Cystic Fibrosis Trust

Transition to adult care

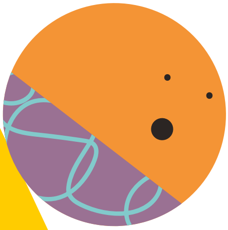
A guide for families and carers

Fighting for a Life Unlimited

Growing up is all about change

Some changes are small, like letting your child go to school on their own for the first time. Others are bigger, like seeing them off to university or their first job. When a child with cystic fibrosis (CF) is growing up, there are other changes to consider too. One of the biggest changes is the transition from paediatric to adult care.

Transition is personal.
We want your child to feel
listened to and empowered,
whatever shape it takes.

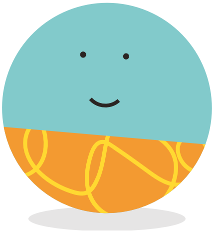


This move can be a challenging and exciting time, full of new opportunities and experiences for young people with CF and those who care for them. It's a time when young people are encouraged to take charge, and adults start to hand over responsibility.

Moving from paediatric to adult care can be a big step for young people with cystic fibrosis. But sometimes people forget that it's a big step for their families too. It's not just a change of clinic, but a change of who takes responsibility for their CF care.

Giving up control might feel scary, but from the moment your child is born you are already giving up little bits of control over their life. Letting them feed themselves or cross the road without holding your hand, and waving them off when they leave home are all moments of encouraging independence. It can be helpful to think of the move from paediatric to adult care as another of these moments.

> **"We did accept that this was the next phase and took it in our stride, but then we've done that through all of Kate's CF journey." – Kate's parents**



What is transition?

Transition is the term used to describe the move from paediatric to adult care. During transition, the paediatric team that cared for your child will hand over that responsibility to an adult team. Your child's new adult team could be in a different hospital to their paediatric team.

Many families will call transition 'starting adult care' or 'moving to an adult CF centre'. However, transition is a useful term to use when thinking about what this process means. Transition shouldn't happen suddenly, but should be a gradual process, tailored to the needs of you and your child.

When does it happen?

The National Institute for Health and Care Excellence (NICE) says that planning for transition should start when a young person is 13 or 14. Transition should only take place if a child's CF team feels that they are 'developmentally ready'. The CF team will think about your child's physical and mental health, emotional maturity, and your family's personal circumstances. The transfer from paediatric to adult centre will usually happen between the ages of 14 and 17, and will often take place around an educational milestone, like after your child's GCSEs.

It's important to remember that transition happens at the same time as a number of other big events for young people, like puberty, exams and first relationships. That's why CF teams usually start talking about transition some time before your child actually moves into adult care.

> **"We received a booklet and were introduced to the whole team but still saw her paediatric team along with some of the adult team. We were prepared for the transfer around six months before the move and had plenty of time to ask any questions." – Elaine**

> **"Our CF nurse began to talk about it to Lucy and myself around the age of 14, I think. It does seem far away at that time, but looking back now, it goes very quickly." – Jill**

Why does my child need to transition to an adult centre?

Years ago, CF was thought of as a 'childhood condition', but today people with CF are living longer, fuller lives. There are now more adults living with CF than there are children, thanks to advances in treatment and care.

As you'll know, paediatric care is catered to young people and their families. In an adult centre your child will receive care catered to their changing priorities as they grow older. They will be supported to achieve important life goals, like higher education, work, relationships or starting a family, and be given access to mental health, education and benefits support.

As people with CF grow older, they can also develop complications related to their CF, like CF-related diabetes. A specialist adult CF team with a wide range of skills and experience will help them to get the best care possible.

It's also important for young people with CF to become more involved in the decisions made about their care. Their new adult CF team will empower them to be more independent and start managing their condition.

Some young people might not understand why they need to move to adult care, particularly if they're close to their paediatric team. Others might be excited to gain independence!

"I personally felt at the time she did transition (age 17) that she wasn't ready, and I don't think she really wanted to leave either." – Jill

"I think we need to encourage people not to be too fixated on clinical transition, this is something very much part of a wider process of them growing up and taking responsibility for their cystic fibrosis." – Ed

What are the differences between paediatric and adult CF centres?

> **“The adult team were very friendly, and tried their utmost to make Lucy feel less worried. It took a few visits to get used to their way of doing things.” – Jill**

When a child is young, their paediatric CF team may have had more of a ‘parental relationship’ with them. This means that decisions were made for them rather than with them. As they grew up their paediatric team will have encouraged them to take more of a leading role in making decisions about their care.

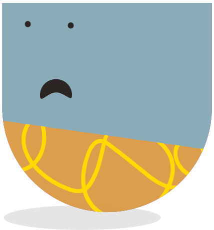
In adult centres, CF teams work directly with young people, and the relationship is more of a ‘partnership’. Adult CF teams encourage young people to take more responsibility for their care, and support their family or carers through this change. CF teams will also try to fit a young person’s treatment around their lifestyle. This can help to make it easier and more likely for them to complete their treatments.

You might find that the adult centre feels a bit different to the paediatric centre. Most people with CF start going to their paediatric centre when they are very young, so by the time they move to adult care, their paediatric centre probably feels very familiar.

> **“The adult team haven’t excluded me as a parent, as that is not what Grace wants at the moment. She still relies on me to manage her medication and appointments. It’s worked well from both our perspectives and I feel the adult team have been very responsive to how we have both felt.” – Sarah**

Connecting with a new team might feel challenging at first, but remember that at one time the paediatric team was new too. Making sure your child can meet their new team, and that they transition at their own pace, can help to build these relationships.

Finally, your child’s adult CF team might talk about things that weren’t discussed in paediatric care, like fertility or pregnancy. Usually your paediatric team will have covered these things with your child before they move. However, you may want to make sure that these topics won’t be a surprise for your child, and find out if they have any questions.



What will happen when my child moves to an adult centre?

> **“It was probably a bigger shift for her mum and me than her. The paeds team started to gear up to the change about a year before and talked to us about it. There was a deliberate shift to put Ella centre-stage in consultations and discussions, and to encourage her to be more clearly defined as the decision-maker rather than her parents.” – Ed**

Children don’t turn into adults overnight. They begin to mature long before they move to adult care and will keep doing so after they’ve moved. To reflect this, transition should be a process that happens slowly over time.

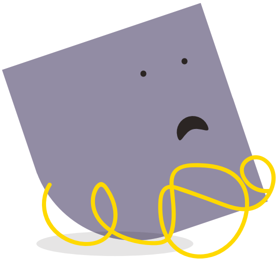
Paediatric and adult CF teams sometimes offer services to help with this. One service is a ‘transition clinic’, where the paediatric and adult teams meet with the young person and their family. In these meetings, families get to know the new team and ask questions with the support of the old team. It’s also a chance for families to talk about their lives, routines and any concerns they have. Not all CF centres hold these clinics, and centres will manage transition in different ways. Some will instead hold ‘open evenings’ for parents or share their own resources. Speak to your CF team about what is available.

Once a young person has moved to adult care, their adult CF centre may try to adapt their services to help them feel more comfortable. This could mean allowing you to be there during appointments or having appointments that you don’t attend. This should depend on the young person’s wishes.

If your child has concerns or queries about the way things work at their adult centre, they should know who to speak to and feel confident in doing so. In the young person’s toolkit, there is an adult CF team template to complete that should help them with this.

> “I went to a transition open day which was really useful as we met the team and got to look round the adult facilities. One of the most useful parts of this was getting to talk to an adult CF inpatient about their views of the adult care they received and how they juggled work, partners etc whilst in hospital.” – Sarah

> “Both boys had introductions to the new adult team on a couple of occasions before moving over from children’s care. Transition for my youngest son was easier as I knew what to expect.” – Lorraine



Will my child stop doing their treatments when they move to adult care?

Doing treatments is sometimes called 'adherence'. If someone is struggling to do all their treatments it might be said that they are 'struggling with adherence'.

Some families have concerns that in moving into adult care and becoming responsible for their treatments, their child might stop doing them. However, it's important to remember that moving to adult care is a process, and your child doesn't need to take responsibility for all their treatments in one go.

For example, when your child was younger you probably gave them Creon with their food. When they got older, you might have started to explain how their Creon works, and how and when to take it. By the time they're ready to move to adult care, they'll probably be confident taking their Creon and understand why it's important.

Eventually, the same will be true for all their treatments. Of course, it might take your child longer to feel confident with some treatments than others. However, with the support of their CF team they should eventually feel confident being in charge of their care.

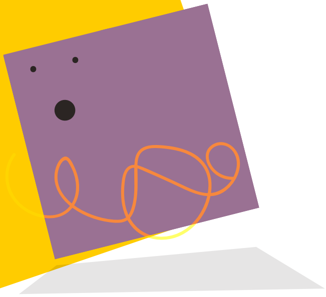
Some families can feel like they are losing control as their child moves to a new clinic, and in a sense they are. However, encouraging independence is an important part of growing up, whether you have CF or not.

"They both know now that their care and treatment is in their hands. If they don't want to go into hospital for IVs the team listens. They are now 'adults' and their choices are a priority. I didn't like this to begin with, but I see now that it's their life – they are old enough to make decisions." – Lorraine

How can I make sure my child understands how important their treatments are?

If you’re worried about your child doing their treatments, you might find yourself trying hard to convince them how important they are. Despite this, they may still forget or choose not to take your advice. Young people think very differently to adults, and they may not understand risk and reward in the same way as you. It might take them a long time to understand the lasting impact of taking, or not taking their treatments.

> **“As her parents, we had been slowly encouraging Ella to take greater control and build greater understanding of her condition in the year or two before this clinical transition, so that probably helped her feel that this was something natural and relatively routine.” – Ed**



Why not work together as partners and come up with a treatment plan that takes account of your child's priorities? For this to work, you'll need to engage with their opinions and accept them, even if you don't agree with them!

For example, your child might think that hanging out with their friends is more important than doing a time-consuming treatment. You probably won't be able to change their mind, but you can try working together to come up with compromises. Your child's new adult CF team may try a similar approach if they are struggling to complete their treatments.

It can also be helpful to encourage your child to talk about the possible consequences of their actions. For example, you could ask them: "What do you think would happen if you didn't take your Creon today/for a week/for a year?" It's important that this is a genuine discussion rather than an opportunity for you to make a point. It will allow your child's feelings to be heard, and for you to understand how they see their treatments.

> **"My youngest son used to get so depressed going into hospital. He was of the mind-set of 'why bother putting any effort in, they are only going to take me into hospital anyway'. Now that he knows it's his choice, his attitude has changed. He has control now and he's a lot happier and his health is better." – Lorraine**

> **"I have noticed recently that Grace has been far more aware of her CF, talking before her appointments about what we need to discuss, talking afterwards about the outcomes of the appointment and opening her own letters, so I can only imagine that is due to the transition." – Sarah**

What if my child makes decisions that negatively affect their health?

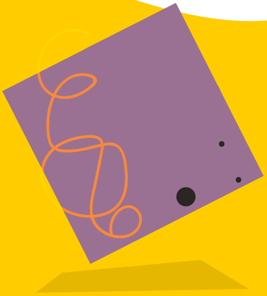
It's important that children with CF start to take charge of their own care as they get older. This helps to prepare them for adult care, but also for the rest of their lives.

It's incredibly difficult to see a child make decisions that could negatively affect their health, but for some families that can happen. We hope that young people will learn from their mistakes and make better choices next time. Families and CF teams can support young people to make good choices, but eventually they will need to take responsibility for their own lives.

If your child has become unwell because they didn't do a treatment, try to discuss this with them rather than becoming angry or frustrated. Give them the opportunity to talk about why they didn't do their treatment. Together, you might be able to work out if there's something that can be learned or changed so it doesn't happen again.

If you have concerns about adherence, you can speak with your child's CF team. They will respect your child's right to confidentiality but can still provide advice and support.

> **"See transition to adult care as a positive step, the start of your child showing some interest in their health, their treatments and their long-term wellbeing. No one will make them do something they don't want to do, it's their choice and their life. The more effort they put in, the better life will be in the long term." – Lorraine**



What will my role be during and after my child's transition?

It's impossible to say what your role in the transition process will be. Every family is unique, and some young people will turn to their families for help while others won't. You might find that your child wants to become more independent, or you might find that they don't engage very much with the transition process.

> **"I didn't feel this way, but at CF conferences I have spoken to parents who felt out of control. One of my friend's sons refuses to let his parents in at clinic, and I know they find this very hard. Lucy still likes me to go into her appointments with her, however when she was admitted to hospital for the first time in October 2018, she found that incredibly hard, as I could not stay with her." – Jill**

Whatever your role is, it should be based on the needs of your child. If you haven't already, you could have a conversation about how they feel about moving to adult care. Ask them how involved they want you to be in the process and try to be guided by them as much as possible. Give them space to ask questions, but don't force it if they're not interested in talking. Just letting them know that they can come to you for support will encourage them to do so in the future.

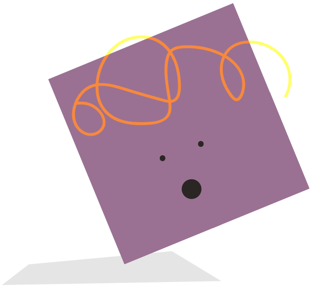
Once your child has transitioned, their adult CF team might discourage you from being as involved in their care as you were before. Some parents find this frustrating, especially if they are used to having a very active role in their child's care. Try to speak to the adult team before your child moves and find out what their plan is for your child's transition. It's better to know in advance if the way you interact with your child's care will change.

In the young person's toolkit, there is a list of questions for your child to ask their CF teams throughout their transition. Why not use these questions to start a discussion about any concerns they might have?

> “I’d looked after him since he was diagnosed, and I found his transition particularly difficult as I felt it was my job to look after him and to do all his care and treatments, and suddenly he wanted to do them himself. Eventually I ‘let go’ as he learned how to drive fairly quickly and took himself off to appointments on his own from age 17!” – Lorraine

Remember, you have probably been a key figure in your child’s life so far. There’s no reason that this will completely change as soon as they move into adult care. However, as they mature they might seek support from other people too. This could include their friends, partners, teachers, employers, colleagues and members of their CF team.

> **“The adult clinic initially refused to respond to emails or calls from us as her parents, saying they were only prepared to deal with Ella directly, even for routine issues like ordering new medicines or checking on appointment times. We did agree a compromise which now works for all of us, but the initial arrangements felt inflexible and unnecessary.” – Ed**



How can I build a good relationship with my child's adult CF team?

> **"We had a good rapport with the respiratory nurse in paediatrics who we had known for 14 years. If we had concerns about Kate, we knew that she was accessible and only a phone call away. We were sad to leave the familiar faces as they had been so supportive from day one." – Kate's parents**

For many families, their child's paediatric CF team has been there for them through good times and bad. Often they have worked with a family since their child was first diagnosed with CF, supported them when their child was very unwell and seen them through challenging procedures. Sharing these big moments can mean that your child's paediatric CF team feel more like a part of your family than a medical team.

Remember, it's possible that you and your child will feel differently about leaving the paediatric team. Your child might not want to say goodbye, and that's okay. Every family will have a unique relationship with their child's CF team.

If you have a close relationship with your child's paediatric CF team, you might want to say goodbye when they move to adult care. This could mean writing a letter or meeting in person with the team before your child moves. Speak to your child and find out how they would like to say goodbye. Having this conversation could help you to find out how you both feel about the move from paediatric to adult care.

It's normal to want to keep in contact with your child's paediatric CF team. However, once your child has transitioned, going back to their paediatric team for advice isn't a good idea. It might feel comfortable to speak to a team you're familiar with, but the paediatric team will no longer be involved directly in your child's care.

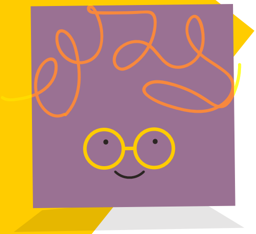
“Inevitably, there was a sense of loss at losing strong relationships with some of the paeds team. There were one or two clinical team members who had been part of Ella’s and our lives for 17 years and so saying goodbye was emotional.” – Ed

Your child will take cues from you about how they should feel about their transition. That’s why it’s important that you both start to treat their adult CF team as their ‘real’ CF team. You can help your child to feel more invested in this change by respecting and collaborating with their new team.

Developing a relationship with your child’s adult CF team might take a while. But by working together and respecting each other’s roles, you’ll be able to better support your child.

> **“Obviously for us, now five years on from transition, it doesn’t seem such a big deal, but I think when you have been with a paediatric team for such a long time, it can be very hard to leave that team. It takes time to put your trust in the adult team, but once you have, and get to know their personalities, the whole transition process is complete.” – Jill**

> **“I would strongly suggest a phase out of paediatric care whilst commencing adult care, so you don’t feel totally cut off from the people who have helped with the care of your child for the past 14 years.” – Kate’s parents**



Finally

We hope this guide will help you prepare for your child's transition, but things may come up that you weren't expecting.

Remember, transition is like any life event; there might be some challenges along the way, but these challenges will be temporary. Moving to adult care is a great opportunity for your child to become more independent, develop new skills and get the right care and support on their journey to adulthood.

A few things to remember:

Plan – find out from your child’s CF team what the plan is for their transition.

Start early – encourage your child to engage with and take responsibility for their care. How early you do this will depend on your child.

Work together – support your child to build a relationship with their new team.

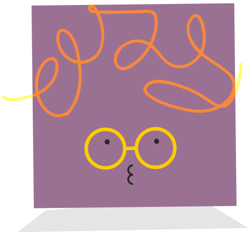
Communicate – speak to your child as an equal about their treatments rather than ‘nagging’ them. Try to accept that you cannot control the decisions they make about their health.

Let go – think about how you want to say goodbye to your child’s paediatric CF team. Once your child has transitioned, try to develop a relationship with their new team.

We’ve developed this booklet to provide some information that might be helpful as your child transitions to adult care.

If you need more information or support, contact your child’s CF team.

You can also speak to the Cystic Fibrosis Trust’s Helpline on **0300 373 1000** or at **helpline@cysticfibrosis.org.uk**



Thank you

The Trust is grateful to all the young people who have shared their stories and given up their time to review these resources. Sincere thanks must also go to the CF professionals who contributed their expertise and time – we would not be able to produce resources like this without your help.

Get in touch

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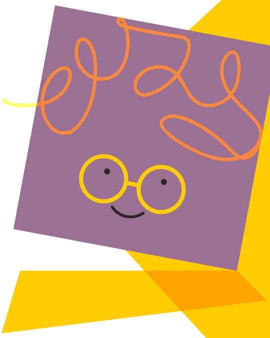
Ask us anything



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