

Clinical Guidelines for Stroke Management

Chapter 8 of 8:
Community participation and long-term care

This is the eighth 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. December 2023.

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DRAFT RECOMMENDATION FOR PUBLIC CONSULTATION - JANUARY 2024

Self-management interventions that are directed by stroke survivors should be offered within the first four months to people living with stroke in the community. The strongest evidence base exists for the ‘Take Charge After Stroke’ intervention. (Fu et al 2020 [18])

Remark:
New recommendation to distinguish between participant led and health professional or volunteer led self-management programs.

 Weak recommendation

 Updated evidence, no change in recommendation

- Stroke survivors who are cognitively able and their carers should be made aware of the availability of generic self-management programs before discharge from hospital and be supported to access such programs once they have returned to the community.
- Stroke-specific self-management programs may be provided for those who require more specialised programs.
- A collaboratively developed self-management care plan may be used to harness and optimise self-management skills.

(Fryer et al 2016 [16]; Oh et al 2022[95])

Driving

Consensus-based recommendations

- All stroke survivors or people who have had a transient ischaemic attack (TIA) who were driving prior to their stroke should be asked if they wish to resume driving.
- Any person wishing to resume driving after a stroke or TIA should be provided with information about how stroke-related impairments may affect their driving and the requirements and processes for returning to driving. Information should be consistent with the Austroads[24]/Waka Kotahi New Zealand Transport Agency[83] standards and any relevant state guidelines.
- For stroke survivors wishing to drive for the first time, the medical and other clinical team members should discuss the feasibility of driving and provide advice as to further steps in line with national standards and any relevant state guidelines.
- Health services where stroke survivors receive care should develop an appropriate site-specific post-stroke fitness to drive pathway in accordance with local legal requirements and resources, and ensure assessments and advice is communicated to the general practitioner.

Non-driving periods

- Stroke survivors should refrain from recommencing driving until both the mandated period of non-driving has elapsed and stroke deficits precluding safe driving (if present) have resolved, as confirmed by their treating doctors (in conjunction with other non-medical clinician/s). Minimum non-driving periods determined by the relevant national standards must be followed. Please note for fitness to drive purposes in Australia TIA is defined as cerebral ischaemic symptoms resolving within 24 hours, irrespective of MRI evidence of infarction.
- For private license holders:
 - In Australia the minimum timeframe is four weeks post stroke (mandated) and two weeks after a TIA (advisory only). (Austroads standards 2022 [24]).
 - In New Zealand the minimum timeframe is one month for a single event (stroke or TIA) and three months for those with recurrent or frequent events (if no further recurrence has occurred within this timeframe). (New Zealand Transport Agency 2014[83])
- For commercial license holders:
 - In Australia the minimum timeframe is three months post stroke (mandated) and four weeks after a TIA (advisory only). (Austroads standards 2022 [24])
 - In New Zealand this generally means permanent stand down after stroke for commercial driving, but this may be appealed in special circumstances. The timeframe after TIA is six months and additional criteria apply (New Zealand Transport Agency 2014[83]).

Fitness to drive assessments

- Any person with stroke or TIA discharged from hospital or seen in a TIA clinic should be screened/assessed for any ongoing neurological deficits that could influence driving safely. Visual, cognitive, physical and behavioural assessment findings should be documented.
- Stroke survivors without physical/sensory or cognitive impairments, and who meet the vision standards for driving (refer to relevant section in standards) should be instructed not to return to driving for a period of time.
- For private license holders:
 - In Australia, where no persisting deficits are identified, the person may recommence driving on their current license after the minimum exclusion period without license restriction or further review. In New Zealand, a follow-up assessment should be conducted by an appropriate specialist to determine medical fitness prior to return to driving. (New Zealand Transport Agency 2014[83])
 - If after the minimum exclusion period the treating clinician is uncertain whether persisting motor, sensory or cognitive changes preclude safe driving, an occupational therapy specialist driving assessment should occur.
 - A conditional license may be required depending on the nature of the deficits (for example vehicle modifications, local area driving only).
- For commercial license holders:
 - In Australia, where no deficits which may impact driving are identified, a conditional license may be considered by the driver licensing authority after at least three months and subject to annual review, taking into account information provided by an appropriate specialist. After three months, if the treating clinician is uncertain whether persisting motor, sensory or cognitive changes preclude safe driving, an occupational therapy specialist driving assessment should occur.

Consensus recommendation

Consensus-based recommendations

On-road driving rehabilitation may be provided by health professionals specifically trained in driving rehabilitation.

Weak recommendation

For stroke survivors needing driving rehabilitation, driving simulation may be used. Health professionals using driving simulation need to receive training and education to deliver intervention effectively and appropriately, and mitigate driving simulator sickness. (George et al 2014 [21]; Classen et al 2014 [23])

Community mobility and outdoor travel

Weak recommendation

Stroke survivors who have difficulty with outdoor mobility in the community should set individualised goals and get assistance with adaptive equipment, information and referral on to other agencies. Escorted walking practice may be of benefit to some individuals and if provided, should occur in a variety of community settings and environments, and may also incorporate virtual reality training that mimics community walking. (Barclay et al 2015 [25]; Logan et al 2014 [27])

Leisure

Weak recommendation

For stroke survivors, targeted occupational therapy programs including leisure therapy may be used to increase participation in leisure activities. (Dorstyn et al 2014 [28]; Walker et al 2004 [30])

Return to work

Weak recommendation

- All stroke survivors should be asked about their employment (paid and unpaid) prior to their stroke and if they wish to return to work.
- For stroke survivors who wish to return to work, assessment should be offered to establish abilities relative to work demands. In addition, assistance to resume or take up work including worksite visits and workplace interventions, or referral to a supported employment service should be offered. (Ntsiea et al 2015 [33])

Sexuality

Consensus recommendation

Consensus-based recommendations

Stroke survivors and their partners should be offered:

- the opportunity to discuss sexuality and intimacy with an appropriate health professional; *and*
- written information addressing issues relating to sexual intimacy and sexual dysfunction post stroke.

Any discussion or written information should address psychosocial as well as physical function.

Support

Peer support

Weak recommendation

Stroke survivors and their families/carers should be given information about the availability and potential benefits of a local stroke support group and/or other sources of peer support before leaving hospital and when back in the community. (Kruithof et al 2013 [57])

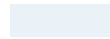
Carer support



Strong recommendation

In review

Carers of stroke survivors should be provided with tailored information and support during all stages of the recovery process. This support includes (but is not limited to) information provision and opportunities to talk with relevant health professionals about the stroke, stroke team members and their roles, test or assessment results, intervention plans, discharge planning, community services and appropriate contact details. Support and information provision for carers should occur prior to discharge from hospital and/or in the home and can be delivered face-to-face, via telephone or computer. (Legg et al 2011 [61]; Eames et al 2013 [62])



Good practice statement

In review

Consensus-based recommendations

- Carers should receive psychosocial support throughout the stroke recovery continuum to ensure carer wellbeing and the sustainability of the care arrangement. Carers should be supported to explore and develop problem solving strategies, coping strategies and stress management techniques. The care arrangement has a significant impact on the relationship between caregiver and stroke survivor so psychosocial support should also be targeted towards protecting relationships within the stroke survivors support network.
- Where it is the wish of the stroke survivor, carers should be actively involved in the recovery process by assisting with goal setting, therapy sessions, discharge planning, and long-term activities.
- Carers should be provided with information about the availability and potential benefits of local stroke support groups and services, at or before the person's return to the community.
- Assistance should be provided for families/carers to manage stroke survivors who have behavioural problems.

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 *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 *2011 NHMRC Standard for clinical practice 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**radings 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 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;

- Stroke in infants, children and youth, i.e. <18 years old (refer to Australian Childhood Stroke Advisory Committee, *Guideline for the diagnosis and acute management of childhood stroke – 2017*, and 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 the management of absolute cardiovascular disease risk 2012* (National Vascular Disease Prevention Alliance [5]) - <https://informme.org.au/en/Guidelines/Guidelines-for-the-assessment-and-management-of-absolute-CVD-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 2019* and *Rehabilitation Stroke Services Framework 2013*, 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).

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

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 Guidelines are designed to provide information to assist decision-making and are based on the best evidence available at the time of development.

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 recommendations: where the guideline panel is uncertain 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

- 8.1 Do self-management programs improve outcomes in stroke patients once they return to the community?
- 8.2 Do driver retraining interventions improve a stroke survivors' ability to return to driving?
- 8.3 What interventions improve stroke survivor's ability to access community transport?
- 8.4 What interventions increase participation of stroke survivors in leisure and/or vocational activities?
- 8.5 What interventions improve a stroke survivors' ability to return to work?
- 8.6 Does access to information and support regarding sexuality issues improve outcomes for stroke survivors?
- 8.7 Does peer support improve the outcomes of stroke survivors?
- 8.8 Do interventions to support carers improve outcomes for stroke survivors?

Community participation and long-term care - overview

Stroke can leave people with long-term and persistent impairments, leading to activity limitations and restriction in participation (Logan et al 2014 [27]). There is evidence that stroke survivors may delay getting back to a normal life, even when they may have made a good physical recovery (Parker et al 1997 [7]).

The National Stroke Audit of Rehabilitation Services (Stroke Foundation 2020 [14]) showed that 65% of stroke survivors were discharged to their usual residence (not including aged care services) however information provided to stroke survivors and carers regarding preparation for life in the community varied. One-in-two patients (48%) were provided with information about self-management programs but only 20% received information on intimacy post stroke. Overall 84% of carers were provided training, however, only 55% were offered information about peer support.

Other important aspects of care such as secondary prevention, including education about behaviour change for modifiable risk factors prior to discharge and appropriate prescription of blood pressure-lowering medication when not contraindicated, also had poor compliance.

In conjunction with this Chapter, healthcare professionals should also consider discharge planning, home-based rehabilitation, goal setting, activities of daily living and cardiorespiratory fitness, discussed in other Chapters.

Self-management

Self-management is defined as management of tasks that individuals must undertake to live with one or more chronic conditions. These tasks include medical and health management, role management and emotional management of their condition (Parke et al 2015 [16]). Self-management aims to help stroke survivors address any lifestyle interventions necessary to reduce the risk of recurrence of stroke. Self-management also aims to help stroke survivors adopt strategies to manage changes in physical and cognitive ability, relationships, and their place of residence, and to better participate in the community.

There are many types of self-management programs but common elements within them all include goal setting, action planning, problem-solving, forming a patient/professional relationship, involvement of family/carers, decision making and taking action.

In the National Stroke Audit of Rehabilitation Services, 48% of stroke survivors were made aware of the availability of generic self-management programs before discharge from hospital (Stroke Foundation 2020 [14]).

More information about self-management can be obtained from the Stroke Foundation at www.enableme.com.au.

Strong recommendation

New

DRAFT RECOMMENDATION FOR PUBLIC CONSULTATION - JANUARY 2024

Self-management interventions that are directed by stroke survivors should be offered within the first four months to people living with stroke in the community. The strongest evidence base exists for the 'Take Charge After Stroke' intervention. (Fu et al 2020 [18])

New recommendation to distinguish between participant led and health professional or volunteer led self-management programs.

Practical info

'Take Charge' is a talking therapy with an illustrated workbook for stroke survivors in the community (within 16 weeks of stroke onset) that encourages exploration of the big life questions in order to get a sense of purpose, autonomy, mastery, and connectedness with others. Participants in the study experienced stroke of mostly mild to moderate severity. In the 'Take Charge' study a second one-to-one follow up session six weeks after the first was found to be more beneficial than a single on-to-one session. It is unclear what impact the intervention would have for stroke survivors still receiving inpatient rehabilitation.

'Take Charge' facilitators were nurses or physiotherapists, many of whom did not have rehabilitation or stroke experience. They were provided with half a day of training, with ongoing support (follow-up session after 2 months, email and phone support, training manual) as needed.

The intervention involved '*one-to-one, non-directive exploration of their views on what and who was important to them in their lives, and what they wanted to prioritize for the next 12 months, from a research clinician trained to facilitate this process. Family members or friends could be present at the person's request. An illustrated workbook was used to structure the process, to help the person consider the future, and to generate ideas (under headings such as mobility and activities of daily living, communication, information needs, financial issues, emotional needs, supports, and stroke prevention) and the booklet remained with them after the session was completed*'. (Fu et al 2021 [18])

Further information and access to the Take Charge booklet and training manual can be found at www.mrinz.ac.nz/programmes/stroke.

Evidence to decision

Benefits and harms

Substantial net benefits of the recommended alternative

Two New Zealand trials have found clear benefits (reduced dependence and improved quality of life) 12 months after stroke with the 'Take Charge' program, a talking therapy aiming to facilitate self-management of stroke recovery. (Fu et al 2020 [18]). Whilst three other small studies (Jones et al 2016, McKenna et al 2015, Sabariego et al 2013) reported two additional participant led interventions were feasible and showed some improvements in functioning and self-efficacy, but between group differences were not significant. There were no adverse events reported in any of the studies. There appears to be small net benefits in participant led self-management interventions due to the between study variance of significant and non-significant improvements.

Certainty of the Evidence

Moderate

The quality of the evidence was assessed as moderate.

Values and preferences

No substantial variability expected

No variation in values and preferences are expected given no harms of the intervention and the potential benefits.

Resources and other considerations

No important issues with the recommended alternative

Resources considerations

There is evidence from a randomised controlled trial conducted in New Zealand that a self-management program (Take Charge) specifically designed for survivors of stroke is cost saving (Te Ao et al 2022 [98]). Costs were \$1412 (US\$, 2018) lower on average in the intervention group compared to the control group from a societal perspective (including healthcare costs, and impacts to employment and receipt of informal care) at 1-year follow-up. In probabilistic sensitivity analysis, it was observed that the intervention was beneficial in terms of costs and outcomes in 92% of simulations.

Implementation considerations

There is also a clinical indicator collected to determine whether patients were made aware of the availability of generic self-management programs before discharge from acute care and/or inpatient rehabilitation.

Rationale

Participant led self-management programs aim to promote quality of life and overall independence. The 'Take Charge' intervention in Maori/Pacific people and people of other western backgrounds included one or two self-reflective talking sessions focusing on important psychological and 'big life' questions which helped them focus on their attitude to life and the support they have around them. The intervention is relatively simple to deliver after training and has been shown to be highly effective and cost-effective. However, secondary analysis of the 'Take Charge' intervention was unable to identify the mechanism for the benefits in terms of mood, activation, medication adherence, or individual risk factors (McNaughton et al 2021 [99]) and further studies in other groups would be useful.

Other types of participant led programs, for example the Bridges stroke self-management program, are feasible but lack clear patient level benefits. Further studies are recommended.

Clinical question/ PICO

Population: Adults with stroke
Intervention: Self-management programs (participant led)
Comparator: Control

Summary

The Cochrane review from Fryer et al (2016) suggests that self-management programs may benefit people with stroke in the community [16]. It showed improved quality of life and self-efficacy (see PICO 5.1). The review included 14 randomised trials (n=1863) but noted wide variation in approaches and outcomes. The working group reviewed included studies and identified which of the included studies took an approach where the participants were deemed to be leading the intervention rather than being a recipient of the approach led by a therapist or volunteer.

Four studies from the review [16] were identified as participant led:

- Harwood et al (2012) tested a 'Take Charge Session' in 172 Maori and Pacific New Zealanders within three months of stroke. A single session to guide rehabilitation was found to increase quality of life (SF-36), were more independent and carers had lower carer stroke scores.
- Jones et al (2016) (n=78) and McKenna et al (2015)(n=25) both used the Bridges stroke self-management program (SMP) involving structured one-to-one rehabilitation sessions using strategies to promote specific behaviors and a stroke workbook that included vignettes, activities, ideas and solutions from other stroke survivors to illustrate successful stroke management, and space to record personal goals and progress after stroke. Both studies found the intervention feasible, and there were some changes in outcomes, but no significant difference between groups.
- Sabariego et al (2013)(n= 213) used a patient education program implementing the International Classification of Functioning, Disability and Health (ICF) model that aims to enhance patients' understanding and awareness of their own level of functioning, and enhance patients' self efficacy, however, no significant difference was found for ICF-based compared to attention-placebo control.

One additional trial and subsequent individual pooled meta-analysis was identified. Fu et al. (2020) [18] (n=400) used the same 'Take Charge' intervention used by Harwood et al (2012) 6 to 12 weeks after stroke and compared a single session (n=132), two sessions six weeks apart (n=138) or a control intervention (n=130). At 12 months the intervention groups scored 2.9 (95%CI 0.95 to 4.9) points higher (better) than control on the Short Form 36 Physical Component Summary. Two sessions were found to improve by 1.9 points (95%CI 0.8 to 3.1) compared to one session. The 'Take Charge' intervention also reduced the odds of being dependent (mRS 3-5) at 12 months (12% vs 19.5%; OR 0.55, 95%CI 0.31 to 0.99). When individual data were pooled with the Harwood et al (2012) study the 'Take Charge' intervention resulted in 3.74 (95%CI 1.95-5.51) improvement in the SF-36 physical component summary score and the odds of mRS>2 OR 0.51 (95%CI 0.32 to 0.80).

Outcome Timeframe	Study results and measurements	Comparator Control	Intervention Self- management programs	Certainty of the Evidence (Quality of evidence)	Summary
Dependence (mRS 3-5) ¹ 12 months	Odds ratio 0.51 (CI 95% 0.32 — 0.8) Based on data from 572 participants in 2 studies. ²	269 per 1000	158 per 1000	Moderate Due to serious risk of bias ³	Self-management programs probably improves independence.

Outcome Timeframe	Study results and measurements	Comparator Control	Intervention Self- management programs	Certainty of the Evidence (Quality of evidence)	Summary
8 Critical	(Randomized controlled)	Difference:	111 fewer per 1000 (CI 95% 164 fewer — 42 fewer)		
Quality of life ⁴ 12 months 8 Critical	Measured by: SF-36 PCS score Scale: 0 — 12 High better Based on data from 572 participants in 2 studies. ⁵ (Randomized controlled)	Difference:	MD 3.74 higher (CI 95% 1.96 higher — 5.51 higher)	Moderate Due to serious risk of bias ⁶	Self-management programs probably improves quality of life.

- mRS score 3-5
- Systematic review with included studies: [18]. **Baseline/comparator:** Control arm of reference used for intervention. **Supporting references:** [18],
- Risk of Bias: serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias (note: blinding of participants and staff was not possible), Missing intention-to-treat analysis. **Inconsistency: no serious. Indirectness: no serious.** Generally mild stroke population. No statistical difference between groups at baseline (TACAS study) but non-significant imbalance in SF-12 PCS scores at baseline. Two combined studies were in different populations (Maori and Pacific Islanders and specifically non-Maori and Pacific Islanders). **Imprecision: no serious.** Data from two studies. Further studies should reduce confidence intervals further.. **Publication bias: no serious.**
- Change scores/post intervention
- Primary study [18]. **Baseline/comparator:** Control arm of reference used for intervention. **Supporting references:** [18],
- Risk of Bias: serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias (but no way to blind participants or staff), Missing intention-to-treat analysis. In 2/400 blind assessors were unmasked.. **Inconsistency: no serious. Indirectness: no serious.** Generally mild stroke population. No statistical difference between groups at baseline (TACAS study) but non-significant imbalance in SF-12 PCS scores at baseline. Two combined studies were in different populations (Maori and Pacific Islanders and specifically non-Maori and Pacific Islanders). **Imprecision: no serious. Publication bias: no serious.**

References

- Fryer CE, Luker JA, McDonnell MN, Hillier SL. Self management programmes for quality of life in people with stroke. The Cochrane database of systematic reviews 2016;(8):CD010442 [Pubmed Journal](#)
- Fu V, Weatherall M, McPherson K, Taylor W, McRae A, Thomson T, et al. Taking Charge after Stroke: A randomized controlled trial of a person-centered, self-directed rehabilitation intervention. International journal of stroke : official journal of the International Stroke Society 2020;1747493020915144 [Pubmed Journal](#)

Weak recommendation

Updated evidence, no change in recommendation

- Stroke survivors who are cognitively able and their carers should be made aware of the availability of generic self-management programs before discharge from hospital and be supported to access such programs once they have returned to the community.
- Stroke-specific self-management programs may be provided for those who require more specialised programs.
- A collaboratively developed self-management care plan may be used to harness and optimise self-management skills.

(Fryer et al 2016 [16]; Oh et al 2022[95])

Practical info

Self-management programs are defined as programs that aim to empower and enable people with long-term conditions to better manage their health by developing soft skills such as problem solving, decision making, resource utilisation, forming patient-healthcare professional relationships, action taking and self-tailoring.

Self-management programs can be delivered effectively in groups, individually and over the phone or via video. Programs can be delivered by health professionals or co-delivered by health professionals and stroke survivors, so long as those who deliver the program have training and expertise in stroke and its consequences. Programs can include modules on stroke-related education (including secondary prevention), self-ratings, problem identification, reinforcing resources and capabilities, self-efficacy and control, accessing the National Disability Insurance Scheme, social support, stress management, goal setting, problem solving, aphasia and speech therapy. Patients who have impaired language following stroke may benefit from aphasia-friendly resources.

Duration of programs varied from four weeks to six months, with the number and timing of sessions differing between several to weekly.

Given that the outcomes of stroke can be very varied, it is important that patients' self-management programs are individualised. It may be useful to ask the patients about the sorts of modules they would like covered as part of their self-management program.

Consider the self-management issues specific to stroke patients who live in regional or remote areas, who do not have a support network around them.

Other than before discharge, self-management programs can be offered at any suitable time for the stroke patients to equip them the opportunity to make an effective change. There can be an overload of information provided at discharge and the intervention should be driven by the patient's willingness to commit.

Many self-management programs are generic, however, some stroke-specific self-management programs have been developed including Restore4Stroke (Tielemans et al 2015), iVerve (Cadilhac et al 2020[20]), Bridges Stroke Self-management program (Jones et al 2016 and McKenna et al 2015) and Getting your life back on track after stroke (Cadilhac et al 2011). Most of these programs are led by health care professional or trained volunteer. A small number of programs are guided by the stroke survivor themselves (refer to previous recommendation).

Evidence to decision**Benefits and harms**

Small net benefit, or little difference between alternatives

Several meta-analyses of self-management programs reported small but statistically significant improvement in quality of life and self-efficacy, and basic activities of daily living with a non-significant trend towards improvement in mood (Fryer et al 2016 [16]; Oh et al 2021[95]). There were no adverse events reported in any of the studies.

Certainty of the Evidence

Low

The quality of the evidence was assessed as low to moderate.

Values and preferences

No substantial variability expected

We believe almost all people would want to be offered self-management interventions as there appears no harm and potential important benefits.

Resources and other considerations

No important issues with the recommended alternative

Resources considerations

No literature to understand or describe the potential economic implications of this recommendation was identified.

Implementation considerations

There is also a clinical indicator collected to determine whether patients were made aware of the availability of generic self-management programs before discharge from acute care and/or inpatient rehabilitation.

Rationale

Low to moderate quality of evidence suggests benefits of self-management programs in stroke survivors in the community. However, the content, format and mode of delivery of the interventions were highly variable, and the amount of evidence was insufficient to explore which factors were the most effective. There is some indication that tailored interventions targeting stroke survivors' problem-solving, decision-making, self-monitoring and coping skills delivered by trained personnel are likely to be effective.

Clinical question/ PICO

Population: Adults with stroke

Intervention: Self-management programs (health professional or volunteer led)

Comparator: Control

Summary

The Cochrane review from Fryer et al (2016)[16] (14 trials, n=1863) suggests that self-management programs appear to have a small beneficial effect on quality of life and self-efficacy, and a non-significant trend in improved mood and independence in daily activities. The review authors concluded that the quality of evidence was low to moderate and the results could be considered indicative despite the relatively small number of sample size. Heterogeneity was low but there was much variation in the types and delivery of programs.

Subsequent systematic reviews are generally consistent with the Cochrane review.

Pedersen et al (2020)[19] included 11 randomised studies (n=2216) with elderly participants (mean age over 65) but due to heterogeneity in interventions, outcomes and timeframes undertook a narrative synthesis. Self-management interventions for people with stroke was found to potentially be beneficial for self-management, self-efficacy, quality of life, activity of daily living, and other psychosocial outcomes. Authors noted study quality and interventions varied limiting robust conclusions.

Oh et al (2021)[95] included 17 randomised studies with action-taking components. There were improvements in self-efficacy (SMD 0.29, 95% CI 0.07 to 0.52; 7 studies, n= 676; low certainty of evidence) and basic activities of daily living (SMD 0.31, 95% CI 0.16 to 0.46; 5 studies, n= 670; low certainty of evidence). No significant differences were found for health-related quality of life (SMD 0.14, 95% CI -0.01 to 0.30; 7 studies, n=752; low certainty of evidence), instrumental activities of daily living (SMD 0.21, 95% CI -0.03 to 0.45; 6 studies, n=596; low certainty of evidence) and depression (SMD -0.26, 95% CI -0.56 to 0.04; 4 studies, n= 283; very low certainty of evidence).

Lau et al (2022)[94] included 13 randomised studies (n= 2,168) focused on self-management interventions that uses theory and behaviour change techniques. The most common theory used (seven studies) was the Social Cognitive Theory. Significant but small effect sizes were found for self-efficacy (SMD 0.27, 95% CI 0.06 to 0.48; 6 studies, n=720) and functional independence (SMD 0.19, 95% CI 0.01 to 0.37; 2 studies, n=494).

Zhou et al (2022)[97] with 15 mixed methods studies (n=1894; 6 RCTs n=430) focused on the effect of self-management programs on post-stroke social participation. Meta-analysis completed with five of the RCTs found there was no significant effect on social participation (SMD 0.08, 95% CI -0.23 to 0.40; 5 studies, n= 287).

Prados-Roman et al (2023)[100] included eight randomised studies (n=1030) involving self-management interventions early after stroke (during hospital care or up to 2 weeks post discharge). Quality of life measures appear higher (SMD 1.07, 95%CI 0.52 to 1.63; 4 studies (6 subgroups); n=318; considerable heterogeneity, $I^2=80\%$) whereas there was no significant change for dependence (SMD 0.80, 95%CI -0.14 to 1.74; 4 studies, n=402, considerable heterogeneity $I^2=95\%$), and self-efficacy (SMD 0.77, -0.44 to 1.98; 4 studies (5 subgroups), n=316; considerable heterogeneity, $I^2=96\%$). Given the significant heterogeneity for all outcomes it is unclear if the same overall effects of self-management interventions early after stroke are as effective than in the subacute, community period.

Subsequent trials reinforce the likely beneficial effects of self-management interventions.

Lo et al (2023)[102](n = 134) trialed an 8-week health professional and volunteer led self-management program, consisting of 4 individual home visits and 5 follow up phone calls. The intervention reported significantly greater improvements in self-efficacy (Effect size: 0.42, 95% CI: 0.04 to 0.79), HRQoL (0.43, 95% CI: 0.016 to 0.80), satisfaction in their self-management behaviours (0.39, 95% CI: 0.02 to 0.76) and community reintegration (0.72, 95% CI: 0.33 to 1.10), compared to usual care.

Brauer et al (2022)[92] (n=119) compared treadmill training and self-management education with usual gait training. The percentage discussions that were participant-led on self-monitoring, goal setting and coping strategies increased from the beginning to the end of the intervention (6% vs 30%, 13% vs 25%, 3% vs 27% respectively). The treadmill group took more steps than the control group immediately after the intervention (MD 1436 steps, 95% CI 229 to 2643) and at 6 months (MD 871 steps, 95% CI -385 to 2129). There were no significant differences between groups for walking and cardiorespiratory fitness.

Sakakibara et al (2021)[96] (n=126) compared the Stroke Coach intervention which involved phone coaching with a trained lifestyle coach and self-management resources with an attention control Memory Training group. There was improved health related quality of life post-intervention for the Stroke Coach intervention (-3.05, 95% CI -5.88 to -0.21) compared to the Memory Training group. No significant differences were found for lifestyle (-2.87, 95% CI -8.03 to 2.29).

Chen et al (2021)[93] (n=96) compared 8 sessions of goal-oriented self-management intervention or control care and reported significant differences between groups after 1 month follow up for the total self-management behaviour score and the scores of the six dimensions, excluding diet management ($p \leq 0.006$). The intervention group had significantly decreased physical burden, emotional burden and

total self-perceived burden scores ($p = 0.015-0.041$).

A feasibility study by Cadilhac et al (2020)[20] ($n = 54$) trialled an eHealth, self-management support intervention (iVERVE) which involved electronic support and educational messages on a daily basis in a 4-week timeframe. The intervention group was found to have non-significant improvements regarding some self-management and quality of life domains.

Overall self-management interventions within the subacute period appear to result in small improvements in self-efficacy and may also improve aspects of activities of daily living and quality of life. Further trials would likely change the effect estimates and our overall confidence in the evidence. There is much variation in approach, timing, mode of delivery and outcome measures making generalisation difficult.

Outcome Timeframe	Study results and measurements	Comparator Control	Intervention Self- management programs	Certainty of the Evidence (Quality of evidence)	Summary
Impairments ¹ 4 weeks - 12 months 8 Critical	Measured by: Hospital Anxiety and Depression Scale Lower better Based on data from 648 participants in 6 studies. ² (Randomized controlled)	Difference:	MD 0.56 lower (CI 95% 1.27 lower — 0.15 higher)	Low Due to serious risk of bias, Due to serious imprecision ³	Self-management programs probably has little or no difference on impairments.
Quality of life ⁴ 4 weeks - 12 months 8 Critical	Measured by: SF-12 or -36; EuroQol; SAQol; SSQol High better Based on data from 469 participants in 6 studies. ⁵ (Randomized controlled)	Difference:	SMD 0.2 higher (CI 95% 0 higher — 0.41 higher)	Low Due to serious risk of bias, Due to serious indirectness, Due to serious imprecision ⁶	Self-management programs may improve quality of life.
Self-efficacy ⁷ 4 weeks - 12 months 7 Critical	Measured by: Stroke self efficacy High better Based on data from 193 participants in 4 studies. (Randomized controlled)	Difference:	SMD 0.33 higher (CI 95% 0.04 higher — 0.61 higher)	Low Due to serious risk of bias, Due to serious imprecision ⁸	Self-management programs may improve self-efficacy.
Activity limitations ⁹ 4 weeks - 12 months 8 Critical	Measured by: FAI, NEADL, or BI High better Based on data from 260 participants in 6 studies. (Randomized controlled)	Difference:	SMD 0.22 higher (CI 95% 0.03 lower — 0.46 higher)	Moderate Due to serious risk of bias ¹⁰	Self-management programs probably have little or no difference on activity limitations.

1. Change scores/post intervention
2. Systematic review [16] . **Baseline/comparator:** Control arm of reference used for intervention.
3. **Risk of Bias: serious.** A number of studies lacked blinding and has incomplete outcome data.

Inconsistency: no serious. Indirectness: no serious. Imprecision: serious. Wide confidence intervals.

4. Change scores/post intervention

5. Systematic review [16] . **Baseline/comparator:** Control arm of reference used for intervention.

6. **Risk of Bias: serious.** A number of studies lacked blinding and has incomplete outcome data.

Inconsistency: no serious. The magnitude of statistical heterogeneity was moderate, with $I^2:51\%$.

Indirectness: serious. Differences between the intervention/comparator of interest and those studied.

Imprecision: serious. Low number of patients, Wide confidence intervals.

7. Change scores/post intervention

8. **Risk of Bias: serious.** A number of studies lacked blinding and has incomplete outcome data.

Inconsistency: no serious. Self-efficacy measured by locus of control did not show significant improvement.

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

9. Change scores/post intervention

10. **Risk of Bias: serious.** A number of studies lacked blinding and has incomplete outcome data.

Inconsistency: no serious. Indirectness: no serious. Imprecision: no serious. Low number of patients.

References

16. Fryer CE, Luker JA, McDonnell MN, Hillier SL. Self management programmes for quality of life in people with stroke. The Cochrane database of systematic reviews 2016;(8):CD010442 [Pubmed](#) [Journal](#)

19. Kristine Stage Pedersen S, Lillelund Sørensen S, Holm Stabel H, Brunner I, Pallesen H. Effect of Self-Management Support for Elderly People Post-Stroke: A Systematic Review. *Geriatrics (Basel, Switzerland)* 2020;5(2) [Pubmed](#) [Journal](#)

20. Cadilhac DA, Andrew NE, Busingye D, Cameron J, Thrift AG, Purvis T, et al. Pilot randomised clinical trial of an eHealth, self-management support intervention (iVERVE) for stroke: feasibility assessment in survivors 12–24 months post-event. *Pilot and Feasibility Studies* 2020;6(1):172 [Journal](#) [Website](#)

92. Brauer SG, Kuys SS, Ada L, Paratz JD. IMproving Physical ACTivity after stroke via Treadmill training (IMPACT) and self-management: A randomized trial. *International journal of stroke : official journal of the International Stroke Society* 17(10):1137-1144 [Pubmed](#) [Journal](#)

93. Chen YU, Wei Y, Lang H, Xiao T, Hua Y, Li LU, et al. Effects of a Goal-Oriented Intervention on Self-Management Behaviors and Self-Perceived Burden After Acute Stroke: A Randomized Controlled Trial. *Frontiers in neurology* 2021;12:650138 [Pubmed](#) [Journal](#)

94. Lau SCL, Judycki S, Mix M, DePaul O, Tomazin R, Hardi A, et al. Theory-Based Self-Management Interventions for Community-Dwelling Stroke Survivors: A Systematic Review and Meta-Analysis. *The American journal of occupational therapy : official publication of the American Occupational Therapy Association* 76(4) [Pubmed](#) [Journal](#)

95. Oh HX, De Silva DA, Toh ZA, Pikkarainen M, Wu VX, He H-G. The effectiveness of self-management interventions with action-taking components in improving health-related outcomes for adult stroke survivors: a systematic review and meta-analysis. *Disability and rehabilitation* 44(25):7751-7766 [Pubmed](#) [Journal](#)

96. Sakakibara BM, Lear SA, Barr SI, Goldsmith CH, Schneeberg A, Silverberg ND, et al. Telehealth coaching to improve self-management for secondary prevention after stroke: A randomized controlled trial of Stroke Coach. *International journal of stroke : official journal of the International Stroke Society* 17(4):455-464 [Pubmed](#) [Journal](#)

97. Zhou X, Du M, Hu Y. The effect of self-management programs on post-stroke social participation: A

systematic review and meta-analysis. Clinical rehabilitation 36(9):1141-1152 [Pubmed Journal](#)

100. Prados-Román E, Cabrera-Martos I, Martín-Núñez J, Valenza-Peña G, Granados-Santiago M, Valenza MC. Effectiveness of self-management interventions during the peri-hospitalization period in patients with stroke: A systematic review and meta-analysis. Clinical Rehabilitation 2023-08-07. [Journal](#)

102. Lo SHS, Chau JPC, Choi KC, Wong RYM, Kwan JCY, Iu IHL. Health Professional- and Volunteer-partnered Self-management Support (COMBO-KEY) to Promote Self-efficacy and Self-management Behaviors in People with Stroke: A Randomized Controlled Trial. Annals of behavioral medicine : a publication of the Society of Behavioral Medicine 2023;57(10):866-876 [Pubmed Journal](#)

Driving

The effects of a stroke can lead to isolation and reduced quality of life as people reduce the amount of community access they had prior to the stroke. The inability to return to driving in particular often has a profound impact on community participation. The issue of returning to driving can be confusing and the topic is often raised by the patient or his/her family/carer, and especially by patients with minor stroke or TIA.

Motor, sensory, visual or cognitive impairments can have a major impact on a person's ability to drive after a stroke.

The current national guidelines describe criteria for unconditional licences and, where conditional licences exist, for private and commercial drivers (Austroads 2022 [24]). For private drivers, stroke survivors are not to return to driving for a minimum of one month (three months for commercial drivers) even if there are no significant neurological, perceptual or cognitive deficits. Stroke survivors are responsible for informing the relevant licensing authority and are advised to contact their car insurance company. An unconditional licence may be granted if there is no significant impairment of any of the following: visuospatial perception, insight, judgement, attention, comprehension, reaction time, memory, sensation, muscle power, coordination and vision (including visual fields). A conditional licence may be considered after the non-driving period, taking into account the opinion of an appropriate specialist, the nature of the driving task and subject to at least an annual review, after consideration of the results of a practical driving assessment. For commercial drivers, the recently updated national guidelines state that a person is not fit to hold an unconditional licence if the person has had a stroke (Austroads 2022 [24]).

In the case of TIA, the national guidelines currently state that private vehicle drivers should not drive for two weeks and commercial vehicle drivers should not drive for four weeks after a TIA. A conditional licence is not required as there is no long-term impairment.

Stroke survivors who held a driving licence pre-stroke should be provided with written information about returning to drive including their legal obligations and the assessments needed including potential neuropsychology and occupational therapy driver assessment. This information should be provided prior to discharge from hospital or at the first visit in the case of those not admitted to hospital after a TIA.

In the National Stroke Audit of Rehabilitation Services, 47% of stroke survivors were asked if they wanted to return to driving with 87% of them stating that they did. Ninety-two percent of patients were then provided with information about the process to return to driving (Stroke Foundation 2020 [14]).

Consensus recommendation

Updated

Consensus-based recommendations

- All stroke survivors or people who have had a transient ischaemic attack (TIA) who were driving prior to their stroke should be asked if they wish to resume driving.
- Any person wishing to resume driving after a stroke or TIA should be provided with information about how stroke-related impairments may affect their driving and the requirements and processes for returning to driving. Information should be consistent with the Austroads[24]/Waka Kotahi New Zealand Transport Agency[83] standards and any relevant state guidelines.
- For stroke survivors wishing to drive for the first time, the medical and other clinical team members should discuss the feasibility of driving and provide advice as to further steps in line with national standards and any relevant state guidelines.
- Health services where stroke survivors receive care should develop an appropriate site-specific post-stroke fitness to drive pathway in accordance with local legal requirements and resources, and ensure assessments and advice is communicated to the general practitioner.

Non-driving periods

- Stroke survivors should refrain from recommencing driving until both the mandated period of non-driving has elapsed and stroke deficits precluding safe driving (if present) have resolved, as confirmed by their treating doctors (in conjunction with other non-medical clinician/s). Minimum non-driving periods determined by the relevant national standards must be followed. Please note for fitness to drive purposes in Australia TIA is defined as cerebral ischaemic symptoms resolving within 24 hours, irrespective of MRI evidence of infarction.
- For private license holders:
 - In Australia the minimum timeframe is four weeks post stroke (mandated) and two weeks after a TIA (advisory only).(Austroads standards 2022 [24]).
 - In New Zealand the minimum timeframe is one month for a single event (stroke or TIA) and three months for those with recurrent or frequent events (if no further recurrence has occurred within this timeframe).(New Zealand Transport Agency 2014[83])
- For commercial license holders:
 - In Australia the minimum timeframe is three months post stroke (mandated) and four weeks after a TIA (advisory only). (Austroads standards 2022 [24])
 - In New Zealand this generally means permanent stand down after stroke for commercial driving, but this may be appealed in special circumstances. The timeframe after TIA is six months and additional criteria apply (New Zealand Transport Agency 2014[83]).

Fitness to drive assessments

- Any person with stroke or TIA discharged from hospital or seen in a TIA clinic should be screened/assessed for any ongoing neurological deficits that could influence driving safely. Visual, cognitive, physical and behavioural assessment findings should be documented.
- Stroke survivors without physical/sensory or cognitive impairments, and who meet the vision standards for driving (refer to relevant section in standards) should be instructed not to return to driving for a period of time.
- For private license holders:
 - In Australia, where no persisting deficits are identified, the person may recommence driving on their current license after the minimum exclusion period without license restriction or further review. In New Zealand, a follow-up assessment should be conducted by an appropriate specialist to determine medical fitness prior to return to driving. (New Zealand Transport Agency 2014[83])
 - If after the minimum exclusion period the treating clinician is uncertain whether persisting motor, sensory or cognitive changes preclude safe driving, an occupational therapy specialist driving assessment should occur.
 - A conditional license may be required depending on the nature of the deficits (for example vehicle modifications, local area driving only).
- For commercial license holders:

- In Australia, where no deficits which may impact driving are identified, a conditional license may be considered by the driver licensing authority after at least three months and subject to annual review, taking into account information provided by an appropriate specialist. After three months, if the treating clinician is uncertain whether persisting motor, sensory or cognitive changes preclude safe driving, an occupational therapy specialist driving assessment should occur.
- Stroke survivors who have physical/sensory or cognitive impairments that may impact driving, or who do not meet the vision standards for driving (refer to relevant section in standards), should be instructed not to return to driving and the medical and other clinical team members should discuss and provide advice as to further steps in line with national standards and any relevant state guidelines.
- If further driving assessment is deemed necessary this may include clinic-based assessments to determine on-road assessment requirements (for example modifications, type of vehicle, timing), on-road assessment and rehabilitation recommendations, provided by a driver assessor occupational therapist.

Update approved by NHMRC July 2023.

Practical info

After stroke, some people will experience a loss of confidence about driving. Providing psycho-social support (considering confidence and emotional adjustment) for patients about a temporary or permanent loss of independence from driving, and the length of time it can take to regain the ability to drive, can be helpful. Loss of independence as a result of not being able to drive is a very significant issue for stroke survivors.

Education should be provided about the influence of motor, vision, sensory/perceptual or speech and language changes on the functional task of driving and that the relevant state driving authority should be notified of a stroke. Information for people with stroke or TIA has been developed by the Stroke Foundation and can be accessed from: [Driving fact sheet | Stroke Foundation - Australia](#).

Education should also be provided about alternate ways to access the community while exploring return to driving to maintain community participation.

For those with speech and language difficulties, clinicians may suggest the person hold a card in their wallet or car that identifies they have had a stroke which impacts on their language production. This may be used if there is ever a need to interact with police.

Medications which may impair the ability to drive safely should also be reviewed. Examples include sedating antidepressants, anticonvulsants or sedatives.

[Checklist for neurological disorders](#). Extracted from [Austroads Standards 2022 \[24\]](#). Box 3, pg 152.

If the answer is YES to any of the following questions, the person may be unfit to drive and warrants further assessment.

1. Are there significant impairments of any of the following?

- [Visuospatial perception](#)
- [Insight](#)
- [Judgement](#)
- [Attention and concentration](#)
- [Comprehension](#)
- [Reaction time](#)
- [Memory](#)
- [Sensation](#)

- [Muscle power](#)
- [Coordination](#)

2. Are the visual fields abnormal? (refer to section 10. Vision and eye disorders, Austroads Standards 2022)

3. Have there been one or more seizures? (refer to section 6.2. Seizures and epilepsy, Austroads Standards 2022)

In addition to the items in the checklist above, visual acuity should also be assessed when considering visual field abnormalities.

Please note for Victoria and South Australia, significant visual field defect requires the Medmont Binocular Driving Test or the binocular Humphrey Esterman test conducted by an optometrist.

Evidence to decision

Resources and other considerations

Implementation considerations

There is a clinical indicator collected in the National Stroke Audit to determine the total number of patients who were asked, during their admission, if they would like to return to driving upon their return to the community. Additionally, there are clinical indicators collected on the number of patients who, if they were asked, wanted to return to driving and were subsequently provided with information about the process of returning to driving.

Rationale

This information is consistent with national standards for return to driving in Australia and New Zealand. Drivers are expected to inform the state driving licencing authority when they have a stroke. Treating clinicians are treating doctors (in conjunction with other non-medical clinician(s)).

Consensus recommendation

Consensus-based recommendations

On-road driving rehabilitation may be provided by health professionals specifically trained in driving rehabilitation.

Weak recommendation

For stroke survivors needing driving rehabilitation, driving simulation may be used. Health professionals using driving simulation need to receive training and education to deliver intervention effectively and appropriately, and mitigate driving simulator sickness. (George et al 2014 [21]; Classen et al 2014 [23])

Practical info

Patients can be referred for driver retraining, including:

- simulator or visual/cognitive/physical training, prior to an on-road assessment, to assist with preparation for the on-road test.
- simulator based, visual/cognitive/physical training, and on-road training post on-road assessment for the resumption of driving.

Lessons in a modified vehicle (if these are necessary) can come under the patient's NDIS plan. Note that modified vehicles can be difficult to source, particularly in regional areas.

Specialist ophthalmologist/optometrist services are available to provide rehabilitation for eye impairments prior to returning to driving.

It is recommended that intervention be provided by health professionals to target impairments related to driving, including motor, vision or sensory changes.

Intervention maximizing community mobility and participation is recommended (refer to community mobility and outdoor travel).

Support/advocacy for access to driving services is required.

Evidence to decision

Benefits and harms

Small net benefit, or little difference between alternatives

Variability exists in access, type and environments offered in driving simulation post-stroke. Simulator sickness, or simulator adaptation, may occur in the post-stroke population. An evidence-based literature review (George et al 2014 [21]) found that factors which probably increase the rate of simulator sickness include: client factors (age, gender), contextual/environmental factors (including refresh rates, scenario design, scenario duration and calibration), and activity demands, such as speed of driving and postural instability.

Certainty of the Evidence

Moderate

There is only one study which has serious imprecision.

Values and preferences

Substantial variability is expected or uncertain

Health professionals may vary in how they translate driving simulation skills to real world driving environments.

Resources and other considerations

Important issues, or potential issues not investigated

Resources considerations

No literature to understand or describe the potential economic implications of this recommendation was identified.

Rationale

Evidence of the effect of driving simulation on cognitive abilities, such as road sign recognition and on-road skills, is weak and based on one study of moderate quality. There is a lack of evaluation of the cost-effectiveness and prevalence of simulator sickness in the post-stroke population.

Adaptation

Adapted from occupational therapy and driving simulation consensus statements (Classen and Brooks 2014 [23]), developed through a literature review and consensus process.

Clinical question/ PICO

Population: Adults post-stroke
Intervention: Driving rehabilitation intervention
Comparator: Control

Summary

George et al (2014) [21] conducted a Cochrane review of interventions to improve driving ability after stroke. Four randomised trials were included with 245 total participants. Interventions used in the trials varied but included driving simulation and retraining visual skills. No meta-analysis was conducted due to the variety of interventions and outcomes used in the trials. No trial showed significant improvements in on-road driving performance, but one trial of a driving simulator intervention showed improved road sign recognition. As the evidence on driving simulators came from a single small trial (N = 73), there is still uncertainty regarding the potential benefits of simulator training.

Further results from the same driver simulator training trial reported by Akinwuntan et al (2010) [22] showed no significant increase in Useful Field of View, a test of visual attention skills, compared to non-computer-based cognitive training.

Outcome Timeframe	Study results and measurements	Comparator Control	Intervention Driving rehabilitation intervention	Certainty of the Evidence (Quality of evidence)	Summary
On-road score 6 months 6 months 7 Critical	Measured by: Test Ride for Investigating Practical Fitness to Drive Scale: 49 — 196 High better Based on data from 83 participants in 1 studies. ¹ (Randomized controlled) Follow up: 6 months.	152.12 driving behaviours (Mean) Difference:	167.12 driving behaviours (Mean) MD 15 higher (CI 95% 4.56 lower — 34.56 higher)	Moderate Due to serious imprecision ²	Simulator training probably improves driving behaviours in an on-road assessment at six months
Road sign recognition ³ 6 months 7 Critical	Measured by: Road sign Recognition Scale: 0 — 12 High better Based on data from 73 participants in 1 studies. ⁴ (Randomized controlled) Follow up: 6 months.	0.72 (Mean) Difference:	2.41 (Mean) MD 1.69 higher (CI 95% 0.51 higher — 2.87 higher)	Moderate Due to serious imprecision ⁵	Simulator training probably improves road sign recognition

1. Systematic review [21] with included studies: Akinwuntan 2005. **Baseline/comparator:** Control arm of reference used for intervention.
2. **Risk of Bias: no serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias. . **Inconsistency: no serious. Indirectness: no serious. Imprecision: serious.** Low number of patients. **Publication bias: no serious.**
3. Sub-test of Stroke Drivers Screening Assessment
4. Systematic review [21] with included studies: Akinwuntan 2005. **Baseline/comparator:** Control arm of reference used for intervention.

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

References

21. George S, Crotty M, Gelinas I, Devos H. Rehabilitation for improving automobile driving after stroke. Cochrane Database of Systematic Reviews 2014. [Pubmed Journal](#)
22. Akinwuntan AE, Devos H, Verheyden G, Baten G, Kiekens C, Feys H, et al. Retraining moderately impaired stroke survivors in driving-related visual attention skills. Topics in stroke rehabilitation 2010;17(5):328-36 [Pubmed Journal](#)

Community mobility and outdoor travel

Stroke can leave people with long-term and persistent impairments, leading to activity limitations and restriction in participation (Logan et al 2014 [27]). If no support is provided, these limitations can lead to isolation and loss of confidence in the ability to perform activities the person did before they had a stroke. Interventions should focus on practising the skills required for active community participation.

Weak recommendation

Stroke survivors who have difficulty with outdoor mobility in the community should set individualised goals and get assistance with adaptive equipment, information and referral on to other agencies. Escorted walking practice may be of benefit to some individuals and if provided, should occur in a variety of community settings and environments, and may also incorporate virtual reality training that mimics community walking. (Barclay et al 2015 [25]; Logan et al 2014 [27])

Practical info

- Each patient's rehabilitation plan should include community mobility and travel training interventions, tailored to their individual requirements and abilities.
- Tailored information about local transport options/alternatives including bus timetables should also be provided.
- A diary, app or electronic device which records outings should be explored with community-dwelling stroke survivors. These tools can support their ongoing involvement in the community.
- It can be helpful to practise public transport related activities with stroke survivors, such as physically getting on and off the mode of transport, and asking for a seat.
- Community mobility and travel training outcomes appear to be influenced by therapist experience (greater experience providing community mobility training increased the number of outings that stroke survivors took), based on the study by Logan et al (2014) [27].
- Intervention should target community based stroke survivors (i.e. those living at home, not nursing home residents).

Evidence to decision

Benefits and harms

Small net benefit, or little difference between alternatives

There were no benefits such as increased walking speed, quality of life or participation from providing community mobility training, based on several trials in one meta-analysis (Logan et al 2014 [27]). Increased number of outdoor journeys were reported in one large trial but no other benefits found (Barclay et al 2015 [25]). No harms were found, such as increased falls from providing more outdoor walking practice or intervention.

Certainty of the Evidence

Low

The overall quality of the evidence remains low despite there being five trials in a meta-analysis and one large multicentre trial (low due to drop outs and lack of blinding resulting in imprecision).

Values and preferences

No substantial variability expected

No reported patient preferences with respect to outdoor mobility training compared to other interventions such as information provision or virtual reality.

Resources and other considerations

No important issues with the recommended alternative

Resources considerations

In one study, it was demonstrated that a community mobility intervention (median of 7 sessions over 4 months) was not cost-effective compared to a control group receiving verbal advice and transport and outdoor mobility leaflets only (Logan et al 2014 [27]). Costs in the intervention group were £3,414 greater per person and the intervention resulted in fewer quality-adjusted life-years gained compared to the control group (cost reference year 2010/2011).

Rationale

The benefit of community mobility interventions on participation and mobility speed remains unclear based on a meta-analysis up to 2014 (Barclay et al 2015 [25]) with evidence of low quality. Therefore, the recommendation is weak. A large randomised controlled trial of moderate quality aiming to increase outdoor journeys found an increase in the number of journeys made but no increase in the quality of life or other secondary outcomes (Logan et al 2014 [27]) . Therefore, routine provision of escorted outdoor mobility training or an equivalent intervention cannot be recommended, nor a change in current practice. However, some individuals with outdoor mobility, travel or participation goals may benefit from a small number of tailored sessions.

Clinical question/ PICO

- Population: Community dwelling adults with stroke
- Intervention: Community ambulation
- Comparator: Control

Summary

A Cochrane review by Barclay et al (2015) [25] assessed interventions for improving community ambulation for stroke survivors, including 5 trials with 266 participants. Interventions used in the trials either used walking practice in a variety of settings, or an activity that mimicked walking such as treadmill walking in a virtual environment or motor imagery. Meta-analysis based on 2 studies (N = 198) showed no significant difference in participant outcomes following the interventions (SMD 0.08, 95% CI -0.20 to 0.35). Gait speed also showed no significant improvement, based on 98 participants in 4 studies (MD 0.12 m/s, 95% CI -0.01 to 0.24). The review authors rated the quality of evidence as low due to bias (lack of blinding and intention to treat analyses in the trials) and imprecision (small numbers of participants resulting in wide confidence intervals).

A Community Stroke Navigation intervention was assessed in a trial using a pretest-post-test design (Egan et al 2010 [26]). The intervention offered the services of a Community Stroke Navigator to stroke survivors and carers, providing services such as emotional support, case coordination and accompaniment. Stroke survivors showed small improvements in community reintegration following the intervention but carers showed no change, and neither group improved in physical and emotional health.

Outcome Timeframe	Study results and measurements	Comparator Control	Intervention Community ambulation	Certainty of the Evidence (Quality of evidence)	Summary
Walking speed -	Measured by: Metres per	Difference:	MD 0.12 higher	Low	Community ambulation

Outcome Timeframe	Study results and measurements	Comparator Control	Intervention Community ambulation	Certainty of the Evidence (Quality of evidence)	Summary
Overall 7 Critical	second High better Based on data from 98 participants in 4 studies. ¹ (Randomized controlled) Follow up: Mean of 3.5 months.		(CI 95% 0.01 lower — 0.24 higher)	Due to serious risk of bias, Due to serious imprecision ²	may improve walking speed - overall
Participation - Overall ³ 7 Critical	Measured by: Pooled outcome - Subjective Index of Physical and Social Outcomes and the Nottingham Leisure Questionnaire High better Based on data from 198 participants in 2 studies. ⁴ (Randomized controlled) Follow up: Mean of 8 months.	Difference:	SMD 0.08 higher (CI 95% 0.2 lower — 0.35 higher)	Low Due to serious risk of bias, Due to serious imprecision ⁵	Community ambulation may improve participation - overall

1. Systematic review [25] . **Baseline/comparator:** Control arm of reference used for intervention.
2. **Risk of Bias: serious.** Missing intention-to-treat analysis, Inadequate/lack of blinding of outcome assessors, resulting in potential for detection bias, Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias. **Inconsistency: no serious. Indirectness: no serious. Imprecision: serious.** Only data from one study, Low number of patients. **Publication bias: no serious.**
3. Pooled outcome from studies using the Subjective Index of Physical and Social Outcomes and the Nottingham Leisure Questionnaire
4. Systematic review [25] . **Baseline/comparator:** Control arm of reference used for intervention.
5. **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, Missing intention-to-treat analysis. **Inconsistency: no serious. Indirectness: no serious. Imprecision: serious.** Low number of patients, Only data from one study. **Publication bias: no serious.**

References

25. Barclay RE, Stevenson TJ, Poluha W, Ripat J, Nett C, Sriksavan CS. Interventions for improving community ambulation in individuals with stroke. Cochrane Database of Systematic Reviews 2015. [Journal](#)
26. Egan M, Anderson S, McTaggart J. Community navigation for stroke survivors and their care partners: description and evaluation. Topics in stroke rehabilitation 2010;17(3):183-90 [Pubmed Journal](#)

Clinical question/ PICO

Population: Community dwelling adults with stroke
Intervention: Outdoor mobility rehabilitation training

Comparator: Control**Summary**

A multicentre randomised trial by Logan et al (2014) [27] assessed an outdoor mobility intervention, involving 568 people with stroke. The intervention consisted of face-to-face rehabilitation with a mixture of exercise and practical activities, providing up to 11 sessions over 4 months. The primary outcome of health-related quality of life showed a non-significant improvement for the intervention group compared to control. Secondary outcomes such as psychological well-being and mobility also showed non-significant changes, although intervention participants were significantly more likely to make journeys at 6 and 12 month follow-ups.

Outcome Timeframe	Study results and measurements	Comparator Control	Intervention Outdoor mobility rehabilitation training	Certainty of the Evidence (Quality of evidence)	Summary
Number of outings ¹ 5 Important	Measured by: Number of journeys made outside the house. Difference reported is an adjusted rate ratio so RR of 1 means no difference High better Based on data from 504 participants in 1 studies. (Randomized controlled) Follow up: 6 months.	Difference:	1.42 higher (CI 95% 1.14 higher — 1.67 higher)	Moderate Due to serious imprecision ²	Outdoor mobility rehabilitation training probably improves number of outings
Mobility ³ 5 Important	Measured by: Rivermead Mobility Index. Reported difference is covariate adjusted. Scale: 0 — 15 High better Based on data from 499 participants in 1 studies. (Randomized controlled) Follow up: 6 months.	Difference:	MD 0.15 higher (CI 95% 0.29 lower — 0.58 higher)	Moderate Due to serious imprecision ⁴	Outdoor mobility rehabilitation training probably improves mobility
HRQoL ⁵ 5 Important	Measured by: Social Function Domain Score from Short-form questionnaire-36 items. Reported difference is covariate adjusted. Scale: 0 — 100 High better Based on data from 500 participants in 1 studies. (Randomized controlled) Follow up: 6 months.	Difference:	MD 4.6 higher (CI 95% 0.55 lower — 9.8 higher)	Moderate Due to serious imprecision ⁶	Outdoor mobility rehabilitation training probably improves HRQoL slightly
Psychological well-being ⁷	Measured by: General health Questionnaire- 12	Difference:	MD 0.96 lower (CI 95% 1.91	Moderate Due to serious	Outdoor mobility rehabilitation training

Outcome Timeframe	Study results and measurements	Comparator Control	Intervention Outdoor mobility rehabilitation training	Certainty of the Evidence (Quality of evidence)	Summary
4 Important	<p>items. Reported difference is covariate adjusted.</p> <p>Scale: 0 — 36 Lower better</p> <p>Based on data from 495 participants in 1 studies. (Randomized controlled)</p> <p>Follow up: 6 months.</p>		lower — 0.01 higher)	imprecision ⁸	probably improves psychological well-being

1. Number of journeys from monthly travel diaries - note that the relative effect estimate is an adjusted rate ratio, not a mean difference
2. **Risk of Bias: no serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias. **Inconsistency: no serious. Indirectness: no serious. Imprecision: serious.** Only data from one study. **Publication bias: no serious.**
3. Rivermead Mobility Index
4. **Risk of Bias: no serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias. **Inconsistency: no serious. Indirectness: no serious. Imprecision: serious.** Only data from one study. **Publication bias: no serious.**
5. Social Function domain score from Short-questionnaire-36 items
6. **Inconsistency: no serious. Indirectness: no serious. Imprecision: serious.** Only data from one study. **Publication bias: no serious.**
7. General Health Questionnaire
8. **Inconsistency: no serious. Indirectness: no serious. Imprecision: serious.** Only data from one study. **Publication bias: no serious.**

References

27. Logan PA, Armstrong S, Avery TJ, Barer D, Barton GR, Darby J, et al. Rehabilitation aimed at improving outdoor mobility for people after stroke: a multicentre randomised controlled study (the Getting out of the House Study). Health technology assessment (Winchester, England) 2014;18(29):vii-viii, 1-113 [Pubmed Journal](#)

Leisure

The majority of stroke survivors are over retirement age and leisure and social activities represent a significant part of their life. Many people with stroke are often unable to continue with their usual leisure activities and/or do not take up new ones, which may lead to social isolation, depressed mood and negative effects on their relationships with their families/carers.

The National Stroke Audit of Rehabilitation Services found that only 13% and 15% (111 hospitals surveyed) had recreational therapists and diversional therapists, respectively, actively involved in the rehabilitation of stroke patients (Stroke Foundation 2020 [14]). Given the positive effects that targeted leisure therapy can have on depressive symptoms, leisure participation and satisfaction, more contact is needed with health professionals to support this facet of rehabilitation. Additional information can also be found at the Stroke Foundations' [enableme](#) website.

Weak recommendation

For stroke survivors, targeted occupational therapy programs including leisure therapy may be used to increase participation in leisure activities. (Dorstyn et al 2014 [28]; Walker et al 2004 [30])

Practical info

Leisure therapy can contribute to a person feeling 'normal' again, doing 'normal' things. It can be important when leisure activities a person previously enjoyed, are no longer an option. Social interaction during leisure therapy is likely to form an important part of the benefits to patients, including increasing motivation.

Transport options to access community activity is an important consideration, but other forms of connection / therapy, eg. use of social media or technology to link to leisure related groups, are becoming increasingly available.

Evidence to decision

Benefits and harms

Small net benefit, or little difference between alternatives

Studies from two systematic reviews (Dorstyn et al 2014 [28]; Walker et al 2004 [30]) suggest leisure therapy may increase leisure activity, may have little or no difference on mobility and independence and probably have little or no difference on extended activities of daily living. No-to-minimal harm would be anticipated.

Certainty of the Evidence

Low

The quality of the evidence is low due to risks of bias, inconsistency and imprecision.

Values and preferences

No substantial variability expected

Health professionals should consider client and carer preferences for return to leisure activity.

Resources and other considerations

No important issues with the recommended alternative

Resources considerations

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 [29]). There were

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 GBP greater in the intervention group than in the control group (cost reference year not reported).

Implementation consideration

There is an organisational indicator collected in the National Stroke Audit to determine whether recreational and/or diversional therapists are actively involved in the management of patients within inpatient stroke rehabilitation services.

Rationale

Recommendation drawn from low quality level evidence. Findings of studies from two systematic differ regarding impact of leisure therapy, with one indicating it probably increases leisure activity (Walker et al 2004 [30]) and another indicating that we are uncertain if it increases or decreases leisure activity (Dorstyn et al 2014 [28]). Studies from these same two systematic reviews suggest it probably has little or no difference on extended activities of daily living (Walker et al 2004) and may have little or no difference on mobility and independence (Dorstyn et al 2014 [28]). A subsequent study (Mayo et al. 2015[31], n=186) reported no significant differences between groups on hours of activity spent outside the house. There is a lack of robust cost-effectiveness information.

Clinical question/ PICO

Population: Adults with stroke

Intervention: Leisure therapy

Comparator: Control

Summary

A systematic review by Dorstyn et al (2014) [28] included 8 randomised trials incorporating leisure activities into stroke rehabilitation. No meta-analysis was conducted, but individual trials included in the review reported significant short-term improvements in quality of life and mood, as well as participation in and satisfaction with leisure activities. Only one included trial reported long-term outcomes and showed non-significant effects.

Walker et al (2004) [30] conducted a systematic review and meta-analysis of community occupational therapy for stroke patients. They identified 8 randomised controlled trials, of which 3 specifically targeted participation in leisure activities. Significant improvements on the Nottingham Leisure Questionnaire were seen following occupational therapy, particularly when restricting analysis to the trials that specifically targeted leisure (MD 1.96, 95% CI 0.27 to 3.66). Significant improvements were seen overall on the Nottingham Extended Activities of Daily Living scale, and on the number of patients showing activity limitation on the Barthel Index and Rivermead ADL scales. However, when restricting analysis to leisure therapy specifically, improvements in extended activities of daily living were non-significant (MD 0.95, 95% CI -0.30 to 2.20). These results suggest greater benefit from targeted interventions, with participation in leisure activities best addressed through interventions specifically focussed on leisure rather than general ADL-based treatments. Improved participation in leisure activities may not translate to improved activities of daily living.

Proffitt et al (2022)[91] conducted a wide ranging review included 47 mixed method articles, three randomised studies related to leisure. Only studies published between 2009 and 2019 were included. No meta-analysis was completed, but there were no significant differences with any intervention (cycling +

coaching, electromyography-controlled upper limb brace with bilateral training or constraint induced movement therapy plus trunk restraint).

Outcome Timeframe	Study results and measurements	Comparator Control	Intervention Leisure therapy	Certainty of the Evidence (Quality of evidence)	Summary
Leisure activity End of intervention 7 Critical	Measured by: Nottingham Leisure Questionnaire High better Based on data from 571 participants in 3 studies. ¹ (Randomized controlled) Follow up: 1.25-6 months intervention.	Difference:	MD 1.96 higher (CI 95% 0.27 higher — 3.66 higher)	Moderate Due to serious inconsistency and some risk of bias ²	We are uncertain whether leisure therapy increases or decreases leisure activity
Extended activities of daily living End of intervention 8 Critical	Measured by: Nottingham Extended Activities of Daily Living High better Based on data from 571 participants in 3 studies. ³ (Randomized controlled) Follow up: 1.25-6 months of treatment.	Difference:	MD 0.95 higher (CI 95% 0.3 lower — 2.2 higher)	Moderate Due to serious imprecision ⁴	Leisure therapy probably has little or no difference on extended activities of daily living
Leisure activity ⁵ 7 Critical	Based on data from 405 participants in 3 studies. (Randomized controlled) Follow up: Post intervention.	Three RCTs provided information on leisure activity post intervention. One RCT (Desrosiers 2007, n=62) reported that the intervention group had a statistically significant improvement in needs/expectations on the Individualised Leisure Profile (d=1.23, 95%CI 0.70 to 1.76) and on the Leisure Satisfaction Scale (d=0.81, 95%CI 0.30 to 1.32). The study failed to find significant differences between groups in use of spare time. Another study (Drummond 1995, n=44) reported a significant improvement on the Nottingham Leisure Questionnaire in both leisure activity (d=0.98, 95%CI 0.35 to 1.61) and leisure score (d=0.97, 95%CI 0.34 to 1.60). A further study (Parker, n=299) found no significant differences between groups in total Nottingham Leisure Questionnaire score.		Very low Due to serious risk of bias, Due to serious inconsistency, Due to serious imprecision ⁶	We are uncertain whether leisure therapy increases or decreases leisure activity
Mobility and independence 7 Critical	Based on data from 398 participants in 2 studies. (Randomized controlled) Follow up: Post intervention.	A systematic review identified two relevant RCTs. Both RCTs (Lund 2011 and Parker 2001) reported no statistically significant difference between groups (measured using the		Low Due to serious risk of bias, Due to serious imprecision ⁷	Leisure therapy may have little or no difference on mobility and independence

Outcome Timeframe	Study results and measurements	Comparator Control	Intervention Leisure therapy	Certainty of the Evidence (Quality of evidence)	Summary
		London Handicap Scale, Up and Go and Nottingham Extended Activities of Daily Living Scale).			

1. Systematic review [30] . **Baseline/comparator:** Control arm of reference used for intervention.
2. **Risk of Bias: no serious.** Most trials included in the systematic review were high quality, with clear randomisation procedures and allocation concealment and blinded assessors. Blinding of participants/ personnel was not possible. **Inconsistency: serious.** The magnitude of statistical heterogeneity was high, with I^2 : 50%.. **Indirectness: no serious. Imprecision: no serious. Publication bias: no serious.**
3. Systematic review [30] . **Baseline/comparator:** Control arm of reference used for intervention.
4. **Risk of Bias: no serious.** Most trials included in the systematic review were high quality, with clear randomisation procedures and allocation concealment and blinded assessors. Blinding of participants/ personnel was not possible. **Inconsistency: no serious. Indirectness: no serious. Imprecision: serious.** Wide confidence intervals. **Publication bias: no serious.**
5. Multiple measures across studies: Individualised Leisure Profile, Leisure Satisfaction Scale, Nottingham Leisure Questionnaire
6. **Risk of Bias: serious. Inconsistency: serious.** due to different findings among studies. **Indirectness: no serious. Imprecision: serious.** Low number of patients. **Publication bias: no serious.**
7. **Risk of Bias: serious. Inconsistency: no serious. Indirectness: no serious. Imprecision: serious.** Low number of patients. **Publication bias: no serious.**

References

28. Dorstyn D, Roberts R, Kneebone I, Kennedy P, Lieu C. Systematic review of leisure therapy and its effectiveness in managing functional outcomes in stroke rehabilitation. Topics in stroke rehabilitation 2014;21(1):40-51 [Pubmed](#) [Journal](#)
30. Walker MF, Leonardi-Bee J, Bath P, Langhorne P, Dewey M, Corr S, et al. Individual patient data meta-analysis of randomized controlled trials of community occupational therapy for stroke patients. Stroke; a journal of cerebral circulation 2004;35(9):2226-32 [Pubmed](#)
91. Proffitt R, Boone A, Hunter EG, Schaffer O, Strickland M, Wood L, et al. Interventions to Improve Social Participation, Work, and Leisure Among Adults Poststroke: A Systematic Review. The American journal of occupational therapy : official publication of the American Occupational Therapy Association 76(5) [Pubmed](#) [Journal](#)

Return to work

Approximately 20% of stroke survivors in Australia are of working age (Baldwin et al 2011 [34]). Return-to-work rates for stroke survivors vary and can be as low as 4% or as high as 75% (Baldwin et al 2011 [34]). In the National Stroke Audit of Rehabilitation Services, 69% of stroke survivors stated they would like to return to work and 67% of them were informed of services to assist with returning to work if they so desired (Stroke Foundation 2020 [14]).

Returning to work is an important goal for people who have had a stroke as it is often critical for a person's financial, psychological and emotional well-being (Killey et al 2014 [35]; Baldwin et al 2011 [34]). Therefore, all people should be asked about their return to work needs, and if they wish to return to work individualised rehabilitation goals and management plans should be provided (Baldwin et al 2011 [34]). It is important that these goals and management plans are developed in collaboration with the stroke survivor, with their voice and opinion given priority (Wolfenden & Grace 2009 [36]). Rehabilitation, work place interventions and information should be tailored to meet the stated return to work goals for people who have had a stroke.

Weak recommendation

- All stroke survivors should be asked about their employment (paid and unpaid) prior to their stroke and if they wish to return to work.
- For stroke survivors who wish to return to work, assessment should be offered to establish abilities relative to work demands. In addition, assistance to resume or take up work including worksite visits and workplace interventions, or referral to a supported employment service should be offered. (Ntsiea et al 2015 [33])

Practical info

Return to work plans should be formulated in collaboration with the stroke survivor, and tailored to their particular work and personal needs. It is important to discuss with the stroke survivor whether there are any underlying pressures influencing their decision to return to work e.g. financial concerns or worrying about being left behind.

Comprehensive assessments specific to the needs of the stroke survivor should be undertaken by appropriately trained personnel. This may include early, pre-work assessments of abilities known to be important to return-to-work, including cognition, language and fatigue, as well as work-specific assessments, such as work-site assessments and functional capacity assessments.

A phased return to work is often advisable and work hardening activities may be beneficial prior to return to work. Referral to experienced return to work service providers (occupational therapist, speech pathologist, psychologist) is recommended, as individualised support for return to work is often required. Such support may be required for a prolonged period of time (up to several years) (Kersten et al 2002 [37]). Additionally, work-based needs of the stroke survivor may change over time, and work circumstances should be flexible. Stroke survivors may benefit from advocacy support to negotiate such changes within their workplace.

Stroke survivors should be provided with advice on the legalities and their rights for returning to work, be it full time or phased return. If possible, it can also be beneficial to provide education to the stroke survivor's workplace on the effects of stroke, so that the workplace has a greater understanding of what the employee may be experiencing.

Evidence to decision

Benefits and harms

Substantial net benefits of the recommended alternative

One study (Ntsiea et al 2015 [33]) showed a higher level of ADL, a higher QoL, and a higher rate of returning to work (365 more per 1000 participants) in the intervention group. The risk of harm is low from this intervention.

Certainty of the Evidence

Low

The results were significant however our confidence in the effect estimates is low due to serious indirectness from the South African study (Ntsiea et al 2015 [33]) where there are significant wage differences compared with Australia; serious imprecision (single study with low numbers) and serious risk of bias.

Values and preferences

Substantial variability is expected or uncertain

Health professionals should speak with the stroke survivor about whether they wish to return to work and if so, the type of work arrangements they desire.

Resources and other considerations

Important issues, or potential issues not investigated

Resources considerations

No literature to understand or describe the potential economic implications of this recommendation was identified.

Implementation considerations

There is a clinical indicator collected in the National Stroke Audit to determine the total number of patients who were asked, during their admission, if they would like to return to work upon their return to the community. Additionally, there are clinical indicators collected on the number of patients who, if they were asked, wanted to return to work and were subsequently informed of services to assist with the process of returning to work.

Rationale

There is a lack of evidence regarding the outcomes of return to work programs. One South African study found a significant increase in those returning to work with a relatively short intervention (Ntsiea et al 2015 [33]). Applicability to the Australian context is unclear.

There is insufficient information to enable us to draw any conclusions about who should undertake the assessment to return to work or when this should occur. Based on the lack of evidence the decision should be made based on the individual.

Clinical question/ PICO

- Population:** Adults with stroke wanting to return to work
Intervention: Workplace intervention programme
Comparator: Usual stroke care

Summary

A randomised trial by Ntsiea et al (2015) [33] included 80 stroke survivors between 18 and 60 years old. A workplace intervention program tailored to the functional abilities of each person was compared to usual care. Participants in the intervention group were significantly more likely to have returned to work at 6 months. However, as the trial was conducted in a South African context therefore the results may not be generalisable to Australian workers.

O'Keefe et al (2018)[38] completed a scoping review and identified 28 mostly qualitative studies in TBI and/or stroke specifically targeting inpatient return to work interventions. There is a lack of studies evaluation program effectiveness.

Pearce et al (2023)[101] (n = 1,183) included 12 studies (three randomised trials, nine observational studies or pilot studies) on return to work interventions ranging in duration from 10 hours to 19 months. Whilst studies varied widely, most interventions were individually tailored and consisted of a range of work-related activities identifying barriers to work, workplace evaluation, work trials, grading of work activities, liaising with employers, work skills, self-management and counselling. Return to work definitions ranged between studies from at least 1 hour paid employment, at least 10 hours work or study per week, to modified work or competitively employed. Pre-stroke employment rate ranged from 48% to 100%. At follow up, the employment rate ranged from 7% to 75.6%.

Chen et al (2023)[103] included five randomised studies (n=626). No meta-analysis was undertaken. Three of the five included studies included focus on mood and fatigue in their intervention, two of which reported improvements in the intervention group. Further studies are needed.

Outcome Timeframe	Study results and measurements	Comparator Usual stroke care	Intervention Workplace intervention programme	Certainty of the Evidence (Quality of evidence)	Summary
Return to work rates 6 month follow-up 7 Critical	Odds ratio 5.2 (CI 95% 1.8 — 15) Based on data from 80 participants in 1 studies. ¹ (Randomized controlled) Follow up: 6 months.	200 per 1000 Difference:	565 per 1000 365 more per 1000 (CI 95% 110 more — 589 more)	Low Due to serious imprecision, Due to serious indirectness, Due to serious risk of bias ²	Workplace intervention programme may improve return to work rates. 60% of those receiving the intervention had returned to work at 6 months whereas only 20% of those in the control group had.
ADL 6 month follow-up 7 Critical	Measured by: Barthel Index Scale: 0 — 20 High better Based on data from 80 participants in 1 studies. (Randomized controlled) Follow up: 6 months.	19.2 (Mean) Difference:	19.9 (Mean) MD 0.7 higher	Low The difference between groups was significant (p = 0.001). Due to serious imprecision, Due to serious risk of bias, Due to serious indirectness ³	Workplace intervention programme may improve ADL

Outcome Timeframe	Study results and measurements	Comparator Usual stroke care	Intervention Workplace intervention programme	Certainty of the Evidence (Quality of evidence)	Summary
Perceived QoL 6 month follow-up 7 Critical	Measured by: Stroke specific quality of life (SSQoL) Scale: 49 — 245 High better Based on data from 80 participants in 1 studies. (Randomized controlled) Follow up: 6 months.	219.5 (Mean) Difference:	225.5 (Mean) MD 6 higher	Low The difference between groups was not significant (p = 0.24). Due to serious imprecision, Due to serious risk of bias, Due to serious indirectness ⁴	Workplace intervention programme may have little or no difference on perceived QOL

1. Primary study[33]. **Baseline/comparator:** Control arm of reference used for intervention.
2. **Risk of Bias: serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias. **Inconsistency: no serious.** **Indirectness: serious.** Study conducted in South Africa. 50+% of the sample earns less than \$500 AUD a month, quite different to Australian workers., Differences between the population of interest and those studied. **Imprecision: serious.** Low number of patients, Only data from one study. **Publication bias: no serious.**
3. **Risk of Bias: serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias. **Inconsistency: no serious.** **Indirectness: serious.** Differences between the population of interest and those studied. **Imprecision: serious.** Low number of patients. **Publication bias: no serious.**
4. **Risk of Bias: serious.** Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias. **Inconsistency: no serious.** **Indirectness: serious.** Differences between the population of interest and those studied. **Imprecision: serious.** Low number of patients. **Publication bias: no serious.**

References

33. Ntsiea MV, Van Aswegen H, Lord S, Olorunju S S. The effect of a workplace intervention programme on return to work after stroke: a randomised controlled trial. *Clinical rehabilitation* 2015;29(7):663-73 [Pubmed Journal](#)
38. O'Keefe S, Stanley M, Adam K, Lannin NA. A Systematic Scoping Review of Work Interventions for Hospitalised Adults with an Acquired Neurological Impairment. *Journal of occupational rehabilitation* 2019;29(3):569-584 [Pubmed Journal](#)
101. Pearce G, O'Donnell J, Pimentel R, Blake E, Mackenzie L. Interventions to Facilitate Return to Work after Stroke: A Systematic Review. *International journal of environmental research and public health* 2023;20(15) [Pubmed Journal](#)
103. Chen NYC, Dong Y, Kua ZZJ. Addressing mood and fatigue in return-to-work programmes after stroke: a systematic review. *Frontiers in neurology* 2023;14:1145705 [Pubmed Journal](#)

Sexuality

Sexuality encompasses sexual orientation, identity and roles, eroticism, intimacy and reproduction (World Health Organisation 2006). Opportunities to express sexuality are valued by stroke survivors and their partners (McGrath et al. 2019 [49]; Stein et al. 2013 [41]). Sexual difficulties after stroke are common and frequently not addressed by healthcare professionals (Sansom et al 2015 [39]; Stein et al 2013 [41]). National Stroke Audits report that only 43% of stroke survivors are offered information on intimacy post stroke and only 20% are offered the opportunity to discuss issues relating to intimacy post stroke (Stroke Foundation 2020 [14]). This finding was reported despite sexuality being seen as a moderately to very important issue in the rehabilitation of stroke survivors (Stein et al 2013 [41]). The cause of sexual difficulties post-stroke is complex and multifactorial (Song et al 2011 [40]) and therefore interventions need to be individualised and address psychological as well as physical factors.

Sexual rehabilitation intervention programs have been well summarised (e.g. Grenier-Genest et al. 2017 [50]; Stratton et al. 2020 [42]). Interventions targeting sexuality after stroke are limited. Even fewer have been evaluated. Those that have been evaluated for effectiveness include pharmacological interventions (e.g. sertraline for premature ejaculation) and non-pharmacological interventions (e.g. written education materials, sexual rehabilitation education and pelvic floor muscle training).

Consensus recommendation

Consensus-based recommendations

Stroke survivors and their partners should be offered:

- the opportunity to discuss sexuality and intimacy with an appropriate health professional; *and*
- written information addressing issues relating to sexual intimacy and sexual dysfunction post stroke.

Any discussion or written information should address psychosocial as well as physical function.

Practical info

Stroke Foundation audits consistently show that only one quarter or less of stroke survivors are offered advice, information or rehabilitation around sexuality. Many barriers exist at the health professional, system and patient/carer level, including unhelpful beliefs and attitudes about sexuality being a taboo topic, a view that patients will be embarrassed, lack of time and private space for discussion, lack of knowledge, skills and confidence, and non-acceptance of this topic as part of the professional role (Dyer et al 2019 [45]; O'Connor et al 2019 [52]).

For practice to change, there is a need for sexuality and intimacy to be acknowledged as an important topic that all team members and disciplines should be trained in and willing to discuss. A broad behaviour change intervention will be needed to change practice across the health system. Training and education of health professionals is required to increase confidence, skills and knowledge, as well as change attitudes and unhelpful beliefs about sexuality as a private and taboo topic.

Time will need to be allocated by at least one team member to discuss sexuality and provide basic information to each stroke survivor. At least 15 minutes, often longer, is needed at a time and place that allows some privacy. In some instances, the presence of a partner will be desirable and preferred. The approach taken during initial consultations is important, so that stroke survivors and their partner are willing to engage and ask questions. Health professionals should be aware of potential preferences by stroke survivors to discuss sexuality with someone of the same sex (i.e., females to a female, and males to a male).

Evidence to decision

Benefits and harms

Small net benefit, or little difference between alternatives

Pharmacological and non-pharmacological interventions to improve sexual functioning have so far shown no effect on sexual function compared to control interventions (Stratton et al. 2020 [42]). Sertraline, an anti-depressant, had some side effects including nausea and diarrhoea for 20/58 or one third of participants (34%), making it less attractive to male stroke survivors with premature ejaculation. No harmful effects or events were reported following pelvic floor muscle training or a 30-minute sexual rehabilitation consultation, but there were no measurable benefits compared to controls.[39]

Certainty of the Evidence

Low

Overall the quality of the evidence was low or very low, and data were insufficient in all studies to provide a true indication of the benefits and risks of each intervention.

Values and preferences

Substantial variability is expected or uncertain

It is unclear if there is substantial variability or not. One trial offered additional counselling, therapy and a more in-depth consultation closer to discharge as part of their treatment, but no stroke survivors actually accepted the offer, nor did any of the control participants accept the offer of the 30-minute consultation at the end of the study. However, we believe that many, but not all, stroke survivors and their partners would want to receive some advice, basic information and support to address sexuality post-stroke. Some male stroke survivors who experience urinary incontinence, affecting their sexual activity and erectile dysfunction post-stroke, may wish to trial a pelvic floor muscle training (PFMT) program. However, to date, no benefits have been reported compared to standard rehabilitation, and the time commitment (and resources) for a 12-week program of muscle training are significant. Furthermore, PFMT involves digital anal palpation by the treating physiotherapist in order to give feedback about muscle contractions, which some male stroke survivors may find embarrassing.

Resources and other considerations

Important issues, or potential issues not investigated

Implementation consideration

Clinical indicators are collected as part of the National Stroke Audit about the provision of written information addressing sexuality and intimacy post-stroke, and; whether stroke survivors and their partners were offered the opportunity to discuss sexuality and intimacy before discharge.

Rationale

Stroke survivors and their partners consistently report a need for information about sexuality and intimacy after stroke (Lever & Pryor 2017 [43], McGrath et al. 2019a [49], McGrath et al. 2019b [51], Prior et al. 2019 [48], Stein et al. 2013 [41]). A Cochrane review (Stratton et al. 2020 [42]) found three trials targeting very different interventions. There was limited or no benefit reported from these interventions, and the overall quality of evidence was very low in two trials and low in the third.

Research to date involving people with chronic conditions including stroke has almost exclusively recruited heterosexual couples or men, and focussed on sexual (dys)function. Few studies have investigated the needs and preferences of adults with other sexual orientation and identities outside the heterosexual population. Further studies are needed.

Clinical question/ PICO

Population: Adults within 3 months post stroke
Intervention: Structured sexual rehabilitation programme
Comparator: Written information alone

Summary

Stratton et al (2020)[42] conducted a Cochrane review and identified one RCT by Ng and colleagues (2017), cited in Stratton 2020 [42], that evaluated the effectiveness of a 30-minute individualised sexual rehabilitation consultation. The consultations were based on a South Korean sexuality rehabilitation program by Song and colleagues (2011)[40]. Stroke inpatients (n=68, mean age 63 years) in one Australian hospital were randomised to receive a single consultation delivered face-to-face by a rehabilitation physician (n=35). Content included information regarding common changes in sexuality post-stroke, and counselling on fears regarding post-stroke sexuality. The rehabilitation physician challenged stereotypical views on sexuality and sexual satisfaction and provided tips and strategies to optimise post-stroke sexual function. Participants were offered additional input from occupational therapy, physiotherapy and/or psychology as required, for counselling or training to improve bed mobility for sexual positioning or to address other aspects of sexuality – an offer that no participant took up. They were also offered a more comprehensive intervention towards the end of their inpatient stay – again an offer that no participant took up. Partners were invited to join the consultations, with consent of the stroke survivor. Twenty-nine participants had a partner, but no partners chose to attend. Intervention (n=35) and control participants (n=33) received written educational material on sexuality after stroke (the Stroke Foundation fact sheet on “Sexuality after stroke”). Most stroke survivors in the intervention group tended to listen to and/or read the written information but posed no questions during the 30-minute consultation. The control group were also offered a face-to-face consultation after the study concluded. Again, this was an offer that no control participant took up.

The primary outcome measure was the Changes in Sexual Functioning Questionnaire (CSFQ-14), administered at six weeks and six months post-baseline. Two thirds of participants (40/68 = 59%) had not had sexual intercourse for at least five years pre-stroke but had been sexually active in other ways (i.e., masturbation, sexual thoughts). There were no between-group differences in sexual functioning at any time point for the CSFQ-14, or for the two other measures (Stroke and Aphasia Quality of Life Scale-39, and Depression, Anxiety & Stress Scale).

Overall, the data are insufficient to provide a true indication of the benefits and risks of a consultation delivered in an inpatient rehabilitation setting. There is also no protocol, manual or algorithm to guide professionals or for use by other researchers who might wish to replicate the study, despite completion of an earlier feasibility trial by the same group (Sansom et al 2015)[39].

The consultations were based on a South Korean sexual rehabilitation program by Song and colleagues (2011) who conducted a controlled trial (n=46). The South Korean intervention significantly increased sexual satisfaction and frequency of sexual activity, but there was no significant difference in sexual knowledge. Similar benefits were not recorded in the Australian study.

All of these trials to date have low methodological quality and high risk of bias.

Outcome Timeframe	Study results and measurements	Comparator Written information alone	Intervention Sexual rehabilitation programme	Certainty of the Evidence (Quality of evidence)	Summary
Sexual functioning ¹ 6 weeks follow-up 8 Critical	Measured by: Change from baseline on CSFQ-14 Scale: 14 — 70 High better Based on data from 68 participants in 1 studies. ² (Randomized controlled) Follow up: 6 weeks.	28 Points (Median) Difference:	26 Points (Median) 2 lower	Low Due to serious imprecision, Due to serious risk of bias ³	Sexual rehabilitation programme may have little or no difference on sexual functioning
Psychological well-being ⁴ 6 weeks follow-up 9 Critical	Measured by: Depression, Anxiety and Stress Scale High better Based on data from 68 participants in 1 studies. ⁵ (Randomized controlled) Follow up: 6 weeks.	2 points (Median) Difference:	4 points (Median) 2 higher CI 95%	Low Due to serious imprecision, Due to serious risk of bias ⁶	Sexual rehabilitation programme may have little or no difference on physical functioning
Quality of life 6 weeks follow-up 9 Critical	Measured by: Change from baseline on SAQOL-39 mean total High better Based on data from 68 participants in 1 studies. ⁷ (Randomized controlled) Follow up: 6 weeks.	4.5 points (Median) Difference:	4.1 points (Median) 0.4 lower	Low Due to serious imprecision, Due to serious risk of bias ⁸	Sexual rehabilitation programme may have little or no difference on quality of life

- Sexual functioning was assessed using the Changes in Sexual Functioning Questionnaire Short-Form (CSFQ-14).
- Systematic review [42] . **Baseline/comparator:** Control arm of reference used for intervention.
- Risk of Bias: serious. Inconsistency: no serious. Indirectness: no serious. Imprecision: serious.** Only data from one study. **Publication bias: no serious.**
- Depression, Anxiety and Stress Scale
- Systematic review [42] . **Baseline/comparator:** Control arm of reference used for intervention.
- Risk of Bias: serious. Inconsistency: no serious. Indirectness: no serious. Imprecision: serious.** Only data from one study. **Publication bias: no serious.**
- Systematic review [42] . **Baseline/comparator:** Control arm of reference used for intervention.
- Risk of Bias: serious. Inconsistency: no serious. Indirectness: no serious. Imprecision: serious.** Only data from one study. **Publication bias: no serious.**

References

- Sansom J, Ng L, Zhang N, Khan F. Let's talk about sex: A pilot randomised controlled trial of a structured sexual rehabilitation programme in an Australian stroke cohort. *International Journal of Therapy & Rehabilitation* 2015;22(1):21-29 [Journal](#)
- Song H, Oh H, Kim H, Seo W. Effects of a sexual rehabilitation intervention program on stroke patients and their spouses. *NeuroRehabilitation* 2011;28(2):143-50 [Pubmed Journal](#)

42. Stratton H, Sansom J, Brown-Major A, Anderson P, Ng L. Interventions for sexual dysfunction following stroke. Cochrane Database of Systematic Reviews 2020;5 [Pubmed Journal](#)

Clinical question/ PICO

Population: Adult males with stroke

Intervention: Sertraline

Comparator: placebo

Summary

Stratton et al (2020)[42] conducted a Cochrane review and identified one RCT, (Lu et al. 2012, cited in Stratton et al [42]) that evaluated the effectiveness of sertraline, an antidepressant medication, on secondary premature ejaculation in men post-stroke, aged between 23 and 45 years. A sample of 114 men was recruited during their inpatient admission in China, provided with 50 mg of oral sertraline, 'psychological and behavioural advice' by a neurologist and urologist, and encouraged to participate in sexual activity frequently (once or twice a week). The control group received the same advice and encouragement but received a placebo medication (0.5 mg of methylcobalamin – Vitamin B12). Medications were taken daily, four to six hours before bed or sexual activity, for eight weeks. Measures were taken at the end of eight weeks, then again four weeks later. There was a statistically significant difference in the primary outcome, intra-vaginal ejaculatory latency time (time between the start of vaginal intercourse and ejaculation) at four, eight and 12 weeks between intervention and control groups. Time to ejaculation of less than 2 mins from the beginning of sexual intercourse or penetration is defined as 'premature' based on expert consensus (Serefoglu et al, 2014 [46]). After eight weeks, the group taking sertraline took on average 5.8 minutes (SD 0.7) to ejaculate, compared to 3.8 minutes (SD 0.5) for controls ($P < 0.01$). At 12 weeks, the intervention group took an average of 6.1 minutes (SD 0.9) to start ejaculating, compared to 4.5 minutes (SD 0.7) for the control group ($P < 0.01$). Lu and colleagues also administered a non-validated measure of sexual functioning and reported a significant increase on that measure at all time points for the sertraline group compared to placebo. Adverse events were increased but reported as 'mild'. Of the 58 stroke survivors receiving sertraline, 20 reported adverse events including gastrointestinal symptoms ($n=9$), dizziness ($n=5$), excessive sweating ($n=2$) dry mouth ($n=2$) and lowered libido ($n=2$). Of the 56 stroke survivors receiving the placebo, 11 reported adverse events including gastrointestinal symptoms ($n=6$), headache ($n=2$), excessive sweating ($n=1$) lowered libido ($n=1$) and fever ($n=1$).

Overall, the quality of the evidence was rated as 'very low', raising concerns about the outcomes. Methodological problems included lack of clarity about allocation concealment, and no blinding of outcome assessors, patient participants or the treating team. Data were insufficient to provide a true indication of the benefits and risks of sertraline for improving sexual functioning in male stroke survivors with premature ejaculation post-stroke.

Outcome Timeframe	Study results and measurements	Comparator placebo	Intervention Sertraline	Certainty of the Evidence (Quality of evidence)	Summary
Adverse effects	Odds ratio 2.15 (CI 95% 0.92 — 5.05) Based on data from 114 participants in 1 studies. ¹	196 per 1000 Difference:	343 per 1000 148 more per 1000 (CI 95% 13 fewer — 356 more)	Very low Due to serious risk of bias, Due to serious imprecision ²	We are uncertain whether sertraline compared with placebo increases or decreases adverse effects
Sexual function	Measured by: mean intravaginal ejaculatory latent time Based on data from 114 participants in 1 studies. ³ (Randomized controlled)	Difference:	MD 2 higher (CI 95% 1.78 higher — 2.22 higher)	Very low Due to serious risk of bias, Due to serious imprecision ⁴	Sertraline compared with placebo may improve sexual function slightly
Partner sexual satisfaction - non-validated measure	Measured by: Mean non- validated measure Based on data from 114 participants in 1 studies. ⁵ Follow up: end of intervention (8 weeks).	Difference:	MD 2.5 higher (CI 95% 1.89 higher — 3.11 higher)	Very low Due to serious risk of bias, Due to serious imprecision ⁶	Sertraline compared with placebo may increase partner sexual satisfaction slightly

1. Systematic review [42] with included studies: Lu 2012. **Baseline/comparator:** Control arm of reference used for intervention.
2. **Risk of Bias: serious. Inconsistency: no serious. Indirectness: no serious. Imprecision: serious.** Only data from one study.
3. Systematic review [42] with included studies: Lu 2012. **Baseline/comparator:** Control arm of reference used for intervention.
4. **Risk of Bias: serious. Imprecision: serious.** Only data from one study.
5. Systematic review [42] with included studies: Lu 2012. **Baseline/comparator:** Control arm of reference used for intervention.
6. **Risk of Bias: serious. Imprecision: serious.** Only data from one study.

References

42. Stratton H, Sansom J, Brown-Major A, Anderson P, Ng L. Interventions for sexual dysfunction following stroke. Cochrane Database of Systematic Reviews 2020;5 [Pubmed Journal](#)
46. Serefoglu EC, McMahon CG, Waldinger MD, Althof SE, Shindel A, Adaikan G, et al. An evidence-based unified definition of lifelong and acquired premature ejaculation: report of the second international society for sexual medicine ad hoc committee for the definition of premature ejaculation. Sexual medicine 2014;2(2):41-59 [Pubmed Journal](#)

Clinical question/ PICO

- Population:** Men with lower urinary tract symptoms and erectile dysfunction more than 1 month following stroke
- Intervention:** Pelvic floor muscle training
- Comparator:** Usual rehabilitation care

Summary

Stratton et al. (2020)[42] conducted a Cochrane review and identified one RCT, (Tibaek et al. 2015, cited in Stratton et al. 2020) that evaluated the effectiveness of a 12-week pelvic floor muscle training (PFMT) group program (n=30, median age 68 years) with home exercises, for male stroke survivors in Denmark with lower urinary tract symptoms (LUTS). The treatment group received the 12-week intensive PFMT program, provided by the same unblinded physiotherapist, modified from a standard group program for stress incontinence (Tibaek et al. 2005 [47]; Bo et al. 1990). The PFMT consisted of an introductory component covering anatomy and physiology of the bladder and pelvic floor muscles, a home exercise PFMT program including strengthening and endurance training that participants were to practise once- to twice-daily, and a once-weekly 60-minute group session of isolated PFM contraction, strength and endurance exercises and sub-maximal PFM contractions, before and during coughing, sneezing, laughing and activities of daily living such as lifting. Men in the control group received the standard generalised rehabilitation program without specific treatment for LUTS. Self-report measures were used to evaluate the effect of the PFMT program on erectile dysfunction, including the International Index of Erectile Dysfunction questionnaire (IIEF-5). An additional non-validated 'ED-induced bother' question was also used ("If you were to spend the rest of your life with your problems as they are now, how would you feel about that?" AND "If you use medicine or other aids/appliances to optimise erection, is that reflected in your answer?"). Answers were rated using an ordinal scale, from 1 = very dissatisfied to 5 = very satisfied. While the IIEF-5 showed a significant improvement in the treatment group from pre-test to post-test, there were no statistical differences between treatment and control groups, pre-test or post-test. At 6 months, the IIEF-5 results showed no between-group or within-group differences (pre-test versus follow-up), and pre-test to follow-up IIEF-5 total scores were worse in the control group. There were no between-group differences in response on the 'ED-induced bother' question at any time point. A sample size of 120 participants was required to adequately power the study and show an effect if one existed. Tibaek and colleagues (2015) stopped the trial due to slow recruitment after recruiting only 35 participants. There are also issues with missing data and the overall quality is rated very low. Further data are required.

Outcome Timeframe	Study results and measurements	Comparator Usual care	Intervention Pelvic floor exercises	Certainty of the Evidence (Quality of evidence)	Summary
Sexual dysfunction 3 months 7 Critical	Measured by: International Index of Erectile Function Questionnaire High better Based on data from 31 participants in 1 studies. ¹ (Randomized controlled) Follow up: 3 months.	18 (Median) Difference:	20 (Median) MD 2 higher CI 95%	Very low	We are uncertain whether pelvic floor exercises increases or decreases psychological well-being

Outcome Timeframe	Study results and measurements	Comparator Usual care	Intervention Pelvic floor exercises	Certainty of the Evidence (Quality of evidence)	Summary
Quality of life 3 months 7 Critical	Measured by: non validated questionnaire Scale: 0 — 5 High better Based on data from 31 participants in 1 studies. ² Follow up: 3 months.	3 (Median) Difference:	4 (Median) MD 1 higher CI 95%	Very low	We are uncertain whether pelvic floor exercises increases or decreases quality of life

1. Systematic review [42] . **Baseline/comparator:** Control arm of reference used for intervention.
2. Systematic review [42] . **Baseline/comparator:** Control arm of reference used for intervention.

References

42. Stratton H, Sansom J, Brown-Major A, Anderson P, Ng L. Interventions for sexual dysfunction following stroke. Cochrane Database of Systematic Reviews 2020;5 [Pubmed Journal](#)

47. Tibaek S, Gard G, Jensen R. Pelvic floor muscle training is effective in women with urinary incontinence after stroke: a randomised, controlled and blinded study. Neurourology and urodynamics 2005;24(4):348-57 [Pubmed](#)

Support

Social support has been shown to correlate directly with outcomes post-stroke. It is common for people with stroke to comment on falling into a "black hole" period when returning home, as they confront the difficulty adjusting to life after stroke, especially when formal interventions have been completed. Support during this phase would seem to be particularly important.

Three important aspects of support have been reported in descriptive studies: emotional, instrumental (practical support such as home help), and informational (Glass and Maddox 1992 [53]). High emotional support along with moderate levels of instrumental support was found to be most the beneficial; however, a trial of a social support intervention based on these assumptions failed to produce significant effects, highlighting the complex nature of social support after stroke (Friedland and McColl 1992 [54]). Counselling services may be important during the reintegration and long-term recovery phase to provide appropriate emotional and informational support (see Counselling). Services that provide support in the community include support groups, community services (e.g. Meals on Wheels, home help, and transport), primary care workers (personal care, respite support), community rehabilitation teams and voluntary services (e.g. providing social support).

Approximately two thirds of survivors require assistance with activities of daily living after stroke. Whilst the greatest recovery is made in the early months after stroke, recovery can continue for many years after formal rehabilitation has finished. Research commissioned by the Stroke Foundation shows that survivors and their families require access to support and tools to help them drive their recovery, particularly when formal inpatient and outpatients rehabilitation has ceased.

The Stroke Foundation's [enableme](#) website delivers personalised information and tools to enable survivors to manage and progress their recovery many years after stroke and from any location; from metropolitan to remote Australia. It helps to address the individual needs of each survivor by providing customised information and support, goal setting and tracking tools and the opportunity to develop and share content, stories and ideas. It aims to empower people affected by stroke to actively participate in making decisions about their own health; thereby contributing to reducing the escalating human, social and economic cost of burden of this disease. The website is also an important tool for healthcare professionals in their care of survivors and provides tools to assist them in providing person centered stroke education, goal setting and connection to a peer support network beyond hospital. A comprehensive list of stroke support groups and state based stroke associations can be accessed on [enableme](#). Users are also able to connect with one another on the site by participating in the community section or by using instant messaging functionality.

StrokeLine's healthcare professionals provide information, advice, support and referral to both stroke survivors and carers, with half of all consumers calling for advice after stroke being carers.

Peer support

Peer support is a process by which stroke survivors may share their experiences with others. Peer support may be delivered face-to-face in a group, online or by telephone. Other topics such as self-management interventions are relevant to this topic as well and these interventions facilitate peer support by the sharing of experiences, social comparisons, vicarious learning and increased motivation. (Clark et al. 2020 [59])

Many stroke survivors are active in establishing and maintaining peer support groups in the community. Individual peer support may also be of value, either to supplement groups or for people who do not want involvement in a group.

Weak recommendation

Stroke survivors and their families/carers should be given information about the availability and potential benefits of a local stroke support group and/or other sources of peer support before leaving hospital and when back in the community. (Kruithof et al 2013 [57])

Practical info

Stroke survivors and carers should have an opportunity early during inpatient rehabilitation to meet with a peer volunteer who has a similar background and experiences. A peer support group could also be provided or recommended post-discharge. Telephone contact with a peer is another alternative post-discharge.

Benefits of peer support visits and groups should be promoted by professionals to all stroke survivors and carers. Benefits include encouragement, validation, better quality of life, social interaction, inspiration and learning new ways to cope. Information about stroke support groups, stroke hubs, online stroke support groups and EnableMe should also be provided. Note that not all stroke survivors or carers will want a peer support visit or to attend a support group, however, it can be helpful to offer these supports to people at different stages, as peoples' circumstances, and their desire for involvement, can change.

The inclusion of staff in peer support groups is viewed as important and helpful by stroke survivors and peer supporters. Staff can add safety and security to a group.

Some form of training for volunteer peer supporters is recommended. Role play can be a good way of training volunteers.

Evidence to decision

Benefits and harms

Substantial net benefits of the recommended alternative

In a systematic review of 11 qualitative studies (Kruithof et al 2013 [57]) the authors found that there was a significant correlation between perceived social support and health related quality of life however they were not able to determine the best type of social support. Subsequent trials all report perceived benefits from stroke survivors and or carers.

No harms were reported in the included studies. Lack of support was mentioned as a barrier to maintaining independence in activities of daily living and social participation.

Certainty of the Evidence

Very low

Our confidence in the effect estimates is very low due to the small number of included studies and the heterogeneity of the methods/interventions used.

Values and preferences

No substantial variability expected

In general support provided in various ways (peer visits, groups, health professional led) appears valuable to stroke survivors and carers/family. However, there are comments in the various studies that a small number of people do not wish to engage in support interventions. [56]

Resources and other considerations

No important issues with the recommended alternative

Resources considerations

No literature to understand or describe the potential economic implications of this recommendation was identified.

Implementation considerations

There is a clinical indicator collected in the National Stroke Audit to determine whether patients with stroke were provided with information regarding peer support before their discharge from hospital.

Rationale

The systematic review (Kruithof et al 2013 [57]) showed a positive relationship between perceived social support and stroke survivors health-related quality of life (HRQoL) however the type or source of the social support was not able to be determined. The quality of the evidence was very low to low due to observational studies, the heterogeneity and size of the studies. Other studies have reported similar benefits in terms of social support, modelling and empowerment.

While difficult to quantify it is apparent that stroke survivors do benefit from social support and the inclusion of health professionals to either facilitate or manage this process is helpful.

Clinical question/ PICO

Population: Adults with stroke

Intervention: Peer support

Comparator: No peer support

Summary

Wan et al (2021)[90] with 11 studies (8 randomised trials, n=1255 and 3 quasi-experimental studies, n=48) five of which were in a hospital setting and six in a community setting. Overall peer support interventions improved activities of daily living (MD 15.53, 95% CI 1.39 to 29.68; 3 RCTs, n=226; substantial heterogeneity $I^2 = 99\%$; very low quality evidence) and decreased symptoms of depression (SMD -1.27, 95% CI -2.18 to -0.36; 4 studies, n=305; substantial heterogeneity $I^2 = 91\%$; very low quality evidence). A improvement in social participation (SMD 0.41, 95% CI 0.09 to 1.39; 4 studies, n=167; moderate heterogeneity $I^2 = 69\%$; low quality evidence) and quality of life (SMD 0.41, 95% CI 0.09 to 0.73; 3 studies, n=153; low quality evidence) was also observed, however, the results are based on generally low-quality evidence with high heterogeneity.

Kruithof et al. (2013) [57] conducted a systematic review of studies assessing stroke survivors' perceived quality of life. They included 11 observational studies (N=1039). The authors examined the correlation between perceived social support and health-related quality of life (HRQoL). The majority of the correlations showed a significant relationship between perceived social support and HRQoL. Due to the small number of included studies and heterogeneity in methods of assessing social support a clear statement about the influence of social support source or type could not be made.

Mohammadi et al (2021)[89] randomised 67 participants to a partnership care model intervention involving education and monthly follow-up in a group setting with compared with routine care at the rehabilitation center. The partnership care model led to significantly improved quality of life and activities of daily living at 3 months and 6 months follow up ($p < 0.05$).

Hill et al. (2019) [60] randomised 450 stroke patients within one month of hospital admission into

three groups; problem-solving therapy from a psychiatric nurse, non-specific support given by trained volunteers (over half had personal experience of stroke) and, treatment-as-usual. The non-specific support given by volunteers group delivered 6-8 visits of talking support. There was no statistically significant differences at six months. At 12 months, patients in the problem-solving therapy group had significantly lower GHQ-28 scores. Other outcomes on social function and cognitive function were not different between groups.

Outcome Timeframe	Study results and measurements	Comparator No peer support	Intervention Peer support	Certainty of the Evidence (Quality of evidence)	Summary
Quality of life 8 Critical	Measured by: EuroQoL-5D,WHOQOL- BREF,AQL High better Based on data from 153 participants in 3 studies. ¹ (Randomized controlled)	Difference:	MD 0.41 higher (CI 95% 0.09 higher — 0.73 higher)	Low Due to serious risk of bias, Due to serious indirectness ²	Peer support may improve QoL.
Social participation 7 Critical	Measured by: RNL, RNLI, CPI, CIQ and HEIQ High better Based on data from 167 participants in 4 studies. ³ (Randomized controlled)	Difference:	SMD 0.74 higher (CI 95% 0.09 higher — 1.39 higher)	Very low Due to serious risk of bias, Due to serious indirectness, Due to serious inconsistency ⁴	Peer support may improve social participation slightly.

1. Systematic review [90] . **Baseline/comparator:** Control arm of reference used for intervention.
2. **Risk of Bias: serious.** Inadequate sequence generation/ generation of comparable groups, resulting in potential for selection bias, Incomplete data and/or large loss to follow up, Selective outcome reporting. **Inconsistency: no serious. Indirectness: serious.** Differences between the intervention/ comparator of interest and those studied. **Imprecision: no serious. Publication bias: no serious.**
3. Systematic review [90] . **Baseline/comparator:** Control arm of reference used for intervention.
4. **Risk of Bias: serious.** Inadequate sequence generation/ generation of comparable groups, resulting in potential for selection bias, Incomplete data and/or large loss to follow up, Selective outcome reporting. **Inconsistency: serious.** The magnitude of statistical heterogeneity was high, with $I^2:69\%$. **Indirectness: serious.** Differences between the intervention/comparator of interest and those studied. **Imprecision: no serious.** Wide confidence intervals. **Publication bias: no serious.**

References

57. Kruithof WJ, van Mierlo ML, Visser-Meily JMA, van Heugten CM, Post MWM. Associations between social support and stroke survivors' health-related quality of life--a systematic review. Patient education and counseling 2013;93(2):169-76 [PubMed Journal](#)
60. Hill K, House A, Knapp P, Wardhaugh C, Bamford J, Vail A. Prevention of mood disorder after stroke: a randomised controlled trial of problem solving therapy versus volunteer support. BMC

neurology 2019;19(1):128 [Pubmed Journal](#)

89. Mohammadi E, Hassandoost F, Mozhdehipanah H. Evaluation of the "partnership care model" on quality of life and activity of daily living in stroke patients: A randomized clinical trial. Japan journal of nursing science : JJNS 19(1):e12448 [Pubmed Journal](#)

90. Wan X, Chau JPC, Mou H, Liu XU. Effects of peer support interventions on physical and psychosocial outcomes among stroke survivors: A systematic review and meta-analysis. International journal of nursing studies 121:104001 [Pubmed Journal](#)

Carer support

An informal (or unpaid) caregiver is a person who provides unpaid help and support to a stroke survivor. National Stroke Audits report that at least 4060% of stroke survivors have a carer and 5544% of them were provided with information about peer support resources prior to discharge (Stroke Foundation 202016 [14]). More than half (58%) of co-resident primary carers of people with stroke who had some ongoing disability spent 40 hours or more per week in their caring role (AIHW 2013 [49]). The physical and psychological demands of the caring role can lead to adverse effects on the physical health and emotional wellbeing of carers, their personal relationships and participation in social activities. Discharge planning that aims to meet the daily needs of stroke survivors is crucial to supporting carers. Government programs such as respite care are available to help reduce the load on carers, however, the majority of co-resident primary carers of stroke survivors have never used respite care (AIHW 2013 [70]).

Strong recommendation

In review

Carers of stroke survivors should be provided with tailored information and support during all stages of the recovery process. This support includes (but is not limited to) information provision and opportunities to talk with relevant health professionals about the stroke, stroke team members and their roles, test or assessment results, intervention plans, discharge planning, community services and appropriate contact details. Support and information provision for carers should occur prior to discharge from hospital and/or in the home and can be delivered face-to-face, via telephone or computer. (Legg et al 2011 [61]; Eames et al 2013 [62])

Evidence to decision

Benefits and harms

Small net benefit, or little difference between alternatives

Support and information provided to informal caregivers may benefit the caregiver by reducing caregiver strain (Legg et al 2011 [61]; Eames et al 2013 [62]). Given the minimal effect of this intervention demonstrated on caregiver strain, burden, depression and quality of life, the harms of providing or not providing support and information are suggested to be minimal (Legg et al 2011 [61]; Eames et al 2013 [62]).

Certainty of the Evidence

Moderate

The overall quality of evidence is moderate based on six studies.

Values and preferences

No substantial variability expected

It is expected that carers of stroke survivors would strongly prefer to be provided support during the recovery process.

Resources and other considerations

No important issues with the recommended alternative

Resource considerations

The TRACS (Training Caregivers After Stroke) randomised controlled trial was conducted in the UK to investigate the benefits of a training programme (the London Stroke Carers Training Course) for caregivers of patients after a disabling stroke compared to usual care (Forster et al 2013 [71]). In a parallel cost-effectiveness analysis, it was found that total health and social care costs for patients and societal costs for patients or caregivers did not differ between groups at 6 months, 12 months or over 1 year. Caregivers in the intervention group had higher health and social care costs at 6 months. On examining the probability of cost-effectiveness by constructing cost-effectiveness acceptability curves using threshold ranges of £0 to £2,000 GBP for points gains on the Nottingham extended activities of daily living and caregiver burden scale and £0 to £50,000 GBP for QALY gains concluded that the intervention is unlikely to be considered cost-effective within current UK policy thresholds of £20,000 to £30,000 GBP per QALY gained.

Two systematic reviews compared the resources use only between intervention and control groups in caregivers intervention studies and care giver/stroke survivors dyad intervention studies. These intervention studies found favourable improvements in terms of fewer illnesses, caregiver reports of emergency room visits, hospital readmissions, hospital days and more home help, reduced institutionalisation and lower costs (Bakas et al 2014 [69]; Cheng et al 2014 [63]). Overall, the findings provide some indications that stroke caregiver and stroke dyad interventions have the potential to provide within the healthcare system.

Rationale

While the effect estimates are minimal in the research included in the review and the quality of such evidence is relatively low, a strong recommendation has been made as it is assumed that any patient would want their caregiver to be offered as much information, contacts and resources as can be offered. Caregivers can only benefit from receiving this information and can choose to utilise it or not in relation to individual circumstances and needs.

Further research is needed on the ideal timing of carer support/information provision and the most efficient and convenient delivery format for consumers.

Clinical question/ PICO

Population: Adult caregivers of stroke survivors

Intervention: Support and information

Comparator: Control

Summary

Legg et al. (2011) [61] investigated interventions targeted at informal caregivers of stroke survivors in a Cochrane review. Eight randomised trials (n=1007 participants) were included, using a variety of interventions including providing information and support, psycho-education, and teaching

procedural knowledge. Pooled analysis combining results from similar interventions showed no significant change in caregiver stress and strain following support and information or psycho-educational interventions, but a single trial of a vocational training intervention showed significantly improved stress and strain.

A subsequent randomised trial (Eames et al. 2013 [62]) that delivered an education and support package to stroke patients and carers (n = 138) showed no significant improvement in caregiver burden, but significant improvements in self-efficacy and satisfaction with information.

A systematic review by Aldehaim et al (2016)[73] with 2 RCTs and 3 pilot studies (n = 343) looked at the impact of technology-based intervention. Four studies (n = 273) assessed caregiver depression, two of which reported significant decreases in symptoms. A study reported on caregiver burden (n= 72) and found no differences post-intervention.

The effects of a support program on resilience to female family caregivers (n=70) found significant differences between the experimental group's means pretest, posttest and follow-up scores for family strains and family distress, but not in family stressors (Inci and Temel 2016 [81]).

A cochrane review investigating carer-mediated exercises with 9 trials (n = 333) found positive effects on quality of life (n = 51, very low-quality evidence) but no difference was observed for caregiver burden (n = 91). (Vloothuis et al. 2016 [72]).

A study by Vloothuis et al (2019) [76](n = 66) in caregiver-mediated exercise and e-health support observed no difference on mobility and length of stay in rehabilitation. However, the intervention was favoured for caregiver's depression (β 2.33, SD 0.77, $p = 0.003$).

A study investigating the effect of telenursing on depression and anxiety found a difference between the mean post-intervention anxiety scores for the intervention and control group (t 3.51, $p = 0.001$, $n=152$ - t -test stats), but no difference was found for depression (Goudarzian et al. 2018[78]).

Pucciarelli et al (2020)[75] investigated dyadic interventions on stroke survivor and caregiver dyads. The systematic review with 16 studies (n=2997) found significantly better quality of life in the treatment compared to control (SMD = 0.17, 95% CI 0.03 to 0.30; 5 studies, n=1259). Caregiver depression was lower in the intervention group (SMD -0.19, 95% CI -0.40 to 0.00; 6 studies, n = 1322) and no difference in burden was found (SMD -0.09, 95% CI -0.26 to 0.09; 8 studies, n = 1636).

Elsheikh et al (2022)[84] with 110 caregivers either received tailored multidimensional interventions (skill building, psychoeducation and peer support) over 6 months or simple educational instructions at a single visit. No significant difference were observed between groups for care burden using the short version of Zarit Burden Interview (ZBI) at 3 months or 6 months follow up. The effects of group and time were only significant for the psychological ($p < 0.001$) and social relationship ($p = 0.036$) domains of the Quality of Life using the WHO Quality of Life-BREF.

Fu et al (2022)[85] with 68 survivor and carer dyads received 9 weeks of a benefit-find intervention or routine health education. The benefit finding intervention improved benefit finding, caregivers burden, and quality of life for the caregiver and patients (all $p < 0.05$).

Kang et al (2022)[86] (n=170) investigated WeChat-based caregiver education or control care involving discharge guidance, health education and reexamination every 3 months after discharge. Anxiety score (6.5 ± 3.1 vs 7.5 ± 2.8 , $p = 0.020$), depression score (6.7 ± 3.1 vs 7.7 ± 3.3 , $p = 0.040$) and depression rate (33.7% vs 48.8%, $P = 0.046$) were lower in the WeChat-based intervention group than control at 12 months. Satisfaction scores were improved in the WeChat-based intervention for

patients (12 months: 8.0 ± 1.2 vs 7.4 ± 1.2 , $p = 0.002$) and caregivers (6 months: 6.6 ± 1.1 vs 6.2 ± 1.3 , $p = 0.038$; 12 months: 7.2 ± 1.1 vs 6.8 ± 1.4 , $p = 0.042$).

Patchwood et al (2021)[87] with 414 carers compared the Carer Support Needs Assessment Tool for Stroke with usual care and found no significant difference to carer strain at 3 months (aMD -0.04, 95% CI -0.20 to 0.13; $n=349$). It was noted the intervention was not fully implemented in this pragmatic cluster randomised controlled trial.

Wang et al (2021)[88] 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 , $p=0.018$), caregivers 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.

Outcome Timeframe	Study results and measurements	Comparator Control	Intervention Support and information	Certainty of the Evidence (Quality of evidence)	Summary
Informal caregiver stress and strain Post intervention 7 Critical	Measured by: Caregiver Strain Index, specially developed burden measure Lower better Based on data from 219 participants in 2 studies. ¹ (Randomized controlled) Follow up: Unclear.	Difference:	SMD 0.29 lower (CI 95% 0.86 lower — 0.27 higher)	Moderate Due to serious inconsistency ²	Support and information probably decreases informal caregiver stress and strain
Global measures of stress or distress 6 months 7 Critical	Measured by: GHQ-28 Lower better Based on data from 183 participants in 1 studies. ³ (Randomized controlled) Follow up: 6 months.	4 points (Mean) Difference:	3.66 points (Mean) MD 0.34 lower (CI 95% 1.64 lower — 0.96 higher)	Moderate Due to serious imprecision ⁴	Support and information probably has little or no difference on global measures of stress or distress
Caregiver Depression 6 to 12 months follow-up 7 Critical	Measured by: GHQ 28 and CES-D Lower better Based on data from 256 participants in 2 studies. ⁵ (Randomized controlled) Follow up: 6-12 months.	Difference:	SMD 0.06 lower (CI 95% 0.31 lower — 0.18 higher)	Moderate Due to very serious risk of bias with one study (Pierce 2004) ⁶	Support and information probably has little or no difference on caregiver depression
Health-related quality of life 12 month follow-	Measured by: EuroQoL Lower better Based on data from 91	22.73 (Mean)	26.37 (Mean)	Moderate Due to serious imprecision ⁸	Support and information probably has little or no difference on health-

Outcome Timeframe	Study results and measurements	Comparator Control	Intervention Support and information	Certainty of the Evidence (Quality of evidence)	Summary
up 7 Critical	participants in 1 studies. 7 (Randomized controlled) Follow up: 12 months.	Difference:	MD 3.64 higher (CI 95% 3.51 lower — 10.79 higher)		related quality of life

1. Systematic review [61] with included studies: Yoo 2007, Mant 2000. **Baseline/comparator:** Control arm of reference used for intervention.
2. **Inconsistency: serious.** The magnitude of statistical heterogeneity was high, with I^2 : 61%..
Indirectness: no serious. Imprecision: no serious. Publication bias: no serious.
3. Systematic review [61] with included studies: Mant 2000. **Baseline/comparator:** Control arm of reference used for intervention.
4. **Inconsistency: no serious. Indirectness: no serious. Imprecision: serious.** Only data from one study. **Publication bias: no serious.**
5. Systematic review [61] with included studies: Pierce 2004, Mant 2000. **Baseline/comparator:** Control arm of reference used for intervention.
6. **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, Incomplete data and/or large loss to follow up. **Inconsistency: no serious. Indirectness: no serious. Imprecision: no serious. Publication bias: no serious.**
7. Systematic review [61] with included studies: Larson 2005. **Baseline/comparator:** Control arm of reference used for intervention.
8. **Inconsistency: no serious. Indirectness: no serious. Imprecision: serious.** Only data from one study. **Publication bias: no serious.**

References

61. Legg LA, Quinn TJ, Mahmood F, Weir CJ, Tierney J, Stott DJ, et al. Non-pharmacological interventions for caregivers of stroke survivors. Cochrane Database of Systematic Reviews 2011. [Pubmed Journal](#)
62. Eames S., Hoffmann T., Worrall L., Read S., Wong A.. Randomised controlled trial of an education and support package for stroke patients and their carers. BMJ Open 2013;3(5) [Journal Website](#)
72. Vloothuis JD, Mulder M, Veerbeek JM, Konijnenbelt M, Visser-Meily JM, Ket JC, et al. Caregiver-mediated exercises for improving outcomes after stroke. The Cochrane database of systematic reviews 2016;12:CD011058 [Pubmed Journal](#)
73. Aldehaim AY, Alotaibi FF, Uphold CR, Dang S. The Impact of Technology-Based Interventions on Informal Caregivers of Stroke Survivors: A Systematic Review. Telemedicine journal and e-health : the official journal of the American Telemedicine Association 2016;22(3):223-31 [Pubmed Journal](#)
75. Pucciarelli G, Lommi M, Magwood GS, Simeone S, Colaceci S, Vellone E, et al. Effectiveness of dyadic interventions to improve stroke patient–caregiver dyads’ outcomes after discharge: A systematic review and meta-analysis study. European Journal of Cardiovascular Nursing

2020;1474515120926069 [Journal Website](#)

76. Vloothuis JDM, Mulder M, Nijland RHM, Goedhart QS, Konijnenbelt M, Mulder H, et al. Caregiver-mediated exercises with e-health support for early supported discharge after stroke (CARE4STROKE): A randomized controlled trial. PLOS ONE 2019/04/08;14(4):e0214241 [Website](#)

78. Goudarzian M, Fallahi-Khoshknab M, Dalvandi A, Delbari A, Biglarian A. Effect of Telenursing on Levels of Depression and Anxiety in Caregivers of Patients with Stroke: A Randomized Clinical Trial. Iranian journal of nursing and midwifery research 23(4):248-252 [Pubmed Journal](#)

81. İnci FH, Temel AB. The effect of the support program on the resilience of female family caregivers of stroke patients: Randomized controlled trial. Applied nursing research : ANR 2016;32:233-240 [Pubmed Journal](#)

84. Elsheikh MA, Moriyama M, Rahman MM, Kako M, El-Monshed AH, Zoromba M, et al. Effect of a tailored multidimensional intervention on the care burden among family caregivers of stroke survivors: a randomised controlled trial. BMJ open 12(2):e049741 [Pubmed Journal](#)

85. Fu BO, Mei Y, Lin B, Guo Y, Zhang Z, Qi B, et al. Effects of A Benefit-Finding Intervention in Stroke Caregivers in Communities. Clinical gerontologist 45(5):1317-1329 [Pubmed Journal](#)

86. Kang K, Li S. A WeChat-based caregiver education program improves satisfaction of stroke patients and caregivers, also alleviates poststroke cognitive impairment and depression: A randomized, controlled study. Medicine 101(27):e29603 [Pubmed Journal](#)

87. Patchwood E, Woodward-Nutt K, Rhodes SA, Batistatou E, Camacho E, Knowles S, et al. Organising Support for Carers of Stroke Survivors (OSCARSS): a cluster randomised controlled trial with economic evaluation. BMJ open 11(1):e038777 [Pubmed Journal](#)

88. Wang J, Liu J, Li L, Man J, Yue S, Liu Z. Effect of education and muscle relaxation program on anxiety, depression and care burden in caregivers of acute stroke survivors: A randomized, controlled study. Medicine 100(4):e24154 [Pubmed Journal](#)

Good practice statement

In review

Consensus-based recommendations

- Carers should receive psychosocial support throughout the stroke recovery continuum to ensure carer wellbeing and the sustainability of the care arrangement. Carers should be supported to explore and develop problem solving strategies, coping strategies and stress management techniques. The care arrangement has a significant impact on the relationship between caregiver and stroke survivor so psychosocial support should also be targeted towards protecting relationships within the stroke survivors support network.
- Where it is the wish of the stroke survivor, carers should be actively involved in the recovery process by assisting with goal setting, therapy sessions, discharge planning, and long-term activities.
- Carers should be provided with information about the availability and potential benefits of local stroke support groups and services, at or before the person's return to the community.
- Assistance should be provided for families/carers to manage stroke survivors who have behavioural problems.

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 are partnering with the Stroke Foundation on the Living Stroke Guidelines project.

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 thrombectomy (also called 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.

Research wastage:

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

References

1. Thrift AG, Hayman N. Aboriginal and Torres Strait Islander peoples and the burden of stroke. *International journal of stroke : official journal of the International Stroke Society* 2007;2(1):57-9 [Pubmed Journal](#)
2. National Stroke Foundation. National Stroke Unit Program. Aboriginal Stroke Project. 2003.
3. Kilkenney MF, Harris DM, Ritchie EA, Price C, Cadilhac DA, . Hospital management and outcomes of stroke in Indigenous Australians: evidence from the 2009 Acute Care National Stroke Audit. *International journal of stroke : official journal of the International Stroke Society* 2013;8(3):164-71 [Pubmed Journal](#)
4. Australian Institute of Health and Welfare. Stroke and its management in Australia: an update. 2013.
5. National Vascular Disease Prevention Alliance. Guidelines for the management of absolute cardiovascular disease risk. 2012.
6. Heart Foundation. Guideline for the diagnosis and management of hypertension in adults. 2016.
7. Parker CJ, Gladman JR, Drummond AE. The role of leisure in stroke rehabilitation. *Disability and rehabilitation* 1997;19(1):1-5 [Pubmed](#)
8. Stroke Foundation. National Stroke Audit – Rehabilitation Services Report 2020. 2020.
9. Warner G, Packer T, Villeneuve M, Audulv A, Versnel J. A systematic review of the effectiveness of stroke self-management programs for improving function and participation outcomes: self-management programs for stroke survivors. *Disability and rehabilitation* 2015;37(23):2141-63 [Pubmed Journal](#)
10. Lennon S, McKenna S, Jones F. Self-management programmes for people post stroke: a systematic review. *Clinical rehabilitation* 2013;27(10):867-78 [Pubmed Journal](#)
11. Kidd L, Lawrence M, Booth JO, Rowat A, Russell S. Development and evaluation of a nurse-led, tailored stroke self-management intervention. *BMC health services research* 2015;15:359 [Pubmed Journal](#)
12. Boger EJ, Demain SH, Latter SM. Stroke self-management: a focus group study to identify the factors influencing self-management following stroke. *International journal of nursing studies* 2015;52(1):175-87 [Pubmed Journal](#)
13. Taylor DM, Stone SD, Huijbregts MP. Remote participants' experiences with a group-based stroke self-management program using videoconference technology. *Rural and remote health* 2012;12:1947 [Pubmed](#)
14. Stroke Foundation. National Stroke Audit - Rehabilitation Services Report. 2020.
15. Stroke Foundation. National Stroke Audit - Acute Services Report. 2019.
16. Fryer CE, Luker JA, McDonnell MN, Hillier SL. Self management programmes for quality of life in people with

stroke. The Cochrane database of systematic reviews 2016;(8):CD010442 [Pubmed Journal](#)

17. Parke HL, Epiphaniou E, Pearce G, Taylor SJC, Sheikh A, Griffiths CJ, et al. Self-Management Support Interventions for Stroke Survivors: A Systematic Meta-Review. PloS one 2015;10(7):e0131448 [Pubmed Journal](#)

18. Fu V, Weatherall M, McPherson K, Taylor W, McRae A, Thomson T, et al. Taking Charge after Stroke: A randomized controlled trial of a person-centered, self-directed rehabilitation intervention. International journal of stroke : official journal of the International Stroke Society 2020;1747493020915144 [Pubmed Journal](#)

19. Kristine Stage Pedersen S, Lillelund Sørensen S, Holm Stabel H, Brunner I, Pallesen H. Effect of Self-Management Support for Elderly People Post-Stroke: A Systematic Review. Geriatrics (Basel, Switzerland) 2020;5(2) [Pubmed Journal](#)

20. Cadilhac DA, Andrew NE, Busingye D, Cameron J, Thrift AG, Purvis T, et al. Pilot randomised clinical trial of an eHealth, self-management support intervention (iVERVE) for stroke: feasibility assessment in survivors 12–24 months post-event. Pilot and Feasibility Studies 2020;6(1):172 [Journal Website](#)

21. George S, Crotty M, Gelinas I, Devos H. Rehabilitation for improving automobile driving after stroke. Cochrane Database of Systematic Reviews 2014. [Pubmed Journal](#)

22. Akinwuntan AE, Devos H, Verheyden G, Baten G, Kiekens C, Feys H, et al. Retraining moderately impaired stroke survivors in driving-related visual attention skills. Topics in stroke rehabilitation 2010;17(5):328-36 [Pubmed Journal](#)

23. Classen S, Brooks J. Driving simulators for occupational therapy screening, assessment, and intervention. Occupational Therapy in Health care 2014;28(2):154-162 [Pubmed](#)

24. Austroads. Assessing fitness to drive for commercial and private vehicle drivers. Medical Standards for Licensing and Clinical Management Guidelines (6th edition). 2022. [Website](#)

25. Barclay RE, Stevenson TJ, Poluha W, Ripat J, Nett C, Srikesavan CS. Interventions for improving community ambulation in individuals with stroke. Cochrane Database of Systematic Reviews 2015. [Journal](#)

26. Egan M, Anderson S, McTaggart J. Community navigation for stroke survivors and their care partners: description and evaluation. Topics in stroke rehabilitation 2010;17(3):183-90 [Pubmed Journal](#)

27. Logan PA, Armstrong S, Avery TJ, Barer D, Barton GR, Darby J, et al. Rehabilitation aimed at improving outdoor mobility for people after stroke: a multicentre randomised controlled study (the Getting out of the House Study). Health technology assessment (Winchester, England) 2014;18(29):vii-viii, 1-113 [Pubmed Journal](#)

28. Dorstyn D, Roberts R, Kneebone I, Kennedy P, Lieu C. Systematic review of leisure therapy and its effectiveness in managing functional outcomes in stroke rehabilitation. Topics in stroke rehabilitation 2014;21(1):40-51 [Pubmed Journal](#)

29. Harrington R, Taylor G, Hollinghurst S, Reed M, Kay H, Wood VA. A community-based exercise and education scheme for stroke survivors: a randomized controlled trial and economic evaluation. Clinical rehabilitation 2010;24(1):3-15 [Pubmed Journal](#)

30. Walker MF, Leonardi-Bee J, Bath P, Langhorne P, Dewey M, Corr S, et al. Individual patient data meta-analysis of randomized controlled trials of community occupational therapy for stroke patients. *Stroke; a journal of cerebral circulation* 2004;35(9):2226-32 [Pubmed](#)
31. Mayo NE, Anderson S, Barclay R, Cameron JI, Desrosiers J, Eng JJ, et al. Getting on with the rest of your life following stroke: a randomized trial of a complex intervention aimed at enhancing life participation post stroke. *Clinical rehabilitation* 2015;29(12):1198-211 [Pubmed](#) [Journal](#)
32. Lee D, Heffron JL, Mirza M. Content and Effectiveness of Interventions Focusing on Community Participation Poststroke: A Systematic Review. *Archives of physical medicine and rehabilitation* 2019;100(11):2179-2192.e1 [Pubmed](#) [Journal](#)
33. Ntsiea MV, Van Aswegen H, Lord S, Olorunju S S. The effect of a workplace intervention programme on return to work after stroke: a randomised controlled trial. *Clinical rehabilitation* 2015;29(7):663-73 [Pubmed](#) [Journal](#)
34. Baldwin C, Brusco NK. The effect of vocational rehabilitation on return-to-work rates post stroke: a systematic review. *Topics in stroke rehabilitation* 2011;18(5):562-72 [Pubmed](#) [Journal](#)
35. Killey J, Gustafsson L, Hoyle M. Paths to Work after Stroke in Australia. *Brain Impairment* 2014;15(2):99-106 [Journal](#)
36. Wolfenden B, Grace M. Returning to work after stroke: a review. *International journal of rehabilitation research. Internationale Zeitschrift fur Rehabilitationsforschung. Revue internationale de recherches de readaptation* 2009;32(2):93-7 [Pubmed](#) [Journal](#)
37. Kersten P, Low JTS, Ashburn A, George SL, McLellan DL. The unmet needs of young people who have had a stroke: results of a national UK survey. *Disability and rehabilitation* 2002;24(16):860-6 [Pubmed](#)
38. O'Keefe S, Stanley M, Adam K, Lannin NA. A Systematic Scoping Review of Work Interventions for Hospitalised Adults with an Acquired Neurological Impairment. *Journal of occupational rehabilitation* 2019;29(3):569-584 [Pubmed](#) [Journal](#)
39. Sansom J, Ng L, Zhang N, Khan F. Let's talk about sex: A pilot randomised controlled trial of a structured sexual rehabilitation programme in an Australian stroke cohort. *International Journal of Therapy & Rehabilitation* 2015;22(1):21-29 [Journal](#)
40. Song H, Oh H, Kim H, Seo W. Effects of a sexual rehabilitation intervention program on stroke patients and their spouses. *NeuroRehabilitation* 2011;28(2):143-50 [Pubmed](#) [Journal](#)
41. Stein J, Hillinger M, Clancy C, Bishop L. Sexuality after stroke: patient counseling preferences. *Disability and rehabilitation* 2013;35(21):1842-7 [Pubmed](#) [Journal](#)
42. Stratton H, Sansom J, Brown-Major A, Anderson P, Ng L. Interventions for sexual dysfunction following stroke. *Cochrane Database of Systematic Reviews* 2020;5 [Pubmed](#) [Journal](#)
43. Lever S, Pryor J. The impact of stroke on female sexuality. *Disability and rehabilitation* 2017;39(20):2011-2020

Pubmed Journal

44. Tibaek S, Gard G, Dehlendorff C, Iversen HK, Erdal J, Biering-Sørensen F, et al. The effect of pelvic floor muscle training on sexual function in men with lower urinary tract symptoms after stroke. *Topics in stroke rehabilitation* 2015;22(3):185-93 [Pubmed Journal](#)
45. Dyer A, Kirby M, White ID, Cooper AM. Management of erectile dysfunction after prostate cancer treatment: cross-sectional surveys of the perceptions and experiences of patients and healthcare professionals in the UK. *BMJ open* 2019;9(10):e030856 [Pubmed Journal](#)
46. Serefoglu EC, McMahon CG, Waldinger MD, Althof SE, Shindel A, Adaikan G, et al. An evidence-based unified definition of lifelong and acquired premature ejaculation: report of the second international society for sexual medicine ad hoc committee for the definition of premature ejaculation. *Sexual medicine* 2014;2(2):41-59 [Pubmed Journal](#)
47. Tibaek S, Gard G, Jensen R. Pelvic floor muscle training is effective in women with urinary incontinence after stroke: a randomised, controlled and blinded study. *Neurourology and urodynamics* 2005;24(4):348-57 [Pubmed](#)
48. Prior S, Reeves N, Peterson G, Jaffray L, Campbell S. Addressing the Gaps in Post-Stroke Sexual Activity Rehabilitation: Patient Perspectives. *Healthcare (Basel, Switzerland)* 2019;7(1) [Pubmed Journal](#)
49. McGrath M, Lever S, McCluskey A, Power E. How is sexuality after stroke experienced by stroke survivors and partners of stroke survivors? A systematic review of qualitative studies. *Clinical rehabilitation* 2019;33(2):293-303 [Pubmed Journal](#)
50. Grenier-Genest A, Gérard M, Courtois F. Stroke and sexual functioning: A literature review. *NeuroRehabilitation* 2017;41(2):293-315 [Pubmed Journal](#)
51. McGrath M, Lever S, McCluskey A, Power E. Developing interventions to address sexuality after stroke: Findings from a four-panel modified Delphi study. *Journal of rehabilitation medicine* 2019;51(5):352-360 [Pubmed Journal](#)
52. O'Connor SR, Connaghan J, Maguire R, Kotronoulas G, Flannagan C, Jain S, et al. Healthcare professional perceived barriers and facilitators to discussing sexual wellbeing with patients after diagnosis of chronic illness: A mixed-methods evidence synthesis. *Patient education and counseling* 2019;102(5):850-863 [Pubmed Journal](#)
53. Glass TA, Maddox GL. The quality and quantity of social support: stroke recovery as psycho-social transition. *Social science & medicine (1982)* 1992;34(11):1249-61 [Pubmed](#)
54. Friedland JF, McColl M. Social support intervention after stroke: results of a randomized trial. *Archives of physical medicine and rehabilitation* 1992;73(6):573-81 [Pubmed](#)
55. Kessler D, Egan M, Kubina L-A. Peer support for stroke survivors: a case study. *BMC health services research* 2014;14:256 [Pubmed Journal](#)
56. Morris R, Morris P. Participants' experiences of hospital-based peer support groups for stroke patients and carers. *Disability and rehabilitation* 2012;34(4):347-54 [Pubmed Journal](#)

57. Kruithof WJ, van Mierlo ML, Visser-Meily JMA, van Heugten CM, Post MWM. Associations between social support and stroke survivors' health-related quality of life--a systematic review. *Patient education and counseling* 2013;93(2):169-76 [Pubmed Journal](#)
58. Sadler E, Sarre S, Tinker A, Bhalla A, McKeivitt C. Developing a novel peer support intervention to promote resilience after stroke. *Health & social care in the community* 2017;25(5):1590-1600 [Pubmed Journal](#)
59. Clark E, MacCrosain A, Ward NS, Jones F. The key features and role of peer support within group self-management interventions for stroke? A systematic review. *Disability and rehabilitation* 2020;42(3):307-316 [Pubmed Journal](#)
60. Hill K, House A, Knapp P, Wardhaugh C, Bamford J, Vail A. Prevention of mood disorder after stroke: a randomised controlled trial of problem solving therapy versus volunteer support. *BMC neurology* 2019;19(1):128 [Pubmed Journal](#)
61. Legg LA, Quinn TJ, Mahmood F, Weir CJ, Tierney J, Stott DJ, et al. Non-pharmacological interventions for caregivers of stroke survivors. *Cochrane Database of Systematic Reviews* 2011. [Pubmed Journal](#)
62. Eames S., Hoffmann T., Worrall L., Read S., Wong A.. Randomised controlled trial of an education and support package for stroke patients and their carers. *BMJ Open* 2013;3(5) [Journal Website](#)
63. Cheng HY, Chair SY, Chau JPC. The effectiveness of psychosocial interventions for stroke family caregivers and stroke survivors: A systematic review and meta-analysis. *Patient Education and Counseling* 2014;95(1):30-44 [Journal Website](#)
64. Bakas T, Austin J, Habermann B, Jessup N, McLennon S, Mitchell P, et al. Telephone Assessment and Skill-Building Kit for Stroke Caregivers: a Randomised controlled Clinical Trial. *Stroke* 2015;3478-3486 [Journal](#)
65. Ostwald K., Godwin M., Cron G., Kelley P., Hersch G, Davis S. Home-based psychoeducational and mailed information programs for stroke-caregiving dyads post-discharge: a randomized trial. *Disability & Rehabilitation* 2014;36(1):55-63 [Journal Website](#)
66. Pfeiffer K., Beische D., Hautzinger M., Berry JW, Wengert J., Hoffrichter R., et al. Telephone-based problem-solving intervention for family caregivers of stroke survivors: a randomized controlled trial. *Journal of Consulting & Clinical Psychology* 2014;82(4):628-643 [Journal Website](#)
67. Bishop D., Miller I., Weiner D., Guilmette T., Mukand J., Feldmann E., et al. Family Intervention: Telephone Tracking (FITT): a pilot stroke outcome study. *Topics in Stroke Rehabilitation* 2014;21 Suppl 1:S63-74 [Journal](#)
68. Smith GC, Egbert N, Dellman-Jenkins M, Nanna K, Palmieri PA. Reducing Depression in Stroke Survivors and Their Informal Caregivers: A Randomized Clinical Trial of a Web-Based Intervention. *Rehabilitation Psychology* 2012;57(3):196-206 [Journal Website](#)
69. Bakas T, Clark PC, Kelly-Hayes M, King RB, Lutz BJ, Miller EL. Evidence for stroke family caregiver and dyad interventions: a statement for healthcare professionals from the American Heart Association and American Stroke Association. *Stroke; a journal of cerebral circulation* 2014;45(9):2836-52 [Pubmed Journal](#)

70. Australian Institute of Health and Welfare. Stroke and its management in Australia: an update. 2013.

71. Forster A, Dickerson J, Young J, Patel A, Kalra L, Nixon J, et al. A structured training programme for caregivers of inpatients after stroke (TRACS): a cluster randomised controlled trial and cost-effectiveness analysis. *Lancet* (London, England) 2013;382(9910):2069-76 [Pubmed Journal](#)

72. Vloothuis JD, Mulder M, Veerbeek JM, Konijnenbelt M, Visser-Meily JM, Ket JC, et al. Caregiver-mediated exercises for improving outcomes after stroke. *The Cochrane database of systematic reviews* 2016;12:CD011058 [Pubmed Journal](#)

73. Aldehaim AY, Alotaibi FF, Uphold CR, Dang S. The Impact of Technology-Based Interventions on Informal Caregivers of Stroke Survivors: A Systematic Review. *Telemedicine journal and e-health : the official journal of the American Telemedicine Association* 2016;22(3):223-31 [Pubmed Journal](#)

74. Minshall C, Pascoe MC, Thompson DR, Castle DJ, McCabe M, Chau JPC, et al. Psychosocial interventions for stroke survivors, carers and survivor-carer dyads: a systematic review and meta-analysis. *Topics in stroke rehabilitation* 2019;26(7):554-564 [Pubmed Journal](#)

75. Pucciarelli G, Lommi M, Magwood GS, Simeone S, Colaceci S, Vellone E, et al. Effectiveness of dyadic interventions to improve stroke patient-caregiver dyads' outcomes after discharge: A systematic review and meta-analysis study. *European Journal of Cardiovascular Nursing* 2020;1474515120926069 [Journal Website](#)

76. Vloothuis JDM, Mulder M, Nijland RHM, Goedhart QS, Konijnenbelt M, Mulder H, et al. Caregiver-mediated exercises with e-health support for early supported discharge after stroke (CARE4STROKE): A randomized controlled trial. *PLOS ONE* 2019/04/08;14(4):e0214241 [Website](#)

77. Cheng HY, Chair SY, Chau JPC. Effectiveness of a strength-oriented psychoeducation on caregiving competence, problem-solving abilities, psychosocial outcomes and physical health among family caregiver of stroke survivors: A randomised controlled trial. *International journal of nursing studies* 2018;87:84-93 [Pubmed Journal](#)

78. Goudarzian M, Fallahi-Khoshknab M, Dalvandi A, Delbari A, Biglarian A. Effect of Telenursing on Levels of Depression and Anxiety in Caregivers of Patients with Stroke: A Randomized Clinical Trial. *Iranian journal of nursing and midwifery research* 23(4):248-252 [Pubmed Journal](#)

79. Mei Y, Lin B, Li Y, Ding C, Zhang Z. Effects of modified 8-week reminiscence therapy on the older spouse caregivers of stroke survivors in Chinese communities: A randomized controlled trial. *International journal of geriatric psychiatry* 2018;33(4):633-641 [Pubmed Journal](#)

80. Minshall C, Castle DJ, Thompson DR, Pascoe M, Cameron J, McCabe M, et al. A psychosocial intervention for stroke survivors and carers: 12-month outcomes of a randomized controlled trial. *Topics in stroke rehabilitation* 2020;1-14 [Pubmed Journal](#)

81. İnci FH, Temel AB. The effect of the support program on the resilience of female family caregivers of stroke patients: Randomized controlled trial. *Applied nursing research : ANR* 2016;32:233-240 [Pubmed Journal](#)

82. Walker MF, Birchall S, Cobley C, Condon L, Fisher R, Fletcher-Smith J, et al. Biopsychosocial intervention for stroke carers (BISC): results of a feasibility randomised controlled trial and nested qualitative interview study. *Clin*

Rehabil 2020;34(10):1268-1281 [Journal Website](#)

83. Medical Aspects of Fitness to Drive. A guide for health practitioners. Waka Kotahi NZ Transport Agency. 2014. [Website](#)

84. Elsheikh MA, Moriyama M, Rahman MM, Kako M, El-Monshed AH, Zoromba M, et al. Effect of a tailored multidimensional intervention on the care burden among family caregivers of stroke survivors: a randomised controlled trial. BMJ open 12(2):e049741 [Pubmed Journal](#)

85. Fu BO, Mei Y, Lin B, Guo Y, Zhang Z, Qi B, et al. Effects of A Benefit-Finding Intervention in Stroke Caregivers in Communities. Clinical gerontologist 45(5):1317-1329 [Pubmed Journal](#)

86. Kang K, Li S. A WeChat-based caregiver education program improves satisfaction of stroke patients and caregivers, also alleviates poststroke cognitive impairment and depression: A randomized, controlled study. Medicine 101(27):e29603 [Pubmed Journal](#)

87. Patchwood E, Woodward-Nutt K, Rhodes SA, Batistatou E, Camacho E, Knowles S, et al. Organising Support for Carers of Stroke Survivors (OSCARSS): a cluster randomised controlled trial with economic evaluation. BMJ open 11(1):e038777 [Pubmed Journal](#)

88. Wang J, Liu J, Li L, Man J, Yue S, Liu Z. Effect of education and muscle relaxation program on anxiety, depression and care burden in caregivers of acute stroke survivors: A randomized, controlled study. Medicine 100(4):e24154 [Pubmed Journal](#)

89. Mohammadi E, Hassandoost F, Mozhdehipanah H. Evaluation of the "partnership care model" on quality of life and activity of daily living in stroke patients: A randomized clinical trial. Japan journal of nursing science : JJNS 19(1):e12448 [Pubmed Journal](#)

90. Wan X, Chau JPC, Mou H, Liu XU. Effects of peer support interventions on physical and psychosocial outcomes among stroke survivors: A systematic review and meta-analysis. International journal of nursing studies 121:104001 [Pubmed Journal](#)

91. Proffitt R, Boone A, Hunter EG, Schaffer O, Strickland M, Wood L, et al. Interventions to Improve Social Participation, Work, and Leisure Among Adults Poststroke: A Systematic Review. The American journal of occupational therapy : official publication of the American Occupational Therapy Association 76(5) [Pubmed Journal](#)

92. Brauer SG, Kuys SS, Ada L, Paratz JD. IMproving Physical ACTivity after stroke via Treadmill training (IMPACT) and self-management: A randomized trial. International journal of stroke : official journal of the International Stroke Society 17(10):1137-1144 [Pubmed Journal](#)

93. Chen YU, Wei Y, Lang H, Xiao T, Hua Y, Li LU, et al. Effects of a Goal-Oriented Intervention on Self-Management Behaviors and Self-Perceived Burden After Acute Stroke: A Randomized Controlled Trial. Frontiers in neurology 2021;12:650138 [Pubmed Journal](#)

94. Lau SCL, Judycki S, Mix M, DePaul O, Tomazin R, Hardi A, et al. Theory-Based Self-Management Interventions for Community-Dwelling Stroke Survivors: A Systematic Review and Meta-Analysis. The American journal of occupational therapy : official publication of the American Occupational Therapy Association 76(4) [Pubmed Journal](#)

95. Oh HX, De Silva DA, Toh ZA, Pikkarainen M, Wu VX, He H-G. The effectiveness of self-management interventions with action-taking components in improving health-related outcomes for adult stroke survivors: a systematic review and meta-analysis. *Disability and rehabilitation* 44(25):7751-7766 [Pubmed Journal](#)
96. Sakakibara BM, Lear SA, Barr SI, Goldsmith CH, Schneeberg A, Silverberg ND, et al. Telehealth coaching to improve self-management for secondary prevention after stroke: A randomized controlled trial of Stroke Coach. *International journal of stroke : official journal of the International Stroke Society* 17(4):455-464 [Pubmed Journal](#)
97. Zhou X, Du M, Hu Y. The effect of self-management programs on post-stroke social participation: A systematic review and meta-analysis. *Clinical rehabilitation* 36(9):1141-1152 [Pubmed Journal](#)
98. Te Ao B, Harwood M, Fu V, Weatherall M, McPherson K, Taylor WJ, et al. Economic analysis of the 'Take Charge' intervention for people following stroke: Results from a randomised trial. *Clinical rehabilitation* 2022;36(2):240-250 [Pubmed Journal](#)
99. McNaughton H, Weatherall M, McPherson K, Fu V, Taylor WJ, McRae A, et al. The effect of the Take Charge intervention on mood, motivation, activation and risk factor management: Analysis of secondary data from the Taking Charge after Stroke (TaCAS) trial. *Clinical rehabilitation* 2021;35(7):1021-1031 [Pubmed Journal](#)
100. Prados-Román E, Cabrera-Martos I, Martín-Nuñez J, Valenza-Peña G, Granados-Santiago M, Valenza MC. Effectiveness of self-management interventions during the peri-hospitalization period in patients with stroke: A systematic review and meta-analysis. *Clinical Rehabilitation* 2023-08-07. [Journal](#)
101. Pearce G, O'Donnell J, Pimentel R, Blake E, Mackenzie L. Interventions to Facilitate Return to Work after Stroke: A Systematic Review. *International journal of environmental research and public health* 2023;20(15) [Pubmed Journal](#)
102. Lo SHS, Chau JPC, Choi KC, Wong RYM, Kwan JCY, Iu IHL. Health Professional- and Volunteer-partnered Self-management Support (COMBO-KEY) to Promote Self-efficacy and Self-management Behaviors in People with Stroke: A Randomized Controlled Trial. *Annals of behavioral medicine : a publication of the Society of Behavioral Medicine* 2023;57(10):866-876 [Pubmed Journal](#)
103. Chen NYC, Dong Y, Kua ZZJ. Addressing mood and fatigue in return-to-work programmes after stroke: a systematic review. *Frontiers in neurology* 2023;14:1145705 [Pubmed Journal](#)