

A Case-Based Monograph Focusing on IBD



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IMPROVING THE TRANSITION PROCESS



FOR PEDIATRIC IBD PATIENTS IN CANADA

The Canadian Association of Gastroenterology (CAG) has reviewed this material and recommends that educational activities related to this program can be recorded for Royal College of Physicians and Surgeons of Canada (RCPSC) Section 2 Credits, in accordance with the guidelines established by the RCPSC and endorsed by the CAG. Participants may claim Section 2 credits; one hour = two credits (Section 2 form is appended and linked to this material). Documentation must be kept to support hours claimed.

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INTRODUCTION

Inflammatory bowel disease (IBD) is complex, especially in the pediatric population. Along with facing the same risks as adult patients, children with IBD also face a number of unique social challenges. Pressure to fit in with peers can be overwhelming in the years leading up to a patient's transition into independence, and many pediatric patients are learning to balance their social life with school and possibly work. Puberty develops at a time when pediatric patients are forming a sense of identity and responsibility, and independence can be a stressful experience without proper preparation.

Ensuring a smooth transition from pediatric to adult care is an ongoing challenge for Canadian health care professionals, with many factors to consider. Pediatric patients who are not properly prepared to accept the responsibilities that come with independence often struggle in many areas of self-care, including communicating with their adult care professionals, adhering to treatment, and becoming a self-advocate. This monograph focuses on teaching Canadian clinicians to effectively transition pediatric patients into an adult care setting and includes strategies to manage and resolve potential barriers to this often challenging process.

TARGET AUDIENCE

This activity is designed for pediatric and adult care gastroenterologists, primary care physicians, physician assistants, nurse practitioners, and other health care professionals who are involved in the transition of IBD patients from pediatric to adult care.

LEARNING OBJECTIVES

Upon completion of this activity, participants should be better able to:

- Identify the needs of IBD patients for a successful transition from pediatric to ongoing adult care
- Explore potential barriers to this transition from the perspectives of patients, families, and medical team members
- Utilize The North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) Foundation for Children's Digestive Health and Nutrition and NASPGHAN checklist and patient Web resource to develop an effective transition plan for pediatric IBD patients, with a focus on developing patient independence, education, and communication
- Incorporate parents and family members of pediatric IBD patients into the planning process to ensure their support
- Develop a team approach (when available) in transitioning IBD patients from pediatric care to adult care, and utilize available transition resources

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Dr. Otley reported that he is a speaker and member of the advisory board for Merck Frosst Canada Ltd. He also reported that he is a speaker for Mead Johnson Nutrition & Company and a member of the advisory board for Nestlé Canada and Abbott Laboratories, Ltd. *Conflicts with Dr. Otley were resolved by restricting the presenters to best available evidence and the ACCME content validation statement.*

Ms. Arnold has nothing to disclose.

Dr. Fishman has nothing to disclose.

Ms. Goldberg has nothing to disclose.

Ms. Wheat has nothing to disclose.

Matt Kilby, medical writer, has nothing to disclose.

Karin McAdams, program manager, has nothing to disclose.

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OVERVIEW

The transition from pediatric care to adult care is an important step for teens with inflammatory bowel disease (IBD), and is often a challenging one. Health professionals face many barriers to successful transition, including the physical and emotional development of patients, resistance from parents, and their own hesitations to the subsequent transfer.

A transition plan should be introduced as soon as possible in pediatric patients, allowing adequate time to facilitate a smooth process. Early preparation can help build patient confidence and self-management skills, assuage reservations and resistance from parents, and establish a clear set of goals for the transferring provider. Transition focuses on patient education and the development of the necessary skills to independently and successfully manage their IBD in a new and unfamiliar setting.

The pediatric provider should guide and prepare the patient for the new culture of adult health care. The adult patient is expected to articulate his/her medical history, tolerate minor physical discomfort, take initiative in asking questions, and participate in more decision making. The adult provider often focuses more on the disease and less on the psychosocial context, favors the patient's autonomy over nurturance, and treats the individual instead of the patient's family.^{1,2}

The North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) Foundation for Children's Digestive Health and Nutrition and NASPGHAN have developed recommendations based on a timeline and educational goals for the transition of pediatric IBD patients. This monograph, specifically tailored to Canadian health care providers and their patients, reviews these recommendations as well as common barriers all involved parties may face.

EARLY PREPARATION AVOIDS LATER OBSTACLES

Why Does Transition Matter?

Transition to adult care is the process of developing a patient's medical independence. IBD will affect pediatric patients throughout their lives. Once in adulthood, patients are expected to communicate directly with their physician and navigate through various aspects of the medical system, including entities such as insurance carriers and pharmacies.³ Abrupt transfer may cause excessive stress in patients, insufficient confidence in parents, and frustration on the part of the adult care provider. The goal of a successful transition plan is to achieve a continuum of care that involves normalization of social and emotional development, acquisition of independent living skills, improved compliance, and effective planning for long-range needs.^{3,4}

A successful transition includes:

- Customizing an approach that takes into account the maturity and personal development of individual patients²
- Openly recognizing and addressing barriers inherent to the transition process

- Recognizing that transition is a process, not a single point in time²
- Creating a developmentally appropriate program aimed at moving adolescent patients toward self-management³
- Starting the process early to establish the necessary skills for self-management, including proper treatment adherence, a general understanding of disease activity, and recognition of flares

Obstacles to a Smooth Transition

THE PATIENT

Children with IBD face many of the same medical risks as adult patients, but unlike adults must also complete the task of growth and development. Studies of height velocity in IBD and its 2 main subtypes – Crohn's disease (CD) and ulcerative colitis (UC) – have demonstrated that up to 46% of children with CD will have a reduced height velocity before the onset of symptoms, contrasted with 3%-10% of children with UC.⁵⁻⁷ Quality of life is often affected by anxieties about inadequate growth, and the prospect of adult short stature can cause significant concern.^{5,8} Delayed growth and late-onset puberty may also have a significant negative impact on psychosocial, mental, and emotional development and may further delay transition from parent-dependent early adolescence to self-dependent late adolescence.

Puberty introduces an often overwhelming pressure to fit in with peers, and disease activity that sets patients apart from their social group can cause increased stress. High-risk behaviors, including experimentation with smoking, alcohol, drug use, and sexual activity, have been reported to be as common in adolescents with chronic illness as in the general population, though with an increased risk of negative outcomes.⁹ During this time of intense physical and emotional changes, adolescent patients experience their first encounter with responsibility, learning to balance their social life with school and health care management.³

Patients often lack the necessary emotional and cognitive skills to cope with treatment regimens. Adherence rates among children with chronic disease are typically reported at approximately 50% and are lowest in adolescence and during remission.^{10,11} The adolescent's limited life experiences and sense of invincibility contribute to a poor understanding of their responsibility in managing their disease state. For example, adolescents often fail to create strategies to remember medications and may refuse parental assistance due to a wish for increased independence.

Transferring into the adult care health system is a major and expected milestone in the lives of pediatric patients, yet is often accompanied by feelings of reluctance in giving up the familiar care of the past.^{2,4} Forced to face this change, patients may experience feelings of abandonment or even anger at the need to leave their comfortable environment. Some patients refuse to engage in the transition process early, waiting until the transfer is imminent. The patient may even expect the pediatric provider to relent and allow them to stay under their care. While this may be possible in the United States, in Canada, transition must occur by the age of 18 years.

THE FAMILY

Transition is a challenging time for the patient's family, often accompanied by fear and a sense of loss.³ Family members who have been intimately involved with their child's care may feel shut out and ignored when adult providers involve them only with the patient's permission.⁴ Families often develop close personal ties with pediatric providers and their staff, forged over time through crisis and shared concerns. Understandably, they are reluctant to leave these comfortable bonds.^{4,12} Perceived lack of knowledge and experience in the adult provider can contribute to the resistance to start over with a new physician.¹ It is important to remember that these family members have previously been involved in all treatment decisions and are now faced with having to let go and gain trust as the adolescent becomes more independent.³

THE PEDIATRIC PROVIDERS

There may be medical or social reasons to choose a time for transfer, but conflicting ideas as to the best time to complete the transition may force the pediatric provider to act as mediator, striking a 3-way balance between their own opinion and the wishes of the patient and parents.^{12,13}

Pediatric providers develop strong ties to patients and their families and may feel that adult providers lack the expertise and preparation to deal with their patients' medical problems and unique psychosocial challenges.⁴ Often, this is a result of the pediatric provider's focus on nurturing their patient rather than providing autonomy. Two myths that pediatric providers may have are:

- "I know my patient better than anyone else could."
- "I can best take care of my patient and if I am not available to them they might not fare well in an adult setting."

To dispel these fears it is imperative that the pediatric provider spends adequate time on the transition process so that difficulties for the patient, family, and adult gastroenterologist are avoided as much as possible.⁹ It is helpful to have the pediatric provider enumerate the positive aspects of adult-centered care.

THE ADULT PROVIDER

Adult health care providers acknowledge the importance of uninterrupted health care. Yet often, they face difficulties when pediatric patients transfer into their care. A survey of adult gastroenterologists (363 responders) reported that they found deficits in patient knowledge regarding medical history (55%) and prescribed medication regimens (69%).¹⁴

Data also show that the adult provider may potentially lack the confidence or training to treat adolescents with childhood-onset disease.⁹ In the Hait et al survey, 96% of adult gastroenterologists believed awareness of medical aspects of adolescent health care was important, with only 73% reporting that they felt competent regarding those issues.¹⁴ Similarly, 89% of responders believed developmental issues were important, but only 46% felt comfortable and competent with addressing developmental or mental health issues in this

population of patients. It is not uncommon for adolescent patients to regress to a lower level of maturity in times of stress and change, thus potentially leading the adult provider to question the appropriateness of the transfer. Difficult and overly involved families may add to the adult provider's doubts about the patient's readiness for transfer. These common occurrences eventually lessen in time.

THE HEALTH SYSTEM

Barriers inherent to the medical health care system often create obstacles in the transition process, such as difficult access to medical records. Additionally, patients who are followed by multiple subspecialists for comorbid conditions require a well-coordinated transfer across specialty areas, which is often logistically difficult to prepare. Hait et al reported that 51% of adult gastroenterologist responders reported receiving inadequate medical histories from pediatric providers.¹⁴ The pediatric gastroenterologist should provide a detailed and informative medical summary to both the patient and the adult provider. Such a summary is a key component in effectively transferring care. Patients who see multiple specialists for comorbid conditions may experience an inconsistency in the transition process because of a lack of collaboration across specialty areas. An improper or untimely transfer of a patient's medical history complicates this process further.

Patients who attend college or university in different provinces will receive a greater amount of care by telephone than those who remain closer to home.⁴ It is also important for the pediatric or adult care provider to ensure adequate communication with the student health services provided by the patient's college or university. For many patients, these services are the first line of health care while attending school. Transfer to an adult provider under these circumstances can prove difficult when done a short time before the patient starts college or university, as the new provider may not have sufficient time to become familiar with the patient or their medical condition. Temporary transition to a physician who is closer to the patient, while convenient, may not provide the consistency necessary for a continuum of quality care. Thus, ensuring a timely and well-organized transfer of care, with sufficient information provided to the adult care provider, is essential to providing appropriate management for transitioning patients.

Insurance coverage and policies must also be factored into the transition process. Private drug coverage/insurance is most often linked to parents' employment and typically ends for the patient between ages 18 and 25 years. Specific coverage and benefits are dependent on the territory/province where the patient resides. Overviews of private and territorial/provincial insurance programs can be found at: <http://www.drugcoverage.ca/default.asp>.

The level of coverage may also be reduced at age 18 years for some patients, especially those in government assistance programs.¹ In Canada, transition is required by age 18 years or once high school is completed. This demarcating line can often create anxiety and frustration about mandatory transition that does not take into account the patient's developmental abilities.¹⁵

PREPARING THE PEDIATRIC PATIENT FOR TRANSITION

Early Steps

The transition process should begin in early adolescence, or from the time of diagnosis, to allow the idea of developing independence and leaving the familiar pediatric environment to take shape in the patient's mind.^{4,13,16-18} Parents can help prepare children even before adolescence by teaching proper medication use and delegating responsibility to the patient to carry out specific medical self-care tasks.¹ This communicates to the adolescents that caregivers have confidence in their ability to eventually learn these skills. Focus group interviews of posttransition patients, family members, and health care providers recommended starting the process early. In their experience, it contributed to patients' improved self-confidence.

NASPGHAN Recommendations

NASPGHAN has developed general recommendations for an effective transition of patients with IBD from pediatric to adult care, including taking early steps to facilitate the transition process, involving the parents in transition planning, and aiding in the selection of the adult provider.⁴ These recommendations are summarized in **Table 1** and will be detailed further in the age-specific timelines in the next section.

While transition to adult care is required at age 18 years, it has been acknowledged that true developmental independence is not traditionally reached until the age of 21 years. For this reason, in the United

States, some patients are followed by pediatric gastroenterologists beyond the age of 18 years and throughout college.

Starting in early to middle adolescence, the pediatric provider should begin seeing patients without their parents.^{4,12} One-on-one conversations with the patient build a relationship that promotes the patient's independence and self-reliance, prepares them for the relationship they can expect from their adult provider, and helps to establish self-care skills well in advance of the eventual transfer of care.

Patients and family members should be informed that an adult-care gastroenterologist is better qualified in the long run to address problems both directly and indirectly related to their underlying condition during the adult years.⁴ Conditions such as pregnancy and fertility, ongoing cancer surveillance, and various common adult health problems will be more adequately addressed by the adult care provider.

After the decision is made to start the transition process, a skilled adult provider should be identified.⁴ The ideal physician is one who has experience with young adults and recognizes the different expectations of patients with childhood-onset IBD and patients with a more recent onset of IBD.

Table 1. NASPGHAN Transition Recommendations^{4,12}

1. Start seeing the patient without their parents to build a relationship that promotes independence and self-reliance
2. Discuss benefits of transition to an internal medicine gastroenterology practice with the patient and family
3. Select an adult gastroenterologist who cares for young adults and identifies with the special considerations in childhood-onset disease
4. Provide all necessary medical records and summaries so that the family will recognize that all providers are working together to deliver excellent care
5. Allow flexibility in transition timing according to individual patient needs up to the age of 18 years

At the time of transfer, the pediatrician should provide necessary medical records and summaries to the adult provider.⁴ Sending a letter that summarizes the patient's medical history to the new physician is also recommended and, if appropriate, a copy should be sent to the patient, especially if they choose to seek care from a different adult care provider. These steps help the patient and family to appreciate that both the pediatric and adult providers are in collaboration to provide the most optimal care for the patient.

Finally, the maturity of the patient is a critical factor when determining if they are ready for additional responsibility or independence and requires careful assessment on the part of the pediatric provider.^{4,9} However, the transition should be appropriately completed when the patient graduates from high school, requiring a balance of the patient's maturity and readiness and the date of this final transfer.

Suggested Timelines for Transition

As stated, an appropriate timeline for transition must be tailored specifically to the developmental abilities of the patient. A joint effort by The NASPGHAN Foundation for Children's Digestive Health and Nutrition with NASPGHAN has produced a general timeline and checklist that reflects the commonly accepted developmental stages, roughly defined by chronological age.

AGES 12-14 YEARS

CASE STUDY 1: *Initiating Transition*

Andrea is 13 years old and has recently been diagnosed with UC. She has recently finished tapering off of prednisone and is now on mesalamine monotherapy for maintenance and considered to be in remission. During visits, Andrea often looks to her father to provide information to her pediatric provider.

How would you introduce the transition process into Andrea's standard care?

- Review baseline information about the digestive system and UC with Andrea
- Discuss with Andrea how to recognize symptoms that warrant medical attention
- Help Andrea and her parents understand the medications being used for her maintenance therapy and their possible adverse effects
- Discuss specific self-management goals and help Andrea to balance her medical tasks (eg, taking medication) with school and social responsibilities
- Discuss the idea of Andrea attending some of the interview and examination without her parents present



Table 2: Patient and Provider Checklist for Ages 12-14 Years^{20,21}

Age Range	Patient	Health Care Provider
12-14 years*	<input type="checkbox"/> Can describe gastrointestinal (GI) condition <input type="checkbox"/> Can name medications, dosage, and times to take them <input type="checkbox"/> Can describe common side effects to medications <input type="checkbox"/> Knows doctors' and nurses' names and roles <input type="checkbox"/> Can use and read a thermometer <input type="checkbox"/> Can answer at least 1 question during health care visit <input type="checkbox"/> Can manage regular medical tasks at school <input type="checkbox"/> Can call doctor's office to make or change an appointment <input type="checkbox"/> Can describe how GI condition affects them on a daily basis	<input type="checkbox"/> Discusses idea of visiting office without parents or guardians in the future <input type="checkbox"/> Encourages independence by performing part of the examination with parents or guardians out of the room <input type="checkbox"/> Begins to provide information about drugs, alcohol, sexuality, and fitness <input type="checkbox"/> Establishes specific self-management goals during office visit

* It is ultimately up to the provider to determine when the patient is ready to move to the next stage of transition.

Between the ages of 12 and 14 years, patients, such as Andrea in case study 1, should demonstrate an age-specific understanding of their GI condition and the medications they are currently taking, as shown in **Table 2**.² As recommended in Andrea's case, this understanding should include disease-specific education and a firm understanding of the possible adverse effects of her pharmacologic treatment. It is recommended that patients in this age group be encouraged to utilize a "3-sentence summary" to explain their condition.¹⁹ Through the 3-sentence summary, patients are able to provide succinct and relevant information regarding their health history and avoid unnecessary interruptions by their health care provider. The summary includes the patient's: age, diagnosis, and brief medical history (sentence 1); treatment plan (sentence 2); and the question or concern they wish to talk about during the current visit (sentence 3). Patients should also be familiar with self-management tasks, such as using and reading a thermometer and identifying strategies to take their medications as directed.

The idea of independent visits should be introduced, acknowledging the patient's privacy by having their parents leave the room for part of their appointment.² Anticipatory guidance should be provided

on the impact of fitness, sexuality, and possible substance use and the potential effect they could have on the patient's underlying condition.

AGES 14-17 YEARS

During this stage, patients should be able to identify the procedures and tests used to evaluate their IBD, as well as their purpose (**Table 3**).² Education should also include adequate communication of their parents' relevant medical histories, articulation of the risk of nonadherence to their prescribed medical regimen, and understanding the impact drugs and alcohol could have on their illness.

Questions and explanations should be directed to the patient, ensuring that body language and eye contact are also directed initially to the patient and not the parents.² It should be explained to the parents that the patient will be asked for input first and then feedback will be solicited from the parents. If not initiated earlier, the health care professional should commence the discussion about the eventual transfer of care and the patient's plans after graduating from high school to determine whether the patient will be transferred to a local adult care provider or one near where they plan to attend postsecondary education.

Table 3: Patient and Provider Checklist for Ages 14-17 Years^{20,21}

Age Range	Patient	Health Care Provider
14-17 years*	<input type="checkbox"/> Knows the names and purposes of routine tests <input type="checkbox"/> Knows what can trigger disease flares <input type="checkbox"/> Knows medical history <input type="checkbox"/> Knows need to transition to adult caregiver <input type="checkbox"/> Reorders medications and calls doctor for refills <input type="checkbox"/> Answers many questions during health care visit <input type="checkbox"/> Spends most of time alone with doctor during visit <input type="checkbox"/> Understands risk of medical nonadherence <input type="checkbox"/> Understands impact of drugs and alcohol on condition <input type="checkbox"/> Understands the impact of GI condition on sexuality	<input type="checkbox"/> Always focuses on patient instead of parents or guardians when providing explanations <input type="checkbox"/> Allows patient to select when parent or guardian is present for examinations <input type="checkbox"/> Informs patient of what the parent or guardian must legally be informed about in regards to condition <input type="checkbox"/> Discusses importance of preparing patient for independence with parents or guardians and addresses any anxieties <input type="checkbox"/> Continues to set specific goals, including filling prescriptions and scheduling appointments and keeping a list of medications and provider contact information in wallet and backpack Discuss in more depth: <input type="checkbox"/> Impact of drugs, alcohol, and nonadherence on disease <input type="checkbox"/> Impact of disease on sexuality and fertility <input type="checkbox"/> Future plans for school/work and impact on health care <input type="checkbox"/> Coordination of care transfer with future school or work plans

* It is ultimately up to the provider to determine when the patient is ready to move to the next stage of transition.

AGES 17 YEARS AND OLDER

CASE STUDY 2: *Leaving Home*

Kevin is an 18-year-old high school senior who will be moving to an out-of-province university in 3 months. He was diagnosed with CD at age 12 years and since that time has gone through 2 recurrences. He is currently in remission, but often has missed days of medication and admits that he resents his dietary restrictions.

How would you address the barriers to Kevin's proper treatment adherence?

How would you prepare Kevin for his move to university or college?

- Patient "buy-in" is critical for maintaining consistent adherence to the treatment regimen. Various communication techniques may help Kevin assess and advance his readiness to take ownership of his health care by exploring personal barriers to regimen adherence and engaging in problem solving to improve adherence and reduce the risk of relapse.
- Provide Kevin with a medical summary for work, school, and transition, and provide a list of potential providers to encourage/facilitate the initial visit
- Discuss with Kevin how he will obtain medication (eg, local pharmacy). He should have the name, address, and phone number of a local pharmacy in the event he needs a new medication. He should be aware of what medications he cannot take as they might interact with the medications he is currently taking for IBD. He should also be aware of the effects of alcohol on the medications he is taking.
- Discuss where Kevin will have routine blood work done and where he will go if he becomes seriously ill (eg, local emergency department)
- Discuss how Kevin will explain his disease to his roommate. Even if he does not expect to share this information, it is likely that the many medications, frequent bathroom trips, and bandages after blood draws may provoke questions. He should have an answer in mind.
- Discuss how Kevin will communicate with his doctor if privacy is not easily found. He may prefer to use e-mail to send messages so he does not need to speak embarrassing details.
- Discuss sexual health and alcohol/drug use with Kevin. This is a time when many young people experiment and take risks; thus, the possible consequences these choices could have on his health must be presented.



Table 4: Patient and Provider Checklist for Ages 17 Years and Older^{20,21}

Age Range	Patient	Health Care Provider
17 years and older	<input type="checkbox"/> Knows which medications to avoid due to interactions with currently prescribed medications <input type="checkbox"/> Is alone with the doctor for entire health care visit or chooses who is present <input type="checkbox"/> Can name new legal rights and responsibilities gained at age 18 years <input type="checkbox"/> Manages all medical tasks outside the home (eg, work, school) <input type="checkbox"/> Knows how to get more information about IBD <input type="checkbox"/> Can book own appointments, refill prescriptions, and contact health care provider <input type="checkbox"/> Can communicate length of coverage under parents' health insurance plan and necessary steps to maintain coverage over next 2 years <input type="checkbox"/> Carries insurance information in wallet/purse/backpack	<input type="checkbox"/> Develops specific plans for self-management outside the home (eg, work, school) <input type="checkbox"/> Provides patient with medical summary for work, school, or transition <input type="checkbox"/> Discusses plans for insurance coverage <input type="checkbox"/> Provides list of potential providers and encourages/facilitates initial visit

During late adolescence, patients should be able to identify ways of independently gathering more information about their illness and demonstrate a consistent ability to access and coordinate medical needs, including appointment scheduling and filling prescriptions (**Table 4**).² Patients should also be able to identify their parent's insurance carrier and plans for future medical coverage. In many cases, students are automatically enrolled in university or college medical plans in addition to their parents' coverage and must opt out in September if they do not want this additional coverage. University-provided coverage generally includes extended health coverage, but may not include dental coverage. Those patients not planning to pursue further education will need to set up their own insurance coverage after high school.

Conversations concerning potential barriers to the transfer, including financial issues, patient attitudes, health care access, and family resistance, should be revisited at this time.² The patient and pediatric gastroenterologist should have discussed and identified a potential adult care provider, scheduling an initial visit during a period of stability from IBD activity. It may be helpful for patients to meet adult provider candidates in advance of the transfer. Some patients may choose to schedule a final visit with the pediatric provider to discuss their first experience with the adult provider. During this last visit, the pediatric provider can help troubleshoot remaining concerns with the patient and family. The patient should have a copy of their medical summary (**Table 5**) and make the pediatric provider aware of the new provider's name and address.

EDUCATING PATIENTS FOR AN EFFECTIVE TRANSITION

In patients who developed IBD in early childhood, much of the initial disease education may have been directed primarily to the parents.⁹ Disease education must often be reviewed repeatedly, taking into consideration the changing cognitive development that lends itself to poor retention of information. Concrete examples are more effective in young adolescents than abstract discussions, which become more appropriate as the patient develops into young adulthood.

Table 5: Suggested Documents for Patients to Bring to Adult Provider at First Appointment²

Medical summary letter from pediatric provider that contains the following: <ul style="list-style-type: none"> • Date of diagnosis • Location and severity of disease • Surgeries and complications • Medical therapies used, including dose and duration • Adverse reactions to medications
Drug plan coverage
Calendar/scheduling book for appointments and tests
Important names and contact information, including: <ul style="list-style-type: none"> • Primary care provider • Pharmacy • Other subspecialists • Transportation company (if physically disabled)

Inviting general inquiry from patients is important to assess their baseline knowledge and fill in any existing knowledge gaps. The patient should be well-versed on their various test results, multiple changes and adaptations of their treatment regimen, and any allergies or intolerances that may have emerged from treatment.

Resources designed to help educate and prepare pediatric IBD patients for transition are available from The NASPGHAN Foundation for Children's Digestive Health and Nutrition and NASPGHAN and include Webcasts, brochures, and information on such topics as disease education, coping strategies, and the transition itself.²² Interactive resources include a personal IBD notebook to assist the patient and family in tracking important information (eg, details about diagnosis, medications, and procedures) and a searchable database of pediatric gastroenterologists. The Crohn's and Colitis Foundation of Canada (CCFC) also offers patient education resources that include articles and personal stories geared specifically toward educating adolescents.²³ Additional resources, including articles and comics, are also available through the Crohn's and Colitis Foundation of America Web site.²⁴

IBD University (IBD U; <http://www.ibdu.org>) provides additional resources specifically for teenagers with IBD and includes articles on education, health care, lifestyle, and self-management.²⁵ Resources are also available for parents, friends, employers, teachers, and health care professionals. Recently, IBD U added a YouTube video channel that provides experiences and tips from adolescents with IBD and includes videos on preparing for college, employment, and independence.

Patients should learn to routinely update their personal medical history, and a “health passport” that patients can download, print, and carry with them to appointments is an easy and practical way to do this.²⁶ MyHealth Passport is a customizable, wallet-size card that provides comprehensive patient information to expedite medical history review when these patients visit a new physician. The passport includes general health information (eg, height, weight, and family history), specific IBD information (eg, disease type and location, current medications and medication allergies, and review of laboratory examinations), as well as contact information for previous and current physicians and the patient’s current pharmacy. MyHealth Passport is freely available to all patients, and is available at <http://www.sickkids.ca/myhealthpassport>.

BUILDING A TEAM APPROACH TO TRANSITION: The Medical Home Model

When available, a team approach to ongoing care and transitioning should also be utilized. Well-coordinated care by an interdisciplinary team allows for more time to address important patient concerns. A team may consist of physicians and nurses or can incorporate a broader range of medical subspecialists, such as social workers and nutritionists. This variety of specialties provides a greater opportunity for problem solving and may maximize the ability to solicit concerns from the patients and family.

In the medical home model, developmentally appropriate care is provided continuously as the patient moves along and within health care systems from adolescence to adulthood.²⁷ One physician provides first contact and continuous, comprehensive care, and is backed by a team of individuals at the practice level who collectively take responsibility for the patient’s ongoing care.²⁸ Care is coordinated across all elements of the health care system (eg, subspecialty care and hospitals) and the patient’s community (eg, family, public, and community-based services). The medical home model is centered around patient advocacy, and patients actively participate in decision-making, providing feedback to ensure their needs are met.

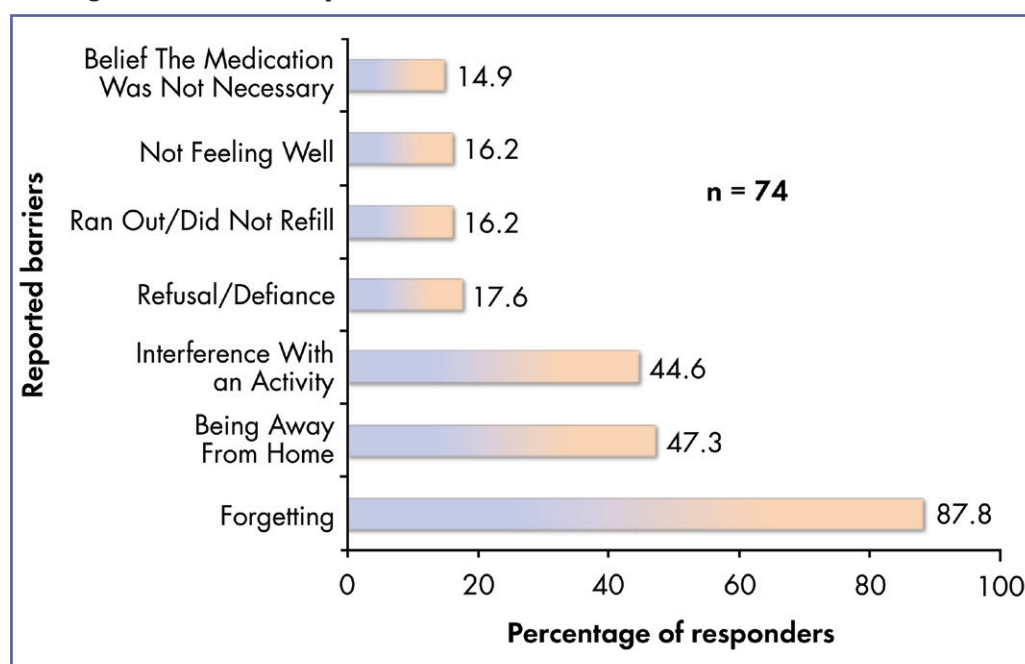
However, a team approach may present its own set of barriers. With multiple individuals tasked with preparing the patient for transition, clear and complete communication becomes critical to ensure that all aspects of the transition plan are properly completed. Team care is also atypical in the management of IBD in adults because of cost and the likelihood that adults will assume responsibility for the details of their care.⁴

Not all physicians have access to the resources and staff to create a team approach to transition, but resources such as the previously mentioned checklists and online materials available through NASPGHAN, The NASPGHAN Foundation for Children’s Digestive Health and Nutrition, and CCFC can provide valuable assistance to the singly responsible pediatric provider.

EMPOWERING PATIENTS TO OVERCOME PERSONAL BARRIERS

Disease self-management can be problematic during adolescence, and treatment adherence often declines.²⁹ Rates of poor adherence among adolescents with IBD range from 50% to 88%. Developmental demands during this period (eg, decline in parental supervision and increase in peer influence and autonomy) likely contribute to these high rates of adherence failure. In a study of 74 adolescents diagnosed with IBD, participants were asked to report the barriers they faced to proper treatment adherence (**Figure 1**). The most commonly reported barriers included forgetting, being away from home, and interference with an activity.

Figure 1: Patient-Reported Barriers to Medication Adherence in IBD²⁹



Identifying and overcoming treatment adherence barriers are important for patients to become empowered and independent. Through proper education and motivational interviewing, patients can learn to assess their own readiness to change self-care behaviors. Simply put, motivational interviewing is a form of information exchange that closely resembles a balanced conversation.³⁰ Patients are encouraged to describe their behavior, ask questions, indicate what they would like to know, or disclose what they do and do not know about their medication. Once the patient has finished, the health care provider becomes active in conveying clear, nonjudgmental information, which, in turn, the patient is then given an opportunity to absorb and reflect upon. Alternately, a patient can also be encouraged to tell a story about a typical day in their life; however, this method can be time-consuming and may not be practical for many consultations. For more information on motivational interviewing, please visit www.motivationalinterview.net. This Web site provides resources for further understanding of motivational interview techniques, as well as suggestions for incorporating this patient-centered approach into current health care scenarios.

ADDRESSING PARENT AND FAMILY MEMBER RESISTANCE

The transition process is additionally stressful for the family members (as with Nicole's mother in case study 3) and can foster anxieties and reservations about the adolescent's developing independence.⁴ Family members must be included in the planning and should be aware of the process, understanding the rationale and eventual goal, which can help prepare them for the difficult life change.²

Counseling, which often involves motivational interviewing, may help the family face their reservations and fears in the same way it helps patients understand their limitations.³⁰ Counseling may also help families problem-solve around common concerns and provide for their unique needs, addressing the specific barriers that may exist for different families.

Gaining parental support is important during transition, because lack of support has been associated with negative outcomes such as poor

CASE STUDY 3: *Protective Parents*

Nicole is 16 years old and was diagnosed at age 11 years with CD. She hates having her mother "nag" her to take her medications all the time. "She follows me around and keeps asking if I've taken my meds," she complains. "If she'd just leave me alone, I'll take them later." The mother insists that, "If I don't remind her, she never takes them. When Nicole says 'later,' she always forgets and I end up finding the pills on the table where I left them." The discussion quickly escalates into a heated argument that appears familiar to Nicole and her mother.

How would you introduce the idea of independence to Nicole and her mother?

- Involve Nicole's mother in the transition process by teaching her methods of helping Nicole to develop independent responsibility for her care (eg, using a pill box or other methods of remembering her medication, having her call the pharmacy for prescription refills, having her detail important medical information on an emergency card, and encouraging her to ask questions at medical appointments)
- Build time into appointments to talk alone with Nicole. Help her to build her knowledge base concerning her disease as well as her communication skills. Allow Nicole to share her current perceptions about having a chronic illness and the possible adversity she may face in maintaining her ongoing care.
- Explore her mother's fears to ensure that her expectations are realistic (eg, Nicole waiting 3 days to report blood in her stool may not do irreparable harm to her body; however, this is an example of a red flag that the pediatric provider needs to be made aware of immediately)
- Consider counseling or motivational interviewing for the mother to help assess and understand her own reservations
- Have Nicole take an active role in future visits, allowing time for her to answer several questions before the parents jump in to "correct" her or possibly be seen alone first. Remind her mother that adolescents may take more time to respond and may amend their answers after a few questions.
- Explore how Nicole can explain her disease and treatment to peers (eg, why she takes so much medication, why her face has been looking so full, and why she was in the hospital for a week). Have her practice discussing these issues to build her comfort level and self-esteem for when she faces her peers.



treatment adherence.⁹ Parents need the pediatric provider's support in the understanding of adolescent development in the context of chronic illness, their important and dynamic role in the process, renegotiation of personal boundaries, and the provision of resources available through medical organizations and within the local community. Transition is very much a family matter and parents should be coached to have faith in their child's newly achieved self-management and that the eventual transfer to an adult care provider will be successful. Parents need to be reminded of their uniquely important role, ensuring that the measures taken by the pediatric provider to develop the patient's independence are supported and continued at home.

SCHEDULING A JOINT VISIT TO IMPROVE TRANSITION OUTCOMES

Paired with effective planning, a joint medical visit with the patient's pediatric and adult care providers may be ideal to foster discussion between the former and future providers of the patient's medical situation.¹³ In a joint visit, the pediatric physician will summarize the patient's record for the new physician and allow the patient and/or parents to contribute whatever further information they feel is necessary. This opens up the possibility for the adult provider to discuss current and future treatment options with all parties involved. Due to geographic barriers or increased time commitment, joint medical visits will not always be practical, but when possible, have shown benefits in the patient transfer.

In a small survey of 34 responding youths with IBD who attended a joint visit at Rennes University Hospital Center in France, 85% felt that they were properly prepared to transfer into adult care.¹³ All patients considered the joint medical visit beneficial for transmitting medical records and information, and 93% considered it helpful in building confidence in the new gastroenterologist. At the time of the survey, 85% continued to be followed up by the same adult gastroenterologist to whom they were transitioned. However, most of these clinics took place in hospitals where both adult and pediatric gastroenterology departments exist. The problem with this system is the diversity of patient location, especially in larger countries. As the number of adult gastroenterology centers exceeds that of pediatric centers, some patients may choose to move to an adult gastroenterologist near where they live, in which case, they would not see the same gastroenterologist from the transition clinic. Available health resources may interfere with arranging transition clinics where patients reside.

A similar study on joint visits involving pediatric IBD patients in the United States is currently underway.³¹ In addition to measures of a successful transition, this study will also assess whether or not the joint visit has any effect in reducing the risk of disease flares during and after transition.

SUMMARY

Transitioning IBD patients from pediatric to adult care is a challenging but critical process with many factors to consider. An effective transition plan develops the patient's independence and understanding of their own disease state and improves overall patient adherence and interaction with their adult care provider. Although many barriers to an effective transition exist, techniques such as including parents in the planning process, motivational interviewing, and visiting jointly with the adult care gastroenterologist may help to avoid or manage the many obstacles that may interfere with a smooth transition. Preparing and implementing a developmentally appropriate transition plan as early in the patient's care as possible promotes essential skills and has been shown to improve patient outcomes in the long-term care of this disease process.

CLINICAL PEARLS

- Assess your patient's level of independence before implementing a transition plan
- The pediatric and adult clinicians must play an active role in support and encouragement towards the patient
- Relieve anxiety in the patient and the family by providing positive support throughout the transfer process
- Empower the patient by providing appropriate education about their disease and promoting communication skills that will be needed in the adult health care setting

THANK YOU FOR PARTICIPATING IN THIS ACTIVITY.

To claim RCPSC Section 2 credits, please print and complete the Section 2 form located at the end of this activity.

A link to the form is also available at:
<http://www.cag-acg.org/cme-online/ibd-transition-program>

Documentation must be kept to support hours claimed.

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FOR MORE INFORMATION AND RESOURCES ON
PEDIATRIC IBD, PLEASE GO TO:

www.PedIBD.org.

Section 2 Credit: Personal Learning Projects

SECTION 2 CREDIT: SELF-LEARNING

Planned Learning Activities:

Learning activities that are planned to address an identified need (question, problem or issue) and where the outcomes are evaluated by the individual physician either independently or in collaboration with a mentor, supervisor or peer group. Examples of activities in this section include personal learning projects, traineeships, and formal studies.

Your participation in certain programs can be recorded for RCPSC **Section 2 Credit**, in accordance with the guidelines established by the Royal College of Physicians and Surgeons of Canada and endorsed by the Canadian Association of Gastroenterology.

Section 2 credits can be acquired through personal structured learning projects that you design to answer your own learning needs. Section 2 credit activities include learning projects that are planned and through which an outcome is recorded. The following is a template that will allow you to readily record your personal learning project and the number of hours that you are recording for credit.

Section 2 Credits for Personal Learning Projects are valued at **2 credits per hour** of the learning activity. A maximum of 60 credits per year (300 per 5 year cycle) can be applied to Section 2 credit, but each project must be documented.

As a routine audit 3% of Fellows will be audited annually and therefore it is critical to maintain the documentation within your personal education files. The RCPSC also provides an electronic diary which can be accessed via the RCPSC web page. All credit must be recorded on the RCPSC MAINPORT site.

Remember that documentation is required for this category of credit. The following is a template which will allow you to readily record your Section 2 activities. This form can be completed in a number of ways:

- 1) Print and manually complete the form.
- 2) If you have Adobe Reader® software, you can electronically fill in the form and print a copy for your records (Adobe Reader® will **not** allow you to save the form once you have entered text into it).
- 3) If you have Adobe Acrobat® software, you can electronically fill in the form and either print a copy for your records, or save a copy of the completed form.

SECTION 2 CREDIT: PERSONAL LEARNING PROJECTS

Section 2 credits are valued at 2 credits per hour. A maximum of 60 credit hours may be applied per year (300 per cycle).

Each project must be documented and records kept for credit validation.

A. Personal Learning Projects: the focus of these projects is to identify a learning need or opportunity and describe the process through which the learning objective is achieved:

1. Identify a question, idea or controversy you would like to answer or address:
2. Identify a stimulus for the above:
3. Define how you will approach the problem (resources or references):
4. Report the learning outcome(s). How will this impact your clinical practice, expertise or current knowledge base?
5. Record the number of hours:

B. Traineeship: The focus of this type of learning activity is to complete a planned educational activity under the mentorship of a supervisor thereby expanding your current area of expertise and competence:

1. Describe the learning objective:
2. Describe the learning activity(ies) that you have completed:
3. Obtain written confirmation of completion of the traineeship from mentor or supervisor and retain with this for your records (name of supervisor and location of traineeship):
4. Record the number of hours:

C. Formal Courses (Preceptored courses, Fellowships, Masters, or PhD programs): The focus of this learning activity is to identify a personal learning objective achieved through a formal course, fellowship or education program offered by a university, college or institution (maximum 25 credits per course).

1. Describe your personal learning objective for each course or component of the program, e.g. could include a specific learning objective related to your research or thesis preparation as well as those related to preparation of grant applications and proposals (these can also be claimed under Section 3 if self audit of performance is done as part of the course):
2. Obtain written documentation and dates confirming that you have completed the course from the university, college or institution (transcript or certificate that describes your program) and retain this for credit validation. Name of institution and dates:
3. Describe the learning outcome(s) that you have identified and/or the anticipated impact on your practice, expertise or knowledge base:
4. Record the number of hours: