



Baseline Survey

CEASAR STUDY

This questionnaire is about your quality of life and other experiences related to your prostate cancer. Please complete this survey and return it as soon as possible. Do not wait until you have started treatment for your prostate cancer.

If you have already started treatment for prostate cancer, please still complete the survey and return it as soon as you can. Some questions may ask you to answer based on how you were feeling in the period just before you started treatment. Please think back to the time just before you started treatment and answer these questions the best you can.

To help us get the most accurate information, it is important that you answer all questions honestly and completely about your own experience. You may skip any questions that you are uncomfortable answering. Your responses will help us in our efforts to learn more about how to best treat prostate cancer.

Information contained within this survey will remain strictly confidential.

Thank you very much for your assistance in answering these questions.



General Instructions

PLEASE READ THESE INSTRUCTIONS CAREFULLY

- Answer each question as best you can. If you choose to skip a question, please write 'skip' next to it.
- Please fill in the oval next to your answer completely using blue or black ink.

Example: Fill in ovals completely, like this:

Not like this: Or this:

- Please follow any instructions that direct you to the next question.

Example: No (**If no, go to the 'If no' section on the next page**)

- If you mark an answer with a line after it, please write the specific information on the line.

Example:

Other, please specify: my friend who is a doctor

- Mark only one response for each question, unless other instructions are given.

- If you mark the wrong oval by mistake, put an X through it and fill in the correct answer, like this:

- As much as possible, please try to answer all of the questions in one sitting.



General Prostate Cancer Questions

1. Today's date: _____ / _____ / 20
Month Day Year

2. What is your current age? _____

3. What is your most recent PSA result? _____.

Don't know

4. Has your doctor told you that your cancer has spread outside your prostate?
(Choose one answer)

- Yes
- No
- Don't know

5. What is your current employment status? *(Choose all that apply)*

- Working full time
- Working part time
- Retired
- Unemployed (or looking for work)

6. Have you started/received any therapy/treatment for your prostate cancer?

- Yes
- No

If yes, what type of therapy *(Choose all that apply)*:

- Surgery (prostatectomy)
- External beam radiation (standard or conformal)
- Radioactive seeds (implants, brachytherapy)
- Hormone therapy (including shots or pills such as Flutamide, Eulexin, Casodex, Zoladex, or Lupron)
- Cryotherapy (freezing of the prostate)
- No active treatment (watchful waiting or observation)
- Other initial therapy (please specify): _____

**General Health**

7. In general, would you say your health is:

- Excellent
- Very good
- Good
- Fair
- Poor
- Very poor

8. During the past 6 months, how often did you feel short of breath?

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. When lying down flat	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. When sitting or resting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. When walking less than one block	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. When climbing one flight of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. When climbing several flights of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

9. Have you ever been told by a physician that you have any of the following problems related to your heart or circulation?: (*Choose one for each item*)

	No	Yes
a. Heart attack	<input type="radio"/>	<input type="radio"/>
b. Congestive heart failure	<input type="radio"/>	<input type="radio"/>
c. Angina	<input type="radio"/>	<input type="radio"/>



10. In the past 6 months, how many times have you had any of the following problems related to your heart or circulation?

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Chest pain or pressure when you exercise	<input type="radio"/>				
b. Chest pain or pressure when resting	<input type="radio"/>				
c. Ankles or legs that swell as the day goes on	<input type="radio"/>				
d. Fainting or dizziness when you stand up	<input type="radio"/>				

For the next set of questions, if you have already started therapy/treatment for your prostate cancer, please think back to the 4 weeks immediately before you began therapy to answer the questions.

11. The following items are activities you might do during a typical day. Does your health now (**if you have already started therapy/treatment for your prostate cancer, please think back to the 4 weeks immediately before you began therapy to answer this question**) limit you in these activities? If so, how much? (Choose one response on each line)

	Yes, I am LIMITED a lot	Yes, I am LIMITED a little	No, I am NOT LIMITED at all
a. <u>Vigorous activities</u> , such as running, lifting heavy objects, participating in strenuous sports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Lifting or carrying groceries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Climbing <u>several</u> flights of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Climbing <u>one</u> flight of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Bending, kneeling, or stooping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Walking <u>more than a mile</u>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Walking <u>several hundred yards</u>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Walking <u>one hundred yards</u>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. Bathing or dressing yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



12. These questions are about how you have felt during the past 4 weeks (**if you have already started therapy/treatment for your prostate cancer, please think back to the 4 weeks immediately before you began therapy to answer this question**). For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks (**or the 4 weeks prior to treatment, if you have already started therapy**)... *(Choose one response on each line)*

	<u>None of the time</u>	<u>A little of the time</u>	<u>Some of the time</u>	<u>A good bit of the time</u>	<u>Most of the time</u>	<u>All of the time</u>
a. Did you feel full of life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Have you been very nervous?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Have you felt so down in the dumps that nothing could cheer you up?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Have you felt calm and peaceful?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Did you have a lot of energy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Have you felt down-hearted and depressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Did you feel worn out?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Have you been happy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Did you feel tired?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



13. During the past 4 weeks (**or the 4 weeks prior to treatment, if you have already started therapy**) how often were the following statements true: (Choose one response on each line)

	<u>None of the time</u>	<u>Some or a little of the time</u>	<u>Occasionally</u>	<u>Most or all of the time</u>
a. I was bothered by things that usually don't bother me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I felt that I could not shake off the blues even with help from my family or friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. I had trouble keeping my mind on what I was doing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. I felt depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. I felt that everything I did was an effort	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. My sleep was restless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. I was happy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. I enjoyed life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. I felt sad	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Specific Health Issues**

For the next set of questions, if you have already started therapy/treatment for your prostate cancer, please think back to the 4 weeks immediately before you began therapy to answer the questions.

Urinary Issues

14. Over the past 4 weeks (or the 4 weeks prior to treatment, if you have already started therapy), how often have you leaked urine? (Choose one)

- More than once a day
- About once a day
- More than once a week
- About once a week
- Rarely or never

15. Which of the following best describes your urinary control during the last 4 weeks (or the 4 weeks prior to treatment, if you have already started therapy)? (Choose one)

- No urinary control whatsoever
- Frequent dribbling
- Occasional dribbling
- Total control

16. How many pads or adult diapers per day did you usually use to control leakage during the last 4 weeks (or the 4 weeks prior to treatment, if you have already started therapy)? (Choose one)

- None
- 1 pad per day
- 2 pads per day
- 3 or more pads per day



17. How big a problem, if any, has each of the following been for you **during the last 4 weeks (or the 4 weeks prior to treatment, if you have already started therapy)? (Choose one for each item)**

	No problem	Very small problem	Small problem	Moderate problem	Big problem
a. Dripping or leaking urine	<input type="radio"/>				
b. Pain or burning on urination	<input type="radio"/>				
c. Bleeding with urination	<input type="radio"/>				
d. Weak urine stream or incomplete emptying	<input type="radio"/>				
e. Need to urinate frequently during the day	<input type="radio"/>				

18. Overall, how big a problem has your urinary function been for you **during the last 4 weeks (or the 4 weeks prior to treatment, if you have already started therapy)? (Choose one)**

- No problem
- Very small problem
- Small problem
- Moderate problem
- Big problem

Bowel Issues

19. How big a problem, if any, has each of the following been for you **during the last 4 weeks (or the 4 weeks prior to treatment, if you have already started therapy)? (Choose one response on each line)**

	No problem	Very small problem	Small problem	Moderate problem	Big problem
a. Urgency to have a bowel movement	<input type="radio"/>				
b. Increased frequency of bowel movements	<input type="radio"/>				
c. Losing control of your stools	<input type="radio"/>				
d. Bloody stools	<input type="radio"/>				
e. Abdominal/pelvic/rectal pain	<input type="radio"/>				



20. Overall, how big a problem have your bowel habits been for you **during the last 4 weeks (or the 4 weeks prior to treatment, if you have already started therapy)? (Choose one)**

- No problem
- Very small problem
- Small problem
- Moderate problem
- Big problem

Sexual Issues

21. Do you currently use any of the following to help with problems with sexual function?

	Yes	No
--	-----	----

- | | | |
|--|-----------------------|-----------------------|
| a. Vacuum suction device? | <input type="radio"/> | <input type="radio"/> |
| b. Penile injections (shots)? | <input type="radio"/> | <input type="radio"/> |
| c. Pills, such as Viagra, Cialis, Levitra? | <input type="radio"/> | <input type="radio"/> |
| d. Urethral pellets or suppositories (Muse)? | <input type="radio"/> | <input type="radio"/> |
| e. Penile prosthesis? | <input type="radio"/> | <input type="radio"/> |

22. How would you rate each of the following **during the last 4 weeks (or the 4 weeks prior to treatment, if you have already started therapy)?**

(Choose one response on each line)

	Very poor to none	Poor	Fair	Good	Very good
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- | | | | | | |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| a. Your ability to have an erection? | <input type="radio"/> |
| b. Your ability to reach orgasm (climax)? | <input type="radio"/> |



23. How would you describe the usual QUALITY of your erections **during the last 4 weeks (or the 4 weeks prior to treatment, if you have already started therapy)? (Choose one)**

- None at all
- Not firm enough for any sexual activity
- Firm enough for masturbation and foreplay only
- Firm enough for intercourse

24. How would you describe the FREQUENCY of your erections **during the last 4 weeks (or the 4 weeks prior to treatment, if you have already started therapy)? (Choose one)**

- I NEVER had an erection when I wanted one
- I had an erection LESS THAN HALF the time I wanted one
- I had an erection ABOUT HALF the time I wanted one
- I had an erection MORE THAN HALF the time I wanted one
- I had an erection WHENEVER I wanted one

25. Overall, how would you rate your ability to function sexually **during the last 4 weeks (or the 4 weeks prior to treatment, if you have already started therapy)? (Choose one)**

- Very poor
- Poor
- Fair
- Good
- Very good

26. Overall, how big a problem has your sexual function or lack of sexual function been for you **during the last 4 weeks (or the 4 weeks prior to treatment, if you have already started therapy)? (Choose one)**

- No problem
- Very small problem
- Small problem
- Moderate problem
- Big problem



27. How big a problem **during the last 4 weeks (or the 4 weeks prior to treatment, if you have already started therapy)** if any, has each of the following been for you? *(Choose one response on each line)*

	No problem	Very small problem	Small problem	Moderate problem	Big problem
a. Hot flashes	<input type="radio"/>				
b. Breast tenderness/enlargement	<input type="radio"/>				
c. Feeling depressed	<input type="radio"/>				
d. Lack of energy	<input type="radio"/>				
e. Change in body weight	<input type="radio"/>				

Concerns Surrounding Impact of Prostate Cancer

28. Sometimes people with prostate cancer have concerns about complications that may develop. How much are you worried or concerned about each of the following? *(Choose one response on each line)*

	Extremely worried	Very worried	Worried	Not very worried	Not worried at all
a. Losing sexual function after treatment	<input type="radio"/>				
b. Having bowel problems after treatment	<input type="radio"/>				
c. Becoming dependent on family or friends because of prostate cancer	<input type="radio"/>				
d. The lack of a cure for prostate cancer	<input type="radio"/>				
e. Dying earlier than most people, because of prostate cancer	<input type="radio"/>				
f. Having other major health problems made worse by prostate cancer	<input type="radio"/>				
g. The overall impact of prostate cancer on your health	<input type="radio"/>				



29. Overall, how much of a burden is your having prostate cancer on you and your family in each of the following areas? (*Choose one response on each line*)

	<u>Very large burden</u>	<u>Large burden</u>	<u>Feel neutral</u>	<u>Small burden</u>	<u>Very small burden</u>	<u>Not a burden at all</u>
a. Our overall health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Our social activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Our lifestyle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Our finances in general	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Our finances due to the cost of my treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Our finances due to the other costs of health care for prostate cancer (such as visits to the doctor, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Our finances due to the cost of my health insurance because I have prostate cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

30. How often have you worried that the cancer treatment you choose will have a significant impact on your close relationships? (*Choose one*)

- Never
- Rarely
- Sometimes
- Often
- Very often

31. How often have you wondered why you got cancer or asked "Why me?" (*Choose one*)

- Never
- Rarely
- Sometimes
- Often
- Very often



32. People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? (Choose one response on each line)

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Someone who can help you out if you need it - for example, by helping you get to the doctor or prepare your meals if you are unable to do it yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Someone to share your most private worries and fears with	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Someone to love and make you feel wanted	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Someone to do something enjoyable with or someone to have a good time with	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Someone to give you good advice or give you information to help you understand a situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Your Relationship with your Doctor and the Healthcare System

Your responses to these questions, like all the questions on this survey, are confidential. They will not be shared with anyone associated with your healthcare, including your doctor.

33. Please think about the care you have received since you were diagnosed with prostate cancer. (Choose one response on each line)

	Never	Rarely	Sometimes	Often	Very often
a. How often did the doctors <u>who take care of your prostate cancer</u> ask you to take some of the responsibility for your treatment?	<input type="radio"/>				
b. If there were a choice between treatments, how often would the doctors <u>who take care of your prostate cancer</u> ask <u>you</u> to help make the decision?	<input type="radio"/>				
c. How often did the doctors <u>who cared for your prostate cancer</u> make an effort to give you some control over treatment decisions?	<input type="radio"/>				

**34. How often do the doctors who take care of your prostate cancer:***(Choose one response on each line)*

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Offer <u>choices</u> in your medical care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Discuss the <u>pros and cons</u> of each option with you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Ask you to state which choice or option you <u>would prefer</u> ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Take your preferences into account when making treatment decisions?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please continue on next page



35. The following questions ask about your beliefs about health and health care. For each statement, please fill the oval on the scale that comes closest to how much you agree or disagree with the statement.
(Choose one response on each line)

	Strongly Agree	Moderately Agree	Feel Neutral	Moderately Disagree	Strongly Disagree
a. I often feel that no matter how hard I try I am helpless (when it comes to influencing my medical care) to change the kind of medical care I get	<input type="radio"/>				
b. More and more, I feel helpless to control my disease	<input type="radio"/>				
c. I often feel like giving up on my medical care	<input type="radio"/>				
d. Almost all treatment decisions are better left up to the doctor	<input type="radio"/>				
e. Even when patients have had diseases for a long time, it is better for the doctor to make all the treatment decisions	<input type="radio"/>				
f. People who are pushy with doctors are not good patients	<input type="radio"/>				

Thank you very much for your participation. Please mail the survey back in the enclosed postage paid envelope. If you have any questions, please contact: