

**Cystic
Fibrosis Trust**



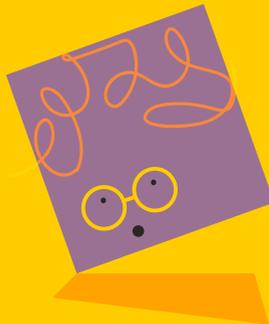
**YOUR
transition to
adult care**

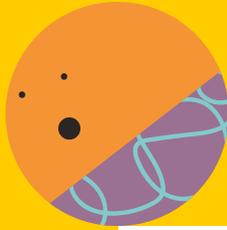
Fighting for a *Life Unlimited*

WHAT is transition?

If you're reading this, the chances are you've heard the word 'transition' a lot lately. It's the medical term for moving from paediatric to adult care.

How the subject of transition comes up is different from person to person. You might get a letter from your clinic telling you that your transition is going to start soon, you might have been unwell and needed specialised care from an adult clinic, or you might not be ready to transition but want to know more.





How you feel about moving to adult CF care is personal, and can be affected by loads of things. For example, how independent you are with your treatments or how close you are to your current CF team. Whether you feel anxious, laid-back or somewhere in between, no one knows your condition better than you. By taking an active role in your transition you can make sure your CF team knows what works for you.

Young people with CF who have transitioned to adult care helped to develop this booklet. We hope it'll give you some tools to make the most of your transition. With preparation it can be an exciting opportunity to gain more independence and take control of your changing CF care.

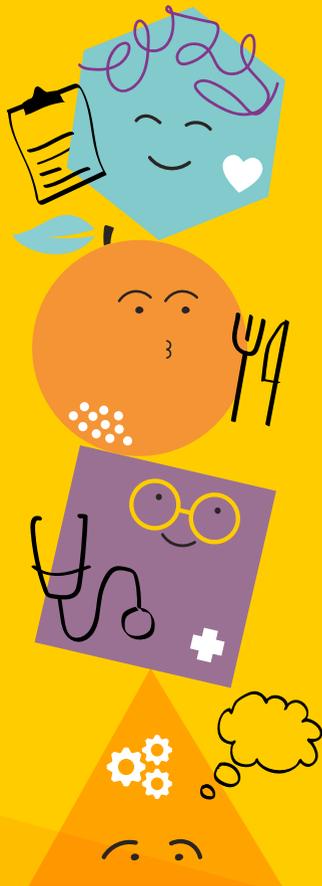


“I first heard about transition in CF services from my friend with CF who was several years older. They were going to transition the following year, and I asked my CF nurse at the time what it was.” – Jordy

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



WHY do I have to transition?



'My paediatric CF team has been looking after me pretty well so far, so why do I need to move?' It's a fair question. But while a paediatric team is great at taking care of you when you're a child, as you get older your needs might change or become more complicated. That's where an adult team comes in.

Adult CF clinics have specialists who can help with your physio, nutrition and mental health, as well as providing advice on benefits or planning for your education. Moving to an adult centre can mean getting a more personalised approach to your care.

"My team includes doctors, nurses, physios, dietitians, psychologists and social workers. Having a whole team focused on every aspect of CF is great, even areas I had never thought of are covered. The psychologists have helped me with many things, from social anxiety to my needle phobia." – Cicely

When you're being cared for by a paediatric team, a lot of decisions will be made for you. When you're younger that makes sense, but as you get older it's only right that you should start making decisions about your own care. An adult team will encourage you to be independent and get more involved in these decisions.

"Moving to adults can be seen as a worrying time but really it can be a chance to start again, to reinvent yourself with cystic fibrosis. You are starting afresh with a new team so if you haven't been as committed to doing your treatments as you maybe should be (I know that was me!) you have the chance to change that and work with your team to provide a better future for yourself." – Cicely

WHY

now?

“We set a date well in advance, so I knew exactly when I was moving.” – Poppy

Transitioning to adult care usually happens between the ages of 14 and 17. Why then? Well, in your mid-to late-teens you'll probably start becoming more independent in other ways too.

It's around the time you'll start thinking about what you want to do after you finish school, whether that's going to university, taking a training course or something completely different. As you're starting to take control over other areas of your life, it makes sense that you'd start taking control of your CF too.

“For me it was a really intimidating thing to do and it took me a long time to adjust.” – Kate

When your transition is based on lots of different things, like where you live, your health and how independent you are with your treatments. This means that some people transition earlier or later than others. It's important that your transition fits in with you and what you need.

“My transition wasn't the smoothest and didn't go how it was planned. I was very unwell and my paediatric team said that I had become too complex for them. I didn't feel ready to move but I knew my team had suggested it because they didn't have the resources or knowledge to treat me to the best of their ability. My transition was more focused on the sake of my health rather than if I was ready to go.” – Cicely



Will the adult service be DIFFERENT?

In the build-up to your transition, you might notice your paediatric team encouraging you to get more involved in making decisions about your care. That's to prepare you for moving to adult care, where your new team will want to make decisions with you rather than for you. While you can still have support during your appointments, your opinion will be what counts the most.

“Adult care really isn't that much different from paedes, apart from having a different team. In fact, it's sort of better because you can be more independent if you want and your family don't have to know everything you discuss with the team.” – Izzie

How involved you are in your care might change, but your care itself shouldn't when you move unless for a medical reason. Your old team should share a detailed, written handover with your new team, and make sure that you continue to receive the appropriate level of care to keep you well.

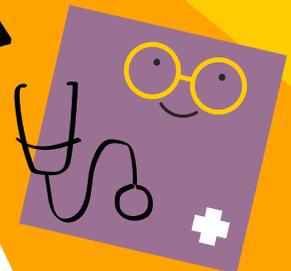
“Of course, at adults they teach you how to be more independent. But everyone is different and it will take everyone different lengths of time to adapt. I'd encourage people to ask questions. No question is silly and the doctors love to chat about your life as well to get to know you more.” – Lucy

What about the new centre itself? When you first visit, it might feel a bit less 'homely'. Paediatric CF centres are set up to make sure young children with CF feel comfortable. Most of the time, people visiting adult CF centres are used to meeting their team and having tests or procedures. Because of this, things might look and feel a bit different to your paediatric centre.

“This was one of my biggest concerns and questions when moving, that the adult clinic would approach illness differently and want to change the medication I was on.” – Poppy



Tell me more!



What will **HAPPEN** when I **move?**



“When I was transitioning up to the adult unit, I was handed a little folder which contained an information booklet and a leaflet about the adult centre. I was also allowed a home visit from one of the specialist nurses from the adult unit, who came to introduce herself and the team and answered any questions myself or my parents had.” – Emily

In the same way that you don't go to sleep one day a child and wake up the next day an adult, transition shouldn't happen overnight. Your transition will probably start with a conversation between you, your family or carer and your CF team. Here, your CF team should explain what transition is and the plan they have for your transition.



“When I was transitioning, my team made a big deal out of it which made me feel more immature than I was.” – Eleanor



You should be able to chat about:

any concerns you have about transitioning

how confident you feel with different areas of your care

areas where you think you could be more independent



Over the next few months, or even years, you'll probably start having more and more conversations about your transition. This might include talking about which CF centre you're going to move to. Eventually you should have a chance to visit your new centre, meet your new team and get to know them.



This is a rough outline of what your transition might look like, but every transition is unique. Your transition will depend on what you're like as a person, your health and your own personal choices. Different CF centres also have different ways of doing things. Some hold transition clinics, where your paediatric and adult teams both attend, and you all get to know each other. Some will have their own resources to share with you, to help make sure you have all the information you need.

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“I had pre-transition clinics which I found beneficial in that I was introduced to some of the primary healthcare professionals who would be playing large roles in my care.” – Hasna

Most importantly, speak to your CF team before you transition, and let them know if you have any questions or worries. They'll be happy to help, and excited that you want to be involved in this important change.



“Personally, I did not have the best transition experience. This was not down to my paediatric team at all but rather because the transition materials were quite outdated. I asked a lot of questions which I discussed with my paediatric team, particularly my nurse.” – Nubi

What is transition?



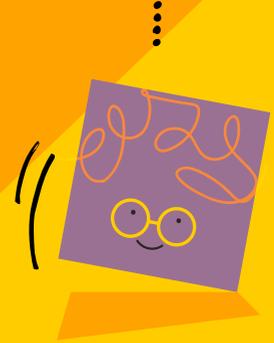
The present day

Oh, it's happening!



Sometime in the not so distant future

Ah... that wasn't so bad



The future

How
LONG
does
it take?

“Although it may seem daunting, it should be a smooth process that is spread out over a couple of months, so that it doesn't just happen all at once.” – Emily

Like everything else, this will depend on you. If you're moved to adult care because you're unwell, it might happen very quickly. If you're worried about moving to adult care, it might happen very slowly. Your CF team should make these decisions with you.

Ask your CF team what plan they have for your transition. This should help to give you an idea of what your transition timeline is, and allow you to work together on a plan that you're happy with.

“When I got to adults I was basically admitted straight away. I had to be admitted as an inpatient for six weeks. That is really how I got to know the team because I was with them 24/7 for that time. I was thrown right into the deep end.” – Cicely

Will I HAVE to go to my appointments on my own ?

“I was always worried that moving to adults would mean my parents wouldn’t be allowed to come in the room or something like that! When of course that’s not the case.” – Kate

You might be worrying that you’ll no longer be allowed to have someone to support you at your appointments once you transition. But we can reassure you right now that there’s no bouncer guarding the appointment room! It’s up to you whether you want other people to continue coming to your appointments or not.

“The doctors tend to speak to you rather than your parents and that was a big change I found. Since I have transitioned, I have always been the one emailing or phoning my doctors rather than my mum. Also, they feedback results directly to you rather than your parents and you can choose whether your doctors can share that information with your parents.” – Hasna

You might also be looking forward to the moment you can take care of your treatment and leave the person who usually supports you in the waiting room. Whatever your feelings are, make sure they’re heard. Chat to your family or carer about your transition and let them know what level of involvement you’re comfortable with. It’s a big change for them as well – they might find it harder to let go than you do.

However you feel, there’s no right or wrong way. Need support? No problem. Can’t wait to become more independent? Great!

“If you don’t feel 100% happy, ask to have an adult support there, a friend or family member, and tell your team you need this support.” – Jordy

What if I forget?

Am I ready?

Will I be

IN CHARGE

of my care now

?

What's for tea?

“I gained so much more independence when I transitioned. I carry out all of my own treatments, set up my own routine that works much better for me and took control of the small things – organising my own appointments and ordering prescriptions!” – Emily

If you're thinking about transition, you probably already have some independence when it comes to your treatments. But independence means different things to different people. Perhaps you know how much Creon you need to take but still need nagging to do your physio. Or maybe you have a wall chart, reminders on your phone and could clean your nebuliser in your sleep! It doesn't really matter what stage you're at, but you'll find that as you move into adult care your team will encourage you to be more independent.

“There was the expectation from paediatrics that I should be able to do all my treatment when I moved over and that pressure was a lot.” – Lucy

Start thinking about the things you need help with and discuss them with your CF team. They can give you techniques to make things easier. Don't feel embarrassed if you find it difficult to manage your cystic fibrosis. Dealing with a condition like CF, and the hours of work that goes into staying well, is something most young people don't have to think about.

“I didn't enjoy going to children's hospital at all, as I didn't feel like I had much of a say when it came to my CF, so I couldn't wait to move up to the adult unit.” – Emily

What if I need help?

It's also important to remember that while you will be encouraged to become more independent when you move into adult care, you will not be expected to become completely independent straight away. Your adult team will understand that it takes time to get used to doing everything on your own, and that you might still need support or reminding to do your treatments. Remember, most people with CF are supported with some parts of their care no matter how old they are.

"I would definitely encourage support and help with ordering prescriptions, as I was clueless and my mum worked full-time and couldn't explain it easily to me." – Jordy

Can I say **GOODBYE** to my old CF team?

You might feel very close to your CF team, especially if they've taken care of you for a long time. Or you might just see them as a team of people that provide your care. Both of these feelings are totally normal. However, if you are very close to some of the people in your paediatric CF team, you might feel a bit sad about leaving them.

"No one said to me that this is your last appointment with us before you move to adults. So I thought there would be a clinic at the new adult hospital, and then I'd go back one last time for my last appointment at paediatrics. But I was really upset in knowing that I'd never see my nurses and doctors again, because you become quite close with them." – Kate

If you feel like you want to say a 'proper goodbye' to your CF team, speak to your family or carer about it. You might find that they have the same feelings you do, and want to join you in saying goodbye to the team. And if you talk and find that you don't feel like you have that kind of relationship with your CF team, that's totally fine.

"I was only diagnosed at 14, so I don't feel like I developed the attachment to my paediatric team that other young people who have been diagnosed as babies have. The CF centre staff talked to me about getting attached to the paediatric team, but I thought this was weird because I hadn't had this experience!" – Hasna

What if I DON'T do all my treatments?

You CF team and your parents might have spoken to you about adherence. It's the technical term for doing your treatments. Many people with CF, no matter how old or experienced they are, struggle to do all of their treatments. Almost no one will do them all perfectly.

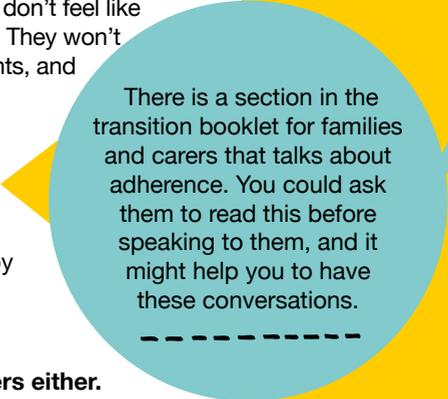
You might plan to take all of your tablets but forget one when you have a busy day. Or you might find that you sometimes skip your physio because it takes up a lot of time. You might even decide to stop doing all of your treatments, even though you know they keep you well. If you find yourself doing any of these things, you certainly aren't alone.



"It's good to be honest with your team as they won't tell you off for missing things. They understand it's a lot to juggle, as well as education or work. More often than not they'll come up with a plan and work with you to get better and this doesn't mean perfect adherence straight away either." – Cicely

If you're struggling with your treatments, try speaking to your CF team. They won't tell you off or be shocked. They've probably spoken to hundreds of people just like you, who will have their own reasons for struggling with their treatments. Instead, they'll want to know why you're struggling and how they can help. Try to be honest with your new CF team as well, and don't feel like you need to make 'a good first impression'. They won't judge you if you struggle with your treatments, and will want to help.

You could also speak to your family or friends, and try to explain to them why you find it hard to do your treatments. You might find that the people who love and care about you are worried or upset by the idea of you not doing your treatments.



There is a section in the transition booklet for families and carers that talks about adherence. You could ask them to read this before speaking to them, and it might help you to have these conversations.



"Don't compare yourself with others either. No one is going to post on social media that they are missing their treatments – they'll only focus on the positives and those who tend to post a lot seem to be 'perfect' when they probably aren't always either." – Cicely

Finally

Whoever you are and whatever your background happens to be, transition is personal. There is no right or wrong way of doing it as long as you feel listened to, empowered and supported by your team.

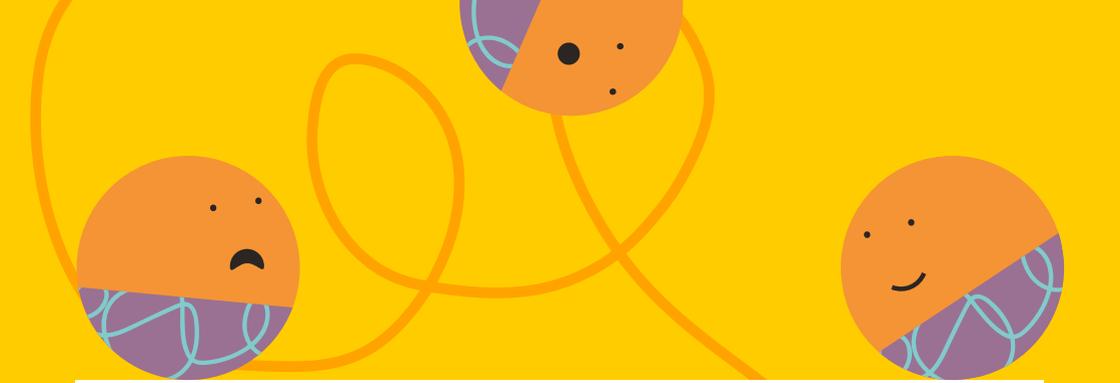
Choose the right path for you

No,
this way

This way

Your way





Some things to remember:

Get the best care possible – moving to an adult team means you can get specialist care you can't get in a paediatric centre.

Take charge – you'll be encouraged to get involved in your CF care, and your family or carer will start to take a back seat. This should happen in your own time, and you should feel comfortable with telling your team if you're struggling.

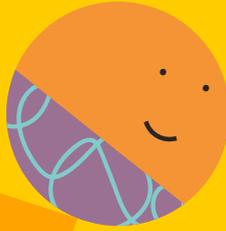
Have a plan – your CF team should be able to tell you all about their plan for your transition. Ask them any questions you have.

Work around you – how long your transition takes should depend on your needs. What you're offered to help you through your transition will depend on your CF centre.

"I know many say it's not about the destination it's about the journey, but for me I take that with a pinch of salt as my journey to adults wasn't easy. But now I'm here, I'm thriving." – Cicely

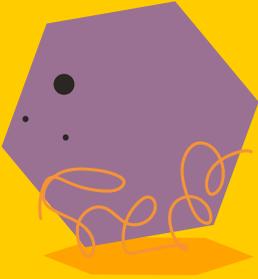
"The team at the CF adult unit were and still are so welcoming, they help with any questions – no matter how small!" – Emily





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.



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