



Kingston and St George's
Faculty of Health, Social Care and Education

Managing your affected arm after stroke

Introduction

Welcome to this online survey.

We are conducting a study titled Managing your affected arm after stroke.

**If you had a stroke and your arm was severely affected,
or if you are caring for a stroke survivor whose arm was severely affected,
we would like to hear from you.**

The person with a severely affected arm

- > can move the arm very little, or not at all**
- > may have spasticity (sometimes also called “high muscle tone”), which is a tightening of the muscles**
- > may have pain and swelling**

You can find more information about this study on our website:

www.healthcare.ac.uk/research/my-arm/

Also, please ask us any questions - my contact details are on the next page.



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This survey will take about 30 minutes to complete.

Your responses are anonymous.

We will summarise and report all responses we receive, but your name will never appear.

We will receive your responses after you complete the survey.

If you stop before you reach the end, your responses will not be included.

As a small thank you for completing the survey, you can choose to enter a prize draw for one of five shopping vouchers (value £5).

To enter the prize draw, you will need to give your name and a way to contact you (e.g. email address or phone number) at the end of the survey. But this will be kept separate from your responses, so your responses will be strictly anonymous.

If you are interested in the outcome of this study, we can send you a short summary at the end.

To receive a study summary, you will need to give your name and a way to contact you (e.g. email address or phone number) at the end of the survey. But this will be kept separate from your responses, so your responses will be strictly anonymous.

If you prefer to complete this survey using pen and paper, please let me know, and I will post you a paper version with pre-paid return envelope.

If you would like some assistance over the telephone to complete this survey, please let me know, and I can ring you at your convenient time.

Also please ask me any questions:

My contact details are given below. I am a researcher at Kingston and St George's.

Thank you for taking the time to assist us with this research.



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Although we do not need to know your name, we would like a little more information about you. We use this to describe the group of people who returned this questionnaire.

Please note:

If the stroke survivor is providing the answers, and you are assisting with inputting their answers, please answer the following with respect to the stroke survivor.

If you are a family member or friend of a stroke survivor, and you are providing the answers from your point of view, please answer the following with respect to yourself.

I am

- ☐ Female
- ☐ Male

My age is

- ☐ Less than 29 years
- ☐ 30-39 years
- ☐ 40-49 years
- ☐ 50-59 years
- ☐ 60-69 years
- ☐ 70 years or more

I live in

- ☐ England
- ☐ Northern Ireland
- ☐ Scotland
- ☐ Wales

Other

I am

- ☐ Asian
- ☐ Black
- ☐ Chinese
- ☐ Mixed
- ☐ White
- ☐ Other

My main job for work is/was

* Please select one:

- ☐ I had a **stroke** and my arm was affected
- ☐ I am **caring for a stroke survivor** whose arm was affected



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When did the stroke happen?

Please tell us the month and year

If there were several strokes, please list the stroke that first affected your arm/hand

The stroke affected my

- ☐ dominant hand
- ☐ non-dominant hand



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The following questions ask **what you can do with your hands** .

For each of the activities listed, please estimate whether it is
IMPOSSIBLE or **DIFFICULT** or **EASY** for you.

When you estimate the activities:

- > It doesn't matter how you go about doing it
- > And it doesn't matter whether you would use both hands, or just your stroke-affected hand, or just your unaffected hand
- > But please imagine you are doing the activities without any technical or human help

How difficult are the following activities for you?

	Impossible	Difficult	Easy	I have never tried this before, so I can't say
Pulling up the zipper of trousers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Peeling onions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sharpening a pencil	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking a cap off a bottle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Filing your nails	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Peeling potatoes with a knife	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Buttoning up trousers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Opening a screw-topped jar	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cutting your nails	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tearing open a pack of crisps	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unwrapping a chocolate bar	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hammering a nail	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How difficult are the following activities for you?

	Impossible	Difficult	Easy	I have never tried this before, so I can't say
Spreading butter on a slice of bread	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Washing your hands	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Buttoning up a shirt	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Threading a needle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cutting meat	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wrapping up gifts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fastening the zipper of a jacket	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fastening a snap or press stud (on a jacket or bag)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Shelling hazelnuts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Opening mail	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Squeezing toothpaste on a toothbrush	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Adapted from the ABILHAND - Manual Ability Measure: www.abilhand.org

Penta M, Tesio L, Arnould C, Zancan A, Thonnard J-L. The ABILHAND Questionnaire as a Measure of Manual Ability in Chronic Stroke Patients: Rasch-Based Validation and Relationship to Upper Limb Impairment. *Stroke* 2001; 32: 1627-1634.



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The following questions ask about **'caring' for your stroke affected arm** , either yourself with your unaffected arm, or by a family member or friend, or a combination of both of these.

For each of the activities listed, please indicate the **amount of difficulty** that either **you or your family member or friend** experience in doing the task.

Please indicate the amount of difficulty caring for the stroke-affected arm

	No difficulty	Mild difficulty	Moderate difficulty	Severe difficulty	Unable to do
Cleaning the palm of the hand	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cutting finger nails	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cleaning the armpit	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cleaning the elbow crease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Positioning arm on a cushion or support in sitting (If never done select "No difficulty")	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Putting arm through a garment sleeve	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Putting on a glove (If never done select "No difficulty")	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Putting on a splint (If never done select "No difficulty")	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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The following questions are about you and your experiences.

There are no right or wrong answers.

Anything that you think is important is also important for our study.

In your own words, please **describe** your stroke-affected arm and hand

Thinking about your stroke-affected arm and hand, what is **important** to you?

Is there anything in particular you do to **look after** your stroke-affected arm and hand?



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If you have or had **any treatment** specifically for your stroke-affected arm and hand, please describe it here.

Please do not mention names of places or individuals

Thinking about your stroke-affected arm and hand, **what advice would you give someone in your position** – please list your top 3

Please let us know **what's missing**.

This can be anything at all that has to do with your stroke-affected arm and hand.



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We ask the following questions to **get a better idea** of certain aspects around your stroke-affected arm and hand.

Please tell us

	Yes	No	Don't know	Other
My stroke-affected arm is mainly weak and "floppy"	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have spasticity (muscle tightness) in my stroke-affected arm/hand	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have pain in my stroke-affected arm/hand/shoulder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have swelling in my stroke-affected arm/hand	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I often get cuts or bruises on my stroke-affected arm/hand	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I struggle to use my stroke-affected arm/hand in everyday activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you have selected "other", please explain here

Please tell us

	Yes	No	Don't know	Other
I have received treatment at a spasticity clinic (e.g. Botox) for my stroke-affected arm/hand	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have been shown exercises for my stroke-affected arm/hand	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am using a splint, brace, glove, or similar item for my stroke-affected arm/hand	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was given advice on how to look after my stroke-affected arm/hand	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you have selected "other", please explain here



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Thank you, we are almost finished.

The final question gives you a chance to mention **anything else** that has come to mind and you feel is important.

Anything else you feel is important

Thank you very much indeed for taking the time to complete this survey.

Our research relies on people like you, and we very much appreciate your participation.

On the following page, you can select to receive a **summary of the study** at the end,

and you can select to **enter the survey prize draw**.

This is optional.

For either, you will need to give your name and a way to contact you. But these will be kept separate from your responses, and **your responses will be strictly anonymous**.



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If you would like to receive a **short summary of the study** at the end, please give your name and a way to contact you (e.g. email address or phone number) here.

If not, leave this blank.

If you would like to **enter the survey prize draw** for one of five Love2Shop shopping vouchers (value £5), please give your name and a way to contact you (e.g. email address or phone number) here.

If not, leave this blank.

After we complete this research project, we will plan another study.

We will be looking for people who had a stroke, and family members and friends, to contribute to our future projects as "**service user representatives**".

This could involve coming to study advisory group meetings, reading through study materials and giving feedback from home, or talking through issues over the phone.

If this is something that interests you, please give your name and a way to contact you (e.g. email address or phone number) here, and we will get in touch with you over the summer.

If not, leave this blank.

Thank you for completing this survey.

Should you have any further queries, please don't hesitate to contact me

