

Foreword

“It’s no longer a question of staying healthy. It’s a question of finding a sickness you like.”

– **Jackie Mason**

HAVING CROHN’S DISEASE is like being transported back to being an infant. People talk at you using an incomprehensible language. No one seeks, welcomes or values your opinion. Mom, in the guise of the medical profession, most definitely knows what’s best for you. Your food is bland, mushy and generally appalling. Your poop becomes an object of fascination for others. Consequently, it is not unusual for a Crohn’s patient to feel as helpless as a two-year old.

But it does not need to be so. Through trial and error I have discovered that having Crohn’s Disease is something you can improve at if you approach it with the right attitude. As with any other aspect of life, when you’re ill, it’s to your advantage to try and be successful at it.

By that I don’t mean heroically finding a cure (there is no cure for Crohn’s), or fighting the illness every step of the way (those people tend to die young). Nor do I mean being a model patient, hanging on every word of wisdom imparted by the massed ranks of the medical profession (model patients tend to have the worst prognosis of all). What I do mean is that being successful at having Crohn’s Disease is about being able to take ownership for your illness and its treatment. The outcome is not just the feeling of triumphing over the medics – although that has its moments – but is about not letting your illness impact your enjoyment of life.

Over a seven-year period I had to see a lot of doctors and have my orifices endlessly probed before I was finally diagnosed at the age of 23

with Crohn's Disease. Since then, I have spent almost thirty years dealing every day with illness, drugs, medics and the not-so-occasional surgery. But, by learning to see the funny side of the ridiculous medical procedures we undergo; by being reminded each and every day of the value of good supportive relationships with family, friends and colleagues; by realizing that Crohn's Disease need not restrict the freedom we have to find our own path through life; by seeing that there are still opportunities to make good choices, the successfully ill have as happy and fulfilled a life as anyone else. This is true despite having an endless cycle of symptoms, surgeries and drug regimes that healthy people would find appalling to contemplate.

My thirty-year grappling match with the illness and the medical profession has taught me more than I would have ever thought possible about how to achieve this goal. In telling you my medical odyssey, I hope to share with you the insights, skills and tips I have picked up in not just surviving my Crohn's but thriving with it.

Tip #1: Take Your Pick

You have a choice how to be ill. You can attempt to carry on as though nothing is wrong and end up killing yourself in the process. Or you can be a victim, weeping and wailing "Why me?" at every turn and killing yourself spiritually in the process. Or you can be a Positive Acceptor: recognizing that your Crohn's is a card you have been dealt in the poker game of life, but one that will not take away your ability to play your hand to the full.

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“Diagnosis: a preface to an autopsy”

– **Anon**

I SAT ALONE and seemingly forgotten in one of the closet-like consulting rooms of the gastro-intestinal clinic at Birmingham’s Royal Free Hospital. Over the previous seven years I had sat in similar rooms countless times, only to have the medic stare at his notes while mumbling the profession’s many different and obtuse versions of “Sorry buddy, we haven’t a clue what’s wrong with you”. It is amazing how many ways they have of saying this, all the time sounding as though they do actually know what’s going on. “We just need to run a few more tests to make sure”, “I think things seem a little better so we’ll keep going as we are”, and so on ad infinitum. I strongly suspect there is a secret part of the Hippocratic Oath that commits a doctor to never owning up to being baffled.

Because of the medical profession’s reluctance to acknowledge fallibility, I had, over the seven years up to that point, been subjected to an endless series of apparently random tests, followed by a variety of treatments for the latest wild guess as to the source of my increasingly dire problems. This hit-or-miss approach had eventually run out of options, only to be followed by the inevitable descent into it all being my fault – stress – then it being pinned on the last resort of the baffled doctor— depression. So I did not have a great sense of anticipation at being there once again.

Although these rooms are as bursting with sensory stimulation as an undertaker’s parlor, I had by this time discovered ways of keeping myself amused while waiting to be graced by the presence of a doctor. I weighed myself on that intriguing example of pre-industrial technology

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where you move the little weights along the bar. One-hundred-and-thirty pounds: my lowest yet. However, the long ruler affixed to the wall reassured me that I was still 5' 8", so it was not all bad news.



Waiting on a word

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Then, of course, pinned to the otherwise barren notice board, was the ubiquitous medical cartoon snipped from one of the more venerable copies of Reader's Digest. This timeless classic was the "Don't use a doctor whose houseplants are dead" one, located above a very sad cactus that looked like it had endured a particularly dry summer in Death Valley. Do doctors find these cartoons funny? Do they think we will?

There was also a complete absence of reading material to pass the time. I don't know what hospital administrators get up to all day when there is so much scope for improvement. If the gastro-intestinal clinic managers had the good sense to procure the same reading matter as did their more enlightened counterparts in the infertility clinic (more on that later), hospital appointments would be a lot less soul-destroying and consequently good for business. But having said that, the gastro clinic was always jammed and running three hours late, so perhaps the management felt that subscriptions to Naughty Neighbors, Urban Nudist and Spankers Weekly would be difficult to justify.

I have come to the conclusion that we're forced to spend so much time waiting for doctors in these desolate rooms in order to break our spirits and make us more susceptible to agreeing with everything they say. After twenty-five minutes of staring blankly at the pale green painted wall, I have usually forgotten everything I planned to say to the doctor or sometimes why I'm there at all. Perhaps it's like this in Guantanamo Bay.

Tip #2 – Stay Alert

Do not be intimidated by the waiting process; feel free to amuse yourself any way you can while enduring the wait. If there's a stethoscope, listen to your own heartbeat. If you're very lucky, you will find one of those special rubber hammers

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for testing your reflexes. If you're caught in the act you will merely get a raised eyebrow, but at least your brain will still be functioning.

Just as I was considering the possibility that I was in fact the last man alive, the rest of Birmingham having been obliterated in some kind of catastrophe, the door opened and in walked the senior registrar of the gastro-intestinal surgical team. Amber alert: I was seeing the second in command rather than the usual overseas student. RED ALERT: Hewas not only making eye contact but had a definite gleam of triumph as he broke it to me.

“Good news Mr. Bradley, we know what is wrong with you.”

So staggered was I at hearing a definitive statement relating to my condition that I almost missed the punch line.

“You have Crohn’s Disease!”

YEEEESSSSSSS!!!!!! If this had been a football match, I would have been cautioned for my ludicrously excessive touchdown celebration. I may have ripped off my shirt and thrown it to the massed drones in the main waiting room, I can’t quite remember. At last my worries were over! Surely the super-slick medical machine, after the seven-year glitch in diagnosis, could now purr into action. As my initial surge of euphoria passed, I realized he was still talking

“...and this hospital is one of the world’s leading centers for the treatment and management of Crohn’s disease.” I now felt guilty for ever having doubted the medics. How lucky was I? World experts! Lead me on!

In complete contrast to the glacial pace of events for the previous half-decade and more, he then jauntily snapped up the phone, called the head of this world-renowned Crohn’s Disease facility, and arranged for me to go straight up. You could stuff your six-month waiting list up your rectum – I was on the fastest of fast tracks now! So off I went to

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the place that would become my second home for the next fifteen years - Ward 8 of the Birmingham Royal Free Hospital.

As I navigated the corridors, still euphoric that I had a known illness as opposed to a completely undetectable and imminently fatal condition, I began to ponder what lay ahead. Well, actually, at that precise moment, the urology ward lay ahead. Backtracking to find the obscured sign towards Ward 8, I had a jaunty step, not realizing how much every single aspect of my life was going to be impacted by the condition first documented by Dr. Burrill Bernard Crohn in 1932.

Well, it wasn't exactly all his own work. Burry, as I like to think of him, was one of three authors of a paper entitled "Regional Ileitis: A new clinical entity". His two colleagues, Dr. Leon Ginzberg and Dr. Gordon D. Oppenheimer, missed out on ever-lasting fame by dint of alphabetical order. Which is a shame really; telling people I had Oppenheimer's Disease would have sounded so much better, conjuring up images of being at the cutting edge of science: "Yes, it all came from the NASA program along with Teflon and write-upside-down pens." I would have been a social magnet, something that is definitely not the case with Crohn's Disease, which sounds like an affliction suffered by mad old women who keep herds of stray cats. Still, things could have been worse; the authors could have merged their names, calling it Croginzenheimer's Ileitis, which would have sounded like some sort of mental illness.

Given that everlasting fame only devolves to the first named author of these team efforts, it is a surprise that more have not made use of the deed poll to change their names and leapfrog their way to the top. But then confusion would reign as we would only suffer from illnesses beginning with the letter "A", "Oh, you think I might have Aardvark's Disease? I thought Aaron's Malady was more likely, or perhaps Aasvogel's Syndrome." But there are signs it may be happening: a quick internet search tells me there are at least 337 illnesses beginning with the

letter “A”, three times the number of illnesses that begin with the letters W,X,Y and Z combined. Now you know why.

As I approached the frosted glass doors that marked the boundary of Ward 8, I had no idea that it would be the source of much pain, misery, distress, frustration, anger, tears and clenching of teeth (and that would just be from listening to Hospital Radio). I pushed through the swing doors and enquired as to the whereabouts of the head honcho, a Dr. Ray. Having been directed to his office, I was struck by his cadaverous features and a booming voice so deep that blue whales plumbng the icy depths of the Barents Sea would have followed his half of the conversation. With white coat, firm handshake and multiple framed certificates on the wall, here, I thought, was my savior.

However, things did not get off to a good start for either of us.

“I’m not sure why he sent you up right now,” rumbled the basso-profundo, which I more felt in my chest cavity than heard. A patient turning up out of the blue was clearly not a welcome sight. Doctors, I have discovered, do not cope well with spontaneity. They like to have complete control of proceedings. You seldom get the response you want when you spring surprises on them. Rather than employ the tactics of the leopard hunting gazelles on the Serengeti, you must think like the spider, coaxing your prey to where you want it, all the while giving it the impression that it, not you, is in charge.

Tip #3: Think Like a Spider

You should always pre-plan any encounter with a doctor. Know what you want from the appointment; have your facts rehearsed and at your fingertips; think how you will phrase things so that you still sound deferential. If you just turn up and start calling the shots, you will usually hit the brick wall of medical intransigence.

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Dr. Ray's vacillation somewhat deflated my euphoria, but his heart was not made of stone. Moved by my crestfallen expression, his hand, which had been poised to summon the heavy mob from the secretary's office, paused over the intercom button.

"Well you're here now. Let's have a look at the X-rays".



Dr. Ray, I presume?

I perhaps should have mentioned that I had made the trek to Ward 8 clutching a very large envelope that contained the photographic evidence which had led to my diagnosis. A couple of weeks earlier, I had

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been subjected to a test known as a barium meal. This test, in which I now consider myself something of an expert having endured it another nine times over the years, is deceptively benign-sounding.

It begins two days prior to the main event with the instruction that one has to cease eating and restrict the diet to clear fluids. This means no milk and being only able to consume things like cups of tea or, as a special treat, jelly. As anyone who has undergone this regimen will tell you, there is no hunger like that which hits you after 24 hours of such abstinence. I would have eagerly snatched food from my starving grandmother's mouth. But soon this primal urge to eat anything or anyone pales into insignificance as you enter the bowel-clearing phase which is essential in order for clear pictures to be taken of your insides.

I have read that the ancient Romans enjoyed nothing more than a good purgative, though I fail to see the attraction myself. Drinking gallons of a salty solution to induce at least a dozen frenzied dashes to the john might have passed as entertainment when the barbarians were at the gates, but it leaves a lot to be desired in the digital era. The only way to get through the ordeal of passing gallons of what seems like sulphuric acid is to imagine the delicious foods upon which one will gorge once the whole event is over.

But there is another sting in the tail. After the barium meal itself you completely lose your appetite: the much anticipated juicy steak turns to ashes in your mouth. This is because of the process itself. One is forced to consume in rapid order a couple of pints of what initially seems like a strawberry milkshake. In fact the illusion continues until the very point of consumption. The orderly whips up the mixture with an electric whisk; it has the uniquely artificial color of a strawberry milkshake; it even smells like one. But the first gulp comes as a shock: it has the consistency and texture of wet cement.

A compound of the metal barium – barium sulphate - is required to act as a contrasting agent in the bowels, which then will show up clearly

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when bombarded by X-rays. Fair enough; bowel is soft tissue so would otherwise blend into the background. Barium's qualifications for this task can be gleaned from the origins of the word itself, deriving from the Greek word *bary*, which means "heavy". But while its heaviness is a benefit in being able to stop the passage of X-rays, there is a downside for the patient: barium sulphate is really, really heavy. The gloop has to be consumed quickly and in its entirety so that you have a big, solid mass of sludge going through your system. Otherwise you have to undergo the whole rigmarole again.

The icing on the cake to a procedure that would have led to much back-patting in the new product development laboratories of the Spanish Inquisition is that you get an injection designed to speed the progress of the barium through the bowel, which would otherwise take a day or three, depending on your own personal digestive system settings. The result being that your digestive tract goes into overdrive with much internal grumbling and sloshing to add to your discomfort.

Your troubles continue immediately after the x-raying is over as the barium drink, now mysteriously shorn of its strawberry coloring, comes racing through. The final indignity is that once the initial rush of liquid barium has passed, its residue seems to hang around forever, coating your doings with a ghostly hue that imparts the buoyancy of divers' boots. No amount of flushing or vigorous toilet brush thrusting can shift the evidence past the u-bend until one is forced to don the rubber gloves and solve the problem manually.

So although the entire event takes upwards of a week from beginning the starvation phase to one's bowels returning to normal, the meat and potatoes of the exercise is spending a mere half hour lying on a flat and extremely hard table being bombarded by five years' worth of radiation. To get better pictures, the radiologist uses a variety of implements to manipulate your bowel loops into the photographic frame. The only benefit is that usually, if you twist your head around, you can

see what he is seeing on the screen. I must admit to finding that part fascinating; watching the graceful peristalsis of one's own bowels feels a bit like looking into one's soul.

Tip #4 – Get Smart

Although the X-ray monitor is set up for the convenience of the radiologists rather than for your optimal viewing, it is always a good idea to get as clear a look as you can. It's your body after all and knowledge gained now on what's going on inside can stand you in good stead when you're told the official results days or weeks later. However, don't pester the radiologists as they really do need to concentrate on what they're doing, but if they seem to be the chatty type, throw in the odd question about what you're seeing on the screen. If you're lucky, you will get a guided tour around your guts.

Back in Doctor Ray's office, it was the X-ray photographs, which he was putting up on his light-box, that contained all the evidence needed to confirm the presence of Crohn's Disease. He pointed out three different areas where the small bowel, normally a good inch in diameter, seemed to have shrunk to no more than a tenth of that. These areas, called strictures, were a classic Crohn's symptom. What the image showed was not that the bowel had shrunk, but that it was, in fact, badly inflamed. When tissue inflames it expands and, as the bowel is a tube, that expansion had reduced the diameter of the tube to next to nothing. This, he explained, accounted for most of my symptoms.

While I found this bit of the impromptu consultation interesting, I was somewhat less enthralled by what followed. In addition to the findings from the barium meal, which were new news, he pointed out a series of other symptoms I was sporting that added up to, he pro-

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claimed, a classic case of Crohn's Disease. Firstly, I was malnourished: 130 lbs on a 5' 8" frame is skinny, really skinny. Added to that, I was massively anemic, which he demonstrated by asking me to outstretch my palm, which was undeniably a uniform white, even in the creases. Even the least perceptive fortune teller in the carnival would have had her easiest palm reading ever with me: "You are going to be very, very ill and very, very soon."

I also had a plethora of other indicators, the most shocking to me being that my fingers were clubbed, as in rounded rather than ending in a bit of a point. I had honestly never thought about the shape of my fingertips, nor that they might be different to anyone else's. But apparently they were, and still are. This is obvious to me today when I attempt to use a BlackBerry, my stumpy fingers being unable to straddle fewer than three keys simultaneously, rendering my messages completely incomprehensible.

So the bottom line was that, in Dr. Ray's opinion, this all added up to a textbook case of Crohn's Disease. Which raised the question in my mind as to why, if it was so bleeding obvious, had diagnosis taken seven years from the onset of the first major symptom? It never takes that long on *House*, but then a TV show where no one gets diagnosed for the first seven seasons might not be a huge hit. I know it wasn't a huge hit with me.

Crossed Wires

“My illness is due to my doctor's insistence that I drink milk, a whitish fluid they force down helpless babies.”

– **W.C. Fields**

OF COURSE, the diagnosis was not the start of my medical odyssey. By that time I was a grizzled veteran of the system and had long since lost the innocent optimism with which we all approach our first encounter with a doctor, an optimism relentlessly created and nurtured by the most impressive PR operation the world has ever seen.

Throughout the last 50 years, we have all been subjected to a ceaseless barrage of good press for all things medical. And it continues today where every newspaper or magazine has weekly or even daily sections devoted to the expounding of a seemingly infinite number of medical breakthroughs. Yet the government can't build hospitals fast enough, so something doesn't add up.

But I went into the medical system as a firm believer, for two good reasons. Firstly, I had watched all the medical dramas and soaps of the 1960s and '70s, from Doctor Kildare to Marcus Welby M.D. via Dr. Quinn and Doogie Howser, where doctors were universally depicted as being omniscient. A few probing questions, a donning of the stethoscope and a tapping of the upper back as though searching for a stud behind drywall preceded the inevitably infallible pronouncement, all the while winking at the giggling nurses at the end of the bed.

The second reason I subscribed to Doctor Knows Best was that, when I was growing up, we had a cheerleader for doctors in our household. My mother spent her entire career in nursing, rising from being a ward nurse up to being the nursing training manager for our local health district, topped off with a couple of inventions of nurse training aids

patented in her name. With such an advocate for the medical profession in the house, it was natural that I should concur, even though my one major medical encounter during my formative years contained a clue that perhaps all was not quite as it seemed.

When I was four years old, I was suffering from a discharge from both ears. This is the kind of condition that causes differing reactions in the school playground: revulsion in the girls, contrasted by admiring gasps of amazement from the boys. My mother, who at that time was the nurse in the outpatients department of the Blackburn Royal Infirmary, sided firmly with her gender and saw it as something to be sorted out ASAP. Consequently, she immediately took me to see the ear, nose and throat consultant – there’s no point having a medical background in the family if you can’t jump the queue.

As he peered into the back of my mouth, using a miners’ lamp and a popsicle stick as implements, he breezily announced, “Well, you’ll be a lot better off without those”, which signaled the imminent demise of not just my adenoids – the most likely suspect – but my tonsils for good measure. Back then, you were lucky to survive any contact at all with the medical profession and emerge with your tonsils intact. Nowadays, the incidence of infants having their God-given tonsils forcibly removed has declined by 90%. Medical opinion seems to have caught up with common sense that they might be there for a reason.

In hindsight, what I should have said to the scalpel-happy hacker, despite running the risk of coming over as a somewhat precocious four-year-old, was, “I beg your pardon? Better off without those? Would you mind telling me why one of God, the Intelligent Designer or a Selfish Gene would have put tonsils in there if it was better for all concerned that you whip them out the first time I have an affliction that raises my status in my peer group?” Of course I said no such thing and merely noisily celebrated the fact that I would be living off ice cream for the next week, my medical faith still intact.

Tip #5: Speak Up at the Back!

When a doctor announces a course of action, usually in a tone that conveys 100% certainty, the lifetime's worth of pro-medical PR with which you have been bombarded impels you to say, "OK". Always resist that urge. Any response, no matter how feeble, that queries the course of action is always better as it will force the doctor to explain a little more of his reasoning. Most times it will make no difference, but on the odd occasion it will give you information that you can take away to check out for yourself.

And that was the sum of my medical experience until what would eventually turn out to be Crohn's Disease reared its flatulent head fourteen years later. Of course I contracted chicken pox, along with every other child in our village; but, somewhat mysteriously, I was spared the measles plague that cut a swathe through my social circle the next year. My elder brother Andrew succumbed, and, even though we shared a bedroom, I remained resolutely unblemished. No one could understand why I had been spared this pestilence. But, despite these common childhood ailments, the fact is that, for most who contract Crohn's Disease, or any other major, chronic condition, it will be the first time we are sucked into the medical machine.

So I was basically a healthy child, growing up in the little village of Tockholes, which is about three miles south of Blackburn in England. I had all the benefits of fresh air, fields and woods to play in, and built up my young muscles every summer helping the local farmer bring in the hay bales. Country pursuits such as drinking water from springs that sprang down-field from herds of cows who liberally filled the water-table with their poop seemed to do me no harm. No doubt due to a more than robust immune system, my school photographs

show me to be what I considered at the time rosy-cheeked. But, with the benefit of hindsight, I must confess to having been a touch chubby, despite my active lifestyle.

Having said that, my diet was not quite the same as everyone else's. Perhaps the biggest clue was that I did not like the fries that came with school lunches, whereas all my friends could have quite happily eaten nothing else. So great was my distaste for them that I would sometimes sell my lunch token to one of the older kids. It wasn't that I just didn't like fries, but if they were less than perfectly fresh, they turned to ashes in my mouth. In addition to my fries aversion, I had no time for vegetables, but this could still be considered fairly normal behavior for a teenager.

Less usual was an addiction I had had as long as I could remember, and had made no effort whatsoever to wean myself off: I just loved to sneak spoonfuls of granulated sugar when no one was looking. Even now, I cannot resist filching little sachets of sugar from restaurants. My idea of Nirvana is when there appears at the table a silver bowl containing sugar lumps, especially those irregularly-shaped, artisanal ones, which I consume as though in training to take on the part of Mr. Ed, the talking horse of the eponymous 1960s television show.

Here were the first two clues that Crohn's Disease was on my horizon, although they went unnoticed at the time. Apparently, Crohn's sufferers are statistically much more likely to eat more refined sugar and many fewer vegetables than average. No one yet knows if these are causes, symptoms or just irrelevant coincidences. It would have been harsh of me to be over-critical of the medical profession at this point for not having as yet come up with a diagnosis. After all, I hadn't told anyone about my food preferences – in fact, this is the first time I have ever confessed to selling my lunch tokens. Also, at that time in my life I wasn't feeling ill in the slightest.

Tip #6: Take an Interest

Without wishing to be an advocate of voluntary hypochondria, in hindsight I wish I had taken a bit more interest in the fact that my diet was different to those of every other single person I knew, and that I had told my mother about it. It's easy to get labeled a hypochondriac by busy doctors, but it's also easy to keep to yourself pertinent information because you either don't realize it might be significant or, even worse, because "you don't want to bother the doctor." If it's not normal, tell someone.

The first real clue that did register on my antennae happened during my first term away at university. At the age of 18, after completing High School, I had gone to the University of Manchester to study math and psychology. But the result was that, being so close to home - only twenty-five miles away - I returned to the nest most weekends to fulfill two objectives: get my clothes washing done and meet up with my girlfriend.

After a few of these trips, I did notice that those who knew me well were passing remarks along the lines that I must not be rising to the challenge of cooking my own meals, having observed that I was not quite as chubby-cheeked as when I had first gone away. As a first-year student, I was accommodated in a university hall of residence where one was expected to cook for oneself. There were hundreds of students in my particular hall with the arrangement of twelve single-sex bedrooms to a "dorm", each sharing a kitchen and bathroom.

I bitterly resented the accusation that I was failing to feed myself. I was having cereal for breakfast while many of my kitchen-mates would just stagger bleary-eyed to the first lecture straight from having rolled out of bed. I usually had a cooked lunch at the university refectory, and was dishing up what I considered to be some quite wholesome and tasty

dinners: steak, eggs over easy and piles of instant creamed potato being my favorite.

In fact, it was no mean achievement to be cooking any sort of meal at all in the circumstances. Having twelve young men share one four-ring electric oven would be difficult enough circumstances in which to shine gastronomically, but there were further challenges to contend with. Sharing one small fridge meant that much confusion arose as to who owned what in there, with the result that more often than not, one of your key ingredients would have gone AWOL at the critical moment. This shrinkage also extended to the dry and tinned ingredients. We each had a small locker, all secured by cheap padlocks, in which we stored our tins of beans and so on. However, we had in our midst a prolific and unrepentant thief who thought it perfectly reasonable to address his own shortages by picking a few locks until he found what he was after.

Even if you could keep your ingredients secure, the next challenge was in gaining adequate ring-time. Twelve hungry men, each cooking meals with two or three components, would put enormous strain on our kitchen's allocation of hot-rings and pots and pans. This would get far, far worse when our kitchen's one Indian student, Raj, would invite what seemed like an entire caste of his chums round for a made-from-scratch curry. Not only did this tie up all four rings for hours on end, but the resulting caked-on curry that had splashed from the various bubbling cauldrons made the hob virtually unusable until someone chipped it off at the end of the week by which time the enamel had usually completely disappeared from sight.

But I was overcoming all these challenges. However, not only was I getting no credit for it, I was being roundly tut-tutted every weekend by the girlfriend, her mother and, of course, my mother, who all probably thought I was something of a mommy's-boy with no survival skills whatsoever. Each would try to outdo the other two in an arms race to fatten me back up again, but in vain. Although no one knew it at the

time, I was gradually losing weight because Crohn's Disease was reducing the effectiveness of my digestive tract. Indeed, the nearest to spotting it was a fellow kitchen user who could not help noticing that I was stuffing my face with mountains of fatten-you-ups brought from home, yet was clearly not gaining any weight. He would regularly ask me how my pet tape-worm was doing.

The false accusation concerning my ability to feed myself was my first encounter with what is usually the first major barrier you face to successfully being ill. When you are ill but are not yet aware of the fact, it seems that the default interpretation for an unclear set of symptoms is that you're not looking after yourself and therefore you are the cause of whatever symptoms ail you.

Tip #7 – It's Not Your Fault

There will be many instances where symptoms are airily dismissed or your diligence in sticking to a course of treatment is questioned. Do not bow to public opinion that you are the problem if you know that you are blameless— keep your self-belief.

Although this early sign had perhaps been easy to fob off, the next one was to be a humdinger that was impossible to ignore, or blame me for, and would begin my thirty-year close encounter with doctors.

Now it is at this point in the book that I should perhaps run a warning advising readers that this story, through the necessity of describing the many wonderful symptoms of Crohn's Disease, is not something you might want to be reading at the dinner table. As it is an illness that primarily affects the digestive tract, it should come as no surprise that many (though not all) of the symptoms in some way, shape or form, involve bodily functions and parts not normally brought up in conversation while taking tea with the vicar. So don't complain that you have not been warned.

The event in question occurred as I was contemplating the sports pages while clearing the traffic on the Hershey Highway. Yes, I was taking a dump. All seemed normal until, as I was finishing up and glanced downwards as my hand reached for the flush, I was stunned to see that the tissue in the bowl was completely bright red.

It seemed like every neuron in my body fired off simultaneously. I had never, in my entire life, had cause to be so disturbed by what confronted me in the bowl at the moment of flushing. If it had been just a smear, I'm sure I would have rationalized it as just a case of being a tad over-vigorous in the cleansing department, but there was no explaining this one away. It looked like a flimsy bandage just removed from a fresh shotgun wound.

Thinking that I was about to suffer the ignominious fate of bleeding to death while locked in with the Great White Throne, I dropped my trousers faster than a bishop in a brothel, grabbed handfuls of bathroom tissue and went to stem the flood. Only there was no flood. Surely, I thought, gaping wounds don't clot in a matter of seconds, but apparently mine had. However, the welcome relief of not having to deal with the unimaginable logistics of summoning help for a hemorrhaging rectum did little to mitigate the initial shock.

The next weekend I described this electrifying event to my mother, who then immediately booked me in to the family doctor for him "to have a look-see." A few days later, I assumed what would become, over the next thirty-two years, a wearisomely familiar position on the doctor's examining table as the first of many medical digits would attempt diagnosis by Braille. Lo and behold, the rectal groping did in fact discover the presence of some small hemorrhoids, so I was duly booked in to have an operation for their removal.

While I was delighted that something was being done, of course this would turn out to be a red herring. I had not been misdiagnosed as such – I did have a couple of hemorrhoids – but the problem was that, of

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Crohn's Disease and hemorrhoids, the latter was assumed to account for a symptom that was in fact caused by the former.

There were two factors at play that combined to cause this misattribution. Firstly, I had only described a condensed version of my toilet trauma: motion, blood. I neglected to describe the fact that plenty of blood was followed almost immediately by hardly any blood at all. If it had been the result of piles, and quite small ones apparently, the initial quantity would have been less and the tailing off not so sudden. The reality was that I had not bled after passing a motion, but that I had passed a rather large and discrete quantity of blood, which is something entirely different. So I had not actually described an accurate version of events.

This was compounded by the second factor, which is what I consider to be the single most misleading bit of training given to doctors. To help allegedly very bright medical students grasp the self-evident fact that common illnesses are more common than rare ones, they have had drummed into them the phrase, "When you hear hoof-beats, think horses not zebras." But, in my experience, this invariably leads to the default assumption that all hoof-beats are caused by horses. In my case, because piles were present, they must be the cause of the bleeding.

The first question the doctor asked was designed solely to validate the initial hoof-beats of hemorrhoids, and was a very difficult question to answer anyway. "Did I strain?" Well, I don't know really. With intimate matters such as these, one has no other reference points as to what constitutes normal. How do you know what goes on in other people's boudoirs and water-closets? One man's straining is another man's gentle coaxing. So I umm'ed and ahh'ed to this question, which served only to convince the medic that I must have been having an eyeball-popping, almost heart-attack inducing battle of wills with the previous day's helping of curry-flavored instant potato. This had clearly, in the doctor's eyes, ruptured the piles – so problem solved. Now, of

course, it is clear that in fact the piles were coincidental and whatever had occurred had been further upstream, where demons lurk.

The reason I so dislike the hoof-beats phrase is that, by its brevity and clarity, it negates the importance of context. I do agree that, on average, the hearing of hoof-beats would indicate the presence of galloping horses in the vicinity.



First past the post

But context and detail are everything. “Where were you when you heard hoof-beats?” is a question that could completely change the answer. The response, “Louisville racecourse on Kentucky Derby

Day” would indeed strongly suggest the presence of horses. If, however, the answer was, “On the sweeping, majestic plains of the Serengeti”, zebras or perhaps wildebeest would be worth a bet. See what I mean?

In order to be correctly diagnosed and avoid being trampled by hoof-beats, the small details are really important. Most doctors, in my experience, do not probe much beyond your own description of events, so, if that is incomplete, they just hear the first hoof-beats that come along. They will then ask you a question aimed at confirming the most likely cause, but it could well be a question you are not able to accurately answer.

Tip #8 – Observe, Record, Describe

When something scary happens, like my bleeding, firstly, do not panic. As soon as you can, write down everything you can remember about the event and keep any evidence that is keepable. Then, when you see a doctor, read your notes out in full and bring along a spare copy to hand over. If you feel a significant point, or indeed any point, is being overlooked – challenge him on it. He won't like it, but a bit of an atmosphere in the consulting room is a lot better than going another seven years undiagnosed, which is what happened to me.

The discovery of piles resulted in my first hospital procedure since the premature termination of my tonsils, only this time there was not the prospect of an ice-cream diet to look forward to. The reward in this case was to be several days sitting on an inflatable ring, which still might have been appealing to a four-year-old, but at eighteen and with university lectures to attend alongside two hundred of my peers, I was less than enthused.

Crossed wires



Piling on the embarrassment

Carry On Up The Khyber

“World’s got two kinds of folks: them’s that got piles and them that’s gonna git ’em”

– **Mrs. Manson in ‘The Ladykillers’, 2004**

GOING INTO A HOSPITAL as a young adult is a very different experience to doing so as a small child, where a gaily decorated children’s ward and the opportunity to make new, albeit temporary, friends make up for the trauma of the unknown. As a grown-up, you are much more aware of the depersonalizing and potentially embarrassing nature of the whole process.

The first stage of the prolonged humiliation is when you are sent to a spartan changing cubicle clutching a brace of hospital gowns. As you unfold these heavily starched, yet worryingly stained garments, the instructions to put this one on at the front and that one at the back seem to make little sense, as they appear to be identical. What if they are subtly different and you get them the wrong way round? Of course, no patient ever comes out from the cubicle to seek clarification. You are on your own now. A fact that becomes more apparent when you try to fasten the ties behind your back as they seem to develop a life of their own, playfully eluding your blind grasps.

There is little in life to match the feeling of vulnerability as you gingerly step out of your changing cubicle, wearing only two voluminous yet still flimsy gowns and a pair of disposable paper slippers. The initial worry as to whether or not you tied the right bits of string together pales into insignificance as you enter the public domain feeling more naked than you have ever done before.

The first thing you notice is that it is quite chilly, especially as, most likely, you are not used to cool air wafting freely in your nether regions.

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Then you are immediately propelled into the presence of other, equally discomforted people wearing exactly the same outfit. As with any visit to a hospital, plenty of waiting around is the order of the day. Of course, wearing next to nothing in the presence of complete strangers dampens down your desire to be sociable, so this initial waiting stage is inevitably conducted in a monastic silence and completely excludes even a glimpse of eye contact.

So, once again, any reading material whatsoever assumes a profound and deep level of interest as you pretend to be engrossed in an eight-year-old, extremely dog-eared Reader's Digest. You ignore the fact that half the pages are missing and the other half fall onto the floor with regularity.



Relaxing in the waiting area

Your equally uncommunicative fellow travelers are picked off one by one as their names are called out from a sheet, and you soon begin to doubt that your name will ever be called at all. Have they forgotten you? Are you in the right waiting area, or even the right hospital? Again, no one ever lets his doubts turn into action as the uncalled sit there mute and forlorn.

You are also acutely aware that, due to the gown arrangement, your baby maker could be in full view of the people sat opposite, which prompts you to adopt the most convoluted seating position to exclude any possibility of exposure. One moment of inattention could result in you unthinkingly adopting the habitual male position of maximum angle between the legs or, even worse, crossing your legs. So the need for complete focus on the seating position means that you have no chance whatsoever of taking in a word on the page in front of you, or even of spotting that the pages you have open were reinserted upside down by a previous reader.

Finally, you are called through. But it proves to be the usual false dawn as you go round a corner only to see that your relatively cozy waiting area has been replaced by a handful of hard-backed chairs in a corridor. I'm sure Walt Disney learned his techniques of how to disguise the length of the wait from a past hospital visit; although he improved on the science with the idea that being entertained by Mickey Mouse enhances the passage of time better than staring at lime-green walls.

Tip #9: Take Something to Read

I have never once regretted taking something to read with me on a hospital visit. These places seem to operate in a parallel universe where time moves at one-tenth the speed it does outside. I sometimes buy small, inexpensive paperback editions of the classics just for this purpose. Sherlock Holmes, Dracula, Dr. Jekyll and Mr. Hyde (not sure about that one), Treasure Is-

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land have all earned their cover price in keeping my mind off things while waiting around in hospitals.

Sitting in the corridor, you then experience another prolonged and unexplained wait, but this time without a randomly ordered Reader's Digest to capture your attention. You might be given a form to fill in or you may just sit there with only your potential groin visibility to keep you occupied. It is at this stage that worries creep in, no matter how outlandish. What if it goes wrong? How long will you be under the anesthetic? Will it be the Nitrous Oxide, last experienced in a nightmarish visit to the dentist's?

While the initial waiting area was mostly nurse-free, you are now in their territory and they are buzzing around like worker bees. And it is at this point you first experience every man's medical nightmare: the fear of the inappropriate and unjustifiable erection.

Of course, it makes no sense in the cold light of day; you cannot imagine a less erotic setting or occasion, which makes the fear ten times worse because there would be simply no way to explain it away. It is not that one thinks it likely that man's best friend will randomly spring into life; it is the certainty of the absolute humiliation that would follow should the unthinkable happen. There would be no hiding it. No number of gyrations could disguise the tent-like structure that the gowns would surely adopt. One might as well set off the fire alarm for the attention that would inevitably follow.

Alas, I have no advice to offer on dealing with this problem. In fact, I have found that the fear only worsens as you get older. At the age of 18, there is at least a shred of justification as the one-eyed beast does have a mind of its own. But at 50, I would just be a dirty old man. Even though it has never happened to me, the fear remains as gripping as it ever did. As the equipment ages and the chances of a random stiffy fade, the stakes get higher because the humiliation would be even

deeper. I don't know what women worry about at this stage, perhaps they sit there thinking, "Oh my God! Is that dirty old man just pretending to read that upside down Reader's Digest while trying to look up my gowns? And I hope that fold in his gown isn't an ERECTION!!!!"

Or maybe it's just me that has erection fear. After all, I have never discussed this issue with a fellow patient. Perhaps I was scarred by the fact that, as I waited in the corridor for the next stage of the pre-pile removal process, the nurse who approached me calling my name was someone I vaguely knew. She had been a classmate of my cousin, and I had briefly met and chatted to her at some school disco or other. Plus, she was nice-looking – in fact, a real hottie.

Uuuurrgh!!!! The potential embarrassment stakes had now shot into the stratosphere. Firstly, I probably had past form in having an erection while talking to this delightful girl. But much worse, not only would I have to face humiliation in some corridor of Blackburn Royal Infirmary, but that same humiliation could be broadcast to a social circle – my cousin's pals – who I considered to be my primary source of potential girlfriends should my current arrangements be terminated. I briefly considered if I would be protected by some kind of nurse-patient confidentiality clause, but rejected that as unlikely. So, with a complete and utter focus on completing difficult mental arithmetic sums, I followed her into the next stage of the process, enraged at myself for not being able to look away from her sashaying, pert-looking tushy.

Tip #10: Don't Ogle the Medical Staff

No good will come of it. Firstly, if you are male, why increase the risks of your own humiliating version of Barnum & Bailey's circumstent, and secondly, none of us look our best wearing institutional gowns so you will only be viewed as being sad and pathetic. If you forgot your book, close your eyes and go to your happy place (not THAT happy place, obviously).

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Once I got into the inner sanctum, events sped up considerably. Before I could take in my surroundings, I was on a gurney with a drip in my arm. Then a reassuringly grey-haired anesthetist loomed over me, told me to count to ten in my head, and then I plunged into oblivion. I have tried many times to get to ten, but always failed. I felt a cold sensation in my arm as the anesthetic was pumped into my vein, then I was momentarily aware of a creeping wooziness before all was black.

Coming round from the anesthetic, as I became aware that I was in a bed in a room, who should be there but my nurse acquaintance? She brightly informed me that the procedure had gone well; two small hemorrhoids had been located and zapped, and that all looked well. She then slipped from nurse mode into acquaintance mode and blushing informed me that, as she was wheeling me from the procedure room to where I now lay, my gowns had been bunched around my armpits until she had protected my modesty via a quick sartorial adjustment. She then admitted to being sorely tempted to tie a little ribbon around Charlie as a nice waking-up present for me, this apparently being a popular gag in the nursing sorority. I thanked her for sparing me this final humiliation that would no doubt have been embarrassingly broadcast to my girlfriend pool during some drunken binge.

Later that day, I was given my release papers and off I went, confident of not seeing the inside of a hospital for a lifetime. After the requisite couple of days sat on the rubber ring, all seemed well. In the following weeks, I had no more bouts of bloodletting and it seemed like the problem had been solved. Assuming that piles had been the problem, and no doubt caused by constipation, my girlfriend took it upon herself to send me off to Manchester on Sunday nights with a cake made, from what I could tell, entirely of All-Bran. The after-effects were as you would imagine, but in the interests of fending off any more hemorrhoid Hammer Horror moments in the lavatory, I meekly complied.

But the underlying problem hadn't been solved. My addiction to sugar lumps and antipathy towards vegetables and less than perfect chips continued unabated as mute evidence that Crohn's Disease was still there, hidden from medical attention. More clues were to appear and fail to trigger a diagnosis. The next sign was a tendency towards mouth ulcers. This again is associated with Crohn's but I assumed was a more tangible sign that perhaps my diet still left a bit to be desired, so I failed to pass on the information.

The rest of my university years passed uneventfully in medical terms, which now makes me think that the illness must have spontaneously gone into remission. This again is a feature of Crohn's Disease that presents a challenge to its diagnosis. It comes and goes completely unpredictably. Actually, it would be more accurate to say that the symptoms come and go; the disease itself never goes away.

Medical science, despite its many advances and its unceasing PR campaign, to me falls at the first hurdle with its inability to explain the feature of remission. I have not once heard a good explanation for why symptoms can disappear for months or even years, only to reappear later. We would not accept this apparent lack of understanding of the basic mechanics of a problem from any other profession. Would you trust a plumber who cannot explain why one day your tap drips profusely but then is perfect for a week before recommencing dripping again? Or an electrician who cannot explain why some days your house has power and other days not? But by giving this huge gap in knowledge a name – remission – doctors are able to maintain the impression of actually knowing what is going on.

Always get straight in your head in the most basic terms what is actually happening to you. Every medical event, especially surgery, is much easier to deal with once you have stripped away the gobbledygook because you can actually relate to what is going on. For example, a common surgery for Crohn's is to remove an affected part of the small

bowel and then join up the ends of what's left. This is no different in principle to how a plumber fixes a burst pipe, yet surgeons refer to this most basic concept as a resection and anastomosis. It's as though they don't want us to know just how basic most surgery actually is.

Tip #11: Learn the Language

Every time you hear a medical term you do not understand, make a note of it and go and look it up. Also, when you are in with a doctor, do not hesitate to seek clarification by repeating back to her what she has just said with the rider, 'does that mean....', filling in the blank with your own understanding, but in plain English.

So, while in remission, my life returned to the normality of never thinking about illness, symptoms, doctors or hospitals. After graduating in 1979, I secured a job with Cadbury Bros., the chocolate firm, based at their centre of operations in Birmingham. My degree in Math and Psychology made, in my view, the ideal preparation for a career in market research, which was the position I had applied for in every company I could find that was looking to recruit graduates in that field. As luck would have it, towards the end of the recruitment process, my best opportunities had come with final interviews at Cadbury and Mars, and being held on reserve for a final interview at Rowntree. So it seemed that chocolate was going to be my calling.

Joining Cadbury would be one of the pivotal moments of my life. I would spend 24 years working for them; meet my future wife on my first day in the office, and benefit enormously from their enlightened and humane approach to helping employees cope with major illness. So, in September 1979 I relocated to Birmingham to begin my career.

Although I was immersed in getting to grips with my new job during the week, at weekends I dutifully traipsed back up to Blackburn to

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feed my decreasingly torrid love affair with my long-time girlfriend. It was during the last reel of this faltering romantic liaison that the Crohn's would awaken from its slumber and hit me with its next punch. By this time I had spent my hard-earned early pay slips on a battered old car, so was now driving up and down the highway. At the tail-end of a normal weekend, I would have my evening meal at my girlfriend's house then set off on the two-hour drive to Birmingham.

Somewhat mysteriously to me, this drive would be punctuated at some point by an agonizing stomach ache that would come from nowhere, last for around a minute and then disappear. And when I say stomach ache, this was not the gentle rumblings of overindulgence, but a doubling-up, sweaty forehead, breathless kind of pain – not something that can be taken easily in one's stride while doing 85mph in the fast lane.

I had no idea what could be the cause of this agony. By then, the All-Bran cakes had long since been consigned to history as our relationship had become increasingly perfunctory, so I couldn't blame those. It was a complete mystery. So, once again, I passed it off as "one of those things" and didn't even mention it to my mother, let alone go to the trouble of finding a family doctor in Birmingham. It merely took its place alongside the sugar bingeing, vegetable avoidance, and grimacing as a sharp corner of a potato chip speared into the by now ubiquitous mouth ulcer, as unexplained aspects of my life.

I would finally be prompted into action one day in spring 1981. I had by then moved on from my first job at Cadbury in market research, and had taken a position in the marketing department as Assistant Brand Manager. One day, a new person had joined the Cadbury team at one of our advertising agencies and, as part of his education, had come to the factory for a tour on which I and my boss would accompany him, passing along various insights and facts as the tour progressed.

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I was feeling absolutely fine until, it seemed, in an instant I was gripped by a stomach pain that dwarfed the highway variety. I could barely speak or walk, but gamely soldiered on, not wanting to disrupt this tour that had taken forever to arrange and for which the guy had come all the way from London. I had never felt time pass as slowly as it did then. The Cadbury factory site is colossal, so a tour in those days was a three-hour event. This was easily the longest three hours of my life to date. The pain, far from passing after a minute or so, would ebb and flow, each time coming back even more intensely. It was akin to enduring a very difficult childbirth while attempting to conceal the fact that it was even taking place.

Eventually I was able to deposit the visitor at the front door and tell my boss that I was going to have to go home. He expressed no surprise at all, saying that he thought I had looked dreadful on the tour, but had put it down to perhaps me having been on an absolute bender the night before. Having spent the evening quietly watching *The Rockford Files*, this seemed an unlikely explanation. So I dragged myself home and then, much to my surprise, immediately fell into a deep sleep despite the pain. Even more to my surprise, I awoke around an hour later feeling perfectly fine. Having by now found myself a family doctor, I booked myself in and was there a couple of days later, explaining this whole strange episode.

The doctor quizzed me on the nature of this pain, asking its location and if it was a sharp pain, a colicky pain and so on. Now one thing that all people who are chronically sick say is that it's a good thing you don't remember pain. However, in this case, it was a very bad thing. I couldn't recall the exact site; it seemed to fill my entire abdominal cavity, although I did seem to recall that it was even more intense in the upper part. Nor could I be of any help in describing its nature. How are you supposed to know what is a colicky pain and what isn't? More medical mumbo-jumbo and hoof-beat searching.

Doctors should know that pain is very difficult to describe, and should have developed a vocabulary that we patients can understand and use to describe it much more clearly. But they haven't. So he did the most logical thing for someone complaining of an unexplained bout of stomach ache and booked me in for my next hospital visit to have my stomach examined visually.

What had actually happened, although I only post-rationalized this after my eventual diagnosis two years later, was that I had been stricken by the next major manifestation of my Crohn's Disease. As I previously explained, an inflamed bowel lessens in diameter quite dramatically; so much so that improperly chewed food can get stuck. The bowel senses the blockage and attempts to clear it through spasms, and it is these that cause the pain.

On my highway trips, I had clearly been rushing my girlfriend's mother's meal and not chewing it properly, with the resulting pain a few hours later as I was Birmingham-bound. This time, though, I must have swallowed a really big piece of food – apple would be my best guess much later as this sequence of events was finally explained – and the spasms had not been able to clear it until the stomach acids and bile had gradually broken it down to the point where it must have finally disintegrated as I slept.

But none of this was apparent from my vague answers to the doctor's perfunctory tunnel-vision questions, so I unquestioningly complied with the prescribed action which was to undergo a process of internal eyeballing of the stomach known as an endoscopy, where a fiber-optic tube is pushed down your throat while you are under a mild sedation. In my case, I was out like a light and remember nothing of the event itself. But the aftermath was to trump the piles incident in terms of being another spurious diagnosis.

For a while, I had been in the habit of mixing myself a gin and tonic in the evening which may have contributed to a slight bout of acid

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reflux. The endoscopy had shown some mild irritation of my esophagus near the junction with my stomach. This was then automatically assumed to be the cause of the recurrent Sunday pain and the crippling episode in the factory. So I was told to avoid all alcohol for a while, stock up on the antacids, and be on my way.

Once again, the most common explanation was being sought, with questions thereafter only aimed at bolstering the initial diagnosis. Cowed by the white coats and general gravitas of the doctors passing such pronouncements, I meekly went along with their blithe assertions that a nightly gin and tonic could cause regular excruciating pain and the occasional three hours of almost unbearable agony. If this was the case, millions of people should have been similarly afflicted; national sales of gin would have gone through the floor, and the makers of Gaviscon and Tums become bigger than Exxon Mobil.

Tip #12: The Common Sense Test

Do not accept a diagnosis if it doesn't feel right to you or doesn't pass the common sense test. Many doctors latch onto a quick-and-easy diagnosis like a drowning man does a life belt. It's not as though we haven't been warned; this scenario is played out in every episode of House where people just shout out diagnoses off the top of their heads and the poor patient is taken to death's door by a succession of incorrect treatments. If challenging the medic gets you nowhere, ask to be referred elsewhere for a second opinion.

Alas, I was to be a victim of the superficial diagnosis for a third time as I returned a few months later to the family doctor complaining of yet more excruciating stomach pains. "What do you do for a living?" enquired the medic. My reply of "marketing" gave him a free hit.

“Stressful is it?” Here was another of those leading questions where you have no reference points by which to calibrate your answer. “Well, I don’t know really. Compared to being a postman or a librarian, I suppose it might be.” And you can fill in the rest yourself. I got a lecture on the alleged benefits of reducing the stress in my life. Here was another incorrect diagnosis made on the flimsiest of evidence that delayed events even further.

Tip #13: Get Stressed about Stress

When you find yourself on the receiving end of a doctoral lecture on stress reduction in place of some real treatment or further investigation, it should immediately move you into red alert status. Quiz the medic hard on why he is doing this. Does it mean he has ruled out anything tangible? On what basis? Don’t be shy, make him earn his corn in this situation; it can add months or years to your being eventually treated if you fall for the placebo treatment trick.

My eventual diagnosis that led me to Ward 8 would depend, not on a long-awaited flash of medical insight, but on happenstance. Two completely separate events would combine to finally make a diagnosis possible: I would become so ill that the fact I was actually ill finally became obvious even to the most hopeless student to scrape through medical school, and, through sheer chance, I would finally be seeing people with a modicum of expertise in Crohn’s.