



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 to 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.

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Healthcare Provider Transitioning Checklist

AGE	PATIENT	HEALTH CARE TEAM
12-14	<p>EARLY ADOLESCENCE <i>New knowledge and responsibilities</i></p> <ul style="list-style-type: none"> <input type="checkbox"/> I can describe my GI condition <input type="checkbox"/> I can name my medications, the amount and times I take them <input type="checkbox"/> I can describe the common side effects of my medications <input type="checkbox"/> I know my doctors' and nurses' names and roles <input type="checkbox"/> I can use and read a thermometer <input type="checkbox"/> I can answer at least 1 question during my health care visit <input type="checkbox"/> I can manage my regular medical tasks at school <input type="checkbox"/> I can call my doctor's office to make or change an appointment <input type="checkbox"/> I can describe how my GI condition affects me on a daily basis 	<ul style="list-style-type: none"> <input type="checkbox"/> Discuss the idea of visiting the office without parents or guardians in the future <input type="checkbox"/> Encourage independence by performing part of the exam with the parents or guardians out of the examining room <input type="checkbox"/> Begin to provide information about drugs, alcohol, sexuality and fitness <input type="checkbox"/> Establish specific self-management goals during office visit
14-17	<p>MID ADOLESCENCE <i>Building knowledge and practicing independence</i></p> <ul style="list-style-type: none"> <input type="checkbox"/> I know the names and purposes of the tests that are done <input type="checkbox"/> I know what can trigger a flare of my disease <input type="checkbox"/> I know my medical history <input type="checkbox"/> I know if I need to transition to an adult gastroenterologist <input type="checkbox"/> I reorder my medications and call my doctor for refills <input type="checkbox"/> I answer many questions during a health care visit <input type="checkbox"/> I spend most of my time alone with the doctor during visit <input type="checkbox"/> I understand the risk of medical nonadherence <input type="checkbox"/> I understand the impact of drugs and alcohol on my condition <input type="checkbox"/> I understand the impact of my GI condition on my sexuality 	<ul style="list-style-type: none"> <input type="checkbox"/> Always focus on the patient instead of the parents or guardians when providing any explanations and <input type="checkbox"/> Allow the patient to select when the parent or guardian is in the room for the exam <input type="checkbox"/> Inform the patient of what the parent or guardian must legally be informed about with regards to the patient condition <input type="checkbox"/> Discuss the importance of preparing the patient for independent status with the parents or guardian and address any anxiety they may have <input type="checkbox"/> Continue to set specific goals which should include: <ul style="list-style-type: none"> • Filling prescriptions and scheduling appointments • Keeping a list of medications and medical team contact information in wallet and backpack
17+	<p>LATE ADOLESCENCE <i>Taking charge</i></p> <ul style="list-style-type: none"> <input type="checkbox"/> I can describe what medications I should not take because they might interact with the medications I am taking for my health condition <input type="checkbox"/> I am alone with the doctor or choose who is with me during a health care visit <input type="checkbox"/> I can tell someone what new legal rights and responsibilities I gained when I turned 18 <input type="checkbox"/> I manage all my medical tasks outside the home (school, work) <input type="checkbox"/> I know how to get more information about IBD <input type="checkbox"/> I can book my own appointments, refill prescriptions and contact medical team <input type="checkbox"/> I can tell someone how long I can be covered under my parents' health insurance plan and what I need to do to maintain coverage for the next 2 years . <input type="checkbox"/> I carry insurance information (card) with me in my wallet/purse/backpack. 	<p>DISCUSS IN MORE DEPTH:</p> <ul style="list-style-type: none"> <input type="checkbox"/> The impact of drugs, alcohol and non adherence on their disease <input type="checkbox"/> The impact of their disease on sexuality, fertility <input type="checkbox"/> Future plans for school/work and impact on health care including insurance coverage. <input type="checkbox"/> How eventual transfer of care to an adult gastroenterologist will coordinate with future school or employment plans <ul style="list-style-type: none"> <input type="checkbox"/> Remind patient and family that at age 18 the patient has the right to make his or her own health choices <input type="checkbox"/> Develop specific plans for self-management outside the home (work/school) <input type="checkbox"/> Provide the patient with a medical summary for work, school or transition <input type="checkbox"/> Discuss plans for insurance coverage <input type="checkbox"/> If transitioning to an adult subspecialist, provide a list of potential 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.