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Identifying Continence OptioNs after Stroke

Patient Outcome Survey

Six weeks after stroke

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How to answer the questions in this booklet

In this booklet, you will find some questions about your health and some questions about bladder problems.

Please work through the booklet, answering each question as you go. At the start of each set of questions, there are some instructions on how to answer those questions. Most of the questions can be answered by ticking a box. Sometimes, you need to write a number in a box. Here is **an example** of how you would answer if you are completing these questions on the fourth of January 2011.

What date is it today?

0	4		0	1		2	0	1	1
Day			Month			Year			

Please answer every question, unless the instructions tell you to do something else. Some of the questions may seem to be asking the same thing, but there are important differences and we need to know how you feel about each.

Do not think too long about any question. What comes into your head first is probably better than a long, thought-out answer. If you have a problem answering any question, please write that problem beside the question.

Your name does not appear anywhere on this booklet. Only the study team will know who answered the questions. We will not tell anyone else what you said.

Section 1: Where you live

1 What date is it today?

(***Please write the date in the boxes provided***. *For example, 1st January 2011 would be written* as) 0 1 0 1 2 0 1 1

Day Month Year

2 Who has completed this form?

*(Please **tick all that apply**)*

- ☐ Patient
- ☐ Relative/Friend
- ☐ Researcher
- ☐ Professional Carer

3 Are you in hospital?

*(Please **tick one box**)*

- ☐ Yes
- ☐ No

If you ticked 'yes', please go to Section 2.

If you ticked 'no', please continue with Question 4.

The next few questions are about where you live.

4a Where are you (the patient) living now?

*(Please **tick one box** only)*

- ☐ House
- ☐ Flat
- ☐ Sheltered housing
- ☐ Residential home
- ☐ Nursing home
- ☐ Other

4b If you ticked **house/flat/sheltered housing** please indicate who else lives with you (*Please* ***tick one box*** *only)*

☐ I live alone

☐ I live with a partner

☐ I live with another family member or friend

5 When did you start living here?

(*Please* ***tick one box*** *only)*

☐ Before I had my stroke

☐ Immediately I left hospital after my stroke

☐ I moved here at some point after discharge from hospital

(*If you pick the last option please* ***write the date you moved*** *in the boxes below*)

Please write the date in the boxes provided. *For example, 1st January 2011 would be written* as 0 1 0 1 2 0 1 1

☐☐ ☐☐ ☐☐☐☐

Day Month Year

Section 2: Your state of health

The next few questions are about how you are at present. For each of the questions below, please **tick one box** that is nearest to your ability today.

1 Bathing: do you need any help to get in and out of the bath/shower?

*(Please **tick one box** only)*

- ☐ Need help
- ☐ Independent

2 Stairs: do you climb stairs?

*(Please **tick one box** only)*

- ☐ Unable to manage or have not tried stairs
- ☐ With help
- ☐ Independent

3 Dressing: do you need any help with dressing?

*(Please **tick one box** only)*

- ☐ Dependent
- ☐ Need help, can do about half
- ☐ Independent (includes buttons, zips, laces)

4 Mobility: do you need any help to walk about indoors?

*(Please **tick one box** only)*

- ☐ Immobile
- ☐ Can get about in wheelchair
- ☐ Need help/supervision of 1 person
- ☐ Independent

5 Transfers: do you need any help to get in and out of bed?

*(Please **tick one box** only)*

- ☐ Unable to sit out of bed
- ☐ Need help of 2 people but can sit out of bed
- ☐ Need help/supervision of 1 person
- ☐ Independent

6 Feeding: do you need any help with feeding or cutting up your food?

*(Please **tick one box** only)*

- ☐ Dependent
- ☐ Need some help, e.g. cutting
- ☐ Independent in all actions

7 Toilet: do you need any help in the toilet (getting on or off, dealing with your clothes)

*(Please **tick one box** only)*

- ☐ Dependent
- ☐ Need some help
- ☐ Independent in all actions

8 Grooming: do you need any help with brushing teeth, combing hair, or (men only) shaving?

*(Please **tick one box** only)*

- ☐ Need help
- ☐ Independent for face/hair/teeth/shaving

9 Urinary function: do you have any problems controlling your bladder?

*(Please **tick one box** only)*

☐ Incontinent (or catheter)

☐ Occasional accident

☐ Fully continent (no accidents)

10 Bowel function: do you have any problems controlling your bowels?

*(Please **tick one box** only)*

☐ Incontinent (or cannot go without enemas)

☐ Occasional accident

☐ Fully continent (no accidents)

The next question is about how you would rate your general health.

11 As a result of your stroke, how would you rate your general health?
*(Please **tick one box** to show which answer is most appropriate for you)*

☐ I am fit and well with no problems

☐ I have some problems but I am able to perform all usual duties and activities

☐ I am unable to perform all previous activities but I am able to look after my own affairs without assistance

☐ I require some help with everyday activities but I am able to walk without assistance

☐ I am unable to walk without assistance and I am unable to attend to my own bodily needs without assistance

☐ I am bedridden and require constant nursing care and attention

Section 3: Your experiences of bladder problems

The next few questions are about your experiences of bladder problems. Please **tick one box** for each question.

1 How often do you experience urinary leakage?
(*Please* ***tick one box*** *only*)

- ☐ Never
- ☐ Less than once a month
- ☐ One or several times a month
- ☐ One or several times a week
- ☐ Every day and/or night
- ☐ Other

If you have ***ticked 'other'****, please* ***specify how often*** *in the box below:*

2 How much urine do you lose each time?
(*Please* ***tick one box*** *only*)

- ☐ None
- ☐ Drops or little
- ☐ More
- ☐ Other

If you have ticked 'other', please ***specify how much*** *in the box below:*

The next four questions are about how you have been on average over the past 4 weeks.

3 How often do you leak urine?
(*Please* ***tick one box*** *only*)

- ☐ Never
- ☐ About once a week or less often
- ☐ Two or three times a week
- ☐ About once a day
- ☐ Several times a day
- ☐ All the time

4 We would like to know how much urine **you think** leaks.

How much urine do you usually leak (whether you wear protection or not)?
(*Please* ***tick one box*** *only*)

- ☐ None
- ☐ A small amount
- ☐ A moderate amount
- ☐ A large amount

5 Overall, how much does leaking urine interfere with your everyday life?

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**

6 When does urine leak?

*(Please tick **all that apply** to you)*

- [ ] Never – urine does not leak
- [ ] Leaks before you can get to the toilet
- [ ] Leaks when you cough or sneeze
- [ ] Leaks when you are asleep
- [ ] Leaks when you are physically active/exercising
- [ ] Leaks when you have finished urinating and are dressed
- [ ] Leaks for no obvious reason
- [ ] Leaks all the time

The next few questions ask some more about your experiences of bladder problems.

7 Thinking over the last 12 months, have you ever found you leak urine/water when you don't mean to?

(*Please **tick one box** only*)

- [ ] Yes
- [ ] No

8 Do you **ever leak** urine when you do the following?
(Please tick **all that apply**)

- [ ] Never – urine does not leak
- [ ] Sneeze
- [ ] Exercise
- [ ] Cough
- [ ] Laugh
- [ ] Bend
- [ ] Stand up
- [ ] Other

*If you have **ticked "other"**, please **specify** in the box below:*

9 When you have the **urge** to pass urine, does **any leak** before you get to the toilet?
(*Please **tick one box** only)*

- ☐ Most of the time
- ☐ Sometimes
- ☐ Occasionally
- ☐ Never

10 **How much** do you leak usually?
(*Please **tick one box** only)*

- ☐ A few drops
- ☐ A dribble
- ☐ A stream
- ☐ A flood

11 When you leak urine, are you?
(*Please **tick one box** only)*

- ☐ Soaked
- ☐ Wet
- ☐ Damp
- ☐ Almost dry

12 How would you describe the **amount of urine** you leak? Is it
(*Please **tick one box** only)*

- ☐ Not noticeable
- ☐ Noticeable to yourself only
- ☐ Potentially noticeable to others
- ☐ Noticeable to others
- ☐ Don't know

13 When you **first** feel the need to pass urine how **strong is the urge** to go usually?
(*Please* ***tick one box*** *only)*

- [ ] Overwhelming
- [ ] Very strong
- [ ] Strong
- [ ] Normal
- [ ] Weak
- [ ] No sensation

14 Do you have difficulty holding urine once you feel the urge to go?
(*Please* ***tick one box*** *only)*

- [ ] Most of the time
- [ ] Sometimes
- [ ] Occasionally
- [ ] Never

15 How many times do you go to the toilet to pass urine during the **daytime**?
(*This is during* ***waking hours****, please put your average number in the box below, e.g. 3 times would be* 0 3 *times)*

16 How often do you get up at night to pass urine, if at all?

(*Please* ***tick one box*** *only)*

- [ ] Not usually
- [ ] Once a night
- [ ] Twice a night
- [ ] Three times a night
- [ ] Four times a night or more

Section 4: What you think about your health

The next few questions are about what you think about your heath. For questions 2 to 6 below, please **tick one box** that gives the best picture of what you think about your health.

1 How well do you feel at the moment?
(*Please* ***tick one box*** *that* ***best describes*** *how you are feeling)*

☐ No illness
☐ Illness present, minimal/no symptoms
☐ Definite illness, mild/controlled symptoms
☐ Definite illness, symptoms not under control
☐ Definite illness, needs vigorous treatment/potentially life threatening situation

For questions 2 to 5, please tick ***one box only*** *for each question*

2

☐ I have no problems in walking about
☐ I have some problems in walking about
☐ I am confined to bed

3

☐ I have no problems with self care
☐ I have some problems washing or dressing
☐ I am unable to wash or dress myself

4

- [ ] I have no problems performing my usual activities

  (e.g. work, study, housework, family or leisure activities)
- [ ] I have some problems in performing usual activities
- [ ] I am unable to perform my usual activities

5

- [ ] I have no pain or discomfort
- [ ] I have moderate pain or discomfort
- [ ] I have extreme pain or discomfort

6

- [ ] I am not anxious or depressed
- [ ] I am moderately anxious or depressed
- [ ] I am extremely anxious or depressed

For each of questions 7 to 28, please put a tick in the one box that is nearest to how you feel:

7 I worry about not being able to get to the toilet on time.

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

8 I worry about coughing and sneezing because of my urinary problems or incontinence.

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

9 I have to be careful about standing up after I've been sitting down because of my urinary problems or incontinence.

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

10 I worry where the toilets are in new places.

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

11 I feel depressed because of my urinary problems or incontinence.

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

12 Because of my urinary problems or incontinence, I don't feel free to leave my home for long periods of time.

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

13 I feel frustrated because my urinary problems or incontinence prevents me from doing what I want.

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

For each of questions 7 to 28, please put a tick in the one box that is nearest to how you feel::

14 I worry about others smelling urine on me.

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

15 Incontinence is always on my mind.

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

16 It's important for me to make frequent trips to the toilet.

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

17 Because of my urinary problems or incontinence, it's important to plan every detail in advance.

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

18 I worry about my urinary problems or incontinence getting worse as I grow older.

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

19 I have a hard time getting a good night of sleep because of my urinary problems or incontinence

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

20 I worry about being embarrassed or humiliated because of my urinary problems or incontinence

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

For each of questions 7 to 28, please put a tick in the one box that is nearest to how you feel:

21 My urinary problems or incontinence make me feel like I'm not a healthy person.

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

22 My urinary problems or incontinence makes me feel helpless.

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

23 I get less enjoyment out of life because of my urinary problems or incontinence.

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

24 I worry about wetting myself.

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

25 I feel like I have no control over my bladder.

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

26 I have to watch what or how much I drink because of my urinary problems or incontinence.

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

27 My urinary problems or incontinence limit my choice of clothing.

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

28 I worry about having sex because of my urinary problems or incontinence.

Extremely ☐ *Quite a bit* ☐ *Moderately* ☐ *A little* ☐ *Not at all* ☐

THANK YOU VERY MUCH FOR ANSWERING OUR QUESTIONS!

Please check that you have answered all the questions in this booklet. When you have finished, please return the booklet to us in the envelope provided. No stamps are needed.

If you would like to ask us anything about the questions or the study in general, please contact Lois Thomas, Denise Forshaw or Alison Hadley at the following address:

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