Cystic Fibrosis Trwat

An easy read guide about cystic fibrosis



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What is cystic fibrosis?



This booklet is about cystic fibrosis.



Cystic fibrosis is also called CF.

CF is a health condition that affects your lungs, digestive system and other organs in your body.

Finding out you have cystic fibrosis



Most people find out they have cystic fibrosis when they are born.



Some people find out they have it when they are older.



When you're told you have CF, you'll have treatments to help you stay well.

Finding out you have cystic fibrosis



Many people with CF now live longer.



Living with CF can sometimes feel stressful.



Your Cystic Fibrosis Team can help you with this.

Cystic fibrosis and the lungs



Lungs are in our chest and we use them to breathe.



If you have CF your lungs don't work properly.



This means people cough a lot and get unwell more easily.



When they get unwell they might feel worse than people who don't have CF.

Cystic fibrosis and the stomach



Our stomach helps digest our food.



CF can affect your stomach. It might mean your stomach doesn't work as well in helping you digest your food.



You might have to eat more food to stay healthy.

This is because eating well and having a healthy body weight helps your lungs to work better.

Cystic fibrosis and the stomach



You might need to take tablets with your food.



You might get a painful tummy.



You might need to go to the toilet quickly.

Staying well if you have cystic fibrosis



There are lots of things you can do to stay well.



You might take medicines.



You might do special exercises to keep your lungs clear.



You might exercise, keep fit and play sports.

Staying well if you have cystic fibrosis



People with cystic fibrosis see a medical team.



This is called the Cystic Fibrosis Team.

It can include...



Doctors who will check your health and talk to you about your treatment.



Nurses who will help with your care and talk about things like appointments.

Physiotherapists who will show you exercises you can do to stay well.

Dietitians who will talk to you about food.



Staying well if you have cystic fibrosis



Social workers who will help you with things like benefits, housing and work.

Psychologists who will talk to you about your mental health.

They will all work with you to keep you well.

Getting unwell if you have cystic fibrosis



People with CF need to make sure they don't go near people with colds or coughs.

This is because they can get really unwell if they catch one.



People with cystic fibrosis shouldn't meet another person with CF.

This is because they could pass on bugs to each other that could harm their lungs and make them unwell.

Getting unwell if you have cystic fibrosis



Sometimes people with CF have to go into hospital if they are unwell.



Sometimes people need to have operations to make them feel better.



Sometimes people need to stay in hospital to have medicines.

Cystic fibrosis and other parts of your body



CF can affect other parts of your body.



It can affect your bones.



It can affect your liver.



It can affect your kidneys.

Cystic fibrosis and other parts of your body



It can give you diabetes.



It can make it difficult to have a baby.



Speak to your team to find out more about how cystic fibrosis affects you.

Lung transplants



Sometimes people with cystic fibrosis become very unwell and their lungs stop working.



When this happens their doctor might talk to them about a lung transplant.



A lung transplant is where your old lungs are taken out and replaced with new lungs.

Lung transplants



If you need a lung transplant you will go on a waiting list.

Your doctor will tell you how long you might have to wait.



Your doctor will talk to you about whether this is the right choice for you.

What can people with cystic fibrosis do?



People with CF can go to school.



People with CF can have jobs.



People with CF can have a family.



People with CF can have relationships.

Disabilities



Cystic fibrosis is a disability.



CF can be known as an 'invisible' disability as there might not be any physical signs of CF for someone to see.

People can get money from the government if they have a disability.

This money is called benefits.

Benefits help pay for extra support for day-to-day life.

Disabilities



People with disabilities are protected from discrimination.



Discrimination is when you are treated unfairly because you have a disability.

We can help

If you want to talk to someone about your CF, you can call our Helpline: **0300 373 1000**.

You can also email our Helpline: helpline@cysticfibrosis.org.uk



Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis.

Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

We won't stop until everyone can live without the limits of cystic fibrosis.

cysticfibrosis.org.uk

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