

Cystic Fibrosis here for schools

Factsheet 1:

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

- **Children with CF should be treated in the same way as their peers.**

They will have their own experiences, thoughts, ideas, and preferences and behaviours, just like any other child. The condition is part of their life, but it doesn't define them and shouldn't limit their school experience. They can usually join in the same activities as other children. Cystic fibrosis does not affect intelligence.



- **Children with CF often don't look ill.**

They have to work very hard, every day, to keep themselves well. Children with CF are very likely to be doing treatments before and after school every day. Sometimes they need to 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 or develop it later in life. There is no cure, but treatments are improving all the time and life expectancy has increased massively. In the 1960s, children with CF often didn't live beyond school age, but today the majority of people with CF will have childhoods, adulthoods and, in some cases, their own families.

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Children with CF cannot mix with other children or adults with the condition.

This is because people with CF can carry infections in their lungs that are not harmful to who do not have CF, but can be very harmful to others with the condition.



Children with CF have a treatment regime which needs to be followed every day to keep them well. This is likely to include, as a minimum:

- Physiotherapy and exercise to keep their lungs as clear of mucus as possible, at least twice a day
- Pancreatic enzymes with every fat-containing meal or snack
- A high calorie, high nutrient diet
- Antibiotics to prevent or fight infection in the lungs
- Regular hospital visits and sometimes hospital stays

Children with CF may have a cough.

This is because CF causes the mucus in the lungs to be thicker and stickier than in people without the condition. This mucus can block the smaller airways and cause repeated infections that permanently damage the lungs. Coughing is a natural way of trying to dislodge and remove mucus from our lungs and airways, and for children with CF coughing should never be discouraged. Their cough is not infectious.

Children with CF can also have problems with their digestive systems. The thick, sticky mucus that affects their lungs can also gather in the pancreas.

Mucus causes blockages that stop enzymes getting out of the pancreas. This back-up of enzymes damages the pancreas and also means that children with CF often need to take supplementary pancreatic enzymes to help them digest their food. As children with CF can have difficulty absorbing fats, proteins and other nutrients, they usually need vitamin supplements as well as a diet that is higher in fat and protein than is recommended for other children.



Children with CF are very vulnerable to bacterial, viral and fungal infections.

These can be very prevalent in certain environments including stagnant water, rotting vegetation, hay and mud. Infections can be very serious, causing permanent damage to the lungs and prolonged additional treatment.

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Factsheet 2:

What this means at pre-school & primary school

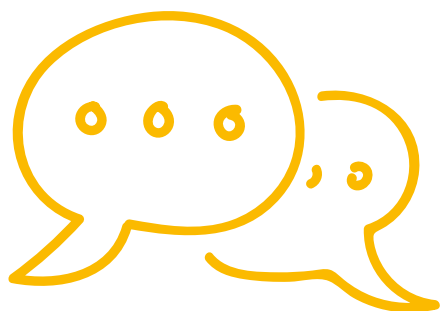


Every child, with or without CF, is different. Even if your school has had experience of a child with CF in the past, the chances are your experience with a new child could be very different. The following gives an outline of the main issues that might affect your pupil. However, it's important to talk to the child's parents or CF nurse to understand how CF uniquely affects that child and their family.

Communication

Parents and teachers have told us that the best way to ensure that a child with CF gets the most out of school is for the parents and teachers to maintain good 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 us on **0300 373 1000** or at **helpline@cysticfibrosis.org.uk**



Creon and diet

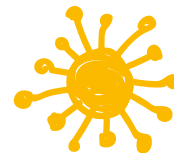
As you now know, most children with CF will need to take pancreatic enzyme supplements, often called Creon. Creon capsules (or granules) are not drugs, they are supplements. If these enzymes are needed and not taken, food won't be digested properly and the nutrients will not be absorbed. This can cause loose and smelly stools and problems with weight gain, nourishment and, over time, the child's physical development.

The enzymes need to be taken with all food or milky drinks (except food with no fat for example fruit, jelly or juice). The child's parents or CF nurse will guide the school on the amount of Creon needed. It's important that the child knows where to get their Creon and can do so easily. Some parents like to provide the school with a stock of Creon, while others may provide the required dose of Creon in a daily pot or, where appropriate, in their packed lunch for each day. Getting the correct dose of Creon can be more of an art than a science. Some parents have said there was a bit of trial and error in achieving the correct dose.

Children with CF will have been taking these enzymes all their lives and are usually very comfortable doing so. If responsible and capable, children may prefer to carry and administer Creon themselves.

A child with CF needs to consume extra calories and is likely to need additional snacks in the day. Their dietitian may recommend fatty snacks that aren't normally considered healthy, or may suggest adding full fat milk or cheese into their usual meals. Children with CF sometimes also need salt added to their diet. This will all be in addition to a balanced diet. It's quite rare, but some children have a gastrostomy, which is a small tube surgically fitted into the child's stomach that makes it easy to deliver supplementary calories and nutrition. The gastrostomy tube should have no impact on the child's time at school, but the CF dietitian or parents will be able to support you with further information.

Children often 'forget' to drink at school! Dehydration can cause a child with CF additional problems, so it's helpful to remind them to drink, especially on hot days. Sometimes CF teams may recommend that a child has an isotonic drink rather than just water.



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Going to the loo

Sometimes, children with CF need to go to the toilet more frequently and urgently and so being allowed to leave the class quickly and with minimal explanation is helpful. The poo of a child with CF can be quite smelly, for example if they haven't had sufficient Creon. Although some children will not be bothered by this at all, others can feel quite self-conscious, so having a toilet where they have privacy (perhaps a disabled toilet) or one with an air freshener could be helpful.

Physiotherapy

Usually, children with CF will do their physiotherapy exercises before and after school. For some children it is necessary to do physiotherapy at school. If this is the case, the child's parents or CF physiotherapist will be involved in supporting the school. Physiotherapy helps the child to clear their lungs of mucus, which is vital to prevent infection. There are lots of different techniques employed to do this, for instance breathing exercises, blowing games, inhaled therapies, nebuliser treatments and PEP (Positive Expiratory Pressure) mouthpiece.

Physiotherapists will also recommend that children with CF participate in physical exercise. Physical activity not only loosens the mucus in the lungs but also increases lung capacity, bone strength and overall wellbeing. Trampolining is a favourite activity for many children with CF, however, any activity that gets the child breathing deeply and raises their heart rate is beneficial.

Infection risks at school

Coughs and colds present more of a risk to children with CF than other children. Their lungs are more vulnerable and can be damaged by repeated infections. Encouraging all children to wash their hands, cough/sneeze into a tissue and use hand gel can reduce the spread of coughs and sneezes, which is great for everyone! Ideally, children with heavy colds, flu or chest infections shouldn't attend school, but if there is a child with a streaming cold, physically distancing them from your pupil with CF could help. Opening windows a little can also help reduce the spread of infection.

There are serious infection risks from the environment too. Several different types of bacteria and fungal spores, which can be harmful to people with CF, exist in soil, rotting vegetation and stagnant water. In a school setting, there may be concern about forest schools, den building, wet sand, mud kitchens, school trips to farms, fish tanks or water play. For some activities the risk can be minimised for example by ensuring water used in water play is fresh or that sand is kept covered, dry and regularly changed. The child's CF team can advise the school on this. The risks of playing in such environments can be reduced by wearing clothing which minimises contact with the mud/water and also thorough hand washing after such play, however there is still a risk of infection.

Parents can have very different views on infection control. Some feel that the joy their child experiences when doing some gardening is such that it outweighs the risk – others will feel strongly that their child should not be allowed to play in such environments. Sometimes compromises can be found so as not to exclude a child, for example if the other children are digging in mud, they could be responsible for taking photographs or writing notes.

Treating CF is all about maximising lung health and managing a delicate balance between the risk of infection and quality of life. This balance will be different for every family and so communication between the school and parents on this is really important.

Cross-infection

People with CF can carry bugs in their lungs which, whilst not harmful to the non-CF population, can be harmful to others with CF or those with severe lung conditions. That is why strict policies are implemented 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 are likely to 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 needed 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 which 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. In this circumstance, the child's parents or CF nurse will support the school in understanding any additional need.

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

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 school work 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.



Factsheet 3:

Treatment burden

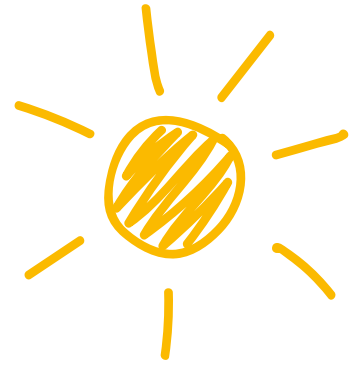
Homework set for Blue Class (year 2) – please hand in on Monday and have a nice weekend...

"Describe, using adjectives and connectives, what you did this weekend. Try to write the events in chronological order."

On Saturday I played football for the school team. It was grate but I did cry becos we was late. That was becos my mum made me do the nebs and the mask and I had to have my brekfast and pink medisin and tummy pills and it took soooooo long. I was grate at football, better than Dan I ran fast and scord a gole and it was epic. Mum brung my tummy pills so I could have my snak and joos. We all went for peetza but I coffed a lot and felt silly and didn't feel well. But then I felt better and had iys creem. A boy in the tolets sed that it was smelly becos of me he was meen. My daddy and me went to the sinama it was grate.



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Note from Mum:

We're really proud that Jack wrote this all on his own and so pleased with his progress in your class. Thank you for everything you do to help him get the most out of school.

I don't know if you're aware that every day of the week Jack does one hour of treatment before coming to school and because of that he has to get up pretty early, even more so at the moment as he also has a nebuliser treatment to squeeze in. I need to make sure Jack has a good breakfast as his CF has resulted in him struggling to gain weight, but he's a slow eater so it's difficult!! That's why he's sometimes tired in class or why we very occasionally run late. Jack has the same treatment routine in the evening, so it's a long day for my little boy!

For his age, he's quite sensitive, as you know. So I'm really appreciative of the small changes you have made to make sure he can take his Creon discretely and that he's allowed to use the visitor's toilet which is private and has an air freshener – he gets very upset about the smelly poos that sometimes happen if his Creon hasn't

been quite right! The little book that Miss James keeps with notes of his Creon use and general health is very helpful to us. I heard that Miss James did a talk on healthy eating the other day but pointed out that some people do have to have higher fat diets because their bodies are just a bit different. He was so pleased about that because he doesn't like to feel as if he's 'breaking the rules'.

I was really grateful that his absence for a routine clinic appointment wasn't held against him and that he was recognised for his good attendance this term. Jack loves school (football in particular!) and doesn't ever want to miss days. I was pleased to hear at parents evening that he's participating in all the PE activities, not just football; he loves sport and it's good for his lungs. I haven't forgotten about the city farm trip and will get back to you about our thoughts on that.

Anyway, I just wanted to thank you for your continued support, it means a lot to us.

