



# Inflammatory bowel disease in transition: challenges and solutions in adolescent care

Sara McCartney

## Correspondence to

Sara McCartney; University College London, 235 Euston Road, London NW1 2BQ, UK; sara.mccartney@uclh.nhs.uk

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## Abstract

The prevalence of inflammatory bowel disease (IBD) in childhood is increasing with a phenotype now established as one of complicated and extensive disease. Adolescent patients form a significant proportion of those requiring lifelong care. One of the most important steps in establishing a personal ability to effectively manage chronic disease is appropriate education, communication and a good relationship with healthcare professionals and a successful transition programme and subsequent transfer to adult care underpins this. It is vital to build trust and include parental input while transferring responsibility to the young person. Although the literature confirms that the majority of paediatric gastroenterology units now have planned provision for transfer, the quality and appropriateness of these services have not been assessed or audited. This article discusses the drivers for establishing and improving transition services from both the patient's and healthcare provider's perspective. This heterogeneity of provision of healthcare for adolescents needs to be addressed and the experience of young people themselves is good evidence of this need. Barriers to optimal care need to be identified and managed and healthcare providers need to 'buy in' to establishing a flexible, patient focused achievable service for their patient population.

## Why we need transition services

Adolescence involves the transition from childhood to adulthood, during which considerable physical and mental changes take place. It usually occurs between 10 and 19 years of age and is widely recognised as a period of uncertainty in life when significant psychosocial and physical development occurs. The onset of a debilitating chronic illness with implications for growth, maturity and sexual development is a major obstacle, requiring additional care and resources for its management.

Transition is defined as "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 healthcare systems."<sup>1</sup> Transfer, however, simply represents a formal handover of care from the paediatric to the adult service providers.

Young people with inflammatory bowel disease (IBD) constitute a sizeable proportion of patients receiving long-term gastroenterology care. The peak incidence of IBD occurs in patients between 15 and 25 years with around 25% of patients diagnosed before the age of 20.<sup>2,3</sup> The incidence of Crohn's disease continues to rise in this group.<sup>4</sup>

We know children and adolescents with IBD have more extensive and rapidly progressive disease and are more likely to develop complications.<sup>5</sup> There is often a diagnostic delay as young people commonly present with extra-enteric symptoms. Owing to longer disease duration they are more susceptible to complications of osteoporosis, malignancy and over-exposure to ionising radiation. Effective education and multidisciplinary care can limit relapse, prolong remission, manage complications and improve quality of life.

At exactly the age when we should be supporting and educating young people with IBD the service offered in the UK appears to be at its most disorganised. A 2001 study in the UK and Ireland showed only 30% of specialist paediatric gastroenterology services had transition provision and only 20% had joint consultation with paediatric and adult gastroenterologists.<sup>6</sup> Although this improved by 2006 to 80%,<sup>7</sup> the quality of these services has not been formally assessed or audited and there is

widespread geographical variation. This lack of specific planned provision for transfer (notwithstanding the longer process of transition) results in young people feeling “dumped, cut off and abandoned” as they reach the transition period.<sup>8</sup> They may end up transferring abruptly to adult services, staying in paediatric services longer than is socially and psychologically appropriate, or becoming lost to follow-up by choice or default.

### When to do it

External forces and local politics have an impact on the provision of transitional care and this becomes obvious looking at North American models. In the United States insurance issues result in formal transfer into adult services occurring after college at around 21 years,<sup>9</sup> late by UK standards. In Canada paediatric hospitals cannot admit patients after 18 years of age so this becomes the point of transfer. In the UK the situation may be forced earlier as many specialist paediatric hospitals cannot admit patients after 16 years and paediatric surgeons are reluctant to operate on patients around this age, particularly if they are likely to require a future operation.

Transition should be based on a patient’s needs rather than simply chronological age. The ideal timing of transition will therefore depend on a combination of chronological age, maturity, current medical status, adherence to treatment, independence in healthcare, self-advocacy skills, preparation, readiness of the young person and availability of an appropriate adult specialist<sup>10</sup> (table 1). Preparatory work by the paediatric hospitals is vital in ensuring successful transition. Around the age of 13 the paediatric team should introduce the idea of transition to the young person and their family, encouraging them to take more responsibility in managing their IBD (eg, managing their medication) and involving them in decision-making rather than this being a parental prerogative. Consent forms may be co-signed by young people. Gradually, for part of the consultation, the young person should see the team alone.

Introducing the concept of transition early with a clear plan and supportive literature is highly beneficial. Patient groups such as the National Association for Colitis and Crohn’s Disease (NACC) and Crohn’s

in Childhood Research Association (CICRA) have produced an excellent series of leaflets for the young person, their family and healthcare professionals detailing the process.<sup>11</sup> Some of the North American centres use a more formal assessment system to ensure that the patient is ready for transfer such as the On TRAC model (Taking Responsibility for Adolescent/Adult Care)<sup>12</sup> or a questionnaire which allows older children to evaluate their own readiness for transition.<sup>13</sup> Benchimol recently assessed patients age 14–18 years and their parents who completed the MyHealth Passport for IBD and compared their responses to information available from the case notes. While information about drugs and IBD classification were clear to both groups, disease location and previous investigations were not accurately identified by either. Knowledge of healthcare provision was also particularly poor among young people. Targeting adolescent education and more widespread use of systems such as the readily available online MYHealth passport system could achieve this.<sup>14</sup>

### The patient’s perspective

The views of young people undergoing transition are often overlooked. Recently, I recognised several posts in an online forum as coming from one of my patients and comments as to how they felt when undergoing procedures in services such as radiology were highly revealing and led to re-evaluation of the service. Positive comments, however, reinforced other aspects of practice. Many young people are surprisingly uncomplaining so only highlight issues when formal feedback is actively sought. A typical range of comments includes “I felt anxious and scared about leaving a doctor I could trust”, “I completely relied on my parents”. Apart from the anxiety of moving on many young people recognise the necessity of change “I realised I needed to be more independent and in control of my illness”, “I wanted someone to talk to me not to my parents” and rather more worryingly “When you get to 16 they get rid of you. I haven’t been to the hospital since I was 16. I know I’m OK at the minute but a lot could happen. No one’s mentioned to me what happens to my condition as I get older.”

Young people want effective communication, education and to close the knowledge gap to facilitate independent control of their illness. Much of this is similar to what adult patients want and has been highlighted by the published IBD standards.<sup>15</sup> Key requirements are easy access to hospital and support services, direct telephone contact and sufficient information to participate in shared decision-making to formulate clear management plans. These should be flexible and responsive to suit the unpredictable course of the disease, offer integrated surgical and medical care and allow easy onward referral for related medical problems.

Achieving successful transition and transfer is easier for some young people than others. How

**Table 1** Factors influencing the ideal timing of transition

1	Emotional and physical maturity
2	Chronological age
3	Disease activity
4	Adherence to treatment
5	Independence in managing healthcare
6	Self-advocacy skills
7	Readiness of the young person (and family)
8	Identification of an appropriate adult specialist

straightforward the transition process is depends on several factors. If puberty is complete and the young person is psychologically ready to transfer then the process is less difficult. They may have 'outgrown' paediatric services and feel ready to begin gaining independence from parental control. Often the young person wants advice on contraception, alcohol, smoking and feel more able to ask for this in an adult clinic (case 1). A complex or difficult transition is often associated with an anxious or dependent personality in which the illness has been managed predominantly by the parents. There may be a history of a 'difficult' time at previous hospital(s). The difficulties may be exacerbated if the age of transfer is set by hospital "rules" rather than a young person's readiness, particularly if they are prepubertal. Medical staff need to be confident about transition arrangements and instil this confidence into parents and young people. There may be

### Case 1 Difficult disease, easy transition

- 1 Diagnosis of perianal and colonic Crohn's disease aged 10
- 2 Colectomy aged 11, continuing perianal disease with recurrent abscess formation
- 3 Refractory to medical treatment including biological agents, required proctectomy
- 4 No formal handover but detailed summary and follow-up at the referring hospital maintained
- 5 Attended clinic with a family friend, felt psychologically ready to move to adult clinic
- 6 Felt he was 'not treated as an adult' and was 'fed up with babies' on the ward
- 7 Subsequently travelled to and attended clinic alone
- 8 Good regular contact with inflammatory bowel disease clinical nurse specialist
- 9 Disease complicated by enteropathic arthritis, further fistulous tracts and pulmonary emboli
- 10 Managed warfarin and subcutaneous methotrexate admirably
- 11 Currently well and in a stable relationship

### Case 2 Straightforward disease, complex transition

- 1 Presented aged 7 with a fever, anaemia and raised inflammatory makers
- 2 Diagnosed with Crohn's disease
- 3 Treated successfully with Modulen and a 5-aminosalicylic acid
- 4 Subsequent excellent growth, post-pubertal, felt ready to transfer
- 5 Both parents and the young person reluctant to transfer
- 6 Transition was discussed in detail with the paediatric consultant
- 7 Single joint appointment in handover clinic with both teams present
- 8 Seen in adolescent clinic, clinically well, alcohol and smoking discussed
- 9 Became unwell at home 1 month later with pain and diarrhoea
- 10 Did not contact the adult hospital—"I didn't know you so well"
- 11 Had been discharged from the referring hospital as transfer complete
- 12 Mother requested return to the paediatric hospital 'where he felt secure'
- 13 After discussion agreed to retry the adult clinic and required daily contact with the inflammatory bowel disease clinical nurse specialist
- 14 After reassessment started azathioprine treatment
- 15 Well on review, happy and gaining weight.
- 16 Mother apologetic over anxiety

a need for slower transition with several joint appointments before transfer and heightened awareness for the need for continuing support (case 2).

Information technology is highly useful in this context, young people are comfortable using text and email to contact their clinical nurse specialist for advice. The internet can be a valuable resource: both NACC and CICRA have sections aimed at young people (IBD and ME and the Cool Zone, respectively). In addition online support groups such as CrohnsZone are useful in sharing experiences while maintaining a degree of anonymity and helping to reduce the feeling of isolation.

Education is a key component to assuming responsibility for self-management and routine assessment of the young person's level of understanding is often overlooked. In one US study only 43% could name their drug and dosages and few were aware of potential side effects.<sup>16</sup> The vast majority relied on their parents for scheduling appointments, arranging repeat prescriptions and contacting the hospital. Barriers to medication adherence relate to lack of time, drug side effects, feeling well on maintenance treatments and more than once-daily drug regimens.<sup>17</sup> Education remains central to managing lifestyle choices which impact on disease and early education regarding smoking, alcohol, contraception and pregnancy has a role in damage limitation and in increasing confidence and knowledge that a normal life is possible. Personal responsibility is vital for managing the more long-term issues of IBD such as chemoprophylaxis, disease and drug monitoring and medication adherence. Awareness of help available outside hospital, particularly in education and employment, is vital to support the young person through school and university.

### Options for transition care

In the UK no one model fits all patients and locations.

In many ways the ideal model is a transitional or adolescent clinic with joint input from adult and paediatric healthcare professionals. Young people could attend clinic from a relatively early age (14 or 15) and complete transition within this environment before moving into an adult clinic, preferably with the same 'adult team'. For a substantial referral practice there

#### Quotations 1 – Living with IBD

"Crohn's is hard to live with ... sometimes it's like you are not even living"  
 "It's hard for me to remember to take all my pills without my parents reminding me"  
 "I don't want to let this disease rule me"

#### Quotations 2 – Psychosocial effects of IBD

"I can't tell my friends or my boyfriend, I just keep it to myself"  
 "No one outside my family knows about my stoma, I don't think I can ever have a relationship because of my Crohn's"

#### Quotations 3 – Taking personal responsibility

"I was very nervous coming to the clinic at first but now I come on my own"  
 "My mum waits outside and I only call her in if there is something I want her to hear as well"

should be access to laparoscopic (up to 80% of the patients with Crohn's disease will require surgery over their lifetime) and pouch surgery, preferential use of non-ionising imaging techniques such as ultrasound and MRI and trained support including psychology. This is appropriate for larger hospitals with 'feeding' paediatric gastroenterology services and is most useful for young people with complex or refractory disease or comorbidities which can be managed by the same provider. The main downsides are the travel distances and expense and may not be cost effective when patient numbers are small.

The commonest model is to offer a joint handover clinic with one (or several) appointments with the paediatric team introducing the young person to the adult team. The majority of young people surveyed in a recent study<sup>18</sup> felt one joint paediatric/adult clinic was appropriate, although this may be insufficient for the more anxious or complex patient.

Where a direct handover clinic is not logistically possible selected young people, particularly with limited or medication responsive IBD may be transferred to a local adult clinic with a detailed care plan outlining previous investigations and treatments in conjunction with 'back-up' appointments at the paediatric hospital.

The provider hospital needs to decide which model it can offer successfully and support. The 'full package' may not be affordable or practical. Trusts need to work within networks with clear plans and policies to optimise transition care (table 2). Unfortunately, from the commissioner's perspective this remains a largely forgotten group and the expensive double running costs of two teams often results in transition being of low priority.

**Table 2** Top tips for the provider hospital: an inflammatory bowel disease transition policy as a foundation for the service; this should ensure the following issues have been fully addressed

1	Identify a 'key worker' to lead the process, usually a clinical nurse specialist
2	Clarify the hospital's overall philosophical approach to transition
3	Establish the timing of transfer with agreed management practice, particularly where there are differences—for example, endoscopy
4	Ensure adequate preparation for transfer, particularly in the paediatric service
5	Outline the step-by-step transfer process
6	Use any formal arrangements already set up
7	Identify how the process is coordinated. Clarify who are the key workers
8	Document the hospital's policy for involving other services
9	State how smooth communication and confidentiality will be maintained
10	Formally agree which hospital will lead transition if patients are receiving shared care
11	Document how the process will be monitored, evaluated and improved

Transition works best when coordinated and overseen by a nominated key worker. The specialist nurse is usually best suited to this role and is generally the patient's first point of contact.

### Barriers to transition

A number of obstacles to transition have been identified (table 3). The most important is difficulty of identifying adult primary care providers, followed by adolescent and family resistance and a lack of institutional support.<sup>19</sup>

Doctors may be a barrier to timely transition. Paediatricians can find it difficult to give up patients after years of providing care. They may feel their adult counterparts cannot provide the same quality of medical and holistic care. Adult gastroenterologists may lack confidence when dealing with younger patients. Hait *et al* surveyed 1132 adult gastroenterologists and only 46% felt competent addressing developmental aspects of adolescents.<sup>20</sup> This suggests work to be done in educating doctors as well as patients.

Rules regarding adult doctors seeing younger patients may present a barrier but basic training in child protection, communication skills and resuscitation techniques is not onerous.

It is important to have a suitable environment for young patients and to remember that to be seen in facilities geared up for very young children may be as inappropriate as the wholly adult environment.

### The future

There is no doubt that this is an area in which we can, and should, do better. Transition practice in the UK lacks consistency. Providers need to identify resources and work within networks to optimise services and attain the expected IBD standards of care (table 4). Adult gastroenterologists require education in adolescent care and paediatricians need to feel confident in transferring patients to adult services. There is currently no formal clinical training in adolescent health in the UK outside of mental health and American data suggest that only a minority of doctors enjoy looking after young people, potentially discouraged by time-consuming consultations and demanding families.<sup>9</sup> By introducing adolescent training into the gastroenterology curriculum, encouraging specialist training days to focus on adolescence and rotating gastroenterology trainees through adolescent clinics we can significantly improve this.

The initial push within the UK has been to set up transition services and this has been broadly

**Table 3** Barriers to transition

1	Adolescent resistance to change
2	Family anxieties
3	Paediatricians' reluctance to 'let go'
4	Lack of identifiable adult specialists
5	Insufficient specialist knowledge in adult practitioners



**Table 4** Inflammatory bowel disease (IBD) standards for the care of children and young people

1	Initial investigation and treatment should be in a paediatric gastroenterology service (part of a paediatric gastroenterology clinical network)
2	For physically and emotionally mature patients without psychological or educational problems investigations may be undertaken locally with shared care between an adult gastroenterologist and a paediatrician with an interest in gastroenterology
3	Standards for staffing and facilities must be met as outlined in the National Service Framework for Children and Young People in England—that is, for a catchment of 2 million people children's wards and children's nurses Endoscopy in a fully child-friendly unit Accredited paediatric anaesthetists Appropriately trained radiology staff Surgeons with an expertise in paediatric IBD An experienced dietician and paediatric nurse specialist Paediatric psychology and endocrinology support
4	Endoscopy should be performed by endoscopists with training and/or extensive experience in endoscopy and ileocolonoscopy in children
5	Information and support must be available to parents and siblings
6	There must be a defined policy and protocol for transitional care with a named coordinator overseeing this (eg, IBD nurse specialist)

successful but data on how to accurately assess young peoples' readiness for transition and monitor and audit outcomes are lacking. If one looks at this along the 'adopting a change' continuum<sup>21</sup> some specialist groups are at the stage of action with a fairly limited number successfully at the maintenance phase; however, a much larger number of units may still require education and persuasion to raise their awareness and convince them of the need for improved transition services. Within our department we are starting to assess knowledge of disease and medication for patients transferring to the adolescent clinic with questionnaires for young people and their parents and this will to be mirrored in paediatric services so we can identify the level of parental input and develop an auditable education programme and transition tool. This is supported by the recently established adolescent and young persons section at the British Society of Gastroenterology, which aims to help improve transition services, build links between paediatric and adult services and promote education and research in this rather lost group often too old for paediatrics but not quite ready for full independence and adulthood.

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