Health concerns:

Cystic Fibrosis

Children with cystic fibrosis require special care and attention, but with a little effort any setting can learn to meet their needs, says charity Cystic Fibrosis Trust...

Cystic fibrosis (CF) is a genetic illness which renders the body unable to control the movement of salt and water through its cells. It causes the body to produce thick and sticky secretions that particularly affect the lungs and digestive tract. The symptoms of CF often include recurrent chest infections, a troublesome cough, digestive problems, and poor weight gain (although these symptoms are not unique to CF).

CF affects a number of organs, including the lungs, digestive system, pancreas and liver. It is one of the most common inherited diseases in the UK and currently affects around 9,300 people. As people are living longer, the numbers of people with CF are increasing. CF shortens life expectancy – current median predicted survival is 41 years, but many people live longer than this. Around one in 25 of the population carries the CF faulty gene and when two people with that gene disorder meet and have a child there is a one in four chance that their baby will have CF.

CF is an inherited condition and other children cannot 'catch' it. Babies are screened through the Newborn Screening programme for CF and the condition is usually diagnosed within three months of birth through the heel prick test.

Characteristics

Because CF affects so many areas of the body it may show up in different ways. Some babies are born with bowel problems or meconium ileus (a blocked bowel at birth), which can be a sign of CF and requires urgent surgical care. As a child with CF gets older they often have a characteristic cough and may have clubbing of their fingers and toes. Otherwise, they will look just like any other child.

Treatment

Parents will have a daily physiotherapy regime at home, which takes up to an hour in the morning and again at night. It takes the form of percussion (patting the body) or blowing techniques to clear mucus from the child's airways. A child with CF may take other medications, including nebulizers, inhalers and tablets to aid digestion.

In the case of children attending nursery, parents and CF Nurses will work with practitioners to ensure that any medications that need to be given during the day are explained and demonstrated. One medicine that most children with CF need to be given during meal times is Creon, which aids the digestion of food. For young children this usually comes in powder form, which can be sprinkled on meals. Children with CF often need higher calorie food to maintain their weight too, so may need to be offered different food or milk at meal times.

If a child has been unwell they may need to have some extra physiotherapy during their day at nursery. It is important for the child to have somewhere private to do this, as it will often lead to the bringing up of mucus, which children may feel self conscious about. There

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may also be a need for extra nebulized antibiotics during the day at particular times.

Child development

It is usual for children to grow as normal providing treatments are going well. There is no mental impairment, but children may appear smaller in stature, though this is by no means always the case. Some children with CF may have to leave nursery for a couple of weeks in order to take up antibiotic treatments in hospital; this can be disruptive to the child's routine, so a close working relationship with parents is a must.

What help is available?

The Cystic Fibrosis Trust is the UK's only national charity offering free advice on aspects of CF. The charity provides help, advice, guidance and welfare support for families affected by cystic fibrosis. The CF Trust also works closely with specialist cystic fibrosis centres and health workers to ensure they are providing the best possible care for patients with CF. Additionally, the charity contributes funding for medical research into cystic fibrosis to help improve and lengthen the lives of people with CF.

Parents and the public can call the Trust's helpline, which is free from a BT landline, from 9am until 4.30pm, Monday to Friday for advice and guidance – call 0300 373 1000, or visit cftrust.org.uk

Things to think about

- Early years settings must be careful that a child with CF does not mix with any other child with the illness, as this may cause cross infection problems. Parents will normally check with the nursery to find out if there is another child with CF attending.
- Beware of spreading infection. All nurseries will have an infection policy, but where there are children with particularly productive coughs at nursery, children with CF can be more susceptible to those bugs, as their lungs are more likely to be affected by respiratory germs. Good hygiene is very important; washing hands after sneezing or wiping noses can make all the difference, as well as regular cleaning of door handles, tables and materials.
- Physical exercise is beneficial for children with CF so they should participate in all the activities, games and running around that other children do.
- When a child has been recovering from an infection, the illness can result in loss of energy, which should be taken into consideration; they may need more nap or quiet time at these points, but be guided by the parents.
- There are very few adjustments needed to care for a child with CF – all that's required is a bit of extra time and a spare room to administer any medical treatments.
- Children with CF have had treatment for their condition almost from birth; for them this is natural and they do not think of themselves as in any way different from other children.

Free Planet Health resources!

For the last two years, the National Schools Partnership and Dettol have run Planet Health – an EYFS and nursery programme that offers free resources to schools and early years settings across the UK, designed to teach children aged 3–7 about personal hygiene in an engaging and memorable way. Almost 6,000 settings have already signed up to receive theirs, and all you have to do to claim yours is register online at tinyurl.com/tnplanethealth. You'll find more information at planet-health-schools.co.uk