The Stroke Association

UK Stroke Survivor Needs Survey

Christopher McKeivitt, Nina Fudge, Judith Redfern, Anita Sheldenkar, Siobhan Crichton and Charles Wolfe
This report is a shorter version of the full length report: *The Stroke Association UK Stroke Survivor Needs Survey.*

When we say *we* in this report, this means the researchers who carried out the study.

**Acknowledgements**

We are grateful to the King’s College London Stroke Research Patients and Family Group for their help in reviewing this report and making it more accessible.

We would like to acknowledge the authors of the following questionnaires for allowing us to use questions they developed in the development of the Stroke Survivor Needs Survey questionnaire:

- Healthcare Commission’s follow up survey of stroke patients 2006
- the Longer-term Unmet Needs after Stroke study
- the Sydney Psychosocial Reintegration Scale
- the South London Stroke Register.

We would like to acknowledge the practice nurses who collected data for the national sample.

We would like to thank the stroke survivors who agreed to take part in the survey and spent time completing the questionnaire.
Contents

Why did we carry out this survey? 6
How did we do the survey? 8
Results 12
What do the results mean? 16
Contact details 19
Why did we carry out this survey?
This survey was carried out to get up to date information about:

• the kinds of **needs** (or problems) that people with stroke have in the long-term

• how many people have **different types** of needs after stroke

• how many of these needs are **not met**.

By **long-term** we mean the consequences of stroke that people may have after discharge from hospital and beyond.

For this survey we contacted people who had their stroke from **one to five years ago**.

The Department of Health and the National Health Service recognise that more should be done to meet the ‘long-term needs’ of people with stroke.

We hope that this study will provide information that can be used to improve services to help people deal with the long-term effects of stroke.
How did we do the survey?
Who carried out the stroke survivor needs survey?

The survey was carried out by a team of researchers from King’s College London, Leeds University, Oxford University and University College London.

How did we contact stroke survivors?

We contacted stroke survivors in England, Scotland, Northern Ireland and Wales through their GP. We did this by first contacting practices throughout the UK which have experience in conducting research with patients registered in their practice.

Sometimes a high proportion of people do not take part in surveys of this kind. Therefore we also contacted stroke survivors through two existing registers of people with stroke, which we knew had high levels of participation. This was a kind of check for the main survey carried out in general practices.

These registers are the South London Stroke Register and the Oxford Vascular Study.

Designing the questionnaire

We designed a questionnaire to ask about changes in everyday activities since the stroke, problems experienced and unmet needs.

The King’s College London Stroke Research Patients and Family Group reviewed early versions of the questionnaire to improve it.
The final questionnaire included 44 questions covering:

- information about stroke
- health after stroke
- everyday living
- work and leisure
- family, friends and use of support groups
- finances.

An open-ended question asked people who took part in the survey to tell us about any other needs they had as a result of the stroke.
Sending out the questionnaire

We included people who were living at home and able to take part in the research.

We asked people who take part in the South London Stroke Register and the Oxford Vascular Study to complete the UK Stroke Survivor Needs Survey during their regular follow up interview.

In the South London Stroke Register, this included people at one, three and five years after their first stroke.

In the Oxford Vascular Study, this included people at one and five years after their first stroke.

In the GP practice survey, we asked nurses in each practice to post the questionnaire to their patients who had had a stroke from one to five years ago.

The nurse offered to complete the questionnaire over the phone, or in person if necessary.

All questionnaires were anonymous. They were returned to the study team at King’s College London for analysis.
Results
Who took part in the survey?

The responses from the general practice patients were very similar to those from the two stroke registers. This means that we can be confident that results from the UK survey are reasonably accurate.

In all we received completed questionnaires from 799 people.

- There were 228 people from the South London Stroke Register and the Oxford Vascular Study combined.
- There were 571 people contacted through general practices across the United Kingdom.

Of all those who took part in the survey:

- 55% were male
- 30% were under the age of 65 years
- 99% were from white ethnic groups
- 26% had a stroke one to two years before the survey
- 45% had a stroke three to four years before the survey
- 29% had a stroke five or more years before the survey.

Compared to the general practices, the two stroke registers had more people from Black and other ethnic minority groups and from younger age groups.
What kinds of needs did people have?

Just over half (51%) said that they had no unmet needs.

But just under half (49%) said they had one or more unmet needs. The number of unmet needs per person ranged from one to 13 but the average number per person was three unmet needs.

Just over half (54%) said they needed more information about stroke.

More people in Wales and Northern Ireland needed more stroke information compared to those in England and Scotland.

Other areas where people did not receive adequate information were:

- diet (37% wanted more information)
- holidays for people with a disability (21%)
- benefits and how to get them (16%)
- aids and adaptations for the home (15%)
- advice about driving (12%).

Over a third (38%) told us that they had emotional problems following the stroke. Most of them (73%) said they did not receive the help they needed for this.

Just over half (52%) said they experienced fatigue since the stroke. Nearly half of them (43%) said that they did not receive the help they needed for this.
Nearly half (45%) said they had problems with concentration since the stroke.

Under half (43%) said they had problems with their memory.

Nearly a quarter (23%) said they had problems reading.

About half (52%) of those who were working before their stroke said that they were not able to return to work or had to reduce their activities as a result of the stroke. People from Black ethnic minority groups were significantly more likely to report this change.

Nearly a fifth (18%) of those contacted through their GP practice and one quarter (25%) of those in the stroke registers said that their income had gone down since the stroke.

About a third (31%) said their expenses had increased since the stroke.

About a quarter (26%) reported negative changes in their family relationships since the stroke. Less than half (42%) reported a negative change in their relationship with their spouse/partner.
What do the results mean?
The findings from this study are important because they provide an idea of how many people with stroke have which kinds of problems long after their stroke.

Although just over half of long-term stroke survivors taking part in this survey reported no unmet needs, the rest said they had at least one ongoing problem as a result of the stroke.

We were not surprised that such a large proportion of people said they did not receive the information they wanted; but it was surprising that it didn’t matter if people had their stroke one year or five years ago – they still said they needed more information.

Over a third of people have emotional problems but only a minority of these felt that they had received the help they need. More should be done to ensure that stroke survivors who do experience emotional problems are properly helped.

Other areas of need reported in this study are not usually considered in medical studies – partly because it is not clear what kind of help can be provided. This includes fatigue and problems with concentration, memory and reading. Since these problems were important to many people who took part in the survey, we need to look more closely at what kinds of solutions might be helpful.

Very few studies have looked at the financial impact of stroke on families but about half the people in this survey who were working at the time of stroke said that they had stopped or reduced their work activities. Between a quarter and a third said they had lost income and about a third said their expenses had gone up since the stroke.
The survey also told us that stroke had consequences for an individual’s spouse, their family and their ability to take part in leisure activities. At the moment we know that there are few services designed to help those who experience these kinds of problems.

**What next?**

The information from this survey will be used by The Stroke Association in developing its plans for services for the next few years and in its lobbying work with the Government.
Contact details

If you have any questions about this study or would like more information please contact:

Dr Christopher McKeivitt
King’s College London
7th Floor Capital House
42 Weston Street
London SE1 3QD

Email: christopher.mckevitt@kcl.ac.uk

This booklet is a shorter version of the full length report: *The Stroke Association UK Stroke Survivor Needs Survey*. To read the full length version of the report visit www.stroke.org.uk/needssurvey
Every five minutes someone in the UK has a stroke. A stroke doesn’t discriminate. It can happen to anyone at any time in their life. Strokes are sudden and their consequences can be devastating. The Stroke Association is the only charity solely concerned with helping everyone affected by stroke across the UK. Our vision is to have a world where there are fewer strokes and all those touched by stroke get the help they need.

The Stroke Association
Stroke House
240 City Road
London EC1V 2PR

Stroke Helpline: 0303 3033 100

www.stroke.org.uk
Tel: 020 7566 0300
Textphone: 18001 0303 3033 100

The Stroke Association is a UK-wide organisation. We have offices in England, Wales, Scotland and Northern Ireland. You can find more contact details on our website.

© The Stroke Association, December 2010

The Stroke Association is registered as a company limited by guarantee in England and Wales No. 61274, and as a charity in England and Wales (211015), in Scotland (SC037789), in the Isle of Man (945), in Jersey (NPO 369), and is also registered in Northern Ireland.