



Cracking the CF code

Your secret guide to working
out the mysteries of CF

Written by young people in
Cystic Fibrosis Trust's Youth Advisory Group



Who's who?

YAG's secret agents are going to take you on a mission to crack the code of CF and uncover some top-secret information!



Chawan

Secret Agent Chawan is 15 and has a brother with CF. Her favourite things are going to the theatre and music. Her special power is remembering everything there is to know about CF!

Secret Agent Rosie is 16 and has CF and CF diabetes. She loves animals and playing guitar. Her secret powers are X-ray vision, and taking 15 tablets in one mouthful of water!

Rosie



Shaan

Secret Agent Shaan is 21 and has CF. He is super interested in railways and his special power is shrinking so he is teeny tiny!

Secret Agent Tehya is 15 and has CF. She loves dancing and her special power is invisibility!

Tehya



Tilly

Secret Agent Tilly is 16 and has CF and CF diabetes. When she's not cracking codes and testing out cool gadgets, she likes acting and reading. Her special power is doing her insulin injections in 10 seconds!

Some words are a bit tricky! We'll help you learn how to say some of them by writing how they sound underneath. The capital letters mean you say that part of the word more strongly.

The secret agents have awesome help from a team at YAG's top secret headquarters – Secret Agent Julia, Special Agent Izzy, Hologram Specialist Bahar, Undercover Agent Jade, Double Agent Ellie, Spymaster Amy, Field Agent Leah, Special Operative Nicola and Intelligence Officer Cicely.

In the hospital

Mission

Secret Agent: Tehya

Mission: Make sure children know their way around the hospital

Special power needed:
Invisibility



Hi, I'm Agent Tehya.

The hospital can be a bit confusing at first. Let me show you round. All I need is my invisibility cloak so we don't disturb anyone!

Inpatient

This is when you stay in the hospital for a while. This might be for one night, for a few days, or even a few weeks.

Inpatient ward

This is an area in the hospital, with lots of bedrooms. You will stay in one of these rooms with your mum, dad or carer when you are an inpatient.



Outpatient

This is when you go into hospital but leave on the same day. You are an outpatient when you go to your hospital for a check-up. Some people call this 'going to clinic'.



Pharmacy

'FAR-muh-see'

This is the place where you get your medicine.

When I was younger I was an inpatient for two weeks. I was really scared that I'd be all by myself, but then my CF team put a second bed in my room so that my parents could stay with me.

Top tip: Bring something fun to do. And snacks!



Prescription

Instructions that your doctor gives the pharmacist so that they know what medicine to give you.

People in the hospital



Pharmacist

'FAR-muh-sisst'

A pharmacist keeps everyone's medicine safe and makes sure everyone gets the right medicine. Sometimes you might have a question about your medicine that they can help you with.

Phlebotomist

'fluh-BOT-uh-misst'

This is someone who is very good at taking a little bit of your blood without it hurting too much.



Nurse

These are the people in the hospital who will take care of you. They do lots of different jobs. They might measure how tall you are and how much you weigh. They might bring you medicine, or if you're lucky, some toast!



I can never say this word!

CF/respiratory nurse

A nurse that helps you with everything to do with your CF. They will talk to you, your family, and the rest of your CF team to make sure you are taken care of. Sometimes they will also speak to your teachers to help them learn about CF.

Dietitian

'digh-uh-TISH-uhn'

This person knows all about the best foods for you to eat so that you can grow and stay well. They can also help you with your enzymes (Creon) and vitamins. If you don't feel very hungry, they might give you tips to make sure you eat enough.

Paediatrician

'pee-dee-uh-TRISH-uhn'

A doctor for children.



Social worker

A CF social worker helps people with CF and their families with lots of different things to do with CF. They work with you and your family to make sure you have everything you need. They are also someone to talk to if you have any worries. They can even find fun things to do when you are not feeling very well!

Psychologist

'sigh-KOL-uh-jisst'

This is someone you and your family can speak to about feelings or emotions about CF. You can tell them about anything you want. Even if you think it is silly, they will always listen to you.

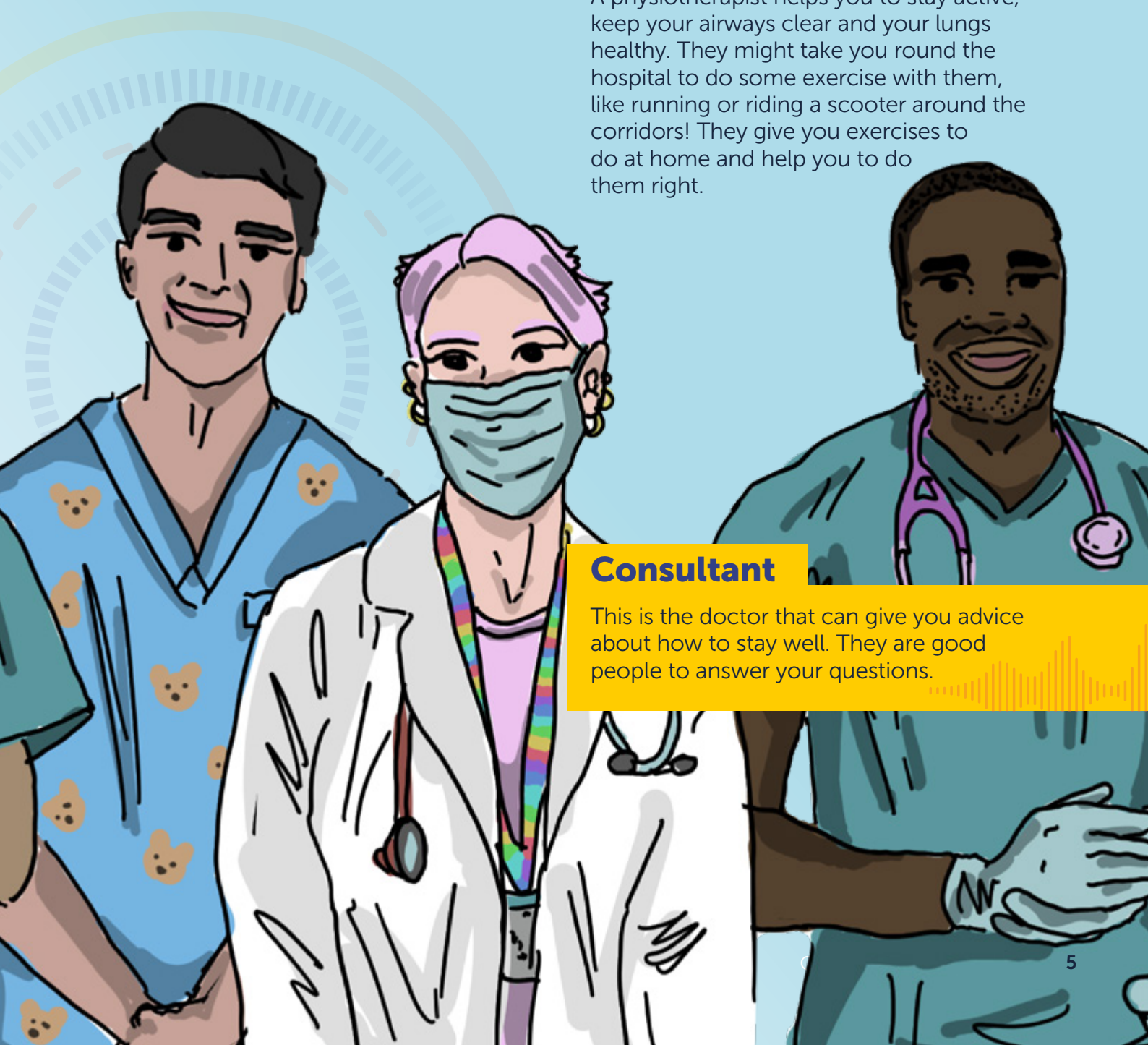
Physiotherapist

'fiz-ee-oh-THERR-uh-pisst'

A physiotherapist helps you to stay active, keep your airways clear and your lungs healthy. They might take you round the hospital to do some exercise with them, like running or riding a scooter around the corridors! They give you exercises to do at home and help you to do them right.

Consultant

This is the doctor that can give you advice about how to stay well. They are good people to answer your questions.



In the body

Mission

Secret Agent: Rosie

Mission: Crack the code of the human body

Special power: X-ray vision

I'm Agent Rosie! I'm going to explain some of the trickiest words to do with our bodies. All I need are my X-ray vision goggles!



Bowel

Your bowel is a long tube that is curled up tightly in your body. If the tube was stretched out you would be taller than a bus! Your food travels to the bowel and all the energy and other good stuff is taken into your body. The leftovers turn into poo!

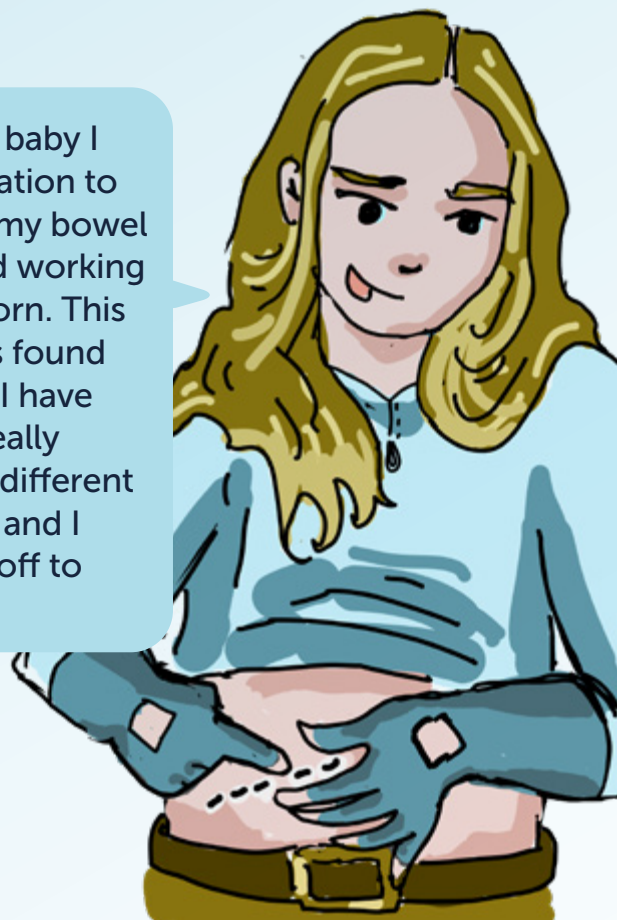
Some people with CF are born with a bowel that is blocked up, like a sink with a plug in it. These people might need to have an operation to unblock it.

Stool

A fancy word for poo!
This is very important because the doctors sometimes look at it to know how well your body is working.



When I was a little baby I had a special operation to take away a bit of my bowel because it stopped working as soon as I was born. This is how the doctors found out I had CF. Now I have a scar that looks really cool! It makes me different to everyone else... and I like that! I show it off to everyone I meet!

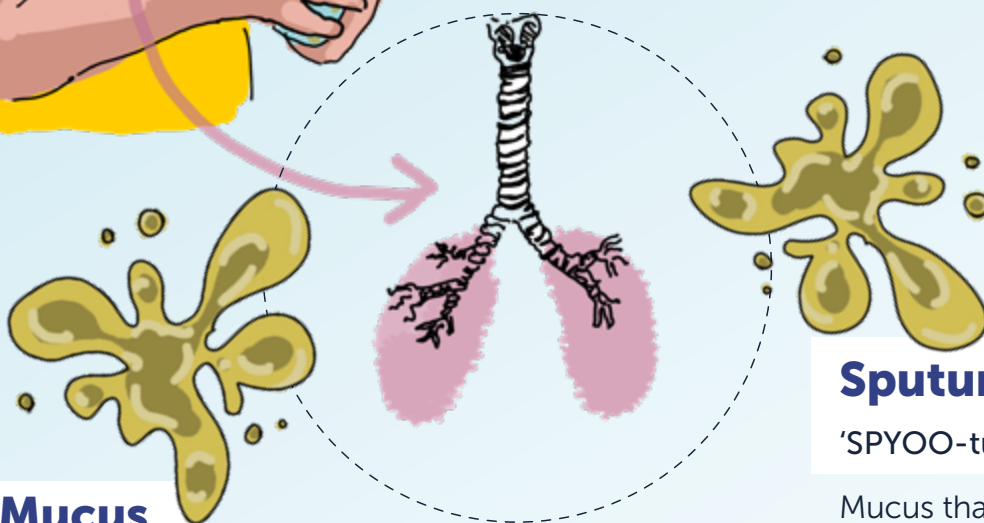




Trachea

'truh-KEE-uh'

Some people call this a windpipe, because that is sort of what it is! It is like a pipe in your body that goes from your mouth to your lungs. When you breathe in and out, air travels through this pipe. Your trachea is really cool. It works with your nose to clean the air going into your lungs.



Mucus

Mucus is the sticky slime that covers the inside of our nose, lungs and digestive system. It helps keep the air we breathe clean and keep our bodies healthy. For some people with CF it can be a bit too sticky.

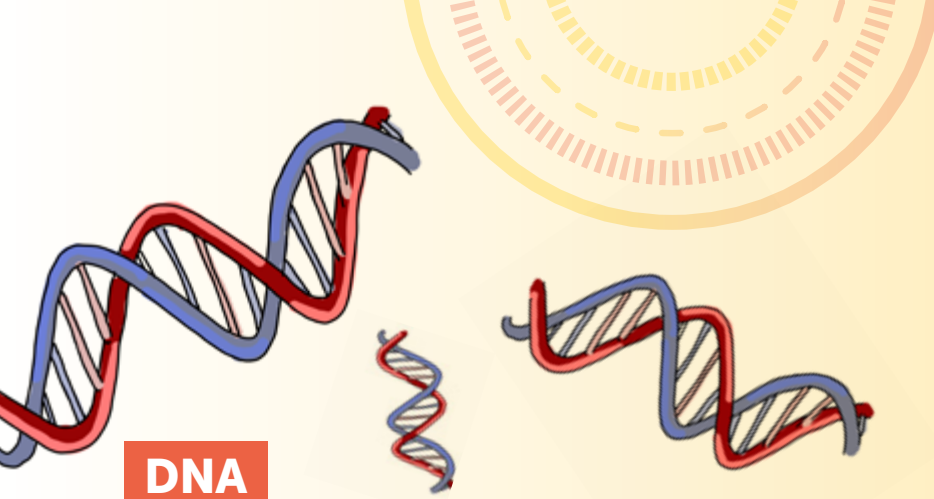
Sputum or Phlegm

'SPYOO-tuhm' or 'flem'

Mucus that comes from your lungs into your throat. Sometimes your CF team will ask you to cough some out. Then they will take it away to check it for infections (we talk more about those in the next chapter).

When I was little I didn't like coughing up mucus because it tasted a bit weird. Some children with CF don't need to cough up mucus very much, especially if they are taking a type of medicine called a 'modulator'. But if you are like me, then here is a tip! My mum and dad gave me lots of jelly so I got used to the feeling of something slimey in my mouth. Then I didn't mind coughing up mucus anymore! Now I know that when I cough it up, I feel so much better.





DNA

You have DNA, I have DNA, a dog has DNA – even a banana has DNA!

DNA is like a secret code that makes you special. It controls lots of things in your body, like your eye colour, hair colour and lots more.

Everybody's DNA is different, that is why every person is different! Your mum and dad both have DNA, and you have a bit of your mum's DNA and a bit of your dad's. This is why you might look a bit like them.

DNA has its own super-power – it's invisible, only secret agents can see it, but with our special light you can too!



Organ

Our bodies can do lots of cool things, and different parts of our body help us do them. Our stomach breaks up our food and our heart pushes blood around our body. Every part of us that is in charge of something is called an organ. We have lots of organs in our body and they are all different shapes and sizes. Our organs mean we can do things like eat cake, breathe, make up stories, run and blow bubbles!

Gene

'jeen'

Genes are very tiny instructions in your body for what makes you who you are! Genes are made of DNA. They have information about all kinds of things, like the colour of your eyes, the shape of your nose, and whether or not you have CF.



Like the ones I wear?!

No no! Not those ones!



Enzyme

'EN-zighm'

Your body makes enzymes in the pancreas. They help you get all the energy you need out of your food.



Airways

These are the paths from your mouth or nose to your lungs. Air follows the path to get into your body and out again.

Lungs

This is the organ that helps you to breathe. The lungs are like balloons that fill up with air and push it out again.

Liver

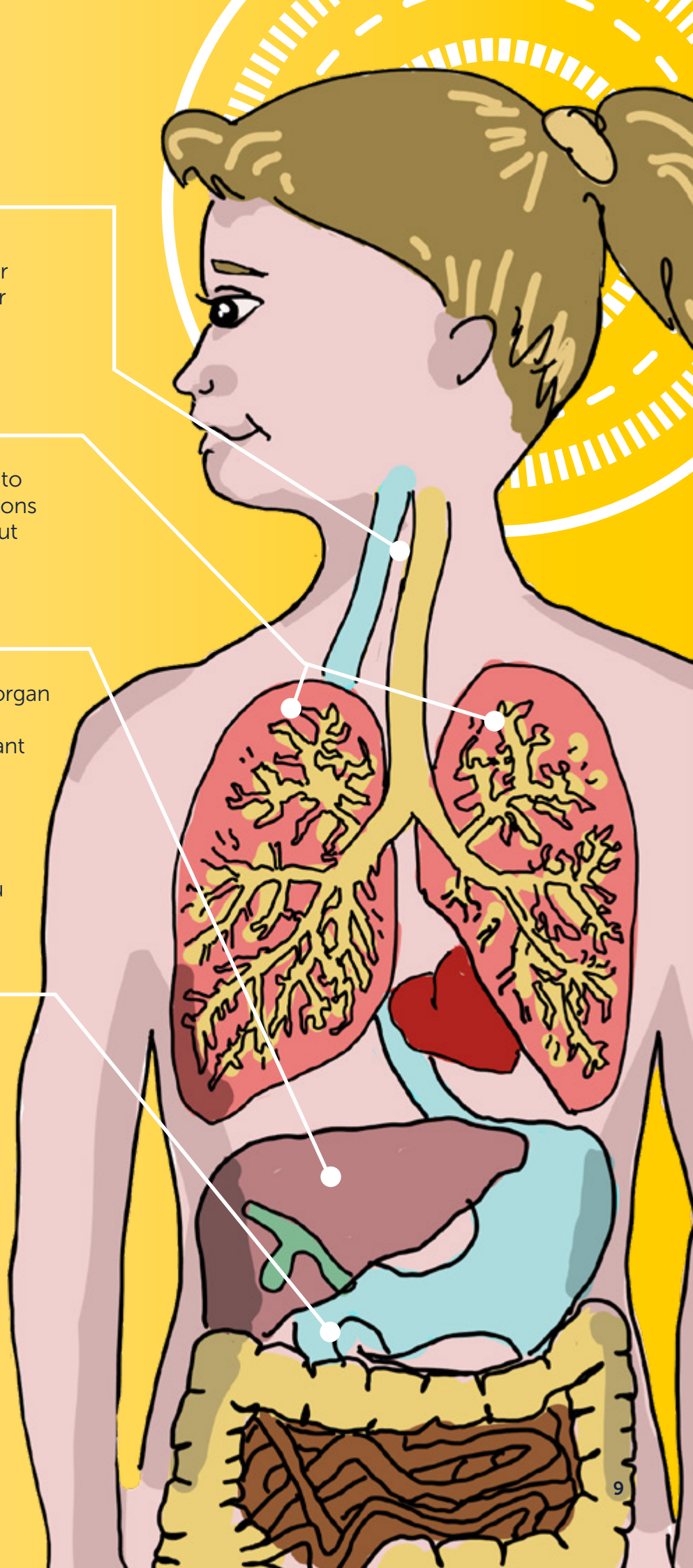
Your liver is another important organ in your body. It does lots of things. Its three most important jobs are...

- 1) Cleaning your blood
- 2) Helping you to digest food
- 3) Keeping energy for when you need it

Pancreas

Your pancreas is near your stomach. It is about the size of your hand. It makes special juices with something called enzymes in them. It also makes a chemical called insulin. Enzymes and insulin help your body to get all the energy it needs out of your food.

Lots of people with CF have a pancreas that doesn't work very well, so they need to take medicine to help it do its job.



My body and CF

Mission

Secret Agent: Shaan

Mission: Reveal the secrets of CF

Special power: Shrinking

Hi I'm Agent Shaan! Because we have CF, our bodies are different to other people's. Sometimes it feels like there is a lot to learn, but you know it better than you think... you are the expert in your own body!

Hang on, I'm going to shrink really tiny so I can reveal the CF secrets to you!



I had a polyp in my nose when I was little. It sort of feels like a big bogey (I called it 'Queen Bogey'... and even the doctors did too!). It was a bit annoying but it didn't hurt.

Polyp

'pol-uhp'

This is a little lump that might grow in places like your ears and nose. Your CF team can give you medicine to try and make it go away.



hi! alright?

bored! you?

me too



Cross-infection

People with CF aren't allowed to meet face-to-face. This is because they might share germs, which our bodies won't like and we could get ill.

All the secret agents meet online to do our missions! So if you are sad that you can't talk face-to-face, remember that there are lots of other ways to make good friends! You can ask your grown-up about joining in with activities Cystic Fibrosis Trust think you'll really love! Search for Cystic Fibrosis Trust's 'Building Brighter Futures' webpage for more information.

DIOS

This stands for lots of long words – distal intestinal obstruction syndrome – but you don't have to remember all of those! This is when your body can't get rid of the fat that was in your food. Then you might get blocked up so you cannot poo. Extra medicine will help your body get rid of the block so you can poo again soon.



Dyspnea/ shortness of breath

'dissp-NEE-uh'

If you are not feeling well you might take shorter and faster breaths. It might feel a bit more difficult to breathe, but your CF team will help you to feel better soon.



Exacerbation

'eg-zass-uh-BAY-shuhn'

This is when you have a bad cough and feel ill. It's OK to be scared, but your CF team will try to help you feel better again soon.

Wheezing

'wee-zing'

If you are feeling ill, this is a funny whistling noise you might hear in your chest when you breathe out.

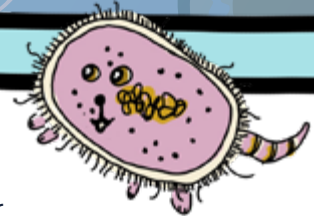
Special report: Bugs!

(Code name for infections)

Infection

This is when nasty germs attack your body. It can make you feel ill and weak. You might need to take extra medicine, go into hospital, or do extra physio. Your CF team will take good care of you!

Here are some names of infections that you might hear: MRSA, staph, pseudomonas, NTM, H.influenzae, aspergillus.



Bacteria

There are lots of bacteria all around you and in your body. They are tiny little things, that you can't see. Some are good for you and some might make you feel ill.

I had an infection in my lungs for a long, long time. That was really annoying, but it didn't stop me from doing all the things I wanted to do, like going to school and seeing my friends.



Fungi

Sometimes we get infections because of something called fungi. These are called 'fungal infections'. Some fungi don't hurt you though – you can even eat some of them (like mushrooms!).

Did you know?

Fungi are a type of living thing... but they are not plants or animals!

Virus

Everyone gets a cold or flu sometimes – this happens because of something called a virus. Our bodies can fight off colds and flu, but when people with CF are ill, they might get more infections.

So what are they then?

Argh it's all too sciencey! I just want to be the fun guy around here!

CF treatments

Mission

Secret Agent: Tilly

Mission: Decode all the different treatments for CF

Special power:

Acing treatments every day!



Airway clearance

This is what people with CF do to get rid of the thick, sticky stuff in their lungs. When you are younger this could be patting on your chest and back. When you get older, you might breathe into a tube or mask that makes you cough.

Hey, I'm Agent Tilly! Having CF means we have to do a lot of different treatments.

It is difficult to remember them all and understand why we have to do them. Luckily, I'm here with my CF superpower to decode it all for you!

Antibiotic

Antibiotics are a really important medicine for people with CF. Sometimes when we get sick it is because of tiny bugs in your body, these are called bacteria. An antibiotic is a special medicine that kills these bugs and tries hard to help you feel better. Antibiotics can be a medicine you swallow, a mist you breathe in, a cream you rub on your skin, or an injection in your arm.

Oral antibiotics

Oral means mouth, so these are pills or syrup you have to swallow. They do not taste as good as sweets, but if your doctor gives them to you, you need to take them to feel better and make your body healthy.





IV antibiotics

IV stands for a long complicated word – intravenous! This word means ‘into your veins’. Sometimes we need to have antibiotics which go straight into our blood, through a cannula, central line or portacath. This means the medicine works more quickly and will help you feel better sooner.

I’m scared of needles, so I was quite scared of having an IV put in my arm. The nurses put Frozen on for me to watch, so I didn’t get too scared. Then I realised that it wasn’t as bad as I thought it would be... and I got a cool sticker!

Oral antibiotics can be quite yucky, so eating something sweet and lots of water helps. My mum gives marshmallows to my younger brother after he takes antibiotics. It stops him getting a sore tummy!



Bronchoscopy

'brong-KOSS-kuh-pee'

This is when a small tube with a tiny camera on the end goes in through your nose or mouth and down to your lungs. Then the doctors can look at what is going on inside you. The doctors might gently take a very tiny bit from your lungs. They will look at this to help find the best treatments for you.

A doctor will give you a medicine to help you relax, or maybe even have a nice nap so you don't feel anything!

My doctors wanted to take a closer look inside my lungs because I used to get really ill with chest infections. I was scared and worried but it was OK. The doctors gave me medicine to send me to sleep. I didn't feel a thing when it happened, and it was all done in less than 20 minutes. I got to see some cool pictures of the little air pockets at the bottom of my lungs which was super cool! My doctors took some samples so they could give me the right medicine to clear my infection – I was winning on all fronts!



Glucose test

Sometimes the doctors want to know how much sugar is in your blood. To do this, they might make a small prick on your finger. Other times, glucose tests are little discs called 'sensors' that you put on to your arm. They test your blood and send the information about the sugar in your blood to your phone and the doctors.

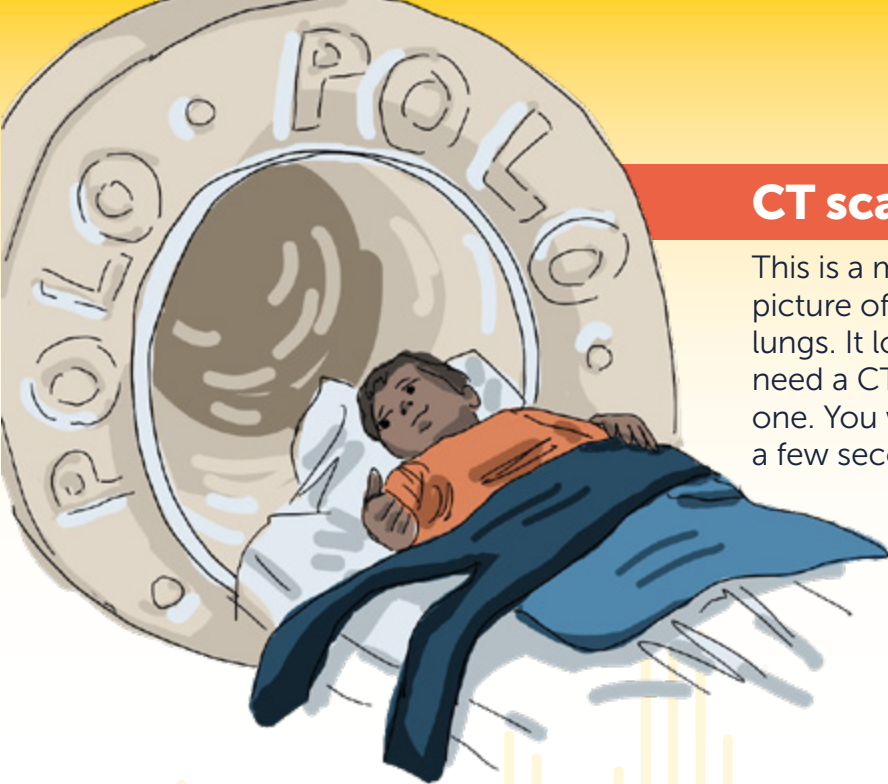


Glucose tests can be super fun! If you have CF diabetes like me, try asking your friends and family to guess what your blood sugar level number might be before you do a glucose test. I love playing this game with my friends – and they love it too!

Cough swab

This is a long, thin stick with some cotton on the end. The doctors or nurses might ask you to cough on it. Then they can look at the germs that are in your lungs.





CT scan

This is a machine that takes a detailed picture of inside your body, especially your lungs. It looks like a giant polo mint! If you need a CT scan you will lie down inside one. You will need to hold your breath for a few seconds to take the picture.

Catheter

This is a bendy tube that goes inside your body. It can take away your wee and other liquids, if you can't do it yourself. Your CF team can also give you medicine through it, so that the medicine gets to the right place quickly.

Modulators

Most of your medicines sort out problems in your body. There are special kinds of medicine which try to stop problems before they even happen! These are called modulators, but you might also hear words like Kaftrio, Kalydeco or Orkambi. A lot of people with CF who take modulators feel lots better. Some people with CF cannot take this medicine. For other people it does not work, or it could even make them feel worse, so it is always important to tell your CF team how you are feeling.

Cannula

'KA-nyu-luh'

This is a tiny tube that a doctor or nurse might put into your vein. Then they can easily give you medicine or take a bit of your blood to look at it closely and understand why you might be feeling ill.



When my brother had a cannula my mum told me to be super dooper careful of his arm especially when we were playing. Of course I was, because I am such a wonderful, perfect sister... not sure he'll agree with that though!

Gastrostomy

Sometimes, someone with CF might not be able to take in enough food and drink by eating and drinking. The doctors might make a little hole in the person's tummy. Then they attach a tube to it, so that all the good things from food can go straight into the person's stomach. This helps them get all the good stuff from food so that they can stay healthy.

Long line

A long line is a thin, bendy tube that goes into the veins in your arms, and then goes up into the bigger veins near your heart. This makes it easy for the doctors and nurses to give you medicine. The tube stays in your arm for as long as you need it. It means you don't need to have lots of injections and it doesn't hurt.

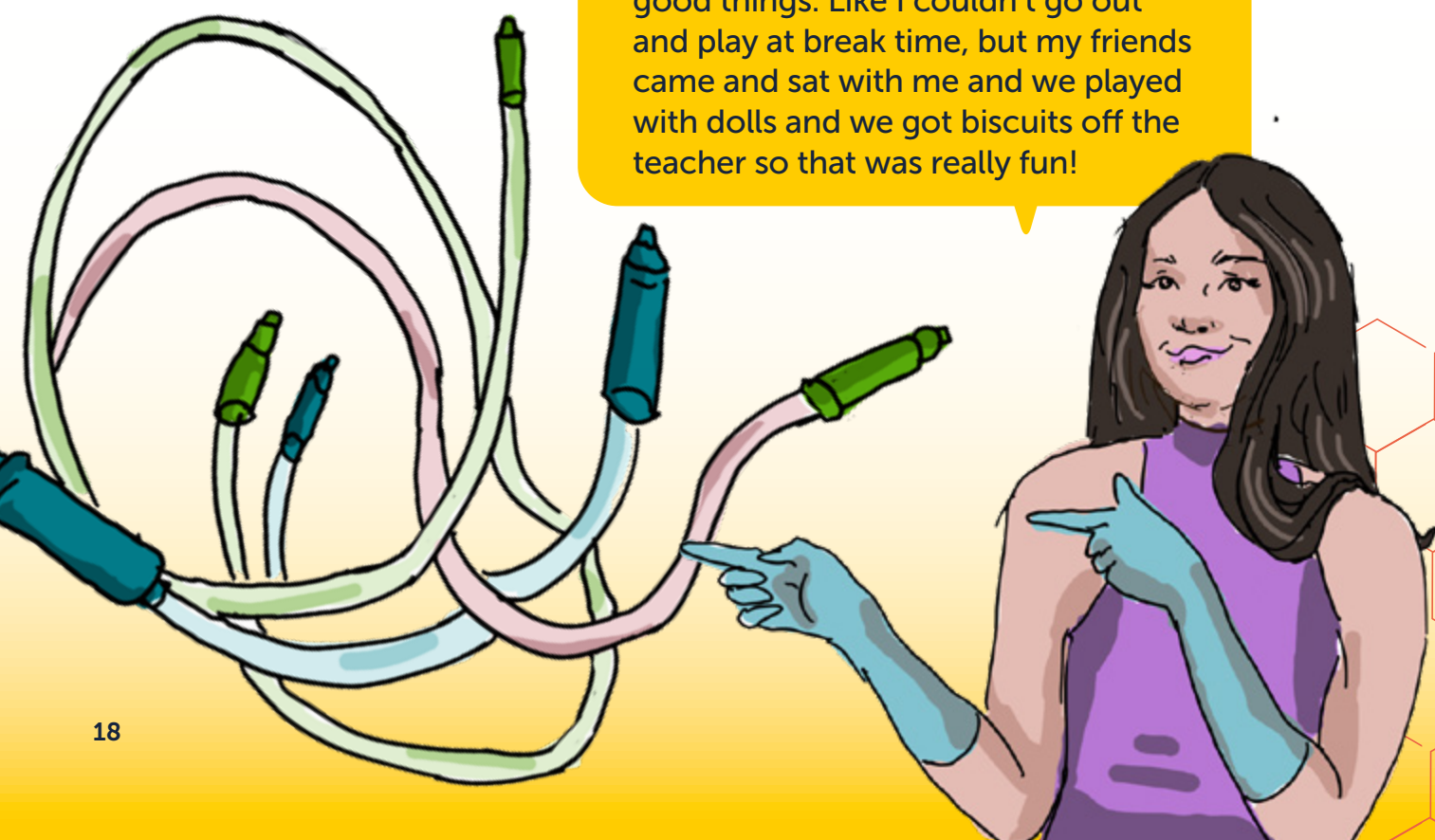
Top secret info

NG stands for 'nasogastric'. You do not need to know that... but you can try testing your doctors and nurses!

NG tube

This is a soft thin tube that goes through your nose, into your food pipe and down into your stomach. Your CF team might use it to give you medicines or water straight into your stomach when you are not feeling well. Your CF team might also use it to give you energy milk drink if you need extra food.

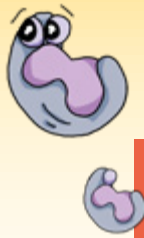
When I was little I had a long line, it wasn't very fun, but there were some good things. Like I couldn't go out and play at break time, but my friends came and sat with me and we played with dolls and we got biscuits off the teacher so that was really fun!





X-ray

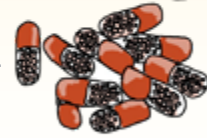
A machine that takes a picture of your bones. The doctors can also use the X-ray machine to take pictures of your lungs (a chest X-ray) or sometimes your tummy.



Pancreatic enzymes

'pang-kree-AT-ik EN-zighmz'

These are little things made in our bodies, in the pancreas. They help break down food. Lots of people with CF do not have these, so they need to take tablets or sprinkles instead.

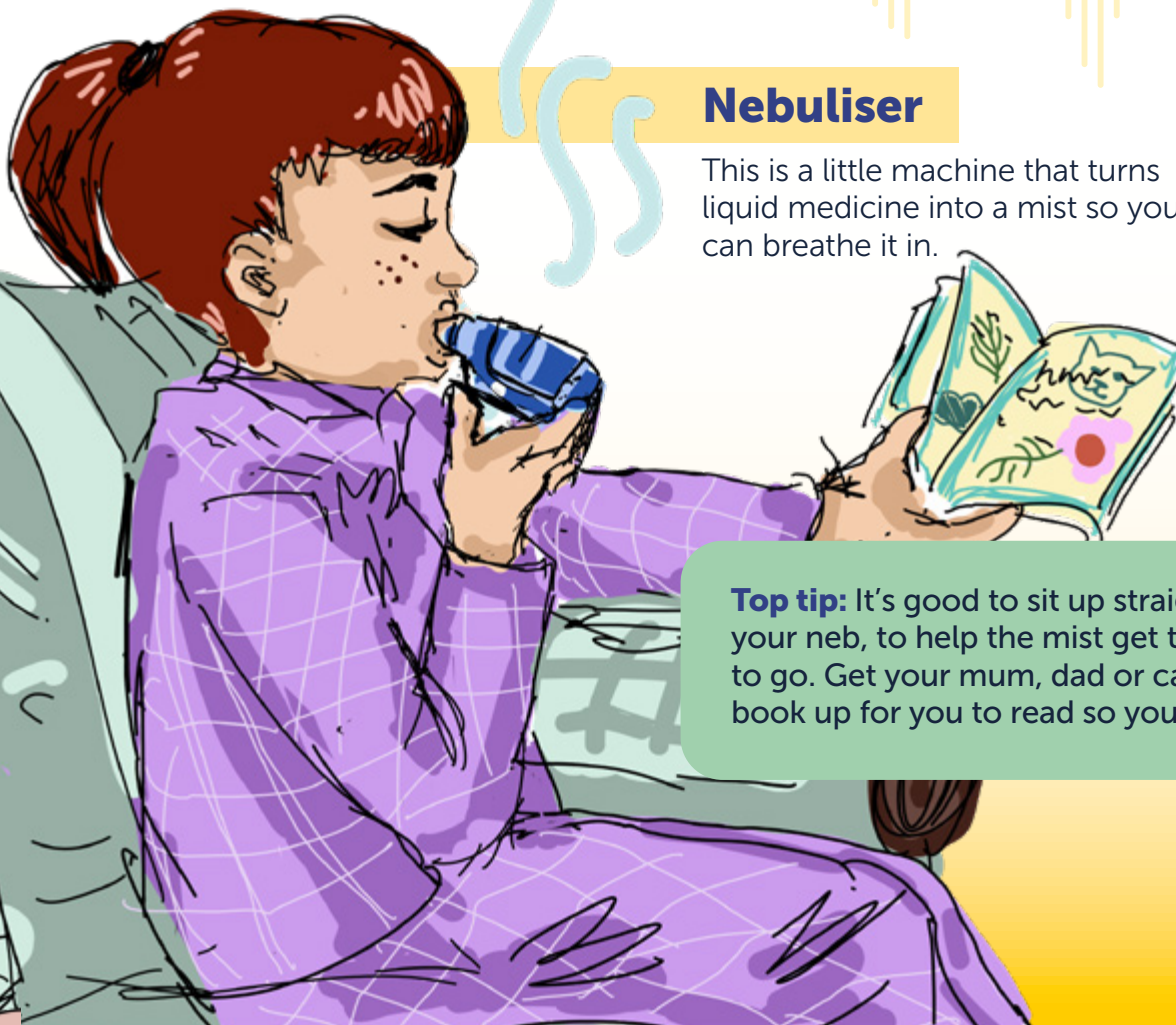


Creon

These are the tablets or sprinkles that replace the pancreatic enzymes. You might take them before you eat, to help your body get all of the goodness out of your food.

Nebuliser

This is a little machine that turns liquid medicine into a mist so you can breathe it in.



Top tip: It's good to sit up straight when you do your neb, to help the mist get to where it needs to go. Get your mum, dad or carer to hold a book up for you to read so you don't get bored!



Portacath

A portacath is sometimes called a port. It is a little circle that a doctor puts under your skin. It looks a bit like a fruit pastille! You can see a small bump where it is. It is joined to a tube that goes all the way to your heart. A needle pushes medicine through the tube. This makes it easier and more comfortable to get the medicine you need straight into your blood and around your body when you feel ill. This means that you can feel better quicker.

Physiotherapy

'fiz-ee-oh-THERR-uh-pee'

This is part of your treatment that you do every day. It might be things like exercise, or patting your chest or back, or using things that the hospital gives you to breathe in and out of, like a PEP mask or an Aerobika. Physiotherapy can help with lots of things, but people with CF do physio mainly to keep their airways clear, especially if they have a chest infection.



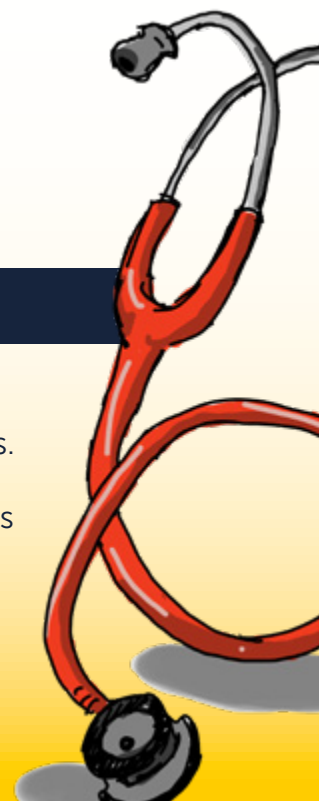
Supplement

If you have CF, sometimes your pancreas might not work that well. This means that it is difficult for your body to get energy from food. You might need to take supplements to keep you fit and healthy. This might be food, drinks, vitamins or tablets that give you extra energy so that you can get stronger.



Stethoscope

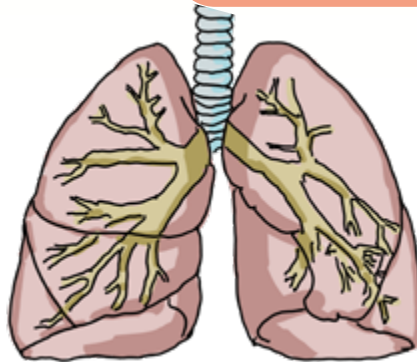
Something the doctor uses to listen to your breathing and heartbeat. You might see it hanging around their necks. It's a metal circle that they put on your chest, which has a tube which connects to their ears.



Surgery

This is when doctors fix a problem inside someone's body to make them feel better. It is also called an operation. If you need surgery or an operation, a special doctor called a surgeon will do it. They will work closely with your CF doctors and will explain everything to you so that you understand it. They will also give you some medicine so you won't feel it.

When I had a surgery in hospital the doctors put a mask on my face that made me feel all silly and sleepy. I didn't feel what they were doing at all! When I woke up my mum and dad were right there ready with my favourite teddy.



Transplant

Sometimes people with CF have parts of their body that don't work properly, like their lungs or their heart. This can make them very ill. If medicine isn't helping them, they might decide to have a special operation called a transplant. This is where the doctors take away the part of the body that isn't working properly and replace it with a healthy one that someone has kindly given. This normally means the person will feel a lot better and their body will be healthy.

Saline

'SAY-leen' or 'SAY-lighn'

This is a salty mist that you might have to breathe in if you are not feeling well. It will tickle your lungs and throat and make you cough up mucus.

An ultrasound doesn't hurt but they put a **REALLY COLD, STICKY** jelly on your tummy. It gets **EVERYWHERE** and then you have to go to school with your T-shirt sticking to you! One time the nurse heated it up a bit before putting it on my tummy and it felt soooo nice!

Top tip: Ask them to warm up the jelly!

Ultrasound

An ultrasound is a way that doctors can quickly take a look inside your body. It doesn't hurt at all. A machine takes pictures of the inside of your body. Mostly, it will help the doctors to look carefully at your liver, but it can also help them to look at many other parts of your body. Then the doctors can work out what they can do to help you feel better.



Other useful words

Hi, I'm Agent Chawan!
Wow, there are so many words to remember. And here are even more! Luckily I have super memory about all things CF, so I can help decode these for you!

Calories

These are the energy in our food. CF can make it difficult for your body to get the energy and nutrients from the food you eat to keep you fit and healthy. This means you might need to go on a high calorie diet. Then you will eat food with lots more energy and good stuff stored in it so that you can get stronger.

My mum spoke to my school and told them I need lots of calories. Now my teachers let me eat in class whenever I want! My friends get jealous of me eating a chocolate bar in maths!

Mission

Secret Agent: Chawan

Mission: Unscramble all these other words that might come in useful.

Special power: Super memory about all things CF.

Digest/Digestion

This is when food is broken down inside you. Your body uses the useful things in your food to make you grow, have energy and be healthy.



Nutrition

Nutrition is about food and what it does to your body. Nutrition looks at all the things that are in your food (like vitamins and fat) and studies how your body uses them.

Absorb

When you eat and drink your body takes in all the good stuff from your food and drink. Another way of saying this, is that it 'absorbs' it. This keeps you fit and healthy.

Huff

This is like when you breathe mist onto a cold window. It might make you cough a bit, but it helps clear the sticky mucus out of your lungs.



BMI

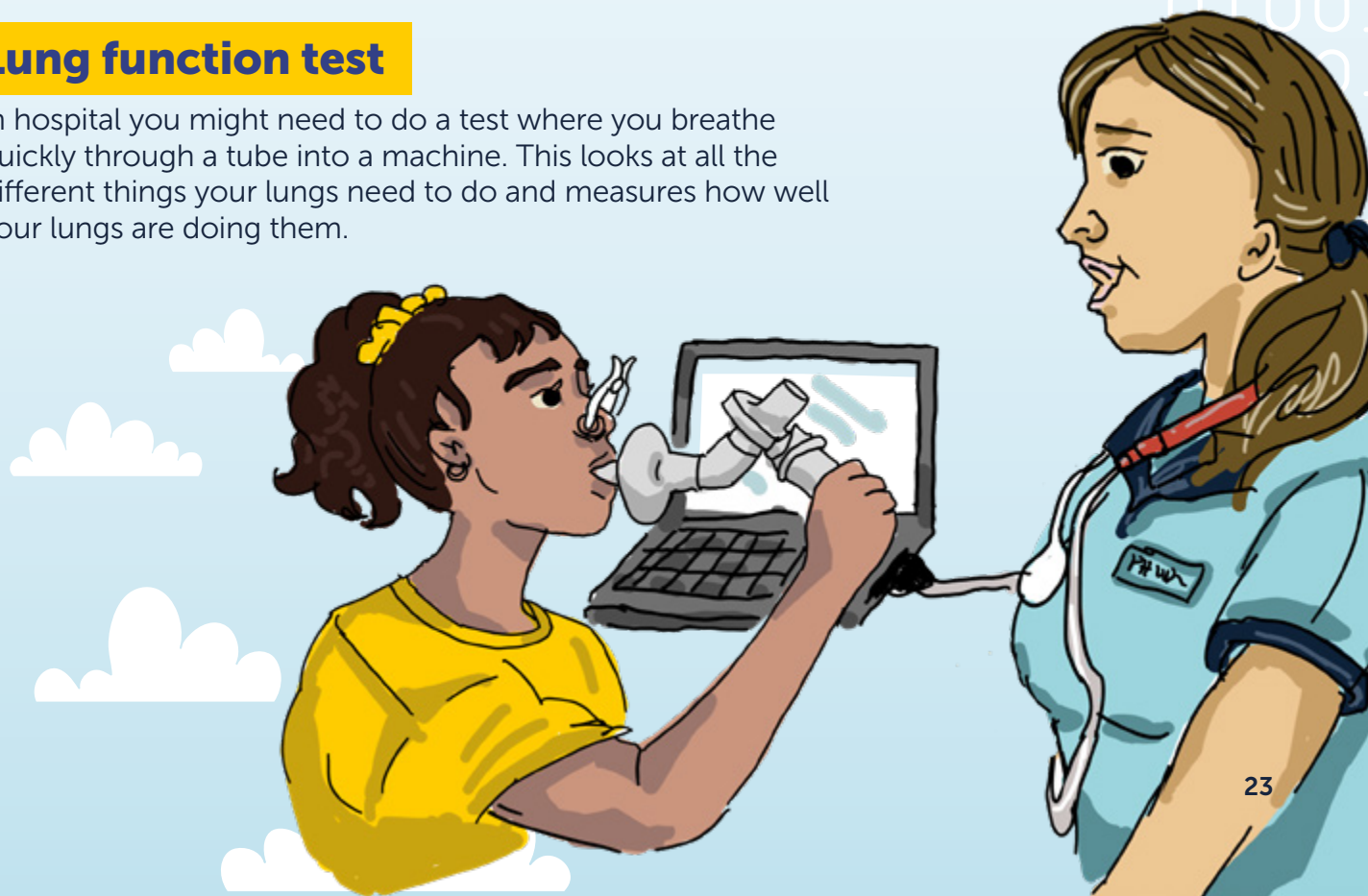
This stands for body mass index. It is a measure that uses your height and weight to tell your CF team if your weight is healthy.

Respiratory

You might hear your CF team use this word about lots of different things. It's just talking about breathing and how body parts, like the lungs, help you to breathe.

Lung function test

In hospital you might need to do a test where you breathe quickly through a tube into a machine. This looks at all the different things your lungs need to do and measures how well your lungs are doing them.





Constipation

This is when you are doing poos less often. This might be because your poo is too hard and big to push out.

Floater

This is if your poo doesn't sink in the toilet and just floats on the top. If it happens a lot, you should tell your mum, dad, carer, or your CF team. It might mean that you need to take a few more Creon with your food.

Mutation

Mutation is a big word that just means 'a change'. You might hear grown-ups talk about 'genetic mutation'. This means that the tiny instructions in your body that make you who you are, are different to most other people's – that's why you have CF. Sometimes your doctor might also call this a 'variant'.

Carrier

I know this one! Like someone who carries all my bags for me?

No no, not that kind of carrier!

Everyone has genes, which are tiny instructions in your body for what makes you who you are! Lots of people have a special hidden gene that builds CF. These people are called 'carriers' – it is a bit like they are carrying the CF gene around with them, but they don't have CF themselves. When two people carrying the CF gene have a baby, their CF genes can mix and they might have a baby with CF. So if you have CF, your parents are both carriers.



Glucose

'GLOO-kohss'

This is in some foods and drinks and we need it for energy. Sometimes a person might need more glucose than they can get from their food. Then they will take medicine to make sure they get enough.

Persistent

This means something that lasts a long time or is very determined. In CF we might use that word for two things:

- 1) Sometimes a cough won't go away – then it is persistent.
- 2) Treatments might be hard to stick to, but staying persistent with your treatments will mean you are healthier.

Clinical trial

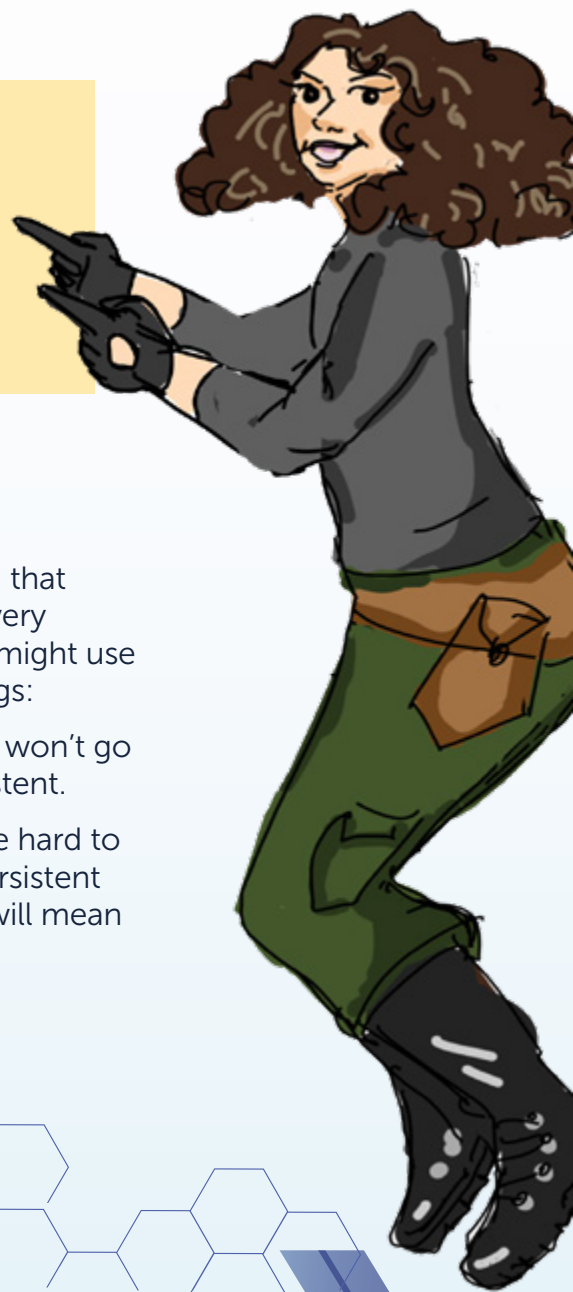
This is a test to find out if a new medicine or treatment for people with CF works properly. It is up to you if you want to take part in a clinical trial. If you want to find out more about this you can ask your CF team.

Mass

Sometimes your CF doctor might feel a lump in your tummy. They might call this a 'mass', but it means a lump.

Productive cough

Hopefully your CF team will help you so you don't cough too much. Sometimes your CF team will say you have a 'productive cough', a 'fruity cough' or a 'wet cough'. This means that when you cough, you produce bits of phlegm or mucus, which come up into your mouth. It can feel like you need to get something out of your chest. If nothing is coming up into your mouth when you cough, they might call it a 'dry cough'.



Thank you so much for coming on this adventure with us. Remember...



Don't let anything stop you from being yourself. You will always be amazing and don't let anyone tell you different.

Tehya

You are your own superhero! Keep using your superpowers to get you through everything!

Chawan



You are more than your CF! You can get through all the difficult times!

Shaan



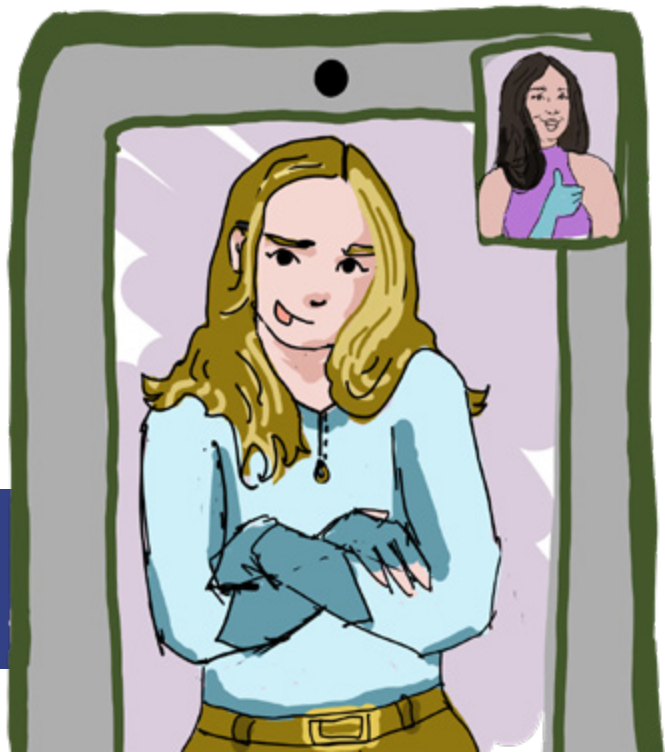
You can do anything you want to do, CF isn't going to stop you from being happy and doing what you love.

Rosie



You can have CF and also live an awesome life! Have fun, do things you love and take care of your incredible body!

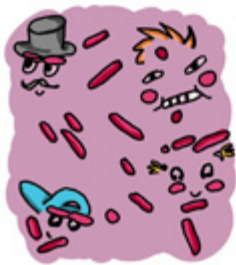
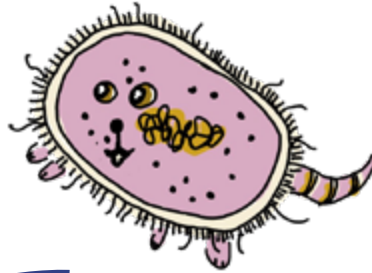
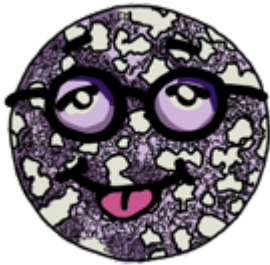
Tilly



If you have any questions or worries about CF, speak to your CF team and they will try to help you.

Germ mix up

One of the agents mixed up the files! Help us match all the different bugs to their names.



Pseudomonas

Aspergillus

H.influenza

MRSA

Staph

These infections might sound scary but they are really tiny like me! And when you look at them close up they are kind of cute.



Index

Absorb	23	Fungi	13	Pancreas	9
Airway clearance	14	Gastrostomy	18	Pancreatic enzymes	19
Airways	9	Gene	8	Persistent	25
Antibiotic	14	Glucose	25	Pharmacist	4
BMI	23	Glucose test	16	Pharmacy	3
Bacteria	12	Huff	23	Phlebotomist	4
Bowel	6	IV antibiotics	15	Phlegm	7
Bronchoscopy	16	Infection	12	Physiotherapist	4
CF nurse	4	Inpatient	3	Physiotherapy	20
CT scan	17	Inpatient ward	3	Portacath	20
Calories	22	Kaftrio	17	Prescription	3
Cannula	17	Kalydeco	17	Productive cough	25
Carrier	24	Liver	9	Psychologist	5
Catheter	17	Long line	18	Polyp	10
Clinical trial	25	Lung function test	23	Respiratory nurse	4
Constipation	24	Lungs	9	Saline	21
Consultant	5	Mass	25	Shortness of breath	11
Cough swab	16	Modulators	17	Social worker	5
Creon	19	Mucus	7	Sputum	7
Cross infection	11	Mutation	24	Stethoscope	20
DIOS	11	NG tube	18	Stool	6
DNA	8	Nebuliser	19	Supplement	20
Dietitian	4	Nurse	4	Surgery	21
Digest	22	Nutrition	23	Trachea	7
Digestion	22	Oral antibiotics	14	Transplant	21
Dyspnea	11	Organ	8	Ultrasound	21
Enzyme	8	Orkambi	17	Virus	13
Exacerbation	11	Outpatient	3	Wheezing	11
Floater	24	Paediatrician	4	X-ray	19

Add your own words

We know we haven't been able to help you understand EVERYTHING about CF, but we think you know enough now to become a CF secret agent just like us. Here's some space for you to write down the new words you learn or any questions you have for your CF team.



Meet other CF secret agents just like you!

**Are you 6-14 years old? Do you have CF?
Or do you have someone in your close
family with CF, like a brother, sister,
mum or dad?**

Then you could meet other CF secret agents at
Building Brighter Futures.

We run loads of free online events like baking, coding,
arts and crafts, games nights, and lots more! We play
games, make friends, learn new skills and laugh...
a lot!

You can join from home or from hospital – all you
need is a laptop, smartphone or tablet. We'll help
you get set up so don't worry if you've never joined
an online meeting before.

To find out more visit
cysticfibrosis.org.uk/bbf

Or email us at cfyouth@cysticfibrosis.org.uk

**Cystic
Fibrosis Trust**

Cystic Fibrosis Trust

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.

This resource was developed and written by members of the Trust's Youth Advisory Group, and Ellie Mindel, Lead for Children and Young People. It was illustrated by Bahar Mustafa. It was reviewed by Helen Love, Consultant Clinical Psychologist and Kevin Southern, Professor of Child Health.

You can copy any information from this resource without our permission. You must not make money from it and you must acknowledge the Cystic Fibrosis Trust as the original author. The information in this resource does not replace advice from your doctor or CF team. You should speak to your CF team before making any change to your treatment.

If you have any feedback on this publication please email infoteam@cysticfibrosis.org.uk

cysticfibrosis.org.uk

© Cystic Fibrosis Trust March 2025
Review due: March 2028

© Cystic Fibrosis Trust 2025. Registered as a charity in England and Wales (1079049) and in Scotland (SC040196). A company limited by guarantee, registered in England and Wales number 3880213. Registered office: Cystic Fibrosis Trust, 33 Creechurch Lane, London EC3A 5EB

