

Pediatric Education Tips on Inflammatory Bowel Diseases

Practical Tips for Nurses and Advanced Practice Providers



These tips have been developed and reviewed by the Crohn's & Colitis Foundation's Nurse & Advanced Practice Committee. You may wish to print these out and discuss with your patients as appropriate during visits.

For more information on resource for nurses and advanced providers, please visit: www.crohnscolitisfoundation.org/nurseandAPP

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Preparing for School

It can be a daunting task for school age children to return to school with IBD. They enter new grades, new classrooms, and sometimes new schools as they progress through the elementary, middle, and high school systems.

As nurses and/or advanced practice providers, we can be a powerful resource for our patients with IBD in preparing for a successful transition back to school.

Use the tips below to help your young IBD patients and their caregivers think through the special needs that may arise during this period of transition to help ensure proper preparation for the academic year.

Elementary, middle and high-school transitions

TIP #1

Provide health education/anticipatory guidance to help students with IBD be better prepared (as developmentally appropriate) for the challenges of having a chronic illness at school. These include measures to ensure:

- Knowledge of their disease
- Knowledge of their medications
- Development of self-management skills
- Development of problem-solving skills (as developmentally appropriate)
- Stress management skills

TIP #2

Stress the importance of maintaining medical and dietary management in order to achieve remission and/or optimize disease control.

Be sure immunizations are up-to-date. This includes pneumococcal vaccine(s) for those who are immunocompromised, and annual influenza vaccine when appropriate.

TIP #3

Encourage the patients and their families to identify anticipated needs that may require accommodations. Offer anticipatory guidance to help them develop strategies and plans.



TIP #4

Encourage students with IBD and/or their families to obtain and keep an ongoing copy of medical records/summary for continuity of care.

TIP #5

Encourage students and/or their parents to prepare for the new school year by discussing the following topics:

Locate Bathrooms in Advance

- Identify bathroom locations along their route to classes. This will help decrease anxiety associated with finding a bathroom when the need arises.

School Supplies

- Remember to include medications and other IBD supplies that may be needed while at school, such as a change of clothes, to the back-to-school list.

Discuss Special Accommodations

- Provide families with notes, letters, and medications for those with special accommodations, such as a 504 plan.

Discuss Stress and School

- Discuss how stress impacts IBD.
- Encourage the student and family to discuss stressful situations that may happen in school in advance. Prepare an action plan to help the student cope with incidents such as accidents or feeling ill during the school day.

TIP #6

Review other special considerations for school-aged children.

- Review information in this [guide for parents on taking IBD to school](#)
- Review information in this [guide for school teachers and other personnel](#) and refer parents to review information about Crohn's disease and ulcerative colitis:
- Emphasize to parents the need for collaborating with the child's teacher and school nurse throughout the semester.



Crohn's & Colitis Foundation resources to share with patients and caregivers:

1. School and IBD: [Information for Parents/Caregivers](#)
2. [Information for teens with IBD](#)
3. [Information for college students](#)
4. [School Accommodations \(504 plan\)](#)
5. [Additional Information for Parents/Caregivers](#)
6. [Animated video on preparing to manage IBD on my own](#)
7. Assessment children can take to become aware of important skills they can practice as they become adults: www.ibdskillsquiz.org/
8. [Brochures for Patients and Parents/Caregivers](#)



Helpful apps*

See note at conclusion of this resource for Crohn's & Colitis Foundation disclaimer.

Medication

1. MyMedicineSchedule
www.mymedschedule.com
2. MyMeds
about.my-meds.com
3. OnTimeRX
www.ontimerx.com
4. MedSimple
www.medsimpleapp.com
5. MediSafe
www.medisafeproject.com/
6. MangoHealth
www.mangohealth.com/
7. RxmindMe (Walgreens)

Stress Management

1. Guided Meditation: Stop, Breath, & Think

Other

1. Bathroom finder: Sit or Squat; Toilet Finder

Additional Resources:

1. Patient outreach and education www.gikids.org/

See page 11 for the reference list.

Preparing for College

It can be a daunting task for any young adult to make the transition from living at home where he/she has the support of family and friends, to entering college and living independently where he/she is surrounded primarily by other young people. Having a chronic disease such as Crohn's disease or ulcerative colitis can add to the complexity of this process.



Students with IBD often have a more difficult time with the transition from high school to college than their healthier peers (Adler et al 2008; Almadani et al 2014). This is thought to be potentially triggered by increased perceived stress, emotional factors, and disease activity (Almadani et al 2014). Increased disease activity has been associated with poorer academic achievement (Almadani et al 2014; Schwenk et al 2014), and lack of self-management skills, problem solving abilities, and stress management can affect college achievement (Schwenk et al 2014).

As nurses and/or advanced practice providers, we can be a powerful resource for our patients with IBD as they prepare for a successful transition to college and to greater independence.

Use the tips below to help your young IBD patients and their caregivers think through the special needs that may arise during this transition period to help ensure preparation for the academic year.

Before going to college

TIP #1

Provide health education/anticipatory guidance to help your patients be better prepared for the challenges of managing a chronic illness in college. These include measures to improve:

- Knowledge of their disease
- Knowledge of their medications
- Self-management skills
- Problem solving skills
- Stress management skills

TIP #2

Stress the importance of medical and dietary adherence (as applicable), to maintain remission and/or optimize disease control.

Be sure immunizations are up-to date; This includes the pneumococcal vaccine(s) in those who are immunocompromised, and the influenza vaccine when appropriate. Refer to the Foundation's [Pediatric Checklist](#).

TIP #3

Encourage the patients and their families to identify anticipated needs that may require accommodations. Offer anticipatory guidance to help them develop strategies and plans.

TIP #4

Encourage the patients and their families to obtain and keep an ongoing copy of medical records for continuity of care. This is especially important for those who are planning on going away for college.

Getting ready for college—thinking ahead

TIP #5

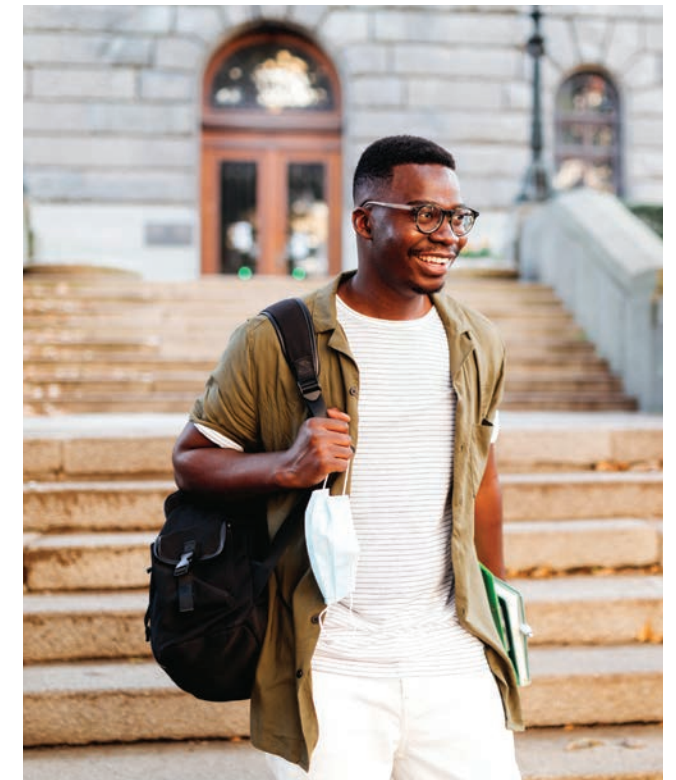
Encourage the patients to think ahead when they are choosing a college. Below lists common factors that could be considered. Encourage them to consider risks and benefits of their options, encourage realistic expectations, and offer anticipatory guidance.

Location

- Local vs. out of state

Housing and Accommodations

- Dorm vs. apartment vs. living at home
- # of students per dorm room
- # of students sharing a bathroom
- Bathroom accommodations
- Availability of refrigerator for medications
- Medication storage



Logistical Considerations

- Academic scheduling/classes
- Availability of special accommodations for testing
- Transportation
- Parking

Dietary Considerations

- Availability of healthy food choices
- Availability of special dietary needs
- Availability of dietary supplements/enteral therapy
- Kitchen availability
- Ability to pack snacks and meals during long academic days

Medication and Treatment Considerations

- How to get prescriptions and refills
 - Pharmacy
 - Mail order
- Continuation of treatments and medication therapy
 - Infusions
 - Therapies

Insurance

- Always carry the insurance card
- Insurance options
 - Remaining on parent's health insurance plan
 - Student health insurance
 - Individual health insurance
- Important information about insurance
 - HMO vs. PPO
 - Private vs. State funded
 - Co-pay
 - Deductible
 - Out-of-pocket-cost
 - Share of cost
 - Network

TIP #6

Discuss plans for ongoing medical care (health maintenance and routine follow-up visits). Listed below are several possible options:

Staying Local

Continuing with Primary GI

- Continue with routine health surveillance and office visits.

Transferring to Adult GI

- Facilitate transition/transfer to an adult GI practice prior to starting college.

Going Away to College

Continuing with Primary GI

- If the school is far enough away that the distance will prevent the student from returning home for 'check-ups' during the school semesters, make sure the student schedules GI visits and other health maintenance appointments in advance for when they are home during winter and spring breaks.

Transferring to Pediatric/Adult GI Closer to College

- Students living far away from home may establish care with a GI specialist close to the school/university. Before school starts, give referrals for GI providers in the vicinity of the school/university.

Co- Management

- This is a management agreement between the primary GI provider and a GI provider closer to school who agree to share in the management of the college student with IBD. In collaboration, the local GI provider will attend to the needs and management while the student is at school. The primary GI provider will attend to the needs and management during holidays and vacation upon the student's return home. This is a special arrangement which requires agreement, communication, and coordination.

TIP #7

Review the importance of recognizing signs and symptoms of an IBD flare.

Discuss and develop a plan for what to do for management of a flare/illness that should include:

- Self-management of early stages of a flare
- When and who to call for advice
- When to seek medical evaluation for management (See specifics in the next section: Going to College with IBD).



TIP #8

Discuss and develop a plan for labs/imaging studies:

- Ensure the student knows where to have labs drawn if needed. Sometimes it can be done at student health.
- Ensure the student knows where to go for imaging studies

TIP #9

Discuss plans for IBD-related sick care or emergency situations. Below lists several possible options:

Staying Local

Continuing with Primary GI

- Continue with usual protocol for management of sick care and emergency situations.
- Encourage student to contact the primary GI for concerns and recommendations.
- Review when to call 911

Transferring to Adult GI

- Encourage student to contact the adult GI for concerns and recommendations.
- Review when to call 911

Going Away to College

Continuing with Primary GI

- Encourage student to contact the primary GI for concerns and recommendations.
- Review when to call 911
- Encourage the student/caregiver to identify a local provider close to campus in case of an emergency situation. This can be done by:
 - Recommendation/referral from primary GI provider
 - Asking the campus health center
 - Contacting insurance provider for recommendations
 - Utilizing apps



Transferring to Adult GI Closer to College

- Encourage student to contact adult GI provider for concerns and recommendations
- Review when to call 911

Co- Management

- Encourage student to contact their closest GI provider for concerns and recommendations
- Review when to call 911

Other Health Care Options for IBD Related illness

College Health Services

- Remind student that the staff may or may not be well trained for management of IBD concerns.
- May be able to help with getting laboratory studies (routine laboratory studies and drug monitoring).
- May be a good resource to provide referral to IBD specialist in the community.

Urgent Care

- May have availability for simple imaging studies as needed.
- May be a good resource to provide referral to IBD specialist in the community.

Local Hospitals

- May be a good option for management of most IBD flares.



- Ability for management of more complex patient care will vary.
- May have availability for more complex imaging studies.
- May be a good resource to provide referral to IBD specialist in the community.

TIP #10

Discuss plans for non-IBD related sick care or emergency situations.

- Review signs and symptoms of illness
- Review when to call primary care provider
- Review when to call 911

Other Health Care Options for non IBD Related Illnesses

College Health services

- May be a good option for minor illnesses, primary care issues, and mental health issues.
- Remind student that the staff may or may not be well trained for management of IBD concerns.

Urgent care

- May be a good option for minor or acute illnesses.
- May have availability for simple imaging studies as needed.

Local hospitals

- May be a good option for minor, acute or more serious illnesses.
- May have availability for more complex imaging studies.

Taking IBD to college

TIP #11

Discuss the importance of registering for special accommodations

Special Accommodations

Registration with the Office of Disability or Accessibility Office*

If there is no Office of Disability or Accessibility Office, seek info from the Dean of Students

- Provide accommodations/benefits for students with chronic illness, potentially including:
 - Bathroom privacy
 - Attendance forgiveness
 - Make up for missed work and tests
 - Priority registration
 - Assigned notetaker
- Extra time for test-taking to allow for bathroom breaks

Carry Over 504 Plan

- Some 504 plans can be carried over to college.
- Most colleges require a 504 be in place during elementary and/or high school in order to make accommodations for college.

TIP #12

Discuss the importance of adherence to medication and disease management. During transitions, routines are interrupted. Use reminders to adhere to a medication schedule.

TIP #13

Discuss and develop a plan for medication management at school

Getting Prescription Refills

Options include:

- Home or specialty pharmacy
- Local pharmacy near college
 - Ensure student knows where the pharmacy closest to their campus is.

- Mail order
 - Consider using a post office box for delivery.
 - Not recommended to have medications delivered to regular mailroom or dorm as confirmation of delivery and safety from loss or tampering cannot be assured.

Injections

Ensure the ability to continue to receive delivery of medications for injection

- Home or specialty pharmacy
- Local pharmacy or specialty pharmacy near college
 - Ensure the student knows where the pharmacy or specialty pharmacy closest to their campus is.
- Mail order
 - Consider using a post office box for delivery.
 - Not recommended to have medications delivered to regular mailroom or dorm as confirmation of delivery and safety from loss or tampering cannot be assured.

Infusions

- GI office: If the student transitions to a local GI provider, they may be able to have access to an office infusion.
- Infusion centers: There are independent outpatient infusion center throughout the country. Many will accept orders from out-of-state providers.
- Home infusions: If the student is receiving home infusions, the infusion companies can provide services in the health center or dorm room.

The students will need to provide medical records to a local infusion center.



Storage of Medications

- Check with college in regards to their rules and regulations about medications
- Ensure that there is a personal and safe place for storage of medications. These should not have communal access. Store medications at bedside (if able) and not in a shared bathroom.
- For medications which require refrigeration, ensure that there is a personal and safe place for storage. This should NOT have communal access.

TIP #14

Provide anticipatory guidance about the following important issues:

Self-Care

- Make time for relaxation and leisure
- Exercise regularly
- Be realistic about what can be achieved
 - Don't take on too much
 - Plan ahead—don't wait until the last minute
 - Learn to delegate
 - Set priorities
- Stay engaged
 - Friends and family
 - Consider a support group

Adherence with Medication Management

- Nonadherence is linked with increased risk for flares, greater health care utilization, poorer health related quality of life, and rising health care costs.
- Challenges are often due to burden of taking medications around peers or interfering with activities; many just want to be “normal” (Greenley, Kunz, Walter, & Hommel, 2013).
- If feeling well, patients may not view adherence as important
- Ways to improve adherence:
 - Education: It is important to review
 - Medications and dosing regimen
 - Purpose and actions of medications

- Importance of taking medications as prescribed. Patients are more likely to exhibit side effects and have limited therapeutic benefit with sporadic dosing
- Consequences of non-adherence
- Behavioral: simplify regimen, use visual/auditory reminders, use reward systems
- Cognitive Behavioral: patient/family identifies barriers, create a solution, and implement the plan (Greenley et al., 2013).

Healthy Lifestyle

- Getting rest
 - 7-9 hours of sleep nightly is recommended for young adults (Hirshkowitz et al., 2015)
- Alcohol /Drugs/Smoking
 - Alcohol can cause hepatotoxicity especially when used in combination with medications such as methotrexate and can be irritating to the GI tract.
 - Marijuana may be helpful for abdominal pain, appetite, and nausea but no human studies have shown improvement in biochemical or disease activity scores (Swaminath et al., 2019).
 - Smoking tobacco with Crohn's disease increases risk for complications and need for surgery. In UC, current smoking is associated with more mild disease course, however, prior smoking (especially heavy use) is associated with increased hospitalizations and need for colectomy (Abegunde, Muhammad, Bhatti, & Ali, 2016).
- E-cigarette use has increased dramatically. Carcinogens and heavy metals have been found in aerosols and the harmful effects of nicotine are still present (U.S Department of Health and Human Services, 2016).
- Sexual health

Review the importance of preventing STDs and unintended pregnancy.

 - STDs: immunosuppressed patients are vulnerable to infections, including STDs.
 - Abstinence is the best way to prevent STDs.
- If participating in sexual activity, recommend:
 - Consistent condom use
 - STD screening

- Limited number of partners can help lessen risk of STDs (Marcell, Bursein, & AAP Committee on Adolescence, 2017)
- Pregnancy prevention:
 - Long-acting reversible contraceptives (LARC) are highly effective and should be considered first-line contraceptive for adolescents with IBD (Marcell et al., 2017 & Limdi, Farraye, Cannon, Woodhams, & Farraye, 2019).
 - Estrogen-containing contraceptive options may increase risk of venous thromboembolism in addition to VTE risk in IBD due to flares (Limdi, et al., 2019)
- Stress management
 - Deep breathing and relaxation exercises such as guided meditation
 - Aroma therapy
 - Reflexology
 - Yoga
 - Counselors on campus through student health
- Small studies show antidepressants and counseling have reduced steroid use and are associated with fewer relapses in disease activity (Gracie et al., 2018)

TIP #15

Discuss how to deal with negative experiences that can be encountered by those with IBD going to college. These negative experiences may be caused by a perceived stigma of having a chronic illness. This perceived stigma is often fueled by a lack of knowledge and education about IBD. For those living with IBD, they may be at risk for experiences which may impact their psychological functioning, adherence, and quality of life (Taft, & Keefer, 2016).



Crohn's & Colitis Foundation resources to share with your students:

1. [Preparing for college](#)
2. [Campus connection](#)
3. [Disability Support Services](#)

References for College & School Tips:

Abegunde, A.T., Muhammad, B.H., Bhatti, O., & Ali, T. (2016). Environmental risk factors for inflammatory bowel diseases: Evidence based literature review. *World Journal of Gastroenterology*, 22(27), 6296-6317. doi: 10.3748/wjg.v22.i27.6296

Adler, J., Raju, S., Beveridge, A.S., Wong, S., Zhu, J., & Zimmermann, E.M. (2008). College adjustment in University of Michigan students with crohn's and colitis. *Inflammatory Bowel Disease*, 14(9), 1281 – 1286. doi.org/10.1002/ibd.20484

Almadani, S.B., Adler, J., Browning, J., Green, E.H., Helvie, K., Rizk, R.S. & Zimmermann, E.M. (2014). Effects of inflammatory bowel disease on students' adjustment to college. *Clinical Gastroenterology and Hepatology*. 12(12), 2055–2062. Published online: April 10, 2014. doi.org/10.1016/j.cgh.2014.03.032

Barfield, E., Sockolow, R., Hoffenberg, E., Saeed, S., Kim, S., Siebold, L., Picoraro, J., Park, K.T. (2019). Assuring quality for non-hospital-based biologic infusions in pediatric inflammatory bowel disease: a clinical report from the north american society for pediatric gastroenterology, hepatology and nutrition. *JPGN*, 66(4), 680-686. doi:10.1097/mpg.0000000000001890

Gracie, D.J., Guthrie, E. A., Hamlin, P.J., & Ford, A.C. (2018). Bi-directionality of brain-gut interactions in patients with inflammatory bowel disease. *Gastroenterology*, 154, 1635-1646. doi: 10.1053/j.gastro.2018.01.027

Greenley, R.N., Kunz, J.H., Walter, J., & Hommel, K.A. (2013). Practical strategies for enhancing adherence to treatment regimen in inflammatory bowel disease. *Inflammatory Bowel Diseases*, 19(7), 1534-1545. doi:10.1097/MIB.0b013e3182813482



Hackett-Hunter, P., Hess, J., Comeau, M. & Sloyer, P. (2015). Just the facts: the 411 on health insurance for young adults age 18 – 30 in Florida. Tallahassee FL. Florida Department of Health. Retrieved from www.floridahats.org/wp-content/uploads/2016/03/JUST-THE-FACTS-GUIDE-JULY-2015-ENTIRE-GUIDE-LOW-RES3.pdf

Hirshkowitz, M., Whiton, K., Albert, S. M., Alessi, C., Bruni, O., DonCarlos, L., Hazen, N., Herman, Katz, E.S, Kheirandish-Goza, L., Neubauer, D.N., O'Donnell, A.E., Ohayon, M., Peever, J., Rawding, R., Sachdeva, R.C., Setters, B., Vitello, M.V., Ware, J.C., & Adams-Hillard, P.J. (2015). National Sleep Foundations' updated sleep durations recommendations: final report. *Sleep Health*, 1(4), 233-243. doi.org/10.1016/j.sleh.2014.12.010

Klostermann, N.R., McAlpine, L., Wine, E., Goodman, K.J. & Kroeker, K.I. (2018). Assessing the transition intervention needs of young adults with inflammatory bowel disease. *JPGN* 66(2), 281-285. doi: 10.1097/MPG.0000000000001677

Lemly, D.C., Lawlor, K., Schere, R. A., Kelemen, S. & Weitzman, E.R. (2014). College health service capacity to support youth with chronic medical conditions. *Pediatrics*, 134(5), 885-891. doi: 10.1542/peds.2014-1304

Limdi, J. K., Farraye, J., Cannon, R., Woodhams, E., & Farraye, F.A. (2019). Contraception, venous thromboembolism, and inflammatory bowel disease: What clinicians (and patients) should know. *Inflammatory Bowel Diseases*. doi: 10.1093/ibd/izz025

Marcell, A. V., Burstein, G. R., and AAP Committee on Adolescence. (2017). Sexual and reproductive health care services in the pediatric setting. *Pediatrics*, 140 (5). doi. org/ 10. 1542/ peds. 2017- 2858

Schenk, H.T., Lightdale, J.R., Arnold, J.H., Goldmann, D.A, & Weitzman, E.R. (2014). Coping with college and inflammatory bowel disease. *Inflammatory Bowel Disease* 20 (9), 1618-1627. doi.org/10.1097/MIB.0000000000000124

Swaminath, A., Berlin, E.P. Cheifetz, A., Hoffenberg, E., Kinnucan, J., Wingate, L., Buchanan, S., Zmeter, N., & Rubin, D.T. (2019). The role of cannabis in the management of inflammatory bowel disease: A review of clinical, scientific, and regulatory information. *Inflammatory Bowel Diseases*, 25(3), 427-435. doi.org/10.1093/ibd/izy319

Taft, T.H. & Keefer, L. (2016). A systematic review of disease-related stigmatization in patients living with inflammatory bowel disease. *Clinical and Experimental Gastroenterology* 9, 49-58. doi.org/10.2147/CEG.S83533

U.S. Department of Health and Human Services. (2016). E-cigarette use among young and young adults: A report of the Surgeon General. Retrieved from e-cigarettes.surgeongeneral.gov/documents/2016_SGR_Full_Report_508.pdf.



Transition of Care

Transition of care is defined as the planned and purposeful movement of adolescents and young adults through the process of changing from child centered to adult-centered health care systems.

As pediatric and adult healthcare providers, we are in a unique position to facilitate the successful transition and eventual transfer of adolescents and young adults with inflammatory bowel diseases (IBD) to adult care. We can help our adolescents and young adults achieve independence in living with IBD by providing:

- Routine assessment of our patients' knowledge, learning needs and self-management skills
- Anticipatory guidance to improve the understanding of their disease, medications, medical tasks, independence and attainment of self-management skills.

For children, adolescents and young adults with IBD, the focus of our interventions is to enable them to improve their knowledge, self-management skills, and independence based on their age and/or developmental abilities.

- For early adolescence (12-14 years of age), the focus should be on **Obtaining Knowledge and Self-management Skills**.
- For middle adolescence (14-17 years of age), the focus should be on **Expanding Knowledge, Independence, and Self-management**.
- For late adolescence/young adults (17 + years of age) the focus should be on **Taking Ownership**.

Transition assessment and planning should commence between 12-14 years of age. For those who are diagnosed later, start the process around the time of diagnosis or once stable

Utilize the following tips and charts to help you guide your patients through the process of transition and successful transfer of care.

TIP #1

Create a transition policy for your practice and discuss the policy with transitioning patients. There are transition policy templates available at gottransition.org (White et al., 2018).

TIP #2

Identify adolescents and young adults in your practice who are candidates for transition assessment and planning.

To help identify your patients with IBD, you can use

- Clinic patient lists
- ImproveCareNow Registry
- ICD 9/ICD 10 Codes

TIP #3

Identify assessment tools which can be used to assess educational needs and self-management skills of adolescents and young adults

- Several assessment tools are available including:
 - **TRAQ** (Transition Readiness Assessment Questionnaire)
 - **STARx** (University of North Carolina's Successful Transition to Adulthood with Rx=Treatment Questionnaire; self-administered)
 - **TRxANSITION Index** (University of North Carolina's Transition to Adulthood Questionnaire; provider administered)
 - **GotTransition**
 - **NASPGHAN IBD Transition Checklist**
- ****Links to these resources can be found at the end of this document**

TIP #4

Have adolescents and young adults (and parents as needed) complete the assessment tools at yearly intervals to monitor their progress.

TIP #5

Based on the assessment obtained, provide education and anticipatory guidance to help our adolescents and young adults achieve the needed knowledge and skills for self-management and independence

The following chart(s) highlight many of the recognized knowledge and skills thought to be essential for successful transitions. They provide information about what needs to be assessed, based on age and stage of development. They also provide recommendations for anticipatory guidance.



Assessment

	Early Adolescence Gaining Knowledge and Self-management Skills	Middle Adolescence Expanding Knowledge, Independence, and Self-management	Late Adolescence/Young Adult Taking Ownership
My Health	<ul style="list-style-type: none"> • Basic information about disease/condition • Information about medications • Names medications, doses, and schedule • Describes common side effects of medications • How to use and read a thermometer • Ability to manage some regular medical tasks at school • Ability to discuss impact of disease on lifestyle and activities 	<ul style="list-style-type: none"> • Knowledge of names and purposes of procedures/tests • Knowledge of medical history • Ability to identify possible triggers of disease exacerbations • Ability to re-order medications and call for refills • Knowledge of impact of condition on sexuality • Understanding of risk of non-adherence • Understanding of impact of drugs/alcohol on illness 	<ul style="list-style-type: none"> • Knowledge of avoiding medications which could interact with regular medications procedures/tests • Ability to manage all medical tasks at home, school, and work • Knowledge of reliable sources of information about disease, disease management, medications, etc.
Independence and Assertiveness		<ul style="list-style-type: none"> • Ability to independently answer most questions asked during health care visits • Able to spend greater portion of office visit alone with provider 	<ul style="list-style-type: none"> • Alone with provider for health visit • Can choose who can be in the room during the visit • Can identify new legal rights and responsibilities which start at 18
Using Health Care	<ul style="list-style-type: none"> • Knowledge of names/roles of health care providers • Ability to answer at least 1 question during health care visits 	<ul style="list-style-type: none"> • Knowledge about eventual transfer to adult provider • Knowledge about available support 	<ul style="list-style-type: none"> • Makes own appointments, refills prescriptions, contacts the medical team • Carries insurance information • Aware of length of coverage with parents' insurance and need to identify options for continued coverage

Adapted from NASPGHAN. (n.d.). Transitioning a patient with IBD from pediatric to adult care. www.naspghan.org/files/documents/pdfs/medical-resources/ibd/Checklist_PatientandHealthcareProdiver_TransitionfromPedtoAdult.pdf

Anticipatory Guidance			
	Early Adolescence Gaining Knowledge and Self-management Skills	Middle Adolescence Expanding Knowledge, Independence, and Self-management	Late Adolescence/ Young Adult Taking Ownership
Health Education	<ul style="list-style-type: none"> • Disease/condition, medications • How to use a thermometer • Impact of disease on life-style and activities 	<ul style="list-style-type: none"> • Anticipatory guidance based on assessed deficits • Impact of drugs, alcohol, and non-adherence of disease • Impact of disease on sexuality and fertility 	<ul style="list-style-type: none"> • Anticipatory guidance based on assessed deficits • Impact of drugs, alcohol and non-adherence on disease • Impact of disease on sexuality and fertility
Foster Independence and Assertiveness	<ul style="list-style-type: none"> • Discuss the importance of part of future office visit being done without the parents • Encourage active participation in office visit 	<ul style="list-style-type: none"> • Continue to encourage active participation in office visit • Focus on the patient, not the parent when providing explanations • Allow the patient to select when the parent is in the room for the exam 	<ul style="list-style-type: none"> • Discuss plans for insurance coverage • Develop specific plans for self-management outside of home (work/school) • Discussion of adult rights at 18 years of age • Future plans for school/work • Care while in college • Develop medical summary in preparation for transition • Provide list of potential providers • Encourage/facilitate an initial visit
Healthy Lifestyle	<ul style="list-style-type: none"> • Begin to provide anticipatory guidance on drugs, alcohol, fitness, sexuality 	<ul style="list-style-type: none"> • Continue to provide anticipatory guidance on drugs, alcohol, fitness, and sexuality 	<ul style="list-style-type: none"> • Identify adult provider • Check insurance • Set up an appointment • Transfer care
Establish Specific Self-management Goals	<ul style="list-style-type: none"> • Learn your medications and doses • Use apps for reminders • Perform a task • Come prepared with a list of questions to ask at next visit 	<ul style="list-style-type: none"> • Filling prescriptions • Scheduling appointment • Keeps a list of medications • Keeps contact information for medical team, pharmacy in wallet or backpack 	

Adapted from NASPGHAN. (n.d.). Transitioning a patient with IBD from pediatric to adult care www.naspgghan.org/files/documents/pdfs/medical-resources/ibd/Checklist_PatientandHealthcareProdiver_TransitionfromPedtoAdult.pdf.

TIP #6

Make mutually agreed upon goals to achieve educational goals and skill attainment.

TIP #7

Periodically reassess transition readiness with assessment tools and update your educational plan and goals as needed.

TIP #8

Once your patients (and families) have achieved their stated goals and have reached the desired self-management skill level and independence, get them prepared for transfer to adult care. Ideally, transfer occurs when the patient's health is stable (White et al., 2018).

TIP #9

Identify adult gastroenterology (GI) providers with IBD expertise in the patient's geographic location for transfer. Consider keeping a regional/national list for referrals

TIP #10

Consider keeping an ongoing summary of your patient's health history (current medications, past medications, endoscopic and radiographic results, surgeries, immunizations etc.) that can be shared with the adult GI upon transfer.

TIP #11

Prepare a final transfer packet to include items such as:

- Transfer letter
- Summary of health history
- Final transition readiness assessment
- Copies of important medical records
 - endoscopy reports
 - imaging reports
 - baseline screening studies (TPMT, serology tests, PPD, Quantiferon TB, etc.)
 - ongoing surveillance screening (PPD, Quantiferon TB)
 - therapeutic drug monitoring results
- Plan of care

TIP #12

Ensure successful transfer completed. Follow up with patients within 6 months of transfer about their experience.

Transition is a process. Transfer is the endpoint.



Crohn's & Colitis Foundation resources to share with patients and caregivers:

1. www.crohnscolitisfoundation.org/justlikeme
2. www.ibdskillsquiz.org/
3. www.crohnscolitisfoundation.org/campus-connection
4. Managing inflammatory bowel disease as a *young adult*



Transition Assessment Tools

1. **TRAQ**—20 question self-report tool which measures transition readiness in 5 domains.
2. **TRxANSITION Index**—32 question scale that measures transition readiness.
3. **STARx**—18 question self-report tool which measures transition readiness.
4. **Got Transition**—a self-report general template for patients, parents and caregivers that can be tailored for individual use.
5. **NASPGHAN**—self-report or administered checklist for patients with IBD. It identifies key areas for successful transition:
 - [Checklist with tasks for adolescents with IBD](#)
 - [Checklist with tasks for adolescents with IBD and corresponding role of providers](#)

Additional Resources:

1. [Booklet](#) for coding and reimbursement for transitions
2. [Got Transition](#)/Center for Health Care Transition Improvement—Their aim is to improve transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families.

References:

Abraham, B. P., & Kahn, S. A. (2014). Transition of care in inflammatory bowel disease. *Gastroenterology & Hepatology*, 10(10), 633-640. Retrieved from www.gastroenterologyand-hepatology.net/

Afzali, A., & Wahbeh, G. (2017). Transition of pediatric to adult care in inflammatory bowel disease: Is it as easy as 1, 2, 3? *World Journal of Gastroenterology*, 23(20), 3624-3631. doi.org:10.3748/wjg.v23.i20.3624

Cohen, S.E., Hooper, S.R., Javalkar K., Haberman C., Fenton N., Lai H., Manan, J.D., Massengill S., Kelly, M., Cantu, G., Medeiros, M., Phillips, A., Sawicki, G., Wood, D., Johnson, M., Benton, M.H., & Ferris, M. (2015). Self-management and transition readiness assessment: concurrent, predictive and discriminant validation of the STARx questionnaire. *Journal of Pediatric Nursing*, 30, 668 -676. doi.org:10.1016/j.pedn.215.05.0060882-5963.

Gray, W. N., Resmini, A., Kaitlin, B., Morgan, P., Holbrook, E., Shehzad, S., Denson, L.A, & Hommel, K.A. (2014). Concerns, barriers, and recommendations to improve transition from pediatric to adult IBD care: Perspectives of patients, parents, and health professionals. *Inflammatory Bowel Diseases*, 21(7), 1641-165. doi.org: 10.1097/MIB.0000000000000419

NASPGHAN. (n.d.). Transitioning a patient with IBD from pediatric to adult care. Retrieved from www.naspghan.org/files/documents/pdfs/medical-resources/ibd/Checklist_Patientand-HealthcareProdiver_TransitionfromPedtoAdult.pdf

Rosen, D., Annunziato, R., Colombel, J.F., Dubinsky, M., & Benkov, K. (2016). Transition of inflammatory bowel disease care: Assessment of transition readiness factors and disease outcomes in a young adult population, *Inflammatory Bowel Diseases*, 22(3), 702-708. doi.org: 10.1097/MIB.0000000000000633

Shapiro, J.M. El-Serag, H.B., Gandle, C., Peacock, C., Denson, L.A., Fishman, L.N., Hernaez, R., & Hou, J.K. (2020). Recommendations for successful transition of adolescents with inflammatory bowel diseases to adult care. *Clinical Gastroenterology and Hepatology*, 18(2), 276-289 e272. doi.org/10.1016/j.cgh.2019.04.063

White, P. H., Cooley, W.C., Transitions Clinical Report Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians. (2018). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, 142(5). doi.org: 10.1542/peds.2018-2587



Summer Camp

Camp Oasis

CAMP OASIS is a life-changing experience for children and teens with inflammatory bowel diseases, and January is the month to begin making plans to take advantage of this great opportunity.



TIP #1

Inform your pediatric patients' parents about the Crohn's & Colitis Foundation's Camp Oasis program and that applications will become available no later than early February.

Pediatric patients with IBD who attended a disease-specific summer camp benefited from the experience. It helps pediatric patients with IBD with psychosocial adjustment and acquisition of knowledge about their disease (Salazar, G and Heyman, M. (2014).

In a recent study of Camp Oasis camper and parent evaluations, campers showed a high rate of improvement in self-confidence and self-assuredness in speaking about their disease. After Camp Oasis, 56% more respondents agreed a lot with being open about their disease with friends; 44% more respondents agreed a lot with being described as confident; and 46% more respondents agreed a lot with being comfortable asking doctors about their disease. (Crohn's & Colitis Foundation data 2012-2019)

“Camp Oasis was my home away from home for one week every August for 8 years! I didn’t have to hide my medical condition; it could be embraced. My cabin mates and I had non-stop fun and have kept in touch throughout the years.”

- Eliza Hyde
Wilmington, DE

Confirm that parents understand:

- Space at camp is limited so early application submission is strongly encouraged.
- The cost to attend camp is \$400, but scholarships are available to families unable to pay for any reason. Families can apply for a scholarship when submitting their applications. Cost should never be a barrier to camp participation.
- Families of newly-diagnosed patients can reach out to others from the Foundation chapter to find out more about Camp Oasis from the patient perspective (camp administrators can arrange an introduction to experienced families).
- Campers have access to 24-hour per day medical supervision by pediatric GI physicians, nurses, nurse practitioners, and mental health specialists.
- At camp, children will have the opportunity to build nurturing relationships with other IBD patients, participate in a wide variety of skill-building activities, and have the opportunity to have a ton of fun and just be a kid!

While our focus will be on the in-person camp experience, a virtual Camp Oasis component will continue to be offered for those who are unable to attend a residential camp. However, parents should note that it will be more self-directed and will offer minimal live sessions.



TIP #2

Serve as a volunteer for Camp Oasis - offering yourself to work in this capacity may expand your understanding of life with IBD in a richer context than could occur in other care-giving interactions, such as clinical settings. [Learn more about the opportunity.](#)

“Volunteering as Medical Director at Camp Oasis is a professionally and personally rewarding experience. It is an amazing opportunity to interact with the kids outside of the clinic walls in an environment where they feel safe and accepted. Without Camp Oasis many of the kids would never experience a place where IBD doesn’t make them feel different. As cliché as it sounds, it’s truly life changing for both the kids and the staff.”

-Diane Kocovsky, RN, MSN
Omaha, NE



Crohn’s & Colitis Foundation resources to share with your patients:

1. Camp Oasis Information page: www.crohnscolitisfoundation.org/get-involved/camp-oasis/
2. Teen website: www.crohnscolitisfoundation.org/justlikeme
3. Campus Connection website: www.crohnscolitisfoundation.org/campusconnection

Reference:

Salazar, G and Heyman, M. (2014). Benefits of Attending a Summer Camp for Children with Inflammatory Bowel Disease. *JPGN* 2014;59: 33-38.



Uniting to Care & Cure



About the Crohn's & Colitis Foundation

We are a non-profit, volunteer-fueled organization dedicated to finding cures for Crohn's disease and ulcerative colitis, and improving the quality of life of children and adults affected by these diseases.

Since our founding in 1967, the Foundation has played a role in every major breakthrough in IBD research. We have invested more than \$350 million into finding the causes, treatments, and cures for Crohn's disease and ulcerative colitis. And we won't stop until we realize our vision of a future free from Crohn's and colitis.

We educate healthcare professionals through education workshops and programs and publish two scientific journals to help health professionals keep pace and contribute to this rapidly growing, ever-evolving field. We also educate, support, and empower patients and their caregivers through patient-centric education and advocacy programs.

Questions?

Contact the IBD Help Center
Monday–Friday, 9:00 a.m.–5:00 p.m. ET
888-694-8872
info@crohnscolitisfoundation.org

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The Crohn's & Colitis Foundation provides information for educational purposes only. The Foundation does not provide medical or other health care opinions or services. We encourage you to review the latest guidelines available on IBD. The inclusion of another company's/organization's/doctor's resources or referral to another company/organization/doctor does not represent an endorsement of a particular individual, group, company, or product.

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