

## Medical Position Statement

# Transition of the Patient With Inflammatory Bowel Disease From Pediatric to Adult Care: Recommendations of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition

Children with inflammatory bowel disease (IBD) should be cared for by a physician trained to manage issues unique to pediatric patients. Pediatric gastroenterologists have the expertise to address a multitude of important problems that occur during childhood, particularly growth and development. Internist–gastroenterologists have a different set of skills that are necessary to provide optimal care to adult patients with IBD.

The passage from adolescence to adulthood is a time of internal turmoil and intense examination of personal goals and wishes. In a few short years, the growing adolescent must shed the sheltered environment of childhood and achieve self-reliance and independent living. This time of growth and change causes frustration about the present and anxiety about the future even in the healthiest of children. For chronically ill adolescents, the transition to adulthood is additionally stressful not only for the child, but also for the family and healthcare providers because of the issues surrounding the transfer of care to an adult internist–gastroenterologist (1–6).

During the transition to an internist–gastroenterologist, adolescent patients, their parents, and other family members may feel threatened by changes in the pattern of care and resentful of the effort required to adjust to a new setting with new staff. Patients and families have weathered many crises and made vital decisions with the support of their pediatric team and have come to regard this strong source of advocacy as a permanent arrangement. In contrast, they may perceive the internist–gastroenterologist, whose patients usually function independently, as less involved or less sensitive to developmental and social needs. Healthcare providers may also feel ambivalent during this period of change and may find it difficult to relinquish the patient to another physician whose style of practice is not well known.

### OBSTACLES TO TRANSITION

The obstacles to transition reside in the family, the pediatric caregiver, the adult caregiver, and the patient.

### THE PATIENT

Patients may be reluctant to move to an adult health-care system because they must give up a familiar atmosphere and services that are a routine part of their pediatric care setting. Nonetheless, to remain in the pediatric setting may delay development of independence and deprive patients of subspecialty care appropriate to their age.

### THE FAMILY

The process of transferring young adults from the pediatric to the adult healthcare system routinely arouses strong feelings. Parents are often reluctant to leave the pediatric caregivers with whom they have bonded over the years. Parents may have close personal ties, forged during moments of crisis and shared concerns, with the pediatric caregivers. In addition, the clinic and hospital staff are often a major part of the family's support system. Parents who have been intimately involved with the care of their child may feel shut out and ignored when adult caregivers involve them only with the permission of the patient. To a great extent, transition is a family matter. Although many young people share their parents' fears about change, they also want to be treated as adults. For a successful transition to occur, the family must be included in the planning.

### THE PEDIATRIC CAREGIVER

The caregivers' attitudes also may also complicate the transition. Pediatric caregivers have strong ties to their patients and families and may want to maintain those relationships. They may feel that no one in the adult system has the expertise to deal with their patients' medi-

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Received December 6, 2001; accepted December 6, 2001.

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cal problems and, more importantly, that adult caregivers are not prepared to meet the psychosocial challenges of chronic illness in pediatric patients.

The American Academy of Pediatrics has raised concerns about the quality of healthcare services for older adolescents. In 1938, the age limit of pediatric practice was defined by the American Academy as 16 to 18 years. In 1972, the upper age limit was increased to 21 years of age. The optimal timing for transition to an internist–gastroenterologist is best determined by the pediatric gastroenterologist in consultation with the patient and family. Ideally, if the pediatric gastroenterologist has a relationship with an internist–gastroenterologist, that individual can be included in the discussion.

### THE ADULT CAREGIVER

Although healthcare is a continuum, the internist–gastroenterologist may feel that patients with childhood-onset IBD are immature and that their families are too involved and demanding. Some may consider the time needed to explain management issues as excessive and redundant. Team care is not the typical model in the management of IBD in adults, partly because of cost and partly because adults are more likely to assume responsibility for the details of their care.

### WHY TRANSITION?

The goal of a transition program is to achieve for each chronically ill patient a continuum of care that includes normalization of social and emotional development and the acquisition of independent living skills. A successful program should result in improved compliance with therapy and effective planning for long-range needs. The successful transition from pediatric to adult healthcare systems is a part of this process.

### RECOMMENDATIONS

The pediatric gastroenterologist should begin seeing adolescent patients without their parents to build a relationship that promotes independence and self-reliance and resembles in part the relationship that they will have with their internist–gastroenterologist.

It is important to introduce the patient and the family to the subject of transition to a gastroenterologist who is also trained in internal medicine. The benefits of transition should be emphasized. Some of these benefits include normalization of development, promotion of independent behavior, promotion of self-reliance, improvement of compliance with therapy, provision of an appropriate environment, planning long-range goals.

In addition, patients and parents should be made aware that a patient entering adulthood needs a physician who has expertise in IBD problems not generally encountered

by a pediatrician, such as pregnancy, fertility, and cancer surveillance, and the common health problems of adulthood not related directly to IBD.

Once the decision to pursue a transition program has been made, the next step is to identify a skilled gastroenterologist who cares for young adults, one who recognizes that young adults with childhood-onset IBD have a different set of expectations than do young adults with recent onset of IBD. The adult practitioner should be aware that young adults diagnosed in childhood may have an increased risk for the development of cancer and may require more immediate cancer surveillance than might newly diagnosed adults. It is important that the pediatrician provide all of the necessary medical records and summaries so the family will appreciate that both the pediatric and adult providers are collaborating to deliver excellent care. It is recommended that a letter summarizing the medical history be sent to the physician, with a copy to the patient when appropriate. It is advisable to give this letter and a brief medical summary (Appendix A) to the patient in the event the patient decides to seek care from a gastroenterologist other than the one identified by the pediatric gastroenterologist.

Timing for transition requires flexibility because many patients have special circumstances. The differences between the healthcare systems in the United States and Canada will also have an impact on the way adolescents are transitioned.

It is recommended that a pediatric gastroenterologist follow-up with adolescents who have additional growth potential as a result of delayed puberty, and that young adults who have completed their education and are financially independent be followed by a gastroenterologist who cares for adults.

### Insurance Issues

In Canada, patients cannot be admitted to a children's hospital after 18 years of age. Therefore, the transition needs to begin earlier in adolescence and be completed by 18 years of age. In the United States, many medical insurers require that hospital admissions take place in the location where the insurance holder resides; this would be the parent's home while patients are in college. Therefore, college students will often need to come home for a hospital admission.

### Special Circumstances

#### *Pregnancy*

Pregnancy during adolescence usually requires referral to an adult gastroenterologist. If the adolescent still requires the services that can only be provided in the pediatric setting, then transition can be postponed.

*Higher Education*

When a patient is away at college, a greater amount of care is delivered via telephone or Internet. This is a difficult time to transition to an adult gastroenterologist in the child's hometown because the adult gastroenterologist may not be sufficiently familiar with the patient's medical condition to be able to manage such a long-distance relationship. Temporary transition to a local physician in the university town may not provide the consistency necessary for quality care. If the patient requires medical evaluation while at school, this can be done through collaboration of the pediatric gastroenterologist working with the adult gastroenterologist or the primary care provider at or near the college.

*Developmental Delay*

Children with neurologic delay are best transitioned to an adult gastroenterologist who has the expertise and the resources necessary to provide comprehensive care.

In summary, the pediatric gastroenterologist should begin the process of transition to an adult setting when a patient enters early to middle adolescence by

- 1) seeing adolescent patients without their parents to build a relationship that promotes independence and self-reliance;
- 2) discussing with the patient and family the benefits of transition to an internal medicine gastroenterology practice;
- 3) developing a relationship with an adult gastroenterologist who is knowledgeable in caring for young adults with a history of childhood-onset IBD;
- 4) providing all of the necessary medical records and summaries so that the family will realize that all providers are working together to deliver excellent care.

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Appendix A (Completed form should be given to patient)

Medical Summary

Date: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

Onset of disease: \_\_\_\_\_

Location of disease: \_\_\_\_\_

Complications: \_\_\_\_\_

Medical therapies: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Procedures

At Diagnosis (Date: \_\_\_\_\_): \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Most recent (Date: \_\_\_\_\_): \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Important issues: (ie. Allergies): \_\_\_\_\_

Other considerations: \_\_\_\_\_