*Full title:*

Information provision for stroke survivors and their carers: Cochrane Review

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Information provision for survivors and carers

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The provision of appropriate, accurate and timely information and advice about stroke is a recommended component of stroke services. Patients should have information that empowers them to share in decisions about their care, access appropriate services and adjust to life after stroke. Yet research suggests that survivors' understanding of stroke, its consequences, and the support available, remains poor. Stroke survivors and carers routinely report dissatisfaction with information provision, and a need for relevant and usable information.

In this review we categorised information provision as either active or passive: active information provision included active participation with subsequent opportunities for clarification and reinforcement; passive information provision provided no systematic follow‐up or reinforcement procedure.

**Objectives**

Primary objective: to assess the effects of active or passive information provision for stroke survivors (people with a clinical diagnosis of stroke or transient ischaemic attack (TIA)) or their identified carers. Primary outcomes: knowledge about stroke and stroke services, and anxiety.

**Search methods**

Searches of the Cochrane Stroke Group Specialised Register were updated on 28 September 2020 and for ten other databases to May/June 2019, including: CENTRAL, MEDLINE, Embase, and CINAHL. We searched seven study registers and checked reference lists of reviews.

**Selection criteria**

Randomised trials involving stroke survivors, their identified carers or both, where information provision was the difference in treatment, or comparisons were between active and passive information provision.

**Data collection and analysis**

Two review authors independently assessed eligibility, extracted data and judged risk of bias. We used GRADE methods to assess the overall certainty of the evidence.

**Main results**

We retrieved 45,483 records from our electronic search updates and identified 4413 records from other sources. Following screening we assessed eligibility of 190 full-text reports. Twelve new studies were included. The previous version of the review already included 21 studies.

This updated review includes 33 studies involving 5255 stroke‐survivor and 3134 carer participants. Twenty‐two trials evaluated active information provision and 11 trials evaluated passive information provision. Most trials were at high risk of bias and the following estimates have low certainty, unless stated otherwise.

For stroke survivors, active information provision may improve stroke‐related knowledge (standardised mean difference (SMD) 0.41, 95% confidence interval (CI) 0.17 to 0.65; 3 studies, 275 participants), and may reduce Hospital Anxiety and Depression Scale Anxiety subscale (HADS-A) cases and scores slightly, where a lower score equals fewer anxiety symptoms (risk ratio 0.85, 95% CI 0.68 to 1.06; 5 studies, 1132 participants; mean difference (MD) −0.73, 95% CI −1.10 to −0.36; 6 studies, 1171 participants). For carers, active information provision may reduce HADS-A scores slightly (MD −0.40, 95% CI −1.51 to 0.70; 3 studies, 921 participants). The evidence is very uncertain (very low certainty) for the effects of active information provision on carers' stroke‐related knowledge, and cases of anxiety.

For stroke survivors, passive information provision may slightly increase HADS-A score (MD 0.67, 95% CI −0.37 to 1.71; 3 studies, 227 participants) and the evidence is very uncertain for the effects on stroke‐related knowledge and cases of anxiety. For carers, the evidence is very uncertain for the effects of passive information provision on stroke‐related knowledge, and anxiety.

**Implications for practice**

Although the effects of information provision remain uncertain, these results suggest that strategies which actively involve stroke survivors and carers and include planned follow‐up for clarification and reinforcement should be used in routine practice, and favoured over passive approaches.

**Implications for research**

Direct comparison of active and passive approaches to information provision would help confirm these tentative implications. Information provision for carers and people with aphasia and cognitive impairment requires further attention.

**Disclosures**

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**Reference**

1. Crocker TF, Brown L, Lam N, Wray F, Knapp P, Forster A. Information provision for stroke survivors and their carers. Cochrane Database of Systematic Reviews 2021, Issue 11. Art. No.: CD001919.pub4. DOI: 10.1002/14651858.CD001919.pub4.

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