

○ Patients' experiences of stroke care

Two national surveys

Stroke patients were recently given a unique opportunity to tell us about their care both during and after leaving hospital by taking part in two national surveys.

Overall, almost nine out of ten patients rated the care they received in hospital as 'excellent', 'very good' or 'good'. They also helped identify key areas for service improvements, as outlined below.

"I was very satisfied with my care while I was in hospital. I could not have been better looked after."

Patient comment

Care and treatment

Most patients said they had confidence and trust in the staff treating them and felt the staff knew enough about the treatment of stroke. However, over a third felt there were not enough nursing staff on duty to care for them:

- one in three did not always get prompt help getting to the toilet or the help they needed with washing
- two out of five said they needed more help eating meals.

Information

Over half the patients (55%) said they understood the information they got about their stroke. However, three out of five patients (62%) said they were not told about medication side effects. One third were not told who to contact if they had concerns after leaving hospital. A number of patients also said they did not get information about exercise (33%) or dietary changes (43%) that might help prevent another stroke.

Rehabilitation

Patients were largely positive about the amount of rehabilitation they received in hospital:

- of those with mobility problems, three out of five said they got enough treatment
- half of those patients with speech and communication difficulties said they got enough help.

Why were the surveys carried out?

The surveys asked patients for their views on their recent healthcare experience. These results are being used by NHS Trusts and the Healthcare Commission to measure the quality of care and to help set priorities to deliver a better service for patients.

Who took part in the surveys?

One in three (51) hospital NHS Trusts in England took part in the surveys. In Autumn 2004, 1700 patients responded to the first survey about the care and treatment they received in hospital.

Over 70% of these respondents then agreed to take part in a second survey about their longer term care. Follow-up questionnaires were sent to patients approximately one year after they had left hospital. Responses were received from 875 patients – a response rate of 75%.

Who carried out the surveys?

The surveys were carried out by the Picker Institute on behalf of the Healthcare Commission. Stroke patients were involved in designing the questionnaire and the following support organisations were consulted during the development of the surveys:

- **Different Strokes:** 0845 130 7172
www.differentstrokes.co.uk
- **Speakability:** 080 8808 9572
www.speakability.org.uk
- **Stroke Association:** 0845 30 33 100
www.stroke.org.uk

Where can I find out more?

The Picker Institute: 01865 208 100
www.pickereurope.org for details on the development of these surveys and others

The Healthcare Commission: 0845 601 3012
www.healthcarecommission.org.uk for more information on the results of the surveys

" Written information on my medication, diet, and continued after effects of the stroke would have been a help for my family and I. "

Patient comment

In summer 2005, a follow-up survey asked some of the same patients about the care they had received since leaving hospital. Together with the first survey, the findings provide a detailed picture of people's experiences of stroke care services over time.

Overall, patients were less positive about the care they had received since they left hospital. One third of patients felt the care they had received since leaving hospital was 'fair', 'poor' or 'very poor'.

Follow-up rehabilitation and care

After leaving hospital stroke patients will often need further rehabilitation and care to help with their recovery at home. Most patients said they had received enough rehabilitation, but some patients felt they did not receive enough help:

- one in four said they did not get enough treatment to improve their mobility
- half of the patients said they did not get enough help for emotional problems
- one in four said they did not get enough help with speaking difficulties.

"It would have been helpful to have had more support, particularly emotionally, to understand and to adapt to the outcomes of the stroke."

Patient comment

Seeing a health professional

Two out of three patients thought their GP knew enough about the treatment of stroke. Most patients (89%) who wanted a home visit from their GP or practice nurse received one. Four out of five patients said their medication had been reviewed by a health professional since they had left hospital. Almost all patients said their blood pressure had been checked.

"Once I left hospital I was to some extent left to contact people for advice. There was little follow up from the hospital or my GP."

Patient comment

Support for everyday living

Most patients said they did not need any support with everyday living but many of those who felt they do need this help are not getting it:

- over half said they had not received any 'Home Help' but would have liked this support
- one third said they had not received help with personal care, such as getting dressed.

Involvement in care

Over half the respondents wanted to be more involved in decisions about their care and their medication. We also discovered that patients were more likely to feel involved in decisions about their care if they had been given enough information about stroke.

Families and carers

No help or support had been given to the patient's carer in almost half the responses. One in three said their carer had not been given enough information about stroke to help them recover.

"I think information should be explained about stroke to the carers, and some help for them to understand what's going on and be able to cope."

Patient comment

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"My GP has been very supportive. He has been monitoring my blood pressure and taken total responsibility for my medication and care."

Patient comment

