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[Intervention Review]

Information provision for stroke patients and their caregivers

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ABSTRACT

Background

Research shows that stroke patients and their families are dissatisfied with the information provided and have a poor understanding of stroke and associated issues.

Objectives

To assess the effectiveness of information provision strategies in improving the outcome for stroke patients or their identified caregivers, or both.

Search methods

For this update we searched the Cochrane Stroke Group Trials Register (June 2012), the Cochrane Central Register of Controlled trials (CENTRAL), the Cochrane Database of Systematic Reviews (CDSR), the Database of Abstracts of Reviews of Effects (DARE), the NHS Economic Evaluation Database (EED), and the Health Technology Assessment (HTA) Database (*The Cochrane Library* June, 2012), MEDLINE (1966 to June 2012), EMBASE (1980 to June 2012), CINAHL (1982 to June 2012) and PsycINFO (1974 to June 2012). We also searched ongoing trials registers, scanned bibliographies of relevant articles and books and contacted researchers.

Selection criteria

Randomised trials involving patients or carers of patients with a clinical diagnosis of stroke or transient ischaemic attack (TIA) where an information intervention was compared with standard care, or where information and another therapy were compared with the other therapy alone.

Data collection and analysis

Two review authors independently assessed trial eligibility and methodological quality and extracted data. Primary outcomes were knowledge about stroke and stroke services, and impact on mood.

Main results

We have added four new trials to this update. This review now includes 21 trials involving 2289 patient and 1290 carer participants. Nine trials evaluated a passive and 12 trials an active information intervention. Meta-analyses showed a significant effect in favour of the intervention on patient knowledge (standardised mean difference (SMD) 0.29, 95% confidence interval (CI) 0.12 to 0.46, $P < 0.001$), carer knowledge (SMD 0.74, 95% CI 0.06 to 1.43, $P = 0.03$), one aspect of patient satisfaction (odds ratio (OR) 2.07, 95% CI 1.33 to 3.23, $P = 0.001$),

and patient depression scores (mean difference (MD) -0.52, 95% CI -0.93 to -0.10, $P = 0.01$). There was no significant effect ($P > 0.05$) on number of cases of anxiety or depression in patients, carer mood or satisfaction, or death. Qualitative analyses found no strong evidence of an effect on other outcomes. Post-hoc subgroup analyses showed that active information had a significantly greater effect than passive information on patient mood but not on other outcomes.

Authors' conclusions

There is evidence that information improves patient and carer knowledge of stroke, aspects of patient satisfaction, and reduces patient depression scores. However, the reduction in depression scores was small and may not be clinically significant. Although the best way to provide information is still unclear there is some evidence that strategies that actively involve patients and carers and include planned follow-up for clarification and reinforcement have a greater effect on patient mood.

PLAIN LANGUAGE SUMMARY

Information provision for stroke patients and their caregivers

Studies have shown that stroke survivors and their carers often report they have not been given enough information about stroke and feel unprepared for life after discharge from hospital. However, the best way to provide information after stroke is unclear. The authors of this review looked at the evidence for the effectiveness of providing information to patients, or carers of patients, who have had a stroke or transient ischaemic attack (TIA), sometimes called a mini-stroke. They examined randomised trials (studies) in which one group of stroke patients or carers who were given the intervention being tested (such as a course of lectures) was compared with a group of stroke patients or carers who received standard care. Twenty-one studies, involving 2289 patients and 1290 carers, are now included in this updated review. Overall, the studies showed that providing information to patients and carers improved their knowledge of stroke and increased patient satisfaction with some, but not all, of the information they received about stroke. There was also an effect on reducing patient depression, although the reduction was small and may not be enough to seem meaningful to patients. When information was provided in a way that more actively involved patients and carers, for example by offering repeated opportunities to ask questions, it had more effect on patient mood than information which was given on one occasion only. There is not much evidence that providing information had effects on other aspects of patient or carer stroke recovery such as independence or social activities.

BACKGROUND

Every year approximately 110,000 people in England have a stroke ([National Audit Office 2005](#)) and at any one time over 300,000 people are living with moderate to severe disability as a result of a stroke ([Adamson 2004](#)). The provision of appropriate, accurate, timely information and advice about stroke has been recommended as a key component of service provision ([Canadian Stroke Network 2006](#); [RCP 2008](#); [National Stroke Foundation Australia 2010](#)). Information, combined with the right support, is the key to better care, better outcomes and reduced costs. Patients should have information and data on all aspects of health care, to enable them to share in decisions about their care and access appropriate services ([Department of Health 2010](#)). The information needs of people who have had a stroke and their carers are diverse and change over time. Information should be tailored to an individual's requirements and provided in a variety of formats ([Department of Health 2007](#); [Eames 2011](#)), taking into account their stroke-specific impairment and personal situation ([RCP 2008](#)).

There is a wide range of nationally and locally produced leaflets, booklets, videos and audio tapes available for patients and carers. However, despite this emphasis on giving information, research suggests that patients' understanding of stroke, its consequences and the support available, remains poor. A recent systematic review identified multiple and diverse unmet educational needs by stroke patients and their caregivers ([Hafsteinsdottir 2011](#)). In a survey of community dwelling adults who suffered a stroke at least one and up to five years previously, over half reported wanting more information about their stroke ([McKevitt 2011](#)).

In a UK study, carers of stroke patients reported that whilst leaflets were available, they were not always appropriate to the situation ([Mackenzie 2007](#)). A survey by primary care trusts in England, of the information provided to patients after stroke, reported that the majority provided good information. However, only 40% contained information relevant to local services. Furthermore, the size, content and organisation of the information varied extensively ([Care Quality Commission 2011](#)). Inadequate provision and receipt of appropriate information has important consequences for compliance with secondary prevention and the longer-term psycho-social outcome for patients and carers ([O'Mahoney 1997](#)). Enhanced knowledge of stroke care by carers may improve the quality of discharge home from hospital for stroke patients ([Evans 1991](#)). Despite the perceived and expressed need for information, successful strategies have not as yet been identified. In order to fully explore available evidence we have undertaken a systematic review of information provision for patients and their carers after stroke.

Description of the condition

A stroke is defined by the World Health Organization as: "Rapidly developing clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than vascular origin" ([Aho 1980](#)). A transient ischaemic attack (TIA) is a brief reversible episode of focal, non-convulsive ischaemic dysfunction of the brain with a duration of less than 24 hours ([Adams 1998](#)). Stroke can lead to death or physical and cognitive impairment ([McKevitt 2011](#); [Mukherjee 2011](#)) and can have long lasting psychological and social implications ([Knapp 2000](#)).

Description of the intervention

The intervention is the provision of information for stroke survivors or their informal caregivers, or both, following a stroke or TIA. The intervention may be provided in a variety of formats such as leaflets, workbooks, or verbal communication including lectures or teaching sessions. Whilst the content of the intervention may vary, it is likely to contain at least one of the following components: information about the causes and nature of stroke; management and recovery from the effects of stroke; prevention or reducing the risk of future strokes; information on resources or services. Whilst the provision of information should be incorporated as standard practice following stroke, evidence suggests it is lacking or inconsistent ([Mackenzie 2007](#); [Care Quality Commission 2011](#)).

How the intervention might work

If stroke survivors and carers are to be active in their decision making and management of the long-term effects of stroke, appropriate information delivered in a timely and effective format is necessary. Information is considered necessary to recognise and act upon symptoms, manage disease exacerbation and to access effective treatments and medicines and produce better outcomes ([Department of Health 2001](#); [Department of Health 2010](#)). Furthermore, inadequate provision of information has implications for compliance with secondary prevention and psycho-social outcomes for stroke patients and carers ([O'Mahoney 1997](#)). Evidence from non-stroke populations suggests providing written information improves adherence to hospital after-care regimens ([Gibbs 1989](#); [Firth 1991](#)) and may assist with self-care ([Coulter 1998](#)), which may indirectly produce beneficial outcomes.

Why it is important to do this review

It has been proposed that information, combined with the right support, is the key to better care, better outcomes and reduced costs ([Department of Health 2010](#)). The information derived from this review has the potential to lead to the development of more effective information provision strategies and highlight which outcomes might be affected by such interventions.

OBJECTIVES

The objective of this review was to examine the effectiveness of information strategies provided with the intention of improving the outcome for stroke patients or their identified caregivers or both.

METHODS

Criteria for considering studies for this review

Types of studies

We included unconfounded randomised trials where an information intervention was compared with standard care or where information and another therapy was compared with the other therapy alone.

Types of participants

Patients with a clinical diagnosis of stroke or TIA and their identified caregivers or both.

Types of interventions

Information provided with the intention of improving the outcome of patients or their caregivers or both. We excluded trials in which information-giving was only one component of a more complex rehabilitation intervention, for example family support worker trials (Forster 1996; Dennis 1997; Mant 2000; Lincoln 2003; Ellis 2005), which are the subject of a separate Cochrane review (Ellis 2010).

Types of outcome measures

We considered that information provision would impact most directly on knowledge and patients' or carers' mood state (anxiety and depression) or both. Therefore, we used the following primary and secondary outcome measures to assess the effectiveness of information provision.

Primary outcomes

1. Patient or carer knowledge about stroke and stroke services or both.
2. Patient or carer impact on mood (e.g. Hospital Anxiety and Depression Scale).

Secondary outcomes

1. Activities of daily living (e.g. Barthel Index).
2. Participation (e.g. London Handicap Scale).
3. Social activities (e.g. Frenchay Activities Index).
4. Perceived health status (e.g. Short-form 36, Nottingham Health Profile).
5. Quality of life (e.g. Dartmouth Coop Chart).
6. Satisfaction with information.
7. Hospital admissions, service contacts or health professional contacts.
8. Compliance with treatment/rehabilitation (e.g. Miller's Health Behaviour Scale).
9. Death or institutionalisation or both.

Resource outcomes

1. Cost to health and social services.

Search methods for identification of studies

See the 'Specialized register' section in the [Cochrane Stroke Group](#) module. We searched for trials in all languages and arranged translation of papers published in languages other than English.

Electronic searches

For this update we searched the Cochrane Stroke Group Trials Register (last searched in June 2012). In addition, we searched the following electronic bibliographic databases and trials registers:

- Cochrane Central Register of Controlled trials (CENTRAL) (*The Cochrane Library* 2012, Issue 4) ([Appendix 1](#));
- Cochrane Database of Systematic Reviews (CDSR) (*The Cochrane Library* 2012, Issue 4) ([Appendix 1](#));
- Database of Abstracts of Reviews of Effects (DARE) (*The Cochrane Library* 2012, Issue 4) ([Appendix 1](#));
- NHS Economic Evaluation Database (EED) (*The Cochrane Library* 2012, Issue 4) ([Appendix 1](#));

- Health Technology Assessment (HTA) Database (*The Cochrane Library* 2012, Issue 4) ([Appendix 1](#));
- MEDLINE (1966 to June 2012) ([Appendix 2](#));
- EMBASE (1980 to June 2012) ([Appendix 3](#));
- CINAHL (1982 to June 2012) ([Appendix 4](#));
- PsycINFO (1974 to June 2012) ([Appendix 5](#));
- Current Controlled Trials (<http://www.controlled-trials.com/>) (June 2012);
- National Rehabilitation Information Center (www.naric.com) (June 2012);
- RePORT Expenditures and Results (RePORTER) query tool (<http://projectreporter.nih.gov/reporter.cfm>) (December 2012);
- Internet Stroke Center stroke trials registry (www.strokecenter.org) (June 2012).

Searching other resources

In an effort to identify further published, unpublished and ongoing trials, we searched bibliographies of relevant articles and books and contacted authors of relevant research and previous articles on information provision.

For the previous version of the review we searched:

- Science Citation Index and Social Science Citation Index (1981 to March 2007);
- ASSIA (Applied Social Science Index and Abstracts) (1987 to March 2007);
- Index to UK theses (1970 to March 2007);
- Dissertation Abstracts (1961 to March 2007);
- National Research Register (www.nrr.nhs.uk) (to September 2007);
- *Journal of Advanced Nursing* (1996 to March 2007).

Data collection and analysis

Selection of studies

Two review authors independently assessed the titles and abstracts of records from the electronic searches and excluded obviously irrelevant studies. We obtained the full text of the remaining studies and at least two review authors assessed these against the review inclusion criteria to determine which trials would be eligible for inclusion. The review authors resolved disagreements by discussion with other members of the review team.

Data extraction and management

At least two review authors scrutinised all the eligible trials to grade methodological quality, patient selection, the intervention, outcome measures used, and length of follow-up. We allocated studies to one of two categories - passive information or active information - according to the nature of the intervention. An intervention was classified as passive if the information was provided on a single occasion and there was no subsequent systematic follow-up or reinforcement procedure. An intervention was classified as active if, following the provision of the information, there was a purposeful attempt to allow the participant to assimilate the information and a subsequent agreed plan for clarification and consolidation or reinforcement. We made this classification because it would inform future research and be helpful for service planners in terms of committing resources.

Two review authors extracted data independently using piloted data extraction forms, and measured agreement. They resolved disagreement through group consensus. Where necessary, we contacted study authors for additional information and data.

Assessment of risk of bias in included studies

We assessed the methodological quality of selected studies using the tool for assessing risk of bias as described in section 8 of the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins 2011). We scored each of the following domains as 'high risk of bias', 'low risk of bias', or 'unclear risk of bias' and reported them in the 'Risk of bias' tables.

- Random sequence generation (selection bias).
- Allocation concealment (selection bias).
- Blinding of participants and personnel (performance bias).
- Blinding of outcome assessment (detection bias).
- Incomplete outcome data (attrition bias).
- Selective reporting (reporting bias).
- Other possible bias.

Measures of treatment effect

We compared studies based on end-of-study results. We used the mean difference (MD) or standardised mean difference (SMD) for continuous outcomes. We treated ordinal data as continuous data and combined them using the MD. We combined dichotomous data using the Peto odds ratio (OR).

Dealing with missing data

If data were missing, we performed an available case analysis. The proportion of participants in each study arm who did not provide data is shown in the 'Data and analyses' section.

Assessment of heterogeneity

We tested for the presence of heterogeneity between the trials using the I^2 statistic. We used a fixed-effect model if we detected no substantial heterogeneity ($I^2 < 50\%$). Where there was substantial heterogeneity ($I^2 \geq 50\%$) we used a random-effects model.

Assessment of reporting biases

We were able to reduce reporting bias by undertaking comprehensive searches of multiple databases and trials registers, and contacting authors. There were no restrictions based on language and translations were undertaken if required. It was not possible to detect reporting bias by the method of assessment of funnel plots as there were insufficient studies included in the meta-analyses.

Data synthesis

We compared studies based on the end-of-study results. Meta-analyses have been undertaken for the domains of knowledge, emotional outcome, death and for selected satisfaction questions. For the domain of knowledge, we combined data using the SMD as all the trials had used different knowledge questionnaires. We combined dichotomous data (domains of mood, satisfaction, death) using the Peto OR. For the domain of mood, we dichotomised the Hospital Anxiety and Depression Scale scores, the Geriatric Depression Scale scores and the General Health Questionnaire scores using the recommended cut-off points

(Zigmond 1983; Sheikh 1986; Goldberg 1988). We treated ordinal data (domain of patient mood) as continuous data and combined them using the MD. For a number of studies both ordinal and dichotomised patient Hospital Anxiety and Depression Scale data were available. If this was the case, we extracted and analysed both forms of data. For other outcomes, we present a narrative summary stratified by subgroup and a summary of the data is provided in the [Data and analyses](#) section.

Subgroup analysis and investigation of heterogeneity

We undertook post-hoc subgroup analyses for the type of intervention (passive and active). We used the method described by Deeks et al (Deeks 2001) to compare the magnitude of treatment effect of the two subgroups.

RESULTS

Description of studies

Results of the search

For this update we reviewed 28,110 titles; 134 papers were reviewed of which duplicate papers were identified for 14 studies, four new studies are included in the review (Johnston 2007; Chiu 2008; O'Connell 2009; Chinchai 2010). Of the 134 papers reviewed for this update, five were commentaries, reviews or meta-analyses, seven trials included non-stroke participants and six studies did not investigate the effectiveness of information provision after stroke; 43 studies have been added to the excluded studies section (details reported in [Characteristics of excluded studies](#)); 14 studies are currently pending assessment and 10 studies are currently ongoing.

Included studies

The current analysis includes 21 completed trials with 2289 patient and 1290 carer participants (Lomer 1987; Evans 1988; Pain 1990; Downes 1993; Banet 1997; Mant 1998; Rodgers 1999; Frank 2000; Johnson 2000; Kalra 2004; Smith 2004; Ellis 2005; Larson 2005; Draper 2007; Hoffmann 2007; Johnston 2007; Lowe 2007; Maasland 2007; Chiu 2008; O'Connell 2009; Chinchai 2010).

Setting

Three of the included trials were conducted in the USA (Evans 1988; Banet 1997; Johnson 2000), 11 in the UK (Lomer 1987; Pain 1990; Downes 1993; Mant 1998; Rodgers 1999; Frank 2000; Kalra 2004; Smith 2004; Ellis 2005; Johnston 2007; Lowe 2007), three in Australia (Draper 2007; Hoffmann 2007; O'Connell 2009), one in Sweden (Larson 2005), one in the Netherlands (Maasland 2007), one in Taiwan (Chiu 2008) and one in Thailand (Chinchai 2010).

Participants

In 19 trials the majority of patients were at least 60 years old (Evans 1988; Pain 1990; Downes 1993; Mant 1998; Rodgers 1999; Frank 2000; Johnson 2000; Kalra 2004; Smith 2004; Ellis 2005; Larson 2005; Draper 2007; Hoffmann 2007; Johnston 2007; Lowe 2007; Maasland 2007; Chiu 2008; O'Connell 2009; Chinchai 2010). Two trials did not report age (Lomer 1987; Banet 1997). Six trials reported carer age (Evans 1988; Downes 1993; Rodgers 1999; Smith 2004; Larson 2005; Draper 2007). Carers were younger than the patients, notably so in Evans 1988 where the mean age of the carers was under 50 years old. This study was carried out at a Veterans Administration Medical Centre and was also exceptional in that 94%

of the stroke patients were male. In [Larson 2005](#) the majority of spouses were female. Ten trials were concerned with the patient only ([Pain 1990](#); [Banet 1997](#); [Frank 2000](#); [Johnson 2000](#); [Ellis 2005](#); [Hoffmann 2007](#); [Lowe 2007](#); [Maasland 2007](#); [Chiu 2008](#); [O'Connell 2009](#)) and in four trials the intervention involved the carer or spouse only ([Evans 1988](#); [Kalra 2004](#); [Larson 2005](#); [Draper 2007](#)). In the remaining trials the focus of the intervention was the patient and carer ([Lomer 1987](#); [Downes 1993](#); [Mant 1998](#); [Rodgers 1999](#); [Smith 2004](#); [Johnston 2007](#); [Chinchai 2010](#)).

Interventions

Two of the included trials evaluated two interventions ([Evans 1988](#); [Downes 1993](#)): one evaluated education and counselling ([Evans 1988](#)) and the other evaluated information provision plus counselling ([Downes 1993](#)). Only the data from the information/education group and the control groups have been analysed in this review.

Category

In nine studies we categorised the intervention as passive and in a further 12 studies we categorised the intervention as active. We considered that one of the 17 studies ([Lowe 2007](#)) exhibited features of both categories. We therefore sought further information from the lead author. Following discussion we agreed that it should be categorised as passive because information was provided on one occasion only with no subsequent opportunity for clarification and consolidation or reinforcement.

Content and administration

Nine trials evaluated a passive intervention ([Lomer 1987](#); [Pain 1990](#); [Downes 1993](#); [Banet 1997](#); [Mant 1998](#); [Hoffmann 2007](#); [Lowe 2007](#); [Maasland 2007](#); [O'Connell 2009](#)). In three trials ([Lomer 1987](#); [Downes 1993](#); [Mant 1998](#)) this comprised written generic information about stroke in the form of booklets and leaflets. In five studies ([Pain 1990](#); [Banet 1997](#); [Hoffmann 2007](#); [Lowe 2007](#); [Maasland 2007](#)) the information was tailored to be of relevance to the individual. In [Pain 1990](#) and [Hoffmann 2007](#) participants were provided with individualised booklets. In [Banet 1997](#) the intervention group were given a copy of their medical history, clinical résumés, test results and leaflets. In [Maasland 2007](#) information was delivered via an individualised multimedia computer programme. In [Lowe 2007](#) the intervention comprised personalised information presented by a research registrar who explained its contents and addressed any additional concerns. In [O'Connell 2009](#), the intervention group were given a patient-held record that included telephone numbers, generic stroke information and fact sheets relevant to the patient's specific stroke problems.

Twelve trials evaluated an active intervention ([Evans 1988](#); [Rodgers 1999](#); [Frank 2000](#); [Johnson 2000](#); [Kalra 2004](#); [Smith 2004](#); [Ellis 2005](#); [Larson 2005](#); [Draper 2007](#); [Johnston 2007](#); [Chiu 2008](#); [Chinchai 2010](#)). In four trials ([Evans 1988](#); [Rodgers 1999](#); [Johnson 2000](#); [Larson 2005](#)) the intervention consisted of a programme of lectures providing information about stroke and services available and an opportunity to ask questions. In addition to this, the four-week course evaluated by [Johnson 2000](#) emphasised the importance of self-esteem and coping strategies. Participants in the trial by [Larson 2005](#) were also able to contact the stroke specialist nurse between sessions for extra information and support. Five studies ([Frank 2000](#); [Kalra 2004](#); [Smith 2004](#); [Ellis 2005](#); [Draper](#)

[2007](#)) evaluated a multi-component intervention. Carers in [Kalra 2004](#) received instruction on a range of topics plus hands-on training. In [Frank 2000](#) the intervention consisted of a recovery plan, an interactive workbook and a weekly phone call from the researcher. In [Draper 2007](#) the programme for carers of aphasic patients included communication strategies, relaxation and stress management. Patients and carers in [Smith 2004](#) were provided with an information manual supported by fortnightly pre-arranged review meetings with their multidisciplinary team. In [Ellis 2005](#), the intervention group patients received a monthly review by a stroke nurse specialist, specially selected relevant written information, and personalised records detailing their individual risk factors and recommended risk factor targets. In [Johnston 2007](#), participants received a workbook which provided information about stroke, task material such as goal setting and an audio relaxation tape. In [Chiu 2008](#), the intervention consisted of information delivered by a pharmacist over a course of six sessions. In [Chinchai 2010](#), the intervention consisted of lectures delivered to carers with weekly follow-up reinforcement at home by health service volunteers. Further details of the interventions are provided in the [Characteristics of included studies](#) table.

Timing

The intervention was implemented prior to discharge from hospital in nine trials ([Lomer 1987](#); [Evans 1988](#); [Banet 1997](#); [Rodgers 1999](#); [Kalra 2004](#); [Smith 2004](#); [Hoffmann 2007](#); [Lowe 2007](#); [O'Connell 2009](#)); within three weeks of discharge ([Johnston 2007](#)) and one month after stroke, or at discharge, which ever was sooner in one trial ([Mant 1998](#)). In the remaining trials the intervention was implemented at varying times post-discharge: soon after discharge ([Pain 1990](#); [Downes 1993](#)); within three months of stroke ([Ellis 2005](#); [Maasland 2007](#)); within 12 months of stroke ([Draper 2007](#)); after 12 months since stroke ([Chiu 2008](#)); six months to three years after stroke ([Johnson 2000](#)); within 18 months of stroke ([Chinchai 2010](#)); within two years of stroke ([Frank 2000](#)), and a mean of 76 days after stroke onset ([Larson 2005](#)).

Outcomes measured

The studies measured a range of outcomes. Details of these are provided in the '[Characteristics of included studies](#)' table.

Assessment of knowledge

Ten trials evaluated patient or carer knowledge or both. All used different questionnaires, the majority of which had been specifically developed for the study. The questionnaire used by [Evans 1988](#) had been validated (Stroke Care Information Test, range 0 to 36) ([Evans 1985](#)). The 26-item knowledge of stroke scale used by [Rodgers 1999](#) and the 17-item knowledge of stroke and services questionnaire used by [Smith 2004](#) were based on instruments used in other studies ([Wellwood 1994](#); [Drummond 1996](#); [Mant 1998](#)), and the content of the specific educational programme under evaluation. In the study by [Hoffmann 2007](#), the 25-item knowledge of stroke questionnaire developed for the study was based partly on a previously validated measure ([Sullivan 2004](#)). The content validity and test-retest reliability of this instrument were assessed prior to the commencement of the study. The questionnaire used by [Lowe 2007](#) was developed from professionals' ideas of what patients should be aware of concerning secondary prevention of stroke and was piloted with 58 stroke patients. In [Maasland 2007](#) the questionnaire was developed and validated in 42 partners of

patients with TIA. None of the questionnaires in the remaining three studies (Lomer 1987; Pain 1990; Mant 1998) had been validated.

Excluded studies

We excluded 51 studies because the information/education was part of a multiple component, complex rehabilitation intervention (Linn 1979; Christie 1984; Printz-Feddersen 1990; Friedland 1992; Forster 1996; Dennis 1997; Goldberg 1997; Hochstenbach 1999; McKinney 1999; Napolitan 1999; Chang 2000; Rimmer 2000; Andersen 2002; Grant 2002; Nour 2002; Clark 2003; Hartke 2003; Leathley 2003; Boter 2004; Glass 2004; Harari 2004; Burton 2005; Tilling 2005; Claiborne 2006; Grasel 2006; Harwood 2006; Nir 2006; Boysen 2007; Desrosiers 2007; Ertel 2007; Habibzadeh 2007; Kendall 2007; Pierce 2007; Bakas 2008; Redfern 2008; Shyu 2008; Allen 2009; Battersby 2009; Chaipayat 2009; Sahebalzamani 2009; Winkens 2009; Gillham 2010; Harrington 2010; Mackay-Lyons 2010; Bacchini 2011; Chang 2011; Cheng 2011; Chumbler 2011; Clarke 2011; Holzemer 2011; Nguyen 2011), nine studies did not include a random allocation procedure (Evans 1984; Folden 1993; Morrison 1998; Ayana 2000; van den Heuvel 2000; Sit 2007; Huijbregts 2009; Oupra 2010; Brier 2011), we excluded three trials because information provision was not the evaluated intervention (Towle 1989; Mant 2000; Lincoln 2003), three trials included participants with conditions other than stroke and the data for stroke were not available separately (Sanguinetti 1987; Dongbo 2003; Brotons 2007), three trials included motivational interviewing (Green 2006; Adie 2010; Byers 2010) and four lacked a suitable control (Lorenz 1992; Skidmore 2008; Jones 2009; Neubert 2011).

Ongoing studies

Ten studies of potential relevance to this review are ongoing (Damush 2006; Boden-Albala 2007; Shaughnessy 2007; Young 2007; Rochette 2008; Dromerick 2008; Graven 2008; Hackett 2008; Hoffmann 2009; O'Carroll 2010).

Studies awaiting assessment

There are 14 trials currently awaiting assessment (Bonita 1995; Jian 1998; Heier 2002; Andrea 2003; Choi 2006; Tuncay 2006; Ostwald 2007; Eames 2008; Piano 2010; Bodin 2011; Cameron 2011; Kim 2011; Sun 2011; Aben 2012). We are awaiting further information from authors.

Risk of bias in included studies

Method of analyses

Twelve studies reported that an intention-to-treat analysis had been conducted (Pain 1990; Banet 1997; Mant 1998; Rodgers 1999; Johnson 2000; Kalra 2004; Smith 2004; Ellis 2005; Hoffmann 2007; Johnston 2007; Lowe 2007; Maasland 2007).

Allocation

Allocation was concealed in nine trials (Mant 1998; Rodgers 1999; Kalra 2004; Smith 2004; Ellis 2005; Hoffmann 2007; Lowe 2007; Maasland 2007; O'Connell 2009). Larson 2005 reported that the sequence could not be predicted but the method of allocation concealment was not reported. Allocation by random number sequence was reported in one study (Downes 1993). However, the method was not described. Johnson 2000 used a matched pair design with one member of each pair randomly assigned (unconcealed randomisation) to either the treatment or control group. The method of random sequence generation was unclear

or not reported in 11 trials (Lomer 1987; Pain 1990; Banet 1997; Frank 2000; Smith 2004; Larson 2005; Draper 2007; Johnston 2007; Lowe 2007; Chiu 2008; Chinchai 2010). One study reported the use of minimisation (Evans 1988). Ellis 2005 reported the use of a computer-generated random sequence procedure. However, they reported that three patients were entered twice in to the treatment group in error. Further details of allocation concealment and methods of randomisation are provided in the 'Risk of bias' tables.

Blinding

Blinding of both participants and personnel was not a feature in any of the trials or blinding was unclear. Blinding of outcome assessors was reported in 14 trials (Evans 1988; Pain 1990; Downes 1993; Mant 1998; Rodgers 1999; Kalra 2004; Smith 2004; Ellis 2005; Hoffmann 2007; Johnston 2007; Lowe 2007; Maasland 2007; O'Connell 2009; Chinchai 2010), not described in five (Lomer 1987; Banet 1997; Larson 2005; Draper 2007; Chiu 2008) and not undertaken in two (Frank 2000; Johnson 2000). Further details of blinding are provided in the 'Risk of bias' tables.

Incomplete outcome data

The studies ranged in sample size from 36 (Pain 1990) to 300 (Kalra 2004). Losses to follow-up ranged from zero (Lomer 1987; Johnson 2000; Chinchai 2010) to more than 20% (Downes 1993; Mant 1998; Rodgers 1999; Smith 2004; O'Connell 2009). A sample size calculation was reported for nine trials (Downes 1993; Rodgers 1999; Kalra 2004; Smith 2004; Ellis 2005; Draper 2007; Hoffmann 2007; Maasland 2007; O'Connell 2009). Of these, Downes 1993 reported final follow-up results for 62 couples rather than the estimated 165, and Draper 2007 recruited only 39 of the 60 caregivers required. Rodgers 1999 recruited the required number of patients and carers in each group but a larger than anticipated number of patients were unable to complete the main outcome measure (Short Form-36) leading to a short fall in the number of patients required to meet the original power calculation (73%, 117 patients of 160). There was also a short fall in the number of carers at final follow-up (106 of 216). In the O'Connell 2009 trial, a combination of recruitment and retention problems and non-use of the intervention resulted in the trial being terminated prior to completion. Sample size was small in a number of trials, particularly: Pain 1990 (N = 36); Banet 1997 (N = 52); Frank 2000 (N = 41); Johnson 2000 (N = 41); and Draper 2007 (N = 39). Further details of attrition bias are provided in the 'Risk of bias' tables.

Selective reporting

Study protocols were not obtained for any of the studies. As a result, it is unclear if selective reporting contributed to bias in the majority of studies. Further details of selective reporting bias are provided in the 'Risk of bias' tables.

Other potential sources of bias

In the trial undertaken by Rodgers 1999, only 51 patients (42%) of those randomised attended three or more out of the six outpatient sessions provided. In Draper 2007, collection of baseline data occurred after randomisation (although participants were still blinded at that point). In O'Connell 2009, the trial was terminated early as it was reported that numerous participants could not remember receiving the information (a sample size of 240 was the

initial target, however, the trial was stopped when 66 participants were recruited).

Effects of interventions

Results are reported separately for patients and carers. Resource outcomes are also presented separately. Meta-analyses have been undertaken for the domains of knowledge, emotional outcome, death, and for selected satisfaction questions. For other outcomes we have presented a narrative summary stratified by subgroup, and a summary of the data are provided in the 'Data and analyses' section.

Patient outcomes

Knowledge

Seven trials (Lomer 1987; Mant 1998; Rodgers 1999; Smith 2004; Hoffmann 2007; Lowe 2007; Maasland 2007) evaluated the effect of a passive or active intervention on knowledge. All had used different questionnaires.

Patient knowledge

Data were available for 536 of 770 participants from six trials (Mant 1998; Rodgers 1999; Smith 2004; Hoffmann 2007; Lowe 2007; Maasland 2007). There was a statistically significant effect on patient knowledge in favour of the intervention (SMD 0.29, 95% CI 0.12 to 0.46, $P < 0.001$) (Analysis 1.1).

Suitable data were not available for one trial (Lomer 1987). Patients followed up at one week knew significantly more about the aetiology of stroke and the treatment they were receiving than the controls ($P < 0.05$) but not about the specific prognosis or help and benefits available. This was a small trial, methods of randomisation and outcome assessment are unclear, and comparability of treatment groups is not reported. The results may therefore be subject to bias.

Subgroup analysis

Data were available from four passive information and two active information trials. There was no significant difference in the magnitude of effect between passive and active information (passive: SMD 0.26, 95% CI 0.04 to 0.48, active: SMD 0.34, 95% CI 0.07 to 0.61, test for subgroup differences $P = 0.65$) (Analysis 1.1).

Emotional outcomes

We performed meta-analyses for the outcomes of patient anxiety and patient depression using both dichotomous and continuous data. For each outcome we report the results of both meta-analyses. A narrative summary is presented for other outcomes.

Anxiety

The majority of trials that evaluated patient anxiety used the anxiety subscale of the Hospital Anxiety and Depression Scale. We converted scale data to dichotomised data using an anxiety subscale cut-off score of 10/11 (Zigmond 1983). Johnston 2007 reported data from the anxiety sub-scale of the Hospital Anxiety and Depression Scale at baseline only and a total anxiety and depression score post-intervention.

Patient emotional outcome: anxiety (dichotomised data)

Dichotomous data were available for 681 of 975 participants from six trials (Downes 1993; Mant 1998; Rodgers 1999; Kalra 2004; Smith

2004; Hoffmann 2007). The pooled result for all trials showed no significant difference in the number of cases of anxiety between the intervention and control groups (OR 0.89, 95% CI 0.57 to 1.38, $P = 0.60$) (Analysis 1.2).

Patient emotional outcome: anxiety (continuous data)

Continuous data were available for 720 of 1016 participants from seven trials (Downes 1993; Mant 1998; Rodgers 1999; Frank 2000; Kalra 2004; Smith 2004; Hoffmann 2007). The pooled result for all trials showed no significant difference in anxiety scores between the intervention and the control groups (MD -0.34, 95% CI -1.17 to 0.50, $P = 0.43$) (Analysis 1.3). Johnston 2007 was not included in the meta-analysis as we were unable to obtain suitable data. However, they reported no significant difference between intervention and control at baseline ($P > 0.05$) and no significant effects post-intervention (data and P value not reported).

Subgroup analysis

As there was no significant overall effect on anxiety, the following subgroup analyses may be unreliable.

1. Dichotomous data were available from three passive and three active information trials. The effect on anxiety was not significant in either subgroup ($P > 0.05$). However, there was a significant difference between active information and passive information on the number of cases of patient anxiety (passive: OR 1.64, 95% CI 0.80 to 3.37; active: OR 0.61 95% CI 0.35 to 1.07, test for subgroup differences $P = 0.03$). There was a trend towards an increase in anxiety from the passive information and a decrease from the active information.
2. Continuous data were available from three passive and four active information trials. The effect on anxiety was significant for the active information subgroup ($P = 0.002$) and not for the passive information subgroup ($P = 0.21$). There was a significant difference between active information and passive information on patient anxiety scores (passive: MD 0.67, 95% CI -0.37 to 1.71; active: MD -0.98 95% CI -1.59 to -0.36, test for subgroup differences $P = 0.008$). There was a trend towards an increase in anxiety from the passive information.

Depression

Twelve trials evaluated the effect of passive or active information on patient depression. Depression was measured using the depression subscale of the Hospital Anxiety and Depression Scale in eight trials (Downes 1993; Mant 1998; Rodgers 1999; Frank 2000; Kalra 2004; Smith 2004; Hoffmann 2007); Johnston 2007 reported the depression sub-scale of the Hospital Anxiety and Depression Scale at baseline and a total score post intervention. Other measures included the Geriatric Depression Scale (short form) (Sheikh 1986) by (Ellis 2005); the Beck Depression Inventory (Gallagher 1982) by Johnson 2000, the Yale single question (Mahoney 1994) by Lowe 2007 and the emotions subscale of the Stroke Impact Scale (Duncan 1999) by O'Connell 2009. Scale data were converted to dichotomous data using the recommended cut-off scores for each outcome measure (hospital anxiety and depression scale depression sub-scale cut-off score of 10/11 and a Geriatric Depression Scale score > 10).

Patient emotional outcome: depression (dichotomised data)

Dichotomous data were available for 956 of 1280 participants from eight trials (Downes 1993; Mant 1998; Rodgers 1999; Kalra 2004;

Smith 2004; Ellis 2005; Hoffmann 2007; Lowe 2007). The pooled result for all trials showed no significant difference in the number of cases of depression between the intervention and control groups (OR 0.90, 95% CI 0.61 to 1.32, $P = 0.59$) (Analysis 1.4).

Patient emotional outcome: depression (continuous data)

Continuous data (Hospital Anxiety and Depression Scale) were available for 720 of 1016 participants from seven trials (Downes 1993; Mant 1998; Rodgers 1999; Frank 2000; Kalra 2004; Smith 2004; Hoffmann 2007). There was a significant effect on depression scores in favour of the intervention (MD -0.52, 95% CI -0.93 to -0.10, $P = 0.01$) (Analysis 1.5).

Two trials were not included in the meta-analysis as we were unable to obtain suitable data (Johnson 2000; Johnston 2007). Johnson 2000 reported no significant difference between the two groups at baseline but when all patients were reassessed one week after completion of the intervention phase (a four-week education course), there was a significant difference in the mean depression scores measured by the Beck Depression Inventory (possible score range 0 to 63) (baseline: treatment group 12.52, control 12.94, $F = 1.36$, $P < 0.53$; follow-up: treatment group 8.5, control 12.61, $F = 2.79$, $P < 0.04$). Johnston 2007 reported no significant difference between the intervention and the control at baseline ($P > 0.05$) and no significant effect post intervention (data and P value not reported).

Subgroup analyses

The following subgroup analyses for depression (dichotomous data) may be unreliable as there was no overall net effect.

1. Dichotomous data were available from four passive and four active information trials. The effect on depression was not significant in either subgroup ($P > 0.05$). However, there was a significant difference between active information and passive information on the number of cases of patient depression (passive: OR 1.57, 95% CI 0.85 to 2.93; active: OR 0.63, 95% CI 0.38 to 1.03, test for subgroup differences $P = 0.02$), with a trend in favour of active information.
2. Continuous data were available from three passive information and four active information trials. The effect on depression was significant in the active information subgroup ($P = 0.002$) and not in the passive information subgroup ($P = 0.44$). There was a significant difference between active information and passive information on patient depression scores (passive: MD 0.39, 95% CI -0.61 to 1.38; active: MD -0.71, 95% CI -1.16 to -0.25, test for subgroup differences $P = 0.05$).

Other emotional outcomes

An active information study (Johnson 2000) evaluated hope and hopelessness (Herth Hope Scale, score range 0 to 90) (Farran 1995) and coping (Ways of Coping-Cardiovascular Accident Scale, score range 0 to 93, specifically developed for the study). There were no differences between the two groups at baseline for either outcome. At one week after completion of the intervention phase (a four-week education course), there was a significant difference between the two groups in the mean hope scale scores (baseline: treatment group 68.89, control 69.2, $P < 0.42$; follow-up: treatment group 73.68, control 66.33, $P < 0.001$). There was no significant difference in the coping scores.

A further active information study (Johnston 2007) evaluated perceived control over recovery utilising the Recovery Locus of Control Scale (Partridge 1989). Scores from nine items on a five-point scale (strongly agree to strongly disagree) are combined such that higher scores indicate greater belief in personal control. A confidence in recovery scale was also administered (Lewin 1992). This scale measured patients' confidence in recovery from 0 (not at all confident) to 10 (totally confident). There was no significant difference ($P > 0.05$) between the intervention and the control for perceived control over recovery. There was a significant group by time interaction effect for patients' confidence in recovery, $F(1, 197) = 10.67$, $P = 0.001$. Confidence in recovery declined over time for control group patients but remained relatively stable for patients in the intervention group.

Activities of daily living

Passive information studies

There is no evidence of an effect of passive information on activities of daily living. There were no significant differences between the intervention and control groups in any of the four trials that evaluated this outcome (Pain 1990; Banet 1997; Mant 1998; O'Connell 2009).

Active information studies

There is no evidence of an effect of active information on activities of daily living. There were no significant differences between the intervention and control groups in any of the four trials that evaluated this outcome (Kalra 2004; Smith 2004; Draper 2007; Johnston 2007).

Participation

Passive information studies

There is no evidence of an effect of passive information on participation. There were no significant differences between the intervention and control groups in any of the three trials that evaluated this outcome (Mant 1998; Lowe 2007; Maasland 2007).

Active information studies

There is no evidence of an effect of active information on participation. There were no significant differences between the intervention and control groups in any of the trials that evaluated this outcome (Rodgers 1999; Kalra 2004; Smith 2004; Draper 2007).

Social activities

Passive information studies

There is no evidence of an effect of passive information on social activities. The one trial that evaluated this outcome (Pain 1990) reported no significant difference in social activities between the intervention and control groups as measured by the Frenchay activities index (Holbrook 1983).

Active information studies

There is no evidence of an effect of active information on social activities. The two trials that evaluated this outcome (Rodgers 1999; Smith 2004) reported no significant differences in social activities between the intervention and control groups as measured by the Nottingham extended activities of daily living (Nouri 1987) or the Frenchay activities index (Holbrook 1983) respectively.

Perceived health status and quality of life

Passive information studies

There is no evidence of an effect of passive information on patient health status or quality of life (Dartmouth COOP Charts) (Rowan 1994) in the two trials that measured this outcome (Mant 1998; Hoffmann 2007).

Active information studies

Four trials (Rodgers 1999; Frank 2000; Kalra 2004; Ellis 2005) evaluated this outcome. Kalra 2004 reported significantly improved quality in life as measured by the EuroQol visual analogue scale (EuroQol Group 1990) at both three and 12 months in patients whose caregivers had received training (intervention) compared with those who had received conventional care (control) (median score (range) at three months: intervention 60 (42 to 70), control 50 (40 to 90), $P = 0.019$; median score (range) at 12 months: intervention 65 (55 to 80), control 60 (41 to 80), $P = 0.009$). Three trials (Rodgers 1999; Frank 2000; Ellis 2005) found no significant difference between the intervention and control groups as measured by the MOS 36-item short-form health survey (SF36) (Ware 1992), the Functional Limitations Profile (Patrick 1989) or the EuroQol (EuroQol Group 1990) respectively. Chinchai 2010 investigated quality of life with the WHO Quality of Life Measure (WHOQOL-BRIEF THAI) (Sakthong 2007). There were significant within group differences ($P < 0.05$) in the intervention group for the physical, psychological and environmental categories. No significant within-group differences ($P > 0.05$) resulted in the control group. Between-group differences were reported pre-intervention only ($P > 0.05$).

Satisfaction with care and information received

Eight trials (Mant 1998; Rodgers 1999; Smith 2004; Ellis 2005; Hoffmann 2007; Johnston 2007; Lowe 2007; O'Connell 2009) evaluated patient satisfaction. Of these, four trials (Mant 1998; Rodgers 1999; Smith 2004; Ellis 2005) measured patient satisfaction using the Pound scale (Pound 1994) or a modified version of that scale. Additionally, the bespoke questionnaire used in the trial by Lowe 2007 included some common items. Meta-analysis was performed for two questions that were considered to be most relevant to the review: (1) satisfaction with information about the causes and nature of stroke; and (2) satisfaction with information about allowances and services. Three trials did not contribute data to the meta-analysis (Hoffmann 2007; Johnston 2007; O'Connell 2009). Hoffmann 2007 used a bespoke questionnaire, Johnston 2007 assessed satisfaction with treatment and advice using a 0 to 10 scale applied in a previous study (Morrison 2000). O'Connell 2009 evaluated whether participants in the intervention group recalled receiving and reading the information and taking action as a result of the information.

Patient satisfaction with information about causes and nature of the stroke

Data were available for 541 of 772 participants from five trials (Mant 1998; Rodgers 1999; Smith 2004; Ellis 2005; Lowe 2007). There was a significant difference in favour of the intervention in satisfaction with information about the causes and nature of stroke (OR 2.07, 95% CI 1.33 to 3.23, $P = 0.001$) (Analysis 1.9).

Patient satisfaction with information about allowances and services

Data were available for 452 of 672 participants from four trials (Mant 1998; Rodgers 1999; Smith 2004; Ellis 2005). There was no significant difference in satisfaction with information about allowances and services (OR 1.18, 95% CI 0.76 to 1.83, $P = 0.46$) (Analysis 1.10).

Subgroup analyses

Satisfaction with information about the causes and nature of the stroke

Data were available for two passive information and three active information trials. There was no significant difference in the magnitude of effect of passive compared to active information (passive: OR 1.86, 95% CI 0.81 to 4.27; active: OR 2.16, 95% CI 1.28 to 3.67, test for subgroup differences $P > 0.2$).

Satisfaction with information about allowances and services

There were insufficient data to perform a subgroup analysis.

Service use

Passive information studies

There is no evidence of an effect of passive information on service use in the one study (Mant 1998) that evaluated this outcome.

Active information studies

There is no evidence of an effect of active information on service use. The four trials that measured this outcome (Evans 1988; Rodgers 1999; Kalra 2004; Smith 2004) reported that there was no significant difference in service use between the intervention and control groups.

Modification of health-related behaviours or risk reduction

Passive information studies

There is no evidence of an effect of passive information on the modification of health behaviours or risk reduction. Two trials (Banet 1997; Lowe 2007) evaluated this outcome. One trial (Banet 1997) reported no statistically significant difference in scores for diet or medication between the group who received their medical records and the group that received information leaflets only, although actual results were not reported. In the other study (Lowe 2007) there were no statistically significant differences in blood pressure between the intervention group and control groups. In Maasland 2007, those who regularly used tobacco or alcohol reduced these behaviours more in the intervention group, but differences were not significant. There was a decrease in systolic and diastolic blood pressure in the intervention and control group but no significant difference between the groups. Patients in neither group reduced their weight. Serum cholesterol dropped significantly in both the intervention and the control group with no differences between the groups.

Active information studies

Three trials evaluated this outcome (Rodgers 1999; Ellis 2005; Chiu 2008). There is limited evidence of an effect of active information on the modifications of health behaviours or risk reduction from one study. In Chiu 2008, there was a statistically significant difference ($P < 0.001$) between the intervention and the control group for satisfactory management of blood pressure. However, there was insufficient information reported to determine the effectiveness

of the blinding of patients, personnel or outcomes assessment and if allocation concealment was undertaken. There was no significant difference for the management of glucose or lipids. Two trials found no significant difference between the intervention and the control group. In [Ellis 2005](#), they reported that their initial (planned) analysis appeared to demonstrate a statistically significant reduction in systolic blood pressure in the intervention group compared with the control group (P value not reported). However, when the analysis was repeated with adjustment for baseline blood pressure the difference was not significant (P = 0.126). There were no statistically significant changes in other major modifiable risk factors: systolic and diastolic blood pressure; reported smoking rate; cholesterol; random blood glucose; or HbA1c. In the other trial ([Rodgers 1999](#)) there was no significant difference in the numbers of patients who stopped smoking after the stroke (intervention 9/25, control 3/17, P = 0.44).

Death

Mortality data were available for 1553 participants from nine trials ([Evans 1988](#); [Mant 1998](#); [Rodgers 1999](#); [Kalra 2004](#); [Smith 2004](#); [Ellis 2005](#); [Hoffmann 2007](#); [Lowe 2007](#); [Johnston 2007](#)). There was no significant difference in mortality between the intervention and control groups (OR 0.86 95% CI 0.59 to 1.25, P = 0.43) ([Analysis 1.13](#)).

Subgroup analysis

Data were available from three passive information and six active information trials. There was no significant difference in the magnitude of effect of passive information compared with active information (passive: OR 0.80, 95% CI 0.34 to 1.86; active: OR 0.88, 95% CI 0.58 to 1.33, test for subgroup differences P > 0.9).

Carer outcomes

Knowledge

Six trials ([Lomer 1987](#); [Evans 1988](#); [Pain 1990](#); [Mant 1998](#); [Rodgers 1999](#); [Smith 2004](#)) evaluated the effect of a passive information or active information intervention on carer knowledge.

Carer knowledge

Data were available for 336 of 469 participants from four trials ([Evans 1988](#); [Mant 1998](#); [Rodgers 1999](#); [Smith 2004](#)). There was a significant difference in carer knowledge between the intervention and control groups in favour of the intervention (SMD 0.74, 95% CI 0.06 to 1.43, P = 0.03) ([Analysis 1.14](#)).

Two small trials did not contribute data to the meta-analysis ([Lomer 1987](#); [Pain 1990](#)); [Lomer 1987](#) found no significant difference in carer knowledge of stroke and no difference in the level of knowledge about the specific prognosis or help and benefits available. [Pain 1990](#) reported that individualised information enhanced the carer's knowledge of how therapists had instructed the patient, although statistical significance was not reached.

Subgroup analysis

There were insufficient data to perform a sub-group analysis.

Emotional outcomes

We conducted a meta-analysis for the outcome of carer stress. As a variety of outcome measures were used to measure stress we only used dichotomous data in the analysis. A narrative summary

is provided for the carer emotional outcomes of psychological distress, depression and burden.

Psychological distress

Psychological distress in caregivers was measured by [Downes 1993](#), [Kalra 2004](#) and [Johnston 2007](#) using the Hospital Anxiety and Depression Scale ([Zigmond 1983](#)). [Rodgers 1999](#) and [Smith 2004](#) used the General Health Questionnaire-30 or the General Health Questionnaire-28 ([Goldberg 1979](#)). we converted scale data to dichotomous data using the recommended cut-off scores of 10/11 for the Hospital Anxiety and Depression Scale and 4/5 for the General Health Questionnaire ([Goldberg 1979](#); [Zigmond 1983](#)).

Suitable data were not available for [Draper 2007](#) or [Johnston 2007](#). [Draper 2007](#) reported no significant difference in carer stress scores at final follow-up (three months). [Johnston 2007](#) reported baseline stress data for carers utilising the anxiety sub-scale of the Hospital Anxiety and Depression Scale. Mean (SD): Intervention 7.64 (4.89), control 7.08 (4.01) and no significant effect of group by time interaction on total Hospital Anxiety and Depression Scale score.

Carer emotional outcome: Psychological distress

Dichotomous data were available for 498 of 643 participants from four trials ([Downes 1993](#); [Rodgers 1999](#); [Kalra 2004](#); [Smith 2004](#)). There was no significant difference in carer stress between the intervention and the control group (OR 1.13, 95% CI 0.65 to 1.97, P = 0.65) ([Analysis 1.16](#)).

Subgroup analysis

There were insufficient data to perform a subgroup analysis.

Depression

Passive information studies

In the [Downes 1993](#) trial, there was no significant difference in depression as measured by the Hospital Anxiety and Depression Scale between carers in the intervention group and the control group (mean depression score at six months (SD): intervention 5.8 (5.2), control 5.1 (3.2). [Johnston 2007](#) reported baseline data for depression of carers, measured by the depression subscale of the Hospital Anxiety and Depression Scale. Mean (SD): intervention 5.7 (4.3), control 4.8 (3.9) and reported no significant effect of group by time interaction on total Hospital Anxiety and Depression Scale score.

Active information studies

One trial ([Kalra 2004](#)) evaluated this outcome. Carers in the intervention group were significantly less depressed as measured by the Hospital Anxiety and Depression Scale than carers in the control group (median depression score at one year (IQR): intervention 2 (1 to 3), control 3 (2 to 5); P < 0.0001).

Burden

Passive information studies

In the one trial that evaluated this outcome ([Mant 1998](#)) there was no evidence of an effect of passive information on carer burden.

Active information studies

Two trials evaluated this outcome. In the study by [Kalra 2004](#) caregiver burden was significantly reduced in carers in the

intervention group compared with the control group at both three months and one year (median score at 12 months (IQR): intervention 32 (27 to 41), control 41 (36 to 50); $P = 0.0001$). In [Draper 2007](#) there were no significant differences in pre to post-treatment scores for either the intervention or wait control group.

Social Activities

Passive information studies

No trials evaluated this outcome.

Active information studies

There was no significant difference in carer social activities in the two trials ([Kalra 2004](#); [Draper 2007](#)) that evaluated this outcome.

Perceived health status and quality of life

Passive information studies

From the one study ([Mant 1998](#)) that evaluated this outcome there is no evidence of an effect of passive information on carer perceived health and quality of life.

Active information studies

Three trials measured this outcome ([Rodgers 1999](#); [Kalra 2004](#); [Larson 2005](#)). The largest of these ([Kalra 2004](#)) reported that carers in the intervention group had a higher quality of life as measured by the EuroQol visual analogue scale ([EuroQol Group 1990](#)) than controls at both three months and one year (median score (IQR) at one year: intervention 80 (70 to 90), control 70 (60 to 80); $P < 0.0001$). In [Rodgers 1999](#) there were no significant differences between carers in the intervention and the control groups on any of the domains of the SF36 except social functioning. This was significantly higher for carers in the control group (intervention group: mean 66.7 ± 29.8 SD; control group; mean 78.1 ± 27.4 SD; difference between means: 95% CI 11.3; 0.09 to 22.7; $P = 0.04$). This may be a chance finding due to multiple testing and the authors suggest that it should be interpreted with caution. In the trial by [Larson 2005](#), there were no statistically significant differences between the groups over time.

Satisfaction

Five trials ([Pain 1990](#); [Mant 1998](#); [Rodgers 1999](#); [Kalra 2004](#); [Smith 2004](#)) evaluated carer satisfaction. Of these, three trials ([Mant 1998](#); [Rodgers 1999](#); [Smith 2004](#)) measured carer satisfaction using the Pound scale ([Pound 1993](#)) or a modified version of this scale. Meta-analyses were performed for two questions considered to be of most relevance to the review: (1) satisfaction with information about recovery and rehabilitation; and (2) satisfaction with information about allowances and services. The remaining studies ([Pain 1990](#); [Kalra 2004](#)) both evaluated aspects of carer satisfaction using a bespoke questionnaire and are not included in the meta-analyses.

Carer satisfaction with information about recovery and rehabilitation

Data were available for 165 of 273 participants from two trials ([Rodgers 1999](#); [Smith 2004](#)). There was no significant difference in satisfaction with information about recovery and rehabilitation (OR 1.78, 95% CI 0.88 to 3.60, $P = 0.11$) ([Analysis 1.19](#)).

Carer satisfaction with information about allowances and services

Data were available for 214 of 322 participants from three trials ([Mant 1998](#); [Rodgers 1999](#); [Smith 2004](#)) for one question only: there was no significant difference in satisfaction between the groups (OR 1.30, 95% CI 0.71 to 2.37, $P = 0.39$) ([Analysis 1.20](#)).

Subgroup analysis

There were insufficient data to perform a subgroup analysis.

Resource outcomes

Cost to health and social services

Passive information studies

No trials evaluated this outcome.

Active information studies

Only one study ([Kalra 2004](#)) evaluated resource use. Total health and social care costs over one year for patients whose carers received training (intervention) were significantly lower (MD -£4043 (\$7249; EUR 6072), 95% CI to -£1595 to £6544). The cost differences were largely due to differences in length of hospital stay.

DISCUSSION

This review has explored the effectiveness of information provision for stroke patients and their carers as a process of care aimed at improving stroke recovery. In order to summarise effectively the available evidence on the core concept of information provision, we categorised the studies according to the nature of the intervention using two categories: passive and active. Our intention was to differentiate between interventions where participation was largely passive with no subsequent systematic follow-up or reinforcement procedure, and those in which there was active participation with a subsequent agreed plan for clarification and reinforcement. This classification was developed, agreed, and adopted prior to results synthesis.

We performed meta-analyses for the outcomes of knowledge, mood and death, and for selected satisfaction questions. We carried out a qualitative analysis for all other outcomes. We performed meta-analyses for the outcomes of patient anxiety and depression using both the reported mean and standard deviation of the Hospital Anxiety and Depression Scale scores and dichotomised data. An advantage of using dichotomised data is that it may provide more clinically meaningful results as it relates to 'cases' of depression and anxiety. However, it has been argued that collapsing ordinal stroke trial data in this way can result in a loss of discrimination between groups such that significant treatment effects are missed ([OAST 2007](#)).

It is worthy of comment that we undertook extensive searches for the update of this review, we reviewed over 20,000 titles, yet only four new studies are included. This reflects a lack of precision of the search strategies but may also be a reflection on research progress. We excluded 73 studies, many of which evaluated a complex intervention of which information provision and education are components. Information provision is acknowledged as a key component of stroke service delivery, provision of leaflets is not effective and it would seem that new multi-faceted ways of addressing the information needs of patients and their carers are being developed and evaluated.

Summary of main results

We have identified a total of 21 trials involving 2289 patients and 1290 carer participants. We found some statistically significant but clinically small benefits supporting the general concept that information provision after stroke might improve outcomes. There was evidence of benefit in relation to improved patient and carer knowledge, some aspects of patient-reported satisfaction and for depression scores in patients. Additionally, we found some evidence that interventions using active information provision may be more effective than passive information for the clinically important outcomes of patient depression and anxiety symptoms. However, as we saw no effect with the dichotomous endpoints of anxiety or depression, effects may be small. We found no evidence that information interventions are associated with improvements in activity limitation, participation or changes in service use.

Overall completeness and applicability of evidence

All included studies were relevant to the review question. There was extensive variation in the content and delivery format of the interventions. This appears to reflect the diversity of interventions provided within clinical practice. Whilst there were sufficient data to address the primary outcomes and the majority of secondary outcomes for this review, there were limited studies to address social activities in carers or resource outcomes. Current practice on information provision after stroke varies nationally and internationally. Our review identified studies from seven countries, thus drawing conclusions on overall applicability of findings internationally is limited.

Quality of the evidence

There was considerable variation in the interventions evaluated and the 21 included trials were of variable quality. Clearly concealed randomisation was achieved in only 10 trials (Mant 1998; Rodgers 1999; Kalra 2004; Smith 2004; Ellis 2005; Larson 2005; Hoffmann 2007; Lowe 2007; Maasland 2007; O'Connell 2009). The rate of attrition was over 20% in five trials (Downes 1993; Mant 1998; Rodgers 1999; Smith 2004; O'Connell 2009). In several trials the sample size was small: less than 75 participants in eight trials (Pain 1990; Downes 1993; Banet 1997; Frank 2000; Johnson 2000; Draper 2007; Maasland 2007; Chinchai 2010).

Our evaluation of the effect on passive or active information provision on the outcome of stroke knowledge was limited by a lack of a consistently-used measure. Knowledge of stroke was assessed in nine of the 21 studies reviewed (Lomer 1987; Evans 1988; Pain 1990; Mant 1998; Rodgers 1999; Smith 2004; Hoffmann 2007; Lowe 2007; Maasland 2007) but as each study had used a different questionnaire, combining the results in a meta-analysis was problematic. Our initial intention was to perform a meta-analysis using dichotomised data (knowledge improved or not improved). However, this was not feasible as in some trials knowledge was measured on one occasion only. We therefore combined the data using the SMD wherein the MDs in outcome between the groups being studied are standardised to account for differences in scoring methods. A disadvantage with this method is that interpretation of the clinical relevance of the treatment effect is difficult as estimated effect sizes serve only as a qualitative measure of the strength of evidence against the null hypothesis (de Beurs 1999). The results should therefore be treated with some caution. In addition, for the majority of the bespoke questionnaires used to

measure knowledge there was limited information available about the reliability of the questions they contained.

Potential biases in the review process

Our search strategy was comprehensive and as we were able to identify a number of unpublished studies, publication bias is unlikely. Study selection, data collection and analysis were undertaken by two people, with a third person or consensus meeting used to resolve differences. As a result we are confident of limited bias in the review process for this review.

Agreements and disagreements with other studies or reviews

The positive effects of information on knowledge and depression demonstrated in this review are supported by the findings of reviews of patient education interventions in other conditions. In a meta-analysis, Brown reported that diabetes education had a moderate to large effect on improving patient knowledge (Brown 1990). A systematic review of education for adults with rheumatoid arthritis showed a small effect on depression (Riemsma 2003). In accord with our review, an overview of systematic reviews of educational interventions for healthcare professionals reported that passive approaches were generally ineffective and unlikely to result in changes in professionals' behaviour, whereas educational approaches involving active learning were more likely to be effective (Grimshaw 2001). A systematic review of education programmes for patients with diabetic kidney disease found education programmes have beneficial effects on improving patients' knowledge of diabetes and some self-management behavioural changes (Li 2011). A meta-analysis of patient teaching strategies showed that the greatest effect size was associated with reinforcement, independent study, and the use of multiple strategies (Theis 1995).

Future direction

This review has demonstrated some positive effects of information provision on patient and carer knowledge, aspects of satisfaction and depression. However, the effects, although statistically significant, were clinically small and more effective information provision strategies after stroke need to be developed. The results of the review suggest that a strategy based on an active, rather than passive intervention approach should be adopted. This is perhaps unsurprising as stroke is a complex condition with wide-ranging effects and probably requires a more profound approach to promote recovery than can be achieved by the provision of passive information alone. The specific components of the active information provision (i.e. involving recipients, planned follow-up or reinforcement), which resulted in modest beneficial effects on some outcomes, requires further investigation. Future work should focus on the further development of a generalisable active information intervention that could be robustly evaluated in a large multicentre study.

AUTHORS' CONCLUSIONS

Implications for practice

There is evidence to support the routine provision of information to stroke patients and their families. Providing information has been shown to improve knowledge of stroke, increase some aspects of patient satisfaction, and reduce patient depression

scores. However, the reduction in depression score (as measured by the Hospital Anxiety and Depression Scale) was small and may not be clinically significant. There is currently no evidence that providing information is effective in improving other patient and carer outcomes. Although the best way to provide information is still not clear, the results of the review suggest that strategies that actively involve patients and carers and include planned follow-up for clarification and reinforcement should be used in routine practice.

Implications for research

Future work should focus on the further development of a generalisable intervention which could be robustly evaluated in a large multicentre study. The evaluation of interventions is currently limited by the lack of a widely recognised measure of stroke knowledge. Attention should be given to the design, development and evaluation of a stroke knowledge questionnaire. Consideration should be given to the most appropriate outcome domains for this type of intervention.

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* Indicates the major publication for the study

CHARACTERISTICS OF STUDIES

Characteristics of included studies [ordered by study ID]

Banet 1997

Methods	Patients who met all criteria and volunteered to participate were randomly assigned to treatment group; no further details given No stated blind outcome assessment 6 patients lost to follow-up; no report of differential losses between groups 6-month follow-up
Participants	St Louis, Mo, USA 58 first- time stroke patients: number allocated to intervention or control not given No details of age Sex: women N = 28 Inclusion criteria: aged 18 years or older, first-time stroke, medically stable, competent to give informed consent, ready for hospital discharge Exclusion criteria: aphasia or motor impairments that hindered ability to complete forms unless neurologist believed it did not interfere with giving consent and had a caregiver who could help complete forms, or could dictate answer to investigator N = 52 for final follow-up
Interventions	Treatment: copy of medical history, clinical resumes, notes on outpatient visits, x-ray, scan reports and pertinent laboratory results. Also received patient education packet containing leaflets on stroke

Information provision for stroke patients and their caregivers (Review)

Banet 1997 (Continued)

care, stroke team, tests and procedures, community resources, defining terms, facts about stroke, how stroke affects behaviour and recovering from stroke

Focus: patient

Setting: hospital

Administration: unclear who gave record

Encouraged to maintain records by incorporating updated information by taking them to all appointments with physicians and all trips during the study

1 contact, length unknown

Patients ready for discharge

Control: given patient education packet containing leaflets on stroke care, stroke team, tests and procedures, community resources, defining terms, facts about stroke, how stroke affects behaviour and recovering from stroke

Outcomes	(1) Disability and handicap (baseline and 6 months) (2) Intention to modify health-related behaviours and compliance (baseline and 6 months) Not included in the review: Global Outcome (baseline and 6 months)
Notes	Validity assessment: use of inappropriate statistical tests

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	The procedure for generating a random sequence was not reported
Allocation concealment (selection bias)	Unclear risk	Reported that patients were randomly assigned but method not described
Blinding of participants and personnel (performance bias) All outcomes	High risk	No report of blinding of participants or personnel but as no intervention provided for the control group, group assignment would have been apparent
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	It was not reported if outcome assessments were blinded
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	Quote: "One volunteer died, and five provided incomplete data. Thus data from 52 subjects was available for analysis." Although losses were relatively small, it was not reported which groups they were from
Selective reporting (reporting bias)	Unclear risk	Quote: "Subjects reported their intentions to modify health-related behaviours by completing the diet, smoking, and medication sub-scales of Miller's Health Intention Scale." Quote: "Because so few subjects smoked, this was not included as a variable in the analysis." Comment: note that this question was typically answered (i.e. data was not generally missing), but only 7 smoked at the time of their stroke

Banet 1997 (Continued)

Other bias	Low risk	No other obvious sources of bias
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Chinchai 2010

Methods	Cluster RCT No participants lost to follow-up
Participants	Chiang Mai, Thailand 60 stroke patients and their primary caregivers (N = 60) Patients: intervention N = 30; control N = 30 Caregivers: intervention N = 30; control N = 30 Age range of patients intervention (years): < 40 N = 9; 40 to 59 N = 8; 60 to 69 N = 9; 70 to 79 N = 7 Age range of patients control (years): < 40 N = 4; 40 to 59 N = 8; 60 to 69 N = 5; 70 to 79 N = 13 Sex of patients male: intervention 60%; control 53% Age range of carers intervention (years): < 40 N = 2; 40 to 59 N = 8; 60 to 69 N = 11; 70 to 79 N = 9 Age range of carers control (years): < 40 N = 5; 40 to 59 N = 12; 60 to 69 N = 6; 70 to 79 N = 7 Sex of carers male: intervention 47%; control 53% Inclusion criteria patient: discharged from hospital < 18 months, physical function recovery level 2 to 4 classified by Brunnstorm; communication (verbal, non-verbal), no complications (e.g. bedsores, pain, fever during data collection), willingness to participate in the study Inclusion criteria carer: primary caregiver (family member or relative), not previously attended the home health care and stroke rehabilitation programme, minimum 8 hours a day caring, willingness to participate in the study Exclusion criteria: not reported
Interventions	Intervention: an education programme for caregivers with follow-up reinforcement. Included lectures and active practice of activities of daily living and written information in guidebooks. Intervention started within 18 months of patient stroke. Carers attended a 1-day, 7-hour education session on 3 consecutive weeks and received weekly visits for reinforcement by health service volunteers Focus: patient and caregiver Setting: primary healthcare unit Administration: occupational therapists with a minimum of 2 years experience Control: usual care information from health stations located in the community

Outcomes	Patient outcomes: Quality of Life (7 days pre-intervention and 2 months post intervention)
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Notes	
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Risk of bias

Bias	Authors' judgement	Support for judgement
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Chinchai 2010 (Continued)

Random sequence generation (selection bias)	Unclear risk	The procedure for generating a random sequence was not reported
Allocation concealment (selection bias)	Unclear risk	Method of allocation concealment not reported
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	Although not specifically reported, control participants received usual care, therefore the (lack of) intervention could have been obvious
Blinding of outcome assessment (detection bias) All outcomes	Low risk	Research assistants blind to group assignment performed assessments
Incomplete outcome data (attrition bias) All outcomes	Low risk	No drop outs or exclusions
Selective reporting (reporting bias)	High risk	When describing the WHOQOL-BREF the authors report the individual items for overall health and overall QOL, as well as a total score (the summation of all items). However these were not presented in the results
Other bias	Low risk	No other obvious sources of bias

Chiu 2008

Methods	RCT by simple random sampling. Patients were stratified by age (over 65 or not) and sex 4 patients from the control group and 2 patients from the intervention group lost to follow-up
Participants	Kaohsiung, Taiwan 160 stroke patients (intervention N = 80, control N = 80) Mean age of patients: intervention 66 years; control 65 years Sex of patient male: 50% Inclusion criteria: stroke out-patients who had visited clinics regularly after stroke (> 12 months) Exclusion criteria: enrolled in other studies, terminal illness, no consent
Interventions	Intervention: consultation (drug effects, lifestyle modification, benefits of therapies, importance of compliance, verification of drug interaction and reminder of adverse events). Focus: patient Setting: unclear Administration: intervention delivered by pharmacist over 6 x 1-hour sessions over a 6-month period Control: no information reported
Outcomes	(1) Management of hypertension (2) Management of lipids

Chiu 2008 (Continued)

(3) Management of glucose

Notes

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Described as simple random sampling but method of sequence generation not reported
Allocation concealment (selection bias)	Unclear risk	No information reported
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	No information reported
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	No information reported
Incomplete outcome data (attrition bias) All outcomes	Low risk	Small number lost to follow-up (2 from intervention and 4 from the control)
Selective reporting (reporting bias)	Unclear risk	Study protocol not available so cannot assess reporting bias
Other bias	Low risk	No other obvious signs of bias

Downes 1993

Methods	Allocation by random number sequence; no other details given Blinded outcome assessment Number lost to follow-up unclear; no report of differential losses between groups 6-month follow-up
Participants	Birmingham, UK Stroke patients and carers (couples): number initially recruited to control and information groups unknown (105 couples recruited to the 3-group trial) Information provided for N = 18 control group, N = 22 information group who completed 6-month assessment Age of patient > 60 years: treatment 91%; control 89% Sex of patient male: treatment 55%; control 44% Inclusion criteria: stroke survivors living at home with their informal carers, recent stroke (not necessarily first) causing increase on modified Rankin Disability Scale and post-stroke Rankin score of 2 to 5 Exclusion criteria: none stated

Downes 1993 (Continued)

Interventions Treatment: information pack designed for study containing information about physical, cognitive and emotional effects of stroke, carer well being and local services

Focus: patient and carer

Setting: home

Administration: single visit by nurse counsellor who demonstrated how to access relevant information and answered questions. 1 x 1-hour visit at least 2 weeks after discharge but exact time unknown

Control: usual care, no intervention

Outcomes (1) Emotional outcome (baseline and 6 months)

Notes

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Quote: "they were allocated by a random number sequence generation." However, method not described.
Allocation concealment (selection bias)	Unclear risk	No information reported
Blinding of participants and personnel (performance bias) All outcomes	High risk	No evidence of blinding of participants or personnel
Blinding of outcome assessment (detection bias) All outcomes	Low risk	Assesment was carried out by a research assistant who was blind to group allocation
Incomplete outcome data (attrition bias) All outcomes	High risk	150 couples originally recruited in to the study but only 62 completed and were in the final analysis. Unclear how many from each group
Selective reporting (reporting bias)	Unclear risk	Study protocol not available so cannot assess reporting bias
Other bias	Low risk	Appears free from other sources of bias

Draper 2007

Methods Allocation by random selection of names by blinded investigator

Postal outcome assessment

8 carers lost to follow-up

Participants Sydney, Australia

39 carers of aphasic stroke patients recruited from rehabilitation services of 3 public hospitals: treatment N = 19; control N = 20

Completed final follow-up: N = 31

Draper 2007 (Continued)

Mean age carer: treatment 64 years; control 60 years

Mean age of patient: treatment 69 years; control 68 years

Sex of carer: not reported

Sex of patient: not reported

Interventions

Treatment: education programme covering the impact of stroke, managing the resulting life changes, communication strategies, relaxation and stress management, managing emotions, accessing community services and relapse prevention strategies. At the end of course the caregivers were encouraged to remain in contact as a self-help group

Focus: carer

Setting: held in outpatient area of hospital rehabilitation department

Administration: 4 x 1-weekly group session, each session 2 hours, numbers in each group varied from 6 to 11, sessions run by a speech pathologist and social worker, clinical psychologist included for 1 session

Control: usual care, wait-list control commenced the treatment after a delay of 3 months

Outcomes

Carer

Primary outcomes

- (1) Psychological distress (4 weeks and 3 months)
- (2) Caregiver burden (4 weeks and 3 months)
- (3) Communication (4 weeks and 3 months)

Secondary outcomes

- (1) Attitudes towards care-giving (4 weeks and 3 months)
- (2) Self-rated health (4 weeks and 3 months)
- (3) Social/recreational activities (baseline, 4 weeks and 3 months)
- (4) Social support (baseline, 4 weeks and 3 months)
- (5) Behaviour and mood disturbance

Patient

- (1) Level of dependency in personal care (baseline, 4 weeks and 3 months)

Notes Shortfall in recruitment: recruited 39/60 required

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Reported as random but specific method not reported
Allocation concealment (selection bias)	Unclear risk	Reported as concealed but specific method for concealment not reported
Blinding of participants and personnel (performance bias)	High risk	Quote: "Caregivers did not know which group they were in when the baseline measures were completed, however this blinding could not be subsequently maintained."

Draper 2007 (Continued)

All outcomes

Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	There was no external outcome assessor
Incomplete outcome data (attrition bias) All outcomes	High risk	Control group lost 40% of participants
Selective reporting (reporting bias)	High risk	Intimate Bonds Measure not reported in results
Other bias	Unclear risk	Baseline data collected after randomisation

Ellis 2005

Methods	<p>Random allocation using a computer-generated random sequence concealed in sequentially numbered opaque sealed envelopes</p> <p>Blinded outcome assessment</p> <p>Stated intention-to-treat analysis</p> <p>13 patients (6 treatment, 7 control) lost to follow-up</p> <p>5-month follow-up</p>
Participants	<p>Glasgow, UK</p> <p>205 patients at stroke clinic or geriatric day hospital: treatment N = 100; control N = 105; completed final follow-up N = 192</p> <p>Mean age of patient: treatment 64 years; control 66 years</p> <p>Sex of patient: male: treatment 54%, control 50%</p> <p>Inclusion criteria: clinical diagnosis of stroke, TIA or amaurosis fugax commencing in the previous 3 months; 1 or more risk factors from raised BP, history of concurrent smoking, high cholesterol, diabetes (regardless of their risk factor control)</p> <p>Exclusion criteria: patients with cognitive impairment (defined as AMT < 5 on screening)</p>
Interventions	<p>Treatment: monthly review with Stroke Nurse Specialist for 3 months at which individual given advice on lifestyle changes, the importance of medication compliance and relevance to secondary prevention</p> <p>Focus: patient</p> <p>Setting: outpatient consultation</p> <p>Administration: reviewed by Stroke Nurse Specialist in consultation lasting approximately 30 minutes. Lifestyle issues including diet, exercise or increased activity and medical services discussed in depth and tailored to the patient's circumstances and functional abilities. Verbal information backed up by written information selected by Stroke Nurse Specialist as relevant to the individual patient. Personalised patient-held records, detailing their risk factors and the recommended risk factor targets given to the patient and updated at each visit (considered a key part of intervention). Patients given opportunity to bring up participants as appropriate. If risk factor (e.g. BP) deemed to be at unacceptable level, patients encouraged to consult their General Practitioner with that information</p>

Ellis 2005 (Continued)

Control: usual care including generic risk factor advice from medical staff as well as the Stroke Nurse Specialist

Outcomes	Primary (1) Proportion of patients whose risk factors were 'on target ' Secondary (1) Survival (2) Perceived health status (3) Mood (4) Satisfaction with stroke services
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Notes

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	High risk	Quote: "eligible patients were randomly allocated to treatment or control groups using a computer-generated random sequence concealed in sequentially numbered opaque sealed envelopes." Quote: "Three patients were entered twice in error, each time to the treatment group. These subjects were analysed on their initial data only and subsequent data were excluded from the analysis." Comment: errors in sequence generation could have subverted randomisation
Allocation concealment (selection bias)	Low risk	Randomly allocated to treatment or control groups using a computer-generated random sequence concealed in sequentially numbered opaque sealed envelopes
Blinding of participants and personnel (performance bias) All outcomes	High risk	Single blinded trial with blinded assessment so presume unblinded participants or personnel
Blinding of outcome assessment (detection bias) All outcomes	Low risk	Quote: "Outcomes were recorded at 5 months by an independent blinded assessor."
Incomplete outcome data (attrition bias) All outcomes	Low risk	Low numbers lost to follow-up and similar across groups
Selective reporting (reporting bias)	Unclear risk	All outcomes specified in the methods were reported in the results. However, study protocol not available so cannot assess reporting bias
Other bias	Low risk	No other obvious sources of bias

Evans 1988

Methods	Allocation by method of Taves (minimisation)
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Evans 1988 (Continued)

	<p>Blinded outcome assessment</p> <p>13 patients and carers (6 treatment, 7 control) lost to follow-up</p> <p>6-month and 1-year follow-up</p>
Participants	<p>Seattle, WA, USA</p> <p>140 stroke patients and carers (majority couples) recruited: treatment N = 70; control N = 70; completed final follow-up: N = 127</p> <p>Mean age of patient: treatment 63 years; control 62 years</p> <p>Sex of patient male: treatment 95%; control 94%</p> <p>Inclusion criteria: all stroke patients on inpatient wards from any referring service, hospitalised primarily for stroke, living with primary caregiver</p> <p>Exclusion criteria: none stated</p>
Interventions	<p>Treatment: 2 classes: (1) lecture and video 'Living with stroke', followed specific outline of information developed by psychiatrists, included basic information about the consequences of stroke; (2) explanation of treatment unique to the family's situation and questions</p> <p>Focus: carer</p> <p>Setting: hospital</p> <p>Administration: occupational therapist (class 1), social worker (class 2). 2 x 1-hour classes during third week of stroke; second class within 3 working days of the first</p> <p>Control: routine care</p>
Outcomes	<p>(1) Knowledge of stroke (6 months and 1 year)</p> <p>(2) Family function (6 months and 1 year)</p> <p>(3) Patient adjustment (6 months and 1 year)</p> <p>(4) Use of social resources (6 months and 1 year)</p>

Notes

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Quote: "Patients were randomly assigned to conditions after minimizing the differences for variates known to predict stroke recovery: mood, self-care ability (Barthel Index), mental status, age, and location of the lesion. The method of Taves[14] was used."
Allocation concealment (selection bias)	Unclear risk	Method of allocation concealment not reported
Blinding of participants and personnel (performance bias) All outcomes	High risk	No information reported. However, as no alternative intervention for control groups, blinding of participants not possible
Blinding of outcome assessment (detection bias)	Unclear risk	No report of blinded assessment

Evans 1988 (Continued)

All outcomes

Incomplete outcome data (attrition bias) All outcomes	Low risk	Small numbers lost to follow-up with similar reasons reported
Selective reporting (reporting bias)	Unclear risk	Study protocol not available so cannot assess reporting bias
Other bias	Unclear risk	Imbalance in reported baseline conditions (marital status and number in household) may mean choice of minimisation factors was incomplete

Frank 2000

Methods	<p>Randomisation using independently prepared envelopes</p> <p>Outcome assessment not blinded</p> <p>2 patients (1 treatment, 1 control) lost to follow-up</p> <p>1 month follow-up</p>
Participants	<p>Fife, UK</p> <p>41 stroke patients: treatment N = 20; control N = 21; completed final follow-up: N = 39</p> <p>Mean age of patient: treatment 64 years; control 64 years</p> <p>Sex of patient: male: treatment 53%; control 50%</p> <p>Inclusion criteria: stroke within 24 months of recruitment, fluent in English, not aphasic, not cognitively impaired</p> <p>Exclusion criteria: none stated</p>
Interventions	<p>Treatment: workbook designed to increase perceptions of control by giving information, enhancing coping resources and rehearsing planning and problem-solving skills. Recovery plan developed with researcher. Weekly phone call (over 3-week period). First part of workbook dealt largely with information about stroke, causes, management, and recovery. Additional sections of relevance to the individual available (e.g. on diet, smoking). Second part introduced methods of coping and relaxation tape and instructions for use</p> <p>Focus: patient</p> <p>Setting: patients' home</p> <p>Administration: workbook introduced in 2 parts: part 1 introduced following baseline assessment; patients asked to work through the sections, answering quizzes and deciding which additional sections were relevant to them; part 2 introduced 1 week later along with relaxation tape and instructions for use. Requests for additional parts of the workbook met. A recovery plan consisting of a daily task with records made as joint exercise between researcher patient, and carer. Over next 3 weeks patient and carer worked independently on workbook and received weekly telephone call from researcher to enquire about progress and give opportunity to ask questions</p> <p>Control: wait control group received the workbook once the study was complete</p>
Outcomes	<p>(1) Functional limitations (1 month)</p> <p>(2) Mood (1 month)</p>

Frank 2000 (Continued)

(3) Perceived control (1 month)

Notes Validity assessment: No stated intention-to-treat analysis

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Method of randomisation not reported
Allocation concealment (selection bias)	Low risk	Used an enveloped prepared independently of the interviewer
Blinding of participants and personnel (performance bias) All outcomes	High risk	No mention of blinding; treatment group received a workbook and control group received nothing until end of trial – would have been obvious which group they were in
Blinding of outcome assessment (detection bias) All outcomes	High risk	The intervention and assessment were undertaken by the same individual
Incomplete outcome data (attrition bias) All outcomes	Low risk	2 of 41 lost to follow-up, 1 from each group, both unavailable
Selective reporting (reporting bias)	Unclear risk	All outcome measures specified in methods were reported. However, study protocol not available so cannot assess reporting bias
Other bias	Low risk	No other obvious sources of bias

Hoffmann 2007

Methods	Randomisation using predetermined computer-generated randomisation sequence Balanced block design where randomisation occurred in blocks of 4 Blinded outcome assessment Stated intention-to-treat analysis 5 patients (3 treatment, 2 control) lost to follow-up 3-month follow-up
Participants	Brisbane, Australia 138 stroke patients: treatment N = 69; control N = 69. Completed final follow-up N = 133 Mean age of patients: treatment 67 years; control 69 years Sex of patients male: treatment 64%; control 46% Inclusion criteria: diagnosed stroke or TIA, medically stable, reported English-proficiency level, corrected hearing and vision and communication status adequate to participate in an interview and complete assessment tasks, no reported or observable dementia, living within 50 km of the hospital

Hoffmann 2007 (Continued)

Exclusion criteria: none stated

Interventions	<p>Treatment: computer-generated tailored written information, customised according to patients' informational needs. 34 topics available covering such issues as: how stroke occurs, risk factors, understanding and managing the effects of stroke, reducing stroke risk, treatment and rehabilitation and managing after discharge</p> <p>Focus: stroke patients</p> <p>Setting: stroke unit</p> <p>Administration: within 1 day of baseline interview the research nurse completed the 'what you need to know about stroke' checklist with the patient. Further information given as needed about the scope and content in each of the available topics. Once the checklist completed, the research nurse entered topic selections, desired version of each topic (detailed, shortened) and desired font size into the database. Then generated and printed an individualised booklet and placed into a ring-binder folder. Patient name written on booklet and given to the patient</p> <p>Control: Within 1 day of the baseline interview, provided by research nurse with a copy of the Stroke Association of Queensland fact sheet</p>
Outcomes	<p>(1) Knowledge of stroke (3 months)</p> <p>(2) Mood</p> <p>(3) Self efficacy (3 months)</p> <p>(4) Perceived health status (3 months)</p> <p>(5) Use of and satisfaction with information</p>

Notes

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Quote: "...database randomly assigned the patient to either the intervention or control group."
Allocation concealment (selection bias)	Low risk	Quote: "One of the database tables contained a predetermined computer generated randomisation sequence, thus ensuring concealed allocation."
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	No report of blinding of participants and may not have been obvious to participants which group they were in as both received written information. However, remains unclear
Blinding of outcome assessment (detection bias) All outcomes	Low risk	Quote: "An outcome assessor who was blind to patients' group allocation, conducted baseline interviews while the patient was in hospital, and follow-up interviews 3 months after discharge."
Incomplete outcome data (attrition bias) All outcomes	Low risk	Low number of losses to follow-up and numbers balanced across groups, with similar reasons
Selective reporting (reporting bias)	Unclear risk	Study protocol not available so cannot assess reporting bias
Other bias	Low risk	No other obvious sources of bias

Johnson 2000

Methods	<p>Matched pairs design based on baseline scores on outcome measures, age, sex and side of stroke. Random assignment within each pair by tossing a coin</p> <p>Not blind outcome assessment</p> <p>All participants reassessed 1 week after intervention group completed a 4-week course</p> <p>No losses to follow-up</p>
Participants	<p>Minneapolis, USA</p> <p>*41 stroke patients identified from hospital-based register of stroke survivors</p> <p>Treatment N = 21; control N = 20. Completed final follow-up N = 41</p> <p>Mean age: treatment 64.2 years; control 63.9 years</p> <p>Sex of patient male: * treatment 38%; control 50%</p> <p>Inclusion criteria: > 18 years of age, English speaking, community dwelling, stroke 6 months to 3 years earlier, gave informed consent</p>
Interventions	<p>Treatment: 8 x 2-hour structured educational classes over a 4-week period. Content included facts on stroke, living with disability, exploring spiritual wellness</p> <p>Control group offered the intervention after the end of the evaluation</p>
Outcomes	<p>(1) Self-reported state of depression</p> <p>(2) Self-reported sense of hope</p> <p>(3) Self-reported ways of coping</p>
Notes	<p>Match pairs design then randomisation by toss of a coin, not concealed</p> <p>Unpaired participant assigned to the treatment group</p>

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Reported that one member of each pair was randomly assigned to either the treatment or control group but method not reported
Allocation concealment (selection bias)	Unclear risk	Method of allocation concealment not reported
Blinding of participants and personnel (performance bias) All outcomes	High risk	No report of blinding of participants and personnel. Control group received usual care (compared with structured education course) so may have been obvious they were not receiving an intervention
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	No report of blinded outcome assessment
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	Unclear if outcomes were reported for all participants

Johnson 2000 (Continued)

Selective reporting (reporting bias)	Unclear risk	Study protocol not available so cannot assess reporting bias
Other bias	Low risk	No other obvious sources of bias

Johnston 2007

Methods	<p>RCT. A statistician prepared 2 separate randomisations for patients with carers who also agreed to participate (carer-patient subgroup) and for carers partnered with a patient who could not participate because of cognitive and communication impairments (carer-only subgroup)</p> <p>Blinded outcome assessment</p> <p>Reported intention-to-treat analysis</p> <p>45 patients (29 intervention, 16 control) and 42 carers (total across intervention and control groups) lost to follow-up</p> <p>6-month follow-up</p>
Participants	<p>Dundee, Scotland</p> <p>203 acute stroke patients and 172 carers</p> <p>Patients: intervention N = 103; control N = 100</p> <p>Carers: intervention N = 82; control N = 90</p> <p>Mean age of patients: intervention 69 years; control 69 years</p> <p>Sex of patient male: intervention 61%; control 61%</p> <p>Mean age of carers: intervention 63 years; control 61 years</p> <p>Carer sex male: 35% (across intervention and control groups)</p> <p>Inclusion criteria patient: fluent in English; discharged from hospital following stroke. Carers identified by the patient as the person most involved in their care</p> <p>Exclusion criteria: not reported</p>
Interventions	<p>Intervention: post-discharge workbook intervention delivered by a workbook implementer over a 5-week period. The workbook provided information about stroke and recovery; guidance on coping skills; and self-management instruction. Task materials (e.g. goal setting), diary sheets and an audio relaxation cassette tape that described simple body relaxation and breathing exercises. Intervention included 2 home visits and 2 telephone contacts. Intervention started within 3 weeks (approximately) of hospital discharge</p> <p>Focus: patient and carer</p> <p>Setting: home</p> <p>Administration: work book implementer</p> <p>Control: usual care</p>
Outcomes	<p>Patient outcomes</p> <p>(1) Disability (baseline, 8 weeks post-intervention and 6 months after baseline)</p> <p>(2) Anxiety and depression (baseline, 8 weeks post-intervention and 6 months after baseline)</p>

Johnston 2007 (Continued)

(3) Perceived control (completed by the patient and by the carer on behalf of the patient at baseline and 8 weeks)

(4) Satisfaction with treatment and advice (8 weeks post-intervention and 6 months after baseline)

(5) Confidence in recovery (baseline)

Carer outcomes

(1) Anxiety and depression (baseline, 8 weeks post-intervention and 6 months after baseline).

(2) Health related quality of life (baseline)

Notes

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Insufficient information reported
Allocation concealment (selection bias)	Unclear risk	Insufficient information reported
Blinding of participants and personnel (performance bias) All outcomes	High risk	Patients asked not to disclose group allocation though potentially broken. Participants would have been aware they were receiving the intervention
Blinding of outcome assessment (detection bias) All outcomes	Low risk	Research assistants blind to the process
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	More losses to follow-up in the intervention group (29 out of 103) compared with the control group (16 out of 100). 42 carers lost (only reported across groups)
Selective reporting (reporting bias)	High risk	Observer Assessed Disability (OAD) not reported at baseline. Hospital and Anxiety Depression Scale (HADS) sub-scales reported for anxiety and depression at baseline but combined post intervention
Other bias	Unclear risk	No other obvious signs of bias

Kalra 2004

Methods	<p>Block randomisation procedures, each block included 10 participants. Allocation schedule prepared in advance using computer-generated random numbers. Allocation codes held in central office remote from study environment</p> <p>Blinded outcome assessment</p> <p>Stated intention-to-treat analysis</p> <p>32 patients and caregivers lost to follow-up: treatment N = 17; control N = 15</p> <p>12-month follow-up</p>
Participants	London, UK

Information provision for stroke patients and their caregivers (Review)

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Kalra 2004 (Continued)

300 patients and caregivers: treatment N = 151; control N = 149. Completed final follow-up: N = 268

Median age of patient: treatment N = 76 years ; control N = 76 years

Sex of patient male: treatment 57%; control 50%

Inclusion criteria: patient - independent in daily living activities before the stroke, medically and neurologically stable at time of baseline assessments, expected to return home with residual disability; carer - no notable disability (Rankin score 0 to 2), willing and able to provide support after discharge

Exclusion criteria: none stated

Interventions

Treatment: conventional care plus 3 to 5 sessions of 30 to 45 minutes comprising instruction by appropriate professional on common stroke-related problems and their prevention, management of pressure areas and prevention of bed sores, continence, nutrition, positioning, gait facilitation, advice on benefits and services. Hands-on training in lifting and handling techniques, facilitation of mobility and transfers, continence, assistance with personal activities of daily living and communication, tailored to the needs of the individual patients

Focus: caregivers

Setting: stroke rehabilitation unit

Administration: training started when patients' rehabilitation needs stabilised and discharge contemplated. Caregivers competencies assessed at the end of training.

Follow-through session conducted by hospital team at home to adapt skills learnt to home environment

Control: conventional care consisting of information on stroke and its consequences, prevention and management options; involvement in goal setting for rehabilitation and discharge planning; encouragement to attend nursing and therapy activities to learn about patient's abilities and informal instruction on facilitating mobility and activities of daily living tasks; advice on community services, benefits, and allowances including contact information for voluntary support services for caregivers

Outcomes

Patients

(1) Death or institutionalisation (3 and 12 months)

(2) Function (3 and 12 months)

(3) Mood (3 and 12 months)

(4) Quality of life (3 and 12 months)

Caregiver

(1) Function and social activities (3 and 12 months)

(2) Emotional health (3 and 12 months)

(3) Quality of life (3 and 12 months)

Economic

(1) Health and social care costs (12 months)

(2) Informal care costs (12 months)

(3) Quality adjusted life years in caregivers (over 1 year)

Notes

Validity assessment: Possibility of limited generalisability (setting was largely middle-class suburban area)

Kalra 2004 (Continued)

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Computer-generated randomisation
Allocation concealment (selection bias)	Low risk	Quote: "Allocation codes were held in a central office remote from the study environment"
Blinding of participants and personnel (performance bias) All outcomes	High risk	Participants were aware of training received
Blinding of outcome assessment (detection bias) All outcomes	Low risk	Reported that an observer who did not participate in allocation or management of patients assessed outcome
Incomplete outcome data (attrition bias) All outcomes	Low risk	Some missing data. However, numbers and reasons for missing data relatively balanced across groups
Selective reporting (reporting bias)	Unclear risk	Study protocol not available so cannot assess reporting bias
Other bias	Low risk	No other obvious sources of bias

Larson 2005

Methods	<p>Randomisation performed by authors using blocks of 20 participants, where 10 would be allocated to each arm of the trial and the sequence could not be predicted</p> <p>Outcome assessment by self-rated questionnaires</p> <p>9 carers(4 treatment, 5 control) lost to follow-up</p> <p>6-month and 1-year follow-up</p>
Participants	<p>Stockholm, Sweden</p> <p>100 spouses of stroke patients: treatment N = 50; control N = 50. Completed final follow-up: N = 91</p> <p>Mean age of spouse: treatment 68 years; control 67 years</p> <p>Sex of spouse female: treatment 76%; control 84%</p> <p>Inclusion criteria: spouse of stroke patient (defined as person living in the same household as the stroke patient)</p> <p>Exclusion criteria: not possible to obtain information from the spouse and/or if patient not able to return home after hospitalisation</p>
Interventions	<p>Treatment: support and education programme led by stroke specialist nurses and group discussion with issues raised by participants. Topics included: the nature of stroke, treatment and recovery, psychological and social effects, how to prevent recurrence. Participants able to call the stroke specialist nurse between sessions to get extra information or support</p>

Larson 2005 (Continued)

Focus: spouse of stroke patient

Setting: hospital

Administration: groups of 10, attended 6 times in 6 months. Session commenced with lecture on 1 of the topics for 20 to 30 minutes, followed by group discussion

Control: regular information during hospitalisation and also at discharge. Possibility of attending 1 open session of 1.5 hours by a stroke physician on the ward (only 3 control participants chose this option)

Outcomes	(1) General Quality of Life (6 and 12 months)
	(2) Life situation (6 and 12 months)
	(3) General well-being (6 and 12 months)
	(4) Perceived health state (6 and 12 months)

Notes

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Randomly assigned to intervention or control group but method of sequence generation not reported
Allocation concealment (selection bias)	Unclear risk	Reported that sequence could not be predicted but method of allocation concealment not reported
Blinding of participants and personnel (performance bias) All outcomes	High risk	No placebo intervention for control group
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	Unclear whether an interviewer was used or whether questionnaires were self-completed. No report of blinding
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	Losses to follow-up low (10% control and ~2% treatment) but reasons not provided
Selective reporting (reporting bias)	Unclear risk	All outcomes described in the methods reported in the results. However, study protocol not available so cannot assess reporting bias
Other bias	Low risk	No other obvious sources of bias

Lomer 1987

Methods	Patients randomly selected to receive leaflets, no further details given
	No stated blind outcome assessment
	No reported losses to follow-up
	1-week follow-up

Lomer 1987 (Continued)

Participants	<p>Southampton, UK</p> <p>Numbers unclear; report states that 73 stroke incidents were assessed</p> <p>No participant characteristics reported</p> <p>Inclusion criteria: admission to medical or geriatric wards of the 2 major teaching hospitals in Southampton, clinical diagnosis of stroke</p> <p>Exclusion criteria: discharge within 7 days of admission, severe illness, aphasia or dysphasia that prevents response to interview, lack of awareness that have had a stroke</p>
Interventions	<p>Treatment: 12-page leaflet prepared for study personalised with name, sections on basic pathologies of stroke, predisposing factors, treatment, recovery, facilities available in the community, and financial benefits available</p> <p>Focus: patient and relative</p> <p>Setting: hospital</p> <p>Administration: presented to patient by a medical student with no explanation other than the leaflet may be interesting for them and their relatives to read. 1 contact, length of time unknown, between 1 and 2 weeks after admission</p> <p>Control: usual care, no leaflet</p>
Outcomes	(1) Knowledge of stroke (1 week)
Notes	Validity assessment: comparability of treatment and control groups unknown as no reporting of participant characteristics

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Method of randomisation not reported
Allocation concealment (selection bias)	Unclear risk	Method for allocation concealment not reported
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	No placebo intervention for control group. However, participants did not appear to be informed of the study when they were provided with the leaflet and staff were not informed who received the leaflet. However, blinding may have been broken
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	Unclear if blinded outcome assessment was undertaken
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	A number of exclusions and unclear at which time point in the study
Selective reporting (reporting bias)	Unclear risk	All outcomes described. However, study protocol not available so cannot assess reporting bias
Other bias	Low risk	No other obvious sources of bias

Lowe 2007

Methods	<p>Randomised using sealed opaque envelopes in blocks of 10 and 1 to 1 ratio. Envelopes prepared by independent researcher</p> <p>Blinded outcome assessment</p> <p>Stated intention-to-treat analysis</p> <p>16 patients (6 treatment, 10 control) lost to follow-up</p> <p>3 and 6-month follow-up</p>
Participants	<p>Liverpool, UK</p> <p>100 stroke patients: treatment N = 50; control N = 50. Completed final follow-up: N = 84</p> <p>Median age of patient: treatment 68 years; control 73 years</p> <p>Sex of patient female: treatment 42%; control 38%</p> <p>Inclusion criteria: Confirmed stroke, all ages, either sex, patients who are discharged home and who can complete a questionnaire, or who have a named carer who can do so</p> <p>Exclusion criteria: pre-existing cognitive impairment, discharge to institutionalised care, discharge home but unable to self-complete questionnaire and no named carer</p>
Interventions	<p>Treatment: CareFile (A5 size laminated 29 page booklet). Includes general information about stroke as well as information personal to the patient, secondary prevention measures, and personal goals aimed at reducing risk of further stroke. Also contains useful telephone numbers for all stroke-related services and local support agencies. Design allows for removal of pages not relevant to the individual. Sections included for members of the multi-disciplinary team to complete summaries of patient's achievements and future rehabilitation goals. Also provided with advice from therapists and offered leaflets from Chest, Heart and Stroke Association</p> <p>Focus: patient</p> <p>Setting: hospital ward</p> <p>Administration: interview arranged between researcher and patient when patient discharge date in place. Carer also invited to attend. The CareFile and its contents explained by the research registrar and any additional concerns or issues addressed in discussion lasting approximately 15 to 20 minutes. Patients advised to take the CareFile with them to all General Practitioner and clinic appointments</p> <p>Control: received the usual stroke information leaflets provided by the stroke unit and follow-up in stroke review clinic</p>
Outcomes	<p>Primary</p> <p>(1) Knowledge of stroke (3 and 6 months)</p> <p>Secondary</p> <p>(1) Utilisation of CareFile (3 and 6 months)</p> <p>(2) Satisfaction with information given (3 and 6 months)</p> <p>(3) Blood pressure (3 and 6 months)</p> <p>(4) Participation (3 and 6 months)</p> <p>(5) Screening question for depression (3 and 6 months)</p>

Lowe 2007 (Continued)

Notes

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Reported that eligible patients were randomised but method not reported
Allocation concealment (selection bias)	Low risk	Reported to have used sealed opaque envelopes
Blinding of participants and personnel (performance bias) All outcomes	High risk	No report of blinding of participants or personnel
Blinding of outcome assessment (detection bias) All outcomes	High risk	Outcome assessors do not appear to have been blinded – "those in the intervention group were asked if they had brought the CareFile to the Review Clinic and if they found it useful"
Incomplete outcome data (attrition bias) All outcomes	High risk	Almost twice as many lost to follow-up in the control group (10/50) compared with the intervention group (6/50)
Selective reporting (reporting bias)	Unclear risk	Study protocol not available so cannot assess reporting bias
Other bias	Low risk	No other obvious sources of bias

Maasland 2007

Methods	<p>Random allocation in blocks of 10 using computer-generated random numbers. Size of blocks unknown to investigators at time of trial</p> <p>Blinded outcome assessment</p> <p>Intention-to-treat analysis</p> <p>7 patients lost to follow-up plus 1 withdrawn (results not reported) as breached inclusion criteria. Differential losses between the groups unclear follow-up at 1 and 12 weeks</p>
Participants	<p>Rotterdam, Netherlands</p> <p>65 patients at TIA/minor stroke clinic: treatment N = 33; control N = 32. Completed final follow-up: N = 58 (results reported for 57)</p> <p>Mean age of patient: treatment 65 years; control 63 years</p> <p>Sex of patient male; treatment 57%; control 63%</p> <p>Inclusion criteria: 18 years or older, TIA or minor Ischaemic stroke within last 3 months, speak/write Dutch fluently, modified Rankin score < 4</p> <p>Exclusion criteria: professionally engaged in cardio-vascular health education, aphasia, dementia, visual impairment to a degree that would interfere with health education delivery</p>

Maasland 2007 (Continued)

Interventions	<p>Treatment: discussion of test results and standard education by physician plus IMCP comprising of modules containing lay information for each of 8 modifiable risks. All modules highly structured and contained combinations of slides shows, background voice and personal address</p> <p>Focus: patient</p> <p>Setting: outpatient clinic</p> <p>Administration: after consultation with physician shown IMCP. Given brief introduction. 1 of 2 versions used according to age and educational level: general introduction of their personal diagnosis, explanation of the used or prescribed medications, then each patient shown 4 risk factor modules, or if has less than 4 risk factors general information about frequent vascular risk factor, printed summary of the information</p> <p>Control: discussion of test results and standard health education</p>
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Outcomes	<p>(1) Knowledge at 1 (primary) and 12 weeks (secondary) post intervention</p> <p>(2) Function (12 weeks)</p> <p>(3) Changes in cholesterol level, weight, cigarette, and alcohol consumption and physical activity (12 weeks)</p>
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Notes

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Quote: "Treatment allocation was random, and based on computer-generated random numbers."
Allocation concealment (selection bias)	Unclear risk	Method of allocation concealment not reported
Blinding of participants and personnel (performance bias) All outcomes	High risk	No report of blinding of participants or personnel and no placebo intervention provided
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	No report of blinded assessment
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	Eight of the 65 participants were lost in total and unclear which groups they were lost from
Selective reporting (reporting bias)	High risk	Blood pressure was not a pre-specified outcome but has been reported
Other bias	Low risk	No other obvious sources of bias

Mant 1998

Methods	Randomisation performed by telephone in computer-generated blocks of 10 using sequentially-numbered opaque envelopes
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Mant 1998 (Continued)

	<p>Blinded outcome assessment</p> <p>Stated intention-to-treat analysis</p> <p>22 patients (11 treatment, 11 control) and 7 carers (4 treatment, 3 control) lost to follow-up</p> <p>6-month follow-up</p>
Participants	<p>Oxford, UK</p> <p>93 stroke patients: treatment N = 48; control N = 45. Completed final follow-up: N = 71</p> <p>56 carers of these patients: treatment N = 32; control N = 24. Completed final follow-up: N = 49</p> <p>Mean age of patient: treatment 70 years; control 76 years</p> <p>Sex of patient male: treatment 65%; control 65%</p> <p>Inclusion criteria: Oxfordshire resident, admission to any Oxford hospital, stroke within past month (could be recurrent)</p> <p>Exclusion criteria: identified over 1 month after stroke, death within 1 month of admission or considered likely to occur prior to follow-up, taking part in another trial involving follow-up interview, dysphasic with no close informal carer, stroke not the major medical problem, admitted from a nursing home, subdural, subarachnoid haemorrhage when no accompanying intracerebral haemorrhage, TIA</p>
Interventions	<p>Treatment: a collection of 8 leaflets published by the Stroke Association assembled in an A5 folder covering what a stroke is, effects, cause, problems that might be experienced and how they might be dealt with. An introductory leaflet was specially prepared plus leaflets giving local and national contact names and addresses of support groups and services</p> <p>Focus: patient and closest informal carer if available</p> <p>Setting: home</p> <p>Administration: pack addressed to both patient and carer (where applicable). No contact at delivery. Sent to home address 1 week after randomisation (4 to 5 weeks after stroke). Pack left with patient and carer for 6 months</p> <p>Control: received nothing</p>
Outcomes	<p>(1) Knowledge of stroke (6 months)</p> <p>(2) Emotional outcome (6 months)</p> <p>(3) Perceived health status and quality of life (6 months)</p> <p>(4) Satisfaction with information and care received (6 months)</p> <p>(5) Disability and Handicap (6 months)</p> <p>(6) Service use (6 months)</p>
Notes	<p>Validity assessment: treatment and control groups not balanced in respect of age</p>

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Computer-generated random sequence generation
Allocation concealment (selection bias)	Low risk	Sequentially numbered opaque envelopes

Information provision for stroke patients and their caregivers (Review)

Mant 1998 (Continued)

Blinding of participants and personnel (performance bias) All outcomes	High risk	No intervention provided for the control group. As a result a high risk of bias
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	Quote: "While in theory the interviewer was blinded to the treatment allocation, in practice she guessed the correct status of the patients more often than might be expected by chance." Correct guessing may indicate blinding was unsuccessful or that the outcome assessor was noticing real differences between participants
Incomplete outcome data (attrition bias) All outcomes	Low risk	Losses to follow-up balanced in numbers and reasons across groups
Selective reporting (reporting bias)	Unclear risk	All measures described in the methods were reported in the results. However, study protocol not available so cannot assess reporting bias
Other bias	Low risk	No other obvious sources of bias

O'Connell 2009

Methods	RCT utilising computer-generated randomised sequence Blinded outcome assessment 27 patients (18 intervention, 9 control) lost to follow-up
Participants	Melbourne, Australia 93 stroke patients (intervention N = 46; control N = 47) Age mean (range): 73 years (32.1 to 91.3) 33 males and 33 females completed second post intervention follow-up (sex details not reported at baseline) Inclusion criteria: > 18 years, able to be discharged home, English proficiency, adequate communication for interview, corrected vision and hearing, no evidence of severe cognitive impairment Exclusion criteria: none reported
Interventions	Intervention: patient held-record (PHR) which included contact details, questions for health professionals, notes on care, useful phone numbers, brochures from the national stroke foundation and fact sheets relating to specific problems associated with their stroke, level of disability and symptoms (movement and balance, swallowing difficulties, continence, driving and vision, mood changes, pain, sexuality, speech and communication). In addition, usual discharge information (health summary sheet listing medication) Focus: patient Setting: hospital prior to discharge Administration: trained health care researcher

O'Connell 2009 (Continued)

Control: usual discharge information (health summary sheet listing medication)

 Outcomes
 (1) Stroke Impact Scale (4 weeks and 4 months post intervention)
 (2) PHR evaluation questionnaire (unclear when administered)

Notes

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Computer-generated randomisation procedure
Allocation concealment (selection bias)	Low risk	Computer-generated randomisation procedure. External researcher held randomisation codes
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	Insufficient information provided
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	Whilst it was reported that the outcome assessor was blinded, one of the measures appeared to be given to the intervention group only which would have compromised assessor blinding (not explained how this was overcome). As a result unclear
Incomplete outcome data (attrition bias) All outcomes	High risk	One-third lost to follow-up. More lost in the intervention group and reasons for losses not reported
Selective reporting (reporting bias)	High risk	Protocol unavailable so cannot determine if all outcomes have been reported. No pre-intervention data reported
Other bias	High risk	This trial was terminated early as a number of the intervention participants were unable to recall receiving the information

Pain 1990

Methods

Computer-generated randomised allocation. Stratified for side of cerebrovascular accident

Blinded outcome assessment

6 patients (2 treatment, 4 control) lost to follow-up

3-month follow-up

Participants

Southampton, UK

36 stroke patients and carers (couples): treatment N = 21; control N = 15. Completed final follow-up: N = 30

Age of patient: number < 65 years: treatment N = 8; control N = 4; number > 65 years: treatment N = 13, control N = 11

Sex of patient male: treatment N = 16; control N = 9

Pain 1990 (Continued)

Inclusion criteria: admission to hospital with a CVA as defined by WHO, discharge home after a minimum period of treatment of 10 days to live with a relative or carer, agreement to participate in the study

Exclusion criteria: none stated

Interventions	<p>Treatment: individualised booklet containing information on persisting symptoms, current aims of rehabilitation, instructions concerning ADLs, description of exercises provided, pertinent photos, useful local and national addresses and contacts. Also provided with advice from therapists and offered leaflets from Chest, Heart and Stroke Association</p> <p>Focus: patient and carer</p> <p>Setting: home</p> <p>Administration: no contact at delivery. Sent within 7 days of discharge (> 17 days post-stroke) by research therapist to home address</p> <p>Control: provided with advice from therapists and offered leaflets from Chest, Heart and Stroke Association</p>
Outcomes	<p>(1) Knowledge of stroke (3 months)</p> <p>(2) Satisfaction with information received (3 months)</p> <p>(3) Disability and Handicap (3 months)</p>
Notes	<p>Validity assessment: unequal numbers in treatment and control, participants in the treatment group had higher levels of impairment and co-morbidity</p>

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Method of random sequence generation not reported
Allocation concealment (selection bias)	Unclear risk	No information provided
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	Therapists were not informed which patients were to receive the booklets. No report of blinding of participants, both groups were provided with advice and offered leaflets in hospital, only treatment group received booklets after discharge – may not have been obvious which group they were in
Blinding of outcome assessment (detection bias) All outcomes	Low risk	Social services occupational therapists who were blind to the trial and control groupings undertook the interviews
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	Slightly more losses to follow-up in intervention group (4/21) than control group (2/15); reasons only given for group as a whole so cannot determine if reasons were similar between groups
Selective reporting (reporting bias)	Unclear risk	All outcomes described in the methods reported in the results. However, study protocol not available so cannot assess reporting bias
Other bias	Low risk	No other obvious sources of bias

Rodgers 1999

Methods	<p>Randomisation by a centralised telephone service. Randomised by computer initially in blocks of 8, stratified by presence of informal carer and incontinence of urine at 24 hours post stroke</p> <p>Blinded outcome assessment</p> <p>Stated intention-to-treat analysis</p> <p>50 patients (31 treatment, 19 control) and 70 carers (42 treatment, 28 control) lost to follow-up</p> <p>6-month follow-up</p>
Participants	<p>North Tyneside, UK</p> <p>204 stroke patients: treatment N = 121; control N = 83. Completed final follow-up: N = 154</p> <p>176 informal carers of these patients: treatment N = 107; control N = 69. Completed final follow-up: N = 106</p> <p>Median age of patients: treatment 74 years, control 76 years</p> <p>Sex of patient male: treatment 49%; control 46%</p> <p>Inclusion criteria: confirmed diagnosis of stroke, medically stable, normally resident in North Tyneside, not in residential home prior to admission, still in hospital within 48 hours of admission</p> <p>Exclusion criteria: none stated</p>
Interventions	<p>Treatment: 7 group sessions (1 during inpatient stay and 6 outpatient) covering the experience and nature of stroke, the role of physiotherapy and occupational therapy, psychological effects, caring, communication and swallowing problems, reducing risk. Leaflet with telephone number of stroke help line, Stroke Association, day hospital and stroke units</p> <p>Focus: patients and informal carer</p> <p>Setting: stroke unit and day hospital</p> <p>Administration: a rolling programme held 7 times during course of study. Presentation by speaker at each session followed by questions and discussion. Opportunity to ask questions at beginning or end of session. Inpatient session 1 x 1 hour, 6 x 1 hour outpatient sessions over 6-week period</p> <p>Control: usual care. All given a basic 2-sided leaflet about North Tyneside stroke service plus staff prompted to provide information about stroke on day of admission and at regular intervals throughout stay. Record of communication and Stroke Association literature available. Given details of telephone hotline run by the stroke service prior to discharge</p>
Outcomes	<p>Primary</p> <p>(1) Perceived health status (6 months)</p> <p>Secondary</p> <p>(1) Knowledge of stroke (6 months)</p> <p>(2) Emotional outcome (6 months)</p> <p>(3) Stress of care-giving (6 months)</p> <p>(4) Satisfaction with hospital services and discharge (6 months)</p> <p>(5) Disability and handicap (6 months)</p> <p>(6) Service use (6 months)</p>
Notes	<p>Validity assessment: large losses to follow-up</p>

Rodgers 1999 (Continued)

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Computer-generated random number sequence
Allocation concealment (selection bias)	Low risk	Central telephone service used
Blinding of participants and personnel (performance bias) All outcomes	High risk	No placebo intervention for the control group
Blinding of outcome assessment (detection bias) All outcomes	Low risk	Quote: "interviewed in their own homes at 6 months after stroke by a researcher who was blinded to the randomisation group."
Incomplete outcome data (attrition bias) All outcomes	High risk	Non-attenders and attenders included in analysis as is appropriate. Approximately 25% lost to follow-up with relatively similar numbers and reasons across groups. However, due to dysphasia or cognitive problems the primary outcome (SF-36) could not be completed by another 37 patients (24%) meaning almost half of these outcomes were missing. Also, approximately 40% of carers were lost to follow-up
Selective reporting (reporting bias)	Unclear risk	All outcomes described in the methods reported. However, study protocol not available so cannot assess reporting bias
Other bias	Unclear risk	Only 51 patients (42%) of those randomised attended 3 or more of the 6 outpatient sessions

Smith 2004

Methods	<p>Patients randomly allocated using random length restricted permuted blocks (block lengths of 2, 4, and 6). Randomisation carried out by independent research assistant by using sealed, numbered, opaque envelopes kept in a locked separate location. Stratified by Barthel Index scores of 0 to 4, 5 to 9, 10 to 14, 15 to 19, presence of aphasia, and presence of a carer</p> <p>Blinded outcome assessment</p> <p>Stated intention-to-treat analysis</p> <p>37 patients (15 treatment, 22 control) and 21 carers (9 treatment, 12 control) lost to follow-up</p> <p>3 and 6-month follow-up</p>
Participants	<p>Bradford, UK</p> <p>170 stroke patients: treatment N = 84; control N = 86. Completed final follow-up: N = 133</p> <p>97 carers of these patients: treatment N = 49; control N = 48. Completed final follow-up: N = 76</p> <p>Median age of patients: treatment 75 years; control 74 years</p> <p>Sex of patients female: treatment N = 46%; control N = 52%</p>

Smith 2004 (Continued)

Inclusion criteria: all patients admitted to the stroke rehabilitation unit with a confirmed diagnosis of stroke

Exclusion criteria: patients with receptive aphasia, cognitive impairment or who did not understand English and did not have a carer

Interventions

Treatment: provided with the Stroke Recovery Programme, a specifically devised manual containing information about causation and consequences of stroke, recovery, financial benefits, relevant services, and a specific section for carers. Also invited to attend specifically convened meetings with members of their multidisciplinary team (doctor, nurse, physiotherapist, occupational therapist). The intention of the meeting was to provide background information about stroke, discuss patient's progress, answer specific questions, and develop shared rehabilitation goals.

Focus: patient but when the patient had receptive aphasia, cognitive impairment or did not understand English the carer was the main focus

Setting: stroke unit

Administration: Stroke Recovery Programme given by stroke unit staff following randomisation. Meetings scheduled to last approximately 20 minutes held in the ward dayroom fortnightly for duration of stroke unit stay. Guidelines developed for use by rehabilitation teams to ensure coverage of the of the key topics included in the Stroke Recovery Programme and record of matters discussed completed following each meeting. Agreed goals recorded in the manual and retained by the patient

Control: Received usual practice. A folder of information about stroke causation, consequences and recovery previously devised by ward staff and stroke association leaflets were available

Outcomes

Primary

(1) Knowledge of stroke (3 and 6 months)

Secondary

(1) Physical function (3 and 6 months)

(2) Social function (3 and 6 months)

(3) Handicap (3 and 6 months)

(4) Patient mood (3 and 6 months)

(5) Carer mood (3 and 6 months)

(6) Patient and carer satisfaction (3 and 6 months)

(7) Use of services and receipt of benefits (6 months)

Notes

Validity assessment: losses to follow-up 22%

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Method of sequence generation not reported
Allocation concealment (selection bias)	Low risk	Quote: "Concealed randomisation was achieved using sealed, numbered, opaque envelopes kept in a locked separate location by an independent research assistant who carried out the randomisation and conveyed patient allocation information to the stroke unit co-ordinator."

Smith 2004 (Continued)

Blinding of participants and personnel (performance bias) All outcomes	High risk	No report of blinding of participants and groupings probably obvious-treatment group attended meetings, control group received usual care
Blinding of outcome assessment (detection bias) All outcomes	Low risk	Patients and carers were followed up by a research nurse who was blind to group allocation
Incomplete outcome data (attrition bias) All outcomes	Low risk	~22% lost to follow-up with similar reasons and proportions across groups.
Selective reporting (reporting bias)	Unclear risk	All outcomes described in the methods reported in the results. However, study protocol not available so cannot assess reporting bias
Other bias	High risk	Quote: "unavoidable contact and associated intervention contamination between the two groups of patients and relatives during the inpatient period"

ADL: activities of daily living

AMT: Abbreviated Mental Test

BP: blood pressure

CVA: cerebrovascular accident

IMCP: individualised multimedia computer programme

N: sample size

QOL: quality of life

RCT: randomised controlled trial

TIA: transient ischaemic attack

WHO: World Health Organization

Characteristics of excluded studies [ordered by study ID]

Study	Reason for exclusion
Adie 2010	The intervention included motivational interviewing
Allen 2009	The information/education provision was part of a more complex rehabilitation intervention
Andersen 2002	The information/education provision was part of a more complex rehabilitation intervention
Ayana 2000	Non-random
Bacchini 2011	The information/education provision was part of a more complex rehabilitation intervention
Bakas 2008	The information/education provision was part of a more complex rehabilitation intervention
Battersby 2009	The information/education provision was part of a more complex rehabilitation intervention
Boter 2004	The information/education provision was part of a more complex rehabilitation intervention
Boysen 2007	The information/education provision was part of a more complex rehabilitation intervention
Brier 2011	Non-random

Study	Reason for exclusion
Brotons 2007	The trial included participants with conditions other than stroke and the data were not available separately
Burton 2005	The information/education provision was part of a more complex rehabilitation intervention
Byers 2010	The intervention included motivational interviewing
Chaiyawat 2009	The information/education provision was part of a more complex rehabilitation intervention
Chang 2000	The information/education provision was part of a more complex rehabilitation intervention
Chang 2011	The information/education provision was part of a more complex rehabilitation intervention
Cheng 2011	The information/education provision was part of a more complex rehabilitation intervention
Christie 1984	The information/education provision was part of a more complex rehabilitation intervention
Chumbler 2011	The information/education provision was part of a more complex rehabilitation intervention
Claiborne 2006	The information/education provision was part of a more complex rehabilitation intervention
Clark 2003	The information/education provision was part of a more complex rehabilitation intervention
Clarke 2011	The information/education provision was part of a more complex rehabilitation intervention
Dennis 1997	The information/education provision was part of a more complex rehabilitation intervention
Desrosiers 2007	The information/education provision was part of a more complex rehabilitation intervention
Dongbo 2003	Study included both stroke and non-stroke patients and data not available separately
Ertel 2007	The information/education provision was part of a more complex rehabilitation intervention
Evans 1984	Non-random
Folden 1993	(1) Not information/education; this was a study of goal setting (2) Non-random
Forster 1996	The information/education provision was part of a more complex rehabilitation intervention
Friedland 1992	The information/education provision was part of a more complex rehabilitation intervention
Gillham 2010	The information/education provision was part of a more complex rehabilitation intervention
Glass 2004	The information/education provision was part of a more complex rehabilitation intervention
Goldberg 1997	The information/education provision was part of a more complex rehabilitation intervention
Grant 2002	The information/education provision was part of a more complex rehabilitation intervention
Grasel 2006	The information/education provision was part of a more complex rehabilitation intervention
Green 2006	The intervention included motivational interviewing
Habibzadeh 2007	(1) The information/education was part of a more complex rehabilitation intervention

Study	Reason for exclusion
	(2) Non-random
Harari 2004	The information/education provision was part of a more complex rehabilitation intervention specifically targeted at improving bowel function
Harrington 2010	The information/education provision was part of a more complex rehabilitation intervention
Hartke 2003	The information/education provision was part of a more complex rehabilitation intervention
Harwood 2006	The information/education provision was part of a more complex rehabilitation intervention
Hochstenbach 1999	The information/education was part of a more complex rehabilitation intervention
Holzemer 2011	The information/education provision was part of a more complex rehabilitation intervention
Huijbregts 2009	(1) The information/education provision was part of a more complex rehabilitation intervention (2) Non-random
Jones 2009	(1) The information/education provision was part of a more complex rehabilitation intervention (2) No control group
Kendall 2007	The information/education provision was part of a more complex rehabilitation intervention
Leathley 2003	The information/education provision was part of a more complex rehabilitation intervention
Lincoln 2003	Information provision was not the intervention evaluated The experimental condition was a support organiser
Linn 1979	The information/education provision was part of a more complex intervention specifically targeted at management of medication
Lorenc 1992	The study lacked a suitable control
Mackay-Lyons 2010	The information/education provision was part of a more complex rehabilitation intervention
Mant 2000	Information provision was not the intervention evaluated. The experimental condition was a support worker
McKinney 1999	The information/education provision was part of a more complex intervention focused on providing feedback of cognitive assessment to patients' carers and members of the multidisciplinary team
Morrison 1998	Non-random
Napolitan 1999	The information/education provision was part of a more complex rehabilitation intervention
Neubert 2011	No usual care group
Nguyen 2011	The information/education provision was part of a more complex rehabilitation intervention
Nir 2006	The information/education provision was part of a more complex rehabilitation intervention
Nour 2002	The information/education provision was part of a more complex rehabilitation intervention

Study	Reason for exclusion
Oupra 2010	Non-random
Pierce 2007	The information/education provision was part of a more complex rehabilitation intervention
Printz-Feddersen 1990	(1) The information/education was part of a more complex rehabilitation intervention (2) Non-random
Redfern 2008	The information/education provision was part of a more complex rehabilitation intervention
Rimmer 2000	The information/education provision was part of a more complex rehabilitation intervention, which included classes in fitness and nutrition
Sahebalzamani 2009	The information/education provision was part of a more complex rehabilitation intervention
Sanguinetti 1987	The focus of the paper is head injury The data for stroke patients are not reported separately
Shyu 2008	The information/education provision was part of a more complex rehabilitation intervention
Sit 2007	Unacceptable randomisation procedure
Skidmore 2008	No control group
Tilling 2005	The information/education provision was part of a more complex rehabilitation intervention
Towle 1989	Information provision was not the intervention evaluated The experimental condition was a support worker
van den Heuvel 2000	(1) Non-random (2) The information/education provision was part of a more complex rehabilitation intervention
Winkens 2009	The information/education provision was part of a more complex intervention (psycho-education)

Characteristics of studies awaiting assessment *[ordered by study ID]*

[Aben 2012](#)

Methods	A randomised controlled trial
Participants	Stroke patients
Interventions	Education about memory after stroke, compensation strategies and psycho-education.
Outcomes	Memory Self-efficacy (MSE) and psychological quality of life, measured with the Metamemory In Adulthood questionnaire and the psychological domain of the WhoQol-bref questionnaire
Notes	

Andrea 2003

Methods

Participants

Interventions

Outcomes

Notes

Bodin 2011

Methods Controlled trial

Participants Stroke patients

Interventions The InfoCom booklet contains general information about aphasia, verbal and non-verbal communications skills

Outcomes Assessment of language deficiency (Montreal-Toulouse-1986) and communication skills (Test Lillois de Communication-TLC and Protocole Toulousain d'Evaluation de la Communication au sein du Couple Aphasique- PTECCA).

Notes

Bonita 1995

Methods

Participants

Interventions

Outcomes

Notes

Cameron 2011

Methods Multi-site mixed methodology pilot randomised controlled trial

Participants Caregivers

Interventions Stroke family support program

Outcomes Outcome measures not reported

Notes

Choi 2006

Methods	
Participants	Primary caregivers of stroke patients
Interventions	Education classes delivered by a researcher
Outcomes	Knowledge
Notes	

Eames 2008

Methods	Single blind randomised controlled trial
Participants	Clients or carers of clients with a current admission for stroke
Interventions	The education and support package consists of a written education booklet that provides tailored information, supplemented by verbal reinforcement and repetition of the information. Verbal reinforcement will occur face-to-face (prior to hospital discharge) and over the telephone (after hospital discharge) for up to 3 months post-discharge. The written education booklet contains topics including the definition, causes, warning signs, risk factors, effects, diagnosis and treatment of stroke, as well as rehabilitation, recovery, returning to activities, going home, practical management strategies and services and support available after stroke
Outcomes	<p>Primary outcome measures: stroke-related knowledge as determined by a stroke knowledge questionnaire</p> <p>Secondary outcome measures: stroke-risk factor awareness (as assessed by an opened ended question and a checklist of stroke-related risk factors requiring a yes/no/unsure response), self-efficacy (using measures designed for this study), stroke risk-related behaviour change, Anxiety and depression (Hospital Anxiety and Depression Scale), client quality of life (using the Stroke and Aphasia Quality of life Scale-39) and carer burden (Caregiver Strain Index), satisfaction (questions regarding satisfaction and usefulness of information received)</p>
Notes	

Heier 2002

Methods	
Participants	
Interventions	
Outcomes	
Notes	

Jian 1998

Methods	
Participants	
Interventions	
Outcomes	
Notes	

Kim 2011

Methods	Controlled trial
Participants	Patients and family
Interventions	A web-based secondary stroke prevention education program
Outcomes	Knowledge and health behaviour compliance
Notes	

Ostwald 2007

Methods	
Participants	Patients who have had a stroke within the last year, 50 years or older with a spouse or partner
Interventions	An interdisciplinary rehabilitation team will provide education, support, skill training, counselling, and social and community linkages to stroke survivors and their spouses for 6 months post-hospital discharge
Outcomes	(1) function, quality of life and perceived health and depression in the stroke survivor; (2) unplanned clinic and emergency room visits, re-hospitalisations and admissions to nursing homes; (3) depression, burden, stress and health of spousal caregivers and (4) cytokine imbalances related to the chronic stress of care-giving among spouses
Notes	

Piano 2010

Methods	A prospective, randomised, open-label controlled clinical trial
Participants	Stroke patients
Interventions	Video based stroke education programme
Outcomes	Stroke knowledge
Notes	

Information provision for stroke patients and their caregivers (Review)

Sun 2011

Methods	Randomised controlled trial
Participants	Seventy patients with stroke
Interventions	Personalized health education
Outcomes	Hamilton anxiety scale (HAMA) to assess anxiety status, Barthel Index and Life Satisfaction Index to assess the life satisfaction of patients
Notes	

Tuncay 2006

Methods	
Participants	Patients with a new diagnosis of cerebrovascular disease
Interventions	A self-care educational brochure
Outcomes	Barthel ADL
Notes	

ADL: activities of daily living

Characteristics of ongoing studies [ordered by study ID]
Boden-Albala 2007

Trial name or title	Stroke Warning Information and Faster Treatment Study (SWIFT)
Methods	
Participants	Patients diagnosed with cerebral infarction or TIA
Interventions	Usual medical care (standard educational information on stroke, warning signs and risk factors) plus a 3-session interactive stroke educational programme
Outcomes	Stroke knowledge and behaviour
Starting date	2005
Contact information	Dr Thania Perez, Columbia Presbyterian Hospital, Neurological Institute, 710 W 168th Street, 6th Floor, Room 640, New York, NY 10032, USA tperez@neuro.columbia.ed
Notes	This study is ongoing, but not recruiting participants (ClinicalTrials.gov, accessed December 2011)

Damush 2006

Trial name or title	Adapting tools to implement stroke risk management to veterans (TOOLS)
Methods	<p>Comparison of 2 regionally matched facilities on rates of secondary stroke prevention guideline care during the course of the study at the intervention sites</p> <p>Allocation: randomised Intervention model: single group assignment Masking: open label Primary purpose: health services research</p>
Participants	Veterans 18 years or older hospitalised with stroke or TIA at Indianapolis VAMC and Houston VAMC
Interventions	<p>Behavioural: physician stroke guideline adherence</p> <p>Behavioural: evaluation of stroke self management</p>
Outcomes	<p>Primary outcome measures: provider based outcomes: guideline adherent treatment, medication management at stroke discharge, 3 and 6 months. Risk factor screening, examination of CPRS records during hospitalisation or following 6 months. Lifestyle counselling, examination of CPRS records</p> <p>Secondary outcome measures: patient demographics at baseline, depression symptoms at baseline, 3 and 6 months; other co-morbidities at 6 months</p>
Starting date	July 2006
Contact information	Teresa M Damush, Roudebush VA Medical Center Indianapolis, USA
Notes	This study is ongoing, but not recruiting participants (ClinicalTrials.gov, accessed December 2011)

Dromerick 2008

Trial name or title	Preventing Recurrence Of Thromboembolic Events through Coordinated Treatment in the District of Columbia (PROTECT DC)
Methods	Randomised controlled trial
Participants	Hospitalised due to ischaemic stroke or intercurrent ischaemic stroke event within the past 30 days or TIA confirmed by stroke neurologist
Interventions	The program trains a lay person (stroke navigator) to provide participants with education on secondary prevention behaviour and to navigate the health and human service system, which will assist participants in obtaining the necessary services and programs to engage in secondary prevention behaviours
Outcomes	<p>Primary outcome measures: low density lipoprotein value, systolic blood pressure value, haemoglobin A1C value, pill count of antiplatelet therapy medications</p> <p>Secondary outcome measures: smoking cessation status, AHA diet status, exercise status, stroke knowledge level</p>
Starting date	June 2008
Contact information	Alexander Dromerick, MD, National Rehabilitation Hospital, Georgetown University, USA
Notes	

Graven 2008

Trial name or title	From rehabilitation to recovery: a model to optimise consumer and carer involvement in the first year post stroke
Methods	<p>Simple randomisation using a randomisation table created by a computer software (i.e., computerised sequence generation)</p> <p>Blinded (masking used)</p> <p>The people receiving the treatment/s</p> <p>The people assessing the outcomes</p> <p>The people analysing the results/data</p>
Participants	<p>Patient admitted for rehabilitation with a primary diagnosis of acute stroke</p> <p>Carers</p>
Interventions	<p>Collaborative goal setting with the patient and carer prior to discharge from rehabilitation</p> <p>Monitoring of goal achievement and barriers to goal achievement</p> <p>Collaborative problem solving to overcome barriers</p> <p>Facilitated referral to health and community agencies, tailored to needs</p> <p>Promotion of healthy and active lifestyles</p> <p>Promotion of self efficacy and self reliance</p> <p>Providing targeted carer support through information provision, emotional support and practical support tailored to needs over a 12-month period</p> <p>Minimum of four interventions, maximum 12</p>
Outcomes	<p>Primary outcome measures:</p> <p>Mean assessment of Quality of Life score for carers</p> <p>Mean Geriatric Depression Scale score for stroke survivors</p> <p>Secondary outcome measures:</p> <p>Zarit Caregiver Burden Scale - carers</p> <p>Functional Independence Measure (motor subset)</p> <p>Minimental State Examination - stroke survivors</p> <p>London Handicap Scale - stroke survivors</p> <p>Activity Card Sort - stroke survivors</p> <p>Strategies Used by People to Promote Health Scale - stroke survivors</p>
Starting date	January 2008
Contact information	<p>Christine Graven, Physiotherapy Department, St.Vincent's Health Melbourne, PO Box 2900, Fitzroy 3065, Victoria, Australia</p> <p>(03) 3288 3827</p> <p>Christine.Graven@svhm.org.au</p>
Notes	

Hackett 2008

Trial name or title	imProving Outcome after STroke (POST)
Methods	RCT
Participants	Recent (within 8 weeks) stroke Non-depressed (< 8 on Hospital Anxiety and Depression Scale depression subscale at baseline)
Interventions	Participants will consent to a baseline screening assessment and interview, and contact from re-search staff for a period of up to 6 months following hospital discharge to determine their outcome and factors that might improve recovery. Specific information is not available for the general public to maintain blinding to treatment allocation and primary hypothesis
Outcomes	Psychosocial outcomes assessed using standard validated questionnaires
Starting date	16 June 2008
Contact information	Dr Maree Hackett, PO Box M201, Missenden Road, NSW 2050, Australia +61 2 9993 4593 mhackett@george.org.au
Notes	

Hoffmann 2009

Trial name or title	Evaluation of brief interventions for enhancing early emotional adjustment following stroke: a pilot randomised controlled trial
Methods	RCT
Participants	Participants diagnosed with stroke, medically stable, adequate English and expressive and receptive communication skills and adequate cognitive capacity to provide informed consent
Interventions	The 8-session self-management intervention will be conducted by an occupational therapist and will include the provision and reinforcement of individualised written information, and activities that are aimed at assisting individuals to learn problem-solving skills, perform functional tasks, and adjust to life post-stroke
Outcomes	Primary outcome measure: Presence or absence, and severity of anxiety and depressive symptoms as determined by structured interview based on the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, and the Hospital Anxiety and Depression Scale Secondary outcome measures: Functional Performance as measured by the Modified Barthel Index and the Nottingham Extended Activities of Daily Living Scale Cognitive appraisal ability as measured by the Stress Appraisal Coping Measure (SAM) Self-efficacy measured by a Self-Efficacy Questionnaire Stroke knowledge measured by Knowledge of Stroke Questionnaire Quality of Life measured by the Stroke and Aphasia Quality of Life Scale (SAQOL)

Hoffmann 2009 (Continued)

Treatment expectations measured by the Treatment Expectations Scale

Self-awareness of deficits as measured by the Self-Perceptions in Rehabilitation Questionnaire (SPIRQ)

Starting date	26/08/2009
Contact information	Dr Tammy Hoffmann, Division of Occupational Therapy, School of Health and Rehabilitation Sciences, Services Road, University of Queensland, St Lucia, QLD 4072, Australia +61 7 3365 2306 t.hoffmann@uq.edu.au
Notes	

O'Carroll 2010

Trial name or title	Improving Adherence to Medication in Stroke Survivors (IAMSS)
Methods	30 patients will be allocated to a brief intervention (2 sessions) and 30 to treatment as usual
Participants	First-time stroke (ischaemic and haemorrhagic) or TIA patients (within 3 months discharged from a ward or clinic on any secondary preventative medication and living at home) Screening of 400 with an expected 75% response rate (300)
Interventions	2 brief sessions (30 to 45 minutes) 2 weeks apart with a trained research fellow. Participants will be given the choice of having home visits or coming into a local hospital-based Clinical Research Facility. Session 1 will focus on helping each patient draw up a specific plan, so as to establish a better medication-taking. The effectiveness of the implementation intentions plan and any barriers/difficulties in following the plan will be reviewed in session 2, with individually tailored coping strategies/plans. Focus on eliciting and, if appropriate, challenging patients' beliefs regarding their medication, e.g. beliefs regarding toxicity, dependence, fears regarding medications interacting harmfully
Outcomes	Primary outcome measures: Medication adherence recorded using Medication Event Monitoring System (MEMS) to report percentage of doses taken, percentage of days on which the correct number of doses was taken and percentage of doses taken on schedule Secondary outcome measures will include MARS self-reported adherence of all secondary preventative medication and systolic and diastolic blood pressure
Starting date	Specific starting date not reported in the study protocol
Contact information	Ronan O'Carroll, Department of Psychology, Stirling University, Stirling, UK Correspondence: reo1@stir.ac.uk
Notes	

Rochette 2008

Trial name or title	You call-we call trial
Methods	Baseline measures will be taken within the first month after stroke onset. Participants will be stratified according to comorbidity level and randomised to 1 of 2 groups: YOU CALL or WE CALL. Both interventions will be offered over a 6-month period
Participants	384 adults who meet inclusion criteria for a first mild stroke across 6 Canadian sites
Interventions	WE CALL is a multimodal (telephone, Internet and paper) support intervention provided to participants randomly allocated to the "WE CALL" group. The telephone component of the intervention is based on the Family Intervention Telephone Tracking model (FITT) YOU CALL group participants are provided with the name and phone number of a trained health care professional who is not involved in providing the "we call" intervention, whom they are free to contact should they feel the need
Outcomes	Primary outcome measures: unplanned use of health services for negative events and quality of life Secondary outcome measures: participation level, depressive symptoms and planned-use of health services for health promotion and secondary prevention
Starting date	Decemeber 2008
Contact information	annie.rochette@umontreal.ca
Notes	

Shaughnessy 2007

Trial name or title	Reshaping Exercise Habits And Beliefs (REHAB)
Methods	Allocation: randomised Endpoint classification: efficacy study Intervention model: parallel assignment Masking: open label
Participants	40 to 85 years old ischaemic stroke patients
Interventions	Exercise: home-based exercise prescriptions with weekly motivational telephone calls Stroke education program with matched attention phone calls
Outcomes	Ambulatory Activity Profile
Starting date	October 2006
Contact information	Marianne Shaughnessy, RN PhD, VA Maryland Health Care System, Baltimore, USA
Notes	

Young 2007

Trial name or title	Education to increase self efficacy for inpatients having rehabilitation after monophasic neurological disability
Methods	
Participants	Adult patients with a monophasic disabling neurological condition admitted to a neurological rehabilitation unit
Interventions	Group education session and video
Outcomes	Self-efficacy Mood Confidence and recovery Goals achieved variance Participation in therapy Practice with nursing staff
Starting date	01 February 2006
Contact information	Dr Carolyn Young, Walton centre for Neurology and Neurosurgery, Lower Lane, Fazkerley, Liverpool, L9 7LJ,UK
Notes	

AHA: American Heart Association
 CPRS: Computerised Patient Record System
 MARS: Medication Adherence Report Scale
 RCT: randomised controlled trial
 TIA: transient ischaemic attack

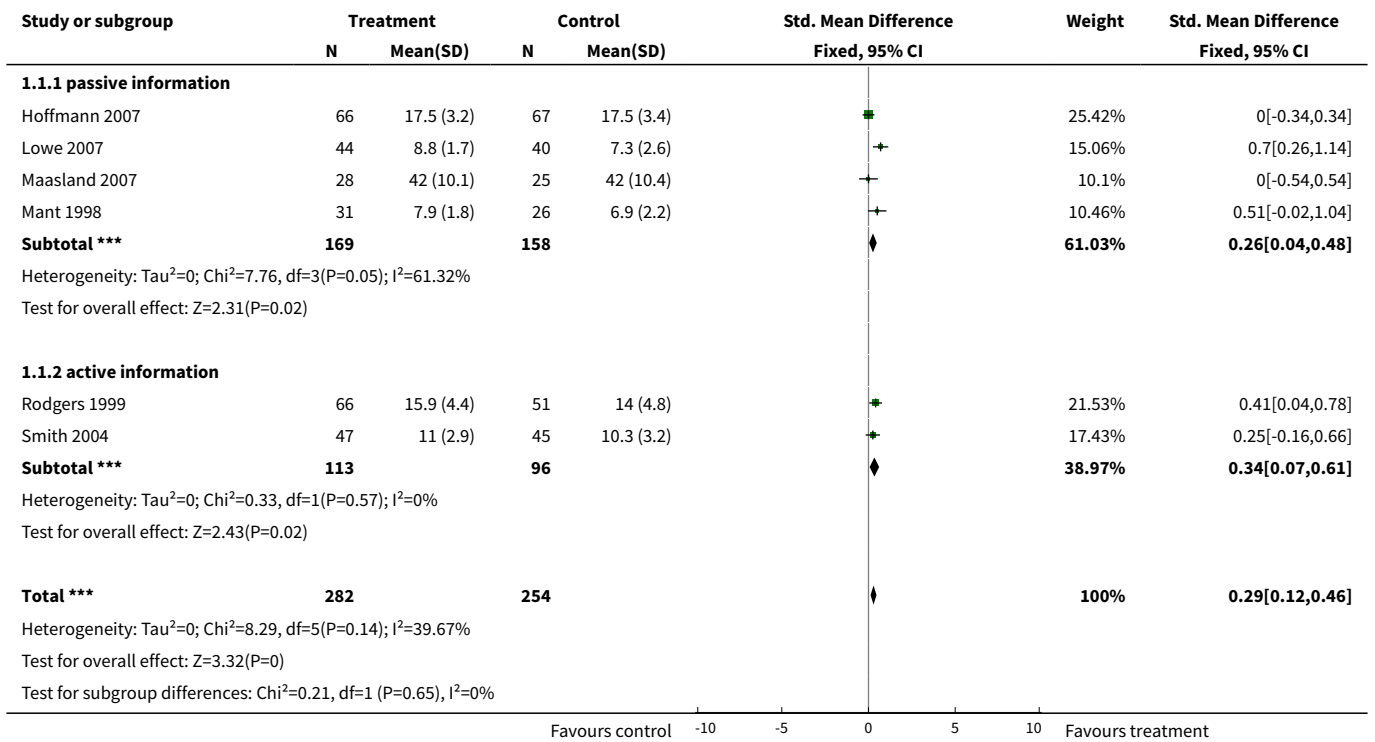
DATA AND ANALYSES
Comparison 1. Passive or active information versus control

Outcome or subgroup title	No. of studies	No. of participants	Statistical method	Effect size
1 Patient knowledge	6	536	Std. Mean Difference (IV, Fixed, 95% CI)	0.29 [0.12, 0.46]
1.1 passive information	4	327	Std. Mean Difference (IV, Fixed, 95% CI)	0.26 [0.04, 0.48]
1.2 active information	2	209	Std. Mean Difference (IV, Fixed, 95% CI)	0.34 [0.07, 0.61]
2 Patient emotional outcome: anxiety (dichotomised data)	6	681	Peto Odds Ratio (Peto, Fixed, 95% CI)	0.89 [0.57, 1.38]
2.1 passive information	3	227	Peto Odds Ratio (Peto, Fixed, 95% CI)	1.64 [0.80, 3.37]
2.2 active information	3	454	Peto Odds Ratio (Peto, Fixed, 95% CI)	0.61 [0.35, 1.07]
3 Patient emotional outcome: anxiety (continuous data)	7	720	Mean Difference (IV, Random, 95% CI)	-0.34 [-1.17, 0.50]

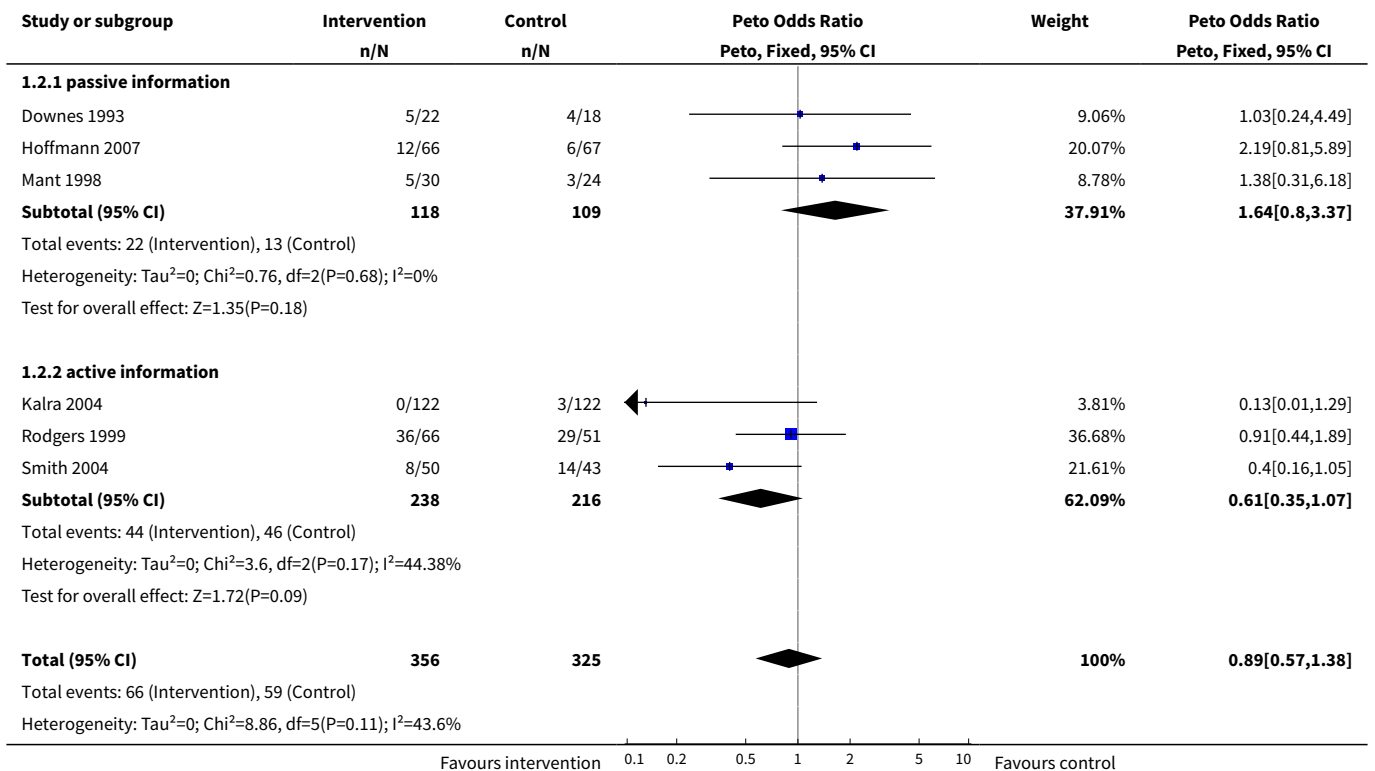
Outcome or subgroup title	No. of studies	No. of participants	Statistical method	Effect size
3.1 passive information	3	227	Mean Difference (IV, Random, 95% CI)	0.67 [-0.37, 1.71]
3.2 active information	4	493	Mean Difference (IV, Random, 95% CI)	-0.98 [-1.59, -0.36]
4 Patient emotional outcome: depression (dichotomised data)	8	956	Peto Odds Ratio (Peto, Fixed, 95% CI)	0.90 [0.61, 1.32]
4.1 passive information	4	311	Peto Odds Ratio (Peto, Fixed, 95% CI)	1.57 [0.85, 2.93]
4.2 active information	4	645	Peto Odds Ratio (Peto, Fixed, 95% CI)	0.63 [0.38, 1.03]
5 Patient emotional outcome: depression (continuous data)	7	720	Mean Difference (IV, Fixed, 95% CI)	-0.52 [-0.93, -0.10]
5.1 passive information	3	227	Mean Difference (IV, Fixed, 95% CI)	0.39 [-0.61, 1.38]
5.2 active information	4	493	Mean Difference (IV, Fixed, 95% CI)	-0.71 [-1.16, -0.25]
6 Patient activities of daily living and participation: summary of results			Other data	No numeric data
7 Patient social activities: summary of results			Other data	No numeric data
8 Patient perceived health status and quality of life: summary of results			Other data	No numeric data
9 Patient satisfaction with information about causes and nature of the stroke	5	541	Peto Odds Ratio (Peto, Fixed, 95% CI)	2.07 [1.33, 3.23]
9.1 passive information	2	143	Peto Odds Ratio (Peto, Fixed, 95% CI)	1.86 [0.81, 4.27]
9.2 active information	3	398	Peto Odds Ratio (Peto, Fixed, 95% CI)	2.16 [1.28, 3.67]
10 Patient satisfaction with information about allowances and services	4	452	Peto Odds Ratio (Peto, Fixed, 95% CI)	1.18 [0.76, 1.83]
10.1 passive information	1	57	Peto Odds Ratio (Peto, Fixed, 95% CI)	0.51 [0.15, 1.75]
10.2 active information	3	395	Peto Odds Ratio (Peto, Fixed, 95% CI)	1.33 [0.83, 2.12]
11 Service use: summary of results			Other data	No numeric data
12 Modification of health related behaviours: summary of results			Other data	No numeric data
13 Death	9	1553	Peto Odds Ratio (Peto, Fixed, 95% CI)	0.86 [0.59, 1.25]
13.1 passive information	3	331	Peto Odds Ratio (Peto, Fixed, 95% CI)	0.80 [0.34, 1.86]

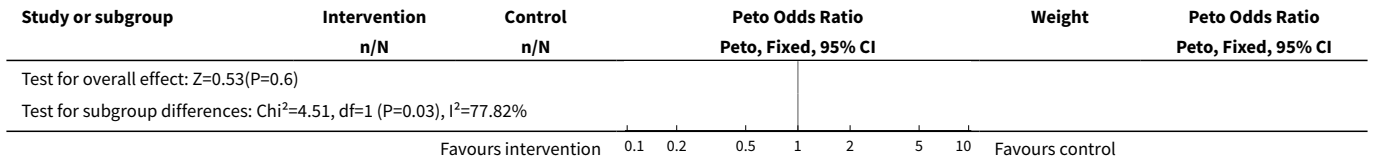
Outcome or subgroup title	No. of studies	No. of participants	Statistical method	Effect size
13.2 active information	6	1222	Peto Odds Ratio (Peto, Fixed, 95% CI)	0.88 [0.58, 1.33]
14 Carer knowledge	4	336	Std. Mean Difference (IV, Random, 95% CI)	0.74 [0.06, 1.43]
14.1 passive information	1	33	Std. Mean Difference (IV, Random, 95% CI)	0.28 [-0.42, 0.97]
14.2 active information	3	303	Std. Mean Difference (IV, Random, 95% CI)	0.88 [0.05, 1.70]
15 Carer emotional outcome: summary of results			Other data	No numeric data
16 Carer emotional outcome: psychological distress	4	498	Peto Odds Ratio (Peto, Fixed, 95% CI)	1.13 [0.65, 1.97]
16.1 passive information	1	51	Peto Odds Ratio (Peto, Fixed, 95% CI)	1.29 [0.31, 5.38]
16.2 active information	3	447	Peto Odds Ratio (Peto, Fixed, 95% CI)	1.11 [0.61, 2.01]
17 Carer social activities: summary of results			Other data	No numeric data
18 Carer perceived health status and quality of life: summary of results			Other data	No numeric data
19 Carer satisfaction with information about recovery and rehabilitation	2	165	Peto Odds Ratio (Peto, Fixed, 95% CI)	1.78 [0.88, 3.60]
19.1 active information	2	165	Peto Odds Ratio (Peto, Fixed, 95% CI)	1.78 [0.88, 3.60]
20 Carer satisfaction with information about allowances and services	3	214	Peto Odds Ratio (Peto, Fixed, 95% CI)	1.30 [0.71, 2.37]
20.1 passive information	1	47	Peto Odds Ratio (Peto, Fixed, 95% CI)	0.61 [0.16, 2.26]
20.2 active information	2	167	Peto Odds Ratio (Peto, Fixed, 95% CI)	1.59 [0.81, 3.13]
21 Cost to health and social services: summary of results			Other data	No numeric data
22 Self management: summary of results			Other data	No numeric data
23 Family functioning and patient adjustment: summary of results			Other data	No numeric data

Analysis 1.1. Comparison 1 Passive or active information versus control, Outcome 1 Patient knowledge.

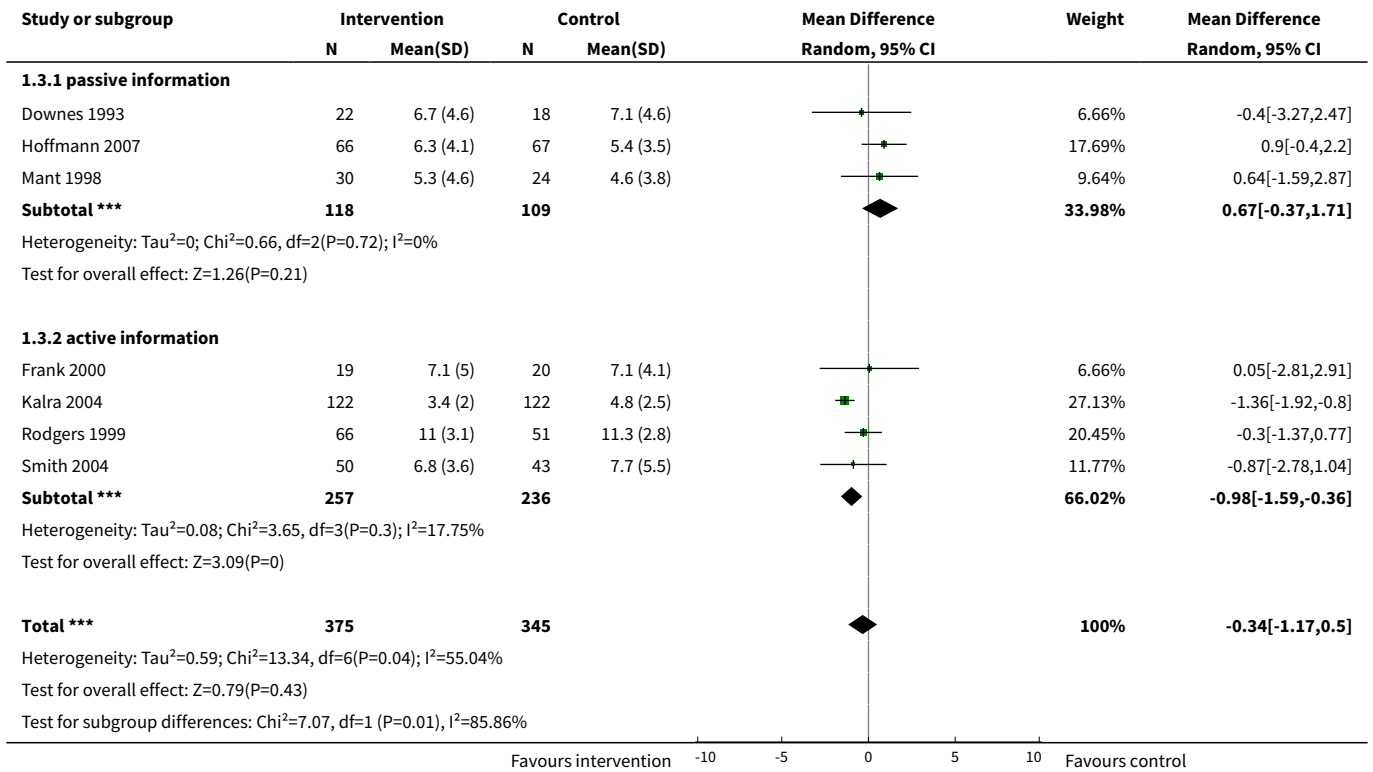


Analysis 1.2. Comparison 1 Passive or active information versus control, Outcome 2 Patient emotional outcome: anxiety (dichotomised data).

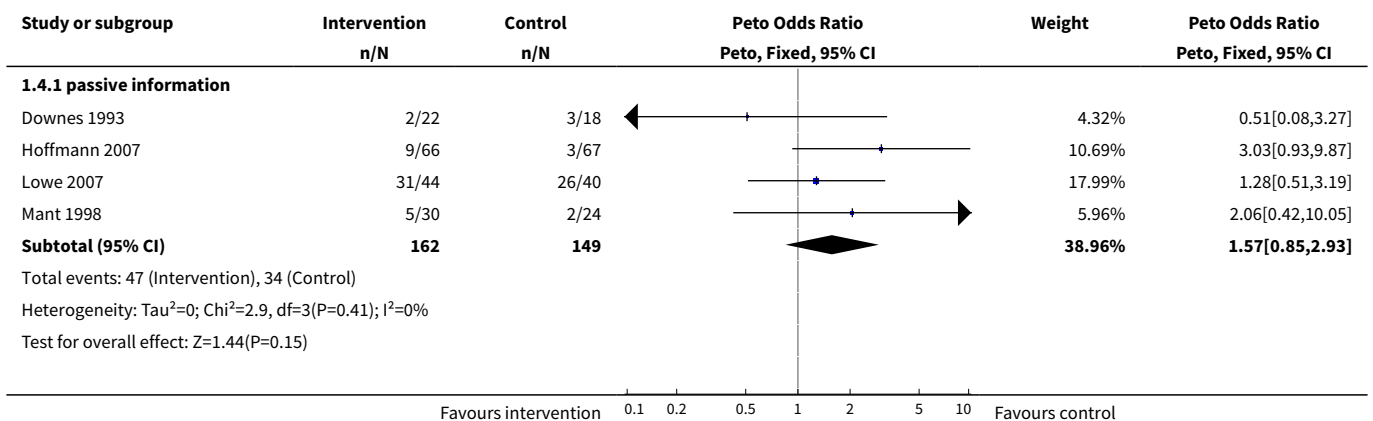


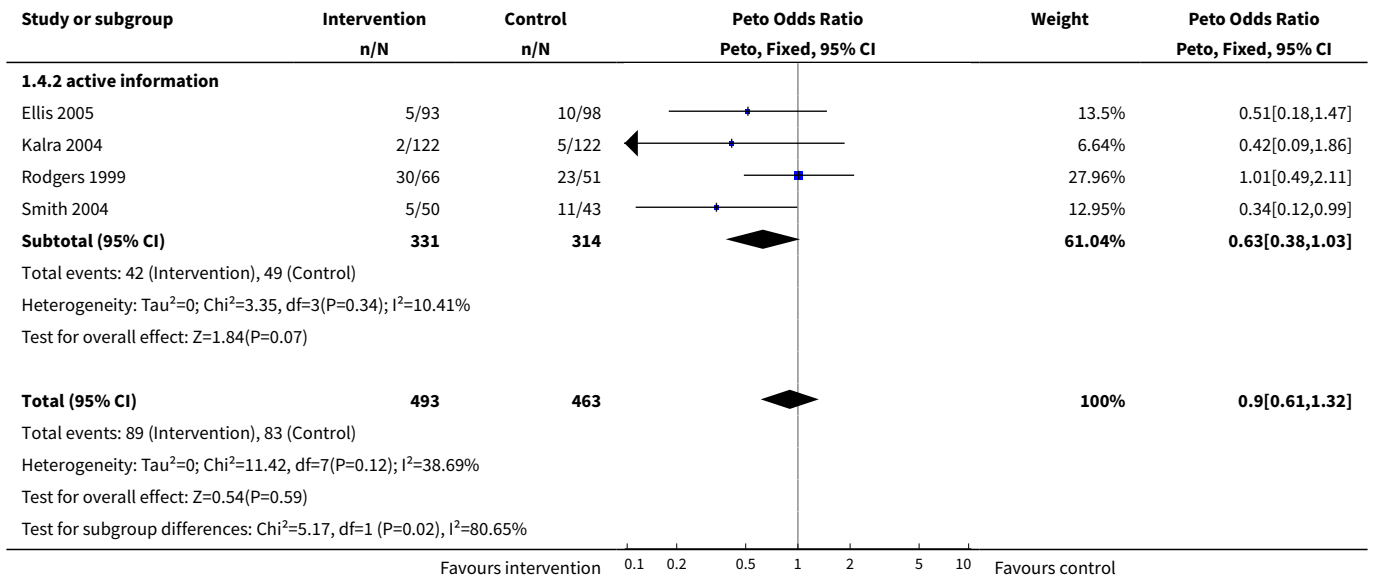


Analysis 1.3. Comparison 1 Passive or active information versus control, Outcome 3 Patient emotional outcome: anxiety (continuous data).

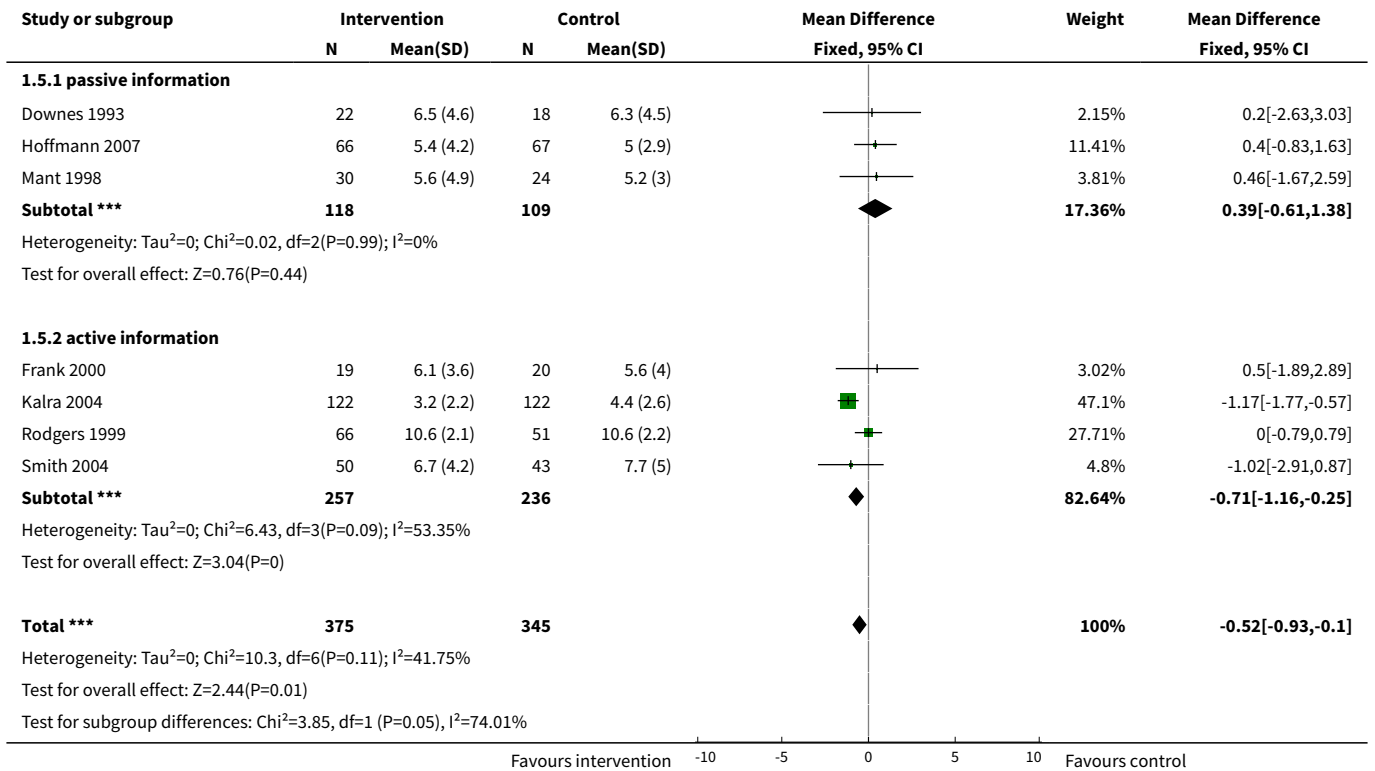


Analysis 1.4. Comparison 1 Passive or active information versus control, Outcome 4 Patient emotional outcome: depression (dichotomised data).





Analysis 1.5. Comparison 1 Passive or active information versus control, Outcome 5 Patient emotional outcome: depression (continuous data).



Analysis 1.6. Comparison 1 Passive or active information versus control, Outcome 6 Patient activities of daily living and participation: summary of results.

Patient activities of daily living and participation: summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
Banet 1997	6 months	Patient education packet and shared medical record versus patient education packet	Glasgow Outcome Scale Global Outcome Scale (not validated)	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: 24/number unclear, control 28/number unclear Comparison between shared record and control groups Glasgow Outcome Scale $F < 0.01$, $P = 0.74$ Global Outcome Scale $F = 1.7$, $P = 0.20$	
Frank 2000	1 month	Workbook + home visits and telephone contact versus wait control	Functional Limitations Profile	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 19/20, control 20/21 Mean score before intervention: intervention 69.62 (SD 17.77), control 71.73 (SD 25.41) 1 month: intervention 64.03 (SD 20.96), control 66.89 (SD 22.87)	
Johnston 2007	8 weeks (post intervention) and 6 months from baseline	Post discharge workbook intervention including information and audio relaxation tape versus usual care	Barthel Index (transformed scores)	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 74/103, control 84/100 Mean score before intervention: intervention 1.57 (SD 0.73), control 1.50 (SD 0.63) 8 weeks: intervention 1.44 (SD 0.65), control 1.43 (SD 0.59) 6 months: intervention 1.43 (SD 0.68), control 1.39 (SD 0.61)	Transformed scores: higher score = higher disability
Kalra 2004	3 and 12 months	Education sessions plus hands on training versus conventional care	Barthel Index Modified Rankin Scale	Number of participants with Barthel Index data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 134/151, control 134/149 Barthel Index score > 18 3 months: intervention 77/141, control 52/140 12 months: intervention 93/134, control 75/134 Number of participants Modified Rankin Score data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 133/151, control 134/149	

Patient activities of daily living and participation: summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
				Modified Rankin Scale score 0 to 2 3 months: intervention 80/141, control 63/140 12 months: intervention 100/134, control 87/134	
Lowe 2007	3 and 6 months	CareFile (29-page personalised information booklet) + discussion with research registrar versus usual information and follow-up	Rankin Scale	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 44/50, control 40/50 Median (range) Before intervention: intervention 3 (2 to 4), control 2 (1 to 3) 3 months: intervention 3 (2 to 3), control 3 (2 to 3) 6 months: intervention 2 (1 to 3), control 2 (2 to 3)	
Maasland 2007	12 weeks	Health education plus computer programme versus health education alone	Rankin Scale	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 30/33, control 27/32 No significant differences between the groups	
Mant 1998	6 months	Information pack versus no intervention	London Handicap Scale Barthel Index	Number of participants with London Handicap Scale data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 34/48, control 34/45 Mean score London Handicap Scale: intervention 0.6 (SD 0.22), control 0.5 (SD 0.18) Number of participants with Barthel Index data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 37/48, control 34/45 Barthel Index: intervention 15.1 (SD 6.42), control 15.1 (SD 4.82)	
O'Connell 2009	4 weeks and 4 months	Patient Held Record (PHR) incorporating fact sheets with patient specific stroke information versus usual discharge information	ADL sub-scale of the Stroke Impact Scale (SIS)	Number of participants with outcome data available at the end of 4 month follow-up/number of participants in group at outset of the trial: intervention 28/46, control 38/47 Mean score SIS ADL sub-scale: at 4 weeks: intervention 71.96 (SD 16.49), control 81.64 (SD 19.03) 4 months: intervention 74.91 (SD 18.25), control 82.43 (SD 17.71)	
Pain 1990	3 months	Individualised information booklet + advice and	Barthel Index	Number of participants with outcome data avail-	

Patient activities of daily living and participation: summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
		information versus advice and information		able at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 16/21, control 13/15 Mean score Barthel Index: at discharge: intervention 77.6 (SD 24.5), control 83.5 (SD 18.5) 3 months: intervention 75.1 (SD 26.0), control 85.0 (SD 17.6)	
Rodgers 1999	6 months	Education programme versus usual care	Oxford Handicap Scale	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 89/121, control 64/83 Mean score Oxford Handicap Scale: intervention 3.1 (SD 1.4), control 3.2 (SD 1.2)	
Smith 2004	3 and 6 months	Stroke Recovery Programme (information manual) + fortnightly meetings with multidisciplinary team versus usual care	Barthel Index London Handicap Scale	Number of participants with Barthel Index data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 69/84, control 64/86 Median change from baseline (range) Barthel Index: 3 months: intervention 6 (-5 to 17), control 5 (-5 to 20) 6 months: intervention 7 (-13 to 17), control 5.5 (-9 to 19) Median score (range) Number of participants with London Handicap data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 69/84, control 64/86 London Handicap Scale 3 months: intervention 57 (9 to 90), control 54 (25 to 95) 6 months: intervention 59 (20 to 94), control 57 (12 to 84)	

Analysis 1.7. Comparison 1 Passive or active information versus control, Outcome 7 Patient social activities: summary of results.
Patient social activities: summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
Kalra 2004	12 months	Education sessions + hands on training versus conventional care	Frenchay Activities Index	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: in-	

Patient social activities: summary of results					
Study	Follow-up	Comparison	Outcome measure	Results	Notes
				intervention 134/151, control 133/149 Median Score at one year: intervention 15 (IQR 9 to 23), control 16 (IQR 8 to 22)	
Pain 1990	3 months	Individualised information booklet + advice and information versus advice and information	Frenchay Activities Index	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 16/21, control 13/15 Mean Score Discharge (baseline): intervention 21.4 (SD 10.6), control 23.8 (SD 7.5) 3 months: intervention 12.5 (SD 8.8), control 13.9 (SD 10.4)	
Rodgers 1999	6 months	Education programme versus usual care	Nottingham Extended ADL	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 84/121, control 61/83 Mean score: intervention 7.6 (SD 6.5), control 8.0 (SD 6.2)	
Smith 2004	3 and 6 months	Stroke Recovery Programme (information manual) + fortnightly meetings with multidisciplinary team versus usual care	Frenchay Activities Index	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 68/84, control 64/86 Median change from baseline (range) 3 months: intervention 1 (0 to 30), control 0 (0 to 23) 6 months: intervention 5 (0 to 32), control 3 (0 to 33)	

Analysis 1.8. Comparison 1 Passive or active information versus control, Outcome 8 Patient perceived health status and quality of life: summary of results.

Patient perceived health status and quality of life: summary of results					
Study	Follow-up	Comparison	Outcome measure	Results	Notes
Chinchai 2010	2 months	An education programme with follow up reinforcement versus usual care information	WHO Quality of Life Measure (Thai version)	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 30/30, control 30/30 Mean (SD) scores Physical: intervention 23.7 (2.2), control 20.5 (1.9) Psychological: intervention 20.9 (1.9), control 18.1 (2.4)	Between group differences reported pre-intervention only (P = 0.23). Within group differences were statistically significant for the intervention group for physical, psychological and environmental categories (P < 0.05). There were no statistically significant within group differences for the control group (P > 0.05).

Patient perceived health status and quality of life: summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
				Social relationship: intervention 8.6 (0.9), control 7.9 (1.4) Environmental: intervention 25.9 (2.2), control 23.7 (2.8)	
Ellis 2005	5 months	Generic risk factor advice + stroke nurse specialist review and written advice versus generic risk factor advice	EuroQol Perceived Health Status	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 94/100, control 98/105 Number (%) with decrease in quality of life (score increase of 1 or more): Mobility: intervention 11 (12%), control 17 (17%) Self-care: intervention 8 (9%), control 16 (16%) Usual activities: intervention 14 (15%), control 22 (22%) Pain: intervention 18 (19%), control 25 (26%) Anxiety and depression: intervention 17 (18%), control 25 (26%) Percentage change (visual analogue scale): intervention 3.5 (-0.9 to 7.9), control 1 (-3.3 to 5.3)	
Hoffmann 2007	3 months	Computer-generated tailored written information versus stroke fact sheets	Coop Charts (patient)	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 66/69, control 67/69. Change scores 0 to 3 months (95% confidence intervals) Physical fitness: intervention 0.4, control 0.4 (-0.4 to 0.4) Feelings: intervention -0.2, control -0.3 (-0.3 to 0.6) Daily activities: intervention -0.1, control -0.1 (-0.5 to 0.6) Social activities: intervention 0.1, control -0.1 (-0.4 to 0.8) Pain: intervention 0.1, control 0.2 (-0.6 to 0.6) Change in health: intervention -1.4, control -1.1 (-0.8 to 0.3) Overall health: intervention -0.4, control -0.1 (-0.6 to 0.2) Social support: intervention -0.4, control -0.2 (-0.6 to 0.2) Quality of life: intervention -0.2, control -0.5 (-0.1 to 0.7)	
Kalra 2004	3 months and 1 year	Education sessions + hands on training versus conventional care	EuroQuol Visual Analogue Scale	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group	Statistically significant difference * P = 0.019 † P = 0.009

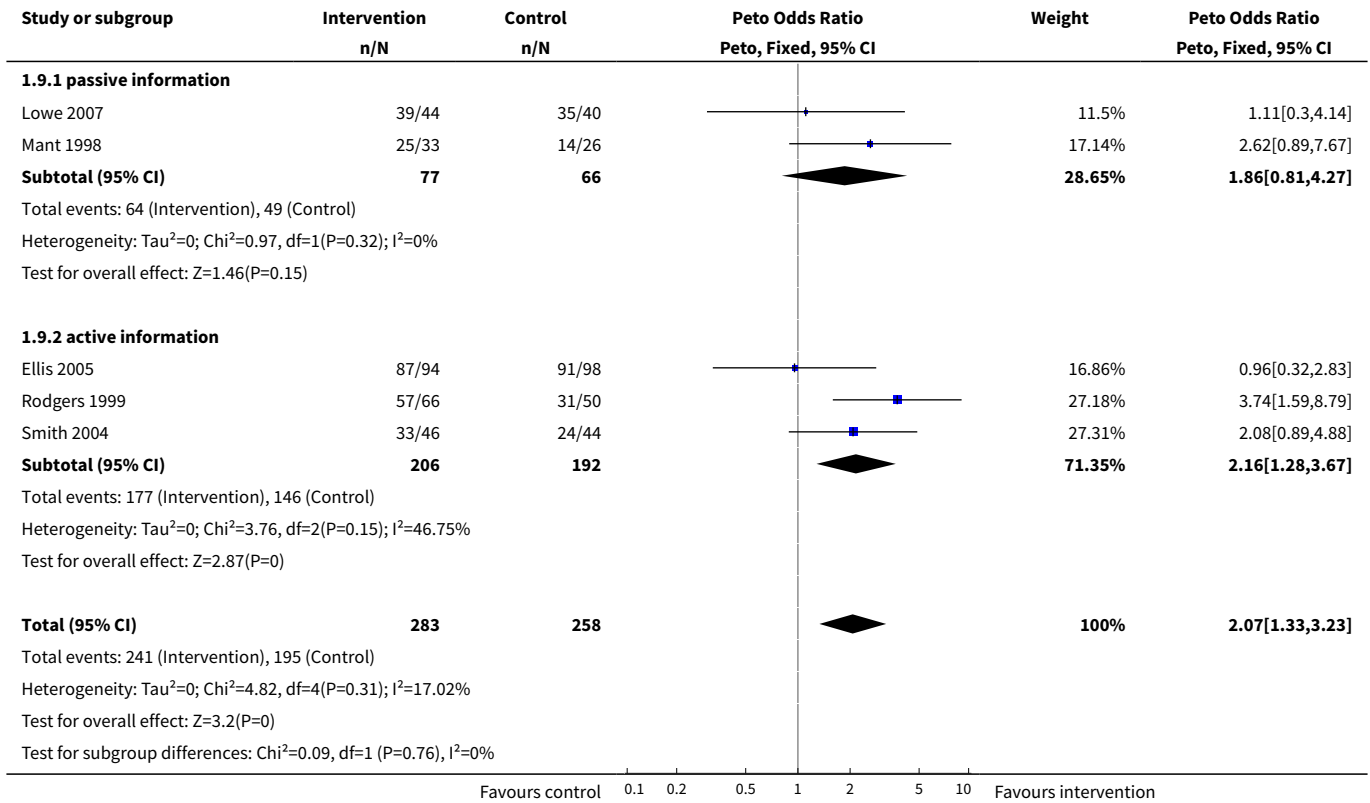
Patient perceived health status and quality of life: summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
				at outset of the trial: intervention 112/151, control 112/149 Median (IQR) before intervention: intervention 85 (75 to 90), control 85 (75 to 95) 3 months: intervention 60 (42 to 70), control 50 (40 to 90)* 1 year: intervention 65 (55 to 80)†, control 60 (41 to 80)†	
Mant 1998	6 months	Information pack versus no intervention	Dartmouth Coop Chart (patient)	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 33/48, control 32/45 Mean score Physical fitness: intervention 4.2 (SD 0.89), control 4.4 (SD 0.76) Feelings: intervention 2.4 (SD 1.41), control 2.2 (SD 1.17) Daily activities: intervention 2.7 (SD 1.63), control 3.4 (SD 1.45) Social activities: intervention 2.2 (SD 1.49), control 2.7 (SD 1.45) Pain: intervention 2.7 (SD 1.66), control 2.9 (SD 1.54) Change in health: intervention 2.8 (SD 0.71), control 2.7 (SD 0.73) Overall health: intervention 3.2 (SD 1.11), control 3.2 (SD 1.07) Social support: intervention 1.3 (SD 0.65), control 1.3 (SD 0.81) Quality of life: intervention 2.2 (SD 0.68), control 2.4 (SD 0.79)	
Rodgers 1999	6 months	Education programme versus usual care	Short-Form 36 (patient)	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 66/121, control 51/83 Mean score Physical functioning: intervention 33.3 (SD 33.3), control 27.8 (SD 26.0) Role physical: intervention 20.8 (SD 37.3), control 14.7 (SD 32.1) Bodily pain: intervention 61.0 (SD 30.55), control 57.5 (SD 29.2) General health: intervention 47.0 (SD 19.8), control 48.8 (SD 22.3) Vitality: intervention 35.4 (SD 24.7), control 43.7 (SD 24.0) Social functioning: intervention 47.2 (SD 33.2), control 44.4 (SD 30.9)	

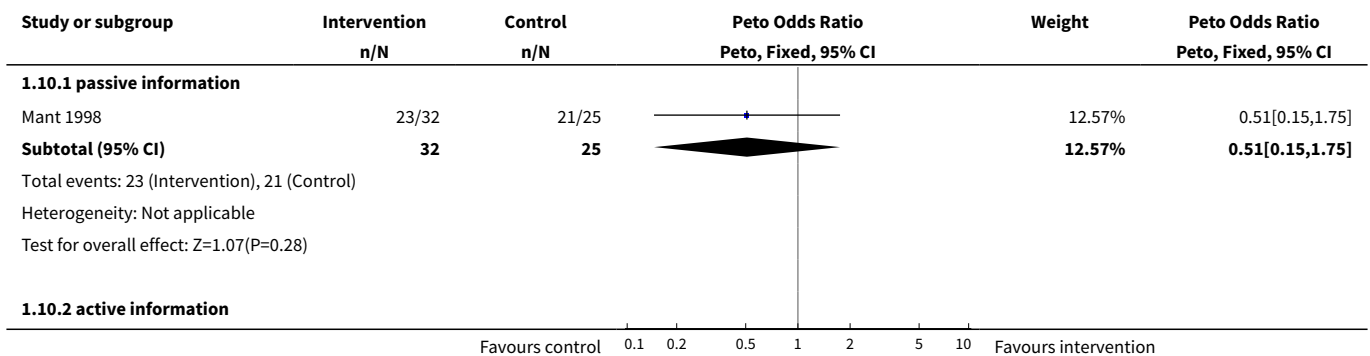
Patient perceived health status and quality of life: summary of results

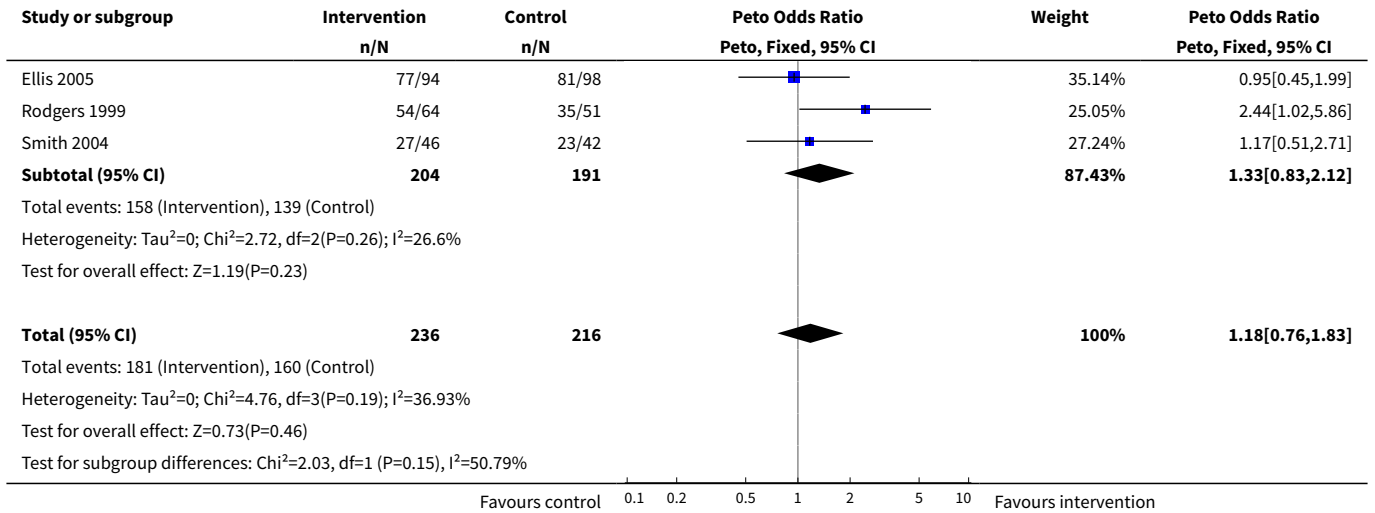
Study	Follow-up	Comparison	Outcome measure	Results	Notes
				Role emotional: intervention 34.4 (SD 43.2), control 36.6 (SD 45.8) Mental health: intervention 61.7 (SD 24.0), control 61.7 (SD 23.6)	

Analysis 1.9. Comparison 1 Passive or active information versus control, Outcome 9 Patient satisfaction with information about causes and nature of the stroke.



Analysis 1.10. Comparison 1 Passive or active information versus control, Outcome 10 Patient satisfaction with information about allowances and services.





Analysis 1.11. Comparison 1 Passive or active information versus control, Outcome 11 Service use: summary of results.

Service use: summary of results					
Study	Follow-up	Comparison	Outcome measure	Results	Notes
Evans 1988	6 months	Education classes versus routine care	ESCROW (social resources use)	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 64/70, control 63/70 Mean scores before intervention: education 10.5 (SD 4.1), control 10.5 (SD 4.6) 6 months post stroke: education 9.2 (SD 2.3), control 9.6 (SD 3.3) 1 year post stroke: education 9.9 (SD 3.3), control 9.8 (SD 2.9)	
Kalra 2004	12 months	Education sessions + hands on training versus conventional care	Use of services/resources	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: numbers varied according to service evaluated: intervention 134 to 151/151, control 125 to 149/149 Resource use: there was a trend towards lesser use of personal and domestic care services in the intervention group but only significant for the use of day care mean difference -2.8, 95% CI -5.1 to -0.5	
Mant 1998	6 months	Information pack versus no intervention	Number/type of health-care professional contacts	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: da-	*P = 0.08 (Mann-Whitney U)

Service use: summary of results					
Study	Follow-up	Comparison	Outcome measure	Results	Notes
				ta obtained for 67 families but no information available on group allocation Number of different types of health professionals seen*: intervention mean 4 median 3, control mean 3 median 2 Types of contact with support groups and healthcare facilities: no difference Contact with any particular type of healthcare professional or type of support group/healthcare facility: no significant differences	
Rodgers 1999	6 months	Education programme versus usual care	Resource utilisation	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 90/121, control 64/83 Residential care: intervention 9 (10%), control 4 (6%) Nursing home: intervention 9 (10%), control 5 (8%) Home care - domestic: intervention 17 (24%), control 19 (35%) Home care - personal: intervention 11 (15%), control 11 (20%) Home help - private: intervention 3 (3%), control 3 (5%) Meals on Wheels: intervention 3 (3%), control 6 (11%) Nursing auxilliary for bath: intervention 3 (3%), control 2 (4%) Laundry services: intervention 3 (3%), control 0 (0%) Day centre/Luncheon club: intervention 3 (3%), control 7 (11%) Day Hospital: intervention 20 (22%), control 13 (20%) District Nurse: intervention 28 (31%), control 18 (28%) Health Visitor: intervention 0 (0%), control 0 (0%) Social Worker: intervention 15 (17%), control 7 (11%) Occupational therapist: intervention 9 (10%), control 7 (11%) Physiotherapist: intervention 32 (36%), control 18 (28%) Chiropodist: intervention 39 (43%), control 29 (45%)	Residential care: P = 0.38 Nursing home: P = 0.61 Home care - domestic: P = 0.26 Home care - personal: P = 0.61 Home help - private: P = 0.79 Meals on Wheels: P = 0.17 Nursing auxiliary for bath: P = 0.83 Laundry services: P = 0.12 Day centre/Luncheon club: P = 0.10 Day Hospital: P = 0.66 District Nurse: P = 0.55 Social Worker: P = 0.26 Occupational Therapist: P = 0.93 Physiotherapist: P = 0.24 Chiropodist: P = 0.93 Continance advisor: P = 0.77 CPN: P = 0.47

Service use: summary of results					
Study	Follow-up	Comparison	Outcome measure	Results	Notes
				Continence Advisor: intervention 2 (2%), control 2 (3%) CPN: intervention 3 (3%), control 1 (2%)	
Smith 2004	6 months	Stroke Recovery Programme (information manual) + fortnightly meetings with multidisciplinary team versus usual care	Service use and receipt of benefits	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 64/84, control 61/86 6 months Number (%) of patients having contact: Social worker: intervention 20 (31%), control 19 (31%) Community nurse: intervention 36 (56%), control 32 (52%) General Practitioner: intervention 60 (94%), control 50 (82%) Therapist: intervention 47 (73%), control:34 (56%) Chiropodist: intervention 29 (45%), 23 (38%) Receipt of: Home support: intervention 18 (28%), control 20 (33%) Day centre attendance: intervention 8 (13%), control 3 (5%) Rehabilitation centre attendance: intervention 2 (3%), control 1 (2%) Receipt of financial and mobility benefits: Disability/mobility allowance: intervention 10 (16%), control 15 (25%) Attendance/carers allowance: intervention 21 (33%), control 15 (25%) Invalidity benefit: intervention 2 (3%), control 2 (3%) Blue badge scheme: intervention 27 (42%), control 20 (33%)	

Analysis 1.12. Comparison 1 Passive or active information versus control, Outcome 12 Modification of health related behaviours: summary of results.

Modification of health related behaviours: summary of results					
Study	Follow-up	Comparison	Outcome measure	Results	Notes
Banet 1997	6 months	Patient education packet and shared medical record versus patient education packet	Miller's Health Intention Scale Miller's Health Behaviour Scale 3 areas of compliance examined: smoking, diet and medication	Number of participants with outcome data available at the end of scheduled follow up/number of participants in group at outset of the trial: intervention 24/number unclear, control 28/number unclear Smoking: no analysis done	

Modification of health related behaviours: summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
				Follow-up variable comparisons between shared record and control groups: diet: F= 0.03, P = 0.85 medication: F=0.02, P = 0.87	
Chiu 2008		Pharmacist lead intervention providing information on drug effects, lifestyle modification, benefits of therapies, importance of compliance, drug interactions and adverse events versus control group (no information reported)	Proportion of subjects with satisfactory management of modifiable risk factors: Blood pressure (defined as <140/90mmHg) Lipids (defined as low-density lipoprotein (LDL) cholesterol <100 mg dL or, if LDL was not available, total cholesterol (TC) <160 mg /dL) Glucose (defined as defined as glycosylated haemoglobin A1c (HbA1c) <7% or, if HbA1c not available, FBG <126 mg dL. When HbA1c or FBG were not available, random post-prandial blood glucose less than 200 mg/dL was used to define adequate control	Number of participants with outcome data available at the end of scheduled follow up/number of participants in group at outset of the trial: intervention 78/80, control 76/80 There was a statistically significant difference (P<0.001) between the groups for management of blood pressure. After the intervention, 65/78 (83.3%) of the intervention group and 33/76 (43.4%) of the control group had satisfactory management of blood pressure No statistically significant difference between the intervention and control groups for management of lipids or glucose. After the intervention, 21/53 (39.6%) of the intervention group and 13/49 (26.5%) of the control group had satisfactory management of lipids. After the intervention, 12/34 (53.5%) of the intervention group and 15/33 (45.5%) of the control group had satisfactory management of glucose	
Ellis 2005	5 months	Generic risk factor advice + stroke nurse specialist review and written advice versus generic risk factor advice	Modifiable risk factors within the recommended treatment range according to the contemporary national and local treatment guidelines: blood pressure (< 140/85 mmHg), cigarette consumption (complete cessation), Random blood glucose (< 80 mmol/l), HbA1c (< 7.5%), Total cholesterol (< 5.0 mmol/l)	Number of participants with outcome data available at the end of scheduled follow up/number of participants in group at outset of the trial: intervention 94/100, control 98/105 Mean (95% confidence intervals) or number (%) 5 months: intervention n = 94, control n = 98 All relevant risk factors controlled: intervention 45 (46.4%), control 41 (41.7%) Individual risk factors: hypertension, change in systolic BP (mmHg): intervention -9.3 (-15.0 to -3.5), control -1.0 (-6.3 to 4.3) hypertension, change in diastolic BP(mmHg): intervention -2.1 (-5.7 to 1.5), control -1.2 (-4.5 to 4.5) smoking, change in number of cigarettes per day: intervention -1.6 (-5.1 to 1.8), control -0.4 (-3.7 to	

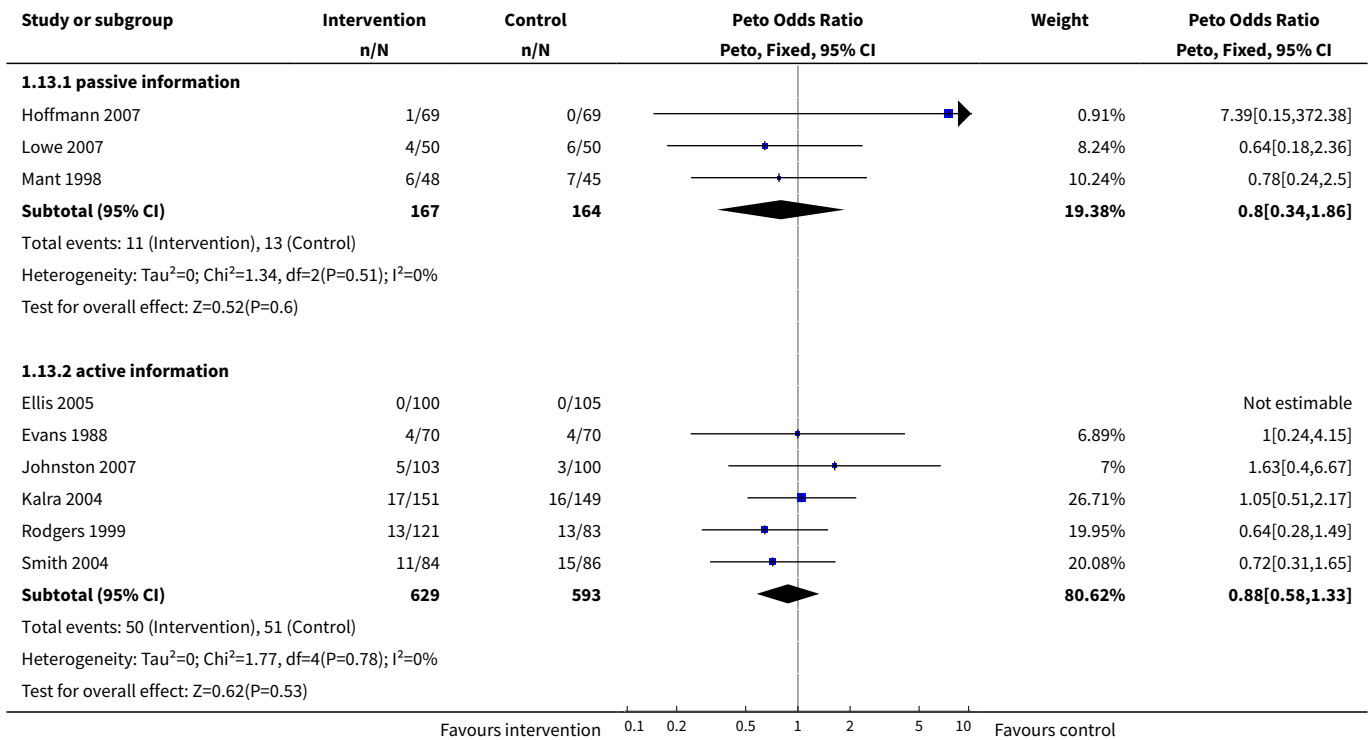
Modification of health related behaviours: summary of results

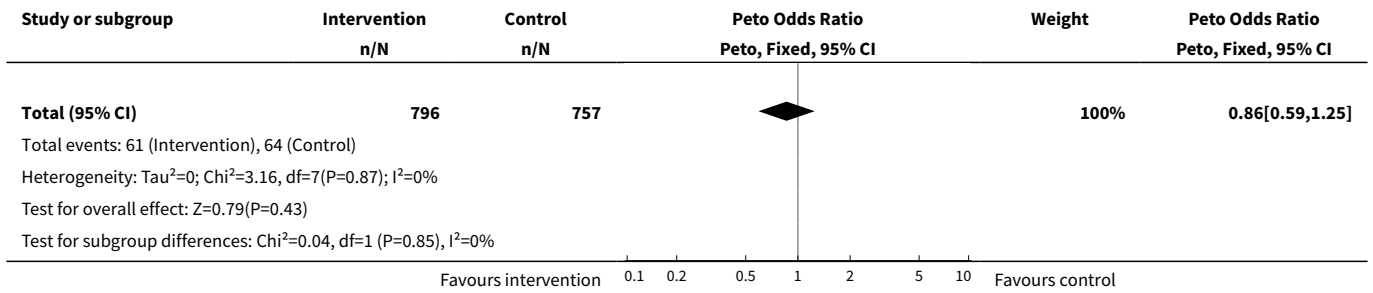
Study	Follow-up	Comparison	Outcome measure	Results	Notes
				2.8) diabetes, change in random blood glucose (mmol/l): intervention 0.92 (-1.39 to 3.23), control 0.89 (-2.09 to 3.87) diabetes, change in HbA1C (%): intervention -0.25 (-0.57 to 0.08), control -0.78 (-1.50 to 0.05) hypercholesterolaemia, total cholesterol (mmol/l): intervention -0.96 (-1.20 to 0.71), control -0.87 (-1.14 to 0.61)	
Lowe 2007	3 and 6 months	CareFile (29 page personalised information booklet) + discussion with research registrar versus usual information and follow up	Risk factor modification: blood pressure	Number of participants with outcome data available at the end of scheduled follow up/number of participants in group at outset of the trial: intervention 44/50, control 40/50 Median (mmHg) (IQR) Before intervention, systolic: intervention 137 (124 to 150), control 130 (116 to 149) Before intervention, diastolic: intervention 77 (70 to 83), control 71 (65 to 80) 3 months, systolic: intervention 140 (130 to 160), control 140 (124 to 150) 3 months, diastolic: intervention 80 (70 to 85), control 76 (70 to 82) 6 months, systolic: intervention 149 (130 to 159), control 138 (130 to 150) 6 months, diastolic: intervention 80 (70 to 84), control 70 (70 to 80)	
Maasland 2007	12 weeks	Health education + computer programme versus health education alone	Risk factor modification: Blood pressure, Serum cholesterol, Serum Triglyceride, Serum LDL, Body mass Index, Number of cigarettes/smoker, Number of alcoholic drinks/drinker	Number of participants with outcome data available at the end of scheduled follow up/number of participants in group at outset of the trial: intervention 30/33, control 27/32 Change from baseline to 12 weeks (intervention effect and 95% CI) systolic blood pressure: intervention -8.4, control -6.9 (1.5 95% CI -7.7 to 10.8) diastolic blood pressure: intervention -5.4, control -6.2 (-0.8 (95% CI -6.1 to 4.5) serum cholesterol: intervention -1.1, control -1.6 (-0.5 95% CI -1.2 to 0.2) serum triglyceride: intervention -0.6, control -0.6 (00 95% CI -0.7 to 0.7) serum LDL: intervention -1.2, control -1.4 (-0.2 95% CI -1.0 to 0.5) body mass index: intervention 0.0, control 0.3 (0.3 95% CI -0.3 to 0.8)	

Modification of health related behaviours: summary of results

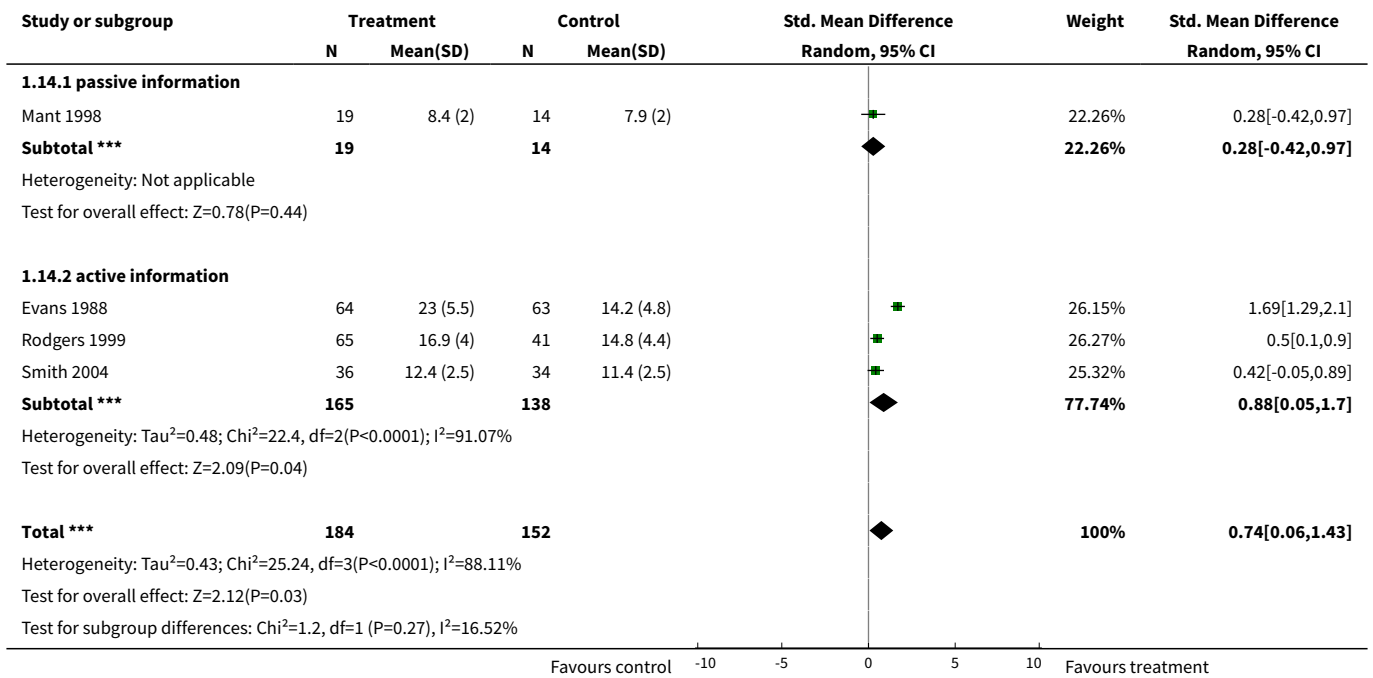
Study	Follow-up	Comparison	Outcome measure	Results	Notes
				number of cigarettes/smoker: intervention -20.1, control -13.2 (6.9 95% CI -16.2 to 30.1) number of alcoholic drinks/drinker: intervention -0.8, control -0.6 (0.2 95% CI -0.6 to 1.0)	
Rodgers 1999	6 months	Education programme versus usual care	Lifestyle and risk factor modifications: smoking, blood pressure, and medication	Number of participants with outcome data available at the end of scheduled follow up/number of participants in group at outset of the trial: intervention 66/121, control 51/83 Smoking: present smoker: intervention 14 (21%), control 14 (28%) smoked 6 months ago: intervention 25 (38%), control 17 (33%) blood pressure, checked since leaving hospital: intervention 61 (92%), control 48 (94%) Medication aspirin: intervention 36 (62%), control 31 (72%) dipyridamole: intervention 2 (3%), control 2 (5%) warfarin: intervention 10 (17%), control 6 (14%)	Smoking: present smoking P = 0.44 Smoked six months ago: P = 0.61 Blood pressure checked since leaving hospital: P = 0.74 Medication: aspirin: P = 0.29, dipyridamole: P = 0.66, warfarin: P = 0.76

Analysis 1.13. Comparison 1 Passive or active information versus control, Outcome 13 Death.





Analysis 1.14. Comparison 1 Passive or active information versus control, Outcome 14 Carer knowledge.

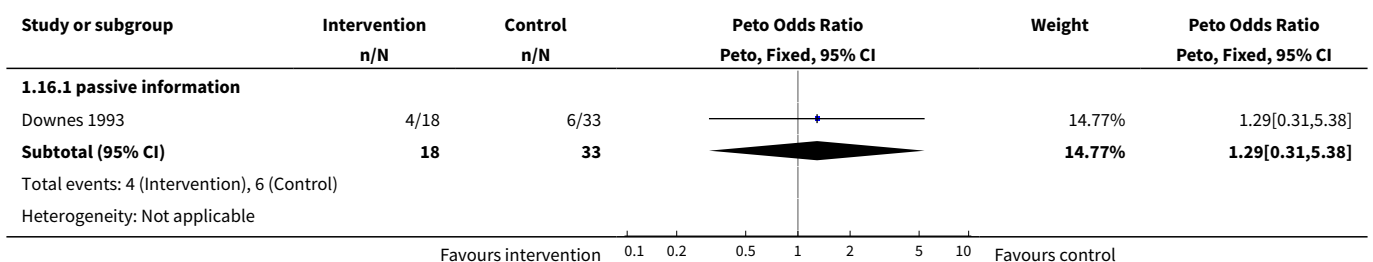


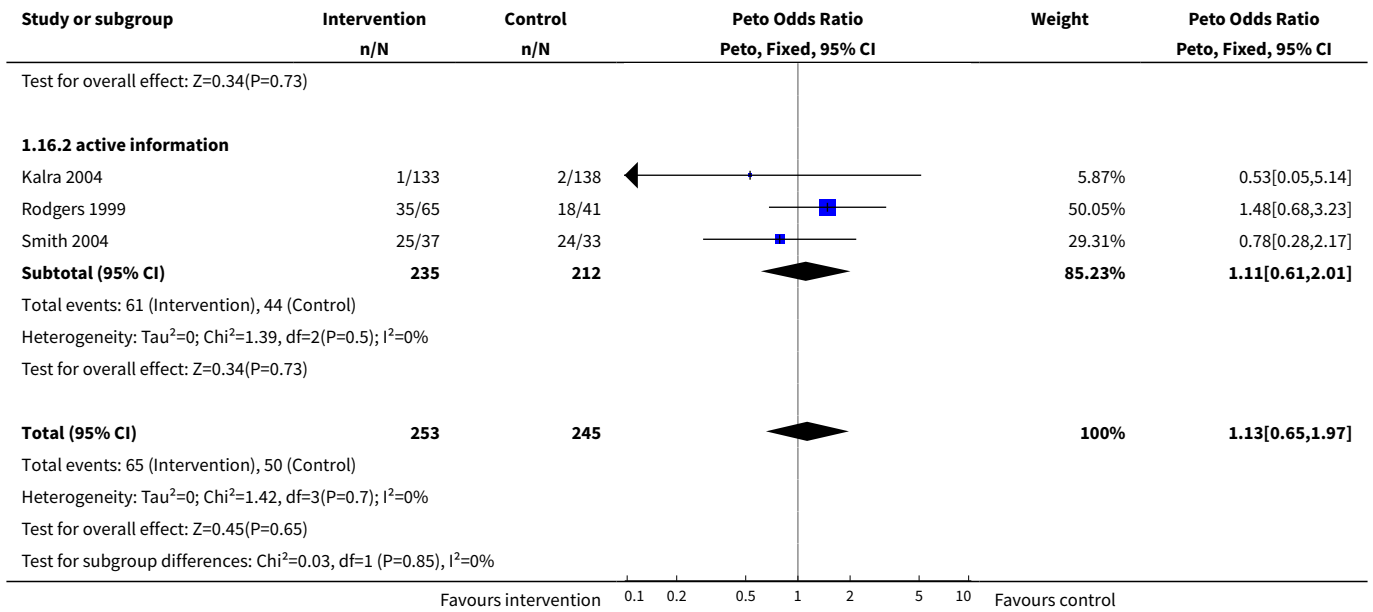
Analysis 1.15. Comparison 1 Passive or active information versus control, Outcome 15 Carer emotional outcome: summary of results.

Carer emotional outcome: summary of results						
Study	Follow-up	Comparison	Outcome measure	Results	Notes	
Downes 1993	6 months	Information pack versus no intervention	Hospital Anxiety and Depression Scale; Depression sub-scale	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 22/?35, control 18/?35 Mean score Baseline: depression: intervention 6.3 (SD 4.0), control 5.4 (SD 3.7) 6 months:		

Carer emotional outcome: summary of results					
Study	Follow-up	Comparison	Outcome measure	Results	Notes
				depression: intervention 5.8 (SD 5.2), control 5.1 (SD 3.2)	
Draper 2007	4 weeks and 3 months	Education programme versus usual care (wait control)	28-item General Health Questionnaire	Number of participants with outcome data at final follow-up: intervention 17/19, wait control 18/20 Mean (SD) Intervention: baseline: 6.26 (5.67) week 4: 3.21 (4.20)* week 16: 4.26 (5.27) Control: baseline: 5.17 (4.11) week 4: not measured week 16: 6.28 (7.01)	* statistically significant result P = 0 .006
Johnston 2007	8 weeks (post intervention) and 6 months from baseline	Post discharge workbook intervention including information and audio relaxation tape versus usual care	Hospital Anxiety and Depression scale (anxiety and depression subscales reported separately)	Number of participants with outcome data at the outset of the trial: intervention 82, control 90 Pre-intervention Anxiety Mean (SD) Intervention 7.64 (4.89) Control 7.08 (4.01) Pre-intervention depression Mean (SD) Intervention 5.65 (4.27) Control 4.77 (3.9) Post-intervention data not reported	Reported no significant group by time interaction (P > 0.05) on total HADS or on anxiety or depression sub-scales
Kalra 2004	12 months	Education sessions + hands on training versus conventional care	Caregiver Burden Scale	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 123/151, control 128/149 Median scores at 12 months: intervention 32 (IQR 27 to 41), control 41 (IQR 36 to 50)*	* statistically significant result P = 0 .0001
Mant 1998	6 months	Information pack versus no intervention	Caregiver Strain Index	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 27/32, control 19/24 Mean score: intervention 3.9 (SD 3.7), control 4.1 (SD 2.74)	

Analysis 1.16. Comparison 1 Passive or active information versus control, Outcome 16 Carer emotional outcome: psychological distress.





Analysis 1.17. Comparison 1 Passive or active information versus control, Outcome 17 Carer social activities: summary of results.

Carer social activities: summary of results					
Study	Follow-up	Comparison	Outcome measure	Results	Notes
Kalra 2004	12 months	Education sessions + hands on training versus conventional care	Frenchay Activities Index	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 133/151, control 133/149 Median score at 1 year: intervention 27 (23 to 30), control 26 (24 to 30)	

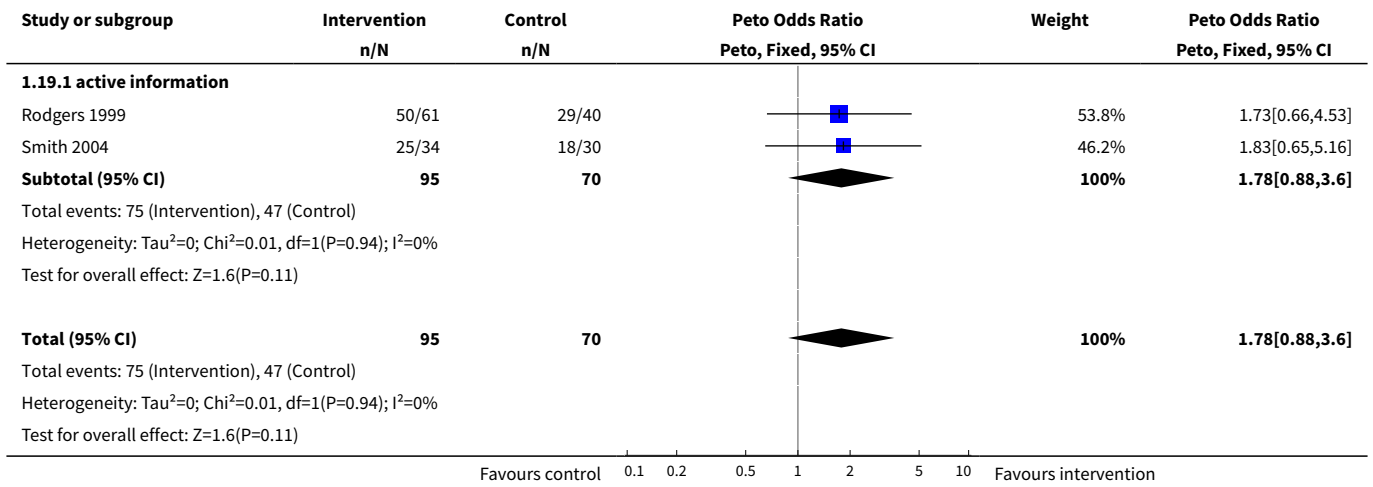
Analysis 1.18. Comparison 1 Passive or active information versus control, Outcome 18 Carer perceived health status and quality of life: summary of results.

Carer perceived health status and quality of life: summary of results					
Study	Follow-up	Comparison	Outcome measure	Results	Notes
Kalra 2004	3 months and 1 year	Education sessions + hands on training versus conventional care	EuroQuol visual analogue scale Quality adjusted life years	Number of participants with outcome data available at the end of scheduled follow up/number of participants in group at outset of the trial: intervention 112/151, control 120/149 EuroQuol visual analogue scale Median (IQR) Before intervention: intervention 90 (80 to 95), control 85 (80 to 90) 3 months: intervention 80 (71 to 90), control 70 (60 to 80)*	statistically significant difference *P = 0.0001 †P = 0.0001

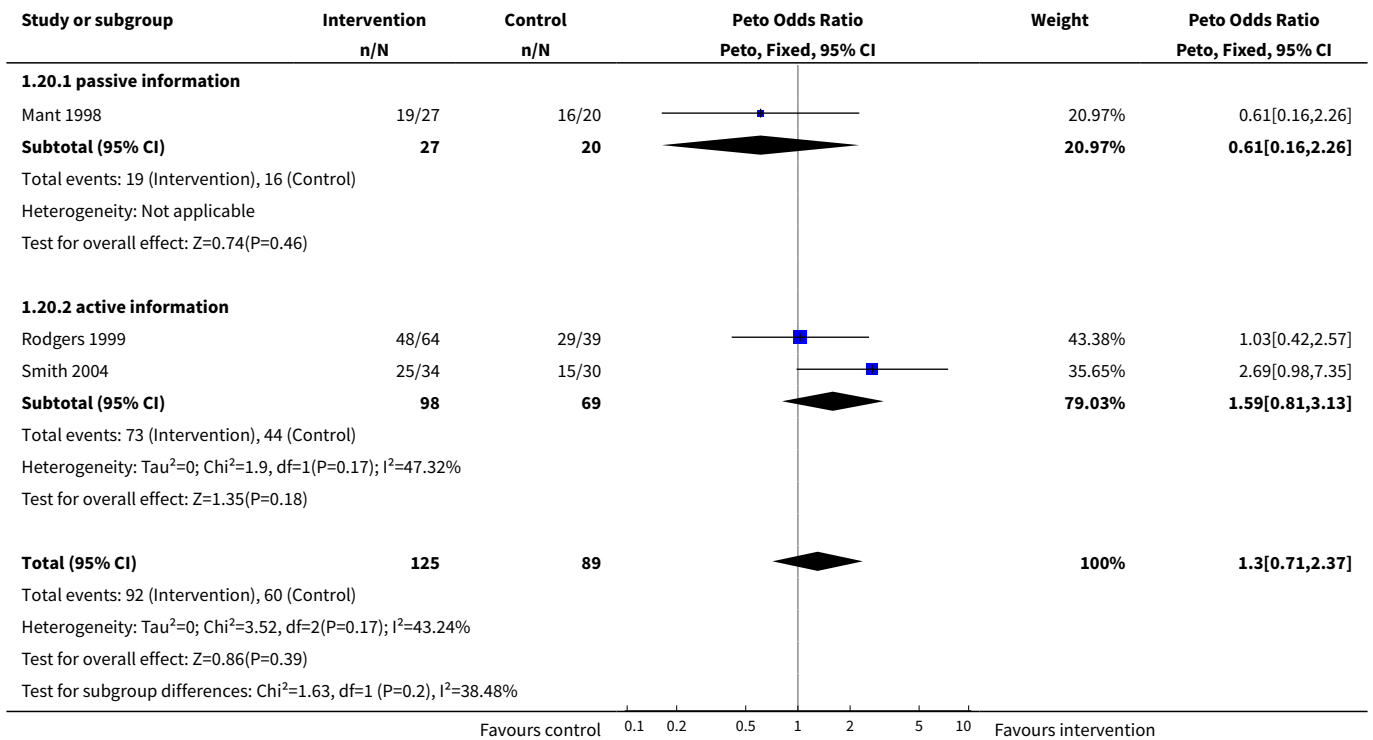
Carer perceived health status and quality of life: summary of results

Study	Follow -up	Comparison	Outcome measure	Results	Notes
				1 year: intervention 80 (70 to 90), control 70 (60 to 80)† Quality adjusted life years mean (SD) Pre-intervention: intervention 0.94 (SD 0.10), control 0.94 (SD 0.14) 1 year: intervention 0.91 (SD 0.11), control 0.90 (SD 0.14)	
Larson 2005	6 months and 1 year	Education programme + support versus regular information and possibility of attending 1 open session	General quality of life visual analogue scale Bradley's well-being questionnaire LISS questionnaire (life situation among spouses after stroke event) EuroQol visual analogue scale	Number of participants with outcome data available at the end of scheduled follow up/number of participants in group at outset of the trial: intervention 46/50, control 45/50 Mean (SD) General quality of life visual analogue scale: Before intervention: intervention 60.08 (22.79), control 60.22 (22.57) 6 months: intervention 63.04 (22.35), control 63.87 (20.45) 1 year: intervention 68.00 (22.89), control 66.78 (20.22) Bradley's well-being questionnaire General well being: Before intervention: intervention 25.28 (5.03), control 25.28 (5.33) 6 months: intervention 25.87 (6.57), control 24.14 (6.57) 12 months: intervention 24.57 (5.87), control 25.91 (6.20) LISS-questionnaire: Life situation total score : Before intervention: intervention 46.47 (10.29), control 47.54 (9.42) 6 months: intervention 48.43 (9.82), control 47.48 (9.26) 12 months: intervention 48.59 (10.91), control 49.11 (9.66) EuroQol visual analogue scale: Before intervention: intervention 72.35 (18.54), control 77.98 (20.18) 6 months: intervention 76.91 (16.39), control 76.85 (18.02) 12 months: intervention 73.63 (17.98), control 77.27 (16.77)	

Analysis 1.19. Comparison 1 Passive or active information versus control, Outcome 19 Carer satisfaction with information about recovery and rehabilitation.



Analysis 1.20. Comparison 1 Passive or active information versus control, Outcome 20 Carer satisfaction with information about allowances and services.



Analysis 1.21. Comparison 1 Passive or active information versus control, Outcome 21 Cost to health and social services: summary of results.

Cost to health and social services: summary of results					
Study	Follow-up	Comparison	Outcome measure	Results	Notes
Kalra 2004	12 months	Education sessions + hands on training versus conventional care	Costs in first year after onset of stroke	Costs: total health and social care costs over one year significantly lower for intervention group, mean difference £4043 (EUR 6072, \$7249) 95% CI -£6544 to - £1595	

Analysis 1.22. Comparison 1 Passive or active information versus control, Outcome 22 Self management: summary of results.

Self management: summary of results					
Study	Follow-up	Comparison	Outcome measure	Results	Notes
Frank 2000	1 month	Workbook + home visits and telephone contact versus wait control	Recovery Locus of Control Scale (RLOC) Perceived Health Competencies Scale (PHCS)	Number of participants with outcome data available at the end of scheduled follow up/number of participants in group at outset of the trial: intervention 19/20, control 20/21 Mean (SD) RLOC Before intervention: intervention 36.10 (4.93), control 35.50 (5.23) 1 month: intervention 36.42 (5.56), control 37.55 (4.08) PHCS: Before intervention: intervention 28.05 (5.91), control 26.80 (5.23) 1 month: intervention 29.21 (5.97), control 26.95 (5.49)	
Hoffmann 2007	3 months	Computer-generated tailored written information versus stroke fact sheets	Self efficacy to perform self-management behaviours scale	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 66/69, control 67/69 Mean (SD) Before intervention: Section 1 (to get information about disease): intervention 8.1(2.3), control 7.9 (2.5) Section 2 (to obtain help from family, community and friends): intervention 7.9 (1.8), control 8.1 (1.5) Section 3 (to communicate with the doctor): intervention 8.6 (1.8), control 9.1 (1.7) Section 4 (to control/manage depression): intervention 7.7 (2.0), control 7.8 (1.8) Section 5 (to manage the disease in general): intervention 7.8 (1.8), control 8.0 (1.9)	

Self management: summary of results					
Study	Follow-up	Comparison	Outcome measure	Results	Notes
				Section 6 (to manage symptoms): intervention 7.3 (2.0), control 7.7 (1.8) Mean change scores 0 to 3 months (95% confidence intervals) 3 months: Section 1 (to get information about the disease): intervention 0.2, control 1.6 (-1.5 to 1.1) Section 2 (to obtain help from family, community, and friends): intervention 0.0, control 0.2 (-0.8 to 0.3) Section 3 (to communicate with the doctor): intervention 0.3, control -0.1 (-0.2 to 1.1) Section 4 (to control/manage depression): intervention 0.0, control 0.3 (-0.8 to 0.2) Section 5 (to manage the disease in general): intervention 0.4, control 0.3 (-0.3 to 0.7) Section 6 (to manage symptoms): intervention 0.0, control -0.2 (-0.5 to 0.9)	

Analysis 1.23. Comparison 1 Passive or active information versus control, Outcome 23 Family functioning and patient adjustment: summary of results.

Family functioning and patient adjustment: summary of results					
Study	Follow-up	Comparison	Outcome measure	Results	Notes
Evans 1988	6 months and 1 year	Education versus routine care	Personal Adjustment and Role Skills Scale (PARS) (patient) Family Assessment Device (FAD) (carer)	Number of participants with outcome data available at the end of scheduled follow up/number of participants in group at outset of the trial: intervention 64/70, control 63/70 Mean scores PARS Before intervention: intervention 50.6 (SD 5.1), control 51.4 (SD 5.60) 6 months: intervention 40.1 (SD 5.8), control 37.6 (SD 5.1) 1 year: 40.5 (SD 6.1), control 39.1 (SD 5.7) FAD problem solving Before intervention: intervention 2.0 (SD 0.40), control 2.1 (SD 0.37) 6 months: intervention 2.2 (SD 0.33)*, control 2.3 (SD 0.35) 1 year: intervention 2.2 (SD 0.37)*, control 2.4 (SD 0.35) Role assignments Before intervention: intervention 2.0 (SD 0.33), control 2.0 (SD 0.35)	*P < 0.01 different from control

Family functioning and patient adjustment: summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
				6 months: intervention 2.2 (SD 0.35), control 2.2 (SD 0.42)	
				1 year: intervention 2.3 (SD 0.39), control 2.3 (SD 0.39)	
				Communication	
				Before intervention: intervention 2.0 (SD 0.39), control 2.0 (SD 0.37)	
				6 months: intervention 2.2 (SD 0.33)*, control 2.3 (SD 0.35)	
				1 year: intervention 2.1 (SD 0.44)*, control 2.3 (SD 0.40)	
				Behaviour control	
				Before intervention: 2.00 (SD 0.36), control 2.0 (SD 0.36)	
				6 months: intervention 2.2 (SD 0.35), control 2.2 (SD 0.36)	
				1 year: intervention 2.2 (SD 0.39), control 2.2 (SD 0.44)	
				Affective involvement	
				Before intervention: intervention 2.0 (SD 0.36), control 2.0 (SD 0.35)	
				6 months: intervention 2.2 (SD 0.38), control 2.2 (SD 0.36)	
				1 year: intervention 2.1 (0.44)*, control 2.3 (SD 0.41)	
				Affective responsiveness	
				Before intervention: intervention 2.0 (SD 0.36), control 2.0 (SD 0.35)	
				6 months: intervention 2.2 (SD 0.41), control 2.2 (SD 0.37)	
				1 year: intervention 2.2 (SD 0.39), control 2.3 (0.53)	
				Global family function	
				Before intervention: 1.9 (SD 0.47), control 2.0 (SD 0.35)	
				6 months: 2.0 (SD 0.41)*, control 2.2 (SD 0.40)	
				1 year 2.1 (SD 0.42)*, control 2.3 (SD 0.37)	

APPENDICES

Appendix 1. Cochrane search strategy

- #1MeSH descriptor Health Education, this term only
- #2MeSH descriptor Health Promotion, this term only
- #3MeSH descriptor Patient Education explode all trees
- #4MeSH descriptor Health Knowledge, Attitudes, Practice, this term only
- #5MeSH descriptor Telephone, this term only
- #6MeSH descriptor Pamphlets, this term only
- #7MeSH descriptor Books, this term only
- #8MeSH descriptor Manuals, this term only
- #9MeSH descriptor Audiovisual Aids, this term only
- #10MeSH descriptor Counseling, this term only

#11MeSH descriptor Tape Recording, this term only
 #12MeSH descriptor Video Recording explode all trees
 #13MeSH descriptor Patient Participation explode all trees
 #14(patient* particip*):ti,ab,kw or (patient* complian*):ti,ab,kw
 #15MeSH descriptor Patient Compliance explode all trees
 #16MeSH descriptor Patient Satisfaction explode all trees#17(patient* satis*):ti,ab,kw
 #18(doctor* patient* communic*):ti,ab,kw or (patient* doctor* communic*):ti,ab,kw or (nurse* patient* communic*):ti,ab,kw or (patient* nurse* communic*):ti,ab,kw
 #19(professional* patient* communic*):ti,ab,kw or (patient* professional* communic*):ti,ab,kw
 #20(consumer* health inform*):ti,ab,kw
 #21(#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20)
 #22(patient*):ti,ab,kw or (inpatient*):ti,ab,kw or (care*):ti,ab,kw or (caregiver*):ti,ab,kw or (family):ti,ab,kw NEAR/5 (education):ti,ab,kw or (information):ti,ab,kw or (support):ti,ab,kw or (knowledge):ti,ab,kw or (counsel*):ti,ab,kw
 #23(patient*):ti,ab,kw or (inpatient*):ti,ab,kw or (care*):ti,ab,kw or (caregiver*):ti,ab,kw or (family):ti,ab,kw NEAR/5 (book*):ti,ab,kw or (leaflet*):ti,ab,kw or (pack*):ti,ab,kw or (video*):ti,ab,kw or (tape*):ti,ab,kw or (manual*):ti,ab,kw or (advice*):ti,ab,kw
 #24(education):ti,ab,kw or (information):ti,ab,kw or (teach*):ti,ab,kw NEAR/5 (book*):ti,ab,kw or (leaflet*):ti,ab,kw or (pack*):ti,ab,kw or (video*):ti,ab,kw or (tape*):ti,ab,kw or (manual*):ti,ab,kw or (advice*):ti,ab,kw
 #25(education):ti,ab,kw or (information):ti,ab,kw or (teach*):ti,ab,kw NEAR/5 (program*):ti,ab,kw or (intervention*):ti,ab,kw or (material*):ti,ab,kw or (resource*):ti,ab,kw
 #26(#21 OR #22 OR #23 OR #24 OR #25)
 #27MeSH descriptor Cerebrovascular Disorders explode all trees
 #28(stroke*):ti,ab,kw or (cerebrovascular*):ti,ab,kw or (transient ischemic attack*):ti,ab,kw or (transient ischaemic attack*):ti,ab,kw
 #29MeSH descriptor Hemiplegia, this term only
 #30(asphasi*):ti,ab,kw or (dysphasi*):ti,ab,kw or (hemianopi*):ti,ab,kw or (hemiplegi*):ti,ab,kw or (hemipar*):ti,ab,kw
 #31(#27 OR #28 OR #29 OR #30)
 #32(#26 AND #31)
 #33(#32), from 2011 to 2012
 #34(#32), from 2011 to 2012
 #35(#32), from 2011 to 2012
 #36(#32), from 2011 to 2012
 #37(#32), from 2011 to 2012

Appendix 2. MEDLINE search strategy

The following search strategy was used for MEDLINE and was modified to suit other databases (/ denotes MeSH headings, .tw denotes words in the title and abstract, \$ is the truncation symbol and adj5 denotes word combinations within 5 words)

1. Health education /
2. Health promotion/
3. Patient education/
4. Knowledge attitudes, practice/
5. Telephone/
6. Pamphlets/
7. Books/
8. Manuals/
9. Audiovisual aids/
10. Counseling/
11. Tape recording/
12. Exp Video recording/
13. Exp Patient participation/
14. Patient\$ particip\$.tw.
15. Exp Patient compliance/
16. Patient\$ complian\$.tw.
17. Exp Patient satisfaction/
18. Patient\$ satis\$.tw.
19. (Doctor\$ patient\$ communic\$ or Patient\$ doctor\$ communic\$).tw.
20. (Nurse\$ patient\$ communic\$ or Patient\$ nurse\$ communic\$).tw.
21. (Professional\$ patient\$ communic\$ or Patient\$ professional\$ communic\$).tw.
22. Consumer\$ health inform\$.tw.
23. Or/1-22
24. (Patient\$ or inpatient\$ or care\$ or care?giver\$ or family).tw.
25. (Education or information or support or knowledge or counsel\$).tw.

26. 24 adj5 25
27. (Book\$ or leaflet\$ or pack\$ or video\$ or tape\$ or telephone or manual\$ or advice).tw.
28. 24 adj5 27
29. (Education\$ or information\$ or teach\$).tw.
30. 29 adj5 27
31. (Program\$ or intervention\$ or material\$ or resource\$).tw.
32. 29 adj5 31
33. 23 or 26 or 28 or 30 or 32
34. Exp Cerebrovascular disorders/
35. Stroke\$.tw.
36. Cerebrovascular\$.tw.
37. Transient Isch?emic attack\$.tw
38. Hemiplegia/
39. (Aphasi\$ or dysphasi\$ or hemianopi\$).tw.
40. (Hemiplegi\$ or hemipar\$).tw.
41. Or/34-40
42. 33 and 41

Appendix 3. EMBASE search strategy

1. cerebrovascular disease/
2. basal ganglion hemorrhage/
3. cerebral artery disease/
4. cerebrovascular accident/
5. stroke/
6. stroke patient/ or stroke unit/
7. vertebrobasilar insufficiency/
8. exp carotid artery disease/
9. exp brain hemangioma/
- 10.exp brain hematoma/
- 11.exp brain hemorrhage/
- 12.brain infarction/ or brain infarction size/ or brain stem infarction/ or cerebellum infarction/
- 13.exp Brain Ischemia/
- 14.exp Cerebrovascular Malformation/
- 15.exp intracranial aneurysm/
- 16.exp occlusive cerebrovascular disease/
- 17.brain injury/
- 18.brain stem injury/ or artery dissection/
- 19.cerebellum injury/
- 20.exp carotid artery/
- 21.exp carotid artery surgery/
- 22.carotid endarterectomy/
- 23.*heart atrium septum defect/ or heart foramen ovale/
- 24.*heart atrium fibrillation/
- 25.paradoxical embolism/
- 26.exp aphasia/ or hemiplegia/ or hemiparesis/ or paresis/ or spastic paresis/ or pseudobulbar palsy/ or hemianopia/ or homonymous hemianopia/ or dysphagia/ or dysarthria/ or dysphasia/ or spasticity/ or apraxia/ or dyspraxia/ or hemiballism/
- 27.(stroke or poststroke or post-stroke or cerebrovasc\$ or brain vasc\$ or cerebral vasc\$ or cva\$ or apoplex\$ or isch?emi\$ attack\$ or tia\$1 or neurologic\$ deficit\$ or SAH or AVM).tw.
- 28.((brain\$ or cerebr\$ or cerebell\$ or cortical or vertebrobasilar or hemisphere\$ or intracran\$ or intracerebral or infratentorial or supratentorial or MCA or anterior circulation or posterior circulation or basal ganglia) adj5 (isch?emi\$ or infarct\$ or thrombo\$ or emboli \$ or occlus\$ or hypox\$ or vasospasm or obstruction or vasculopathy)).tw.
- 29.((lacunar or cortical) adj5 infarct\$).tw.
- 30.((brain\$ or cerebr\$ or cerebell\$ or intracerebral or intracran\$ or parenchymal or intraventricular or infratentorial or supratentorial or basal gangli\$ or subarachnoid or putamen or posterior fossa) adj5 (haemorrhage\$ or hemorrhage\$ or haematoma\$ or hematoma\$ or bleed\$)).tw.

- 31.((brain or cerebral or intracranial or communicating or giant or basilar or vertebral artery or berry or saccular or ruptured) adj5 aneurysm\$).tw.
- 32.(vertebral artery dissection or cerebral art\$ disease\$).tw.
- 33.((brain or intracranial or basal ganglia or lenticulostriate) adj5 (vascular adj5 (disease\$ or disorder or accident or injur\$ or trauma\$ or insult or event))).tw.
- 34.((isch?emic or apoplectic) adj5 (event or events or insult or attack\$)).tw.
- 35.((cerebral vein or cerebral venous or sinus or sagittal) adj5 thrombo\$).tw.
- 36.(CVDST or CVT).tw.
- 37.((intracranial or cerebral art\$ or basilar art\$ or vertebral art\$ or vertebrobasilar or vertebral basilar) adj5 (stenosis or isch?emia or insufficiency or arteriosclero\$ or atherosclero\$ or occlus\$)).tw.
- 38.((venous or arteriovenous or brain vasc\$) adj5 malformation\$).tw.
- 39.((brain or cerebral) adj5 (angioma\$ or hemangioma\$ or haemangioma\$)).tw.
- 40.carotid\$.hw.
- 41.(patent foramen ovale or PFO).tw.
- 42.((atrial or atrium or auricular) adj fibrillation).tw.
- 43.asymptomatic cervical bruit.tw.
- 44.(aphasi\$ or apraxi\$ or dysphasi\$ or dysphagi\$ or deglutition disorder\$ or swallow\$ disorder\$ or dysarthri\$ or hemipleg\$ or hemipar\$ or paresis or paretic or hemianop\$ or hemineglect or spasticity or anomi\$ or dynomi\$ or acquired brain injur\$ or hemiball\$).tw.
- 45.((unilateral or visual or hemispacial or attentional or spatial) adj5 neglect).tw.
- 46.or/1-45
- 47.health education/
- 48.health promotion/
- 49.patient education/
- 50.exp patient attitude/
- 51.patient counseling/
- 52.patient guidance/
- 53.patient information/
- 54.exp information/
- 55.patient participation/
- 56.patient\$ particip\$.tw.
- 57.patient compliance/
- 58.patient complian\$.tw.
- 59.patient satisfaction/
- 60.patient\$ satis\$.tw.
- 61.(doctor\$ patient\$ communic\$ or patient\$ doctor\$ communic\$).tw.
- 62.(nurse\$ patient\$ communic\$ or patient\$ nurse\$ communic\$).tw.
- 63.(professional\$ patient\$ communic\$ or patient\$ professional\$ communic\$).tw.
- 64.exp consumer health information/
- 65.consumer\$ health inform\$.tw.
- 66.attitude/
- 67.telephone/
- 68.book/
- 69.exp audiovisual equipment/
- 70.education program/
- 71.teaching/
- 72.education/
- 73.comprehension/
- 74.self help/
- 75.((written or printed or oral) adj1 information).tw.
- 76.(education\$ adj1 method\$).tw.
- 77.((patient\$ or inpatient\$ or carer\$ or care?giver\$ or care?provider or family) adj5 (education\$ or information or support or knowledge or (understand\$ or comprehen\$ or counsel\$ or self?help))).tw.

- 78.((patient\$ or inpatient\$ or carer\$ or care?giver\$ or care?provider\$ or family) adj5 (book\$ or leaflet\$ or pack\$ or video\$ or work?book\$ or tape\$ or telephone or phone or manual\$ or advice)).tw.
- 79.((education\$ or information or teach\$ or self?help) adj5 (book\$ or leaflet\$ or pack\$ or video\$ or work?book\$ or tape\$ or telephone or phone or manual\$ or advice)).tw.
- 80.((education\$ or information or teach\$ or self?help) adj5 (program\$ or intervention\$ or material\$ or resource\$ or meeting\$ or session \$ or strateg\$ or work?shop\$ or visit\$)).tw.
- 81.or/47-80
- 82.randomized controlled trial/
 83.randomization/
 84.controlled study/
 85.control group/
 86.clinical trial/ or phase 1 clinical trial/ or phase 2 clinical trial/ or phase 3 clinical trial/ or phase 4 clinical trial/ or controlled clinical trial/
 87.crossover procedure/
 88.double blind procedure/
 89.single blind procedure/ or triple blind procedure/
 90.latin square design/
 91.parallel design/
 92.placebo/
 93.multicenter study/
 94.experimental design/ or experimental study/ or quasi experimental study/
 95.experimental therapy/
 96.drug comparison/ or drug dose comparison/
 97.drug screening/
 98.evaluation/ or "evaluation and follow up"/ or evaluation research/ or clinical evaluation/
 99.methodology/
 100'types of study"/
 101research subject/
 102comparative study/
 103'systematic review"/
 104meta analysis/
 105random\$.tw.
 106controlled adj5 (trial\$ or stud\$)).tw.
 107clinical\$ adj5 trial\$).tw.
 108(control or treatment or experiment\$ or intervention) adj5 (group\$ or subject\$ or patient\$)).tw.
 109surgical adj5 (group\$ or subject\$ or patient\$)).tw.
 110quasi-random\$ or quasi random\$ or pseudo-random\$ or pseudo random\$).tw.
 111(multicenter or multicentre or therapeutic) adj5 (trial\$ or stud\$)).tw.
 112(control or experiment\$ or conservative) adj5 (treatment or therapy or procedure or manage\$)).tw.
 113(singl\$ or doubl\$ or tripl\$ or trebl\$) adj5 (blind\$ or mask\$)).tw.
 114coin adj5 (flip or flipped or toss\$)).tw.
 115latin square.tw.
 116versus.tw.
 117(cross-over or cross over or crossover).tw.
 118placebo\$.tw.
 119ham.tw.
 120(assign\$ or alternate or allocat\$ or counterbalance\$ or multiple baseline).tw.
 121controls.tw.
 122treatment\$ adj6 order).tw.
 123meta-analy\$ or metaanaly\$ or meta analy\$ or systematic review or systematic overview).tw.
 124r/82-123
 125human/
 126nonhuman/
 127125 and 126

12&126 not 127
 12&124 not 128
 130&6 and 129
 131&130 and 81
 132&limit 131 to yr="2008 - 2010"
 133&limit 132 to english language

Appendix 4. CINAHL search strategy

S154 S63 and S128 and S153
 S153 S129 or S130 or S131 or S132 or S133 or S134 or S135 or S136 or S137 or S138 or S139 or S140 or S141 or S142 or S143 or S144 or S145
 or S146 or S147 or S148 or S149 or S150 or S151 or S152
 S152 TX "meta*analys*" or TX "meta analys*" or TX "systematic review*"
 S151 TX counterbalance* or TX ("multiple baseline*") or TX("ABAB design*")
 S150 TX(clin* N10 trial*) or TX (intervention* N10 trial*) or TX (compar* N10 trial*) or TX (experiment* N10 trial*) or TX (preventive N10
 trial*) or TX (therapeutic N10 trial*)
 S149 TX (crossover or "cross over" or placebo* or control* or factorial or sham*)
 S148 TX (trebl* N25 blind*) or TX (trebl* N25 mask*)
 S147 TX (tripl* N25 blind*) or TX(tripl* N25 mask*)
 S146 TX (doubl* N25 blind*) or TX (doubl* N25 mask*)
 S145 TX (singl* N25 blind*) or TX (singl* N25 mask*)
 S144 TX random*
 S143 PT ("clinical trial") or PT ("systematic review")
 S142 MH community trials or MH experimental studies or MH one-shot case study or MH pretest-posttest design or MH solomon four-group
 design or MH static group comparison or MH study design
 S141 MH clinical nursing research or MH clinical research
 S140 MH meta analysis
 S139 MH placebos
 S138 MH nonrandomized trials
 S137 MH quasi-experimental studies
 S136 MH factorial design
 S135 MH control group
 S134 MH "control (research)"
 S133 MH comparative studies
 S132 MH clinical trials+
 S131 MH crossover design
 S130 MH random sample+
 S129 MH random assignment
 S128 S64 or S65 or S66 or S67 or S68 or S71 or S74 or S75 or S78 or S79 or S81 or S82 or S85 or S87 or S88 or S94 or S98 or S99 or S100 or
 S102 or S103 or S104 or S105 or S106 or S107 or S108 or S109 or S110 or S111 or S112 or S113 or S114 or S115 or S116 or S117 or S118 or
 S119 or S120 or S123 or S124 or S125 or S126 or S127
 S127 TX (occupational and therapy) or TX(activity and therapy)
 S126 MH cognition disorders+
 S125 MH "activity therapy (iowa nic)"
 S124 MH home occupational therapy or MH occupational therapy
 S123 S121 and S122
 S122 TX (disorder* or therap* or impair* or rehabilitation)
 S121 TX (speech or cognit* or language)
 S120 MH articulation disorders or MH fluency disorders or MH speech disorders
 S119 MH "impaired verbal communication (nanda)"
 S118 MH "rehabilitation, speech and language+"
 S117 MH language disorders
 S116 TX (swallow* and impair*) or TX (swallow* and disorder*) or TX (swallow* and problem*) or TX (swallow* and difficult*)
 S115 TX (dysarthri* or dysphag* or aprax* or dysprax*)
 S114 MH apraxia or MH neurologic manifestations
 S113 MH "swallowing therapy (iowa nic)"
 S112 (MH "Swallowing Impairment (Saba CCC)")
 S111 MH "impaired swallowing (nanda)"
 S110 MH deglutition disorders
 S109 MH communicative disorders
 S108 MH dysarthria

S107 TX ("unilateral neglect" or "neglect syndrome*" or "visual neglect" or hemianop*)
 S106 TX (aphasi* or dysphasi* or hemipleg* or hemipar*)
 S105 MH "unilateral neglect (nanda)"
 S104 MH hemiplegia
 S103 MH aphasia+
 S102 S93 and S101
 S101 (MH "Embolism and Thrombosis (Non-Cinahl)+")
 S100 TX atrial fibrillation
 S99 MH atrial fibrillation
 S98 S72 and S97
 S97 S95 and S96
 S96 TX (fistula* or malformation* or aneurysm*)
 S95 TX (arteriovenous or venous)
 S94 (S89 and S93)
 S93 (S90 or S91 or S92)
 S92 MH cerebral arteries
 S91 MH cerebral veins
 S90 MH brain+
 S89 MH arteriovenous malformations+
 S88 TX carotid*
 S87 (S83 and S86)
 S86 MH arterial occlusive diseases+
 S85 S83 and S84
 S84 MH endarterectomy
 S83 MH carotid arteries
 S82 (MH "Endarterectomy, Carotid")
 S81 (MH "Carotid Arteries/SU")
 S80 TX tia
 S79 TX ("trans* ischaemic attack*" or "trans* ischemic attack*")
 S78 S76 and S77
 S77 TX (intracranial or venous N5 sinus or sagittal N5 venous or sagittal N5 vein or cranial N5 sinus)
 S76 TX thrombo*
 S75 TX "sinus thrombosis"
 S74 S72 and S73
 S73 TX (haemorrhage or hemorrhage or haematoma or hematoma or bleed* or aneurysm)
 S72 TX (cerebral or intracerebral or intracranial or parenchymal or brain* or intraventricular or periventricular or cerebellar or infratentorial or supratentorial or subarachnoid)
 S71 S69 and S70
 S70 TX (infarct* or ischaemi* or ischemi* or thrombo* or emboli* or vasospasm* or apople*)
 S69 TX (cerebral or cerebellar or brain* or vertebrobasilar)
 S68 TX "cerebral vascular*"
 S67 TX cerebrovasc*
 S66 TX cva*
 S65 TX stroke*
 S64 MH cerebrovascular disorders or MH carotid artery diseases+ or MH cerebral aneurysm or MH "cerebral embolism and thrombosis" or MH cerebral ischemia+ or MH cerebral vasospasm or MH intracranial hemorrhage+ or MH vertebral artery dissections or MH stroke patients or MH stroke units
 S63 S1 or S2 or S3 or S4 or S5 or S6 or S7 or S8 or S9 or S10 or S11 or S12 or S13 or S14 or S15 or S16 or S17 or S18 or S19 or S20 or S21 or S22 or S23 or S24 or S25 or S26 or S27 or S28 or S29 or S30 or S31 or S32 or S33 or S34 or S35 or S36 or S37 or S38 or S39 or S40 or S41 or S42 or S43 or S44 or S45 or S46 or S47 or S48 or S49 or S50 or S51 or S52 or S53 or S54 or S55 or S56 or S57 or S58 or S59 or S60 or S61 or S62
 S62 TX (education* N5 resource* or information* N5 resource*)
 S61 TX (education* N5 material* or information* N5 material*)
 S60 TX (education* N5 intervention* or information* N5 intervention*)
 S59 TX (education* N5 program* or information* N5 program*)
 S58 TX (education* N5 advice* or information* N5 advice* or material* N5 advice* or resource* N5 advice*)
 S57 TX (education* N5 manual* or information* N5 manual* or material* N5 manual* or resource* N5 manual*)
 S56 TX (education* N5 telephone* or information* N5 telephone* or material* N5 telephone* or resource* N5 telephone*)
 S55 TX (education* N5 phone* or information* N5 phone* or material* N5 phone* or resource* N5 phone*)
 S54 TX (education* N5 tape* or information* N5 tape* or material* N5 tape* or resource* N5 tape*)
 S53 TX (education* N5 video* or information* N5 video* or material* N5 video* or resource* N5 video*)
 S52 TX (education* N5 pack* or information* N5 pack* or material* N5 pack* or resource* N5 pack*)
 S51 TX (education* N5 leaflet* or information* N5 leaflet* or material* N5 leaflet* or resource* N5 leaflet*)

S50 TX (education* N5 book* or information* N5 book* or material* N5 book* or resource* N5 book*)
 S49 TX (patient* N5 advice* or inpatient* N5 advice* or care* N5 advice* or caregiver* N5 advice* or "care giver*" N5 advice* or family N5 advice*)
 S48 TX (patient* N5 manual* or inpatient* N5 manual* or care* N5 manual* or caregiver* N5 manual* or "care giver*" N5 manual* or family N5 manual*)
 S47 TX (patient* N5 telephone* or inpatient* N5 telephone* or care* N5 telephone* or caregiver* N5 telephone* or care giver* N5 telephone* or family N5 telephone*)
 S46 TX (patient* N5 phone* or inpatient* N5 phone* or care* N5 phone* or caregiver* N5 phone* or "care giver*" N5 phone* or family N5 phone*)
 S45 TX (patient* N5 video* or inpatient* N5 video* or care* N5 video* or caregiver* N5 video* or "care giver*" N5 video* or family N5 video*)
 S44 TX (patient* N5 video* or inpatient* N5 video* or care* N5 video* or caregiver* N5 video* or "care giver*" N5 video* or family N5 video*)
 S43 TX (patient* N5 pack* or inpatient* N5 pack* or care* N5 pack* or caregiver* N5 pack* or "care giver*" N5 pack* or family N5 pack*)
 S42 TX (patient* N5 leaflet* or inpatient* N5 leaflet* or care* N5 leaflet* or caregiver* N5 leaflet* or "care giver*" N5 leaflet* or family N5 leaflet*)
 S41 TX (patient* N5 book* or inpatient* N5 book* or care* N5 book* or caregiver* N5 book* or "care giver*" N5 book* or family N5 book*)
 S40 TX (Family N5 education or family N5 information or family N5 support or family N5 Knowledge or family N5 counsel*)
 S39 TX ("care giver" N5 education or "care giver" N5 information or "care giver" N5 support or "care giver" N5 Knowledge or "care giver" N5 counsel*)
 S38 TX (caregiver N5 education or caregiver N5 information or caregiver N5 support or caregiver N5 Knowledge or caregiver N5 counsel*)
 S37 TX (care* N5 education or care* N5 information or care* N5 support or care* N5 Knowledge or care* N5 counsel*)
 S36 TX (inpatient* N5 education or inpatient* N5 information or inpatient* N5 support or inpatient* N5 Knowledge or inpatient* N5 counsel*)
 S35 TX (patient* N5 education or patient* N5 information or patient* N5 support or patient* N5 Knowledge or patient* N5 counsel*)
 S34 TX ("consumer* health inform*")
 S33 MH consumer health information
 S32 MH health information
 S31 TX (professional* patient* communic*) or TX (patient* nurse* communic*)
 S30 TX ("nurse* patient* communic*") or TX ("patient* nurse* communic*")
 S29 TX ("doctor* patient* communic*") or TX ("patient* doctor* communic*")
 S28 TX ("patient* satis*")
 S27 MH patient satisfaction
 S26 TX ("patient complian*")
 S25 MH patient compliance+
 S24 TX (patient* N1 particip*)
 S23 TX (patient* N1 consumer*)
 S22 MH consumer participation
 S21 MH videorecording
 S20 MH audiorecording
 S19 (MH "Teaching, Guidance, and Counseling (Omaha)")
 S18 (MH "Counseling Service (Saba CCC)")
 S17 MH counseling "(Iowa Nic)"
 S16 MH counseling
 S15 MH optical disks+
 S14 MH multimedia
 S13 MH teaching materials
 S12 MH audiovisuals
 S11 MH books
 S10 MH pamphlets
 S9 MH telephone information services
 S8 MH telephone consultation "(IOWA NIC)"
 S7 MH telephone
 S6 MH information resources
 S5 MH attitude to health
 S4 MH health knowledge
 S3 MH patient education
 S2 MH health promotion
 S1 MH health education

Appendix 5. PsycINFO search strategy

1. Health Education/
2. health promotion/

3. client education/
4. health knowledge/
5. instructional media/ or educational audiovisual aids/ or reading materials/
6. printed communications media/
7. books/
8. counseling/ or rehabilitation counseling/
9. internet/
10. television/
11. teaching machines/ or computer assisted instruction/ or programmed instruction/
12. videotapes/
13. computer mediated communication/
14. client attitudes/
15. group counseling/
16. written communication/ or verbal communication/
17. treatment compliance/
18. client participation/
19. client satisfaction/
20. ((patient\$ or client\$) adj particip\$).tw.
21. ((patient\$ or client\$) adj complian\$).tw.
22. ((patient\$ or client\$) adj satisfact\$).tw.
23. patient\$ doctor\$ communicat\$.tw.
24. doctor\$ patient\$ communicat\$.tw.
25. patient\$ nurse\$ communicat\$.tw.
26. nurse\$ patient\$ communicat\$.tw.
27. patient\$ professional\$ communicat\$.tw.
28. (professional\$ adj (client\$ or patient\$) adj communicat\$).tw.
29. "provider to client communication".id.
30. "therapeutic communication".id.
31. educational programs/
32. teaching/
33. education/
34. exp verbal comprehension/
35. comprehension/
36. consumer\$ health information.tw.
37. or/1-36
38. ((patient\$ or client\$ or inpatient\$ or carer\$ or care?giver\$ or care?provider\$ or family) adj3 (education or information or support or teach\$ or training or knowledge or counsel\$)).tw.
39. ((patient\$ or client\$ or inpatient\$ or carer\$ or care?giver\$ or care?provider\$ or family) adj5 (book\$ or leaflet\$ or sheet\$ or pack\$ or video\$ or tape\$ or telephone or phone or internet or www or manual\$ or advice)).tw.
40. ((education or information or support or teach\$ or training or knowledge or counsel\$) adj5 (book\$ or leaflet\$ or sheet\$ or pack\$ or video\$ or tape\$ or telephone or phone or internet or www or manual\$ or advice)).tw.
41. ((program\$ or intervention or material\$1 or resource\$1) adj5 (education or information or support or teach\$ or training or knowledge or counsel\$)).tw.
42. 37 or 38 or 39 or 40 or 41
43. exp cerebrovascular disorders/
44. exp traumatic brain injury/
45. exp carotid arteries/
46. *"fibrillation (heart)"/
47. (stroke or poststroke or post-stroke or cerebrovasc\$ or brain vascul\$ or cerebral vascul\$ or cva\$ or apoplex\$ or isch?emi\$ attack\$ or tia\$1 or neurologic\$ deficit\$ or SAH or AVM).tw.
48. ((brain\$ or cerebr\$ or cerebell\$ or cortical or vertebrobasilar or hemispher\$ or intracran\$ or intracerebral or infratentorial or supratentorial or MCA or anterior circulation or posterior circulation or basal ganglia) adj5 (isch?emi\$ or infarct\$ or thrombo\$ or emboli\$ or occlus\$ or hypox\$ or vasospasm or obstruction or vasculopathy)).tw.

- 49.((lacunar or cortical) adj5 infarct\$).tw.
- 50.((brain\$ or cerebr\$ or cerebell\$ or intracerebral or intracran\$ or parenchymal or intraventricular or infratentorial or supratentorial or basal gangli\$ or subarachnoid or putaminal or putamen or posterior fossa) adj5 (haemorrhage\$ or hemorrhage\$ or haematoma\$ or hematoma\$ or bleed\$)).tw.
- 51.((brain or cerebral or intracranial or communicating or giant or basilar or vertebral artery or berry or saccular or ruptured) adj5 aneurysm \$).tw.
- 52.(vertebral artery dissection or cerebral art\$ disease\$).tw.
- 53.((brain or intracranial or basal ganglia or lenticulostriate) adj5 (vascular adj5 (disease\$ or disorder or accident or injur\$ or trauma\$ or insult or event))).tw.
- 54.((isch?emic or apoplectic) adj5 (event or events or insult or attack\$)).tw.
- 55.((cerebral vein or cerebral venous or sinus or sagittal) adj5 thrombo\$).tw.
- 56.(CVDST or CVT).tw.
- 57.((intracranial or cerebral art\$ or basilar art\$ or vertebral art\$ or vertebrobasilar or vertebral basilar) adj5 (stenosis or isch?emia or insufficiency or arteriosclero\$ or atherosclero\$ or occlus\$)).tw.
- 58.((venous or arteriovenous or brain vasc\$) adj5 malformation\$).tw.
- 59.((brain or cerebral) adj5 (angioma\$ or hemangioma\$ or haemangioma\$)).tw.
- 60.carotid\$.tw.
- 61.(patent foramen ovale or PFO).tw.
- 62.((atrial or atrium or auricular) adj fibrillation).tw.
- 63.asymptomatic cervical bruit.tw.
- 64.exp aphasia/ or hemiplegia/ or hemianopia/ or dysphagia/ or dysarthria/
- 65.(aphasi\$ or apraxi\$ or dysphasi\$ or dysphagi\$ or deglutition disorder\$ or swallow\$ disorder\$ or dysarthri\$ or hemipleg\$ or hemipar \$ or paresis or paretic or hemianop\$ or hemineglect or spasticity or anomi\$ or dysnomi\$ or acquired brain injur\$ or hemiball\$ or pseudobulbar palsy or musc\$ spas\$).tw.
- 66.((unilateral or visual or hemispatial or attentional or spatial) adj5 neglect).tw.
- 67.or/43-66
- 68.42 and 67
- 69.limit 68 to yr="2008 - 2010"
- 70.limit 69 to english language

WHAT'S NEW

Date	Event	Description
18 July 2012	New citation required but conclusions have not changed	The results and the conclusions for this update are the same as for the previous version of the review.
30 December 2011	New search has been performed	This review update has added four new trials (Johnston 2007 ; Chiu 2008 ; O'Connell 2009 ; Chinchai 2010).The review now includes 21 trials involving 2289 patient and 1290 carer participants. Additional data have been added for analysis for the patient outcome for death.

HISTORY

Protocol first published: Issue 1, 2000

Review first published: Issue 3, 2001

Date	Event	Description
12 May 2008	Amended	Converted to new review format. Additional text added to the 'Acknowledgements' section and a new 'External sources of support' included.

CONTRIBUTIONS OF AUTHORS

Anne Forster and John Young conceived and designed the review and wrote the research proposal to obtain funding for the original review and this update. John Wright assisted in designing the review and writing the research proposal. He also provided methodological expertise.

Peter Knapp, Anne Forster, John Wright, John Young, Allan House and Jane Smith all contributed to refining the original protocol. Jane Smith and Anne Forster co-ordinated the first update of the review. Anne Forster and Lesley Brown co-ordinated the review of papers, data extraction, obtaining additional information and writing of this second update.

DECLARATIONS OF INTEREST

John Young, Jane Smith and Anne Forster have conducted a randomised trial evaluating an education programme for patients and carers after stroke. The trial is included in this review ([Smith 2004](#)).

SOURCES OF SUPPORT

Internal sources

- R&D Levy Funding, UK.
- Bradford Teaching Hospitals NHS Foundation Trust, UK.

External sources

- NHS Executive Northern and Yorkshire R&D, UK.
- Department of Health's NIHR Programme Grants for Applied Research, UK.

INDEX TERMS

Medical Subject Headings (MeSH)

Caregivers [*psychology]; Depression [*rehabilitation]; Health Knowledge, Attitudes, Practice; Health Services Accessibility; Ischemic Attack, Transient [*psychology]; Patient Education as Topic [*methods] [standards]; Randomized Controlled Trials as Topic; Stroke [*psychology]

MeSH check words

Humans