Women & Fibroids & the Scary (& Unscary) Truths

By Aimee Lee Ball

So this guy walks into his doctor's office and says, "Doc, we gotta do something about these fibroids...."

Wait a minute. Fibroids in a *man*?

This scenario is admittedly farfetched. But you may be surprised to learn that it is not impossible, which speaks to the mother lode of misconceptions and specious information about fibroids. The term itself has come into common parlance like an armored assault lately, and there is new vigor (read money) behind research efforts to determine why it seems that *everybody* knows somebody who is affected.

Fibroids are benign tumors found in smooth muscle, most frequently the smooth muscle of the uterine wall but also, potentially, in the arteries, the intestines, or the lining of the stomach. Since the uterus is almost *all* smooth muscle, and since fibroids feed on the female hormone estrogen, the uterus makes an especially felicitous home for them. They are the most common tumors in human beings: It is estimated that one out of four women in their reproductive years have fibroids that are recognizable on a pelvic exam, and a whopping three out of four have microscopic fibroids.

"Some physicians tell me they think all women have them," says Janet Andersen, Ph.D., a molecular biologist who is studying fibroids at the State University of New York at Stony Brook. "I don't think I have them, but they laugh at me and say, 'You probably do.'" Most women will never be troubled by this condition. Despite the alarming word *tumors*, the chance of these growths becoming cancerous is so statistically remote that physicians virtually ignore the possibility, and with few exceptions, a woman who has fibroids can conceive and carry to term: The tumors would interfere with conception only if they were blocking the fallopian tubes or preventing the placenta from attaching itself to the uterine lining; they would interfere with labor and delivery only if they were obstructing the birth canal.

That's what we know about fibroids. Here's what we don't know: We don't know why some women get them and some don't, or why some women have one the size of a cantaloupe and others have 40 tiny ones. We don't know why some women have no symptoms—they may be shocked by the diagnosis during a regular gynecological visit—while others have symptoms that range from minor bloating to heavy bleeding to pelvic or back pain. We don't know if there is any connection to diet, stress, or lifestyle. We don't know whether you're more likely to develop fibroids if your mother did, whether it's part of your genetic blueprint like freckles or curly hair. And we don't know why they grow during certain times of a woman's life—typically in the late 30s and early 40s, before menopause (when we *do* know that they shrink).

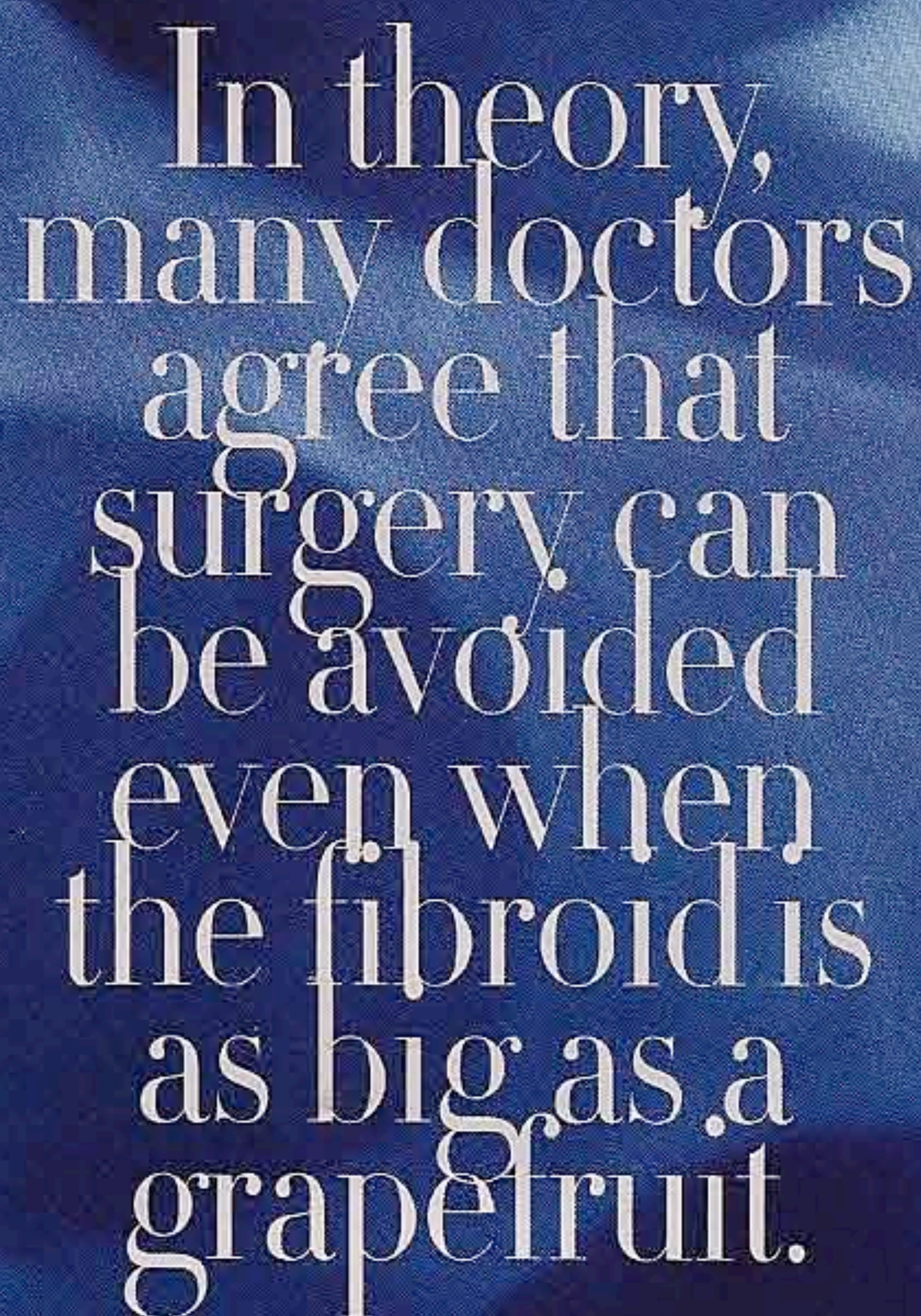
One other thing we do know: Fibroids are of unique concern to women because they are the primary reason for having a hysterectomy, which is the second most common major surgery

The white mass pictured is a large (2 x 3 centimeter) fibroid tumor in the center of a young woman's uterus, which the patient was able to have removed via laser surgery.

in this country. (The *most* common major surgery—regardless of gender—is cesarean section.) This assault on our wombs has come under increasing scrutiny. In a study published last May in the *Journal of the American Medical Association*, only 58 percent of the hysterectomies analyzed were deemed appropriate.

Nora W. Coffey thinks that number is high. Coffey started the HERS Foundation—Hysterectomy Educational Resources and Services—in Bala Cynwyd, PA, after having what she now feels was unnecessary surgery at age 36, and she is almost rabidly opposed to hysterectomies (she prefers the more visceral word *castration*). She cites a recent HERS survey about serious lifelong, adverse consequences of the surgery: 75 percent reported joint and muscle pain, 88 percent reported loss of sexual feeling, 70 percent reported profound short-term-memory loss—and 94 percent said their doctors didn't warn them these things could happen.

In theory, many doctors agree that surgery can be avoided even when the fibroid is as big as a grapefruit—even if you have to wear muumuus, run to the bathroom every hour, and sleep on your back. "It's a quality-of-life issue, rather than a life-and-death situation," asserts Milton Goldrath, M.D., of Sinai Hospital in Detroit. "It can be annoying if you wake up five times a night, but you can do it. What one woman will put up with another will not." But surgery *can't* be escaped if the condition starts jeopardizing other organs. "Occasionally as a fibroid grows, it impinges on the ureter, the tube from the kidney to the bladder," explains Murray L. Nusbaum, M.D., chairman of the American College of Obstetricians and Gynecologists in New York State. "It can cause serious kidney damage without the woman being aware of it." That kind of damage is slow and silent—you wouldn't notice it because your other kidney would take over—and you could lose a kidney. It's rare but worth monitoring, according to Nusbaum.



The problem is that the only "cure" for fibroids is hysterectomy, and American doctors tend to go for the cure. "There is no question that surgery for fibroids is excessive," declares Francis L. Hutchins, Jr., M.D., vice-chairman of the department of gynecology at Graduate Hospital in Philadelphia. "It has to do with attitude. If you took the same population treated by European physicians, the incidence of hysterectomy would be lower just because of the difference in style and approach. If you're a woman living in the southeastern part of this country, you will have a far harder time holding on to your uterus than if you live in the Northeast. It has nothing to do with women being sicker in the South—it just has to do with more aggressive surgical approaches. If we within the profession have to admit that 40 percent of hysterectomies appear to be without justification, I think that's obscene."

Hutchins traces this "obscenity" back to physicians' training. "I came out of medical school in 1969," he says, "with the understanding that fibroids were a relatively hopeless kind of situation, and we should take the uterus out because they're just going to get bigger and cause problems. But the majority of women will probably *never* develop any significant symptoms, and most women can anticipate that when they achieve menopause, their fibroids will stop growing and will reduce in size by 40 to 60 percent. There are a number of alternatives, including observation, that are available today to a far greater degree than in the recent past."

The insurance industry has also been implicated in the high rate of hysterectomies in this country. "Generally speaking," says Hutchins, "insurance companies are fairly eager to pay for a hysterectomy and are very reluctant to pay for anything that preserves the uterus. They have tended to take the attitude that the uterus is a liability, and if they can destroy it, they can cut their losses. As long as a woman has a uterus, she can have all kinds of crazy things happen: She can get pregnant, she can bleed, she can get cancer—all kinds of stuff."

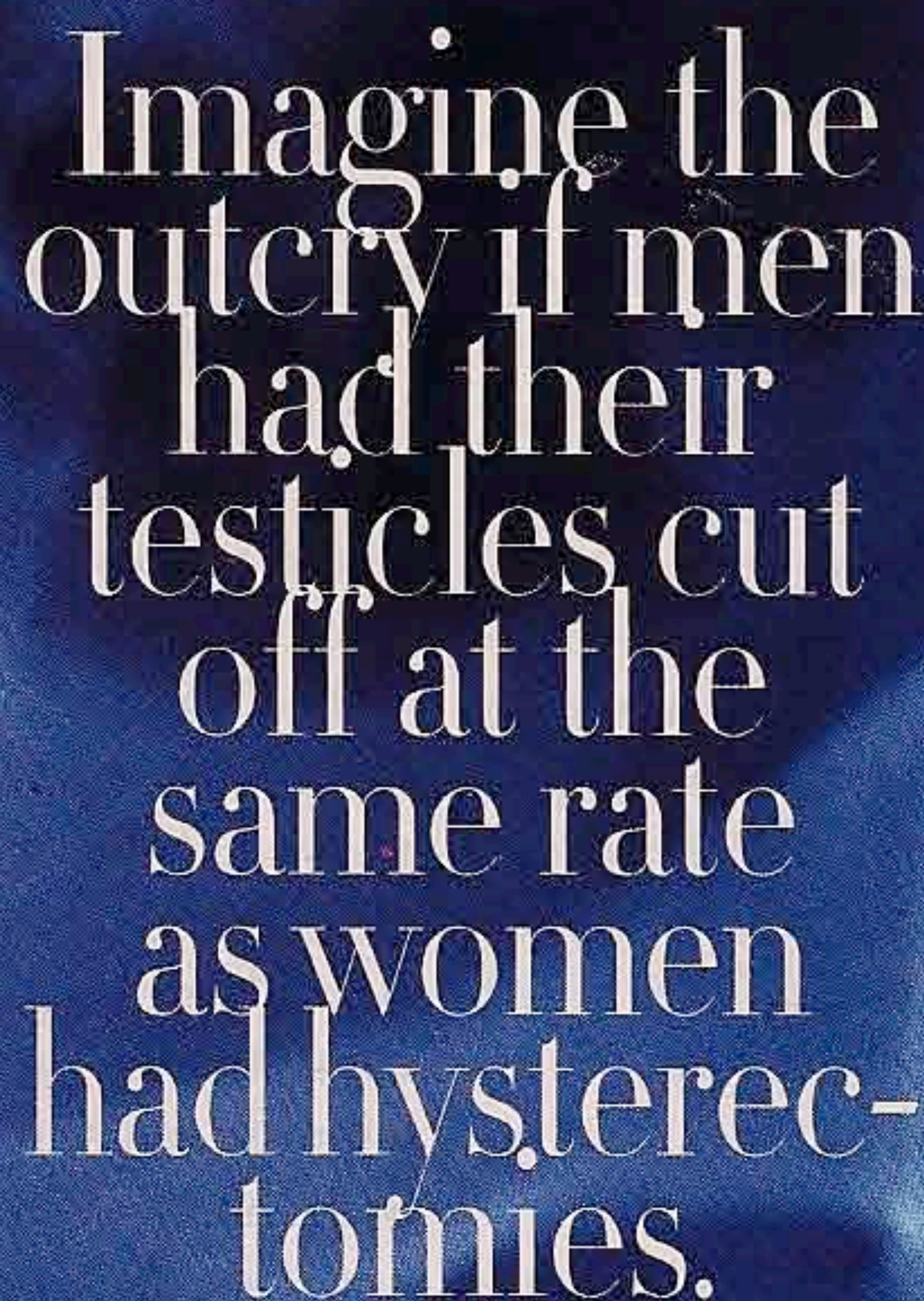
The smorgasbord of alternatives (with varying success rates) includes vaginal rather than abdominal surgery, zapping the fibroids with a laser, and laparoscopy using a tiny video camera and cutting device inserted through a small incision (less bleeding, shorter recovery, Band-Aid-size scar). The hot, and hotly debated, approach of the moment is myomectomy, in which the tumors are removed but the uterus is left intact. Myomectomy is controversial because of recurrence: Not even the most gifted surgeon can be sure of getting *all* the fibroids in a uterus that is prone to them, leaving open the possibility of a new crop—and more surgery—in the future. And laparoscopy, the kinder, gentler technique heralded as such a boon to patients, started *killing* people—so many people that last year the New York State Department of Health became concerned. "It became clear that doctors were going to weekend courses put on by the manufacturer of the equipment and receiving training on pigs," reveals department spokesperson Frances Tarlton. "Some of the courses didn't even have that hands-on aspect. So our guidelines call for hospitals to ensure that the surgeon has training and proctored practice."

The newest nonsurgical treatment of fibroids involves a group of drugs known collectively as GnRH analogs—one common brand name is Lupron—which trick the pituitary into shutting down production of a hormone that stimulates the ovaries, so they stop producing estrogen. "These are drugs that duplicate menopause," explains Milton Goldrath.

"In a true menopause, the pituitary produces an *enormous* amount of these stimulating hormones, but the ovaries won't respond anymore because they've run out of follicle tissue. It's sort of a phony menopause, but it does the trick. The uterus will shrink, and the fibroids will shrink in a few months."

The GnRH analogs are seen by some as an exciting advance in the treatment of fibroids: A smaller, shrunken fibroid is a better candidate for less-invasive surgery. And those women whose fibroids are causing heavy bleeding may actually be anemic. "If you're contemplating surgery and you're already anemic, you have a greater chance of needing a blood transfusion," says Andrew J. Friedman, M.D., a Harvard researcher prominent in the field. "So it makes sense to stop a woman's bleeding, build up her blood count; and then she's better able to donate blood for her surgery."

But Lupron is no day at the beach. "By creating a pseudo-menopause, Lupron has potentially bad side effects," admits Friedman. "Things like hot flashes are a nuisance, but the real issues are things like osteoporosis. The average woman may lose one percent of bone every month that she uses the drug, and once you stop the drug, some of that bone will re-form, but not all of it."



And guess what? Lupron is not FDA-approved for treating fibroids. (It *is* approved for prostate cancer and endometriosis.) Because it's not approved, many insurance companies will not reimburse the cost of the drug (once-a-month injections at $300 to $500 a shot). But Celso-Ramón Garcia, M.D., a gynecologist at the University of Pennsylvania Medical Center in Philadelphia who served on the FDA committee examining Lupron, is also concerned that women are being used as guinea pigs. He questions whether the drug brings about a *significant* reduction in the size of fibroids, and he is alarmed about the allergic reactions that have been reported, however mild. "You never know when the *next* dosage can blow up into such proportions that you may lose the patient."

Many physicians don't believe that there are more fibroids today, just that there are more being *diagnosed*, thanks to sophisticated new technologies such as ultrasound. But researcher Janet Andersen thinks there is also a connection between the "epidemic" of fibroids and the relatively recent tendency to delay childbearing. "Many people wonder why there's more incidence of fibroids in modern women, and it's possibly because years ago women had children early on, and they had many children," she says. In the past, doctors feared a correlation between high-dose birth-control pills and fibroids. "Now the more children that women have had, and the longer they've been on low-dose birth-control pills—which essentially mimic the state of pregnancy because of the high levels of progesterone—the less incidence of fibroids."

There's an aphorism in the scientific community that government funds what it fears, and fibroids have been an ignored stepchild in mostly male Washington. (Imagine the outcry if men had their testicles cut off at the same rate as women had hysterectomies, only to be told by the AMA that 58 percent of the procedures were unnecessary.) It was Representative Patricia Schroeder of Colorado who pushed for National Institutes of Health funding for fibroid research.

"Fibroids are very common, and they're also not considered really important," says Romana Nowak, Ph.D., a reproductive biologist at Harvard and one of several scientists who received an NIH grant. "Even though it's not pleasant to have fibroids, it's not life-threatening, and it's thought that they can easily—if you want to call it easily—be cured by doing a hysterectomy. So there wasn't much push from the medical side to do much about it. Now there is. Women are more aware, and they want some medical therapy that's not so invasive."

There is still no research about the influence of lifestyle on fibroids. "Nobody's really looked at that at all," confirms Andrew J. Friedman. "We don't know whether it makes a difference if you're an athlete or you're sedentary, if you eat a lot of Egg McMuffins or just bread and water." Since fibroids feed on estrogen, the female hormones given to poultry and cattle (with FDA sanction) to make them bulk up faster have been implicated: Several years ago there was a public-health crisis in Puerto Rico, where little girls and boys were developing female sex characteristics (like breasts), and the FDA joined the Centers for Disease Control in testing for estrogen residue in the animals. None was found—neither was the cause of the crisis. The European Common Market has banned the use of the same hormones that the FDA allows, although the stated reason is not a health concern but an overabundance of cattle. But the fact remains: The Big Mac you eat on the Champs-Elysées is different from the one you get in Iowa.

There is some good news. "The natural course of events with fibroids is that as time goes on, they tend to outgrow the blood supply that nourishes them and go through a sort of aging process," reminds Francis L. Hutchins, Jr. "The fibroid tissue is replaced with scar tissue, which doesn't grow anymore. It doesn't rot or become gangrenous. It scars over and shrinks." It's a virtual certainty that fibroids will shrink at the time of menopause. If you can't wait for this natural phenomenon, if you are given a diagnosis of fibroids and a recommendation of surgery, do not panic.

But you might want to run screaming from the room for a second opinion. ■