# 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/visiting the toilet more frequently
- · 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 have not been given, 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 to visit the school.

## **Cystic Fibrosis Nurse**

Tel: 01270 612071

E-mail: cyphct@mcht.nhs.uk

This leaflet is available in audio, Braille, large print and other languages. To request a copy, please telephone 01270 612071.



# **Cystic Fibrosis**

Information for nursery and pre-school staff





Because you Matter

#### 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?

Cystic Fibrosis is a life-threatening 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 keeping 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 exciting treatments and medications for CF. These aim to keep children in better health for longer, or to minimise their symptoms.

The CF Team at Leighton Hospital see each child with CF every 8 weeks. This is to make sure they are growing well and that their symptoms are under control. Parents are encouraged to contact the CF 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 preventative treatment (a dose once or twice a day). Occasionally, you may be asked at Nursery or Pre-School to help give a lunchtime or early afternoon dose.

Children with CF 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 the 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 will increase. 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, to 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 can 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 they 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 ensure 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 also be avoided.