Information for teachers

What you need to know about children with cystic fibrosis (CF)

Children with CF often don't look ill

However, they often have to spend a lot of time and energy doing treatments, such as physiotherapy, and taking medication to stay well. Usually, they do these treatments before and after school. Sometimes they need to take time off school if they have an illness, or to attend clinic appointments. They will sometimes go to hospital.

Children with CF will always have CF

They are born with it and will have it for life. It is caused by a faulty gene, which means you can't catch CF. The condition mostly affects the lungs and digestive system but can affect other parts of the body. There is no cure, but treatments are improving all the time. Life expectancy has increased greatly. Today, most people with CF will have full childhoods and enjoy much longer, healthier adult lives.

Children with CF have a treatment regime which needs to be followed every day to keep them well

This may include:

- Physiotherapy and exercise to keep their lungs as clear of mucus as possible. This might be done twice a day.
- Creon (pancreatic enzymes) with every fat-containing meal or snack.
- A special diet to help them maintain a healthy weight.
- Antibiotics to prevent or fight infection in the lungs.
- Regular hospital visits and sometimes hospital stays.

Children with CF can get very sick if they get a bacterial, viral or fungal infection

The most high-risk environments for getting these are:

- stagnant water
- rotting vegetation
- hay and mud

Infections can be very serious, causing permanent damage to the lungs and the need for ongoing extra treatments.

Some children with CF can also have problems with digestion

Thick, sticky mucus can build up in the pancreas. This stops enzymes getting out of the pancreas. The blocked enzymes then damage the pancreas. This means that children with CF often need to take Creon (pancreatic enzymes) to help them digest their food.

Children with CF may have a cough

This is because CF can cause the mucus in the lungs to be thicker and stickier. This mucus can block the smaller airways and cause repeated infections. This can permanently damage the lungs. Coughing is a natural way of trying to dislodge and remove mucus from our lungs and airways. Children with CF should never be told not to cough. Their cough is not infectious.

What this means at nursery and primary school

All children with CF are different. Even if you have had a pupil with CF before it is likely they will have different needs.

Here we look at some of the more common issues children with CF have when going to school or nursery. However, it is important to talk to the child's parents or CF nurse to understand how CF affects them.

Communication

Having open lines of communication means that parents and teachers can work from an agreed healthcare plan and adjust it if necessary, as time goes on. Changes in the child's health or behaviour should be shared with the parents by whatever means works best – some parents use a communication book, which is kept in the child's school bag. While CF is often just part of their life, from time to time some children struggle with the burden of treatment, loss of energy or with a sense of being different, so keeping in touch with parents can help identify and deal with any issues early on.

Cystic Fibrosis Trust and the family's CF team are here to support you. If you need further information or advice, please contact the Trust on **0300 373 1000** or **020 3795 2184**.

Email on **helpline@cysticfibrosis.org.uk**

Message us on WhatsApp on **07361 582053**

Or find us on Facebook or Instagram

Taking Creon

Most children with CF will need to take Creon (pancreatic enzymes) when they eat. Creon capsules (or granules) are supplements.

If a child needs Creon, and doesn't take it with food, the food will not be digested properly. They also will not absorb the nutrients in it. This can cause loose and smelly stools. It can also make it hard to put on weight and get the nutrients they need. This can cause problems with physical development.

Creon needs to be taken with most food and with milky drinks. It does not need to be taken with food with no fat, for example fruit, jelly or juice.

The child's parents or CF nurse will tell the school how much Creon the child needs. It's important that it's easy for the child to get their Creon and that they know where to get it from. The child's parents will tell you how they would like Creon to be given. This could be:

- a stock of Creon that stays at school
- a daily pot
- in their packed lunch.

Getting the right dose of Creon can take time. Some parents find it takes a bit of practice to get the right dose.

Most children will have taken Creon all of their life. As they get older, some children may look after their own Creon and take it on their own.

Gastrostomy tubes

It's quite rare, but some children have a gastrostomy. This is a small tube surgically fitted into the child's stomach that makes it easy to give calories and nutrition. It should not cause any problems at school. The child's dietitian or parents will be able to explain more about the tube if you have any questions.

Remind them to drink

Children often 'forget' to drink at school. Not drinking enough can cause a child with CF additional problems. So, it is helpful to remind them to drink, especially on hot days.

Going to the toilet

Sometimes, children with CF need to go to the toilet more often and urgently. They should be allowed to leave the class quickly and with minimal explanation. The poo of a child with CF can be quite smelly, especially if they have not had enough Creon. Some children will not mind this, but others will feel embarrassed. It can help to have a toilet which other children aren't using (for example, a disabled toilet or one with an air freshener).

Physiotherapy

Usually if children need to do physio they will do it before and after school. But some may need to do it at school. The child's parents or CF physiotherapist will let the school know what they need to do.

It's important children with CF take part in physical activity. Physiotherapists recommend that children with CF do physical activity because it loosens the mucus in the lungs, increases lung capacity and bone strength, and improves health and wellbeing. Any activity that gets the child breathing deeply and raises their heart rate is helpful.

Infection risks at school

Coughs and colds are more of a risk to children with CF than other children. Their lungs are more easily damaged by these infections. You can reduce the risk of infection by telling all children to:

- wash their hands
- cough or sneeze into a tissue, and put it in the bin
- use hand gel.

Ideally, children with heavy colds, flu or chest infections should not come to school, but if there is a child with a bad cold it can help to keep them away from the child who has CF. Opening windows a little can also help reduce the spread of infection.

There are infection risks from the environment too. Bacteria and fungal spores which would not cause a problem for someone who does not have CF can be harmful to people with CF. These are found in:

- soil
- rotting vegetation
- stagnant water.

In a school this might mean infection risks from:

- forest schools
- garden buildings
- wet sand
- mud kitchens
- school trips to farms
- fish tanks or water play.

For some activities the risk can be reduced. For example, making sure that water used in water play is fresh or sand is kept covered, dry and regularly changed.

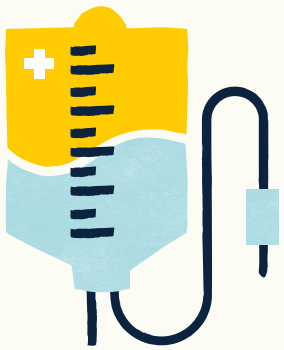
The child's CF team can advise the school on this. The risks of playing in these areas can be reduced by wearing clothing which protects them (as much as possible) from the mud/water and washing hands thoroughly afterwards.

Parents can have very different views on infection control. Some feel that if their child loves doing something (for example gardening) it is worth taking some risk. Others will feel strongly that their child should not be allowed to play in these areas. Sometimes compromises can be found, for example, if the other children are digging in mud, they could take photos or write notes.

Looking after a child with CF is all about managing the balance between doing the best for a child's health and quality of life. This balance will be different for every family and so communication between the school and parents is really important.

Cross-infection

People with CF can carry bugs in their lungs. While these are not harmful to people who do not have CF, they can be harmful to others with CF or those with severe lung conditions. This is why strict policies are in place at hospital clinics to ensure that people with CF are never in a room at the same time. Having more than one child with CF in a school needs careful consideration and a plan for risk management should be put in place in collaboration with the local CF team.



Antibiotics

Children with CF sometimes require antibiotics on a regular basis either to treat or prevent bacterial infection. Usually the antibiotics will be oral, but sometimes children with CF will require intravenous (IV) antibiotics. If these need to be taken during school hours, oral antibiotics should be stored at the school and administered according to your medicines policy. If a child has an IV line they may attend school. In this case the line will usually be bandaged securely on their arm and they will be able to participate in school normally with the exception of swimming and contact sports. The child's parents or CF nurse will support the school in understanding any additional needs.

If a child is receiving their IV antibiotics at home or in hospital, they may be well enough to continue with their schoolwork. Keeping in touch with their parents and CF team will ensure they receive the appropriate amount of schoolwork.

Some children have a semi-permanent line fitted in their chest which allows easy access for antibiotics and again limits them only in swimming and contact sports.

Absence

Children with CF will have clinic visits at least every 8–12 weeks. They may also have some periods of absence due to illness. If a child requires an inpatient stay in hospital this is usually for a two-week period, although this can vary. They may have access to a hospital school or it may be appropriate for them to have schoolwork on the ward, depending on their health. Rewarding their attendance, taking into account their CF, can be a boost for a child who is unlikely to ever achieve 100% attendance.

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