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A blue slide titled "Participating in the Webinar" from a "Virtual Grand Rounds" session. The slide includes three callout boxes with instructions: "All attendees will be muted and will remain in 'Listen Only Mode'", "Type your questions here so that the moderator can see them. Not all questions will be answered but we will get to as many as possible.", and "A handout with the slides and room to take notes can be downloaded from your control panel." The slide also shows a control panel on the right with icons for mute, hand, chat, and download, and an "Exit" button at the bottom.

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ACG Virtual Grand Rounds

Join us for upcoming Virtual Grand Rounds!




Week 21 – Thursday, May 25, 2023
 The Role of Non-Invasive Modalities in Colorectal Cancer Screening
 Faculty: Douglas J. Robertson, MD, MPH
 Moderator: T.R. Levin, MD, FACP
At Noon and 8pm Eastern




Week 22 – Thursday, June 1, 2023
 Prior Authorization in GI: Tips from the ACG Prior Authorization Task Force
 Faculty: Baharak Moshiree, MD, MSc, FACP, and Stephen T. Amann, MD, FACP
 Moderators: Daniel J. Pambianco, MD, FACP, and Dayna S. Early, MD, FACP
At Noon and 8pm Eastern

Visit gi.org/ACGVGR to Register

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Disclosures



Sandra C. Kim, MD
Dr. Kim has no financial relationships with ineligible companies.



Amy Bugwadia, MS
Ms. Bugwadia has no financial relationships with ineligible companies.



Mara Shapiro, BA
Sandoz Pharmaceuticals: Speaker (terminated)

*All of the relevant financial relationships listed for these individuals have been mitigated

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Crash Course in Caring for the Emerging Adult Living with IBD: It's NOT "Mission Impossible"

Sandra C. Kim, MD
Cleveland Clinic
Children's Hospital



Amy Bugwadia, MS
Stanford University
School of Medicine



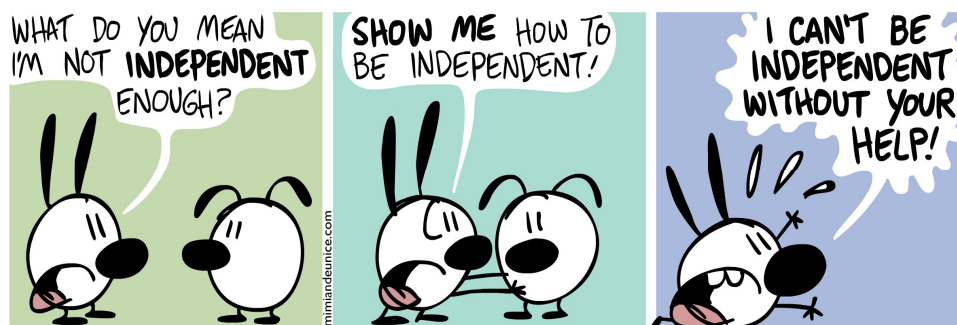
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OBJECTIVES

- Define the concepts of transitioning and transfer of care for young adults with IBD
- Recognize the psychological impact of IBD for the transitioning adolescent and their caregivers
- Discuss common barriers to care
- Review factors that prepare the adolescent patient to successfully transfer *and* transition to adult care
- Develop a transition plan/expectations that includes the pediatric and adult GI providers, young adult patient, and family
- Provide resources and tools to help in these processes

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The Road to Independence



- Crucial to start/ramp up transitioning process early
 - Gradual process: parents shift into role of “coach”
 - Preparation for being away from home after high school
- Adult GI teams will expect young adults to be independent

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What is Transitioning?

- Transition ≠ Transfer
- Transfer of care
 - Moving from one provider to another
- Transition
 - Planned, purposeful process of adolescent patients towards independence from pediatric to adult –focused healthcare systems
 - Flexible, dynamic process
 - *Timing important

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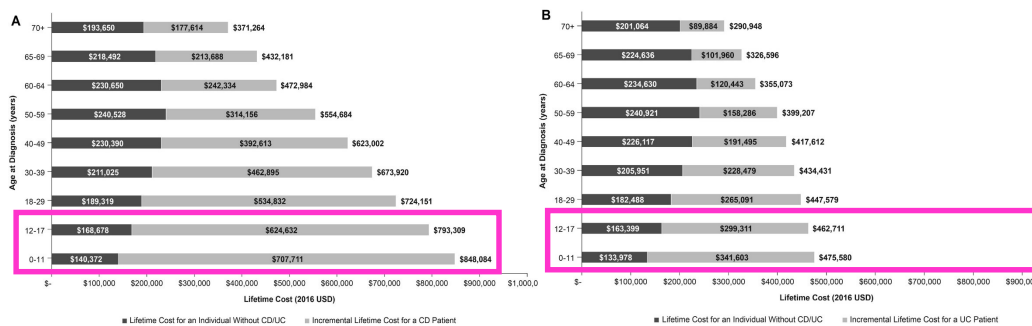
NASPGHAN: Transitioning of Care

“The goal of a transition program is to achieve for each chronically ill patient a continuum of care that includes normalization of social and emotional development and the acquisition of independent living skills.”

- NASPGHAN Medical Position Statement 2002

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The Cost Of Disease In Pediatric IBD

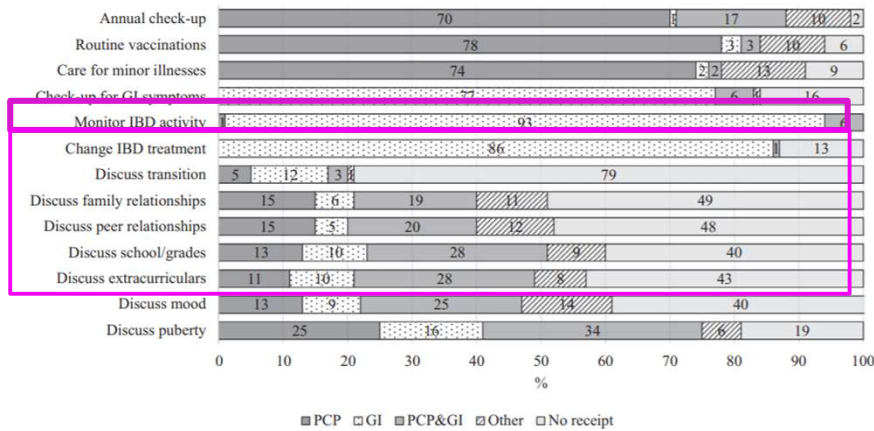


- *Overall per - patient costs greater in children vs. adults
- Lifetime cumulative costs highest in patients with earlier onset IBD

Kappelman, et al. 2008. Gastroenterology
Lichtenstein, et al. 2020. Clin Gastro Hepatol

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Greatest Gaps Noted in Psychosocial Care



Michel, et al. 2020. J Peds

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Psychosocial Development is Delayed in Adolescent IBD Patients

	Patients with IBD		Norm group	
	%	N	%	N
Leaving the parents' home				
No	84.2	32	70.4	95
Yes	15.8	6	29.6	40
Educational level ¹				
High	0	0	0	0
Middle	50.0	16	61.9	78
Low	50.0	16	38.1	48
Employment status				
Employed	25.0*	9	56.6	75
Not employed	75.0	27	44.4	60
Marital status				
Married/living together	3.1	1	6.3	8
Single	96.9	31	93.8	120

IBD = inflammatory bowel disease.
 * $P < 0.01$ according to logistic regression analysis by group, age, and sex.
¹ Highest level completed: low—primary education, technical, and vocational training; lower and middle general secondary education; middle—middle vocational education, higher general secondary education, preuniversity education; high—higher vocational education, university.

Hummel, et al. 2013. JPGN

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School Functioning and Performance Affects K-12, Higher Ed, and Beyond

- Children with IBD have poorer school functioning compared to healthy children

(Mackner *et al.* 2012. *J Clin Beh Psych*)

- Poorer functioning but only significant differences were in absences (although decreased GPA and QOL as well)

- Predictors for worse educational outcomes:

(Singh, *et al.* 2015. *J Peds*)

- Age, gender–matched children with IBD to controls
- Predictors: *Lower SES and diagnosis with mental health issues, but not age at diagnosis, IBD type, steroids, or hospitalizations

- Higher ed can impact future jobs, economic/insurance status

(Almadani, *et al.* 2014. *Clin Gastro Hepatol*)

- More difficult adjustment to college, lower attendance and self-efficacy for students with IBD (especially when experiencing symptoms)

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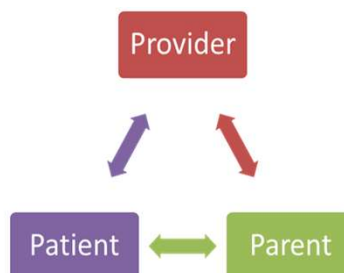
Adolescence to Adulthood... Is It REALLY a Seamless Process?



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Considerations for Care in Young Adults

- Shift in roles
- Social pressures
- Developmental changes
- Life changes
- Issues of confidentiality
- Redefining responsibility
- Financial and insurance considerations
- Increasing independence and autonomy
- Shared-decision making



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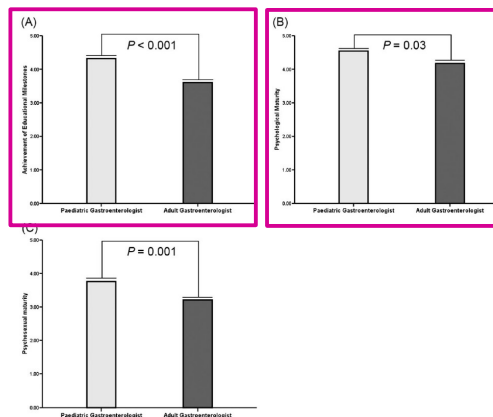
Transitioning in IBD Care

- Adolescent IBD patients have low baseline knowledge of disease
- Discrepancies in adult vs. pediatric GI MD perceptions of patient readiness
 - Inadequate disease knowledge, lack of self - advocacy
 - Insufficient time/clinical resources
- Poor correlation between clinician vs. measures - defined health literacy readiness in adolescent IBD patients
 - Lowest correlation in patient-reported self-efficacy in disease management
 - Differences in how clinicians and patients define health literacy

Boamah, et al. 2010. *JPGN*
 Benchimol, et al. 2011. *Inflamm Bowel Dis*
 Huang, et al. 2012. *Clin Gastro Hepatol*
 Sebastian, et al. 2012. *J Crohns Col*

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Psychosocial Readiness in Young Adults

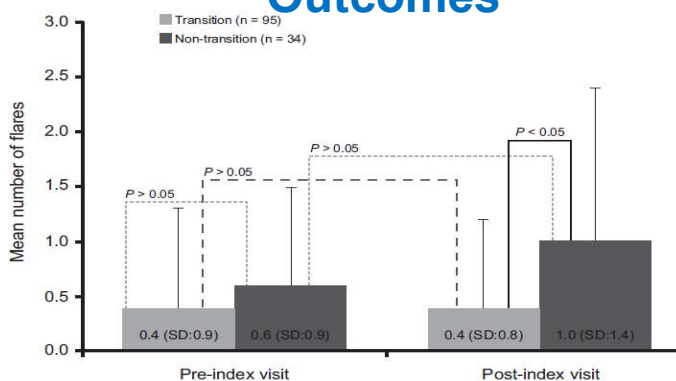


- Adult GI MD: Self – efficacy most important
- *Psychosocial readiness more important than age
- Barriers: poor medical handoff; patient lack of self-responsibility

Wright, et al. 2014. *Int Med J*

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Effective Transitioning Impacts Clinical Outcomes



- TRANSIT study: GI centers in the UK
- “Structured transition:” ≥ 2 GI visits (Peds + Adult GI clinicians)
- *Disease flares significantly less in transition group
- *Higher steroid – free remission in transition group (71% vs 41%)

McCartney, et al. 2022. *JPGN*

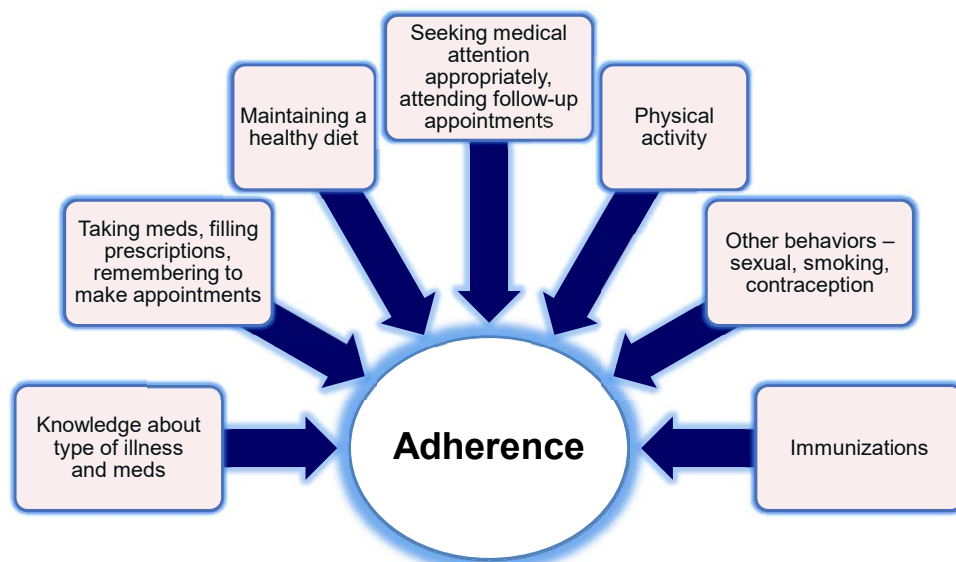
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Transitioning from Pediatrics to Adults...

- Recognizing and reconciling differences in approaches to care
 - Differences in style
 - Differences in management
 - Differences in time allotted for office visit
 - Differences in procedures and sedation
- Planning for care at college/time away from home
- Balancing parent and patient interests

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Health Maintenance is NOT Just About Medication



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How Can Adult GIs Effectively Address This?

- Many Pediatric GIs currently use:
 - Readiness assessments
 - Utilization of checklists
 - Educational and self-management tools
 - Written comprehensive healthcare plan
- Adult GIs can consider implementing...
 - Dedicated clinics for the adolescent (annual visits)
 - Dedicated APP/Nurse Coordinator
 - Discussions of the Transition Readiness domains during initial visits

Hait, et al. 2006. JPGN
Leung, et al. 2012. Inflamm Bowel Dis

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Transition Readiness Tools

Transition Readiness Assessment Questionnaire (TRAQ)

Directions to Youth and Young Adults: Please check the box that best describes your skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

Directions to Caregivers/Parents: If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes your skill level. Check here if you are a parent/caregiver completing this form.

	No, I do not know how to do this	No, but I want to learn to do this	No, but I am having trouble doing this	Yes, I have started doing this	Yes, I always do this when I need to
Managing Medications					
1. Do you fill a prescription if you need it?					
2. Do you know what to do if you are having a bad reaction to your medication?					
3. Do you take medications correctly and on your own?					
4. Do you monitor medications before they run out?					
Appointment Keeping					
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests, check-ups or shots?					
7. Do you prepare for your visit to medical appointments?					
8. Do you call the doctor about unusual changes in your health (for example, allergic reactions)?					
9. Do you report for health insurance if you change?					
10. Do you know what your health insurance covers? (For example, are there copays?)					
11. Do you manage your money & budget for health expenses? (For example, are there deductibles?)					
Tracking Health Issues					
12. Do you fill out the medical history form, including a list of your allergies?					
13. Do you keep a calendar or list of medical and other appointments?					
14. Do you make a list of questions before the doctor's visit?					
15. Do you get feedback/help with school or work?					
Talking with Providers					
16. Do you tell the doctor or nurse what you are feeling?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
Managing Daily Activities					
18. Do you help plan or prepare meals/food?					
19. Do you keep housework clean or organized after meals?					
20. Do you use neighborhood stores and services (for example, grocery stores and pharmacy stores)?					

© Wood, Saravali, Rassi, Livingston & Kremen, 2014

- Patients
- Medication management
 - Appointment keeping
 - Tracking health issues
 - Managing ADL
 - Communication with providers

Sample Transition Readiness Assessment for Youth Six Core Elements of Health Care Transition 2.0

Please fill out this form to help us see what you already know about your health and how to use health care and the areas that you need to learn more about. If you need help completing this form, please ask your parent/caregiver.

Name: _____ Date of Birth: _____

Transition Importance and Confidence On a scale of 0 to 10, please circle the number that best describes how you feel right now.

How important is it to you to prepare for change to an adult doctor before age 22? 0 1 2 3 4 5 6 7 8 9 10 (Very)

How confident do you feel about your ability to prepare for change to an adult doctor? 0 (Not) 1 2 3 4 5 6 7 8 9 10 (Very)

My Health Please check the box that applies to you right now. None at all A little Fairly well Very well

I know my medical needs.

I can explain my medical needs to others.

I know my symptoms including ones that I usually need to see a doctor for.

I know what to do in case I have a medical emergency.

I know my own medicines, what they are for, and when I need to take them.

I know my allergies to medicines and medicines I should not take.

I carry important health information with me every day (e.g., insurance card, allergies, medications).

I understand how to use my health care services.

I can explain my medical history.

Using Health Care

I know or I can find my doctor's phone number.

I make my own doctor appointments.

Before a visit, I check about questions to ask.

I have a way to get to my doctor's office.

I know when to go to get medical care when the doctor's office is closed.

I know when to go to get medical care when the doctor's office is closed.

I have a list of where to go for medical information.

I have a copy of my current plan of care.

I know how to get referrals to other providers.

I know where my pharmacy is and how to fill my medicines.

I know when to get blood work or a test if my doctor orders them.

I have a plan I can keep my health insurance after 18 or older.

My family and I have discussed my ability to make my own health care decisions at age 18.

© 2014 Institute of Medicine. Health Care Transition 2.0: Six Core Elements of Health Care Transition 2.0. A report of the National Research Council on Health Care Transition. Washington, DC: National Academies Press; 2014. www.nationalacademies.org

- Patients, parents, caregivers
- Transition importance and confidence;
 - My health
 - Skills for using health care




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Healthcare Provider Transitioning Checklist

AGE	PATIENT	HEALTH CARE TEAM
12-14	EARLY ADOLESCENCE <i>New knowledge and responsibilities</i> <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	MID ADOLESCENCE <i>Building knowledge and practicing independence</i> <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 travel to an adult gastroenterologist <input type="checkbox"/> I know how to book an appointment for one of my doctors <input type="checkbox"/> I know how to get a prescription for one of my medicines from my insurance during my visit <input type="checkbox"/> I understand the risk of medical non-adherence <input type="checkbox"/> I understand the impact of drugs and alcohol on my condition <input type="checkbox"/> I understand the impact of drugs and alcohol on my quality of life 	<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 do when working with parents with a serious condition <input type="checkbox"/> Encourage the patient to work with parents with a serious condition to establish an independent status with the parent 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"> <input type="checkbox"/> Attending endoscopies and scheduling appointments <input type="checkbox"/> Attending school <input type="checkbox"/> Attending work
17	LATE ADOLESCENCE <i>Taking charge</i> <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 	DISCUSS IN MORE DEPTH: <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 <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

So... What Are We Missing in the Transition Process?

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Medical Summary

- Date of (and age at) IBD diagnosis
- IBD phenotype: Disease distribution/severity
- IBD-related surgeries and complications
- Medication/therapy history (including prior adverse reactions)
- Diagnostic testing results: most recent endoscopies and imaging
- Vaccination/screening status: Hepatitis B, pneumococcal vaccines; TB status
- Recent labs (including TDM results)

Menon & Afzali.2019. AJG

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What to Discuss with Young Adult Patients

“Administrative” issues related medical care

- Accommodations

- College (Disability office; letters/forms)
- Academic internships/work programs
- Work – related (FMLA)



- Dealing with insurance mandates

- Type of insurance and coverage
- Understanding insurance versus pharmacy benefits manager (PBM)
- Prior authorizations



* Not everyone needs to be a health policy expert! But patients *do* need a baseline understanding in order to be an active partner in their care!

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What to Discuss with Young Adult Patients

- Health management

- Emergency support/contacts (and disclosure)
- Knowing where to get your medications, and how to use them
- Scheduling visits, tests, and procedures
- Knowing when and how you should contact your healthcare team

- Health maintenance

- Understanding medication interactions
- Understanding self-protection in the time of COVID (and other future pandemics/viral seasons)
- Sexual health and family planning

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Resources to Provide Your Patients

THE TRANSFER TOOLKIT the transition task force of IMPROVECARENOW™

A GUIDE FOR YOUNG PEOPLE WITH IBD, THEIR FAMILIES, AND THEIR CARE TEAMS with tools and stories to ease the transfer to adult care






A guide for teens with IBD

Download This Brochure
www.crohnscolitisfoundation.org/brochures

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Crohn's and Colitis Young Adults Network



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The number of articles or videos created by and for young adults with IBD since 2020.

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Countries represented in our Fellowship Program from 2020 - 2023

WHO WE ARE
The CCYAN is a community and international fellowship program for young adults with IBD.

OUR FELLOWSHIP
We facilitate a yearlong fellowship that brings together a select group of young adults with IBD from around the world. Our fellows produce monthly content, convene virtually to hear from influential speakers, engage in speaking opportunities and receive a stipend for their participation.

AND MORE...

- **Virtual community meetings for young adults with IBD**
- **Roundtable on Young Adults with IBD**
a yearlong learning community comprised of monthly discussions between patients and providers
- **IBD Medical Student Scholars**
a unique program for medical students interested in gastroenterology and internal medicine to learn about the global challenges and needs of adolescents and young adults with IBD

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Peer Support Networks

- Crohn's and Colitis Young Adults Network (CCYAN)
 - [Resources](#) and [virtual meetings](#)
- ImproveCareNow Pediatric Advisory Council ([PAC](#))
- Crohn's and Colitis Foundation
 - National Council of College Leaders (NCCL) and [Campus Connection](#)
 - Young Professionals Groups ([Chapter-specific](#))
 - Camp Oasis ([Counselors](#))
 - [Power of Two](#) program
- Clinic and hospital-based support groups
- College-based groups
 - Student clubs, Disability Office events
- Fostering 1:1 mentorship/connections

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Psychosocial Readiness → Routine Practice

- Pediatric GI MD:
 - Be proactive and provide appropriate resources for young adult patients
 - Focus on patient self – management of their disease...and life
 - Ask the tough questions!
 - Have a comprehensive medical summary ready
- Adult GI MD:
 - Collaborate with the peds team in the early stages of care transfer
 - Anticipate existing gaps of knowledge and self – management skills
 - Prepare for more time for questions, additional education... and parents

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Teamwork is the Key to Success

- Transition of medical care coincides with other life transitions, which may or may not promote effective medical transition
 - School and college
- Transition is a gradual process (“continuum of care”) of achieving autonomy as an independent young adult in medical care and overall health management
- One size does NOT fit all!
- Transition is most successful when patients, parents, AND clinicians are involved.

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Ultimate Goals

- Empower your emerging adult patients
 - Acknowledge the challenges they are encountering as they form their own identity as a young adult with a chronic illness
- Ensure that there is an effective therapeutic alliance
 - Shared decision making on all levels
 - Open communication
 - Safe space
- Educate on available resources
 - Within the healthcare institution
 - Additional scientific and patient – focused information

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Questions



Sandra C. Kim, MD



Amy Bugwadia, MS



Mara Shapiro, BA

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CONNECT AND COLLABORATE IN GI



ACG & CCF IBD Circle



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ACG GI Circle

Connect and collaborate within GI



ACG Hepatology Circle



ACG Functional GI
Health and Nutrition Circle



ACG Women in GI Circle

ACG's Online Professional Networking Communities
LOGIN OR SIGN-UP NOW AT: acg-gi-circle.within3.com



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