A Common Tale

At 47, Beverly Johnson had a hysterectomy to eliminate uterine fibroids. Today, the supermodel wishes she had known more about other available treatments. Johnson almost died from severe complications of the operation—only to have premature menopausal symptoms seriously throw her life out of balance. Now a health activist, she is making sure other women are fully informed about their options.

February 27, 2009 By Kate Ferguson

While in her 30s and at a routine visit to her gynecologist, Beverly Johnson was unprepared for what the doctor said as he inspected her pelvic area: “Hmmm. You have a tumor here.”

Alarmed, the history-making supermodel, actress, author and businesswoman listened as her doctor explained that he’d found a benign fibroid in her uterine wall. Although she’d previously heard about fibroids, she wasn’t aware that she had any. Anxious to know more, Johnson fired a few basic questions at her doctor and got surprising answers.

“Why do you get them?”

“Well, we don’t know. But African-American women get them more than anyone.”

“Why is that?”

“Well, we don’t know.”

What doctors do know about uterine fibroids is that they are noncancerous tumors that grow within the uterine wall. They most often appear during women’s childbearing years. Not associated with an increased risk of uterine cancer, fibroids are also called fibromyomas, leiomyomas or myomas.

According to research, as many as three out of four American women have uterine fibroids. Statistics also reveal that African-American women are three times more likely to have uterine fibroids than Caucasian women. As Johnson’s physician indicated, the exact cause of uterine fibroids is unclear, but doctors have indicated that there is a hormonal and genetic connection.

“I still revere doctors,” Johnson says. “But at the time [of my diagnosis], I thought they knew everything, particularly about your body. To have those kinds of responses [was not very reassuring].” Neither was the news that uterine fibroids grow and multiply—even though more than 99 percent of the cases never turn into anything else but benign tumors.

“What my gynecologist told me was, ‘We’ll just wait and see; we’ll just watch them,’ which is a scary suggestion,” she says.

And so Johnson waited and watched, religiously going in for her annual checkups. When she reached her early 40s, however, her once very mild menstrual cycle became a menacing stranger in her body. “My periods started to get longer and heavier; I had more irritability,” she recalls. “I could actually feel the PMS symptoms happening. I could tell when I was going into my cycle. I’d never had that before in my entire life.”

Johnson’s doctor explained that the fibroids were causing these changes—and they were getting bigger. When she asked her gynecologist what was going to happen, he told her that if she could make it to menopause, her fibroids could decrease in size and possibly disappear. (Estrogen levels decline after menopause, and fibroids require this hormone to grow.) If they didn’t, the doctor said, there were several options she could take.

Soon after, Johnson’s uterine fibroid condition worsened. “I was practically menstruating every day for a year,” she says. “And my story is not uncommon. But, for me, it still feels like I was the only one in the world who was at home having to be near a bathroom—no modeling, no golf, no relationship—the quality of my life just dipped.”

After considering the options given to her, Johnson chose to undergo a myomectomy—a surgical procedure to remove only the fibroids. Johnson’s symptoms, however, did not improve. Two years later, in 1999, her fibroids returned. Desperately wanting relief from her symptoms, she opted for her doctor’s most extreme recommendation. She got a hysterectomy.

“I had the procedure and, unfortunately, suffered severe complications from it,” Johnson says. “While hysterectomy is a viable choice for some women, there are other treatment options that may be better suited for others. I wasn’t given an option, and, I admit, I didn’t do research to learn what else was available.”

Unaware of the impact the hysterectomy would have on her life, Johnson saw the major operation only as the “end of the most horrible ordeal” she’d been living since she’d turned 30. Although she was aware that a hysterectomy would mean being unable to have another child (she already had one daughter) and losing her uterus, she didn’t consider any of the other life-changing consequences the procedure might have.

“I think I took for granted a little bit the seriousness of the operation because I did not tell my mother, my daughter or anyone,” she reveals. “I went into surgery with my business manager and my holistic boyfriend—who was trying to treat me with acupuncture and herbs.”

Initially thinking that she would be in the hospital for only three days followed by six weeks of recovery, Johnson wound up staying in the hospital for over a month. Complications from the hysterectomy led to an additional surgery to save her life—an event she calls “my first near-death experience.”

Hospitalized, Johnson was besieged by family and friends demanding to know why she had kept her diagnoses a secret. Lying on the hospital bed, she was confronted with the sight of her daughter, upset and in tears. That's when Johnson realized the gravity of her actions.

Still, there was one more repercussion Johnson hadn't considered. "It was a very long recovery going from that sort of double operation. Once you lose your uterus and ovaries, menopause sets in," she recalls. "I had forgotten that part."

Johnson was not ready for this permanent side effect. "That brought me to a whole 'nother stage of my womanhood that I was unprepared for in my 40s," she says. "I was preparing for it in my 50s, but I wasn't preparing for it then. It was really a nightmare—a long, long nightmare."

No longer suffering from the heavy bleeding that had kept her under house arrest for a year, Johnson now faced other quality-of-life issues. Triggered by severe menopausal hormonal imbalances, she experienced weight gain, skin problems, fatigue and a total loss of sex drive. On top of that, night sweats deprived her of regular sleep.

After trying a number of holistic and herbal treatments, Johnson opted for hormone replacement therapy (HRT) "to get her body and life back into balance."

Doctors consider HRT—also known as PHT (post-menopausal hormone therapy) and ERT (estrogen replacement therapy)—to be an effective treatment for menopausal symptoms in general, but it's not without side effects. Some include headache, breast tenderness, spotting or bleeding and nausea. Additionally, cancer risks may be associated with long-term use of hormones, according to the American Cancer Society (ACS).

The ACS defines HRT as administering both estrogen and progestin, the two hormones that diminish with the onset of menopause. (ERT uses estrogen alone for treatment.) Before women make the decision to use hormone replacement therapy, however, the ACS advises them to consult with their doctors to weigh the benefits and possible risks of the treatment. Risks include breast, endometrial and ovarian cancer or other serious conditions, such as heart disease, stroke and blood clots.

For Johnson, HRT worked. But this time, she had made her decision for treatment as a more informed patient. She knew that despite the effectiveness of the treatment, it came with caveats to consider. "Finally, I found that kind of hormonal cocktail that works for me," she says. "But I am also aware of all of the reports and studies that discuss what happens when one ingests estrogen."

Absent from the modeling scene because of her uterine fibroid condition and the consequent surgeries, Johnson resumed her career and started telling friends what had happened. She was surprised to hear how many women had shared her experience. "The story is so common," she says. "The exact same things have happened to so many women. We're talking about one out of every four American women, and, by 50, 80 percent of African-American women suffer from uterine fibroids."

Once Johnson began sharing her story, several magazines approached her for interviews to detail her experiences. She also appeared on talk radio programs.

“It’s really important that women know and empower themselves so they can go to their doctors knowing the options they have available,” Johnson says. “I would have saved myself—and, of course, hindsight is 20/20—so much aggravation.”

At the time of her diagnosis, Johnson didn’t know that uterine fibroids were as prevalent. She also didn’t know that she could have explored noninvasive treatments and other options.

“A hysterectomy may have very well been the best thing for me to do—I’m not doubting that—but I would have loved to have known all about uterine fibroids,” she says. “I would have loved to be equipped with knowledge and not feel it was this whole doom and gloom [situation] where it’s, ‘Oh my God, I’ve got something growing inside me, and I can’t tell anybody.’”

Because of her experiences, Johnson became a spokesperson for the Ask4Tell4 campaign, sponsored by BioSphere Medical Inc. The campaign, along with its companion website, Ask4Tell4.com, highlights four questions every woman should ask about uterine fibroids—and then suggests they tell four or more friends about the information.

Now a health advocate for life, Johnson plans to stay with the campaign forever. “I say ‘forever’ meaning that it’s really great that women can go to a website where they can have an extensive wealth of knowledge about uterine fibroids. My story is also there, putting a face on uterine fibroids.”

But fibroid awareness is not the only cause Johnson champions. “I’m a very big woman’s health activist,” she says. “It’s not something that I’m just doing for the moment. I feel very strong about preventive health—going in for your mammogram, your PAP smear, that lung X-ray—all those things that one needs to just reassure oneself that, ‘Hey, I’m doing right by my body; I’m taking care of myself.’” It’s great, says Johnson, that appearance-enhancing cosmetic procedures are available, but they are not crucial for good health.

Johnson also wants women to start speaking with each other about their health. She says her mother also had a hysterectomy—but, to this day, it’s never been discussed. “I think there’s this stigma or this taboo about [it] from generation to generation,” Johnson says.

The Ask4Tell4 campaign has helped open a dialogue among women, including between Johnson and her daughter, Anansa. “She knows my whole campaign better than I do because I’m around her all the time,” Johnson says. “She’s not going to have to go through the angst that I went through if, in fact, she does have fibroids or if, in fact, they are symptomatic. She’ll know about other noninvasive ways to treat fibroids.” To Johnson, passing on this knowledge will help make her hellish hysterectomy experience a not-so-common tale for other women with this very treatable condition.

Uterine Fibroid Treatment Options

Depending on the circumstances, treatment options for uterine fibroids—benign tumors of muscular tissue—vary. RH encourages women to conduct research, speak to other women with uterine fibroids and discuss with their gynecologists what options may be best for them.

No treatment necessary

If your uterine fibroids don’t cause any symptoms or problems, treatment may be unnecessary. For women who experience occasional pain or mild symptoms, however, doctors may suggest over-the-counter or prescription pain medication.

Medical therapy

Another nonsurgical option for uterine fibroid treatment is prescription medication. These include hormones such as gonadotropin-releasing hormone agonists (GnRHa), as well as antihormonal agents such as mifepristone. Hormone treatments offer only temporary relief, however, and may cause menopausal symptoms.

Nonsurgical procedures

These include MR-guided focused ultrasound (MRgFUS) in which ultrasound waves penetrate the abdominal wall, heat fibroid tissue and shrink the tumor. Another procedure is uterine fibroid embolization (UFE), which shrinks fibroids by blocking blood flow to them. With each of these treatments, fibroids may return.

Surgical procedures

Options range from minor to major surgery. Endometrial ablation removes the uterus lining to reduce heavy menstrual bleeding primarily caused by submucosal fibroids. (These fibroids expand from the uterine wall into the uterine cavity.) This option ends fertility. A myomectomy removes only fibroids; it leaves the uterus—and fertility—intact. The only way to permanently cure uterine fibroids, a hysterectomy also removes the uterus and ends fertility. Hysterectomies also trigger menopausal symptoms.
