



Transitioning a Patient With IBD From Pediatric to Adult Care

Transitioning to adulthood with IBD

The majority of adolescents with inflammatory bowel disease (IBD) will transition from a pediatric to an adult specialist. This transition can be challenging if they are not prepared to take ownership of their healthcare. Even those who remain with their pediatric specialist should be transitioning from dependence on their parents to independent self-management. A successful transition to an adult specialist requires collaboration among the patient, family and healthcare team.

It is critically important to educate the patient as much as possible about their disease and healthcare needs. In addition, it is important to encourage the patient do to as much as they can on their own. The patient should be encouraged to ask questions and participate actively in their care. Some key areas for successful transition are listed below.

Key areas for successful self-management and transition:

KNOWLEDGE

- Disease
- Medications (name, dose, purpose, side effects, interactions)
- Tests

INDEPENDENCE AND ASSERTIVENESS

- Independent health behaviors
 - Responsible for medications, doctor's visits (scheduling and self-reporting at visit)
- Self-advocacy
 - School, work
 - Insurance issues

HEALTH AND LIFESTYLE

- Effect of drugs, smoking
- Consequences of nonadherence
- Fertility/sexuality

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

The checklist on the reverse side will help as a reminder of what and when to encourage the patient in taking on more responsibility.



CDHNF

CHILDREN'S DIGESTIVE
HEALTH & NUTRITION
FOUNDATION

NASPGHAN

NORTH AMERICAN SOCIETY FOR
PEDIATRIC GASTROENTEROLOGY,
HEPATOLOGY AND NUTRITION

www.KidsIBD.org
www.CDHNF.org
www.NASPGHAN.org

CDHNF National Office:
P.O. Box 6, Flourtown
PA 19031

Phone: 215-233-0808

Educational support for The CDHNF
Pediatric IBD Campaign was provided by

**Procter & Gamble
Pharmaceuticals**

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

Knowledge

Independence, Health, and Activities of Daily Living

AGE

HEALTH CARE TEAM

12-14

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

14-17

- Always focus on the patient instead of the parents or guardians when providing any explanations and
- 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 condition
- Discuss the importance of preparing the patient for independent status with the parents or guardian and address any anxiety they may have
- Continue to set specific goals which should include:
 - Filling prescriptions and scheduling appointments
 - Keeping a list of medications and medical team contact information in wallet and backpack

DISCUSS IN MORE DEPTH:

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

17+

- Remind patient and family that at age 18 the patient has the right to make his or her own health choices
- 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, provide a list of potential providers and encourage/facilitate an initial visit.