

Clinical Guidelines for Stroke Management

Chapter 7 of 8:
Discharge planning and transfer of care

This is the seventh in a series of eight guideline chapters that provide evidence-based recommendations for recovery from stroke and TIA in adults.

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Disclaimer

These Clinical Guidelines are a general guide to appropriate practice, to be followed subject to the clinician's judgment and the patient's preference in each individual case. The Clinical Guideline is designed to provide information to assist decision-making and are based on the best evidence available at the time of development. The Clinical Guidelines can be viewed at www.informme.org.au - Citation: Stroke Foundation. Clinical Guidelines for Stroke Management. Melbourne Australia. © No part of this publication can be reproduced by any process without permission from the Stroke Foundation. July 2024.

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Summary of recommendations

Introduction

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Information and education

Strong recommendation Updated evidence, no change in recommendation

- All stroke survivors and their families/carers should be offered information tailored to meet their individual needs using relevant language and communication formats. (Crocker et al. 2021 [9])
- Information should be provided at different stages in the recovery process. (Crocker et al. 2021 [9])
- An approach of active engagement with stroke survivors and their families/carers should be used allowing for the provision of material, opportunities for follow-up, clarification, and reinforcement. (Crocker et al. 2021 [9])

Info Box

Practice points

- Stroke survivors and their families/carers should be educated in the FAST stroke recognition message to maximise early presentation to hospital in case of recurrent stroke.
- The need for education, information and behaviour change to address long-term secondary stroke prevention should be emphasized (refer to [Secondary Prevention](#)).

Discharge care plans

Strong recommendation Updated evidence, no change in recommendation

Comprehensive discharge care plans that address the specific needs of the stroke survivor should be developed in conjunction with the stroke survivor and carer prior to discharge. (Johnston et al. 2010 [20]; Goncalves-Bradley et al. 2016 [21])

Info Box

Practice point

Discharge planning should commence as soon as possible after the stroke patient has been admitted to hospital.

Consensus recommendation

Consensus-based recommendation

A discharge planner may be used to coordinate a comprehensive discharge program for stroke survivors.

Consensus recommendation

Consensus-based recommendations

To ensure a safe discharge process occurs, hospital services should ensure the following steps are completed prior to discharge:

- Stroke survivors and families/carers have the opportunity to identify and discuss their post-discharge needs (physical, emotional, social, recreational, financial and community support) with relevant members of the multidisciplinary team.
- General practitioners, primary healthcare teams and community services are informed before or at the time of discharge.
- All medications, equipment and support services necessary for a safe discharge are organised.
- Any necessary continuing specialist treatment required has been organised.
- A documented post-discharge care plan is developed in collaboration with the stroke survivor and family and a copy provided to them. This discharge planning process may involve relevant community services, self-management strategies (i.e. information on medications and compliance advice, goals and therapy to continue at home), stroke support services, any further rehabilitation or outpatient appointments, and an appropriate contact number for any

post-discharge queries

A locally developed protocol or standardised tool may assist in implementation of a safe and comprehensive discharge process. This tool should be aphasia and cognition friendly.

Patient and carer needs



Consensus recommendation

Consensus-based recommendation

Hospital services should ensure that stroke survivors and their families/carers have the opportunity to identify and discuss their post-discharge needs (including physical, emotional, social, recreational, financial and community support) with relevant members of the interdisciplinary team.

Home assessment



Consensus recommendation

Reviewed, no new evidence

Consensus-based recommendation

Prior to hospital discharge, all stroke survivors should be assessed to determine the need for a home visit, which may be carried out to ensure safety and provision of appropriate aids, support and community services.

Carer training



Weak recommendation

Updated evidence, no change in recommendation

Relevant members of the interdisciplinary team should provide specific and tailored training for carers/family before the stroke survivor is discharged home. This training should include, as necessary, personal care techniques, communication strategies, physical handling techniques, information about ongoing prevention and other specific stroke-related problems, safe swallowing and appropriate dietary modifications, and management of behaviours and psychosocial issues. (Forster et al. 2013 [34])

Glossary and abbreviations

Introduction

The Stroke Foundation is a national charity that partners with the community to prevent, treat and beat stroke. We stand alongside stroke survivors and their families, healthcare professionals and researchers. We build community awareness and foster new thinking and innovative treatments. We support survivors on their journey to live the best possible life after stroke.

We are the voice of stroke in Australia and we work to:

- Raise awareness of the risk factors, signs of stroke and promote healthy lifestyles.
- Improve treatment for stroke to save lives and reduce disability.
- Improve life after stroke for survivors.
- Encourage and facilitate stroke research.
- Advocate for initiatives to prevent, treat and beat stroke.
- Raise funds from the community, corporate sector and government to continue our mission.

The Stroke Foundation has been developing stroke guidelines since 2002 and in 2017 released the fourth edition. In order for the Australian Government to ensure up-to-date, best-practice clinical advice is provided and maintained to healthcare professionals, the NHMRC requires clinical guidelines be kept current and relevant by reviewing and updating them at least every five years. As a result, the Stroke Foundation, in partnership with Cochrane Australia, have moved to a model of living guidelines, in which recommendations are continually reviewed and updated in response to new evidence. This approach was piloted in a three year project (July 2018 -June 2021) funded by the Australian Government via the Medical Research Future Fund.

This online version of the *Australian and New Zealand Living Clinical Guidelines for Stroke Management* updates and supersedes the Clinical Guidelines for Stroke Management 2017. The Clinical Guidelines have been updated in accordance with the *2016 NHMRC Standards for Guidelines* and therefore recommendations are based on the best evidence available. The Clinical Guidelines cover the whole continuum of stroke care, across 8 chapters.

Review of the Clinical Guidelines used an internationally recognised guideline development approach, known as GRADE (**G**rating of **R**ecommendations **A**ssessment, **D**evelopment and **E**valuation), and an innovative guideline development and publishing platform, known as MAGICapp (**M**aking **G**rade the **I**rresistible **C**hoice). GRADE ensures a systematic process is used to develop recommendations that are based on the balance of benefits and harms, patient values, and resource considerations. MAGICapp enables transparent display of this process and access to additional practical information useful for guideline recommendation implementation.

Purpose

The *Clinical Guidelines for Stroke Management* provides a series of best-practice recommendations to assist decision-making in the management of stroke and transient ischaemic attack (TIA) in adults, using the best available evidence. The Clinical Guidelines should not be seen as an inflexible recipe for stroke management; rather, they provide a guide to appropriate practice to be followed subject to clinical judgment and patient preferences.

Scope

The Clinical Guidelines cover the most critical topics for effective management of stroke, relevant to the Australian and New Zealand context, and include aspects of stroke management across the continuum of care including pre-hospital, assessment and diagnosis, acute medical and surgical management, secondary prevention, rehabilitation, discharge planning, community participation, and management of TIA. Some issues are dealt with in more detail, particularly where current management is at variance with best practice, or where the evidence needs translation into practice.

The Clinical Guidelines do not cover:

- Subarachnoid haemorrhage (refer to other available guidelines like the *2023 Guideline for the Management of Patients with Aneurysmal Subarachnoid Hemorrhage: A Guideline from the American Heart Association/American Stroke Association* (Hoh et al 2023 [47]);
- Stroke in infants, children and youth, i.e. <18 years old (refer to Victorian Subacute Childhood Stroke Advisory Committee, *Guideline for the subacute management of childhood stroke – 2019*, <https://informme.org.au/Guidelines/Childhood-stroke-guidelines>); or
- Primary prevention of stroke. (Refer to *Guidelines for assessing and managing cardiovascular disease risk 2023* (Australian Chronic Disease Prevention Alliance [5]) - <https://informme.org.au/guidelines/guideline-for-assessing-and-managing-cardiovascular-disease-risk>, and *Guideline for the diagnosis and management of hypertension in adults 2016* (Heart Foundation [6]) - <https://www.heartfoundation.org.au/for-professionals/clinical-information/hypertension>).

Target audience

The Clinical Guidelines are intended for use by healthcare professionals, administrators, funders and policy makers who plan, organise and deliver care for people with stroke or TIA during all phases of recovery.

Development

The Guidelines are published in eight separate chapters:

Pre-hospital care

Early assessment and diagnosis

Acute medical and surgical management

Secondary prevention

Rehabilitation

Managing complications

Discharge planning and transfer of care

Community participation and long-term care

The Clinical Guidelines have been developed according to processes prescribed by the National Health and Medical Research Council (NHMRC) under the direction of an interdisciplinary working group. Refer to the document on [InformMe](#) that details the Interdisciplinary Working Group Membership and Terms of Reference.

Use

The primary goal of the Clinical Guidelines is to help healthcare professionals improve the quality of the stroke care they provide.

Guidelines differ from clinical or care pathways (also referred to as critical pathways, care paths, integrated care pathways, case management plans, clinical care pathways or care maps). Guidelines are an overview of the current best evidence translated into clinically relevant statements. Care pathways are based on best practice guidelines but provide a local link between the guidelines and their use.

In considering implementation of the Guidelines at a local level, healthcare professionals are encouraged to identify the barriers, enablers and facilitators to evidence-based practice within their own environment and determine the best strategy for local needs. Where change is required, initial and ongoing education is essential and is relevant to all recommendations in the Guidelines.

Aboriginal and Torres Strait Islander People

Refer to the document on [InformMe](#) for information regarding Aboriginal and Torres Strait Islander people.

Decision-making

Stroke survivors should be treated in accordance with the principles of shared decision-making contained within the *Acute Stroke Care Clinical Standard*, *Acute Stroke Services Framework 2023* and *Rehabilitation Stroke Services Framework 2022*, which include, among other things, that treatment should be patient-centred. Therefore, stroke survivors should be involved in decisions about their care at all times; but where they do not have capacity, or have limited capacity, family members should be involved in the decision-making.

Consent

The principles of informed consent underpin these Clinical Guidelines and therefore the wording of the recommendations are directed at the healthcare professional; that is, the intervention should/may be used, rather than offered, for the stroke patient. For patients with aphasia and/or cognitive disorders requiring formal consent, easy English or aphasia-friendly written versions of an information sheet and consent form should be offered and clearly explained to patients and their families in order to assist understanding and agreement.

Endorsement

The Clinical Guidelines have been endorsed (based on the 2017 version) by a number of organisations and associations. Refer to the document on [InformMe](#) that details the organisations formally endorsing the Clinical Guidelines.

Evidence gaps

Refer to the document on [InformMe](#) that details the gaps in evidence identified, noting areas for further research.

Reports

Refer to documents on [InformMe](#) - Technical Report, Administrative Report and Dissemination and Implementation Report.

Resources

Refer to documents on [InformMe](#) that provide supporting resources to assist with implementation of the Clinical Guidelines.

Publication Approval



Australian Government

National Health and Medical Research Council

The 2017 guideline recommendations were approved by the Chief Executive Officer of the National Health and Medical Research Council (NHMRC) on 25 July 2017 under Section 14A of the National Health and Medical Research Council Act 1992 with a subsequent amendment approved on 22 November 2017. Since moving to a continual (living) guideline model, further updates have been approved:

- 9 July 2018 (updated recommendations for neurointervention)
- 7 November 2019 (updated recommendations for thrombolysis, acute antiplatelet therapy, and patent foramen ovale management)
- 11 February 2021 (updated recommendations for oxygen therapy, cholesterol lowering targets, new acute antiplatelet agent, shoulder pain and weakness)
- 7 July 2021 (updated recommendations for standing, antiplatelet therapy, and activities of living)
- 22 December 2021 (updated recommendations for pre-hospital care, acute telehealth, head position, telehealth for rehabilitation, swelling of extremities, memory, management of atrial fibrillation, lifestyle modifications, and virtual reality for arm function)
- 5 August 2022 (updated recommendations for pre-hospital care [mobile stroke unit], assessment for rehabilitation, aphasia, dysarthria, prevention and treatment for depression, treatment of anxiety, personality and behaviour, pressure injury)
- 6 December 2022 (updated recommendations for aphasia and incontinence)
- 27 July 2023 (updated recommendations for driving, neurointervention, oxygen therapy, and central post-stroke pain)
- 8 December 2023 (updated recommendation for management of atrial fibrillation)
- 2 January 2025 (updated recommendation for self-management).

In approving the guidelines recommendations the NHMRC considers that they meet the NHMRC standard for clinical practice guidelines. This approval is valid for a period of five years.

NHMRC is satisfied that the guideline recommendations are systematically derived, based on identification and synthesis of the best available scientific evidence and are developed for health professionals practising in an Australian health care setting.

This publication reflects the views of the authors and not necessarily the views of the Australian Government.

Disclaimer

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Funding

The Stroke Foundation gratefully acknowledges the financial assistance provided to establish the living guidelines between 2018-2021 by the Australian Government, Medical Research Future Fund. Funding is currently being provided by the Australian Living Evidence Consortium (<https://livingevidence.org.au>) to assist the continuation of the Stroke Living Guidelines. The development of the final recommendations are not influenced by the views or interests of any funding body.

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Methodology

Development of questions

Questions have been extensively developed and reviewed over the four iterations of the guidelines. In this 'living' phase the Content Steering Group reviews the PICO questions on an annual basis. The clinical questions are listed at the start of each chapter. Individual PICOs (population, intervention/s, comparator, outcomes) are listed in the research evidence section as related to each topic or recommendation.

Literature identification

On a monthly basis, we monitor the literature for relevant, new evidence by screening all randomised controlled trials or systematic reviews related to stroke published in the Pubmed database. One member of the project team initially screens all abstracts and excludes clearly irrelevant studies. Potentially included studies are allocated to relevant topics covered by the guidelines and a second member of the project team reviews and confirms included studies prior to sending to the relevant working group members. In addition, each month new economic studies and studies related to patient values and preferences are also captured.

Clinical expert review

Where new evidence has been identified by the project team a summary is sent to content experts who review and make a final decision to include or exclude the study and also to assess the potential impact of the new evidence on current recommendations. As a result of this assessment one of two options will be communicated for each topic:

- a. New evidence is unlikely to change current recommendations: review and potentially integrate information in the next review cycle; or
- b. New relevant evidence may change current recommendations: rapidly review.

Data extraction, updating evidence summary and GRADE profile

For rapid updates, the project team incorporates the new evidence into the existing body of evidence by:

- Updating the Summary of Findings table including the risk of bias assessment
- Review any additional studies related to Preferences and values of patients on the topic

Concurrently members of the economic working group review newly published economic studies.

The project team then drafts changes to the overall summary (GRADE profile). This profile is then reviewed and modified by clinical content experts and people with relevant lived experience (consumers). Finally changes to the changes to the recommendation, rationale and practical considerations are considered, discussed and agreed.

Draft changes are then circulated to the wider expert working groups (including consumer panel) for internal review. Once signed off by the Steering Group a period of public consultation is undertaken. Feedback is then reviewed and any changes made in response to feedback before finally submitting to the National Health and Medical Research Council (NHMRC) for approval.

Brief summary of GRADE

The Guidelines were developed following the GRADE methodology (Grading of Recommendations, Assessment, Development and Evaluation).

GRADE 'evidence to decision' framework includes a minimum of four factors to guide the development of a recommendation and determine the strength of that recommendation:

1. The balance between desirable and undesirable consequences.
2. Confidence in the estimates of effect (quality of evidence).
3. Confidence in values and preferences and their variability (clinical and consumer preferences).
4. Resource use (cost and implementation considerations).

For full details of how GRADE is used for developing clinical recommendations, refer to the GRADE handbook, available at: <http://gdt.guidelinedevelopment.org/app/handbook/handbook.html>.

Strength of recommendations

The GRADE process uses only two categories for the strength of recommendations, based on how confident the guideline panel is that the "desirable effects of an intervention outweigh undesirable effects [...] across the range of patients for whom the recommendation is intended" (GRADE Handbook):

- **Strong** recommendations: where guideline authors are certain that the evidence supports a clear balance towards either desirable or

undesirable effects; or

- **Weak (conditional)** recommendations: where the guideline panel is less certain about the balance between desirable and undesirable effects.

These strong or weak recommendations can either be for or against an intervention. If the recommendation is against an intervention this means it is recommended NOT to do that intervention. There are a number of recommendations where we have stated that the intervention may only be used in the context of research. We have done this because these are guidelines for clinical practice, and while the intervention cannot be recommended as standard practice at the current time, we recognise there is good rationale to continue further research.

The implications of a strong or weak recommendation for a particular treatment are summarised in the GRADE handbook as follows:
Table 1: Implications of GRADE recommendation categories (for a positive recommendation) for patients, clinicians and policy makers.
Source: GRADE Handbook (<http://gdt.guidelinedevelopment.org/app/handbook/handbook.html>)

	Strong Recommendation	Weak Recommendation
For patients	Most individuals in this situation would want the recommended course of action and only a small proportion would not.	The majority of individuals in this situation would want the suggested course of action, but many would not.
For clinicians	Most individuals should receive the recommended course of action. Adherence to this recommendation according to the guideline could be used as a quality criterion or performance indicator. Formal decision aids are not likely to be needed to help individuals make decisions consistent with their values and preferences.	Recognise that different choices will be appropriate for different patients, and that you must help each patient arrive at a management decision consistent with her or his values and preferences. Decision aids may well be useful helping individuals making decisions consistent with their values and preferences. Clinicians should expect to spend more time with patients when working towards a decision.
For policy makers	The recommendation can be adapted as policy in most situations including for the use as performance indicators.	Policy making will require substantial debates and involvement of many stakeholders. Policies are also more likely to vary between regions. Performance indicators would have to focus on the fact that adequate deliberation about the management options has taken place.

For topics where there is either a lack of evidence or insufficient quality of evidence on which to base a recommendation but the guideline panel believed advice should be made, statements were developed based on consensus and expert opinion (guided by any underlying or indirect evidence). These statements are labelled as 'Practice statements' and correspond to 'consensus-based recommendations' outlined in the NHMRC procedures and requirements.

For topics outside the search strategy (i.e. where no systematic literature search was conducted), additional considerations are provided. These are labelled 'Info Box' and correspond to 'practice points' outlined in the NHMRC procedures and requirements.

Explanation of absolute effect estimates used

The standardised evidence profile tables presented in the Clinical Guidelines include "Absolute effect estimates" for dichotomous outcomes. These represent the number of people per 1000 people expected to have the outcome in the control and intervention groups. This estimated risk in people receiving the intervention is based on a relative effect estimate which might be adjusted, e.g. to account for baseline differences between participants or when effect estimates have been pooled from different studies in a systematic review and adjusted to account for the variance of each individual estimate. Therefore, this estimated risk in the intervention group may differ from the raw estimate of the intervention group risk from the corresponding study. The estimated risk reflects the best estimate of the risk in the relevant population, relative to the risk observed among patients receiving the control or comparator intervention.

Wherever possible (i.e. when the relevant study reported enough information to allow the calculation to be done), these estimates were calculated using the following procedure:

1. Obtain the relative effect estimate (odds ratio or relative risk) and confidence interval from the best available study (systematic review or primary study) providing evidence about the effects of the intervention.

2. Use the observed number of events in the control group of the same study to calculate a baseline risk per 1000 people (or “assumed control risk”).
3. Calculate an estimate of the corresponding risk per 1000 in people receiving the intervention using the relative effect estimate. This can be done using methods based on the formulas for calculating absolute risk reductions provided in the *Cochrane Handbook for Systematic Reviews of Interventions* (<http://handbook.cochrane.org/>). Applying the same calculations to the upper and lower bounds of the confidence interval for the relative effect estimate gives a confidence interval for the risk in the intervention group, which is then used to calculate the confidence interval for the difference per 1000 people, reported in the evidence tables.

Cost effectiveness summaries

There are several important points to consider when interpreting the cost-effectiveness information provided in the *Resources and Other Considerations* sections of the Clinical Guidelines.

Firstly, an intervention can be cost-effective without being cost-saving. This means that although there is an additional cost for the health benefits gained from the intervention, the intervention is still considered worthwhile. The incremental cost-effectiveness ratios (ICER) presented (e.g. cost per quality adjusted life year gained) are an indication of the cost-effectiveness or “value-for-money”, with lower ICERs indicating better cost-effectiveness of an intervention.

Secondly, whether or not the intervention is cost-effective is a judgment call; and should reflect a society’s willingness-to-pay to have the intervention for the potential outcomes achieved. An ICER that is approximately or equivalent to US\$50,000 has been commonly used by researchers in the past as a threshold for judging an intervention as being cost-effective (<http://www.nejm.org/doi/full/10.1056/NEJMp1405158#t=article>). However, no scientific basis for this threshold exists and actual willingness-to-pay may differ. For example, in a survey of 1000 Australian respondents conducted in 2007, the willingness-to-pay for an additional quality adjusted life year in Australia was estimated to be \$64,000 (<https://www.ncbi.nlm.nih.gov/pubmed/19382128>).

Thirdly, there is no absolute threshold for determining whether an intervention should be funded based on the ICER (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5153921/>). ICERs are only one of the major factors considered in priority setting (the process to decide which interventions should be funded within a given resource constraint). Other considerations include affordability, budget impact, fairness, feasibility and other factors that are important in the local context (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5153921/>).

Lastly, in areas where there are no data from economic evaluations that support the recommendations or practice statements, it remains unclear whether the additional costs of providing the intervention above usual care for the additional potential benefits obtained is justified. However, this should not detract from implementing the Clinical Guideline recommendations.

Use of language related to timing of interventions

Immediate: without delay, or within minutes, not hours (life critical action required).

Urgent: minutes to several hours (immediate action but not life critical).

Very early: within hours and up to 24 hours.

Early: within 48 hours.

For all Clinical Guideline recommendations we make the assumption that healthcare professionals will be appropriately qualified and skilled to carry out the intervention.

Clinical questions

- 7.1 Does the provision of information and or education improve outcomes after stroke?.
- 7.2 Does the use of discharge care plans improve outcomes after stroke?
- 7.3 Does assessment of patient and carers needs prior to discharge improve outcomes after stroke?
- 7.4 Does conducting a home assessment of the stroke patient prior to discharge improve outcomes?
- 7.5 Does the provision of training for carers improve outcomes after stroke?

Discharge planning and transfer of care - overview

Good discharge planning is crucial for successful reintegration into the community and effective and efficient use of limited hospital resources. Stroke survivors and carers/family report that this phase of the recovery process is a critical step and that often insufficient attention and resources are provided (Stroke Foundation 2007 [7]). One group that is of particular concern is younger stroke survivors (i.e. <65 years) who may require residential care post-discharge. While the ideal discharge outcome may be to an in-patient rehabilitation facility, this is not always feasible in all geographical locations. Careful consideration needs to be given to discharge destinations (other than a rehabilitation facility) to ensure the stroke survivor is transferred to appropriate accommodation and receives the necessary services at that location.

Discharge planning relies on effective communication between team members, stroke survivors, families/carers, and community service providers including general practitioners. Important aspects of care which should be considered during this phase include team meetings, family meetings, information and education and care after hospital discharge.

The Stroke Foundation has developed multiple resources to assist stroke survivors and their carer as well as healthcare professionals in the process of discharge planning and transfer of care. [My Stroke Journey](#) is an information pack which should be given to stroke survivors and their caregivers prior to hospital discharge. [StrokeLine](#) is a free telephone support service staffed by healthcare professionals which provide information and advice on stroke prevention, treatment, and recovery. [EnableMe](#) is a free web-based resource which provides information, a community forum and a tool to track personal goals for recovery.

Information and education

The provision of information and education is particularly important for stroke survivors and their families/carers (Stroke Foundation 2007 [7]). This may need to be offered repeatedly over various timeframes as information needs change (Stroke Foundation 2007 [7]). Information should also be provided in a language and format that can be understood. National Stroke Audit results show that 61% of stroke patients in rehabilitation services (Stroke Foundation 2024 [14]) and 62% in acute services (Stroke Foundation 2023 [51]) received information regarding stroke.

Strong recommendation

Updated evidence, no change in recommendation

- All stroke survivors and their families/carers should be offered information tailored to meet their individual needs using relevant language and communication formats. (Crocker et al. 2021 [9])
- Information should be provided at different stages in the recovery process. (Crocker et al. 2021 [9])
- An approach of active engagement with stroke survivors and their families/carers should be used allowing for the provision of material, opportunities for follow-up, clarification, and reinforcement. (Crocker et al. 2021 [9])

Practical info

Patients and their carer/s should be informed about the way the health system works, including how and when different services are accessed.

Evidence to decision

Benefits and harms	<div>Small net benefit, or little difference between alternatives</div> <p>Active information provision may improve patient knowledge and quality of life, may reduce symptoms of depression and anxiety and may slightly improve or have little to no effect on carer's symptoms of depression and anxiety (Crocker et al. 2021 [9]). Passive information may slightly worsen or have little to no effect on patient symptoms of depression and anxiety (Crocker et al. 2021[9]).</p> <p>Harm reported for this intervention was minimal. Nevertheless, providing health education is a critical aspect for a health care professional's role and it is important for health care professions to be knowledgeable about how and when to deliver health education in order to maximise benefit and to prevent any possible harm.</p>
Certainty of the evidence	<div>Low</div> <p>Overall certainty ranged from low to moderate for active approaches and very low to low for passive approaches.</p>
Values and preferences	<div>No substantial variability expected</div> <p>Stroke survivors and carers would usually want to be provided with information</p>
Resources and other considerations	<div>Important issues, or potential issues not investigated</div> <p>Resources considerations</p> <p>A cost-consequence analysis has been conducted parallel to a randomised controlled trial comparing a community-based exercise and education scheme to usual care (Harrington et al 2010 [13]). There were</p>

significant improvements in physical integration in patients receiving the intervention compared to those receiving usual care at nine weeks and at one year. The mean cost per patient, excluding inpatient care, was £296 greater in the intervention group than in the control group (cost reference year not reported).

There is some evidence from Patel et al [35] that carer training during inpatient rehabilitation can reduce total costs due to earlier discharge (saving of £4,043, reference year 2001/2002) and improved health outcomes. In a clinical trial with a parallel cost-effectiveness analysis, a structured training programme for caregivers of inpatients after stroke was compared to usual care (Forster et al 2013 [15]). In this study it was found that the probability of caregiver training being cost-effective based on quality adjusted life years was low. In a systematic review, three economic evaluations of carer training/information interventions were identified (Heslin et al 2016 [16]). The interventions were found to be cost-effective compared to usual care, with the interventions being less costly with better or equivalent for clinical outcomes including depression, life satisfaction, anxiety, quality of life and carer burden.

Implementation consideration

There is a clinical indicator collected in the National Stroke Audit on the provision of relevant information covering stroke, hospital management, secondary prevention and recovery to patients and/or their family or carer prior to discharge. There is also an organisational indicator collected to determine whether stroke-specific information is routinely provided to patients prior to discharge and, if so, what this information includes.

Rationale

Information provision for stroke survivors and their caregivers is a critical aspect of the patient journey. There is pooled evidence that the provision of information using active approaches improves knowledge and reduces symptoms of anxiety and depression in stroke survivors but there is less certainty on the impact with carers. No significant changes were found using passive approaches, but the certainty of evidence is very low or low. (Crocker et al 2021. [9]).

Clinical question/ PICO

Population: Stroke patients and their caregivers

Intervention: Complex interventions including information/education

Comparator: Control

Summary

A Cochrane review by Crocker et al. (2021) [9] assessed the effectiveness of information provision strategies in improving outcomes for stroke patients and carers. Thirty-three randomised trials were included, 11 using a passive intervention in which information was provided on a single occasion with no follow-up or reinforcement and 22 using an active intervention (5,255 survivors of stroke and 3134 carer participants). Overall, there was no significant differences for any outcomes with passive information provision but there were significant benefits of active information provision (see other PICO for details).

Other systematic reviews of mostly complex interventions where information/education is one component have reported some benefits.

Mou et al. (2022) with 11 studies (1769 survivors and 1578 family caregivers) investigated dyadic psychoeducational interventions and found a significant immediate effect on family caregiver's burden (SMD -0.25, 95% CI -0.50 to -0.01; 3 studies, n= 261) and long-term effect on survivor's quality of life (SMD -0.30, 95% CI -0.53 to -0.07; 3 studies, n= 291). No significant effects were found for survivor's functional independence (SMD 0.14, 95% CI 0.01 to 0.28; 5 studies, n= 888), depression (SMD -0.50, 95% CI -1.07, 0.08; 5 studies, n= 367) and emotional distress (SMD -0.09, 95% CI -0.31, 0.13; 3 studies, n= 338), and family caregivers' medium term burden (1 to <6 months SMD -0.16, 95% CI -0.64 to 0.32; 3 studies, n= 266), depression (SMD -0.23, 95% CI -0.49 to 0.04; 3 studies, n= 220) and coping (SMD 0.09, 95% CI -0.06 to 0.24; 3 studies, n= 690).

Kontou et al. (2020) [18] conducted a scoping review aimed to identify the evidence regarding psychoeducational interventions for people after a TIA or minor stroke. Psychoeducation was defined as any intervention that included a component of education, support, and management strategies. Fifteen RCTs were identified (n=1500 participants). Various interventions were included, including education/psychoeducation (n = 4); exercise and lifestyle advice (n = 3); telephone-based education/counseling (n = 3); secondary prevention education (n = 1); motivational interviewing (n = 2); self-management (n = 2). Several significant changes were reported in

the studies. Three studies reported a significant increase in stroke knowledge or self-efficacy/management. Other studies reported improvement in secondary prevention measures, such as reduced cholesterol, improved self-reported exercise, and an improved global health score. There was a significant reduction in recurrent strokes or TIAs in one study after an 8-week exercise and education program. However, the authors concluded that many interventions were not adequately described, therefore making it difficult to determine if the aim was to provide information or support post-TIA/minor stroke and further trials are needed.

Pucciarelli et al. (2020) included 13 RCT and 3 quasi-RCT studies (n=2997 stroke survivors and 2187 carers) comparing dyadic (involving both person with stroke and their carer/family) interventions that involved information, education and support focused. The overall effects appear to have a small reduction in depression for both stroke survivors (SMD -0.16) and carer (SMD -0.19). It also improves stroke survivor QOL (SMD 0.17) although numbers of trials are low (maximum 5 studies for any one outcome) and effects are small.

Other randomised trials not included in the systematic reviews include:

- An education program based on the International Classification of Functioning, Disability and Health (ICF) was compared to an attention control group (Sabariego et al. 2013 [12]). A total of 213 survivors of stroke were included. No significant differences were seen between groups in perceived self-efficacy, participation or emotional functioning.
- An intervention that combined social worker case management after hospital discharge along with access to online stroke-related information produced greater gains in patient-reported physical health and activation compared with usual care or case management alone. (Reeves et al. 2019 [19]).
- A nurse-led health coaching programme with 140 dyads found a significant increase in self-efficacy, stroke survivor's quality of life, stroke-related knowledge and reductions in hospital readmissions and caregiver burden. (Lin et al 2022)[50]

Outcome Timeframe	Study results and measurements	Comparator Control	Intervention Complex interventions including information/ education	Certainty of the evidence (Quality of evidence)	Summary
Death End of study 9 Critical	Odds ratio 0.86 (CI 95% 0.59 — 1.25) Based on data from 1,553 participants in 9 studies. ¹ (Randomized controlled) Follow up: 3-12 months.	85 per 1000 Difference:	74 per 1000 11 fewer per 1000 (CI 95% 33 fewer — 19 more)	Moderate Due to serious indirectness ²	Information provision probably has little or no difference on death
Patient anxiety ³ End of study 7 Critical	Odds ratio 0.89 (CI 95% 0.57 — 1.38) Based on data from 681 participants in 6 studies. ⁴ (Randomized controlled) Follow up: 3 to 12 months.	182 per 1000 Difference:	165 per 1000 17 fewer per 1000 (CI 95% 69 fewer — 53 more)	Moderate Due to serious indirectness ⁵	Information provision probably has little or no difference on patient anxiety
Patient depression ⁶ End of study 7 Critical	Relative risk 0.9 (CI 95% 0.61 — 1.32) Based on data from 956 participants in 8 studies. ⁷ (Randomized controlled) Follow up: 3-12 months.	179 per 1000 Difference:	161 per 1000 18 fewer per 1000 (CI 95% 57 more — 70 fewer)	Moderate Due to serious indirectness ⁸	Information provision probably has little or no difference on patient depression
Carer psychological distress ⁹ End of study	Odds ratio 1.13 (CI 95% 0.65 — 1.97) Based on data from 498 participants in 4 studies. ¹⁰	204 per 1000	225 per 1000	Moderate Due to serious risk of bias ¹¹	Information provision probably has little or no difference on carer psychological distress

Outcome Timeframe	Study results and measurements	Comparator Control	Intervention Complex interventions including information/ education	Certainty of the evidence (Quality of evidence)	Summary
7 Critical	(Randomized controlled) Follow up: 6-12 months.	Difference:	21 more per 1000 (CI 95% 61 fewer — 131 more)		
Patient ADL and participation End of study 8 Critical	Based on data from 821 participants in 8 studies. ¹² (Randomized controlled) Follow up: 3-12 months.	There was no evidence of an effect of provision of information on activities of daily living from 8 trials (4 passive information and 4 active information) . 7 trials that assessed the effects of information provision on participation also found no significant differences (3 passive information and 4 active)		Moderate Due to serious risk of bias ¹³	There were no significant difference between the intervention and control groups in any of the trials that evaluated these outcomes Information provision probably has little or no difference on patient ADL and participation
Patient QOL End of study 8 Critical	Based on data from 791 participants in 6 studies. ¹⁴ (Randomized controlled) Follow up: 1-12 months.	From 6 trials (2 passive and 4 active) 5 trials found no effect of information provision and patient quality of life. Scales used included SF-36, Functional Limitations Profile and EuroQol		Moderate	From 6 trials, 5 trials indicated no significant differences between intervention and control group. The one positive trial was fundamentally different as that trial provided interventional training for the stroke survivor whereas the others did not. Information provision probably has little or no difference on patient quality of life
Carer QOL End of study 8 Critical	Based on data from 546 participants in 4 studies. ¹⁵ (Randomized controlled) Follow up: 6-12 months.	4 trials evaluated this outcome measure (1 passive and 3 active information studies). The largest trial, using active information provision, reported higher carer quality of life in the intervention group on EuroQol. Another trial found a significant difference in favour of the control group on the SF-36 social functioning subscale.		Moderate Due to serious risk of bias ¹⁶	Information provision probably has little or no difference on carer quality of life

1, 4, 7, 10. Systematic review [39]

2. **Risk of Bias: no serious.** It was noted by Forster et al. that the trials did not have blinding of participant to the intervention; however considering that the intervention was receiving education I have not viewed this as compromising the integrity for bias. Inadequate concealment of allocation impacted 9 trials during randomization process, resulting in potential for selection bias, the method of random sequence generation was unclear or not reported in 11 trials. **Inconsistency: no serious. Indirectness: serious.** Many trials excluded for speech/language impairment, a limited number excluded for cognitive impairment. As the speech, language and cognitive impairment are a common stroke presentations, this raises the questions if the patients in the trials are 'different' to the patient population which is seen clinically. there was no consistent follow up between the studies with a mean of 76 days, but a range of 3 weeks to 2 years follow up. **Imprecision: no serious.** The absolute effect and confidence interval are both small the range in participants ranged from 36 to 300, and loss to followup ranged from 0 to 20% common issues of the trail was that there were under powered in design. **Publication bias: no serious.**

3. Forster et al. (2012) classified scores of 10/11 on the anxiety subscale of the Hospital Anxiety and Depression Scale as showing anxiety

5. **Risk of Bias: no serious.** Inadequate/lack of blinding of outcome assessors, resulting in potential for detection bias, Inadequate sequence generation/ generation of comparable groups, resulting in potential for selection bias, Inadequate concealment of allocation during randomization process, resulting in potential for selection bias. **Inconsistency: no serious. Indirectness: serious.** Many trials excluded for speech/language impairment, a limited number excluded for cognitive impairment. As the speech, language and cognitive

impairment are a common stroke presentations, this raises the questions if the patients in the trials are 'different' to the patient population which is seen clinically. . **Imprecision: no serious. Publication bias: no serious.**

6. From Forster et al. (2012), depression scores were dichotomized using "hospital anxiety and depression scale depression sub-scale cut-off score of 10/11 and a Geriatric Depression Scale score > 10"

8. **Inconsistency: no serious. Indirectness: serious.** Many trials excluded for speech/language impairment, a limited number excluded for cognitive impairment. As the speech, language and cognitive impairment are a common stroke presentations, this raises the questions if the patients in the trials are 'different' to the patient population which is seen clinically. . **Imprecision: no serious. Publication bias: no serious.**

9. In Forster et al. (2012), carer distress was dichotomised using "cut-off scores of 10/11 for the Hospital Anxiety and Depression Scale and 4/5 for the General Health Questionnaire"

11, 16. **Risk of Bias: serious.** Inadequate concealment of allocation during randomization process, resulting in potential for selection bias, Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias, Inadequate/lack of blinding of outcome assessors, resulting in potential for detection bias. **Inconsistency: no serious. Indirectness: no serious. Imprecision: no serious. Publication bias: no serious.**

12, 14, 15. Systematic review [39]. **Supporting references: [9],**

13. **Risk of Bias: serious.** Inadequate concealment of allocation during randomization process, resulting in potential for selection bias, Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias, Inadequate/lack of blinding of outcome assessors, resulting in potential for detection bias. **Inconsistency: no serious. Indirectness: no serious.** Differences between the population of interest and those studied. **Imprecision: no serious. Publication bias: no serious.**

Clinical question/ PICO

- Population:** Stroke patients and their caregivers
- Intervention:** Active information provision
- Comparator:** Control

Summary

A Cochrane review by Crocker et al. (2021) [9] assessed the effectiveness of information provision strategies in improving outcomes for survivors of stroke and carers. Thirty-three randomised trials were included, 11 using a passive intervention in which information was provided on a single occasion with no follow-up or reinforcement, and 22 using an active intervention. Meta-analyses showed that active information provision improved survivor knowledge (survivor SMD 0.41, 95% CI 0.17 to 0.65; 3 studies, n=275; low certainty) and improved survivor depression scores (MD -0.8, 95% CI -1.27 to -0.34; 8 studies, n=1,405; moderate level certainty) and anxiety scores (MD -0.73, 95% CI -1.1 to -0.36; 6 studies, n=1,171; low certainty). Active information provision may reduce the number of survivors with depression (RR 0.83, 95% CI 0.68 to 1.01; 6 studies, n= 1,315; low certainty) or anxiety (RR 0.85, 95% CI 0.68 to 1.06; 5 studies, n=1,132; low certainty) but both of these outcomes didn't reach statistical significance. Sensitivity analysis adjusting for clustering found active information significantly reduced people depressed but numbers with anxiety remained with a chance of no difference. Active information may improve quality of life with all four domains of the World Health Organisation Quality of Life Short Form higher compared to control although confidence intervals were all wide and there was chance of no effect (physical, MD 11.5, 95% CI 7.81 to 15.27; psychological, MD 11.8, 95% CI 7.29 to 16.29; social, MD 5.8, 95% CI 0.84 to 10.84; environment, MD 7.0, 95% CI 3.00 to 10.94; 1 study, n=60; low certainty). Active information provision for carers did not have significant effect on the symptoms of depression (MD -0.3; 95% CI -1.53 to 0.92; 3 studies, n=924; low certainty) and anxiety (MD -0.40, 95% CI -1.51 to 0.70; 3 studies, n=921; low certainty). Active information provision for carers may improve knowledge (SMD 0.68; 95% CI -0.03 to 1.39; 4 studies, n=356; very low certainty). There was no effect found on positive mental well-being assessed with Bradley's well-being questionnaire (MD -0.18, 95% CI -1.34 to 0.98; 1 study, n=91) or quality of life (MD 1.22, 95% CI -7.65 to 10.09; 1 study, n=91). Active information had no impact on survivor death (OR 0.91, 95%CI 0.70 to 1.19; 8 studies, n=2460).

Outcome Timeframe	Study results and measurements	Comparator Control	Intervention Active information provision	Certainty of the evidence (Quality of evidence)	Summary
Patient depressive	Measured by: HADS-D score Scale: 0 — 21 Lower better	6.58	5.78	Moderate	Active information provision probably decreases patient

Outcome Timeframe	Study results and measurements	Comparator Control	Intervention Active information provision	Certainty of the evidence (Quality of evidence)	Summary
symptoms End of study 8 Critical	Based on data from 1,405 participants in 8 studies. ¹ (Randomized controlled)	(Mean) Difference:	(Mean) MD 0.8 lower (CI 95% 1.27 lower — 0.34 lower)	Due to serious risk of bias ²	depression slightly
Patient knowledge End of study 8 Critical	High better Based on data from 275 participants in 3 studies. ³ (Randomized controlled)	Difference:	SMD 0.41 higher (CI 95% 0.17 higher — 0.65 higher)	Low Due to serious risk of bias, Due to serious imprecision ⁴	Active information provision may improve patient knowledge slightly.
Patient anxiety symptoms End of study 8 Critical	Measured by: HADS-A score Scale: 0 — 21 Lower better Based on data from 1,171 participants in 6 studies. ⁵ (Randomized controlled)	6.52 (Mean) Difference:	5.79 (Mean) MD 0.73 lower (CI 95% 1.1 lower — 0.36 lower)	Low Due to serious risk of bias, Due to serious inconsistency ⁶	Active information provision may decrease patient anxiety slightly
Carer depressive symptoms End of study 8 Critical	Measured by: HADS-D score Scale: 0 — 21 Lower better Based on data from 924 participants in 3 studies. ⁷ (Randomized controlled)	4.59 (Mean) Difference:	4.29 (Mean) MD 0.3 lower (CI 95% 1.53 lower — 0.92 higher)	Low Due to serious risk of bias, Due to serious inconsistency ⁸	Active information provision may have little or no difference on carer depression
Carer knowledge End of study 8 Critical	High better Based on data from 356 participants in 4 studies. ⁹ (Randomized controlled)	Difference:	SMD 0.68 higher (CI 95% 0.03 lower — 1.39 higher)	Very low Due to serious risk of bias, Due to serious imprecision, Due to serious inconsistency ¹⁰	We are uncertain whether active information provision increases or decreases carer knowledge
Carer anxiety symptoms End of study 8 Critical	Measured by: HADS-A score Scale: 0 — 21 Lower better Based on data from 921 participants in 3 studies. ¹¹ (Randomized controlled)	6.26 (Mean) Difference:	5.86 (Mean) MD 0.4 lower (CI 95% 1.51 lower — 0.7 higher)	Low Due to serious risk of bias, Due to serious inconsistency ¹²	Active information provision may have little or no difference on carer anxiety
Carer quality of life End of intervention 8 Critical	Measured by: Visual analogue scale Scale: 0 — 100 High better Based on data from 91 participants in 1 studies. ¹³ (Randomized controlled)	66.78 (Mean) Difference:	68 (Mean) MD 1.22 higher (CI 95% 7.65 lower — 10.09 higher)	Low Due to serious risk of bias, Due to serious imprecision ¹⁴	Active information provision may have little or no difference on quality of life

1, 3, 5, 7, 9, 11, 13. Systematic review [9]

2. **Risk of Bias: serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias, Inadequate/lack of blinding of outcome assessors, resulting in potential for detection bias. **Inconsistency: no serious. Indirectness: no serious. Imprecision: no serious. Publication bias: no serious.**
4. **Risk of Bias: serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias, Inadequate/lack of blinding of outcome assessors, resulting in potential for detection bias. **Inconsistency: no serious. Indirectness: no serious. Imprecision: serious.** Low number of patients. **Publication bias: no serious.**
6. **Risk of Bias: serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias, Inadequate/lack of blinding of outcome assessors, resulting in potential for detection bias. **Inconsistency: serious.** The confidence interval of some of the studies do not overlap with those of most included studies/ the point estimate of some of the included studies.. **Indirectness: no serious. Imprecision: no serious. Publication bias: no serious.**
8. **Risk of Bias: serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias, Inadequate/lack of blinding of outcome assessors, resulting in potential for detection bias. **Inconsistency: serious.** The magnitude of statistical heterogeneity was high, with I^2 : 86%, Point estimates vary widely. **Indirectness: no serious. Imprecision: no serious. Publication bias: no serious.**
10. **Risk of Bias: serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias, Inadequate/lack of blinding of outcome assessors, resulting in potential for detection bias. **Inconsistency: serious.** The confidence interval of some of the studies do not overlap with those of most included studies/ the point estimate of some of the included studies., The magnitude of statistical heterogeneity was high, with I^2 : 90%.. **Indirectness: no serious. Imprecision: serious.** Low number of patients. **Publication bias: no serious.**
12. **Risk of Bias: serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias, Inadequate/lack of blinding of outcome assessors, resulting in potential for detection bias. **Inconsistency: serious.** The confidence interval of some of the studies do not overlap with those of most included studies/ the point estimate of some of the included studies., The magnitude of statistical heterogeneity was high, with I^2 : 78%.. **Indirectness: no serious. Imprecision: no serious. Publication bias: no serious.**
14. **Risk of Bias: serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias, Inadequate/lack of blinding of outcome assessors, resulting in potential for detection bias. **Imprecision: serious.** Low number of patients, Wide confidence intervals.

Clinical question/ PICO

- Population:** Stroke patients and their caregivers
- Intervention:** Passive information provision
- Comparator:** Control

Summary

A Cochrane review by Crocker et al. (2021) [9] assessed the effectiveness of information provision strategies in improving outcomes for survivors of stroke and carers. Thirty-three randomised trials were included, 11 using a passive intervention in which information was provided on a single occasion with no follow-up or reinforcement, and 22 using an active intervention. Meta-analyses showed that passive information provision had no significant difference on any survivor or carer outcome.

Outcome Timeframe	Study results and measurements	Comparator Control	Intervention Passive information provision	Certainty of the evidence (Quality of evidence)	Summary
Patient knowledge End of intervention 8 Critical	High better Based on data from 270 participants in 3 studies. ¹ (Randomized controlled)	Difference:	SMD 0.23 higher (CI 95% 0.23 lower — 0.69 higher)	Very low Due to serious risk of bias, Due to serious inconsistency, Due to serious	We are uncertain whether passive information provision increases or decreases patient knowledge.

Outcome Timeframe	Study results and measurements	Comparator Control	Intervention Passive information provision	Certainty of the evidence (Quality of evidence)	Summary
				imprecision ²	
Patient anxiety symptoms End of intervention 8 Critical	Measured by: HADS-A Scale: 0 — 21 Lower better Based on data from 227 participants in 3 studies. ³ (Randomized controlled)	6.52 (Mean) Difference:	7.19 (Mean) MD 0.67 higher (CI 95% 0.37 lower — 1.71 higher)	Low Due to serious risk of bias, Due to serious imprecision ⁴	Passive information provision may or may not increase patient anxiety slightly.
Patient depressive symptoms End of intervention 8 Critical	Measured by: HADS-D Scale: 0 — 21 Lower better Based on data from 227 participants in 3 studies. ⁵ (Randomized controlled)	6.58 (Mean) Difference:	6.97 (Mean) MD 0.39 higher (CI 95% 0.61 lower — 1.38 higher)	Low Due to serious risk of bias, Due to serious imprecision ⁶	Passive information provision may or may not increase patient depression slightly.
Patient quality of life End of intervention 8 Critical	Measured by: Dartmouth Primary Care Cooperative Function Assessment Charts Scale: 1 — 5 Lower better Based on data from 198 participants in 2 studies. ⁷ (Randomized controlled)	2.2 (Mean) Difference:	2.24 (Mean) MD 0.04 higher (CI 95% 0.45 lower — 0.53 higher)	Very low Due to serious inconsistency, Due to serious risk of bias, Due to serious imprecision ⁸	We are uncertain whether passive information provision increases or decreases patient quality of life.
Carer knowledge End of intervention 8 Critical	High better Based on data from 33 participants in 1 studies. ⁹ (Randomized controlled)	Difference:	SMD 0.28 higher (CI 95% 0.42 lower — 0.97 higher)	Very low Due to serious risk of bias, Due to very serious imprecision ¹⁰	Passive information provision may have little or no difference on carer knowledge
Carer anxiety symptoms End of intervention 8 Critical	Measured by: HADS-A Scale: 0 — 21 Lower better Based on data from 40 participants in 1 studies. ¹¹ (Randomized controlled)	6.26 (Mean) Difference:	5.96 (Mean) MD 0.3 lower (CI 95% 3.25 lower — 2.65 higher)	Very low Due to serious risk of bias, Due to very serious imprecision ¹²	We are uncertain whether passive information provision increases or decreases carer anxiety
Carer depressive symptoms End of intervention 8 Critical	Measured by: HADS-D Scale: 0 — 21 Lower better Based on data from 40 participants in 1 studies. ¹³ (Randomized controlled)	4.59 (Mean) Difference:	5.29 (Mean) MD 0.7 higher (CI 95% 1.93 lower — 3.33 higher)	Very low Due to serious risk of bias, Due to very serious imprecision ¹⁴	We are uncertain whether passive information provision increases or decreases carer depression

1, 3, 5, 7, 9, 11, 13. Systematic review [9]

2. **Risk of Bias: serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias, Inadequate/lack of blinding of outcome assessors, resulting in potential for detection bias. **Inconsistency: serious.** The confidence interval of some of the studies do not overlap with those of most included studies/ the point estimate of some of the included studies., The magnitude of statistical heterogeneity was high, with I^2 : 70%.. **Indirectness: no serious. Imprecision: serious.** Wide confidence intervals,

Low number of patients. **Publication bias: no serious.**

4, 6. **Risk of Bias: serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias, Inadequate/lack of blinding of outcome assessors, resulting in potential for detection bias. **Inconsistency: no serious. Indirectness: no serious. Imprecision: serious.** Low number of patients. **Publication bias: no serious.**

8. **Risk of Bias: serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias, Inadequate/lack of blinding of outcome assessors, resulting in potential for detection bias. **Inconsistency: serious.** The magnitude of statistical heterogeneity was high, with I^2 : 70%, Point estimates vary widely. **Imprecision: serious.** Wide confidence intervals, Low number of patients.

10. **Risk of Bias: serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias, Inadequate/lack of blinding of outcome assessors, resulting in potential for detection bias. **Inconsistency: no serious. Indirectness: no serious. Imprecision: very serious.** Wide confidence intervals, Low number of patients, Only data from one study. **Publication bias: no serious.**

12. **Risk of Bias: serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias, Inadequate/lack of blinding of outcome assessors, resulting in potential for detection bias. **Inconsistency: no serious. Indirectness: no serious. Imprecision: very serious.** Low number of patients, Only data from one study. **Publication bias: no serious.**

14. **Risk of Bias: serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias, Inadequate/lack of blinding of outcome assessors, resulting in potential for detection bias. **Inconsistency: no serious. Indirectness: no serious. Imprecision: very serious.** Low number of patients, Only data from one study, Wide confidence intervals. **Publication bias: no serious.**

Info Box

Practice points

- Stroke survivors and their families/carers should be educated in the FAST stroke recognition message to maximise early presentation to hospital in case of recurrent stroke.
- The need for education, information and behaviour change to address long-term secondary stroke prevention should be emphasized (refer to [Secondary Prevention](#)).

Practical info

The FAST (Face, Arm, Speech, Time) recognition test is the awareness message endorsed by the Stroke Foundation. It involves testing three of the most common signs of stroke (Facial asymmetry or mouth droop; Arm weakness; Speech slurred or unintelligible) and prompt for Timely action.

Further information and resources are found at <https://strokefoundation.com.au/About-Stroke/Stroke-symptoms>.

Consider also providing the patient and their carer/s with a list of do's and don't's, tailored to their circumstances, including the cause of the patient's stroke. In addition, ensure the patient and their carer/s have access to, and know how to use, EnableMe.

Discharge care plans

A post-discharge care plan is normally completed prior to discharge and identifies appropriate management strategies to guide care after the stroke survivor returns to the community. Care plans are based on the needs and goals identified in the pre-discharge assessment and may be useful in building self-management strategies for the stroke survivor. Ideally, all team members, including the stroke survivor, the family/carer, the general practitioner, and community-based service providers are involved in developing and documenting an agreed plan that takes into account the complex adjustments needed, especially when changing settings or care. A formal family meeting or conference is often used to develop such a plan.

Discharge planning may be coordinated by one member of the team (e.g. in-patient care coordinator) or it may be undertaken by someone who coordinates discharges for multiple teams or the whole hospital (e.g. discharge care planner, continuing care nurse). National Stroke Audit results of Rehabilitation Services reported that 83% of stroke patients received a discharge care plan (Stroke Foundation 2024 [14]). In acute services, 70% of stroke patients received a discharge care plan and the majority were involved in the planning (96% of patients and 58% of families) (Stroke Foundation 2023 [51]).

Strong recommendation

Updated evidence, no change in recommendation

Comprehensive discharge care plans that address the specific needs of the stroke survivor should be developed in conjunction with the stroke survivor and carer prior to discharge. (Johnston et al. 2010 [20]; Gonçalves-Bradley et al. 2016 [21])

Practical info

It is important to discuss the broad support systems available to the individual person with stroke and their family as part of the discharge planning.

For people of working age, consider the timeframe for them to return to work after discharge, and the implications of that for rehabilitation, and vice versa.

Evidence to decision

Benefits and harms	<div>Substantial net benefits of the recommended alternative</div> <p>A meta-analysis of adults admitted to hospital showed that discharge planning reduced readmission and length of stay but no significant difference on mortality was found during the follow-up of 6-9 months (Gonçalves-Bradley et al 2016 [21]).</p> <p>There is also evidence from a randomised controlled trial that standardised discharge planning specifically for stroke patients may improve the rate of optimal secondary prevent treatment (Johnston et al 2010 [20]).</p>
Certainty of the evidence	<div>Moderate</div> <p>The quality of evidence is moderate due to potential risk of bias. The population included in the meta-analysis was all adults admitted to hospital but the result is likely to be transferable to stroke patients.</p>
Values and preferences	<div>No substantial variability expected</div> <p>It is expected that the majority of patients would want to be provided with and involved in discharge planning.</p>
Resources and other considerations	<div>Important issues, or potential issues not investigated</div>

Resources considerations

Health professionals involved in the patient care may have competing commitments and lack time for this practice. Gonçalves-Bradley et al (2016) [21] also assessed the cost. There was evidence that costs could be reduced due to a lower readmission rate and length of stay . Evidence for the use of care plans in primary care was limited and heterogeneous .

Implementation considerations

There is a clinical indicator for the provision of care plans (outlining post-discharge care in the community and developed with input from the team and the patient) routinely collected in both the Australian Stroke Clinical Registry and the National Stroke Audit. This clinical indicator is collected in the Acute Stroke Clinical Care Standard, with patients excluded from calculations if they were transferred to inpatient rehabilitation or for further acute care or if they refused to develop a care plan.

Rationale

Moderate quality of evidence demonstrates benefits of discharge planning in reduced readmission and length of stay. Moreover, it is likely that the majority of patients would want to be provided with discharge care planning to support the transition back into the community following hospital care.

Clinical question/ PICO

- Population:** Adults with stroke
- Intervention:** Standardised stroke discharge orders
- Comparator:** Usual care

Summary

Johnston et al (2010) [20] conducted the only cluster-randomised trial for standardised stroke discharge orders up to date. The template for ischaemic stroke discharge orders included 3 specific interventions: "a statin prescription for all patients regardless of cholesterol level, antihypertensive medications for those with hypertension, and warfarin prescription in all patients with atrial fibrillation". The primary analysis (reported here) was a conservative hospital-level analysis, finding no significant difference in rates of optimal treatment. Analyses at the patient level comparing optimal treatment rates pre- and post-intervention found point estimates in favour of the intervention hospitals, but again no significant differences.

Outcome Timeframe	Study results and measurements	Comparator	Intervention	Certainty of the evidence (Quality of evidence)	Summary
Optimal secondary prevention treatment ¹ 6 months 7 Critical	Odds ratio 1.39 (CI 95% 0.71 — 2.76) Based on data from 3,361 participants in 1 studies. ² (Randomized controlled) Follow up: 6 months.			Low Due to serious imprecision, Due to serious risk of bias ³	Standardised stroke discharge orders may improve optimal secondary prevention treatment

1. Optimal treatment was a binary outcome, indicating whether all 3 of the following criteria had been filled (where applicable). Quoting from Johnston, 2010: 1. Documentation of a filled statin prescription that covers a date 6 months (30 days) after hospital discharge; 2. Achievement of controlled blood pressure (defined as systolic blood pressure 140 and diastolic blood pressure 90) for all patients, regardless of whether they had diagnosed hypertension at the latest measurement during the period 4 to 8 months after discharge (those with no measurement and a history of hypertension were considered uncontrolled); and 3. Either documentation of a filled prescription for warfarin or an International Normalized Ratio (INR) blood test on a date 6 months (30 days) after discharge (for patients diagnosed with atrial fibrillation only). Patients with contraindications to warfarin who did not receive it were also considered to have satisfied this criterion.

2. [20].

3. **Risk of Bias: serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias.
Inconsistency: no serious. Indirectness: no serious. Imprecision: serious. Wide confidence intervals, Only data from one study.
Publication bias: no serious.

Clinical question/ PICO

- Population:** Adults admitted to hospitals
- Intervention:** Discharge planning
- Comparator:** No discharge planning

Summary

Gonçalves-Bradley et al (2016) [21] conducted a meta-analysis of randomised controlled trials of discharge planning in hospitals. They found that a discharge plan tailored to the individual patient probably brings about a small reduction in hospital length of stay and reduces the risk of readmission to hospitals at three months follow-up for older people with a medical condition. Discharge planning may also lead to increased satisfaction for patients and health professionals.

The COMPASS study by Duncan et al (2020)[40] (n=6024) compared a comprehensive post acute stroke transitional care management program which informed an individualised care plan (COMPASS-CP) compared to current standard of post acute care. There was no significant difference between groups for the primary outcome of physical functioning (SIS-16, MD 0.61, 95% CI -1.74 to 2.97; n=3,476). Home blood pressure monitoring was improved in the intervention group (OR 1.43, 95% CI 1.21 to 1.70; n=3,033). There were no significant differences between groups for mortality at 90 days, disability (mRS), medication adherence, being physically active, cognition, less fatigue, self-rated general health, satisfaction with provider communication and satisfaction with care coordination.

Demir Avci and Gozum 2023 [44] (n=126) trialed a transitional care model (The Transitional Care Model Stroke Turkey) for patients with stroke and their caregivers for 13 to 20 weeks. The intervention included a 12 week follow up after discharge, a minimum of three hospital visits, one home visit, minimum 18 phone calls and web-based training. The intervention group showed significantly improved caregiver competence (Effect size: 0.88), preparedness for caregiving (Effect size 1.23), and e-health literacy (Effect size: 1.08) compared to the control group.

Aoki et al (2024)[49] (n=99) trialed the influence of decision aids for matching older patients with stroke (aged 65 and older) and their families' values, regrading decisions for discharge destination. The intervention did not significantly reduce decisional conflicts or increase patient roles in decision making. A significantly higher number of patients in the intervention group had already decided at admission their discharge destination (66.7% vs 45.8%) and were discharged to the same place as before admission (70.6% vs 60.4%) compared to usual care, which may reflect an uneven distribution of stroke severity between groups. The study was conducted in Japan and further information is needed.

Outcome Timeframe	Study results and measurements	Comparator	Intervention	Certainty of the evidence (Quality of evidence)	Summary
Mortality 6-9 months 9 Critical	Relative risk 1.02 (CI 95% 0.83 — 1.27) Based on data from 2,654 participants in 8 studies. ¹ (Randomized controlled) Follow up: 6-9 months.	106 per 1000 Difference:	108 per 1000 2 more per 1000 (CI 95% 29 more — 18 fewer)	Low Due to serious risk of bias, Due to serious imprecision ²	Discharge planning may have little or no difference on mortality
Readmission 3 months 8 Critical	Relative risk 0.88 (CI 95% 0.79 — 0.97) Based on data from 4,853 participants in 17 studies. ³	250 per 1000 Difference:	220 per 1000 30 fewer per 1000	Moderate Due to serious risk of bias ⁴	Discharge planning probably decreases readmission

Outcome Timeframe	Study results and measurements	Comparator	Intervention	Certainty of the evidence (Quality of evidence)	Summary
	(Randomized controlled) Follow up: 3 months.		(CI 95% 7 fewer — 52 fewer)		
Length of stay Until discharge 8 Critical	Measured by: Hospital stay - days Lower better Based on data from 2,193 participants in 11 studies. ⁵ (Randomized controlled)	Difference:	MD 0.73 lower (CI 95% 1.33 lower — 0.12 lower)	Moderate Due to serious risk of bias ⁶	Discharge planning probably decreases length of stay

1, 3, 5. Systematic review [21]
2. **Risk of Bias: serious.** Inadequate concealment of allocation during randomization process, resulting in potential for selection bias: systematic review reported that allocation concealment was unclear in many trials. **Inconsistency: no serious. Indirectness: no serious.** The population wasn't specific to stroke but this is unlikely to cause issues. **Imprecision: serious.** Wide confidence intervals. **Publication bias: no serious.**
4, 6. **Risk of Bias: serious.** Inadequate concealment of allocation during randomization process, resulting in potential for selection bias: systematic review reported that allocation concealment was unclear in many trials. **Inconsistency: no serious. Indirectness: no serious.** The population wasn't specific to stroke but this is unlikely to cause issues. **Imprecision: no serious. Publication bias: no serious.**

Info Box

Practice point
Discharge planning should commence as soon as possible after the stroke patient has been admitted to hospital.

Evidence to decision

Benefits and harms

Rationale

Discharge planning is critically important to consumers and should be done comprehensively. Planning should commence early after hospital admission.

Consensus recommendation

Consensus-based recommendation
A discharge planner may be used to coordinate a comprehensive discharge program for stroke survivors.

Practical info

Discharge planning can be coordinated by one member of the treating healthcare team (e.g. in-patient care coordinator) or coordinated by someone who coordinates discharges for multiple teams. Discharge planning must take into account the wishes of the patient and carer/s, and everyone (including health professionals, supports etc), should be clear about next steps.

Consensus recommendation

Consensus-based recommendations

To ensure a safe discharge process occurs, hospital services should ensure the following steps are completed prior to discharge:

- Stroke survivors and families/carers have the opportunity to identify and discuss their post-discharge needs (physical, emotional, social, recreational, financial and community support) with relevant members of the multidisciplinary team.
- General practitioners, primary healthcare teams and community services are informed before or at the time of discharge.
- All medications, equipment and support services necessary for a safe discharge are organised.
- Any necessary continuing specialist treatment required has been organised.
- A documented post-discharge care plan is developed in collaboration with the stroke survivor and family and a copy provided to them. This discharge planning process may involve relevant community services, self-management strategies (i.e. information on medications and compliance advice, goals and therapy to continue at home), stroke support services, any further rehabilitation or outpatient appointments, and an appropriate contact number for any post-discharge queries

A locally developed protocol or standardised tool may assist in implementation of a safe and comprehensive discharge process. This tool should be aphasia and cognition friendly.

Patient and carer needs

Assessment of discharge needs should start as soon as possible after admission. A pre- and/or post-discharge needs assessment examines, for example, the social, emotional, physical and financial needs of the stroke survivor and their family/carer. Any cognitive or behavioural issues identified should be discussed and management strategies incorporated into any discharge plan (e.g. monitoring of mood). National Stroke Audit results showed that 62% of caregivers of stroke survivor in acute services (Stroke Foundation 2023 [51]) and 69% in rehabilitation services (Stroke Foundation 2020 [14]) received needs assessment prior to discharge.

Consensus recommendation

Consensus-based recommendation

Hospital services should ensure that stroke survivors and their families/carers have the opportunity to identify and discuss their post-discharge needs (including physical, emotional, social, recreational, financial and community support) with relevant members of the interdisciplinary team.

Evidence to decision

Resources and other considerations	Implementation considerations
	There is a clinical indicator collected in the National Stroke Audit to determine whether carers of patients with stroke received a documented formal needs assessment before the patient's discharge. This clinical indicator is included in the Acute Stroke Clinical Care Standard, with carers excluded if they declined the needs assessment or if the patient was transferred to inpatient rehabilitation for further acute care.

Rationale

No high-quality studies were found that examined health-related quality of life, unmet needs, healthcare utilisation, or caregiver burden. Limited qualitative evidence shows that the various needs across care continuum should be addressed (Young et al 2014 [22], Cameron et al 2013 [25], MacIsaac et al (2011) [26], Hafsteinsdóttir et al (2011) [27]).

Home assessment

Almost all stroke survivors will require an occupational therapy assessment to identify the person-environment fit of the stroke survivor in consideration of their discharge destination. This is undertaken initially by in-hospital interview but may also include a home-visit. Factors to consider include the environmental barriers at home, specific physical, communication and/or cognitive impairments, the risk of falls and the desires of the stroke survivor and their family/carer. The need for home modifications or assistive equipment can then be determined. National Stroke Audit of Rehabilitation Services showed that 75% of stroke survivors discharged home received home assessments but it is unclear if home-visits were undertaken in all cases (Stroke Foundation 2024 [14]).

Consensus recommendation

Reviewed, no new evidence

Consensus-based recommendation

Prior to hospital discharge, all stroke survivors should be assessed to determine the need for a home visit, which may be carried out to ensure safety and provision of appropriate aids, support and community services.

Practical info

Additional information about Assistive technology for safe discharge and OT home visits is available from: <https://informme.org.au/News/2020/04/24/Assistive-technology-importance-for-independence-and-safe-discharge>

Evidence to decision

Benefits and harms	<div>Small net benefit, or little difference between alternatives</div> <p>A feasibility study (Drummond et al 2013 [28]) compared a pre-discharge home visit and a structured hospital-based interview. Even though the study was underpowered, the patients who had the interview seemed to have similar outcomes to those who had a home visit assessment. This may reflect that the in-depth 'control' intervention attenuated any outcome differences between the two groups, or may reflect a genuine lack of efficacy of home visits.</p>
Certainty of the evidence	<div>Very low</div> <p>It is uncertain if the effect estimates reflect the true comparison between the interventions. This is because the study was a feasibility trial that identified issues of consistency in applying the protocol in the randomised controlled trial e.g. some people received a home visit or an access visit when they should not or received more than one visit or were discharged on the visit. There were also key issues identified regarding the control group. It is likely that patients in this group received more intervention than is standard care in most centres - in some hospitals patients are discharged from hospital following a stroke without any visits and interviews are not routine practice.</p>
Values and preferences	<div>Substantial variability is expected or uncertain</div> <p>It is uncertain if patients and their family/carer would want a physical home visit given the similar outcomes to comprehensive in-hospital review.</p>
Resources and other considerations	<div>Important issues, or potential issues not investigated</div> <p>Cost consideration</p> <p>Cost was recorded in the feasibility study (Drummond et al 2012 [28]). The main resource use associated with home visits related to the amount of staff time required, which was attached to NHS staff costs. The mean (SD) across all home visits was £208 (£107), and the mean (SD) total cost of a hospital interview was £75 (£40). There was a 47% chance that home visits are cost-effective at a willingness-to-pay of</p>

£20,000 per quality-adjusted life year but there was high uncertainty. (Sampson et al. 2014 [32])

Implementation consideration

There is a clinical indicator collected in the National Stroke Audit to determine whether a home assessment was carried out for patients with stroke prior to their discharge.

Rationale

The safety of the home environment is essential for those recovering from stroke who return to the community following hospital care. An interview by an occupational therapist with the person with stroke and their family/carer should be undertaken to assess the home and to ascertain if a physical home-visit is required prior to discharge. There is limited evidence comparing the benefits of pre-discharge home visit to a structured hospital-based interview both in people with stroke and in wider patient cohorts. (Drummond et al. 2013 [28]; Lockwood et al. 2015 [29]; Clemson et al. 2016 [30]) Data available suggests there is limited difference between home-visits and hospital-based interviews but further trials are needed. Factors to consider when deciding if a home-visit is required include the person's physical, cognitive and social needs along with therapist experience and practical considerations such as staff availability and competing demands (Godfrey et al. 2019 [31]).

Clinical question/ PICO

Population: Adults with stroke

Intervention: Home visit

Comparator: No visit

Summary

Drummond et al (2012) [28] conducted a feasibility trial of pre-discharge home visits for stroke patients. They assigned eligible patients for whom there was clinical uncertainty about the need to conduct a home visit to a randomised controlled trial (RCT). At the same time, a cohort study was conducted in which patients for whom a visit was judged 'essential' were enrolled. In the 93 patients enrolled in the RCT, no significant difference was found in the primary outcome Nottingham Extended Activities of Daily Living. This could be due to inadequate statistical power to detect a difference, or control group practices that are more intensive than standard care in most centres, or a genuine lack of efficacy. The uncertainty precludes a definitive conclusion.

Outcome Timeframe	Study results and measurements	Comparator No visit	Intervention Home visit	Certainty of the evidence (Quality of evidence)	Summary
ADL ¹ One month post discharge 8 Critical	Measured by: Nottingham Extended Activities of Daily Living (NEADL) Scale: 1 — 22 High better Based on data from 85 participants in 1 studies. ² (Randomized controlled) Follow up: One month.	20 points (Median) Difference:	14.5 points (Median) 5.5 lower	Very low The difference between groups was non-significant (p = 0.52). Due to serious risk of bias, Due to serious indirectness, Due to serious imprecision ³	We are uncertain whether home visits increase or decrease ADL
HRQoL ⁴ One month post discharge 9 Critical	Measured by: EQ-5D questionnaire High better Based on data from 83 participants in 1 studies. ⁵ (Randomized controlled) Follow up: One month.	0.5 (Mean) Difference:	0.53 (Mean) MD 0.03 higher	Very low The difference between groups was non-significant (p = 0.74). Due to serious risk of bias, Due to serious indirectness, Due to serious imprecision ⁶	We are uncertain whether home visits increase or decrease HRQoL

Outcome Timeframe	Study results and measurements	Comparator No visit	Intervention Home visit	Certainty of the evidence (Quality of evidence)	Summary
Falls Timeframe unclear 8 Critical	Measured by: People experiencing one or more falls Lower better Based on data from 85 participants in 1 studies. (Randomized controlled) Follow up: One month.	9 people Difference:	13 people 4 more n/a	Very low The difference between groups was non-significant. Due to serious risk of bias, Due to serious indirectness, Due to serious imprecision ⁷	We are uncertain whether home visits increase or decrease falls
Readmissions One month post discharge 8 Critical	Measured by: Count Lower better Based on data from 85 participants in 1 studies. (Randomized controlled) Follow up: One month.	2 people readmitted Difference:	8 people readmitted 6 more n/a	Very low The difference between groups was significant (p = 0.04). Due to serious imprecision, Due to serious indirectness, Due to serious risk of bias ⁸	We are uncertain whether home visit increases or decreases readmissions

1. The primary outcome measure was the Nottingham Extended Activities of Daily Living (NEADL)

2, 5. [28]. **Comparator:** [28].

3, 8. **Risk of Bias: serious.** Non adherence to protocol, Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias. **Inconsistency: no serious. Indirectness: serious.** It is likely that patients in the control group received more intervention than is standard care in most centres. **Imprecision: serious.** Only data from one study. **Publication bias: no serious.**

4. Secondary outcome measured using the EQ-5D questionnaire

6, 7. **Risk of Bias: serious.** Non adherence to protocol, Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias. **Inconsistency: no serious. Indirectness: serious.** It is likely that patients in the control group received more intervention than is standard care in most centres. **Imprecision: serious.** Only data from one study.

Carer training

Carers often report feeling inadequately trained, poorly informed, and dissatisfied with the extent of support available after discharge (Greenwood et al 2009 [37]). Their support and training requirements include personal care techniques, communication, physical handling and transfers, and information about ongoing prevention of functional decline and other specific stroke-related problems. National Stroke Audit of Rehabilitation Services showed that 50% of stroke survivors had carers, of whom approximately 72% received training (Stroke Foundation 2024 [14]), whereas only 62% of carers of stroke patients discharged from acute services in hospitals received training (Stroke Foundation 2023 [51]).

Weak recommendation

Updated evidence, no change in recommendation

Relevant members of the interdisciplinary team should provide specific and tailored training for carers/family before the stroke survivor is discharged home. This training should include, as necessary, personal care techniques, communication strategies, physical handling techniques, information about ongoing prevention and other specific stroke-related problems, safe swallowing and appropriate dietary modifications, and management of behaviours and psychosocial issues. (Forster et al. 2013 [34])

Practical info

Training may cover a range of aspects that are specifically relevant to the person affected by stroke.

Training may need to encompass different types of information and advice based on the needs and preferences of the person and their family/carers e.g. written information along with practical demonstrations and practice with feedback. Furthermore, training often will require very practical strategies related to activities of everyday living and ongoing rehabilitation after discharge which should be clearly explained and documented for future reference and provided for consistency for all those who will take on a carer role. Advice on emotional challenges (such as depression) and awareness and coping skills is very important for both the person affected by stroke and their family/carers.

Further resources such as face-to-face peer groups and online information or suport groups should be discussed and written down or integrated within the discharge care plans (e.g. My Stroke Journey resource).

Instances where a person affected by stroke is in residential care most of the time, but spending days or weekends in the 'care' of a partner can require different training for carers than when a person is returning home 'full time'.

It's important that, whilst noting some stroke survivors may need some assistance from carers, many remain fully, enabled people - treating them otherwise can be offensive for both the carer and the person affected by stroke.

Evidence to decision

Benefits and harms

Small net benefit, or little difference between alternatives

No difference was shown between a structured training programme for caregivers and usual care for self-reported extended activities of daily living or carer burden at 6-months in a large (N=928) robust trial (Forster et al 2013 [34]). However, a previous Cochrane review (Legg et al 2011 [36]) concluded teaching procedural knowledge was effective in reducing carer burden (result was from one study of 255 patients). It is unclear if the inconsistent results were from differences in study design or intervention.

Certainty of the evidence

Moderate

The quality of evidence was moderate.

Values and preferences

No substantial variability expected

A systematic review of qualitative literature of informal primary carers of stroke survivors highlighted the training needs as one of the most commonly reported themes (Greenwood et al 2009 [37]).

Resources and other considerations

No important issues with the recommended alternative

Resources considerations

There is some evidence from Patel et al (2004) [35] that carer training during inpatient rehabilitation can reduce total costs due to earlier discharge (saving of £4,043, reference year 2001/2002) and improved health outcomes. In a clinical trial with a parallel cost-effectiveness analysis, a structured training programme for caregivers of inpatients after stroke was compared to usual care (Forster et al 2013 [34]). In this study it was found that the probability of caregiver training being cost-effective based on quality adjusted life years was low. In a systematic review, three economic evaluations of carer training/information interventions were identified (Heslin et al 2016 [38]). The interventions were found to be cost-effective compared to usual care, with the interventions being less costly with better or equivalent for clinical outcomes including depression, life satisfaction, anxiety, quality of life and carer burden.

Implementation considerations

There is a clinical indicator collected in the National Stroke Audit on the provision of relevant training for carers of patients with stroke before the patient's discharge. This clinical indicator is included in the Acute Stroke Clinical Care Standard, with carers excluded if they declined the training or if the patient was transferred to inpatient rehabilitation or for further acute care.

Rationale

Moderate evidence shows inconsistent results in the effectiveness of carer training. However, it is expected stroke survivors and their caregivers would highly prefer to be provided with training in assisting daily activities. Therefore, training should be provided to carers of stroke survivors but the effective forms of training remain unclear.

Clinical question/ PICO

Population: Carers of adult stroke patients

Intervention: Structured training program in hospital

Comparator: Usual care

Summary

Forster et al (2013) [34] conducted a pragmatic, multicenter, cluster RCT in 36 stroke units (N=928). The intervention was a structured training program for caregivers which includes assessment of competencies in knowledge or skills essential for the day-to-day management of disabled survivors of stroke (for example, knowledge of stroke, handling for activities of daily living). The program had 14 components, six components were mandatory and eight non-mandatory dependent on individual patient and caregiver needs. Patients' self-reported extended activities of daily living did not differ between groups at 6 months, and neither did the caregiver burden scale.

A Cochrane review of non-pharmacological interventions for carers of survivors of stroke concluded that teaching procedural knowledge delivered to caregivers prior to the survivor's discharge from hospital appear to be the most promising intervention (Legg et al 2011 [36]). It is unclear if the inconsistent results resulted from the design of the study or the intervention.

A subsequent randomised trial (Eames et al. 2013 [11]) that delivered an education and support package to patients with stroke and carers (N = 138) showed no significant improvement in caregiver burden, but significant improvements in self-efficacy and satisfaction with information. The intervention included a tailored written information booklet, verbal reinforcement of information and telephone contact at 1 month intervals for 3 months following discharge, in addition to standard stroke unit care received by the control group.

Wang et al (2021)[45] with 110 caregivers found education and muscle relaxation program reduced anxiety (6 months: 5.7 ± 2.3 vs. 6.9 ± 3.4 , $p=0.04$; 12 months: 5.4 ± 2.3 vs 7.1 ± 3.9 , $p= 0.006$), anxiety rate (6 months: 18.2% vs 38.2%, $p= 0.02$; 12 months: 16.4% vs 38.2%, $p=0.01$), anxiety severity (6 months: $p=0.019$; 12 months: $p=0.006$), depression (6 months: 6.1 ± 1.7 vs 7.0 ± 2.5 , $p=0.036$; 12 months: 6.3 ± 1.7 vs 7.2 ± 2.4 , $p=0.018$), caregiver burden (6 months: 43.5 ± 11.6 vs. 48.5 ± 14.3 , $p=0.046$; 12 months: 42.9 ± 10.9 vs 49.5 ± 14.9 , $p=0.009$) and degree of care burden (12 months: $P=0.031$). There was no difference for depression rate and severity.

Mack and Hildebrand (2023)[42] reviewed 29 studies exploring the effectiveness of different occupational therapy practice interventions for caregivers. Occupational therapy interventions that included a combination of problem-solving training, cognitive-behaviour training, stroke education and individual carer support helped caregivers maintain participation in the caregiver role. Providing combined delivery modes (before discharge, inpatient sessions, follow up in-home visits, and telephone calls) had better outcomes than delivery of any one mode alone.

Qureshi et al (2022)[43] reviewed 12 studies exploring the evidence of interventions aimed at building resilience among informal carers, finding that interventions comprising of information provision, problem solving skills and psychoeducation appear to be beneficial to improve resilience, noting high heterogeneity of interventions and outcome measures. Intervention delivery modes included before discharge, inpatient sessions, follow-up in-home visits, telephone calls and information by mail.

Avci and Gozum (2023)[44] evaluated (n = 126) the effectiveness of Transitional Care Model Stroke Turkey in patients with stroke and caregivers, compared to routine discharge, during patient transition from hospital to home. Improved caregiver competence (Effect size = 0.88), preparedness for caregiving (Effect size = 1.23) and e-health literacy (Effect size 1.08) was observed in the intervention compared to the control. The intervention group had fewer return to hospital rates (15.2% v 23.3%), pressure ulcers (3.0% v 6.7%) and frequency of coming to hospital (21.2% v 33.3%) compared to the control group.

Outcome Timeframe	Study results and measurements	Comparator Usual care	Intervention Structured training program in hospital	Certainty of the evidence (Quality of evidence)	Summary
Carer burden 6 months 8 Critical	Measured by: Caregivers Burden Scale Scale: 0 — 88 Lower better Based on data from 665 participants in 1 studies. ¹ (Randomized controlled) Follow up: 6 months.	45 (Mean) Difference:	45.5 (Mean) MD 0.5 higher (CI 95% 1.7 lower — 2.7 higher)	Moderate Due to serious imprecision ²	Structured training programs in hospital probably have little or no difference on carer burden
Patients' extended ADL 6 months 8 Critical	Measured by: Nottingham Extended Activities of Daily Living Scale: 0 — 66 High better Based on data from 678 participants in 1 studies. ³ (Randomized controlled) Follow up: 6 months.	27.6 (Mean) Difference:	27.4 (Mean) MD 0.2 lower (CI 95% 3 lower — 2.5 higher)	Moderate Due to serious imprecision ⁴	Structured training programs in hospital probably have little or no difference on patients' extended ADL

1, 3. [34].

2, 4. **Inconsistency: no serious. Indirectness: no serious. Imprecision: serious.** Only data from one study, Wide confidence intervals.

Publication bias: no serious.

Glossary and abbreviations

Glossary

Activities of daily living: The basic elements of personal care such as eating, washing and showering, grooming, walking, standing up from a chair and using the toilet.

Activity: The execution of a task or action by an individual. Activity limitations are difficulties an individual may have in executing activities.

Agnosia: The inability to recognise sounds, smells, objects or body parts (other people's or one's own) despite having no primary sensory deficits.

Aphasia: Impairment of language, affecting the production or comprehension of speech and the ability to read and write.

Apraxia: Impaired planning and sequencing of movement that is not due to weakness, incoordination or sensory loss.

Apraxia of speech: Inability to produce clear speech due to impaired planning and sequencing of movement in the muscles used for speech.

Atrial fibrillation: Rapid, irregular beating of the heart.

Augmentative and alternative communication: Non-verbal communication, e.g. through gestures or by using computerised devices.

Central register: collection of large dataset related to patients' diagnoses, treatments and outcomes

Cochrane: Cochrane is a worldwide, not-for-profit organisation that produces systematic reviews of medical research. Systematic reviews summarise all the research that has been done on a given topic, so that health professionals, patients and policy-makers can make evidence-based decisions.

Cochrane review: a comprehensive systematic review and meta-analysis published online in Cochrane library, internationally recognized as the highest standard in evidence-based health care resources

Conflict of Interest (COI) form: A conflict of interest form is signed by all working group members (including all members of the consumer panel). It highlights whether there is any risk of the person's professional judgement (eg. their assessment of research) being influenced by a secondary interest they may have, such as financial gain or career advancement.

Covidence: Covidence is computer software that Cochrane uses to help identify research for systematic reviews. It reduces the workload by allowing the person using it to quickly scan-read and screen scientific papers for relevance, make a summary of their main findings, and assess how well the research was done and whether there is a risk of bias. Covidence will be used to screen all stroke-related research articles so that only the most accurate ones go into the Living Stroke Guidelines.

Deep vein thrombosis: Thrombosis (a clot of blood) in the deep veins of the leg, arm, or abdomen.

Disability: A defect in performing a normal activity or action (e.g. inability to dress or walk).

Drip and ship: A model of thrombolysis service provision that involves assessment of patients at a non-specialist centres with telemedicine support by stroke specialists, commencing thrombolysis (if deemed appropriate) and subsequent transfer to the stroke specialist centre.

Dyad: involvement of both patients and their caregivers

Dysarthria: Impaired ability to produce clear speech due to the impaired function of the speech muscles.

Dysphagia: Difficulty swallowing.

Dysphasia: Reduced ability to communicate using language (spoken, written or gesture).

Emotionalism: An increase in emotional behaviour—usually crying, but sometimes laughing that is outside normal control and may be unpredictable as a result of the stroke.

Endovascular therapy (also called endovascular thrombectomy, mechanical thrombectomy or endovascular clot retrieval): a minimally invasive procedure performed via angiogram, in which a catheter passes up into the brain to remove the clot in the blocked blood vessel.

Enteral tube feeding: Delivery of nutrients directly into the intestine via a tube.

Evaluation (of project): An evaluation is an assessment of a project. The aim of an evaluation is to determine the project's effectiveness, efficiency, impact and sustainability.

Evidence-based decision-making: Evidence-based decision-making is a process for making decisions about an intervention, practice etc, that is grounded in the best available research evidence.

Evidence summary: An evidence summary is a short summary of the best available evidence for a particular (guidelines') question. It aims to help clinicians use the best available evidence in their decision-making about particular interventions.

Executive function: Cognitive functions usually associated with the frontal lobes including planning, reasoning, time perception, complex goal-directed behaviour, decision making and working memory.

Family support / liaison worker: A person who assists stroke survivors and their families to achieve improved quality of life by providing psychosocial support, information and referrals to other stroke service providers.

GRADE: The GRADE approach (Grading of Recommendations Assessment, Development and Evaluation) is a standardised way of assessing research (also known as the *quality of evidence*) and determining the strength of recommendations. It was designed to be transparent and rigorous and has become the leading method used for guideline development. GRADE will be applied to the Living Stroke Guidelines to ensure that their recommendations are accurate and robust.

Impairment: A problem in the structure of the body (e.g. loss of a limb) or the way the body or a body part functions (e.g. hemiplegia).

Infarction: Death of cells in an organ (e.g. the brain or heart) due to lack of blood supply.

InformMe: InformMe is the Stroke Foundation's dedicated website for health professionals working in stroke care.

Inpatient stroke care coordinator: A person who works with people with stroke and with their carers to construct care plans and discharge plans and to help coordinate the use of healthcare services during recovery in hospital.

Interdisciplinary team: group of health care professionals (including doctors, nurses, therapists, social workers, psychologists and other health personnel) working collaboratively for the common good of the patient.

Ischaemia: An inadequate flow of blood to part of the body due to blockage or constriction of the arteries that supply it.

Neglect: The failure to attend or respond to or make movements towards one side of the environment.

MAGICapp: MAGICapp is an online platform for writing (authoring) and publishing guidelines and evidence summaries. MAGIC stands for MAKing GRADE the Irresistible Choice.

The platform guides authors through the different stages of planning, authoring, and publishing of information. It then publishes the guidelines online for clinicians and their patients to access. People can dig as deep into the information as they need, in order to make well-informed healthcare decisions.

MAGICapp is the technology that will be used to write and publish the Living Stroke Guidelines.

Neglect: The failure to attend or respond to or make movements towards one side of the environment.

NHMRC: The National Health and Medical Research Council (NHMRC) is the Australian Government agency that provides most of the funding for medical research. It develops health advice for the Australian community, health professionals and governments, and develops and maintains health standards. It also provides advice on ethical behaviour in health care and in conducting health and medical research. The NHMRC are responsible for approving the stroke clinical guidelines.

Participation: Involvement in a life situation.

Participation restrictions: Problems an individual may experience in involvement in life situations.

Penumbra-based imaging: brain imaging that uses advanced MRI or CT angiography imaging to detect parts of the brain where the blood supply has been compromised but the tissue is still viable.

Percutaneous endoscopic gastrostomy (PEG): A form of enteral feeding in which nutrition is delivered via a tube that is surgically inserted into the stomach through the skin.

Pharmaceutical Benefits Scheme (PBS): A scheme whereby the costs of prescription medicine are subsidised by the Australian Government to make them more affordable.

Phonological deficits: Language deficits characterised by impaired recognition and/or selection of speech sounds.

PICO: PICO is a common way to define what research you are looking for to answer a clinical or healthcare question. Each systematic review of research is based on a specific PICO, or group of similar PICOs. PICO stands for:

P – patient, problem or population

I – intervention

C – comparison, control or comparator

O – outcome.

For example, for the question, “does care on a stroke unit improve outcomes for people with stroke?” the PICO is:

P: all people with stroke

I: care on a dedicated stroke unit (the systematic review defines what a stroke unit actually is)

C: care on a general ward

O: death, institutionalisation rate, dependency by the end of a defined follow-up period, or length of stay in a hospital or institution

Each recommendation in the Living Stroke Guidelines will be broken down into its PICO components. The scientific papers searched will need to match as closely to the PICO elements as possible.

Public consultation: Public consultation is a process by which the public's input on matters affecting them is sought. Its main goals are to improve the efficiency, transparency and public involvement, in a project – in this case in the update of the stroke guidelines.

Pulmonary embolism: Blockage of the pulmonary artery (which carries blood from the heart to the lungs) with a solid material, usually a blood clot or fat, that has travelled there via the circulatory system.

Qualitative research: Qualitative research is about words. It aims to answer questions of ‘why’. It is best used to explore perspectives, attitudes and reasons.

Quantitative research: Quantitative research is about numbers. It is best used to answer questions of ‘what’ or ‘how many’.

Randomised control trial: A controlled trial is a clinical study that compares the results of a group of people receiving a new treatment that is under investigation, against a group receiving a placebo treatment, the existing standard treatment, or no treatment at all. These comparison groups are examples of ‘control’ groups.

Rehabilitation: Restoration of the disabled person to optimal physical and psychological functional independence.

Research Ethics Committee: A Research Ethics Committee is a group that reviews all research proposals involving human participants to ensure that the proposals are ethically acceptable.

Risk factor: A characteristic of a person (or people) that is positively associated with a particular disease or condition.

Retiring (a question): A guidelines’ question is ‘retired’ when it is removed from the guidelines’ list – this means that we will no longer search for new research (evidence) for that particular question.

Stroke unit: A section of a hospital dedicated to comprehensive acute and/or rehabilitation programs for people with a stroke.

Stroke: Sudden and unexpected damage to brain cells that causes symptoms that last for more than 24 hours in the parts of the body controlled by those cells. Stroke happens when the blood supply to part of the brain is suddenly disrupted, either by blockage of an artery or by bleeding within the brain.

Systematic review: Systematic reviews summarise all the research that has been done on a given topic, so that health professionals, patients and policy-makers can make evidence-based decisions.

Task-specific training: Training that involves repetition of a functional task or part of the task.

Transient ischaemic attack: Stroke-like symptoms that last less than 24 hours. While TIA is not actually a stroke, it has the same cause. A TIA may be the precursor to a stroke, and people who have had a TIA require urgent assessment and intervention to prevent stroke.

Abbreviations

ACE	Angiotensin-converting enzyme
ADL	Activities of daily living
AF	Atrial fibrillation
AFO	Ankle foot orthosis
BAO	Basilar artery occlusion
BI	Barthel Index
BMI	Body mass index
BP	Blood pressure
CEA	Carotid endarterectomy
CEMRA	Contrast-enhanced magnetic resonance angiography
CI	Confidence interval
CIMT	Constraint induced movement therapy
CT	Computed tomography
CTA	Computed tomography angiography
CVD	Cardiovascular disease
DALY	Disability-adjusted life years
DBP	Diastolic blood pressure
DOAC	Direct oral anticoagulant
DSA	Digital subtraction angiography
DUS	Doppler ultrasonography
DVT	Deep vein thrombosis
DWI	Diffusion-weighted imaging
ECG	Electrocardiography
ED	Emergency department
EMG	Electromyographic feedback
EMS	Emergency medical services
ESD	Early supported discharge
ESS	European Stroke Scale
FAST	Face, Arm, Speech, Time
FEES	Fibre-optic endoscopic examination of

	swallowing
FeSS	Fever, Sugar, Swallowing
FFP	Fresh frozen plasma
FIM	Functional independence measure
GP	General practitioner
HR	Hazard ratio
HRQOL	Health related quality of life
HRT	Hormone replacement therapy
IA	Intra-arterial
ICH	Intracerebral haemorrhage
ICU	Intensive care unit
INR	International normalised ratio
IPC	Intermittent pneumatic compression
IV	Intravenous
LMWH	Low molecular weight heparin
LOS	Length of stay
MCA	Middle cerebral artery
MD	Mean difference
MI	Myocardial infarction
MNA	Mini Nutritional Assessment
MR	Magnetic resonance
MRA	Magnetic resonance angiography
MRI	Magnetic resonance imaging
mRS	Modified rankin scale
MST	Malnutrition screening tool
MUST	Malnutrition universal screening tool
N	Number of participants in a trial
NASCET	North American Symptomatic Carotid Endarterectomy Trial
NG	Nasogastric
NHMRC	National Health and Medical Research Council
NIHSS	National Institutes of Health Stroke Scale
NMES	Neuromuscular electrical stimulation
NNH	Numbers needed to harm
NNT	Numbers needed to treat
OR	Odds ratio

OT	Occupational therapist
PBS	Pharmaceutical Benefits Scheme
PE	Pulmonary embolism
PEG	Percutaneous endoscopic gastrostomy
PFO	Patent foramen ovale
PPV	Positive predictive value
QALYs	Quality-adjusted life years
QOL	Quality of life
RCT	Randomised controlled trial
rFVIIa	recombinant activated factor VII
RHS	Right hemisphere syndrome
ROC	Receiver operator curve
ROM	Range of motion
ROSIER	Recognition of stroke in the emergency room
RR	Relative risk
RRR	Relative risk reduction
rTMS	repetitive transcranial magnetic stimulation
rt-PA	Recombinant tissue plasminogen activator
SBP	Systolic blood pressure
SC	Subcutaneous
SD	Standard deviation
SE	Standard error
SES	Standardised effect size
SGA	Subjective global assessment
sICH	symptomatic intracerebral haemorrhage
SMD	Standardised mean difference
SSS	Scandinavian stroke scale
TEE	Transoesophageal echocardiography
TIA	Transient ischaemic attack
TOE	Transoesophageal echocardiography
TOR-BSST	Toronto Bedside Swallowing Screening test
tPA	Tissue plasminogen activator
TTE	Transthoracic echocardiography
UFH	Unfractionated heparin
UK	United Kingdom

UL	Upper limb
VF or VFS	Videofluoroscopy
VR	Virtual reality
VTE	Venous thromboembolism
WMD	Weighted mean difference

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