

# Cystic Fibrosis here for schools

My name is:

I have cystic fibrosis (CF). It's a genetic condition that causes the mucus, which our bodies naturally produce, to be thicker and stickier than in people without the condition. It affects my lungs and digestive system in particular - the build-up of this mucus can

cause lung infections and blockages in my pancreas that affect my digestion. I have to work really hard every day to stay well. Cystic fibrosis can be an invisible condition, so even though I might look well, I might not be feeling well.

1

There isn't a cure. Treatment usually involves physiotherapy to clear my airways at least twice a day, enzyme supplements (Creon capsules) with every meal or snack, nebulised (inhaled) treatments, antibiotics and other medications. It can all take a really long time and I have to get up earlier than other pupils to do these treatments. I have to do it all again when I get home. This can be really tiring. I'm not asking you to do anything about this, but it makes it easier if you can be understanding if I'm late, really tired in class or finding it difficult to concentrate.

2

I might have a persistent cough - this is my body trying to shift the mucus from my lungs. It can make me feel embarrassed but I need to do it to keep my lungs clear. My cough isn't infectious.



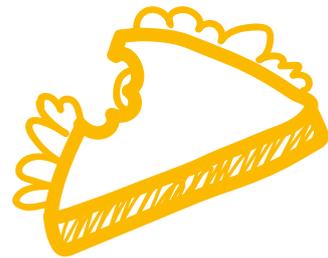
3

I usually manage my treatments at school on my own. Most people with CF have to take enzyme supplements (Creon) to help absorb and digest food. If I don't take them, or take too few, I can get a stomach ache and might need to go to the toilet urgently. I'll have my Creon in school with me and take them with every meal and snack.



4

I might need a diet that is higher in calories and fat than other people, due to the difficulty I have digesting food. So the usual healthy eating guidelines might not apply to me - eating food like chocolate or roast potatoes can actually be part of my treatment plan, to make sure I get the calories I need.



5

People with CF can't mix with other people with the condition. We can carry bugs in our lungs that wouldn't be harmful to those without the condition but can be to others with cystic fibrosis. If there's ever a risk of this happening at school, please let me or my parents/carers know, as we'll need to get advice from my clinical team.

6

There are bugs in the environment (Pseudomonas for example) that can cause very difficult infections in people with CF - these bugs live in damp, rotting vegetation or stagnant water. I might need help to do some activities safely, for example school trips, some outdoor activities or even some science experiments. Everyone thinks about infection risk differently, so some people with CF will be stricter on environmental risk than others - please ask me or my parents/carers.

# Cystic Fibrosis here for schools

**7** Bugs that cause coughs and colds can affect me very badly, so I might need to sit away from anyone with a heavy cold.

**8** Being active is good for my lungs! I should be able to do most sports, unless I'm ill in which case my parents/carers will let the school know.

**9** I might be absent from school sometimes for clinic visits or if I need to have antibiotics given to me through a drip in hospital - it'd be great if you could stay in touch with me about my homework so I don't fall behind.

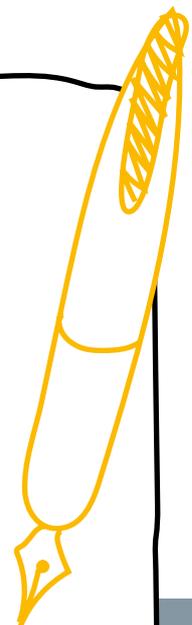
**10** Some people with CF are happy to tell everyone about it and others are really private. Please talk to me about this, to make sure we're both on the same page with sharing information about my CF with others.



If you would like any more information about cystic fibrosis generally, have a look at

[cysticfibrosis.org.uk](http://cysticfibrosis.org.uk)

Space for individualised information



Thank you for reading this. Knowing that you and other school staff understand how CF can affect me makes things a lot easier and helps me feel more confident about dealing with my CF at school. Cystic fibrosis shouldn't affect my goals at school, it might just be a bit more challenging for me to achieve them sometimes.

If you want to understand more about how CF affects me, please talk to me and if I don't feel comfortable talking about it, then I'll pass you on to my parents or carers.