

iHaveUC **Feeling Crappy** **to Feeling Happy**



NO PAIN
NO DRUGS
NO SURGERIES

written by Adam Scheuer

Thank you for your interest in my ebook. Up until Thanksgiving Day 2019, I had this exact ebook for sale on the iHaveUC website since I published it nearly ten years prior. The proceeds from the ebook have helped to pay for the costs associated with the website, and more than anything, several thousand UC'ers and their families have benefited from reading my story.

But, I have decided to make this ebook something that no longer has an up-front cost. Rather, if you would like to show your appreciating for the ebook and the website, please feel free to buy me a roll of toilet paper/make a donation of support to iHaveUC via this simple PayPal link.

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Introduction

My name is Adam. I have Ulcerative Colitis(UC). This book is entirely dedicated to all of the hundreds of thousands of people who have or will someday have UC. This book is also meant for anyone and everyone who works, sleeps, cooks, or cleans with patients who are dealing with UC. Much of the book is based off of my personal experiences, feedback from family members, and real life medical records that I have accumulated in the previous months and years. My personal encounter with UC has led me to meet with 6 gastroenterologists(several from internationally known medical institutions), many more medical assistants, the MRI machine, more blood tests than I can count, medications of all types, and much more.

Through all of the different experiences, I have come out on-top feeling pretty darn good. My colon is still in-place, and I'm real happy about that. But I realize everyone has a unique situation before and after a UC diagnosis. For many people, surgery is the best decision and leads to a very happy life. I've learned how to beat Colitis without surgery, and I'm happy to share all the details with you.

WHAT I'VE DONE EVERYONE CAN DO

For this book to really make sense, you should understand who I am. Up until the time where my symptoms of UC began impacting my life, I'd consider myself as average and normal as anyone. I grew up in a family of divorced parents in the Silicon Valley region of California. I attended public schools all of my life. I also had friends that were from quite a few different socio/economic backgrounds, which was very common in my area. I learned to speak Spanish, AND I still speak it quite a bit. When I was a teenager, I started working different jobs, mostly in local pizza restaurants. I even bought a used 1979 VW super beetle for my first car when I was sixteen with money that I earned on my own. I am still proud of that.

Through high school, I was never the "most popular" person. I had some good guy friends, and some girlfriends, but never a "steady girlfriend" back in those days. I played a bit of sports as a teenager, soccer, golf team, and some bike riding for fun. I was athletic, but I was never considered to be someone who could play competitive sports in college, and that wasn't my goal anyways. When it came time for college, I attended a four year university. I was an average student overall, some classes I did alright, others, not so good. I don't think I failed any courses, but I may have come close a few times.

After college, I fell into the category of someone who was lost and not sure what to do. At that time, I had a girlfriend, and I was feeling really good health-wise, but I had no direction. I did a bit of moving around after college, and eventually found a town to settle in on the California coast called Santa Barbara. Without too much delay, I eventually found an apartment to rent, and a job that paid the bills and allowed me to continue on with life.

After several years, and some more moving around, I ended up back in my hometown which is where I ended up receiving my UC diagnosis. Like most people, I waited longer than I should have before seeking proper medical attention. And like most people, I was scared when I was diagnosed. That was over three years ago. Time does fly, even after being told you have UC. It's pretty incredible but it's true.

When I look at my life, not much has changed. Of course I've had UC for several years now, and of course that's a pretty big "medical event", but it has NOT stopped everything else from moving forward.

The Point Is This:

I'm a normal average Joe. My name just happens to be Adam, and I happen to have UC. Most importantly, I'm living a normal happy life, despite what I thought was going to happen to me after I was diagnosed.

- Do I think its a miracle that I've got my UC under control? HELL NO!
- Do I think that in anyway I'm different than other UC'ers of the world? Again, HELL NO!
- Do I think a normal happy life is possible for everyone with UC? OF COURSE!

These three questions and answers are the motivation that has me writing this book. I hope you can understand now that I'm not some miracle, I'm not any different, and I'm pretty darn happy with my UC life.

- For anybody who is not sure about your future, I understand your concerns.
- For anybody who is scared this very second, I understand those feelings too.
- For anybody who feels that UC is the end of the world, I disagree completely.

What I've done everyone can do.

One More Time!

What I've done everyone can do.

With UC as well as life, here is the big decision:

Do you want to be a victim or not?

I've made my decision, and now it's time for you.

Part 1: Alone With UC

EARLY DAYS

Most people don't know anything about UC. Most people who have it, don't even know it's name until after the diagnosis happens. I was one of those people. Sure, I'd heard about Crohn's Disease. My uncle was diagnosed with that a long time ago. But UC was something new for me. I was also oblivious to the details of eating and pooping out food. That was one of those life processes that I assumed "happened some how".

Growing up, I was one of those kids who was always complaining about an upset stomach. During the bus ride home from school, right after dinner, and even while playing video games, there were so many times where I felt some light cramping that came and went. Maybe these were the signs of what was lying ahead.

My memories of early childhood are great. Riding bikes with the other kids in the neighborhood, throwing the occasional roll of toilet paper on some other friend's house. Getting in some occasional trouble, learning some lessons early, and others not at all. I know there were some really hard poops and a bunch of normal bowel movements mixed in over the years. I also remember many times where I was stuck in the bathroom while my family was getting ready to leave the house. It went something like this:

"Hey Adam and Todd, let's get going!", my dad would yell out.

"I'm in the bathroom, give me a few minutes", I would yell back. This was really common.

I was just a kid, how was I supposed to know that there was even a word called "Colitis"? I just knew that when you needed to poop, you went to a bathroom and squeezed everything out. They you wiped with some toilet paper. Nothing too complicated, it was just part of life.

Did I spend more time in the bathroom than others?

Yes I did.

Did I think it was unusual in any way?

Nope, not at all. This was just my ordinary life.

HIGH SCHOOL

During my high school years, my parents never suspected that I could have a major health problem. Because my symptoms weren't causing me to miss out on the usual activities of a teenager, my "stomach aches" were pretty much left unexplored. I was one of those high schoolers who was getting decent grades. Better grades in math, less spectacular in reading. For athletic activities, I played soccer and golf, and I was in pretty good physical shape.

Back to my stomach aches...well, that was still a mystery. I thought stomach aches were caused in these ways:

- bad food
- nervous about something
- too many sweets or candy
- little bit of gas
- being plain old hungry
- scared about a test or difficult homework

Nobody is suspecting inflammatory bowel disease when you say your tummy is hurting. Not even GI doctors. In hindsight, I had some signs that could fit a colitis patient nicely. For example, after every meal I would be heading straight to the bathroom to take a crap. I would usually be the first at the dinner table to ask, "May I be excused?" and then I was off. It may have seemed a bit strange to my family at first, but it eventually became part of the evening and blended into everything else that was going on at home.

Some of those bathroom visits would consist of me thinking to myself:

- wow, did that meal really go through me so quickly?

- how is that physically possible?
- aren't the intestines super long?
- does it just take a few minutes for food to exit?
- what about the stomach?

I had no idea what was going on inside, so I pretty much avoided my questions until the next bathroom visit. One to three bowel movements per day was what I was averaging back then. That seemed normal to me. I do not remember any blood on the toilet paper, or blood within my hard and often soft stools during teenage years, but that of course changed. Slow change is a tricky thing when it comes to your health. Just when you start seeing symptoms of something "unusual", it easily can become part of your life. You can even forget entirely when symptoms started. That's exactly what happened to me.

OFF TO COLLEGE

After graduating from high school, I attended four years of college out in Boulder Colorado at the university. Great time, excellent memories, and I'd recommend college to anyone who is on the fence with that type of decision. I don't think my undiagnosed UC made a huge impact on my college days, but then again I may have already adjusted to the mild symptoms. As much as college was full of learning, it was also full of extra curricular activities. I was pretty impressed with how much freedom college life meant. Not that I didn't have all kinds of freedom growing up in the Bay Area. I had that too, but college was a whole different thing for me. There were college football games, keg parties, dance parties, weekends to mountains, and many options for where to find food. I was now making all the decisions on my own, and that was the beginning of a lifelong theme that still continues today.

During my first year at college, I joined a fraternity, and also started lifting weights again. I had dabbled in weight lifting in high school, but nothing too serious. The college gym was a great place to workout. Not only was I usually there with some good friends lifting weights, but there were all kinds of girls too. Back in those days, I thought some more muscles might increase my chances with the ladies. I'm probably not the first person who has dreamed that idea up before.

So how did UC impact my college days? Probably just like my earlier life. More trips to the bathroom than the average Joe. Longer durations while in the bathrooms. Some subconscious pre-trip bathroom planning. What I mean by that is, I found ways to use the bathroom and

"empty out" before going off on long excursions. For example, before heading up on the "4x4 Bring A Date Camping Trip" with the fraternity, I made sure to take a big poop before the drive to the campgrounds.

Just over halfway through my junior year in college, I was lucky enough to head over to Europe for a study abroad program. That's where I met my first "long term girlfriend". She was from Indiana. Since I have not talked to her since being diagnosed with UC, and because we don't talk anymore, I'll probably never know if she suspected something was strange with my bathroom needs. When you think about mild symptoms: cramping and loose stools for days/weeks/months on end, it sounds like it would be hard to hide. But you really can hide it. People with UC are professionals at hiding the symptoms.

My 4th and final year of college was also uneventful in terms of UC, I never went to the doctors, I just dealt with the extra bathroom visits on my own. Nobody ever really paid much attention to it. I lived with two guys and two girls my last year, and there were two bathrooms in our house. Two bathrooms definitely helped me disguise my high amount of BMT(Bowel Movement Time). And let's face it, Boulder was still a party school, you could be in the bathroom for a number of reasons. Even if one of my roommates was using the bathroom an extra special amount of time, I doubt I would have said a word. There's just too many reasons someone might need the bathroom more than others. People don't think you're using bathrooms to take loose stool craps. That never comes to mind. Your college roommates are suspecting all kinds of other things before colitis symptoms are guessed. Has anyone ever taken a beer crap after an extra long night of drinking? I rest my case.

I remained with the Indiana girlfriend all the way through our seniors years(turned into a long distance relationship) and then we re-united after graduation. I moved out to Indiana for the summer, and within 3 weeks I was out of there. I only found work doing graveyard shifts at the local grocery store and I couldn't make sense of having a job I didn't like. So I moved home, and she joined me out West maybe a month or two later. Actually, I shouldn't say that I just "moved home". For quite a bit of time, I felt it was much more of an "ESCAPE". A great friend of mine, actually one of my oldest friends flew into Chicago, and we drove back together in my car. We did some camping and cruising across the country. Mike, that was a great trip, thanks so much for coming and kidnapping me!

DOWN TO S.B.

Once I was back in California, the girl from Indiana moved out West and we re-united after just a few months. A quick decision was made, and we both drove down to Santa Barbara to start a new life together. Neither of us had ever been there, but it seemed like a perfect place. Beaches, young people, great weather, what the heck could go wrong? I started wondering how it was possible to go so long and never even visit this dream town. Had I visited Santa Barbara during the college decision days, who knows? Seems pretty irresistible to me.

After just a few days of looking, we moved out of the nasty hotel we were sleeping in, and began renting a tiny apartment. There was just enough room for our tiny bed that barely fit the two of us and our clothes that we would scatter all over the floor. The bathroom was also pretty tiny. I don't remember if my girlfriend ever walked passed me to jump in the shower while I was taking a poop or not, but if she did, we would have been bumping knees for sure.

Things didn't not end well with that relationship, but that wasn't the end of the world. We broke up after about a year of completely un-necessary living together. Not only were we fighting, but both of us simply weren't happy together. OK, for the record she broke up with me, and I was heart broken for a little while. It took some time to get over it, but soon enough, I was out meeting new people, working a dream job, and turning the ship around. Maybe it was dumb luck, but my early twenties turned into some excellent years. The change from happiness to depression and then back to happiness all happened real fast.

In Santa Barbara, I reached a peak in terms of my physical and mental health. Not only was I living a great lifestyle, but I was living with some of the greatest friends, all who were co-workers. There were days when I would go to work all day, and within 30 minutes of getting home, I'd be ready to hit the local gym with several co-workers. While there, I would either take part in a yoga class, or more often than not, get into a pumped up weight lifting session with my buddies. It was awesome, I was physically fit, and eating well. I can remember getting up to the 245 pound mark with the bench press, which was an all time record for me. Think about it, a 165 pound guy, doing a legitimate (not half-assed or assisted) bench press a few times if pretty respectable right?

Eating meals back in those days was pretty fun too. Several nights a week for dinner I'd run down to the local Vons or Albertson's grocery store. With my roommates, we'd all put together a massive BBQ night with other friends or girlfriends. God I loved those evenings! Cranking out

some grilling, cracking some cans of beer, and shooting the shit with my buddies. It was always fun seeing such a mix of people rolling over to our house as the nights would drag on.

In Santa Barbara, my fascination with the local bar scene spiked. As many young 20 year olds find out, it's not too hard to turn a simple night on the town into a full on drunken mess 50-100 dollars later. Of course it wasn't a big deal to wake up at 6:30 in the morning and get ready for work and still be productive back in those days.

For just about two years I was living out my dream of being a sailor as well. There was a point where I lived on a sailboat in the Santa Barbara harbor, WOW, that's some great living too. Not only is the rent super cheap compared to an apartment or renting a room in a house, but it's also the place to meet all kinds of other people who are looking to have a good time. There all all types of folks in harbors and marinas. You get the dirty squid fishermen who come back from a week at sea, hands all black from squid ink, stinky as ever, and looking for as many beers as they can carry back to their fishing boat. There's also the posh yacht club types, who are looking for a perfect day to take their boat out on the water with friends and family. And then of course there were people similar to me, young guys and a very few girls living onboard a small boat trying to save money on rent and live the boat life.

As it turns out, life in the Santa Barbara Harbor also prepared me to make use of public restrooms. That's right, I'm an expert at using public bathrooms now! That's where I did all of peeing and craping for two full years. It's no big deal for me to poop in a public bathroom anymore. I never knew how important it would be once I was diagnosed to accept the fact that it may not always be possible to saddle up in your own bathroom when nature calls. In the harbor, I would always try to get my bathroom business completed first thing after they were cleaned daily at 10:00am. You would usually see me making my way with my towel and toiletries down the dock in my board shorts right around 9:55 AM to be among the first to use the freshly cleaned facilities. But, there were plenty of times where I'd be in there dropping a Number 2 later on in the day as well. Wiping my butt with the rough 1ply toilet paper that most public bathrooms have to offer. You know what I mean don't you? Those big huge two foot diameter industrial use rolls of toilet paper that are probably close to a mile long and paper thin. (Thanks marina 3 restroom for teaching me to be happy with a public pooper...)

WORK BATHROOMS

Punch me in the face for not noticing, but of course, I did spend more than my fair share of time in the work bathroom. My first real job after college was with a software company. I had several roles there, and most of the other employees were young and just out of school like me. The company was situated in a large building on the outskirts of Santa Barbara, actually the town was called Goleta. I started off assisting the sales department with completing contract documentation and quotes for the services we offered. My boss was a great guy named Mike, and I was his only direct report. We did a bit of shuffling around in terms of where our department was located in the building, but early on, I was just about 20 steps from the bathroom. The only bathroom in the whole place. With 80% males in the company, it sometimes was crowded.

I used that bathroom to poop either once or twice a day. So yeah, that's definitely more than the average person, but it never seemed strange to me. The work bathroom was different from the bathroom at the marina. I always was more self conscious of the noises that I would pass while taking a poop. As hard as it was at times, I'd always try to cover up the loud gassy sounds that flew out from under me.

These slow signs of extra bathroom use was beginning to creep into my life very slowly. But nothing that made me concerned, and it didn't bother me or my outside life. So I didn't ever mention anything, not to my family and not to my friends.

ANOTHER GIRLFRIEND, STILL NO POTTY TALK

I think I went about a year or so without a steady girlfriend, just doing my thing. I can't really count the Swedish girl who dumped me after just a month as another girlfriend. She was great, but things were uncomfortable early on. The Swede lived in this little cottage with a kitchen, living room, and bedroom. The bathroom was attached to the bedroom. When it came time for me to take a poop there, things got difficult. She could hear everything. I mean everything. Imagine a bedroom with a doorway that leads to the toilet. And then imagine instead of a door, there is just a hanging rug for the door. Definitely not the ideal soundproof bathroom you'd love to be using when you just start dating someone. But bathrooms aren't always perfect. There was a wall in the "bathroom toilet area", but it did not go up to the ceiling. So my sounds traveled up, and then down right to her ears while she was asleep in the bed a few feet away from me. (Of course she was probably not sleeping through a big morning grump that was usually somewhat gassy.)

- Great girl? Yes.
- Was it a great month and a half with her? Yes.
- Did she ever ask about my mostly noisy poops? No.
- Did I try to muffle the sounds from my poops by turning on the radio pre-poop whenever possible? YES
- Was it awkward blowing out a nasty one and thinking of her sleeping naked a few feet away? YES SIR!

Not long after the Swedish girl, I met what turned out to be my second long term girlfriend "J". We were together for three years. She was a great person, we slept together most nights, but still renting our own places. She never said anything to me about my pooping. I never complained about extra pooping to her while we were together either. Maybe I had a few more "stomach aches" than the average boyfriend or person, but still, I was doing a really great job of hiding the early symptoms of my eventual UC.

MY FIRST DIET RESTRICTIONS

Some of my earliest moves to alter my previous "NO RESTRICTIONS DIET" took place while living in Santa Barbara. After my gym workouts, I would try to get tons of protein in my body as well as carbohydrates. I was never a big huge guy, I probably topped out at 165 pounds, but I was very strong for my size. It wasn't too hard for me to do several sets of 10 reps or more at 185 pounds on the bench press. But I still wanted to get bigger. I thought eating more would help with that. Milk started to become a big part of my diet for both protein, fat, and carbs. I would dump a ton of Hershey's Chocolate Syrup in the milk. It had to be chocolate milk or it just wouldn't work. And let me tell you something, I could drink a shit-load of chocolate milk in about two seconds.

After going on a milk break all through college, I noticed fairly quickly that normal milk didn't seem to agree with me. So, instead of telling any doctors about the diarrhea that I was feeling, I simply started getting the LACTOSE FREE MILK. That seemed to help a little bit, but things still weren't perfect. I was doing more bathroom breaks than most people, and the stools were rarely hard and rock like. The semi soft version was the usual if not a constant for weeks at a time. But, I convinced myself it was just a lactose intolerance. That seemed easy enough to settle my brain and worries.

It wasn't all just gym and healthy stuff in SB. There's some hardcore drinkers down there too. Throw in several beers and drinks from a night on the town, and I can definitely remember nasty diarrhea the morning after. So I made some modifications. Nothing complicated. It was simple. I would stick to hard alcohol for the majority of my drinking. Beer and wine weren't doing it for me, so they got cut. Hard alcohol was going to be my solution. From then on, when the bartender asked me, "What can I get for you?" I stopped asking what types of beers they had.

If you asked any friends from those days what they'd expect me to show up with at a party, for sure they would say some Jack Daniels, compared to the typical 6-pack in hand which was more common. It wasn't until the very end of my SB stay that I migrated more towards Vodka on the rocks which seemed to cause me less bathroom stress the next day.

CRASHING THE PARTY POOP STYLE

For some of my stay in Santa Barbara, we lived in a great house, 2047 Mountain Avenue, Santa Barbara. And we often threw house parties since the pad was perfect for it. As much as I was usually the life of the party, I can remember tucking away into one of the two bathrooms for a mid-party poop break more often than not. Who does that...goes and drops a stinky, loud, gassy poop in one of the two bathrooms during a party where there's 50 half drunk half stoned partygoers all around inside, outside, in the front, and back of the house? Well, that was me. And at this point, I was 24 years old. I just couldn't wait until everybody was gone. It wasn't worth it to wait until the morning when everyone was passed out and asleep to take my poop. I was starting to go when I needed to go. Some things were starting to catch up to me, and it was right there in the toilet bowl. No blood yet, but very little hard poops.

BACK HOME STILL SILENT

At 26, I moved back to Menlo Park where I'm from. I still had NOT visited a doctor regarding my bowel movements, and it wasn't really concerning me. The thought never crossed my head that my uncle with Crohn's Disease might have some insight into what I was doing in the toilet. "It wasn't affecting me. Nope, not at all." That's how my denial was going back then. I was still with my girlfriend J, she actually moved back up north the same time as me. I landed a great job at a company where I managed a growing sales team of young, happy, excited, smart people. Work was fun. Money wasn't a concern anymore and I thought I was healthy. Nobody ever came close to questioning my health. What could possibly be wrong?

- **First:** I was using the bathroom more than anyone else. That was not so much of an issue being the manager, but still people noticed.
- **Second:** Who goes out for lunch everyday and eats a big burrito that costs five bucks, and then right afterwards runs to the bathroom?
- **Third:** Who also goes back to the bathroom maybe an hour later?
- **Fourth:** Who has to excuse himself from meetings to go and use the bathroom, even when you're meeting with people from the executive team? Well, that would be me. Maybe it would have been much easier to come clean and simply declare:

"My name is Adam, and I like taking multiple loose stool poops everyday.
Any questions?"

But of course that never came out of my mouth. My brain kept telling me this was some unique situation that was going to pass in the future. And that's what I believed. I think some smart doctors with PhD's might call this denial. You make the call.

LOWER BACK PAIN

It wasn't until about a year into this job, that I did something revolutionary. I brought one of those big blow up "stretching balls" to sit on instead of using my chair. I had started to notice my lower back feeling like hell as the day wore on. It became worse and worse over time, so I thought it was the chair. It wasn't the chair. What was happening in hindsight, was another sign of my growing inflammation. It would come and go, just like the softness and hardness of my poops.

Back pain. Maybe it was because I exercised so much?

During those years, I was biking to work most days, and biking on the weekends. I completed a 1800 mile solo bike trip to Croatia and a smaller one to Argentina. Why was my body starting to break down on me now? Did I pull a muscle somewhere along the way? Maybe I injured myself playing soccer back in high school and it was something in my back. That must be what happened. Or maybe that one time I got up from the couch and felt some pain the next day, did I pull a muscle then?

Who knows how many different ideas I drew up in my head? I probably told others all sorts of ideas for why the back pain was happening, I can't even remember. But I pushed forward, kept working hard, the company kept growing, and things were still fun. One thing that wasn't working out though was my relationship with J. We went our separate ways, and once again I was alone and out of a long relationship. I haven't talked with her since being diagnosed, but I wonder what she would say if I told her my real story now with the UC diagnosis. Did she see any signs, did she ever want to say something or ask a question. Was it weird how much time I spent taking craps in the bathroom?

FINALLY MET THE ONE

Just a few short weeks after breaking up with J, I got really lucky. One night, I was at a local Palo Alto bar with a co-worker named Mo. We both had a ton to drink. It may have ended up being a \$100 bar tab, actually I think it was over 150 bucks. But it was worth it. I met a girl there. She was from Mexico and was having a party at her house later that weekend and invited me to come along. So, we did the usual, shared numbers, and didn't think much of it. Let me add, we spoke in Spanish pretty much the whole conversation, as that was better than us trying to hack it out in English. I wasn't super attracted to her, but I was always game to meet some new people, especially if some Mexican food might be involved. And, isn't meeting new people what being single is all about? That's what I thought at the time.

So the weekend came, she sent me a text message with the address of the party. I dragged two co-workers with me to the Belmont Hills, and we were off in search of a party. My friend drove his ride, and nobody had a clue what to expect. Were we on a wild goose chase? Was this going to be a good time? What the heck were we getting into? There was a growing feeling as the drive became longer and longer that we might end up at a bar back in Palo Alto or maybe even San Francisco for the night. The expectations started to dwindle the farther we drove up into the hills. But sure enough, the address did exist. We finally parked the car on the street and it was time to find out what was really up.

When we arrived at the house, something seemed funny. Was this non English speaking person really living up in this fancy neighborhood? It just seemed strange. And what did she tell me she did for a living? I had been drinking heavily when we met, if I asked her, I definitely didn't remember. So I walked up, friends behind me, and knocked on the door. It seemed really quiet. Just a couple cars parked on the streets. This might be a total bust is what I was thinking. If that was the case, we already had some backup plan ideas. The night was still early. But there she was, the Mexican girl from the bar in Palo Alto. She opened the door up and we walked in.

It didn't take too long for me to realize this was the place I wanted to be. In the backyard there was a whole herd of foreign girls. What was the occasion? Well, the owners of the house were out of town on vacation, and the au-pair was having a party with about 10 other au-pairs. The feeling was similar to going down the elevator at a Las Vegas casino after you've arrived and unpacked and hearing all of the slot machines dinging away. "Ding Ding Ding Ding"

- **Excited? Yes I was.**
- **Happy to be there? Um...A BIG FATTY YES SIR.**

Soon enough, I met Michaela who was different than all the rest. She was a bit of a hard ass compared to the others. But she was from Prague, Czech Republic. And lucky me, I'd been there a few times. So racking my brain as much as I could I started busting out questions about Prague and trying to act as interested as I could. One thing I've realized in my short time with chasing women is that asking questions about their lives back home wherever they are from, usually is better than talking about yourself all night long. The only trouble that evening was her English was 2 months old. She had just arrived off the boat a few months before. I'm not joking, she had arrived in June, and we met at the end of July. But that didn't stop my pursuit. We talked, maybe even danced, no kissing though, I'm not that aggressive. But I did catch her phone number.

After spending the night on a couch at this party house(my friends had all left at some point), I woke up and gave Michaela a call. I needed a ride out of this place. I left her a message. It turns out she was in the shower and missed the call, but I asked if she wanted to get breakfast together. To my surprise, she called back just a few minutes later and we made plans. I also threw the request for her to pick me up at the house from the party. Lucky enough, she lived just a few blocks away. Maybe twenty minutes later, we were off to share our first meal together. She realized at some point that next day that I was stranded and for sure needed a ride, luckily, that did bother her too much.

EXTRA LONG BATHROOM TIME FOR ADAM

Our first meal was at a breakfast restaurant in downtown Menlo Park called Stacks. It's one of those American Breakfast places, with the big menu. All kinds of pancakes, egg dishes, and whatever else you can imagine you'd find at a place like that.

Breakfast was going great, but I needed a bathroom real bad. I held in my usual bathroom breaks with the hope of finding a more comfortable situation in the near future the entire night before. When I couldn't bear it any longer, I remember taking a break from the breakfast and heading off in search of the restroom. I left the table for a little while, but I can't imagine it was for too long. Two years later, when we started talking more and more about my colitis symptoms, Michaela let me know that I must have left her for 20 minutes or more on our first breakfast. What can I say? For me a twenty minute bathroom break was totally normal, even if I was on a first date!

Michaela and I had a great beginning of a relationship. I was taking her out to expensive meals, spending money, trying to get her excited. You know, the usual early moves of so many guys. I loved introducing her to all my friends and family, now I was the guy with the exotic girlfriend from the Communist Lands. Even though we were so very different right from the start, that didn't seem to matter to us. The days and weeks started rolling on, and Michaela started spending the night at my place. Actually it was my dad's house where I lived at the time.

When we talk about it now, it's funny, she remembers so many mornings where she'd wake up and be all alone in bed. Initially she often wondered if I already left for work, and just left her. But, she quickly realized that maybe 15 or 20 minutes later I would roll back into bed. Nothing to worry about, I was just in the bathroom taking my morning poop. Playing it off like I was just reading the news, I would sometimes walk back into the bedroom with the newspaper incase there were further questions or suspicions. Come on everyone, by this time I was a very seasoned veteran when it came to covering up my long bathroom visits throughout the day. And I know there are others who are professionals at this too.

If I could change anything up to this point, I would have used a different bathroom in our house growing up. The one I liked the most was the one farthest away from my bedroom, which may seem odd. This bathroom also has a dark porcelain toilet, and there wasn't much light in the room either. Dark walls, dark everything. But I liked it. The one problem with this type of bathroom is that its hard to see your poop. You can feel it, you can smell it, I guess touch it, BUT it's hard to see what's coming out. And because of this, I never got to see several years of super soft runny poops. My view was only watching the toilet paper going around in circles. Maybe my mind moved me to this bathroom because of this reality. Maybe my mind was sick of looking at non hard poops, and by choosing this bathroom, it could all be avoided. Another mystery of colitis.

Michaela never once asked me any direct questions about my bathroom needs. She didn't once. And since I was so used to the bathroom as being a part of my day, maybe an hour a day at this point, I didn't see any reason for alarm. This was just normal old Adam.

MY FIRST VISIT TO A DOCTOR(RED ON THE TOILET PAPER)

After being with Michaela for some time, I started to see tiny bits of bright red blood on my toilet paper after I wiped. Also, some very slight cramping feelings were making their way into my life. So, I decided eventually to go to the Urgent Care in Palo Alto, which was the closest place to go that wasn't an Emergency Room. This sure as hell wasn't an emergency. How much time passed from when I saw the blood to when I made it to the Urgent Care doctor's office? Great question. I wish I could say just a few hours. Although I'm not for sure, I'll bet it was several weeks or more. And it wouldn't surprise me if a few months went by.

Once I arrived at Urgent Care, I put up with the usual wait, and was eventually seen by a doctor. It wasn't some horror story ten hour wait or anything, only an hour or so. I was called in, and brought by a nurse to the exam room. There was a couple of chairs, and a full table you could lay down on. I took the chair and just sat there waiting. This should be a pretty quick in an out meeting was my hope. On one hand yes, there was some bleeding going on, and it was coming out of my ass. But on the other hand, this wasn't really affecting my life at all. Or at least that's how it seemed to me. It was the weekend. I hadn't been to any doctor for a really long time. How bad could this really be?

I remember the doctor well. He was nice, seemed smart, and he wore street clothes. This was pretty cool to me. Actually, I'm not sure if he was a doctor or a physician's assistant, but I didn't care. I was finally going to see someone about my plumbing, and all I wanted was to hear something that calmed my brain down. He asked me some questions, and I gave him some answers. I wish I told him about my Uncle's Crohn's Disease, and my grandpa's gastro problems. I left that important bit of family details out. I started telling him, "maybe some sort of an ulcer..." An ulcer seemed like the most possible reason for all this. A stomach bleeds, you have an ulcer, maybe it comes out red. That's where my head was at.

He did the finger test, he put on a glove, and stuck his finger up my butt. It definitely didn't feel too good. He was checking to see if there was any blood. I think he had some type of gauze pad at the end of this finger tip that was hopefully going to pick up whatever was just inside the butt hole. How strange that experience was. It was a relief once the few seconds were over. Out came his finger. He found a trace amount of blood, meaning a very little bit. And it seemed as though it was nothing to worry about. We did some blood tests too, and that was that. When the test results came back, I wasn't dying and nothing too crazy appeared, so I simply wrote it all off as nothing to worry about. One of those things that would fix itself.

Had the cramping been more severe, or had there been just one day of lots of dripping blood in a toilet bowl where I could make out all the red, maybe my diagnosis would have happened much faster. Or maybe had that doctor told me to meet with a gastroenterologist who would then ask me to undergo a colonoscopy or sigmoidoscopy, maybe that would have caught my UC sooner. It's really tough to say. I'm sure there was some type of inflammation and active UC symptoms several years before I was officially diagnosed, but that's just doesn't matter. I kept everything to myself, and moved forward with life.

What's the Big Idea:

- When your ass is bleeding out blood, go see a gastroenterologist. That's what they are for!
- When your having rectal bleeding, it's serious. Go see a GI doctor(gastroenterologist). That's the type of doctor who deals with those types of symptoms!

COME AND GO SYMPTOMS

After less than a year together, Michaela and I decided to up and move back to the Czech Republic. She hated the family she was an au-pair for, and I was always up for an adventure. She could have renewed her contract with the family who's kids she watched, but she decided not to. All of a sudden, I resigned from my job and hoped for an even better time with Michaela in Prague. It was one of those situations in life where you go with your gut feelings and make decisions accordingly. Leaving a well paying job, and heading off into the unknown surprised some of my friends and family, but it wasn't too crazy an idea to me.

I can't say for sure, but had I already been diagnosed with UC, my guess is I would have been staying in the United States and not flying overseas. I would have been too worried about dealing with foreign doctors and the unknown that might happen in a foreign hospital. It's unfortunate but true. UC can trap you, no matter how strong or independent of a person you are. When you are living without a diagnosis, you just don't think your symptoms can really hurt you. Maybe that's a good thing, maybe it's not. But by leaving for the Czech Republic, I delayed my diagnosis even longer.

It wasn't too much time between deciding to make the move, and boarding the airplane. Not even a month. One night at the apartment rented, Michaela and I were on the computer looking up plane tickets. We found what seemed like the perfect deal. Two one way tickets with several stops. The first being from San Francisco to Las Vegas. Three days later to Boston, and then a week later off to Prague. The Vegas portion was all kinds of fun, we met up with my boy Brad

from Santa Barbara. (He's an old roommate from down there) All three of us, took off to the Grand Canyon for a night's camping. Then once we flew to Boston, we headed up to Maine to see my Dad, Stepmom, and Uncle Bennett. Uncle Bennett's my uncle who had Crohn's Disease.

While we were in Maine, I definitely remember my lower back pain getting pretty bad. It seemed to come and go, but it was mostly present for those last few days in the US. I remember talking with my uncle about it too. I also told him I had a bit of blood on the toilet paper. Actually, I'm pretty sure I left that little detail out. I wish I had explained it all to him back then. He would have known exactly what to ask me and what to do. He was diagnosed with UC by Dr. Crohn (the Crohn's Disease gastro doc) years ago. It wasn't until his surgery that they realized he had Crohn's disease. He lived one of the most remarkable lives of anyone I know. He struggled with the worst symptoms for so many years. Things got much worse during his college years down in Miami. He struggled through so much, my dad was there to help him out, but life with active symptoms is never easy. My uncle knew what I was going through, he had lived it for years, and he also had seen how nasty things can get. It would have been so simple to tell the truth to him, and take his advice. But my silence of the truth continued. I covered up all the symptoms once again. I didn't want to open up a can of worms, especially before we were headed over to Eastern Europe just a few days later.

We arrived in Prague, Czech Republic July of 2007. Right off the bat, Michaela and I moved in with her mom into a 1 bedroom apartment. The apartment was in a big building just off the Skalka metro stop. About 20 minutes from the main square. A perfect location. Not right in the downtown, but not out in the boon docks either.

I had no idea what the bathroom situation was going to be like in our new living quarters, but it worked out just fine. I had a hard time communicating to Alena, Michaela's mom, but I'm hoping that Michaela filled her in with my unusual bathroom habits. Or at least the fact that I made use of the toilet more than most. But, things were starting to get more uncomfortable as the days went by. I was so used to having a private secluded bathroom to unload in. One where you wouldn't hear all that was taking place inside. Instead, the walls were thin and the Czech toilet wasn't as good at flushing as it's American cousins are. Everything did go down, but my extra toilet paper required multiple flushings.

Compared to how out of control my colitis symptoms became just one year later, my early days in Czech were a walk in the park. My stomach pains would come and go, but I was able to deal with all of it without Michaela questioning me. Michaela and I would be sitting with her mom in the apartment's living room. Then all of a sudden I would simply get up and go to the bathroom when the urgency feeling hit me. No big deal. And after 10 minutes or so, I'd be back

sitting on the couch listening to a TV that I didn't understand since it was all in Czech. And who knows, maybe an hour later the same routine might pop up again and back to the bathroom I would go.

After a month in Czech, Michaela and I shoved off on a 1 month bike trip. We had two bicycles, two sleeping bags, saddle bags, and a tent, and that was my grand introduction to Czech and Slovak. We spent the nights in pensions, campgrounds, and a few nights with her family down in Czecke Budevice. Once we were back in Prague, we quickly found another apartment to rent that was super close to Michaela's mom.



*(August 2007. Me repacking some bags on Michaela's bike. just about a week into
our
month long bike trip in Czech Republic and Slovakia)*



(above, picking blueberries during the bike trip, near Telc, Czech Republic)



(me crossing into Slovakia on a pretty challenging 80 km day of riding,

*there's a pretty nasty mountain you need to cross before you get to Nove Mesto
Slovak)*



(Michaela going downhill near Horni Stuba, Slovakia)



(Biking near Ostrava, CZ

15 months before my diagnosis)

I was still able to go out and meet friends at the local pubs, and pull all-nighters every once in a while. My body was holding up to the point where it was still pretty easy to go under-cover

with my true symptoms. The bleeding was mostly confined to mixed in with the poops, it was never dripping blood as I remember. "It must be some sort of ulcer", that was still my thinking. This was probably the time where I started to look up what ulcers were with the help of Google. And of course, after a few minutes searching, I came to the conclusion that there was absolutely nothing to worry about. Had someone told me to search "UC", well that would have been a whole different story. "UC" was just as foreign to me as all the Russians and Ukrainians I was playing poker with on Friday nights, in the dingy bar that didn't mind our gambling and craziness.

My symptoms were not normal, but I was still able to hide everything very easily. For example, I landed a sales job at a company in downtown Prague. It was a metro ride and two trams from our apartment. Tons of fun too. I was one of two Americans there, and the rest were young people like me from probably 15 different European countries. All sorts of great people, and we all partied together on the weekends too. But for me, my frequent bathroom visits weren't hard to hide. In Czech, there are tons of smokers, and taking breaks to smoke was super common at this job. So me slipping out to take a few craps throughout the day wasn't even on the radar. I fit right in.



(Dec. 2007, Bratislava, Slovak. 10 months before my diagnosis.

Lots to drink at the holiday party)



(New Years 2008, in the mountains of Czech near Poland, 9 months before my diagnosis)

After 10 months in Prague, Michaela and I decided to get married. Right in the heart of the Old Town Square. It was raining that day, but that didn't matter at all. It was the time of my life. We had a very interesting ceremony, one where I was required by the Czech government to pay for an English interpreter. And one where we had to decide if we wanted the organ player to play 1 or 3 songs.(We opted for 3, the additional cost was around five bucks). After the ceremony, our whole wedding party and some friends and family members of Michaela's, headed for one of our favorite restaurants. This place was actually a brewery, but they served Pork Knuckle with horseradish and mustard. My favorite meal in Czech. It all ended up being a perfect day. And we stayed in a hotel room that night which my mom bought us for a wedding present.



*(April 2008, moments after we married in
Prague's Old Town Square)*

As happy as I was on the outside, on the inside my colon symptoms were slowly getting worse and worse. The hard poop was almost non-existent anymore. Traces of blood were mixed in with the soft stools daily. And my guess is that I was using the bathroom 3-4 times per day. Was it all the beer and goulash I was eating that was causing me to poop so much? Was it stress in my life? Whatever was happening inside of me was still a mystery. Not too much later things started to unravel.

Part 2: Married and Back in the USA

Like any good husband, I was up and out of the Czech Republic within just a few hours after getting married. There was a new job waiting for me with an exciting start-up company back in the Silicon Valley, and I was supposed to be running the sales department. Although I was not excited to be leaving my brand new wife, I was assured by Mario, the Director of the Visa Department at the US Embassy in Prague, that Michaela would be back in the states within a month. I held on to Mario's business card for dear life. In my mind he was the gate-keeper to me seeing Michaela again. (Thanks for keeping your word Mario, she was back about 5 weeks after I left the Czech.)



(Early May 2008, Santa Barbara, CA. Off to the bars.)

May 30, 2008, was the day. That's when I picked Michaela up at San Francisco Airport. It sure is tough leaving someone you love and relying on trust that you'll see each other again in the future. Five weeks seemed like several years, but I know this is nothing compared to what some other couples go through.



*(The weekend after Michaela arrived back in America,
5 months before my diagnosis)*



*(Me on the right, CJ on the left, during a beer run.
Celebrating 4th of July 2008 in Santa Cruz, CA)*



(August 31, 2008. 1 month before my diagnosis and looking skinny)

STRESS AND BLOOD IN THE WORKPLACE

While Michaela and I were apart for those 5 weeks, I was busy getting settled and trying to figure out how to sell solar panels to people all over the United States. The economy was just starting to tank, and banks were starting to realize the credit problems that were all over the place. Needless to say, most people were not interested in buying solar panels, at least not from me. Work was pretty stressful. I had several heated discussions with another member of the team and on several occasions I felt I might be working with a lunatic. I'm sure this person felt the exact same way about me. But none of this really mattered. I was getting very sick, and things were starting to get out of control.

Within just a few months, after a personnel shuffle, I became the general manager of the solar company. The other employees were reporting to me. Producing results was a challenge. Not so much on the management side of things, but more on the sales side. I wanted so badly to prove to everyone that this new startup was going to kick some butt. My hopes of being the “Rock Star Adam” that I used to be at my previous companies wasn't happening. I was failing pretty bad. Emotionally, it was super tough to deal with. Never before in my professional career had I failed at making big things happen. Even in Prague, the sales job I had there was just like all the rest. After 1 month, I was at the top of the sales charts. Not this time. No way senior! Sales at the solar company were horrible, and that was the least of my problems. My health was wearing me down, and stopping me dead in my tracks.

I was having some really scary bowel movements. My colon was now spitting out little bright red drops of ink into the toilet bowl. These red blood drops weren't just happening while I was working, they were dripping into every toilet bowl I used. I was bleeding at work bathrooms, other family member's toilets, bathroom's at my friend's houses, and of course at our small apartment. But I wasn't ready to tell anyone just yet.

It can be such a demoralizing event, the act of taking a crap. Once all the normal people are finished flushing the mess down the toilet, that was just the beginning for me. Unless I was in a public bathroom or in a huge hurry, I had more work than just the flushing. I had to complete a toilet inspection each time. I'm talking about pulling up the seat from the toilet, and checking to see if there is any loose blood spots around the toilet bowl. Sometimes, the blood was easy to spot. It would be right there on the seat in plain view, but other times the blood spatter would creep into some cracks and crevices within the toilet's outer shell. If it wasn't a public toilet, I'd take some toilet paper, wet it down, and begin my routine of wiping away any evidence of my blood. The public toilets I was less gracious in my exit from the bathroom.(I know its selfish and horrible) Back in the early days before getting diagnosed, I paid much closer attention to cleaning up all the bloody mess. I can't imagine a friend of mine approaching me with”

"Hey Adam, my wife said she saw some fresh blood around the toilet seat you just used a little while ago. Are you on your period?"

Luckily again, that conversation never came up, and nobody from my work ever said anything either.

TIME TO TALK WITH MICHAELA

Michaela and I had been married for just about 5 months. I can remember clear as day driving away from my mom's house one day and looking over at her and simply saying, "I'm not feeling very good at all. I'm bleeding out of my ass." For sure there was more to the initial conversation, but I guess that's all you need to say. What else can be more dramatic than that? Rectal bleeding. It's pretty clear and to the point right? One things is for sure: when I told her I was bleeding out of my butt, Michaela had just one response: "We're going to the hospital!".

That was the beginning and the end. There was no negotiating out of this one. And that's exactly what I needed. A hospital, a doctor, and some medical help soon. I so badly needed someone to tell me what to do. The 5-10 trips to the bathroom each day was becoming more and

more painful to go through. My health was making me crazy, the toilets at work were shiny white porcelain, the blood shining back at me was breaking me down physically and emotionally. It wasn't like the dark bathroom toilet I used growing up. This was real blood dripping from my butt and sometimes spewing. And it was **NOT** getting better on it's own. It was getting worse. The days of hoping that this bleeding would slowly calm down and go away were now over. I wasn't able to play that game anymore. The news was out. My wife now had the missing piece of information. And to my surprise, the quick turn of events was a relief. By coming clean with my dirty bathroom routine, I was moving forward. Going at it alone wasn't going to be an option anymore. I let the crap out of the hat. So off we went.

Learn From My Experience:

1. When you are seeing rectal bleeding(if you're diagnosed already or not), make sure to tell someone!
2. Waiting for your bleeding to stop can take forever, it may never happen, so tell someone else
3. Tell your doctor when you notice rectal bleeding, DON'T WAIT!
4. Tell someone in your family about the bleeding, don't go at it alone

BACK TO URGENT CARE

The drive to Urgent Care was different than most car rides. I remember wondering what the heck the news was going to be. Still, I had never once heard of or known the words UC. This still must be some bad ulcers or maybe a hemorrhoid is what I was thinking.

Once we arrived, I was seen pretty quickly when we told them what was happening. And again, the doctor asked me some questions, and did some blood tests. But this time, he told me to see a gastroenterologist right away. That was pretty much it, specific instructions for me to see a special doctor. A gastroenterologist. Yet another word I had no idea existed, and of course that would soon change forever.

I remember walking out and feeling a bit relieved, but there really wasn't any news to share with Michaela. All I could say was some doctor with a jacked up specialty of looking up butt holes is who I needed to talk with next. That's when I called my dad to say what was going on. That phone call was one of the worst calls a parent can receive, but I had to make it. This was all

uncharted territory for me, and I was pretty much driving blind down this healthcare road and I needed some help. Luckily enough, my father knew of a good gastroenterologist doctor from just down the street, and he immediately booked an appointment for me to see him. Just a few days later I was in this GI's office with my father, and we were talking about my symptoms. He didn't do any sort of anal probing or butt checks that I remember, but he did tell me I needed a colonoscopy to see exactly what was happening. His calendar had an opening a few days later, and we booked the colonoscopy with this doctor right away.

So there it was, some guidance from a specialist whom we told about the family history of IBD. I remember my dad talking about Uncle Bennett and how he had Crohn's Disease. He also went into details about Grandpa Simon and the digestive troubles that he dealt with. But all I could think was, wow, this GI doc is well known for checking out "The Deep, The Dark, The Doo Doo Hole" with a camera!! And in a few day's, he's going to be looking up mine?

WHY GET HELP?

If you are anything like me, you were in denial that you had something very wrong with your body. And that is normal. You may think your body can heal itself on its own. That's what I was thinking too. For a very long time. In fact, I still think that way. But, when I was dealing with all the symptoms of bleeding, cramping, and diarrhea, **I wasn't able to fix the problems on my own. I needed some help.** For me, agreeing to drive to the Urgent Care medical office in Palo Alto, California that one evening with my wife was not an easy thing to do. All of a sudden I was throwing in the towel on my health. On one hand, I had been betting all along on my health being so great, and being able to work itself out of anything. But of course the reality was that my health was declining. By making that drive to the doctor's offices, I was quickly throwing my hands up in the air and admitting some sort of defeat. It's hard to do. Especially when you are one of those types of people who always wants to win.

When you make the decision to seek help with your symptoms, that moment is even more important than the day you are diagnosed. Of course I remember the exact day of my diagnosis very well, but that would have just been delayed had I continued to deny my awful symptoms.

UC is a nasty disease. That cannot be denied. It can cause people to turn into totally different personalities, and totally different looking people, **especially if you lose control of it.** I grew up next to Stanford Hospital and the Stanford Medical Center, so you can say that I've been

near world class medical care my whole life. But I'm not one who thinks western medicine is the **ONLY** solution for gaining control of UC. The same goes for surgery, eastern medicine, tai chi, yoga, and all the other different types of treatment options that I have learned about or experimented with. What I do believe is that trying to fight UC by yourself is very difficult and can be a fatal decision unless you are confident and happy with your results.

There will always be groups of people who think they can **always** heal themselves. I still run into people with "unknown bleeding and symptoms" who think they can get rid of their health issues on their own. Some of these people think their body just needs more time. And that's great. That was me for so many years. And I was so very stupid, in so many ways to think like that. Here is why: For the majority of us who have undiagnosed active UC symptoms, there is a gastroenterologist doctor within twenty miles(or thirty kilometers) who would be more than happy to help us figure out our medical problems. That's right, a specific doctor who is trained to help people who are pooping out blood, and cramping with diarrhea for weeks on end. You don't have to feel like you are a loser in this health battle if you drive yourself to the hospital, or if you take a few days off work to see some doctors. That is perfectly fine, and nearly all of the UC patients of the world have done just that. Some UC patients have done that many times throughout their life even after diagnosis. Living with this disease and trying to hack it through your normal lifestyle undiagnosed is not going to work very long. Eventually you will end up with such horrible complications from the symptoms, that you will need to spend a ton more time getting back on your feet. And that often leads to days and nights spent in the hospital. Who the heck wants to do that?

*Common UC Mistakes That Often Lead to a **DELAYED** DIAGNOSIS:*

- Being scared of the truth when your body is not working right (I'm guilty of this one!!)
- Hiding the symptoms from others (I was guilty of this too!)
- Feeling so confident that you have healthy genes, and never realizing that we all are human
- Taking pain pills to help deal with the cramping(which only covers up the real problems and potentially wreaks havoc on your stomach and other organs....i.e. your colon)
- Hiding how much you use the toilet (this was me for sure)
- Not being honest during the annual physical exam with your primary care doctor, GP, or Internal medicine doctor. It's so easy to completely forget about your constant cramping and loose stools during that once a year doctor's exam, especially if you have gotten used to these feelings.

- Always blaming the previous meals as the reasons for abdominal pains or bathroom visits (I was a PRO at doing just this for oh so very long!)
- Being scared to talk about symptoms
- Thinking it just hemorrhoids (I didn't know what hemorrhoids were, but I thought that's what I had)
- Always feeling that foods are the source of the cramping
- Sometimes, a long string of mis-diagnosed symptoms can unfortunately delay everything (I can't tell you how many people have written to me the list of illnesses their doctors' have previously come up with before the eventual UC. This frustrates the hell out of me, but it does exist.)

Extra Reading:

There was a paper written in December of 1993 by three distinguished doctors about denial and getting past denial. Specifically the paper was concerning cancer patients who were denying their symptoms and other parts of their health. What is excellent is how this paper lays out some very basic and effective ways to get past denial both as a patient, and as a family member of a patient. If you change the idea of “cancer” to simply “UC”, you will probably realize and learn many things on how to go about “fixing” denial if that still exists with you or your family. [Denial among cancer patients. Tips and traps.](#) Brock G, Gurekas V, Deom P. Temiscaming Centre de Santé, Que. December 1993.

Part 3: Getting A Diagnosis

It was late September, and I was all lined up for a colonoscopy at the doctor's preferred colonoscopy center. I remember the relief that I was feeling prior to my colonoscopy. Mentally, I just finished the marathon. It was going to be downhill from here. Help is arriving. The helicopter was coming in to pick me up and take me home. But physically, things were only getting worse. The bleeding was dripping during bowel movements, and I was having 10-15 per day. I was feeling weaker and weaker as the clock ticked forward. If shit didn't turn around soon, time wasn't on my side.

On top of all of this, we had a visitor. A sister of an old co-worker from Prague was coming to stay with us that weekend. This girl was coming all the way from Russia. It must have been an odd weekend for Anna's sister Elena. Our apartment was tiny. I was in the bathroom much of the time. Our trip to San Francisco to see that comedian was somewhat of a downer. I had no energy. It turned out I was anemic, and probably was for a long time. Had this been any other weekend, there's a good chance Elena would have had some great things to say about life here in California on the west coast, but this weekend was more or less a disaster.

The weekend ended, and the day came for my ass inspection.

COLONOSCOPY PREP URGENCY

First off, getting ready for your colonoscopy is not something to be freaked out about. It's not something that you need to dread either. If you're anything like me, and have symptoms of bleeding and cramping, and loosey-goosey bloody non formed scattered all over bowel movements, you probably need a colonoscopy. That type of lifestyle is NOT NORMAL. Things can get better. It sure as shit can!

And as much as anyone complains about the whole colonoscopy experience, in the end, it is so necessary. You need to find out what is wrong with you, and until there is some better way to diagnose UC, a butt scoping is the best way to take care of it.

My GI doctor gave me some instructions on how to prepare for the colonoscopy. He wrote a prescription for a 1 gallon jug which contained a powdered mix that you only add water to. And

I was supposed to drink all of it the night before. So that's what I did. Actually, I did not finish all of it. I couldn't, but two-thirds to three-quarters of it I drank. One gallon of beer, or a gallon of my favorite Mint Oreo Milkshake from the Peninsula Creamery in Palo Alto, I could drink a gallon of that. But not this stuff. That colon cleaner stuff is pretty nasty, but in the end, it helped me get a formal diagnosis and that was the goal.

Soon after I started drinking this colon cleanser solution I began wondering, "geez, its been 15 minutes and no running to the bathroom, is this stuff for real?" And sure enough it hit me, and it hit hard. Can we all say "URGENCY!"?

As you may know, urgency is a very common UC symptom, so it wasn't new to me. But this was different. Instead of sitting at work, or laying on the couch and feeling a building pain in my abdomen which suggested a trip to the bathroom was needed, this was a different ballgame. This urgency was very direct. There was no question about it. A vacant toilet was needed very soon or most definitely I would be pooping my pants in front of Michaela. Off to the bathroom I ran, and just made it to the pot in time. We'll never know for sure, but had there been a few seconds of delay in anyway for whatever reason, carpet cleaning may have been on the chores list that night.

All sorts of semi hard stuff came flying out of me. I noticed some blood as well. Not tons and tons of it, but definitely there was bleeding going on. It was strange how after taking 3-4 more poops in the next hour or two, I started to see less and less blood come out each time. It was starting to become just straight liquid with almost no detectable blood whatsoever. This gave me some BIGTIME hope. Maybe all I needed was to clean myself out. Maybe this colonoscopy will actually cure me. That's how my imagination was working that night before my diagnosis.

What was really happening inside my colon during the colonoscopy prep is just like what happens when you cut your finger and place it under the sink's running water. At first there's lots of blood. After a few seconds with water running by, the blood seems to go away. Then, when you stop the water, it appears again.

As for abdominal pain and cramping that I was experiencing up until that night, it never went away. After my quick adrenaline rush wore off, the reality of my health not being fixed that night sunk in. Somehow I got some semi decent sleep. A sleep which would be my second to last before moving forward with my future life.

Extra Reading

If you are interested in reading more about Colonoscopy Preparations...There is an excellent scientific study that will give you all the details you could ask for from a scientific perspective on this procedure's preparation. [Bowel Preparation for Colonoscopy](#), February 2010. David E. Beck M.D. Department of Colon and Rectal Surgery, Ochsner Clinic Foundation, 1514 Jefferson Hwy., New Orleans, LA 70121

GETTING THE COLONOSCOPY

As much as I was happy to be moving forward with treating my symptoms, and yes, having a doctor look up my butt-hole I consider "moving forward", I was also very scared. One of the scariest days of my life. I never said anything to anyone, but it's a scary time when you're undiagnosed. To require such a strange anal exam, just to determine what might be wrong with you isn't easy to grasp. Especially for someone who has spent such little time in a hospital environment. The biggest medical procedure I had up to this point was getting my wisdom teeth pulled out ten years earlier. And I don't remember any of that because they got me doped up on so much laughing gas when they were yanking my chompers.

My wife drove me over to the colonoscopy center, it was real early in the morning. After getting taken back into a room with one nurse, I dis-robbed and threw the gown on. This is not the ordinary type of gown, it basically allowed for my butt to be exposed for easy access by the doctor. They also placed an IV in my arm to throw in some anesthesia. (I'm pretty happy to have been out cold for the colonoscopy. I had plenty of time later on getting sigmoidoscopies and having the chance to look in the TV screen at my inner colon. Pretty cool too!)

Before I go any further, there's one recommendation that I want to make. Make sure you are comfortable with the doctor who is going to be performing the colonoscopy. If you are not comfortable with the person who is supposed to be performing your colonoscopy, that is OK. Try to find a different doctor before you make any final decisions. It's not impossible to change your colonoscopy doctor, almost all GI docs can perform the procedure.

There wasn't much time between walking into the colonoscopy center and getting put to sleep by the anesthesia. Maybe just 20 minutes or so with the final preparations. This was just enough time for my mind to start racing. Even though my symptoms were present for quite some time, years to be exact, I was still hopeful. There must be a chance this will all end

quickly. The nurses didn't look at me and say anything strange. I didn't hear them say, "You probably have this disease", or, "maybe you have UC Adam". So there must be a chance for me.

I am an optimistic type of person, I like dreaming big. That's how I've tried to live my life. I'm not trying to make excuses now, but there must be other people who feel the same way. There must be other people who have lived for a very long time in complete silence about the strange symptoms that come and go. There's got to be other people who have felt that no matter how bad the bleeding has been, it just won't go on forever. And for sure there must be tons of other people just like me, who had no clue that after their colonoscopy they would be getting diagnosed with some long named inflammatory bowel disease.

Note:

Most people who are diagnosed with UC have colonoscopies once every 1-3 years moving forward. Talk with your doctor about what schedule you should consider to keep a close eye on your colon.

Additional Reading on the “Sigmoidoscopy” Procedure:

I had several sigmoidoscopy procedures. I like to think of the sigmoid scope as a mini version of a full colonoscopy. If you are not familiar with this procedure, you might want to give a peek into this scientific survey which has quite a bit of great information about sigmoidoscopies. [Canadian credentialing guidelines for flexible sigmoidoscopy](#), February 2008. Robert Enns, MD FRCPC,¹ Joseph Romagnuolo, MD FRCPC FASGE MScEpid,² Terry Ponich, MD FRCPC,³ Jonathon Springer, MD FRCPC,⁴ David Armstrong, MA MB BChir FRCPC FRCP(UK) AGAF FACG,⁵ and Alan N Barkun, MD CM MSc FRCP. Division of Gastroenterology, University of British Columbia, Vancouver, British Columbia.

I HAVE UC

When I woke up after being anally violated, I was sitting in a wheelchair, inside a waiting room. My wife and mom were there and they had some pieces of paper which were my new prescriptions. There was also news of UC. I don't remember my thoughts very well right after the colonoscopy. As it turns out, the doctor came into the waiting room and talked with the three of us about the news. He said I had UC and then he went over the medications I should start taking and the follow up prescriptions. Thankfully my mom and wife were able to remember what he was saying, because I didn't even know he spoke with us afterwards, the anesthesia was still affecting me quite a bit. My GI doc prescribed a low prednisone dose along with Asacol.

He also talked about what I should be eating in the immediate future. My wife remembers the gastro doctor saying that I should avoid red meat, fruits, vegetable and salads, and to stick with easy to digest foods like pastas, rice, soups, and white breads.

When it was time, I was happy to get the heck out of there. I was hoping that the recommended pills would take care of this, and life would soon get back to normal. I wasn't really scared anymore. I had lived through the colonoscopy. I didn't die. And now I had an official diagnosis with instructions on what to do next. Could life get any better than this?

In HindSight I'm Happy:

It has taken months to realize it, but I'm so thankful that my diagnosis happened when it did. Had I gone a while longer un-diagnosed, my health might have failed me completely.

Part 4: Diagnosis Dementia

Don't worry if you think this section of the book is all about going crazy. It's not. But there are a bunch of mental battles most people face after getting diagnosed. I've learned how these mental games are totally normal. UC can be real hard on the colon, and our brains can become a major hurdle during the early diagnosis days as well. Learning how to handle mental battles and life situations that came up during my early days after my diagnosis was very important to my overall success. One thing you must realize right away after a UC diagnosis is that your life doesn't automatically fall apart. Yes, life will be tough, and difficult times will arise, you can count on that to happen. But no matter who you are, and no matter how bad your current symptoms become, life can and will get better again. By focusing on what is probable and possible, the whole post diagnosis period can be a great learning experience that will be valuable forever.

Here's a list of things that did not change in my life after my diagnosis:

1. My family still loved me, probably even more than they used to
2. All of my friends still thought of me the same way when I broke the news
3. My wife Michaela didn't walk out on me (even after being married only a half year)
4. My favorite TV shows were still just as enjoyable as they were before
5. My credit card bills and utility bills kept on rolling in
6. My sex drive was still there, thankfully, don't want that going out on me
7. Everyone who I told my diagnosis was interested and wanted to learn more

Here's a different list of what did change in my life after my diagnosis:

1. Started losing a few more pounds
2. Started to realize that my body needed to rest more than before
3. Reduced my alcohol intake
4. Started to think much more about other people's health and well-being
5. Started reducing the stressful parts of my life
6. Started telling my wife and family more about my current symptoms

7. Started paying much more attention to my bowel movements
8. Had less anxiety each time I saw blood in the toilet bowl
9. Started worrying about health insurance, and not losing my health coverage
10. Started adjusting my diet
11. Thought more about toilets, and where they would be located during the day
12. Planned more carefully for long car trips
13. Gained a much better understanding of the medical system (SUPER VALUABLE)
14. Started talking about my poop during meals much more than before (wife made me add that)

So let's get this straight, some parts of your life will change, and there will be other parts that won't change at all. My exact experiences might be different than other people's, but overall the main point remains: **a UC diagnosis is not the end of the world.**

Here is a list of a few questions that sometimes kept me awake at night after I was diagnosed:

1. Was all this bleeding I was having normal?
2. Was I bleeding more than the average person with UC?
3. Could I bleed too much and actually die?
4. Was my body starting to shut down because the food wasn't going anywhere but out my ass?
5. Was this going to affect my chances of having children later on?
6. Was I going to need surgery?
7. Did I need to get my colon taken out?
8. What was all that talk about biopsies during the colonoscopy and colon cancer about?

The list goes on and on. I was worried about my health, and I wanted answers. I also wanted the medications to kick in right away and fix everything. These questions are all normal. Don't worry if you're thinking similar thoughts. It is part of having UC. Just like a bunch of things in life, this whole UC business isn't taught to us in schools. And no patients or family members should ever feel bad for not knowing the answers to UC related questions. (I say this because I have received hundreds if not thousands of emails from parents, friends, and of course UC

patients themselves who have all sorts of UC related questions. It's 100% normal to have tons of questions, and it's 100% normal to be lost in terms of the answers.)

Just a few hours after leaving the colonoscopy, I had a pretty heavy dose of "Diagnosis Dementia". My first false start to healing occurred. Three hours after getting the diagnosis, I took the Prednisone (Prednisolone) prescription. And like a true miracle, I started feeling so much energy and excitement. "I think I'm getting better", I even said to my wife. That was the short term bump from the prednisone, it didn't last forever. The pain was back by the evening. But what a nice little mental lift after such a traumatic start to the day.

Those medication bumps are bound to happen. The immediate highs can often lead to quick lows. Feeling like you finally found the cure is a great feeling, but it can add to the "Diagnosis Dementia" if it's only a prednisone high. So be careful. The goal is longterm health. Good health that you have control over. When you start to see results that's great! But let your body adjust to the changes, and let things take their time. If you continue to see positive results after a few more days, and then a few weeks or even months and years, that's what we're looking for.

The Positive:

The post-diagnosis early days of UC are almost always a roller coaster ride for everyone including family members and friends. You can put me and my UC on that list FOR SURE! And that's OK. It's normal to feel out of control emotionally. But you have to remember one BIG IDEA:

With some preparation and self discovery, your "Diagnosis Dementia" will also end.

FAMILY MEDICAL ADVICE

There's an interesting part to the "Diagnosis Dementia" phase that many people with UC will uncover. It involves family members and close friends. I know I said that my family members and friends still thought of me the same, but there's more to the story. During those first few days, and maybe the first few weeks and months following diagnosis, medical advice was growing on trees. To the patients of the world out there, you should be ready for this as well. If you're not ready for it, it can increase your "Diagnosis Dementia" exponentially.

Medical advice from close family members, friends, and even distant relatives happens. Some ideas may come from the western medicine side of the spectrum, and other ideas may have

you signing up for new religions in the jungles of South America. It is amazing. When the medical advice was rolling in, I felt like the local post office. Family and friends would be dropping off letters and emails filled with brand new medical ideas. It can become overwhelming, especially when you are in the middle of a horrible bent over cramping session and your uncle Joe is telling you about something he heard on the radio that day which might make you feel better.

This just might happen to you as well. Be prepared. It's totally up to the you, the patient, to decide how far you want to look into other treatment ideas aside from your doctor's advice. That's a decision you need to make on your own or with your close family. But in terms of accepting advice, there are some simple ways to make everyone happy, including yourself, which can also REDUCE "Diagnosis Dementia".

Here's are some ideas on how to accept medical advice:

1. Listen when advice is offered to you (by family member, friend etc...)
2. Get that big smile out and say "Wow, Thank you so much for thinking of me"
3. Let them know that you will be meeting with your doctor soon and will talk about their idea. ex. "I am meeting with my doctor later this week, I will definitely talk about this in my appointment"
4. On your own, research the different treatment ideas. If they still seem interesting to you after your own research, explore them further.

It's that simple. **When you are sick with UC, other people want to help you out.** The fact that you just started taking a brand new medication, or that you are actually seeing a gastroenterologist who specializes in your condition isn't always clear to others. And that is perfectly alright. Outsiders can't be expected to know everything. And as a new patient, you can't be expected to know everything either.

When I was receiving advice from others, I didn't handle the situation very well. Instead of thanking everyone for thinking of me, I often became combative. I can recall telling people over and over again that my doctor would have told me about "that type of herb" or "that new medication" if they really worked, and I was always refusing the advice from others. And then afterwards, later in the day or later that night, I would sit and talk to my wife and tell her how frustrating it was to have people always trying to get me to jump on board a new treatment bandwagon. It frustrated the hell out of me. But it didn't have to be that way.

I had no idea this was normal. This is what happens when you are sick. People want to help you out. People want you to start feeling better. When you are in pain, your friends and family feel the pain too. And nobody likes that.

Had I just said "thank you for your advice" and then completed some additional research on the different ideas, those nights would have been so much easier on me. I was trying to relieve sources of stress, and by becoming angry and upset with all these outsiders trying to help me, I was not reaching that goal.

Here's My Challenge:

Handle these types of situations better than I did, and you'll have a very high likelihood of being much happier afterwards. UC is something you deal with throughout your life, so you need to start getting used to these types of situations. The early you adapt, the better off you will be. And the happier you will be as well. It's that simple.

LET THE DRUGS BEGIN



(November 2008. About 1 month after my diagnosis)

My plan was to meet up with the GI doctor a few days after the colonoscopy to talk about how I was feeling and to talk about the biopsy results. When I met this first GI doctor initially, he said that if he found something from my colonoscopy he would need to transfer me to a second GI doctor. This new doctor would then "manage" me moving forward. My original colonoscopy GI doctor was not accepting new patients with newly diagnosed inflammatory bowel disease. So that's exactly what ended up happening. This transfer process took a few weeks, so I kept on working with the original doctor in the meantime.

It wasn't too many days, maybe I let it go one week, when I called my GI doctor's office for help. I'm know there are many new UC patients(or concerned family members) who end up calling the doctor back within just a few hours of the diagnosis asking questions. And that's

perfectly normal. When you're bleeding out blood and you have a phone number to a GI doctor, it's got to be natural instinct to call it a few times. For me, things were not getting any better, and in-fact, my symptoms seemed to have gotten much worse after the colonoscopy. I was seeing more blood than ever before. The cramping was getting so bad, sometimes I only found relief when lying down in bed. Things were getting ugly, and nothing was letting up. I wanted help that made me feel better.

Quick Note: Over the next few years, I came to learn from other UC patients that it is very common for symptoms to get worse after a colonoscopy. I wish someone had told me that before. My symptoms were really bad leading up to the scope, but after the ass probing, and the diagnosis, things just kept on sliding. I started thinking to myself that my colon was probably irritated from having biopsies taken (small pieces of colon snipped with the colonoscopy device).

My brain started thinking that maybe the doctor accidentally cut open my colon and made things much worse during the colonoscopy, and that could be the reason for all the additional pain, cramping, and blood. But of course that wasn't the case. My colon was already inflamed and bleeding, and the added stress from the colonoscopy along with the massive colon wash out the night before was to blame. In the end, I just wasn't having great results with the medications, so my GI doctor bumped my prednisone dosage to a slightly higher amount.

Some Valuable Ideas About UC Medications:

When you are recently diagnosed with UC, it's common to be bouncing around from medication to medication and changing doses often. Most people start off with a certain medication, and if that medication doesn't help, your doctor might prescribe another medication for you. There are a whole bunch of common prescriptions that are handed out to new colitis patients. Here are some of those medications: Lialda, Sulfasalazine, Asacol, and Colazal to name a few. There are several enemas and suppositories that are also very common. And of course the prednisone/prednisolone steroids that so many of us will use at some point in time.

I highly encourage everyone to take time to talk with your doctor to learn about the medications. Why not be interested in what types of medications you are being prescribed, and what the potential side effects

are? Certain side effects are relatively rare, but there are others that are very common, so you might as well be informed. The more you know and understand as a UC patient, the easier the whole process of getting back to normal will be. Think of how angry you could be if you are sitting at home watching TV one day, and you start to notice your skin peeling off your legs. That would probably piss most people off. It might even scare you so bad, it sends you to the crazy house. Especially if you were recently prescribed a new medication. But, if you were told that there is a chance that your skin might peel off your leg after taking that medication, you might be a bit more relaxed.(OK, maybe that's not the best example, but you understand the point right?)

After a few more days of still feeling horrible, my doctor's increased my Prednisone dose again. I can remember setting up a piece of paper tacked to the wall by the kitchen table that had my prescriptions, how much, and when I needed to take them. If you've never been prescribed multiple medications at the same time, it's a new experience. I would setup a little plastic container in the morning with everything I needed to take for the day. After one look over the schedule, I'd be all set. When I forgot where I was with the pills, all I had to do was go back and look at my schedule. Yes, you might feel like your grandpa or grandma, but that's OK too. Just like so many other UC'ers, I had no idea how much prescription medications would fall into my life. The employees even began to remember my face at the Walgreens Pharmacy. The workers stopped asking for my identification when I picked up new pills. They must have known from the look on my face, the major fatigue, and from the unusual gastro prescriptions that I was pretty sick.



*(My medication schedule
all sorts of medications and dosage amounts)*



(November 3rd, 2008. One month after my diagnosis. Maybe you can see my left hand on my stomach. I was not feeling good this night.)

Because 5-ASA medications are so common, here is a study published you might enjoy reading:

[5-ASA in Ulcerative Colitis: Improving Treatment Compliance](#), September 2009. Cosimo Prantero and Marina Rizzi

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THE BATHROOM

In the early days after my diagnosis, I wasn't sure how my relationship with the bathroom would unfold. So much time had passed since the days of seeing consistently hard poops dropping from my butt. Years had gone by. And here I was, 29 years old, living 3-4 hours per day in the doodie room. Not too long after my diagnosis I can remember bringing the computer into the bathroom. I tried to multi-task while using the toilet. I was checking out the news, reading stories, even sending emails to friends and family. While I was sitting in the bathroom, I also started researching UC online. The online search for information was not exactly what I wanted though. My searches usually turned out with me finding a drug company sponsored website with information about different medications or treatments. It just wasn't what I was looking for while sitting on the toilet. I wanted to read about real people, and real stories of patients who were just like me. It would have been great to meet somebody else with this disease. Even if I could only meet just one other person, that would have been enough for me. If I could meet another person with UC, they for sure would understand how it's possible to spend 4 hours a day on the toilet.

Back in October was also a time where I learned one very valuable bit of information. DO NOT STRAIN. As I became more and more concerned with the amount of blood that I was seeing, the term "Killing Whales" was how I would explain to my wife a particularly bloody bowel movement. And it became very common to the point where I started telling it to my brother and others who asked the question, "How are you feeling today Adam?". When I would strain to poop out whatever watery mess was inside of me, it often resulted in even more blood. So I tried to relax. Gravity was still working, and that was all I needed. I had too little energy to be wasting it straining to squeeze my colon clean.

More Bathroom Ideas:

1. Buy yourself some wet-wipes (I think they are usually used for babies) You can use these to wipe your butt when toilet paper just doesn't get everything clean, and you can use them to clean off the toilet seat after you make a mess of it
2. Bring in some good reading material, you are going to have some time in there, make use of it
3. Try not to lean over to one side or the other, keeping good posture in the bathroom helps to minimize lower back pains
4. Try to line up your butt hole, with the center of your toilet, to reduce diarrhea spray(my wife thinks this is the most important)

5. If you do happen to lay a rock hard poop, without any blood, feel free to let out a loud "YIPPIE"

NEW DOCTOR

Towards the end of October 2008, I had an appointment with a new GI doctor. Actually, it was more of an interview. I wanted to interview a few doctors and decide which one I liked the most. The "I've got a serious disease" realization was starting to sink in, and with the help of my mother, father, stepdad and stepmother, taking some time to determine who I wanted to "work with" was great advice. Lucky for me, I had a "Choose Your Doctor" or PPO type of insurance plan with my job. My job which I hadn't shown up to for several weeks now. Unfortunately because of how the health insurance programs work in the US and other countries, not everyone is able to choose their own gastroenterologist. That is something that I hope changes in the future all over the world. Patients should be able to choose who is in charge of treatment.

My first potential GI doctor was a young woman. She was young, pretty, super nice, and she conducted a 2 hour exam with me. My wife was in the room the whole time to help me out on details I forgot. She did a "Doodie Man Poke", that's right, she threw the gloves on and put her finger(hopefully it wasn't more than one) up my butt. And then we talked some more. It was the most thorough exam I'd ever had. Michaela and I left that place, and I was not sure what to say. This new GI doctor was great, nice, seemed very interested in me as a person(I think she liked my butt too :)), and probably would be a great fit.

But, my father also setup a meeting for me with another much more experienced GI doctor from a different medical facility. I met with this doctor who was a male, and had another very long meeting, not nearly as long as the other one, but he was great too. It was going to be a tough decision. But as I would learn later on, one of the most important decisions of my life.

CHOOSING YOUR DOCTOR

Choosing your doctor who is going to treat your UC is a big decision. After talking with several people, and talking a lot with my mom and dad, I decided to go with the second GI doctor. I think it was a good decision. I thought it might be easier for me to talk about my colon, poops, butt, and rectal issues with another guy instead of a woman. I felt he had quite a bit more

experience as well. He had been practicing for decades, and the facility and medical office was also really nice. So that was my decision. Door number two it was.

For anybody who has the option to choose your GI doctor, realize the importance of your decision. Take into account what you are doing. If something doesn't feel right, or if you are not comfortable with the doctor, realize that. If you are not comfortable, investigate some other choices. Doctors are real people, they are here to help people who are sick and not feeling well. That is their job, and they know that. In many ways, we as patients are their customers. Nobody is perfect, and doctors have their bad days, but finding a doctor whom you are happy with is REALLY IMPORTANT! "Hey everyone, I got news for you: You might spend more time than you expect with this doctor. And they will know your ass hole better than anyone else... hopefully."

My new doctor and I came up with a game plan. The plan was to first try Asacol and prednisone together, and then Colazal and prednisone if the Asacol did not reduce my symptoms. (Asacol is a "Mesalamine or 5-ASA" medication. Colazal is an anti-inflammatory drug that often is called Balsalazide. Balsalazide/Colazal is converted into mesalamine once inside the body.) It wasn't very long, maybe three or four weeks, and the decision was made to get off the Asacol and try out the Colazal. My bleeding, cramping, and overall health was deteriorating, and I wanted to try something new. I was starting to get really depressed, but I was still hopeful that a medication switch would help me get out of the hole. After a doctor's visit, my gastro and I talked about the Colazal medicine, and I had a new prescription. The Colazal I was supposed to take 3 times a day just like the Asacol.

As the early weeks of working with my new GI doctor slowly moved forward, we had many meetings together in his exam room. I was in there sometimes several times a week. And as far as the game plan, it was constantly being re-adjusted and changing due to my colitis symptoms. What I remember real well was all of the adjustments we would make to my prednisone doses. My doses of prednisone was changed many times. Depending on how my symptoms were acting up, my doctor would sometimes increase or decrease my prednisone. Many times when I was beginning to taper off the steroids, I would start to see symptoms come back. So we would up the prednisone once again. Little did I know how unbelievably common this "Prednisone Dance" is for so many other people living with UC. In the months and years since I've learned how to control my UC, I've heard thousands of stories from other UC patient's. One common theme that almost everyone mentions is how difficult it can be to taper off prednisone without having symptoms return. As much as it was frustrating for me too, eventually I learned how to stop the prednisone game. An incredibly slow tapering schedule is what worked for me the best.

Doctor Choosing Advice:

1. Ask your friends and family if they have ever seen a gastroenterologist doctor before in your area. If so you might be able to get some personal recommendations or inside opinions on doctors you might work with.
2. Have a set of questions you want to ask:
 - How many patients with UC do you currently work with?
 - What types of results have you seen from these patients?
 - How many years have you been practicing gastroenterology? (a doctor might be old, but he might be new to GI STUFF)
 - Do you also perform colonoscopies and sigmoidoscopies yourself?
 - Can I call you on our home phone when your office is closed (rarely you'll get a y e s here, but worth a try)
 - Are there any other gastroenterologists that you highly recommend that maybe I should also speak with?
 - How is your style of practicing medicine different than other gastro doctors?
 - Ask about the type of approach the doctor uses regarding treatments. Is the doctor more of a "traditional" doctor, or one who is more open to holistic natural approaches?
3. Ask the doctor how long his/her staff has been working with him (I became very close with several of the medical assistants from my doctor's office. And since they were all very friendly and cared about my health too, it made the overall experience at the doctor's office that much better and easier to deal with.)
4. **Ask your doctor how long he/she plans on practicing medicine before retiring.** This is important because living with UC is an ongoing life adventure. If your doctor is going to be retiring in the near future, you want to take that into consideration and look for another doctor that is going to be around for a while longer. Every person with UC is unique, and if you are anything like me, you very well might spend many many hours with your gastro doctor. The more this doctor can remember you and understand you and your symptoms, the better you are going to be.
5. You can always read the online doctor reviews as well.
6. Your gut instincts are usually some of the most valuable assets you have. Listen to them! If you are very uncomfortable with a particular doctor, recognize that. That's OK. Maybe you can find another doctor to work with instead.

Another Great Idea About Doctor Visits

Meetings or “doctor visits” are very common if you have UC, lets not deny that. I had well over twenty doctor visits my first year after being diagnosed. One of the most valuable parts of nearly every visit with my gastroenterologist(s) was something you might not easily guess. I brought either my wife or sometimes my father to most of my doctor visits, and it made a HUGE DIFFERENCE. Inviting someone to join me during my doctor visits was an excellent decision. I wish that more patients who are living and dealing with UC symptoms would do the same thing.

Why An Extra Person is IMPORTANT:

- When you are symptomatic with UC symptoms, it is SUPER EASY to forget details
- The simple idea of “going back to the doctor” can go from being something you dread, to not such a bad thing if you have someone who cares about you at your side
- Your “extra person” probably has some questions that they want to ask as well
- You don’t get billed extra for bringing extra people along with you(believe that, something for free!!)
- Your extra person will be an extra set of ears to listen to any instructions or guidance your doctor provides (Again, its easy to forget details, especially details your doctor explains to you when your mind is racing a million miles or kilometers per hour)
- And of course, by bringing someone else along for the ride, it will force you to become more open about your disease and symptoms, and if this is a special person in your life, the chances are that you really do want them to know the inner details of what your life is like with UC

AT MY WORST

For many years I had been living with active symptoms. I can't deny that anymore. My very worst days of active colitis symptoms was the end of 2008. Things have come a long ways since back then, and I’m very thankful that my health has made major improvements too. It's been a while now, but I still remember everything. There were many consecutive days of really awful symptoms. Three weeks of 24/7 non-stop symptoms. That early part of November 2008 was when my symptoms went from really bad to horrible.

I can’t forget how much time was spent in the bathrooms. The sound of the vent that automatically went on when I entered the bathroom would blast for 30-40 minutes sometimes without stopping. There must have been some hour or more bowel movement sessions too. Can

you believe that? An hour long crap! If you have UC, you can. Back when I was at my worst, the symptoms seemed to find a whole new degree of severity.

The cramps were awful, this is what I remember:

- out of nowhere abdominal pains
- I would have to sit or lay down in bed right away
- sometimes the sharp pains would last for ten seconds
- sometimes the pains would last for several minutes
- during the height of the cramping I couldn't move
- eventually, the pains would go away and be gone

When people would ask me what the cramping felt like, it was hard to describe. When a healthy person is asking you about the worst pain you have felt how can you really convey the message? I usually would pull out my hands and make the motion of wringing out a towel. The only difference is that my intestines would be the towel. I don't know the scientific reasons for the pain everyone feels from UC cramping, but a twisted up colon was usually enough to make the point.

The bowel movements were ugly as well. They would come in spurts. Sometimes there would be two constant hours of going back and forth from the bathroom to the bed. Afterwards, there might be a break for an hour or two. Then the next hour would be filled with all kinds of gas, and bleeding poops just like before. The gas obviously did not smell good at all. But the blood was even more difficult to handle. When so many minutes of the day are spent looking down into the toilet bowl, and all you see is a clear water turning light and sometimes darkish red, you feel useless. I started to judge the level of horribleness based on how red the water turned.

When I was at my worst, I was scared out of my mind. My emotions were on such a roller coaster ride, nothing made any sense. My mood would go from feeling bad to complete depression, and it would only take one flush of the toilet. The thoughts that all of the pain and discomfort was happening inside my own body, and was resulting in so much rectal bleeding became harder and harder to accept. If you have never met another person with UC, it's easy to think that you are the only person alive who's seen so much blood in the toilet bowl. But that's not true. There are hundreds of thousands and actually millions of other people who have lived

past the worst UC symptoms known to man. It's amazing and horrible at the same time, but it's true.

Here's a poem that gives some more details. It's called: "**At My Worst**"

I remember the bloody days,
several years ago.

I was real sick with UC,
Only a few places to go.

It was hard to understand,
All the blood that I did see.

But I really am very thankful,
At least it wasn't from my pee.

The mind is an incredible thing(you've heard that before right!), and the memories of how difficult my struggles were with UC has been a challenge to move past. But progress has been made. If you are right in the middle of your worst flare up or UC symptoms, there is good news. It doesn't ruin your life forever. I know it is really hard to believe that, especially when you see nonstop bleeding. But other UC'ers would agree as well.

For me, I was very lucky. I had someone on my side from the beginning. My uncle. The one who had Crohn's Disease. During the dark days of horrible symptoms, I can remember him telling me one simple thought. **He would say this, "Adam, these symptoms will pass too."** And he meant it. I heard him tell me that over the phone from 2500 miles away countless times. But it's still hard to cope with. It's almost a miracle that UC patients get out of flares. Especially when the symptoms drag on for weeks and months and years.

Even back during these horrible days of my UC, I tried to keep hope alive. I wasn't going to church or temple, and saying prayers or things like that. My hope was something that I kept to myself. I didn't want to give up on my body just yet. I didn't want to get surgery. There has to

be more options for me. That's what I was thinking. Soon or later I had to hear or feel a hard poop drop into the toilet bowl. Over time, the blood wasn't even the issue anymore. I just wanted to see something hard for a change. A bloody hard poop would be fine with me. At least that would let me know my colon could still do its job.

THANKFUL ON THANKSGIVING (C-DIFF)

Thanksgiving time November 2008 had me very thankful. I remember doing a stool sample a few days before, and late at night, my cell phone rang. Michaela and I were out to dinner at Marie Calendar's, a chain restaurant in our area. When I picked it up, it was my Gastro Doctor. Wow, this was a holiday weekend, and he was calling to say he had some news. That's pretty incredible when you think of it. "Adam, your stool sample results show that you are positive for C-Difficile", he explained.

"That's great news right?" I said in a happy tone. "Maybe that's what my problem has been all along", I added. He wanted to know where I was and was sending over a prescription for Vancomycin right away. I told him the pharmacy that was open this late at night, and off Micheala and I went.

I can remember the excitement in the short car ride to the 24 Hour Pharmacy. Thoughts that maybe this whole thing was just a bacteria or at least that must be the main problem here, and some antibiotics would just take care of it all. I finally had some hope. Being told that you tested positive for anything is usually not great news, but for me on this holiday weekend, I was happier than I'd been in a long time. It had been a month and a half since getting diagnosed, and good news or even hope of a quick fix to my colitis was not something Michaela and I talked about. Maybe this was the get out of jail free card we'd been silently waiting for the past few weeks. As it turned out, I had come down with some out of control C-Diff bacteria and it took me two different rounds of antibiotics to knock it out. The first antibiotic I was prescribed, Vancomycin, worked well. When I had another stool sample test towards the end of December 2008, the C-Diff test came back positive again. It had made it's second appearance just in time for New Years. A few days later, and armed with a Flagyl antibiotic prescription, I was able to wipe out the C-diff for good and it hasn't come back since.

Clostridium Difficile Information (C- Diff):

1. C-Diff is a bacteria
2. It can cause diarrhea, cramping, and other symptoms very similar to UC

3. When I had C-diff, the gas I was passing was EXTREMELY nasty smelling, (smelled like a buffalo fart if you've ever had the opportunity)
4. You can get tested very easily for C-diff with a simple stool sample test(a poop test)
5. Many people with UC go undiagnosed with C-diff for quite some time because they think the additional symptoms and pain are simply their "regular UC symptoms"
6. If you have a suspicion that your symptoms have gotten way out of control really quickly, get tested for C-diff. It may be adding to your symptoms.
7. If nothing else is working regarding your UC treatment and your symptoms are really bad, talk to your doctor about C-diff
8. C-diff definitely exists with UC patients, I'm not the only one who came down with it in 2008
9. C-diff is known to relapse over time, that's what happened to me, if you feel that your c-diff is coming back, talk to your doctor right away.
10. As your doctor about C-diff, any doctor who is treating someone for UC should be very knowledgeable on this. Too many people with UC go untreated for long amounts of time with out of control C-diff that is very treatable. Don't let that be you.

DISABILITY

The end of November and the whole month of December 2008 I was super sick. Everyone with UC has their times when they are super sick, and the final two months of 2008 was it for me. The bathroom and the bed were my two resting places, the spots where I spent the majority of my time. Our dingy little apartment down in Mountain View was not the ideal spot to be holed up for days and days. Right out our window was a super busy car wash, the type that has probably about 50 workers and hundreds of cars rolling through each hour. Especially at lunchtime. The sounds from the carwash were so loud that I'd always leave the balcony's sliding glass door closed, otherwise I'd have to blast the TV to compensate. The place was nothing special. But life rolled on. It was during these early days of being diagnosed that I did something new, something that actually ended up working out well for me. I went on disability.

Disability for me meant submitting some signed paperwork from my doctor to the state of California, along with some other forms I filled out, and then waiting for Arnold Schwarzenegger's check to arrive in the mail. Since these were the days of the financial crisis, and California definitely wasn't sitting on a huge bank account, I never really expected anything to arrive in the mail. But sure enough, within a few weeks a check with a few hundred dollars arrived for a few days of November, and then a few weeks later, a much larger check for December's disability payment arrived as well. This was pretty cool I thought. All along I had

been having money deducted from my paychecks for just this reason, and now some of it was coming back to me. And the paperwork hassle really wasn't that bad at all.

Nobody really wants to be on disability when you have UC, it might be nice to sit at home and watch the TV for hours on end, but it gets old. But if you are like me, and have been paying into the state's disability fund for years, now is your time to collect. Ask your doctor about your options with this. Your doctor should have answers for you.

Side Note on Taking Disability:

Since I've become active in the world UC community over the past several years, it has surprised the heck out of me **how few people with UC take disability from work**. I realize that some people might not be eligible for disability time off for all kinds of reasons, but there is also a huge amount of people who are 100% eligible to take paid time off from work while you are in the middle of bad UC symptoms. **TALK TO YOUR DOCTOR** to find out if this is an option for you.

FINISHING UP 2008 - HONEYMOON STYLE

Towards the end of 2008, my thoughts were starting to think about the future, and what was going to happen to me.

- Was I really going to need to be taking so many pills for the rest of my life?
- Was this maintenance drug schedule going to be with me until I was an old man?
- Was the C-diff going to get better and go away after I finished the antibiotics?
- Would I need to get a poop infusion if the C-diff came back, would my brother be a good donor for that?
- Were these medications ever going to start working on my colitis?

I had recently been prescribed some of the enemas, which I never gave a full chance. Some pretty large boxes of them sat next to the bed and instead of using them nightly...well let's just say I "tried" them a bit. The feelings from shooting up this white creamy stuff in my butt hole at night time and then getting back into bed with it was too much for me. I know that stuff works well for some people, but I just couldn't get it done. It was hard to keep in, and it always scared

me to think that I might be poking something with the end of the enema tube that shouldn't be poked. After a few times squeezing it in my butt, and then just five or ten minutes later pooping it out, I gave up. I had to imagine that my butt hole region was totally torn open at this point. It had been bleeding for days and days, so some foreign object like an enema must not be a welcomed visitor.

There was something to look forward to before the year was done. My wife and I had been married for almost a year now, and long ago, way back in the days of the summer before my diagnosis, we had planned on going on our overdue honeymoon. My mom who was a part-time travel agent, found us a really great deal on a cruise ship. The ship was leaving out of Ft. Lauderdale, Florida, and at the time it sounded like a perfect week long getaway. We actually turned it into an even longer stay because we were going to meet up with my Aunt Judy and her husband Gary for a few days down in Miami.

I can remember meeting with my GI doctor just a week before our departure date. Since so much was up in the air with my health it was going to be a game day decision if we actually would leave the Bay Area or not. First of all, I was in the middle of taking hardcore antibiotics to get rid of the C-Diff, I was also on prednisone and Colazal, and my symptoms were still pretty bad. The previous several weeks I had been sitting in bed all day, watching TV nonstop and just getting out from the covers to take blood filled diarrhea poops. I remember talking with my mom, dad, and brother and coming up with the idea that maybe a big change of scenery would help my deteriorating health condition. And as the days leading up to our departure crept closer, the antibiotics seemed to be doing their thing. I was noticing some gradual improvements with my symptoms. I wasn't taking hard poops by any means, and there was for sure tons of blood and bleeding still, but some of the horrible cramping was starting to go away. That must have been from the antibiotics killing off the C-Diff bacteria.

One final doctor visit right before we left also helped make the honeymoon possible. My doctor gave me some more emergency pills, I think they were some form of travelers diarrhea pills to take if something crazy started happening, and I definitely had a full bottle of prednisone, colazal, antibiotics, and a few butt pumps(enema bottles). I was a stocked up pharmacy, and the security people at San Francisco Airport took notice. When it came time to go through the security screening, the security people looked through my personal bag which had all the goodies, but it didn't seem to be an issue. Off we went to find our gate.

California to Florida is a pretty long flight, about five or six hours depending on the winds. Michaela and I made sure to get an isle seat for me, there would for sure be several walks or runs to the lavatory during this long stretch. Thankfully no accidents happened on the flight. It was

the first time getting away from home since being diagnosed, and although my body was in total chaos and I was a bit nervous, we were finally off on our honeymoon.

When we arrived in Florida, we had a one night stay in a hotel, and the next day we took a taxi to our Carnival Cruise Ship. The actual boat was called "Splendor" and it was huge. Jam packed with people, must have been several thousand, and all ages, sizes and colors indeed. But everything wasn't smooth sailing. Not for the two of us at least. Michaela has a pretty nasty seasickness thing going on. She is the only person I know who can get seasick while lying in a hammock after only a few seconds. We weren't 30 minutes from leaving the port when she started feeling really sick. We were up in our cabin. It must have been up on the tenth deck or so, way above the water and she was starting to use the bathroom more than me. I was hoping that this would get better in the next few hours or so, but it definitely did not.

And then we ran into another problem. I needed to drop a load, or some UC'ers might call it a bloody awful poop. But in this tiny five square foot of a bathroom, there is simply no room for two people, and there's only one toilet, so what was I to do? It was either she could go run out to the balcony and throw up all over the side of the ship and maybe hit some other vacationers, or I needed to find another bathroom and fast. It was a quick decision, and moments later, I was off roaming the ship in search of a bathroom. I just made it in-time, and now I knew where our second backup bathroom was located.



(here's the bathroom we had on our honeymoon cruise.

*I wasn't doing 20 poops per day during the cruise,
but I for sure got to know that crapper pretty well.)*

There were a few memorable moments on the Splendor, and one of them happened the first night at dinner time. Since Michaela and I were only a twosome, we were paired up with six others. To me, this is great, you get the chance to meet other people, and I like doing that. Our table was filled with a very interesting crew. It was three other young couples, and as it turns out, I was the only American. One couple was from Germany, another was from Uzbekistan, and another couple was from India. They were all about our age, late twenties, early thirties, and we all got along well. I think Michaela is still Facebook friends with a few of them.

But, it wasn't long until I spilled some of the beans that I was pretty sick, and I even told one of the girls that I was taking some antibiotics. She actually was a nurse at a hospital back where she lived on the East coast, and so this didn't seem to be a very big deal to her at all. But then she asked me, "Which antibiotics are you taking?"

I responded by saying, "I'm in the middle of taking Vancomycin", and her reactions made me really question my health. Right away I felt strange. I could tell instantly from her facial expression that I must be very sick with something bad. Without saying a word her face let me know that vancomycin was the one antibiotic you are prescribed when you are just about to die, or at the minimum, when something is very serious. I didn't follow up with any more questions, and somehow I moved past this realization, but I'll never forget it. All medications are not created equal, whether it's crack cocaine or vancomycin, people just might be judging you depending on what you're taking.



*(December 2008, out at sea aboard the cruise ship
Carnival Splendor, I'm the guy at the very end of
the table on the left side. Pretty cool group of people, and luckily,
I never had any bathroom accidents)*

Somehow Michaela and I managed to make it through the cruise. Oddly enough, even though I was sick the whole time with UC, I'm pretty sure I enjoyed the cruise a bit more than she did. Although I definitely didn't feel in control of my UC back in those early days, if I had to choose between feeling sea sick or UC for a week, I'd go with the colitis for sure.

We finished up our honeymoon with a few days at my Aunt's house in Miami. What a treat. My Aunt Judy lived with my Uncle Bennett for many years. Uncle Bennett had Crohn's Disease and he dealt with all sorts of medical stuff that goes along with that. Surgeries, obstructions, you name it. And for much of it, Aunt Judy was right there living next to him. I had not seen her in quite some time, but to sit and talk with her about how I was feeling was something very special. When you have a disease like UC, it is very hard to feel normal during your early days. Especially if you don't know anyone else who has been diagnosed. But when you have the chance to meet someone else who either has the disease, or has lived with an IBD patient, it may be your first real opportunity to relax.



(Miami, FL December 2008

Aunt Judy and Gary who we stayed with after the cruise.)

Taking A Break From Life

One of the best decisions I've made since being diagnosed was to go on the honeymoon. I was definitely concerned that I would be away from my doctors and hospitals, and I worried a little that my UC would get out of control while away. But after a few days I started to relax and I knew the trip was going to work out just fine. I didn't come back from our honeymoon feeling perfect, and I surely wasn't cured, but mentally I was able to take a break from the constant symptoms that were staring me in the face for so long. My advice to everyone who is in the heat of very bad UC symptoms is to take the opportunity to get away from it all if you can. If the opportunity does not present itself to you easily, try to make it happen. Some relaxation without the normal hassles of everyday life might be very beneficial for your UC and your sanity.

HAPPY NEW YEAR - SULFASALAZINE STYLE

2009 rolled in, but it wasn't the typical new years celebrating I was doing in the past. Back in the old days, it was always hanging out with friends, going out to the bars, and drinking quite a bit. Having fun. Staying out late, maybe dancing, seeing some live music. This time, I was still very sick, weak, and down quite a bit on my weight. I was usually weighing 165 pounds when I was healthy years before, now I was down to around 130 pounds. Considering I'm 5 foot 10 inches, that's a skinny person no matter which country you live in. That's how I looked, and that's also how I felt. Pretty down and out. I wasn't able to do much but watch TV, go to the bathroom and complain. I had stopped working at this point for about seven or eight weeks, and I was home almost all the time. During the day my wife was out at the community college, and I was just waiting for the medications to take over and start working. I still had some hope that these pills would eventually kick in and turn some of these symptoms around. It is one of the toughest mental battles that started up each day. The medication waiting game. When you are so used to taking pills for some infection, or a headache, and then right away you see them work, the delayed response of new medications is flat out hard to swallow. When the days barely move by and you are lying in bed waiting for pills to work, it is pretty easy to go negative and pessimistic. If you are anything like me, you begin to wonder what the heck the actual pills are made from.

The team decision was finally made. My GI doctor, my wife and I all decided that we were going to try one last oral medication called sulfasalazine. If it worked along with the prednisone which I hadn't stopped taking, that would be great. But if it didn't work well, I was going to try Remicade infusions.

At this point, I was strictly a "pill popper colitis patient". Yes, my doctor had prescribed what I call butt plugs/suppositories or enemas, and I dabbled with them, but come on folks. Who really wants to squirt shit up your ass when you're wiping blood from it all day long? I tried out the enemas with little success. I never could put the suppositories up there, this type of solution just didn't sit well with me. Don't give me an "A" for effort, I don't deserve it with enemas or suppositories, but I sure did try the sulfasalazine. I was at the end of the line with the colitis pills, and the next step would be a whole different league of medicine.

Right away after starting the sulfasalazine pills, some severe headaches rocked my world. Ask my wife if you want, but I'm pretty sure she'd agree. The one thing I don't complain of is headaches. I've had several girlfriends who often had headaches(probably from me), but that wasn't something I ever experienced myself. Of course there was the headache that lasted all

night back in high school when I suffered a concussion while playing soccer and running into the goalie. And then there was a headache that same season when I went up to head a ball and another player came at me from an angle with his head. But that is way different. There was an explanation there. And it went away by the next day. After taking the sulfasalazine pills, a pounding headache started, ten times worse than any of the concussion headaches, and unfortunately it didn't stop. It lasted all day, and all night too. When I woke up the next day, I called my doctor to get some advice. (Note to everyone else, if you ever feel like something is NOT right, call your doctor. There is no shame in that.) The advice I got was to drop the sulfasalazine dose in half which I did right away. Like magic, the headaches went away by that afternoon. That was just what I needed. The headaches were worse than the UC symptoms. I can deal with going to the bathroom ten to twenty times a day and seeing the blood flowing out of there. But when it comes to pounding headaches that don't let you rest, that is unbearable.

As January moved forward, my UC symptoms did not fade. They were still right there. Some day to day variations, but 3 months after my diagnosis and the bleeding, cramping, and fatigue was still present. Nights were usually filled with lousy sleep, if you want to call it that. Every single night my wife would fall asleep at a normal hour, and I'd be awake for several hours more watching late night TV shows until two or three in the morning. Three to four hours of combined sleeping segments was just about all I was good for. Some of my least favorite parts of the night were the night sweats. It wasn't every night, but it happened enough for me to form a plan of attack.

Word to the Wise:

All people are not created equal in the eyes of medications. Some people react one way, other people react another way. And some different people have no reactions to medications at all. That is how medicine works in our modern world. IF you notice side effects after you begin taking a new medication, CALL YOUR DOCTOR or go to the hospital. It's OK. Doctor's offices get phone calls all day everyday from their patients because of situations just like this. They are there to help you. There's no reason to sit at home in extra pain in these circumstances.

NIGHT SWEATS

Picture this: you've been sleeping. Sleeping for maybe an hour. It's 4:30 in the morning, and the TV is finally off after you've flipped through every channel for hours on end. If you have a bed partner, he/she is probably in deep REM sleep next to you, not moving at all. And all of a sudden you start to wake up. But, unlike most arousals, this wake up is different. It's hard to understand at first, but after just a second or two you realize you are really hot. So you try to just

go back to sleep. Maybe you do fall back to sleep for a few moments or maybe even a few minutes or more. But eventually you wake up again, and this time you are up for good. Your brain is focusing more clearly now, and the hot feelings are totally gone. Now, you are getting colder each second that passes. And your body is sliding around on the pillow and sheets. You almost think to yourself, "Did I wet the bed?". But right away you know that's not the case. Just a few more seconds later you start to understand what's going on. Sweat. Hardcore sweating. That's right, all of this water came from you. It's amazing how it happens.

That is how things started off for me with the night sweats. I remember being fascinated knowing that my body was capable of sweating out so much water. The pillows and sheets were drenched. If you've ever jumped into a swimming pool, and instantly jumped into your bed, it was probably similar to that. But what the heck do you do afterwards? Do you go back to sleep? Do you sit there in bed wide awake and worry that something is wrong with you? Could it be related at all to UC?

Night sweats are fascinating, but in the end, the fascination fades quickly and turns into reality. You need to get decent sleep every night. Sleep is very important to good overall health. Going back to sleep with dry sweat all over yourself is no fun. Add a super wet sweaty bed doesn't help you sleep either. The first few nights of my night sweats, Michaela and I would pull off all the sheets and pillow cases, and do a quick change over. I would hop in the shower and get all fresh and clean. Maybe even take a poop if nature called. This quick plan worked well, but come on, that's not a long term solution. After a few nights, I made some changes. I decided to do what most people do, and wear a t-shirt to bed. I placed a spare pillow and t-shirt next to my side of the bed incase the night sweats came back. When they did, instead of waking everyone up, I would simply change pillows and shirts, and get back to sleeping. It wasn't too long until this plan had a chance to be tested out, and sure enough it was a great solution. No more waking up Michaela, no more freaking out in the middle of the night, and more sleep for everyone. Win, win, all the way around the horn.

If you're an UC patient or plan on someday being one, be sure to tell your doctor if you get night sweats, but don't think you're strange. Along with many other UC'ers, I had night sweats too.

Side Note about Night Sweats:

Night sweats are common for UC patients. Nobody really knows the exact scientific reason for this, but they do happen. In my own experiences, I've never had night sweats at all when my symptoms are under control. So, if you are sick and dealing with night sweats, the good news is they don't last forever.

WOULD I DIE?

It's not something I'm proud of by any means, but I went through and dealt with some terrible symptoms since being diagnosed with UC. There was one particular night which I'll never forget. This hard to forget night was in the middle of January 2009, just a few months after my diagnosis. It was during a week where my symptoms were out of control. I remember feeling horrible all day, and being extremely exhausted too. Lack of energy would be an understatement. I was totally pooped. Probably a little anemic from the constant bleeding too. It's sounds horrible, but these feelings can easily creep into the life of an UC patient from time to time.

I would usually go to bed around midnight or eleven o'clock, but this night I made it to bed a bit earlier. I needed rest. But something was way off. Of course all the usual symptoms were there, the cramping feelings, the slight joint pains, and the exhaustion. But there was this extra evil bonus that night. **I had the shakes. FULL ON SHAKING. Uncontrollably. My body was shaking like I had hypothermia. It was scary.**

Michaela saw me lying there in bed, and I told her I was feeling worse than normal. She was getting ready to go to sleep also but interrupted her teeth brushing and whatever else was part of her bedtime routine and started throwing blankets on me. I had the usual blankets which were plenty warm, but she also gave me two other huge blankets. I don't even know if I was cold, but blankets just seemed like the right thing to do. But the out of control shaking continued. It wouldn't stop. And it was starting to become violent shaking. Our bed was on a frame that had rollers and it was starting to move around the room. I can remember trying to curl up underneath all the blankets praying that the shaking would stop. That didn't work. So then I started thinking maybe I was having a crazy medication reaction. But that's wasn't the case, I had already been using prednisone and sulfasalazine for quite a while. What the heck was it? I was getting really scared.

When you are laying in bed, in such a horrible state, you really start to wonder. The thoughts that I might not make it through the night flew into my head. That's right, I started thinking I might die here, sitting in bed. What a horrible thought that was. It was not fun at all. After a few more minutes of the same, I thought my only option that night was going to be the emergency room. Maybe they could help me, or at least keep me alive until they had my new medical problems figured out.

For so long, I thought if UC was going to kill me, it was going to be from the dreaded "**toxic megacolon**". This was one of those terms I learned about during the early days of my disease.

It takes place when your colon ruptures and you have internal bleeding and the spreading of bacteria in your abdomen. Toxic megacolon was on my mind quite a bit for the first few weeks after the diagnosis, but I quickly learned that it was very rare, and most GI doctors had never even seen a patient who suffered that fate. But my out of control shaking definitely wasn't toxic megacolon. But the shakes scared the living shit out of me. I don't even remember how long it went on for. I just know that we didn't visit the emergency room that night, and somehow I woke up to my usual 3:00 am bathroom breaks.

It's a big surprise to wake up after an episode like that, and to realize you made it through the night. And then right away my new hope was that those violent shakes would never return. And they never did.

When you start to meet other people with UC, you start to realize how similar some experiences are. Not everyone has the exact same stories or problems, but we all have a ton in common. There are so many people that I met later in life who dealt with severe symptoms. Some of these people felt they had close brushes with death also. Even if the medical doctors felt that death wasn't anywhere near, as a patient you don't always know what your body's limits are until you reach them. The disease can be scary, especially to new patients who don't understand what symptoms may come up. When I talked with my doctor about the symptoms I was experiencing that particular night, it didn't surprise him too much. Somehow that made me feel better.

HOW ARE YOU FEELING TODAY?

Maybe living with out of control UC symptoms can make you crazy. Call me what you want, but I've got no problem if you throw a "crazy" in there once in a while. Do people really want to know how the symptomatic colitis sufferers of the world are feeling? Or do they want to know the details on how we are REALLY FEELING, and what's actually happening inside our colons? I think they want to know the actual details. The good stuff. Otherwise, they are going to have to rely on outside information sources that just might not be the truth.

- Did I filter my responses on how I was feeling when people asked? Yes, I sure did.
- Did I give all the details away right off the bat? No, I did not.

- Over time, did it get easier to explain how I was really feeling with a whole bunch of people?
Yes for sure.

When people would ask me "So...how are you feeling today?". I would think to myself before responding:

1. How many poops had I already had?
2. How much blood was there?
3. How bad was the cramping so far?
4. Were there any night sweats to chat about?

Once I had an answer to those questions, I'd usually respond something like this:

"Oh, not too bad, still going to the bathroom a lot, not killing whales as much as yesterday."

or

"Pretty good, I think I might be getting better actually, I've only had to go to the bathroom 3 times this morning and there wasn't even any dripping blood."

or

"Not feeling too good today. I was up all night going to the bathroom. It felt like right when I would go back to bed, I'd need to get up and take another poop, just straight blood dripping out. I also woke up like I jumped in a swimming pool, crazy night sweats again."

What was really interesting to see take place, was the response that people would have when I explained my symptoms. During the early days, everything was new, I had no idea how people would react when they learned that good old Adam was bleeding, and going through some

unusually scary times. Surprisingly, most people would want to learn more. Unless they were grossed out right off the bat when you mentioned blood, but those people were actually rare.

Talking about your Symptoms with Other People:

If you are not sure about how much details to tell someone regarding your symptoms, just ask them if they want to hear the whole story. Tell them there's blood involved. You'll know right away if they want to hear the whole story or not. And if you are talking with someone who does not want to hear all of the bloody details, that's perfectly alright too.

REMICADE

The end of January 2009 I started my first attempts with some hardcore immune suppressants to try and control my UC. Up until this point, nothing seemed to work at all. The initial prednisone high I felt after my colonoscopy was very short lived, and all the other medications like Asacol and Colazal weren't getting me into remission. I can remember talking for quite some time with my doctor about what we should do next. We talked about Remicade ("Infliximab" is the more scientific name for this medication). Since the authorization with my insurance company was already approved, and since so many people respond well to this medication, I thought the risks were well worth the rewards. Also, I just wanted to feel normal again. If anything on the planet was capable of making a hard poop, without blood squirting from my butt hole, than I was interested in learning more.

My remicade infusion took place at the infusion center which was part of the medical center I was using. The whole process took about 3 hours from beginning to end. After they hooked up the IV to my forearm, shortly afterwards the medicine started to flow into my body. My wife sat by my side the whole time which I'm forever thankful for. How could she have imagined after getting married only a few months earlier that she would be sitting there with me? Not only was I her husband now, but I was sitting amongst 70 and 80 year olds in the infusion room at a hospital.

That night, I went out to dinner with three friends to one of our favorite Mexican restaurants named "Los Charros" in downtown Mountain View. I told them what had happened with my treatment and how I was now using Remicade. I tried to explain the gist of the medication as much as I could, but explaining some UC medications can be difficult. Luckily enough, one of my friends was finalizing his PhD in immunology and he was able to do ALL of the explaining to the others. He told me how Remicade was one of the "blockbuster" drugs from the past

decade. That had me excited. Although Remicade was now going to be my fifth medication(not including the enemas or suppositories), I was still very hopeful that something could fix my UC and get me back to normal. You have to think that way. And when you hear such good news from someone who has inside knowledge into the immunology world, it's makes you happy.

The next day was another mini miracle. **Within 24 hours of getting the Remicade infusion, I had my first hard poop in maybe a year.** Also, no dripping blood from my rectum. It was difficult to contain my excitement. I told Michaela right away, and everyone else who I spoke to that day. As my next few poops were more of the same, harder and harder and less and less blood mixed in, I thought for sure this was going to be the answer to all of my problems. I can remember thinking how I wanted to meet the scientist who invented Remicade and do whatever he/she wanted. I'd cook this scientist breakfast, lunch, and dinner for the rest of my life. This was truly amazing. What still amazes me is how the colon can produce a hard poop so quickly after having a long time period of bleeding and only sending out bloody diarrhea. Our bodies are amazing, and so was my first Remicade infusion. My next infusion wasn't for two weeks, but it looked like there was some time to relax now.

Having such a long run of active colitis symptoms, it was great to finally chill out. It didn't take long, but I started to think about my life again, and my future. So much of my previous 3 months had been filled with medical this, medical that, take this pill, take that pill. Cramping, pain, bleeding, and above all this, no working plan. Maybe Remicade was going to be the one for me after all.

Unfortunately for me, the remicade infusion started wearing off before my next infusion, but the little reprieve was very much appreciated. Once I started seeing symptoms coming back, maybe 10 days after my first infusion, my positive attitude quickly changed. I started to doubt Remicade as a longterm treatment. The second and third infusions confirmed what I was worried about. I never had a fourth Remicade infusion, after just 3, it was voted out as an option. My symptoms were back. I started increasing the prednisone again, and my doctor and I began talking about another medication and in some ways we were back to the drawing board.

Remicade Survey Information:

If you are interested in reading some stories from UC patients who use/used Remicade, there is an excellent survey filled with information on the www.iHaveUC.com website. [Remicade Survey Data - Click Here](#)



(I'm one of the groomsmen. I barely made it through this wedding ceremony without crapping my pants. It was April 2009, and I made sure to take a poop right before the ceremony, and I ran off and took another one right afterwards. My colitis was real active back then.)

HUMIRA

Was I disappointed at this point with how my treatment was going? Of course I was. Who wouldn't be. I was disappointed that the Remicade once again was this short term solution. Looking back, when I asked how likely a medication was going to work for me, I kept falling into the very small percent of people the medication didn't help. With a limited list of other medical treatments, my doctor and I agreed to try Humira injections. This would end up being the last of the new medications I've tried.

I hate needles and injections and I've never understood how heroin addicts can possibly get addicted. They need to use a needle right? Humira surely isn't heroin, and it actually isn't even a needle, but it is close, at least in my opinion it is. They call it a subcutaneous injection, or pen. Just fancy marketing to me. Either way, it scared the heck out of me. I needed to learn from my doctor's nurses how to use this Humira medication. Everyone was hoping that it would be the medication that finally worked for me. If that ended up happening, I'd need to take it every two weeks.

My first experience with the medication was at my doctor's office. The super nice nurse was kind enough to sit with me for over a half an hour while she injected the medication. This nurse

falls into a very small group of people, along with my good friend CJ and of course my wife, who know how much of a wimp I really can be. Surely this nurse was expecting me to be in and out within 5 minutes. Four quick Humira injections, and then I'm out right? Nope. Not even close. Each time she would get ready to inject the stuff, I would start to count down from 10. Once we got to about 4 or 5, I would come up with some horrible excuse and then I would start asking her questions again. It was bad. But I was scared. I hate any type of needle, no matter how small it is!

I heard rumors that the stuff burned right after you shot it in, and along with it being another immune suppressing medication, my mind was racing. Of course I was still on prednisone and dealing with active symptoms too. I think I might have ran off in the middle of the Humira training to take a 20 minute dump. And I apologize to whoever had to clean up that toilet.

Eventually, I had all four injections in me, no immediate side effects for the ten or fifteen minutes I hung around, and I was free to go home. The next injections weren't for two full weeks, so that was the next big date on my medication calendar.

When the two weeks were up, my symptoms had not changed, but it was injection time again. I decided to head over to CJ's apartment with my Humira box and instructions. I needed some moral support of a friend, as I was scared to be doing this to myself again. Just like with the nurse, the whole countdown from ten to one took way too long. Probably even longer. But I found a way to get the two injections in this time. CJ even did one of them for me. He must have been getting pretty annoyed with my constant delays. So when I asked him to do one of the Humira injections, he went straight through the countdown and didn't stop. That's what friends are for I guess.

The Humira works for many people, but again I fell in group who don't receive any benefit. It was different than the Remicade though. The humira didn't have any positive effects on me at all. However, I did develop some really nasty psoriasis which never existed before. So back up on the prednisone, and back to the drawing board.

PREDNISONE/PREDNISOLONE

If there is one medication that most UC patients can talk about and share common feelings on, it most definitely is prednisone. At least that's what it's called in the US. In many other

countries of the world, they might call the same medication “prednisolone”, but its the exact same thing. Come the summer of 2009, I had been taking prednisone just about non-stop since my diagnosis in October of the previous year. Like most people who are newly diagnosed, I had several different tapering sessions(times where my dose would get hiked up if symptoms were bad and then slowly weaned off again). Even after a long time of being off prednisone, it’s hard to say how much of a benefit it was giving me back in my first year with UC. I’d like to think it was helpful in containing my symptoms. But I know it never had me in full remission.

What frustrates me the most with prednisone, is the difficulty many UC’ers have weaning off it. I know now that I’m not alone in having troubles with stopping prednisone. In the years since my diagnosis I’ve received too many emails and messages from other UC’ers who have dealt with the exact same dilemma. It’s not just some big coincidence. That’s pretty clear. The reality is that getting off prednisone is a big challenge. It’s not impossible, but it’s usually not as easy as one might think. I don’t have them anymore, but I can remember my doctor writing out for me a very detailed tapering schedule on the back of his business cards and handing it to me every time we discussed my future dosage of prednisone. He always wanted to make sure that I understood exactly how to come down from those little white pills.

Prednisone is a powerful medication. It’s an anti-inflammatory steroid, and it works for most people. The problem is that our bodies can’t handle it for long periods of time. There’s too many potential side effects to make it a healthy choice for a “maintenance” drug for UC.

PREDNISONE SURVEY

In September of 2011, I ran a survey for ulcerative colitis patients who have used prednisone/prednisolone steroids. You can read the full survey results on this page:

<http://www.ihaveuc.com/prednisone-prednisolone-use-side-effects-survey-results/>

The 42 participants answers the following questions:

- How long have you been diagnosed, and how long have you been using prednisone/prednisolone steroids?
- Did you experience side effects?
- Did you get “MOONFACE” from prednisone (that’s a common side effect where your face can blow up like a balloon.(You can notice it a little bit in some of my pictures, although my “moonface” was pretty mild)
- If you experienced side effects, which ones did you experience?
- Did your side effects go away?
- Was the prednisone effective in treating your ulcerative colitis?

- If your doctor recommended prednisone/prednisolone to you again, would you take it?
- What advice would you offer to others with UC who need to take prednisone?



(June 6, 2009 Up at a bar in San Francisco with Michaela and two friends. I'm the guy holding my stomach with both hands. It's crazy how I was able to have a smile on my face, but when you look a bit closer, you can tell that my stomach is what's really on my mind.)



(June 20th, 2009. Michaela and I were out partying. I was taking Humira and Prednisone at this point and still dealing with symptoms. Probably a big alcohol night.)



(June 29, 2009 Stanislaus River, California. No bathrooms or sinks where we camp, so... I was most scared of getting a mosquito bite on doodie hole.)

When Do You Decide Steroids ARE NOT Working?

So many patients, actually almost everyone with UC will be introduced to prednisone/prednisolone steroids at one point in time. What might be helpful for everyone to understand, is what some researchers came up with about steroid effectiveness, and knowing when steroids are not working for severe UC patients. [Severe ulcerative colitis: At what point should we define resistance to steroids?](#) September 2008. Maria Esteve, Department of Gastroenterology, Hospital Universitari Mútua de Terrassa, Fundació per la Recerca Mútua de Terrassa, University of Barcelona, Terrassa, Catalonia, Spain. Javier P Gisbert, Department of Gastroenterology, Hospital Universitario de la Princesa, Madrid, and Centro de Investigación Biomédica en Red de Enfermedades Hepáticas y Digestivas, Spain.

SUMMER 2009

I stopped Humira officially in July of 2009. My UC symptoms had improved a little bit and I think that was due to the prednisone I was on. I wasn't killing whales anymore in the bathroom, just bloody toilet paper and super soft/runny snakes in the toilet bowl. Maybe a tiny bit of dripping blood on occasion. And of course on and off diarrhea. The real problem though was my need of 30-40 mg of prednisone per day. Those tiny little white pills, damn I hate them! I was off all medications but prednisone, and this is what I thought my options were:

1. start a new medication
2. surgery

It was tough. As the options were looking fewer and fewer, I made an appointment with a different gastroenterologist in San Francisco for some outside opinions. This doctor was considered to be a top doctor in the Bay Area, and although I really liked my current doctor, it felt like the right move to make at this point in the game.

It's always a good idea to get a second opinion when you're not sure of which direction to go down. Second opinions are very interesting, you sometimes get some different ideas, and you sometimes get the same. When you are up against big decisions in your treatment, why not

get a second set of eyes on your health? Starting new medications is a big decision. Having surgery is an even bigger decision. At this point in my post diagnosis life, I only had some preliminary talks with my existing GI doctor about surgery. We really just danced around the edges during that conversation. I'm sure he could sense that I was not really considering surgery seriously. It sounded scary, and I wanted to keep my colon. Although my colon was bleeding inside, and possibly keeping me from doing all the things I wanted to do in my life, I was still attached to it. The thought of cutting it out was not something I'd considered yet.

Sitting in your doctor's office and asking the question, "So what are my options if this drug doesn't work?" can lead to a very uncomfortable conversation. At least it did for me. I can remember sitting there and listening to my GI doctor talk about how the surgery worked, and going into some light details about the procedure. It hated listening to that. Instead of saying out loud, "**Fuck that, I'm not getting my colon taken out!**", I sat there and turned quiet and sad. It was not an easy conversation to be going through. Especially when you have been fighting for your life to save your colon for so long.

The visit to the doctor in San Francisco was interesting to say the least. This gastroenterologist came highly recommended as the best of the best. But that's not the impression I had. At this point, I'd met with several GI doctors, and I felt like I was becoming a bit of an expert in rating doctors(I'm guessing that all of us start to feel that way after enough doctors go into your butt-hole right...). This particular doctor gave me the least amount of time asking questions. The doctor didn't listen to what my father or I had to say. I didn't like the doctor one bit, but most importantly, there just wasn't any trust on my side. I wasn't sold on what the doctor was saying and what was recommended. Something was off. As you might have expected, one of the recommendations this doctor gave me was to speak with a colorectal surgeon about surgery.

My father and I left the medical building and went for some Mexican food afterwards to discuss what had just happened. When we sat down, I'm pretty sure I blurted out to my dad right away that I didn't like the doctor, and I wasn't really interested in taking any advice from the doc either. My dad felt the same. We had been dealing with the medical system for quite some time. Both of us were starting to realize that this disease just wasn't a simple quick fix. Every doctor had said the surgery route was the only way to literally remove the disease. But I just wasn't there yet. I'd lived through so many days and months of horrible symptoms. I had bled so much blood out of my butt, yet I was still standing. **Surgery meant giving up on my body, and I wasn't giving up just yet. I wanted to become better without surgery. I also wanted to either find a medication that worked with very low chances of side effects, or better yet, get off medications completely.**



(Having a beer with my dad while I was in the middle of UC symptoms, and heavy prednisone again, how about that puffy face:)

DID I ACCEPT THE IDEA OF SURGERY?

When I was facing surgery as my final UC solution, I was scared, sad, and almost feeling defeated. But something inside me wanted to keep on fighting. I just couldn't accept surgery as my ultimate fate with my colitis. That was a personal decision that every UC patient needs to make.

Looking back, I knew deep down inside that my colon was able to function the way that god intended. I knew that my ass still remembered how to take a hard crap. The remicade showed me that. I also had a few sporadic harder than normal bowel movements every once in a while. I can remember an early conversation with one of my gastro doctors. He was telling me that GI doctors often felt like they had lost the battle if they referred their patients to get colon removal surgery. He said with so many modern advances in the medical world, surgery was not necessary as much as it was before. This made me feel really good as a patient, and probably made me even more stubborn with accepting surgery as a medical solution.

Who knows, had I never seen any improvement from the time I was diagnosed, I may have opted for surgery back in the summer of 2009. Had I met with other UC patients who talked highly about successful surgeries, maybe I would have gone that route as well. But that wasn't the case. I hadn't met any other patients who had moved forward with surgery. Back in those days, I just learned about the J-Pouch surgery. That's the surgery where they remove your colon and reconstruct a "colon" which allows you to take normal poops again without "the bag". If you are a patient just listening to doctors about this process, it can be overwhelming, and I just didn't pay it much attention. Learning about surgery is valuable, and in hindsight, I wish I took more time to understand my options back when I was sick. But knowing when to make that big decision is something entirely different. That's a decision that each UC patient/family needs to make on their own. Doctor's can't force anyone to have surgery.

Back in the summer of 2009, I did not accept the idea of surgery. When I did spend time thinking about having surgery, there were too many unanswered questions.

Here are some of the questions and worries that bounced around in my head:

1. What are the chances I would have complications?
2. Would I need to be on medications?
3. How painful would the surgery be?

4. What is the average recovery time?
5. Would I need to worry about infections all the time?
6. How long would I need the bag for?
7. Would I be able to have children afterwards?

Even after all the questions, my biggest holdup with surgery was feeling like I gave up on my body. I just wasn't able to get past that. The thought of never having a colon seemed like I was admitting that my body just wasn't good enough to make it on this planet. In my very unclear thinking at the time, surgery meant that I had completely lost the entire battle with UC. The battle that had now been going on for years.

For anyone who is in a similar situation with out of control UC and no solution, please realize that my ignorance about surgery was not helpful. Had I known more of the details about surgery, I think it would have been better for me moving forward. With the exception of just very few people, surgery has been the BEST option, and the best decision that so many UC'ers have made. There are some very experienced doctors all over the world who have perfected colon surgery, and I know they have made so many people and families very happy. Getting an organ completely removed from your body might sound horrible and drastic, but it actually happens everyday. It's not nearly as big a deal as it sounds.

Surgery Recap

Once again, I wasn't ready for surgery back in the summer of 2009. I wasn't on board mentally, and I didn't want to be operated on. **And I'm happy as hell about that decision.**

GETTING LUCKY

Towards the beginning of August in 2009, my father helped me out big-time. He told me that through work, he met another father who's daughter also had UC. Wow, this was pretty amazing, someone else with the same disease as me. Just as you could imagine, my father asked how she is doing with the disease. I'm sure he was looking for any advice considering my current options and condition. The reality was that this man's daughter had tried just about the same amounts of medication as me, and she was also recommended for surgery too. But she found a way to be medication and symptoms free instead. **And she still had her colon. BINGO!**

I remember the phone conversation I had with my father. He told me the news. He also text messaged me her name and email address to contact her, which I did. We setup a time to meet at my place a few days later.

Part 5: Enter Diet

IMPORTANT MEETING

She came over one afternoon, the girl who also had UC. It was another one of those days where I was sitting at home and not feeling well. I remember feeling really weak, looking thin, and still dealing with blood and cramping. We sat down on the couch, and right then and there, I was excited. Here was a girl who had UC too, and looked healthy as anyone else out there. Energy, life, and a happy smile. **This is the life that I wanted back.** And when we sat down and started talking, for the first time in a long time, I felt really at home. Here was someone who knew exactly what I was going through on a patient to patient level. There's not enough of these interactions in modern medicine, but I liked it. This would end up being one of the most important meetings of my life.

We both went into details about what medications we had tried, and side effects that we had suffered. We talked about doctors and ideas and ways to go about treatment. But also, we got to the topic of how she was treating the disease with a new diet. I had already heard the Cliff Notes version from my dad, but she gave me all the details. And before we went further, I asked her a real simple but important question: "Are you taking any medications at all?".

I don't remember her exact response, but her answer was, "No".

We talked for a little while longer about the diet, but I'd already heard enough. **I didn't even think it was possible to have UC and be medication free.** I asked if we could go into my kitchen and pull open the fridge. She said sure, and we walked in there. Right away she started telling me about what she does and does not eat. It was sounding like everything from a book I was given almost 10 months before. My brother's wife's family gave me a book about the exact diet. It's called the "Specific Carbohydrate Diet™" and although I did read most of it, I never gave it a full chance. So many doctors had told me, "Diet Has Nothing to Do with It". And plus, the diet was going to cut out a ton of my favorite foods. Especially some of my favorite things like my daily fix of chocolate chip cookies. I lived off those cookies. Ten months before, I thought there was absolutely no way I could make it on that diet. So back then, I put the book

under some pile of something and forgot about it. But everything had changed from a year before, and with the proof standing in front of me of another colitis patient doing well, and dare I say medication free, I was super excited again! This time I was ready to try changing my diet. That's for damn sure!

In case you are wondering, this is what I thought my options were:

1. try another medication
2. colon removal surgery
3. listen to this beautiful, happy, UC patient about her medication free diet

Finally, I had a simple decision to make. I was going to give this diet a try. And that's what I did. I didn't give a crap what any doctor had to say at that point.

EARLY DAYS ON THE DIET

I started off by throwing out all sorts of things that I didn't need to be eating anymore. I used to love eating cereals, you know the sugary ones. And I'd drink it with lactose free whole milk. This was one of my favorites. It was easy for me to put back 3 or 4 bowls of cereal in less than 15 minutes. I would get into hyper-eat mode. Almost like a farm animal I think. The only thing on my mind would be to chow down on the cereal until the box was empty. This type of stuff I threw in the trash. But that wasn't all that Michaela and I threw away.(Before I go any farther, here's something to think about: Starting a new diet no matter if its for UC or anything else is infinitely easier if you have a partner to start it with you. Thanks Michaela!) Michaela and I threw out the bagels, we threw out the french bread, all of the ice cream, the milk, and the chocolate. Oh my god, it was a sad day, but a day that needed to happen.

The girl told me to give the diet a try for 2 months, and if it didn't work at all to consider other options. But she also told me that she knew two other people who had great luck with the diet and who also were lined up for colon surgery before they tried it. The only requirement was that I needed to be super strict. I could tell that when she was explaining how she does it, she wasn't cutting corners very much at all. And definitely not when she was getting started with the diet. I wasn't too worried about being serious on the diet, whatever she was saying I totally absorbed and took as the full on colitis truth. I was going to listen to her just like she was listening to me. She was able to understand me, she knew what I was going through, and she was healthy.

What's the Science Behind Treating UC with Diet?

It's actually very simple. The goal is to control the gut bacteria that lives in our colon by controlling the food that enters the digestive system.

If you combine that goal with the assumption that UC is an imbalance of gut bacteria, then diet might be your answer. That's the main idea. No rocket science going here, it is really that simple. As I would later discover, there are all sorts of different diets both for treating IBD and other related autoimmune disorders that are based off controlling gut bacteria within our colon.

As the first few days on the diet came to a close, so did some of my UC symptoms. I was starting to feel some harder poop flowing out of my butt, and it felt great.(Hardening up poops for the first time in a long time is cause for celebration!) The visual and audio portion of the bathroom visit was starting to sound somewhat like old times again. Everything was very gradual, but for the first time, I seemed to have some positive trends starting to appear. And my only medication was a relatively low dose of prednisone. By the end of the first week on the diet, I had some bowel movements that were harder than anything I'd had since the first Remicade infusion. That was positive results no matter how you slice it!

I think I told Michaela that this girl must be a saint. Such a simple solution this was, all I need was the right food to be eating. It wasn't too complicated and logically it made sense, much more than the medications I was trying for so long. If I kept this up, who knows, maybe within a couple of weeks things would be 100% back to normal. But of course, linear improvement does not usually exist with UC patients coming out of symptoms. Remission is definitely possible, but ups and downs are all part of the process too. That was also the case for me. I would have a couple of days of harder poops and reduced blood, but then out of nowhere would be a more bloody poop, maybe somewhat harder than the old ones, but not as good as the last. This was the common theme for quite awhile. But the overall trend was clearly that I was getting better.

TAPERING OFF PREDNISONE

I started the new diet in August of 2009. At the time, I was taking 15mg of prednisone per day. I slowly continued to taper off the steroids, and by the beginning of November, I was off all

medications. **It was awesome.** I wasn't cracking champagne(because that's not allowed on the diet, I wasn't pounding beers, that's not allowed either) but getting off medications and feeling in control of your UC deserves more than just a glass of bubbly.

That final prednisone tapering session was tricky. Although I was seeing great results in the toilet bowl, I was still scared to stop taking the medications. I don't know if I had some mental addiction to popping little white pills at that point or what, but it was hard to accept being through with all the drugs. To give you an idea, I took 2.5mg per day of prednisone the final two or three weeks. That's a tiny amount. And my doctor actually thought I was going to stop taking them at 5mg per day. But I decided to take it another step and ease the weaning off the drugs even more. When I ran out of the 5mg pills and only had 10mg pills left, I'd have to try and cut them in half and then half again to make one 2.5mg which is what I needed. I felt like a common junkie, but it worked. No drug rehab centers needed for me, I got off that shit fair and square.

I'm no doctor, you all know that by now, but I'll tell you this: prednisone is unique for every single person on this planet. What works for me, might not work for you. What works for your brother, might not work for your sister. So, if you are like every other UC patient and are having a hard time getting off prednisone successfully, **LET YOUR DOCTORS KNOW.** If you've had no success with getting off the drug in the past, try to figure out if your tapering program might need to be altered moving forward. You won't be the first person that needed some tweaking in that area. I'll never know for sure, but had I come off prednisone much quicker than I did, maybe my initial start of treating my UC with diet might have failed. We'll never know.



(this is September 7 2009 Lake Tahoe, CA. Prednisone Steroids in my shirt pocket, oh that nasty little bottle... maybe even a little moon-face on me too)

ACCEPT THE DIAGNOSIS?

There is yet to be a magical formula detailing how to accept a UC diagnosis. It's not an easy process for any new patient. The same is true for concerned family members. I was in denial for a very long time, and I didn't want to accept the idea that my UC was actually my disease. Thankfully that has all changed for the better. Beginning with meeting the local girl who explained the diet I follow, and then afterwards meeting other people who have UC and Crohn's Disease, everything started to click. My UC became even more real. When you are the only one with UC, it can be difficult to visualize what your life can be like "living with UC". Once I met other people, and actually saw them alive right next to me, I was able to finally accept UC as my disease.

Thankfully there are resources like the Internet and social groups where people can turn to easily connect with others. But even with groups like that, it's the initial reaching out to others that is often so difficult. In my opinion, it would be great if doctors forced their patients to meet another UC patient within a few days of being diagnosed. **I know it sounds crazy, but I'm positive that by coming together and communicating with fellow patients, the healing and acceptance process can begin much quicker.**

How long did it take me?

It took me a year to accept my diagnosis, I hope everyone else can find acceptance faster than me. Meeting another person with my disease helped me out more than anything.

BACK TO THE HOSPITAL

Although there are definitely people who have conquered UC before with very little difficulty, that sure as hell isn't my story. It always amazes me to hear of other people who had relatively easy cases of UC. When you are sick with UC symptoms, it seems impossible, but it is true. There are other people who only needed one minor prescription medication to put all their UC symptoms into remission for years on end. That's right, just one prescription is sometimes all it takes.

Whether my personal battles with UC are difficult, unusual, worse than normal, or something else is up to other UC'ers to decide. What sticks out as a particularly tough part of my whole UC experience actually involves my joints and skin. What started as a small issue was getting out of

control right in front of me. To think that I had figured my health out, wasn't entirely true. The body is very complex, and no single person(doctor/scientist/Albert Einstein etc...) knows it completely. Yes my colon was making much better looking poops, but there was much more to the story. So as an added prize, my joint and skin problems were now at the top of the priority list.



(My legs the fall of 2009. The rashes were particularly bad on the soles of my feet and palms of my hands, sexy right!)

When I started up the Humira medications earlier in the year, some strange things started happening. My joints in my upper body began to hurt. Really bad. I also noticed some small itchy spots on my lower legs near my ankles and feet. Then the itchiness spread to other parts of my body. My scalp in particular was becoming very itchy. The same goes for the soles of my feet and palms of my hands. And how could I leave out the fingernail on my right hand's ring finger(say that 5 times fast why don't ya) that was becoming deformed more and more each day? What was happening was a mystery. But just like my original UC symptoms, the skin problems started very slowly and progressed and became out of control by October 2009. The joint pains came on a bit faster. Together they were driving me crazy.

Back in June of 2009 a few months earlier, I went to the dermatologist at my health clinic a few times regarding the skin stuff. My hope was the skin problems would be a quick fix. I was

usually prescribed some creams with added steroids, but the problems didn't go away. The skin kept on cracking, peeling, and eventually bleeding. It's pretty crazy when you see your skin looking so horrible. It gets very awkward when you need to go shake hands with people too. Have you ever tried to hide the palms of your hands all day long? I know people who pick at their fingernails all the time, but picking the dead skin off your hands, and scratching the heck out of your legs and shins during a business meeting...who does that? But more than anything else, the realization that I lost control of my body once again was very frustrating. All this was going on right when my poops were getting better, it made no sense at all.

My joints were a different story than the skin. The joint pains had existed for several years in a very mild form. But after Humira injections, the pain and discomfort went through the roof. Luckily, the joint pains never spread to my feet or knees, only my upper body joints were affected. What was so strange was how the joint pains would come and go. I could be complaining to my wife that I wasn't able to lift my arms, and then ten minutes later I would feel as though my joints were totally cured once again. Hurting, not hurting, back and forth the joint pain dance just never stopped. I had no clue what to do.

In September 2009, my wife and I were up in Lake Tahoe at a friend's wedding. By chance, I ran into an old family friend who is a leading immunologist, and very well respected throughout the world. He knew about my UC, and he asked me how things were going and how I was feeling. I explained the current problems and symptoms real briefly, I mentioned my skin issues, and my joint pains and I'm sure I told him how I was really bummed out that I wasn't totally back to normal after so much time. Since he knew so many people in the medical world, he told me to stay in touch, and he would try and arrange a doctor's visit with someone he felt could help. Luckily enough, I was able to meet with a very specialized team of physicians shortly afterwards with his help. The doctors were from a Rheumatology and Dermatology combined clinic. Before the office visits, I took some time and Google'd the two doctors I was to meet with. Sure enough, both of them had a very long resume and they looked to be exactly the types of physicians who could help me out of these symptoms. This appointment was in mid-October of 2009, just over a year after my original diagnosis.

Below are the details of that visit in my own words.

Adam Scheuer - Reason for Office Visit :

Evaluate current symptoms such as joint pain and skin lesions and skin eruptions.

Introduction to Mr. Adam Scheuer:

Adam Scheuer was a healthy young man for much of his life, however that changed upon his diagnosis of UC back in October 2, 2008. Although he was struggling with symptoms for several years beforehand, he was still able to carry on a normal life. After trying many medications such as Asacol, Colazal, Sulfasalazine, Remicade and Prednisone steroids, Adam was introduced to Humira in April of 2009. Very shortly after initiating the Humira medication, he began to develop stiff joints as well as eruptions of the skin in many different parts of the body. Although the legs seem to be unaffected, the upper body specifically the shoulders and back are getting hit very hard with pain. The pain is often worse during the nights and in the mornings. The skin problems were most severe on the hands and soles of the feet. There was also major skin eruptions on the scalp and on some parts of the lower legs. THANKFULLY, the genitals were not affected, nor was the buttocks.(It's a miracle!)

After just a few months of trying out Humira to treat his disease, Adam made the decision to discontinue use of the medication due to the side effects which were significant.

The Overall View and Suggestions Were:

It is not possible to determine if Adam's current symptoms are from medication, or if the skin and joint problems are related to the inflammatory bowel disease. Some recommendations as far as medical treatments moving forward are:

1. **Narrow-band UVB** to treat the skin
2. going back to using **Sulfasalazine** which has a chance to help both the skin and the joints
3. **Methotrexate** for both the joints and the skin
4. **Ustekinumab** which is helpful for the skin and sometimes helpful for joint also

Although I wasn't really in the mood to start trying some other medications, I was super happy to have been seen by these doctors. But mentally it's hard. When you are thinking to yourself, "Recovery time is happening!", and then all of a sudden you realize you're still in a hole... It sucks, and it's not easy. Everyone has problems, everyone. But no matter what anyone says or thinks, health problems are different. We're not talking about some financial hurdles. These problems are not relationship based. These problems are with your body. And my body

was doing some crazy things. I was starting to feel like a 90 year old snake who could not move properly and who's skin was peeling off!

In the end, I treated this visit like a second opinion. Nothing totally new came about, and in fact, it seemed clear that I was becoming an odd case in terms of my symptoms. I always liked being original growing up, but when it comes to medical problems, cookie cutter issues with cookie cutter solutions would be just fine. But as most UC'ers know, it's usually not that simple. October 2009 ended with me still struggling just like I was a year before, but at least the colon was much happier. Michaela and I even made a trip down to Santa Barbara. We stayed with my old roommate and even visited the sailboat I used to live on in Santa Barbara harbor.(It looked like the new owner hadn't sailed her a single time in the previous 3 years...)



(there she is, good old Pura Vida Oct. 2009, my old boat, if you get the chance, go live on a sailboat, its way fun, and cheaper than paying rent)



(Oct. 30, 2009, Beach in Santa Barbara you can see my legs are still pretty nasty, and it looks like I didn't change from the previous picture...?)



*(Michaela and I scraping together last minute costumes-thanks Bob for the gear.
Halloween 2009-Santa Barbara)*

MEDICAL VACATION TO SCOTTSDALE

The month of November 2009 started off with a bang, this was going to be my Showcase Showdown with the medical world, but I'll try to play it off as a vacation if that's possible.

As a quick recap, here I was just over a year since my diagnosis with UC, and feeling pretty good poop wise. I was off all medications. I also had recently finished my prednisone taper. But now I was dealing with ugly skin lesions that some doctors had called psoriasis, and nasty joint pains that some other doctors had called arthritis. I was frustrated that there were still some hardcore medical problems going on.

The month before in October, my father managed to make an appointment for me at the Mayo Clinic in Arizona. Actually, "appointment" is definitely not the best word. It was more like a 3 day intensive visit with all types of different specialists. The Mayo Clinic has a few different campuses within the Scottsdale/Phoenix area, and I "vacationed" at a few of them. The goal was to figure out once and for all what my skin and joint problems really were, and to learn what recommendations world class doctors might have for me.

So what is this Mayo Clinic? Well, it's a pretty impressive medical clinic. Not to say that my previous healthcare providers were some derelict places to be treated, because they definitely are not, quite the opposite in-fact. But the Mayo Clinic is something special. I'm not even sure that "clinic" really describes what Mayo is all about.

I thought "Mayo" was only used for abbreviating "mayonnaise". Well, I was dead wrong again.

In Scottsdale, Arizona, if you use the word "Mayo", most people will be thinking of this elite group of physicians, who are recognized worldwide as providing the ultimate in medical care to patients from all over the world. That's right, I **WAS NOT** the only sick dude flying in there by any means. Most people go to Scottsdale, Arizona to watch spring training for the Major League Baseball teams. Or maybe some people go to Scottsdale to enjoy a nice round of golf at the one

of the fifty-bazillion spiffy country clubs that are scattered throughout the desert. Not me. I left San Francisco Airport on a roundtrip flight to get some more top notch healthcare. And once again, the goal was to come to some conclusions about my skin and joint problems that were keeping me from being normal.

At first, when my father told me about the Mayo Clinic idea, I was totally against it. My thinking was simple, "**I'm not going to see anymore damn doctors!**". To me, I had already done this. For starters, I went to see the gastro doctor up in San Francisco who recommended me to have my colon removed. And also, I just had a doctor visit with some other highly recommended doctors who didn't really have any new "news" that sounded good to me. What possibly could these doctors in a different state have to say that might be any different?

Before any final decisions were made about the Mayo Clinic, I can remember clearly talking with my Uncle Bennett about the dilemma. My uncle's thinking was totally different and he changed my mind.

"Adam, what in the world do you have to lose by going there for a couple of days? If I had the opportunity to have a full body examination by the best doctors in our country at a state of the art medical clinic like Mayo, I'd be there in a second. You're lucky to have this opportunity, and you've got absolutely nothing to lose, and everything to gain. What's the worst thing that can happen Adam? Maybe they don't have any news for you. So what? At least you will know their opinion on what's happening with you."

And after my uncle who had lived so many years with an ostomy bag at his side said this to me, my decision was made. I was heading to Arizona. It was a good decision to go. For all kinds of reasons actually. Along with making use of the incredible Mayo Clinic, I had the added bonus of seeing my family who live in Phoenix. All sorts of cousins and my Aunt and Uncle live out there too, so maybe it would be a vacation after all.

I remember sitting in the airport and thinking how ridiculously crazy it was to be starting a trip like this. Taking a full week off work, then flying out of state to get a whole review of my body. I fully disclosed my health conditions a few months earlier when I applied for the new job I was working at, but certainly they couldn't have imagined I'd be asking for time off, let alone a full week for an out of state medical review so quickly. Thankfully, they didn't have any problems at all with the request, and that's all I could ask for from my new employer.

When the plane landed, I remember stumbling through the airport terminal. Yes, the thought definitely crossed my mind to ask for that guy who drives the old people and disabled people around on the carts to give me a lift. You know, the guys who are always honking at you in those electric oversized golf cart mobiles. Wheeling my little bag on its wheels I eventually made it to the rental car counter. I must have looked real sick, I couldn't move my arms very well, and my skin was cracking all over. I requested an automatic car, definitely not manual, any chance to minimize body movements was the goal here! It was late in the afternoon but there was still plenty of light, and I was finally off. Taking off with a shiny new rental car, in search of some medical answers. Hopefully, answers that didn't require much medication, and answers that didn't require surgery. I asked the lady at the gate before you leave the rental car lot, "which way to Scottsdale?". She gave me directions, and I sped off. I probably even burned out the tires a bit, come on, who gives a crap, it's a rental car!

Out there in the desert, in-between the cactus and the Indian Reservations, is where the Mayo Clinic is located. It's not right in the middle of Scottsdale like I expected, but it wasn't a very far drive either. I definitely didn't think there's anything else out there next to the hospital looking buildings, but there is. There's a small hotel. A hotel for people just like me. For sick people, or maybe just some more people who are using the clinic during their Arizona vacation.

That hotel was my home for the next several days. I've only been to a retirement home to visit my grandparents, and that's what it felt like. I remember walking to my room and thinking for sure I was the youngest person who stayed at this place for a very long time. And then I started thinking some more... "what the heck was going on with me? Why was I doing this whole Mayo Clinic thing. I was a healthy person for so long!"

As most people get to their hotels rooms and are so happy to see a perfectly made bed, nice clean white sheets and extra pillows everywhere. This vacation wasn't starting off so bright and happy for me. And with the thoughts starting to race through my head, I started to think about my past. What had I ever done that led me to this hotel room? Was tomorrow going to be the beginning of my final judgement days?

I was getting scared.

Up until now, everything was pretty much bad news in terms of my health, but it never was fatal news. There's a big difference there. You can tell me I have UC, and you can tell me that I have to take medication this, or medication that, but as long as you have an idea of what is happening, and if you can provide a name for the condition, I can accept that. But when people

don't know what's wrong, and if there are no answers at all, that's going to freak me out. Only a few minutes after walking into the hotel room, I laid down on the bed. I wasn't crying or smiling, more of a very emotional disbelief. Instantly, the mind game was turned on. And it was moving really fast. Hockey game speed times ten. The questions and answers started flying into and out of my head.

“How did I end up in this hotel room? I shouldn't be here. Go back in my history, go pull out my chart notes. Go talk to my pediatrician, go talk to all the doctors. I wasn't ever sick growing up. I wasn't sick in high school, I wasn't sick in college. I rode my bike 1800 miles alone in Croatia, and I used to play soccer all the time.

(And then my brain really lost it.)

WHAT THE HELL IS HAPPENING HERE? Why am I now sitting in this bullshit hotel room, out in the middle of butt fucking Egypt, with my long list of doctor's appointments for the next several days? Why are my joints not working, and why is my skin falling off? What is wrong with my body? Did I do something to deserve this crap? I thought for sure everyone liked me!"

Somehow I fell asleep that night, and I woke up to an alarm. Judgement day was here.

JUDGEMENT DAYS

Tuesday November 3, 2009

After waking up and taking a shower, I was off to my continental breakfast, which was included with the hotel room. I don't remember what I had to eat, but I'm sure I wasn't really enjoying anything. It's a strange feeling sitting alone in a dining room with other groups of people and families who are also doing the exact same thing as you: Riding the 2 minute shuttle across the street to the Mayo Clinic.

Who knows what everyone else was being examined for, I definitely didn't see anyone with skin flaking off like mine was. Besides a few old-timers, I seemed to have a more jacked up walk going due to my joint problems also. I remember reading the USA today paper, and then gathering all my documents(insurance, some recent chart notes etc...)

QUICK NOTE TO EVERYONE: If you are feeling down and out, go grab a copy of USA TODAY. There's a section which has little news briefs for each of the 50 United States. You will most certainly find some **ridiculous news stories** that will make you instantly feel very good about yourself. And that's exactly what I needed on this day.

I can remember how nice the shuttle driver was, you know the guy who shuttles everyone back and forth from the hotel to the medical facility. I can't imagine that job though. Bussing people all day long, back and forth to get some news on why your medical condition is so messed up. But surprisingly, the bus driver was way cool, he was a pro at this. He knew just what to say to make everyone feel comfortable, and it was much appreciated.

When I finally stepped inside the Mayo Clinic for the first time, something changed. **This place wasn't some big scary Judgement Day center after all.** It was an incredible medical clinic. These people weren't going to tell me I was going to be dying any minute now. Or at least that didn't really linger in my head much longer. I was off to find out where my first appointment was. In my case, there wasn't a formal schedule at the beginning of my introduction to the Mayo Clinic. For me, I was to start off with a detailed examination with a general practitioner type of doctor. After that, I would then be referred to all sorts of specialists who would be able to further evaluate me.

I remember waiting in a large waiting area on the second floor, I guess this was the waiting area for this type of doctor. And there must have been 50 other people waiting next to me. There were a few others that looked like they might be near or around my age, but for the most part, the rest of the sick crew was definitely in the senior citizens category. And these people didn't look all too sick, some of them looked pretty healthy actually. It was quite a few people I would characterize as upper class country club types, big diamond rings and all that jazz types of people. But either way, I sat and waited for my name to be called out.

"Mr. Adam Scheuer?"

Once I heard that, I gave a quick look around to make sure there wasn't another one of me, and I was up waddling to the nice pretty nurse who showed me to the exam room. It wasn't long until the actual doctor made his way into the room and by that time, I was already wearing the usual hospital type gown. You know, the one where your ass is blowing in the wind. We had a nice long talk, I gave him the full background, from early on up until the present, and I made sure to tell him about how I was finally medication free and of course all the details about the

Remicade and Humira medications. He was a nice old man. Probably the oldest doctor I had met so far. I remember him wearing his black suspenders, he was the type of guy who sat back in his chair with his legs crossed. I must say, I really liked him, and I really liked his style. He put me at ease. He also explained to me the details about how things were going to unfold over the next few days.

This first doctor wanted me to visit with several other doctors from several different specialties. First, he wanted me to meet with a Dermatologist. It wasn't a big mystery why he was suggesting that, after all, I was vacationing in Arizona to get my skin fixed. He also wanted me to see a Rheumatologist, and once again, no surprise there. He wanted me to meet with one of the Gastroenterologist doctors, which was fine. But then, there was a little surprise, he wanted me to see an Ear doctor as well. Upon him looking into my ears with the microscope deal, he noticed that I had a definite ear infection in one ear, and possibly one in the other ear. That was interesting. I definitely felt some strange feelings in my ears lately, and I also even remembered some severe wax buildup type of stuff going on a few nights before, but somehow this just wasn't anything that concerned me. Who knows, maybe if your skin is falling off, you just aren't too concerned if your ears start piling up the ear wax and you start to have a hard time hearing things. **How crazy our bodies and minds can become when you forget what total health feels like.**

In addition to these different appointments with other doctors, there also was a ton of different diagnostic tests he ordered, an EKG for example to check out my heart. He ordered tons of different X-RAYS as well. The X-RAYS were mostly to check out my joints. After about an hour or so, our initial meeting was over. He said we would meet again as my final doctor visit once all the others were finished at the end of the week. The final visit with him would be a recap where we'd both go over all the other doctor's ideas and recommendations for moving forward.

Without any pain at all, my first Mayo Clinic doctor's appointment was over. Off he went to meet with another sick person just like me. And off I went to find my pants and shirt. My next stop was downstairs at the main lobby. After waiting for a half hour or so, I picked up my formal itinerary with all the other doctor's visits and the times and locations for the rest of the week. It was almost like picking up your class schedule when you start a new session of school. At least that's what it felt like for a little while.

I flagged down the hotel's shuttle bus outside the main building, and within a few more minutes, I was back in my hotel room. Nothing too crazy so far, and no horrible news to report.

Two hours later and it looked like I might live after all. The Mayo Clinic Vacation was starting to feel like a great decision.

Not a Big Deal:

For all of the freaking out and heavy emotions I had about going to the Mayo Clinic, it really wasn't a big deal. In hindsight, I wish I didn't get all worked up about this medical vacation. Very little things in life are worth added stress, that's something I continue to learn. Deep down inside there is one main reason I was hesitant with going to the Mayo Clinic.

Here it is:

I was scared these "super doctors" were going to find something horribly wrong with me like cancer or some other disease. That's some foolish thinking though. If you do have something horribly wrong, why wouldn't you want to find out ASAP? That's a huge lesson I've learned and it took me traveling all the way to Arizona to get it all figured out.

YOU NO COME BACK AGAIN

On my second night at the hotel, I remember going out to dinner at some local brew pub. It was nothing fancy, just one of those sports bar type of spots. After sitting around and watching everyone else pounding beers and drinks for long enough, I decided to make the drive back to where I was staying. But before I pulled out of the strip mall's parking lot, I noticed a sign that said "Massage". And the light went on in my head. I needed one of those. Maybe a nice massage would help out with some of the joint problems and lower back pain I was having. Heck, it was worth a try at least. So, I re-parked my rental car, and stumbled on in. It was probably about nine o'clock at night, for sure it was dark out, and I can remember the pinkish red neon lights outside of this place.

As much as I can appreciate a nice professional massage, I am by no means an expert on picking out massage parlors. I'm also not the type of person to set aside a weekend with my wife, and head out of town to a fancy spa resort or anything like that. Actually, the last time I had a massage was with Michaela back in eastern Czech Republic. In the summer of 2007 when we were biking around Czech and Slovak for a month, we spent the night in a small town called Smradavky (because the village is sitting on-top of a shit-load of sulfur). I guess it translates into "Stinky Village" or something close to that. Anyways, we stopped in this town for two reasons. First, they had a nice campground with a restaurant(if you want to call it that). And second, a popular Czech band called "Tri Sestry" was playing one of the nights in the courtyard of the town's castle. As a side bonus, there was a "Spa" we didn't know about, located just a few minutes walk from where we pitched out tent.

So, after biking for several days, we both walked into the spa and ordered up two massages. In addition, we ordered the hot tub for 30 minutes before, we both thought this might be a good way to get clean, and relaxed before the actual massaging took place. In good Czech fashion, there was some alcohol waiting for us in the hot tub room, a nice bottle of champagne, which we both enjoyed. When the time came, Michaela and I both were called into our separate massage rooms, I happened to get the owner of the spa, and Michaela had a younger Czech girl. I didn't take any pictures, but let's just say it was a pretty good massage. **But I found out how hard it is to relax when you have a supermodel doing the massaging.**

Although I was a little bit on edge with heading into the massage parlor in Scottsdale, Arizona, for some reason I wasn't very self conscious of my disgusting peeling skin that was in some places oozing with white puss around my legs and ankles. Since I was bored, and had

absolutely nothing to do until my doctor's meetings the next morning, I ordered an hour long massage.

I wish my instincts could have talked to me. Right away, something felt a bit off with this red-light district looking place from the inside. All the lights were pretty much off, there were a few dim neon lights, and a few candles, and several Asian women at the front desk to greet me. When I explained to them that I wanted a massage to help my back out, they seemed a bit confused. But sure enough, one of them led me back to a room and closed the door. So there I was, alone again in another room on my medical vacation. I remember taking off my shirt, but leaving on my pants. There was nothing that needed to happen tonight other than a nice back massage. In the middle of the small room, a few candles were lit on a small end table, and there was a nice big massage table in the center. So, as I thought I was supposed to do, I went and laid down to wait for the masseuse.

It wasn't but a few minutes later, and there she was again. The same woman who walked me in, a middle aged lady who didn't seem to speak much English. But she gave me a look that something was wrong. Right away, she motioned and asked me to take off my pants. It wasn't really in a nice way either. Although I didn't want to expose my massive light and dark red rashes, and the peeling skin that was so bad on my legs and feet, somehow I gave in. I got up from the table, swung my legs to the floor and dropped my pants and then hopped back up to the table. But that wasn't enough for her. She wanted everything off. She motioned again and mumbled some more Chinese or Japanese or maybe it was actually English, and I could tell she was expecting me to get full on naked in her room. As I looked down at my boxer shorts, I noticed that it was really dark in the room. So dark, that I could barely see the skin problems I was trying to hide. It seemed like quite a while, but probably within a second or two I was now naked and jumping back onto the massage table and laying face down with a blanket covering me.

It had been a few years since the massage in the Czech campground, but I still wasn't able to relax.

My instructions for the "back massage" must have been unclear, or not even understood. It didn't take long for me to realize this wasn't an ordinary massage. No sir. Not even close. She had no clue that the butt she was trying to massage had probably taken more poops in the past year than she's taken her entire life. And I had no idea I was walking into an exotic massage establishment with all kinds of tugging going on. Maybe she heard "Butt Massage Please" when I ordered a "Back Massage"? Who knows.

But then things started getting really interesting about halfway into the ordeal. The lady started to rub my legs and feet, and although she had a ton of oils and jellies mixing in with my skin, there was no way to avoid the skin problems any longer.

After just a few minutes, she was taking the towels and recovering my legs. And then she was doing some massaging motions on top of the towels. How strange it must have been for her. She was probably expecting some normal skinned white guy who was looking for some special touching. But now she was probably thinking I was spreading some nasty disease. Things got weird, and definitely before my hour was up, the massaging stopped. I can remember her saying something about "this finished", and then I was left alone. Alone in the room to get dressed and get out. I had already paid, so thankfully I didn't have to deal with her again. But before I was out of the room, she came back in and told me something I've never been told before by any business, "**You NO Come Back Again!**".

So, night two of the vacation was a bit rocky, but somehow I was able to laugh it off. By the time I drove back to the hotel, all that was on my mind was my next day at the Mayo Clinic. I had several appointments that were scheduled, one with the ear doctor, and the other with the dermatologist. And maybe if I was lucky, I'd have a decent night of sleep.

MAYO DERMATOLOGY

On day two, I met with a super nice young woman dermatologist. It was a bit awkward sitting in an examination room and seeing a young blonde haired doctor walk in who looked like she might even be younger than me. At first I assumed it was some type of assistant, I mean come on, she looked too young to be a dermatologist. But after just a few seconds, she handed me her business card like all the doctors do at the Mayo Clinic, and then the exam began. I was going into the details about my skin problems. Maybe it was because she was younger than most doctors, or maybe it was something else, but I was showing her and trying to tell her everything I could think of about my skin.

It wasn't the first time I explained the skin story. Yesterday, I basically said the exact same words to the first doctor. And the doctors I had met back home the previous month, well, they all now heard the same story. As a sick patient, some things repeat themselves. And if you are out getting second opinions, you have to get used to constantly re-explaining your whole medical story over and over again. I remember sending to the Mayo Clinic all of my previous chart notes

a week or two before I arrived. But I can't imagine that the doctors had enough time to read through everything I sent. And I can't blame them. If each of the doctors at Mayo had to read my entire chart notes before I arrived, they would need a few days to go through all the pages thoroughly. My file was hundreds and hundreds of pages at this point. Countless blood test results, X-ray reports, office visit notes, and everything else you can imagine.

My exam with Mayo Dermatology was very good. I was very pleased with the listening that took place on both sides, and I even was given a small gift. Well, it was actually a medical article that the doctor printed up during the exam. It talked in very heavy details about **Anti-TNF-alpha medications and induced psoriasis**. Although I wasn't able to follow all of the scientific talk, I was pretty impressed that she got this for me. At least I had some reading to do that night which would for sure keep me out of the massage parlors. As for recommendations, almost all of the recommendations I received were identical or very similar to the recommendations I had from prior doctor visits. I was obviously hoping for some breakthrough news, but that just didn't happen yet.

So, once the visit was over, I went downstairs and picked up a few prescriptions, a couple of compounded creams that she ordered for me. Then, it was off to the hotel for a break.

EARS

On the same day as the dermatology visit, I also met with the Ear Nose and Throat department of the Mayo Clinic in Arizona. This particular department was not part of the buildings that were close to the hotel. I actually had to drive about a half an hour with the rental car to see these specialists. Once I arrived at this new building, I was pretty impressed. In the big huge parking lot there were those golf cars driving around. Shuttle services which took you from your car to the entrance of the building. Maybe that's because it is so damn hot in the summer and sick people simply can't be expected to walk in that heat?

After getting oriented and checking in with the receptionist at the proper counter, I had a few minutes to sit and watch all of the other hospital patients. This particular location was a bit different. There were many more people waiting to be seen. It almost felt like I was sitting down at an airport gate before the plane takes off. But sure enough, my name was called again, and it was time for the ear doctor.

It turned out that I met with a physicians assistant or "PA-C". He was great. I gave him a real brief overview of my colitis and joint and skin issues, and then he started checking out my ears. It wasn't too long until he confirmed that I definitely had an ear infection. He also told me that I had some pretty hefty amounts of earwax buildup that he was going to remove. So after he flicked a few switches and turned on the big screen TV for me to look at, the chair I was sitting in reclined and pretty soon the quick procedure began.

If you have never had your earwax sucked out of your ear before, it's one hell of an experience. And to watch the whole procedure right in-front of you on the TV is pretty awesome. I guess I'd never looked into my ears before.

For the actual procedure, he was using some very small but very powerful suction tube. He said it should not hurt at all, but it might be a bit loud for obvious reasons. There was a little camera lens attached somehow to the suction device, and that's what we were watching on the TV. It was pretty nasty looking once he was inside the ear canal. You could see it was all very red, and it looked like it must be pretty sore. But, sure enough, some large clumps of dead skin and wax were getting sucked away, and within a few minutes it was all over. The whole meeting with this guy was probably just twenty minutes or so. He felt that the psoriasis or skin cracking might have taken place also in my ear, and some small infection may have started as well. So he prescribed some antibiotic ear drops for me, and told me they should take care of everything. And there went another doctors visit. All I needed to do now was head to the pharmacy which was inside of the building and start dropping some liquid antibiotics into my ears.

HEALTHY COUSINS

With no more medical visits for the day, I was free to roam around Scottsdale. I picked up a bite to eat, and later on that night I went to visit my cousins.

If you want to try and forget about your health for a while, go watch the local gymnastic teams during training. One of my cousins who lives in the Phoenix area is an incredible gymnast. I've spent my fair share of time watching the gymnastic events on TV, mainly the Olympic events with my mom as she was big into that stuff. But to watch these people workout and to hear the coaches, and equipment banging around live, it's amazing. After focusing on my poor health for so long, it was great to go and see healthy people pushing their bodies to the limits. And to see a cousin of mine doing so much strenuous physical activity, well it made me feel really good. Even though it wasn't me, it sent me a reminder that our family has some tough

genes somewhere. What a perfect way to end another day of living in the medical world. That was the highlight of the vacation for me.

RHEUMATOLOGY

When I woke up the next morning, I decided to do something a bit different. I heard there was a cafeteria at the medical building near the hotel. So, after getting shuttled over to the clinic, the cafeteria was my first stop of the day. Sure enough, there was food available, and a much bigger selection compared to the hotel. What do you know, the day was starting off pretty darn good.

When it came time to meet with the Rheumatologist, I was hopeful that he would have some new thoughts on how to control my joint pains. The joint pains, and the lower back pains were so hard to understand. They would come and go, some times they would come and stay. And other times they would go and be gone for a week or more. It just didn't make any sense to me. The pain would make me crazy, then ten minutes later I'd feel normal again, but 20 minutes after that, the pain would turn me into a complete wreck all over. Trying to become the detective and figure out the reasons for the coming and going of the pain was a joke as well. You can call me a fool, but I spent hours upon hours thinking to myself that it must be something I'm doing to my body that was causing all this pain. Either it was from something in my diet, or some types of motions I was making, it just had to be something of my doing. Or at least that's what I started to believe.

Nothing was very concrete regarding the joint pains. But, I was certain my joints started getting really bad **after taking the Humira injections**. If this doctor could just verify that some other patients complained of the same thing happening after Humira, that would have eased my worries so much, and maybe I was NOT going to be declared mentally insane after all.

The Rheumatologist was a super nice guy. He was also pretty young, I'd say in his late thirties or early forties. We had the usual talk about my background history, and then we got into some of the details about the pains. I remember he did some tapping on different parts of my legs and arms. Then he started asking me some more questions.

What stuck out to me from this visit, was how interested the doctor was in my diet modifications. I went into lots of details with him. He asked exactly what types of changes I'd made with eating, and I gave him most of the main ideas. He wasn't able to offer me any new ideas regarding my joint problems, but the simple fact that he showed interest in how I was treating my colitis with diet made me feel really good.

GASTROENTEROLOGY

I guess in some ways it was a bit odd for me to be meeting with a gastro doctor on this “Skin and Joint Pain Medical Vacation”, but what the heck. What's another GI doctor at this point? I'd already seen so many of them, it sure wasn't going to kill me. And maybe he might be the one who had seen some strange side effects like my skin problems from other patients who had started using the immune suppressant drugs. That was my hope. But it still was strange. I had come to Arizona to fix my skin and joints, my colon seemed to be working pretty good at this point...

Before flying to the Mayo Clinic, I did a bit of investigating online. I guess that one side of me that always wanted to be in the FBI was coming out. I checked out the doctors who were from the gastroenterology department. There were all sorts of different medical studies listed that the GI doctors were involved with, so I spent some time looking into those as well. Who knows, maybe there was a report titled: "Young Men with UC Who Have Skin Problems Is Common". When the GI doctor walked into the exam room, I recognized his name as one of the doctors I had read about online. That was neat. And we had the usual chat. He asked me about my background, and what had led up to where I was right now.

I didn't really like him that much. He gave me the feeling that I was just another patient. And I didn't like that. After all that I've been through with this disease, I was starting to consider myself an expert with my UC. **Of course I had all kinds of things to still learn, but doctors who act like you don't know anything are the worst.** And it bugged me when he dismissed the idea of my recent diet changes as having a big impact on my UC symptoms.

In hindsight, it's very simple. You just might not like all the doctors you meet. And there's nothing wrong with that. That was the case with this doctor. He was professional, and for sure he was super experienced, but he gave me a funny feeling. There came a point in our discussion where he wanted to have a sigmoidoscopy with me the following day. That's where they place a small scope camera up your butt and check it out. I already had several of those with my doctor back home, and although they are relatively painless, they're not much fun either. I declined getting the sigmoid procedure, and I played it off that I'd rather have my doctor at home do that since he'd been up in there so many times before. Maybe that was a good decision, maybe it wasn't, but either way, I wasn't getting anally violated in Arizona, not on this trip at least. Not on this vacation!

The most beneficial part of the meeting with the gastro doctor was actually very significant. For the first time in my life, I met someone who had seen another patient with the same skin problems after using an immune suppressant like me. That's right, I wasn't some strange one-off case of weird health anymore. And if nothing else, this made the trip worth it. Knowing I wasn't alone with the skin symptoms was pretty amazing. Besides calming some of my fears, it made me wonder who these other people were. Sure would be nice to meet some of them someday.

The overall recommendation from this gastro doctor was for me to start using 6-MP as a longterm maintenance drug. My doctor back home had recommend that to me as well, but I wasn't there yet. I gave him a few head nods, "Yeah, yeah, yeah, OK doctor", is how I responded to that recommendation, but I knew I wouldn't be taking any of it. I was doing just fine medication free and controlling my symptoms with diet alone.

Bottomline: You Might Not Like Every Doctor

Yeah it's true. You just might not become best of friends with every single GI doctor you encounter on your UC roller coaster ride. **AND THAT'S JUST FINE!!!** There is nothing wrong with you if that's your situation too. But, just as much as you might not like a particular doctor's personality, you still might be able to learn from the doctor. My advice to everyone is to try very hard to take your ego and emotions out of the exam room when it comes time to learning new things about your disease from doctors. That doesn't mean you have to like every single doctor and bow down to everyone, but don't miss out on opportunities to learn from GI's. In the end, they are all some pretty smart people just like you! Instead of looking down at the toilet bowl each day, they just happen to look up butt holes instead.

OUT OF THE MAYO

On the final day of my vacation, I had an hour long recap meeting with the very first doctor. The primary care doctor whom I really liked. It was great seeing him again. It felt like just a few hours earlier I had met him for the first time. How time flies on a medical vacation...

He had all of the notes from the other physicians, and we went through them together. Here are the impressions and recommendations the doctor had for me:

Impression:

- 1) Colitis getting into remission with taper of prednisone steroids
- 2) Psoriasis likely related to Humira use.
- 3) Joint pains probably related to the inflammatory bowel disease.
- 4) Right ear infection which is being taken care of with medication
- 5) Ear wax all squared away(due to suction procedure)

Recommendations:

As for treating the UC, 6MP([mercaptopurine](#)) was the overall recommendation(the same medication my existing gastro doctor back home was recommending). When/if flare ups occur, prednisone use was recommended as well. Some different topical prescription creams were recommended for the skin issues.

SIDE NOTE: This doctor wrote down “he has a good attitude and he is very knowledgeable about his disease” and that I also had a great group of professional doctors back home who I was currently working with. That was pretty cool to read in the notes. I guess in all my meetings up until that point, I didn’t ever remember a doctor saying that I was “very knowledgeable”. I know it wasn’t a grade on my report card, but it sure felt good. And it gave me even more confidence in myself and how I was going about my disease.

With a big handshake and a few thank you's both ways, I was up and out of the Mayo Clinic and back to my final ride in the shuttle bus.

For more information on the Mayo Clinic, feel free to visit: <http://www.mayoclinic.com/>

It truly is an impressive facility in every way.

MEDICATION FREE

As November moved forward, I was excited about my colon's recovery. My poops were still regularly regular, and usually nice and hard. I had just started a new job, and I was starting to get my sea legs again. My energy was coming back quickly, and I was starting to feel stronger.

I began focusing more and more on the diet, and I even went out to have a meal with the girl who introduced me to it. I couldn't thank her enough. She is quite possibly the main reason I

elected not to have colon surgery. The diet was amazing. It got me off medications. I wasn't taking prednisone anymore. I wasn't taking Asacol, sulfasalazine, or any other drugs.

Big coincidence?

I don't think so.

My confidence in knowing how to treat my disease was growing. Although I was going against the recommendations of my doctors, I didn't give a crap. There was no good reason to start popping more pills, I already had good results. It was that simple.

Come December of 2009, my wife was excited to visit the Czech Republic after a year and a half in the US. I don't think she would have gone home if my condition was still real bad. I'm pretty positive of that. I couldn't fend for myself most of the time when I was sick with UC. But now that I was on the up and up, and it had been going that way since mid August, we were both confident I would be fine for three weeks alone. And sure enough I was. Although it's not my favorite thing to be apart from my wife for so long, the first days for sure are the toughest. It really wasn't that bad.

Part 6: Starting iHaveUC

December 2009, my health was great, wife was gone, and I needed something to do. Several years earlier, I learned how to build websites while working for an old employer. So I decided to build a website. I have no idea when, but I thought it should be called "iHaveUC". That was the beginning. I wanted to learn more about my disease, and to spread the word on my success with treating the symptoms through diet. **Another goal was to learn about some other alternatives for treating this disease either medically or holistically.** (The word "holistic" well, that's probably going to be the fanciest word in this book. I don't know the exact definition, but my definition is: fixing the colitis symptoms without medications that have side effects.) At this point in time, while I was starting up the iHaveUC website, I also wanted to vent out some feelings towards how I felt the medical system mis-treated me. It seemed so strange to me that everyone from the medical world always told me diet had nothing to do with my disease. My health and my ability to get off all medications at this point was so strong in my mind and heart. I wanted to share these thoughts with whoever wanted to listen or was feeling the same. There had to be other people in my situation, or at least similar.

I started by writing a few different web pages. And then I let it sit for a little while. What blew my mind was how people started reading what I was writing down and then writing back to me. Within just a few weeks, I had communicated with several people all over the world who also had UC. **This was really something!**

The feelings I had when I first met that girl who also had UC started happening all over again. Here I was, at home, wife out of town for several weeks, and communicating with others who had the same disease as me. People from all over the world, not just the United States. All of this communication got me really excited. And I quickly started realizing that the people who were writing to me wanted to know about my history with UC and what I had been through. But that wasn't all. People started asking questions that I didn't always have the answers to. Other UC'ers had all sorts of questions. Sometimes the same questions as me.

Here are just a couple of examples of some early day questions:

- "what medications have you already tried?"
- "how long did it take you to come off of prednisone(prednisolone)?"
- "how long have you been off medications?"

- "how has this affected your relationship?"
- "can the intestine repair itself?"
- "can I get a flu shot if I'm on Remicade?"
- "can a person with colitis eat chicken salad?"
- "how long does it take for Remicade to start working?"
- "how long for moon face to go away?"

And of course, one of the most popular questions has always been:

will I need surgery for UC?

Pretty soon, I thought it would be great to setup a place on iHaveUC where others could go to add their stories. And that's what I did. To my surprise, other people began to add their stories to the website as well. It was, and still is very hard to read some of the stories that are sent to iHaveUC. So many old memories come rushing back.

From the very beginning, I have noticed that parents, friends, siblings and other relatives were making use of the information on iHaveUC as well. And it makes sense! These people are also deeply affected by UC even though they are not the one diagnosed with it.

If you want to, GO Start a Colitis Website!

For everybody who thinks that making a website is some big complicated thing, IT'S NOT! It's actually super simple, and anybody can do it. All you need is a computer and an internet connection. I've got quite a bit of experience in the web world, but I'm by no means an expert. For anybody who is interested and wants some ideas on how to get started with your own site, I'd be happy to give you some ideas.

MEETING PEOPLE WITH UC

Feeling normal is difficult when you have UC. But knowing that there are other people on this planet(probably in your own town) who also have the disease, has always been comforting for me. How difficult would it be to never meet someone who suffers from the same disease as

you? That would be incredibly hard. Since starting the iHaveUC site and Facebook group: one thing is very clear: **BEING ABLE TO TALK ABOUT THE DISEASE WITH OTHERS WHO CAN RELATE IS EXTREMELY BENEFICIAL.**(read that again why don't ya!) The internet makes this possible. But since we are dealing with a disease that many people have never heard of, finding someone who will understand is the challenge.

If anybody is wondering how to connected face to face with someone with UC, feel free to go to the www.facebook.com/iHaveUC page and post a comment that you live "wherever" and would like to hang out with someone else with UC. You'll freak out when you get a reply from someone who is super close to you.

I guess what I'm trying to say is, iHaveUC started as a project when my wife was away from home for several weeks. But it turned into a really neat way for people to share experiences about life with UC. Being able to pass on my knowledge and experiences with diet to other people who are interested in giving it a try, has been very cool as well. Event though in our modern Western Medicine society, we are trained to only accept medical advice and help from doctors, it is become so very clear to MANY people that reaching out to other patients is of considerable value too.

When Michaela came back from her trip to Prague and she asked me what I had been up to, I took her over to the computer and there it was. My life up on the internet. I think I even mentioned her a few times back in the early days.

I Told You Once, I'll Tell You Twice

This is going to be a common theme if you haven't realized already: MEET OTHER PEOPLE WITH UC! No matter who you are, if you are reading this book Colitis is something you should learn more about. And there is no better place than through real life UC patients.

Besides the iHaveUC.com website and the www.facebook.com/iHaveUC group, here are some other ideas on how to go about meeting other people with UC:

- A great website called Crohnology has some fun tools and exciting ways for people to interact. You can go to www.crohnology.com to look at that.
- There is also an excellent online community called Crohn's Disease Support Network. Jason who is the founder of that group is an excellent guy, and there is a growing number of UC patients using that community as well. www.crohnsdiseasesn.com is the website for that.
- The Crohn's and Colitis Foundation of America(CCFA) for all the Americans is something that may be beneficial. This organization helps organize "Team Challenge" events and groups such

as the Team Challenge teams that meet at the annual Las Vegas half marathon in December. www.ccfa.org is the website for CCFA. I was previously a member of this organization as well.

- A great service is called MeetUp. www.meetup.com has different “meetups” from all over the world. There are groups that you can join with people who have similar interests. For example, there is an IBD meetup group in my local area that I have attended numerous times. If there is not already a meetup group in your local area, you can be the founder of one. There are instructions on the site about how to form a new one.

Patient To Patient:

An **excellent study** that goes into detail about the value in patient to patient communication in comparison to doctor to patient communication. [Managing the personal side of health: how patient expertise differs from the expertise of clinicians.](#) August 2011. Division of Biomedical and Health Informatics, School of Medicine, University of Washington, Seattle, WA 98195, United States.

THE VENTING AREA

For many people, (it's getting close to 1000 people now), the Colitis Venting Area on iHaveUC has been the first place to ever vent about the disease. How can you really explain what you are going through to people who haven't also been there? It's hard. You can do it, but for me, it's just not the same. I'm confident that the people from iHaveUC would agree. Some people wonder why there are so many unhappy stories on iHaveUC.com. The reason is that many people find the website when they are feeling lousy. But there is a positive side happening at the very same moment. These people are finally being allowed to share their feelings with others who completely understand.



*(this was the original image that linked to the
now famous “Colitis Venting Area”*

<http://www.ihaveuc.com/home/write-about-your-ulcerative-colitis/>)

It's incredible how many emails I've received from people over the years. So many UC'ers stating they felt so much better after being able to write freely about their colitis. Not having to worry if everyone will understand the story. I get it. I feel the exact same. I'm sure that for the hundreds of thousands of visitors all over the world each year to the website, being able to read stories of what real people with the same disease are going through, is equally valuable. You don't even have to share your own story if you don't want to.

What started as a fun hobby, turned into something that expanded my mind about UC. Even though I have found something that has worked for me, I've also learned that there is much more to UC than diet alone. Getting past UC is a lifestyle. That's what UC is. And that's what everyone wants to know: How can I get on with my life?

As more and more time passed, I started to tell my wife about the people I was meeting from the site. The other UC'ers. The ones who were sharing their stories with me and all the other readers. She was starting to get interested too. It's not like she didn't know something about UC. She lived it right next to me. She was there when I passed out while sitting on the toilet and landed on the carpet with bloody poop running down my leg. Michaela definitely knows a lot about what other people are going through. The website has been a super valuable resource for her as well. There are so many valuable tidbits of information from other people's stories on the

site which sometimes I don't notice, but she does. I'm pretty sure one of her favorites is when we learn of other new recipes or ways to get creative in the kitchen from other people who have started the diet. I'm pretty good at cooking and coming up with new things, but turn other UC'ers loose on the kitchen and you never know what you'll learn.

Part 7: Moving Past UC

JANUARY 2010 - GETTING THE BALL MOVING AGAIN

Whether I liked it or not, many months and years had gone by since I was really living life. My brain was a few years behind. My previous struggles of just making it through the day in one piece had taken over. Before I reached remission, my health was falling apart because of my colitis symptoms. The same was true for my emotions and day to day thoughts. You can call it depression if you want, but it was more than that. Back when I was a teenager, I brushed aside my longer and longer bathroom visits. I thought I was unique and really enjoyed quality time in the bathroom more than my high school friends. I thought that maybe my body was faster at processing foods and that explained everything. **But really it was a classic case of denial.**

Since living with UC, I've learned how my brain is just as important as my physical body when it comes to healing and being happy. Logical thinking, and logical game-plans are really helpful when your body is falling apart. **Being able to deal with potential roadblocks, or bumps in the road to recovery is also extremely important.** It's easier said than done, but our minds are capable of pulling this off - **AND THAT'S FRIGGIN GREAT!**

When I was feeling more and more confident that I was on the road to recovery in early 2010, I was also developing a new type of respect for my disease. UC is not what I would consider a standard disease. Everyone's struggle is different, much like life itself. And like other aspects of life, there are so many different stages that anyone with UC can be at from pre-diagnosis, right after diagnosis, remission, flare ups, mild on-going symptoms, very sick and in the hospital, depressed and feeling ill, even feeling well but still depressed. These are just a few stages that I have gone through, I'm sure there are literally hundreds more that we could list.

In 2010, I wanted to take back my normal life. And that's where I put my energy and efforts.

Some Really GOOD NEWS

Remission is possible. I'm living proof of that. UC symptoms can definitely get controlled, that I know as well. But what is even more amazing is that your life can become even better than you remember. It's possible. And that is what's happening to me. Going to the grocery store, meeting a good buddy for dinner, fishing out on the ocean with friends, well, these are all things I

enjoy so much more after being diagnosed. The reason is simple: I know how difficult my life was when I was sick with UC, but now that I'm healthy, I truly can appreciate being alive and well. I didn't know these feeling before I was diagnosed with UC.



(January 24, 2010 monkey friends were over again, this time I was all smiles and feeling great until the baboon took a nice little pee on me...)



(CJ and I fishing up in Alaska for halibut. He's the guy who stuck me with the Humira...that's what friends are for right? This picture is from June 2010)

TALKING WITH FAMILY

I decided to hide my symptoms from my family for many years, and I eventually paid the price for those actions. When I finally went to the doctor and admitted things were very wrong inside, I was super severe with UC. The whole colon was inflamed, and it looked nasty in the pictures. I'm convinced that had I told my family the true details about my bathroom habits and what was going down the drain in the toilet much earlier, there's a good chance that my UC may never have become so severe. We'll never know, but hiding it was not the best move to make.

A simple thing that anyone can do is to just ask yourself, "Would I want to know if someone in my family was suffering from pain, cramping, strange symptoms and RECTAL BLEEDING?" Before you even think of a single family member, the answer is going to be a big fat "YES!". It's that simple, everyone in anybody's family wants to know when someone is not feeling well, no matter how messed up your family is. Tell your folks, tell your close relatives, there is absolutely no shame whatsoever in telling anybody you want to about this disease. You're not going to let anyone down, but you will if you don't bring up your symptoms until it is too late.

Here are 3 lessons I learned:

1. Talk to your family about how you are feeling, they definitely care
2. Talk to your family about how you are feeling, they can help you
3. Talk to your family about how you are feeling, it is the right thing to do

SIDE BONUS:

There is also a big side bonus for people who like myself have close relatives with IBD, those people are a great source of information. And most importantly, they can also understand your feelings and the pain and suffering you are going through like any other person who has lived with the disease. They'll have some answers too. One of the most important questions someone with IBD can ask your parents and other family members is:

**"IS THERE ANYBODY ELSE IN THE FAMILY
WHO HAS/HAD IBD(inflammatory bowel disease)?"**

If you ask this question, you very well may be shocked by what you find out. This IBD stuff often runs in families, and there's a decent chance that you can uncover some hidden information right there in your family tree.

TALKING WITH FRIENDS

In 2010 when my health was allowing me to become mobile again, I started meeting up with my friends much more often. It's great not worry about toilets, bleeding, and feeling weak. What was so interesting to me was how some people still had a hard time understanding the basic ideas about UC. Although I had told many of them before, some of them would still look glassy eyed when I'd say "UC". You can't let this upset you. **You can't blame your friends for not knowing the ins and outs of UC. Really, the person to blame I thought was myself for never explaining some of the details.** So, I decided to go ahead and educate my friends on what I had been going through for the past few years of my life.

I didn't care if I was talking to my guy friends or my girlfriends either, there was no reason to deviate from my standard answers across the board. Whether it was parents, or even co-workers, I usually gave everyone a very similar story as to what I was going through for so long. I'm not trying to say that I would go into all the exact details of how much blood I would often see dripping from my rectum area into the toilet bowl, and how when the drops would hit the water the color would disappear unless it was a really bloody time where the toilet bowl water was a nice reddish brown from so much blood. No No No, I never went into details like that with any friends ever. But, I would start out with answering the question, "So Adam, what is it that you have?" with something like this:

"Well, UC is a gastrointestinal autoimmune disease. This basically means that my body is constantly attacking itself, but it doesn't know how to turn itself off."

Then I would go into this random idea of an army:

"It's basically like an army out there fighting away shooting all it's guns off all the time, but there is no enemy, and those bullets that are flying around are tearing up my colon and causing it to bleed."

That's what I was telling people in the early days of my disease, and I continued that thinking during early 2010, but my answers started to change once I saw so much success on the diet I

was following. Not to far into 2010, when I ran into new people I did not know, or older friends from the past who were not aware of my UC, I talked about my UC a bit differently. This is how it probably sounded:

"Well, I have UC. It's similar to Crohn's Disease if you have ever heard of that. Basically, my colon has a unique set of gut bacteria that helps our bodies break down foods. I can't eat certain foods because my body can't process them correctly. If I went off and starting eating like I used to without any restrictions, my symptoms would probably return and would lead to me bleeding inside of my colon and needing to run off to the bathroom all day long again. That could cause me to start using medications again, and probably lose a lot of weight."

What I've found is that not only are my friends and acquaintances really interested in the disease, but also in how I am doing. And the more information I share with friends and family about the disease, the easier it is for them to understand what the UC lifestyle is all about. Everyone who cares about you shares one thing in common, they want to know you better. And that is what UC has allowed me to do, teach my friends and family about what my lifestyle is really like. Sharing as much of the truth as I've ever wanted has only helped me on my way to feeling normal and making progress. I know it is not easy to do. When you are feeling really sick and tired and worn out, talking about your UC symptoms might not be on the top of your priorities. But I think everyone with UC should do it. Share your experiences with others. Release what's going on inside of you to other people. They are interested to know how you are feeling. And it will make you feel much better.

GETTING PAST A FREAK OUT

I had a conversation once, with a very good friend of mine named Bob. I met Bob years ago. He was one of my room mates and someone I can talk to freely about anything, just like Brad and Joe, the other two roommates from my days in Santa Barbara. Right before we talked, I was getting a bit down on my symptoms. Just like one of those periods where you are seeing some good improvements in the bleeding going down, and the poop is getting harder, but then all of a sudden, it seems like you instantly went backwards. Bleeding, and scatter poops (SP's) all of a sudden.

This situation is not fun. And unfortunately for UC people like myself, it's one of those things that comes up unexpectedly. But, that's what friends are for. I remember calling up Bob on the phone, he lived about 300 miles away from me, and I told him what was going on. When

he asked how I was doing, "Not too great, all of a sudden I had some setbacks with my improvement. Saw some blood again, and it looks like the flare is not out for good", I told him.

"What do you mean?" Bob came back with. I know he was a bit surprised since I talked with him just a day before, and told him I was having a massive comeback week. He knew that a few weeks earlier I was getting into some colitis symptoms after a long remission.

"Bob, I don't really know, this stuff's pissing me off though. I haven't done anything different over the past few days. The only bit of a difference would be what Michaela and I did on Sunday. We went for a really long walk, actually a hike for 7 miles Sunday morning. It was pretty strenuous. So I don't know. Maybe my body just can't take the physical stuff anymore like it used to be able to", I tried to explain. With so much time under my belt now since being diagnosed, I sometimes forget what my "bad" symptoms were like back in the "old days" of '08 and '09.

I started telling Bob about a guy I had recently had dinner with who also has UC. Actually, he "previously had" UC. Big difference. I was telling Bob how this guy had his colon removed a few years previously and that he was living with a J-Pouch. Bob had no idea what that was, so I tried to explain the best I could the J-Pouch surgery. My description to Bob was something like this, "Well, what the doctor's do is take out your colon and give you a new butt pipe with some of your small intestines..."

Bob right away said, "Are you serious? Oh mannnn...".

And then I went on to the whole point, "Bob, I'm telling you this guy was acting totally normal, just like I used to be. He was eating pizza and drinking beers. You would never know he even had UC. He seemed totally normal. After the doctors remove your colon, they give you a poop bag for a little while. That's what my uncle had for 35 years. You just poop out from your side, and then there's another surgery where they finish things off and allow you to poop normal again. The doctors form a small colon with some of your small intestines and re-attach that to your rear end. It really doesn't sound to crazy! "

And then Bob brought me back to planet Earth. He said, "Adam, you are nowhere there yet buddy. Take it easy, you just had a great week, and so what if you had a little setback. You've had those before. Surgery is for when nothing else is working. You're just not there yet. Just relax, surgery will always be an option for you forever."

After we talked a few minutes more, I realized that tomorrow was another day. If I was going to freak out each time a bowel movement wasn't perfectly hard, I might be getting taken to the crazy home before I'm a grandpa. We ended the call with me telling Bob thanks so much for the support, and especially for bringing me back down to Earth.

As things would turn out, the next day, I only went to the bathroom once, and it was much much better again. It's so easy to feel good when you're not experiencing any symptoms, but at the same time it's so easy to freak out when you see UC coming back. Looking past the bumps in the road, and not going crazy, is also part of having UC. Even though I've had so many great days over the past two years, I get thrown through a loop sometimes too. It's normal with UC. It happens to all of us. Realizing that I might shoot out a soggy crap every once in a while is still an ongoing learning experience, but I'm getting much better at it.

CHANGING MY DRINKING HABITS

One subject that has always been very popular on the iHaveUC website has been about alcohol and "drinking with UC". And I totally understand this. The usual ages when people are diagnosed with UC (late teenage years and twenties) coincides with the typical ages that people start dabbling in alcoholic beverages. I get it. My UC diagnosis ended up being a big part in the decisions towards drinking alcohol moving forward.

***So here's my opinion
on UC and Alcohol:
"Alcohol and UC
are NOT a great match".***

I have talked with too many people who are following all sorts of different colitis treatments, and the nearly unanimous answer is that less or no alcohol makes life with UC much better. This isn't to say that alcohol should be totally off limits. No, I'm not saying that, but scaling back on beer, wine, and mixed drinks definitely helps most people's UC symptoms. I've not met anyone who disagrees with this thinking either.

How do I deal with the social occasions that come up where "Everyone is Drinking"? It really hasn't been all too hard. My approach is quite simple. I just drink water instead of what I used to drink which was Jack on the Rocks, Vodka Sodas, or beers. Water is almost always available, and it sure costs much less than drinks all night at a bar. And, I always feel better in the morning.

What do my friends think of this? Well, the friends who I am with when these situations arise all know my story, they all know I have UC, and they all know I watch what I eat and drink like a hawk. And I think that compared to the days where I was out drinking cocktails and beers, but was running off to the bathroom much more frequently, they like the change. No longer do my friends have to imagine what Adam's doing in the bathroom every few hours. I have that under control now, and the same goes for my alcohol intake.

It's safe to say that for the whole year of 2010, I had less than 10 drinks, all of which were Vodka Sodas, or Vodka on the rocks. Vodka has very little sugar, so that settles much better with my body compared to other more sugary drinks. I don't think you will catch me drinking a Margarita, Beer, or any of those other foo foo cocktails ever again. And funny enough, I never really liked the sugary drinks in the first place. I would only drink them if they were available or if someone ordered a pitcher of them at a bar or restaurant. Champagne is also on my DND List (Do Not Drink).

A funny situation, actually it was definitely NOT a funny situation which occurred several months after being diagnosed. My wife and I had just moved to a new town called Menlo Park, California. We were invited over to a dinner party with some neighbors that lived down the street. Since I did not know anyone (and nobody knew of my UC) and the same went for my wife, I decided to make friends with the white wines they were pouring. Hopefully this would loosen me up and make me more talkative. I'm sure most people who are arriving at a new place, with new people probably know the exact feelings. Depending on your personality, meeting new people can be as awkward as hell. Sometimes you fit in nicely, and quickly you start thinking you have a new best friend. Other times you meet a group of new folks and all you can think of is how to pull off a quick escape. This particular night was neither of those extremes, but I still had one thing on my mind. "Let's get drunk Adam!". Horrible decision. I've made a few of those. I didn't start dancing on the tables and kissing everybody's girlfriends and wives, but I was getting a little loopy in the head. Not a good idea, especially with active UC.

The next day I had the start of an awful downward spiral of my symptoms. It was like I hit a freight train full of blood and awful cramping. I have not held a full glass of white wine since.

The same thing goes for Champagne. It's so funny because whenever someone with UC writes to me and asks me if it is alright to drink white wine instead of beer or other alcoholic spirits, I always think about that night at the neighbors' dinner party. Oh what a night to forget.

I've attended a few weddings since being diagnosed, and the customary toast of champagne is something that I'm always happy to be a part of. But it is usually followed with me taking an ultra small sip of the bubbles, and then looking over at my wife or a friend and saying, "Hey, you want to finish this off? I can't drink this stuff". That's how I do it now.

For me, going alcohol free, or damn near that is a decision I'm very happy to have made. Besides the fact that I've probably saved a few thousand dollars over the past two years, it allows me to live with much fewer UC symptoms.

I learned an important lesson about my ability to drink alcohol at a good friend Big Joseph's wedding. It was the early summer of 2010 and a super special event. Not only was Joe getting married to a great girl, but all of the old roommates from Santa Barbara were showing up. Brad, Bob, and Randolph were going to be there. I used to live with all these guys seven or eight years before in my post college party days down in Santa Barbara. We all rented a house for the weekend(not with Joe, but with everyone else), and as you can imagine they were all drinking quite a bit. I was able to hold out of the drinking until the final night. The wedding reception is where I lost it. Somehow, with so much excitement and fun, I decided to walk up to the bar and just started ordering whiskey's and vodkas without any care in the world. I can remember walking back to our table and my wife looking a bit surprised at what I had in my hand. Probably I said something like, "I just want to have one".



(May 24, 2009

Las Vegas, NV - Joe and Jill's Wedding

I'm not sure if this picture is from after I started

drinking or before, the booze was not a good idea at all)

Well, the "just one" went really quickly. I actually lost count of how many drinks I put down that night. I don't think I ever started in on the beer, but several Jack Daniels and Vodka drinks were all mine. Additionally, I think I started eating some foods after getting slightly buzzed that were not on my diet, one thing was definitely leading to another... The next day and for about one week afterwards, I started seeing some symptoms trying to creep back into my life. The slight cramping was coming and going, and some blood was starting to appear. And of course the stools were no longer hard, but much softer now too.

We will never know for sure, but I think it is very likely that my night of drinking alcohol and dabbling in some foods that I wasn't supposed to eat were to blame for my post Joe's Wedding Mini-Flare. The good news was that it ended quickly, and I learned a valuable lesson: One night of drinking isn't worth 1 week of colitis symptoms. I don't even think it is worth 5 hours of colitis symptoms.

As a general rule, I don't drink alcohol. Within the past two months, I have had just one drink, and it was a vodka on the rocks. Had I been dealing with even very slight colitis symptoms at the time, I would have avoided the alcohol and gone drink-less that night. But I was feeling good and I stuck to one drink, and that was it. I have not had a beer for over two years now. Beer is something that I definitely miss, but not enough to risk the chance of my symptoms coming back.



(that's me on the right hand side, this picture was from a birthday party at a bar in San Francisco back in early 2010, it was a great night, AND I drank ABSOLUTELY ZERO alcohol)



(me on the left at my birthday party in 2010, I was master of the BBQ and maybe the only one staying away from the alcohol)

MY ALCOHOL REALIZATION

Once I started feeling better, and recognizing the reasons for my recovery, I have some new priorities. Although to an outsider, drinking and alcohol might have looked like a priority when I was younger, it sure is NOT anymore. And most importantly, I haven't seen any negative effects from ending my relationship with alcohol as I knew it. None of my friends stopped being friends with me because I would only drink glasses of water when we are out on the town. Nobody looks at me funny when I tell the waiter "Just a glass of water" when he is taking drink orders. That's how I roll now.

I know this might sound like a broken record already, but my alcohol advice is simple, the quicker you can cut the drinking, there's a VERY GOOD CHANCE you will make even more progress with your recovery from active colitis symptoms. And, like most other parts of my current diet, you start to miss the drinks and feelings you get from them as time moves forward. For me it was just that simple. And from everyone who agrees with me about alcohol, they all feel the same.

How Do I Avoid Getting Caught in Alcohol Filled Situations?

- Telling everyone that alcohol affects my health in very different ways from most people
- I make sure to order water when I am out in the “bar scene” with my wife or friends
- I offer to be the “designated driver” as much as possible which instantly removes me from any temptations to start drinking beers and wine and everything else that is always available
- Constantly reminding myself when the decision time comes up that “just one drink” is simply not worth it, and sticking to that the WHOLE NIGHT! (It’s happened to me hundreds of times since I’ve stopped drinking and it is always the best decision)
- Re-evaluating how and where I spend my free time. Alcohol is a big part of so many social functions, but not all of them. Meeting friends in coffee shops **instead** of bars is not a difficult thing to pull off. It is usually cheaper and just as much fun.
- For college students or young people, there are plenty of groups, clubs, and other fun activities that you can ALWAYS be a part of which don’t require you to drink alcohol.

Extra Reading on Alcohol

If you would like to read more on this topic, one of the most popular postings of all time on the iHaveUC website is on this exact topic. Here it is for you to read through: <http://www.ihaveuc.com/can-you-drink-alcohol-when-colitis-is-acting-up/>

WORK AND ALCOHOL

There is one other added bonus that I just can't forget to mention. Back in 2002, the software company I worked for in Santa Barbara was holding their annual Holiday Party. It was the most anticipated event of the year. That year, I happened to be a single guy, and I was in full swing during night of the party. All dressed up in a suit and tie, I decided to take full advantage of the open bar (free drinks) that everyone was entitled to. My only problem is that I ended up way too drunk, way too early in the night.

With everyone from the company having a great time, I was allegedly dancing on the stage and getting out of control. Somehow, I must have realized on some level that I was going to pass out and my gut instincts allowed me some time to take safe shelter. In this drunken mess, I left the restaurant, and found a bush just outside and crawled down and fell asleep. That's right with my suit and tie on, I passed out cold in the mud under a bush just out of view of most people. It wasn't until sometime early the next morning when it was just getting light out that I awoke. Of course it took me a moment to realize where I was, and once I was on my feet I started worrying who might have seen me from the company. Did my boss see this, how about my friends? What the heck was I thinking?

This might be worse than some other people's stories, but I could rattle off a list of other alcohol and work related stories that I've witnessed which sometimes ended up with the "drinker" getting fired. I've got some pretty excellent friends, and other acquaintances who I admire very much. But at the same time, some of these people do and say things that I'm sure they would like to take back when they have been drinking alcohol. And it is unfortunate to witness this type of stuff when it comes up. **For me, I don't worry about "being stupid" or "making a fool of myself" anymore, simply because I don't drink. I guess another added bonus of my UC.**

ENOUGH ABOUT ALCOHOL:

OK, I know you're getting sick and tired of me talking about alcohol, but it is important. And if you have UC and you drink alcohol, (and I know that most people with active UC symptoms drink alcohol) this is especially important.

Here's my final thoughts:

I don't drink alcohol because it ignites my UC, and I still have a great life without it. Period!

WEIGHT LOSS, WEIGHT GAIN

Putting on the weight I had lost, and reducing the odd symptoms of UC such as creepy joint/tendon pains was also a major goal of mine in 2010. I had lost so much weight over the previous year from all of the issues with my digestive system, it was time to turn things around. This is such a difficult challenge managing your weight when you have UC. Oftentimes, people gain incredible amounts of weight due to medications such as prednisone/prednisolone. I myself always lost weight when I was dealing with flare ups(UC active symptoms). I don't have any experience with losing weight that prednisone brings on, but from what most people with UC tell me who have had that experience, the extra prednisone-weight slowly or sometimes rapidly goes away once the steroid use is discontinued.

I was around 150 pounds when January 2010 came around, and I was hoping to get back up to 160 pounds or somewhere close. This might not sound like a big deal, but for me, I wasn't eating many of the high calorie foods that I used to enjoy freely. Foods such as breads and many of the dairy products I used to enjoy were no longer in my diet at all. But what I did rely on was consistently eating at least 3 meals per day, and definitely not skipping any meals. I also would try to work in some small snacks every once in a while whenever I could.

Slowly, I did find myself putting back on the weight, and I eventually got into the high 150's and then I hovered around 160 pounds which was a miracle. I can remember looking at myself in the mirror when I weighed 130 pounds thinking, "How did my life come to this?". It did not seem real. I was horrified at how skinny my body was due to the colitis symptoms. Without a doubt in my mind, the key to my weight gain was my digestion process working again. I wasn't making bloody messes of runny diarrhea for each bowel movement. The days of hard formed stools was alive again. With the bleeding gone, the poop factory was running properly..

I have heard from so many people who are struggling to gain weight, and it is very difficult to think about. Many people with severe UC symptoms can lose over 30% of their body weight. That's incredible. And its very unfortunate. Especially when all they want to do is gain weight back, but are unable to. Before I was aware of the diet which I follow, I can remember eating all sorts of high calorie foods like breads for example, and I was hoping they would help me put

back on a few pounds. So I would eat more and more as the days went by. All that seemed to happen was more of the same, more bloody diarrhea. Unfortunately, I know that exact situation is very common with other UC'ers who have active colitis. Sometimes that approach works with gaining weight, but other times it does not. Healing really needs to be happening to see great improvements with our overall bodies.



*(sitting in the forest of Lake Tahoe, CA August 2010,
medication free, and 1 year after changing my diet)*

HOW MEDICATION SIDE EFFECTS IMPACTED MY LIFE

Some of my most vivid UC memories are from medication side effects. It's amazing. But exactly how they impacted my life is a happy story. If it wasn't for medication side effects, I have absolutely no idea what I would be doing right now. So let me explain.

The early days of my UC was very similar to lots of people. I was diagnosed and quickly put on Asacol and prednisone/prednisolone steroids. After the initial steroid dose wasn't working for me, the amount was increased considerably. And that is probably when the side effects began. Below is a list of the medications I was prescribed by my doctors, and the side effects that came up afterwards:

Prednisone:

- kept me awake many nights, especially on the higher doses
- allowed me to have thousands of tiny red spots on my back termed "steroid acne"
- made me more agitated, or fidgety if you know that word
- I believe it was the reason behind me rear-ending another car that was stopped
- many people have mentioned how depth perception gets messed up during prednisone use (not just me)

Asacol:

- No noticeable side effects

Colazal:

- No noticeable side effects

Sulfasalazine:

- Right when I started taking sulfasalazine, the dose was too high, gave me bad headache (this headache was the worst headache of my life (I swear). Once we cut the dose in half, it went away

Enemas:

- I didn't notice any side effects, but I only used them 3-5 times before stopping. I couldn't get over the idea, call me a wimp, but I am. I know of several people who are able to pull it off daily, and I applaud them!

Remicade:

- No noticeable side effects during use, or right after stopping

Humira:

- My peeling and flaking skin problems started soon after taking this medication

- one masseuse refused my business due to the nastiness
- My joints became very inflamed after using this medication as well
 - in terms of physical pain from side effects, for me, this was the worst
 - at times, I couldn't lay back in bed without shooting pains
 - certain use of muscles all over my body would set the pains off
 - My normal walking motions became very "old man" looking
- Can't forget, one of my fingernails stopped growing and became deformed
 - after about a half year or more, it went back to normal
- You inject this medicine, and that scared the heck out me (again, call me a wimp, I don't care!)

Vancomycin & Flagyl:

- No noticeable side effects

This might seem like a huge list, but it really isn't. Other patients have a much longer list, and many UC'ers have a shorter one. Everyone's different, and that's especially true with our reactions to different medications. What's interesting from my experience, is how my side effects influenced my decision making on future treatments.

One year after being diagnosed, something finally snapped. I decided not to move forward with 6MP as a final medication before surgery.(This was the medication my current doctor and several other GI doctors recommended I start taking.)

At that point, my diet changes were helping me out bigtime, and I was worried what another medication might do to me. Potential side effects worried me. What if another medication started making my legs numb? What if a never ending headaches started after taking a new prescription?

If this is called being scared, then I was scared.

If this is called being fed up with taking medications, I was fed up.

If this is called losing faith in western medicine, go ahead and call it that.

No matter what, my previous side effects happened at a perfect time.

When I wasn't interested in taking any more medications, that's exactly when I met the girl who introduced me to diet. Had the Humira side effects never happened, I probably would have moved forward with the 6MP. Maybe 6MP would have worked well for me. Maybe it would have put me in remission. Maybe it would have given me some bad reactions. Who knows?

Medication Side Effects are Difficult to Understand.

Nobody understands them completely.

- Some people have adverse reactions
- Some people have no side effects
- Some people say the side effects are worth the benefits
- Some people say the side effects are not worth the benefits

Everyone is unique.

My own personal approach to side effects is pretty simple. But this might not work for everyone. It depends on what type of person you are. I am the type of person who is interested in knowing what potential side effects exist. So, when I was prescribed medications, I was always reading the labels and asking my doctors tons of questions. Of course I was interested in knowing what percent of people found benefits from certain medications, but I also wanted to know what side effects to expect.

But there's also another approach.

For example, other people would rather not know anything about the potential side effects to a medication. To me that is strange, but it works just fine for many. If you would rather take a medication without knowing the side effects that may come up, that is up to you. You won't be alone if your thinking is similar. Without knowing what side effects exist, some people feel that they can relax more when starting a new medication.

Extra Reading

If you just can't get enough of the medication side effects information, here is a link to several different stories on the iHaveUC website about side effects from medications: <http://www.ihaveuc.com/category/ulcerative-colitis-drugs/medication-side-effects/>

STRESS

I've learned some incredible things since my UC diagnosis. One particular topic that has been super interesting, involves **the world's conflicting views about stress and UC**. That's something I thought about a while back. And who doesn't wonder how stress is impacting your life once you are diagnosed with UC? I remember asking my doctors long ago if stress was something I should be concerned with my colitis. Back in 2008, my doctors told me that stress played no part in my disease. So that's what I assumed for quite some time.

It wasn't until I met a doctor who is an amazing world renowned scientist that my beliefs on stress changed completely. **The doctor's name is Dr. John Medina**. He's a "developmental molecular biologist", damn that's a long title. He gave a talk with a growing software company in San Francisco back in November of 2010. It's a long story about how I was able to attend, but I made it. I even arrived an hour early and had the chance to talk with him for about twenty minutes before his presentation started.

This doctor is a genius.

He recently wrote a book titled "Brain Rules" which everyone should be required to read. I've read it several times now, and plan on reading it over and over forever. One of my favorite sections of the book to read is about stress.

Dr. Medina writes,

"Chronic stress also can coax your immune system to fire indiscriminately, even at targets that aren't shooting back - like your own body..."

People who experience chronic stress are sick more often...They are also more likely to suffer from autoimmune disorders..."

Dr. John Medina. "Brain Rules". Page 176-177, developmental molecular biologist, First Peer Press. paperback edition, 2009 (here's his website: <http://brainrules.net/>)

This opened up my mind to re-examine both my life with stress and without stress. And I started to reconsider how stress affected my UC. What I uncovered was how my life had actually changed dramatically since my pre-diagnosis and post-diagnosis days. When my colitis

symptoms were active, I didn't have full control of my body. My symptoms were doing their own thing, no matter what prescriptions I was using. I clearly had some short term benefits from medications, like when I tried the Remicade infusions, and when I used prednisone steroids, but that was only short term benefits for me. During these tough times my stress level was way the hell up there! After I changed my diet and saw my symptoms go away, I was finally in control again. As the research shows, having control of your life is a great way to eliminate stress. And gaining control of my colitis gave control back to me.

Can other people enjoy the same benefits I'm talking about once you find a UC treatment that works well for you?

OF COURSE!

There are so many stressful parts of life with UC that I haven't been forced to play over and over again. The list can go on forever.

Here are a few stressful examples that have gone away:

1. Feeling the overwhelming urges to take a crap while driving on the freeway
2. Looking at the blood in the toilet bowl first thing in the morning
3. Watching my weight get lower and lower
4. Deciding to start a new medication (or not to start a new medication)
5. Getting my blood drawn constantly
6. Worry about the possibility of toxic megacolon
7. Worrying about what my life without a colon
8. Worrying if my wife would eventually give up on me because of my health

You get the point, this list can run for a very long time. But that's not what's important here. What's important was I put an end to the horrible stress cycle that my colitis was creating. And by heavily reducing the stress in my life by gaining control of my disease, it's allowed me to speed up my overall recovery. Don't get upset and angry if you are living with stress. If you have UC and the symptoms are active, it's very normal. Once you gain control of your colitis

symptoms, there is an excellent chance that the stress will go **WAY DOWN**, and that's a huge positive!

If you haven't already ordered it, you should locate your closest bookstore that sells the book *Brain Rules*. It will blow your mind how much useful information there is about stress that really makes sense. Both scientifically, and in basic everyday life examples.

Here are some stress reducing tactics that have helped me:

1. If something is out of my control, I try to realize that quickly and let it go
2. Nothing is as important as good health, if something is compromising that, or beginning to compromise my health in anyway, I try to change course quickly
3. Realizing some parts of my life which used to bother me, and taking them much less seriously.(Until I understand Czech, I simply won't understand what my wife is talking about sometimes, and that's OK.)
4. Learning to "Just Say No", when I'm offered food or drinks that I really don't want to eat (Being invited to someone's house for a meal, and then suffering through eating something that disturbs my colitis is just not worth it.) Telling people about my situation beforehand has helped me avoid this so many times.
5. Being open and honest with my friends when I do not feel well. This has meant staying home on a few occasions, and taking some time for myself. Not being able to attend every single function or event has definitely helped me recover from flare ups.
6. Yoga, I still don't practice yoga enough, but its hard to feel stressed after a good yoga class(and if you do attend a class with me, please don't laugh)
7. Reading a good book. I never used to read when I was really sick. But I love reading books that interest me now. I'm not talking about books for school or for work, but books of my choosing. If you don't have any ideas for books, try asking friends of yours which books they enjoy.

Part 8: Flares

NOTICING A FLARE UP IS HAPPENING

The year of 2010 was great in terms of my colitis. I was getting very confident that I had the tools and the ability to finally control my UC symptoms, and that was exciting for me. We can call it "empowerment". Maybe comparable to learning how to read or write when you're a kid, just more body/health related. I was starting to think that everything was simply going to be alright moving forward, and that the thousands of pills we had stashed away in the closet from un-used medications would never be needed. Well, I was wrong.

In September of 2010 I enrolled in the Crohn's and Colitis of America's Team in Training/ Team Challenge. This was definitely going to be a bit of a challenge, but nothing that I was too worried about. A thirteen mile walk was long, but it wasn't anything too crazy. Come on, I remember going for walks like that when I was a kid, up in the mountains with my stepdad carrying 40 pounds on my back. How tough could it be to walk down Las Vegas Boulevard?

As the Team Challenge events started out, I was feeling like this would be super easy. The short walks were nothing that even got me sweating. And then we started to get to the point where we were doing 2-3 miles per walk. And that soon turned into 3-5 miles per walk. It wasn't too long after signing up for the event that I decided I would say "to hell with the walk, I'm going to run this thing". And that's what I started to train for.

A good friend of mine Jenny who lived nearby was an avid half marathon runner. She told me that she'd be happy to help me train. We met at my house on our first official training day. I had recently purchased some nice running shoes from the Nike store, and I had on my favorite board shorts and dirty T-Shirt. I was ready to get this party started. (Now bear in mind that I hadn't ran at all since high school soccer practices. That was about 15 years earlier)

Needless to say, after about a quarter mile of running a 10 minute mile pace with Jenny, I was thinking I might be close to a heart attack. I just couldn't keep up. How could this be, how on earth was I so out of shape? This was definitely going to be a struggle. To be honest, I wasn't sure I'd be running the whole half marathon. It was almost October, and the race was in early

December! The one thing I had going in my favor was my UC symptoms had been completely quiet, like they were on vacation for one whole year at this point. But that started to change. Just a few days after starting to run, I started to see some loose stools again. It pissed me off a little bit, but I just thought my body was adjusting to the new running program, and maybe the physical strain was waking up my digestive system. It never dawned on me that this was actually UC saying, "Hi there Adam, It's me, you're old friend, I'm still here".

The days moved forward, and I kept training for about another week or two. My UC symptoms did not go away. They were back, pretty mild, but back indeed. I was probably up from 1-2 craps per day to the 2-4 range. And the consistency was getting back to soft/very soft. As for bleeding, I was starting to notice some red stuff on the toilet paper once again. This was tough to see. It wasn't too much longer and I decided to stop the training. No more running for me. Las Vegas - Yes. Running in the half marathon - No.

As I laid off the physical activity, and went back to some basics on my diet by eliminating more of the complex foods my symptoms gradually got better once again. I was pretty relieved that this didn't turn into a situation where I needed medications, but it was tough to see that blood again.

This flare up gave me a few different signs it was making it's way into my life. First, I started to see and feel some changes in the bowel movements. They simply were not hard anymore. And it eventually turned into occasional diarrhea. Blood, you know, that bright red stuff on the toilet paper came out and played with my head too. Some slight cramping in my abdomen area. Lastly, some of the joint pains I had experienced during my original nasty flare up started to come and go as well.

RECAP:

It is definitely not what you want, to start another UC flare after you've been in a long remission. But, if you can recognize the signs and symptoms of one, and not be in denial, that's going to be HUGE for You!

MY WORST FLARE UP

Right before the Las Vegas Half Marathon in December 2010, I had no intention of running the race. I spent the night at my buddies Joe's house the night before the race. He's my old roommate who lives in Vegas. Both of us were all signed up with our numbers and we showed up bright and early to the Mandalay Bay Casino with 35,000 other runners the next morning for race day and **my plan was to walk the 13 miles.**(If you've never entered in a race before, the start is pretty exciting)

Back when Joe and I registered for the event in September, I wrote down my goal of finishing the race in 2 hours. Because of that, I was placed with all the other people who wanted to finish in the same amount of time. There were thousands of people in that particular group. Luckily, Joe was right there as well. When our group was set to begin the race, the excitement was way too much. I couldn't stand to walk it with all these runners jumping around. So off I went. Running.

The miles seemed to fly by, and before I knew it, we were passing MGM Grand and the Paris Casino. There goes Harrah's, and the Venetian too. I remember looking over to Joe and thinking to myself that I might be able to run this whole race. Just a few miles later, I knew that wasn't going to happen. After 6 miles, I told Joe to continue on without me. I started slowing down, and eventually I was walking. That's when things got scary. All of a sudden I could not breathe. I walked to the side of the race and started looking for a police officer. I didn't see anybody who could help, but just a few minutes later I caught my breath. This was strange, why would I be having a tough time breathing after I stopped running? The previous 6 miles seemed fine to me, no breathing problems at all. After a few more minutes of collecting my thoughts on the side of the road, I began walking the rest of the race. It was difficult at times, but I finished the whole thing.

That night I celebrated with staying up all night gambling. I don't know exactly, but I think I fell asleep at about 3:00 am. **This was also the beginning of my worst flare up.**

Within a few days of flying back home, I started to see my symptoms REALLY coming back. The bleeding and cramping and 2-5 bowel movements per day were coming on. My colitis was

getting out of control. I remember talking with Michaela about it. I also remember wondering what the heck was going on. I was still following the diet very strictly. Of course there certainly were some foods that may have slipped in here and there, maybe foods that I should not have been eating. But things just didn't make any sense.

The holiday season was just about to start, and for me and my diet, that is usually difficult. All of the holiday cookies and candies and treats and pies, all of the desserts that I used to love were now off limits to me again. Just like last year. But this time I was in a flare. Bleeding was starting to show up too. **Not just the blood on the toilet paper. I'm talking about the dripping rectal blood.**

It had been nearly a year and a half since I had symptoms like this. The emotions from feeling out of control were all coming back to me. **I started to even question the diet that I was on.** But then out of nowhere, I'd have a couple of really good days with noticeable improvements. So then I would get some more confidence that everything would work itself out naturally. Maybe my colon would come through again for me. My wife and I decided that if by January 1st, there wasn't serious improvements, I'd be calling up my gastro doctor and making an appointment. This seemed like a smart idea. After all, my poop maker had not been normal for a few weeks now, and I hadn't seen the doctor in over a year. It would be great to meet and see what he has to say. I was worried that he would prescribe some other medications. I was also worried about something else: I failed to tell him about my diet over a year and a half ago when I started it. He had always told me that diet had nothing to do with my disease. So I didn't see the point in explaining what I was doing and the success I was having if he didn't believe in it.

When I saw him last, it was in November of 2009, he had performed a sigmoidoscopy on me. My results were great. No lacerations to my colon lining, no inflammation, and no excessive mucus either. **What a great time it would have been to break the news to this doctor, the news that I was treating myself with diet alone. But I kept it secret.**

January 1st came, and I pulled out the doctor's telephone number. I had an appointment for a few days later. This was going to be interesting. On the day of the appointment, I remember telling Michaela that probably a small dose of prednisone could get me through this flare. I wasn't killing whales yet, and I hadn't lost that much weight, so in my mind, it was maybe "moderate inflammation". But that was just my guess.

As I expected, my doctor's visit was pretty interesting. We talked about what was happening, and about possible treatment ideas. Again, the idea of 6MP came up. That didn't surprise me.

He also thought that right away I should get on a small dose of prednisone, 15 mg/day was the plan. And, he wanted me to get some blood tests to see what the blood was looking like. **I remembering bringing up some questions about diet, and I also remember him right away saying that it just wasn't part of my disease. This frustrated the heck out of me.** I had a feeling right then and there that I simply wasn't going to be able to work with this doctor anymore. When I got home, I was obviously upset. I told the whole story to Michaela. I didn't know what to do. I had a prescription in one hand for 6MP which I was to start immediately. I also had a prednisone prescription in the other hand, which I was happy to start at a small dose like 15mg.

I only started the 15mg/day prednisone course, which I tapered very slowly like the last time I was on it. I wasn't off prednisone until 2 months later, going down very very slow. **At the same time, I began to start over with the SCD diet once again. This time, I cut out a few foods I was eating the first year and half which I shouldn't have been like tortilla chips and potato.** Within one week of starting prednisone, I began to notice very good improvements, and by the time I was two weeks into the steroids, I was having very hard bowel movements and my excitement was growing. But like before, I was nervous as most people are to come off prednisone/prednisolone. What is going to happen when you aren't taking steroids anymore? Are my symptoms going to come back? Those questions were dancing around in my head. Thankfully, my brain fell back on my previous experience starting this diet. That brought back the recent memories of living free and happy. With my faith on the diet's side, I eventually was medication free. At the time of publishing this book, the last prednisone pill I took was in very early March 2011. So for me, getting out of my worst "post diagnosis" flare was a combination of Prednisone and starting the diet all over again.

SAYING GOODBYE TO MY DOCTOR

Having a doctor that you really believe in is very important. If you have a doctor who believes in you, that's also great. In early 2011, I felt it was time for a change. My current GI doctor was such a nice guy, my wife really liked him too, but there was one major thing that we completely disagreed on, and that was my diet. He felt it had nothing to do with my UC symptoms, I felt otherwise. That in itself isn't that big of a deal actually, you won't always agree with your doctor, and he won't always agree with you. But when you want to try something out concerning your treatment that has worked better than all other alternatives to date, and your doctor won't support you one bit, well I've got a problem with that!

Since I had my doctor's email address, I decided to send him an email. I had my doctor's cell phone number too, but I thought it would be better to have my thoughts down in writing. According to my dad, I can get a bit unglued sometimes over the phone, and I did not want that to happen. Getting into a back and forth heated conversation when you are feeling sick is usually not going to make you feel better either.

Below is the exact email I sent to my doctor on January:

Hi Dr. X,

Thank you for your phone call to follow up with me, after I canceled tomorrow's sigmoidoscopy. I have several concerns regarding moving forward with my UC treatment and the medication plan you explained earlier today. I needed a few moments to digest our meeting and came to the conclusion that there are some pretty big issues at hand which I will try to outline for you to make some sense of everything.

Over the past 16 months, I have started treating my UC with a very specific diet and for the most part have had some great success. There have been some bumps in the road (like right now), but I have been very happy with most of the outcomes. I have been off all medications for just over 14 months, and the last pill I took was 2.5mg of prednisone which was the end of a very slow taper that lasted for several months which you might remember.

I was told about this diet from a local girl who has had UC for over 10 years and is a few years younger than me. Like me, she has tried many medications (remicade, colazal, asacol, prednisone, 6MP, enemas) but she did not try Humira. Like me, she did not respond to any of those meds. But, one of her physicians recommended she read a book about a diet that has helped other UC people. She did just that, and within several weeks she was symptoms free and eventually medication free and has been off meds for 3 years without any flares. The long story short, is I tried the diet starting August 11, 2009, and within a few days, I started seeing noticeable relief of my UC. On Oct. 5th 2009, I finished my taper of prednisone, and was on a roll, and was excited as well. You and I did a sigmoid sometime in Nov. 2009 and you noticed that things were looking really good, which also excited me.

Right now, I am very worried about moving forward with you as my doctor for helping with my UC. The main reason for this is your feelings towards diet and the disease. I would rather be working with someone who is supportive of my goal with trying to treat my UC with diet until I

feel it is no longer working, or until something else seems to be a better solution. I am not interested in medications for a long term treatment at this point.

I would be more than happy to talk with you about this further if you would like to. Right now, I think it might be best for me to search for another physician who is more aligned with my treatment goals. Once again, if you would like to discuss any of this email at anytime, I would be happy to talk with you further. I hope that if this diet ends up failing, you would be willing to see me once again.

Kindest regards,

Adam Scheuer

On a side note, I started building a website about one year ago which has grown into stories from around the world of UC people's lives and struggles and successes. If you are interested, it's right here:

www.iHaveUC.com

FALL 2011

Call me an idiot or whatever else you want, but when the end of September 2011 rolled around, I was doing some things over again just like the year before. I was feeling great, coming off a medication free summer without any UC symptoms, and also getting ready for the Las Vegas Half Marathon again. This year was going to be a bit different though, Michaela and I were going to enter together! This made me so excited, to be able to complete a half marathon with my wife, WOW, and she was excited too. We recently moved to Berkeley, California and she was beginning to take classes there to complete her undergraduate degree. The timing was perfect, school was starting, the weather was great. What else could you ask for to begin training for a half marathon?

Things started out just great. We ran together, and then slowly we started adding distance. I was up to 3 miles per day. And just like that, I noticed some loose stools several days in a row. Then I started seeing some very light bleeding too. This was a bummer. Could it be, the same exact situation that happened to me the year before when I started training for the half marathon? Well, who knows, but this time, I stopped running right away, and went back to basics on my diet

too. My symptoms never got to the point where there was dripping blood, but I definitely had several days in a row of diarrhea and probably 3-5 bowel movements per day at its worst.

It took me three weeks, but things started coming around, and once again, the 1-2 hard poops made their way back into my routine. I credit stopping my flare (without medications) to the complete removal of hardcore running, removal of all decaf coffee (which I was drinking in the morning and evening) and some other minor changes to my diet.

When the week of the race arrived, Michaela and I didn't end up making it down to Las Vegas together. She came down with a nasty cold a few days before, and she decided to stay home. Her finals at Berkeley were the following week, and she needed to be feeling much better for those exams. But I still made it to Nevada. And as luck would have it, I sprained my ankle just a few days before flying there. So instead of running, I stuck to taking pictures on the sidelines come race-day. But that wasn't the end of the world. I learned my lesson the year earlier about my body's limits, and Vegas was still all kinds of fun. Come on, we're talking about Vegas here!

I say this to everybody, and there's no reason to stop now:

If you have the chance to take part in a race benefiting UC, SIGN UP! It's bound to be a good time.

My favorite part this year was meeting up with a fellow UC'er who was racing with the Crohn's and Colitis Foundation. She was there with her family, and I felt like I'd known her for years and years. Several months before, she wrote her story on the iHaveUC site, so I knew quite a bit about her. But it was way better to finally meet in person.

VIDEO: For anybody who is interested, you can watch a great video I made. It is a documentary of exactly what I ate and drank for a full week during my October 2011 flare.

<http://youtu.be/eGiyPF3w1iA>

WHERE I'M AT TODAY

So, I started out as a healthy person, living an average life. OK, I guess the 53 day solo bike trip in Croatia isn't too average. But for the most part, I'm a normal guy. October 2, 2008 was my day when the doctor told me I had UC. Then, I went through a long period of horrible UC symptoms. I thought my life was coming to an end. But you know what happened....

I'm still alive.

I'm also starting a new year medication free and feeling in control of my colitis like everyone should be. I'm not doing anything new in terms of my treatments, I'm just sticking to the diet I follow. Most days, I have 1-2 bowel movements. Every once in a while, things might get a little out of whack, and maybe an extra crap or two might slip in, but that's about it. Most of the days I'm taking hard poops. But its not every single time. There are some days where out of the blue my poops might be softer, but that doesn't get me down.

Learning how to live my life the way I want even with Colitis, is a present I keep receiving. It wasn't easy, and there were setbacks along the way, but now I know how a good life is possible with UC. That's what keeps me motivated. As much as I felt the bleeding and symptoms would go on forever, they do stop. Back during the days of bloody symptoms, it felt like I'd be going to the doctors at least once a week for the rest of my life. But that stopped too. I haven't seen a GI doctor in over a year now. I almost miss seeing them(well... not really).

What I'm most looking forward to is early March 2012. That's when I'll be hitting the one year mark since I took my last prednisone steroid pill. That's going to be a day for celebration. I hope Michaela's ready for a big night coming up!

Part 9: Recap

This is the final section of my book. And I hope that for most of you, it will be your favorite part. If I write a future edition of the book, which I plan on doing, I'll definitely follow up on several of the chapters below. Thank you so much for reading my story so far. I also would like to thank my wife and everyone else who has been a part of this book. Without all of the support and input from my friends and family, it would have been much more difficult to put all of my Colitis Years on paper.

To stay up to date with me, make sure to stay connected to me and the rest of us with UC.

Twitter: @iHaveUC

YouTube: youtube.com/iHaveUC

Facebook: facebook.com/iHaveUC

-Adam Scheuer

WHAT I DID WHEN MEDICATIONS WERE NOT WORKING

One of the major crossroads that so many UC patients are forced to deal with involves medications. Specifically when a medication is not working. This happened to me numerous times. Here is how I moved forward:

Have A Treatment Plan in Place

For me, I don't like medical surprises. I like having a medical plan. It makes me feel better knowing that I have something in place if something does not work out as expected. This is a personal decision, and it has worked well for me. Very early on, once I started seeing my GI doctor, we developed a plan. It was actually pretty simple. I wanted to know what medications I could expect to take in the future. After a few different meetings and conversations, I learned what to expect. (Prednisone, Colazal, Asacol, Sulfasalazine, 6MP, Remicade and maybe even Humira. OK, yes, I also learned about the different enemas and suppositories, and we talked about how you use them too.)

Talked with My Doctor about Concerns

Here are some questions/conversations I had with my GI doctor:

- When could I expect to see some changes in my symptoms? (That I've learned is a very hard question to answer with different medications, but it's a great one to talk with your doctor about)
- How long will I keep going with these symptoms before we decide to change medications or do something else?
- What things could I be doing to help out with healing my body?
- Even if these medications start working, will I be able to come them eventually?

Researched Medications Online

(Now I would find other patients to speak with also)

Back in the days before I started the iHaveUC.com website, there were many periods where I was testing out new medications. Unfortunately as is true for so many people, I wasn't getting into remission. Without knowing very much about colitis medications, I spent time researching medications online. It was usually dominated by drug company advertisements and content. (I can remember my doctor telling me not to get too caught up in the horror stories you find online also.)

Now, since I know so many other people with UC, I would definitely be asking other patients about their experiences. In my opinion, learning from other colitis patients is some of the best research anyone can do. I'm not trying to bash scientists who have spent decades learning and studying at the best colleges around the world. But, from all the interactions that I've had since being diagnosed, the patient to patient experiences have taught me the most. People with UC who are usually happy to talk about their disease. It's not just me. The more people you talk to, the more well rounded your research will be.

Here's an example of what I would do:

- Let's say you had access to a whole bunch of other people's opinions about colitis (like on the facebook.com/iHaveUC page)
- So, if you wanted to know what other people thought about a new medication or treatment, why not ask everyone?

- That's what I would do, I'd go to the Facebook group and ask:
- Here's what I might write: "Hey UC'ers, I'm wondering if anyone here has taken "Colitis Butt Plugs" and if so, how are they working for you?" (Expect to get a whole bunch of different answers. But that's OK. You might have some new ideas to talk with your doctor about. This whole process helps me make better informed decisions, and I use it all the time with many things outside of my UC life too. I'm not doing rocket science, it's called "FEEDBACK". You might getting some too.)

I Eventually Changed My Diet

For me, there came a time when I made a pretty big decision. Who should I listen to? Me or my doctor? I decided to stop taking the advice of my doctor, and I ended up moving forward with my treatment on my own. If I had to do it over again, there's several things I would change. But it was a big decision. One that is very difficult to make when you are feeling horrible. And as my story explains, its a decision that changed my life.

Without seeing any positive changes from medications, I was down to just a few medical options. More medicine or surgery. That was pretty much it as far as I knew. But there was a problem, I didn't want more medications and I was scared of surgery. So I took the chance and started eating differently. And as I started to see, my diet changes worked for me. It was great. And it couldn't have come at a better time. Seeing your symptoms go away is such a great feeling. It would have been sweeter with my doctor on board too. But you can't always have everything, in life and with UC.

For anybody who is living through the dilemma of "UC Medications NOT Working", don't feel alone. It's unfortunately very common, and there are hundreds of thousands of people who have been there before you. Although the medications did not work properly for me, life did go on, and I've found ways to move forward just like so many other UC'ers out there!

MY FUTURE EXPECTATIONS

Now that you know my story, you might have questions about what I expect to happen moving forward. Specifically, you might be wondering how I see my life and my UC as the

months and years move by. So let me explain where I'm at with regards to the future. I'll first give you some predictions about life, and I'll wrap it up with predictions about my Colitis.

Living Expectations Moving Forward:

If my colitis remission continues, or even if my UC returns, my future plans and ideas with Michaela are looking pretty awesome. We plan to remain in Northern California until she is finished with her undergraduate degree which might be until January 2013. After that, there's several ideas we are tossing around. Our goal has always been to complete some more international traveling before we settle down and start a family, and January 2013 might be the perfect time for that. One idea is to find a sailboat to live on in some cheaper foreign country and navigate the water and land until we have had enough or until we go broke. Another idea is taking a long range bike trip to South America. Nothing is set in stone, and quite possibly the biggest factor is the budget we can come up with in the next year. But I'm sure something fun is going to happen.

Looking out a few more years into the future, the expectation we both have is to settle in Europe somewhere closer to Michaela's family. Who knows, maybe Czech, or maybe somewhere down on the Mediterranean. I'm always a fan of warm weather, and I've always enjoyed the time living abroad in a foreign country.

As for work, that surprisingly is not something I've ever worried about too much. I know from past experiences that my UC has not stopped employers from hiring me, I've had it down on my resume now for over two years and so far its always been an asset. (My resume's hobby section says: "I enjoy helping other people who have UC") But when it does come time to work again, I'm going to be more selective in what type of jobs to inquire about. If a potential job appears to be very stressful, it's not going to make the cut for me anymore. Those days are long over. No matter what the pay is, it's not going to be worth it.

With regards to my personal physique, I want to stay in shape, and continue to get stronger! I have an expectation AND a goal to continue my strength training and cardiovascular workouts. I really enjoy taking long walks, biking, kayaking, yoga, and doing simple things like pull-ups and push-ups. As I've grown older, I'm starting to understand that I don't need to be a member at some expensive local gym or fitness club, it's not necessary. All that I need is a pair of athletic shoes and some decent weather outside. And how could I forget, maybe a few more Las Vegas Half Marathons mixed in here and there.

My Colitis Treatment Moving Forward:

From the hundreds of colitis people I talk with each month, I realize I'm doing something right with my approach to treating my UC. Most importantly, I've found ways to control my colitis while maintaining a medication free lifestyle. **For most people, that's a big win.** It's a big win for me too. Since I've had such great results treating my UC with diet, I don't plan on changing that anytime soon. A focused diet treatment is working for me and tons of other people right now, so that's what I plan on sticking to. Who knows, maybe there might be some other treatment that clearly becomes a better alternative for me someday? I just don't have that answer yet. But if some other UC treatment looks like it will be a better fit for me, I'll have no problem making a treatment change. I'm not tied to the diet I'm using right now, which is the same as my feelings about all the medications I was using previously. My goal is very clear, remission and an unaffected lifestyle with a minimum risk of future health problems and side effects. I think this is what every UC patient should be expecting.

Do I expect to have flare ups moving forward? Yes, I do, and that might be surprising to some people reading this book. I think it is reasonable to believe that a 100% symptom free life forever probably won't happen. Even though I have had very long periods already without symptoms, active colitis may very well come back someday. If that happens, I will probably go back to starting over the diet with very restrictive rules on food for a short while to see if the flare can be contained. This is exactly how I treated my flare up in October of 2011 and previous flare ups as well. After this "re-boot" and starting over process on the diet, my expectations would be for symptoms to go away quickly.

If I find myself in a flare up with symptoms that don't appear to go away from restricting my diet, at that time I will probably look into other medical options that I have not tried already such as different enema treatments or some other alternative therapies. One great benefit that I have along with everyone else is the power behind the iHaveUC.com website. With so many people using the website daily, it's very easy to learn what others are doing that is working, and that's definitely a place I would turn for help if help is needed.

If you remember from earlier in the book, there were several GI doctors including my main GI doctor who prescribed and recommended 6MP (6-mercaptopurine) as the next medication that I should try. Although I really respect each and everyone of these doctor's professional opinions and advice, getting started with that medication is not something that would interest me even if I became very sick again. (Just say no to drugs, well, maybe that's what I'm saying to myself?)

If you are wondering which alternative treatment currently has me the most interested, I'd have to say the “**fecal microbiota transplants**” that have gained so much hype in the past few years. Yes, you read that correctly, fecal transplants in normal words is all about taking someone else's poop and pumping it up your colon. If you can get past the nasty visuals, the ideas are based on changing the microbial gut communities within your colon, and this thinking is very much the same as the goals of the diet treatment I follow. I'm not there yet, but as more and more data comes out, this type of therapy really does excite me, and it might be a huge benefit for all of us with UC.

If my colitis begins to get very out of hand, and alternative therapies are simply not working, my current thinking would probably lead me to getting my colon removed. Remember, I've already tried quite a few medications, and for me they didn't work. Surgery is a very big decision, and I would need to think it through quite a bit, but that's how I'd lean right now. Too many people have had such a great experience with surgery that it would be a big mistake for me to look it over.

Expectation Recap

I've been feeling really good for several years since getting my UC under control, and if last year was any indication, I'm still continuing to get healthier and healthier with my current treatment. It will be awesome if my health continues, but if my health declines, I've got some plans in place to work through any tough times that may arise. The future for a UC patient is not something to fear and be worried about, it really isn't. By having a treatment plan in place, even if its one just in your head and not written down on paper, you'll be able to deal with whatever comes your way. That's type of thinking has worked well for me and equally well for other UC'ers too.

CONCLUSION

I hope everyone has enjoyed the story so far. It's true, I'm just an average person living with UC. Like most people, I had no idea about what this disease was until I was diagnosed. Also, I had no idea on how anyone would go about treating this disease until I was really sick.

If there was nobody to talk with about UC, things would be very difficult. Over the years of building up the iHaveUC.com website, I've tried to make myself available to as many people as possible. It is always a treat to read emails and correspondence from others who are living with or know someone who has UC. Even though the subject is often dark and gray, filled with pain and agony, we are all in the same tribe together. I've always thought that is something special about people and family members living with UC.

In the future, I'll continue to update everyone on how things are unfolding with my disease, just make sure to follow the iHaveUC.com website. I hope to keep everything on the same course it's on right now for a long long time. As I already mentioned, current plan is to simply continue with my diet, refrain from any strenuous physical activity for at least another year, and then maybe I'll give another half marathon a try in Las Vegas...Join me if you can!

If I can get past March 2012 without any medications, and no flare ups, that will be a great milestone for me. Hitting the one year mark and being medication free(remember, the last pills I took were prednisone pills in March of 2011) is going to be here very soon. Judging by how things are going right now, I'm pretty sure it's going to happen.

For everyone who has already had surgery to remove your colon, I respect you all very much. That is such a huge decision, and one which many people think about each day. It is very clear that the overwhelming majority of people who have had colon surgery due to out of control UC are EXTREMELY happy with their decisions, and that makes me really happy, and it's also very comforting to know. Being a UC patient and always having a last resort option that has made many people very happy is absolutely a positive part of our disease. If the final outcome is happiness, that is tough to beat.

Thank you so much for reading my book, and keep me posted on your UC. It's always a treat hearing from other UC'ers and concerned family members. Good luck with your poops today. Hard logs are possible. And no matter how awful your symptoms are, they too will pass.

Adam Scheuer

Appendix:

TREATMENT OPTIONS

As the worldwide list of treatments for UC is very long, I've included some treatments that writers on the iHaveUC site are using successfully. I encourage you to speak with your doctor about all treatments that sound interesting to you, once again, that is what doctor's are there for.

Surgery:

This is considered the "last resort" option by many people, doctors included. But, I am positive that if you ask patients who have already had surgery if they are happy to have had their colon out, the answer is almost always "YES!". Most patients who have had their colon removed say it was the best decision of their lives, and that's pretty powerful! I can even remember my GI doctor telling me that when I was in the middle of my severe symptoms for months on end with no relief. Surgery is considered by many people, both doctors and patients to be the only real "cure" for ulcerative colitis.

There are several different types of surgery that a patient may have the option to choose from. For example, there is a relatively newer type of surgery that is sometimes referred to as the "J-Pouch" surgery. This surgery removes the colon, and effectively uses the small intestine as a new colon which attaches to the rectum or output area. Believe it or not, but after this surgery, patients can still use the bathroom like a normal person. To me it is amazing! And I know several people who have their life back in their control thanks to having surgery.

This is just one type of surgery that is possible for patients with ulcerative colitis. Another common surgery that some patients end up moving forward with is called an Ileostomy.

The "Ileostomy" is the surgery where colon and rectum are removed, and an opening is created in the abdomen. This is where the end of the small intestine will be connect. This opening is referred to as a "stoma". People who move forward with this type of surgery will collect their waste that passes through the small intestine in a bag that attaches to the opening. (This is the surgery that my uncle had, and he had virtually no problems for almost 35 years of his life.)

The reality is that most people with ulcerative colitis never need to have surgery, but if an ulcerative colitis patient does decide to have surgery, that is usually a very good thing. Again, time and time again the people who I have come into contact with who have suffered from ulcerative colitis and want to move past it once and for all via surgery, are living normal healthy lives and very happy with their decisions.

- Here is a link to a 26 person survey from UC patients who have already had colon surgery. The information that was provided is fascinating: [Colon Surgery Survey](#)
- Here is a link from the iHaveUC website that talks more about: [patient stories of surgery](#)
- A past writer on iHaveUC.com who has completed colon removal survey maintains an excellent website called “[Know Guts](#)”. It’s a great site with tons of details and pictures.

Oral Medications:

The vast majority of people who are diagnosed with ulcerative colitis have been prescribed some sort of prescription medication to help control their symptoms. It is very hard to determine which medication is the best for most people, and to my knowledge, there isn't any real data to truly answer this question yet. But, what I can tell you is that there are people all around the world who are successfully using medications to completely control ulcerative colitis symptoms to the point where a normal healthy lifestyle can be enjoyed.

Here is a list of some oral medications that other UC'ers are currently using successfully:

Lialda

Asacol

Colazal

Sulfasalazine

Pentasa

***One part of this disease that has always been amazing to me is how some patients don't respond well to a certain drug listed above, but sometimes respond better to another drug. I wish it was easier to pin down right away, but sometimes it simply takes time.

Corticosteroids: (Prednisone/Prednisolone and Hydrocortisone)

Steroids are also very commonly prescribed. They are very well known to help reduce inflammation. Like any other medications, you should be most definitely consulting with your physician when you think about taking these types of medications as there are many different possible side effects that you should be aware of. Also, long term use of prednisone is not advised as well. Most patients are prescribed prednisone/prednisolone steroids for a short period of time. They are not intended to be a long term treatment.

There is super interesting survey from 42 patients who used prednisone/prednisolone that goes into detail about side effects located here:

<http://www.ihaveuc.com/prednisone-prednisolone-use-side-effects-survey-results/>

Remicade:

Reserved most often for patients who are not responding to other medical treatments, Remicade is administered by intravenous infusion. This medication helps to stop the autoimmune response that ultimately causes ulcerative colitis symptoms.

This type of treatment is often given every 6-8 weeks indefinitely. Many patients who are using Remicade stop using all other medications, and many patients using Remicade continue using some medications additionally.

There is a 35 patient survey regarding Remicade use that has all sorts of valuable information located here: <http://www.ihaveuc.com/remicade-infliximab-reviews-and-survey-for-ulcerative-colitis/>

Enema Treatments:

There are many different ways to treat your ulcerative colitis, and one way that has been going on for many years is with the help of enemas. There is a recent preliminary study regarding the positive effects of Vitamin E enema treatments on a group of ulcerative colitis patient, here is the link to read more about this: <http://www.ncbi.nlm.nih.gov/pubmed/18932276>

GAPS DIET:

This is another diet protocol that is very similar to the SCD Diet I follow, but it is one that many people with ulcerative colitis have/are also using successfully. Here is the book for sale on Amazon which explains this diet: [Gaps Book](#)

Specific Carbohydrate Diet or SCD:

This is the diet that I follow to treat my ulcerative colitis. It has allowed me to be medication free for over 90% of the time since I started the diet. This diet is scientifically based on correcting an imbalance within the gut bacteria colony inside our colon. With restricting the types of food you consume by following the SCD Diet, the theory is that the gut bacteria community can be changed so it no longer upsets the immune system. In real basic terms, "bad bacteria" is forcing the immune system to respond. Until that "bad bacteria" is eliminated or reduced significantly, the immune system will just keep responding. The original book which talks about the SCD diet is available on Amazon here: ["Breaking the Vicious Cycle"](#)

SCIENTIFIC STUDIES AND UC RELATED RESEARCH

Below is a list of different publications that are all free to view. There are literally thousands of studies published and available for everyone to read online. I wanted to be sure and include several studies that I suspect you will find interesting. In most of these studies, the "Abstract" or "Introduction" section, is a general overview of the entire study. As is the case with most research and scientific papers, some of the language can be confusing. That's alright. Take it

slow, and I assure you that most of the information will make sense to you. ALSO, if you are like me, you might sometimes have additional questions. Many of the published documents below list contact information for the Doctors or Scientists who were involved with the research. I can't tell you how many times I've emailed these people and received responses to my questions within just a few hours(pretty amazing if you ask me!).

- [**Preliminary Evidence Supporting a Framework of Psychological Adjustment to Inflammatory Bowel Disease**](#), October 2010. Center for Psychosocial Research in GI, Northwestern University, Feinberg School of Medicine, Division of Gastroenterology, Chicago, Illinois.
- [**Shining a Light on Intestinal Traffic**](#), November 2011. Alimentary Pharmabiotic Centre, University College Cork, National University of Ireland, Cork, Ireland.
- [**Management of Acute Colitis and Toxic Megacolon**](#), December 2010. Department of Colorectal Surgery, Cleveland Clinic, Cleveland, Ohio.
- [**Laparoscopic Surgery for Ulcerative Colitis**](#), December 2010. Department of Colorectal Surgery, Digestive Disease Institute, Cleveland Clinic, Cleveland, Ohio.
- [**Pros and Cons of Medical Management of Ulcerative Colitis**](#), December 2010. Center for Inflammatory Bowel Disease, Digestive Disease Institute, Cleveland Clinic, Cleveland, Ohio.
- [**Ulcerative Colitis in Infancy**](#), November 2011. Department of Paediatric Gastroenterology and Nutrition, Bangabandhu Sheikh Mujib Medical University, Dhaka, Bangladesh.
- [**Common misconceptions about 5-aminosalicylates and Thiopurines in inflammatory bowel disease**](#), August 2011. Javier P Gisbert, María Chaparro, Gastroenterology Unit, Hospital Universitario de La Princesa, Instituto de Investigación Sanitaria Princesa (IP) and Centro de Investigación Biomédica en Red de Enfermedades Hepáticas y Digestivas, 28006 Madrid, Spain.
- [**Current Treatment of Ulcerative Colitis**](#), July 2011. Johannes Meier, Andreas Sturm, Department of Hepatology and Gastroenterology, Charité-Universitätsmedizin Berlin, Campus Virchow Clinic, 13353 Berlin, Germany.
- [**Is Moderate Red Wine Consumption Safe in Inactive Inflammatory Bowel Disease?**](#), August 2011. Department Digestive Diseases, Rush University Medical Center, Chicago, Ill., USA.
- [**Extraintestinal Manifestations of Inflammatory Bowel Disease**](#), April 2011. Jonathan S. Levine, Dr. Levine is an Associate Physician in the Division of Gastroenterology, Hepatology, and Endoscopy at Brigham and Women's Hospital and an Instructor of Medicine at Harvard Medical School, both in Boston, Massachusetts.

- [Anti-inflammatory effects of nicotine in obesity and ulcerative colitis](#), 2011. Global Neuroscience Initiative Foundation, Los Angeles, CA, USA School of Health and Medical Sciences, Seton Hall University, South Orange, NJ, USA.
- [Optimizing clinical use of mesalazine \(5-aminosalicylic acid\) in inflammatory bowel disease](#), July 2011. Inflammatory Bowel Disease Research Institute, Cedars-Sinai Medical Centre, Los Angeles, CA, USA, Inflammatory Bowel Disease Clinic, Division of Gastroenterology, University of Calgary, Calgary, Alberta, Canada, Head of the Department of Medicine, University of Calgary, Foothills Medical Centre, Calgary, Alberta, Canada, Division of Gastroenterology and Department of Microbiology and Infectious Diseases, Faculty of Medicine, University of Calgary, 1705 Health Sciences Centre, 3330 Hospital Drive NW, Calgary, Alberta, Canada T2N 4N1.
- [Inflammatory Bowel Disease in Pregnancy](#), June 2011. Dawn B Beaulieu, Division of Gastroenterology, Vanderbilt University, Nashville, TN 37232, United States. Sunanda Kane, Division of Gastroenterology and Hepatology, Mayo Clinic, Rochester, MN 55905, United States.
- [Current and emerging drugs for the treatment of inflammatory bowel disease](#), April 2011. Department of Gastroenterology, Center for Inflammatory Bowel Disease, “Saint Panteleimon” General Hospital, Nicea, Greece.
- [Maintaining remission in ulcerative colitis – role of once daily extended-release mesalamine](#), February 2011. The Department of Medicine, Section of Gastroenterology, University of Chicago Medical Center, Chicago, IL, USA.
- [The Bowel Microbiota and Inflammatory Bowel Diseases](#), August 2010. Department of Microbiology and Immunology, University of Otago, P.O. Box 56, Dunedin 9054, New Zealand.
- [Chronic fatigue is more prevalent in patients with inflammatory bowel disease than in healthy controls](#), November 2010. Østfold Hospital Trust, Fredrikstad, Norway, Oslo University Hospital Aker, Oslo, Norway, University of Oslo, Institute of Clinical Medicine, Oslo, Norway.
- [Impact of pain on health-related quality of life in patients with inflammatory bowel disease](#), July 2010. Anja Schirbel, Anne Reichert, Daniel C Baumgart, Bertram Wiedenmann, Andreas Sturm, Division of Gastroenterology and Hepatology, Department of Medicine, Charité-Campus Virchow Clinic, Universitätsmedizin Berlin, 13353 Berlin, Germany Stephanie Roll, Institute for Social Medicine, Epidemiology and Health Economics, Campus Mitte, Charité-Universitätsmedizin Berlin, 10117 Berlin, Germany. Carsten Büning, Division of Gastroenterology, Hepatology and Endocrinology, Campus Mitte, Charité-Universitätsmedizin Berlin, 10117 Berlin, Germany Bianca Wittig, Division of Gastroenterology, Infectiology and Rheumatology, Department of Medicine, Charité-Campus Benjamin Franklin,

Universitätsmedizin Berlin, 12203 Berlin, Germany Axel Dignass, Department of Medicine I, Markus-Hospital, Wilhelm-Epstein-Str. 4. 60431 Frankfurt/Main, Germany.

- [**New Research in Ulcerative Colitis-Optimizing 5-ASA Administration for Efficacy and Adherence**](#), January 2010. Charles A. Sninsky, Digestive Disease Associates Gainesville, Florida.
- [**Efficacy of methotrexate in ulcerative colitis: failure or promise**](#), August 2010. Division of Gastroenterology and Hepatology, Department of Medicine, University of North Carolina, Chapel Hill, North Carolina 27599, USA. hherf@med.unc.edu.
- [**Should my patient with inflammatory bowel disease on immunosuppressive therapy be vaccinated against influenza virus?**](#) February 2010. ¹Department of Medicine (Division of Gastroenterology) and Farncombe Family Digestive Health Research Institute.
- [**Direct comparison of two different mesalamine formulations for the induction of remission in patients with ulcerative colitis: A double-blind, randomized study**](#), September 2010. Digestive Disease Center of Excellence, Kitano Hospital, The Tazuke Kofukai Medical Research Institute, Osaka, Japan.
- [**Medication beliefs among patients with inflammatory bowel disease who report low quality of life: a qualitative study**](#), June 2007. Nicola J Hall,¹ Gregory P Rubin,¹ APS Hungin,² and Audrey Dougall³ ¹School of Health, Natural and Social Sciences, University of Sunderland, Sunderland, UK ²Centre for Integrated Health Care Research, Durham University, Stockton on Tees, UK ³Department of Anthropology, Durham University, Stockton on Tees, UK