

READINGS

[Diagnosis]

WOMEN'S TROUBLES

By Abby Norman, from *Ask Me About My Uterus*, which was published last month by Nation Books. Norman is an editor at *Futurism*, a science and technology website.

The novelist Hilary Mantel began experiencing pelvic pain, nausea, and fatigue, like I did, when she was a teenager; she had a hysterectomy when she was twenty-seven. In her memoir *Giving Up the Ghost*, she describes being repeatedly misdiagnosed with what she recalls as “stress, caused by overambition,” for which she was given tranquilizers. “Little Miss Neverwell,” one doctor called her. “The more I said that I had a physical illness, the more they said I had a mental illness,” she writes. “The more I questioned the nature, the reality of the mental illness, the more I was found to be in denial, deluded.” One psychiatrist suggested that if she wanted to feel better, she should stop writing.

Mantel had endometriosis. Like many sufferers, she recognized the disease in a medical textbook and was diagnosed only after she told her physicians about it. Endometriosis, she notes, had a reputation for plaguing high-achieving women. People called it “the career woman’s

disease’: the implication being, there now, you callous bitch, see what you get if you put off breeding and put your own ambitions first?”

This dismissive and victim-blaming attitude has a long history. In a study published in 1941, the American physician Joe Vincent Meigs argued that the condition was the result of delayed maternity. Women had the same physiology as apes, he wrote, and “it must be wrong to put off childbearing until fourteen to twenty years of menstrual life have passed.” Meigs also suggested that endometriosis was more common among the upper class. Wealthy women seemed to have “a difference in attitude” toward motherhood; if they wanted to be cured of endometriosis, the implication went, they should have more babies. His theories provided the foundation for decades of research that erroneously considered the disease to befall mainly well-educated white women and to affect fertility above all else.

Endometriosis is no longer understood to be the result of a woman’s choice to delay childbirth, but it is still widely believed to cause infertility. The link between endometriosis and infertility, however, is correlative, not necessarily causative. About a third of women with the condition are infertile, but it is not known that one leads to the other. Endometriosis is widespread, affecting between 2 and 10 percent of women of reproductive age. It is characterized by the growth of uterine tissue outside the uterus, which causes bleeding, inflammation, and

scarring. Diagnosis is by no means straightforward; some lesions are clearly visible in the body, but others are detectable only with a tissue biopsy. Most women begin having symptoms a few years after their first period. Chronic pelvic pain is a typical complaint, but other symptoms are inconsistent. Many are difficult to articulate, or embarrassing. It's not easy to speak freely about pain during penetrative sex, say, or about diarrhea.

Endometriosis is sometimes called an invisible illness, because a person may show no obvious sign that she is sick. Sufferers don't lose their hair; their skin doesn't turn gray. They are not wheelchair-bound or walking with a cane. They may well get up every day, wash their hair, put on makeup, get dressed, and go to work. But they are in great discomfort, far more than even those closest to them are likely to know.

When I first got sick, a persistent ache took up residence between my midriff, hip bones, and

lower back. Sudden, breathtaking nausea would overcome me after just a few bites of food. At night, I would lie half-awake on the bathroom floor, trying to hold my breath because the movement of my diaphragm and lungs intensified the nausea. I was constantly exhausted. I became unusually prone to spilling things, knocking things over, running into walls. I lost nearly fifty pounds. During my periods, I bled profusely.

The prevailing theory of the disease, developed by the gynecologist John Sampson in the Twenties, when endometriosis was first recognized as a medical condition, is the theory of retrograde menstruation: menstrual effluent "backwashes" from the uterus through the fallopian tubes and out into the pelvic cavity, where it then implants itself as endometrial tissue.

This theory, though formed nearly a century ago, has never been adequately proved. And although recent research has found evidence of endometriosis in embryos, suggesting that it is genetic, we still know little about the disease's etiology. Why do some women get endometriosis and others do not? Why do some women suffer for a relatively short period of time? Why do some women with few lesions experience debilitating symptoms and others with many lesions feel fine? We don't know the answers to these questions. Most medical textbooks seem to consider the condition uninteresting, or not of sufficient weight to demand attention. Even books devoted entirely to reproductive endocrinology or gynecologic surgery contain only brief passages on endometriosis. If you enter "endometriosis" into PubMed, the search returns 25,000 results. Diabetes, which affects a comparable portion of the global population, returns 600,000.

Doctors and surgeons who have not extensively treated or operated on women with endometriosis often discuss the disease as though it isn't serious. They might offer patients birth control or a course of the injectable hormone Lupron, or advise a patient to get pregnant—because they believe, incorrectly, that pregnancy is curative, and because they think endometriosis always leads to infertility. Some, not knowing what else to do, will inform a patient that a complete hysterectomy is her only option—but the surgery comes with numerous side effects, and endometriosis can in fact recur; removal of the uterus does not definitely cure a disease that exists outside the uterus. Many doctors who see patients with endometriosis say nothing at all, I suspect, simply because they aren't familiar enough with the condition to identify it. On average, seven and a half years will elapse from the time a woman experiences first symptoms until she receives a diagnosis.

[Duties]

THE DEVIL WEARS NADA

From descriptions of professional tasks performed by Sandeep Rehal for Harvey Weinstein while she was employed as his personal assistant. She held the position from 2013 to 2015. In January, Rehal filed a complaint against the Weinstein Company in a New York district court.

Listening to his calls
Reading and responding to his emails
Managing his doctors' appointments
Managing his drivers
Doing his shopping
Getting him clean underwear
Taking dictation of emails from him while he was naked
Maintaining his list of contacts with a special asterisk that identified his sexual partners
Obtaining and setting up an apartment close to the office for sexual liaisons
Purchasing lingerie and gifts for women
Managing the stock of Caverject shots for his erectile dysfunction
Picking up his used Caverject shots
Picking up his used condom
Cleaning up the semen on the couch in his office



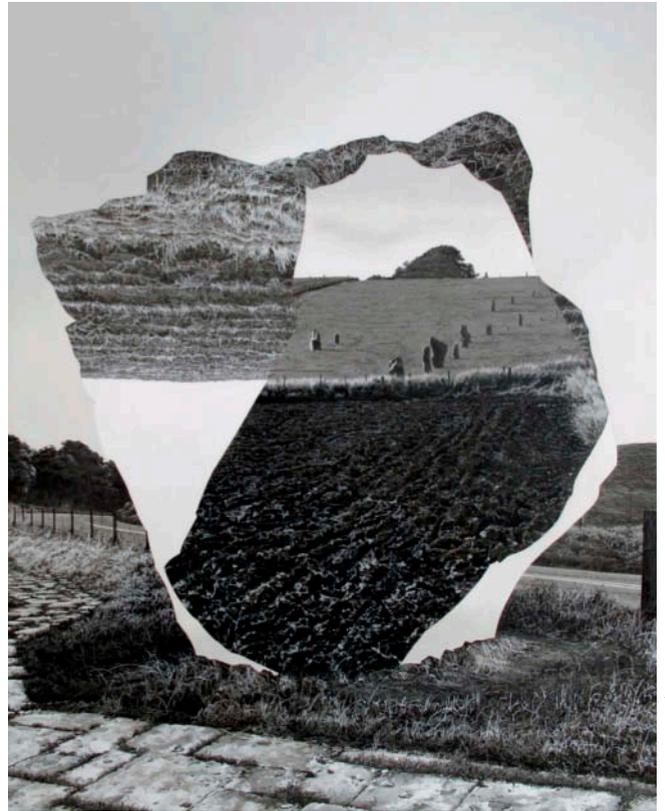
COURTESY THE ARTIST AND MODERNISM INC., SAN FRANCISCO

Flying Jib, a painting by Naomie Kremer, whose work was on view in *March at Modernism Inc.*, in San Francisco.

Even doctors who have experience treating the disease still view it primarily as a problem of fertility, not of debilitating pain. A 2003 study of how the condition is represented in the media found that anecdotes follow a similar pattern: women getting diagnosed are devastated because they believe they have become, or may become, infertile; the doctors counseling them encourage them to get pregnant as soon as possible.

In my own case, it seems clear that my intention to remain childless influenced how I

was treated. During my first operation, my doctor discovered a blood-filled endometrioma, or cyst, that was at risk of rupturing. She chose not to remove the cyst because it was attached to one of my fallopian tubes and she was afraid surgery would cause damage. My doctor emphasized to me that any procedure involving my reproductive organs could threaten my fertility. I didn't want to have children, so damage to my fallopian tube didn't concern me. The costs that did concern me—the pain, the nausea, the loss of activities I loved (eating,



COURTESY THE ARTIST AND ELIZABETH HOUSTON GALLERY, NEW YORK CITY

Untitled (Study for the Guardian Stone) and Untitled (The Swindon Stone), paintings by Colin Hunt, whose work was on view in February at Elizabeth Houston Gallery, in New York City.

dance, sex)—didn't seem to concern my doctor. Why didn't my plight hold as much weight as that of a woman who wanted to have children?

Those suffering from endometriosis struggle to explain in definite terms what it feels like. The pain is just similar enough to pain arising from other sources—such as severe cramps or irritable bowel syndrome—to be confused with them. Sometimes the sensation is all-consuming, at other times peripheral. It took only a few years for my own discomfort to become a part of me. I began to notice not the flare-ups but rather their rare absence. Even now, it's been so many years that I've lived in some agony that I hardly remember what it feels like to be without it.

Most people are familiar with the pain scale, which asks patients to rate their pain numerically: 0 for no pain, 10 for the worst pain you can imagine. But the application of the scale is not as simple as it would seem. Presumably, patients rate their sensations by comparing them with sensations they've experienced in the past. ("It's not as bad as late-stage labor," a woman might say.) And since pain is subjective and people tolerate it to varying degrees, the scale can be arbitrary—

especially when you take into consideration the biases of the administering doctor. Indeed, women and girls are frequently perceived as anxious instead of in pain. A 1990 study found that after operations, women are more likely to be given sedatives, whereas men are more likely to be given pain medication. When women do receive pain medication, they get a lower dose (even controlling for differences in weight). The same goes for children. One study showed that after operations, boys were more likely than girls to be given codeine; the girls were given acetaminophen. (Women are affected by bias when it swings the opposite way, too. Recent studies have found that doctors who perceive women as less capable of coping with pain are more likely to prescribe them opioids.)

Women are taught to keep their pain private—when they don't, they are ignored or disbelieved. Nineteenth-century doctors knew little about the workings of the nervous system and didn't find it reasonable for a woman to proclaim that she felt her uterus. The harder she tried to explain it, the more unhinged they thought she was. Doctors today often refer to the diseases that exclusively befall women—ovarian cancer, endometriosis—as "silent" and "unseen." This is unsurprising; those who are doing the describing are frequently men.

Women might use different language. When you talk to the women who have had endometriosis, you will find that it isn't that the disease is silent but that no one is listening.

[Confession]

KISS AND TELL

From a letter written by Marina Tsvetaeva to Boris Pasternak in 1927. Tsvetaeva (1892–1941) was a poet. The letter was included in the February issue of the PN Review. Translated from the Russian by Christopher Whyte.

Darling Boris,

Here is the story of a temptation. It reaches far back, it has its roots in Moscow when I was fifteen. She was the most beautiful of all the girls who went to secondary school, so beautiful it hurt. She was one year below me, and when we passed in the corridor, I couldn't take my eyes off her. In a year during which we met each day, I didn't say one word to her. 1918–1919. Love. Offense. (Clouds pass over the screen.) 1925, Paris. Three days since I arrived. A letter to *The Latest News*, forwarded to me. "Marina! Probably you won't remember me. I used to study with you at secondary school, I liked you but was afraid of you," and so on. I reply. And so on. And so on. She is ill, gets treatment. Nine meetings in two years. Once I called on her, in a cramped apartment by Porte de Passy, against a background of poor-quality furniture, no space for anything, with her mother, cheerful and fine-looking. This summer I visited her twice, in a sanatorium. Talk of literature, unnatural across the abyss of those letters. Of this and of that. 1927, a month ago. One in the afternoon. A knock on the door. A lady. I: "How delightful! Please, let's go into my room." "But where is your room?" A low, muffled voice. Fur, burning cheeks, she can hardly get her breath, because the way from the station to where we live is uphill, and then there are the stairs, and of two lungs, all she has left is a faint half-crescent. All consumed. Chess, guests, a snack. We decide to take a walk together. Well, our street barely climbs. I imagine how it must be for her, both of us are panting. Going back, I think with misery of the stairs. And, the moment we are through the door: "Could I lie down now?" She lies down on my battered, mouselike

couch, beautiful, young (you would never say she was thirty-two, more twenty-two). She says nothing. Looks around. I want to take my work to the table, she stops me with a movement of her head, her eyelids, her self. I sit down. Prompted by everything that is in the room, I take her hand. A hand longs for a hand (one takes hers, the other goes to her hair), I bend over, in my head: "Myriads." And fully aware of the crime I am committing—right to the heart of her infection. In full awareness.

Boris! The resistance of that mouth was so different from the others. And with what shame it yielded. My first genuine kiss. And, perhaps, her desire. Boris, I kissed death. My wish to compensate for everything, in the name of life. Life itself kissed death. Boris, every kiss ought to be like that, not for life but for death, in full awareness of the price and the cost.

[Doctrine]

BEARER OF BAD NEWS

From the style guide of the Daily Stormer, a white supremacist news website. The guide, which was reportedly written by Andrew Anglin, the site's founder and editor, was acquired in December by HuffPost.

The site is in many ways modeled off of successful liberal blogs such as Gawker. They have produced a great method to appeal to the same age demographic we want to appeal to.

The goal is to continually repeat the same points, over and over and over and over again. The reader is at first drawn in by curiosity or the naughty humor, and is slowly awakened to reality.

Packing our message inside existing cultural memes and humor can be viewed as a delivery method. Something like adding cherry flavor to children's medicine.

We are covering very negative content, but as much effort as possible should be put into presenting a positive message. We should always claim we are winning and should celebrate any wins with extreme exaggeration. We play up ourselves. We overestimate our influence.

We mustn't leave any room for nuance. Everything should be painted in black and white. The idea is that everyone on our side is 100 percent good and everyone who isn't is 100 percent evil.