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Illustrations by
LOU BEACH

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Endangered



uterus

*Your doctor has recommended a
HYSTERECTOMY. Don't make a decision until
you read this startling report on the real risks
of surgery and the LESS-INVASIVE alternatives your
ob-gyn may not be mentioning*

BY PEG ROSEN

IF SOMEONE suggested that you undergo an elective procedure that could keep you out of work—and in pain—for six weeks, might leave you incontinent, deep-six your sex life, increase your risk of osteoporosis and heart disease, and possibly shorten your life span, would you do it? Maybe not—but what if your trusted ob-gyn told you it was a good move?

Chances are you would agree to it. In fact, every day, as often as 11 times every 10 minutes, women in the United States struggling with noncancerous pelvic conditions—including fibroids, endometriosis and heavy periods—agree to resolve the problem by getting rid of their reproductive organs. Ninety percent of hysterectomies in this country

are performed for reasons other than cancer treatment, and the vast majority involve major open abdominal surgery. Women between 40 and 54 are most at risk, and not just because the onset of many pelvic disorders occurs during the years leading up to menopause. The hysterectomy rate is so high because many of us take our doctor's word that once we are finished bearing babies, it's no great loss if our problematic uterus, and maybe even our ovaries, are removed. Don't believe it. And don't believe that there are no alternatives to open abdominal surgery. The question is, why isn't your doctor telling you about them?

WHY THE UTERUS IS WORTH KEEPING

EVIDENCE IS GROWING that our reproductive organs serve a purpose beyond birthing babies. In 2005 a landmark study showed that removing ovaries, which is still done during most hysterectomies to reduce the relatively small risk of ovarian cancer, actually increases the risk of heart disease and osteoporosis, according to study coauthor William Parker, MD, of the UCLA School of Medicine. While the ovaries produce a diminishing level of estrogen after you turn 45, for decades they will continue to produce testosterone and androstenedione, hormones that convert to estrogen when they circulate throughout the body. These provide crucial protection against heart disease and osteoporosis. Testosterone also helps preserve our sex drive, bolster energy levels and maintain lean body tissue. Even though some women opt to keep their ovaries when they undergo a hysterectomy, Parker says that within four years of the operation about 15 percent will experience postoperative ovarian failure, which triggers premature menopause.

All of this might be acceptable if doctors had no alternatives to offer women suffering from noncancerous pelvic disorders. But that is far from the case. Over the past two decades, there has been a virtual explosion of new ways to treat pelvic problems.

Laparoscopic technology now allows ob-gyns to remove endometriosis and accompanying scar tissue, as well as fibroids, without cutting open the abdomen. Uterine artery embolization (UAE), which is performed through a minor incision in the groin, can shrink fibroids by cutting off their blood supply. Endometrial ablation, an outpatient procedure, can end bleeding by destroying the uterine lining via vaginal probe. Pessaries—which are diaphragm-like devices—and other fixes can lessen pain by lifting a fallen uterus back into place rather than removing it. Birth control pills, the progesterone IUD and other nonsurgical therapies have also been shown to relieve disabling pain and bleeding while leaving the uterus intact. “It’s true that many of the new treatments may not provide a permanent solution. After uterine artery embolization, bleeding can return,” says Carla Dionne, of the National Uterine Fibroids Foundation. “But many pelvic disorders naturally subside as women get closer to menopause, after which recurrence is less likely.” In other words, midlife women don’t necessarily need a permanent solution; we just need a bridge treatment that can relieve symptoms of noncancerous pelvic conditions until we reach menopause.

Many of these treatments have existed since the 1980s, which is why it’s appalling that the annual rate of nearly 600,000 hysterectomies in the U.S. hasn’t declined significantly in 10 years, according to the Centers for Disease Control’s statistics. What’s more, almost 70 percent of these hysterectomies are still being performed via open abdominal surgery, which was pioneered in 1843, despite the fact that laparoscopic hysterectomy, available since the mid- to late-1990s, is a less-invasive removal method. The surgery is guided by a tiny camera inserted into the body via a small incision, in a procedure that causes less pain, less scarring and less risk of infection. And women who have laparoscopic surgery are back at work in about one third the time as those who undergo an open abdominal hysterectomy.

With such effective alternatives now available, why do physicians



Stand Up to Your Insurance Company

Kathryn Friedman, 53, of California, knew the facts about the dermoid cyst on her ovary. So when her ob-gyn said the only treatment was abdominal surgery to remove her ovary, she said no thanks. “Dr. William Parker told me he could remove just the cyst laparoscopically,” Friedman says. The only problem: Like many specialists, Parker didn’t participate in any insurance plan.

If you find yourself in Friedman’s situation, don’t assume that you must work with in-plan practitioners who lack the right qualifications. You may need to fight, but you may win—as Friedman did. With Parker’s help, she took her case to a state agency, the California Department of Managed Health Care (DMHC), arguing that none of the physicians in her plan were qualified to perform the procedure Parker proposed. She had to pay for the operation up front, but in the end Blue Cross reimbursed her entirely—and paid a price for its cost-consciousness. “The DMHC fined them \$85,000 for trying to make me undergo the slice and dice,” Friedman says.

If your insurer denies coverage, take these steps.

> **Call the insurer’s utilization or case management department** and ask to discuss the denial. Take detailed notes of every conversation.

> **Request a formal review** Submit an appeal via certified mail and request a return receipt. Ask the specialist to write a letter explaining why she is suited to treat you; including that in your appeal can help overturn the denial.

> **Look for allies** Many states have agencies to help resolve disputes. Do a Google search using your state’s name plus words such as *ombudsman*. To learn how to file a complaint, go to the Kaiser Family Foundation’s guide at statehealthfacts.kff.org.

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*Find the
Right Doctor,
Find the
Right Treatment*

If your ob-gyn recommends an invasive procedure, go for a second opinion. Here's how to get the best advice.

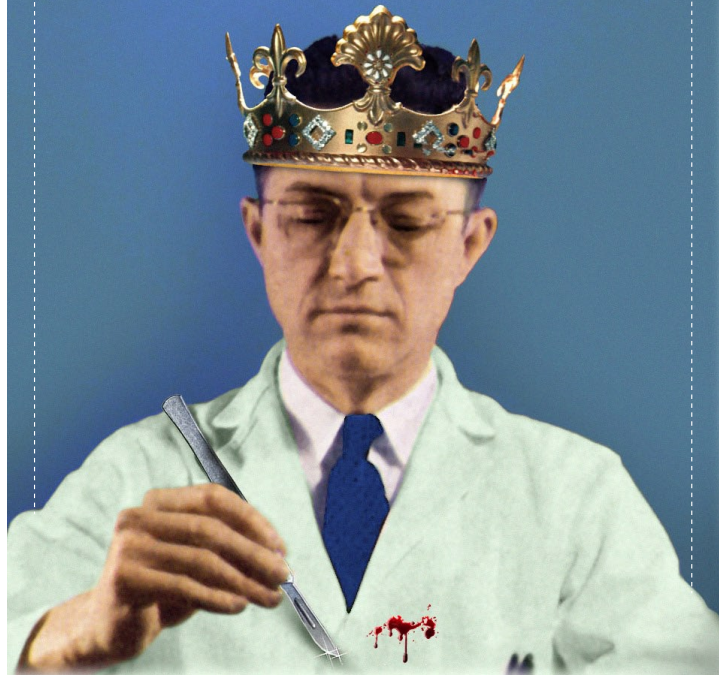
> **Look beyond your own community** Doctors are often hesitant to disagree with peers who practice in the same circles. Instead, check out the staffs of nearby teaching hospitals, and ask for names from support groups such as endometriosisassn.org.

> **Consult experts in other cities—without leaving home** New online services benefit patients who live far from big centers and can put your case in the hands of impartial physicians. Partners Online Specialty Consultations (econsults.partners.org) and some centers, such as the Cleveland Clinic (ecleveland.clinic.org), offer online consults. If the second opinion differs, seek out a local doctor who can perform the alternative treatment.

> **Ask about options** Whichever doctor you see, request a diagnosis and an explanation of all the possible treatments. Ask what would happen if you chose to do nothing.

> **Let your regular ob-gyn know you are getting other opinions** "If your doctor resists, that's a red flag. Don't try to spare someone else's feelings at the risk of harming yourself," says Richard Bercik, MD, of the Yale School of Medicine.

continue to treat non-life-threatening problems by removing our reproductive organs? Why, even when a hysterectomy is appropriate for non-cancerous conditions, is it being done in the most scarring and disabling way possible? And why are we—a generation of women who research and challenge personal trainers, investment advisers and other professionals in our lives—allowing this?



OUR MISTAKEN
ACCEPTANCE

THE IDEA THAT hysterectomy is OK is deeply ingrained in our culture, Dionne says. "The 20 million American women who have had hysterectomies indoctrinate their daughters, sisters and friends: Just do it. You'll feel so much better once the pain is over." Granted, if you are a woman who is seriously worried because she is bleeding heavily, any relief will seem like an improvement. "What many women don't realize is that they might have resolved their problem without such a drastic measure or without the physical complications that may result—the complications that many of their friends and relatives don't connect with the removal of their uterus," Dionne says. One eye-opening statistic: Compared with women who haven't undergone the surgery, those who've had a hysterectomy have a 60 percent greater risk of being incontinent after age 60, according to a study from the University of California, San Francisco.

"Women also may not realize that the uterus supports everything above it. Removing it is like pulling out the cork from an upside-down wine bottle. Unless the woman has strong muscles, her bladder or her bowels can descend into her vagina," says Beth Battaglino Cahill, RN, of The National Women's Health Resource Center (NWHRC), in Red Bank, New Jersey. Finally, the surgery itself can shorten the vagina and damage nerves, making sex less enjoyable or downright painful.

Some research has nonetheless suggested that hysterectomy improves women's sexual lives, but that claim is controversial. "I'm wary of such studies," says biologist Winnifred Cutler, PhD, author of the upcoming *Hormones and Your Health*. As an example, she cites the 1995 Maryland Women's Health study, in which women two years beyond hysterectomy reported they were more sexually active, more orgasmic and had sex more frequently than before the surgery. "But the researchers asked the women about their sex lives in the 30 days prior to the surgery [to establish a baseline]. What woman, experiencing and fearing pain, is going to be

having a lot of sex in the month before her operation?" With such a low baseline, Cutler notes, any increase may be misconstrued as improvement due to the hysterectomy. Her own findings with coauthors on sexual response postsurgery, presented in 2000 to the American College of Obstetrics and Gynecology (ACOG), showed just the opposite: Hysterectomy can have a negative impact on sexuality. That is why she urges women considering the procedure to look closely at the facts.

WHAT MOST DOCTORS WILL TELL YOU

PATIENTS FIRST HEAR about possible treatments from their doctors—and for gynecologists, open abdominal hysterectomy is also a deeply ingrained tradition. It's their default recommendation, not because it's a big moneymaker but because they're comfortable doing it. And feeling comfortable with a procedure usually reduces the doctor's chance of error—a big factor in a specialty in which lawsuits are a major concern.

Not surprisingly, most ob-gyns do what they know. "When residents first go into practice, most have a huge number of obstetrics patients," explains Barbara Levy, MD, coauthor of *So You're Having a Hysterectomy*. After years of being on call to deliver babies, many settle into the saner schedule of gynecological practice. But their skills may not be as up-to-date or well-honed as they should be. "Since they've spent years performing C-sections, abdominal surgery is what has become most familiar, and that's what they tend to do," Levy says.

The bottom line: Open abdominal surgery is frequently performed when another, less-invasive procedure could solve the problem, and the doctor's skill level is often the reason. Vaginal hysterectomy—a decades-old, minimally invasive procedure that enables a physician to remove the uterus through the vagina—is underused because many ob-gyns consider it too difficult. And laparoscopic hysterectomy, a newer treatment, has not been fully embraced because most of the ob-gyns

practicing today do not have enough experience in the required technology. "Many doctors talk their patients out of laparoscopic surgery and other [less-invasive] procedures because they aren't trained to do them and don't want to lose the business to someone who is," claims Harry Reich, MD, who performed the first fully laparoscopic hysterectomy in 1988.

NOT MOTIVATED TO MODERNIZE?

IT'S NOT AS IF doctors can't retrain midstream. General surgeons crowded in for classes when it became clear that laparoscopy was the future of gallbladder surgery. Even though the procedure requires training and great technical skill, the market demand forced doctors to get with the program. Today, 80 percent are performed via the laparoscopic route as compared with 15 percent of hysterectomies.

Compensation may be a factor. Minimally invasive gynecological surgery is more difficult—and takes longer—than the open abdominal version. Yet insurance companies pay ob-gyns virtually the same fee—around \$900—no matter how they get the job done. Perhaps it's not surprising, then, that most time-pressed practitioners choose what is, for them, the quicker, simpler and, from a doctor-liability point of view, lower-risk option. "Doctors face the question of, do I do a quick 90-minute abdominal surgery, or do I invest in training, increase my liability, spend three hours in hard surgery and get not a penny more for my trouble? What's in this for me?" Parker says.

For general surgeons, like those who remove gallbladders, the rewards of retraining are much more immediate. Because they rely primarily on referrals, they need to be more competitive, which means offering the latest treatments. "If you were referred to a general surgeon who said he wanted to remove your gallbladder the old-fashioned way, by opening up your abdomen, you wouldn't think twice about finding someone else who could do it laparoscopically," says Franklin Loffer,



When Hysterectomy May Be the Answer

- > If you have been diagnosed with uterine, cervical, ovarian or one of the other cancers affecting the pelvic region, a hysterectomy can stop the spread of disease and may save your life.
- > If your uterus hemorrhages or ruptures during or after childbirth.
- > If you have severe, intractable bleeding that does not respond to a variety of non-surgical, less-invasive therapies. "In the vast majority of cases, however, bleeding can be controlled by a physician knowledgeable about minimally invasive techniques," says Grace M. Janik, MD, of the Reproductive Specialty Center, in Milwaukee.
- > If you have been diagnosed with adenomyosis, a buildup of endometrial tissue that invades the uterine wall, hysterectomy might provide pain relief. (Endometriosis alone, even when it is extensive, rarely requires hysterectomy when it is treated by an expert in the field.)
- > If your uterus has prolapsed and is falling out of your body through your vagina. However, you should first try less drastic measures, such as using a pessary or having corrective surgery, and resort to hysterectomy only if other treatments don't work.

MD, of the American Association of Gynecologic Laparoscopists (AAGL). "Women, on the other hand, have a relationship with their ob-gyns. They trust them and tend to stay loyal to them. That makes ob-gyns less motivated to change what they are accustomed to doing."

If doctors should be moving beyond their comfort zone for the sake of better patient treatment, so should women. "No matter how much you love your ob-gyn, it's time to rethink the idea that the doctor who delivered your babies in your twenties and thirties

should be the same one who deals with your pelvic pain in your forties and fifties,” says Grace M. Janik, MD, president of AAGL’s fellowship board. “If you have a problem, you need to ask how many cases like yours the doctor has handled and who she knows who’s done more of them. Your own doctor may be able to treat you. But you must ask yourself, is she the best person out there for this job?”

That’s what Hope Waltman, 45, did when, in 2001, her longtime ob-gyn determined that fibroids were causing her painful periods and immediately proposed major surgery. “He really didn’t talk about any possibility except abdominal surgery,” says Waltman, who lives in Carlisle, Pennsylvania.

Unnerved by the idea of a major operation, she researched fibroids and found a treatment that piqued her interest: uterine artery embolization. “I went back to my doctor and asked him about UAE. Only then did he pull out pamphlets about the procedure. He told me it was new, that his office didn’t do the procedure and that he didn’t know of anyone he could refer me to. You could tell he wasn’t happy to even discuss alternatives,” Waltman says. She eventually found another doctor, underwent UAE and has been symptom-free ever since. “My ob-gyn had been my doctor for 15 years. I don’t know if it was that he was arrogant or that he didn’t want to lose business, but I couldn’t believe how unwilling he was to provide me with information. It just made me so blasted mad, I never went back.”

YOUR RIGHT TO KNOW

IF OB-GYNS CHOOSE not to develop skills that may inflict less pain on their patients, are they doing anything wrong? No, says bioethics professor Arthur Caplan, PhD, of the University of Pennsylvania. “A doctor takes an oath to offer treatment he can perform safely and that will relieve a patient’s symptoms.” Open abdominal hysterectomy meets those criteria.

However, when a doctor like Hope Waltman’s fails to inform the patient

that other procedures exist, even if he prefers not to perform them, that omission violates a patient’s right to informed consent. This cornerstone of modern medical ethics requires physicians to inform patients of all reasonable treatment options, Caplan notes. The informed consent requirement is spelled out in ACOG’s code of ethics. But ACOG, which defines itself as a voluntary membership organization, “does not monitor its physicians” regarding their adherence to the code, according to a spokesperson.

Recognizing this, women’s health activists have fought to put some teeth in informed consent by backing it up with legislation. Currently, three states (California, New York and Texas) have passed informed consent laws specific to hysterectomy. “But as they are

written and enforced now, these laws are pretty much a joke,” the National Uterine Fibroids Foundation’s Dionne says. The law in California was passed in 1987, the one in Texas in 2003—but when *More* called medical board representatives in these states, they weren’t even aware such a law existed. They later reported that few, if any, complaints had been filed—not surprising, since presumably few patients are aware of the laws either. Since 1991, any New York State physician recommending hysterectomy has been required to give the patient information published by the state department of health (DOH) that provides details about the procedure as well as alternatives. But *More*’s investigation found little evidence that the information is actually getting into the hands of the women who need it. Within the past year, DOH records show that fewer than 20 ob-gyn practices in the entire state ordered copies of the booklet. That poses the questions: How many of the more than 4,000 ob-gyns in New York are actually complying with the law and providing the required information every time they recommend hysterectomy—and how many, perhaps unknowingly, are breaking the law by not doing so? The DOH spokesperson says it has not received any complaints from patients, and that doctors can download the required information from the DOH Web site. But there’s no system to track how often doctors do download, and if they do, whether the information reaches patients, says Assemblywoman Helene E. Weinstein, who cosponsored New York’s law. “It’s the job of the DOH to ensure physicians distribute it . . . The purpose was to inform patients who didn’t know to ask questions. The ball was dropped,” she says.

Caplan cites another problem with informed consent: Even when physicians mention alternatives, they often build in their own bias. They may tell you that laparoscopic or vaginal hysterectomy will carry a higher risk of complications than an open abdominal procedure. “But they are not finishing the sentence and telling you that this is true in their hands, but not necessarily in the hands of others,” Caplan says.

“DOCTORS CONTINUED ON PAGE 157



How to Find Alternative Treatments

If you want to know more but aren’t sure where to start, check out these resources.

> To learn more about endometrial ablation and other less-invasive treatments for heavy bleeding, go to the Guide to Uterine Health at healthywomen.org.

> Investigate laparoscopic myomectomy and other minimally invasive treatments for fibroids at fibroidsecondopinion.com or nuff.org.

> For more on laparoscopy and other minimally invasive treatments for endometriosis, go to endometriosis.org.

> For information about pessaries and other treatments for uterine prolapse, go to althysterectomy.org/prolapse.htm and mayoclinic.com/health/uterineprolapse/DS00700.

> If you need a hysterectomy, go to aagl.org to learn more about laparoscopically assisted vaginal surgery and other alternatives to open abdominal surgery.

often finesse informed consent in this way because they don't want to lose business." Even ACOG's pamphlet on fibroid treatment, which is what you're most likely to find in ob-gyn offices, avoids mentioning the importance of the doctor's skill. It clearly states that whether a hysterectomy is performed vaginally or abdominally "depends on the size of the fibroids." That's true, as far as it goes. But the brochure fails to mention another crucial element: ability. The larger the fibroid, the more difficult the removal, however it is accomplished. But in many cases, experienced surgeons can do it laparoscopically, vaginally or a combination of both, and do it well. A 2005 review of 27 trials conducted by the nonprofit Cochrane Collaboration concluded that a physician's decision on which type of surgery to perform (open abdominal, laparoscopic or vaginal) "is tightly tied to experience and comfort level."

CHANGE:
IT'S IN OUR HANDS

GIVEN THE WAY that doctors are trained, women should not look to the medical schools for any immediate improvement. Although less-invasive gynecological procedures are being taught, residents have scant opportunities to refine their skills. "Ob-gyn has become complex. In addition to gynecology, residents must now train in many things, like perinatology and ultrasound," Levy says. Residents are expected to "understand" laparoscopic hysterectomy but not necessarily "be able to perform it independently," according to the list of requirements issued by ACOG's educational arm known as CREOG (Council on Resident Education in Obstetrics and Gynecology.) "This should change," says Alan Decherney, MD, of the UCLA School of Medicine.

That change will probably not be spearheaded by ACOG, which is not a consumer advocacy group. Haywood Brown, MD, former chair of CREOG,



*Take the Fight
National*

> We can't change this situation one ob-gyn at a time. For big-picture action, ask your representatives in Congress to support the Uterine Fibroid and Education Act, cosponsored by Maryland Senator Barbara A. Mikulski and the late Ohio Representative Stephanie Tubbs Jones. The act "allocates funding for patient education to help women make informed decisions about what treatment is right for their bodies and their lives," Mikulski tells *More*. "It's time to break the silence and change the way uterine fibroids are treated and understood. Women deserve it." Go to senate.gov and house.gov, and plug in your state's name or ZIP code to find links to contact your senators and representatives.

believes trainees may not be completely comfortable with every major procedure at the end of training, and that those interested in subspecialty training can continue. And although ob-gyns are required to take continuing medical education courses, ACOG's spokesperson says the group can't require that members sign up for any particular subject. "If you know most of your physicians are doing open abdominal surgery, how are you going to retain membership if you tell them that has to change?" the AAGL's Loffer says. No group wants its members to withdraw.

Others say ACOG could still make a difference. "Maybe ACOG can't enforce anything, but they set standards. Why can't they call this the Year of Modern Fibroid Management and set it forth as a priority?" Decherney asks.

Numerous physicians in the field say that in the future, change may come as the

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specialty evolves. Already, ob-gyns are beginning to subspecialize in areas like urogynecology, which deals with disorders such as incontinence. “Within the next 10 years, you’re probably going to see a split. Residents will either train to be an office ob-gyn, doing prenatal care and basic gynecology, or they’ll train to be a hospital ob-gyn and do surgery,” Decherney says. That means that if the pills your ob-gyn prescribes to end your bleeding don’t help, you won’t have to leave her for another doctor if you want to consider other options; it will be standard for you to move on to a gynecological surgeon. Others believe the split may separate obstetrics and gynecology into two different fields, which could mean that, at midlife, women would stop seeing an obstetrician—deeply experienced in doing C-sections—and start seeing a dedicated gynecologist, for whom surgery would be only one of many options he considers every day.

But for women suffering right now, 10 years is too long to wait. When it’s time to make a treatment decision, we need to find the doctor who is best qualified to handle our case in the safest, most effective and least-invasive way possible, and that means doing our own research. And we need to start making noise about this outrageous situation. “Only when women began to talk about breast cancer, only when they began to demand research and to call for procedures like lumpectomy, did we begin to have alternatives to radical mastectomy,” says the NWHRC’s Cahill. “Men are willing to talk about erectile dysfunction today, and we’ve got to start talking about our reproductive organs. We can’t wait for doctors to start the conversation about alternatives to open abdominal hysterectomy. We have to educate ourselves and start demanding. Just like we’ve done with everything else.”

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