

# **A Patient's Perspective**

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## **I. Communication**

The knowledge that patients have is variable, and we use this presentation as an educational tool, but we mostly emphasize the quality of life issues. We have come to see that communication between a patient and physician is absolutely necessary for optimum treatment results, and this is an area where significant improvement is needed.

Patients believe that one-on-one discussions with an experienced patient advocate help them more than anything else that they have done. It helps them to talk to one patient or several patients who have been through it before them. Every choice they make has pros and cons, and they need to sort through the issues with someone who has made those decisions also.

## **II. Active Surveillance**

As an example, many patients don't know about active surveillance. It may not be the best choice for them necessarily, but patients need to still hear about the choices and be given the opportunity to make the best decision for them. A major advantage is that it avoids ED and incontinence though there is anxiety about the possible risk of developing undetectable, aggressive cancer. Repeat biopsies are certainly not acceptable, and they may make the surgery more difficult in the long run. It is not just a prostate cancer patient, but it is a person with a prostate cancer problem.

## **III. Hormone Therapy**

Another topic is the discussion of hormone therapy. The side effects are a major cause of concern for patients, and they want to talk about the side effects. I made the choice of using androgen ablation therapy. For the last almost ten years what I have been doing is taking the pills for seven to eight months continuously, and I then go off it for three or four months. I could give it a try, and if it didn't work I had other options. So far it seems to be working. There is the potential for cardiovascular problems, and there is the issue of the loss of libido, which Viagra does not help. There is no doubt that intermittent hormone therapy is the one that is preferred.

## **IV. Advanced Disease**

If I am reaching the state of advanced disease, I want to know in what order I should proceed. Not only that, if I take a drug in some of the clinical trial protocols, it precludes me from participation in another, which is information that I want to know up front. I am not always confident that my oncologist has all of the information or has the time to inform me appropriately. In addition to that, there are difficulties with Medicare and

insurance that I need to understand, and a lot of support needs to be provided to patients regarding these issues. With some of the new medications there are some difficulties in weighing the few months' prolongation of life against the cost, whether in side effects or financial cost. Patients also need information about clinical trial design such as placebo control, etc. The patient's benefit may be delayed or non-existent depending on the trial design.

## **V. Surgery and Radiation Therapy**

Sometimes healthcare providers do not give patients enough information particularly post-surgery and post-radiation, and patients end up in the emergency room because of that lack of information. We get vague descriptions about ED and incontinence, and percentages do not necessarily help because we don't know where in the percentages we are going to fall. Doctors have limited time, but there are times when patients need to be more assertive in demanding explanations.

## **VI. Live Long and Prosper**

There are many new diagnostic and treatment options for prostate cancer patients that were not available only a few years ago. Even men with very serious prostate cancer can live long and productive lives.