

The Importance Of Belonging To A Support Group

Gene Van Vleet, Vice President and Director
Informed Prostate Cancer Support Group, San Diego, California

Following the recent consternation provoked by the recommendation of the U.S. Preventive Services Task Force (USPSTF) panel to discontinue PSA testing, it is fitting that we address the benefits provided by support groups in dealing with Prostate Cancer.

Commonly a man visits his general practitioner on an annual basis for a general physical. This can include bloodwork that includes a PSA test and a digital rectal exam (DRE). Make sure you keep a log of your results. Too often the patient is not informed of the results but rather is informed "everything is OK". If the PSA test and/or the DRE is of concern to the physician the patient is referred to a urologist for further diagnosis. All too often the next step is a biopsy. Once a biopsy is performed, the roller coaster of treatment options begins. WAIT A MINUTE!!! What is missing here? Patient knowledge and understanding!

As principals of a highly active support group it is our experience that we are most commonly contacted by patients either after a biopsy or after a relapse following treatment. We can help fill the knowledge gap and lead men to information with which they can learn to be their own case managers rather than be reliant on physicians' recommendations. We are by no means medical professionals but we have the knowledge of collective experience to aid men through the confusion of dealing with our troublesome disease. Further, we bring specialists in dealing with our disease to our group meetings to keep us informed of the latest developments without the restrictions of learning and protocol too often suffered within the medical community.

Let us begin with the myth of the PSA test. It was never intended to be utilized as an indicator of the seriousness of the cancer. Its best value is as a marker to monitor elevation over time. Concerns should develop if the score doubles within a year. Simple logic must be used if the score begins rising. It could be because of an ancillary infection. It could be because the test was performed by a different laboratory. It could be because of strenuous exercise prior to the test. One should first verify the test before proceeding. If the PSA is proved to be validly escalating, be real careful about the usual next step---Biopsy.

There has been significant progress lately in prostate imaging that can analyze the condition of the prostate BEFORE an invasive biopsy is performed. Should such imaging indicate the need, a biopsy can then be performed aided by that imaging. Please, no more random biopsies that may miss the troublesome area! Where do you get these tests? Your support group is a good place to find where such imaging is available in your area.

The Importance Of Belonging To A Support Group

If you have reached the stage of having a biopsy performed a Gleason score results which has been the landmark for determining the seriousness of the cancer. Other tests are arising and being validated that can assist in this determination as well. Your support group will likely know their status or can lead you to sources that will know.

We hear too often of cases where a patient is given treatment without a complete medical check-up. Pity the poor man who saw his urologist because his PSA was rising rapidly. He was given a hormone injection and consequently suffered atrial fibrillation and, later, a mild stroke. His physician failed to check overall physical condition. Incomplete medical training associated with proper health investigation before treatment can be a problem.

Once a Gleason score is rendered, too often treatment is implemented before a thorough understanding of the possible effects on the patient's life are achieved. Surgery? Radiation? Cryoablation? HIFU? Hormone Therapy? Et al. What a maze of possibilities exist. Get involved with your support group and benefit from their knowledge and experience.

We think one of the major oversights in treatment possibilities is no treatment at all or Active Surveillance (often called Watchful Waiting). Dr. Duke Bahn has quantified those tests that can be monitored by a patient over time in concert with his doctor without undergoing invasive treatment (see PAACT article in March, 2011 issue). An important element of this choice is the mental capacity to overcome a man's natural urge to do something to "cure" the disease. Be careful of that word. When someone uses it, make them define to you what they mean. It might be that they consider you "cured" if you don't experience signs over a much shorter time span than you expect.

If you are faced with making a treatment choice, be sure you develop an understanding of the possible side effects of the chosen treatment. Another unfortunate issue in dealing with prostate cancer is that it is difficult to predict how a patient will react to the treatment. Your physician may cite percentages of success, but there is yet no way to ensure what your experience will be. Be sure to check the experience of the doctor treating you. The most experienced doctor will achieve the best results. And, for sure, seek second opinions from unassociated doctors. This can be difficult because of insurance coverage limitations, but it will be in your best interest. Remember, you are your own case manager. Have confidence that unless you are diagnosed at a late stage the disease is generally slow moving. You have time to assess your treatment possibilities before committing.

The Importance Of Belonging To A Support Group

Stay involved with your support group. You will find comfort in networking with others to help them as you are being helped. The natural tendency is to be involved through treatment and then disengage. There is value in continuing to stay involved to learn of advances in diagnosis and treatment. It keeps you aware of monitoring your own condition. Too many of the newcomers to our group are experiencing recurrence. Staying abreast of your condition and what is developing in the treatment of the disease will surely give you the opportunity to deal with it successfully. Remember, YOU CAN LIVE WITH PROSTATE CANCER!

Gene Van Vleet Vice President and Director
Informed Prostate Cancer Support Group, San Diego, California
<http://ipcsq.org> 1-619-890-8447 Gene@ipcsq.org