Expectations for Parent and Young Adult IBD Patients

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Planning for Transition to Adult Care
Objectives

- Review Goals of Transition
- Discuss Obstacles to the Transition
- Understand Transition Process
- Discuss Resources for the Transition
Introduction

• ~1.5 million Americans are diagnosed with IBD

• ~30% of CD and 20% of UC patients have disease onset < age of 20

• Rising incidence of pediatric IBD over the last decade

• Projected prevalence of pediatric IBD is 10,000 new cases annually

• IBD is a chronic disease: children with IBD eventually require a transition of care to an adult GE.

• Two key elements to this transition:
  • transition of care from the primary caregiver to the patient
  • transfer of responsibility from the pediatric GE to an adult provider
Transition versus Transfer of Care

- **Transition** = process over a period of years
  - “The purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems”
    - Allows for self-empowerment
    - Imparts confidence upon the young adult

- **Transfer of care** = single act
  - Movement of care from pediatric GI to adult GI

## Why Transition to Adult Providers?

<table>
<thead>
<tr>
<th>Social</th>
<th>Medical</th>
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</thead>
<tbody>
<tr>
<td><strong>Age-appropriate care</strong></td>
<td><strong>Comorbidities</strong></td>
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<tr>
<td>• Privacy</td>
<td>• High blood pressure</td>
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<tr>
<td>• Autonomy</td>
<td>• Thyroid</td>
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<tr>
<td><strong>Environment</strong></td>
<td><strong>Screening/Complications</strong></td>
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<tr>
<td>• Work (not school)</td>
<td>• Colon cancer</td>
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<tr>
<td><strong>Financial Resources</strong></td>
<td>• Blood clots</td>
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<tr>
<td>• Insurance</td>
<td><strong>Interactions</strong></td>
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<tr>
<td>• Scholarships</td>
<td>• Smoking</td>
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<td><strong>Relationships</strong></td>
<td>• Alcohol</td>
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<td>• Marriage</td>
<td>• Drugs</td>
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<td>• Children</td>
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<td>• Fertility</td>
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How Does Pediatric Care Differ from Adult Care in IBD?

- Adult visits are often shorter and patient-focused, whereas pediatric visits are often longer and family-focused

- Therapies and clinical trials available to adult patients may not be available or as accessible for children and adolescents.

- Significant differences in the functioning and feel of an adult hospital vs a pediatric hospital.

- Procedure-related care also differs; children and adolescents typically have full sedation and anesthesia during procedures, whereas adults usually have conscious sedation.
Goals of Transition and Transfer

- Uninterrupted care
- Coordinated care
- Age-appropriate care
- Anticipated transfer (no surprises)
  - Ideally, when feeling well and on stable medications
  - When patient feels confident
  - When a patient has needed skills
Goals in the Process of Transition in IBD

• Get the patient ready for transfer, having attained specific skills and knowledge

• Get the parents ready for transfer

• Get the pediatric GE prepared for the transition and the adult GE ready and well informed
Transition of care involves multiple stakeholders invested

**Parent/Caregiver**
- School
- Work

**Pediatric Team**
- Pediatric GI
- Nurse
- Dietician
- Psychologist
- Social Worker

**Adult Medicine Team**
- Adult GI
- Nurse
- Dietician
- Counselor

**Health Care System**
- Insurance Provider
- Pharmacy
- Infusion Center

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Afzali A, Wahbeh G. Transition of pediatric to adult care in IBD. World J Gastroenterol 2017 May 28;23(20):3624-3631
Transition Should Occur in Several Phases

Phase 1
- Pediatric provider introduces transition care process
- Expresses expectations and responsibilities of the patient, parents, and provider in an open dialogue

Phase 2
- Young adult begins to accumulate knowledge necessary to be an independent patient: parents start to “step back”

Phase 3
- Adult provider assumes responsibility for care
- Patient shows self-management skills

1. Philpott JR. Gastroenterol Hepatol. 2011;7:26-32
Initiate Transition Process Around Stage of Development

Age 12-14
- Ability to name illness, medications, adherence, trade/school

Age 15-18
- Nutrition, self-management, insurance, issues of reproduction

Age 18-21
- Ongoing support, new health providers

Checklists available at www.naspghan.org

https://www.med.unc.edu/transition/
**EXAMPLE:**

**TRAQ (Transition Readiness Assessment Questionnaire)**

<table>
<thead>
<tr>
<th><strong>Managing Medications</strong></th>
<th><strong>No, I do not know how</strong></th>
<th><strong>No, but I want to learn</strong></th>
<th><strong>No, but I am learning to do this</strong></th>
<th><strong>Yes, I have started doing this</strong></th>
<th><strong>Yes, I always do this when I need to</strong></th>
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<tbody>
<tr>
<td>1. Do you fill a prescription if you need to?</td>
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<td>2. Do you know what to do if you are having a bad reaction to your medications?</td>
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<td>3. Do you take medications correctly and on your own?</td>
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<td>4. Do you reorder medications before they run out?</td>
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<td><strong>Appointment Keeping</strong></td>
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<td>5. Do you call the doctor’s office to make an appointment?</td>
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<td>6. Do you follow-up on any referral for tests, check-ups or labs?</td>
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<td>7. Do you arrange for your ride to medical appointments?</td>
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<td>8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?</td>
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<td>9. Do you apply for health insurance if you lose your current coverage?</td>
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<td>10. Do you know what your health insurance covers?</td>
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<td>11. Do you manage your money &amp; budget household expenses (For example: use checking/debit card)?</td>
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<td><strong>Tracking Health Issues</strong></td>
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<td>12. Do you fill out the medical history form, including a list of your allergies?</td>
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<td>13. Do you keep a calendar or list of medical and other appointments?</td>
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<td>14. Do you make a list of questions before the doctor’s visit?</td>
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<td>15. Do you get financial help with school or work?</td>
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<tr>
<td><strong>Talking with Providers</strong></td>
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<td>16. Do you tell the doctor or nurse what you are feeling?</td>
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<td>17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?</td>
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<td><strong>Managing Daily Activities</strong></td>
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<td>18. Do you help plan or prepare meals/food?</td>
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<td>19. Do you keep home/room clean or clean-up after meals?</td>
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<tr>
<td>20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?</td>
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What Parents Can Do To Help

• Allow alone time with adolescent and provider
  • Take the lead and leave the room without being asked
• Gradually give more responsibility to your teenager or young adult
  • Calling in and picking up prescriptions
  • Making and keeping track of their own medical appointments…use that smart phone for a good cause!

• Participate in discussion with provider and young adult regarding finding adult provider

• Assist with gathering medical records to take or send to adult gastroenterologist
  • Medical summary from pediatric gastroenterologist
What Young Patients Can Do

• Be Prepared
  • Don’t wait for until the last minute
  • Schedule your appointments as soon as possible and show up on time
  • Write down questions for your providers

• Self-empowerment
  • Speak up for yourself and ask questions
  • Know information about your disease history, such as when you were diagnosed, and important changes you've been through
  • Be open with your doctor about topics like sexuality or alcohol and drugs, and trust that the nurses and doctors will be professional about these questions and offer good advice
What Young Patients Can Do

- Participate in decision making:
  - It is OK to let your doctor know that you want more information about a topic before making any decisions around your care.
  - Decisions about your care should be a collaboration between you and your doctor. The goal is to search for your best treatment plan.
  - Sometimes you may need to make the decision to get a second opinion, or select another doctor if you are not comfortable with the doctor you have.
  - Adult patients search for the best treatment for them. Adult patients know that it is OK to change doctors, or to search for a doctor that they get along with.
What Resources and Tools are Available to Adolescents During the Transition Process?

- The Crohn’s and Colitis Foundation has several useful tools for patients to facilitate the transition process:
  - Online database of IBD providers across the country
  - GI Buddy application for smartphones: useful for tracking symptoms, diet, and medications while promoting disease awareness and community involvement with others who have IBD.
  - MyIBD application, by The Hospital for Sick Children Toronto, Canada is another useful application to track symptoms, medication adherence, and medical history.
- Smart Phones
- A number of websites have been developed to promote engagement of adolescents as well as transition knowledge.
THANK YOU
School Resources
The 504 Accommodations Plan

- Section 504 of the federal Rehabilitation Act ensures accommodations for children with disabilities
- Template available at [www.crohnscolitisfoundation.org](http://www.crohnscolitisfoundation.org)

<table>
<thead>
<tr>
<th>Contact List</th>
<th>Student File Letter</th>
</tr>
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<tbody>
<tr>
<td>School nurse</td>
<td>Definition of IBD</td>
</tr>
<tr>
<td>Guidance counselor</td>
<td>Symptoms, cyclical nature of disease</td>
</tr>
<tr>
<td>School social worker</td>
<td>Home tutoring option</td>
</tr>
<tr>
<td>Teachers</td>
<td>Gym considerations</td>
</tr>
<tr>
<td>Administrators</td>
<td>Mind-gut connections</td>
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</table>
Requesting a 504 Accommodations Plan

- Make the request in writing
- Include supporting medical documentation
- Parents, patient (if age-appropriate), school nurse, administrator, and guidance counselor should meet to develop a workable plan

Sample 504 Plan Accommodations

- Bathroom pass
- Nurse’s office pass
- Nurse’s training for medicine administration
- Food/drink in class
- Stop-the-clock testing
- Postponement of cumulative term grades
- Revised seating chart
- Extra set of books
- Increased time between classes
- Copies of syllabi, lesson plans
- Permission to copy class notes
- In-home/after school tutoring prior to prolonged absence
- Field trip/extracurricular transportation
Requesting Support in College

All public, government-funded colleges and universities expected to comply with Section 504

• Most colleges have disability services office

• Accommodations
  • Providing a dorm with close bathroom access or a private bathroom
  • Mid-morning or late classes if you have bathroom activity in the early morning
  • Test accommodations

• Speak to the disability services office prior to starting school
• Visit [www.crohnscolitisfoundation.org/campus-connection](http://www.crohnscolitisfoundation.org/campus-connection) to learn more tips!
Self-Management
Self-Management

- Tasks that individuals must undertake to live well with one or more chronic conditions
  - Medical management
  - Role management
  - Emotional management

- Self-Management support
  - The care and encouragement provided to people with chronic conditions and their families
    - Understand their central role in managing their illness
    - Make informed decisions about care
    - Engage in healthy behaviors
Involving Children in their IBD Care

• Screening
  • Is there a support network of family members/friends?
  • Is a counselor or psychologist needed for anxiety or depressive symptoms?
  • Are school accommodations needed and in place?
  • Does child/adolescent need help with stress reduction?
  • Is the family having difficulty adjusting to the diagnosis of IBD?

• Self-management
  • Disease education and knowledge
    • Encourage use of resources available on the web
    • Review educational materials together
  • Learn necessary skills and prepare for independence
  • Reinforce past success – be their biggest fan!
Importance of Treatment Adherence

Rates of oral medication non-adherence range from 2% to 93%\(^1\)-\(^2\)
- “Forgot”
- “Wasn’t home”
- “Interferes with activity”

Adherence generally associated with improved outcomes
- Decreased risk of disease progression
- Reduced inflammation and increased healing of GI tract
- Possible decreased risk of colorectal cancer
- Less likely to experience flares

Adherence to Medical Therapy

Importance of Adherence

Adherent patients have an 89% chance of maintaining remission compared with only 39% for nonadherent patients ($P = 0.001$)

Effective Communication Between Patients and Health Care Providers is Key

- Effective communication can improve trust in patient-provider relationship
- Enable patients/parents time to voice concerns and ask questions
- Empower child to be involved in treatment plans and decision making
Strategies for Improving Medication Adherence

• Improve communication between health care provider and patient
• Educate the patient/family
• Acceptable treatment plans
• Simplify medication regimens – reducing dosing interval
• Schedule routine medical visits; assess and reward adherence
To Increase Treatment Adherence

• Find support for emotional and social issues
  • Crohn’s & Colitis Foundation support groups, Community site: [www.crohnscolitiscommunity.org](http://www.crohnscolitiscommunity.org)
  • Medical social workers
  • Power of Two
  • Facebook

Living With IBD
Emotional Wellness in IBD

- 25-30% of children with IBD have symptoms of depression and/or anxiety.
- Predictors of depression
  - Stressful life events,
  - Maternal depression
  - Family dysfunction,
  - Steroid treatment,
  - Older age
- These rates are similar to children with other chronic illnesses.
In times where you are having these feelings, you may have an approach to help you cope, such as:

• Social Support group
• Meditation
• Exercise (examples: brisk walk, taking a swim, yoga, or other exercise)
• Breathing exercises
• Going out with friends
• Doing something relaxing, like a reading a book
• Talking to a psychologist or mental health professional
• Do not ignore these feelings, and be sure to talk to your doctor about these mental health symptoms
• Attending a summer IBD camp
Body Image

Inflammatory bowel diseases (IBD) can impact how you view your body.
Diet & Nutrition is Important

• IBD tends to increase the body’s need for calories, nutrients, and energy
• During IBD flares, it may be difficult to maintain adequate nutrition
• Maintaining good nutrition will improve your overall wellness, promote healing and immunity, increase your energy levels, and may lessen some gastrointestinal symptoms.
Exercise

• Exercise can help you maintain a healthy weight, reduce stress, improve skin, reverse muscle weakness, and strengthen your bones and immune system.
• It can also increase the feeling of happiness (due to endorphin release - the “feel good” hormone).
• Exercise is a healthy and important coping mechanism to improve and maintain one’s mental health.
Peer Pressure

- The effects of complying with certain peer pressure situations may be detrimental to your health as a patient.
- One way of dealing with negative peer pressure is to educate your peers and friend group about Crohn’s and colitis. Once those around you understand the circumstances surrounding your resistance to go along with the situation at hand, they will hopefully be more sympathetic and understanding.
- If your peers are not understanding of your choice, then it is best to surround yourself with people that will be supportive of your decisions. It’s also important to learn to say no to negative peer pressure.
Substance Abuse & IBD

Alcohol

• Alcohol can affect each IBD patient differently, so you should know the risks of consuming alcohol just as you would for the medications that you are taking to treat your disease.

• The use or abuse of alcohol or other drugs, either illicit or over the counter can have damaging effects on your GI tract, including your liver, and may interfere with your medications.

• Alcohol can irritate the lining of the gastrointestinal tract, cause malabsorption and bleeding in people with Crohn’s disease and ulcerative colitis. It is best to avoid consuming alcohol until you are of legal age.

Smoking

• There are many health risks associated with smoking, including but not limited to lung cancer, and heart disease.

• Smoking tobacco can trigger flares, and people with Crohn’s disease have more frequent need for surgery and medications that suppress their immune system.
Support Resources: Crohn’s & Colitis Foundation

• Foundation website: [www.crohnscolitisfoundation.org](http://www.crohnscolitisfoundation.org)
  - Pediatric-focused publications (teacher’s guide, parent’s guide, comic book, activity book)

• Camp Oasis: [http://www.crohnscolitisfoundation.org/get-involved/camp-oasis/](http://www.crohnscolitisfoundation.org/get-involved/camp-oasis/)
  - Safe and supportive summer camp for children ages 7-18
  - 12 camps throughout the US

• Just Like Me IBD: [http://www.justlikemeibd.org/](http://www.justlikemeibd.org/)
  - Resources for kids and teens with IBD

• Campus Connection: [www.crohnscolitisfoundation.org/campus-connection](http://www.crohnscolitisfoundation.org/campus-connection)
  - Connect with other college students and learn tips for campus life

• Support Groups and Power of Two
  - Connect with other parents or children with IBD
NASPghan Resources

- What is NASPghan?
  - North American Society for Pediatric Gastroenterology, Hepatology and Nutrition
- Several resources for patients, families with IBD
  - Locate a pediatric GI doctor
  - Learn about pediatric IBD research
  - [www.gikids.org](http://www.gikids.org)
  - [www.ibdu.org](http://www.ibdu.org)
  - IBD publications and podcasts
  - Transition checklists
  - Doc4me app
Other Resources

• ImproveCareNow
  • A collaborative learning health care system of more than 100 pediatric centers developing standardized care with collaboration between caregivers, patients, and researchers
    • [http://improvecarenow.org](http://improvecarenow.org)
    • ICN Self-management handbook
      • [http://improvecarenow.org/handbook](http://improvecarenow.org/handbook)
• Got Transition
  • Developed by the National Alliance to Advance Adolescent Health
    • [www.gottransition.org](http://www.gottransition.org)
Questions?