

Transitioning a Patient with Inflammatory Bowel Disease From Pediatric to Adult Care

As adolescents with inflammatory bowel disease (IBD) grow older, they will eventually need to transition from a pediatric to an adult specialist. This transition can be challenging if young adults are not prepared to take responsibility for their healthcare. Even young adults who choose to remain with their pediatric specialist should transition from dependence on their parents to independent self-management. Successful transition to an adult specialist requires collaboration among the patient, family, and healthcare teams.

Healthcare providers, parents, and the young adult themselves all need to take responsibility for educating the patient about his or her disease, medications, and other healthcare needs. Ideally this should be done before a young adult with IBD begins their first job or goes to college. The patient should be encouraged to ask questions and participate actively in care. Some key areas for successful transition are listed below.

KNOWLEDGE:

- What is the patient's disease (Crohn's disease, ulcerative colitis)?
- Where in the intestine is the disease located?
- What medications does the patient take (name, dose, purpose, side effects, interactions)?
- If the patient has had surgery, what kind of surgery was it?

- What tests have been done, and what are the results of those tests (imaging studies such as CT, upper endoscopy, colonoscopy, liver biopsy)?

INDEPENDENCE AND ASSERTIVENESS

Independent health behaviors are an important step before transition. The patient should be responsible for:

- Medications, doctors' visits (scheduling and self-reporting at visit)
- Self-advocacy at school and work
- Understanding insurance issues and information

HEALTH AND LIFESTYLE

- Diet, formula supplement
- Effect of drugs, smoking
- Consequences of nonadherence
- Fertility/sexuality

The precise age at which children and adolescents assume these tasks and responsibilities varies based on their psychological, emotional, and social maturity as well as their disease activity, environment, and support systems. This process is dynamic and is not the same for everyone.

The checklist on the reverse side provides a reminder of what and when to encourage the patient to assume more responsibility.



THIS CHECKLIST SHOULD SERVE AS A GENERAL GUIDE FOR THE HEALTHCARE PROVIDER

Knowledge

Independence, Health, and Activities of Daily Living

AGE 12–14

- Discuss the idea of visiting the healthcare office without parents or guardians in the future
- Encourage independence by performing part of the exam with parents or guardians out of the exam room
- Begin to provide information about drugs, alcohol, sexuality, and fitness
- Establish specific self-management goals during office visit

AGE 14–17

- Always focus on the patient instead of the parents or guardians when providing any explanations
- Allow the patient to select when the parent or guardian is in the room for the exam
- Inform the patient of what the parent or guardian must legally be informed about with regards to the patient's condition
- Discuss the importance of preparing the patient for independent status with the parents or guardian and address any anxieties
- Continue to set specific goals with the patient, which should include:
 - Taking medication on the patient's own (?)
 - Filling prescriptions and scheduling appointments
 - Keeping a list of medications and medical team contact information in wallet and backpack

DISCUSS IN GREATER DETAIL:

- The impact of drugs, alcohol, and non-adherence on the disease
- The impact of the disease on sexuality, fertility
- Future plans for school/work and impact on healthcare, including insurance coverage
- How eventual transfer of care to an adult gastroenterologist will coordinate with future school or employment plans

AGE 17+

- Remind patient and family that at age 18, the patient has the right to make his or her own health choices
- Remind patient and family of the reasons why medicines were stopped or not used
- Develop specific plans for self-management outside the home (work/school)
- Provide the patient with a medical summary for work, school, or transition
- Discuss plans for insurance coverage
- If transitioning to an adult subspecialist, refer patient to Doc4Me app to provide adult providers and encourage/facilitate an initial visit

This checklist was based on faculty expertise, review of existing publications, and adaptations of “Transition Planning Checklist” by the Children’s & Women’s Health Centre of British Columbia.

➔ **Locate a Pediatric Gastroenterologist**

IMPORTANT REMINDER: This information from the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) is intended only to provide general educational information as a definitive basis for diagnosis or treatment in any particular case. It is very important that you consult your doctor about your specific condition.

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