Cystic Fibrosis

What is 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

How does it affect:

Health

PHYSICAL – Children with CF usually have a programme of physiotherapy that is designed to keep their lungs clear from mucus. Physical activity is typically really good for children's lungs because it helps to dislodge mucus, build lung capacity and help them to be generally fit and healthy.

MEDICATION – Many children with CF need to take supplementary pancreatic enzymes (called Creon) to help them digest and absorb fat, protein and starch from their food. Creon is needed with all fat-containing food, including milk, and will be required at mealtimes during the school day.

HYGIEN – 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 cystic fibrosis. There are certain bugs, such as Pseudomonas and Aspergillus, which are found in the environment and can be harmful to people with cystic fibrosis; mud, rotting vegetation and stagnant water are all ideal environments for these bugs to thrive. Use of detailed environmental and subject specific risk assessments can help to reduce the risk of infection. Parents will be instrumental in agreeing with the school what risks they feel are acceptable while still trying to enable their child to be included as much as possible.

As a general rule, people with CF should not meet because of cross infection leading to serious lung infections. Schools cannot have two pupils with CF unless they are from the same household. Liaise closely with parents if planning to take a class to an indoor event with other schools present.

PERSONAL CARE – Sometimes young children with CF need to go to the toilet quite 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 a toilet pass for a quick exit and access to a private toilet, eg disability toilet and an air freshener in the toilet.

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DIGESTION – Most children with CF need to take supplementary pancreatic enzymes (called Creon) to help them digest and absorb fat, protein and starch from their food. Creon is needed with all fat-containing food, including milk, and will be required at mealtimes during the school day. 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). Children also need to have access to water to ensure they are hydrated throughout the day, particularly during periods of warm weather. Sometimes a feeding tube directly into the stomach is needed to help gain and maintain weight. Supplementary feeds are generally given overnight.

ENVIRONMENT – Many parents can be rightly concerned about the risk the learning environment poses especially in outdoor learning environments in the Early Years. Environments containing mud, stagnant water, rotting vegetation, hay and sand for example can be harmful to children with CF. The risk can be minimised by taking some steps, for example: ensuring that clean water is always used for play, only dry sand is used and it is always covered after a session and frequently changed, clearing the area of rotting leaves, drilling holes in containers so that rainwater does not collect. Activities can often be adapted to enable children with CF to take part safely. All risks need to be weighed up against the child's quality of life. Parents will need to make their own decisions about whether their child will participate in activities such as Forest School and school trips to rural locations.

Psychologically – emotional response

Early on, younger children may be accepting of the regimes and treatments in place for them. Over time, a child is likely to question these and may become more frustrated by them and the restrictions they place on their daily living activities. The amount of time for daily health regimes and frequent periods of absence for hospital visits and illness can also have a significant impact of self-esteem.

Schools may need to monitor this and make extra provision regarding this. For example, within the PSHE curriculum or using an adapted 5 point scale that focusses on expressing needs and finding the language to talk about their condition in Primary School. Access to a school counsellor or named member of the pastoral support team in Secondary School should also be considered.

Socially

The need to live a life with certain restrictions can impact on the development of friendships. Many children and young people with CF will try to avoid letting their friends know that they have to be treated differently because of their health needs. It can reduce the burden on the child or young person around letting friends know what their condition is all about if the class teacher in primary school includes PSHE lessons about managing health needs and opens up a class discussion, or the child may be happy, with the support of their teacher, to talk to the class about their health. In secondary school this is something that could be addressed during form time – sometimes with the student present, and sometimes with them absent depending on how they feel, to raise awareness with their peer group. Friends can become a really important support for young people when their health needs are impacting on their life in a negative way.

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What are the implications for school?

Care plans – there should be a personal health care plan in place which identifies any medicines that may need to be given in school, health procedures, identified signs of illness where parents should be informed and what might constitute an emergency situation where an ambulance may need to be called. These plans will need to be completed by the school SENCO, parents and a health professional, usually a CF specialist nurse. Personal health care plans should be reviewed at least once a year or if there is a change in health needs, including a change to medicine or procedures in school

Risk Assessments – should be completed to reflect the learning environment and specific activities which may present a risk, eg outdoor environment, use of dust producing materials, eg hay, trips to outdoor activity or farm destinations, trips where the students will be mixing with students from other school. See Risk Assessments on this website

PEEPs – Personal Emergency Evacuation Plans are generally written for CYP with additional needs where they may need help or special procedures in the event of an emergency. The PEEP for a child or young person with CF will need to reflect where their refuge or muster point is to make sure that it will not compromise their health, eg not under a tree where fallen leaves can collect or by muddy puddles.

Living with CF

The following extract helps to bring the challenges of living with CF into context as it written from a child's perspective.

By the time I have arrived at school each day I may have undergone about an hour to an hour and a half of treatments.

Cystic fibrosis affects my digestion – to help with this I have to take enzymes with most of the foods that I eat, this means with every snack and meal. • Sometimes this can look like a lot of capsules, but it is what I need. • It would help if these could be kept in a safe place or with an adult that I know so that I can have them with my meals. • It can help if I can take them in a more private place. It can be helpful if I can go to the top of the lunch queue, but sometimes I worry that this will make me appear 'different'.

This can also mean that I need access to a private toilet whenever I need to (Creon enzymes can cause poo to be really smelly hence the need for privacy). • An 'Exemption Card' would really help me. • I may also need to use inhalers at school.

Other effects – I can often feel breathless and moving around in a large school can be difficult for me. • It really helps if I can leave class a bit earlier. • Maybe my teachers could make sure that they don't wait right until the end of class to give out homework.

When I have chest infections I may not be in hospital, but at home. • An extra set of books at home is really helpful because then I can carry on with my work when I am feeling well enough. • Also it means I don't have to carry a very heavy school bag between home and school.

I can have very bad headaches in the mornings (similar to a hangover). • This is caused by having low oxygen levels, or if I have to have oxygen during the night.

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See also advice sheet Fatigue Management for advice and strategies on supporting pupils who have medical absence and fatigue which affects their attendance and/or participation in class

What are the implications for wider school life?

Educational Visits – It is important that children with CF have access to the same new 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, reflect school policies and The Equality Act 2010, ie all planned trips should take into account the need to include all students or reasonable adjustments may be made, eg an alternative activity if not all of the trip is suitable for the student. This should include infection risks and a plan for the additional treatment needs if the trip is longer than the usual school day. See School Trips advice sheet for further guidance.

Resources and recommendations to support inclusion and progress

Links to external websites

Pre-school and Primary School Pack
https://www.cysticfibrosis.org.uk/life-with-cystic-fibrosis/pre-school-and-primary-school

Secondary School pack
https://www.cysticfibrosis.org.uk/life-with-cystic-fibrosis/secondary-school

Cystic Fibrosis for Teachers – many useful resources to help teachers understand about the condition, explain to the class and support the individual pupil to know more about their condition
https://www.cysticfibrosis.org.uk/what-is-cystic-fibrosis/cf-for-teachers

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