

3 Health support

“I was brought up and encouraged to do anything I wanted”

School, preschool and childcare staff are trained and expected to care for children/students in a manner which enhances their learning and independence, and which respects their privacy, dignity and right to feel and be safe at all times.

- ★ Health care management training for education and childcare staff is generally limited to supervision for safety and first aid. Additional care required by children/students should be written by the doctor (or other relevant health professional) in a health care plan detailing routine and potential emergency care recommendations within the education and care setting. Staff can then use this plan to develop a health support plan, detailing how staff will address the child/student’s health care support needs.
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The health care plan and support plan must reflect respect for the child/student's privacy, dignity, safety and comfort. Confidentiality issues should be explicitly negotiated with the family.

3.1 Confidentiality, privacy, dignity and safety

Young children often enjoy sharing the news and their experiences of living with CF with their classmates. The degree and nature of this sharing should be discussed with parents so that they can support their child in this process.

Older children and adolescents often wish to keep their illness and experiences private or confined to a very small group. At this age they can be particularly wary of teachers' respect for their privacy. They may also be fearful that by sharing the information they will be treated differently by their teachers and peers.

Information exchange between the family and health professionals and school, preschool or childcare is essential to support academic progress and enhance peer support. The sharing of information needs to be assessed and negotiated for each child with CF, with due consideration to their needs. Staff need information about routine and predictable emergency care as it affects the child/student's access to curriculum and their safety.

The following guidelines have been adapted from material written by Dr Christine Simons (Women’s and Children’s Hospital South Australia, 1996).

Confidentiality means that the information provided to medical personnel by patients, or their parents, is done so in confidence. Such information remains the property of the child and their parents.

This means that, except in circumstances where there is a legal obligation to do so (for example in child protection situations) medical personnel are not free to divulge personal information about children/students without their parents' or their consent. They may provide general information about, for example, the nature of CF and care for people with CF – information generally available to the community.

Families of chronically ill children of uncertain prognosis are chronically stressed families. It would not be surprising if even the most stable and well-adjusted parents and children were, at times, anxious and touchy.

The most undermining threat to the trust between family and the school, preschool or childcare service is the feeling of things happening behind the family's back. Staff need to be acutely conscious of this in their dealings with the family and with/between other members of staff. Liaison between education and careworkers and medical personnel is usually welcomed. However some very private people may find any discussion of their lives an intrusion.

Families may also be reluctant for liaison for a range of other reasons, for example:

- feeling embarrassed, guilty, ambivalent or overwhelmed by the diagnosis/condition
- uncertain whether they can trust the people who are seeking the information
- negative experiences, if such consultations have 'gone wrong' in the past.

Generally, the situation can be clarified through a sensitive exploration of the concerns and clear identification and agreement of what will and will not be discussed and with whom, and the anticipated benefit to the child.

Adolescents are particularly sensitive about information distribution. In particular, at the beginning of secondary schooling, it may require a great deal of work to persuade them that anyone at school be told anything. Early contact with school staff may determine how they resolve this issue in the longer term.

3.2 Health care planning

Our son has been missing a considerable amount of school. This means he is falling behind in his work and has to try to catch up with more homework. This comes at a cost, ie more homework means either less sleep or less free time or less treatment. (Parent)



A health care plan for a child/student with cystic fibrosis should address the following components:

- overall wellness
- diet
- therapy and care
- internal body temperature control
- curriculum participation issues
- potential emergency/first aid situations.

This information should focus on what education and care staff need to know to provide routine and emergency care. It will be used by staff in planning support for the child.

Overall wellness

Fluctuations in wellness/recent hospitalisation

Schools, preschools and childcare staff need to know if recent/frequent hospitalisation and/or general unwellness mean additional care and consideration. They also need to know of any infection control issues in addition to standard precautions. It is important to the future health of a child with CF to minimise the risk of cross infection of bacteria and viruses from others. This must be balanced with efforts to encourage children with CF to lead as normal lives as possible. Teachers can help by understanding if parents wish to keep their child with CF at home when a particularly virulent strain of virus is present in the classroom. All children in the class should be encouraged to not sneeze or cough on or near each other, as a normal public health measure. If possible, a child with CF should, discretely, not be partnered or sit next to another child with an obvious cold or cough.

Cough management

Children with CF have a persistent and necessary cough or wheeze. Their coughing is essential to help clear the lungs of mucus and fight chest infections. It is not contagious. Teachers can help by not drawing attention to the coughing. Often children with CF are so used to it, they are not even aware of it. A more frequent and moist or wet cough can be an early indication of a chest infection.

Management of port

A child with a port cannot play contact sports. If knocked, a port may be very tender to touch.

Staff need to inform parents if children report any redness, swelling or bruising in the vicinity of the port. Injury to the port should be reported to the child's parents as soon as possible.

Management of an intravenous (IV) line

If a child/student has a short intravenous line attached, the line will be covered, and the forearm splinted and wrapped to protect the line from being dislodged or damaged. If a child/student has a long flexible line, the forearm will be wrapped but not splinted. Education and centre staff do not have to manage these protective measures: they will be put on at home or by a nurse and will remain on during schooling/care.

Mental health issues

Living with an illness like CF, with on-going treatment regimes and hospitalisations, can have social, emotional and behavioural impacts on the student. Other family members are also affected. Siblings may feel sad, scared or resentful of the extra attention the child with CF receives. Parents have the task of striving to maintain a normal lifestyle for themselves and their family while adjusting to the meaning of the illness and all it entails for the family.

Children with CF who have been hospitalised have often been exposed to illness, treatments and death (actual or through discussion) at an early age. They may speak about death in ways unexpected for their age. Talk of death can also be an indicator of the meaning their illness has for them and so should be dealt with sensitively by all concerned.

Younger children commonly exhibit their emotions through their behaviour. If so they require understanding and the maintenance of clear firm limits. Older students sometimes express their feelings in more direct ways and present with a depressed mood, and decreased motivation or focus on their studies.

It is not uncommon for a child to become uncooperative and poorly motivated to attend to treatments. This is worrying to parents, education and careworkers and the health care team and requires a coordinated approach to help the child meet the demands of treatment.

All students with CF experience interruption to their studies and their relationships with peers and teachers. The centre or school can help to minimise the effects of this by an understanding approach with realistic expectations. Sensitive, clear communication with the student, their family and the health team will facilitate this support.

Could you stomach up to 60 tablets a day?

Some children with cystic fibrosis do.

⊕⊖⊖⊖⊗⊗⊗⊗	Before breakfast	⊗	Around 4pm
⊕⊕⊕⊕⊕⊕⊕⊕⊕⊕	With breakfast	⊕⊕⊕⊕	Snack foods
⊗	After breakfast	⊕⊕⊕⊕⊕⊕⊕⊕⊕⊕	Tea time
⊕⊗⊖	Before lunch	⊕⊗⊖	After tea
⊕⊕⊕⊕⊕⊕⊕⊕⊕⊕	With lunch	⊕⊕⊕⊕	Supper
⊕⊕⊕⊕	Afternoon tea	⊗	Before bed

⊕ enzymes ⊗ vitamins ⊖ antibiotics

Diet

Special dietary requirements

Children with CF have difficulty maintaining their weight and growth patterns as they cannot absorb essential vitamins, minerals, fat and proteins. They lose large amounts of salt in their sweat, suffer stomach cramping, and have frequent, sometimes foul smelling stools. They take vitamin and mineral supplements, and pancreatic enzymes to help the body digest fat. Their diet therefore needs to be high in fat, protein, salt and calories as well as incorporating all essential food groups.

Children with CF need much more food than a routine healthy diet (as described in the Australian Dietary Guidelines). They are encouraged to eat foods like chips, lollies, hamburgers, biscuits and highly salty foods and add foods such as cream, salt, ice-cream and butter to many of their everyday meals. They eat more food, more frequently than other children. Extra food will need to be provided for school activities and camps. The high calorie, high protein diet they need to fit in each day is often not easy.

Children with CF often report being teased by other children about having poor eating habits. Education and childcare workers can help by encouraging the child with CF to eat during all breaks, and to normalise their eating pattern to other children.

Gastrostomy button

Children who need additional food supplements will receive them through a gastrostomy button located in their stomach. During school, preschool and childcare this button is closed and does not affect the child's ability to participate in any activity. A credentialed careworker can assist with the procedures for supplementary feeding at night. There are no routine care issues associated with a gastrostomy button for education and childcare workers. If the area becomes red or inflamed, parents should be informed as soon as possible. Staff should be aware that many children/students do not want others at school to know about their gastrostomy button.

Enzyme supplements

Children with CF take pancreatic enzyme supplements daily by mouth with food. They come as powder-filled capsules, beads or tablets.

Most children have learnt to swallow tablets by the age of six or seven. For younger children, capsules need to be opened and the beads or powder inside mixed with one or two tablespoons of soft food. Children need to drink after taking enzymes this way, as enzyme powder will irritate the gums and tongue if it remains in the mouth.

Children should have their enzymes with them at all times. For younger children it may be useful for the education or childcare worker to carry extra enzymes. For older children it is important for them to be allowed to take their enzymes when they see fit and not to draw attention to adherence.

Enzymes are not classed as pharmaceutical drugs. Children with CF may also be taking pharmaceutical drugs such as antibiotics in addition to their enzymes. Enzyme supplements are not considered to be dangerous substances and therefore can be carried by the children and stored where the child can access them when needed.

Therapy and care

Nursing and physiotherapy

Some children/students with CF may require complex/invasive health support, such as physiotherapy, while attending school, preschool or childcare. This support should be provided by a visiting nurse or therapist.

Nebuliser treatments

Some children with CF require nebulised medication prior to physiotherapy. While education and childcare staff can supervise nebulised medication, this will generally be managed by the child/student themselves or the visiting health worker. Education and childcare staff need training before supervising administration of medication via a nebuliser.

Home based care

In South Australia families can sometimes opt for their children to receive intravenous (IV) drug medication through the Women's and Children's Hospital home IV program. This program works to minimise disruption to the child and their family caused by frequent or lengthy hospital admissions. The child/student is able to attend school during home IV treatment but will have an intravenous access line or an accessed port (see section 2.4 Intravenous drug therapy). The child will be supported by daily visits from a physiotherapist who may need to visit during school time.

The child/student will not be able to take part in any sport or physical activity during this time.

Because this IV treatment is to counteract an infection, the child/student might be more tired than usual and not be able to attend programs for the whole day. Staff should be sensitive and flexible in response to this episodic attendance.

Body temperature control

Clothing

Children/students may need to be reminded to adjust their clothing to help their internal body temperature control. Special allowances may be needed regarding school uniform requirements.

Environmental management

A child with CF will have problems with internal temperature control and should be kept at a steady temperature in winter and summer. It is beneficial to place the child with CF in classrooms that have heating and cooling.

Salt tablets/powder

Salt tablets are taken during warm weather and before playing sport. Teachers should be informed about the required timing and amount of salt tablets and ensure the child has access to fluids at all times. This may mean keeping a drink bottle on their desk - a healthy practice for all students. Families need to provide a medication authority detailing required dosage and timing of salt tablets.

Curriculum/workplace participation

Tiredness

An increase in fatigue or feeling tired is common for a child with CF. A lot of effort is required of a person with CF, on top of normal childhood activities, to maintain their health. They sometimes tire more easily during physical activity.

Because children with CF have problems with malabsorption, they may be shorter or thinner than their classmates with potentially reduced body strength.

Children also need to fit at least two sessions of intensive physiotherapy into their day. These often take place early in the morning and in the evening.

There will automatically be an increase in tiredness with any worsening of lung condition.

Shortness of breath

During the onset of infections, children with CF may experience difficulty breathing or catching breath. This is caused by thick mucus secretions blocking the airways. It often goes hand in hand with increased coughing to clear the airways. Staff should be aware that, as with other children, breathing difficulties also can be asthma related.

Difficulty in concentration

These symptoms often make it very difficult for children with CF to concentrate in class. Children with CF are continually battling infections or recovering from them. With low energy levels come low levels of concentration. Excessive tiredness later in the day and in the evening can have a profound effect on concentration span.

Education and childcare workers may need to make special arrangements for activities scheduled late in the day and provide extensions for school assignments.

Fluctuating capabilities

Most young people cope with their CF very well. However, their capability to function at what is considered a normal level for them will fluctuate with the onset of infection, during treatment and after hospitalisation. This is beyond the child/student's control and is a result of both physical and psychosocial issues. They can be hospitalised up to four or five times a year. Older children may need to negotiate school workload and curriculum during this time.

Need for frequent, self-monitored physical activity

A regular exercise program is very beneficial to children with CF, because it helps loosen mucus, stimulates coughing and helps build up strength and endurance of the breathing muscles. Children with CF should be allowed and encouraged to take part in exercises such as swimming, bicycling, sports and games. However, it is important to remember that ability to perform will fluctuate with health status. Children who have a port will not be able to take part in contact sports. Children at school with an intravenous (IV) line will not be able to participate in strenuous physical activities.

Children with CF can become dehydrated much more quickly than other children. This is because the gene that causes CF affects the way cells work in the body. An imbalance in sodium chloride (salt) exchange means that cells will not hold water. Sweat is therefore very salty, and hot weather and exercise can lead to salt loss and dehydration. Education and childcare workers should:

- encourage frequent drinks during and after exercise, and on warm days
- ensure salt tablets are taken either before or after exercise on warm days
- avoid scheduling physical activity during temperature extremes
- ensure children with CF remain, as far as is practical, in a fairly constant temperature, neither too hot nor too cold.

Sports skills, fitness and energy levels will vary from time to time depending on growth spurts, onset of chest infections, hospital admissions, or deterioration of their condition and overall health. Some adolescents may find that they are unable to maintain their fitness levels against their peer group. They should be encouraged to maintain the degree of fitness with which they are comfortable and with which their body can cope at any one time. People with CF usually know their own physical capabilities. The teacher should respect the child/student's assessment of their capabilities.

Need to plan for episodic attendance

Students may know some days in advance that they are due for a hospital admission. Occasionally they are admitted straight from a clinic appointment. It is important to plan with the student for hospital admissions. Secondary students appreciate getting work in advance so that they can make work plans around medical procedures and bouts of tiredness.

Hospital is not the easiest venue to work in and students will need all the support and motivation available to complete simple assignments. Students of all ages welcome contact from their school during a hospital admission. They may often feel 'cut off' and isolated from the daily environment and need reassurance that they are not forgotten. Children with a chronic illness, such as CF, who suffer regular and frequent admissions, often do not have time to initiate and keep up this level of contact. Yet it is vital to their psychological well-being that the school keeps in touch with them.

Potential emergency situations

Emergency situations associated with CF are rare.

If children/students have an intravenous line for medication, there are specific standard first aid responses which may be anticipated:

- Child reports discomfort, nausea, rashes or general unwellness.
Call family emergency contact. If they cannot be reached, call the nominated cystic fibrosis nurse for advice.
- Child reports redness, pain, inflammation or swelling at site.
Call nominated cystic fibrosis nurse for advice, and then advise family emergency contact.
- There is a leakage of some sort from the site.
Call nominated cystic fibrosis nurse for advice, and then advise family emergency contact.
- A needle or line falls out.
Use standard first aid and apply pressure to stop any bleeding, call nominated cystic fibrosis nurse for advice, then advise family emergency contact.

If any action is required, in addition to standard first aid, this will be documented on the individual first aid plan.

Additional information

Medication

Children/students with CF need to take their enzymes before eating. These are essential dietary supplements.

Normal tablet intake may temporarily increase when infection is present, or when children need vitamin supplements. It may seem at times that these children are forever taking something.

In addition, some of the children may have medication for other conditions. This should be managed in the same manner as medication for any other child/student.

3.3 Health support planning

Sometimes when studying if I'm not feeling 100 per cent then I find it very hard to concentrate (sic) on my studies. It's hard to improve in this area because there are always days in the week where I don't feel 100 percent. (Student)

- ★ The health support plan for an individual child/student will be developed by the principal, director or home-based carer with the family. It will be based on the child's health support needs as identified in their CF care plan and other care information (for example if the child also has asthma or diabetes).

A health support plan documents individualised support which staff have agreed to provide in the areas of:

- first aid
- supervision for safety
- personal care, including infection control
- behaviour support
- special curriculum support to enable continuity of education.

In schools or centres, the support plan will identify a staff member who will be the contact person for the family and health service providers. This staff member will ensure all staff has information on a need to know basis, as negotiated with the family, while respecting the family's privacy.

First aid

If any action is required, in addition to standard first aid, this will be documented on the individual care plan.

Supervision for safety

The child/student's health support plan may include a range of routine accommodations so they can continue to access learning programs while effectively managing their health care. Accommodations could include:

- provision of additional time to support children managing their dietary requirements
- access to fluids and food, and the toilet, as needed
- rescheduling of physical activity to support body temperature control
- supportive and sensitive encouragement to participate in physical activity
- targeted social skills programs: frequent absences mean that some children with cystic fibrosis have difficulty making and retaining friends
- modification of the program and activities in response to the demands of therapy and treatment

- regular review of progress to keep everyone informed about changes and how best to plan for and support the child.

Personal care, including infection control considerations

Education and childcare staff should plan to ensure that therapy and dietary management causes the least disruption to the learning program while maximising care. For example, the school timetable might be adjusted to ensure the same learning area is not always affected by therapy sessions. Personal care should not be routinely scheduled in recess and lunch breaks: recreation, socialisation and relaxation should also be accommodated.

Planning should respect students' privacy and dignity. For example, staff could organise discreet access to the toilet during lesson time to avoid embarrassment due to odour.

Staff should be aware that, where there is more than one family in the school or care community with CF, cross-infection is a serious health risk. Children with CF colonise different bacteria at different times. This affects their health status and future development of the disease. It is often necessary to take special precautions to segregate children with CF from different families. This matter should be addressed in confidence, with the families concerned.

Behaviour support

As for all children, behaviour expectations for children/students with CF should be consistent and predictable, and also sufficiently flexible to accommodate periods of stress and other potential mental health issues.



The health support plan should encourage self-management. Children with CF have to learn to live with their condition for life. It is therefore important for education and childcare staff to work with the parents and child to encourage self-management of the condition as the child matures.

A child is on a continual learning curve in all aspects of their life and their self-care will not be perfect at first nor all the time. Self-management is not a smooth process. It is often hard for parents to stand back and hand over responsibility for management. Teenagers in particular are dealing with many new responsibilities, not just CF management. Remembering to take tablets and do their physiotherapy is tedious and boring. Children should not be punished for non-compliance. Mistakes help children learn, but feeling bad or guilty about a mistake makes learning harder.

Having CF is neither convenient nor fun. Children find it frustrating and unpleasant at times to behave responsibly. They need support to understand the importance of compliance with treatment.

Curriculum

One year our son missed 10 weeks of school. School sent work for him which was OK, but I don't know what will happen when he's in high school. (Parent)

Planning and review processes should ensure continuity of access to education and care as the child moves between home, school/preschool/childcare and hospital.

While school students should not be expected to maintain the pace of curriculum participation when they are unwell, they should have the opportunity to choose to participate if and when they are able. Staff can assist by:

- providing course overviews, with key assignments and timelines highlighted, and negotiated as relevant
- developing an individual learning management plan to maximise continuity of access to curriculum, including additional curriculum support hours and links with the school's volunteer learning assistance program
- planning ways to continue communication with the student whatever the setting for learning, for example, fax, telephone, and e-mail
- liaising with hospital and/or open access teachers to maintain continuity of learning programs
- considering additional support to facilitate the ease of transition between the various learning settings, for example linking with a volunteer (learning assistance) support worker
- planning re-entry after periods of absence due to illness or hospitalisation, for example not requiring assessment tasks to be completed immediately upon return to school
- forward planning for camps, excursions and other special events to ensure the student does not miss out either through poor timing, inappropriate expectations of participation, or lack of sensitivity to health and personal care support needs.

The health support plan could also document curriculum issues for other students, for example:

- nutrition education including information on individual dietary needs which fall outside national dietary guidelines
- growth and development lessons taking into account the reasons many adolescents can be below average for height and weight
- drug education including reference to pharmaceutical drugs necessary for health and other substances, such as dietary supplements, which support health and well-being
- education about grief, loss and change
- anti-harassment sessions, as needed
- disability awareness sessions, as part of the overall strategy to support inclusion.

Any curriculum planning should ensure teachers do not make individual students, or their personal health issues, the content of the curriculum. Rather, confidentiality should be respected and issues raised in a one-step-removed, generic approach. If children/students choose to disclose personal issues, they should do so advisedly and teachers should ensure that the children concerned understand the potential impact of their disclosure.