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ADVICE TO THE NEWLY DIAGNOSED Donna Pogliano

Donna Pogliano is the co-author of the book "A Primer on Prostate Cancer, The Empowered Patient's Guide" ISBN 0-9658777-6-0 and is also a prostate cancer activist. Here is an edited version of the post she put on a Mailing List in December 2004. There have been changes in some treatment options since then – notably the growth in popularity of RALP (Robotic Assisted Laparoscopic Surgery), but most of what she has to say is still relevant.

The background to her post was a request for advice from a man who said he had a Gleason 6 and a PSA of 5.15. He had been recommended by a friend to consider having radiation treatment rather than surgery and he was asking for information or advice on these two options.

Her basic advice can be summarised as:

Start educating yourself further. You have time. You don't need to rush into a treatment decision you may live to regret. At minimum, you should:

- **Have your Gleason verified by an expert**
- **Answer the question: Do I really need to be treated or am I a candidate for giving Active Surveillance a try?**
- **If immediate treatment is indicated based on thorough staging of the extent and nature of disease, be sure the procedure is done by an expert.**
- **If you are considering local treatment you need to be fully informed regarding the details of how the procedure is conducted, what the side effects are, what the probability of recurrence is likely to be, what the financial ramifications of your treatment are and how they will be handled, and what salvage options are available to you if primary treatment should be unsuccessful.**
- **If you are considering a form of local treatment you need to know how your present age, other health issues, urinary status and priorities figure into the equation.**

Here is the full version of what Donna said to him:

I'm sure this is way more than you wanted to know, but there might be other guys out there that could use some of this information, so I'll try to touch most of the bases.

You should have your Gleason 6 reviewed by an expert pathologist experienced in reading prostate cancer slides. I would also encourage you to avail yourself of imaging techniques such as color-doppler ultrasound or MRI with spectroscopy to establish your true extent of disease.

You need to educate yourself about all the options once you know your true extent of disease, not just the one your friend might choose or the one your doctor

(probably a urologist who is a surgeon) recommended. Consult with, at minimum, a urologist and a radiation oncologist so you have the advantage of being able to view the problem from different perspectives. If you're interested in cryosurgery, visit the CryoCarePCA website and find a cryosurgeon to consult with as well.

If you have organ-confined disease, you have the full array of local treatment options open to you. There are surgical options including both radical prostatectomy and laparoscopic surgery. Surgery has some side effects that might not be practical or palatable for you, and it's lost its lustre as the Gold Standard. No matter. There are plenty of alternatives. Some form of radiation might appeal to you, including permanent seed implants (SI) or high dose rate brachytherapy (HDR), perhaps even as monotherapy if it turns out that you have a small tumor volume. This may be the least disruptive treatment option you can undertake and still be treated with a local therapy. Men with incidental disease who are not emotionally comfortable with Watchful Waiting sometimes opt for definitive treatment with brachytherapy as monotherapy or for focal cryosurgery. Cryosurgery which might be possible using focal cryosurgery to spare at least one erectile nerve might be a consideration if a man's cancer is confirmed to be confined at least at present to only one side of the prostate. Usually there are small sub clinical foci of cancer in addition to tumors large enough to be imaged, but cryosurgery can be repeated so it provides its own salvage treatment, as long as the cancer is determined to still be organ-confined. Are you beginning to see how imaging can help you in your decision-making process? You need to know what you're dealing with before you can start figuring out what to do about it.

If you have a low tumor volume, the first option you should consider in my opinion, is the least invasive one (Active Surveillance/Watchful Waiting), not the most invasive one (some form of surgery). You have garden-variety prostate cancer if you have a non-palpable tumor with Gleason 6 as verified by an expert pathologist and a PSA under 10. You need to monitor your PSA doubling time and velocity so that you can judge the tempo of your disease. You need to figure out what else in your life might need to be fixed that might take precedence over leaping into treatment for what might be relatively indolent prostate cancer. It would help if we knew your clinical stage as determined by DRE (Digital Rectal Examination). A palpable tumor might require a more aggressive course of disease management as opposed to one that can't be felt on DRE. The location of the tumor is important. Transitional zone cancers close to the center of the gland don't present the same risk for extracapsular penetration as tumors which arise in the peripheral zone. This could be a factor in deciding what course of disease management is appropriate to your stage and grade of tumor. Are you beginning to see why imaging could be important to establish where your tumor is located and how large it is?

Radiation therapy is a highly volume-dependent treatment modality. Sometimes men with large glands or large tumor volumes can benefit from a course of androgen deprivation therapy prior to radiation treatment. This may improve the outcome for certain patients. Medical oncologists specialize in the principles and practice of androgen deprivation therapy. If you need to use ADT (Androgen Deprivation Therapy), avail

yourself of the services of an expert medical oncologist. Improperly used, androgen deprivation therapy can actually make your situation worse.

You need to know your gland volume as well as your tumor volume. If you know your gland volume, you can calculate how much benign PSA would be produced by a gland of your size. The difference between that amount and the total amount of PSA would be indicative of the amount of PSA that might be attributable to a prostate cancer tumor, and that amount of PSA can be used to calculate your tumor volume. But tumor volume and location are best determined by LOOKING at the tumor. As expert ultrasonographer Dr. Fred Lee quotes, "One look is worth a thousand words."

It doesn't matter what your friends with prostate cancer decide to do. That doesn't have any relevance in terms of what YOU should do. You are unique in all the world. Your cancer is unique, your goals and dreams and priorities are unique, your emotional and coping habits are unique and the way your body works is unique to you. One thing you BOTH should do is to know everything that it is possible to know about your cancer BEFORE making a treatment decision.

But before undertaking any local treatment, including some flavor of radiation therapy, you should know the probability of systemic disease using other markers in addition to PSA. Monitoring blood tests such as CGA, NSE and CEA can help to give indication of sub clinical micro metastases too small to detect with currently available technologies. Ploidy analysis on the original tumor material found in the biopsy sticks can also help to predict the success of local treatments. PAP can help to predict the success of surgery or radiation. There is a detailed discussion of the implications of an elevated PAP and many other issues in "A Primer on Prostate Cancer, The Empowered Patient's Guide", written by renowned medical oncologist Dr. Stephen Strum and by me. In our book, we outline a strategy of disease management designed to optimize outcomes for patients like you and your friend.

You can't cure systemic disease with local treatments. You can debulk the disease, but you can't cure it. Debulking the disease has advantages sometimes for some patients, but it shouldn't be undertaken with curative intent in patients who already have systemic disease because it is doomed to fail. For systemic disease you need systemic treatments, such as androgen deprivation therapy in one of its many forms, treatment with an estrogenic compound, treatment with high dose ketoconazole and hydrocortisone (HDK +HC) or treatment with one of the many chemotherapy protocols, such as Taxotere-based regimens. Taxotere was approved by the FDA for the treatment of prostate cancer because it was demonstrated that it can prolong the life of patients with advanced prostate cancer. These would be some of the available options depending (again) on the nature of the tumor cell population, the aggressiveness of the disease, the assessment of the proportion between androgen-dependent and androgen-independent tumor based on the response to androgen deprivation therapy, other risk assessments and other staging data.

And ALSO depending on the preferences of the patient. Some patients and doctors favor minimal intervention and maximum surveillance as does renowned medical oncologist Dr. Israel Barken. Some are of the belief that

the way to go is to hit the cancer hard with a full arsenal of weapons while the cancer is weak and the body is strong. Expert medical oncologist Dr. Mark Scholz in Marina del Rey, California often uses Taxotere chemotherapy protocols relatively early in the course of disease management of advanced prostate cancer, often with good results. Different and sometimes diametrically opposing opinions regarding how aggressively to treat patients with advanced prostate cancer, but the final arbiter is the well-informed patient himself, since he's the one that lives with the consequences of his own well-reasoned decisions regarding his own strategy of disease management.

It is not wise to either over treat or under treat your disease regardless of the stage of disease be it early stage, locally advanced or metastatic, but to know what treatment is appropriate, you first need to have an accurate profile of the extent and nature of your disease. We are making great strides in our effort to develop better tools to enable us to do that, including the use of USPIO particle scanning to detect lymph node metastases and other technologies, but we need to use them wisely and effectively if they are to benefit the patient. Although this should be the province and responsibility of the medical community, failure to use the available tools properly and to the benefit of the patient is sadly, much too prevalent. In such an environment, empowered patients who know what state of the art medicine looks like can do themselves a world of good. The environment of ignorance in the world of prostate cancer is all too pervasive, so let the buyer beware. The responsibility to obtain quality medical care in this realm rests largely with the patient since there are so many variables to consider, so many personal consequences to weigh and so many controversies to wade through. This might seem overwhelming at first, but the educated patient, dedicated to the idea of enjoying the best possible outcome who rises to the challenge and then uses his wisdom in the service of others not only extends his own benefits to others, but benefits himself in every way—body, mind and spirit.

Are you beginning to grasp how much you have to learn before you make a disease management decision? Share this with your friend. Share it with your doctor. Both of you need to enlist the help of expert physicians and both of you need to be proactive, empowered patients who take responsibility for the direction of the healthcare you receive under the concept of informed consent.

Do you know about the side effects of treatment and how your present urinary status might be a factor in which treatment might be best for you?

Surgery often results in side effects that are often not disclosed, such as penile shrinkage, the potential for urine leakage upon arousal or orgasm, as well as the well-known potential for urinary incontinence in varying degrees and impotence in varying degrees that is usually more prevalent than usually stated, particularly in the hands of a less than expert surgeon. Surgery is a highly operator-dependent treatment modality and there is a relatively high recurrence rate probably due to the presence of micrometastatic disease, which was not, or could not have been identified prior to the procedure. The knife can't reach that. In cases in which a surgical patient is bothered by high volume urinary incontinence, an artificial urinary sphincter can be surgically

implanted, but there are other, less invasive remedies that can be tried prior to making the decision to employ a surgical solution.

Surgical patients typically start the recovery process impotent and tend to improve over time, while radiation patients typically have a decline in erectile ability during the recovery period, then experience a return to baseline with whatever potency they enjoyed prior to treatment and then after a few years, tend to experience a decline in erectile ability from their baseline performance. Advancing age may be a variable in degree of potency in the years following treatment in addition to the impact of the radiation on nerves and blood vessels. The proactive patient can affect his outcomes in regard to potency under the "use it or lose it" law of nature. And individual differences confound attempts to predict with any certainty the eventual erectile dysfunction or lack thereof, of any individual.

Younger patients and sexually active men with good erectile ability prior to treatment fare better than older men with pre-existing erectile difficulties, and in case you were wondering, frequent ejaculation or lack thereof probably had no affect on whether or not you were going to get prostate cancer. But every now and then there's a new study (usually a rather unscientific analysis based on the recollection of the men being studied) to swing the pendulum to one side or the other.

Surgical patients have a pathology report in hand to immediately verify if their cancer was organ-confined, while radiation patients judge their response to treatment by monitoring their PSA over time, enduring PSA anxiety with every blood draw, wondering if any rise in PSA is recurrence or just the PSA bump or PSA bounce phenomenon which has no clinical significance whatsoever in terms of long term outcomes. Of course late recurrence in surgical patients ten or more years after treatment can undermine the confidence of surgical patients in regard to the success of their treatment as well, while radiation patients rarely experience recurrence if it has not occurred within the ten years following treatment. So there are pros and cons to weigh and individual preferences to prioritize.

Radiation of the seed implant type is a very elegant treatment with a low incidence of rectal burning, but a high incidence of usually temporary urinary difficulties such as frequency and urgency, difficulty in starting a urine stream and sometimes a burning sensation upon urination. All of these can be handled with medications, at least to some extent. In cases of severe urinary blockages in men who were probably not well selected for radiation treatment to begin with, catheterisation is used and if there is persistent difficulty, men are taught to self-catheterise. A man with pre-existing urinary difficulties is going to find that the difficulties become worse after any form of radiation. The possibility of at least some degree of impotence after radiation depends in part on the quality of erections prior to treatment, age and how sexually active the man was prior to treatment.

An alternative to permanent seed implants or high dose rate brachytherapy is external beam radiation and for some patients, both forms of radiation administration are indicated. Some doctors use seed implants followed by external beam radiation, some feel that some external beam radiation prior to seed implant has benefits. External beam radiation using state-of-the-art IMRT has advantages over 3D conformal beam in reducing the

incidence of rectal burning and injury, but bowel problems and urinary problems, as well as persistent erectile difficulties are commonly seen. Some patients sail through a course of daily IMRT treatments given weekdays over the course of several weeks with nothing but a little fatigue near the end of the treatment and others have rectal bleeding and skin damage to delicate rectal tissues the equivalent of a sunburn, requiring topical treatment to heal them.

Should impotence be a problem after treatment, many remedies are available including oral medications like Viagra, Levitra and Cialis, the use of a vacuum erectile device with a constriction ring, or the use of penile injections with injectible agents in various combinations, made less threatening by use of auto-injectors with thin needles. Penile implants are possible for those who are not successful or are not satisfied with less invasive measures. Oral erectile medications are often effective in radiation patients as opposed to surgery patients because radiation is inherently nerve-sparing. It is important to maintain good blood flow to the penile tissues to prevent atrophy regardless of the reason for the lack of erectile ability. It is believed that penile atrophy and shrinkage are related to maintaining the penis in the flaccid state for extended periods during the recovery period. Exercise with a vacuum erectile device several times a week and therapeutic doses of oral erectile agents can be used to maintain proper blood flow and increase the probability of regaining unassisted erections.

Radiation efficacy depends on dosage, and combination treatments with seeds and external beam are sometimes used to deliver optimal doses more safely and with fewer side effects than can be achieved with one or the other alone. Expert radiation oncologists like Dr. Dattoli in Sarasota and Dr's Grimm and Blasko in Seattle can help you determine what dosage and method of administration of radiation are tailor-made for your extent of disease if you decide on radiation. Radiotherapy Clinics of Georgia is a popular mecca for seed implant treatment. Their protocol includes seed implants in combination with external beam radiation for all patients. Monotherapy is not an option at RCOG.

Definitive cryosurgery designed to destroy the entire gland results in profound impotence. Frozen nerves don't recover. Partially frozen nerves may still conduct a nerve impulse but failure to treat the entire gland may spare tumor cells as well as sparing nerves. (This is sometimes an issue with nerve sparing radical prostatectomy surgery as well.) The nerve-sparing cryosurgery depends on being certain, usually via saturation biopsy techniques and imaging, that there is no tumor detectable on the side of the prostate where nerves are to be spared. Dr. Gary Onik in Celebration, Florida and Dr. Duke Bahn can be consulted as experts in focal cryosurgery if nerve-sparing is a possibility under discussion. Expert ultrasonographer and cryosurgeon Dr. Fred Lee in Michigan says that if the patient is potent when he's done with him, he hasn't done a good job.

That's my reader's digest condensed version overview of treatment options. Starting with the least invasive, sometimes called "Active Surveillance", "Watchful Waiting" or "Ongoing Objectified Observation" as we discuss it in the Primer, and eliminating alternatives that don't work for you for one reason or another is a good

idea. Active Surveillance is not popular with doctors because it doesn't result in much revenue. But Johns Hopkins and other centres are helping patients who are candidates for Active Surveillance to optimize their outcomes by doing everything possible to discourage disease progression. Active Surveillance doesn't mean sitting around doing nothing waiting for the cancer to progress to the point where treatment is indicated. It means active monitoring with PSA's, DRE's and annual imaging to assess tumor location, volume and progression. It means undertaking a faithful regimen of diet and lifestyle modifications, including a prostate cancer friendly diet, supplement use, exercise, meditation, prayer, yoga, laughter and continuing education to know what's going on in the world of prostate cancer in the event the time comes to go to Plan B and be treated. Some men don't have the patience, will-power or persistence for this. It's much more difficult than it appears, done properly. Much more challenging than going in for an outpatient procedure to have seeds implanted and going through a few months of knowing where every rest room in town is. Men who do watchful waiting aren't just cowards who won't be treated because of some wimpy desire to side-step side effects. Active Surveillance is not for sissies. These men are aggressively attacking their disease with every weapon in the arsenal while watching over their shoulder for an ambush. Some men can't handle this emotionally and are never comfortable that their disease is sufficiently under control. Living in fear can cause problems in the REST of your body in terms of stress, so this is a decision that affects not only the body, but the mind and spirit. Be honest with yourself. Are you going to be so anxious that you can't enjoy life as you once did if you aren't treated definitively? This is a question that takes time to answer. If you try it for a while and you find yourself comfortable with controlling your disease as opposed to eradicating it, you're a winner as long as there is no dangerous progression that indicates that treatment is appropriate. If after a fair trial, you are fraught with fear, dread and anxiety, you're not doing yourself any good.

All primary treatments designed to destroy the prostate result in loss of ejaculate and therefore, even though the testicles still produce sperm, there is a very, very low probability of being able to father children in the usual manner. There are a few reported instances of men who have had radiation subsequently fathering children, but not enough to shake a stick at. So if you are contemplating completing a family, you might want to undertake watchful waiting at least at the outset after diagnosis if you are a suitable candidate for Watchful Waiting. If you have bulky or aggressive disease and require relatively immediate intervention (as your Gleason 8 friend may), he would want to bank sperm prior to treatment to be used later in an artificial insemination procedure if he wishes to father children in the future. We don't know for sure what effect radiation may have on genetic material so even though the testicles may still produce sperm which might be aspirated after treatment and used in artificial insemination, we might be more uncertain of the quality of the sperm and the genetic material therein. There isn't much of a track record to go on here, I don't think. But in any case, a prudent couple wouldn't want to have to deal with an uncertain degree risk of birth defects if that possibility could be avoided by means of banking healthy sperm.

So, start educating yourself further. You have time. You don't need to rush into a treatment decision you may live to regret, particularly if your staging to determine extent of disease is not yet complete. There are other treatment options including other forms of radiation, other combination protocols, androgen deprivation therapy as primary treatment and a whole bunch of stuff to know, some of which is essential and some of which is relatively more optional. At minimum, you should:

- Have your Gleason verified by an expert
- Answer the question: Do I really need to be treated or am I a candidate for giving Active Surveillance a try?
- If immediate treatment is indicated based on thorough staging of the extent and nature of disease, be sure the procedure is done by an expert.
- If you are considering local treatment you need to be fully informed regarding the details of how the procedure is conducted, what the side effects are, what the probability of recurrence is likely to be, what the financial ramifications of your treatment are and how they will be handled, and what salvage options are available to you if primary treatment should be unsuccessful.
- If you are considering a form of local treatment you need to know how your present age, other health issues, urinary status and priorities figure into the equation.

Proper selection of the patient for a treatment protocol, proper preparation of the patient for the treatment protocol, and minimizing side effects and maximizing the potential for successful treatment by enlisting an expert physician are essential elements in our attempt to optimize outcomes.

Good luck. Get back to us with your questions as you go along. Many of your questions, including some you haven't yet thought of, will be answered if you obtain a copy of the Primer and read it cover to cover. Then you'll know more about prostate cancer than most doctors, and moreover, you'll know it as it applies to YOU. Your doctor has many cases to monitor. You only have your own. So you need to be the expert. Keep a prostate cancer digest with the results of all the testing you've undergone, all the pathology reports, all the dates and details of treatment undertaken, all the medications, supplements and other health data that is pertinent to you, including your history and the details of the other health concerns you may have. Your body is an integrated system, not an isolated one, so what affects one part of you has the potential for affecting your prostate cancer as well as other organs and systems of your body.

I wish you and your friend low PSA's and may your days be good and long upon the earth.

Donna Pogliano