

Tips for when your child with cystic fibrosis starts day care, primary school or high school



Communicating with your child's school

It can really help if you are able to form a good relationship with the Deputy /Principal of the school, as he/she will usually support education of all teachers concerned in regards to cystic fibrosis (if that is what you wish) and will often make sure that this happens on an annual basis to keep teachers updated.

The school's primary objective will be to provide your child with a high quality education, however there may be times when your main objective will be your child's health and he/she may not be well enough to complete school work. It can help if the teachers understand your perspective about your child's education and health in advance, as that will take the pressure off you in regards to absences and homework not being completed, later on down the track.

Who needs to understand about cystic fibrosis in the school?:

- In day-care centres: centre coordinator and a few staff members, including the cook
- In primary schools: class teacher, principal or deputy, phys ed teacher and any other relevant teachers eg. music, art, parents and fellow class mates (if appropriate), other parents
- In high schools: year co-ordinator, form teacher, deputy or principal, school nurse, school counsellor any other relevant teachers such as Health and Physical Education and fellow class mates (if appropriate)

What to discuss with the school:

- Enzymes how and when? If your child is in day care, kindy or pre-primary the class teacher or teacher assistant can assist your child in taking his/her enzymes.

Ideally once your child becomes responsible for his/her enzymes when he/she reaches an appropriate age, it is good to keep the enzymes with the lunchbox (if stored in a cool place). However not all children take their enzymes when they should, so keeping in regular contact with the teacher to check how your child is managing the enzymes is useful.

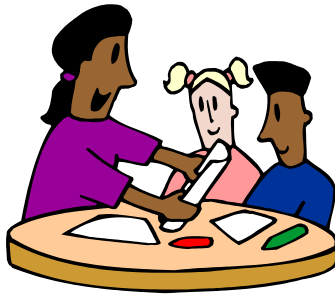
Some schools are against a child having medication in their bag and want it to be distributed by the class teacher or by admin staff in the office. It is often possible to talk schools around if your child is able to take his/her enzymes independently. (CFWA is happy to help in this situation)

- Salt loss in sweat: Sport, hot weather, how managed? Does your child need an extra salty drink during summer eg cordial or Gatorade

- CF diet: High fat, like a cube rather than a pyramid. Will your child be eating a high fat diet at school?
- Colds, flu, gastro, chicken pox: How they could impact on your child.
- Good hand washing practices: by students and teachers.
- How will absences be managed? : Getting homework, catch-up notes. Will teacher email? Is there a friend in class who can gather notes?
- Do you need to discuss if your child is in hospital or on HITH: he/she may not be well enough to do homework? Can the teacher mark your child on the work he/she does throughout the year, and not deduct marks for the work she/he hasn't been able to do?
- Cross Infection if another student with CF is at the school: If another child with CF is in a different year group, the risk of cross infection is not as great, however teachers need to be aware in case the different year groups interact.
- Phys Ed: dehydration and getting tired or coughing during exercise etc?
- Does your child become extra tired in afternoon or in morning?
- Toilet breaks: is your child a long time on the toilet?
- Pools of stagnant water: gardening activities? Is pseudomonas a risk?
- School camps and school excursions:

Find out:

- When will you speak to the teaching staff about your child? Before the year starts or early into the school year? Or both.
- When will you need to fill out the medical plan and update it when needed?
- How and when do teachers pass information on each year to the next teacher about CF?
- Will you have regular communication with the teacher/staff to discuss any issues? How? eg. email, regular chats, communication diary?
- Education sessions can be done on your behalf by CFWA, for all types of groups eg. teachers, students, other parents, school nurse, community groups eg. Scouts and also family groups. We can help to back up what you are saying to the school.



Things to consider for day care – pre primary

- Hand washing: Do they have paper towels and soap and warm water? (not shared) Do they have hand sanitiser readily available? Do they regularly clean computer keyboards, shared pencils, toys etc?
- Colds: Are they teaching the children about coughing into their sleeve, not their hands? Throwing away tissues and washing hands afterwards. Letting other parents know about bringing their children who have bad colds etc? What is the school's policy on children who are really unwell (eg. green mucus or vomiting the night before and being brought to school)?
- Water bottle: Will your child use a water bottle at the school or centre? Will it come home each night or stay at the centre?
- Water play: how fresh is the water? Germs can be transferred through water, so ask about how water play is managed and the best way your child can participate without being exposed to unnecessary risks.
- Fruit time: will you want your child to have a bit extra to go with the fruit? Some kindy centres have the capacity to allow a child with CF who needs bulking up, to have a smoothie or high calorie drink with their fruit.

Things to consider for Primary school

- Will peers need to know about CF? It can make things easier, but it really depends on how your child feels.
- How will you deal with difficult questions your child may ask, from doing Google searches or speaking to other children?
- Missing school: Keep documentation of hospital appointments and admissions, all in one file, as may be eligible for tutoring. eg Ronald McDonald Learning Program
- Encourage to be in local sports association (good for physio and friends)
- Encourage good organisation and study habits early on, so can make most of times when your child is well, and if he/she is unwell, you can focus on their health and not stress about your child's education.

Things to consider for High school

- Homework: how will your child catch up, if she/he has to miss school, due to hospital admissions or HITH? Can the teacher find an average mark on the work your child has been able to do, rather than include the 0 score for work that has not been completed due to hospital admissions etc?
- Keep all documentation from doctors etc as to school missed, as proof for Ronald McDonald Learning Program, or exemption from exams etc.
- Year 12: your child may need special exam arrangements or provisions. There are forms that need to be filled out in advance with WACE (Western Australia Curriculum Council). You can discuss with your child's year coordinator.
- Encourage good study habits and organisation during the times that your child is well.
- Sleep: Adolescents need about 9 hours sleep, does your child need more? Does this need to be discussed with school, if struggling to get there on time.
- Disclosure to peers? During the later stages of high school, it can be useful if other students understand a bit about cystic fibrosis and how it affects your child in the school setting, however it is very common for an adolescent with CF, to not want everyone else knowing about their condition. But if a few close friends understand the basics, they can be very supportive and helpful.

A few educational services that may be useful

- CFWA: We can provide education sessions for teachers, other parents or children at the school. We will work around when the teachers are available and can contact the school once you have given us permission. We also have a range of brochures and educational resources that you may wish to give to the school to be distributed. It can be useful in some situations to have an extra voice that will back up what you have explained to the school about CF and how it affects your child.

Education Officer: 08 9346 7337

Email: educationofficer@cysticfibrosiswa.org

Web: www.cysticfibrosis.org.au/wa/

- Other parents who have children with CF: If you need, CFWA can connect you with another parent who has been through the school system and who is willing to share their tips or experiences with you. Parents who have children with CF are a valuable resource as they know more than anyone what you are going through.

- Hospital School Services : provide educational support for students when they are in hospital. They can liaise with your child's class teacher so there is consistency with the school work completed. The Hospital School Services also run a CF information seminar for primary and high school teachers once a year, in early March at PMH. Details are advertised in the School Matters magazine and CFWA also advertises the dates in E-News and RED magazine.

Principal and General Enquiries: 08 9340 8529

Email: hss@det.wa.edu.au

Web: www.hospitalschoolservices.wa.edu.au

- Ronald McDonald Learning Program: This program supports the educational needs of children recovering from serious illness, by providing individual learning programs. The programs provide 40 hours of tutoring, at the school by a qualified teacher per year. Parents can contact the organisation directly to find out if their children can qualify to access the service. Usually a child has to miss approximately 40 days of schooling to qualify but this is negotiable.

The National Operations Manager is Anita Neville: 03 9345 4781

Email: twebster@mcdonalds.com.au

Web: www.rmhc.org.au

- The School Volunteer Program: offers various programs where volunteers can engage in mentoring students for one hour per week for a minimum of one term. Mentors, by being caring and positive, reinforce improvements and encourage the student to tackle learning more positively in the general classroom.

Telephone: (08) 9444 8646

Email: svpwa@svp.org.au

Web: www.svp.org.au



Tips from Parents who have a child with CF

- Could make a small laminated card that lists a few party food items eg. cupcakes, Freddo frogs etc, that are common in schools and children's parties and how many enzymes your child needs for each food item. Also include your contact number and explain that without the enzymes, there could be unpleasant consequences (yucky runny poos!). Could give the card to teachers and keep a copy in your child's lunchbox.
- Make yourself available to visit the class teacher, to regularly find out how things are going.
- Be open with teachers about CF from the start.
- Communication with teachers and the school needs to be number 1 priority and is continuous.
- Educating teachers about CF in your child's school is an ongoing process, don't presume information about your child will be passed onto the next year's teacher. You may have to keep the school updated every year to ensure a smoother transition for your child.
- Included post it note in lunch box with number of enzymes needed for each food item (for child and/or teacher)
- Teach your child to their own cleanliness, as can't control what other students are doing, but if your child has good hand washing practices etc, will reduce the risk of catching colds etc to some extent.
- Routine is so important and although a drag can make life easier. Even in school holidays it is good to try and stick to a bit of a routine eg. physio (maybe not so early) so your child doesn't get out of the habit by the time school starts again.
- Medibands could be useful for your child, when he/she is young and not able to communicate about CF. They can write whatever you want on the wristband explaining your child's needs briefly. The website is www.mediband.com.au
- Store enzymes in something like Tupperware key rings, for older child (eg. 10 +) to add to lunchbox.

- Was available to attend parties that daughter was invited to, so could keep eye on the food and enzymes until daughter was 8. Made things less stressful.
- One Kindy had a coughing/sneezing station with tissues and Aqium, where children were shown good hygiene practices, through their play.
- Let drinking fountains run for a bit, to avoid pseudomonas

High school tip:

- Sent letter about child to Year co-ordinator and emailed all teachers involved with a brief run down on CF and how it affects a student in school. At parent/teacher night, asked all relevant teachers if they had read/ received email.