

Cystic Fibrosis here for families

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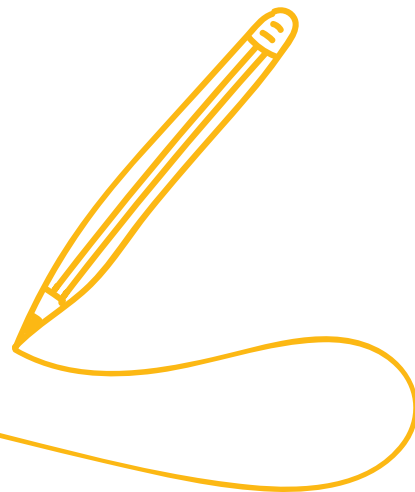
School and cystic fibrosis:
a guide for parents from
pre-school to primary

Fighting for a Life Unlimited

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Georgia age four

Introduction

Cystic fibrosis (CF) shouldn't stop your child enjoying a full and rewarding school experience. Compromises may need to be found, and minor adjustments made, but working in partnership with the school and your CF team will help ensure your child's education is not limited by cystic fibrosis.

Parents, teaching staff and CF professionals have shared their experiences and expertise in the hope that they will be helpful to you and your family as you get ready for the school years. As one dad pointed out: "everyone is on their own journey". Having CF doesn't mean that your child's experience of life, including school, will be the same as that of any other child with the condition, but the stories in this pack highlight that there are often common issues.

This booklet is designed to outline some of the concerns or challenges that may come up when your child starts pre-school or primary school, including infection control, diet management and your relationship with the school. It cannot cover every eventuality, so we urge you to work with your CF team and school to build a strong team with the common goal of ensuring that your child the best possible school experience.

If you need more information after reading this booklet, please contact our helpline on **0300 373 1000** or at helpline@cysticfibrosis.org.uk or speak to your CF team.

"CF shouldn't hold her back and shouldn't define her as a person."

Sarah, mum to Grace



Education policy across the UK

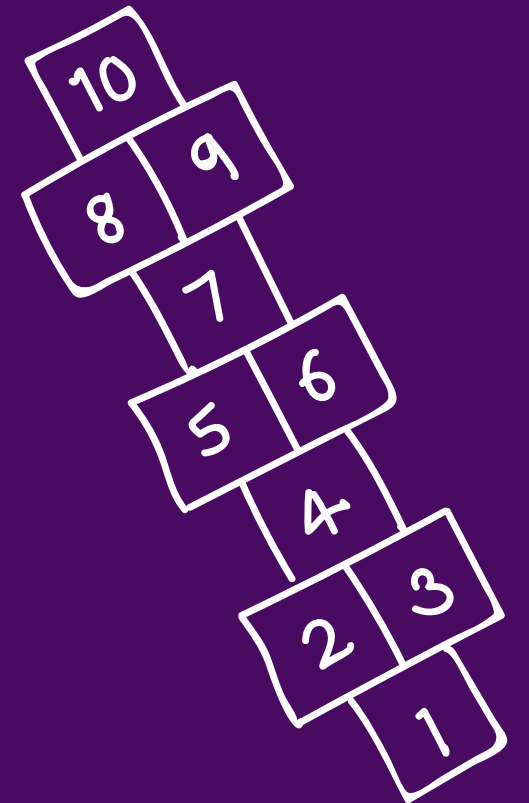
Policy and legislation (law) is in place to ensure that your child has the same access to education and school experience as their peers. Parents, schools and CF teams often communicate and work together very well, so there is usually no need for any reference to policy or the law. However, if you are experiencing difficulties, understanding your rights is important.

Education is a devolved matter, meaning that legislation and policies vary between England, Northern Ireland, Scotland and Wales. There is no one policy or piece of legislation that covers all aspects of education and support for children with medical needs for the UK.

There is a range of legislation that provides for children with conditions like cystic fibrosis. However, it's not practical to describe this in detail here. Please refer to the 'further information' section at the back of the booklet where you will find a brief overview of some legislation, as well as links to useful websites.



Pre-school and nursery



"Georgia is a happy and popular member of my class who continues to learn, grow and develop amongst her friends and peers".

Karen Piper,
Georgia's teacher

Georgia age four

Pre-school and nursery

Children may attend pre-school or nursery for a variety of reasons: education, socialisation, childcare or just for parents to get a few hours break in the week! Starting pre-school can be very exciting for young children; an opportunity to make new friends, take part in new activities and enjoy a new stage of independence from parents or carers. Some children take it in their stride; others might need a little more coaxing! It can be an emotional transition for all parents, but for those of children with CF it can be quite an anxious time too. Mums and dads told us about some of their initial worries: who will give him his Creon, who will make sure she drinks enough, what if they play outdoors in the mud, will she pick up lots of bugs, and can anyone do his treatment as well as me? Pre-school age children are generally less likely to be aware of or understand risks than older children, and this can be a source of concern for parents too.



Many parents find that these worries can be dealt with through meeting with the pre-school staff together with the CF team. These meetings are a useful opportunity for the staff to learn about CF and what it means for your child. It also gives you the chance to raise any concerns and work together to find satisfactory solutions before your child even starts at the pre-school.

"Arthur's parents and CF nurse met with us and went through everything about Arthur's CF at home and nursery. I didn't know anything about CF before meeting Arthur so this meeting was kind of like 'an idiots guide to CF'! The meeting was really informal and the CF nurse explained everything really well. All of the teaching staff found this meeting and the support of the CF nurse and Arthur's parents, really helpful. I think this face to face meeting is essential."

Claire Cusack, pre-school teacher

"I met with the manager of the pre-school and Joshua's key worker to draw up an action plan for Joshua's care. Someone from the CF team would have attended but I felt confident in telling them about CF and how it affects Joshua. The pre-school have been fantastic."

Elena, mum to Joshua

¹For ease of reference, pre-school is used throughout this booklet to refer to pre-school or nursery.

It is not always plain sailing and sometimes parents worry that the pre-school doesn't fully understand CF and what it means for their child. If this sounds like you, contact your CF team and ask them to run an additional session with the staff.

"The nursery were very anxious about Ashley's CF and people there seemed to be confusing CF with spina bifida. They were concerned about his extra needs and I felt that they just weren't understanding that he didn't have special education needs or learning difficulties."

Kristel, mum to Ashley

"Isabella didn't have lunch at nursery because she only went for short sessions during the week, so that made her Creon management quite easy."

Elaine, mum to Isabella



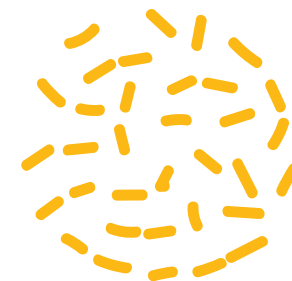
Working parents may have to choose pre-school session times to meet their childcare needs; for example, you may need a full day session to enable you to work. However, where there is no childcare requirement, the flexibility of pre-school timings can help parents manage their child's treatment more easily. For example, a morning session may not include lunch, so worries about diet are limited to the mid-morning snack. There is also not the same pressure to be on time or to achieve a certain level of attendance as in primary school.

It's also worth bearing in mind that there is a higher staff-to-child ratio at pre-schools than at primary schools, so there will be more staff available to keep an eye on your little one.

"I decided to put Saira-Jane in pre-school the term before she was due to go to school. This was mainly for socialisation and she just went for two hours in the morning. This meant that I could still do her treatment at home except for the Creon she needed for her snack."

Fiona, mum to Saira-Jane

Worries about infection risk

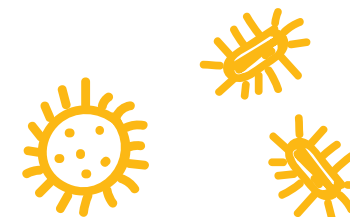


Coughs and colds

Avoiding infection is a very common and valid worry. Childhood illnesses and the usual coughs and sneezes are inevitable in pre-schools. Your child, like all other children attending pre-school, is likely to pick up some of the usual bugs and illnesses that go around. The risk can be minimised with simple but effective infection-control measures such as encouraging good hand hygiene, having a supply of tissues (and encouraging children to cough or sneeze into them), using hand sanitising gels, opening windows

and asking staff to keep children with coughs and colds apart, where possible, from your child.

However, even with these measures in place, it is still likely that your child will at some point pick up a cold or other illness. The balance between quality of life and managing infection risk is one that people with CF deal with on a daily basis.



Environmental risk

The infection risk posed by the environment is often of more concern to parents. There are certain environments, such as mud, stagnant water, rotting vegetation and hay that harbour bacteria and fungi that can be harmful to children with cystic fibrosis. This has implications for some pre-school activities, including playing outdoors in the mud, water play, sand pits and playing in fallen leaves. Some minor practical adjustments can help reduce the risk; for example, if water play is being offered, staff should

ensure that the water used is always fresh and that the table is cleaned and dried at the end of each day. Toys that are used to squirt water can hold onto stagnant water and can become mouldy on the inside; your CF team may advise caution with such toys. Sand can feel dry at the top but can hold stagnant water underneath and so fresh, dry sand is recommended for sand play. Sometimes, old tyres are used for outside play – drilling holes in these to allow rain water to drain freely can minimise the infection risk.

If you or your CF team feel uncomfortable with your child taking part in specific activities, the staff at the pre-school could encourage your child to be involved in a different way. For example, if children are planting bulbs and you don't want your child digging in the soil, your child might be tasked with taking photographs, counting the bulbs or drawing pictures of what they will look like when they flower.

"We have found that risk assessment is personal and is likely to vary between families; you have to find your own way and live your lives. We have a different perception of risk even between us. I was a firefighter so I think that's given me a different perception of life and risk to my wife, Cat. Because risk assessment isn't set in stone, it's really important to have good communication with the school."

David and Cat, parents to Arthur

Parents have told us that assessing the risk is a very personal process and is also dynamic, so it can change over time. Risk assessment will also depend on your child; perhaps if your child has been well with CF, your risk assessment would be quite different to someone whose child has been poorly. Children's personalities will come into risk assessment too; a mum to a 3 year old who is liable to get into a mud fight might have a different risk assessment to dad of a 4 year old who is very calm and enjoys planting seeds. It's important to remember that life can be risky – we all have to weigh up risk against quality of life.

"Aimee started at nursery when she was 3. I didn't want her to miss out on all the things other children do. I was worried though because you hear about all the bugs and illnesses that children pass around at nursery. However, Aimee rarely got a cold and has never been very symptomatic with her CF. The community nurse did suggest that Aimee shouldn't play in the sand or in the mud but I disagreed and said she could as long as the nursery were very careful about handwashing."

Allison, mum to Aimee

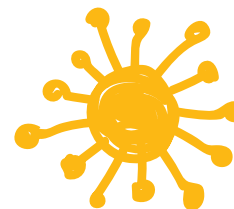
"At our nursery, we were most concerned about Arthur playing with water. His mum and dad were keen for him to be involved in all activities so we make sure that the water is always fresh. We also make sure that he's got on appropriate clothing and that there's lots of handwashing. I think a lot of it is common sense and communication."

Claire Cusack, pre-school teacher

Unfortunately there is no list of what the exact risks for each activity are. How likely it is that a child could get *Pseudomonas* from playing in mud would depend on multiple factors on that day. So we would suggest it's best to err on the side of caution and avoid activities which involve extensive contact with mud, stagnant water or rotting leaves, for example, but balance this with some perspective. You can't stop a child jumping in puddles and if it's fresh rain puddles it's unlikely to do them any harm – by contrast, a child in a muddy field jumping a puddle

Cross infection

As you will know, children with CF cannot meet other children with CF. This is because people with CF can have infections in their lungs which are harmful to other people with the condition. It's an important consideration when looking for a pre-school. Occasionally, there will be pre-schools or schools that have more than one child with CF, most usually when they are siblings. However, a thorough risk assessment and plan would need to be in place to ensure that the risk of cross-infection is minimised. In the case of siblings with CF, a different approach to cross-infection will be taken, given that they inevitably share space together at home.

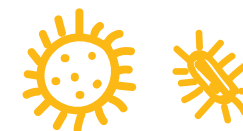


of stagnant, muddy water would obviously be more concerning.

You can't protect children from all risk but you can work with your CF team and the pre-school to minimise the risk.

"And as for the forest school, well Rhys has his wellies and his waterproofs. He may not be able to get covered in mud or roll about in the wet sand but he still gets involved and if they are doing activities where the teachers think it would be too much then Rhys gets a different role, he never misses out and that's the way I always want it to be."

Sarah, mum to Rhys



"Both Georgia and Leo were at pre-school at the same time but they are siblings, they can't be apart at home and so they weren't separated at pre-school either! The pre-school followed the infection control rules we have at home so not sharing drinking cups for example."

Lisa, mum to Georgia and Leo

Creon and diet

Children with CF are usually very comfortable taking Creon, but pre-school staff can feel quite anxious initially about it as it's new to them and they are worried about getting it wrong. With guidance, they often settle into a routine very easily.

Occasionally, young children may not behave according to your plan! Staff may find that the dose of Creon has been given but that the child has decided that they no longer fancy what is on offer. If you think this is likely to happen with your child, it's useful to offer the staff some advice on what to do. For example, the first Creon dose could be given midway through the meal to cover what has been eaten and a second dose towards the end if your child continues to eat. Or perhaps ask your child to try the food prior to getting their Creon. You will know what would work best for your child, just make sure the staff are aware of what you would like them to do in that situation.



"Sammy's dietitian always says getting the Creon right is an art, not a science. Telling the pre-school staff that even my husband and I sometimes make mistakes with giving the right dose helped to ease their anxiety. The pre-school staff always report back on what Sammy has eaten and will also let us know if there have been any unusual nappies so we can alter the Creon dose if necessary.

Juliette, mum to Sammy

"I was a bit concerned about the Creon but it's all been fine. I think it's been really important for me and the rest of the staff that we understand why Arthur needs to take Creon and why he can't be around stagnant water or other children with cystic fibrosis."

Claire Cusack, pre-school teacher

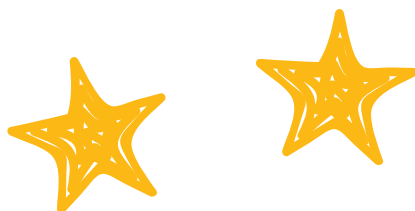


Rhys age four

Top tips

- Research the pre-schools in your area by looking at their websites and inspection reports. It's a good idea to visit, once with your child so you can see how they are treated, and once without so you can have the conversations you want to have without distraction. Many pre-schools will allow you to pop in without an appointment; do check first though.
- Ask about their provision for children with medical needs. Have they looked after a child with CF before?
- Ask your CF team if they can visit the pre-school to talk to the staff about CF, your child's needs and answer any questions the staff may have.

- Ask for the menus for lunch and snacks. Your CF dietitian will be able to help you work out the Creon doses.
- When you do find a suitable pre-school, work at building up a good relationship. Communication is key.
- Talk to your CF team about any concerns you have.



"When I was looking for a pre-school for Luis I really wanted to understand how they would deal with children with additional need so I looked at their websites and Ofsted reports. I felt the first pre-school I checked out just wasn't taking CF seriously. The second one I contacted had an excellent Ofsted and worked with children with multiple health needs. I called them and the pre-school teacher spoke to me for an hour! When I visited the next day the manager had downloaded information about CF and taken notes on how the pre-school could adapt to meet Luis's needs. I felt confidence in them immediately."

Christina, mum to Luis



Georgia age four



Rhys age four

Registered childminders

Many families choose to use childminders to provide their childcare. Registered childminders will look after your child in their own home and are regulated and inspected by Ofsted in England, Care Inspectorate in Scotland, Health and Social Care Trusts in Northern Ireland and the Care and Social Services Inspectorate in Wales.

It's important to have a detailed discussion at the outset about what CF is and what it means for your child. It might be helpful to draw up a healthcare plan, which will describe your child's needs in detail. Your CF team may be able to help you with this. Your childminder might find our factsheets for schools helpful for providing an overview of what CF is and how it can affect children. However, it is still very important to talk about your child's specific requirements. The factsheets or schools and a template for a healthcare plan are available on our website at www.cysticfibrosis.org.uk/school

As well as discussions around the care of your child's CF needs, other questions to consider might include: how many other children do you care for and how old are they (will your child have suitably aged children to play with), what activities do you do with the children (will your child get plenty of opportunity for physical activity), what pre-schools/schools do you drop off/pick up at (this could be important if you still need a childminder when your child starts school)? Details of professional childcare associations are listed at the back of this booklet.

Primary school

"Before Georgia joined my class it was important to meet with Georgia's mum and her CF nurse to gather information about Georgia's individual CF needs to ensure we all knew how to keep her well and safe in school and to limit any risks to her health. It is great to know that we can call parents or the CF nurse if we have any concerns".

Karen Piper, Georgia's teacher





Ashley age ten and dad, Gary

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 generally means you live closer to other families at the school, making life easier for playdates, parties and other school community events.

Visiting the school and speaking with the head teacher or special educational needs coordinator (SENCO) will help you to choose the best school for your child. Inspection reports alone will probably not address the detail or the give you the 'gut feel' you need to understand how a school manages children with medical needs.

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

- Does your school have experience of children with medical needs and specifically cystic fibrosis?
- Are there any other children at this school with cystic fibrosis?



- My child has to take enzyme supplements with snacks and meals, what's your policy on storing and administering such supplements?
- Can my child have a packed lunch?
- My child needs a high-fat snack between meals, how will this work with your healthy eating policy?
- My child is on medication that makes them more susceptible to UV rays, would you reapply sun-cream with my permission?
- If my child needs to do physiotherapy exercises, would you be able to accommodate that? Is there a space where physio could be done?
- How flexible is your absence and lateness policy? Cystic fibrosis means that my child has to attend clinics every 8-12 weeks and may also have inpatient stays. Sometimes physiotherapy takes longer and we might occasionally be late, would my child be penalised for this?
- Do you have an individual healthcare plan template?

Applying for a school

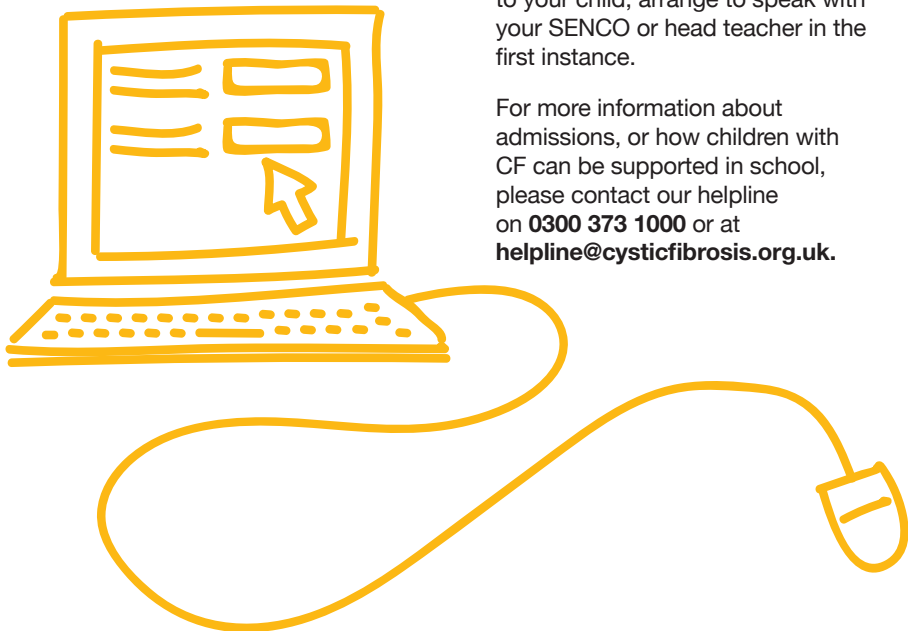
Admissions policy

Applying for primary school can be fraught, particularly in areas where there is significant demand for school places. In some areas of the UK, medical need is a criteria for admission; however, this is not the case everywhere. You can contact the school to find out about their admissions criteria.

There is guidance and policy in place to support children with medical conditions when they are at school, and this varies across the UK nations. Please refer to our website at www.cysticfibrosis.org.uk/school for links to the most up to date information and policy.

There are times when some children with CF need more support than the school can provide, and schools may need to access extra funding to deal with this. If you think this could apply to your child, arrange to speak with your SENCO or head teacher in the first instance.

For more information about admissions, or how children with CF can be supported in school, please contact our helpline on **0300 373 1000** or at helpline@cysticfibrosis.org.uk.



Individual Healthcare Plans

Individual healthcare plans (IHP) are developed to help school staff understand what a particular medical condition means for a child at school. An IHP should describe the condition, treatment and how it might affect the child at school and should be drawn up by the school with input from parents/carers and health professionals.

Even where individual healthcare plans are not mandatory, it's a good, common-sense idea. Some parents develop their own plans or create "All about me" documents for younger

children. It should include information about CF and how it affects your child, treatment details, dietary needs and contact details for the relevant health professionals. It should also address confidentiality. You need to tell the school who should be informed about your child's CF – all school staff, all their class peers or on a need-to-know basis?

"When a child is in reception, I think that their healthcare plan should be reviewed before the Christmas holidays because so much crops up that you might not expect. For example, my son Luis is a slow eater which isn't a problem at home but is at school. He has also become quite dehydrated at school and needs to be reminded to drink. Now that he's going into year 1, the school have a new plan in place, they've learnt lots from reception and have incorporated these lessons into the new plan."

Christina, mum to Luis



Many schools have their own individual healthcare plan templates, but if not, a healthcare plan template is available on our website at www.cysticfibrosis.org.uk/school



Grace D age eleven

Starting school

The first day at 'big school' is a significant and exciting milestone for any child. For some parents this will be the first time that their child has been away from them for the whole day. For children with CF, it may be the first time that someone else has responsibility for their care and so understandably some parents feel anxious about this transition.



"When I went to the induction meeting for Leo starting at primary school, I found that his pre-school had already been liaising with the primary about Leo's Creon. I didn't have to prompt them at all. I'm really pleased with their proactive approach."

Lisa, mum to Leo and Georgia

For some children, schools might consider additional support, depending on availability of funding, for this transition. This was the case for Saira-Jane, who had a heavier treatment burden than some other children with CF:

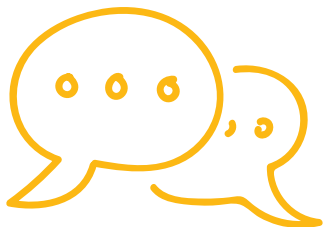
"My main worry about Saira-Jane going to school was that she had never allowed anyone else to do her treatment apart from me or her dad. She has a portacath and generally has IVs every 3 months. We met with the school to go through everything with them and the teacher suggested that Saira-Jane might benefit from some extra settling in sessions. So she had extra sessions with the TA who was going to be doing the majority of her care and they did activities to help build up trust and get Saira-Jane used to physical contact. The teaching assistant put in a lot of time and effort into building this relationship."

Fiona, mum to Saira-Jane

If your child has been to pre-school the transition into primary can be less daunting, but primary school is a little different. The following section will outline key areas for consideration.

Communication

Parents and teachers have told us that communication is key to ensuring that children with CF are appropriately cared for at school. All the relevant staff should know about your child's needs through their session with the CF team or the individual healthcare plan. However, do keep in mind that teachers have a lot to remember and often have 30 children (some of whom may have their own additional/medical needs) in their class, so day-to-day communication and reminders are helpful. In addition, it's important to communicate with the school if there are any changes in your child's health, treatment or behaviour.



"Rhys is now happily settled into school, as far as I'm aware he has not told his friends about his CF although I know he would never try to hide it. I have not told any of the parents yet either. If anyone asks I would never lie, I am not ashamed of Rhys and his condition and would never hide it away. I want people to get to know Rhys for the wonderful person he is first, CF is part of him but he is still Rhys."

Sarah, mum to Rhys

"We operate on a need-to-know basis in terms of who we tell about Isabella's CF. We'll leave it up to Isabella to decide how she wants to handle it as she gets older."

Elaine, mum to Isabella

Remember to be clear with the school about confidentiality, particularly if your child doesn't want other children to know about their CF.

"Sometimes if Alicia is prescribed steroids her behaviour can change, so I will always let the staff know if she's on them."

Ruth, mum to Alicia

The school should keep you informed about any changes in your child's symptoms, missed Creon doses or any other aspect of their day which could be relevant to their CF. It's helpful to let the school know how you want this information communicated. Many parents find that communication books work well but whether you use a book or chat at the school door, it doesn't matter, as long as lines of communication are open!

"My main concern when Grace started primary school was, who will care for her? Will they take this responsibility seriously enough? I quickly realised that I needn't worry they were doing a great job and just needed me to support them by providing the necessary information."

Sarah, mum to Grace

Infection risk

The concerns around infection risk are largely the same as discussed in the pre-school section on page 13. In primary school, children will be more aware of risk and might be more likely to try to avoid infection risk. Children at primary school will also be introduced to a wider range of activities and sports including tennis, football and dancing which should present no significant infection risk at all. Some primary schools have more than one pupil with CF - schools need to seek the advice of the local CF team to establish if they can manage this safely.

"Quality of life versus risk will always be an issue and it's personal for every family."

Sarah, mum to Grace



Diet

You will probably have the option of school meals or a home-made packed lunch, although some schools have a 'no packed lunches' policy. Most schools will be able to make the school menus available to you and they can often be found online. Your CF dietitian will be able to help you work out the Creon doses for the menus. If your child requires additional calories or salt in their school meal, contact the school and ask to be put in touch with the school caterers.

Your child is likely to need at least one snack during the school day - this could be milk and the same snack that the other children are having. However, some children will need more. Sometimes the high-fat snacks that you need to give your child are not in line with school healthy eating policies. However, this should not be a problem as it constitutes part of your child's treatment.

"When Ashley was starting primary school, we arranged for the CF nurse to give a presentation to the staff about cystic fibrosis. This helped them to understand that Ashley needed high calories snacks that were in contravention of their healthy snack policy. The other children understood after a while but there were complaints from parents about Ashley having chocolate when their children weren't allowed. I tried to explain but some parents couldn't get past the 'unfairness' of this. Children often would say to Ashley that he was 'lucky' to be able to eat chocolate every day. Now that he's older he replies along the lines of 'have my CF and see if you feel lucky.'"

Kristel, mum to Ashley



Ashley age ten

Creon

Schools all have their own systems of storing and administering Creon. Some are happy for a daily dose of Creon to be kept in the child's lunchbox which is then stored separately to the other lunch boxes; other schools will have a large pot of Creon which is stored in a secure cupboard and a daily dose administered according to the child's individual healthcare plan. If your child is independent with their Creon and usually self-administers, you could talk to the school about them carrying their own Creon. Getting the Creon dose right can be a bit of an art, particularly when a child first starts school. Some children initially may not like the school meals or they don't finish their packed lunch because they want to go out and play. Keep in touch with the school about your child's eating habits and Creon dose.

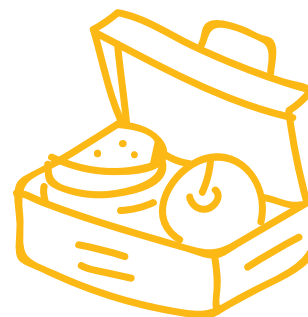
"At primary school all the teachers knew about my CF and I had one special helper who gave me help with my medications, mainly my Creon."

Grace D age eleven

Your child may be asked about the Creon by other children, which is often resolved by them saying 'It helps my tummy' or something similar. Speak to the school about whether you would prefer your child to take their Creon 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 it really is a matter of personal preference.

"When Leo's teacher was asked by another child what the Creon was for, she told him it was to stop Leo getting tummy aches and that was the end of it really."

Lisa, mum to Leo and Georgia



"I developed a little laminated card with instructions on how much Creon to administer – on one side there were instructions for packed lunches and on the other for school dinners."

Sarah, mum to Grace

Attendance

A concern for some parents is that their child will be penalised for absence. Most schools have absence policies in place and reward systems for children who achieve 100% attendance. For children with CF it can seem that they are set up to fail on this one. It is worth speaking to your SENCO or head teacher about this, as many schools will be able to offer flexibility on attendance rewards.

"If Erin has a planned admission the school will give her work to take with her and then liaise with the hospital school to make sure she's got enough. She doesn't fall behind with her work but she does miss her friends and can't make new friends in hospital."

Jane, mum to Erin

"I was clear with the school from the outset that if Saira-Jane's treatment was taking longer than usual we would be late for school. Her treatment will always take priority and the school were very understanding about that."

Fiona, mum to Saira-Jane

When children are admitted to hospital they are often well enough to either attend hospital school or have work sent on from their own teacher. We'd suggest you liaise with the school and CF team about the best arrangement for your child. Sometimes children can attend school with an IV line in place. In this circumstance the school should be notified in advance and have input from the CF team on any special measures which might need to be taken.

Parents told us that on occasion it's difficult to get to school on time, particularly if their child is struggling with mucus and physiotherapy is taking longer than usual. Schools are normally quite sympathetic if they are kept informed; the teachers we spoke with felt it was better that the child comes to school late rather than not at all.



"Grace was at school with a long line for around 2 weeks. The school were worried about it being knocked during playtime so they organised for a friend to sit with her during breaks to keep her company."

Sarah, mum to Grace

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 recorded in the individual healthcare plan what you want the teacher to say in response to questions from inquisitive children. Most often when given direct answers, young children will be satisfied and lose interest.

"We found that in year 1, the children started to become a bit more curious and so, with Grace's permission, I went to the school to do a talk and Grace also decided she'd like to speak. This stopped all of the questions. I think children of that age can be quite accepting once their questions have been answered."

Sarah, mum to Grace



"Everyone in my class knew I had CF, but I didn't really want to talk to them about it."

Grace D age eleven



Rhys age four and dad, Daniel

Getting the most out of school

School isn't just about classroom learning – it's about sport, music, hobbies, friendships, trips and new experiences. Children with CF can and should enjoy a range of extra-curricular activities. Physical activity is very good for your child's lungs - encouraging them to take part in regular PE and other activities will have a significant health benefit. Your CF physiotherapist can help you identify activities and support you in getting your child involved.

"Dylan plays football four times a week. He plays at quite a high level, he plays for the district. He's got his sights set on a professional football contract, as many 13 year olds do!"

Vicky, mum to Dylan



"Alicia swims at club level and has had many medals. She's a fantastic swimmer and is often competing against older children."

Ruth, mum to Alicia

It doesn't have to be activities like football, hockey or athletics – singing or playing a 'wind' musical instrument can also help exercise the lungs (although some care is needed to make sure wind instruments are cleaned and dried properly).

In addition, these extra-curricular activities allow your child to mix with children who have similar interests and can encourage new friendships.

From reception onwards, your child may have the opportunity to go on school trips. Talk to the school in advance if you have any concerns about infection risk or if the length of trip means additional medications or treatments will be needed. We recommend that your child is as involved as much as possible with school, including trips. Your CF team can help if the school needs any additional support in preparing for outings.

Looking ahead

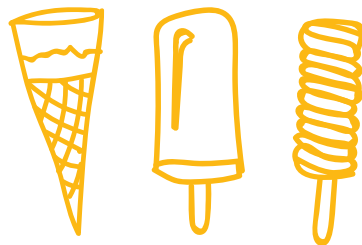
Feeling different

At primary school, children with CF may become more aware that they are 'different' – by teaching them that other children have differences, including conditions like asthma or diabetes that can affect their daily routines, you and the school can help them adjust to this realisation.

Some may feel a sense of unfairness when they start to notice that they have to do things every day that other children their age do not have to do. Offering your child space to talk about CF can be helpful. Ask for support from your CF team if your child is struggling with these difficult feelings.

“Emily is 12 now and has started to be quite self-conscious about being different from her friends. On holiday, I noticed that while her friends had ice-cream, Emily had an ice-lolly. This was because she didn't want to take her Creon in front of them.”

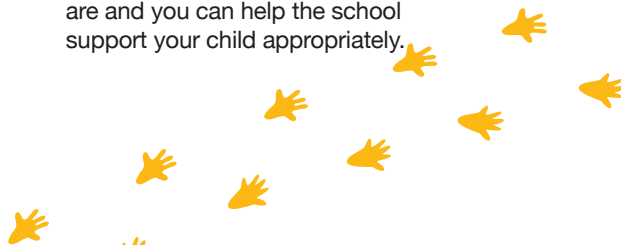
Serena, mum to Emily



Self-management

All children achieve milestones at different ages, and this is no different for children with CF. Whenever possible, try to involve your child in their CF care and make this process part of their everyday life. Children will develop independence with their

CF treatments at their own pace, as they will with any other task, e.g. getting washed and dressed independently. As parents, you will know best what your child's abilities are and you can help the school support your child appropriately.



Ashley age ten and Guinea pig 'Gingey'



Grace D age eleven

Overnight trips and sleepovers

Going on overnight trips is a normal part of growing up and there is no reason why your child can't join in. For informal overnights, we'd suggest you talk to the adults in charge and ensure they are aware of your child's needs. It may be reassuring for you and the adults looking after your child to know that you can be contacted at any time during the trip. For residential school trips, ask your CF team for advice. Some CF teams are able to liaise with the school and support them in preparing for the trip.

"Aimee is very social and has lots of sleepovers, her CF has never got in the way. She's eight now and I'm very confident in her ability to take her own Creon and I know the parents who look after her really well and they're very supportive."

Allison, mum to Aimee

"Emily had a residential trip in year 6. This was really exciting for her – a little nerve wracking for me! We were disappointed that she wasn't allowed to take responsibility for her own medications though. The school insisted that she should be supervised whilst taking her medications. It was all fine though and she took back control of her treatment when she came back home."

Serena, mum to Emily



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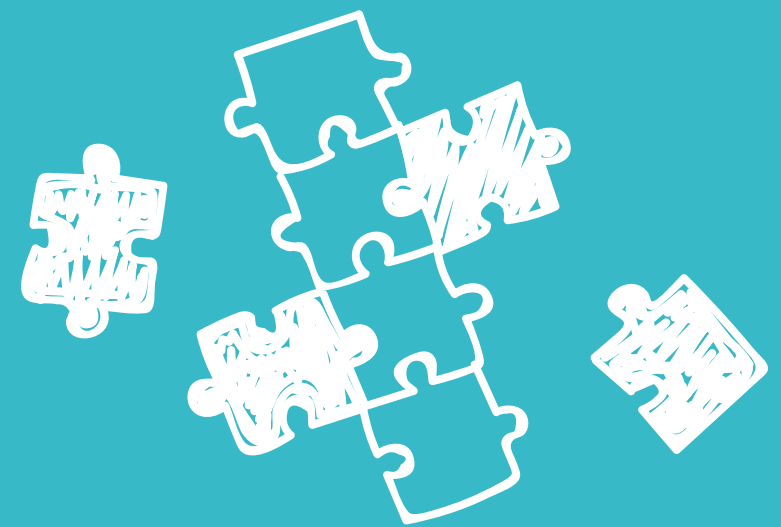
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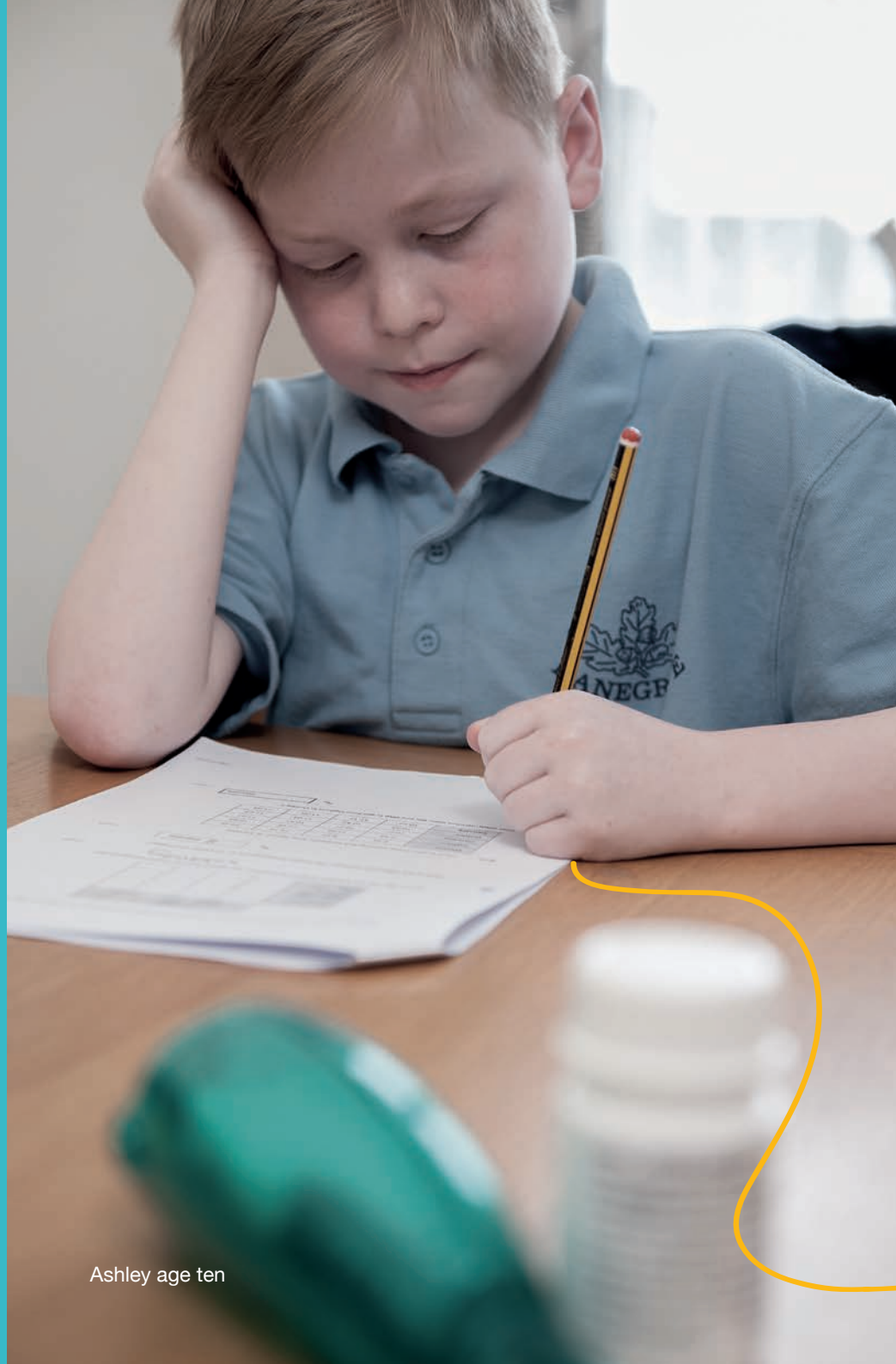
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Resolving difficulties





Ashley age ten

Resolving difficulties

With good communication between you, the school and your CF team, your child will be able to enjoy the full school experience. If you are having difficulties and feel that the school is not adequately supporting you or your child, it may be helpful to speak with your child's teacher or head teacher early on.

If you have concerns about your child's school and you feel they haven't been addressed sufficiently, you can always ask for further help and support from your CF team or from the Cystic Fibrosis Trust helpline. You can reach the helpline on **0300 373 1000** or at **helpline@cysticfibrosis.org.uk**.

"Luis's transition into school seemed to be quite smooth until he had a two-week hospital stay and upon returning found that his teacher had left suddenly. This change was really difficult for us because it seemed information was not correctly shared and the new teacher wanted to communicate differently. I felt that mistakes started to happen because the communication was not there. So for example, the class went for a woodland walk and Luis was asked not to pick things up when the other children were because the new teacher wasn't sure if he was allowed to or not. Luis stood and watched while everyone else picked up leaves – that's not what I would have wanted. He needs to be involved but with care. Luis was not being reminded to drink and as a result was dehydrated. He was losing weight to the extent that the CF team were concerned. When I heard about the individual healthcare plans and the fact that these are mandatory I used this as a lever to request a meeting. We completed the plan together and things began to improve after that."

Christina, mum to Luis





Sarah, mum of Rhys age four

Top tips for parents, from parents





Rhys age four and mum, Sarah

Top tips from parents

Don't be afraid to persevere if you feel you aren't being heard.



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.

Most importantly: build good communication with staff at your child's school.

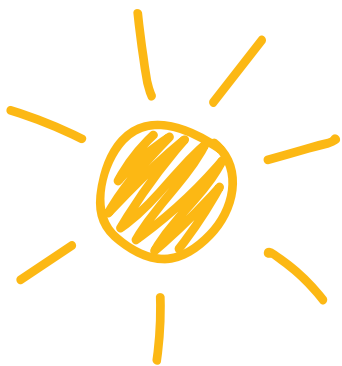


Make sure the right people at school understand that healthy eating may mean something different for your child. Remember that you can get help from your CF dietitian.

Do go to the school if you have concerns. Remember that you are doing the best you can to meet your child's needs.



Finally



This booklet provides an overview of some of the issues that may come up as your child starts their early years education but we understand you may need more detail or tailored advice. Your CF team or the Cystic Fibrosis Trust helpline will be able to provide additional support and information. Our trained helpline staff can provide a listening ear, practical advice or direct you to other sources of advice and support. The helpline can be contacted by calling **0300 373 1000** or **helpline@cysticfibrosis.org.uk** and is open Monday to Friday from 9am-5pm.



Ashley age 10 and mum, Kristel

Further information

Policy and Legislation

There is a range of policy and legislation in place that should support your child in pre-school and school. All schools should have a medical policy in place to guide the school on educating and supporting children with medical needs. In England, schools are legally required to have this policy.

The Equality Act 2010 (which applies to England, Scotland and Wales) makes broad provision to protect children with disabilities demanding that schools (including independent schools) must make reasonable adjustments to ensure that children with disability are not put at substantial disadvantage compared

with their peers. The equivalent piece of legislation for Northern Ireland is the Disability Discrimination Act. There are many other pieces of legislation that include provision for children with medical needs. It's not feasible to list these here. Please visit www.medicalconditionsatschool.org.uk for a more complete review of the legislation relating to children with medical needs in school.

In addition, each nation has its own guidance on managing medical conditions in school. As policies change regularly, please visit our website for the latest guidance documents for each nation at www.cysticfibrosis.org.uk/school



Useful links

- **England:**

Independent parental special education advice (IPSEA): www.ipsea.org.uk

Legal information and advice on education law in England:

<http://childlawadvice.org.uk>

Professional Association of Childcare and Early Years (PACEY):

www.pacey.org.uk

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

- **Northern Ireland:**

Equality Commission for Northern Ireland: www.equalityni.org

Northern Ireland Childminding Association: www.nicma.org

School inspection reports: www.etini.gov.uk/index/inspection-reports.htm

- **Scotland:**

Enquire provides information on additional support for learning:

<http://enquire.org.uk>

Legal expertise in matters of education: www.edlaw.org.uk

School inspection reports: www.educationscotland.gov.uk/inspectionandreview

Scottish Childminding Association: www.childminding.org

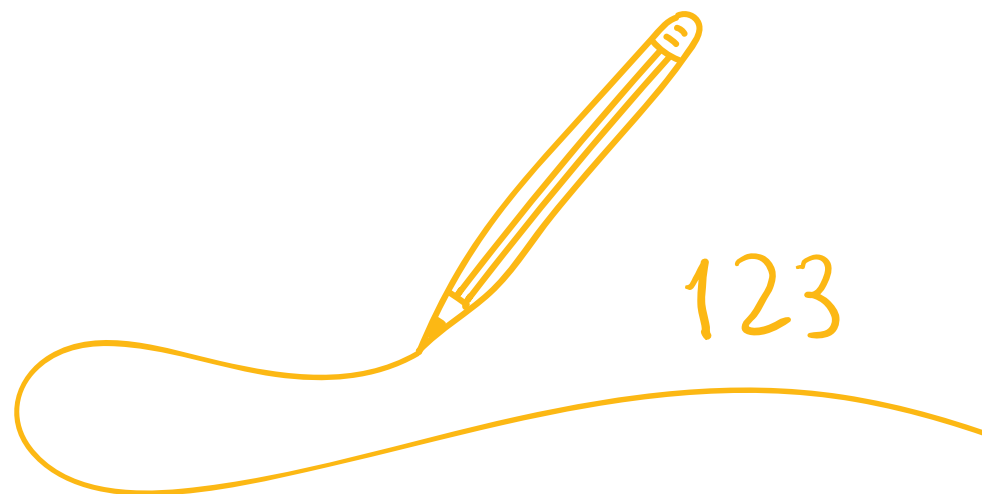
- **Wales:**

Professional Association of Childcare and Early Years (PACEY):

www.pacey.org.uk

School inspection reports: www.estyn.gov.wales/inspection

Snap Cymru provides information and advice for children with medical conditions or disabilities: www.snapcymru.org



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