

Dear Doctors,

The following are remarks made by one man but echoing that remarked by multitudes of patients on most all online prostate cancer support lists (and there are many such support lists with thousands of subscribers). I see these remarks as very important and addressing them by each of you would greatly enhance increased respect by your patients for being open and forthcoming with the issues addressed. These are concerns at all levels of treatment from Urology to Radiation Oncology to Medical Oncology; patients want to know “up front” what to expect. They are incensed in learning post-whatever treatment administered the side effects they are experiencing that were either never explained to them, were briefly explained but making statements that whatever occurred could be entirely remedied when that is not the case, or were intentionally neglected to explain. And then when these side effects arise, in the eyes of patients too many physicians try to make light of them and/or offer little to no concern in providing reasonable and appropriate remedies. The last sentence of this patient’s remarks should be strongly considered.

“I reluctantly support PSA testing, because it is all we have. What I cannot support is a prostate cancer treatment industry that promotes harmful and unnecessary treatment with misinformation and outright lies. What part of this do they think is better as a surprise and not a part of informed consent? Lack of orgasm? Urine leakage during sex? Shrinkage and atrophy? Depression and contemplation of suicide? These were among my surprises after treatment at a "center of excellence" and "comprehensive cancer treatment center". I think the answer is that they simply don't care. Their follow up questionnaires, while purporting to express a concern about how the patient is doing, are really cleverly designed to ignore the details and generate statistics that they can use to promote their program. The really tragic thing about all of this is that if they never ask the right questions about what is going on with their patients they will never identify the consequences of their treatments let alone develop effective treatments for those consequences. In fact, the best help I have received with my post-treatment problems has come not from physicians, but from people on this list. I wish I had known about Chuck's site before I made my treatment decision.

So what do we do? I wish I knew. I have had follow up discussions with my treating physicians that contributed to some improvements (routine early prescription of daily PDE5's and more mental health referrals). Nonetheless, we continue to see guys in support groups with problems and stories about their treatment experiences that are little different from what I experienced in 2010. What is really needed is a dedicated group of physicians, patients and other health

care providers to develop "best practices" for prostate cancer treatment, including pre-treatment disclosure, delivery of appropriate treatment, mental health counseling and, for those who want it, the most effective rehabilitation possible.”