

# CYSTIC FIBROSIS MANAGEMENT POLICY

Cystic fibrosis is a genetic disorder that predominantly affects the lungs and digestive system (Cystic Fibrosis Australia, 2017). Our Service will make every effort to fully include children/babies with cystic fibrosis in our program and provide a safe and healthy environment for them.

## NATIONAL QUALITY STANDARD (NQS)

QUALITY AREA 2: CHILDREN'S HEALTH AND SAFETY		
2.1.1	Wellbeing and comfort	Each child's wellbeing and comfort is provided for, including appropriate opportunities to meet each child's needs for sleep, rest and relaxation.
2.1.2	Health practices and procedures	Effective illness and injury management and hygiene practices are promoted and implemented.
2.2	Safety	Each child is protected.
2.2.1	Supervision	At all times, reasonable precautions and adequate supervision ensure children are protected from harm and hazard.
2.2.2	Incident and emergency management	Plans to effectively manage incidents and emergencies are developed in consultation with relevant authorities, practiced and implemented.

EDUCATION AND CARE SERVICES NATIONAL REGULATIONS	
77	Health, hygiene and safe food practices
90	Medical conditions policy
90(1)(iv)	Medical Conditions Communication Plan
91	Medical conditions policy to be provided to parents
92	Medication record
93	Administration of medication
94	Exception to authorisation requirement—anaphylaxis or asthma emergency
95	Procedure for administration of medication
136	First aid qualifications

**RELATED POLICIES**

Administration of first aid Policy Control of Infectious Disease Policy Hand Washing Policy Incident, Illness, Accident, Trauma Policy	Medical Conditions Policy Nutrition and Food Safety Policy Supervision Policy
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**PURPOSE**

We aim to create and maintain a safe and healthy environment for all children enrolled at the Service. This policy aims to provide a basic understanding and awareness of the possible needs of children with cystic fibrosis: It does not constitute a replacement for medical advice or instructions provided by an individual child’s family or health care professionals.

**SCOPE**

This policy applies to children, families, staff, management, and visitors of the Service.

**DUTY OF CARE**

Our Service has a legal responsibility to provide;

- a. A safe environment, and
- b. Adequate Supervision.

Staff members including relief staff must have adequate knowledge of cystic fibrosis and the individual needs of children in attendance with cystic fibrosis.

**BACKGROUND**

Cystic fibrosis is a genetic disorder present at birth that affects cells in the body that make mucus, sweat, and digestive fluids, causing the lungs and digestive system to get clogged with mucus. This frequently results in recurrent infections. Different people exhibit symptoms to different degrees and while there is no known cure, treatment can help manage the condition (Cystic Fibrosis Australia, 2017). A child with cystic fibrosis is likely to have many health professionals working with him/her which may include:

- Clinical nurse
- Gastroenterologist
- Dietitian
- Physiotherapist

- Respiratory physician
- Social worker

Symptoms of cystic fibrosis include:

- A phlegmy persistent cough
- Wheezing
- Constantly runny nose
- Sinusitis
- Repeated lung infections
- Foul-smelling, greasy and/or bulky stools
- Diarrhoea and/or constipation
- Poor growth and low body weight (despite a healthy appetite)
- Inability to engage in physical play or exercise.

TREATMENT (from Cystic Fibrosis Australia, 2017).

The treatment for cystic fibrosis is ongoing and lifelong and varies from child to child. However, it generally involves:

- Daily physiotherapy to clear the lungs
- Exercise to assist in clearing the airways and build core strength
- The use of a nebuliser to assist in opening the airways
- A nutritious diet high in calories, salt and fat: In some cases, extra calories/salt/fats are required, but not always – the dietitian and families will provide individual information of dietary requirements.
- Medications including (as required):
  - Enzyme replacement microspheres or capsules taken with food to aid digestion: Children/babies with cystic fibrosis vary in their ability to digest food naturally – some may need these while others will not.
  - Antibiotics as required to treat lung infections
  - Anti-inflammatory medication to prevent airway passage inflammation
  - Mucus thinners to assist the child in coughing up mucus and decreasing the risk of lung infection
  - Bronchodilators to open up and relax the muscles around the bronchia (lungs).

### DEHYDRATION (from Cystic Fibrosis Australia, 2017 and CFWA, 2016)

If a child/baby is lacking in salt they can quickly become dehydrated. Signs of dehydration include:

- Fewer wet nappies than normal
- Dark sunken eyes
- Dry lips or skin
- Crying without tears
- Dark yellow urine
- Rapid breathing
- Drowsy and/or lethargic
- Salt crystals on the skin

### EARLY WARNING SIGNS OF A LUNG INFECTION (from CFWA, 2016)

As children with cystic fibrosis are likely to frequently develop lung infections it is important to be aware of the early warning signs, which include:

- Coughing more than normal, or a 'different' sounding cough
- Coughing up more mucus than normal or a change in the colour of coughed-up mucus
- Wheezing sounds while breathing, or unable to breathe while feeding
- Reduced appetite
- Decreased energy
- Fevers

### INFECTION CONTROL (from Cystic Fibrosis Australia, 2017 and CFWA, 2016)

Minimising the risk of infection for children with cystic fibrosis is imperative for their ongoing health.

Precautions to take include:

- Frequent and thorough hand washing
- Encouraging the child to wash hands after coughing, and at all other usual times (after toileting, before eating etc.)
- Keeping a child/baby with cystic fibrosis away from other children with a cold or are otherwise ill
- Ensuring children's immunisations are up to date
- Cleaning and drying all medical equipment thoroughly
- Not allowing the child with cystic fibrosis to share cups or eating utensils
- Not leaving containers of water lying around where germs that cause lung infections can breed
- Keeping the classrooms dry and well-aired.

## IMPLEMENTATION

We will involve all educators, families, and children in regular discussions about medical conditions and general health and wellbeing throughout our curriculum. The Service will adhere to privacy and confidentiality procedures when dealing with individual health needs.

### Management and Nominated Supervisor will ensure:

- Upon employment at the Service all staff will read and be aware of all medical condition policies and procedures, including the Cystic Fibrosis Management Policy.
- To identify children with cystic fibrosis during the enrolment process and inform all staff.
- The immunisations of all children attending the Service are kept up to date.
- Classrooms and areas occupied by children are kept dry and well ventilated.
- Families provide the Service with written documentation on the treatment required by their child throughout the day (i.e. any enzymes or other medications to be taken).
- Families of all children with cystic fibrosis provide all necessary medications/treatments showing the expiry date and clearly labelled with the child's name.
- That all staff are informed of individual children's cystic fibrosis treatment requirements and strictly follow instructions provided by the family.
- That all staff adhere to high levels of hygiene at all times.
- That all staff maintain a long-term written record of medications/treatments administered to a child with cystic fibrosis.
- Communication between management, educators, staff and parents/guardians regarding the Service's Cystic Fibrosis Policy and strategies are reviewed and discussed regularly to ensure compliance and best practice reflecting latest research.
- All staff members are able to identify the early warning signs of lung infection for children with cystic fibrosis attending the Service.
- Children with cystic fibrosis are not discriminated against in any way.
- Children with cystic fibrosis can participate in all activities safely and to their full potential.
- To communicate any concerns with parents/guardians regarding the management of children with cystic fibrosis at the Service.

### Educators will ensure:

- They are aware of the Services Cystic Fibrosis Management Policy and treatments required for each individual child with cystic fibrosis.
- They are able to identify the early warning signs of a lung infection.

- They are able to identify the signs of dehydration.
- Children/babies with a cold or other illness are isolated from children/babies with cystic fibrosis while waiting to be collected from the Service by their parent/guardian.
- That children's personal immunisation treatments are taken on excursions or other offsite events, including emergency evacuations and drills.
- To adhere strictly to the child's cystic fibrosis Treatment Plan and the Service's Administration of Medication Policy.
- To adhere to the highest levels of hygiene when dealing with a child/baby with cystic fibrosis. For example, high levels of hand hygiene, close supervision during meal and snack times to prevent sharing of cups etc.
- Extra hygiene precautions are taken when there is an outbreak of an illness, including the common cold, including cleaning of the premises, toys, and equipment.
- To consult with the parents/guardians of children with cystic fibrosis in relation to the health and safety of their child, and the supervised management of the child's condition.
- Communicate any concerns to parents/guardians if a child's cystic fibrosis is limiting his/her ability to participate fully in all activities.
- That children with cystic fibrosis are not discriminated against in any way.
- That children with cystic fibrosis can participate in all activities safely and to their full potential, ensuring an inclusive program, whilst ensuring a high level of supervision to ensure children with cystic fibrosis do not over-exert themselves.
- Families are advised of any early warning signs of a lung infection as soon as practicable.

#### Families will:

- Read the Service's Cystic Fibrosis Management Policy.
- Inform staff, either on enrolment or on initial diagnosis, that their child has cystic fibrosis.
- Provide a copy of their child's Treatment Plan to the Service, ensuring it has been prepared in consultation with, and signed by, a medical practitioner.
- Ensure all details on their child's enrolment form are completed prior to commencement at the Service.
- Provide an adequate supply of cystic fibrosis medications/treatments (as required).
- Notify staff in writing, of any changes to the information on the Cystic Fibrosis Action/Treatment Plan, enrolment form, or medication record.

- Communicate regularly with educators/staff in relation to the ongoing health and wellbeing of their child, and the management of their child's cystic fibrosis.
- Encourage their child to learn about their cystic fibrosis, and to communicate with Service staff if they are experiencing discomfort or difficulty in breathing.

FURTHER RESOURCES

Cystic fibrosis: Infection control in schools: <https://www.cfwa.org.au/wp-content/uploads/2018/02/CF-Fact-Infection-Control-In-Schools.pdf>

Starting school with CF: <https://www.cysticfibrosis.org.au/CysticFibrosis/media/Shared-content/Brochures/CF-Fact-Starting-School-with-CF.pdf>

Cystic fibrosis: Nutrition for babies: <https://www.cfwa.org.au/wp-content/uploads/2018/02/CF-Fact-Nutrition-for-Babies.pdf>

Cystic fibrosis: Nutrition for children: <https://www.cfwa.org.au/wp-content/uploads/2018/02/CF-Fact-Nutrition-for-children.pdf>

Cystic fibrosis: Medications: <file:///E:/CCD%20Oct%2018%20new/November%202019/CF-Fact-Medications.pdf>

SOURCE

CF Smart: Cystic fibrosis education program: <https://cfsmart.org/>

CFWA. (2016). Cystic fibrosis: Newly diagnosed: <https://www.cfwa.org.au/wp-content/uploads/2018/03/CFWA-Newly-Diagnosed.pdf>

Children's Hospital Foundation for Sick Kids: <https://www.childrens.org.au>

Cystic Fibrosis Australia. (2014). A guide to cystic fibrosis for early childhood educators: <https://cfsmart.org/wp-content/uploads/2017/02/Early-childhood-teacher-information-booklet.pdf>

Cystic Fibrosis Australia. (2017). Infection control in schools: <https://cfsmart.org/wp-content/uploads/2018/04/CF-Fact-Infection-Control-In-Schools.pdf>

REVIEW

POLICY REVIEWED	DECEMBER 2019	NEXT REVIEW DATE	DECEMBER 2020
MODIFICATIONS	<ul style="list-style-type: none"> <li>• New policy drafted</li> </ul>		