

Trust Your Instincts

By Jan Manarite and John Mullineaux, PCRI Helpline Facilitators

Recently, the PCRI Helpline received a call from a newly diagnosed man. Having no health insurance, Mr. R.'s only entry into the health care system was as a military veteran through his local VA center. A PSA test had come back elevated the year before and his doctor wanted him retested. For some reason the test got delayed, and Mr. R. had to call his urologist several times to try and reschedule. After months of delays, Mr. R. had a second PSA test that was also high, 13.8. Because he is African-American and at higher risk for prostate cancer, his doctor scheduled him for a biopsy.

Mr. R. was informed that he had prostate cancer by a message left on his answering machine, which was overwhelming and frustrating for him. He was also told to schedule an immediate appointment to see his urologist. At that appointment, Mr. R. was told he had to schedule surgery immediately, but he left with no understanding of his personal cancer characteristics. He did not know his

Gleason Score or what a Gleason was. He did not know how many biopsy cores were cancerous, or the size of his prostate. And he left with no medical records.

Following his instincts, Mr. R. told his doctor he needed to understand other options first and called the PCRI Helpline. During that call, the Helpline explained that every prostate cancer is different, and it is critical to understand the characteristics of each case. We suggested he obtain copies of his medical records and gave him a short and simple list of what to ask for at his doctor's office.

On the follow up call, the Helpline staff helped Mr. R. understand his biopsy report which showed significant amounts of Gleason Score 9, and cancer in all 12 cores. He was only age 56. We helped him understand that he would be categorized as high risk prostate cancer because of his Gleason and PSA, and it would be prudent to also get an opinion

from a radiation oncologist. We helped him to look at both risk and benefit when choosing a treatment, and helped him develop questions for his physicians based on his personal situation. Even though this was overwhelming at times, Mr. R. was confident, determined, and felt glad that he trusted his instincts to not rush into surgery. He felt empowered that he now had a basic but clear understanding of his Gleason and PSA.

The PCRI Helpline also helped to connect Mr. R. with an UsTOO support group in his city, where some of the men were familiar with the VA system, and local resources. This contact might help give him ongoing support through whatever treatment decision he makes. He now understands that every prostate cancer is different, and most importantly, how his case was different. His instincts to follow up, ask questions, and not rush into a treatment were validated by what he learned, and his instincts served him well. □