

TRANSITION

Inflammatory Bowel Disease
Transition to Adult Health Care
Guidance for Parents



NACC
CICRA

What is Transition and Transfer?

‘Transition’ is the process of handing over medical care from children’s or paediatric services to adult care. The process is an important part of the treatment of children with Ulcerative Colitis, Indeterminate Colitis and Crohn’s Disease (together referred to as Inflammatory Bowel Disease or IBD).

‘Transfer’ is the formal handover or transfer of care from paediatric to adult health providers.

The transition process includes, but is not limited to, the transfer of care. If transition is done well, it can increase your child’s ability to work with medical staff in managing their condition.

The transition process starts with learning about transition and how your child’s hospital

manages the handover of care. The transfer of care usually occurs between sixteen to eighteen, although it can be later than this depending on your child’s circumstances.

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. The process should take account of you and your child’s preferences, and should be adaptable to your child’s illness and symptoms.

Transition involves important decisions:

- **When will your child be ready for the transfer of care?**
- **What do you need to do to be ready for your child’s transition?**
- **Can your child remain within the same hospital or would it be better for him/her to transfer to a different hospital?**

You should have help during transition with all these questions.

“I’ve enjoyed the independence of not having my parents overlooking me all the time”

Transition can seem daunting, but once it begins most young people and families adapt quickly and find that the change is a positive one. Adult health providers are as experienced as paediatric staff in caring for people with IBD.

This booklet sets out what you should expect from those caring for your child.

In this booklet, we use “parents” to mean the young person’s parents, guardians or carers.



Key principles of transition for young people with IBD

- **Young people with IBD have a right to a managed transition process when moving from paediatric to adult care.**
- **Transition is a process, not an event.**
- **Transition should not compromise your child’s current care or treatment options.**
- **Transition begins in paediatric services, but adult services are responsible for its successful completion.**
- **Transition works best when it is coordinated and overseen by a named key worker or coordinator, usually the paediatric consultant or specialist nurse.**
- **Transition should be provided by multidisciplinary teams of paediatric and adult health professionals working together.**
- **Your child (and you too if your child wishes) should be involved or represented in planning their transition.**
- **Hospitals should have a transition policy covering all conditions, and also have a specific policy for IBD.**
- **The hospital should aim continually to review and improve its transition service for the benefit of young people, their families and the hospital staff.**

“Letting go”

You have given your child special care ever since their problems with IBD began.

As your child grows older, you and they will begin to prepare for their entry into adulthood. Becoming an adult in managing their disease is just another part of their journey. Your journey as a parent is moving from being protective to enabling them to look after themselves, however hard that might be.

You can help them get ready for the change.

One of the hardest challenges for young people can be adjusting to the different expectations that doctors have of their adult patients: that they will stand up for themselves and speak for themselves, ask the questions they need to, and be responsible for their own health care. Most young people manage the transition to adult health care with no problems.

“Hospitals differ in their arrangements after young people’s 16th birthday.”

How may transition happen?

Each hospital will start transition at different times, and do it in a different way.

Whatever the hospital offers, your child has the right to a transition from paediatric care, which takes account of their illness and wishes.

Hospitals differ in their arrangements after the young person is sixteen.

Some hospitals have transitional clinics for young people, usually aged 16-19 years, with the child’s doctor and a doctor from the adult clinic present. Your child may stay in a transition clinic until they are ready to transfer completely to the adult clinic.

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

Some Hospitals may transfer your child will be transferred 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 their transfer. If this is so, a detailed care plan will be given to their new doctors outlining their disease, what treatments they have had and those to which they have responded well.

On the next page you'll find the usual stages of transition. All these stages depend on your child's circumstances and illness, so these stages may not be followed exactly.



“Most young people manage the transition to adult health care with no problems.”

When does transition happen?

**Ages
13-16:**

The consultant, doctor or specialist nurse may begin to talk to you and your child about transition. The discussion will include how you can help your child to do more for themselves to manage their IBD.

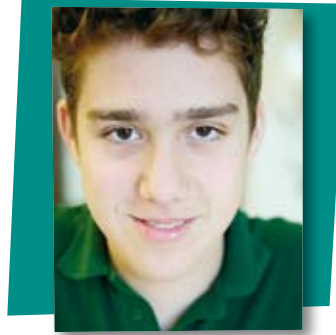
Gradually your child will find out more about what it's like to be looked after by doctors who treat adults rather than children. This means your child will be expected to make decisions for themselves, take medicine without being reminded and be able to arrange appointments on their own. The consultant





**From
16:**

From 16 years your child will be seen in one of the three ways described above. You can discuss these options with the consultant or specialist nurse to find out how your child's outpatient care will continue, including when you will meet the new doctors.



If you feel you are not being sufficiently involved in, or informed about, your child's treatment, you can ask to see their consultant at the next outpatient review.

will also discuss with you the services (if any) your current hospital has for adult patients with IBD, and other possible hospitals your child may transfer to.

Other new things might start happening: for example, the medical staff may begin asking for your child's signed consent for some medical procedures, but they still need your signed consent until your child is 16. They might also encourage you to let your child have part of their hospital appointments without you being present (see the section "What you can do to help" for more information on this).

“Gradually your child will find out more about what it's like to be looked after by doctors who treat adults rather than children.”

How might transition affect your child?

You won't need to be told how challenging teenage behaviour can be. Transition comes at a time when your child is encountering other big issues in their lives: their sense of self, their sexuality, what career they might have, and when and how they might leave home.

In relation to IBD, this challenging behaviour may

show in various “risky” behaviours: not taking their medication, eating the wrong foods, not keeping hospital appointments, even not telling you what's going on for them inside. You may find that your child begins to turn more to their friends rather than to you for support and information.

“Think about what your child needs in order to take responsibility for their own care”

Barriers to good transition

Teenage patients have identified barriers to good transition as including not getting sensitive care from adult professionals, not having enough time to adjust to the fact of transition, and finding jargon and inappropriate expectations by the doctor difficult to cope with. Other teenagers report ‘burnout’ with their condition, feeling exhausted by the health care they require. This is especially so when the care is concerned solely with treatment and taking their medication, instead of including the impact of the condition on the overall physical and emotional development.



What you can do to help

As a parent, you can help your child by encouraging them to meet the consultant or nurse alone – not necessarily for every appointment, but every now and then.

You can also encourage them to think of and ask their own questions of the professionals. For example, you can plan to sit down together a day or so before an appointment to make a list of things they want to tell the doctor or questions they want to ask.

Think about what your child needs in order to take responsibility for their own care. This might be to do with practical tasks, communication skills, or managing their feelings. Ask your child's doctor how ready your child is to move into the adult health

care system. Ask how they are helping to get your child ready – and how you can help the process.

Many of the skills that you can help your child gain in order to transfer into adult health care are skills which are useful in other parts of life.

These include: taking responsibility for themselves; making decisions about what they want to happen; speaking up for themselves; and good communication skills.

There should be lots of time to prepare for transfer. If the transition process is managed well, there will still be lots of support available to you after the transfer of care.

In the meantime, you can plan how you will help your child be ready.

Each hospital or clinic manages transition in a different way. However, you should expect your child's consultant or specialist nurse to:

- **Make sure your child's medical care, and the options available, aren't affected by the transition process.**
- **Be available to meet with you if you want to. They will have to respect your child's confidentiality (subject to your child suffering or being at risk of harm), but you can still ask questions or raise your concerns.**
- **Give you the name of your child's transition key worker or coordinator as your first port of call for any questions about transition.**
- **Include you in the decision about how and when your child's transfer takes place.**
- **Offer longer appointment times once your child has transferred to adult care, and consider other ways in which they can support your child in the first few years of health care as a young adult.**



What if your child is transferring to a hospital a long way from the hospital they currently attend?

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

- You might not get a chance to meet the new doctors or look round the clinic before your child's first appointment there.
- Discharge from paediatric services may happen at an outpatient appointment which is not attended by your child's new doctors.
- The handover may happen simply by your child's current doctor sending a detailed summary of your child's diagnosis and treatments to the new hospital, and you and your child then making an appointment with the new doctor.

Once you know which hospital your child will transfer to, make sure you know what to expect from the staff and services there.

Ask what transfer arrangements your current hospital may have established with the new hospital.

If your child is going to college in another area, make sure you and your child are clear who will care for your child when they are ill. Will it be the local health services or specialist care near your home or the health services or specialist care near to your child's college?

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Support and information

NACC 0845 130 2233

www.nacc.org.uk - information service, parent to parent support and family events.

CICRA 020 8949 6209

www.cicra.org - support for families of children with Crohn's Disease and colitis.

www.cafamily.org.uk - Contact A Family, providing advice, information and support to parents of children with a chronic illness or disability.

Information from other Crohn's and colitis associations around the world:

www.ccfa.org (USA),

www.cafc.ca (Canada),

www.acca.net.au (Australia) and

www.efcca.org (Europe)

www.the-ia.org.uk Ileostomy and internal pouch support group

www.face2facenetwork.org.uk

befriending site for parents of disabled children

www.youngminds.org.uk/

publications "Looking after Ourselves": a leaflet for parents about how to look after their own needs

www.tsa.uk.com Trust for the Study of Adolescence: information and resources.

You may also find support from your local Carers' UK group, religious or community centre or Council for Voluntary Services.

This booklet was written by John Gray from Framework with a working group involving the British Society for Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN), the IBD Section of the British Society for Gastroenterology (BSG), the Colitis and Crohn's Nurses Group of the Royal College of Nursing (RCN), Crohn's in Childhood Research Association (CICRA) and the National Association for Colitis and Crohn's Disease (NACC)

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