

# Cystic

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## Individual Healthcare Plan



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### Child's details

Name:

### Family contact information

Name:

Name:

Tel:

Tel:

Mob:

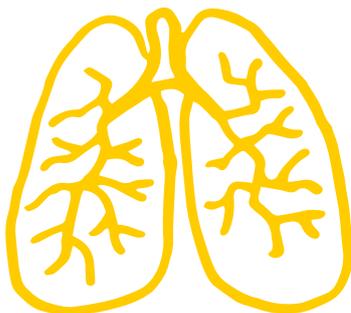
Mob:

Email:

Email:

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This plan describes the needs of a child with cystic fibrosis (CF). It outlines how CF affects their daily life, how it is treated and highlights the role of the school in ensuring that the child has a full and safe school experience. This plan should be a dynamic document and must be updated with any new information or guidance. As a minimum, it should be reviewed on an annual basis. It has been developed with input from the specialist CF nurse and the child's parents and approved by the school.



## About cystic fibrosis

Cystic fibrosis (CF) is a genetic condition that mainly affects the lungs and digestive system. It causes the mucus in the lungs and digestive system to be thicker and stickier than in people without the condition. In the lungs, this mucus can block the smaller airways and cause repeated infections that damage the lungs. For most children CF also affects the digestive system; the blockages caused by this thick mucus stop digestive enzymes getting out of the pancreas. This back-up of enzymes damages the pancreas and also means that children with CF need to take supplementary pancreatic enzymes (called Creon) to help them digest and absorb nutrients from their food.

There is no cure for CF but improvements in modern CF care have led to great increases in life expectancy. It's important that children with CF follow their treatment plan to ensure their best possible health.

Further detail about CF can be found in the factsheets for schools on the Cystic Fibrosis Trust website at [cysticfibrosis.org.uk/school](http://cysticfibrosis.org.uk/school)

## Taking care of the lungs

Children with cystic fibrosis may cough in class. This is the body's natural way of trying to dislodge and remove mucus from the lungs and airways, and for children with CF coughing should never be discouraged. Some children might prefer to cough up the mucus in private, perhaps in the toilet, others may be comfortable to cough into a tissue in front of others. The cough is not infectious. If the child is coughing more than usual, please inform their parents.

## Physiotherapy

Children with CF usually have a programme of physiotherapy that is designed to keep their lungs clear from mucus.

Physiotherapy activity	Time	Duration
e.g. Acapella	Usually before breakfast and before evening meal	10 mins for each session

**Notes:** e.g. There is no need for the school to be involved in physiotherapy at present apart from to be aware of the additional burden Mary has in her day. It is normal for Mary to be particularly tired and a little quiet in the mornings as Mary does not enjoy waking early for physiotherapy.

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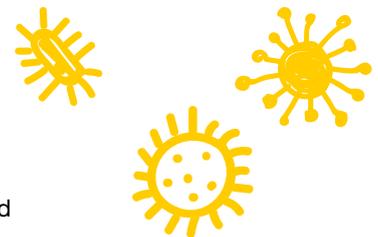
## Physical activity

Physical activity is really good for people with CF because it helps to dislodge mucus from the lungs, build lung capacity and help them to be generally fit and healthy.

e.g. Mary should be included in all regular school physical activity unless advised otherwise by her parents. If the weather is very cold and wet, Mary should be encouraged to play inside instead.

## Infection control

Children with CF can suffer worse effects from coughs and colds than other children. Minimising contact with children with streaming colds, encouraging frequent handwashing and reminding children to cough or sneeze into a tissue and then put it in the bin can help reduce infections for everyone and is particularly beneficial to children with CF.



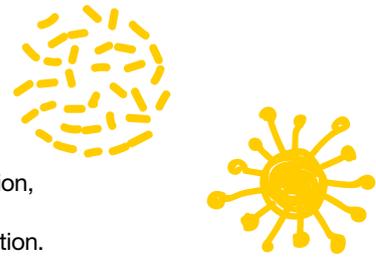
There are certain bacteria and fungi, such as *Pseudomonas* and *Aspergillus*, which are found in the environment and can be harmful to people with CF; mud, rotting vegetation and stagnant water are all ideal environments for these bugs to thrive.

e.g. The school has agreed to clean and dry the water play area daily, put holes in the tyre play area to ensure water doesn't stagnate there and to communicate with Mary's parents about other activities that might pose a risk to health.

Children with CF may be prescribed antibiotics to treat or prevent a chest infection. Sometimes antibiotics will need to be taken during the school day.

Medication	Storage	Time	Dose	Administration	Notes
e.g. Flucloxacillin	In fridge	60 mins prior to lunch	5mls	Office staff to administer	Mary tolerates well

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## Cross-infection risk

People with CF can have lung infections which, while not harmful to the wider population, can be harmful to others with CF or other serious lung conditions. Staff, visitors or other children with CF should not meet or mix with your pupil with the condition.

e.g. There is not currently a child or staff member at the school known to have CF. The school will contact the CF team for advice if another adult/child with CF applies to the school.

## Taking care of the digestive system

### Creon

Most children with CF need to take supplementary pancreatic enzymes (sometimes called Creon) to help them digest and absorb fat, protein and starch from their food. These enzymes are needed with all fat-containing food, including milk, and will be required at mealtimes during the school day. It's useful if the school can provide parents with lunch menus and notification of events that involve extra/different food (e.g. parties or baking at school) to help them calculate enzyme doses.



Meal or snack	Number of capsules	Storage	Administration
e.g. Morning milk	2	Secure cupboard in classroom	Teaching assistant responsible for administration. Mary can take capsules whole but needs supervision. Record in communication book.

**Notes:** e.g. Enzyme capsules are provided to the school by Mary's parents. Mary calls them her magic beans.

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## Diet

Children with CF may need a higher fat diet than other children and because of the effect the condition has on their salt balance, might also need salt added to their food (especially in hot weather). This may be contrary to the school's healthy eating policy but is an essential part of the child's CF treatment. Children also need to have access to water to ensure they are hydrated throughout the day, particularly during periods of warm weather.



e.g. The school will ensure that Mary can have her extra snack. Mary's parents will inform the school if she requires additional salt in her food in which case the catering staff will be notified. The school will ensure that teaching around healthy eating emphasises that some people do need different diets to keep them healthy.

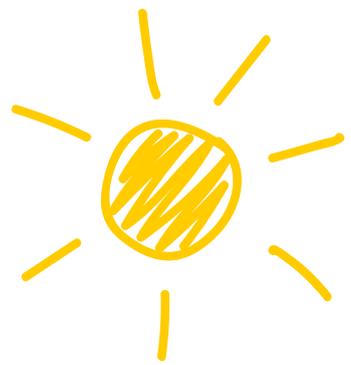


## Toilet

Sometimes children with CF need to go to the toilet more frequently and urgently and may complain of having a sore tummy just before going to the toilet. To help reduce anxiety or embarrassment, it's helpful if the school can have a plan in place to ensure the child can quickly access the toilet when needed. They may also spend longer in the toilet than other children. Some children, especially older children, may appreciate access to an air freshener in the toilet.

e.g. Mary has permission to use the disabled toilet which is more private than the infant's toilet area. The door on that toilet is unlockable from the outside.

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## Child's understanding of CF

It's useful to discuss and record what the child understands about CF and how much information should be shared with other children.

e.g. Mary is aware of the cystic fibrosis but does not really talk about it or engage with it. Mary is unlikely to be able to describe to friends or teachers what CF is in any detail. She finds it hard to answer questions from other children but is happy for them to be aware of her CF. The 'CF: What's it all about?' video can be shown when children start asking questions.

## School life

### School trips and outings

It's important that children with CF have access to the same experiences and opportunities as other children. Risk assessments will be needed to highlight any necessary precautions or additional treatment. Each risk assessment should be drawn up with input from parents and the CF team. This should include infection risks and a plan for the additional treatment needs if the trip is longer than the usual school day.



Trip/outing	Date	Risk assessment
e.g. Museum	June 2016	Risk assessment completed (attached) with CF nurse and Mary's mum. No additional treatment needed.

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## School attendance

Most children with CF need to attend the CF clinic every 8-12 weeks for a routine review, and have a longer annual review once a year. These appointments are likely to be during school time. In addition, children may also require admissions to hospital if intravenous antibiotics are needed.

If known, it's helpful to plan for admissions and ensure that school work is available to do whilst in hospital.

Date of admission	Likely duration	Learning plan
e.g. 15 May 2015	14 days	Liaise with hospital school to help Mary maintain interest.

Children with medical conditions should not be penalised, or miss out on rewards, for their attendance where the absence is due to their medical condition. The school should discuss their policy on attendance rewards and consider amendments to ensure it is fair to those with medical conditions.

e.g. The school will take into account Mary's CF and will focus on 'best possible attendance' rather than 100% attendance.

## Communication

Communication between the school, parents and the CF team is essential to ensure a child with CF has the best possible experience at school.

e.g. Mary's parents are keen to maintain good communication with the school. There is a communication book in Mary's bag and they wish to emphasise that they are happy to be telephoned with any queries. Any changes in symptoms or behaviour should be recorded in the communications book. The book should be checked each morning by the class teacher or teaching assistant.

## Useful contacts

### Specialist cystic fibrosis nurse

Name:

Tel:

Email:

### Cystic fibrosis physiotherapist

Name:

Tel:

Email:

### Cystic fibrosis dietitian

Name:

Tel:

Email:

### Hospital school contact

Name:

Tel:

Email:

The school, parents and CF team should keep a copy of this plan. The detail of this plan should be reviewed at least annually or if there are any changes in the child's health or treatment.

## Signatures

Special Educational Needs Co-ordinator/Class teacher:

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CF Nurse:

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Parent/Carer:

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Date of signing:

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Date for review:

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