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**CROHN'S &  
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FIGHTING  
INFLAMMATORY  
BOWEL DISEASE  
TOGETHER

# TRANSITION: MOVING TO ADULT CARE

A GUIDE FOR YOUNG PEOPLE WITH CROHN'S OR COLITIS

# WHAT'S ALL THIS ABOUT THEN?

“

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, diagnosed with Ulcerative Colitis in 2006

Transition means moving from the children's 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 booklet 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.

## OUR WORDS

In this booklet we've used the words Inflammatory Bowel Disease (IBD) a lot. When we say IBD we mean a group of conditions, of which Crohn's Disease and Ulcerative Colitis (UC) are the two main forms. It is not always possible to tell the difference between them, in which case doctors may have told you that you've got IBDU (IBD Unclassified) or Indeterminate Colitis.

We've also said parents or carers quite a lot. By that we mean mums, dads, guardians or anyone else who is caring for you.

## HOW WE PRODUCE OUR PUBLICATIONS

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# 01

## 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, or sometimes in a different one.

Transition should be a gradual process that your IBD team help you prepare for, but eventually you'll have 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, diagnosed with Ulcerative Colitis in 2015

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 booklet about how you can get ready for the move and how to cope if it's making you feel stressed.





## Why do I need to transition?

You might be wondering why you have to leave the doctors and nurses who may have looked after you since you were little. They are experts at looking after children, but you're a young person, and at some point soon you'll be an adult, so you need a team who are experts in young people and adults with IBD.

Lots of good things can come out of making the move. Other young people say that moving to adult services helped them get to grips with their IBD. And, OK it's a bit of a cliché, but they also said they felt like they 'grew' as a person during the process.

## How will I transition?

It's done differently in different places, but:

- ✓ It shouldn't be a sudden thing.
- ✓ You should have a 'transition co-ordinator'. 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.

## When will I transition?

Transition often happens between the ages of 16 and 18, 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 give you a handle on 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 like this.
- ✓ 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.

It can be quite a long process. Maybe you're bored of your team asking you lots of questions to check if you're ready for transition, but it's just because they care! They just want to make sure you're prepared for the change.

## Where will I move to?

Again, this varies - often you'll be moving to a totally different hospital, sometimes just changing to the adult team in the same hospital. You might have a choice of hospitals. It might also depend on whether you're planning to move away for work or university. 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. We can't promise anything but you might be able to mix it up. Some people have infusions in a hospital near their university, but still have catch-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.

“

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, diagnosed with Ulcerative Colitis in 2015





## 02

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### GETTING READY

#### Knowledge is power

Taking control of your own IBD journey could be the answer to an easier time when you move to the adult IBD team. They'll probably expect some more input from you.

The children's IBD team are probably helping you to prepare for this, but it could all still feel like a bit too much, so we've made the chart on the next page that you could fill in and take to hospital with you. There's also an online version: [www.sickkids.ca/myhealthpassport](http://www.sickkids.ca/myhealthpassport)

We know that's not for everyone though – so you don't have to do it. But even just a simple note of some of the main facts about your IBD saved 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.

# MY IBD DETAILS

What is the name of your condition?

When were you diagnosed?

Whereabouts in your gut is your disease?

Are any other parts of your body affected?

<input type="checkbox"/> Swollen joints	<input type="checkbox"/> Skin rashes	<input type="checkbox"/> Mouth ulcers
<input type="checkbox"/> Red or swollen eyes	<input type="checkbox"/> Liver problems	<input type="checkbox"/> Swollen lips

Have you ever had?

☐ An abscess - collection of pus often near your back passage (anus)

☐ A fistula - a narrow tunnel between the gut and another organ, than can leak pus or poo

☐ An operation to help with your IBD

What medication are you taking now?  
(It might help to write down the date you started taking it.)

<input type="checkbox"/> Sulfasalazine	<input type="checkbox"/> Mesalazine (Pentasa, Asacol, Salofalk)
<input type="checkbox"/> Budesonide (Entocort)	<input type="checkbox"/> Azathioprine (Imuran)
<input type="checkbox"/> Prednisolone	<input type="checkbox"/> Mercaptopurine <input type="checkbox"/> Methotrexate
<input type="checkbox"/> Tacrolimus	<input type="checkbox"/> Ciclosporin (Neoral)
<input type="checkbox"/> Infliximab (Remicade, Remsima, Inflectra)	
<input type="checkbox"/> Adalimumab (Humira)	<input type="checkbox"/> Vedolizumab (Entyvio)
<input type="checkbox"/> Ustekinumab (Stelara)	<input type="checkbox"/> Golimumab (Simponi)
<input type="checkbox"/> Antibiotics (for example Ciprofloxacin or Metronidazole)	
<input type="checkbox"/> Others (including medication that isn't for your IBD) write their names here:	

What medication have you taken for your IBD in the past?  
(Again any dates you can remember may help and other useful info, like if you had a bad reaction to a medication.)

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

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



## Get the facts

There are other ways you can arm yourself with the facts:

- ✓ Talk to your parents or healthcare team
- ✓ Our website has loads more information on your condition, treatments and how to look after yourself, see **How we can help you**.
- ✓ Ask your IBD team whether they run days about transition or other IBD educational days.
- ✓ 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 or try our Facebook forum:  
[www.facebook.com/groups/CCUKforum](https://www.facebook.com/groups/CCUKforum)

“

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 Disease in 2013





“

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, diagnosed with Indeterminate Colitis in 2005

## Know your meds

There's a bit to fill in about your medication earlier in this booklet. The adult team will probably ask you about your meds, 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, diagnosed with Ulcerative Colitis in 2015

Everyone's different. Maybe you've been looking after your pills 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, work towards just knowing the names as a starting point.

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

## Fed up with meds?

This is pretty normal. Keeping up with your treatment is important, but lots of people go through stages of struggling with their IBD medication - for lots of different reasons. If this rings a bell, 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. Friends and family can be a great help, even if it's just someone to chat to in the waiting room! 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.

“I've slowly grown more independent. But it's taken many years and work between me, the staff and my mum.”

---

**Nick**, age 21, diagnosed with Ulcerative Colitis in 2006

## A few things to ease you into managing your IBD are:

- ✓ Ask to have a copy of your clinic letter.
- ✓ Jot 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'll have been given an email address or phone number. If you don't have it, ask your parents – they'll have it or know where to find it!

“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, diagnosed with Ulcerative Colitis in 2008





## 03

### QUESTIONS WORTH ASKING

Here are some ideas of questions to go to your team with. There's probably even more you want to ask, so we've left some space on the next page.

- 01:** What is the plan for my transition or transfer?
- 02:** When am I moving to the adult IBD team?
- 03:** Can I choose which adult IBD team or hospital I move to?
- 04:** What is different about the adult IBD team?
- 05:** Can I meet the adult staff before I leave children's services?
- 06:** Can I visit the new clinic or hospital to look around?
- 07:** Are there any young people I can talk to about transition or transfer?
- 08:** What do I need to know before I move to the adult service?
- 09:** How can I start getting more involved in my healthcare?
- 10:** How might my Crohn's Disease, Ulcerative Colitis, IBDU or Indeterminate Colitis affect my future, such as my education and employment prospects?
- 11:** Can you tell me if my condition or treatment will affect my sex life and relationships?
- 12:** Can you tell me if my condition or treatment will affect my fertility?
- 13:** What will happen if I smoke?
- 14:** What will happen if I drink alcohol?

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**JOT DOWN ANY  
OTHER QUESTIONS  
YOU HAVE HERE:**

---

**NOTES**





## 04

### MOVING TO ADULT CARE

#### What's it like?

We've got to be upfront and say that seeing the adult team will be different. Different doesn't mean bad, but any change normally takes a while to get used to.

“

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, diagnosed with Ulcerative Colitis in 2008



# MOVING TO ADULT CARE



## 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. For more information about who could be involved in your care read our booklet: **My Crohn's and Colitis Care**.

### 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.



## 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 geared up for adults. So there won't be any kids' books, or toys around!

You might have appointments less often than before and book your appointments in a different way.

### 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.

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

“

**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, diagnosed with Ulcerative Colitis in 2006



## Treatment & 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 IBD in young people and adults can be different from treatment for IBD in children. For example, if you do 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 have some key facts about your condition and meds at your fingertips. It can also help to know about how to get the best out of your IBD care. Our booklet **My Crohn's and Colitis Care** highlights 10 essentials that make up a good IBD service.

Take a list of questions you want to ask them.

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

Once you're being treated by the adult IBD team, if you need to go to hospital as an emergency for planned care or an operation, you'll stay on an adult ward.

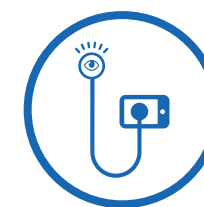
### What helps?

It's normal to feel worried about going into hospital, so talk to your team and ask what they could 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 about 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 in with you to keep you busy. Having your own photos, duvet and pillows could help you feel more at home.



## Having an endoscopy

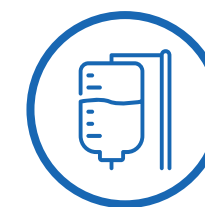
Once you're being treated by the adult IBD team, if you need an endoscopy, you'll have it with sedation rather than a general anaesthetic. It shouldn't be painful, but it can feel a bit uncomfortable. You can have pain relief, and even though you'll be awake, the sedation will make you feel sleepy and relaxed. Because you're not having a general anaesthetic you'll normally go home the same day.

### What helps?

Your IBD nurse can talk you through it and help calm any nerves.

Remember the team who do these tests, do them day in, day out and 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 paediatric 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, diagnosed with Crohn's Disease in 2007





“

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, diagnosed with Ulcerative Colitis in 2006

# 05

## 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...we could go on. And oh yeah, you've got IBD, and they want to make you leave your nice friendly paediatric team and go and meet some new doctor you've never heard of before.

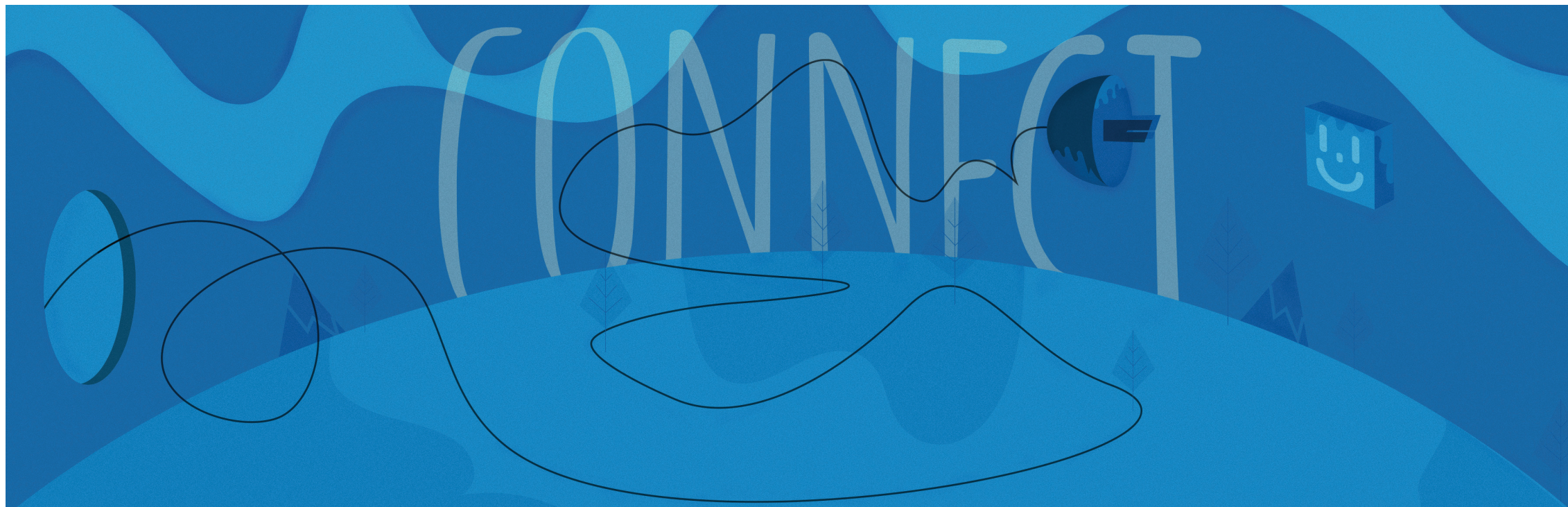
Well, it's not surprising if that's stressful. The good news is that the new adult team are likely to be more geared up to helping with all of those more adult things.

You can ask them about moving to a hospital in a different city if you're planning to go to university, they will know about managing your condition at work, and they'll be open to answering questions about sex and fertility.

If asking about sex and all of that is too embarrassing, we've included a list of questions in **Questions worth asking**, that you can point to – “I want to know about this please!”

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 as it's really important you're getting the support and treatment that is right for you.





## Ways to cope

“

It's OK to have good and bad days. Don't just bottle it up and wait for your next appointment.”

**Leanne, age 24, diagnosed with Crohn's Disease in 2007**

Like Leanne says, everyone has good days and bad days. It's tempting (and pretty normal) to distract yourself with other things, sometimes things that are not that great for you – like drinking, smoking, 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 isn't quite right.

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

## Looking after yourself

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. 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.

### Lean on me

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. You could also speak to a volunteer trained in giving emotional support through Crohn's and Colitis UK. See **How we can help you**.

### Get connected

It can also be useful to connect up with other young people who have IBD. They are likely to understand what you're going through. 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 IBD in general: [www.crohnsandcolitis.org.uk/young-person](http://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 a pretty powerful medicine.

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

If you feel like you need a bit more than that, then talking therapies such as cognitive behavioural therapy (CBT) can be really helpful for some people with IBD. Ask your team or GP to refer you. If you're at college or university, you can often access support through them. Or find out other ways of getting support through The Mix and Young Minds, organisations aimed at young people. Read our information sheet: **Counselling for IBD** for more details, or see **How we can help you**.





## 06

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# YOUR PARENTS AND OTHERS WHO CARE

“

I think it's about giving them more responsibility now as they turn into adults. My role has started to drop off. I still keep an eye, but I slightly take a back seat now.”

---

**Warren**, dad of George, age 15, diagnosed with Crohn's Disease in 2013

Your parents have probably been looking out for you for years. It's likely their support has been massively important to you. You've probably relied on them for a lot.

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, diagnosed with Crohn's Disease in 2011

### 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 meds, see if you could start picking up the prescription every now and then.

### Work as a team

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

Parents of children with IBD can get stressed and down, but there's support available for them too (see **How we can help you**).

“

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, diagnosed with Ulcerative Colitis in 2007

## CROHN'S & COLITIS UK

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## OTHER USEFUL ORGANISATIONS

Crohn's in Childhood Research Association (CICRA)  
[www.cicra.org](http://www.cicra.org)

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

PINNT (including Half Pinnt) - Patients on Intravenous and Nasogastric Nutrition Therapy  
[www.pinnt.com](http://www.pinnt.com)

The Mix: Essential support for under 25s  
[www.themix.org.uk](http://www.themix.org.uk)

Young Minds: Information and support for young people about mental health and emotional wellbeing  
[www.youngminds.org.uk](http://www.youngminds.org.uk)



## ABOUT CROHN'S AND COLITIS UK

We are a national charity established in 1979. Our aim is to improve life for anyone affected by Crohn's or Colitis. We have 40,000 members and 50 Local Networks throughout the UK. Membership starts from £15 per year with concessionary rates for anyone experiencing financial hardship or on a low income. We also offer free membership to young people aged 16 - 18 years and to students in full time education.

This publication is available free of charge, but we would not be able to do this without our supporters and members. Please consider making a donation or becoming a member of Crohn's & Colitis UK. To find out how call **01727 734465** or for more information, visit: [www.crohnsandcolitis.org.uk/membership](http://www.crohnsandcolitis.org.uk/membership)

## HOW WE CAN HELP YOU

You can download all our information sheets and booklets from our website: [www.crohnsandcolitis.org.uk/publications](http://www.crohnsandcolitis.org.uk/publications). You can also request them free of charge from our office – contact our helpline.

Our helpline is a confidential service providing information and support to anyone affected by Crohn's Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease (IBD). Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- put you in touch with a trained support volunteer who has personal experience of IBD

Call 0300 222 5700 or email [helpline@crohnsandcolitis.org.uk](mailto:helpline@crohnsandcolitis.org.uk).

To find out about the helpline, and information and support events for young people, visit our website: [www.crohnsandcolitis.org.uk/support](http://www.crohnsandcolitis.org.uk/support)

This booklet was highly commended at the BMA Patient Information Awards 2018