



# *ColitiScope*

*Andrew Tubesing*

**LIVING WITH CROHN'S DISEASE  
AND ULCERATIVE COLITIS  
ADVENTURES ■ HUMOR ■ INSIGHTS**

*Charming and earnest...an open-hearted and informative reflection on the experience of living with IBD.*

—**Jonathan Braun, MD, PhD**  
Professor and Chair  
Pathology and Laboratory Medicine  
UCLA David Geffen School of Medicine

*Where was this book ten years ago when I needed it? When I was a freshman in college, I told my boyfriend that I had ulcerative colitis. Being the sensitive young man he was, he laughed and kept repeating, "Oh my god, you have bloody diarrhea? You have bloody diarrhea?"*

*I suppose it goes without saying that my feelings were quite bruised. If I had been armed with your book at the time I could have either clobbered him over the head with it or told him to read it and get a clue.*

*Colitiscope is a practical resource and a self-esteem booster all wrapped into one.*

—**Emily Sippola, RN, BAN**  
Minneapolis, Minnesota

*As a parent, I have watched and experienced my son's struggles with Crohn's disease, but reading your words gives me a better understanding. I can really relate as a loved one.*

*I think this is a great book that has never been written before and should be on the reading list of everyone with IBD—to realize there is still life after diagnosis. This is very practical, and all ages will find parts they can identify with. It's a quick read with lots of humor and smiles.*

—**Carolyn Bloom, PT**  
Lawrence, Kansas



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**Living with Crohn's Disease  
and Ulcerative Colitis  
Adventures • Humor • Insights**



***Andrew Tubesing***



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Adventures • Humor • Insights*

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*To my wife Heather  
and my ever-supportive  
friends and family*

*And to all supporters  
of people with chronic conditions*

*You are our heroes*

*A portion of the proceeds from this book will be used  
to support efforts that work toward curing IBD and  
improving the lives of IBD patients.*

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# ***Foreword***

I have inflammatory bowel disease, also known as IBD. Mostly it appears to be ulcerative colitis, but some indicators suggest that I might have Crohn's disease. This book is the story of my life with colitis, from the initial discovery to the many resulting adventures that have followed. It offers perspectives on living with IBD and the laughs and tears it can bring.

There's no shortage of books that cover the clinical elements—the diagnosis, the details of the disease, the treatments and medications. But there are few publications that focus on the life this illness brings, the coping tools, the joy and sorrow. And there are even fewer that are funny. Call it the softer side, if you like, but after reading all the encyclopedic medical material, I was ready for the second act, the part about how to make life work in the midst of a chronic disease. From that gap grew my inspiration for this book. I can't promise you a foolproof solution, but I can give you a picture of what my life is like, and maybe that's a start.

If I had my way, IBD patients would read, enjoy, laugh, and learn from my experiences—and also share my insights with their family and friends as a way to help them understand what we go through. If I can articulate some of my quirky observations in a meaningful way that you can all enjoy, then I have accomplished my purpose.

In these pages you'll find funny stories, interesting tidbits, advice, insight, and much more. I have interspersed escapades with parables, and mixed in plenty of practical tips as well. I have also included information about common procedures, medications, and symptoms—but it will be unlike the stuff you've read elsewhere. Here I'll give you the straight talk, the inside scoop, and you will laugh, I promise. It's time to set your embarrassment aside and get out your funny bone.

The chapters are organized into two sections. Part I introduces the chronological development of my disease and associated adventures—which represents the “Colitis” side of *Colitiscopes*. Part II explores the perspectives, life challenges, and solutions—making up the “Scope” and “Cope” portions of *Colitiscopes*. From this collection, it is my hope that you will learn, share, and laugh.

\* \* \*

My wife, Heather, is the most patient person I’ve ever known, and I can never thank her enough for that and everything else. My parents have supported and encouraged me, instilling in me the tools I need to live a whole life. My brother, friends, colleagues, and others all make sacrifices which accommodate my illness (and strangeness, freakishness, and whatever else I may be). My doctors and advisors, my contacts at the Crohn’s and Colitis Foundation of America (CCFA), and so many others have helped me to get where I am. I thank you all.



# Part I

## *Colitis*







## ***Bloody Bongiorno***

It was about an hour before sunrise on earth, but perhaps only a few minutes before from my vantage point. Flying at 35,000 feet above Greenland, my brother, Phil, and I peered out the window of a 747. We were on our way to spend two weeks in Italy, France, and Spain with our parents and my wife, Heather. The northern lights were spectacular. Green and blue streaks of ghostly iridescence danced in the dawn sky, shimmering across a backdrop of stars and planets. It was a truly magical sight. We had been enroute for quite some time. We were landing in Amsterdam in a few hours then boarding another plane to Rome. It was the night before Christmas Eve, and we would spend it in Rome. As a family we had taken a Caribbean cruise together at Christmas time, but otherwise this was our first time spending the holidays away from home. We were all looking forward to it.

I normally experience some digestive trouble when I travel. There's nerves, there's getting up way too early in the morning to leave for the airport, and there's strange foods on an odd schedule. It all usually gives me a stomach ache and unpredictable bowels. I call it "travel tummy" as it's so common with air travel for me. But this time it was different. I had more than an unsettled stomach—it was more like an ache, like the kind you get before the flu. I wasn't nauseous at all, just troubled at the other end. I wrote it off as a worse-than-usual case of travel nerves.



We landed in Amsterdam where we had a significant layover. With access to the airline's upscale travel club, we spent the idle time in style. Free champagne and food, nice environs, Internet access—and thankfully, nice bathrooms, because that's where I spent most of my time. I was hitting the toilet every fifteen minutes at that point. It wasn't very productive, just small amounts of quasi-solid waste, but it came out rather strangely, with an unusual kind of discomfort. Not pain exactly, just a sort of general unpleasant sensation, like passing a pine cone with the grain.

For travel tummy I could hardly have asked for better accommodations. The bathroom was immaculately clean, covered floor to ceiling in small white square tiles with solid brass faucets on elegant sinks and ivory glass light fixtures giving it a warm glow. The stalls were actually separate rooms walled in the same shiny tile with real solid wood doors. It was a lovely way to spend seven hours on the can, if such a thing is possible.

I was hoping for some sleep on the next flight, assuming my tummy would settle down as the travel demands eased up. No such luck. We arrived in Rome and took a taxi to the apartment we had rented for the week. It was just around the corner and a block down from Piazza Navonna. On arrival, out of necessity, I immediately familiarized myself with the bathroom. Our lodging was a cozy little academic pad with floor-to-ceiling bookshelves stocked with musty volumes, a small kitchen, and a couple of bedrooms. It was an old structure from a time before electricity so there was a vertical shaft through the middle of the building to which you could open windows in the kitchen and bathroom for light and ventilation.

We briefly explored the neighborhood, had a snack from the local deli, and went to bed. Finally I got some sleep. In the morning we went about exploring the area. It was Christmas eve, so by nightfall there were crowds of people out walking the narrow streets. Church bells were ringing everywhere, and it was generally festive.

My digestive system seemed to have gotten some relief from the night's rest, but it was still being rather unpredictable. The quasi-solids gave way to mostly-liquids. I was having a hard time finding menu items that seemed appealing—my system didn't want to ingest food that badly. I had no trouble salivating over the fresh chocolate crepes though; they were delicious. We also frequented



the deli nearby, enjoying fresh baked breads, unbelievably good pesto, and thinly-sliced salami.

As we spent our days seeing the sights and absorbing the history, my system became increasingly agitated. Bathroom visits were more frequent and urgent and hardly ever solid anymore. They say Rome is the city of fountains—well there was an extra one in town that week. I gave some thought to renaming my backside Trevi. It's not always easy to find a bathroom in big cities, especially when you're linguistically challenged. I had taken a lot of Spanish classes, so that helped a little, but Italian is really quite different.

At some point my bathroom visits started getting painful. Sometimes it felt like my rectum was on fire. Was Nero's ghost still roaming around Rome? Had he somehow taken up in my back door? The episodes came and went, so I was able to be out and about enough to enjoy the visit, but my nerves were growing ever less comfortable with what I was experiencing.

My mood changed significantly, however, when I started to see blood in the toilet. Shifting from discomfort to serious concern, I immediately started to wonder what sort of bug I might have picked up over there, but remembered that the problems really started on the airplane. Planes are easy places to pick up viruses and other germs, but I wondered if any transmittable illness could have taken hold that quickly.

I remembered a former co-worker who once had rectal bleeding. Another colleague whose wife was a nurse commented on the situation, "That can mean a lot of things, but nothing good." Which left me with the impression that rectal bleeding is definitely bad news. I remember hearing about his doctor visit where they wanted to do some sort of test and him saying something like,

"You want to stick a *what* in my *where*? No way I'm gonna let you do that. Good bye."

He walked out and never went back. That was very much like him. He worked hard and had obvious carpal tunnel in his wrists, which bothered him all the time, but he would always be tough and shake things off. So it didn't surprise me that he might try to shake off the bleeding too. I never did learn what it was all about; he is not at all the sort of guy to talk about that with anyone, so I was left to assume the worst.





And now that it was happening to me, it made me nervous. I kept it to myself, though it was hard for others not to pick up on the frequency of my porcelain visitations. Heather remembers noticing my distress but claims that I didn't say anything about blood until we got home. I don't remember it that way, but it certainly could have been possible—I didn't even want to admit it to myself. Discovering a mysterious medical problem while traveling overseas was highly disconcerting. It was truly a bloody unwelcome welcome to Rome.

So I went about the trip trying to enjoy it as much as possible. But the digestive issues continued to develop.



## ***I Left My Underpants in Ancient France***

I love boats more than just about anything—even more than I love macaroni and cheese, but not quite not as much as I love my wife. So I guess that's where they sit, number two on my romance list. Not surprisingly, Heather and I parted with the family after Rome and headed to Venice for its waterborne lifestyle. We spent over half of our two-week trip budget in just twenty-four hours, but it was worth every penny. Aside from enjoying all the great shopping and a ridiculously ornate Venetian glass chandelier in our hotel room (it literally occupied the entire ceiling), we rode on four different kinds of boats and saw all kinds of others, including a rickety old skiff with an outboard motor, piled high with a mountain of DHL overnight packages. Conditions in my belly were still just developing at this point, so I didn't have terrible bathroom trouble there, but that all changed once we got to France.

We rented a car in Nice and meandered our way through Provence to meet up with my brother in Avignon a few days later. The three of us would later rejoin my folks in Barcelona at week's end. However, there was some confusion about meeting Phil at the train station as planned because he didn't appear to get off the TGV train from Rome like he was supposed to. We waited a while



and worried that for some reason his plans had changed. Our pre-arranged agreement was to communicate by email if such a thing were to happen. So Heather and I decided to split up. She would stay and wait for him while I went to town in search of an Internet café. I got directions and headed out to the parking lot.

There I encountered one of those stressful occasions in which situations that appear familiar are actually completely different in a new culture. I got in the rental car and made my way to the parking lot exit. As I would expect with a pay lot in the states, I drove to the exit gate to pay for my time and be on my way. Well, there was no attendant at the exit, instead just a vending machine of some sort, but it had no coin slot, and the paper feeder didn't match the size of any of the French bills I had accumulated. There were some instructions—but all in French, though I recognized the word “*sortie*” as exit which was an encouraging find. The rest of what I stood a chance of comprehending was all in symbolic pictures. After a lot of staring, turning my head sideways, diagramming the activities pictured, (and some honking from cars behind me in line), I realized that the three or four icons I was gazing at ostensibly were meant to be the international language for “Before leaving the train station, guess at your parking duration, pay money into a vending machine inside the station, and bring the dispensed ticket here to get out.” Brilliant. I was suddenly reminded of a college history professor who constantly chided the French throughout history. He would set up a dramatic story, which at some point would climax with something like “...and guess who was there to screw it all up? FRRRRANCE!” He would growl loudly enough to wake sleeping students in adjacent classrooms.

For a moment I considered driving right through the gate in front of me. I looked in the rearview mirror and saw several cars waiting behind me. I checked the side mirrors and realized that we were all being funneled into this lane by curbs on both sides leading back at least three car lengths, penning us in. Turning back to the machine, scowling, I gave it “the finger,” thus communicating the international symbol for “Why not put the stupid payment machine out here instead of inside the train station?”

I looked in the mirror again, signaling to the guy behind me that he needed to back up and let me out. I put the car in reverse, hoping



the back-up lights would give him a clue. He honked, and I could see he was making international symbols of his own. I waved him back. He motioned behind him like he was stuck, making a point of showing his irritated expression. At this point, I finally tried to get out of the car so I could signal the drivers behind him that I am an American idiot who needs everybody to back up because I don't know their backward rules. Instead I got pinched in the door because it hit the machine and wouldn't open far enough to let me out. I writhed around for a few seconds until finally someone got the idea and the cars started backing out to let me finish embarrassing myself.

I parked again and went back inside the train station to buy a parking ticket. Actually I didn't mind it much at that point because my rear end was signaling that it was ready for a sortie of its own. I briefly wondered again why I was having all these urgent bathroom visits and took care of that need first, then found the parking ticket kiosk. I had no idea how much time to pay for, so I bought the most expensive option, which I assumed was an all day pass—it might have been a penny or a hundred bucks, I had no idea, the French money had only been in my pocket for a day or two, so I hadn't yet adapted to the conversion.

This time I successfully exited the parking lot and made my way to old town where I was told I could find Internet access. After a moderate hassle parking on the street and dealing with a parking meter, I logged on at a café and found no email from my brother. I sent him a message saying we would wait at the train station and check email every two hours until we heard something.

On my way back I encountered a less-than-delightful maze of one-way streets. Approaching the station I accidentally chose the wrong ramp and had to circle back. Finally I returned and searched the terminal for Heather. I found her sipping coffee with my brother in a pair of lounge chairs, drenched in morning sun streaming through the glass wall behind them. Contrary to my disposition at the time, they looked relaxed, almost bored. Then I heard the wonderful news. Turns out he was on the train after all, and she found him only a couple minutes after we split up. Yep, before I humiliated myself in the parking lot, before I came in for the bathroom and the



parking ticket, before I even went into town. Ugh. *Hopefully this day will get better*, I thought to myself. Well, it didn't.

Heather and Phil both studied French in high school, so as we headed for the parking lot, they bought the parking ticket this time—paying considerably less money than I did. On the way out of town we stopped at a suburban shopping center for some lunch. Because I visit hardware stores everywhere I travel, no matter what, we also stopped at the French version of Home Depot, where I couldn't resist buying some light fixtures to mail home (which I have yet to install, of course).

Our primary destination was Carcassonne, an old city near the Spanish border whose fortifications date back to Roman times. It is a beautiful ancient city, all of which is old by our standards, but the really old part is the hilltop inner fortress, which is only accessible on foot. We spent a lovely afternoon exploring the stone walls and cobblestone pathways. We shopped and gazed at the architecture. While perusing the Basilica's cavernous interior, after eating something with a forgettable name (but an entirely memorable result), I felt the inklings of a bathroom call. Inklings quickly turned to pestering, and I suddenly had an emergency on my hands. Oh wow, it was bad. I signaled to Heather and Phil that I needed a bathroom, quick. We all looked around, there didn't appear to be anything inside the sanctuary. One of them asked a docent, "Le somethingorother merci..." who pointed us outside and up the pathway to a public restroom.

I hurried outside, but by the time I could see my destination I was pretty sure it was already too late. I scrambled up the street to some stone steps leading down into the bathroom. It had a Gothic arched doorway, and the floor was paved with large chunks of stone, worn in by the ages. Dark and cavernous like a dungeon, the only light inside streamed in through slits in the rock wall high above me. Some horribly out-of-place modular restroom wall dividers sectioned off a stall in the middle of the open room with urinals to the left, sinks to the right. I was really crowning by then, and as I entered the stall some gas escaped. Or so I thought, but it wasn't just gas, too wet for that. I didn't even have my pants down yet. *Crap!*

Inside the stall, much to my chagrin, I found a Turkish toilet. A Turkish toilet is less like a toilet and more like a hole in the floor.



I didn't even know they had them in France. *I was in Carcassonne after all*, I reminded myself. *Some of it was built during the Ottoman Empire; perhaps this bathroom still had some original fixtures.* The toilet was made of stone or clay and resembled a urinal, turned on its back and recessed in the floor. Apparently I was supposed to straddle this thing, balancing in a squat position with my pants around my ankles while trying not to fall over or soil myself. But it appeared as though I had already done that. It was also apparent that a previous visitor didn't like the toilet any more than I did and had decided not to use it. There was crap on the floor in the corner, literally. It smelled awful, though it also seemed perfectly fitting for the medieval context. I breathed through my mouth to minimize the stench.

I carefully took down my pants as quickly as I could, and before I even finished squatting the juice was flowing. This episode was rather painful, coming out in spasms, sort of like when you vomit. I was in a large stall; the walls were spaced wide enough that I could not reach them from the middle. As I crouched precariously with nothing in reach to aid my balance, I inspected my pants. My boxers had suffered damage, but I couldn't find any remnants elsewhere. I could see that it indeed was not just gas that snuck out; instead it was mostly blood with some other not-so-appealing substances mixed in. I turned to look at what I'd let out behind me, but couldn't make the contortion to bring it into view. I shuffled my feet and turned a bit to see that it was indeed bloody and yucky. *What does this mean?* I wondered quietly. I swallowed the panic, reassuring myself that I'd be home in a week, and if it hadn't stopped by then I would see a doctor. With the circulation cut off at my knees, my feet were going numb. Squatting is not a natural position for me. The last thing I needed was to fall backward into my own mess.

It seemed as though I was finished so I looked around for some toilet paper—and that's when my day really took a downhill turn. There wasn't any paper, but it wasn't because they had run out. Rather I saw absolutely no evidence of there ever having been toilet paper there, not even a dispenser. The history professor's voice echoed in my head, "*FRRRRANCE!*" Now this was not current-day France; there was no cute little butt-shower there either. Carcassonne was built long before the advent of Prissy-Pants France. I



don't know when the bidet was conceived, but if they never figured out the toilet paper thing, I guess I can't really blame them for its invention.

My knees were burning by then so I had to stand up. I could feel a couple drops of blood falling free as I raised up to a quasi-erect, bent-over position, keeping my knees bent slightly, ensuring some overhang to protect my clothes. I braced my hands on my knees and took a deep breath. It stunk. *What do I do now?* I puzzled. I had nothing but a postcard in my pocket. I looked down again at my underwear. Could they be revived? I pondered the situation for a long moment. My legs started trembling slightly from fatigue, telling me I needed to figure it out soon. Then it hit me. I could take my boxers off, use the unsoiled parts to clean myself up, and then throw them away. *Oh man. Oh man!* My heart sank in painful agony as I considered what I had to do. I am sure the look on my face reflected the disgusting situation I was in and the tragedy I was about to inflict upon myself.

Now hold that picture of my expression in your mind for a moment. This is the part in a movie where the screen freeze-frames on the protagonist's face while he is enduring some egregious hardship and making a bizarre expression. We get an extended look at that face while he narrates some back story that makes sense of what you are about to witness. We get snapshots of these past moments. In this case, he (I) says,

Now let me tell you something. I love my underwear. Maybe not as much as boats or my wife, but it's certainly up there with mac and cheese. And these weren't any old underwear, these were precious...irreplaceable.

Finding good underwear is a painstaking and expensive process. It takes a few tries before you find the ones that will work for the long haul, then you go back and get more. Well the ones I wear now I had discovered about 8 years ago. They're simple cotton knit boxers, but instead of the bulky bunched-together elastic waistband common to most standard boxer shorts, these have some stretchy Lycra in the fabric, and the top edge is simply folded over and sewn down in a two-inch hem, making for a very low-profile and comfy waist. There's nothing else like it on the market. When I first found



them, I fell in love. I bought a sufficient supply and went on with life. At the time I was working on a nationwide publicity tour and lived on the road for nine months straight. When I returned home and readjusted to normal life, I went back to Penneys to stock up on my magic underwear. But I couldn't find it. I searched everywhere. Finally I asked a clerk where they were.

"Do you mean those Jockey Zone boxers?" She asked.

"Yes, those are the ones."

"Oh they were discontinued a couple months ago, we won't be getting any more."

"You mean discontinued by the manufacturer, or did you just stop carrying them?" I asked.

"No they stopped making them."

My jaw dropped. I couldn't believe my ears. Not again. It seems like every product I come to love inevitably gets discontinued. Friends and family make fun of me for how product-loyal I can be. I am the world's most harsh product critic, but when I find something that's perfect, I am a subscriber for life. When they discontinued my deodorant, I called the company and ordered a full case of it from their backstock. People said it wouldn't last, it would evaporate, but they were wrong. Last year I finished the last of it after rationing it out to myself for more than a decade. Yes I'm a freak. In fact, on this very trip to France I had rediscovered my old favorite shaving gel, which had been discontinued in the States, so I was thrilled to see it still available in Europe, and I bought more everywhere I saw it. My brother, who travels a lot, was still bringing it to me up to a couple years ago. But none of us can find it anymore, even overseas—or on eBay. (I am nearly out now. If you have some or know where to get it, please send it to me care of the publisher. It's called Gillette Shaving Concentrate and comes in a silver oblong ribbed plastic bottle, SKU#50785896. I will reward you handsomely.)

I was furious. *That was the best underwear ever made, how could they stop making it?* I started breathing heavily. The clerk stared at me. My peripheral vision started going fuzzy, then dark. I could see only a blurry circle in front of me. I walked away from the counter. Turning down the maze of department store aisles, I navigated with foggy tunnel vision. When I got back to the car I had to take some deep breaths and calm myself down before driving home.





I guess it is sort of funny looking back, but I certainly wasn't amused at the time. Later I told a friend about it. She knew how much I loved my undies and understood the tragedy, but she laughed anyway. Fair enough, I always laughed at her because her family called underwear "chuds." Perhaps now you'll understand how angry I was when I found the waistband of one of these boxers in the backyard crap of my roommate's dog. It was bad enough being out there poop-scooping, but to find that the dog had shredded and eaten a pair of my priceless shorts added significant insult. In any case, the tragedy is now tempered by the fact that boxers are simply incompatible with inflammatory bowel disease for obvious practical reasons. Like it or not, I didn't need them any more.

So back to Carcassonne, the cameras are rolling again. There I stood in ancient France wearing irreplaceable underpants. The world's supply of these boxers was down to eleven, and I was preparing to obliterate nine percent of the stockpile in one fell swoop. Not to mention, on a long trip losing a pair of chuds has a significant impact on laundry planning. I hated to admit it to myself; I cringed at the thought, but I knew what I must do. Easier said than done, however.

As I mentioned earlier, there was already somebody else's scat on the floor, and who knows what else had been there. I was going to have to remove my shoes and extract my undies from my pants and legs without smearing anything on myself or dripping anything from my bum. I slowly pried each shoe off, standing on top of them. I held my boxers at mid-thigh spreading my knees enough to keep them taut and elevated, while carefully working my jeans off by stepping on each cuff with the other foot and wiggling my legs out. With the precision of that buzzing Operation game from my childhood, I raised each foot through the leg holes of my shorts without touching them on the way out. Somehow I succeeded in keeping myself clean throughout this delicate procedure. I meticulously wrapped and folded the boxers as I turned them into the world's most precious ass wipe. It pained me to treat them this way, but I had no choice. I set them on the floor and carefully re-dressed, being sure not to track nasty bathroom floor-ness onto my socks and into my shoes. I would have to finish the



day commando style. If nature were to make another emergency call I would be in big trouble. *Better not eat anything until we find our hotel*, I concluded.

I waited to be sure there was no one else in the bathroom and emerged from the stall with my tragedy in hand, heading straight for the trash can. I said goodbye to the yucky bundle, looking at it one more time before I let the spring-loaded cover close over the can. I washed my hands about seventeen times, double-checked my clothes for unwanted remnants, and headed back into the light.

Ascending from the dungeon, I found Heather and Phil sitting on a short section of stone wall chatting about something. I had been gone a long time. Heather gave me a concerned look, and Phil just sat there patiently, looking ready to move on. This would be the beginning of a very unusual relationship for them. Everywhere we went, from that point forward, the two of them would be left to entertain themselves while I ran for the toilet. We travel together a lot, so over the years I suspect they've had hundreds of these chats. I wonder what they talk about all that time, which of the world's problems they could solve while I'm in the can. They could probably write a book to describe their side of the adventures we share from opposite sides of bathroom walls.





## ***Diagnosed / Be Prepared***

Upon returning to the states from those two weeks in Europe, during which time my situation had evolved from a simple tummy ache to incessant diarrhea and bloody stools, I made a beeline for the doctor.

I first saw a nurse practitioner at my family physician's office. I had seen a doctor for hemorrhoids once a number of years previous and received a taste of the awkwardness of confessing and surrendering to inspection of problems in such a personal location. But that visit was relatively simple—just a quick slice with a scalpel, and it was over. This time, we shared several long minutes of probing with a track & field relay baton (the sterile version of which is called a proctoscope). It's a rigid hollow pipe about an inch thick that allows inspection of the rectum and lower sigmoid colon.

After a bit of spelunking around with a flashlight, she concluded quite readily that I needed a more sophisticated evaluation. She said I definitely had some inflammation and that I'd need to see the local surgeon for a colonoscopy so they could determine the extent of my problem. After a bunch of questions and explanations, they called and got me an appointment. The procedure seemed simple enough except for two things. First, it required sedation, which meant I had to come with someone to drive me home. Second, it was to be performed in an operating room. OK, in my book, nothing that requires an O.R. and a chaperone is a casual affair. I was definitely curious,



if not mostly nervous. To me, it seemed like a procedure that fancy must mean bad news. But at least I was finally getting help for my mysterious problem; most of the previous weeks on vacation had been pretty nerve-racking.

Before I left the office, the staff gave me a bunch of papers describing what I had to do to get ready for the colonoscopy. Instructions for preparation were lengthy and required that I obtain some supplies from the pharmacy, notably a bottle of Fleet Phospho-soda (a liquid laxative) and a plethora of fluids—everything from apple juice to beef broth.

I so enjoy the concept they refer to as “preparation.” This is one of those government-style euphemisms where they try to make a fifty-ton bomb sound like a firecracker. I know what that’s all about; the university where I work has a division that specializes in explosives testing, which they so delicately refer to as “Energetic Materials Research.”

The purpose of preparation is to empty your system of any and all food remains. They want a perfectly clear view of your insides when they shove that six-foot hose up your porthole. If there’s anything still in the intestine it can get in the way or be mistaken for problems, so they advise eating nothing red for a couple days (sorry kids, no beets tonight!). Then you get only clear liquids for the last twenty-four hours and nothing for the final six or so, not even water. Obviously there’s a reason the GI procedure lab has a “no food or drink” policy, even for visitors. It’s to stop those thoroughly prepared folks from causing riots in the waiting room.

The day before my procedure I got out my bottle of Fleet Phospho, read the directions, referred back to the doctor’s instructions one last time, and started swigging away. Now that was an education. I quickly learned that the real meaning of preparation is drinking between a quart and a gallon of this vile seawater solution which, within the hour, comes out the other end as the entire Pacific Ocean. Talk about energetic materials, wow! I think I had enough rocket boost to put the space shuttle in orbit. If there were a way to harness this hydropower, we could solve the energy crisis—then people would be running around talking about how cool it is to have colitis. But at the time I had no idea how “cool” I was destined to become.



When they say “prepared,” they *really* mean prepared. I mean *everything* empties out—breakfast, lunch, and dinner, yesterday’s spinach salad, last night’s hot wings (ouch)...even the matchbox car you swallowed at Billy Zinkewicz’s seventh birthday party, and all that gum you ate in junior high. I swear if I’d still had an appendix it would have come out too.

This process brings new meaning to the Boy Scout motto, “Be prepared,” only in this case it feels less like something one does voluntarily and more like something that is done to them, “to be prepared,” sort of like to be robbed, or invaded, or served, or subpoenaed...glamorous indeed. The Fleet Phospho should come with a free T-shirt that says “I’ve Been Prepared” with their logo under it. But somehow I don’t think they’re going to be marketing to the general consumer any time soon. Another of the preparation laxatives they sometimes use is called Golytely, which is a gallon jug of 100 percent pure irony.

Funny that the two days of preparation would seem like the easy part, which it definitely is not. It’s forty-eight hours of misery all to get ready for a fifteen-minute procedure. Then it’s suddenly over.

Anyway, on colonoscopy day my nervous wait continued at the hospital where I was assigned a room to get ready and to which I would be returning later for recovery. A nurse came in to start my IV. She picked up on my anxiety and offered me something to calm me down. I declined—I thought I would be having enough medications that day as it was. I waited about fifteen minutes in the bed with Heather sitting by my side. Finally they came to take me to the O.R. Heather stayed behind and read her book.

The operating room looked pretty calm, though I was definitely not feeling calm. The nurse anesthetist talked me through what we were about to do together. I asked some questions, mostly wanting to know what it would feel like and what the drugs would do to me. Of everything going on, the medication was the scariest part for me. Drugs that transport a person to La-La Land make me nervous. Plus, after doing some reading on the topic, I realized that a good portion of the risk in this procedure is with the drugs themselves. What they used was basically a strong sedative that would relax me and suppress my memory, without really putting me to sleep. After



a few minutes of hooking me up to various machines, he shot a syringe-full into my IV tube and I drifted off.

The procedure was performed by a general surgeon. I learned later that this is relatively unusual. These days, colonoscopies are typically performed by gastroenterologists (doctors who specialize in the digestive system). However, since I lived in a small community isolated in the desert southwest, relatively distant from the nearest specialist, this surgeon was the only qualified colonoscopy practitioner in town.

One of the books I read later contained an interesting comment. It was trying to reassure the reader that, while partially conscious during sedation, you won't say embarrassing things; this must be a concern for some patients I guess. I couldn't take that as anything but a bunch of hooey though, because of my memory of this colonoscopy experience. I woke up speaking Spanish to the nurse. I have no idea what I was saying, but much of the Spanish that I remember is not the sort of stuff you say in front of decent company. Nearly everybody speaks Spanish in New Mexico, so I'm sure at least half the room knew what I was saying—I only wish I knew myself. It must have been either funny or embarrassing because I do remember them chuckling at something I said, but I was pretty woozy, so it's a vague memory at best.

They wheeled me back into the hospital room to regain my senses. I found Heather waiting for me there. The surgeon had already stopped by to explain everything to her. As I re-oriented myself, she described what he had said. I remembered very little of it later so she had to repeat it again. We spent about an hour there while I drank fluids and finished waking up, and then they let me go. I was a little disappointed that the surgeon never came back to explain it all to me personally, but Heather had gotten the word so I guess they figured that was good enough.

He had told her that I had colitis, an inflammation of the colon that could be mitigated with medication. He showed her some pictures taken during the procedure with the fiber-optic scope camera, and explained a little about what he saw. She did her best to translate it to me later, but there wasn't a lot of information to go on.

I went in for a follow-up a few days later. That is where I got the colitis diagnosis personally. But, as I would come to learn later, the



surgeon did a terrible job of explaining it. He told me basically the same thing he'd told Heather after my procedure. It was an inflammation of the colon, and I should take Asacol and come back in a month.

This all sounded simple enough. Sort of like strep throat or a sinus infection. Take these meds and come back for a check-up. So I took the Asacol as directed, and my symptoms resolved in a couple of weeks. After a month I saw the surgeon again, and he cleared me to stop taking the meds. Another follow-up a month later got me fully discharged from his care without any fanfare or warnings—in fact no indication at all that there was anything to worry about.

Piece of cake. At no point during any of this was I given the impression that it was anything other than a quick-fix problem. So I didn't worry about it much, and I went on with life. I had a busy summer planned and started preparing for my upcoming projects.

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A note on the colonoscopy experience before we move on: I have since had several more of these procedures, but I've never used sedation again. I did some research on the topic and found that using sedation as a routine part of the procedure is much more common in America than anywhere else. Most other places around the world don't use it, and consider it unnecessary except in cases of extreme discomfort. The reasoning is, as I said earlier, that the medication introduces an additional level of risk. Very rarely the colon can be perforated by one of the instruments, which requires emergency surgery, but problems with the sedatives also occur which increase the total risk of complications.

Another disadvantage of being sedated is that it extends the recovery time. On following occasions, when I declined the sedatives, I was able to get off the bed, get dressed, and go home—instead of spending an hour in recovery and a queasy day or so of expelling the drugs from my system.

The most important part about staying awake for the colonoscopy is that it gives you a whole new understanding about your condition—with the ability to watch and track your progress yourself with your own eyes—and a new language to discuss it. You can talk with the doctor as it's happening, and he or she can explain what



they see and what it means. And it's truly interesting to see what it all looks like inside.

So, given these factors, why is the use of sedation still so popular in America? First, I suspect that medical professionals prefer to sedate patients because they are easier to work with. Second, it offers the patient a way to escape the embarrassing process of being worked on in a private area. To me, the drugs are not worth it, but some people would rather not be conscious. Regardless of your preference, understand that you do have a choice, and it's one you can research and consider for yourself.

One thing that gave me the confidence to decline sedatives during my second colonoscopy is that I'd had several sigmoidoscopy procedures prior to it. A sigmoidoscopy is a miniature colonoscopy done in the gastroenterologist's office. The scope goes in about half as far, and it only takes a few minutes. I typically don't need to prepare for this one, and there's no sedation involved, so it's sort of a warm-up to the biggie.

It seems like allowing such a personal inspection would be embarrassing, but it's a lot easier if you realize that they do this all day, every day. These procedures we're not accustomed to experiencing are things they do all the time, so they understand what you're going through and take measures to ease your awkwardness.

If you are inclined to try a colonoscopy without sedation, it may be difficult to convince the procedure team that you really want to (or can) do it. It's a pretty unusual request, and they generally don't like to do it that way. But I insist on it when I go, and it's really not that difficult for me. You'll have an IV in your arm anyway, so they can administer the meds during the procedure if you find you want or need them. I once had a colonoscopy team confess afterward that they'd put wagers on whether I would make it through without sedation. I think most of them lost money betting against me.

If the team talks you into doing the colonoscopy sedated, you'll miss all the fun and just wake up farting in the recovery room. During the procedure, you may be observant and conversational, but it's likely that you won't remember it. That's why staying fully awake for this procedure is so valuable—it allows you to see firsthand what your symptoms look like, and remember it all. And that's worth it to me. On the other hand, upper endoscopy (the one that goes down



your throat) is a bit more difficult without sedation, despite the anti-gag throat-numbing spray (make sure they use a lot of it). The other bummer with this procedure is you really can't watch it because you and the doctor are not facing the same direction.

