ID

OFFICE USE ONLY

NATIONAL CANCER INSTITUTE

National Survey of Prostate Disease and Quality of Life

CONFIDENTIAL

1. Please write today's date ____/____/____
Mo. Day Yr.

2. Have you **ever** been told that you have prostate cancer?

☐ Yes

☐ No

If you answered **YES**, please **GO TO THE NEXT PAGE** and continue the survey.

If you have **NEVER** been told you have prostate cancer, please **STOP** and return this questionnaire in the enclosed postage-paid envelope. Thank you for your help with this important survey.

If you have questions, please call our office.

PLEASE READ ALL INSTRUCTIONS

This quality of life survey asks 2 types of questions, those about how prostate cancer may affect your daily activities, and those about your general health. Answer all questions even if you have not yet had treatment for prostate cancer. After each question, mark the box next to the answer that most closely fits your usual situation. Your answers will be grouped with answers from other men who are medically similar to you. All of your answers are strictly confidential.

Your help is important. Please fill out and return this survey as soon as possible in the enclosed postage-paid envelope.

Some questions are about different time periods. Time periods are shown in **bold lettering** to tell you which time period you are being asked about.

SECTION I: MEDICAL HISTORY

These questions are about your symptoms **IN THE MONTH JUST BEFORE** your prostate cancer, and medical treatments you may have had **AFTER YOU FOUND OUT** you had prostate cancer.

3. Which of the following physical signs or symptoms did you have **just before** you found out you had prostate cancer?

   (Check "Yes" or "No" for each sign or symptom.)

Yes	No	
☐	☐	Difficulty or discomfort urinating (passing water)
☐	☐	Having to urinate too often (frequent urination)
☐	☐	Weak urinary stream
☐	☐	Infection of bladder or prostate
☐	☐	Blood in urine
☐	☐	Pains or aches in back, hips, or legs
☐	☐	More tired or worn out than usual
☐	☐	Other physical symptoms

The next few questions are about what happened **AFTER THE DOCTOR TOLD YOU** that you had prostate cancer.

4. Did any doctor talk with you about having surgery to remove your prostate gland?

   ☐ Yes ☐ No

5. Did any doctor talk with you about having radiation treatment for prostate cancer?

   ☐ Yes ☐ No

6. Did any doctor talk with you about having no treatment at all for prostate cancer (sometimes called "watchful waiting")?

☐ Yes ☐ No

7. Have you had surgery to remove your prostate gland?

☐ Yes ☐ No

8. a) Have you had radiation treatment for prostate cancer?

☐ Yes ☐ No (Skip to 9)

IF YES → b) Are you receiving radiation treatment now?

☐ Yes ☐ No

9. a) Have you had hormone shots for prostate cancer?

☐ Yes ☐ No (Skip to 10)

IF YES → b) Are you receiving hormone shots now?

☐ Yes ☐ No

10. a) Have you taken hormone pills for prostate cancer?

☐ Yes ☐ No (Skip to 11)

IF YES → b) Are you taking hormone pills now?

☐ Yes ☐ No

11. Have you had surgery to remove the testicles?

☐ Yes ☐ No

12. As far as you know, are you free of prostate cancer **now**?

☐ Yes ☐ No ☐ Don't know

The next questions are about medical conditions you may have besides prostate cancer.

13. Look at each medical condition below and check "Yes" or "No" to show whether a doctor has **EVER told you** that you had the condition.

If you have been told you have the condition, then answer both questions B and C about the condition:

B. Check "Yes" or "No" to show whether the condition limits any of your current daily activities; and

C. Check "Yes" or "No" to show whether you are currently taking any prescription medicines for the condition.

If "Yes" to A, answer B and C.

	A. Has a doctor EVER told you that you had this condition?			**B. Are any of your current activities limited by this condition?**		**C. Do you currently take prescription medicine for this condition?**	
	No	Yes		No	Yes	No	Yes
Arthritis or rheumatism	☐	☐	IF YES ➡	☐	☐	☐	☐
Diabetes or high blood sugar or sugar in urine	☐	☐	IF YES ➡	☐	☐	☐	☐
Inflammatory bowel disease or colitis or Crohn's Disease	☐	☐	IF YES ➡	☐	☐	☐	☐
Bleeding from stomach ulcers	☐	☐	IF YES ➡	☐	☐	☐	☐
Chronic lung disease or bronchitis or emphysema	☐	☐	IF YES ➡	☐	☐	☐	☐
Heart failure or congestive heart failure	☐	☐	IF YES ➡	☐	☐	☐	☐

If "Yes" to A, answer B and C.

	A. Has a doctor EVER told you that you had this condition?			B. Are any of your current activities limited by this condition?		C. Do you currently take prescription medicine for this condition?	
	No	Yes		No	Yes	No	Yes
Stroke or brain hemorrhage	☐	☐	IF YES ➡	☐	☐	☐	☐
High blood pressure (hypertension)	☐	☐	IF YES ➡	☐	☐	☐	☐
Heart attack or myocardial infarction	☐	☐	IF YES ➡	☐	☐	☐	☐
Chest pain or angina	☐	☐	IF YES ➡	☐	☐	☐	☐
Liver disease or cirrhosis	☐	☐	IF YES ➡	☐	☐	☐	☐
Depression or anxiety	☐	☐	IF YES ➡	☐	☐	☐	☐

14. Do you have any other medical conditions or problems that limit your **current** daily activities?

☐ Yes ☐ No (Go to next page)

IF YES ⬇

Please write conditions here:

_____

_____

_____

_____

SECTION II: URINARY HABITS (Please read instructions.)

This section is about your urinary habits in the **MONTH JUST BEFORE** your prostate cancer, and your urinary habits **NOW, OVER THE PAST MONTH**. For each question, answer for both time periods, even if you have experienced no changes. Mark the answer that best describes your usual situation for each time period. At the end of this section, you may write down any additional information about urinary problems you may be having.

ANSWER FOR BOTH TIME PERIODS

15. Which of the following best describes your urinary control?

	JUST BEFORE PROSTATE CANCER	NOW, OVER PAST MONTH
Total control	☐	☐
Occasional leaking	☐	☐
Frequent leaking	☐	☐
No control	☐	☐

16. How often have you leaked or dripped urine (been incontinent)?

	JUST BEFORE PROSTATE CANCER	NOW, OVER PAST MONTH
Not at all	☐	☐
Less than once a week	☐	☐
About once a week	☐	☐
Once or twice a day	☐	☐
More than twice a day	☐	☐

17. How many pads or adult diapers, if any, have you usually used to help with leaking or dripping?

	JUST BEFORE PROSTATE CANCER	NOW, OVER PAST MONTH
No pads	☐	☐
1 pad per day	☐	☐
2 pads per day	☐	☐
3 or more pads per day	☐	☐

ANSWER FOR BOTH TIME PERIODS

18. Overall, how big a problem have you had with leaking or dripping urine?

	JUST BEFORE PROSTATE CANCER	NOW, OVER PAST MONTH
No Problem	☐	☐
Very Small Problem	☐	☐
Small Problem	☐	☐
Moderate Problem	☐	☐
Big Problem	☐	☐

19. How often have you had to urinate again less than 2 hours after finishing urinating?

	JUST BEFORE PROSTATE CANCER	NOW, OVER PAST MONTH
Rarely or not at all	☐	☐
Less than half the time	☐	☐
About half the time	☐	☐
More than half the time	☐	☐
Almost always	☐	☐

20. How often have you had to push or strain to begin urination?

	JUST BEFORE PROSTATE CANCER	NOW, OVER PAST MONTH
Rarely or not at all	☐	☐
Less than half the time	☐	☐
About half the time	☐	☐
More than half the time	☐	☐
Almost always	☐	☐

21. One problem some prostate cancer patients have is called strictures. Strictures or scar tissue can form in the urinary tract and can make it hard to urinate.

Since you found out you had prostate cancer, has a doctor had to stretch your urinary tract or perform any surgery **to treat strictures**?

☐ Yes ☐ No ☐ Don't know

22. **Since you found out** you had prostate cancer, have you worn a clamp or a bag and catheter to help with urine leakage?

☐ Yes ☐ No (Skip to 23)

IF YES →

b. Do you wear a clamp or a bag and catheter **now**?

☐ Yes ☐ No

23. Are you **now** taking any pills to help control urine flow (prevent incontinence)?

☐ Yes ☐ No (skip to 24)

IF YES →

b. How much do the pills help?

☐ A lot

☐ Somewhat

☐ Not at all

24. You may write down any other information about urinary problems you may be having.

_____

_____

_____

_____

_____

_____

SECTION III: BOWEL HABITS (Please read instructions.)

This section is about your bowel habits **IN THE MONTH JUST BEFORE** your prostate cancer, and your bowel habits **NOW, OVER THE PAST MONTH**. For each question, answer for both time periods, even if you have experienced no changes. Mark the answer which best describes your usual situation for each time period. At the end of this section, you may write down any additional information about bowel problems you may be having.

ANSWER FOR BOTH TIME PERIODS

25. How often have you had more than 3 bowel movements on a single day?

	JUST BEFORE PROSTATE CANCER	NOW, OVER PAST MONTH
Almost every day	☐	☐
Some days	☐	☐
Rarely or not at all	☐	☐

26. How often have you had any pain or discomfort before, or during, bowel movements?

	JUST BEFORE PROSTATE CANCER	NOW, OVER PAST MONTH
Almost every day	☐	☐
Some days	☐	☐
Rarely or not at all	☐	☐

27. How often have you had urgent bowel movements (you could not wait to go to the bathroom)?

	JUST BEFORE PROSTATE CANCER	NOW, OVER PAST MONTH
Almost every day	☐	☐
Some days	☐	☐
Rarely or not at all	☐	☐

ANSWER FOR BOTH TIME PERIODS

28. How often have you had wetness in the rectal area?

	JUST BEFORE PROSTATE CANCER	NOW, OVER PAST MONTH
Almost every day	☐	☐
Some days	☐	☐
Rarely or not at all	☐	☐

29. How often have you had problems with painful or bleeding hemorrhoids?

	JUST BEFORE PROSTATE CANCER	NOW, OVER PAST MONTH
Almost every day	☐	☐
Some days	☐	☐
Rarely or not at all	☐	☐

30. Overall, how big a problem have you had with urgent, frequent, or painful bowel movements?

	JUST BEFORE PROSTATE CANCER	NOW, OVER PAST MONTH
No Problem	☐	☐
Very Small Problem	☐	☐
Small Problem	☐	☐
Moderate Problem	☐	☐
Big Problem	☐	☐

31. **Since you found out** you had prostate cancer, have you tried any of the following to help deal with bowel problems?

	No	Yes	
a) Did you change your diet?	☐	☐	IF YES ➡ How much did this help? ☐ A lot ☐ Somewhat ☐ Not at all
b) Did you take medicine? (including those not prescribed)	☐	☐	IF YES ➡ How much did this help? ☐ A lot ☐ Somewhat ☐ Not at all
c) Did you take enemas or suppositories?	☐	☐	IF YES ➡ How much did this help? ☐ A lot ☐ Somewhat ☐ Not at all
d) Did you get a blood transfusion or take iron pills?	☐	☐	IF YES ➡ How much did this help? ☐ A lot ☐ Somewhat ☐ Not at all

32. You may write down any other information about bowel problems you may be having.

_____

_____

_____

_____

SECTION IV: SEXUAL FUNCTION (Please read instructions.)

This section is about sexual function and sexual satisfaction in the **MONTH JUST BEFORE** your prostate cancer and sexual function **NOW, OVER THE PAST MONTH**. For each question, answer for both time periods, even if you have experienced no changes. Mark the answer which best describes your usual situation for each time period. REMEMBER, YOUR NAME DOES NOT APPEAR ANYWHERE ON THIS SURVEY, AND ALL RESPONSES ARE STRICTLY CONFIDENTIAL. At the end of this section, you may write down any additional information about problems with sexual function you may be having.

ANSWER FOR BOTH TIME PERIODS

33. How interested have you been in sexual activity (including kissing, hugging, fondling, having intercourse, or masturbating)?

	JUST BEFORE PROSTATE CANCER	NOW, OVER PAST MONTH
A lot	☐	☐
Somewhat	☐	☐
Only a little	☐	☐
Not at all	☐	☐

34. How often have you engaged in any sexual activity?

	JUST BEFORE PROSTATE CANCER	NOW, OVER PAST MONTH
Several times a week	☐	☐
Once a week	☐	☐
2-3 times a month	☐	☐
Once a month	☐	☐
Not at all	☐	☐

35. Have you had any erections firm (hard) enough for sexual intercourse?

	JUST BEFORE PROSTATE CANCER	NOW, OVER PAST MONTH
Yes	☐	☐
No	☐	☐

ANSWER FOR BOTH TIME PERIODS

36. Have you had any partial erections that were not firm enough for sexual intercourse?

	JUST BEFORE PROSTATE CANCER	NOW, OVER PAST MONTH
Yes	☐	☐
No	☐	☐

37. How much difficulty have you had **keeping** an erect penis during sexual activity?

	JUST BEFORE PROSTATE CANCER	NOW, OVER PAST MONTH
No difficulty at all	☐	☐
A little difficulty	☐	☐
Some difficulty	☐	☐
A lot of difficulty	☐	☐
Do not get erections at all	☐	☐

38. Overall, how big a problem do you consider your sexual function to be?

	JUST BEFORE PROSTATE CANCER	NOW, OVER PAST MONTH
No Problem	☐	☐
Very Small Problem	☐	☐
Small Problem	☐	☐
Moderate Problem	☐	☐
Big Problem	☐	☐

39. Do you have a sexual partner?

	JUST BEFORE PROSTATE CANCER	NOW, OVER PAST MONTH
Yes	☐	☐
No	☐	☐

40. **Since you found out** you had prostate cancer, have you tried any of the following to help with problems with sexual function?

a) Have you used a vacuum suction device?
☐ No ☐ Yes → IF YES: How much did this help?
☐ A lot
☐ Somewhat
☐ Not at all

b) Did you have penile injections (shots)?
☐ No ☐ Yes → IF YES: How much did this help?
☐ A lot
☐ Somewhat
☐ Not at all

c) Did you take any medicine?
☐ No ☐ Yes → IF YES: How much did this help?
☐ A lot
☐ Somewhat
☐ Not at all

d) Did you talk with a sex therapist or psychologist?
☐ No ☐ Yes → IF YES: How much did this help?
☐ A lot
☐ Somewhat
☐ Not at all

e) Did you get a penile implant or prosthesis?
☐ No ☐ Yes → IF YES: How much did this help?
☐ A lot
☐ Somewhat
☐ Not at all

41. Some men with prostate cancer have hot flashes. **Over the past month,** how often have you had hot flashes?
(Check ONE answer.)

- ☐ Never
- ☐ Less than once a week
- ☐ Once a week
- ☐ More than once a week

42. Some men with prostate cancer have swelling of their breasts. **Over the past month,** to what extent have you had breast swelling?

(Check ONE answer.)

- ☐ Not at all
- ☐ Only a little
- ☐ Somewhat
- ☐ A lot

43. You may write down any other information about problems with sexual function you may be having.

_____

_____

_____

_____

_____

SECTION V: OVERALL EFFECTS OF PROSTATE CANCER

(Please read instructions.)

This section contains some questions about your prostate cancer. For each question, please give the **ONE** answer that comes closest to how you have usually felt over the past **MONTH**.

44. Please answer all the questions below, **whether or not you have had any treatments for your prostate cancer.**

(Check ONE answer on each line.)

	A LOT	SOME	ONLY A LITTLE	NONE AT ALL
a. How much physical discomfort have you had because of anything related to your prostate cancer or your treatment?	☐	☐	☐	☐
b. How much do you worry about your health because of anything related to your prostate cancer or your treatment?	☐	☐	☐	☐
c. How much have your daily activities been limited by anything related to your prostate cancer or your treatment?	☐	☐	☐	☐
d. Overall, how much have you been bothered by anything related to your prostate cancer or your treatment?	☐	☐	☐	☐

45. Overall, how do you feel about how your treatment (or not getting treatment) for prostate cancer has worked out?

(Check ONE answer.)

- ☐ Delighted
- ☐ Pleased
- ☐ Mostly Satisfied
- ☐ Mixed, about equally satisfied and dissatisfied
- ☐ Mostly Dissatisfied
- ☐ Unhappy
- ☐ Terrible

46. Would you make the same treatment decisions again if you had the chance?

- ☐ Definitely Yes
- ☐ Probably Yes
- ☐ Probably Not
- ☐ Definitely Not

SECTION VI: GENERAL HEALTH STATUS

(Please read instructions.)

The following questions (Questions 47 through 52) are about your health in general. For these questions, consider the effects of **any** medical conditions or problems you have, including prostate cancer.

47. In general, would you say your health is:
(Check ONE answer.)

- ☐ Excellent
- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor

48. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of your **PHYSICAL HEALTH**?

a. Cut down the **amount of time** you spent on work or other activities
☐ Yes ☐ No

b. **Accomplished less** than you would like
☐ Yes ☐ No

c. Were limited in the **kind** of work or other activities you did
☐ Yes ☐ No

d. Had **difficulty** performing work or other activities (for example, it took extra effort)
☐ Yes ☐ No

49. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of any **EMOTIONAL PROBLEMS** (such as feeling depressed or anxious)?

a. Cut down the **amount of time** you spent on work or other activities

☐ Yes ☐ No

b. **Accomplished less** than you would like

☐ Yes ☐ No

c. Didn't do work or other activities as **carefully** as usual

☐ Yes ☐ No

50. How much **bodily** pain have you had **during the past 4 weeks**? (Check ONE answer.)

☐ None
☐ Very mild
☐ Mild
☐ Moderate
☐ Severe
☐ Very severe

51. **During the past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)? (Check ONE answer.)

☐ Not at all
☐ Slightly
☐ Moderately
☐ Quite a bit
☐ Extremely

52. These questions are about how you feel and how things have been with you **during the past 4 weeks.** For each question, please give the one answer that comes closest to the way you have been feeling. (Check ONE answer on each line.)

How much of the time **during the past 4 weeks**...

	ALL OF THE TIME	MOST OF THE TIME	A GOOD BIT OF THE TIME	SOME OF THE TIME	A LITTLE OF THE TIME	NONE OF THE TIME
a. Did you feel full of pep?	☐	☐	☐	☐	☐	☐
b. Have you been a very nervous person?	☐	☐	☐	☐	☐	☐
c. Have you felt so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐	☐
d. Have you felt calm and peaceful?	☐	☐	☐	☐	☐	☐
e. Did you have a lot of energy?	☐	☐	☐	☐	☐	☐
f. Have you felt downhearted and blue?	☐	☐	☐	☐	☐	☐
g. Did you feel worn out?	☐	☐	☐	☐	☐	☐
h. Have you been a happy person?	☐	☐	☐	☐	☐	☐
i. Did you feel tired?	☐	☐	☐	☐	☐	☐

SECTION VII: GENERAL QUESTIONS

The following questions are about general information.

53. What is your race or ethnic group?

- ☐ White
- ☐ Black or African-American
- ☐ American Indian
- ☐ Alaskan Native
- ☐ Asian or Pacific Islander
- ☐ Mixed or other, please specify: _____

54. Are you of Spanish, Latino, or Hispanic descent?

- ☐ Yes
- ☐ No
- ☐ Don't know

55. What is the highest level of education you have completed?

- ☐ 8 Grades or less
- ☐ Some high school
- ☐ High school graduate
- ☐ Some college
- ☐ College graduate
- ☐ Advanced or graduate training

56. Are you **now** married?

- ☐ Yes
- ☐ No

57. How many persons are living in your household, including yourself?

Number: _____

58. What is your employment status **now**?
(Check ONE answer.)

- ☐ Working full-time
- ☐ Working part-time
- ☐ Retired
- ☐ Other

59. To what extent did your prostate cancer cause financial problems?
(Check ONE answer.)

- ☐ Not at all
- ☐ A little
- ☐ Somewhat
- ☐ A lot

60. To what extent has your insurance coverage (or lack of coverage) influenced your decisions about treatment for prostate cancer?
(Check ONE answer.)

- ☐ Not at all
- ☐ A little
- ☐ Somewhat
- ☐ A lot

61. Which best describes your 1994 total household income before taxes? Include all sources of income (wages, pensions, social security, investments).
(Check ONE answer.)

- ☐ Under $10,000
- ☐ $10,001 up to $20,000
- ☐ $20,001 up to $30,000
- ☐ $30,001 up to $40,000
- ☐ $40,001 up to $50,000
- ☐ $50,001 up to $75,000
- ☐ $75,001 or more
- ☐ Not sure

62. Since you were diagnosed with prostate cancer, have you had any problems related to prostate cancer not covered in this survey?

- ☐ Yes
- ☐ No

If yes, please briefly describe the problem(s):

_____

_____

_____

_____

_____

_____

Thank you for your cooperation with this survey.
Please return the questionnaire in the enclosed postage-paid envelope as soon as possible.