

Guide to living with

Health**monitor**®

# IBD

INFLAMMATORY BOWEL DISEASE

**MAKE  
EVERY DAY  
AMAZING!**

- Forge a solid relationship with your care team
- Track your symptoms
- Find the right treatment for you
- Get inspired by other IBD thrivers

**20+ TIPS**  
to feel  
great!

**"I took my life  
back from IBD!"**

With the right treatment, **Josh Hall** is back to being there for his family—and spending quality time with wife Alaina

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# Guide to living with IBD

INFLAMMATORY BOWEL DISEASE



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RAM20



# Embrace your days with confidence!

Today, treatment advances for inflammatory bowel disease (IBD) can help you take back control and make the most of your days!



These days, Melodie Narain-Blackwell has energy to spare for her family and business endeavors. Kind of unbelievable, considering the Washington, DC, entrepreneur is not only 20 weeks pregnant but also in the middle of a video project documenting the effect of IBD on her pregnancy—*plus*, she's in the midst of starting a non-profit for minorities who suffer with IBD and chronic illness. All that, of course, in addition to taking care of her family—namely, six-year-old son Zaden and husband Ronald. You think Melodie's slowing down? Not a chance! And the reason for that is the medication that's put her Crohn's in remission and given her the freedom and energy to do the things she loves most—taking care of business *and* her family!

## "Crohn's once brought me to my knees!"

For two years, Melodie experienced bloody diarrhea, pain on elimination ("like razors in my colon") and stomachache, along with baffling joint pain, before a golf ball-size abscess at the end of her colon burst. Diagnosis: perianal Crohn's disease, characterized by inflammation at or near the anus, including tags, fissures, fistulae, abscesses or stenosis. Melodie had two procedures to repair her colon and started on oral medication for her IBD.

But the foot and leg pain that had been chalked up to gout, rheumatoid arthritis or "something

autoimmune"? Melodie would soon learn that was related to her Crohn's, too. And it quite literally brought her to her knees one night, when the pain forced her to *crawl* up the stairs to her home. (In fact, joint inflammation, marked by pain and swelling, is the most common extraintestinal complication of IBD. It occurs when inflammation affects areas outside of the GI tract. This type of arthritis affects as many as 30% of people with Crohn's disease or ulcerative colitis, according to the Crohn's & Colitis Foundation.)

Coupled with a 30-pound weight loss (food went "out" as quickly as it went "in"), severe fatigue, hair loss and yellowing skin, Melodie truly hit her rock bottom. That's when she knew it was time to try a new IBD medication—a biologic—that her gastroenterologist prescribed.

## "It's been working!"

Since becoming pregnant, Melodie has been feeling great, in large part thanks to the care of her robust medical team—"my obstetrician, colon surgeon, gastro and perinatologist [a doctor who monitors high-risk pregnancies]." Always a positive thinker, she's never stopped smiling. Although there is one thing she prayed for, she says: "When I couldn't walk [because IBD-related arthritis made it painful just to stand], I prayed to be able to dance again." These days, she does dance—and her Instagram followers check it out for themselves—a short clip on the photo-sharing site shows Melodie and Ronald moving to a slow groove, loving every minute.



## What is IBD?

IBD is an umbrella term for conditions that affect the gastrointestinal (GI) tract, which increase your risk for colorectal cancer. The two main types are Crohn's disease and ulcerative colitis (UC). Both are marked by chronic inflammation that can damage part of the GI tract. They can also share common symptoms such as:

- Persistent diarrhea
- Rectal bleeding/bloody stools
- Loss of appetite/unintentional weight loss
- Urgent need to move the bowels, or feeling of incomplete bowel movement
- Abdominal pain and cramping
- Loss of energy
- Low-grade fever

In addition, Crohn's disease and UC can trigger inflammation-related symptoms outside the GI tract (called extra-intestinal symptoms), such as joint pain and swelling, eye problems and skin sores.

However, there are a few key differences between these diseases. One of them is *where* they occur (see diagrams, *next page*): Crohn's disease can affect any part of the GI tract from the mouth to the anus, while UC affects the colon (also called the large intestine). In addition, the inflammation associated with UC is generally confined to the innermost lining of the colon. But with Crohn's, inflammation may reach through multiple layers in the walls of the GI tract and potentially affect other nearby organs. Regardless of their differences, both are lifelong diseases

## Take charge today!

Because IBD is the type of disease that progresses differently in different people, there's no single treatment plan that works for everyone. In addition, IBD can change over time, affecting your body in new ways. To avoid complications that may occur when inflammation is severe and chronic, stay current with your appointments and blood tests. And keep in mind that no matter what treatment you're receiving now, your regimen may have to be adjusted later to keep your symptoms controlled. So, speak up if you're not feeling your best, and ask to discuss your treatment options. (Learn more about them on p. 10.)

Finally, don't be afraid to aim high. With the latest treatment advances, the goal of IBD treatment is to put the disease into remission, which means you're relatively free of symptoms. Partner with your care team so that you, too, can enjoy the life you love—despite IBD.



with symptoms that can come and go—and flare for no reason.

### What factors come into play?

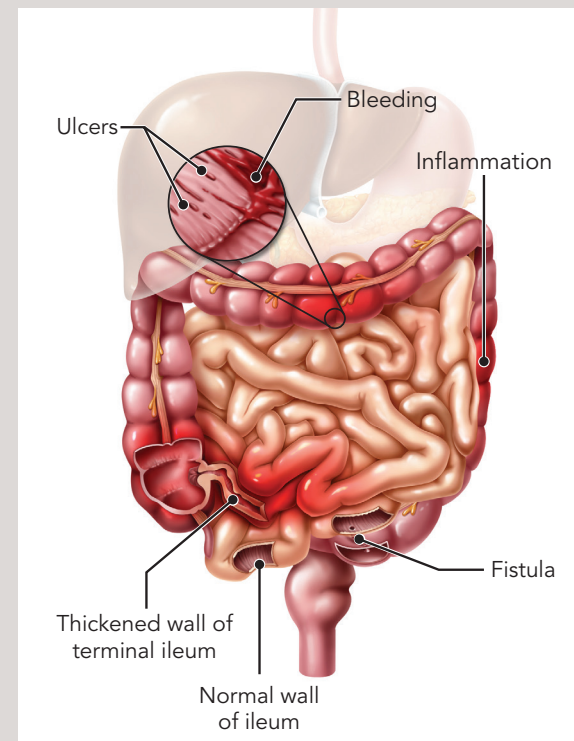
While the exact cause of IBD is unknown, it seems to develop as a result of genetics, environmental factors (e.g., smoking) and immune system abnormalities. You are also more likely to develop IBD if a close family member has it.

One theory is that IBD occurs when the immune system overreacts to or misrecognizes harmless bacteria that aid digestion, flooding the body with white blood cells to fight infection. Some of these cells stay in the intestine, ultimately leading to chronic inflammation there. The cells may travel to other parts of the body, too, which explains why some people with IBD develop

symptoms outside the GI tract.

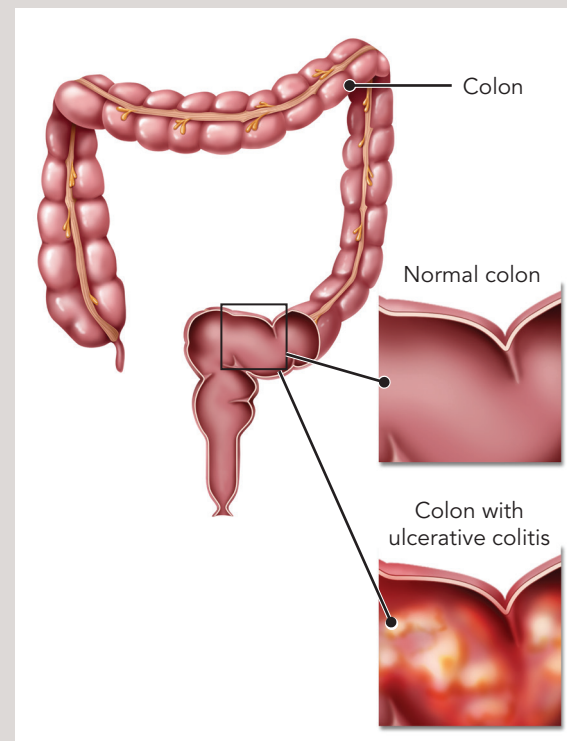
In addition, it's important to understand what IBD is *not*: It is not the same as irritable bowel syndrome (IBS), which does not cause inflammation. And IBD is *not* caused solely by diet or stress, although these can aggravate your symptoms. IBS is much more common than IBD, and the two can coexist in the same patient.

## The two forms of inflammatory bowel disease



### In Crohn's disease...

- Inflammation occurs anywhere in the GI tract (from the mouth to the anus), although it often strikes the small intestine and beginning of the colon
- May cause thickening of the intestine and scarring
- Damage is "patchy," with normal areas between patches of diseased intestine
- Inflammation may reach through multiple layers of the GI tract walls and out to other organs (fistula)



### In ulcerative colitis...

- Inflammation occurs in the colon (large intestine) and rectum
- Causes tiny open sores (ulcers) that produce pus, mucus and blood, which may appear in the stool
- Damaged area is continuous, usually starting at the rectum and spreading higher into the colon
- Inflammation affects only the innermost lining of the colon

### What you can do

While IBD cannot be cured, it *can* be effectively managed, and this three-step approach is the best way to take control:

#### 1. Work closely with your doctor.

Getting help for IBD starts with telling your healthcare provider about your symptoms and the problems you're having. For example: How many times a day do you use the bathroom? Is the urge so strong you sometimes don't make it? The answers to such questions can help your doctor find your best treatment. *Tip:* To get the conversation started, fill out the worksheet on p. 16 and discuss it at your exam.

#### 2. Follow your treatment plan.

Together, you and your healthcare provider will decide on a course of action. But, if you're having trouble taking your medication or cannot tolerate it, alert your care team. (Learn more about your treatment options on p. 10.)

#### 3. Monitor your progress.

Stay in close contact with your healthcare provider, and between visits track your symptoms; if they're getting worse, or if new ones appear, tell your care team right away. Because IBD can change over time, your treatment may no longer work as well as when you started it. Discussing different options with your doctor will help you find the therapy that's best for you.

Whether you have Crohn's disease or UC, one thing's for sure: Not addressing your symptoms may lead to serious, long-term consequences. Start taking charge right now by reading this guide to learn more about what you can do. And get inspired by people like Josh (p. 8), Marya, Jason and Melodie (p. 18), who refused to let IBD take away their freedom. Like them, you, too, can find relief and live the active life you want! 🍌



## Your IBD care team

These medical professionals can help you manage IBD:

- **Gastroenterologist:** This MD specializes in treating digestive disorders of the gastrointestinal tract.
- **Primary care physician (PCP):** MD who checks your overall health and coordinates care with your gastroenterologist.
- **Gastrointestinal (GI) surgeon:** This MD specializes in surgery of the digestive system.
- **Physician assistant (PA)/nurse practitioner (NP):** This healthcare professional has received specialized training and is licensed to provide routine care, including writing prescriptions.
- **Infusion nurse:** A registered nurse who specializes in administering medication through an intravenous (IV) line.
- **Registered dietitian (RD):** This nutrition professional can counsel you on dietary changes to help ease your symptoms and ways to avoid nutrient/vitamin deficiencies.



# “I got the scoop on my IBD—and now *I’m in remission!*”

Now that Josh Hall has taken control of his ulcerative colitis, this journalist has time to spare—for his job *and* his family! —BY KATHLEEN ENGEL

For reporter Josh Hall, being able to mobilize at a moment’s notice is critical for covering the news in Red Deer, Alberta, CA. It’s also key for doing the “Dad” things he loves—like taking five-year-old daughter Brynley sledding, teaching her how to ice skate and volunteering at her kindergarten class.

And since Josh got treatment that put his ulcerative colitis (UC) in remission four-and-a-half years ago, he’s been packing in as many fun times as he can with Brynley and his wife, Alaina. Before that, though, Josh’s UC made “family fun” next to impossible.

## “It started with cramps”

In 2007, Josh went to a walk-in clinic to investigate stomach cramps he thought might be the flu. The cramps never went away, and the following year, Josh learned the reason: UC. It was the beginning of a roller coaster ride made worse because Josh moved so much—in each new hometown, he’d see a new gastroenterologist and try a new medication. But, in 2015, things grew more serious.

“I remember it like it was yesterday,” he says. “I was driving

to work around lunchtime when I had an accident in the car. I was shocked! It was awful and embarrassing.” Josh drove home, cleaned up, changed and went back to work. “But driving home that night, I had another accident. And from the next day on, I did not want to go out any more than I had to—I had such high anxiety about driving or going out anywhere.

“For the whole year I was having a flare, I wasn’t able to fully function,” he recalls. “I had diarrhea and just an unpredictable bowel. I’m a journalist. If there’s a house fire, for example—you’ve got to go to the scene, talk to the fire chief, take pictures. *Where’s the nearest bathroom?* There were times there was breaking news and I had to ask a coworker to go out to the scene.”

His daily routine was upended, too. “The first thing I’d do in the morning is get in the bathroom and spend about three hours in there. I’d ‘get it done’ so, hopefully, I wouldn’t have to worry about it for the rest of the day. I didn’t get to work on time for an entire summer! And I couldn’t eat either! I was so afraid I’d have to go to the bathroom, I basically starved myself. Over a span of six weeks, I went from 150

to 125 [pounds]. I didn’t have the energy to do anything!”

## “A new medication made all the difference”

Finally, Josh’s new gastro in Red Deer prescribed a biologic drug. “After about three to four infusions, it started to work,” he says. Within a few months, “I saw it was having an effect [on my UC], and I was less anxious!” The following year, with his confidence up and having regained his strength and some of the weight he’d lost, Josh added a dietitian to his healthcare team. Plus, he’d made a decision: “I wanted to do a spartan race [an obstacle course race]. The dietitian knew all about my GI issues and advised me on the best things to eat while training and had me drinking lots of water. At one point, [because of my UC], my iron levels were really low, so she had me eating iron-rich foods.”

Eventually, the new regimen paid off: “No more anxiety, no more accidents. I was healthier in general! And, now, I try to make the most out of life and savor every minute I’m feeling good. For me, that comes down to spending time with my family.” 📧

*“I savor every minute with my family!”*

## “Own your IBD”

Here, Josh shares his tips for managing his UC.

**1. Be determined.** “You can’t let your IBD own you. You have to own it,” he says. His mindset through the years has always been: “I’m going to do everything I can to feel better and make the symptoms go away.” To that end, he was always willing to try a new treatment. “I was happy to hear they wanted me to try something new—it meant I might find some additional relief!”

**2. Be 100% honest with your medical team.** “In the beginning, I was reluctant to talk about personal things, like having accidents. That stuff is humiliating and very personal. But my gastro makes it so it’s not uncomfortable. If you leave something out [of what you tell them], they can’t take it into account. You’re only doing yourself a disservice.”

**3. Advocate for yourself.** Josh believes in being a proactive patient. “If you’ve learned about other treatment options, go to your doctor and ask, ‘What about this?’ or ‘Can we try this?’”





# Find the best treatment for *you*

Partnering with your doctor is the first step toward taking charge!



**Don't settle for good enough!**

Following your treatment plan and still not feeling 100%? Ask your doctor what medication is most likely to lead to clinical remission, and get rid of your IBD symptoms altogether!

and there are no signs of active disease. That's especially important because uncontrolled intestinal inflammation can not only trigger symptoms but also lead to serious complications such as severe ulcers and bowel blockage. What's more, it can increase the risk of developing cancer or pre-cancerous lesions in the long term.

Above all, remember this: You are the most important member on the team. By providing your doctor with vital information—i.e., describing your symptoms and how they affect daily activities, and sharing any concerns about your treatment—you can stay one step ahead of IBD.

**Will I need medication?**

That depends, which is why you should never miss an exam or be shy about telling your doctor anything. Knowing how you're feeling and how IBD affects your daily life will help your doctor determine which therapy to try. Also, never skip a blood test, as your doctor uses the results to assess how well your treatment is working and to check for any side effects.

And if something you've tried hasn't helped, resist throwing your hands up and thinking, *I'll just live with this*. IBD is different for everyone, and there's no one-size-fits-all solution. Because the disease can change over time, you may need to switch treatments to find the one that works best for you.

**What about surgery?**

Most patients with IBD can be managed with medical therapy; however, surgery is also an option in emergency situations and when medical therapy has failed. For Crohn's, one type of surgery is resection, where a portion of the diseased intestine is removed and the normal ends are reattached.

This type of surgery may require a temporary ostomy where a stoma, or opening, is created on the abdomen and an appliance and bag are worn over it to collect output. Another surgery option for Crohn's is strictureplasty, in which intestine that has narrowed due to scar tissue buildup is widened. There are also surgical solutions available

to address fistulas (abnormal connections between organs caused by severe, uncontrolled inflammation), and drains can be placed by radiologists for abscesses (infected cavities filled with pus found near the anus or rectum).

A surgery option for those with UC is a proctocolectomy (removal of the entire colon and rectum) along with the creation of an internal pouch to collect stool; the most commonly used pouch is the J-pouch.

Last, surgery may be a consideration if pre-cancerous lesions or colon cancer develops over the course of the disease.

**WHICH MEDICATION?** Medication can help keep your symptoms and inflammation under control. It may even help you avoid surgery or improve the outcome if an operation becomes necessary. Talk about all the symptoms you're having to help your doctor determine the right treatment plan for you!

MEDICATIONS	HOW THEY WORK
Anti-inflammatories (aminosalicylates)	Heal the inflammation that causes symptoms
Corticosteroids	Lower inflammation and suppress the immune system; generally recommended for short-term use
Immune system suppressors	Lessen the body's immune response, reducing inflammation and helping to prevent symptom flares
Biologics	The newest therapies, biologics help control inflammation and relieve symptoms by blocking specific immune system signals
Antibiotics	Help prevent or control infection (used if you have a fever, a sign of infection)
Anti-diarrheal agents	Reduce diarrhea
Anti-spasmodics	Ease your abdominal pain and discomfort

**The importance of lifestyle choices**

First and foremost: If you use tobacco, quit! Research shows that smoking can trigger more frequent and more severe symptoms. Also, although there's no proven diet to treat IBD, certain foods or drinks could be triggers for you. Keeping a symptom diary can help you pinpoint possible culprits (see p. 17). And avoid taking over-the-counter NSAIDs (nonsteroidal anti-inflammatory agents) like ibuprofen, as these can trigger symptoms.

Finally, stay on top of your overall health: Get good sleep, find ways to relieve stress and keep active. Also, because having IBD increases your risk of colorectal cancer, you will need more frequent colonoscopy screenings. 📄

**H**ere's the good news: Your dreams of freedom—from painful symptoms, unpredictable bowel habits and being held back by inflammatory bowel disease (IBD)—are within reach. Even though there is no cure for diseases like ulcerative colitis (UC) and Crohn's, treatment advances can help you feel as if you don't have it. The key to unlocking that potential? Working closely with your doctor toward a common treatment goal: remission.

**Tell me about remission—and how I get there!**

When you're in remission, it means the disease is no longer active—and

not causing damaging inflammation to your gastrointestinal tract. In general, signs of remission include:

- You experience no more, or very few, symptoms such as diarrhea, abdominal pain and fatigue.
- Blood tests show no signs of inflammation.
- Lesions in your bowel start to heal.
- You feel normal and enjoy better quality of life.

Achieving remission often takes perseverance—things like keeping all your medical appointments, taking medication as directed, and being willing to try other therapies until your symptoms are well controlled





With moderate to severe ulcerative colitis or Crohn's disease when current treatment isn't working well enough.

## WHEN YOUR HEAD SAYS ONE THING BUT YOUR GUT SAYS "NOT TODAY"

Ask your doctor about GI-focused ENTYVIO.

- Acts specifically in the gastrointestinal (GI) tract to help control damaging inflammation.
- The only biologic approved just for ulcerative colitis and Crohn's.

ENTYVIO is clinically proven to provide long-term relief and remission.

Individual results may vary



### Uses of ENTYVIO® (vedolizumab):

ENTYVIO is a prescription medicine used in adults:

- **with moderate to severe ulcerative colitis (UC) when certain other UC medicines have not worked well enough or cannot be tolerated. ENTYVIO may help to:** begin reducing some symptoms, induce and maintain remission, reduce or stop the use of corticosteroids, and improve the way the lining of your large intestine looks to your healthcare provider.
- **with moderate to severe Crohn's disease (CD) when certain other CD medicines have not worked well enough or cannot be tolerated. ENTYVIO may help to:** begin reducing some symptoms, achieve remission, and reduce or stop the use of corticosteroids.

### Important Safety Information about ENTYVIO®

- Do not receive ENTYVIO if you have had an allergic reaction to ENTYVIO or any of its ingredients.
- ENTYVIO may cause serious side effects, including:
  - Infusion and serious allergic reactions can happen while you are receiving ENTYVIO or several hours after treatment. You may need treatment if you

have an allergic reaction. Tell your healthcare provider or get immediate medical help if you get any of these symptoms during or after an infusion of ENTYVIO: rash, itching, swelling of your lips, tongue, throat or face, shortness of breath or trouble breathing, wheezing, dizziness, feeling hot, or palpitations (feel like your heart is racing).

- ENTYVIO may increase your risk of getting a serious infection. Before receiving and during treatment with ENTYVIO, tell your healthcare provider if you think you have an infection or symptoms of an infection, such as fever, chills, muscle aches, cough, shortness of breath, runny nose, sore throat, red or painful skin or sores on your body, tiredness, or pain during urination.
- It may be possible for a person to get progressive multifocal leukoencephalopathy (PML) (a rare, serious brain infection caused by a virus). People with weakened immune systems can get PML, which can result in death or severe disability. There is no known treatment, prevention, or cure for PML. Tell your healthcare provider right away if you have any of the following symptoms:

confusion or problems thinking, loss of balance, change in the way you walk or talk, decreased strength or weakness on one side of the body, blurred vision, or loss of vision.

- Liver problems can happen in people who receive ENTYVIO. Tell your healthcare provider right away if you have any of the following symptoms: tiredness, loss of appetite, pain on the right side of your abdomen, dark urine, or yellowing of the skin and eyes (jaundice).
- The most common side effects of ENTYVIO include common cold, headache, joint pain, nausea, fever, infections of the nose and throat, tiredness, cough, bronchitis, flu, back pain, rash, itching, sinus infection, throat pain, and pain in extremities. These are not all the possible side effects of ENTYVIO. Call your healthcare provider for medical advice about side effects.
- Before receiving ENTYVIO, tell your healthcare provider about all of your medical conditions, including if you: have or think you may have an infection or have infections that keep coming back; have liver problems; have tuberculosis (TB) or have been in close contact with someone with TB; have

recently received or are scheduled to receive a vaccine; or if you are pregnant, breastfeeding, plan to become pregnant, or plan to breastfeed.

**Please see the Important Facts for ENTYVIO on the adjacent page and talk with your healthcare provider.**

You are encouraged to report negative side effects of prescription drugs to the FDA.

Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch) or call 1-800-FDA-1088.

  
vedolizumab



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## IMPORTANT FACTS

ENTYVIO (en ti' vee oh)  
(vedolizumab)

for injection, for intravenous use

### What is the most important information I should know about ENTYVIO?

#### ENTYVIO may cause serious side effects, including:

- **Infusion and serious allergic reactions.** These reactions can happen while you are receiving ENTYVIO or several hours after treatment. You may need treatment if you have an allergic reaction. Tell your healthcare provider or get medical help right away if you get any of these symptoms during or after an infusion of ENTYVIO: rash, itching, swelling of your lips, tongue throat or face, shortness of breath or trouble breathing, wheezing, dizziness, feeling hot, or palpitations (feel like your heart is racing).
- **Infections.** ENTYVIO may increase your risk of getting a serious infection. Before receiving ENTYVIO and during treatment with ENTYVIO, tell your healthcare provider if you think you have an infection or have symptoms of an infection such as fever, chills, muscle aches, cough, shortness of breath, runny nose, sore throat, red or painful skin or sores on your body, tiredness, or pain during urination.
- **Progressive Multifocal Leukoencephalopathy (PML).** Although it has not been reported with ENTYVIO, it may be possible for a person to get progressive multifocal leukoencephalopathy (PML) (a rare, serious brain infection caused by a virus). People with weakened immune systems can get PML. PML can result in death or severe disability. There is no known treatment, prevention, or cure for PML. Tell your healthcare provider right away if you have any of the following symptoms: confusion or problems thinking, loss of balance, change in the way you walk or talk, decreased strength or weakness on one side of the body, blurred vision, or loss of vision.
- **Liver Problems.** Liver problems can happen in people who receive ENTYVIO. Tell your healthcare provider right away if you have any of the following symptoms: tiredness, loss of appetite, pain on the right side of your stomach (abdomen), dark urine, or yellowing of the skin and eyes (jaundice).

See “What are the possible side effects of ENTYVIO?” for more information about side effects.

### What is ENTYVIO?

ENTYVIO is a prescription medicine used in adults:

- **with moderate to severe active ulcerative colitis (UC) when certain other UC medicines have not worked well enough or cannot be tolerated:**
  - to begin helping some of your symptoms
  - in people who respond to ENTYVIO, to help get UC under control (induce remission) and keep UC under control (maintain remission)
  - for people who respond to ENTYVIO, you may be able to reduce or stop the use of corticosteroid medicines
  - to improve the way the lining of your large intestine looks to your healthcare provider during colonoscopy
- **with moderate to severe active Crohn's disease when certain other Crohn's disease medicines have not worked well enough or cannot be tolerated:**
  - to begin helping some of your symptoms
  - in people who respond to ENTYVIO, to help get Crohn's disease under control (achieve remission)
  - for people who respond to ENTYVIO, you may be able to reduce or stop the use of corticosteroid medicines

It is not known if ENTYVIO is safe and effective in children under 18 years of age.

### Who should not receive ENTYVIO?

**Do not receive ENTYVIO if you** have had an allergic reaction to ENTYVIO or any of the ingredients in ENTYVIO.

### Before receiving ENTYVIO, tell your healthcare provider about all of your medical conditions, including if you:

- have an infection, think you may have an infection or have infections that keep coming back (see “What is the most important information I should know about ENTYVIO?”).
- have liver problems
- have tuberculosis (TB) or have been in close contact with someone with TB.
- have recently received or are scheduled to receive a vaccine. Talk to your healthcare provider about bringing your vaccines up-to-date before starting treatment with ENTYVIO.
- are pregnant or plan to become pregnant. It is not known if ENTYVIO will harm your unborn baby. Tell your healthcare provider right away if you become pregnant while receiving ENTYVIO.
  - **Pregnancy Registry:** There is a pregnancy registry for women who use ENTYVIO during pregnancy. The purpose of this registry is to collect information about the health of you and your baby. Talk with your healthcare provider about how you can take part in this registry or you may contact the registry at 1-877-311-8972 to enroll.
- are breastfeeding or plan to breastfeed. ENTYVIO can pass into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take ENTYVIO.

**Tell your healthcare provider about all the medicines you take,** including prescription and over-the-counter medicines, vitamins and herbal supplements. Especially tell your healthcare provider if you take or have recently taken Tysabri (natalizumab), a Tumor Necrosis Factor (TNF) blocker medicine, a medicine that weakens your immune system (immunosuppressant), or corticosteroid medicine.

### How will I receive ENTYVIO?

- ENTYVIO is given through a needle placed in a vein (intravenous infusion) in your arm.
- ENTYVIO is given to you over a period of about 30 minutes.
- Your healthcare provider will monitor you during and after the ENTYVIO infusion for side effects to see if you have a reaction to the treatment.

### What are the possible side effects of ENTYVIO?

**ENTYVIO may cause serious side effects, see “What is the most important information I should know about ENTYVIO?”**

**The most common side effects of ENTYVIO include:** common cold, headache, joint pain, nausea, fever, infections of the nose and throat, tiredness, cough, bronchitis, flu, back pain, rash, itching, sinus infection, throat pain, and pain in extremities.

These are not all of the possible side effects of ENTYVIO.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

### General information about ENTYVIO

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. You can ask your pharmacist or healthcare provider for information about ENTYVIO that is written for health professionals. Do not use ENTYVIO for a condition for which it was not prescribed.

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Deerfield, IL 60015

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For more information, go to [www.ENTYVIO.com](http://www.ENTYVIO.com) or call 1-877-825-3327  
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## Answers to your most pressing questions about inflammatory bowel disease (IBD)



*options? Should I give up hope for getting relief from my symptoms?*

**A** Definitely not! “Refractory” is a term we use to indicate that the therapies that have been tried so far have not produced optimal results. Depending on whether you have ulcerative colitis or Crohn's disease, there are multiple medical treatment options available. Generally, when medical therapies are not working, another option is surgery. Talk to your gastroenterologist about your treatment options, or consult with an expert at an IBD center, such as Crohn's & Colitis Foundation ([crohnscolitisfoundation.org](http://crohnscolitisfoundation.org)).

### IS PREGNANCY POSSIBLE?

**Q** *I was diagnosed with Crohn's last year at age 20. Someday, I'd like to start a family. Will that be possible? Is it safe for me to get pregnant while I'm on medication?*

**A** It is certainly possible to have Crohn's disease and have a family! While certain surgeries (such as ileal pouch-anal anastomosis, also referred to as J-pouch surgery) can affect fertility, most IBD medications are safe to take during pregnancy. It is best to conceive when your disease is in remission and you will need to closely follow up with your physician team during pregnancy. Advance planning and compliance with treatment will ensure the best possible outcomes for you during your pregnancy and for your new baby.

### GIVING UP ON RELIEF?

**Q** *My doctor told me I had “refractory IBD.” Now, I'm worried! Does this mean I'm out of*

as ibuprofen), as these can affect disease activity. Commonly recommended supplements for patients with IBD include calcium, iron, folate, B12, vitamin D and zinc. Consult with your GI physician before starting any of these.

### ANXIETY-IBD CONNECTION

**Q** *My anxiety is through the roof. My mom says it's only going to cause my IBD to get worse, but it's because of my IBD that I have anxiety! Does it make sense to get treated for the anxiety—and could that interfere with my IBD treatment?*

**A** Anxiety in patients with a chronic illness is totally understandable. There is a relationship between stress and IBD, where one can make the other worse. To break this cycle, try meditation, yoga or regular exercise, and consider joining a support group (in person or online). If these are not enough to lessen your anxiety, medications are available that can help. These do not generally interfere with IBD treatment, and your gastroenterologist can help guide you. 🧠

### OUR EXPERT:

**Selvi Thirumurthi, MD, MS, FASGE, FACG**, is an Associate Professor of Gastroenterology, Hepatology & Nutrition at The University of Texas MD Anderson Cancer Center, Houston, TX.



# How are you feeling?

Help your care team understand how your Crohn’s disease and/or ulcerative colitis affects you. Fill out this worksheet and review it with them.



1. In the past month, I’ve experienced:

	Constantly	Often	Sometimes	Never
Diarrhea or loose stools	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cramps/ abdominal pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fever	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rectal bleeding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fatigue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Urgent need to use the bathroom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Inability to get to the bathroom in time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Loss of appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Weight loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mouth sores	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skin problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Joint pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Eye irritation or vision problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain around the anus or genital area	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Distress/ embarrassment about gas or diarrhea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fear/anxiety about my future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. In the past month, IBD has caused me to:

	Constantly	Often	Sometimes	Never
Lose sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skip meals/ avoid eating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Miss work/school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Avoid exercise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Avoid activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Wear adult diapers or pads	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Carry “emergency” clothes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. IBD negatively affects my:

	Yes	No	Somewhat
Energy levels	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stress levels	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Activity level	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Work life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sex life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall quality of life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. I have noticed the following seem to trigger a flare:

- ☐ Certain foods/beverages (list:)
- ☐ Stress (circle: work, family, financial, relationship)
- ☐ Other (list:)

5. Check the box:

	Yes	No	Somewhat
I smoke.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I eat a high-fat diet.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I eat a lot of processed foods.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a lot of stress.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am anemic.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have bone loss (osteopenia or osteoporosis).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am underweight or malnourished.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have arthritis (joint pain).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel dehydrated.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I always check for the nearest bathroom.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I buy over-the-counter antidiarrheal medicine.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. Medications I take or have recently taken:

- ☐ Nonsteroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen or naproxen sodium
- ☐ Antibiotics    ☐ Oral contraceptives
- ☐ Other (List:)

# Track your meals and symptoms

Make copies of this worksheet, fill it in for at least two weeks, and take it to your next appointment. It can help you and your care team assess your treatment and also spot connections between what you eat and the symptoms you experience.



Date \_\_\_\_\_

Meal	Food(s)	Amount	Symptoms*/time
Breakfast			
Morning snack			
Lunch			
Afternoon snack			
Dinner			
Nighttime snack			

\*Symptoms may include: diarrhea, bloody diarrhea, loose stools, cramps/abdominal pain, gas, bloating

Sample:

Meal	Food(s)	Amount	Symptoms*/time
Breakfast	• shredded wheat cereal • 2% milk • fresh blueberries • orange juice • coffee	1 cup ¾ cup ½ cup 4 oz. 1 cup	loose stools, cramps, gas 1 hour after meal



# “Our smart strategies put IBD in the background of our lives”

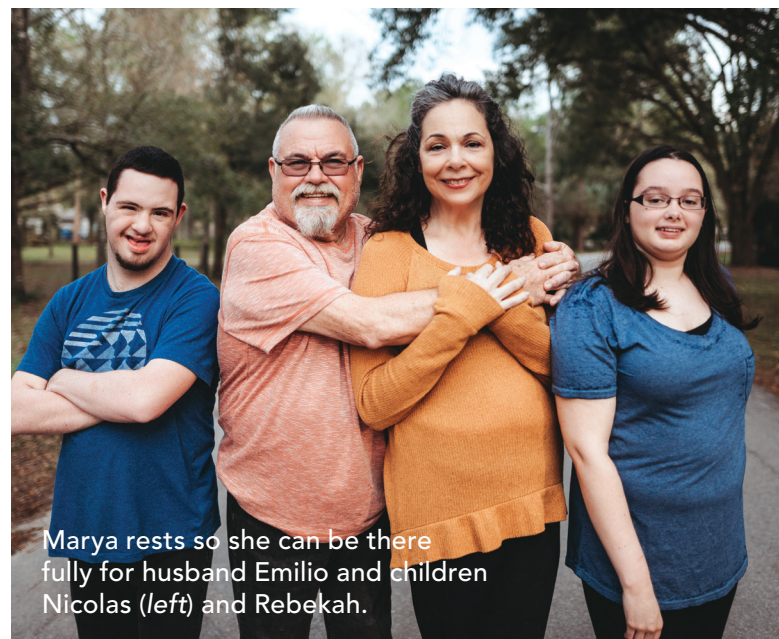
Thanks to Marya, Jason and Melodie’s thought-out moves, IBD is now something they successfully manage. No wonder they’re thriving in spite of it. —BY KATHLEEN ENGEL

## “Rest and restore”

**Marya Mesa,**  
*chronicmomlife.com*  
Wesley Chapel, FL  
Diagnosed with ulcerative colitis in 2018

**Start your day calm.** “It’s important to set my spiritual compass the moment I get up,” says Marya, a mother of four, including two children with special needs. Taking time in the morning for self-care helps fend off the stress that can trigger UC symptoms, she explains, admitting she first had to kick an early-morning Facebook habit. “Now I read from the Bible every morning for 10 to 15 minutes. It sets the tone for the day. Most mornings, I follow that up with yoga.” She selects a yoga video from YouTube—and on days she’s not feeling her best, will opt for one from one of the ‘yoga for chronic illness’ channels.

**Avoid foods that aggravate your symptoms.** “If I have something with almond flour, I’ll spend most of the morning in the bathroom,” says Marya, who has experimented with foods to see what she can tolerate. Eggs, yogurt and bananas are tops among her



Marya rests so she can be there fully for husband Emilio and children Nicolas (left) and Rebekah.

PHOTO BY KRISTINE FREED PHOTOGRAPHY

“safe” foods, she says. “If I start getting too adventurous with food, that’s when I have a problem. It’s hard, because I grew up eating a lot of ethnic foods and I miss them! I’m from Queens [NY], so anything Italian, Chinese, rice and beans, plantains, cannolis...”

**Take it easy!** “I struggle with fatigue, so most days I take a 60- to 90-minute nap,” says Marya, who, as a homemaker and blogger at

*chronicmomlife.com*, enjoys the freedom to do that. Tiredness and exhaustion is a common IBD symptom, experienced in up to 72% of people with IBD who are in a flare and up to 41% of people whose IBD is in clinical remission, according to a study in the online journal *PLoS One*. “My symptoms are unpredictable, so I have to be really careful about pacing myself,” she adds. “I’m usually in bed with my dogs by 8 PM, listening to a podcast.”

## “Do all you can do”

**Jason Fontana,** Tampa, FL  
Diagnosed with ulcerative colitis in 2013

**Look at your diet.** Back in 2013, Jason had just finished doing a marathon. “I was in the best shape of my life, but my UC symptoms were ‘off the chart.’” He was diagnosed with UC following a colonoscopy, and his doctor prescribed medication. “I continued drinking alcohol and eating what I wanted—and found when I ate certain things, like pizza, I’d have issues.” So, he started keeping a food journal, along with avoiding sugary and greasy foods. “Within 10 days, I felt the difference,” he says. Today, Jason is a committed vegetarian, and he’s cut out alcohol and coffee completely. Currently in training for a marathon, he eats a high-calorie diet of mostly beans, fruits and vegetables. Breakfast today, for example: “Avocado toast on whole wheat bread with last night’s five-bean soup that I made.”

**Try a “good, better, best” approach to food.** “I’d love to be ‘good’ 24/7, but there are days a chocolate brownie is calling my name,” Jason admits. “But I’ll find one that’s sugar- and dairy-free.” His new approach has helped: He no longer suffers from intermittent abdominal pain, needing to “go” 20 times in the morning and severe fatigue. “I would crash at 2 PM and need a three-hour nap, then go to



When training for a race, Jason eats a vegetarian diet rich in beans.

PHOTO BY KRISTINE FREED PHOTOGRAPHY

bed early.” He was so tired, he says, “I’d forget my own name. I’d watch a TV show and couldn’t remember the names of the characters.”

**Adjust your attitude.** “I’ve been trying to adopt a more positive outlook in general,” says Jason, a facilities manager at shopping centers who lives with his wife and three dogs in Tampa. “I’ve been trying to get into meditation more. I try to do

yoga more,” he adds. “The mental part [of managing IBD] is just as important as the physical part.” Gone are his days of hunkering down in front of the TV. “I try to be ‘present’ more,” he explains. “I let a lot of stuff slide and take ‘problems’ in stride—they’re usually not life or death, so I keep things in perspective. And I’ve made a conscious effort to show more empathy for people. I don’t have a lot of stress anymore.” ▶



## “Pay attention to IBD—and to your health!”

**Melodie Narain-Blackwell**  
Washington, DC  
Diagnosed with Crohn’s disease in 2018

**Educate yourself about your disease.** “Crohn’s is like a ‘deterioration monster,’ ” says Melodie, an entrepreneur, wife and mom-of-one living in Washington, DC. “If you’re not aware of all the things that can happen, you can wind up needlessly suffering.” Case in point: Melodie didn’t make the connection between her IBD and joint pain until she was literally forced to crawl, not walk, up the stairs to her home. It was a lightbulb moment, and now she realizes: “When my stomach’s not right, my limbs aren’t right.” These days, she says, “I read everything that having Crohn’s can lead to and prepare myself: *This can potentially happen. How can I handle this?*”

**Put your health first.** “I was in denial about having Crohn’s—even after an abscess ruptured in my lower colon,” she admits. “I thought that they could simply ‘fix’ what had burst and I’d be back to normal. I was a young mom, had a demanding job as an executive assistant and was an entrepreneur with two businesses.” Everything and everyone else took priority, she says, until her health situation could no longer take a back seat. “Now I promote preventive care. If something isn’t right, get it checked out. Don’t wait; you may exacerbate things—and that could cost you your life.”

**Be specific about your symptoms.** “Doctors can’t help you if you don’t tell them everything you’re experiencing,” says Melodie, who acknowledges it isn’t always easy to discuss every detail. But, she says, “Your doctor’s office is a safe space. No one is judging you. You didn’t ask for this. I know I didn’t sign up for blisters in my butt!” Also, important: “Accept that there’s no quick fix for IBD. There’s no one-size-fits-all treatment. You have to pay attention to how your body responds.”

**Get support.** “I’m grateful for the friends and family members I could draw on for support [during my flares],” says Melodie. “They were aware I needed support and did not wait for me to ask for it. But, whether it’s family or a support group on Facebook or through the Crohn’s & Colitis Foundation—you need to be able to talk with others about what you’re dealing with. What you learn in an IBD support group—and there may be things you didn’t know or hadn’t thought of—can help you physically and mentally.”



PHOTO BY JPIX STUDIO



## Resources you can use!

Visit these organizations to learn more about how you can manage your Crohn’s disease and/or ulcerative colitis.



**patient.gastro.org** The American Gastroenterological Association (AGA) is the trusted voice of the GI community. Founded in 1897, AGA has grown to include more than 16,000 members from around the globe who are involved in all aspects of the science, practice and advancement of gastroenterology.

### American Society of Colorectal Surgery

**fascrs.org/patients** The American Society of Colon and Rectal Surgeons is the premier society for colon and rectal surgeons and other surgeons dedicated to advancing and promoting the science and practice of the treatment of patients with diseases and disorders affecting the colon, rectum and anus. More than 2,000 of the Society’s 3,800 members are certified by the American Board of Colon and Rectal Surgery.

We believe in patient-centered, high-quality, high-value healthcare. We achieve this care through professionalism, unique knowledge and skills, and the fellowship of the Society’s members.



**crohnscolitisfoundation.org** The Crohn’s & Colitis Foundation is the largest public non-profit organization focused on inflammatory bowel disease (IBD). The Foundation’s mission is to cure Crohn’s disease and ulcerative colitis, and to improve the quality of life for the more than 3 million Americans living with IBD, through research, education, support, and public policy initiatives. The Foundation is dramatically accelerating the research process through their investment initiatives, and they provide extensive educational resources for patients and their families, medical professionals, and the public.

### IBD Support Foundation

**ibdsf.org** At the IBD Support Foundation, our goal is to prevent IBD patients from ever feeling alone because of their disease. The IBD Support Foundation has been built by patients for patients, because it is patients who truly understand. We are available to patients 24 hours a day, seven days a week, to help individuals through crises, to answer questions, and to make sure that no patient ever feels alone.



# 5 ways to tame stress

Coping with the day-to-day symptoms of inflammatory bowel disease (IBD)—the uncontrollable diarrhea and the relentless fatigue—can make you anxious, frustrated and undermine your confidence. Not surprisingly, all that stress can make it even harder to manage your IBD, creating a vicious cycle. What you can do? Be open with your doctor about how you feel and ask for professional support. Also, consider these five easy, self-help tricks that can help take the edge off.



**1 Hug your pet.** Just 10 minutes spent petting a dog or cat lowers stress, according to a study from Washington State University. Researchers say it triggers the release of oxytocin, the bonding hormone. **No pet?** A stuffed animal may be just as comforting, according to a British study which found that a significant number of adults—women

and men—pack a “comfort doll,” such as a teddy bear, when they travel.

**2 Get classical.** Making dinner, doing housework or getting ready for work? Put some Bach or Vivaldi on in the background. Classical music can slow your heart rate, lower levels of stress hormones and prompt the release of dopamine,

a feel-good hormone. Researchers credit the tempo of classical music: At 60 to 100 beats a minute, it’s similar to a normal heart rate. **Have a listen!** Try Beethoven’s “Moonlight Sonata (1st Movement),” Erik Satie’s “Gymnopédie No. 1” or JS Bach’s “Prelude No. 1.” Don’t like classical? Select any music you love that helps you relax and feel good.

**3 Stop multitasking.** Rapidly switching from one task to another causes your body to ramp up production of cortisol and adrenaline. Overexposure to these stress hormones increases your risk for mental health disorders as well as heart disease, weight gain, digestive issues and cognitive problems.


**A good start?** Stowing your smartphone! Studies show the average person checks their phone every 12 minutes. All that distraction not only lessens productivity, it’s also linked to depression, anxiety and aggression. Turn your phone off while you are working and schedule check-in times during the day. And turn off app notifications so you’re not interrupted by frequent pings.

**4 Add some citrus to your meals.** Fruits such as oranges, grapefruits and lemons are rich in vitamin C, which, studies show, helps you both cope with stress and bounce back from stressful episodes. The reason? Vitamin C prevents spikes in levels of cortisol, the stress hormone that puts your body in “fight or flight mode,” say University of Alabama researchers.

**Not a citrus fan?** Other top vitamin C sources include red and green peppers, kiwifruit, broccoli, strawberries, Brussels sprouts, tomatoes and cantaloupe.



**5 Be an early bird.** People who reported greater exposure to morning light (between 8 AM and noon) not only fell asleep more easily and slept more soundly, they were less likely to report feelings of depression and stress, according to a study in the journal *Sleep Health*. Morning sunlight helps regulate your body’s natural

sleep-wake cycle and also boosts production of serotonin, the happiness hormone. **Maximize the benefit!** Get your morning light in a green space, whether the backyard or a nearby park. Multiple studies show a “nature hit” helps lower blood pressure, ease anxiety, lift depression and stop your mind from dwelling on negative thoughts. 



## Don't let IBD stop you from socializing!

*Embarrassment causes some people with IBD to limit their social activities. But studies show loneliness and social isolation can be just as damaging to your physical and emotional health as cigarette smoking and obesity. In addition to seeking treatment for IBD, try these strategies:*

**Stop unsolicited comments—cold.** Has someone commented on your frequent bathroom visits? Try saying, “I have a chronic medical condition. I have no control over it.”

**Keep this in mind:** People who are self-conscious tend to feel others are focusing on them, according to research published in the *Journal of Experimental Psychopathology*. But it’s likely that others aren’t paying as much attention to you as you think!

**Find a support person.** Ask a friend or loved to help you out by joining you in everyday activities, like taking a walk in the park or going out to see a movie.



# Questions to ask today

Knowing the answers can help  
you better understand your IBD  
and your treatment journey.



1. Do my symptoms indicate I have either Crohn's disease or ulcerative colitis?  
\_\_\_\_\_  
\_\_\_\_\_
2. Does my condition increase my risk for any other medical concerns, such as anemia or bone loss?  
If so, how can I avoid these?  
\_\_\_\_\_  
\_\_\_\_\_
3. Do I need any special health screenings, such as a colonoscopy, or a CT scan or blood tests?  
\_\_\_\_\_  
\_\_\_\_\_
4. Is my condition under control if I'm still having flare-ups?  
\_\_\_\_\_  
\_\_\_\_\_
5. What kind of treatment do you recommend and why? What are the risks and benefits of this treatment?  
\_\_\_\_\_  
\_\_\_\_\_
6. How will you know if my treatment is working?  
\_\_\_\_\_  
\_\_\_\_\_
7. If I'm already on treatment, how well is my current treatment working?  
Am I a candidate for any other treatment?  
\_\_\_\_\_  
\_\_\_\_\_
8. Do I need to make any adjustments to my diet to be sure I'm getting enough nutrients?  
\_\_\_\_\_  
\_\_\_\_\_
9. Is my stress level contributing to my condition? If so, what do you recommend for reducing stress?  
\_\_\_\_\_  
\_\_\_\_\_
10. Should I see any additional health professionals, such as a nutritionist or dietitian?  
If so, can you recommend one to me?  
\_\_\_\_\_  
\_\_\_\_\_