

# Educate, Communicate, Anticipate—Practical Recommendations for Transitioning Adolescents With IBD to Adult Health Care

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**Abstract:** The cyclical nature of chronic illness requires that children with inflammatory bowel disease be transitioned to the adult medical system with as much continuity of care as possible. Transition from pediatric to adult medical care continues to present significant barriers. The philosophy of transition centers on a process, with the actual transfer to adult care as a point along this clinical pathway. Concrete steps can be taken to help patients prepare for new responsibilities. The aim of this review is to propose a clinical and developmental timeline for both patients and their medical team, including specific responsibilities for both, so that the partnership can best promote a successful transition.

**Key Words:** adolescents, inflammatory bowel diseases, continuity of patient care, continuum of care

(*Inflamm Bowel Dis* 2006;12:70–73)

Inflammatory bowel disease (IBD) has been recognized as one of the most serious chronic diseases of childhood. It is a relapsing and remitting disease with high morbidity but low mortality.<sup>1</sup> As such, most of our pediatric patients with IBD survive well into adulthood.

Children with IBD have unique issues and concerns when compared with adults, and are usually managed by pediatric gastroenterologists. Transitioning from pediatric to adult medical care is a major milestone in the life of a young person with IBD, yet it is often poorly done. Several obstacles to successful transition exist as outlined in the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition medical position paper on this subject<sup>2</sup>; they include the reluctance of the patient, the patient's family, and the patient's medical providers. These barriers to transition appear

to be universal among chronic conditions with a childhood onset. In addition, pediatric medical providers may not have a clear and consistent route to follow in preparing themselves and their patients for the transition. In this article, we draw on the experiences of our colleagues who care for patients with congenital cardiac conditions, cystic fibrosis, organ transplantation, and juvenile diabetes,<sup>3–8</sup> as well as existing pathways for timelines of transition.<sup>9,10</sup>

The successful transfer of care of adolescents with IBD from the pediatric to adult gastroenterologist is essential and requires careful planning. At the Center for Inflammatory Bowel Disease at Children's Hospital Boston, we are fortunate to have a multidisciplinary team including nurses and social workers who are trained in this transition process. We believe that simple measures can be taken even in the setting of smaller community-based practices that may not have the same resources as a large tertiary IBD referral center. We propose that the transition process should begin early and should be done in a consistent and open manner. When done effectively, transition can be an extremely empowering experience for patients. In this article, we provide a suggested timeline and guidelines for this transition process.

## DEFINING TRANSITION

Essential to the success of a transition, is the recognition that it is a process, not a single point in time. It does not involve the mere act of giving a patient the contact information for an adult provider. The actual act of transfer to an adult provider may be the culminating step in a planned program that includes providing developmentally and age-appropriate uninterrupted health care and the promotion of skills in communication, decision making, self-care, assertiveness, self-determination, and self-advocacy.<sup>5,11</sup>

There are considerable differences between pediatric and adult medical services, and this distinction has a significant impact on the success of transition. Pediatric care tends to be multidisciplinary, family focused, and requires parental direction and consent. Adult care is often provided by a single doctor, patient focused, and more investigational, and it expects the patient to be autonomous and independent.

Received for publication October 11, 2005; accepted October 12, 2005.

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Supported by the Wolpov Family Fund and the NIH Pediatric Gastroenterology Research Training Grant T32 Dk 07477.

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The most important element in the transition process is anticipation, which can then allow for practice and problem solving. To anticipate the course of the transition process, practitioners must approach this within a developmental framework that mirrors the developmental stages of the patient. The process should be initiated well before the act of transferring care and should encompass services and supports that surround the adolescent and young adult with the skills necessary to empower them to navigate the world of adult health care.<sup>11</sup>

### WHAT DOES IT LOOK LIKE? A TIMELINE

When considering the protocol for a transition, we recommend that the child be approached from the commonly accepted developmental stages, roughly defined by chronology

of ages 11 to 13, ages 14 to 16, ages 17 to 19, and ages 20 to 23. The transition process is most sensibly begun as soon as a patient is capable of abstract thinking and future orientation. Table 1 is a checklist of tasks for both the medical team and the patient. The provider can also use these guidelines as a measure of the patient’s progress toward mastery and self-advocacy.

### Ages 11 to 13

At this age, the child should be able to articulate his or her gastrointestinal (GI) condition. The patient should be able to name medications as well as their dosages and major side effects. Patients in this age group should start to identify strategies to take their medications. They should be able to use and read a thermometer. The patient should be able to articulate the impact of his or her disease on the school sphere

**TABLE 1.** Checklist of Tasks for the Patient and the Medical Team Based on Chronological Age

Age	Patient	Medical Team
11–13	<ul style="list-style-type: none"> <li><input type="checkbox"/> Able to articulate his or her GI condition</li> <li><input type="checkbox"/> Able to name medications, doses, side effects</li> <li><input type="checkbox"/> Knows strategies to take his or her medications</li> <li><input type="checkbox"/> Able to use and read a thermometer</li> <li><input type="checkbox"/> Articulates impact of IBD on school and daily life</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Introduces idea of future independent visits</li> <li><input type="checkbox"/> Asks parents to remain in waiting room for a portion of the visit</li> <li><input type="checkbox"/> Anticipatory guidance about fitness, sexuality, and substance abuse</li> </ul>
14–16	<ul style="list-style-type: none"> <li><input type="checkbox"/> Able to identify medical team</li> <li><input type="checkbox"/> Knows names and purposes of procedures and tests done on him or her</li> <li><input type="checkbox"/> Knows his or her medical history</li> <li><input type="checkbox"/> Knows names of IBD social support groups and community organizations</li> <li><input type="checkbox"/> Understands the medical risk of nonadherence</li> <li><input type="checkbox"/> Understands the impact of drugs and alcohol on the illness</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Directs all questions and explanations to patient</li> <li><input type="checkbox"/> Patient asked for input first</li> <li><input type="checkbox"/> Explores family’s apprehensions about patient taking on primary role</li> <li><input type="checkbox"/> Clarifies to patient what must legally be disclosed to parents</li> <li><input type="checkbox"/> Determines when the patient wants his or her parents in and out of the room</li> <li><input type="checkbox"/> Initiates discussion about eventual transfer of care</li> <li><input type="checkbox"/> Determines post–high school plans (social, employment, education)</li> <li><input type="checkbox"/> Instructs patient how to access medical records</li> <li><input type="checkbox"/> Instructs patient to keep names of medications, dosages, and medical team contact in wallet/purse/backpack</li> <li><input type="checkbox"/> Instructs patient on how to get prescriptions filled and how to call and schedule appointments</li> </ul>
17–19	<ul style="list-style-type: none"> <li><input type="checkbox"/> Knows how to gather information about IBD</li> <li><input type="checkbox"/> Demonstrates consistent ability to book own appointments, fill prescriptions, contact medical team</li> <li><input type="checkbox"/> Able to name his or her insurance coverage and plans for next 2 years of coverage</li> <li><input type="checkbox"/> Carries insurance information in wallet/purse/backpack</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Initiates conversation about potential barriers to transition</li> <li><input type="checkbox"/> Identifies potential adult GI providers</li> <li><input type="checkbox"/> Encourages patient to meet and interview providers</li> <li><input type="checkbox"/> Reminds patient and family that at age 18 the patient has the right to make his or her own health choices</li> </ul>
20–23	<ul style="list-style-type: none"> <li><input type="checkbox"/> Has had a telephone conversation with potential adult GI providers</li> <li><input type="checkbox"/> Initial visit with adult GI is scheduled while IBD stable</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Provides patient with medical summary and checklist (see Table 2)</li> <li><input type="checkbox"/> Transfers medical records to adult provider</li> </ul>

and on overall daily life. The child should be able to articulate overall healthy lifestyle choices.

The medical team should introduce the idea of future independent visits. They should start advertising the patient's privacy by having the parents remain in the waiting room for a portion of the visit. The physician should start providing anticipatory guidance on the impact of fitness, sexuality, and substance use on their illness.

### **Ages 14 to 16**

Patients in this age range should be able to identify the family members and community professionals who are involved in their health care and in what role. They should be able to name the procedures and tests that evaluate their IBD and their purpose. Patients should be able to articulate their own parents' relevant medical histories. They should be able to identify names of IBD social support groups and community organizations. Patients should be able to articulate the medical risk of nonadherence to their prescribed medical regimen, and they should have an understanding of the impact of drugs and alcohol on their illness.

It is important that the medical team direct all questions and explanations to the patient, with body language and eye contact directed toward the patient, not the parent. It should be clearly explained to the parent that the physician will ask the patient for input first, and then solicit feedback from the parent. At this point, the physician should explore and address the family's apprehensions about the patient taking on the primary role during the office visit. As with all adolescent patients, the physician must clarify with the patient what must legally be shared with his or her parents. The physician should ask the patient during which portions of the visit he or she would like his or her parents to be in or out of the room.

The physician should initiate discussion about the eventual transfer of care and why this is important to the patient's optimal health. There should be discussion initiated by the medical team on post-high school plans in the social, employment, and educational arenas. The team should begin intermediate goal setting to achieve these plans. The patient should be instructed how to schedule appointments, fill prescriptions, access his or her medical records, and to keep names of medications, doses, and medical team contact information in his or her wallet/purse/backpack.

### **Ages 17 to 19**

At ages 17 to 19, patients should be able to identify ways to gather information about their illness. Patients should demonstrate consistent ability to access and coordinate medical needs, including booking their own appointments, filling prescriptions, and articulating whom on the medical team to call. They should be able to name their insurance carrier and plans for the next 2 years of coverage, and they should carry their insurance information in their wallet/purse/backpack.

The medical team should initiate conversation about potential barriers to transfer of care, including financial issues, attitudes, access, and family resistance. The physician should identify potential adult providers for the patient to begin exploring, and the patient should be encouraged to meet and interview potential providers. The patient and family should be reminded that at age 18, the patient has the right to make his or her own health care decisions. The medical team should initiate discussion about differences in the cultures of pediatric and adult GI settings and medical models.

### **Ages 20 to 23**

By this age, the patient should have had phone conversations with potential adult GI providers. The patient should schedule his or her initial visit with an adult GI provider while his or her IBD is stable. The patient may choose to have a final visit with his or her pediatric provider to discuss his or her experience with the adult provider. The pediatric gastroenterologist and family can then troubleshoot remaining concerns. Medical records should then be transferred to the identified new provider.

## **CONSIDERATIONS**

This timeline is not a rigid protocol. It is important to note that this clinical transition course must be tailored to the developmental abilities of the patient. It may not, in fact, be based on only chronological age but reconciliation with a competency level involving demonstrated emotional and cognitive maturity. It is likely to be most successful if the actual act of transfer of care occurs at a time of relative medical and social stability for a patient. This may occur at different ages for various patients. For those who attend college, the transfer may be after graduation and after a job is secured or graduate education has begun. For those who choose not to attend college, this actual transfer of care can occur at a time when housing and employment arrangements are stabilized, suggestive of the patient's entry into adulthood in the social arena.

## **EDUCATION AND COMMUNICATION**

It is clear that the transition process is a long and complex one. All participants, including providers, patients, and family, should be aware of the process and understand the underlying rationale and eventual goal. This can help prepare the family for the difficult life change and what is often experienced as a loss, without feeling abandoned. Multiple strategies can be used to mark the progression through the transition. The medical team could send a letter to all patients at the time of their 16th birthday, sending birthday wishes and stating that the medical team looks forward to the patient becoming a more active member of the healthcare team. At the second-to-last visit with the pediatric team, before the first visit

with the adult team, the process can be formalized with a signed provider's letter expressing gratitude for having been part of the patient's healthcare team, and providing a checklist outlining documents to bring to a first appointment (Table 2). It may also include questions to ask the adult provider and details to share about the patient's medical history.

### CONCLUSION

Anticipation of the changing role of a patient, when moving from pediatric to adult medical care, can help guide the preparation process. Graduated responsibility is best done in a developmental context and in an open manner. Oppor-

tunity to anticipate and practice the new roles for family and patient allows patients to problem solve and gain a sense of mastery, thereby increasing their sense of empowerment, self-efficacy, and self-determination. These are the traits needed to make a successful transition of care and allow competent negotiation of the adult healthcare world.

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**TABLE 2.** Suggested Documents for Patients to Bring to First Appointment With an Adult Health Care Provider

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Medical summary letter (provided by pediatric gastroenterologist)
Date of diagnosis
Location and severity of disease
Surgeries (and complications)
Medical therapies used: doses, duration
Adverse reactions to medications
Health insurance information
Calendar/scheduling book for scheduling appointments and test
Important names and contact information
Primary care provider
Pharmacy
Home health company (if relevant)
Other subspecialists
Transportation company (if physically disabled)

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