



**How
Much
Pain**

**Is Too
Much
Pain?**

By Hilary Mantel

learned early in my life that a pain is almost never just a pain. The ripples spread from the nervous system into the sufferer's whole life. If you stub your toe or burn your finger, it hurts but it's quickly over. Anything more complicated—and especially the kind of pain that is recurring or chronic—has an impact on the patient's personality and relationship with the world. Pain does not happen in a laboratory. It happens to an individual, and there is a cultural context that informs the individual's experience. What a pain is, and whether it matters, is not just a medical question.

I have suffered from three painful conditions: gout, migraine, and endometriosis. The way I've experienced them, and the way they've been dealt with, says a good deal about medical practice and how society deals with sick people.

The esteemed English writer chronicles her challenges with pain – and those of the doctors who treated her – as well as her efforts to cope with intractable, confounding questions.

Gout is a comedy ailment to those who haven't got it, but to those who have it's a source of dread. It struck, memorably, on my 55th birthday, the attack starting in textbook fashion in the small hours, when I woke up and had the impression I had somehow sprained my ankle while lying in bed. I didn't know what it was. It hurt intensely for some hours but cleared by evening. The next attack, a few weeks later, struck at the joint of my big toe. This was recognizably gout as I knew it from cartoonists. The young doctor I saw the next day bounced down to examine my foot with an athleticism that illustrated every bit of the difference between her and me. "I think it's...gout?"

The hesitation came, I think, because she wondered if I'd say, "Gout? Me? Never!" It is a stigmatizing illness

because of its association with old soaks and "rich living." But there it was, quickly recognized, quickly dealt with. Within a few weeks, I was established on allopurinol and largely free from attacks. I was amazed and grateful. Usually, when I've had a pain, a doctor has told me that I hadn't really got it, and/or that I'd just have to put up with it, and that anyway it wasn't as bad as I thought.

Gout is, of course, recognizable in a straightforward way. It's also, and I say this ruefully, largely a man's disease. It trails some cultural baggage, and it involves some shame, but it doesn't raise the same issues as those pains distinctive to women, which are to do with forbidden parts of the body. And no one would say to a patient with gout, "Perhaps you have a low pain threshold."

Pain cannot easily be divided from the emotions surrounding it. Apprehension sharpens it, hopelessness intensifies it, loneliness protracts it by making hours seem like days. The worst pain is unexplained pain. Gout is explicable and it's visible; the hot and throbbing joint illustrates the inner pathology. It's not frightening, like a pain in the body cavity. It's a pain you have, not a pain you are.

But one thing interests me, and I've never seen it mentioned in the patients' handbooks I've read. In the cartoons, the earl sits with his swaddled gouty foot raised on a stool; his teeth are clenched, and lines of stress strike out from his coronet. The gout sufferer feels intensely vulnerable. If a pet or a small child comes within a room's distance, he is sure he is about to be trampled. The sufferer is in a state of high alertness and of anger looking for a cause. What strikes me is that (in my case anyway) anger comes before the pain: a wash of strong, predictive, irrational emotion that I don't feel at any other time. Luckily, it dissipates with the attack; and anyway, you won't find gout sufferers fighting in the streets.

My experience with endometriosis has been almost lifelong. I can never forget the pain and distress of my first menstrual period. I suffered badly through my teenage years but dared not broach the matter with our crusty old family doctor, who also ministered to the nuns at my convent school and would have been horrified if a young girl had mentioned anything below her waist.

Menstruation was not something young girls thought they could discuss with each other. In those years, the late

sixties, we were caught up in a cultural shift. A few years earlier, a schoolgirl like me would have been “off games” for a week every month. But the new idea was that, since menstruation wasn’t an illness, you should carry on as if it wasn’t happening. For most young women it’s a good enough approach, but it was hard on me. I lost confidence even in my own pain; I thought I wasn’t tough enough. My mother would not have let me see a doctor alone, and as she had never been troubled in that way, the whole matter seemed trivial to her. Regrettably, in my long career with this condition, women doctors were no more helpful to me than the men. Their attitude was, “I’m a woman, so I know; you’re making a fuss about what we all have to endure.”

When I was 18 I went on the pill, and my period pain eased. And when I began to develop other debilitating symptoms—pain in my legs, nausea, fatigue—I didn’t associate them with anything gynecological. I began to ask for help when I was 19, but the doctors at my student health service didn’t really listen. No one suggested I keep a chart or record. No one even examined me physically. I was told I was neurotic.

As a young working woman, I sought help from my GP, though my major complaint now was my continual tiredness, and I appreciate that’s a complaint so vague that it’s hard for any doctor to address. I would get a test for anemia, but I wasn’t anemic, and at that point I would be written off. I was offered tranquilizers and antidepressants. When I reached 24, I came off the pill. I sensed that the diverse and baffling symptoms had something to do with my cycle, and I wondered if the pill was to blame. In fact, as I understand now, it had retarded the condition. My pain quickly became much worse: the kind of pain that doubles you up and knocks the breath out of you.

A new doctor, in another country, offered me help. “My dear,” he said, “you don’t have to suffer like this.” I almost cried. He was the first doctor to speak to me with kindness, not dismissive scorn. He gave me effective pain relief, and for two years I felt better. Of course, what he should have asked is, “Why do you have this pain?” Though he saw I needed help, he assumed it was “normal” pain and that it was enough to alleviate it. I was 27 when I first read about endometriosis and realized I fit the textbook description. But there was scant pleasure in being right, as the subsequent surgery found a wide area

of involvement through my pelvis. It led to the loss of my womb and ovaries. I was told that I was cured. This was not the case. I now know that endometriosis is not so easily eradicated. It’s not enough to remove what’s easily seen. It needs a specialist surgeon with time and skill.

When, two years later, I was in pain again, I had to repeat the whole sorry saga. I couldn’t have that pain, I was told. I’d had surgery, hadn’t I? Didn’t I know that endometriosis doesn’t grow back? In fact, my intestines were badly affected. In subsequent years, I also had to cope with the knock-on effect of having lost my ovaries. Thyroid failure was predictable, though for years it was denied because “the lab tests show your levels are normal.” Never mind that I was obese, always cold, and losing my hair and my memory. I was normal. It was only by a private consultation with an endocrinologist that I was able to get out of this vicious loop.

But that’s another story. This time I was better informed, so I was able to cut through the process by which my experience was being denied. I was given drug treatment for the endometriosis that remained, but the drugs had alarming side effects and didn’t work very well. In the mid-eighties, I decided to learn to live with the pain. It helped me a great deal that around this time a group for sufferers had formed, and information became more freely available to the laywoman. I learned the “autogenic technique”

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of relaxation, and that enabled me to contain the pain where it was, instead of letting it tense up my whole body and make everything hurt.

continued in this way, with pain crises of varying severity, until recently. Sometimes in a strange city I would wonder if I should turn myself in at the nearest A&E [accident and emergency] department. This raises the questions I could never solve:

How much pain is too much pain? How do you know when you are in danger? How do you know if your stoicism is admirable or ridiculous? How do you recognize an emergency?

From day to day, I got some relief from over-the-counter remedies. Daily life was hard because the workings of my gut were so unpredictable. You will wonder why I didn't demand help more urgently. But a person in pain is not an empty vessel, filled temporarily with a sensory experience that can be emptied out like water and leave no trace. Pain changes us. It takes more than a pill to reverse or manage that change.

I was aware that my condition was exacerbated by stress, and I knew that if I confessed to this, stress would be blamed for everything, and my career success (the only thing I could cling to) would come to look like an aspect of my pathology. Besides, every visit to every doctor would begin with a lecture about my weight. Since I was often unable to eat, and as I'd gained weight in the first place as a consequence of the drug treatment for endometriosis, I found this unbearable—less bearable than the pain, in truth.

In the end it was the weight problem that forced a crisis. For six months, I took Reductil under medical guidance. I lost very little weight but gained intractable constipation. In 2010, I saw a surgeon who said I had diverticulitis and needed an operation quickly. Scans failed to show anything unexpected, and the operation was scheduled as routine, but it turned into an eight-hour marathon as the surgeon picked apart the adhesions caused by endometriosis. It was some years since the disease had been active, but what was hurting was the damage it had left behind. The recovery from the operation was complicated and prolonged, but now for the first time since I was a child I am almost free from abdominal pain. The transformation

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in my life was not instant, and I have to manage my body carefully, as I now have a number of different conditions to cope with. But I am not afraid any more.

Sadly, the diagnosis of endometriosis is not much more efficient than it was when I was a teenager. I still hear stories just like mine, though thankfully they don't usually end so disastrously. It is a difficult condition to diagnose, with a dizzying variety of presentations. The key, as always, is listening. Then, the giving of information, the sorting out of options because this is a condition that affects fertility, career and family life, and the obvious solutions to the doctor may not be ones best suited to the individual. Then, after diagnosis, after treatment, the sufferer still needs help, both pain management and psychological support. And above all, as in many conditions, a sufferer needs a way of talking about pain—permission to talk about it—without feeling judged, without the implication that you lack moral fiber, or are exaggerating, or that you are in some way rebelling against your femininity.

I began to suffer from migraine when I was 18. It came as a "replacement" condition, a substitute for what had dogged my childhood. My family has a complex of allergies. In my case, allergic rhinitis eased, and migraine began. It seemed too neat to be coincidence. My mother suffers from migraine, but I didn't at first recognize my complaint as hers. I thought migraine was a bad headache. I didn't realize how diverse the symptoms can be. I managed it with over-the-counter medication and by paying attention to my life—learning, for example, that fasting and lack of sleep put me in danger of an attack and eventually learning to feel the warning signs and take avoiding action by resting if I could.

A few years ago, when the pattern of pain had become more insistent and less easily managed, I was referred to a neurologist. My hour with him stays with me as a shining example of good practice. His history-taking was so structured, so searching, so thorough, that I felt that, for the first time, my pain was being listened to. The consultation was, in itself, therapeutic. At the end of it he offered me three options. I chose to try the simplest, and it worked. So I have about 75 percent success in aborting an attack, and what's left, I feel I can live with.

Nowadays, migraine to me is less a pathology than a way of living a life. Sometimes I feel my head is going to explode, in the face of an uncontrollable overflow of creativity or when I have become drawn into a feat of empathy. Then my body will arrange for me the need to withdraw to a dark and silent place, where my brain will be turned down from boiling point to a slow simmer. I realize migraine is part of my inner economy. I am subject to a lengthy and tortuous lead-in syndrome, an aura that can last for a week before the pain manifests. And sometimes, if I am in control of my own time and not running on other people's schedules, the aura will dissolve and the attack is over without a crisis.

I think the family and friends of sufferers don't understand how many faces migraine has. They think, "Surely, either you have a headache, or you haven't." The notion of a pre-headache is hard to grasp until you've experienced it. Until I read Oliver Sacks's book *Migraine*, I did not realize how diverse and individual the manifestations of the aura could be. For a patient, knowledge is power, and I felt

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reassured by the book. Migraine aura is often described in terms of visual disturbances. But those phenomena are usually short-lived and easy to recognize for what they are. More subtle and complex are the disturbances of thinking and feeling: the "daymares" and nightmares, prolonged episodes of *déjà vu*, the creepy sense of a presence. Once I understood these oddities to be part of the condition, I could cope with them.

I have two continuing areas of concern, and they are not personal. One is to do with our understanding and treatment of long-term pain. If I had a health service to run, I would devote attention and resources to pain management to help patients remain physically and economically active and catch them before they fall into a pattern of chronic suffering—before pain erodes their personality and intellect.

My other concern is with the doctors and nurses who have to deal with patients who are in pain. I think it must be a depressing and unsettling business, unless you are well-trained and supported. Sometimes medics seem callous, and I often wonder if they are frozen

because they are afraid. People who are suffering often have an aura of unapproachability. They are cut off, turned inward, preoccupied with their inner experience. Pain requires a kind of concentration, and it's easy to feel helpless and useless in the face of the patient's otherness. What healers need to do is muster their own resources of personality and professional knowledge and address the fear as well as the pain: to provide reasoned reassurance, information, and above all, hope.

Hilary Mary Mantel is an English writer whose work ranges in subject from personal memoir and short story to historical fiction and essay. She has twice been awarded the Booker Prize, a literary prize awarded each year for the best original full-length novel written in the English language by a citizen of the Commonwealth of Nations, Ireland, or Zimbabwe.