THE STRUGGLE TO BE MORTAL
By Patrick Tobin
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When I tell people I'm a recovered hypochondriac, they laugh as if it's the hilarious punchline to a joke I haven't yet told. For most people hypochondria *is* a joke. Hypochondriacs are fakers – drama queens looking for attention or malingerers looking for sympathy. Think of Woody Allen in a frenzy of angst over an imagined brain tumor, or the sitcom character who always has a sore back when there's work to be done. That's America's idea of hypochondria. Funny. Not to be taken seriously.

It's not always been this way. In Carla Cantor's book *Phantom Illness* she writes that hypochondria originated with Hippocrates, who used a transliteration of *hypo* (under) and *chondros* (cartilage of the ribs) to describe disorders affecting the soft tissues beneath the rib cage – particularly those organs associated with moods. She also writes that hypochondria was a popular complaint in Elizabethan England and not a shameful condition. It wasn't until Freud's work with hysteria that medicine began to erect a great divide between mind and body, when the phrase *all in your head* became a stigma. Psychosomatic illness became equated with weakness, a character flaw.

In other words, a joke.

Hypochondria is certainly no joking matter: it's a misunderstood and costly epidemic. According to a recent estimate in Time magazine, hypochondriacs cost the U.S. health care system up to $20 billion annually in unnecessary testing and treatment. While this number is staggering, it is perhaps not surprising given the results of a 1996

Health magazine survey of doctors, a third of whom felt that at least half of their patients were experiencing psychosomatic symptoms.

Then there's the emotional and physical cost to patients experiencing hypochondria. Hypochondriacs are *not* fakers. Their symptoms are frighteningly real to them and can cause genuine suffering, distress which intensifies as doctors fail to find a concrete diagnosis. Spiraling medical bills, social withdrawal and isolation, and absenteeism at work create enormous stress for hypochondriacs and everyone in their lives: family, friends, colleagues, employers.

I know, because I've been there.

I started having trouble breathing two years ago and was diagnosed with asthma. Despite medication, my breathing problems didn't improve. I have to confess: I was still smoking, so I attributed the lack of improvement to the cigarettes.

Around this time, I moved to Sweden. It was an exciting change for me, finding a new apartment, learning a new culture and language. The only setback was that my breathing problems worsened – it felt like I could never get a full breath.

Because I'd smoked for over ten years, I began to wonder if I might have something more serious than asthma. Reputable web sites offered up a smorgasbord of diseases from which to choose. Late at night I would have difficulty breathing and imagine I had emphysema. Or cancer. Images of blackened lungs and oxygen tanks danced in my head.

I wasn't covered under the Swedish healthcare system, so I had to use a private same-day clinic in Stockholm that charged a $120 just to walk in the door. One time I was told I had a chest infection and was given a prescription for penicillin. The antibiotic didn't help. Another time I was told by a humorless Russian doctor that she couldn't find anything wrong with me.

"Are you perhaps having much stress in your life?" she asked.

I said yes. My father was facing serious legal trouble back in the States and he was relying on me for financial and emotional support – his world was falling apart. The doctor cracked what was, in hindsight, a prophetic smile: of course, *this* is the problem. As I left the examining room to pay my $120, I thought the problem was her incompetence in not ordering a lung biopsy immediately.

The silver lining? I was so obsessed with my breathing that I finally stopped smoking for good, after years of failed attempts to break the nicotine habit. I thought my problems would eventually improve once I quit, but they didn't. I suffered through the next few months, waiting for the asthma medication to restore my smoke-free aveoli to full function, waiting to be able to take a full breath again.

Instead, I started getting winded climbing the stairs to my apartment. I had been swimming laps three or four times a week, but I stopped going to the pool – what if I was swimming and I couldn't breathe? My Swedish was so bad I could just imagine trying to communicate with the tall blond lifeguard. *Do – you – speak – English*? I would spit out, right before collapsing.

It wasn't long before I was sleeping with the cordless phone and an Albuterol inhaler next to me. On the handle of the phone I wrote 1-1-2, Sweden's version of 911. I knew that if I stopped breathing I probably wouldn't be able to remember the number. Despite my ritualistic precautions, I was never able to get a full night's sleep.

I was convinced something sinister was happening inside my lungs. The anxiety increased until I was unable to focus on my work or my relationships. Finally a friend referred me to a doctor who told me that because my asthma medication was obviously not working, it was clear something else was going on. Something more serious. He said I should return to the States as soon as possible, in case the symptoms worsened and I became unable to travel.

In case I became unable to travel.

It was as if he'd just given me six weeks to live. I booked the next flight back to the States. I didn't care that the ticket was nearly fifteen hundred dollars. Fourteen day advance purchase? I'll be dead by then, I thought.

Back home I made dozens of appointments. I had x-rays taken and lots of blood drawn. I had CAT scans and MRIs. I did pulmonary tests until I was literally blue in the face.

The results? No lung cancer. No emphysema. Not even chronic bronchitis. In fact, an allergist told me that I probably didn't have asthma at all. He thought that I was simply hyperventilating. I thought that he was out of his mind, especially when he recommended I carry around a paper bag to breathe into whenever I started hyperventilating.

It was then, when no one was able to come up with a diagnosis, that I found Dr. Ingvard Wilhelmsen's web site. I took the Whitely Index test on Dr. Wilhelmsen's site – it's one of the tools used to diagnose hypochondria. When I finished taking the test I realized there was a serious problem: I'd scored 51 out of a maximum of 55. I sent Dr. Wilhelmsen an email asking if I could meet with him when I returned to Scandinavia. He wrote back yes, and eventually we set a date.

Dr. Wilhelmsen is a licensed psychiatrist and a gastroenterologist who teaches and practices at the University hospital in Bergen, Norway. In 1996 he established a clinic at the hospital for patients with hypochondria. His interest in the disorder grew out of ulcer research he did in the early 90s, before it was confirmed that ulcers are not caused by stress. Dr. Wilhelmsen had hypothesized that ulcer patients might benefit from cognitive therapy – the branch of psychology that deals with your thought processes and

how they can be examined and changed. His hypothesis turned out to be quite untrue, except for the patients who really weren't suffering from ulcers: the hypochondriacs.

Given the emotional turmoil I'd been enduring, Bergen turned out to be a perfect tonic. It's unbelievably beautiful – a quaint harbor surrounded by steep hills, multi-colored houses and cobblestone streets. It seems hard to believe that anyone here suffers from hypochondria, let alone anxiety.

Dr. Wilhelmsen is charming and low-key. He apologized right away that he would have to interrupt our interview in a little while, because his mother was on her way to the hospital – she'd suffered a mild stroke earlier that morning and called him to see what she should do. I thought to myself, this is why families all over the world push to have their children become doctors.

Dr. Wilhelmsen. talks about hypochondriacs having a "project" in their lives, and the project is this: to not die. Not dying would seem to be a normal goal for anyone, since no one actually *wants* to die, and Dr. Wilhelmsen is quick to point out that everyone experiences some degree of health anxiety at different points in life. He used his mother as an example of normal health anxiety. She'd woken up in the morning with no feeling in her right hand. This would be a concern to anyone, let alone someone who is elderly, and it was entirely appropriate for her to seek out immediate medical care.

For the hypochondriac, however, every symptom, great or small, becomes worrisome because the "project" is really an obsessive quest for immortality. "My patients spend all of their energy on not dying, instead of living," Dr. Wilhelmsen says. "Because people's actions and feelings are understandable when we know their attitudes,

the [hypochondriac's] searching of the body for signs of disease is *very* understandable if you *can't* die."

The hypochondriac begins evaluating the body and its symptoms with, as Dr. Wilhelmsen. puts it,"increased severity." In my case I began to monitor my breathing all the time. (Focusing on any of your autonomic bodily functions, like breathing or swallowing, nearly always throws them off – try it some time.) I would then become anxious when my breathing seemed *strange*. Because almost every symptom, from headache to gastrointestinal distress, can be caused by anxiety (like the anxiety caused by *strange* breathing), my symptoms became a never-ending, self-fulfilling cycle.

The problem is that it never occurs to the hypochondriac that the symptoms are anything other than an indication of serious illness. The medical care system is partly to blame for this. "It's very common for a doctor to take symptoms at face value," Dr. Wilhelmsen says. He adds that it's seldom that a doctor sits down with patients and asks how they evaluate and interpret their symptoms. "That's a different thing, but that's the *important* thing, because symptoms can change, but the basic attitudes [underlying hypochondria] are usually stable, and they are the problem."

These attitudes create the framework for hypochondria. "If your project is 'I must live' then you can really lose your mind," says Dr. Wilhelmsen. "We don't know when we're going to die, how we're going to die – it's *impossible*. Every time someone tries to control the uncontrollable [he or she] is doomed to run into trouble."

The "project" can be incited by a myriad of events. For many women the onset of hypochondria seems to coincide with the birth of children – a new mother begins to

wonder what would happen to her child if she were to die. For some it might be the traumatic death of loved one.

In all cases, the progression of the disorder is much the same. Doctors are unable to find any underlying illness, while at the same time the hypochondriac is catastrophizing, often without expressing his or her innermost fears to anyone. A cough equals lung cancer. A headache equals stage four brain cancer. As Dr. Wilhelmsen. puts it "headaches come and go, and chest pains can be quite normal. It's how people deal with their symptoms. If they catastrophize then they're doomed to [hypochondria]."

It is only when doctors begin asking questions that hypochondria can be diagnosed. *How do you feel about your symptoms*? *What do you think you have*? *Why do you think that way*?

When doctors in Bergen suspect a patient has hypochondria, they refer them to Dr. Wilhelmsen. "The people who come to me don't know what is the driving force behind their hypochondria. They just see that they're afraid." Dr. Wilhelmsen begins therapy by not focusing on test results or labwork, or even the inciting event. "What we focus on is [the patient's] basic attitudes concerning life, death, symptoms, disease, things like that. Then people can reflect on their attitudes."

It is by carefully examining the patient's flawed thought processes that Dr. Wilhelmsen often sees a breakthrough in the first or second session. "When the patients realize that what they believe so strongly is questionable – even ridiculous – that's the moment when they can look at themselves from the outside." A patient who is convinced he or she has cancer, even though every test has proven otherwise, is forced to answer the question *why*? Why do you think you have cancer? Why do you not trust your doctors?

Why do you think you're special – that you can detect your cancer when medical professionals can't.?

As an exercise, Dr. Wilhelmsen has the hypochondriac enlist the help of a friend whom the patient perceives as being healthy The friend is instructed to focus on his or her body for an hour, and then report the results. One of Dr. Wilhelmsen's former patients, Inger Johanne Isaksen, 38, was amazed to find that her best friend developed a great deal of health anxiety during the exercise. "The thing with my friend was, she started to notice things in her foot, her head, everywhere." Inger Johanne began to realize that by constantly focusing on her own body she was contributing to her anxiety and thereby creating and worsening symptoms. "It was a good exercise for me, because my friend is very healthy."

Inger Johanne developed hypochondria after her middle child Magnus, now 10, was born. "He had fevers and bone infections. He was always sick and in and out of the hospital." Eventually Magnus recovered completely, but Inger Johanne couldn't shake the feeling of vulnerability, especially after her father was diagnosed with kidney cancer and died five weeks later. Losing a parent, and nearly losing her child, proved the breaking point. "I was only thinking about dying. I saw my children at my funeral, standing there crying."

She began to experience breathing problems. Like me, she was a smoker and became convinced she had lung cancer, even though numerous x-rays and CAT scans revealed nothing. She also became convinced that if she didn't drink water regularly she would have a heart attack. She trained her children to dial 112 "in case mommy stopped

breathing." At the lowest point in her disorder, Inger Johanne quit working to stay home with her children all the time, often rushing them, and herself, to the emergency room.

Instead of the traditional approach to hypochondria – talk therapy focused on the inciting event coupled with anti-depressants, which is still the treatment of choice in the U.S. – Inger Johanne was cured entirely through cognitive therapy. "It's been my experience that you don't need drugs," Dr. Wilhelmsen says. "Patients re-evaluate their assumptions. They examine their symptoms and then realize they have anxiety and not [impending] death." He adds that hypochondriacs are already overly sensitive to symptoms, and drugs such as Paxil or Prozac almost always have side effects. Adding symptoms, including the potential withdrawal problems associated with Paxil, can only muddy the therapeutic process.

According to Dr. Wilhelmsen, the ultimate goal is to help the hypochondriac learn to live with uncertainty. "I talked with one guy yesterday and he said 'aren't there any more tests we could do?' And I said told him that was the wrong way of asking. There are *lots* of tests we *could* do, but it wouldn't lead us anywhere. I suggested he ask if there were any more tests we *ought* to do. That's a different question. Because we live in a world where anything *could* happen. But you don't take that into account usually, as a way of living. Otherwise you can't fly, you can't go by car, because anything *could* happen all the time. You could be shot, you could be killed."

Ultimately, the hypochondriac must also face the fact that he or she is mortal, that death can't be cheated. "If you keep having tests, how long does [the negative result] last? Like an electrocardiogram. How long? Are you going to check again tomorrow?" This doesn't mean Dr. Wilhelmsen advocates a world where people don't take care of

themselves and don't practice preventative medicine. "What do people in Norway do to not die?" he asks. "They drive on the right side of the road. They eat apples and fruit. Some of them don't smoke. But what can you *really* do to stop death? Nothing."

Inger Johanne says that the struggle to become mortal was probably the hardest part of her therapy. "Dr. Wilhelmsen can be very hard. He says 'of course you can die. You can go out of my office and a car can hit you.' And it just hits you in the face, this. And you see that you must learn how to face it."

Dr. Wilhelmsen claims to have a 90% cure rate, and has refined the course of treatment from sixteen sessions when he first started in 1996, down to five. Inger Johanne and other former patients have helped spread the word in the Norway, destigmatizing the disorder and encouraging those suffering from hypochondria to seek help. Inger Johanne has been featured in dozens of magazine articles and television shows. When she first appeared in print, she was overwhelmed with phone calls. "Old people, rich people, lower class people. Everyone." Inger Johanne says the common denominator among the callers was the relief of realizing what was wrong, and that there was hope. "Loads of women who have children get hypochondria. There are just so many people who have suffered with this."

And the problem isn't confined to Western countries. Early in his work, Dr. Wilhelmsen thought hypochondria was a disorder of the rich – in other words, people would have to have access to the kind of medical care traditionally available only in Europe and North America. Volunteer work in Kenya and Brazil has shown him otherwise. "Even in poor areas they have health anxiety. The minute you get a doctor in these areas [the hypochondriacs] start coming all the time."

Are there people who can't be cured? Dr. Wilhelmsen says about 10% of his patients never recover from hypchondria. "There are different reasons," he says. Some patients have other disorders in addition to hypochondria. "Some people have situations where it's very hard to change. An ex is trying to kill them. No job. Lots of kids. They don't have the time or energy to sit down and re-evaluate their assumptions and change. And change takes energy and effort."

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How am I doing these days? I'm actually sleeping through the night, for the first time in a year, without wondering if my breathing is a little *off*. I find myself avoiding web searches that involve the phrases "unexplained weight loss" or "fatigue." I also am rigorously aware of my thoughts and, more importantly, how I'm interpreting my thoughts. If I feel a twinge in my chest, I try to rationalize with myself. *Is that really a heart attack? Might it be a muscle that I tweaked swimming? Do I need to make an appointment with my doctor right now?* I practice meditation and relaxation techniques – yoga has been particularly helpful.

Financially, I'm not doing so hot. Extensive medical procedures and office visits and last minute flights from Sweden tend to take their toll on a Visa card. When I spoke to Inger Johanne about the money problems I was having she laughed knowingly. "It's *very* expensive to be a hypochondriac," she said, with the authority of a woman who had rung up thousands of dollars in bills. She expressed her hope that someday the United States would implement treatment programs such as Dr. Wilhelmsen's.

I hope so too. You would think the medical care industry would be flocking to Norway to learn from Dr. Wilhelmsen. Five sessions? 90% cure rate? No drugs? All I can say is, Bergen is a beautiful place to learn how to be mortal.

[call out box]

What is Hypochondria? According to the DSM-IV, hypochondriasis (the technical term for the disorder) involves the following symptoms:

1. Because of misinterpreting bodily symptoms, the patient becomes preoccupied with ideas or fears of having a serious illness.
2. Appropriate medical investigation and reassurance do not relieve these ideas.
3. These ideas are not delusional and are not restricted to concern about appearance.
4. They cause distress that is clinically important or impair work, social or personal functioning.
5. They have lasted 6 months or longer.

If you suspect you have hypochondria:

1) Take the Whitley Index. **[link to test]**
2) Talk frankly with your doctor. Take the results of the Whitley Index test with you. Thoroughly discuss your options and don't automatically accept that medication is the best treatment approach.
3) Enlist the support of your family and friends. There is *nothing* to be ashamed about, because hypochondria is a legitimate disorder and is one that can be cured. Have them read this article. As an exercise, have a friend or family member focus on his or her body for an hour and report back to you. You will be amazed at the results.
4) Explore the option of cognitive behavioral therapy (CBT). Many health plans love CBT because it is goal oriented and therefore less expensive, as opposed to traditional talk therapy which is more open-ended.
5) Keep a journal of your symptoms. What were you feeling? When did you experience the symptoms? What did you think about your symptoms? Be diligent and bring this journal with you to therapy. Discuss the journal with your therapist, because often just reading it out loud will help readjust your thought processes.
6) Avoid the internet. For the hypochondriac, the web is like a petri dish filled with every imaginable fatal disease. During the worst phase of my illness, I became convinced I had Addison's disease. Don't ask me what Addison's is – I couldn't tell you. All I know is I typed in a few symptoms and Google returned the Addison's survivor's home page.