Educational Tips on Inflammatory Bowel Diseases
For Nurses and Advanced Practice Providers
These tips have been compiled from our monthly tips resources developed during 2017-2018 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
Adherence to treatment is an important factor in monitoring and improving inflammatory bowel diseases’ course. Adherence has two components: consumption (use), and time (persistence). Adherence is the preferred term over compliance, as compliance connotes patient obedience and blame, and is paternalistic. Adherence to medications in IBD is approximately 50 percent, and non-adherence is associated with more flares, hospitalizations, and higher medical costs.

**TIP #1**


Non-adherence in IBD is complex and multifactorial, but can be broken down into treatment-related, illness-related, or patient-related factors.

**Treatment-related:**
- Dosage/dosing regimen
- Convenience
- Formulation
- Cost/reimbursement
- Adverse effects
- Effectiveness

**Illness-related:**
- Severity, extent, and/or duration of disease
- Frequency and intensity of flare-ups
- Complications

**Patient-related:**
- Skills/knowledge to follow regimen
- Belief systems/insights
- Psychiatric disorders
- Male gender, non-married

**TIP #2**

**Determine the reason for non-adherence (Herman & Kane, 2015)**

Is the non-adherent behavior accidental or intentional?

- **Accidental** non-adherence may be most effectively addressed by practical behavioral strategies such as:
  - Simplify the regimen—take medications at the same time every day, and in a single dose when possible
  - Visual cues—put medication near the toothbrush, place a sticky note on the medication, use a weekly medication dispenser, and/or set a phone alert
Set a reminder to get new prescriptions when visiting the provider, and to renew medications before they run out.

Involves family and significant others in remembering medications.

Download apps on smartphones that help patients adhere with a medication regimen.

**Intentional** non-adherence may be most effectively addressed by reinforcing and/or increasing the patient’s understanding of issues related to adherence and the effects of non-adherence.

**TIP #3**
How to assess adherence (Greenly, Kunz, Walter, & Hommel, 2013)

There are a few ways to measure adherence:

1. Direct patient inquiry
   a. Don’t ask if they have been taking their medication. Rather, state: “Many patients forget to take their medications at times. Has this been an issue for you?” If the answer is yes, ask how often this has been an issue. Question the patient about the number of flares during the interval last seen, and any symptoms next, to associate medication adherence with symptoms/flares.

2. Use of adherence scales
   a. Modified Morisky Adherence Scale (MMAS-8): This is the only scale validated in IBD, and the most widely used adherence scale (Trindale, Ehrlich, Kornbluth & Ulman, 2011).

3. Pill counts
4. Pharmacy fill data
5. Electronic monitoring (pill caps)

**TIP #4**
Strategies for improving adherence (Haynes et al, 2008; Kane, 2006; Lopez-Sanroman & Bermejo, 2006; Traynor, 2005)

- Evaluate adherence as a vital sign, at every visit
- Ask if they ever miss a dose when doing med rec
- Educate them on why medications are important (decreased risk of progression and flare-ups), and how their medications work
- Simplify their regimen
- Discuss their reminder systems
- Involve family/others
- Explain the association of adherence with reduced risk of flares and a better quality of life
- Facilitate shared decision-making and mutual goal-setting

**TIP #5**
Promoting alliance, not compliance: Communication strategies (Dudley-Brown, 2008)

- Use of a patient-centered approach is associated with better adherence, satisfaction, and illness adjustment
- Consider the use of a therapeutic alliance—a “we” rather than “me” approach to chronic illness
- Consider the use of motivational interviewing techniques

“Drugs don’t work in patients who don’t take them.”
– C. Everett Koop, MD, Former US Surgeon General
TIP #6
Share some apps that patients can utilize for medication reminders (Note, these are not supported or endorsed by the Crohn's & Colitis Foundation but are often used by patients as a resource.)

- **Medisafe** sends reminders through automated phone calls and text messages: [https://medisafe.com](https://medisafe.com)
- **Dosecast** has a variety of smart scheduling features: [www.dosecast.com](http://www.dosecast.com)
- **Medhelper Pill Reminder** has similar functions as dosecast, but contains exportable reports: [medhelperapp.com](http://medhelperapp.com)
- **My Pillbox** monitors adherence through an analytics dashboard: [pillboxok.com](http://pillboxok.com)

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

1. [www.crohnscolitisfoundation.org](http://www.crohnscolitisfoundation.org)
2. [www.ibdpartners.org](http://www.ibdpartners.org)

Disease tracking apps:


References:


Complementary and Alternative Medicine

Alternative Therapy Considerations
Patients with inflammatory bowel diseases commonly use complementary and alternative medicines (CAMs) or non-allopathic therapies at some point during their disease course. CAMs include herbal supplements, prebiotics, and probiotics, as well as mind-body therapies such as acupuncture and hypnosis.

Although 30-50 percent of patients use CAMs in order to supplement conventional therapies and help ease their symptoms, they are reluctant to mention it to their treating providers. Due to limited, small sample size controlled and uncontrolled clinical trials of CAMs, these therapies have not been widely accepted by providers as part of mainstream medical IBD care. Providers should familiarize themselves with the variable CAMs used by IBD patients and be open to discuss and ensure that they are used safely. Patients need to understand that CAMs should not be used in place of accepted and well-studied medical therapies that are available. Further research is necessary for validation of use. (Cheifetz, et al., 2017)

Four major domains of CAMs:
• Mind-Body Medicine (prayer, tai chi, hypnosis, meditation, biofeedback, and yoga)
• Manipulative and Body-Based Practices (chiropractic manipulation, massage, and reflexology)
• Energy Medicine (biofield therapies and bioelectromagnetic-based therapies)
• Biologically-based Practices (dietary supplements and functional foods)

**Medical Cannabis—Although cannabis may reduce symptoms associated with IBD, there is little evidence to support an anti-inflammatory role outside of animal models; and there is no evidence that it positively alters the disease course. There is no way to control the dosing in routine clinical practice and with the unpredictable psychoactive effects, its unwanted side effects from conventional therapies; however, adherence rates to conventional treatments were not found to be correlated to CAM use (Weizman et al., 2012). The level of trust in the healthcare provider was not found to be different between CAM users and non-users (Weizman et al., 2012), suggesting that CAM use on the part of your patient is not a sign of distrust in you as a provider. Because even seemingly innocent vitamins might contain ingredients that could interact with medications, it is important to build a bridge of communication that keeps you fully informed of your patients’ use of CAM.

Be aware that CAM use by your patients is likely and encourage them to alert you to any CAM therapies they are using.

CAM use has been found to be especially prevalent among university-educated individuals and individuals who have experienced ineffectiveness and/or
use cannot be recommended to treat IBD. Dosing strategies also cannot be recommended for patients with IBD until more data are available from clinical trials. (Cheifetz, et al., 2017)

For more information on CAM modalities in the context of IBD, see the Crohn’s & Colitis Foundation fact sheet:

www.crohnscolitisfoundation.org/resources/complementary-alternative.html
www.crohnscolitisfoundation.org/resources/CAM-webcast.html

TIP #2
Familiarize yourself with the most common forms of CAMs.

Herbs and Dietary Supplements:

1. **Medical Cannabis**: this is available in multiple formulations and 21 states currently allow for the medical use of cannabis. Results from human trials: possible therapeutic potential in CD, reduction in CDAI score symptom driven, no evidence for mucosal healing. Adverse effects (AE): cognitive and motor impairment, anxiety, dizziness, nausea, psychosis, loss of balance.

2. **Curcumin/Tumeric**: curcumin is known for its anti-inflammatory properties and it may have a role in maintenance of remission in patients with UC. Results from human trials: 50% increased response vs placebo. AE: rare nausea and diarrhea, yellow stools.

3. **Fish Oil**: found predominantly in oily fish and thought to have anti-inflammatory effects. Human studies: results have been unconvincing for consistent effects. (Cheifetz, et al., 2017)

Probiotics:

Little is known about the mechanisms and beneficial effects of probiotics. The largest effects have been observed in patients given VSL#3. Results from human trials: possible increase in clinical remission in UC; pouchitis prevention; and reduction in relapse. AE: rare bloating and diarrhea. (Cheifetz, et al., 2017)

Other Therapies:

1. **Trichuris Suis**: animals with parasitic infections have evidence for reduced colitis. Small open-label studies as well as randomized controlled trials were done with IBD patients after administration of eggs of T. Suis. Results: T. Suis appears to be well-tolerated and may have some efficacy in patients with IBD. Further studies are needed.

2. **Acupuncture and Moxibustion**: these Chinese therapies have been used for over 4,000 years. Results from human studies are positive but carry multiple limitations since patients on immune modulators or biologics are excluded in these studies. Evidence-based clinical application should therefore be restricted to patients that receive no other therapy or are unwilling or unable to be treated with conventional treatment.

3. **Mind-Body Therapies**: psychologic stress and IBD are intricately related. Patients with IBD have higher rates of anxiety and depression and a lower quality of life. There are links between psychologic stress and IBD flares. Cognitive techniques are safe adjunct approaches to improve psychological status and quality of life in patients with IBD. These therapies may not affect inflammatory activity directly and require further studies.

4. **Exercise**: It is likely that mild to moderate exercise programs provide multiple benefits to patients with IBD. Exercise does not appear to have detrimental effects on disease activity although reductions in intestinal inflammation have not been shown. (Cheifetz, et al, Gastro 2017)

**Always be respectful of patients’ decisions to supplement their disease management using reputable CAM practices/practitioners, and be ready to have a thoughtful discussion regarding the most common types of CAMs.**
Related article: Mindfulness May Be Helpful for People with Ulcerative colitis
nccih.nih.gov/research/results/spotlight/041114

For more information on CAM modalities see the National Institutes of Health’s, National Center for Complementary and Alternative Medicine website at: nccam.nih.gov

**For a comprehensive review of CAM refer to: Complementary and Alternative Medicines Used by Patients with Inflammatory Bowel Diseases, Gastroenterology 2017; 152, pages 415-429.

**TIP #3**

Be mindful of the potential need for you to be proactive regarding the recommendation of supplements.

Intestinal inflammation, pharmaceutical agents, and intestinal resections are some of the conditions that can predispose individuals with IBD to serious nutritional deficiencies. Careful assessment and supplementation can help avoid these deficiencies and maximize health. Therefore, assessment of nutritional status is always warranted and supplementation may be needed even in cases of clinical remission and in the absence of obvious pharmaceutical or surgical risk factors.

Additional considerations include patients on steroids, who especially need supplemental calcium and Vitamin D, and patients on methotrexate or sulfasalazine, who especially need folic acid supplementation. Patients with ileitis as well as patients who have had an ileocolic resection may need SQ or intranasal B12 supplementation since Vitamin B12 is absorbed in the terminal ileum. Iron deficiency anemia is commonly seen in the IBD population and should be monitored and treated appropriately.

Children and adolescents with IBD are particularly vulnerable to nutritional deficiencies as they are growing. IBD affects the bone health of these young patients. Approximately 10-40 percent of children with IBD have bone mass deficits at diagnosis, especially those with Crohn’s disease (Breglio & Rosh, 2013). Vitamin D levels should be monitored on a regular basis and supplemented.

To learn more about anemia and malnutrition in clinical IBD practice, see the Virtual Preceptorship program at: www.crohnscolitisfoundation.org/science-and-professionals/programs-materials/virtual-preceptorship.html
For a review of the added requirements for calcium and vitamin D in IBD, see “Bone Loss in IBD:”
www.crohnscolitisfoundation.org/resources/bone-loss.html

For a review of other deficiencies common in IBD, see the Crohn’s & Colitis Foundation’s Complementary and Alternative Medicine (CAM) fact sheet:
www.crohnscolitisfoundation.org/resources/complementary-alternative.html

**TIP #4**
Discuss with patients how to decipher credible internet sites and to ask questions about complementary medicines since patients use internet resources to get information and buy products related to CAM.

**TIP #5**
Always remember to document discussions you have regarding supplementation and CAM use in the patient’s chart.

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

1. Bone Loss in IBD:
   www.crohnscolitisfoundation.org/resources/bone-loss.html

2. Complementary and Alternative Medicine Fact Sheet:
   www.crohnscolitisfoundation.org/assets/pdfs/CAM.pdf

3. Complementary and Alternative Medicine in IBD Webcast:
   www.crohnscolitisfoundation.org/resources/CAM-webcast.html

4. Anemia and malnutrition Virtual Preceptorship:

**Additional Resources:**

1. Mindfulness resource from NIH:
   nccih.nih.gov/research/results/spotlight/041114

2. NIH National Center for Complementary and Integrative Health:
   nccih.nih.gov

**References:**


We can do our patients with inflammatory bowel diseases (IBD) a service by providing them with reliable resources about the risk and prevention of colorectal cancer (CRC).

**TIP #1**

Help your patients understand that surveillance colonoscopies are particularly important because IBD increases the risk of developing CRC. In addition, if your IBD patient has Primary Sclerosing Cholangitis (PSC), they require annual colonoscopies.

Increased risk associated with the IBD diagnosis starts eight to 10 years after diagnosis (Crohn’s & Colitis Foundation, 2013). Several studies report that IBD patients have a two to five times higher risk than the general population in comparable age groups (Guagnozzi & Lucendo, 2012). Stressing the importance of surveillance colonoscopies to your patients will also help them remember the date of their last colonoscopy, and when the next surveillance exam is necessary.

**TIP #2**

Inform your patients that the symptoms of IBD can mimic the symptoms of CRC.

Symptoms of CRC, such as fatigue, diarrhea, cramps, bloating, blood in stool, weight loss, and abdominal pain, may be mistakenly attributed to IBD because these symptoms are similar to those periodically experienced in the course of living with Crohn's disease and ulcerative colitis. For these reasons, it is especially important for patients with IBD to understand the crucial need to follow through on surveillance CRC screening schedules, as determined by the healthcare provider, in accordance with the individual patient’s history and circumstances.

**TIP #3**

Reassure your patients that most individuals with IBD will never develop CRC, and that maintaining the appropriate screening schedule is the best way for prevention and early detection of CRC, thereby resulting in better long-term outcomes.

Nurses who encourage their patients to maintain the appropriate screening schedule can help increase the chances that if CRC develops, it will be caught early, and will be in a highly treatable stage. Educational information can be downloaded through the Crohn’s & Colitis Foundation’s website: [www.crohnscolitisfoundation.org](http://www.crohnscolitisfoundation.org)
TIP #4
Familiarize yourself with the range of CRC screening recommendations for individuals with IBD.

Each professional society of gastroenterologists (the American Gastroenterological Association, the American College of Gastroenterology, the European Crohn’s and Colitis Organization, and the British Society of Gastroenterology) has its own CRC screening guidelines. Guidelines are determined by patient characteristics, such as the length of time since diagnosis and the location of diseased tissue. They are also based on studies that examine the effectiveness of several surveillance technologies in the detection of colorectal cancer.

For example, according to SCENIC guidelines (2015), when performing surveillance with white-light colonoscopy, high-definition (HD) is recommended rather than standard definition. Dysplasia is identified in twice as many patients undergoing HD endoscopy compared to standard definition (Laine, 2015; Subramanian, 2012). In a study by Yu, et al. (2016), when performing surveillance colonoscopy, chromoendoscopy is recommended rather than standard or HD white-light colonoscopy. Another study found that when performing surveillance with HD colonoscopy, chromoendoscopy is suggested rather than white-light colonoscopy (Laine, 2015). More investigation on surveillance for CRC will help providers discuss options and make the best recommendations for their patients. See Table 1 at the end of these tips.

TIP #5
Provide your patients with strategies for reducing risk of CRC through the adoption of simple, healthy lifestyle habits that represent controllable variables related to a low level of risk for CRC.

Patients cannot alter CRC risk factors such as their genetic make-up, their age, or whether or not they have IBD. However, patients with IBD can choose the foods and drinks that they consume and the activities in which they engage. Therefore, dietary intake and activity level are important controllable variables related to CRC risk. Nurses can disseminate the good news that an estimated 45 percent of CRC cases in the U.S. might be prevented through the adoption of simple lifestyle changes (American Institute for Cancer Research, 2013). By visiting the American Institute for Cancer Research (AICR) website, nurses can equip themselves to quickly and easily share recommendations for patients in the natural course of delivering standard nursing care. See Table 2 at the end of these tips.

TIP #6
Ensure your patients know that taking their IBD medications on a regular basis, as prescribed, reduces their risk of CRC.

Nurses can emphasize that individuals with IBD further decrease their risk of CRC when they reduce intestinal inflammation by practicing consistent medication adherence (Crohn’s & Colitis Foundation, 2013).
**Table 1:** Summary of the differences in recommendations for colorectal cancer surveillance for patients with IBD (adapted from Guagnozzi & Lucendo, 2012).

<table>
<thead>
<tr>
<th>Guidelines</th>
<th>Beginning of Surveillance (years after diagnosis)</th>
<th>Surveillance Schedule</th>
<th>Endoscopic Technique Recommended</th>
</tr>
</thead>
</table>
| **AGA 2010** | Eight years (pancolitis) 10 years (left-sided colitis) | Every one-three years.  
• Yearly if PSC.  
• History of CRC in first-degree relatives, ongoing active endoscopic or histologic inflammation, or anatomic abnormalities such as a foreshortened colon, stricture, or multiple inflammatory pseudopolyps, may benefit from more frequent surveillance. | No formal recommendation |
| **ACG 2010** | Eight-10 years | Every one-two years  
• Annually with PSC | No formal recommendation |
| **ECCO 2013 Crohn’s Disease** | Six-eight years after symptom onset | Every five years  
• Colitis affecting <50 percent of the colon surface area  
• Extensive colitis w/mild endoscopic or histological active inflammation  
Every three years  
• Post-inflammatory polyps  
• Colorectal cancer in a first-degree relative older than 50 years  
• Extensive colitis w/moderate or severe endoscopic or histological inflammation  
Annual colonoscopy  
• Stricture w/in the past five years  
• Dysplasia w/in the past five years in patient who declines surgery  
• Colorectal cancer in a first-degree relative younger than 50 years  
• PSC | Chromoendoscopy  
(For more information on chromoendoscopy, see Subramanian, Mannath, Ragunath, & Hawkey, 2011) |
| ECCO 2013 Ulcerative Colitis | Eight years (with at least left-sided colitis) from symptom onset | Every five years  
| | Annually following a diagnosis of PSC | • Colitis affecting less than 50 percent of the colon surface area  
| | | • Extensive colitis w/mild endoscopic or histological active inflammation  
| | | Every three years  
| | | • Post-inflammatory polyps  
| | | • Colorectal cancer in a first-degree relative older than 50 years  
| | | Annual colonoscopy  
| | | • Stricture w/in the past five years  
| | | • Dysplasia w/in the past five years in a patient who declines surgery  
| | | • PSC  
| | | • Colorectal cancer in a first-degree relative younger than 50 years  
| | | • A rectal remnant still requires standard-interval surveillance  
| BSG 2010 | 10 years | Every five years  
| | | • Lower risk  
| | | • Extensive colitis w/NO ACTIVE endoscopic/histological inflammation  
| | | OR left-sided colitis  
| | | OR Crohn's colitis <50 colon  
| | | Every three years  
| | | • Intermediate risk  
| | | • Extensive colitis w/ MILD active endoscopic/histological inflammation  
| | | OR post-inflammatory polyps  
| | | OR family history age 50+  
| | | Every year for higher risk  
| | | • Extensive colitis w/ MODERATE/SEVERE active endoscopic/histologic inflammation  
| | | OR stricture in past five yrs.  
| | | OR dysplasia in past five yrs. declining surgery  
| | | OR PSC/transplant PSC  
| | | OR family history in aged <50  
| | | Chromoendoscopy  

AGA, American Gastroenterological Association; ACG, American College of Gastroenterology; ECCO, European Crohn’s and Colitis Organization; BSG, British Society of Gastroenterology
### Table 2: Examples of lifestyle recommendations for CRC prevention (adapted from American Institute of Cancer Research and American Cancer Society websites, 2018)

<table>
<thead>
<tr>
<th>Source</th>
<th>Recommendations for reducing CRC risk</th>
<th>Notes</th>
</tr>
</thead>
</table>
| AICR   | 1. Fit activity into your day  
2. Stay a healthy weight and watch out for belly fat  
3. Eat plenty of fiber  
4. Cut red meat and processed meat consumption  
5. Go moderate on the alcohol  
6. Enjoy plenty of garlic | Each of these six recommendations suggests one small “first step” to get started in the right direction. More information about the research on which these recommendations are founded is contained in the World Cancer Research Fund/American Institute for Cancer Research. Continuous Update Project Expert Report (2018). |
| ACS    | 1. Don’t smoke  
2. Limit consumption of red and processed meats  
3. Generously consume fruits and vegetables  
4. Generously consume foods rich in calcium and vitamin D  
5. Stay at a healthy weight and avoid weight around the mid-section  
6. Increase the intensity and amount of your physical activity | |

AICR, American Institute of Cancer Research; ACS, American Cancer Society
### Crohn’s & Colitis Foundation resources to share with your patients:

1. **Risk Factors for Developing Colorectal Cancer**
2. **IBD & Colorectal Cancer—I’ll Be Determined**
3. **Am I at Risk for CRC?**
4. **Fact Sheet: Colorectal Cancer**

### References:

Smoking is a risk factor associated with Crohn’s disease (CD) expression and increased disease activity in individuals who have already been diagnosed with CD (Ananthakrishnan, 2013). Current smokers have twice the risk of developing CD as compared to individuals who have never smoked (Calkins, 1989). Smoking increases the frequency of flares and steroid use, and smoking cessation reduces the frequency of flares and steroid use to the same rate as that of non-smokers (Cosnes et al., 1999). After surgery, a two-fold increased risk of CD relapse continues for smokers in a dose-dependent manner (Yamamoto and Keighley, 2002). Thus, smoking is an important modifiable factor to address while managing the care of patients with CD who smoke. A combination of medical treatment and behavioral interventions increases the success of smoking cessation (Mallin, 2002). The approach to patients should include both strategies. There are a number of free online smoking cessation programs that you can inform your patients about.

**TIP #1**

Take an accurate smoking history for all newly diagnosed CD patients, and advocate for smoking cessation for all who smoke.

Medical management that focuses on pharmacologic and surgical therapies during busy office and clinic visits can leave non-pharmacologic interventions unaddressed (Löfberg, 2003); however, nurses caring for patients with CD can help fill the gap by drawing attention to smoking as a known, modifiable risk factor.

**TIP #2**

Suggest a referral to a smoking cessation program and/or to the use of an anti-smoking agent.

Referrals to smoking cessation programs and use of anti-smoking agents each increase the smoking
cessation success rate (Johnson, Cosnes, & Mansfield, 2005).

**TIP #3**

Track your patient’s progress in their smoking cessation endeavor over time during follow-up visits.

Tracking smoking cessation progress demonstrates the value that you place on this non-pharmacologic intervention, and may promote smoking cessation success.

Members of the healthcare team should document smoking cessation counseling to ensure that there is continuity of care for inflammatory bowel diseases (IBD) patients.

**TIP #4**

Take an accurate smoking history, and advocate for smoking cessation for all young patients with CD who smoke. Practicing in a pediatric setting does not negate the value of proactively addressing the topic of smoking.

Statistics show that a high percentage of adult smokers started their smoking habit in childhood, when they were under the age of 18 (American Lung Association, 2013). Developing the smoking habit at a young age results in a more severe addiction to nicotine compared to starting the habit later (American Lung Association, 2013), and can predispose young people to a lifetime of health problems if the habit is not interrupted. In young people with CD for whom health problems can be significant without smoking, adding the deleterious habit of smoking can compound ill health. For example, patients with CD already have an elevated risk of osteoporosis (Crohn’s & Colitis Foundation, 2012). Additionally, teen smoking may increase the risk of osteoporosis, especially in girls (Cincinnati Children’s, 2012).

**TIP #5**

Remind your patients, or parents of pediatric patients of the danger of secondhand smoke.

Secondhand smoke is a human carcinogen, and can cause disease and premature deaths in non-smoking adults and children (US Department of Health and Human Services).
**TIP #6**
Teach your patients that, in addition to cigarettes, other forms of tobacco (smokeless tobacco, cigars, pipes, hookahs (water pipes), bidis, and kreteks) are harmful forms of tobacco that can impact the health of IBD patients (US Department of Health and Human Services).

**TIP #7**
Identify online tools and apps to help with smoking cessation.

Online tools for creating and implementing a quit plan are available from the National Cancer Institute and the Truth Initiatives.

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

1. [www.crohnscolitisfoundation.org](http://www.crohnscolitisfoundation.org)

**Additional Resources:**

1. [https://smokefree.gov/](https://smokefree.gov/): Smokefree.gov is an initiative from the National Cancer Institute to help you or someone you care about quit smoking.

2. 1-800-QuitNow is a free telephone service that will link callers to a trained quit coach in their area to help them quit tobacco.

3. [https://www.cancer.gov/about-cancer/causes-prevention/risk/tobacco/help-quitting-fact-sheet](https://www.cancer.gov/about-cancer/causes-prevention/risk/tobacco/help-quitting-fact-sheet)—This is a great fact sheet that you can give to your patients as a handout.


5. [https://smokefree.gov/build-your-quit-plan](https://smokefree.gov/build-your-quit-plan)

6. [https://www.cdc.gov/tobacco/quit_smoking/how_to_quit/resources/index.htm](https://www.cdc.gov/tobacco/quit_smoking/how_to_quit/resources/index.htm)—This CDC campaign website lets you view their ads, learn more about the people featured and their health conditions, and access quit-smoking resources.
References:


(b) US Department of Health and Human Services (Feb 7, 2018) Smoked Tobacco Products Retrieved from HHS.gov

Gender-specific Issues for Women

Women with inflammatory bowel diseases face many gender-specific issues with body image, menstruation, sexuality, fertility, pregnancy, mode of delivery, menopause, and bone health. Disease activity is a major component of IBD that affects these issues. It is important that we as providers proactively discuss women's health maintenance as well as issues that they face in the context of IBD. Shared decision-making should be implemented to address these important issues as well as sexual health, family planning, reproductive counseling, and psychosocial issues so that informed decisions can be made (Feagins & Kane, 2016; Nee & Feuerstein, 2015; Rosenblatt & Kane, 2015; Peppercorn & Mahadevan, 2017).

TIP #1

Address sexual health and body image (Feagins & Kane, 2016; Rosenblatt & Kane, 2015; Mahadevan Friedman, Gawron, & Dubinsky, 2015)

Sexual health in women with IBD is important to address due to the major impact it has on young women in the midst of their reproductive years. An estimated 40-66 percent of women with IBD report sexual dysfunction when asked by their providers. Sexual dysfunction encompasses predominantly the physical aspect of sexuality, and we often neglect to address the other areas of sexual health. Sexual function can be influenced by multiple factors including depression, anxiety, and body image. Disease activity is one of the most important factors affecting sexual function. Active disease with symptoms such as diarrhea, pain, fatigue, or active perianal disease affects feelings of sexual attractiveness and desire and can cause associated discomfort during intercourse. Body image plays an important role in quality of life and sexual function. Dissatisfaction with body image was associated with increased disease activity in IBD patients and was linked to low self-esteem, anxiety, depression, and decrease in sexual satisfaction. Medication side effects, surgical scars, and ostomies are major contributors to this problem as well.
TIP #2

Review menstrual cycle and bowel pattern fluctuation (Mahadevan Friedman, Gawron, & Dubinsky, 2015; Bharadwaj, Kulkarni & Shen, 2015)

Many aspects of IBD management cross gender lines equally. However, the menstrual cycle is a gender-specific variable that often influences IBD activity and requires specific attention from the healthcare provider. Patients with IBD may have delayed menarche and menstrual cycles may be irregular.

Confirm your patient’s awareness of the potential impact of menses on IBD gastrointestinal symptoms, and offer additional help as needed. Bowel pattern fluctuation is common during the menstrual cycle and may produce diarrhea, loose stools, constipation, abdominal cramping, and pain. Women with a J-pouch also report loose stools during their menstrual cycle. In some cases, oral contraception may be needed if symptoms become debilitating (see below regarding risks of hypercoagulability). Avoid NSAIDs for menstrual cramps due to the increased risk of causing a flare.

TIP #3


Women with IBD, especially those who are on immunosuppressants, may be at increased risk for cervical dysplasia. Therefore, it is recommended that these patients have regular pap smears, especially if they have multiple partners. According to recommendations from the American College of Obstetricians and Gynecologists (ACOG), women 21-29 years old should have a pap smear every three years, and HPV testing is not recommended. Women 30-65 years old should have a pap smear and HPV testing every five years or a pap smear only every three years. Women with IBD who are immunocompromised may require more frequent screening rather than these routine guidelines. A population-based nationwide cohort study by Rungoe and colleagues found a slightly increased risk for cervical neoplasia among patients with Crohn’s disease regardless of immunosuppression exposure, suggesting that the disease alone may be associated with this finding.

According to the Center for Disease Control (CDC), HPV vaccines are routinely recommended for adolescents who are 11 or 12 years old. Vaccination is also recommended for females who are 13 to 26 years old.

TIP #4

Review contraceptive basics (Matin, Kane, & Feagins, 2016; Mahadevan, Friedman, Gawron, & Dubinsky, 2015)

- Contraceptive methods should be selected by the patient and provider based on their clinical and personal concerns.
- Women with IBD are able to use standard contraception measures.
- An intrauterine device (IUD) can be considered as first-line contraception especially if there is concern for lack of absorption of oral contraceptives, but should be avoided in patients with a history of a rectovaginal fistula.
- Due to potential increased risk of developing venous thromboembolism with IBD, women should avoid when possible estrogen-based contraceptive methods such as oral combination contraception pills, combination hormonal transdermal patches, and combined hormonal vaginal rings.
- Patients must avoid smoking if using oral contraceptives due to increased risk for thromboembolic events.
- Counseling should be provided to patients on safe behavioral choices and barrier protection from sexually transmitted diseases.

TIP #5

Plan for pregnancy and schedule patient for a preconception visit (Mahadevan, McConnell, & Chambers, 2017; Kane, 2016; De Lima, Zelinkova, Mulders, & van der Woude, 2016; Mahadevan Friedman, Gawron, & Dubinsky, 2015; Selinger, Eaden, Selby, Jones, Katelaris, Chapman, McDonald, McLaughline, Leong, & Lal, 2012).

- Preconception care is essential with the goal to establish and maintain remission prior to conception.
- Prospective studies show that education reduces IBD flares during pregnancy by promoting medication adherence, smoking cessation, and improving outcomes.
Review healthcare maintenance such as surveillance colonoscopy, routine vaccines, baseline labs, folate, iron studies, B12 (CD patients), vitamin D, and pap smears.

Increase folate intake, prenatal vitamins, and improve nutritional status.

Confirm remission—clinical symptoms and objective findings, e.g., labs (albumin, ESR, CRP, Fe studies), colonoscopy, CTE/MRE, baseline fecal calprotectin.

Communicate with your multidisciplinary team and agree on a treatment plan.

Review medication safety for pregnancy and breastfeeding (PIANO Registry)

Avoid agents with dibutyl phthalate (DBP) coating when possible.

Discuss the risk of children inheriting IBD (one parent with IBD ~6-9 percent, both parents with IBD ~36 percent).

TIP #6

Review fertility and pregnancy (Kane, 2016; Matin, Kane, & Feagins, 2016; Mahadevan, Friedman, Gawron, & Dubinsky, 2015)

IBD affects women in every age range and is often present by the time a young woman is going through the childbearing years. Pregnancy-related decisions require knowledge that is often lacking, leading to voluntary childlessness in 15-35 percent of patients. Lack of counseling may lead to lack of adequate knowledge about conception. Identifying lack of pregnancy-related knowledge and working to fill in the gaps can help reduce the risk of uninformed decision-making.

TIP #7

Educate your IBD patient regarding controlling active disease prior to pregnancy since this is an important factor in producing a healthy pregnancy for both mother and baby (Nguyen et al, 2016).

- A pregnant woman with IBD, compared with age-matched controls, is at higher risk for adverse outcomes including spontaneous abortion, preterm birth, low birth weight, and complications of labor and delivery (Toronto Consensus Statement).
- The risk of adverse outcomes increases further with active disease.
- Close monitoring by a maternal-fetal medicine specialist is important in order to identify inadequate gestational weight gain, fetal growth, evidence of preterm labor, medication compliance, and to discuss mode of delivery.
- Patients who have a J-pouch are at greater risk for infertility due to surgical manipulation in the pelvis and pelvic adhesions.

TIP #8

Review medication safety and dosing recommendations (Mahadevan, McConnell, & Chambers, 2017)

TIP #9

Continue monitoring during pregnancy (Peppercorn & Mahadevan, 2017; Kane, 2016; Mahadevan, Friedman, Gawron, & Dubinsky, 2015)

- Make sure patient has close follow-up in the office, as well as with the maternal and fetal medicine (MFM) provider, especially if they are experiencing any symptoms.
- Check labs, medication levels as needed, and fecal calprotectin since ESR can be elevated during pregnancy and therefore is not accurate.
- Remind your patient that in order to have the best pregnancy outcome, she must adhere to the treatment plan.
**TIP #10**

**Discuss mode of delivery** (Mahadevan, McConnell, & Chambers, 2017; De Lima, Zelinkova, Mulders, van der Woude, 2016; Mahadevan, Friedman, Gawron, & Dubinsky, 2015)

Mode of delivery should be discussed with the OBGYN in conjunction with the GI provider, especially for patients with a history of perianal disease.

- In general, patients with IBD can have uncomplicated vaginal deliveries if they have not had a history of perianal disease.
- Patients with active perianal disease and/or open rectovaginal fistula should have a C-section to avoid any complications.
- A healthy mother with IBD, without perianal disease should be able to have a successful vaginal delivery.

**TIP #11**

**Review medication safety with breastfeeding** (Mahadevan, McConnell, & Chambers, 2017; Mahadevan et al, 2015)

- PIANO registry is a prospective registry of pregnancy outcomes in women with IBD exposed to immunomodulators and biologic therapy.
- Breastfeeding is safe with most IBD medications.
- Breastfeeding is not associated with disease flares.
- Breastfeeding was not associated with infant infection risk or delayed developmental milestone achievement in any of the PIANO registry drug exposure categories.

***LactMed is a free online database with information on medications and lactation.***

**TIP #12**

**Schedule a postpartum visit** (Mahadevan, U, McConnell, & Chambers, 2017; De Lima, Zelinkova, Mulders, & van der Woude, 2016).

- Review patient’s medications and adherence, breast feeding, and any other concerns.
- Check labs with Fe studies, medication levels, and fecal calprotectin as needed.

**TIP #13**

**Review bone health and supplement as needed** (Feagins, & Kane, 2016; Rosenblatt & Kane, 2015; Mahadevan, Friedman, Gawron, & Dubinsky, 2015).

- Corticosteroids and IBD can impact bone health, increasing the risk for osteopenia and osteoporosis. Therefore, be sure to supplement calcium and vitamin D as needed.
- Vitamin D levels should be checked as necessary.
- Bone density scan should be done for IBD patients who have had cumulative exposure to steroids at least 5mg for at least three months or longer.
- If a patient has osteopenia or osteoporosis, refer to a specialist for further evaluation/treatment.

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

2. The Intimate Relationship of Sex and IBD Facts Sheet: [www.crohnscolitisfoundation.org/assets/pdfs/ibdsexuality.pdf](http://www.crohnscolitisfoundation.org/assets/pdfs/ibdsexuality.pdf)
3. Facebook live video on women, pregnancy, and IBD: [youtu.be/03JPBSx5deY](https://youtu.be/03JPBSx5deY)
4. Women and IBD Fact Sheet: [www.crohnscolitisfoundation.org/assets/pdfs/womenfactsheet.pdf](http://www.crohnscolitisfoundation.org/assets/pdfs/womenfactsheet.pdf)
### References:


College Tips and Back-to-School Needs

It can be a daunting task for any young adult to make the transition from living at home with support of family to living at college surrounded primarily by other young people. Chronic diseases such as Crohn's disease and ulcerative colitis add extra complexity to the process of preparing for a successful transition to greater independence. August is also a time of transition for younger patients, as each new school year begins. They enter new grades, new classrooms, and sometimes new schools as they progress through the elementary, middle, and high school systems.

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**College transitions**

**TIP #1**
Help the soon-to-be college student to think ahead and locate the following list of resources in advance:

- **Medical care on campus**
  Make sure the student knows where the health center is on campus. Typically, health center staff persons are available to meet during orientation week. It may be helpful for the student to meet with a member of the health center staff and provide copies of medical records in advance, so that they can be prepared in the event of a flare.

- **Office for Disabilities**
  Encourage the student to schedule a visit with the disabilities office during college visits. This will aid in understanding what accommodations are available and what documentation will be needed from the GI provider.

- **Discuss storage of medications**
  Students who live in a dormitory may need refrigeration facilities to store medications.

- **Find a local GI provider**
  Encourage the student/caregiver to identify a local provider close to campus in case of an emergency situation by asking the campus health center or home GI provider for recommendations.

- **Locate the nearest pharmacy or infusion center**
  Ensure the student knows where the pharmacy closest to their campus is for prescription refills. For students on infused medications they will also need to locate and provide medical records to a local infusion center.

- **Determine where to have lab work drawn**
  Ensure the student knows where to have labs drawn if needed. Sometimes it can be done at student health.

**TIP #2**
Discuss stigma of IBD: Patients living with IBD may experience stigma and this in turn may impact psychological functioning, adherence, and quality of life (Taft, & Keefer, 2016)
TIP #3
Discuss the best plan for the scheduling of routine follow-up appointments for students going away to school.

If the school is far enough away that the distance will prevent the student from returning home for ‘check-ups’ during 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.

During transitions, routines are interrupted, and it is important to use reminders to adhere to the medication schedule.

Additionally, it is practical for the student living far away from home to establish a client-provider relationship with a GI specialist close to the school/university. Some practices may suggest a 2-hour drive as a guiding point. Collaborate with the client before school/university starts and give referrals for GI providers in the vicinity of the school/university.

TIP #4
Have a frank discussion with college students about the added risks of alcohol consumption for individuals with IBD.

Students with IBD need to be particularly careful about their hydration status as they enjoy all that college life has to offer. Alcohol in particular is dehydrating and can be even more dangerous for individuals with IBD when ingested in large quantities. Medication interactions can occur, and the combination of alcohol and some medications increase the likelihood of liver damage.

TIP #5
Inform college students of the Crohn’s & Colitis Foundation’s National Council of College Leaders as a way to help raise awareness about IBD and encourage them to become involved once they are acclimated to college life. Refer them to the website at: www.crohnscolitisfoundation.org/campus-connection/connect-with-others/meet-national-council-of-college-leaders/

TIP #6
Encourage elementary through high school students and/or parents of students to prepare for the new school year by discussing with them the following topics:

- **Locate bathrooms in advance**
  When heading back to school, remind parents and students to identify locations of bathrooms along their route to classes. This will help decrease anxiety associated with finding a bathroom when the need arises.

- **School supplies**
  Advise parents and students to remember to add medications and other IBD supplies that may be needed while at school, such as a change of clothes, to the list of back-to-school preparations.

- **Discuss special accommodations**
  Provide families with notes, letters, and medications for those with special accommodations such as a 504 plan. Most colleges require a 504 be in place during elementary and/or high school in order to make accommodations for college.

Elementary through high-school transitions
• **Discuss stress and school**
  Discuss with the patient and their families how stress impacts IBD. Encourage the student and family to discuss stressful situations that may happen in school in advance and prepare an action plan for the student that will help them cope with incidents such as accidents or feeling ill during the school day.

**TIP #7**

**Review other special considerations for school-aged children**

- Review information in this guide for school teachers and other personnel and refer parents to review information about Crohn’s disease and ulcerative colitis: [www.crohnscolitisfoundation.org/resources/guide-for-teachers.html](http://www.crohnscolitisfoundation.org/resources/guide-for-teachers.html)
- Emphasize to parents the need for collaborating with the child’s teacher and school nurse throughout the semester.

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


2. Campus connection: [www.crohnscolitisfoundation.org/campus-connection](http://www.crohnscolitisfoundation.org/campus-connection)


5. School and IBD: [www.crohnscolitisfoundation.org/resources/taking-ibd-to-school.html](http://www.crohnscolitisfoundation.org/resources/taking-ibd-to-school.html)


[www.crohnscolitisfoundation.org/kids-teens/for-parents.html](http://www.crohnscolitisfoundation.org/kids-teens/for-parents.html)


10. Animated video on preparing to manage IBD on my own: [www.youtube.com/watch?v=uPG3QG6oJRA](http://www.youtube.com/watch?v=uPG3QG6oJRA)

11. Assessment children can take to become aware of important skills they can practice as they become adults: [www.ibdskillquiz.org](http://www.ibdskillquiz.org)

12. Infographic highlighting important skills children can learn: [www.crohnscolitisfoundation.org/assets/pdfs/peds-infographic.pdf](http://www.crohnscolitisfoundation.org/assets/pdfs/peds-infographic.pdf)


**Additional resources:**

1. Patient outreach and education: [www.gikids.org](http://www.gikids.org)

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**Reference:**

Holidays can be stressful for everyone, and it is not uncommon for patients with IBD to experience flares in their symptoms during this time of year.

**TIP #1**

Help your patients to recognize that over-committing themselves can have the potential to worsen their symptoms during the holidays. An individual who picks and chooses the most important commitments during this busy time of year can reduce the number of stressors encountered and thereby reduce the stress load on the body.

The below stress mechanisms have implications for the symptoms of IBD:

- Although glucocorticoids are often used as powerful anti-inflammatory agents, a paradoxical stress-induced potentiation of inflammation is thought to occur in response to the levels of cortisol produced during acute stress. (Mawdsley & Rampton, 2005; McCance, Forshee, & Shelby, 2006) Specifically, cortisol can cause suppression of the systemic immune response while simultaneously increasing localized inflammation by up-regulating the local inflammatory response. (McCance, Forshee, & Shelby, 2006)

- In the nervous system, stress activates the sympathetic autonomic nervous system, and this activation causes the release of adrenaline from the adrenal medulla. Adrenaline has been shown to increase IL-6, a pro-inflammatory cytokine associated with the mucosal immune response. (Søndergaard, Ostrowski, Ullum, et al., 2000) The central sympathetic autonomic nervous response also sends messages directly to the enteric nervous system, a system consisting of 100 million neurons.

- Activation of the enteric nervous system is thought to cause an increase in colonic motility, an increase in water and ion secretion, and an increase in colonic mucus secretion. (Mawdsley, Rampton, 2005)

- Acute psychological stressors (i.e. the holidays) are shown to decrease the thresholds for pain perception, which may also explain the increase in reports of IBD symptomatology around stressful times. (Mawdsley, Rampton, 2005)

- In animal experiments, stress is shown to cause an increase in intestinal mucosal permeability and can alter bacterial-host interactions, allowing for increased uptake of certain bacteria. This leads to sensitization of T-cells and production of IFN-gamma and TNF-alpha, which may initiate inflammation and allow for more permeability. (Mawdsley, Rampton, 2005)

Given the above known consequences of stress and direct brain-gastrointestinal tract connection, it’s no wonder that our patients may experience GI distress during times of stress, such as the holiday season.
**TIP #2**
Share stress-relieving tips with your patients to utilize during this time of year.

The GI Research Foundation, a non-profit supporting IBD healthcare professionals, presents a series of video and audio exercises entitled “Active Practice: Yoga & Meditation in Inflammatory Bowel Disease (IBD).” Studies have shown improvement in quality of life of IBD patients practicing yoga. After eight to 12 weeks of consistent practice, fewer patients reported arthralgia, there were lower reports of intestinal colic pain, as well as the reduction of anxiety levels.

Modalities available for viewing at: [giresearchfoundation.org/resources](http://giresearchfoundation.org/resources)

**TIP #3**
Remind IBD patients that alcohol can cause an increase in diarrhea. Alcohol can also interact with medications.

The *IBD Partners* Questionnaire found that participants overwhelmingly reported that alcohol consumption worsens their symptoms, (Cohen, Lee, Long, et al., 2012) and holiday parties often include alcohol. Thus, November is a logical time of year to remember to disseminate this timely tip and discuss medications and alcohol use.

- Avoid consuming alcohol while on metronidazole as it can cause abdominal pain, nausea, and vomiting.
- Patients on maintenance therapy with methotrexate should exercise caution and limit consumption of alcoholic beverages due to increased risk for hepatotoxicity.

**TIP #4**
Help your patients evaluate food choices.

- Many patients in the IBD Partners cohort reported that in general, yogurt, rice, and bananas improve symptoms. Vegetables, spicy foods, fruits, nuts, fried foods, milk, red meat, carbonated beverages, popcorn, dairy, alcohol, high-fiber foods, corn, fatty foods, seeds, coffee, and beans were more likely to worsen symptoms. (Cohen, Lee, Long, et al., 2012)
- Patients with history of bowel resection or bowel obstruction should avoid eating nuts and seeds as they can cause intestinal obstruction.
- Many individuals with Crohn's disease avoid dietary fiber (Brotherton & Taylor, 2013) as it can lead to increased frequency of bowel movements.
- If your patient avoids dietary fiber, help him or her evaluate if the avoidance is warranted based on individual circumstances and sound assessment. For example, is the patient's diet restricted because of recent surgery, or is there a partial obstruction present? Such reasons justify fiber avoidance.
- If patients need to avoid certain foods or restrict their diet for any reason, make sure their GI provider is routinely checking for vitamin and mineral deficiencies. Common deficiencies include iron, vitamin B12, zinc, folate, vitamins a, e, and d. A daily multivitamin is recommended if patients need to restrict their diet.
Encourage your patients to bring his or her own appetizers or main dishes to holiday parties, so they know there will be a dish that they can tolerate at the event.

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


2. Get involved with a local chapter and attend a Nutrition & IBD Program when presented locally: [www.crohnscolitisfoundation.org/chapters](http://www.crohnscolitisfoundation.org/chapters)


4. Signs & Symptoms of Depression Videos: [www.crohnscolitisfoundation.org/resources/depression.html](http://www.crohnscolitisfoundation.org/resources/depression.html)


6. Emotional Factors: [www.crohnscolitisfoundation.org/assets/pdfs/emotional.pdf](http://www.crohnscolitisfoundation.org/assets/pdfs/emotional.pdf)


8. Community Website: *Diet & Nutrition Discussion Forum*

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**References:**


GI Research Foundation. [www.giresearchfoundation.org/resources/?mc_cid=34f73d21fo&mc_eid=d1238878c2](http://www.giresearchfoundation.org/resources/?mc_cid=34f73d21fo&mc_eid=d1238878c2)
Travel Considerations
Travel can be stressful and requires a lot of planning. Being prepared and feeling in control can help travelers with a chronic and unpredictable disease relax. Use of advanced planning and practical on-the-go strategies will increase the chances that travel will be fun and enjoyable for an individual with IBD. You can share the below tips with your patients.

TIP #1
Start early to assemble all of the information that you may need while traveling

- Input names and phone numbers of all of your physicians in your smart phone and/or other devices in case of an emergency or a flare.
- Before you leave, speak with your doctor about a flare-up plan.
- Before traveling abroad, ask your doctor or contact the International Association for Medical Assistance to Travellers (IAMAT) for names of physicians in the cities you plan to visit. www.iamat.org
- If you are traveling to an area of the world that requires special vaccinations, discuss the risks with your health care provider and obtain medically-related information from IAMAT or the U.S. State Department about international travel and the vaccinations that are required. If you are on immunosuppressant medications, such as immune-modulators or biologics, you should avoid LIVE vaccines.
- International organizations dedicated to Crohn’s and colitis could be a great source of information regarding the resources available in the country you will visit. Contact the Crohn’s & Colitis Foundation’s IBD Help Center for a list of these international organizations.
- A typed statement from your physician, describing your medical history and the drugs you are taking, will be helpful if customs officials question you or if an emergency arises.
- If you use injectable medication, you may want to have a letter from your health care provider that you can carry with you through security.
- Before traveling on trains or buses, find out about the availability of bathrooms onboard.
- Before committing to an airline reservation, check to see if you will be able to reserve a seat on the aisle near the bathroom.
- When mapping a road trip, check trip planning guides such as AAA or others, for rest stops along the way.
- The Transportation Security Administration (TSA) has a webpage specifically for travelers with medical conditions. Check it out before you embark on air travel because you may need to make a verbal or written declaration of any liquid medication or nutrition supplement in excess of 3.4 ounces or 100 ml.
- Download the free *Foundation Air Travel Talking Points Card* and keep in your wallet for you to refer to as you travel.
- Download UOAA’s (United Ostomy Association of America) Travel Communication Card as an aid in dealing with airline security [www.ostomy.org/Ostomy_Travel_Tips.html](http://www.ostomy.org/Ostomy_Travel_Tips.html).
- If traveling to a foreign country, it is a good idea to have critical ostomy information written in the local language. International Ostomy Association may be of help with this translation as well as with locating supplies while visiting abroad.

**TIP #2**

**Prepare for your trip by carefully assembling all of the supplies you will need**

- The diet that works for you at home should dictate your meal plans while travelling, so don’t become a victim of circumstances. Take packable dry foods, like oatmeal and nutrition bars and packets of electrolyte supplements.
- Always travel with your own toilet paper, soothing wipes, ointments, changes of underwear, extra clothes, and any other items you may need in case of accidents.
- Keep hand sanitizer handy in small bottles that can go through airport security.
- If possible, bring enough medication to last throughout your trip. If it is not possible, due to refrigeration or other issues, prepare in advance for obtaining medications while away from home. It may be helpful to contact the manufacturer to see if the medication is sold in the country you will be visiting. The IBD Help Center is a resource for individualized travel suggestions [www.crohnscolitisfoundation.org/living-with-crohns-colitis/talk-to-a-specialist](http://www.crohnscolitisfoundation.org/living-with-crohns-colitis/talk-to-a-specialist)
- It is a good idea to take along a copy of your prescription (including generic names—as the brand names can be different from country to country) just in case you need additional supplies.
- If traveling to remote areas, consider asking your healthcare provider for an “emergency” prescription of steroids or antibiotics to fill and take with you just in case you flare and do not have access to healthcare.
- Always pack your medications and ostomy supplies in your carry-on to with you on the airplane.
- If you have an ostomy, pre-cut all pouches at home, as you may wish to avoid having scissors in your carry-on luggage. Pack ostomy supplies in at least two places—carry on and checked luggage. Take extra supplies in case you are stranded where supplies may not be available.
- Keep your medications in original containers—use pillboxes to carry small amounts needed during the course of a day—obtain the appropriate storage container for medications that must remain cool while traveling. Manufacturers may be able to provide free travel packs for keeping medications cool, but check to see how long the travel packs remain effective at cooling.
- Take along anti-diarrheal medications to help lessen diarrhea if needed.
- Take bottled water with you if it will be your only source of safe drinking water while away.
- Do not forget your sunscreen and lip balm—certain medications such as sulfasalazine may cause photosensitivity so sunscreen is even more important for these patients.

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**TIP #3**

While you are away, take steps to ensure ease of travel, comfort, health, and safety

- If you have an ostomy, alert security personnel at checkpoints at airports. They are trained to anticipate and respond to medical needs while they are screening travelers. Ostomy supplies are permitted through security checkpoints.
- Hydrate, hydrate, hydrate. Traveling can often dehydrate you if you do not drink adequately. When the weather is hot, hydration is especially important—aim for at least 8 full glasses of water a day.
- Drink water that has been boiled or bottled water to avoid contaminated water.
- Do not take risks with street vendor foods—locate supermarkets where you can buy fresh meals.
- Avoid or limit your use of fast food restaurants to known safe options.
- Be especially diligent in reapplying sunscreen throughout the day.
- Preventing mosquito bites is just as important as taking medications. You can help protect yourself by wearing light colored clothing to cover arms and legs, and by using an effective insect repellent.
- Sunscreen may not be as effective if applied after insect repellent so when you need to wear both, it is always a good idea to apply sunscreen first.
- Blood clots can be a risk for anyone sitting still on a long journey. You can reduce this risk by: rotating your ankles and flexing your calf muscles regularly; walking at regular intervals around the cabin or during stops on bus or car travel; wearing travel compression socks and loose fitting, comfortable clothing; avoiding smoking; and drinking plenty of fluid, avoiding alcohol or caffeine drinks before and during the journey.

**TIP #5**

Be mindful of food safety

- Always be watchful and pay attention to what you eat.
- Be extra careful with drinking water, and always use bottled water (even for brushing teeth) and be careful to not to drink it by accident when you are taking a bath or shower.
- Remember to ask for drinks without ice, unless the ice is prepared using bottled water.

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

1. CAir Travel 101-TSA FAQ webpage: [www.crohnscolitisfoundation.org/resources/TSA-air-travel-101.html](http://www.crohnscolitisfoundation.org/resources/TSA-air-travel-101.html)
2. Traveling with IBD webpage: [www.crohnscolitisfoundation.org/resources/traveling-with-ibd.html](http://www.crohnscolitisfoundation.org/resources/traveling-with-ibd.html)
3. Travel tips for Summer Vacation webpage: [www.crohnscolitisfoundation.org/resources/on-the-road-again.html](http://www.crohnscolitisfoundation.org/resources/on-the-road-again.html)

**Additional Resources:**

1. International Association for Medication Assistance to Travelers (IAMAT): [www.iamat.org](http://www.iamat.org)
2. International Ostomy Association (can provide information on where to purchase ostomy supplies outside the US) [www.ostomyinternational.org](http://www.ostomyinternational.org)
3. United States Department of State: [www.state.gov/travel](http://www.state.gov/travel)
4. United Ostomy Associations of America, Inc. [www.ostomy.org/Home.html](http://www.ostomy.org/Home.html)
5. Travel Communication Card. [www.ostomy.org/Ostomy_Travel_Tips.html](http://www.ostomy.org/Ostomy_Travel_Tips.html)
6. TSA Cares: Toll Free 1-855-787-2227 Monday through Friday, 8am–11pm, Eastern time Weekends and Holidays, 9am–8pm, Eastern time
Camp Oasis

*CAMP OASIS* is a wonderful summer camp program for children and teens with inflammatory bowel diseases, and January is the month to make 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 in mid-January.

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).

“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!

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, MNS
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.justlikemeibd.org
3. Campus Connection website: www.crohnscolitisfoundation.org/campusconnection

Reference:

Uniting to Care & Cure

About the Crohn's & Colitis Foundation
Established in 1967, the Crohn's & Colitis Foundation is a non-profit, volunteer-driven organization dedicated to finding the 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, the Foundation has remained at the forefront of research in Crohn’s disease and ulcerative colitis. Today, we fund cutting-edge studies at major medical institutions, nurture investigators at the early stages of their careers, and finance underdeveloped areas of research.

Beyond research, the Foundation is collaborating with healthcare providers to improve IBD quality of care, as well as educating, supporting, and empowering patients and their caregivers through patient-centric education and advocacy programs.

Questions?
Contact the IBD Help Center
Monday–Friday, 9:00AM–5:00PM 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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