Cystic Fibrosis Trust

My CF planner

Fighting for a Life Unlimited

Cystic Fibrosis Trust

A message from the Cystic Fibrosis Trust:

This plan has been designed with the help and guidance of young people living with cystic fibrosis (CF) and their CF healthcare teams. The views and experiences of these young people have been quoted throughout.

This plan is a template to be jointly completed through conversations with a young person, their parents, the staff at their secondary school and the young person's CF team. It may be used in conjunction with the Local Authority education, health and care (EHC) plan or any school used plan.

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Hello, my name is …… and I have cystic fibrosis, or CF. This is my plan for dealing with my CF and staying healthy at school. It outlines how CF affects my daily life, describes my treatment and highlights what my school should be aware of and can do to make sure I have a happy and safe school experience. I want the same opportunities as everyone else, and not to let CF limit me. This plan will help me to do that.

My daily treatment for CF can change depending on how well I am. This school plan should be updated with any new information and reviewed just ahead of or at the start of the academic year, or more often if things change. It would be really helpful to have a key member of staff to go to if I have any concerns or problems without having to explain everything about my CF again. That key staff member should also be responsible for reviewing this plan with me.

My key contact is ……
[add the name of the key staff member].

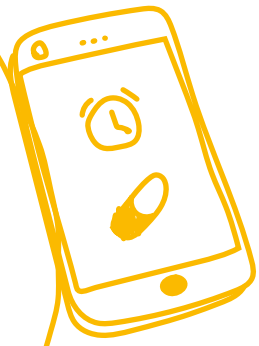
I thought it might be helpful to explain a bit about CF to you, though it's worth knowing that CF affects everyone differently.

So, what is CF and how does it affect me?

Cystic fibrosis (CF) is 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 the lungs and digestive system in particular; the build-up of this mucus can cause lung infections and blockages in the pancreas that affect digestion. I have to work really hard every day to stay well. CF is often described as an 'invisible condition', so even though I might look ok, I might not feel okay all the time.

The way I'm feeling can often change very quickly. I might feel fine enough to go to school but a few hours later I might feel so bad I have to go home early. I may be fine all day at school and then feel so exhausted that doing my homework is impossible that evening. Or I might have left school early as I feel terrible, but by the evening I feel good again and can do my after school club! This is normal with CF.

"Sometimes things change hour by hour!"



"I had spotted [CF] in some of the science books in school and I didn't like what I saw (old and outdated). I knew I wouldn't want my child to see it!"

(Parent of a young person with CF.)

Important!

- I have grown up with CF and learnt a lot about how it affects me and what I need to do to try to stay well. It can be difficult if adults and people my age don't fully understand my condition and why I may need to do things differently to other people. [Say 'Yes' if the sentence applies to you, and leave the other space blank.]

  I talk about CF to my friends

  I don't talk about my CF to my friends.

- I might need to leave the classroom without permission.
- I might cough a lot at times, but I'm not infectious.
- I always have to be able to access my medication.
- I can often get tummy aches and can become uncomfortable.
- I may have to eat and drink more often for energy, for digestive reasons, to take my medication, to keep hydrated or if I have CF-related diabetes.
- I'm good at assessing a room for any risks to my health, so please listen to me if I tell you I'm not comfortable. For example, with a student who appears ill and is sat near me or for other reasons.

Learning about CF as part of school subjects

If we're going to be covering CF in a lesson, **please come and talk to me about it first** so I know in advance.

- Cystic fibrosis is widely used in GCSE biology to explain genetic inheritance.
- The treatment of CF has changed quite rapidly over recent years so it would be good if teaching materials are checked to make sure they have not become out of date. For trusted information visit **cysticfibrosis.org.uk**
- It would be good if my key contact person or a Special Educational Needs Coordinator (SENCO) is aware of these issues as I progress through the school years and can highlight them, particularly to the science teachers.
- I might not have talked much, or at all, about my condition with my friends and classmates.
- Please ask me if I would feel comfortable if you told the class I have CF or if I don't want the class to know, or if I want to contribute or not.
- You might be discussing things about my condition that I haven't yet learnt for myself, which could be awkward or upsetting for me and maybe you.

> "I didn't really talk about CF with my friends - I didn't really know how to."

Cross-infection

You might not know this about CF, but **people with CF cannot meet each other or be in the same space.** This is because people with CF can have bugs (bacterial or fungal infections) in their lungs which, whilst not harmful to the wider population, can be harmful to others with CF.

If there is more than one person with CF at the school, a plan should be set up to help us avoid coming into contact with each other in person, or using the same rooms/classes/halls at the same time or in the same day.

Cross-infection can happen through:

- Direct contact – handshakes, hugs or sharing food and drink.
- Indirect contact – one person with CF using the same classroom or desk that another person with CF used earlier in the day where bugs might remain on surfaces.

It's very important that a policy is developed by the school, the people with CF and their parents/carers to keep us safe. **This applies to anyone at the school with CF, whether they are a student, staff, visiting parent, sibling, or a volunteer.**

If you have more than one person with CF at the school, you should speak with their CF teams for some guidance.

Record any notes relevant to your school here. Eg ‘There is not currently a student or staff member at the school known to have CF. The school should contact the CF team for advice if another adult/student with CF applies to the school.’

School work and attendance

I attend CF clinic at ……..……..……

[insert hospital name] every …… [say how often you go to CF clinic, eg every two months] for a clinic review. I'm seen by a multidisciplinary team, so appointments take at least two hours but are often longer. These appointments are compulsory and are always in school time. If I am unwell and need extra treatments or tests, I may need to attend hospital in addition to these routine appointments and may be admitted for treatment for two weeks or more.

Sometimes I may have increased medication to take that could disrupt my school day. I may have to start late, leave in the middle of the day or leave early. At times, I have to get up extra early to do additional medication before school, or I may have very late nights completing medication before bed. This can affect my concentration in school and participation in some lessons, like PE.

Taking care of my CF can take up lots of time. I will try to complete my homework whenever I can but sometimes, due to medication and tiredness, it might not be completed on time. Please don't penalise me if I have a genuine reason for the homework not being completed.

If I need to stay in hospital, my access to education is reviewed either by a hospital school teacher, a CF social worker or another member of my CF team. Please pass on work and communications from my teachers to help me keep up to date with my school work. The hospital school or CF team will usually contact my school if I am admitted to hospital.

My nominated key contact at school can liaise with the hospital teacher or social worker and can collect work from all my teachers so it can be passed onto me.

There are extra tips in our Starting Secondary School Magazine to help support young people from falling behind with their school work.

Visit cysticfibrosis.org.uk/secondaryschool to find out more. Teachers can also suggest online learning resources and websites which can help their student to study.

Exam time

- Being absent or unwell might cause me anxiety, especially around exam times.
- If I become unwell during the exam period, I might need extra support in the classroom, during breaks or after school.
- I'd benefit from having a key staff contact who I can share any anxieties with.
- I might need extra time in exams.
- I might need to be sat in a separate room so that I can cough, have access to a toilet regularly or have snacks if I'm diabetic, without worrying about disturbing others in the exam room.

My CF social worker or nurse will be able to provide you with a letter to support any requirements I may have or any adjustments I might need.

Attendance rewards and disciplinaries

Young people with long-term health conditions should not miss out on rewards for their attendance where the absence is due to their medical condition. Likewise, penalising low attendance when the reason is a medical condition can put undue pressure on an already stressful situation. The school should discuss their policy on attendance rewards and disciplinary action and consider amendments to ensure it is fair to those with medical conditions.

Medications

Some people with CF may have CF diabetes. This is specific to CF and not the same as Type 1 or Type 2 diabetes. It may mean having to eat more often, taking insulin or having a special food box available with the right snacks ready to take. [Say 'Yes' if the sentence applies to you, and leave the other space blank.]

I have CF diabetes (CFD).

I do not have CFD.

I do airway clearance physiotherapy (physio) every day to clear my lungs of mucus. My routine can change or increase if I'm ill.

Record any notes relevant to you. Eg 'I do physio before breakfast and after dinner every day. I use inhalers, nebulisers and a physio device. My physio takes me 20-40 minutes each session when I'm well. If I have a chest infection, it can take longer or I have to add more sessions each day.'

Often there is no need for the school to be involved in my physiotherapy, apart from being aware of the additional burden it has on my day. If I do need to do my physiotherapy at school I may need some extra support.

Exercise is important for helping me to stay well but places a huge time burden on me. It is also good physio (read more in the 'Physical activity' section).

I may take lots of other medications when I'm at home but do not need them in the school day.

Additional medications

If I have a chest infection, I will take extra medication.
[Say 'Yes' if the sentence applies to you, and leave the other space blank.]

I will carry my medication on me and will self-administer it.

I would like support with taking my medication at school.

- I will need to be allowed to take my medications at the correct time.
- I may want a private space to administer some medications.
- I may take liquid medication that needs to be kept in the fridge.

A chest infection can make me very tired and some medications can have nasty side effects. These may be physical and can particularly affect my gut or appetite, but they can also have emotional or behavioural side effects. Some are so strong I don't feel like me when I'm on them, but I know they are necessary. Talk to me if you notice changes in my mood or behaviour, especially if you think it is uncharacteristic of me. Some medication can make my skin more sensitive to the sun, so I may need to apply sunscreen more regularly or avoid being outside for long periods on sunny days.

Sometimes I have to take intravenous (IV) antibiotics. This requires either temporary access to the bloodstream via a tube or a surgically inserted tube (IV central line or port). The tube will be well covered and protected and will not need to be used during the school day but I may not be able to take part in certain activities (eg swimming and contact sports).

- Sometimes I can choose to have IV antibiotics in hospital or at home.
- I might feel well enough to attend school between doses.

Record any notes relevant to you at school. Eg 'When I have an IV tube in, I cannot go swimming but can take part in all other school activities.'

Taking care of my lungs

Cystic fibrosis affects my lungs.

- Thick and sticky mucus can build up in my lungs.
- Bacteria and fungi can get trapped in the mucus instead of being cleared away naturally.
- These can turn into a bad chest infection and **can cause lung damage.**

Because of this, I work hard each day to look after my lungs.

- I probably have to get up earlier than my friends to do my physiotherapy treatment to help keep my lungs clear.
- I have to do my physiotherapy each evening too.

Add physiotherapy treatments to a usual school day (including after school clubs, homework, time to relax, eat, and having fun) and you can see the day is very long for someone with CF.

- Sometimes I may cough in class (and occasionally I can have long coughing fits). This is the body's natural way of trying to dislodge and remove mucus from the lungs and airways. Coughing shouldn't ever be discouraged and it's nothing to worry about, but I might need a drink, to take an inhaler or to leave the classroom.

> "If I have a particularly bad cough that day and can't control it, it sometimes makes us feel uncomfortable. Everyone's looking at us and judging us and I may want to leave the room as I'm feeling conscious about it or to try and get the cough under control before returning to the classroom."

Record any notes relevant to you at school. Eg 'I may cough a couple of times, or it could be more and for longer. If I feel I need to leave the class to do some airway clearance please allow me to leave without having to explain why. I may prefer to do airway clearance somewhere other than in class, I will go to a place we have agreed I can use, and return when I am coughing less.'

Taking care of my digestive system

Cystic fibrosis can affect the digestive system.
[Say 'Yes' if the sentence applies to you, and leave the other space blank.]

I can often have tummy aches and discomfort; I may also be bloated. This can be from certain medications, foods and sitting in one place for long periods.

I do not need to take enzymes.

I need to take enzymes, I take Creon® or Nutrizym 22® with every snack and meal. Creon®/ Nutrizym 22® is not a drug but a supplement. It helps me to grow and maintain a healthy weight. It's essential I take my enzymes whenever I eat throughout the school day as they only work for a short time. I take my enzymes with food, drink or snacks that contain fat.

I carry enzyme capsules with me at all times and manage them myself.

I may need to be prompted or encouraged to take my enzymes.

I may need to be prompted or encouraged to drink water or non-sugary drinks.

CF makes my body use up lots of energy so I may need to eat a high-fat diet. I see a dietitian regularly so I know which foods will help me to keep a healthy weight. **'Healthy eating' for me might look different to what others think of as healthy, and I may need to eat high calorie food, snacks or shakes during my school day**.

My CF can also make me need lots of salt in my diet. I might get this from salting my food, or having salty snacks and isotonic drinks. I might need to increase the amount of salt I have when the weather is hot or when I have done lots of sports.

I need to drink loads! This helps my lungs and keeps my gut healthy. I probably need to drink more than my friends. **I should be allowed to have a drink during lessons, breaks and especially during sports.** I'll need to drink even more when it's hot or if the central heating makes it warm and dry.

Some people with CF may need extra help to take in more nutrients to keep their weight on. This may be done as an overnight feed, either by a nasal tube or a tube in the stomach. This would only be carried out at home but awareness of this additional burden is important.
[Say 'Yes' if the sentence applies to you, and leave the other space blank.]

I do have overnight feeds

I do not have overnight feeds.

This is what a typical lunch/snack is for me. It has been approved by my parent/carer and my dietitian. Eating this keeps me healthy.

List a typical lunch/snack you will have at school:

Record any notes relevant to you at school. Eg 'I will keep my Creon in my bag and I know how many I need to take with my food and snacks. I eat a high fat diet. Sometimes I drink isotonic drinks during sports and I put them in a dark bottle so my friends think I'm drinking water like them. My CF team says I might need to start tube feeds overnight.'

Leaving the classroom

As CF causes problems with digestion, I may need to go to the toilet quickly or frequently and may have tummy aches. Some of the symptoms can also be quite embarrassing. Symptoms can fluctuate between diarrhoea and constipation. If I have abdominal discomfort I might need to have a place I can go to for rest or quiet time.

To help reduce my anxiety or embarrassment, it's helpful if the school can have a plan in place to let me have quick access to a disabled toilet rather than a communal toilet facility.

> "A toilet pass is a must. I have one and can show it discreetly to the teacher and just go with no questions asked."

Sometimes everything I'm managing with my CF, or the way I'm feeling physically, can get me down. CF is a big burden that often I don't let bother me but sometimes a chat with my key contact can really help.

Record any notes relevant to you at school. Eg 'I have been told I can use the disabled toilet in blocks 1 and 2 if I want to. I have been given an access key. I have been given a 'medical card' to show/hold up rather than having to explain why I need to leave the room or wait for permission/acknowledgement.'

Physical activity

Physical activity is really good for me. It helps to dislodge mucus, build lung capacity, maintain good mobility and posture, encourages good bone health and generally keeps me fit and healthy. All these things help me fight infections if I get ill. If my chest is ‘bad’, it may mean that I cough a lot or that I am a little more short of breath than others. This does not mean I shouldn’t join in but I may be slower than others at times. Not being able to keep up can sometimes make me feel different to people in my class.

My physiotherapists recommend that I actively participate in all school sports. They can give further advice if my health condition changes.

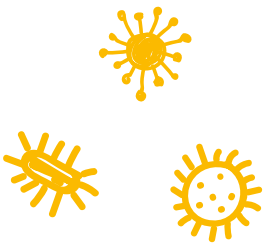
Record any notes relevant to you at school. Eg ‘I will take part in all PE lessons and will try to join a sports afterschool club.’

Infection control

As I have CF the effects of getting colds and viruses can be more serious, and an infection may cause lasting damage to my lungs. For this reason I may choose to move away from friends and peers if they are unwell. However, I may not always want to tell friends or peers why I'm sitting somewhere else, and it would help me if I could ask if I can move seats or, if you notice, you could move people around for that lesson.

> "I dreaded having to tell my teacher I was worried about sitting next to a friend who was coughing. If I found the courage to ask, they were moved and everyone in the class knew I had asked for that to happen, so awkward! If I didn't ask, I'd be so focused on the person with a cough that I missed everything I was supposed to be learning that lesson."

Students who are ill with a cold or virus should be encouraged to stay at home, for the wellbeing of everyone at school.



To me, infection control also means minimising my exposure to bacteria and fungi that live in the environment, as some can be harmful to people with CF. **These can live and thrive in mud, earth, rotting vegetation, straw, hay, sawdust, ponds and stagnant water and in fish tanks.** If you are planning an activity, lesson or school trip that might expose me to these things, please involve me and my family in discussions as early as possible. There are usually ways to minimise the risk to me without excluding me from the activity. My parents and I have been doing this my whole life so that I don't miss out but stay safe at the same time!

Everyone with CF manages these risks differently so it's crucial you involve the student in discussing these activities in advance. No young person ever needs to be excluded from activities their peers do, they may just need to do them in a different way.

Environments which might need thought and planning include:

- Forest schools
- Muddy assault courses
- Water-based activities in ponds and lakes
- Hot-houses, tropical greenhouses and butterfly houses (which use a circulating air humidification system)
- Aquariums
- Farms or zoos

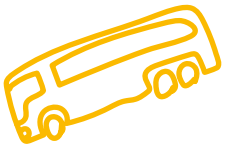
Record any notes relevant to you at school. You can include anything about COVID-19 in the notes here too. Eg 'Some activities at the Forest School or the year 9 residential trip might need a bit of consideration so I can take part but minimise the risks of me picking up an infection from the environment.'

Trips and residentials

On residential trips I will need to continue to do my daily treatments and physiotherapy. This can be managed while I'm away with good communication between the school, me and my family. I may not be confident completing my treatments and physiotherapy alone, and a school trip might even be the first time I have taken on the responsibility of doing my own physiotherapy and treatments for myself. To support this, I may need some private space to do my treatments in, and possibly some support or encouragement from a friend or staff member. I may also need access to a fridge where I can store my medicines and a sink and space to wash and dry my equipment. The opportunity to take responsibility for my own treatments is an important step towards independence and will help me greatly in the future.

CF is considered a disability, so young people that have CF have a legal right to reasonable adjustments to ensure they have access to new experiences and opportunities, as other children do. Risk assessments will be needed to highlight any necessary precautions or additional treatment.

Each risk assessment should be drawn up with input from the student, family and their CF team. This should include infection risks and a plan for the additional treatment needs if the trip is longer than the usual school day.



Forthcoming trips and dates

Please note down any forthcoming trips with a description of the trip and highlight any identified risks.

CF and emotional health

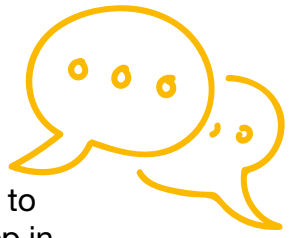
As well as physical effects, CF can sometimes have impacts on emotional health too. Managing CF on top of other life demands can be stressful at times and if so, this can affect a young person's mood or make them anxious. Knowing what information to share with friends and peers about CF can be an extra stress at times, and sticking to CF treatment regimes can also be challenging and can cause tension within family relationships. Cystic fibrosis does not have psychological impacts for everyone, but it is useful for school staff to be aware that this can occur at times.

"It's important to have one or two specific adults who you can go to in times of need or just for a chat."

"Being aware that CF is tricky to navigate is helpful, a student may not have shared anything about it, even with their closest friends."

"Yes we have to do PE - its essential - but due to the condition, people with CF may not be able to keep up with the other kids, which can affect mental well-being as you feel different to your peers."

Communication



I'd like to have the best school experience possible; making sure we talk to each other can make sure this happens. The key people who should keep in contact with each other are my family and my teachers, but sometimes my CF team can help to support us too.

> My support leader has always been amazing and rings my mum to have chats if there are any problems or just to get an update. He then passes information to the relevant teachers. I know I can always approach him if needed.

Having a key point of contact at the school to discuss any changes in my CF planner (for example, a form tutor or Head of Year) can be very useful to ensure that good communication is maintained.

My key contact at school is .....

Work out the best way to tell the key contact about planned hospital appointments so teachers know in advance and school work can be arranged around them.

Record any notes relevant to you at school:

The young person, family, school and CF team should keep a copy of this plan. The detail of this plan should be reviewed at least annually or if there are any changes in health or treatment.

This plan is strictly confidential, and the data in it shouldn't be used for anything else. A discussion should take place between all parties who had a part in creating this plan about who it should be shared with and who can't see it.

It should be stored in accordance with your confidentiality policy in line with GDPR/the Data Protection Act 2018.

Date of completion:

Date of review:

Contact information

My name: **My date of birth:**

My mobile number: **My email:**

School nurse:

Telephone number:

Email:

Family contact information

Name:
Relationship to the young person:
Telephone number:
Mobile number:
Email:

Name:
Relationship to the young person:
Telephone number:
Mobile number:
Email:

CF team contact information

Name of specialist cystic fibrosis nurse:

Telephone number:

Email:

Name of specialist cystic fibrosis social worker:

Telephone number:

Email:

Name of specialist cystic fibrosis dietitian:

Telephone number:

Email:

Name of specialist cystic fibrosis physiotherapist:

Telephone number:

Email:

Name of contact at the hospital school:

Telephone number:

Email

Other contact information

Name of GP:

Telephone number:

Email:

Fighting for a Life Unlimited