

Initial number

CONFIDENTIAL

DAY

MONTH

YEAR

Today's date

Living with a long term catheter

This form can be filled in by a carer, friend or family member, as well as, or instead of by you, but it needs to be your own opinions about your catheter (not theirs). We have used “**you**” to refer to the **person with the catheter** throughout the form – no matter who fills in the form.

Please could you tell us who is answering the questionnaire by ticking the box:

Catheter user ¹ Carer ² Family member/friend ³ Other ⁴

1. Is the catheter user (tick one):

Female Male

2. Please write in the catheter user's date of birth:

DAY MONTH YEAR

3. What type of catheter do you currently have? (Tick one box)

urethral (between the legs/into the penis) 1

supra-pubic (into the abdomen) 2

Catheter function and concern

4a. Do you have confidence in your catheter equipment (catheter, tubing and bag)? (Tick one box)

never 4

occasionally 3

sometimes 2

most of the time 1

all of the time 0

4b. How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
not at all a great deal

5a. Is the possibility of the catheter leaking on your mind? (Tick one box)

never 0

occasionally 1

sometimes 2

most of the time 3

all of the time 4

5b. How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
not at all a great deal

6a. Is the possibility of the catheter blocking on your mind? (*Tick one box*)

never 0
 occasionally 1
 sometimes 2
 most of the time 3
 all of the time 4

6b. How much does this bother you?
 Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 **10**
 not at all a great deal

7a. How problematic is your catheter? (*Tick one box*)

problem free 0
 some problems but I would rather keep it 1
 some problems but I have to keep it 2
 lots of problems 3

8a. How often do you have ‘urine infections’ that make you feel unwell or require you to take antibiotics? (*Tick one box*)

several times per month 5
 about once a month 4
 once every 2-3 months 3
 a couple of times a year 2
 less than once a year 1
 never 0

8b. How much does this bother you?
 Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 **10**
 not at all a great deal

9a. Does your catheter cause you to worry about smell? (*Tick one box*)

never 0
 occasionally 1
 sometimes 2
 most of the time 3
 all of the time 4

9b. How much does this bother you?
 Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 **10**
 not at all a great deal

10a. Are you embarrassed by having a catheter? *(Tick one box)*

- never 0
- occasionally 1
- sometimes 2
- most of the time 3
- all of the time 4

10b. How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
 not at all a great deal

11a. Do you feel you have adapted to life with a catheter? *(Tick one box)*

- not at all 4
- not really 3
- somewhat 2
- mostly 1
- completely 0

11b. How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
 not at all a great deal

11c. Please provide further details if you would like

12a. Overall, how much does having a catheter affect your everyday life?

Please ring a number between 0 (overall having a catheter is good) and 10 (overall having a catheter is bad)

0 1 2 3 4 5 6 7 8 9 10
 overall good overall bad

Catheter function and concern score: sum scores 4a-12a

Lifestyle impact

13. Does your catheter affect your ability to travel? (Tick one box)

I don't travel but for other reasons 5

I don't travel because of my catheter 4

the catheter limits my ability to travel 3

the catheter has no effect on my ability to travel 2

the catheter has helped my ability to travel 1

14. Does your catheter affect your social activities (for example, going out for a meal)? (Tick one box)

I don't take part in social activities but for other reasons 5

I don't take part in social activities because of my catheter 4

the catheter limits my ability to take part in social activities 3

the catheter has no effect on my social activities 2

the catheter has helped my ability to take part in social activities 1

15. Does your catheter affect your ability to go out of the house? (Tick one box)

I don't go out but for other reasons 5

I don't go out because of my catheter 4

the catheter limits my ability to go out 3

the catheter has no effect on my ability to go out 2

the catheter has helped me to go out 1

Lifestyle impact score: sum scores 13-15

Unscored items

16a. Do you use pads as well as your catheter because of your bladder? (Tick one box)

never 0

occasionally 1

sometimes 2

most of the time 3

all of the time 4

16b. How much does using pads because of leaks bother you?
Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 **10**
 not at all a great deal

17a. Does your catheter cause you any pain, discomfort or soreness? (Tick all that apply)

- never 0
- occasionally 1
- sometimes 2
- most of the time 3
- always 4

17b. How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
not at all a great deal

18a. Do you experience any bladder spasm (tightening of the bladder when you don't want it to)? (Tick one box)

- never 0
- occasionally 1
- sometimes 2
- most of the time 3
- always 4

18b. How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
not at all a great deal

19a. Does having a catheter prevent sexual activity? (Tick one box)

- never 0
- occasionally 1
- sometimes 2
- most of the time 3
- all of the time 4
- not applicable 8
- don't wish to answer 9

19b. How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
not at all a great deal

Thank you very much for answering these questions.