Deciding Not to Treat My Cancer

Active surveillance spares men with low-risk prostate cancer, like me, from aggressive treatment and its side effects.

March 10, 2025 By Howard Wolinsky

In spring 2010, I was 63 and undergoing a physical exam. My internist ordered a prostate-specific antigen (PSA) blood test, a measure of a protein produced by the prostate. The male sex gland is about the size of a walnut or small lemon and is located below the bladder. Among other functions, it produces liquid in semen for sperm.

Higher levels of PSA—the threshold is 4 nanograms per milliliter (ng/mL)—can indicate an enlarged prostate, or possibly prostate cancer, the second most common cancer in men (after skin cancer) and the second most deadly cancer (after lung cancer) in American men. Biopsies can diagnose or rule out cancer.

Howard WolinskyCourtesy of Howard Wolinsky/Jean Lachat Photography

A PSA test can trigger a cascade of events leading to a prostate cancer diagnosis and aggressive treatment with side effects that can land you in adult diapers and render you impotent.

Like most men, I took the test with eyes wide shut. I never expected it to detect cancer. I was wrong, but this story has a happy ending.

My PSA was 3.95 ng/mL, and my internist was growing jittery. So he referred me to a urologist, who conducted a needle biopsy during which he poked my anesthetized prostate 14 times to remove tiny samples of tissue called cores. A pathologist examined the pattern of cells to determine whether cancer was present; if so, its aggressiveness would be ranked using the Gleason score, which ranges from 2 to 10. Gleason scores of 6 and above indicate cancer.

A world-renowned uropathologist found that I had a noncancerous growth that pathologists used to think might increase the risk of prostate cancer. (These days, experts don't worry about such growths.)

I had a transrectal biopsy six months later.

I wasn't warned that this type of biopsy, which passes a needle through the germy rectum, could cause sepsis that could be disabling and deadly.

Norwegian researchers estimate that each year, 2,000 American men die of biopsy-caused sepsis. European urologists prefer the safer transperineal biopsy that passes through the germ-free perineum, situated between the anus and the testicles.

The evening of December 3, 2010, the urologist called me at home and announced, "Mr. Wolinsky, you have cancer." He said we needed to meet to go over results and plan the next steps.

The urologist brought my wife, Judi, and me into a room and played a DVD on which he did the voice-over, describing various options: cryotherapy, which uses cold to destroy cancer cells; radical prostatectomy to remove the prostate; and radiation therapy. Treatment had risks, including temporary or permanent incontinence and erectile dysfunction.

Later, the doctor said he had "good news"—he could "cure" my cancer by removing the gland.

He didn't tell me, as I discovered later, that I had low-risk Gleason 6 prostate cancer, which really was the good news. (Gleason 6 is now called the less scary Grade Group 1; the most aggressive cancer is GG 5.)

I did my research before deciding whether to have surgery. I had heard about a young urologist at the University of Chicago, Scott Eggener, MD, who had started a new program for men like me to follow an emerging approach known as active surveillance (AS) in which patients are monitored closely via PSA tests, biopsies, digital rectal exams and the newly introduced multiparametric MRI prostate scans.

I asked urologist no. 1 about AS. He told me: “I don’t support that modality,” which was typical for 2010. (He supports it now.)

Eggener said the other urologist could indeed cure me but warned of the side effects. In my mid-60s, I found them unacceptable. Eggener called me “the poster boy for AS.”

Eggener shared with me a study by Laurence Klotz, MD, of the University of Toronto, one of the developers of AS, which found that the death rate for men with Gleason 6 prostate cancer was the same whether they went on active surveillance, had surgery or did radiation therapy.

I thought, Why have surgery or radiation, if I can get the same results with active surveillance and potentially live the rest of my life untreated? The decision was one of the fastest I ever made, though I understand that many men cannot stand the thought of living with even a “wimpy” cancer.

Eggener predicted that my low-risk prostate cancer wouldn’t grow in 10 years. In fact, the cancer hasn’t been seen in four subsequent biopsies.

Klotz proposes that my immune system vanquished the cancer. And yet, I still am tagged as a prostate cancer patient because most experts think the cancer is lurking in my prostate.

I have not had an MRI, now considered a first step before sticking men with needles for a biopsy, since 2016. Rather, I’ve been on a de-intensified version of AS known as watchful waiting—I call it AS lite. If my PSA level increases, I will have an MRI or, after that, a transperineal biopsy, if needed.

When I went on AS in 2010, only 6% to 10% of American men with Gleason 6 chose this approach. Today, 60% go on AS, according to the American Urological Association. That’s a big jump, but it means that 40% of men are still undergoing aggressive treatment, compared with fewer than 5%

of comparable men in the United Kingdom and Sweden.

Here’s a tip for men diagnosed with prostate cancer: Get a second or third expert opinion of the biopsy results—which are wrong 20% of the time.

During my 14 years on AS, care has changed dramatically. MRIs play a growing role in helping about half of men like me avoid biopsies, unnecessary cancer diagnoses and surveillance.

Newer biomarker tests, such as Stockholm 3, MyProstateScore 2.0 and IsoPSA, can produce similar results. The ArteraAI Prostate Cancer Test, approved in 2024, uses artificial intelligence analysis of biopsy images and has recommended that 60% of patients are candidates for active surveillance.

Genetic testing is becoming more common to help set the course for treatment. And digital rectal exams, which many men find uncomfortable, are being phased out because of the MRI.

Looking at the future of low-risk prostate cancer, I see fewer men being diagnosed, which can lead to emotional distress and financial toxicity—such as denial of life insurance—and fewer men going on active surveillance, which itself is stressful for many.

Howard Wolinsky is a 27-year veteran of the Chicago Sun-Times and a two-time Pulitzer Prize nominee. He’s a cofounder of the low-risk prostate cancer support groups Active Surveillance Patients International and the virtual active surveillance group for the AnCan Foundation. He is the editor of the Substack newsletter TheActiveSurveillor.com.

Editor’s note: An earlier version incorrectly stated that ArteraAI prevents 60% of biopsies; in fact, it is based on biopsies and recommends that 60% of its patients are candidates for active surveillance. We regret the error and updated the article.
