Amy Reed is changing medicine, fighting to put an end to a high-tech surgical technique that can turn a routine hysterectomy into a catastrophe—as it did for her.

Doctor. Mother of six. Stage 4 cancer patient. Amy Reed may not

WHEN CUTTING EDGE KILLS

have much time to live, but she's making sure her death won't be in vain.

PHOTOGRAPHS BY JAMIE YOUNG

BY HARRIET BROWN

On good mornings, Hooman Noorchashm wakes early, a relic of the days when he rose at 4:30 AM for surgical rounds at Brigham and Women's Hospital. He pads through the quiet house to pop a coffee pod into the machine, then heads for his home office, where, over the course of the day, he will calmly, deliberately compose and send dozens of e-mails.

His wife, Amy Reed, sleeps till 6:30 AM, when she slips on a red Phillies T-shirt, snugs a maroon jersey cap over her stubbled head, and begins the work of getting six children under 12 ready for the day. An anesthesiologist at Beth Israel Deaconess Medical Center, Reed was on the team that treated both the Boston Marathon bomber and his victims. She is by nature even-keeled. You'd want her as your anesthesiologist. You'd want her sharp intelligence and steady presence with you in the OR. She and her husband aren't people who "do drama," as they put it. They're experienced doctors who argue logically rather than raise their voices or yell or cry.

On good mornings, then, in the face of events that have devastated their family, this composure seems both a gift and a burden. Last fall, a routine hysterectomy seeded cancer throughout Reed's abdomen. The hysterectomy didn't cause the cancer, but it very likely transformed it from stage 1 disease, with a 60% 5-year survival rate, to stage 4 disease, with a grim prognosis. About 85% of women like Reed are dead 5 years after diagnosis.

Reed's surgeon, one of the best in the country, wasn't to blame for the catastrophe. Nor was this a random disaster, the kind of bad-luck bolt from the blue that can strike anyone—the brick falling off the building, the truck spinning on the icy highway. The cancer upstaging was a preventable consequence of a surgical technique, one that is still being used in operating rooms around the country.

And this is what Noorchashm and Reed can't bear. This is what keeps him doggedly online, in the research, on the phone, whether he's home or sitting by Reed's hospital bed or driving her to and from chemo. The effort has led to international attention, much of it critical. Noorchashm's incendiary question: When new technology makes medicine cheaper and more convenient, how many patients have to die to prove it's not worth it?

On good mornings, his arguments land as powerfully as his wife's even gaze. "People have faulted my husband's enthusiasm," Reed says on one of those mornings. "But women are having this surgery right now. Today. And they're going to have their lives destroyed, just like ours."

This year, more than half a million women in the United States will undergo hysterectomies. The majority will be between 40 and 55 years

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old, and, like Reed, most will have the surgery for fibroids, benign growths in the uterus that can cause pain, bleeding, and other symptoms. Five years ago, only about 12% of these surgeries were performed laparoscopically, done through incisions just big enough to fit a scope and tiny camera. Last year, nearly 30% were done that way, and the numbers were considered likely to rise.

Compared with traditional open abdominal procedures, laparoscopic surgeries were said to result in shorter hospital stays (and, therefore, lower costs for insurers), faster healing, less pain, fewer infections, and smaller scars. Still, when Reed first discussed hysterectomy with her surgeon, she asked for an open operation, despite the larger incision and longer recovery time. "I said, 'I'm an anesthesiologist. I know how they operate. I'd rather have them see what they're dealing with and not mess around with little holes,'" she recalls. "Laparoscopic surgery's not all it's touted to be sometimes."

She'd known about her fibroids for a while, but the bleeding and pain had ramped up dramatically during her last pregnancy. Her husband arranged a consult with a colleague, Michael Muto, who directs the gynecological oncology fellowship at Brigham and Women's, which is Harvard's teaching hospital and an industry standard-bearer. As Reed remembers, Muto reassured her that the problem was "a no-brainer"; she'd have her uterus removed, and that

would be that. "He told me, 'This is not cancer, it's not anything terrible, this is what fibroids do.' " She says this quietly, matter-of-factly, 3 months later, sitting in the sun-splashed living room of a white clapboard house on a narrow street in the Boston suburb of Needham. From time to time she reaches under her cap to rub at a spot where her hair is starting to grow back, white fuzz now laced through the dark.

Muto said no surgeon would do what she wanted. You're young and healthy, Reed remembers being told; there's no reason in the world to have this done as an open surgery. "Dr. Muto wears a nice white coat with the Harvard emblem on it," says Noorchashm, sitting across from Reed. "He's my colleague, and we trust our own establishment." He pauses, and then corrects himself. "I trust*ed* the establishment."

So Reed had MRIs and biopsies to check for cancer, as is standard before a fibroid operation, and went ahead with the laparoscopic hysterectomy. She went home that afternoon, and everything was fine until the surgeon called 8 days later to say that the pathology report showed leiomyosarcoma, a cancer in her uterus. And nothing has been fine since then.

Imagine a hive filled with angry bees flying this way and that, buzzing, darting, stingers at the ready. Now picture that hive inside a woman's belly, where at any moment the bees could explode through the body, wreaking the deadliest kind of havoc. The hive, says Noorchashm, is a good metaphor for a sarcoma, a kind of cancer that can grow anywhere in the body. He's operated on sarcomas and knows that the way to handle them is to carefully remove them in one piece. Now imagine inserting a long spinning saw—something like a handheld blender—into the hive while it's still inside the woman's body and cutting it up into tiny pieces. "What's going to happen," says Noorchashm, "is a million bees are going to come out and you're dead."

That saw is called a morcellator, and over the past 10 years or so, it's become standard procedure in laparoscopic surgeries to remove fibroids, the uterus, or both. "Morcellation prevents you from having to make a larger incision," says Larry Kaiser, dean of the Temple University School of Medicine. "You couldn't take the uterus with fibroids out through these small ports used for the camera and instruments."

The trouble is, some cancers—like leiomyosarcoma—don't show up on biopsies or MRIs done before surgery. If a woman's uterus is morcellated inside her body, cancer cells are spewed around the abdomen, where they cling to internal organs and, inevitably, grow. Even benign tissue that's morcellated can implant in the abdomen and trigger pain, bowel obstructions, and other problems.

Morcellation Explained

A basic look at the suddenly controversial technique

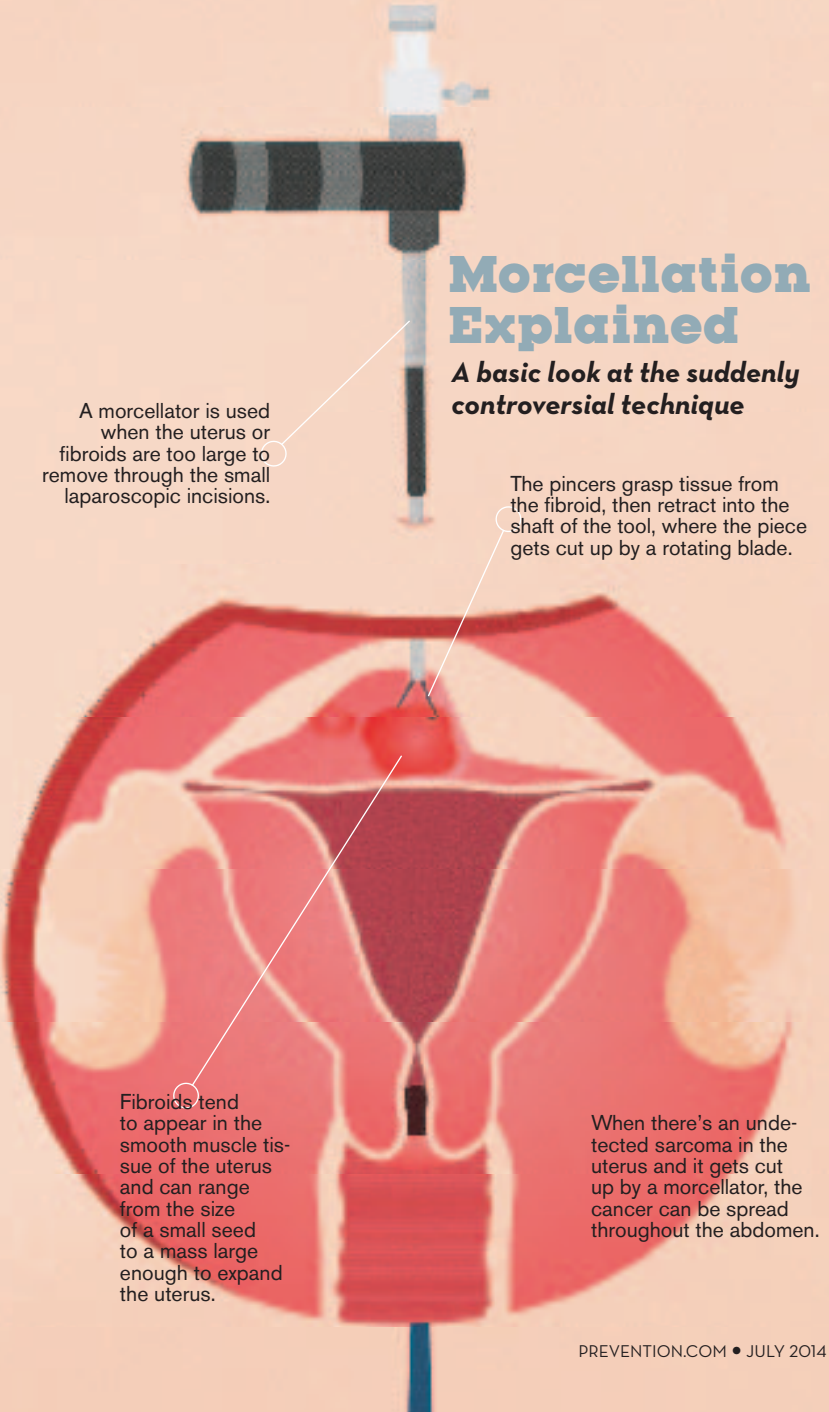

ILLUSTRATION BY SCRIPT & SEAL

Source: Kimberly Kho, MD, University of Texas Southwestern Medical Center

Though Reed's odds of living to see her youngest son graduate from high school are slim, she chooses not to focus on the numbers.

Morcellation is what Reed and Noorchashm want to stop, arguing that it's unacceptable if there's any chance of hidden cancer—and there's pretty much always a chance. "It's flawed surgical procedure," says Noorchashm. Some ob-gyn surgeons say morcellation is safe if it's done in a containment bag, something like the bag inside a vacuum cleaner. Noorchashm disagrees. Bags can break, he says, especially when you're using a rotating power saw. Instead, he and Reed want surgeons to remove the whole, unmorcellated uterus vaginally when they can, and do the old-fashioned open surgery when they can't.

On the day Reed got the bad news, Noorchashm was down at Duke, preparing for surgery. After he got the call, he scrubbed out, booked a ticket home, and left. In the cab on the way to the airport, he called Muto, who told him what he'd already told Reed: Leiomyosarcoma is so rare there are no protocols for treating it, no best practices, no good survival statistics. Some doctors do nothing, waiting to see if it comes back; some start chemotherapy to try to stave it off; some schedule surgery to clean out anything that's already growing.

Noorchashm was horrified, both by

the stark reality of the facts and by the offhand way he felt they were being delivered. "In my mind, when I hear *sarcoma*, and the sarcoma has been broken up inside, that's a five-alarm fire," he says. "And here's a surgeon thinking, *We have three options, including watching and waiting*. That's like taking a water gun and shooting at a five-alarm fire."

That day in the Raleigh-Durham airport, an advocate was born. Noorchashm began researching, making phone calls, and sending hundreds of e-mails to anyone he thought might make a difference—family, friends, colleagues, doctors, researchers, journalists, editors of medical journals. He and Reed (who at the time felt physically fine despite the cancer inside her) created a petition on Change.org calling for a ban on the practice.

Doctors and administrators maintained that what happened to Reed was unfortunate but incredibly rare and that it didn't make sense to abandon morcellation—a convenient and widely usable technique—because of such an unusual occurrence. The largest professional organization for ob-gyn surgeons, the American Association of Gynecologic Laparoscopists, issued an official statement disagreeing with putting limits on the procedure.

Some ob-gyns pointed out that the alternative laparoscopic techniques (removing tissue vaginally or morcellating in a bag) aren't an option for women with large fibroids—and worried that restrictions would lead to thousands of unnecessarily invasive open surgeries. These can cause more blood clots and infections, both of which can be lethal, says Joseph Ramieri, an ob-gyn surgeon and professor at Mount Sinai School of Medicine. "I'm not defending morcellation—as a technique, it leaves an awful lot to be desired," he says. "But it needs further study before we put limitations on it."

Noorchashm and Reed were asking for a huge shift in medical practice, and physicians, especially surgeons, can be slow to change, says Brian Van Tine, a physician who heads the Sarcoma Program at Barnes-Jewish Hospital in St. Louis. Part of the resistance was likely financial. If, say, half of the women who have hysterectomies have abdominal surgery rather than laparoscopy and must spend an extra day or two in the hospital, that's a lot of extra costs for insurance companies to cover. "Morcellation saves money," Van Tine

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says, "and these surgeries are a huge moneymaker."

As a result of the couple's efforts, new information emerged about just how uncommon leiomyosarcoma really was. Reed says that Muto, who refused to comment for this story, told her the cancer affects 1 in 10,000 women, but that statistic was based on the population at large. Among women with symptomatic fibroids, the number may be closer to 1 in 415, Noorchashm discovered—incredibly, from a paper listing Muto himself as a coauthor. In fact, Reed was the second woman within a year whose cancer was upstaged by morcellation at Brigham and Women's Hospital alone. The first woman has since died. Since Reed's surgery, at least five other women around the country whose cancers were upstaged by morcellation have come forth. And there are certainly others out there.

"They closed ranks on me," Noorchashm says sadly. "I broke the white code of silence; I hung out our dirty laundry."

As the winter progressed, Reed committed herself to doctors' visits and weighing treatment options—and remaining an upbeat, present mom to her children. Noorchashm stayed up nights writing strongly worded letters, posting comments on every Web site remotely relevant to the cause, and having strategic conversations with anyone who would talk to him. The only resulting change he saw was in his own reputation. He'd gone from star surgeon to social leper, shut out of the operating room at his own hospital (though he can't prove it was because of the campaign) and avoided by colleagues and former friends. "They closed ranks on me," he says now, with sadness in his voice. "I broke the white code of silence; I hung out our dirty laundry."

But he pushed on. He contacted hospital executives, the FDA, legislators. In return, his bosses at Brigham e-mailed faculty and staff warning them not to talk to Noorchashm and to speak to the hospital's chief medical officer if contacted by Noorchashm. Gerald Joseph, vice president of the American Congress of Obstetricians and Gynecologists, wrote to a colleague about Noorchashm: "Nothing is going to create any peace in this man."

And then, in February, something shifted. Kaiser (the dean at Temple) passed Noorchashm's materials to the head of gynecology, who responded by making the institution the first to ban open morcellation, requiring surgeons to use an isolation bag or not morcellate at all. Within weeks, another hospital got

on board: Rochester General Health System declared that its surgeons wouldn't morcellate without a bag. Noorchashm wasn't satisfied—the bags could break, he said. He carried on with his campaign.

At the end of March, 5 months after the surgery that spread Reed's cancer, Brigham and Women's—Noorchashm's own employer—did the thing no one expected. The same administrators who had shaken their heads at this angry, disenfranchised surgeon finally acknowledged his case. They banned fibroid morcellation without a bag. Then, in mid-April, the FDA came out with a new analysis: A shocking 1 in 350 women seeking the removal of symptomatic fibroids has a hidden cancer, it said. The FDA issued an advisory strongly discouraging the use of morcellation, crediting Noorchashm with bringing the issue to its attention. More institutions, including the University of Pennsylvania

The New Hysterectomy Problem

If you're one of the half-million-plus American women facing the surgery this year, you may have a hard choice to make.

In April, crediting the couple's campaign, the FDA issued a statement discouraging the use of morcellation. In May, ACOG came out saying it was still a valid technique. Until there's consensus, the decision to morcellate or not lies with you, the patient. The options now:

OPEN HYSTERECTOMY

About 40% of hysterectomies in the United States are open abdominal surgeries, which require 6 weeks of recovery time, have a higher rate of complications, and leave a large scar.

VAGINAL HYSTERECTOMY

Here, the uterus is cut away laparoscopically and removed through the vaginal canal. Thanks to minimal incisions and a short 2-week recovery period, there's a lower rate of complications, which makes it ACOG's approach of choice. Only about 20% of hysterectomies are done vaginally, since it's not possible with enlarged uteruses or large fibroids.

MORCELLATION HYSTERECTOMY

Until now, a third of hysterectomies involved power morcellators, with or without isolation bags. These tools cut apart a uterus that has become enlarged so it can be removed either through the small incisions or vaginally.

OTHER TECHNIQUES

Fibroid treatments beyond hysterectomy include ultrasound surgery (in which sound waves are used to heat and destroy fibroids) and minimally invasive procedures like embolization, in which blood flow to the fibroids is cut off, causing them to shrink and die.

Health System and Cleveland Clinic, changed policies. And Johnson & Johnson, the biggest morcellator maker in the United States, suspended production and sale of the tool. Noorchashm's life was shattered, but he had achieved much of his goal. "We have the privilege of being able to give meaning to what's happened to us," he says. "That gives us strength."

But he and Reed aren't finished. The FDA will hold a hearing in July, and Noorchashm expects it to be contentious. "That's when the likes of Gerald Joseph"—the man who said that Noorchashm would never find peace—"will come in with their suits and their lawyers and make arguments about the 'benefit of the majority,'" he says. "But medicine is not a popularity contest. You have to practice in a way that every single person matters."

Reed knows her chances of living to see her youngest son graduate from high school are slim. She copes, in part, by resisting the urge to focus on probabilities. The first time she Googled *leiomyosarcoma*—the day the surgeon called her—was also the last. "If your chance of living is 30% versus 70%—I don't even know what to do with that," she says. "You don't live 30%. You live or die. And either way, today I could be hit by a car."

She certainly wasn't the type to wait around for her cancer to spread. She opted instead for a radical procedure, performed by only a few surgeons in the country. The Sugarbaker operation, named for its inventor, Paul Sugarbaker, is a brutal 9-hour surgery that removes all visible evidence of sarcoma, as well as the patient's appendix, gallbladder, omentum (the fatty covering of the intestines), and peritoneum. Once the organs are gone, surgeons pour heated chemotherapy into the abdominal cavity and let it sit for 90 minutes. Sugarbaker told Reed that if the surgery went well, she'd have an 80% chance of having no recurrence in her belly in 10 years. In other words, she'd be back to baseline, back to where she would have been if the cancer had not been upstaged. "That was the best number I'd heard," she says, her eyes a little teary for the first time. So in November, she and Noorchashm

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flew to Washington, DC, for the surgery. Before getting on the plane, she nursed her youngest son, then 14 months old, for the last time and handed him to her mother.

Reed's recovery was more grueling than she'd anticipated. She couldn't eat for 10 days and lost 20 pounds. The incision, which runs from her sternum to her pubic bone, was so taut she couldn't stand up straight for weeks; even now she sometimes hunches to minimize the pain. Once that healed, she started on a course of chemotherapy, which just finished. And now comes the hardest part. "I'm afraid to be done with chemo," she says one afternoon, her youngest son curled on her lap under a blanket. "At least I was poisoning the cancer. Now what happens? Now I wait?"

Her son sits up suddenly and grabs a plastic hippo, making it clomp across the kitchen table. Reed holds the boy loosely, one arm across his legs, and when he slides off her lap to chase a squirrel from one window to another, she lets him go without hesitation. She's started making plans for the near future, for the time when they can get back to some semblance of normal life. She's maintained a research lab over the past 10 years, and she and Noorchashm are talking about working together to study, and ultimately defeat, leiomyosarcoma. "We have the know-how, and we certainly have the drive," she says.

At 2 AM the house is quiet. Reed and the children sleep upstairs, but Noorchashm is still awake downstairs. He sits alone in a small pool of light, staring at a bronze statue on the mantel: St. George on his horse, his magical spear poised to slay the dragon. In the story, George kills the dragon to save not just the princess but also the rest of the town's children, who were being fed to the dragon one by one to appease it.

It's a metaphor, Noorchashm thinks. No, it's more than a metaphor; it's the new story of their lives, a fight to the death with the powerful creature that has changed their world forever. The horse is the media and doctors he's rallying to the cause; the shield represents the status of being a cardiac surgeon at Harvard. In some versions of the myth, the princess lives but George winds up dead; in others they get a happily-ever-after ending.

Noorchashm is a realist; he knows that odds are he will lose his wife sooner rather than later. He may also lose his career, but he's not worried about that just now. He's focused on the moment, the here and now. This fight he and his wife are immersed in, a fight not of their choosing.

He taps his long surgeon's fingers against the metal, sets the statue down on the desk, pulls the laptop closer, and opens a new e-mail. He is not just George but the spear itself, aimed at the dark and bitter heart of the monster.