordinator.



- Have ongoing, short talks with your child about how they are coping at school and managing their CF.
- Share feelings with other CF parents who have been through the process. There are some great Facebook support groups CFWA can put you in contact with.

"My child is very anxious about keeping up with her work and I communicated as much as I could with the teachers until Year 11 (she is more confident now). We communicate often about real expectations of results and trying to enjoy her life at school" Mum of 17-year-old

"It is a challenging time in adolescence with constant challenges around personal hygiene, housework and added school work. With no appetite, eating, taking medications and doing physio is just more things on the list of daily challenges" Mum of 16-year-old

"Try to do treatments before and after school. It's hard to shuffle around homework, sports/activities and physio so we try to compromise by doing physio in the car - he doesn't like this though. I keep in contact with school when he's not there and they email work through - allowing extra time for completion" Mum of 13-year-old



CHOOSING A SCHOOL

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

Before settling on a school, we recommend meeting with a member of staff such as the Year 7 co-ordinator, deputy or teacher in charge of pastoral care, to discuss your child's medical needs. This initial meeting will allow you to gauge if you feel comfortable with the school's support and if it is right for your child.

Some questions to consider asking the school in relation to CF may be:

- Are there any other students with CF attending the school?
- How does the school cater for children with medical needs? Do they have a school nurse?
- Are they willing to have relevant staff educated about CF?
- What is the school's medication policy?

Other considerations may include:

- Health and wellbeing policies.
- Ability to provide additional care and support when needed.
- Hygiene and cleanliness.
- Modern, new air conditioning that is regularly serviced.
- Environmental risks, e.g. wet areas, ponds, water gardens, mulch etc.



*"We chose a school that was community minded, not only high score driven"***Mum of 17-year-old**

*"We chose a small, private, local Christian school due to the lower classroom numbers and more individual focus and accountability"***Mum of 16-year-old**

*"We were lucky that our son is in a Kindy to Year 12 school so that transition was easier. It's an independent school so there are less kids than the local high school"***Mum of 13-year-old**

EDUCATING THE SCHOOL

Health Care Plan

High schools require that students with medical conditions to have a Health Care Plan, which needs to be updated annually. If the high school has a school nurse, it can be useful to meet and discuss your child's Health Care Plan which can then be communicated to all relevant teachers. The school should have a Health Care Plan document, or you can download a CF specific one from www.cfsmart.org

Disclosure

Once a child reaches high school they may not feel comfortable with everyone knowing that they have CF. It is worth having a conversation to gauge your child's thoughts on this. While it is important that the teachers have an awareness of how CF may affect your child in a school setting, your child may not want other students to know, so the school would need to be aware of this.

"I spoke to the head of each year group as my child needed to self-medicate. My child chose who she disclosed to" **Mum of 17-year-old**


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

PHOTOCOPY
DOWNLOAD

School:	Date plan created:
Student's name:	Date for plan to be reviewed for following year:
Date of birth:	Medical Practitioner contact:
Year level:	Phone:
Student's teacher:	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.	<input type="checkbox"/> Inform teacher of additional medications which may be required during the year.
<input type="checkbox"/> Provide teacher with clear information about the medication e.g. how and when to be administered and side effects.	<input type="checkbox"/> Inform teacher/school when child has to go to hospital, clinic appointments, is home on IV treatment or is unwell at home.
<input type="checkbox"/> Discuss appropriate location for storing medications.	<input type="checkbox"/> Inform teacher if there are any changes in the child's health.
SIGNS OR SYMPTOMS TO BRING TO PARENTS' ATTENTION AT END OF THE DAY:	
<input type="checkbox"/> Toilet issues e.g. diarrhoea, constipation, frequent trips to toilet or on toilet for a long time.	<input type="checkbox"/> Complaints of stomach aches or abdominal swelling.
<input type="checkbox"/> Lethargic, extra tired.	<input type="checkbox"/> Markedly decreased or increased appetite.
<input type="checkbox"/> Increased coughing.	<input type="checkbox"/> If child has eaten food without consuming enzymes.
<input type="checkbox"/> Small amount of blood in mucus.	<input type="checkbox"/> Changes in child's behaviour.

"The enrolment forms require medical conditions to be detailed, which we did. He prefers his friends not to know he has CF as he fears being considered differently to others. This has caused issues for him as he says no one understands CF, whereas if others have asthma etc, everyone knows and understands and it's no issue" **Mum of 16-year-old**



"Practically everyone in the school knows. As parents we told teachers/head of school and our son chose to tell who he wanted. It's great to have everyone on board though" **Mum of 15-year-old**

"At school, the health nurse knows and most or all teachers are aware - mainly because of my contacting Head of Year before finishing term the year before. My son does not disclose to fellow students, although those who have been with him since kindy know he has regular hospital appointments and time off school when he's not well. They obviously know he has a cough and can get short of breath during sports when his cough is more active"

Mum of 13-year-old



Educating the staff about CF

Educating all the required staff in high school can be quite a difficult and daunting process compared to primary school.

A good approach is to arrange an initial meeting with a key staff member, such as the Year Co-ordinator, your child's Form Teacher, a staff member in Student Services or the school nurse. You can provide that staff member with all the pertinent information including your child's Health Care Plan and request that they disseminate the information to appropriate teachers who will be working directly with your child. In some cases, you may be able to send an email with the required information that can be forwarded to the appropriate teachers.

Your local state CF organisation or CF Clinic may have a staff member

available who can assist in providing education to school staff about CF and the specific needs of your child. This can be a good way of targeting multiple staff at once, as education sessions can be arranged during a staff meeting.

The key points to consider discussing are:

- An overview of CF
- Other CF related complications (where relevant), e.g. Cystic Fibrosis Related Diabetes
- Medications, e.g. enzymes, salt, ventolin
- Bowel issues/toilet needs
- Infection prevention and control
- Dehydration
- Absences
- Exam requirements



If teachers understand your child's needs, they are more likely to:

- Allow your child quick and easy access to the toilet or in some cases provide access to a separate toilet if needed. Some schools will allocate a toilet pass, so a student doesn't need to ask permission each time they need to go to the toilet.
- Be aware of, and address, any serious changes in your child's health, e.g. dehydration, fatigue, coughing, on the toilet more often, etc.
- Be understanding of absences and aware of the possibility of needing to liaise with hospital school services during admissions.



- Be aware of your child requiring medication such as enzymes and salt tablets and assist in encouraging this if your child is not always taking the medication.
- Allow your child to move seats if they are near someone who is unwell.
- Allow leniencies for assignment deadlines, exams, etc. due to illness.

"Frequent toilet breaks needed to be understood as not an evasion of work" **Veronika, mum of 17-year-old**

"Sport was an issue if it was too hot, however the teacher was very understanding as he knew about CF"

Mum of 17-year-old

"In year 7 we brought in the Education Officer from the local CF organisation who ran through everything with the Form Teacher and a couple of other teachers" **Mum of 15-year-old**

"I identified the Head of Year and met with her prior to my son starting Year 7" **Mum of 13-year-old**

Ongoing Communication

It is important to maintain ongoing communication with your chosen contact at the school to ensure they are aware of any changes in your child's health. They should also be made aware of any impending absences, such as if your child needs to have a hospital admission.

Providing education will be an ongoing process as teachers change or as your child's medical needs change. Email is a great way to contact or update multiple teachers at once.

"Keep in close contact with the appropriate teacher. Try to be organised and contact them well ahead of the start of the school year so you can meet with them or email information to them, particularly when your child is unwell."

Mum of 13-year-old

"If I have any queries during the year I know I can email Head of Year and will be listened to. They sometimes email me if there's a measles outbreak or other illness known within the school" **Mum of 13-year-old**



MANAGING CF NEEDS AT SCHOOL

There are many aspects of CF care that will need to be discussed with your school.

Providing education about the CF diet, medications including enzymes and salt, dehydration, infection prevention and control and other medical issues will help the school understand how to support your child while they are at school.

The CF Diet

It is important that the school understands the high calorie, high salt diet as part of the treatment plan for most children with CF, and that sometimes your child's food may not be in line with the school's healthy eating policies. Your child may worry about standing out with lunch boxes filled with high fat, high calorie foods so they may choose to leave these items for home.





Medications

Management of medication at high school is often one of the major concerns for parents. There are many things to consider including where medication will be stored, how it will be administered, and how independent your teenager is with taking their regular medication like enzymes and salt tablets.

All medications required at school must be included in their health care plan and discussed with the school. Each school will have their own medication policy and it is important to start discussions early to set up a system that works for you, your child and the school. Make sure your teenager is included in these discussions as they will have some valuable ideas about how they would like to manage medications at high school.

Enzymes

Usually by high school children with CF are independent in taking their enzymes and may keep them in their bag or pocket and take them when needed.

Most schools will allow this,





however, some may have rules about medications being kept in the school office, so it is a good idea to discuss this with the school early on. As enzymes are required as a life-long medication, it is preferable for your child to be able to keep hold of them, rather than go to the office to receive them from a teacher/ school nurse, etc.

At this age, many children start to worry about being different. If your child wishes to be discreet about taking enzymes or other medications, here are some ideas you can share with your child:

- Store enzymes in a mint or lolly container.
- Take enzymes while walking to lunch and have them in your pocket so you can quickly put them in your mouth before you take a drink or stop off to the toilets and take them there.
- Explain the tablets to your core group of friends who are most often going to see you taking them. Often a simple "I need these, so I can digest my food" is all it takes for people to stop asking questions.
- Arrange somewhere private to be able to take your enzymes.



Exercise and Dehydration

It is important to discuss dehydration risks with the school. Make sure they know that your child will need regular access to water, this is particularly important in warm weather or during physical activity.

Make sure the teachers are aware of signs of dehydration and how to act if

they think your child is dehydrated.

Encourage your child to:

- to carry a water bottle with them
- have sports drinks available if expecting to participate in sport
- have access to salt tablets
- take salty snacks to school



Environmental Risks

As you probably know, there are germs in the environment which can affect the lungs of people with CF. Certain environments can pose a risk, including mud, stagnant water, rotting vegetation, hay and fungi. This has implications for certain school activities which may

expose your child to these elements.

You can speak with your child's CF team about any activities you have concern with and get their advice. It is important to weigh up risk against quality of life. In most cases, your child should be able to participate but perhaps in a different way.



Cross-Infection

It is important the school understands the risk of cross-infection if there is more than one child with CF attending the school, or if a staff member has CF. This does happen occasionally and requires a Risk Management Plan to ensure that the risk of cross-infection is minimised.

Children with CF should not be in the same classes, however, if the children are in different year groups, or if there is a staff member at the school with CF, this can be managed.

- See our 'Cross-Infection at School' factsheet for more information www.cfsmart.org/wp-content/uploads/2018/05/Cross-infection-in-schools-.pdf

Absences

Your child is likely to have some absences from school due to general illness, clinic appointments or hospital admissions. Discuss this with your school so they can provide updates, liaise with the hospital school (if your hospital has one) or provide extensions.

If your child's hospital has a hospital school service, they may be able to liaise with your child's relevant teacher/s to arrange school work during admissions. Referrals are received through the Department of Health with parent consent.

Some children may return to school with a PICC line. This is a personal decision, and if you decide to do this, the school should be provided with information about keeping the PICC line safe at school.

"When in hospital, I contact the Head of Year and his school work is emailed to him. We have easy email access, so it's been a relatively easy process to contact teachers. I know not all high schools have this. At other times I ring in, you get to know the admin girls well!"

Mum of 13-year-old

"He has about two admissions per year which thankfully we have been able to arrange for during holidays; the few days affecting school we have advised the teachers directly"

Mum of 16-year-old



If your child is falling behind in school work following absences from school, they may be eligible to access the Ronald McDonald Learning Program. This is a free tutoring program helping children with serious illness catch up on their missed education following lengthy hospital stays and absence from school. Each program is tailored depending upon the child's needs, location and family situation. Most children will receive up to four school terms of one-on-one tuition with a qualified and registered teacher, along with speech and/or occupational therapy if required.

Ronald McDonald Learning Program

www.rmhc.org.au/our-programs/learning-program

PICCs, Ports and PEGs

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



Exams

If your child has exams, make sure the school is aware of any additional needs your child may have such as toilet breaks, a water bottle, etc.

If your child is sitting an ATAR course in Year 11 and 12, the school can ask for special examination arrangements to be put in place, if required, because your child has CF. This application must be made prior to the exams to The School Curriculum and Standards Authority. Your child's Year 11 and 12 coordinators will be able to make the application. They may need information from your child's GP or respiratory

doctor and ideally will have already made these arrangements for your child if necessary in previous years.

The request for special exam arrangements could include; sitting by the door to make it easier to access the toilet, extra toilet breaks or rest breaks, allowing extra time to complete the exam and bringing additional water into the exam room.

In some situations, your child might need to do their exams in a separate room or be allowed to sit the exam at another time if they are unwell.





Camps and School Trips

Having the opportunity to go on a camp or a school trip is fantastic for all young people and can allow for developing new skills and becoming more independent and confident. Your child going away and having to be responsible for his or her treatment can be a daunting thought, however, there are some tips to consider that can ensure your child can attend a camp or trip with minimal issues.

The main things to consider are:

- Arrange a meeting with the camp organiser and discuss the treatment your child will need to do while on the camp. Possibly bring in nebs and any tablets to show the teacher.
- Ask that your child has a private location to do treatment if needed, with access to a power point, somewhere to rinse and dry physio equipment.
- If the camp or trip is interstate or overseas,

arrange with your child's CF clinic for any paperwork and ask about the contact details of the closest CF clinic.

- Arrange in advance any insurance that may be required if interstate or overseas.
- Ask about location and activities, storage of medications, who will be responsible for ensuring your child does their treatment and takes medications.

"Camp time is a nervous time, well for me. But the school are really good, and my son keeps all his meds on him and has full control of them, as he does at home." **Mum of 15-year-old**

"I type up a list of needs, medications, physio, times, what to avoid and they are able to follow that with no issue." **Mum of 13-year-old**



SCHOOL CAMP CHECKLIST

CHECKLIST

<input type="checkbox"/>	Discuss specific requirements with the student and parents.
<input type="checkbox"/>	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.
<input type="checkbox"/>	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.
<input type="checkbox"/>	Provide a location where the student can conduct his/her physiotherapy and take medication in private, with minimal disturbance.
<input type="checkbox"/>	The student may require salt supplements, salty drinks and water if participating in strenuous activity and in warm weather.
<input type="checkbox"/>	Check the student's dietary requirements as he/she may require extra salt, cream, butter in meals.
<input type="checkbox"/>	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.
<input type="checkbox"/>	Suitable storage for medication and physiotherapy equipment is required, somewhere dry and not too hot.
<input type="checkbox"/>	Providing electricity for the use of the nebuliser. Some nebulisers can be operated by car batteries or normal batteries (for camping purposes).
<input type="checkbox"/>	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.
<input type="checkbox"/>	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:

This checklist is available on www.cfsmart.org **here** : <https://cfsmart.org/wp-content/uploads/2017/02/CFF035J-HST-School-Camp-Checklist.pdf>

AVAILABLE RESOURCES AND CONTACT DETAILS

The CFSmart website has a range of resources for teachers, parents and students to access such as:

- **'A Guide to Cystic Fibrosis for High School Teachers' booklet** www.cfsmart.org/wp-content/uploads/2017/02/CFF035J-Booklet-CF-for-High-School-Teachers_HighQualitySinglePages.pdf
- **CF e-learning modules online at** www.cfsmart.org/elearning.
- **PDF Summary of what CF is and factors to consider in the classroom:** <https://cfsmart.org/wp-content/uploads/2017/02/Summary-for-High-school-relief-teachers.pdf> and <https://cfsmart.org/wp-content/uploads/2017/02/CFF035J-HST-A-summary-for-managing-CF-in-the-classroom.pdf>
- **Tips and Ideas for High School Students with CF** www.cfsmart.org/wp-content/uploads/2017/08/CFSmart-High-School-Booklet-for-students-v1-2.pdf
- **'Life at Boarding School When You Have CF' blog** www.cfsmart.org/life-boarding-school-cystic-fibrosis
- **For further information on exercise and dehydration** please see our Factsheets: <https://www.cfwf.org.au/wp-content/uploads/2018/07/CF-Fact-Dehydration.pdf>
<https://www.cfwf.org.au/wp-content/uploads/2018/07/CF-Fact-Exercise-and-Sport-in-School.pdf>
- **'Infection Control in Schools' factsheet** www.cfwf.org.au/wp-content/uploads/2018/02/CF-Fact-Infection-Control-In-Schools.pdf
- **'Common Infections' factsheet** www.cfwf.org.au/wp-content/uploads/2018/02/CF-Fact-Common-Infections.pdf
- **For further details see: The School Curriculum and Standards Authority** <https://senior-secondary.scsa.wa.edu.au/assessment/examinations/special-provisions>

CFTalk Magazine: an online magazine with the first issue featuring articles for young people with CF, about starting high school. Available on www.cfsmart.org and www.cfwf.org.au

CFTalk Films: a series of films where young and older people with CF have been asked questions about living with CF and how they have managed school, work and relationships. Available on www.cfsmart.org and www.cfw.org.au

What is Cystic Fibrosis and How do you Get it?: A short animated film explaining CF to audiences aged 13 and upwards <https://www.youtube.com/watch?v=wx-97TdcgEM>

OTHER RESOURCES

- '5 Tips for Starting Secondary School' by the CF UK Trust www.youtube.com/watch?time_continue=10&v=adAdh4LrVtw
- "The Rest is Up to Me" by the CF UK Trust <https://www.youtube.com/watch?v=BXU-dtaFzhw>

Cystic Fibrosis Western Australia (CFWA)

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

education@cfwa.org.au

08 6457 7333 Web: www.cfw.org.au

Cystic Fibrosis Community Care Victoria

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

dmin@cfcc.org.au Web: www.cysticfibrosis.org.au

03 9686 1811

Cystic Fibrosis Community Care New South Wales

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

Email: regionalsupport@cfcc.org.au

Phone: 02 4960 2922



Cystic Fibrosis South Australia

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

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

Cystic Fibrosis Association of ACT Inc

P: (02) 6292 9866

E: info@cfact.org.au W: www.cysticfibrosis.org.au

Cystic Fibrosis South Australia

P: (08) 8221 5595

E: cfসা@cfসা.org.au W: www.cysticfibrosis.org.au

Cystic Fibrosis Tasmania

P: (03) 6234 6085

E: general@cftas.org.au W: www.cysticfibrosis.org.au

Cystic Fibrosis Queensland

P: (07) 3359 8000

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