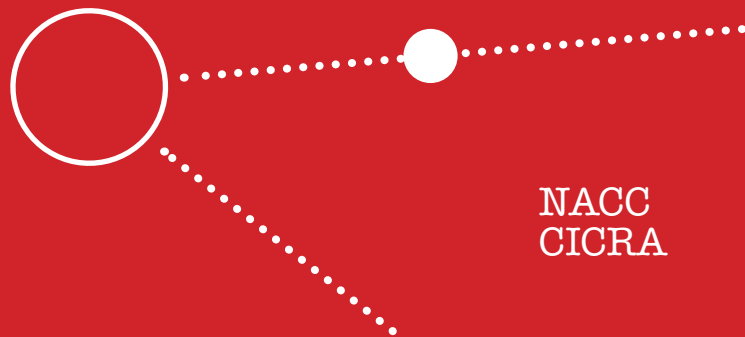


# TRANSITION



Inflammatory Bowel Disease  
Transition to Adult Health Care  
Guidance for Young People



NACC  
CICRA

## What is transition?

At the moment you are looked after by a children's health care team.

**“Transition”** is the process of getting ready to be looked after by adult doctors.

**“Transfer”** is when your care is formally handed over from children's (paediatric) services.

The transition process starts with learning about how your hospital manages the handover of care. The actual transfer of care usually occurs between ages sixteen to eighteen. Transition should be a gradual process, not a

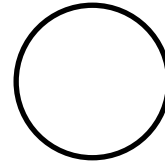
sudden or unexpected jump from one hospital to another, or from one set of medical staff to another.

**Transition involves** important decisions:

- When are you likely to be ready for transfer of care?
- What do you need to do to be ready for transition?
- Can you remain within the same hospital, or would you prefer to move to a different hospital?

You should have help during transition with all these questions.

**Transition can seem daunting. But once it begins, most young people with Inflammatory Bowel Disease (IBD) and their parents or carers adapt quickly and find that the change is a positive one. Adult health care teams are as experienced as paediatric staff in caring for people with IBD. This booklet sets out what you should expect from the doctors and nurses who look after you.**



## Key principles of transition for young people with IBD

- As a young person with IBD, you have a right to a managed transition process when moving from paediatric to adult care.
- Transition should not affect your current care or choices about which treatments you have.
- You should be told the name of a key worker or coordinator who is in charge of making sure your transition goes smoothly.
- You (and your parents if you wish) should be involved or represented in planning your transition.



“I’m looking forward to being more independent, but a bit worried about managing my disease”


## Taking control of looking after yourself

Transition marks the time when you – rather than your parents – begin to take over the main role in managing your Inflammatory Bowel Disease.

Transition comes at a time when other big things in your life are also happening: exams, leaving school, finding new freedoms with your friends, travel, finding out about your sexuality, and making choices about jobs and where you want to live.


These issues can be tricky to sort out with your family. It's not surprising that changing to a new set of medical staff can also sometimes prove difficult. Or you may find that the change to adult doctors goes really smoothly.

Everyone's experience is different.



"I am concerned about having to move on and about not knowing the new people"

## How may transition happen?



Each hospital will start transition at different times and do it in a different way. Hospitals also differ in their arrangements after your 16th birthday.

**Some hospitals have transitional clinics** for young people, usually aged 16-19 years, with your doctor and a doctor from the adult clinic present. You may stay in a transition clinic until you are ready to transfer

completely to the adult clinic. **Other hospitals may offer a joint clinic** for one or two appointments before handing you over to the care of the adult clinic.

**Some hospitals may transfer** you to the adult clinic, either in the same hospital or in another hospital, in a planned way but without having met the doctors from the adult clinic before your transfer. If this is so, a detailed care plan will be given to your new doctors outlining your disease, what treatments you have had and those to which you have responded well.

The usual stages of transition to adult care are described in the following

two pages. All these stages depend on your own circumstances and illness, so you may not follow each stage exactly. Whatever the hospital offers, you have the right to a transition from paediatric care, which takes account of your illness and your wishes.

## When does transition happen?

**Ages  
13-16:**

Your consultant, doctor or nurse may begin to talk to you and your parents about transition. They'll discuss how you can do more yourself to manage your IBD.

Gradually you will find out more about what it's like to be looked after by doctors who treat adults rather than children. Basically it's the same as now, but they will treat you as an adult. This means they will expect you to make decisions



for yourself, take your medicine without anyone having to remind you, and be able to arrange appointments on your own. So before all this happens, this is the time to begin to practise what skills you'll need.

For example, the paediatric staff caring for you at the moment may begin to ask you to give your signed consent for some medical procedures. And you might begin having part or all of your hospital appointments without your parents present – if that's what you would like.

**From  
16:**

You will be seen in one of the three ways described on page 5. You can discuss these options with your consultant or specialist nurse to find out how your outpatient care will continue, including when you will meet your new doctors.

At any stage, you should be able to talk through your questions with your doctors, and – if you're in touch with them – other people your age with IBD. See the section at the end of these Guidelines for details of on-line discussion forums for young people with IBD.



When you start seeing the consultant or specialist nurse on your own remember that they will want to make sure that your parents understand the decisions you have taken about your health, so that they can support you. You may want to talk to the consultant or nurse about what information is given to your parents.

**Because no two people with IBD are alike, you might find that some your age seem further along than you. That's probably because your doctors are timing your health care to meet your own circumstances.**

## How can you get ready for transition?

- ✓ You can:
  - ✓ Decide when you want to start meeting your consultant or nurse without your parents going along too.
  - ✓ Ask your own questions about your condition and treatments.
  - ✓ Practise making appointments and collecting your medication.
  - ✓ Find out what keeps you healthy.
  - ✓ Your medicine, your diet, and your lifestyle all contribute to making you feel more or less well.
  - ✓ Learn what you can do for yourself if you have a flare-up.
  - ✓ Learn about your condition. At this stage your parents may well know more than you do, and now it's your turn to know more about your body and your condition.





“I had the same concerns as the other young people quoted in this booklet, but I’m actually quite happy with the care I’ve received and I’ve got to know the new team as well as the children’s team”

## **Your consultant or nurse should:**

- ✓ Tell you the name of a transition key worker or coordinator at the hospital. They are someone who can answer your questions or concerns.
- ✓ Involve you in planning your transition. This means they should listen to what you want, even though they may not agree with everything you ask for. If they don’t agree with what you want, they should explain why not and try to reach a compromise with you.
- ✓ Help you ask questions about the transfer to adult care, and give you clear answers.
- ✓ Give you and your parents time to make important decisions.
- ✓ If your adult care is at the same hospital that you are being cared for now, they should introduce you to your new nurses and doctors and arrange for you to visit the new clinics and wards.



## What if your new hospital is a long way from the hospital you go to now?

If the new hospital isn't near the hospital you go to now:

- You might find that you don't have a chance to meet the new doctors or look round the clinic before your first appointment.
- Transfer may happen at an outpatient appointment, which is not attended by your new doctors.
- The handover may happen simply by your current doctor sending a detailed summary of your diagnosis and treatment to the new hospital, and you and your parents then making an appointment with the new doctor.

**Once you know which hospital will be looking after you, make sure you know what to expect when you transfer to the doctors there.**

## Want further help?

**At hospital:** your consultant, specialist nurse, dietitian, psychologist, ward nurse or anyone else who looks after you.

**At home:** your parents, family and friends.

**NACC** 0845 130 2233

**www.nacc.org.uk** - information, support, over 16's discussion forum for young people with colitis and Crohn's Disease.

**CICRA** 020 8949 6209

**www.cicra.org**

support for young people with Crohn's Disease and colitis including an under 18's cool zone on their website.

## Further support for young people:

**www.the-ia.org.uk** - Ileostomy and pouch support group; has a young person's area.

**www.teenagehealthfreak.org** - health information for teenagers.

**www.childrenfirst.nhs.uk** - online guide to health and hospital life.

**www.connexions-direct.com** - confidential advice, support and information for 13-19 year olds.

**www.youthhealthtalk.org** - audio and video clips of young people talking about their experience of health or illness.

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