Clinical Guidelines for Stroke Management 2017

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.

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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 Guidelines are 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 2017. Melbourne Australia. © No part of this publication can be reproduced by any process without permission from the Stroke Foundation. August 2017.
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Summary of recommendations

1 - Introduction
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### Weak 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]*)

### 6 - Driving

#### Practice Statement

**Consensus-based recommendations**

- All stroke survivors or people who have had a transient ischaemic attack should be asked if they wish to resume driving.
- Any person wishing to drive again after a stroke or TIA should be provided with information about how stroke may affect his/her driving and the requirements and processes for returning to driving. Information should be consistent with the Austroads standards and any relevant state guidelines.
- For private licenses, stroke survivors should be instructed not to return to driving for a minimum of four weeks post stroke. People who have had a TIA should be instructed not to drive for two weeks. *(Austroads standards 2016 [21]*)
- For commercial licenses, stroke survivors should be instructed not to return to driving for a minimum of 3 months post stroke. People who have had a TIA should be instructed not to drive for four weeks. *(Austroads standards 2016 [21]*)
- A follow-up assessment should be conducted by an **appropriate specialist** to determine medical fitness prior to return to driving. *(Austroads standards 2016 [21]*)
- If a stroke survivor is deemed medically fit but has residual motor, sensory or cognitive changes that may influence driving, they should be referred for an occupational therapy driving assessment. 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.

#### 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 [18]; Classen et al 2014 [20]*)
7 - 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 [22]; Logan et al 2014 [24])

8 - 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 [25]; Walker et al 2004 [27])

9 - 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 [28])

10 - Sexuality

**Practice Statement**

**Consensus-based recommendations**

Stroke survivors and their partners should be offered:

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

Any interventions should address psychosocial as well as physical function.
11 - Support

11.1 - Peer support

<table>
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<th>Weak Recommendation</th>
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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 [40])

11.2 - Carer support

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<th>Strong Recommendation</th>
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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 [41]; Eames et al 2013 [42])

Practice Statement

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.

12 - Glossary and abbreviations
1 - 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. The existing Clinical Guidelines for Stroke Management 2010 were approved by the National Health and Medical Research Council (NHMRC) in September 2010.

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 5-years. As a result, the Stroke Foundation was contracted by the Australian Government Department of Health to update the Clinical Guidelines for Stroke Management 2010, commencing July 2015.

The Clinical Guidelines for Stroke Management 2017 updates and supersedes the Clinical Guidelines for Stroke Management 2010. 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 (Grading of Recommendations Assessment, Development and Evaluation), and an innovative guideline development and publishing platform, known as MAGICapp (Making Grade the Irresistible Choice). 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 2017 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, 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 management, 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); or

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. Refer to documents on InformMe that provide a 2-page summaries of the Clinical Guidelines – one for healthcare professionals, and one for consumers.

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.

Refer to the document on InformMe that summarises all the Clinical Guidelines recommendations.

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 2015 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 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

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
These guidelines 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. 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 5 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. The NHMRC expects that all guidelines will be reviewed no less than once every five years.

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
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Citation

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2 - Methodology

Brief summary of GRADE

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

GRADE methodology includes 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 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)

<table>
<thead>
<tr>
<th></th>
<th>Strong Recommendation</th>
<th>Weak Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>For patients</strong></td>
<td>Most individuals in this situation would want the recommended course of action and only a small proportion would not.</td>
<td>The majority of individuals in this situation would want the suggested course of action, but many would not.</td>
</tr>
<tr>
<td><strong>For clinicians</strong></td>
<td>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.</td>
<td>Recognise that different choices will be appropriate for different patients, and that you must help each patient arrive at a management decision consistent with his values and preferences. Decision aids may 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.</td>
</tr>
<tr>
<td><strong>For policy makers</strong></td>
<td>The recommendation can be adapted as policy in most situations including for the use as performance indicators.</td>
<td>Policy making will require substantial debate and involvement of many stakeholders. Policies are 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.</td>
</tr>
</tbody>
</table>
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.
3 - 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?
4 - 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 [24]). 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 2016 [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. Two-in-five patients (41%) were provided with information about self-management programs but only 15% received information on sexuality. Overall 75% of carers were provided training, however, only 44% 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.
5 - 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, 41% of stroke survivors were made aware of the availability of generic self-management programs before discharge from hospital (Stroke Foundation 2016 [14]).


Weak 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])

Key Info

Benefits and harms

The most recent meta-analysis of self-management programs reported statistically significant improvement in quality of life and self-efficacy, and a non-significant trend towards improvement in mood and activity limitation (Fryer et al 2016 [16]). On the other hand, the amount of evidence did not allow further exploration of the optimal format and content of self-management program delivery (Fryer et al 2016 [16]). Other systematic reviews largely supported these findings (Fryer et al 2016 [16]; Lennon et al 2013 [10]). There were no adverse events reported in any of the studies.

Quality of evidence

The quality of the evidence was assessed as moderate - multiple systematic reviews reporting similar findings with some included RCTs showing inadequate blinding and outcome reporting in some studies.

Preference and values

The evaluation study reported by Kidd et al (2015) [11] involved stroke survivors in the development and evaluation of a structured self-management program for the first year following a stroke. In the development phase twenty stroke survivors were recruited from various NHS localities ranging in age from 43-84 years (mean 64 years) with 60% of participants being 1-6 month post stroke and the remainder 7-12 months post stroke. Half of the participants had moderate to moderately severe disability/symptoms based on the Modified Rankin Scale (MRS). The key aspect of this nurse led intervention was the use of the Patient Activation Measure (developed by Hibbard and Gilbert 2014) to develop a tailored, person led self management support intervention that took account of the stroke survivors needs, expectations and ability to self manage. This information was then used to develop a tailored self management action plan with the stroke nurse designed in a booklet format. Motivational interviewing was used in the goal setting process that included lifestyle modification, psychosocial skills and secondary prevention. The qualitative evaluation of this pilot program is based on the questionnaires completed by participants, semi-structured interviews with six stroke survivors and focus groups with the stroke nurses. The study concluded that this pilot nurse led stroke self management program was feasible and acceptable to stroke survivors and stroke nurses but required further work to refine components of the intervention and address the issues related to delivery of the program.
The qualitative study by Boger et al (2015) [12], also undertaken in the UK, was designed to investigate the factors that facilitate or hinder stroke self management from the patient’s perspective, in particular the influences on self management in the absence of any formal self management program. The findings of this study are based on a purposive sample of stroke survivors recruited from established stroke support groups and broadly representative of socio demographic variations including, gender, age, ethnicity, urban and rural locations and level of impairment. The participants were aged over 18 years, not less than 3 months following their stroke and living in the community (excluding nursing home and supported accommodation). The five focus groups of four to nine participants, led by trained nurses, used a semi structured interview guide and were digitally recorded. The data was analysed iteratively using thematic analysis to identify emerging salient issues to inform the subsequent focus group. The analysis identified three key themes that contribute to self management following stroke; individual capacity, support for self management and the self management environment. These findings suggests stroke survivors may be unable to self manage independently to achieve their full recovery potential in the absence of a structured program to support their needs. The implications for health services in relation to unsupported “self management” could include a general decline in health including physical and emotional well being leading to continued demand on health and social services.

Taylor et al (2012) [13] assessed remote participants experiences of a group based self management program that was conducted using videoconferencing. This qualitative study explored the views of participants in the Moving on after Stroke (MOST) groups in remote communities in northwestern Ontario, Canada. The group based self management program included information sharing, facilitated discussion, goal setting, exercise and self management skills in a supportive environment. Previous research found that participation in MOST is associated with improved community reintegration and positive health behaviours in stroke survivors. Nineteen participants with an average age of 66.2 (range 48-84) agreed to be interviewed using semi structured face to face interviews. The interviews were transcribed and analysed for common categories using qualitative interpretive thematic analysis. Overall participants in this study were satisfied with the MOST delivery experience in terms of the knowledge they gained and the participation in ongoing exercise. They also reported being able to connect with the group and benefit from this connection. Although the videoconferencing provided a safe motivating exercise environment there were limitations in the facilitator’s ability to assess whether individuals were struggling to perform specific exercises or were finding the exercises too easy. The study identified a number of areas for improvement in the delivery of stroke self management group programs for remote stroke survivors using videoconferencing, in particular the importance of collaboration with onsite coordinators and volunteers and enhanced use of the technology.

Resources and other considerations

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
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 at 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 |
| Comparator: | Control |
Summary

The Cochrane review from Fryer et al suggests that self-management programs may benefit people with stroke in the community [16]. It showed improved 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. However, the authors did not give specific reasons of why the quality of evidence was given such rating.

Two other systematic reviews were conducted before Fryer et al (2016). Warner et al (2015) [9] conducted a systematic review of self-management programs following stroke, focusing on participation and functional ability outcomes. Nine studies were included, six of which were randomised controlled trials (RCTs). One RCT found significant improvements on some sub-scales of the Stroke Specific Quality of Life scale including family roles and functional ability in fine motor tasks. Another RCT found significant improvements in functional ability using the Functional Independence Measure, as well as global assessment of health, psychosocial symptoms, and dietary and medication adherence. There was a large degree of heterogeneity across trials in treatment delivery, stroke severity and the choice of outcome measures, so meta-analysis was not carried out.

Lennon et al (2013) [10] conducted a similar review of self-management programs following stroke. Fifteen studies were included, including 9 randomised controlled trials. The review reported statistically significant benefits of the self-management program on at least one outcome in 6 out of 9 RCTs. These included improvements in disability, confidence in recovery, stroke knowledge, and self-efficacy, as well the improvements in family roles and fine motor tasks discussed above. The review authors rated the quality of the RCTs as low to moderate, emphasising small sample sizes and a lack of power calculations, meaning studies were likely to be underpowered to detect treatment effects.

The three systematic reviews included different studies, possibly due to different inclusion criteria. Fryer et al (2016) had the most strict inclusion criteria and review process and thus considered better quality. It had the similar findings as Lennon et al (2013) that self-management programs can improve quality of life and self-efficacy, whereas it did not support the suggestions by Warner et al (2015) of improved functional ability and participation. All three reviews highlight heterogeneity in content, timing, mode of delivery and outcome measures of self-management programs, and therefore the factors contributing to success remain unclear.

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Timeframe</th>
<th>Study results and measurements</th>
<th>Absolute effect estimates</th>
<th>Certainty in effect estimates (Quality of evidence)</th>
<th>Plain text summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of life</td>
<td>4 weeks - 12 months</td>
<td>Quality of life measured by SF-12 or -36; EuroQol; SAQol; SSQol. High better. Based on data from: 469 patients in 6 studies. (Randomized controlled)</td>
<td>Difference: SMD 0.34 more (CI 95% 0.05 more - 0.62 more)</td>
<td>Moderate Due to serious risk of bias</td>
<td>self-management programs probably improves quality of life</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>4 weeks - 12 months</td>
<td>Measured by: Stroke self efficacy. High better. Based on data from: 193 patients in 4 studies. (Randomized controlled)</td>
<td>Difference: SMD 0.33 more (CI 95% 0.04 more - 0.61 more)</td>
<td>Low Due to serious risk of bias, Due to serious imprecision</td>
<td>self-management programs may improve self-efficacy</td>
</tr>
<tr>
<td>Activity</td>
<td></td>
<td>Measured by: FAI, NEADL,</td>
<td></td>
<td>Moderate</td>
<td></td>
</tr>
</tbody>
</table>
1. **Change scores/post intervention**
2. **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 $I^2$ 2.51%. **Indirectness:** **No serious**. **Imprecision:** **No serious**.
3. **Change scores/post intervention**
4. **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**.
5. **Change scores/post intervention**
6. **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;
7. **Change scores/post intervention**
8. **Risk of bias:** **Serious**. A number of studies lacked blinding and has incomplete outcome data; **Inconsistency:** **No serious**. **Indirectness:** **No serious**. **Imprecision:** **No serious**.

**References**


6 - 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 2016 [21]). 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 2016 [21]). As for private drivers, a conditional licence may be considered by the driver licensing authority after at least three months and subject to at least annual review.

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, 44% of stroke survivors were asked if they wanted to return to driving with 76% of them stating that they did. Eighty-eight percent of patients were then provided with information about the process to return to driving (Stroke Foundation 2016 [14]).

Practical Info

Refer to Austroads standards 2016 [21] for further information.
Key Info

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 [18]; Classen et al 2014 [20])

Practical Info

Patients can be referred for driver retraining, including:
- simulator or visual/cognitive/physical, 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.

Key Info

Benefits and harms

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 [18]) 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.

Quality of evidence

There is only one study which has serious imprecision.

Preference and values

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

Resources and other considerations

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 [20]), developed through a literature review and consensus process.

Clinical Question/ PICO

<table>
<thead>
<tr>
<th>Population:</th>
<th>Adults post-stroke</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention:</td>
<td>Driving rehabilitation intervention</td>
</tr>
<tr>
<td>Comparator:</td>
<td>Control</td>
</tr>
</tbody>
</table>

Summary
George et al (2014) [18] 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) [19] showed no significant increase in Useful Field of View, a test of visual attention skills, compared to non-computer-based cognitive training.

<table>
<thead>
<tr>
<th>Outcome Timeframe</th>
<th>Study results and measurements</th>
<th>Absolute effect estimates</th>
<th>Certainty in effect estimates (Quality of evidence)</th>
<th>Plain text summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>On-road score 6 months 6 months</td>
<td>Measured by: Test Ride for Investigating Practical Fitness to Drive Scale: 49-196 High better Based on data from: 83 patients in 1 studies. (Randomized controlled) Follow up 6 months</td>
<td>152.12 driving behaviours (Mean) 167.12 driving behaviours (Mean)</td>
<td>Moderate Due to serious imprecision</td>
<td>Simulator training probably improves driving behaviours in an on-road assessment at six months</td>
</tr>
<tr>
<td>Road sign recognition 6 months</td>
<td>Measured by: Road sign Recognition Scale: 0-12 High better Based on data from: 73 patients in 1 studies. (Randomized controlled) Follow up 6 months</td>
<td>0.72 (Mean) 2.41 (Mean)</td>
<td>Moderate Due to serious imprecision</td>
<td>Simulator training probably improves road sign recognition</td>
</tr>
</tbody>
</table>

2. Risk of bias: No serious. Inadequate/lack of blinding of participants and personnel, resulting in potential for performance bias.
3. Inconsistency: No serious. Indirectness: No serious. Imprecision: Serious. Low number of patients; Publication bias: No serious.
Consensus-based recommendations
On-road driving rehabilitation may be provided by health professionals specifically trained in driving rehabilitation.

References


7 - 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 [24]). 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 [22]; Logan et al 2014 [24])

Practical Info

- Tailored information about local transport options/alternatives including bus timetables, and a diary which records outings should be considered as a low-cost intervention for community-dwelling stroke survivors.
- 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) [24].
- Intervention should target community based stroke survivors (i.e. those living at home, not nursing home residents).

Key Info

Benefits and harms

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 [24]). Increased number of outdoor journeys were reported in one large trial but no other benefits found (Barclay et al 2015 [22]). No harms were found, such as increased falls from providing more outdoor walking practice or intervention.

Quality of evidence

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).

Preference and values

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

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 [24]). 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 [22]) 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 [24]). 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) [22] 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 [23]). 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.

<table>
<thead>
<tr>
<th>Outcome Timeframe</th>
<th>Study results and measurements</th>
<th>Absolute effect estimates</th>
<th>Certainty in effect estimates (Quality of evidence)</th>
<th>Plain text summary</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Walking speed - Overall</strong></td>
<td>Measured by: Metres per second High better Based on data from: 98 patients in 4 studies. (Randomized controlled) Follow up Mean of 3.5 months</td>
<td>Difference: <strong>MD 0.12 more</strong> (CI 95% 0.01 fewer - 0.24 more )</td>
<td><strong>Low</strong> Due to serious risk of bias, Due to serious imprecision 1</td>
<td>Community ambulation may improve walking speed - overall</td>
</tr>
<tr>
<td><strong>Participation - Overall</strong></td>
<td>Measured by: Pooled outcome - Subjective Index of Physical and Social Outcomes and the Nottingham Leisure Questionnaire High better Based on data from: 198 patients in 2 studies. (Randomized controlled) Follow up Mean of 8 months</td>
<td>Difference: <strong>SMD 0.08 more</strong> (CI 95% 0.2 fewer - 0.35 more )</td>
<td><strong>Low</strong> Due to serious risk of bias, Due to serious imprecision 3</td>
<td>Community ambulation may improve participation - overall</td>
</tr>
</tbody>
</table>

1. **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.

2. Pooled outcome from studies using the Subjective Index of Physical and Social Outcomes and the Nottingham Leisure Questionnaire

3. 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

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) [24] 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.

<table>
<thead>
<tr>
<th>Outcome Timeframe</th>
<th>Study results and measurements</th>
<th>Absolute effect estimates</th>
<th>Certainty in effect estimates (Quality of evidence)</th>
<th>Plain text summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of outings</td>
<td>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</td>
<td>Difference: 1.42 more (CI 95% 1.14 more - 1.67 more)</td>
<td>Moderate Due to serious imprecision</td>
<td>Outdoor mobility rehabilitation training probably improves number of outings</td>
</tr>
</tbody>
</table>
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. **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**.

7. General Health Questionnaire

8. **Inconsistency:** **No serious**. **Indirectness:** **No serious**. **Imprecision:** **Serious**. Only data from one study; **Publication bias:** **No serious**.

| Mobility | 5 Important | Based on data from: 504 patients in 1 studies. (Randomized controlled) Follow up 6 months | Measured by: Rivermead Mobility Index. Reported difference is covariate adjusted. Scale: 0-15 High better Based on data from: 499 patients in 1 studies. (Randomized controlled) Follow up 6 months | Difference: **MD 0.15 more** ( CI 95% 0.29 fewer - 0.58 more ) | **Moderate** Due to serious imprecision 4 | Outdoor mobility rehabilitation training probably improves mobility |
| HRQoL | 5 Important | Based on data from: 499 patients in 1 studies. (Randomized controlled) Follow up 6 months | 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 patients in 1 studies. (Randomized controlled) Follow up 6 months | Difference: **MD 4.6 more** ( CI 95% 0.55 fewer - 9.8 more ) | **Moderate** Due to serious imprecision 6 | Outdoor mobility rehabilitation training probably improves HRQoL slightly |
| Psychological well-being | 4 Important | Based on data from: 495 patients in 1 studies. (Randomized controlled) Follow up 6 months | Measured by: General health Questionnaire- 12 items. Reported difference is covariate adjusted. Scale: 0-36 Lower better Based on data from: 495 patients in 1 studies. (Randomized controlled) Follow up 6 months | Difference: **MD 0.96 fewer** ( CI 95% 1.91 fewer - 0.01 more ) | **Moderate** Due to serious imprecision 8 | Outdoor mobility rehabilitation training probably improves psychological well-being |
References

8 - 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 12% and 15% (121 hospitals surveyed) had recreational therapists and diversional therapists, respectively, actively involved in the rehabilitation of stroke patients (Stroke Foundation 2016[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[25]; Walker et al 2004[27])

Key Info

Benefits and harms

Studies from two systematic reviews (Dorstyn et al 2014[25]; Walker et al 2004[27]) 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.

Quality of evidence

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

Preference and values

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

Resources and other considerations

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[26]). 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[27]) and another indicating that we are uncertain if it increases or decreases leisure activity (Dorstyn et al 2014[25]). 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[25]). 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) [25] 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) [27] 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 Barthe 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.

<table>
<thead>
<tr>
<th>Outcome Timeframe</th>
<th>Study results and measurements</th>
<th>Absolute effect estimates</th>
<th>Certainty in effect estimates (Quality of evidence)</th>
<th>Plain text summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leisure activity</td>
<td>Measured by: Nottingham Leisure Questionnaire High better Based on data from: 571 patients in 3 studies. 1 (Randomized controlled) Follow up 1.25-6 months intervention</td>
<td>Difference: MD 1.96 more (CI 95% 0.27 more - 3.66 more)</td>
<td>Moderate Due to serious inconsistency 2</td>
<td>Leisure therapy probably increases leisure activity</td>
</tr>
<tr>
<td>End of intervention</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 Critical</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extended activities of daily living</td>
<td>Measured by: Nottingham Extended Activities of Daily Living High better Based on data from: 571 patients in 3 studies. 3 (Randomized controlled) Follow up 1.25-6 months of treatment</td>
<td>Difference: MD 0.95 more (CI 95% 0.3 fewer - 2.2 more)</td>
<td>Moderate Due to serious imprecision 4</td>
<td>Leisure therapy probably has little or no difference on extended activities of daily living</td>
</tr>
<tr>
<td>End of intervention</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 Critical</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leisure activity</td>
<td>Based on data from 405 patients in 3 studies.</td>
<td></td>
<td>Very Low Due to serious risk of bias, Due to</td>
<td>We are uncertain whether leisure therapy increases or decreases</td>
</tr>
</tbody>
</table>
References


9 - Return to work

Approximately 20% of stroke survivors in Australia are of working age (Baldwin et al 2011 [29]). Return-to-work rates for stroke survivors vary and can be as low as 4% or as high as 75% (Baldwin et al 2011 [29]). In the National Stroke Audit of Rehabilitation Services, 14% of stroke survivors stated they would like to return to work and 57% of them were informed of services to assist with returning to work if they so desired (Stroke Foundation 2016 [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 [30]; Baldwin et al 2011 [29]). 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 [29]). 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 [31]). 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 [28])

Practical Info

Return to work plans should be formulated in collaboration with the stroke survivor and tailored to their particular work and personal needs. Comprehensive assessments should be undertaken by appropriately trained personnel, specific to the needs of the stroke survivor. This may include work-site assessments, functional assessments as well as cognition and language support. A phased return to work is often advisable. Referral to appropriate return to work services should be provided.

Individualised support for return to work is often required in the longer term (up to several years) (Kersten et al 2002 [32]). Work-based needs of the stroke survivor may change over time and should be flexible.

Key Info

Benefits and harms

One study (Ntsiea et al 2015 [28]) 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.

Quality of evidence

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 [28]) where there are significant wage differences compared with Australia; serious imprecision (single study with low numbers) and serious risk of bias.

Preference and values

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

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 [28]). 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) [28] included 80 stroke survivors between 18 and 60 years old. A workplace intervention programme 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.

<table>
<thead>
<tr>
<th>Outcome Timeframe</th>
<th>Study results and measurements</th>
<th>Absolute effect estimates</th>
<th>Certainty in effect estimates (Quality of evidence)</th>
<th>Plain text summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Return to work rates 6 month follow-up</td>
<td>Odds Ratio 5.2 (CI 95% 1.8 - 15) Based on data from 80 patients in 1 studies. (Randomized controlled) Follow up 6 months</td>
<td><strong>Odds Ratio 5.2</strong>&lt;br&gt;<strong>200</strong> per 1000&lt;br&gt;Difference: <strong>365 more</strong> per 1000 (CI 95% 110 more - 589 more)</td>
<td>Low&lt;br&gt;Due to serious imprecision, Due to serious indirectness, Due to serious risk of bias</td>
<td>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.</td>
</tr>
<tr>
<td>ADL 6 month follow-up</td>
<td>Measured by Barthel Index Scale: 0-20 High better Based on data from: 80 patients in 1 studies. (Randomized controlled) Follow up 6 months</td>
<td><strong>19.2</strong> (Mean)</td>
<td><strong>19.9</strong> (Mean)</td>
<td>Low&lt;br&gt;The difference between groups was significant (p = 0.001). Due to serious imprecision. Due to serious risk of bias</td>
</tr>
<tr>
<td>Perceived QoL</td>
<td>6 month follow-up</td>
<td>Measured by: Stroke specific quality of life (SSQoL)</td>
<td>Scale: 49-245 High better Based on data from: 80 patients in 1 studies. (Randomized controlled) Follow up 6 months</td>
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<tr>
<td></td>
<td>7 Critical</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>219.5 (Mean)</th>
<th>225.5 (Mean)</th>
<th>Difference: MD 6 more</th>
</tr>
</thead>
</table>

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 [28]. **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**

10 - Sexuality

Sexual difficulties after stroke are common and frequently not addressed by healthcare professionals (Sansom et al 2015 [33]; Stein et al 2013 [34]). National Stroke Audits report that only 15% of stroke survivors are offered information on sexuality and only 12% are offered the opportunity to discuss issues relating to sexuality (Stroke Foundation 2016 [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 [34]). The cause of sexual difficulties post-stroke is complex and multifactorial (Song et al 2011 [34]) and therefore interventions need to be individualised and address psychological as well as physical factors.

Practice Statement

Consensus-based recommendations
Stroke survivors and their partners should be offered:

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

Any interventions should address psychosocial as well as physical function.

Key Info

Benefits and harms
There was only one randomised controlled trial of 12 stroke survivors (Sansom et al 2015 [33]). An individualised sexual rehabilitation session and generic written materials provided to the control group were equally effective in improving outcomes. Both groups showed overall improvements, indicating benefits of sexual education programs generally.

Quality of evidence
There was only one randomised controlled trial of 12 stroke survivors (Sansom et al 2015 [33]). The trial is too small to reflect the general population. A Cochrane review should be available in the near future.

Preference and values
Outcomes of sexual rehabilitation programs regardless of type appeared positive compared to no intervention/education/rehabilitation for sexuality post stroke. Therefore, it is likely that stroke survivors would want to receive some form of support in sexual rehabilitation.

Resources and other considerations
Implementation consideration
There are clinical indicators collected in the National Stroke Audit on the provision of written information addressing issues relating to sexuality post-stroke and, additionally, whether patients with stroke were offered the opportunity to discuss issues relating to sexuality before discharge.

Rationale
Despite only one randomised controlled trial, an individualised sexual rehabilitation session compared to generic written materials which were provided to the control group were equally effective in improving outcomes (Sansom et al 2015 [33]). Both groups showed overall improvements, indicating benefits of sexual education programs generally. Another previous non-randomised study (Song et al 2011 [34]) (N=46 participants) was used to develop an education model that was subsequently used by Sansom (2015) [33] in the pilot randomised trial. The former study reported increased sexual satisfaction and frequency of sexual activity, but did not promote sexual knowledge. Further studies are needed.
11 - 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 [35]). High emotional support along with moderate levels of instrumental support was found to be most 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 [36]). 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.

11.1 - 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. 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 [40])

Key Info

| Benefits and harms |

In a systematic review of 11 qualitative studies (Kruithof et al 2013 [40]) 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.

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.
**Rationale**

The systematic review (Kruithof et al 2013 [40]) 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 low to moderate due to the heterogeneity and size of the studies. Another study by Morris and Morris (2012) [39] reported patients' experiences with peer support and concluded:

- Peer support groups for stroke survivors and their carers, provided early during in-patient rehabilitation, are experienced as beneficial by survivors, carers and peer supporters alike.
- Peer supporters with similar backgrounds and experiences to the stroke survivors and carers are experienced as the most helpful.
- The inclusion of staff in the groups is viewed as important and helpful by participants.
- Therapeutic benefits experienced in the groups include: empowerment and inspiration; sense of belonging; learning new ways to cope; feeling helpful; feeling secure; being able to express feelings; a sense of increased agency and independence.

In another study by Kessler et al (2014) [38], the authors examined a volunteer peer support program that provided acute care visits and telephone follow-up post-discharge. Factors considered were a) type of support provided, b) benefits for the stroke survivor and care partner, c) potential harms to the stroke survivor, d) impact of providing support on the peer supporter, and e) required processes. Semi-structured interviews were carried out with 16 new stroke survivors and 8 care partners immediately following hospital discharge and then 6 months later, and with 7 peer supporters, 3 program co-ordinators and 4 health professionals to gather feedback from multiple stakeholders. Emotional, affirmational and informational support were perceived as being offered by the peer supporters.

Peer visits were perceived as providing encouragement, motivation, validation, and decreased feelings of being alone. However, the visits were not perceived as beneficial to all stroke survivors. The impact on the peer supporters included increased social connections, personal growth, enjoyment, and feelings of making a difference in the lives of others. Involvement of the healthcare team, peer supporter training and a skilled coordinator were crucial to the success of this program. The authors concluded that peer support can potentially enhance service to stroke survivors and promote community reintegration for peer volunteers however further research is needed to determine the preferred format and timing of peer support, and the characteristics of stroke survivors most likely to benefit.

**Quality of evidence**

Our confidence in the effect estimates is moderate due to the small number of included studies and the heterogeneity of the methods used.

**Preference and values**

In a paper by Morris and Morris (2012) [39], the authors examined stroke patients' carers' and volunteer supporters' experiences of peer support groups during hospital rehabilitation. They used semi-structured interviews and questionnaires and conducted an inductive thematic analysis. Participants also answered a standardised Therapeutic Factors Inventory (TFI). Eight participants returned their questionnaires. Five themes and several sub-themes were apparent. These included Practical issues (difficulties with communication; splitting into small groups; unhelpful group members; choice of topics; briefing of recipients); Staff presence; Similarity-difference; Comparison with other group members and the value of peers. The authors concluded:

- Peer support groups for stroke survivors and their carers, provided early during in-patient rehabilitation, are experienced as beneficial by survivors, carers and peer supporters alike.
- Peer supporters with similar backgrounds and experiences to the stroke survivors and carers are experienced as the most helpful.
- The inclusion of staff in the groups is viewed as important and helpful by participants.
- Therapeutic benefits experienced in the groups include: empowerment and inspiration; sense of belonging; learning new ways to cope; feeling helpful; feeling secure; being able to express feelings; a sense of increased agency and independence.

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**Resources and other considerations**

*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.
cope; feeling helpful; feeling secure; being able to express feelings; a sense of increased agency and independence.

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

Kruithof et al. (2013) [40] 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.

<table>
<thead>
<tr>
<th>Outcome Timeframe</th>
<th>Study results and measurements</th>
<th>Absolute effect estimates</th>
<th>Certainty in effect estimates</th>
<th>Plain text summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>HRQoL Various</td>
<td>Based on data from 956 patients in 11 studies.</td>
<td>No peer support</td>
<td>Peer support</td>
<td>Moderate</td>
</tr>
</tbody>
</table>

Peer support probably improves HRQoL

1. Various HRQoL measure were used in the studies including SF-36 mental health subscale; Stroke and aphasia quality of life scale-39; Quality of Life Index-Stroke Version; Sickness Impact Profile; HRQoL in stroke patients questionnaire; Assessment of Quality of Life Stroke Impact Scale Version 3.0

References

11.2 - 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 60% of stroke survivors have a carer and 44% of them were provided with information about peer support resources prior to discharge (Stroke Foundation 2016 [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 [49]).

**Strong Recommendation**

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 [41]; Eames et al 2013 [42])

**Key Info**

**Benefits and harms**

Support and information provided to informal caregivers may benefit the caregiver by reducing caregiver strain (Legg et al 2011 [41]; Eames et al 2013 [42]). 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 [41]; Eames et al 2013 [42]).

**Quality of evidence**

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

**Preference and values**

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

**Resources and other considerations**

**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 [51]). 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 caregiver/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 [49]; Cheng et al 2014 [43]). 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

<table>
<thead>
<tr>
<th>Population</th>
<th>Adult caregivers of stroke survivors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention</td>
<td>Support and information</td>
</tr>
<tr>
<td>Comparator</td>
<td>Control</td>
</tr>
</tbody>
</table>

Summary
Legg et al. (2011) [41] investigated interventions targeted at informal caregivers of stroke survivors in a Cochrane review. 8 randomised trials with 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 [42]) 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.

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Study results and measurements</th>
<th>Absolute effect estimates</th>
<th>Certainty in effect estimates (Quality of evidence)</th>
<th>Plain text summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informal caregiver stress and strain</td>
<td>Measured by: Caregiver Strain Index, specially developed burden measure. Lower better. Based on data from: 219 patients in 2 studies.</td>
<td>Difference: SMD 0.29 fewer (CI 95% 0.86 fewer - 0.27 more)</td>
<td>Moderate Due to serious inconsistency</td>
<td>Support and information probably decreases informal caregiver stress and strain</td>
</tr>
<tr>
<td>Global measures of stress or distress</td>
<td>Measured by: GHQ-28. Lower better. Based on data from: 183 patients in 1 studies.</td>
<td>4 points (Mean)</td>
<td>3.66 points (Mean)</td>
<td>Moderate Due to serious imprecision</td>
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<tr>
<td>2. <strong>Inconsistency</strong>: Serious. The magnitude of statistical heterogeneity was high, with $I^2$: 61%.: <strong>Indirectness</strong>: No serious. <strong>Imprecision</strong>: No serious. <strong>Publication bias</strong>: No serious.</td>
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<td>4. <strong>Inconsistency</strong>: No serious. <strong>Indirectness</strong>: No serious. <strong>Imprecision</strong>: Serious. Only data from one study; <strong>Publication bias</strong>: No serious.</td>
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<tr>
<td>6. <strong>Risk of bias</strong>: 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; <strong>Inconsistency</strong>: No serious. <strong>Indirectness</strong>: No serious. <strong>Imprecision</strong>: No serious. <strong>Publication bias</strong>: No serious.</td>
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<td>8. <strong>Inconsistency</strong>: No serious. <strong>Indirectness</strong>: No serious. <strong>Imprecision</strong>: Serious. Only data from one study; <strong>Publication bias</strong>: No serious.</td>
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</table>

### References


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.
12 - 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 review**: A comprehensive systematic review and meta-analysis published online in Cochrane library, internationally recognised as the highest standard in evidence-based health care resources.

**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.

**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.

**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.

**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.

**Participation**: Involvement in a life situation.

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

**Penumbral-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.

**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.

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

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

**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.

**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

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ACE</td>
<td>Angiotensin-converting enzyme</td>
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<td>ADL</td>
<td>Activities of daily living</td>
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<td>AF</td>
<td>Atrial fibrillation</td>
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<td>AFO</td>
<td>Ankle foot orthosis</td>
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<td>BAO</td>
<td>Basilar artery occlusion</td>
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<td>BI</td>
<td>Barthel Index</td>
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<td>BMI</td>
<td>Body mass index</td>
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<td>BP</td>
<td>Blood pressure</td>
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<td>CEA</td>
<td>Carotid endarterectomy</td>
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<tr>
<td>CEMRA</td>
<td>Contrast-enhanced magnetic resonance angiography</td>
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<tr>
<td>CI</td>
<td>Confidence interval</td>
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<tr>
<td>CIMT</td>
<td>Constraint induced movement therapy</td>
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<td>CT</td>
<td>Computed tomography</td>
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<tr>
<td>CTA</td>
<td>Computed tomography angiography</td>
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<tr>
<td>CVD</td>
<td>Cardiovascular disease</td>
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<td>DALY</td>
<td>Disability-adjusted life years</td>
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<td>DBP</td>
<td>Diastolic blood pressure</td>
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<td>DOAC</td>
<td>Direct oral anticoagulant</td>
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<td>DSA</td>
<td>Digital subtraction angiography</td>
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<td>DUS</td>
<td>Doppler ultrasonography</td>
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<td>DVT</td>
<td>Deep vein thrombosis</td>
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<td>DWI</td>
<td>Diffusion-weighted imaging</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Description</td>
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<tr>
<td>ECG</td>
<td>Electrocardiography</td>
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<tr>
<td>ED</td>
<td>Emergency department</td>
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<td>EMG</td>
<td>Electromyographic feedback</td>
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<tr>
<td>EMS</td>
<td>Emergency medical services</td>
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<tr>
<td>ESD</td>
<td>Early supported discharge</td>
</tr>
<tr>
<td>ESS</td>
<td>European Stroke Scale</td>
</tr>
<tr>
<td>FAST</td>
<td>Face, Arm, Speech, Time</td>
</tr>
<tr>
<td>FEES</td>
<td>Fibre-optic endoscopic examination of swallowing</td>
</tr>
<tr>
<td>FeSS</td>
<td>Fever, Sugar, Swallowing</td>
</tr>
<tr>
<td>FFP</td>
<td>Fresh frozen plasma</td>
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<tr>
<td>FIM</td>
<td>Functional independence measure</td>
</tr>
<tr>
<td>GP</td>
<td>General practitioner</td>
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<tr>
<td>HR</td>
<td>Hazard ratio</td>
</tr>
<tr>
<td>HRQOL</td>
<td>Health related quality of life</td>
</tr>
<tr>
<td>HRT</td>
<td>Hormone replacement therapy</td>
</tr>
<tr>
<td>IA</td>
<td>Intra-arterial</td>
</tr>
<tr>
<td>ICH</td>
<td>Intracerebral haemorrhage</td>
</tr>
<tr>
<td>ICU</td>
<td>Intensive care unit</td>
</tr>
<tr>
<td>INR</td>
<td>International normalised ratio</td>
</tr>
<tr>
<td>IPC</td>
<td>Intermittent pneumatic compression</td>
</tr>
<tr>
<td>IV</td>
<td>Intravenous</td>
</tr>
<tr>
<td>LMWH</td>
<td>Low molecular weight heparin</td>
</tr>
<tr>
<td>LOS</td>
<td>Length of stay</td>
</tr>
<tr>
<td>MCA</td>
<td>Middle cerebral artery</td>
</tr>
<tr>
<td>Acronym</td>
<td>Definition</td>
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<tr>
<td>---------</td>
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</tr>
<tr>
<td>MD</td>
<td>Mean difference</td>
</tr>
<tr>
<td>MI</td>
<td>Myocardial infarction</td>
</tr>
<tr>
<td>MNA</td>
<td>Mini Nutritional Assessment</td>
</tr>
<tr>
<td>MR</td>
<td>Magnetic resonance</td>
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<tr>
<td>MRA</td>
<td>Magnetic resonance angiography</td>
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<tr>
<td>MRI</td>
<td>Magnetic resonance imaging</td>
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<tr>
<td>mRS</td>
<td>Modified rankin scale</td>
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<tr>
<td>MST</td>
<td>Malnutrition screening tool</td>
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<tr>
<td>MUST</td>
<td>Malnutrition universal screening tool</td>
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<tr>
<td>N</td>
<td>Number of participants in a trial</td>
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<tr>
<td>NASCET</td>
<td>North American Symptomatic Carotid Endarterectomy Trial</td>
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<tr>
<td>NG</td>
<td>Nasogastric</td>
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<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
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<tr>
<td>NIHSS</td>
<td>National Institutes of Health Stroke Scale</td>
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<tr>
<td>NMES</td>
<td>Neuromuscular electrical stimulation</td>
</tr>
<tr>
<td>NNH</td>
<td>Numbers needed to harm</td>
</tr>
<tr>
<td>NNT</td>
<td>Numbers needed to treat</td>
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<tr>
<td>OR</td>
<td>Odds ratio</td>
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<tr>
<td>OT</td>
<td>Occupational therapist</td>
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<tr>
<td>PBS</td>
<td>Pharmaceutical Benefits Scheme</td>
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<tr>
<td>PE</td>
<td>Pulmonary embolism</td>
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<tr>
<td>PEG</td>
<td>Percutaneous endoscopic gastrostomy</td>
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<tr>
<td>PFO</td>
<td>Patent foramen ovale</td>
</tr>
<tr>
<td>PPV</td>
<td>Positive predictive value</td>
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<tr>
<td>Abbreviation</td>
<td>Definition</td>
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<tr>
<td>QALYs</td>
<td>Quality-adjusted life years</td>
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<td>QOL</td>
<td>Quality of life</td>
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<tr>
<td>RCT</td>
<td>Randomised controlled trial</td>
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<tr>
<td>rFVIIa</td>
<td>Recombinant activated factor VII</td>
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<tr>
<td>RHS</td>
<td>Right hemisphere syndrome</td>
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<tr>
<td>ROC</td>
<td>Receiver operator curve</td>
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<tr>
<td>ROM</td>
<td>Range of motion</td>
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<tr>
<td>ROSIER</td>
<td>Recognition of stroke in the emergency room</td>
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<tr>
<td>RR</td>
<td>Relative risk</td>
</tr>
<tr>
<td>RRR</td>
<td>Relative risk reduction</td>
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<tr>
<td>rTMS</td>
<td>Repetitive transcranial magnetic stimulation</td>
</tr>
<tr>
<td>rt-PA</td>
<td>Recombinant tissue plasminogen activator</td>
</tr>
<tr>
<td>SBP</td>
<td>Systolic blood pressure</td>
</tr>
<tr>
<td>SC</td>
<td>Subcutaneous</td>
</tr>
<tr>
<td>SD</td>
<td>Standard deviation</td>
</tr>
<tr>
<td>SE</td>
<td>Standard error</td>
</tr>
<tr>
<td>SES</td>
<td>Standardised effect size</td>
</tr>
<tr>
<td>SGA</td>
<td>Subjective global assessment</td>
</tr>
<tr>
<td>sICH</td>
<td>Symptomatic intracerebral haemorrhage</td>
</tr>
<tr>
<td>SMD</td>
<td>Standardised mean difference</td>
</tr>
<tr>
<td>SSS</td>
<td>Scandinavian stroke scale</td>
</tr>
<tr>
<td>TEE</td>
<td>Transoesophageal echocardiography</td>
</tr>
<tr>
<td>TIA</td>
<td>Transient ischaemic attack</td>
</tr>
<tr>
<td>TOE</td>
<td>Transoesophageal echocardiography</td>
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<tr>
<td>Acronym</td>
<td>Term</td>
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<td>---------------------------------------------------</td>
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<tr>
<td>TOR-BSST</td>
<td>Toronto Bedside Swallowing Screening test</td>
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<tr>
<td>tPA</td>
<td>Tissue plasminogen activator</td>
</tr>
<tr>
<td>TTE</td>
<td>Transthoracic echocardiography</td>
</tr>
<tr>
<td>UFH</td>
<td>Unfractionated heparin</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>UL</td>
<td>Upper limb</td>
</tr>
<tr>
<td>VF or VFS</td>
<td>Videofluoroscopy</td>
</tr>
<tr>
<td>VR</td>
<td>Virtual reality</td>
</tr>
<tr>
<td>VTE</td>
<td>Venous thromboembolism</td>
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<tr>
<td>WMD</td>
<td>Weighted mean difference</td>
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</table>
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