Cystic Fibrosis
a lifelong challenge

Information for training providers, colleges and universities

Fighting for a Life Unlimited

What is cystic fibrosis?

Cystic fibrosis (CF) is a life-shortening, inherited condition caused by a faulty gene. You can't catch CF, or develop it later in life.

The faulty gene causes the mucus, which our bodies naturally produce, to be thicker and stickier than in people without cystic fibrosis. This sticky mucus causes problems in the lungs and digestive system, but can also affect other parts of the body. The small airways in the lungs can get clogged with mucus, causing infection and, over time, damage to the lungs. For many people with CF, blockages in the pancreas mean a lifelong need for enzyme supplements, a special diet and, for some, insulin.

1 in 25 people carry the faulty gene that causes cystic fibrosis.

What are the symptoms?

Often CF is a relatively invisible condition; people with CF don't usually look ill unless they are very unwell, and for this reason, CF can be classed as a non-visible disability.

The most noticeable symptom of the condition is a cough; people with CF generally cough, and sometimes may cough a lot. This is the body trying to clear the lungs of mucus. The cough is not infectious and they shouldn't ever be discouraged from coughing.

It's important to be aware that not everyone with CF will have exactly the same symptoms. There are many different faults (mutations) that cause the condition and as such there are variations in symptoms and severity. So even if you have been involved in educating or training someone with CF in the past, please be aware that their symptoms and experience could be quite different to someone else with the condition.

Anything else I should know?

People with CF can carry bugs in their lungs that wouldn't be harmful to those without the condition, but can be very harmful to others with cystic fibrosis. To avoid bugs being passed between people with CF through something called cross-infection, people with the condition are advised not to mix with each other at all.

For this reason, it's important to make your student/apprentice aware if there is another individual with CF at your college/university/workplace. This will need to be done sensitively and with respect to confidentiality. Your student's clinical team will be able to work with you and your students to develop a plan to minimise the risk of cross-infection.

There are some environments that can harbour bugs which are harmful to people with CF: stagnant water, mouldy/damp environments and hay/rotting vegetation can all present an infection risk to people with cystic fibrosis. Please ask your student or their clinical team for more information about possible infection risks from the environment.

Making reasonable adjustments

for young people with cystic fibrosis

A young person with CF will encounter the same issues that can come up for any young person starting out in a new phase of their life. On top of this there may be additional support needs because of their condition.

As you'll know, education providers have a duty of care to students with disabilities and that includes making reasonable adjustments to ensure that they aren't discriminated against, either directly or indirectly. For students with CF, reasonable adjustments may simply refer to flexibility around assignment dates or access to accommodation on the ground floor. Needs will be variable and some students with CF may require no additional support at all.

The main support that you, or your colleagues, can offer is to actively listen and engage with what the problem or concern is. Good communication is key to ensuring that a student with CF gets the most out of their time at college/university or in training. Here are some tips to consider.

- Talk to your student about how CF could affect their studies/training. As mentioned earlier, people with CF differ in how the condition affects them, and it is important to be clear from the outset how your student is affected. Cystic fibrosis is a fluctuating condition; ensuring that your student knows they can come to you if their health is changing, would be helpful.
- Establish a contingency plan about how any absences could be managed. For example, is it possible to get extensions for work should they be in hospital or struggling with the daily treatment burden? Is it possible to be given more time to complete exams?
- Cystic fibrosis symptoms can be made worse because of stress or tiredness. It's useful to be aware of this and work with your student to minimise stress and encourage them to be open if they are feeling under too much pressure.
- This might be the first time your student has been really independent in their own care, so being available to provide support and encouragement might be appreciated.

More than

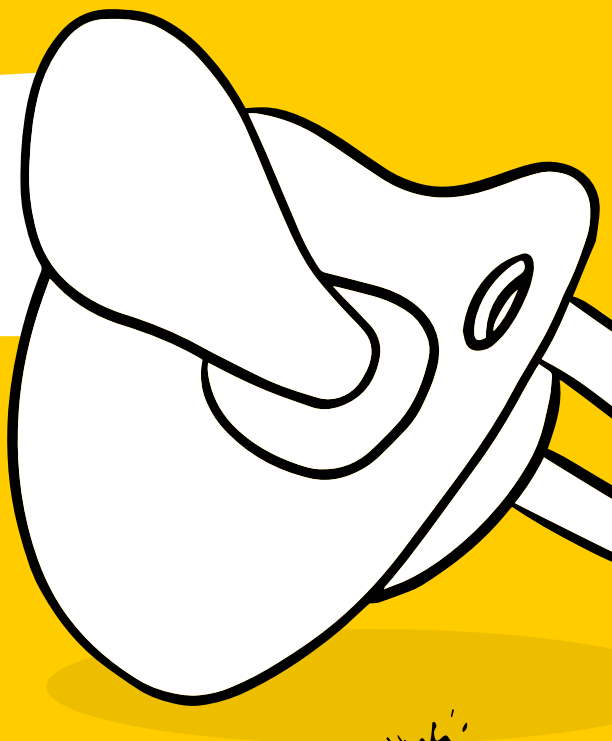
10,400

people in the UK have cystic fibrosis.

67.5% of people with CF are either studying or employed.

More information about my CF

Each week five babies are born with cystic fibrosis.



Need more information about cystic fibrosis?

Contact our helpline on **0300 373 1000** or at **helpline@cysticfibrosis.org.uk** or visit our website at **cysticfibrosis.org.uk**

Find us online

cysticfibrosis.org.uk

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