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CROHN'S & COLITIS FOUNDATION

Tips for 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.

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)

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- **STARx** (University of North Carolina's Successful Transition to Adulthood with Rx=Treatment Questionnaire)
- **UNC TRxANSITION** Scale (University of North Carolina's Transition to Adulthood Questionnaire)
- **GotTransition**
- **NASPGHAN IBD Transition**

- **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	○ 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	○ 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 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

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	○ Ability to manage some regular medical tasks at school ○ Ability to discuss impact of disease on lifestyle and activities	○ Knowledge of impact of condition on sexuality ○ Understanding of risk of non-adherence ○ Understanding of impact of drugs/alcohol on illness	management, medications, etc.
Independence and Assertiveness		○ Ability to independently answer most questions asked during health care visits ○ Able to spend greater portion of office visit alone with provider	○ 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	○ Knowledge of names/roles of health care providers ○ Ability to answer at least 1 question during health care visits	○ Knowledge about eventual transfer to adult provider ○ Knowledge about available support	○ 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. https://www.naspghan.org/files/documents/pdfs/medical-resources/ibd/Checklist_PatientandHealthcareProdiver_TransitionfromPedtoAdult.pdf

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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	○ Disease/condition, medications ○ How to use a thermometer ○ Impact of disease on lifestyle and activities	○ Anticipatory guidance based on assessed deficits ○ Impact of drugs, alcohol, and non-adherence of disease ○ Impact of disease on sexuality and fertility	○ 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	○ Discuss the importance of part of future office visit being done without the parents ○ Encourage active participation in office visit	○ 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	○ 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	○ Begin to provide anticipatory guidance	○ Continue to provide anticipatory guidance on drugs,	○ Identify adult provider ○ Check insurance

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	on drugs, alcohol, fitness, sexuality	alcohol, fitness, and sexuality	○ Set up an appointment ○ Transfer care
Establish Specific Self-management Goals	○ Learn your medications and doses ○ Use apps for reminders ○ Perform a task ○ Come prepared with a list of questions to ask at next visit	○ 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 https://www.naspghan.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 Doc4Me app to help patients find providers around the country.

Tip #10: Consider keeping an ongoing summary of you 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)

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- therapeutic drug monitoring results
- Plan of care

Transition is a process. Transfer is the endpoint

Resources

Transition Assessment Tools

- **TRAQ** - 20 question self- report tool which measures transition readiness. It measures 5 domains: medication management, appointment keeping, tracking health issues, managing ADL and communication with providers. https://www.rheumatology.org/Portals/0/Files/Transition-Readiness-Assessment-Questionnaire.pdf

- **UNC TRxANSITION** - 32 question scales that measures transition readiness. It is administered by trained professional. It measures 10 domains: type of illness, medications, adherence, nutrition, self-management skills, support, new provider knowledge, life issues (work, school), reproductive health and knowledge on insurance. https://www.med.unc.edu/transition/transition-tools/starx-questionnaire/versions-of-the-trxansition- indextm/

- **UNC STARx -** 18 question self-report tool which measures transition readiness. It measures 6 factors: medications management, communication with providers, knowledge about disease, knowledge about adult health care responsibilities, use of resources and engagement. https://www.med.unc.edu/transition/transition-tools/trxansition-scale/versions-of-the-starx-questionnaire

- **Got Transition**- a self–report general template for patients, parents and caregivers that can be tailored for individual use. It assesses 3 domains: transition importance and confidence; my health and using health care. https://www.gottransition.org

- **NASPGHAN -** self-report or administered **c**hecklist for IBD patient. It identifies key areas for successful transition: knowledge about disease; development of independence and assertiveness; and health and lifestyle. This is a checklist that you can print and give to your patients for them to complete. You can structure your anticipatory guidance based on their response. There are 2 versions:

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- Checklist with tasks of adolescents with IBD https://www.gikids.org/files/documents/resources/IBD-TransitionTeenIBD.pdf
- Check list with tasks of adolescents with IBD and corresponding role of providers https://www.naspghan.org/files/documents/pdfs/medical-resources/ibd/Checklist_PatientandHealthcareProdiver_TransitionfromPedtoAdult.pdf

Additional Resources:

- Managing inflammatory bowel disease as a young adult: Here is a pdf that you can print and give to the young adult. It includes information on transitioning, healthcare, self-care mind and body, educating others, and social settings. http://www.crohnscolitisfoundation.org/resources/managing-ibd-young-adult.html

- Resources for coding and reimbursement for transitions: Here is a booklet – 2018 update for reimbursement and coding. https://www.gottransition.org/resourceGet.cfm?id=352

- Information for healthcare professionals and patients: Here is an excellent newsletter that is available electronically. Share the website with your colleagues and patients. Got Transition/Center for Health Care Transition Improvement is a cooperative agreement between the Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health. 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. https://www.gottransition.org/about/index.cfm

- NASPGHAN and the NASPGHAN Foundationdeveloped a mobile app Doc4me to assist with transitioning, including finding new doctors and a checklist to enable good transition. Please click on the link below for more information. http://www.doc4me-app.com/

Crohn's & Colitis Foundation Resources:

- www.justlikemeibd.org
- http://www.ibdskillsquiz.org/
- www.crohnscolitisfoundation.org/campus-connection
- http://www.ibdu.org/
- https://www.gikids.org/

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