

Cystic Fibrosis here for schools

You may find this information useful if you have a young person with cystic fibrosis (CF) in your class. We know that CF is often discussed in schools when teaching about genetics and genetic conditions and sometimes this lesson can be difficult for a young person with the condition.

Young people can have varying levels of knowledge about their condition. We know that sometimes they can find out information about CF that they weren't aware of during a lesson – this can be upsetting for them and for their teacher.

There are particular topics that can be distressing or sometimes surprising for young people with CF, and we'd suggest talking to parents about these to ensure their son or daughter is prepared for a class that discusses cystic fibrosis. It's also important to be aware of your student's preferences around confidentiality – please don't assume that their classmates friends or even close friends,

Fertility

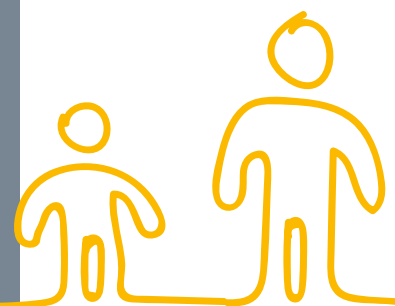
As you may be aware, boys with CF are usually infertile. For girls with CF, the picture is less clear but it is thought that CF can make it harder to conceive and for those who do get pregnant there can be health implications.

Some young people with CF are not aware of the impact the condition can have on their fertility. Sometimes boys may also misunderstand what infertile means and worry that they can't have sex properly (sometimes infertility can be confused with impotence). It can be reassuring therefore to be clear about what infertility means and also to highlight that fertility treatments are a possibility, and that many people with CF (male and female) do go on to have their own families.

Life expectancy

There have been significant developments in the understanding and treatment of CF in recent years. This is most dramatically illustrated by the increase in life expectancy – nowadays it's thought that more than half of people with CF will live beyond 53 years and that life expectancy may be even longer for a baby born today.

If you are covering life expectancy in your lesson, it could be helpful to talk to the parents or carers of the child with CF to ensure your pupil is aware that CF is a life-limiting condition, but that the outlook is improving all the time.



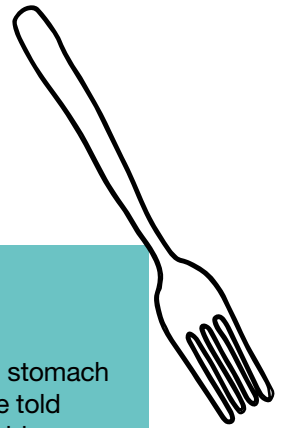
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Digestive health

For many people with CF, blockages in the pancreas restrict the secretion of digestive enzymes leading to a lifetime need for replacement enzymes (Creon) to enable digestion and the absorption of nutrients. Digestive problems can cause a range of symptoms including loose stools, a more frequent and urgent

need to go to the toilet and stomach aches. Some students have told us that they felt uncomfortable with this topic being discussed in class, particularly if their friends and classmates are aware that they have cystic fibrosis. Talking to your student or his/her parents about this could help minimise embarrassment.



Treatment update

Developments in research and treatments move quickly. Over the last couple of years, precision medicines, called modulators such as Kaftrio®, Symkevi® and Kayldeco® have become widely available. They tackle the underlying cause of CF, rather than just the symptoms, but they are not a cure. Many people taking these medications have said their lung function and general symptoms have massively improved.

However, some of the CF population cannot take these medications, and some have not experienced these improvements.

There is a range of other precision therapies in the pipeline, and gene therapies that could help everyone with CF are currently being trialled. There is good reason to feel optimistic about future treatments for CF. You can find out more about research and treatment at cysticfibrosis.org.uk/research

We have a range of publications available online at

cysticfibrosis.org.uk/publications



Our friendly Helpline team is always happy to speak with teachers. You can contact the Helpline on **0300 373 1000** or **020 3795 2184** (Mon-Fri 10am-4pm), at helpline@cysticfibrosis.org.uk, or by WhatsApp on 07361 582053.

