Cystic Fibrosis Trust

Trusted Information Creator
Patient Information Forum

School and cystic fibrosis

A guide for parents from nursery to primary

Cystic Fibrosis Trust

School and cystic fibrosis

A guide for parents from nursery to primary

Contents

Introduction

Children with cystic fibrosis (CF) should be able to enjoy a full and rewarding school life. Compromises may need to be found and minor adjustments made, but by working together with the school and your CF team, you can make sure your child's education is not limited by CF.

> "My concerns of giving someone else the responsibility of my daughter's care vanished when we visited the nursery and its staff. They are experienced and trained to look after children with medical needs, it is no longer an issue. A plan was easily formulated to keep her safe and let her enjoy a 'normal' nursery experience, while keeping my nerves at bay!"
>
> **Julia, mum to Olivia, aged 4**

Choosing a nursery*

You can research nurseries in your area by looking at their websites and inspection reports. When you have found some nurseries you like, it's a good idea to visit twice. Once, with your child so you can see if the setup of the nursery and the staff are a good match for your child. Then again without your child so you can talk to the staff without feeling distracted.

When you visit it can be helpful to find out:

- How they look after children with medical needs.
- Whether they have looked after a child with CF before.
- What the menus for lunch and snacks are. Your CF dietitian will then be able to help you work out the Creon doses.
- If there are any children or staff at the nursery who have CF.

Your CF team can also visit the nursery to talk to the staff about CF, your child's needs and answer any questions they have. If there's anything you are not sure about after visiting the nursery, you can talk this through with your CF team. They will be able to help you decide if it's something you can work with the nursery to change.

When you find a nursery you like, work at building a good relationship with them. Parents have told us good communication with their child's nursery — being able to discuss any problems — was the best way to make sure their child received the care they needed.

> **"Establishing a good relationship with the nursery staff is key. As much as you need to feel at ease, they do too, so they can freely ask advice or confirm medication. We found these extra conversations helped build relationships with the staff, who took a professional pride in looking after our daughter."**
>
> **Julia, mum to Olivia, aged 4**

---

* For ease of reference, nursery is used throughout this booklet to refer to a nursery or a pre-school

Nursery and pre-school

Starting nursery can be very exciting for young children. It's a chance to make new friends, try new activities and enjoy being more independent. It can be an emotional time for all parents but if your child has CF you might have some other concerns too.

Parents have told us they had a number of questions including:

- Who will give them their Creon?
- What if they play outdoors in the mud and sandpits?
- Will they pick up lots of infections?
- Will the staff do their treatments as well as me?
- Who will manage the risks if I'm not there? My child is too young to understand what they shouldn't do.

CF nurse visit

Many parents find they feel more confident about their child starting nursery after meeting with the nursery and their CF team. These meetings help the staff learn about CF and find out what your child will need. It also gives you the chance to raise any concerns and work with the nursery to find solutions.

“It was really good, it takes the pressure off a bit. You don’t want to be giving the teacher lots of extra work, but it’s really important they understand what needs to be done.

It also sends a strong message that this isn’t just a parent being pedantic or asking for unnecessary things — this is a genuine medical need.”

Laura, mum to Jasper, aged 2

“My nurse had a conversation with the SENCO which worked really well because she talked about things that I didn’t even know to talk about.”

Tracey, mum to Freddie, aged 10

Making the most of flexibility

Nurseries are often more flexible than schools about the times your child attends. This can make starting nursery a little easier.

It’s also worth remembering that there is a higher staff-to-child ratio at nurseries than at primary schools. There will be more staff available to help your child with any extra care they might need.

If you do not need full-time childcare, the flexibility of nursery timings can also help you manage your child's treatment more easily. For example, a morning session may not include lunch, so you would only need the staff to give Creon for the mid-morning snack.

Dealing with issues once your child has started nursery

Some parents have found their child's nursery didn't fully understand CF and their child's needs. Often you can sort out these kind of problems by asking for a meeting with the nursery. If you are still not happy with the nursery's response contact your CF team. They can help and may run another session with the staff.

Concerns about infection risk

Avoiding infection is a very common and valid worry. Your child, like all other children, will pick up some coughs, colds and childhood illnesses. However, the risk can be minimised by asking staff to put in place simple but effective infection control measures. These should include:

- making sure children wash their hands regularly
- showing children how to wash their hands properly
- having a supply of tissues (and asking children to cough or sneeze into them)
- using hand sanitiser
- opening windows and asking staff to keep children with coughs and colds away from your child (when this is possible).

Even with these measures in place it is still likely that your child will, at some point, pick up a cold or other illness. You are probably used to balancing quality of life with managing infection risk. Over time, most parents find a way to balance this risk at nursery too.

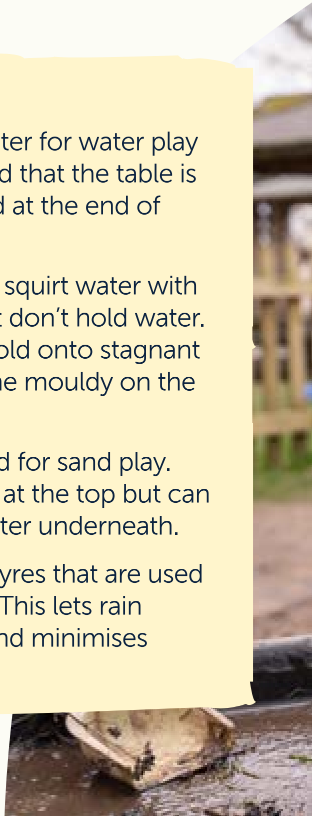
Outdoor and messy play

Parents are often more concerned about their child picking up an infection from activities or play areas in the nursery than they are about coughs or colds. Nurseries might have play areas and materials that can contain bacteria and fungi which can be harmful to children who have CF. For example, mud or stagnant water.

Some small, easy changes can help reduce the risk.

Staff can:

- Make sure the water for water play is always fresh and that the table is cleaned and dried at the end of each day.
- Replace toys that squirt water with different toys that don't hold water. These toys can hold onto stagnant water and become mouldy on the inside.
- Use fresh dry sand for sand play. Sand can feel dry at the top but can have stagnant water underneath.
- Drill holes in old tyres that are used for outdoor play. This lets rain water drain out and minimises the infection risk.



If you, or your CF team, feel uncomfortable or concerned about your child taking part in an activity, nursery staff can find a different way for your child to take part.

For example, if children are planting bulbs and you don't want your child digging in the soil, they could take photographs, count the bulbs or draw pictures of how the flowers will look.

Parents have told us that deciding what was safe for their child was a very personal process, that changed over time. What you decide is safe for them will also depend on your child. For example, if your child has been well with CF, what you feel is safe for them will be very different from someone whose child has been poorly.

Children's personalities will make a difference as well. Which activities are safe for a three-year-old who is likely to get into a mud fight, might be very different to a four-year-old who is very calm and enjoys planting seeds.

It is important to remember that life can be risky – we all have to decide how much risk we are willing to live with and balance this with the things we want to do.

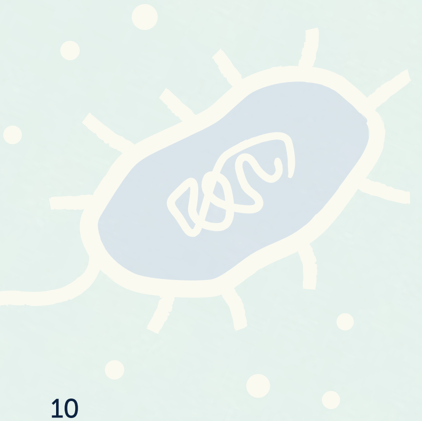
Unfortunately, there is no list of the exact risks for each activity. Whether a child could get a *Pseudomonas* infection from playing in mud would depend on many different things that had happened that day. So, we would suggest it is best to be cautious and avoid activities which involve spending a lot of time in contact with:

- mud
- stagnant water
- or rotting leaves.

However, it is almost impossible to stop a child having any contact with these things. It's about reducing risk rather than getting rid of all risks. For example, you can't stop a child jumping in puddles (if it's fresh rain puddles, it's unlikely to do them any harm). However, jumping in a puddle of stagnant muddy water in a muddy field would be greater cause for concern.

Remember…

You can't protect children from everything, but you can work with your CF team and the nursery to minimise the risk.



"By the time my daughter attended nursery, she was very used to washing her hands and not putting them in her mouth when playing outside. The nursery staff were aware of the risks of her playing outside, so we developed a plan to allow her to join her friends while keeping her safe. There was also no way she would have stayed in the classroom while her friends played outside!"

Julia, mum to Olivia, aged 4

"Forest time was a big event in reception but I just couldn't get comfortable with allowing Kate to dig in the mud. So her class teacher gave her the role of noting down the observations of the other children. This meant she could be involved but with minimal risk which kept everyone, including Kate, happy."

Catherine, mum to Kate, aged 11

Cross-infection

Children with CF cannot meet other people with CF. This is because people with CF can have infections in their lungs which can be harmful to other people with CF. It's important to think about whether a nursery will have children or staff members who have CF.

Rarely will nurseries have more than one child with CF. A detailed risk assessment and plan would need to be in place to make sure the risk of cross-infection is minimised in these situations.

Usually when a nursery has two children with CF it's because they are brothers or sisters. When this happens, they will have a different way of dealing with cross-infection because they already share spaces at home.

Creon

Most children with CF take Creon on a daily basis and are usually very used to taking it. However, nursery staff can feel unsure about giving Creon at first. It's new to them and they may worry about getting it wrong. With advice from you and your CF team, they can quickly become confident giving Creon.

Changing appetites – giving Creon at nursery

Young children often change their minds about what they want to eat and when they want to eat, from day to day. Staff may give a dose of Creon and then the child may decide they don't want to eat what is on offer.

If you think this is likely to happen with your child, it's useful to give the staff some advice on what to do. For example, the first Creon dose could be given halfway through the meal to cover what has been eaten. They can then give a second dose towards the end of the meal if they keep eating. Or they can ask the child to try the food before giving them their first dose of Creon. You know what works best for your child. Just make sure the staff know what you would like them to do in different situations.

"Our nursery sends us the menus in advance so we can calculate the Creon dosage. When they are unsure they phone to confirm, but they have also become more confident to make the calculations themselves. This is based on experience and conversations we've had with them so we're happy for them to have this freedom."

Julia, mum to Olivia, aged 4

"Kate has always been notoriously slow and inconsistent in terms of eating, so we have always split Creon doses for meals and snacks to make sure she is getting the correct dose."

Catherine, mum to Kate, age 11

Registered childminders

Many families choose to use childminders to provide their childcare. Registered childminders will look after your child in their own home.

All of the information about how to choose a nursery, and how to prepare them for looking after a child with CF, also applies to childminders. It's important to have an in-depth talk with the childminder about what CF is and what it means for your child.

It might be helpful to write a healthcare plan, which will describe your child's needs in detail. Your CF team can help you with this. Your childminder might find our factsheets for schools helpful. They explain the basics about what CF is and how it can affect children. However, it is still very important to tell them exactly what your child needs.

The factsheets for schools and a template for a healthcare plan are available on our website at: **cysticfibrosis.org.uk/school**

As well as talking about your child's CF care, you can also get an idea of what life would be like for your child at the childminders by finding out:

- How many other children do they care for and how old are they?
- Will there be children around the same age to play with?
- Are there any other children or staff that have CF?
- What activities are available?
- Will your child get plenty of chances to run and be active?
- Which schools do they drop off and pick up from? (This could be important if you still need a childminder when your child starts school).

Primary school

Looking for a school

Ideally, your child's school will be close to your home. It's very good for your child's health to walk, scoot or cycle to school. Attending the local school also means you live closer to other families at the school, making life easier for playdates, parties and school events.

Visiting the school and speaking with the headteacher or special educational needs coordinator (SENCO) will help you decide on the best school for your child.

It's helpful to read inspection reports, but they don't usually give you the detail you need to make a decision. It's also important to visit the school to see how they look after children with medical needs. It's also a chance to get a 'gut feel' for whether the school will be right for your child.

It's a good idea to note down any questions or concerns you have before meeting with the school staff. Some questions to think about are:

- Do they seem interested in finding out about CF and open to making the changes your child would need?
- Do they listen to what you have told them about CF and come back with questions when they don't understand?
- What does the school timetable look like? How often does the school do PE or outdoor activities (for example, forest school)?

- Are there any other children with CF at this school?
- My child has to take enzyme supplements with snacks and meals, what's your policy on storing and giving prescription medicines?
- My child is taking medication that makes their skin more prone to sun damage. Would you reapply sun-cream with my permission?
- If my child needs to do physiotherapy exercises, would you be able to give them time out of lessons or break times to do this? Is there a space where they could do their physio?
- How flexible is your absence and lateness policy? CF means that my child has to go to clinics every 8–12 weeks and may also have to stay in hospital sometimes. Morning treatments can sometimes take longer and we might occasionally be late, what would the school do in these situations? Would we be penalised?
- Do you have an individual healthcare plan (IHP) template I can fill in?

Applying for a school

Getting a school place

Applying for primary school can be stressful, particularly in areas where there is a lot of demand for school places. It's a good idea to tell the school when you're applying that your child has CF so there is time for the school to make any changes.

Medical need and school places

In some parts of the UK, having a medical need can mean your child is given a higher priority for a place at your chosen school. But the rules are different in different areas. You can check the rules your local council uses to decide who gets a place. It can help to tell them why your child needs to go to a particular school. For example, you have more to do in the mornings and need to be near to the school.

Support for children with medical conditions

There is government guidance and policy in place to support children with medical conditions when they are at school. There are different policies depending on whether you live in England, Wales, Scotland or Northern Ireland. If you live in England or Wales, you can find out more about the policies at: **healthconditionsinschools.org.uk**

If you live in Scotland or Northern Ireland, we have included website links in our 'further information' section.

For more information about admissions, or how children with CF can be supported in school, please contact our Helpline. See our 'Support' section for contact details.

Individual healthcare plans

Individual healthcare plans (IHPs) help school staff to understand what care a child will need and how their condition might impact their learning or behaviour in school.

An IHP should explain:

- the condition
- the treatment (including who will give it and how to give it, and where and when treatments will happen)
- how it might affect the child at school.

It should be written by the school with input from you and your CF team.

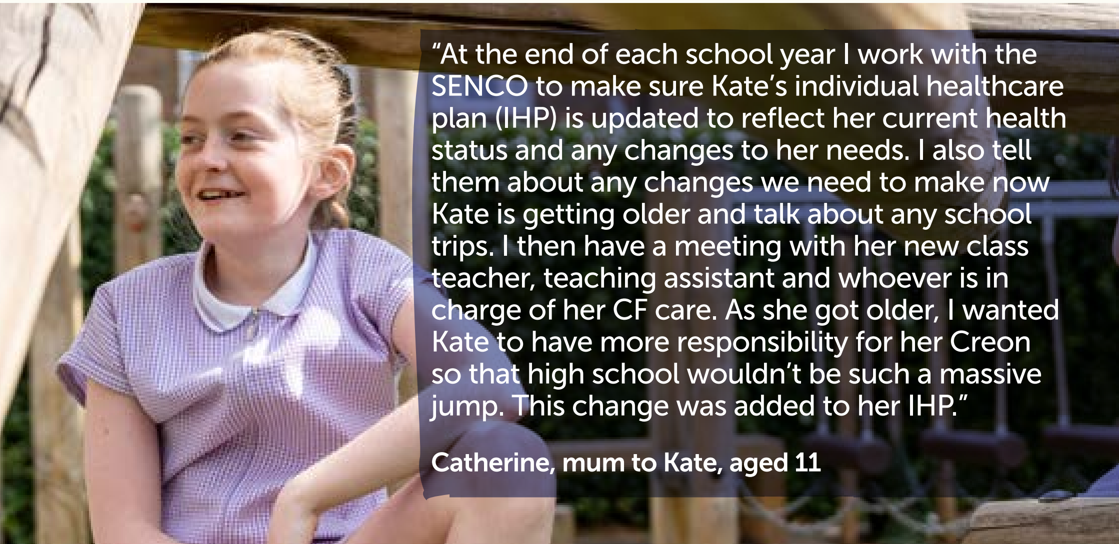
Even if your school doesn't ask for an individual healthcare plan it's a good to have one. Some parents write their own plans or 'All about me' sheets for younger children.

These should include:

- information about CF and how it affects your child
- treatment details
- dietary needs
- contact details for health professionals who work with your child
- information about confidentiality. You need to tell the school who you want to be told about your child's CF. This could be staff, the children in their class, or on a need-to-know basis.

Many schools have their own individual healthcare plan templates. If your school doesn't have one you can download one from our website: **cysticfibrosis.org.uk/school**

Children with CF will often need to have access to the toilet whenever they need it. Make it clear in the healthcare plan that your child may need to leave lessons to go to the toilet. You can also download a toilet pass from our website. The child can show this to the teacher if they need to leave a lesson to go to the toilet.



"At the end of each school year I work with the SENCO to make sure Kate's individual healthcare plan (IHP) is updated to reflect her current health status and any changes to her needs. I also tell them about any changes we need to make now Kate is getting older and talk about any school trips. I then have a meeting with her new class teacher, teaching assistant and whoever is in charge of her CF care. As she got older, I wanted Kate to have more responsibility for her Creon so that high school wouldn't be such a massive jump. This change was added to her IHP."

Catherine, mum to Kate, aged 11

Starting primary school

The first day at school is a big and exciting step for any child. For some parents, this will be the first time their child has been away from them for the whole day. It may be the first time that someone else is looking after their child and it's understandable if some parents feel concerned about their child starting school.

For some children, schools may think about whether they can provide additional support to your child when they start school. This could be the case if your child has a heavier treatment burden than some other children with CF.

If your child has been to nursery, starting primary school might feel a bit easier. Much of the advice about starting nursery also applies to starting school. However, there are some things that will be different and the following sections will cover these.

Communication

Parents and teachers have told us that communication is key to making sure that children with CF are properly cared for at school. All the relevant staff should know about your child's needs after their meeting with the CF team or reading the individual healthcare plan (IHP).

As well as teachers, think about who else might help look after your child, for example, teaching assistants and office staff. Make sure they also see the information about your child's needs.

> **"Every time he has a new teacher, I have a meeting with them. Ideally before he starts school. I meet with the teaching assistant as well because it's not always the teacher who deals with everything. I also meet with the lady in the office (who's first aid trained) because she's giving the medicine. I think the more people that know the better. However, you need to get the right balance because you also don't want too many cooks."**
>
> **Tracey, mum to Freddie, aged 10**

It's important to remember that teachers have a lot of different things to manage. They often have 30 children in their class, some with additional or medical needs. So regular communication and reminders are really helpful. It is also important to tell the school if there are any changes in your child's health, treatment or behaviour and be clear with the school about who they can share this information with. If your child doesn't want other children to know about their CF, it's good to tell the school this.

The school should tell you about:

- any changes in your child's symptoms
- missed Creon doses
- anything else that could be relevant to their CF.

It's helpful to tell the school how you want to get this information. Many parents find that a communication book works well. However, you might find a chat at the door or email works better for you. The most important thing is that you and the school can talk openly about problems and find solutions together.

Infection risk

Infection risks are mostly the same as those in nurseries (see 'worries about infection risk' and 'outdoor and messy play'). However, in primary school, children will be more aware and might be more likely to try to avoid infection risks. As they get older they will get better at managing these risks.

Children at primary school will also try new activities and sports. This could be things like tennis, football and dancing which should present no significant infection risk at all. Some primary schools have more than one pupil with CF, or a staff member with CF. If this happens, the school needs to speak to the local CF team to find out if they can manage this safely.

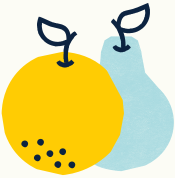
"Risk management is a very personal thing. We believe our daughter knows the fundamentals of avoiding germs (handwashing etc), to allow her to do most outside activities. We also knew she would want to do what her friends did, so it was up to us to find ways of allowing her to do that while keeping her safe. Good communication with the teachers is key, as they often suggested ways of achieving this."

Julia, mum to Olivia, aged 4

"It was incredibly important to us that Kate be given the same opportunities and experiences as everyone else. Our school was brilliant in ensuring that subtle changes ensured Kate could be involved so she never felt hard done by."

Catherine, mum to Kate, aged 11

Diet and Creon



You will probably be able to choose to have school meals or a homemade packed lunch.

Most schools will be able to give you the school's menu (often they are online). Your CF dietitian will be able to help you work out the Creon doses for the menus.

> **"My stipulation is please don't let Freddie miss out on anything. Just ask. For example, if there's party food or a food tasting, the school photograph the packet and send it to me and I let them know the Creon dose."**
>
> **Tracey, mum to Freddie, aged 10**

Schools all have their own systems of giving and storing Creon. Some are happy for a daily dose of Creon to be kept in the child's lunchbox (it is then stored separately to the other lunch boxes). Other schools will have a large pot of Creon which is kept in a secure cupboard, they can then give your child a daily dose (following the child's individual healthcare plan). If your child takes their own Creon without your help, you could talk to the school about them looking after their own Creon.

Getting the Creon dose right can take a bit of practice, especially when a child first starts school. Some children may not like the school meals or don't finish their packed lunch because they want to go out and play. Keep talking to the school about how much your child is eating until you feel you are getting the Creon dose right.

Your child may be asked about Creon by other children. You can help your child to work out a simple reply. For example: "It helps my tummy" or "it's medicine to make my tummy work better". Some older children may feel embarrassed (or self-conscious) about taking Creon. If your child is embarrassed about taking their Creon in front of other children you can ask the school to be discrete and find a place where they can take it in private.

Many parents don't want their child to feel that CF is something to be ashamed of and so they don't hide the treatment. But you know your child best and what will work for them.

Time off school and coming in late

A concern for some parents is that their child will be penalised for absence. Most schools have absence policies and rewards for children who have 100% attendance. For children with CF it can seem that they will never be rewarded for their attendance. It is worth talking to your SENCO or head teacher about this. Schools should be able to reward attendance in a way that doesn't disadvantage your child if they need to take time off because of their CF.

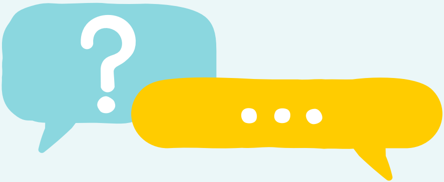
There may be times when you want to keep your child off school because you are worried about them picking up an infection from

other children. You can talk to the school and explain why you are doing this. They will most likely agree to it if it is in your child's best interests. You can also ask for work that they can do at home. If you need to do this more regularly, talk to your CF team and they can help you come up with a plan for dealing with these situations.

It is good to let schools know if you are doing physio or taking medicines before school. If they know mornings may be busier for you than other parents, they can be more understanding if you are sometimes late.

Hospital treatment

If children are admitted to hospital they are often well enough to go to hospital school or have work sent in from their teacher. Ask your school and CF team about what would work best for your child. Sometimes children can go to school with an IV line in. The school should be told in advance and be contacted by the CF team to explain any special measures which might need to be taken.



Questions from other children

At some point, other children will start asking about your child's CF. They might have seen them taking Creon or 'huffing'. It's really important to make sure you've spoken to the teacher and have written in their individual healthcare plan what you want the teacher to say in response to children's questions. Most often when given simple and honest answers young children will accept the answer and lose interest.

"I have genuinely been surprised by how accepting children are to Olivia's CF, and noticing her medical routine. Some ask questions, some watch, but all are pleasant and polite. I guess children are exposed to these situations more than I was when I was their age."

Julia, mum to Olivia, aged 4

"When Kate started school I let parents know via the WhatsApp group that Kate had CF. I said that if they or their children had any questions, they should ask me or Kate directly. Kate was always very open, and actually as the children grew up together some of the kids would spot potential risks ahead of the teachers."

Catherine, mum to Kate, aged 11

Sports, music, hobbies and trips

School isn't just about learning, it's also a time to try new sports, make new friends, get involved in music, hobbies, friendships and trips away. Children with CF can (and should) be included in all of these experiences. Being active and doing sports is great for your child's lungs. Encourage them to take part in PE, sports and dance, they are all good ways to improve their health. Your CF physiotherapist can help you find activities that will suit your child and support you to get them involved.

It doesn't have to be activities like football, hockey or athletics. Singing can also help exercise the lungs. These activities also allow your child to meet children with similar interests and can be the start of new friendships.

Your child may also have the chance to go on school trips. Talk to the school if you are concerned about infection risks. If it is a longer trip you will need to provide any medicines or treatments that will be needed.

Going on overnight trips is a normal part of growing up and there is no reason why your child can't join in. Talk to the adults in charge about your child's needs. You might find it reassuring to explain that you can be contacted at any time during the trip. Your CF team can give you advice about school trips and work with the school to help prepare them for the trip.

"Kate's school went on a two-night residential in Year 3. Initially we were going to go with them. However, after meeting with staff and speaking to her CF team we agreed that because it was a short trip she could reduce her treatments while she was away. We also had a WhatsApp group with key staff so they could ask questions and check Creon doses. We spoke to Kate each evening to make sure she was okay. Kate had an amazing time and has been on many residentials since."

Catherine, mum to Kate, aged 11

Feeling different

At primary school, children with CF might start to feel they are 'different' to other children. By showing them that other children have differences too, you and the school can help your child adjust to this realisation. You could explain that some children:

- have conditions that can affect their daily routines (for example asthma or diabetes)
- need help walking or have to wear glasses to help their eyes
- have physical differences, for example, hair colour
- have different interests. For example, some children enjoy football and some children like drawing.

Your child's understanding of what CF is and how they feel about it will change with age, and over time. As they get older and have different experiences they will start to think about how having CF fits with the rest of their identity.

"Once they start school, you're already used to managing environmental risks, it becomes more about managing the emotional aspects. You start thinking about their classmates: what questions are they going to ask? Jasper has a big scar, so how can we help him explain that? It's about helping him feel comfortable with his CF and confident as he grows."

Laura, mum to Jasper, aged 2

Some children may feel a sense of unfairness when they start to notice that they have to do things every day (like treatments) that other children do not. They may ask questions and get upset, angry or frustrated. It can help to listen and show you understand their feelings. Your CF team can help with any problems your child is having. Your CF team can also work with the school and your child to help them feel more confident about dealing with the emotional impact of having CF. They will think about what will work for your child and give you advice that is right for their age (and developmental stage). Ask for support from your CF team if your child struggles with these difficult feelings.

"She would probably react quite robustly if there was something her CF was stopping her from doing. So it's worth talking to the teacher. You can prepare them about how your child could react when they are coming to terms with some of the limits they may encounter because they have CF."

James, dad to Olivia, age 4

Doing their own treatment (self-management)

All children achieve milestones at different ages and it's the same for children with CF. Try to involve your child in their CF care as much as you can and make this part of their everyday life. Children will learn to do their treatments without help at their own pace. You will know what your child is ready to do on their own. You can let the school know how they can help your child to do their own treatments when they are ready to take this step.

Dealing with problems

Good communication between you, the school and your CF team should mean your child will be able to enjoy the full school experience. However, if you are having difficulties and feel that the school is not properly supporting you or your child, it can help to talk to your child's teacher or headteacher early on.

If you feel that your child's school has not done enough to sort out these problems, you can ask your CF team or the Cystic Fibrosis Trust's Helpline for more help and support.

You can find out more about the law and policy that has been created to make sure your child has the same access to education and other experiences at school in the 'Education policy across the UK' section.

Top tips from parents

1. Don't be afraid to persevere if you feel you aren't being heard.
2. Most importantly, build good communication with staff at your child's school.
3. Don't forget that your CF team is there to help you. Speak to them if you have any concerns about your child's health at school.
4. Do go to the school if you have concerns. Remember that you are doing the best you can to meet your child's needs.

Support

This information looks at some of the issues that may come up as your child starts nursery or school but we understand you may need more detailed or tailored advice. Your CF team or Cystic Fibrosis Trust's Helpline will be able to provide this.

Our Helpline is open 10am–4pm Monday to Friday. It's available to anyone looking for information or support with any part of cystic fibrosis, a listening ear, or just to talk things through.

How to reach us:

- call **0300 373 1000** or **020 3795 2184**
- email **helpline@cysticfibrosis.org.uk**
- chat with us on Facebook, Twitter or Instagram
- message us via WhatsApp on **07361 582053**

Our resources are free to download and order, but we would be grateful if you would consider making a donation to help us continue our important work. Visit **cysticfibrosis.org.uk/donate**

Education policy across the UK

Education legislation and policies can be slightly different in England, Northern Ireland, Scotland and Wales (because it is a devolved matter).

There isn't a single piece of legislation or policy in the UK that covers everything about education and support for children with medical needs. However, all schools should have a medical policy to help support children with medical needs. In England, it's a legal requirement for schools to have this policy.

The Equality Act 2010 (which covers England, Scotland, and Wales) protects children with disabilities. It requires schools to make changes (reasonable adjustments) so they can take part in school (as far as possible) in the same way as children who don't have disabilities. In Northern Ireland, the Disability Discrimination Act protects children with disabilities in a similar way. There are also many other pieces of legislation that protect children with medical needs at school. For more information, you can visit: **healthconditionsinschools.org.uk**

Further information about primary schools and nurseries

England

Independent parental special education advice (IPSEA):

ipsea.org.uk

Legal information and advice on education law in England:

childlawadvice.org.uk

Professional Association of Childcare and Early Years (PACEY):

pacey.org.uk

School inspection reports:
www.gov.uk/government/organisations/ofsted

Northern Ireland

Equality Commission for Northern Ireland:

equalityni.org

Northern Ireland Childminding Association:

nicma.org

School inspection reports:

etini.gov.uk/publications/type/inspectionreports

Scotland

Information on additional support for learning:

enquire.org.uk

Law information and advice:

govanlawcentre.org/education-law-unit

School inspection reports:

education.gov.scot/inspection-and-review

Scottish Childminding Association:

childminding.org

Wales

Professional Association of Childcare and Early Years (PACEY):

pacey.org.uk

School inspection reports:

estyn.gov.wales/latest-inspection-reports/

Information and advice for children with medical conditions or disabilities:

www.snapcymru.org

Find us online

cysticfibrosis.org.uk

facebook.com/cftrust

youtube.com/cftrust

instagram.com/cftrustuk

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.

We welcome your feedback on our resources.

You can also ask for this resource in large print or as a text file. Email **infoteam@cysticfibrosis.org.uk**

cysticfibrosis.org.uk

Review due: May 2029

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: 33 Creechurch Lane, London EC3A 5EB

Uniting for a life *unlimited*