The Marin Chapter of the UsToo/ Man-to-Man Prostate Cancer Support Group has compiled this very comprehensive list of questions concerning diagnosis, selection of treatment, treatment itself, and follow-up care.

While there are way too many questions to pose during one interview with your physician, many can be answered with a little research on your part. We strongly recommend you find your own answers by reviewing two sources provided in the comprehensive package given to you on your initial visit:

UCSF Medical Center Your Health Matters – Prostate Cancer & its Treatment

For most visits you may not have time for more than 5 – 10 questions. We recommend you select questions that are more specific to your particular situation, and harder to answer through published sources.

Introduction

Dealing with prostate cancer is a big challenge both emotionally and intellectually. The good news is that there are several treatments available. For some men, that also can be bad news. It means dealing with ambiguity--digesting lots of information and making difficult decisions about what treatment to have and where to have it. This document was put together by a group of prostate cancer patients to assist in the process. Our goal is to help patients sort out all 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 information was 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 is 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 different medical specialists that 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 particular kinds of specialists.

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.

6. You might also want to ask two more questions as your appointment is concluding:

7. Is there anything else we haven’t covered that I should know about?

8. If a question comes up later, is it OK to contact you by e-mail or telephone and how do I reach you?
General questions for your internist

1. At what age should men start being screened for prostate cancer?

2. In your opinion, should men stop being screened for prostate cancer after a certain age?

3. How often should I get a PSA? What is the difference between regular, free and ultra-sensitive PSA’s and which kind should I get?

4. What is the normal range for a PSA at my age?

5. What PSA results would cause some concern?

6. Are there additional, perhaps more accurate tests such as the PCA-3 test that we should be using?

7. Is it a good idea to keep track of my PSA over time? What should we be looking for?

8. Should I refrain from sexual or other activities for some time before having a PSA?

9. What is PSA doubling time and what is its significance for me?

10. What is the rate of false positives/false negatives with PSA results?

11. If my PSA is low, does that rule out prostate cancer?

12. 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?

13. Does a nodule on the prostate always indicate prostate cancer?

14. What are the symptoms of prostate cancer? Can those symptoms also result from other conditions?

15. Can you have prostate cancer without any symptoms?

16. What causes prostate cancer? What are the risk factors for prostate cancer?

17. Are there things I can do to reduce my risk of getting prostate cancer (medications, lifestyle, supplements, diet, exercise)?
Questions Prior to a Biopsy

1. Why do I need a biopsy?
2. How is a prostate biopsy done?
3. How many prostate biopsies have you done?
4. How many samples do you plan to take?
5. Will it hurt? Will you use topical and injected Lidocaine or other anesthetic prior to the biopsy?
6. Can I take a sedative such as Valium prior the biopsy and will you prescribe it?
7. Should I stop taking aspirin and certain other medications and supplements at some point prior to the biopsy? When can I resume taking them?
8. Do I need to take antibiotics before or after the biopsy?
9. What should I expect during and after the biopsy?
10. Can there be complications from a biopsy? After the biopsy, what things should alert me to call you?
11. Can a biopsy cause any cancer to spread?
12. When and how will I get the biopsy results? May I please have a copy of the written report?
13. What pathology lab will analyze the biopsy?
14. Who will retain my biopsy slides?
15. Are there false positives/false negatives in biopsies?
16. Should I get a second opinion from another pathology lab? If so, can you recommend a lab?
17. If the biopsy is negative, does that mean I don’t have prostate cancer? What follow up will I need?
18. Is it possible that if a very small amount of low grade cancer is found that I may not have to have any therapy?
Questions for Men Recently Diagnosed with Prostate Cancer

1. What stage and grade is my prostate cancer and what is the significance of this?

2. What is the size of my prostate?

3. What is my current prostate-specific antigen (PSA) level? At what rate has my PSA level risen?

4. What is my Gleason score? What does that score mean?

5. 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? May I please have a copy of the pathology report?

6. If the biopsy showed that I have “PIN,” what is the significance and what follow up is needed?

7. Should my biopsy slides be examined by another pathology lab for a second opinion and who do you recommend?

8. Should I bring my spouse/partner to my doctors’ appointments?

9. Are there any additional tests that will help determine if my cancer is confined to the prostate or has spread?

10. Should I have any imaging studies before deciding on a treatment and, if so, what kind and where should I have them?

11. Would color Doppler or other ultrasound provide useful information about my cancer?

Questions after having imaging studies:

12. 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? May I please have a copy of the images?

13. What is the prognosis for my degree of prostate cancer?

14. 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?

15. Might chemotherapy be appropriate to treat my prostate cancer, including in a clinical trial?

16. What treatment(s) do you recommend and why?

17. Should I consider treatments available in other countries but 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?

18. Does this mean the end of my sex life?

19. 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 conceive? Shall I be banking sperm?

20. Can ejaculatory urinary incontinence occur after a prostatectomy or after radiation? What can be done about it?

21. If you recommend surgery, what kind of surgery do you recommend (open, laparoscopic, robotic) and why?
22. How many patients have you operated on in this way and over what period of time?

23. To be asked of Internists and medical Oncologists: If you had prostate cancer, what surgeon (or radiologist) who you go to?

24. I know there are privacy issues, but is there a way to talk to other patients who have undergone this treatment?

25. Is “active surveillance” an option in my case? If so, what are the pluses and minuses and what tests (biopsies, ultrasound, PSA, etc.) would I need and how often would I need them? If I choose active surveillance, what would trigger switching to another option?

26. How do I decide what treatment is best for my cancer?

27. Can you help me rank the available options in order of what’s best in my situation?

28. How soon do I need to make a decision and are there risks in waiting? How soon do I need to have treatment?

29. 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?

30. Once I decide, how long does it take to get on the schedule and for treatment to begin?

31. Are there any clinical trials that I should consider?

32. Can you suggest additional resources for information that might be helpful?

33. What reference materials (books, web sites, pamphlets, etc.) do you recommend and where can I get them?

34. Do you know of a local prostate cancer support group?

35. How can I get help dealing with the emotions I'm experiencing as a result of my diagnosis?

36. Are there any new treatments on the horizon that might be worth considering?

37. Are there any alternative treatments or dietary and nutritional approaches that might be worth trying?

38. What factors determine the possibility of recurrence following treatment?

39. 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?

40. What tools are available (such as “nomograms”) to help predict my prognosis and where can I find them?

41. When would I be considered “cured” of prostate cancer?

42. 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?

43. Does prostate cancer put me at increased risk for other kinds of cancers?
Questions about Radiation Therapy for Prostate Cancer

1. Do you recommend any other treatments, such as hormone therapy, before I begin radiation? Why, why not?

2. Do you recommend external radiation therapy or brachytherapy to treat my prostate cancer? Why do you recommend this type of treatment?

3. For external radiation therapy, what kind of radiation 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?

4. For external radiation, how much radiation (measured in Grays) do you think I would need and what is the significance of this?

5. 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?

6. For brachytherapy, how many seeds would you recommend and what kind of seeds?

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

8. 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?

9. How will I feel while I'm receiving radiation? Will it affect my job, home life or social activities?

10. 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?

11. Who should I contact if I experience severe side effects or complications during treatment? Telephone number to call:

12. What is the success rate for this therapy?

13. 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?

14. What is the rate of side effects such as ability to achieve erection and urinary incontinence?

15. Do I have any pre-existing conditions that would increase the possibility of side effects?

16. If I had previous prostate treatment or surgery (such as TURP), would that make a difference?

17. If I have received radiation previously for something else, am I still a candidate for prostate radiation?

18. Does radiation to the prostate present an increased risk of other kinds of cancers?

19. If I have prostate radiation and some day develop another kind of cancer, would I still be able to receive more radiation?

20. How often will I receive radiation treatments? How long will each treatment take?
21. For external radiation, how will the radiation be targeted on the prostate?

22. Do some kinds of radiation cause less damage to surrounding tissues than others?

23. How can I expect to feel during treatment? Can I continue with my normal daily activities?

24. 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?

25. How will my prostate cancer be monitored during and after radiation therapy?

26. What should my PSA be after radiation therapy? What is a “PSA bump”?

27. What type of follow-up care will I receive after radiation therapy?

28. 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

1. Do you recommend surgery for me? Do you think surgery is a better alternative than other treatments? Why?

2. What type of surgery do you recommend (open, laparoscopic, robotic)?

3. 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? Do you consider the lack of tactile feedback to be an issue in robotic surgery?

4. What is the difference between retropubic and perineal surgery? Which method do you prefer and why?

5. What are the benefits/disadvantages of these types of surgery?

6. What are the possible side effects of this surgery?

7. 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? Are my personal feelings about potency vs. recurrence risk a factor in making this decision?

8. 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 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?

9. Do I have any conditions or risk factors that would weigh against having surgery? Should I have any tests to help determine this?

10. If I had previous prostate treatment or surgery (such as TURP), does that present any issues when considering a prostatectomy?

11. 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/effect the recovery time?

12. If cancer outside of the prostate gland is found during surgery, what will be the course of action?

13. Who actually will perform the surgery and what role do interns/residents play during the surgery (in teaching hospitals)?

14. How should I prepare for surgery both mentally and physically?

15. What pre-surgical tests do you order? Are there any additional pre-surgical tests I should have?

16. Should I be tested for MRSA (a kind of staph infection) prior to surgery?

17. Do I need to allow time for the biopsy to heal before surgery?

18. 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?

19. Can you prescribe a sedative (such as Valium) for me to take the day of the surgery?
20. What kind of anesthesia will be used? Is there any choice? Who will be the anesthesiologist and how experienced is (s)he?

21. About how long will the operation last?

22. How long will I be in the hospital following surgery? What determines when I am ready to be discharged?

23. Will I experience much pain after the surgery? What kind of pain is most prevalent--pain at the incisions, testicular pain, stomach cramps, or pain in other areas? What can be done to relieve the pain?

24. Are there supplies I will need to have at home following the surgery? Is there a list available?

25. 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?

26. Do I need to follow any particular diet after surgery?

27. How long should it take for bowel function to return after surgery? Do you suggest using a stool softener?

28. 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?

29. 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:

30. If I need emergency care after coming home, where should I go?

31. 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?

32. 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?

33. Do I need to take any antibiotics before or after catheter removal?

34. 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)?

35. Do I need to discontinue any medications or supplements prior to surgery? How long before surgery should I do this?

36. What can I do to reduce the risk of infection after surgery?

37. How soon will I be able to walk, go up and down stairs, drive and take a shower after surgery?

38. Will there be any stitches to remove and, if so, how long after surgery and who will remove them?

39. About how long will it take before I can return to work, drive, exercise, have sexual activity?

40. 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?

41. Are there limitations on how much I can lift and certain other activities after surgery?
42. 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?
43. How will my condition be monitored following surgery? What tests will be performed?
44. When should I get a PSA after surgery? How frequently should I get PSA’s after surgery and for how many years?
45. 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?
46. Will you give me a lab order to request the PSA?
47. Does it matter what lab I go to for my post surgery PSA’s?
48. If there is a recurrence after surgery, what are my options?
49. Will the surgery affect the size of my penis?
50. How long does it typically take to regain continence? Potency? If I experience incontinence or impotence, what treatments are available?
51. Will we be able to conceive after surgery? If not, can I bank sperm if I want to conceive in the future?
52. How do I care for the surgical incisions?
Questions about Hormone Therapy for Prostate Cancer

1. Should I have hormone therapy prior to radiation to help the radiation work more efficiently? How about if want to be very aggressive?

2. What is hormone therapy?

3. What kinds of hormone therapy are there?

4. Are different hormones sometimes used in combination?

5. What are the most common side effects of anti-androgens, luteinizing hormone-releasing hormone (LHRH) analogs, and luteinizing hormone-releasing hormone antagonists?

6. What are the pluses and minuses of different hormones/combinations of hormones?

7. What type of hormone therapy do you recommend?

8. Does hormone therapy cure prostate cancer?

9. How common are hot flashes after hormone therapy? Can hot flashes be treated with medication?

10. How common is osteoporosis and how can it be treated?

11. Should I have a bone density test before receiving hormone therapy?

12. What are other side effects of hormone therapy? Are there ways to reduce the side effects?

13. How long does it take to recover from the effects of hormone therapy?

14. How often would and for how long would I receive the hormones? Is there a choice between shorter and longer lasting hormones?

15. How are the hormones administered? Are there alternative ways of administering the hormones?

16. How will my condition be monitored during hormone therapy?

17. What is my prognosis with hormone therapy?

18. What options are there if my PSA starts rising after hormone therapy?

19. Might surgical removal of the testicles (orchiectomy) be necessary?

20. If orchiectomy is performed, may I choose to have a testicular prosthesis?

21. What are my options for treatment?

22. How will treatment affect my sexual and emotional well-being? How will treatment affect my fertility?

23. What type of follow-up care is necessary after treatment? Do I need to begin treatment right away?

24. If my treatment is delayed, how will the cancer be monitored?

25. Am I eligible for a clinical trial?