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**CITY OF HOPE NATIONAL MEDICAL CENTER  
QUALITY OF LIFE QUESTIONNAIRE FOR PATIENTS WITH AN OSTOMY**

In advance, thank you for taking the time to complete this questionnaire.

We want to ensure that your responses are anonymous. Your completed questionnaire is mailed directly to the Department of Nursing Research at City of Hope where an identification number will be assigned to the questionnaire. This front sheet will be separated from the questionnaire.

Name \_\_\_\_\_ Date

A current address, if changes have occurred.

Current telephone number including area code

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**Demographic Information**

Following are some questions about yourself.

1. What kind of ostomy do you have? (Check (/) all that apply.)  
**ileostomy** \_\_\_\_\_ **colostomy** \_\_\_\_\_ **urinary diversion** \_\_\_\_\_
2. If you have a colostomy, is it **permanent**? \_\_\_\_\_ or **temporary**?
3. If you have a urinary diversion, do you wear a bag at all times? **No** \_\_\_\_\_ **Yes** \_\_\_\_\_
4. What illness or diagnosis led to your need for an ostomy?
5. If cancer was the reason for your ostomy, please specify the type of cancer.
  
6. For how many months/years have you had your  
**ileostomy**? \_\_\_\_\_ **colostomy**? \_\_\_\_\_ **urinary diversion**?
7. What is your **gender**? **Male** \_\_\_\_\_ **Female** \_\_\_\_\_
8. What is your **current age**? \_\_\_\_\_
9. What is your **height**? \_\_\_\_\_
10. What is your **current weight**? \_\_\_\_\_
11. What is your **ethnicity**?  
**African American** \_\_\_\_\_ **American Indian** \_\_\_\_\_ **Asian** \_\_\_\_\_ **Black** \_\_\_\_\_  
**Caucasian** \_\_\_\_\_ **Hispanic** \_\_\_\_\_ **Other** \_\_\_\_\_, please specify
12. What was your **marital status prior** to the surgery for your ostomy?  
**Single** \_\_\_\_\_ **Married** \_\_\_\_\_ **Divorced** \_\_\_\_\_ **Widowed** \_\_\_\_\_ **Separated** \_\_\_\_\_
13. What is your **marital status now**?  
**Single** \_\_\_\_\_ **Married** \_\_\_\_\_ **Divorced** \_\_\_\_\_ **Widowed** \_\_\_\_\_ **Separated** \_\_\_\_\_

For the following questions, please answer **NO, YES, or NA (NOT APPLICABLE)** by placing a check mark (/) in the appropriate column.

	No	Yes	NA
<b>Work-related items</b>			
14. Are you working full-time?			
15. Are you working part-time?			
16. Are you retired?			
17. Are you working in the same occupation that you had before your ostomy?			
18. If you are not working in the same occupation as before your ostomy, was the change related to having an ostomy?			
<b>Health insurance</b>			
19. Do you currently have health insurance?			
20. Have you had difficulty getting health insurance?			
21. Have you had difficulty maintaining your health insurance?			
22. Does your insurance pay <b>all costs</b> for your ostomy supplies?			
23. Does your insurance pay <b>part of the costs</b> for your ostomy supplies?			
<b>Sexual activity</b>			
24. Were you sexually active before getting your ostomy?			
25. Have you resumed sexual activity since having your ostomy?			
26. Is your sexual activity satisfying?			
27. <b>If you are male</b> , do you have a problem getting an erection or keeping			

	No	Yes	NA
an erection?			
<b>Psychological Support/Concerns</b>			
28. Were you depressed after having your ostomy?			
29. Since having your ostomy, have you ever considered or attempted suicide?			
30. Do you belong to an ostomy support group?			
31. Do you belong to another kind of support group?			
32. Have you had the opportunity to talk with someone else who was going to have or had a new ostomy?			
<b>Clothing</b>			
33. Does the location of your ostomy cause you problems?			
34. Have you changed the style of clothing you wear because of your ostomy?			
<b>Diet</b>			
35. Do you adjust your diet because of your ostomy?			
36. Do you change your diet to prevent passing gas in public?			

Please answer the following questions **in relation to the amount of time since the surgery for your ostomy**. Your choices are **MONTHS, YEARS, OR NEVER**. Please place a check mark (/) in the appropriate column.

	Months	Years	Never
37. How long was it before you felt comfortable with your daily ostomy care?			
38. How long was it before you felt comfortable with your diet?			
39. How long was it before your appetite returned?			

For the following questions, please answer **NO, YES, or NA (NOT APPLICABLE -- meaning that you do not drink or eat these foods)** by placing a check mark (/) in the appropriate column.

Food Groups	No	Yes	NA
40. I avoid drinking carbonated beverages.			
41. I avoid eating dairy products.			
42. I avoid eating fruits.			
43. I avoid eating snacks.			
44. I avoid eating vegetables.			

Following are some questions related to the care of your ostomy. Please write in your answers.

- 45. On the average, how long does it take to do your daily ostomy care?
- 46. If you wear a pouch, please identify the brand name.
- 47. If you wear a pouch **AND** have encountered any problems with it, please explain what those problems are/were.

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Directions: We are interested in knowing how the experience of having an ostomy affects your quality of life. Please answer all of the following questions based on **your life at this time**.

Please **circle** the number from 0 - 10 that best describes your experiences. For example:

How difficult is it for you to **climb stairs**?

not at all difficult 0 1 2 3 4 5 6 7 8 9 10 extremely difficult

Circling A2≅ means you have some but not a lot of difficulty climbing stairs.

**Related to your ostomy**, to what extent are the following a problem for you?

1. **Physical strength**  
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
2. **Fatigue**  
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
3. **Skin surrounding the ostomy**  
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
4. **Sleep disruptions**  
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
5. **Aches or pains**  
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
6. **Gas**  
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
7. **Odor**  
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
8. **Constipation**  
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
9. **Diarrhea**  
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

10. **Leaking from the pouch (or around the appliance)**  
**no problem** 0 1 2 3 4 5 6 7 8 9 10 **severe problem**
11. **Overall physical well-being**  
**no problem** 0 1 2 3 4 5 6 7 8 9 10 **severe problem**
12. **How difficult has it been for you to adjust to your ostomy?**  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **a great deal**
13. How **useful** do you feel?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **extremely useful**
14. How much **satisfaction or enjoyment in life** do you feel?  
**None at all** 0 1 2 3 4 5 6 7 8 9 10 **a great deal**
15. How much are you **embarrassed** by your ostomy?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **extremely embarrassed**
16. How good is your **overall quality of life**?  
**Extremely poor** 0 1 2 3 4 5 6 7 8 9 10 **excellent**
17. How is your ability to **remember** things?  
**Extremely poor** 0 1 2 3 4 5 6 7 8 9 10 **excellent**
18. How difficult is it to **look** at your ostomy?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **extremely difficult**
19. How difficult is it for you to **care** for your ostomy?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **extremely difficult**
20. Do you feel like you are **in control** of things in your life?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **completely**

21. How satisfied are you with your **appearance**?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **extremely satisfied**
22. How much **anxiety** do you have?  
**none at all** 0 1 2 3 4 5 6 7 8 9 10 **severe**
23. How much **depression** do you have?  
**none at all** 0 1 2 3 4 5 6 7 8 9 10 **severe**
24. Are you **fearful that your disease will come back**?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **extremely fearful**
25. Do you have **difficulty meeting new people**?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **extremely difficult**
26. How much **financial burden** resulted from your illness or treatment?  
**none at all** 0 1 2 3 4 5 6 7 8 9 10 **extreme**
27. How distressing has your illness been for your **family**?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **extremely distressing**
28. How much does your ostomy interfere with your **ability to travel**?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **completely**
29. Has your ostomy interfered with your **personal relationships**?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **completely**
30. How much **isolation** is caused by your ostomy?  
**none** 0 1 2 3 4 5 6 7 8 9 10 **a great deal**
31. Is **support** from friends and family sufficient to meet your needs?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **extremely**

32. Has your ostomy interfered with your **recreational/sports activities**?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **a great deal**
33. Has your ostomy interfered with your **social activities**?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **a great deal**
34. Has your ostomy interfered with your **ability to be intimate**?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **a great deal**
35. Do you have enough **privacy at home** for doing your ostomy care?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **a great deal**
36. Do you have enough **privacy when traveling** for conducting your ostomy care?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **a great deal**
37. How much **uncertainty** do you feel about your future?  
**none at all** 0 1 2 3 4 5 6 7 8 9 10 **extreme**
38. Do you sense a **reason** for being alive?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **a great deal**
39. Do you have a sense of **inner peace**?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **a great deal**
40. How **hopeful** do you feel?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **extremely**
41. Is support you receive from **personal spiritual activities** such as prayer or meditation sufficient to meet your needs?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **completely**
42. Is support you receive from **religious activities** such as going to church or synagogue sufficient to meet your needs?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **completely**
43. Has having an ostomy made **positive changes** in your life?  
**not at all** 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

**Many people have shared stories about their lives with an ostomy. Please share with us the greatest challenge you have encountered in having an ostomy.**