

NEWLY DIAGNOSED – Some Basic Considerations
By Charles (Chuck) Maack – Prostate Cancer Activist/Mentor

DISCLAIMER: Please recognize that I am not a Medical Doctor. I have been an avid student researching and studying prostate cancer as a survivor and continuing patient since 1992. I have dedicated my retirement years to continued research and study in order to serve as an advocate for prostate cancer awareness, and, from a activist patient’s viewpoint, to voluntarily help patients, caregivers, and others interested develop an understanding of prostate cancer, its treatment options, and the treatment of the side effects that often accompany treatment. There is absolutely no charge for my mentoring – I provide this free service as one who has been there and hoping to make your journey one with better understanding and knowledge than was available to me when I was diagnosed so many years ago. Readers of this paper must understand that the comments or recommendations I make are not intended to be the procedure to blindly follow; rather, they are to be reviewed as my opinion, then used for further personal research, study, and subsequent discussion with the medical professional/physician providing your prostate cancer care.

The following information is important to you, and if married or have a partner, to that person as well. You both should take time to review and study the information below. If this diagnosis has caused you or your spouse/partner extreme anguish it is important to read this paper and bring the information explained to the attention of your treating physician: “Understanding Mental Issues in Patients With Cancer and Caregivers” <http://tinyurl.com/hz92oad>

What I am striving for YOU is to have learned enough to be able to make your own, personal, decision as to the form of treatment you eventually consider would be most appropriate and reasonable for YOU. I want you to be aware of side effects that most always accompanies treatment options so that you are not surprised or upset because you were not aware. There can be erectile function issues. There can be a period of incontinence. For both these issues some are fortunate in having early rehabilitation and return to, or near to, their function prior to treatment. For many others the time-frame for recovery can run into months or even years, and unfortunately for some, these side effects can end up being permanent requiring continuing treatment. This awareness is important for you to recognize, understand, accept, and set your mind to learning what will then be most appropriate to treat these issues. I don’t want you to have later regrets that you were unaware and wish you had chosen a different treatment option. Try to never look back at “what-if?” What has passed has passed and you should

dedicate your future to learning the answers to “what now?” An upbeat attitude provides significant relief from worry and depression. Life goes on because we, as individuals, engage ourselves in continued learning in order to ensure “what the doctor orders” is appropriate.

If you have not already provided me, I would like to know the answers to several questions. That will include PSA blood levels leading up to the present, and if a biopsy has already been performed, how many tissue samples were extracted, of that number how many showed evidence of prostate cancer and from what location(s), Gleason Score assigned to each of those individual tissue samples, and the percentage of cancer noted on each of those individual samples.

But let’s get to the information you need to understand more about Prostate Cancer, and in this case, YOUR prostate cancer, and options to treat (or not immediately treat) that cancer. PLEASE make sure to take your time and ENTIRELY read this information as well as open and read the referenced URLs within. As you do, write down any and every question/concern you (of if married, your wife) come upon and don’t understand and get back with me to address.

I would like to know the name of the Urologist you now have and his/her facility/location, as well as if you intend to visit with a Radiation Oncologist, his/her facility/location.

Do not let the Urologist or Radiation Oncologist push you to absolute immediate treatment. Listen to what they say and recommend, but then advise them that you want to take a couple weeks to make a decision as to the treatment option YOU will feel most comfortable in pursuing. Note that I include questions to specifically ask the Radiation Oncologist you are going to see, as well as questions to ask the Urologist if you have not already done so. These are important and will provide you answers you need. Do not be afraid to ask these questions as well as insist they be answered. Here we go with your important EDUCATION and I’ll be waiting to hear from you:

I would like to know the results of the pathology report of the biopsy. Information of important relevance that I provide all new patients and, granted, requires taking the important time to read in order to empower yourself with sufficient knowledge to understand your status and be able to play a dual role with the physician who will treat your prostate cancer, are ...

If your wife/partner is able, it would be a good idea to accompany you to appointments. With both hearing the remarks of the physician they will be better remembered. A good idea is to have paper and pen handy and write down anything you think important to remember. Your wife/partner may also have questions that you may not have thought of, and should ask them if noting you haven't asked them. Remember this, Prostate Cancer is "a couple's disease" for every man with a spouse or partner. There is an emotional impact that hits the spouse/partner just about as traumatic as it is for the man to be told he has "cancer." With treatment it is important the spouse/partner be aware of side effects the man will be experiencing that, without being aware, leaves that spouse/partner worried and concerned why their loved one may be acting distant, quiet, not sharing discussion. Be open with each other with any questions/concerns since with both looking out for the other there is less worry. That word "CANCER" frightens most everyone diagnosed as well as their loved ones. The word gives the impression that death is imminent when that is more often not the case at all. Prostate Cancer has been considered a cancer wherein one will likely die of something else before they would of this cancer, though unfortunately for some with very advanced and aggressive disease, that may not be the case.

Are you aware if you also have an enlarged prostate and if so, its size/volume?

One must not procrastinate when it comes to prostate cancer developing. The longer one puts off knowing more, the better chance that cancer has in being aggressive as well as cells dividing and multiplying. If found to be in early development, you likely have a month or two to research, study, and come to a treatment decision. However, if found to be higher grade and aggressive, time becomes more limited requiring an earlier decision.

In any event, it is absolutely important to find out your status...just what is going on.

If you haven't already had a biopsy, a biopsy is necessary to determine just what is in development and its extent. And be sure to ask the Urologist if he will be including a pain reliever while the biopsy is being conducted. I would expect at least 12 tissue samples will be extracted that will cover both lobes of the prostate gland as well as base/top to apex/bottom on those lobes in order to hopefully find all locations of any cancer in development, and the extent of that development that is measured in what are known as Grades. The pathologist will study the tissue samples and with each sample, if there is cancer present, will first determine what grade (measured most often as 3, 4, or 5) differentiation is most prominent and

assign it a grade, then he will look again and see what is the second most present grade. He then adds those two together for a “Gleason Score.” At the same time he identifies the percentage of cancer in that tissue sample. His pathology report back to the Urologist will then provide such explanation and the hope for Gleason Score would be 3+3/6 since this would indicate earlier development and likely less a problem to hopefully eradicate. Often with this Gleason Score, and if only found in one or two tissue samples of less than 15% development, one can choose “Active Surveillance” wherein no treatment must be performed immediately and the physician and patient will work together to arrange no more than every three months diagnostics to make sure the cancer is not becoming more aggressive. This option can then continue until such time as PSA levels and other diagnostics indicate the necessity to choose either surgical removal - now most often performed as Robot assisted Laparoscopic Radical Prostatectomy (RaLRP) since this is less invasive than “open” surgery with less blood loss and more rapid recovery – the patient usually goes home the day following the surgery and recuperation comes about more rapidly. The advantage of surgical removal provides the Pathologist with the actual prostate gland, adjacent lymph nodes, and seminal vesicles (the pathway for cancer to spread from the gland) to get a more accurate picture of how far the cancer is in development. With radiation therapy chosen rather than surgical removal, neither patient nor physician knows the actual extent of cancer and both must then wait for some months after radiation treatment measuring PSA levels to see if those levels are receding over subsequent months as an indication the radiation may have eradicated all cancer cells. There are three primary forms of radiation ...external beam radiation with Intensity Modulated Radiation Therapy/IMRT usually accompanied by Image Guided Radiation Therapy/IGRT (or if available in your area and you prefer, Proton Beam Therapy), with this form of radiation administered daily Monday thru Friday for seven or eight weeks; if available in your area, a form of stereotactic radiation therapy known as Cyberknife administered every other day for five treatments with completion within about ten days; or brachytherapy (brachy meaning “within”) wherein either seeds are implanted to radiate and eradicate cancer from within the gland, or high dose pellets are inserted to radiate within the prostate immediately rather than seeds that radiate over time. If you become interested in Radiation Therapy rather than surgical removal, you need only ask the Urologist for referral to a local Radiation Oncologist to discuss radiation. I provide questions to be asked later in this paper. There would be no obligation to have to go further with a Radiation Oncologist other than to hear the methods of treatment available, side effects that may be experienced, and his/her explanation of the procedure. Once you have discussed treatment methods with the Urologist and Radiation Oncologist, you then have the right to make your own choice of treatment and

proceed for a date to begin whatever procedure you choose. I am personally not an advocate for Cryotherapy/Cryosurgery/Cryoablation (freezing of the prostate gland) since too often this treatment can result in total loss of libido and erectile function. If this form of freezing of the prostate gland interests you, you can find further information by searching the internet.

A little more about Gleason Scores: depending on what the Pathologist sees under the microscope, the Gleason Score, depending on cancer development could increase to 3+4/7, 4+3/7 (more advanced in development), 4+4/8, 4+5/9, 5+4/9 (even much more advanced), and 5+5/10 which would be fully advanced and more than likely spread into bones or other tissue known as “metastasized” (moved beyond the prostate gland and requiring very aggressive treatment unlikely to eradicate the cancer but hopefully with appropriate medications and supplements being able to rein in development and manage it indefinitely). If your cancer has already metastasized and androgen deprivation therapy or chemotherapy or a combination of both is being considered or prescribed, you should move to the care of a Medical Oncologist. Information in these papers may be helpful:

<http://tinyurl.com/odf28lb> and <http://tinyurl.com/3s76t6x>

Now, I am going to provide you papers that are important for you (and your spouse/partner if she wants to be closely aware) to take the time to read, take notes if you don't understand something you are reading, and then get back with me with any questions/concerns you wrote down and I will address them. By reviewing and studying each of these papers, you will become much more understanding regarding your cancer and what should be its appropriate treatment...and thus able to participate with your physician in making decisions rather than simply “following the doctor's orders” since there are too many times those “orders” may not be the best for you. We who have been or continue to be dealing with our prostate cancer have learned that by being “empowered” with knowledge regarding our disease, we end up with much better results. If you ever have a physician arguing against your asking questions and insisting on answers, leave him/her and find another who is more willing to work with you than have the attitude “my way or the highway.” When that becomes the case we take the highway.

Okay, here we go with your “studies:” ☺

Newly Diagnosed – Questions to ask your Urologist* <http://tinyurl.com/kgxc8eu>

Newly Diagnosed – Questions to ask your Radiation Oncologist*
<http://tinyurl.com/m6k74re>

Newly Diagnosed – Questions to ask your Medical Oncologist
<http://tinyurl.com/mzpqgpx>

Practices Important to Begin Prior to and Continuing Beyond Surgical Removal of the Prostate Gland or Radiation therapy to the Prostate Gland:
<http://tinyurl.com/mx7ph3w>

You will very likely experience a period of both Erectile Dysfunction as well as Incontinence following either surgical removal of, or radiation to, the prostate gland. The next few papers explain how to deal with these experiences.

Erectile Dysfunction; <http://tinyurl.com/3oz7u8l>

Incontinence: <http://tinyurl.com/7gy7fld>

This next paper should also be read by your spouse/partner to better understand what you may be experiencing:

Intimacy Challenged by Surgery, Radiation, or ADT: <http://tinyurl.com/39q2k3a>

With surgical removal of, or radiation to, the prostate gland, men often experience what they perceive as a shortened penis because of the treatment. What has actually occurred is a traumatic effect that does result in this shortening of the penis but that can be corrected by personal attention to how to do so. This next paper explains:

Penile Length following surgical removal of the prostate gland:
<http://tinyurl.com/artg62p>

If choosing Robot assisted surgical removal of the prostate gland, this paper explains: Robotic Prostatectomy: <http://tinyurl.com/8p2p2d6>

Diet & Supplements: <http://tinyurl.com/6z5l8fm>

Be aware that often Urologists recommend surgical removal while Radiation Oncologist recommend radiation; stands to reason since either are their specialty. Important is to not permit either to rush you into treatment. Unless one has extremely advanced prostate cancer, he has

time to study his options and make his own decision as to what form procedure he prefers.

Feel free to contact me for my comments before agreeing to a form of treatment. Once you have biopsy results we will have a better idea of your status and what would be the most appropriate strategy of treatment

This is enough to have you pretty knowledgeable regarding your current status, what to expect from treatment, and what you, yourself, can do to counter or improve any occurrences.

I hope this provides you considerations to further research to help you determine that with which you would be most comfortable. Take the time to visit with the physicians who provide these options to hear what they have to say while at the same time taking that information and comparing to what you find in your own, personal, research.

Finally, if interested in my prostate cancer, advocacy, and mentoring background, (my “credentials” if you may) please visit the following www.theprostateadvocate.com where you can also click on the menu word "Observations" and access over 200 papers I have either authored, compiled, or posted from medical friends regarding prostate cancer, recurring prostate cancer, treatment options, treatment of the side effects that often accompany most all treatment options, and more.