PELICAN
cancer foundation

Low Rectal Cancer Study

Quality of Life Questionnaire

Name……..

Date of Birth .../.../….

EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials: _____

Your birthdate (Day, Month, Year): _____

Today's date (Day, Month, Year): 31 _____

		Not at All	A Little	Quite a Bit	Very Much
1.	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2.	Do you have any trouble taking a long walk?	1	2	3	4
3.	Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4.	Do you need to stay in bed or a chair during the day?	1	2	3	4
5.	Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:

		Not at All	A Little	Quite a Bit	Very Much
6.	Were you limited in doing either your work or other daily activities?	1	2	3	4
7.	Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8.	Were you short of breath?	1	2	3	4
9.	Have you had pain?	1	2	3	4
10.	Did you need to rest?	1	2	3	4
11.	Have you had trouble sleeping?	1	2	3	4
12.	Have you felt weak?	1	2	3	4
13.	Have you lacked appetite?	1	2	3	4
14.	Have you felt nauseated?	1	2	3	4
15.	Have you vomited?	1	2	3	4
16.	Have you been constipated?	1	2	3	4

Please go on to the next page

During the past week:	**Not at All**	**A Little**	**Quite a Bit**	**Very Much**
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your family life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your social activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

30. How would you rate your overall quality of life during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

EORTC QLQ – CR38

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

During the past week :	**Not at All**	**A Little**	**Quite a Bit**	**Very Much**
31. Did you urinate frequently during the day?	1	2	3	4
32. Did you urinate frequently during the night?	1	2	3	4
33. Did you have pain when you urinated?	1	2	3	4
34. Did you have a bloated feeling in your abdomen?	1	2	3	4
35. Did you have abdominal pain?	1	2	3	4
36. Did you have pain in your buttocks?	1	2	3	4
37. Were you bothered by gas (flatulence)?	1	2	3	4
38. Did you belch?	1	2	3	4
39. Have you lost weight?	1	2	3	4
40. Did you have a dry mouth?	1	2	3	4
41. Have you had thin or lifeless hair as a result of your disease or treatment?	1	2	3	4
42. Did food and drink taste different from usual?	1	2	3	4
43. Have you felt physically less attractive as a result of your disease or treatment?	1	2	3	4
44. Have you been feeling less feminine/masculine as a result of your disease or treatment?	1	2	3	4
45. Have you been dissatisfied with your body?	1	2	3	4
46. Were you worried about your health in the future?	1	2	3	4

During the past <u>four</u> weeks:	**Not at All**	**A Little**	**Quite a Bit**	**Very Much**
47. To what extent were you interested in sex?	1	2	3	4
48. To what extent were you sexually active (with or without intercourse)?	1	2	3	4
49. Answer this question only if you have been sexually active: To what extent was sex enjoyable for you?	1	2	3	4

Please go on to the next page

During the past four weeks:

	Not at All	A Little	Quite a Bit	Very Much
For men only:				
50. Did you have difficulty getting or maintaining an erection?	1	2	3	4
51. Did you have problems with ejaculation (e.g., so-callled "dry ejaculation")?	1	2	3	4
Only for women who have had intercourse:				
52. Did you have a dry vagina during intercourse?	1	2	3	4
53. Did you have pain during intercourse?	1	2	3	4

54. Do you have a stoma (colostomy bag)? **No** **Please answer questions 55 to 61**

(Please circle No or Yes) **Yes** **Please skip questions 55 to 61 and answer questions 62 to 68**

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
Only for patients WITHOUT a stoma (colostomy bag):				
55. Did you have frequent bowel movements during the day?	1	2	3	4
56. Did you have frequent bowel movements during the night?	1	2	3	4
57. Did you feel the urge to move your bowels without actually producing any stools?	1	2	3	4
58. Have you had any unintentional release of stools?	1	2	3	4
59. Have you had blood with your stools?	1	2	3	4
60. Have you had difficulty in moving your bowels?	1	2	3	4
61. Have your bowel movements been painful?	1	2	3	4
Only for patients WITH a stoma (colostomy bag):				
62. Were you afraid that other people would be able to hear your stoma?	1	2	3	4
63. Were you afraid that other people would be able to smell your stools?	1	2	3	4
64. Were you worried about possible leakage from the stoma bag?	1	2	3	4
65. Did you have problems with caring for your stoma?	1	2	3	4
66. Was your skin around the stoma irritated?	1	2	3	4
67. Did you feel embarassed because of your stoma?	1	2	3	4
68. Did you feel less complete because of your stoma?	1	2	3	4

PLEASE ONLY COMPLETE IF YOU DO NOT CURRENLY HAVE A STOMA

Please tick the box that comes closest to your situation. There are no right or wrong answers. Please feel free to write any other comments on the questionnaire.

1. **How often do you open your bowels on a typical day?.....times.**

2. **When you need to open your bowels, do you have to hurry?**

Yes ☐	No ☐	Varies ☐

3. **If yes, how long can you usually hang on:**

Under 1 minute ☐	1-5 minutes ☐	5-15 minutes ☐	over 15 minutes ☐	It varies ☐

4. **Would you say that usually your stools (bowel motions) are:**

Hard ☐	Normal ☐	Soft but formed ☐	Mushy ☐	Liquid ☐	Variable ☐

5. **Do you ever not get to the toilet in time and have a bowel accident?:**

Never	☐
Very rarely	☐ No accidents in the past 4 weeks, but it happens sometimes
Rarely	☐1 accident in the past 4 weeks
Sometimes	☐ More than 1 accident in the past 4 weeks but not 1 a week
Weekly	☐1 or more accidents a week but not every day
Daily	☐1 or more accidents a day

6. **If you have accidents on the way to the toilet, does this depend on how hard your stools are?**

Yes ☐	No ☐	N/A ☐

7. **Do you get any soiling after you have opened your bowels?:**

Never	☐
Very rarely	☐ No leakage in the past 4 weeks, but it happens sometimes
Rarely	☐ 1 episode of leakage in the past 4 weeks
Sometimes	☐ More than 1 episode in the past 4 weeks but not 1 a week
Weekly	☐ 1 or more episodes a week but not every day
Daily	☐1 or more episodes a day

8. **Do you get any bowel leakage at other times (not when you need to go, and not after you have been, leakage which just seems to happen?):**

Never	☐
Very rarely	☐ No leakage in the past 4 weeks, but it happens sometimes
Rarely	☐ 1 episode of leakage in the past 4 weeks
Sometimes	☐ More than 1 episode in the past 4 weeks but not 1 a week
Weekly	☐ 1 or more episodes a week but not every day
Daily	☐ 1 or more episodes a day

9. **Is this leakage which is not associated with urgency or after you have opened your bowels:**

At night in bed ☐	When walking ☐	When bending or lifting ☐
During sport or exercise ☐	Any time, no pattern ☐	

10. **If you get any type of bowel accidents on the way to the toilet, or bowel leakage, is this: (tick all that apply):**

Loss of solid stool □	Loss of liquid stool □	Loss of mucus □	No leakage □

11. **If you get any leakage, is this (if it varies, tick all that apply):**

No leakage	□	
Minor stain only	□	(leakage just between buttocks or marks on pants)
Small amount	□	(about a teaspoon full)
Moderate amount	□	(about a tablespoon full)
Large amount	□	(large patch or whole bowel motion)

12. **Do you need to wear a pad because of bowel leakage:**

Always □	Usually □	Sometimes □	Never □

13. **If you do wear a pad, is this:**

Small pant liner □	Sanitary towel size □	Incontinence pad □

14. **Can you control wind (flatus)**

Always □	Usually □	Sometimes □	Never □

15. **Do you feel that your bowel control currently (within the past month) restricts your life**

Not at all □	A little □	Quite a lot □	A great deal □

If your bowel control does restrict your life, please briefly describe in what way/s:

.....
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.....
.....
.....

16. **Do you have any trouble emptying your bowels now?**

Yes □	No □	N/A □	
If yes, is this: Need to strain □	Unable to empty completely □	Hard stools □	

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.....

17. **Please rate how good your bowel control is now:**
(Please circle a number, where 0= no control and 10= perfect control):

0 1 2 3 4 5 6 7 8 9 10

18. **Any other comments:**

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.....
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.....
.....

PLEASE ONLY COMPLETE IF YOU CURRENLY HAVE A STOMA

Stoma-QOL
A Quality of Life Questionnaire
For People with Ostomy (a stoma)

User Initials: _____

Date:_____/_____ 20____

*Please tick the response that best describes how you are feeling **at the moment***

	Always	Sometimes	Rarely	Not-at-all
1. I become anxious when the pouch is full	□1	□2	□3	□4
2. I worry that the pouch will loosen	□1	□2	□3	□4
3. I feel the need to know where the nearest toilet is	□1	□2	□3	□4
4. I worry that the pouch may smell	□1	□2	□3	□4
5. I worry about noises from the stoma	□1	□2	□3	□4
6. I need to rest during the day	□1	□2	□3	□4
7. My stoma pouch limits the choice of clothes that I can wear	□1	□2	□3	□4
8. I feel tired during the day	□1	□2	□3	□4
9. My stoma makes me feel sexually unattractive	□1	□2	□3	□4
10. I sleep badly during the night	□1	□2	□3	□4
11. I worry that the pouch rustles	□1	□2	□3	□4
12. I feel embarrassed about my body because of my stoma	□1	□2	□3	□4
13. It would be difficult for me to stay away from home overnight	□1	□2	□3	□4
14. It is difficult to hide the fact that I wear a pouch	□1	□2	□3	□4
15. I worry that my condition is a burden to people close to me	□1	□2	□3	□4
16. I avoid close physical contact with my friends	□1	□2	□3	□4
17. My stoma makes it difficult for me to be with other people	□1	□2	□3	□4
18. I am afraid of meeting new people	□1	□2	□3	□4
19. I feel lonely even when I am with other people	□1	□2	□3	□4
20. I worry that my family feel awkward around me	□1	□2	□3	□4