

Cystic Fibrosis here for families



School and cystic fibrosis:
a guide for parents of children
starting secondary school

Fighting for a *Life Unlimited*



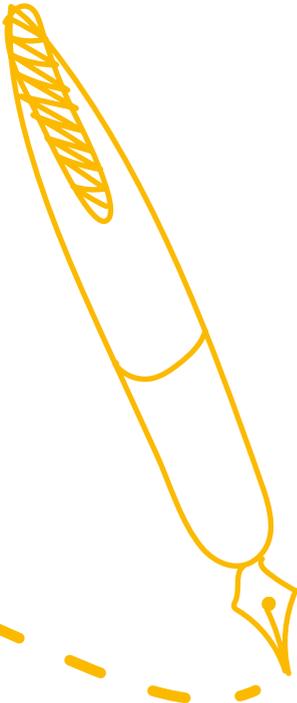
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There's no doubt about it - moving from primary school to secondary school is a big step for any child and their family, regardless of whether they have cystic fibrosis (CF). It's not just a change of school, it's a whole new life stage. Secondary school is the beginning of a process of passing on responsibility and encouraging a child towards independence. It can be scary for parents, and hard to let go, especially when you are giving up some control of the management of your child's CF, but it's also an exciting milestone for young people and their parents.

We'd love to give you a 'Here's how to do it guide', but sadly there's no such thing. What we can offer is some practical information about moving from primary to secondary, some shared stories from other families about their experiences, and expertise from specialist CF psychologists about supporting children through this transition.



Before we get started, we wanted to share with you a blog post, written by Louise, whose son James has CF and has just started secondary school. In this blog extract, Louise describes what happened when James started secondary school.



Louise's blog

12 June

So I received an information pack today from James' new secondary school - very glad he's in and all looks great... except, no mention of medical conditions, nothing. Don't know who to speak to or how to go about any of this. I guess I'd thought that the primary school would tell them all about it and then when he got his place, the school would know and they'd drop me a note to say:

"Dear Mrs Miller, we are delighted that James is starting with us in the autumn and understand he has cystic fibrosis. We'd be very grateful if you could get in touch with his head of year, Mrs Headofyear, to talk about this further..." Boo, no such luck!



19 June

Been very proactive today and called the school - have got a meeting with the Special Educational Needs Coordinator (SENCO) and our fab CF nurse, Pam, is coming too. Feeling much happier today.

3 July

GREAT meeting. The SENCO really listened, took lots of notes. We spoke about Creon, cross-infection, absence - everything they need to know really and we wrote it all up in his Individual Healthcare Plan. It was good to have Pam there too, it just kind of reinforced that this is a condition that needs management.

James had his two-day induction this week - he seems happy and excited. Maybe it helps having his sister there already? Doesn't matter, he's fine and so it's all good.

4 July

Can't believe it. Just been to the parents evening and met James' form tutor, who was lovely but knew NOTHING about his cystic fibrosis. She didn't know he even had a medical condition. This is the person who will be with him throughout his school career, his go-to person for any issues - WHY doesn't she know?? I assumed the SENCO would have told her. I've asked her to look at





the Cystic Fibrosis Trust website so she can get a little bit clued up on the condition.

6 September

Big day is here and my boy is off to secondary school! All smiles, didn't seem too bothered at all in fact.

20 September

Two weeks in and he's still NEVER remembered to take his Creon at school – arrrggggg! What can I do?!

22 September

Had another meeting with James' tutor, much better this time, feel like we're getting on the same page now. We are making progress...! She's asked for some specific information about CF and how it can affect James at school – VERY happy to provide that and we've spoken about his Individual Healthcare Plan and how that info is shared.

13 October

It's been a few weeks now... life's busy. James is loving secondary school - very pleased to say that

he's doing well academically (clever one, like his mum) and has lots of friends - they don't all know about his CF and he's not bothered about telling them. He's kind of just cracking on. Creon is better, but not great yet, plus he's doing loads of football and not eating enough so he's lost a bit of weight. His dietitian will have words I'm sure. Of course I remind him about Creon, but he thinks I'm just being a naggy mum. He says he wants a 'proper' phone, apparently the one he has is pretty embarrassing. Maybe we'll do that, but with a built in deal that he uses it to help him remember his Creon and manage his time a bit better... We'll get there, we have a lovely relationship. I'm trying to walk the fine line between wrapping him in cotton wool and letting him grow up and take responsibility for his own condition. I don't suppose I'll ever get it exactly right and we will make mistakes and hopefully learn from them. I'm foreseeing lots of ups and downs and battles ahead but I suppose it's like that for most families, it's just that CF makes it all seem so much more important. I'll keep you posted.





Perhaps you can relate to some parts of Louise's story, but of course children with CF and their families will have their own unique experiences and feelings about moving into secondary education.

CF inevitably has a role to play in this transition but it's not the only factor - developmental changes, new friendships, new routines and hormonal changes all shape experiences at this time. It's useful to bear this in mind and remember that your child has a lot to adapt to, as well as managing their condition.

"You feel it's your job to keep your child well. So it's hard to let them 'own' their illness. There's no right or wrong, it'll be different for different families."

Kerri, mum to Faith (age 18)

"In some ways, secondary school is easier because Ashley has more awareness of her condition and of risks so she can make her own good decisions."

Rebecca, mum to Ashley (age 16)

"To be honest, I had no worries when transferring to secondary school. I saw it as a cool challenge that I could overcome and I was excited to see how it was."

Dylan (age 14)







Getting ready for secondary school





Getting ready for secondary

Parents have told us that empowering a child to be independent in their own care is really valuable when preparing them for secondary school. Starting this process in small steps, before moving from primary school, can help a child focus on starting their new school without the worry of managing their treatment for the first time. As children all develop differently, you'll be best placed to know when your child might be ready for new responsibilities.

"I think empowering your child as much as possible, helping them to develop resilience and become expert patients, is what will make the move into secondary school and beyond as smooth as possible. They need to learn to make their own good decisions and understand why they do the treatment they do."

Vicky, mum to Dylan (age 14)

"I did work with Joe to get him more independent before he started secondary school but he still found the first term hard."

Elaine, mum to Joe (age 18)

"I have tried to encourage independence, for Faith and me, in small steps. At clinic, I used to encourage Faith to go with the nurse to get her weight and height checked without me - even that felt a little strange at first. Occasionally, I would find an excuse to pop out during consultations with her CF nurse or doctor - just nipping to the loo - I wanted Faith to get used to communicating with them independently."

Kerri, mum to Faith (age 18)



Sometimes children start to feel differently about their CF around this stage and might see the transition into secondary school as a time to change the way they relate to their condition. Very often their primary school friends and teachers would have known about their CF, but they may feel differently about telling people as they move into secondary and into a new stage of their life. It's helpful to talk to them about this before they start so that both you and the school can make sure their privacy is respected. See 'Ask the psychologists' (page 51) for more information about CF and feeling different.

"When I started high school I didn't want any of my new friends to know because I didn't want a big fuss over me. The reason I didn't want a big fuss was because they will ask questions a lot so it will be really annoying and I just want to be a normal kid. I asked my friends from primary school not to tell any of my new friends."

Lewis (age 11)

"My close friends just gradually began to know about CF as they got to know me, and my friend from primary also told them a bit as well, other friends just don't know."

Dylan (age 14)



"I didn't want to tell people about my CF until I got to know them properly. I'd generally tell friends about it but not in detail until I felt more comfortable with them. My group of friends are really supportive."

Grace (age 14)



“The school asked Olivia if she wanted them to explain to her classmates about her CF, but she didn’t want that. Instead she has just told her close friends. She doesn’t want to feel different.”

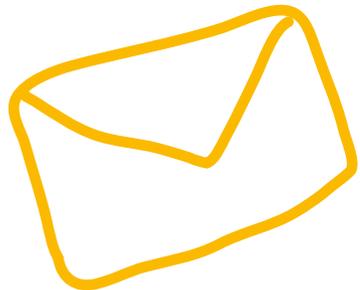
Melanie, mum to Olivia (age 15)

“All Joseph's teachers and friends knew about his CF at primary school. I think he felt differently about telling people once he moved into secondary. Early on he had his wrist bandaged to secure his IV lines, but he told his new friends that he had broken his wrist.”

Mandy, mum to Joseph (age 13)

“Alexander was adamant that he didn’t want anyone at school to know, he was worried that they’d treat him differently. So the teachers that need to know are aware but none of his friends are. That can make it difficult for his social life because he’s worried about having friends over in case they see his medications or any evidence of cystic fibrosis.”

Yvonne, mum to Alexander (age 15)





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The new school

In the same way as you possibly did with primary school, researching and visiting secondary schools will give you and your child a feel for which is the best fit. When visiting, you might find it helpful to ask about the school's provision for children with medical conditions. All schools in England are required by law to have Individual Healthcare Plans in place for children with medical conditions - these or similar plans may be used in schools in the rest of the UK but aren't currently required by law. Asking about these plans - how they are developed and how the information is shared, for example - will give you a feel for the school's level of involvement in supporting pupils

with medical conditions. It's important to remember that secondary schools will not usually be able to provide the intense levels of supervision and support that your child may have received at their primary school and indeed this isn't always helpful for children at this stage, who will be making steps towards more independence.

Once you've accepted a school place, you might want to think about arranging a meeting with the school to talk about CF and how it can affect your child. Parents have told us that having a meeting with the school before the summer holidays helped make for a smoother transition.

"The school that Dylan goes to had never had a student with CF before so I was very proactive and contacted the school reception in the June before Dylan started to find out who I should speak to about his condition. I was advised to speak with the head of pastoral care. Dylan has an Individual Healthcare Plan and I have good communications with the school, so it all works really well."

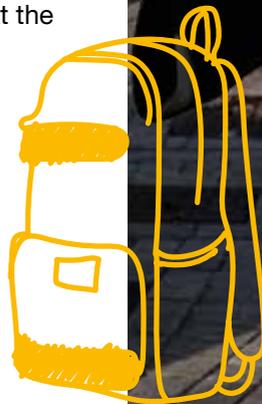
Vicky, mum to Dylan (age 14)

“Joseph’s primary school is on the same campus as the secondary school, so they have strong links. The transition is very well handled by both schools and because the children already know the environment and many of the staff, it’s not such a big deal. Joseph has a Learning Support Assistant who oversees his wellbeing at school and will be with him throughout his time there. We had everything in place before he started.”

Mandy, mum to Joseph (age 13)

“When Alasdair was still in primary, the guidance teacher from the secondary school met with us at the primary school to talk about his condition. This was followed up by a meeting at the secondary school, which Alasdair, his guidance teacher, year head, CF nurse and myself all attended. Alasdair was very involved in the meeting and I felt it was beneficial to have this before he started in secondary.”

Pamela, mum to Alasdair (age 14)



In secondary school there is generally a member of staff who'll have an overview of your child's wellbeing - it varies between schools and can include a pastoral teacher, head of year, form tutor or other member of staff. It is likely that this person will be your point of contact for discussing CF although it may be that other staff will be involved too, for example a school nurse or the office staff. If you're not clear who has this role, contact the school office and ask for this information. With so many new teachers involved in their life at their new school, it's important that your child knows who to go to for CF, or other non-school-related issues.

“Alasdair attended the early meetings with the school and was involved in all decision making. From this the school made a few adjustments to make his life easier - allowing him to leave class five minutes before the lunch bell so he can take his Creon and get ahead of the lunch queue and also giving him a key for the disabled toilets so he has the privacy he can't get in the boys toilets.”

Pamela, mum to Alasdair (age 14)

“My daughter has self-managed her CF since primary school so she doesn't really need input from the secondary school staff. We've worked hard to instil confidence in Ashley to make sure that she could self-manage and communicate any concerns independently.”

Rebecca, mum to Ashley (age 16)

“Olivia has been given a 'time out pass', which she can show if she needs privacy for her Creon or insulin or even if she just needs some time out to rest. She's allowed to go to the SENCO area where there's a sofa and a fan, if it's hot. She also has a toilet pass and is allowed to use the disabled toilet rather than the pupil toilets. The school have been really understanding and supportive.”

Melanie, mum to Olivia (age 15)



Sharing information

Making sure that the right people have the right information about CF means that additional support or consideration can be given to your child if needed. As already mentioned, information about CF and how it affects your child should be documented in an Individual Healthcare Plan or similar document. Ideally, these plans would be developed in partnership between you, your child and the school - your CF team may also be able to support you with this.

A factsheet for secondary school staff is available to help make sure they have key information about the condition, although of course the school will also need information about how CF affects your child specifically. You can download or order a copy of this factsheet at cysticfibrosis.org.uk/teachers.

“It’s very useful to get email addresses for the school’s staff that you’ll be dealing with most regularly. I find that’s the easiest way to stay in touch.”

Sarah, mum to Grace (age 14)

“I felt anxious about establishing trust with my teachers at secondary school, because there were so many of them and I didn’t know them. I was worried that they’d forget I have CF and then put me in a position that I didn’t feel comfortable with, especially with infection risk.”

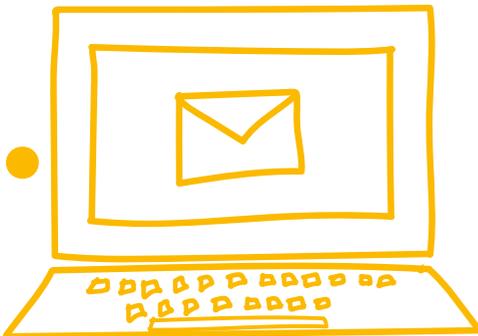
Ashley (age 16)

“I felt that at primary school, I was more in control of Joe’s CF - there was only one teacher and you tend to know them personally. That’s not the case at secondary school and I did experience a real gap in communication, which is made worse because you don’t know the teachers. I think parents need to think about what the school needs to know. Parents need to take the lead, with help from the CF team where possible.”

Elaine, mum to Joe (age 18)

“I just want to be sure that the teachers and teaching staff at my school understand that I have CF and appreciate how that can affect me.”

Olivia (age 15)



As you will be all too aware, the treatment burden for CF can be intense and making teachers aware of this helps them to appreciate why a child with CF might be tired, has incomplete homework or may sometimes seem distracted. Being aware of this can help teachers better understand the full impact of this condition.

“A teacher once asked me why Faith hadn’t done her homework and yet had time to go to the cinema and out for dinner. I calmly explained that Faith had spent two hours after school doing her treatment whilst her sister worked on her own homework. We had a family trip to the cinema planned and it wasn’t fair to either of them to cancel it – we all would have suffered and I felt on this occasion that family time took precedence.”

Kerri, mum to Faith (age 18)

“I do tend to remind the school about Grace’s CF because I worry that they don’t always understand the severity of it. At primary school that’s easier but obviously at secondary there are so many more teachers.”

Sarah, mum to Grace (age 14)

“I think it's so important for teachers to understand the impact CF has on the school day: there's the treatment burden, the impact of absence and the psychological effects too. Joseph looks so well, it could be easy to forget what he has to go through to maintain his health.”

Mandy, mum to Joseph (age 13)

Providing this information to the school is the start of a conversation that will continue throughout your child’s time at school. Having good communication with the school - being available to answer queries, giving them prompt notice of absence or lateness and raising any concerns early on - can help to foster good relationships.





Treatment



"Try not to stress too much, I know that's not easy, I have three boys with cystic fibrosis. Aim to get the treatment done every day, but be realistic, do what you can."

Pamela, mum to Alasdair (age 14)



Treatment

There's a lot going on at secondary school and for some children and young people, fitting treatments into this new routine can be challenging. There's not a magic answer, but some possible tactics include: talking about priorities (yours and theirs), working on time management and educating them, if they are not already aware, about what these treatments actually do.

Children and young people with more complex health needs are likely to have a heavier treatment burden and it may be useful to ask your CF team to work with you and the school to develop a manageable plan that incorporates treatment and school demands.

See 'Ask the psychologists' on page 51 for more on this topic.

"I set my alarm 30 minutes before I need to actually get up because one of my tablets needs to be taken a bit before breakfast. I don't always do my acapella as well as I'd like because sometimes I worry that I'll be late for school. I normally watch YouTube or TV while I'm doing my acapella just so the time goes quicker and it helps me to relax as well."

Alice (age 15)



"Getting teenagers up can be difficult anyway but of course Dylan has to get up 20 minutes earlier to do his physio in the morning. Sometimes if he's running late, I have to think 'Do I make him do his treatment and he'll be late for school or does he miss his treatment?' There are compromises, challenges and times to choose your battles."

Vicky, mum to Dylan (age 14)

"I think Grace is more tired at secondary school. She has to get up that bit earlier, travel further, carry a large school bag as well as walk between classes. It's all manageable, it just takes a bit of planning and getting used to."

Sarah, mum to Grace (age 14)

Creon and diet

Parents and young people tell us that Creon can be an issue at secondary school with some children finding it hard to remember to take it – of course there are exceptions and this will vary from person to person. If your child isn't already independent with their Creon, it might be useful for them to practise over the summer holidays. Talking to your child about how they want to take their Creon at school and working on a plan together might be a good approach. Are they comfortable taking it in front of friends? Will they carry it in their jacket or bag? Do they want to ask about a lunch queue pass? What will they tell new friends? Will there be a pot of spare Creon in school?

“In secondary school I carry my own Creon. Sometimes I do forget to top up my tub and have to go and see the nurse to get some. So yeah now I have more independence than I did in primary because the teachers used to just give me the Creon.”

Dylan (age 14)

“When other students have asked me about my Creon, I've just told them that I have an allergy. There have been times I've taken my Creon in the toilet to avoid being noticed.”

Ashley (age 16)

“Lewis didn't take any Creon at lunchtime for the first two weeks at secondary school. I don't think it was an issue for him not wanting to take it, I just think he was genuinely forgetting. It had no effect on him but in a way I wish it had a little so that he'd be more motivated to remember. I think parents should try to introduce independence with Creon before secondary school.”

Katie, mum to Lewis (age 11)



"The school lunches are so busy and everyone wants the pepperoni pizza and there's a big rush for it, so I take my tablets quickly and discretely so I don't miss out."

Lewis (age 11)

"Sometimes if Dylan gets into trouble, he has to go for 'last dinners' at school, as a sort of punishment. This can be difficult for him because there might be nothing left that he likes and obviously I don't want him in that situation. But he does have to learn."

Vicky, mum to Dylan (age 14)

We know that some children and young people with CF become anxious about their diet following lessons at school on healthy eating. It's worth flagging this with the school if your child does need a higher energy diet. There is information in the factsheet for secondary schools and your CF dietitian may also be able to support you.



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"Everything is new at secondary school, there's so much for them to remember. So I've tried to make it as easy as possible for Grace. We talked about it and one of the solutions we came up with was using her phone to set alarms for her treatments. A little pill emoji pops up when it's time for any meds. It works really well for her."

Sarah, mum to Grace (age 14)

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Infection control



Many, but not all parents find that infection control can feel less daunting by this age - children may be better able to understand and avoid infection risks and there's a change in activities (no more mud kitchens!). Some parents find their perspective on infection risk changes with their child's growing independence.

There will still be activities and environments at secondary school, as there will be throughout your child's life, where there are possible infection risks. It's worth chatting about this with your CF team and child to explore your own feelings about acceptable risk and ensure that this is recorded in the Individual Healthcare Plan or other school records. Feelings about managing infection risk will differ from family to family.

"By secondary school age young people aren't really playing, they're hanging around and chatting so there aren't the same infection risks as in primary where they might like to be splashing around outside! There are still some concerns, more so with school trips. It's worth checking what activities are planned and speaking to the school. It's all about having clear and open communication."

Sarah, mum to Grace (age 14)

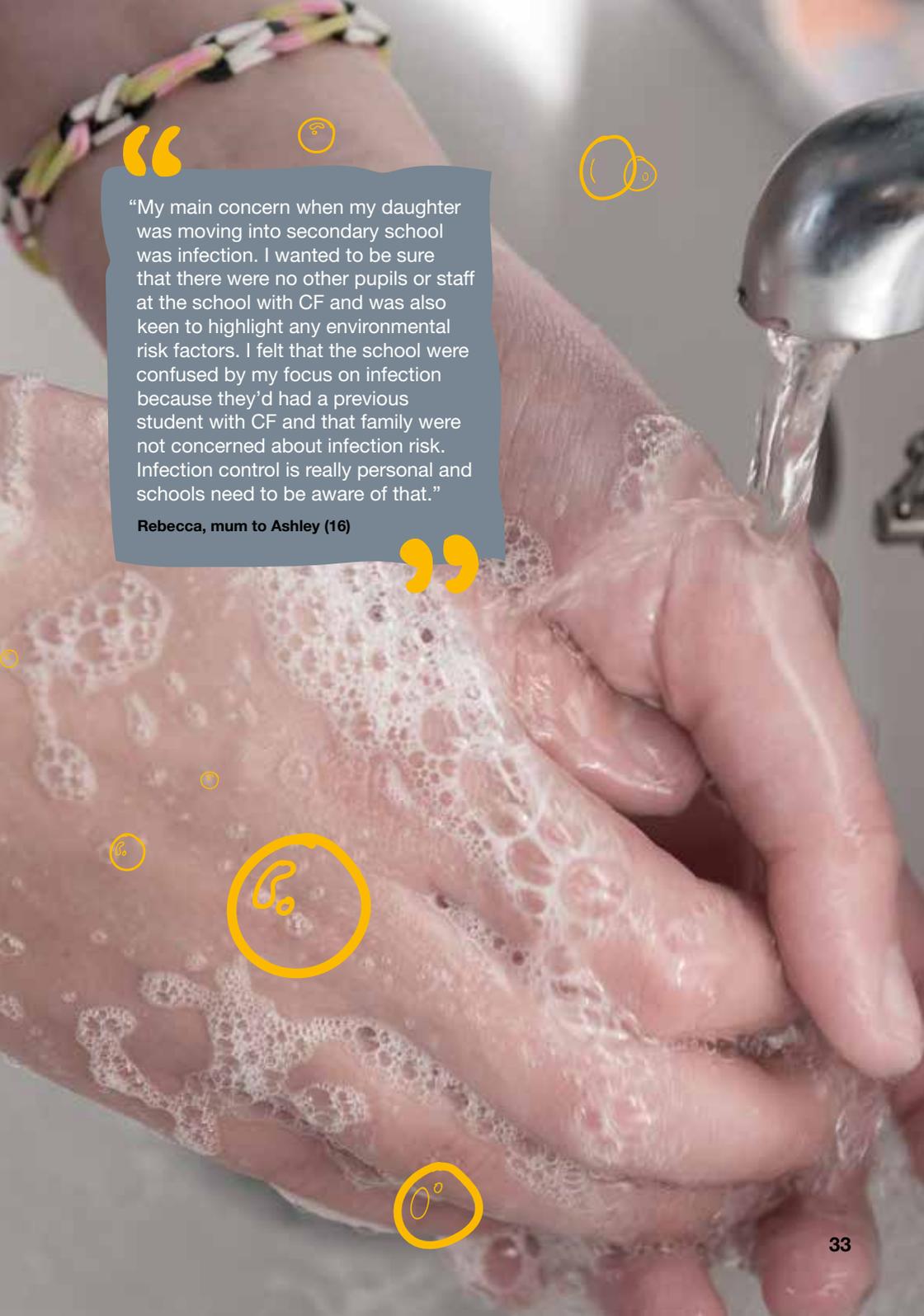
"I think schools need to know that just because they've taught one person with CF, doesn't mean it'll be the same situation with another, particularly around infection control concerns, it's very personal. People with CF, like everyone else, are unique."

Ashley (age 16)

"I'm more relaxed as a parent now. He's out playing football in the rain, doing slide tackles and all that. He's got to live his life. I am strict about Jacuzzis though, although I would never say no to him, he needs to be able to make his own informed decisions."

Vicky, mum to Dylan (age 14)



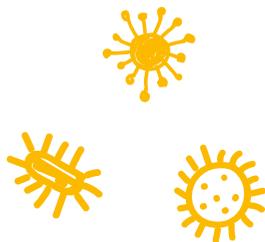


“My main concern when my daughter was moving into secondary school was infection. I wanted to be sure that there were no other pupils or staff at the school with CF and was also keen to highlight any environmental risk factors. I felt that the school were confused by my focus on infection because they’d had a previous student with CF and that family were not concerned about infection risk. Infection control is really personal and schools need to be aware of that.”

Rebecca, mum to Ashley (16)



Cross-infection



As you'll know, people with CF cannot mix with others who have the condition because of the risk of cross-infection. If there is another pupil or member of staff with CF at the school your child is due to attend, a thorough risk assessment and plan put together by the school would need to be in place to minimise the infection risk to your child and the other person with the condition. The school should liaise with your CF team in this instance.

"The school contacted me to say that there was going to be a new pupil coming to the school who also had CF. I'm not sure they really realised how significant this was. A plan was put in place and fortunately because the girls are in different years and house groups their paths don't ever cross. They also have a photo of each other to help them avoid contact. The girls actually exchanged emails for a while and Grace was able to give her some advice on how to handle CF at school."

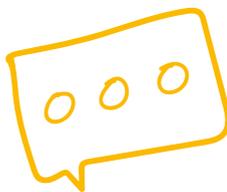
Sarah, mum to Grace (age 14)

"Just before my exams the school said that someone else with CF might be coming to the school. I was really stressed and found it hard to concentrate on my studies. I try to be as normal as possible but I wouldn't tolerate a cross-infection risk."

Ashley (age 16)

"There is a teacher at his school who also has CF, but there is a plan in place to keep them both safe and their paths do not cross."

Yvonne, mum to Alexander (age 15)



Physical activity

Physical activity is really good for the lungs so children and young people with CF are encouraged to take part in anything that gets them active - sports, dance and even playing some musical instruments or singing can do this. One of the great things about secondary school is the wider variety of sports and hobbies on offer. Your CF physiotherapist may also be able to help identify and access sports and activities that could be good for your child's health.

“My son doesn't like PE at all, however I won't write him an absence note just because of CF, unless he's actually unwell.”

Yvonne, mum to Alexander (age 15)

“Grace has recently completed a two night expedition with the Duke of Edinburgh's Award. I must admit I was slightly anxious about her doing this, I worried about the heavy rucksacks and whether she'd be able to do it. I had a chat with the DofE leader and was totally reassured. They made adjustments for her, so she carried her day bag but didn't have to carry the tent and sleeping bag. They arranged for close monitoring of the group that Grace was in and a plan was put in place for her to be collected by mini bus if needed. This worked out very well and enabled her to fully enjoy the experience with confidence.”

Sarah, mum to Grace (age 14)

“We do PE for two hours a week at school, I'm not that keen on sport to be honest. But I love dancing and do ballet and modern dance.”

Grace (age 14)

“I do netball, hockey and rounders in PE. I also tried cross-country at school for the first time and really enjoyed it, so now I do it outside of school too.”

Alice (age 15)



“Dylan hasn't had any issues with participation in PE, he's quite well and fit and very able at sports. His teachers have never had to be concerned so there's no question of him not taking part.”

Vicky, mum to Dylan (age 14)



Absence

Most children and young people with CF will miss some school because of their condition - whether that's running late because of treatments, attending a routine clinic appointment or having IV antibiotic treatment. Wherever possible, keep the school informed about planned absences or speak to them if your child is struggling with the time pressure of any additional treatments.

Children on IVs may be well enough to do school work, either at home or in hospital. We'd suggest that you liaise with the school to arrange work to be sent home or speak to your CF team about access to hospital school. If your child is going to attend school with an IV line in place, please do notify the school in advance and make sure they are aware of any restrictions that need to be in place, for example avoiding contact sports.

"Alexander was running late for school because of the additional treatment for the Pseudomonas. I spoke to the school about it and they've been great, allowing him to come in an hour later to accommodate his treatment."

Yvonne, mum to Alexander (age 15)

"Olivia found the move from primary to secondary very tiring. She has other health conditions as well as CF and has had a tough time with colds, coughs and Aspergillus. As a result, she missed quite a lot of school. I have to say that the school have been really supportive and very good at staying in touch and sending work for Olivia. In addition they do have lessons online so Olivia can catch up from home if necessary."

Melanie, mum to Olivia (age 15)

"CF doesn't get in the way of school too much but I do have to miss it for doctor appointments or hospital checks. I text my friends to ask them to help me catch up, like getting worksheets for me and things like that. I do worry a bit about falling behind especially when my GCSEs start."

Alice (age 15)



"Joseph was quite poorly just around the time he was starting secondary school. That was really hard for him because he was absent quite a lot from the very outset, so he missed out on those early days of making new friendships and I think it worried him a bit. However, the school have been fantastic and very supportive. He's got a really good group of friends now."

Mandy, mum to Joseph (age 13)

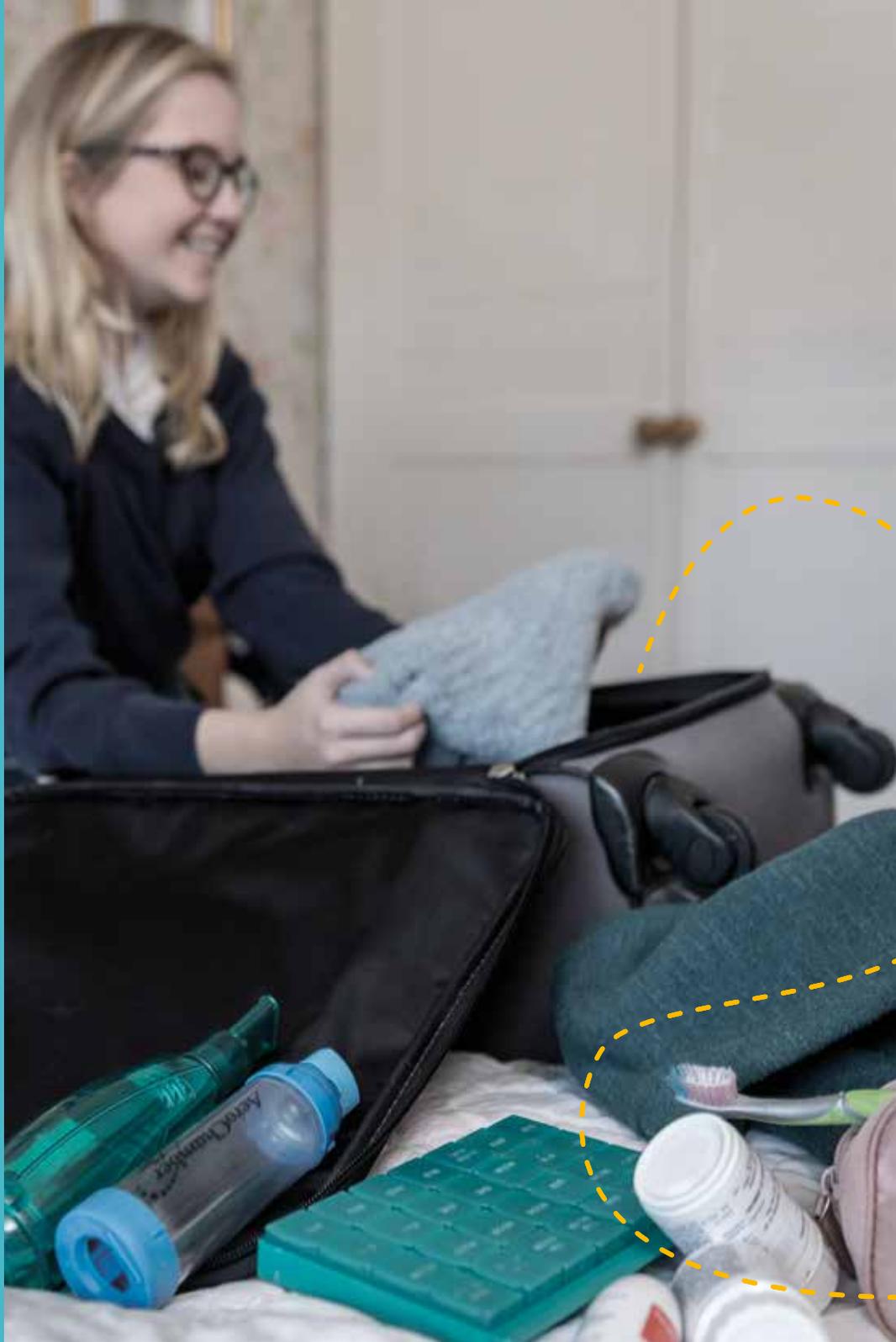
"When Joe did miss school, I found it difficult to get work from the school to help him catch up. I'd have to call each teacher and arrange for them to send homework to me – it wasn't easy. I was really on top of this because I didn't want him to fall behind and lose the thread. I think it's really important for young people to do the best they can, it's important for their self-esteem."

Elaine, mum to Joe (age 18)



School trips and top tips





School trips

Going away with school friends on trips is an exciting opportunity and part of the process of becoming more independent. Although trips away from home can be worrying for all parents, particularly those with a child who has a medical condition, children and young people can feel a real sense of confidence, achievement and growth from these adventures.

There are some practical things to check in planning for a trip, including:

- Does the school's travel insurance cover a child with a pre-existing medical condition?
- Does your child need immunisations for the trip?
- Who will carry their medications and will they be able to self-administer?

"I do find school trips stressful, I think it's the lack of control. Alasdair has a gastrostomy and I know he can manage his overnight feeds himself but I worry about the smaller things like what if the noise of the machine disturbs others or what if it leaks and makes a mess? I've written information about it all for the school, but Alasdair manages it himself at home, I know he'll be fine."

Pamela, mum to Alasdair (age 14)



"Dylan has been away lots with the football team and on school trips. I was really nervous when he went abroad the first time, because I knew I couldn't just jump in the car and go and get him. He's been fine on trips though, the school let him carry his medications and do his treatments unsupervised. Usually he doesn't take his nebuliser if he's on a trip, it's a compromise between quality of life and treatment."

Vicky, mum to Dylan (age, 14)

"School trips weren't a problem. The school checked their insurance policy to ensure that Faith would be covered and that was fine. The school did expect Faith to be independent in her treatment, I don't know how it would have worked if she hadn't been able to do her treatment."

Kerri, mum to Faith (age 18)

Cystic fibrosis on the curriculum

Genetics is usually taught as part of the biology curriculum and CF is sometimes included as part of this subject. Some young people have also told us that CF has been discussed in religious education or other classes where they cover genetics and ethics. Ideally the school will raise this with you in advance. However, because we know such warnings don't always happen we'd suggest that you ask the school whether CF is likely to be included in your child's lessons.

We have developed a factsheet specifically for teachers who will be giving a lesson on CF, which you might find useful. You can download or order this factsheet at cysticfibrosis.org.uk/teachers. This gives a brief update on the latest information about CF and also reminds teachers to contact parents in advance of the lesson to make sure their pupil isn't going to be surprised or upset by any of the content (fertility and life expectancy for example). Other pupils learning about CF for the first time may ask your child questions and it can be useful to think about how they might respond to this, particularly if life expectancy is raised.

"One of Alexander's classmates asked him about his CF and whether or not he was going to die. Alexander handled it really well and replied that any one of us could die, you could, after all, walk out of school and be hit by a bus. I was glad that he coped so well with this."

Yvonne, mum to Alexander (age 15)

"Grace was doing a project at school that involved charities and so she looked at the Cystic Fibrosis Trust website. That's when she found out that CF is life-shortening. We spoke about those statistics and what they means, how's it's an average and not specific to her. These topics can come up quite unexpectedly."

Sarah, mum to Grace (age 14)

"I was in RE once and we were talking about illnesses. The teacher told the class about a girl with CF who died. I was on the verge of tears and spoke with the teacher at the end of the class. The teacher apologised and was really upset, she'd forgotten that I have cystic fibrosis."

Ashley (age 16)

“

“I was really pleased that the school contacted me when my eldest daughter, who doesn't have CF, was going to be taught about CF in class. Very considerate of them, and much appreciated. We spoke about it again when Faith was about to do the same class a couple of years later.”

Kerri, mum to Faith (age 18)

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Top tips for parents

"I think if I could change anything about the way I handled Faith going into secondary school, it would be to step back a little more. I wish I'd encouraged her a little more to take control of her own situation rather than nagging. Sometimes children do have to learn through their mistakes and I don't say that lightly. It's part of growing up, but very difficult for us parents."

Kerri, mum to Faith (age 18)

“

"Try to get good communication established with the school, ideally before your child starts there. Knowing who to speak to about any issues that come up and having a system in place for sharing information is really helpful."

Katie, mum to Lewis (age 11)

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"I think it's really important that teachers are aware of the possible emotional impact of CF - children are dealing with symptoms and the treatment burden as well as everything else in life, and for some children it can be hard living in the shadow of this condition."

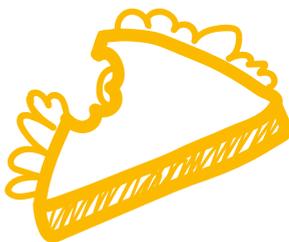
Rebecca, mum to Ashley (age 16)

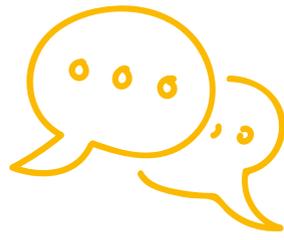
"Make sure teachers know that a 'healthy diet' for other children isn't necessarily healthy for children with cystic fibrosis. The extra calories are of course part of their treatment, it's useful for teachers to know this so they're not labelling your child's diet as 'unhealthy'."

Pamela, mum to Alasdair (age 14)

"Think about simple things that the school can do to make things a little easier for your child - getting a fast pass for the lunch queue and having a conveniently situated locker are small requests but can make a big difference."

Sarah, mum to Grace (age 14)







Checklist



There's a lot to think about! Here's a quick checklist to help you organise your thoughts:

- Work on increasing your child's independence before going to secondary school.

See our 'Ask the psychologists' section for ideas on how to do this.

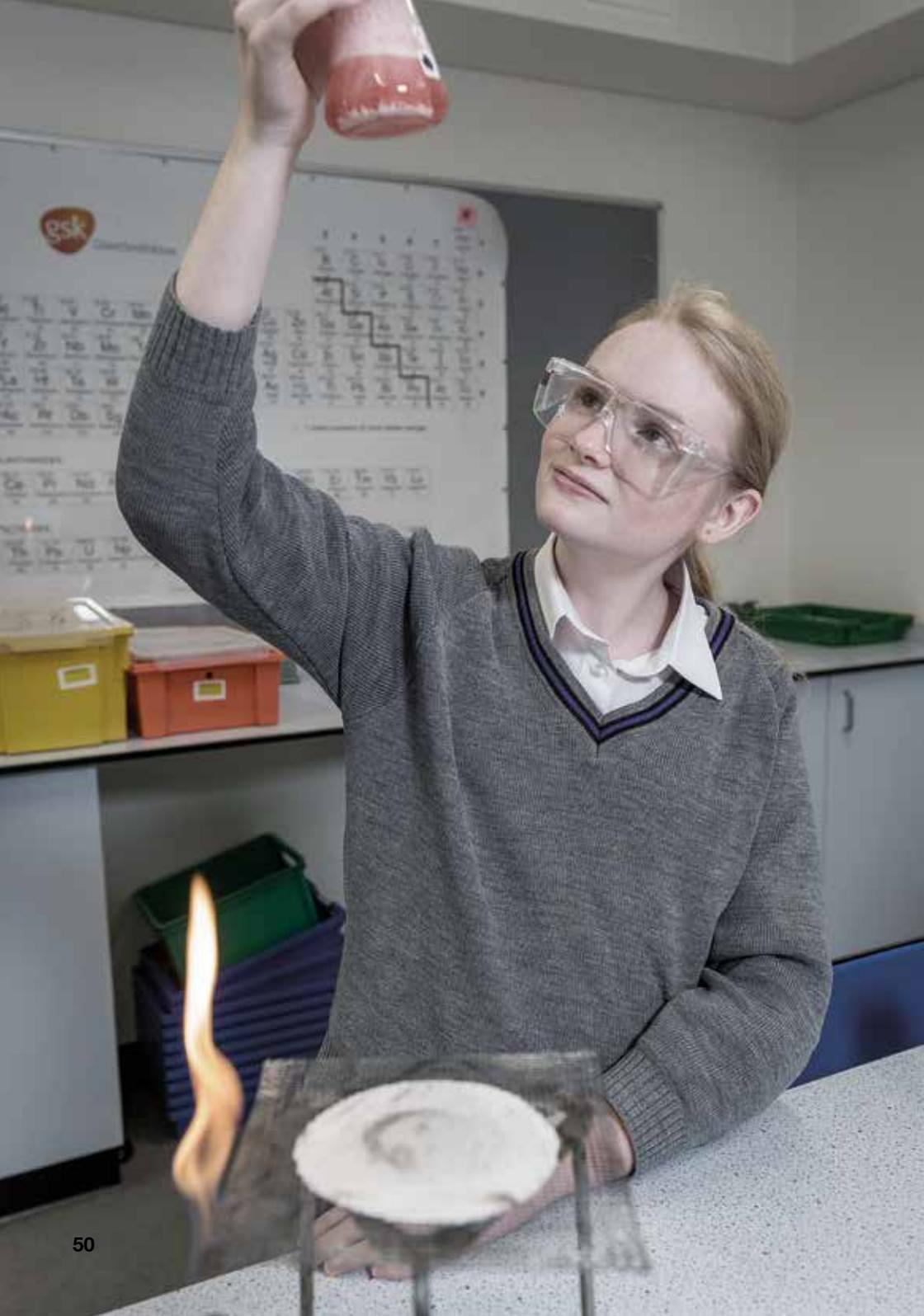
- Contact the secondary school once you've been offered a place to identify key contacts.

- Talk to your child about how they want to manage their CF at school (including Creon dosing and remembering confidentiality).

- Talk to the school or your CF team if your child is having any difficulties, they may be able to make small adjustments to make life easier.

- Arrange a meeting with the school to formulate an Individual Healthcare Plan or similar document. Remember to talk about the best way to communicate, the treatment burden, diet, managing absence, cross-infection, participating in PE and CF on the curriculum.





Ask the psychologists



Ask the psychologists...

Parents told us what their main worries had been in the early days of their child being at secondary school - there were some common themes so we took these questions to a team of CF psychologists to get their expert views. Here's a summary of their advice. For tailored, specific advice do contact your own child's CF team.

Q "I'm really worried about Abby starting secondary school; who will check that she's taking her Creon? Who will make sure she eats what she's meant to? Who will be there to check that she's not doing something where infection could be a risk?"

A This is a question about independence. The reality at secondary school is likely to be that there is much less teacher/staff involvement in your child's CF management. So it's important that children with CF are starting to get ready to be more independent in their own care in preparation for secondary school.

Approaching this as a good opportunity to re-assess how you manage CF within your family might help give this a more positive starting point. It might feel like you're losing control and in a sense you are - but encouraging your child to be independent is an important part of them growing up and developing the resilience and skills they need in adult life. Children with CF are all different and will be more or less prepared for this journey to independence!



Between the ages of 10 and 13, ideally there should be a gradual transfer of knowledge from you to your child. Encouraging your child to work out their own Creon and take it independently before they join secondary school is a really good start to encouraging independence. Planning this in partnership, rather than telling them what to do, is more likely to result in success.

Sometimes parents can be quite anxious about treatment adherence and very keen to impress the importance of treatment on the child. That is understandable but it's important to remember that children of this age, and even beyond into teenage years, are not mini adults. Their brains function very differently and as a result their control of emotions is different to an adult brain and they also have different



perceptions of risk and priorities. So, just because you say it and give them the sensible adult reasoning, does not mean that it will always be remembered and acted upon.

Working together to come up with a realistic plan that takes account of their needs and priorities is more likely, but not at all guaranteed, to help them stick to their treatments.



When I'm in clinic, I ask children and parents if they've thought about this change and how they'd like to approach it. Sometimes parents and children have very different views about how they want to deal with the change to secondary school, for example telling others about CF, managing Creon at school and dealing with absence. It's good to get it out in the open, even if you don't agree, so that you can talk about it together and work out a plan.



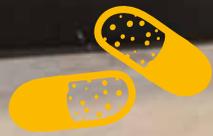
Q "My son has been at secondary school for a few weeks now and I'm struggling to get him to take his Creon. It feels like a constant battle. He just keeps 'forgetting'. I don't want to be a 'nag' - help!"

A Again we are thinking about independence but also about communication here. Lots of parents, including those who don't have a child with CF, feel that they are often accused of nagging. It is, unfortunately but naturally, the case that parents will be considered to be a 'nag'. However, there are some strategies that could help minimise this. Working together to find other forms of reminder might reduce tension, for example using an alarm, checklist or good friend to remind a young person to take their antibiotics or do their physiotherapy. CF teams may also be able to support you all by starting conversations about treatment priorities and drawing up timetables.

“Remember to take your Creon! Have you taken your Creon? Please take your Creon! Where's your Creon?”

Talking with children and young people about what they want is a helpful, partnership approach and gets you all on the same page. Crucially, identifying where they want to be independent and where they want help is a good start to developing a plan.









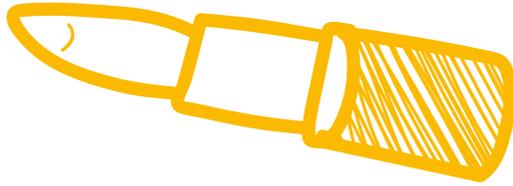
"My daughter is quite embarrassed by her CF and doesn't want her new friends and teachers at secondary school to know about it - she thinks she won't fit in. I'm worried that if they don't know, they won't know to look out for her."



We often find that children and young people don't want to tell all their classmates about CF and generally take their own time to share this information. This obviously varies from child to child and will also depend on how you, as parents, view and talk about the condition. In terms of fitting in, it's important

to talk with your child about what it means to be 'like everyone else' - remind them that we are all different. Aiming for 'normalcy' is important and by that we mean having the opportunity to take part in the activities other children take part in, engaging and having a full school experience and having fun rather than being exactly the same as everyone else.





Q "My daughter has become quite image conscious since starting secondary school. I don't know if it's just her age or the influence of her new friends but she has talked about wanting to be slim. Nothing else, but it worries me, I want to nip it in the bud."

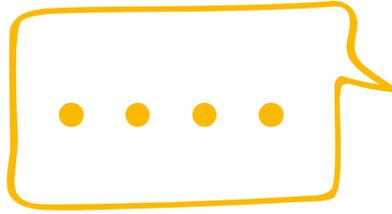
A With so many images of impossibly slim, sculpted and blemish-free bodies, it's hardly surprising that negative body image is an issue for people across the world - men and women, young and old. It's really helpful to make sure children know that people don't really look like this. Airbrushing and other digital techniques along with professional lighting and plenty of make-up can make someone look very different to reality!

As with children without CF, it is helpful if weight and appearance are not over valued. Parents, especially mums, can be hard on themselves about weight - try not to talk about being overweight, needing to diet or being critical of yourself in front of your children.

CF dietitians are a wealth of knowledge about nutrition and what a growing body needs. They are also well-placed to have a discussion with your child to explain why sticking to the treatment plan is important and what it means for their body.

It can be helpful to reinforce the connection between a good diet and keeping their body strong and fit and able to do fun, active things. A good diet can also help keep skin, hair and nails healthy too, and this might be a useful trigger for some young people.

Where children are struggling with body image, contact your CF psychologist who will be able to advise further.



Q "My son is a sensitive boy and he's got a lot to deal with: starting secondary school, having CF and being quite shy. I worry about how he'll cope with all this plus the pressures of secondary school and beyond. What can I do to make sure he's happy and coping?"

A Moving into secondary school and beyond into teenage years is likely to be a time of many emotions! Some children find the transition into secondary quite daunting or may experience times of worry or sadness as they get used to their new routine. As with any child, look out for a change in behaviour, loss of appetite, reluctance to socialise or your child seeming withdrawn. Red flags such as these suggest that something might not be quite right. As a parent, your child needs you to be available to speak to and to know that you will really listen. You may need to brave some slammed doors and upset, but persevere. It can be a stormy and difficult time for children and your role is to be their calm and steady rock (as much as you can!).

Children are growing up in a complicated world with social media playing a more important role than we could ever know and understand as adults. Whilst this can be quite positive for some young people with CF who wouldn't otherwise be able to connect, it's important to be open about the harmful impacts of social media too. Try not to shy away from any difficult discussions about the pressure that social media can place on them and encourage conversation and time away from the digital world.

More Information

This booklet provides an overview of some of the issues that may come up as your child starts in secondary school but we understand that you may need more detail or tailored advice. Your child's CF team or the Cystic Fibrosis Trust Helpline will be able to provide additional support and information. 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 on WhatsApp on 07361 582053

Visit cysticfibrosis.org.uk/helpline for more information.

You may also find the following websites useful:

- medicalconditionsatschool.org.uk for information about policy on children with medical conditions at school, including information about the Equality Act 2010 (applies to England, Scotland and Wales) and the Disability Discrimination Act (for Northern Ireland).
- ipsea.org.uk for independent parental special education advice (IPSEA).
- enquire.org.uk for information about additional support for learning in Scotland.
- gov.uk/government/organisations/ofsted for school reports in England.
- etini.gov.uk/publications/type/inspectionreports for school reports in Northern Ireland.
- education.gov.scot/inspection-and-review for school reports in Scotland.
- estyn.gov.wales/inspection for school reports in Wales.

Cystic Fibrosis Trust is very grateful to all the families who were involved in producing this booklet. We would also like to sincerely thank the CF professionals for their valuable input, in particular the CF psychologists who provided such helpful content.



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