Transition: moving to adult care

A guide for young people with Crohn's or Colitis

Transition means moving from the children's (paediatric) to the adult IBD team. You might be feeling nervous about this and that's totally normal. It can help to know what to expect. Transition is different for everyone. We can't say exactly what it will be like for you, but we can give you some general ideas.

This information may help you to understand more about what might happen and how you can prepare for the change.

We wrote this information with the help of young people who've been where you are now (and their parents). They shared their stories with us so we could give you tips to make transition easier.

> **They did it at such a gradual pace, it's not as scary as people think it might be. It's quite a smooth and gradual transition.**
>
> **Nick, age 21**
> Living with Colitis

Contents

Key facts about transition

- **Transition is a gradual process of moving from the children's to the adult IBD team. You will usually transition to the adult team when you are 16 to 18 years old. Planning for transition will usually start when you are 14 to 15 years old, so you have plenty of time to find out about your new team and ask any questions!**
- **Your IBD team will help you get ready for transition. They will make sure the new team has all of your notes and information. It can also help for you to take details of your condition to appointments - see page 9.**
- **It can take a while to get used to seeing the adult team. If you feel worried or stressed, talk to a health professional you trust. Sometimes it can be difficult to speak up, so you could ask for support from a friend or family member if you need it.**
- **If you are unsure of anything, ask your IBD team!**

Our words

In this information, we've used the words parents or carers quite a lot. By that we mean mums, dads, grandparents, guardians or anyone else who is caring for you.

Crohn's and Colitis are types of Inflammatory Bowel Diseases. We also use the term Inflammatory Bowel Disease (IBD) team to refer to the health professionals who support you with every aspect of your care. The team could be made up of IBD specialists, nurses, dietitians, paediatrician, gastroenterologists, surgeons, pharmacists and psychologists.

What is transition?

By now you might have heard your doctors and nurses say the word 'transition'. They've probably already explained that it means moving from the children's to the adult IBD team. This may be in the same hospital you go to now, or a different one.

Transition should be a gradual process that your IBD team help you prepare for. But eventually you'll have all your appointments, tests and treatments in an adult department. The idea is that as you're getting older you'll gradually get used to doing more for yourself.

You may also hear the word 'transfer'. This is less of a gradual process, and it just means that your care will be handed over to the adult IBD team. But transfer can also work well, especially when it's planned carefully. So, if your care is being transferred you can still use this guide to make the best of the change.

> **I felt a bit out of place in the kids' clinic. I felt like I am this 17-year-old giant compared to them, with a beard and everything.**
>
> **Andy, age 17**
> living with Colitis

Maybe like Andy, it feels like the right time to make the move, maybe you're worried, or maybe you don't mind either way. All these feelings are normal. There's more later in this information about how you can get ready for the move and how to cope if it's making you feel stressed.

Your feelings

You've probably got a lot on your plate.

Maybe lots of changes are happening all at once – exams, college, university, jobs, friendships, relationships, sex, going out, money...and much more. And now they also want you to go and meet some new doctor you've never heard of before.

It's not surprising if you find that stressful. The good news is that the new adult team will be able to help with all of those more adult things.

> **At that early stage when you're not quite sure of who you are as a person, IBD can be very, very impactful on your whole life. It's a very clichéd thing to say, but it does get better.**
>
> **Nick, age 21**
>
> Living with Colitis

Why you need to transition

You might be wondering why you have to leave the doctors and nurses who may have looked after you for a long time. They are experts at looking after children, but you're a young person now and soon you'll be an adult. So you need a team who are experts in young people and adults with Crohn's or Colitis. Lots of good things can come out of making the move. Some young people say that moving to adult services helped them find out more and manage their condition. And they also said they felt like they 'grew' as a person during the process.

How transition works

Transition is done differently in different places, but:

- It shouldn't be a sudden thing.
- You should have a 'transition coordinator.' That's normally your IBD nurse or another person who works with the IBD team.
- There should be some kind of overlap between being cared for by the children's IBD team and the adult IBD team.

You might have some appointments where you, your current IBD team and your new adult IBD team are all there at the same time. This will be a chance for you to meet your new team, and for them to learn more about you. They will also have all your medical notes. And it's your chance to ask lots of questions, if you feel up to it. A few hospitals have IBD teams or services that are set up just for young people - often 16 to 24 year-olds - where children and adult IBD teams work together.

> **I'm going to have an appointment with the children's service but the adult doctor is actually going to come in as well. So I will basically see two doctors, but I will still be in the children's department.**
>
> **Andy, age 17**
>
> Living with Colitis

When you might transition

The transition process usually starts before you are 16. It usually starts when you are 14 to 15 years old. but it can sometimes be earlier or later.

But it's not just about your age. Not everyone is ready to move on at the same time, so the hospital should aim to be flexible about when it happens.

Your team will try to think about:

- Your opinion (and your parents' if they're involved). It's your life and your treatment, so it's really important that you have a say. Being involved as much as you can, should help you understand what's going on.
- Your current health and how well your treatment is working. If you're not well at the moment, it might not be the best time to make a change.
- How you're doing with looking after yourself. You might hear this called 'self-management.' These are all the skills we cover later in this booklet.

Transition can be quite a long process. You might get bored of your team asking you lots of questions to check if you're ready for transition! But they want to make sure you're prepared for the change.

It might help to use the NHS Ready Steady Go transition programme. It has questionnaires you can fill in to see the parts of transition that you are confident in and the parts where you might like some extra help with. You can show these to your IBD team.

Where you will move to

This varies. You might move to a totally different hospital, or you might just change to the adult team in the same hospital. Some people have a choice of hospitals. It might also depend on whether you're planning to move away to work or study. Ask your IBD team what the options are and chat to them about the pros and cons. Talk to your teams (new and old) about your ambitions. Some people have their care shared between two hospitals. Some people have infusions in a hospital near their university, but still have check-ups with their team back home. There's no harm in asking about this type of thing. In fact, your IBD team would probably prefer that you ask.

> **It was a little daunting to move over to the adult hospital, but I also found it an opportunity to take ownership of my own health. I gradually learned to start managing appointments and medication myself and began to forge a closer relationship with my IBD team.**
>
> **Muzher**
>
> Living with Crohn's

Getting ready

Knowledge is power

Knowing more about your condition can help you have an easier time when you move to the adult IBD team. They will probably expect some more input from you than you're used to. The children's IBD team are probably helping you to prepare for this, but it could all still feel like a bit too much. You could fill in the table on page 9 and take it to your appointment.

We know that's not for everyone though – so you don't have to do it. But even just noting some of the main facts about your condition on your phone might help. Your new IBD team will have all your notes, and hopefully you'll already have met and had a chat.

Get the facts

To find out more about Crohn's or Colitis in general, you could:

- Talk to your healthcare team.
- Read our medical terms information. This is an A-Z of words to do with Crohn's and Colitis.
- Look at our website. It has loads more information on the conditions, treatments and how to look after yourself.
- CICRA also provide information on Crohn's and Colitis for children and teenagers.
- Ask your IBD team whether they run information or open days for young people with Crohn's or Colitis.
- Connect with other young people who've been through transition and come out the other side. Ask your IBD team if they can put you in touch.

> **At the moment George is on the cusp of transition, his nurse has told us that they run groups that meet for teenagers at this stage. They have a session talking about their concerns and getting support.**
>
> **Warren**
>
> Dad of George, age 15 - diagnosed with Crohn's

Your details

What is the name of your condition?

When were you diagnosed?

Are any other parts of your body affected?

☐ Swollen joints ☐ Skin rashes ☐ Mouth ulcers

☐ Red or swollen eyes ☐ Swollen lips ☐ Liver problems

Other:

What medicines are you taking now for your Crohn's or Colitis? It might help to write down the date you started taking them and how much you are taking (the dosage).

Are you taking any other medicine that isn't for your Crohn's or Colitis? For example, antibiotics.

What medicine have you taken for your Crohn's or Colitis in the past? Any dates you can remember may help, and other useful information like if you had a bad reaction to a medicine.

Have you ever stayed in hospital or had any operations? Add in any dates you can remember.

Any other information about your condition that you think is important:

Know your medicines

The adult team will probably ask you about your medicines, how you're finding them, and if you've had any problems.

> **I like to know why I am taking what I am taking, and what the risks and benefits are.**
>
> **Andy, age 17,**
> Living with Colitis

Everyone's different. Maybe you've been looking after your tablets or injections yourself for a while. Or maybe you don't even know their names and your parents do all of that!

See if you can gradually take more control of this. It doesn't have to be all at once – try working towards knowing all the names as a starting point.

In the end you'll probably be doing it all and getting your prescriptions too.

> **Emma has got an app on her phone to remind her to take her pills – it just flashes at her until she takes them! That really does help.**
>
> **Helen**
> Mum to Emma, age 19, living with Indeterminate Colitis

Fed up with medicines?

This is pretty normal. Keeping up with your treatment is important, but lots of people go through stages of struggling with their medicines for lots of different reasons. If this sounds familiar, it's a good idea to talk to someone about it. Your IBD team will be able to help, they deal with this sort of stuff all the time.

Getting confident

You won't be expected to suddenly do everything on your own. Go easy on yourself and take things step by step. Gradually, you'll feel ready to do more by yourself. There will be other stuff in your life you do alone already without even thinking about it. Friends and family can be a great help, even if it's just someone to chat to in the waiting room!

> **I've slowly grown more independent. But it's taken many years and work between me, the staff and my mum.**
>
> **Nick, age 21**
>
> Living with Colitis

To ease yourself into managing your own condition, you could:

- Ask to have a copy of your clinic letter.
- Write down any questions you have before your appointment. This can help if you don't have your parents there to remind you.
- Ring up or go in and make a few appointments on your own (if you don't know what to say write a few things down before you do it). If you have any questions or problems, contact your nurse or doctor yourself. You should have an email address or phone number for them. If you don't have it, ask your parents – they'll have it or know where to find it!

Find contact details for your local IBD service by using our IBD Nurse Specialists map.

> **Make sure you know where you are going before your first appointment in the adult clinic so that it's not as stressful on the day.**
>
> **Scarlett,** age 17
>
> Living with Colitis

Questions worth asking

Here are some ideas of questions about transition to ask your team. There's probably even more you want to ask, so we've left some space at the bottom of this page.

- What is the plan for my transition or transfer?
- When am I moving to the adult IBD team?
- Can I choose which adult IBD team or hospital I move to?
- What is different about the adult IBD team?
- Can I meet the adult staff before I leave children's services?
- Can I visit the new clinic or hospital to look around?
- Are there any young people I can talk to about transition or transfer?
- What do I need to know before I move to the adult service?
- How can I start getting more involved in my healthcare?

Write down any other questions you have here:

For more questions in general about Crohn's and Colitis, see our appointment guide. It has a list of questions about your lifestyle, support, medicines and surgery that you may want to ask your IBD team.

Moving to adult care

What's it like?

Seeing the adult team will be different. But this doesn't mean it will be bad. It just might take a while to get used to.

The new team will be really interested in getting to know you, what you like doing and how they can support you with your interests outside of school or college. They might ask about sports, activities or hobbies that you enjoy and also how you like to relax. They might also ask if you have any plans for studying at college or university or if you plan to start work or an apprenticeship.

You can ask them about moving to a hospital in a different city if you're planning to go away to study. They can also help with information about managing your condition at work. The adult team may also ask some questions that surprise you, for example if you smoke, drink alcohol or take recreational drugs.

> **I was slightly apprehensive that I wouldn't get as much support, but the consultation with the adult IBD team was much the same. They were really friendly and asked if I had any questions or concerns.**
>
> **Scarlett,** age 17
>
> Living with Colitis

Your IBD team

The gastroenterologist (doctor), nurses and any other health professionals you see will specialise in IBD care for adults and young people, but they will know about IBD in children as well.

Your new IBD team might be quite big. You can find more information about who could be involved in your care in our appointment guide.

What helps?

Meeting the adult team together with your old team, and parents, to start with.

You should be given a way of getting in touch with your new team outside of appointments or in emergencies. And they'll let you know which signs and symptoms you should tell them about quickly. Usually, you can phone or email them. Some clinics have a system where you can text a phone number and get a call back. You will usually need to provide your own contact details, rather than your parents.

The clinic

The clinic could be in another part of your usual hospital or a completely different hospital. The waiting area, appointment system and clinic room are suited to adults. So, there won't be any kids' books, or toys around.

What helps?

Go and have a look round before you move to adult care. Sometimes you can take a virtual tour on the hospital website. Some IBD teams will offer a "meet and greet" during the transition process where you can meet some of the team and be taken on a tour of relevant parts of the hospital such as the clinic, ward, endoscopy and infusion units. If you feel like a tour would be helpful, ask your IBD team if they can arrange one.

Take stuff to do if you think the waiting room might be boring.

You might have appointments less often than before and book your appointments in a different way. Your appointments at the adult clinic may be shorter than your appointments were in the children's clinic. Your IBD team will still answer any questions you have and make sure you have the information you need. If you think of a question after your appointment, make a note for next time or contact your IBD team by phone or email.

> **Before it was my parents who answered all the questions, it has forced me to have a more interested role in it, because I am the one that's got to report how I am doing and how I am finding things.**

Nick, age 21

Living with Colitis

Treatment and care

The adult team will want you to be involved in managing and making decisions about your condition. They might ask you more direct questions (rather than your parents).

They might go over your treatment and suggest changes (with your say). Treatment for Crohn's or Colitis in young people and adults can be different from treatment for Crohn's or Colitis in children. For example, if you have a flare-up, your team may be less likely to treat it with a liquid diet, and instead they might suggest trying other things.

What helps?

Knowledge is power – it can help to know the key facts about your condition and medicines. It can also help to know how to get the best out of your care. Our appointment guide has tips on talking about your condition and how you are feeling.

It's a good idea to take a list of questions you want to ask.

Remember there will be good bits to this – the chat might be more on your level; the team are used to talking to adults and not kids!

Going into hospital

After your transition, if you need to go to hospital as an emergency, for planned care or an operation, you'll stay on an adult ward.

What helps?

It's normal to feel worried about going into hospital. You could talk to your team and ask what they can put in place to help you. You can ask your new IBD nurse to come and visit you when you're in hospital.

See if you can look round the ward and meet the staff there before you go in. Let the staff know how involved you want your parents to be in your care.

Find out when your parents, family and friends can visit if you want them to. Most hospitals will have policies in place for looking after young people and will try and include your parents and family.

Take some things with you to keep you busy. Having your own photos could help you feel more at home.

Having an endoscopy

After your transition, if you need an endoscopy, you'll usually have it with sedation rather than under general anaesthetic. It should not be painful, but it can feel a bit uncomfortable. You can have pain relief if you need it. Even though you'll be awake, the sedation will make you feel sleepy and relaxed. You can usually go home the same day. Our tests and investigations information has more detail about endoscopy, including how to prepare.

What helps?

Your IBD nurse can talk you through the process and help calm any nerves. Remember the team who do these tests know their stuff! They want to make you feel as relaxed as possible. It's normal to feel nervous, but if it's really getting to you, speak to your family, team or someone else you trust to get more support.

Having an operation

If you need an operation it will probably be with a surgeon who specialises in doing operations on adults.

What helps?

Your children's team or surgeon will speak to the adult team or surgeon about your operation and care. This is all part of the transition process.

We keep saying it – but make sure you ask them all your questions!

> **When I was 17, I had life-changing surgery taking place. Adult surgeons and consultants were involved in my care, so I felt that there was a very good line of communication.**
>
> **Leanne, age 24**
>
> Living with Crohn's

If things are not going right

If you feel like something isn't going right with your transition or with your care more generally, start by speaking to a health professional you trust. It's probably worth asking your parents or a friend to support you with that. It's not always easy speaking up, but it's worth doing. It's really important you're getting the support and treatment that is right for you.

There are different ways of raising comments or concerns about your healthcare in each nation:

England

The NHS Patient Advice and Liaison Service (PALS) can help resolve concerns or problems when you're using the NHS. Find a PALS service on the NHS website.

Wales

If you have concerns about your care or treatment, visit NHS Wales complaints and concerns: Putting Things Right

Scotland

The Patient Advice and Support Service provides free, accessible information if you want to raise a comment or concern about your care.

Northern Ireland

Nidirect have information on what to do if you are not happy with the treatment or quality of care you have received.

Looking after yourself

> **It's OK to have good and bad days.**
> **Don't just bottle it up and wait for your next appointment.**
>
> **Leanne,** age 24
> Living with Crohn's

Like Leanne says, everyone has good days and bad days. It's tempting (and pretty normal) to distract yourself with other things. Sometimes these might not be that great for you – like drinking, smoking or vaping, going out all the time, or maybe not going out at all. You know what is normal for you, but if you're feeling and acting differently it could be a sign that something is not quite right.

And if the bad days are happening more often than not, then it's time to do something about it.

Everyone has different ways of coping with stress. What works for you? Here are some things that could help you cope:

Do what you like to do

It might be getting creative, watching films, computer games or keeping fit. Whatever it is that makes you feel more like yourself and that you get a buzz from.

Chill

Some people find that taking time out to do something relaxing helps them de-stress. That might be full on meditation or just listening to music. Maybe you could play an online game. Even just going out and seeing a friend can help take your mind of things.

Have a rest

Sleeping well is a big part of feeling well, getting a good night’s sleep could help lift your mood.

Know yourself

Think about what it is you can and can’t control about your life and your condition. Working on the things you can change might lift your spirits.

Ask for support

It’s OK to need support from others – we all do. It can be tricky, but getting things off your chest and talking to your family, friends or your IBD team can be a massive help.

Get connected

It can also be useful to connect up with other young people who have Crohn’s or Colitis. They are likely to understand what you’re going through.

Check out CICRA’s E-Pal scheme, they can help connect you with other young people with Crohn’s or Colitis.
You could ask your team if they can put you in touch with someone who’s been through transition or see **How we can help you** for other ways to make connections.

We have some short videos on our website where other young people talk about how they cope with transition, and Crohn’s and Colitis in general:
www.crohnsandcolitis.org.uk/young-person

Who can I talk to?

It's not always easy talking about your feelings, but it can actually be pretty powerful.

Just finding someone you trust to confide in can be a starting point.

If you feel like you need a bit more than that, talking therapies like cognitive behavioural therapy (CBT) can be really helpful for some people with Crohn's or Colitis. You can ask your team or GP to refer you. If you're at college or university, you may be able to access support through them. Or look at ways of getting support through The Mix and Young Minds, organisations aimed at young people. Read our information on **mental health and wellbeing** for more details, or see **How we can help you**.

Your parents and others who care

> **When my son transitioned to adult services we were both nervous as we had a really supportive IBD team, and also the fact I needed to let go! The new team were just as lovely and he settled in quickly with them, managing his own appointments and meds. I managed to let go too as I was reassured by the support he receives! The app, telephone appointments and work support make it so much easier for him.**
>
> **Angela**
>
> Parent to Keenan, age 24 - living with Crohn's

Your parents or the people who care for you have probably been looking out for you for years.

They're never really going to let go of that totally. But they might have to take a bit of a step back.

What helps?

Have a chat

Have an open and upfront chat with your parents about how involved you want them to be in your care. Let your doctors and nurses know as well.

> **Tell your parents they've done an amazing job, but they can try and relax a bit now!**
>
> **Harry, age 16**
>
> Living with Crohn's

Take small steps

Do things gradually. Maybe ask your parents if they could just sit and wait outside when you have an appointment. If they still get all your medicines, see if you could start picking up the prescription every now and then.

Work as a team

Transition is hard for parents as well! They may have some of the same worries as you. You could show them this information – it will probably be useful for them too. Also, they may know lots of stuff about your condition that you need to know now. Let them pass this on to you.

Crohn's or Colitis can have an impact on friends and family too. We have a guide for friends and family that can help.

> **I've been with Alex on the journey since he was very young, I've had to know a lot and get involved. But it's very important to let them manage their own life.**
>
> **Christine**
>
> Mum to Alex, age 17 – living with Colitis

Other organisations

Crohn's in Childhood Research Association (CICRA) www.cicra.org

IA (Ileostomy and Internal Pouch Support Group), including Young IA for children and young people www.iasupport.org

PINNT (including Half Pinnt) - Patients on Intravenous and Nasogastric Nutrition Therapy) www.pinnt.com

The Mix: Essential support for under 25s www.themix.org.uk

Young Minds: Information and support for young people about mental health and emotional wellbeing www.youngminds.org.uk

Help and support from Crohn’s & Colitis UK

We’re here for you whenever you need us. Our award-winning information on Crohn’s Disease, Ulcerative Colitis, and other forms of Inflammatory Bowel Disease have the information you need to help you manage your condition.

We have information on a wide range of topics, from individual medicines to coping with symptoms and concerns about relationships and employment. We’ll help you find answers, access support and take control.

All information is available on our website: crohnsandcolitis.org.uk/information

Our Helpline is a confidential service providing information and support to anyone affected by Crohn’s or Colitis.

Our team can:

- Help you understand more about Crohn’s and Colitis, diagnosis and treatment options
- Provide information to help you live well with your condition
- Help you understand and access disability benefits
- Be there to listen if you need someone to talk to
- Help you to find support from others living with the condition

Call us on **0300 222 5700** or email helpline@crohnsandcolitis.org.uk.

See our website for LiveChat: crohnsandcolitis.org.uk/livechat.

Crohn’s & Colitis UK Forum

This closed-group community on Facebook is for everyone affected by Crohn’s or Colitis. You can share your experiences and receive support from others at: facebook.com/groups/CCUKforum.

Help with toilet access when out

Members of Crohn's & Colitis UK get benefits including a Can't Wait Card and a RADAR key to unlock accessible toilets. This card shows that you have a medical condition, and will help when you need urgent access to the toilet when you are out. See crohnsandcolitis.org.uk/membership for more information, or call the Membership Team on **01727 734465.**

Crohn's & Colitis UK information is research-based and produced with patients, medical advisers and other professionals. They are prepared as general information and are not intended to replace advice from your own doctor or other professional. We do not endorse any products mentioned.

About Crohn's & Colitis UK

We are Crohn's & Colitis UK, a national charity fighting for improved lives today – and a world free from Crohn's and Colitis tomorrow. To improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives. We're here for everyone affected by Crohn's and Colitis.

This information is available for free thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis:
call **01727 734465** or visit crohnsandcolitis.org.uk.

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We hope that you've found this information helpful. You can email the Knowledge and Information Team at evidence@crohnsandcolitis.org.uk if:

- You have any comments or suggestions for improvements

- You would like more information about the research on which the information is based
- You would like details of any conflicts of interest

You can also write to us at **Crohn's & Colitis UK, 1 Bishops Square, Hatfield, Herts, AL10 9NE** or contact us through the **Helpline: 0300 222 5700**.

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