

Stroke Rehabilitation Research Project

# *EXTRAS*

24 Month Questionnaire  
(for relative or friend (carer))

Name:

Study Number:

Centre Number:

**Thank you for completing this questionnaire.**

## HOW TO ANSWER THE QUESTIONS

Thank you for filling in this questionnaire. All of your answers will be treated as confidential and are for research purposes only. Please try to answer every question even if you do not think it applies to you, or it if seems repetitive.

There are several types of questions in this booklet. Most of them can be answered by ticking a box ✓ for either NO or YES.

For example:

Do you live in North Tyneside?

NO

YES

Some of these questions have several boxes and you may be asked to tick one only, or tick as many boxes as apply to you.

For example:

Which vegetables do you like?

*(please tick all boxes that apply)*

Carrots

Spinach

Brussel sprouts

Cabbage

A small number of questions ask you to write in your answer on a line.

For example:

In what area of North Tyneside do you live?

I live in Whitley Bay

If you need help with the questions, please ask a friend or relative to assist you.

If you are unsure how to answer any of the questions, you can contact us on the telephone number below.

If you find a question too difficult to answer or if you do not wish to answer it, please move on to the next question.

If you have any queries or concerns about the EXTRAS trial, please contact:

Stroke Research Group  
Institute for Ageing & Health  
Newcastle University  
3-4 Claremont Terrace  
Newcastle upon Tyne  
NE2 4AE

Telephone: 0191 222 6779

## PART ONE – YOUR DETAILS

1. Please provide your contact details so we can ensure that our records are correct.

Address:

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Telephone number: \_\_\_\_\_

Email address: \_\_\_\_\_

2. Date questionnaire completed:

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## PART TWO – PROVIDING SUPPORT OR CARE TO A RELATIVE OR FRIEND WHO HAS HAD A STROKE

**Below is a list of things which some people have found to be difficult when supporting or caring for someone when they come home from hospital after a stroke. For each question, please tick the box which applies to you.**

1. Sleep is disturbed (e.g. because my relative/friend who has had a stroke is in and out of bed or wanders around at night).

No  Yes

2. It is inconvenient (e.g. because helping takes so much time or it's a long drive over to help).

No  Yes

3. It is a physical strain (e.g. because of lifting in and out of chair, effort or concentration required).

No  Yes

4. It is confining (e.g. helping restricts free time or cannot go visiting).

No  Yes

5. There have been family adjustments (e.g. because helping has disrupted my routine, there has been no privacy).

No  Yes

6. There have been changes in personal plans (e.g. had to turn down a job; could not go on holiday).

No  Yes

7. There have been other demands on my time (e.g. from other family members).

No  Yes

8. There have been emotional adjustments (e.g. because of severe arguments).

No  Yes

9. Some behaviour is upsetting (e.g. because of incontinence; my relative/friend who has had a stroke has trouble remembering things; or my relative or friend who has had a stroke accuses people of taking things).

No  Yes

10. It is upsetting to find my relative/friend who has had a stroke has changed so much from his/her former self (e.g. he/she is a different person than he/she used to be).

No  Yes

11. There have been work adjustments (e.g. because of having to take time off).

No  Yes

12. It is a financial strain.

No  Yes

13. Feeling completely overwhelmed (e.g. because of worry about my relative/friend who has had a stroke; concerns about how you will manage).

No  Yes

## PART THREE – YOUR GENERAL HEALTH\*

**Please note – these questions apply to YOUR health, not your friend or relative who has had a stroke.**

**For each of the five sets of statements below please tick one box that best describes your own health TODAY:**

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### Mobility

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I have no problems in walking about

I have slight problems in walking about

I have moderate problems in walking about

I have severe problems in walking about

I am unable to walk about

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### Self Care

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I have no problems washing or dressing myself

I have slight problems washing or dressing myself

I have moderate problems washing or dressing myself

I have severe problems washing or dressing myself

I am unable to wash or dress myself

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**Usual Activities (e.g. work, study, housework, family or leisure activities)**

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I have no problems doing my usual activities

I have slight problems doing my usual activities

I have moderate problems doing my usual activities

I have severe problems doing my usual activities

I am unable to do my usual activities

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**Pain/Discomfort**

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I have no pain or discomfort

I have slight pain or discomfort

I have moderate pain or discomfort

I have severe pain or discomfort

I have extreme pain or discomfort

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**Anxiety/Depression**

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I am not anxious or depressed

I am slightly anxious or depressed

I am moderately anxious or depressed

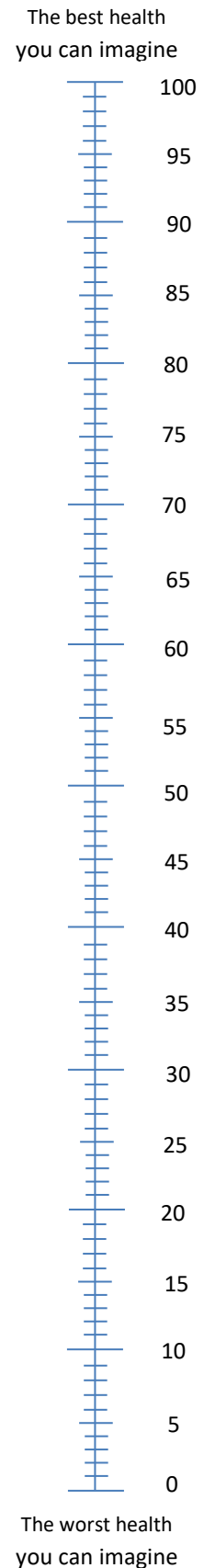
I am severely anxious or depressed

I am extremely anxious or depressed



- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine. 0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

**YOUR HEALTH TODAY =**



## PART FOUR – EXPERIENCE OF SERVICES

Please could you tell us about your experience of the services which your relative or friend has received in the last 12 months as a result of their stroke. Please tell us to what extent you agree with the following statements by ticking the box which best reflects your views.

### A. About the services

	To what extent do you agree that...	Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply
1.	Staff were welcoming and friendly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	Staff treated your relative/friend with dignity and respect.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	Staff assessed your relative/friend's needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	Staff met your relative/friend's needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	You have been involved as much as you wanted to be in decisions about their care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	You were able to discuss your preferences, beliefs, and concerns as part of their care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	You were told who to contact if you had any worries or concerns.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	You were confident that the staff who saw your relative/friend had the right skills and knowledge to help them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

To what extent do you agree that...		Strongly Disagree	Disagree	Agree	Strongly Agree	Does Not Apply
9.	Your relative/friend was treated fairly, regardless of their age, race, gender, belief, sexual orientation or disability.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	You were given the information you wanted.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11.	Your relative/friend was able to see the same healthcare professional/team whenever possible.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12.	If you had important questions to ask, you got answers that you could understand.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13.	If your relative/friend needed more than one service, staff made sure they were well coordinated.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14.	If your relative/friend needed more than one service, staff made sure that their care information was clearly and accurately shared.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15.	You were told who to contact if your relative/friend had any ongoing health care needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

16. If you answered 'Strongly Disagree' or 'Disagree' to any of the questions above, please tell us more about this and how this could be improved:

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**B. Overall**

1. Overall, how satisfied are you with the services your relative/friend received?

Extremely Satisfied	Very Satisfied	Quite Satisfied	Not Very Satisfied	Extremely Unsatisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**C. Meeting your relative/friends needs**

1. In the last 12 months, has your relative/friend had enough help with **speaking difficulties** from the NHS?

Yes, definitely	Yes, to some extent	No, they did not get enough help from the NHS	They did not have any speaking difficulties
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. In the last 12 months, has your relative/friend had enough treatment to help **improve their mobility** (e.g. walking, moving their legs) from the NHS?

Yes, definitely	Yes, to some extent	No, they did not get enough treatment from the NHS	They did not have any mobility difficulties
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. In the last 12 months, has your relative/friend had enough help with **emotional problems** (such as confusion, depression or crying) from the NHS?

Yes, definitely	Yes, to some extent	No , they did not get enough help from the NHS	They did not have any emotional problems
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Contact for further information:**

If you have any queries or require further information about the EXTRAS trial please contact:

Stroke Research Group  
Institute for Ageing & Health  
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NE2 4AE  
Tel: 0191 222 6779

**This is the end of the questionnaire.**

**Thank you for the time you have taken to complete it.**

**Please could you take a moment to check that you have answered as many questions as possible.**

**Please return it to us in the stamped addressed envelope provided.**