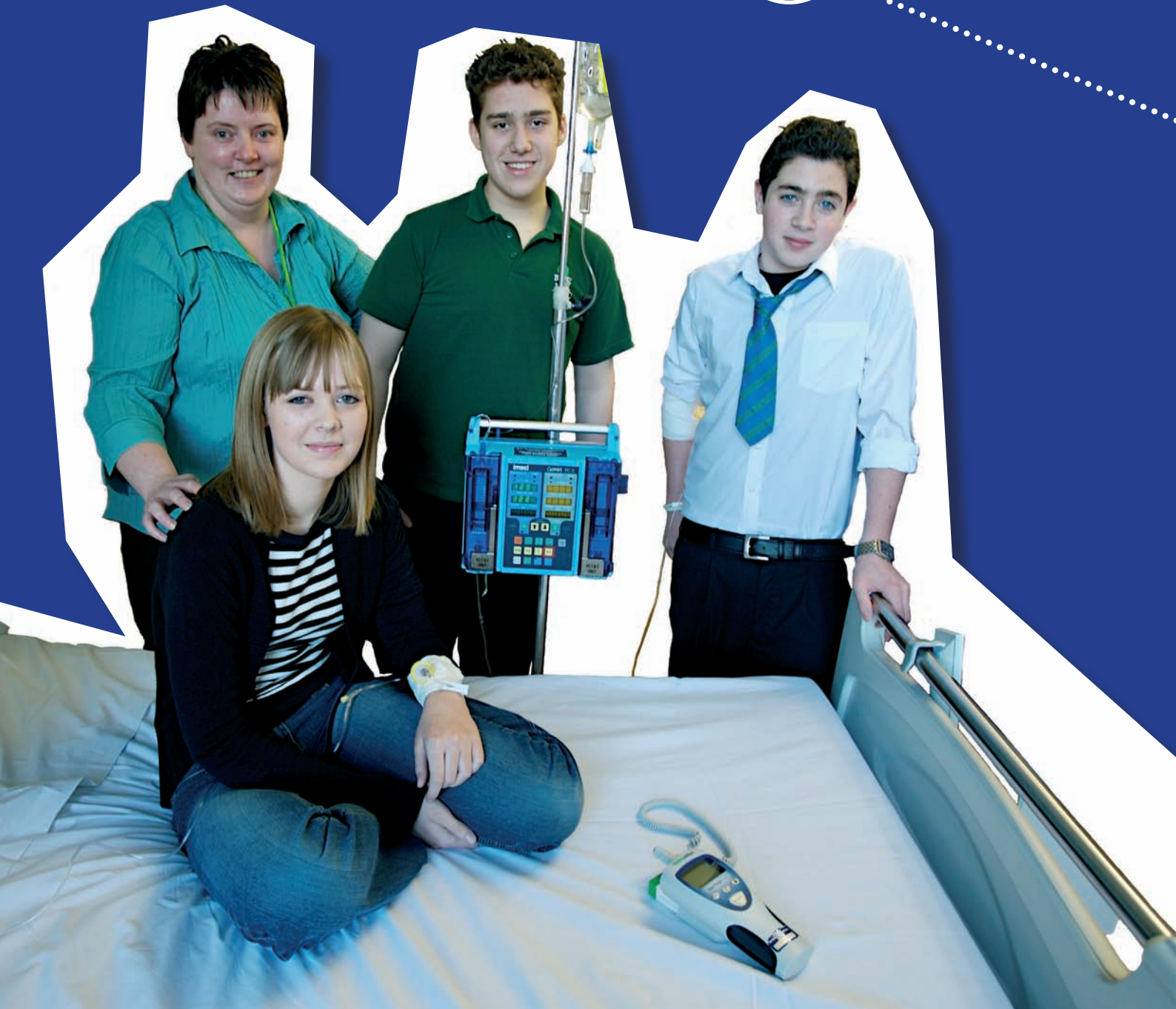


# TRANSITION

Inflammatory Bowel Disease  
Transition to Adult Health Care  
Guidance for Health Professionals

NACC  
CICRA





# Introduction

## THE DIFFERENCE BETWEEN TRANSITION AND TRANSFER

Transition is the planned move of adolescents and young adults with long-term physical conditions from child-centred to adult-orientated health care.

Transfer is the successful handover of care to adult services. Transition is therefore a process which includes, but is not limited to, the formal transfer, from paediatric care. The National Service Framework for Children, Young People and Maternity Services' guidance relies on the following definition of transition:

**“A purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems.”<sup>1</sup>**

Transition is thus an important part of the young person's personal development. If handled well, transition can increase the young person's capacity to be an effective partner with health professionals in managing their condition.

There is a growing body of evidence to suggest that effective transition promotes improved disease control, adherence to appointments after transfer, and improvements in quality of life, knowledge, and satisfaction with health care provision.<sup>2</sup>

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# Transition and IBD

Ulcerative Colitis, Crohn's Disease and Indeterminate Colitis are increasingly diagnosed in childhood. Symptoms and treatment can differ widely between patients of similar ages and diagnoses. Some aspects of treatment by paediatricians may differ from those of adult doctors, such as endoscopy procedures, the use of enteral feeding and the monitoring of the young person's physical growth.

For these reasons, it is particularly important that transition is carefully planned and adapted to individual needs. All young people with IBD should continuously be prepared throughout their teens to ensure they are ready for the formal transfer of care to adult services.

A study in 2003 reported no adolescent or transition clinic provision in two thirds of UK paediatric gastroenterology services.<sup>3</sup> Provision has almost certainly improved since then, but more remains to be done to

ensure effective and appropriate transition arrangements for all young people with IBD.

These guidelines have been written by a working group of health professionals and representatives from the British Society of Gastroenterology, the British Society of Paediatric Gastroenterology, Hepatology and Nutrition, the Colitis and Crohn's Nurses Group of the Royal College of Nursing, the National Association of Colitis and Crohn's Disease and the Crohn's in Childhood Research Association.

You are encouraged to reproduce all or parts of these guidelines in creating or developing your transition policy and procedures for young people with IBD.

**“All young people with IBD should be continuously prepared throughout their teens to ensure they are ready for the formal transfer of care to adult services.”**



# Key principles and guidance

Young people with IBD have a right to a managed transition process when moving from paediatric to adult care.

The benefits of well-managed transition are established and transition should be regarded as a standard element of care for young people with IBD.<sup>1,2 & 4</sup> It is the responsibility of the commissioning service, PCT or Foundation Trust to ensure a transition service is provided.

Transition arrangements should be planned to meet the needs of young people with IBD and their parents, and should be responsive to changes in medical or personal circumstances. Throughout the process all health professionals should retain a patient-centred approach. The young person (and parent if the young person wishes) should be involved or represented in planning their transition.

Where possible, transfer should take place during remission or whilst symptoms are relatively stable.

Transition is a process, not a single event. Transition should not compromise the young person's current care or treatment options.

Paediatric services should retain primary responsibility for treatment until a clearly defined moment of transfer to adult services takes place.

It is important to develop flexible transition arrangements which can deal with a range of needs. To avoid an abrupt change of care arrangements, some hospitals provide specialist adolescent units, usually caring for a range of conditions, not just IBD. Others hospitals have developed transition appointments (jointly staffed by paediatric and adult clinicians) which can run for a year or more, depending on the young person's needs and circumstances. The flexible nature of these clinics allows the young person to determine the timing of the move to adult care.<sup>5</sup>

Many factors are important in timing the transfer from child to adult care.

These include:

- Child and adult services currently available.
- Disease treatment, and compliance with therapy.
- Stability of condition and current complications – where possible transfer should occur during remission or comparative stability of symptoms.
- Duration of condition.
- Sources and quality of the young person's support – from family, professionals (both in and beyond the NHS), and their peers.
- The young person's physical, cognitive and psychological maturity – all may be delayed or otherwise affected by IBD.
- The young person's emotional, relationship and communication skills.

In-patient paediatric services should transfer young people to adult providers by 18 years. Hospitals differ in their arrangements after young people's 16th birthdays.

**Some hospitals have transitional clinics** for young people usually aged 16-19 years with their doctor and a doctor from the adult clinic present. They 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 them over to the care of the adult clinic.

**A third possibility is that they 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.

For those who are diagnosed with IBD as young children the idea of transition can be introduced at any time after their 13th birthday.

Transfer itself may be delayed beyond the normal age of 16-18 to avoid the young person being transferred away from paediatric services too soon after they have begun being cared for by them.

## STAGES IN TRANSITION

Services should be flexible to meet individual circumstances and preferences. Typical stages for transition to adult care are:<sup>5,6,7 &8</sup>

### 13-16 years

The transition process may be mentioned for the first time. The young person begins to participate in their own care.

The aim over this period is for them to gain increased understanding of transition and its implications. The young person practises skills, gathers information, and sets own goals to participate in own care. They are encouraged by the medical team to consider being seen for a part or all of their appointments without their parents. They may begin to be asked to give their signed consent for some medical procedures.

### From 16

Ready to leave paediatric care with confidence. The young person uses skills and independent health care behaviours in the adult system. The young person will be seen in one of the three ways described on page 4.

Any gaps in the young person's readiness should be addressed, particularly in respect of their emotional and communication skills.<sup>4</sup> This could be done by exploring their support networks, providing developmental opportunities for the young person as part of the transition process, or by referral to other medical specialists and/or to local education or community services. Parents' involvement can help this process. They can contribute their knowledge of the young person's progress and how they manage their illness. It is important that parents understand any decisions that are made about the young person's treatment.

Getting the right balance between keeping parents informed and involved, whilst gradually giving the adolescent more independence and responsibility, is extremely difficult. It may require a different approach for different individuals and families.

**Transition begins in paediatric services but adult services bear responsibility for its successful completion.**

The adult team to which the young person with IBD is transferring, bears the following responsibilities to:

- Establish and maintain good contact with paediatric/adolescent staff, especially if there are joint clinics which require co-ordinated care.
- Know the key developmental issues relating to IBD in young people and young adults.
- Anticipate questions from the young person about IBD, medications and their impact on other aspects of health – particularly sexual health.
- Be competent in promoting self-management in young people with IBD.
- Be aware of the main barriers to successful transition from paediatric care.
- Train in the skills and competencies of service provision to adolescents and young adults.
- Support and educate the young person in understanding the adult health care system.
- Adapt the adult service for those newly transferred, such as initially offering longer appointment times.<sup>9</sup> NSF standards require that developmentally-appropriate adolescent services be provided in the adult sector.
- Undergo relevant child protection training, if regularly providing services to under 19's.

## PREPARATION FOR TRANSITION

Young people need well-developed social, interpersonal and emotional skills to successfully enter the world of adult health care.<sup>12</sup>

Young people will be ready for transfer when they:

- have a high awareness of their own needs and how to manage their condition,
- have a high degree of knowledge of the services and care options available to them,
- Are emotionally well-equipped and skilled to represent themselves to adult professionals.

One identified barrier to successful transition is coping with the different level of expectations between paediatric and adult services.<sup>10</sup> For example, adult patients are expected to take more self-responsibility for their care and managing their medication, and may be expected to make on-the-spot decisions at clinics. These responsibilities can be difficult for young people newly transferred from paediatric services and who may be missing the support from paediatric services that they have been used to.

Professionals should arrange where possible for support for the young person to develop these skills prior to the formal transfer of care. The young person should be able – and encouraged – to ask questions, give opinions and make decisions.

The language used in leaflets and information sheets should be jargon-free, age-appropriate, consistent and honest. The hospital should also use other ways of informing and keeping in touch with the young person, such as text messaging, e-mail and via the internet.

The transition key worker or coordinator (see section below) should assess whether additional support services, such as advocacy or social services, would be helpful in ensuring a positive transition to adult care. Some young people with IBD may also need emotional or psychological support during the transition process.

Support after transition may be just as necessary. Adolescents 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 clinician

expectations difficult to cope with. Other teenagers report 'burnout' with their condition: becoming exhausted by the health care they require, especially when the care is solely concerned with treatment and compliance, and does not include the impact of their condition on their overall physical and emotional development.<sup>10</sup>

It may be appropriate to offer back-up appointments with the paediatric team and/or telephone support until after the first or second appointment at the adult clinic. At the very least, the paediatric team can check that the young person did attend their first adult appointment. Where possible, buddying or mentoring arrangements should be set up with adolescents and/or young adults with IBD who have already made the transition to adult care.

## ROLE OF THE KEY WORKER

Transition works best when it is coordinated and overseen by a nominated key worker or coordinator.<sup>4,11</sup>

Key workers would typically be the paediatrician or specialist nurse.

The role of the key worker includes: writing and overseeing the young person's transition plan, coordinating care during the transition process, facilitating the decision as to when formal handover should occur, and providing support to young people and their families.

The key worker will ensure that transition is complete and that the young person's care – including that provided by any other specialist health teams - is properly integrated into adult services.

If a key worker is not nominated, then at the very least, the young person and their parents should have a named contact for questions and concerns.

Each young person with IBD should have an individual transition plan. Guidance on writing individual plans can be found in Section Five of the Royal College of Nursing's Adolescent Transition Care.<sup>5</sup> Reviewed on an annual basis, the plan enables the paediatric team to assess progress every year towards transition, to timetable any necessary preparation, and to finalise a date for transfer.

**“Transition works best when it is coordinated and overseen by a nominated key worker or coordinator. Key workers would typically be the paediatrician or specialist nurse.”**



Transition should be provided by multidisciplinary teams of paediatric and adult health professionals working together.<sup>13</sup>

Adolescent and adult services should join the transition process at an early stage and steadily increase their involvement as the process unfolds. As IBD is a long-term condition, GPs and primary care services, education, social services and community services also have an important role to play in the transition process.

Effective transition requires good coordination between professionals within paediatric and adult settings, whether within the same hospital or between different hospitals. Young people with IBD may have more than one option for adult care, and this increases the amount of coordination needed.

Health professionals will need to take particular care with arrangements for young people with IBD transferring between hospitals located far from each other.

This can be complicated further where the young person attends college and has to choose whether to be treated at their hospital near home or near to the college.

An IBD database can add greatly to effective management of the transition process, including providing case summaries on transfer.

The adult services specialist IBD nurse, if there is one within the hospital, will play a key link in managing transition.

When transferring to adult care, arrangements will need to be made for the transfer of relevant documentation

A discharge letter to the new medical team, copied to the young person and their parents, should summarise:<sup>14</sup>

- Date of diagnosis
- Site and severity of disease
- Results of investigations, such as endoscopy, histology, pathology and/or radiology
- Surgery and complications
- History of medications
- Sensitivities/adverse reactions
- Named contact in the team from which the young person is transferring

# An IBD Transition Policy

Hospitals should have a transition policy covering all conditions, and also have a specific policy for IBD.

A good transition policy is the foundation for the service which patients and families receive. It serves as a reference point for professionals, and establishes what patients can expect and contribute. It also guards against loss of expert knowledge should personnel change.

The increasing prevalence of IBD in childhood, the wide variety of symptoms, the possibility of delayed growth and some significant differences in treatments between children and adult patients, are all important reasons for creating a specific IBD transition policy.

Hospitals may already have a general transition policy which can be adapted for IBD patients. Alternatively, the hospital may have well-established arrangements, which have not yet been written down into a formal policy.

Where appropriate, the policy should be agreed by paediatric services, adolescent services (if any) and the adult service to which young people with IBD will transfer.

The typical section headings for an IBD transition policy are:

- The hospital's overall philosophical approach to transition. This should include a) the intended aims for transition and the expected outcomes for patients; and b) an understanding of the role of developmental, social and medical factors influencing transition.
- The timing of transfer, and typical impact of IBD on patients' readiness for transfer.
- Agreed practice for management, which differs between paediatric and adult patients, such as endoscopies.
- Preparation for transfer, to cover patients diagnosed as young children as well as those entering the system as teenagers
- A step-by-step transfer process, incorporating the main stages and key

**“The increasing prevalence of IBD in childhood, the wide variety of symptoms, the possibility of delayed growth and some significant differences in treatments between children and adult patients, are all important reasons for creating a specific IBD transition policy.”**



milestones. A useful clinical pathway can be found in Adolescent Transition Care: Guidance for Nursing Staff, Royal College of Nursing, 2004.

- The purpose and process of transition clinics.
- Any formal arrangements already set-up with standard 'destination' providers.
- How the process is coordinated. This should include the role of nominated coordinators or key workers and how they are trained and supported.
- Policy for involving other services as appropriate: primary health care, social services, community services, education, and specialist medical care.
- The smooth communication of necessary interprofessional medical, social care and other relevant summaries, copied to the young person and to their parents. There is a duty of confidentiality towards the young person, including when communicating with their parents, subject to harm or risk of harm to the young person.
- Agreement about which hospital will lead on transition if the young person is under shared care with both a local and a specialist hospital. Similar plans need to be made if the young person is attending college away from home, for sharing care between their specialist hospital at home and at college.
- How the transition process will be monitored, evaluated and improved.

The hospital should aim continually to review and improve its transition service for the benefit of staff, young people and their families.

Feedback can help improve the service for staff, for young people with IBD and their families.

The staff member coordinating the transition is well placed to evaluate the success of the process for individual patients and also to assess how well the various procedures and communication channels have worked. This will flag up any necessary organisational or procedural changes.

Ideally, feedback about the transition should be gathered from:<sup>13</sup>

- The young person and their parents, using a standardised satisfaction questionnaire.
- The paediatric consultant.
- Other relevant professionals from the paediatric team, and the adult team now responsible for the young person's care.

Feedback should assess:

- Whether clinical outcomes have been improved or maintained.
- The quality of the experience and outcomes for both the young person and their parents.
- The level of the young person's/parental involvement in planning, developing and delivering services.
- The level of the young person's self-determination in managing their condition, and other measures of psychosocial development.
- Adult clinic attendance and treatment adherence post transfer.
- The suitability of assessment measures as appropriate indicators of patient's readiness to transfer.

**“Feedback can help improve the service for staff, for young people with IBD and their families.”**

# References, further reading and websites

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12 Department of Health. National Service Framework for Children, Young People and Maternity Services. 2004

13 Example templates available at [http://www.rch.org.au/transition/prof.cfm?doc\\_id=8145](http://www.rch.org.au/transition/prof.cfm?doc_id=8145)

14 Royal College of Nursing 2004; Hait 2007; Shaw 2005; Adolescent Health Committee 2006; Paone 2001

## FURTHER READING

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While A, Forbes A, Ullman R, et al. Good practices that address continuity during transition from child to adult care: syntheses of the evidence. *Child: Care, Health and Development*. 2004; 30(5): 439-452.

## WEBSITES WITH RESOURCES

[www.dreamteam-uk.org/index.php?trans](http://www.dreamteam-uk.org/index.php?trans)  
[www.rch.org.au/transition](http://www.rch.org.au/transition)  
<http://www.sickkids.ca/good2go/>  
<http://hctransitions.ichp.edu/>  
<http://depts.washington.edu/healthtr/index.html>  
[www.ibdtransition.org.uk](http://www.ibdtransition.org.uk)  
[www.cicra.org](http://www.cicra.org)  
[www.nacc.org.uk](http://www.nacc.org.uk)

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To find out more about the information and support provided by NACC and CICRA visit their websites:

**[www.nacc.org.uk](http://www.nacc.org.uk)**

**[www.cicra.org](http://www.cicra.org)**

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