

## **INTERVIEWS WITH YOUR PROSTATE CANCER DOCTORS A GUIDE FOR THE NEWLY DIAGNOSED**

A friend of mine was recently diagnosed with prostate cancer. Needless to say both he and his lovely wife were distraught and stunned. They had an appointment to visit an urologist to discuss the results of the biopsies

Although the wife had done some research into this disease and the treatments, they were still bewildered and asked me to please accompany them on this visit. **As a general rule, it is always good to have someone with you and / or a portable tape recorder. This avoids doubts later on when trying to recall exactly what was said.**

As a result of this, I've generated a list of items and questions that every person should have when he visits the three prostate cancer specialists. Many of these questions are valid not only at the time of initial diagnosis, but if you need further treatment should your cancer come out of remission.

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When you entered your doctor's office, you knew your diagnosis was prostate cancer. The pathology report told you that. You are meeting with the urologist to obtain his/her assessment of your situation and to discuss treatment options. Specifically, the purpose of your visit is threefold:

- A-Determine the status and severity of your specific case.
- B-Select the treatment that has the best probability of curing you and
- C-Select a treatment that offers you the best quality of life after the treatment

When the doctor makes his opening statement, he will probably have answered a few of the following questions. I will never-the-less, list the questions that you should have answers for by the time you leave his/her office:

### -----**YOUR VISIT WITH THE UROLOGIST**-----

- Q-What is the PSA ? Note that a rapid increase in PSA value is usually a warning indication requiring further investigation ( Note 12)
  
- Q -What is the Gleason Grade ? Obtain the two part breakdown. For example is it 3 plus 4 or 4 plus 3 ? (note 1 )
  
- Q -How many biopsy cores were taken?
  
- Q- What percent of each core was cancerous?
  
- Q - What are the locations of each biopsy?
  
- Q- How close to the margin (Peripheral border of the prostate ) were the positive biopsies ?
  
- Q-What did my Cat Scan indicate ? (Note 9 )
  
- Q-What did my Bone Scan indicate ? (Note 9 )
  
- Q- What did my MRI Scan indicate ? ( Note (9)

- Q-Do you think there is any Seminal Vesicle involvement ? (Note 10)
- Q- Is it possible that I have Transitional Prostate Cancer ? (Note 11)
- Q - What would you estimate are the chances that the cancer is contained within the prostate ?  
( The Doctors use the Partin Tables and other nomograms to make this assessment )
- Q - Dr., what treatment would you recommend ?
- Q –Why do you prefer this treatment ?
- Q - What are the side effects of this treatment ? (note 2)
- Q – What are the chances ( percent) I will have this/ these side effects ?
- Q- If I select surgery, would you recommend nerve sparing for me ?  
( If the doctor says “yes” then ask )
- 1
- Q- Bilateral (both sides spared) or Unilateral ( one side spared ) ?
- Q- How many of these procedures have you done?(Note 17)
- Q- Why do you recommend this option ?
- Q- What is the probability of my cancer recurring with the treatment you propose ? (Note 19)
- Q-Would you recommend I do nothing now, just wait (Watchful Waiting (WW)) ?  
( If the Dr. says that watchful waiting is not for you, then ask)
- Q- Dr., why is watchful waiting not good for me ? See criteria for WW
- Q- Are there any other treatment options appropriate for me ?  
( If the Dr. says radiation, then ask :)
- Q-Which type of radiation, External Beam, or Seeds (Brachytherapy ) ?
- Q- What are the advantages and disadvantages of each type ?
- Q- Regardless of which he suggests, ask why not the other form of radiation ?
- Q-What about a combination of both Seeds and External Beam radiation ?
- Q- What are the side effects of each radiation choice ?
- Q- Are they long term or short term side effects ?
- Q- What is the probability of any of the side effects occurring with each one of these choices?

Q- If I select radiation, would you recommend Hormone treatments with the radiation? (note 8)

Q- I plan to consider my options which may take 4 to 6 weeks. Would you suggest I have a hormone shot in the interim ? NOTE: This may effect any new PSA reading before your treatment.

You may also ask this specialist the same questions about whether you should have an MRI or bone scan, or if you have a high PSA, whether you might have Transitional Prostate Cancer. ( Notes 10 & 11)

Q May I have a copy of my medical records, including all scans and tests ? ( You are entitled to these)

Q To eliminate the possibility of an error in reading my biopsy slides, how may I obtain a second opinion from another medical institution ?

Q-If the PSA is slightly elevated, ask, “do I have a large / enlarged prostate “?

Q-If I have the treatment you suggest, how long will it be before I may return to my normal activities ?

Q- Is this treatment covered by my insurance ? (Note 15)

Q-Considering my other medical conditions and medications, are the treatment / medications you suggest safe or will they interfere with eachother? (Note 16)

Q- Would I be a good candidate for Watchful Waiting (also called Active Surveillance) ? (see criteria for watchful waiting)

At this juncture you should inform your urologist that you would like to have a consultation  
With a Radiation Oncologist

Q- Which Radiation Oncologist would you recommend ?

Q- Does he have much experience treating prostate cancer patients ?

Q- Does he do both External Beam and Seed Implant Radiation ?

Q- How long has he been doing Seed Implant Radiation ? How long External Beam Radiation ?

At this point you should make an appointments to see a Radiation Oncologist and also a Medical Oncologist to save time. Visit the Medical Oncologist after the Radiation Oncologist. Each doctor will transfer your records and tests or will give them to you.

When you visit the Radiation Oncologist, many of the same question should be asked, but remember , you are there to obtain his expertise.

Allow this specialist to tell you his analysis of your situation. Then ask the following questions unless his opening statements answered some of them:

-----YOUR VISIT WITH THE RADIATION ONCOLOGIST-----

Q-What treatment, if any, does he believe you should have ?

If he recommends a Radical Prostatectomy (surgery ), Ask why he believes this.?

If he recommends radiation, proceed as follows:

Q - What would you estimate are the chances that the cancer is contained within the prostate ?  
(He too uses the Partin Tables but you want his opinion and interpretation )

Q-Which type of radiation, External Beam, or Seeds (Brachytherapy ) do you recommend ? (Note 13)

Q- Regardless of which he suggests, ask why not the other form of radiation ?

Q-What about a combination of both Seeds and External Beam radiation ? (note 4 )

Q- What are the side effects of each radiation choice ? (Note 2)

Q- Are they long term or short term side effects ?

Q- What is the probability of any of the side effects occurring with each one of these choices?

Q-If I select radiation, would you recommend Hormone treatments with the radiation ?

Q-Would you recommend I do nothing now, just wait ( Watchful Waiting ) ?

Q- How many prostate cancer patients have you treated this way ?

Q-If I have the treatment you suggest, how long will it be before I may return to my normal activities ?

Q- Is this treatment covered by my insurance ? (Note 15)

Q-Considering my other medical conditions and medications, are the treatment / medications you suggest safe or will they interfere with eachother? (Note 16)

Q- What is the probability of my cancer recurring with the treatment you propose ? (Note 19)

Q-Would you recommend I do nothing now, just wait ( Watchful Waiting ) ?  
( If the Dr. says that watchful waiting is not for you, then ask)

Q- Dr., why is watchful waiting not good for me ?

If both specialists agree that surgery is best, it probably is. If both recommend radiation is best, it probably is.

If the surgeon says surgery, and the radiation oncologist says have radiation, now is the time to visit a Medical Oncologist ( Note 7 ). It is best to see one who sees many prostate cancer cases. Some specialize in Prostate cancer.

You should ask both the urologist and radiation oncologist to recommend a highly qualified medical oncologist.

-----**YOUR VISIT WITH THE MEDICAL ONCOLOGIST**-----

When you visit the Medical Oncologist, many of your question may be the same, but again you want his expert opinion.

Q - What would you estimate are the chances that the cancer is contained within the prostate ?

Q - Dr., what treatment would you recommend ?

Q -Why do you prefer this treatment ?

Q- How many men have been on this protocol or used this treatment?

Q- What is the probability of my cancer recurring with the treatment you propose ?

Q- What is the probability of my cancer recurring with the treatment you propose ? (Note 19)

Q- Would you recommend I do nothing now, just wait ( Watchful Waiting ) ?

( If the Dr. says that watchful waiting is not for you, then ask)

Q- Dr., why is watchful waiting not good for me ?

You should repeat many of the questions you asked the other physicians, specifically:

Chances of having the various side effects short term and long term with any treatment? Having hormones with radiation ? Combined radiation ? Having nerve sparing, bilateral vs unilateral with surgery? Watchful Waiting ? A hormone treatment if you have not had one. If your PSA is high, ask if you may have Transitional Prostate Cancer (Note11)

Always ask why he prefers choice A to choice B or C ? No question is a bad one.

If you are still uncertain after meeting with the three specialists, it is quite customary to obtain a second opinion. A second opinion means visiting another Urologist or another Radiation Oncologist or a second Medical Oncologist, (or all 3). Seeing different specialists is NOT a second opinion.

When visiting any of these doctors, it is a good idea to bring some one with you and even a portable tape recorder to review what was discussed at your leisure.

Prostate cancer is a slow growing cancer. Stay calm and seek the best treatment for you. Take a few months to explore your options

Notes:

1-The Gleason Grade relates to the aggressiveness of the cancer, with 5 being the worst ( most aggressive ) and 1 being the least , or not very bad. A 4+3 is worse than a 3+4 because it signifies there are more 4 grade cancers in the biopsy, than 3 grade, even though the total is 7 in both cases.

2-Overcoming the side effects from being treated for prostate cancer is usually discussed in great detail at most Prostate Cancer Support Groups. The statistics about incontinence and especially

impotence are obtained from the members of these support groups, and is much greater than those found in books or newspaper articles often written with a bias. **Remember, every treatment has side effects.**

3-Cryotherapy , (Freezing the prostate) is another treatment option, but is not done often

4-Hot Seeds is another treatment option, wherein higher dose radiation seeds are applied to the prostate for a shorter period of time and then removed, unlike the usual permanent seeds.

5-The side effects with External Beam Radiation may not only be incontinence and impotence, but may also include rectal damage and bladder damage which may occur years later.

6-With all other factors being equal, a physician frequently advocates treating you in his specialty, which may or may not be ideal or even appropriate for you. Although most specialists are somewhat knowledgeable about other related specialties, it is usually best to directly consult with each related specialist.

7-A Medical Oncologist is a doctor who specializes in cancer that has spread to other parts of the body, i.e., systemic disease. He usually treats the patient in more advanced situations, but a medical oncologist who specializes in prostate cancer is a valuable source of information.

8- Hormones have their own side effects, such as loss of libido, and bone density loss and perhaps hot flashes. However in this case the hormone treatment is for a few months and the hot flashes and libido loss are temporary.

9-If this test was not done, inquire whether one is necessary.

10- An MRI ( Magnetic Resonant Imaging) can frequently detect seminal vesicle involvement.

11- Transitional Prostate Cancer is when the cancer is located in the center of the prostate, rather than towards the peripheral area, and usually is indicated by a very high PSA (25, 70 and higher ). For example, a PSA of 50 in Transitional Prostate Cancer is usually not as severe as the same reading with Peripheral Prostate Cancer, but the exact correlation is not known )

12-A rapid rise in a PSA reading, such as 2 or more points in one year, may indicate further testing is called for. Although a PSA may be a low value, such as a 4 or 5, if it was 2 or 3 a year ago, this may be a serious problem because the percentage rise in these examples is huge. On the other hand a PSA rise from 8 to 9 is not a blessing, it is not considered as serious. A doubling within a year is considered very serious.

PSA values may raise suddenly under certain circumstances such as if an infection or inflammation of the prostate exists, or when a physician palpates the prostate, or shortly after an ejaculation or a bouncy motorcycle ride. These causes can easily be eliminated.

13- The use of seeds is usually not an option if the prostate is very large

14- Unless you have an aggressive prostate cancer, i.e., very high PSA &/ or Gleason Grade of 8,9, or 10, you may take approximately, two to three months to make a treatment decision. In this case immediately visit a medical oncologist.

15- Some Insurance policies cover doctors & / or procedures in certain hospitals, but do not cover them in others. Ask. .

16- People with diabetes and heart conditions should visit these specialists before having any prostate cancer treatment. Certain medications used for treating advanced prostate cancer, may interfere with heart medications. Check with your doctors.

17-If you are going to have a nerve sparing procedure, ask the doctor to have about four or five of his/her patients, who had this procedure in the last two years, contact you. You do not want a patient who just had the procedure. The doctor cannot give you their names, but he /she is allowed to ask them to contact you with your permission.

18A-Watchful Waiting, also called Active Surveillance is an option **only** for men with low to intermediate cases of prostate cancer. The procedure is not to have any active or invasive treatment at the present time, but repeating the PSA in 4 to 6 months. If there is no change or only a small change, then repeat this process. Usually every 12 to 18 months another biopsy is performed. As long as your situation remains constant, whether for a few years or forever, you do not have treatment. At any time the situation changes, treatment could be started.

18B-- The following criteria is generally being used by a few teaching hospitals in various cities, including Boston:

- A- No Gleason Score above 3+3=6.
- B- No Gleason Grade of 4 or 5 detected
- C- No more than three cores in a biopsy should be positive (contain cancer)
- D- No biopsy core shall contain more than 50 % cancer. (Some Drs. say not more than 30%)
- E- The PSA doubling time shall be greater than one year. Less than three years, based upon 8 determinations
- F- The PSA shall be under 10
- G- No seminal vesicle or lymph node shall be positive. If either of these are positive, no go,
- H- No distant metastases
- I- No lump or irregularity detected by a DRE

19- There is a very high probability that after any treatment, even with a low or intermediate case of prostate cancer, that the cancer will recur.

20-If nerve sparing cannot be done, ask if one of the nerves from your foot / heel can be used.

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