

The Children's Hospital, Cystic Fibrosis Team
**Information about Cystic
Fibrosis for Nursery and
Pre-school Staff**



Introduction

This leaflet explains the important points about cystic fibrosis (CF) and the additional care and supervision that children with CF require.

What is cystic fibrosis (CF)?

Cystic fibrosis is a life-limiting genetic disease that is passed on to children from their healthy parents. It is a disease that mainly affects the secretions that their body produces. This can cause particular trouble in their lungs and digestive system.

Caring for a child with CF is mainly about trying to keep them as healthy as possible. Families are taught about how to minimise and manage risks of infection. This helps to prevent the development of the more serious effects of the disease.

There are great strides in the development of new and exciting treatments and medications for CF. These aim to keep children in better health for longer, or minimise their symptoms.

The Cystic Fibrosis Team in Oxford see each child with CF every two months. This is to make sure that they are growing well and that their symptoms are under control. Parents are encouraged to contact the Cystic Fibrosis Team if they have any concerns in-between appointments.

Treatment

Children with CF have physiotherapy twice a day to help shift the secretions that they produce in their lungs. This is usually done by one of their parents in the morning, before breakfast, and again in the evening, before bedtime.

Children with CF are often on antibiotics. These may be as part of a prophylactic regime (a dose once or twice a day) to help prevent infections, or given to treat a current infections (a dose up to four times a day). Occasionally, you may be asked at Nursery or Pre-school to help give a lunchtime or early afternoon dose.

Children with cystic fibrosis are usually pancreatic insufficient, which means that their pancreas does not work normally. For this reason, they may need to have a food supplement called Creon with all foods or drinks containing fat or protein. The child's parents, hospital dietitian or hospital nurse will discuss with you how to give this dose of Creon. This will help make sure that this can be done safely and at the correct time when they are eating.

As a child grows, the dose of Creon increases. This is to match the amount of fat present in their food and the larger portion sizes of food that they eat. Please accept parental advice on changing Creon doses, as this is reviewed frequently with a dietitian.

Nursery and Pre-school

At Nursery and Pre-school it is important that, where possible, children with CF are treated like their peers. They should be encouraged to do as much activity as possible, go outside, and enjoy doing all the things that their classmates do, in order to experience the world around them. However, there are several things that are important to point out:

- Stagnant or still water can carry bacteria that may cause bacterial chest infections in children with CF. If water play is encouraged, children should take part, but water should be changed daily and children should wash their hands afterwards.
- Children should be discouraged from splashing in puddles or playing near water-butts.
- Fish tanks or bubble tubes are not recommended because of the aeration of the water and growth of potentially harmful bacteria.
- Soil and wet sand may equally be an area of concern because of the bacteria that it may contain. This means that digging around in soil or playing with sand should be discouraged. If the child does get their hands dirty, please make sure they thoroughly wash their hands and nails with soap and water.
- Hay, straw, or any rotting vegetation contains fungal spores that may cause an additional irritation and discomfort for children with CF, and therefore should be avoided.

Symptoms to look out for

Please speak to the child's parents if you think that the child you have responsibility for is:

- coughing more than usual
- producing more dirty nappies/going to the toilet more often
- behaving differently to normal.

Medications

Children with CF may need to take medications during the day. The child's parents will be able to explain when and how to give the medicines, but if you would like us to give you advice about this please let us know. **If any of the medications are accidentally forgotten, please contact the child's parents.**

Most of the care for the child will be done at home. However, if you would like further information or specific advice we can arrange visits by staff from the hospital.

Contact details

Cystic Fibrosis Nurses

Tel: **01865 234 087**

(Monday to Friday, 9.00am to 5.00pm)

Email: **cathy.mckenny@ouh.nhs.uk**
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If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALSJR@ouh.nhs.uk**

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