When his PSA score spiked, prostate surgery loomed, but NIH offered another way

Daniel Peck/Peck Studios - For Jim Cassell and his wife, Marilyn Fenichel, a warning about prostate cancer left them feeling “as though we’d fallen down a medical rabbit hole.”

By Marilyn Fenichel, Published: February 25, 2013 E-mail the writer

A few weeks before our long-awaited trip to Italy in 2011, my husband, Jim, received a disconcerting phone call about one of the results of his annual physical. Jim’s PSA, a blood test that screens for early-stage prostate cancer, had been rising over the past couple of years. His internist was becoming concerned, and he suggested that Jim get another PSA when he returned from Europe.

I didn’t think much about this while we were away. I assumed my healthy, youthful husband, in his early 60s, couldn’t possibly be one of the almost 2.5 million American men living with prostate cancer. So I was surprised when the PSA test Jim had after our trip showed a continued increase. With this latest information, Jim’s internist thought it was time for him to see a urologist.

We made an appointment and unknowingly entered into the contentious arena of how to respond to potentially worrisome prostate cancer tests.

Originally used to track the progress of cancer treatment, the PSA test is now widely used to detect possible signs of early-stage prostate cancer. But it is an imperfect tool — so imperfect, in fact, that recently the U.S. Preventive Services Task Force, which is charged with tracking medical practices and treatments, said the test should no longer be part of routine standard of care.The test does more harm, through unnecessary surgery, than good, the group said. The recommendation, which reversed the task force’s previous position, has been extremely controversial, with many urologists, cancer doctors and prostate cancer survivors decrying it, saying the PSA test had saved lives.

All of this, though, was well in the future. For now, all we knew was that his PSA was elevated. The question was what to do. In trying to answer that, we felt as though we'd fallen down a medical rabbit hole.

A puzzling about-face

The medical consensus has been that if the PSA number is above 4.0 and this is confirmed in a second test, a biopsy should be done. Clinicians also get concerned when the PSA number rises too quickly; a two-point rise — say, from 1.5 to 3.5 over a two- or three-year period — can be a red flag. My husband fell into the latter category. But as the urologist took great pains to tell us, the rise could mean nothing. Some men who have prostate cancer fall below 4.0, and others whose number is above 4.0 do not have cancer.

We found the doctor's realistic assessment of the PSA reassuring, and we were sure he wouldn't recommend a biopsy unless Jim's third PSA, done through the urologist's own lab, showed an increase. When the result came back, Jim's PSA number had stabilized, but the doctor nonetheless recommended a biopsy. When Jim asked why, the doctor expressed concern about the PSA numbers and thought that a biopsy was warranted.

We were puzzled by what seemed to be an about-face: First, the PSA was not to be trusted, then it was the reason to perform a painful, invasive procedure. But the doctor seemed sure, so Jim went ahead with the biopsy the next week.

When the results came back, the doctor explained them by laying out a diagram of Jim's prostate. He pointed to a bar, with a small area shaded in, on the lower-right segment, or core, which he said indicated the presence of a small, early-stage tumor. The doctor said the virulence of the tumor, measured by the Gleason score, was 6, which meant it was slow-growing. Two other cores had spots that looked suspicious, meaning they might develop into cancer down the road.

Fortunately, we were somewhat prepared for this moment. While waiting for the biopsy results, we had scoured the Internet about treatment options. At that time, the task force was in favor of "watchful waiting" for small tumors. This usually involves further testing at six-month intervals and biopsies yearly. Yet our search told us that 90 percent of men with early-stage cancer were treated, typically either with surgery to remove the prostate gland or with radiation.

After hearing Jim's diagnosis, we were hopeful that the urologist would recommend watchful waiting. But when I suggested that, he demurred. Then he launched into a speech I'm sure he had given many times before.

"Some men in our practice are on this protocol," he began. "But it's unnerving. You're never sure when the other shoe is going to drop, and the anxiety can wear you down. In cases like this, our recommendation is either external beam radiation or brachytherapy." Then he pulled out a long, clear syringe and explained that second option: radioactive beads implanted into the prostate in a two-hour outpatient procedure.

"The good news is that it's less invasive than surgery," the doctor told us. "But," he added, "you don't get something for nothing. Immediately following the procedure, you'll experience some urinary incontinence and perhaps some bowel irritation, but both should resolve in four to six weeks. There may be erectile dysfunction, which can be addressed with medications like Viagra."

We listened carefully, struck by the potential for extreme side effects when attempting to eradicate a small tumor. Mumbling that we would think about his recommendation, we left the office feeling unsettled. At the very least, this procedure would result in short-term complications, and there was a good chance that the problems would never go away completely.

Shortly after this session, we heard about two other possibilities. One was the active surveillance program at Johns Hopkins Hospital; the second was a clinical trial at the National Cancer Institute, where an MRI scanning device takes high-precision images of the prostate, revealing changes in tumors or the appearance of new malignant cells with greater accuracy. This is followed by treatment or active surveillance, depending on what is found. Jim called NCI but couldn't get an appointment soon. A Hopkins prostate cancer expert was able to see us almost right away. So we drove

from Silver Spring to Baltimore, optimistic that after seeing Jim's slides from the biopsy, the doctor would recommend surveillance.

The second opinion

Our meeting at Hopkins lasted about 20 minutes. After a brief introduction, the urologic oncologist gave Jim a quick exam, glanced at his PSA and biopsy results, and then gave his opinion: Although Jim's tumor would not cause him harm at this time, the rising PSA levels showed that the tumor might be more aggressive than it appeared. His recommendation was surgery, and the sooner the better. He handed us a folder showing the outcomes of his surgeries and a list of the names and phone numbers of men whom he had treated.

I left that meeting fearful that Jim's cancer was more virulent than I had thought and pushed for him to schedule surgery immediately. But Jim's response was more measured. He needed time to learn about the procedure. A week or two went by. Finally, he called a couple of the men whose contact information he had been given at Hopkins. Those conversations began to shed light on what really happens after surgery.

While trying to put a positive spin on it, most men reported side effects. There was post-surgery urinary incontinence, and the information about erectile dysfunction was particularly sobering. Even with medication, normal erectile function does not return completely, and some impotence was still reported a few years following surgery.

It was November, and we had been dealing with this issue for most of the year. Did it make sense to wait another month for the NCI appointment so that an MRI could be scheduled? Or should Jim just go ahead and get some form of treatment? I had recently seen a brochure advertising a local hospital support group for prostate cancer survivors and their wives. "Let's go to this," I said, and he agreed.

The hospital conference room was crowded with men at various stages of the prostate cancer continuum. Some were quite sick, dealing with metastatic disease that had spread to the bones. Others were Jim's age who, with a similar diagnosis, had opted for surgery. Hesitant to touch the delicate topic of impotence, the men instead discussed incontinence issues and the rate of improvement. In a difficult situation, most were seeing the glass as half full. Compared with many of the men, Jim was in an enviable position. He had a small tumor, and he had time to educate himself and make an informed decision.

After the session, an older man came up to us. "I think you should have the advanced MRI offered by NCI, and see if you can get into the surveillance protocol," he told Jim. Now approaching 80 years old, the man said that he had entered that protocol when he was younger. Then, at age 75, his prostate had become enlarged and he had no choice but to have it removed. But for the many years that he was on watchful waiting, he was only monitored and he was able to live without treatments and their side effects. He seemed robust and healthy.

He told us that the MRI device maps the entire prostate and that the information it produces would allow us to decide about treatment based on facts, not speculation. It made sense; Jim would keep his appointment at NCI before making any decisions.

'A breakthrough in imaging'

For almost a decade, research oncologists and medical engineers have been developing and refining a system using an advanced MRI device to take images of all 12 cores of the tiny prostate gland. This method "is a breakthrough in imaging for prostate cancer, analogous to the introduction of mammography for breast cancer," said Peter A. Pinto, head of the prostate cancer section of NCI's urologic oncology branch.

The advanced scanning and the physicians with expertise to interpret them are available at a couple of academic centers in this country. The MRI identifies potential cancerous sites, which can then be biopsied if necessary, but with a huge

advantage: “When we do a biopsy, we have a map in front of us,” Pinto said. “The information provided by the MRI guides the biopsy. It is no longer hit-or-miss,” which he said is often the case with regular biopsies.
When the NCI physicians looked at Jim’s MRI results, they were able to see that his prostate was free of large tumors. They saw the same small tumor, or lesion, that had shown up in the community hospital biopsy, but that was all. What’s more, the suspicious areas identified in the earlier biopsy looked totally normal. The precision of the MRI meant the doctors would be able to do a targeted biopsy. And they were thrilled to have Jim in the surveillance program, which meant no treatment, just regular monitoring

About six months after that MRI at NCI, Jim returned for a scheduled MRI-guided biopsy. We assumed that the tumor would be about the same. What we didn’t expect was the news we received: The tumor was smaller than originally thought. We even wondered whether Jim had cancer.

“Yes, the cancer is there, but it’s so microscopic that the needle doesn’t always pick it up,” Pinto told Jim. “And because your tumor is low-volume and low-grade, it doesn’t present an immediate threat, and it’s possible it may never do so.” He added that this is the kind of situation physicians hope for when recommending surveillance.

I can’t tell you the mix of emotions we had: relief and happiness, of course. But also a heightened awareness that it was only through a combination of luck and Jim’s stubbornness in putting his cancer fears on hold — and helping me assuage mine — that we were able to avoid unnecessary treatment.