

Dear Friend,

Welcome to the Marin Prostate Cancer Support Group meeting. Feel free to discuss your case in an atmosphere of understanding, friendship and experience.

We encourage you to fill out the accompanying sheet that will be used by you and other group members to communicate with each other about common problems and solutions. It will not be released outside the group without your specific authorization. You can ask us to search our data base so that you can speak to a person with any particular condition or treatment.

We encourage each member to become so well informed about prostate cancer that he can confidently make his own decisions about managing his disease. We usually advise a second opinion on your treatment, and a possible second reading of your biopsy slides. You will want to get a clear understanding of all your options before deciding on what is the best course for you.

We maintain a library of books, newsletters, and other materials free for you to checkout. Please ask to see these materials.

We hope that you get a lot from these meetings and welcome you back as often as you can make it. We meet every Tuesday from 7:00 PM to 8:30 PM in the Staff Medical Library in the East Wing at Marin General Hospital.

During the COVID pandemic we are meeting online. You will get the invitations by email.

We are not doctors and do not give medical advice; we only exchange experiences.

Two of us (among many) who would welcome your phone call are:

Stan Rosenfeld (415) 459-4668 or vegstan2@ix.netcom.com

May 12,
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Bruce Zweig (415) 515-6341 or bruce@brucezweig.com

Only the above two men have access to the data base for you.

May 12,

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Marin Prostate Cancer Support Group

For over 25 years the Marin Prostate Cancer Support Group has been providing an environment for the exchange of information and support to hundreds of prostate cancer patients from newly diagnosed patients to patients with advanced disease.

The Group is very careful in informing everyone participating in its meetings that it does not provide any medical advice but an opportunity for patients to share their experiences with those of others. This is made clear by a letter that is sent to everyone when they start participating in the Group's meetings. (See attachment with Welcoming Letter.)

The Group is also preparing and distributing papers listing the different therapies available to prostate cancer patients, questions to ask their doctors regarding their disease and treatments (See attachments below) and information regarding publications that freely available on the web pages of different academic institutions, such as the Your Health Matters Prostate Cancer Education Documents from the Urology department of UCSF (<https://urology.ucsf.edu/prostate-cancer-education-documents>) and maintains a library of books that patients may borrow.

This document is intended to be used as a brief overview of some available options for prostate cancer. You will probably want to read more and come to a support group meeting.

Treatment	Description	Pros	Cons
Intensity Modulated Radiation Therapy (IMRT) and Image Guided Radiation therapy (IGRT)	X-ray treatment from outside the body, usually applied in 35-40 daily treatments.	Non-invasive. Incontinence and impotence a little less likely than surgery. Can continue with current life style. For short term, sex life continues as before. Possible treatment for those who do not qualify for surgical procedures. Many long term studies.	If cancer recurs, follow up surgery difficult, and with increased side effects. Often more than a year wait to know likelihood of cure. 35-45 trips to radiation facility. Mostly temporary bowel and urinary problems may occur. Small risk of secondary cancer (1-1.5%) in another organ approximately 15 years in future. Fatigue may occur during treatment.
Brachytherapy – Low dose rate - Permanent radioactive seeds	Rice grain size radioactive seeds are implanted in your prostate. Over the course of weeks or months the emitted radioactivity kills the cancerous cells.	Minimally invasive outpatient surgery lasts 1-2 hours with a possible overnight stay; most return to normal activities in a few days. Many long term studies.	Could make any existing urinary problems that you are currently experiencing, worse. Not suited for large prostates or high Gleason scores.
Brachytherapy - High dose rate – temporary radioactive wires	A radioactive source is attached to or embedded in the end of a wire which is inserted into the prostate and then removed in just minutes.	There is the theory that for certain cancers, high levels of radiation given over shorter amounts of time are more likely to effect a cure. Many long term studies.	Usually requires an overnight stay. One to two treatments are usually given.
Surgery – open- retropubic	The entire prostate and seminal vesicles are removed through a 5 to 8-inch incision in the abdominal area.	Removed prostate is analyzed in detail for amount and grade of cancer present. Can be followed by external beam radiation if required. One to two nights in hospital on average. Average time away from work is three to five weeks. Many long term studies.	Major surgery. Possible need for blood transfusion. Several weeks recovery. 7-10 day inconvenience of urinary catheter. Short term incontinence and impotence and possibility of long term incontinence and impotence.
Surgery - robotic	The entire prostate and seminal vesicles are removed through 4-5 small incisions in the abdominal area.	Removed prostate is analyzed in detail for amount and grade of cancer present. Can be followed by external beam radiation if required. Hospital stay may be slightly shorter than open surgery. The incisions are smaller and the time back to work may be shorter than open surgery and possibly with less pain.	Major surgery. Less need for blood transfusion than open surgery. Several weeks recovery. 7-10 day inconvenience of urinary catheter. Short term incontinence and impotence and possibility of long term incontinence and impotence. Some problems with gas as a result of robotic surgical procedures. Long term studies coming in.
Hormone Therapy	Prostate hormone therapy suppresses, blocks, or eliminates testosterone to slow the tumor's growth. Can be administered intermittently to allow the	May be used in conjunction with radiation therapy to increase radiation's effectiveness. May be used in cases of failed radiation or surgery. Works throughout the entire body. May be used as a primary treatment in certain cases.	Probable loss of libido. Possible loss of unassisted erections, probable hot flashes, fatigue, weight gain. Long term use, e.g. greater than approximately one year may result in weakening of bones, memory problems, cardiovascular problems. Onset or aggravation of diabetes or

This document was put together from the non-medical opinions and experiences of several prostate cancer survivors. It should not substitute for medical advice under any circumstances.

February 4, 2019

Treatment	Description	Pros	Cons
	body to recover from low testosterone.		heart problems.
Active Surveillance (Used to be called Watchful Waiting)	Careful monitoring instead of aggressive treatment for men with low grade, small amount of tumor contained within the prostate. May also be applicable to men with other serious illnesses or otherwise short life expectancy.	Avoids the side effects of most active treatments. Can switch to active treatment when and if cancer becomes aggressive. If follow recommended life style changes, will benefit entire body. Some possibility that new treatment will be developed during surveillance period.	Risk of having misdiagnosed cancer as less aggressive than it really is. Will require periodic tests, including biopsies or MRI scans. Possible anxiety.
Cryotherapy	Freezes the prostate to kill the cancerous cells, killing healthy cells as well. May be used to freeze only the portion of the prostate where the cancer was found.	No cutting, no radiation. Performed on outpatient basis. Can be used after failed radiation. May be appropriate treatment for men who do not qualify or want any other treatment. Can be repeated.	Highest risk of permanent urinary incontinence and other urinary problems as well as highest risk of permanent impotence. Requires 2 to 3 weeks of catheterization. May not be covered by insurance. Only partial freezing may miss some cancer.
Chemotherapy	Various drugs that attempt to kill the cancerous cells. Generally used after hormone therapy fails, but recently being tried <u>with</u> hormone therapy.	Generally, treats the cancer throughout the body.	Many have very bothersome side effects, reducing quality of life, while extending its length.
High Intensity Focused Ultrasound – HIFU	Prostate tumors are heated via ultrasound waves to cause their death. Ultrasound crosses the rectal wall nondestructively; no needles are used. FDA approved (2015) for prostate-tissue ablation.	Shorter-term studies show cancer control for localized, intermediate-risk disease is as good as with surgery. Documented side effects are significantly less than with RP or RT.	Reliable studies of outcomes are limited to 5-10 years (as compared to 15-20 years for RP and RT). If HIFU is used focally, such use elevates the risk of missing MRI-undetectable disease elsewhere in the prostate.
Clinical Trial	Clinical trials test new drugs, new combinations of drugs or new anticancer treatment strategies. Trials are available for most stages of prostate cancer including active surveillance.	May get an effective treatment which is not yet available to the general public. Advance medical science.	You may not get the experimental treatment in a placebo-controlled trial. You may experience unpleasant side effects.
Hypo-fractionated radiation such as Cyberknife	External beam radiation which is delivered in about 5 high intensity doses. High precision is claimed. Has been used up until now for other than prostate.	Fewer trips to radiation facility	Long term results still coming in..

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Introduction

Dealing with prostate cancer is a big challenge emotionally and intellectually. The good news is that there are several treatments available. For some men, that can also add more stress. It means dealing with ambiguity--digesting lots of information and making difficult decisions about what treatment to choose and where to have it done. A group of prostate cancer patients created this document to assist you in that process. Our goal is to help patients sort-out the information needed to make informed decisions and to provide physicians with a list of questions that may be going through patients' minds.

Things to keep in mind:

1. This questions were put together by patients, not doctors. It should not be considered medical advice. It is intended to help you decide what questions to ask medical professionals.

2. While we have tried to be comprehensive, the number of different scenarios and diagnoses makes that impossible. There may be other questions pertaining to your situation that should be added to the list.
3. One area we have not tried to cover is the cost of treatment and insurance/HMO issues. Obviously, it's important to determine what is covered by insurance, whether pre-certification is necessary, who will submit the necessary information to your insurance company, whether your doctors/hospital belongs to your PPO, and other such questions.
4. There are many medical specialists you may want to consult for advice, including Radiation Oncologists, Urologic Surgeons, Medical Oncologists and Internists. Some of the questions below are more appropriate for one or another kind of specialist.
5. Your doctors will not have time to answer all the questions on these lists. Not all the questions on these lists will apply to you. It is important to narrow down the issues of greatest relevance and concern, to prioritize your questions and perhaps to research some answers on your own in books and on reliable web sites. (should we list some such sites?)
6. You might also want to ask two more questions as your appointment is concluding:
 - o Is there anything else we haven't covered that I should know about?
 - o If a question comes up later, is it OK to contact you by e-mail or telephone (and how do I reach you)?

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General Questions for an Internist

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- At what age should men, like me, start being screened for prostate cancer?
- In your opinion, should men, like me, stop being screened for prostate cancer after a certain age?

- **How often should I get a PSA test? What is the difference between regular, free and ultra-sensitive PSA, and which kind test should I get?**
- **What is the normal PSA range for a man my age?**
- **What PSA results would cause some concern?**
- **Is it a good idea to keep track of my PSA over time? What should we be looking for?**
- **Should I refrain from sexual or other activities for some time before having a PSA test?**
- **What is PSA doubling time and what is its significance for me?**
- **What is the rate of false positives/false negatives with PSA results?**
- **If my PSA is low, does that rule out prostate cancer?**
- **How often should I get a digital rectal exam? Should I have a digital exam with my Internist or would it be better to see a Urologist?**
- **Does a nodule on the prostate always indicate prostate cancer?**
- **What are the symptoms of prostate cancer? Can those symptoms also result from other conditions?**
- **Can you have prostate cancer without any symptoms?**
- **What causes prostate cancer? What are the risk factors for prostate cancer?**
- **Are there things I can do to reduce my risk of getting prostate cancer (medications, lifestyle, supplements, diet, exercise)?**
- **PSA screening has been controversial (whether to screen or not). What is your opinion about that controversy?**

Questions Prior to a Biopsy

December 5, 2019

- Why do I need a biopsy?
- How is a prostate biopsy done?
- How many prostate biopsies have you done?
- How many samples do you plan to take?
- How about other tests to see if I need a biopsy such as 4Kscore, PHI, ExoDx, etc.?
- Can I get a multi-parametric MRI before the biopsy? Will insurance cover it?
- Will it hurt? Will you use topical and injected Lidocaine or another anesthetic prior to the biopsy?
- Can I take a sedative such as Valium prior to the biopsy and will you prescribe it?
- When should I stop taking aspirin and certain other medications and supplements prior to a biopsy? When can I resume taking them?
- Do I need to take antibiotics before or after the biopsy?
- What should I expect during and after the biopsy?
- Can there be complications from a biopsy? After the biopsy, what things should alert me to call you?
- Can a biopsy cause any cancer to spread?
- When and how will I get the biopsy results? Could I choose to have results in-person versus over the telephone? May I please have a copy of the written report?
- What pathology lab will analyze the biopsy results?
- Who will retain my biopsy slides?
- Are there false positives/false negatives in biopsies?
- Should I get a second opinion from another pathology lab? If so, can you recommend a lab?

- **If the biopsy is negative, does that mean I don't have prostate cancer? What follow up will I need?**
- **Is it possible that if a very small amount of low-grade cancer is found that I may not have to have any therapy?**
- **Would you please explain Active Surveillance?**
- **How could I arrange to have a specimen of my biopsy genetically tested? What is your opinion about such testing and what will it tell me?**

Questions for Men Recently Diagnosed with Prostate Cancer

- **What stage and grade is my prostate cancer and what is the significance of this information?**
- **What is the size of my prostate? What is my PSA density and what is its significance? How does the prostate size affect my diagnosis or treatment?**
- **What is my current prostate-specific antigen (PSA) level? At what rate has my PSA level risen?**
- **What is my Gleason score? What does that score mean?**

How soon should I get treatment? Is it ok to research the options for a few months? Can I wait 6 months?

- **How many core samples were taken during my biopsy and how many were positive? What are the lengths of cancer, in millimeters, in each positive sample? Is the entire cancerous portion of the same Gleason score? If not, what is the percentages of the different portions with different Gleason score? May I please have a copy of the complete pathology report?**
- **If the biopsy showed that I have "PIN," what is the significance and what follow up is needed?**
- **Should my biopsy slides be examined by another pathology lab for a second opinion and if so, which do you recommend?**
- **Should I take my spouse/partner to my doctors' appointments?**

- Are there any additional tests that will help determine if my cancer is confined to the prostate or if it has spread?
- Should I have any imaging studies before deciding on a treatment and, if so, what kind and where should I have them? What could such studies tell me?
- Would color Doppler or other ultrasound provide useful information about my cancer?
- Would an **multiparametric** MRI provide useful information about my cancer?

(After having imaging studies)

Does the cancer appear to be confined to the prostate? How many tumors are visible and what is the size of the tumors? How accurate are these imaging studies?

- **What is the prognosis for my degree of prostate cancer?**
- What types of treatments are available to treat my prostate cancer? What are the benefits and side effects/complications of each? What is the success rate of each treatment?
- Do you think I might be metastatic? Might chemotherapy or abiraterone (Zytiga) be appropriate to treat my prostate cancer, including in a clinical trial?
- **What treatment(s) do you recommend and why?**
- Should I consider treatments available in other countries but are not U.S. FDA approved (such as high frequency ultrasound)? What are the advantages and disadvantages of these treatments? Where do you go to get them? How do you find a well-qualified doctor and hospital for these treatments?
- Does this mean the end of my sex life?
- Will I be able to have erections?
- Will I be able to have an ejaculation after treatment for prostate cancer? Will I be able to have an orgasm? Will I be able to impregnate a female spouse/partner? Should I bank sperm?

- **What urinary problems can occur after a prostatectomy or after radiation? What can be done about it?**
- **If you recommend surgery, what kind of surgery do you recommend (open, laparoscopic, robotic) and why?**
- **How many patients have you operated on in this way and over what period of time? What parts of the surgery will you perform versus what will be done by residents working with you? Who else will have input about how my surgery will be performed?**
- **(To be asked of Internists and Medical Oncologists. If you had prostate cancer, what surgeon (or radiologist) who you go to?**
- **I know there are privacy issues, but is there a way to talk to other patients who have undergone this treatment?**
- **Is “Active Surveillance” an option in my case? If so, what are the pluses and minuses and what tests (biopsies, ultrasound, genomic, MRI, PSA, etc.) would I need and how often would I need them? If I choose active surveillance, what would trigger switching to another option?**
- **How do I decide what treatment is best for my cancer?**
- **How would you rank the available options in order of what’s best in my situation?**
- **Please tell me how my personal preferences for the procedure I choose, time off from work, side-effects etc., play into my decision for treatment?**
- **How soon do I need to decide and are there risks in waiting? How soon do I need to have treatment?**
- **Are you comfortable with me exploring other treatment options and speaking with other specialists before deciding upon a final plan of action (Radiologists, Surgeons and Medical Urologic Oncologists)? Can you provide recommendations/help me get appointments?**

- Once I decide, how long does it take to get on the schedule and for treatment to begin?
- **Are there any clinical trials that I should consider?**
- Can you suggest additional resources for information that might be helpful?
- What reference materials (books, web sites, pamphlets, etc.) do you recommend and where can I get them? **Are there any medical conferences that may be coming up that you think might be of help to me in better understanding my disease and the treatment that may be appropriate for me to consider.**
- Do you know of a local prostate cancer support group?
- How can I get help dealing with the emotions I'm experiencing as a result of my diagnosis?
- Are there any new treatments on the horizon that might be worth considering?
- Are there any alternative treatments or dietary and nutritional approaches that might be worth trying? How could the UCSF Osher Center for Integrative Medicine assist me? What dietician at UCSF or MarinHealth Medical Center, or my hospital could I consult for advice about nutrition **for prostate patients and about exercises that may be helpful in slowing the progression of my prostate cancer?**
- What factors determine the possibility of recurrence following treatment?
- What is a local failure and a distant failure? If my PSA goes up after treatment, how do you determine which kind of failure has occurred? Are local and distant failures treated differently?
- What tools are available (such as “nomograms”) to help predict my prognosis and where can I find them?
- When would I be considered “cured” of prostate cancer?**Is there such a thing as a “cure” from prostate cancer?**

- **I understand my sons and other male relatives are at increased risk for prostate cancer because of my diagnosis. What can they do to reduce their risk and monitor their prostate health?**

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- **Does prostate cancer put me at increased risk for other kinds of cancers?**

Questions about Radiation Therapy for Prostate Cancer

- **Do you recommend any other treatments, such as hormone therapy, before I begin radiation? Why, why not?**
- **Do you recommend External Beam Radiation Therapy, Brachytherapy, or CyberKnife or any combination of the above, to treat my prostate cancer? Why do you recommend this type of treatment?**
- **Do you recommend additional radiation treatment directed to the pelvic lymph nodes (whole pelvic radiation)?**
- **For external radiation therapy, what kinds of treatment are available (IMRT, IGRT, CyberKnife, Proton beam, etc.) and what are the pros and cons of each? What do you recommend and why? Where would I receive this treatment? How many treatments would I receive and how long would each treatment take? Could I get periodic blood panel tests to ensure radiation does not**

adversely affect my blood production? Could I get a baseline panel to begin and proceed from there?

- For external radiation, how much radiation (measured in Grays) do you think I would need and what is the significance of this?
- For brachytherapy, what are the pros and cons for me of Low Dose Rate vs. High Dose Rate? **What kind do you recommend and why?** How is the procedure performed? How do I prepare for the procedure? Is anesthesia used and what kind? What is the recovery time from the procedure? Is it done on an inpatient or outpatient basis? How will I feel after the procedure?
- For brachytherapy, how many seeds would you recommend and what kind of seeds?

What are the pros and cons of the different types of seeds for Low Dose Rate Brachy?

- What are the potential short-term and long-term side effects of radiation therapy for prostate cancer? Can radiation cause incontinence or other urinary symptoms, impotence, changes in bowel functions, skin irritation?
- How will I feel while I'm receiving radiation? Will it affect my job, home life or social activities?
- For external radiation, what happens if the machine is down on a day when I'm supposed to receive treatment? What happens if I need to be out of town during a time when I'm scheduled for treatment?
- **Who should I contact if I experience severe side effects or complications during treatment?**
Telephone number to call:
- What is the success rate for this therapy?
- **How many times have you administered this treatment?** How many have you done in the last year? How many have been done in the last year at the hospital or facility where I would receive treatment?

- **What is the rate of side effects such as ability to achieve erection and urinary incontinence?**
- **Do I have any pre-existing conditions that would increase the possibility of side effects?**
- **If I had previous prostate treatment or surgery (such as TURP), would that make a difference?**
- **If I have received radiation previously for something else, am I still a candidate for prostate radiation?**
- **Does radiation to the prostate present an increased risk of other kinds of cancers “secondary cancers” and over what period of time?**
- **If I have prostate radiation and then later develop a secondary cancer, would I still be able to receive radiation again?**
- **How often will I receive radiation treatments? How long will each treatment take?**
- **For external radiation, how will the radiation be targeted on the prostate?**
- **Do some kinds of radiation cause less damage to surrounding tissues than others? How could it affect my body’s ability to produce blood?**
- **How can I expect to feel during treatment? Can I continue with my normal daily activities?**
- **Can my radiation affect others? Will my partner or family need to take any precautions while I am receiving radiation? Can I have sexual activity while receiving radiation/after getting seeds?**
- **How will my prostate cancer be monitored during and after radiation therapy?**
- **What should my PSA be after radiation therapy? What is a “PSA bump”?**
- **What type of follow-up care will I receive after radiation therapy?**
- **If there is a recurrence after radiation, what treatment options are available? What is the success of these treatments? What are the risks and side effects?**

Questions about Prostate Cancer Surgery

- **Do you recommend surgery for me? Do you think surgery is a better alternative than other treatments? Why?**
- **What type of surgery do you recommend (open, laparoscopic, robotic)?**

What are the differences between these types of surgery in terms of length of the operation, surgical margins, blood loss, pain, length of hospital stay?

- **What is the difference between retropubic and perineal surgery? Which method do you prefer and why?**
- **What are the benefits/disadvantages of these types of surgery?**
- **What are the possible side effects of this surgery?**
- **How do you decide whether to spare the nerves to help preserve the ability to achieve an erection or to remove nerves if it might prevent the cancer from spreading? How should I weigh my personal feelings about potency vs. recurrence risk when making this decision?**
- **About how many times have you performed this procedure? How many of these procedures have you performed in the last year? What is the rate of negative margins in your surgeries? What % of your patients still experience urinary incontinence a year after surgery? What % of patients experience lasting impotence? What % of patients experience other complications? What is the mortality rate of this surgery?**
- **Do I have any conditions or risk factors that would weigh against having surgery? Should I have any tests to help determine this?**
- **If I have trouble urinating due to BPH, will surgery help with that problem?**

- **If I had previous prostate treatment or surgery (such as TURP), does that present any issues when considering a prostatectomy?**
- **Will a lymph node dissection be necessary and why (or why not)? What does a lymph node dissection involve and does it prolong the surgery/increase the risk of complications/affect the recovery time? How many lymph nodes will you dissect and could I decide if I'd like to have more nodes taken?**
- **If cancer outside of the prostate gland is found during surgery, what will be the course of action?**
- **Who actually will perform the surgery and what role do interns/residents play during the surgery (in teaching hospitals)? Who will perform what and do I have a say about this?**
- **How should I prepare for surgery both mentally and physically?**
- **What pre-surgical tests do you order? Are there any additional pre-surgical tests I should have?**
- **Should I be tested for MRSA (a kind of staph infection) prior to surgery?**
- **Do I need to allow time for the biopsy to heal before surgery?**
- **What % of your patients need a transfusion during this type of surgery? Should I store blood prior to the procedure? Does having that much blood drawn not long before surgery present any disadvantages (weakness, anemia, etc.)? Can friends/family donate blood for me?**
- **Can you prescribe a sedative (such as Valium) for me to take the day of the surgery?**
- **What kind of anesthesia will be used? Is there any choice? Who will be the anesthesiologist and how experienced is (s)he?**
- **About how long will the operation last?**
- **How long will I be in the hospital following surgery? What determines when I am ready to be discharged?**

- **Will I experience much pain after the surgery? What kind of pain is most prevalent--pain at the incisions, bladder spasms, testicular pain, stomach cramps, or pain in other areas? What can be done to relieve the pain?**
- **Are there supplies I will need to have at home following the surgery? Is there a list available?**
- **Will you give me a prescription for pain medication, anti-spasmodic medication (such as Oxybutinin) and any other medications I may need at home following the surgery?**
- **Do I need to follow a certain diet after surgery? How much alcohol could I drink post-surgery, or for how long should I abstain following the operation?**
- **How long should it take for bowel function to return after surgery? Do you suggest using a stool softener?**
- **What kind of care will I need at home following the surgery? Will I need someone to help me and, if so, for how long?**
- **What complications can develop during or after surgery? Who should I contact if I have questions or experience severe side effects? Telephone number to call:**
- **If I need emergency care after coming home, where should I go?**
- **How long will the catheter remain in? Who will explain how to care for the catheter? Will I be able to sleep with the catheter in place?**
- **Will any tests be done to determine whether I am ready to have the catheter removed? When do I need to schedule an appointment for catheter removal?**
- **Do I need to take any antibiotics before or after catheter removal?**
- **What can I do to reduce the chance of post-surgery problems (such as Kegel exercises and ways to reduce the chance of blood clots)? Do I need to discontinue any medications or supplements**

prior to surgery? How long before surgery should I do this? What supplements, if any, do you recommend I take post-treatment?

- **What can I do to reduce the risk of infection after surgery?**
- **How soon will I be able to walk, go up and down stairs, drive and take a shower after surgery?**
- **Will there be any stitches to remove and, if so, how long after surgery and who will remove them?**
- **About how long will it take before I can return to work, drive, exercise, have sexual activity?**
- **Do you prescribe Viagra (or similar medication) after surgery and how many days after surgery should I begin to take it? How about injection therapy?**
- **Are there limitations on how much I can lift and certain other activities after surgery?**
- **When will the final pathology report be available after the surgery? How will I be contacted with the results? What are the significant things to look for in the report?**
- **How will my condition be monitored following surgery? What tests will be performed?**
- **When should I get a PSA after surgery? How frequently should I get PSA's after surgery and for how many years?**
- **What kind of PSA should I get (regular or ultra-sensitive)? What PSA result is considered good after surgery? What result might indicate a recurrence?**
- **Will you give me a lab order to request the PSA?**
- **Does it matter what lab I go to for my post-surgery PSA tests?**
- **If there is a recurrence after surgery, what are my options?**
- **Will the surgery affect the size of my penis? What kind of penile rehabilitation practices should I adopt and when?**
- **How long does it typically take to regain continence? Potency? If I experience incontinence or impotence, what treatments are available?**

- **Will we be able to conceive after surgery? If not, can I bank sperm if I want to conceive in the future?**
- **How do I care for the surgical incisions?**

Questions about Hormone Therapy for Prostate Cancer

- **What is hormone therapy?**
- **Please explain the difference between short term and long-term hormone therapy.**
- **What type of doctor will manage and administer the hormone therapy?**
- **What type of hormone therapy do you recommend?**
- **What are the side effects of hormone therapy? Are there ways to reduce the side effects?**
- **How long does it take to recover from the effects of hormone therapy?**
- **How often, and for how long would I receive the hormones? Is there a choice between shorter and longer lasting hormones?**
- **How are the hormones administered?**
- **Please tell me the difference between Lupron and Firmagon.**
- **How will my condition be monitored during hormone therapy?**
- **What is my prognosis with hormone therapy?**
- **What options are there if my PSA starts rising after hormone therapy?**
- **Should I consider surgical removal of the testicles (orchiectomy) be necessary?**
- **How will treatment affect my sexual and emotional well-being?**
- **How common are hot flashes after hormone therapy? Can hot flashes be treated with medication?**
- **How will treatment affect my fertility? My libido?**
- **What type of follow-up care is necessary after treatment?**

- **Do I need to begin treatment right away?**
- **Are different hormones sometimes used in combination?**
- **What are the pluses and minuses of different hormones/combinations of hormones?**
- **Can hormone therapy cure prostate cancer?**
- **How will hormone treatments affect my muscle mass and what types of exercise could I do to help alleviate some of the treatment's side effects?**
- **How common is osteoporosis and how can it be treated? Can I have a DEXA scan and a Vitamin E blood level test done before hormone therapy to establish a baseline bone density and potential vitamin deficiency reading respectively?**
- **If I am osteoporotic, what treatments are available and suggested for me (Prolia, Boniva, etc.). For how long would such drugs be administered to me and what precautions should be taken (should Boniva follow when Prolia is finished so as to preserve the beneficial effects of Prolia, etc.)?**
- **Will hormone therapy "feminize" my body in any way? If so, how? What can I do if hormone treatments cause my breasts to enlarge and/or become painful?**
- **What type of follow-up care is necessary after treatment?**
- **Am I eligible for a clinical trial?**

Questions for your Medical Oncologist (Advanced cancer)

Why was I referred to a Medical Oncologist?

What will you do that is different from the treatment I had before?

Will you be my main doctor from now on?

(For hormone therapy see questions in section above.)

December 5, 2019

Am I finished with other treatments: focal, surgery, radiation, hormone therapy?

What is systemic therapy? Why is it necessary?

What is involved with receiving chemotherapy?

What medications are you considering for me? What are the pros and cons of each?

Do you want me to check my PSA? How often? Where?

Will I be receiving any further diagnostic tests including imaging?

What is the history/track record of the drugs you may prescribe?

Am I eligible for any trials?

What is abiraterone/Zytiga?

What is enzalutamide/Xtandi?, Apalutamide/Erleada?

What is Ra223?

What is Lu177?

Will my insurance pay for the treatments you are prescribing?